

Strengths-Based Approaches to Intellectual and Developmental Disabilities

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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. Feeble-minded 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. Feeble-mindedness (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 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 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 & Salvador-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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