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About the Editor-in-Chief

Laraine Masters Glidden, PhD, is distinguished professor emerita in the Department of Psychology at St. Mary's College of Maryland. She grew up in Queens, New York, where she attended excellent public schools and learned to love words. In 1960, she graduated from Jamaica High School, where she was mentored by several teachers who encouraged her to apply to colleges that her working-class parents could not afford. Nonetheless, she followed their advice, and received a full scholarship from Mount Holyoke College, earning a bachelor's degree, graduating *magna cum laude*, Phi Beta Kappa, with a major in psychology and minors in physiology and sociology. Dr. Glidden went on to pursue graduate studies in experimental psychology and found a welcoming environment at the University of Illinois, where she did research in classical conditioning and learning and memory. She wrote her dissertation on memory strategies in adolescents with intellectual disability, and earned her PhD in 1970, supervised by Dr. Keith Scott, who had earned his PhD at the University of Connecticut under the tutelage of Dr. David Zeaman.

Dr. Glidden has maintained an active research, teaching, administrative, writing, and editing career over the past 50 years. Grants from the National Institute of Child Health and Human Development (NICHD), the National Institute of Mental Health, the National Science Foundation, and other organizations helped to fund her research. She is probably best known for her longitudinal Project Parenting study, which was funded by the NICHD for 25 years and helped to change the narrative that raising a child with intellectual or other developmental disabilities invariably leads to chronic sorrow. Rather, it is more typically a story of initial grief, but is usually followed by adaptation and positive well-being. Dr. Glidden's research and other work has resulted in the publication of one authored book and 17 edited books (six by guest editors) during the years that she was series editor for the *International Review of Research in Mental Retardation* (now the *International Review of Developmental Disabilities*) book series. She has published 20 book chapters and 79 peer-reviewed articles and book reviews, and presented hundreds of professional papers. In addition to decades of service as a grant reviewer for the NICHD and the U.S. Office of Education, Dr. Glidden has held leadership positions in Division 33 (Intellectual and Developmental Disabilities/Autism Spectrum Disorder) of the American Psychological Association (APA) and in several other organizations. She received multiple awards in recognition of her contributions to the field of intellectual and developmental disabilities, including the Arc Distinguished Research Award in 2008, an appointment as a Global Scholar of Special Olympics International in 2011, the Edgar A. Doll Award for Lifetime Achievements in Intellectual and Developmental Disabilities from APA Division 33 in 2015, and in 2020 the Presidential Award from the

American Association on Intellectual and Developmental Disabilities for Exceptional Service in Advancing Its Mission, Goals, and Principles.

Dr. Glidden served in both teaching and administrative roles at St. Mary's College of Maryland, a public honors college, arriving there as an associate professor in 1976 after holding positions at Clarkson University and Teachers College, Columbia University. She taught courses in developmental psychology, including those related to intellectual and developmental disabilities, and mentored dozens of undergraduate students in research, many of whom went on to obtain graduate degrees. She retired as distinguished professor of psychology and human development in 2012, but she came out of retirement in 2015 to serve as acting provost for 18 months. Following the publication of this handbook, she will return to other writing projects, some in gestation and others not yet imagined.

About the Associate Editors

Leonard Abbeduto, PhD, is the director of the MIND Institute, the Tsakopoulos-Vismara Endowed Chair, and professor in the Department of Psychiatry and Behavioral Sciences at the University of California, Davis. Dr. Abbeduto's research is focused broadly on the development of language across the lifespan in individuals with intellectual and developmental disabilities and on the family context for language development. He has published more than 200 articles, chapters, reviews, and books on fragile X syndrome, autism, Down syndrome, and child development. Dr. Abbeduto's program of research has been funded nearly continuously by the National Institutes of Health since 1985. His current research is focused on understanding variation in language outcomes in various conditions associated with intellectual disability, the measurement of treatment effects in clinical trials, and the use of distance technology to deliver behavioral treatment. He serves as principal investigator and director of the National Institute of Child Health and Human Development–funded MIND Institute Intellectual and Developmental Disabilities Research Center, which provides core support to more than 80 projects and 40 scientists at the UC Davis MIND Institute. Dr. Abbeduto has received numerous awards, including the Emil H. Steiger Award for Distinguished Teaching from the University of Wisconsin–Madison; the Faculty Stewardship Award from the University of California, Davis; the Enid and William Rosen Research Award from the National Fragile X Foundation; and the Edgar A. Doll Award for Distinguished Research Contribution from Division 33 (Intellectual & Developmental Disabilities/Autism Spectrum Disorder) of the American Psychological Association (APA). He is a fellow of the American Association on Intellectual and Developmental Disabilities and Division 33 of the APA. He earned his PhD in psychology from the University of Illinois at Chicago in 1982 and completed a postdoctoral fellowship at the Kennedy Center of Vanderbilt University. Dr. Abbeduto came to UC Davis in 2011 after 24 years on the faculty at the University of Wisconsin–Madison.

Laura Lee McIntyre, PhD, is professor and head of the Department of Special Education and Clinical Sciences and director of the Prevention Science Institute at the University of Oregon. Dr. McIntyre's research involves early identification and treatment of childhood developmental and behavioral problems, with an emphasis on the multiple systems of care that support children (e.g., families, schools, health care). Within this broad framework, three specific lines of research emerge: (a) parent training, education, and support; (b) transition to kindergarten; and (c) child risk factors and family well-being. Over the past 20 years, Dr. McIntyre's work has focused on understanding and promoting parent and child well-being in families with children with developmental delays or disabilities, including autism spectrum disorder. Her

professional background blends the fields of school psychology, special education, and pediatric child clinical psychology and centers on the early identification and treatment of childhood developmental and behavioral problems. Her work emphasizes developing parent–professional partnerships and working with a variety of caregivers who support children. She is especially interested in early intervention and prevention work with families who have young children with developmental problems who are at risk for negative social, emotional, and behavioral outcomes at home and at school. Her research has received funding from the Eunice Kennedy Shriver National Institute of Child Health and Human Development; the National Institute of Mental Health; the National Institute of Disability, Independent Living, and Rehabilitation Research; and the U.S. Department of Education/Institute of Education Sciences. Dr. McIntyre is a past president of the American Psychological Association’s Division on Intellectual and Developmental Disabilities/Autism Spectrum Disorder (Division 33) and currently serves as the president of the American Association on Intellectual and Developmental Disabilities.

Marc J. Tassé, PhD, is a professor in the Department of Psychology and the Department of Psychiatry and Behavioral Health at The Ohio State University. He is also the director of the Ohio State Nisonger Center, a University Center for Excellence in Developmental Disabilities. He has more than 30 years of experience in conducting research and providing clinical services in the fields of intellectual disability (ID), autism spectrum disorder (ASD), and other related neurodevelopmental disorders (ND). He has significant clinical and research experience working with people with ID/ASD, including people with co-occurring mental/behavioral health concerns. Dr. Tassé has been involved in the development of a number of standardized assessment scales for people with ID/ASD, including the Diagnostic Adaptive Behavior Scale, Supports Intensity Scale for Children, Supports Intensity Scale for Adults, Nisonger Child Behavior Rating Form, and the Quebec Adaptive Behavior Scale. His publications include more than 150 articles in peer-reviewed journals, book chapters, and books in the area of ID/ASD/ND. He has given more than 275 scientific and professional presentations on topics related to ID, ASD, and other ND. He is a fellow of the American Association on Intellectual and Developmental Disabilities, American Psychological Association (APA), and International Association for the Scientific Study of Intellectual and Developmental Disabilities. His work has been recognized by the American Association on Intellectual and Developmental Disabilities (Exceptional Service Award: 2007, 2009, and 2011) and the APA (Division 33’s John W. Jacobson Award for “meritorious contributions to the field of intellectual and developmental disabilities in an area related to behavioral psychology, evidence-based practice, dual diagnosis or public policy”). He is a past president of the American Association on Intellectual and Developmental Disabilities (2012–2013). Dr. Tassé is also actively involved in conducting evaluations and giving expert testimony in capital cases where intellectual disability may be an issue.

Introduction

This *APA Handbook of Intellectual and Developmental Disabilities* is long overdue. Although other handbooks have focused on intellectual and developmental disabilities, starting with the first edition of the *Handbook of Mental Deficiency, Psychological Theory and Research*, edited by Norman R. Ellis (1963), none has been as comprehensive as the two current volumes, as the earlier handbooks have, for example, focused mostly on practice (e.g., Singh, 2016) or only on a few aspects of development (e.g., Burack et al., 2012). Jacobson et al. edited a comprehensive single-volume *Handbook of Intellectual and Developmental Disabilities*, but with a 2007 publication date, it is now outdated.

COMPREHENSIVE COVERAGE

The study of intellectual and developmental disabilities requires expertise from multiple disciplines in the biological, behavioral, and social sciences as well as input from specialists drawn from law, medicine, philosophy, history, and other domains of research and practice. Because the study of people with intellectual and developmental disabilities is akin in most respects to the study of people more generally, this handbook contains chapters that address etiology and specific conditions as well as functioning in multiple domains and throughout the lifespan. We live in societies that are organized into small and intimate units (e.g., families) as well as larger systems (e.g., neighborhoods and nations), and the roles of these systems and how they influence people with intellectual and developmental disabilities are described and discussed throughout this handbook. This comprehensive treatment provides a compendium that will be valuable to a wide array of scientists and educators; legal, medical, psychological, and social work professionals; and policymakers. Both undergraduate and graduate students who are studying in those fields are also likely readers.

ORGANIZATION AND TERMINOLOGY

Consisting of two volumes, each with multiple parts, the organization of the *Handbook* is by volume and by part within volume. Volume 1 provides the *Foundations* of the field with three parts that focus on Origins and Overviews; Causality and Variation; and Assessment, Diagnosis, and Labeling. Volume 2 is primarily devoted to *Clinical and Educational Implications: Prevention, Intervention, and Treatment*. Its two parts address Evidence-Based Practice and Treatment and a variety of Lifespan Issues. In a final chapter, I and the three associate editors summarize the preceding 37 chapters and address important future directions for the field.

In all chapters, authors have been thorough in considering multiple approaches and up-to-date information. Most chapters rely on substantial basic and applied research findings, and generally include a summary of domains wherein there is a relative paucity of research and/or substantial disagreement in results. Disagreements or controversies within a discipline can be catalysts to greater attention and interest which, in turn, may lead to resolution of those disagreements and advances that propel further exploration. This exploration is being conducted by scientists trained in a large array of fields, using many diverse research methods and samples. Not surprisingly, a cauldron of creativity ensues, and important discoveries are leading to rapid advances. Most of the chapters in this handbook bring us up-to-date on the science and practice related to intellectual and developmental disabilities. Moreover, they point us to what we can expect in the future.

Intellectual disability has been recognized for millennia, and throughout those many centuries, different terms have been used to describe what we currently call intellectual and developmental disabilities. Some of the terms that began as scientific descriptors, such as “moron,” “imbecile,” and “idiot,” assumed a pejorative meaning and are still used in lay language. In some chapters in this handbook, these and similarly outdated terms are used occasionally for historical accuracy and when older sources are directly quoted. Otherwise, authors use *intellectual disability*, *developmental disabilities*, and abbreviations of ID, DD, and IDD, when referring to each and both together.

Volume 1 of the *APA Handbook of Intellectual and Developmental Disabilities* begins with Part I, Origins and Overviews, in which the historical foundations of the field are described and analyzed (Chapter 1, by Trent), and the definitions of intellectual and developmental disability are provided and compared (Chapter 2, by Schalock & Luckasson). In Chapter 3, McDonald et al. review legal, ethical, and social issues relevant to people with intellectual and developmental disabilities and how societal views of their rights have changed over time and place.

Part II, Causality and Variation, consists of 11 chapters. In Chapter 4, Durkin and Rubenstein provide fundamentals of epidemiology and the value of tracking incidence and prevalence over time, and in Chapter 5, Dykens describes the most up-to-date genetic technologies that have led to earlier and more accurate screening of intellectual and developmental disabilities. The next seven chapters in this part describe the etiology and features of seven different conditions that result in intellectual and/or other developmental disabilities: Down syndrome (Chapter 6, by Hodapp & Fidler), fragile X syndrome (Chapter 7, by Abbeduto et al.), chromosome 15 syndromes (Chapter 8, by DiStefano & Jeste), autism spectrum disorder (Chapter 9, by Pellicchia et al.), acquired brain injury (Chapter 10, by Jacobson & Gerner), cerebral palsy (Chapter 11, by Chin et al.), and fetal alcohol spectrum disorders and other teratogenic conditions (Chapter 12, by Mattson et al.). Causes, characteristics, and variability are addressed, along with treatment, although the last topic is reviewed more extensively in Part I of Volume 2: Evidence-Based Practice and Treatment. The two remaining chapters in Part II of Volume 1 focus respectively on aspects of causality and variation in identification and treatment of persons with intellectual and developmental disabilities that may result from poverty (Chapter 13, by Wachs & Gorman) and the influence of culture, race, and ethnicity on diagnosis, treatment, and individual and family reactions to various interventions (Chapter 14, by Magaña & Vanegas).

Part III of Volume 1, Assessment, Diagnosis, and Labeling, provides the basis for understanding the nature of intellectual and developmental disabilities and the cultural and social ramifications of labeling. The first two chapters in this part address the defining constructs

of intellectual disability in their focus on theories and measurement of intelligence (Chapter 15, by Floyd et al.) and adaptive behavior (Chapter 16, by Tassé & Balboni). The processes of assessment and diagnosis include the possible detection of mental health disorders (Chapter 17, by Lunskey et al.), as people with intellectual and developmental disabilities are at greater risk for them than people in the general population. Intellectual and developmental disabilities, as well as mental health disorders, are stigmatized conditions, and the final chapter in this part and volume discusses societal attitudes, stigma, and ableism toward people with intellectual disability (Chapter 18, by Dell'Armo & Tassé).

Both volumes of this handbook are tied closely to current theory and research relevant to intellectual and developmental disabilities. In Volume 2, *Clinical and Educational Implications: Prevention, Intervention, and Treatment*, chapters are more likely to relate to practice involving people with intellectual and developmental disabilities. Indeed, Part I of Volume 2 is titled *Evidence-Based Practice and Treatment*, and the eight chapters in this part consider varied approaches to achieving the goal of maximizing functioning of individuals with intellectual and developmental disabilities in collaboration with their families, schools, and communities. In Chapter 1 (by McIntyre et al.) and Chapter 2 (by Machalicek et al.), the value and effectiveness of both early intervention and applied behavior analysis are established with thorough reviews of research. The subsequent three chapters (Chapter 3, by Wehmeyer; Chapter 4, by Yell et al.; and Chapter 5, by Copeland & Griffin) focus on special education, and together they provide a comprehensive portrait that incorporates educational theory, law, placement, programming, curriculum, and pedagogy.

Chapters 6 (by Gulsrud & Renno) and 7 (by Friel et al.) focus on the management of two developmental disabilities with a high prevalence, autism and cerebral palsy. Despite the differences in these two conditions and the specifics of these developmental disabilities, the authors of both chapters conclude that progress in treatment and services has been substantial, but definitive research as to effective outcomes of interventions remains to be conducted.

The last chapter in this part does not focus on a particular condition or treatment. Rather, in Chapter 8, Foxx addresses the importance of good science and the multiple instances when treatments, therapies, and theories in science and practice related to intellectual and developmental disabilities have failed to use it. An essential chapter, particularly for scientists in training, it is a reminder to all of us that we cannot suspend our critical thinking when evaluating evidence in the process of making decisions regarding teaching or treatment, as they affect the lives of students and patients. Just as important, the research decisions that we make affect the progress of science.

The second part in Volume 2 focuses on various Lifespan Issues. Chapters 9 (by Glidden et al.) and 10 (by Orsmond & Long) address family impact, with a focus on parents in Chapter 9 and siblings in Chapter 10. In keeping with the lifespan focus, both chapters review family adjustment at multiple life stages during childhood, adolescence, and adulthood, including aging. Indeed, when parents age, and their own health problems make caregiving difficult, siblings often become substitute caretakers in the short and long term.

Because the transition to adulthood is a period in which individual and systemic change both accelerate, it is a much studied time, and deservedly receives its own treatment in Chapter 11 (by DaWalt et al.). Families, schools, and other local and state agencies are involved in this transition to adulthood, as students leave the school system and are served by a variety of agencies that provide employment (Chapter 13, by Wehman et al.) and residential services (Chapter 14, by Lakin et al.). It is also the time when persons with

intellectual and developmental disabilities may first encounter the criminal justice system, and in Chapter 12, Olley and Cox describe the many vulnerabilities that can lead to maltreatment.

For some people with intellectual and developmental disabilities, adulthood can be a time when they are able to integrate into the general population, engage in romantic relationships, marry, and bear and raise children, as described by McConnell et al. in Chapter 15. Part of this integration may involve a religious life, and in Chapter 16, Carter describes the value of spirituality in a religious community wherein worshippers with intellectual and developmental disabilities may be able to achieve acceptance from others of similar faith.

In Chapters 17 (by Hickson & Khemka) and 18 (by Haverkamp et al.), lifespan reviews of maltreatment and health provide additional evidence of the difficulties experienced by people with intellectual and developmental disabilities throughout the life course. They are more likely to be maltreated at all life stages than people without disabilities, and not only do they have more health problems, but they are less likely to find health care professionals who are willing to treat them and more likely to be unable to afford quality health care.

Appropriately, the final chapter before the summary in Part II of Volume 2 (Chapter 19, by Heller & van Heumen) reviews the process of aging in people with intellectual and developmental disabilities. The difficulties encountered at this life stage are similar to those faced by aging individuals who have not had disabilities and, for the first time, may need services provided by caregivers. The future portends an explosion of numbers of people aged 65 or older, with the United States facing a projected 32% increase of residents in this age group from 2020 to 2030. The country must start planning for increases in residential services, including caregivers and health care providers who specialize in gerontology.

ACKNOWLEDGMENTS

The final chapter in the *APA Handbook of Intellectual and Developmental Disabilities* provides a summary and an attempt to predict the future. Its authorship includes the three associate editors—Len Abbeduto, Laura Lee McIntyre, and Marc Tassé—each of whom offer a vast set of experience and leadership in the field of intellectual and developmental disabilities. Together, they and I developed the Table of Contents for this handbook. We recruited lead authors, and each had responsibility for being the primary reviewer for approximately 20% to 25% of chapters. In addition to their role as associate editors, each also was lead author on one chapter. Wayne Silverman, consulting editor, recruited authors for and reviewed three chapters, as well as consulted on the Table of Contents. Despite his retirement and cross-country relocation, he remained available throughout the 3-year gestation of the *Handbook*. I am and will continue to be grateful for all members of this team. They were patient and dedicated, and offered support and wise guidance when it was needed. They and the contributors of all the other chapters created this handbook. Despite numerous other responsibilities, these dozens of professionals were responsive to feedback and cognizant of deadlines. I thank them all.

An additional important acknowledgment goes to APA staff. Although there were undoubtedly many staff members who labored in anonymity, but nonetheless were essential, Katherine Lenz, the reference project editor at APA for this handbook, was a known asset and also a decidedly important one. From the beginning, she was always available and generous with her time. She was patient when I struggled early on with some of the technical aspects of the production, and she offered sage advice when we had problems to solve. On behalf of the editors and authors, I thank her.

Finally, when I was contacted by the APA acquisitions editor, Chris Kelaher, in spring 2016, I was completing 18 months as acting provost at St. Mary's College of Maryland. Even though I knew that I could not begin work on this project for several months, I sensed from the first that it would be a labor of love. More than 50 years ago, in 1966, I began working in the field of intellectual and developmental disabilities as a graduate research assistant to Dr. Keith Scott at the University of Illinois. I view this project as a culmination of my work in the field, needing the kind of perspective that someone with a long history could bring to it. During those 50 years, I met many of the people whose contributions are cited in this handbook, as well as the authors who cited them, and I collaborated with some of them. Throughout these years, they have hovered close to me, and to all of them, I and the field of intellectual and developmental disabilities owe a debt of gratitude and a heartfelt thank-you.

Laraine Masters Glidden
Editor-in-Chief

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