A Comprehensive Guide to Intellectual and Developmental Disabilities

Second Edition

edited by

Michael L. Wehmeyer, Ph.D.
University of Kansas

Ivan Brown, Ph.D.
Brock University

Maire Percy, Ph.D.
University of Toronto
Surrey Place Centre

Karrie A. Shogren, Ph.D.
University of Kansas

and

Wai Lun Alan Fung, M.D., Sc.D.
University of Toronto

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About the Editors

Michael L. Wehmeyer, Ph.D., Ross and Marianna Beach Distinguished Professor of Special Education; Director and Senior Scientist, Beach Center on Disability; Co-Director, Kansas University Center on Developmental Disabilities, University of Kansas, 1200 Sunnyside Avenue, Room 3136, Lawrence, KS 66045.

Michael L. Wehmeyer is Ross and Marianna Beach Distinguished Professor of Special Education; Director and Senior Scientist, Beach Center on Disability; and Co-Director, Kansas University Center on Developmental Disabilities, all at the University of Kansas. Dr. Wehmeyer is the author or coauthor of more than 350 peer-reviewed journal articles or book chapters and has been an author or editor for 35 books on disability- and education-related issues, including issues pertaining to self-determination, conceptualizing intellectual disability and supports, applied cognitive technologies, and the education and inclusion of learners with extensive and pervasive support needs. Dr. Wehmeyer is Past President and a Fellow of the American Association on Intellectual and Developmental Disabilities (AAIDD); Past President of the Council for Exceptional Children's Division on Career Development and Transition; a Fellow of the American Psychological Association, Intellectual and Developmental Disabilities Division (Division 33); and a Fellow and former Vice President for the Americas of the International Association for the Scientific Study of Intellectual and Developmental Disabilities. He is former Editor of the journal *Remedial and Special Education* and is a founding Co-editor of the AAIDD journal *Inclusion*. He is a coauthor of the AAIDD *Supports Intensity Scale* (2004) and the 2010 AAIDD *Intellectual Disability: Definition, Classification, and Systems of Supports* manual. He has been recognized for his research and service with awards from numerous associations and organizations, including the American Psychological Association Distinguished Contributions to the Advancement of Disability Issues in Psychology Award, the AAIDD Research Award, the Distinguished Researcher Award for lifetime contributions to research in intellectual disability by The Arc of the United States, the Burton Blatt Humanitarian Award from the Council for Exceptional Children (CEC) Division on Autism and Developmental Disabilities, and the CEC Special Education Research Award for 2016. Dr. Wehmeyer holds undergraduate and master's degrees in special education from the University of Tulsa and a master's degree in experimental psychology from the University of Sussex in Brighton, England, where he was a Rotary International Fellow from 1987 to 1988. He earned his Ph.D. in human development and communication sciences from the University of Texas at Dallas, where he received a 2014 Distinguished Alumni Award.

Ivan Brown, Ph.D., Adjunct Professor, Centre for Applied Disability Studies, Brock University, St. Catharines, ON, Canada; Director, Academy on Education, Teaching and Research, International Association for the Scientific Study of Intellectual & Developmental Disabilities; Founding editor of *Journal on Developmental Disabilities*

Ivan Brown is an internationally recognized expert in intellectual and developmental disabilities. He has a strong history of community involvement in disability, serving on numerous government, legal, and community agency committees, task forces, and boards and acting in leadership roles with several professional organizations. In particular, he was a longtime member of the Board of Directors of the Ontario Association on Developmental Disabilities and served a term as its Chair. For almost 2 decades, he has held positions in the International Association for the Scientific Study of Intellectual and Developmental Disabilities, is a Fellow of that organization, sits on the governing Council, and is currently Co-chair of the Quality of Life Special Interest Research Group and Director of its Academy for Education, Teaching, and Research. Dr. Brown has published widely in the academic literature and has written or edited 14 scholarly books and many journal articles and book chapters, and he has authored numerous reports and measurement scales. With co-editor Professor Maire Percy,

he has edited three editions of the highly successful text *Developmental Disabilities in Ontario*. In addition, he has been a member of the editorial boards of several journals in the field of intellectual and developmental disabilities over the years and has contributed hundreds of peer reviews. During his career at the University of Toronto, he initiated several major quality of life studies and managed two national research centers with a special focus on disability issues as they relate to health promotion, child welfare, and indigenous populations. As a retiree, Dr. Brown remains an active contributor to the field of intellectual and developmental disabilities through ongoing lecturing; leading workshops; writing and editing; consulting; volunteering with disability organizations; serving as Director of the International Association for the Scientific Study of Intellectual and Developmental Disabilities' Academy on Education, Teaching and Research; and teaching as an adjunct professor of Applied Disability Studies at Brock University in Canada.

Maire Percy, Ph.D., Professor Emeritus, Departments of Physiology and Obstetrics and Gynaecology, Faculty of Medicine, University of Toronto; Former Director of the Neurogenetics Laboratory, Surrey Place Centre; Vice-Chair, Research Ethics Board, Surrey Place Centre, 2 Surrey Place, Toronto, ON M5S 2C2, Canada

Maire Percy is an internationally recognized Canadian neurogeneticist, a full emeritus professor of the University of Toronto (Physiology and Obstetrics and Gynaecology), and Vice Chair of the Research Ethics Board at Surrey Place Centre (an organization dedicated to improving the quality of life for people with developmental disabilities and their families). From 1989 to 2012, she was Director of the Surrey Place Centre Neurogenetics Laboratory. She obtained degrees from the University of Toronto (B.Sc., physiology and biochemistry; M.A., medical biophysics; Ph.D., biochemistry; and A.R.C.T. from the Royal Conservatory of Music of Toronto, piano). As a Medical Research Council postdoctoral fellow, she trained in immunology and genetics at the Agricultural Research Council of Animal Physiology (Babraham, United Kingdom) and the Hospital for Sick Children (Toronto, Canada). Supported initially by a National Health Research Scholar Award, she established award-winning research and student training/mentoring programs to identify genetic, metabolic, and environmental risk factors causing or contributing to serious human diseases and disorders, including dementia among older people with Down syndrome. Material from an innovative and interactive graduate course that she developed (called The Neuroscience of Developmental Disabilities) motivated the conception of two textbooks co-edited with her colleague, Ivan Brown: *Developmental Disabilities in Ontario* (now in its third edition) and the first edition of *A Comprehensive Guide to Intellectual and Developmental Disabilities*. Although formally retired, she continues to publish research articles and book chapters, review articles and grant applications, organize community courses for later-life learners, and serve on the editorial boards of two journals (*Journal on Developmental Disabilities* and *International Journal of Developmental Disabilities*). Honors include the Ontario Association on Developmental Disabilities Award of Excellence and the June Callwood Award for important contributions to the field of developmental disabilities. Asteroid 32207 is named after her.

Karrie A. Shogren, Ph.D., Professor, Department of Special Education; Co-Director and Senior Scientist, Kansas University Center on Developmental Disabilities; Associate Director, Beach Center on Disability, University of Kansas, 1200 Sunnyside Avenue, Room 3136, Lawrence, KS 66045

Karrie A. Shogren is Professor of Special Education; Co-Director and Senior Scientist, Kansas University Center on Developmental Disabilities; and Associate Director, Beach Center on Disability, all at the University of Kansas. Dr. Shogren's research focuses on self-determination and systems of support for people with disabilities as well as applications of positive psychology and strengths-based approaches to people with intellectual and developmental disabilities; she has a specific interest in contextual factors that affect student outcomes. Her work focuses on developing and researching the efficacy and effectiveness of assessment and intervention approaches for students with and without disabilities to promote self-determination, with a particular focus on the role of these approaches in the transition to adult life and engagement in meaningful adult roles and responsibilities. Dr. Shogren has published more than 100 articles in peer-reviewed journals,

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is the author or coauthor of 10 books, and is a coauthor of *Intellectual Disability: Definition, Classification, and Systems of Support*, the 11th edition of the American Association on Intellectual and Developmental Disabilities' (AAIDD's) seminal definition of *intellectual disability* (formerly *mental retardation*). In addition, she is a coauthor of AAIDD's *Supports Intensity Scale—Children's Version* and *Supports Intensity Scale—Adult Version*. Dr. Shogren has received grant funding from several sources, including the Institute of Education Sciences and National Institute on Disability, Independent Living, and Rehabilitation Research. Dr. Shogren is Co-editor of *Inclusion* and *Remedial and Special Education* and Associate Editor of *Research and Practice for Persons with Severe Disabilities*. She has received the Council for Exceptional Children's Division for Research Distinguished Early Career Research Award and the American Association on Intellectual and Developmental Disabilities Early Career Award. Dr. Shogren completed bachelor and master's degrees in psychology at Ohio State University and the University of Dayton, respectively, and her doctoral degree at the University of Kansas.

Wai Lun Alan Fung, M.D., Sc.D., Assistant Professor, University of Toronto Faculty of Medicine; Chair of Research Ethics Board and Medical Director of Research, Department of Psychiatry, North York General Hospital, 4001 Leslie Street, Toronto, ON M2K 1E1, Canada

Wai Lun Alan Fung is a medical specialist in psychiatry who is also board certified in the subspecialties of Behavioral Neurology & Neuropsychiatry (United Council for Neurologic Subspecialties, United States) and Sleep Medicine (American Board of Psychiatry and Neurology). He serves as Medical Director of Research of the Department of Psychiatry, as well as Chair of the Research Ethics Board, at North York General Hospital—an affiliated teaching hospital of the University of Toronto Faculty of Medicine in Toronto, Ontario, Canada. He is also Assistant Professor of Psychiatry at the University of Toronto as well as Affiliate Scientist of the Toronto General Research Institute. As a neuropsychiatrist focusing on genetic disorders, he has particular clinical and academic interests in 22q11.2 deletion syndrome (22q11.2DS) and Huntington disease in adults and in adolescents making the transition to adulthood. His interests in intellectual and developmental disabilities were first ignited through a medical school research project as part of Ivan Brown's pioneering Family Quality of Life in Intellectual Disabilities study. Dr. Fung has subsequently continued his professional involvement with intellectual and developmental disabilities through his work in 22q11.2DS. He was the lead coauthor of the first set of guidelines for managing adult patients with 22q11.2DS, endorsed by the 22q11.2 Society (the international professional organization dedicated to the study of chromosome 22q11.2 and related disorders). He has also served as Founding Knowledge Officer of The 22q11.2 Society. During 2012–2015, he served as Founding Co-Director of the Dalglish Family 22q Clinic at Toronto General Hospital in Canada—the first comprehensive, multidisciplinary clinic of its kind worldwide fully dedicated to the care of adults with 22q11.2DS and their families. He is a member of the International Consortium on Brain and Behavior in 22q11.2DS as well as an investigator member of the Huntington Study Group. He has also served in leadership roles in such professional organizations as the American Psychiatric Association and the American Neuropsychiatric Association. His other professional interests include neuropsychiatric genetics and pharmacogenetics; the cultural and spiritual dimensions of mental health care; medical quality improvement through knowledge mobilization, utilization of information technology, intra- and interprofessional collaboration, and education; and patient- and family-centered collaborative care. He has published in leading journals such as *Journal of the American Medical Association, JAMA Psychiatry, Lancet Psychiatry, American Journal of Psychiatry, British Journal of Psychiatry, World Psychiatry, Neurology, Genetics in Medicine,* and *Social Science and Medicine*. Dr. Fung completed his undergraduate and medical degrees, as well as his residency training in psychiatry, at the University of Toronto. He also completed a master's degree in epidemiology at the University of Cambridge, United Kingdom, and a research doctorate and research fellowship in neuropsychiatric genetic epidemiology at Harvard University. He is a Fellow of both the Royal College of Physicians of Canada and the American Psychiatric Association.

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Changing Perspectives on Intellectual and Developmental Disabilities

Michael Bach

WHAT YOU WILL LEARN

- How the term *intellectual and developmental disabilities* is currently understood
- Three perspectives on disability: legal, biomedical, and social and human rights models
- The historical roots in law of these perspectives
- Limitations of perspectives that focus only on "deficits" and "impairments"
- How the claims to human rights are changing predominant perspectives on disability

This chapter looks at three different perspectives on intellectual and developmental disabilities and at how these have influenced supports to people with disabilities. Perspectives have shifted over time as the limitations of certain concepts of disability became apparent and alternatives were put forth. Underlying the shifting perspectives are different responses to the following questions: What is disability? How should society identify and come to know the needs of people labeled this way? What are family, community, and state obligations to this group?

UNDERSTANDING DISABILITIES

Intellectual and developmental disabilities are often understood to be one of a cluster of categories used to refer to people whose intellectual capacities, communication skills, and/or behavior are determined to be developing, or to have developed, at a slower rate or to a lesser extent than what is deemed to be typical. In defining *intellectual and developmental disabilities* this way, the focus is on what scientific, legal, and service communities have determined to be "normal" paths of human development. These terms suggest that there is a normal path to human development and to human intellectual activity and that people who are deemed to have disabilities in these areas are somehow different because they do not fit within the normal path. The notion that normalcy can be reliably defined in these areas—as well as the advisability of even doing so—have increasingly come into question since the mid-1990s (Amundson, 2000; Davis, 2010; Withers, 2012).

Today, what is considered to be normal or abnormal, competent or incompetent, or abled or disabled is a matter of perspective—the vantage point from which one views the world and others. This view, referred to as *postmodernism,* claims that, for everything, there can be several or multiple "truths" and that these "truths" about the same thing sometimes compete with one another. The word *truth* is placed in quotation marks on purpose, because truth is recognized to be a social construction—that is, an idea or an understanding constructed at a particular time by particular people. Certain constructions come to be normalized as a common-sense way of seeing

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the world. For example, McIntosh (2002) and Peters (2000) showed how others actively socially construct people with disabilities as being passive and in need of control and management. Also, as Fawcett (2000) suggested, those humans with the power to generate and control the use of knowledge and language often pathologize other humans because of their particular intellectual, physical, and genetic characteristics.

However, even deeply rooted and accepted truths can be challenged. New social constructions are born as those who have been objectified by dominant ways of seeing and knowing speak back and challenge so-called truths that do not actually reflect their own ways of seeing themselves—often experienced as violations to their dignity and equal respect. This is certainly the case as women, ethnoracial, and sexual minorities challenge dominant gendered, sexist, racialized, and heteronormative labels and categories. Similarly, people with intellectual and developmental disabilities, and their advocates, increasingly challenge the idea that intellectual and developmental disabilities are by definition "deficits" or "impairments," and instead some are beginning to call for recognition of "cognitive diversity." Around the world, people with intellectual and developmental disabilities and their families are calling for an end to poverty and exclusion, for a right to live in communities outside of institutional care, for full inclusion in quality education, and for the right to have their legal capacity and decisions over their own lives respected, including the right to vote, to marry, and to control their own bodies and their own property (Inclusion International, 2006, 2009, 2012, 2014).

In this respect, legitimate knowledge about disabilities emerges from the diverse voices of people with disabilities themselves rather than from others talking about them. These and other views may seem to compete with one another, and indeed many do, but each represents its own "truth" about how disabilities are understood. Together, these views aid understanding that intellectual or developmental disability is not a fixed and absolute fact or feature of a person. It is a human-made lens shaped through culture, law, and political struggles throughout history (Carlson, 2010). The starting point is to recognize, as critical theorists in this area have done since the latter part of the 20th century, that intellectual or developmental disability—or one of its predecessor categories such as mental retardation, mental deficiency, or feeble-mindedness—are unstable and heterogeneous categories. As Carlson noted, they are constructed through various disciplines and power relations that often end up leaving people with intellectual disabilities objectified as different from the norm:

> What is fascinating about mental retardation as a classification is its persistence. Perhaps it is precisely because of, not in spite of, its heterogeneity, instability, ability to generate prototype effects, and its place within various constellations of power that it survived for so long. As long as there are experts in different disciplines to define them, institutions to house them, schools to teach them, scientists to study them, psychologists to test them, educators to classify them, people to judge them, and theorists to debate the validity of the label itself, persons with intellectual disabilities will continue to be objects of knowledge. (2010, p. 101)

Three of the most important lenses for viewing intellectual and developmental disability—legal, biomedical, and social and human rights perspectives—are discussed in this chapter, and an emerging "radical disability" lens is touched upon as well.

DEVELOPMENTAL DISABILITY AS A LEGAL STATUS

There are many legal and social histories to the terms *intellectual disability* and *developmental disability* (and similar terms that predate them). They evolved in tandem with the institution of legal personhood, which expresses what defines individuals to whom rights and responsibilities apply in any particular legal context. Early Roman law established the legal category of *personne,* and thus provided a legal norm from which those now thought of as having intellectual or developmental disabilities began to be marked as different. Carrithers, Collins, and Lukes (1985) reviewed the development of notions of personhood in different cultures over the centuries preceding and succeeding this early Roman innovation and showed how the category of person, just like the category of intellectual disability, is subject to shifting perspectives and conflicts over what counts as personhood.

In this section, I pick up the threads of the legal history of personhood in English law in the 14th century, where the roots of the terms *intellectual disability* and *developmental disability* can be found in legal distinctions that still influence public policy and services today. The 14th century English statute under Edward II, titled *De Prerogativa Regis,* or the royal prerogative, now referred to as the *parens patriae* jurisdiction, imposed an obligation on the state to

provide for those deemed incompetent to manage their personal or financial affairs. Chapter IX of the law states, "The King shall have the Custody of the Lands of natural Fools, taking the Profits of them without Waste or Destruction, and shall find them their necessaries" (Shelford, 1833, p. 10).

Determinations of incompetency to manage one's estate or person were made by jury trials at inquisitions called for the purpose. These determinations were the purview of the courts and juries exclusively, but they acted on the royal prerogative—the *parens patriae* power (Neugebauer, 1996). As Foucault (1965) argued, it was from the 14th century on that reason and rationality became the defining feature of what it meant to be a person, and culture, science, and public policy since that time rests largely on this assumption. Development of statutory law during this period suggests that what *reason* comes to mean is constructed in tandem with the legal articulation of lunacy and idiocy.

State obligations to people with a disability were consolidated in England with the passage of the Poor Law in 1601 (Hirst & Michael, 2003; King, 2000; Rushton, 1988). This statute established a distinction between the "worthy" and the "unworthy" poor and was later adopted in many of England's colonies. Adults with disabilities considered unable to work were, by this law, deemed worthy and entitled to state provision. The law contributed to a marginalized economic and social status for people with disabilities that still continues. By linking disability and inability to work, the law and its ensuing amendments institutionalized the idea that people with disabilities did not fit into the labor market, an assumption that still drives much employment-related policy. In addition, by considering people with disabilities as "worthy poor," the state promised slightly better provision than for the "unworthy" poor—those who were deemed able-minded and able-bodied but unwilling to work. However, the cost of obtaining richer provision was the adoption of disability as a legally sanctioned charity status, one that people with disabilities are still trying to shake in favor of recognition as full citizens.

As contracts between people increasingly came to define both economic and social relationships, especially with industrialization beginning in the 18th century, a figure of "market man," a freely contracting agent, began to emerge. To protect the sanctity of contracts, parties had to be seen to fully understand their nature and consequences. Thus, industrialization and the infrastructure of contract law that supported it established requirements for what it meant to be a person at law and to be recognized as such in social and economic relationships (Cossman, 1990; Poole, 1985, 1991). People with intellectual or developmental disabilities thus came to be seen as a threat to the upholding of contract law—they were not seen as having the necessary reason and rationality to exercise responsibility in entering into and fulfilling contracts. So a means other than providing them a right to enter contracts had to be found to ensure their basic needs were met.

The 1890 English Lunacy Act was a successor to *De Prerogativa Regis* and consolidated legal provisions related to lunacy and the *parens patriae* jurisdiction of the courts. The legislation was made effective under colonial law in many other countries under British colonial rule. By conferring a differential legal status on people with a developmental disability, the *parens patriae* power helped to institutionalize the idea that what made a human being a person was the ability to meet certain tests of reason. Institutional care for people labeled as "idiots," "fools," or "lunatics" grew in succeeding years for those who were not considered to have the requisite "reason" to be recognized as a person, and thus to enter contracts or take on other rights and responsibilities. Consequently, such people were shut more and more away from the mainstream of society.

The traces of these legal boundaries of intellectual and developmental disability are still embedded in law. The statutory equation in guardianship law, for example, between legal capacity and mental capacity demonstrates the deeply entrenched assumption that in order to have legal power over one's life respected and protected, one must meet certain standards of intellectual functioning. Despite international human rights treaties to challenge this equation between the right to legal capacity and having certain levels of mental capacity, and the obligation to provide support in decision making rather than to rely on substituted decision making, domestic law in many countries is still shedding this centuries-old assumption (Bach & Kerzner, 2010).

THE BIOMEDICAL VIEW

By the 18th century, a legal perspective on disability was beginning to be supplanted by a biomedical one. With the rise of institutional care, the need grew for regulation, licensing, and due process in

committal to institutions. The growing medical profession was called upon to play this regulatory role and, over the 18th and 19th centuries, the powers to determine competence shifted from juries of inquisition under the courts to physicians. By the end of the 18th century, the Royal College of Physicians in England was responsible for the licensing of "madhouses." By mid-19th century, resident physicians were required in madhouses of more than 100 people. In the same period, the Association of Medical Officers of Hospitals for the Insane was established, and the organization published a diagnostic manual that included such categories as "mania," "melancholy," "monomania," "dementia," "moral insanity," "idiocy," "imbecility," "general paralysis," and "epilepsy" (Weistubb, 1990). The manual is one of the precursors of the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (American Psychiatric Association, 2013), widely used to "diagnose" intellectual, developmental, and other disabilities.

The idea that disability was not a status that was conferred, but was in fact an individual deficit, gained strength in the early 20th century when Binet and Simon developed the first intelligence test to identify children in France who were not progressing in school. The test was adapted and, increasingly over the 20th century, became the most common instrument for diagnosing "feeble-mindedness," "mental deficiency," and "mental retardation." Standardized intelligence tests were developed for different age ranges and normal deviations were constructed as a means of identifying as subnormal those who fell below the range considered to be normal. Developmental tests were later designed to measure how closely individuals met "developmental" targets at each age. The discrepancy in measures on language, motor, and behavioral development assisted in defining various categories of what is now called *intellectual and developmental disability*.

These various strands in the evolution of the law and science of disability converged with research and public policy in disability generally. Many definitions were generated over the 20th century and, in 1980, the World Health Organization (WHO) suggested three elements of a definition within what came to be known as the *International Classification of Impairments, Disability and Handicaps*:

- *Impairment.* In the context of health experience, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function.
- *Disability.* In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- *Handicap.* In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual. (Wood, 1980, pp. 27–29)

This definition, with its focus on abnormality and lack of ability in relation to a norm and on placing pathology within the individual's body (Siebers, 2008; Straus, 2010), is consistent with the language of intellectual and developmental disability since its inception in law more than 600 years ago. It is also consistent with the many other definitions where developmental or intellectual disability is related to "deficits" or "impairments" in conceptual, practical, and social intelligence (Greenspan & Driscoll, 1997) or lower than "normal" functioning in intellectual abilities (e.g., reasoning, acculturation knowledge, short and long-term memory, visual and auditory processing, processing speed, quantitative knowledge; Horn & Noll, 1997).

The main limitation of the biomedical view is that it categorizes individuals as abnormal in relation to norms of intelligence, even though these vary through history. Thus, as Goodey (2011) suggested, a person identified in the 21st century as "intellectually disabled" would not have the same qualities as a person seen to be lacking the needed capabilities to meet norms of intelligence in the classical Greek era. Intellectual disability is always defined (by others) in relation to norms of intelligence and intellectual capacity, which are themselves bound by social, cultural, and economic contexts. For example, the most recent definition of intellectual disability adopted by the American Association on Intellectual and Developmental Disabilities (AAIDD) uses these norms (AAIDD, 2013; Schalock et al., 2010). To AAIDD, *intellectual disability* is a disability that becomes apparent before the age of 18 and that is characterized by significant limitations in intellectual functioning (general mental capacity; e.g., learning, reasoning, problem solving) and in adaptive behavior (everyday social and practical skills), both measured against normative standards set by professionals.

Measurement of population characteristics can be conducted in ways to statistically define certain

"norms" of development, but these norms remain just that—statistical constructions. Deviations from the norms do not signify "abnormal" development; they merely represent statistical deviations from a presumed norm. In this view, if children, youth, or adults do not proceed developmentally through a set of common functions, developmental stages, or critical developmental periods, then they are to be considered abnormal or to have deviations in physical, emotional, or skill development. This assumption, which has served to frame much of the practice in education, developmental psychology, and social science research, is increasingly being called into question (Amundson, 2000; Skrtic, 1991). It has been suggested that rather than being scientific and objective, the concept of functional normality reflects the beliefs, preferences, and cultural expectations of a majority of the members of society. As Amundson suggested, if what it means to be normal is indeed a product of the culture, then the yardsticks for measuring normalcy lack universal and scientific validity, and "disadvantages experienced by people assessed as abnormal derive not from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation" (p. 33). The definition of *normal* becomes arbitrary, relative, and specific to the historical context in which it occurs (Goodey, 2011).

A critique of normalcy does not suggest that particular individuals do not have real limitations and difficulties or face barriers as a result or that they do not require early intervention to help remediate limitations or address diseases and ill health. It simply means that each person must be considered as a unique person. A person's developmental progress will proceed like no other person's, even though at a population level, trends in development can be found across children and subgroups of children.

Mackelprang and Salsgiver (1999) pointed to some of the intellectual foundations of a broader view of developmental theory that begin to address the cultural biases of predominant approaches based on normalcy. This work stresses that the focus in developmental theory must be shifted from measuring the gap between age and expected developmental achievements and measuring the standard deviations of that gap to focusing on the conditions that enable children and adults with disabilities to carry out "developmental tasks" that are culturally shared and defined. To be able to communicate with others, for instance, is a developmental task whose achievement need not be measured by verbal language skills in the dominant language. Moving into adulthood need not be defined by the capacity for independence, which would exclude from successful adult achievement those who require ongoing personal supports. It can also be defined by the control one is given over one's supports; development of mutually supportive, interdependent relationships; and the opportunity to develop and pursue a wider range of goals.

The WHO definition, its antecedents, and its contemporaries all placed *disability* firmly within the individual while recognizing that it often brings needs for support from others and social stigma for not measuring up to the norm. This is also the case with the AAIDD definition, which recognizes that

> In defining and assessing intellectual disability… additional factors must be taken into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave. (2013, p. 1)

A biomedical view of disability is not inherently harming to people with intellectual or developmental disabilities. It can provide an understanding of a person's genetic differences and possible consequences. It can provide information (e.g., through a diagnosis) at an early stage of a person's life about the particular challenges to be faced in communication, motor, and behavioral development, and thus it can encourage access to early intervention programs and other developmental supports. Such information is vital to a child and to his or her family seeking to nurture as many life chances as possible.

The "harm" in a biomedical perspective comes from using it as the only way of viewing a person. This often leads to the assumption that all the challenges to be faced arise from genetic or other differences. In order to address the challenges that arise from a devalued legal and social status, a broader perspective for viewing a person is needed—one that sheds light on how the legal system and economic, social, educational, and other environments in which a person lives can determine his or her life chances. A social and human rights perspective on developmental disability can help to shed this light.

THE SOCIAL MODEL OF DISABILITY

An alternative social and human rights model of disability—often referred to simply as the *social*

model—has been advanced by those who find in the WHO and other definitions a "reductionist" tendency—reducing the disability to individual characteristics (Barnes, 1991; Oliver, 1996; Pothier & Devlin, 2006; Rioux, 1996; Rioux, Basser, & Jones, 2011). In a social model, disability arises from the discrimination and disadvantage individuals experience in relation to others because of their particular differences and characteristics. This shift in thinking finds a primary source in feminist and other identity theories of "difference" wherein the challenge is to recognize such differences as gender, race, sexual identity, and disability without assigning social or economic value on the basis of these differences (Carlson, 2010; Garland-Thomas, 2010; Minow, 1990).

A parallel and closely related body of theory in disability, critical disability theory, contends that past and current conceptualizations of disability and their accompanying policies and practices have been both discriminatory and oppressive, and that redress is necessary through overt action that seeks to situate disability in a full and value-neutral way within the human condition. Critical disability theory's value-based approach, which identifies and brings into focus past and current harm from social, cultural, and political relationships, and emphasizes the need to redress this harm, lends a call to action to the social model that is helpful to society assuming its responsibility for providing in an equitable way for all of its citizens, including those with all disabilities (see, e.g., Davis, 2010; Hosking, 2008; Meekosha & Shuttleworth, 2009; Pothier & Devlin, 2006).

The social model, in today's context, embraces human rights as a key method for society to assume its responsibility to ensure equal treatment and opportunities for all of its citizens (Rioux, Pinto, & Parekh, 2015). This reintroduces the notion of people with disabilities as legal entities described at the beginning of this chapter but stresses equality and citizenship rights in a way that brings into question the status that was first carved out for them under statutes such as *De Prerogativa Regis* and also questions the forms of institutional and community care that have taken away their basic rights to self-determination, citizenship, and freedom from discrimination in employment. Instead, the social model suggests a reconstruction of the legal, social, and economic status of people with disabilities, starting with recognition that, first and foremost, people are full, rights-bearing citizens. The purpose of this reconstruction is not to restrict opportunities, but to ensure that opportunities to a full life are protected and enhanced and that these will be appropriate to capabilities of people with all disabilities (Brown, Hatton, & Emerson, 2013).

In a social model of disability, the "pathology," to use Rioux's (1996) terminology, is not individual, but rather social in nature. The unit of analysis shifts from the individual to the legal, social, economic, and political structures that calculate value and status on the basis of difference. Informed by principles of human rights and an equality of outcomes that takes account of differences, the social model does not reject biomedical knowledge of impairments and research on individual rehabilitation. Rather, it celebrates impairment as part of the human condition and looks at achieving equity for people with impairments in terms of the social, cultural, and political contexts (Goodley, 2011).

There remains some question about the place of "impairment" within the social and human rights model of disability. In the response of Disabled Peoples' International (DPI) to the WHO definition, the term *handicap* was dropped, but "impairment" and "functional limitation" were kept as the foundation of the definition (DPI, 1982). Oliver (1996) suggested that this emphasis reinforces normalizing tendencies within the definition that need to be questioned. In keeping with Oliver's view, Shakespeare (1996) suggested that only by turning to the stories and experience of people with disabilities themselves can a legitimate place be given to their lived realities of impairment as the meaning they give to their physical and intellectual differences. He also called for recognition that with impairments can come "intrinsic limitations" (Shakespeare, 2006, p. 41), a reality that must be figured into understanding the disadvantage people with disabilities face. Thomas (2004) continued this thread in her outline of a "social relational model" of disability, which recognizes that physical or cognitive impairments can have real effects and limitations in a person's life. These approaches acknowledge the reality of impairment while challenging the assumption that one person is given the status to define another as "impaired" from some "objective" criteria of "normal" functioning. It is argued that by their very nature, such assessments reinforce a norm at the same time as they define someone as deficient in relation to the norm. Rather, impairment is a lived and subjective reality, given meaning within the individual and in collective narratives expressed by

people with disabilities themselves and those who are in personal relationships with them. Frazee (1997) has stressed the importance of creating a "culture" of disability wherein people's differences, or impairments if they define them as such, can be named, given meaning, celebrated, and thereby transformed into a cultural and personal resource, even while people may experience limitations and needs for support.

The notions of a "social model of disability," "personal experience of impairment," and a "culture of disability" may not at first glance provide much hope of liberation to people with more profound intellectual and developmental disabilities, and indeed there has not been nearly as much attention in critical disability studies to the lived realities of this group. Many who are labeled with an intellectual or developmental disability have very challenging needs, are unable to communicate in ways that most others understand, sometimes act in ways that bring alarm to others, and sometimes demand attention from family and support workers. Those who advocate a social rather than biomedical perspective for understanding disability argue that it is most important to bring this perspective to individuals who are in such a situation. It is they whose voices about their own lives and life conditions are least likely to be heard but need to be for an understanding of disability (see Charlton, 1998, 2010; Couser, 1997, 2010). It is they who are most at risk of being devalued in society for their differences, who are defined as furthest from the norm, and who are perceived to be lacking a personal story or narrative that others value. As Eva Kittay—a philosopher who has a daughter with a profound intellectual disability—argued, the differences people with intellectual and developmental disabilities have in relation to others cannot be defined away as "social constructions." These differences are real. It is the defining of them as "problems" that must be addressed:

> The cognitive impairments of the severely and profoundly retarded are not merely contingently disabling. Unlike many disabilities, Sesha's [her daughter's] are not simply social constructions. Someone such as my daughter could not survive, much less thrive, without constant vigilant attention.…We might say, however, that in the case of developmental disabilities, especially severe ones, though the disability itself is not socially constructed, the view that mental retardation is a "problem" rather than a possible outcome of human physiology is. (Kittay, 2002, p. 265)

CHALLENGES IN MOVING A SOCIAL MODEL INTO REALITY

How can a social and human rights model best be moved into law, policy, and practice in a way that makes a practical difference in addressing the inequalities and disadvantages experienced by people with intellectual and developmental disabilities? How can that be done in a way that also recognizes that the term *intellectual disability* does not signify a homogenous group and is but one of the identities (although often the dominant one) that people live with at the intersection with their gender, ethnoracial-cultural identity, sexual orientation, and other identities—the intersections that the "radical" model calls upon everyone to recognize (Withers, 2012)? Through the 1980s and 1990s, much was accomplished in codifying in law human rights protections for people with disabilities and prohibitions against discrimination on this basis. In 2006, the United Nations' *Convention on the Rights of Persons with Disabilities* (United Nations, 2006) established a comprehensive human rights standard to guide states (countries) in developing their own human rights and to provide a basis for global monitoring of human rights and disability. The dilemma now is how to put those commitments into reality.

Although human rights laws have advanced, not as much has changed in the lives of people with disabilities in terms of poverty rates, unemployment, exclusion from regular education, exclusion from community activities, exclusion from housing, and rates of abuse (especially neglect; see Chapter 35). Moreover, the inequities affecting people with disabilities within countries and between countries grow. The WHO, for example, estimates a far lower participation rate of children with disabilities than children without disabilities in primary and secondary education (WHO, 2011). In the more affluent countries of the world, where children with disabilities are required to go to school, it is still challenging to move from a segregated to an inclusive approach, as the social model would require.

So, if legal change that significantly addresses the centuries of differential legal status imposed on people with disabilities has been accomplished, what are the next steps? In sectors across society—education, recreation, employment, public sector services, health care, and others—there is a growing commitment to, and belief in, the equality of people with disabilities. However, the leadership, relationships,

and knowledge required in these sectors to make full inclusion a reality is often missing. Closing the gap between exclusion and inclusion will require new roles and partnerships, including actors who for many years advocated for legal change working alongside service providers and people with disabilities themselves. For example, more individualized and person-centered planning, funding, and support services are essential if people with intellectual and developmental disabilities are going to be supported to maximize achievement, contribution, success, and belonging, each person along his or her unique developmental path. However, funding arrangements and service delivery systems in education, residential, employment, and community supports still largely foreclose this possibility because of their emphasis on congregate and often segregated approaches. Systems are beginning to change as individualized and person-directed approaches are tested and increasingly adopted (Kendrick, 2011). Nonetheless, the limits of reform will depend on the extent to which a fuller transformation can be made from the predominant biomedical view of disability to a social or human rights approach and even more radical views.

In addition, recognition will be required that people with intellectual and developmental disabilities are not a homogenous group. They are located simultaneously in gendered, racialized, and culturally defined roles and relationships that also structure the limits and possibilities of reform at any point in time and place. For a social and human rights model of disability to take full account of the realities of people with intellectual and developmental disabilities, it must also attend to this more radical perspective on the multiple, sometimes conflictual, and always evolving nature of social identities. This perspective helps people to better understand the double and triple disadvantage some individuals face and also to identify opportunities to build common understanding and solidarity with groups who share forms of social and economic exclusion. These alliances can help to further unsettle the hold that negative and devaluing constructions of intellectual disability have held over people's lives and developmental possibilities.

IMPORTANCE OF A HUMAN RIGHTS APPROACH

This brief overview of the terms *intellectual disability* and *developmental disability,* public policy, and their historical roots makes clear that there are different ways of making sense of the terms *intellectual disabilities* and *developmental disabilities*. Since the late 20th century, a broad perspective has begun to take shape that goes significantly beyond delineating norms to guide the assessment of disability (e.g., intelligence, adaptive behaviors, social competencies, genetic structure), focusing instead on what needs to be done so that people, whatever their personal challenges and social and economic disadvantage, can exercise their human rights and full citizenship.

The discourse of human rights has not yet influenced thinking in the area of intellectual and developmental disability as much as it has in other areas, such as gender, race, sexual identity, or physical disability (Carlson, 2010). Nonetheless, with the recognition that the label has brought with it a devalued legal, social, and economic status, a human rights framework now has an irrevocable impact on understanding intellectual and developmental disability. Since 1948, when the *Universal Declaration of Human Rights* was adopted, and more recently with the United Nations *Convention on the Rights of Persons with Disabilities,* human rights provisions have been successively passed by national and state or provincial governments. The implications of these changes are being witnessed in the reform of federal and regional statutes—for the right to vote, the right to participate on juries, the right to have access to health care, the right to education, and other rights.

The adoption of a human rights perspective for understanding state obligations to its citizens is arguably the most profound conceptual advance for understanding intellectual and developmental disability since the terminology was first born in law hundreds of years ago. Human rights provisions have become indispensable foundations for a social model of disability and indeed have helped make a social model perspective on disability possible in law, policy, and practice. They are a crucial instrument in challenging the discrimination and inequality that arises from assigning people with intellectual and developmental disabilities differential and devalued legal, social, and economic status on the basis of assessed, or assumed, intellectual differences.

By stressing the value of human rights in understanding intellectual and developmental disability, a social model needs not reject biomedical information. There is much to be learned and valued from an understanding of people's particular differences

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and the biomedical consequences and challenges they bring. A social model recognizes a biomedical view as one source of information for understanding disability. However, it changes the vision and purpose of intervention from "fixing," "impairments," and "abnormalities" to supporting people to exercise their human rights and thereby become full and valued members of society.

Although the implications of human rights obligations are still to be fully worked out, the vantage point they allow helps to reveal the inequalities in status between people with disabilities and the rest of the population and among people with disabilities themselves. They provide a legitimate ground on which to restructure the institutions and policies that have brought inequality in the past and to consider what entitlements people require in order to fully exercise their citizenship and equality rights. They also demand a restructuring of outmoded approaches to service delivery that still congregate and segregate people on the basis of intellectual and developmental disabilities. As understandings of these inequalities in status inch further and further into public consciousness, it can be hoped that genetic, behavioral, communicational, and intellectual differences will be seen for what they are—signs of diversity, horizons of human possibility, and a place to nurture support, belonging, and reciprocity.

SUMMARY

Intellectual and developmental disability is usually thought of as an intellectual deficit or developmental delay arising from a genetic "deficiency" or other condition, which becomes visible in the early years of life. Stepping back from this assumed definition, it can be seen that *disability* is, first and foremost, a term applied by some people to others. The term is rooted in legal distinctions that go back hundreds of years to a time when the state first became concerned with distinguishing those considered to have the requisite "reason" to manage property and financial affairs.

The biomedical view, in which intellectual and developmental disability tends to be seen primarily as a delay in normal human development, arose as the medical profession was increasingly called upon to determine to whom the category would be applied. A social and human rights model of disability has more recently emerged to question the exclusive focus in a biomedical perspective on "deficits" and "delays." It aims to shed light on the social, economic, and political barriers to full citizenship that come when a person is labeled as intellectually "delayed" or "disabled."

The legal, biomedical, and social perspectives on disability all underlie public policies for people with intellectual and developmental disabilities. There has been a gradual shift in public policy from "care" for people with disabilities to policies that enable greater social and economic inclusion of such people. However, concerns are growing that there is a "re-medicalization" of disability underway that will be used to distinguish between those who are deemed worthy of public support and those who are not. With human rights commitments now in place, the next step is to develop the knowledge needed for all sectors of society to build inclusive policies and practices that enable people with intellectual and developmental disabilities to take their rightful place.

FOR FURTHER THOUGHT AND DISCUSSION

1. Why do you think it is that a person with a disability has a right to health care and medical interventions in many countries (even if this right is not always fulfilled) but can only obtain disability-related supports as a matter of charity?
2. What arguments would you use to encourage a potential employer who would like to hire a person with a disability but who is concerned about the functional and behavioral assessments provided by a vocational counselor?
3. You are supporting a young person with a developmental disability and her parents. The mother is 3 months pregnant and finds out that her second child will have Down syndrome. The mother turns to you for advice on whether she should abort her fetus. How do you counsel her?
4. Children have a right to education. However, some are excluded from attending their neighborhood school because they do not have the communication capacities or the needed augmentative communication systems are considered too expensive or cumbersome in the classroom. Should education be a matter of right or of capacity? Can functional and other biomedical assessments be used to help a child and a school to more fully exercise the right to education? In what ways might they undermine the possibility of full inclusion?

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5. What is the difference between a physician's knowledge about the human rights of a person with a disability, knowledge about how to provide medical care to a person with an intellectual disability, and knowledge about how to ensure that a person with an intellectual disability can have access to the physician's office and be supported to make health care decisions?

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