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Nirbhay N. Singh *Editors*

Handbook of Positive Psychology in Intellectual and Developmental Disabilities

Translating Research into Practice

Springer

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Editors

Handbook of Positive Psychology in Intellectual and Developmental Disabilities

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For all those who seek the strengths in others

Karrie A. Shogren

For Shane

Michael L. Wehmeyer

For my brother Bramah for his amazing contributions to cardiology

Nirbhay N. Singh

Preface

This handbook examines the growing movement toward applying principals of positive psychology to research and practice across the field of intellectual and developmental disabilities. The handbook explores how this movement is being spurred by several factors, from changing perceptions of disability that emphasize strengths and supports to promote involvement in typical environments to the growth in applications in positive psychology in general. Contributions to this unique volume focus on the applications of positive psychology across such fields as mental health, education, and medicine that provide services and supports to people with intellectual and developmental disabilities and their families. The handbook describes how the emphasis is shifting to one of positive psychology, focusing on harnessing each person's strengths and abilities to enhance each individual's quality of life. It explores ways in which practitioners can focus on what a person is capable of achieving, thereby leading to more effective approaches to supports.

The handbook begins with an introductory section, with chapters providing overviews of positive psychology, strength-based approaches in the intellectual disability field, the supports paradigm and emerging strength-based approaches to assessment. These chapters set the stage for the second section of the book which focuses on applications of positive psychology in the intellectual and developmental disability field. Chapters highlight existing and emerging research and practices directions in positive psychology and intellectual and developmental disabilities, including self-determination, mindfulness, positive behavior supports, supports planning, quality of life, social well-being, decision-making, physical well-being, character strengths, adaptive behavior, problem-solving, goal setting, supported decision-making, assistive technology, motivation, community living, career design, supported and customized employment, retirement and again.

Lawrence, KS, USA	Karrie A. Shogren
Lawrence, KS, USA	Michael L. Wehmeyer
Augusta, GA, USA	Nirbhay N. Singh

Contents

Part I Introduction

1 **Introduction to Positive Psychology** 3
Karrie A. Shogren, Michael L. Wehmeyer and Nirbhay N. Singh

2 **Strengths-Based Approaches to Intellectual and Developmental Disabilities** 13
Michael L. Wehmeyer, Karrie A. Shogren, Nirbhay N. Singh and Hatice Uyanik

3 **The Supports Paradigm and Intellectual and Developmental Disabilities** 23
James R. Thompson, Michael L. Wehmeyer, Karrie A. Shogren and Hyojeong Seo

4 **Assessment in the Application of Positive Psychology to Intellectual and Developmental Disabilities** 37
Karrie A. Shogren, James R. Thompson, Michael L. Wehmeyer, Hyojeong Seo and Mayumi Hagiwara

Part II Applications of Positive Psychology in Intellectual and Developmental Disabilities

5 **Self-determination** 49
Karrie A. Shogren, Michael L. Wehmeyer and Kathryn M. Burke

6 **Mindfulness: An Application of Positive Psychology in Intellectual and Developmental Disabilities** 65
Nirbhay N. Singh, Giulio E. Lancioni, Yoon-Suk Hwang, Jeffrey Chan, Karrie A. Shogren and Michael L. Wehmeyer

7 **Building Positive, Healthy, Inclusive Communities with Positive Behavior Support** 81
Matt J. Enyart, Jennifer A. Kurth and Daniel P. Davidson

8 **The Mindfulness-Based Individualized Support Plan** 97
Monica M. Jackman, Carrie L. McPherson, Ramasamy Manikam and Nirbhay N. Singh

9 **Translating the Quality of Life Concept into Practice** 115
Robert L. Schalock, Miguel A. Verdugo and Laura E. Gomez

10 **Focus on Friendship: Relationships, Inclusion, and Social Well-Being** 127
Laura T. Eisenman, Brian Freedman and Marisa Kofke

11 **The Role of Positive Psychology in Interpersonal Decision Making** 145
Ishita Khemka and Linda Hickson

12 **Exercise, Leisure, and Physical Well-Being** 173
James K. Luiselli

13 **Character Strengths** 189
Karrie A. Shogren, Ryan M. Niemiec, Dan Tomasulo and Sheida Khamsi

14 **Adaptive Behavior** 201
Marc J. Tassé

15 **Problem Solving and Self-advocacy** 217
Michael L. Wehmeyer and Karrie A. Shogren

16 **Goal Setting and Attainment and Self-regulation** 231
Michael L. Wehmeyer and Karrie A. Shogren

17 **Supported Decision-Making as an Alternative to Guardianship** 247
Jonathan G. Martinis, Tina M. Campanella, Peter Blanck, Michael L. Wehmeyer and Karrie A. Shogren

18 **Assistive Technology** 261
Giulio E. Lancioni, Nirbhay N. Singh, Mark F. O'Reilly, Jeff Sigafoos, Francesca Campodonico and Gloria Alberti

19 **Intrinsic Motivation** 285
Karrie A. Shogren, Jessica Toste, Stephanie Mahal and Michael L. Wehmeyer

20 **Teaching Community Living Skills to People with Intellectual and Developmental Disabilities** 297
Raymond G. Miltenberger, Heather Zerger, Marissa Novotny and Rocky Haynes

21 **Career Development and Career Design** 311
Laura Nota, Lea Ferrari, Teresa Maria Sgaramella and Salvatore Soresi

22 **Supported and Customized Employment** 329
Wendy Parent-Johnson and Laura Owens

23 Retirement 339
Roger J. Stancliffe, Michelle Brotherton, Kate O'Loughlin and Nathan Wilson

24 Aging 357
Lieke van Heumen and Tamar Heller

Index 373

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Part I

Introduction

1 Introduction to Positive Psychology

Karrie A. Shogren, Michael L. Wehmeyer
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Introduction

The goal of this handbook is to examine the growing movement toward applying principles of positive psychology to research and practice in the field of intellectual and developmental disabilities. The handbook explores how this movement is being spurred by several factors, including the emergence of new models of understanding disability that are shifting the focus to building on personal strengths (Chap. 2) as well as the emerging supports paradigm that focuses on assessing support needs and building strengths-based systems of supports that promote involvement in community environments (see Chap. 4). Other chapters focus on the application of practices linked to positive psychology across such diverse fields as mental health, education, and medicine that provide services and supports to people with intellectual and developmental disabilities and their families. All of the chapters in the handbook describe how the emphasis on the intellectual disability field is shifting to one aligned with positive psychology, focusing on harnessing each person's strengths and abilities to enhance each person's quality of life. We hope these chapters will serve as a resource for researchers, clinicians/practitioners, graduate students, educators, and others involved in supporting people with intellectual disability through research, policy, and practice to focus on what a person is capable of achieving, thereby leading to more effective approaches to providing supports and enhancing outcomes.

The editors of this handbook believe that to understand the current context and emerging application of positive psychology to the intellectual and developmental disability field, a brief history of deficit-based models in the disability and psychology field is necessary, as that background provides a context for understanding the emergence of positive psychology and strengths-based approaches and how the application of positive psychology practices, such as those discussed in this handbook, provides a means for the future of supports and services to be strengths-based and aligned with the values, interests, and preferences of people with intellectual and developmental disabilities. Thus, this chapter will provide a brief history of deficit-based approaches in the psychology and disability field to provide a context for the emergence of positive psychological approaches, then discuss critical factors in the emergence of positive psychology, key terms and constructs in positive psychology, and the alignment of

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positive psychology with emerging models the intellectual and development disability field, setting the stage for further elaboration of these models in the chapters that follow.

Deficit-Based Models in Psychology and Disability

The fields of psychology and intellectual and developmental disabilities share a common history—a history dominated by a focus on deficits and limitations. In the disability field, disability has historically been viewed through a medical lens with a focus on identifying the presence of disability and attempting to cure or remediate its characteristics (Wehmeyer, 2013b; Wehmeyer et al., 2008). As we will show in this handbook, there are strengths-based approaches that have emerged from medicine and related health professions for people with intellectual and developmental disabilities (e.g., mindfulness, see Chap. 6; exercise, sport, and physical well-being, see Chap. 12); however, throughout much of modern history, the focus was on identifying pathology rather than on building strengths and supports (Wehmeyer et al., 2008). This is reflected in the diagnostic systems used historically and currently for intellectual and developmental disabilities, as well as the terminology used over time. As Wehmeyer et al. (2008) wrote about the assumptions that undergirded the diagnostic term "mental retardation," which preceded intellectual disability, as well as the terms that preceded "mental retardation" (e.g., mental deficiency, mental subnormality):

> The first such assumption was that the disability resided within the person. To have mental retardation was to be defective. The loci of that defect was the mind. The term *mental*, which is common to all of these terms, means of or pertaining to the mind. The nature of the defect of the mind (mental deficiency) was inferior mental performance (mental subnormality) characterized by mental slowness (mental retardation)… It is a disability determined by indicators of performance linked to limitations in human functioning (p. 312).

The process of diagnosing intellectual disability continues to be rooted in these ideas, as diagnostic criteria involve identifying significant limitations in intellectual functioning and adaptive behavior (Schalock et al., 2010). Similarly, developmental disabilities are defined by mental or physical impairments that lead to substantial functional limitations in major life activities ("Developmental Disabilities Assistance and Bill of Rights Act of 2000"). While the support model (see Chap. 3) asserts that the purpose of diagnosis is to establish the need for supports and to initiate a systematic process of assessing support needs and planning for supports linked to personally valued outcomes (Schalock et al., 2010, 2012), historically, disability diagnosis and classification was viewed as an end. Diagnosis was used to place people with intellectual disability into programs, and throughout history, such programs were characterized by segregation and unequal treatment. Driven largely by the dominance of IQ testing, which emerged in the fields of psychology and disability in the early 1900s, diagnosis and classification based on IQ dictated the options available with differing programs. The underlying premise of segregation was that because of the deficits experienced by people with intellectual and developmental disabilities, they needed separate and specialized settings for remediation that would enable them to, after addressing the deficits, be reintegrated into society. As such, programs were created, particularly in the education system, based primarily on level of intellectual functioning. Such programs, however, did not consider support needs or strengths and preferences of people with intellectual disability. And, the educative focus of segregated settings, particularly institutions for people with intellectual disability, was quickly lost, with segregated settings becoming places of custodial care, characterized by neglectful and even abusive treatment of people with intellectual disability, principally because they were not viewed as fully human given their "deficits."

The psychology field has also been characterized as a deficit-oriented history, shaped by the focus that emerged in the twentieth century of classifying and remediating mental illness, in large part because of needs of veterans returning from World War II and the establishment of the

Veterans Administration and the National Institute of Mental Health, which provided funding for research and treatment of mental illness. As such, psychology essentially adopted a disease model of human functioning (Linley, Joseph, Harrington, & Wood, 2006), building classification and treatment systems for mental illness, rather than for mental health. This combined with the emphasis within psychology on operant psychology and abnormal development during this time led to, as Seligman (1998) described it:

> Human beings were seen as passive foci: Stimuli came on and elicited "responses," or external "reinforcements" weakened or strengthened "responses," or conflicts from childhood pushed the human being around. Viewing the human being as essentially passive, psychologists treated mental illness within a theoretical framework of repairing damaged habits, damaged drives, damaged childhoods and damaged brains" (p. 2).

Emergence of Positive Psychology

Subsequent chapters will more fully describe emerging models in the intellectual and developmental disability field that provide an alternative to the historic, deficit-based models of disability. Briefly, however, emerging models of disability are strengths-based and focus on person–environment fit; they shift to understanding disability not as a characteristic of a person, but as a function of the interaction between personal characteristics and environmental demands. They assume that each person, including each person with and without disabilities, has a unique profile of strengths and limitations that influence their functioning across different environments.

When thinking about disability, the reference environment should be typical community environments, not segregated environments, and the purpose of developing a profile of personal strengths and limitations, including disability characteristics, is to identify the individualized supports needed by the person to be successful in the environments that the person wants to access. Thus, the person's preferences, interests, and values should guide the identification of relevant community environments, and supports should be identified that promote success in those environments, building on strengths and based on an understanding of support needs. Critical to this perspective is the inherent value of the person and their values, preferences, and strengths both in identifying environmental demands and in planning for supports to address those demands. Further, supports do not just involve changing the person (e.g., teaching new skills), but supports also involve changing the environment to make it more accessible (e.g., cognitively accessible materials). As such, these models are closely linked to positive psychology, with its emphasis on positive traits, values, and institutions, described next.

Martin Seligman, during his tenure as president of the American Psychological Association, the largest professional organization in psychology, is credited with calling attention to the need for a "reoriented science" of psychology that "emphasizes the understanding and building of the most positive qualities of an individual" (Seligman, 1999, p. 559). He elaborated that "psychology has moved too far away from its original roots, which were to make the lives of all people more fulfilling and productive, and too much toward the important, but not all-important, area of curing mental illness" (Seligman, 1999, p. 559). And, since Seligman first introduced the term "positive psychology" in 1999, significant and organized attention has been devoted to the science of positive psychology (Yen, 2010).

For example, in 2000, a special issue of *American Psychologist* was published and Seligman and Csikszentmihalyi (2000) defined positive psychology in an introductory article. They characterized positive psychology as focusing on three "pillars": (a) valued subjective experience, (b) positive individual traits, and (c) civic values and the institutions that support them. Articles were included in the special issue on positive experiences: subjective well-being (Diener, 2000), optimal experience (Massimini & Della Fave, 2000), optimism (Peterson, 2000), and happiness (Myers, 2000); and on positive traits: self-determination (Ryan & Deci, 2000), wisdom (Baltes & Staudinger, 2000), mature defenses (Vaillant, 2000), and exceptional performance (Lubinski & Benbow, 2000; Simonton, 2000). Hart and Sasso (2011), in a review of the literature since 2000, found that more than 20,000 articles had been published in the area of positive psychology, with a steady growth since the early 2000s and the publication of the Seligman and Csikszentmihalyi special issue. A journal, *The Journal of Positive Psychology*, was established in 2006 to "provide an interdisciplinary and international forum for the science and application of positive psychology."

In addition to a new journal and peer-reviewed articles, there have been a number of scholarly books published that describe the science of positive psychology. *The Oxford Handbook of Positive Psychology* (Snyder & Lopez, 2002), now in its second edition (Lopez & Snyder, 2009), defines positive psychology and constructs included within its parameters. Specialized handbooks have been published, considering the role of positive psychology in disability (Wehmeyer, 2013a), work (Linley, Harrington, & Garcea, 2009), and education (Gilman, Huebner, & Furlong, 2009). Texts have been published on methods in positive psychology (Ong & van Dulmen, 2006) and assessment in positive psychology (Lopez & Snyder, 2003). Classification systems aligned with positive psychology have also been developed. For example, *Character Strengths and Virtues: A Handbook and Classification* (Peterson & Seligman, 2004) was published as a definition and classification system for strengths and virtues, much like the *Diagnostic and Statistical Manual* defines and classifies mental disorders. The VIA (formerly Values in Action) classification system identified in this text has been used to create character strengths assessments that can be used by children and adults to identify and attempt to capitalize on their character strengths in multiple domains of life (Park & Peterson, 2006) (see Chap. 13) Undergraduate textbooks in positive psychology have been published (Baumgardner, 2008; Peterson, 2006; Snyder, Lopez, & Pedrotti, 2010), and courses are offered at universities all over the USA and Europe (Yen, 2010).

Key Terms and Constructs

Anytime a new field emerges and experiences such quick growth, there are going to be ongoing discussions and debates about its parameters. For example, researchers have found that multiple definitions of positive psychology have been introduced in the field, and there are multiple frameworks for the constructs that fall within its parameters. For example, Hart and Sasso (2011), in their review of the literature, found that although Seligman and Csikszentmihalyi (2000) described three pillars, only the first two pillars—valued subjective experiences and positive individual traits—were well represented in the literature. Limited research and definitional consistency had emerged around civic values and institutions. Further, they identified another area in the field not included in Seligman and Czikszentmihalyi's framework—resiliency under conditions of adversity.

Interestingly, this area of research may have emerged in response to early critiques of the field of positive psychology. Early critiques suggested positive psychology was ignoring the negative in life and adopting a hedonistic view of happiness that was not based in reality (VanNuys, 2010a, b). Positive psychology researchers have argued, however, that positive psychology does not ignore the negative, but instead focuses both on identifying and understanding the positive aspects of life, as well as using this understanding to address and navigate barriers that are encountered in life. For example, Diener (2009) wrote: "positive psychologists do not ignore the negative in life. However, they maintain that often one form of solution to problems, and in some cases the most effective one, is to build on the positive rather than directly work on the problem" (p. 10).

Overall, however, the umbrella of positive psychology is broad and expanding. Seligman and Czikszentmihalyi (2000) included 15 constructs representing the field. When the 2nd Edition of The Handbook of Positive Psychology (Lopez & Snyder, 2009) was published, it included 65 chapters, on topics ranging from emotional intelligence (Salovey, Mayer, Caruso, & Yoo, 2009) and creativity (Simonton, 2009), to love (Hendrick & Hendrick, 2009) and humility (Tangney, 2009), to happiness and positive growth after physical disability (Dunn, Uswatte, & Elliott, 2009). The handbook also included interdisciplinary efforts in the field, such as the role of neuropsychology in understanding positive affect (Isen, 2009) and the role of the heart in generating and sustaining positive emotions (McCraty & Rees, 2009).

Alignment with the Disability Field

As mentioned previously, there has been a significant increase in research in positive psychology, generally, and when looking at research in the intellectual and developmental disability field specifically, there has been a growing focus on positive psychology and strengths-based approaches and constructs as well. A review of research published in leading journals in the intellectual and developmental disability field through the mid-2000s found that older articles were much less likely to adopt a strengths perspective articles than more recently published articles (Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006). For example, from 1975 to 1984, only 22% of articles adopted a strengths perspective; however, by 1995–2004, 50% of articles did. When specifically looking at constructs directly associated with positive psychology (such as happiness and subjective well-being), only 9% of articles from 1975 to 1984 focused on a positive psychology construct, from 1985 to 1995, 15% of articles, and from 1995 to 2004, 24% of articles.

Chapters have also been in general positive psychology texts on the role of positive psychology in understanding disability (Wehmeyer & Shogren, 2014), and disability researchers have analyzed the degree to which positive psychology aligns with and advances research in various domains in the disability field, including rehabilitation (Dunn & Dougherty, 2005; Ehde, 2010), mental health (Baker & Blumberg, 2011), quality of life (Schalock, 2004), family supports (Blacher, Baker, & Berkovits, 2013), and supporting students with autism spectrum disorders (Groden, Kantor, Woodard, & Lipsitt, 2011; Zager, 2013). Researchers have also systematically analyzed the measurement and application of constructs from positive psychology studied in the general population with people with intellectual and developmental disabilities, including character strengths (Niemiec, Shogren, & Wehmeyer, in press; Shogren, Wehmeyer, Forber-Pratt, & Palmer, 2015), subjective well-being, and hope (Shogren et al., 2006).

Overall, this body of work suggests a growing focus on strengths-based approaches and positive psychology in the intellectual and developmental disability field, highlighting the need for this handbook and a comprehensive review of applications of positive psychology and strengths-based approaches in the intellectual and developmental disability field. In the following chapters, we provide the most recent information on the growing application of positive psychology to the intellectual and developmental disability field, with the goal of providing a resource that will enable the implementation of strengths-based approaches that will harness each person's strengths and abilities to enhance each person's quality of life.

Overview of Handbook of Positive Psychology in Intellectual and Developmental Disabilities

The remaining chapters in this introductory section continue the discussion pertaining to positive psychology, strengths-based approaches to disability, and intellectual and developmental disabilities. Chapter 2 examines strengths-based models of disability that emphasize the fit between personal capacity and the demands of the environment and supports that enable people with intellectual and developmental disabilities to function successfully in typical contexts. Chapter 3 examines in greater detail the support and support needs constructs in promoting successful functioning. Chapter 4 introduces assessments and assessment practices that can enable the design of practices to apply principles of positive psychology, determine the efficacy of supports to promote personal strengths, and evaluate personal growth and outcomes.

The next section introduces various applications of positive psychology in the field of intellectual and developmental disabilities. Chapter 5 introduces the self-determination construct, examines its application to intellectual and developmental disabilities, and provides an overview of practices to promote self-determination and self-direction. Chapter 6 provides a review of mindfulness-based approaches to the care and treatment of individuals with intellectual and developmental disabilities. Chapter 7 describes approaches to system-wide efforts to promote positive behavioral outcomes within schools, juvenile justice systems, and other systems supporting people with intellectual and developmental disabilities. Chapter 8 examines traditional Individual Support Plans and an emerging alternative plan that is based on mindful engagement and aligned with positive psychology. Chapter 9 reviews the literature pertaining to quality of life and people with intellectual and developmental disabilities and provides a framework for quality of life as an organizing structure for intellectual and developmental disabilities services and supports. Chapter 10 examines the knowledge base pertaining to building friendships and social networks for people with intellectual and developmental disabilities and examines practices in school and other environments to promote friendship building, improve social inclusion, and enhance social capital. Chapter 11 discusses what is known pertaining to problem-solving and decision-making and people with intellectual and developmental disabilities, as well as reviewing programs and practices that promote positive outcomes for this population. Chapter 12 explores what is known about exercise, sport, and physical fitness and well-being for people with intellectual and developmental disabilities and provides an overview of practices to promote positive outcomes. Chapter 13 examines the application of character strengths assessment and interventions to the lives of people with intellectual and developmental disabilities, with a focus on the use of the VIA Strengths survey.

Chapter 14 describes the measurement of adaptive behavior and ways to promote positive adaptive behavior and autonomous functioning in people with intellectual and developmental disabilities. Chapter 15 discusses the hope construct, its measurement, and ways to intervene to promote hope and pathways thinking for people with intellectual and developmental disabilities.

Chapter 16 examines goal setting, focusing on interventions that have been shown to promote self-regulated problem-solving leading to setting and attaining goals in education, employment, health, and other domains for people with intellectual and developmental disabilities. Chapter 17 explores how, increasingly, a strengths-based approach to disability is driving attention away from the use of plenary guardianship and toward models of supported decision-making that enable people with intellectual and developmental disabilities to participate in decisions that impact the quality of their lives. Chapter 18 reviews evidence-based approaches to using assistive technologies for enhancing preferred skills of individuals who have complex physical and medical issues and increasing their quality of life through self-determination and choice. Chapter 19 examines the role of motivation in achieving positive outcomes, with a focus on Self-Determination Theory's structure of intrinsic, autonomous motivation and ways to enhance intrinsic motivation in school, sport, and other settings. Chapter 20 examines the skills that can be enhanced to support individuals with intellectual and developmental disabilities to enable their physical and social integration in community settings. Issues such as participation in community activities, safety skills, and immersion in the community will be covered.

Chapter 21 examines the changing landscape in career decision-making, moving from models of career development that emphasize stages of development to a focus on career design in which individuals are active participants in actions leading to future employment opportunities. Chapter 22 discusses positive approaches to employment for people with intellectual and developmental disabilities, beginning with supported employment and including self-employment and customized employment models. Chapter 23 explores emerging practices in Australia supporting people with intellectual and developmental disabilities to retire to a life of preferences and choices. And, finally (for this section), Chap. 24 examines positive approaches to supporting people with intellectual and developmental disabilities as they age at home and in their communities.

Overall, the chapters provide direction for research and practice that applies positive psychology approaches to the intellectual and developmental field and creates pathways for new conceptualizations in research and practice.

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2

Strengths-Based Approaches to Intellectual and Developmental Disabilities

Michael L. Wehmeyer, Karrie A. Shogren,
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Introduction

The opening chapter introduced the growing field of positive psychology and provided a context within which to understand and apply strengths-based approaches to intellectual and developmental disabilities. This chapter, in turn, examines historical understandings of disability, how those impacted understandings of intellectual disability, and how changing understandings of disability are leading to strengths-based conceptualizations of intellectual disability and focusing the field on promoting the health and well-being of people with intellectual and developmental disabilities. Chapter 3 will examine the supports paradigm in intellectual and developmental disabilities, as derived from strengths-based approaches to disability, and examine the role of supports in promoting successful functioning in typical environments.

Different and Pathological

Shogren, Wehmeyer, and Singh (2017) briefly recounted historical understandings of intellectual disability, but it is worth exploring in a bit more depth how what we now call intellectual disability has been understood across time. There has, of course, always been people with neurological impairments who have had difficulty functioning in society (Wehmeyer, 2013). The risk factors that result in or cause intellectual disability—biomedical, psychosocial, behavioral, and educational (Schalock, 2013)—have, by and large, always existed. For the vast majority of time across history, however, people with cognitive impairments were simply indistinguishable from the poorest and least advantaged members of society (Wickham, 2013). Keeping in mind that intelligence, as a construct, is a relatively modern convention, the earliest depictions of people with intellectual impairments in the Middle Ages and into the early modern era were of people who were viewed, primarily, as simply different from or apart from the rest of society. The term *idiot* is one of the oldest terms applied to categorize and describe people with cognitive impairments. It derives from the Greek word *idios*, which meant uniquely one's own, private, or peculiar; and the Latin *idiota*, meaning an outsider (Wehmeyer, 2013, p 29). By the time the term began to be applied to people with

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cognitive impairments (twelfth century in France, referring to an uneducated or ignorant person; fourteenth century in England, meaning someone incapable of ordinary reasoning), the generalized sense of peculiar and outside the norm had morphed into a sense of someone who was constitutionally different from other people by reason of their (perceived) lack of capacity to reason or think and, thus, function typically.

This sense of differentness took on a medical patina as the field of intellectual disability emerged, beginning in the nineteenth century. In the late 1700s and early 1800s, pioneers in the field of psychiatry in England and France had begun to differentiate—categorically and diagnostically—between people with mental illness and people whose cognitive impairments were global and long term, and by the mid-nineteenth century, institutions had been established to habilitate and provide for people with intellectual impairments. The term idiot was initially used to delineate the entire class of people with cognitive impairments, eventually, though, becoming a term that was used in classification systems to describe people with the most extensive levels of impairment. Feebleminded became the preferred overarching term, with such categories as idiot, imbecile, and moron used to delineate subcategories. The institutions were called hospitals because they were run by physicians and organized in the same ways—architecturally and process-wise—in which hospitals to treat the sick were organized.

Logically and inevitably, intellectual disability (and disability, in general) was conceptualized by these medical professionals as if it was a disease. Diseases are pathologies, by definition. A person has a disease, and that disease results in symptoms and signs. Feeblemindedness (and, later, mental deficiency and mental retardation) was construed as a type of pathology, as internal to the person and resulting in aberrant or atypical functioning. The field of intelligence testing grew in the early twentieth century, and as psychologists wrested control of the discipline from medical practitioners, the terms they used reflected, increasingly, conceptualizations of defective mental processes from mental deficiency (defective mind) to mental subnormality (subnormal mind) to mental retardation (slow mental functioning).

So, as late as the 1970s, the sole conceptualizations of what we now refer to as intellectual disability reflected the dual characteristics of differentness and defect. Attitudes about people with intellectual impairments changed—from the eugenics era and its stigmatizing characterizations of people with intellectual disability as menaces to society and responsible for many of societies social ills to the post-World War II era and its characterizations of people with intellectual impairments as victims of their pathology but worthy of pity and charity (Smith & Wehmeyer, 2012; Wehmeyer, 2013). Yet, what did not change was the understanding of intellectual disability as an internalized, pathological state and the perception of people with intellectual disability as different and peculiar.

Beyond the Medical Model

When it was established in 1948 as the public health branch of the United Nations, the World Health Organization (WHO) took on, as part of its mission, the classification of diseases. What existed at that time were a series of lists of diseases, causes of mortality, and classifications for morbidity statistics. The WHO took those lists and structured them into what was referred to as the *International Classification of Diseases, Injuries, and Causes of Death*, or, just ICD. There were minor revisions to the ICD in 1955 and 1965 and major revisions in 1979 (ICD-9) and 1994 (ICD-10). Specifically, the ICD is a taxonomy of diseases and disorders. It is a diagnostic tool used for epidemiological, health management, and clinical purposes. Diseases are defined as pathological processes manifesting in characteristic signs and symptoms and impacting health. According to the WHO-International Union of Psychological Science survey of practicing psychologists, 70% of clinicians in the world use the ICD-10 in their day-to-day clinical work. Within the ICD-10, mental retardation was included as a disorder, as it had been in every prior version and as would be expected if it was considered a disease (World Health Organization, 1999).

Over the decades during which the ICD developed, however, there was a paradigm shift in medicine, from a system that primarily engaged acute illness to one that focused on management of chronic conditions. For the first half of the twentieth century, the healthcare system was a configured to respond to acute illnesses, most notably infectious disease like tuberculosis, polio, smallpox, and so forth. Hospitals were settings where diseases were diagnosed, patients were isolated, and most care was palliative (Goldsmith, 1990). Goldsmith (1990) noted:

> An acute illness was a crisis brought on by an external agent that threw the body into violent, life threatening disequilibrium. With luck, the threat would pass, but the health care system's primary function was to comfort the patient until death occurred (p. 13).

One by one, however, vaccines and advances in medical care turned the tide against these illnesses, and life expectancy increased dramatically. The life expectancy for a female in the USA in 1948, when the WHO was established, was 69.9 years. For a male, it was 64.6 years. At the end of the century, that had risen to 79.5 years for females, 73.8 for males. Although it is true that deadly infectious diseases still exist, the change in the medical system as a result of the successes of the previous decades was an increased focus on managing chronic conditions for longer life and on preventing disease.

By the time the ICD-9 was published in 1979, there was as much interest in issues of managing chronic conditions as in diagnosing acute illnesses, and, in 1980, the WHO introduced the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH), which was proposed to provide a system for classifying the *consequences* of disease (instead of diseases themselves) and of their implications for the lives of people living with chronic conditions, including disability.

Essentially, the ICIDH proposed different perspectives or planes of experience for looking at human functioning and for describing the consequences of diseases on typical functioning. Within this perspective, human functioning referred to all life activities of a person. The ICIDH perspectives for describing the impact of a health condition or pathology on human functioning were: (a) the exteriorization of a pathology in body anatomy and functions (e.g., as pertaining to intellectual disability, central nervous system and intelligence), (b) objectified pathology as expressed in the person's activities (e.g., adaptive behavior skills), and (c) the social consequences of pathology (e.g., participation in social life domains) (World Health Organization, 1980, p. 30).

Essentially, the ICIDH recognized that besides the impact of health condition factors (pathology), contextual factors (environmental or personal factors) are of pivotal importance for understanding human functioning, and that limitations in human functioning are not necessarily linear or causal consequences of a pathology, but are a function of multiple interactive processes where each factor can influence each dimension of functioning and each other factor either directly or indirectly.

The changes in understanding intellectual disability introduced by the WHO and the ICIDH in 1980 began to appear in the definitional and diagnostic procedures used by the field. The 9th Edition of the *Definition, Classification, and Systems of Supports* manual published by the American Association on Mental Retardation (Luckasson et al., 1992) stated:

> Mental retardation is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. It is not a medical disorder, although it may be coded in a medical classification of diseases… Nor is it a mental disorder, although it may be coded in a classification of psychiatric disorders… Mental retardation refers to a particular state of functioning that begins in childhood and in which limitations in intelligence coexist with related limitations in adaptive skills.

> As a statement about functioning, it describes the "fit" between the capabilities of the individual and the structure and expectations of the individual's personal and social environment" (p. 9).

Primarily due to political reasons, the term "mental retardation" was still used in this definition and in the name of the association, but this edition marked a stark difference in how the term was defined. Intellectual disability is not something one has or something one is. It is not something that is a medical disease or a mental disorder. It is a state of functioning existing when there is a lack of fit between the person's capacities and the demands of the environment.

The prior edition of the manual, issued by the then-still-named American Association on Mental Deficiency (Grossman et al., 1983) also aligned with the prevailing WHO conceptualization, ICD-9, but did not adopt the framework proposed by the ICIDH, and there is no mention of capacities, capabilities, or strengths of people with cognitive impairments to be found. The 1992 edition, which embraced (though does not explicitly cite) the ICIDH, is peppered with references to the person's capacities, most notably in three assumptions listed as part of the definition of "mental retardation":

- The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports;
- Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; and
- With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve (p. 1).

So, this shift in how disability was understood marked the first step toward strengths-based approaches to intellectual disability and introduced conversations about personal capacities and capabilities, support needs and supports, and functioning in typical contexts and environments.

Human Functioning

In 2001, the WHO published its successor to the ICIDH, titled the *International Classification of Functioning, Disability, and Health* (ICF; WHO, 2001). The ICF "provides a standard language and framework for the description of health and health-related states (WHO, 2002, p. 2). The ICF:

> … is WHO's framework for health and disability … it is the conceptual basis for the definition, measurement and policy formulations for health and disability… it is named as it is because of its stress is (sic) on health and functioning, rather than on disability. Previously, disability began where health ended; once you were disabled, you where (sic) in a separate category. We want to get away from this kind of thinking. WE want to make ICF a tool for measuring functioning in society, no matter what the reason for one's impairments. This is a radical shift. From emphasizing people's disabilities, we now focus on their level of health. (pp. 2–3).

Within ICF, functioning is an umbrella term for all life activities of an individual and encompasses body structures (anatomical parts of the body) and functions (physiological and psychological functions of body systems), personal activities (the execution of tasks or actions), and participation (involvement in a life situation) areas. Problems or limitations in functioning (that is, all life activities of a person) are referred to as disability. Disability can result from any problem in one or more of the three dimensions of human functioning; problems in body structures and functions are referred to as impairments; problems in personal activities are referred to as activity limitations; problems in participation are referred to as participation restrictions. The ICF situates these impairments, activity limitations, and participation restrictions within the interactions between health conditions, environmental factors, and personal factors (WHO, 2002).

The ICF model has been referred to as a social model (as contrasted with a medical model), a social-ecological model (emphasizing the relationship between personal and environmental factors), a biopsychosocial model (emphasizing the interaction of biological, psychological, and social factors), and a person–environment fit model (emphasizing that disability lies in the gap between personal capacity and the demands of the environment). Though all such descriptors have utility, it is the latter that most clearly provides a path toward strengths-based approaches to intellectual disability. Within ICF, disability is seen only as the lack of fit between a person's strengths, capacities, abilities, and capabilities and the demand of the environment in which that person must function.

The 2002 edition (10th) of the (still) American Association on Mental Retardation's Definition, Classification, and Systems of Supports manual (Luckasson et al., 2002) explicitly stated that edition's alignment with the ICF and person–environment fit models of disability, including adding "context" as a fifth dimension of the theoretical model presented. The assumptions presented as part of the definition were even more forthcoming about the importance of a strengths-based approach, stating that:

- Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
- Within an individual, limitations often coexist with strengths.
- An important purpose of describing limitations is to develop a profile of needed supports.
- With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation will generally improve (p. 1).

In the most recent Definition, Classification, and Systems of Supports manual issued by the now-named American Association on Intellectual and Developmental Disabilities (AAIDD) in 2010 (Schalock et al., 2010), the term defined was (finally) changed to intellectual disability and the manual reaffirmed the assumptions to the definition (above); defined support needs; and added chapters on context, supports, and community-based support systems.

Strengths-Based Approaches to Disability

Of course, medical, psychological, and other conceptualizations of disability are not the only factors that have provide impetus for changing how supports are provided to people with intellectual and developmental disabilities. Although how the construct we now refer to as intellectual disability was understood did not change until the later decades of the twentieth century, there were dramatic changes in society in post-WWII that, in turn, directly influenced policy and practice. Starting in the 1950s, parents began to advocate for options for their sons and daughters with intellectual and developmental disabilities other than the institutions that had dominated the service system during the first half of the century. Federal legislation in the 1960s emphasized community-based services. The civil rights movement in America influenced people with disabilities and their advocates to take on the mantle of civil liberty and equal rights. Eventually, legislation addressing discrimination and equal access emerged, including federal acts pertaining to equal access to education, protections for people with developmental disabilities and, ultimately, the Americans with Disabilities Act of 1990 (Wehmeyer, 2013).

Federal protections and investments in community-based supports led to a decline in institutions. The institution census (number of people with intellectual and developmental disabilities living in state-run institutions) peaked in 1967 at 194,650 people. The census fell below 100,000 the first time in 1988 and, as of 2005, was down to 40,532 people residing in these state-run institutions. Simultaneously, the number of smaller, community-based residential settings rose. In 1977, the number of people with intellectual and developmental disabilities living in state-funded or private community-based residences with six or fewer people totaled 20,400. By 1992, that number had risen to 119,675 and, by 2005, was slightly less than 300,000 people. An additional 50,000 people lived in slightly larger community residences supporting 7–15 people (Prouty, Smith, & Lakin, 2006).

The increased presence of people with disabilities in their communities, including the opportunity for children with disabilities to attend schools, resulted in greater opportunities for employment and school and community inclusion, which led to innovations in efforts to promote community-based outcomes, like supported employment. In fact, if one considers the basics of supported employment, which emerged in the late 1970s to mid-1980s, it is a model for how person–environment fit understandings of disability impact supports provisions. At its core, supported employment begins with a person's strengths and interests, considers the demands of the context (work site, job, etc.), and implements actions that improve personal capacity and modify the demands of the environment. In essence, the field began to move toward practices driven by person–environment fit models of disability before such models were widely promulgated.

This text takes the unequivocal position that historical pathology-based models of disability have run their course and are no longer relevant, although it must be noted that they are still far too prevalent in society. The success of people with disabilities in all aspects of life as a result of civil protections and equal opportunities has made pathology-based understandings of disabilities irrelevant or inaccurate. It is well past time to begin to consider intellectual and developmental disabilities within a strengths-based focus. The chapters in the next sections of this text do so within the lenses of positive psychology and a supports model.

Examining the literature in the field of intellectual and developmental disabilities suggests that the trends are toward these strengths-based approaches. Shogren, Wehmeyer, Buchanon, and Lopez (2006) conducted a content analysis of 30 years of the literature in the field of intellectual disability to examine the degree to which research emphasized the strengths and capacities of people with intellectual disability and the degree to which the literature base included constructs associated with positive psychology. Shogren, Wehmeyer, and colleagues found a gradual progression of the implementation of constructs found in positive psychology across decades (beginning in 1975 through 2004), with only slightly more than 27% of articles that studied some aspect of human functioning identifying positive constructs from 1975 to 1984, slightly more than 44% from 1985 to 1994, and 63% from 1995 to 2004. From among all of these constructs, examinations of personal control, problem-solving, goal setting, and self-determination constituted the largest percentage of positive constructs studied (15% of the 27% total from 1975 to 1984, 19% of 44% total from 1985 to 1994, and almost 30% of the 63% total from 1995 to 2004).

The chapters in this text reflect topics that provide applications of positive psychology and strengths-based practices to the field of intellectual disability as they lead to a new paradigm for disability supports. Some such topics (self-determination, positive behavior supports, quality of life, supported and customized employment) are well established practices in the field. Other topics (problem-solving and decision making, goal setting and attainment) are topics that are discussed, but may have had limited applications in the field. Still other topics have had very little coverage in the field (mindfulness, character strengths, hope). And, one must note, if one examines the topics that are listed in typical texts pertaining to positive psychology, there are many topics that are simply still absent from the discussion in the field of intellectual and developmental disabilities (optimism, creativity, curiosity, compassion, spirituality, etc.).

For example, one of the most widely studied constructs in positive psychology is well-being and all its facets. Happiness and life satisfaction are recognized as the pillars of emotional well-being (e.g., subjective well-being, happiness, psychological well-being, social well-being). Diener, Lucas, and Oishi (2002) defined subjective well-being as a person's "cognitive and affective evaluations of his or her life with emotional reactions and cognitive judgements of fulfillment" (p. 63). Keyes and Lopez (2002) elaborated on in this concept by dividing subjective well-being concept into two groups: emotional well-being, which includes satisfaction or happiness; and positive functioning, which includes social well-being (social integration) and psychological well-being (personal growth). Ryff and Singer (2002) characterized psychological well-being as a "declaration of the highest levels of human functioning" (p. 542). Thus, in positive psychology, subjective well-being has been divided into two constructs: expressive emotions (presence or absence of happiness) and general satisfaction with life (Lucas-Carasco & Salavador-Carulla, 2012).

And yet, while the numbers of studies of the constructs cited above (happiness, well-being, lifestyle satisfaction, etc.) numbers in the thousands and thousands in the psychological literature, the studies that focus specifically on these constructs as they pertain to people with intellectual disability are in the tens. (Note that the closely related construct of quality life, represented in this text, has direct connections to well-being and satisfaction constructs, but research in this area focuses largely on *systems* that support quality of life; in providing an ecological framework for promoting well-being, and not, as it were, research on individual well-being or life satisfaction.) The gist is, we know little about what contributes to happiness and well-being with regard to people with intellectual disability.

In a review of research pertaining to the "well-being" construct and people with intellectual disability, we identified only a handful of studies. For example, Rey, Extremera, Duran, and Ortiz-Tallo (2013) investigated the possible contribution of emotional competence to the subjective well-being of 139 adults with intellectual disability in Spain. In addition to finding that emotional competence was a predictor of well-being for these adults, the authors found that better understandings about regulating emotions resulted in better coping skills when dealing with emotional issues and, thus, psychological well-being might increase if people were provided opportunities to learn emotional regulation skills. Carmeli, Orbach, Zinger-Vaknin, Morad, and Merrick (2008) investigated physical activity among 62 older adults with intellectual disability and found that a group that engaged in exercise more regularly increased their well-being scores. The authors suggested that improved fitness might also influence psychological well-being.

Additionally, we only located a few studies examining lifestyle satisfaction and people with intellectual disability. Bramston, Bruggerman, and Pretty (2002) focused on examining how community connectedness could affect the life satisfaction of 132 Australian adolescents with intellectual disability and found a moderate correlation between self-reported lifestyle satisfaction and community belonging. Similarly, Schwartz and Rabinovitz (2003) investigated the life satisfaction of 93 Israeli young adults with intellectual disability who lived in residences their communities, though the focus of the study was mainly on relationships between resident life satisfaction scores and proxy estimates of resident life satisfaction by staff (they were highly correlated). Finally, Shogren, Lopez, Wehmeyer, Little, and Pressgrove (2006) explored associations between hope, optimism, locus of control, self-determination, and life satisfaction for adolescents with and without disabilities. These constructs were highly correlated for all participants, and hope and optimism directly predicted life satisfaction.

Conclusion

The point of this brief summary of the application of the well-being and life satisfaction constructs to people with intellectual disability was to simply note that even in areas in positive psychology that are well studied in the general population, investigations with regard to people with intellectual disability are still limited. This is, we would argue, because too many people in the field and in the general public still ascribe to models of disability that emphasize pathology and deficit. As we move toward models that emphasize strengths, we anticipate that the literature based on topics such as optimism, well-being, compassion, and spirituality will become a focal point for research and practice to support people with intellectual disability.

The movement to a person–environment fit model of disability opens the door for strengths-based approaches to disability through the provision of supports that reduce the gap between personal capacity and the demands of typical environments. The chapters in the next section of this text provide information on the practices that have emerged, at this point, to apply these strengths-based, positive approaches to intellectual and developmental disabilities. The next chapter examines the supports paradigm and how supports and support needs are conceptualized and implemented.

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The Supports Paradigm and Intellectual and Developmental Disabilities

3

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Introduction

In the *Structure of Scientific Revolutions*, Thomas Kuhn (1970) posited that advances in a scientific field proceed via paradigmatic shifts. A classic example of a paradigmatic shift is the Copernican Revolution in the 1500s. Astronomers worked for over a thousand years to develop and refine mathematical approaches that predicted astronomical occurrences (e.g., positions of stars and constellations) based on the Ptolemaic paradigm, which held that the earth was the center of the universe. Everything changed when Copernicus introduced his Heliocentric paradigm (i.e., the Sun, not the Earth, was the center of the universe). As Galileo would surely attest, the new paradigm encountered some initial resistance. But it was eventually recognized as a superior means to guide work in the field of astronomy because planetary motion could be far more accurately predicted with its application.

The Copernican Revolution was not the simply the result of Copernicus coming up with a novel idea out of the blue. Rather, he (and others before him) was dissatisfied with the scope of inaccurate predictions and the contradictory information that resulted from applying the dominant paradigm. When errors and contradictions emerging from the application of a paradigm become untenable, the search begins for a better paradigm that provides more satisfactory solutions. As Kuhn (1970) pointed out, “Ptolemaic astronomy had failed to solve its problems; the time had come to give a competitor a chance” (p. 76).

In this chapter, we use the term paradigm to mean the *widely accepted truths, assumptions, and viewpoints that guide people’s work in a given field*. Specifically, we refer to paradigms with regard to how the work by members of the field is conducted, in this case, what do services and supports for people with intellectual disability across contexts and domains look like? Chapter 2 discussed the myriad of factors that led to a paradigm shift in the field of intellectual and developmental disabilities, including changing understandings of disability, increased legal protections against discrimination, improved interventions focused on the community, and the emergence of the self-advocacy field. The social sciences and human services to people with disabilities do not have paradigms that are

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comparable to those in the hard sciences, yet the work of people in a field such as intellectual and developmental disabilities most certainly is driven by widely accepted truths, assumptions, and viewpoints. This chapter is focused on ways in which the field has shifted (and continues to shift) to a Supports Paradigm because it offers a more satisfactory direction for practice to overcome obstacles that have impeded progress in reaching the field's ultimate goal of maximizing opportunities for people with disabilities throughout their life span to experience a high quality of life as full and valued participants in schools and adult society.

Butterworth (2002) offered an early description of the Supports Paradigm when he wrote that the "New Supports Paradigm suggests that individuals should first, without restriction, define the lifestyles they prefer and the environments they want to access. Their goals and priorities then become the basis for intensity and types of support they need to succeed in these environments" (p. 85).

Thompson, Schalock, Agosta, Teninty, and Fortune (2014) expanded on Butterworth's description by noting:

> Effectively arranging supports that are truly personalized is the overarching purpose that coalesces the intent of public policies and funding, the actions of jurisdictional agencies, the missions of community-level provider organizations, the activities of planning teams that are formed around individuals with ID/DD, and the work of direct support professionals (p. 87).

As mentioned previously, a paradigm in a multidisciplinary, human service field such as intellectual and developmental disabilities is an amalgamation of truths, assumptions, and viewpoints. It is a product of values that have developed over time as well as the knowledge gained from prior experience, which includes knowledge obtained through scientific research. The discussion pertaining to the shift to strengths-based models of disability in Chap. 2 illustrates the latter.

Historic Paradigms in the Field of Intellectual and Developmental Disabilities

If the Supports Paradigm is a new paradigm for the field of intellectual and developmental disabilities, it is reasonable to ask what paradigms proceeded it, why were the previous paradigms found to be less than satisfactory, and in what way does the Supports Paradigm provide better solutions. Thompson et al. (2014) suggested that two prior paradigms dominated the field at earlier times, and remnants of their influence are evident to this date.

The Medical-Institutional Paradigm

Chapter 2 provided an overview of the Medical-Institutional Paradigm, derived from pathology-based models of disability. These conceptualizations emphasized assessments to identify pathology, most notably intelligence testing; segregation and homogeneous grouping; and, eventually, eugenics and sterilization. The Medical-Institutional Paradigm was in full bloom by the 1930s with intellectual disability being understood as a pathology, and people with intellectual disability understood as defective human beings who were not deserving of the same rights as other citizens in the general population.

In hindsight, the shortcomings of the Medical-Institutional Paradigm are glaring. Being understood as person lacking a desirable trait and living in a society where institutions were the only service option was a combination that resulted in lives of segregation from others in society with very few opportunities to explore personal interests and make contributions to the world. Additionally, regardless of what now-archaic disability label (e.g., feeblemindedness, mental deficiency, mental retardation) was used, acquiring this diagnosis made people vulnerable to having their most basic human rights taken away.

Advances in prevention and instruction. Of course, not all of the work in the field of intellectual and developmental disabilities that was completed during the time the Medical-Institutional Paradigm dominated the field lacked merit. As Silverman (2009) observed, certain causes of disability have been virtually eliminated in industrialized countries due to advances in medical research and interventions [e.g., intellectual disability due to congenital hypothryroidism and phenylketonuria (PKU) are completely preventable through newborn screening and treatment]. Moreover, the application of principles of applied behavior analysis led to the development of effective instructional strategies (e.g., see Brown, McDonnell, & Snell, 2015).

Although knowledge gained from medical research focused on curing and/or preventing specific conditions and psychoeducational research focused on identifying and refining effective interventions remains relevant to work in the field today, as noted in the previous chapter, by the start of the 1950s there was an increasing awareness that, on balance, the Medical-Institutional Paradigm was not promoting satisfactory solutions for challenges facing the field. Parents of children with disabilities led the way in rejecting practices that called for narrow perspectives of their children that focused on describing deficits, and they questioned why the only publicly funded service options involved institutional care (Wehmeyer, 2013). During the 1950s and 1960s, the Medical-Institutional Paradigm was discarded in favor of the Normalization-Community Services Paradigm, which called for both people with disabilities and public funded services to be moved out of institutions into local communities.

The Normalization-Community Services Paradigm

Normalization. The principle of normalization was first introduced in Scandinavian countries in the late 1950s, but was not widely introduced in the USA until the 1960s. "The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969, p. 181). Normalization was antithetical to the practice of institutionalizing people. Therefore, normalization provided a compelling justification—both intellectually and morally—for introducing public policies that promoted deinstitutionalization and expanded services offered to children and adults in local communities. By the mid-1970s, normalization had become fully embraced as a philosophically unifying concept in the USA.

Normalization forced policymakers and professionals to ask straightforward, yet profound, questions such as "Why wouldn't people with disabilities want the same types of life conditions and experiences that are valued by the vast majority of others from the general population?"; "Wouldn't it make sense that denying people access to culturally valued settings and experiences harms their learning and development, and therefore exacerbates their limitations and problems?"; and "Why are people wasting their lives away in institutions, when they could be contributing members of society?" Table 3.1 shows Nirje's normalization guidelines (i.e., what the principle of normalization means in action) alongside Robert Perske's (2004) reports of practices at the institution in which was working at the time he became aware of the normalization principle. Perske drew contrasts between his daily work at the institution and Nirje's "eight planks of normalization" to illustrate how he came to question the need to institutionalize people and the wisdom of the Medical-Institutional Paradigm.

Deinstitutionalization and community services. The major implications of the Normalization-Community Services Paradigm for public policies were deinstitutionalization (i.e., move people out of institutions into local communities and prevent new institutional admissions) and establishing a community-based service system. Throughout the USA, large "multipurpose institutions" that provided all services (i.e., residential, vocational, educational,

Table 3.1 Comparing Nirje's (1969) guidelines to Perske's (2004) experiences at an institution

Nirje's (1969) normalization guidelines	Perske's (2004) reflections on institutional life
"*Normalization means a normal rhythm of the day*" (p. 183) (e.g., getting out of bed and getting dressed in the morning; eating meals and snacks as the day proceeded; having things to do, people to see, and places to go during the day; not having to go to bed earlier than same-age peers)	"The rhythm of the day at the institution where I worked was remarkably abnormal. All of our residents were dressed and fed before the 7 a.m. shift change. They were in bed by 8:30 in the evening." (p. 147)
Normalization means a normal routine of life p. 183) (e.g., people live in one place, attend work or school in another, have leisure activities in lots of places, and every minute of the day is not structured with group activities)	"In the institution where I worked, the sleeping, eating, learning, working, and recreating took place within the same enclosed compound." (p. 147)
Normalization means to experience the normal rhythm of the year, with holidays and family days of personal significance (p. 183) (e.g., people refresh their bodies and minds by celebrating holidays and going on vacation)	"At my institution, special days such as Christmas, Easter, and Independence Day were seen as 'skeleton crew days.' It was the staff members whose rhythm of the year was honored." (p. 147)
Normalization also means an opportunity to undergo normal developmental experiences of the life cycle (p. 183) (e.g., children, youth, adults, and older adults have different experiences in life based on their physical, intellectual, and emotional wants and needs during different periods of life)	"Our residents did not receive the touching and caressing that little children need. Later, they were denied the atmospheres in which adolescents normally thrive. Still later, they would not enjoy atmospheres adult and elderly persons usually receive." (p. 147)
The normalization principle also means that the choices, wishes, and desires of the mentally retarded themselves have to be taken into consideration as nearly as possible, and respected (p. 184) [e.g., choices ranging from the lower stakes, everyday (choosing what to wear) to the higher stakes, long-term (what vocation to pursue) need to be available]	"In my institution, the workers made all of the decisions. 'No, John, I can't let you do that because if I did everyone else on the ward would want to do it.' 'No, John, what you are asking is inappropriate.'" (p. 147)
Normalization also means living in a bisexual world (p. 184) (i.e., a world with both sexes). (e.g., date, marry, and engage in consensual intimate and loving relationships)	"Periodically, the recreation department scheduled a Saturday night dance, but many staff members were pressed into action, too - watching the residents like hawks." (p. 148)
Normalization means normal economic standards. (p. 185) (e.g., being in control of one's own money, including spending it how one wishes to spend it)	"We kept real money out of the hands of our residents. There were no savings accounts." (p. 148)
Normalization means the standards of the physical facility should be the same as those regularly applied in society (p. 185) (e.g., people with disabilities should not live in homes that are clearly substandard or different than others)	"My institution contained wards of 40 persons. In each ward one found a large room with 40 beds in two or three long rows, a day room with many benches, and an aide station in the center." (p. 148)

leisure) in one place were replaced by an array of service provider organizations in local communities that offered a variety of services and programs. Community-based residential, vocational, recreational, and educational services expanded rapidly throughout the 1970s and 1980s.

As discussed in Chap. 2, data showing the decline of institutions and growth of community-based settings over the past 50 years are striking. Today, there are fewer than 25,000 people with intellectual and developmental disabilities living in state-run institutions (Larson et al., 2014). Conversely, Braddock et al. (2015) reported that from 1982 to 2013 the number of people nationwide living in settings with 6 or fewer people increased from 33,000 to 505,000.

Of course, inclusion in life in local neighborhoods and communities involves much more than housing. Residing in a local community most certainly offered more and richer options for inclusion in the full range of activities that constitute a life. However, in terms of recreation-leisure services, most provider organizations still focused efforts on "group activity" types of programs that were targeted only to people with disabilities, perpetuating models of segregation that had prevailed for decades under this, supposedly, new paradigm (Hoge & Dattillo, 1995; Schleien & Werder, 1985).

The same thing happened in other domains. In terms of vocational services, the most common approach during the Normalization-Community Services era involved establishing a "community vocational center" where there was a continuum of programs that were designated by names such as "day activity," "prevocational work," and "sheltered work" (typically the highest level). In sheltered work, the vocational center procured a contract from a community employer, and workers with intellectual and developmental disabilities were paid on a piece rate basis (i.e., based on the amount of work they completed). Some centers also had a competitive employment job component where workers were transitioned from sheltered employment to employment on a competitive job in the community, though research by the end of the 1970s showed that moving upward through vocational preparation levels and ultimately finding employment in a community job paying a competitive wage was very rare (US Department of Labor, 1979). This remains the case to the current day (Cimera, 2011). Again, the "new" paradigm perpetuated old models of segregation because of the way that people with intellectual and developmental disabilities continued to be understood.

So, not surprisingly perhaps, when efforts to implement the new federal law pertaining to access to education in the late 1970s occurred, despite language in the legislation emphasizing education within general education settings with specially designed instruction, what emerged were models where children with intellectual and developmental disabilities were segregated in special schools and special classes (Pyecha et al., 1980). Children with intellectual and developmental disabilities remain among the most segregated populations in schools. Only 17.1% of children with intellectual disability and 13.1% of children with multiple disabilities spend 80% more of their day in general education classrooms—these are the two smallest percentages of the 13 disability categories counted by the federal government. Additionally, these two disability groups are the most (proportionally) represented in segregated programs, with 56.3% of children with intellectual disability and 70.7% of children with multiple disabilities being educated in general education settings for less 40% of their school day, or in "other environments" (e.g., special schools).

There can be little argument that many positive changes occurred as the result of the shift from the Medical-Institutional Paradigm to the Normalization-Community Integration Paradigm. As time progressed, however, it became apparent that the Normalization-Community Integration Paradigm would only take the field of intellectual and developmental disabilities so far, in large measure because of how disability was understood during that era. It became increasingly evident that to continue progressing and more fully address the needs and concerns of people with disabilities and their families, a new paradigm was needed. The Supports Paradigm emerged as an alternative in the 1980s, and unlike the Normalization-Community Services Paradigm, the Supports Paradigm was linked to the understanding of disability introduced by the ICIDH and ICF (Chap. 2) and to the person-environment fit model of disability associated with these changes.

The Supports Paradigm

Progress in an applied field such as intellectual and developmental disabilities is rarely, if ever, linear. Oftentimes, two steps forward are followed by one step back. Nevertheless, an important milestone in the field's shift to Supports Paradigm occurred with the publication of the of the *Definition, Classification, and Systems of Supports* manual published by the American Association on Mental Retardation (Luckasson et al., 1992). As was discussed in detail in Chap. 2, this manual first introduced the social-ecological or person-environment fit model to understanding intellectual disability.

How Person-Environment Fit Models of Disability Impact Practice

Person-environment fit models, such as those forwarded in ICF and the AAIDD 2010 Classification manual (see Chap. 2), facilitated a shift to a new paradigm in several ways. Pathology-based models view disability as a chronic medical condition, which, in turn, call for long-term treatment and care in specialized settings. Specialized settings, by Definition, limit people's opportunities to participate in the larger society. Just as people who experience serious health problems need care in a hospital setting, for many years it was assumed that people with intellectual and developmental disabilities required treatment from specialized professionals in separate settings (e.g., institutions, sheltered workshops, separate special education schools and classes) and reintegration to the community was something that could *only* occur once people had progressed to the point that they were ready to come back.

Thus, an implication stemming from focusing on people's deficits was a "readiness approach" to entry into community life. The readiness approach called for people to be taught and to demonstrate prerequisite skills prior to having access to settings and activities that others in the community value (Cimera, 2011). The problem with the readiness approach is that people with intellectual and developmental disabilities have historically languished in readiness programs for years. Most people never reach the point where they are deemed to be *ready* to attend general education classrooms, work on jobs for community employers, or participate in recreational activities and settings available to the general public. Therefore, the readiness approach resulted in people spending their lives segregated from the rest of society; stuck in settings and activities in which few others in the population would choose to spend time.

The contrasting Supports Paradigm perspective derived from person-environment fit models of disability is that "[i]ntellectual disability is best understood in terms of the fit between personal competency and the demands of community environments. Understanding people this way focuses professional efforts on modifying the context by either changing the environment, such as is accomplished through universal design, or introducing personalize supports" (Thompson, 2013, p. 516). Evaluating whether or not a person is ready for participation in community activities and settings is not relevant to a person-environment fit model of disability. What is relevant is evaluating whether or not supports are in place that enable a person to be successful in typical environments. Therefore, when there is a lack of success, is not because people were not sufficiently ready, but rather it is the result of supports that were not in place.

The critical implication of the person-environment fit model of disability for professional work is to prioritize time and energy on (a) enabling people to improve their capacity, (b) modifying environments and activities so that a person can more fully participate, and (c) providing personalized supports that enable more successful participation. The ultimate goal or purpose of a system that is based on person-environment fit models of disability is to enhance opportunities for people with disabilities to better access and enjoy the people, places, and activities that they value.

Environmental modifications are undertaken to make settings and activities more accessible and to support function within those environments. For example, providing a computer with an interface that allows both pictures and text might enable a person with reading difficulties and memory limitations to use that computer efficiently and effectively at work. Such an environmental modification is really no different than building a ramp to allow physical access to a building for a person with a physical disability—both the computer modification and building modification are done to promote access to locations and activities that would otherwise not be available.

Another way to improve the person-environment fit is to provide individualized supports. Individualized supports are "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (Luckasson et al., 2002, p. 151). The first step in providing supports is to understand a person's support needs. Thompson et al. (2009) defined support needs as "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (p. 135). For supports to be individualized, they must be identified, arranged, and implemented based on a person's support needs and the life activities and settings in which they are engaged. Although support needs are stable, they are not fixed. Moreover, people's preferences change over time. Therefore, individualized support planning is an ongoing process, and planning team members should continually strive to make sure support plans are aligned with people's current needs and aspirations (Thompson et al., 2015, 2016).

In summary, a critical difference between prior paradigms and the Supports Paradigm is that former paradigms called for addressing deficits within the person and the Supports Paradigm calls for addressing a person's support needs arising from a person-environment mismatch. Understanding people with intellectual and developmental disabilities through a social-ecological lens directs the attention of professionals toward identifying settings and life activities in which people want to participate, as well as the personalizing supports and environmental modifications people need to meaningfully participate. Contemporary trends and best practices, as well as changes in public policies, illustrate how the Supports Paradigm is shaping the field today.

Inclusive Education

Today's emphasis on inclusive education is well-aligned with the Supports Paradigm and with person-environment fit models of disability. That is, students with intellectual and developmental disabilities are viewed as learners who experience a mismatch between their personal competency and what they are expected to do in general education classrooms and schools. Inclusive education practices are resources and strategies (e.g., supports) that improve that fit through environmental modifications and/or personalized supports. At the individual student level, the focus of inclusive education is on identifying, arranging, and implementing accommodations, adaptations, and modifications (i.e., adjustments to the environment that allow greater and more meaningful participation) and providing personalized supports (e.g., peer tutors, assistive technology) to encourage maximal participation and enhance learning outcomes. In describing what he calls the "third generation" of inclusive practices, Wehmeyer (2014) explained that

> These practices emphasize enhancing personal capacity and modifying the context in which the student learns, including modification to the curriculum itself, which reduces the gap between the student's capabilities and the demands of the environment. These practices include applying universal design for learning (UDL), using educational and assistive technology, applying positive behavior interventions and supports (PBIS), and promoting access to the general education curriculum (p. 11).

Supported Living

In 2012, the Board of Directors of the American Association on Intellectual and Developmental Disabilities and the Congress of Delegates of the Arc of the USA endorsed the following statement on Housing:

> People with intellectual and/or developmental disabilities (I/DD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults

> should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities (AAIDD, 2012, para 1)

As the position statement indicated, expectations in the field of intellectual and developmental disabilities have moved well beyond accessing a residence with an address in a community neighborhood. Lakin and Stancliffe (2007) concisely summarized the goals of the supported living movement by stating:

> - People will have "real homes" in places where they "control their own front doors," and choose their homes and the people with whom they live.
> - Choice of settings for everyday living will not subsume choosing services and supports for those settings; that is, people will not be compelled to choose certain living sites because assistance they need is located only in those sites.
> - People will be helped to define the lifestyles they want and supported in achieving them, and where their experiences have been limited, people are helped to develop and express lifestyle preferences (p. 154).

As discussed previously, there have been dramatic shifts as to "where" people with intellectual and developmental disabilities live. Lakin and Stancliffe (2007) reported that between 1995 and 2005, the number of people receiving residential support (a) outside of homes they shared with family members and (b) in homes that were owned or rented in their names increased from 40,881 to 101,143. Larson et al.'s (2014) most recent data show that in 2013 the number had increased to 503,826. Unfortunately, in the same report Larson and colleagues indicated that there were 110,039 people who qualified for residential services who were on waiting lists for services, but were not receiving any. The "waiting list issue" has been a perpetual problem in adult supports for people with intellectual disability and related developmental disabilities. People have been known to remain on waiting lists for years upon years, and most often, the only way to jump to the top of the list is to experience a "crisis" situation (e.g., a person's parent dies and there is no other support person available) (Braddock et al., 2015).

Despite inequitable resource allocation issues, it is clear that Supports Paradigm has been driving much of the effort in the area of residential supports for the past several decades. The supported living movement involves identifying and arranging personalized supports and making environmental modifications to enhance participation in life activities that are based on personal interests and preferences. Researchers have consistently found that the community provides better life experiences than an institution, and a smaller setting in the community provides better life experiences than a larger setting. Benefits include greater personal freedom, more choices, enhanced self-determination, more participation in social activities, fewer reports of loneliness, increased contact with family and friends, adaptive behavior skill gains, and greater personal satisfaction including a better sense of well-being and safety (see Amado, Stancliffe, McCarron, & McCallion, 2013; Howe, Horner, & Newton, 1998a, b; Lakin & Stancliffe, 2007).

Supported Employment

As mentioned previously, the initial response to deinstitutionalization and the establishment of a community-based service system was the creation of vocational centers that offered a continuum of day activity programs, some of which included the opportunity for paid work. Foremost among the many criticisms of these centers was the reality that very few people ever graduated to paid work in community jobs. Starting in the mid-1980s, the Support Employment movement provided an alternative to the work center approach. As Wehman, Brooke, Lau, and Targett (2013) pointed out "[s]upported employment was initially conceived as an employment support service for people with severe IDD, many of whom were spending their days in sheltered workshops and day activity centers" (p. 296).

Although different models of supported employment have been proposed over time (e.g., individual placement, small business, mobile work crew, enclave) (Wehman et al., 2013), the key features of supported employment are (a) paid employment, (b) in an integrated work setting, with the (c) the provision of ongoing support that most other workers do not need.

All of the features associated with the Supports Paradigm are evident in supported employment. Supported employment begins with respecting people's choices and preferences. Sometimes supports are needed to help people identify their vocational interests, especially in cases where people have not had prior opportunities to work on different types of jobs (Everson & Reid, 1997; Horrocks & Morgan, 2009). Once a person's vocational goals, preferences, and priorities are established and a corresponding job opportunity is secured, the focus of supported employment is providing ongoing support to assure people are successful on their jobs. Just as is done in inclusive education and supported living, the Supports Paradigm calls for the providing personalized supports and environmental modifications to bridge the gap between people's competencies and the demands of vocational settings and activities.

Self-determination

Since the early 1990s, there has been a growing emphasis on enabling people with intellectual and developmental disabilities to become the primary causal agents in their own lives, to understand their rights and responsibilities, and to advocate on their own behalf; all of which is aligned with promoting self-determination. As discussed in a subsequent chapter, the widespread acceptance of self-determination as an important goal (see Wehmeyer, 2015) provides additional evidence that work in the today's field of intellectual and developmental disabilities is coalescing around the Supports Paradigm. People with opportunities to make choices, the power to make decisions, and who have developed self-determination skills over time are in an excellent position to do exactly what Butterworth (2002) indicated was fundamental to the Supports Paradigm, namely that "individuals first, without restriction, define the lifestyles they prefer and the environments they want to access" (p. 85).

Public Policies

Trends in public policies (i.e., laws, mandates, regulations) over the past several decades also suggest that the field of intellectual and developmental disabilities is coalescing around the importance of providing supports that enable people with disabilities to fully participate in school and society.

Civil Rights Laws. The Developmental Disabilities Assistance and Bill of Rights Act (2000) states in its preamble that disability is a *natural part of the human experience*. Like gender, ethnicity, height, sexual orientation, and eye color, disability is part of the landscape of individual differences that confirms that no two people are exactly the same. The landmark American with Disabilities Act (ADA) of 1990 codified into law that individuals with disabilities are entitled to the same legal protection against discrimination as other people who have been historically marginalized and who's civil rights have been denied. As President George H.W. Bush stated when signing of the law:

> This act is powerful in its simplicity. It will ensure that people with disabilities are given the basic guarantees for which they have worked so long and so hard: independence, freedom of choice, control of their lives, the opportunity to blend fully and equally into the rich mosaic of the American mainstream. Legally, it will provide our disabled community with a powerful expansion of protections and then basic civil rights. It will guarantee fair and just access to the fruits of American life which we all must be able to enjoy. (U.S. EEOC, nd.)

Self-directed supports. The Medicaid Home and Community-Based Waiver Services (HCBS) program has become the primary means of funding for community-based services in the USA, particularly long-term residential services.

First authorized by Congress in 1981, federal HCBS "Waiver" spending has grown extensively over the past three decades, from $1.2 million in 1982 to $31.4 billion in 2013 (Braddock et al., 2015). Home and Community-Based Waiver Services programs are called "waiver" programs because states receive permission from the federal government to waive certain requirements/rules associated with the federal government's Medicaid program. Most states have multiple waiver programs, targeting different groups of people and offering different levels of service (e.g., offering different benefits to groups such as children and adults with physical disabilities, children and adults with developmental disabilities, people over age 65), and no two states are exactly the same.

An analyses-state HCBS program is well beyond the scope of this chapter, but Ng, Harrington, Musumeci, and Reaves (2015) reported that in 2014 there were 42 states offering some forms of self-direction in at least one of their waiver programs. Depending on the state, self-directed support programs may also be known as consumer-directed support as well as participant-directed support programs. These programs provide people with disabilities and their families with funding to directly manage their supports. The funding goes straight to the person and his/her family who use individually set budgets to select, purchase, and manage their own supports within an established framework of guidelines. They can recruit, hire, and manage their own direct support workers, or can contract with one or more service provider organizations, or can do a combination (i.e., hire their people for certain things and service provider organizations for others) (Hall-Lande, Hewitt, Bogenshutz, & LaLiberte, 2012).

The steady expansion of self-directed support programs over the past two decades (Ng et al., 2015) provides further evidence that the Supports Paradigm is driving new policies and practices in the field of intellectual and developmental disabilities. By providing funding directly to the people receiving the services and the supports, power is shifted from the provider organizations to the individual. With self-directed support programs, people with disabilities and their families make choices about the supports they receive. Moreover, individualized budgeting (based on interests, activities, and support needs) and the authority to employ staff and contract with programs enhances budget flexibility and provides opportunities for more efficient use of resources. Individuals and families will not be inclined to purchase redundant services nor will they use resources for services they perceive to be ineffectual.

Education regulations. From the time it was first enacted, what is now referred to as the Individuals with Disabilities Education Act (IDEA) stipulated that parents had the right to participate in educational decision making and made it clear that parents did not have to meekly abide by decisions their school district made with which they did not agree. Due process procedures were included in the law that assured parents had a mechanism to appeal to an independent third-party when disagreeing with their school district's decisions. The reauthorizations of the law continued to expand the leverage of parents and students in educational planning and decision-making processes. In particular, the 1997 reauthorization strengthened the influence of parents in evaluation, IEP development, and placement decisions, and required schools to invite a student to attend the IEP when transition services and post-secondary goals were discussed (Yell, 2016).

Today, involving students of all ages in educational planning is recognized as best practice (Thoma & Wehman, 2010). The continuing theme of students with disabilities and their parents having assuming increased influence and control over their educational services and supports, and not simply being the passive recipients of professionals' decisions, is one which is in complete alignment with the concept of consumer empowerment that is central to the Supports Paradigm.

Supports and supplementary aids and services. The IDEA regulations specifically require schools to provide accommodations, modifications, supports, and supplementary aids and services that are needed by a student to be involved in and progressed in the general curriculum (Yell, 2016). Accommodations refer to any change that helps a students work around their disability in order to complete a task or participate in an activity. For example, allowing a student who has difficulty writing to provide answers orally is an accommodation. A modification typically refers to changes in what is taught to or expected from a student. Making an assignment easier so a student is not doing the same level of work as other students, but is still learning the same type of content, is an example of a modification. Supports have been defined previously in the chapter, but in terms of IDEA, they are usually referenced in terms of resources introduced in general education classrooms that enable a child's participation (e.g., assistance from a paraprofessional in certain activities). Supplementary aids and services include adaptive equipment (e.g., special chair to keep a child comfortable and upright), assistive technology (e.g., augmentative communication device to assist a child in communicating), and adaptive materials (e.g., highlighted notes in a text book to assist the child in getting meaning from expository text written above his or her reading level) (Thompson et al., 2016).

Clearly, schools have the responsibility to provide supports in the general education classroom that maximize a student's learning and participation, which is a concept fundamental to the Supports Paradigm. Given the expanse of knowledge on how to support children with intellectual disabilities and related developmental disabilities in general education settings (e.g., see Kurth & Gross, 2015) as well as abundant examples of how supports can be used to enable children with even the most complex needs to meaningfully participate in general education classrooms (Giangreco, Dymond, & Shogren, 2015).

Conclusion

In this chapter, we proposed that the Supports Paradigm has become the dominant paradigm in the field of intellectual and developmental disabilities, and it was contrasted with paradigms from prior eras. The Supports Paradigm is based on widespread agreement regarding the value of inclusion for children in schools and for adults in the broader society, the rejection of segregated service options, the importance of protecting and expanding people's civil rights, the need for higher expectations in terms of personal outcomes, the significance of self-determination in pursuit of goals, the evolution of laws (e.g., ADA, IDEA) and public policies (e.g., self-directed support programs), changing professional roles and practices (e.g., special educator as inclusive education facilitator), and new approaches to service organization and delivery (e.g., supported employment, supported living). All of the trends mentioned above can logically coalesce under the umbrella of the Supports Paradigm.

In summary, the Supports Paradigm encompasses the following tenets:

- The most important difference between people with intellectual and related developmental disabilities and the general population is the former require more intense support in order to fully participate in school and society.
- People's support needs can be effectively addressed by modifying the environment and/or providing personalized supports.
- Supports provided to people should be provided in integrated, community settings and be as unobtrusive as possible.
- Supports should be arranged to build on (i.e., take advantage of) people's relative strengths as well as address their relative limitations.
- Support planning and provision is most effective when people with disabilities have developed self-determination skills and become fully vested (i.e., have acquired a sense of ownership) in their personal goals and aspirations and are operating as the causal agents in their lives.
- When provided the opportunity to establish optimistic goals and provided Systems of Support that build upon personal strengths while addressing gaps between personal

> competence and environmental demands, people's personal outcomes and quality of life will improve.

The final chapter in this section will discuss issues pertaining to assessment in the era of supports and strengths-based approaches to disability. The remainder of the text involves chapters that articulate how to turn theory into practice with regard to the application of positive psychology to the field of intellectual and developmental disabilities.

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4

Assessment in the Application of Positive Psychology to Intellectual and Developmental Disabilities

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As described in Chap. 1, positive psychology emphasizes the importance of strengths-based approaches to understanding human functioning. However, just as deficits-based models have dominated the fields of psychology and disability so have deficit-based assessments. Assessment tools utilized in the intellectual disability field have emphasized the quantification of deficits, typically deficits in intellectual functioning and adaptive behavior, rather than the identification of strengths. Assessing only deficits in functioning reinforced the focus on remediation and "fixing problems," rather than identifying and building on strengths and assets. Central to implementing a strengths-based approach is having strengths-based assessment tools that can be used to identify and build upon personal strengths to promote personal growth and outcomes. Thus, a central focus of the operationalization of new paradigms within positive psychology and disability has been the development of new assessment approaches that are strengths-based and enable the identification of strengths, abilities, values, interests, and preferences to guide intervention to enhance valued personal outcomes.

Given the role of positive psychological assessment in the implementation of a strengths-based approach, the purpose of this chapter is to highlight emerging directions in positive psychological assessment and discuss specific applications in the field of intellectual and developmental disabilities with a focus on strengths-based assessments that have been developed and used with people with intellectual and developmental disabilities.

Positive Psychological Assessment and Practice

As mentioned previously, developing measurement tools that enable the assessment of strengths and positive psychology constructs is critical to advancing positive psychological assessment and practice. As Lopez and Snyder (2003) wrote "by only focusing on weaknesses, psychologists have perpetuated an assessment process that is out of balance" (p. 5). If only weaknesses and deficits are measured during the assessment process, it is likely that only

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weaknesses and deficits will be targeted with interventions and support derived from the assessment process. This is not only to suggest that assessing needs and areas that could be targeted for improvement should not be a part of the assessment process, but by also assessing strengths and assets, a more balanced picture can be developed and an understanding of strengths and assets can be leveraged to enhance personal outcomes.

Within the subfield of counseling psychology, which is closely aligned with positive psychology, a framework has been developed to promote an increased focus on assessing strengths aligned with positive psychology as part of the counseling intake and treatment plan development process. This framework, the Comprehensive Model of Positive Psychological Assessment (CMPPA; Owens, Magyar-Moe, & Lopez, 2015), is a seven-step process that can be used by clinicians to develop—through interviews, tests, and observations—a balanced picture of strengths and weaknesses and enables the development of a balanced approach to the counseling process. An important aspect of the model that has generalizability beyond the field of counseling psychology is its emphasis on practitioners being aware and reflective of their own perspectives and practices, and how this influences the balance achieved in the assessment process. For example, the first three steps of the CMPPA model are directly related to the practitioner and their actions, not the actual assessment process.

The first step asks the practitioner to reflect on their own background, values, and biases. This is to ensure that one's own cultural background is understood, as well as its influences on what is considered a strength and a weakness. Practitioners must acknowledge that the people they are supporting may have differing values that must be considered in the assessment process. The second step asks practitioners to reflect on and ensure that they understand that all people have both strengths and weaknesses and that without understanding the strengths and assets a person has to build upon, those strengths and assets may be overlooked. The third step provides guidance related to how initial paperwork and interview questions are selected to ensure that they reflect the diversity present in society and that each person experiences. The model's authors also provided a comprehensive summary of strengths-based assessment tools related to an array of positive psychological constructs and outcomes, including attachment, career development, coping, emotions, forgiveness, grit, gratitude, hope, humor, mindfulness, optimism, personal growth, meaning, quality of life, religion and spirituality, satisfaction, self-compassion, self-efficacy, self-esteem, strengths, well-being, and therapy processes and outcomes. Several of these constructs and associated measures will be discussed in greater detail in this and other chapters, with a specific focus on their application in the field of intellectual and developmental disabilities. However, what this list communicates is the wide array of assessment tools that are available both to counseling psychologists and others interested in understanding and supporting the use and development of strengths. For example, measures of hope, well-being, and character strengths developed in the general positive psychology field have been validated with people with intellectual and developmental disabilities (Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006; Shogren, Wehmeyer, Lang, & Niemiec, 2016), meaning these tools can be reliability used to identify and develop strengths by practitioners working with people with intellectual and developmental disabilities.

In the CMPPA model, only after these initial three steps targeting practitioner behaviors and attitudes are completed should the practitioner begin to gather data from the person with regard to strengths and weaknesses and use this data to build a plan to support the person in addressing their areas of need. While this model was not developed for, nor tested with people with intellectual and developmental disabilities, the notion of assessing and building on strengths in the process of building individualized support plans for children and adults with intellectual and developmental disabilities is central to the application of positive psychology practices to the intellectual disability field, as further described in Chaps. 5–24 of this handbook. While these chapters will provide depth of coverage on specific applications of positive psychology and the intervention and assessment approaches aligned with these areas, in the remainder of this chapter, we will discuss emerging directions in the application of positive psychology assessment in the field of intellectual and developmental disabilities, setting the stage for later discussions of the application of positive psychology.

Positive Psychological Assessment and Intellectual and Developmental Disabilities

As described in Chap. 2, the person-environment fit model of disability defines disability by the interaction of personal competencies and environmental demands. Assessing the fit (or lack thereof) between personal competencies and environmental demands is critical to identifying the supports needed by a person with an intellectual or developmental disability to achieve the outcomes they want in life. However, central to this perspective is ensuring that, when developing an understanding of both personal competencies and environmental demands, the person is directing this process. The assessment of personal competencies can be strengths-based, using tools aligned with positive psychological constructs described previously. Further, understanding environmental demands must be directly linked to the community environments that a person with a disability accesses based on their age, culture, and preferences and interests. A fundamental premise of the social–ecological model is that such environments are age-appropriate and inclusive.

The movement toward strengths-based assessment in the intellectual and developmental field is increasingly reflected in policy. For example, the Individuals with Disabilities Education Act (2004) stated that in developing a student's individualized education program (IEP), the IEP team must consider "the strengths of the child" as well as the concerns of the parents, the results of the initial or most recent evaluation, and the "academic, developmental, and functional needs of the child." Further, for youth with disabilities who are planning for the transition from school to the adult world, the law stated that transition services must take into the "child's strengths, preferences, and interests." Each of these statements presumes the role of the strength-based assessment in the educational assessment and IEP development and transition planning processes. And, researchers have developed tools that are strengths-based in the disability field from which meaningful IEP and transition goals can be developed (Epstein, 2004); however, in practice, deficit-based assessments still dominate (Shogren, 2013), perhaps because of a lack of frameworks such as those introduced in counseling psychology field to organize strengths-based assessment approaches in the context of education planning. Just as operationalized in the CMPPA model, change is needed not only in how educational practitioners approach assessment, including considerations related to selection of assessment tools, but also beliefs about the assessment and the role of identifying and building on strengths and assets in education planning.

Strengths-based assessment is also increasingly being recognized as a critical part of planning for supports and services in adulthood for people with intellectual and developmental disabilities. Much of this focus has been driven by the growing emphasis on the multiple factors that influence human functioning and the focus on personal outcomes, particularly the enhancement of individual quality of life. In terms of the multiple factors that influence human functioning, Schalock et al. (2010) introduced a multidimensional framework of human functioning that defined five domains that influence human functioning: intellectual functioning, adaptive behavior, health, participation, and context. Schalock et al. (2010) asserted that only by understanding each of these domains, their relationship to personal outcomes, and the role of support in mediating the relationship between strengths and weaknesses in each of these domains and outcomes can enhance human functioning result. Schalock et al. (2010)

acknowledged that in the intellectual disability field, most of the emphasis has been placed on deficits in the first two domains, intellectual functioning and adaptive behavior. Clearly, there is a need for the adoption of strengths-based approaches and tools to understand functioning across each of the domains, to enable the identification of supports that enhance outcomes. Subsequent chapters will provide information on strengths-based assessments and interventions in multiple domains related to adaptive behavior, health, participation, and context.

In addition to the emphasis on a multidimensional framework for human functioning, there has also been a growing emphasis on assessing and evaluating the quality of supports and services based on personal outcomes. Historically, the focus tended to be on program outcomes (e.g., dollars spent and numbers served), but there was limited focus on if supports and services were leading to the outcomes people with intellectual and developmental disabilities wanted in their lives. Shifts, however, have placed growing emphasis on the assessment of quality of supports and services aligned with the outcomes desired by people with intellectual and developmental disabilities (Bradley & Moseley, 2007). Chapter 9 will provide further discussion on the emergence of quality of life assessment frameworks in the disability field, highlighting the impact of these frameworks on supports, services, and outcomes assessment.

Strengths-based Assessment in the Intellectual and Developmental Disability Field

As mentioned previously, tools have emerged within the disability field that align with positive psychological assessment principles and practices, and provide opportunities to identify and build on strengths. In the following sections, we briefly review work within the intellectual and developmental disability field that supports strengths-based approaches to assessment and supports planning.

Support Needs Assessment

As described previously, a major focus in the person-environment fit model of disability is to identify the supports needed due to the mismatch between personal competencies (i.e., personal strengths and weaknesses across the domains of human functioning) and environmental demands. We discussed previously the importance of the reference environment being inclusive, community environments that are aligned with the interests, preferences, and values of people with disabilities. We also mentioned that the primary focus, historically, of assessment in intellectual disability had been quantifying deficits in intellectual functioning and adaptive behavior, rather than assessing the mismatch between personal competencies and environmental demands. To address the lack of tools available to identify these mismatches and the intensity of supports a person needs to function in community environments, there was a need for new tools that specifically examined support needs aligned with a supports model of examining human functioning. Such tools do not focus on what a person cannot do; instead, they focus on what a person needs to be successful. Chapter 3 provide an introduction to the supports model and its implications for building strengths-based systems of supports, but in this section, we will describe an assessment tool, the *Supports Intensity Scale—Children's* and *Adult Version*—that was created to enable the assessment of the psychological construct of support needs, defined as the "pattern and intensity of support a person requires to participate in activities associated with typical human functioning" (Thompson et al., 2009, p. 135).

The Supports Intensity Scale (SIS; Thompson et al., 2004) was the first standardized measure developed to assess the support needs of adults with intellectual and developmental disabilities. It was developed to align with the social–ecological model of disability, and assesses the type, frequency, and duration of supports needed by adults with intellectual and developmental disabilities to participate in seven key adult life domains, Home Living, Community Living, Lifelong Learning, Employment, Health and Safety, Social Activities, and Protection and Advocacy. The scale also asks a series of questions about the presence of exceptional medical and behavioral support needs that may influence support needs, consistent with the multidimensional model of human functioning.

An interviewer works with two respondents who know the personal with an intellectual disability well to complete the items on the scale. The scale was standardized for adults ages 16–64 years, and standardized scores (which provide an indication of the support needs of the person in relation to the population of people with intellectual and developmental disabilities) for overall support needs, as well as each of the life domains mentioned previously. The SIS has been widely adopted, nationally and internationally by intellectual and developmental disability organizations to facilitate individualized support planning and inform decision-making in regard to the allocation of resources.

Given the widespread use of the SIS, a refreshed version of the original scale, the SIS-Adult Version (SIS-A; Thompson et al., 2015a) was published in 2015, which included an updated User's Guide (Thompson et al., 2015b) that provided additional information on the administration of the assessment and the use of assessment data. Further, the need for a tool that could be used with children and youth with intellectual and developmental disabilities was identified, leading to the development of the SIS-Children's Version (SIS-C; Thompson et al., 2016). The SIS-C was developed using the SIS-A framework, but the life domains were modified, as were items, to reflect environmental demands faced by children and youth ages from 5 to 16 years. Thus, there is not only some overlap between domains on the SIS-A and SIS-C, but also differences to reflect environments typically encountered by children. The SIS-C includes seven support need domains: Home Life, Community and Neighborhood, School Participation, School Learning, Health and Safety, Social, and Advocacy Activities. Thus, the School Participation and Learning domains are unique to the SIS-C and replaced the domains of Lifelong Learning and Employment domains on the SIS-A. Like the adult version, the SIS-C has an exceptional medical and behavioral support needs section that provides information about medical conditions and challenging behaviors that create unique support needs for children regardless of their relative intensity of support needs in other domains.

Assessment information derived from the SIS-A and SIS-C provides a profile of the supports needed by a child, adolescent, or adult with intellectual and developmental disabilities. Support teams, which can include IEP/ISP teams, person-centered planning teams, or a network of friends and family, can then use this information to identify specific and personalized supports that build on the interests, preferences, and values of a person, enabling the person to achieve outcomes they value in their community.

Self-determination Assessment

The self-determination construct has been aligned with the field of positive psychology, generally, and has received significant attention in the intellectual and development disability field since the early 1990s. The focus on self-determination in the disability field emerged largely because of systematic advocacy by people with intellectual and developmental disabilities for the right to direct their own lives. Promoting self-determination has been identified as a means of enabling youth and young adults to develop the skills they would need to direct their own lives and achieve outcomes they value. Chapter 5 provides further detail on the self-determination construct and practices that promote the development of self-determination.

However, to understand and promote self-determination, assessments of self-determination skills and opportunities were needed. In the early 1990s, several research teams developed tools that could be used to understand self-determination in adolescents and adults with intellectual and developmental disabilities. Two widely used assessments developed during this time include *The Arc's Self-Determination Scale* (Wehmeyer & Kelchner, 1995) and the *American Institutes for Research (AIR) Self-Determination Scale* (Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994). *The Arc's Self-Determination Scale* was aligned with the functional model of self-determination (Wehmeyer, 1999) and measured overall self-determination along with its essential characteristics which included: autonomy, self-regulation, psychological empowerment, and self-realization. The *AIR Self-Determination Scale* focuses on assessing both student capacity for self-determination, as well as the opportunities available in the environment, and included reports from youth, parents, and teachers. Each assessment has been used in research to examine opportunities for self-determination (Carter, Lane, Pierson, & Glaeser, 2006; Carter, Owens, Trainor, Sun, & Swedeen, 2009) and the relationships between self-determination and other positive psychology constructs, such as quality of life (Lachapelle et al., 2005), hope, and satisfaction with life (Shogren et al., 2006), as well as the impact of interventions on post-school outcomes (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). The Arc's Self-Determination Scale has also been used to explore the relationships between self-determination and career development interventions in adults with disabilities (Shogren, et al., in press).

Recently, an effort was undertaken to update existing measures of self-determination, aligning measurement with developing theory in self-determination (Shogren, et al., 2015) and in positive psychology. The *Self-Determination Inventory System* (Shogren et al., 2014a, b) builds on previous research conducted with The Arc's Self-Determination Scale and the functional model of self-determination, aligning the assessment of self-determination with the latest iteration of the functional model, Causal Agency Theory (see Chap. 5), which addresses issues related to self-determination in the disability field as well as in the field of positive psychology related to positive psychological assessment. The *Self-Determination Inventory System* is currently being validated with a large sample of students with and without disabilities aged 13–22 and includes both a student self-report as well as an "other" report that can be completed by teachers or parents. Next steps will include the development of an adult version of the scale.

The scale assesses three essential characteristics of self-determined action: volitional action, agentic action, and action-control beliefs. Multiple constructs, including autonomy, self-initiation, self-direction, pathways thinking, self-regulation, psychological empowerment, self-realization, and control expectancy, are assessed within each of these essential characteristics. Pilot testing of the scale has suggested its reliability and validity in students with and without disabilities (Shogren, et al., in press (b)), providing a means of understanding self-determination. The scale is being validated with students with and without disabilities to ensure that, in inclusive schools and communities, self-determination is viewed as relevant and important to understand for all students, ensuring that students with intellectual and developmental disabilities get the supports they need to develop their self-determination skills.

Emerging Application of Assessments from Positive Psychology to the Intellectual and Developmental Disability Field

In addition to assessments that are developed for or emerge from the intellectual and developmental disability field, there is a growing recognition of the importance of ensuring that tools developed in the field of positive psychology for all people are accessible, reliable, and valid for people with intellectual and developmental disabilities.

For example, as will be further discussed in Chap. 13, within positive psychology, the assessment of character strengths and virtues has received significant attention. A classification system, the VIA *Classification of Strengths* (Peterson & Seligman, 2004) (formerly referred to as the "Values in Action Classification"), was developed to provide a framework for defining, classifying, and developing interventions to build on the strengths that people display. The assessment provides rankings of 24 character strengths (e.g., creativity, bravery, self-regulation, and humor) and six overarching virtues (i.e., wisdom, courage, humanity, justice, temperance, and transcendence), based on self-report. After identifying one's highest rated strengths, various activities have been developed to use these strengths in new ways to enhance one's life. Two assessment tools based on the VIA framework have been developed, the VIA *Inventory of Strengths* (VIA-IS; Peterson & Seligman, 2004) and the VIA *Inventory of Strengths for Youth* (VIA-Youth; Park & Peterson, 2006). The VIA-IS was developed for adults, and the VIA-Youth for youth, ages 10–17. Both have been extensively used in the general population. Recent research with the VIA-Youth has suggested that youth with disabilities, including intellectual disability, are able to self-report on their strengths and that the tool is as reliable and valid for use with adolescents with disabilities as it is for youth without disabilities (Shogren et al., 2016). Based on this work, administration guidelines for supporting youth with intellectual and developmental disabilities were created (Shogren, Wehmeyer, Forber-Pratt, & Palmer, 2015) and ongoing work is examining applications of the VIA-IS and the application of interventions that promote the use and development of character strengths in adolescents and adults with intellectual and developmental disabilities (Niemiec, Shogren, & Wehmeyer, in press). Further information on strategies to build on character strengths is described in Chap. 13. Tools have also been developed for students with significant intellectual disability to enable others to provide ratings on their character strengths and use this information to guide supports planning. For example, the Assessment Scale for Positive Character Traits-Developmental Disabilities (ASPeCT-DD) tool was developed to measure strengths using an other-report format. The scale has been shown to have reliability in measuring strengths and can be used to support strengths-based assessment that incorporates the perspectives of people in the lives of people with intellectual disability (Woodard, 2009).

In addition to assessments of character strengths, researchers have also explored the assessment and measurement of other constructs associated with positive psychology, including hope, well-being, and happiness. For example, researchers have developed observational assessments to identify indicators of happiness in people with extensive and pervasive support needs who have difficulty communicating through traditional means (Dillon & Carr, 2007). Researchers have also identified tools developed in the broader field of positive psychology, such as the Children's Hope Scale (CHS, Snyder et al., 1997) a measure of hope; the Life Orientation Test-Revised (LOT-R, Scheier, Carver, & Bridges, 1994) a measure of optimism; the Nowicki-Strickland Internal-External Scales (ANS-IE, Nowicki & Duke, 1974) a measure of locus of control; and the Satisfaction with Life scale (SWL, Diener, Emmons, Larson, & Griffin, 1985) and the Self and Global subscales of the Multidimensional Life Satisfaction Scale (MSLSS; Huebner, 1994; Huebner, Laughlin, Ash, & Gilman, 1998) measures of life satisfaction, and validated these tools with populations with intellectual and developmental disabilities (Shogren et al., 2006). Each of these measures can be used to better understand strengths, informing supports provided in multiple domains, including education, supports and services, therapy, and health (Baker & Blumberg, 2011; Prout, 2009).

Conclusions

Within the fields of positive psychology and disability, issues of assessment are critical to moving forward the application of strengths-based approaches. This chapter provided an overview of emerging directions in positive psychology assessment and explored broad implications and applications of positive psychological assessment in the intellectual and developmental disabilities field. The chapters in the next section on the Applications of Positive

Psychology in Intellectual and Developmental Disabilities will further elaborate on ways that strengths-based assessments and approaches can be used to enhance outcomes for people with intellectual and developmental disabilities.

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Part II

Applications of Positive Psychology in Intellectual and Developmental Disabilities

5 Self-determination

Karrie A. Shogren, Michael L. Wehmeyer
and Kathryn M. Burke

Introduction

Self-determination has been extensively studied within the fields of positive psychology and disability, in parallel but complementary ways. Within positive psychology, Self-Determination Theory (SDT), which is more fully discussed by Shogren, Toste, Mahal, and Wehmeyer (2017), has been identified as falling within the parameters of positive psychology since the inception of the field. Self-Determination Theory is a meta-theory of motivation (Ryan & Deci, 2000) that highlights the importance of autonomous motivation and the fulfillment of basic psychological needs for competence, relatedness, and autonomy. Self-Determination Theory has been applied in the disability field (Deci & Chandler, 1986), albeit in a limited fashion, with a focus on how the creation of autonomy-supportive environments enables students to act in ways that address their need for autonomy and to enhance autonomous motivation and well-being. Within the disability field, Causal Agency Theory (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015) emerged as a theoretical framework that draws from the work of SDT related to motivational aspects of self-determination, but focuses more explicitly on self-determination as a dispositional characteristic and the importance of the creation not only of autonomy-supportive environments but also autonomy-supportive instructional strategies that promote self-determination and causal agency. The purpose of the present chapter is to provide an overview of Causal Agency Theory, describe its emergence and application in the intellectual and developmental disability field, and provide an overview of practices to promote self-determination and causal agency.

Emergence of Self-determination in the Intellectual and Developmental Disability Field Self-determination and Causal Agency Theory

Self-determination has received significant attention in the disability field in recent decades. The earliest use of the term, in relation to people with intellectual and developmental disabilities, was in 1972, when Bengt Nirje highlighted the importance of self-determination in his influential writing on the normalization principle. Nirje (1969, 1972) argued that people with disabilities, as all people, deserved to be treated with respect and to have access to their communities and to typical activities and routines. Essential to this was ensuring that people with disabilities had opportunities to make choices and to assert themselves over their lives. As Nirje (1972) wrote:

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> One major facet of the normalization principle is to create conditions through which a [person with a disability] experiences the normal respect to which any human is entitled. Thus, the choices, wishes, desires and aspirations of a [person with a disability] have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one's family, friends, neighbors, co-workers, other people, or vis-a-vis an agency is difficult for many people. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. Thus, the road to self-determination is indeed both difficult and all-important (p. 177).

Despite this early discussion of the importance of self-determination in the context of supporting people with disabilities to live full lives in their communities, self-determination did not receive significant attention again in the intellectual and developmental disabilities field until the 1990s, when it became a critical focus in the self-advocacy movement (Wehmeyer, Bersani, & Gagne, 2000) as well within the growing emphasis on supporting the transition from school to adult life for students with disabilities (Wehmeyer, 1992). Essentially, self-determination became recognized as a critical element of enabling people with disabilities to direct their own lives and attain outcomes aligned with personal interests and preferences. Within the self-advocacy movement, there was a strong focus on empowerment, and the rallying cry of, "Nothing about us, without us," highlighted the emphasis people with intellectual and developmental disabilities placed on directing their lives and leading the self-advocacy movement. In the transition field, skills associated with self-determination (e.g., goal setting and attainment, choice making, decision making, problem solving) were identified as central to enabling adolescents with intellectual and developmental disabilities to become self-determined and to identify, go after, and achieve the things they wanted in the future, namely community living, employment, and meaningful participation (Ward, 1988, 1996). Self-determination emerged as a critical area of focus given not only the personal experiences of people with disabilities, but also the data suggesting the lack of opportunities for people with disabilities to make choices and decisions about their lives (Stancliffe, 1997, 2001; Stancliffe, Abery, & Smith, 2000; Stancliffe et al., 2011; Stancliffe & Wehmeyer, 1995; Tichá et al., 2012). Further, data on the poor post-school outcomes of youth with disabilities transitioning from school to adult life (Blackorby & Wagner, 1996) and indications that promoting self-determination was a way to address these disparate outcomes, led to significant attention being directed to developing interventions to support self-determination.

As a result, a focus emerged in the field of special education on promoting positive post-school outcomes by promoting the self-determination of youth with intellectual and developmental disabilities. Between 1990 and 1994, the US Department of Education's Office of Special Education Programs (OSEP) funded 26 model demonstration projects to develop methods, materials, and strategies to promote the self-determination of youth and young adults with disabilities during the transition from school to adult life (Sands & Wehmeyer, 1996; Ward, 1996). These projects resulted in numerous interventions and curricula to promote goal-setting and attainment, problem-solving, decision-making, and self-advocacy skills and specially designed instructional methods, materials, and strategies to promote self-determination in students with disabilities (Carter-Ludi & Martin, 1995; Field, Martin, Miller, Ward, & Wehmeyer, 1998; Martin & Marshall, 1996; Sands & Wehmeyer, 1996; Serna & Lau-Smith, 1995; Van Reusen, Bos, Schumaker, & Deshler, 1994; Wehmeyer, Agran, & Hughes, 1998). Several definitional frameworks for applying the self-determination construct also emerged (Abery, 1994; Field, 1996; Field & Hoffman, 1994; Mithaug, 1996; Powers et al., 1996; Wehmeyer, 1996; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003; Wehmeyer, Kelchner, & Richards, 1996). The assumption was that by developing interventions and definitional frameworks to promote self-determination, enhanced adult outcomes related to community participation and employment would result.

One of the frameworks that emerged from these efforts was the precursor to Causal Agency

Theory, the functional model of self-determination (Wehmeyer, 1992). The functional model focused on how to promote the self-determination of youth with disabilities and defined self-determined behavior as “the attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference” (p. 305). The theory emphasized that people who are causal agents are people who make or cause things to happen in their lives, rather than others (or other things) making them act in certain ways. The functional model was empirically validated (Wehmeyer et al., 1996) and assessments (Wehmeyer & Kelchner, 1995) and interventions (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) developed to enable its use in school and adult service systems to foster the development of self-determination and the creation of environments that are supportive of self-determination.

Causal Agency Theory

As described previously, the functional model provided a foundation to operationalize a construct that was highly valued by people with disabilities and those that support them. However, given the growth of positive psychology and emerging applications of person-environment fit models of disability and of the supports paradigm in the disability field, a need emerged for an expansion of the functional model to address developing knowledge and highlight applications of self-determination for all people, including people with intellectual and developmental disabilities. Causal Agency Theory provides that expansion (Shogren, Wehmeyer, Palmer, Forber-Pratt, et al., 2015).

Within Causal Agency Theory, self-determination is defined as a

> …dispositional characteristic manifested as acting as the causal agent in one’s life. Self-determined *people* (i.e., causal agents) act in service to freely chosen goals. Self-determined *actions* function to enable a person to be the causal agent in his or her life (Shogren et al., 2015, p. 258).

The definition includes several key terms that are critical to understanding its meaning and application to the lives of people with intellectual and developmental disabilities. First, a *dispositional characteristic* is an enduring tendency used to characterize and describe differences between people; it refers to a tendency to act or think in a particular way, but presumes contextual variance (i.e., socio-contextual supports and opportunities and threats and impediments). As a dispositional characteristic, self-determination can be measured, and variance will be observed across individuals and within individuals over time, particularly as the context changes (e.g., supports and opportunities are provided for self-determined action). And, as people with intellectual and developmental disabilities have opportunities to act in a self-determined manner, it leads to them becoming more and more self-determined. Environments that support greater opportunities for people to act as a causal agent promote development of self-determination, and those that restrict such opportunities impede its development. Research has shown that congregate work and living settings for people with intellectual and developmental disabilities restrict opportunities for making choices and expressing preferences compared with non-congregate, community-based environments and that people with intellectual and developmental disabilities who live or work in non-congregate, community-based settings have higher levels of self-determination (Wehmeyer & Bolding, 1999, 2001). This highlights the need for attention to be directed to how environments are structured to support the development of self-determination, and central to this is promoting autonomous motivation and addressing psychological needs for autonomy, competence and relatedness, as further described in Chap. 19.

Second, with regard to key terms that are critical to understanding the Causal Agency Theory definition of self-determination, is the use of the term causal agency. Broadly defined, *causal agency* implies that it is the individual who makes or causes things to happen in his or her life. Causal agency implies more, however, than just causing action; it implies that the individual acts with an eye toward *causing* an effect to *accomplish* a *specific end* or to *cause* or *create change*. Causal agents engage in self-determined actions, and self-determined actions are characterized by *essential characteristics*—volitional actions, agentic actions, and action-control beliefs (Shogren, Wehmeyer, Palmer, Forber-Pratt et al., 2015). It is these actions that contribute to causal agency and the development of self-determination. The essential characteristics of self-determination address basic psychological needs for autonomy, competence, and relatedness described by Self-Determination Theory and enable people to act as a causal agent in their lives.

Volitional Action. The first such essential characteristic of self-determined action is volitional action. Volitional actions refer to actions based upon conscious choice that reflect one's preferences. Conscious choices are intentionally conceived, deliberate acts that occur without undue external influence. As such, volitional actions are *self-initiated* and function to enable a person to act *autonomously* (i.e., engage in self-governed action). Volitional actions involve the initiation and activation of causal capabilities —the capacity to cause something to happen—in one's life—and involve initiating goals.

Agentic Action. The second essential characteristic is agentic action. Agentic actions are *self-directed* toward a goal. When acting agentically, self-determined people engage in *pathways thinking*. The identification of pathways is a proactive, purposive process that identifies ways to create change and reach a specific end. Agentic actions are *self-regulated*, self-directed, and enable progress toward freely chosen goals. Agentic actions involve sustaining actions toward a goal.

Action-Control Beliefs. The third essential characteristic of self-determined action involves action-control beliefs (Little, Hawley, Henrich, & Marsland, 2002). These beliefs emerge as people engage in volitional and agentic actions, developing a sense of personal empowerment. People learn that there is a link between their actions and the outcomes they experience and believe they can make progress toward their goals. Action-Control Theory (Little, Snyder, & Wehmeyer, 2006) posits three types of action-control beliefs: beliefs about the link between the self and the goal (*control expectancy beliefs*; "When I want to do ____, I can"); beliefs about the link between the self and the means for achieving the goal (*capacity beliefs*; "I have the capabilities to do _____"); and beliefs about the utility or usefulness of a given means for attaining a goal (*causality beliefs*; "I believe my effort will lead to goal achievement" vs. "I believe other factors—luck, access to teachers or social capital—will lead to goal achievement"). As adaptive action-control beliefs emerge, people are better able to act in a *psychologically empowered* and *self-realizing* manner.

Development of Causal Agency

People develop causal agency as they respond to opportunities (or impediments) in their environments. Supportive environments enable people to meet their psychological needs described by Self-Determination Theory (see Chap. 19) and to learn to develop skills that enable them to engage in self-determined action (volitional action, agentic action, and action-control beliefs). This process is depicted in Fig. 5.1 (Wehmeyer, Shogren, Little, & Lopez, in press). The outcome of enhanced self-determination is that people are able to engage in more self-determined actions, acting as causal agents, initiating and engaging in actions directed toward goals.

As such, self-determination develops across the life span, emerging as adolescents develop and acquire multiple, interrelated skills, referred to as component elements of self-determined action that enable the expression of the essential characteristics and component constructs of self-determination including learning to make choices and express preferences, solve problems, engage in making decisions, set and attain goals, self-manage and self-regulate action, self-advocate, and acquire self-awareness and self-knowledge. Table 5.1 highlights key skills, called component elements that support the development of volitional action, agentic action, and action-control beliefs. It is at this level that

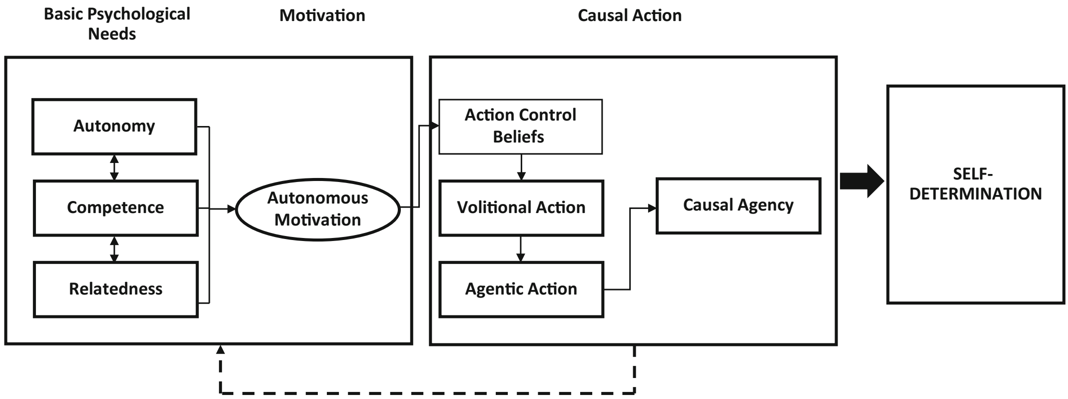


Fig. 5.1 Causal agency theory in the development of self-determination

Table 5.1 Component elements of causal agency theory

Essential characteristics	Component constructs	Component elements
Volitional action	Autonomy Self-initiation	Causal capabilities • Choice-making skills • Decision-making skills • Goal-setting skills • Problem-solving skills • Planning skills
Agentic action	Self-regulation Self-direction Pathways thinking	Agentic capabilities • Self-management skills (self-monitoring, self-evaluation, etc.) • Goal attainment skills • Problem-solving skills • Self-advocacy skills
Action-control beliefs	Psychological empowerment Self-realization Control expectancy Agency beliefs Causality beliefs	• Self-awareness • Self-knowledge

interventions can be implemented to support the development of self-determination and its essential characteristics.

Practices to Promote Self-determination and Causal Agency

As highlighted throughout this chapter, it is critical to consider how to promote causal agency through the creation of autonomy-supportive environments (Eisenman, Pell, Poudel, & Pleet-Odle, 2015), and to provide opportunities for choice making and for students to engage in action that support autonomous motivation, as well as addressing the basic need for autonomy, competence, and relatedness. Shogren et al. (2017) provide more detail on how environments can be structured to support autonomous motivation. The focus of the remainder of this chapter will be on autonomy-supportive interventions that can be used to support the development of self-determined action, and the component elements listed in Table 5.1: choice making, decision making, goal setting, problem solving, planning, self-management, goal attainment, self-advocacy, self-awareness, and self-knowledge.

One evidence-based, autonomy-supportive instructional strategy that has been extensively researched with adolescents with intellectual and developmental disability field is the Self-Determined Learning Model of Instruction (SDLMI; Wehmeyer, Palmer, et al., 2000) and a modified version that has been applied with adults engaged in career development activities called the Self-Determined Career Development Model (SDCDM; Wehmeyer, Lattimore, et al., 2003).

The SDLMI and the SDCDM infuse instruction and support on the component elements of self-determined action (shown in Table 5.1), the process of self-regulated problem solving, and research on self-directed learning. The SDLMI and SDCDM focus on promoting self-regulated problem solving in service of learning goals and job and career goals, respectively. The SDLMI and SDCDM are appropriate for use with youth and adults with and without disabilities across a wide range of domains and contexts and can be individualized to the unique needs of students with intellectual and development disabilities with a range of support needs. For example, the self-directed question that drives the model can be modified to be cognitively accessible and to be delivered through technology and other means.

The SDLMI and SDCDM are models of instruction that are implemented by a facilitator to support people with intellectual and developmental disabilities to learn to self-regulate problem solving in service of a goal. These models provide a framework that teachers and support staff can use to "design instructional materials, and to guide instruction in the classroom and other settings" (Joyce & Weil, 1980, p. 1). The SDLMI and SDCDM are designed to be self-directed in that the person with a disability is directing the learning process, with the supports needed to do so. This differs from how instruction and supports usually occur in the disability field, when other directedness characterizes instruction and supports. But, to promote self-determination and casual agency, there is a need to focus on enabling the person with a disability to direct the process, with the supports needed to do so.

Using the SDLMI and the SDCDM to support people with disabilities consists of a three-phase instructional process. Each phase presents a problem to be solved, and the problem relates to some aspect of learning or the job and career development process. In essence, as the person answers the questions in each phase, he or she must: (a) identify the problem, (b) identify potential solutions to the problem, (c) identify barriers to solving the problem, and (d) identify the consequences of each solution. The problem the person with a disability must address in the first phase is "What is my goal?" The problem presented in the second phase is "What is my plan?" The third phase addresses the problem "What have I learned?" A facilitator can use the model to support the person with the disability to maximally participate in learning the problem-solving sequence, answering the questions presented in each phase, and moving from one phase to the next within a goal-oriented context.

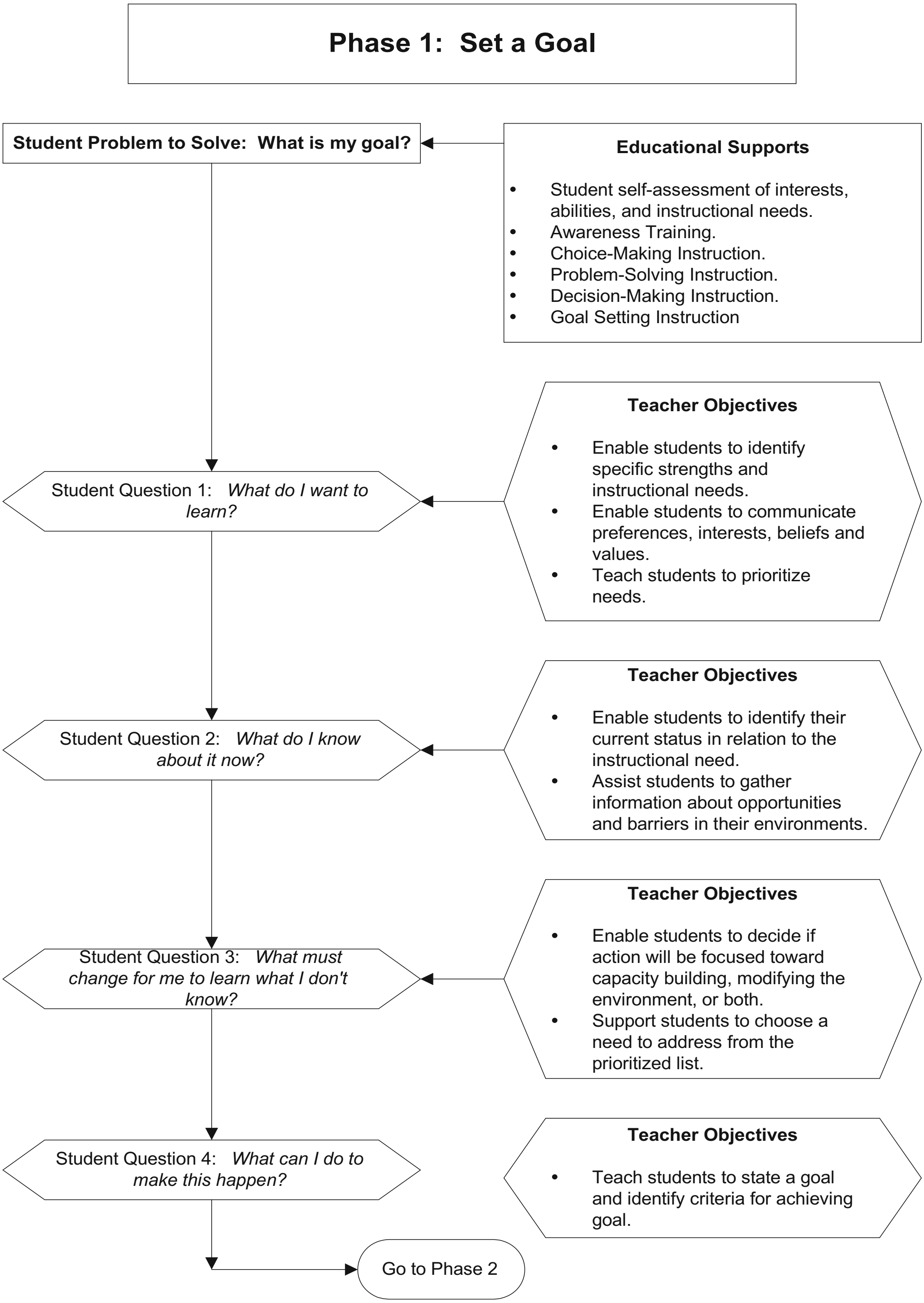
Each question is also linked to a set of *Facilitator Objectives* that provides facilitators with guidance on what they are trying to support each person to achieve in answering the questions. To meet the Facilitator Objectives, each instructional phase also includes a list of *Educational* (for the SDLMI) and *Employment* (for the SDCDM) *Supports* that facilitators can use to enable people with disabilities to self-direct learning. It may be necessary to use the Education and Employment Supports before the person with a disability can answer each question. By providing this instruction, then, the facilitator is enhancing the self-determination skills and the causal agency of the person. The SDLMI and SDCDM are designed to be used iteratively, moving from one goal to another, and thus, the person with a disability will become increasingly self-directed and self-determined over time as they have multiple opportunities to work through the problem-solving process. The SDLMI process is depicted in Fig. 5.2 and the SDCDM in Fig. 5.3. These figures highlight the questions that drive the process, the Facilitator Objectives, and the Education and Employment Supports. Implementation is an individualized process and will be tailored not only to the learning or career development goals, but also the supports needed by each person, and the past learning histories that shape the development of self-determination.

Research on the Impact of Self-determination on Academic and Transition Outcomes

The SDLMI has a large body of evidence supporting its implementation in school settings to enhance the self-determination, goal attainment, and post-school outcomes of youth with disabilities, and a growing body of evidence on its implementation in adult settings to support people with intellectual and developmental disabilities in the career development process. Researchers have also found, generally, that teaching skills leading to enhanced self-determination can improve academic skills (Konrad, Fowler, Walker, Test, & Wood, 2007), attainment of academic (Agran, Blanchard, Hughes, & Wehmeyer, 2002; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Wehmeyer, Palmer, et al., 2000) and transition (Devlin, 2011; McGlashing-Johnson, Agran, Sitlington, Cavin, & Wehmeyer, 2003; Shogren et al., 2012; Wehmeyer, Palmer, et al., 2000; Woods & Martin, 2004) goals, as well as promoting greater access to the general education curriculum (Agran, Wehmeyer, Cavin, & Palmer, 2008; Lee, Wehmeyer, Palmer, Soukup, & Little, 2008) for students with disabilities. Researchers have also found that increased self-determination is linked to enhanced recreation and leisure participation (Dattilo & Rusch, 2012), to increased choice opportunities (Neely-Barnes, Marcenko, & Weber, 2008), and to enhanced quality of life (Lachapelle et al., 2005; Wehmeyer & Schalock, 2001). And, while interventions to promote self-determination have been primarily focused on adolescents and adults with disabilities, students as young as kindergarten have been effectively supported to set goals and self-regulate problem solving with the SDLMI (Palmer & Wehmeyer, 2003).

Researchers have also found that multi-component interventions (i.e., those that target multiple component elements, such as the SDLMI and SDCDM) tend to be the most effective (Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009). Specific to the SDLMI and SDCDM, Wehmeyer et al. (2012) reported the results of a group randomized control study of the efficacy of the SDLMI. Over 300 students with intellectual disability or learning disabilities in the treatment group reported significantly greater increases in self-determination, with the greatest growth in the second year of instruction, suggesting the importance of ongoing exposure to instruction promoting self-determination, particularly for students with intellectual disability. Shogren et al. (2012) conducted a group randomized control study of the impact of the SDLMI on access to the general education curriculum and goal attainment and found that students in the SDLMI group (vs. the control group) made significantly more progress on education goals and had significantly greater increases in their access to the general education curriculum than students assigned to the control group; further, teachers reported significant changes in their perceptions of student's capacity for self-determination (Shogren, Plotner, Palmer, Wehmeyer, & Paek, 2014). Shogren, Wehmeyer, Palmer, Rifenbark, and Little (2015) followed youth with disabilities, including youth with intellectual and developmental disabilities, for two years after high school who were exposed to multi-component interventions to promote self-determination, and found increased employment and community participation outcomes for youth who were more self-determined. Powers et al. (2012) had similar results for youth in foster care and special education, showing that intervention to promote self-determination resulted in better community access outcomes.

With regard to the SDCDM, Wehmeyer et al. (2003) worked with vocational rehabilitation counselors to implement the SDCDM, found that



Phase 1: Set a Goal

Student Problem to Solve: What is my goal?

Educational Supports

- Student self-assessment of interests, abilities, and instructional needs.
- Awareness Training.
- Choice-Making Instruction.
- Problem-Solving Instruction.
- Decision-Making Instruction.
- Goal Setting Instruction

Student Question 1: *What do I want to learn?*

Teacher Objectives

- Enable students to identify specific strengths and instructional needs.
- Enable students to communicate preferences, interests, beliefs and values.
- Teach students to prioritize needs.

Student Question 2: *What do I know about it now?*

Teacher Objectives

- Enable students to identify their current status in relation to the instructional need.
- Assist students to gather information about opportunities and barriers in their environments.

Student Question 3: *What must change for me to learn what I don't know?*

Teacher Objectives

- Enable students to decide if action will be focused toward capacity building, modifying the environment, or both.
- Support students to choose a need to address from the prioritized list.

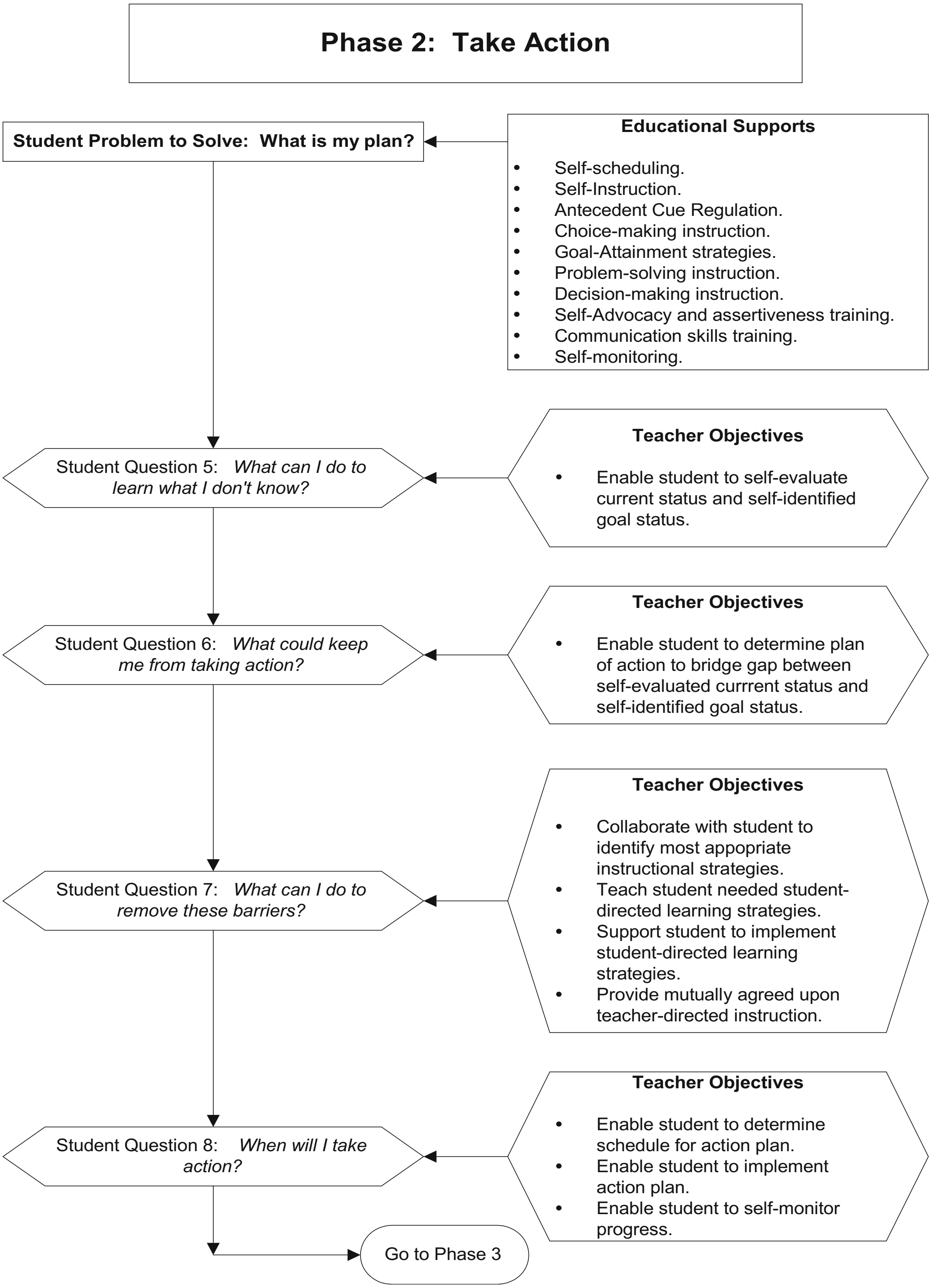
Student Question 4: *What can I do to make this happen?*

Teacher Objectives

- Teach students to state a goal and identify criteria for achieving goal.

Go to Phase 2

Fig. 5.2 The self-determined learning model of instruction (Wehmeyer, Shogren, et al., 2003)



Phase 2: Take Action

Student Problem to Solve: What is my plan?

Educational Supports

- Self-scheduling.
- Self-Instruction.
- Antecedent Cue Regulation.
- Choice-making instruction.
- Goal-Attainment strategies.
- Problem-solving instruction.
- Decision-making instruction.
- Self-Advocacy and assertiveness training.
- Communication skills training.
- Self-monitoring.

Student Question 5: *What can I do to learn what I don't know?*

Teacher Objectives

- Enable student to self-evaluate current status and self-identified goal status.

Student Question 6: *What could keep me from taking action?*

Teacher Objectives

- Enable student to determine plan of action to bridge gap between self-evaluated currrent status and self-identified goal status.

Student Question 7: *What can I do to remove these barriers?*

Teacher Objectives

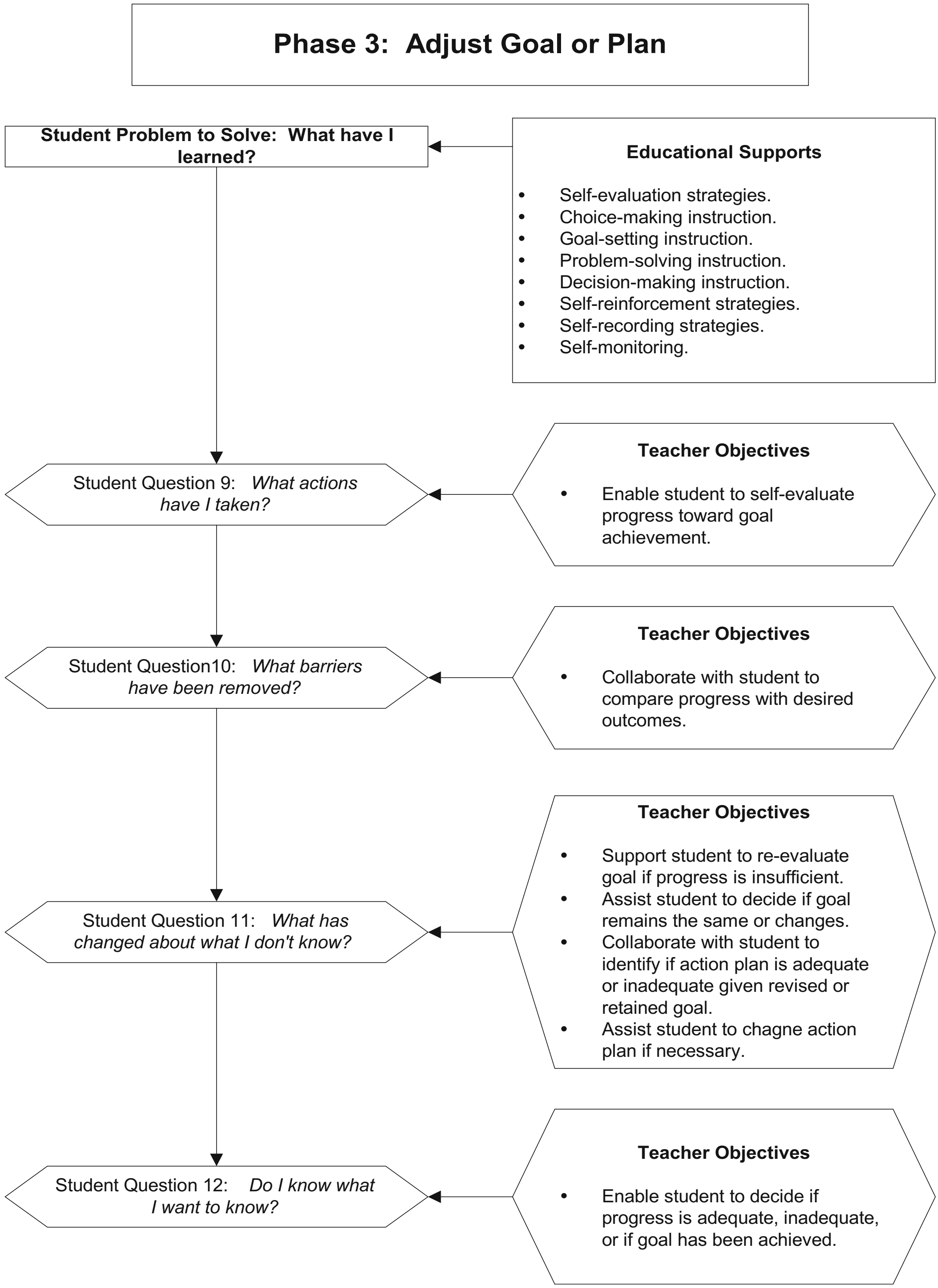
- Collaborate with student to identify most appropriate instructional strategies.
- Teach student needed student-directed learning strategies.
- Support student to implement student-directed learning strategies.
- Provide mutually agreed upon teacher-directed instruction.

Student Question 8: *When will I take action?*

Teacher Objectives

- Enable student to determine schedule for action plan.
- Enable student to implement action plan.
- Enable student to self-monitor progress.

Fig. 5.2 (continued)



Phase 3: Adjust Goal or Plan

Student Problem to Solve: What have I learned?

Educational Supports

- Self-evaluation strategies.
- Choice-making instruction.
- Goal-setting instruction.
- Problem-solving instruction.
- Decision-making instruction.
- Self-reinforcement strategies.
- Self-recording strategies.
- Self-monitoring.

Student Question 9: *What actions have I taken?*

Teacher Objectives

- Enable student to self-evaluate progress toward goal achievement.

Student Question10: *What barriers have been removed?*

Teacher Objectives

- Collaborate with student to compare progress with desired outcomes.

Student Question 11: *What has changed about what I don't know?*

Teacher Objectives

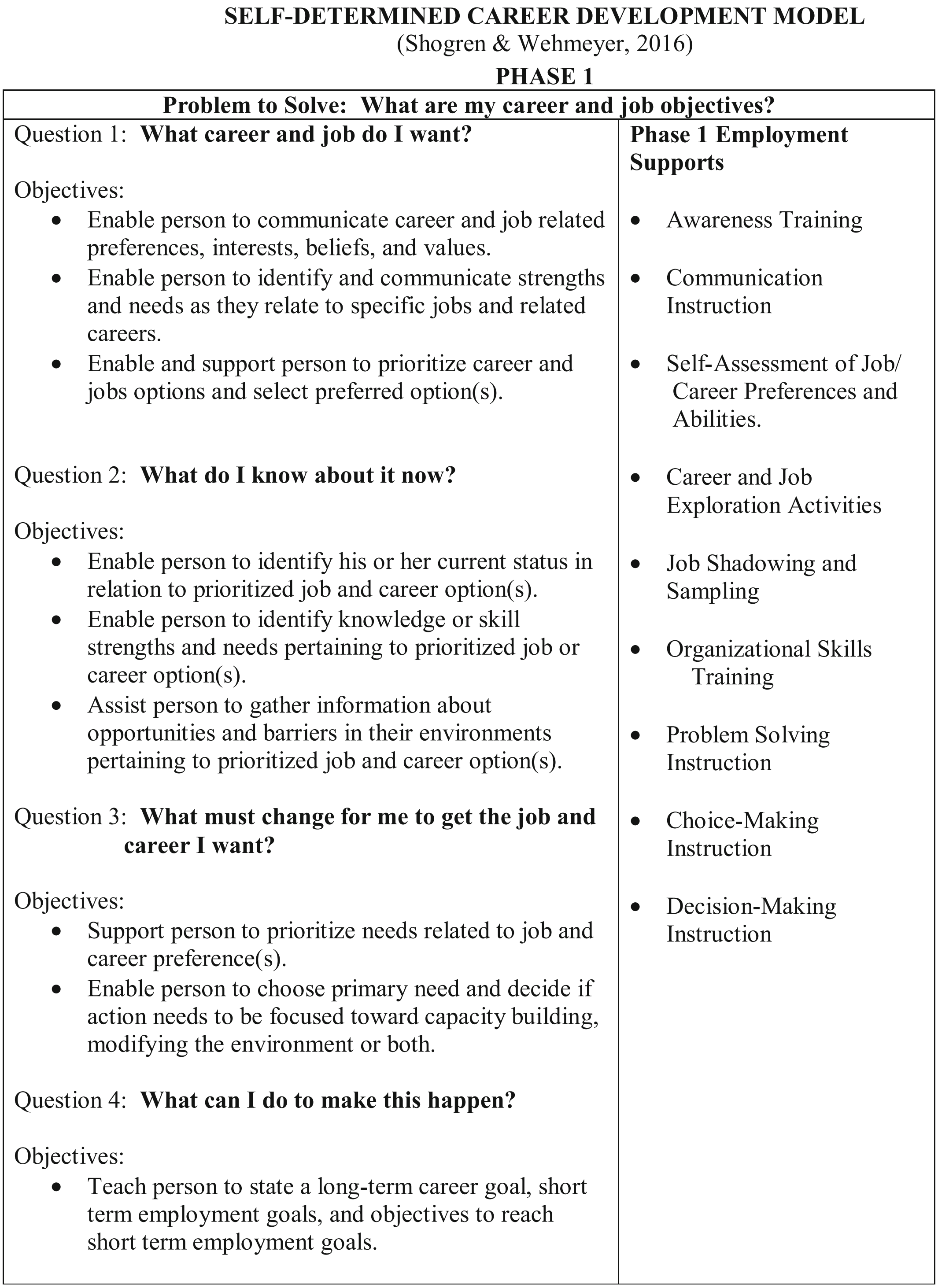
- Support student to re-evaluate goal if progress is insufficient.
- Assist student to decide if goal remains the same or changes.
- Collaborate with student to identify if action plan is adequate or inadequate given revised or retained goal.
- Assist student to chagne action plan if necessary.

Student Question 12: *Do I know what I want to know?*

Teacher Objectives

- Enable student to decide if progress is adequate, inadequate, or if goal has been achieved.

Fig. 5.2 (continued)



SELF-DETERMINED CAREER DEVELOPMENT MODEL
(Shogren & Wehmeyer, 2016)
PHASE 1

Problem to Solve: What are my career and job objectives?	
Question 1: **What career and job do I want?** Objectives: • Enable person to communicate career and job related preferences, interests, beliefs, and values. • Enable person to identify and communicate strengths and needs as they relate to specific jobs and related careers. • Enable and support person to prioritize career and jobs options and select preferred option(s). Question 2: **What do I know about it now?** Objectives: • Enable person to identify his or her current status in relation to prioritized job and career option(s). • Enable person to identify knowledge or skill strengths and needs pertaining to prioritized job or career option(s). • Assist person to gather information about opportunities and barriers in their environments pertaining to prioritized job and career option(s). Question 3: **What must change for me to get the job and career I want?** Objectives: • Support person to prioritize needs related to job and career preference(s). • Enable person to choose primary need and decide if action needs to be focused toward capacity building, modifying the environment or both. Question 4: **What can I do to make this happen?** Objectives: • Teach person to state a long-term career goal, short term employment goals, and objectives to reach short term employment goals.	**Phase 1 Employment Supports** • Awareness Training • Communication Instruction • Self-Assessment of Job/ Career Preferences and Abilities. • Career and Job Exploration Activities • Job Shadowing and Sampling • Organizational Skills Training • Problem Solving Instruction • Choice-Making Instruction • Decision-Making Instruction

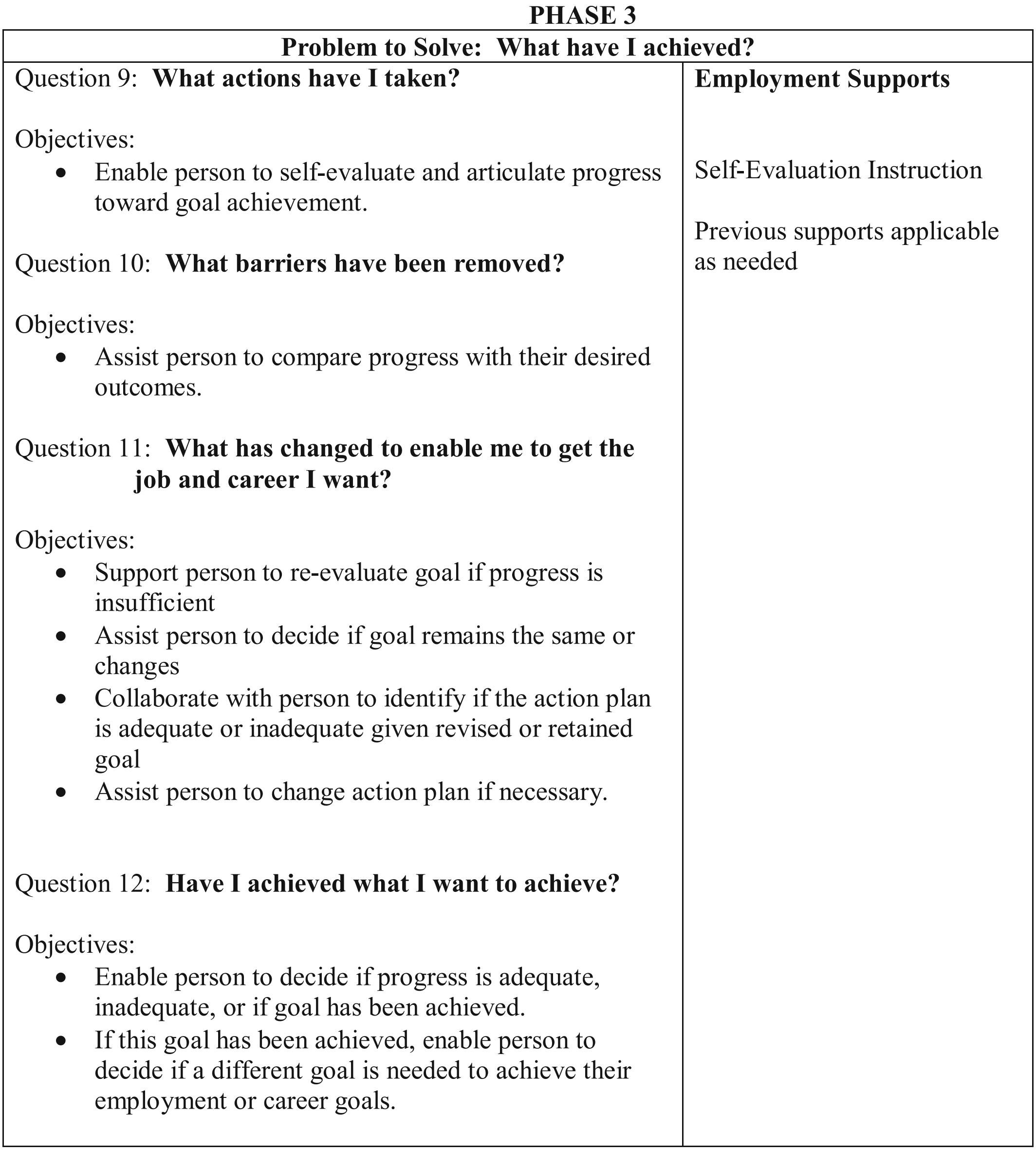
Fig. 5.3 The self-determined career development model (Shogren & Wehmeyer, 2016)

PHASE 2

Problem to Solve: What is my plan	
Question 5: **What actions can I take to reach my career or employment goal?** Objectives: • Enable person to identify action alternatives to achieving career or employment goal. • Assist person in gathering information related to consequences of action alternatives. • Enable person to select best action alternatives Question 6: **What could keep me from taking action?** Objectives: • Support person to identify barriers to implementing action alternatives. • Support person to identify actions to remove barriers. Question 7: **What can I do to remove these barriers?** Objectives: • Assist person in identifying appropriate employment supports to implement selected action alternative • Teach person knowledge and skills needed to implement selected supports. Question 8: **When will I take action ?** Objectives: • Enable person to determine schedule for action plan to remove barriers and implement supports. • Support and enable person to implement the action plan. • Enable person to self-monitor their progress	**Phase 2 Employment Supports** • Exploration of Community Resources and Supports. • Problem Solving Instruction • Goal Setting Instruction • Self-Scheduling Training • Self-Instruction Training • Antecedent Cue Regulation Training • Decision-Making Instruction • Self-Advocacy Instruction • Assertiveness Training • Self-Monitoring Instruction • Self-Evaluation

Fig. 5.3 (continued)

adults with disabilities who were supported to use the model made progress on self-selected employment goals, and felt that they had gained important skills. Wehmeyer et al. (2009) also used the SDCDM as part of a larger intervention package with young women with developmental disabilities, with results showing that these young women found the model useful and effective in setting and working to achieve career development and employment goals. Shogren et al. (in press) examined implementation of the SDCDM with direct support providers as facilitators, examining the impacts on self-determination of adults with intellectual and



PHASE 3

Problem to Solve: What have I achieved?	
Question 9: **What actions have I taken?** Objectives: • Enable person to self-evaluate and articulate progress toward goal achievement. Question 10: **What barriers have been removed?** Objectives: • Assist person to compare progress with their desired outcomes. Question 11: **What has changed to enable me to get the job and career I want?** Objectives: • Support person to re-evaluate goal if progress is insufficient • Assist person to decide if goal remains the same or changes • Collaborate with person to identify if the action plan is adequate or inadequate given revised or retained goal • Assist person to change action plan if necessary. Question 12: **Have I achieved what I want to achieve?** Objectives: • Enable person to decide if progress is adequate, inadequate, or if goal has been achieved. • If this goal has been achieved, enable person to decide if a different goal is needed to achieve their employment or career goals.	**Employment Supports** Self-Evaluation Instruction Previous supports applicable as needed

Fig. 5.3 (continued)

developmental disabilities served by intellectual and developmental disability support provider organizations in the community. Shogren et al. found that the SDCDM influenced self-determination-related outcomes. However, differences in how the provider organizations implemented the SDCDM and supported staff to facilitate its implementation significantly influenced outcomes, suggesting the importance of autonomy-supportive environments and the sneed to concurrently address these factors in interventions to impact outcomes. Finally, Shogren et al. (2016) combined the SDCDM with the Discovery process and found impacts on self-determination when implemented with adults with intellectual and developmental disabilities receiving supports for employment from community service provider organizations.

Overall, these findings suggest the power of multi-component interventions to promote self-determination, like the SDLMI and SDCDM, for providing autonomy-supportive interventions that, when implemented in autonomy-supportive environments, lead to significant changes in self-determination and goal attainment, enabling people with intellectual and developmental disabilities to set and go after goals that enable them to go after what they want and need in life.

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6

Mindfulness: An Application of Positive Psychology in Intellectual and Developmental Disabilities

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Introduction

The cultivation of mindfulness is a centuries-old practice that is commonly found in many of the world's wisdom traditions (Singh, 2014a). Mindfulness entered the Western lexicon when Davids (1881) translated the Pali term *sati* as *mindfulness* in the context of meditation (*dhyāna* in Sanskrit). Although instructions in mindfulness meditation in the West were available for several decades (e.g., Thera, 1962; Hahn, 1976; Suzuki, 1970), it caught the imagination of the general public with Kabat-Zinn's (1990) program, Mindfulness-Based Stress Reduction (MBSR), for treating stress arising from pain and suffering. Over time, mindfulness has become somewhat of an elusive term, because it has been used in practice and research to describe a state, trait, practice, and an intervention. Furthermore, the term has generated multiple definitions, giving rise to questions as to exactly what is being measured across studies that use different measures of mindfulness (Gethin, 2011; Grossman & Van Dam, 2011). Regardless of these growing pains in the development and measurement of mindfulness as an accepted meditation practice, there is a general consensus on the core aspects of mindfulness-based interventions (see Kabat-Zinn, 1990).

Some researchers have equated the use of MBSR with the management or reduction of psychological stress or distress. Thus, they equate MBSR and other mindfulness-based interventions with traditional psychological treatments that focus on disease, disorder, dysfunction, and disabilities. The assumption is that reduction of negative emotional states or pathology will enhance both mental and physical well-being. In this sense, mindfulness-based interventions could be seen as being antithetical to the principles of positive psychology, which is focused on personal growth—the strengthening of positive mental states and well-being. This view is based on a superficial understanding of MBSR as an intervention primarily focused on reducing stress and suffering, as implied by the title of the MBSR program. People who undertake MBSR and related mindfulness-based courses experience personal transformation that enables them to self-regulate their emotional responses to the vicissitudes of life itself, with increasing equanimity. Immersion and deepening

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of mindfulness through disciplined meditation practice enables people to be nonjudgmentally aware of their own patterns of maladaptive behavior and to consciously cultivate beneficial mental states. The focus of mindfulness meditation is on personal, transcendent growth, which produces positive, ineffable changes that build on their inherent strengths. In this sense, interventions based on mindfulness and positive psychology are synergistic experiential approaches that can be subjected to experimental verification.

This chapter provides an overview of mindfulness-based approaches used in the general field of intellectual and developmental disabilities. It provides a comprehensive but not exhaustive narrative review of the published research on mindfulness-based interventions that have been used by people with intellectual and developmental disabilities and their support providers—family members, direct support staff, and teachers—and the effects of these interventions.

Individuals with Intellectual and Developmental Disabilities

A number of mindfulness-based interventions have been taught to individuals with intellectual and developmental disabilities, typically to those individuals who have higher levels of intellectual functioning. These interventions include mindfulness-based therapies, customized mindfulness-based programs, meditation on the soles of the feet, acceptance and commitment therapy, and dialectical behavior therapy.

Mindfulness-Based Programs

Several studies have demonstrated that adolescents and adults with disabilities can master mindfulness skills to enhance their daily lives as well as manage a variety of disorders and problems.

Mindfulness-Based Stress Reduction (MBSR). MBSR, which was very skillfully developed by Kabat-Zinn (1990), is the mother of all mindfulness-based programs. It includes the following: eight weekly classes; an all-day silent retreat; four formal mindfulness meditation practices—body scan meditation, gentle Hatha yoga, sitting meditation, and walking meditation; informal mindfulness practices; and homework assignments. The MBSR program has been used both in its original format and, more recently, in various adaptations depending on the needs or abilities of the participants.

Miodrag et al. (2013) evaluated the feasibility and effectiveness of an adapted MBSR program with 24 adults with Williams syndrome, a neurodevelopmental disorder. People with this syndrome invariably have mild-to-moderate impairments in intellectual functioning (Howlin et al., 2010) and high rates of internalizing and externalizing problems (Morris, 2010). Following a five-day mindfulness training, the adults showed reductions in physiological (i.e., salivary cortisol and alpha-amylase), psychological (self-reported anxiety), and behavioral outcomes (parent/caregiver reports of somatic complaints and attention problems). Reductions in the cortisol and alpha-amylase levels were recorded following daily mindfulness sessions, suggesting increasing self-control of stress-related symptoms as training progressed.

Mindfulness-Based Cognitive Therapy (MBCT). MBCT, which is based on the MBSR program, combines meditation practices with aspects of cognitive therapy to develop mindfulness (Segal et al., 2002). As with MBSR, it is typically used in its original format or adapted to the needs of specific populations. For example, Bögels et al. (2008) used an adapted version of the MBCT program with adolescents (some of whom had autism spectrum disorder) and their parents. Following eight weeks of MBCT training, the adolescents reported substantial improvements on personal goals, happiness, mindful awareness, internalizing and externalizing complaints, and attention problems. This study suggested that these adolescents learned skills that helped them in multiple ways to navigate daily life in a positive manner.

Spek et al. (2013) used a modified MBCT protocol—termed Mindfulness-Based Therapy for Autism Spectrum Disorder (MBT-AS)—in a randomized controlled trial with 44 adults with autism spectrum disorder. The MBT-AS was presented in nine weekly training sessions that included a mindful eating exercise, body scan, mindful breathing meditation, mindful walking, yoga, sitting meditation, listening meditation, psychoeducation on ruminative thoughts, meditation on observing thoughts, and home practice following each week's training. When compared to the control group, the participants reported significant reductions in depression, anxiety, and rumination. In a follow-up study using the MBT-AS with 50 adults with autism spectrum disorder, Kiep et al. (2015) reported significant reductions in anxiety, depression, agoraphobia, somatization, inadequacy in thinking and acting, distrust and interpersonal sensitivity, and sleeping problems. Of importance was that the clinically significant changes were maintained for nine weeks following the termination of mindfulness training. These two studies suggested that adults with autism spectrum disorder can learn how to self-manage their psychological well-being in daily life through mindfulness meditation.

Idusohan-Moizer et al. (2015) developed a mindfulness-based program, based on MBCT, for adults in the community with moderate-to-borderline impairments in intellectual functioning and either recurrent depression or anxiety, or both clinical conditions. The intervention included mindfulness of the breath, basic yoga exercises, the raisin exercise for mindful eating, a diary of pleasant and unpleasant events from MBCT, metaphors and analogies from acceptance and commitment therapy (ACT), exercises on developing self-compassion, and the meditation on the soles of the feet (SoF) procedure (Singh & Jackman, 2017a). They ran the program for nine weeks, with a follow-up at six weeks post intervention. The participants experienced improvements in depression, anxiety, self-compassion, and compassion. These improvements were maintained at the six-week follow-up, suggesting emergent transformative changes in the participants.

Customized Mindfulness-Based Programs. Chilvers et al. (2011) developed a customized mindfulness program that was introduced and assessed for effectiveness in a medium-secure psychiatric ward for female offenders. The program was effective in reducing three proxy measures of aggression—number of observations, physical interventions, and seclusions. The program had multiple components, only some of which were based on mindfulness, and it cannot be concluded that mindfulness was responsible for reductions in aggression. However, the data were suggestive of female offenders being able to self-regulate their emotions with a treatment package that included training in mindfulness.

Meditation on the Soles of the Feet

In the first application of a mindfulness-based procedure in the field of intellectual and developmental disabilities, Singh et al. (2003) taught a 27-year-old man to use a newly developed mindfulness-based procedure, meditation on the Soles of the Feet (SoF), as a simple self-management strategy for anger management. The man, who had a comorbid psychotic disorder, had been institutionalized at the age of 7 years due to uncontrolled aggression, placed in foster care at 15, admitted for inpatient psychiatric care at 16, and discharged to a community group home at 17. For 10 years thereafter, he was admitted and discharged from psychiatric hospitals for his aggressive behavior. Following his self-referral for treatment, he was taught the SoF procedure, which he mastered to control his anger and aggression, and thereafter managed his community placement without engaging in aggressive behaviors. Indeed, he was not only able to manage his own aggressive behaviors but also teach his peers to use the same procedure to successfully manage their aggressive behaviors (Singh et al., 2011a).

The SoF procedure was originally developed as a mindfulness-based procedure for self-managing the *precursors* of emotionally arousing behaviors that may give rise to anger and aggression (Singh & Jackman, 2017b). It provides a skillful means of abating rising anger by shifting one's attention and awareness from the emotionally charged situation, and any subsequent perceptions of the situation, to a neutral point on the body, the soles of the feet. It enables the person to downregulate the surging emotion due to either an internal or external situational change. The meditation enables the person to volitionally exercise inhibitory control and, with practice, this control becomes almost automatic. While SoF has been used most extensively for managing anger and aggression, therapists have found it to be generally useful as an effective way of regulating one's mental state when faced with other emotionally arousing situations, such as anxiety and worry.

Extant research using single-subject research designs and a randomized controlled trial has shown that people with intellectual disability can effectively use the SoF procedure to self-manage their aggressive behaviors (Singh et al., 2013a). In addition, children and adolescents with autism spectrum disorder have also been successful in using the SoF procedure to manage aggressive behavior. For example, Singh et al. (2011b) taught three adolescents with autism to manage their physical aggression with the SoF procedure. They were able to reduce their aggressive behavior from a mean range of 14–20 per week during baseline to zero during the last 4 weeks of intervention. In addition, they were able to maintain control of their aggressive behavior at about one physical aggression per year during the three-year follow-up. In a related study, Singh et al. (2011c) taught three adolescents with Asperger syndrome to manage their low-rate physical aggression with the SoF procedure. They were able to reduce their physical aggression from a mean baseline rate of about three per week to almost zero during intervention, with no instances during a four-year follow-up. These studies suggest that the SoF procedure provides individuals with a simple but effective way of responding positively under adverse conditions.

People with intellectual and developmental disabilities have used the SoF procedure, alone and in combination with other procedures, in a variety of contexts and for different behaviors. We provide a brief overview of such use.

Community placements. Occasionally, people with intellectual disability who live in the community are threatened with more restrictive and segregated placements due to their aggressive behaviors toward peers and support staff. In such cases, it invariably leads to more restrictive lifestyles and their quality of life is compromised, but this need not be the case if appropriate interventions can be developed for them. For example, Singh et al. (2007a) taught the SoF procedure to three adults who had moderate impairments in intellectual functioning and were at risk of being placed in more restrictive settings because of high-intensity, uncontrolled aggressive behaviors. Given their level of functioning, they found it somewhat difficult to understand the visualization instructions, but were able to master the procedure when the instructions were concretized with recent episodes of aggressive behaviors they exhibited, and additional prompts were provided. They were successful in managing their anger and aggression, and in maintaining long-term community placements without further professional intervention. This study suggested that people functioning at lower cognitive levels may be able to master the SoF procedure if individual-specific instructional accommodations are made for them.

Forensic settings. Individuals in forensic settings often engage in aggressive and violent behavior, and it is no different for those who have intellectual and developmental disabilities. Singh et al. (2008a) taught the SoF procedure to six offenders with mild intellectual and developmental disabilities for self-management of their anger and aggression. They were able to successfully decrease their physical and verbal aggression, thereby preempting the need for the medication and physical restraints they were typically subjected to following an aggressive incident. In addition, this study showed that the additional cost of their care due to their aggressive behavior was reduced by 95.7% when the individuals were able to self-manage their physical aggression. In another study, Singh et al. (2011d) taught mindfulness skills to three adult sexual offenders with intellectual disability to control their sexual arousal. The men were minimally successful at controlling their sexual arousal when viewing printed stimulus materials that they usually found sexually arousing. The men achieved some success with the SoF procedure, but were most successful in controlling their sexual arousal with a Mindful Observation of Thoughts meditation procedure. This procedure required them to (1) focus on their breath, (2) observe the beginning, middle, and end of their thoughts, (3) observe their thoughts as clouds passing through their awareness, and (4) observe the precursors to their sexual arousal as thought clouds without (a) pushing the thoughts away, (b) engaging with the thoughts, or (c) becoming emotionally attached to the thoughts. This study suggested that individuals with intellectual disability can, with appropriate mindfulness training, exert inhibitory control over strong emotionally arousing situations in their life.

Smoking. Smoking is a recognized risk factor for various health conditions, as well as for death and dying. In the first of three studies, Singh et al. (2011e) developed and implemented a three-component mindfulness-based smoking cessation procedure with a 31-year-old man with mild intellectual disability who had been smoking for 17 years. The procedures included (a) intention, (b) mindful observation of thoughts, and (c) SoF. The man was able to demonstrate control over successive reductions in the number of cigarettes smoked through a changing-criterion design until he quit smoking in less than three months. He demonstrated control over abstinence during a 12-month follow-up. In a second study, three men who smoked up to 40 cigarettes a day were able to achieve abstinence in just over two to five months and maintain abstinence during the three-year follow-up period (Singh et al., 2013b). The efficacy of the meditation procedures for smoking cessation in this population was demonstrated in a third study, a randomized controlled trial (Singh et al., 2014b). These studies indicated that people with intellectual disability can be mindful of their health and volitionally overcome their smoking addiction.

Health and Wellness. Research suggests that people with neurodevelopmental disorders can use mindfulness-based procedures to manage their health and wellness issues. For example, individuals with Prader–Willi syndrome have an insatiable appetite that often leads to overweight and obesity, a health issue that has not been amenable to traditional medical or behavioral treatments. Two proof-of-concept studies indicate that customized mindfulness-based procedures may assist such people to manage their eating disorder through a mindfulness-based lifestyle change program. In the first study, Singh et al. (2008b) used an incremental procedure to evaluate the effects of a multicomponent health and wellness intervention on weight management by an adolescent with Prader–Willi syndrome and mild impairments in intellectual functioning. The components were regular exercise; regular exercise plus healthy eating; and regular exercise, healthy eating, and mindfulness-based procedures that included (a) mindful eating, (b) visualizing and labeling hunger, and (c) rapidly shifting attention away from hunger by engaging in SoF. In the second study, Singh et al. (2011f) used an enhanced multicomponent health and wellness procedure that consisted of: (a) physical exercise, (b) food awareness, (c) mindful eating to manage rapid eating, (d) visualizing and labeling hunger, and (e) the SoF procedure as a self-management strategy against temptation to eat between meals. Three adolescents with Prader–Willi syndrome and mild intellectual disability were able to reduce their weights to within the accepted body mass index range despite their biologically driven insatiable appetite. In both studies, the adolescents were able to maintain their body weights during a three-year follow-up period suggesting long-term gains in self-control and enhanced healthy lifestyles.

Telehealth. The rapid growth of information and communications technology over the last few decades has given rise to its use in medicine and health care, generally known as telemedicine, telehealth, or eHealth, and the more recent rise of mobile technology has led to mobile health or mHealth (Davis et al., 2016). Telehealth is particularly helpful in providing services to underserved populations like those in rural areas that do not have access to clinical professionals. Recently, telehealth has been adopted as an effective technology for delivering behavioral health assessments and interventions (Wacker et al., 2016). For example, Singh et al. (2017) reported the use of telehealth technology to teach three teachers in a rural school district the basics of the SoF procedure. The teachers then taught three students with intellectual disability to successfully use the SoF procedure to manage their physical and verbal aggression. It is likely that the SoF procedure could be used more widely with telehealth technology.

Acceptance and Commitment Therapy

Acceptance and Commitment Therapy (ACT), a modified form of cognitive behavior therapy, is based on relational frame theory and includes a variety of techniques depending on the context of therapy or training. Its six core principles include cognitive diffusion, acceptance, contact with the present moment, observing the self, values, and committed action. ACT is an evidence-based therapy for a large number of psychological and psychiatric conditions (Hayes et al., 2016). Modified versions of ACT activities have been used with people with intellectual disability. For example, Brown and Hooper (2009) used mindfulness and ACT-based experiential activities to successfully treat anxious and obsessive thoughts in an adolescent with moderate-to-severe impairments in intellectual functioning. Pahnke et al. (2014) evaluated the feasibility and outcomes of a six-week ACT-based skills training group with high-functioning students with autism spectrum disorder. Initial results showed that the ACT-based intervention resulted in decreased stress, hyperactivity and emotional distress, and increased prosocial behavior.

Dialectical Behavior Therapy

Dialectical behavior therapy (DBT), another modified form of cognitive behavior therapy, is especially relevant for people who engage in self-harm behaviors, such as suicidal thoughts, urges, and attempts. These behaviors are symptomatic of individuals diagnosed as having borderline personality disorder (BPD) and have comorbid problems, such as depression, anxiety, eating disorders, and substance use. DBT is an evidence-based therapy that is being used not only with individuals with BPD, but also with individuals who have a number of other issues (e.g., binge-eating) in adolescents and adults (Linehan, 2014). Following an early description of a modified DBT program for individual with intellectual disability (Lew et al., 2006), there have been a few accounts of its use in community settings as well as a few studies with small samples (e.g., Baillie & Slater, 2014; Morrissey & Ingamells, 2011; Sakdalan et al., 2010; Verhoeven, 2010). There are some suggestions in the extant literature that DBT may enable people with intellectual disability to enhance their ability to function in a socially acceptable manner in community and secure forensic settings despite their personality or forensic issues.

In sum, individuals with intellectual and developmental disability can master a variety of mindfulness-based techniques—both as a part of a course of instructions in multiple mindfulness meditations (e.g., MBSR, MBCT), mindfulness techniques in the context of cognitive behavior therapies (e.g., ACT, DBT), and an individual mindfulness-based meditation (i.e., SoF) alone and combined with other procedures and meditations. Extant research suggests that people with intellectual and developmental disability can benefit from individual as well as group instruction in mindfulness procedures. The outcomes of these mindfulness instructions are statistically and clinically significant, positive, and enduring.

Parents of People with Intellectual and Developmental Disabilities

There is emerging research suggestive of the role mindfulness may play in the lives of parents of people with intellectual and developmental disabilities. For example, MacDonald and

Hastings (2010) reported a direct relationship between fathers' level of mindfulness and involvement in child-related parenting tasks—more mindful fathers are more involved with their children's socialization. Beer et al. (2013) found higher levels of mindful parenting were correlated with lower levels of depression and stress. Furthermore, lower levels of mindful parenting were correlated with higher levels of child behavior problems. In a study with mothers of children with autism, Conner and White (2014) found that mindfulness is associated with levels of maternal stress above and beyond child behavior problems. Jones et al. (2014) reported mediation effects of mindful parenting on maternal anxiety, depression, and stress. These theoretical findings suggest that enhancing mindful parenting may be of benefit not only for parents, but also for their children with intellectual and developmental disabilities.

Mindfulness-Based Programs

A number of mindfulness-based practices have been taught to parents of individuals with intellectual and developmental disabilities. These include MBSR, MBCT, and customized mindfulness-based therapies.

Mindfulness-Based Stress Reduction. When compared to a waiting-list control condition, Neece (2014) found that parents who completed a standard MBSR program reported significant reductions in stress and depression, and enhanced life satisfaction. In addition, parent training in MBSR was correlated with reduced attention problems and symptoms of attention-deficit hyperactivity disorder in their children. Using a sub-sample from the Neece study, Lewallen and Neece (2015) reported that children of parents who participated in the MBSR program showed improvements in self-control, empathy, and engagement. Furthermore, teachers reported that these children showed improvements in communication, responsibility, and cooperation.

In a large randomized controlled trial, Dykens et al. (2014) compared the relative effects of MBSR and positive adult development (PAD: a positive psychology practice) programs on mothers of children with autism and other disabilities. Both programs were effective, but mothers trained in MBSR showed greater improvements in anxiety, depression, sleep, and well-being. Bazzano et al. (2015) used a community-based participatory approach to offering training in MBSR to parents and primary caregivers of people with developmental disabilities. At termination and two months following termination of the MBSR training, parents and caregivers reported significantly lower levels of perceived stress and increased mindfulness, self-compassion, and well-being. In another community-based sample, Roberts and Neece (2015) used the standard MBSR program with parents of children with intellectual and developmental disabilities and reported improvements in the parents' mental health and positive changes in their children's behavior.

Mindfulness-Based Cognitive Therapy. Ferraioli and Harris (2013) compared the effects of mindfulness (based on MBCT and the mindfulness module of DBT) and skills-based parent training programs for parents of children with autism. Assessments for parental stress and global health outcomes were undertaken at pre-treatment, post-treatment, and three-month follow-up. Statistically significant improvements were evident on both outcome measures only for parents who received the mindfulness training. Lunsky et al. (2015) evaluated the effects of a mindfulness-based coping with stress group (based on MBCT and MBSR) for parents of adolescents and adults with IDD. While no significant changes were found in the parents' mindfulness or mindful parenting scores, parents who completed the training showed significant reductions in stress, the primary outcome targeted in this study.

Customized Mindfulness-Based Programs. In one of the earliest mindfulness-based parenting studies with parents of children with autism, Singh et al. (2006a) developed a customized 12-week multicomponent mindfulness-based parenting program. They taught the mindfulness program to three parents of children with autism and evaluated the effects of the program on outcomes for the children. They reported that enhanced mindful parenting skills of the parents decreased the aggression, noncompliance, and self-injury in their children and increased the parents' satisfaction with their parenting skills and social interactions with their children. Singh et al. (2007b) replicated these procedures with four parents of children with intellectual and developmental disabilities and reported similar findings. In an extension of these efforts, Singh et al. (2014c) developed an eight-week mindfulness-based program combined with streamlined positive behavior support that aimed to teach participants a broad-based mindfulness practice and skills to develop and mindfully implement positive behavior support for individuals with challenging behaviors. Results of this study with mothers of adolescents with autism spectrum disorder showed that there was a significant decrease in the mothers' stress as well as improvements in the adolescents' behavior. These improvements were maintained for over 30 weeks during the follow-up period. These studies suggest that customized mindfulness-based programs can be developed and successfully meet the needs of families with members who have intellectual and developmental disabilities.

In a novel study, Hwang et al. (2015) developed a customized eight-week mindfulness program for mothers of children with autism spectrum disorders and problem behaviors. They initially taught the program to the mothers and when they were successful in their mindfulness practice, the mothers taught mindfulness activities to their children. Although the outcomes of the training varied among the mothers and their children, in general, the mothers reported increased levels of mindfulness for themselves and reduced problem behaviors for the children following the termination of training, and reduction of parenting stress. Following instructions in mindfulness activities by their mothers, the children exhibited less anxiety and thought problems. Additional details on the study and outcomes can be found in Hwang and Kearney (2016).

Heifetz and Dyson (2016) developed and evaluated a mindfulness-based group for teens with intellectual and developmental disabilities and their parents that was run in parallel. The aim was to assist the teens to reduce their difficulties with emotional regulation and to increase social behaviors. The parent training was for the parents to learn mindfulness skills so that they could guide and support their teens in their mindfulness practices. The teens were able to master the mindfulness practices and, following training, they appeared to be more happy, relaxed, and less worried, while the parents exhibited increased mindfulness.

In sum, there is an emerging evidence base of standard and customized mindfulness-based interventions that show much promise in enhancing the ability of parents of individuals with intellectual and developmental disabilities to mindfully support their children. These interventions assist parents in reducing their own perceived psychological stress and in increasing their psychological well-being. In addition, children and adolescents with intellectual and developmental disabilities show enhanced emotion regulation and psychological well-being when they receive parallel training in mindfulness activities or when their parents receive the training alone. These studies support the notion that mindfulness for parents has a bidirectional effect with their children, although intuitively one could suggest that the effects would be strongest when both parents and their children receive mindfulness training either together or separately.

Support Providers of Individuals with Intellectual and Developmental Disabilities

As with parent caregivers, paid support providers are often stressed due to the nature of caregiving in the field of developmental disabilities (Hastings et al. 2006; Hensel et al. 2012). Support providers may be unable to cope with the emotional and physiological reactions to job-related demands, often leading to burnout, which results from depleted physical and emotional strength due to prolonged stress (Crawford et al. 2010).

Eventually, caregiver burnout leads to diminished quality and safety in care and may compromise the quality of lives of people with developmental disabilities (Salyers et al. 2016). Issues of stress and burnout are rooted in personal emotional regulation in the face of internal and/or external pressure to perform one's job under adverse conditions. Thus, mindfulness-based interventions may be helpful for paid support providers because it teaches them how to regulate their emotion under demanding circumstances (Vago and Silbersweig 2012). In line with this thinking, a small number of mindfulness-based practices have been taught to paid support providers of individuals with intellectual and developmental disabilities.

Mindfulness-Based Programs

Customized Mindfulness-Based Programs. In the earliest use of a customized mindfulness-based intervention with support providers, Singh et al. (2004) provided mindfulness training to three support providers who were yoked to three control support providers. They assessed the effects of caregiver mindfulness training on the level of happiness of three adults with intellectual and developmental disabilities who were at the profound level of intellectual functioning. Regardless of their baseline rate, all three individuals increased their levels of happiness when supported by staff trained in mindfulness, but remained at baseline levels with the control staff. Singh et al. (2006b) provided a five-day intensive mindfulness training to support providers in group homes for individuals with intellectual and developmental disabilities following behavioral training. When compared to baseline rate, caregiver behavioral training resulted in a small reduction in aggressive behavior by the individuals, but their aggressive behaviors were significantly reduced only following caregiver mindfulness training. Similarly, there was some increase in the number of learning objectives mastered by the individuals following caregiver behavioral training, but substantial increases occurred only when the support providers completed mindfulness training.

Mindfulness-Based Positive Behavior Support. In an early version of the mindfulness-based positive behavior support (MBPBS) program, Singh et al. (2009) provided a 12-week mindfulness training course to group home staff. As training progressed and following completion of the training, staff reduced and then eliminated the use of physical restraints contingent on the aggressive behavior of persons they were supporting. In addition, the use of emergency medication decreased substantially, and staff and peer injuries resulting from the individuals' aggressive behavior decreased to near-zero levels. In the first formal use of MBPBS with paid caregivers, Singh et al. (2015) provided a seven-day mindfulness training to group home staff. When compared to baseline measures, the staff showed clinically and statistically significant reductions following mindfulness training in the use of verbal redirection in response to aggressive behaviors of the adults with intellectual and developmental disabilities and terminated the use of physical restraints. They reduced their own perceived stress, which eliminated staff turnover. In addition, once the individuals' aggressive behaviors were under control, all staff and peer injuries stopped. Furthermore, benefit–cost analysis showed a substantial financial savings for the group homes due to staff training in MBPBS. These findings were essentially replicated by Singh et al. (2016a) with caregivers in community group homes for people with intellectual disability with mild intellectual impairments, and by Singh et al. (2016b) in a randomized controlled trial with support providers in a congregate care facility for individuals with intellectual disability who were at severe or profound levels of intellectual functioning.

Occupational Mindfulness

Brooker et al. (2013) developed the Occupational Mindfulness (OM) program, based on MBSR and MBCT, for support providers in Australia. Training was provided to 34 participants

(22 managers and 12 disability support workers) at baseline and following completion of the training. Results showed the participants positively evaluated the program and reported significant increases in positive affect and the mindfulness facet of observing. However, they also reported increases in negative affect, perceived stress, anxiety, and negative emotional symptoms. In a follow-up study, Brooker et al. (2014) assessed the effects of the OM program on the use of restrictive interventions by disability support workers. They reported reduced use of "as required" medications (PRN, pro re nata), seclusions, and chemical restraints. These findings replicated the earlier findings of Singh et al. (2009), which reported that mindfulness-based training of staff reduced restrictive interventions.

Acceptance and Commitment Therapy

In two related studies, Noone and Hastings (2009, 2010) evaluated the impact of Promotion of Acceptance in Carers and Teachers (PACT), an intervention based on ACT, on support staff stress, work-related stressors, and psychological well-being. Following training, staff reported less psychological distress without a reduction in the perceived level of work stress. These studies suggested that support providers may benefit from ACT and mindfulness-based interventions. Bethay et al. (2013) developed two training modules—one focused on ACT and applied behavior analysis (ABA) and the other on ABA alone—for staff from a state-funded residential facility for people with intellectual and developmental disabilities. The participants received training in either the ACT + ABA or ABA alone. When compared to staff who received ABA alone, those who received the ACT + ABA training showed greater reductions in psychological distress as well as a concurrent decrease in the believability of burnout-related thoughts. McConachie et al. (2014) evaluated the effectiveness of an acceptance and mindfulness-based stress management workshop with staff working with people with intellectual and developmental disabilities and challenging behaviors. Staff attending the workshop showed significant improvements in psychological distress, which was maintained at six-week follow-up.

In sum, the emerging research on providing mindfulness training to paid support providers of people with intellectual and developmental disabilities suggests that it reduces their stress and burnout, and changes the nature of their bidirectional interaction with those they support. That is, their transactional interactions change from using restrictive procedures, such as restraints and emergency medicines, to more positive approaches that produce happiness in the lives of the individuals. Furthermore, people with intellectual and developmental disabilities appear to master more learning objectives following the support providers being trained in mindfulness. The benefits of mindfulness training for support providers extend to financial benefits for agencies as well because it reduces the extra costs involved in hiring additional staff to serve individuals with severe aggressive behavior, training for new staff, and compensation for staff injuries.

Teachers of Individuals with Intellectual and Developmental Disabilities

Teachers of children and adolescents with intellectual and developmental disabilities can experience emotional dysregulation if they are not provided adequate support to provide individualized instruction within group settings that is responsive to the changing needs of each student, maintain structure and order in the classroom while providing individualized instruction to students with special needs, and adhere to the specific requirements of each student's individualized education plans. Often these teachers feel ill-prepared to teach children and adolescents with special needs and face stress and burnout.

Recently, there has been a surge of mindfulness training and research in schools, but much of this has involved general education (Schonert-Reichl & Roeser, 2016), and very little meaningful work has been done with teachers in special education (Smith & Jelen, 2016).

In a mixed-population study of parents and educators of children with special needs, Benn et al. (2012) assessed the effects of the MBSR-based SMART-in-Education (Stress Management and Relaxation Techniques) program (Cullen & Wallace, 2010) that was presented twice a week over a five-week period. Overall, the parents and teachers experienced significant reductions in stress and anxiety, as well as increased mindfulness, self-compassion, and personal growth at the completion of the program and at a two-month follow-up. Singh et al. (2013c) assessed the impact of an early version of the MBPBS mindfulness training program for teachers on the behavior of their preschool children with disabilities. Results showed that the children's challenging behaviors and negative social interactions began decreasing, and their compliance with teacher requests began increasing during mindfulness training for the teachers and continued following training. This study suggested that, in the absence of any direct intervention with the children, simply teaching mindfulness skills to their teachers positively affects the children's behaviors.

In sum, while the evidence for the positive effects of mindfulness training for teachers is evident in research in general education, there is nascent research with teachers of students with intellectual disability in inclusive settings.

Conclusion

There is rapidly growing research attesting to the positive effects of mindfulness training for people with intellectual and developmental disabilities and their parents, support providers, and teachers (Hwang and Singh, 2016). There is great diversity in the mindfulness training programs, lineage of the mindfulness practices, embodiment of the practices by the trainers, length of training programs, homework practices, and maintenance. Notwithstanding this diversity in the training, the emerging research clearly indicates the positive effects of mindfulness training on people with intellectual and developmental disabilities and those that support them. This is likely because of the transformative effects of mindfulness practices, and, in this respect, mindfulness enables the participants to reach for optimal human functioning—the bedrock of positive psychology (Peterson, 2006). Although programs like MBSR and MBCT were designed to ameliorate specific mental conditions, the focus of the trainings has not been on eliminating these conditions but rather on how to respond to these conditions through acceptance, nonjudgmental awareness, and understanding of the transience of all things. Thus, like positive psychology, mindfulness enables the participants to cultivate human strengths, virtues, and adaptive responses to situations, regardless of whether they are societally characterized as positive or negative. While the methods used to achieve these ends are different in mindfulness and positive psychology, the journey is probably the same.

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7

Building Positive, Healthy, Inclusive Communities with Positive Behavior Support

Matt J. Enyart, Jennifer A. Kurth and Daniel P. Davidson

Envisioning Positive, Healthy, and Inclusive Communities

Contemplate for a minute what it means to be fully included in your community. Is it simply having an address in the community? Are friends and a job included in the criteria? What feelings are associated with a sense of community belonging? Does everyone have a right to full inclusion in their communities? Is it possible for communities to ensure the inclusion of all citizens? Most professionals responsible for enabling the development and implementation of school, work, home, and community supports would respond affirmatively. Communities have diversified to offer a spectrum of federal, state, and locally funded supports and services for children, youth, families, and adults with various strengths and needs. This comprehensive array of academic, vocational, home, and community supports can address individualized needs and promote inclusion.

People with intellectual and developmental disabilities, however, may not always be purposefully considered when developing these supports. Limited resources, increased accountability, and disjointed community systems are common barriers community-support providers face when including adults with intellectual and developmental disabilities in all aspects of the community (Schalock, 2012). Additionally, long waiting lists for services and inadequate staff training often delay or reduce the effectiveness of support implementation. This dynamic, combined with inconsistent community-wide objectives, fragmented systems, lackluster practices, and ineffective program evaluation, can result in a support model which fails to meet the needs of all community members (Schalock, 2012). As a result of these shortcomings, community services and supports can become punitive, restrictive, and expensive (Nelson, Sprague, Jolivette, Smith, & Tobin, 2010a, Nelson, Jolivette, Leone, & Mathur, b; Schalock, 2012; Sprague et al., 2013). As a result, people with intellectual and developmental disabilities, as well as those who engage in challenging behaviors, may be denied full citizenship as they become secluded or excluded (Morningstar, Kurth, & Johnson 2016).

Across the USA, this reactive, exclusionary trend is reflected in the disproportionate number of incarcerated youth and adults with disabilities and behavioral health needs (Nelson et al., 2010a, b; Geis, 2013; Quinn, Rutherford, Leone, Osher, & Poirier, 2005). Equally concerning are the number of youth and adults with intellectual and developmental disabilities spending the majority of their time in secluded and segregated resource rooms, congregate living homes, and

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"workshop" settings (Schalock, 2012). Both the American Association on Intellectual and Developmental Disability (AAIDD) and the World Health Organization (WHO) have adopted the social-ecological model of disability (Schalock, 2013). Through this lens, disability is defined as a mismatch between personal capacities and environmental demands (Thompson, Schalock, Agosta, Teninty, & Fortune, 2014). Within this conceptualization of disability, supports are necessary to bridge the gap between what is (a state of incongruence due to mismatch between the person's competence and the demands of the environment) and what could be (a meaningful life with positive outcomes; Thompson et al., 2009).

While the WHO, AAIDD, researchers, advocates, families, self-advocates, and many other stakeholders have begun to shift from disability models focusing on deficits, the majority of our communities and schools are still trailing behind in their understanding of disability and community supports. Existing policies, regulations, and service models are often driven by diagnosis and deficits versus strengths (Wehmeyer, 2013). Many professionals, organizations, and systems continue to place blame for both behavior and ability squarely on the shoulders of the person. Problems, challenges, and punitive responses are emphasized rather than strengths, teaching desired behavior, and utilizing positive interventions and supports. This tends to be especially true for people with intellectual and developmental disabilities (Schalock, 2012; Wehmeyer, 2013).

Environmental contexts affect everyone's ability to obtain optimum quality of life outcomes across home, work, school, and community settings (Carr et al., 2002a, b; Dunlap, Sailor, Horner, & Sugai, 2010). A person's skills, knowledge of surroundings, access to technology, and environmental modifications can be a bridge within each of these environmental settings (Thompson et al., 2014), if they are aligned with a person's support needs and the demands of the environment (Carr et al., 2002a, b; Dunlap et al., 2010).

There is a direct relationship between the behaviors each of us engage in and our environment, existing skills, internal emotional factors, and access to technology and supports (Carr et al., 2002a, b; Carr, 2007; Dunlap et al., 2010). Unfortunately, as a society we continue to struggle with delivering appropriate and necessary individualized environmental modifications, effective behavioral, therapeutic, and socio-emotional supports, and accommodations to those who need them (Freeman et al., 2015). In the absence of these effective community-based interventions, people exhibiting challenging behaviors are either pushed into secluded work, home, and school settings, or expelled outright from our communities and placed into psychiatric or correctional facilities. Recent school to prison pipeline research, for example, has highlighted that more than half of the current corrections population in the USA have disabilities which would have made them eligible for special education services as children (Geis, 2013; Krezmien, Leone, Zablocki, & Wells, 2010; Nelson et al., 2010a, b; Quinn et al., 2005). There are some indications the trend toward segregation and expulsion may be changing, however. For example, McLeskey, Landers, Williamson, and Hoppey (2012) examined trends in educational placement for students with disabilities and found a 93% increase in the number of students with high-incidence disabilities (e.g., learning disabilities) accessing the general education (inclusive) setting between 1990 and 2008.

Such trends reflect the increasing commitment to including people with disabilities in typical settings and activities in USA and international law. For example, Article 3 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states persons with disabilities should have "full and effective participation and inclusion in society," including an inclusive education system (Article 24; United Nations Convention on the Rights of Persons with Disabilities [UNCRPD], 2016). The Americans with Disabilities Act (1990), as well as federal education law (Individuals with Disabilities Education Improvement Act, 2004) further protect the rights to inclusive lives of children and adults with disabilities in the USA.

Despite these mandates, progress toward gaining full inclusion, particularly for people with intellectual and developmental disabilities, remains limited. For example, in an analysis of trends in accessing general education settings for school-age students with significant disabilities (e.g., autism, deaf-blindness, intellectual disability, and multiple disabilities), Morningstar, Kurth, and Johnson (2016) found US states have made remarkably little progress in educating more students in general education settings. Likewise, adults with disabilities struggle to gain access to work and living arrangements in their communities. Consequently, states across the country have faced scrutiny because adults with intellectual and developmental disabilities are predominantly secluded in sheltered workshops, earning subminimum wages, and living in group homes with roommates they did not choose (Wehmeyer, 2013).

Findings from implementation science, positive behavior support, and organizational psychology provide research-based solutions to this pervasive problem in our communities and schools. Yet, implementing and sustaining evidence and research-based practices is difficult without several critical features in place (Fixsen et al., 2005; Schalock, 2012). Across research studies and fields, the importance of organization culture, environmental context, strong administrative support, a long-term commitment to training, effective evaluation, and the willingness to reframe all systems and procedures are identified (Schalock, 2012). A review of implementation science research identified core implementation components include teaching, coaching, and performance measurement. Additionally, organizational components include the selection of the evidence-based practice, program evaluation, administration support, and system-level intervention. Also identified was the influence of social, economic, and political factors (Fixsen et al., 2005). Positive behavior support and organizational psychology both reflect these elements for successful implementation (Dunlap et al., 2010; Seligman, 2000; Seligman, Steen, Park, & Peterson, 2005). The majority of professionals within schools and human service organizations want to effectively support the youth or adults they work for. However, ineffective practices, organizations, or systems can result in low morale or a challenging culture (Schalock, 2012). Intellectual and developmental disability organizations face specific and significant challenges including dwindling resources, increased demand for services and supports, shifts from general to individualized supports, an increased emphasis on personal outcomes, calls for increased effectiveness and efficiency, resource allocation based on support needs, an emphasis on self-determination and self-direction, and pressure to utilize evidence-based practices (Schalock, 2012).

Given these challenges, it is not difficult to understand why there continues to be a trend of exclusion of people with intellectual and developmental disabilities. Positive behavior interventions and supports (PBIS) provides a proven framework, using multitiered interventions and a systematic, data-driven approach, which when implemented effectively, creates a mechanism for all people to achieve quality of life goals and be fully included across environments (Carr et al., 2002a, b; Dunlap et al., 2013). This chapter will describe how families, professionals, and organizations can utilize PBIS to achieve quality of life outcomes and contribute to the creation of positive, healthy, and inclusive communities.

Description and Evolution of Positive Behavior Interventions and Supports

Positive behavior interventions and supports (PBIS) has long history of use in teaching skills and improving behavioral outcomes for people with intellectual and developmental disabilities. For example, PBIS strategies have been used to improve choice-making and quality of life outcomes (McClean & Grey, 2012), communication skills (Hetzroni & Roth, 2003), and self-management skills (Lee, Poston, & Poston, 2007). PBIS has been effectively utilized in a variety of settings, including school (e.g., Ross &

Horner, 2014), home (e.g., Buschbacher, Fox, & Clarke, 2004), and across the lifespan (Carr et al., 2002a, b). However, providing individualized supports for *all* students in a community, including those with infrequent problem behaviors, is resource-prohibitive and unduly time consuming. As a result, system-wide approaches to behavior problems have been developed (Crimmins & Farrell, 2006).

System-wide approaches, including school-wide positive behavioral interventions and supports (SWPBIS) and organization-wide positive behavioral interventions and supports (OWPBIS), have been meticulously assembled and researched within schools, organizations, and community settings. Both are applied through a multitiered continuum, focusing on teaching positive, prosocial behavior skills to all students or members of a school or organization (Hawken & O'Neill, 2006; Walker et al., 1996). Specific evaluation procedures and practices exist within each tier, including universal (tier 1), targeted (tier 2), and intensive (tier 3; Sugai, Simonsen, Bradshaw, Horner, & Lewis, 2014).

Universal interventions involve clear and consistent expectations which are systematically taught, reinforced, and corrected for all service recipients and staff. An example of universal expectations would be posting and reviewing lunchroom expectations with all students before they enter the lunchroom. When people engage in desired expectations, they are reinforced verbally with positive, specific praise. Approximately, 80% of students or community members respond well to these types of universal interventions. Targeted interventions include interventions for people who are not responding to universal interventions (expected to be approximately 10–15% of people). An example would be a providing additional scheduled times throughout a person's day to teach and reinforce expectations. This could include a specific prosocial skill development curriculum or an additional lesson and reinforcement on expectations in the lunchroom. Intensive interventions are provided when universal and targeted interventions are not effective in reducing challenging behavior and increasing desired behaviors. Intensive interventions include the completion of a functional behavior assessment and the creation of function-based interventions. Approximately, 5% of students or community members will require intensive interventions. It is important to note that even receiving targeted or intensive interventions, students or community members should also continue to be exposed to universal interventions, which are the starting point for determining the need for targeted or intensive interventions. Ultimately, the primary concern of PBIS across all three tiers is to improve the quality of life of people served, the organization, and the community as a whole.

Today, critical features of PBIS as a multitiered framework have been well defined. Perhaps the most critical of these features is the dedication to adapting and contextualizing PBIS procedures, practices, and evaluation to support people across environments, systems, and the lifespan. Committed to the continual expansion of PBIS, researchers collaborate closely with stakeholders as they use available research and data to modify features without jeopardizing the science (Carr et al., 2002a, b; Dunlap et al., 2010; O'Neill, Albin, Storey, Horner, & Sprague, 2015). Today, PBIS procedures, practices, and evaluation are being adapted, utilized, and researched in juvenile correction facilities, mental health centers, psychiatric residential treatment facilities, intellectual and developmental disability organizations, and other alternative settings (Carr et al., 2002a, b; Dunlap et al., 2010; Nelson et al., 2010a, b; O'Neill et al., 2015; Sprague et al., 2013).

While PBIS has resulted in positive outcomes for youth in schools and organizations (Horner, Sugai, & Anderson, 2010), significantly less progress has been made regarding home and community PBIS research, practice, and policy. In part, this has been due the limited funding community-based, adult services organizations have received (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). However, researchers are now able to draw from the SWPBIS research to reinvest in home and community applications of PBIS in collaboration with lessons learned from positive psychology, quality of life, and person-centered planning. Each is strengths-based and focused on improving outcomes for marginalized populations in communities. And, with a primary objective of improving quality of life, PBIS is uniquely situated to improve outcomes for people with intellectual and developmental disabilities.

Foundations of Positive Behavior Interventions and Supports

Throughout history, humanity has not always been kind to people who do not readily respond to the environmental, social, or behavioral expectations placed upon them (Wehmeyer, 2013). For those who have, or who are perceived to have, intellectual and developmental disabilities, experiences including isolation in institutional settings, the denial of access to communities, sterilization, and living in subhuman conditions are all too common (Smith & Wehmeyer, 2012). Prior to the 1960s in the USA, people with intellectual and developmental disabilities were largely relegated to institutions, often living in deplorable conditions (Blatt & Kaplan, 1966). As these conditions came into public view during the civil rights movement of the 1960s, applied behavior analysis (ABA) research emerged demonstrating that all people, regardless of the significance of their disability, could learn. However, ABA (at the time) relied heavily on the use of aversive techniques such as slapping, pinching, and even shocking people with intellectual and developmental disabilities to achieve these learning results. Many in the ABA field felt the new, fast growing discipline of ABA lacked oversight and should only be used when carefully balanced with values.

While this debate ensued, researchers Nirje (1969) and Wolfensberger, Nirje, Olshansky, Perske, and Roos (1972) focused on community inclusion and social roles of people with intellectual and developmental disabilities. Their work defining the normalization principle described how the value placed on people is reflected in how and where they are represented in the community. People perceived as having low social worth are treated poorly and not included in or accepted as "normal" within their communities. Normalization researchers believed everyone has a right to the same opportunities and that people with disabilities should not be excluded (Nirje 1969; Wolfensberger et al., 1972). A group of like-minded ABA researchers looking for an alternative to aversive techniques, with an increased focus on inclusion, joined Nirje and Wolfensberger to lay the foundations of PBIS. Their goal for PBIS was to develop a technology that was preventative and changed the environmental context, leading to rapid, consistent, durable, and generalized change in problem behavior, while facilitating the development of broad improvements in quality of life with ecological validity (Carr et al., 2002a, b; Dunlap et al., 2010; O'Neill et al. 2015).

Implementing PBIS Across Settings

Firmly rooted in applied behavior analysis, PBIS procedures and tools, particularly when implemented at the intensive, individualized level, include functional behavior assessments (FBA), function-based interventions, and knowledge of setting events, operations, value of available consequences, competing behavior response options, and maintaining consequences (Sugai et al., 1999). Intensive positive behavior support interventions use strategies associated with applied behavior analysis, person-centered planning, and improving quality of life. The primary features and overall process are the same regardless of the individual. However, PBIS requires that interventions are contextualized to meet the needs of the person, their environment, and available resources.

Intensive PBIS interventions start with a functional behavior assessment (FBA) to determine the function of a problem behavior for the person. Observations are completed across environments, times of day, and with various support staff or family members. The FBA requires close attention to the setting event, antecedent, behavior, and consequence. Setting events can be anything that alters the likelihood of behavior by momentarily altering the value of a reinforcer or punisher (Horner, Vaughn, Day, & Ard, 1996). For example, a setting event could be a crowded or loud room. A person with hypersensitivity to sound or crowds may be more likely to engage in physically aggressive behavior when these setting events are present in order to communicate that they want to escape the noise, particularly if no other communication supports are in place. Setting events are like primers or slow triggers—they set the stage, making an antecedent more or less likely to elicit a problem behavior. Antecedents, also called fast triggers, are what occur immediately before the behavior occurs. For example, a person with hypersensitivity to sounds and crowds might shove someone immediately after they entered his personal space and said “hello,” if they are in a loud, noisy room. Saying “hello” is the antecedent in this case because it triggered the problem behavior (shoving). The person would not shove another when greeted, however, if they were in a quiet place (setting event). Nor would he shove if a person did not say “hello” and entered his personal space (antecedent).

In completing the FBA, the observer takes detailed notes to operationalize the behavior. A clear operational definition of the behavior increases the likelihood all team members observe and record the challenging behavior in the same way. This is critical in determining the function of the behavior and when collecting pre- and post-intervention data. For the purpose of conducting the FBA, the consequence is any response immediately following the behavior. If the person described previously was removed from the noisy and crowded room after shoving his fellow party guest, thus escaping from the crowd and noise, he is accessing a reinforcing consequence (or what he hoped to achieve—avoid the noise and crowd). Observations should occur across environments, at different times, and with different people. In addition to observing challenging behaviors, the observer should also work to identify the person’s preferences, strengths, and where, when, and which events do *not* elicit challenging behaviors.

Collectively, these operationalized behaviors and comprehensive observations are all considered to develop a hypothesis to explain the function of each of the behaviors. This should be done carefully as it is possible the same behavior may serve a different function in a different environment, at an alternative time of day, or with another support provider. Each person’s person-centered planning team, those who know the person best, should be actively involved in hypothesizing the function of the behaviors and should assist with creating function-based interventions.

Once the functions of a behavior are identified, the team should identify the desired behavior and replacement behavior or skill to be taught. Importantly, the replacement behavior should serve the same function as the problem behavior. In our example, teaching the person to request more personal space or to choose not to go to crowded, noisy environments may be necessary. Teaching replacement skills is critical to individualized positive behavior support interventions. By teaching the person the behavior or prosocial skills needed to effectively achieve the same or a similar maintaining consequence, and making environmental adjustments as needed, we are not just addressing one challenging behavior but are improving a person’s skillset and increasing the tools each person has to achieve their desired quality of life. Individualized PBIS is strengths-based and driven by a person-centered plan in which a person is ensured their voice and choice as they identify their dream for the future and collaborate with their team to identify their goals and related action steps.

The end result of the individualized PBIS process is a comprehensive plan that includes tenants of individualized planning, applied behavior analysis, and measurable quality of life outcomes. These plans should be dynamic, sustainable, and linked to the settings the person values. One strategy for doing so is use of the life outcomes through integrated systems (LOTIS) wheel. The LOTIS wheel is a framework to implement multitiered PBIS interventions across home, school, work, and community contexts by embedding quality of life domains across each context (Freeman et al., 2015). As a planning tool, person-centered teams work through each of the domains and identify the individual needs and universal, targeted, or intensive supports to achieve domain-related goals.

Promoting Strengths-Based Approaches for All Members of the Team

The role of support providers in promoting quality of life and implementing PBIS is critical and in addition to the focus on implementing individualized or organization-wide PBIS, it is also important to understand the impact of acting as a change agent (i.e., support provider) on quality of life for this support providers, and the impact this has on people with intellectual and developmental disabilities. People providing support and instruction often experience substantial impacts on their own quality of life.

Support providers, particularly parents, can be at risk of experiencing reduced quality of life related to their children's problem behaviors and the inherent difficulty associated with managing these behaviors, while maintaining their child's dignity if appropriate supports are not in place. The presence of challenging behaviors, including self-injury and aggression, has be associated with family breakdown and financial strain without appropriate supports, as the management of these behaviors can be labor- and resource-intensive (Oliver, Petty, Ruddick, & Bacarese-Hamilton, 2012). Parents of children who engage in challenging behavior report experiencing chronic stress, which in turn can be associated with coercive parenting practices and the entrenchment of problem behaviors (Singh et al., 2007), again, when effective supports are not in place. Finally, parents of children who engage in frequent problem behaviors can also experience isolation, exhaustion, concerns about their safety and the safety of other family members, home expenses, a difficulty to fulfill need for respite care, and limited professional supports (Hodgetts, Nicholas, & Zwaigenbaum, 2013). Together, these experiences can result in threats to the quality of life of those who support people who demonstrate challenging behaviors at home and at school, necessitating greater focus on strengths-based supports such as those emerging in positive psychology and PBIS to address challenging behaviors and the needs of all members of the support team.

Paid support providers, including school teachers and community-based support providers, also can experience threats to their quality of life by virtue of challenging behaviors. For example, student problem behavior affects teacher stress levels and can negatively impact the student–teacher relationship (Schaubman, Stetson, & Plog, 2011). Likewise, student challenging behavior can impact teacher emotional well-being, with challenging behavior associated with increased teacher burnout and emotional exhaustion when not effectively addressed (Hastings & Brown, 2002). Additionally, people working with students who engage in aggressive behaviors, usually due to lack of communication and other supports, are at risk of physical harm (Finlayson, Jackson, Mantry, Morrison, & Cooper, 2015; Langone, Luiselli, Galvin, & Hamill, 2014). Furthermore, paid support providers can be at risk of financial hardships by virtue of their profession. Teachers and community-support providers (e.g., job coaches, group home managers) often experience low pay, limited career ladder opportunities, and an overall low status compared to non-caregiving professions.

Functional Behavior Assessment and PBIS in Context

With these challenges in mind, the potential benefits of positive psychology in supporting all members of the support team in implementing PBIS to impact quality of life outcomes for people with intellectual and developmental disabilities cannot be understated. One aspect of positive psychology involves "benefit finding," defined as identifying the positive effects that result from a traumatic event (Helgeson, Reynolds, & Tomich, 2006), such as the presence of challenging behaviors, or the broad range of positive changes that emerge following stress (Bower, Hales, Tate, Rubin, Benjamin, & Ward, 2008). Benefit finding has been studied in many areas of human trauma or adversity, including with people that experience cancer, parents of children with severe health problems, people who have experienced heart attacks, war veterans, people with HIV/AIDS, people with Alzheimer's disease (Farran, Miller, Kaufman, Donner, & Fogg, 1999) and with Asperger syndrome (Pakenham, Sofronoff, & Samios, 2004).

Strengths-based outcomes and perspectives on raising a child with a disability have been identified (Hebert & Koulouglioti, 2010). For example, Scorgie and Sobsey (2000) relate how parents identify benefits associated with having a child with a disability, including learning about themselves, feeling greater success and confidence, developing compassion, and feeling stronger spiritual convictions and a stronger sense of what is important in life. Often, parents identify the contributions that their child makes to their family and the world, stating they would not change their child (Myers, Mackintosh, & Goin-Kochel, 2009). Positive psychology research focused on building on character strengths, such as that described in Chap. 13, provides important information for building on these identified strengths, rather than focusing on challenges.

Yet many support providers, including family members and paid providers, lack access to effective strengths-based supports and interventions. However, emerging research from PBIS and positive psychology, when considered together, provide direction for support teams implementing individualized supports. These include the following:

1. **Conduct quality FBAs within relevant contexts that include analysis of the interaction between people with intellectual and developmental disabilities and their support providers (sometimes called coercion analysis)**. Lucyshyn et al. (2004) demonstrated how coercion analysis within typical family routines could be used to see how the parent–child interaction influenced behavior. They observed parent–child interactions to better understand how parent attention may have been reinforcing child behavior problems in some routines and escape from parent demands reinforced others. They also found evidence to suggest that the temporary termination of child behaviors reinforced parental behavior. This pattern, sometimes called a coercion cycle, occurs when parents and children "train" each other to act in certain ways. For example, when parents demand compliance, children increase their problem behaviors, and parents reduce their demands. This cycle can be changed, but must be identified to enable change and strengths-based interventions.
2. **Develop Behavior Support Plans** that:

    (a) Include functionally equivalent replacement behaviors so that support providers can enable people with intellectual and developmental disabilities to communicate what they want and reduce the need for challenging behavior.
    (b) Focus on prevention so that support providers have fewer challenging behaviors to address.
    (c) Replace support provider person with intellectual and developmental disability coercion cycles with interaction patterns that support the positive and effective behavior of both.
    (d) Allow for supports that enable all parties to find the relevance of the plan to their own personal goals.

3. **Enable support providers and people with intellectual and developmental disabilities to identify and define positive things in life**. In a Web-based study by Seligman et al. (2005), the authors evaluated the influence of various exercises on participants' happiness, including the following, each of which could be embedded in PBIS interventions:

    (a) **Complete a gratitude visit**. Write and deliver a letter of gratitude to someone who has been kind, but has not been properly thanked.

   (b) **Identify three good things in life**. List three things that went well each day, every night, for one week. Then, provide a causal explanation for each good thing.
   (c) **Describe you at your best**. Write about a time you were at your best. Reflect on the personal strengths you displayed. Then, review the story once every day for a week and reflect on the strengths identified.
   (d) **Use signature strengths in a new way**. Complete an inventory of character strengths online at (www.authentichappiness.org) and receive individualized feedback about your top five "signature" strengths. Use one of these top strengths in a new and different way every day for one week.

4. **Enable support providers to see how following the behavior support plan can provide them with opportunities to experience positive outcomes aligned with their strengths identified in the previous step.**

   (a) If support providers want to be more compassionate, then provide strategies to address this, such as acknowledging the feelings of a person with an intellectual or developmental disability after the episode is over (not during).
   (b) If support providers want to be more patient, provide strategies to ignore (as long as this is not dangerous) challenging behaviors, allowing them to dissipate naturally.
   (c) If support providers want to be more effective, teach prompting strategies for replacement and alternate behaviors.
   (d) If support providers want to be more firm, teach them not to give into demands, but instead to solicit replacement behaviors and reinforce those.
   (e) If support providers want to be more confident. then provide strategies for prevention, including changing the environment.

5. **Enable support providers and people with intellectual and developmental disabilities to experience the success of using their strengths**. Promote greater recognition not only of the success associated with changes in the behavior of people with intellectual and developmental disability, which is not always immediate, but also in the support provider. If the definition of success also includes measures of how well the support provider used their character strengths, then support providers can experience reinforcement and quality of life, alongside people with intellectual and developmental disabilities.
6. **Enable support providers and people with intellectual and developmental disabilities to use approaches developed in positive psychology, including mindfulness (see** Chap. 6**), building on character strengths (see** Chap. 13**), and promoting autonomous motivation (see** Chap. 19**) to experience positive outcomes**. Using these approaches enhances the well-being of all members of the team and can facilitate environmental contexts that reduce the need for problem behavior.
7. **Enable support providers and people with intellectual and developmental disabilities to self-monitor their own behavior, thoughts, feelings, and use of strengths**. Create strategies that support providers can use to monitor the things they want to change or build on in themselves (e.g., reminders to practice, using a rating scale to self-evaluation, etc.). Questions such as the following can be useful:

   (a) Did I acknowledge the person's feelings only after the episode ended?
   (b) Did my praise outweigh my criticism?
   (c) Did I prompt the replacement behavior?
   (d) Did I identify ways to redesign the environment to make problem behavior less effective?
   (e) Do I feel more confident about my ability to handle difficult situations?

Creating Positive Culture and Consistent Expectations in Organizations

Organizations, just as individuals, all have their own personalities, characteristics, and behaviors, each of which creates unique environmental demands for all people within the organization. Some organizations can feel warm and welcoming with happy, productive employees. Others can feel cold and unapproachable with low morale and inconsistent outcomes. Whether a business focuses on painting houses, developing Web sites, or helping humans achieve their goals, they all require similar core systems, practices, and data to achieve their objectives. Organization-wide PBIS (OWPBIS) and school-wide PBIS describe the universal implementation phase as a time when leadership teams are developed to systematically improve quality of life and decrease problem behaviors for all of those served by the organization (Sugai & Horner, 2010). As described previously, there is a need to focus on the behavior and needs of all people in the organization, not just those served by the organization, when implementing OWPBIS. In this section, we describe how support providers, who often work in challenging circumstances, can be supported to find happiness and meaning in their work through OWPBIS and positive psychology.

Finding Happiness and Optimism in Challenging Work

Positive psychology informs us of the importance of happiness, personal meaning, and purpose in one's life. When contextualized in the support provision relationship associated with delivery of PBIS, there are several implications. Sometimes, work itself is intrinsically motivating. Such work is "marked by the interest, curiosity, continued learning, and spirit of challenge experienced by an employee when stimulated by the work itself rather than external outcomes (Deci & Ryan, 1985)" (Guo, Liao, Liao, & Zhang, 2014, p. 733). However, any work environment and activity can also be stressful, and demands associated with the environment and activities can limit one's motivation. Promoting happiness in such environments can be enhanced by "keeping a balance between being consumed by a job that seems overwhelming with no relief in sight and the 'perfect' job environment" (Davidhizar & Hart, 2006, p. 67).

So what makes difficult work rewarding? Locke and Latham (1990) assert work that is challenging and focused on specific goals is most rewarding to employees. Employees must be committed to the goals, and some value must be associated with goal attainment (e.g., money, personal meaning). When employees have clear goals and high intrinsic motivation to achieving those goals, employees persist longer at tasks. Likewise, completing tasks in which employees feel successful contribute to more self- and task-satisfaction, pride in performance, and sense of achievement. Finally, employees who are satisfied tend to stay on the job and be good citizens (e.g., help co-workers, do extra work), while dissatisfied employees are more likely to quit, be absent, file grievances, and put in less effort. Together, these findings suggest the importance of setting specific, challenging goals to guide the work of PBIS support providers. This may include goals for how the support provider will set up the environment for improved success to enhance individual outcomes (such as those described in previous sections), or specific goals for how a support provider will react to and support a person with an intellectual and developmental disability when faced with a challenging behavior.

The work of providing support has several unique challenges that contribute to high staff turnover and low employee motivation (e.g., low pay, low status). Further, the skills required for such work are largely unrecognized, often go unnoticed, and are poorly rewarded (Payne, 2009). Support providers may experience poor working conditions and a lack of organizational support (Johnson, 2015). Consequently, many support providers may feel emotionally involved with their work, but in a nonsupportive organization context can become emotionally exhausted, and have difficulty separating from the support role (Johnson, 2015), all of which can lead to less positive outcomes for the person with an intellectual or developmental disability.

Emerging research in positive psychology and agency in work may be informative in improving the conditions and quality of life of support providers, and enhancing the outcomes of people with intellectual and developmental disabilities. Agency is “the capacity [of a support provider] to make an impact or exert power” (Gourd, 2016, p. 6). Most support providers have agency within constraints. For example, PBIS policies may require support providers to act on a behavior when it is deemed dangerous to the person or to others. Because this notion of “danger to self and others” is ill-defined, support providers have the choice to act based on their own convictions and philosophies. In these situations, support providers may reproduce the status quo or may use this as an opportunity to build communication skills, identify motivating factors, and improve the quality of life of the person served. Promoting greater agency can lead to greater motivation and more positive outcomes for everyone.

Directions for Future Research and Practice

In this chapter, we have discussed the relationship between positive psychology, PBIS, and quality of life outcomes. We have focused on how to put functional behavior assessment in context with a particular focus on the roles and well-being of support providers and the need for creating positive cultures and consistent expectations within organizations. Each of these factors is critical to create supportive environments that promote positive outcomes for all members of a community. However, ongoing work is needed to integrate PBIS and tenants of positive psychology.

Enhance the Focus on Quality of Life Outcomes

Much of the PBIS literature remains focused on devising interventions and measuring the fidelity of those interventions, with the focus on changing the behavior and skills of the person with an intellectual or developmental disability. However, this does not bring enough attention to the desired quality of life outcomes for the person, nor the relationship of the person to the members of the support team and their experiences and outcomes. Understanding the support team and the organizations that provide support not only benefits the person, but also all members of the support team. Integrating OWPBIS and positive psychology strategies can potentially further enhance individual quality of life, as well as support provider and organizational outcomes, and further research and practice strategies are needed.

Moving Research into Practice

The challenge of bridging the research to practice gap is well established (e.g., Hood, 2002; Shonkoff & Bales, 2011). Researchers struggle to effectively disseminate research findings, and practitioners struggle to translate research into practice (Cook, Cook, & Landrum, 2013). Thus, the field of implementation science has emerged (Fixsen et al., 2005). Implementation science is focused on what will be implemented, how it will be implemented, and who will do the work of implementation (Ogden & Fixsen, 2014). Ogden and Fixsen summarize obstacles and facilitators of implementation as being associated with “characteristics of the innovation itself, the provider, the practitioner adopting the practice, the client or consumer, and the inner and outer concept of the service delivery organization” (p. 5). Thus, establishing a strong contextual fit between the support provider, the intervention, and the service recipient is critical. Yet how this can be done, at scale, is not well understood. Lessons learned from implementation science, including the importance of finding a good balance between treatment integrity and local adaptation, and responding constructively to variability and focusing on continuous improvement will all be critical to fully implementing PBIS in communities.

The expansion of organization-wide PBIS, the critical role of quality of life, the combination of the two as represented in the LOTIS wheel framework, and additional strategies from positive psychology outlined in this chapter, all require additional research and evaluation within the context of intellectual and developmental disabilities organizations, other human service organizations, and communities as a whole. Careful, ongoing evaluation and research is needed as researchers, practitioners, policy makers, and advocates collaborate to build positive, healthy, and inclusive communities.

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8 The Mindfulness-Based Individualized Support Plan

Monica M. Jackman, Carrie L. McPherson, Ramasamy Manikam and Nirbhay N. Singh

Introduction

Treatment plans, the bedrock of medical and mental health services, are grounded in the medical model of care, which assumes that diseases, disorders, and deficits can be overcome with professionally developed plans of care. When applied to people with intellectual and developmental disabilities, this model of care equates providing services with remediation of the deficits or impairments associated with the disability. As our understanding of the civil rights of institutionalized persons, especially people with intellectual and developmental disabilities, has become more nuanced and socially enlightened, there has been a gradual shift over the last few decades in the type and nature of service systems utilized for them. The current disability-related policies and programs emphasize individual empowerment, strengths, self-determination, choices, preferences, and quality of life (Harris & Greenspan, 2016). This has resulted in a change in the nature of service provision, and, instead of the traditional treatment plan, a person-centered plan of support is now the sine qua non for providing services to people with intellectual and developmental disabilities (Ratti et al., 2016). Person-centered planning is a collaborative effort between the person and the person's treatment team and significant others (e.g., family members, friends) that results in the development, caregiver training, and implementation of an individualized support plan for achieving the individual's personal goals.

Historically, the focus of person-centered service plans was on health, safety, and development of skills, often without any consideration being given to the individual's personal goals in life (Bigby & Frawley, 2010; Holburn, 2002). While this was a move in a positive direction, even this shift in service provision failed to consider the civil rights of people with disabilities as individuals with a capacity for self-determination, control or choice and did not go beyond assessment and treatment of functional deficits of the person. One of the key constraints was that the person's treatment team controlled the collaborative process and often engaged in benevolent decision making on behalf of the person, instead of following the lead of the person with a disability. Several advocates realized this problem, and various "true" person-centered models were developed, such as the essential lifestyle planning process (Smull & Burke-Harrison, 1992), personal futures planning (Mount & Holburn, 1996), and the McGill action planning system (MAPS; Forest &

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Lusthaus, 1989; Vandercook, York, & Forest, 1989). Within this diversity of models, the defining characteristics of a person-centered approach included the following (Schwartz, Jacobson, & Holburn, 2000, p. 238):

1. The person's activities, services, and supports are based on his or her dreams, interests, preferences, strengths, and capacities.
2. The person and the people important to him or her are included in lifestyle planning and have the opportunity to exercise control and make informed decisions.
3. The person has meaningful choices, with decisions based on his or her experiences.
4. The person uses, when possible, natural and community supports.
5. Activities, supports, and services foster skills to achieve personal relationships, community inclusion, dignity, and respect.
6. The person's opportunities and experiences are maximized, and flexibility is enhanced within regulatory and funding constraints.
7. Planning is collaborative, is recurring, and involves an ongoing commitment to the person.
8. The person is satisfied with his or her activities, supports, and services.

A recent systematic review of the effectiveness of person-centered planning for people with intellectual and developmental disabilities found the evidence for the general effectiveness of this approach to be limited and of low quality (Ratti et al., 2016). While there was some indication of positive outcomes (e.g., in community participation, participation in activities, and daily choice-making), the anticipated transformative change in the quality of life of people with IDD has not been fully realized. Apparently, what happens in practice is often somewhat removed from the principles of person-centered planning because of local conditions of support—fiscal management priorities, staff shortages, time, skill level of staff, length of support plans, understanding the intent of person-centered plans—and implementation degenerates into what is convenient for the staff (Singh, 2016). While treatment teams still develop long and complex person-centered support plans, the process often turns out to be an exercise in treating the documentation for external reviews and quality assurance rather than in support providers actually providing services that enhance quality of life. Treatment teams often write individualized goals to address skill areas that are easy to implement and measure in a clinical setting, but do not necessarily contribute to the individual's meaningful engagement in daily life. Authentic person-centered care involves more than a change of the domains within the treatment planning process; it also requires a mindshift among the treatment team members to a state of open minded non-judgmental engagement. These findings have resulted in alternative approaches to care, such as the active support model (Toogood, Totsika, Jones, & Lowe, 2016).

In this chapter, we describe a field-tested model of service provision that is grounded in positive psychology (Wehmeyer, 2014), self-determination (Wehmeyer & Shogren, 2016), and mindfulness (Shonin, Van Gordon, & Singh, 2015; Singh, 2014), with an emphasis on growing the strengths of people with intellectual and developmental disabilities (Shogren, Wehmeyer, Buchanan, & Lopez, 2006). This model, the Mindfulness-Based Individual Support Plan (MBISP), triangulates supports for individuals with intellectual and developmental disabilities, their family members, and paid support providers. The MBISP is based on a mindful engagement approach to person-centered services that is in compliance with the Interpretive Guidelines for ICF/IID State Operations Manual (Centers for Medicare and Medicaid Services [CMS], 2015). The MBISP provides a present-focused positive approach that builds on incremental, dynamic, short-term achievable goals, which telescope into an enhanced quality of life for individuals with IDD.

Mindfulness-Based Individualized Support Plan

Mindfulness

Mindfulness is the art of being present in each moment, thereby paying attention to whatever you are (or should be) engaged in, and being aware of everything that goes on around you and in your mind and body. It is an art because anyone can develop mindfulness through various lifestyle practices, with mindfulness meditation and/or specific cognitive strategies being the most common approaches. Mindfulness has been defined as "the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment to moment" (Kabat-Zinn, 2003, p. 145). This definition has been used widely in scientific studies of meditation, but the concept of mindfulness defies a unitary definition in the scientific sense because it is an inexact western translation of a Pali word, *sati*, which could be roughly translated as remembering to be present (Singh et al., 2008). In a practical sense, mindfulness "is not thinking, but experiencing from moment to moment, living from moment to moment, without clinging, without condemning, without judging, without criticizing choiceless awareness…. It should be integrated into our whole life. It is actually an education in how to see, how to hear, how to smell, how to eat, how to drink, how to walk with full awareness" (Munindra in Knaster, 2010, p. 1). This definition approximates how mindfulness is used in MBISP to provide care and support of people with intellectual and developmental disabilities, and supports for their parents, family members, teachers, and paid staff.

Mindful Engagement

Mindful engagement is a way of living life to its fullest and thriving even in the face of impairments or difficult life circumstances. It involves the active investment of one's self into daily activities, with a focus on engagement rather than on outcomes or rewards (Jackman, 2014). Engagement is different from *doing* or *participating* in that it requires one to be fully attentive to what is happening in each moment as well as being aware of everything else that is happening. Participation, or doing things just to get them done, can result in going through the motions of completing a task in a mindless manner. Mindful engagement is the state of being present while doing. Being present can bring enjoyment and opportunities that might be missed if a person is doing a task out of a sense of obligation, for extrinsic reward, or to avoid the consequences for not doing it. Mindful engagement is a way of living and interacting with other people and the environment that can be learned through the practice of mindfulness meditation.

Mindfulness can be developed through meditation and cognitive training. Some people with intellectual and developmental disabilities may have limited skills needed to practice formal mindfulness meditation, but they can learn to be mindful through other activities that hold their attention and provide an enriched environment to enhance awareness. Others might not be able to experience mindful engagement without the support of caregivers. Many people with intellectual and developmental disabilities depend on others to support them and to enable them make decisions about what they will do, where they will go, and what they will learn and explore each day. Often, caregivers, therapists and team members develop plans to keep people safe and to follow the rules and regulations set by surveyors and funding agencies (e.g., CMS). However, these plans do not always make the person's life better or more enjoyable and can often result in the person being subjected to tasks and learning activities that are non-functional and meaningless. Too often the individual support plan (ISP) focuses on what paid staff will do to address or compensate for the person's limitations rather than on how the staff can use the person's current abilities and interests to create engagement opportunities for them. The MBISP approach to care and support is designed to give staff tools to develop plans that make an individual's life better by discovering enjoyment in each day. It enables staff to focus on noticing and building on the strengths of the person rather than on working to eliminate challenging behaviors or compensate for limitations.

Mindfulness in Action

Before support providers can enable others to have better lives, they must first develop and enhance their own skills for being present, aware, and mindful in daily life. Mindfulness is the ability to be fully in the present while paying attention to what is in front of you, being aware of what is within and around you, and doing it with an open heart, without judgment or expectation. Mindfulness is our hidden natural state. However, without explicitly training the mind, we let it incessantly jump around and think about the past or future and at times fail to attend to what is going on around and in front of us. We can also find ourselves hurrying so much to get things done that we forget to enjoy what we are doing. We can become overwhelmed by responsibilities, feelings, and thoughts to the point that it causes stress, anxiety, compassion fatigue, and burnout.

Support providers can learn to live mindfully by practicing mindfulness meditation. This is a simple practice of focusing on a chosen object, usually the breath, to improve one's ability to stay present and aware. MBISP includes meditation training for support providers that can help them to develop mindfulness so that they not only feel better, but also are more effective in supporting people with intellectual and developmental disabilities to have a better quality of life (Singh et al., 2016b, c). Being mindful with the goal of helping others is called *right mindfulness* or *mindfulness in action.* Practicing mindfulness while caring for others can improve our ability to notice important things, stay calm, cope with stress, and remember to act with loving kindness, compassion, and joy.

MBISP Versus Traditional Individual Support Planning

To better understand the MBISP approach, it can be helpful to compare it to the traditional ISP or individual life plan (ILP). The traditional ISP treatment planning, which is aligned with a medical model of care, tends to be more focused on a person's physical and mental disabilities, medical and psychiatric disorders, and physical and functional deficits. While the ISP approach is nominally "person-centered," it often results in planning for daily activities that are chosen by the treatment team based on goals related to medical and psychiatric care, health risks, or skill building to achieve treatment goals. In contrast, the MBISP planning is focused on improving each person's quality of life in the immediate and long-term, with an emphasis on self-determination, opportunity, preferences, and choices. In other words, while the traditional ISP may incrementally enhance the person's skills and reduce challenging behaviors, the MBISP supports each person's goal of a life worth living, no matter what challenges she or he faces. Table 8.1 shows some of the differences between the ISP and the MBISP approaches to care and treatment planning.

A key aspect of the MBISP planning process is that all treatment team members—caregivers, clinical and professional staff, family members, friends, and significant others—are always in a support role. If the person with intellectual and developmental disabilities cannot make a choice due to functional limitations, the choice is made by parents and significant others who know the person well. However, even then, the MBISP approach requires that the suggested option(s) advanced by others be presented to the person as a choice and be modified and individualized in such a way that the person can indicate a preference (Samaha, Bloom, & Koehler, 2016). The essence of the approach is to acknowledge that not being able to indicate a preference or choice is never a shortcoming of the person, but a limitation of the service system in not finding a better way to make it possible for the person to display self-determination, indicate preferences, and make choices. There is always another way of presenting choices in a manner that is functional and meaningful to the person, regardless of his or her apparent limitations.

The MBISP Template

The MBISP is a dynamic document that is completed with the person's input and then continually updated as he or she progresses through successive short-term goals and objectives. Figure 8.1 presents the MBISP template. The document is short by comparison with

Table 8.1 Comparative characteristics of the ISP and MBISP approaches to treatment planning

Individual Support Planning	Mindfulness-Based Individual Support Planning
Institutionalized schedule Schedule and times for activities such as bathing and eating are determined by supervisors and usually based on hospital and staff schedules. Example: *Everyone bathes in the morning and then has breakfast at the same time* Activities are done when and where it is convenient to the daily schedule. Example: *Jane works on range of motion in the therapy clinic*	**Individualized routines** Routines and daily activities are scheduled based on each person's needs and rhythms. Example: *John is very tired in the morning because of medication side effects, so he can choose to sleep in, eat breakfast later in the morning, and take a bath in the evening* Activities are done when and where they best support the person to be engaged. Example: *Jane works on range of motion during bathing and dressing, since these are the tasks that she needs range of motion for*
Reaction Changes to a person's treatment are often done after something has happened. Example: *Michael gets a temporary wheelchair and starts being seen at physical therapy after he falls and breaks a hip*	**Response** Changes to a person's treatment plan are made, as needed, based on ongoing awareness of things that are noticed by paying attention to the person before something happens. Example: *A caregiver notices that Michael is becoming a little wobbly when walking on uneven surfaces. She contacts the physical therapist who adds balance activities to Michael's home therapy program using dance moves and music (done outside on the grass) that Michael has selected and enjoys*
Assisting and Teaching Staff uses set plans to teach a person how to do something in a specific way and sequence (i.e., in a task analysis format). Only the team members who write them can change the plans. Example: *To teach Mary to eat independently, start with assisted handhold, then move to maximum assistance, then move to moderate assistance. Change the goal after the individual meets each step for two months*	**Support** Caregivers provide just the right amount of support that the person needs based on their awareness of how the person is doing in that moment. Caregivers use the plan as a guide and use observation of individual's cues and instinct to adjust the level of support as needed. Example: *Since Mary is often tired in the afternoon and evenings, the caregiver gives her more assistance with holding her spoon. During breakfast, Mary can almost hold her spoon independently as she has more energy and, breakfast is her favorite meal*
Prescribed activities or exercises Activities or exercises to build skills to meet a goal or to reduce risk. These are usually done as part of a program that involves a number of repetitions or minutes and requires data collection. Example: *Anthony stands for 15 min in the standing box, has range of motion to his shoulders 20 times each, and lifts a 2-pound weight 10 times for each arm*	**Activity engagement** Activities that work on skills to support a person to improve ability to engage in things that he/she enjoys. These activities are more flexible, functional for the person, can be improved by staff creativity and spontaneity, and are designed to generate fun and interaction. Example: *Anthony gets staff assistance to blow up balloons with a balloon pump. He then gets staff assistance to stand and hold a weighted tennis racket to play balloon tennis with a friend who is sitting in a wheelchair*
Independence Independence and skill building is usually valued as a goal of services. Example: *Allison can improve her skills to walk by herself for short distances. She gets easily tired, and her goal is to walk 50 ft with a gait belt*	**Autonomy** The person is able to choose what he or she wants to do independently, and what he or she gets help with. Example: *Allison could use her energy to walk independently, but she chooses to save her energy to play daily wheelchair basketball and wheelchair t-ball*
Participation When a person is participating, he or she is doing a task because it is expected of him/her, or is linked to a goal that the treatment team has written. The person can be observed to be going through the motions of the task	**Engagement** When a person is engaged in an activity, he/she is invested in it and "caught up" in the moment. The staff responds to the individual's cues and adjusts the activity and the environment to make sure it is not too difficult

(continued)

Table 8.1 (continued)

Individual Support Planning	Mindfulness-Based Individual Support Planning
and may be bored, not paying attention, or not necessarily enjoying or learning from the experience. Example: *Jackson needs to learn to control his hitting behavior so his goal is to participate at his day program for 30 min without hitting anyone or himself. He usually sits with a 1:1 care staff and looks out of the window*	(which can cause frustration) and not too easy (which can cause boredom). Example: *When Jackson starts feeling the need to hit, his care staff engages him in a fun boxing game on the Wii, followed by a game to hit an inflatable punching target while listening to Jackson's boxing music playlist*
Change the services to change people Given that people with intellectual and developmental disabilities may have diseases, disabilities, and deficits, they need assistance to change their behaviors and prevent injury and accident. This is usually achieved by prescribing or changing medications and changing services, as needed. Numbers are most often used to measure progress	**Transform ourselves to benefit people** By practicing mindfulness and using openhearted awareness and presence, supporters can *be* with a person, rather than *do to* or *for* the person. This creates opportunities for meaningful connection and fun, and the ability to meet a person's changing needs in each moment from being in tune with what he or she wants

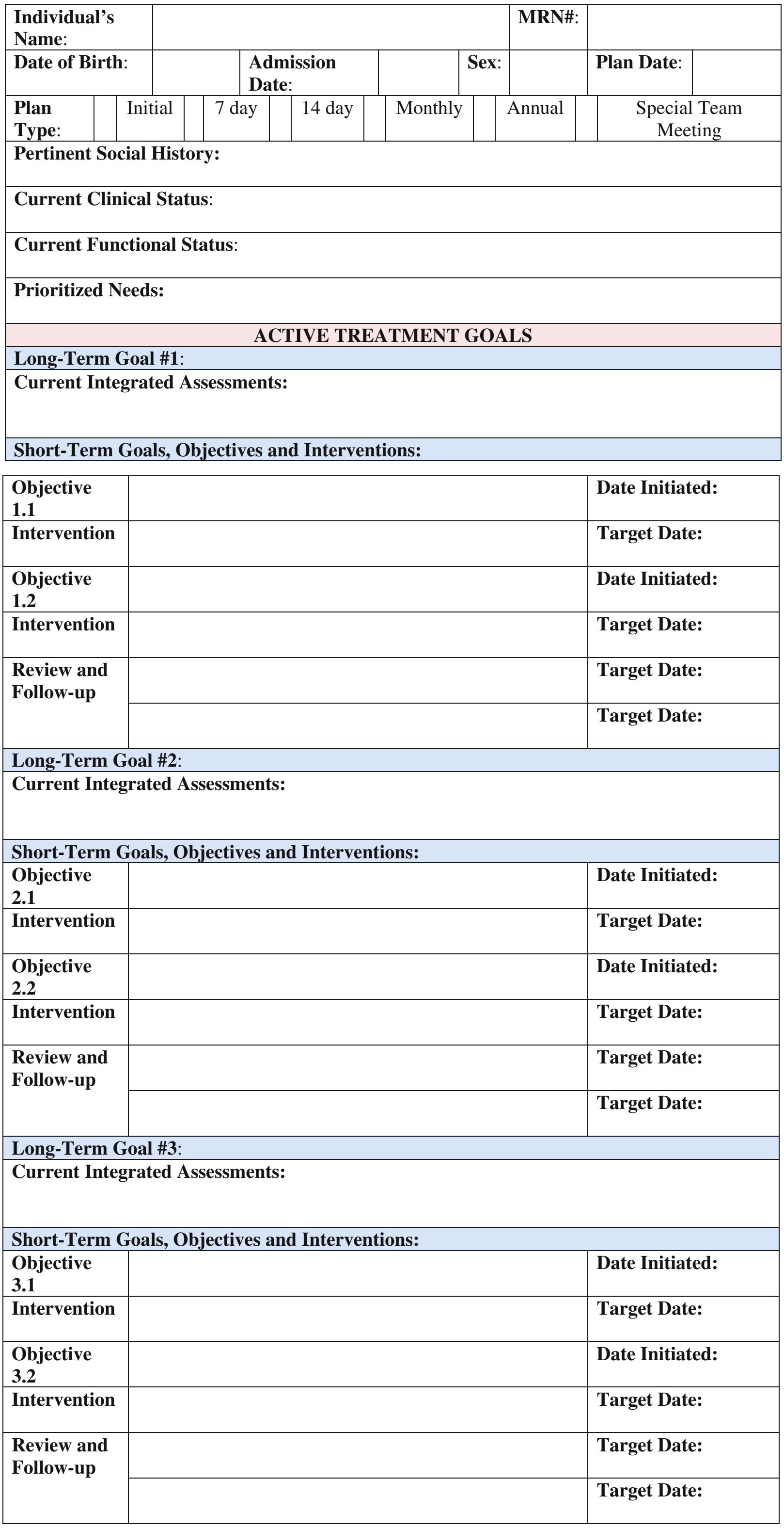
standard ISP formats, some of which can be upward of 40 pages when completed. By contrast, the MBISP is typically 5–10 pages at most, and each update contains only the current assessments and learning and service plans. The plans are written in such a manner that it is understood at first reading. People with intellectual and developmental disabilities who can read and/or listen with comprehension should be able to navigate through their MBISP with the assistance of their support providers. The plans are devoid of jargon and other shorthand communication devices often used by clinicians.

The initial MBISP is developed by asking the person with intellectual and developmental disabilities the foundational question, "If we could do anything to make your life better, what would it be?" or, if the person is unable to make this decision for any reason, the question is redirected at the individual's team members, "If we could do anything to make this person's life better, what would it be?" Some team members may see this as a challenging question to answer if a person is unable to communicate verbally, especially if the person is new to the team. However, this can be a good thing because the team is open to new ideas and has not yet formed opinions about what the person can or cannot do, or what the person likes or doesn't like, which is what often occurs in long-term residential settings. The answers to this question are prioritized as long-term goals and serve as the foundation for the development of the MBISP. Openly exploring what the team can do to make the person's life better is at the heart of the MBISP planning, and all goals, services, and outcomes relate to areas that rapidly impact the quality of the person's life. The underlying assumption is that the individual can thrive even under life's adverse circumstances, and that the team's role is to develop a transactional pathway by which this can be made possible. The time lines are short, with most short-term goals and learning interventions being achievable within a week, and outcomes measured in terms of quality of life changes that are meaningful and functional for the person.

Brief Instructions for Developing the MBISP

Relative to the standard ISP, the MBISP is relatively simple to complete and not very time-consuming. The typical procedure is for the person with intellectual and developmental disabilities, family members, and treatment team (including all caregivers who know the person best or those whose who will provide daily supports) to meet and complete the MBISP at one meeting. The MBISP is updated as often as necessary, typically when new assessments and consults are completed, and when the person meets a specific objective, intervention, or requires an updated intervention for the same objective. The person's self-determined preferences, choices, and quality

Fig. 8.1 Format of the mindfulness-based individualized support plan attachment: treatment team members' names, signatures, and date



Individual's Name:		**MRN#**:	

Date of Birth:		**Admission Date**:		**Sex**:		**Plan Date**:	

Plan Type:		Initial		7 day		14 day		Monthly		Annual		Special Team Meeting

Pertinent Social History:
Current Clinical Status:
Current Functional Status:
Prioritized Needs:
ACTIVE TREATMENT GOALS
Long-Term Goal #1:
Current Integrated Assessments:
Short-Term Goals, Objectives and Interventions:

Objective 1.1		**Date Initiated:**
Intervention		**Target Date:**
Objective 1.2		**Date Initiated:**
Intervention		**Target Date:**
Review and Follow-up		**Target Date:**
		Target Date:

Long-Term Goal #2:
Current Integrated Assessments:
Short-Term Goals, Objectives and Interventions:

Objective 2.1		**Date Initiated:**
Intervention		**Target Date:**
Objective 2.2		**Date Initiated:**
Intervention		**Target Date:**
Review and Follow-up		**Target Date:**
		Target Date:

Long-Term Goal #3:
Current Integrated Assessments:
Short-Term Goals, Objectives and Interventions:

Objective 3.1		**Date Initiated:**
Intervention		**Target Date:**
Objective 3.2		**Date Initiated:**
Intervention		**Target Date:**
Review and Follow-up		**Target Date:**
		Target Date:

Fig. 8.1 (continued)

Long-Term Goal #4:		
Current Integrated Assessments:		
Short-Term Goals, Objectives and Interventions:		
Objective 4.1		**Date Initiated:**
Intervention		**Target Date:**
Objective 4.2		**Date Initiated:**
Intervention		**Target Date:**
Review and Follow-up		**Target Date:**
		Target Date:
Long-Term Goal #5:		
Current Integrated Assessments:		
Short-Term Goals, Objectives and Interventions:		
Objective 5.1		**Date Initiated:**
Intervention :		**Target Date:**
Objective 5.2		**Date Initiated:**
Intervention :		**Target Date:**
Review and Follow-up		**Target Date:**
		Target Date:
SERVICE PLANS (add more sections as needed)		
1.0		**Staff Responsible:**
Services		
2.0		**Staff Responsible:**
Services		
3.0		**Staff Responsible:**

of life issues take precedence over those of all others.

Information About the Person

Identification. This information for this section is obtained from the person's admission notes or medical chart.

Plan Type. The plan types include initial (at admission), 7-day (completed on or about the 7th day following admission), 14-day, monthly (with the 3rd monthly being a quarterly), annual (with the 12th monthly being an annual), and special team meeting (required by policy for documenting adverse events). The type of plan is an interval summary of the person's progress through his MBISP.

Pertinent Social History. This section includes a summary of the following: why the person was admitted to the facility or group home; where the person lived before current admission; important family circumstances; preferences, choices, non-negotiables; religious preference; guardianship; and education.

Current Clinical Status. This section includes a summary of the following: current medical diagnoses; how medical conditions are being

Fig. 8.1 (continued)

Services		
4.0		**Staff Responsible:**
Services		
5.0		**Staff Responsible:**
Services		

Rights Restriction and Restoration		
Rights Restriction and Restoration:	**Date Restricted**	**Date Restored**
Review and Recommendations:		**Target Date:**
Team Leader Monthly Update		
Team Meeting Update		

Individual's Signature ____ Date ________________

treated; nutritional status; physical health status; therapies; all prescribed medications and treatments; recent laboratories/diagnostic results; mental health status—psychiatric and psychological issues; level of supervision; and consult. Each medical condition or disorder in this list is linked to a service plan in the Service Plan section of the MBISP.

Current Functional Status. This section includes a summary of the following: What the person is able to do functionally stated in behavioral terms; required assistance for self-care; special eating and drinking considerations or modifications; communication ability; self-regulation and coping skills; adaptive equipment; procedures and plans; strengths, current level of engagement and protective factors; and quality of life preferences and choices. Areas from this list that are determined to be important to the person's quality of life are linked to the goals in the active treatment goals section of the MBISP.

Active Treatment Goals

Active treatment goals enable the person to maximize self-determination, preferences, and choice to enhance his or her quality of life. These goals are functional, meaningful to the individual, and designed to enhance independent functioning, improve autonomy, and increase opportunities for new experiences. The goal of active treatment is not to make the person with intellectual and developmental disabilities simply fit better in the current residential setting, but to afford the person the same opportunities for self-discovery, social connection, and for experiencing life available to a person without intellectual and developmental disabilities. The goals are conducive to physical and social integration in the person's community or, if the person is in a congregate care facility, the proposed community upon leaving. The active treatment goals are linked to the person's current functional status and are developed to make the person's life better now, within a few days or weeks, rather than months later.

Long-Term Goals. Each long-term goal is based on the person's self-determined quality of life needs, preferences, and choices, and begins with the answer to the initial question of how to make the person's quality of life better now. A long-term goal may take some time to achieve, and it is written in terms of what the person will do that can support more enjoyment or engagement in life. Another name for a long-term goal is a *quality of life* goal.

Current integrated assessments: In the context of each long-term goal, the treatment team as a group identifies and undertakes pertinent cross-disciplinary assessments that inform the development of short-term goals. These assessments are dynamic and repeated as the person progresses on each short-term goal, which further informs the changes that need to be made to short-term goals. These assessments are integrated in the sense that each discipline builds on the findings of other pertinent disciplines, and findings are all specific to a functional area of engagement that is meaningful to the individual. For example, if a person with a dysphagia diagnosis, who requires a modified food texture for safety, wants to try to learn to safely eat a favorite food again, he may have an integrated assessment by an occupational therapist, speech therapist, physician, and dietitian. It should be understood that a different mix of assessments might be needed as the person makes progress on each short-term goal. Recommendations include discipline-specific responsibilities for further assessments and target date(s) for the proposed assessments. The assessments integrated in this section pertain only to the long-term quality of life goal listed above it. Discipline-specific monthly assessments that are generic and do not pertain to the specific long-term goal may be filed in the person's chart, but are not included in his or her MBISP.

This section also includes information from all pertinent team members on how the person is doing in each specific long-term goal area in terms of motivation, level of supports needed, ability, and engagement. This is different from the current functional status because that section provides a global picture of the individual, and this section addresses a specific functional area in some detail. Assessment data can come from observations, practical assessments, formal clinical evaluations, tests or consultations from outside professionals, caregiver data collection sheets, and video observations.

Short-Term Objectives and Interventions. The short-term goals telescope into the long-term goal. That is, the short-term goals collectively form the long-term goal. Each short-term goal specifies the objective(s) and interventions. The plan includes the date initiated, target date, and discipline responsible. The objectives and interventions are written in plain language that can be understood by everyone, including parents, guardians, and care staff upon first reading. The interventions are stated in flexible terms—going with the flow of the individual—as opposed to a rigid schedule that does not take into account the changes in the person's behavioral, social emotional, and medical issues. The interventions state how caregivers and clinicians will support the person to achieve the short-term goals as efficiently and effectively as possible.

The interventions linked to each objective are developed as instructions for staff members. These instructions are sometimes called mindful engagement support (MES) worksheets and are readily available to caregivers in the person's residential, work, and leisure settings. The MES worksheets help the caregivers in implementing each of the interventions. Implementing the interventions is a matter of supporting and mindfully guiding the person with intellectual and developmental disabilities, as opposed to rigidly teaching the person to achieve the objective. Interventions can be programs, supports, or opportunities that help the person to learn or practice skills along a pathway to meeting personal quality of life goals.

Service Plans

Service plans are linked to the current clinical status (and, occasionally, the current functional status) and provide a list of all services that clinicians and direct care staff will provide to the person with intellectual and developmental disabilities. Each medical or health condition or diagnosis that affects the person's health, safety, or quality of life should have a matching service plan listed in this section. A service plan is a guide to the kinds of interventions, medications, or services a person needs to maintain or improve health and wellness. Some disciplines, such as nursing and therapies, have protocols that can be used to guide therapeutic services for each person that are based on evidence-based standards of practice. The treatment team may refer to these protocols in the service plans, without further elaboration.

Rights Restoration

Typically, the individual's MBISP should not include any restriction of rights. If there is a restriction, it is stated in this section, together with a plan to restore the right as rapidly as possible.

Team Leader Monthly Update

In this section, the team leader, typically a Qualified Intellectual Disabilities Professional (QIDP) summarizes the participation of the person with intellectual and developmental disabilities, family members, guardians, and significant others in the MBISP reviews and updates. The summary also includes recommendations for revisions in the MBISP, monthly contact with family and guardians, change in transition status, and other significant events (e.g., trips to community, risk thresholds, incidents, change in work status, or residential setting).

Team Meeting Update

This section is a summary of the current team meeting.

Supporting People with Intellectual and Developmental Disabilities to Mindfully Engage with Their MBISP

Individuals with intellectual and developmental disabilities often need support with daily activities. However, if a person has limited mobility or ability to communicate, his or her options may also be somewhat restricted. It is more likely for engagement to occur if a person is doing a task that is challenging enough to be interesting, but not too difficult to be frustrating. Similarly, a person is likely to engage in an activity if it is motivating, pleasurable, functional, and meaningful.

How to CREATE Engagement Opportunities

Caregivers can support people with intellectual and developmental disabilities to enhance the quality of their lives by restructuring the environments and contexts in which they engage in life activities. The acronym CREATE provides a framework for developing the necessary supports in terms of service provision and physical environment that enhance engagement opportunities for people with intellectual and developmental disabilities. The CREATE domains are various aspects of engagement that collectively form a holistic picture of potential for meaningful quality of life experiences. Staff and caregivers can make changes to each of these factors as needed to help people to be more present and invested in daily activities.

C: Choice, Control, and Curiosity. Choice and control empower a person to make decisions about the kinds of activities to engage in throughout the day. In some settings, such as in some residential or group home settings, choice and control are often limited, especially when a person has difficulty in communicating clearly. It is important to continually update *preference assessments* to help figure out what the person likes (e.g., foods, places, comfort items, activities, household chores, types of music, beverages, smells). A *preference assessment* involves offering the person different options and documenting his or her response to each option, so that these choices can be used to help support engagement (Samaha et al., 2016). It is also important to remember that a person's preferences might change over time, and the person may like something now and not like it little later, or conversely, begin to take interest in something that was not previously a source of enjoyment. Another important factor is curiosity. Research shows that if someone is curious about something, she is more likely to learn from the experience and remember it (Kidd & Hayden, 2015). Offering a person something new or providing an activity in a new setting can help to get them curious and motivated, which can lead to a more engaging experience.

R: Response, Regret Prevention, and Reinforcement. Supporting a person's needs requires paying attention and being aware of the person and the environment so that we can respond rather than react. Reacting is reflexive and usually happens when we are not paying attention or being aware. Responding is more careful and occurs when we are aware of what is going on around us not only right now, but also with consideration of things that have happened in the past. For example, if we are sitting at a red light and the light turns green and we go immediately, this is a reaction. If we look both ways to make sure no people or cars are coming before we go, then this is a response. We may take an extra second to look before going if we have been in an accident due to someone running a red light in the past, this is the remembering part. Regret prevention is about making a response that involves thinking about the consequences of our actions before responding—it prevents us from regretting having made a mindless response. For example, if a person is trying to eat independently and accidently splashes some food all over our clothes, a reaction may include an upset tone that could hurt the person's feelings (e.g., "You made a mess!"), but a response would require a pause to contemplate a positive response and offer words that will not make the person feel badly (e.g., "That was a good try. Let me get a washcloth to clean us up"). Reinforcement is offering praise and attention for a response from the person rather than intervening negatively when something goes wrong (Williams, Lee, & Grossett, 2016). Reinforcement of effort and attitude over outcomes can be beneficial for people who struggle with task performance.

E: Environment. This factor involves an understanding of how the environment can support engagement and learning (Staddon, 2016). It can be difficult for people to be engaged in an activity if the environment is uncomfortable. For example, if a person with intellectual and developmental disabilities has a goal to get dressed independently so that he can have more privacy, he may have problems dressing if the room is too cold after his bath, or if his caregiver is rushing him. It is important to notice how the person is responding to the physical environment (e.g., he seems distracted by bright lights and becomes anxious if a peer is yelling) and the social environment (e.g., he feels a sense of connection with peers and seems to trust his caregivers), so that we can make changes as needed to support him to have more success, sense of safety, enjoyment with the activity. Finally, we should also consider the temporal environment because the time of day can affect how a person engages in an activity (e.g., a person may like to have an afternoon snack, but not a morning snack because he is hungry later in the day following his afternoon walk).

A: Awareness, Attention, and Attitude. Awareness is the process of noticing what is happening inside and around us, and attention is the process of focusing on what is in front of us, one thing at a time. For example, when our attention is directed at an interesting movie and we are snacking on popcorn at the same time, we might not be fully aware of eating a large tub of popcorn, and we may not enjoy it because our attention was elsewhere. Mindfulness involves a balance of awareness and attention; for example, if a person is focusing her attention on a beautiful flower, but not aware that she has stepped on an ant pile, she may experience pain as a result of limited mindful awareness. The best way we can support a person to be engaged and have a better quality of life experience is to give the person our full attention, and be aware of what the person is doing, as well as his or her needs and wants. This lets the person know that we are there to meet his or her needs and that we care about what is happening. Awareness involves the process of noticing what is going on so that we can ensure that the environment is safe and best able to support the person to have an engagement experience. For example, if we are working outside with a person to water plants, and we notice that a bee buzzing close to him is bothering him (who also happens to be allergic to bees), we would be able to help the person change locations for the activity, or go inside to take a break. Balancing our presence and attention on the person with awareness of what is going on around us can be really difficult, and this is why we practice mindfulness meditation to help us with attention and awareness (Hwang & Singh, 2016). Finally, having a compassionate and nonjudgmental attitude, and being open to anything that can happen, is a key part of really supporting the person. It also helps us to remember why we are working with the person, which is not to meet written goals or to slavishly follow a treatment plan, but to make that person's life better in the here and now.

T: Task Demands. People with intellectual and developmental disabilities may need physical assistance to complete tasks that are meaningful, and helping them to have more independence can give them more control when engaged in functional activities (Lancioni & Singh, 2014). If we want to help a person to be more independent with an activity, we can teach the person new skills, or we can change the task itself to make it easier. For example, if person is not able to use two hands at the same time, he may benefit from special equipment such as a rocker knife, or a cutting board with a special nail in it to hold the food in place. Being aware of the person's strengths and abilities can help us to come up with new ways to change a task, the task demand, or use assistive technology that will help the person to succeed.

E: Energy. When supporting someone to engage in an activity, it is important to remember that different activities require different levels of energy. If a person is tired, she may want to engage in a task that does not take a lot of energy (e.g., listening to music), but if she is moving and excited, she may want to engage in a task that requires a lot of energy (e.g., dancing or playing drums). Also, different types of activities can be used to help wake people up (e.g., washing face with cool cloth, smelling peppermint), or calm them down (e.g., low lighting, weighted blanket). Noticing a person's energy level can help us to make decisions about what kind of activities to provide and when to provide them, or save them for another time. For example, if a person usually exercises in the afternoon, but was sedated at the dentist that morning, something easy such as watching the birds outside or having a hand massage would be a better choice than active exercise to promote an engagement experience.

How to Develop CREATE Engagement Plans

When the treatment team identifies a quality of life goal and objectives for someone, it also develops related interventions that support

Fig. 8.2 Format of the caregiver mindful engagement support worksheet

Name:	**Home:**	**Activity Week:**
Short-term Goal and Objective:		
What Activity:		
Why:		
Where		
When:		
How: Prompts and assistance		
How: Strategies to promote engagement		
How: Mindful response and reinforcement		

providers can use to support the person to attain these goals and objectives. In the MBISP, we translate the interventions into mindful engagement support (MES) worksheets that provide detailed guidance and individualized suggestions to support providers in how they might best support a person with intellectual and developmental disabilities to be more engaged in the activities that would enhance a quality of life experience. These worksheets include details about the "what, why, when, where, and how" of engagement and are written with input from all treatment team members, especially the people who support the person with intellectual and developmental disabilities on a daily basis. These worksheets are guides, not mandates, and support providers are encouraged to make changes in terms of the degree of support needed by the person. Indeed, support providers are encouraged to make changes to the worksheets as the person makes progress in the chosen activity or indicates changes in preference and/or motivation.

Figure 8.2 presents a template of a MES worksheet. The five component sections include:

What Activity. This section lists the intervention linked to the person's short-term goal and objectives in the MBISP. Each MES worksheet covers one intervention from the MBISP.

Why. This section informs the support provider why this activity is meaningful and functional for the person being supported, and how it will enhance the quality of his or her life in a specific area of engagement.

When. This section lists the time(s) of day or night that the activity and support will occur, based on the person's preferences and rhythm of life.

Where. This section lists the location(s) where the activity and support will take place. It may also include a description of where and how the person might be best supported (e.g., wheelchair, armchair, near a window, feet elevated with pillow under knees), and special equipment or positioning considerations to enhance safety and/or comfort.

How: Prompts and assistance. This section includes suggestions for the type of prompts and assistance that support providers will provide to best support the person. A 5-step prompting procedure is often used:

1. Gently make a request (e.g., "Vida, press this button to turn on the iPad").
2. Pause before you provide the first prompt (i.e., give her time to show whether she can do it independently).
3. Give a general prompt (e.g., ask, "Vida, what are you supposed to do next?").
4. Give a specific prompt (e.g., model it—physical/gestural or verbal prompt). Repeat #4.
5. Give physical guidance (i.e., least-to-most—If she knows how to do it OR most-to-least—if he does not know how to do it).

Support providers should begin with #1 and work their way down to the step at which the person can perform the activity.

How: Strategies to promote engagement. This section provides helpful hints for how support providers might use the person's motivation, preferences, choices, and strengths to encourage him or her to be engaged. The information in this section gives support providers ideas and suggestions for making the activity more enjoyable, meaningful, and personalized, or for making the person more comfortable or successful.

How: Mindful response and reinforcement. This section includes strategies for how to mindfully respond and reinforce the person's behaviors. The strategies are specific and individualized (e.g., physical reinforcement such as a "high five" that is highly preferred by the person rather than the generic verbal "good job").

Conclusion

The essence of an individualized support plan is not to prescribe a set of mandated tasks for support providers to execute, but to develop a pathway that caregivers can use as a guide to support a person to thrive regardless of physical, mental, medical, or psychological circumstances (Singh, Lancioni, Harris, & Winton, 2016a). For people with intellectual and developmental disabilities, these plans should enable a life worth living, with a focus on maximizing the person's inherent potential, and not degenerate into institutionalized care for the convenience of the caregivers and the service providers. Implementation of these plans should focus on the person's well-being and personal aspirations, and the role of the support providers is to support them to be fully engaged in a life of their choice, within the outer boundaries of what nature has imposed on them (Thomas, 1996). It is within their civil rights to expect us to push the boundaries of what nature has given them, and to assist them to fully control what they may do with what they have.

The MBISP provides a framework for providing supports to people with intellectual and developmental disabilities that respects and enables them to engage in self-determined action, identify preferences, and make choices that enrich their lives with quality and meaning. The mindfulness training components enable staff to implement the plans with wisdom, loving kindness, and compassion. Given that some people with intellectual and developmental disabilities may engage in challenging behaviors, caregivers' support skills can be buttressed with additional training in mindfulness-based positive behavior support to preempt the use of aversive or negative consequences (Singh et al., 2016d). In essence, the MBISP translates Dworkin's (1994) two "interests" that make life worth living: *experiential* interests—engaging in activities that one finds pleasurable and exciting, and *critical* interests—engaging in activities that give meaning to our lives.

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Translating the Quality of Life Concept into Practice

9

Robert L. Schalock, Miguel A. Verdugo and Laura E. Gomez

Introduction and Overview

In a recent chapter discussing the concept of quality of life (QOL) and positive psychology (Schalock & Verdugo, 2013), we suggested that the QOL concept has had five significant effects on the field of intellectual and closely related developmental disabilities. These are that the concept fosters the provision of individualized supports, furthers the development of evidence-based practices, encourages the evaluation of personal outcomes, provides a quality framework for continuous quality improvement, and is a catalyst for organization and system-level transformation. In the conclusion of the chapter, we identified the significant challenges that researchers, policy makers, and practitioners need to address regarding the long-term impact of the QOL concept on policies and practices related to persons with intellectual and developmental disabilities as well as other diagnostic groups. These challenges relate to whether the concept and its application enhance human functioning, inclusion, and equity and reduce the discrepancy between valued personal outcomes for persons with a disability and those of persons without a disability.

Overcoming these challenges and furthering the incorporation of the QOL concept into disability-related policies and practices require that we continue to understand and address the factors that influence the translation of the QOL concept into practice. Our hypothesis is that these factors are the same as—or very similar to—those factors that influence the translation of positive psychology into practice.

Quality of life-related concepts and the themes found in positive psychology are closely related, since both influence how people think and act. Their parallel nature is shown in Table 9.1 that aligns the components of a language of thought and action (Pinker, 2005), with core positive psychology themes (Hart & Sasso, 2011), and QOL-related actions (Reinders & Schalock, 2014; Schalock et al., 2016).

In this chapter, we discuss six factors that significantly influence not only the translation of the QOL concept into practice but also by inference, the translation of positive psychology into practice. These factors are a validated QOL conceptual model, QOL enhancement strategies, application fidelity, research, evidence-based practices, and a systematic approach to translating evidence into practice.

Throughout the chapter, QOL is defined as a *multidimensional phenomenon composed of core domains that constitute personal well-being.* Corollaries stemming from this definition are that (a) these domains, which are important to all people, reflect the holistic and individualistic

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Table 9.1 Parallel nature of the concepts of positive psychology and quality of life

Components of a language of thought and action	Positive psychology themes	Quality of life-related concepts
A cast of basic concepts	Virtues, character strengths, positive personality traits, abilities, talents	Equity inclusion, empowerment, self-determination, rights (legal and human)
A set of relationships	The good life or the life worth living	Interactions, social networks, community participation, valued roles, positive experiences
A system of spatial concepts	Thriving and flourishing, resilience or adaptive functioning	Inclusion, active participation, being in and of the community
A family of causal relations	Developmental processes, actualization of potential	Autonomy/personal control, choices, self-advocacy
The concept of a goal	Happiness, emotional well-being, fulfillment, quality of life	Personal outcomes, inclusive environments, possessions

nature of a life of quality, although their relative importance will vary across age, gender, and cultures; (b) one's quality of life is the product of personal characteristics and environmental factors and is enhanced through quality enhancement strategies; (c) personal growth does not only pertain to realized outcomes but also to the processes involved, including what the person contributes to bringing about change, and what person-centered supports and opportunities facilitate a life of quality; (d) no one is excluded on the basis of disability from the quality of life enhancement process; and (e) indicators of QOL domains can be assessed in reliable and valid ways (Brown et al., 2013; Mansell & Beadle-Brown, 2012; Nussbaum, 2009, 2011; Reinders & Schalock, 2014; Schalock & Verdugo, 2008; Schalock et al., 2016; Sen, 1999; Verdugo et al., 2005).

QOL Conceptual Model

Translating the QOL concept into practice starts with a validated conceptual model that is used to explain the QOL concept, integrate current work in the field, and provide the basis for application. Our work to date incorporates a conceptual model of individual quality of life based on QOL domains and moderator and mediator variables.

Quality of Life Domains

In our conceptual model, quality of life is composed of eight core domains that were initially synthesized and validated through an extensive review of the international quality of life literature across the areas of intellectual and developmental disabilities, special education, behavior and mental health, and aging (Schalock & Verdugo, 2002). These core domains are personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being. Subsequent cross-cultural validation of the etic (i.e., universal) properties of these eight domains has been reported by Jenaro et al. (2005), Schalock et al. (2005), and Wang et al. (2010).

In addition to confirming the factor structure of the eight, first-order domains listed above, research has also determined the hierarchical nature of the quality of life concept. Based on both cross-cultural data (Wang et al., 2010) and data obtained from Spain (Gomez et al., 2011), three higher order factors have been identified. These are *independence* (composed of personal development and self-determination), *social participation* (composed of interpersonal relations, social inclusion, and rights), and *well-being* (composed of emotional, physical, and material well-being).

Other conceptual models of individual quality of life can be found in the work of Brown et al., (2013), Cummins (2005), Gardner and Carran (2005), Felce and Perry (1995), Petry et al. (2005, 2009), and Renwick et al. (2000). Analogous models of family quality of life can be found in the work of Chiu et al. (2013) and Zuna et al. (2010). Common to these models is the inclusion of *quality of life domains* that are the factors composing personal or family well-being, and *quality indicators* that are QOL-related perceptions, behaviors, and conditions that give an indication of a person's or family's well-being. The measurement of quality of life is based on assessing the perceived status (based on self-report or report of others) of the quality indicators.

Moderator and Mediator Variables

Translating the QOL concept into practice: (a) is based on an ecological model of disability that focuses on person–environmental interaction, the congruence between personal competence and environmental demands, and the use of QOL enhancement strategies that bridge the gap between what is and what can be; and (b) requires an understanding of two classes of variables that influence QOL domains, indicators, and QOL-related outcomes: moderator and mediator variables.

- A *moderator variable*, which can be continuous or categorical, alters the relation between two variables and thus modifies the form or strength of the relation. A moderator effect is an interaction in which the effect of one variable is dependent on the level of the other (Farmer, 2012; Frazier et al., 2004; McKinnon, 2008).
- A mediator variable, which is generally continuous, influences the relation between an independent variable and outcome and exhibits indirect causation, connection, or relation. A mediator effect is created when a factor intervenes between the independent and outcome variable (Farmer, 2012; Frazier et al., 2004; McKinnon, 2008).

There has been initial work in the field of intellectual and developmental disabilities identifying those variables that potentially act as either 'quality of life moderators' or 'quality of life mediators.' These are summarized in Table 9.2. The listing in Table 9.2 is based on the work of Chiu et al. (2013), Cummins (2005), Gomez et al., (in preparation), Reinders and Schalock (2014), and Schalock et al., (2007, 2010).

Quality of Life Enhancement Strategies

Implementing QOL enhancement strategies is an essential step in translating the QOL concept into practice. As summarized in Table 9.3, enhancement strategies should be aligned with quality of life principles and applied at the micro-, meso-, or macrosystem level. Material presented in Table 9.3 is based on the published work of Barron and Kenny (1986), Brown et al. (2013), Claes et al. (2012), Gardner and Carran (2005), Morin et al. (2013), Reinders and Schalock (2014), Schalock and Verdugo (2012, 2013a, b, 2014), Schalock et al. (2007, 2011), and Thompson et al. (2014).

Application Fidelity

The effectiveness of the quality of life enhancement strategies listed in Table 9.3 is influenced significantly by application fidelity. Such fidelity involves the following (Bigby et al., 2014; Hogue & Dauber, 2013; Reinders & Schalock, 2014): the quality or extent to which the QOL enhancement strategy is delivered within the organization's policies and practices (i.e., adherence), the quality or skill of delivery (i.e., competence), and the degree to which the QOL enhancement strategy focuses on quality of life and not quality of care (i.e., differentiation). In addition, application fidelity incorporates best practices in the field. As discussed by Reinders and Schalock (2014), Schalock and Luckasson (2014), and Schalock and Verdugo (2014), these

Table 9.2 Quality of life moderator and mediator classes and associated variables

QOL moderator/mediator class	Specific variables studied to date
QOL moderators	
– Personal demographics	– Gender, race, intellectual functioning, adaptive behavior, social economic status
– Organization culture	– Level of personal involvement of the client, level of personal growth opportunities
– Family-unit factors	– Family income, size of family, family geographical location, religious preference, family structure
QOL mediators	
– Personal status	– Residential platform, employment status, health status, and level of self-determination and subjective well-being
– Provider system	– Services, individualized supports
– Community factors	– Normative expectations, attitudes, media impact

Table 9.3 Quality enhance strategies

Systems level	QOL-related principles	Exemplary QOL strategies
Individual (microsystem)	Empowerment Skill development Involvement	– Decision making, choice making, risk taking, goal setting, self-advocacy, self-management – Functional training and use of technology to enhance cognitive, social, and practical skills – Participation, inclusion, knowledge sharing
Organization (mesosystem)	Opportunity development Safe and secure environments Supports alignment	– Integrated employment, inclusive education, community-based, less restrictive living options, community integration activities, transportation, social networks – Environments characterized by safety, security, and personal control – Aligning individualized supports to personal goals and assessed support needs
Society (macrosystem)	Accessibility Attitudes Environmental enrichment	– Ensuring human rights (e.g., empowerment and inclusion) and legal rights (e.g., citizenship, due process) – Positive interactions – Nutrition, cleaner environments, reduced abuse and neglect, safer environments, adequate housing and income

are the following: (a) employing support teams that include service/support recipients and their family, direct support staff who are involved in the provision individualized supports, relevant professionals, and a support coordinator; (b) developing QOL-focused individual support plans around the individual's personal goals, assets, and assessed support needs; (c) implementing a system of supports that encompasses an array of operationally defined support strategies, including natural supports, cognitive supports, assistive technology, information technology, skills and knowledge development, environmental accommodations, building on personal goals and assets, and professional services; and (d) employing user-friendly support plan that provides delineate support provision and outcomes.

Research

Research should incorporate an ecological framework, be sensitive to application fidelity, and be guided by the three foundational elements discussed in the following section on establishing evidence-based practices. In addition, QOL-related research requires clear operational definitions of both the independent variable (i.e., QOL enhancement strategies that can act as moderators or mediators) and the dependent variable (i.e., assessed personal outcomes).

Independent Variable: QOL Enhancement Strategies

The QOL enhancement strategies listed in Table 9.3 are best practices that stem from research-based knowledge, professional values, professional standards, and empirically based clinical judgment. These (and analogous) strategies can be used to generate research hypotheses such as:

- At the individual (microsystem) level: QOL outcomes are enhanced through decision making, choice making, goal setting, self-advocacy, self-management, use of technology, participation, and social networks.
- At the organization (mesosystem) level: QOL outcomes are enhanced through integrated employment, inclusive education, community-based living and participation, transportation, safe and secure environments, personal control, and individualized support strategies targeted to personal goals and assessed support needs.
- At the societal (macrosystem) level: QOL outcomes are enhanced through ensuring human and legal rights, developing and experiencing positive community attitudes, and maximizing environmental enrichment related to health, safety, and social economic status.

Dependent Variable: Personal Outcomes

The current approach to the measurement of QOL-related personal outcomes is characterized by its multidimensional nature, the coexistence of universal and culture-bound indicators, the use of measurement pluralism that involves self-report and report by other significant persons, and the involvement of persons with disabilities in the design and implementation of the assessment instrument and the assessment process. QOL-related research should also reflect a number of best practice test development and assessment practices. As discussed by Gomez et al. (2012) and Gomez and Verdugo (2017), these involve the following: (a) a well-formulated and validated conceptual model, (b) culturally sensitive indicators, (c) a Likert scale scoring metric, (d) acceptable psychometric properties, (e) administration by a qualified interviewer, and (f) the use of self-report and report of others' versions that include the same indicator and scoring metric. The use of comparable versions (i.e., self-report and report of others) allows researchers to address long-standing questions about response perseveration, concordance rates among respondents, and the relation between subjective and objective data.

Research involving the assessment of personal outcome determines whether or not there is a significant relation between a specific QOL enhancement strategy and a measured QOL-related outcome. Thus, outcome evaluation is an essential step in establishing evidence-based practices.

Establishing Evidence-Based Practices

Despite the widespread advocacy for evidence-based practices (EBPs) across disciplines and human service areas (see, e.g., Archibald, 2015; Claes, 2015; Means et al., 2015; Mihalic & Elliott, 2015; Schalock et al., 2011), there are three important foundational elements that need to be addressed in establishing best practices as evidence-based practices: (a) clear operational definitions of key terms, (b) what evidence-gathering strategy should be used that best addresses the question(s) being asked, and (c) what evaluation standards should be employed to interpret the significance of the evidence (Schalock, Gomez, Verdugo, & Claes, 2015).

Operational Definitions of Key Terms

The key terms involved in establishing EBPs are evidence, practices, outcomes, and evidence-based practices.

- *Evidence*: quantitative or qualitative results that furnish proof of the significant relation (causal or correlational) between specific enhancement strategies and measured outcomes. Current best evidence is information obtained from credible sources that used reliable and valid methods and/or information based on a clearly articulated and empirically supported theory or rationale.
- *Practices and best practices:* interventions, services, strategies, supports, and policies that focus on enhancing human functioning and personal well-being. Best practices can come from research-based knowledge, professional values and standards, and empirically based clinical judgment. Best practices can also be derived from a rigorous process of peer review and evaluation indicating effectiveness in improving outcomes.
- *Outcomes*: specific indicators of the benefits derived by program recipients that are the result of the practice(s) employed. These indicators are assessed via quantitative or qualitative methodologies and focus on human functioning, social participation, and/or personal well-being. Outcome indicators need to be: (a) based on a clearly articulated and validated conceptual and measurement model, (b) assessed reliably, and (c) have utility in that they are used to demonstrate effectiveness of the aforementioned practices.
- *Evidence-based practices*: practices that are based on current best evidence of a significant relation between a specific practice and measured personal outcome(s) and that are used as the basis for clinical, managerial, and policy decisions.

These operational definitions encompass the factors that play a role in decision making including scientific evidence, cultural appropriateness, the multidimensional and individual nature of quality of life, and concerns and emphasis on equity and human rights (Archibald, 2015; Navas et al., 2012; Schalock et al., 2011; Verdugo et al., 2012; United Nations, 2006). They also reflect the potential use of EBPs to inform clinical decisions about intervention/support strategies; managerial decisions about value-based policies, resource utilization patterns, and organization structure, and policy and funding decisions and mandates (Donaldson et al., 2009; Means et al., 2015; Mihalic & Elliott, 2015; Schalock & Verdugo, 2012).

Evidence-Gathering Strategies

Evidence-gathering strategies can be organized into two broad measurement perspectives with specific research designs associated with each: quantitative and qualitative. An overview of these designs and techniques based on the formulation of Neutens and Robinson (2010) and Norwood (2010) is presented in Table 9.4. The specific evidence-gathering strategy used to establish EBPs will depend on the practice or policy being evaluated, the limitations imposed by statutory/regulatory bodies or professional standards and ethics, the constituents involved in the evidence-gathering activities, and the available level of expertise. Additional information regarding evidence-gathering strategies can be found in Burke (2001), Claes et al. (2015), Creswell et al. (2007), Grimshaw et al. (2000), Schalock and Verdugo (2012), and Schalock et al. (2011).

Evaluation Standards

The evidence obtained via an evidence-gathering strategy is used to evaluate the hypothesis that a particular practice is either effective or ineffective. As discussed by Biesta (2010) and Bouffard and Reid (2012), and Schalock et al. (2015), it is important to remember that evidence is useful only within the context of the question(s) being asked, what is best for whom, and what is best for what. In addition, evidence is also evaluated on the basis of the perspective taken. In that regard, there are three perspectives on evidence: the empirical-analytical, the phenomenological-existential, and the post-structural (Broekaert et al., 2010; Claes et al. 2015; Schalock et al., 2011; Shogren et al., 2015). These three perspectives lead to different approaches to evaluating evidence, the outcome domains selected, and the evaluation standards used.

The evaluation of evidence is based on three currently employed standards that allow one to align the questions being asked, what is best for whom, and what is best for what. These three evaluation standards are the quality of the evidence, the robustness of the evidence, and the relevance of the evidence.

Quality of evidence. The quality of evidence is related to the type of measurement perspective the particular research design used. In reference to quantitative designs, the quality of evidence can be ranked from high to low, with experimental designs highest, followed by quasi-experimental and nonexperimental designs (Gugiu, 2015; Sackett et al., 2005). In reference to qualitative designs, the quality of evidence is evaluated based on its validity, generalizability, and objectivity (Daly et al., 2007; Lincoln & Guba, 1985; Gugiu, 2015).

Robustness of evidence. Robustness refers to the magnitude of the observed effect. In quantitative research designs, the magnitude is determined from probability statements, the percent of variance explained in the dependent variable by variation in the independent variable, and/or the statistically derived effect size (Daly et al., 2007; Given, 2006). In qualitative research designs, the robustness of evidence is determined by whether the practice or strategy is based on a validated conceptual framework, a diversified sample, data-triangulation, a clear report of the analysis, and/or the generalizability of the findings (Claes et al., 2015; Daly et al., 2007; Schalock et al., 2011).

Relevance of evidence. The relevance of evidence is based on the purpose and use of the practice in question, and how the practice enhances personal well-being and supports policy goals. For those making clinical decisions related to diagnosis, classification, and planning supports, relevant evidence is that which enhances the congruence between a specific clinical function and a desired outcome. For those

Table 9.4 Overview of evidence-gathering strategies

Measurement perspective	Research designs
Quantitative	
– Experimental	Independent measures/groups
	Repeated measures
	Matched pairs
– Quasi-experimental	Uncontrolled before and after studies
	Time series designs
	Controlled before and after studies
– Nonexperimental	Descriptive/predictive/explanatory
	Retrospective/cross-sectional/longitudinal
Qualitative	Narrative research
	Grounded theory
	Ethnography/phenomenological
	Participatory action research
	Case study

making managerial decisions, relevant evidence is that which identifies organizational policies and practices that enhance human functioning and personal outcomes. For those making policy decisions, relevant evidence is that which supports and enables organizations and systems to be effective, efficient, and sustainable; influences public attitudes toward people with intellectual and developmental disabilities; enhances long-term outcomes for service recipients; changes education and training strategies; encourages efficient resource allocation practices; and aligns policy goals, supports, and policy-related outcomes (Claes et al., 2015; Schalock et al., 2011; Shogren et al., 2015; Turnbull & Stowe, 2014).

A Systematic Approach to Translating Evidence into Practice

If the QOL concept is to have a lasting, significant, and positive impact on disability-related policies and practices, it must evolve to a well-recognized and accepted evidence-based practice (Brown et al., 2013; Gomez et al., 2015; Schalock & Verdugo, 2013a). In our judgment, this evolution requires two things in addition to research related to establishing evidence-based practices. The first is to develop clear guidelines for translating evidence into practice; the second is to establish a dialog and partnership among policy makers, practitioners, and researchers.

Guidelines for Translating Evidence into Practice

Four guidelines have emerged in the literature to facilitate the translation of evidence into practice. As discussed by Biesta (2010), Claes et al. (2015), and Pronovost et al. (2008), they involve the following: (a) being sensitive to the organization or system's receptivity to the practice; (b) considering evidence-based practices within the social-ecological perspective on disability and thus providing both a broader range of targets for intervention/quality enhancement and the design of interventions that are minimally intrusive; (c) implementing the quality enhancement strategies via consultation and learning teams; and (d) stating clearly outcomes that are targeted to concrete, observable behavior(s) that are objectively measured over time.

Dialog and Partnership

The high stakes involved in successfully translating the QOL concept into practice require both a dialog and a partnership. The dialog should focus on what is evidence; what are best practices; what perspectives should be used to frame evidence-based practices; what evidence-gathering strategy is best to use and in what situations; and what evaluation standards should be used in making clinical, managerial, and policy decisions.

The partnership should involve policy makers, practitioners, and researchers. In this partnership, policy makers should incorporate the concept of outcome-driven policy formation to formulate policy-relevant questions, specify QOL-related policy goals and targeted QOL-related outcomes, and indicate policy-relevant perspectives on evidence. Researchers should act on the policy-related questions, policy goals, targeted outcomes, and the relation between specific QOL enhancement strategies and the targeted outcomes. Practitioners (including system-level personnel) should focus on developing policies and practices that incorporate a quality of life language of thought and action; understanding the essential role that EBPs play in professionalism, quality services, and the quality of life of their service/support recipients; accessing the published literature regarding best practices and evidence-based practices; and transforming their policies and practices to successfully infuse the QOL concept into their organization's culture.

Conclusion

In this chapter, we have discussed the factors that in our estimation significantly influence the translation of the QOL concept into practice.

These factors involve using a validated QOL conceptual model, employing best practice QOL enhancement strategies that are applied with fidelity, conducting research that is centered on hypothesis testing and leads to the establishment of evidence-based practices, and using a systematic approach for translating evidence into practice.

These factors compliment five major trends currently impacting our field. The first is the ecological model of disability that focuses on person–environmental interaction and the congruence between personal competence and environmental demands (Schalock & Luckasson, 2014; Shogren et al., 2014). The second is the supports paradigm that is based on the assessment of support needs across major life activity areas and the provision of individualized supports that reduce the discrepancy between personal competence and environmental demands (Brown et al., 2013; Thompson et al., 2014). The third is the infusion of the principles of positive psychology that include valued subjective experience, positive individual traits, and civic values (Hart & Sasso, 2011; Wehmeyer, 2013). The fourth is the capabilities approach to disability that emphasizes that no one is excluded on the basis of cognitive impairments from the QOL enhancement strategies (Nussbaum, 2009, 2011). The fifth is the international recognition of the rights of persons with disabilities and the potential of a conceptual model of individual quality of life to operationalize the major articles contained in the *U.N. Convention on the Rights of Persons with Disabilities* (Navas et al., 2012; United Nations, 2006; Verdugo et al., 2012).

The importance of the quality of life concept is that it integrates these five trends into a value-based, person-centered, and systematic approach to services, supports, and outcomes evaluation. The sustainability of the QOL concept, however, depends not only on its continued use to guide person-centered practices, quality enhancement strategies, and organization and system-level policies and practices, but also on its acceptance and widespread use as an evidence-based practice. When this occurs, the quality of life concept will then have evolved from a sensitizing notion, to a change agent, to an evidence-based practice.

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Focus on Friendship: Relationships, Inclusion, and Social Well-Being

10

Laura T. Eisenman, Brian Freedman and Marisa Kofke

Human relationships, including friendships, play a central role in promoting a better quality of life and a sense of well-being for people with or without disabilities. Social well-being is inextricable from any definition of quality of life, whether considered from the perspectives of philosophy, social science, health, or public policy. Across disciplines, a "good life" is framed in terms of objective measures, such as those related to safety and health, that assure basic human needs are met, but also includes subjective assessments of well-being, such as feelings of belonging and general satisfaction with one's situation (Johnson, Walmsley, & Wolfe, 2010; van Asselt-Goverts, Embregts, & Hendriks, 2015).

Affiliation and social-connectedness are fundamental human capabilities that encompass more than physical presence in a community (Amado, Stancliffe, McCarron, & McCallion, 2013; Johnson et al., 2010; Nussbaum, 2011). Social well-being relates to experiences of acceptance, engagement, and belonging. Within the national (U.S.) research goals on social inclusion of people with intellectual and developmental disabilities suggested by Bogenschutz et al. (2015), social well-being is viewed as an outcome of interest itself and as connected to other critical life outcomes. The connections among physical and mental health and a sense of social well-being are well-documented in the research literature on people with and without disabilities, and these connections hold true across the lifespan (Gilmore & Cuskelly, 2014; Lafferty & McConkey, 2013; Mason, Timms, Hayburn, & Watters, 2013; Mazurek, 2014).

The impact of having a diminished sense of social well-being is clearly demonstrated in studies of loneliness among people with intellectual and developmental disabilities (Amado et al., 2013; Gilmore & Cuskelly, 2014; Koegel, Ashbaugh, Koegel, Detar, & Regester, 2013; Mazurek, 2014; van Asselt-Goverts et al., 2015). Loneliness is common among this group and, as people age, they tend to have fewer friends and more limited interaction with them. However, loneliness is more than just the absence of or limited engagement with others. Loneliness reflects a person's sense that they are missing meaningful social connections and intimacy. People with intellectual and developmental disabilities typically experience less social-connectedness and fewer intimate relationships than their peers without disabilities. These experiences of social and emotional isolation

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have been linked to feelings of depression and suicidal thinking.

Social relationships have emotional and protective functions. Having larger numbers of people in an individual's social network provides increased protection by increasing the likelihood of human engagement. However, the quality and frequency of engagement with others, especially friends, may matter more (Kreider et al., 2016; Mazurek, 2014; van Asselt-Goverts et al., 2015). Although greater presence in the community is necessary, it is not sufficient to promote social well-being (Amado et al., 2013; Hall, 2009). Engagement with others as part of community and structured activities, creation and maintenance of reciprocal relationships, and a sense of belonging reflect the fuller dimensions of social inclusion.

Friendship as a Key to Social Well-Being

In their discussion of aligning intellectual disability policy, research, and practice across socioecological contexts, Shogren, Luckasson, and Schalock (2015) identified three broad interconnected policy goals—human dignity and autonomy, human endeavor, and human engagement. In this model, human engagement is represented by the three personal outcome domains of well-being, inclusion in society and community life, and human relationships. These outcome domains are in turn influenced by a variety of factors. A recurring factor across all three outcome domains and contexts is friendship.

Having a variety of social relationships is important to social well-being, yet friendships have a significant and unique role in most people's lives. Adults with intellectual and developmental disabilities have indicated that they find added value in friendships versus familial and other types of social relationships (Lafferty & McConkey, 2013; Mason et al., 2013). Friendship is perceived as offering a desirable type of emotional engagement that is different from other types of social relationships. Although friendships may be the source of personal stress or sadness, they also offer benefits in the form of a continuing commitment to another, access to instrumental and emotional supports, close companionship, the possibility of more intimate relationships, and feelings of contentment.

When asked about qualities of friends (Knox & Hickson, 2001; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006), people with intellectual and developmental disabilities have suggested that friends share activities and interests, act as trusted companions, and engage in two-way communication. Over time a sense of shared history is created. "Best" or more intimate friends offer unconditional regard and can be expected to provide support whenever needed. Professional caregivers are sometimes identified as friends by people with intellectual and developmental disabilities, which may reflect their physical proximity and the intimate nature of caregiving relationships (e.g., shared residence, physical support) as well as the more limited social networks of many people with disabilities. Philosophical and some professional perspectives on friendship qualities often include the idea that friends must be reciprocally chosen, in addition to demonstrating other relationship characteristics of mutual acceptance, affection, trust, and support (Grieg, 2015; Schuh, Sundar, & Hagner, 2015).

The idea of choice as an element of friendship has raised questions about whether individuals with the most profound intellectual disabilities have capabilities for friendship. Given their more limited means of expressing choice, communicating recognition of another, or actively demonstrating reciprocity, can a mutual friendship be said to exist? Bogdan and Taylor (1989) noted that people involved in close relationships with others who had significant cognitive impairments viewed those relationships in terms of acceptance. Differences were not ignored, but neither were they perceived as negative. The relationships were characterized as longstanding, close, and affectionate. This suggests the possibility for an ethic of friendship that does not depend on purposive reciprocated action. In this view, a vulnerable and dependent person who has been accepted and befriended by another person has participated in creating the social good of friendship (Grieg, 2015; Hughes, Redley, & Ring, 2011).

Promoting Friendship

Any effort to promote friendships with or on behalf of people with intellectual and developmental disabilities to extend their social relationships, inclusion, or social well-being must acknowledge multiple, overlapping socioecological layers of influence (Bogenschutz et al., 2015; Gilmore & Cuskelly, 2014; Hall, 2009; Mason et al., 2013; Shogren et al., 2015; Simplican, Leader, Kosciulek, & Leahy, 2015). Friendships are bound in societal (e.g., cultural attitudes about disability), organizational (e.g., opportunities for involvement in community groups), interpersonal (e.g., establishing and maintaining relationships), and individual (e.g., social awareness) dimensions. In the following sections, practices that may help to promote friendships at each socioecological level are considered across the lifespan and different social contexts. In alignment with positive psychology and disability studies frameworks (Brueggeman, 2013; Shogren, 2013), the intent is to examine practices that create opportunities for friendship based on a strengths-based perspective, account for individual choice and agency across a range of capabilities, and value disability as a natural part of human diversity.

Societal

Promoting a worldview in which intellectual and developmental disabilities is not only accepted but valued has the potential to create mutually transformative social relationships (Grieg, 2015). Intentionally recognizing others' common humanity in the midst of diversity and purposefully creating opportunities for being with each other as friends opens the door for both individual and societal development that would not be possible otherwise. Friendship interventions have too often focused on changing the individual with the disability. Driven by a deficit orientation, these interventions typically have been mediated by professionals who aim to teach or remediate social skills of children and young adults so that they will use socially normative behaviors that minimize difference and make them more likeable to nondisabled peers (Meyer, Park, Grenot-Scheyer, Schwartz, & Harry, 1998). Less attention has been given to the social and cultural contexts that frame understandings of friendship with and among people with IDD. Fein (2015) also noted the emphasis in many western cultures on establishing friendships based on personal choice and liking another; an approach that tends to neglect the broader social interaction patterns that affect individuals with disabilities' opportunities for friendships.

Intervening at the societal level requires acknowledging that cultural attitudes about disability and the social policies regarding where individuals with intellectual and developmental disabilities live and learn are interconnected. Attitudes of people without disabilities can be positively shaped by opportunities for learning about disability and sharing activities within the context of inclusive educational policies (Rillotta & Nettelbeck, 2007). Likewise, policies and policy statements that facilitate community presence and participation of people with intellectual and developmental disabilities are essential to the development of the variety of interpersonal relationships that represent personally meaningful social inclusion and promote a sense of belonging (Andrews, Falkmer, & Girdler, 2015). The US Supreme Court's Olmstead decision (Dinerstein, 2016), which rejected unjustified segregation of people with disabilities and reiterated an underlying principle of least restrictive environment, represents movement in that direction. Following from Olmstead, policies aimed at rebalancing government expenditures to prioritize supports for integrated community living arrangements and employment while also facilitating person-centered life choices hold promise for changing the societal patterns of engagement that influence the friendships and social well-being of people with intellectual and developmental disabilities. The federal policy statement on inclusion of students with disabilities in early childhood settings (US HHS & DOE, 2015) cites the development of friendships with peers, specifically, as one of several outcomes that can result from increased efforts toward fostering more inclusive settings. Such policy statements can be helpful as they offer the evidence, legal grounds, and resources to support states, organizations, and families in advocating for environments that will more naturally facilitate social engagement and friendships.

Organizational

The interconnectedness of personal and environmental factors in creating the conditions for friendship is also evident at the organizational level, where policies are translated into practices. Across residential, employment, education, and leisure domains setting factors and individual characteristics both play a role in determining the quality of social interactions and the nature of friendships.

Residential. In studies of different types of supported residential arrangements (e.g., supported living, group homes, clustered congregate), the setting type tends to be a stronger predictor of social activities and friendships than the characteristics of the individuals with disabilities (McConkey, 2007). People in group or clustered arrangements may have easier access to their friends, who also tend to be other people with intellectual and developmental disabilities. However, in general, people living in supported living arrangements are more likely to engage in friendship activities outside their homes and have larger networks of friends. Yet, some people with intellectual and developmental disabilities in more dispersed settings, including people with higher levels of social competence, may be at higher risk of social isolation. Aging is also sometimes associated with a sense of loss of family and friend relationships (Leroy, Walsh, Kulik, & Rooney, 2004). Regular (e.g., weekly) access to community groups and activities are necessary foundations for social inclusion and forming and maintaining friendships (Amado et al., 2013; Money, Friends and Making Ends Meet Research Group, 2012; White & McKenzie, 2015).

People with intellectual and developmental disabilities often count their paid caregivers as friends. In L'Arche communities, this dynamic is embraced, and efforts are made to develop reciprocal relationships supported by the larger residential community in which people with intellectual and developmental disabilities are viewed as valued members with unique gifts (Pottie & Sumarah, 2004). Friendships are facilitated by sharing daily living situations and major life passages that become woven into a co-constructed story of life together. The larger L'Arche community context supports friendships and a sense of belonging through a culture of valuing and celebrating each person and finding ways to involve all members in common activities (e.g., decision-making meetings). Friendships can become strained when contact is diminished or lost due to staff turnover or competing responsibilities. Lack of privacy, staff's position of authority, and straying from a communal vision all may cause tensions in friendships.

Employment. Similar to individualized supported living arrangements, supported employment can lead to more integrated and larger social networks for people with intellectual and developmental disabilities (Cramm, Finkenflugel, Kuijsten, & van Exel, 2009). Contact with co-workers within the structure of work and engagement in work-related social interactions have been associated with a greater sense of well-being reported by people with intellectual and developmental disabilities. However, those experiences vary widely, and there is limited evidence that workplace interactions directly translate into reciprocal relationships or friendships outside of work. Interestingly, people of retirement age who participated on a weekly basis in a community group related to an area of personal interest experienced increased friendships, acquaintances, and social satisfaction when compared to people who continued to work all week (Amado et al., 2013). This suggests the importance of creating structured, socially focused activities rather than relying solely on shared work activities to cultivate friendships.

Education. Within education, friendship development may occur as a secondary outcome of inclusive classroom structures. Structured peer supports in inclusive classrooms can promote increased social interactions and friendships for adolescents with intellectual and developmental disabilities (Carter et al., 2016; Feldman, Carter, Asmus, & Brock, 2016). Students with more extensive support needs may be physically present in a classroom with their nondisabled peers, but are less likely to be engaged with peers unless attention is given to the forms of classroom supports that are used (e.g., paraprofessionals, peers, collaborative learning). Systematically shifting academic and social supports to peers with the guidance of a paraprofessional or teacher has produced increased academic engagement for adolescents with more extensive support needs while also increasing their level of social interaction, participation, and goal attainment. Additionally, peers reported having more friendships with students with severe impairments as compared to peers in classrooms with teacher-delivered supports. Creating structured opportunities for participation by young adults with intellectual and developmental disabilities in inclusive higher education classes and dormitories also may contribute to friendship formation as peers become familiar with and accepting of each other (Griffin, Summer, McMillan, Day, & Hodapp, 2012; Hafner, Moffat, & Kisa, 2011).

School-wide positive behavior intervention and supports systems (SW-PBIS) also may impact friendships by facilitating an environment that promotes prosocial behavior and decreases challenging and bullying behavior. SW-PBIS requires a commitment from the entire school to promoting a multi-tiered system of support (Dunlap, Kincaid, & Jackson, 2013). First, a set of expectations for prosocial behavior and social competencies is established, promoted, and reinforced across all students (Tier 1). Under Tier 1, expectations are clearly communicated to all students, routines are established and rewards are provided for positive behavior. Next, more targeted support is offered (Tier 2) to those students who are less responsive to Tier 1 supports. This could include self-management skills and social skills instruction (Tier 2). The next level of support offers a more individualized approach (Tier 3) for students who require additional intervention beyond what is offered through Tier 1 and Tier 2, including functional behavior assessments and formal behavior intervention plans. While friendship for students with intellectual and developmental disabilities is not necessarily a targeted outcome, SW-PBIS creates a context that promotes inclusion and expects appropriate and positive social relationships among all students. For example, participation in SW-PBIS has been associated with less bullying and peer-rejection, and this impact was stronger the longer a student had participated in SW-PBIS (Waasdorp, Bradshaw, & Leaf, 2012). Further, peer- and teacher-mediated interventions promoting friendship may be incorporated as Tier 2 interventions.

Friendship development also may be an explicit goal within an education curriculum. For example, the Youth Empowerment Services (YES) curriculum for youth with and without disabilities involved students for four hours once per month to learn about friendships and social relationships, establishing an inclusive school community, leadership development and mentoring, and student-directed planning (Schuh et al., 2015). Participants reported that friendships, which developed inside and outside the group, were not limited by disability identification, supported them to talk about their transition goals and strategies, and led them to meet their goals. Students further indicated that friendships gave them greater feelings of acceptance and inclusion as compared to feelings of stigma and exclusion they faced in schools.

Other examples of creating educational social spaces that can help to promote friendships for youth with intellectual and developmental disabilities and/or autism are recreationally focused activity programs sponsored by schools (e.g., Recreation Experience Activity Club for Teens-REACT—Barber, 2015) or adult education organizations (e.g., Next Chapter Book Club—NCBC—Fish, Rabidoux, Ober, & Graff, 2006). These programs have an underlying instructional purpose (i.e., social skills and literacy, respectively), but utilize community environments and activities to enhance opportunities for social interactions. Typically, a group of people with and without disabilities plus a group facilitator gather once or twice each month in a public venue. Facilitators and peers model the targeted skills while also encouraging engagement with other group and community members. Informally, participants of such programs have indicated that the activities are fun and help them to make new friends.

Leisure. Friendships are more likely to develop through integrated campus and community leisure and recreational activities when attention is given to providing structure for shared activities, connecting people with shared interests, and building in adaptations that facilitate participation (Andrews et al., 2015; Eisenman, Farley-Ripple, Culnane, & Freedman, 2013; Ross, Marcell, Williams, & Carlson, 2013). Lack of accommodation in leisure activities can lead to individuals with disabilities having feelings of being tolerated, but not invited to belong. Acceptance is more often perceived in situations where activities have clear role definitions, formal instruction is provided over time, and the focus is on skill-building or appreciation (Devine & Lashua, 2002). In turn, feeling socially accepted is perceived by people with intellectual and developmental disabilities as a foundation for building friendships and greater satisfaction with leisure activities. Special Olympics offers an interesting example of how a leisure activity that is often perceived by nondisabled outsiders as segregated and stigmatized creates a recreationally focused kinship group (Caldeira, 2015). People with intellectual and developmental disabilities may identify Special Olympics as the place where they meet their friends. Families value the shared information and resources. In both cases, the social group revolves around shared activities premised on shared disability identity. Acceptance within the group of a range of intellectual and physical differences combined with an ethic of teamwork and sportsmanship facilitates a sense of belonging.

Similar strategies can be successful in recreational programs that purposely target individuals with and without intellectual and developmental disabilities. Unified Sports is a branch of Special Olympics that creates sports teams that include people with and without intellectual and developmental disabilities who have similar athletic skill. The purpose is to foster friendships and social inclusion through practices and competition. In a study of program outcomes among adolescent and young adult participants from five European countries, McConkey, Dowling, Hassan, and Menke (2013) found increases in personal development, bonding between participants, and positive perceptions of people with intellectual and developmental disabilities, all of which seemed to foster more friendships. The extent of these friendships was unclear, although athletes with intellectual and developmental disabilities and their families indicated the multiple ways in which this type of program helped them to develop athletic skills (which translated into increased social desirability) and interpersonal skills. Participants without disabilities described their changing perceptions, increased comfort level, authentic connections, and bonding that occurred. While the underlying principles of Unified Sports facilitated an environment that fosters equality, shared interests and social inclusion, a team's overall success did appear to be dependent on the coach's skill in promoting this type of environment while also coaching sports-specific skills. Therefore, resources to identify and develop more coaches were seen as critical (McConkey et al., 2013).

Siperstein, Glick, and Parker (2009) established a summer sports program that included equal numbers of students with and without intellectual and developmental disabilities. Emphasis throughout the camp was put on strengths, personal skill development and team cohesion. Traditional athletic competition between and among teams was down-played. Staff members created an inclusive atmosphere that encouraged equal participation among all participants. By the end of the program, nondisabled peers were just as likely to identify friendships with students with intellectual and developmental disabilities as they did with other nondisabled campers. Interestingly, improvement in athletic ability was strongly correlated with stronger social connections, regardless of whether a person had a disability or not. This may reflect the importance to all participants of the value in a sports camp of having strong athletic ability.

Organized recreational and leisure spaces can also be designed to flexibly incorporate individuals with different social, communication, and literacy skill levels. Examples include online social media and virtual worlds that attract individuals with similar interests, permit personal control over level of involvement, afford opportunities for novices and experts to interact, and motivate interaction through sharing of information, games, or role play in ways that are less dependent on the types of communication and social cues used in the physical world (Fein, 2015; Mazurek, 2013; Stendahl & Balandin, 2015). Especially for people with conditions associated with social participation difficulties (e.g., autism spectrum disorders), these types of social spaces can promote a person's use of flexible social repertoires while also providing opportunities for them to develop and sustain multiple friendships. In a study of adults with autism spectrum disorders, Mazurek (2013) learned that individuals who used social media were more likely to report having close friends, although decreased loneliness was associated with higher quality and quantity of offline friendships.

Interpersonal

Beginning in childhood, friends are often identified by each other as a result of shared interests, activities, and characteristics (Carter et al., 2013; Frankel, 2010). Individuals with or without disabilities themselves may take the lead in creating friendships. At other times, personal characteristics related to disability may make initiating friendships more challenging. Further, the education and adult support systems in the United States often create isolating experiences for people with intellectual and developmental disabilities. Whether a person is placed in a segregated setting (literally isolated) or in a poorly managed inclusive setting (figuratively isolated), people with intellectual and developmental disabilities are often at an immediate disadvantage for connecting with others and forming friendships. As a result, they may rely on others in their lives—peers, teachers, and parents—to help foster and facilitate friendships.

Self-directed approaches. Adults with intellectual and developmental disabilities have shared their perspectives on the types of behaviors and activities that they use to support friendships that foster a sense of well-being (Having Friends, 2012; Knox & Hickson, 2001; Mason et al., 2013). The level of intimacy in a friendship may be differentiated by the higher degree to which these activities are expected, the intensity of emotional engagement, and the acknowledgment of a deeper commitment to the other. Shared leisure activities and being intentional about making arrangements to be together are commonly mentioned components for building and maintaining friendships. Friendships are also kept alive through sharing stories and memories. Friends allow each other to find time to be alone and participate in other relationships. Friends are expected to be kind and helpful both practically (e.g., meeting at a bus stop to travel together) and emotionally (e.g., talking about things that would not be shared with others). A sense of reciprocity is enjoyed, although being in more of a helping role with some friends may be an accepted or valued part of a particular friendship. Sharing a common identity, especially focused on a common disability, can support a sense of equality. Perceiving an unbalanced power dynamic may be associated with feelings of vulnerability and fears of exploitation.

Peer-mediated intervention. Peer influence on the development of friendships begins at an early age and continues through adulthood. Peer-mediation as an intervention is typically part of a programmatic effort in schools.

Preschool. Preschool classrooms are environments that seem to be particularly conducive to developing friendships, since social-emotional learning, which includes learning how to develop positive relationships with peers, is considered critical for early childhood (Denham & Brown, 2010). The strongest literature on relationship and friendship development among preschool children with autism comes from the LEAP model (Strain & Bovey, 2014). Within these classrooms, students with and without autism are taught methods for playing with and relating to one another. Based on research about play behaviors among young children with and without autism, all children are taught how to engage in: getting a peer's attention; reciprocal sharing; using play organizers (e.g., "Let's play princesses"); and giving compliments.

The LEAP model is driven by peer-mediated support whereby students are taught how to teach and reinforce social engagement behaviors to their peers with autism (Strain & Bovey, 2014). All students are taught prosocial engagement skills in a large group setting and then teachers facilitate play in smaller group settings, prompting peers to engage or encourage engagement from students with autism. Teachers also purposely set-up play centers to include known activities of interest for students with autism and manipulate the number of centers available and the amount of students at each center, in order to ensure adequate opportunities for interaction. The intervention is manualized and designed to be delivered by teachers in public schools. However, intervention efficacy was more limited when manual use was not paired with on-site coaching by experts in the intervention (Strain & Bovey, 2011). Still, outcomes for LEAP are promising. Children with autism spectrum disorders showed an increased amount of social participation and improved quality of social engagements and these gains were significantly higher than for students who received more traditional social skill training from an adult (Kohler & Strain, 1999). These social gains also spanned settings (Strain & Hoyson, 2000) and time (Strain & Bovey, 2011), setting the stage for greater friendships with others in other settings.

Elementary school. Given the lack of generalizability of social skills taught in isolated settings (Bellini, Peters, Benner, Hopf, 2007), peer-mediated interventions can create a more immediate and direct impact on relationships by providing information and strategies to peers and then supporting them in the facilitation of social engagement. Peer training in elementary school can take multiple forms.

Kasari, Rotheram-Fuller, Locke, and Gulsrud (2012) trained peers over 12-weeks on how to engage their fellow students with social participation limitations on the playground. Social challenges were described more broadly so that students with autism (the target population) were not specifically identified. Peers received training on identifying a child who appeared isolated, strategies for engaging the student, modeling prosocial behaviors, and including the student into games and activities. Teachers reinforced peers as they facilitated interactions. Students with autism benefited more from a peer-mediated intervention in comparison to a traditional intervention that directly targeted the child. However, students with autism fared best when they participated in *both* interventions. Students with autism whose classmates received the peer-mediated intervention, either alone or when paired with an individualized skills-based curriculum, had a decrease in isolative play on the playground and were nominated as friends more often on measures of classmates' social networks. Yet, there was very little change in reciprocal relationships (i.e., students with autism and peers nominate each other as friends) suggesting that perhaps strong friendships had not quite been reached or students with autism were either not interested in their peers as friends or did not recognize them yet as a friend.

Owen-DeSchryver, Carr, Cale and Blakeley-Smith (2008) trained peers using a more explicit approach regarding education on disabilities. Peers were taught specifically about people with autism and the benefits of being in an inclusive setting. They were guided through activities aimed to help them understand the importance of peer friendships to all students, including students with autism spectrum disorders. Peers were supported in identifying strengths of specific children with autism spectrum disorders. Finally, peers learned strategies for connecting with students with autism, encouraging their participation, and teaching them how to play. Although social networks and friendship development were not measured, all students with autism as well as trained peers *and* un-trained peers increased their social initiations with one another by the end of the intervention and at a 12-week follow-up. Furthermore, these initiations occurred in contexts that were more favorable for play and friendship development (e.g., lunch and recess). It's important to note that peer-mediated interventions do not always result in stronger social engagement (Kasari et al., 2016) and most intervention studies do not necessarily target friendship as a direct outcome (Carter et al., 2013). However, these peer-mediated interventions can create the conditions under which friendships are more likely to occur.

Adolescence. Adolescence can be a particularly difficult time for students with intellectual and developmental disabilities to form or maintain connections with their peers. Although they may be in inclusive classrooms, many teenagers with intellectual and developmental disabilities report feeling disconnected from peers and lonely (Carter et al., 2013). In fact, fewer than 25% of students with intellectual and developmental disabilities or multiple disabilities frequently see friends outside of school and fewer than 50% frequently receive phone calls from friends (Wagner, Cadwallader, Garza & Cameto, 2004). The nature of relationships often changes as cliques develop and friendships occur outside of structured instructional spaces and times where adults may not be present. Opportunities for social connections may be diminished due to the formation of new friendship groups and limited availability of integrated leisure activities. Developing peer mentoring activities may be a way to counteract these changes. In a study of adolescents with autism, Bottema-Beutel, Mullins, Harvey, Gustafson, & Carter (2016) noted the youths' preference for learning social skills with peers, as opposed to direct instruction by a teacher. Peers also reported enjoying working together toward social skills development (Hochman, Carter, Bottema-Beutel, Harvey, & Gustafson, 2015). When youth with autism and peers have the opportunity to participate in activities that focus on areas of strength authentic friendships can be fostered (Diener, Wright, Dunn, Wright, Anderson, & Smith, 2015).

Dopp and Block (2004) provided suggestions for implementing peer leaders at the secondary level to promote conflict resolution support at a high school. While friendship was not an explicit goal of the peer leader program, the students who participated as peer leaders completed the program with increased social development. Teachers, or other practitioners like a guidance counselor, acted as a facilitator for peer leaders. The facilitators trained a group of peer leaders within a single day on targeted social skills. Then, the peer leaders worked with students in their classes. The peer leaders consisted of an array of students, including those with disabilities. Ideas for conflict resolution strategies to use in their classrooms were encouraged from the peer leaders with approval from the facilitators. The peer leader program was received enthusiastically from classmates. The peer leaders with disabilities reported more positive social development as a result of being a peer leader; specifically, students with behavioral disorders reported increased ability in resolving their problems and patience.

Several of the ideas put forth by Dopp and Block were successfully implemented in a study of four students with intellectual and developmental disabilities and/or autism. Students worked with several peer coaches (called a peer network) during lunchtime along with an adult facilitator, which led to increased socialization for the participants during the sessions. The facilitators and peer network coaches were trained in study protocols and objectives, with peer coaches completing data, and the teacher facilitator providing feedback to the peer coaches after the sessions. Participants did not immediately generalize their social relationships to other settings. However, it was noted that students and their peer coaches had informal exchanges at other times of the school day. The peer coaches concluded that they had made a new friend with their participant (Hochman et al., 2015).

Adults. One of the best known peer-mediated interventions is Best Buddies, in which a person with intellectual and developmental disabilities is matched with a nondisabled person for the purposes of enjoying social interactions and developing a friendship. Buddies commit to doing activities with each other one or more times each month, maintaining more regular contact through email or telephone, and joining larger group activities with other buddies from their local chapter at least once each month. Best Buddies programs may be based in schools or colleges to foster relationships among students and near-age peers or in the community for adults. Hardman and Clark (2006) surveyed buddies from 140 college programs nationally to gain insight into the buddy relationship and outcomes. They noted that buddy pairs frequently were of mixed gender, consistent with other studies of friendships between people with and without intellectual and developmental disabilities. Female college students were more likely to be the nondisabled member of the pair and the buddy with intellectual and developmental disabilities tended to be older than his or her partner. Both members in buddy dyads often reported that they liked doing activities together. They also typically indicated that the partnership improved the life of the person with intellectual and developmental disabilities, although this aspect was noted less frequently by the member with the disability.

Mediation by significant others. Friendships occasionally may be informally, yet intentionally, facilitated by parents, teachers, staff, or other friends. For many adults as well as children with intellectual and developmental disabilities, major barriers to pursuing a friendship include the lack of independent community transportation that is necessary to connect in person, establishing time and space for activities, and navigating interpersonal problems with friends (Eisenman, Tanverdi, Perrington, & Geiman, 2009; Lafferty & McConkey, 2013; McVilly et al., 2006; White & McKenzie, 2015). Although friendship cannot be forced, it can be supported through instrumental actions such as creating regular, planned opportunities to meet with peers in the community and one's own home and offering encouragement and advice about how to approach others and join activities.

Parents. Family members can be engaged as social instructors in the home and community (Bateman, Bright, & Boldin, 2003). These trainings typically occur simultaneously while the child is receiving social skills intervention in school. Elementary-school age children benefit from their parents' support to create a social network, identify peers with similar interests, organize play dates, and identify other play environments that the child can join (Frankel & Whitham, 2011). Once play dates are created or social situations are identified, parents learn how to help their child initiate or join an activity, as well as to facilitate the activity successfully and navigate conflicts that arise (Frankel et al. 2010). In some cases, interventions have been converted into more easily digestible manuals and offer stand-alone support for families to help their child form friendships (e.g., Laugeson, 2013). In this manner, PEERS is a unique program due to the flexibility of curricular implementation in a variety of settings with different facilitators. Using the family-based guide, families can successfully implement the curriculum, with positive effects relating to the increased social ability of their youth (Laugeson & Frankel, 2010). Families also successfully incorporate homework assignments related to the social skills curriculum, which suggests their desire to incorporate social interventions in the home (Karst et al., 2014).

Interventions utilizing the child friendship training model (Frankel & Myatt, 2003) with children described as having high functioning autism and Fetal Alcohol Syndrome have shown an increase in child's popularity, more productive use of playdate time (e.g., less isolative electronic games) and less reported loneliness among participants (Frankel et al., 2010).

However, the intervention did not consistently result in reciprocated playdates, suggesting that there may be limitations to the levels of friendship that might be achieved, at least after only a few months beyond treatment completion. It may be that there was some reluctance to reciprocate playdates initially and that this could increase over the course of time as parents and peers identify the value in the friendship.

Teachers and other professionals. Beyond formal instructional practices, other opportunities (e.g., lunch, recess, and extracurricular events) are available in the school and community for play and friendship-building. Carter et al. (2013) suggested key practices for a school staff to consider in helping establish and facilitate a successful peer network between students with intellectual and developmental disabilities and their nondisabled peers: make connections between students with shared interests, identify specific times for peer network meetings to ensure meeting consistency, encourage reciprocal relationships and not just helping relationships, and guide students without disabilities on strategies for initiating with students with intellectual and developmental disabilities (e.g., how to converse with someone who uses communication device).

Staff in community recreational programs can also offer informal (i.e., less clinical) opportunities for people with intellectual and developmental disabilities to connect with others and form friendships. Such settings typically offer structured activities and can be identified based on particular interest, such as theater or sports, allowing the person greater opportunity to connect with others who have a shared interest, which is critical for friendship development. For example, Becker and Dusing (2010) described a process they used for incorporating an 11-year old with Down syndrome into a community theater group. A physical therapist provided modifications to choreography in order to support her involvement. Over time, peers reportedly became more involved and less formal support was required. While it was not reported whether friendships were formed through her participation in the theater group, parent-reported measures of quality of life did improve. Fennick and Royle (2003) reported mixed findings in trying to create opportunities for children with intellectual and developmental disabilities to join a local community center's recreational activities and have their support facilitated by a specially trained coach. Successful integration into the group was dependent upon the level of support needed for participation, openness by the activity's coach to having students with intellectual and developmental disabilities participate, and successful match between the support coach and participant and family. Due to the informal nature of the activities, raising awareness about the availability of the program proved difficult. And, since these programs were somewhat randomly identified, the goodness of fit for meeting the goals of participation were not always ideal.

Residential staff also act as mediators of access to friendship opportunities. Their beliefs about what constitutes social inclusion and the social capabilities of people with disabilities can make a difference in whether they arrange for and support activities that render individuals with intellectual and developmental disabilities as merely present in the community or identify ways to ensure that people they support enjoy full participation in social activities with others, including those with and without disabilities (Clement & Bigby, 2009).

Support groups. Circles of support (Gold, 1994) purposefully blend instrumental and social activities by bringing together a group of acquaintances, friends, and/or family members to support an individual with disabilities. The group focus is not exclusively on developing friendships; most participants have already established a relationship with the person at the center of the circle. However, by assisting the person to make additional connections in the community and problem-solve around personal and environmental concerns, the group can provide a basis for further friendship development. For people with more extensive support needs, purposefully orchestrating opportunities to engage with others, who view them as unique and valued individuals whose presence in social activities is appreciated, can be another avenue toward friendship (Bogdan & Taylor, 1989; Hughes et al., 2011).

Individual

Building communicative competencies, acquiring social knowledge about self and others, and establishing a personally validated positive identity can help to improve social outcomes and social capital of individuals with intellectual and developmental disabilities and/or autism. These in turn create new opportunities for friendship and experiencing well-being (Fein, 2015; Mehling & Tasse, 2015).

Communicative competency. Numerous school-based approaches exist for supporting a person with intellectual and developmental disabilities to connect with peers and build friendships by developing social communication skills. Such practices may be executed in connection with a formal goal in an Individualized Education Plan or as a more informal avenue for facilitating connections between the student and others. The large majority of interventions involve direct instruction either in isolation (e.g., conversational turn-taking; Hunt, Alwell, & Goetz, 1991), as a package that includes multiple skills (Kasari et al., 2016), or a package of skills plus education in social-emotional concepts and/or perspective-taking (Laugeson & Frankel, 2010). These practices are offered in group settings that include multiple students with social challenges. The large majority of studies have been conducted with students with autism. Group social skills interventions specifically for children with autism have shown to impact improvement in friendships and decreased loneliness (Reichow, Steiner, & Volkmar, 2013) although several reviews identified studies that did not show positive effects, had inconsistent results and/or poor generalization/maintenance of skills (Reichow & Volkmar, 2010), particularly when conducted in school settings (Bellini et al., 2007).

The PEERS curriculum is an empirically validated social skills program that uses scripted lessons with an emphasis on learning ecologically valid social skills. Student motivation to lean social skills and completion of homework assignments incorporating opportunities for social practice in the home are important components of this curriculum. While intended for use with students with autism, students with intellectual disability could also benefit from participation in the lessons (Laugeson & Frankel, 2010). Students participate in small group lessons, role plays, and other exercises to learn cognitive strategies that enhance their social perspective-taking and problem-solving (Laugeson & Park, 2014). Another example of a school-based approach is Social Thinking (Crooke & Winner, n.d.). This framework utilizes a breadth of materials and strategies such as social stories and video modeling, along with curriculum packages. Teachers choose from many materials they think will work with their students' social goals. This approach, although not empirically validated, has become popular with secondary level teachers, because of its flexibility and promise to address the social skills needs of secondary, postsecondary, and adult individuals with autism and/or intellectual disability.

A critical consideration for developing communicative competence is to ensure that individuals have access to augmentative and alternative communication (AAC) as needed. Teaching and implementing AAC techniques can enable greater peer interaction and, therefore, create circumstances in which friendships may be formed. In their review of 31 different studies involving AAC, Chung, Carter, and Sisco (2012) found that implementation of low technology devices (e.g., communication books) have shown promise in supporting peer interaction. Peer training, along with introduction of the AAC device, was indicated as an important component of the more successful interventions. Similarly, interventions involving visual cues, such as video models have also shown promise in enhancing social skills (Reichow & Volkmar, 2010).

Social knowledge. In conjunction with promoting social communication skill, systematic instruction related to knowledge about friendship and social awareness can be beneficial. For example, Jobling, Moni, and Nolan (2000) described an 8-week program for young adults ages 18–21 that was intended to help participants understand friendships. Topics included different types of friendships, emotions related to friendships, and gender roles. Explicit didactic instruction coupled with videos and discussions about participants' own experiences were utilized to support individual understanding. Program staff reported that the most challenging aspects of the approach included the literacy demands of the materials and teaching about abstract ideas and emotions. Managing discussion of the participants' friendships, which were a dynamic in and outside the group, also required staff to consider ways that supported individuals to feel comfortable with sharing personal experiences.

Ward, Atkinson, and Smith (2013) conducted an evaluation of a program intended to teach individuals with IDD the skills they needed to participate in healthy intimate relationships and avoid violence with intimate partners. The 10-week program (total of about 30 h) alternated classroom-based instructional sessions with community-based experiential sessions. Topics advanced from learning about feelings and types of relationships to exploring personal boundaries, modes of communication, strategies for meeting people, managing first impressions, and planning social and dating activities. Later topics included personal safety, sexual health, and gender differences. Results, maintained over a 10-week period post-program, indicated that participants increased their social networks and incidents of interpersonal violence decreased.

Another approach is to teach individuals the skills necessary for social activities planning. Koegel et al. (2013) supported college students with Asperger's Syndrome through weekly 1-h sessions to learn and independently apply the steps involved in social planning for participation in activities related to personal interests plus the organizational skills (e.g., making notes in a daily planner, arranging transportation). Although friendships were not an explicit target of the intervention, participants reported increases in the number of friends and other peers with whom they socialized and greater satisfaction with peer interactions.

Yet another avenue for acquiring social knowledge is through online communication forums. The online community spaces of formal associations such as the Autistic Self-Advocacy Network (ASAN) or the Society for Disability Studies (SDS) neurodiversity caucus provide springboards for communication with like-minded individuals as well as opportunities for individuals to get to know each other and to learn about autism and neurodiversity. Some people who identify as neurodiverse view these as the only spaces where they can connect with others who understand and support them (Brownlow, Rosqvist, & O'Dell, 2013) Engaging in these communities may impact positive identity development with adults (Davidson & Orsini, 2013).

Positive identity. People with intellectual and developmental disabilities often recognize the negative stereotypes associated with their impairments and may accept a negative social identity, leading to lower self-esteem and less psychological and social well-being (Ali, Hassiotis, Strydom, & King, 2012; Paterson, McKenzie, & Lindsey, 2012; Spassiani & Friedman, 2014). Similarly, in Baines' (2012) and Bagatell's (2007) ethnographies, adolescent males strived to mask their autism while at school and pass as nonautistic. This involved great effort on their parts to not only hide their autistic traits but also involved denigrating their autistic label. After graduation from high school, the participant in Bagatell's study described his initial surprise to meet other autistic adults and participate in an adult autistic group, where they demonstrated pride in having autism. In another study Alverson, Lindstrom, and Hirano (2015) noted that high school students who had positive identification and understanding of autism when they were in high school had more positive postsecondary outcomes.

When viewing disability from a sociocultural perspective, identifying with disability can provide individuals with a positive frame for understanding their disability experiences. Brueggeman (2013) puts forth an identity model of disability, which promotes claiming disability and recognizing a larger disability community. Identifying one's disability as an integral part of self and finding membership in a community can lead to positive perception of disability. In addition to connecting young adults with accepting communities, promoting positive disability identity development can be accomplished in part by teaching self-determination strategies (Wehmeyer, 2008). From the earliest ages, this involves supporting individuals to develop self-awareness and self-advocacy skills and to have agency in planning their life goals in the context of high expectations, communities that value choice, and meaningful social connections with family and friends (Wehmeyer, Field, & Thoma 2012).

Conclusion

Opportunities for friendships among people with intellectual and developmental disabilities and others have been negatively shaped by longstanding patterns of social segregation. Even as social inclusion has become a prominent goal of policy and practice, the quantity and quality of friendships experienced by people with intellectual and developmental disabilities continue to be influenced by the cultural attitudes and social interactions that have framed traditional understandings of disability and friendship. All people with intellectual and developmental disabilities have innate capacities for a range of meaningful relationships that can be actualized when organizational structures that contribute to segregation in residential, employment, education, and leisure domains are removed and structures that support regular, interpersonal interactions around shared interests are created. Practitioners, peers, and family members can further support people with intellectual and developmental disabilities to develop friendships by working from a strengths-based perspective to build communicative competencies, promote acquisition of social knowledge about self and others, and establish positive identities that do not pathologize disability. The goal of these efforts must not be narrowly construed as skill building or restricted to those individuals deemed mostly likely to benefit based on degree of intellectual impairment. Rather, the purpose must be to support access to others, with and without disabilities, who can share in the experiences of companionship, commitment, and caring that characterize the friendships most desired by people with intellectual and developmental disabilities. Friendships, including intimate partner relationships, are an important key to their social well-being.

Although there are a variety of self-directed, peer-mediated, and parent- or professional-facilitated approaches to friendship development described in the literature, there is room for further exploration of approaches that incorporate a wider array of voices and perspectives of people with intellectual and developmental disabilities within and across diverse macrocultural contexts. Disability communities that value disability identity also represent important contexts—whether located in online social media or other venues—for examining friendship and social well-being. The impact of increasing social inclusion from early childhood through adulthood on friendships among people with intellectual and developmental disabilities and others who do not identify as disabled may also change the nature of the questions asked about friendship and social well-being. With a cultural shift toward recognizing disability as a natural part of human diversity, people with intellectual and developmental disabilities may be acknowledged for the contributions they make as friends to the social well-being of others and the greater social good.

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11

The Role of Positive Psychology in Interpersonal Decision Making

Ishita Khemka and Linda Hickson

Traditionally, research in the disability field has focused on remediating deficits rather than building on strengths. Historically, “people with disabilities were viewed as objects to be fixed, cured, rehabilitated and, at the same time, pitied” (Wehmeyer, 2013, p. 5). However, as reflected throughout this text, there is a shift from a medical model toward a social–ecological or person–environment fit model of disability. According to the social–ecological model, a disability is viewed as a mismatch between personal capacities and environmental demands (Shogren, 2013), rather than as a defect to be fixed or a disease to be cured. The social–ecological perspective encourages the development of systems of supports that build on a person’s strengths to improve their quality of life and promote optimal functioning. A focus on promoting decision making is reflective of this changing perspective.

Decision making is of interest to many divergent fields, including economics, business, law, health, and psychology. Decision-making research tasks have ranged from abstract laboratory tasks to real-life personal and interpersonal situations. There is no doubt that decision making plays a pivotal role in all areas of people’s lives and that increasing decision-making competence can have a profound positive impact. For example, people are routinely called upon to make potentially life-changing decisions in interpersonal (e.g., whom to trust) as well as personal situations (e.g., how much money to spend). The focus of the present chapter is primarily upon interpersonal decision making, which is central to maintaining a positive quality of life but which poses particular challenges to people with intellectual and developmental disabilities. Interpersonal decisions are at the crux of the well-documented social vulnerability of people with intellectual and developmental disabilities (Cappadocia, Weiss, & Pepler, 2012; Christensen, Fraynt, Neece, & Baker, 2012; Hickson & Khemka, 2016; Hickson, Khemka, Golden, & Chatzistyli, 2008; Rose, Espelage, & Monda-Amaya, 2009). Research to better understand and strengthen interpersonal decision making offers a potential avenue to reducing social vulnerability and increasing positive quality of life. For nearly 20 years, we have focused our research on finding ways to enable people with intellectual and developmental disabilities to have as much choice and control as possible in their lives. We believe that enabling them to acquire a repertoire of effective interpersonal decision-making skills can provide them with a powerful tool for building positive, satisfying friendships and intimate relationships as well as for ensuring their own personal safety and preventing harm.

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To design interventions to enable people with intellectual and developmental disabilities to acquire a repertoire of effective decision-making skills, it is necessary to (a) adopt a model of decision making that encompasses the component processes involved in different types of decisions and (b) to understand the likely strengths and vulnerabilities that may influence how a person with intellectual and developmental disabilities will approach a particular decision-making situation. The present chapter begins with a brief discussion of our *Pathways Model of Decision Processing* (Hickson & Khemka, 2013) followed by a description of some key decision-making research and intervention studies aimed at providing adults and adolescents with intellectual and developmental disabilities with a useful repertoire of decision-making skills. This chapter concludes with suggestions for future directions for research and practice in decision making.

Pathways Model of Decision Processing

Our *Pathways of Decision Processing* model (see Hickson & Khemka, 2013 for a detailed description) is a working model that can be applied across a range of interpersonal decision-making situations. The model builds upon our past models (e.g., Hickson & Khemka, 1999, 2001; Khemka & Hickson, 2006) as well as the extensive theoretical literature on decision making. The *Pathways* model is consistent with the thinking reflected in the more recent dual-process theories (e.g., Kahneman, 2011; Newell, Lagnado, & Shanks, 2015; Stanovich, 2011).

According to the *Pathways* model, decision processing must be considered in light of the situational and environmental context that gives rise to different types of decisions. Many interpersonal decisions take place in the context of positive, healthy relationships, or social situations where risks are minimal or nonexistent. In these cases, decisions can be made freely according to personal values and preferences. However, other interpersonal decisions involve threats, coercion, or overt abuse and carry considerable risk to the decision-maker. The studies considered in this chapter cover a wide range of types of healthy and abusive situations, including sexual, physical, and verbal/psychological abuse. Each of the three types of abuse also can occur in a variety of situational contexts, including financial exploitation, cyber abuse, and disability-specific abuse. Another type of situation associated with the social vulnerability of people with intellectual and developmental disabilities involves negative peer pressure or coercion. This type of decision-making situation can occur in a variety of situational contexts, including situations that involve threats to physical safety by pressuring the decision-maker to engage in risky behavior, threats to health by pressuring the decision-maker to use alcohol, tobacco, or other drugs (ATOD), risks of getting into trouble at school or work by pressuring the decision-maker to shirk a responsibility, or risk of getting into trouble with the law by engaging in stealing or other criminal behavior.

In our own research to date, we have aimed to deepen understanding of the requirements for effective decision making in healthy relationship situations and positive peer interactions as well as effective decision making in abusive situations and negative or coercive peer interactions. Our research tasks have typically consisted of brief vignettes based on real-life situations. Respondents are asked what the featured decision-maker should do. An overarching goal of our studies is to identify interventions and supports to assist people with intellectual and developmental disabilities to calibrate their selection of decision processing pathways to the specific needs of situations that they are likely to encounter in their lives.

In the *Pathways* model, we set forth four alternative decision pathways and highlight the various factors that may play a role in decision processing along these pathways. These factors include the basic mental processes of cognition, motivation, and emotion as well as the contextual demands of a particular decision-making situation. Further, we recognize that the biological/neurological/developmental characteristics of the decision-maker are key factors in determining which decision pathway will be selected and how it will be applied in a specific situation.

The *Pathways of Decision Processing* model presents the following four alternative pathways illustrated with examples of vignette situations drawn from our studies:

Pathway 1

Pathway 1, the intuitive automatic decision processing pathway utilized in most everyday decisions, relies almost entirely on intuitive automatic (type 1) processing (Stanovich, 2011). Type 1 processes are deployed rapidly and automatically with little or no effort. They are typically based upon a gist-based representation of the situation. For example, in a healthy relationship situation, Amanda's coworker, Marisa, may say to Amanda, "It is really nice to work with you. Would you like to go out for lunch today?" Most likely, Amanda would be able to use *Pathway 1* to make a quick decision based on whether she is free and/or whether she would like to go out to lunch with Marisa.

Pathway 2

Pathway 2 involves reasoned reflective (type 2) processing based on a fairly detailed, verbatim representation of a situation. Type 2 processing is slow and analytic (Stanovich, 2011). Reasoned reflective decision processing typically involves multiple components or steps and requires higher-order hypothetical thinking for the generation and evaluation of alternative courses of action. Complex situations with serious long-term consequences often require Pathway 2 processing. For example, in the following abuse situation, whenever Trisha's uncle comes to family parties, he forces Trisha into a bedroom and touches her private parts. Trisha's uncle tells Trisha not to tell anyone. This situation is fairly complex with multiple possible solutions and serious potential consequences. Trisha may need to apply a reasoned reflective strategy to consider her options in light of their possible consequences and to find the best way to stop the abuse in the immediate situation as well as in the future.

Pathway 3

Pathway 3 involves a shift from an initial intuitively based (type1) decision process to a reasoned reflective (type 2) process after self-regulatory mechanisms detect that the situation requires a more deliberative process and overrides the initial type 1 process. This may occur in interpersonal situations that at first glance appear benign, but later reveal themselves to involve threats or coercion. For example, in a seemingly benign cyber situation, Carlos has been visiting an online forum for guitar players who share songs that they like. Then, Juan, another forum user, posts, "Carlos must be retarded if he likes that song." Carlos will likely need to employ a *Pathway 3* process, involving a shift from an initial intuitive automatic process with respect to his use of the online forum to a reasoned reflective decision-making process to figure out how best to handle the cyber abuse consisting of humiliating verbal taunt by Juan.

Pathway 4

Finally, a *4th Pathway* can develop over time as practice from repeated decision-making experiences with a range of situations in a specific domain accumulates. The feedback and experience from repeated reasoned reflective decision processing can build familiarity with alternatives and their likely consequences in a specific domain such that, over time, a new pathway of decision processing evolves to create a new type of intuitive (type 1) decision process in the form of a learned response to be activated from memory in a particular type of situation. Emergency workers rely heavily on this fourth pathway to build up a repertoire of effective decision actions that they can draw upon and implement rapidly in frequently occurring types of emergency situations (Klein, 1998, 2009). For example, in a physical abuse situation, Stewart sometimes argues with his roommate, Doug, about cleaning their room. Whenever, they argue, Doug pushes Stewart. Assuming that Stewart has had considerable experience with roommate situations (his own and those of his friends), he may have employed a reasoned reflective strategy in past situations. After many years of experience, he may have learned that an effective way to handle this type of situation is to, first, tell Doug not to push him. Then, if Doug does not stop, report the situation to his case manager and request a change of roommates. *Pathway 4* can only occur to the extent that a decision domain follows a regular, predictable pattern.

The *Pathways* model for self-determined, interpersonal decision making for people with intellectual and developmental disabilities (see Hickson & Khemka, 2013) can serve as a useful guide for research aimed at gaining a greater understanding of decision-making processes as well as a framework for the intervention and assessment parameters involved in building capacity and opportunity for individualized models of *supported decision making*, a widely embraced and fast-growing alternative to traditional, guardianship-based models of decision making (Jameson et al., 2015) (see Chap. 17).

It is likely that many people with intellectual and developmental disabilities will require systematic training to replace ineffective decision-making routines based on their past experience with new decision-making skills and strategies that will build on their strengths and lead to more positive decision outcomes aligned with their goal priorities. The *Pathways* model was developed to provide a basis for designing and evaluating interventions aimed at supporting people with intellectual and developmental disabilities to acquire a repertoire of effective decision-making strategies.

Role of Cognitive, Motivational, and Emotional Processes in Decision Making

It has been long understood that decision making involves the interaction of cognitive, motivational, and emotional processes. As early as 1986, Kuhl pointed out that although each of the three processes performs unique functions in decision making, these processes also interact with each other in complex ways to produce decision outcomes. Recently, increasingly specific information has been emerging about the neural substrates of these processes as a result of the intensified interest in decision making in fields such as neuropsychology and neurodevelopment. Recent neurological evidence supports the existence of brain regions that underlie intuitive type 1 decision processing (i.e., the amygdala–striatal system) and deliberative type 2 decision processing (i.e., the ventromedial prefrontal cortex) (Reyna & Zayas, 2014). These systems are highly interconnected, and recent evidence suggests the possible importance of a third system in decision making, the insula, which may modulate the activity in the amygdala-striatal system and the ventromedial prefrontal cortex system to alter the perceived reward value of potential decision outcomes (Reyna & Zayas, 2014).

In our research on interpersonal decision making of people with intellectual and developmental disabilities, we have begun to explore the relative importance of the roles played by cognitive, motivational, and emotional processes in different types of decisions. Although the cognitive challenges inherent in the memory, language, and information processing demands of decision making for people with intellectual and developmental disabilities are apparent, they necessarily operate in relation to motivational factors, including personal agency beliefs and goal processes, and emotional and personality factors in shaping the decision-making effectiveness of this group. It is possible that, although motivational and emotional factors can interfere with effective decision making, they may also have the potential to enhance decision making by compensating for limited cognitive capacity. Acknowledging that these three variables never operate in isolation, in the following sections we will focus on studies aimed at illuminating their relative contributions in particular types of decision-making situations.

Role of Cognition

In a study examining the decision-making effectiveness of adolescents with intellectual and developmental disabilities in situations of peer coercion (Khemka, Hickson, Mallory, & Zealand, 2013), we performed exploratory correlational analyses to examine relationships between participants' effective decision-making scores and several cognitive variables (IQ, language functioning, and risk perception). Language functioning was measured by composite scores on the CREVT-2. Risk perception was measured by responses to a question (i.e., *What could happen if _____ decides to _____ (go along with the coercion?*) asked after the presentation of each of 12 decision-making vignettes involving peer coercion. The relationship between effective decision making and a motivational variable (self-actualized goal orientation) was also assessed.

The correlations were performed first for the entire sample of adolescents with intellectual and developmental disabilities ($n = 49$) and then separately for a subgroup with an autism spectrum disorder diagnosis ($n = 18$) and for a subgroup with no autism diagnosis ($n = 31$). The results provide preliminary evidence of robust, but varying, contributions of cognitive variables to effective decision making for adolescents with and without autism spectrum disorders. For the combined sample, strong positive correlations were found between effective decision-making scores and language functioning scores ($r = .54$, $p < .01$) and correct risk perception scores ($r = .80$, $p < .01$). The high positive correlation between risk perception scores and effective decision making (actions to resist peer coercion in this study) points to the likely cognitive contribution of risk awareness to effective decision making in adolescents with intellectual and developmental disabilities.

When measured separately for the two groups, the effective decision-making scores also correlated significantly positively with language functioning (ASD: $r = .56, p < .01$; non ASD: $r = .51$, $p < .01$) and risk perception scores (ASD: $r = .86$, $p < .01$; non ASD: $r = .80$, $p < .01$). In addition, for adolescents in the ASD group only, a significant relationship was observed between effective decision making and self-actualized goal orientation ($r = .52$, $p < .05$) and between effective decision making and IQ ($r = .47$, $p < .05$), corroborating the importance of levels of cognitive functioning in decision making. The strong association between self-actualized goal orientation and decision making among adolescents with ASD suggests that higher awareness of adaptive goal priorities can help provide the evaluative framework and requisite motivation to approach decision making in a more focused, effective way for these individuals.

Role of Motivation

In our consideration of what constitutes effective decision making, we have focused on the need for people with intellectual and developmental disabilities to make independent, self-actualizing, decisions consistent with their personal agency beliefs and goal priorities. In essence, the process of effective decision making is synonymous with the exercise of self-determination by the decision-maker to make a decision in her/his own best interest and reflective of her/his capacity to handle a decision situation. These considerations suggest an opportunity to influence the decision-making behavior of people with intellectual and developmental disabilities by improving the integration of their goal priorities and internal perceptions of control, beyond simply making goal information available or providing the opportunity to exercise control.

In a continued exploration of decision making in interpersonal situations involving peer pressure (Khemka & Hickson, 2016), we examined the role of personal goal orientation. Forty-nine adolescents with intellectual and developmental disabilities (mean age = 15.86 years; mean IQ = 70.53) were given a goal selection inventory of 18 statements representing a self-actualization based goal value system (e.g., *How important is it for you to be safe? How important is it for you to stay out of trouble?*) or an other-oriented goal value system (e.g., *How important is it for you to go along with what others want? How important is it for you to be liked by your friends?*). Respondents were asked to rate how important each listed goal was to them personally on a Likert scale (*always important, sometimes important, never important*). Based on the mean rating derived for the 11 self-actualization based goals, the adolescents were divided into two groups representing either a relatively high (n = 23) or relatively low (n = 26) self-actualization-based goal orientation system. The results of a t-test (t (47), t = 8.62, p < .01) confirmed that the two groups were significantly different in their reported ratings for self-actualization-based goals.

The two groups were then compared on their ability to suggest effective decisions in response to hypothetical interpersonal situations involving negative peer pressure, as measured by the *Adolescent Decision-Making Scale (ADMS)* (Khemka, Hickson, & Mallory, 2016). The *ADMS* features 12 decision-making vignettes depicting situations in school, work, and community settings that involve negative peer pressure to engage in one of the following four types of risk-taking behaviors (stealing/breaking the law; shirking a work responsibility; facing physical danger; engaging in substance use). Each vignette includes a brief three-sentence description of a decision situation featuring a female or male protagonist as the decision-maker in a situation of negative peer pressure. Vignettes were read aloud to the student by the examiner, followed by a decision action question (e.g., *What is the best thing for ______ to do?*)? Responses to the decision action question were coded as effective if they included any effort to resist the negative peer pressure, with a total maximum possible score of 12 for effective decision-making responses. Effective decision-making action responses included suggestions to make immediate, direct attempts to confront the pressuring peer (e.g., verbal refusal, negotiation) or take an action that implied not going along with the negative peer pressure (e.g., seeking help, don't do it). All other decision responses (e.g., decisions to comply with peer pressure, to ignore the situation, or incomprehensible responses) were considered to be errors. The *ADMS* was designed to also include a within-subjects external goal manipulation variable by varying the goal intentionality of the key protagonist in the vignettes. The vignettes were balanced to include equal numbers of no-goal intentionality statements, goal statements cueing for a self-actualizing intent (e.g., *Lisa would like to keep her job.*), and goal statements cueing for an other-oriented goal intent (e.g., *Brian would like to please his friend*).

A two-way mixed analysis of variance using type of goal intentionality statement as the repeated measures variable and the high versus low self-actualizing goal orientation groups as the between-subjects variable indicated that the effect of the goal intentionality statements on effective decision-making was not significant (F (2, 94) = 1.29, p = .65). However, the between-subjects goal orientation factor yielded a significant difference (F (1, 47) = 4.35, p = .04) with adolescents in the high self-actualizing goal orientation group suggesting more effective decisions for handling the negative peer pressure than their counterparts in the low self-actualizing goal orientation group. This study carries important implications for the role of internalized goal orientation in the decision-making process for people with intellectual and developmental disabilities. However, the question of whether goal intentionality can be readily manipulated will require further research.

Role of Emotional and Personality Factors

Emotion is another of the basic processes that play an integral role in decision making. Early decision theorists typically envisioned the role of emotional factors in decision making as a negative one. It was often assumed that decision-making effectiveness would decline in situations involving high levels of stress or anxiety (e.g., Janis & Mann, 1977; Toda, 1980). Elster (1985) suggested that emotions could overwhelm the rational cognitive processes needed during decision making. More recently, the prevailing view is that the relationship between emotional arousal and decision-making effectiveness resembles an inverted U-shape (e.g., Gutnik, Hakimzada, Yoskowitz, & Patel, 2006). They proposed that, under high levels of arousal, the focus of attention is too narrow and important information may be overlooked. Under low levels of arousal, the focus of attention is too broad and may include unnecessary irrelevant information. Moderate levels of arousal, on the other hand, are conducive to a more balanced allocation of attention. A somewhat different pattern was observed in a study by Leprohon and Patel (1995) who studied the decision making of nurses in emergency telephone triage situations. Three patterns of behavior were observed. In situations of the highest urgency, decisions were made extremely rapidly with nearly 100% accuracy. Situations of moderate urgency were characterized by information seeking and requests for clarification. This pattern was associated with the lowest level of accuracy. The third pattern, under conditions of lowest urgency, was typified by deliberative problem solving and planning. Klein's (2009) research on naturalistic decision making has shown that extensive experience with a decision domain can have a powerful influence on these patterns.

Understanding that stress and decision making are intricately connected, Starcke and Brand (2012) conducted a review of studies that had investigated the impact of stress on decision making. The review included studies that looked at laboratory-induced stress and naturally occurring stress. It was clear from the literature that stress affects decision making. However, whether the effect is positive or negative is determined by the type of decision-making situation. Both laboratory-induced and naturalistic stress were found to affect underlying mechanisms of decision making, including strategy use, feedback processing, and reward and punishment sensitivity. The effects were most likely to be detrimental in situations involving risk avoidance, strategy use, or other higher level systems. The mechanisms may include cardiovascular, hormonal, or neural reactions. In other situations, such as those where the stress is perceived as a challenge rather than a threat, cardiovascular reactions may actually foster increased cognitive capacity. Starcke and Brand concluded by noting that other factors (e.g., personality, demographics) may either confound or mediate the relationship between stress and decision making, suggesting the need for future research.

Two pilot studies by Khemka (2016) involving transition-aged adolescents (ages 18–21 years) with intellectual and developmental disabilities with more extensive support needs are described here. In the first study, 19 participants were interviewed to assess their level of preparedness to handle situations of coercion or threat of coercion involving interaction via the Internet or phone (cyberbullying). A six-vignette scale presenting hypothetical situations involving risk for cyber abuse was administered to the participants of the college program, and they were assessed for their ability to suggest an independent, prevention-focused decision response (verbally speak up right away, sign off the Internet/walk away, stop being friends with the perpetrator) in countering the cyber risk. Participants also completed the Levenson IPC scales (Levenson, 1973) and scores on the internality scale (reflecting an internal locus of control) were computed. Preliminary data indicate that effective decision responding was fairly limited with the participants recommending an effective decision response only 50.83% of the time (mean score = 3.05). The remaining responses equally spanned asking someone for help or being avoidant (e.g., Just ignore it) or complacent (e.g., Go along with it). Although the sample was fairly small, a strong correlation ($r = .52$, $p < .01$) was found between internality scores and effective decision-making that involved resisting coercion. The relationship between positive decision outcomes and participants' internal control perceptions corroborate the growing evidence supporting the importance of personal agency beliefs in shaping independent and self-determined decision-making behaviors.

The 19 participants who responded to the decision-making situations of cyberbullying were also asked to respond to a feeling/emotion identification question presented at the end of each vignette situation "*How do you think (the key protagonist in the vignette) might be feeling in this situation*?" Responses tallied across four descriptive emotion identification categories showed that responses predominantly fell in one category of feelings. Almost 75% of the time the adolescents described that the key protagonists would experience feelings or emotions of distress (e.g., sad, hurt, bad, betrayed) and internal devaluation (e.g., ashamed, embarrassed). Other feelings identified included feeling angry or being mad 12.57% of the time; feeling anxious, scared, or nervous for 10.78% of the time. Positive feelings were identified a negligible 3.59% of the time. Although no formal analysis was undertaken to explore how participants' evaluation of the decision situations, in terms of emotions, impacted their decision choices, the emotions identified do reflect participants' understanding and feelings about the situations and thereby their immediate coping with the situations. The dominant distress-based emotions observed indicate a high level of consistency in the participants' views of feelings associated with interpersonal situations involving coercion through cyberbullying and depict a high emotion-focused approach to coping that entailed a low sense of personal control and agency in decision situations involving others. Only 12.57% of the time did participants endorse emotions of feeling angry or mad that would suggest possible action-focused behavioral responses to the coercive situations. As described by Izard (1984), the emotion of *anger* "mobilizes energy for physical action as well as confidence in one's powers" (p. 18). In contrast, the high levels of distressed inward feelings reported by the participants suggest the motivation to either avoid or accept the status quo, leading to a less active form of decision responding. Future studies will need to follow up on examining the role of the different emotional states, especially in situations requiring quick decisions. Since emotions have been described as personal evaluative states that regulate individuals into taking action, they have important consequences for behavior and adaptive functioning.

Emotion or feeling identification has been assigned a central role in our decision-making interventions on the premise that the evaluation of a situation in terms of the affect and arousal it generates sets the intensity of decision-making engagement for the decision-maker and has consequences for her/his behavior by compelling the actions required for decision making in that situation. As defined by Izard (1984), "the function of an emotion for an individual is evidenced in the motivational value and action tendency that stem from the quality of consciousness that characterizes the 'felt emotion.' The primary social functions of emotion are (a) signaling something of the expresser's feelings and intent, (b) providing a basis for certain inferences about the environment, and (c) fostering social interactions that can facilitate the development of interpersonal relationships" (p. 18). In keeping with the notion that each different emotion brings a different quality of motivation resulting in different behavioral alternatives, we have in our decision-making intervention efforts with people with intellectual and developmental disabilities focused on enhancing recognition and understanding of emotions that would trigger adaptive responses in a decision situation, allowing the decision-maker to adopt a more task-approaching rather than task-avoiding approach to a decision-making situation, leading to an overall more self-regulated and adaptive functioning decision-making style.

In the second pilot study, the ability of 16 adolescents with intellectual and developmental disabilities to suggest prevention-focused decisions that involved independently and verbally confronting the perpetrator to act to stop the abuse from happening was measured using a

12-vignette scale presenting hypothetical situations of abuse or a threat of abuse (sexual, physical, or verbal abuse). A repeated measures analysis of variance was used to compare decision-making performance of the participants in three types of abuse situation. An overall main effect (F (2, 30) = 4.20, p = .025) for type of decision situation was obtained with post hoc analyses, indicating that the participants were least likely to verbally speak up and resist in situations involving verbal abuse (mean = .56, SD = .73) than in situations of sexual abuse (mean = 1.31, SD = 1.01) or physical abuse (mean = 1.50, SD = 1.21). Prevention-focused decision making, involving independent, empowered, verbally resisting actions (*Say No; Speak up and say stop.*), was observed only 28.16% of the time across the three types of situations (mean = 3.38, SD = 1.86), revealing severe limitations in self-protective decision-making preparedness. The within-subjects difference, with verbal abuse situations being most problematic for effective decision making, has been observed in our previous studies (e.g., Khemka & Hickson, 2000) and suggests that people with intellectual and developmental disabilities find it easier to make effective decisions when consequences of actions are more obvious (e.g., someone hurting your body as in sexual or physical abuse) than when the coercion is more subtle or implied (e.g., someone denigrating or shouting at you as in verbal abuse).

Although a large body of literature exists concerning the impact of self-related variables (e.g., self-esteem, self-efficacy, internal attribution beliefs) on academic performance and a host of other task performance behaviors, including response to traditional bullying (e.g., Bandura, 1993; Findley & Cooper, 1983; Radliff, Wang, & Swearer, 2015), research exploring the relationship of such key constructs to cyberbullying experiences and decision making is fairly recent. Patchin and Hinduja (2010) found a statistically significant moderate relationship between low self-esteem and experiences with cyberbullying in a large random sample of middle school students. In this study, although the temporal ordering of the relationship between cyberbullying and self-esteem was not clear (i.e., whether cyberbullying results in lower self-esteem or low self-esteem increases vulnerability to cyberbullying), there is convincing evidence that self-esteem and possibly other related personality variables play a critical role in how adolescents shape their responses to situations involving coercion through the use of technology. Previous research (Hickson & Khemka, 1999; Khemka & Hickson, 2000) has emphasized the relationship between self-related variables, specifically locus of control beliefs, and decision-making effectiveness in interpersonal situations for people with intellectual and developmental disabilities. Khemka's (2016) pilot study results also underscored a positive correlation between internal locus of control beliefs and effective decision making in response to cyberbullying by transition-aged adolescents with intellectual and developmental disabilities. In light of these findings, the role of self-related variables, in mediating motivational and cognitive reactions to decision-making situations, appears to merit further study.

Future studies to isolate the impact of individual personality variables, such as self-esteem, locus of control, empowerment, self-determination, on the decision-making behaviors of people with intellectual and developmental disabilities are required so that the underlying personality variables can be fully addressed during decision-making training as integral elements of the decision-making process. This is perhaps even more pertinent to people with intellectual and developmental disabilities effectively handling decision-making situations of coercion involving cyberbullying where the impact on the individual is largely relational or psychological, and perhaps linked more directly with perceptions of self. Promoting positive and healthy perceptions of self is critical to the overall self-determination of people with intellectual and developmental disabilities, especially during the critical period of adolescent development, where an adolescent's perceptions and acceptance of self can direct personal trajectories of growth toward lower or higher self-determination and independent decision making. In addition to enhancing dispositions toward more internal perceptions of control, it is apparent that the environments and opportunities for people with intellectual and developmental disabilities need to be better structured and supported to help induce and maintain positive perceptions of self (Wehmeyer, 2013).

Although we have begun to examine some of the non-cognitive variables (e.g., locus of control, goal orientation) in our studies of decision making in adolescents and adults with intellectual and developmental disabilities, we acknowledge that responses to a decision-making situation can be influenced by a gamut of developmental and personal trait factors such as self-concept, impulsivity, friendship networks, and social belonging, all of which can pose challenges especially during adolescence. Consideration of the impact of each of these variables on the decision-making behaviors of people with intellectual and developmental disabilities is clearly warranted.

Disability-Specific and Age-Specific Patterns of Decision Making

In addition to the overall decision-making difficulties posed by the social and cognitive limitations of people with intellectual and developmental disabilities, there is evidence of disability-specific difficulties that can differentially affect patterns of decision making. Based on a review of the available literature, Hickson and Khemka (2014) identified factors that have been differentially associated with decision-making difficulty in individuals with intellectual and developmental disabilities. Some of the factors that were uniquely associated with people with intellectual disability included cognitive factors (e.g., intelligence, comprehension, and ability to forecast rewards), motivational factors (e.g., personal agency beliefs), and emotional factors (e.g., ability to identify the emotions and intentions of others). Factors that have been uniquely associated with decision-making difficulty in individuals with autism spectrum disorders included motivational factors (e.g., avoidant decision style, idiosyncratic goal priorities, lack of behavioral flexibility, and restricted interests) and emotional factors (e.g., limitations in processing emotional cues and emotion regulation).

Research with people with intellectual disability, mainly adults with mild and moderate levels of impairment, has indicated various shortcomings in their decision-making effectiveness, relative to the performance of adults without disabilities. Most of the studies point to people with intellectual disability having difficulty in comprehending decision situations, applying a systematic decision-making process, generating alternative choice options, or failing to anticipate possible negative consequences. (Castles & Glass, 1986; Healey & Masterpasqua, 1992; Hickson & Khemka, 1999; Jenkinson & Nelms, 1994; Smith, 1986; Tymchuk, Yokota, & Rahbar, 1990; Wehmeyer & Kelchner, 1994). In situations of decision making involving victimization or potential risk of injury or loss, people with intellectual disability tend to show impulsive responding with less effective, self-protective decision making with greater risk-taking behaviors that makes them highly vulnerable to victimization and harm (Khemka & Hickson, 2000; Khemka, Hickson, Casella, Accetturi, & Rooney, 2009). Research that has examined decision making across a wide range of personal decisions including forecasting of monetary rewards, giving consent, and making medical or legal decisions (e.g., surgery, court testimony) (e.g., Gunn, Wong, Clare, & Holland, 2000; Luke, Clare, Ring, Redley, & Watson, 2012; Murphy & Clare, 2003; Willner, Bailey, Parry, & Dymond, 2010; Wong, Clare, Gunn, & Holland, 1999; Wong, Clare, Holland, Watson, & Gunn, 2000) validates that people with intellectual disability experience difficulty in evaluating and predicting immediate and long-term consequences of a particular risky decision action and tend to choose behaviors that are high in immediate subjective desirability or excitement, but that may carry the potential for injury or loss. This raises concern about their ability to weigh short-term versus long-term outcomes in complex social interpersonal situations that involve coercion and to navigate these environments successfully and make decisions in their own best interest. Information processing capacity is also a pervasive issue for individuals with intellectual disability. In particular, this can interfere with their ability to meet the demands for sustained hypothetical thinking involved in reasoned reflective decision making (e.g., Hickson & Khemka, 2014).

Recent studies focusing on people with autism spectrum disorders have identified several patterns of the decision-making styles. Alerted by Luke et al. (2012) that people with autism spectrum disorders often try to avoid making decisions because they find decision making exhausting, Brosnan, Chapman, and Ashwin (2014) compared adolescents with and without autism on a jumping-to-conclusions task. Unlike previously tested individuals with psychosis, adolescents with autism spectrum disorders showed little tendency to jump to conclusions during decision making. In fact, they showed a pattern of careful, circumspect reasoning where they gathered more data prior to deciding relative to adolescents without autism. Although this tendency could slow down and interfere with effective decision making in healthy interpersonal situations where an automatic intuitive strategy would be sufficient, it could prove to be an asset in more complex or threatening situations where a reasoned reflective strategy is called for.

Robic et al. (2015) scrutinized the decision-making performance of a group of adults with autism spectrum disorders relative to that of adults without disabilities in a social versus nonsocial environment in a predictable versus unpredictable task context. The study utilized a laboratory task in which participants were asked to choose one of two boxes. On each trial, one box was rewarding and one was not. In the predictable condition, the probability of winning was 75% for one box and 25% for the other. In the unpredictable condition, the probabilities associated with the boxes were unstable. In the nonsocial cue condition, the cue was an arrow. In the social cue condition, the cue was a short movie with an actor who looked at the chosen box. The performance of the two groups did not differ in the predictable condition in the nonsocial context. However, the participants with autism spectrum disorders had more decision-making difficulty relative to the non-disability group in the unpredictable condition and in the social context. Robic et al. concluded that both the social nature of the environment and its unpredictability can cause decision-making difficulty for people with autism spectrum disorders. They suggested that people with autism spectrum disorders could be taught the regularities of both social and nonsocial domains.

Levin et al. (2015) reported a pilot study examining the decision-making competence of a group of high-functioning, college-aged students with autism spectrum disorders relative to a comparable-aged group without disabilities. Both groups completed a battery of measures tapping various aspects of decision making. Performance of the two groups was comparable on many of the traditional measures of decision-making competence. They found that the groups did differ significantly in decision style. Young adults in the autism spectrum disorders group were less inclined to use and less successful at using intuitive impressions and feelings to make decisions than were individuals in the non-disability group. The groups did not differ in reliance on and ability to use rational/deliberative thinking in making decisions. The autism spectrum disorder group also made fewer risky choices and was less likely to endorse behaviors that violated social norms than the non-disability group.

Khemka et al. (2013) compared adolescents with an autism spectrum disorders diagnosis as indicated on IEP records ($n = 18$) with their counterparts in the same educational setting with no such diagnosis ($n = 31$) on a decision-making task consisting of situations involving peer coercion. Diagnoses of the adolescents in the non-autism spectrum disorders group included intellectual disability, speech/language disorder, and learning disabilities. Both groups attended self-contained, special education classrooms in public schools in the NYC area and did not differ significantly on their mean IQ score or age. The adolescents responded to the set of 12 hypothetical decision-making vignettes measured on the ADMS and were assessed for their ability to effectively and independently resist negative peer pressure in interpersonal social situations presenting four different types of risks: (1) pressure to engage in alcohol, smoking, or drug use (ATOD use); (2) pressure to shirk job responsibilities at the urging of a friend; (3) pressure to break the law and steal something at work; and (4) pressure to risk physical safety by going with an unfamiliar/unknown person. The situations targeted for study had been validated by teachers and counselors at the participating schools as being relevant to their daily social lives with peers and often posing difficulties for these young adolescents. In particular, the situations involving safety risk were considered to be especially challenging for the students with autism spectrum disorders who tend to be eager to please others and can to be lured easily by strangers to follow them. A mixed analysis of variance with type of decision situation as the within-subjects factor, and autism spectrum disorders versus non-autism spectrum disorders as the between-subjects factor was computed.

Significant main effects were found for both disability type (F (1, 47) = 8.33, $p < .01$) and type of situation (F (3, 141) = 3.13, $p < .05$), with no significant interaction effect. Adolescents with autism spectrum disorders performed significantly lower (mean = 5.78) on effective decision making, which indicated resisting peer pressure, than those without autism spectrum disorders (mean = 8.90). Both adolescents with and without autism spectrum disorders exhibited lower levels of effective decision making in situations of safety risk (42.75% effective responding) than in situations that involved pressure to engage in ATOD use (52.5% effective responding) or situations that involved pressure to shirk responsibility at work (52% effective responding). Performance with situations that involved stealing at work (46.5% effective responding) did not differ significantly from the other situations. This specific pattern of differences based on the type of risk/peer pressure in the decision situations highlights the challenges that adolescents with intellectual and developmental disabilities might face in anticipating risks, and therefore the consequences of their decisions, in situations where the risk is implicit (as in going with an unfamiliar neighbor) and not obvious. The observed difficulties in exercising self-determined, effective decision making for adolescents with intellectual and developmental disabilities, especially those with an autism spectrum disorders diagnosis, are likely to negatively impact how they navigate peer situations and how well they are able to access the social benefits and peer networks available within inclusive settings.

The decision-making differences cannot be explained by cognitive differences between the two groups as they were equivalent to IQ and their language functioning. The results clearly indicate the presence of other non-cognitive intervening variables, possibly emotional and biological/personality variables that might have affected the decision making of the two groups of adolescents differentially. For instance, Rieffe, Camodeca, Pouw, Lange, and Stockmann (2012) compared young adolescents with autism spectrum disorders with a control group of typically developing children to examine the role of basic emotions in victimization and bullying and found that compared to the control group, adolescents with autism spectrum disorders exhibited higher dysregulation of anger which was associated with more victimization and bullying. Given the marked differences in social and behavioral abilities of adolescents with autism spectrum disorders in comparison with their counterparts without disabilities and peers with other developmental disabilities, a broader gamut of personal variables and their inputs to decision making behaviors is worth considering in future studies. Specifically, in situations of peer pressure or coercion, decision making by people with autism spectrum disorders might be impacted by their atypical interests and intense emotional and/or behavioral reactivity, adding to their vulnerability to becoming easy targets for victimization (Matson & Nebel-Schwalm, 2007). Assertive and direct communication with peers during decision making in interpersonal situations is essential, especially when a risk of victimization is present. People with autism spectrum disorders might be substantially limited due to their communication and social impairments, and abilities to interpret social cues and assess risk in peer interactions. Van Roekel, Scholte, and Didden (2010) studied 230 adolescents with autism spectrum disorders, finding that adolescents who more frequently misinterpreted bullying situations as non-bullying experienced higher rates of victimization, as reported by self and teachers. Other studies (Frith & Hill, 2004; Loveland, Pearson, Tunali-Kotoski, Ortegon, & Gibbs, 2001) have shown that children with autism spectrum disorders struggle with perspective-taking and interpreting cues in social situations. This tendency occurs especially when situations are complex and contain multiple verbal and nonverbal cues.

To date, very few studies have examined the decision-making skills of people with autism spectrum disorders in complex and uncertain social contexts. Ruble, Willis, and Crabtree (2008) found that children with autism spectrum disorders had difficulty generating alternatives during decision-making tasks. These findings are possibly due to autism-related behavioral rigidity and inflexibility. DeMartino, Harrison, Knafo, Bird, and Dolan (2008) reported that young adults with autism spectrum disorders have difficulty incorporating emotional cues into their decision processing. This finding adds to earlier evidence (i.e., DeMartino, Kumaran, Seymour, & Dolan, 2006; Kahneman & Frederick, 2007) that the inability to adequately process emotional cues is related to a neurobiological deficit. Youth with autism spectrum disorders likely experience difficulty capitalizing on emotional cues in complex and uncertain social contexts. Peer victimization might subsequently limit intuitive and self-regulatory decision-making processing. Core deficits in social communication and behavioral rigidity combine with a high prevalence of worry- and anxiety-related symptoms in individuals with autism spectrum disorders (Ghaziuddin, 2002; White, Oswald, Ollendick, & Scahill, 2009).

Dramatic changes in decision processing take place during adolescence which warrant special attention (e.g., Chein, Albert, O'Brien, Uckert, & Steinberg, 2011). Steinberg (2008, 2010), basing his ideas on emerging evidence from developmental neuroscience, has proposed a dual-process theory to explain some of these changes. It appears that two different brain systems that play a key role in decision making mature at different time during the adolescent period. Changes in the brain's socio-emotional system occur at the time of puberty and are associated with a sudden increase in risk taking in conjunction with increased reward-seeking, especially in the presence of peers. Risk taking eventually declines between late adolescence and adulthood as the brain's cognitive regulatory system matures. Blakemore and Robbins (2012) described the reward system associated with risk taking as being hypersensitive to rewards in early adolescence. In contrast, they refer to the slow-developing system of impulse control and response inhibition. They go on to suggest that emotional and social factors may be important modulators of decision making during adolescence. According to Crone and Dahl (2012), neuroimaging studies indicate that adolescent risk taking and other dangerous behaviors are linked to changes in social-affective processing. They assert that the primary task of adolescence is to achieve mature levels of social competence. Crone and Dahl point out that this process is intertwined with adjustments in goal priorities. They suggest that these changes may confer benefits, along with the vulnerabilities, to the extent that adolescents have the capacity to quickly shift goal priorities.

There is considerable evidence to confirm that adolescents engage in risk-taking decisions, despite well understanding the consequences of their actions and the risks involved. Adolescents demonstrate the ability to estimate some of their risks in real-life situations quite reasonably (Fischoff et al., 2000; Reyna & Adam, 2003; Reyna & Farley, 2006). However, they will often make choices not by rationally calculating relative risks and consequences of their behaviors but by weighing their choices heavily on their individual subjective experiences, such as feelings and social influences (Steinberg, 2004, 2007).

Given the complexities of disability-specific influences on decision making and their potential interactions with the profound age-related changes that take place during adolescence, special consideration is required in designing decision-making interventions for adolescents with intellectual and developmental disabilities to make sure that they are carefully calibrated to their specific and changing needs.

Interventions to Support Positive Decision-Making Outcomes with Adults with Intellectual and Developmental Disabilities

In an effort to find ways to strengthen decision-making effectiveness in people with intellectual and developmental disabilities, we have conducted several intervention studies. With a focus on adults with intellectual and developmental disabilities, we developed and evaluated a series of decision-making/abuse-prevention curriculum interventions to determine whether people with intellectual and developmental disabilities can acquire deliberative decision-making strategies and the ability to distinguish situations that require their use from situations that can be handled successfully with an automatic intuitive approach (Hickson, Khemka, Golden, & Chatzistyli, 2015: Khemka, 2000; Khemka, Hickson, & Reynolds, 2005).

Khemka (2000) initiated this line of research by designing a cognitive/motivational intervention that was highly effective at improving the interpersonal decision making and locus of control performance of a group of women with intellectual and developmental disabilities. The performance of the women in the intervention group was superior to that of women who had been randomly assigned to a group whose training focused only on cognitive skills or to a control group. Based on Khemka's intervention, the initial version of the *ESCAPE* curriculum was developed and shown to be effective at teaching self-protective decision-making skills to women with intellectual and developmental disabilities relative to a randomly assigned control group (Khemka et al., 2005).

Subsequently, the *ESCAPE-DD* version of the curriculum (Khemka & Hickson, 2008) was developed to extend its applicability to males as well as females with intellectual and developmental disabilities. It was evaluated in a study involving 58 women and men with mild and moderate intellectual and developmental disabilities (Hickson et al., 2015). Participants were randomly assigned to either an intervention group, which received *ESCAPE-DD*, or a wait-list control group, which was given delayed access to the curriculum upon completion of posttesting. Posttests consisted of six decision-making vignettes depicting situations involving sexual, physical, and verbal abuse. After each vignette was read to them, participants were asked the following decision-making question: *What should (name of protagonist) do?* Responses were considered to reflect effective decision making if they indicated an attempt to seek safety through independent action or by seeking help. Participants in the intervention group produced significantly more overall effective decision-making responses than did participants in the control group. Overall, approximately 84% of the intervention group's posttest responses constituted attempts to seek safety, while only 63% of the control group's posttest responses represented such attempts.

The *ESCAPE-DD* curriculum consisted of 12 small-group instructional lessons and six support group sessions. The curriculum was designed to address the interplay among the cognitive, motivational, and emotional processes involved in decision making. Unit 1 (Lessons 1–5) focused on concepts that distinguished abusive from healthy relationships and emphasized the importance of three safety goals: (1) be independent, (2) be safe now, and (3) be safe later. Unit 2 (Lessons 6–12) focused on modeling and providing guided practice with a four-step decision making strategy for handling abuse situations: (1) PROBLEM: Is there a problem?;

(2) CHOICES: What are the possible choices?; (3) WHAT IF: What could happen if? (check each choice with the 3 goals); and (4) DECISION: What should _____ do in this situation?

In an effort to better understand how ability to apply the four strategy components related to decision-making outcomes, we performed correlations between mastery scores for each of the four component steps and posttest safe-now decision-making scores, which measured the extent to which the recommended decision action indicated an attempt to avoid or stop the abuse by seeking immediate safety. We found a significant correlation with posttest safe-now scores for only the third component step, which consisted of considering the extent to which the possible consequences of each choice would meet the three goals. This finding was consistent with a suggestion by Stanovich (2011) that the hypothetical thinking required for evaluating the possible consequences of alternative choices would likely be impaired in those with cognitive limitations.

In light of recent theoretical advances and in keeping with the social–ecological model of disability, we have updated and modified the decision-making strategy featured in our latest, recently completed version of the *ESCAPE* curriculum, *ESCAPE-NOW* (Khemka & Hickson, 2015) (www.escapenow.wikischolars.columbia.edu), so that it is aligned more closely with the strengths and vulnerabilities of intellectual and developmental disabilities individuals. The flowchart used to guide participants through the four component steps of the decision-making strategy that is the linchpin of *ESCAPE-NOW* is shown in Fig. 1. The structure of the four component steps parallels that of *ESCAPE-DD*, but the specifics of the four steps in *ESCAPE-NOW* are more sharply focused. Step 1 of *ESCAPE-NOW*, (1) PROBLEM: Is there a problem of abuse in this situation? is similar to Step 1 in *ESCAPE-DD,* but the yes/no response is prompted by questions evoking the feelings associated with abusive or healthy relationships accompanied by sad/happy face emoticons. Step 2, (2) CHOICES: What are the possible choices? has been modified in *ESCAPE-NOW* to reflect a "satisficing" strategy, rather than an exhaustive search strategy, for generating possible alternative choices. Participants are asked to generate only a single choice (alternative) prior to going on to Step 3, (3) CONSEQUENCES: Would the choice meet the 2 safety goals: Safe now and Safe later? In Step 3, participants are asked to check their single choice to see whether it meets both safety goals. If yes, they can go on to Step 4. If no, they are asked to think of another possible choice, repeating Steps 2 and 3. Finally, in Step 4, (4) DECISION: Decide how to act upon the selected choice, participants are asked to state their decision in a way that shows how it meets both goals.

The modifications in the *ESCAPE-NOW* decision-making strategy are consistent with decision-making research and theory, indicating that most decisions involve either rapid, intuitive processes, or in the case of deliberative processing, trying the first alternative that seems promising (satisficing) and considering a 2nd alternative only if the 1st proves unworkable. The rationale for shifting to this new strategy was to reduce the information processing load for participants likely to have limited processing capacities. For the same reason, the *ESCAPE-NOW* decision-making strategy reduced the number of goals from three to two. This more focused strategy works best when applied in a familiar, predictable domain. *ESCAPE-NOW* addresses this issue by building familiarity with the abusive/healthy relationship domain. Extensive practice is provided with a large number of healthy and abusive situations, spanning sexual, physical, and verbal abuse in a variety of contexts, including Internet-based and financial situations as well as disability-specific abuse situations where people with intellectual and developmental disabilities have been particularly vulnerable.

Furthermore, *ESCAPE-NOW* was designed to foster the recognition and adoption of emotions likely to lead to adaptive and self-protective decision actions. For instance, in the *ESCAPE-NOW* curriculum, the lesson entitled "Understanding Healthy and Abusive Relationships" requires the participants to distinguish feelings

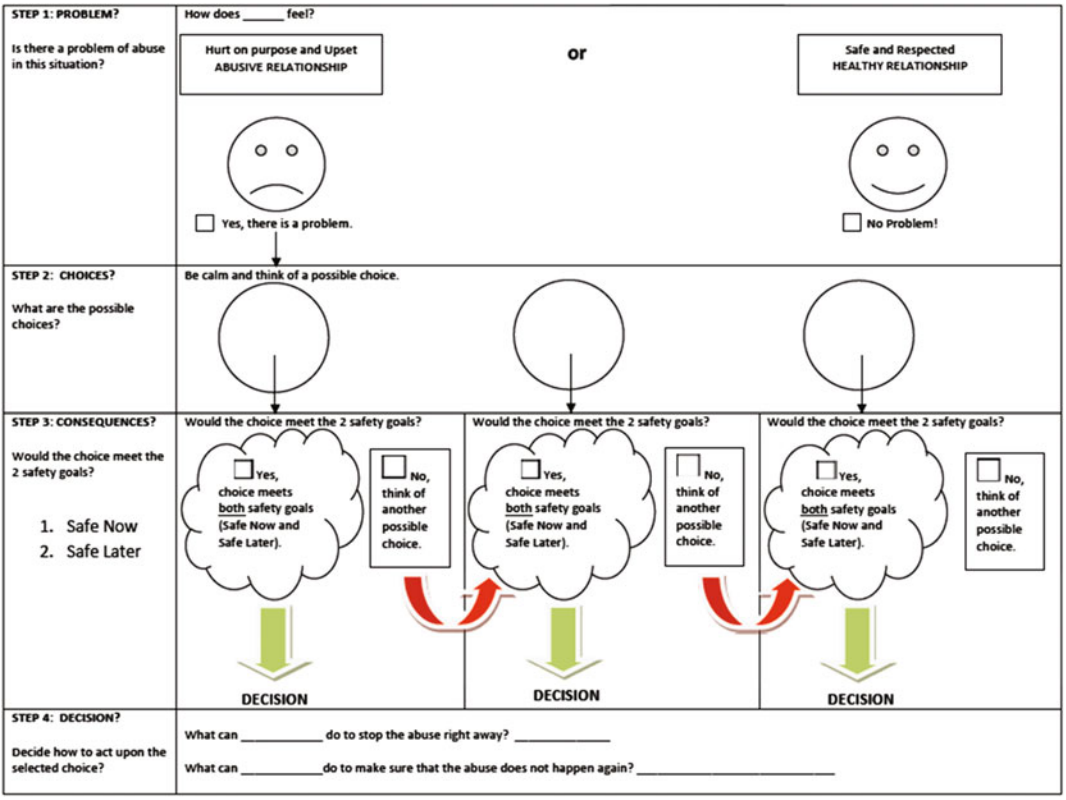

Fig. 1 Decision-making chart (Khemka & Hickson, 2015)

associated with healthy and positive personal relationships (e.g., *safe, respected, happy, relaxed, cared about*) from relationships involving coercion or pressure (e.g., *upset, hurt on purpose, angry, worried, afraid*). In addition, emotions are tied to coping profiles (helpful to solve a problem versus not helpful to solve a problem) to illustrate a gamut of feelings tied to a situation to help shift attention from plausible task avoidant emotions (e.g.,. *getting upset, feeling ashamed, experiencing sadness*) to more adaptive/task-approaching emotions (e.g., *feeling* angry, *being annoyed*). Further, activities in the lesson on "Coping with Abuse and Distress" build awareness of sensory and bodily arousal tied to varied emotional experiences. The physiological changes accompanying emotional experiences determine the subjective experience linked with the emotions and in turn serve to communicate essential information required for cognitive processing of a reaction in response to the experience of the emotion.

Rehearsal with emotion identification builds a repertoire of emotional understanding and cues the participants to reflect on the primacy of the identified emotion, in turn, guiding the motivational inputs in the decision-making process. It is assumed that over time, the emotional-cognitive processing that results in the overall understanding and handling of a decision situation will become fairly automatic or intuitive, and the participant will gradually operate along a continuum of adaptive emotional states rather than maladaptive, avoidant states of emotional responding. In addition to recognition of different emotional states, the ability to vary one's level of emotional reaction according to circumstances is critical for competence, as in some situations (e.g., situations of abuse with high risk), the need for spontaneity and emotional intentionality might be high, in comparison with other situations (e.g., conflict with a friend), where a more reflective and controlled emotional reaction might be more functional. In essence, the self-regulation of emotions, along with appraisal of self in relation to others, is an important component of effective decision making in interpersonal situations.

Although most of our decision-making training efforts have focused on preparing people with intellectual and developmental disabilities to effectively handle situations of coercion or abuse, we are consistently extending our training to also highlight and help individuals build positive, healthy emotional and motivational states leading to more pro-social behaviors and adaptive social functioning and adjustment. This is consistent with the theoretical perspectives associated with the positive psychology of emotions (see Fredrickson, 2001) that posit that positive emotions enable people to broaden their momentary thought-action repertoires, in turn increasing their enduring personal resources, ranging from physical and intellectual resources to social and psychological resources.

Interventions to Support Positive Decision Making Outcomes with Adolescents with Intellectual and Developmental Disabilities

Although reducing the alarmingly high rates of abuse of people with disabilities has been a driving force in our research and intervention work with adults with intellectual and developmental disabilities (see Hickson & Khemka, 2016), we have begun to explore the potential of intervening earlier, before abuse patterns have been established. Our work with adolescents is aimed at supporting the development of positive relationships and strengthening the ability of adolescents to distinguish healthy relationships from negative relationships involving bullying or coercive peer pressure. Because adolescents are known to have a heightened sensitivity to peer influences, we have focused our initial efforts on peer relationships.

Based on preliminary studies affirming that the decision making of adolescents with intellectual and developmental disabilities is vulnerable to various coercive tactics (Khemka & Hickson, 2006; Khemka et al., 2009; Khemka, Hickson, Zealand, & Mallory, 2011), we developed and evaluated a decision-making curriculum for teaching adolescents with disabilities to resist negative peer pressure. The *PEER-DM (Peers Engaged in Effective Relationships—Decision-Making)* curriculum introduces various concepts relevant to peer relationships and teaches a 4-step strategy for making decisions that are consonant with two key goals: (1) Stay out of trouble and (2) be safe and healthy. The four strategy steps include: (1) identifying a situation as a problem, (2) generating possible alternatives, (3) considering possible consequences of each alternative, and (4) choosing a decision course of action. The curriculum, which consists of six small-group sessions, uses modeling, guided practice, and fading to provide numerous opportunities to apply the decision-making strategy with a wide range of peer situations involving positive and negative peer pressure (Khemka & Hickson, 2013).

In a recent study to evaluate the effectiveness of *PEER-DM* (Khemka, Hickson, & Mallory, 2016), 42 adolescents with disabilities were randomly assigned to receive the *PEER-DM* intervention or to a wait-list control group. Posttest measures included responses to (1) decision action questions, (2) risk perception questions, and (3) questions about knowledge of peer relationship concepts. Results indicated that adolescents who received *PEER-DM* produced significantly more correct risk perception responses and more effective decision action responses to a set of vignettes depicting negative peer pressure situations than did the adolescents in the control group. Correct risk perception reflected the ability to anticipate the possible consequences of going along with the negative peer pressure. A significant difference in favor of the intervention group was also found on a knowledge test of peer relationship concepts. These performance patterns were maintained when the subgroup of adolescents with autism spectrum disorders in intervention group ($n = 10$) and control group ($n = 6$) were compared. These findings support the line of research that has explored the use of cognitive-motivational models of decision-making training to increase awareness of social risks and improve self-protective decision making in response to complex, social decision-making situations involving threats and coercion (see Hickson & Khemka, 2014).

Application of Four-Step Decision-Making Strategies

In keeping with the premise that individuals approach decision-making tasks by operating along different pathways of information processing, leading to alternative approaches to decision making and mediated by different underlying factors (e.g., cognitive, motivational, emotional, biological), there is no one way to teach how best to approach a decision-making situation. However, given that deliberative decision making, a metacognitive-based process, entails distinct phases of problem recognition, generation of alternative choice options, evaluation of possible consequences of choices, and selection of final choice leading to decision action and requires a fair amount of self-regulation and executive functioning (working memory and impulse control), a strategy-based approach designed to make the decision process as overt and systematic as possible has been found to be highly effective. We regard the conscious consideration of alternative choice options and selection among available or known options based on individual goal expectancies to be a meaningful, effortful act and as the core of a decision-making process, driven by one's internal agency and implemented or maintained by one's self-regulatory mechanisms. The form of choosing based on weighing information about available choice options, goal striving and consequence evaluation, and selecting the option that appears most likely to be adaptive in a given situation is viewed as representing the most effective and self-determined decision solution for that situation. Additionally, efficient decision making involves basic self-evaluation and the ability to initiate and maintain goal intentions and resulting motivations (i.e., self-regulation). Therefore, the study of effective decision-making components requires us to bring the whole individual into consideration, within the situational demands of the decision-making context.

The systematic decision-making strategies which are at the core of *ESCAPE-NOW* (see Figs. 1 and 2) or *PEER-DM* (see Figs. 3 and 4) represent variations of the step-by-step sequence of decision-making components with key self-regulatory inputs explicitly identified. Both explicit strategies have components of visual representation (e.g., a visual schema for the 4 steps, cues for emotion identification, arrows to regulate the sequence of choice generation and evaluation) that offer a visual schema as a scaffold for easy recall of 4 key steps involved in the decision-making process and the primary components (e.g., using goals as evaluative standards for choice selection, *Does this choice meet …?*) that build the self-regulatory skills for implementing the sequence of steps. The strategies also allow for an interactive approach to learning (e.g., using stickers, checklist options) and extend learning scaffolds in the form of built-in prompts for think-aloud, verbal reasoning, and self-instruction. In addition, the application of the *ESCAPE-NOW* decision-making strategy involves a role-playing component (see Fig. 2) to provide participants with the opportunity for decision application by rehearsing how best to act upon a selected choice in a decision-making situation (*What can (the key protagonist) do to stop the abuse right away? What can (the key protagonist) do to make sure that the abuse does not happen again?*). Embedded in the role-playing activity is the reinforcement of individual empowerment and impulse control mechanisms, critical to successful and self-determined decision responding in a real-life situation.

The strategy described above has been customized for the context of our intervention work primarily focused on improving decision-making

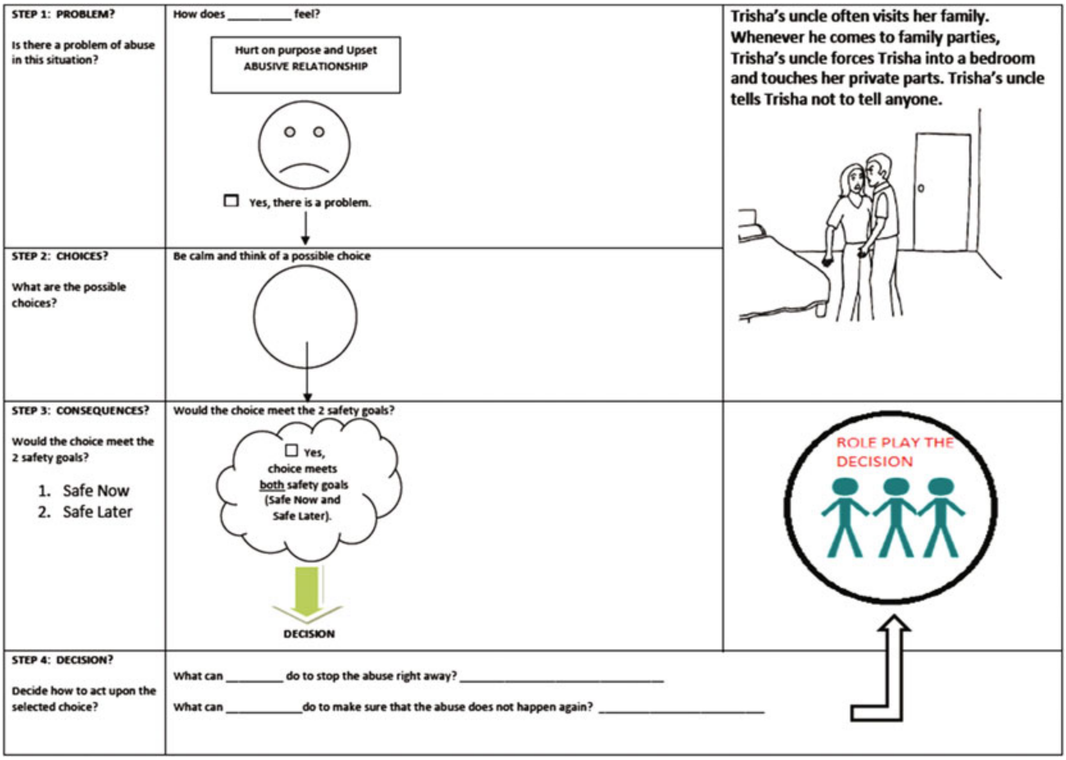

Fig. 2 Decision-making chart with role-playing (Khemka & Hickson, 2015)

preparedness of people with intellectual and developmental disabilities in situations of abuse or threat of coercion or peer pressure. However, the four-step decision-making strategy provides a generalized approach for systematically teaching a decision-making process and related skills and can be easily extended to other novel decision-making tasks or situations. The strategy addresses the overall needs of any deliberate, effortful decision-making process, including planning (cognitive and metacognitive structures), personal resources (emotional and motivational resources), and a range of executive functions, including self-regulation. Given that much of the time people make decisions ultimately by routine, habit, instinct, or automatic processes (Kay, 2002), it is our belief that exposure to reasoned, strategy-based training in decision making will provide effective tools to people with intellectual and developmental disabilities, so that in the event that they do not apply a reasoned, calculated decision-making process, they will proceed with intuitive, automatic decision responding in a more cautious and controlled manner. This view has most relevance for individuals, for whom difficulties with executive function, impulse control and/or elevated anxiety, predispose them to more impulsive or hasty forms of decision responding (e.g., Hickson & Khemka, 2014).

New Directions for Research and Practice in Decision Making

In as much as individual decision-making competence exerts powerful influences on the quality of interpersonal relationships, social functioning, self-determination, and ultimately the personal agency and quality of life outcomes of people with intellectual and developmental disabilities, the continuing study of decision-making processes and the development of evidence-based approaches for improving decision-making

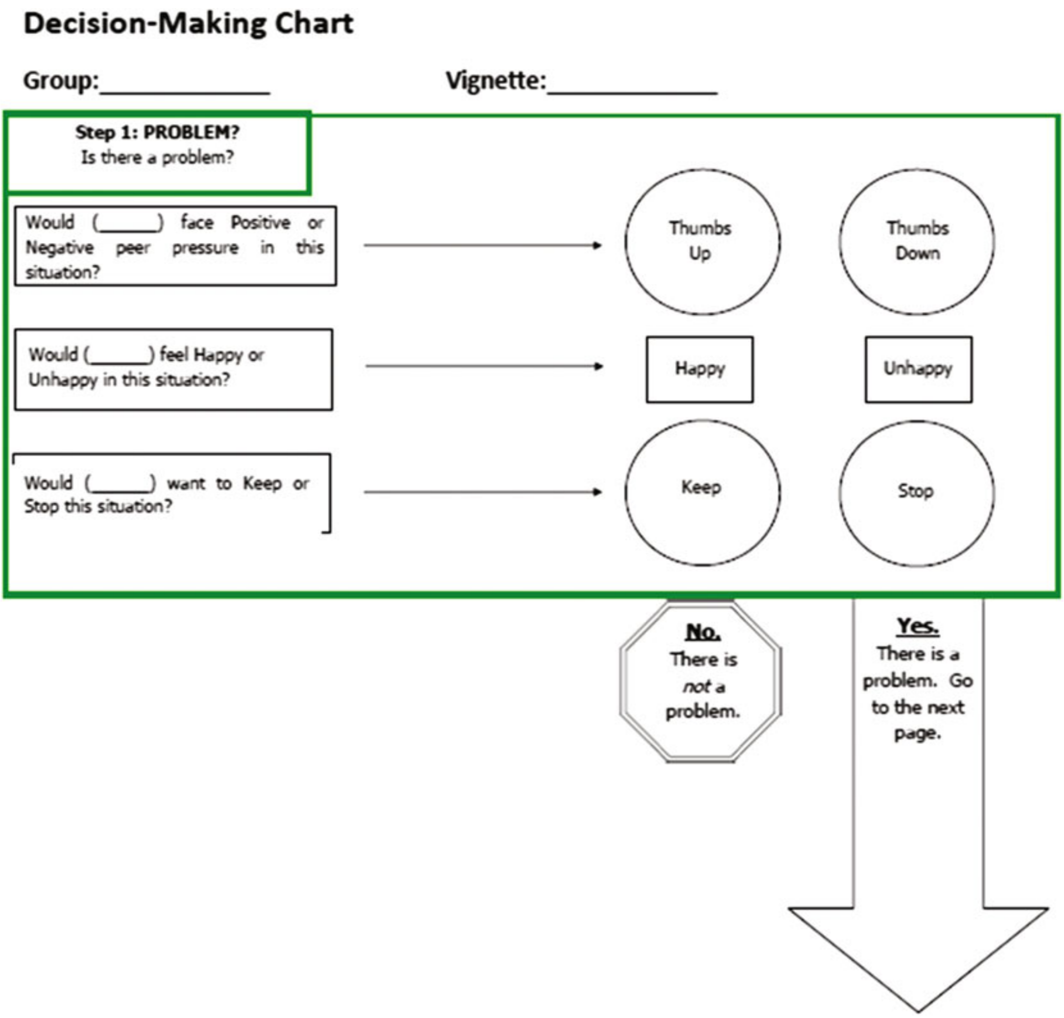

Fig. 3 Decision-making chart, Part I (Khemka & Hickson, 2013)

outcomes is a valued priority. Although much progress has been made in understanding the nature of decision-making processes for both adolescents and adults with intellectual and developmental disabilities, the field is still fairly nascent. Research evidence substantiates that across different types of decisions, the underlying mechanisms spanning cognitive (e.g., *IQ, risk perception, language functioning*), motivational (e.g., *locus of control, goal orientation*), and emotional factors (e.g., *emotion recognition, anxiety*) systematically influence decision-making performance. However, the range of these underlying mechanisms is not fully known and the extent to which these factors differentially impact different disability sub-types (e.g., *autism spectrum disorders, intellectual disability*) within the larger group of people with developmental disabilities needs to be further investigated. Growing understanding of these aspects of decision processing will provide a more informed basis for designing effective decision-making interventions, differentiated by disability- and age-specific needs and addressing the full breadth of difficulties posed by different types of decision-making situations.

The finding that motivational inputs were more important for decision making of people

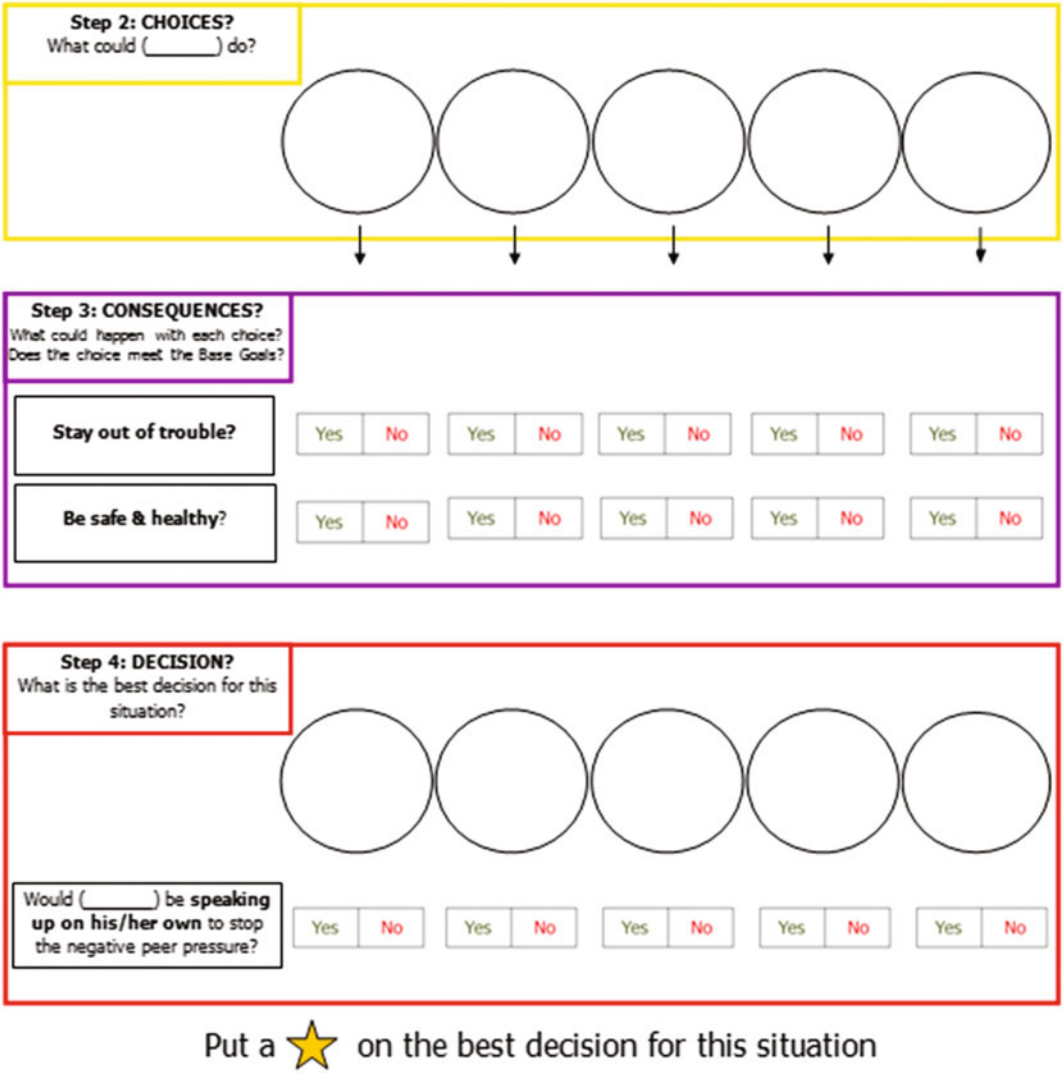

Fig. 4 Decision-making chart, Part II (Khemka & Hickson, 2013)

with autism spectrum disorders than for people without autism has important implications for the design of differentiated intervention approaches by disability type. Further, the need to develop differentiated and multifaceted interventions to address the varying patterns of functioning seen within the autism spectrum disorders population is evident. Carter et al. (2014) and Sterzing, Shattuck, Narendorf, Wagner, and Cooper (2012) have brought attention to the need for differentiation in relation to enhancing social competence through effective peer relationships and protective peer groups for adolescents with autism spectrum disorders. Given the marked differences in the social and behavioral abilities of adolescents with and without autism spectrum disorders, a broader study of cognitive, motivational, and emotional inputs to decision making behaviors is required to fully understand the complexities of decision-making behaviors by disability type and to tailor interventions to effectively improve preparedness for enhanced decision-making outcomes and social functioning.

Based on our research, it is apparent that the continued investigation of decision-making patterns will require considering the developmental and situational factors that might impinge on a decision-maker's goal preferences or their assessment of a decision situation, thereby influencing the evaluative framework used to interpret possible consequences of an option and choose a course of action. For instance, adolescents' decision making might be marked by risk-taking behaviors, more emotional charge, or undue influence of social factors, such as desire for social belonging or wanting to impress a friend, characteristic of the developmental period of adolescence. In this case, adolescents may be well aware of possible risk consequences and may possess skills for reasoned decision making, but are nevertheless likely to alter their course of decision making and make choices that serve their immediate impulses and conform to social expectations or a desire for acceptance. Simultaneously, there is growing discussion, suggesting that adolescent experience with risk taking or learning to navigate peer pressure may be adaptive developmental steps to greater self-reliance and useful social behaviors in adulthood (see Smith, Chein, & Steinberg, 2014; Steinberg, 2014). Therefore, the messages or reinforcements (reward vs. punishment) communicated to adolescents must be developmentally calibrated. Also, the potential power of positive peer pressure in helping adolescents be more persistent, less anxious, and willing to attempt greater challenges is being increasingly acknowledged (e.g., Wang, 2013). Research on normative developmental perspectives informs the priorities for decision-making training, especially for people with intellectual and developmental disabilities, who might need concerted support and rigorous instruction for specific skill learning, such as being able to anticipate risks, set personal boundaries, or communicate feelings, in comparison with their counterparts without disabilities, for whom such skills may evolve developmentally over time. Our decision-making curricula (*ESCAPE-NOW* and *PEER-DM*) encompass these perspectives and are differentiated further to address the decision-making situations and needs most relevant to the experiences of people with intellectual and developmental disabilities. Further, we are committed to keeping the curricula updated to reflect new research findings and changing environmental and social contexts, as is reflected in our added focus on studying decision making in situations of cyberbullying and expanding the dialogue of self-protective interpersonal decision making to both resisting negative peer pressure and negotiating positive peer pressure pro-socially.

Although much of our research work has focused on developing evidence-based training approaches for improving decision-making skills of people with intellectual and developmental disabilities, we recognize that people with intellectual and developmental disabilities are still often marginalized due to lack of inclusive experiences or social support in their schools or communities and that they often face limited opportunities to develop capacity and gain experience with decision making. With the emerging trend toward supported decision making for people with intellectual and developmental disabilities, opportunities to make their own important life decisions will inevitably expand and will become a key element in improved quality of life for many individuals (Kohn, Blumenthal, & Campbell, 2012). Given this trend, it is likely that our evidence-based approach for developing effective and individualized training approaches for improving interpersonal decision making can help lay the foundation for the more complex and challenging decision processing required for adult life decisions and for building the decision-making skills that will allow people with intellectual and developmental disabilities to engage in successful supported decision making.

The focus on self-actualizing goal setting leading to attainment of positive relationship-based outcomes is also supported by past research. Higgins (1997) highlighted that framing one's goals in terms of promoting positive outcomes versus preventing negative outcomes (by setting promotion versus prevention goals) helps goal attainment, as does anticipating internal versus external rewards by setting intrinsic versus extrinsic goals (see Ryan & Deci, 2001). Locke and Latham (2002, 2013) urged that goals can lead to better performance when they are stated with precision, listing specific desired future outcomes, rather than as general desired standards. In the decision-making strategies presented in *ESCAPE-NOW* and *PEER-DM*, the goals that are fostered as evaluative standards for assessing the possible consequences of choices in situations of abuse (e.g., stay safe now, stay safe later) or peer pressure (e.g., stay out of trouble, stay healthy) are scripted clearly, with the presumption that rehearsal of goal alignment with decision making will proceed automatically over time.

In conclusion, we fully support the consideration of "context" as integral to promoting outcomes for people with intellectual and developmental disabilities, in this case adaptive decision making outcomes (Shogren, 2013). Shogren (2013) described context, a necessary component of human functioning, as an integrated and diverse array of personal and environmental factors and supports, including policy, carrying formidable influence on the functioning of people with intellectual and developmental disabilities and thus amenable to manipulation in the interest of enhancing functioning and desired outcomes. Therefore, to foster attainment of valued decision-making outcomes for people with intellectual and developmental disabilities, we too argue that the interventions must occur both at the individual, personal level to build decision-making skills and at the systems level to improve opportunities and foster positive attitudes and supports in order to enable independent decision-making participation. With the rapidly evolving movement toward supported decision-making models for people with intellectual and developmental disabilities, developing a context of promoting effective decision making in interpersonal situations from an early age will be highly pragmatic and beneficial. Overall, in keeping with the tenets of positive psychology, efforts to increase understanding of decision-making processes and to bolster the decision-making competence of people with intellectual and developmental disabilities have much to contribute to the success of strength-based models of intellectual and developmental disabilities.

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Exercise, Leisure, and Physical Well-Being

12

James K. Luiselli

Introduction

Picture the following scenario: Robert, a 24-year-old man with intellectual and developmental disability, lives in a community group home with other similarly diagnosed men and attends a vocational training center in a nearby neighborhood. He has limited verbal language but communicates using a speech-generating assistive device. Robert has few interests, preferring to be alone, occasionally listening to music in the privacy of his bedroom. He is overweight, refuses to exercise, and avoids any planned physical activities with his housemates. Despite the recommendation of his primary care physician, Robert does not maintain a healthy diet and mostly consumes "junk" food throughout the day. The supervising care-providers at the group home and Robert's parents are worried about his health status, isolate behavior, and poor quality of life but have been unable to change these circumstances for many years.

Like Robert, many people who have intellectual and developmental disabilities do not exercise, have few leisure outlets, and experience physical health problems. This is an unfortunate situation because exercising regularly, engaging in leisure pursuits, and achieving physical well-being are essential determinants of a positive lifestyle. However, many individual and group-focused interventions have effectively addressed these concerns and with promising future directions (Luiselli, 2014, 2016b). This chapter describes the most effective behavioral teaching and support strategies, as gleaned from the extant literature, and demonstrated through research-to-practice translation.

Overview of Behavioral Intervention

Most behavioral practices targeting exercise, leisure, and physical well-being include objective outcome measurement through direct observation, mechanical instrumentation, or combination of both. There are also occasions in which a person with intellectual and developmental disabilities self-records one or more dependent measures. Measurement further extends to the variables that impede exercise, leisure, and physical well-being, as well as factors that may support them more desirably. This type of measurement is typically accomplished through functional behavioral assessment (FBA) and functional analysis (FA) (Neidert, Rooker, Bayles, & Miller, 2013). A third common element of intervention is implementing procedures based on assessment results. Assessment-derived intervention usually incorporates multiple methods that are matched to identified functional influences. Finally, effective intervention must consider other programmatic priorities such as care-provider training, intervention integrity,

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social validity, and post-intervention maintenance.

The intervention approaches presented in this chapter are formulated principally from the disciplines of applied behavior analysis (ABA), behavioral psychology, and social learning theory. Most behaviorally oriented research relies on single-case experimental designs to evaluate outcome and control for internal validity of programmed intervention (Barlow, Nock, & Hersen, 2009; Kazdin, 2011). Single-case research methodology also accommodates well to the heterogeneous presentation of many people with intellectual and developmental disabilities. This idiographic orientation emphasizes systematic replication of intervention effects to support the external validity of particular procedures and multiprocedural treatment plans.

Additionally, the research and practice applications represented in the chapter address treatment, risk reduction, and primary prevention efforts. Most intervention models, in fact, integrate tertiary, secondary, and primary foci to affect symptom reduction and simultaneously harness a person's strengths and abilities for achieving a more fulfilling quality of life. Notably, a concentration on secondary and primary prevention aligns favorably with principles of positive psychology.

Finally, it should be noted that some interventions in the areas of exercise, leisure, and physical well-being have been evaluated as purely therapeutic methods. For example, certain forms of exercise preceding teaching sessions have been studied as a strategy for reducing instruction-interfering responses (e.g., stereotypy), inattention, and non-compliance (Oriel, George, Peckus, & Semon, 2011; Rosenthal-Malek & Mitchell, 1997). Horseback riding, an enjoyable leisure activity, is sometimes proposed as a therapy for children who have developmental disabilities (Jenkins & DiGennaro Reed, 2013). Healthy eating to improve physical well-being also encompasses various elimination and supplementation diets purported to treat core symptoms of autism (Flood, Lynn, Mortensen, & Luiselli, 2010). However, in this chapter, interventions aimed at exercise, leisure, and physical well-being are not reviewed from the perspective of therapeutic change but instead, the positive effects on health, personal enjoyment, pursuit of happiness, and quality of life.

Research Basis for Practice

Research with typically developing children, youth, and adults has documented several behavioral intervention procedures for increasing and maintaining exercise (Normand, Dallery, & Ong, 2015). Much of this work developed direct observational instruments for coding activity levels (Brown et al., 2006; McIver, Brown, Pfeiffer, Dowda, & Pate, 2009), but also actigraphy measurement devices such as pedometers, accelerometers, and heart rate monitors (Sasaki, da Silva, da Costa, & John, 2016; Tryon, 2011). Other ABA research with typically developing populations has evaluated procedures to improve diet and consumption of healthy foods (Horne et al., 2009; Lowe, Horne, Tapper, Bowdery, & Egerton, 2004; Normand & Osborne, 2010). A third area consistent with the focus of this chapter is managing compliance with medical regimens and routinely monitoring health status—these essential components of preventive medicine and tertiary care can overcome conditions like diabetes, asthma, hypertension, and obesity (Allen & Kupzyk, 2016).

Albeit fewer in number, many of the assessment and intervention procedures directed at people who were typically developing have also been applied in intellectual and developmental disabilities to foster desirable changes in exercise, leisure, and physical well-being. The following sections describe the research base for these applications, practice implications, procedural variations, and considerations for future inquiry.

Exercise

It is widely established that routine exercise and planned physical activity confers numerous health benefits (Centers for Disease Control, 2011; Eklund et al., 2012; Yamaki, Rimmer, Lowry, & Vogel, 2011). Engaging in moderate-to-vigorous physical activity (MVPA) also has a positive effect on mood, is stress-reducing, and lessens anxiety sensitivity (Otto & Smites, 2011). However, many people with intellectual and developmental disabilities are sedentary, physically inactive, and rarely exert themselves strenuously through exercise. For example, Rimmer, Riley, Wang, Rauworth, and Jurkowski (2004) conducted a survey of "people with disabilities" and found that 56% of the sample reported having no leisure-time physical outlets. Similarly, Carroll et al. (2015) documented that among adults who had hearing, vision, cognitive, and motor disabilities, 47.1% were physically inactive compared to 26.1% of adults without disabilities.

By not exercising and being physically active, people with intellectual and developmental disabilities may develop weight, cardiovascular, and respiratory health problems (De, Small, & Bauer, 2008; Mann, Zhou, McDermott, & Poston, 2006; Peterson, Janz, & Lowe, 2008; Seekins, Traci, Bainbridge, & Humphries, 2005). Obesity, in particular, is commonly associated with physical inactivity (Bazzano et al., 2009; Curtin et al., 2013). Another important finding is that MVPA among people with intellectual and developmental disabilities may improve self-concept, cognitive functioning, and community adjustment (Gabler-Halle, Halle, & Chung, 1993; Oriel et al., 2011; Rosenthal-Malek & Mitchell, 1997). These findings argue persuasively for intensified research efforts that will identify dependable interventions and practices for promoting and sustaining exercise within a most vulnerable population.

An additional element of exercise research in intellectual and developmental disabilities concerns the social validity (acceptance and approval) of intervention objectives and outcomes. Specifically, most parents and care-providers of people with intellectual and developmental disabilities endorse procedures to increase exercise and acknowledge the many salutary effects (Glidden, Bamberger, Draheim, & Kersh, 2011; Luiselli, Woods, Keary, & Parenteau, 2013; Weiss, 2008). This level of support predicts exemplary procedural fidelity when implementing exercise interventions. That is, care-providers who approve the procedures they are requested to use are likely to implement those procedures consistently and accurately.

Understanding the challenges to routine exercise and planned physical activity is a first step toward successful remediation. Some of the barriers include persistent medical conditions in people who have IDD and family factors such as limited financial resources, social isolation, and exposure to unhealthy living conditions (Batshaw, 2002; Emerson, 2007; Scheepers, Kerr, & O'Hara, 2005). Furthermore, people with intellectual and developmental disabilities and their families often do not have access to information and guidance about the quality of life enhancement derived from exercise (Krahn, Hammond, & Turner, 2006). Environmental barriers prevalent in outdoor settings and indoor locations such as health clubs further constrain exercise participation (Rimmer, Riley, Wang, Rauworth, and Jurkowski 2004). Difficulties arise, too, when there is limited capacity to extend evidence-based methods from research-controlled settings to the natural environments in which people with intellectual and developmental disabilities receive services (Luiselli, 2016a).

Only a few publications have surveyed the types of exercise performed by people who have IDD and related neurodevelopmental disorders. Lang et al. (2010) conducted a systematic review of exercise research among children and youth with autism spectrum disorder (ASD). Sixty-one percent (61%) of studies involved jogging and running, followed by bike riding, weight training, roller-skating, swimming, and water aerobics. Also focusing on an autism spectrum disorders population, Sowa and Meulenbroek (2012) completed a meta-analysis that revealed jogging, swimming, horseback riding, weight training, and walking to be the most common types of exercise. For children with multiple disabilities receiving intervention to increase locomotor skills, Lancioni et al. (2009) found that 81% of published studies featured treadmills, with proportionately fewer programs using walkers equipped with microswitch activated sensory stimulation. Of course, the population specificity of these reviews makes it difficult to generalize findings to the larger population of people with intellectual and developmental disabilities.

Luyben, Frank, Morgan, Clark, and DeLulio (1986) published one of the first ABA studies in the area of exercise. The participants were three adults with intellectual and developmental disabilities who were taught to execute a side-of-the-foot soccer pass. A trainer followed a 9-step task analysis with each adult, implementing verbal and manual prompting, prompt-fading, praise, and verbal cues as instructional methods. This combination of procedures was effective in teaching the soccer pass in isolation—however, responding reciprocally with a peer or during team play was not evaluated in the study.

Another early ABA study, by Dowa and Dove (1980), taught swimming to three children with spina bifida (their level of cognitive functioning was not specified in the study). "Swimming behavior" was measured as the number of responses the children completed according to a 35-response rating checklist. The training methodology had them watch brief segments of swimming self-modeling videotapes which depicted increasingly superior performance. This intervention was moderately successful with all of the children.

Rogers, Hemmeter, and Wolery (2010) reported a more contemporary study of three swimming responses (flutter kick, stroking with front-crawl motion, and turning head to side) performed by three children with autism. The intervention consisted of time-delay prompting, applied progressively with each child, until they were able to demonstrate the swimming responses independently. This method of prompting allowed the children to display the swimming responses independently before guidance was initiated from an instructor.

Some exercise intervention has taken place in the context of athletic games. Cameron and Capello (1993) prepared a man with intellectual and developmental disabilities for jumping hurdles at a Special Olympics track event. He learned initially to jump over hurdles that were flat on the floor, then by clearing hurdles at gradually increasing distances from the floor, culminating in a terminal height of 12 in. After reaching this height during training sessions, he ran successfully at the Special Olympics track event. This study illustrates the highly desirable objective of minimizing and ideally eliminating response errors when instituting instructional methods with people who have intellectual and developmental disabilities (Cooper, Heron, & Heward, 2007).

Luiselli et al. (2013) also targeted Special Olympics in a study with two adult men who had intellectual and developmental disabilities. Both individuals received behavioral coaching to prepare them for a 100-m sprint event. Their running times were measured in a baseline phase, and subsequently they were exposed to intervention procedures consisting of goal setting, verbal performance feedback, positive reinforcement, and video modeling. Compared to baseline performance, the average running times of both men decreased during intervention. The most optimal findings were associated with the combination of goal setting, performance feedback, and positive reinforcement. The faster running times were maintained when the men participated in the Special Olympics track event one week following the study.

A key factor in promoting exercise, discussed in greater detail later in the chapter, is selecting convenient, inexpensive, and readily accessible options. Bike riding, as an example, is a popular form of physical activity with children and adults alike. Cameron, Shapiro, and Ansleigh (2005) intervened with a 9-year-old boy diagnosed with Asperger syndrome by having him pedal for 5 min on a stationary kinetic trainer. Once he mastered this performance objective, he was taught to pedal longer, then brake, and finally dismount. The next stage of intervention was removing the bike from the stationary kinetic trainer and having the boy ride his bike a short distance outside his home. Eventually, he was able to ride his bike independently with supervision in his neighborhood.

Like bike riding, walking is another versatile and highly adaptable form of exercise, particularly well-suited to people who have intellectual and developmental disabilities. LaLonde, MacNeill, Eversole, Ragotzy, and Poling (2014) successfully increased the number of steps five adults with ASD took during a walking activity at their day-program. During all phases of a multiple baseline design, they wore a pedometer that recorded daily step frequency. The contingencies in effect during intervention were encouraging the adults to set daily step frequency goals, reinforcing goal attainment with preferred “rewards,” and gradually increasing the step frequency goals when progress was demonstrated. All of the adults consistently increased the number of steps they took and were walking 10,000 or more steps each day by the end of the study.

The benefits of walking notwithstanding, many people with intellectual and developmental disabilities also have motor, sensory, and orthopedic impairments which impede fluent ambulation. Lancioni, Singh, O’Reilly, Sigafoos, and Oliva (2016) summarized how assistive technology devices can facilitate walking in people who have intellectual and developmental disabilities and multiple disabilities affecting motor functioning. This line of research establishes specific ambulatory routes within habilitation care settings and measures travel distance and duration under baseline and intervention conditions. With intervention, individuals wear optic microswitches on their shoes, activated when walking, and producing pleasurable sensory stimulation such as vibration, music, and lights. The step-contingent sensory stimulation functions as positive reinforcement in increasing distance and time spent ambulating (Lancioni et al., 2012, 2013, 2014). Walking as exercise can then occur spontaneously or be scheduled as a planned physical activity.

Assistive technology of another kind, exergaming, appears to be effective intervention for increasing exercise in typically developing children (Fogel, Miltenberger, Graves, & Koehler, 2010; Leiringer, Coles, & Gilbert, 2010; Shayne, Fogel, Miltenberger, & Koehler, 2012). Exergaming links a person’s physical movements to electronic video games in the context of individual and team sports. With respect to people who have IDD, Lotan, Yalon-Chamovitz, and Weiss (2009) found that a virtual reality program of game-like exercises improved physical fitness of adults with cognitive challenges. Dickinson and Place (2014) also reported improved physical fitness in children with autism who viewed and interacted with a computer-based activity program featuring Olympic events such as fencing, aquatics, rowing, archery, shooting, and gymnastics. Other research suggests that exergaming arrangements may lead to increased energy expenditure and corollary health gains in youth who have intellectual and developmental disabilities (Strahan & Elder, 2015). Persons exposed to exergaming and similar computer-assisted programs may be more motivated to exercise because the types of sensory stimulation and games can be matched to their preferences. This attribute of intervention contrasts favorably against more conventional types of exercise which people perceive as being monotonous and unappealing. Another advantage of exergaming is that it makes exercise convenient and accessible within a person’s home or other community-dwelling location.

Leisure

Leisure skills and activities enable people with intellectual and developmental disabilities to experience the pleasure from recreation, different entertainment sources (e.g., movies, music, and television), hobbies, and many other high-interest areas. Individual leisure choices themselves can be rewarding but group participation allows for peer interaction, development of social competencies, and opportunity to learn behavior-coping skills (Eratay, 2013). Group leisure events also permit people with intellectual and developmental disabilities to further develop and expand their communication abilities.

Similar to exercise, multiple responses usually comprise leisure skills, making it necessary to conduct training until a person achieves fluent performance. Most leisure skills training research has relied on conventional ABA instructional methods such as prompting, prompt-fading, and positive reinforcement. More recently, the training focus has embraced instructional media via computers and an ever-increasing array of portable platform devices (Luiselli & Fischer, 2016).

Ideally, the choice of leisure skills training objectives should be informed by a person's identified preferences relative to age, gender, and demonstrated ability. For example, before teaching leisure activity schedules to children with autism, Carlisle, Reeve, Reeve, and DeBar (2013) surveyed grade-equivalent general education students to ascertain their interest in 30 toys and leisure materials. Preference assessments of the most enjoyed items were later carried out with the children who had autism in order to confirm individual training choices. Carlisle et al. (2013) illustrates an exemplary approach to assessment by selecting leisure materials and activities that were both age-appropriate and preferred by the training recipients.

Lagomarciano, Reid, Ivancic, and Faw (1984) published one of the earliest leisure skills training programs with four adolescent young adults who had IDD. The program emphasized dancing as a leisure activity, defined as "continuous body movement in an apparent attempt to dance while music is playing" (p. 73) with additional arm and leg responses specified operationally. The researchers socially validated the skill definitions by observing the dancing behavior of same-age people who were both typically developing and had IDD (Kazdin, 1977; Wolf, 1978). Training occurred serially for leg, arm, and combined leg–arm movements using modeling, verbal feedback, error-contingent practice, and social reinforcement. To enhance generalization of the dance movements, several trainers implemented the program in different settings. As a result of training, all of the participants learned to dance and with post-training supervision danced appropriately during generalization assessments with novel peers and staff.

Video-based instruction has strong evidence support with children and adults who have developmental disabilities (Gardner & Wolfe, 2013; Wang & Koyama, 2014). The method of video prompting incorporates a device such as iPod Touch to depict task analyses of target skills. In typical format, a video demonstrates each step of the task analysis, with accompanying audio narration, serving as prompts for the person viewing the video. Additional verbal and physical prompting is provided if the video prompts alone do not occasion the task analysis steps. In one study, Edrisinha, O'Reilly, Choi, Sigafoos, and Lancioni (2011) used video prompting to teach the leisure activity of taking and printing digital pictures with four adults who had IDD. Similarly, Chan, Lambdin, Van Laarhoven, and Johnson (2013) trained an adult with IDD the skills necessary to paint pictures, listen to music, and take digital photographs via visual prompting and other guidance procedures. Once an individual acquires the trained skills, it is usually possible to fade and ultimately withdraw video prompting until it is no longer necessary to support performance.

In contrast to video prompting, video modeling shows an entire skill sequence, which a person watches, and then imitates the demonstrated responses after viewing the visual depiction (Nikopoulos, Luiselli, & Fischer, 2016). The video medium makes it possible to film a variety of skills, matched to a person's current performance level, under simulated and natural conditions. Natural setting videos are especially helpful in promoting generalization and transfer of learning. The range of leisure skills taught to people with intellectual and developmental disabilities through video modeling has been impressive, including watching movies, photography, and listening to music (Hammond, Whatley, & Gast, 2010; Kagohara, 2011; Kagohara et al., 2011). Care-providers can purchase commercially prepared products or create their own videos with camera-equipped smartphones and computer tablet devices (Allen, Vatland, Bowen, & Burke, 2015). Custom-made videos have the advantage of individualizing models and scenarios to a person's unique learning objectives.

Digital devices can also support people with intellectual and developmental disabilities in completing daily activity schedules. Carlisle et al. (2013) evaluated an iPod Touch for prompting four children with autism to perform leisure skills in their classroom. Each child was provided a device that had pictures of individually preferred leisure activities. The children learned to select from a leisure activity schedule preceding play opportunities. Following intervention, they independently followed the iPod Touch visual schedules, increased their on-task behavior, and generalized leisure activity selection to novel settings and schedules. When individuals have confirmed leisure preferences, a digitally assisted intervention showing daily schedules can maximize their exposure to and full participation in pleasurable activities. Learning to operate a digital device independently also reduces the intensity of supervision demanded from care-providers.

Yoga is a healthy leisure activity with widespread appeal in the general population (Choudhury, 2000). Various yoga poses can improve body posture, balance, and flexibility, as well as contribute to a contemplative mental state (Chong, Tsunaka, Tsang, Chan, & Cheung, 2011; Ross & Thomas, 2010; Telles, Singh, Bhardwaj, Kumar, & Balkrishna, 2013). Recently, Gruber and Poulson (2016) evaluated parent-implemented teaching of yoga to three young children with autism. During a baseline phase, the children watched a DVD of a yoga instructor performing a 24-step response chain of two yoga poses (asanas) without direct instruction from their parents. Yoga training consisted of the parents guiding the children through the poses, correcting response errors when they occurred, and reinforcing proper responding with praise and preferred items. All of the children increased independent matching of yoga responses from the DVD and in two cases demonstrated generalization to a new instructor.

Note, too, that video modeling instruction may be effective in teaching basic yoga responses to people who have intellectual and developmental disabilities, as reported in a study by Downs, Miltenberger, Biedrinski, and Witherspoon (2015) with two typically developing adults. The participants watched themselves executing yoga poses in videos and then self-rated the correct and incorrect responses they performed. One of the adults also received video performance feedback from an instructor after viewing practiced poses. The self-evaluation and performance feedback variants of video modeling were successful with both adults learning the yoga poses, although the immediate results of instruction diminished somewhat 2–5 weeks following intervention. Nonetheless, video modeling that encourages self-evaluation and can be combined with performance feedback has potential application for instructing yoga as a meaningful leisure activity for people with intellectual and developmental disabilities.

Concerning recreational activities, the trend has been toward inclusive leisure lifestyles whereby people with IDD can interact with typically developing peers and other community members (Schleien, Miller, & Shea, 2009; Schleien, Stone, & Rider, 2005). Miller, Schleien, and Lausier (2009) accounted for several factors that have encouraged and challenged inclusive service delivery (ISD) practices over the years. They noted that although many agencies have adopted evidence-supported procedures, various methods and accommodations remain highly individualized and less systematic in actual implementation. Some of the common omissions to effective service provision are as follows: (a) not completing comprehensive client assessments, (b) failing to secure adequate program resources, (c) limited environmental accommodations, (d) having to intervene with problem behavior, (e) poor recruitment of inclusion support staff, and (f) minimal on-site technical assistance. Overcoming these system-level concerns is critical to the success of recreational programming with people who have intellectual and developmental disabilities.

Physical Well-Being

There are other tertiary and preventive interventions that can enhance the physical well-being of people with intellectual and developmental disabilities beyond exercise and leisure activities.

Notably, behavioral methods have demonstrated effectiveness in treating feeding problems that compromise a person's weight, nutritional status, and caloric intake (Volkert, Patel, & Peterson, 2016). Rumination disorder, another serious condition with complicated health risks, has also been reduced and eliminated through behavioral intervention (Luiselli, 2015a). If obesity threatens a person's physical well-being, a too frequent occurrence in intellectual and developmental disabilities (Moran et al., 2005; Stancliffe et al., 2011), feeding, nutrition, and exercise interventions should be integral components of a comprehensive and multidisciplinary intervention plan (Fleming, 2011).

Getting sufficient hours of sleep and practicing proper sleep hygiene further contribute to physical well-being. Many sleep problems are evident in intellectual and developmental disabilities (Richdale & Baker, 2014), negatively affecting mood, energy level, and executive function (Stores, 2002), and posing increased health risks (Colton & Altevogt, 2006; Doran et al., 2006). Durand (2014a) and Luiselli (2016c) reviewed several ABA interventions which can improve sleep and overcome sleep-related problems in people with intellectual and developmental disabilities, specifically delayed sleep onset, night awakenings, disruptive bedtime routines, and daytime sleeping (hypersomnia). Sleep hygiene can be addressed by presenting relaxing activities at least 30 min before going to bed. A second step toward satisfying sleep is eliminating sleep-interfering stimulation in the bedroom (e.g., noise, light, uncomfortable temperature). Other practical guidelines are restricting caffeine consumption in the evening and establishing consistent bedtime–wake up schedules. A systematic, practitioner friendly guide to behavioral sleep intervention can be found in Durand (2014b).

Substance use is not uncommon in people with IDD despite unsystematic screening–assessment practices and limited evidence-based treatment research (Didden, VanDerNagel, & van Duijvenboda, 2016). Nonetheless, service professionals are encouraged to study the risk factors for developing addictive behavior, design outpatient and inpatient treatment programs, and secure relapse prevention aftercare alternatives. Noteworthy in the area of addiction research, Singh et al. (2013) described a mindfulness-based smoking cessation program with three men who had mild intellectual and developmental disabilities and smoked between 14 and 35 cigarettes daily. The program integrated mindfulness intention, mindfulness observation of thoughts, and meditation practices. At the conclusion of intervention and one year later, the men had abstained from smoking. Singh et al. (2014) extended this line of research by comparing a mindfulness treatment protocol administered with 25 men who had mild intellectual and developmental disabilities (average smoking history = 15 years) with a treatment-as-usual group of 26 men who had mild intellectual and developmental disabilities (average smoking history = 17.2 years). A significant number of the mindfulness treatment group participants stopped smoking whether they completed or dropped out of the study and one-year post-intervention.

Mattson, Roth, and Sevlever (2016) reviewed the contribution of personal hygiene to physical well-being, highlighting grooming, menstrual care, and preventive oral practices (tooth brushing, flossing, dental checkups). They noted that "with respect to behavioral health, establishment of personal hygiene skills leads to an improved quality of life, improved medical outcomes for an individual, and reduction in disease incidence" (p. 43). Many ABA-styled programs have taught personal hygiene skills with different prompting methods, video modeling, self-monitoring, picture cues, and positive reinforcement (Anderson, Jablonski, Thomeer, & Knapp, 2007). Two programmatic priorities are transferring personal hygiene skills training from simulated to natural conditions, and promoting the highest level of independent responding possible.

Further impact on the physical well-being of people with intellectual and developmental disabilities comes from establishing compliance with medical routines. However, many individuals fear medical procedures and resist well-care visits that can identify and treat minor illnesses and potentially greater threats to physical health (Allen & Kupzyk, 2016). The most effective behavioral interventions for compliance problems combine graduated exposure to fear-provoking stimuli, response shaping, modeling, and positive reinforcement. Research supports this integrative treatment model for desensitizing people with intellectual and developmental disabilities to tolerate physical examinations (Cavalari, DuBard, Luiselli, & Birtwell, 2013; Gillis, Hammond, Lockshin, & Romanczyk, 2009), blood draws (Cromartie, Flood, & Luiselli, 2014; Grider, Luiselli, & Turcotte-Shamski, 2012), immunizations (Wolf & Symons, 2012), and dental cleanings (Conyers et al. 2004). Compliance with explicit medical treatments has also been trained with these same procedures (Allen & Hine, 2015).

Practice and Research Directions

It is encouraging that many of the intervention procedures reviewed in this chapter were evaluated in naturalistic settings that deliver services to people who have intellectual and developmental disabilities. Research-to-practice translation allows for dissemination of evidence-based methods to care-providers, schools, organizations, and families. These high-quality practices targeting exercise, leisure, and physical well-being must be empirically supported to gain acceptance by practitioners in "real-world" settings. There are other considerations about the implementation efficiency of recommended procedures, intervention integrity, social validity, and factors contributing to a personally fulfilling lifestyle.

In natural settings, such as schools, human services organizations, community agencies, and homes, teachers, direct-care staff, instructional assistants, and parents are typically the care-providers responsible for implementing intervention procedures. Care-provider training has been a productive area in ABA (Lerman, LeBlanc, & Valentino, 2015; Luiselli, 2011, 2015b) and applicable to the procedural demands necessary for improving exercise, leisure skills, and physical well-being. The most effective methodology is conducted in vivo and directed at observable performance according to a competency-based and behavioral skills training (BST) model (Luiselli, 2015b; Parsons, Rollyson, & Reid, 2013; Reid, Parsons, & Green, 2012). Thus, in training personnel to apply an after-school exercise enrichment program with students who have IDD, care-providers would first be taught the steps comprising the program through didactic instruction, demonstration, role-playing, and simulated practice. This preliminary training is followed by observing care-providers interacting with service recipients. The trainer conducting observation delivers feedback to the care-providers about their performance using modeling, guided practice, reinforcement of skill accuracy, and error correction. Training must be intensive enough to establish competent performance by care-providers, then gradually faded with periodic monitoring to promote maintenance over time.

Care-provider training, by itself, is not sufficient unless there is complimentary assessment of intervention integrity (Sanetti & Kratochwill, 2014). Integrity measurement evaluates whether care-providers implement procedures accurately, as defined in a written plan, and consistent with expected performance criteria. Similar to the format of in vivo training, intervention integrity assessment requires a professional to observe care-providers applying procedures, document procedural fidelity, and reinforce-correct implementation accuracy and errors, respectively. For example, to measure intervention integrity in the Chan et al. (2013) study that taught leisure skills via video modeling, "an observer noted the instructor's completion of components of the intervention (i.e., gaining the participant's attention, showing the videos, allowing time to respond, systematically providing extra prompts, and ending the activity" (p. 415) during approximately 50% of intervention sessions. When intervention integrity is less than desirable (below 85% accuracy), the intervention components responsible for misapplication must be re-trained to the performance criteria required for intervention success.

Several of the studies presented in this chapter illustrated the process of social validity assessment of exercise and leisure skills intervention. LeLonde et al. (2014) asked service recipients whether they liked or disliked wearing a pedometer to measure walking distance and if they would want to wear it and set walking goals in the coming year. Social validation in this study further requested the program instructor to rate the acceptability and effectiveness of intervention. Gruber and Poulson (2016) had parents complete a survey based on a 7-point Likert-type scale (7 = completely satisfied and 1 = completely dissatisfied) to ascertain satisfaction with their child's enjoyment of yoga and learning yoga as a new skill. A meaningful finding from social validity assessment research is that acceptance of and satisfaction with intervention objectives, procedures, and results by care-providers appear to be a good indication of procedural fidelity and therapeutic maintenance (Kennedy, 2000).

Chan et al. (2013) suggested another measure of social validity through direct observation of people's activity engagement and enjoyment. Describing an adult with IDD who acquired new leisure skills, they wrote, "he frequently smiled and laughed when he had the opportunity to take pictures" and "he also appeared to enjoy looking at pictures on the iPod and often browsed through old pictures stored in the device" (p. 418). Various objectively defined and recorded indices of happiness such as smiling, laughing, initiating motor responses, and activating sources of sensory stimulation are noteworthy social validity measures. These measures are especially valid for people who have severe-profound IDD and are unable to conventionally express pleasure and satisfaction from exercising, being physically active, and participating in leisure events (Lancioni et al., 2005, 2007).

A preliminary step in motivating and reinforcing people with intellectual and developmental disabilities to engage in exercise and other health promoting interactions is formally assessing their preferences (Tiger & Kliebert, 2011). As reviewed previously, exergaming can increase MVPA by having a person play virtual sports that might otherwise be inaccessible. Exergaming and similar modalities also make physical and leisure activities convenient, a factor that correlates highly with exercise compliance and maintenance (Brawley, Rejeski, & King, 2003). For individuals who enjoy social attention, group-oriented activities would be the optimal venue. Finally, in research conducted with typically developing children, Normand and colleagues (Hustyi, Normand, Larson, & Morley, 2012; Larson, Normand, Morley, & Hustyi, 2014) found that simply providing access to certain types of fixed equipment (e.g., slides, monkey bars, stairs) can increase physical activity. Another contextually effective intervention was strategically planning interactive play with contingent attention from adults. Increased physical activity was also occasioned by having children play in groups instead of playing alone. By virtue of implementation efficiency, these and similar methods should be evaluated with people who have intellectual and developmental disabilities. A further benefit from low-demand interventions of this kind is high social validity among care-providers.

All of the intervention objectives outlined in this chapter have been aided demonstrably by the emergence and continued refinement of assistive and telehealth technologies (Luiselli & Fischer, 2016; McKay, Przeworski, & O'Neill, 2016). To reiterate, assistive devices permit automatic tallying of exercise and physical activity responses (e.g., steps taken, distance travelled, energy expenditure), prompt leisure participation, and model skills that can be acquired via imitative learning. Many computer-based and internet-sources applications enable intervention to be conducted remotely, adapted to personal lifestyles, economized to scale, and evaluated through instantaneous data recording, summary, and visual display. For people with intellectual and developmental disabilities, technology-focused intervention represents one of the most promising approaches in the areas of exercise, leisure, and physical well-being. Among many influences on the maximum utility of assistive technology, service professionals must consider the financial costs of devices and instrumentation, care-provider training, systems support, operations troubleshooting, and maintaining intervention integrity without direct supervision.

The success of behavioral intervention notwithstanding, there are many large-scale issues that impact feasibility of program implementation in natural settings. For one, settings must have the financial resources to hire care-providers, train them accordingly, purchase materials, and as is often the case, retain psychologists and other behavior specialists in a consultation role (Guion, Olufs, & Freeman, 2016). Increased public funding to service agencies remains a priority in line with policy initiatives and standards advancing health and wellness guidelines devoted to people with IDD (U.S. Public Health Services, 2002; U.S. Department of Health and Human Services, 2005). The population of behaviorally trained psychologists and related intellectual and developmental disabilities professionals must certainly increase to adequately serve the many needs of children, youth, and adults.

Prevention is one of the common attributes linking ABA and positive psychology, as evident by antecedent interventions that arrange environmental conditions and numerous prompting strategies which encourage exercise, leisure participation, and behaviors contributing to physical well-being. Competency-based objectives are similarly congruent between ABA and positive psychology—the goal is to teach people with intellectual and developmental disabilities the skills necessary to function successfully in all facets of living. Both ABA and positive psychology embrace the opinions of service recipients and care-providers when evaluating the outcomes from intervention. These stakeholder perspectives broaden the determinants of program success. Socially responsive evaluation further measures the "fit" between recommended practices and the lifestyles, resources, desires, and cultural values of people in need of services.

Commenting on the health advancements achieved with ABA intervention, Allen and Kupzyk (2016) cautioned that, "While this approach is highly valued within a natural science of behavior, interventions that are highly individualized do not lend themselves to wide dissemination or adoption, even within applied behavior analysis and certainly not within medical/dental clinics where these problems are typically first encountered" (p. 38). Therefore, behavioral psychology professionals must be able to interact collaboratively with multidisciplinary colleagues in many service, primary care, and health settings. In summary, positive psychology that embraces contemporary ABA concepts and methodologies will contribute to the discipline-shared goals of translating research findings to effective practices for establishing and sustaining exercise, leisure skills, and physical well-being in the lives of people with intellectual and developmental disabilities.

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Character Strengths

13

Karrie A. Shogren, Ryan M. Niemiec, Dan Tomasulo
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Character Strengths

The field of positive psychology emerged as an initiative to better understand optimal human functioning, emphasizing positive emotions, positive traits, positive relationships, and positive institutions, rather than negative aspects of functioning (Lopez & Snyder, 2011; Seligman & Csikszentmihalyi, 2000). Positive psychology does not replace traditional psychology, rather it complements deficit-based approaches, offering science to inform, reframe, and/or improve traditional psychological approaches. One area within positive psychology that has received significant attention has been the identification and leveraging of character strengths and virtues (Peterson & Seligman, 2004). Character strengths are understood to be positive, trait-like capacities that benefit oneself and others (Niemiec, 2014) and are "shown in feelings, thoughts, and actions" (Park & Peterson, 2009, p. 3). Each person has a unique constellation of character strengths that vary in degree based on the context. While it is assumed that character strengths are universal across cultures and found in every person, each person has a unique profile of character strengths. The assessment of character strengths is a useful and meaningful endeavor, and assessment data can be used to guide interventions and supports that are individualized to each person's specific profile of character strengths.

Researchers in the field of character strengths engaged in a systematic process, over a three-year period, of identifying character strengths and virtues valued across nations, cultures, and beliefs. This resulted in the VIA *Classification of Character Strengths and Virtues* (Peterson & Seligman, 2004). The VIA Classification defined 24 character strengths that met various inclusion criteria, such as each had to be ubiquitous across cultures, measureable, personally fulfilling, trait-like, and when expressed could not diminish others, to name a few criteria. These are organized under six overarching virtues (i.e., wisdom, courage, humanity, justice, temperance, and transcendence), which are core characteristics of humans that have been valued by the world religions, by moral philosophers, and by leading virtue thinkers throughout the centuries. Table 13.1 provides this VIA Classification structure and the concepts related to each character strength and virtue.

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Table 13.1 VIA classification of character strengths and virtues

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Wisdom—cognitive strengths that entail the acquisition and use of knowledge
• **Creativity** [originality, ingenuity]: thinking of novel and productive ways to conceptualize and do things; includes artistic achievement but is not limited to it
• **Curiosity** [interest, novelty seeking, openness to experience]: taking an interest in ongoing experience for its own sake; finding subjects and topics fascinating; exploring and discovering
• **Judgment** [open-mindedness; critical thinking]: thinking things through and examining them from all sides; not jumping to conclusions; being able to change one's mind in light of evidence; weighing all evidence fairly
• **Love of learning**: Mastering new skills, topics, and bodies of knowledge, whether on one's own or formally; related to the strength of curiosity but goes beyond it to describe the tendency to add systematically to what one knows
• **Perspective** [wisdom]: Being able to provide wise counsel to others; having ways of looking at the world that make sense to oneself/others
Courage—emotional strengths that involve the exercise of will to accomplish goals in the face of opposition, external or internal
• **Bravery** [valor]: Not shrinking from threat, challenge, difficulty, or pain; speaking up for what's right even if there's opposition; acting on convictions even if unpopular; includes physical bravery but is not limited to it
• **Perseverance** [persistence, industriousness]: Finishing what one starts; persevering in a course of action in spite of obstacles; "getting it out the door"; taking pleasure in completing tasks
• **Honesty** [authenticity, integrity]: Speaking the truth but more broadly presenting oneself in a genuine way and acting in a sincere way; being without pretense; taking responsibility for one's feelings and actions
• **Zest** [vitality, enthusiasm, vigor, energy]: Approaching life with excitement and energy; not doing things halfway or halfheartedly; living life as an adventure; feeling alive and activated
Humanity—interpersonal strengths that involve tending and befriending others
• **Love** (capacity to love and be loved): Valuing close relations with others, in particular those in which sharing and caring are reciprocated; being close to people **Kindness** [generosity, nurturance, care, compassion, altruistic love, "niceness"]: doing favors and good deeds for others; helping them; taking care of them
• **Social intelligence** [emotional intelligence, personal intelligence]: being aware of the motives/feelings of others and oneself; knowing what to do to fit into different social situations; knowing what makes other people tick
Justice—civic strengths that underlie healthy community life
• **Teamwork** [citizenship, social responsibility, loyalty]: Working well as a member of a group or team; being loyal to the group; doing one's share
• **Fairness**: Treating all people the same according to notions of fairness and justice; not letting feelings bias decisions about others; giving everyone a fair chance
• **Leadership**: Encouraging a group of which one is a member to get things done and at the same time maintain good relations within the group; organizing group activities and seeing that they happen
Temperance—strengths that protect against excess
• **Forgiveness** [mercy]: Forgiving those who have done wrong; accepting others' shortcomings; giving people a second chance; not being vengeful
• **Humility** [modesty]: Letting one's accomplishments speak for themselves; not regarding oneself as more special than one is
• **Prudence**: Being careful about one's choices; not taking undue risks; not saying or doing things that might later be regretted
• **Self-regulation** [self-control]: Regulating what one feels and does; being disciplined; controlling one's appetites and emotions

(continued)

Table 13.1 (continued)

Transcendence—strengths that forge connections to the universe and provide meaning
• **Appreciation of beauty and excellence** [awe, wonder, elevation]: Noticing and appreciating beauty, excellence, and/or skilled performance in various domains of life, from nature to art to mathematics to science to everyday experience
• **Gratitude**: Being aware of and thankful for the good things that happen; taking time to express thanks
• **Hope** [optimism, future-mindedness, future orientation]: Expecting the best in the future and working to achieve it; believing that a good future is something that can be brought about
• **Humor** [playfulness]: Liking to laugh and tease; bringing smiles to other people; seeing the light side; making (not necessarily telling) jokes
• **Spirituality** [religiousness, faith, purpose]: Having coherent beliefs about the higher purpose and meaning of the universe; knowing where one fits within the larger scheme; having beliefs about the meaning of life that shape conduct and provide comfort

VIA Classification of Strengths

The 24 character strengths and the six virtues described by the VIA Classification provide a complement to traditional classification systems for deficits used in the psychology field, such as the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (*DSM-5*; American Psychiatric Association, 2013) and the *Diagnostic Manual-Intellectual Disability* (Fletcher et al., 2007), an evidence-based manual that helps to improve the accuracy of diagnosing people with intellectual disability and to ensure psychiatric conditions are not overshadowed and left untreated (Griffiths et al., 2002; Reiss, Levitan, & Szyszko, 1982). Since its introduction, the VIA Classification of Strengths has been extensively studied, amounting to hundreds of peer-reviewed publications in a short time period (Niemiec, 2013; VIA Institute, 2016), and researchers have suggested that the nomenclature and classification system has applicability across time and cultures (Biswas-Diener, 2006; Dahlsgaard, Peterson, & Seligman, 2005). Additionally, assessments have been developed that allow for the identification of character strengths in youth and adults.

VIA Inventory of Strengths (VIA-IS)

The VIA *Inventory of Strengths* (VIA-IS; Peterson & Seligman, 2004) was developed to align with the VIA Classification System and assesses the 24 character strengths and six virtues described in Table 13.1. The scale was developed for self-report by adults ages 18 and over. When completing the scale, people rate a series of items on a 5-point Likert scale (1 = very much like me; 2 = mostly like me; 3 = somewhat like me; 4 = a little like me; and 5 = very much unlike me). Sample items include the following: "I find the world a very interesting place" (Curiosity); "I am aware of my own feelings and motives" (Social Intelligence); "I always speak up in protest when I hear someone say mean things" (Bravery); and "When I look at my life, I find many things to be grateful for" (Gratitude). The original version of the scale consists of 240 items, but two shorter versions, the VIA-120 and the VIA-72, with the best items from each of the character strength domains that maintained adequate validity have also been created (Littman-Ovadia, 2015). Researchers have found that scores on the long and short versions of the VIA-IS have adequate reliability with adult populations in the USA (McGrath, 2014; VIA Institute on Character, n.d.). The VIA-IS has also been translated into 32 languages, including Danish, Dutch, French, Italian, Japanese, Portuguese, Brazilian Portuguese, Spanish, Swedish, Turkish, simplified Chinese, and traditional Chinese (McGrath, in press) and has been shown to have strong measurement properties across cultures (Littman-Ovadia & Lavy, 2012; Ruch, Weber, Park, & Peterson, 2014; Singh & Choubisa, 2010).

Ongoing research, however, continues to look at the best way to understand character strengths and virtues. For example, several researchers have found that the character strengths tend to be highly related (Brdar & Kashdan, 2010; Haslam, Bain, & Neal, 2004; Littman-Ovadia & Lavy, 2012; Macdonald, Bore, & Munro, 2008; Peterson, Park, Pole, D'Andrea, & Seligman, 2008; Ruch et al., 2010; Shryack, Steger, Krueger, & Kallie, 2010; Singh & Choubisa, 2010), suggesting there may be different ways to understand and define the virtues and the character strengths that align with them. For example, researchers have suggested that rather than the original six virtues of wisdom, courage, humanity, justice, temperance, and transcendence, there might be alternative virtue groups, such as interpersonal or sociability strengths, or intellectual or cognitive strengths (Peterson et al., 2008; Shryack et al., 2010).

VIA-Youth

The VIA *Inventory of Strengths for Youth* (VIA-Youth; Park & Peterson, 2006b) was created to allow for the assessment of character strengths based on the VIA Classification in adolescents and youth ages 10–17 years. The assessment is a modified version of the VIA-IS, with changes made to items to make them for age appropriate for youth of these ages. The same character strengths are assessed, just in ways that are relevant to youth and the settings and situations most familiar to them. Modified items were reviewed by youth, teachers, and parents (Steen, Kachorek, & Peterson, 2003). The original VIA-Youth included 198 items, but a short form (96 items) was created to promote usability. Both the long and short version have good reliability (VIA Institute on Character, n.d.). Researchers have shown the tool could be effectively used with US (Park & Peterson, 2006b) and South African youth (van Eeden, Wissing, Dreyer, Park, & Peterson, 2008), and that teacher's ratings of students strengths are correlated with youth ratings (Macdonald et al., 2008; Park & Peterson, 2006a). Assessing character strengths provides unique information, and when youth highly endorse character strengths, this predicts various positive outcomes, including academic achievement and social skills (Macdonald et al., 2008; Weber, Wagner, & Ruch, 2014) as well as well-being and happiness (Toner, Haslam, Robinson, & Williams, 2012).

As discussed subsequently, research has begun to explore the application of the VIA-Youth with adolescents with disabilities, including adolescents with intellectual disability. Before over viewing that work, however, it is worth looking at what one might do with assessment information on character strengths. Having valid and reliable measures of character strengths provides a means through which people with and without disabilities and people who support them can understand the strengths and virtues that people feel reflect them, and this information can then be used to build on each person's strengths, using interventions such as those described in the following sections.

Interventions to Enhance Character Strengths

As briefly described in the previous section, understanding the character strengths that people demonstrate can lead to the development of interventions and supports that build on those strengths. Existing research suggests the importance of building on strengths. Multiple positive outcomes are predicted by character strengths (Harzer & Ruch, 2014; Vertilo & Gibson, 2014; Weber et al., 2014), suggesting that efforts to enhance strengths have the potential to promote more positive outcomes. For example, temperance and perseverance have been found to predict academic achievement, and hope and zest predict well-being (Park & Peterson, 2006b; Park, Peterson, & Seligman, 2004).

Strengths-Spotting

Strengths-spotting involves at least two steps: (1) Look for and label a character strength in oneself or others, and (2) offer a rationale/behavioral evidence for the character strength that is being displayed. Strengths-spotting is a skill that can be cultivated by anyone, including people with disabilities. Research has supported strengths-spotting of children by parents, finding that parents identify numerous character strengths in their children with intellectual disability and/or autism across multiple domains of life, and the strengths were predicted by greater involvement in community activities (Carter et al., 2015).

As is true for all people, additional support is sometimes helpful with strengths-spotting practices for people with disabilities. Examples include the use of a VIA Classification grid (e.g., a user-friendly list with definitions of the 24 character strengths), question prompts (e.g., “Which of these best describes who you are?”), and structured discussions/activities (e.g., “Tell me a story of something good that you did recently” followed by “What character strengths were in that story?”). Pairing the strengths with valued activities such as watching movies, reading, playing video games, doing artwork, or playing a sport is helpful to the integration of learning (Niemiec & Wedding, 2014) (e.g., “What are the highest strengths of Anna in *Frozen*?” or “What character strengths did you use, while you were playing basketball today?”). Strengths-spotting is a key starting point for supporting people to understand and develop “a common language of strengths” and is the precursor for strengths use as well as the development of a “strengths mindset” (Niemiec, 2014).

Promoting Signature Strengths

One of the strongest findings in all of positive psychology is that a person’s signature strengths—those qualities that are most core to who they are—are of extreme importance, as they are related to personal identity, performance, and various outcomes. One commonly used intervention that has been shown to have high impact in people’s lives is called “use your signature strengths in new ways each day.” In this intervention, people choose one of their signature strengths that emerged high in their VIA Survey profile (the results of the assessment); then, they are asked to use that signature strength in a new way each day. For example, a person who has Curiosity as a signature strength might use that to explore a new Web site one day and try a new food the next day. A person with a signature strength in Social Intelligence might approach someone new at work and ask them a couple of questions. A person high in Kindness might offer to give a friend a ride home one day and then bring his or her coworker a coffee the next day. This intervention has been used with various groups, including youth (Madden, Green, & Grant, 2011), older adults (Proyer, Gander, Wellenzohn, & Ruch, 2014), employees (Forest et al., 2012), and people with traumatic brain injuries (Andrewes, Walker, & O’Neill, 2014). It has also been used across cultures (Duan, Ho, Tang, Li, & Zhang, 2013; Mitchell, Stanimirovic, Klein, & Vella-Brodrick, 2009; Mongrain & Anselmo-Matthews, 2012). In each circumstance, positive outcomes have been found that last beyond the week that is the target of the intervention, and in some cases, the benefits to increased happiness and reduced depression last for six months (Gander et al., 2012; Seligman et al., 2005).

Using Character Strengths to Promote Other Strengths

If you ask 100 practitioners whether or not they are “strengths-based,” it is not uncommon to see 100 hands rise up. But, there will be 100 different definitions for what it means to be strengths-based and what a strength is in the first place. Indeed, human beings have many different kinds of strengths. Niemiec (2014) has outlined several types, including talents (i.e., hardwired abilities such as spatial intelligence and mathematical-logical intelligence); skills (i.e., proficiencies people develop such as typing or painting houses); interests (i.e., passions people are pulled toward such as artwork and playing sports); and resources (i.e., external strengths that support people such as having a caring family, good friends, and living in a safe neighborhood). It is the character strengths that drive the other strengths categories and offer pathways for developing or tapping into skills, talents, resources, and interests. How can a person who has a musical talent not tap into their character strengths of self-regulation and perseverance? How could a person make use of their resource of a spiritual community without using their character strengths of hope, spirituality, and gratitude? Unfortunately, there has been a disconnect in the disability field between character strengths and other strengths. Research, education planning (e.g., IEPs), and support programs have largely focused on building skills, interests, and resources for individuals with disability and given far less attention to strengths that reveal who the individual is at their core—their character strengths. Recently, researchers asked parents of children with intellectual disability and/or autism to name their child's strengths, and overwhelmingly the responses from the parents fell within the domain of character strengths with less focus on the child's skills, interests, and so forth (Carter et al., 2015).

Therefore, we argue for the conversation to shift—not just from disability to ability (deficit-based to strengths-based)—but to shift from generic strengths to character strengths. This does not mean to replace the development of strengths in other categories, but to include and give priority to who the individual is at their core. Practitioners can take action by assessing character strengths, asking questions about the person's character strengths, merging curriculum in schools with character strengths, training parents/support providers/medical teams to discuss character strengths with people, and offer activities and interventions designed to boost or unleash the person's signature strengths.

Aware-Explore-Apply Model

There are a multitude of strengths-based approaches and models that practitioners use and tailor to their population, discipline, and/or theoretical orientation. A character strengths-based model that reflects most of these while reflecting the core features of what practitioners are ultimately doing when they take a strengths approach is the Aware-Explore-Apply model (Niemiec, 2013, 2014). This three-phase model is intentionally simple and practical. The Aware phase focuses on supporting general awareness of character strengths, making sure people can engage in strengths-spotting, begin to develop their character strengths fluency (i.e., their vocabulary related to the 24 character strengths), and ensuring that barriers to understanding strengths are addressed. The second phase, Explore, promotes linkages between character strengths, previous experiences, and valued outcomes to enable people to see how they have used their character strengths at the best and worst of times and to understand that character strengths offer pathways to improved happiness, relationship, and achievement in their future. The person is supported to explore how to use character strengths in everyday life, from task to task, and from conversation to conversation. Finally, in Apply, the person learns to focus on taking action using character strengths and implementing strategies to reach personal or professional goals. These phases build on each other and are part of a cycle of growth, development, and growing awareness and action (e.g., Fredrickson, 1998).

Research and Practice with People with Intellectual and Development Disabilities

The field of positive psychology and the application of constructs associated with positive psychology, such as character strengths, has typically focused on the general population. However, researchers have clearly noted the potential of assessment and intervention to promote character strengths in the lives of people with intellectual and developmental disabilities (Dykens, 2005; Groden, Kantor, Woodard, & Lipsitt, 2011a; Niemiec, Shogren, & Wehmeyer, in press). For example, Dykens (2005) suggested the need for strengths-based models that address character strengths to better understand the experiences and outcomes of families and siblings of people with intellectual disability. Groden et al. (2011b) suggested that people with autism spectrum disorders, if supported to do so, can enhance their character strengths and experience more positive outcomes. Niemiec et al. (in press) suggested ways that character strength interventions could be used in the lives of people with intellectual disability. Each of these authors highlighted the potential for more research and intervention development that focuses on assessing and building on character strengths to enhance outcomes for people with intellectual and developmental disabilities and those that support them.

Assessing Character Strengths

While the VIA-IS and VIA-Youth were developed in the general population, researchers have begun to explore the application of the VIA-Youth with adolescents with disabilities, including adolescents with intellectual disability. Findings suggest that the scale has similar reliability and validity in youth with disabilities, although youth with disabilities, particularly intellectual disability, tend to rate themselves lower in their strengths than their peers without disabilities (Shogren, Wehmeyer, Lang, & Niemiec, 2016; Shogren, Shaw, Khamsi, Wehmeyer & Niemiec, 2016). This suggests the need for interventions such as strengths-spotting and Aware-Explore-Apply with this group of students, particularly as it is widely acknowledged that assessment in this population tends to focus more on deficit and remediation, rather than building on strengths (Epstein, Synhorst, Cress, & Allen, 2009). To support youth with intellectual disability to complete the VIA-Youth, Shogren, Wehmeyer, Forber-Pratt, and Palmer (2015) developed a resource that lists accommodations and supports that can be provided during administration to promote the reliability of the scale, but enable people with intellectual disability to communicate their perceptions of their character strengths.

Other researchers have developed proxy report measures of strengths that can be completed by parents, teachers, or others that know the person with a disability well. The Assessment Scale for Positive Character Traits-Developmental Disabilities (ASPeCT-DD; Woodard, 2009) was developed to assess 10 character strengths and predated the VIA Classification System. However, it has been shown to be a valid way of engaging others in understanding and thinking about the strengths of people with disabilities. Using both self- and proxy reports can be an effective way to enable all members of a support team to orient themselves toward strengths, changing the emphasis on deficits that often dominates assessment activities.

The Interactive Behavioral Therapy Approach

Identifying and encouraging character strengths gives practitioners such as treatment facilitators new tools in supporting sustainable changes. In one model, interactive behavioral therapy (IBT), a group format is used, which has been specifically developed for people with intellectual disability and concomitant psychiatric disorders. IBT is an evidence-based psychotherapy developed more than 25 years ago with techniques drawn from components of many therapeutic interventions, but chiefly from Moreno's psychodrama (Blatner & Blatner, 1988; Razza & Tomasulo, 2005), the work of Yalom and Leszcz (2005), and more recently from positive psychotherapy (Rashid, 2015; Seligman, Rashid, & Parks, 2006). IBT has been the subject of a number of studies (e.g., Daniels, 1998) and the emphasis of the APA's first book on psychotherapy for people with IDs (Razza & Tomasulo, 2005).

The model was fashioned around the activation of therapeutic factors originally identified by Yalom and Leszcz (2005), as these elements were the standards in group therapy outcome studies. Therapeutic factors are those features that have therapeutic value for members in a group and are identified as acceptance/cohesion, universality, altruism, instillation of hope, guidance, vicarious learning/modeling, catharsis, imparting of information, self-disclosure, self-understanding, interpersonal learning, corrective recapitulation of the primary family, development of socializing techniques, and existential factors. Initially, IBT facilitators were trained on what to look for when a therapeutic factor emerged and how to identify and support its occurrence (Razza & Tomasulo, 2005). However, more recently, facilitators have also been trained to spot the presence of character strengths (Tomasulo, 2014). This addition of character strength-spotting by facilitators builds on the work by Fluckiger et al. (2008). They have developed a procedure, resource priming, where the facilitators of psychotherapy take a few minutes before their session to focus on the strengths of their individual client. Priming leads to resource activation where group participants focus on the positive perspective of their behavior. In people without intellectual disability, this leads to better progress in therapy as measured by a reduction in symptoms and higher levels of well-being. By using this technique and adding strengths-spotting to the recognition of therapeutic factors, the IBT model is expanding the ways in which therapeutic changes can be facilitated (Tomasulo, 2014).

Tomasulo (2014) offered an adaptation of the traditional use of the gratitude visit (Seligman et al., 2005) in which participants wrote and delivered a letter of gratitude to a person they felt they had not properly thanked. However, this powerful method as originally researched requires the users be able to read and write to take advantage of its effectiveness. In the IBT model, it has been modified for people unable to read and write by making the gratitude visit virtual through a role-playing exercise within the group. The use of role playing has many advantages for people with intellectual disability because it enhances the engagement of the members while activating more of the senses (Tomasulo & Razza, 2006).

Within the IBT format, the virtual gratitude visit (VGV) has also been used effectively to enable people with intellectual disability to express the character strength of gratitude to those people who may no longer be accessible to the person because they have moved, passed away, or toward someone unknown, such as a stranger who was kind. In this exercise, the protagonist expresses his or her gratitude for the person symbolized by the empty chair. Following this, the protagonist reverses roles and becomes the person they are expressing gratitude toward. By role, reversing the person responds as if the gratitude had just been expressed to him or her. Then, the protagonist returns to his or her original chair and responds (Tomasulo, 2014).

Conclusions

Further work is needed, in research and in practice, documenting the use and the impact of the character strengths interventions described in previous sections with people with intellectual and developmental disabilities. However, there is every reason to believe, particularly given the lower endorsement of strengths in adolescents with disabilities, that strengths-spotting, the promotion of signature strengths, and the Aware-Explore-Apply model can potentially increase awareness of strengths and lead to more positive outcomes for young people with disabilities. Signature strengths interventions have been used with other populations, with success, again suggesting the need to explore the use, and necessary supports and modifications, of this strategy with people with intellectual and developmental disabilities. For example, Samson and Antonelli (2013), in a study of 33 people with autism spectrum disorders, discovered humor to be a lower or underused strength, ranking 16th out of 24, whereas in a matched group of people without autism spectrum disorders, it was 8th. Since the strength of humor is linked with hedonic happiness and positive emotions, an intervention such as “three funny things” (Gander et al., 2012) for people interested in boosting this lower strength might be considered. The study found that such reframing was found to be useful not only for the participants with autism spectrum disorders, but also for people that supported them. Groden, Kantor, Woodard, and Lipsitt (2011a) described exercises, such as modeling appropriate laughter to boost the strength of humor and the direct encouragement of the strength of kindness through a kind deeds program at school, as concrete ways to enhance character strengths in adolescents with autism. Such approaches, however, could easily be embedded in supports planning activities, such as those described in Chap. 3, as well as in many of the strategies describe in the Applications chapters included in Part 2 of this text.

More work is needed to develop strategies to enable people with intellectual and developmental disabilities to understand their character strengths, and to leverage these strengths across all domains of life (education, employment, social, community). In doing so, this not only shifts the focus from deficit-based assessment and intervention approaches, but also embraces the strengths that are inherent to each of us and enables the use of these strengths to build positive relationships, develop resilience, enhance well-being, navigate barriers and challenges, and enjoy meaningful activities.

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14

Adaptive Behavior

Marc J. Tassé

Introduction

Adaptive behavior is defined as behavior that has been learned and is performed to meet society's expectation across living settings, including the home, school, work, and other community settings (Schalock et al., 2010). Adaptive behavior is indexed on chronological age because as a society, we have different expectations of all members of our community as they age.

Adaptive behavior is a required criterion of all diagnostic systems defining intellectual disability (see American Psychiatric Association, 2000; Schalock et al., 2010; World Health Organization, 1992). The American Association on Intellectual and Developmental Disabilities defined adaptive behavior as the collection of Conceptual, Social, and Practical Skills that have been learned by people to function in their everyday lives (Luckasson et al., 2002; Schalock et al., 2010). The three adaptive behavior skill areas have been defined as follows: (1) conceptual skills consist of communication skills, functional academics, and self-direction; (2) social skills consist of interpersonal skills, social responsibility, following rules, self-esteem, gullibility, naiveté, and avoiding victimization; and (3) practical skills consist of basic personal care skills such as hygiene, domestic skills, health and safety as well as work skills.

The American Association on Intellectual and Developmental Disabilities (AAIDD) is generally considered the leading professional authority in defining "intellectual disability." The AAIDD, first established in 1876, is the oldest interdisciplinary professional association in the field of intellectual and developmental disabilities (Tassé & Grover, 2013). The AAIDD has led the field in establishing the definition and diagnostic criteria for intellectual disability for over a century. Since its first definition of intellectual disability in 1905, AAIDD has revised its definition 10 times to reflect the changes in research and understanding of this condition. The AAIDD definition of intellectual disability has historically been adopted by all federal and state governments as well as the American Psychiatric Association's Diagnostic and Statistical Manual (DSM) in defining intellectual disability. It was not, however, until the 5th edition of its diagnostic manual, that AAIDD required the assessment of adaptive behavior as a criterion for defining intellectual disability (Heber, 1959, 1961).

The American Psychiatric Association has historically adopted the AAIDD definition and diagnostic criteria of mental retardation in its Diagnostic and Statistical Manual of Mental Disorders. The DSM first included adaptive behavior in its diagnostic criteria of intellectual disability in its 2nd edition of the DSM (American Psychiatric Association, 1968). In fact, in the DSM-2, the American Psychiatric Association actually refers the reader to the AAIDD 1961 definition of intellectual disability (see Heber, 1961) for a fuller definition of intellectual

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disability (see p. 14; DSM-2). In fact, the text in the DSM-2 reads "*Mental retardation refers to subnormal general intellectual functioning which originates during the developmental period and is associated with impairment in either learning and social adjustment or maturation, or both*" (p. 14). The DSM-2 defined adaptive behavior using the wording found in Heber (1959), which defined it as maturation, learning, and social adjustment. The 2002 and 2010 editions of the AAIDD Terminology and Classification Manual returned to the psychometrically supported framework of three adaptive behavior domains, including Conceptual, Social and Practical Skills (see Luckasson et al., 2002; Schalock et al., 2010), originally proposed by Heber (1959, 1961). Hence, the definition of intellectual disability and the conceptualization of the adaptive behavior construct has not really changed in the last 50 years.

Relationship Between Intellectual Functioning and Adaptive Functioning

One of the forefathers of intelligence testing used the concept of "adaptation" in his definition of "intelligence" (Binet & Simon, 1905). For a long time and still to this day—the two concepts are sometimes intertwined but increasingly, the larger definition of intelligence is much more focused on mental capabilities and capacity whereas adaptive behavior is much more focused on the actual performance of skills when needed and in response to societal demands and expectations. The definition of intelligence adopted by AAIDD (Schalock et al., 2010) comes from the existing consensus position of prominent intelligence researchers and is defined as follows:

> Intelligence is a very general mental capability that, among other things, involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly and learn from experience. It is not merely book learning, a narrow academic or test-taking smarts. Rather, it reflects a broader and deeper capability for comprehending our surroundings—'catching on,' 'making sense' of things, or 'figuring out' what to do. (Gottfredson, 1997, p. 13).

There are a number of studies that have examined the changes in adaptive functioning among adults with developmental disabilities after deinstitutionalization (Felce, deKock, Thomas, & Saxby, 1986; Fine, Tangeman, & Woodard, 1990; Silverman, Silver, Sersen, Lubin, & Schwartz, 1986). Consistently, a meaningful positive change in adaptive functioning has been reported after moving from a more institutional living environment to a less restrictive community setting (Lakin, Larson, & Kim, 2011). Charlie Lakin and his colleagues did a review of the research literature that included 23 longitudinal studies published between 1977 and 2010 and reported that all but three studies documented adaptive behavior improvements when individuals moved to less restrictive community-based living arrangements. The increase in adaptive behavior was especially marked in the following skill areas: self-care, domestic skills, and social skills.

As conceptual constructs, intelligence and adaptive behavior are somewhat related but are clearly distinct from one another (Keith, Fehrmann, Harrison, & Pottebaum, 1987; McGrew & Bruininks, 1990). Thus, discrepancies in the measurement of intelligence and adaptive behavior are to be expected. Not everyone with significant limitations in intellectual functioning will have commensurately limited adaptive behavior and conversely, not everyone with significant limitations in adaptive behavior will have comparable significant limitations in intellectual functioning. Due to a wide range of measures for IQ and adaptive functioning, conducting research on children with developmental disabilities and interpreting the results can be challenging. However, some studies have reported a low-to-moderate correlation between the measures (Harrison & Oakland, 2015; Sparrow, Balla, & Cicchetti, 2005). A much small number of studies have (Carpentieri & Morgan, 1996) demonstrated a high correlation, while others have demonstrated that a larger portion of the variance (35%) in adaptive functioning among adults with intellectual disability can be explained by environmental variables other than intellectual ability (21%; Hull & Thompson, 1980). As a way to examine the relationship between these two constructs, some studies generated tables of values needed for statistical significance between various IQs and adaptive behavior scores. They concluded that a difference of at least 10 or more standard points was needed for a statistical difference between two measures when a 95% confidence level was adopted. They concluded that it is not unreasonable to interpret the IQ-adaptive score discrepancy as indicative of a real underlying difference between cognitive capacity and day-to-day performance. Research findings have tended to document higher correlation between these two constructs in individuals with more severe to profound deficits in intellectual functioning than for those who present with milder impairments in intellectual functioning (Childs, 1982; Sattler, 2002).

Information about changes in IQ and adaptive measures over time and their relationship to each other is useful for diagnosing mental retardation, predicting prognosis, and planning treatments. Many questions, however, remain unanswered. IQ scores appear to be stable over time, yet they might be somewhat different across IQ levels. Changes in adaptive functioning have not been well studied, especially for children with mental retardation. The general consensus in the field appears to be that the IQ and adaptive behavior constructs are distinct constructs but remain constructs that have a modest relationship. Thus, adaptive behavior is a construct that provides valuable information about the person's functioning that is not captured by measures of intellectual functioning.

Assessing Adaptive Behavior

Although the assessment of intellectual functioning has a longer history (e.g., first standardized test was developed in 1905) than the measurement of adaptive behavior, standardized tests of adaptive behavior have progressed significantly since the first such scale was published (Vineland Social Maturity Scale, Doll, 1936). The first version of the Vineland instrument consisted of items organized into six broad domains (self-help: general, dressing, and eating; self-direction; communication; socialization; motor; and work). Reflective of the times, the 1936 Vineland scale had items measuring the persons use of telephone Doll (1953) defined the construct of social competence as "*the functional ability of the human organism for exercising personal independence and social responsibility*" (see page 10). Doll's vision of assessing social competence (what would later be called adaptive behavior) remains ingrained in today's definition of adaptive behavior and associated standardized measures: "Our task was to measure attainment in social competence considered as habitual performance rather than as latent ability or capacity" (see Doll, 1953; page 5). This interpretation is consistent with AAIDD's current position that the assessment of adaptive behavior focuses on the individual's typical performance and not maximal ability (see Schalock et al., 2010, 2012). This is a critical distinction with the assessment of intellectual functioning, where we assess best or maximal performance.

According to Tassé et al. (2012), the critical aspects of assessing adaptive behavior for the purpose of diagnosing intellectual disability include:

- assessing the individual's typical behavior (and not maximal performance);
- assessing the individual's present adaptive behavior;
- assessing the individual's adaptive behavior in relation to societal expectations for his age group and culture;
- using standardized adaptive behavior scales that were normed on the general population;
- using a convergence of information (i.e., several informants, informants from different life contexts [home, school, work, play/leisure], over time [childhood, adulthood], multiple modalities and sources [see listed below]);
- using clinical judgment throughout the assessment process.

The American Association on Intellectual and Developmental Disabilities has specified: "*For the purpose of making a diagnosis or ruling out*

ID [intellectual disability], a comprehensive standardized measure of adaptive behavior should be used in making the determination of the individual's current adaptive behavior functioning in relation to the general population, The selected measure should provide robust standard scores across the three domains of adaptive behavior: conceptual, social, and practical adaptive behavior" (Schalock et al., 2010; p. 49). It is possible in some cases that the use of a standardized assessment instrument will not be possible. A standardized adaptive behavior scale is generally completed with the information from a respondent. Multiple adaptive behavior scales can be completed, but generally only one respondent is used to complete the entire scale, per administration procedures.

Standardized Adaptive Behavior Scales

Adaptive behavior scales are used predominantly for two purposes. The first purpose is in assessing the person's adaptive behavior for the purposes of establishing planning goals for intervention and habilitation. The other reason these standardized scales are used to assess a person's adaptive behavior is to determine whether or not there is a presence of significant deficits or not for the purpose of determining if the person meets criteria for a diagnosis of intellectual disability or developmental disability. Some instruments have been developed to attempt to serve both functions while other instruments focus on one aspect. We will briefly describe the following adaptive behavior instruments that are most suitable for use in assessing adaptive behavior for the purpose of determining intellectual disability: (1) *Adaptive Behavior Assessment System—3rd Edition* (*ABAS-3;* Harrison & Oakland, 2015), (2) *Vineland Adaptive Behavior Scale—2nd Edition* (*Vineland-II;* Sparrow, Cicchetti, & Balla, 2005), (3) *Scales of Independent Behavior—Revised* (*SIB-R;* Bruininks, Woodcock, Weatherman, & Hill, 1996), (4) *Adaptive Behavior Diagnostic Scale* (*ABDS,* Pearson, Patton, & Mruzek, 2016), and (5) Diagnostic Adaptive Behavior Scale (Tassé et al., in press).

Adaptive Behavior Assessment System—3rd Edition

The *Adaptive Behavior Assessment System, 3rd Edition* (ABAS-3; Harrison & Oakland, 2015*)* is the third edition of the ABAS, first published in 2000. The ABAS-3 is a comprehensive norm-referenced measure of adaptive behavior that can be used for multiple purposes, including the following: (1) assisting in the diagnosis and classification of intellectual disability, developmental disabilities, learning disabilities, behavioral disorders, and emotional disabilities; (2) identify functional limitations of individuals with conditions such as autism spectrum disorder, attention deficit/hyperactivity disorder, and Alzheimer's disease; (3) document a person's eligibility for special education services, social security administration benefits, and placement for other types of interventions; (4) assist with identifying and measuring progress toward adaptive behavior and daily functioning intervention goals, and (5) use as an outcome measure in program evaluation and treatment studies. The ABAS-3 can be used to assess the adaptive behavior of individuals between the ages of 0 and 89 years. There are 5 distinct questionnaire forms for the ABAS-3:

- **Parent or Primary Caregiver Form** (0–5 years old): can be used to assess adaptive behavior of infants to preschoolers in the home and other community settings. The respondents for this form are generally the child's parents or other primary caregivers.
- **Teacher or Daycare Provider Form** (2–5 years old): can be used to assess adaptive behavior of toddlers and preschoolers in a childcare, preschool, and other similar setting. The respondents for this form are generally the child's teachers, daycare or childcare aides, or other similar childcare or preschool personnel.

- **Parent Form** (5–21 years old): this form is used to assess adaptive behavior of children to adults in the home and other community settings. The respondents for this form are generally the child's parents or other primary caregivers.
- **Teacher Form** (5–21 years old): this form is used to assess adaptive behavior of children to adults in their school settings (K-12). The respondents for this form are generally the child's teachers, aides, and other school personnel.
- **Adult Form** (16–89 years old): this form is used to assess adaptive behavior of adults in the home and across other community settings. The respondents for this form can be any number of individuals, including the person her- or himself, family members, work supervisors, peers, others who are familiar with the individual's everyday functioning. There are separate normative tables for the Adult Form for self-ratings and ratings from third-party respondents.

Although the User's Manual (Harrison & Oakland, 2015) indicated that the administration time is approximately 15–20 min, the more realistically time of administration is probably closer to 30–40 min to complete the Adult Form. The ABAS-3 continues to be the only standardized adaptive behavior scale that provides norms for self-reported adaptive behavior when using the Adult Form.

The ABAS-3 yields standard scores (Mean = 100; standard deviation = 15) for each of the three domains: Conceptual, Social, and Practical, as well as a standard score for General Adaptive Composite, which combines information from all items and provides an overall estimate of the person's adaptive behavior. The ABAS-3 scoring also provides standard scores based on a mean = 10 and standard deviation = 3 across potentially all 11 adaptive skill areas: communication, functional academics, self-direction, leisure, social, community use, home/school living, health and safety, self-care, motor (only on forms for children <6 years old), and work (ratings are obtained only when assessed person has a part-time or full-time employment). The standard scores for the 11 adaptive skill areas have intervention, treatment, and other similar clinical utility.

Since the ABAS-3 is a very recently published revision, few independent reliability and validity data have yet been published. Harrison and Oakland (2015) reported excellent psychometric properties. The internal consistency of the ABAS-3 GAC ranges from 0.96 to 0.99 and from 0.85 to 0.99 for the adaptive behavior domains (conceptual, social, and practical), yielding lean average standard error of measure (SEM) coefficients for the adaptive behavior domains and GAC.

Vineland Adaptive Behavior Scale—3rd Edition

The *Vineland Adaptive Behavior Scale* (*3rd edition; Vineland-3;* Sparrow, Cicchetti, & Saulnier, 2016) is the third iteration of what is probably the better-known comprehensive standardized adaptive behavior scales. It was first published as the Vineland Social Maturity Scale (Doll, 1936) and then revised by Sparrow, Balla, and Cicchetti (1984) as the Vineland Adaptive Behavior Scales and again as the Vineland-II (Sparrow, Cicchetti, & Balla, 2005). The Vineland-3 was developed to assess adaptive behavior in individuals from 0 through 90 years old and has two versions: comprehensive and domain level—of each of the Vineland-3 forms: Interview Form, Parent/Caregiver Form, and Teacher Form. The comprehensive-level forms offer a more in-depth evaluation much like the previous Vineland-II version, providing results across: adaptive behavior composite, domains, subdomain, and item level. The domain-level versions provide a briefer set of items across each form and yields standard scores only at the domain level (Daily Living Skills, Communication Skills, and Social Skills), adaptive behavior composite, and item level. The domain-level forms can be used for diagnostic purposes, whereas the comprehensive-level forms can be used for both diagnostic and intervention planning purposes.

- **Interview Form**: Provides a comprehensive assessment of individual adaptive behavior. The assessor administers the Vineland-3 Interview Form to a parent or caregiver using a semi-structured interview format. This approach gathers more in-depth information with its open-ended questions (with or without probes) and promotes rapport between the interviewer and respondent. According to Sparrow et al. (2016):
    - Comprehensive: 0–90 years; 502 items; administration time is approximately 35–40 min.
    - Domain Level: 3–90 years; 195 items; administration time is approximately 23–27 min.
- **Parent/Caregiver Rating Form**: The Parent/Caregiver Rating Form contains the same content as the Interview Form, but uses a rating scale format. This alternative approach works when time or access to the respondent is limited. The Parent/Caregiver Rating Form is also a valuable tool for progress monitoring. The Vineland-3 Manual suggests using the Interview Form for an initial assessment and then uses the Parent/Caregiver Rating Form to track progress over time. According to Sparrow et al. (2016):
    - Comprehensive: 0–90 years; 502 items; administration time is approximately 20–25 min.
    - Domain Level: 3–90 years; 180 items; administration time is approximately 10–15 min.
- **Teacher Form**: Assesses adaptive behavior for students in preschool or school. The Teacher Form uses a questionnaire format completed directly by the child's teacher or daycare provider. The Teacher Form covers content that a teacher would observe in a classroom setting. According to Sparrow et al. (2016):
    - Comprehensive: 3–21 years; 333 items; administration time is approximately 15–20 min.
    - Domain Level: 3–21 years; 149 items; administration time is approximately 8–10 min.

It should be noted the administration times reported above are the times provided in the Vineland-3 user's manual and appear to be somewhat low-ball estimates of time needed to complete the different scales.

The domain names of the Vineland-3 are Communication Skills (i.e., expressive and reception language skills, and written language), Socialization Skills (interpersonal skills, play and leisure skills, and coping skills), Daily Living Skills (personal care, self-care skills, domestic skills, and work skills), and Motor Skills (is optional and only used for children from 3 to 6 years old). These Vineland-3 domains do not align with the current tripartite model of adaptive behavior (Conceptual, Social, and Practical) used in existing diagnostic systems (e.g., AAIDD, DSM-5). Tassé, Schalock, Balboni, Spreat, and Navas (2016) proposed the following alignment of the Vineland-3 subscales with the existing tripartite model of adaptive behavior: Communication = Conceptual Skills; Socialization = Social Skills; and Daily Living Skills = Practical skills.

The Vineland-3 also has an optional Maladaptive Behavior Domain that assesses the presence and severity of problem behavior and may be used for planning behavioral intervention around these behaviors but is not taken into consideration when computing the person's adaptive behavior level. The Vineland-3 has an extensive and representative normative sample. It has a long-track record of use and strong psychometric properties. The structure of the Vineland-3 provides standard scores with a mean = 100 and standard deviation = 15 for each of the four domains: Motor Skills (<6 years old), Daily Living Skills, Communication Skills, and Socialization Skills. The Vineland-3 continues to be available as a paper–pencil questionnaire administration but can now also be administered electronically using Pearson's Q-Global.

Scales of Independent Behavior—Revised

The *Scales of Independent Behavior—Revised* (SIB-R; Buininks et al., 1996) is a comprehensive standardized adaptive behavior scale that was standardized on a representative sample of individuals from the general population. It was developed for use with individuals from 3 months to 80+ years old and consists of three separate forms: Early Development (3 months–8 years old), Comprehensive Form (3 months–80 years old) and Short Form. The Developmental Form and Short Form are a different subset of 40 items drawn from the full SIB-R instrument. The SIB-R may be administered using the structured interview or a checklist procedure where the respondent completes the questionnaire directly.

The SIB-R full-form contains two sections: adaptive behavior items and problem behavior items. The adaptive behavior contains a total of 259 and yields a total standard scores called Broad Independence and 4 domain scores: Motor Skills, Social Interaction and Communication Skills, Personal Living Skills, and Community Living Skills. The problem behavior section contains 8 distinct challenging behaviors rated for their frequency (0–5) and severity (0–4). The SIB-R requires approximately 60 min to complete and may be completed either as a rating scale directly by the respondent or via an interview between an interviewer and a respondent.

Although the reliability and validity psychometric data for the Comprehensive Form are adequate, the psychometric properties of the Short Form and Developmental Form are questionable (Maccow, 2001).

Adaptive Behavior Diagnostic Scale

The *Adaptive Behavior Diagnostic Scale* (ABDS; Pearson, Patton, & Mruzek, 2016) is a recently released standardized adaptive behavior scale (Pearson, Patton, & Mruzek, 2016). It is a replacement adaptive behavior scale for PRO-ED's Adaptive Behavior Scale—Residential Community scale that previously only had been normed on adults with intellectual disability. The ABDS is an interview-based scale that assesses the adaptive behavior of individuals between the ages of 2 and 21 years and is normed on a typically developed population. The structure of the scale includes the three prevalent domains, including Conceptual, Social, and Practical Skills. The scale administration is structured according to these three domains and each domain consists of 50 discrete adaptive skills. The results obtained yield standard scores with a mean = 100 and standard deviation = 15 for each of the three domains: Conceptual, Social, and Practical as well as an overall Adaptive Behavior Index.

Having only been recently released, there exists no independent psychometric evaluation of the ABDS. The authors (Pearson et al., 2016) report excellent psychometric properties, including internal consistency coefficients for all domain and overall index standard scores above 0.90. The authors also reported a sensitivity coefficient of 0.85 and specificity coefficient of 0.99.

A review of the scale and its user's manual supports the use of the ABDS for use in obtaining standardized adaptive behavior assessment information for the purpose of making an intellectual disability determination.

Diagnostic Adaptive Behavior Scale

The *Diagnostic Adaptive Behavior Scale* (DABS; Tassé, Schalock, Balboni, Bersani, Borthwick-Duffy, Spreat, Thissen, Widaman, & Zhang, in press) was designed specifically for the purpose of being a standardized assessment instrument to assist with the diagnosis of intellectual disability. The DABS was designed from its earliest conception to assist in the ruling in or ruling out of intellectual disability (formerly mental retardation) by providing a comprehensive assessment of an individual's current adaptive behavior and be most precise and reliable at the cutoff score that is equivalent to 2 standard deviations below the population mean. The DABS was developed based upon the conceptual framework of the AAIDD 2002 and 2010 definition of adaptive behavior (Luckasson et al., 2002; Schalock et al., 2010) and measures the following three domains: Conceptual, Social, and Practical Skills.

The DABS was standardized on a large national sample of typically developing children and adults between the ages of 4 and 21 years (inclusively). The DABS was developed across a period of approximately 7 years. There are numerous steps involved in the development of such a scale. The interested reader is encouraged to consult the DABS Manual (Tassé et al., in press) for a detailed description of the development and standardization of the DABS. This chapter summarizes only essential elements of the scale's development.

The DABS was specifically developed to tap the three domains (Conceptual, Social, and Practical Skills) of adaptive behavior based on current factor analytic work and was developed to be a relatively shorter and more efficient assessment instrument that focuses solely on the diagnosis of intellectual disability and not on identifying programming/intervention or support needs. The DABS' item pool includes relevant items that relate directly to the concepts of gullibility, vulnerability, and social cognition (that involve social perception, the generation of strategies for resolving social problems, and consequential thinking)—often lacking from existing measures of adaptive behavior. One major innovation of the DABS is that it was developed and its scoring is entirely based on item response theory (IRT).

The DABS consists of a total of 75 items (25 items are administered in each of the three domains) and is administered via face-to-face interview between a professional (i.e., interviewer) and a respondent (e.g., parent, grandparent, caregiver, teacher). The estimated administration time for the DABS Interview varies slightly depending on the interviewer and number of persons being interviewed simultaneously but on average, the DABS administration is approximately 30 min. The scoring of the DABS is done using a computerized scoring system that uses IRT algorithms to analyze the response patterns and computes a standard score for each of Conceptual, Practical, and Social Skills as well as a Composite Score. The standard scores have a mean of 100 and standard deviation of 15.

At the time of completion of this chapter, the DABS was not yet available commercially. It is expected that the American Association on Intellectual and Developmental Disabilities will be making the DABS available in late 2017.

In Addition to the Use of Standardized Measures

The use of standardized measures of adaptive behavior should not be used in isolation. There are many instances where the use of standardized adaptive behavior scales may be insufficient or impossible. This might be because there are no reliable respondents available to provide comprehensive information on the assessed person's adaptive behavior, the respondents providing the adaptive information can only provide partial information, or the evaluator cannot ensure the proper administration of the instrument per test guidelines. In these instances, alternate sources of adaptive behavior information should be referenced as complementary or alternative sources of the person's adaptive behavior.

The AAIDD (Schalock et al., 2010, 2012) and Olley (2015) recommend using several of the following different sources of adaptive behavior information as part of a comprehensive adaptive behavior assessment:

- medical records.
- school records.
- employment records.
- previous psychological evaluation reports and raw data (adaptive behavior, IQ, achievement, mental health, employment, career counseling, etc.).
- therapy or intervention reports and records (e.g., mental health, habilitation services, employment support, developmental disability services).

- drivers and motor vehicle bureau records.
- information from state or federal offices that might have eligibility information (social security administration, state developmental disabilities department, medicaid).
- in criminal cases: affidavits, declarations, transcripts of testimony or interviews, prison records.
- informal interviews with individuals who know the person and had the opportunity to observe the person in the community, etc.
- interview with the defendant/assessed person.

All types and sources of information should be reviewed and analyzed critically for content, relevance, and accuracy. One should also ascertain the comparison group when determining ability and limitations. “For example, in some special education programs, a ‘C’ grade denotes something very different in achievement level than a ‘C’ grade granted in a regular education classroom” (Schalock et al., 2010; p. 48).

Respondents

Adaptive behavior scales are typically completed via input and observations of the assessed individual’s adaptive behavior and either directly rate items on an adaptive behavior scale or provide this information via an interview with an adaptive behavior assessor who is responsible for the adaptive behavior assessment. Generally, the best respondents are typically adults who know well the assessed individual and have the most knowledge and have had opportunities to observe the assessed individual in his or her everyday functioning across settings (Tassé, 2009). Adaptive behavior respondents are most often selected among the assessed person’s family (e.g., parents or guardians, grandparents, older sibling, aunts/uncles), spouse, and/or roommates. Other individuals who can also provide valuable adaptive behavior information include neighbors, teachers, coworkers, supervisors, coaches, and others who have had multiple opportunities to observe the assessed person functioning in everyday community settings such as school, work, leisure, community). The interviewer or person responsible for conducting the adaptive behavior assessment also has the responsibility of ensuring that the respondents are able to provide reliable and accurate information. The use of clinical judgement and professional experience with clinical interviews and the assessment of adaptive behavior will guide the evaluator in making these determinations.

There may be situations where there is no respondent available who has knowledge of the assessed individual that is sufficiently comprehensive to be able to complete a standardized adaptive behavior scale. In these instances, the assessor will need to rely more heavily on the use of respondents who provide qualitative information in discrete areas of life (e.g., school or work or neighborhood). In such instances, the use of multiple respondents and sources of adaptive behavior information (see school records, medical history, DMV, etc.) are even more important.

Retrospective Assessment

The diagnosis of intellectual disability implicitly requires two conditions related to the adaptive behavior criterion: (1) adaptive functioning (*i.e.*, Conceptual, Social, Practical Skills) is defined as behavior that is learned and typically performed to *meet society’s expectations/demands* for individuals of his chronological age and cultural group, and (2) the assessment of the individual’s *present adaptive functioning*. These two conditions, however, are often at odds when assessing adaptive behavior in criminal cases where the individual’s “present” adaptive functioning can only be assessed against life in prison (Tassé, 2009). It is in these situations that an expert will need to conduct a retrospective evaluation of the individual’s adaptive functioning to a time period when he lived in the community (*i.e.*, prior to incarceration). Using retrospective assessment has been endorsed by AAIDD (Schalock et al., 2010, 2012).

Again, adaptive behavior is defined as conceptual, social, and practical adaptive behavior that is learned and performed to meet community standards of personal independence and social responsibility, in comparison with same-age peers and of similar sociocultural background (APA, 2013; Schalock et al., 2010). The assessment of a person's adaptive behavior is done with a combination of standardized adaptive behavior scales, clinical evaluations, and interviews of significant others, and a thorough review of all available records. The historical records can inform the expert's clinical judgment regarding prong 3, but often, a retrospective method of conducting adaptive behavior interviews can provide two valuable sources of information: assessed person's adaptive functioning level prior to incarceration (i.e., while still living in the community) and provide an assessment of the person's adaptive functioning prior to age 18.

Using a retrospective assessment to make a determination of intellectual disability relies heavily upon the informant's memory of the assessed individual's functioning and their ability to accurately recall this information. Sometimes in when a person has been living with their aging parents and not receiving any paid services and supports cases, the retrospective recall is going back 15–20 years. The above-mentioned adaptive behavior scales are the preferred measures to use in assessing adaptive behavior and have all been standardized using contemporary psychometric methods. Although there are a number of authors who have appropriately cautioned users regarding the dangers of breaking standardization and the validity of the obtained ratings from a retrospective adaptive behavior assessment (Stevens & Price, 2006), the author of this chapter agrees with others (Macvaugh & Cunningham, 2009; Olley & Cox, 2008) that with proper precautions and critical considerations experts should be able to use retrospective assessments when making an intellectual disability determination using a retrospective approach.

The AAIDD User's Guide (Schalock et al., 2012) provided some guidelines to follow when conducting a retrospective assessment/diagnosis of intellectual disability:

1. Conduct a thorough social history.
2. Conduct a thorough review of all available records (see above).
3. Assess adaptive behavior:
    - using multiple informants and multiple contexts;
    - recognizing that limitations in present functioning must be considered within the context of community environments typical of the individual's peers and culture;
    - with awareness that many important social behavioral skills, such as gullibility and naiveté, are not measured on current adaptive behavior scales;
    - using an adaptive behavior scale that assesses behaviors that are currently viewed as developmentally and socially relevant;
    - understanding that adaptive behavior and problem behavior are independent constructs and not opposite poles of a continuum; and
    - realizing that adaptive behavior refers to typical and actual functioning and not to capacity or maximum functioning.
4. Recognize that self-ratings have a high risk of error in determining "significant limitations in adaptive behavior." However, consistent with the need for multiple informants or respondents, self-ratings can be used under the following cautions:
    - people with ID are more likely to attempt to look more competent and "normal" than they actually are—which is sometimes incorrectly interpreted as "faking";
    - people with ID typically have a strong acquiescence bias or inclination to say "yes" or try to please the authority figures; and
    - ID is a social status that is closely tied to how a person is perceived by peers, family members, and others in the community.
5. Conduct a longitudinal evaluation of adaptive behavior that involves multiple raters, very specific observations across community environments (especially in regard to social competence), school records, and ratings by peers during the developmental process.
6. Do not use past criminal behavior or verbal behavior to infer level of adaptive behavior or about having ID.

Tassé (2009) proposed the following instructions for the expert conducting the retrospective adaptive behavior interview:

- Identify a clear time period during which you want the informant to focus their report of the individual's adaptive behavior. For example, you might instruct the respondent to recall the assessed individual before he was incarcerated.
- Build rapport with the informant and ask her or him to think about where the assessed person was living at that specified time, what school/grade he was in, where was he working, etc. These points of reference will be important to assist the respondent to recall that time period.
- Periodically, remind the respondent that she or he is assessing the individual's adaptive behavior in that specific time period.

In the end, using retrospective assessment may be the only method available to establish whether the person's adaptive skill deficits were present during the developmental period. It is the responsibility of the clinician to use her or his clinical judgment in reviewing the totality of the available clinical information in reaching a well-founded conclusion regarding the age of onset criterion and the overall determination of intellectual disability.

Deficits of Adaptive Behavior Can Be Explained by Other Factors

It is important to recall one of the AAIDD assumptions regarding the definition of intellectual disability (see Schalock et al., 2010): Adaptive behavior deficits can and do coexist with mental illness and other behavioral disorders. The presence of other mental illnesses or behavior health problems do not dismiss or explain away deficits in adaptive behavior nor do they negate a diagnosis of intellectual disability. The DSM-5 (APA, 2013) is categorical, as it has been in previous iterations of its diagnostic manual, there are NO exclusionary conditions to a diagnosis of intellectual disability. That means, regardless of the presence of any other coexisting behavioral or mental illness (such as antisocial personality disorder, to mention one), a diagnosis of intellectual disability should be made if the individual meets all three diagnostic prongs of intellectual disability, regardless of etiology or comorbid conditions. Holland and his colleagues (2002) in fact reported that comorbidity of intellectual disability and antisocial behavior or disorder is quite common in the criminal justice population. As it pertains to a diagnosis of "antisocial personality disorder" explaining the deficits of adaptive behavior and precluding a diagnosis of intellectual disability, firstly, they can coexist. Secondly, a diagnosis of intellectual disability originates before the age of 18 years (see AAIDD; Schalock et al., 2010; APA, 2013), but the diagnosis of antisocial personality disorder is not made until after the age of 18 years (DSM-5; APA, 2013). Again, there is no exclusionary criterion between intellectual disability and antisocial personality disorder. They can and do coexist.

People with intellectual disability can acquire a mental illness, substance abuse disorder, or other secondary health conditions. In fact, people with intellectual disability are 3–4 times more vulnerable than people in the general population to presenting with a comorbid mental or behavioral disorder (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Fletcher et al., 2007; Reiss, 1994; Rojahn & Tassé, 1996). Substance abuse by people with intellectual disability is not as common overall but is more prevalent in adults with intellectual disability intersecting with the criminal justice system (Chapman & Wu, 2012; McGillivray & Moore, 2001). For adults with an intellectual disability and substance abuse problem increases the likelihood of criminal behavior and arrests for criminal activities (Holland et al., 2002). Sadly, many adults with intellectual disability make poor choices and end up using and abusing alcohol and drugs. To use the presence of a substance abuse disorder as a reason to rule out or explain the presence of deficits in adaptive behavior or intellectual disability is clearly tautological. These conditions can and do cooccur, especially in a forensic population. Generally speaking, when someone stops using alcohol and drugs, they will not be cured of their intellectual disability.

Adaptive Behavior Assessment Is Objective

There is a clear distinction to be made between information that is provided by a subject and subjective information. Yes, adaptive behavior assessment relies on the reporting of observed adaptive behavior, but this is done in a rigorous, standardized, and objective manner. When the respondent is asked about the assessed person's adaptive behavior, they are asked about behaviors that they have directly observed. They are not asked to estimate or imagine whether he could do such and such a behavior. In fact, if they do guess on more than 2 items in one domain, that informant's information will be viewed as less reliable than one that has no guessing. Having a standardized set of items, administered in a systematic fashion and scored in a prescribed manner that then yields results that are compared and converted statistically to a normative scale, yields quite objective results. In fact, standardized adaptive behavior scales yield standardized results that are presented on the same normative metric as IQ scores, where an average score = 100 and the population deviation score = 15 (Harrison & Oakland, 2015; Sparrow, Cicchetti, & Balla, 2005).

Typical Performance not Potential

Adaptive behavior assessment is focused on what a person typically does and the degree to which they perform that behavior independently, which aide or support (Schalock et al., 2010; Tassé, 2009). Adaptive behavior scales provide clear guidance that the person providing information regarding their observation of the person performing a behavior or skill. Hence, the independent performance of a discrete adaptive behavior captures the person's knowledge or prior learning of the behavior, recognition that the behavior needs to occur (e.g., "finds the bathroom in a public place"), their willingness or motivation to perform said behavior (e.g., "chooses not to say mean or embarrassing things"), the degree of prompting or assistance the individual needs to perform the behavior adaptive (e.g., "performs behavior when needed and without reminders or help").

Adaptive behavior scales measure a complex array of cognitive and behavioral aspects to adaptive functioning. And in so doing is interested in measuring not what does the person know or do they know how to do but rather do they do it. For example, there is an item in the Home-Living Scale on the ABAS-3 that asks "folds clean clothes." The assessed behavior is not "can…" or "does he know how…" but rather [does he] fold clean clothes without prompts or help? This is an important difference in the assessment of adaptive behavior. If a person has learned a behavior and possesses a skill but chooses not to perform that behavior when needed or expected, he or she does not get full credit for that adaptive behavior. For the purposes of assessing adaptive behavior to make a determination of intellectual disability we assess "what does this person typically do." If we were conducting an assessment of adaptive behavior for the purpose of intervention planning, we would likely follow-up our initial assessment with a series of follow-up queries to determine whether the person does not perform the behavior due to a lack of knowledge, skill, or willingness. Of course, it takes the combination of many items where the skill/behavior is lacking to yield a standard score that is significantly subaverage. In contrast to adaptive behavior, the assessment of intellectual functioning seeks to capture the person's fullest potential and capacity. Further illustrating that these are two different and distinct constructs of human functioning and both are necessary to make a determination of intellectual disability (Tassé, Luckasson, & Schalock, 2016).

Measurement Error

In the same way, standardized tests of intellectual functioning yield observed scores that should be interpreted with clinical judgment and consideration for all sources of measurement error, so do the results from adaptive behavior scales. The observed scores should be interpreted within the accepted recommended practice (see Schalock et al., 2010) of 95% confidence interval or plus/minus 2× the test's standard error of measurement. Unlike with performance on tests of intelligence, current research on adaptive behavior assessment results does not indicate a rise in obtained scores or significant inflation in results due to obsolescence of adaptive behavior test norms. Because of the nature of adaptive behavior assessment, practice effects are a non-issue. Adaptive behavior assessment also seems to be immune to the phenomenon of rising scores over the years following norming of standardized tests, as has been clearly documented with standardized tests of intellectual functioning (i.e., Flynn effect).

Summary

All major diagnostic systems (AAIDD & APA) are in alignment in defining intellectual disability as a developmental disability requiring the presence of significant deficits in both intellectual functioning and adaptive behavior (as expressed in Conceptual, Social, and Practical Skills). A comprehensive evaluation and determination of intellectual disability requires clinical judgment (Schalock & Luckasson, 2014). Although individually administered standardized tests play a critical role in assessing a person's intellectual functioning and adaptive behavior, results from standardized tests must be interpreted using clinical judgment and in conjunction with relevant information from multiple collateral sources.

Adaptive behavior is an essential construct used for the purpose of making a determination of intellectual disability and also plays an important role because of its value as an outcome indicator for evaluating the effectiveness of intervention programs across the life span. Adaptive behavior is what Henry Leland once referred to as the skills that make one "invisible" in society. The more adaptive skills we learn and perform, the less we stand out. Hence, teaching adaptive skills to persons will equip them to better respond to their community's demands and society-at-large's expectations. Adaptive skills are translatable into better coping skills, consumer skills, social interaction, personal health care, hygiene, cooking and home-living skills, employment, etc. When Schalock and his colleagues (2010) assert the assumption/aspiration: "*With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability generally will improve*" (p. 1), what they are talking about are the person's adaptive behavior. With proper intervention and supports, any person can learn and improve their ability to meet society's expectations. This is important because we can teach anyone with an intellectual disability, no matter their level of ability/disability, new adaptive skills that will contribute to their improved independence/interdependence and resulting quality of life.

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Problem Solving and Self-advocacy

15

Michael L. Wehmeyer and Karrie A. Shogren

Introduction

This chapter and Chap. 16 address the closely related concepts of problem solving, self-advocacy, goal setting and attainment, and self-regulation. The former two, the topics of this chapter, share a common thread: at the broadest level, they involve how one responds to threats and opportunities in one's environment. Problem-solving skills enable one to sort out the nature and extent of the problem and generate solutions, while self-advocacy skills apply those skills to advocating on one's own behalf or on behalf of others. In the next section, we examine definitions of both of these constructs, research that has been conducted in the context of problem solving and self-advocacy for people with intellectual disability, and then conclude by examining interventions and supports that enable people to solve problems and self-advocate.

Conceptualizing Problem Solving and Self-advocacy

Problem Solving

Navigating life's problems is a hallmark of adulthood in most societies. Most people learn to solve problems by watching others (usually parents or teachers) solve problems and through the experience of solving small problems, then larger and larger problems. As discussed in Chaps. 5 (self-determination) and 11 (decision making), problem solving is integral to becoming self-determined and engaging in decision making processes.

What Is Problem Solving? Most simply put, a problem is a task, activity, or situation for which a solution is not immediately identified, known, or obtainable. Solving a problem, therefore, is the process of identifying solutions that resolve the initial perplexity or difficulty and selecting the best such solution. Because most people equate a "problem" with something negative (e.g., a problem child and financial problems), it may be more useful to think of problem solving within the context of goal-driven behavior, where problem solving seeks to bridge the gap between a person's current situation and a desired outcome. Bransford and Stein (1993) suggested that "a problem exists when there is a discrepancy between an initial state and a goal state, and there is no ready-made solution for the problem solver" (p. 7). When working toward goals and self-regulating one's actions in

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service of goals, situations will be encountered where the best solution or pathway to goal attainment is unknown, not clear, or not available. Problem solving is the process of identifying the solutions to remove the discrepancy between the initial and goal states. Once you have identified all possible solutions, you must then make a decision about which solution is the best for your current needs.

The process of navigating problems and engaging in self-regulated, goal-directed actions gives rise to causal action. The process of solving a problem is generally assumed to involve five steps: (a) identifying and defining the problem, (b) listing possible solutions, (c) identifying the impact of each solution, (d) making a judgment about a preferred solution, and (e) evaluating the efficacy of the judgment (D'Zurilla & Goldfried, 1971).

While early research focused on the application of these steps to solving problems with finite solutions, most research has focused on applications of problem solving in more complex situations, in which there is not a finite solution, and when environments are highly dynamic. Some researchers have described this as complex problem solving. Complex problem solving requires the use of cognitive skills related to acquiring information in dynamic situations, generating novel solutions, and representing complex information. Buchner (1995) defines complex problem solving as "the successful interaction with task environments that are dynamic (i.e., change as a function of user's intervention and/or as a function of time) and in which some, if not all, of the environment's regularities can only be revealed by successful exploration and integration of the information gained in that process" (p. 14). Within these dynamic environmental situations, problem-solving skills are critical to acting agentically and making progress toward one's goals. It is necessary to integrate information and make a judgment about a preferred solution to continue to make progress toward one's goals as the environment changes.

Researchers have focused on complex problem solving in social situations and in everyday situations. In social situations, people engage in social and interpersonal interactions that tend to be dynamic and require nuanced understandings to identify, generate, and evaluate possible solutions (Chang, D'Zurilla, & Sanna, 2004; Elias & Tobias, 1996). In everyday or practical problem solving, there are also dynamic situations or tasks, but more focus is on the complexity inherent in everyday environments and tasks across environments (Berg, Skinner, & Ko, 2009; Sinnott, 1989). Researchers have found that everyday problem solving emphasizes the importance of being able to generate more than one potential solution, particularly when dealing with a dynamic or complex situation, and the role of evaluating alternate solutions using logical thinking skills and defining or redefining of the problem to enable the generation of alternative solutions (Pezzuti, Artistico, Chirumbolo, Picone, & Dowd, 2014).

In addition to the specific skills needed to solve complex problems, researchers have emphasized the role of self-appraisal in solving problems, suggesting that how a person perceives their ability to solve problems directly influences their application of problem-solving skills across situations (Butler & Meichenbaum, 1981). The terms problem solving and decision making are often used synonymously, although that usage is technically incorrect. Decision making is a process of selecting or coming to a conclusion about which potential solution is the best. The problem-solving process "starts earlier" as it identifies possible solutions that might be the focus of a decision making process.

Self-advocacy

Self-advocacy involves, quite simply, advocating for oneself or for a cause that one supports. Algozzine, Browder, Karvonen, Test, and Wood (2001) found that teaching self-advocacy skills was among the most common activities related to promoting self-determination among students with disabilities. Test, Fowler, Wood, Brewer, and Eddy (2005) developed a conceptual framework of self-advocacy based on the definitions found in the literature and stakeholders' input that includes four components: (a) knowledge of self, (b) knowledge of rights, (c) communication, and (d) leadership. In this chapter, we consider two "forms" of self-advocacy, general self-advocacy skills and self-advocacy through student involvement in educational planning.

General Self-advocacy Skills. There is an array of skills or areas of knowledge that have been included in discussions pertaining to teaching general self-advocacy skills, beginning with communication skills, which are, as Test, Fowler, Wood, Brewer, and Eddy (2005b) noted, critical to successful self-advocacy. Gould (1986) suggested that secondary-age instruction in self-advocacy should include instruction and practice in some or all of the following areas:

- assertive behavior
- public speaking skills
- leadership skills
- decision making skills
- problem resolution skills
- legal and citizenship rights and responsibilities
- transition planning
- goal setting and attainment
- using community resources
- communication

Again, the overlap between topics such as goal setting and attainment, problem solving, self-regulation, and self-advocacy shows up in this list. We will look at practices that have been shown to be effective in promoting these areas of self-advocacy in a subsequent section.

Self-advocacy through Student Involvement. When, in the 1990 reauthorization of the Individuals with Disabilities Education Act (IDEA), the transition mandates required that students with disabilities be invited to their Individualized Education Program (IEP) meeting when transition-related goals were to be discussed. This initiated a focus on efforts to actively engage and involve young people in their educational and transition planning (Wehmeyer & Sands, 1998). Essentially, such efforts focused on promoting self-advocacy, goal setting, problem solving, and related skills that would enable students to play a meaningful role in their planning process. The IEP meeting provides an excellent context for teaching and supporting self-advocacy skills, as students can learn how to get what they want through interactions with other IEP team members. There are several student involvement processes that have evidence with regard to their efficacy that will be discussed subsequently.

Problem Solving and People with Intellectual and Developmental Disabilities

Perhaps because many people do not expect people with intellectual and developmental disabilities to engage in problem solving, a task that is typically construed as cognitively complex, there have been a limited number of studies examining issues pertaining to problem solving with this population. The earliest research with people with intellectual disability pertaining to problem solving examined individual differences in cognitive problem solving. This research was not focused on promoting problem-solving skills, but instead on problem-solving capacity (or incapacity) as differentiated among people with intellectual disability as a function of level of impairments. This research documented that people with intellectual disability exhibited a relatively inflexible pattern of problem solving (Ellis, Woodley-Zanthos, Dulaney, & Palmer, 1989; Ferretti & Butterfield, 1989; Ferretti & Cavelier, 1991; Short & Evans, 1990). This pattern, labeled cognitive rigidity by Gestalt psychologists, "is characterized by repetition of past strategies to solve current problems without adapting to new stimuli or new task demands" (Short & Evans, 1990, p. 95). Wehmeyer and Kelchner (1994) determined that people with intellectual disability were able to generate solutions to problems, but, in general, generated fewer and less complex means to solve problems than their peers without intellectual disability. These authors argued that the study confirmed that people with intellectual disability could solve problems, and that discrepancies between the number and complexity of solutions generated by people with intellectual disability, when compared to their non-disabled peers, were as much a function of opportunity and experience to learn to problem solve as they were capacity issues. A few studies from that era suggested that given opportunities to learn problem-solving skills, people with intellectual disability would benefit (Castles & Glass, 1986) and a few others incorporated efforts to promote problem-solving skills into real-world situations. Park and Gaylord-Ross (1989) showed that adults with intellectual disability provided problem-solving instruction had improved employment outcomes, and Tymchuk, Andron, and Rahbar (1988) showed that teaching mothers who had intellectual disability how to solve problems in relation to their children's health resulted in better parenting skills.

More recent research has found that people with intellectual disability can, if provided opportunities, exhibit problem-solving skills (Erez & Peled, 2001). Cote et al. (2010) and Agran, Blanchard, Wehmeyer, and Hughes (2002) conducted single-case design studies using the *Self-determined Learning Model of Instruction* process (discussed in Chap. 5 and, in less detail, later in this chapter) to teach self-regulated problem-solving skills to youth with intellectual and developmental disabilities in educational contexts. Both studies found that students were able to learn and use problem-solving skills. Cote and colleagues found that instruction enabled youth with intellectual and developmental disabilities to improve in their ability to identify problems and possible solutions. Edeh and Hickson (2002) investigated cross-cultural differences in problem solving of people with intellectual disability. All participants were able to generate solutions to problems, with participants from Nigeria actually evidencing more self-generated solutions to problems than their peers with intellectual disability from the US (both white and African-American), but also evidenced more cooperative (compared to individualistic) problem-solving styles. Edeh and Hickson ascribe these differences to cultural differences and emphasize the importance of considering cultural context issues when teaching youth with intellectual and developmental disabilities problem-solving skills.

In general, we know little about problem solving and people with intellectual disability. It is clear that without instruction and supports, people with intellectual disability will not be able to be as effective at identifying problems and generating solutions as are their non-disabled peers. It is also evident, though, that people with intellectual disability can acquire these skills if provided adequate instruction and support. Those will be discussed in a subsequent section in the chapter.

Self-advocacy and People with Intellectual and Developmental Disabilities

Research on General Self-advocacy Skills

As was noted, promoting self-advocacy and its related components have been among the most frequently implemented practices in efforts to promote self-determination. Several literature reviews provide a comprehensive look at research pertaining to self-advocacy. In what was among the first of these, Merchant and Gajar (1997) conducted an analysis of the literature on self-advocacy skills programs for students with learning disabilities, and concluded that such efforts were effective in promoting self-advocacy, but that there were too few such studies available. Algozzine et al. (2001) found 19 studies that focused on self-advocacy and that met the criteria for their meta-analysis of self-determination-related skills. This meta-analysis did not analyze effect sizes for individual topic areas (e.g., problem solving, goal setting, etc.), but for overall efforts to promote self-determination-related skills, and found that both group design and single-case studies showed moderate to strong effects. Test, Fowler, Brewer, and Wood (2005a) conducted a literature review of 25 studies specific to self-advocacy and found "evidence that individuals with varying disabilities and ages can learn self-advocacy skills" (p. 120). In general, then, there is evidence that teaching general self-advocacy skills to students with disabilities, including students with intellectual and developmental disabilities, has positive benefit, though there is clearly need for more methodologically sophisticated research in this area.

Research on Self-advocacy Through Student Involvement

To a large degree, the impetus for research in promoting general self-advocacy skills was the same as that for research on promoting self-advocacy through student involvement. In the early 1990s, the Individuals with Disabilities Education Act (IDEA) was reauthorized and included language pertaining to the provision of transition services and the need for such services to be based upon student needs, taking into account student interests and preferences. The law required that students for whom transition services were to be discussed at their annual meeting be invited to the meeting. This, in turn, ushered in a focus on the design and evaluation of efforts to promote self-advocacy and to promote student involvement in transition planning.

There is a relatively large literature base on the positive impact of promoting student involvement in transition and educational planning, though there are two distinct "classes" of studies. Most studies, exemplified by a literature review by Test et al. (2004), discussed subsequently, lacked the research rigor to provide causal evidence of the impact of such efforts. More recently, data has emerged from randomized control studies for two specific interventions (*Whose Future is it Anyway?* and *The Self-Directed IEP*), providing causal evidence of impacts. The latter will be discussed in the section, below, discussing efforts to promote self-advocacy through student involvement.

In a review of most of studies examining student involvement up 2005 (after which the aforementioned RCT studies began to be published), Test et al. (2004) conducted a narrative review of the literature to examine the impact of practices used to promote student involvement. They found 16 studies, coding each study for six variables, including (a) purpose, (b) participants/setting, (c) design, (d) dependent variables, (e) independent variable, and (f) results. The purpose of a majority of the studies was to determine the efficacy of a specific curriculum on student involvement and participation in their IEP meetings. Several studies compared the effects of student-led or student-directed IEPs to person-centered planning processes. Participants involved students across disability categories, including adolescents with intellectual disability (20% of population). Almost all studies were conducted in a special education resource room or a segregated special education classroom. In all studies using a quantitative ($n = 12$) research design, students showed increased involvement in educational planning after instruction and, for those that measured it, enhanced self-determination. Social validation measures indicated that students valued the opportunity to learn to be involved and, in one study, teachers perceived students to be more self-confident and better able to self-advocate (Mason, McGahee-Kovac, Johnson, & Stillerman, 2002). Despite these promising findings, a secondary analysis of the National Longitudinal Transition Study-2 found that only 3.3% of students with intellectual disability had a role in leading their transition planning meeting (significantly lower than their peers with learning disabilities or emotional/behavioral disorders), were less likely to provide input during their transition planning, and were more likely to report no progress toward transition goals than the other two groups of students (Katsiyannis, Zhang, Woodruff, & Dixon, 2005).

As mentioned, the literature covered to this point on promoting self-advocacy through student involvement is limited by the nature of the research (quasi-experimental pre-/post-intervention designs, some without a control group, single-case designs with an insufficient number of students or power). Studies conducted subsequently (discussed below) have provided more evidence of the positive impact of student involvement on student engagement in planning meetings, student self-advocacy, and student self-determination.

Promoting Problem Solving

Interventions to Promote Problem Solving

There have been two illustrations in previous chapters of this text of the types of interventions to promote the problem-solving skills of youth with intellectual disability that might provide direction for additional such efforts. The first is the *ESCAPE-DD* process described in Chap. 11. Unit 2 of *ESCAPE-DD* emphasizes problem-solving skills in the process of decision making. Like most decision making processes, the first step in the ESCAPE-DD decision making process is to identify what the problem is and to identify potential solutions about which a decision is to be made. The *ESCAPE-DD* curriculum is focused on enabling people with intellectual and developmental disabilities to make decisions and solve problems that enable young people to avoid high-risk situations of potential abuse, so the problems students learn to solve involve real-world situations in which students might find themselves at greater risk for abuse, neglect, and exploitation.

The second intervention incorporating problem-solving instruction that has already been discussed in this book is the Self-Determined Learning Model of Instruction (see Chap. 5), which enables teachers to teach students a self-regulated problem-solving process to set and attain goals. One element of the SDLMI involves student questions, four in each of the three phases, which, when answered by the student (with support from the teacher or facilitator) form a problem-solving process consisting of (a) identifying the problem, (b) identifying potential solutions to the problem, (c) identifying barriers to solving the problem, and (d) identifying the consequences of each solution.

Like most problem-solving models, the SDLMI problem-solving sequences are derived from a five-step model of D'Zurilla (1986): (a) problem orientation, (b) problem definition and formulation, (c) generation of alternative solutions, (d) choice of solution, and (e) solution implementation. And, it is instruction on these steps, whether in the context of processes like the SDLMI or curricula like the ESCAPE-DD or just in the context of learning to solve day-to-day problems, that lead to enhanced problem-solving skills.

General Problem-Solving Instruction

When teaching problem-solving skills, generally, instruction focuses first on problem perception—the recognition and labeling of problems. As part of this step, students should address the following questions: (a) Is the problem caused by myself or someone else? and (b) How important is the problem? Students should also learn how to estimate the time they will need to solve a problem during this step.

Second, students learn to gather as much information about the problem as possible, set problem-solving goals, and re-examine the importance of the problem's resolution to their well-being. This will allow them to better understand how to identify effective solutions.

Third, students learn to generate alternative solutions to the problem. This step is often problematic for students with disabilities. Many students with intellectual disability tend too often to focus on and stay with alternatives that are ineffective. To help solve this problem, you might provide more experiences with social problems; that is, you might expand the experience base from which the student can draw when generating alternatives; "instruction" may be as simple as expanding a student's experiences in social interactions. You also might provide instructional opportunities that would enable students to generate at least one solution for a frequently encountered social dilemma. After generating one solution, they should learn to generate a small list of alternatives, and finally to brainstorm alternatives. Many programs have been developed that follow this basic problem-solving model introduced by D'Zurilla. The following is an example of one such program.

Benjamin (1996a, b) developed programs to get students thinking about problems they encounter at school and work. Students are taught the following four-step process:

(1) Understand: Students learn, through role-playing and simulated activities, to observe and analyze the situation, to identify the problem in the situation, and to name that problem.
(2) Plan and Solve: Students are taught to think about possible options that might be a solution to the problem. If they cannot identify any existing solutions, they are taught how to access resources, such as libraries and talking to others, to generate possible solutions.
(3) Check: Once a student has identified specific solutions and selected one, the student is encouraged to see if there is still a problem. If so, what can he or she do to change the plan?
(4) Review: Students explore how they can use strategies to solve similar problems in other circumstances.

As one teaches problem solving, it is important to get students to think about the consequences of various alternatives. Teach students to determine the risk involved in each option. Students need to understand the relative risk associated with social interactions, particularly given that peer pressure is often a significant factor in whether students choose to engage in high-risk behavior such as drug, tobacco, or alcohol use.

Role-Playing. Role-playing is frequently used to teach social skills and is equally useful to teach social problem-solving skills. Role-playing provides students with practice opportunities to learn to deal with social problems; a problem is presented, a potential solution is acted out, and the outcomes of that solution are discussed. Role-playing is intended to be beneficial both for students play-acting the problem scenario and for students observing.

Implementing role-playing requires some specific teaching skills. Role-play situations are generally less structured than other instructional activities, so the teacher must maintain a balance between too much and too little control. This involves setting the various steps in motion and guiding students through the discussion and evaluation activities. Questions and comments should encourage a free and honest expression of ideas and feelings, particularly in the discussion phases. In most circumstances, teachers will want to identify the problem issues, script the role-play scenario, and generate the questions and options for alternative responses. Students can be involved in many of these activities as well.

Modeling. Modeling appropriate problem-solving skills is also an important component of instruction. Effective modeling keeps the following issues in mind:

- The modeled behavior or action needs to be clear to students, and students need to be able to easily distinguish it from other behaviors.
- The person modeling the behavior or action should be someone whom the student will want to imitate.
- The behavior or action should be modeled in circumstances that are motivating, interesting, and reinforcing.
- Teachers need to be sure that students can adequately see and hear the modeled behavior.
- The more complex a behavior or action, the more times it will need to be modeled.
- Modeling should be followed by opportunities to practice the modeled behavior.

Video and technology-based options can augment and improve both role-playing and modeling instructional activities.

Promoting Self-advocacy

Promoting General Self-advocacy Skills

Students with disabilities need to learn the skills to advocate on their own behalf. To be an effective self-advocate, students have to learn both how to advocate and what to advocate for. A staple of instruction in self-advocacy is to provide opportunities for young people to learn about their rights and related responsibilities. Such instruction often includes instruction on citizenship skills related to voting, community participation, and so forth.

When teaching students how to advocate for themselves, the focus should be on teaching students how to be assertive, how to effectively communicate their perspective (either verbally or in written or pictorial form), how to negotiate, how to compromise, and how to deal with systems and bureaucracies. Students need to be provided real-world opportunities to practice these skills. This can be done by embedding opportunities for self-advocacy within the school day, by allowing students to set up a class schedule, work out their supports with a resource room teacher or other support provider, or participate in IEP and transition meetings (as will be discussed subsequently).

Legal Rights and Citizenship Skills. Gould (1986) suggested that the primary emphasis in teaching self-advocacy should be "sensitizing transition-age students to their own needs and rights and ways of pursuing them" (p. 39). Gould described the issue of rights as central to self-advocacy and listed two types of rights: (a) legal or statutory rights that apply to citizens by virtue of laws or regulations enacted by political representatives and (b) personal or human rights that apply to everyone by common agreement. Key areas of training in citizenship rights include:

- Defining legal and citizenship rights for all citizens;
- Important legal or civil rights for individuals with disabilities;
- Responsibilities associated with citizenship;
- How laws are made and how citizens can be involved;
- What safeguards apply in cases of limitations of rights;
- How rights are protected and by whom;
- What someone should do when their legal rights are violated (Gould, 1986).

There have been a number of successful strategies developed to teach civil and legal rights to students with disabilities. Sears, Bishop, and Stevens (1989) implemented strategies to teach students with intellectual disability their Miranda rights so that they might better advocate for themselves if they encountered the criminal justice system. They suggested starting with efforts to increase literal comprehension of rights (using written materials like textbooks or other training materials), and then developing vignettes and role-playing potential situations in which the knowledge of civil and legal rights might be used.

Interactions with the legal system can be problematic for people with intellectual disability who, through a variety of factors, may be at greater risk for negative outcomes in the judicial and criminal justice system (Smith, Polloway, Patton, & Beyer, 2008). After reviewing the literature showing the potential pitfalls of people with intellectual disability engaging with the criminal justice system, Smith et al. recommended that interventions maximally empower the young person to be able to act on their own, to recognize and solve problems associated with the interaction, and to know how to advocate for himself or herself.

Teaching students about the Constitution of the United States and the Bill of Rights is one means of increasing student knowledge of civil and legal rights. This is typically an activity undertaken in secondary social studies, government, or political science classes. In many cases, students with disabilities have few, if any, opportunities to learn about these issues, either because they are not included in classes where the topics are covered or because it is not considered important to the student's educational program. However, there have been strategies developed to teach these topics to youth with disabilities. For example, Howard (1988, 1991) developed two sets of material that enable secondary teachers to teach students with disabilities, particularly students with intellectual disability, about the Constitution and Bill of Rights. The first set, We the People, is a teaching unit on the Constitution for high school students with disabilities. Materials in this set include a student-directed workbook, audio and videotapes, and student booklets on the Constitution and voting. The second set of materials, the Bill of Rights Series, incorporates multimedia elements to further students' understanding of the Bill of Rights, including cartoon-style booklets on the First Amendment, Arrest and Trial and Voting Amendments, and a card and board game. These materials stress a cooperative learning strategy, in which students work together in groups of from 2 to 5 members. Howard (1991) makes a number of suggestions to augment instruction on civil rights:

- Visit the city council or county board of supervisors [or commissioners].
- Visit a voter registration office and practice filling out forms in class.
- Take a tour of the state capitol building or legislative offices. Ask a legislator to speak to students if possible.
- Watch C-SPAN when programming takes place in the Congress.
- Write to the League of Women Voters for information about local elections.
- Analyze newspaper articles and editorials for opposing views.
- Hold a mock trial.

A third area of focus is to teach students about their rights and responsibilities under specific laws or regulations that particularly impact their lives. The Individuals with Disabilities Education Act (IDEA) is one such law and will be pertinent to all students receiving special education services. Students can learn what the Act was written to achieve, what the Act requires in the way of educational meetings and program delivery, what the law says about transition services and requires in terms of student involvement, and what procedural guidelines are in place to ensure compliance. Similar instructional efforts could target Section 504 of the Rehabilitation Act or the Americans with Disabilities Act.

Leadership and Teamwork Skills. Abery, Smith, Sharpe and Chelberg (1995) suggested that most people, with or without a disability, do not view themselves as leaders, in part because of the images of "leader" in our society. Leaders, contend Abery and colleagues, are "viewed as charismatic individuals who inspire others to action through fiery speeches. Leaders are thought of as unusually attractive, intelligent, powerful, talented and/or prosperous. Still others think of leaders as martyrs who sacrifice all for a cause" (Abery et al., 1995, p. 1).

Too often in our society, disability and leadership are often viewed as being mutually exclusive. Consequently, there have been only a limited number of efforts to promote leadership for students with disabilities (outside the context of the IEP meeting, that is). Given that the role of leader is the one that is valued by most adults in our society, this omission serves to further marginalize adults with disabilities. However, stereotypes to the contrary, most people probably have the capacity to become a leader, if one examines more closely what it means to lead. Leaders are people who guide or direct others on a course of action, influence the opinion and behavior of other people, and show the way by going in advance. Leadership can take many forms, and many leaders do not fit the stereotypes described earlier. As such, the types of skills that leaders need to possess are varied and, in some cases, redundant to skills discussed in the chapter on assertive behavior. There are a number of skills associated with leadership training, in general, which include:

- Locate and use resources that will be of benefit to the individual or group;

- Communicate effectively with the group and the public;
- Help the group to describe and communicate a common goal, objective, or vision;
- Understand group and individual needs;
- Are goal oriented, organized, and have strategic planning skills;
- Set an example for others;
- Teach and mentor others;
- Facilitate teamwork and cooperation;
- Provide feedback and evaluation;
- Resolve conflicts and solve problems;
- Direct group activities and equitably distribute resources and responsibilities.

Leadership, by definition, is contextual. That is, a leader guides or directs others in defined settings or circumstances. The most common opportunities to experience leadership roles are in group settings, such as at meetings and in clubs, volunteer organizations, religious or charitable organizations, and other groups or entities. Within an organization or group, the types of leadership roles can vary considerably. For example, taking the lead to ensure that a mailing gets out to the members of a volunteer organization requires different skills and actions than chairing a governmental committee or volunteer board of directors.

While skill development is an important part of learning to be a leader, it is also important that students have opportunities to learn to lead by leading. The educational planning process is an ideal venue in which to teach leadership skills and to provide opportunities for students to assume some leadership responsibilities, as discussed below. In addition, there are a number of school and community-based extracurricular activities, such as clubs or sports, in which students can assume leadership roles. Over the past two decades, a system of self-advocacy organizations—chapters and organizations run by people with intellectual and developmental disabilities with the focus of advocating for one's own and other's needs—has emerged and teachers can link adolescents and young people with these entities (go to http://www.sabeusa.org/ for more information).

Promoting Self-advocacy Through Student Involvement

The IEP and transition planning meetings are ideal circumstances in which students can learn and practice self-advocacy skills. Two student involvement processes have causal evidence of their impact. *The Self-Directed IEP* (SDIEP; Martin & Marshall, 1995) and *Whose Future is it Anyway?* (Wehmeyer et al., 2004), both mentioned previously, have causal evidence of their impact on student self-determination and student involvement.

The Self-Directed IEP (SDIEP; Martin & Marshall, 1995) is a process to teach students to direct their own IEP meeting. The SDIEP is part of a larger intervention, the ChoiceMaker series, focusing on teaching students goal-setting and self-advocacy skills. Using the SDIEP, students learn 11 steps for leading their own transition planning meeting, including stating the purpose of the meeting, introducing attendees, reviewing past goals and progress, stating new transition goals, summarizing goals, and closing the meeting by thanking attendees. Martin et al. (2006) provided causal evidence of increased involvement in the IEP process by students who had participated in the process. They found that students who went through the SDIEP process significantly increased the percentage of time they talked during meetings and were able to start and lead meetings. Seong, Wehmeyer, Palmer, & Little (2015) conducted a randomized-trial control group study of the impact of the SDIEP on the self-determination and transition empowerment of youth with disabilities. This study found that instruction using the SDIEP resulted in significant differences between control and treatment group students on self-determination and transition knowledge. In both cases, students who received instruction had more positive outcomes.

Whose Future is it Anyway? (WFA; Wehmeyer et al., 2004) is a student self-regulated process to promote more meaningful involvement in transition planning. Developed for students with intellectual and developmental disabilities, the WFA process consists of 36 sessions enabling students to self-direct instruction related to (1) self- and disability-awareness; (2) making decisions about transition-related outcomes; (3) identifying and securing community resources to support transition services; (4) writing and evaluating transition goals and objectives; (5) communicating effectively in small groups; and (6) developing skills to become an effective team member, leader, or self-advocate. The materials are student-directed in that they are written for students as end-users. The level of support needed by students to complete activities varies greatly. Some students with difficulty reading or writing need one-to-one support to progress through the materials; others can complete the process independently. Wehmeyer, Palmer, Lee, Williams-Diehm, and Shogren (2011) conducted a randomized-trial study of the effect of the WFA on student self-determination and transition knowledge and skills. The results indicated that instruction using the WFA process resulted in significant, positive differences in self-determination when compared with a control group and those students who received instruction gained transition knowledge and skills. (Both the ChoiceMaker materials and the WFA materials are available online at no cost at http://www.ou.edu/education/centers-and-partnerships/zarrow.html.)

Conclusions

Problem-solving skills and self-advocacy skills are important to enabling young people with intellectual and developmental disabilities to live richer, fuller lives in their communities. There has been far too little research on how to promote the problem-solving skills of youth and young adults with intellectual and developmental disabilities, but that which exists seems to confirm that when provided opportunities to do so, people with intellectual and developmental disabilities can acquire, use, and benefit from such opportunities. The same holds true for self-advocacy skills. These skill sets are essential to other critical areas in strengths-based approaches to disability, including goal setting and self-regulation, covered in the next chapter.

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Goal Setting and Attainment and Self-regulation

16

Michael L. Wehmeyer and Karrie A. Shogren

Introduction

Chapter 5 discussed issues pertaining to self-determination and Causal Agency Theory as they have impacted practice in the field of intellectual and developmental disabilities. Promoting self-determination is at the heart of the person–environment fit models of disability discussed in Chap. 2 and the Supports Paradigm discussed in Chap. 3. Goal setting and attainment skills are central to enabling people to act in a self-determined manner. Causal Agency Theory defines self-determination as:

> …dispositional characteristic manifested as acting as the causal agent in one's life. Self-determined people (i.e., causal agents) act in service to freely chosen goals. Self-determined actions function to enable a person to be the causal agent in his or her life (Shogren et al., 2015, p. 258).

Self-determined action is volitional action in service of a goal. Self-determined action is, fundamentally, goal-oriented and goal-driven action. Similarly, "the setting of goals and their translation into action is a volitional process" (Latham & Locke, 1991, p. 23). Self-determined action, therefore, can also be understood as self-regulated action. Causal Agency Theory positions self-determination with constructs that are important in understanding human agency, where action is considered not only goal-directed, but self-regulated. Human agentic theories assume that actions are volitional and that an agentic person uses self-regulated and goal-directed agentic actions to "plot and navigate a chosen course through the uncertainties and challenges of the social and ecological environments … continuously interpreting and evaluating actions and their consequences" (Little, Hawley, Henrich, & Marsland, 2002, p. 390).

In this chapter, we provide a more in-depth look at self-regulation and goal-directed action using Causal Agency Theory as a framework, and then examine what is known about promoting goal setting and attainment activities for people with intellectual and developmental disabilities.

Conceptualizing Goal Setting and Attainment and Self-regulation

Goal Setting and Attainment

Self-determined actions are purposeful; that is, people use self-determined actions to achieve an end or, more accurately, attain a goal. Thus, goal-directed behavior enables people to act as causal agents in their lives and, over time, such action leads to enhanced causal agency and self-determination. Goal setting and attainment skills, as such, are critical to agentic action and the development of self-determination. At the broadest level, goals are "mental representations

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of desired outcomes to which people are committed" (Mann, de Ridder, & Fujita, 2013, p. 488). Goals specify what a person wishes to achieve and act as regulators of human behavior, creating a sense of urgency and motivating the person to act (Mann et al., 2013). If a person sets a goal, it increases the probability that he or she will perform actions related to that goal or desired outcome (Locke & Latham, 2006). As discussed in detail subsequently, setting a goal creates a tension between a person's current state and a desired state, or goal state (Mithaug, 1996).

Goal setting is a process used to determine one's goals and what constitutes successful achievement of those goals (Mann et al., 2013), while goal attainment is the successful achievement of the goal that was set. The process of goal setting and attainment involves: (1) identifying and defining a goal clearly and concretely, (2) identifying pathways to achieve the goal, and (3) specifying and implementing the pathways most likely to achieve the desired outcome. At each step, choices and decisions must be made about what goals to pursue and what actions will lead to goal attainment.

There are many types of goals. For the purposes of this chapter, we focus on what are referred to as approach goals, which are intended to secure a wanted or desired outcome (Elliott & Dweck, 1988). Approach goals can either be performance (achievement of a specified standard) or mastery (improvement or development of a skill) focused (Elliott & Dweck, 1988). Traditionally, research has suggested that the most effective goals are those that are challenging, but not so challenging that they are unattainable (Locke & Latham, 2013). If goals are too easy, a person is not motivated to engage in actions necessary to attain them, nor is there a feeling of accomplishment after achieving them. There seems to be more benefit to goals that are a just-right fit (Mithaug, 1996), that is, challenging but not unattainable. However, recent evidence has suggested that even unattainable goals can have a positive impact with regard to motivation to act (Mann et al., 2013) if they motivate a person to strive for an outcome. This may be related to another finding with regard to goals, specifically that when goals reflect the preferences and interests of the person, motivation to take actions to pursue the goal is enhanced (Hortop, Wrosch, & Gagné, 2013). Generally, goals that have personal meaning, or come to have personal meaning, are more likely to be attained (Locke & Latham, 2002, 2006).

As people pursue goals, a number of factors impact the process of goal setting and attainment, including (a) the capability to perform causal actions, which can subdivided into causal capacity and agentic capacity, and (b) threats to and opportunities for goal-directed action that emerge in the environment and promote causal action. Figure 16.1 provides a graphic to illustrate the goal-generation sequence envisioned by Causal Agency Theory to illustrate the process by which goal setting and attainment occurs.

As discussed in Chap. 5, two essential characteristics of self-determined action include volitional actions and agentic actions. Volitional actions refer to actions based upon conscious choice that reflect one's preferences. Volitional actions involve the initiation and activation of causal capabilities—the capacity to cause something to happen in one's life—and involve initiating goals. Referring to Fig. 16.1, then, the goal action process begins with a goal-generation process that uses causal capabilities. Causal capability includes the knowledge, skills, self-perceptions, and beliefs about one's environment that enable the expression of causal action. Having the capacity to engage in goal pursuit enables a person to prioritize goals, identify what is in line with personal preferences and interests, and initiate actions that enable one to choose and pursue a goal.

The goal action schema depicted in Fig. 16.1 culminates with the employment of agentic capabilities. Agentic actions, according to Causal Agency Theory, are self-directed actions that enable people to sustain action toward achieving a goal. As discussed in Chap. 15, when acting agentically, self-determined people use pathways thinking, which identifies various ways to get to a specific end or cause or create change. The identification of pathways, or pathways thinking, is a proactive, purposive process. Agentic actions

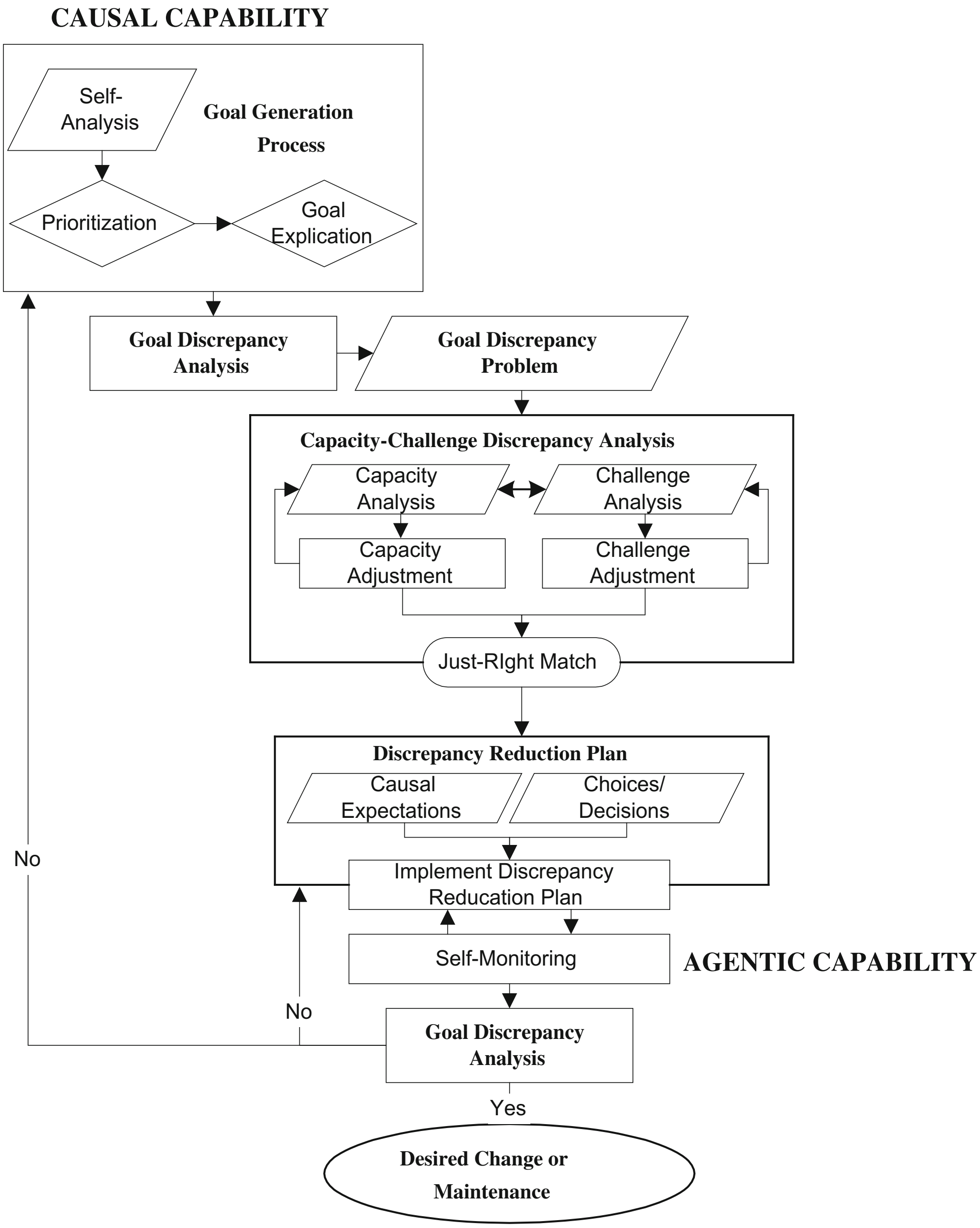

Fig. 16.1 Overview of goal action schema

are self-regulated and self-directed and enable progress toward freely chosen goals. Agentic capabilities (skills to sustain agentic action) include the skills and knowledge associated with self-management, goal attainment, problem-solving, and self-advocacy. A critical element of agentic capability is the act of comparing one's current state with one's anticipated goal state, self-regulating, and evaluating whether the chosen pathway is leading to progress toward the outcome.

Both causal and agentic capabilities work together in complex ways to achieve or maintain a desired goal. When opportunities or challenges emerge in the environment, a person begins a *goal-generation process*, consisting of self-analysis and exploration concerning one's strengths, limitations, preferences, values, and wants with regard to the environmental circumstances. After prioritizing actions, the goal state is defined in terms of the most important action. Knowledge of oneself and one's vision for the future is central to this prioritization process and the definition of the goal state. With a goal state in mind, the person then engages in a *goal-discrepancy analysis* wherein the current status and the goal status are reconciled and pathways and action steps are identified and prioritized. This is the *goal-discrepancy problem*; essentially the person needs to identify the pathways they need to take to reduce the discrepancy and achieve their goal by conducting a *capacity-challenge discrepancy* analysis. The person evaluates his or her capacity to solve the problem and examines the degree to which the challenge will support goal attainment. In this process, the person maximizes adjustment in capacity (e.g., acquires new or refines existing action skills) or adjusts the challenge presented to create a "just-right match" between capacity and challenge so as to optimize his or her probability of solving the goal-discrepancy problem (Mithaug, 1996; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003).

Next, a person creates a *discrepancy-reduction plan* that is regulated by the third essential characteristic of Causal Agency Theory, the person's action-control beliefs. As discussed in Chap. 5, such beliefs influence the expectations and choices a person makes in service of their goal. The person then monitors their progress to reduce the discrepancy between their current status and goal status, determining whether their actions led to goal attainment, or they encountered barriers and must re-evaluate their goal or the action plan. If the goal is achieved, an agentic person will return to the goal-generation process, identifying the next goal in the sequence. If the progress is satisfactory but the goal is not yet achieved, the person will continue implementing the discrepancy-reduction plan. If progress is not satisfactory, the person either reconsiders the discrepancy-reduction plan and modifies that component, or returns to the goal-generation process to re-examine the overall goal, its priority, and, possibly, cycling through the process with a revised or new goal. All of these actions require self-regulation of one's goal-directed behavior.

Self-regulation

Simply put, self-regulation is "the most widely used term referring to various processes involved in attaining and maintaining regular goals" (Day & Unsworth, 2013, p. 158). At its broadest level, self-regulation refers to "bidirectional causal interactions between individuals and their contexts" (Geldhof, Fenn, & Finders, 2017). Within Self-determination Theory, self-regulation is conceptualized as an organizational function that "coordinates" systemic behaviors and serves as a foundation for autonomy and the sense of self (Ryan & Deci, 2004). Within Causal Agency Theory, self-regulation has been broadly defined as "cognitive or self-controlled mediation of one's behavior" (Shogren et al., 2015, p. 252).

Self-regulation involves the coordinated mediation of one's interactions with one's context. This is, fundamentally, a goal-oriented process. Day and Unsworth (2013), for example, identified four "key processes" in self-regulation: "(a) goal establishment (adopting, adapting, or rejecting a goal), (b) planning (processes involved in preparing to pursue a goal), (c) striving (moving toward or maintaining a goal), and (d) revision (processes involved in changes or disengagement from a goal" (p. 159). The Self-determined Learning Model of Instruction, described in Chap. 5, is described as self-regulated problem-solving to enable students to self-direct learning, and uses processes virtually identical to those described by Day and Unsworth.

Mithaug (1993) described four "regulatory functions" in self-regulation theory: "(1) the identification of gain that will reduce a discrepancy (expectation proposition), (2) the selection of behaviors or operations that will produce that gain (choice proposition), (3) the distribution of responses between producing gain and gathering information (response proposition), (4) the gain toward total attainment produced by interactions between past gains, expectations, choices, and responses (gain proposition)" (p. 127). Returning to Fig. 16.1, one can see elements of both the key processes of self-regulation proposed by Day and Unsworth (2013) and the regulatory functions proposed by Mithaug (1993) in the goal-generation, goal-discrepancy analysis, capacity-challenge discrepancy analysis, and discrepancy-reduction plan processes.

Goal Setting, Self-regulation, and People with Intellectual and Developmental Disabilities

The literature that addresses goal setting and people with intellectual and developmental disabilities is limited. The literature pertaining to self-regulation is, however, more extensive. Researchers have examined multicomponent strategies and interventions that support the development or use of various types of self-regulation or self-management strategies, such as self-monitoring and self-evaluation. In the following sections, we will examine what known about strategies to support goal setting and attainment and self-regulation of people with intellectual and developmental disabilities.

Goal Setting and Attainment

Copeland and Hughes (2002) reviewed empirical investigations of the effects of goal setting on task performance of persons with intellectual disability and identified 17 articles that used either group experimental designs or single-subject designs studies. In 15 of these 17 research reports, there was evidence of increases or improvements in task performance following instruction in goal setting skills (Copeland & Hughes, 2002). However, Copeland and Hughes found that the outcomes targeted by goal setting were rather limited: 65% looked at the impact of goal setting on rate and accuracy of sorting and assembly tasks; these were mainly older studies focused on improving the performance of people with intellectual disability on tasks common in sheltered employment. However, this does not mean that goal setting instruction and supports are not effective in integrated employment settings; it simply reflects that most research was being conducted in segregated settings at this time. In terms of children and youth with intellectual and developmental disabilities and goal setting and attainment, only two studies examined the impact of goals on academic tasks for this population. Gardner and Gardner (1978) incorporated goal setting as an instructional strategy to improve performance on spelling and vocabulary tests, and found that students who were provided direct instruction on goal setting scored significantly higher on both spelling and vocabulary post-tests. Warner and DeJung (1971) examined goal and no-goal groups' performance on spelling tasks and found that the goal setting group performed significantly better on a spelling post-test, although there were no effects of hard versus easy goals.

So, what has been found since the Copeland and Hughes review in 2002? In some ways, quite a bit, if one considers the literature examining the impact of multicomponent interventions that incorporate goal setting as part of self-management or self-regulation interventions. On the other hand, studies specifically examining goal setting, as a stand-alone intervention, by people with intellectual and developmental disabilities are still rare. In fact, to our knowledge, only one such study has been published in the past decade. McConkey and Collins (2010) conducted a study in which adults with intellectual disability were supported to set social inclusion goals they wanted to achieve in a 9-month period. After the first 9-month period, 57% of the 130 participants with intellectual disability had attained one of the goals they had set. Importantly, people who lived in smaller community-based settings were significantly more likely to have attained goals.

Self-regulation

As noted, the scarcity of studies examining the impact of goal setting, itself, on outcomes that impact the lives of people with intellectual and developmental disabilities is, to some degree, mediated by the proliferation of research incorporating multicomponent interventions to promote self-regulation and self-determination that incorporate goal setting as one element of the instruction or support provided. We begin this section with a broad overview of the impact of stand-alone self-regulation strategies, particularly self-monitoring and self-evaluation, with people with intellectual and developmental disabilities.

Self-regulation strategies. The most commonly implemented self-regulation strategies involve self-instruction, self-monitoring, and self-evaluation and self-reinforcement. *Self-instruction* involves teaching students to provide their own verbal cues prior to the execution of target behaviors. Students and adults with intellectual disability have been taught to use self-instruction to solve a variety of work problems, including to complete multistep sequences and generalize responding across changing work environments (Wehmeyer et al., 2007).

Self-monitoring involves teaching students to observe whether they have performed a targeted behavior and whether the response met whatever existing criteria were present. Teaching students self-monitoring strategies has been shown to improve critical learning skills and classroom involvement skills of students with intellectual disability (Agran et al., 2005; Hughes et al., 2002) as well as to promote access to the general education curriculum for students with intellectual disability (Agran, Wehmeyer, Cavin, & Palmer, 2008, 2010; Wehmeyer, Hughes, Agran, Garner, & Yeager, 2003). In adults, Woods and Martin (2004) found that teaching supported employees to self-manage and self-regulate work tasks improved work performance and employers' perceptions of the employee.

Self-evaluation and *self-reinforcement* involve teaching people to compare their performance (as tracked through self-monitoring) with a desired goal or outcome and to administer consequences to themselves (e.g., verbally telling themselves they did a good job). Self-reinforcement allows people to provide themselves with reinforcers that are accessible and immediate. Given access to self-administered reinforcement, behavior change may be greatly facilitated and the combined use of self-evaluation and self-reinforcement has been shown to improve generalization of learning (Agran, King-Sears, Wehmeyer, & Copeland, 2003).

Multicomponent strategies. Most interventions that incorporate self-regulation strategies do not implement them individually, but as part of a multicomponent package containing multiple self-regulation strategies and goal setting instruction and supports. Cobb, Lehmann, Newman-Gonchar, and Alwell (2009) conducted a narrative metasynthesis of interventions to promote self-determination. A metasynthesis is a review of existing meta-analytic and systematic reviews on a topic. The Cobb et al. metasynthesis concluded that the most effect interventions to promote self-determination were interventions that had multiple components. This confirms the power of combining elements such as self-monitoring, self-instruction, and goal setting into a multicomponent intervention. The Self-Determined Learning Model of Instruction, discussed in Chap. 5 and in some more detail subsequently, is itself a multicomponent intervention, incorporating goal setting, self-monitoring, self-evaluation, problem-solving, and several other components. In another example of multicomponent intervention used to support people with intellectual disability, Copeland, Hughes, Agran, Wehmeyer, and Fowler (2002) implemented an intervention to support improved classroom performance by high school students with intellectual disability in general education settings. The intervention included (a) modification of teacher-assigned worksheets, (b) instruction for students in assignment completion strategies, (c) instruction for students in self-monitoring of classroom performance skills, (d) including students in setting performance goals, and (e) instruction for students in goal progress self-evaluation. Students receiving the intervention learned to participate in goal setting, learned to self-monitor and self-evaluate their progress toward their goals, and showed improved classroom performance.

Self-determined Learning Model of Instruction. Because research has established the importance of promoting the self-determination of students with disabilities, most of the multicomponent interventions that involve goal setting and self-regulation strategies have been implemented in service of promoting self-determination and improving student and school outcomes. And, the majority of that research has involved the Self-determined Learning Model of Instruction (SDLMI), discussed in Chap. 5. We will not reiterate the SDLMI process in this chapter (readers are referred to Chap. 5), but will simply note that the SDLMI is a model of teaching that enables teachers to teach students to self-regulate problem-solving leading to goal setting and attainment. Students are at the center of this goal setting process and use a series of questions to enable them to solve problems (What is my Goal? What is my Plan? What have I learned?) that enable them to set goals, monitor their progress toward the goal, and adjust the action plan or goal as needed to be able to attain the goal.

As discussed in Chap. 5, there are many studies at various levels of evidence supporting the efficacy of the SDLMI. There are multiple studies using randomized control trial designs providing causal evidence with regard to the efficacy of the SDLMI to promote self-determination (Lee, Wehmeyer, Soukup, & Palmer, 2010; Wehmeyer et al., 2012) and more positive school-related outcomes, including educational goal attainment (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012). In addition, there are more than a dozen single-case design studies that have examined the efficacy of the SDLMI. Lee, Wehmeyer, and Shogren (2015) conducted a meta-analysis of single-case design studies evaluating the SDLMI. They identified 15 studies published in peer-reviewed journals between 2002 and 2012 with a total of 50 participants. Eleven of the participants were elementary-school age students, 25 were middle and high school students, and 14 were 18–21 years of age. Twenty-nine (58%) were students with intellectual disability. The overall Percent Non-Overlapping Data (PND) across all participants was 79.8% (scores between 70 and 90% are considered effective treatments). So, the SDLMI is an example of a multicomponent intervention that incorporates goal setting and self-regulation strategies that has been shown to be effective across multiple educational and transition domains, across age-groups, and across disability categories, but particularly for adolescents with intellectual and developmental disabilities.

In summary, then, it is evident that people with intellectual and developmental disabilities can participate in the goal setting process and in doing so can lead to multiple positive outcomes related to learning and functional (e.g., employment, community living) outcomes. There is, however, a need for research to examine in greater detail what aspects of goals contribute to greater goal attainment for this population.

Promoting Goal Setting, Goal Attainment, and Self-regulation

Teaching anyone, including people with intellectual and developmental disabilities, to set goals involves instruction on the series of steps that move a person from goal identification to goal articulation. There are obviously many domains that instruction on goal setting can occur within, but to illustrate the process of teaching goal setting skills, we will focus on learning goals, given the importance of teaching these skills to children and adolescents. However, any of these strategies can also be applied across the life span by anyone who is supporting people with intellectual and developmental disabilities.

Teaching Goal Setting Skills

Step 1: Identify the goal. The first step in setting a goal is to identify the goal or target. This starts by having students think about what they want or need to learn. This may be as straightforward as the person identifying the performance standards associated with a given content area, or students may need to consider their present knowledge about or mastery of content information or skills to identify what the next step in the learning process would be.

Step 2: Write the goal. Having the student write (or dictate to be written) a goal serves a number of purposes, including making it more real to the student, ensuring that the goal will not be forgotten, and providing a starting point for refining the goal. To begin with, have the student simply write what it is that he or she sees as the goal. Once that is done, work with the student to expand or revise the goal to ensure the following characteristics or features:

Is the goal so clear and specific that students know immediately whether or not they have met it? Doll and Sands (2005) noted that students may have a tendency to express goals in vague or broad terms. As a starting point, then, students need to refine their goal to be sure that the behaviors and outcomes are clear and stated precisely. For performance goals, the outcome must be clearly and specifically described. For process goals, the actions or processes to be implemented must, likewise, be clear and specific. Goal specificity can be linked to goal measurability, as discussed subsequently.

Kish (1991) noted a number of potential barriers to setting clear and specific goals:

1. *Lack of knowledge and information*—Some adolescents cannot set goals because they lack information or knowledge. Providing necessary information is an important step in the goal setting process because it may help students develop a new perspective on their problems.
2. *Lack of skills*—A lack of skills may prevent students from setting and attaining goals. Teachers may need to help students develop specific skills such as assertiveness, problem-solving, self-management, communication, and decision making in order to proceed with the goal setting process.
3. *Risk taking*—Fear of taking risks may interfere with goal setting. Teachers may need to help students overcome their fear of risk taking through strategies such as role-play.
4. *Lack of social supports*—Students with disabilities too often have few supportive relationships. Helping them develop support networks may facilitate goal attainment.

Is there a time established for the accomplishment of the goal? Goals only regulate behavior when they cause us to act, and setting specific deadlines by which to achieve a goal, or steps in the goal process, is one way to regulate our action. Shorter-duration goals are more likely to be linked to positive performance. Given that students with intellectual disability may have difficulty conceptualizing “time” and may not understand the time frame within which longer-term goals should be achieved, a focus on shorter-duration goals can be affective, particularly when teaching goal setting skills.

In some cases, it may also be most effective to have the goal delineate a starting date as well as a completion date. A start time, date, or event provides impetus to begin working toward a goal. The start date should be within the near future. If it is in the too distant future, the goal may be forgotten or it may no longer be an appropriate goal when the time comes to start working on it. Starting and completion dates are also helpful in estimating the total time for goal completion.

Is the goal measurable? Clarity and specificity are important so that students know when they have achieved a goal. This, in turn, leads to the importance of ensuring that such progress is measurable. Goals should be defined in terms of observable or measurable outcomes. Encourage the use of specific measures (e.g., frequency or percent correct, hours of effort) so that it will be easy to determine when the goal was met.

Can the goal be broken into component steps or objectives? Objectives are the actions or steps needed to achieve a goal. Objectives can be used as a measure of progress and to provide milestones for reaching a goal. In fact, the process of laying out objectives may also be helpful in evaluating the appropriateness of a goal. If there are too many objectives, maybe the goal is too complex and needs to be broken into several smaller goals. A well-defined goal will have clear objectives that are easily measurable.

Is the goal written to be positive and future oriented? Goals should be written in a positive manner. The goal should project something that is increased, gained, or added rather than something that is restricted, taken away, or reduced. The goal should result in something good, such as better health, greater professional expertise, or a more organized office.

Is the goal attainable? This may sound like it is redundant to previous considerations, but in fact it is worth considering on its own merit. Certainly, aspects such as completion time and goal measurability will come into play with regard to goal attainment, but there are other factors that impact this outcome as well. For example, is the goal something that the student actually has control over and can modify, change, or otherwise ensure progress? Another factor might be that the goal is too advanced. Again, research shows that harder (though still attainable) goals lead to greater effort, persistence, and thus enhanced performance when compared to easy goals, but the "tough but still attainable" caveat to that rule is important. Goals that are too hard or too far away from attainment decrease motivation and persistence.

Teaching Goal Attainment

Once the student has set a goal that takes into account the above-noted conditions, they must then focus on attaining that goal. This involves several more steps.

Step 3: Create an action plan. An action plan describes the strategies students will implement to achieve the goal they have set and establishes how they will monitor that progress. A student should consider some of the following issues when creating an action plan:

What strategies or actions will be needed to achieve the goal? Teachers should support students to identify instructional and other strategies or actions that will help them close the gap between their current performance or mastery and their goal performance level. Sometimes, those actions involve student acquisition of new knowledge and skills, and in many cases, students do not know all the strategies they can use. As such, teachers can provide that information.

What resources will be needed to implement the action plan? Resources can be broadly understood to include needed materials, transportation, and adult or peer assistance. The action plan should include specific information on the resources that will be needed and how those resources will be obtained.

What schedule will be needed to implement the strategies or actions? Students need to determine how often and when they are going to work on the activities leading to the goal. Teaching students self-scheduling procedures can be valuable in this context.

What process will be used to measure time spent implementing the action plan? Students will need to track how often they work on their action plan so that when they evaluate their progress toward the goal, they can decide whether the commitment to the action plan has been sufficient.

What self-monitoring strategy will be implemented to monitor progress? Every action plan should include a specific self-monitoring strategy that will enable students to collect data with regard to their goal attainment progress. It will be important to establish baseline levels of performance using these self-monitoring strategies, with which students can compare future performance.

What other sources of feedback can provide information about progress? In addition to the data generated through the self-monitoring procedure, there may be other sources of data or feedback that students can tap into and which will make their self-evaluation more effective.

What schedule will be needed to track progress toward the goal? Just as student engagement in activities specified in the action plan should be scheduled, so too intervals at which data will be collected should be scheduled. In general, more frequent data collection is preferable. Teachers can work with students to teach them how to record the data they are gathering in ways that will assist in evaluating their progress.

Step 4: Evaluate progress and adjust plan or Goal. In evaluating their progress toward their goal, students should be taught to use data collected through the self-monitoring process and through other means of obtaining information to determine the following issues:

Is my progress adequate? All of the self-evaluation processes involve comparing current status versus goal status. Students should use data collected to determine whether they have reached their goal. If not, they need to determine whether they have made progress from their baseline level. If progress has been made, students should determine whether the progress is adequate given the timeline set in the original goal. If so, the action the student will take will be to continue implementation of the action plan.

If the student determines that they are making progress, but are not on course to meet the deadlines established in the goal, they should reconsider the frequency, duration, or intensity in which they are involved with or engaged in the action or strategies set in the goal.

If the student determines that they have not made any progress toward the goal or if they have readjusted their action plan several times and still does not seem to be on track to complete the goal in a timely manner, then they will need to revisit the goal and adjust it accordingly. It may be that the goal was too broad or was addressing an outcome that was too hard or too distant. In most cases, students will want to look at the objectives they developed and determine whether one of those might be a better goal, serving as an intermediary step between current status and the longer-term goal. Optionally, students may just want to revise the timeline set. Whatever the action, the key is that the student uses the information from the evaluation to adjust their plan or goal.

Teaching Self-regulation Skills

Students with intellectual disability can learn to self-instruct, self-monitor, and self-evaluate, and if they do so, they benefit and can apply these skills in the process of setting and going after goals. The following sections will review effective strategies to teach self-regulation skills.

Teaching self-instruction skills. Hughes and Carter (2000) provided a training sequence for teaching students to self-instruct.

Step 1: Provide rationale. The first step in the process is to provide a rationale to the student on the value of self-instruction. The reasons for this are obvious: By informing the student about the intervention, it allows them to have a better understanding about what will be done and why. This is, of course, particularly important for an intervention that is student-directed, since the effectiveness of the intervention will be contingent on the student's commitment to its use. As such, the teacher must make effort to inform the student about the appropriateness of the strategy for the particular target behavior selected. Ideally, a situation can be created in which the student is provided the opportunity to select both the target behavior and the self-directed strategy, since this will enhance the student's ownership to the desired change and the intervention. Needless to say, target behavior selection should be based on the student's wishes, preferences, and self-determined needs, with input from parents, teachers, and related personnel or peers. Based on this selection, specified student-directed strategies (e.g., self-instruction, self-monitoring) are suggested, based on demonstrated effectiveness, ease of use, and, of course, the student's preferences.

Regarding self-instruction, one point should be emphasized. As mentioned previously, self-instruction involves self-talk. Consequently, students aware of negative social consequences of talking aloud may be reluctant to select this strategy or consistently use it. If this is a current or potential problem for the student, it is prudent to discourage its use. However, if the student has a concern about the strategy's social acceptance but is willing to use it, the teacher may want to recommend to the student to self-instruct quietly or in a whisper so as not to get negative attention, or explore other strategies such as writing the self-instructions down or using technology.

Step 2: Teacher models self-instruction. This step involves the target behavior and the related self-instructions. For this step, the teacher models the behavior and the self-instructions and the student observes.

Step 3: Student performs and teacher instructs. As in Step 2, this step involves task completion and self-instruction; however, in Step 3, the student performs the task and the teacher self-instructs. An assumption that being made in this teaching sequence is that performing the task and self-instructing may be too daunting for many students, hence the reason for phasing in the self-instructions.

Step 4: Student performs and instructs. In this step, the student is asked to repeat the self-instructions and to perform the target behavior. After observing the teacher demonstrate both the self-instructions and task performance, the student is supported to perform what they have observed in previous phases.

Teaching self-monitoring skills. Agran, King-Sears, Wehmeyer, and Copeland (2003) provided steps to teaching students to self-monitor.

Step 1: Introduce the behavior to be self-monitored. In Steps 1–3, teachers work with students to identify the specific behavior that students will self-monitor, but the self-monitoring process is not used yet. The focus is initially on naming the behavior and showing examples and non-examples of the target behavior. Later steps will incorporate using self-monitoring in role-play and then the natural setting, but these issues are not the focus for initial steps. Usually, students are involved in Steps 1–3 for one instructional session, and then they move to the next sequence of steps.

In this step, teachers work with students to name the desired behavior and demonstrate examples and non-examples. Teachers often find it easiest to begin with the non-examples for Step 1, as those are the behaviors that the student is already doing that the teacher wants to see changed. What is most helpful for students, however, is to put more specific names on those non-examples; that is, being off-task looks like a student staring into space, or playing with the calculator instead of using it to do calculations, or talking with others about topics other than what is being taught or practiced. The focus for Step 1 is to ensure the student is familiar with the name of the desired behavior, what it looks like, and what it does not look like.

Step 2: Discuss the benefits of the desired behavior. Teacher communicates the impact of changing the targeted behavior from Step 1. In Step 2, the "why" or rationale for improving the behavior described in Step 1 is provided and/or elicited, promoting student ownership and motivation for change.

Step 3: Provide practice of the desired behavior and name the mastery criteria. The purpose of Step 3 is to ensure the student is familiar with the examples and non-examples named in Step 1, remind the student of the benefits identified in Step 2, and ensure the student can perform the desired behavior (i.e., the examples) to the desired performance level.

Step 4: Introduce self-monitoring. Step 4 focuses on teacher demonstration of the self-monitoring system. Students are not responsible, at this stage, for proficiently and independently using self-monitoring. Instead, they are simply introduced to the self-monitoring system and shown how to use it. For many students, these steps can be accomplished in one instructional session. For some students, the self-monitoring system will be a tally card where the student makes a symbol to indicate they are on-task, an index card divided into two columns indicating appropriate or inappropriate behaviors, or a worksheet with yes/no responses so that students can record whether they were paying attention and following directions or not. For other students, self-monitoring could be putting a marble in a jar for each self-initiated behavior, placing a checkmark after a picture indicating a task is completed, or moving an object from one side of a magnet board to another to indicate that they are on the next problem. Pictures and objects are appropriate to use on self-monitoring devices for younger students or students who have limited expressive language skills. Commercially available picture communication systems are excellent resources from which to select pictures, and some teachers may select to use technology as or with a self-monitoring device.

At this point, teachers show students the self-monitoring system, tell the students how to use it, and remind students the benefits of using self-monitoring to enhance specific behaviors. The teacher also should work with the student to determine what will cue the student to self-monitor. A variety of cueing systems can be used, and most are audible cues, from timers, to alarms on smartphones, to natural events (when a teacher gives a direction, when it is time to change activities).

Step 5: Model the self-monitoring process while performing the desired behavior. During this step, teachers go beyond telling the student about the self-monitoring device and how to use it—the teacher thinks aloud as if they were the student and talks about how to make decisions for notations on the self-monitoring device. During this modeling step, it is helpful for the teacher to fill out the self-monitoring system using the examples and non-examples of the targeted behavior. In other words, the teacher's modeling includes the decision making that students will need to discriminate whether their behaviors were appropriate or inappropriate. If a teacher only focuses on appropriate behaviors, then the student will be less clear about how to record or monitor inappropriate behaviors.

Most instructional time is spent in Steps 6 and 7, when the students practice using the self-monitoring procedures in role-play situations. Then, the specific situation or setting in which the students will use self-monitoring is discussed, and practice sessions are provided. When students begin using self-monitoring independently in the natural setting, teachers continue data collection (which began in the initial phase when teachers measured students' current performance level of a behavior) so that they can determine whether self-monitoring has achieved its intended outcome—students assuming more control over their own behaviors.

Step 6: Provide guided practice for using self-monitoring and role-play the desired behavior. This step involves the student's practice of the strategy. Prior to this, only demonstration has occurred. Now, the students begin to use the self-monitoring system more and more on their own, but within controlled or role-play situations.

Step 7: Assess student's mastery of self-monitoring within role-play situations. After several role-play situations have occurred, consider using a checklist to assess how well the students can use self-monitoring and whether students remember why they are using self-monitoring (i.e., the benefits and motivation for them to enhance behaviors). Some students and teachers initially consider this checklist assessment a "test," but it is not a test. In fact, some teachers find it very beneficial to share the checklist with students so they know in advance what they need to do well and remember. Continue role-plays during this step, since students are not expected to demonstrate mastery on their first try. Consider that Step 7 is continued guided practice in which the students' proficiency with using self-monitoring increases with continued use.

Step 8: Discuss the authentic situations in which self-monitoring will be used. Although teachers' goals may be to have the student effectively self-monitor across the school day, it is generally better to target one natural situation and focus there initially. In this way, success with self-monitoring is more easily observed (e.g., teachers are focused on one specific situation or time frame instead of the whole day), feedback specific to one situation is more efficient to provide (because the teacher has been able to observe during that situation), and both the teacher and the student will find it more motivational to use self-monitoring in other situations once success in one situation has been achieved. Discuss the real situation with the student—specifically, when and where to use self-monitoring. Consider during Step 8 any logistical factors that will need to be worked out for a student to get and return the self-monitoring system from a specific place.

Step 9: Provide independent practice opportunities within the natural situation. Students may not need a lot of additional practice opportunities, but teachers should alternate between this and the next step to determine how much practice as necessary.

Step 10: Assess student's master of self-monitoring within the natural setting. When a student begins using self-monitoring in the natural setting, more frequent observations are necessary to ensure the monitoring process is being used appropriately. As a student's proficiency becomes evident, the teacher can decrease observations. When a teacher does not follow-up on the student's use of self-monitoring, the student may inadvertently receive the message that it no longer matters. A suggestion is to gradually decrease observations across time, then observe intermittently and unannounced, and also follow-up directly with the student to receive feedback, provide reinforcement, and check to make sure the self-monitoring system is having the desired impact.

Teaching self-evaluation skills. Put simply, self-evaluation involves teaching students to both monitor their behavior and determine whether their performance meets a standard. The instructional process for teaching self-evaluation mirrors the 10 steps for teaching self-monitoring, except teachers are introducing a self-evaluation system (and students practice and master that). Data come, typically, from the self-monitoring process. Self-evaluation rating systems can use pictures, numbers, phrases, or letters that represent a range of performances.

Conclusions

Goal setting and attainment and self-regulation skills are at the heart of efforts to promote self-determination and to apply principles and practices in positive psychology to the lives of people with intellectual and developmental disabilities. Although goal setting as a stand-alone intervention has not been extensively studied, goal setting and attainment as a component of multicomponent interventions to implement self-regulation strategies has been well established as an effective practice in promoting positive outcomes across the life span. It is clear that people with intellectual and developmental disabilities can benefit from efforts to promote goal setting and attainment and the use of self-regulation strategies and, when they do, benefit across multiple life domains.

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Supported Decision-Making as an Alternative to Guardianship

17

Jonathan G. Martinis, Tina M. Campanella, Peter Blanck, Michael L. Wehmeyer and Karrie A. Shogren

Self-determination, as discussed in detail in Chap. 5, has been shown to contribute to more positive quality of life outcomes for people with intellectual and developmental disabilities (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1997). This is likely to be the case because, as discussed in Chap. 5, people who are more self-determined are more likely to be integrated into their community, employed, and safer (Khemka, Hickson, & Reynolds, 2005; Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2013; Wehmeyer & Palmer, 2003). By the same token, when people with disabilities have limited self-determination, their quality of life diminishes. Research on motivation using Self-Determination Theory (discussed in Chap. 19) has shown that people who are not autonomously motivated can feel "helpless, hopeless, and self-critical" (Deci, 1975, p. 208) and experience symptoms similar to clinical depression, including "low self-esteem, passivity, and feelings of inadequacy and incompetency," severely impacting their ability to function (Winnick, 1995, p. 21).

Societies have long appointed others—such as guardians, and other substitute decision-makers—for people they deem "by reason of age or disability … incapable of making such decisions for themselves" (Winick, 1995, p. 27). Legally authorized substituted decision-making began as early as in ancient Rome, where *curators* were appointed for people with disabilities (Fleming & Robinson, 1993). The practice continued in England, for example, through the early 1324 statute, *De Praerogativa Regis*, authorizing appointment of "committees" to make decisions for "idiots" and "lunatics" (O'Sullivan, 2002; Regan, 1972). Years later, the USA followed this tradition, granting state courts the authority to appoint guardians (O'Sullivan, 2002). Even today, while each state has its own guardianship laws, a person with a disability typically is placed under a guardianship arrangement when the court determines that he or she cannot make decisions, and when there are believed to be no other decision-making options that would be less-restrictive than guardianship (Blanck & Martinis, 2015; Quality Trust for Individuals with Disabilities, 2013).

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Throughout its history, guardianship has been viewed as benevolent and non adversarial because "all parties were on the same side in seeking the well-being of the respondent/ward" (Wright, 2010, p. 352). Consequently, there remains a fundamental disconnect between modern research on the importance of self-determination and current views and practice of guardianship (Millar, 2007). Overly broad and undue guardianship, for example, a plenary guardianship, imposed on an individual who is able to make his or her own decisions (Hatch, Crane, & Martinis, 2015), "not only divests the individual of the important right to self-determination but also marginalizes that person and removes him or her from a host of interactions involved in decision making" (Salzman, 2010, p. 160).

People with intellectual and developmental disabilities subjected to such guardianships often experience a "significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010, p. 354). This effect has been compounded by the fact that, historically, professional practices have questioned the capacity of people with intellectual and developmental disabilities to make their own decisions (see Chap. 11 for full discussion of decision-making skills and people with intellectual and developmental disabilities) and have imposed legally mandated limitations on personal control (Blanck, 1998, 2016). Many times, stereotyped judgements about individual capacity are reached, even though opportunities for life experience and learning related to decision-making have been limited or nonexistent.

In spite of growing evidence to the contrary, society continues "to hold deeply embedded tendencies toward protection over autonomy, and courts continue to issue guardianship orders that are not necessary and are overly broad in scope" (Salzman, 2010, p. 178). Indeed, despite federal laws and policies mandating equal protections for people with disabilities and, as such, ensuring greater freedom and liberty (e.g., Americans with Disabilities Act, 2006; Developmental Disabilities and Bill of Rights Act, 2006; Rehabilitation Act of 1973, 2014), the number of American adults placed under guardianship has approximately tripled during the years from 1995 to 2011 (Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011). Only recently have state legislatures, state and federal policymakers, and researchers and practitioners acknowledged the need to implement decision-making options that are less-restrictive than plenary guardianship to advance individual self-determination (Kohn, Blumenthal, & Campbell, 2013).

Supported Decision-Making as an Alternative to Guardianship

Supported Decision-Making (SDM) is "an alternative to and an evolution from guardianship" (Martinis, 2015a, p 109). While there is no singular model of SDM (Quality Trust for Individuals with Disabilities, 2013), in general, people use SDM when they engage meaningfully with friends, family members, and professionals to understand the daily situations and choices they face in order to make their own decisions (Blanck & Martinis, 2015). In this way, SDM is similar to "what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents and consent to medical procedures: they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices" (Martinis, 2015a, p. 109).

Although Canada's province British Columbia, Sweden, and certain German states had already enacted versions of SDM, international recognition and momentum in favor of SDM was spurred by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (Dinerstein, Grewel, & Martinis, 2016). Entered into force in 2008, and thereafter ratified by over 150 countries, the CRPD addresses areas critical to the human rights of people with disabilities around the world, including access to employment, community integration, recreation, voting, and health care (United Nations, 2006). Article 12 of the CRPD creates a right to and legal mandate for SDM, declaring that all "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and have a right to the "support they may require in exercising their legal capacity" (United Nations, 2006, p. 9).

In the USA, SDM increasingly is recognized and implemented as an alternative to plenary guardianship (Kohn et al., 2013). In 2012, a New York state court terminated the guardianship of Dameris L. because she is "able to engage in supported decision making" (*In re Dameris L.*, 2012). The court stated "proof that a person with an intellectual disability *needs* a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends, and mental health professionals" (*In re Dameris L.*, 2012). The court hailed Damaris' SDM network of people who "understood [their] role, not as deciding for her, but in assisting her in making her own decisions," as "a perfect example of the kind of family and community support that enables a person with an intellectual disability to make, act on, and have her decisions legally recognized" (*In re Dameris L.*, 2012).

In 2013, in a case described in detail below, Margaret "Jenny" Hatch, a woman with Down syndrome, defeated a petition to place her under a permanent plenary guardianship because she had established an effective SDM network (*Ross v. Hatch*, 2013). At trial, Ms. Hatch presented evidence that she worked with supportive friends and professionals to make her own decisions. The court named Ms. Hatch's preferred supporters as her temporary limited guardians for one year, "with the … goal of transitioning to the supportive [*sic*] decision making model." In so ruling, the court charged the temporary guardians to "assist [Ms. Hatch] in making and implementing decisions we have heard termed 'supported decision making'" (*Ross v. Hatch,* Final Order, 2013).

In the USA, state legislatures, policymakers, and professional organizations have begun to recognize and recommend SDM as an alternative to guardianship. In 2009, the Texas State legislature passed legislation authorizing and funding a pilot program to "promote the provision of supported decision making services to persons with intellectual and developmental disabilities and persons with other cognitive disabilities who live in the community" [Tx. Gov't Code Ann. § 531.02446 (2009) (expired on Sept. 1, 2013)]. The program utilized volunteers trained to support people with disabilities in making "life decisions such as where the person wants to live, who the person wants to live with, and where the person wants to work, without impeding the self-determination of the person." After the pilot program expired, Texas passed a new law recognizing "Supports and Services"—formal and informal resources and assistance enabling people to care for their health, manage their finances, and make personal decisions—as an alternative to guardianship (Tex. Est. Code Ann. §1101.101, 2015). Texas also amended its guardianship law to require courts to find by clear and convincing evidence that a person cannot make decisions with the assistance of such "Supports and Services" before placing the person under guardianship (Tex. Est. Code Ann. §1002.031, 2015). In addition, Texas passed other laws giving legal recognition to SDM agreements (Tex. Est. Code. Ann. §1357.003, 2015) and providing a model form that people may use to designate supporters to provide assistance in making life decisions (Tex. Est. Code. Ann. §1357.056, 2015).

In 2014, the Virginia General Assembly authorized a study of SDM and a report to "recommend strategies to improve the use of supported decision-making in the Commonwealth and ensure that individuals are consistently informed about and receive the opportunity to participate in their important life decisions" (H.J.R. 190, Reg. Sess. 2014). The resultant report called on Virginia to increase the public's knowledge and use of SDM, including amending state law to recognize SDM as a "legitimate alternative to guardianship"; creating a legal requirement that guardians be trained in and commit to using SDM; and developing a statewide, standard training on SDM for professionals (H.J.R. 190, Nov. 2014).

Also in 2014, at the US federal government level, the Administration on Community Living in the US Department for Health and Human Services made funding available to create a national training and technical assistance center on supported decision-making (Blanck & Martins, 2015). The Administration cited the importance of people "retain[ing] their own decision-making authorities … with the assistance of appropriate services and supports" (Administration on Community Living, 2014, p. 2).

In 2015, the National Guardianship Association (NGA), an organization representing more than 1000 guardians across the USA whose mission is to "advance the nationally recognized standard of excellence in guardianship" (http://www.guardianship.org/overview.htm), issued its formal position statement on Guardianship, Surrogate Decision-Making, and Supported Decision-Making. The NGA found: "Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary" (National Guardianship Association, 2015, p. 2).

Supported Decision-Making as an Alternative to Guardianship in Practice

Supported Decision-Making builds on the decades of research showing the benefits of increased self-determination for people with disabilities (Shogren et al., 2013; Wehmeyer & Schwartz, 1997) because it is "based on respect and uses the person's expressed will and preferences to guide action" (Campanella, 2015, p. 35). *Supporters* are charged to engage with the person to explore his or her interests and desires and use them as the basis for exploring and implementing possible decisions. As one leading advocate writes:

> For example, if the choice is related to where to live, support starts with seeking to understand what experience the person already has and the preferences he or she expresses. Additional activities are then planned to help the person learn about other various living options that are available and assess which option is preferred. (Campanella, 2015, p. 35).

Thus, SDM involves people and their chosen supporters discussing areas and arenas where they may want support in making decisions and exploring ways to provide that support. A *Supported Decision-Making Brainstorming Guide* developed by the American Civil Liberties Union and Quality Trust for Individuals with Disabilities encourages SDM teams to think broadly about where the person may need or want support and the types of support that can be provided, and to memorialize them in writing (American Civil Liberties Union and Quality Trust for Individuals with Disabilities, 2016). In that way, the guide gives structure to a conversation that "must remain focused on the person AND what the person wants" (Campanella, 2015, p. 36). For example, to help SDM teams explore decisions and support around what to do during the day, the guide provides the following information and suggestions:

- If she does whatever she feels like and no one ever discusses her work, activities, or social life with her, that is not supported decision-making.
- If someone else decides what she should do and who she should see and forces her to do it regardless of what she wants, that is not supported decision-making.
- Anything else—helping the person find a job based on her interests, responding to her preferences about what she does every day, teaching her to take transit to get where she wants to be, talking about safety, consent, and choice in relationships, helping her think about different options and decide which is the best fit for her—is supported decision-making (American Civil Liberties Union and Quality Trust for Individuals with Disabilities, 2016, p. 3).

Further, the guide directs teams to consider "How we work together to help the person with a disability decide how to spend his/her time" and "additional supports that we might want to start using" (American Civil Liberties Union and Quality Trust for Individuals with Disabilities, 2016, p. 3). The Brainstorming Guide, which also suggests ways to engage in SDM for financial and health care decisions, illustrates how SDM is "not a contract so much as it is an authorization. The adult authorizes another to be the person to advise and consult with them" (Jameson, Risen, Polychronis, Trader, Mizner, Martinis, & Hoyle, 2015, p. 38).

The SDM relationship may become strained, however, when the person wishes to do something that his or her supporters feel is objectively unwise or not what they would do in the situation. In such instances, supporters are encouraged to remember that all decisions made by all people, with and without disabilities, involve risk (Campanella, 2015). Therefore, the fact that a person makes a decision that others may not agree with is not and must not be seen as proof that the person cannot make decisions. Instead, it is an example of the person accepting the "Dignity of Risk" that all people have when they live independently, as full members of society, and make decisions regarding their lives (Salzman, 2010, p. 23). Accordingly, it is the supporters' obligation to "provide people with the opportunity and individualized supports needed to develop the skills and abilities needed in different situations" while always having the option of "respectfully declining to assist the person to pursue certain goals" (Campanella, 2015, p. 36). In that way, the interplay between person and supporter maintains the "relationship of give and take" that characterizes all supportive relationships (Campanella, 2015, p. 36).

Because every person makes decisions in his or her own way (Campanella, 2015), SDM can be "of more or less formality and intensity" depending upon the person's abilities and preferences (Dinerstein, 2012, p. 10). Support may include informal advice from friends, family, and others who "speak with, rather than for, the individual with a disability" (Dinerstein, 2012, p. 10). Others may opt for more formal arrangements, like private SDM agreements or legal Power of Attorney and Advanced Directives which spell out who will give support, how, and when (e.g., American Civil Liberties Union and Quality Trust for Individuals with Disabilities, 2016; National Resource Center for Supported Decision-Making, 2015). A more formal approach can involve a *Micro Board* or *Circle of Support* (e.g., Kohn et al., 2013). These differ from the "traditional" view of SDM because they typically involve a larger group of supporters, similar to a personal board of directors (e.g., Kohn, et al., 2013). In these arrangements, the group meets regularly to talk with and advise the person, offer options, and help him or her explore and consider the decisions that must be made.

These models, and other forms of SDM, are premised on supporters providing the assistance the person wants and needs "to understand relevant information, issues, and available choices, to focus attention in making decisions, to help weigh options, to ensure that decisions are based on his or her own preferences, and … to interpret and/or communicate his or her decisions to other parties" (Salzman, 2011, p. 306). Hence, in entering into and implementing SDM relationships, all parties recognize:

(1) that the person has the right to make his or her own decisions;
(2) that the person can receive support in making decisions without giving up his or her right to be the final decision-maker;
(3) that there are many ways to receive support in making or communicating decisions including "through such means as interpreter assistance, facilitated communication, assistive technologies and plain language" (Dinerstein, 2012, pp. 10–11).

Through these methods, SDM may increase self-determination by ensuring that the person is and remains the causal agent over his or her life by being the focus of the decision-making process and the final decision-maker. In contrast to traditional guardianship, which "divests the individual of the ability to make crucial self-defining decisions" (Salzman, 2011, p. 291), SDM "retains the individual as the primary decision maker, while recognizing that the individual may need some assistance … in making and communicating a decision" (Dinerstein, 2012, p. 10). Accordingly, using SDM may provide people access to the research-recognized benefits of self-determination, including increased "independence, employment, and community integration" (Blanck & Martinis, 2015, p. 31). Figure 17.1 provides a case study of one SDM case.

Illustrative International and Domestic Models of Supported Decision-Making

As has been discussed, several countries, individual states, and leading organizations have launched SDM programs and models designed to help people with disabilities access and implement the support they need and want to make their own decisions. Several such efforts are summarized in this section.

British Columbia

Since 1996, British Columbia has used its Representation Agreement Act to implement SDM-like "Representation Agreements" in which the person with disabilities appoints a "representative" to provide support (*Representation Agreement Act*, R.S.B.C. 1996, c. 405). The "representative" is then authorized to assist the person in directing his or her financial, health, and other affairs (Crane, 2015). The Representation Agreement Act deviates from recognized practices in SDM because it empowers the "representative" to disregard the person's wishes if he or she feels they are not "reasonable" (Crane, 2015, p. 195). However, Crane (2015) found that people using representation agreements worked with their representatives several times per week, suggesting that the system was increasing people's self-determination and personal involvement.

When Margaret "Jenny" Hatch was 29 years old, she lived in her own apartment in the community, held the same job for five years, had an active social life, volunteered on political campaigns, and was involved in her church (Hatch, 2015). Unfortunately, at this time, Jenny, who has Down syndrome, was injured in a car accident and had back surgery.

While she was in the hospital, the lease on her apartment expired. When no one else would take her in, she moved in with her friends, Jim Talbert and Kelly Morris (Hatch, 2015). Shortly thereafter, her parents moved for full guardianship over her (Hatch, Crane, & Martinis, 2015). They argued to the court that, due to her Down Syndrome, Jenny could not make decisions for herself (*Ross v. Hatch*, Petition, 2013).

At a preliminary court hearing, a doctor who examined Jenny testified, "She's going to need assistance to make decisions regarding her health care, her living arrangements and such like that. She will need someone to guide her and give her assistance" (*Ross v. Hatch*, 2013, see testimony of Robert Dinerstein citing doctor, p. 64). In reviewing Jenny's ability to manage her finances, understand legal issues, complete activities of daily living, the doctor noted that she may be able to do those and other things if she "had assistance" (*Ross v. Hatch*, 2013, testimony of Robert Dinerstein, p. 66). When asked what would be best for Jenny, the doctor testified:

> I believe that what would be beneficial to Jenny is that she is afforded the opportunity to have individuals around her who support her and love her, who give her the support she needs (*Ross v. Hatch*, 2013, testimony of Robert Dinerstein, p. 71)

Fig. 17.1 Supported decision-making case study

After that hearing, the court ordered Jenny into a temporary guardianship pending a full trial (*Ross v. Hatch*, Order Appointing Temporary Guardians, 2013). The guardians placed her in a segregated group home, where her cell phone was taken away, her Facebook password was changed, and she was not allowed to see her friends or go to her church (Hatch, Crane, and Martinis, 2015). Instead of working at her job, which she loved, she was forced to work in a segregated workshop where she "snapped snaps together" (Hatch, 2015). When she said she wanted to go back to her old job and church, and live with her friends, she was told "get used to living in a group home" (Hatch, 2015).

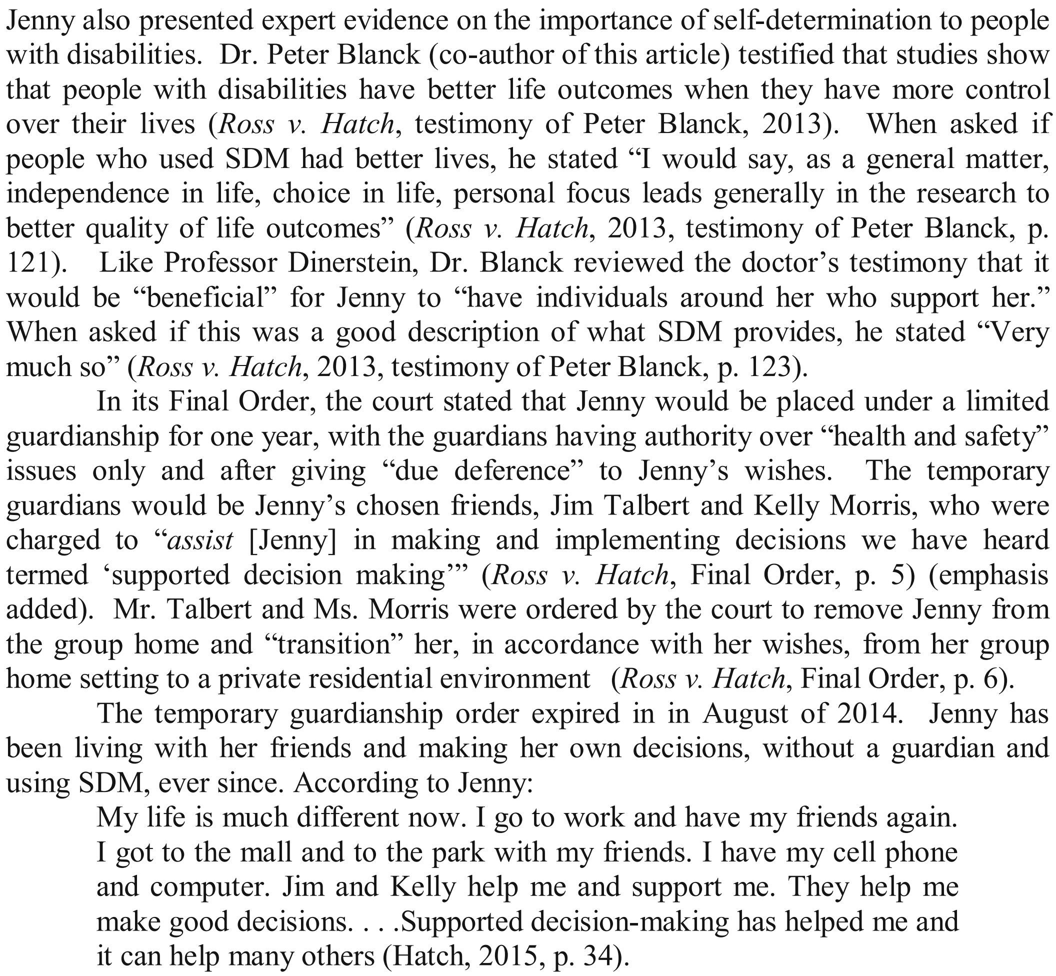
At trial, represented by the first author of this chapter, Jenny presented evidence that she can, and does, make her own decisions using SDM. An expert, Professor Robert Dinerstein, stated that the "assistance" the doctor said Jenny needs could be provided through SDM. When shown the doctor's testimony that it would be "beneficial" for Jenny to have "individuals around her who support and love her and give her the assistance that she needs," Professor Dinerstein noted that was a good description of what SDM does. He stated, "I might quote it the next time I write about this. That's exactly it. She even uses the word 'support.' Precisely" (*Ross v. Hatch*, testimony of Robert Dinerstein, p. 71). For example, Jenny could receive "assistance" to understand legal documents from people who explain them, using plain language (*Ross v. Hatch*, testimony of Robert Dinerstein, pp. 66-67 2013). Professor Dinerstein then reviewed evidence that Jenny had signed a Power of Attorney, with her parents' and an attorney's support, years before. He stated that the support they provided–explaining the document in plain language, giving her the opportunity to ask questions, taking extra time to make sure she understood it–were "textbook" examples of SDM (*Ross v. Hatch*, 2013, testimony of Robert Dinerstein, pp. 72-73).

Professor Dinerstein also reviewed evidence of support Jenny had received to apply for services, authorized release of her medical records, and take part in her Individualized Service Plan. In one instance, Jenny's case manager testified that Jenny was able to play a leading role in her Service Plan because they supported her with "Explanations, examples are given, questions asked so that she can explain herself and her questions to get the answers to put in her plan" (*Ross v. Hatch*, 2013, testimony of Robert Dinerstein, pp. 77-78). He testified that this and other examples of support Jenny received were types of SDM, stating, "I don't know that [they] realized it, but they have actually been providing supported decision-making here without naming it as such" (*Ross v. Hatch*, testimony of Robert Dinerstein, p. 2013, p. 79).

Fig. 17.1 (continued)

Sweden

In Sweden, local courts are empowered to appoint a supporter, called a *god man*, for a person with a disability who has limitations in decision-making (Herr, 2003). The *god man* is appointed by the court with duties tailored to the person's needs including "representation for individual rights (e.g., making an application on appeal for special services); supervision of financial matters (e.g., administering property), and/or attending to the person's other needs for support and guidance" (Herr, 2003, p. 6). Like the British Columbia law, however, the Swedish



Jenny also presented expert evidence on the importance of self-determination to people with disabilities. Dr. Peter Blanck (co-author of this article) testified that studies show that people with disabilities have better life outcomes when they have more control over their lives (*Ross v. Hatch*, testimony of Peter Blanck, 2013). When asked if people who used SDM had better lives, he stated "I would say, as a general matter, independence in life, choice in life, personal focus leads generally in the research to better quality of life outcomes" (*Ross v. Hatch*, 2013, testimony of Peter Blanck, p. 121). Like Professor Dinerstein, Dr. Blanck reviewed the doctor's testimony that it would be "beneficial" for Jenny to "have individuals around her who support her." When asked if this was a good description of what SDM provides, he stated "Very much so" (*Ross v. Hatch*, 2013, testimony of Peter Blanck, p. 123).

In its Final Order, the court stated that Jenny would be placed under a limited guardianship for one year, with the guardians having authority over "health and safety" issues only and after giving "due deference" to Jenny's wishes. The temporary guardians would be Jenny's chosen friends, Jim Talbert and Kelly Morris, who were charged to "*assist* [Jenny] in making and implementing decisions we have heard termed 'supported decision making'" (*Ross v. Hatch*, Final Order, p. 5) (emphasis added). Mr. Talbert and Ms. Morris were ordered by the court to remove Jenny from the group home and "transition" her, in accordance with her wishes, from her group home setting to a private residential environment (*Ross v. Hatch*, Final Order, p. 6).

The temporary guardianship order expired in in August of 2014. Jenny has been living with her friends and making her own decisions, without a guardian and using SDM, ever since. According to Jenny:

> My life is much different now. I go to work and have my friends again. I got to the mall and to the park with my friends. I have my cell phone and computer. Jim and Kelly help me and support me. They help me make good decisions. . . .Supported decision-making has helped me and it can help many others (Hatch, 2015, p. 34).

Fig. 17.1 (continued)

statute does not follow all principles of SDM. First, where SDM is a voluntary relationship between a person and the supporters he or she chooses, a *god man* may be appointed whether or not the person wants it. Also, as in the British Columbia law, the *god man* may take action or make some decisions on behalf of the person without the person's consent (Crane, 2015).

Israel

Israel is, as of this writing, the most recent country to implement SDM. In March of 2016, the Israeli Knesset amended Israel's Capacity and Guardianship Law to recognize SDM as a legal tool and alternative to guardianship. The law defines the supporter's functions, including helping the person obtain information, understand the information and the available alternatives, and execute the decision. Significantly, the law states that supporters may not make decisions on behalf of or instead of the person and requires courts to consider SDM before ordering a guardianship (Cannon, 2016).

American Models

National Resource Center for Supported Decision-Making. In 2014, after a competitive selection process, the National Resource Center for Supported Decision-Making (NRC SDM) received funding from the Administration on Community Living in the US Department for Health and Human Services to create "a national training and technical assistance center on … supported decision making" (Administration on Community Living, 2014, p. 2).

The NRC SDM works to increase knowledge and implementation of SDM through education, research, and dissemination of best practices in SDM (Blanck & Martinis, 2015). It maintains research and resource libraries, including the most recent studies and commentaries on SDM, model SDM forms from across the country, and stories of people who have successfully used SDM (National Resource Center for Supported Decision-Making, 2016a, b). The NRC SDM sponsors and engages in research to document the effects SDM has on people's quality of life and has presented to thousands of people, families, supporters, and professionals on the positive aspects and implications of SDM.

Texas. As of this writing, Texas is the only US state that has fully implemented a law recognizing SDM. The Texas law authorizes people to create, and gives legal recognition and force to, SDM agreements (Tex. Est. Code. Ann. §1357.003, 2015). Under the law, people may use a model form to designate supporters to help them with life choices and tasks such as "obtaining food, clothing, and shelter," "taking care of my physical health," and "managing my financial affairs." (Tex. Est. Code. Ann. §1357.056, 2015). People may also create their own forms, identifying areas where they choose to receive decision-making assistance, as long as the agreements are substantially similar to the model.

Massachusetts. Two Massachusetts organizations, the Center for Public Representation and Nonotuck Resource Associates, jointly operate an SDM Pilot Project designed to support people with intellectual and developmental disabilities enter into SDM agreements and create SDM networks to make decisions (Center for Public Representation, 2015). The Pilot Project works with people to develop and implement Representation Agreements to identify areas where need support in making decisions and to designate supporters to help them reach their decisions. Supporters are required to agree to respect the person's choices and decisions (Center for Public Representation, 2015).

Designing Supports to Enable Supported Decision-Making

One component of the previously mentioned National Resource Center for Supported Decision-Making involves the design of an assessment to enable people with intellectual and developmental disabilities and their support network what supports may need to be put into place to enable maximum involvement in the decision-making process. Shogren & Wehmeyer, (2015) proposed a framework within which to design such an assessment that is based upon social-ecological models of disability that emphasize disability as a "state of functioning resulting from the interaction between personal capacities and environmental or contextual demands" (Shogren & Wehmeyer, 2015, p. 19) rather than as a deficit within the person. Based upon a comprehensive review of the literature in psychology, education, social welfare, and related disciplines, Shogren, Wehmeyer, Lassman and Forber-Pratt (in press) suggested that to understand and apply supports for decision-making to enable SDM, there is a need to understand (a) contextual factors relevant to decision-making, (b) environmental demands for decision-making, and (c) supports needed for decision-making. Based on an understanding of these three domains, personalized systems of support for decision-making can be developed that facilitate self-determination and causal agency in decision-making, matched to the specific demands of the environment, personal characteristics, and support needs of each person. Ongoing activities within the NRC SDM are developing an assessment system based upon this framework that will support people with disabilities and their supporters to identify and put in place individualized supports that enable them to participate maximally in the decision-making process.

Supported Decision-Making: Next Steps

While preliminary research indicates that SDM shows promise as a means of increasing people's self-determination and improving life outcomes (Blanck & Martinis, 2015), commentators caution that presently there is a lack of data on its long-term use and effects (Kohn et al., 2013). To address this gap in research, in 2015, the Burton Blatt Institute, the Kansas University Center on Developmental Disabilities, and Quality Trust for Individuals with Disabilities began a five-year project to systematically study whether and how people who use SDM show increases in self-determination and improved life outcomes (Blanck, Wehmeyer, & Shogren, 2015).

This next-generation research on SDM will involve conducting a set of studies across the USA with hundreds of people with intellectual and developmental disabilities and other disabilities to address the present gaps in the research (Blanck et al., 2015). For example, studies will use the assessment instrument developed through the NRC SDM for primary data collection on decision-making supports, self-determination, quality of life, community living and participation, and other personal and environmental factors of interest. This data collection will be supplemented by secondary data collected on personal and environmental factors, such as individual decision-making status (i.e., guardian vs. no guardian). We will be able to explore the variables impacting SDM and examine relationships among SDM, self-determination, choice opportunities, and satisfaction with life.

Importantly, another study in this program of research involves a randomized-controlled trial intervention effort to examine a model SDM intervention program to enable people with intellectual and developmental disabilities to self-regulate problem solving when making decisions. These interventions are predicted to lead to the establishment of goals related to major life decisions, action plans to achieve those goals and make decisions, and processes to self-monitor and self-evaluate progress toward those goals and decisions. This new line of study is the first attempt to systematically and longitudinally study and document whether and, if so, to what extent, SDM is a measurably effective alternative to standard guardianship. Based on these efforts, the research program aims to develop evidence-based best practices in SDM to inform and enhance the lives of people with disabilities, supporters, educators, researchers, and practitioners.

Conclusion

Supported Decision-Making shows great promise as an alternative to traditional guardianship, and a means of increasing self-determination for people who historically have had their decision-making rights restricted, substituted, and removed. As research and best practices develop, SDM can serve as a way for people with intellectual and developmental disabilities to be and remain the "primary causal agent" (Wehmeyer, 2005, p. 117) in their lives, encouraged and empowered to make their own decisions—choices "easy and hard, silly and significant … that make us who we are and shape our life course" (Martinis, 2015b, p. 226).

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Assistive Technology

18

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Introduction

Assistive technology is the general expression used to refer to any technical device/resource that can be employed to help persons with disabilities (a) improve their general performance and social image and (b) accordingly limit the negative aspects of their disabilities (Bauer, Elsaesser, & Arthanat, 2011; Belva & Matson 2013; Brown, Schalock, & Brown, 2009; Lancioni, O’Reilly, Singh, Oliva, & Groeneweg, 2003; Lancioni, Singh, O’Reilly, Sigafoos, & Oliva 2014d; Reichle, 2011; Shih, 2011). In essence, it would be possible to suggest that the use of assistive technology is aimed at promoting the achievement of positive intervention outcomes and personal growth, with special emphasis on individuals’ final sense of success and satisfaction (happiness) more than on their limits/restrictions. One could also suggest that the use of assistive technology is an apparently functional strategy that is largely consistent with the view of Positive Psychology and makes this psychology’s objectives more realistically achievable with persons with disabilities (Paweleski, 2016a, b; Szymanski, 2000).

The devices/resources employed as assistive technology can vary widely depending on the aim of the program and the characteristics of the participants involved in it (Lancioni et al., 2016). Obviously, a program aimed at promoting communication (requests) is likely to be based on the use of speech-generating devices (SGDs) while a program aimed at promoting small responses and independent access to environmental stimulation in a largely passive, virtually motionless person is bound to be based on (a) microswitches (i.e., sensors) to record those responses and (b) a computer system to regulate stimulation access in relation to those responses (Gutowski, 1996; Mechling, 2006; Saunders, Smagner, & Saunders, 2003; Sigafoos et al., 2009, 2013). The SGD technology used could vary for different participants, based on (a) the number of requests the participants can handle (i.e., on the participants’ communication range and level of functioning), (b) the way the target requests are represented, and (c) the participants’ sensory-motor conditions (Lancioni et al., 2016). Similarly, microswitches selected for promoting small responses may differ based on the participants’ motor repertoire (i.e., on the responses viable for them). For some participants, hand or

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finger movements may represent simple and easily realistic responses that can be detected via a pressure or tilt microswitch (Lancioni, Sigafoos, O'Reilly, & Singh, 2013b). For some other participants, these movements may be largely unrealistic. For these latter participants, the most usable responses might involve eyelid or lip movements that can be detected via optic microswitches.

In light of the above, one can argue that assistive technology solutions need to be envisaged and selected in relation to the characteristics of the participants involved in the intervention programs and the general education/rehabilitation objectives of those programs (Bauer et al., 2011; Borg, Larsson, & Östergren, 2011; Burne, Knafelc, Melonis, & Heyn, 2011; Lancioni et al., 2013b). This implies that the development of technological resources needs to be pursued within a work group that includes (a) expertise in assessing the persons with disabilities and determining the most relevant education/rehabilitation objectives for them as well as (b) expertise in designing the technology and the intervention, that is, professionals who share their knowledge for planning and realizing practical technology solutions and then adapting those solutions into fitting intervention programs (Borg et al. 2011; Burne et al. 2011; Lancioni et al., 2013b, 2014d; Rispoli, Franco, van der Meer, Lang, & Camargo, 2010).

This chapter provides an overview of intervention programs based on the use of assistive technology for persons with severe/profound and multiple disabilities. Specifically, the chapter examines (a) microswitch-based programs to help persons with pervasive disabilities acquire/strengthen small responses to connect with their immediate environment, (b) microswitch-aided programs to help persons develop assisted-ambulation responses, (c) microswitch-aided programs to help persons increase adaptive responses and curb problem behaviors or incorrect postures, (d) programs based on the use of SGDs to promote communication (requests) and related engagement, (e) programs based on technology packages providing orientation cues and stimulation to promote basic activity or assembly-task engagement and mobility, and (f) programs based on technology packages to promote contact/communication with distant partners. The programs and related technology arrangements are illustrated through summary descriptions of studies published in the area. The final part of the chapter formulates a number of considerations about the studies (programs and related technologies) reviewed, analyzes the implications of the studies and their outcomes for daily contexts, and envisages some new, possible developments in the area (Lancioni et al., 2007a, Lancioni, Singh, O'Reilly, Sigafoos, & Oliva, 2014e, 2016; Rispoli et al., 2010; Sigafoos et al., 2009, Sigafoos, O'Reilly, Lancioni, & Sutherland, 2014a; Thunberg, Ahlsén, & Sandberg, 2007). Table 18.1 presents a brief map of the chapter by listing (a) the research areas covered in the chapter and (b) the studies summarized in the text for illustrating the technology and intervention conditions available within each of those areas.

Microswitch-Based Programs to Help Persons with Pervasive Disabilities Acquire/Strengthen Small Responses to Connect with Their Immediate Environment

Persons with pervasive motor and/or multiple disabilities tend to have a very poor motor repertoire and fail to establish functional contacts with the outside world. This causes the preclusion of any control of this world and of the stimulation sources available in it (Holburn, Nguyen, & Vietze, 2004; Lancioni et al., 2014e). As a consequence of this situation, those persons are generally reported to be withdrawn and passive, and to lack initiative (i.e., remaining totally dependent on others). Passivity and dependence prevent any positive development (response/skill acquisition) and can also contribute to inadequate stimulation with negative implications for the persons' sense of satisfaction and ultimately quality of life (Brown, Hatton, & Emerson, 2013). Inadequate stimulation might imply excessive or insufficient levels of environmental

Table 18.1 Chapter summary map

Areas/Studies	Number of participants	Technology to detect responses or provide instructions
Microswitch-aided programs to help persons develop small responses to connect with their immediate environment		
Lancioni et al. (2005a)	1	Optic microswitch to detect eyelid responses
Mechling (2006)	3	Pressure microswitches to detect hand/arm responses
Lancioni et al. (2007a)	1	Optic microswitch to detect eyelid and mouth responses
Lancioni et al. (2010a)	2	Camera-based microswitch to detect eyelid and mouth or eyelid responses
Lancioni et al. (2013d)	2	Optic microswitch to detect eyebrow responses
Microswitch-aided programs to foster assisted ambulation		
Lancioni et al. (2005c)	1	Optic microswitches to detect step responses
Lancioni et al. (2007d)	4	Optic microswitches to detect step responses
Lancioni et al. (2010b)	5	Optic microswitches to detect step responses
Lancioni et al. (2013g)	3	Optic microswitches to detect step or pushing responses
Microswitch-aided programs to increase adaptive responses and curb problem behaviors or postures		
Lancioni et al. (2004)	1	Optic microswitch for adaptive step responses and pressure microswitch for problem posture
Lancioni et al. (2007g)	1	Pressure microswitch for adaptive hand response and tilt microswitch for problem behavior
Lancioni et al. (2007f)	2	Wobble or vibration microswitch for adaptive hand response and optic microswitch for problem behavior
Lancioni et al. (2013e)	2	Optic, tilt, and/or vibration microswitches for adaptive hand response and optic and tilt microswitches for problem behavior
Programs based on the use of SGDs to promote communication (requests)		
Lancioni et al. (2011d)	1	SGD with five symbols/requests activated via touch response
Van der Meer et al. (2012a)	4	SGD with three symbols and one target request activated via touch response
Sigafoos et al. (2013)	2	SGD with one symbol/request activated via touch response
Lancioni et al. (2016)	3	SGD with 15 mini objects or tags for as many requests activated via touch response
Programs providing orientation cues and stimulation to promote basic activity or assembly-task engagement and mobility		
Lancioni et al. (2014a)	3	Computer-aided system providing auditory cues to guide transition across activities
Lancioni et al. (2015)	5	Computer-aided system providing auditory cues to guide transition across activities or object collection

(continued)

(continued)

Areas/Studies	Number of participants	Technology to detect responses or provide instructions
Lancioni et al. (2014b)	3	Computer-aided system providing visual cues to guide object assembling
Programs based on technology packages to promote contact/communication with distant partners		
Lancioni et al. (2013f)	2	Computer-aided system for presenting partners for phone calls and an optic microswitch for choice response
Lancioni et al. (2011c, 2014c)	3	Computer-aided system for presenting partners for phone calls and a pressure microswitch for choice response

inputs and/or forms of environmental inputs that might not be the most preferred by the persons.

Maybe the only way to modify this kind of situation is to offer the persons a chance to use one or more of their small/minimal responses functionally, that is, to establish contact with their environment and control some of the stimulation available. Such a chance can only materialize if assistive technology is employed. In this case, a microswitch-aided program would be required, in which microswitches (sensors) suitable to the persons' available responses would be monitoring the occurrence of such responses and make them instrumental for the persons to access environmental stimulation (Gutowski, 1996; Lancioni et al., 2010a; Mechling, 2006; Saunders et al., 2003). For example, a pressure or touch microswitch inside the palm of the persons' hand could enable their slight hand-closure responses to become functional to access environmental stimuli considered interesting for them (Lancioni et al., 2013b). Similarly, an optic microswitch on the wheelchair's headrest or on the side of the persons' mouth could allow their head sideward movements or mouth-opening responses to be functional to access environmental stimuli (Lancioni et al., 2014e). In practice, microswitch-aided programs may be viewed as intervention strategies, which help the participant develop or strengthen simple responses and make them functional to establish a link with the environment and successfully control specific events available in it. Those responses would be totally irrelevant (i.e., unable to have any impact on the environment) without assistive technology (Holburn et al., 2004; Lancioni et al., 2007a, b, 2013b; Mechling, 2006; Roche, Sigafoos, Lancioni, O'Reilly, & Green, 2015).

A few figures are included to provide basic information on microswitches developed for monitoring small/minimal responses. In particular, the figures show simple representations (sketches) of microswitch devices for monitoring (a) sound-emission, that is, vocal responses (Figs. 18.1 and 18.2); (b) chin- and lip/mouth-movement responses (Figs. 18.3 and 18.4); (c) eyelid responses (Figs. 18.5 and 18.6); (d) forehead skin or eyebrow movement responses (Figs. 18.7); (e) smile responses (Fig. 18.8), and (f) hand-closure responses (Fig. 18.9) (Lancioni et al., 2013b). Figure 18.10 shows a face with small dots (i.e., at the nose and lower lip) to enable a camera-based microswitch to monitor mouth-opening and/or mouth-closing movement responses (Lancioni et al., 2011a, b, 2013b).

Five studies are summarized to illustrate microswitch-aided programs for promoting small or minimal responses and making them functional to access/control environmental stimulation (Lancioni et al., 2005a, 2007e, 2010a,

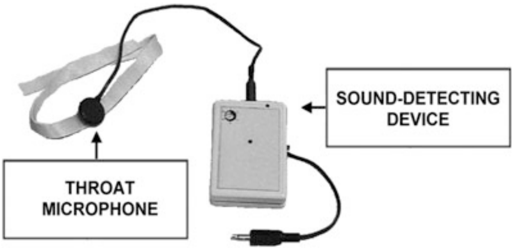

Fig. 18.1 Representation of a sound-detecting device linked to a throat microphone for monitoring vocal responses

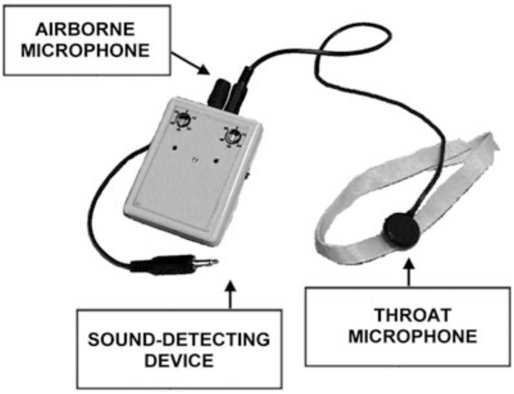

Fig. 18.2 Representation of a sound-detecting device linked to throat and airborne microphones for monitoring vocal responses

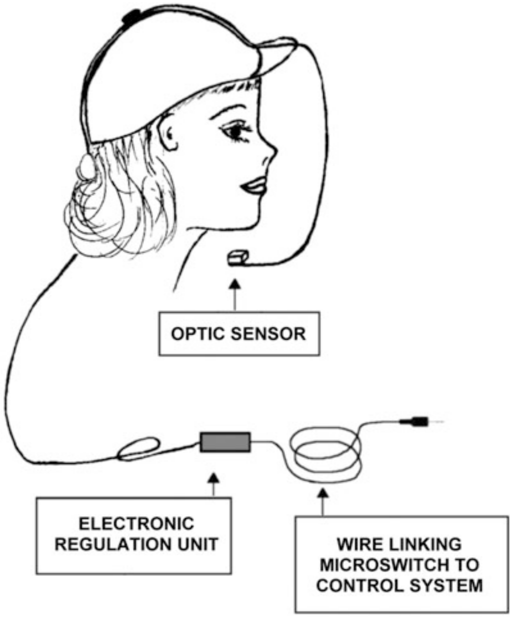

Fig. 18.3 Representation of an optic sensor held under a person's chin for monitoring chin-movement responses

2013d; Mechling, 2006). Lancioni et al. (2005a) carried out their work with a child with congenital encephalopathy, profound multiple disabilities including pervasive motor impairment. The response targeted for him consisted of repeated eyelid movements (i.e., two blinks within a 2 s interval). This response was already present in his repertoire, but at a relatively low frequency. The microswitch for monitoring the response was an optic sensor on an eyeglass's frame (such as the one sketched in Fig. 18.5) that the child wore. The occurrence of the response triggered the microswitch and, consequently, the control system, which enabled the child to access stimulus events such as video-recordings and moving lights, which were considered highly preferred for him. The results of the study showed that the child had a relatively high response level during the intervention phases of the study, obtaining extensive access to preferred environmental stimuli.

Mechling (2006) taught two children and an adolescent with profound intellectual disabilities and serious motor impairment to use hand/arm or head movements in combination with pressure microswitches to access various environmental stimuli. Initially, sessions were divided into three sections each of which involved a specific stimulus condition, which the participants could access with their target (hand/arm or head) responses. The stimulus conditions involved adapted toys and devices, commercial cause-and-effect software, and instructor-created video programs. Subsequently, the sessions were no longer involving different segments, and responding allowed the participants to access the type of stimulation that they had shown to prefer in the first part of the study. The results of the initial phase of the study indicated that the participants had the largest increase in responding when this allowed them to access the instructor-created video stimulation condition. During the second part of the study (when this stimulation condition was regularly present), the response level remained satisfactory for all participants.

Lancioni et al. (2007e) carried out a study with an adolescent with blindness, intellectual disability, and pervasive motor impairment. The study was to determine the possibility of replacing his head and hand responses (which were no longer feasible due to his physical deterioration) with minimal eyelid and mouth movements within a microswitch-aided program. The new movements, which consisted of eye- and mouth-opening, were introduced individually and then combined. That is, the optic microswitches for the responses were

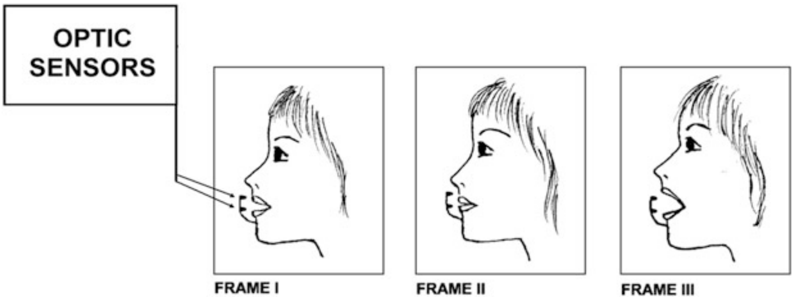

Fig. 18.4 Representation of optic sensors held in front of a person's mouth for monitoring changes in lip/mouth positions (Frames I–III)

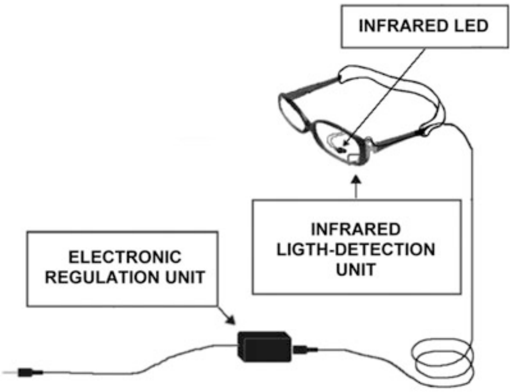

Fig. 18.5 Representation of an optic sensor (infrared LED and infrared light-detection unit) mounted on an eyeglasses' frame for monitoring eyelid responses

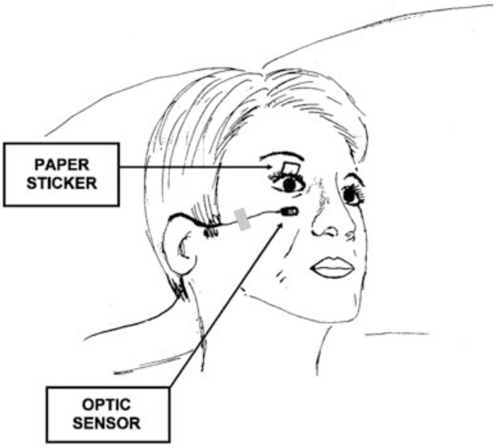

Fig. 18.6 Representation of an optic sensor attached to a person's cheekbone with a paper sticker on the person's eyelid for monitoring eyelid responses

simultaneously available and the participant could perform either one at will. Data showed that the participant learned to perform the new movements (responses) successfully and maintained them over time as indicated by a check carried out 2 months after the end of the intervention. In addition to the increase in the frequencies of the aforementioned responses, the participant showed mood improvement, that is, he displayed multiple indices of happiness during the program sessions. In conclusion, the program was effective in enabling the participant to access stimulation with minimal responses and reach a condition of satisfaction/enjoyment.

Lancioni et al. (2010a) carried out two case studies in which camera-based microswitch technology was used for the eyelid and mouth responses of two adult participants with profound multiple disabilities and minimal motor behavior. The first participant had previously used optic sensors fixed on an eyeglasses' frame. However, a deterioration of his head posture was making the use of the eyeglasses' frame progressively more difficult. The second participant did not seem suited for using an optic microswitch to detect his eyelid responses given his sideward lying position and dystonic head movements. The camera-based microswitches, in contrast with the optic microswitches described above, did not require the use of any material on the participants' face except for small color marks. The camera system was located in front of the participants and monitored the size of or distances between those marks. Responses were

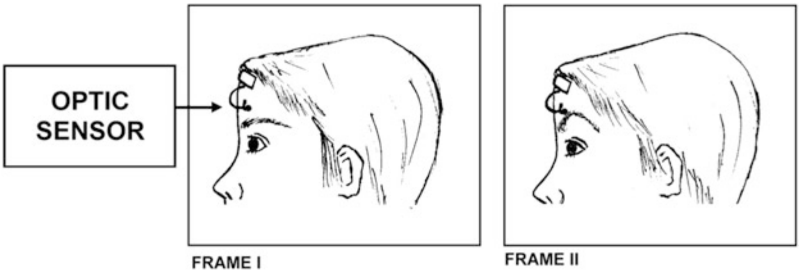

Fig. 18.7 Representation of an optic sensor attached to a person's forehead for monitoring forehead skin movements or eyebrow movements

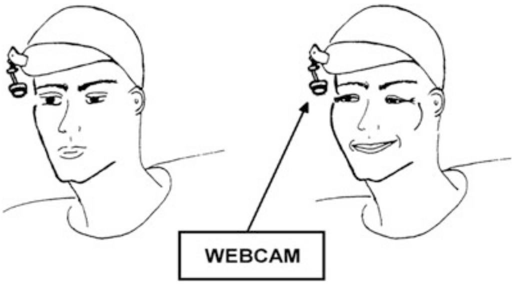

Fig. 18.8 Representation a Webcam positioned on the edge a person's cap for monitoring the person's smile responses (upsurge/enlargement of the cheekbone)

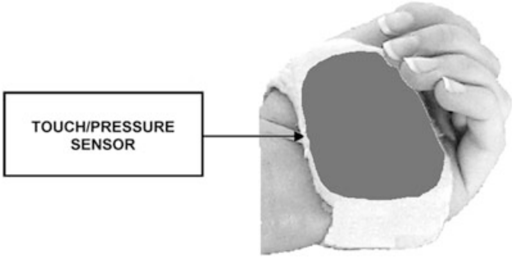

Fig. 18.9 Representation of a touch/pressure sensor fixed into a person's hand for monitoring hand-closure responses

recorded when the size of or distances between marks changed beyond a critical value. Results showed that the use of the camera-based microswitches was effective with both participants who had large increases in responding during the intervention periods (i.e., when their responses allowed them to access preferred stimulation).

Lancioni et al. (2013d) conducted a study with two adults, who had congenital encephalopathy with pervasive motor impairment and presumably profound intellectual disability. They lacked any interaction with objects and any recognizable form of communication and were living in a condition of passivity and marginality, without any opportunity to impact their context. The response selected for them was a small upward movement of the forehead skin (see Fig. 18.7). The microswitch was an optic sensor positioned above the participant's left or right eyebrow in combination with a black mini sticker. The sticker was fixed about 2 mm below the optic sensor. The target response (i.e., upward movement of the forehead skin) activated the microswitch by bringing the sticker under the optic sensor. This triggered a computer system that ensured the participants' access to preferred stimuli. Both participants showed an increase in responding, thus achieving extended access to (control of) the stimuli with consequent enrichment of their sensory input.

Microswitch-Aided Programs to Foster Assisted Ambulation

Ambulation (walking) is a critical skill, whose presence or absence can have widespread implications for the person's practical and social life. In fact, ambulation can be considered crucial for allowing the person opportunities to reach stimuli and persons that he or she may consider attractive (reinforcing) and/or carry out activities that could be instrumental for accessing relevant sensory and social feedbacks. Obviously, the

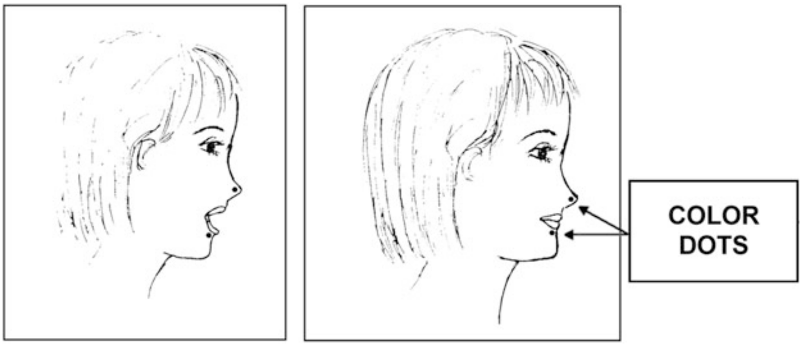

Fig. 18.10 Representation of color dots drawn at a person's nose and lower lip to allow a camera-based microswitch to monitor mouth responses

absence of ambulation would be considered a serious obstacle toward the achievement of the aforementioned goals (Hayakawa & Kobayashi, 2011; Lancioni et al., 2009). Ambulation can also be used as a strategy by which a person promotes his or her overall fitness and health condition (Cirignano, Du, & Morgan, 2010; Lee, Watson, Mulvaney, Tsai, & Lo, 2010; Lotan, Isakov, Kessel, & Merrick, 2004).

The acquisition and performance of walking skills appear very natural and simple for typically developing persons (Cernak, Stevens, Price, & Shumway-Cook, 2008; Cherng, Liu, Lau, & Hong, 2007; Chia, Guelfi, & Licari, 2010; Katz-Leurer, Rotem, Keren, & Meyer, 2010). For persons with severe/profound and multiple disabilities, independent and effective ambulation may remain out of reach for multiple reasons. For example, they may have poor balance and limited motor skills and thus never achieve a physical condition sufficiently mature for performing adequate ambulation (Maher, Evans, Sprod, & Bostok, 2011; Whittingham, Fahey, Rawicki, & Boyd, 2010). They may also have limited or no motivation to perform a demanding type of response that does not produce any interesting or reinforcing consequence for them. In fact, they may not be motivated by the discovery and manipulation of objects within their physical environment nor find the reaching of and contact with specific persons highly exciting (as typically developing children do).

For a number of these persons, ambulation may eventually be feasible only through some level of support ensured via the use of walker devices, and the availability of preferred stimulation contingent on the performance of ambulation steps (Lancioni et al., 2009, 2013g; Nolan, Savalia, Yarossi, & Elovic, 2010; Van Gestel, Molenaers, Huenaerts, Seyler, & Desloovere, 2008). A technology-based approach employed for these persons combines the use of walker devices with microswitches. The walker devices, which can be equipped with supporting features, serve to promote postural control and partial weight lifting (i.e., to guarantee the basic physical conditions for the step responses involved in ambulation). The microswitches, which can be linked to the participant's feet or walker device, serve to monitor his or her step responses and ensure via a related control/computer system the automatic delivery of environmental stimulation contingent on those responses (Lancioni et al., 2005c, 2007d). This stimulation would be essential to motivate the participant to ambulate (i.e., making the effort required for step performance) (Catania, 2012; Kazdin, 2001; Lancioni et al., 2007c, 2013b).

For example, Lancioni et al. (2005c) conducted a study with an adolescent considered to function in the profound intellectual disability range, who presented with blindness, spastic tetraparesis, and scoliosis. He could walk only if physically supported by a person or through a walker device. With the walker, he tended to perform only few steps apparently because of a motivation problem. Indeed, his ambulation was relatively costly in terms of efforts and did not produce any positive/reinforcing consequences. Given this situation, the use of a microswitch-aided program was considered essential to promote his ambulation performance. The program relied on optic microswitches to monitor his step responses and a control system that ensured the occurrence of preferred stimulation (e.g., audio-recordings of brief music segments and praise statements) contingent on their performance. Data showed that during the intervention phases of the study (i.e., when the program was applied), the participant's mean frequency of steps per session more than doubled compared to the baseline values (i.e., those available without program). During the intervention phases, moreover, the participant showed an increase in indices of happiness (i.e., smiles or excited vocalizations).

Lancioni et al. (2007d) conducted two studies to evaluate the effects of automatically delivered stimulation for walker-assisted step responses with two children and two adults with multiple disabilities. In the first study, the two children wore optic microswitches at their heels and could activate those microswitches through step responses. Each step (microswitch activation) produced a 2.5 s stimulation during the intervention and post-intervention periods. In the second study, the two adults wore a single optic microswitch at their right leg. Microswitch activation produced 5 or 6 s of stimulation during the intervention phases. The results showed that both technical arrangements were effective. Indeed, all four participants had significant increases in their assisted ambulation (i.e., frequencies of step responses) and also in their indices of happiness during the intervention phases of the study.

Lancioni et al. (2010b) extended the use of microswitch-aided programs to promote ambulation to five new children whose level of functioning was reported to be in the severe or profound intellectual disability range. All children were affected by spastic tetraparesis, and four of them also presented with visual impairment. They were used to a four-wheel walker supporting them around their chest and under their arms and including a harness or saddle to assist their postural control and lift part of their body weight. The microswitch-aided program involved the use of optic microswitches to monitor each foot's steps (for four participants) or a single optic microswitch to monitor the right foot's steps. In the first case, each step was followed by a brief stimulation (i.e., 3.5 s). In the second case, the stimulation following step responses performed with the right foot produced longer (i.e., 8 s) stimulation periods, in line with conditions applied in previous studies. The findings were consistent with those reported earlier.

Lancioni et al. (2013g) carried out three single-case studies using walker devices and microswitch technology to promote ambulation responses in two children and an adult with multiple disabilities. The walker devices were equipped with support and weight lifting features. The microswitch technology ensured that ambulation responses would allow the participants to access brief stimulation events. The ambulation responses of the first child consisted of regular steps, while those of the second child consisted of pushing efforts. The child made those efforts (i.e., pushed himself forward with both feet) while he was sitting on the walker's saddle. The ambulation responses of the man (third participant) consisted of regular steps emitted at low frequency and interspersed or combined with problem behavior, such as shouting or slapping his face. The results of the study were satisfactory for all three participants. The children had a large increase in the number of steps/pushes performed during the ambulation periods set up for them and in the percentages of those periods that they completed without any external help. The man improved his ambulation performance while showing a decline in his problem behavior and an increase in his indices of happiness.

Microswitch-Aided Programs to Increase Adaptive Responses and Curb Problem Behaviors or Postures

The first goal of education and rehabilitation staff working with persons with extensive intellectual and multiple disabilities is to promote adaptive responding, that is, to enable those persons to carry out positive/practical responses and use those responses as means to control environmental stimulation and improve their general condition (Lancioni et al., 2013a; Zucker, Perras, Perner, & Murdick, 2013). The studies reviewed above could be considered as attempts in that direction. Another goal pursued with many of these persons is the reduction of problem behaviors (e.g., hand mouthing and eye poking) or problem postures (e.g., head forward bending). Traditionally, intervention programs have been set up to pursue the two objectives separately. More recently, efforts have been made to deal with those two objectives within a single intervention approach that uses clusters (combinations) of microswitches to simultaneously monitor both the adaptive responses and the problem behaviors/postures (Lancioni et al. 2007f, 2008b, 2013a, b, e).

For example, Lancioni et al. (2004) assessed the use of a microswitch cluster to improve assisted ambulation, that is, to increase the frequency of steps performed and reduce inappropriate posture (i.e., leaning on the walker's table) in a man with multiple disabilities. The cluster included optic microswitches positioned at the man's heels to detect his steps and a pressure microswitch under his right arm to detect his body posture (i.e., whether he had an appropriate upright posture or was inappropriately leaning on the walker's table). The man received 2.5 s of preferred stimulation at each step provided that his posture was appropriate. Data showed that the man had an increase in his overall frequency of steps as well as in his appropriate posture during walking throughout the intervention phases and the 3-month follow-up.

Lancioni et al. (2007g) investigated the possibility of using a microswitch cluster to promote an adaptive hand response (i.e., pushing on a panel) and curb a problem behavior (i.e., face hiding) in a woman with profound developmental disabilities. Initially, the woman was taught the adaptive hand response. This allowed her to access brief periods of preferred stimulation. Subsequently, her hand response led to preferred stimulation only if it was performed in the absence of the problem behavior (i.e., free from face hiding). The study also included a 3-month post-intervention and generalization check, and a social validation assessment. Data showed that the woman (a) increased the frequency of her adaptive responses, (b) learned to perform these responses without the presence of the problem behavior, and (c) maintained and generalized the improved performance across different settings. A social validation assessment provided highly positive rating for the improved performance and the technology used to achieve such an outcome.

Lancioni et al. (2007f) used microswitch clusters for two children functioning in the profound intellectual disability range, and presenting with motor impairment and limited residual vision or blindness. The adaptive response taught to the two children consisted of manipulating objects. The problem behavior to be reduced consisted of hand or object mouthing. The microswitches were wobble or vibration sensors combined with optic sensors. Initially, the children were taught the adaptive response. They received positive stimulation for each occurrence of such response. Subsequently, the participants received stimulation for the adaptive response only if it occurred in the absence of the problem behavior. Moreover, the stimulation would be interrupted if the problem behavior appeared during its delivery. The results showed both children acquired high levels of adaptive responding and also displayed a drastic decline of the problem behavior. The effects of the intervention were maintained during post-intervention checks underlining the participants' ability to remain active and display a distinct form of self-control (Carter, Owens, Trainor, Sun, & Swedeen, 2009; Carter et al., 2013; McDougall, Evans, & Baldwin, 2010).

Lancioni et al. (2013e) carried out microswitch-cluster programs to promote object manipulation (i.e., adaptive response) and reduce inappropriate head or head–trunk forward leaning with a boy and a woman with multiple disabilities. The adaptive response was monitored via optic, tilt, or vibration microswitches. The problem posture was monitored via optic and tilt microswitches. During the initial intervention, the adaptive response was always followed by preferred stimulation. During the subsequent intervention phases, the adaptive response led to preferred stimulation only if the inappropriate posture was absent at the start of the response and during the scheduled stimulation period. The results showed that both participants succeeded in reaching large increases in adaptive responding and eventually combining this achievement with a drastic reduction in inappropriate posture.

Programs Based on the Use of SGDs to Promote Communication (Requests)

SGDs, also known as voice output communication aids (VOCAs), are assistive technology resources that can be used to enable persons without functional speech to produce easily understood verbal messages (i.e., requests and statements). In practice, the persons who would have most obvious benefits from the use of this technology are those who do not possess effective communication within their context due to (a) failure in developing any speech abilities or production of totally/largely unintelligible speech and (b) lack of functional nonverbal means of communication (Lancioni et al., 2011d, 2013b; Sigafoos et al., 2009, 2013, 2014a, b; Van der Meer et al., 2012a, Van der Meer, Sutherland, O'Reilly, Lancioni, & Sigafoos, 2012b). The availability of such technology can be seen as a way to allow the persons an effective form of active communication (i.e., the opportunity to make clear requests).

The first prerequisite for a successful use of SGDs is that the persons for whom it is available have an interest in their environment and the stimuli that it contains (i.e., want to obtain/reach some of those stimuli and are unable to reach them on their own; Gevarter et al., 2013a, b; Kagohara et al., 2013). The second prerequisite concerns the skills needed for the use of the device. In other words, persons can be expected to use a device if they have the visual and motor skills necessary to do so without excessive effort and possibly without errors. The third prerequisite for a successful use of SGDs is the availability of a communication partner (e.g., staff member or parent) who can listen and respond to the communication messages/requests produced by the participants. Satisfaction of the participants' communication efforts is essential to motivate them to strengthen their overall communication behavior and maintain and expand it over time (Kagohara et al., 2013; Lancioni et al., 2013b; Sigafoos et al., 2009, 2014a, b). In light of the above, it seems obvious that the types of SGDs adopted and levels of communication pursued depend on the participants and their skills (Gevarter et al., 2013b; Mullennix & Stern, 2010). The four studies summarized in this section provide a clear illustration of different SGDs and different communication levels.

Lancioni et al. (2011d) used a commercial SGD (Go Talk 9; Special Needs Products of Random Acts Inc., USA) to help a woman with multiple disabilities to request various activities. At each request, the woman was (a) provided material for the activity she wanted to carry out, and (b) offered a choice between different material options. The SGD was a tablet-like tool with nine cells, only five of which were used during the program (i.e., one for each of the activities the participant was interested in requesting). Each of the five cells used contained the pictorial representation of one of the activities (e.g., listening to music/songs and watching videos). To request a specific activity (and make the SGD produce the verbalization of the request message), the woman produced a light pressure on the cell with the representation of such an activity. The woman was generally allowed to engage in the activity requested for about 2 min. Thereafter, she was to make a new request (i.e., for the same or a different activity) in order to continue her engagement. Results showed that during the intervention with the SGD, she was quite busy with an average of about eight requests per 20–25 min session.

Van der Meer et al. (2012a) assessed the use of SGD technology and manual signs with four children who were diagnosed with intellectual/developmental disabilities and autism spectrum disorder. The SGD used for the study was an Apple iPod Touch with Proloquo2Go software. The intervention aimed to teach the children to request for their preferred stimuli. The iPod was set up to show three graphic symbols, which corresponded to snacks, play, and social interaction. Touching any of those symbols activated a synthetic speech output matching the symbol being touched. For each participant, only one of the symbols (i.e., the snack or play) was the target of the intervention, that is, represented the request for the stimuli available to him or her. The other two symbols were used as distractors. Data showed that all children acquired the appropriate use of the SGD while only three of them acquired manual signs. Moreover, three of the children were reported to prefer the SGD above the manual signs.

Sigafoos et al. (2013) carried out a study with two children, who were diagnosed with autism spectrum disorder and presented with marked developmental delays, showing inadequate adaptive and communication behaviors. The objective of their intervention was to enable the two children to request the continuation of their play with a specific (preferred) toy via an Apple iPad device with Proloquo2Go software. The iPad contained a single graphic symbol representing the toy with which the children had chosen to play within the session. The children were allowed 3–10 request trials/opportunities per session. Each trial started with the experimenter gently removing the toy with which the child was playing. To get the toy back and thus continue to play with it, the child was to touch the symbol of the toy on the iPad and thus, trigger the request for such a toy. Following a request, the experimenter delivered the toy back allowing play to resume. Both children were successful in learning to request for the toy and resume their playing. Parallel to this communication acquisition, the children got rid of behaviors such as hitting the person and reaching for the object, which were displayed at the removal of the toy during the baseline period. The new abilities were apparently maintained over time and generalized to other stimuli.

Lancioni et al. (2016) carried out a study to assess a new SGD developed for people whose multiple disabilities included blindness. Three adults were involved as participants. The side of the SGD facing the participants measured 35 cm × 20 cm and was divided into 15 sections/cells. Each section contained an optic sensor, which was covered by a small object or tag with a word in Braille referring to an activity. Removal of an object/tag uncovered and activated the underlying optic sensor and caused the SGD to verbalize a request for the activity that the object/tag represented. The caregiver would then respond to such request by ensuring the necessary conditions for the occurrence of the related activity. During the baseline, the mean frequencies of communication events per 60-min session were zero or close to zero. During the intervention phase, those events increased to between about six and 11 and led to a mean cumulative activity time per session exceeding 45 min for each of the participants. Moreover, each participant indicated preference for entering sessions with the use of the SGD over alternative forms of occupation.

Programs Providing Orientation Cues and Stimulation to Promote Basic Activity or Assembly-Task Engagement and Mobility

Promoting occupation in persons with multiple disabilities is a crucial objective that poses serious challenges. In fact, many of these persons (a) may have limited activity skills that allow them to use only few, specific types of material/objects and basic response schemes and (b) may be unable to move from one simple activity to the next due to their limited initiative and/or the insecurity deriving from their blindness or serious visual disabilities (Foley et al., 2013; Fox, Burke, & Fung, 2013; Lancioni et al., 2008a, 2014a; Maes, Vos, & Penne, 2010; Sheppard & Unsworth, 2011). Given this situation and the relevance of ensuring independent and sustained engagement to these persons, recent research has emphasized two points. First, arranging small activities or activity steps (e.g., as required within an assembly-task sequence) at different places may be more functional/practical for helping the participants' correct engagement than presenting those activities or steps at a single place (Frey, 2004; Lancioni et al., 2013c, 2014a). Second, technology may be crucial to (a) help the participants move/travel from one place to the next (i.e., from one activity or activity step to the next) and (b) ensure that the participants receive forms of reinforcing stimulation during their performance and thus maintain their motivation to continue for the time required (Bellamy, Croot, Bush, Berry, & Smith, 2010; Catania, 2012; Chantry & Dunford, 2010; Lancioni et al., 2013c, 2014a; Näslund & Gardelli, 2013; Uslan, Russell, & Weiner, 1988).

Recently, Lancioni et al. (2014a) carried out two studies in line with the aforementioned points to assess technology-aided programs for supporting activity engagement and mobility (indoor traveling) in persons with multiple disabilities. These persons were deemed unable to move through sequences of activities on their own, regardless of whether the activities were arranged within a small space or at different places. In the first study, the two participants with severe intellectual disability and blindness were provided with an automatic presentation of (a) auditory cues aimed at guiding them to different work areas where small activities could be carried out, and (b) musical and social (reinforcing) stimulation contingent on their arrival at each of the work areas. In the second study, a participant with severe to profound intellectual disability and moderate hearing impairment was provided with (a) combinations of auditory and visual cues for guiding her to the work areas and (b) positive social consequences contingent on her arrival to those areas. The results of both studies were largely positive. The participants' mean percentages of independent moves/travels from one work area to the next (i.e., from one activity to the next) increased from zero or below 20 during the baseline conditions (i.e., when the program was not in use) to about 95 by the end of the study (i.e., with the support of the programs).

Lancioni et al. (2015) extended the evaluation of the technology-aided programs just described (Lancioni et al., 2014a) with two additional studies involving participants with severe to profound intellectual disability and blindness or limited residual vision. In the first of the two studies, the program was similar to those described above (Lancioni et al., 2014a) and (a) provided auditory cues to guide three participants to various work areas, at each of which a simple occupational activity was to be performed, and (b) ensured preferred stimulation contingent on the arrival at each of the work areas. In the second study, the program (a) provided auditory cues or combinations of visual and auditory cues to guide two participants to five different work areas where they could gather different objects and transport and place each of these objects into a container located at a sixth work area, and (b) ensured preferred stimulation at each of the work areas. The results of both studies were largely positive with all participants traveling from one area to the next independently and dealing with the activities/objects properly.

Lancioni et al. (2014b) used a technology-aided program similar to those mentioned above for a more complex and practically relevant occupational objective. Specifically, they used it to teach three adult participants with deafness, severe visual impairment, and reportedly profound intellectual disabilities to carry out an assembly task (i.e., to assemble five-component water pipes). The program controlled the presentation of (a) light cues to guide the participants to the work areas containing the single pipe components (in the right sequence) and to the large container where the completed pipes were to be stored and (b) the stimulation available at each of the aforementioned places. The results were positive and all three participants showed independent and accurate engagement in pipe assembling performance.

Programs Based on Technology Packages to Promote Contact/Communication with Distant Partners

As indicated in the previous sections of this chapter, persons with extensive multiple disabilities may find themselves in a condition of passivity and isolation and in need of support programs to alleviate such condition (Bell & Clegg, 2012; Blain-Moraes & Chau, 2012; Holburn et al., 2004; Lancioni et al., 2008b; Lancioni, O'Reilly, Singh, & Oliva, 2011c, d; Leung & Chau, 2010; Mechling, 2006; Memarian, Venetsanopoulos, & Chau, 2011; Stainton & Clare, 2012; Taylor & Hodapp, 2012). The programs might involve, among others, the use of (a) microswitches to access and control environmental stimuli (Lancioni et al., 2013b), (b) SGDs to make requests for attention, environmental stimuli, and preferred activities, and (d) computer-aided telephone systems to establish telephone contact with socially relevant partners, such as family members and friends not directly present in the context where the persons are (Lancioni et al., 2011c).

For example, Lancioni et al. (2013f) assessed whether two participants (a girl and a woman) with multiple disabilities (including intellectual disabilities, minimal residual vision, and absence of speech) (a) could make phone contacts with relevant partners through a special telephone technology and (b) would enjoy their telephone-mediated contacts. The technology involved a net-book computer, a global system for mobile communication modem, an optic microswitch, and specific software. The computer was programmed to present the names of the partners available for contact, and the participants could choose a partner by activating their microswitch (i.e., with lip or chin movements) after the presentation of his or her name. Such response triggered the computer to place a phone call to that partner. When the partner answered the call, the system provided the name of the participant who was calling. From there on, the partner was expected to talk with (tell a story to) the participant who had placed the phone call. The partner was allotted a specific time within which to complete the call. Both participants (a) were successful in using the program and contacting relevant partners and (b) showed high indices of happiness (e.g., smiles) during the phone calls.

Lancioni et al. (2011c, 2014c) assessed a slightly more sophisticated computer-aided telephone system than the one described above with three adult participants who presented with blindness or severe visual impairment and motor or motor and intellectual disabilities but possessed speech abilities. For two of the participants, the computer presented the partners in groups (e.g., family members and friends). Once they had selected a group, the computer presented the names of the partners included in that group so that one of them could be selected for the call. For the third participant, the computer proceeded by presenting the names of the partners available individually and also (b) provided reminders of the response needed to select a partner for a call. Selection of a group and/or of a partner occurred through activations of a microswitch (i.e., a pressure panel that could be triggered with a simple hand movement). Data showed that all three participants learned to use the system very rapidly and were successful in making phone calls independently.

Considerations on the Different Types of Programs Reviewed and Their Outcomes

Microswitch-Aided Programs

!These types of programs have been described as means for helping participants with severe/profound and multiple disabilities (a) acquire and strengthen small responses to connect with their immediate environment and thus access and control environmental stimulation, (b) develop assisted-ambulation responses, and (c) increase adaptive responses and curb problem behaviors or incorrect postures. The results of the studies reviewed in relation to each of the objectives just mentioned seemed to be very encouraging, thus emphasizing the positive impact of the programs and their potential for daily contexts.

A basic condition for the successful application of these programs is the availability of feasible adaptive responses and the use of reliable microswitches. In order to be feasible, a response needs to be relatively easy to perform and/or not excessively tiring for the participant. In view of this, one could argue that for many participants, only fairly small or minimal responses might be considered feasible. For step responses (i.e., supported ambulation) to be feasible, it is necessary that the participant possesses a step scheme and some strength in his or her lower limbs and/or that the support system to be used during ambulation is arranged in such a way so as to lift part of his or her body weight (Lancioni et al., 2010b, 2013g). Microswitches are reliable when they can monitor a response with a high level of accuracy, that is, without false positives or false negatives. With regard to this point, it may be noted that (a) conventional microswitches (e.g., pressure and tilt sensors) are not necessarily reliable or even applicable with small or minimal responses and (b) great efforts have been made during the last 10–15 years to develop new, experimental microswitches that could be applicable with those responses (Lancioni et al., 2011a, 2013b, 2014d, e; Lui, Falk, & Chau, 2012).

The environmental stimulation that the participants can access through their responses is critical for the strengthening of those responses and eventually for the success of a program (Catania, 2012; Kazdin, 2001; Lancioni et al., 2013b). The importance of this stimulation may be even more obvious in programs aimed at promoting adaptive responses and curbing problem behavior. In those programs, the participant is faced with the choice between (a) pursuing environmental stimulation through performance of the adaptive response and restraint from the problem behavior and (b) continuing with the problem behavior and accepting to loose the environmental stimulation. Given that the problem behavior is most likely maintained by some form of automatic reinforcement (Lancioni et al., 2007f, 2014e), one can expect the participant to choose in favor of the adaptive response and against the problem behavior only if the stimulation following the former exceeds (is more satisfactory than) the consequences of the problem behavior (Lancioni et al., 2006b, 2013a, b; Mitchell, 2012; Tullis et al., 2011). The possibility of helping participants reduce problem behavior based on the aforementioned choice amounts to helping them develop a clear form of self-control that frees them from outside restrictions and makes them look much more responsible and mature (Lancioni et al., 2013e; McDougall et al., 2010; Singh et al., 2008a, b).

The change from isolation and passivity or isolation and problem behavior to sustained adaptive engagement with the environment and reduction of the problem behavior can vastly modify the social perception of the participant (i.e., the consideration the participant receives within his or her context). Obviously, independent engagement and absence of problem behavior promote a more positive image of the participant. In specific situations, such as those in which the adaptive engagement concerns ambulation, the impact of the change can be relevant not only in terms of social image but also with regard to the participants' physical fitness and health condition (Lancioni et al., 2014a, b, 2015). Evidence of the beneficial effects of the aforementioned changes can be found in social validation studies in which social raters were employed to judge (a) the participants' general behavior during the program sessions and outside of the sessions and (b) the possible impact (i.e., benefits) of the program in the participants' daily context (Dillon & Carr, 2007; Lancioni et al., 2005b, Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005d, Lancioni et al., 2006a, 2007d, 2013b).

One final consideration about microswitch-aided programs concerns their cost. It may be worthwhile to underline that these programs can generally be set up in a relatively inexpensive manner, thus are affordable within most school and rehabilitation settings (Borg et al., 2011; Hubbard Winkler et al., 2010; Kagohara et al., 2013; Lui et al., 2012). In fact, single microswitch devices usually cost less than 300 US dollars. To this cost, one should then add the cost of a portable computer, interfaces, and basic software required for the complete program. While economically affordable, the long-term success of those programs may depend on technology upgrading. Upgrading would require developing new forms of microswitches and new interfaces so as to facilitate the application and friendliness of the programs in general and also make the programs suitable for extensively compromised persons who cannot (largely) benefit from current technology solutions.

SGD-Aided Programs

The literature has shown that the use of SGDs can be highly useful in all those daily situations in which the participants (a) are unable to produce easily understood verbal or nonverbal messages (i.e., requests and statements) and (b) are interested in making requests/statements and accessing specific (message-related) environmental events or caregiver attention/mediation (Sigafoos et al., 2009, 2013, 2014a, b). One can envisage the importance of this technology in multiple daily situations and over periods of time and ranges of options that can vary quite extensively. For example, one could use a relatively basic device for relatively basic communication in snack situations as well as in play or occupational situations (Sigafoos et al., 2009, 2013, 2014a, b; Van der Meer et al., 2012a, b). One could also use relatively complex devices for rather extensive communication opportunities (i.e., including vast range of messages) over relatively long periods of time (Lancioni et al., 2016). Indeed, the studies reviewed above provide a clear picture of the possible differences among SGDs in terms of the number of messages included, in terms of the technology used and the way the messages/requests are portrayed, and in terms of the responses required to the participants for activating them. Obviously, the devices used, the number of messages/requests contemplated within the devices, and the responses required to activate those messages are to be adapted to the characteristics of the participants involved in the programs (e.g., Van der Meer et al., 2012a, b; Lancioni et al., 2011d, 2016).

New research will need to investigate when and how programs can proceed (a) from single requests to multiple requests and (b) from specific, relatively brief sessions to large sections of the day. Answers to some of these issues may also depend on the improvement of the technology (i.e., the possibility of making it easily portable) and the successful integration of the technology within the main education/rehabilitation plan available for the participants. Until easily portable technology solutions are available (so that the participant can have any such solution with him- or herself regularly), one could envisage a context containing several SGDs. This arrangement would ensure that the participant has one of the devices almost always visible, with the hope that this presence/visibility may foster his or her communication initiatives. Systematic and repeated searches of motivating/reinforcing environmental (social and nonsocial) stimuli may be necessary so as to increase the likelihood of including interesting request options also for those persons who seem minimally attracted by their environment (Davies, Chand, Yu, Martin, & Martin, 2013; Li, Bahn, Nam, & Lee, 2014).

Technology-Aided Programs for Basic Activity or Assembly Tasks and Mobility

Programs aimed at helping persons with intellectual and multiple disabilities to be positively engaged in basic/occupational or vocational activities and move freely to carry out those activities would be considered relevant because they (a) provide all those persons an active role within their domestic and education/rehabilitation environment and (b) ensure that the persons with the largest levels of sedentariness can practice mild physical exercise, with beneficial effects for their muscle tone and blood circulation (Blick, Saad, Goreczny, Roman, &

Sorensen, 2015; Frey, 2004; Lancioni et al., 2014a). The studies reviewed indicate that different types of activity engagement and different technology solutions may be envisaged to suit the characteristics of the persons being served.

For example, for participants who can perform simple, relatively repetitive types of activities but fail to transit from an activity to the next, one can set up a technology-aided program that guides and motivates them to do so through (a) auditory and/or visual cues as well as (b) positive stimulation contingent on their arrival at (contact with) each new activity. For participants who do not possess the ability/consistency for performing the aforementioned types of activities but are capable of manipulating (e.g., taking, transporting, and putting away) single objects, one can set up a technology-aided program that guides them to (a) different areas (i.e., one area at a time) where they can pick up single, specific objects of a collection and (b) a final destination where the single objects are placed together. This program also would rely on the use of auditory and/or visual cues to help the participants orient themselves and move successfully, and on the presentation of preferred stimulation. This can be scheduled in relation to the participants' arrival at the different areas (and/or in relation to them taking the target object) and in relation to them placing the object away at the final destination. For participants who have the ability to manipulate and put together (assemble) simple, two- or three-component objects, one can envisage the possibility of developing assembly tasks that might have functional/vocational value. To that end, one can set up a technology-aided program that (a) guides the participants through a series of work areas (i.e., including the single object components to be assembled and a final storing place), (b) repeats this guidance process a number of times so as to ensure that the participants assemble and put away a relevant number of objects, and (c) provides the participants feedback and stimulation at each of the work areas and, in particular, at the end of every round (i.e., after the completion/assembly of each object).

The programs described are three possible examples of successful strategies aimed at supporting positive engagement in persons with severe/profound and multiple disabilities. Other examples might easily be envisaged for participants such as those involved in the studies reviewed as well as participants who have higher levels of functioning and higher activity skills. Those programs could be based on the use of pictorial instructions (e.g., video prompts) for the single steps of the tasks targeted and include occasional stimulation events to motivate the participants' engagement and accuracy (Cannella-Malone et al., 2011, Cannella-Malone, Mizrachi, Sabielny, & Jimenez, 2013; Lancioni et al., 2013b; Perilli et al., 2013a).

Technology-Aided Programs for Contact or Communication with Distant Partners

The first consideration one can make with regard to the studies reviewed in this area is that participants with multiple disabilities, with or without speech abilities, can be helped to establish telephone contact with relevant partners not directly available within the participants' context. The fact that the participants were able to use the technology employed in the studies and to make telephone contacts with relevant partners successfully indicates that such technology and the program set up with it were suitable to them. The combination of the computer's presentation of the partners (i.e., by listing their names directly or by listing their groups first) and the availability of microswitches to choose among them with a simple response proved adequate for all participants.

The verbal presentation of the partners' names, which appeared effective for the participants involved in the studies reviewed, could be supplemented with the presentation of the partners' photographs for some participants. This could make their recognition of the partners faster and more accurate, thus improving their choice and avoiding possible selection errors

(Lancioni et al., 2013f, 2014c; Perilli et al., 2013b). The program set up for nonverbal participants should always alert the partner regarding the author of the call. In that case, the partner would know how to proceed with that author/participant avoiding hesitation or possible errors (e.g., switching off the call because of no voice signal). In some of those situations, the partner may simply greet the participant and provide him or her with a number of positive social remarks. In some other cases, the partner may tell a little, personal or participant-related, story as a form of interaction that may be perceived as an emotionally reach event by the participant and thus motivate new calls toward that partner. The importance of using a simple/suitable response and a convenient microswitch for choosing the partners can never be overemphasized (Lancioni et al., 2013b; Lui et al., 2012; Memarian et al., 2011).

The implications of this type of intervention program for the participants appear quite obvious (i.e., in terms of participants' initiative, social status, and happiness; see Lancioni et al., 2013f, 2014c). It is also reasonable to believe that the program is likely to produce changes/improvements in the social–emotional condition of the partners and eventually enrich the interaction between participants and partners (Hostyn & Maes, 2009; Lancioni et al., 2013f).

Conclusion

The studies reviewed, their outcomes, and the considerations formulated above can be taken to suggest that assistive technology (or more appropriately, technology-aided programs) can have an important role in helping people with severe/profound and multiple disabilities (a) reach positive performance objectives and (b) experience a sense of success and personal satisfaction (happiness) (i.e., in full accordance with the main emphasis/aim of Positive Psychology; Pawelski, 2016a, b). Microswitch-aided programs have been widely used and data show that they can be a valuable resource for a large range of intervention situations, which can be considered highly significant within education and rehabilitation plans for persons with severe/profound and multiple disabilities (Lancioni et al., 2013b). Those situations include, among others, any attempts to (a) strengthen adaptive responses and foster independent access to (control of) environmental stimuli, (b) develop supported ambulation (i.e., step responses), and (c) increase adaptive responses and use them and the stimulation available for them as a way to curb problem behaviors or incorrect postures (i.e., via clear forms of self-control; Lancioni et al., 2013e; McDougall et al., 2010; Singh et al., 2008a, b).

SGD technology and SGD-aided programs can be viewed as critically relevant instruments to allow persons without any (or any effective) communication ability to reach a satisfactory communication performance (i.e., make readily understood requests/statements). Again, the technology and related programs can vary widely to suit the characteristics of the participants. The literature has shown the possibility of using technology/programs aimed at promoting basic levels of communication as well as technology/programs aimed at allowing rather extensive ranges of messages and thus richer forms of interaction extending over relatively long periods of time. Given that improving communication remains a central goal of any education and rehabilitation context, one may expect numerous developments in this area both in terms of technology solutions and in terms of program strategies.

Technology-aided programs for basic activity or assembly tasks can be considered a highly valuable resource for professionals working with ambulatory individuals with different levels of functioning and different rehabilitation perspectives. Those programs can provide an opportunity of simple activity engagement and mobility (i.e., a combination of occupational engagement and mild physical exercise) for lower functioning individuals and an opportunity to develop a successful form of vocational engagement for higher functioning participants. For the former participants, the programs can be seen as the best opportunity to promote a level of independence and activation that can have direct beneficial effects and might be perceived positively within the participants' context with favorable implications in terms of image and social attention. For the latter participants, the programs can be seen as a valid support in view of a potential transition from an occupational center to a work context along the lines of the supported employment philosophy (Vornholt, Uitdewillingen, & Nijhuis, 2013; West, Targett, Wehman, Cifu, & Davis, 2015).

Technology-aided programs for contact or communication with distant partners might be seen as a way to help persons confined to a restrictive environment due to their disabilities to maintain consistent connection with loved ones and friends and thus enjoy their emotional proximity. Verbally able participants can use these programs for starting and entertaining verbal communication exchanges with their partners in a fairly typical manner. Nonverbal participants can use the technology to take the initiative in starting contact with their partners and indirectly prompting/encouraging the partners to express forms of emotional interaction with positive consequences for their overall bonding (Lancioni et al., 2013f).

In conclusion, one needs to stress that the long-term applicability and impact of all these programs would largely depend on the possibility to adapt them to the characteristics of the persons involved and eventually on their upgrading. Upgrading can take two different directions. On the one hand, it may be considered as the development of more advanced versions of the technology available or the development of new, more satisfactory and practical alternatives. On the other hand, upgrading may be seen as an effort to replace experimentally developed components with commercially available ones so as to facilitate a more immediate usability of the programs with positive implications regarding the number of persons finally served.

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Intrinsic Motivation

19

Karrie A. Shogren, Jessica Toste, Stephanie Mahal
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Intrinsic Motivation

The field of motivational psychology is framed around two central constructs: intrinsic motivation (the individual's desire to perform the task for its own sake) and extrinsic motivation (contingent rewards). In a seminal experiment of motivation (Deci, 1972), college students were asked to work through a series of complex puzzles either with or without pay. While it initially appeared that those who received an extrinsic motivator dedicated more time to the puzzles, their commitment to the task waned. Those in the no-reward condition played with the puzzle significantly more in a later unrewarded "free-time" period than paid subjects, and also reported a greater interest in the task. This experiment has since been replicated many times with different tasks and populations, garnering increased support for Deci's original belief that intrinsic motivation supports human learning and that external rewards actually serve as a threat to individuals' intrinsic interest. The study of motivational processes has evolved from several research traditions and, as such, an array of theory-driven constructs has been investigated.

Although motivational constructs may differ slightly in definition, they are all framed around the central premise that intrinsic motivation results in increased engagement and achievement (Schutz & Pekrun, 2007). Built on the assumption that people are actively involved in their own development with tendencies toward growth and mastery (Deci & Ryan, 1985, 2000, 2008; Ryan & Deci, 2000), Self-Determination Theory (SDT) is a widely recognized theory of human motivation. In the following section, we will discuss SDT as a motivational framework that aligns with work in self-determination in the field of intellectual and developmental disabilities (see Chap. 5).

Research in intellectual and developmental disabilities is not devoid of a focus on motivation, of course. Indeed, there has been a considerable amount of research focused on motivation systems in intellectual and developmental disabilities over the years (Switzky, Hickson, Schalock, & Wehmeyer, 2003). A significant proportion of this research, however, has focused on problems in motivation, motivation deficits, or the linkages between poor performance and motivation among people with intellectual disability. Our intent in this chapter is not to provide a comprehensive overview of the study of motivation among people with intellectual

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disability, but instead to focus on the application of one theory of intrinsic motivation, Self-Determination Theory, which is featured prominently in positive psychology.

Self-determination Theory

SDT attempts to explain how to support effective and healthy behavior through an understanding of human's basic psychological needs. As Deci wrote in an early text, *The Psychology of Self-Determination* (1980):

> People have considerable capacity for self-determination, and the operation of will—that capacity to choose behaviors based on inner desires and perceptions—is the basis of self-determination (p. 5).

Since this and other early writings explicating SDT (Deci & Ryan, 1980, 1985), SDT has received attention in the field of motivational psychology and has been recognized within positive psychology since the inception of the field (Ryan & Deci, 2000). Central to SDT is the belief that humans are active organisms who are proactive and growth oriented (Deci & Ryan, 2012). SDT theorists believe that humans have the capacity to integrate their internal states with the social and environmental circumstances they encounter. SDT, in this way, differs from behavioral theories or social learning theories, which focus to a greater degree on how people are shaped by their environments (Deci & Ryan, 2012).

SDT posits that humans are motivated by three basic psychological needs that shape their growth-striving actions. These basic psychological needs are the need for autonomy, competence, and relatedness, and are described in greater detail in subsequent sections. SDT also explicitly integrates the role of the environment in supporting or hindering these needs being met. Environments that support these needs enable the development of autonomous motivation, and the self-regulation of extrinsic motivation, which is central to being self-determined.

Basic Psychological Needs

As mentioned previously, SDT posits that humans have three basic psychological needs, and that humans actively seek to meet these basic needs through engagement with their environment. The need for autonomy describes the drive people have to be able to make choices and act volitionally. The need for competence describes the desire people have to feel that they can master their environments and feel effective in their environments. The need for relatedness has to do with feeling connected to others, and feeling that you will be cared for and will have the chance to care for others (Deci & Ryan, 2012). Self-Determination Theory suggests that people are driven to address their need for autonomy, relatedness, and competence, and engage in actions to attempt to address these needs. Environments that are supportive of the attainment of these needs enable people to become energized about engaging in actions for their own sake to meet their needs (Vansteenkiste & Ryan, 2013). In such environments, people are intrinsically or autonomously motivated and are acting volitionally to address their needs. As Deci, Vallerand, Pelletier, and Ryan (1991) wrote, "social contexts that support people's being competent, related, autonomous will promote intentional (i.e., motivated) action, and furthermore, that support for autonomy in particular will facilitate that motivated action's being self-determined (rather than controlled)" (pp. 332–333). However, under other circumstances, where behavior is directed and controlled by others or external circumstances, people are less autonomously motivated. Self-Determination Theory acknowledges, however, that there will be circumstances under which extrinsic factors motivate behavior, but that people can also grow in the degree to which they self-regulate extrinsic motivation, recognizing the relationship between acting volitionally in the context of external demands. Thus, the ultimate goal of SDT is to enable people, including people with disabilities, to act in a self-determining way that promotes autonomous motivation and self-regulation of extrinsic motivation.

Applications of Self-determination Theory

Given the central role of motivation, and environments that support autonomous motivation by enabling basic psychological needs for competence, relatedness, and autonomy to be met, research and applications of SDT have focused on exploring applications of SDT to the creation of environments that promote autonomy (i.e., autonomy-supportive environments) and address the need for competence and relatedness. By creating autonomy-supportive environments, the assumption is that intrinsic motivation will be enhanced, promoting valued outcomes across multiple life domains. In a meta-analysis of research on intrinsic motivation and its impact on outcomes across domains, Deci, Koestner, and Ryan (1999) looked at the impact of extrinsic rewards on motivation. They found that, generally, tangible rewards and contingent rewards alone, restricted intrinsic motivation, likely because they were controlled by others and did not support internal needs being met. They found that positive feedback, when delivered in an autonomy-supportive way, enhanced intrinsic motivation, but if the feedback was controlling, it decreased intrinsic motivation. These findings suggest the importance of supporting people with and without disabilities to identify the reasons they are engaged in actions in their environment, and linking those to the attainment of basic needs related to autonomy, competence, and relatedness. This promotes self-driven actions and self-regulation of behavior and outcomes, while still promoting feelings of competence and relatedness when received positive feedback from others. Each of these elements enhances intrinsic motivation across multiple domains.

Self-determination Theory and Education

Early research established the impact of autonomy-supportive educational environments and teaching practices on student motivation and outcomes. For example Deci, Schwartz, Sheinman, and Ryan (1981) found that autonomy-supportive teachers, who created a learning environment that enabled students to make choices and act volitionally, were associated with students reporting higher levels of intrinsic motivation, perceived competence, and self-esteem. Other research has also linked autonomy-supportive teachers with enhanced student self-regulation, learning and achievement, and engagement (Vansteenkiste et al., 2012).

Vansteenkiste emphasized that autonomy-supportive teachers support students to focus on deep conceptual learning, rather than extrinsic goals associated with external indicators of success. Researchers have found when students understand the reasons they are learning, what they are learning, and are driven by the pursuit of an outcome that aligns with their need for autonomy, competence, and relatedness, students more actively process information and show greater conceptual learning, compared to conditions where behavior was managed through extrinsic rewards, such as grades and teacher evaluations (Grolnick & Ryan, 1987). Researchers have suggested similar impacts on motivation associated with autonomy-supportive parenting practices (Grolnick, 2009; Grolnick & Ryan, 1989; Katz, Kaplan, & Buzukashvily, 2009; Mageau, Bureau, Ranger, Allen, & Soenens, 2015; Roth, Assor, Niemiec, Ryan, & Deci, 2009; van der Kaap-Deeder et al., 2015).

Gottfried, Fleming, and Gottfried (2001) conducted one of the first studies of motivation development focusing on the continuity of academic intrinsic motivation at five time points for students ages 9 through 17 years. Results indicated that academic motivation was a stable construct over time and, more interestingly, that the mean levels of motivation declined with age. This study used a generalized measure of academic motivation, the Children's Academic Intrinsic Motivation Inventory (CAIMI; Gottfried, 1986) that tapped students' enjoyment of learning, orientation toward mastery, curiosity, persistence, and interest in subject-specific tasks. This finding is consistent with other correlational studies that have noted a marked decrease in intrinsic motivation as students enter the upper-elementary grades and middle school (Gottfried, 1985; Guthrie, Wigfield, & VonSecker, 2000), which may occur given the changing nature and demands of school tasks as students get older.

A small body of research has examined autonomous motivation in students with disabilities, finding that students with disabilities tend to have lower autonomous motivation compared to students without disabilities (Grolnick & Ryan, 1990) and that there are also differences based on disability label, with students with emotional disabilities reporting even lower autonomous motivation (Deci, Hodges, Pierson, & Tomassone, 1992). However, it is acknowledged that students with disabilities have typically been served in more controlling environments with greater focus on external rewards. Researchers have therefore suggested the need for and potential of autonomy-supportive classrooms to enable greater intrinsic motivation and achievement in students with disabilities (Deci & Chandler, 1986). Reeve (2002) reviewed research on autonomy-supportive teaching behaviors to provide guidance for characteristics that could be used in school environments to promote autonomous motivation, concluding that autonomy-supportive teachers listen, avoid directives and criticism, provide answers less often and instead encourage students to answer, and motivate through student interest. Essentially, in autonomy-supportive classrooms students have meaningful roles, set goals, and are actively engaged in their learning, and this influences engagement (Collie, Martin, Papworth, & Ginns, 2016). It is promising to note that teachers can learn to enhance supports for autonomy provided in the classroom. Reeve, Jang, Carrell, Jeon, and Barch (2004) examined the impact of online training on the providing autonomy-supports in the classroom, finding that after the training, long-term teachers showed increases in their ability to teach and motivate their students in more autonomously supportive ways, which led to increased student engagement. Researchers have also documented how such practices can be embedded across content areas, including science (Hagay & Baram-Tsabari, 2015).

Strategies to enhance autonomous motivation have been embedded in academic interventions for struggling learners. For example, Toland and Boyle (2008) sought to change the ways that children explained their lack of achievement to themselves. Children identified as having low self-esteem participated in group sessions and were provided with modeling of positive thinking about learning. Findings indicated that students in the intervention placed increased effort on tasks, with associated improvement in the areas of reading and spelling. Similarly, specific instructional dialogue based in motivational theory has been embedded in daily practices in Concept-Oriented Reading Instruction (CORI; Guthrie, McRae, & Klauda, 2007; Swan, 2003), with resulting increases in students' intrinsic motivation for reading. Berkeley, Mastropieri, and Scruggs (2011) embedded a modeling and self-talk approach to attributional retraining in a reading comprehension strategy intervention with adolescents with learning disabilities—also reporting an increased use of strategies by the participants. In recent work by Toste and colleagues (Toste, Capin, Vaughn, Roberts, & Kearns, 2016; Toste, Capin, Williams, & Vaughn, 2016), motivational training was embedded within a word reading intervention for upper-elementary students; students who received reading intervention alone and those with the additional motivational component outperformed the control group on measures of word reading. Further, students who received motivational retraining also outperformed the control group on measures of sentence comprehension and reading attributions. These findings further support the assumption that when students achieve success counter to their expectations, their beliefs about their potential may shift. This enhances students' investment in academic tasks, thus promoting positive processes and academic success.

Self-determination Theory and Health and Wellness

In a recent meta-analysis of research on motivation and health, Ng et al. (2012) reports similar findings as those reported in the education domain. Specifically, when health and wellness contexts and professionals were autonomy-supportive, patients reported greater attainment of basic psychological needs as well as more positive health outcomes, including outcomes related to healthy eating (Girelli, Hagger, Mallia, & Lucidi, 2016; McSpadden et al., 2016) and physical activity (Kinnafick, Thøgersen-Ntoumani, & Duda, 2016; Mack, Gunnell, Wilson, & Wierts, 2016). Researchers have examined the impact of autonomy-supports on people with physical disabilities engaged in rehabilitation activities (Saebu, Sorensen, & Halvari, 2013), finding that during physical activities when supports for autonomy are provided, there were increases in autonomous motivation and physical activity over the course of the intervention. Similar findings have also been established in sport and physical activity more generally. For example, research on SDT and sport has shown athletes who are intrinsically motivated and self-determined in their behaviors will exude more effort (Fortier & Grenier, 1999; Li, 1999; Pelletier et al., 1995; Williams and Gill, 1995), have higher levels of concentration (Boiche & Sarrazin, 2007; Brière et al., 1995; Calvo et al., 2010; Holmberg & Sheridan, 2013; Pelletier et al., 1995), are more persistent or avoid burnout (Fortier & Grenier, 1999; Pelletier et al., 2001, 2003; Sarrazin et al., 2001) and perform better (Beauchamp et al., 1996; Pelletier et al., 2003) than athletes who rely on non-self-determined types of motivation. For example, a large body of research has examined the impact of autonomy-supportive coaching in sports, physical education, and physical activity interventions, generally finding that when coaches and teachers create autonomy-supportive environments, athletes are more internally motivated and perform better (Amorose & Anderson-Butcher, 2007; Gagné, Ryan, & Bargmann, 2003; Pelletier et al., 1995, 2001; Reiboth, Duda, & Ntoumanis, 2004). For example, Curran, Hill, and Niemiec (2013) found that when coaches used structural supports such as providing expectations and promoting goal direction, athletes showed greater attainment of psychological needs and behavioral satisfaction. Casey, Wang, and Boucher (2014) found that swimmers with Down syndrome who participated in community-based inclusive swimming showed higher intrinsic motivation than extrinsic motivation, suggesting the importance of community-based, autonomy-supportive experiences for youth with disabilities (Powrie, Kolehmainen, Turpin, Ziviani, & Copley, 2015). In another study, Mageau and Vallerand (2003) report there are seven behaviors that define a coach as autonomously supportive: (a) provide choice within specific rules and limits; (b) provide a rationale for tasks and limits; (c) acknowledge the other person's feeling and perspective; (d) provide athletes with opportunities for initiative taking and independent work; (e) provide non-controlling competence feedback; (f) avoid controlling behaviors (e.g., overt control, criticizing statements, tangible rewards for interesting tasks); and (g) prevent ego-involvement in athletes. These behaviors suggest that an autonomously supportive coach is more complex than just offering choices:

> Autonomy-supportive coaches provide choice, but also a rationale for requested tasks, rules and limits, acknowledge athletes' feelings and perspective, provide opportunities for initiative taking and transmit non-controlling competence feedback [and] avoid controlling behaviors in the form of physical and psychological control, tangible rewards, and ego-involvement induction (Mageau & Villerand, 2003, p. 892).

Bartholomew et al. (2009) present a taxonomy of six controlling strategies employed by coaches to motivate their athletes. The authors acknowledge that while these strategies may induce short-term compliance or desired outcomes; evidence suggests these strategies may be more damaging long term to an athlete's psychological well-being. The six controlling strategies include: (a) tangible rewards (e.g., a coach who promises rewards to athletes for completing a task asked of them or uses the athlete's scholarship as leverage to complete a task); (b) controlling feedback (e.g., a coach only uses feedback to direct future behavior, opposed to providing information for current performance, only focuses on negative aspects of athlete's performance, and does not comment on the positives); (c) excessive personal control (e.g., authoritative demeanor and is unresponsive to their athletes' questions and ideas and commands athletes to complete tasks through the use of orders and directives); (d) intimidation behaviors (e.g., threat of punishment, embarrasses athletes in front of team if they do not complete a task as desired, and directs derogatory comments at their athletes); (e) promoting ego-involvement (e.g., evaluates athletes in front of one another, promotes an environment of competition between his or her athletes, and solely focuses on winning); (f) conditional regard (e.g., a coach says things to make athlete feel guilty or only focuses on athlete when they are winning and does not interact when they are losing). These controlling strategies lack empirical research evidence within sport (research supporting these strategies stem from parenting and educational contexts); however, the goal of illuminating this 'dark side' of coaching is for coaches to be self-reflective of the motivational strategies they employ with their athletes. Further, "over the long term, continued exposure to controlling coach behaviors will thwart athletes' psychological needs and, in turn, contribute to the development of controlled motives" (Bartholomew et al., 2009, p. 229).

Self-determination Theory and Work

Researchers have also begun to examine the impact of autonomy-supportive environments on workers' motivation, finding that when work environments enable autonomous motivation, multiple positive outcomes result (Gagné, 2014). Gagné and Deci (2005) developed a framework for understanding the role of autonomous motivation in work outcomes, suggesting that job characteristics, supervisors and work leaders autonomy-support, and job feedback predicted autonomous motivation and behavioral regulation of job activities. However, the framework also suggests that a variety of contextual factors, related to the work environment, can also influence outcomes. For example, researchers suggest that motivation as well as alignment of strengths with work activities not only influences performance but also worker attitudes, including engagement, well-being, and commitment (Guntert, 2015; Leroy, Anseel, Gardner, & Sels, 2015; Schultz, Ryan, Niemiec, Legate, & Williams, 2015; Van Den Broeck, Lens, De Witte, & Van Coillie, 2013). Researchers have also suggested the importance of building on character strengths, as described in Chap. 13, in combination with interventions to promote autonomous motivation, particularly in the work context (Kong & Ho, 2016).

Self-determination Theory and Intellectual and Developmental Disabilities

Chapter 5 detailed the research pertaining to self-determination and people with intellectual disability and provided a model linking intrinsic and autonomous motivation to the development of self-determination. While there is a substantial knowledge base with regard to the benefits of promoting the causal agency of people with intellectual and developmental disabilities, there has been only limited research on issues pertaining to the satisfaction of basic needs and autonomous motivation with this population. What does exist tends to focus on motivation in engagement in sports. For example, as discussed previously, Casey, Wang, and Boucher (2014) used SDT as a frame to examine the motives behind participation in swimming by people with intellectual disability. More autonomous motivation predicted engagement in swimming in both people with and without intellectual disability.

The limited research applying SDT to understanding (and promoting) intrinsic motivation of people with intellectual and developmental disabilities does not, however, reflect the relative importance of such efforts. This has been well illustrated by research in the field of intellectual disability documenting the phenomenon of *outerdirectdness*. Outerdirectedness is “the term used to describe approaches in which individuals rely on external cues rather than on their internal cognitive abilities to solve a task or problem” (Bybee & Zigler, 1998, p. 435). It is, more specifically, a “motivational style of problem solving in which the child uses external cues rather than relying on his own cognitive resources” (MacMillan & Cauffiel, 1977, p. 643). Research has established that children with intellectual disability exhibit outerdirectedness at a greater rate than do typically developing children, likely due to multiple factors, including prompt dependency and overreliance, repeated experiences with failure, and task difficulty (Bybee & Zigler, 1998). This same body of research documents that outerdirectedness results in the lack of initiation of action, reduced problem solving efficacy, and poorer school performance (Bybee & Zigler, 1998). Clearly, there is a need to examine issues pertaining to intrinsic motivation and its role in promoting self-determination and more positive outcomes for people with intellectual and developmental disabilities.

Conclusions

Self-Determination Theory provides a comprehensive theory to understanding the role of autonomous or intrinsic motivation in shaping the outcomes experienced by all people, including people with intellectual and development disabilities. Although the research with children, youth, and adults with intellectual and development disabilities is more limited than research in the general population, there is no doubt that all humans strive to meet basic psychological needs for autonomy, competence, and relatedness and that promoting intrinsic motivation requires access to autonomy-supportive environments and people in those environments. Given research that suggests that people with intellectual and developmental disabilities have restricted opportunities to access autonomy-supportive environments, particularly related to making choices and decisions and engaging in personally valued goal-directed action (Stancliffe et al., 2011; Tichá et al., 2012), this suggests the critical need for increased attention on creating autonomy-supportive environments across the lifespan.

Structuring environments to be autonomy-supportive and supporting children, youth, and adults across life domains in ways that promote intrinsic motivation by promoting choice, goal-directed behavior, a sense of mastery and connectedness, have the potential to enhance school and post-school outcomes and to foster greater well-being and engagement in work, health, learning, and social activities. In addition to research in the general population in areas ranging from education to employment to health and physical activity, a small but growing body of research has documenting the role of intrinsic motivation in the lives of people with disabilities. This work has significant implications for considering how to design and deliver systems of supports across life domains as described in Chap. 3. Further, as described in Chap. 5 on Self-Determination, by combining autonomy-supportive environments with autonomy-supportive interventions that actively teach people with and without intellectual disability the skills associated with self-determined action, including goal setting, problem solving, decision-making, and self-advocacy skills this can enable the attainment of valued outcomes across the lifespan.

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Teaching Community Living Skills to People with Intellectual and Developmental Disabilities

20

Raymond G. Miltenberger, Heather Zerger,
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Introduction

Adults diagnosed with intellectual or developmental disabilities often lack the types of skills that are necessary for living independently in the community. Community living skills are of major importance given that they promote independence and contribute to an individual's overall quality of life. For example, some individuals diagnosed with an intellectual or developmental disability may have not developed the skills to use public transportation independently, therefore limiting the destinations to which they could travel (e.g., place of employment, the grocery store, the mall, and doctor's appointments) or may not have developed independent living skills, thus limiting their residential options. Community living skills are any behaviors that contribute to independence in the community and include such skills as shopping, meal preparation, and cooking, restaurant use, apartment upkeep, personal hygiene, laundry skills, public transportation use and pedestrian skills, leisure skills, use of technology, job skills, money management and ATM use, and a variety of personal safety skills (e.g., Goh & Bambara, 2013; Lumley & Miltenberger, 1997; Mechling & O'Brien, 2010; Miltenberger & Shayne, 2011; Page, Iwata, & Neef, 1976; Scott, Collins, Knight, & Kleinert, 2013; Sigafoos et al., 2005).

Behavioral deficits in community living skills have been addressed through a variety of training methods to increase the overall independence of people with disabilities. The purpose of this chapter is to discuss the training methods that have been used to teach a variety of community living skills to adults with intellectual or developmental disabilities. This chapter will review prompting, computer simulation, behavioral skills training (BST), simulated environments, video modeling, video prompting, and picture prompting strategies.

Procedures for Teaching Community Living Skills

Community living skills, like any functional skills, consist of chains of behavior (stimulus-response chains) that occur in the proper context (in the presence of the relevant discriminative stimulus or S^D). Before implementing behavioral procedures to teach these skills, the behavioral chains must be task analyzed into the individual stimulus-response components. The steps in the task analysis occur in sequence and each response results in the S^D for the next response in the chain (see Table 20.1 for an example of a task analysis). Once the behavioral chain is task analyzed, the trainer can assess the steps in the task analysis

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Table 20.1 Task analysis for washing clothes in a top-loading washing machine (from Horn et al., 2008)

Step	S^D	Target behavior
1	Standing in front of washer with basket of clothes	Turn dial to setting for regular wash
2	Dial set for regular wash	Pull dial to start running water
3	Water running	Open washer door
4	Washer door open	Take detergent off the shelf
5	Detergent in hand	Take cap off detergent
6	Cap off detergent	Pour detergent into cap
7	Detergent in cap	Pour cap-full of detergent into water
8	Detergent cap empty	Put cap back on detergent
9	Cap on detergent	Put detergent on shelf
10	Water running, detergent in washer	Put clothes in washer
11	Clothes in washer	Close washer door

before and after training to measure the effectiveness of training. Training can then consist of one of two approaches; a chaining procedure (forward or backward chaining) in which each step in the task analysis is trained separately and chained together or total task presentation in which the entire chain of behaviors is prompted and reinforced in each learning trial.

Prompting

Prompting is a procedure that uses the presentation of stimuli before a behavior to make it more likely that a particular behavior will occur at the correct time and contact reinforcement (e.g., prompting evokes a response in the presence of the S^D so it can be reinforced, Miltenberger, 2016). Once the prompts consistently evoke the correct behavior in the presence of the S^D, the prompts are faded (gradually eliminated over trials) so the behavior continues to occur in the presence of the S^D with no further assistance. Response prompts involve the behavior another person to get the desired behavior to occur. They include verbal prompts in which the trainer emits a verbal response to evoke the correct response (i.e., the least intrusive prompt), gestural prompts in which the trainer engages in some movement to evoke the correct response, model prompts in which the trainer executes the target behavior as a model to evoke the correct response, and physical prompts in which the trainer physically guides the learner through the correct response often using hand over hand guidance (i.e., the most intrusive prompt). Other prompts, known as stimulus prompts, involve the change in or addition or removal of a stimulus to make a behavior more likely to occur and do not involve the behavior of other individuals. Research has focused on the use of response prompts to promote community living skills in adults with developmental disabilities.

Dollar, Fredrick, Alberto, and Luke (2012) used simultaneous prompting, in which verbal prompts and model prompts were provided together, to teach independent living skills and leisure skills to three adults diagnosed with severe intellectual disabilities. The skills included using an iPod, a CD player, and a DVD player, folding t-shirts and underwear, and hanging pants. Using a total task presentation training approach (i.e., the trainer uses prompts to evoke the entire chain of behaviors in each learning trial), the trainer provided praise after each correct response. Additionally, when the chain of behaviors was completed, a natural or tangible reinforcer was delivered. The prompting procedures increased the number of correct steps completed for each participant.

Batu, Ergenekon, Erbas, and Amanoglu (2004) examined the effectiveness of a most-to-least prompting strategy to teach a variety of pedestrian skills to five adolescent males diagnosed with developmental disabilities. Most-to-least prompting consists of the use of most restrictive prompting strategies (physical prompts) that are faded to least restrictive (verbal prompts) as the learner successfully engages in the correct behavior over trials. The participants were taught to cross the street using an overcrossing, cross the street using pedestrian lights, and cross the street in the absence of traffic facilitators. Each skill was presented in a total task presentation procedure and the prompts were presented from most intrusive to least intrusive. First, a verbal prompt plus a full physical prompt was provided, followed by a verbal prompt plus a partial physical prompt, and ending with a verbal prompt only. Each time the task was completed, praise and tangible reinforcers were provided. Presenting the prompts using a most-to-least strategy increased correct pedestrian skills for each of the five participants. In another study focusing on pedestrian skills, Harriage, Blair, and Miltenberger (2016) used behavioral skills training (instructions, modeling, rehearsal, and feedback) to teach parents of three adolescents with autism to implement most-to-least prompting procedures to teach street-crossing skills to their children. The parents conducted the procedures with fidelity and the pedestrian skills increased for all three adolescents.

Conversely, Chan, Lambdin, Van Laarhoven, and Johnson (2013) taught leisure skills using a least-to-most prompting procedure in addition to video prompting. In the least-to-most prompting strategy, the least intrusive prompt (i.e., verbal prompt) is used first and more intrusive prompts (gestural and physical) are used only if the least intrusive prompts are not effective (they do not evoke the behavior). Painting skills, listening to music, and taking pictures were taught to an adult male diagnosed with Down syndrome and a moderate intellectual disability. A video prompting procedure was used to teach each behavior involved in the skills. However, when the video prompt was unsuccessful in producing the correct behavior, a verbal prompt was provided followed by a physical prompt if necessary. The combination of the two strategies increased correct responding involved in these leisure activities. Additionally, no reinforcers were provided for the completing of individual responses or the overall activity, indicating that antecedent strategies can be successful in increasing a variety of skills. It is likely that the leisure skills targeted in this study were naturally reinforcing so no external reinforcers were necessary. In general, when teaching leisure skills it is important to choose skills that are reinforcing to the participant and that the participant can access on a regular basis. In this way, the skills are most likely to maintain.

Computer Simulations

Computer simulations can be a cost-effective training strategy that is particularly beneficial when conducting training in the natural environment is not feasible. Computer simulations allow for cues to be presented in life-like simulations with demonstrations of the appropriate behavior in response to the cues that mimic those found in the natural environment. Additionally, unlike video modeling in which individuals passively learn, computer simulations allow participants to engage with the simulated environment that mimics the natural environment, therefore facilitating active learning. Mechling, Pridgin, and Cronin (2005) used computer-based video instructions (CBVI) to teach three individuals with intellectual disabilities how to respond to cashiers and engage in other purchasing skills while at fast food restaurants. During CBVI, training videos of a model engaging in different behaviors related to ordering a meal at a fast food restaurant played on the computer. Throughout the training sessions, the video paused, and the computer prompted the participant to respond to questions related to what the model should do next. Participant responses included either engaging in a verbal response or touching a picture on the computer screen. During training, participants were initially prompted to engage in correct responding with a 0 s delay. Once correct responding occurred consistently, the delay increased to 3 s. This prompt delay procedure is used to transfer stimulus control from the prompt to the natural S^D. The prompt initially evokes the correct response, but across training trials, the participant begins to make the correct response in the presence of the S^D before the prompt is delivered (Miltenberger, 2016). Prompts included the trainer instructing the participant what to say, or gesturing to the correct picture to push. Following training, generalization probes were conducted at fast food restaurants within the participants' natural environment. All three participants engaged in 100% correct responding through CBVI, and all three participants engaged in at least 80% correct responding during generalization probes.

Mechling and Ortega-Hurndon (2007) used similar procedures to teach three adults multiple-step job tasks. During CBVI, participants were shown three pictures of steps in the tasks to complete, and the participants were required to touch the subsequent step. When participants engaged in the correct response, a video segment displaying the correct performance of the task was shown to the participants. Following the training procedure, generalization probes were conducted at each participant's job site. After training, correct responding increased to over 90% for all three participants, and the skills generalized to their job sites. Mechling also used computer-based video instructions to teach bus-riding skills to three young adults with mild or moderate intellectual disability (Mechling & O'Brien, 2010). During CBVI participants watched a video of a model entering a bus, using a pass, and sitting down. They were then instructed to press the "request to stop button" when they saw a target landmark. All three participants engaged in the correct response of pressing the "request to stop button" through CBVI alone, and responses generalized to in vivo probes in which they rode a real bus to the target location.

With handheld technology being readily available to individuals, CBVI programming has been adapted so that it can be used on tablets and mobile phones. Burke, Allen, Howard, Downey, and Bowen (2013) used video modeling on tablets to increase workplace skills for four males diagnosed with autism. A video was developed to depict a model engaging in correct responding related to a shipping task. During intervention participants were given a tablet that contained the video model. Participants were taught how to start, pause, and fast-forward the video. They were then instructed to do the best they could at the shipping task. As a prompt to complete the task correctly, the participants were allowed to watch the video as they completed the task. Task completion substantially increased from baseline to intervention when video modeling and prompting were provided.

McMahon, Cihak, Gibbons, Fussell, and Mathison (2013) taught seven adults with intellectual disabilities to use a mobile application to identify whether food items contained specific allergens. Participants were given scenarios in which a person had a specific food allergy and were asked if that person could eat a particular food item. During baseline, participants were given a list of food allergies and the food packaging. They were required to answer "yes" or "no" for eight scenarios regarding whether the person could eat the provided food item. During intervention participants were taught to use a mobile application that scanned a food item barcode and listed whether the item had common allergens. Participants were again given a list of scenarios and asked whether the person was able to eat the food item; however, they were allowed to use the mobile application to help them determine whether the item contained the specific allergen. During baseline the number of problems solved correctly ranged from two to six. Once participants were given the mobile application, correct responding increased to at least seven correct responses with most sessions including participants responding correctly to all eight questions. In a return to baseline when participants were no longer allowed to use the application, their correct responding decreased to baseline levels.

With rapid advances in technology and the development of a large variety of applications for handheld devices, it is likely that researchers will continue to evaluate applications that can promote the successful use of community living skills by people with disabilities (e.g., Kagohara et al., 2013).

Simulation and Behavioral Skills Training

Teaching skills through computer simulations can be expensive if it requires the school or agency to purchase the necessary equipment and software to conduct training. In addition, if computer simulations are not already prepared for training situations, time and expertise is required to prepare videos. Therefore, for some agencies or schools, it may not be possible to use computer simulations. When time, technical expertise, or money constraints negate the use of such training methods, non-technological simulations may be beneficial.

Page et al. (1976) evaluated simulation training to teach pedestrian skills to adolescents with disabilities. They developed a cardboard layout simulating four square city blocks, to teach pedestrian safety skills. They also developed a model pedestrian light that showed "Walk and Don't Walk," and a model traffic light that could be placed at different intersections within the simulated city. Participants included five adolescent males diagnosed with intellectual disabilities who were taught to engage in correct pedestrian skills by maneuvering a doll through the cardboard simulation. They were taught to cross the streets safely at intersections in a variety of locations including two types of intersections with stop signs, intersections with "Walk/Don't Walk" lights, and intersections with tricolored traffic lights. Before and after training, assessments on the individual safety skills were conducted using the cardboard simulations and within the natural environment at different intersections in the community. Results of Page et al. demonstrated that for all participants correct responding increased from about an average of four out of 17 task analysis steps in baseline, to 16 out of 17 steps during treatment, and responding maintained during follow-up sessions within the simulation and natural environment.

Neef, Iwata, and Page (1978) conducted a similar study in which they taught adults with intellectual disabilities public transportations skills. They conducted simulation training using the same cardboard model of city streets (Page et al., 1976) and a life-size simulated bus created with cardboard in the classroom. The participants manipulated a doll to engage in the correct behavior in the simulated city streets and rehearsed actual bus-riding behaviors in the model of the bus. The researchers also included slides that showed instances in which participants should and should not respond (e.g., board the bus when the correct bus is shown, do not board when the incorrect bus is shown). Participants were taught how to approach and board the bus, sit while riding the bus, and pull the cord indicating they would like the bus to stop at the correct time. The training procedure consisted of praise for correct performance and modeling prompts to evoke correct performance both in the tabletop simulation and life-size simulation. After training with a cardboard bus, participants were shown the slides of different instances in which they should and should not respond and were instructed to answer questions about how they should respond in each situation. Assessments were conducted within the natural environment to see whether skills taught within the classroom would generalize. Results indicated that correct responding increased for all participants from 10 or fewer correct responses out of the 21-item task analysis in baseline to either 20 or 21 correct responses (95–100% correct) in training. Correct responses also generalized to the natural environment, including novel buses.

Generalized restaurant skills have also been taught to adults with intellectual disabilities using classroom simulations (van den Pol et al., 1981). Skills were separated into four components: locating, ordering, paying, and eating and exiting. As in Neef et al. (1978), participants were required to respond correctly to a series of slides and practiced the skills within a simulated setting with trainers acting as restaurant staff. Skills were assessed within the natural environment at two local fast food restaurants before and after training was conducted. Results of van den Pol et al. (1981) demonstrated an increase in correct responding from less than 50% correct to nearly 100% correct for all participants, along with increased generalization of skills to the natural environment. Results of these three studies demonstrate that community living skills can be taught to people with intellectual disabilities with low-tech simulations in the classroom. Although these skills are often taught in highly structured simulated situations, research has demonstrated that they can generalize to the natural setting and maintain over time.

A training approach that is used in simulation training and in natural settings is behavioral skills training (BST). BST consists of delivering instructions and modeling correct responses, providing opportunities for the individual to rehearse the correct responses within a controlled environment, and providing feedback on which skills the individual performed correctly and what skills needed improvement. Aeschleman and Schladenhauffen (1984) used both mnemonic training and BST to teach grocery shopping skills to people with disabilities. During the mnemonic training, participants were instructed to draw symbols to represent items they needed to purchase at the store. In order to ensure that each symbol would act as a cue, participants were instructed to match the symbols to the corresponding items. After mnemonic training, BST was used to teach a variety of skills needed for grocery shopping. The classroom was arranged to simulate a grocery store, and sessions started with the participants drawing the symbols for the food they needed to purchase. Researchers gave the participants money and a grocery basket and instructed them to buy the items on their shopping list. During subsequent training, if the participant made an error during a step in previous sessions, the trainer stopped the participant at the step he or she missed and modeled the correct response. If participants responded correctly in 19 out of 20 steps in two consecutive training sessions, in vivo training was used in which sessions were conducted in the same grocery store from baseline. The same training conducted in classroom sessions was implemented during the in vivo sessions. Average responding for all participants increased from 45% correct responding in baseline to 90% correct responding during intervention, which maintained during a 20-week follow-up session.

Burke, Andersen, Bowen, Howard and Allen (2010) used both BST and a performance cue system (PCS) to teach vocation skills to six adults with autism. Participants were trained to assist in the delivery of a fire safety education program, which consisted of 63 scripted behaviors. The participants wore an inflatable firefighter mascot costume while assisting the firefighters conducting the training. During BST, participants were given a training script and shown a training video. Participants practiced during a mock assembly and were given praise and corrective feedback on components they performed incorrectly. If participants did not perform to criterion during BST, they were introduced to PCS, which consisted of cues appearing on an iPhone that participants wore within the mascot head. One participant achieved criterion performance (80% correct) through BST alone. The other two participants, however, required the PCS to reach criterion. Burke et al. also looked at acquisition of skills with PCS alone without BST for three adults diagnosed with autism. Two participants reached criterion with only PCS, while one participant required BST and PCS to reach criterion. This study provides a nice example of the value of BST to teach the skills and the use of technology to cue the skills in the natural environment if they do not generalize.

Video Modeling

The use of video modeling to teach community living skills has been shown to not only be effective at increasing the accuracy of skills being taught, but also lead to generalization to more natural environments. This technology has been used to teach a variety of community living skills such as job skills (Goh & Bambara, 2013), laundry skills (Horn et al., 2008), meal preparation and cooking skills (Mechling & Collins, 2012; Rehfeldt, Dahman, Young, Cherry, &

Davis, 2003), and appropriate use of fire extinguishers (Mechling, Gas, & Gustafson, 2009). In each of these studies, the researchers first video recorded an actor performing the task from the perspective of the learner. This allowed the learner to see the skill being completed from the perspective they would experience when completing the task. Individuals were required to review the entire video model before attempting to complete the task. A variety of prompting methods were used in conjunction with video modeling, including constant time delay, verbal prompts, task termination, and least-to-most prompting.

Goh and Bambara (2013) used video modeling to teach adults with intellectual disabilities to complete their job task without the need for prompts from supervisors. The researchers video recorded the participants performing the task while receiving instruction from their job coach. Each participant was shown the video model during an instructional setting. After watching the video the participant was given a choice to view the model again or practice the task. Once the participant practiced the task during the instructional setting, the individual was immediately taken to the work area to perform the task. Three different phases were conducted including video modeling alone, video modeling plus feedback (i.e., praise), and video modeling plus feedback and practice. For the majority of skills, all participants required video modeling plus feedback and practice to achieve mastery.

Video modeling has also been shown to be effective without the use of corrective feedback. Rehfeldt et al. (2003) found that individuals were able to watch an entire 2.5-min model before independently making a sandwich. If participants missed a step, the researcher did not provide feedback, but simply completed the step and had the participant begin with the subsequent step in the chain. Similarly, Mechling et al. (2009) demonstrated that individuals could learn to appropriately use a fire extinguisher to put out a cooking fire by watching a video model. If any steps were not completed correctly, participants were required to re-watch the video.

Horn et al. (2008) evaluated the use of video modeling to teach adults with disabilities to use a washing machine to wash a load of clothes. Specifically, each participant was instructed to watch an entire video of a person following a 10-step task analysis to wash clothes and was then instructed to perform the task. When this approach was not successful, Horn et al. divided the 10 step video into two 5-step segments of the video. This method required the participants to watch the first five steps before performing the first half of the task and then to watch the second five steps before completing the second half of the task. Two participants reached mastery after this training. For the third participant, the researchers faded from the 5-step segments to single step segments (video prompting) and added a least-to-most prompting procedure. Results demonstrated video modeling as an effective procedure for two of the three participants, with the third requiring video prompting and physical prompting. These findings demonstrate that different individuals may require different modes or intensities of training to successfully learn a community living skill.

Video Prompting

Like video modeling, video prompting requires a learner to view a video model of a targeted skill being completed. However, video prompting requires the learner to watch a video segment, pause the video and complete the step in the task analysis shown in the video segment, restart the video, and repeat the process for all steps in the task analysis. Video modeling involves watching the entire task being completed on video before beginning to engage in the task. Video prompting has been used to teach a variety of community living skills including cooking (Sigafoos et al., 2005), washing dishes (Sigafoos et al., 2007), correct ATM/debit card use (Scott et al., 2013), and leisure activities (Chan et al., 2013).

Laarhoven, Johnson, Laarhoven-Myers, Grider, and Grider (2009) demonstrated the effectiveness of video prompting when teaching job skills to an individual with an intellectual disability. The authors developed the video clips by video recording the task being completed, taking a still shot of the most salient part of each step, and placing the picture at the beginning of each video clip. In addition, each step included a voiceover narration. The video clips were loaded onto an iPod for the participant to use while completing the task. During training, the participant was directed to watch the clip again on his iPod for the first error (i.e., a missed step). The second error resulted in the use of physical or model prompts. The authors found video prompting, video feedback, and prompting were effective at increasing the accuracy of job completion as well as job independence. In a similar study, Scott et al. (2013) uploaded video podcasts to an iPod to teach correct ATM/debit card use. The authors used a simulated ATM to produce all of the videos, which included audio narration (i.e., verbal cues). Unique to this study, the authors elected to video record peers performing the task used on the podcast. The results of both studies demonstrated that video prompting was not only effective at teaching skills, but generalization to real and novel ATMs could also be achieved without direct training. In another study, Chan et al. (2013) also demonstrated video prompting was effective at teaching an individual to engage in leisure activities. The researchers first presented the participant with a video model. If the participant did not respond within 5 s, a fixed 5 s time delay was used before using least-to-most prompting. It is important to note that, although the participant was able to complete the leisure activities, prompting continued to be required.

Sigafoos et al. (2007) investigated whether they could fade video prompting by systematically chunking the video together to transition to a video modeling intervention. The goal of this study was to answer whether individuals could become completely independent at dish washing after learning the skill through video prompting. First, the researchers taught the participants to complete the dish-washing steps with the use of video prompting. Second, the researchers evaluated whether participants could complete the task without video prompting present. All three participants' performances quickly decreased after the removal of the video prompts. Third, the researchers systematically chunked the video clips together to create a full length video of the dish-washing task. Although the authors demonstrated the effectiveness of video prompting, they failed to completely fade the video prompts for all participants.

In an effort to ascertain whether video modeling or video prompting is more effective at teaching new skills, Cannella-Malone et al. (2006) compared the two methods. Each participant was taught to set a table using video modeling and put away groceries using video prompting. The results showed that video prompting was more effective than video modeling at teaching the new skill. The authors then used video prompting to teach table setting, which resulted in immediate acquisition of the skill. These finding suggested video prompting was more effective than video modeling for teaching new skills. However, video modeling has been demonstrated to be an effective approach in other studies (Goh & Bambara, 2013; Mechling & Collins, 2012; Rehfeldt et al., 2003) suggesting that the choice of procedures should be tailored to the needs of the individual.

Audio Cues Within Video

The videos created for video modeling and video prompting procedures often make use of voiceover instructions in which the narrator provides instructions to accompany the modeling or asks the learner questions regarding the models behavior. For example, Poche, Yoder and Miltenberger (1988) created videos showing abduction prevention skills. In each scenario in the video, an actor demonstrated the skills (say “no,” run away, and tell an adult when presented with an abduction lure) as the voiceover described the skills. In addition, after a few scenarios, subsequent scenarios involved pauses in which the voiceover described the abduction lure shown in the video and asked the viewer what the actor should do next. In this way, the voiceover directed the viewer's attention and provided an opportunity for active verbal responding while watching the scenarios. After the pause, the voiceover then stated the correct answer as feedback for the learner's verbal response (e.g., "If you said the boy should say 'no,' run away, and tell an adult, you are right!").

To evaluate the importance of voiceover, or verbal cues, Mechling and Collins (2012) compared video modeling with and without verbal cues for the acquisition of cooking tasks. Each participant was taught three different cooking skills with each separate skill assigned to either video modeling with verbal cues, video modeling without verbal cues, or to the control (i.e., no audio or video). Using an alternating treatment design, the researchers evaluated which treatment was most effective at teaching the cooking skill. After determining the most effective treatment for each participant, that treatment was used to teach the skill assigned to the opposite treatment. For example, if video modeling with verbal cues was found to be the most effective, that method was used to teach the skill assigned to the video modeling without verbal cues. Last, the most effective treatment was then used to teach the skill from the control group. For all four individuals, the percentage of correct cooking steps increased in both video conditions relative to control. Video modeling with verbal cues was the most effective method for two participants, the two video conditions were equally effective for one participant, and video without verbal cues was most effective for one participant. Although these results slightly favor the inclusion of verbal cues in voice over, all participants benefitted from both teaching methods.

Picture Prompts

A low-tech strategy similar to video modeling or video prompting is the use of picture prompts. In the picture prompting procedure, a series of pictures illustrating each step in the task analysis is presented to the learner to evoke the correct behavior at each step in the task analysis. Often, the sequence of pictures is bound in a three ring binder so the individual can flip through the pictures as he or she completes each step in the task. Picture prompts have been shown to be effective for the acquisition of a variety of skills for people with disabilities including ATM use and purchasing skills (Alberto, Cihak, & Gama, 2005), vocational tasks (Steed & Lutzker, 1997), cleaning (Wacker, Berg, Berrie, & Swatta, 1985), laundry (Wacker et al., 1985), and pedestrian navigation skills (Kelley, Test, & Cooke, (2013). In the study by Kelley et al. (2013), the pictures used in the picture prompting procedure were digital photos presented on an iPod that the individual carried as he or she walked from one location to another. The pictures were of landmarks in the city that the individual used to help navigate to a specific location.

Laarhoven, Kraus, Karpman, Nizzi, and Valentino (2010) compared the effectiveness of picture prompts and video prompts in teaching daily living skills. Picture prompts were presented in the sequence of correct steps bound by a ring clip. The participants were taught to review the picture and corresponding text, complete the step, and turn to the picture ring for the next instruction. Conversely, the video prompts displayed video models with voiceover narration. Video prompting and picture prompts were both found to be effective at teaching new skills, but video prompting resulted in more independence, higher percentage of correct responding, and fewer prompts to utilize the technology. These findings suggest that, if clinicians have the ability to use video technology with clients, their clients would benefit by gaining independence faster with the new skill.

Summary

Research demonstrates that a variety of behavioral training procedures are effective for teaching the range of community living skills needed by people with disabilities to promote the maximum degree of independence and autonomy in the community. Common to all approaches is the need for a task analysis of the skill being taught, a teaching approach that evokes the correct responses in the chain of behaviors, reinforcement to strengthen the behavior, and strategies to promote generalization so the skills occur in the natural environment. Below, we offer some guidelines for teaching community living skills to people with disabilities.

1. Identify the skill to be taught and the time and place in which the skill should occur. Of the many community living skills that can contribute to independence and autonomy, some will be chosen over others based on the needs of the individual and the skills already present in the individual's repertoire. The intervention team will evaluate the individual's current residential and vocational placements, access to leisure activities, and the individual's interests in choosing what skills to target.
2. Conduct a task analysis of the skill. As stated in the chapter, a task analysis must be conducted for each skill to identify all component behaviors (steps) and the S^Ds for each step. This information is needed to adequately assess and train the skill.
3. Identify all the relevant discriminative stimuli (S^Ds) in the community in the presence of which the skill should occur. Each community living skill must occur at the appropriate time and in the appropriate circumstances. For example, playing a video game on a smart phone is appropriate at home during leisure time but not at home when other tasks must be carried out (meal preparation, grooming, etc.) and not at work or at church. Identifying the S^Ds associated with best times and places to engage in the skill allows the trainer to incorporate those stimuli into training to promote appropriate stimulus control and generalization.
4. Identify the training approach best suited for the learner and the skill being taught. This chapter identified a number of training approaches demonstrated effective for learners with disabilities including various prompting strategies, computer simulations, video modeling and video prompting, picture prompts, and behavioral skills training. If the learner has more severe disability, more intensive approaches such as prompting and behavioral skills training may be needed. If the learner has less severe disabilities, less intensive approaches such as video modeling may be appropriate. Some approaches require technology and would be appropriate when the trainer, school, or agency has access to the technology (hardware, software, applications) used in training and when the individual has experience with the technology.
5. Identify the environment in which training will occur and all the stimuli needed to conduct training. Training can occur in an environment separate from the community where the skills need to occur or training can occur in the community (i.e., the natural environment). If training occurs in a separate environment (e.g., classroom or clinic), the training environment should simulate the natural environment so the skills come under the stimulus control of stimuli from the natural environment. For example, if teaching shopping skills in the classroom, actual items from stores can be arranged on shelves to simulate the shopping experience that would occur in a store. Sometimes training will occur in a classroom or clinic and, if the skills do not generalize, training will continue in the natural environment. For example, Miltenberger et al. (1999) taught sexual abuse prevention skills to women with intellectual disabilities in a classroom setting and when the skills did not generalize, the researchers conducted in situ training which is training in the natural environment where the skills should be occurring. Likewise, Bakken, Miltenberger, and Schauss (1993) taught parenting skills to parents with intellectual disabilities in a classroom setting and when the skills did not generalize, they taught the skills in the homes of the parents with their children present.
6. Identify the strategies to be used to promote generalization of the skill to the natural environment. Strategies to promote generalization should be planned in advance and incorporated into skills training. To promote generalization, all S^Ds should be identified

and, to the extent possible, incorporated into training. By including all relevant stimuli (multiple exemplars), the stimuli from the natural environment are more likely to exert stimulus control over the behavior. In addition, skills should be chosen that will contact naturally occurring reinforcement whenever possible. For example, dance skills might be targeted for individuals who like to dance and can attend weekly dances near their residence or the use of computer games might be taught to individuals who have access to computers and have at least rudimentary computer skills. Finally, it might be necessary to prompt the skills in the natural environment and arrange for reinforcement of the skills as they occur in the natural environment, at least initially, so the skills are more likely to occur and strengthened in the natural environment.

7. Identify strategies to assess the skills in the natural environment. Valid assessment strategies should be developed to measure the effectiveness of the training procedures. Valid assessment, often called in sit assessment or in vivo assessment, will measure the use of the skills in the natural environment where the skills would naturally occur without any prompts. When skills occur in the natural environment consistently without prompts, training is deemed successful.

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Career Development and Career Design

21

Laura Nota, Lea Ferrari, Teresa Maria Sgaramella
and Salvatore Soresi

Introduction

There is increased interest in the application of Life Design models (described subsequently) to career development, including the extension of such models to childhood and early adolescence. These changes are motivated, from one side, by rapid technological advancements in society and, on the other, by cultural and theoretical advancements in understandings of early ages as crucial for future career development (Hartung, 2015). To be successful in rapidly changing societies, young people with and without disabilities will need to acquire skills and competencies considerably different from those required in past decades. For example, the Global Challenge Insight Report issued by the World Economic Forum (2016), which focused on employment skills and workforce strategy for the "fourth industrial revolution," underscored that about "65% of children entering primary school today will ultimately end up working in completely new job types that don't yet exist" (p. 3). Such dramatic societal shifts will require that promoting self-determination become a focus of career development for all students, including younger children (Wehmeyer, 2015).

The importance of early career development is also supported by an emerging emphasis in psychology and related disciplines on positive human development and on the need to guarantee and increase participation for all in work and life contexts (Nota, Soresi, & Ferrari, 2014; WHO, 2001). Indeed, a consistent integration between individual strengths and contextual factors and resources in supporting positive development has become a key point of many recent career development approaches. The construct of *Positive Youth Development* (PYD; Lerner, von Eye, Lerner, & Lewin-Bizan, 2009; Lerner, Phelps, Forman, & Bowers, 2009), for instance, considers adolescence as an age of flourishing (rather than turmoil and chaos, as many theories of adolescence depict the period) during which youth mobilize their resources and navigate toward higher levels of self-regulation, agency, and self-initiatives to achieve developmental milestones. Some longitudinal studies (Lewin-Bizan et al., 2010; Phelps et al., 2009) conducted to test the PYD have shown the existence of different developmental trends from childhood to adolescence supporting the validity of the five components (five Cs) included in the model.

According to PYD, when youth experience *Competence* (a positive view of one's action in

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social, academic, cognitive, and professional domains), *Confidence* (a generally positive view of self as opposed to domain-specific beliefs), *Connection* (a set of positive exchanges that characterizes people and institutions), *Character* (following social and cultural rules, principles, and values that guide the behavior, what is right and wrong, and integrity), and *Caring* (attitudes of sympathy and empathy toward others), they are more likely to be on a positive development trajectory and develop attitudes and behaviors that lead them to be individuals who contribute to their family, their community, and society.

Models of youth development such as PYD emphasize the interaction between the personal strengths and capacities of the young person and the demands of the context and environment. What is necessary for the field of career development is that children and youth acquire skills that will enable them to create a “fit” between their skills and abilities and the demands of work and life contexts. This will consequently increase the probability for children to actively participate in the future to the world of work and achieve higher levels of life satisfaction, which in turn requires investing in personal aspirations, hopes, cognitive and behavioral skills and, at the same time, in family, school, friends, and community supports. What emerges as relevant in career development is embracing strength-based models of development that stress positive resources and move away from deficit-based models (Wehmeyer, 2015).

In the school context, Nota et al. (2014) and Wang and Algozzine (2011) noted that teaching academic content and skills should be accompanied by instruction in attitudinal, behavioral, cognitive, motivational, and social skills (such as optimism, flexibility, self-knowledge, and self-regulation) that will enable young people to engage successfully in the world of work. This is equally important for young people with disabilities, for whom expectations about success in work are generally lower. In fact, in studying teachers’ views about the future of students with Down syndrome, Nota and Soresi (2009) found most teachers focused more on the limitations and deficits they ascribed to the disability and the child, instead of the child’s abilities and competencies. These respondents were generally negative in their beliefs that these students might one day work in competitive, inclusive work settings and self-determine their own future. As such, it is critically important that career development models applied to youth with disabilities assume competency and take strength-based approaches to education (Shogren et al., 2015; Wehmeyer 2015).

In line with this view of career and life participation, a special issue on children and career development of the *International Journal for Education and Vocational Guidance* (Nota, Ginevra, & Santilli, 2015) called for research in career education activities promoting extensive and accurate occupational knowledge; increasing children’s abilities to collect information about the world of work; and reducing gender-occupational stereotypes so as to adequately prepare young people to cope with complex and changing work realities (Nota et al., 2015).

This chapter examines the most recent career development research trends that concern children, preadolescents, and adolescents, including children and youth with intellectual disability. Subsequently, suggestions for assessment and career education activities based on the work we are conducting at the Larios Laboratory at the University of Padova will be discussed.

Early Career and Vocational Development from Childhood to Preadolescence

As previously discussed, changes in the world of work that require potential workers to interact with and impact different work environments to succeed have led some scholars interested in career issues to emphasize the need of adopting a lifelong perspective and to conduct more in-depth studies of antecedents of career development as key elements for subsequent work adaptation and well-being (Hartung, Porfeli, & Vondracek, 2005; McMahon & Watson, 2008; Porfeli, Hartung, & Vondracek, 2008;

Schultheiss, 2008). This has resulted in increased research on career development during childhood and preadolescence, although such research remains fairly scarce (Rohlfing, Nota, Ferrari, Soresi, & Tracey, 2012; Schmitt-Wilson & Welsh, 2012), somewhat fragmented (Schultheiss, 2005), and involves mainly children without disabilities.

According to the Life Design approach, development during childhood can be conceptualized in terms of its role as an antecedent to later career- and self-constructions (Hartung, 2015). Vocational exploration and developing a positive mindset, each discussed below, are primary dimensions identified when beginning career development activities in early ages, since they are prerequisites of career adaptability and career preparedness (Hartung, Porfeli, & Vondracek, 2008).

Vocational Exploration

Career exploration plays a major role in career and life designing as a mechanism capable of supporting positive activities for children and preadolescents. From an early age, children's career exploration takes place through participation in leisure and school activities, which, in turn, help children and preadolescents prepare themselves for interactions in the work context (Cheung, 2015). Vocational exploration involves cognitive and affective activities; it is also important in analyzing past and present experiences and in planning future actions (Taveira & Moreno, 2003). Cognitive aspects of vocational exploration refer to the specific knowledge people acquire when exploring about themselves and their relevant educational, social, and occupational worlds. An affective component involves feelings about information and insights arising during the exploration process (Flum & Blustein, 2000).

As suggested by Porfeli et al. (2008), career and vocational exploration can be considered as "pivotal mechanisms" that allow ones vocational identity and self-knowledge (related to work and career) to develop. During childhood and preadolescence, exploration and learning can be promoted to gather appropriate knowledge both about oneself, such as identifying personal interests and values, and about the world of education and work, such as collecting information about education, training courses, and occupations (Patton & Creed, 2007; Porfeli & Lee, 2012). Higher levels of exploration are related to a wide range of career interests, and supporting their development and enlargement is considered a resource for future career development for children with disability (Harkins, 2001).

Research conducted with typically developing children supports the idea that career exploration is closely related to the occupational knowledge children develop and is strongly influenced by the opportunities provided in work-related contexts (Schultheiss, Palma, & Manzi, 2005). In a recent study involving elementary and middle school students, Ferrari, Sgaramella, & Soresi (2015) found that career exploration activities such as gathering appropriate knowledge both about self (e.g., interests and values) and about the world of education and work (e.g., education, training courses, and occupations) predict children's enhanced knowledge about occupations. In designing career exploration activities for young children, linking such activities to more familiar domains (social) can enhance learning in less-familiar vocational domains (Ferrari et al., 2015).

When examining issues pertaining to vocational exploration activities and children and preadolescents with intellectual and developmental disabilities, some recent research has shown that as is the case with their peers without disability, vocational exploration plays a role in children gaining knowledge about their interests and skills, as well as gaining knowledge about the world, and that their participation in out-of-school activities plays a crucial role (King, Shields, Imms, Blacj, & Arern, 2013). These results underscore the relevance of increasing parents and teachers' awareness about the importance of offering career exploration activities to children in order to expand their understanding of the world of work.

Determining areas of career interests is a primary task of early career development. Despite the fact that children with disabilities often have more restricted opportunities than do their peers without disabilities, research has shown that they have a comparable number of such interests. For example, Turner-Brown, Lam, Holtzclaw, Dichter, and Bodfish (2011) asked parents of 60 children with autism spectrum disorders and 63 children without disabilities from 6 to 17 years to evaluate their interests. They found the number of interests of children with autism spectrum disorders did not differ from that of their peers. It was true, though, that children with autism spectrum disorders were more likely to be interested in machines, mechanical systems, vehicles, building, computers, physics, object motions than in social activities that involve people, religion, politics aspects, were less interested in social games, and show a higher tendency to prefer playing alone. Similar results have been found by Anthony et al. (2013).

Some evidence also suggests that there are gender differences in children with and without disability in relation to their early career development preferences. For both groups (with/without disabilities) boys prefer action-based activities such as Legos and videogames and girls prefer social and artistic activities (Schultheiss et al., 2005; Ferrari et al., 2015; Anthony et al. 2013). These findings suggest the early influence of gender stereotyping; children are influenced by what they see others doing and what opportunities they are provided to explore various options.

On the whole, these findings support the benefit of involving children in reflective activities that relate to career and vocational interests, and of the need to provide non-stereotyped knowledge about the world and the world of work (Meijers & Lengelle, 2012; Porfeli & Lee, 2012). Taveira and Moreno (2003) highlighted the importance of emotionally supportive role models, including parents and teachers, for 9–12-year-old children in facilitating their career exploration and information gathering. Children in this study reported that adults supported them in constructing their occupational knowledge by taking them to places such as museums and libraries, or giving them the opportunity to observe workers in their typical employment environment. The importance of parents in the development of interests and preferences was further validated by Marquis and Baker (2015), who found low level of participation in sport activities by elementary school children with developmental delays, as compared with typically developing children, was related to parenting factors and not disability-related factors. We agree with Shields, Synnot, and Kearns (2015) who underscored that in implementing interventions to increase the participation of children with physical, intellectual, multiple, or other disabilities, it is critical to take into account children’s preferences and interests. At the same time, increasing parents’ capacities to promote career exploration with their children would appear to expand their child’s understanding of the world and their interests (Levine & Sutherland, 2013).

Positive Mindset

Looking to the future with hope and optimism is among attitudes and skills that allows young people to act in a self-determined manner and successfully cope with the complexities of the work world. Such beliefs begin to emerge in childhood, become more solidified by adolescence, and persist into adulthood (Masten & Tellegen, 2012). In this section, we focus on hope and optimism as attitudes that are important to the development of career and vocational development.

Hope is a motivational process that involves three components: goals, pathways, and agency goal-directed thinking (Snyder, 2002). Research has highlighted that higher levels of hope are related to more positive health and career outcomes. In a study involving 529 students without disabilities and 327 students with learning disabilities from 10th to 12th grades, Idan and Margalit (2014) found that high levels of hope mediated the relationship between various risk and protective factors related to positive development, as well as mediating the relationship between academic self-efficacy and student attributions of achievement and effort.

Optimism refers to a stable predisposition to “believe that good rather than bad things will happen” (Scheier & Carver, 1985, p. 219). During the course of development, it is negatively associated with depression, anxiety, non-adaptive behaviors, and suicide risk, and positively correlated with physical health, life satisfaction, and positive interpersonal relationships (Malinauskas & Vaicekauskas, 2013; Reivich, Gillham, Chaplin, & Seligman, 2013). For example, Deptula, Cohen, Phillipsen, and Ey (2006) studied 232 3rd to 6th grade elementary school students and showed optimism was associated with more positive relationships, higher social acceptance, and lower levels of loneliness and isolation. Ginevra, Carraro, and Zicari (2014), assessed hope and optimism in 340 4th and 5th grade students and found that more positive levels of hope and optimism predicted better social skills, better life satisfaction, and more positive self-perception. Moreover, they observed that hope and optimism correlated with resilience.

With regard to these issues as they pertain to students with intellectual disability, Muller and Prout (2009) selected a group of 269 students with intellectual disability from a national dataset and matched them with 267 students without disabilities. All students were between 7th and 12th grade. They found that optimism did not increase across time from preadolescence to later adolescence, as it did in typically developing students. These authors suggested that to facilitate of optimism among youth with intellectual disability, these young people needed to be provide more opportunities to engage in future planning, set goals, and learn the kinds of pathways thinking emphasized in hope theory and in promoting self-determination.

Researchers focused on issues of disability and positive mindset study parents of children with disabilities more than their children (Shogren, 2013). Hope and optimism have been identified as factors that sustain parental resilience, positive parenting, and overall family well-being (Blacher, Baker & Berkovits, 2013). In fact, across parents and families with and without a child with a disability, parents with a positive mindset transmit such attitudes to their children. Porfeli, Ferrari, and Nota (2013), for example, found that the more parents assumed a positive attitude toward their work and described their experiences positively, the more likely it was that their children had positive attitudes toward work and higher school achievement.

To promote the development of hope and optimism and a positive mindeset, people interested in early career and vocational development need to provide positive experiences and supports for young people to be future oriented. (Lopez, Rose, Robinson, Marques, & Pairs-Riberio, 2009; Zager, 2013).

Career Assessment Instruments for Children and Preadolescents

The increasing interest in promoting career development starting at younger ages has triggered the creation of numerous qualitative and quantitative assessment instruments. In this section, we mainly focus on instruments for assessing occupational knowledge and positive mindset.

With regard to assessments of occupational knowledge, several self-report and structured interview formatted assessments have utility, including the *Revised Career Awareness Survey* (McMahon & Watson, 2001), the *Job Knowledge Survey* (Loesch, Rucker, & Shub, 1978), the Inventory of Children’s Activities-Paired (Tracey & Darcy, 2002; Tracey & Caulum, 2015), and the *Career Exploration Scale* (Tracey, Lent, Brown, Soresi & Nota, 2006). In the Italian context, Ferrari et al. (2015) developed the *Occupational Knowledge Interview* to assess children’s perception of occupational knowledge and actual occupational knowledge. It is composed of 12 cards, each depicting one occupation, two from each of Holland’s categories: *Realistic* (airplane pilot, fireman), *Investigative* (pharmacist, veterinary), *Artistic* (actor/actress, journalist), *Social* (nurse, schoolteacher), *Enterprising* (shop assistant, taxi driver), and *Conventional* (accountant, administrative assistant). The interview consists of two sections: the first section probes perceptions of knowledge in 12 occupations, using a 4-point Likert scale (1 = *I do not know*; 4 = *I know very well*); the second investigates actual occupational knowledge, asking participants to list any action, task, or activity that is carried out by workers in the same 12 occupations. The interrater agreement for the measure was over 96% for each of the analyzed occupations. Moreover, the interview allowed researchers to differentiate children by age and gender and to detect occupational knowledge changes.

There are a number of assessments of hope that are widely available, including the *Young Children's Hope Scale* developed by McDermott, Hastings, Gariglietti, and Callahan (1997) for children aged 5–7 years, and the *Children's Hope Scale* developed by Snyder et al. (1997) for participants aged 8 to 16 years. In the Italian context, to assess hope in 4th and 5th grade students, Ginevra, Carraro, et al. (2014) developed a self-report measure titled *My Hope*. It consists of six items (e.g., "I think how to get things that are important for me") on a 6-point scale ranging from 1 (*never*) to 6 (*very often*). The validity and reliability analyses were positive, with a Cronbach's alpha of .77.

As is the case with measures of hope, there are several instruments published in the international literature to measure optimism for children, preadolescents, and adolescents. Among these, there are: the *Optimism-Pessimism Test Instrument* (Stipek, Lamb, & Zigler, 1981), for children aged 6–12 years; the *Youth Life Orientation Test* (Ey et al., 2005) for children 7–16 years; and the *Life Orientation Test* (Scheier & Carver, 1985) for children as young as 8 years of age. In the Italian context, Ginevra, Carraro, et al. (2014) developed a 6-item self-report scale titled *What Will Happen to Me?*. Items are constructed using a 5-point scale (1 = *I never think so*; 5 = *I always think so*) to measure the child's propensity to expect more positive, rather than negative, events. An example of item is "I think more good things will happen to me than bad things." The validity and reliability analyses conducted by the authors showed positive results, with Cronbach's alpha of .91.

For preadolescents, *Visions about the Future* was developed (see Table 21.1) to measure orientations toward hope and optimism (Ginevra, Santilli, Di Maggio, Nota, & Soresi, under review). The version for middle school students includes 19 items on a 5-point Likert scale (1 = *not strong*; 5 = *strongest*) and assesses orientation toward hope (seven items, e.g., "In the future I will be involved in very important projects"); orientation toward optimism (six items, e.g., "Even in the face of difficulties, I think I will remain an optimist"); and orientation toward pessimism (six items, e.g., "It is useless to hope in the future: I will not be able to do what I have in mind"). The confirmatory factor analysis carried out supported a second-order structure, regarding a general sense of positive orientation toward the future. Additionally, high levels of internal consistency were found (ranging from .76 to .91).

Adolescents with and Without Intellectual Disability

As young people reach adolescence, themes such as career exploration and development of a positive mindset are still relevant (Lerner et al., 2005; Lerner et al., 2009b). This period is also characterized by numerous, rapid developmental changes in identity development and by adolescents' interactions with their environments and contexts (Lerner et al., 2009a; Rutter, 2007). Because forces such as those discussed previously have dramatically changed the work market and context, resulting in more complex and frequent work-related transitions (Savickas et al., 2009), adolescents need support to become experts in "designing" a life that fits their wants, interest, and needs. These skills have become critical to enable youth to anticipate and deal with transitions and to develop resources to manage frequent career and life transitions (Nota,

Table 21.1 *Visions about the future* questionnaire for preadolescents (Ginevra et al., under review)

Visions about future
Instructions
Listed below there is a set of statements which refer to things you could think or do. Please, read them one at a time and while choosing an answer remember that
1 stands for "it describes me **not at all**"
2 stands for "it describes me **a little**"
3 stands for "it describes me **fairly well**"
4 stands for "it describes me **well**"
5 stands for "it describes me **very well**"
.
1. I think I am an optimist
2. I experience many moments of happiness
3. Usually, I am full of enthusiasm and optimism
4. Certainly, I will experience more positive things than negative ones
5. I consider myself as a person who thinks positively
6. I will not realize what I really care about
7. Even in the face of difficulties, I think I will remain an optimist
8. I feel that I will get by quite well
9. I know eventually I will get what I desire
10. In the future, I will do what I am not able to do today
11. Certainly in the future, I will be able to realize something interesting for me
12. In the future, I will work with persons who will estimate me so much
13. In the future, I will settle for what I will be able to do
14. I will hardly find a job really suitable for me
15. I will have little hopes in the future
16. In the future, I will be involved in very important projects
17. In the future, I will stop dreaming and hoping
18. It is useless to hope in the future: I will not be able to do what I have in mind
19. I know I will fulfill my desires one day

Ginevra, Santilli, & Soresi, 2014; Savickas et al., 2009). These include issues pertaining to adaptability, career and life preparedness, and courage.

Adaptability

Adaptability is a psychosocial construct grouping individuals' resources relevant to interacting with and adjust to contexts, situations, dilemmas, and opportunities. Career adaptability refers to the skills and attitudes that people need to use to adapt to unexpected circumstances related to the changing work market and job conditions (Savickas & Porfeli, 2012). Career adaptability is critical to actively constructing one's career life, coping with situations experienced in changing work environments (Karaevli & Hall, 2006; Savickas, 2013). The four resources that lead to career adaptability include: (1) concern for the future, meaning the ability to connect past with present and to be positively projected toward future; (2) control, referring to the tendency to consider the future at least in part manageable and to keep people involved in the task; (3) curiosity, or the predisposition to explore the environment and to acquire information about oneself and the outside world; and (4) self-confidence, the belief in own ability to handle challenges, obstacles, and barriers that may be encountered in pursuing life and work goals (Savickas, 2011).

The propensity to look to the future, recognizing one's right to make decisions autonomously, to explore vocational opportunities and build up a sense of efficacy in coping with the challenges contributes to the development of adaptability during adolescence (Hartung, et al., 2008). In examining career adaptability predictors and adaptability effects on the development of a sense of power and life satisfaction, Hirschi (2009) found goal directedness, capability beliefs, and social context were predictors of career adaptability. Moreover, higher levels of career adaptability predicted a sense of growing power and life satisfaction experienced by adolescents. Additionally, Hirschi (2010) observed that the degree of adaptability explained realism and stability of career aspirations.

Career adaptability is also strongly positively correlated with vocational identity, in-depth career exploration, and identification with career commitments in adolescents (Porfeli & Savickas, 2012) as well as with motivation in educational environments (Pouyaud, Vignoli, Dosnon, & Lallemand, 2012). Adolescents with higher career adaptability have more sense of personal control and consequently may be able to more easily navigate the world of work proactively (Duffy, 2010). A study conducted by Soresi, Nota and Ferrari (2012) underlined the relevance of career adaptability in adolescent development, showing that higher levels of adaptability are associated with lower perceived internal and external career barriers, a broader range of career interests, and with a higher quality of life. Additionally, adolescents with higher career adaptability were more career directed, more projected toward the future, and more competent as with regard to their future career intentions and in transforming their intentions into goal-oriented behaviors. More recently, Wilkins, Santilli, Nota, Tracey, and Soresi (2014) in a sample of 242 Italian high school students found that both hope and optimism significantly predicted career adaptability components and that curiosity and confidence mediated the relationship between hope and students' subcomponents of satisfaction.

Although, as discussed, numerous studies have shown the relevance of career adaptability resources for adolescent development, studies involving adolescents with intellectual and developmental disabilities are rare. A study involving 120 adults with intellectual disability who had worked in competitive job settings for at least six months (Santilli, Nota, Ginevra, & Soresi, 2014) showed that career adaptability indirectly, through agency and pathway components of hope, predicted life satisfaction, thus supporting the idea that the same dimensions are at work in people with intellectual disability and that career adaptability may facilitate positive life and career design.

Indirect evidence for the role that confidence may play has been provided by Holwerda, Brouwer, de Boer, Groothoff, and van der Klink (2015), who conducted a qualitative study involving 341 people with intellectual and developmental disabilities, aged 17–20 years. With a one self-constructed question (with response options *yes, completely/yes, partly/no)*, these authors analyzed expectations for future work of young people with intellectual or developmental disabilities, and the extent to which these expectations predicted work outcomes. Confidence in being actively involved in work strongly influenced future employment outcomes for these young people. The study provides further support to the relevance of addressing adaptability resources in research involving adolescents with intellectual and developmental disabilities.

Career and Life Preparedness

Requests and challenges posed by the context are often unexpected and unpredictable. As such, career and life preparedness skills become important. Preparedness can be defined as being prepared to respond to situations characterized by uncertain outcomes; being prepared to identify barriers and to capture opportunities (Sweeny, Carroll, & Sheppard, 2006), and to be able to develop plans and goals and evaluate opportunities and competencies needed to reach these goals (Salmela-Aro, Mutanen, & Vuori, 2012).

According to Lent (2013), preparedness includes the ability to manage environmental barriers and supports, together with the ability to recall personal experiences and attitudes, all in order to face transitions and challenges. Career preparedness can be viewed as vigilance to threats and opportunities in work life and involves the resources and skills to respond to such threats and opportunities. Earlier intervention studies have shown that preparedness for work-life transitions can be enhanced through group interventions that apply social modeling and active learning techniques (Vuori, Price, Mutanen, & Malmberg-Heinonen, 2005). Detailed studies on preparedness in adolescents and, more specifically, in adolescents with disabilities have yet to be conducted.

Sgaramella, Di Maggio, Bellotto, and Castellani (2014) conducted a pilot study examining these issues with university students, who completed questionnaires dealing with attitudes toward the future and their resources to deal with threats and challenges, including a questionnaire dealing with preparedness. Results highlighted that preparedness to deal with barriers, vigilance, and exploration was the strength for young people with disabilities, when compared to a group of peers without disability. Additionally, hope was associated with a set of skills relevant for preparedness, such as the ability to do not let themselves be caught off guard; to anticipate both barriers to future goals and search for supports to persist even in front of difficulties; the propensity to change and flexibility by showing interest in new activities, and investment in education.

Courage

A resource which can foster the ability to positively face continuous challenges to well-being and full inclusion is courage. A recent special issue of the *Journal of Positive Psychology* examined various emerging theories of courage (Rate, Clarke, Lindsay, & Sternberg, 2007). Using multiple methodologies and measurement approaches, authors identified some common components in definitions of courage found in the literature: intentionality, fear, risk, and nobility of purpose.

Studies in career counseling and vocational guidance have shown an association between courage and the propensity to persevere, be open minded, be resilient, and have a future orientation (Hannah, Sweeney, & Lester, 2007; Pury, Kowalski, & Spearman, 2007; Rachman, 2004). Courageous individuals are more confident in their personal ability to manage complex and unexpected situations, and in dealing with barriers (Amundson, Borgen, Iaquinta, Butterfield, & Koert, 2010). A recent study conducted in the Larios Laboratory involved 70 adolescents, aged 15–17 years, who answered several questionnaires dealing with attitudes toward the future and resources to address that future (hope, optimism, resilience, future time perspective, and adaptability) and five questions dealing with the courage they recognized in themselves. A regression analysis showed the predictive role of courage that adolescents recognized in themselves on both attitudes toward the future and the level of adaptability they recognize in themselves (Sgaramella, 2015).

Indirect evidence about courage in people with intellectual and developmental disabilities can be found in studies involving parents or caregivers of people with intellectual disability. Carter et al. (2015) analyzed answers provided by 427 parents or caregivers of youth with intellectual disability or autism between 13 and 21 years old, to two items dealing with courage in the *Assessment Scale for Positive Character Traits–Developmental Disabilities* (ASPeCT-DD; Woodard, 2009). The study showed that about 70% of these young people were considered to be somewhat to extremely courageous, as rated by parents or caregivers. Using the same two items, Toigo (2014) found that in a group of 27 young adults with Down syndrome, young adults who were perceived as more courageous by their teachers were also characterized by higher hope and higher levels of future-oriented thinking.

Instruments Addressing Life Design Dimensions in Adolescents

Life Design strengths in adolescents can be assessed by both formal and informal processes (Erickson, Clark, & Patton, 2013). Such determinations are best conducted in the context of person-centered planning processes (Carter, Boehm, Biggs, Annandale, et al., 2015; Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2010).

With regard to assessment instruments, the *Career Adapt-Abilities Scale* is widely used and is composed of 24 items that assess the core dimensions of adaptability: concern, control, curiosity, and confidence (CAAS; Savickas & Porfeli, 2012). The reliability of the CAAS subscales and the combined adaptability scale ranges from acceptable to excellent, depending upon the language.

Another comprehensive instrument analyzing career adaptability, the *Career and Work Adaptability* questionnaire, was designed to assess adolescents' career adaptability. Nota, Ginevra, and Soresi (2012) developed this 31-item self-report measure, which collects information on dimensions of career and work adaptability: concern, curiosity, control, confidence, and cooperation. These dimensions reflect the ability to cooperate with others, to establish positive interactions useful to facilitate reflections about the future, and to create supportive social networks (Nota & Soresi, 2003). The measure also highlights the importance of relationships developed in different life areas, for both professional and personal reasons.

From a qualitative perspective, the *Career Style Interview* (Savickas, 2005) is a useful means to identify life themes, gathering information in the form of stories narrated by clients, among others, about adaptability strategies, motivations, and personality style. Questions such as "How can I be useful to you in constructing your career?" are used to elicit clients' goals for counseling, while seven core questions are used to elicit narratives from clients for understanding and constructing their life and career stories.

The *Career Preparedness Questionnaire* was developed by Soresi, Nota, Ferrari, and Sgaramella (2014). The dimensions covered include accepting responsibility to reach personal and career goals (four items; alpha .79); anticipating barriers and difficulties and identifying alternative solutions to reach personal goals (seven items; alpha .81); propensity to change and show flexibility with regard to interests in new activities and changes in the work context (five item; alpha .78); capacity to take advantage of opportunities in the work context (six items; alpha .79); persevering when facing difficulties and unpredictable events (six items; alpha .82); exploring the environment and collecting information on the world of work (four items; alpha .77); finding supports and resources to be ready when facing difficulties (four items; alpha .72); and investing in education (five items; alpha .78).

The most widely used measure of courage is the Norton and Weiss (2009) self-perceived courageousness measure, based upon an operational definition of courage as persistence or perseverance despite having fear. Items are rated by a 7-point Likert-type scale, from 1 (Never) to 7 (Always). Example items include "I tend to face my fear"; "If the thought of something makes me anxious, I usually will avoid it"; "Even if I feel terrified, I will stay in that situation until I have done what I need to do."

Two research centers in Italy [Larios Laboratory of the Centro di Ateneo Disabilità, Trattamento e Integrazione (University Centre for Disability, Treatment and Inclusion) at the University of Padova] have developed a qualitative process to examine career and vocational elements, including courage. Examples of questions from this qualitative procedure are reported in Table 21.2.

Table 21.2 Example of questions on courage

1. *In the past, in your life did it happen to you to be courageous* yes☐ no ☐
If yes, try to describe a situation in which according to your opinion you showed courage
2. *Recently, did you have the opportunity to be courageous* yes☐ no ☐
If yes, try to describe a situation in which according to your opinion you showed courage
3. *Do you believe that future will require you to be courageous* yes ☐ no ☐
If yes, try to describe a situation in which according to your opinion you will be asked to be courageous
4. *Try to tell a story someone in your family or a person close to you has told or still tells you which in your opinion represents a particularly courageous experience*

In questions 1, 2, and 3 (see Table 21.2), respondents are asked to reflect on and then rate (from least amount of courage to a great deal of courage, as determined by a 5-point Likert-type scale) a situation that required courage, *when* the situation occurred, *where* it happened, and *who* was there. Further, respondents relate *what* they did and how they felt*; what* they achieved and *how*, and eventually *how* people near him/her behaved.

The instruments described in this and in the previous section can be used in school contexts to give attention to occupational knowledge, positive mindset, career adaptability, career preparedness, and courage and start to plan and implement preventive actions. In this chapter, we focus on career education programs for primary school children.

Career Education Programs for Children with and Without Disability

According to a Life Design approach, people interested in career development and the life satisfaction of young people should act and intervene in ways that equip these young people to interact with their environments and develop the skills that enable them to create or design their own career (Savickas et al., 2009). Researchers have the responsibility to develop and test specific intervention efforts that could be easily learned and implemented by teachers and parents and to facilitate school-family collaborations to increase the young person's opportunities to participate in daily and community life. With regard to children with disabilities, supporting and intervening in integrated, real work contexts is critical (Shogren, Luckasson, & Schalock, 2014; Wehmeyer, 2015). Such efforts should, for example, stimulate critical thinking and creativity; promote self-determination, social justice, and solidarity; reduce contextual and social barriers to these dimensions; and support children to develop their resilience in the face of occupational adversities (Nota, Ferrari, & Sgaramella, & Soresi, in press; Soresi et al., 2012; Wehmeyer, 2013). As Hartung (2015) suggested, it is necessary to consider children within career and Life Design research and invest in career education training program to promote the early development of career adaptability's prerequisites with young children.

Given this need to carry out early career education programs, over the past two years, we have devoted our efforts to develop career education programs from childhood to adolescence, aimed at stimulating critical thinking and creativity; promoting equal relations with others; emphasizing social justice and solidarity; developing self-determination, hope, and optimism toward the future; and fostering skills to manage their careers and lives (Nota, Ferrari, Sgaramella, & Soresi, in press; Soresi et al., 2012). Two of these interventions, one on occupational knowledge and one on hope and optimism, are described in the sections that follow.

A career education program titled "*They are Working. What are they Doing? First Steps Toward Knowledge of the World of Work*" was carried out with the aim of promoting occupational knowledge in children ages 3–5 years. This career education program consists of 10 steps: the first eight intend to illustrate 16 professions (two for each step), the ninth focuses on the kindergarten teacher and children's parents' jobs, and the last considers jobs familiar in the children's daily life. Each step lasts about 45 min and involves a small group of about five children. In the first eight steps, actions, tools, workplace information, and the skills and knowledge required for undertaking 16 professions are presented. In addition, so as to prevent and reduce the formation of stereotypical ideas about the world of work, male and female workers are presented for each profession. The professions, related to the six professional fields of Holland, are listed in Table 21.3 together with the 10 steps.

A manual for the facilitator was created. For each step, the manual includes a description of the goal in terms of skills that should be encouraged, the prerequisites that should be checked at the beginning of each step, and how to present the goal in the step to the children.

Table 21.3 Steps of the early career education program '*They are working. What are they doing*? First step toward the knowledge of the world of work'

First step: "They are working. What are they doing? Knowing the job of nurse and salesman and saleswoman"
Second step: "They are working. What are they doing? Knowing the job of the fireman and firewoman and of the musician"
Third step: "They are working. What are they doing? Knowing the job of veterinary and the waiter and waitress"
Fourth step: "They are working. What are they doing? Knowing the job of the gardener and the pharmacist"
Fifth step: "They are working. What are they doing? Knowing the job of the policeman and policewoman and the painter"
Sixth step: "They are working. What are they doing? Knowing the job of the accountant and the computer technician"
Seventh step: "They are working. What are they doing? Knowing the job of the builder and the photographer"
Eighth step: "They are working. What are they doing? Knowing the job of the postman and the hairdresser"
Ninth step: "They are working. What are they doing? Knowing the job of the kindergarten teacher and that of father and mother"
Tenth step: "They are working. What are they doing? Knowing where people work in my neighborhood"

Moreover, the manual includes a description of verbal and nonverbal behavior the facilitator should use, as well as teaching techniques and materials for goal pursuit and attainment. To engage children and facilitate learning for each step, video, photographic, and graphic materials are provided, as are recommendations for other multimedia sources from the Internet.

Forty-eight kindergarten children were involved in a pilot study of the process. Among the 25 children in the experimental group, one had intellectual disability. To verify the efficacy of the intervention, a modification of the *Occupational Knowledge Interview* (Ferrari et al., 2015), described previously, was developed. Results showed that children, included the child with intellectual disability, increased their knowledge about various professions, including those of their parents (Ferrari & Nota, in press).

Another component of our efforts to begin career development with younger children focuses on hope and optimism. *Nuggets of Optimism and Hope to School* (Ginevra et al., 2014) is a 3-h workshop for elementary school children developed to get them to begin to reflect on the meanings of optimism and hope, to identify similarities and differences between the two, and to identify the main characteristics of an optimistic and hopeful child. By using examples from school and extracurricular settings, the children with and without disabilities are trained to recognize optimistic thoughts and distinguish them from negative ones, highlighting the importance of optimistic ways of thinking and behaving for growth and future development. With regard to the development of hope, exercises to facilitate goal setting and the production of hopeful and optimistic ideas to pursue their goals are presented. The workshop ends with a vignette (*Valeria's Story*), and children are guided to identify her optimistic thoughts and the strategies she used to achieve her goals. To verify the efficacy of this workshop, 71 elementary and middle school students were asked to complete a pre- and posttest of the following sentences: "The optimistic person is…", and "The hopeful person is…". At the end of the workshop, participants expressed a clear understanding of the discussed topics and described with more detail the characteristics of an optimistic and hopeful person, significantly improved over the pretest.

Conclusion

This work has offered us the opportunity to delve into issues pertaining to career development and Life Design of children with and without intellectual disability from infancy to adolescence from a positive and strength-based perspective. This chapter underlines the limited number of studies available in the literature in the field of career and Life Design involving children and adolescents with intellectual and developmental disabilities. Results from studies involving children and adolescents without disability clearly suggest the relevance of devoting more efforts to depicting a positive mindset could have on career and life outcomes as well as the relevance of dimensions stressed by the Life Design approach, such as career adaptability, preparedness, and courage.

Additionally, the emphasis on preventive actions aimed at stimulating better knowledge of the world of work and introducing information about prerequisites of career resources appear promising both for children with disability and their peers without disability. In a changing labor market exemplified by decreased employment opportunities, diminished job security, anticipated and unanticipated transitions, fast-changing technology, and an increase in personal responsibility for keeping up with an evolving body of knowledge in one's field of specialization, these approaches and an early start become critically important.

Finally, increasing the awareness of contextual supports, such as teachers and family members, as well as services providers and employers, about these issues and investing resources to adequately prepare them to build a culture of work inclusion in their normal contexts of life is critical to career development. Also, career counselors should be trained to adequately work on career and life development issues in an inclusive perspective, focusing on young people with and without disabilities as capable of performing meaningful work. More attention must be paid to increasing knowledge and skills about disability to contribute to a culture of inclusion (Soresi, Nota, Ferrari, & Sgaramella, 2013).

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Supported and Customized Employment

22

Wendy Parent-Johnson and Laura Owens

Introduction

As a practitioner, you may ask "What can I do to contribute to a person's happiness and well-being?" After all, your role may be very prescribed, as in diagnosing or providing treatment; it may be brief, as dictated by insurance and other parameters; or it may be specific, as a therapist or subspecialty provider. Or, while you may be an essential member of the support team, you may not be the person who has responsibility for leading and coordinating the many people providing supports. For people with intellectual and development disabilities whom you support, this question may seem even more complicated. So, how can you make a difference?

It is important to consider every interaction you have as an opportunity to enhance and contribute to the factors that promote personal growth, life satisfaction, and happiness. Remember, you may be the one person who plants the seed and changes the trajectory for that person's life. Start by having high expectations for all people, regardless of disability label. Recognize the whole person beyond the diagnosis. Focus on identifying each person's strengths, introducing the concept of supports and encourage active involvement of the person with a disability in their supports planning. The recommendations you make can impact the career and life goals guiding other team members and service delivery areas.

Research has shown that happiness influences health, which in turn influences school, work, and quality of life (e.g., Graham, 2008; Veenhoven, 2008; Diener & Chan, 2011). Work is a major contributor to the overall happiness of all people, including those with intellectual and developmental disabilities. It is what we do every day. People work for many reasons: to contribute to society, meet new people and grow as a person, be a social player, and make money. The contribution of all people is needed for our communities to thrive, and integration and work are a normative part of everyone's life. Work gives us meaning, status, purchasing power, connections, and engagement in our communities. Further, work is a means for gaining status, building self-determination, and achieving personal goals and is connected to obtaining possessions, prestige, power, and influence. All of these reasons for work are tied to positive psychology, in particular, happiness, well-being, social capital, and resiliency. In effect, positive psychology impacts everything we do, particularly work.

Unfortunately, people with intellectual and developmental disabilities may never experience the positive benefits that work has to offer. High unemployment rates for this population contribute to lives frequently characterized by

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increased poverty (Institute on Disability, 2014), poorer health (Yee, 2011), greater health disparities (Office of Disease Prevention and Health Promotion, n.d.), social isolation (Disabled World, 2011), lack of friends and loneliness (Gilmore & Cuskelly, 2014; Tracey, 2015), and reduced social capital (Mithen, Aitken, Ziersch, & Kavanagh, 2015). This chapter will describe how you can be a catalyst for changing to promote integrated employment and enhance the quality of life outcomes associated with positive psychology for people with disabilities.

Work and Positive Psychology

Whether we like it or not, facing obstacles is part of life; challenges help us to grow, change, and adapt to the world around us. Every challenge and every difficulty we successfully confront in life serve to strengthen our will, confidence, and ability to overcome future obstacles. Herodotus, the Greek philosopher, said, "Adversity has the effect of drawing out strength and qualities of a man that would have lain dormant in its absence." Historically, services and supports for people with intellectual and developmental disabilities have been guided by a "fix the person" model that emphasizes the disability and not the many abilities that characterize each person. This medical or system approach often imposes criteria that people must meet before they are considered ready and able to pursue certain life events, such as employment, often limiting the options available to them. Over the years, psychology, embedded in this medical model, has typically focused on the negative aspects of disability.

Similarly, in the fields of special education and rehabilitation, systems have also been established that emphasize disability and focus on deficits as opposed to assets or strengths. However, recently, a shift has occurred in the way we think about life and work for people with intellectual and developmental disabilities. Positive psychology emphasizes traits such as well-being, optimism and perseverance, satisfaction and interpersonal skills, and happiness (Seligman & Csikszentmihalyi, 2000). Simply stated, positive psychology focuses on what makes life most worth living. Positive psychology is grounded in the belief that people want to lead meaningful and fulfilling lives, to cultivate what is best within them, and to enhance their experiences in love, work, and play (Positive Psychology Center, 2016). People with disabilities also need to have meaning in their lives, and work offers that to them. Finding meaning and purpose in life is something we all strive for and is the desired outcome of positive psychology. Positive psychology, as it relates to work, focuses on four indicators: happiness, well-being, social capital, and resiliency. All four of these indicators build human capability and quality of life.

Happiness

Positive psychology is the study of three characteristics of what makes life worth living: (1) positive emotions; (2) positive traits such as strengths and talents; and (3) positive institutions such as democracy, strong families, and free inquiry (Seligman, 2002, 2004). People with disabilities want the same things as the rest of us—a meaningful life. They want to contribute to their communities, have friends, use their skills and abilities, and have interesting things to do.

Positive thinking and happiness have the ability to create positive change in the work lives of everyone. According to research, happy people: are more productive at work, are more creative; make more money, have better jobs; are better leaders and negotiators; have more friends and social support; are physically healthier (and even live longer); are more helpful; and cope better with stress and trauma (Lyubomirsky, King, & Diener, 2005). Research also shows that happy people nurture and enjoy their social relationships, are comfortable in expressing gratitude, are often the first to help others, are optimistic about the future, live in the present moment, and are committed to meaningful goals (Lyubomirsky, 2001; Diener, Suh, Lucas, & Smith, 1999; Diener & Lucas, 1999). These findings are important for employers because businesses with employees who have high levels of employee happiness tend to report greater customer satisfaction and loyalty to the business, higher levels of productivity, and lower turnover rates (Keyes & Magyar-Moe, 2003). As Confucius stated, “Choose a job you love, and you will never have to work a day in your life.”

Well-Being

Well-being is often used interchangeably with happiness. According to Linley and Joseph (2004), well-being differs from happiness and can be understood as “the sum of life satisfaction plus positive affect minus negative affect” (p. 5). Sheldon and Lyubomirsky (2004) suggest that happiness and well-being both are influenced by three elements: (1) pleasure (or positive emotion); (2) engagement; and (3) meaning. Each of these elements can be enhanced, ultimately improving happiness and well-being. According to Sheldon and Lyubomirsky (2004), we can increase our positive emotion about the past by fostering gratitude and forgiveness; the present, by valuing and practicing mindfulness; and the future, by building hope and optimism. In addition to cultivating positive emotions, such as happiness, well-being also involves engagement or participating in activities that are interesting, also known as a state of “flow” (Csikszentmihalyi, 1990). Flow transforms important tasks into interesting activities which may lead to long-term well-being. Flow does this by promoting the use of positive resources such as building on talents, developing interests, and improving skills. Other benefits of flow include building psychological capital, experiencing positive emotions (Peterson, 2006), and cultivating persistence (Nakamura & Csikszentmihalyi, 2002). The final component to happiness and well-being is meaning. Researchers have suggested that finding meaning in life is important to the well-being of a person (e.g., Frankl, 1992; Steger, Kashdan, Sullivan, & Lorentz, 2008). Meaning allows people to develop positive social relationships and connect to a purpose in their lives (Seligman, 2002). This sense of purpose ultimately provides people with goals that guide action and promote well-being (Baumeister & Vohs, 2002).

Pleasure, engagement, and meaning can also be used to enhance happiness and well-being relative to work activities and outcomes. Work has the potential to enable people to engage in meaningful activities that build on their talents and strengths, focus on interests and improve and develop new skills. The Gallup Organization has found that using your strengths leads to improved health and wellness outcomes (Sorenson, 2014). The more hours each day that we can use our strengths to do what we do and like best, the less likely we are to experience worry, stress, anger, sadness, or physical pain during the day (Sorenson, 2014). Research has shown that the way to influence happiness is to make connections with the people around you by creating new and strengthening old relationships (Ryan & Deci, 2001; Seligman, 2011) which can occur in work environments and activities. According to the research on happiness, our moods are contagious and can enhance our social relationships and promote happiness (Enticott, Johnston, Herring, Hoy, & Fitzgerald, 2008; Rizzolatti & Craighero, 2004).

Social Capital

“Fifty years of working in a medical model on personal weakness and on the damaged brain has left the mental health professions ill equipped to do effective prevention. We need massive research on human strength and virtue” (Seligman, 1998, p. 2). Social relationships are one of the strongest correlates of positive emotions, which relates directly to social capital. Many research studies have found a strong relationship between social relationships and happiness (Bradburn, 1969; Diener & Seligman, 2002; Myers, 1999). Work is tied directly to social capital—it can be where we meet our friends and significant others; where we learn to be a friend and become a friend. Social capital is tied to people getting jobs, finding others to live with, finding transportation, and being respectful, kind, and helpful. When people increase their social capital, they advance and achieve more (Condeluci, 2008).

Developing social capital allows a person to actively participate in their networks and legitimizes their access to those networks. For example, a person who is engaged in their community is connected to other people and businesses that can lead to a job contact and employment, the primary way we all enter the labor market. Similarly, once a person becomes employed, the opportunity to expand their network increases through new and additional acquaintances and relationships which in turn opens new doors. Building social capital accrues benefits that extend beyond the person to all people in the network.

The same benefits of social networks for all people are also benefits for people with intellectual and developmental disabilities. And, the positive impacts of having a person with an intellectual and developmental disability as part of one's social network benefit all members of that network. It is not uncommon for businesses that hire people with intellectual and developmental disabilities to report an overall positive influence on the workplace and the other employees such as improved morale and teamwork, and increased customer loyalty (Siperstien, Romano, Mohler, & Parker, 2006).

Resiliency

Positive psychology emphasizes the study of human strength and virtue with the goal to understand and facilitate positive developmental outcomes (Seligman & Csikszentmihalyi, 2000). A resilience framework offers a powerful tool to help people realize the goals of positive psychology under situations of adversity. Resiliency emphasizes the power of strengths when facing adversity. Resiliency has long been important to consider when supporting people with disabilities. In contrast to traditional medical models that seek to eliminate disease or pain, resilience models focus on promoting health and well-being. Research on resiliency has led to the development of interventions that emphasize attainable goals aligned with a person's competencies as opposed to an emphasis on optimal performance. Further, the importance of setting positive goals that build on strengths and talents, rather than focusing on avoiding problems and challenges, has been noted (Masten, 2011). The resiliency model moves beyond the medical model and begins to look at a person-centered approach to supports and services. The focus is on abilities and what can happen with appropriate supports rather than focusing on "fixing" the person or problem. An emphasis on resilience shifts the focus from deficit-focused orientations toward models centered on positive goals, promoting protective factors, and adaptive capacities (Masten, 2011).

Researchers have found that resilience can be learned and developed by taking care of yourself, having optimism and perspective, focusing on strengths, helping others, and building positivity (Happiness Institute, 2013). Resiliency and social capital may have positive effects on both performance and work attitudes. Using a resilience framework can be growth-oriented and informative and enable the implementation of positive psychology in practice with people with intellectual and developmental disabilities.

Work and People with Intellectual and Developmental Disabilities

Employment is a critical outcome for people with intellectual and developmental disabilities and their families. For more than two decades, one of the principal goals of disability policy in the USA has been to improve employment opportunities for young people with disabilities as they exit secondary education programs (Johnson, 2009). Supported employment is based on the principle that people with complex disabilities have the right to be employed in community businesses where they can earn comparable wages, work side-by-side with coworkers with or without disabilities, and experience all of the same benefits as other employees of the company. This idea has been referred to as

"Employment First." Supported and customized employment models assist people with complex disabilities by providing individualized supports that enable them to choose the kind of job they want and to become successful members of the workforce.

Employment First and supported and customized employment are similar concepts. The values revolve around these eight areas: (1) the presumption of employment, (2) the presumption of integrated employment—on the payroll of community-based employers, working alongside non-disabled coworkers, (3) control and power of supports—building social capital, (4) capabilities and capacities—building on strengths and turning deficits into assets, (5) commensurate wages and benefits, (6) developing and maintaining relationships, (7) participating in the community, and (8) systems or organizational change. All of these directly relate to positive psychology and how we can support people with intellectual and developmental disabilities in creating a meaningful life and career (Brooke, Inge, Armstrong, & Wehman, 1997).

Supported employment is paid employment in an integrated work setting, with ongoing supports and services. Supported employment is often used to enable people with severe disabilities to obtain competitive employment, particularly when competitive employment has not been considered a possible outcome because of the complexity of their support needs (Wehman 2012). Customized employment strategies result in individually designed services, supports, and jobs negotiated to fit the needs of a specific job seeker or employee. These strategies may include aspects of other employment approaches, such as individualized person-centered assessment, supported entrepreneurship services, microenterprises or small businesses, individualized job development, job carving, and restructuring (Riesen, Morgan, & Griffin, 2015). Supported and customized employment models are similar in that they are individualized, not group-based, and focus on personal preferences, values, and visions, not traditional vocational evaluations/ assessments. They are, however, approaches that focus on creating the supports needed for each person to obtain competitive employment. Core principles include the following: identifying business needs, identifying employment conditions benefiting the individual and employer, and engaging in job exploration to recognize the person's strengths and assets. Supported and customized employment models can be used with any person with a disability and bypass comparisons of applicants made through competitive hiring processes, and facilitate natural relationships, supports, and training.

The foundation of supported employment is on the strengths and talents of the person with an intellectual or developmental disability. It is based on the idea that there is no "job readiness" and that there is a job for everyone who wants a job. Supported employment further addresses the idea of strengths, passions and interests. The assessment or person-centered planning process identifies what makes the person happy—what is their passion in life and how do we build on that passion? Focusing on an individual's strengths and identifying ways that things that had previously been considered deficits can be reframed as assets are a critical component in supported employment.

Unfortunately, despite the evidence supporting supported and customized employment, the majority of people with intellectual and developmental disabilities are still relegated to segregated services; many people with intellectual and developmental disabilities are unemployed or underemployed. Most communities have no or very limited public transportation options, particularly in rural areas. And, without engagement in employment activities, particularly in early adulthood, social networks and capital decline, leading to social isolation. Considering strategies related to promoting happiness, well-being, social capital, and resiliency emerging from positive psychology can further enhance support and customized employment supports and enable the achievement of valued outcomes related to employment as well as positive psychology, including: (1) rising to life's challenges, making the most of setbacks and adversity, (2) engaging and relating to other people, (3) finding fulfillment in creativity and productivity, and

(4) looking beyond oneself and help others to find lasting satisfaction, and wisdom (Keyes & Haidt, 2003). Work gives people with intellectual and developmental disabilities the same opportunities as the general population to take risks, learn from experience, make choices, and influence the happiness in their lives.

As the field of positive psychology has focused more on looking at what works instead of what does not, increased attention has focused on the benefits of strengths identification and development, which directly relates to supported employment. Research has shown that the identification of strengths is connected to greater work satisfaction, engagement, and increased productivity. People grow more by focusing on strengths rather than remediating weaknesses (Niemiec, 2014). Focusing on strengths can be energizing and enhance performance. Did you ever notice yourself involved in something where you lost track of time because you were so engaged? That is an indication that you were using one or more of your strengths. Strengths that are energizing align with your values. People who use their strengths daily are six times more likely to be engaged on the job, according to research by Gallup (Sorenson, 2014), and are less likely to experience stress or anxiety. The results of this research strongly indicate that people who regularly use their strengths are more engaged and happier at work. Similar studies have found the additional benefit of lower employee turnover. Assessment or discovery strategies within supported and customized employment are designed to get to know the person and identify his/her skills, interests, preferences, and passions to facilitate employment decisions that utilize personal strengths and promote happiness at work (Brooke et al., 1997; Callahan, n.d.).

People gain more when they build on their talents, than when they make efforts to improve their areas of weakness (Happiness Institute, 2013). The best way for people to grow and develop is to identify how they most naturally think, feel, and behave—their talents—and then build on those talents to create strengths. As practitioners, it is critical to maintain optimism about the future lives of people with intellectual and developmental disabilities, to believe that people can and should work in the community and making meaningful contributions. In supported employment, this is known as a "job match" where the job seeker's abilities are matched with the needs of a business, and the individual's strengths and passions are used to build their skill on the job. In supporting employment outcomes, the role of strengths and talents and building on these strengths and talents cannot be underestimated.

Possibilities for People with Disabilities

All too often the focus when considering employment for people with intellectual and developmental disabilities have change have to has been on what a person cannot do. Statements may be made about how the person cannot communicate verbally when you ask a question. Or that they have difficulty sitting still or participating in the activities that the job currently requires. But, such a focus leads to deficit-based thinking and questions such as, How could this person ever work?, What employer would hire them?, and What recommendations can I make? However, research and best practice in positive psychology and supported and customized employment suggest the power of reframing the question to ask: What would this person like to do?, What are their passions and interests?, and What kind of support would help to make them successful? Beginning with these questions, rather than deficit-based questions, can significantly change the conversation and outcome.

Becoming familiar with what is possible can be an eye-opening experience for professionals who provide change provides to provides support change supports to supports people with intellectual and developmental disabilities. A critical part of the job development process for all members of the support team can be learning where other people with intellectual and developmental disabilities work and how they became successfully employed. Meeting with the local vocational rehabilitation office, community support provider organization, and supported employment providers can provide information about resources and supports that are available. Often, arrangements can be made to visit a job site and observe firsthand the contributions of workers with disabilities. Other resources that can be of assistance include school personnel (e.g., teacher, transition coordinator), case managers, benefits planners, independent living organizations, assistive technology specialists, and self-advocacy groups (e.g., People First, Self-Advocates Becoming Empowered). Boxes 1, 2, and 3 provide illustrations of how building on strengths and using supported and customized employment strategies can lead to enhanced employment outcomes.

Box 1. Justin's Employment Experiences

Justin is a young man with cerebral palsy who uses an electric wheelchair. He gets his message across, but his verbal language can be difficult to understand for some. During his last year of high school, he had a person-centered planning transition meeting. At that meeting, Justin invited his family (mother, father, brothers, and sisters), his teacher, and a friend. It was clear that Justin was interested in sports—he was wearing a Milwaukee Bucks shirt for the meeting and on the tray of his wheelchair, were decals and information about all the Wisconsin sports teams. Justin ran the meeting with the support of a facilitator. Justin's strengths, interests, challenges, and support needs were discussed, and an action plan was developed for employment. This led to the use of customized employment strategies to create a position for Justin to work as the "human Zamboni" at Marquette University. After conducting an informational interview with the Student Recreation Center, a position was developed based on the needs of Marquette and the skills of Justin, using an adapted mop attached to his wheelchair. He cleans all five basketball courts during peak times. He also collects stranded basketballs and other miscellaneous tasks.

Box 2. William's Employment Experiences

William is a young man with Asperger's syndrome. His support team conducted a positive personal profile and identified many of his interests, in particular, his enjoyment of history. William enjoyed talking about the various wars and loved the uniforms and hats from various wars. He worked with his employment consultant to conduct an informational interview at a local military surplus store. The manager was so intrigued with William's knowledge about history (which was his passion too) that he agreed to a work experience. After the work experience, William was hired to stock and assist customers.

Box 3. Megan's Employment Experiences

Megan is a young woman with an intellectual disability. She is bright and pleasant, and when asked what her career goals were she stated, "I want to make Abby-cakes!" She loved baking and thought that someday she could run her own business making fancy cupcakes. She obtained a work experience at a "gourmet" restaurant/bakery—washing the dishes. But her career was only beginning. Megan washed the dishes and just before the work experience ended, the bakery got a big cupcake contract with a local grocery chain. There was a sudden need to begin packaging large amounts of the product on a weekly basis. Megan was hired to package in addition to the dishes and did it well. These days, she is just one of the crew, no job coach, and has started to deliver meals to the customers at the tables.

Regardless of your role, you can play an integral part in influencing employment outcomes for individuals with intellectual and developmental disabilities. Several strategies have proven to be helpful in those efforts. First, get to know the person as a person and explore his or her and the family's dream. The supports you provide and the recommendations you make are helpful when congruent with and supportive of these long-term goals. Second, promote skills and experiences important for employment and a quality life engaged in one's community. During your time together, provide opportunities to practice skills, such as answering questions and making decisions, and suggest other situations and environments where similar learning experiences can occur. Third, identify the supports that the person uses in everyday life and encourage their involvement during the appointment or services that you provide. Similarly, consider the use of supports to enhance an individual's active participation and offer ideas to insure they are aware of additional options that might be available. Often, participation is determined by a person's ability to complete the task independently overlooking the important point of focusing on the outcome and the realization that we all rely on supports within our own lives. Fourth, prepare concise person-centered summaries that highlight these positive aspects of the person in addition to the technical information you are providing. Other members of the team can benefit from the introduction you provide describing who this person is, what their strengths and passions are, the skills they exhibited during their time with you, the types of supports that facilitated their participation, and your recommendations for achieving their employment and life goals. Finally, learn about best practices and the outcomes that can be achieved and the state, national, and local resources that are available. This information can be invaluable to inform your own decision making as well as provide useful resources to share with all members of the team.

Conclusion

Integrated employment is a critical and valued outcome for people with intellectual and developmental disabilities that can lead to enhanced happiness, well-being, social capital, and resiliency, all key constructs in the field of positive psychology. Having a purpose in life, which a career can contribute to, enables all people, including people with intellectual and developmental disabilities, to feel they are part of something meaningful which enhances happiness and well-being. Through employment, meaningful relationships can be achieved, and as experiences are shared, social capital can be built which can contribute to future outcomes. Employment can also contribute to enhanced ability to navigate challenges that emerge and perceptions of control over one's future path, enhancing resiliency. Overall, employment both contributes to positive psychological outcomes and is enhanced by greater happiness, well-being, social capital, and resiliency. Promoting supported and customized employment for people with intellectual and developmental disabilities by integrating best practices related to employment supports and positive psychological interventions is a natural fit that can lead to enhanced outcomes in multiple domains.

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23

Retirement

Roger J. Stancliffe, Michelle Brotherton, Kate O'Loughlin and Nathan Wilson

Introduction

There is a growing trend in research in the field of intellectual disability that is compatible with positive psychology and self-determination; that is, a focus on 'the *strengths* and *capabilities* of the person *in the context* of typical environments with a priority on natural supports' (Shogren, Wehmeyer, Pressgrove, & Lopez, 2006, p. 338). In examining retirement research in this chapter, we note that the limited available research on people with intellectual and developmental disabilities suggests a lack of self-determination regarding retirement decisions and a reliance on segregated environments in retirement, especially for workers in sheltered employment. However, later in this chapter, in the section on research to practice, we also present examples of retirement interventions that have many of the characteristics referred to by Shogren et al. (2006).

Following the Introduction, this chapter deals with three main areas of content: (a) mainstream retirement research, (b) retirement research with people with intellectual disability, and (c) research to practice. The chapter's authors are all from Australia and this reality is reflected in the content by a notable focus on Australian research and practice. No doubt this emphasis is a result of our familiarity with this work, but it is also due to relatively little attention being given to retirement of people with intellectual disability by researchers in other countries.

We are aware that many readers may not be familiar with Australian policies and practices regarding disability employment services, the disability support pension, retirement savings and the like, so we will provide brief details about these issues where needed. It is important to understand these contextual factors because they could influence the timing and manner of retirement, as well as post-retirement adjustment. Different contextual factors in other countries may affect retirement in different ways. For example, per-person government funding for sheltered employment in Australia currently requires employees with disability to work a minimum of eight hours per week. So long as that minimum is met the employment provider is eligible for the *full* amount of government funding through the Employment Assistance Fee (Australian Government, Department of Social Services, 2015). Most workers in sheltered employment work far more than eight hours per

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week. This funding arrangement means that sheltered employment providers experience no reduction in government funding if an employee cuts down their weekly work hours from, say, 24 to 16 h as the person begins to develop a retirement lifestyle and gradually transitions to retirement. Therefore, the employer is usually willing to accommodate reductions in weekly work hours to enable partial retirement. Indeed, this was the experience in the *Transition to Retirement* project described in the Research to Practice section of this chapter. Employers in other countries where government funding for sheltered employment is proportional to hours worked may be more reluctant to approve such arrangements, so a *gradual* transition to retirement may be more difficult to achieve.

What Is Retirement?

In this chapter, we interpret retirement to mean withdrawal from paid work. As opposed to unemployment (seeking work but temporarily not being in paid employment), retirement is usually permanent. Retirement does not preclude unpaid 'work' such as volunteering (Fesko, Hall, Quinlan, & Jockell, 2012). Regrettably, many people with intellectual disability have never had the opportunity to do paid work. People who have never worked for pay cannot retire under this definition, so their situation falls outside this chapter's scope. We will include all forms of paid work by people with intellectual disability – both mainstream and sheltered employment.

Why is retirement important? Throughout the twentieth century, life expectancy in western countries has increased steadily. Today, in the USA, UK, and Australia, average life expectancy ranges from the high 70s to mid-80s (World Health Organization, 2016). In these countries, the notional 'retirement age' is around the mid-60s (i.e., age when retirement savings and/or government benefits typically become available), but the actual average retirement age of the general population in Australia, for example, is actually in the 50s (Australian Bureau of Statistics, 2013). Therefore, most people can expect to spend decades in retirement, so this phase of life provides sustained opportunities for personal growth, positive relationships and enjoying a good life. Likewise, people with intellectual disability are living longer and many also face an extended retirement phase of their life (Bittles et al., 2002; Patja, Iivanainen, Vesala, Osanen, & Ruoppila 2000).

Demographic factors also make retirement a key issue for people with intellectual and developmental disabilities and the services that support them. For example, the 20,000 Australians with disability working in sheltered employment are an aging workforce (McDermott, Edwards, Abelló, & Katz, 2009; Wilson, Stancliffe, Bigby, Balandin, & Craig, 2010) with large and increasing numbers approaching or reaching retirement age. Given that around 75% of this workforce has intellectual disability (McDermott et al., 2009) this reality has major implications for the intellectual disability service system, which will need to respond on a much larger scale and with greater flexibility around both living and working arrangements, as well as with support for participation in retirement. The effect of these demographic factors is magnified by the lack of retirement planning, services, and policy, and results in ad hoc responses for individuals confronted with imminent retirement (McDermott et al., 2009; Wilson et al., 2010).

Finally, older adults with intellectual disability themselves state that they want to continue to participate in their community and be active and productive in older age (Buys et al., 2008). Older people with intellectual disability deserve to experience active aging like the rest of the community (Wilson et al., 2010). In recognition of these and other issues, retirement is one focus of key national research agendas. For example, a focus on retirement was one of four USA national goals for research, practice, and policy identified recently in relation to aging (Hahn, Fox, & Janicki, 2015). Before examining what is known about retirement by people with intellectual disability, we will briefly look at mainstream retirement research and issues to provide a context for understanding retirement by people with intellectual disability.

Retirement Among People in the General Community: Key Issues and Findings

The concept of retirement is historically associated with the industrial revolution and the changes that occurred in work and employment patterns at that time. However, it has taken on a new meaning in the context of population aging and increased life expectancy, particularly around planning for and transitioning to retirement, as well as the adjustment to, and experiences in retirement for the post WWII baby boom cohorts now reaching mid to later life.

Retirement is a key milestone in the lives of people as they leave behind the social and economic structure of working life (Kim & Moen, 2002). When people leave paid work they forego a regular income and move away from the social networks built up in the workplace. They also leave behind the routine of the working day and the sense of identity and status associated with being an employee (van Solinge & Henken, 2008).

Retirement age. The notion of an official retirement age in most developed countries is associated with the age at which one can access a retirement or age pension; traditionally it has been between 60 and 65 years. However, this age varies across countries depending on the type of social welfare and retirement income system in place. Data for OECD countries show that the average retirement age in 2012 was 64.2 years for men and 63.1 years for women (OECD, 2013); however, the data also show that in 22 OECD countries the actual exit age was lower than the official retirement age. In Australia, for example, retirement from the mainstream labor force for people 45 years and over averaged 53.8 years in 2012–2013 (men 58.5 years, women 50.0 years) (Australian Bureau of Statistics, 2013).

Voluntary and involuntary retirement. Although countries may have a retirement age linked to their pension system, the decision to remain in or leave paid work may be influenced by factors including social and financial circumstances, poor health or injury, discrimination, and caregiving responsibilities. These are often referred to as 'push' and 'pull' factors (De Preter, Van Looy & Mortelmans, 2013; Ebbinghaus, 2006) associated with decision-making around retirement and whether it is planned for, voluntary and a gradual process, or unplanned and involuntary. The pull factors denote more positive factors shaping the decision to retire (e.g., financial security, increased family and leisure time) and convey a sense of personal choice and control over the transition period. In contrast, the push factors are often associated with an early or abrupt exit from paid work and shaped by more negative aspects, such as chronic health conditions or workplace experiences (e.g., discrimination, redundancy). Therefore, it is important to note that not everyone can choose the timing of their retirement and that there are variations in the degree of choice and control based on socio-economic and gender differences (Marmot, 2005). Those who have had an interrupted work history (e.g., women with child-care responsibilities) and those who have had a more marginal employment status (part-time, casual, semi-skilled workers) may have reduced retirement income and therefore need to remain in paid work for longer (Raymo, Warren, Sweeney, Hauser, & Ho, 2011; O'Loughlin et al., 2010).

There is extensive research examining the timing of, intention to, and transition patterns related to retirement. What this shows is that while many are able to retire on their own terms, involuntary retirement is also a common experience (Noone, O'Loughlin, & Kendig, 2013). Reasons for this include health status (Majeed, Forder, & Byles, 2014), family caregiving (Kröger & Yeandle, 2013), ageist attitudes and discrimination (O'Loughlin & Kendig, 2017), and labor market supply and demand (Ebbinghaus, 2006).

The key message is that planning for, and having some control over the timing and transition process to retirement not only facilitate longer workforce participation - a policy goal of governments – but also have a greater positive impact on psychological and social well-being in later life (de Vaus, Wells, Kendig, & Quine, 2007; Noone, Stephens, & Alpass, 2009).

Self-evidently, these findings are in accord with the tenets of positive psychology.

Delayed retirement. Governments globally are contending with the economic and social challenges thrown up by population aging and increased longevity by introducing policies focusing on financial preparedness for, and income security in retirement, maintaining health, well-being and quality of life, and living and support arrangements as people live to increasingly older ages (World Health Organization, 2016). Across the developed world, the major policy response has been twofold in an effort to provide income security in retirement and sustainable pension schemes: (a) encourage mature-age workers to delay retirement and stay in paid work for longer, and (b) increase the pension eligibility age (Chomik & Piggott, 2012; OECD, 2013). While there are possible economic and health benefits to extending working lives from an individual and societal point of view (Noone et al., 2013), as outlined previously, not everyone has control over the decision to retire. Those who are financially secure and have planned for retirement may want to leave paid work at an earlier age, while those with health issues may be forced to leave and those who have had an interrupted work history may have no choice but to remain in employment.

Planning for retirement. With increased life expectancy and therefore an extended period in retirement, pre-retirement planning has become a focus in the mainstream retirement literature as well as in public policy discussions around healthy and productive aging (Adams & Rau, 2011; Noone et al., 2013). Although much of the attention has been around financial preparedness to ensure income security into older age, planning is also expected to include health, lifestyle and psychosocial issues to assist in adjusting to retirement and coping with change (Noone, Stephens, & Alpass, 2010; 2009; Wong & Earl, 2009). As noted, in retirement people move away from the routine of work and their sense of identity and status associated with being a worker, so they need to prepare for new social roles (e.g., volunteering, grandparenting), as well as remaining physically active and socially engaged, as these are known to influence the level of retirement satisfaction (van Solinge & Henken, 2008).

Views about retirement. Retirement is a major turning point in the life course and, for some, signifies 'official' entry to older age. Research shows that many people have mixed feelings about permanently leaving paid work, particularly when it is seen as being 'pensioned off;' that is, you are no longer considered as contributing to economic and social life. What people hope for is to have the financial and personal resources, including health, to retire from paid work and maintain their independence and a sense of purpose (Windsor et al., 2015), and to participate and contribute to family and social life (Kendig, Loh, O'Loughlin, Byles, & Nazroo, 2015).

Mainstream research based on a life course perspective shows that across all age categories, including retirement age, those with limited social support, poor health, or restricted incomes have lower levels of subjective well-being (Dannefer & Settersten, 2010). What we need to understand however is that people in varying circumstances, including those in retirement and later life, do have the capacity to maintain or improve their subjective quality of life if they have appropriate personal and social support (Cummins, 2014).

Policies about retirement, active aging, and support arrangements. Current theoretical and policy frameworks applied in most developed countries around aging use positive discourses (productive aging, successful aging, aging well) to focus attention on the need for people to maintain their independence, health and well-being by remaining physically active and socially engaged (Kendig, 2017; Rowe & Kahn, 2015). Within these frameworks, there is an expectation by policy makers that individuals in their retirement will engage in activities and behaviors to maintain physical function and cognitive capacities so that they can remain living in and socially engaged with the community. Central to this is the concept of *aging in place*; that is, as people age they will be supported to remain living in the community, as this is the preferred option of older people, their families, and governments. While this policy approach is seen to provide a more cost-effective alternative for all stakeholders, it also offers the opportunity for the development of age-friendly communities (Kendig, 2017) that support and facilitate interactions at the personal and public level.

Although positive discourses predominate, few studies specifically refer to a positive psychology framework. One example is Asebedo and Seay (2014), who evaluated the association of retirement satisfaction with the five dimensions of Seligman's (2012) PERMA framework of well-being (Positive emotions; Engagement; Positive Relationships; Meaning, and Accomplishment). Individuals who reported higher scores on 'positive emotion,' 'positive relationships' (support from family), 'meaning,' and 'accomplishment' also reported higher levels of retirement satisfaction (Asebedo & Seay, 2014).

Retirement and People with Intellectual Disability

Many of the research findings about retirement by members of the general community noted above will likely also apply to workers with intellectual disability. Factors such as a longer life span, the need for retirement planning, push and pull factors that influence retirement decisions, and the importance of choice and control of the timing of and transition to retirement all likely also affect people with intellectual disability. However, as will be seen, to date there has been little research involving people with intellectual disability to test the applicability of these factors. Moreover, there are some important differences in the work situation and life circumstances of workers with intellectual disability that may also have important effects on retirement.

Key Differences for People with Intellectual Disability

As noted, a focus on financial preparedness for retirement is a central consideration for most people in the general community. As will be seen later in the chapter, this issue appears to have lower priority among many workers with intellectual disability. The reality of very low wages in sheltered employment provides little or no opportunity for saving. Moreover, in Australia most people in sheltered employment earn less than the monthly earnings threshold that mandates that employers pay into the worker's retirement savings (superannuation) account. When discussing workers in sheltered employment, McDermott and Edwards (2012) noted: 'The majority of workers interviewed will retire with no superannuation even though they have worked for most of their lives' (p. 428).

The financial situation for people with intellectual disability who work in mainstream employment is somewhat different (Brotherton, Stancliffe, Wilson, & O'Loughlin, 2016a). First, they earn more, so the loss of wage income at retirement may be a more influential factor in deciding when to retire. Second, in Australia, the earnings of workers with intellectual disability in mainstream employment typically do exceed the income threshold meaning that employers are required to pay into the worker's retirement savings (superannuation) account providing some savings to draw on when they retire. Even so, workers with intellectual disability are often poor with limited or no retirement savings thus limiting housing, leisure and other options in retirement.

It is notable that legislative attention has been given recently in the USA to enabling people with disability to save for future needs related to their disability under the *Achieving a Better Life Experience*, or ABLE, Act (H.R.647, 2014). Although not specifically targeting retirement, the Act allows for tax-free savings accounts which are exempt from the $2000 cap on other savings that affect eligibility for Medicaid and Supplemental Security Income (SSI) benefits.

Eligibility for the Australian disability support pension. As noted by Brotherton et al. (2016a), age of access to a government pension differs markedly for people with and without intellectual disability, a fact that may influence decisions about the timing of retirement. In

Australia, currently, you must be 65 to be eligible for the age pension (Australian Government, Department of Human Services, 2016). This fact is known to influence the timing of retirement among the general population. By contrast, Australians with an IQ less than 70 are entitled to the disability support pension (DSP) from the age of 16 (Brotherton et al., 2016a; Department of Social Services, 2014), which provides income and other entitlements similar to the age pension. There is no requirement that one must work to receive the DSP. Thus, retirees with intellectual disability have a financial safety net that is not age dependent. They do not need to wait for the 'retirement age' of 65 to be eligible for this pension, so access to the age pension may be a less important factor in decisions about when to retire than for other Australians who are not DSP eligible.

DSP recipients can work and earn wages while still receiving a means-tested part-pension. Once income exceeds the threshold (currently AU$81 per week), the pension is reduced by 50 cents for each dollar earned above the threshold. Likewise, when wages cease the full amount of the pension is reinstated, thus partly offsetting a reduction in income due to retirement.

On average, the life circumstances of older people with intellectual disability differ from those of the general community in that many people with intellectual disability have no children, so they do not have to pay for the needs of dependent children, nor do they have the opportunity to take on the later-life role of grandparents. Likewise, they usually do not have adult children to provide social and financial support in retirement. Being poor has numerous drawbacks, but it also means that most adults with intellectual disability do not own their home so do not have a mortgage to service that requires continued income from paid work.

Research on Retirement by People with Intellectual Disability

Internationally, retirement by people with intellectual disability has received little research attention, despite the substantial literature on employment for this group. For example, a recent major review of research on employment and economic self-sufficiency made no mention at all of retirement, retirement planning or retirement savings (Nord, Luecking, Mank, Kiernan, & Wray, 2013). Research in the area of mainstream work for people with intellectual disability continues to focus on increasing employment participation (Griffin, Hammis, Geary, & Sullivan, 2008; Nord et al., 2013). The transition from school to work for people with intellectual disability has therefore received considerable attention (Luecking & Luecking 2015; Wehman et al. 2016), but much less is known about retirement.

Understanding of and Views About Retirement

Retirement is poorly understood by many people with intellectual disability. Most research on this topic has involved people in sheltered employment, and it is only recently that investigations have begun to include individuals with intellectual disability working in mainstream employment. Available research discussed below suggests that there may be differences in perceptions of retirement by employment type, but this research is in its infancy and no direct comparisons have yet been made. Nevertheless, given the important differences in the employment circumstances of these two groups, we will discuss them separately.

Workers in Sheltered Employment

Attitudes about retirement. Australian research indicates that many older people with intellectual disability currently working in sheltered employment tend to be negative about retirement and focus on the perceived loss of both meaningful activity and social connections (Buys et al., 2008; McDermott et al., 2009). As one person with intellectual disability put it: 'You're sitting at home and you've nothing to do' (Bigby, Wilson, Balandin, & Stancliffe, 2011, p. 170). These workers also fear the loss of valued workplace social relationships following retirement because these relationships are largely limited to their sheltered employment settings (Bigby et al., 2011; McDermott & Edwards, 2012).

These negative attitudes were reinforced because older people with intellectual disability had little insight into or knowledge of the range of activities available in retirement. Their quite limited ideas were based on familiar activities such as housework or watching television (Bigby et al., 2011; McDermott & Edwards, 2012). These views were further strengthened because family members and disability support staff also saw retirement by people with intellectual disability as leading to a serious risk of inactivity (Bigby et al., 2011).

These rather negative attitudes about retirement may arise from a lack of education about options in retirement, a failure to provide appropriate pre-retirement planning, or a lack of positive role models. Such views can become self-fulfilling, especially when family members and disability staff share this pessimistic outlook. For example, older workers in sheltered employment have expressed a wish to continue working as long as possible, even in the face of deteriorating health, to avoid the perceived boredom and loneliness of retirement (Bigby et al., 2011; McDermott & Edwards, 2012).

Consequently, one important task for research and service provision is to support older workers to learn more about the range of positive options for meaningful activity and social engagement in retirement, with the explicit aim of raising expectations. Carter, Austin, and Trainor (2012) reported that more positive expectations by parents about future work were linked with better post-school employment outcomes for young adults with severe intellectual disability. We know of no similar research related to retirement, so it is unknown what interventions may result in more positive retirement expectations by people with intellectual disability and their families.

Later in this chapter in the section on Research to Practice, we describe an intervention that resulted in positive retirement outcomes (Stancliffe, Bigby, Balandin, Wilson, & Craig, 2015). Expectations about retirement may have become more optimistic as a result of such experiences, but this research did not measure retirement expectations, so this issue remains unexamined. Likewise, the use of video-based positive retirement role models in this *Transition to Retirement* program (Stancliffe, Wilson, Gambin, Bigby, & Balandin, 2013b) could also contribute to more positive views of retirement, but this proposition also remains untested.

Views about retirement finances. One intriguing feature of the Australian research about retirement is the relative absence of comment by people with disability in sheltered employment on finances in retirement and retirement savings (Bigby et al., 2011; McDermott & Edwards, 2012). A small number of individuals did mention the loss of wage income in retirement or not being able to afford costlier activities (e.g., travel) when retired. However, most made no mention of financial issues and there was no sense of the major focus on financial planning for retirement, as is the case in the general community (Noone et al., 2013).

This finding may be associated with a variety of factors that affect the person's involvement with their own finances or their income in retirement. These factors include more limited understanding by many people with intellectual disability of financial matters (Suto, Clare, Holland, & Watson, 2005) and/or having one's finances managed by someone else (e.g., a family member); a lifetime of low income (including low wages in sheltered employment) such that financial constraints in retirement simply represent an unalterable reality; or, as we have noted, the fact that Australians with intellectual disability continue to receive the disability support pension regardless of the age when they stop work (see Brotherton et al., 2016a), meaning that retirement at any age in adulthood has the financial safety net of the disability pension.

Views of people who have already retired from sheltered employment. McDermott and Edwards (2012) interviewed ten Australian retirees who took part in pilot programs for retired older workers with intellectual disability. The activities offered included volunteering, walking or fishing and took place during what previously had been working hours. Transportation was provided for community access. In contrast with the negative views about retirement described previously by workers still working in sheltered employment, McDermott and Edwards reported that people who had retired and attended these pilot retirement programs were much more positive about life in retirement. Participants reported enjoying the activities and social connections as well as the slower pace of life in retirement. However, such programs remain rare in Australia and elsewhere.

By contrast, one participant in Bigby et al.'s (2011) study returned to sheltered employment after retiring because 'I got bored stiff' (p. 170). These divergent findings suggest that adjustment in retirement is partly related to the availability of meaningful activity and social connections and the support needed for these outcomes to be achieved consistently.

Self-determination about retirement. McDermott and Edwards (2012) found that older workers in sheltered employment were not making self-determined decisions about retirement. These authors recommended that better information about retirement, greater flexibility in service provision, the opportunity to try real retirement activities and support for self-determination were all needed to address this problem.

Workers in Mainstream Employment

We know of only one study (Brotherton, Stancliffe, Wilson & O'Loughlin, 2016b) that directly explored retirement and workers with intellectual disability in mainstream (integrated) employment. In this study, 18 participants with intellectual disability, aged over 40 and currently employed in a mainstream job were interviewed. Consistent with previous research on sheltered employment, they had narrow views of the leisure options available to them. However, their perspectives on other retirement issues differed from the views of workers in sheltered employment noted above.

Attitudes about retirement. A key difference was that workers in mainstream employment were generally positive about retirement, seeing it as an opportunity to relax or to be free to spend more time on leisure activities or socializing. Most expected to retire when they were older and/or when they 'had enough' of work. A decline in health or physical capacity to perform work tasks was the most common reason cited that would determine when it was time to retire.

Consistent with views of people in sheltered employment, participants recognized that there was a need to keep active in retirement and the few who said they didn't want to retire were primarily concerned with being bored. In discussing the social connections that they would miss in retirement, it was not only work colleagues that were mentioned but also work-related interactions with members of the public, such as customers in retail or residents in an aged-care facility. Participants valued both the conversational interaction and the opportunity to contribute through providing assistance to others. Also evident was that participants viewed having and maintaining a job in mainstream employment as an accomplishment and showed pride in achieving recognition of their years of service in their job. This finding suggests aiming for, or achieving celebrated milestones such as 10 or 20 years' service could be an important influence on the timing of voluntary retirement for people with intellectual disability.

Views about retirement finances. While many managed their day-to-day spending money, all participants relied on family members or paid disability support staff to assist with financial decisions. Participants raised concerns about the financial ramifications of retirement, particularly those living independently and/or relying on wages to pay bills. Many lacked understanding of disability pension adjustment for partial or full retirement whereby an increase in the pension partly offsets lost wage income. Similarly, people knew of the existence of superannuation (retirement savings through compulsory employer contributions) but were not aware of the details. Exposure to colleagues talking about retirement finances may be a factor in their showing greater concern about retirement income than people in sheltered employment. For example, stories of non-disabled co-workers not having enough money to retire on were shared in the interviews.

Several other factors affected the perceived financial impact of future retirement for Brotherton et al.'s (2016b) participants. Wages in their mainstream jobs—minimum wages or above—were much higher than for sheltered employment. Therefore, wage loss at retirement is much greater and may be more central to their retirement decisions. In addition, a few workers with intellectual disability have purchased their own home, meaning that they need to continue to earn enough to make mortgage repayments.

Travel issues. Travel was seen as a potential barrier to participating in community leisure activities, with safety concerns about traveling to unknown places or traveling at night on public transport. The commute to work was identified as something that could become more difficult with age and likely would affect the timing of retirement. For some, traveling to and from work was viewed as an opportunity to socialize with fellow commuters.

These initial findings suggest that there may be differences in views about retirement between people with intellectual disability in sheltered versus mainstream employment. It seems possible that these differences are directly related to the differing workplace environments, peer groups, wages, and experiences. However, these are preliminary findings that require both replication and more direct comparison between these two groups. At present research is silent on possible group differences in self-determination about retirement and personal growth, positive relationships and enjoyment of life in retirement.

Related Research About Mainstream Employment

Social connections and leisure participation. There is a little evidence that mainstream employment enables some workers with intellectual disability to make friends and socialize outside of work (Forrester-Jones, Jones, Heason, & Di'Terlizzi, 2004). However, most research has shown that these workplace friendships are largely limited to the mainstream work situation (Jahoda, Kemp, Riddell, & Banks, 2008). Such findings suggest that these friendships likely are lost on retirement, a factor that may influence retirement decisions in a similar manner to workers with intellectual disability in sheltered employment as noted previously.

Part-time work. Part-time work predominates for workers with intellectual disability in mainstream jobs (Butterworth et al., 2015). Therefore, these workers have time available for non-work activities and could be supported to begin to develop a retirement lifestyle (e.g., volunteering, leisure, and social activities) while *still working*, without the need to disrupt working hours. Indeed, Butterworth et al. (2015) found in the USA that 46% of workers in mainstream jobs also participate in a second (usually unpaid) day activity.

Job security. We could not locate comprehensive data on job tenure by age cohorts for people with intellectual disability. Available research does show poor retention rates within the first year of mainstream employment for people with intellectual disability. In Australia, only 44% of mainstream job placements for people with intellectual disability lasted 6 months or more (Department of Employment, 2015). This report also identified large variation in retention outcomes between individual service providers that support people with intellectual disability to work in the mainstream workforce, with 6-month retention rates ranging from 20 to 96%. Indeed, some employment support services reported jobs lasting over 10 years (Galinovic, 2014). One specialist intellectual disability service in Australia has reported an average job tenure of 6.8 years (Tuckerman, 2015).

Compared to sheltered employment, the nature of mainstream employment holds higher risk of job loss that may, in turn, prompt retirement in older workers with intellectual disability.

Retirement Age for People with Intellectual Disability

We know of no robust data on the age at which workers with intellectual disability retire, although some survey data suggests that they may retire quite young. Cross-sectional data on employment rates by age in the USA (Butterworth et al., 2015, p. 41, Fig. 10) and Australia (Australian Government Department of Education, Employment and Workplace Relations, 2014, p. 125, Fig. 8.1) show notably higher rates of employment of young adults receiving disability benefits in their 20s but with substantial and continuing decline for progressively older age groups beginning in the 30s. This trend could represent people retiring from their mid-30s onwards, but it may also partly reflect cohort effects due to greater recent support for employment that is accessed more by younger people with intellectual disability entering the adult service system. It seems likely that health issues are one important factor, but it is unclear what the full range of factors are that drive decisions to retire, particularly in one's 30s or 40s and what effect such factors have on one's life experience in retirement. Much better data about retirement (both longitudinal and cross-sectional) are needed if we are to understand the age at which workers with intellectual disability retire and the factors that influence their retirement decisions. It is only with a sound understanding of these issues that effective methods can be developed to support retirees with intellectual disability to experience an active, socially connected and inclusive retirement.

Research to Practice: Examples of Effective Approaches to Retirement by People with Intellectual Disability

Commonly, people who retire from sheltered employment move to a segregated day program where people with intellectual disability take part in unpaid activities (Bigby et al., 2011; Lawrence & Roush, 2008). As noted by Fesko et al. (2012, p. 504), "Rather than creating separate activities for individuals with intellectual disability, it will be necessary to work with existing programs to ensure they are inclusive of all seniors, including those with disabilities." As shown in the sections that follow, these more socially inclusive retirement options are now beginning to receive research attention. The projects described below warrant particular attention in a book on positive psychology because inherent in their design is a focus on support for self-determined choices in retirement timing and activities. In addition, these approaches build on the person with intellectual disability's existing capacities and identify what is meaningful to them to establish new social connections and community roles in mainstream environments.

Transition to Retirement Project

Transition to Retirement (TTR) is an Australian applied intervention that combined the principles of active aging with tested support methods to promote a gradual transition to an active, socially inclusive retirement lifestyle for older adults with disability. Most participants had intellectual disability. The project supported workers aged 45 or older in sheltered employment to take part in a *mainstream* community group or volunteering opportunity (Bigby et al., 2014; Stancliffe et al., 2013b). Participants joined groups such as community gardens, craft groups (e.g., knitting; woodworking), older people's exercise groups, seniors' centers, a community choir, or volunteered at a charity shop or soup kitchen. Groups were chosen based on the person's expressed activity preferences and/or current or former interests.

Older people with disability acknowledged that they may require supports to make community participation activities, such as volunteering, successful for all parties (Balandin, Llewellyn, Dew, Ballin, & Schneider, 2006). Likewise, community group members were willing to support older people with a disability, but were unsure about how to best provide support (Balandin, Llewellyn, Dew & Ballin, 2006). The TTR program uses existing community group members as mentors and trains them to support the person with intellectual disability at the group using an approach called active mentoring (Wilson et al., 2010).

Active mentoring. Active mentoring combines the methods of *Active Support* with the principles of co-worker training to ensure that people with intellectual disability take part in activities and social interaction at their community group. Active Support is a means of increasing participation in activities so that the person with intellectual disability does not become a passive observer (Stancliffe, Jones, Mansell & Lowe, 2008). It involves ensuring that activities are available and that needed support is given to enable participation. Co-worker training was developed for mainstream employment where a co-worker is trained to provide support to a fellow worker with disability (Farris & Stancliffe, 2001).

An example from the TTR project of support for participation in an activity concerns a mentor helping a woman with intellectual disability, Leone, play bingo at her community group. During bingo, Leone and the mentor sat together. If Leone missed a number the mentor pointed to it on the bingo sheet to remind Leone to cross it off. An example of supported social interaction involved a mentor making sure that a man with intellectual disability knew when it was time for morning tea and then used verbal prompts and simple questions to help him contribute to the conversation.

The TTR intervention. The TTR research project consisted of 6-months of support and data collection where older workers dropped one day of sheltered employment and replaced it with participation in a mainstream community or volunteering group. By design, only one TTR participant joined each community group in order to foster a greater sense of belonging and to focus on the individual and their specific retirement needs. The main components of the TTR program are set out in Fig. 23.1.

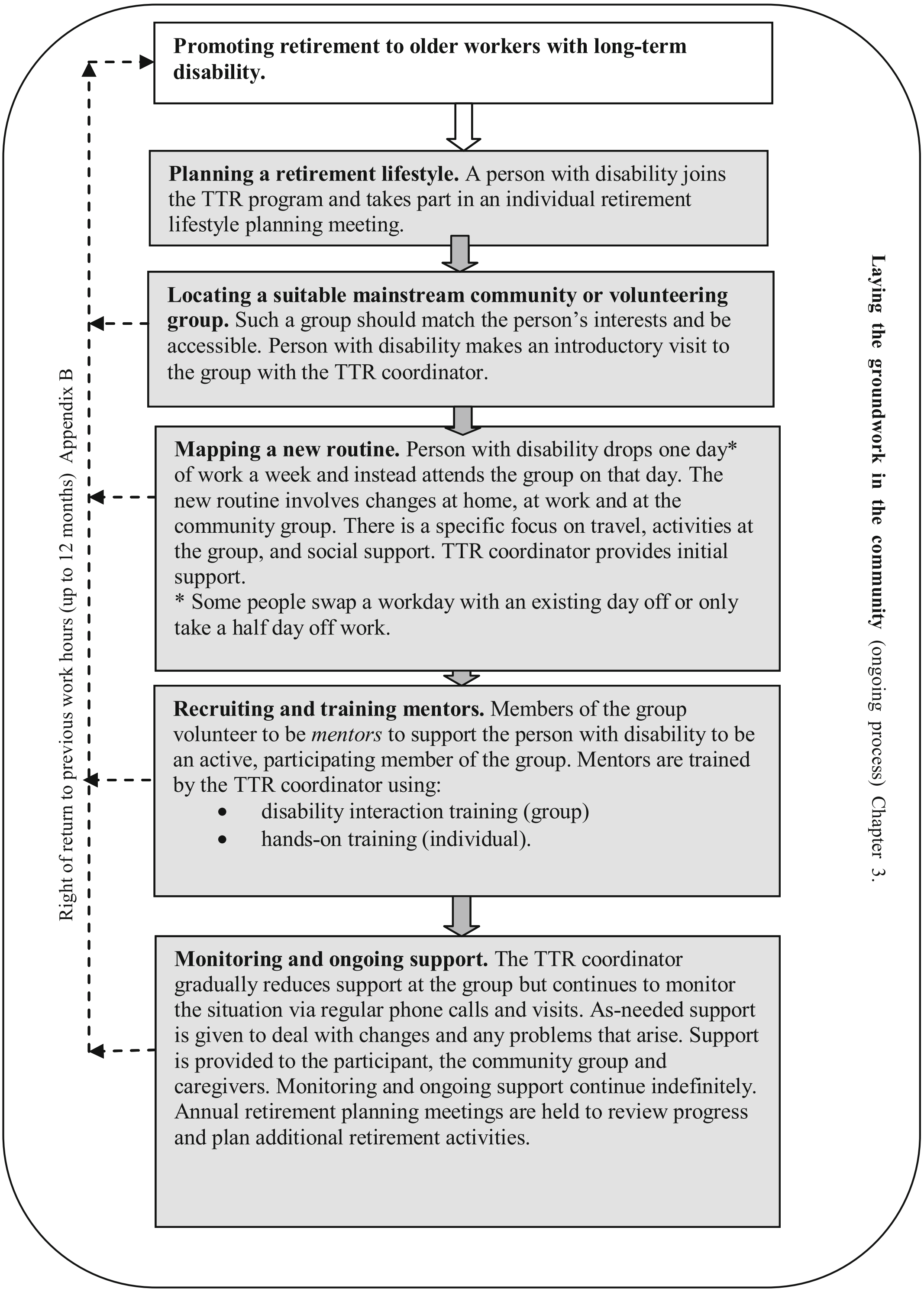
Feasibility and outcomes of the TTR intervention. Stancliffe et al. (2015) reported that the TTR intervention was feasible and durable, with 86% of intervention participants attending their mainstream community group for at least six months. Community groups were mostly very willing to accept a new member with a disability, and recruiting and training mentors from among group members was achieved without undue difficulty.

The TTR program was also beneficial (Stancliffe et al., 2015). As expected, intervention participants significantly increased their socially inclusive community participation, made new friends and reduced their work hours. Following the 6-month intervention, participants were more socially satisfied (i.e., reported having friends and social support) than matched comparison group members who continued to work unchanged hours and did not join a community group.

Stancliffe et al. (2015) also reported possible mental health benefits. Using life events as a moderator variable, at post-test intervention-group participants had significantly lower depression scores for proxy-reported depression. The authors proposed that the TTR intervention had protective effects against depression for individuals experiencing multiple adverse life events. Job loss and retirement themselves are considered adverse life events that can increase the risk of depression (Mandal & Roe, 2008), so a retirement intervention that protects against depression is of value. Independent replication of these findings would further strengthen their credibility.

As noted, the research project provided support to participants and mentors for six months. The main disability service provider partner, the Australian Foundation for Disability (AFFORD), continued TTR as a part of its usual service delivery. Consequently, a number of research participants have sustained their original activities for more than five years and added new socially inclusive activities on other days as they develop their retirement lifestyle further.

Self-determination. As noted, McDermott et al. (2012) reported low levels of self-determination regarding retirement from sheltered employment in Australia under standard service provision arrangements.



Promoting retirement to older workers with long-term disability.

Planning a retirement lifestyle. A person with disability joins the TTR program and takes part in an individual retirement lifestyle planning meeting.

Locating a suitable mainstream community or volunteering group. Such a group should match the person's interests and be accessible. Person with disability makes an introductory visit to the group with the TTR coordinator.

Mapping a new routine. Person with disability drops one day* of work a week and instead attends the group on that day. The new routine involves changes at home, at work and at the community group. There is a specific focus on travel, activities at the group, and social support. TTR coordinator provides initial support.
* Some people swap a workday with an existing day off or only take a half day off work.

Recruiting and training mentors. Members of the group volunteer to be *mentors* to support the person with disability to be an active, participating member of the group. Mentors are trained by the TTR coordinator using:

- disability interaction training (group)
- hands-on training (individual).

Monitoring and ongoing support. The TTR coordinator gradually reduces support at the group but continues to monitor the situation via regular phone calls and visits. As-needed support is given to deal with changes and any problems that arise. Support is provided to the participant, the community group and caregivers. Monitoring and ongoing support continue indefinitely. Annual retirement planning meetings are held to review progress and plan additional retirement activities.

Fig. 23.1 TTR program flow chart. *Shaded boxes* denote activities focused on a specific individual with long-term disability. Modified version of Fig. 1.1 from Stancliffe et al., (2013b). Used with permission

Conceptually, a gradual retirement process such as TTR provides opportunities for participants to control the timing, extent, and pace of their retirement. Stancliffe et al. (2013a) described strategies to support self-determination that formed part of the TTR program, including opting into the program, choice of activities and companions at the community group, but to date, there has been no formal assessment of the extent of self-determination actually experienced. From the standpoint of positive psychology, it is important to identify how self-determined people with intellectual disability are when making decisions about retirement and about their lifestyle when retired, and how to increase self-determination in these contexts.

Costs of implementing TTR. One feature of the TTR model is that routine support at the community group is provided by other group members who volunteer as mentors. In addition to the social inclusion benefits of this approach, it also reduces support costs because volunteer mentors are unpaid. However, much initial support is provided by the paid TTR coordinator. This work includes determining the person's interests, locating a suitable community group, supporting the person during initial visits to the group, planning a new routine, teaching travel skills (if needed), and recruiting and training mentors. Bigby et al. (2014—see Fig. 2) showed that within the first six months or so these important tasks require an average of 90 h of the TTR coordinator's time per client, with the most intensive work occurring in the weeks prior to and immediately following the first visit to the group. Importantly, once the person had successfully attended their group for several weeks, TTR coordinator support hours rapidly fell to a low level. Given the evident sustainability of the TTR approach, this initial investment of intensive TTR coordinator support appears cost-effective as mentors soon take over day-to-day support at the group.

The TTR inclusive practice manual. To facilitate translation into practice, an inclusive TTR practice manual and DVD was developed to enable practitioners to implement the TTR intervention (Stancliffe et al., 2013b). The manual's chapters largely reflect the major components of the TTR program illustrated in Fig. 1. The DVD contains 5 to 8-min video segments depicting the individual experiences of six older workers with intellectual disability who each joined a different type of community group. These videos are intended to provide role models and concrete examples of a range of retirement activities and support practices.

Conclusions about TTR. While promising, currently the TTR program is not widely available, so many older workers with intellectual disability are limited to segregated retirement options (Bigby et al., 2011; Lawrence & Roush, 2008). There is clearly a need to develop and test effective approaches to scaling up such socially inclusive interventions. In addition, the research on TTR involved a single project and research team, so independent replication is also a priority. Finally, greater focus by researchers on the positive psychology dimensions of TTR would help to identify the extent to which such approaches promote self-determination, personal growth, positive relationships and enjoyment of a good life in retirement.

Retirement Intervention for Workers in Mainstream Jobs

The literature on best practice for supporting people with intellectual disability in mainstream employment has a focus on identifying the interests and talents of the individual rather than functional deficits and on understanding what is personally meaningful to them in way that is consistent with positive psychology. Customized employment involves focusing on the strengths, interests or the choices of the person to negotiate a work role that meets the needs of both the person with intellectual disability and the employer (Griffin, et al., 2008). Building on the *Transition to Retirement* work described previously, Brotherton et al. (2016) proposed that the practices of successful mainstream disability employment services can be utilized to support people to participate in and contribute to their community including customized volunteering roles in their leisure time or post-retirement Through partnership with a high-performing disability employment service that specializes in mainstream employment for people with moderate intellectual disability, a project is currently underway to evaluate the effectiveness of this approach.

Conclusions

This chapter examined retirement from paid employment by people with intellectual disability. While a good deal is known about retirement by members of the general community, retirement by people with intellectual disability has received little systematic attention by researchers, policy makers or service providers. The limited available research suggested that there may be important retirement-related differences between people with intellectual disability working in sheltered employment and those in mainstream work, but these notions need to be tested using direct comparisons between the two groups. Basic data are currently not available about when and why workers with intellectual disability retire. These data are vital if effective support is to be provided for retirees with intellectual disability. Even so, we described examples of retirement interventions that resulted in active, socially connected and inclusive retirement activities. As these interventions showed, many aspects of retirement are consistent with positive psychology, but to date, little mainstream or intellectual disability-specific research has explicitly linked positive psychology and retirement. We hope that the issues noted in this chapter may help focus future research attention on the considerable potential for examining retirement by people with intellectual disability from a positive psychology perspective.

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Aging

24

Lieke van Heumen and Tamar Heller

Introduction

Research on older adults with intellectual disabilities often focuses on age-related losses in functioning and on ways to prevent decline (Heller & van Heumen, 2013). A positive psychology perspective on aging focuses on creating a positive and meaningful aging experience. It enables the formulation of supports and services informed by the life stories, experiences, and individual needs and preferences of these adults. This chapter discusses the main aging issues and concerns among the population of older people with intellectual disabilities, introduces a life course perspective to aging with intellectual disabilities, and focuses on the main late life transitions for this population. It concludes with three upcoming areas of strengths-based supports to foster aging well among adults with intellectual disabilities: future planning, social network interventions, and life story work.

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The Aging Population

Life expectancy at birth has increased worldwide because of improvements in health and social care (Sheets, 2011). A child born in the USA in 2011 can expect to live 78.7 years, about 30 years longer than a child born in 1900 (Administration on Aging and Administration for Community Living, 2012). The population is getting older, and the cohort of older people is larger than ever before (Victor, 2010). Since 1900, the number of older Americans increased over 13 times (from 3.1 million to 41.4 million) and the percentage of older Americans more than tripled (from 4.1% in 1900 to 13.3% in 2011). One in every eight Americans is now over the age of 65 (Administration on Aging and Administration for Community Living, 2012).

The same medical and social factors that have led to the increase in longevity of the overall population have also significantly increased the life spans of people with disabilities (Kemp & Mosqueda, 2004; Sheets, 2011). The evidence base regarding the demography of aging of people with disabilities in the USA is growing even though substantial gaps remain (Freedman, 2014). We know that people aging with a disability form an increasing proportion of the population (Sheets, 2005). Data from the 2008–2012 American Community Survey five-year estimates indicated that 38.7% of the population of adults aged 65 and over reported having one or more disabilities, the equivalent of 15.7 million people (He & Larsen, 2014). This includes both people

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with mid- or late life onsets (who are said to experience disability ‘with’ aging or age ‘into’ disability) and people with early-onset or lifelong disabilities (who are said to ‘age with disability’) (Putnam, 2007; Verbrugge & Yang, 2002).

Aging of People with Intellectual Disabilities

The largest group of people aging with lifelong disabilities is those with intellectual disabilities (Bigby, 2004). The life expectancy of this group is increasing, but still lower than that of the general population. Recent studies conducted in higher income countries estimated that people with moderate intellectual disabilities live into their late 60s and those with severe intellectual disabilities into their late 50s. The estimated life expectancy of people with mild intellectual disabilities is 74 years and approaches that of the general population (Bittles et al., 2002; Haveman et al., 2009).

Over the next 20 years, the US population of older adults with intellectual disabilities will likely increase considerably. Based on data from the US Census (Population Division US Census Bureau, 2008; US Census Bureau, 2010) and Larson et al. (2001), Factor, Heller, and Janicki (2012) estimated there are 850,600 people with intellectual and developmental disabilities aged 60 and older living in the USA. By 2030, their numbers are expected to swell to an estimated 1.4 million due to increasing life expectancy and the aging of the baby boomer generation.

Persons with intellectual disabilities are a priority population due to several biological, social, and societal factors. They have on average twice as many health problems than those in the general population (van Schrojenstein Lantman de-Valk & Noonan-Walsh, 2008) and are likely to develop secondary and unique conditions related to their disabilities as they age (Lightfoot, 2007). This population therefore requires more health care (Heller, 2004) and is confronted with complex medical decisions (Kapp, 1999). Not all changes in health and function that are common among this population are inevitable (Heller & Marks, 2006; Mosqueda, 2004). Healthier lifestyles, better nutrition and more exercise, and greater surveillance of health risks are ways to improve the health status of adults with intellectual disabilities (Acharya, Schindler, & Heller, 2016; Haveman et al., 2010; Heller & Marks, 2006). In addition, it is important to remove societal barriers for people with disabilities that impede their ability to receive appropriate health care, including healthcare providers’ lack of knowledge (Ansello & Janicki, 2000; van Schrojenstein Lantman-de Valk, 2009), complex bureaucracy, and physical and societal attitudinal barriers (Heller & Marks, 2006; Lightfoot, 2007).

Aging is associated with many aspects of loss, such as gradual diminishment of physical and possible mental capabilities, retirement, and possible relocating to a new residence. Coping with the loss of significant others is another universal experience of older adults (Ludlow, 1999). People with intellectual disabilities might experience some age-associated losses at a younger age. They might not experience the consequences of adult children leaving the home, but be confronted with the consequences of loss of family and staff caregivers, as well as peers. The natural processes of aging may be more stressful for older adults with intellectual disabilities because of their greater need for everyday support, limited ability to understand what is happening to them resulting from communication or cognition impairments, or societal attitudes that deny them access to information and support needed to successfully cope with and adjust to losses. In addition, they are at a higher risk to face their own mortality alone as they lose their next of kin (Parker Harris, Heller, Schindler, & van Heumen, 2012). Due to these reasons, older adults with intellectual disabilities need adequate additional supports to promote their well-being. Unfortunately, the disability and aging fields rarely conduct research aimed to retrieve the views of older people with intellectual disabilities themselves on aging, on how they would like to be supported to have a better quality of life, and on what they consider important to age well (Bigby, 2004).

The Aging Experience of People with Intellectual Disabilities

Only a limited number of researchers have engaged with retrieving the experiences of older adults with intellectual disabilities regarding the aging experience. In the Netherlands, Urlings et al. (1993) found in a qualitative study with older people with intellectual disabilities that aging was only a major topic of interest for individuals over 70. These individuals related the decline of self-help skills and the anxiety of becoming physically ill and bedridden to the perceived concept of aging. Growing old and dying were major issues for these older adults.

In a study of adults with intellectual disabilities aged 40 and older conducted in Ireland, most of the adults interviewed described their health as very good to excellent but expressed negative views of the consequences of aging (Burke, McCarron, Carroll, McGlinchey, & McCallion, 2014). Brown and Gill's (2009) participatory study with older women with intellectual disabilities also found that these women thought about getting older in mostly negative ways. They understood aging as a physical process and thought of getting ill and dying as part of the aging process. The women also expressed that with aging, they experienced the loss of loved ones, such as parents, friends, or siblings. Some women also identified positive aspects of aging, such as 'getting discounts' and the idea that older people 'deserve more respect.' Family members' and peers' words and attitudes often shaped how the women framed understandings of aging and disability. A study conducted on older women with intellectual disabilities in Israel found that these women desired to be active and were reluctant to retire (David, Duvdevani, & Doron, 2015). Furthermore, they also associated aging with physical deterioration and decline.

Functional aspects of aging might be more important than chronological age for older persons with intellectual disabilities' experiences of aging. Milestones such as reaching 50, 60, or 70 might not be meaningful for persons who are only able to count to twenty. Adults with intellectual disabilities may start to feel old when they begin to notice difficulties with walking, seeing, hearing, eating, and talking (Haveman et al., 2009).

Life Course Perspective to Aging with Intellectual and Developmental Disabilities

To understand the experiences and the needs of adults with intellectual disabilities as they age and in order to provide appropriate supports, it is important to have insight into their experiences in earlier stages of life. Aging is a lifelong process, and circumstances, events, behavior, and relationships earlier in life influence the development of people at older ages (Elder, Kirkpatrick Johnson, & Crosnoe, 2004; Marshall, 1996; Passuth & Bengtson, 1988). Examples of such life course factors that can impact the health and well-being of people with intellectual disabilities later in life include lack of education, institutionalization at an early age, limited social networks, loss of close and confiding relationships, bereavement, absence of valued social roles, low income and poverty, service breaks and transitions, and shifting patterns of interdependence with parents during the life cycle (Grant, 2005). These circumstances can have formative and cumulative effects on the long-term economic, social, psychological, and physical well-being of these individuals (O'Rand, 2009).

Unfortunately, little research has addressed lifelong disability from a life course perspective (Jeppsson Grassman, Holme, Taghizadeh Larsson, & Whitaker, 2012; Kelley-Moore, 2010; Parker Harris, Heller, & Schindler, 2012; Priestley, 2003; Yorkston, McMullan, Molton, & Jensen, 2010). The experiences of younger persons, mid-life adults, and older adults with disabilities are often approached independently, without acknowledging life course processes (Kelley-Moore, 2010). A life course approach that addresses disability issues across generations and through various life stages such as the aging process is complex, but useful to inform and further our understanding of disability. Disabling barriers affect the circumstances, experiences, and opportunities of people with disabilities of different generations in different ways through the life course. As a consequence, there are differences in the life experiences of different age cohorts of persons with disabilities. Additionally, disability can be experienced differently in different life stages (Irwin, 2001; Parker Harris, Heller, & Schindler, 2012).

Late Life Transitions Among People with Intellectual and Developmental Disabilities

A useful concept in understanding the experiences of aging adults with intellectual disabilities from a life course perspective is that of late life transitions. Transitions refer to disruptions in individuals' day-to-day lives. These can include both daily stressors and major life events (Elder, 1985). Major life events and changes such as leaving home or losing loved ones can cause a great deal of stress (Almeida & Wong, 2009). Adults with intellectual disabilities may face additional challenges in navigating late life transitions due to their changes in supports. Henceforth, three major late life transitions for older adults with intellectual disabilities will be discussed: the transition to retirement, transitions in social networks, and the final transition of death and dying.

The Transition to Retirement

The population of people with intellectual disabilities differs from the general population in work experiences. Before the deinstitutionalization movement, employment for people with developmental disabilities who lived at home was uncommon. Employed individuals who lived in institutions tended to hold jobs that were limited to in-service or agricultural tasks related to the functioning of the environment. After the deinstitutionalization movement, the majority of older adults experienced only sheltered work and only a small minority have achieved competitive employment (Sterns, Kennedy, Sed, & Heller, 2000).

Longer lives mean that persons with intellectual disabilities now live beyond the relevance of traditional skills development or job programs (Ansello & Janicki, 2000; Bigby, 1997). For older people in the general population, retirement often consists of phasing out of employment and receiving other financial means to support a non-employment lifestyle. Retirement of people with intellectual disabilities in the USA is not financially driven in the same way, and daily support structures and environments often change little, as government financial supports do not change and usually neither do residential settings. The focus of daily activities for older people with intellectual disabilities might move from employment to socialization. Retirement opportunities for older adults who live in residential settings are usually determined by the policies of the agency that supports them, and for older adults living at home with family few changes might occur (Hahn et al., 2016).

A major concern is evidence that despite their aspirations for continuing inclusion, older people with intellectual disabilities experience few opportunities to participate in meaningful day and leisure activities of their choice (Heller, 1999). Natural approaches to retirement for both people with and without intellectual disabilities promote active engagement in non-paid activities that provide purpose and meaning. These may include involvement in senior organizations and services in local communities (Hahn et al., 2016). For example, senior centers can provide people with intellectual disabilities able to participate the opportunity to learn and grow in a new and integrated environment (Factor et al., 2012).

In Australia, Stancliffe, Bigby, Balandin, Wilson, and Craig (2015) designed a program to support older people with intellectual disabilities in the transition to retirement. Participants in the program attend mainstream community groups around activities of their interest once a week (e.g., choir, walking and knitting group, community garden) and received support to participate by community group members trained as mentors. An evaluation of the program demonstrated that participants increased their community participation, made an average of four new social contacts, decreased their work hours, and were more socially satisfied than individuals in the control group. Stancliffe et al. concluded that participation in mainstream community groups with support from trained mentors is an effective tool to develop meaningful retirement for older people with intellectual disabilities.

Social Networks and Aging

Supportive networks play a critical role in older individuals' life quality and happiness (Barrera, 2000; Bigby, 2004; Kennedy, 2004). Satisfaction of the fundamental human need to develop close, long-lasting, and supportive relationships (Baumeister & Leary, 1995) is associated with positive health outcomes (Knipscheer & Antonucci, 1990), subjective well-being, happiness, and positive affect in general (Baumeister & Leary, 1995; Hogan, Linden, & Najarian, 2002). When persons experience social isolation and a lack of social support, they are prone to experience negative affect, depression, loneliness, and anxiety as a consequence (Antonucci, Akiyama, & Sherman, 2007; Baumeister & Leary, 1995; Berkman, Ertel, & Glymour, 2011; Broese van Groenou & van Tilburg, 2007; Cohen & Syme, 1985; Due, Holstein, Lund, Modvig, & Avlund, 1999; Hogan et al., 2002; Knipscheer & Antonucci, 1990; Stevens, Martina, & Westerhof, 2006; Wills & Shinar, 2000).

The lives older people have lived shape their social networks (Knipscheer & Antonucci, 1990). These networks reflect earlier life circumstances and transitions. Additionally, they represent individual opportunities and needs and choices to maintain and develop supportive relationships (Antonucci & Knipscheer, 1990; Broese van Groenou & van Tilburg, 2007).

Social Networks of People with Intellectual Disabilities

The literature on social relations of people with intellectual disabilities is limited but diverse. It has primarily explored the association between well-being and social relations for people with intellectual disabilities, the number and types of social relations included in their social networks, and the social interactions between those with and without intellectual disabilities (Kersh, Corona, & Siperstein, 2013).

Generally, the networks of people with intellectual disabilities are small. Their networks lack contact with people who do not have intellectual disabilities outside of family members and direct support staff (Lippold & Burns, 2009; van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014; Verdonschot, Witte, Reichrath, Buntinx, & Curfs, 2009). Many adults with intellectual disabilities spend free time alone (Krauss & Erickson, 1988), and loneliness is prevalent in all age-groups of those with intellectual disabilities (Hogg, Moss, & Cooke, 1988; Krauss & Erickson, 1988; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Stancliffe et al., 2007).

Qualitative research with people with intellectual disabilities indicates that they value companionship, closeness, support, and stability as the most noteworthy aspects of their friendships (Kersh et al., 2013). A growing number of studies have documented their desire to engage in more community activities and to have more friends (Abbott & McConkey, 2006).

Social Networks of Older People with Intellectual Disabilities

Familial relations are important for the optimal development and well-being of people with intellectual disabilities (Bigby, 2003; Buys, Aird, & Miller, 2012; Noonan Walsh, 2002). However, many older persons with intellectual disabilities have limited or no contact with family members and/or only have contact with parents and siblings (Maaskant, 1999, 2007; Meeusen &

Maaskant, 2004). Most older people with intellectual disabilities do not have spouses and children (Bigby, 2004, 2005; Seltzer, 1985) on whom they can depend for support (Seltzer, 1985). This also means they do not assume the roles of being grandparents or in-laws. As they tend to have long-lasting close relationships with their siblings who often become primary caregivers after parents die (Bigby, 2002; Heller & Arnold, 2010), sometimes adults with intellectual disabilities assume the roles of being (great-) aunts and (great-)uncles (Bigby, 2004, 2005).

Older people with intellectual disabilities tend to have fewer stable and close friendships to complement their familial relationships than older adults in the general population. Instead, they are more likely to have acquaintances rather than close friends (Bigby, 2002; Lippold & Burns, 2009; Maaskant, 1999, 2007; Meeusen & Maaskant, 2004; Robertson et al., 2001).

With longer life expectancy is a greater likelihood of the adult with a disability outliving his or her parents than in the past (Heller & Caldwell, 2006). Relocation after the death of parents often results in a loss of relationships (Bigby, 2000b). When parents die, there is a danger that incidental contact with extended family such as cousins, nieces, nephews, aunts, and uncles is lost without specific efforts by relatives to involve them, as the people with intellectual disabilities usually no longer live in the parental home where family events took place. Although contact with shared family friends might be retained after the parents' death, such friends are likely to be from an older generation and to predecease the adult with a disability (Bigby, 2005).

For some people with intellectual disabilities, the loss of their parents can signify a shift to an adult rather than child role and create the opportunity to develop new intimate friendships (Bigby, 2005). For these people, later life can be a time when their social worlds expand and, freed from the restrictions imposed by parents, they can build new relationships as participants in community activities (Bigby, 2002).

As adults with intellectual disabilities age, direct support staff members increasingly replace parents as primary caregivers. They become an integral part of the support networks of many older people with intellectual disabilities (Bigby, 2000b, 2002). Lippold and Burns (2009) concluded that the social networks of older people with intellectual disabilities who rely on formal services may not be stable over time, as the relationships within these networks tend to be role-prescribed and characterized by minimal reciprocity.

Formal supports from staff and professionals cannot fully replace the affective support provided by informal network members (Bigby, 2000a, 2002, 2003). Older people with intellectual disabilities who lack informal network members may have no one to protect their rights and oversee their well-being. It is difficult for formal organizations or paid relationships to commit to advocating for an individual long term (Bigby, 2005). Hence, formal services need to nurture, build, and strengthen informal supports for the individual (Bigby, 2000a, 2005). However, many residential settings do not provide sufficient opportunities for older residents to participate in community activities (Hsieh, Heller, & Freels, 2009; McConkey, 2005).

The body of knowledge on the social relations of older adults with intellectual disabilities is incomplete and mostly dated. Little research has explored the perspectives of older adults with intellectual disabilities on their social relations. Buys et al. (2008) interviewed older service users with intellectual disabilities ($N = 16$) and found that these individuals valued satisfying relationships and support as elements to active aging. They defined companionship as having someone to engage with in activities and friendship as having a trusting and satisfying relationship. Some participants reported that church or social group membership and employment enhanced their social interaction and supported their friendships. They reported needing both formal and informal supports to participate in desired activities. Even though the importance of including perspectives of people with intellectual disabilities in research has been widely acknowledged, research of this nature remains limited (Lunsky, 2006; Mactavish, Mahon, & Lutfiyya, 2000).

Death and Dying

Bereavement is often a source of trauma for people with intellectual disabilities. Distressing bereavements after the death of parents can occur when adults with intellectual disabilities witness the parent dying or find them dead (Mitchell & Clegg, 2005). People with intellectual disabilities are more likely to develop mental health problems following bereavement than those in the general population (Bonell-Pascual et al., 1999). Caregivers may be concerned about the capacity of people with intellectual disabilities to understand and cope with the finality of death or do not recognize the need of the person with a disability to be informed and included, and to grieve (Blackman et al., 2003; Parker Harris, Heller, & Schindler, 2012; Sterns et al., 2000). Such interference denies this population important opportunities to learn and grow (Ludlow, 1999).

The need for appropriate death education and bereavement counseling for people with intellectual disabilities has been recognized by many in the field (Sterns et al., 2000). The work of Tuffrey-Wijne (2013) on breaking bad news to people with intellectual disabilities aims to include, inform, and help these adults cope with age-associated losses.

Similarly, issues around death and dying and end-of-life care for people with intellectual disabilities themselves have yet to receive adequate attention in research, policy, and practice (Hahn et al., 2016; Tuffrey-Wijne, 2003). One of the factors influencing the quality of end-of-life care is communication barriers between medical professionals and people with intellectual disabilities. People with intellectual disabilities have difficulty verbalizing their needs, including any pain they are experiencing, or understanding information provided to them by care providers. Care providers often lack the skills and training to effectively communicate with people with intellectual disabilities (Tuffrey-Wijne, Hogg, & Curfs, 2007). Several policy documents recommend improved training of health professionals in communication with people with intellectual disabilities (Meijer, Carpenter, & Scholte, 2004). Every effort must be made by health professionals to provide information in a person-centered way that is most appropriate to help the individual with an intellectual disability understand. To improve communication and accessibility of information, it might be helpful to read the information to the individual or to use nonverbal modes of communication such as pictures (Department for Constitutional Affairs, 2007; Heller, 2004; van Schrojenstein Lantman-de Valk, 2005).

Disability services are often unprepared to handle the last phase of the life span of adults with intellectual disabilities. Staff might lack knowledge of the amount and types of support required for these individuals as well as for themselves during the dying process. Additionally, many practitioners are unsure whether to inform persons with intellectual disabilities that they are dying (Todd, 2004, 2005). This takes away an opportunity for these adults to be involved in decision-making about their own end-of-life. A lack of health guidelines exist of how to inform and counsel adults with intellectual disabilities about the course of diseases and the dying process (Hahn et al., 2016). Two resources were recently created to help adults with intellectual disabilities understand disease and talk about end-of-life planning when facing a serious illness. The tool developed by Watchman, Tuffrey-Wijne, and Quinn (2015), 'Jenny's Diary,' aims to support conversations about dementia with people who have intellectual disabilities. Tomasa (2014) created a tool for opening up communication about end-of-life planning among people with intellectual disabilities, families, direct support staff, and medical professionals.

Future Planning

Planning for the future is a task encountered by all people as they age but particularly important for people with intellectual disabilities (Heller & Caldwell, 2006; Kapp, 2007). Without adequate plans and supports in place, people with intellectual disabilities are at risk of facing emergency placements in inappropriate settings and inadequate or inflexible financial and legal safeguards when primary caregivers become unable to provide supports (Freedman, Krauss, & Seltzer, 1997; Heller & Caldwell, 2006).

Despite concerns about the future, many families have not made concrete plans. Frequently identified barriers to planning include lack of information, unavailability of desired services, difficulty affording attorneys, benefits resulting from the caregiving role, reciprocity of caregiving, and emotional issues concerning mortality (Freedman et al., 1997; Heller & Caldwell, 2006). Even though siblings often take on future caregiving roles (Bigby, 1997; Freedman et al., 1997), many parents do not discuss future plans with siblings. Additionally, people with intellectual disabilities are seldom involved in future planning (Bigby, 1997, 2000b; Heller & Caldwell, 2006). Although there is growing recognition that people with intellectual and developmental disabilities should be active participants in planning processes, sufficient supports need to be provided to make this a reality (Heller & Caldwell, 2006).

The terms 'future planning' and 'person-centered planning' are used interchangeably in the field. Person-centered planning aims to develop collaborative, goal-oriented supports focused on community participation and positive relationships (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2010). The field has started to develop person-centered and future planning activities to support adults with disabilities at different moments in their lives such as their transitions from childhood into adulthood and from middle age into old age (Heller & Caldwell, 2006; Heller, Sterns, Sutton, & Factor, 1996; Schippers & van Boheemen, 2009). Planning tasks relate to education and training, current and future vocational choices, residential options, retirement and leisure-time activities, social supports, and end-of-life wishes (Parker Harris, Heller, & Schindler, 2012). The planning process increases the knowledge of late life options and provides an opportunity for people with intellectual disabilities to develop and assert their choice making and self-determination skills (Heller & Caldwell, 2006; Heller et al., 1996). A growing literature base suggests that the development of self-determination of adults with intellectual disabilities leads to an enhanced quality of life (Blacher, 2001; Wehmeyer & Schwartz, 1998) and promotes aging well of this population (Heller, 2004).

A peer support intervention, called 'The Future is Now' (Heller & Caldwell, 2006), aims to support aging caregivers and adults with intellectual disabilities to plan for the future. The intervention consists of a legal and financial training and is followed by five small-group workshops using a peer mentoring co-trainer model. An evaluation found that families who received the intervention were significantly more likely to complete a letter of intent, take action on residential planning, and develop a special-needs trust compared to the families in a control group. Additionally, caregiving burden significantly decreased for families in the intervention, and the daily choice making of people with disabilities increased.

Two related interventions to supplement and integrate into future planning activities have yet to receive adequate attention in practice: social network mapping and life history work. Both hold potential to make future planning more person-centered and effective and will be discussed in more detail henceforth.

Social Network Interventions

Often overlooked is that people with intellectual disabilities need externally provided support to develop and maintain their social networks (Bigby, 2002; McConkey, 2005). Both personal skills and social opportunities are required for people to develop relations (McConkey, 2005; Newton, Olson, Horner, & Ard, 1996). People need to actively contribute to the process of making friends. Important personal skills to do so include motivation, self-confidence, interpersonal skills, and abilities to resolve conflict and express feelings. People with intellectual disabilities can benefit from social skills training (McConkey, 2005). As a lack of social intuition can place them at a heightened risk for abuse, gaining these skills is important for them (Heller et al., 2010).

Inclusion requires connection to others. Simply providing services in community-based settings does not ensure the social inclusion of persons with intellectual disabilities within those communities (Bigby, 2005). Membership in community groups, having acquaintances, spending time with others, and shared activities and concerns all provide pathways to social opportunities and the development of relationships (Bigby, 2005; McConkey, 2005). Person-centered plans should explore strategies for community participation to maintain and strengthen the social relationships of the individual (Bigby, 2005).

Support from formal relationships can foster development of informal relationships but also, through neglect and ignorance, obstruct or disrupt them (Bigby, 2008). Service providers often view their role from a limited perspective as other facets of support are given priority (McConkey, 2005). Direct support staff can encourage the growth of informal networks of supports (Power, 2010) by implementing network interventions to expand and strengthen social networks (van Asselt-Goverts et al., 2014). Strategies to support informal relationships and build new ones range from consciousness raising, reorientation of everyday structures, and support to implementation of more formal network building programs (Bigby, 2004). One approach may be the implementation of a dedicated function, whereby a skilled inclusion/relationship worker is employed to work across a cluster of residents, to be responsible for mapping resident's family constellations and creatively tackling the continuing engagement of families in the lives of residents, as well as developing individual strategies for the fostering of friendships or advocacy relationships (Bigby, 2008). Family relationships may need active support as relatives age and encounter problems with driving or using public transport. A proactive approach to maintaining contact and supporting visits that adapts to changed circumstances will help to keep relationships alive (Bigby, 2004).

Within person-centered planning, each individual's network should be actively mapped, and the history and significance of relationships understood (Bigby, 2004, 2005). The social network mapping process can not only chart individuals' social networks but importantly also investigate individuals' needs and desires regarding social relations. Discrepancies between current and the desired networks can be addressed by setting goals as part of person-centered future planning processes. These goals can be to expand the social network with new contacts and/or to strengthen existing ties with social relations, such as family members (Bigby, 2004; van Asselt-Goverts et al., 2014). Regular mapping of relationships with the person with an intellectual disability can address potential challenges with maintaining social relationships when circumstances change (Bigby, 2004). This is particularly useful during transitions that are likely to disrupt social networks.

In person-centered future planning processes, such as the Planning Alternative Futures with Hope (PATH) tool (Wetherow & Wetherow, 1998), close family members or friends are asked to take responsibility in helping the individual with an intellectual disability achieve goals. The lack of social relationships of those with intellectual disabilities has been identified as an impediment to person-centered planning (Claes et al., 2010). Action based on social network mapping can address this obstacle by helping expand the support network so that person-centered planning can be more successful.

Life Story Work

Life review promotes aging well (Butler, 1963), and retrieving memories, also called reminiscence, is an important activity in older age (Erikson, 1997). Understanding past experiences of older adults with intellectual disabilities is helpful to understand their current needs. The subjective well-being of older adults is not only determined by what they experience today, but also by what happened to them in the past, and by their retrospective view on those life events (Westerhof, Dittman-Kohli, & Thissen, 2001).

Three main perspectives can be identified in work done to date with the life experiences and stories of people with intellectual disabilities (Meininger, 2003, 2005; Van Puyenbroeck & Maes, 2008). In all three approaches, the process is more important than the product. In other words, most important is that the telling of the story is meaningful to the person with an intellectual disability (Van Puyenbroeck & Maes, 2008). The critical approach revolves around recovering the voices of people with intellectual disabilities. In this approach, the facilitator is a critical educator who coaches persons with intellectual disabilities to claim authorship and ownership of their own life stories. In this approach, life histories, autobiographies, and narratives enhance awareness for people with intellectual disabilities of their past (Van Puyenbroeck & Maes, 2008). In the clinical approach, reminiscence is an alternative diagnostic instrument and counseling method for people with intellectual disabilities (Van Puyenbroeck & Maes, 2008).

'Life story work' aims to 'retell, study, and discuss life stories in contacts between persons with intellectual disabilities, their relatives, and friends and caregivers' (Meininger, 2005, p. 108). Life story work also aims to inform the attitudes and acts of the persons involved in everyday support of the person with an intellectual disability (Meininger, 2003, 2005; van den Brandt-van Heek, 2011) and, therefore, is an important tool that can enhance person-centered planning (Aspinall, 2010; Van Puyenbroeck & Maes, 2008) by increasing understanding of the person with intellectual disability and relational intimacy. This approach includes activities that create a written record of a life story such as compiling a 'life book' (Van Puyenbroeck & Maes, 2008). Life story work has begun receiving increasing attention in the intellectual disability research, particularly in Europe (e.g., Atkinson, Doeser, & Varga, 2000; Atkinson, Jackson, & Walmsley, 1997; Atkinson & Walmsley, 1999; Cadbury & Whitmore, 2010; Goodley, 1996; Gray, 1997; Hreinsdottir, Stefansdottir, Lewthwaite, Ledger, & Shufflebotham, 2006; Husain, 1997; Mee, 2010; Roets, Goodley, & van Hove, 2007; Roets, Reinaart, & Van Hove, 2008; Roets & Van Hove, 2003; Van Puyenbroeck & Maes, 2004). Life story work can assist direct support staff to get to know the needs of the person with an intellectual disability better (Meininger, 2003).

The more severe the impairment of an individual, the more important it is to use creative and accessible methods that do not rely primarily on verbal communication and content. Life stories can include various media such as a photo-album, an audio account, a video report, or a 'memory box,' which uses physical objects to represent memories. The concept of multimedia life stories using computer technology is particularly interesting to further explore and develop. For example, after having worked with a facilitator to create the life story, persons with limited or no verbal communication can be in control of presenting it by simply pressing keys on the computer keyboard (or any number of alternative input devices). As sound is very important to most persons, being able to include music and sounds in a multimedia life story can make it a more animated and more personal experience (Aspinall, 2010).

Conclusion

While adults with intellectual disabilities experience the same transitions associated with later life as the general population and have many similar support needs, they also have unique needs and considerations. In addressing major transitions such as retirement, changes in social networks, and death and dying, strategies that bolster person-centered services and supports that use inclusive methods can facilitate aging well for persons with intellectual disabilities. Promising practices that are showing success in navigating these transitions include peer-mentored future planning, active mentored retirement planning, social networking, and life story telling. Future research should focus on further implementation, testing, and refining of these strategies.

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Index

A
AAC, *See* Augmentative and Alternative Communication (AAC)
AAIDD, *See* American Association on Intellectual and Developmental Disabilities (AAIDD)
ABA, *See* Applied Behavior Analysis (ABA)
ABDS, *See* Adaptive Behavior Diagnostic Scale (ABDS)
ABLE Act, *See* Achieving a Better Life Experience (ABLE) Act
Accelerometers, 174
Acceptance and Commitment Therapy (ACT), 66, 70, 74
Achieving a Better Life Experience (ABLE) Act, 343
ACT, *See* Acceptance and Commitment Therapy (ACT)
Action-control beliefs, 52, 54
Active treatment goals, 105–107
Activities/exercises, 101
Activity engagement, 101, 182, 273, 278
ADA, *See* Americans with Disabilities Act of 1990 (ADA)
Adaptability, 317–318
Adaptive behavior, 201–213
  assessing, 203–204
  defined, 201
  respondents, 209
    adaptive behavior deficits, 211–212
    measurement error, 213
    objective assessment, 212
    retrospective assessment, 209–211
    typical performance, 212
  skills, 201
  standardized scales, 204–209
Adaptive Behavior Assessment System—3rd Edition (*ABAS-3*), 204–205, 212
Adaptive Behavior Diagnostic Scale (ABDS), 207
Adaptive functioning and intellectual functioning, relationship between, 202–203
Adaptive responses, microswitch-based programs for, 270–271
ADMS, *See* Adolescent Decision-Making Scale (ADMS)
Adolescent Decision-Making Scale (ADMS), 150, 156
Adolescents
  friendship, 135–136
  with intellectual and developmental disabilities
    career exploration and development, 316–319
    interventions to support positive decision-making outcomes with, 161–162
  life design dimensions in, instruments addressing, 319–321
Adults
  friendship, 135
  with IDD, interventions to support positive decision-making outcomes with, 158–161
Advanced Directives, 251
Affiliation, 127
AFFORD, *See* Australian Foundation for Disability (AFFORD)
Age/aging, 341, 357–367
  death and dying, 363
  future planning, 363–366
  with intellectual and developmental disabilities, 358
    late life transitions, 360
    life course perspective, 359–360
  life story work, 365–366
  population, 357–358
  retirement, 342
    intellectual and developmental disabilities, 348
  social networks and, 361–362, 364–365
  Transition to Retirement, 360–361
Agency, defined, 91
Agentic action, 52, 54
Age-specific patterns of decision making, 154–158
Aggression, 87
Aging in place, 342–343
Alcohol, tobacco, or other drugs (ATOD), 146, 156
Ambulation
  fostering, by microswitch-based programs, 267–269
American Association on Intellectual and Developmental Disabilities (AAIDD), 17, 82, 201–204, 208–211
American Association on Mental Deficiency, 16
American Association on Mental Retardation, 15, 17, 28
American Civil Liberties Union, 250–251
American Institutes for Research (AIR) Self-Determination Scale, 42
American Psychiatric Association (APA), 200, 201
Americans with Disabilities Act of 1990 (ADA), 17, 31, 33, 82, 225
Anxiety, 164

K.A. Shogren et al. (eds.), *Handbook of Positive Psychology in Intellectual and Developmental Disabilities*, Springer Series on Child and Family Studies, DOI 10.1007/978-3-319-59066-0

APA, *See* American Psychiatric Association (APA)
Apple iPod Touch, 272
Applied Behavior Analysis (ABA), 74, 85, 174, 176, 178, 180, 181, 183
Appreciation of beauty and excellence, 191
Approach goals, 232
The Arc's Self-Determination Scale, 42
ASAN, *See* Autistic Self-Advocacy Network (ASAN)
ASD, *See* Autism Spectrum Disorder (ASD)
Assessment Scale for Positive Character Traits–Developmental Disabilities (ASPeCT-DD), 43, 319
Assisted ambulation, 267–269
Assisting and teaching, 101
Assistive technology, 182, 261–279
  microswitch-aided programs, 274–276
  microswitch-based programs, 262, 264–267
    to foster assisted ambulation, 267–269
    to increase adaptive responses and curb problem behaviors or postures, 270–271
  orientation cues and stimulation, 272–273
  SGDs-aided programs, 276
  speech-generating devices' problems in promoting communication, 271–272
  technology-aided programs
    for basic activity or assembly tasks and mobility, 276–277
    for contact or communication with distant partners, 277–278
  technology packages, for promoting contact/communication with distant partners, 274
Athletic games, 176
ATOD, *See* Alcohol, tobacco, or other drugs (ATOD)
Attention, 109
Attitude, 109
Audio cues within video, 304–305
Augmentative and Alternative Communication (AAC), 138
Australian disability support pension, eligibility for, 343–344
Australian Foundation for Disability (AFFORD), 349
Autism Spectrum Disorder (ASD), 7, 83
  and adaptive behavior, 204
  assistive technology and, 272
  behavioral skills training and, 302
  and character strength, 194–197
  and cognition, 149
  computer simulations and, 300
  and courage, 319
  and decision making, 154–157, 161–162, 164, 165
  and exercise, 175–177
  and friendship, 131–136, 138, 139
  and leisure activity, 178, 179
  mindfulness-based programs for, 66–67, 70–72
  and prompting, 299
  and strengths-spotting, 193
  and vocational exploration, 314
Autistic Self-Advocacy Network (ASAN), 139
Autonomous motivation, promoting, 89
Autonomy, 101, 286
Autonomy-supportive environments, 61, 289, 290, 291
Autonomy-supportive instructional strategy, 49, 54
Aware-Explore-Apply model, 194, 196
Awareness, 109

B
Basic psychological needs, 286–287
Behavioral health, 70, 81
Behavioral interventions, 173–183
  exercise, 174–177
  leisure skills, 177–179, 182
  organization-wide, 84, 90, 91
  physical well-being, 179–181
  practice and research directions, 181–183
  research basis for practice, 174
  school-wide, 84, 131
Behavioral psychology, 174
Behavioral Skills Training (BST), 181, 301–302
Behavior support plans, developing, 88
Benefit finding, 87–88
Bereavement, 363
Best Buddies, 136
Best practices, operational definition of, 120
Bike riding, 176
Bill of Rights, 224, 225
Biopsychosocial model, 16–17
Blatt Institute, 256
Borderline Personality Disorder (BPD), 71
BPD, *See* Borderline Personality Disorder (BPD)
Brainstorming Guide, 251
Bravery, 190
British Columbia
  Supported Decision-Making, 252–254
BST, *See* Behavioral Skills Training (BST)
Bush, George H.W., 31

C
CAIMI, *See* Children's Academic Intrinsic Motivation Inventory (CAIMI)
Capacity-challenge discrepancy analysis, 234
Career, *See also* Employment
  adaptability, 317–318
  assessment instruments, for children and preadolescents, 315–316
  design, 311–323
  development, 311–323
  exploration, 313–314
  preparedness, 318–319
Career Adapt-Abilities Scale, 319
Career and Work Adaptability, 320
Career Exploration Scale, 315
Career Preparedness Questionnaire, 320
Career Style Interview, 320
Caregiver mindful engagement support worksheet, format of, 110
Care-provider training, 173, 181

Caring, 312
Causal agency, 51
Causal Agency Theory, 49, 51–52, 231, 232
  component elements of, 54
  practices to promote self-determination and, 53–62
  self-determination, development of, 52–53
Centers for Medicare and Medicaid Services (CMS), 98
Character, 312
Character strengths, 89, 189–197
  intellectual and development disabilities and, 194–196
    character strength assessment, 195
    interactive behavioral therapy, 195–196
  interventions to enhance, 192–194
    Aware-Explore-Apply model, 194
    to promote other strengths, 193–194
    signature strengths, promoting, 193
    strengths-spotting, 192–193
Child friendship training model, 136
Children
  career assessment instruments for, 315–316
  with/without disability, career education programs for, 321–322
Children's Academic Intrinsic Motivation Inventory (CAIMI), 288
Children's Hope Scale (CHS), 43, 316
Choice, 108
Choice making, 50
CHS, *See* Children's Hope Scale (CHS)
Circle of Support d, 251
Citizenship skills, 224–225
Civil rights laws, 31
Civil rights movement, 17
CMPPA, *See* Comprehensive Model of Positive Psychological Assessment (CMPPA)
CMS, *See* Centers for Medicare and Medicaid Services (CMS)
Coaching, 83
Cognition, role in interpersonal decision making, 149
Communication, 271–272, 274, 277–278
Communicative competency, 138
Community living skills, teaching, 297–307
  audio cues within video, 304–305
  behavioral skills training, 301–302
  computer simulations, 299–301
  picture prompting strategies, 305
  prompting, 298–299
  simulated environments, 301–302
  video modeling, 302–303
  video prompting, 303–304
Community placements, 68
Community services, 25–27
Community vocational center, 27
Compassion, 18
Competence, 286, 311–312
Competency, communicative, 138
Component behaviour, 306
Comprehension, 154
Comprehensive Model of Positive Psychological Assessment (CMPPA), 38, 39
Computer simulations, 299–301
Concept-Oriented Reading Instruction (CORI), 288
Confidence, 312
Congenital hypothryroidism, 25
Constitution of the United States, 224, 225
Control, 108
Copernican Revolution, 23
CORI, *See*Concept-Oriented Reading Instruction (CORI)
Counseling psychology, 38
Courage, 189, 190, 319, 320
CREATE engagement
  opportunities, 107–109
  plans, developing, 109–111
Creativity, 6, 18, 190
CREVT-2, 149
Critical interests, 111
Cultural context, 129, 220
Curb problem behaviors, microswitch-based programs for, 270–271
Curiosity, 18, 108, 190, 193
Cyberbullying, 151–153, 166

D
DABS, Diagnostic Adaptive Behavior Scale (DABS)
Danger to self and others, 91
Daytime sleeping, 180
DBT, *See* Dialectical Behavior Therapy (DBT)
Deaf-blindness, 83
Death and dying, 363
Decision making, 18, 50, 218
  interpersonal, role of positive psychology in, 145–167
Deficit-based models of psychology/disability, 4–5, 37
Deinstitutionalization, 25–27, 202
Delayed retirement, 342
Delayed sleep onset, 180
Developmental disabilities, *See* Intellectual and developmental disabilities (IDD)
Diagnosis, 4
Diagnostic Adaptive Behavior Scale (DABS), 207–208
Diagnostic and Statistical Manual of Mental Disorders, 2nd edition (*DSM-2*), 201
Diagnostic and Statistical Manual of Mental Disorders, 5th edition (*DSM-5*), 191, 211
Diagnostic Manual-Intellectual Disability, 191
Dialectical Behavior Therapy (DBT), 71
Digital devices, 178–179
Disability
  deficit-based models in, 4–5
Disability-specific patterns of decision making, 154–158
Disability Support Pension (DSP)
  eligibility for, 343–344
Discriminative stimulus (S^D), 297, 298
Disruptive bedtime routines, 180
Down syndrome, 312

DSP, *See* Disability Support Pension (DSP)

E
EBPs, *See*Evidence-Based Practices (EBPs)
Education friendship, 131–132
Education regulations, 32–33
Elementary school friendship, 134–135
Emotion(s)
  expressive, 19
  recognition, 164
  role in interpersonal decision making, 150–154
Emotional intelligence, 6
Emotional well-being, 18
Employment
  peoples with intellectual and developmental disabilities, 332–334
    possibilities for, 334–336
  supported and customized, 329–336 *See also* Career; Work
Employment First, 332–333
Employment friendship, 130–131
Empowerment, 50
End-of-life care, for peoples with intellectual disabilities, 363
Energy, 109
Engagement, 101
Environment, 108–109
Environmental modification, 28–29
ESCAPE-DD, 158–159, 222
ESCAPE-NOW, 159–160, 162, 166, 167, 222
Evaluation standards, 120–122
  quality of evidence, 121
  relevance of evidence, 121–122
  robustness of evidence, 121
Evidence
  operational definition of, 120
  into practice, systematic approach to translating
    dialog and partnership, 122
  quality of evidence, 121
  relevance of evidence, 121–122
  robustness of evidence, 121
    guidelines for, 122
Evidence-Based Practices (EBPs), 119–120
  operational definition of, 120
Evidence-gathering strategies, 120, 121
Exercise, 101, 174–177
Exergaming, 177, 182
Expressive emotions, 19

F
FA. *See* Functional Analysis (FA)
Fairness, 190
Family support, 7
FBA, *See* Functional Behavior Assessment (FBA)
Feeblemindedness, 14, 24
Flexibility, 312
Forensic settings, 68–69
Forgiveness, 190
Friendship, 127–140
  individual, 138–140
  interpersonal, 133–137
  networks, 154
  organizational, 130–133
  promoting, 129
  societal, 129–130
Functional Analysis (FA), 173
Functional Behavior Assessment (FBA), 85–89, 173
Future planning, 363–366

G
General satisfaction, 19
Global Challenge Insight Report (World Economic Forum), 311
Goal
  accomplishment, 238
  action schema, 233
  attainment, 18, 50, 62, 231–234
    intellectual and developmental disabilities and, 235
    teaching, 239–240
  measurement, 238
  orientation, 150, 154, 164
  setting, 18, 50, 220, 231–234
    barriers to, 238
    intellectual and developmental disabilities and, 235
    skills, teaching, 238–239
Goal attainment, 55, 235, 239–240
Goal-directed action, 218, 231, 232
Goal-discrepancy analysis, 234
Goal-generation process, 234
Goal setting, 235, 238–239
Go Talk 9, 271
Gratitude, 191
Group home managers, 87
Guardianship, 247–256

H
Happiness, 5, 18, 330–331
  in challenging work, finding, 90–91
HCBS, *See* Home and Community-Based Waiver Services (HCBS)
Health and wellness, 69
  role of Self-Determination Theory, 289–290
Heart rate monitors, 174
Home and Community-Based Waiver Services (HCBS), 31–32
Honesty, 190
Hope, 191, 314–315, 321
Human functioning, 16–17
  multi-dimensional framework of, 39–40
Humanity, 189, 190
Humility, 190
Humor, 191

Hypersomnia, 180

I

IBT, *See* Interactive Behavioral Therapy (IBT)
ICD, *See* International Classification of Diseases, Injuries, and Causes of Death (ICD)
ICF, *See* International Classification of Functioning, Disability, and Health (ICF)
ICIDH, *See* International Classification of Impairments, Disabilities and Handicaps (ICIDH)
IDD, *See* Intellectual and Developmental Disabilities (IDD)
IDEA, *See* Individuals with Disabilities Education Act of 2004 (IDEA)
Idiot, 13–14
IEP, *See* Individualized Education Program (IEP)
ILP, *See* Individual Life Plan (ILP)
Impulsivity, 154
Inattention, 174
Inclusion, 27, 127, 365
Inclusive education, 29
Inclusive Service Delivery (ISD), 179
Independence, 116
Independence and skill building, 101
Individualized Education Program (IEP), 39, 219, 221, 225
Individualized routines, 101
Individualized support plans, *See also*Mindfulness-Based Individualized Support Plan (MBISP), 38, 41
Individualized supports, 29
Individual Life Plan (ILP), 100
Individual Support Plan (ISP), 99
  distinguished from Mindfulness-Based Individualized Support Plan, 100, 101–102
Individuals with Disabilities Education Act of 2004 (IDEA), 32, 33, 39, 82, 219, 221, 225
Individuals with IDD, *See* Intellectual and Developmental Disabilities (IDD)
Institutionalized schedule, 101
Institutional life, 26
Intellectual and Developmental Disabilities (IDD), 66–70
  and character strength, 194–196
  CREATE engagement plans/opportunities for, 107–111
  and goal attainment, 235
  and goal setting, 235
  parents, role of, 70–72
  and problem solving, 219–220
  and retirement, 343–344
  and self-advocacy, 220–222
  Self-Determination Theory, 290–291
  and self-regulation, 236–237
  support providers, role of, 72–74
  teachers, role of, 74–75
Intellectual disabilities, 361–362, 363
Intellectual functioning and adaptive functioning, relationship between, 202–203
Intelligence, 154, 164
  mathematical-logical, 193
  social, 190, 193
  spatial, 193
Interactive Behavioral Therapy (IBT), 195–196
Interests, 111
Internal attribution beliefs, 153
International Classification of Diseases, Injuries, and Causes of Death (ICD)
  ICD-10, 14–15
  ICD-9, 14–16
International Classification of Functioning, Disability, and Health (ICF), 16–17, 27
International Classification of Impairments, Disabilities and Handicaps (ICIDH), 15, 16, 27
Interpersonal decision making, role of positive psychology in, 145–167
  applications of, 162–163
  cognition, 149
  disability-specific and age-specific patterns, 154–158
  emotions, 150–154
  motivation, 149–150
  outcomes
    adolescents with IDD, interventions to support, 161–162
    adults with IDD, interventions to support, 158–161
  Pathways Model of Decision Processing, 146–148
  personality, 150–154
  research and practice, new directions for, 163–167
Interpersonal friendship, 133–137
Interpretive Guidelines for ICF/IID State Operations Manual, 98
Intervention integrity, 173
Intrinsic motivation, 285–291
Involuntary retirement, 341–342
ISD, *See* Inclusive Service Delivery (ISD)
ISP, *See* Individual Support Plan (ISP)
Israel
  Supported Decision-Making, 254
Item Response Theory (TRT), 208

J

Job coaches, 87
Job Knowledge Survey, 315
Job security. *See also* Career; Employment, 347
Judgment, 190
Justice, 189, 190

K

Kansas University Center on Developmental Disabilities, 256
Kindness, 190

L

Language functioning, 164
Late life transitions, among people with intellectual and developmental disabilities, 360

Leadership, 190
  skills, 225–226
LEAP model, 134
Learning disabilities, 82
Legal rights, 224–225
Leisure
  friendship, 132–133
  and mainstream employment, 347
  skills, 177–179, 182
Life course perspective, to aging with intellectual and developmental disabilities, 359–360
Life design dimensions, 319–321
Life expectancy, 15
Life Orientation Test, 316
Life Orientation Test-Revised (LOT-R), 43
Life Outcomes Through Integrated Systems (LOTIS), 86, 91
Life preparedness, 318–319
Life story work, 365–366
Locus of control, 153, 154, 164
Loneliness, 127
Long-term goals, 106
LOTIS, *See* Life outcomes through integrated systems (LOTIS)
Love, 7, 190
Love of learning, 190

M
Mainstream employment
  attitudes about retirement, 346
  job security, 347
  part-time work, 347
  retirement interventions, 351–352
  social connections and leisure participation, 347
  travel issues, 347
  views about retirement finances, 346–347
Making friends, 364
MAPS, *See* McGill Action Planning System (MAPS)
Massachusetts
  Supported Decision-Making, 255
Mastery goals, 232
Mathematical-logical intelligence, 193
Mature defenses, 6
MBCT, *See* Mindfulness-Based Cognitive Therapy (MBCT)
MBISP, *See*Mindfulness-Based Individualized Support Plan (MBISP)
MBPBS, *See*Mindfulness-Based Positive Behavior Support (MBPBS)
MBSR, *See*Mindfulness-Based Stress Reduction (MBSR)
McGill Action Planning System (MAPS), 97
Mediation by significant others, 136–137
Medicaid
  Home and Community-Based Waiver Services, 31–32
Medical-Institutional Paradigm, 24–25
  advances in prevention and instruction, 25
Medical model, 14–16
Meditation
  on soles of the feet procedure, 67–70
Mental deficiency, 4, 14, 24
Mental health, 7
Mental retardation, 4, 14, 24, 202
  defined, 15–16
Mental subnormality, 4
MES, *See* Mindful Engagement Support (MES)
Micro Board, 251
Microswitch-aided programs, 274–276
Microswitch-based programs, 262, 264–267
  to foster assisted ambulation, 267–269
  to increase adaptive responses and curb problem behaviors or postures, 270–271
Microswitches, 177, 261–262, 264–266, 268–271, 275
Mindful engagement, 99
Mindful Engagement Support (MES), 107, 110
Mindfulness, 4, 89, 98–99
  in action, 99–100
  -based programs, 65–75
Mindfulness-Based Cognitive Therapy (MBCT), 66–67, 71
Mindfulness-Based Individualized Support Plan (MBISP), 97–111
  brief instructions for developing, 102, 104–107
    active treatment goals, 105–107
    person information, 104–105
    rights restoration, 107
    service plans, 107
    team leader monthly update, 107
    team meeting update, 107
  distinguished from individual support planning, 100, 101–102
  Interpretive Guidelines for ICF/IID State Operations Manual, 98
  peoples with intellectual and developmental disabilities, supporting
    CREATE engagement opportunities, 107–109
    CREATE engagement plans, developing, 109–111
  template, 100, 102, 103–105
Mindfulness-Based Positive Behavior Support (MBPBS), 73
Mindfulness-Based Stress Reduction (MBSR), 65, 66, 71
Mindfulness-Based Therapy for Autism Spectrum Disorder (MBT-AS), 66–67
Mindful Observation of Thoughts meditation procedure, 69
Mobile health (mHealth), 69
Moderate-to-Vigorous Physical Activity (MVPA), 175, 182
Motivation
  autonomous, promoting, 89
  intrinsic, 285–291
  role in interpersonal decision making, 149–150
MSLSS, *See* Multidimensional Life Satisfaction Scale (MSLSS)
Multidimensional Life Satisfaction Scale (MSLSS), 43
Multipurpose institutions, 25
MVPA, *See*Moderate-to-Vigorous Physical Activity (MVPA)

N
National Guardianship Association (NGA), 250
National Institute of Mental Health, 5
National Resource Center for Supported Decision-Making (NRC SDM), 254–255
NCBC, *See* Next Chapter Book Club (NCBC)
Next Chapter Book Club (NCBC), 132
NGA, *See* National Guardianship Association (NGA)
Night awakenings, 180
Non-compliance, 174
Normalization, 25, 49–50, 85
  guidelines, 26
Normalization-Community Services Paradigm, 25–27
  deinstitutionalization and community services, 25–27
  normalization, 25
Nowicki-StricklandInternal-External Scales (ANS-IE), 43
NRC SDM, *See* National Resource Center for Supported Decision-Making (NRC SDM)
Nuggets of Optimism and Hope to School, 322

O
Occupational Knowledge Interview, 315–316, 322
Occupational Mindfulness (OM), 73–74
Office of Special Education Programs (OSEP), 50
OM, *See* Occupational Mindfulness (OM)
Optimal experience, 5
Optimism, 5, 18, 312, 315, 321
  in challenging work, finding, 90–91
Optimism-Pessimism Test Instrument, 316
Organizational friendship, 130–133
Organizations
  positive culture and consistent expectations in, creating, 90
Organization-Wide Positive Behavioral Interventions and Supports (OWPBIS), 84, 90, 91
OSEP, *See* Office of Special Education Programs (OSEP)
Outcomes, operational definition of, 120
Outerdirectedness, 291
OWPBIS, *See*Organization-Wide Positive Behavioral Interventions and Supports (OWPBIS)

P
Palliative care, 15
Paradigmatic shifts, 23
Parental friendship, 136–137
Parent–child interactions, 88
Participation, 101
Participation restrictions, 16
Part-time work, 347
PATH, *See* Planning Alternative Futures with Hope (PATH)
Pathways Model of Decision Processing, 146–148
PBIS, *See* Positive Behavior Interventions and Supports (PBIS)
PCS, *See* Performance Cue System (PCS)
Pedometers, 174
PEER-DM (Peers Engaged in Effective Relationships—Decision-Making) curriculum, 161, 162, 166, 167
Peer leaders, 135
Peer-mediated intervention, 133–136
PEERS, 136, 138
People First, 335
Performance Cue System (PCS), 302
Performance goals, 232
Performance measurement, 83
PERMA framework, 343
Perseverance, 190
Personal agency beliefs, 154
Personality, role in interpersonal decision making, 150–154
Person-centered planning, 97, 98, 364, 365
Person-environment fit models of disability, 17, 28–29, 39, 145
Person information, 104–105
Perspective, 190
Phenylketonuria (PKU), 25
Physical well-being, 179–181, 183
Picture cues, 180
Picture prompting strategies, 305
PKU, *See* Phenylketonuria (PKU)
Planning Alternative Futures with Hope (PATH), 365
Planning for retirement, 342
Policies, retirement, 342–343
Positive Behavior Interventions and Supports (PBIS), 81–92
  in context, 87–89
  description and evolution of, 83–85
  envisioning, 81–83
  foundations of, 85
  functional behavior assessment, 87–89
  future research and practice, directions for, 91–92
  happiness and optimism in challenging work, finding, 90–91
  positive culture and consistent expectations in organizations, creating, 90
  across settings, implementing, 85–87
  strengths based approaches for team members, promoting, 87
Positive behavior support
  building positive, healthy, inclusive communities with, 81–92
Positive emotions, 189
Positive functioning, 18–19
Positive, healthy, inclusive communities with positive behavior support, building, 81–92
  envisioning, 81–83
  functional behavior assessment, 87–89
  future research and practice, directions for
    moving research into practice, 91–92
    quality of life outcomes, enhancing, 91
  happiness and optimism in challenging work, finding, 90–91

interventions and supports
  description and evolution of, 83–85
  foundations of, 85
 PBIS across settings, implementing, 85–89
 positive culture and consistent expectations in organizations, creating, 90
 strengths based approaches for team members, promoting, 87
Positive identity, 139–140
Positive institutions, 189
Positive mindset, 314–315
Positive psychology, 3–9
 alignment with disability field, 7
 emergence of, 5–6
 to intellectual and developmental disabilities, assessment of, 37–44
 pillars of, 5
 and quality of life, similarities between, 116
 role in interpersonal decision making, 145–167
 work and
  happiness, 330–331
  resiliency, 332
  social capital, 331–332
  well-being, 331
Positive reinforcement, 178, 180, 181
Positive relationships, 189
Positive traits, 189
Positive Youth Development (PYD), 311–312
Post-intervention maintenance, 174
Postures, microswitch-based programs for, 270–271
Power of Attorney, 251
Practices, operational definition of, 120
Preadolescents, career assessment instruments for, 315–316
Preference assessment, 108, 178
Preschool friendship, 134
Prevention, 25, 108, 183
Problem behaviors, 72, 86, 87, 270–271, 275
Problem-solving, 18, 50
 defined, 217–218
 general instruction, 222–223
 intellectual and developmental disabilities and, 219–220
 interventions to promote, 222
Professionals friendship, 137
Proloquo2Go software, 272
Prompt-fading, 178
Prompting, 178, 298–299
 picture, 305
 strategies, 299
 video, 303–304
Prudence, 190
Psychological well-being, 18, 19, 341
Psychology
 behavioral, 174
 counseling, 38
 deficit-based models in, 4–5
 positive, *See* Positive psychology
Psychosis, 155
Ptolemaic paradigm, 23
Public policies, 31–33
Punishment vs. reward, 166
PYD, *See* Positive Youth Development (PYD)

Q
QIDP, *See* Qualified Intellectual Disabilities Professional (QIDP)
QOL, *See* Quality Of Life (QOL)
Qualified Intellectual Disabilities Professional (QIDP), 107
Quality enhancement strategies, 122
Quality Of Life (QOL), 7, 115–123
 application fidelity, 117–118
 conceptual model, 116–117
 domains of, 116–117
 enhancement strategies, 117–119
 evaluation standards, 120–122
 evidence-based practices, establishing, 119–120
 evidence-gathering strategies, 120, 121
 evidence into practice, systematic approach to translating, 122
 moderator and mediator variables, 117, 118
 outcomes, 91
 personal outcomes, 119
 and positive psychology, similarities between, 116
 research, 118–119
Quality Trust for Individuals with Disabilities, 250–251, 256

R
REACT, *See* Recreation Experience Activity Club for Teens (REACT)
Reaction, 101
Recreational activities, 179
Recreation Experience Activity Club for Teens (REACT), 132
Regret prevention, 108
Rehabilitation, 7
Rehabilitation Act
 Section 504, 225
Reinforcement, 108, 111
 positive, 178, 180, 181
Relatedness, 286
Reminiscence, 365–366
Residential friendship, 130
Resiliency, 332
Response, 101, 108, 111
Retirement, 339–352
 age, 341, 348
 defined, 340
 delayed, 342
 importance of, 340
 involuntary, 341–342
 of peoples with intellectual and developmental disabilities, 343–344
  age of retirement, 348

effective approaches to, 348–351
mainstream employment, 346–347
sheltered employment, 344–346
planning for, 342
policies about, 342–343
views about, 342, 344
voluntary, 341–342
Revised Career Awareness Survey, 315
Rewards, 177
ability to forecast, 154
vs. punishment, 166
Reward-seeking, 157
Right mindfulness, 99–100
Rights restoration, 107
Risk perception, 164
Risk taking, 157, 166
Role-playing, 223
Rumination disorder, 180

S
Sati, 65, 99
Satisfaction With Life scale (SWL), 43
Scales of Independent Behavior—Revised (*SIB-R*), 207
School-Wide Positive Behavioral Interventions and Supports (SWPBIS), 84, 131
SDCDM, *See*Self-Determined Career Development Model (SDCDM)
SDIEP, *See*Self-Directed Individualized Education Program (SDIEP)
SDLMI, *See*Self-Determined Learning Model of Instruction (SDLMI)
SDM, *See* Supported Decision-Making (SDM)
SDS, *See* Society for Disability Studies (SDS)
SDT, *See*Self-Determination Theory (SDT)
Self-advocacy
defined, 218–219
intellectual and developmental disabilities and, 220–222
movement, 50
promoting, 224–227
skills, general, 219, 220–221, 224–226
through student involvement, 219, 221–222, 226, 227
Self-Advocates Becoming Empowered, 335
Self-appraisal, 218
Self-concept, 154
Self-determination, 5, 31, 49–62, 83, 321
on academic and transition outcomes, impact of, 55–62
assessment, 41–42
Causal Agency Theory, 52–62
defined, 51, 231
in intellectual and developmental disability field, emergence of, 49–52
about retirement, 346, 349, 351
Self-Determination Inventory System, 42
Self-Determination Theory (SDT), 49, 247, 285
applications of, 287–291
health and wellness, 289–290
intellectual development and disabilities, 290–291
work, 290
basic psychological needs, 286–287
Self-Determined Career Development Model (SDCDM), 54–55, 59–62
Self-Determined Learning Model of Instruction (SDLMI), 54–58, 62, 220, 222, 237
Self-directed approaches, 133
Self-Directed Individualized Education Program (SDIEP), 226
Self-directed supports, 31–32
Self-direction, 83
Self-efficacy, 153
Self-esteem, 153
Self-evaluation, 236
Self-evaluation skills, teaching, 243
Self-injury, 87
Self-instruction skills, teaching, 240–241
Self-knowledge, 312
Self-monitoring, 180, 236
skills, teaching, 241–243
Self-regulatedproblem-solving skills, 220
Self-regulation, 190, 312
defined, 234
of emotions, 161
intellectual and developmental disabilities and, 236–237
multicomponent strategies, 236–237
skills, teaching, 240–243
strategies, 236
theory, regulatory functions in, 234–235
Self-reinforcement, 236
Service plans, 107
SGDs, *See*Speech-Generating Devices (SGDs)
Sheltered employment
attitudes about retirement, 344–345
retired employees, views of, 346–347
self-determination about retirement, 346
views about retirement finances, 345
Short-term goals, 106–107
Signature strengths, promoting, 193
Simulated environments, 301–302
Simulation, computer, 299–301
SIS, *See* Supports Intensity Scale (SIS)
SIS-Adult Version (SIS-A), 41
SIS-Children's Version (SIS-C), 41
Sleep hygiene, 180
Smoking, 69
Social belonging, 154
Social capital, 331–332
Social competence, 203
Social-connectedness, 127
Social connections, and mainstream employment, 347
Social-ecological model, 16, 39, 82, 255
Social intelligence, 190, 193
Social justice, 321
Social knowledge, 138–139
Social learning theory, 174
Social model, 16

Social networks
  and aging, 361
  interventions, 364–365
  of older peoples with intellectual disabilities, 361–362
  of peoples with intellectual disabilities, 361
Social participation, 116
Social problem-solving skills, 223
Social validity, 174
Social well-being, 18, 127, 130, 341
Societal friendship, 129–130
Society for Disability Studies (SDS), 139
Socio-ecological model, 16, 39, 145
SoF procedure. *See* Soles of the Feet (SoF) procedure
Soles of the Feet (SoF) procedure
  meditation on, 67–70
Solidarity, 321
Spatial intelligence, 193
Special Olympics, 132, 176
Speech-Fenerating Devices (SGDs), 261, 262, 278
  -aided programs, 276
  problems in promoting communication, 271–272
Spirituality, 18, 191
Stereotypy, 174
Strengths-based approaches
  to intellectual and developmental disabilities, 13–20, 39–42
    different and pathological, 13–14
    human functioning, 16–17
    medical model, 14–16
    self-determination assessment, 41–42
    support needs assessment, 40–41
  for team members, promoting, 87
Strengths-spotting, 192–193
Student involvement, self-advocacy through, 219, 221–222
Student–teacher relationship, 87
Subjective well-being, 5, 19, 342
  defined, 18
Substance use, 180
Support, 101
Supported Decision-Making (SDM)
  as alternative to guardianship, 247–256
  American models, 254–255
  British Columbia, 252–254
  case study, 252–254
  design of, 255
  Israel, 254
  next-generation research on, 256
  in practice, 250–252
Supported Decision-Making Brainstorming Guide, 250
Supported employment, 30–31
Supported living, 29–30
Support needs, 29
  assessment, 40–41
Support providers, 87, 88–89
  of individuals with intellectual and developmental disabilities, 72–74
Supports friendship, 137
Supports Intensity Scale (SIS), 40–41
  Adult Version, 40
  Children’s Version, 40
Supports Paradigm, 24, 27–33
  inclusive education, 29
  person-environment fit models, 28–29
  public policies, 31–33
  self-determination, 31
  Supported Employment, 30–31
  supported living, 29–30
Supports planning, 40, 43, 197, 329
Swimming, 176
SWL, *See* Satisfaction With Life scale (SWL)
SWPBIS, *See*School-Wide Positive Behavioral Interventions and Supports (SWPBIS)

T
Task analysis, 176, 178, 297–298, 301, 305
Task demands, 109
Teachers, 74–75
Teachers friendship, 137
Teaching, 83
  assisting and, 101
Team leader monthly update, 107
Team meeting update, 107
Teamwork, 190, 225–226
Technology-aided programs
  for basic activity or assembly tasks and mobility, 276–277
  for contact or communication with distant partners, 277–278
Technology packages, for promoting contact/communication with distant partners, 274
Telehealth, 69–70, 182
Temperance, 189, 190
Texas
  Supported Decision-Making, 255
‘The Future if Now’, 364
Transcendence, 189, 191
Transition to Retirement (TTR) project, 340, 345, 348–351
  active monitoring, 349
  aging, 360–361
  implementation costs, 351
  inclusive practice manual, 351
  intervention, 349
  program flow chart, 350
  self-determination, 349, 351
Travel issues, and retirement, 347
Treatment teams, 98
TRT, *See* Item response theory (TRT)
TTR project, *SeeTransition to Retirement* (TTR) project

U
UDL, *See* Universal Design for Learning (UDL)

U.N. Convention on the Rights of Persons with Disabilities, 123
UNCRPD, *See* United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 248–249
  Article 3, 82
  Article 24, 82
Universal design for learning (UDL), 29
US Department for Health and Human Services
  Administration on Community Living, 249–250
US Department of Education
  Office of Special Education Programs, 50

V
Values in Action (VIA) classification system, 6, 42–43
  VIA Inventory of Strengths, 43
  VIA Inventory of Strengths for Youth, 43
Veterans Administration, 5
VGV, *See* Virtual Gratitude Visit (VGV)
VIA-120, 191
VIA-72, 191
VIA *Classification of Character Strengths and Virtues*, 189–191
VIA classification system, *See* Values in Action (VIA) classification system
VIA *Inventory of Strengths* (VIA-IS), 43, 191–192, 195
VIA *Inventory of Strengths for Youth* (VIA-Youth), 43, 192, 195
VIA Survey, 193
Video modeling, 178, 180, 181, 302–303
Video prompting, 178, 303–304
Vineland Adaptive Behavior Scale—2nd Edition (*Vineland-II*), 205–206
Vineland Social Maturity Scale, 203
Virtual Gratitude Visit (VGV), 196
Visions about the Future, 316, 317
Vocational development, 312–313
Vocational exploration, 313–314
Voice Output Communication Aids (VOCAs), *See*-Speech-Generating Devices (SGDs)
Volitional action, 52, 54
Voluntary retirement, 341–342
Volunteering, 340, 342

W
Walking. *See also* Ambulation, 177
Well-being, 116, 331
  emotional, 18
  physical, 179–181, 183
  psychological, 18, 19, 341
  social, 18, 127, 130, 341
  subjective, 5, 18, 19, 342
We the People, 225
WFA, *SeeWhose Future is it Anyway?* (WFA)
What Will Happen to Me?, 316
WHO, *See* World Health Organization (WHO)
Whose Future is it Anyway? (WFA), 226–227
Wisdom, 6, 189, 190
Work, *See* Career; Employment
  happiness and optimism in, finding, 90–91
  and positive psychology
    happiness, 330–331
    resiliency, 332
    social capital, 331–332
    well-being, 331
  role of Self-Determination Theory, 289–290
World Economic Forum
  Global Challenge Insight Report, 311
World Health Organization (WHO), 82

Y
YES, *See* Youth Empowerment Services (YES)
Yoga, 179
Young Children's Hope Scale, 316
Youth Empowerment Services (YES), 131
Youth Life Orientation Test, 316

Z
Zest, 190