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The Construct of Developmental Disabilities

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Developmental disabilities have a history as old as humankind. They have been viewed as possessions by the evil spirits, retributions for past sins, scientifically identified syndromes, culturally situated social phenomena, and portals for accesses to supports and services (Harris, 2006). The construct is dynamic in that (1) it changes over time as scientific knowledge of and cultural perspectives on disabilities evolve and (2) it may serve multiple purposes, with the purposes influencing the specific definition established. Perhaps more importantly, the term "developmental disabilities" is more than an academic concept—it affects the lives of real individuals with a wide array of characteristics and abilities. The purpose of this chapter is to propose a working definition for developmental disabilities, as well as a framework for understanding the construct of developmental disabilities based upon function and purpose, and to examine the future implication for this construct on social policy, practice, and research.

A NOTE ON TERMINOLOGY

A reflection of the dynamic and evolving nature of developmental disabilities is the change that is occurring in terminology, as of this writing. In the United States, developmental disabilities has been broadly construed as an umbrella term that includes other more discretely defined disability classifications sharing some common characteristics. For example, the Administration on Developmental Disabilities (ADD) at one time grouped within the developmental disabilities classification, mental retardation,

autism, cerebral palsy, traumatic brain injury, and epilepsy, with the rationale that people with these disabilities had significant life limitations across several developmental areas. Yet, in the United States, terminology is changing to represent a broader conceptualization. Recently, the American Association on Mental Retardation (AAMR) changed the terminology of its constituent interest to intellectual and developmental disabilities. This change brings the U.S. definition into closer conformity with terminology used in the United Kingdom and other parts of the world, and more in line with the international research organization pertaining to developmental disabilities, the International Association for the Scientific Study of Intellectual Disability (IASSID; see *www.iassid.org/*).

For this chapter, we define developmental disabilities as a set of abilities and characteristics that vary from the norm in the limitations they impose on independent participation and acceptance in society. The condition of developmental disabilities is developmental in the sense that delays, disorders, or impairments exist within traditionally conceived developmental domains such as cognitive, communication, social, or motor abilities and appear in the "developmental period," which is usually characterized as before 22 years of age. While low IQ scores are typically associated with and can even be markers for developmental disabilities, other conditions (e.g., cerebral palsy, Asperger syndrome) may impose limitations on individuals with developmental disabilities whose intelligence is at or above average. Typically, in establishing the parameters of developmental disabilities, limitations associated with sensory impairments (i.e., deafness, blindness) are not folded into the definitions unless these impairments occur in combination with impairment in intellectual functioning (e.g., multiple disabilities). Similarly, the focus on developmental and adaptive abilities may distinguish developmental disabilities from most psychiatric conditions, although it is widely acknowledged that individuals may have a dual diagnosis (see Paschos & Bouras, Chapter 24, this volume for a thorough review).

SOCIAL CONSTRUCTION OF DEVELOPMENTAL DISABILITIES

Having offered a working definition of developmental disabilities, we also have to acknowledge that developmental disability is a social construction. As a species, humans are social beings. The evolution of language as a mode of communication created a capacity to share information and construct a shared sense of what is real in the world. In any discussion, the social construction of reality can be reduced to its most solipsistic form, but to live, work, and exist in the world, most humans come to explicit or tacit agreements about what exists. In fact, this agreement is functional in that it allows society to operate as a social system. Science, one of humankind's most important social constructions, emerged from an Aristotelian tradition based on logic and during the "Age of Reason" evolved into an empirical tradition that gathers information from the world to verify one's understanding of a phenomena. Yet even the understandings we construct from medical science, which is considered a most highly empirical science, change over time. One needs go no further than the cradle of a newborn baby to see an example. Twenty years ago, parents and caregivers would routinely place their babies on their stomachs to sleep, based on medical, scientific advice. Subsequent research found that babies sleeping on their stomachs were more likely to experience

sudden infant death syndrome (SIDS), and in 1992 the American Academy of Pediatrics recommended placing babies on their backs to sleep. Since then there has been a 40% drop in SIDS (Schmidt, 2006). The point here is that as we learn from science, the understandings we construct and that guide our actions sometimes change.

Perhaps a more relevant example may be seen in our understanding of autism. As originally conceived, autism was a psychiatric disorder (Asperger, 1944; Kanner, 1943) with an etiology based in the psychodynamic relationship between the child with autism and his/her mother (Bettelheim, 1967). It was originally proposed as a low incidence disorder (1 to 2 per 10,000 children) and treatment recommendations were psychotherapeutic and focused on "fixing the mother." Scientific evidence related to treatments, as well as reactions of individuals involved in the therapeutic process, have led to a different conceptualization of autism as a broad spectrum of disorders sharing common characteristics, a different perspective on etiology, and an awareness that the incidence is much greater than ever imagined. In the 21st century, the social context of autism is much changed from Kanner's and Asperger's day, yet many children seen in autism diagnostic clinics today bear similar characteristics to those reported by Kanner and Asperger in the 1940s.

The social construction of developmental disabilities allows individuals to communicate in ways that are useful for accomplishing certain purposes. We propose that because of these different purposes, developmental disability is a multidimensional construct. Drawing on an earlier conceptualization of mental retardation by the AAMR (Luckasson et al., 1992), we propose three purposes or functions of this construct: (1) to allow a common framework for further scientific understanding; (2) to qualify individuals for social services like special education or social security through the documentation of life limitations; and (3) to plan for the provision of supports for individuals with certain ability levels. Each of these conceptualizations evolves as new knowledge emerges. In addition, these purposes are not completely independent, so knowledge from one conceptualization of developmental disabilities may well inform other definitions or purposes.

Scientific Purpose: The Value of a Diagnosis

As noted, developmental disability is a summative descriptor for individuals that share common characteristics. While useful when speaking in generalities and for formation of some public policy (see H. R. Turnbull, Stowe, A. P. Turnbull, & Schrandt, Chapter 2, this volume), precise diagnostic definitions are important for identification of etiology, prediction of effects on development or behavior, design of intervention, and organization of scientific programs of study. Accurate diagnostic information is critical for some types of scientific research. In medical research, the determination of the effectiveness of a pharmacological treatment, the association of a certain set of chromosomes, or the reoccurrence of features on structural or functional brain images are made meaningful when individuals' characteristics or phenotypes are precisely defined. In behavioral research, developmental characteristics associated with diagnostic conditions may inform scientific knowledge about cognitive or social processes. Similarly, there is a strong emphasis in psychological and educational research on determining the features or characteristics of individuals with diagnosed developmental disabilities that may predict their response to treatment (see Odom, Rogers, McDougle, Hume, & McGee, Chapter 10, this volume).

Formal diagnostic classification may also be linked to medical treatment or educational decisions. For example, a diagnosis of phenylketonuria (PKU) leads to an immediate decision about nutrition in order to prevent developmental disabilities. Children diagnosed with Prader–Willi syndrome will require close supervision of their access to food. Most clinicians and educators agree that children diagnosed with autism require early and intensive instruction in communication and social interactions. Even for children with Down syndrome, in which cognitive and adaptive abilities vary substantially, monitoring for early congenital heart defects and sensory impairments is important (Batshaw, 2002).

Prominent diagnostic classification systems have been established that include specific developmental disabilities. These will be briefly described, but for a more in depth description, the readers are referred to an excellent review by Harris (2006). Several of these systems have emerged from the medical community. The most prominent international system, the *International Classification of Diseases* (ICD-10), was created by the World Health Organization (1992) to provide consistent diagnostic criteria for physical diseases, but it also includes classification for mental disorders. ICD-10 is a multiaxial system that specifies assessment related to the individual diagnostic disorder, as well as information about medical conditions, psychiatric conditions, psychosocial disability, and abnormal psychosocial conditions. ICD-10 does not have a single diagnostic classification for developmental disabilities, but it provides precise classification for mental retardation, autism, Asperger syndrome, and cerebral palsy.

In the United States, the *Diagnostic and Statistical Manual of Mental Disorders*, known as the DSM, was established by the American Psychiatric Association for purposes similar to the ICD. The manual is now in a revised form of its fourth edition, DSM-IV-TR (American Psychiatric Association, 2000). Like ICD-10, DSM-IV-TR is multiaxial, with five axes organized around clinical disorders (i.e., all disorders but mental retardation), underlying pervasive or personality disorders (e.g., mental retardation), general medical conditions, psychosocial and environmental functioning, and global assessment of functioning. Again, like ICD-10, DSM-IV-TR does not have a general classification for developmental disabilities, but does have specific criteria and guidelines for mental retardation and pervasive developmental disorder (PDD), the latter being a summary diagnosis that contains specific criteria for autistic disorder, Asperger syndrome, and pervasive developmental disorder-not otherwise specified (PD-NOS). In layperson terms, these PDD categories are now called autism spectrum disorders.

The American Association on Intellectual and Developmental Disabilities (AAIDD; formerly the AAMR) has a long history in establishing diagnostic criteria for mental retardation (MR). In 1959, AAIDD defined MR as "subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, (3) social adjustment" (Heber, 1959, p. 3). By this definition, subaverage referred to an IQ score "less than one standard deviation (SD) below the population mean of the age group involved on measures of general intellectual functioning" (p. 3). In addition, impairments in maturation, learning, and/or social adjustment (later called adaptive behavior) and onset before the age of 16 were two other critical diagnostic features of the definition (Schalock, Luckasson, & Shogren, 2007). One of the best examples of the social construction of developmental disabilities and evolution of the construct occurred in 1973, when the seventh revision of the AAMR definition lowered the IQ diagnostic criteria for mental retardation from 85 to less than 70 (Grossman, 1973). With this change in criteria, the social construction of mental retardation was redefined to

exclude individuals with IQs between approximately 85 and 70, which significantly reduced the official prevalence of mental retardation.

Current IQ criteria in the AAMR definitions remain essentially unchanged from 1973 until present (Schalock et al., 2007). During this same time period there also has been consistency in the two other defining criteria (i.e., that concurrent significant limitations exist in adaptive behavior/skills, and that the age of onset must occur before 18 years). These three AAMR diagnostic criteria influenced the criteria established in the ICD-10 and original DSM classifications.

Perhaps the most current change in the conceptualization of mental retardation is the recent decision to substitute the term "intellectual disability" for "mental retardation," with the definition and assumptions of intellectual disability/mental retardation remaining the same as those set forth by AAMR in 2002 (Luckasson et al., 2002). Schalock et al. (2007) make the case for intellectual disability belonging within the general construct of disability and being a preferred term to replace mental retardation. They argue that the term intellectual disability: "(a) reflects the changed construct of disability proposed by AAIDD and WHO; (b) aligns better with current professional practices that focus on functional behaviors and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social-ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology" (p. 12).

In summary, from a scientific/diagnostic perspective, our working conceptualization of developmental disabilities would enfold formal diagnostic classifications of mental retardation, autism and pervasive developmental disabilities, cerebral palsy, and more specifically identified syndromes that exhibit mental retardation and/or other behavioral manifestation (e.g., Down syndrome, Prader–Willi syndrome, Williams syndrome, Rett syndrome).

Eligibility for Services and Life Limitations

Society's response to developmental disabilities has often been to provide educational and social services that would prepare individuals to live as independently as possible; support the participation of individuals in community, home, and workplace; and provide the financial supports needed for medical and social services. To provide such support, social institutions and agencies must decide who is eligible for services, which again requires definitions and classification.

The educational system in the United States is a primary mechanism for providing training and preparation for independent functioning in society. Broadly construed, educational and multidisciplinary services may begin at the birth of a child with developmental disabilities (See Dunst, Chapter 8, this volume) and extend up to the individual's 22nd birthday. To qualify for special education services, the Individuals with Disabilities Education Improvement Act (IDEIA) in the United States has established eligibility criteria similar to the diagnostic criteria noted previously. The key feature distinguishing this set of criteria from others, such as the DSM or ICD systems, is that the identified disability must affect the child's or youth's educational performance. Several, but not all, of the disability classifications in IDEIA fall within our working definition of developmental disabilities. For example, for infants and toddlers who qualify under Part C of the law, the classification of "developmental delay" is admissible, and states now have the option to use the classification for older children as well. Other classifications used for children from 3 to 22 that could fit into a developmental disabilities clas-

sification are autism, deaf-blindness, mental retardation, multiple disabilities, orthopedic disabilities, and traumatic brain injury.

The Administration on Developmental Disabilities (ADD), within the U.S. Department of Health and Human Services, defines developmental disabilities as

> severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities:
>
> - Capacity for Independent Living
> - Economic Self-sufficiency
> - Learning
> - Mobility
> - Receptive and Expressive Language
> - Self-Care
> - Self-Direction (Administration on Developmental Disabilities, 2007).

As the primary U.S. federal agency responsible for implementing legislation and policy that provides support for individuals with developmental disabilities (e.g., the Developmental Disabilities Assistance and Bill of Rights Act of 2000), the ADD definition serves as a guide for the development of eligibility criteria for state and local social service agencies. Notably, the current definition focuses on "substantial limitations of major life activities" and does not identify specific disabilities. This represents a shift in ADD definition, in that previous descriptions of developmental disabilities included specific disability designations such as mental retardation, autism, cerebral palsy, epilepsy, and traumatic brain injury, as well as the life limitations designation in the current definition.

The life limitation approaches employed by the U.S. federal government agencies provides a mechanism for setting criteria for children, youth, and adults with developmental disabilities who will receive resources through the educational and social service systems. It may also indicate the types of and extent of services provided. That is, individuals with more extensive life limitations may be in need of more services, although the specific social support or education plan is usually not based on this definition or these criteria. Rather, more specific information about the functional abilities of individuals and the quality of support needed provides the foundation for planning and implementing specific services. The necessity of this information underlies a third purpose of the construct of developmental disabilities and a different set of definitional criteria—those of functional abilities and support.

Functional Abilities and Life Support

A paradigmatic shift in the conceptualization of developmental disabilities occurred in the 1990s and, in retrospect, seems to be a natural evolution of the developmental disabilities construct. The diagnostic approach established developmental disabilities through behavioral or medical criteria. The life limitation approach expanded the conceptualization of developmental disabilities to recognize the impact of the disability on features of an individual's life, implicitly involving an individual's life circumstances in determining the limitations that exist for the individual. The shifting paradigm for the late 1990s and into the current century has established a greater emphasis on the match between the individual's abilities and the requirements of environmental context.

Rather than applying a deficits approach and documenting the things an individual cannot do, the functional abilities and life support perspective focuses on skills and abilities that an individual possesses and the types of supports needed for successful participation in the individual's specific environmental context (e.g., home, school, community). Although the importance of functional skills for individuals with developmental disabilities had long been recognized (Brown et al., 1979; Snell, 1978) and been used in developing educational and habilitation programs for individuals with disabilities, they were never part of the definitional portion of developmental disabilities.

The 1992 AAMR revision of the definitional and classification criteria for mental retardation (Luckasson et al., 1992) is a prime example of this shift. Rather than continuing with level of intellectual and adaptive abilities as the primary defining criteria for mental retardation, AAMR established "level of support" as the central feature of the organization's classification system. Level of support is the amount of assistance an individual needs to participate in normal life activities. AAMR identified four levels of support: (1) intermittent (i.e., provided on an "as needed" basis), (2) limited (i.e., time limited but provided consistently over time), (3) extensive (i.e., ongoing support provided regularly in some environments), (4) pervasive (i.e., provided throughout the day and across environments). The specific support provided and its intensity are based on the assessment of an individual's functional and adaptive abilities and their match with requirements of their environment. Environment, we maintain, should be construed broadly as different contexts in which an individual participates. Bronfenbrenner (1979) identified these as microsystems (e.g., home, class, community), as well as the culture or cultures in which an individual lives (e.g., Bronfenbrenner's macrosystem).

A similar shift has occurred in international classification. To describe the functional abilities and characteristics of individuals with health impairments and developmental disabilities, in 2000 the World Health Organization approved the *International Classification of Functioning, Disability, and Health* (ICF). The purpose of the ICF is to provide a common and international language across disciplines for communicating functional abilities and to serve as a clinical and educational tool for planning treatments. The ICF is a revision of the *International Classification of Impairments, Disabilities, and Handicaps* (ICIDH), which was published in 1980 but infrequently used. Although important at the time because it distinguished between disease (or disability) and its consequences, the ICIDH was limited in that it did not reference function and disability to requirements of the environment (Simeonsson et al., 2003). In their revision, the WHO shifted the conceptualization of their classification system from one of disease to one of health (or abilities) (World Health Organization, 2002). Assessment of individuals occurs in four domains: body function, body structure, activities of participation, and environmental factors. This broad set of information allows for examination of the dynamic relationship between abilities of an individual and the functioning of that individual in different environmental contexts.

In summary, the functional abilities and life support perspective moves the focus of developmental disabilities from that of the individual to the individual situated in several ecological contexts. It implies that assessment would include the individual, the environmental contexts, and the relationship between the two. In addition, as Simeonsson, Lolar, Hollowell and Adams (2000) and Bronfenbrenner and Morris (1998) remind us, such relationships also operate in a developmental and temporal context (i.e., the relationships are different for individuals with developmental disabilities and their families at different points of the lifespan).

FUTURE DIRECTIONS AND THE CONCEPTUALIZATION OF DEVELOPMENTAL DISABILITIES

As we look to the future two assumptions appear important. The first is that developmental disabilities will continue as a social construct understood in the context of broader societal trends. The second is that the construct will continue to evolve as science improves our understanding of the basic mechanisms and intervention strategies affecting disability. We argue here that our understanding of developmental disabilities as a social construct is important for effective science as well as for social change. How we define, understand, and respond to this construct affects family adjustment to disability, as well as the social roles, societal investment, and daily opportunities available to people with disabilities in our society. We see the following as trends worthy of consideration for all people concerned about individuals with developmental disabilities.

Social Trends Affecting Our Understanding of Developmental Disabilities

Among the greatest social shifts occurring world wide is the increasing heterogeneity of society (Friedman, 2006; Shinagawa & Jang, 1998). An array of global factors is transforming traditional monocultural communities into diverse sub-societies. Communities that were defined by a "majority" culture are being redefined, not just by "minorities" who become the new "majority," but by diversity itself (Hatton, 2004). This trend will affect the social construct of developmental disability. For example, there are discussions within both the autism spectrum disorders and the deaf communities about the cultures of autism (Mesibov, Shea, & Schopler, 2005) and deafness (Hyde & Power, 2006), respectively.

Increasing contact with social differences will likely bring both conflict and gradual recognition that "differences" are part of the long-term social fabric of society (Miles & Ahuja, 2007). We are optimistic in perceiving this trend as having the long-range effect of changing the perception that differences are inherently suspect. Developmental disabilities are handicaps when they create barriers to personal and social development of an individual within the expectations, constraints, and supports available. As perceptions of social "difference" shift, so will perceptions of developmental disabilities. Our message is not one of Pollyanna optimism, but a call to frame future science, technology, and social policy in the context of broader social themes. Research, and the use of research, occurs within social contexts. The application of research in developmental disabilities over the next 20 years will be affected by the social context in which that research is received.

Changing Terminology and the Risks for Individuals with Developmental Disabilities

Whenever a disability definition changes the individuals included under its umbrella may also change, potentially creating risks for these individuals. For example, in 1992, the AAMR definition of mental retardation was accompanied by several essential assumptions. One assumption stated that the life functioning of persons with mental retardation who were given "the appropriate supports over a sustained period" would generally improve (Luckasson, 1992, p. 5). Family members quickly expressed concern

that such improvement in their children would disqualify them for the diagnosis and that supports and services would be removed by schools and adult agencies. The authors had not anticipated that this statement about the positive effect of supports would threaten ongoing supports and acted to clarify that "the use of supports can fluctuate" and "supports should not be withdrawn prematurely" (Schalock et al., 1994, p. 187).

In the wake of the Supreme Court's ruling in *Adkins v. Virginia* (2002), the AAMR's 2002 manual on definition and terminology has become a guide for determining "whether a criminal defendant should or should not be exempted from the death penalty on the grounds of having mental retardation" (Greenspan & Switzky, 2006, p. 283). State laws now must state an accepted definition of mental retardation and the steps for its diagnosis. Juries, lawyers, and judges play various roles in determining whether the death penalty can be considered or will be carried out. But on the horizon another change in terminology may create risks for individuals with this disability. Schalock and his coauthors (2007) argue that "intellectual disability" replace "mental retardation" and that this term covers "the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability" (Schalock et al., 2007, p. 120). While this change is applauded by many as being more respectful and consistent with international usage, there is also concern that it may pose new risks. In changing terminology, it is possible that judges and lawmakers may become confused and the protections in the law may be reduced. Similarly, concerns exist about whether the legal system can absorb this change without having people fall between definitional cracks.

Integrating Basic Research on Disabilities

The future of developmental disabilities will also be affected by our emerging understanding of the basic mechanisms affecting the etiology and structure of disabilities. As examples, our understanding of the genetics, physiology, and neurochemistry of autism spectrum disorders, Lesch–Nyhan disease, Down syndrome, and mental retardation is changing our perception of these disabilities, as well as our ability to both prevent and remediate core limitations (see Tartaglia, Hansen, & Hagerman, Chapter 6, this volume; Odom et al., Chapter 10, this volume; Sandman & Kemp, Chapter 7, this volume).

Research on the basic mechanisms of disabilities will continue to expand our understanding and dispel myths we have held dear. But this simple linear process has long been part of the field. In this changing context lies a tremendous challenge to integrate new knowledge from different arenas. The information now becoming available about the neurochemistry of self-injurious behavior (Sandman & Kemp, Chapter 7, this volume), learning (Pakulak & Neville, 2006), and pharmacology (Thompson, Moore, & Symons, Chapter 25, this volume) are exciting advances as individual programs of study. Understanding behavioral phenotypes (Dykens, Hodapp, & Finucane, 2000), aging (Bigby, Balandin, & Fyffe, 2004), and sleep disorders (Doran, Harvey & Horner, 2006) for individuals with disabilities will continue to be important. However, research agendas that will lead to the greatest gains will likely come from our ability to integrate these areas of knowledge. Effective integration will challenge both our current standards for research methods and our process for research collaboration (Parmenter, 2004).

Transforming Research Findings into Support Strategies

Research can make a difference. The knowledge from research findings helps us understand what is, what is not, and what might be. Research findings in developmental disabilities come to life, however, when they are transformed into strategies for how we should organize schools, work settings, medical supports, and social policy. Family contexts are also impacted by research, particularly when it affects the purchase of services to support families. Too often the gap between what is known and what is done is embarrassingly large (Carnine, 1997). Describing research findings is insufficient if we do not transform those findings into strategies that produce valued improvements in the lives of people with disabilities (Kame'enui & Carnine, 2002; Schalock, 2000; Schalock & Felce, 2004). For example, documenting the value of living in community settings is insufficient if we cannot weave the full fabric of supports for establishing, adapting, assessing, and improving community support options over time (see Felce & Perry, Chapter 20, and Stancliffe & Lakin, Chapter 21, this volume). Any developmental disabilities research agenda for the 21st century will need to include formal strategies for transforming advances in basic knowledge into efficient strategies for organizing and delivering support.

CONCLUSION: A PERSPECTIVE

We offer in this chapter a perspective on the current, past, and future meanings of developmental disabilities as a useful social construct. We hope this perspective may serve as a context in which to examine the following chapters. The goal in each chapter is to provide both a statement about the current knowledge related to a topic and a proposed research agenda aimed toward moving the field of developmental disabilities forward. We believe these chapters emerge from a rich social, scientific, and policy foundation. We further believe that the next 20 years hold potential for research advances that can be truly transformational. To achieve this vision, however, we will need highly credible and rigorous scholarship that is applied to practical, efficient, and effective systems of support.

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