Sam Goldstein · Jack A. Naglieri
*Editors*

# Assessing Impairment

## From Theory to Practice

*Second Edition*

Springer

# Assessing Impairment

Sam Goldstein • Jack A. Naglieri
Editors

# Assessing Impairment

## From Theory to Practice

Second Edition

Springer

*Editors*
Sam Goldstein
Neurology, Learning and Behavior Center
Salt Lake City, UT, USA

Jack A. Naglieri
Curry School of Education
University of Virginia
Centerville, VA, USA

ISBN 978-1-4899-7994-0 ISBN 978-1-4899-7996-4 (eBook)
DOI 10.1007/978-1-4899-7996-4

Library of Congress Control Number: 2016955435

Printed on acid-free paper

This Springer imprint is published by Springer Nature
The registered company is Springer Science+Business Media LLC
The registered company address is: 233 Spring Street, New York, NY 10013, U.S.A.

*This volume is dedicated to the memory of Dr. Thomas Oakland, a contributor to both editions of this book. Tom developed ten standardized tests and edited 15 books, over a hundred book chapters, and 200 scholarly articles. He served as a journal editor and practiced as a forensic neuropsychologist. Tom's contribution to multiple fields in psychology, neuropsychology, and education over the past 50 years is unparalleled. His ideas and science shaped the lives of countless generations of clinicians and educators. Tom's contribution and his wonderful collegiality will be missed by all.*

*Sam Goldstein*
*Jack A. Naglieri*

*For my grandchildren, Isaac and Avery. May they find a path to make all their hopes and dreams a future reality. I also dedicate this new text to a bright new future in education and mental health, a future in which our goal is to understand and strengthen rather than pathologize or repair the lives entrusted to us.*

*S.G.*

*I dedicate this book to my wife, Kathleen Kryza, in thanks for the inspiration she has continually provided.*

*J.N.*

# Preface

In 2009, the first edition of our *Assessing Impairment* text was published. At that time, it was still the case that a consensus definition of functional impairment in human behavior was still a distant goal. Significant progress has been made since the publication of this first edition in 2009. However, it is still the case that the definition of impairment varies widely despite the World Health Organization's efforts to create a standardized nomenclature for the assessment of human impairment. A recent Internet search of functional impairment in people resulted in tens of thousands of peer-reviewed and related articles focused on understanding, defining, evaluating, and treating impairment as a consequence of broad physical, emotional, and environmental phenomena. With the publication of the new DSM-5 (APA, 2014) and ICD-10 (ICD, 2010), the fields of medicine, allied health, and mental health are increasingly directed to appreciate disorders and disabilities as foundationally defined and understood by the level of impairment they cause. In this second edition volume, we have added a number of new chapters, particularly those related to the development of valid and reliable tools to assess impairment, as well as updated many of the chapters from the original volume. We have attempted to examine the methodologies behind the measurement of impairment. Developmental, legal, ethical, and social issues suggest that a comprehensive and consensually based understanding of impairment is essential in the treatment of medical, mental health, and educational challenges, adversities, disabilities, and disorders.

We have devoted our professional lives to the identification, assessment, and treatment of the developmental, cognitive, behavioral, and emotional problems that impact a significant percentage of our population across the life span. Though we are still a long way from understanding all of the powerful forces that ultimately combine to explain why some very disabled individuals lead lives of minimal impairment and vice versa, since 2009 the field has made significant progress. It is now well accepted that not all individuals with similar disabilities, disorders, or symptoms are equally impaired in everyday life. We continue to anticipate that the examination of impairment and its relevance to diagnosis and treatment will define a new era in our understanding of medical, mental health, and educational disabilities. We continue to be indebted to the creative and visionary ideas of the contributors to this volume. Their thoughts and research will shape the future of this important field.

Salt Lake City, UT, USA Sam Goldstein
Centerville, VA, USA Jack A. Naglieri

## References

American Psychiatric Association. (2014). *Diagnostic and statistical manual* (5th ed.). Washington, DC: Author.

International Classification of Diseases. (2010). ICD-10. World Health Organization.

# Quotes

There are two kinds of disabled persons: Those who dwell on what they have lost and those that concentrate on what they have left.

Thomas Szasz

What would happen they conjectured if they simply went on assuming their children would do everything? Perhaps not quickly. Perhaps not by the book. But if they simply erased these growth and development charts with their precise, constricting points and curves. What if they kept their expectations but erased the timeline? What harm could it do? Why not try?

Kim Edwards

Life is about balance. Since I have only one leg I understand that well.

Sally Fussell

# Contents

Part I Background

Part II Modeling Impairment

Part III Assessment and Reduction of Impairment

# Contributors

**Russell A. Barkley** Medical University of South Carolina, Mt. Pleasant, SC, USA

**Samantha Benevenuto Skolnik** Philadelphia College of Osteopathic Medicine, Philadelphia, PA, USA

**Christopher R. Brigham** Brigham and Associates, Inc., Hilton Head, SC, USA

**Jeffery Ditterline** Rush-Henrietta Central School District, Henrietta, NY, USA

**Shannon E. Dowd-Eagle** Department of Counseling, Educational Leadership and School Psychology, Rhode Island College, Providence, RI, USA

**John W. Eagle** Department of Counseling, Educational Leadership and School Psychology, Rhode Island College, Providence, RI, USA

**Gregory A. Fabiano** University at Buffalo, State University of New York, Buffalo, NY, USA

**S. Andrew Garbacz** Department of Special Education and Clinical Sciences, University of Oregon, Eugene, OR, USA

**Sam Goldstein** Neurology, Learning and Behavior Center, Salt Lake City, UT, USA

**Michael Gordon** Department of Psychiatry, SUNY, Syracuse, NY, USA

**Diana Joyce-Beaulieu** School of Special Education, School Psychology, and Early Childhood Studies, College of Education, University of Florida, Gainesville, FL, USA

**Stacey A. Krauss** Employee of CEC Associates, Inc.

**Norma Leclair** Leclair Behavioral Health, Gray, ME, USA

**Steven Leclair** Leclair Behavioral Health, Gray, ME, USA

**Lawrence J. Lewandowski** Department of Psychology, Syracuse University, Syracuse, NY, USA

**Andrew Livanis** Long Island University – Brooklyn Campus, Department of Counseling and School Psychology, Brooklyn, NY, USA

**Benjamin J. Lovett** Department of Psychology, SUNY, Cortland, Cortland, NY, USA

**Keith D. McGoldrick** Neurology, Learning and Behavior Center, Salt Lake City, UT, USA

**Jack A. Naglieri** Curry School of Education, University of Virginia, Centerville, VA, USA

**William E. Pelham Jr.** Department of Psychology, Florida International University, Miami, FL, USA

**Lesley Ritchie** Neuropsychology Service, Department of Clinical Health Psychology, College of Medicine, University of Manitoba Health Sciences Center, Winnipeg, MB, Australia

**Tammy L. Stephens-Pisecco** Midwestern State University, Houston, TX, USA

**Michael L. Sulkowski** Department of Disability and Psychoeducational Studies, School Psychology Program, College of Education, University of Arizona, Tucson, AZ, USA

**Holly Tuokko** Department of Psychology, University of Victoria, Victoria, BC, Canada

Institute on Aging and Lifelong Health, University of Victoria, Victoria, BC, Canada

**Jasen M. Walker** CEC Associates, Inc., Valley Forge, PA, USA

# About the Editors

**Sam Goldstein, Ph.D.** is a doctoral level psychologist with areas of study in school psychology, child development, and neuropsychology. He is licensed as a psychologist and certified as a developmental disabilities evaluator in the State of Utah. Dr. Goldstein is a fellow in the National Academy of Neuropsychology and American Academy for Cerebral Palsy and Developmental Medicine. Dr. Goldstein is an assistant clinical instructor in the Department of Psychiatry. Since 1980, Dr. Goldstein has worked in a private practice setting as the director of a multidisciplinary team, providing evaluation, case management, and treatment services for children and adults with histories of neurological disease and trauma, learning disability, adjustment difficulties, and attention deficit disorder. Dr. Goldstein is on staff at the University Neuropsychiatric Institute. He has served as a member of the Children's Hospital craniofacial team. He has also been a member of the Developmental Disabilities Clinic in the Department of Psychiatry at the University of Utah Medical School.

Dr. Goldstein has authored, coauthored, or edited 38 clinical and trade publications, including 17 textbooks dealing with managing children's behavior in the classroom, genetics, attention disorder, and adult learning disabilities. With Barbara Ingersoll, Ph.D., he has coauthored texts dealing with controversial treatments for children's learning and attention problems and childhood depression. With Anne Teeter Ellison, he has authored *Clinician's Guide to Adult ADHD: Assessment and Intervention*. With Nancy Mather, Ph.D., he has completed three texts for teachers and parents concerning behavioral and educational issues. With Michael Goldstein, M.D., he has completed two texts on attention deficit hyperactivity disorder. He has edited three texts with Cecil Reynolds, Ph.D., on neurodevelopmental and genetic disorders in children. With Robert Brooks, Ph.D., he has authored 11 texts including *Handbook of Resilience in Children*, *Understanding and Managing Children's Classroom Behavior—2nd Edition*, *Raising Resilient Children*, *Nurturing Resilience in Our Children*, *Seven Steps to Help Children Worry Less*, *Seven Steps to Anger Management*, *The Power of Resilience*, *Raising a Self-Disciplined Child*, and *Raising Resilient Children with Autism Spectrum Disorders*. With Jack Naglieri and Sally Ozonoff, Ph.D., he has authored a number of texts on autism, assessment of intelligence, and executive functioning. He has coauthored a parent training program and is currently completing a number of additional texts on resilience, ADHD, and genetics. Dr. Goldstein is the editor in chief of the *Journal of Attention Disorders* and serves on seven editorial boards. He is also the coeditor of the *Encyclopedia of Child Behavior and Development*. With Jack Naglieri, Ph.D., Dr. Goldstein is the coauthor of the Autism Spectrum Rating Scales, Comprehensive Executive Functioning Inventory, Rating Scales of Impairment, and Cognitive Assessment System—2nd Edition.

Dr. Goldstein, a knowledgeable and entertaining speaker, has lectured extensively on a national and international basis to thousands of professionals and parents concerning attention disorders in children, resilience, depression, adjustment and developmental impairments, autism, and assessment of brain dysfunction.

**Jack A. Naglieri, Ph.D.** is a research professor at the University of Virginia, senior research scientist at the Devereux Center for Resilient Children, and professor emeritus of psychology at George Mason University. He is a fellow of APA Divisions 15 and 16 and recipient of APA Division 16 Senior Scientist Award (2001). He earned degrees in school psychology from St. John's University (1975) and worked as a school psychologist in Bethpage, New York, from 1975 to 1977. He obtained his Ph.D. in educational psychology from the University of Georgia in 1979 and taught school psychology at Northern Arizona University (1979–1982), The Ohio State University (1982–2000), and George Mason University (2000–2010). Dr. Naglieri's main interest is in the development of psychological and educational tests and the implications these approaches have for diagnosis and academic or emotional interventions.

The author of more than 250 scholarly papers, chapters, books, and tests, he has concentrated his efforts on psychological theory and measurement. His areas of research include fair assessment, cross-cultural issues, cognitive interventions, learning disabilities, ADHD, mental retardation, gifted, and factors related to resilience. He has published several books including *Assessment of Cognitive Processes: The PASS Theory of Intelligence* (1974), *Essentials of CAS Assessment* (1999), *Helping Children Learn: Intervention Handouts for Use in School and at Home* (2003), *Helping Gifted Children Learn* (Naglieri, Brulles, & Lansdowne, 2008), *Assessment of Autism Spectrum Disorders* (Goldstein, Naglieri, & Ozonoff, 2008), and *Essentials of WNV Assessment* (Brunnert, Naglieri, & Hardy-Braz, 2008). He is also the author of the *Wechsler Nonverbal Scale of Ability* (2006), *Cognitive Assessment System* (1997, 2013), the *CAS Rapid Score* (2002), the *General Ability Measure for Adults* (1997), *Naglieri Nonverbal Ability Tests* (1997, 2003, 2008), *Devereux Early Childhood Assessments* (1997, 2003), *Devereux Elementary Student Strength Assessment* (DESSA; 2011), *DESSA-mini* (2011), *Devereux Scales of Mental Disorders* (1994), *Devereux Behavior Rating Scales—School Form* (1994), *Draw A Person: Screening Procedure for Emotional Disturbance* (1990), *Draw A Person: Quantitative Scoring* System (1988), and Matrix Analogies Tests (Naglieri, 1985).

In summary, Dr. Naglieri has an extensive research program that includes scholarly research, books, and psychological tests with an emphasis on uniting sound theory with scientific practice.

# Part I

# Background

# Defining the Evolving Concept of Impairment

# 1

Sam Goldstein and Jack A. Naglieri

In Western medicine, the medical model guides diagnosis and treatment in all aspects of medicine, mental health, and to some extent, education. The purpose of this model is to identify treatments for diagnoses based on evidence of specific symptoms assumed to suggest problems inherent within one or more organs of the body. The medical model has driven research and theory about physical and mental health problems on the basis of causation, symptom relief, and cure and in many cases has been quite successful (e.g., tuberculosis, measles). As the fields of medicine, psychology, and education have evolved, interest in the degree of impairment an individual may experience in a given situation, regardless of diagnosis, has increased. For example, since the publication of the first edition of this volume in 2009, a recent Google search revealed thousands of relevant books and scientific articles addressing impairments caused secondary to physical, mental health and educational conditions. The second edition of this volume is a testament to the growth of this field.

In part interest in impairment has been spurred by a shift towards the evaluation of disability. The term "disability" had an almost Cinderella effect on the appreciation of impairment in medical, educational, and mental health conditions (Üstün & Kennedy, 2009). Many of these disorders had never been placed on public health priority lists. When disability entered into the equation, as was the case with adjusting life expectancy based on a specific disability, mental, educational, and related medical disorders ranked equal to many more serious diseases and illnesses.

---

S. Goldstein, Ph.D. (✉)
Neurology, Learning and Behavior Center,
230 South 500 East, Suite 100, Salt Lake City, UT 84102, USA
e-mail: info@samgoldstein.com

J.A. Naglieri, Ph.D.
Curry School of Education, University of Virginia,
6622 White Post Road, Centerville, VA 20121, USA
e-mail: jnaglieri@gmail.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_1

Despite the fact that the concept of disability in mental and educational disorders has been well known, the frequency and outcome of these disabilities has never been well defined nor carefully scientifically studied. Furthermore, its use in formulating diagnoses has only been reflected in recent shifts in diagnostic philosophy. For example, the American Psychiatric Association in the new DSM-5 (APA, 2013) very heavily emphasizes the role of impairment over and above symptom presentation. However, the issue of disability has been complicated and often confused with the severity of a particular condition. There is no doubt that there is a positive correlation between the severity of a condition and consequent disability or impairment but many studies have demonstrated that the relationship is not particularly robust (see Lewandowski, Lovett and Gordon, Chap. 10 in this volume). However, the term "functional impairment" is a concept that easily equates with disability in the World Health Organization's International Classification of Functioning, Disability and Health (World Health Organization, 2001).

Until very recently, functional impairment has not been a major focus in diagnosis or treatment in either physical, educational, or mental health problems. Interest has been sparked by an emerging body of literature that has suggested that symptoms and functional impairment need to be considered separately in making diagnostic decisions and evaluating treatment response (Bird et al., 1996) because symptoms and impairment appear to be separate (e.g., orthogonal) concepts (Barkley et al., 2006; Eriksen & Kress, 2005). Functional impairment ratings, for example, for patients with psychosis more likely reflect symptom severity rather than impairment in everyday life (Smith et al., 2011). These findings suggest that the lives of individuals who do not meet specific symptom criteria may be just as impaired and disrupted as the lives of individuals who meet various criteria. Further, many who may meet symptom count for a specific diagnosis may not be significantly impaired. It is therefore not surprising that in a previous version and the most recent revision of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (APA, 2000) a requirement of significant impairment was noted in more than 70 % of the disorders listed as a criterion for diagnosis (Lehman, Alexopoulos, Goldman, Jeste, & Üstün, 2002). This requirement has continued in the new DSM-5 (APA, 2013). Given trends demonstrating an increased incidence of mental health and physical symptoms across the population (Castle, Aubert, Verbrugge, Khalid, & Epstein, 2007), it is not unexpected that there is an increasing need to demonstrate functional impairment as part of a diagnostic process for medical, mental health and even educational conditions. In addition, in this volume, a foundation is provided to further appreciate why understanding impairment is by far the most important and greatest challenge facing medical, educational, and mental health care providers today. This assumes, of course, that impairment can be defined and differentiated from symptoms and disability. Further, a global factor such as culture must also be understood in appreciating the relationship between a particular condition or challenge and everyday functional impairment. Given the complexity of this phenomena, the nature of impairment and the criteria for defining and assessing impairment have been not unexpectedly overlooked in much of the literature (Rapee, Bőgels, van der Sluis, Craske, & Ollendick, 2012).

Webster's New College Dictionary (2008) defines the word *impair* as "the state or fact of being impaired," which means to be weakened or damaged based on the Latin word *pejor* meaning worse. To be impaired means to be unable to perform whatever daily activities are required. But, exactly how does impairment relate to symptom count and severity of a specific condition? How do symptoms and impairments contribute to disability, handicap, and deficits in adaptive functioning? Though impairment in a specific situation might be addressed by asking one question (e.g., Do you have problems at school?), a range of behavioral questions must be answered to appreciate the "why" of the impairment and design treatment. As was our goal in the first volume of this text, it is also our goal and intent in this second edition to begin addressing in an even broader and more comprehensive way than previously these and other critical issues in this fast emerging area of research and practice. Our opinion in 2007 in the first edition of this volume that these and other critical issues in this emerging area would continue expanding has been borne out by the literature. There continues to be an increasing focus on functional impairment in medical, mental health and educational diagnosis and treatment. The need to appreciate the available literature in this area, and even more so to address many unanswered questions, continues to be paramount. Yet, there is still no consistent agreement on even the simplest nomenclature issues about impairment (Rapee et al., 2012). In fact, even as researchers advocate for an expanding appreciation and understanding of impairment in the diagnostic process, progress in clinical practice is slow (Rapee et al., 2012). For example, the DSM-5 Impairment and Disability Assessment Study Group recommended that impairment be viewed as a consequence of a disorder rather than a requisite feature of the disorder itself and that clinical criteria alone should not be used to determine thresholds for diagnosis (DSM-5 Impairment Disability Assessment Group, 2011). Yet, these recommendations fell on deaf ears and the DSM-5 not only did not change this process but completely omitted any organized means of evaluating impairment.

Axis V in the DSM-IV was comprised of the Global Assessment of Functioning (GAF) scale. This scale represented the clinician's judgment of an individual's overall level of functioning in everyday life. Despite research suggesting that the GAF was valid and reliable (Pedersena & Karteruda, 2012), it was dropped from the DSM-5 reportedly for several reasons, including a lack of conceptual clarity and suggestions of questionable psychometrics (Canino, Fisher, Alegria, & Bird, 2013). Instead, the authors of the DSM-5 suggest that the World Health Organization Disability Assessment Schedule (WHODAS) be included in the DSM-5 "for further study" (p. 16). WHODAS is based on the International Classification of Functioning Disability and Health. The authors of the DSM-5 decided to maintain "a manageable size" (p. 17) of their volume to not include these measures but instead suggest that the measures used in field trials be placed online and available for use. However, no census matched, normative data is provided.

A critical question is how to operationalize the constructs in the ICF in a relevant way so that reliable and valid data can be collected concerning cognition, communication, mobility, self-care, interpersonal relations, domestic and occupational life as well as community, social and civic life across the life span (see Fig. 1.1).

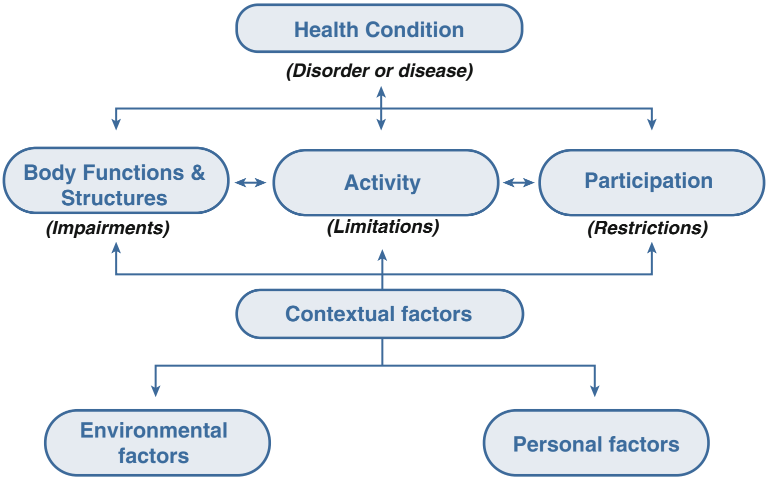


**Fig. 1.1** International Classification of Functioning, Disability and Health (ICF) model of disablement

To be impaired means to be unable to perform whatever daily activities are required. But exactly how does impairment relate to symptom count and severity of a specific condition? How do symptoms and impairments contribute to disability, handicap, and deficits in adaptive functioning? What variables within the family, community, and broader culture may insulate or contribute to impairment. In longitudinal studies, impairment among individuals with mental health disorders is very clearly chronic (Cleverly, Bennett, & Duku, 2013). Further, some symptoms in an algorithmic model are more potent than others in predicting impairment (Vera, Ezpeleta, Granero, & de la Osa, 2010). Further, at certain ages, gender may differentially affect the expression of some symptoms and the severity of functional impairment. Impairment is also very clearly not appreciated on a linear continuum (Baillargeon & Bernier, 2010). Further, the relationship of a particular condition to levels of impairment is also not evenly distributed across a bell curve. Youth of minority status or parents with limited socioeconomic status may experience much greater severity of impairment despite symptoms that are equal to youth in other social classes (Baillargeon & Bernier, 2010). Complicating matters further is the fact that certain conditions may cause more or less impairment in certain settings. This suggests that context and rater may play a significant role in severity of impairment reported (Watabe, Owens, Evans, & Brandt, 2014). Despite 7 years since the first edition of this text, there continues to be limited agreement on even the simplest of nomenclature issues about impairment. The term impairment is used differently by medical, mental health and educational professionals. Without a clear definition, the task of quantifying a method for evaluating impairment is difficult and the application of this important construct in clinical practice further delayed. The expanded contributions in this volume highlight these issues and progress further in laying a foundation to develop a consensus model of functional impairment and more importantly, the role of impairment in diagnosis and treatment.

**Table 1.1** Key definitions

| Key term | Definition |
|---|---|
| Impair | To weaken or damage |
| Impaired | To be unable to perform whatever daily activities are required |
| Impairment | The state or fact of being impaired |
| Symptoms | A physical or mental feature that is regarded as indicating a condition of disease. A sign of the existence of something of an undesirable situation |
| Disability | A physical or mental condition that limits a person's movements. A disadvantage or handicap. With respect to an individual, a physical or mental impairment that substantially limits one or more of the major life activities of such individual, a record of such an impairment or being regarded as having such an impairment (P. L. 108–446, 2004) |
| Disabled | A physical or mental condition that limits a person's movements, senses, or activities |
| Injury | The fact of being injured, harmed, or damaged |
| Injured | To suffer physical harm or damage of one's body |
| Adaptive | Making something suitable for a new use or purpose. Modifying to a new condition |
| Adaptive behavior | A type of behavior that is used to adapt to another type of behavior or situation |

We can take a simple example of a child's activity level to illustrate these differences. A parent is asked to evaluate whether he or she believes his or her child is overactive. The parent endorses a high level of activity in the child. This represents a symptom. In and of itself, it does not necessarily speak to any level of impairment. The parent is then asked to rate whether the child's excessive activity level causes problems and, if so, in what situations? The parent endorses the dinner table as a source of problems. At this point, we know that the symptom presents in a specific situation to a significant degree. The level of impairment is still unknown. The parent is then asked whether the child is capable in any situation of sitting still. The parent responds affirmatively. The parent notes, however, that at the dinner table the child does not sit still. The parent is further asked if the child knows how to properly use dinner utensils and feed him- or herself. The parent again responds affirmatively. At this point, it is clear that the child possesses adaptive skills. That is, the child knows what to do but, as the parent describes, is not doing what he or she knows. This represents a failure to exhibit adaptive behavior but in and of itself is still short of providing the needed information about functional impairment. The parent is then asked to describe what takes place during dinner. Because of the child's symptom severity, an insufficient number of calories is consumed, and food is spilled. This phenomenon represents the impairment caused by this child's hyperactive behavior. Table 1.1 summarizes terminology relevant to the study of impairment. Table 1.2 provides overview of existing conceptualizations of impairment relative to different professional and conceptual perspectives.

An exhaustive review of the literature demonstrates that the relationship between symptoms and functioning remains unexpectedly weak and often bidirectional (McKnight & Kashdan, 2009). These authors suggest that functional impairment may be a better way to evaluate outcome than reduction of symptoms. Further, even minimal symptoms falling below diagnostic threshold will cause impairment

**Table 1.2** Existing conceptualizations of impairment

| Condition | Definition |
|---|---|
| Mental health | The consequences that ensue for an individual as a result of symptoms (Barkley et al., 2006) |
| Medical | A significant deviation loss or loss of use of any body, structure, or function in an individual with a health condition disorder or disease (ICD) |
| Mental retardation | Limited intellectual ability and adaptive behavior as expressed in conceptual, social, and practical skills |
| Educational | A discrepancy between actual and expected performance |
| Resilience | Lack of capacity to function effectively in the face of adversity |

(Balázs et al., 2013). Very clearly impairment exists absent formal diagnosis. Subthreshold symptoms can and do predict impairment (Wille, Bettge, Wittchen, Ravens-Sieberer, & The BELLA Study Group, 2008). Though it is generally true that the more symptoms and the severity of those symptoms presenting, the more impairment noted (Booster, DuPaul, Eiraldi, & Power, 2012; Szuromi, Bitter, & Czobor, 2013). As noted, a broad range of factors may additionally contribute to impairment. Higher maternal education, parents perceived child functional impairment, teachers perceived impaired peer relationships, symptoms of hyperactivity and impulsivity as well as child physical and developmental challenges are all contributing factors to reported impairment in children with ADHD for example (Gau et al., 2010). Further, even when symptoms diminish below diagnostic thresholds, impairments in everyday functioning often remain (Karsten, Penninx, Verboom, Nolen, & Hartman, 2013). Childhood adversities related to maladaptive family functioning, parental mental illness, criminality, family violence, abuse, and neglect contribute significantly to reports of impairment with some simulation studies suggesting that childhood adversity may contribute 20 % of the variance to a child's level of daily impairment (McLaughlin et al., 2010). The complexity of predicting impairment is further appreciated when evaluating the level of a particular variable such as cognitive functioning. Cognitive functioning has not been found overall to be a good predictor of impairment (Naglieri & Goldstein, 2010). However, at the extreme, cognitive limitations very clearly are predictive of significant daily impairment (Kulisevsky et al., 2013; Rog et al., 2014).

Exploratory factor analyses have identified symptoms that reliably cause other symptoms as well as functional impairment (Frewen, Allen, Lanius, & Neufeld, 2012). Very clearly symptoms and symptom severity contribute part but not all of the variance in reported impairment (Gili et al., 2013). McGrath et al. (2013) demonstrated that psychiatric symptom severity was a significant predictor of functional impairment. However, it accounted for less than one third of the variance across disorders. Further, symptoms vary substantially in their associations with impairment with a wide range of outcome. Total variance may range from a low of 0.7 % for conditions such as hypersomnia to nearly 21 % for depression (McGrath et al., 2013). Symptoms appear to have different impacts on different domains. For example, symptoms such as sadness and poor concentration have been found to demonstrate the highest unique associations with broad everyday life impairment in all five life domains (Fried & Nesse, 2014).

## 1.1 Why Should We Care About Impairment?

### 1.1.1 Impairment is a Consequence of All Conditions

In light of the undeniable fact that impairments not diagnoses nor symptoms are the targets of treatment, it might have been expected that diagnostic protocols would have developed initially with impairments and not symptoms in mind. Every medical, mental health or educational condition causes some level of impairment. Often outcome is filtered through many variables within the individual, immediate community and culture eventually leading to the measure of observed impairment. Attention Deficit Hyperactivity Disorder is a condition that has been well known to cause broad levels of impairment (Anastopoulos et al., 2011; Caci et al., 2014; Deault, 2010; Harrison, Vanest, & Reynolds, 2011). Internalizing conditions are also culprits of impairment. Post-Traumatic Stress Disorder (Kassam-Adams, Marsac, & Cirilli, 2010), depression (Holtmann et al., 2011; Karsten, Hartman, Ormel, Nolen, & Penninx, 2010; Lam, Filteau, & Milev, 2011), anxiety (Aderkaa, Hofmanna, Nickersona, Hermes, & Schechtman, 2012); Bertisch, Long, Langenbahn, Rath, & Diller, 2013), and personality disorders (Hengartner, Muller, Rodgers, Rossier, & Ajdacic-Gross, 2014) are representative of the consistent, adverse impact of symptoms and disorders on impairment. Additionally consider:

- Some symptoms in an algorithmic way are more predictive than diagnoses of impairment (Henderson et al., 2009).
- The act of physical aggression by and towards children is a significant, unique predictor of future impairment (Fernàndez, Ezpeleta, Granero, de la Osa, & Domènech, 2011; Hart & Ostrov, 2013).
- Symptoms of inattention are strong predictors of academic impairment while symptoms of hyperactivity/impulsivity are strong predictors of classroom and playground disruption (Garner et al., 2013).
- Children's exposure to violence has also been found to be a powerful predictor of daily functional impairment (Fernàndez et al., 2011).

### 1.1.2 Impairment as a Diagnostic Criterion

Lovett, Gordon, and Lewandowski note in Chap. 6 of this volume that, despite the inclusion of an impairment criterion in two thirds of mental health diagnoses in the DSM-IV, it remains uncertain whether clinicians actually adhere to this practice. As Gordon, Lewandowski, Murphy, and Dempsey (2002) noted, it appears that most clinicians count symptoms when making diagnoses rather than making directed efforts to assess impairment. Chapter 3 authors address important issues about the relationship between symptoms and impairment, inquiring whether individuals who have greater behavioral manifestations of certain conditions may have more negative life consequences. They conclude that in general this is the case, but it remains the fact that far too many variables remain to be addressed before a thorough understanding is developed between symptom count, severity, and functional impairment.

### 1.1.3 Impairment as the Target

The authors of many of the chapters included in this second edition note, the true measure of quality of life is not found in diagnosis or symptom count but in one's ability to successfully perform daily activities. As Walker and Krauss note in Chap. 14, the accurate assessment of a disability, in particular in the vocational arena, should be the primary concern of professionals as well as public policy makers and society in general. The enormous direct and indirect costs to the population at large are driven by these functional impairments, not diagnoses, symptom count or severity. Walker and Krauss note that the critical link between impairment and disability is functional capacity. Disability evaluation must accurately assess functional capacity to truly understand the impact of an injury or handicap on everyday life. They point out the traditional limitations in assessment of impairment, focusing primarily on the traditional medical model of physical capability rather than everyday life.

### 1.1.4 Knowing What to Do or Doing What You Know ?

As Ditterline and Oakland describe in Chap. 3, some individuals may not know what to do, yet others may know what to do but fail for one reason or another to do so in a functional way. Understanding functional impairment requires an appreciation of the interaction between physical capability, past learning, mental health, and most importantly, environmental factors.

As these authors note, each influences the other. An individual may, absent any level of disability, have not had opportunities to learn and develop functional skills. Thus, failure to exhibit functional skills may not be a function of disability but lack of opportunity. Further, in the face of a specific health or mental health disorder, this person may be even more impaired than someone with a history of functioning capably prior to the onset of a particular illness.

As Eagle and colleagues describe in Chap. 2, impairment has a widespread impact that extends beyond the individual. Family functioning, routines, activities, and relationships between family members are ultimately adversely impacted. Thus, conceptualization and understanding of impairment must take on an ecological perspective. Some families may have a number of adversities and fewer resources, which can increase the likelihood of impairment in any of its members when problems are encountered. The issue of impairment is also relevant throughout the life span. In Chap. 5, Tuokko and Ritchie address the issue of impairment in the geriatric population.

### 1.1.5 Valid and Reliable Assessment of Impairment

Traditionally, impairment has been determined by direct observation. Despite the fact that this may in the best circumstances lead to moderate inter-rater reliability, there is a need for a greater evidence based method (Lundh, Kowalski, Sundberg, Gumpert, & Landén, 2010). It is also clear that there is a need for multiple rather than singular measures to evaluate and appreciate impairment (Francis, Ebesutani, & Chorpita, 2012). Further, broad spectrum scales to evaluate impairment may eventually lead to specific impairment scales relative to certain populations (Lewis et al., 2013; Springate, Tremont, & Ott, 2012). It is also the case that effort is increasingly being undertaken to much more closely tie symptoms, diagnoses, and impairment in a predictive relationship (Langley et al., 2014). As of the writing of the first edition of this volume, there was not a comprehensive, valid, reliable, evidence-based system or tool to assess impairment. Over the last 5 years, a number of well-developed scales with census-matched samples have become available. In Chap. 11, Goldstein introduces the Rating Scale of Impairment, an instrument developed to evaluate functional impairment in children. In Chap. 12, Russell Barkley describes his set of scales to assess impairment across the life span. In Chap. 13, Tammy Stephens provides an overview of the Neuropsychological Impairment Scale. These instruments address past concerns about poor inter-rater reliability in measures of impairment (Brigham, Uejo, Dilbeck, & Walker, 2006). In the past this made evaluation results inconsistent across clinicians. These new tools have been created with theory as a foundation and empirical factor analysis as a statistical foundation. Four to six factors have been found in these instruments to predict much of the total variance. This research has begun to help drive an emerging appreciation that impairment can be measured reliably and validly and will load in a number of critical areas. For example, Konstantinos et al. (2012) report four factors, including everyday functioning, social and interpersonal functioning, school functioning, health and welfare. Goldstein and Naglieri (2016) report six factors, including school, home, and social; Singer, Eack, and Greeno (2011) report three factors, school/work, social and home/family; and finally, Herrell et al. (2014) report four factors, physical, occupational, social, and personal. Very clearly there is a consensus that impairment can be reliably and validly measured across various domains and situations. Functional impairment has now become a necessary criterion for all conditions. It is recognized and accepted that all diagnostic and related assessments must address impairment.

## 1.2 Conclusion

The second edition of this volume has added multiple chapters, including sections on modeling, assessment, and intervention. It is our intent that this second edition volume continues the important process of creating a consensus and an integrated, cross-disciplinary conceptual model of impairment. Such a model must include defensible definitions of terminology, methods of assessment, methods to evaluate treatment success and, most importantly, methods to predict outcome over time. We are increasingly realizing that the relationship between symptoms, diagnoses, and impairment is multidirectional. While reducing symptoms will reduce impairment, it is also the case that reducing impairment improves symptoms and quality of life (Huppert, Simpson, Nissenson, Liebowitz, & Foa, 2009). We believe this second volume advances this agenda and sets the stage for continued future work and enhanced clinical practice.

## References

Aderkaa, I. M., Hofmanna, S. G., Nickersona, A., Hermes, H., & Schechtman, E. G. (2012). Functional impairment in social anxiety disorder. *Journal of Anxiety Disorders, 26*, 393–400.

American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text revision). Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Anastopoulos, A. D., Smith, T. F., Garrett, M. E., Morrissey-Kane, E., Schatz, N. K., Sommer, J. L., et al. (2011). Self-regulation of emotion, functional impairment and comorbidity among children with ADHD. *Journal of Attention Disorders, 15*(7), 583–592.

Baillargeon, R. H., & Bernier, J. (2010). The burden of disability in children and youths associated with impairments of psychological functions. *Psychiatry Research, 177*, 199–205.

Balázs, J., Miklósi, M., Keresztény, A., Hoven, C. W., Carli, V., Wasserman, C., et al. (2013). Adolescent subthreshold-depression and anxiety: psychopathology, functional impairment and increased suicide risk. *Journal of Child Psychology and Psychiatry, 54*(6), 670–677.

Barkley, R. A., Cunningham, C. E., Gordon, M., Faraone, S. V., Lewandowski, L., & Murphy, K. R. (2006). ADHD symptoms vs. impairment: Revisited. *The ADHD Report, 14*, 1–9.

Bertisch, H. C., Long, C., Langenbahn, D. M., Rath, J. F., & Diller, L. (2013). Anxiety as a primary predictor of functional impairment after acquired brain injury: A brief report. *Rusk Institute of Rehabilitation Medicine, 58*(4), 429–435.

Bird, H. R., Andrews, H., Schwab-Stone, M., Goodman, S., Dulcan, M., Richters, J., et al. (1996). Global measures of impairment for epidemiological and clinical use with children and adolescents. *International Journal of Methods in Psychiatric Research, 6*, 295–307.

Booster, G. D., DuPaul, G., Eiraldi, R., & Power, T. J. (2012). Functional impairments in children with ADHD: Unique effects of age and comorbid status. *Journal of Attention Disorders, 16*(3), 179–189.

Brigham, C., Uejo, C., Dilbeck, J., & Walker, P. (2006). Errors in impairment rating: Challenges and opportunities. *Journal of Workers Compensation, 15*(4), 19–42.

Caci, H., Doepfner, M., Asherson, P., Donfrancesco, R., Faraone, S. V., Hervas, A., et al. (2014). Daily life impairments associated with self-reported childhood/adolescent attention-deficit/hyperactivity disorder and experiences of diagnosis and treatment: Results from the European Lifetime Impairment Survey. *European Psychiatry, 29*, 316–323.

Canino, G. J., Fisher, P. W., Alegria, M., & Bird, H. R. (2013). Assessing child impairment in functioning in different contexts: Implications for use of services and the classification of psychiatric disorders. *Open Journal of Medical Psychology, 2*, 29–34.

Castle, L., Aubert, R. R., Verbrugge, M. K., Khalid, M., & Epstein, R. S. (2007). Trends in medication treatment for attention deficit hyperactivity disorder. *Journal of Attention Disorders, 10*, 335–342.

Cleverly, K., Bennett, K., & Duku, E. (2013). Effects of functional impairment on internalizing symptom trajectories in adolescence: A longitudinal, growth curve modelling study. *Journal of Adolescence, 36*, 45–53.

Deault, L. C. (2010). A systematic review of parenting in relation to the development and comorbidities and functional impairments in children with attention-deficit/hyperactivity disorder (ADHD). *Child Psychiatry and Human Development, 41*, 168–192.

DSM-5 Impairment and Disability Assessment Study Group. (2011). *Mental disorders: Separating symptoms and disabilities in DSM-5*. Retrieved from http://www.dsm5.org/proposed revision/pages/proposed revision.aspx?rid=465

Eriksen, K., & Kress, V. E. (2005). *Beyond the DSM story: Ethical quandaries, challenges, and best practices*. Thousand Oaks, CA: Sage.

Fernàndez, E. B., Ezpeleta, L., Granero, R., de la Osa, N., & Domènech, J. M. (2011). Degree of exposure to domestic violence, psychopathology, and functional impairment in children and adolescents. *Journal of Interpersonal Violence, 26*(6), 1215–1231.

Francis, S. E., Ebesutani, C., & Chorpita, B. F. (2012). Differences in levels of functional impairment and rates of serious emotional disturbance between youth with internalizing and externalizing disorders when using the CAFAS or GAF to assess functional impairment. *Journal of Emotional and Behavioral Disorders, 20*(4), 226–240.

Frewen, P. A., Allen, S. L., Lanius, R. A., & Neufeld, R. W. (2012). Perceive d casual relations: Novel methodology for assessing client attributions about causal associations between variables including symptoms and functional impairment. *Assessment, 19*(4), 493.

Fried, E. I., & Nesse, R. M. (2014). The impact of individual depressive symptoms on impairment of psychological functioning. *PLoS One, 9*(2), e90311. doi:10.1371/journal.pone.0090311.

Garner, A. A., O'Connor, B. C., Narad, M. E., Tamm, L., Simon, J., & Epstein, J. N. (2013). The relationship between ADHD symptom dimensions, clinical correlates, and functional impairments. *Journal of Developmental & Behavioral Pediatrics, 34*, 469–477.

Gau, S. S., Lin, Y., Shang, C., Liu, S., Chiu, Y., & Soong, W. (2010). Emotional/behavioral problems and functional impairment in clinic- and community-based children with attention deficit/hyperactivity disorder in Taiwan. *Journal of Abnormal Child Psychology, 38*, 521–532.

Gili, M., Toro, M. G., Armengol, S., Garcia-Campayo, J., Castro, A., & Roca, M. (2013). Functional impairment in patients with major depression disorder and comorbid anxiety disorder. *Canadian Journal of Psychiatry, 58*(12), 679–686.

Goldstein, S., & Naglieri, J. A. (2016). *Rating scale of impairment*. Toronto: Multi Health Systems.

Gordon, M., Lewandowski, L., Murphy, K., & Dempsey, K. (2002). ADA-based accommodations in higher education: A survey of clinicians about documentation requirements and diagnostic standards. *Journal of Learning Disabilities, 35*, 357–363.

Harrison, J. R., Vanest, K. J., & Reynolds, C. R. (2011). Behaviors that discriminate ADHD in children and adolescents: Primary symptoms, symptoms of comorbid conditions, or indicators of functional impairment? *Journal of Attention Disorders, 15*(2), 147–160.

Hart, E., & Ostrov, J. M. (2013). Functions of aggressive behavior and future functional impairment. *Early Childhood Research Quarterly, 28*, 683–691.

Henderson, C. M., Rosasco, M., Robinson, M., Meccarello, J., Janicki, M. P., Turk, M. A., et al. (2009). Functional impairment severity is associated with health status among older persons with intellectual disability and cerebral palsy. *Journal of Intellectual Disability Research, 53*(part 11), 887–897.

Hengartner, M. P., Muller, M., Rodgers, S., Rossier, W., & Ajdacic-Gross, V. (2014). Occupational functioning and work impairment in association with personality disorder trait scores. *Social Psychiatry and Psychiatric Epidemiology, 49*(2), 327–335.

Herrell, R. K., Edens, E. N., Riviere, L. A., Thomas, J. L., Bliese, P. D., & Hoge, C. W. (2014). Assessing functional impairment in a working military population: The Walter Reed Functional Impairment Scale. *Psychological Services, 11*(3), 254–264.

Holtmann, M., Buchmann, A. F., Esser, G., Schmidt, M. H., Banaschewski, T., & Laucht, M. (2011). The child behavior checklist: Dysregulation profile predicts substance use suicidality and functional impairment: A longitudinal analysis. *Journal of Child Psychology and Psychiatry, 52*(2), 139–147.

Huppert, J. D., Simpson, H. B., Nissenson, K. J., Liebowitz, M. R., & Foa, E. B. (2009). Quality of life and functional impairment in obsessive compulsive disorder: A comparison of patients with and without comorbidity, patients in remission, and healthy controls. *Depression and Anxiety, 26*(39), 39–45.

Karsten, J., Hartman, C. A., Ormel, J., Nolen, W. A., & Penninx, B. W. J. H. (2010). Subthreshold depression based on functional impairment better defined by symptom severity than by number of DSM-IV symptoms. *Journal of Affective Disorders, 123*, 230–237.

Karsten, J., Penninx, B., Verboom, C. E., Nolen, W. A., & Hartman, C. A. (2013). Course and risk factors of functional impairment in subthreshold depression and anxiety. *Depression and Anxiety, 30*, 386–394.

Kassam-Adams, N., Marsac, M. L., & Cirilli, C. (2010). Post traumatic stress disorder symptom structure in injured children: Functional impairment and depression symptoms in a confirmatory factor analysis. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*(6), 616–625.

Konstantinos, V., Tsiakiri-Vatamidis, A., Tripsianis, G., Tsivgoulis, G., Ioannidis, P., Serdari, A., et al. (2012). Mild cognitive impairment: Effect of education on the verbal and nonverbal tasks performance decline. *Brain and Behavior, 2*(5), 620–627. doi:10.1002/brb3.88.

Kulisevsky, J., Fernández de Bobadilla, R., Pagonabarraga, J., Martínez-Horta, S., Campolongo, A., García-Sánchez, C., et al. (2013). Measuring functional impact of cognitive impairment: Validation of the Parkinson's disease cognitive functional rating scale. *Parkinsonism & Related Disorders, 19*, 812–817.

Lam, R. W., Filteau, M. J., & Milev, R. (2011). Clinical effectiveness: The importance of psychosocial functioning outcomes. *Journal of Affective Disorders, 132*, S9–S13.

Langley, A. K., Falk, A., Peris, T., Wiley, J. F., Kendall, P. C., Ginsburg, G., et al. (2014). The child anxiety impact scale (CAIS): Examining parent- and child-reported impairment in child anxiety disorders. *Journal of Clinical Child and Adolescent Psychology, 43*(4), 579–591.

Lehman, A. F., Alexopoulos, G. S., Goldman, H., Jeste, D., & Üstün, B. (2002). Mental disorders and disability: Time to re-evaluate the relationship? In D. J. Kupfer, M. B. First, & D. A. Regier (Eds.), *A research agenda for DSM-V* (pp. 201–218). Washington, DC: American Psychiatric Association.

Lewis, K., Elam, K., Sellers, R., Rhoades, K., Jones, R. B., Thapar, A., et al. (2013). The depression impairment scale for parents (DISP): A new scale for the measurement of impairment in depressed parents. *Psychiatry Research, 210*, 1184–1190.

Lundh, A., Kowalski, J., Sundberg, C. J., Gumpert, C., & Landén, M. (2010). Children's global assessment scale (CGAS) in a naturalistic clinical setting: Inter-rater reliability and comparison with expert ratings. *Psychiatry Research, 177*, 206–210.

McGrath, L. M., Cornelis, M. C., Lee, P. H., Robinson, E. B., Duncan, L. E., Barnett, J. H., et al. (2013). Genetic predictors of risk and resilience in psychiatric disorders: A cross-disorder genome-wide association study of functional impairment in major depressive disorder, bipolar disorder and schizophrenia. *American Journal of Medical Genetics, Part B, 162B*, 779–788.

McKnight, P. E., & Kashdan, T. B. (2009). The importance of functional impairment to mental health outcomes: A case for reassessing our goals in depression treatment research. *Clinical Psychology Review, 29*, 243–259.

McLaughlin, K. A., Green, J. G., Gruber, M. J., Sampson, N. A., Zaslavsky, A. M., & Kessler, R. C. (2010). Childhood adversities and adult psychopathology in the National Comorbidity Survey Replication (NCS-R) III: Associations with functional impairment related to DSM-IV disorders. *Psychological Medicine, 40*, 847–859.

Naglieri, J. A., & Goldstein, S. (2010). Resilience and impairment: An exploratory study of resilience factors and situational impairment. *Journal of Psychoeducational Assessment, 28*(4), 349–356.

Pedersena, G., & Karteruda, S. (2012). The symptom and function dimensions of the global assessment of functioning (GAF) scale. *Comprehensive Psychiatry, 53*, 292–298.

Rapee, R. M., Bőgels, S. M., van der Sluis, C. M., Craske, M. G., & Ollendick, T. (2012). Conceptualising functional impairment in children and adolescents. *Journal of Child Psychology and Psychiatry, 53*(5), 454–468.

Rog, L. A., Park, L. Q., Harvey, D. J., Huang, C. J., Mackin, S., & Farias, S. T. (2014). The independent contributions of cognitive impairment and neuropsychiatric symptoms to every day function in older adults. *The Clinical Neuropsychologist, 28*(2), 215–236.

Singer, J. B., Eack, S. M., & Greeno, C. M. (2011). The Columbia impairment scale: Factor analysis using a community mental health sample. *Research on Social Work Practice, 21*(4), 458–468.

Smith, G. N., Ehmann, T. S., Flynn, S. W., MacEwan, G. W., Tee, K., Kopala, L. C., et al. (2011). The assessment of symptom severity and functional impairment with DSM-IV Axis V. *Psychiatric Services, 62*, 411–417.

Springate, B. A., Tremont, G., & Ott, B. R. (2012). Predicting functional impairments in cognitively impaired older adults using the Minnesota Cognitive Acuity Screen. *Journal of Geriatric Psychiatry and Neurology, 25*(4), 195–200.

Szuromi, B., Bitter, I., & Czobor, P. (2013). Functional impairment in adults positively screened for attention-deficit hyperactivity disorder: The role of symptom presentation and executive functioning. *Comprehensive Psychiatry, 54*(7), 974–981. doi:10.1016/j.comppsych.2013.04.002.

Üstün, B., & Kennedy, C. (2009). What is "functional impairment?" Disentangling disability from clinical significance. *World Psychiatry, 8*(2), 82–85.

Vera, J., Ezpeleta, L., Granero, R., & de la Osa, N. (2010). Antisocial behavior, psychopathology and functional impairment: Association with sex and age in clinical children and adolescents. *Child Psychiatry and Human Development, 41*, 465–478.

Watabe, Y., Owens, J. S., Evans, S. W., & Brandt, N. E. (2014). The relationship between sluggish cognitive tempo and impairments in children with and without ADHD. *Journal of Abnormal Child Psychology, 42*, 105–115.

Webster's New College Dictionary. (2008). New York: Houghton Mifflin.

Wille, N., Bettge, S., Wittchen, H. U., Ravens-Sieberer, U., & The BELLA Study Group. (2008). How impaired are children and adolescents by mental health problems? Results of the BELLA study. *European Child and Adolescent Psychiatry, 17*(Suppl 1), 42–51.

World Health Organization. (2001). *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.

# The Role of Family and Cross-Setting Supports to Reduce Impairment and Promote Success

# 2

John W. Eagle, Shannon E. Dowd-Eagle,
and S. Andrew Garbacz

## 2.1 Introduction

Families provide an invaluable resource in assessing and supporting the needs of individuals experiencing impairment. Impairment manifests itself in many ways within the family and has an impact on family functioning, routines, activities, and relationships between family members. However, all manifestations are contextually and developmentally relevant. An ecological perspective provides an alternative conceptualization of impairment to a biological, medical model. This framework extends the focus of assessment and intervention beyond the individual to other contexts within which the individual interacts. Families have a great deal of knowledge and expertise regarding an individual's level of behavioral, social, and academic functioning in multiple settings. In addition, development is an ongoing process and the role of families in assessing and reducing impairment must also consider the context of that individual across the life span. Life course theory provides a way to conceptualize impairments based upon an individual's developmental needs, resources, and supports available.

There are several benefits for partnering with families during the assessment process and the development and implementation of support plans. First, incorporating information from family members during the assessment process provides for greater conceptualization of impairment and how it may manifest during different family routines. It also allows professionals to gain an understanding of the family's

---

J.W. Eagle, Ph.D. (✉) • S.E. Dowd-Eagle, Ph.D.
Department of Counseling, Educational Leadership, and School Psychology,
Rhode Island College, Providence, RI 02908-1991, USA
e-mail: jeagle@ric.edu; seagle@ric.edu

S.A. Garbacz, Ph.D.
Department of Special Education and Clinical Sciences, University of Oregon,
Eugene, OR 97403-5208, USA
e-mail: andyg@uoregon.edu

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_2

strengths, needs, and available resources. Second, family members can greatly enhance the intervention development process. Understanding family roles, expectations, and routines allows for a contextual fit between interventions and the family environment. Third, family members can also play an essential role in the implementation of support plans. Developing a shared ownership for intervention implementation with the family can enhance treatment integrity and generalization of treatment effects across settings. Fourth, long-term support programs for individuals with impairment require extensive involvement of family members. Developing a professional–family partnership throughout the assessment and intervention process can promote empowerment within the family to become more self-sufficient in providing support and eliciting additional resources.

## 2.2 Overview of Research

The role of families in the process of assessment and intervention development has long been the interest of research endeavors in the area of impairment. This chapter provides a review of research that explores the relationship between impairment and family functioning, as well as the role of family involvement in comprehensive assessment and support development.

### 2.2.1 Impairment and Family Environments

Families represent extremely complex systems; all families have strengths and needs, and all families, at times, function well and poorly. The presence of impairment provides new challenges to all members of the family and affects many different family aspects. Conoley and Sheridan (2005) identified five different forms of family stressors related to impairment that may be experienced by families: multiple treatment settings, financial stress, effect of impairment on siblings, managing support networks, and family dysfunction. Not all family stressors fall within these categories, but these five represent a solid framework of stressors to assess and manage. They are described in detail below.

#### 2.2.1.1 Multiple Treatment Settings

One of the greatest stressors for families supporting an individual with impairment is the extensive number of settings within which assessment and treatment may take place. Many impairments require the assistance of a specialist to provide a comprehensive evaluation. Often these specialists are not located within immediate proximity of the family (Jackson & Haverkamp, 1991). In addition, the assessment process can be lengthy and can require multiple professionals and specialists in different disciplines and settings (Sloper & Turner, 1992). Thus the assessment and eventual treatment process requires a great deal of organization and coordination between services. This presents the family with the responsibility of rearranging their own schedules, paying traveling expenses, and expending their personal resources of time and energy. Added to this is the consideration that supports to address impairment are often implemented across several environments and include a team of service providers (e.g., physicians, social/case workers, physical therapists, occupational therapists, psychologists, and counselors). Many impairments also involve a variety of treatment modalities, such as behavioral management, psychopharmacologic therapy, family therapy, and educational interventions (Gellerstedt & Mauksch, 1993).

#### 2.2.1.2 Financial Stress

Families requiring services resulting from impairment also tend to experience multiple situations that may increase financial stress (Mactavish, MacKay, Iwasaki, & Betteridge, 2007). The cost of providing services for families, especially those receiving services from multiple agencies, can place a strain on the family's economic viability. Traveling expenses, uncovered medical expenses, legal expenses, counseling expenses, rehabilitation expenses, and environmental modifications (e.g., alterations to the home) are all part of the picture for many families (Conoley & Sheridan, 2005). However, preliminary research indicates that a reduction of quality of life due to available financial resources may be experienced more by mothers than fathers of a child with impairment (Wang et al., 2004).

#### 2.2.1.3 Effects on Siblings

Another potential stressor for families is the impact of impairment upon siblings. Siblings respond to impairment in differing ways and at different times. The role of impairment upon a sibling's development and functioning remains unclear. Control studies have documented an increase in behavioral problems in siblings of children with different forms of impairment (Breslau, 1983; Gath & Gumley, 1987). Alternatively, studies have also demonstrated that siblings of children with impairment are not at risk for problem behavior (McHale, Sloan, & Simmeonsson, 1986).

Parent and family factors appear to play a significant role in the manner in which impairment affects siblings. To further explore this, Giallo and Gavida-Payne (2006) conducted research to evaluate factors that contributed to sibling adjustment to sibling impairment. They reported that the family degree of resilience and risk level were better predictors of sibling adjustment than the sibling's own coping ability and stress levels.

The manner in which siblings are cared for and disciplined by parents and caregivers is also a significant consideration. Parents have reported that they feel uncomfortable when providing differing degrees of discipline among their children with and without impairment (Fox, Vaughn, Wyatte, & Dunlap, 2002). In addition, parents have also reported concerns that their children without impairment may perceive parental favoritism towards siblings with impairment.

#### 2.2.1.4 Managing Support Networks

Families also have several support networks that they need to balance. These networks include formal supports, such as professionals and service providers, and informal supports, including friends and family. Families often receive information and advice from both formal and informal supports. At times this information competes against each other, forcing family members to decide between the two. Potential criticism from relatives can also be a significant source of stress for the family (Miller, 1993).

Friends and relatives offer a great deal of support at the initial point of impairment (e.g., birth or trauma); however, over time these social networks taper their support to the family (Conoley & Sheridan, 2005). Over the long course of rehabilitation or treatment, individuals outside the immediate family begin to lessen their level of attention and availability.

Further, families may also find new support networks composed of parent support groups related to the nature of impairment. Typically, these groups are useful resources of information and advocacy related to the individual's social–emotional, behavioral, and academic functioning. However, sometimes the family does not identify with the experiences of members of the group, based on differences in the nature of impairment. This is particularly true of families with an individual who has multiple impairments. For example, an individual with both cognitive and physical impairments may not find a fit with support groups for cognitive impairments or physical impairments alone. This also can add stress to the family as they struggle to find social support groups that identify with their particular situation.

#### 2.2.1.5 Family Dysfunction

Family functioning is heavily affected by a family's degree of resilience in the face of a crisis. The presence of impairment in a family tends to alter previous family roles, financial resources, family expectations, and family relationships. Impairment within a family can also increase stress, anxiety, depression, anger, blame, and hopelessness within family members (Heru & Ryan, 2002; Zarski, DePompei, & Zook, 1988). All of these changes can instigate difficulties in family functioning and potentially create dysfunction.

Although all families react to the presence of impairment in different ways, families with certain characteristics are more at risk for functional difficulties than others. Adverse effects upon family functioning are greater for (a) families that had poor family functioning before the advent of impairment and (b) families with parents who have existing psychological disorders (Wade, Drotar, Taylor, & Stancin, 1995). Families who are effective problem-solvers, have a sense of strong family coherence, develop effective coping strategies, and have an ability to adapt are more likely to maintaining strong family functioning in the presence of impairment (Ylven, Bjorck-Akesson, & Granlund, 2006).

### 2.2.2 Positive Behavior Support and Families

Positive behavior support is a "collaborative, assessment-based approach to developing effective, individualized interventions for people with problem behavior" (Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002, p. 7) that builds upon the strengths and capabilities of families. Positive behavior support with families provide a paradigm shift away from a deficit approach of impairment to one that promotes the positive contributions of an individual with a disability upon the family (Lucyshyn, Kayser, Irvin, & Blumberg, 2002). Within a positive behavior support framework, families are crucial and integral components of a comprehensive assessment. They are essential partners in (a) understanding contextual factors, setting identification/prioritization, of needs, and determining the functional purpose of behavior; (b) setting appropriate and relevant goals; and (c) developing and implementing support plans. Families are viewed as experts related to an individual's disability, familial impact, and important family cultural and ecological variables (Turnbull & Turnbull, 2001).

There is a practical emphasis on promoting positive behavior support within natural contexts, such as home or school environments (Fox et al., 2002). To accomplish this, collaboration between families, teachers, and professionals has become essential. It is only through effective communication and partnering with caregivers and educators that supports can be developed that fit the environment and context of these complex systems.

Lucyshyn, Albin, and Nixon (1997) assessed positive behavior support in relation to family environment and demonstrated the use of family input in establishing contextual fit. Working with the family of a 14-year-old with multiple disabilities, the researchers conducted a functional behavioral analysis, incorporating information provided by the family into functional hypothesis development and intervention implementation. Four specific family routines were targeted to identify six elements: (a) time and location; (b) people involved; (c) material resources; (d) structure and items to be completed; (e) family goals, values, and beliefs; and (f) typical interaction patterns. A comprehensive assessment was conducted, including an assessment of family ecology and a functional analysis. Behavioral support plans for each of the four routines were designed based on family strengths, resources, and goals. Direct behavioral observations and ratings of social validity indicated the support plans were effective in reducing problem behaviors and acceptable to the family. The contextual fit of the interventions also increased the family members' implementation of procedures with fidelity and consistency.

In an effort to better understand the experiences of families involved with family-centered positive behavior support, Fox et al. (2002) qualitatively evaluated the situations of 20 family members that participated in the process. The participants were involved with the "Family Network Project," a support program for families with children diagnosed with developmental disabilities and behavioral concerns. Families involved with the project were recruited from underserved communities and participated in positive behavior support interventions delivered through in-home services and group support. Through research interviews with participating families, three common themes emerged related to their experience with impairment. The first theme, "something is not right," was directly related to the assessment process and determining the nature of impairment. It was in these early stages that the family continued to seek answers for what was "wrong" with their child. Many families indicated some form of knowledge seeking to provide self-diagnosis or information gathering related to the impairment. The second theme, "a shoulder to cry on," described the families' experiences with formal and informal support.

Both support from professionals and social supports from friends and other families were reported to be helpful and commonly used. Family members described professionals, friends, and relatives who provided emotional support and encouragement as the most helpful. The final and most pervasive theme, "it's a 24-hour, 7-day involvement," depicted how impairment affects the entire family system and nature of family functioning. Families reported some discomfort when responding to problem behavior related to the impairment and difficulties providing consistent supports and consequences across all children in the family.

There has been a great deal of research demonstrating the effectiveness of family-centered, positive behavior support that extends far beyond the scope of this chapter. Positive results have been documented in the areas of: (a) reducing disruptive behavior in multiple settings (Fox, Vaughn, Dunlap, & Bucy, 1997); (b) producing greater generalization, maintenance, and treatment fidelity (Moes & Frea, 2000); and (c) high levels of family reported social validity and acceptability of the process (Koegel, Steibel, & Koegel, 1998).

## 2.3 Guidelines for Assessment

Conducting a comprehensive assessment of impairment involves gaining a greater understanding of the contextual factors involved. An ecological-behavioral model for assessing impairment provides a perspective that includes immediate and surrounding contextual considerations within a developmentally appropriate framework. The goal is to understand the nature and degree of impairment within the current situation, based on what is occurring in the immediate setting (i.e., proximal variables) *and* factors from outside settings (i.e., distal variables) that may also contribute significantly to the impairment. Approaches to assessing impairment may be effective in determining proximal variables (e.g., antecedents, consequences) that have an impact on impairment; however, many assessment processes do not extend to understand distal variables (e.g., family environment, school environment, experiences in other settings) that also may have an effect on exhibited behavior. The consideration of both proximal and distal variables is essential for developing a comprehensive assessment of impairment.

An ecological-behavioral model follows the frameworks provided by ecological systems theory (Bronfenbrenner, 1979) and behavioral theory. The ecological-behavioral model is an alternative to previous deficit models of impairment, and conceptualizes problems as a mismatch between the individual and the environment, not solely within the individual. Thus, an individual's learning and behavior are viewed as a function of continuing interactions between individuals and the multiple settings in which they interact (Pianta & Walsh, 1996; Sheridan & Gutkin, 2000).

Bronfenbrenner identified four systems involved in an individual's development: (a) microsystem, (b) mesosystem, (c) exosystem, and (d) macrosystem. The ecological environment consists of these interdependent systems embedded within each other, like a set of Russian dolls. Therefore, the contextual environment relevant for an individual's development does not simply consist of the immediate

**Table 2.1** Guidelines for incorporating family members and situational factors in the assessment process

- Develop a collaborative partnership
- Address issues related to diversity
- Assess family functioning
- Utilize a family-centered approach
- Assess previous courses of action
- Conduct a functional behavior assessment with family
- Link assessment to intervention

setting, as these four systems are interrelated. Taken together, these systems provide a multitude of influences upon impairment and are critical considerations in the assessment and support building processes.

The *microsystem* consists of the relationship between the child and the child's immediate environment. Examples of this environment can include either the family or classroom setting. It is important to note that the microsystem is the interaction between the child and the environment, not just the child or environment on its own. The *mesosystem* reflects the interaction between two different environments with in which the child interacts. As such, a mesosystem can be comprised of the interaction between the home and school settings. The *exosystem* refers to an environment or context, in which the child is not involved, that has an impact on other members of a major ecosystem. In doing so, the exosystem has an impact on the child's development in the immediate setting. This includes such factors or events at a family member's place of work or a teacher's home life. The fourth system, the *macrosystem*, consists of the larger overall context. This includes cultural and societal emphases and patterns, on which all other ecologies are based, such as (a) the overall societal attitudes, traditions, and beliefs and (b) the overarching political, legislative, and economic policies of society.

Behavioral theory, based on operant conditioning, contends that all behavior is governed by consequences and antecedents. *Antecedents* are events in the environment that cue an individual to exhibit a particular behavior. *Consequences* are the actions in the environment that occur after a behavior is exhibited. Although antecedents cue behavior, the occurrence of a behavior is controlled by the consequences of performing a behavior. If the consequence of a behavior is desired by the individual, then they are more likely to perform the behavior in the future. If the consequence is undesired, then it is less likely that the behavior will occur again. There are two categories of consequences within operant conditioning, reinforcement and punishment. Consequences are *reinforcing* if they increase the likelihood of a behavior's occurrence in the future; alternatively, consequences are *punishing* when they reduce the probability of future occurrence. Problem behavior related to impairment can be effectively addressed by evaluating the nature and influence of consequences and antecedents.

The steps outlined in Table 2.1 indicate guidelines for conducting an assessment of impairment within an ecological-behavioral framework. This process utilizes a collaborative partnership with the family to assess contextual situations and how the impairment is manifested. All of these steps emphasize different considerations during the assessment process and are critical for establishing a more comprehensive understanding of the context surrounding the impairment. These guidelines may be followed in many ways, but the core considerations are presented below.

### 2.3.1 Develop a Collaborative Partnership

The first step for including family members within a comprehensive assessment of impairment is to develop a collaborative partnership with the family. A *collaborative partnership* with families is defined as

> “the establishment of a truly respectful, trusting, caring, and reciprocal relationship in which [professionals] and family members believe in each other’s ability to make important contributions to the support process; share their knowledge and expertise; and mutually influence the selection of goals, the design of behavior support plans, and the quality of family-practitioner interactions” (Lucyshyn, Horner et al., 2002, p. 12).

This is a critical philosophical shift for many professionals. To partner with families, one has to approach assessment with the fundamental belief that everyone has expertise to share. Family members have extensive expertise in the history of an individual’s impairment, how the impairment is exhibited in different settings, the functioning of the family, family need and resources, what has been attempted before to address or manage the impairment, and the goals for seeking services for the impairment. Professionals have expertise in approaches to assessment, professional judgment, information needed to be attained, and summarizing multiple sources of information (e.g., indirect and direct forms of assessment).

However, the emphasis for collaboration should be on developing a partnership with the family, not merely obtaining additional information. This provides an egalitarian approach to assessment and should continue through intervention development, implementation, and evaluation. A systemic way for family members to be involved through the assessment process should be developed. Often this includes established structured interviews of family members, but it should also incorporate a free-flowing conversational component to allow for open-ended questions that may be easier for families to respond to in a less-threatening questioning style (Turnbull & Turnbull, 1991). Further, family members should be allowed and encouraged to participate fully in the assessment process. This may require modifying language in the assessment process to reduce professional jargon and substitute common language for technical terms (Lucyshyn, Kayser, et al., 2002). A full collaboration with the family throughout this process ensures a complete contextual perspective of an individual’s impairment.

### 2.3.2 Address Issues Related to Diversity

The American society is one of the most diverse in the world. However, the American culture is based upon a Euro-American worldview. This worldview contains the following beliefs and values: individualism, competition, mastery and control over nature, a separation of science and religion, time as a unitary and static construct, and religion based on Christianity (Katz, 1985). Human service providers have been criticized for maintaining an individualized approach to assessing and addressing impairment (Quinn, 1995). This perspective is limiting and does not provide critical information regarding the influence of the family and community.

A foundation to working effectively with diverse families is for professionals to develop their own cultural competence. This begins with awareness of one's own cultural background and framework. Through this process, an individual becomes aware of personal values, priorities, and expectations. For professionals assessing impairment, this includes evaluating their own goals for assessment and intervention, their role as the assessor/professional, their meaning of impairment for individuals and families, their perspective of how families should be structured, and what they consider to be effective styles of communication and parenting (Brassard & Boehm, 2007). Only through this self-evaluation can professionals be able to identify whether a difference in worldviews may exist between themselves and the people with whom they work.

In addition, professionals need to refrain from making assumptions about the priorities, goals, and resources of individuals and families from diverse linguistic and cultural backgrounds (Brassard & Boehm, 2007). Each family and community are different despite any linguistic or cultural similarities, and it is extremely detrimental to approach any situation based on perceived stereotypes. In the same manner that professionals self-assess their own beliefs, they should assist families to verbalize their own perspectives. The goal is to identify common and shared beliefs, goals, and expectations. Without determining shared goals, it is difficult to develop a collaborative partnership.

Communication with families from linguistically and culturally diverse backgrounds is also extremely important and can pose some challenges. Effective communication strategies allow for as much reciprocal dialogue as possible among individuals, families, and professionals. First, professionals often need to modify the terminology used in conducting assessments. Jargon and professional terminology can impede the understanding of the individual who is providing or receiving the information. Second, different families have different communication styles, both verbal and nonverbal. Not all families from diverse backgrounds are comfortable with probing and direct questioning from the person(s) conducting the assessment (Chen, Downing, & Peckham-Hardin, 2002). In these situations, more informal and casual questioning can be beneficial. Further, families from diverse backgrounds may favor informal contacts with individuals instead of formal meetings (Harry, 1992), indicating the importance for professionals to build relationships with the family (Chen et al., 2002). Third, it is sometimes essential to utilize an interpreter to facilitate communication between professionals and family members. It is always recommended to use a qualified interpreter rather than a family member. When using an interpreter, it is preferred for all parties to look at each other as they are talking instead of the interpreter. It is also extremely important to consider how specific words may be transferred from one language to another. Many times, nuances are not able to transfer and unwanted connotations may be added, making it important for everyone to have effective communication with the interpreter to ensure the best possible communication.

Gaining an understanding of the family's values, beliefs, resources, and expectations allows the professional to truly assess the context surrounding the impairment. Developing an understanding of culture enables a person to view the world "through the eyes" of that person. Thus, being "multicultural" refers to being "multivisional" in perspective or extending one's ability to understand other people (Soriano, Soriano, & Jimenez, 1994). *Multiculturalism* refers to a "broad range of significant differences (race, gender, sexual orientation, ability, and disability, religion, class, etc.) that so often hinder communication and understanding among people" (Sue & Sue, 1999, p. 1064). This approach to a comprehensive assessment allows for intervention development to fit within the context of the individual and family.

## 2.3.3 Assess Family Functioning

Family functioning plays a critical role in the manner in which impairment is exhibited, maintained, or managed by the individual and its affect on other members of the family. It is widely accepted that family functioning is a multidimensional construct that is highly influenced by the relational processes within families. Common factors related to family functioning that should be assessed include family cohesion, family involvement, family adaptability, parenting styles, and a family belief system. In general, each of these aspects of functioning falls along a continuum with optimal functioning and family resilience existing within moderate degrees, outside of the extremes.

### 2.3.3.1 Family Cohesion

The concept of *family cohesion* represents "family members' close emotional bonding with each other as well as the level of independence they feel within the family system" (Turnbull & Turnbull, 2001, p. 124). Levels of emotional connectedness between family members are influenced by the culture, age, and stage of life of the family member and vary significantly between and within families. Family cohesion exists on a continuum, ranging from enmeshed (very high), to very connected (moderate to high), to connected (moderate), to somewhat connected (moderate to low), to disengaged (very low) (Olson & Gorall, 2003). Interactions that are enmeshed are characterized by an overidentification with the family, resulting in extreme levels of consensus and limited individual autonomy and independence. Families that are disengaged are marked by high autonomy and low bonding, depicting little attachment to the family system. Families that have a balance between enmeshment and disengagement tend to have healthier levels of functioning (Olson & Gorall, 2003).

#### 2.3.3.2 Family Involvement

The extent to which family members value and display interest in the activities of other family members defines the notion of affective involvement (Epstein, Ryan, Bishop, Miller, & Keitner, 2003). Affective involvement emphasizes the degree of interest as well as how family members demonstrate their interest and investment in each other, and exists on a continuum, ranging from lack of involvement to over-involvement. Considered to be the optimal level, *empathetic involvement* refers to a genuine interest; family members are invested for the sake of others in the family unit. Empathetic family involvement practices promote healthy functioning within families.

#### 2.3.3.3 Family Adaptability/Flexibility

The presence of impairment certainly highlights a family's ability to adapt to new situations. Family adaptability or flexibility represents a family's ability to modify its rules, roles, and leadership based on new situations or experiences. This restores a balance between (a) family members and the family unit and (b) the family unit and the community (Olson & Gorall, 2003; Patterson, 2002b). Families have differing degrees of adaptability that fall along a continuum from rigid/inflexible (extremely low) to somewhat flexible (low to moderate), to flexible (moderate), to very flexible (moderate to high), to chaotic/overly flexible (extremely high) (Olson & Gorall, 2003). Moderate degrees of adaptability (e.g., structured or flexible) may allow for healthier degrees of family functioning than those on the extremes (e.g., rigid or chaotic).

Families need to be both stable and able to adapt in order to function as a healthy system. Healthy, functional families are able to determine when it is appropriate to maintain stability or address change (Olson & Gorall, 2003). Successfully adaptive families (a) are proactive in the socialization and development of individual family members and (b) understand the importance of maintaining the family unit (Patterson, 2002a).

#### 2.3.3.4 Parenting Styles and Problem-Solving Processes

A family's ability to communicate and problem solve effectively is highly related to family functioning. This is particularly true of families who have an individual with impairment. Clear, direct, and honest communication, active listening, and positiveness are all communication styles associated with healthy family functioning. Family functioning also benefits from collaborative problem-solving that includes shared decision-making among family members, is goal-oriented, follows concrete steps, and builds on successes (Walsh, 2003).

A family's ability and overall style of communication and problem-solving is represented by the interactions between parents and children. Four types of parenting styles have been outlined by Baumrind (1991): authoritarian, indulgent, uninvolved, and authoritative. Authoritarian parenting styles are marked by high levels of authority and control, with limited negotiation regarding standards of behavior. Indulgent parents, in contrast to authoritarian parents, allow children to regulate their own activities, standards, and rules, with few decisions imposed by caregivers. Uninvolved parents are not responsive to their children and do not provide behavioral demands. Authoritative parenting, is marked by a balance between freedom and responsibility. Authoritative parents engage family members in problem-solving processes to negotiate compromise and manage conflict.

#### 2.3.3.5 Shared Beliefs and Values

Another critical component of healthy family functioning is the presence of a shared belief system. Shared values and beliefs reinforce specific patterns regarding how a family reacts to new situations, life events, and crises and are necessary for strong family resilience. A family's response to impairment is often dependent upon the existence of shared family values and expectations. Having a common belief system helps families to make meaning of crises, situational events, and impairment and also facilitates hope and a positive outlook (Walsh, 2003).

Related to a shared belief system, a strong family schema represents a perspective that the family interacts with the world from a collective "we" versus "I" orientation (McCubbin, McCubbin, & Thompson, 1993). Strong family schemas help families perceive life in a realistic manner and not expect perfect solutions to difficulties that life presents (McCubbin et al., 1993).

#### 2.3.3.6 Measuring Family Functioning

When adopting an ecological-systems perspective, there is not one best way of assessing family functioning; rather, it is often necessary to evaluate multiple aspects of how the family operates (Bray, 1995). Methods of evaluating family functioning include family member self-report measures, observation of family interactions, and clinician rating scales.

Commonly used measures of family functioning include the McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983), Family Adaptability and Cohesion Scales (FACES IV; Olson, Gorall, & Tiesel, 2005), Family Environment Scale (FES; Moos & Moos, 2002), Parenting Stress Index—Fourth Edition (PSI; Abidin, 2012), Family Functioning Style Scale (Deal, Trivette, & Dunst, 1988), and the Family Functioning Scale (FFS; Bloom, 1985).

### 2.3.4 Identify Family Needs and Resources

Families are best included in the assessment process through the use of a family-centered approach. A family-centered approach for assessment follows four guiding principles (Dunst, Trivette, & Deal, 1994): (a) determining family-identified needs and goals, (b) addressing family strengths and resources, (c) determining the family's social network, and (d) evaluating the family's degree of empowerment.

#### 2.3.4.1 Family-Identified Needs

Individual and family interventions related to impairment have the greatest impact when they are developed to address the specific needs of the family (Dunst et al., 1994). As such, the most effective assessments provide information regarding self-determined needs of the family, not those identified by the professional. Professionals working with families in the assessment process assist family members to identify, define, and prioritize their specific needs. Needs are often identified within a hierarchy that determines the relative importance and immediacy for the family. A family's ability to address these needs is enhanced through the development of specific objectives. To help families achieve these objectives, professionals should also assist families in developing short- and long-term goals.

#### 2.3.4.2 Family Strengths and Resources

All families have varied strengths and resources available to them that they can use to help address any issues related to impairment. It is important during the assessment process to not only identify these strengths and resources, but also determine the accessibility of the resources. Environmental or systemic conditions can sometimes provide families with barriers to attain resources. Thus, it is critical to determine how families may utilize their strengths to mobilize available resources.

#### 2.3.4.3 Social Networks

In addressing individual and family needs and strengths related to impairment, connections between other systems and networks also need to be assessed. Collaborations with intra- and intersystemic partners are necessary for addressing the needs of the individual and family (Sheridan, Eagle, & Dowd, 2005). These linkages often exist within Bronfenbrenner's mesosystem and connect different environments within which an individual exists. During the assessment process, it is beneficial to determine the nature of any partnership between the family and human service, educational, health care, neighborhood, spiritual, or other community organizations. Importantly, not all networks need to be formal; informal and natural social networks are also quite helpful for families and provide extensive support.

#### 2.3.4.4 Family Empowerment

A comprehensive assessment based on family-centered services also evaluates the family's degree of self-sufficiency. That is, what competencies does the family possess to achieve the identified goals? This is a picture of where the family is at the moment, or what skill or capacity development might enhance the family's ability to address issues related to impairment. This level of assessment allows for interventions to be developed that build capacities within the family as opposed to simply correct a problem.

### 2.3.5 Assess Previous Courses of Action

Families can provide extensive information on previous efforts to address concerns related to impairment. Primarily, they can assist in understanding (a) what supports have been implemented previously and (b) whether they were effective. These two questions provide an opportunity to gain vital information related to the social validity of previous support plans and the fidelity with which plans were implemented. Assessing previous efforts is a critical component to establishing current support plans that are contextually appropriate and have the best chance to be implemented appropriately and consistently. Building from previous efforts can expedite the process and prevent one from "reinventing the wheel."

#### 2.3.5.1 Social Validity

A key aspect of assessing past strategies is to ascertain the family's perspective of the effectiveness and acceptability of the intervention. This is referred to as the social importance of an intervention, or social validity. Whether or not a family perceived a previous support plan to be effective or acceptable for their unique context provides fundamental information for the development of a new plan. The key is to incorporate or modify aspects that the family deemed effective or acceptable into current strategies. Even the best plans will not be implemented if they are considered to be unacceptable for a given situation or context.

#### 2.3.5.2 Treatment Fidelity

Not surprisingly, a support plan is only effective if it is implemented appropriately. Support plans that are not implemented as intended or consistently are likely to fail to produce beneficial results. There are many reasons that an intervention may not be implemented effectively, including (a) a lack of knowledge or expertise, (b) limited resources to provide the opportunity, or (c) a lack of contextual fit between the plan and the surrounding environment. Family members can provide information regarding their ability and resources available to carry out a support plan consistently. This assists professionals in determining if training, modeling, repeated practice, additional resources, or other modifications are necessary to ensure that the support plan developed is implemented with fidelity.

### 2.3.6 Conduct a Functional Behavior Assessment

One of the key purposes of conducting an assessment is to gain information that will assist in developing interventions that have a contextual fit. In many cases this contextual fit may involve home or schools settings, and often both. A prominent and evidence-based method to assess how to support an individual with an impairment is through functional behavior assessment. A functional behavior assessment is a systematic process designed to evaluate how impairment is associated with behavioral, academic, or social difficulties within specific situations, environments, or contexts. Functional behavior assessment also provides an opportunity to partner with families to evaluate the effect of situational problems upon impairment, and should be conducted with input from the family to ensure that they are contextually appropriate.

There are two forms of functional behavior assessment used when assessing the nature and degree of impairment: (a) contextual, those that evaluate conditions within a single setting (e.g., home or school) and (b) cross-setting, those that look

**Table 2.2** Guidelines for conducting a functional behavior assessment

| |
|---|
| • Identify and operationally define a prioritized concern |
| • Identify antecedents, consequences, and setting events |
| • Develop hypotheses regarding the function of the problem |
| • Build behavioral support plans derived from hypotheses |

at similarities and differences within conditions across settings (e.g., both at home and school). Although contextual functional behavior assessment may gather information regarding proximal variables from the immediate setting, cross-setting assessment also provide information of distal variables from outside, additional settings.

Information attained in a functional behavior assessment comes from multiple informants (e.g., the individual, family members, caregivers, educators, service providers) and multiple sources. Typically, a functional behavioral assessment includes information from record reviews, structured interviews, and direct behavioral observations. Record reviews provide background information from previous assessment reports, educational achievement, social service case history, and documented progress towards behavioral or educational planning goals. Structured interviews allow for a professional to discuss more detailed information in person with the individual and family. However, not all information provided by the family needs to be received through structured interviews as informal conversations can also provide useful, detailed information. Through behavioral observations, direct information regarding how the impairment is manifested in different contexts can be ascertained. Direct observations are used to collect data on the frequency, duration, or intensity of specified difficulties. In addition, direct behavioral observations provide assessment information that includes what happens before and after problem behaviors occur.

Functional behavior assessment consist of four major components that are outlined in Table 2.2. In general, a functional behavior assessment serves to answer two basic questions: (a) under what conditions a behavior occurs more/less frequently (e.g., setting, surrounding individuals, time of day), and (b) what might be the possible reasons for a behavior to occur.

First, professionals and family members (and/or teachers) work together to collaboratively define, in operational terms, how the impairment manifests itself into identified difficulties or needs. Through this process family members (and/or teachers) identify their concerns related to the impairment and prioritize the most important area, difficulty, or need to support. Generalized difficulties are redefined and prioritized into one or two specific, primary difficulties for immediate intervention.

Second, through a series of interview questions the family identifies the before and after events related to the identified concern. This process identifies the antecedents, consequences, and setting events that may maintain or govern the specific difficulty or problem behavior. Additional information can also be obtained through behavioral observations of the individual in the home or school setting.

To comprehensively assess the context surrounding the impairment, it is advised that professionals also assess family routines and the family environment (Lucyshyn, Kayser, et al., 2002). This can also be conducted through interviews with family members, open-ended conversations, rating scales, and observations.

Third, using this information, family members (and/or teachers) and professionals collaboratively develop potential hypotheses regarding the function, or purpose, of how the impairment may be exhibited through problem behavior or identified difficulties/needs. These hypotheses should be testable, meaning that through observations a generated hypothesis can be verified or rejected. Other than determining that a problem behavior related to impairment represents a skill deficit, there are two main functions of behavior (Crone & Horner, 2003). First, a behavior may occur in order to get something, either a tangible object or attention. Second, the motivation for performing a behavior may result from avoiding or escaping something undesired.

Fourth, information and data collected during the assessment process are connected to intervention development. Behavioral support plans are developed that are linked explicitly to the hypothesized function. Specifically, alternate, more appropriate behaviors are reinforced that serve the same function as the problem behavior. A major principle in developing behavioral support plans through functional behavior assessment is for the individual to experience the same function for performing the appropriate behavior as the inappropriate behavior.

Family members should be involved throughout the functional behavior assessment process within the guidelines of the collaborative partnership. Information provided by the family is typically ascertained through the use of structured interview forms, such as the Functional Assessment Interview (FAI) form (O'Neill et al., 1997) and the Functional Behavioral Assessment Interview (Crone & Horner, 2003). There are also several valid observation forms that are used with a functional behavioral assessment, including the functional observation interview (FOI) form (O'Neill et al., 1997) and behavioral observation scatterplot forms.

### 2.3.7 Link Assessment to Intervention

The final component of a quality, comprehensive assessment is to link the findings from the assessment to supports or interventions for the individual or family. It is important to utilize the information ascertained in the assessment process to enhance the effectiveness of supports provided. This link between assessment and intervention ensures that the services delivered are contextually appropriate. Otherwise, interventions that are developed will not be implemented with fidelity.

Information attained from both family-centered service and functional behavior assessment approaches allow for a systematic way for the assessment process to be connected with intervention development. Both assessments and interventions provided within a family-centered framework follow the same four principles: (a) family-identified needs and goals, (b) family strengths and resources, (c) family's social network, and (d) family's degree of empowerment. This makes it easier to connect the information received from families to the provision of supports. Similarly, functional behavior assessment systematically generates hypotheses of behavioral function that lead directly to intervention development. The creation of a competing pathways model (Crone & Horner, 2003) during functional behavior assessment and positive behavior support development ensures a direct link between assessment and intervention.

However, in all instances, it is the development of a collaborative partnership between families and professionals that truly influences the quality of assessment information and adherence to treatment recommendations. Through open communication, supports can be developed that address needs related to impairment and fit within the ecology of the family. But, a true partnership establishes a shared ownership of the (a) problem or area of need, (b) implementation of supports, and (c) evaluation of support plan effectiveness.

## 2.4 Life Course Theory

The life course theory proposes that development is an ongoing and interactive process that occurs across an individual's life span. Further, the theory posits that early experiences and the broader ecological context strongly influence development, particularly during critical or sensitive periods (Fine & Kotelchuck, 2010). Given this perspective, it is helpful to consider the family's role in assessment and intervention practices at different life stages including early childhood, school-aged, and the transition into adulthood. Families represent the one constant and stable presence across the course of a child's life and thus are uniquely positioned to provide a longitudinal perspective regarding their child's development.

### 2.4.1 Early Childhood Assessment

Early childhood experiences provide the foundation for later development, and assessment conducted during these formative years can support optimal delivery of early intervention and prevention services. Early childhood assessment consists of a "flexible, collaborative decision making process in which teams of parents and professionals repeatedly revise their judgments and reach consensus about the changing developmental, educational, medical and mental health service needs of young children and their families" (Bagnato & Neisworth, 1991, p. xi). Best practice guidelines in early childhood assessment highlight the importance of authentic assessment procedures that are family centered, developmentally appropriate, and purposeful (Neismworth & Bagnato, 2007). These guidelines are supported by professional organizations including the National Association for the Education of Young Children (NAEYC), the National Association of Early Child Specialists in State Departments of Education (NAECS/SDE), and the Division of Early Childhood (DEC).

### 2.4.2 Authentic Assessment Practices

Authentic assessment practices gather information about a child's social, developmental, and behavioral functioning from knowledgeable caregivers within naturally occurring contexts (Dennis, Rueter, & Simpson, 2013). This approach emphasizes assessment techniques such as interviews and observations in lieu of individually administered standardized assessments. In contrast to traditional methods, children are assessed while participating in age-appropriate activities that incorporate familiar materials, events, and situations so that the results reflect the child's actual performance. The use of multisource and multi-informant assessment measures can provide a comprehensive picture of a child's strengths and areas of need across settings. Further, results can be used to inform instruction, intervention, and program planning (Macy & Bagnato, 2010).

### 2.4.3 Purposes of Early Childhood Assessment

Assessment must serve a specific purpose, and results must be used towards the intended objective. One purpose of assessment is to inform instruction. In this case, assessment results are used to support teaching decisions and improve learning by providing instructionally relevant strategies that early childhood educators can implement in their classrooms. A second purpose of assessment is to identify individual or groups of students that may benefit from targeted intervention. These data are used to select evidence-based interventions that can support a child's functioning and enhance their developmental trajectory. A third purpose is to evaluate the effectiveness of early childhood programs. When assessing programs, data are used to improve practices and measure progress toward outcomes. Finally, as children transition from early childhood programming to school-based contexts, assessment data are often used to determine eligibility for services.

### 2.4.4 Transition from Early Childhood to School-Based Services

The transition from early childhood to school can be an exciting time; however, it often represents a significant adjustment for children with disabilities and their families. The success of this transition can play a critical role in influencing future educational outcomes and life opportunities (Dockett & Perry, 2007; Fabian & Dunlop, 2006), so careful consideration must be paid to the selection and administration of assessment instruments. Although best practice guidelines recommend the use of a family-centered approach (Neismworth & Bagnato, 2007), many caregivers find the assessment process challenging. Specifically, families may encounter difficulties such as limited understanding of the assessment processes, duplication of assessments, waiting lists, discontinuity of services, limited communication, and disregard for family experiences (Tudball, Fisher, Sands, & Dowse, 2002). To promote a successful transition, it is important to consider the degree to which assessment practices engage parents as partners by (1) promoting bidirectional communication to demystify the process, (2) valuing caregivers' expertise and experiences, (3) encouraging joint development of educational goals, and (4) coordinating supports to minimize gaps in service delivery.

### 2.4.5 Assessment of School-Aged Children

The current educational landscape promotes preventative frameworks for supporting the academic, social–emotional, and behavioral development of school-aged children. Rising out of this framework is an integrated model for assessing and supporting student and family needs: Multi-Tiered System of Supports (MTSS). MTSS is a framework that integrates current educational models based upon a three-tiered system of prevention, namely School-Wide Positive Behavioral Interventions and Supports (PBIS) for behavioral/social concerns and Response to Intervention (RtI) for academic needs. These preventive models provide opportunities for assessment and intervention at three levels of support: universal, targeted, and individualized. Degrees of intensity of assessment procedures and intervention are increased as students are provided supports at higher level of the framework. Universal supports are provided to all students in a school. Targeted supports are provided to groups of students who need more additional support. And, individualized supports provide the most intensive and complex assessment and interventions, often being multifaceted and multi-setting.

This multi-tiered model should not be viewed as existing within the structure of the school alone; it also extends to the delivery of services based upon collaborative school, community, and family partnerships. Each level of support (e.g., universal, targeted, individualized) provides opportunities for schools to partner with families. As such, families have a great role in the assessment procedures used within all three tiers; however, varying in degrees of intensity.

#### 2.4.5.1 Family Involvement in Assessment at the Universal Level

As part of a MTSS scoped and sequenced school-wide initiative, families can be actively involved in universal (school-wide) procedures. The ecological approach to family intervention and treatment (EcoFIT; Dishion & Stormshak, 2007; Fosco, Dishion, & Stormshak, 2012; Stormshak & Dishion, 2009) is a school-wide approach to providing family-centered services and facilitating healthy family–school connections. At the universal level, several strategies are employed, including developing a family resource center, engaging school personnel in proactive collaborative contacts with families, and a screening system to identify students who may benefit from additional support (Fosco et al., 2012).

The screening system is particularly relevant for family involvement in assessment. At the beginning of the school year, schools using EcoFIT may distribute a parent student readiness screener (Moore et al., 2016) that asks parents to rate areas of concern for their child (e.g., avoiding difficult or challenging tasks). In addition to rating whether children may have concerns in specific areas, parents can also indicate whether they believe their child would benefit from additional support. The use of a proactive parent screener allows all parents in a school community to report about their children's needs. It also serves as an important entry point for school personnel to partner with families to address child needs (Fosco et al., 2012). In fact, parent report of concerns about their child on a parent screener in the fall have been found to be statistically significantly correlated with parent-report of school initiations of contact the following spring (Moore et al., 2016). Thus, it may be that proactively engaging families who report concerns or request support in the fall may prevent future school-initiated contacts later in the school year when child behaviors may have increased in severity and/or frequency.

#### 2.4.5.2 Family Involvement in Assessment at the Targeted Level

Within the MTSS framework, many schools notify families of academic, social–emotional, or behavioral concerns when determining the appropriateness of targeted interventions at the second tier. The determination for providing more intensive supports to a student not responding to core universal instruction requires more intensive assessment, and often requires family consent. This assessment is twofold, (a) whether the child requires more intensive supports and (b) what are the appropriate supports to provide.

Families are able to provide critical assessment information when considering providing targeted supports. Targeted supports can be provided in areas of behavior, social–emotional, and academic functioning. Each of these areas has unique ways for families to be involved in the assessment and intervention process. Without this family input, schools may have significant difficulty providing the type of support that best matches the need.

Within the behavioral and social–emotional realms, families are often asked to complete rating scales related to the areas of functional difficulty. Parent rating scales provide information regarding home and community settings and are often compared to teacher ratings for the same set of behaviors/degree of functioning. There are many widely used rating scales in schools. The Behavioral Assessment Scale for Children-3 Parent Rating Scale (BASC-3 PRS; Reynolds & Kamphaus, 2015) provides parent input regarding problem behaviors, and can be helpful for making determination for classifications based on the Inidividuals with Disabilities Education Act (IDEA 2004) and the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013). The Social Skills Improvement Rating Scales-Parent (SSIS-Parent; Gresham & Elliott, 2008) provides information related to social functioning. And, the Multidimensional Anxiety Scale for Children-2 Parent form (MASC; March, 2012) assesses difficulties related to anxiety.

Determining appropriate academic supports at the second tier of MTSS requires specific information from families regarding the child's present level of academic performance. This information includes family input regarding the primary language spoken at home, opportunities for practice at home, family culture and value system, and acculturation and socialization considerations.

#### 2.4.5.3 Family Involvement in Assessment at the Individualized Level

Coordinated family involvement in assessment and intervention at the universal and targeted levels is essential to address impairment and promote child and youth success. However, there are some children and youth who will need specialized individual supports. The Family Check-up (Dishion & Stormshak, 2007) and Conjoint Behavioral Consultation (Sheridan & Kratochwill, 2008) are two structured models with extensive empirical support (Garbacz, Swanger-Gagné, & Sheridan, 2015) that actively engage families through comprehensive assessment, intervention development, intervention implementation, and progress monitoring.

The Family Check-up (FCU; Dishion & Stormshak, 2007) is the primary service available for families who receive EcoFIT (Stormshak & Dishion, 2009). As previously mentioned, EcoFIT is a multilevel model for engaging and intervening with families (Stormshak & Dishion, 2009). At the universal level, a family resource room is established at the school (Fosco, Frank, Stormshak, & Dishion, 2013). The family resource room includes information and resources for families about available services. A parent consultant can work with families to provide relevant information about their child's needs, briefly consult (e.g., about homework), and attend school meetings with families. In addition, parent seminars about topics relevant to family needs can be provided. For families that may benefit from additional support, the FCU can be initiated.

The FCU is derived from the Drinker's Check-up (Miller & Rollnick, 2002) and uses similar motivational features. The FCU includes assessment and feedback for families in a three-session format (Dishion & Stormshak, 2007). The first session builds on prior initial contacts (e.g., telephone) and focuses on discussing goals and histories, supporting parents, expressing optimism, and assessing motivation (Dishion & Stormshak, 2007). In the second session, parents may complete an assessment packet. The assessment focuses on ecological characteristics of the systems affecting the child (Dishion & Stormshak, 2007). As an augment to the self-report assessments, families may also be videotaped completing a structured task (Stormshak & Dishion, 2009). In the third meeting, the feedback about assessment findings is discussed with families in terms of their motivation and appropriate resources based on assessment findings and linked to a menu of intervention options (Stormshak & Dishion, 2009). The menu of intervention options is collaboratively examined with families to identify reasonable next steps. Interventions may include (a) support and problem-solving and (b) skill-building interventions. Following the FCU check-ins may be conducted by the parent consultant.

Reviews of research on the FCU have consistently found strong empirical support for its use (Garbacz et al., 2015; Stormshak & Dishion, 2009). Specifically, the FCU is associated with improvements for young children and adolescents. The FCU is linked with improved problem behavior for young children (Dishion et al., 2008). For adolescents, family engagement in the FCU is associated with better school attendance (Stormshak, Connell, & Dishion, 2009), lower substance use (Dishion, Nelson, & Kavanagh, 2003; Stormshak et al., 2011), increased self-regulation (Fosco et al., 2013; Stormshak, Fosco, & Dishion, 2010), and lower rates of antisocial behavior (Stormshak et al., 2011).

Conjoint Behavioral Consultation (CBC; Sheridan & Kratochwill, 2008) is a structured model for addressing impairment through comprehensive assessment, intervention development, and intervention implementation. CBC brings together family members, educators, and other service providers within a partnership framework. Within this model, members of the consultation team work collaboratively to address the developmental, academic, social, and behavioral needs of an individual with impairment and the needs of the family.

CBC follows a structured but flexible, evidence-based, problem-solving model and is based on both (a) an ecological-systems perspective (Bronfenbrenner, 1979) and (b) the principles of positive behavior support including behavioral problem-solving (Kratochwill & Bergan, 1990). Through the process of CBC, parents, educators, and other service providers share in the identification of the strengths and needs of families and the development, implementation, and evaluation of interventions to address those needs in home and school environments. The problem-solving model of CBC follows four stages (i.e., needs/problem identification, needs/problem analysis, plan/treatment implementation, plan/treatment evaluation) and allows for each phase to be recycled as needed.

Research examining CBC has consistently found that CBC is efficacious for children with academic and social behavior concerns (Sheridan, Clarke, & Ransom, 2014). CBC can improve behavior outcomes for elementary-age students at school (Sheridan et al., 2012), reduce behavior problems at home (Sheridan, Ryoo, Garbacz, Kunz, & Chumney, 2013), and strengthen the parent–teacher relationship (Sheridan et al., 2012). CBC and interventions that include CBC are associated with positive effects on children's homework performance, family involvement in education, and the family–school relationship (Power et al., 2012; Weiner, Sheridan, & Jenson, 1998). Furthermore, CBC has been applied to pediatric settings and effectively addressed presenting concerns (e.g., blood glucose levels; Lasecki, Olympia, Clark, Jenson, & Heathfield, 2008; Sheridan et al., 2009).

### 2.4.6 Transition to Adulthood

As youth begin transitioning from educational settings and close adult supervision to postsecondary schooling, employment, and independent living, there are many activities families can engage in with their children to reduce impairment and support life success. Many of the aforementioned topics (e.g., use of positive behavior support) continue to be relevant during this stage. In fact, promoting child and youth life success includes building upon the firm foundations created throughout a child's life.

Children identified with an educational disability have an Individualized Education Program (IEP). Prior to ninth grade, the IEP focuses on services the school provides to address the child's educational needs (PACER Center, 2013).

By age 16, or before, the IEP begins including specific ways to plan for the youth's life after high school. Federal law mandates that schools solicit parent engagement in IEP meetings (34 C.F.R. § 300.322); however, evidence suggests many families do not attend some IEP meetings (Landmark, Zhang, & Montoya, 2007). Reviews and meta-analyses of parent involvement in secondary schooling suggest that parent involvement is associated with improved youth academic performance and achievement (Catsambis, 1998; Jeynes, 2008). Empirical evidence for parent involvement at the secondary level underscores the legal mandates, and indicates the importance of continued family involvement as youth transition to adulthood.

In addition to empirical evidence and legal mandates, it is conceptually meaningful for parents to be engaged in their youth's transition services. By the time a youth begins making the transition to adulthood, parents will have been the constant throughout many IEP meetings comprised of different individuals across several schools. Families have also provided proximal support to their child and contributed meaningful information to educational stakeholders and community advocates. Thus, parents are the backbone and sine qua non in their youth's life (Timmons, Butterworth, Whitney-Thomas, Allen, & McIntyre, 2004).

There are many ways families can support their youth during transition planning activities. For example, parents can advocate for their youth when key decisions are made about their educational or vocational plans (Timmons et al., 2004). In addition, parents can attend and actively participate in IEP meetings and other school meetings, and communicate regularly with their child's educators (Landmark et al., 2007). It may be more difficult for some families to navigate the transition planning process than it is for other families; it may be particularly difficult for families from culturally and linguistically diverse backgrounds (Kim & Morningstar, 2005). Thus, it is important for educators to support families as they advocate, share information, and collaboratively plan for their youth's transition to adulthood. Educators can share information, encourage family involvement, facilitate supportive connections across families, and increase social supports for families (Kim & Morningstar, 2005).

## 2.5 Conclusion

Families provide an invaluable, and often underutilized, resource in the contextual assessment of impairment and the development and implementation of support plans for individuals with impairment. A framework based on ecological-behavioral theory and life course theory provides the backdrop for partnering with families to assess and address strengths and needs. Conducting contextually and developmentally appropriate, comprehensive assessments includes establishing a collaborative partnership with family members. Through this partnership, issues related to diversity can be addressed and appropriate, collaborative goals can be developed. Information provided by family members helps assess the level of family functioning, current family needs and resources available, and previous efforts to address those needs. Family members should also be included in the development of cross-setting functional behavioral assessments and the process of using assessment information to drive the development and implementation of contextually appropriate support plans. Undoubtedly, families provide a wealth of knowledge, expertise, and resources that are extremely beneficial in understanding context, reducing impairment, and promoting success.

## References

Abidin, R. R. (2012). *The Parenting Stress Index professional manual*. Odessa, FL: Psychological Assessment Resources.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Bagnato, S. J., & Neisworth, J. T. (1991). *Assessment for early intervention: Best practices for professionals*. New York: Guilford Press.

Baumrind, D. (1968). Authoritarian vs. authoritative parental control. *Adolescence, 3*, 255–272.

Bloom, B. L. (1985). A factor analysis of self-report measures of family functioning. *Family Process, 24*, 225–239.

Brassard, M. R., & Boehm, A. E. (2007). *Preschool assessment: Principles and practices*. New York, NY: Guilford.

Bray, J. H. (1995). Family assessment: Current issues in evaluating families. *Family Relations, 44*, 469–477.

Breslau, N. (1983). The psychological study of chronically ill and disabled children: Are healthy siblings appropriate controls? *Journal of Abnormal Child Psychology, 11*, 379–391.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Catsambis, S. (1998). *Expanding knowledge of parental involvement in secondary education* (Rep. No. 27). Washington, DC: Center for Research on the Education of Students Placed At Risk.

Chen, D., Downing, J. E., & Peckham-Hardin, K. D. (2002). Working with families of diverse cultural and linguistic backgrounds. In L. K. Koegel, R. L. Koegel, & G. Dunlap (Eds.), *Positive behavior support: Including people with difficult behavior in the community* (pp. 133–154). Baltimore: Paul H. Brookes.

Conoley, J. C., & Sheridan, S. M. (2005). Understanding and implementing school-family interventions after neuropsychological impairment. In R. C. D'Amato, E. F. Fletcher-Janzen, & C. R. Reynolds (Eds.), *Handbook of school neuropsychology* (pp. 721–737). New York: Wiley.

Crone, D. A., & Horner, R. H. (2003). *Building positive behavior support systems in schools: Functional behavior assessment*. New York: Guilford.

Deal, A. G., Trivette, C. M., & Dunst, C. J. (1988). In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Enabling and empowering families: Principles and guidelines for practice* (pp. 175–184). Cambridge, MA: Brookline Books.

Dennis, L. R., Rueter, J. A., & Simpson, C. G. (2013). Authentic assessment: Establishing a clear foundation for instructional practices. *Preventing School Failure, 57*(4), 189–195.

Dishion, T. J., Nelson, S. E., & Kavanagh, K. (2003). The family check-up with high-risk young adolescents: Preventing early-onset substance use by parent monitoring. *Behavior Therapy, 34*, 553–571.

Dishion, T. J., Shaw, D., Connell, A., Gardner, F., Weaver, C., & Wilson, M. (2008). The family check-up with high-risk indigent families: Preventing problem behavior by increasing parents' positive behavior support in early childhood. *Child Development, 79*, 1395–1414.

Dishion, T. J., & Stormshak, E. (2007). *Intervening in children's lives: An ecological, family-centered approach to mental health care*. Washington, DC: APA.

Dockett, S., & Perry, B. (2007). *Transitions to school: Perceptions, expectations, experiences*. Sydney, Australia: University of New South Wales Press.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1994). Enabling and empowering families. In C. J. Dunst, C. M. Trivette, & A. G. Deal (Eds.), *Supporting and strengthening families: Methods, strategies, and practices* (pp. 175–184). Cambridge, MA: Brookline Books.

Epstein, N. B., Baldwin, L., & Bishop, D. S. (1983). The McMaster family assessment device. *Journal of Marital and Family Therapy, 9*, 171–180.

Epstein, N., Ryan, C., Bishop, D., Miller, I., & Keitner, G. (2003). The McMaster model: A view of healthy functioning. In F. Walsh (Ed.), *Normal family processes* (3rd ed., pp. 581–607). New York: Guilford Press.

Fabian, H., & Dunlop, A-W. A. (2006). *Outcomes of good practice in transition processes for children entering primary school*. Paper commissioned by the van Lee foundation as evidence for their response to the EFA Global Monitoring Report 2007.

Fine, A., & Kotelchuck, M. (2010). *Rethinking MCH: The life Course Model as an Organizing Framework Concept Paper*. U.S. Department of Health and Human Services and Services Administration Maternal and Child Bureau. Retrieved from http://www.hrsa.gov/ourstories/mchb75th/images/rethinkingmch.pdf

Fosco, G. M., Dishion, T. J., & Stormshak, E. A. (2012). A public health approach to family-centered prevention of alcohol and drug addiction: A middle school strategy. In H. J. Shaffer (Ed.), *APA addiction syndrome handbook: Vol. 2. Recovery, prevention, and other issues*. Washington, DC: American Psychological Association.

Fosco, G. M., Frank, J. L., Stormshak, E. A., & Dishion, T. J. (2013). Opening the "black box": Family check-up intervention effects on self-regulation that prevents growth in problem behavior and substance use. *Journal of School Psychology, 51*, 455–468.

Fox, L., Vaughn, B. J., Dunlap, G., & Bucy, M. (1997). Parent-professional partnership in behavioral support: A qualitative analysis of one family's experience. *Journal of the Association for Persons with Severe Handicaps, 22*, 198–207.

Fox, L., Vaughn, B. J., Wyatte, M. L., & Dunlap, G. (2002). What we expect other people to understand: Family perspectives on problem behavior. *Exceptional Children, 68*, 437–450.

Garbacz, S. A., Swanger-Gagné, M. S., & Sheridan, S. M. (2015). The role of school-family partnership programs for promoting student social and emotional learning. In J. Durlak, T. Gullotta, C. Domitrovich, P. Goren, & R. Weissberg (Eds.), *The handbook of social and emotional learning: Research to practice* (pp. 244–259). New York, NY: The Guildford Press.

Gath, A., & Gumley, D. (1987). Retarded children and their siblings. *Journal of Child Psychology and Psychiatry, 28*, 715–730.

Gellerstedt, M. E., & Mauksch, L. (1993). Chronic neurologic impairment: A family problem. *Family Systems Medicine, 11*, 425–431.

Giallo, R., & Gavida-Payne, S. (2006). Child, parent, and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research, 50*, 937–948.

Gresham, F. M., & Elliott, S. N. (2008). *Social skills improvement system rating scales*. Minneapolis, MN: NCS Pearson.

Harry, B. (1992). Developing cultural self-awareness: The first step in values clarification for early interventionists. *Topics in Early Childhood Special Education, 12*, 222–250.

Heru, A., & Ryan, C. (2002). Depressive symptoms and family functioning in the caregivers of recently hospitalized patients with chronic/recurrent mood disorders. *International Journal of Psychosocial Rehabilitation, 7*, 53–60.

Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

Jackson, A., & Haverkamp, D. E. (1991). Family response to traumatic brain injury. *Counselling Psychology Quarterly, 4*, 355–356.

Jeynes, W. H. (2008). Effects of parental involvement and family structure on the academic achievement of adolescents. *Marriage & Family Review, 37*, 99–116.

Katz, J. (1985). The sociopolitical nature of counseling. *The Counseling Psychologist, 13*, 615–624.

Kim, K.-H., & Morningstar, M. E. (2005). Transition planning involving culturally and linguistically diverse families. *Career Development for Exceptional Individuals, 28*, 92–103.

Koegel, L. K., Steibel, D., & Koegel, R. L. (1998). Reducing aggression in children with autism toward infant or toddler siblings. *Journal of the Association for Persons with Severe Handicaps, 23*, 111–118.

Kratochwill, T. R., & Bergan, J. R. (1990). *Behavioral consultation in applied settings: An individual guide*. New York, NY: Plenum Press.

Landmark, L. J., Zhang, D. D., & Montoya, L. (2007). Culturally diverse parents' experiences in their children's transition: Knowledge and involvement. *Career Development for Exceptional Individuals, 30*, 68–79.

Lasecki, K., Olympia, D., Clark, E., Jenson, W., & Heathfield, L. T. (2008). Using behavioral interventions to assist children with Type 1 diabetes manage blood glucose levels. *School Psychology Quarterly, 23*, 389–406.

Lucyshyn, J. M., Albin, R. W., & Nixon, C. D. (1997). Embedding comprehensive behavioral support in family ecology: An experimental, single-case analysis. *Journal of Consulting and Clinical Psychology, 65*, 241–251.

Lucyshyn, J. M., Horner, R. H., Dunlap, G., Albin, R. W., & Ben, K. R. (2002). Positive behavior support with families. In J. M. Lucyshyn, G. Dunlap, & R. W. Albin (Eds.), *Families and positive behavior support: Addressing problem behavior in family contexts* (pp. 3–43). Baltimore: Paul H. Brookes.

Lucyshyn, J. M., Kayser, A. T., Irvin, L. K., & Blumberg, E. R. (2002). Functional assessment and positive behavior support at home and families: Designing effective and contextually appropriate behavior support plans. In J. M. Lucyshyn, G. Dunlap, & R. W. Albin (Eds.), *Families and positive behavior support: Addressing problem behavior in family contexts* (pp. 3–43). Baltimore: Paul H. Brookes.

Mactavish, J. B., MacKay, K. J., Iwasaki, Y., & Betteridge, D. (2007). Family caregivers of individuals with intellectual disability: Perspectives on life quality and the role of vacations. *Journal of Leisure Research, 39*, 127–155.

Macy, M., & Bagnato, S. J. (2010). Keeping it "R-E-A-L" with authentic assessment. *NHSA Dialog, 13*(1), 1–20.

McCubbin, H. I., McCubbin, M. A., & Thompson, A. I. (1993). Resiliency in families: The role of family schema and appraisal in family adaptation to crises. In T. H. Brubaker (Ed.), *Family relations: Challenges for the future* (pp. 153–177). Newbury Park, CA: Sage.

McHale, S., Sloan, J., & Simmeonsson, R. (1986). Relationships of children with autistic, mentally retarded and non-handicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*, 399–415.

Miller, L. (1993). Family therapy of brain injury: Syndromes, strategies, and solutions. *American Journal of Family Therapy, 21*, 111–121.

Miller, W. R., & Rollnick, S. (2002). *Motivational interviewing: Preparing people for change* (2nd ed.). New York, NY: The Guilford Press.

Moes, D. R., & Frea, W. D. (2000). Using family context to inform intervention planning for the treatment of a child with autism. *Journal of Positive Behavioral Interventions, 2*, 40–46.

Moore, K. J., Garbacz, S. A., Dishion, T. J., Gau, J. M., Brown, K. L., Stormshak, E. A., et al. (2016). Proactive parent engagement in public schools: Using a brief strengths and needs assessment in a multiple-gating risk management strategy. *Journal of Positive Behavior Interventions, 4*, 230–240.

Moos, R. H., & Moos, B. S. (2002). *Family environment scale manual: Development, applications, research*. Palo Alto, CA: Mind Garden, Inc.

Neismworth, J. T., & Bagnato, S. J. (2007). What are the professional standards for assessment of preschool children? In S. J. Bagnato (Ed.), *Authentic assessment for early childhood intervention: Best practices*. New York: Guilford Press.

O'Neill, R. E., Horner, R. H., Albin, R. W., Sprague, J. R., Storey, K., & Newton, J. S. (1997). *Functional assessment and program development for problem behavior: A practical handbook*. Pacific Grove, CA: Brooks/Cole.

Olson, D. H., & Gorall, D. M. (2003). Circumplex model of marital and family systems. In F. Walsh (Ed.), *Normal family processes* (3rd ed., pp. 514–547). New York: Guilford Press.

Olson, D. H., Gorall, D. M., & Tiesel, J. W. (2005). *Faces IV package*. Minneapolis, MN: Life Innovations.

PACER Center. (2013). *A guide to preparing your child with a disability for life beyond high school*. Minneapolis, MN: PACER Center.

Patterson, J. M. (2002a). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349–360.

Patterson, J. M. (2002b). Understanding family resilience. *Journal of Clinical Psychology, 58*, 233–246.

Pianta, R. C., & Walsh, D. J. (1996). *High risk children in schools: Constructing sustaining relationships*. New York: Routledge.

Power, T. J., Mautone, J. A., Soffer, S. L., Clarke, A. T., Marshall, S. A., Sharman, J., et al. (2012). A family–school intervention for children with ADHD: Results of a randomized clinical trial. *Journal of Consulting and Clinical Psychology, 80*, 611–623.

Quinn, W. H. (1995). Professional understanding of the community: At a loss for words? In P. Adams & K. Nelson (Eds.), *Reinventing human services: Community- and family-centered practice* (pp. 245–259). New York, NY: Adeline de Gruyter.

Reynolds, C. R., & Kamphaus, R. W. (2015). *Behavior assessment system for children – Third Edition (BASC-3)*. Bloomington, MN: Pearson.

Sheridan, S. M., Bovaird, J. A., Glover, T. A., Garbacz, S. A., Witte, A., & Kwon, K. (2012). A randomized trial examining the effects of conjoint behavioral consultation and the mediating role of the parent-teacher relationship. *School Psychology Review, 41*, 23–46.

Sheridan, S. M., Clarke, B. L., & Ransom, K. A. (2014). The past, present, and future of conjoint behavioral consultation research. In W. Erchul & S. Sheridan (Eds.), *Handbook of research in school consultation* (2nd ed.). New York, NY: Routledge.

Sheridan, S. M., Eagle, J. W., & Dowd, S. E. (2005). Families as contexts for children's adaptation. In S. Goldstein & R. Brooks (Eds.), *Handbook of resiliency in children*. New York: Kluwer Academic/Plenum.

Sheridan, S. M., & Gutkin, T. B. (2000). The ecology of school psychology: Examining and changing our paradigm for the 21st century. *School Psychology Review, 29*, 485–502.

Sheridan, S. M., & Kratochwill, T. R. (2008). *Conjoint behavioral consultation: Promoting family-school connections and intervention* (2nd ed.). New York: Springer.

Sheridan, S. M., Ryoo, J. H., Garbacz, S. A., Kunz, G. M., & Chumney, F. L. (2013). The efficacy of conjoint behavioral consultation on parents and children in the home setting: Results of a randomized controlled trial. *Journal of School Psychology, 51*, 717–733.

Sheridan, S. M., Warnes, E. D., Woods, K. E., Blevins, C. A., Magee, K. L., & Ellis, C. (2009). An exploratory evaluation of conjoint behavioral consultation to promote collaboration among family, school, and pediatric systems: A role for pediatric school psychologists. *Journal of Educational and Psychological Consultation, 19*, 106–129.

Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development, 18*, 259–282.

Soriano, M., Soriano, F. I., & Jimenez, E. (1994). School violence among culturally diverse populations: Sociocultural and institutional considerations. *School Psychology Review, 23*, 216–235.

Stormshak, E. A., Connell, A. M., Véronneau, M.-H., Myers, M. W., Dishion, T. J., Kavanagh, K., et al. (2011). An ecological approach to promoting early adolescent mental health and social adaptation: Family-centered intervention in public middle schools. *Child Development, 82*, 209–225.

Stormshak, E. A., Connell, A., & Dishion, T. J. (2009). An adaptive approach to family-centered intervention in schools: Linking intervention engagement to academic outcomes in middle and high school. *Prevention Science, 10*, 221–235.

Stormshak, E. A., & Dishion, T. J. (2009). A school-based, family-centered intervention to prevent substance use: The family check-up. *The American Journal of Drug and Alcohol Abuse, 35*, 227–232.

Stormshak, E. A., Fosco, G. M., & Dishion, T. J. (2010). Implementing interventions with families in schools to increase youth school engagement. The Family Check-Up Model. *School Mental Health, 2*, 82–92.

Sue, D. W., & Sue, D. (1999). *Counseling the culturally different*. New York, NY: Wiley.

Timmons, J. C., Butterworth, J., Whitney-Thomas, J., Allen, D., & McIntyre, J. P., Jr. (2004). Managing service delivery systems and the role of parents during their children's transitions. *Journal of Rehabilitation, 70*, 19–26.

Tudball, J., Fisher, K. R., Sands, T., & Dowse, L. (2002). *Supporting families who have a child with a disability, for Families First Inner West*, SPRC Reports 1/03. Sydney: Social Policy Research Centre, UNSW.

Turnbull, A. P., & Turnbull, H. R. (1991). Family assessment and family empowerment: An ethical analysis. In L. H. Meyer, C. A. Peck, & L. Brown (Eds.), *Critical issues in the lives of people with severe disabilities* (pp. 485–488). Baltimore: Paul H. Brookes.

Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionality: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

Wade, S., Drotar, D., Taylor, H. G., & Stancin, T. (1995). Assessing the effects of traumatic brain injury on family functioning: Conceptual and methodological issues. *Journal of Pediatric Psychology, 20*, 737–752.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*, 1–18.

Wang, M., Turnbull, A. P., Summers, J. A., Little, T., Poston, D., Mannan, H., et al. (2004). Severity of disability and income as predictors of parents' satisfaction with their quality of life during early childhood years. *Research and Practice for Persons with Disabilities. Special Issue: Family and Disability, 29*, 82–94.

Weiner, R. K., Sheridan, S. M., & Jenson, W. R. (1998). The effects of conjoint behavioral consultation and a structured homework program on math completion and accuracy in junior high students. *School Psychology Quarterly, 13*, 281–309.

Ylven, R., Bjorck-Akesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities, 34*, 253–270.

Zarski, J. J., DePompei, R., & Zook, A. (1988). Traumatic head injury: Dimensions of family responsivity. *Journal of Head Trauma Rehabilitation, 3*, 31–41.

# Relationships Between Adaptive Behavior and Impairment

# 3

Jeffrey Ditterline, Thomas Oakland,
and Keith D. McGoldrick

## 3.1 Relationships Between Adaptive Behavior and Impairment

Adaptive behavior generally refers to one's ability to meet daily living responsibilities and to respond to the needs of others. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines adaptive behavior as "the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives" (AAIDD, 2010, p. 76). The AAIDD's 2010 definition cited three primary domains of that constitute adaptive behavior: conceptual skills, social skills, and practical skills. The *Diagnostic and Statistical Manual of Mental Disorders* (*DSM*) emphasizes the importance of these domains in its diagnostic criteria for intellectual disability (intellectual developmental disorder) (American Psychiatric Association (APA), 2013).

## 3.2 Standards Guiding the Development and Use of Measures of Adaptive Behavior

Four sets of standards guide the development and use of measures of adaptive behavior in reference to impairment: (a) those governing test development and use; (b) those informing diagnoses and classifications; (c) those established by laws and

---

J. Ditterline, Ph.D. (✉)
Rush-Henrietta Central School District, 1799 Lehigh Station Rd., Henrietta, NY 14467, USA
e-mail: jditt@ufl.edu

T. Oakland, Ph.D., A.B.P.P., A.B.P.N. (deceased)

K.D. McGoldrick, Ph.D.
Neurology, Learning and Behavior Center,
230 South 500 East, Suite 100, Salt Lake City, UT 84102, USA
e-mail: keith@samgoldstein.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_3

related legal policies and practices, including case law; and (d) those guiding ethical behaviors of professionals. Each is reviewed next, with emphasis placed on the second and third.

### 3.2.1 Standards Governing Test Development and Use

The Standards for Educational and Psychological Testing (American Educational Research Association, American Psychological Association, and National Council on Measurement in Education, 2014; hereafter referred to as the standards) provides the most authoritative industry standards governing ways tests should be developed and used. Assessment practices associated with adaptive behavior and other psychological constructs are addressed in the standards, including test construction, evaluation, and documentation; fairness in testing; and test applications. Some key features from these standards that lay a foundation for sections of this and perhaps other chapters in this book are summarized next.

The standards define a *test* as "a device or procedure in which a sample of an examinee's behavior in a specified domain is obtained and subsequently evaluated and scored using a standardized process" (American Educational Research Association et al., 2014, p. 2). "Assessment is a broader term than test, commonly referring to a process that integrates test information with information from other sources (e.g., information from other tests, inventories, and interviews; or the individual's social, educational, environment, health, or psychological history (American Educational Research Association et al., 2014, p. 2).

Test validity constitutes a test's most important quality (American Educational Research Association et al., 2014). *Validity* refers to the accuracy with which a test measures a construct and how the results may be used appropriately. Validity is judged in light of theory and empirical evidence that support the manner in which test data are interpreted and used. Strictly speaking, a test does not have validity. Validity may be attenuated by various conditions. Two that are most prominent include construct underrepresentation (i.e., when a test fails to measure important aspects of the construct) and construct irrelevance (i.e., when qualities extraneous to the construct attenuate its measurement).

Test *reliability* refers to the consistency of scores. The standards define reliability as "the degree to which test scores for a group of test takers are consistent over repeated applications of a measurement procedure and hence are inferred to be dependable, and consistent for an individual test taker; the degree to which scores are free of random errors of measurement for a given group" (American Educational Research Association et al., 2014, p. 223).

### 3.2.2 Standards Informing Diagnosis and Classification

Seven international sources are used to define disabilities and disorders. All have implications for the use of scales that assess adaptive behavior and skills. Three sources provide the most authoritative, comprehensive, and widely used systems to classify mental disorders: the fifth edition of the *DSM* (*DSM-5*) (APA, 2013); its international edition (APA, 1995); and the *International Classification of Diseases and Related Health Problems, Tenth Edition* (*ICD-10*; World Health Organization (WHO), 1992a). The disorders identified by the *ICD-10* generally are consistent with those cited in and are cross-referenced to the *DSM*'s international version (APA, 1995). The International Classification of Functioning and Disability (ICIDH-2, formerly International Classification of Impairments, Disabilities, and Handicaps; WHO, 1992b) and its revision, the *International Classification of Functioning, Disability, and Health* (*ICF*; World Health Organization, 2001) provide a unified and standard language framework for describing human functioning and disability components of health, including physical and mental health. The Organization for Economic Co-operation and Development (2004) proposed the use of three broader criteria to classify children with disabilities: those with organic difficulties (e.g., hearing impairments or severe cognitive disabilities), those for whom social disadvantage is the origin, and those with learning difficulties whose origins may be organic or social disadvantage (e.g., dyslexia). The diagnostic criteria promulgated by the AAIDD, formerly known as the American Association on Mental Retardation, also has an international influence in reference to one disability category: development disabilities, including intellectual disability.

Information on methods promulgated by the *DSM* and the AAIDD as well as the *ICF* is summarized next, given the prominence of the first two and emerging importance of the last (Table 3.1).

## 3.3 Diagnostic and Statistical Manual of Mental Disorders

The DSM-5 (APA, 2013) uses the WHO Disability Assessment Schedule, Version 2.0 (WHODAS 2.0) (Kostanjsek, Chatterji, & Rehm, 2010) as a global measure of disability. The use of the WHODAS 2.0 was a major shift from the previous DSM-IV-TR (APA, 2000) that relied on a multiaxial system and the Global Assessment of Functioning (GAF). A GAF score was used to indicate overall level of functioning and reflected one's level of impairment. The GAF was based on the Global Assessment Scale, described by Endicott, Spitzer, Fleiss, and Cohen (1976). Ratings include psychological symptoms as well as occupational and social functioning and exclude impairment due to environmental or physical limitations. The DSM-5 removed the GAF due to "its conceptual lack of clarity (i.e., including symptoms, suicide rise, and disabilities in its descriptors) and questionable psychometrics in routine practice" (APA, 2013, p. 16).

The WHODAS 2.0 is included, for further study, in the DSM-5 Section III: Emerging Models and Measures. The WHODAS is based on the International Classification of Functioning, Disability and Health (ICF) and is used across all of medicine and health care. In addition to the WHODAS 2.0, a modified version created by the Impairment and Disability Study Group of the DSM-5 was developed for children/adolescents. Both the WHODAS 2.0 and modified child/adolescent version were included in the DSM-5 field trial (APA, 2013).

**Table 3.1** American Association on Intellectual and Developmental Disabilities adaptive skills and domains

| | |
|---|---|
| Communication | Speech, language, and listening skills needed for communication, including vocabulary, responding to questions, and conversation skills |
| Community use | Skills needed for functioning in the community, including use of community resources, shopping skills, and traveling in the community |
| Functional academics | Basic reading, writing, mathematics, and other academic skills needed for daily, independent functioning, including telling time, measurement, and writing notes or letters |
| Home/school living | Skills needed for basic care of a home, living setting or school, including cleaning, organizing, maintaining and repairing property, preparing food, and performing chores |
| Health and safety | Skills needed for the protection of health and to respond to illness and injury, including following safety rules, using medicines, and showing caution |
| Leisure | Skills needed for engaging in and planning leisure and recreational activities, including playing with others, engaging in recreation at home, and following rules in games |
| Self-care | Skills needed for personal care including eating, dressing, bathing, toileting, grooming, and hygiene |
| Self-direction | Skills needed for independence, responsibility, and self-control, including starting and completing tasks, keeping a schedule, following time limits, following directions, and making choices |
| Social | Skills needed to interact socially and get along with other people, including having friends, showing and recognizing emotions, assisting others, and using manners |
| Work | Skills needed for successfully holding a job and functioning in a part-time or full-time work setting, including completing work tasks, working with supervisors, and following a work schedule |
| Motor skills[a] | Basic fine and gross motor skills needed for locomotion and manipulation of the environment as well as for the development of more complex activities, including sitting, pulling up to a standing position, walking, fine motor control, and kicking |
| Three domains and associated skills | |
| Conceptual | Includes communication, functional academics, and self-direction |
| Social | Includes social skills and leisure skills |
| Practical | Includes self-care, home/school living, community use, health and safety, and work skills |

[a] Although fine and gross motor development is not included as one of the ten skills identified by the American Association on Intellectual and Developmental Disabilities, it is included in some scales of adaptive behavior

The WHODAS 2.0 is a 36-item measure used to assess disability in adults ages 18 years and older. Disability is assessed across six domains using a five-point Likert scale of "none," "mild," "moderate," "severe," and "extreme or cannot do." The six domains include understanding and communication, getting around, self-care, getting along with people, life activities—household, life activities—school/work, and participation in society. The scale is completed by an individual who is asked to rate the level of difficulty he or she has had in a specific area over the past 30 days. If an individual is unable to complete the scale, a knowledgeable informant may act as a proxy using the proxy-administered version. For population norms and interpretation of the WHODAS 2.0, the DSM-5 refers readers to Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0) (Kostanjsek et al., 2010). The WHODAS 2.0 can be administered in regular intervals to track changes of an individual's level of disability.

## 3.4 The American Association on Intellectual and Developmental Disabilities

Adaptive behavior has been linked closely with intellectual disability. Thus, further knowledge of intellectual disability, particularly its diagnosis, informs us of the important role of adaptive behavior for this disorder. The AAIDD and its predecessor, the AAMR, have been the most authoritative voice in reference to issues pertaining to persons with intellectual disability. Its current definition of intellectual disability is: "A disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" (AAIDD, 2010, p. 6). Five assumptions important to this definition then are discussed.

> 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture. 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors. 3. Within an individual, limitations often coexist with strengths. 4. An important purpose of describing limitations is to develop a profile of needed supports. 5. Within appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve. (AAIDD, 2010, p. 6–7)

Almost all definitions of intellectual disability make reference to significant deficits in intellectual functioning as well as adaptive behavior that occur before age 18. Some definitions provide specific scores (e.g., <75) to demarcate levels that constitute significant deficits (APA, 2013).

## 3.5 International Classification of Functioning, Disability, and Health

The WHO's *International classification of functioning, disability and health (ICF)* (WHO, 2001) provides a framework for viewing behaviors from three broad and different perspectives: physiologic, physical, and psychological functions; the extent to which persons engage in functional life activities; and their participation in social settings. The *ICF* does not emphasize pathology or lead to a diagnosis. However, the *ICF* can be used as a companion to WHO's *ICD-10* (1992a) when diagnosing disorders. The *ICD-10* provides a system for classifying and diagnosing health conditions, including diseases, disorders, and injuries based on etiology. In contrast, the *ICF* emphasizes a client's full and accurate description, not diagnosis, based on medical and social models of disability through biological, individual, and social perspectives of health. When a diagnosis is needed to obtain benefits, the *ICD-10* may be used to classify a client's disability. The combined use of the *ICF* and *ICD-10* provides for more comprehensive descriptions and is useful for program planning and intervention services.

The *ICF* places considerable emphasis on identifying functional impairments and thus strongly emphasizes the importance of adaptive behavior. Specifically, its activities and participation components address the execution of a task or action by an individual and his or her involvement in life situations (WHO, 2001). The term *activities* refers to tasks or actions a client is able to perform. Examples for older children and adults include writing, talking, and calculating. The term *participation* refers to activities that become integrated into one's life. Examples for children include regularly taking others to nearby places, talking by telephone with family and friends, and refraining from embarrassing others.

Activities and participation include the following nine domains (with examples of corresponding adaptive skills in parentheses): learning and applying knowledge (e.g., functional academics); general tasks and demands (e.g., work); communication (e.g., communication); mobility (e.g., fine and gross motor skills); self-care (e.g., self-care); domestic life (e.g., school and home living); interpersonal interactions and relationships (e.g., social skills); major life areas (e.g., health and safety, leisure skills); and community, social, and civic life (e.g., community use). The skills in parentheses are those identified by the AAIDD (2010) and *DSM-5* (APA, 2013) as important adaptive skills.

A *skill deficit* occurs when a person does not display a needed behavior. A *performance deficit* occurs when a person has displayed a needed skill yet does not use it when needed. For example, a child who does not have the ability to dress oneself displays a skill deficit. In contrast, a child who has displayed the ability to dress oneself and does not do so regularly is described as having a performance deficit. If deficits in adaptive behavior and skills have been identified and an individual is in need of services, then the *ICF* aids in describing the disability in terms of an interaction between impairment, functioning, and the environment. Strengths or weaknesses may be identified, including the adequacy of one's adaptive skills, in light of environmental needs.

An understanding of a client's health requires knowledge of the dynamic nature among body functions, body structures, activities as well as participation, and environmental factors. Each influences the others. The *ICF* emphasizes the importance of identifying possible conditions that have an impact on activities and performance deficits. An understanding of a client's activities and performance requires knowledge of personal, social, and environmental conditions that may be having an impact on them. For example, a person's adaptive skills may be influenced adversely by his or her body functions (e.g., mental, sensory, and neuromusculoskeletal functions) and structures (e.g., nervous, cardiovascular, and metabolic systems). In addition, his or her environment may not provide needed opportunities to acquire adaptive skills as well as support and reward their use. Thus, knowledge of a client's adaptive skills in conjunction with body functions, structures, and environment is important for diagnosis and is essential to the design, delivery, and monitoring of services intended to have an instrumental and functional impact on a client's life.

An overlap between the *ICF*'s activities and participation framework and adaptive behavior is clear. Thus, there is considerable agreement among the WHO, AAIDD, and the APA regarding the importance of these skills. The assessment of adaptive behavior is directly applicable to the utilization of the *ICF* and can assist in better understanding, describing, and classifying functioning, disability, and health under this model.

### 3.5.1 Legal Standards Governing the Use of Measures of Adaptive Behavior

Professionals working in public schools typically rely on federal laws and policies that become translated into state board of education agency rules and policies when diagnosing disorders. Although the *DSM* is known and may be considered by school-based professionals, diagnostic criteria approved by their state boards of education constitute the protocol to be used in public schools.

## 3.6 Individuals with Disabilities Education Act

The federal government partially funds education and support services for approximately 6.5 million individuals with special education needs (U.S. Department of Education, 2006). The Individuals with Disabilities Education Act (IDEA; U.S. Code Service, 2007) governs the provision of early intervention, special education, and related services by state and local educational agencies for children over age 2 to young adults age 21 (U.S. Code Service, 2007).

Part C of IDEA addresses assistance for infants and toddlers beyond age 2 and authorizes states to develop and maintain early intervention programs for infants and toddlers with disabilities (Apling & Jones, 2005). Eligibility is based on a diagnosis of developmental delay that requires early intervention services. The assessment of adaptive behavior provides data that are helpful in establishing impairment and eligibility for services.

Part B of IDEA addresses assistance for students with disabilities ages 3 through 21 (Apling & Jones, 2005). Eligibility is based on 13 categories of disabilities (U.S. Department of Education, 2006). The assessment of adaptive behavior is needed to determine eligibility for students with developmental and intellectual disabilities. In addition, measures of adaptive behavior are helpful for determining the strengths and weaknesses in daily living skills of any student suspected of having a disability.

IDEA requires local educational agencies to use multiple assessment methods and sources of information when compiling developmental and functional information. These data have three purposes: to assist in determining whether a child has a disability, to inform the content of an educational plan, and to provide baseline data useful for determining later changes (Council for Exceptional Children, 2004). Local educational agencies should emphasize the assessment of functional skills, thereby supporting interventions that can have a direct and functional impact on important practical life skills.

Measures of adaptive behavior provide important information about a child's behavior and functional age-related daily living skills. This information is critical when determining whether a child has intellectual disability or developmental disabilities and can be useful by indicating the presence of other difficulties or disabilities; informing the contents of educational programming; determining progress and current performance of academic, daily living, and work skills; and providing information for reevaluations.

For example, the results of a measure of adaptive behavior may show a weakness in practical daily life skills such as those associated with community use, health and safety, and self-care. Following intervention with the student, including psychoeducation, consultation, modeling, guided practice, and opportunities for independent monitoring, follow-up assessment of adaptive behavior may show improvement toward meeting goals for the performance of these important life skills. School districts are obligated to develop and implement a program to help students receiving special education services to transition from school to work and other postsecondary life activities. Given their focus on functional behaviors, measures of adaptive behavior should be used to assist students, their parents, and educators in identifying life skill strengths and deficits, particularly those associated with practical behaviors (e.g., work skills) and their personal behavior (e.g., communication, functional academic, and social skills). No single measure may be used to determine whether a child is served by the appropriate educational or work program. However, a measure of adaptive behavior may provide the most important information when planning a transition program for students served under IDEA. Results inform the proceedings of transition-planning conferences, indicate particular proficiencies and areas of impairment, and thereby facilitate a successful progression to gainful life activities.

## 3.7 Social Security Disability and Supplemental Security Income

The federal Social Security Administration administers the Social Security and Supplemental Security Income disability programs for individuals with disabilities who meet medical criteria (Social Security Administration, 2015). The Social Security Administration defines disability in adults as "the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." (Social Security Administration, 2015). A multistep sequential evaluation process determines whether a person who is not working meets criteria to be considered disabled by determining whether the person's condition is severe and if the person can perform either work they previously performed or other work (Social Security Administration, 2015). Results from measures of adaptive behavior help answer these questions.

An applicant for Social Security disability or Supplemental Security Income must have a medical condition sufficiently severe to interfere with basic work-related activities. Eligibility decisions for Social Security can be based partially on information from measures of adaptive behavior that reveal functional limitations in daily life activities, including impairment in work skills.

For example, an individual with a physical or mental disorder must demonstrate severe functional limitations for at least 12 months to qualify for Supplemental Security Income. Functional limitations are determined, in part, by whether a person displays self-care, maintains one's physical well-being, and works. Adaptive behavior measures that evaluate self-care, health and safety, and work skills provide needed information to address these questions. Their use is integral to establishing impairment and functional limitations leading to eligibility for services.

Subsequent reevaluations can help establish the stability of an individual's impairment and disability. Therefore, a comprehensive and valid assessment of adaptive behavior can provide a systematic and scientifically supported method that is respected by the legal system, including courts, to help provide information that has an impact on legal matters in these and other life-altering situations.

## 3.8 Atkins v. Virginia

The *Atkins v. Virginia* (2002) U.S. Supreme Court ruling prohibits the execution of individuals with intellectual disability (intellectual developmental disorder). The impact of this ruling applies to prisoners currently being adjudicated as well as those who were adjudicated previously and are on death row. Responsibility for establishing standards and methods for evaluating intellectual disability was left to the states. Prominent attorneys and professional organizations have recommended procedures to implement *Atkins* at the state level (American Bar Association, 2006; Bonnie, 2004; Bonnie & Gustafson, 2007; Ellis, 2003). However, many details remain controversial (Duvall & Morris, 2006; Olley, Greenspan, & Switzky, 2006). No nationwide policy exists on these issues. Although all diagnoses can lead to important life-changing events, the decision regarding whether a prisoner is diagnosed with intellectual disability can lead to life-and-death decisions.

The assessment of adaptive behavior figures prominently in the decision regarding whether a prisoner is diagnosed with intellectual disability. The requirement for impairment of adaptive behavior was more pertinent in *Atkins* petitions from the *Hall v. Florida* (2014) ruling. Here the defendant, despite having IQ scores below the cut-off of 70 in Florida had his Atkins petition rejected, as there was not enough evidence to support impairment of adaptive behavior. In *Hall v. Florida* (2014) Justice Kennedy stated, "intellectual disability is a condition, not a number" and noting that all evidence including both intellectual and adaptive behavior needs to be considered.

As noted elsewhere in this chapter, definitions of intellectual disability generally require evidence of adaptive behavior deficits before age 18. If this standard is established by a state, then information on a death row inmate's adaptive behavior is needed before age 18. This possesses considerable challenges when assessing a person aged 20 or older—especially those aged 50 and older. The examiner must locate and interview others who knew the person while a teenager and rely on records that provide this information. Locating and gaining access to such records and persons are difficult at best and often not possible. Furthermore, some courts are allowing prison guards to provide information about the prisoner's adaptive behavior and skills displayed in prison. This practice is unsupportable and should not occur. Olley and Cox (2008) discussed more fully the use of adaptive behavior measures in adult forensic cases.

### 3.8.1 Ethical Standards Governing Use of Measures of Adaptive Behavior

Professions and those societies in which they are practiced are linked through an unwritten social contract whose broad principles are clear. A society agrees to establish and fund institutions that enable professions to select and prepare neophytes, define and license a profession's practice, and fund related research. In turn, professions are expected to serve all members of the society well by addressing critical national issues. The profession's ethics code communicates the ways the profession will serve society.

Ethics codes often are based on fundamental principles that underscore the profession's commitment to provide high-quality services to their clients. The American Psychological Association's 2002 *Ethical Principles of Psychologists and Code of Conduct* (amended 2010) emphasizes the following five principles: beneficence, fidelity and responsibility, integrity, justice, and respect for people's rights and dignity.

The principle of beneficence underscores the need to strive to provide services that benefit others. Minimally, professionals strive to do no harm. The principles of fidelity and responsibility underscore the importance of establishing relationships based on trust. Professionals uphold professional standards of conduct, clarify their professional roles and obligations, accept appropriate responsibility for their behavior, and seek to manage conflicts of interest that could lead to exploitation or harm. The principle of integrity underscores the importance of promoting accuracy, honesty, and truthfulness in one's services. Moreover, professionals strive to keep their promises and to avoid unwise or unclear commitments.

The principle of justice underscores the right of all persons to have access to and benefit from professional contributions and to equal quality in the processes, procedures, and services being conducted by them. The principle of respect for people's rights and dignity underscores a person's rights to privacy, confidentiality, and self-determination. Professionals are aware of and respect cultural, individual, and role differences, including those based on age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, and socioeconomic status and consider these factors when working with members of such groups.

The use of measures of adaptive behavior should be guided by these ethical principles. For example, professionals strive to develop relationships with those who complete these measures (i.e., the respondents) based on honesty, accuracy, and trust, thus encouraging respondents to complete the measures honestly, accurately, and in a timely fashion. Professionals discuss possible uses of information obtained from these measures. Their use should result in some benefits derived by those being assessed, their family, or caregivers. After scoring these measures, professionals communicate the results in ways that accurately describe a person's adaptive skills and behaviors, identify limitations in the data, and discuss implications of this information. Professionals recognize that, although the data may be useful when forming diagnoses, their benefit ultimately lies in informing caregivers and others about practical and functional uses of this information. In addition, professionals are aware of, respect, and do not discriminate on the basis of cultural, individual and role differences, age, gender, gender identity, race, ethnicity, culture, national origin, religion, sexual orientation, disability, language, and socioeconomic status. Moreover, they consider these qualities, if needed, when interpreting data.

## 3.9 Measures of Adaptive Behavior

Thus, as noted, measures of adaptive behavior can be used in various ways. The assessment of adaptive behavior and skills is useful for diagnosis and classification; the clinical assessment of individuals' strengths and weaknesses; treatment planning, implementation, and evaluation; documenting and monitoring progress; and conducting research. Data from measures of adaptive behavior help determine eligibility for special services (e.g., IDEA or Social Security Disability and Income), differentiate diagnoses and classifications, inform treatment planning, and establish baseline data from which to evaluate change. Although adaptive behavior measures have been used principally with individuals who display intellectual disability and developmental delays, they also provide useful information regarding children who display autism spectrum disorder (ASD), emotional and behavioral disorders, and learning disabilities. Three popular norm-referenced measures of adaptive behavior are reviewed next.

### 3.9.1 Adaptive Behavior Assessment System: Third Edition

The Adaptive Behavior Assessment System—Third Edition (ABAS-3; Harrison & Oakland, 2015) provides an assessment of adaptive behavior and skills for individuals from birth through age 89 (Table 3.2). The standardization sample consists of

4500 individuals who completed 7737 research forms and is representative of 2010 US census data for gender, race/ethnicity, and socioeconomic status (Harrison & Oakland, 2015). The sample is primarily derived from typically developing individuals with a proportion of the sample including individuals with disabilities. Five forms are provided in English and Spanish: Parent/Primary Caregiver Form (for ages 0–5), Teacher/Day Care Provider Form (for ages 2–5), Parent Form (for ages 5–21), Teacher Form (for ages 5–21), and an Adult Form (for ages 16–89). All forms can be administered either using paper forms or online.

The ABAS-3 was developed to reflect current standards of adaptive behavior and subsequently diagnosing conditions that may be impaired (e.g., AAIDD, 2010; APA, 2000, 2013; IDEIA, 2006; WHO, 2001). Consistent with the adaptive behavior model promulgated by the AAIDD and APA, the ABAS-3 provides a three-tier model: 11 skill areas, three domains, and a general adaptive composite. Nine skill area scores combine to produce standard scores in the following domains: conceptual (communication, functional pre-academics/academics, and self-direction skill areas); social (social and leisure skill areas); and practical (self-care, home or school living, community use, and health and safety, skill areas) (Table 3.2). A motor adaptive area is included for those from birth to 5 years old and is not included in any of the three domains, but is included in the adaptive general composite. A general adaptive composite score is derived from the skill area scores.

The ABAS-3 is a psychometrically sound instrument and demonstrates high internal consistency (Harrison & Oakland, 2015). Reliability coefficients for the standardization sample range from .96 to .99 for the general adaptive composite, .85 to .99 for the three adaptive domains, and .72 to .99 for the skill areas. Likewise, reliability coefficients for the mixed clinical sample range are .99 for the general adaptive composite, .96 to .99 for the adaptive domains, and .91 to .98 for the skill areas. Test-retest reliability coefficients conducted between 5 days to 7 weeks (mean = 3 weeks) range from .82 to .89 for the general adaptive composite, whereas form averages range from .76 to .85 for the three domains, and .70 to .80 for the skill areas. Interrater reliability coefficients (e.g., between teachers, daycare providers, and parents) range from .72 to .92 for the general adaptive composite, whereas the form averages range from .77 to .83 for the three domains, and .67 to .87 for the skill areas.

Support for the validity of scores on the ABAS-3 is based on the test's sound theoretical structure and empirical evidence, which support interpretations of scores for their intended purpose. The theoretical structure of the ABAS-3 is derived from the model of adaptive behavior promulgated by the AAIDD (2010) and DSM-5 (2013), legal and processional standards applicable to special education and disability classification, as well as research into diagnosis and classification of individuals with disabilities. "Consistent with this theoretical structure, the ABAS-3 items comprise 10 adaptive skills areas, all of which are expected to be internally consistent and sensitive to age differences. Furthermore, the adaptive skill areas are expected to share common variance, yet also be demonstrably independent of one another" (Harrison & Oakland, 2015). Intercorrelational data support the theoretical structure of the ABAS-3. Intercorrelations among the skill areas are moderate

**Table 3.2** Current assessment measures in adaptive behavior

| Title and date of publication | *Adaptive behavior assessment system—Third edition* (2015) | *Scales of independent behavior—Revised* (1996) | *Vineland adaptive behavior scales—Third edition* (2016) |
|---|---|---|---|
| Authors | Harrison and Oakland | Bruininks, Woodcock, Weatherman, and Hill | Sparrow, Cicchetti, and Balla |
| Forms and ages | Parent/Primary Caregiver Form (ages 0–5 years); Teacher/Day Care Provider Form (ages 2–5 years); Parent Form (ages 5–21 years); Teacher Form (ages 5–21 years); and Adult Form (ages 16–89) | Full scale (ages 3 months–80 years); Short Form (ages 3 months–80 years); and Early Development Form (infancy to 6 years of age or to older individuals with developmental ages less than 8 years) | Interview Form—Comprehensive (birth–90+ years); Interview Form—Domain-Level (3–90+ years); Parent/Caregiver Form—Comprehensive (Birth–90+ years); Parent/Caregiver Form—Domain-Level (3–90+ years); and Teacher Rating Form—Comprehensive and Domain-Level (3–21 years) |
| Behavior domains and skills measured | Domains: general adaptive composite, conceptual, social, practical | Domains: motor; social interaction and communication; personal living; community living; broad independence; internalized maladaptive behavior; asocial maladaptive behavior; externalized maladaptive behavior; problem behaviors (general) | Domains: adaptive behavior composite; communication; daily living skills; socialization; motor (optional); maladaptive behaviors (optional) |
| | Skills: communication, functional pre-academics/academics, and self direction skills; leisure and social skills; community use, home/school living, health and safety, and self-care skills; work and motor (optional) | Skills: gross motor and fine motor; social interaction, language comprehension, and language expression; eating and meal preparation, toileting, dressing, personal self-care, and domestic skills; time and punctuality, money and value, work skills, and home/community orientation; hurtful to self, unusual or repetitive habits, and withdrawal or inattentive behavior; socially offensive and uncooperative, hurtful to others, destructive to property, and disruptive behavior | Skills: receptive, expressive, and written skills; personal, domestic, numeric and community skills; interpersonal relationships, play and leisure, and coping skills; gross and fine motor skills (optional); internalizing and externalizing behaviors and critical items (optional) |

and lower than those between skill areas and the general adaptive composite; also, intercorrelations between skill areas and their respective adaptive domains are higher than those between skill areas. Evidence of the ABAS-3's construct validity is provided through confirmatory factor analyses using data from the standardization sample, which confirmed that a one-factor model of adaptive behavior provides the most parsimonious fit, although a three-factor model also provides a close fit to the data (Harrison & Oakland, 2015). The work and motor adaptive skill areas were excluded in the confirmatory factor analyses. The authors note the factor structure is consistent with AAIDD (2010) descriptions of adaptive behavior (Harrison & Oakland, 2015).

Items on which clinicians often rely were selected to ensure the measurement of adaptive skills relevant to clinical and applied practice. Each rating form has a sufficient number of items and an acceptable level of internal consistency to ensure a robust measure of each skill area. Items with strong behavior references were selected for use to ensure the measurement of qualities that could be readily observed. Concurrent validity with the Vineland Adaptive Behavior Scales—Second Edition, Adaptive Behavior Composite range from .77 to .89 (Harrison & Oakland, 2015). Investigations using the ABAS-3 with clinical samples, described in the adaptive behavior research section of this chapter, provide additional support for the validity of the measure.

### 3.9.2 Scales of Independent Behavior: Revised Edition

The Scales of Independent Behavior—Revised Edition (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996) provides an assessment of adaptive behavior and skills for individuals from 3 months through 80 years (Table 3.2). The norm group of 2182 individuals was reflective of data from the 1990 US census for gender, geographic region, occupational status and level, race/ethnicity, and type of community. A portion of the norm group also was administered Woodcock-Johnson Tests of Cognitive Ability to obtain a concurrent estimate of intellectual functioning. The SIB-R provides three forms: a Short Form, an Early Development Form, and a Full Scale Form. The Short Form serves as a screener for all ages and contains items from the 14 subscales that comprise the Full Scale Form. The Early Development Form is used with children from infancy through age 6 or with older individuals with severe disabilities who function at developmental levels below age 8.

The SIB-R provides adaptive behavior scores on the following clusters based on data from 14 skill areas: motor skills (gross motor skills and fine motor skills); social interaction and communication skills (social interaction, language comprehension, and language expression); personal living skills (eating and meal preparation, toileting, dressing, personal self-care, and domestic skills); and community living skills (time and punctuality, money and value, work skills, and home/community orientation). A broad independence score is derived from all skill area scores.

The Maladaptive Behavior Scale assesses problem behavior in the following three domains and eight problem areas: internalized maladaptive behavior (hurtful to self, unusual or repetitive habits, and withdrawal or inattentive behavior); asocial maladaptive behavior (socially offensive and uncooperative behaviors); and externalized maladaptive behavior (hurtful to others, destructive to property, and disruptive behavior). A general problem behaviors score is based on scores from the eight problem areas.

The SIB-R displays suitable internal consistency (Bruininks et al., 1996). Median corrected split half reliabilities range from .97 to .98 for the broad score, .84 to .96 for the four clusters, and .70 to .88 for the skill areas. Test-retest reliability coefficients range from .98 to .99 for the broad score, .96 to .99 for the four clusters, and from .83 to .98 for the skill areas. Coefficients for the Short Form, Early Development Form, and Maladaptive Behavior Scale are somewhat lower and generally range from .74 to .92. Interrater reliability coefficients (e.g., between parents or teachers and teacher aides) range from .80 to .96 for the broad score, .74 to .97 for the four clusters, and .58 to .96 for the skill areas.

Support for the content validity of the SIB-R is based on the test's development. The SIB-R subscales assess critical skills identified by various definitions, models, research findings, and theories on adaptive behavior. "The content of the SIB-R includes adaptive behaviors found to predict personal and community independence among elderly people … and among adults with mental retardation" (Bruininks et al., 1996, p. 186). Correlations between the current and prior Scales of Independent Behavior generally are in the .90s.

Several studies with normal and clinical groups were conducted to assess the validity of the SIB-R. High correlations among SIB-R subscales provide support for the construct validity of the measure. Subscale correlations are higher with the clusters in which they are included than with other clusters. Correlations between the subscales and broad independence scores also are high. Criterion-related validity is demonstrated through correlations between SIB-R adaptive behavior scores and Woodcock-Johnson Revised Broad Cognitive Ability scores. Correlations were low, providing evidence that adaptive behavior and cognitive ability, as measured by these two tests, represent different competencies and patterns of development (Bruininks et al., 1996). A concurrent validity study between the SIB-R Early Development Form and the Vineland Adaptive Behavior Scales' Early Screening Profiles reported correlations ranged from .77 to .90 for the four clusters (Bruininks et al., 1996).

A review of the SIB-R noted various positive features, including easy administration and scoring procedures (Maccow & Zlomke, 2001). Training objectives are provided for each subscale to determine which skills are most impaired and thus need the most improvement. Further, the SIB-R provides information about maladaptive behaviors that may impair independent daily living.

### 3.9.3 Vineland Adaptive Behavior Scales: Third Edition

The Vineland Adaptive Behavior Scales—Third Edition (Vineland-3; Sparrow, Cicchetti, & Balla, 2016) provides an assessment of adaptive behavior for individuals from birth through age 90+ (Table 3.2). The Vineland-3 was normed on a sample representative of the 2014 US census for geographic region, educational level, race/ethnicity, and gender. The normative sample for the Interview and Parent/Caregiver forms comprise 2560 individuals aged birth through 90+ years old, whereas the Teacher form sample comprises 1415 students aged 3 through 18 years old.

The manual states for students aged 19 through 21 the norms for 18 year olds should be used. The Vineland-3 has six forms. The Interview Form-Comprehensive and Parent/Caregiver-Comprehensive age ranges from birth to 90+ years old. The Interview Form-Domain-Level and Parent/Caregiver Form-Domain-Level ranges from 3 years old to 90+ years old, whereas the Teacher-Comprehensive and Domain-Level Forms range from 3 years to 21 years old. Trained professionals use a semi-structured interview format to administer the Interview Forms. The Comprehensive Forms comprise 246 to 381 core items with an additional 87 to 121 optional items for the motor skills and maladaptive behavior domains. The Domain-Level Forms are shorter and are based on 96 to 135 core items and 53 to 60 optional items. Forms can be administered either through paper-and-pencil administration or online administration.

The Vineland-3 provides scores in various domains. Domains (with subdomains in parentheses) include: communication (receptive, expressive, and written); daily living skills (personal, domestic/numeric, and community/school community); socialization (interpersonal relationships, play and leisure, and coping skills); motor skills (gross and fine motor); and maladaptive behavior (internalizing, externalizing, and critical items) (Table 3.2). Scores from the communication, daily living skills, and socialization domains are used to comprise an adaptive behavior composite score. The motor skills and maladaptive behavior domains are optional and not included in the composite score.

The Vineland-3 generally demonstrates suitable internal consistency. Test-retest reliability coefficients using an interval of 12 to 35 days range from .78 to .92 for the adaptive behavior composite, .62 to .94 for the five domains, and .60 to .93 for the subdomains (Sparrow et al., 2016). Interviewer and interrater reliability coefficients range from .58 to .93 for the adaptive behavior composite, .46 to .93 for the five domains, and .22 to .94 for the subdomains.

Empirical and theoretical evidence for the validity of the Vineland-3 is based on the test's content, response process, test structure, clinical groups, and relationships with other measures (Sparrow et al., 2016). The theoretical structure, which includes adaptive behaviors and skills in three domains, is based on models promulgated by the AAIDD and APA (DSM-5; APA, 2013). An investigation of item-scale functioning provides supportive evidence for content validity. Additionally, the hierarchical structure of adaptive behavior was investigated through intercorrelations between subdomains and hierarchical factor analysis (Sparrow et al., 2016). Subdomain correlations within a domain tend to be larger than those between domains.

Further evidence of the measure's validity is derived from investigations with clinical groups. The Vineland-3 showed meaningful patterns of deficits in groups of individuals with diagnoses including: developmental delay, intellectual disability, ASD, visual impairment, and hearing impairment. Evidence for validity also is provided through correlations between the Vineland-3 and other measures.

High to moderately high correlation coefficients between the Vineland-3 and the Vineland Adaptive Behavior Scales, Second Edition (Vineland-2) indicates a high degree of consistency between the forms in the measurement of adaptive functioning.

## 3.10 Research on Adaptive Behavior

The use of adaptive behavior data traditionally is associated with eligibility decisions for persons with intellectual and developmental disabilities, such as intellectual disability and ASD. Measures, including the ABAS-3 (Harrison & Oakland, 2015) and the Vineland-3 (Sparrow et al., 2016), show sensitivity between clinical and nonclinical groups as well as different profiles of strength and weakness displayed by children, adolescents, and adults who have been diagnosed with developmental and intellectual disabilities as well as other disorders, such as emotional and behavioral disorders, ADHD, learning disabilities, and visual/hearing impairment.

### 3.10.1 Developmental and Intellectual Disabilities

On the ABAS-3, individuals with intellectual disability displayed below average general adaptive behavior with score differences compared to matched samples falling two standard deviations lower in almost every adaptive skill area across all forms. This is consistent with current research (Harrison & Oakland, 2015). On the Vineland-3, individuals with intellectual disability displayed impaired general adaptive behavior as well as deficits in communication, daily living, socialization, and motor skills (Sparrow et al., 2016). Thus, those with intellectual disability have difficulty independently displaying general adaptive behavior, including impairments in various skill areas. Given the pervasive influence of adaptive behavior on developmental and intellectual disorders, researchers have investigated the adaptive behavior of persons who display other disabilities and disorders (Harrison, 1990; Reschly, 1990), including ASD (Bölte & Poustka, 2002; Fisch, Simensen, & Schroer, 2002; Freeman, Del'Homme, Guthrie, & Zhang, 1999; Gilotty, Kenworthy, Sirian, Black, & Wagner, 2002; Harrison & Oakland, 2003; Liss et al., 2001; Schatz & Hamdan-Allen, 1995; Sparrow et al., 2016); externalizing problems and psychological disturbances (Clark, Prior, & Kinsella, 2002; Harrison & Oakland, 2015; Sparrow & Cicchetti, 1987); ADHD (Harrison & Oakland, 2015; Sparrow, Cicchetti, & Balla, 2005); and learning disabilities (Harrison & Oakland, 2015; Leigh, 1987; Strawser & Weller, 1985; Weller & Strawser, 1987).

### 3.10.2 Autism Spectrum Disorder

On the Vineland-3, children with autism spectrum disorder (ASD) displayed impairment in general adaptive behavior (Sparrow et al., 2016). Specifically, those with IQs of 70 and above fell two standard deviations below typically developing peers, whereas those with IQs less than 70 fell three standard deviations below typical peers. The most relevant impairments were displayed in social communication and social interaction in the communication domain, and interpersonal relationships and play in the socialization domain. The authors purport that restricted and repetitive patterns of behaviors, interests, or activities are not adaptive behavior skills; rather they are maladaptive behaviors (Sparrow et al., 2016). Therefore, these behaviors are captured in the maladaptive critical items. Likewise, the ABAS-3 found children diagnosed with ASD had clinically meaningful impairments in all domains and skill areas when compared to typically developing peers (Harrison & Oakland, 2015). Findings from these studies are consistent with the dominant definition of ASD that emphasizes impairment in communication (verbal and nonverbal) and socialization skills (APA, 2013).

Research on the adaptive behavior and skills of children with ASD generally reveals social skills deficits. The general adaptive behavior as well as adaptive conceptual, social, and practical behaviors were far below average in 24 students with ASD (mean age 10.3) (Ditterline, Banner, Oakland, & Becton, 2008). The students displayed significant impairment in community use, health and safety, communication, self-direction, social, leisure, and self-care skills, yet relative strength in functional academics and school living—thus suggesting that the educational programs for these students were responsive to their needs. Adaptive daily living and socialization skills were studied in 72 children and adolescents with ASD (mean age of 8.2) (Schatz & Hamdan-Allen, 1995). Daily living skills were found to be least impaired and socialization skills to be most impaired. This is consistent with other findings (e.g., Bölte & Poustka, 2002) as well as the accepted definition of ASD.

A finding that adaptive communication and socialization skills are correlated with the metacognitive abilities of initiation and working memory in 35 children with ASD (mean age 10.5) suggests that ASD is associated with deficits in executive functioning (Gilotty et al., 2002). Correlates of adaptive behavior were compared for 35 9-year-old children with high-functioning ASD and 40 9-year-old children with low-functioning ASD (Liss et al., 2001). Intelligence limited the ability of lower functioning children to acquire adaptive skills, while specific deficits including autistic symptomology as well as impairments in language and verbal memory limited the ability of higher functioning children.

When children with ASD were compared to those with intellectual disability, Schatz and Hamdan-Allen (1995) found those with ASD displayed smaller increases in adaptive behavior at progressively higher levels of intellectual functioning. This suggests that the impact of intelligence on adaptive behavior may be less for children with ASD than for those with intellectual disability.

Partial support for this finding was found in a study of the adaptive social skills of 210 individuals with ASD (ages 3 to 19) (Freeman et al., 1999). Improvements in social skills were unrelated to participants' intellectual ability. However, improvements in communication and daily living skills were related to their intellectual ability. Individuals with IQs above 70 made greater gains in communication and daily living skills compared to those with IQs below 70. Further, adaptive behavior improved with age (Freeman et al., 1999). In contrast, a longitudinal 2-year study of

18 children with ASD (ages 3–12) found they generally acquired general adaptive behavior, communication, daily living, and socialization skills at a slower-than-average rate (Fisch et al., 2002). Further longitudinal research with larger samples is needed to determine the specific relationships among age, IQ, and adaptive changes in children with ASD (Table 3.3).

### 3.10.3 Externalizing and Internalizing Disorders

On the ABAS-3, children with emotional and behavioral disorders (ED/BD) had significantly lower adaptive skills than matched controls (Harrison & Oakland, 2015). Those with comorbid intellectual disability and ED/BD demonstrated the lowest adaptive functioning when compared to others with comorbid disorders. The comorbid intellectual disability and ED/BD sample exhibited the lowest adaptive skills in communication and functional academics. Children with comorbid ADHD and ED/BD demonstrated lowest functioning in self-direction (Harrison & Oakland, 2015). Impairments in social skills also were evident. Another study found adaptive conceptual and social behaviors to be below average in 28 students receiving special education services for emotional disturbance (mean age 8.3). Impairment was most severe in self-direction, social, and self-care skills (Ditterline et al., 2008). The Vineland-3 did not conduct any studies of those with ED/BD and deferred to the previous edition due to the high correlations between versions (Sparrow et al., 2016) On the Vineland-2, individuals with emotional and behavioral disturbance exhibited below average general adaptive behavior. They displayed significant impairment in adaptive socialization, receptive and expressive language, and daily living skills as well as elevated (i.e., abnormal) internalizing and externalizing behaviors (Sparrow et al., 2005). Results confirmed that those with emotional and behavior disorders display general impairment when interacting with others as well as difficulty in various discrete adaptive skill areas.

For individuals who display externalizing disorders (e.g., ADHD, conduct disorder, and oppositional defiant disorder), the severity of impairment in adaptive behavior tends to increase with the severity of their emotional disturbance (Sparrow & Cicchetti, 1987). Deficits in socialization are displayed most often. Although some children with externalizing disorders display deficits in communication and daily living skills, these patterns are less predictable than patterns indicating deficits in socialization.

The adaptive social and communication skills of 110 adolescents were compared across four groups: an oppositional defiant disorder/conduct disorder-only group, an oppositional defiant disorder/conduct disorder and ADHD group, an ADHD-only group, and a control group (Clark et al., 2002). Compared to the control group, all three clinical groups displayed lower adaptive social skills. Among the clinical groups, participants in the ADHD group displayed the highest social skills and the lowest communication skills. Adolescents in the oppositional defiant disorder/conduct disorder group displayed the lowest social skills and the highest communication skills.

**Table 3.3** Research of adaptive behavior with clinical samples

| Disability | ABAS-3 | Vineland-3 |
|---|---|---|
| Developmentally delayed | | No domains under 2 SD |
| Intellectual disability (IQ 50–70) | | ABC, communication, daily living skills, socialization, receptive (3–18 years), expressive, written, community, interpersonal relationships (19+ years), play and leisure, coping skills (19+ years) |
| Intellectual disability (IQ 35–49) | | Ages 3–18 years: ABC, communication, daily living skills, socialization, receptive, expressive, written, personal, community, play and leisure, coping skills |
| | | Ages 19+ years: ABC and all domain and skill areas |
| Intellectual disability (IQ <35) | | ABC and all domain and skill areas |
| Intellectual disability (general) | Ages 0–5: GAC, conceptual, social, practical, communication, community use, home living, health and safety, self-care, self-direction, social | |
| | Ages 5–21 years: GAC and all domain and skill areas | |
| Autism spectrum disorder | Ages 0–5 years: GAC, conceptual, social, practical, communication, community use, functional pre-academics, home living, health and safety, leisure, self-care, self-direction, social | IQ <70: ABC, communication, daily living skills, socialization, receptive, expressive, written (9–20 years), personal, domestic (3–8 years), community, interpersonal relationships, play and leisure, coping skills, fine motor (3–8 years) |
| | Ages 5–21: no domain or skill areas <2 SD | IQ >70: Ages 3–8: no domain or skill areas <2 SD; Ages 9–20: ABC, socialization |
| ADHD | No domain or skill areas <2 SD | |
| Learning disorders | Communication, functional academics, self-direction | |
| Hearing impaired | No domain or skill areas <2 SD | No domain or skill areas <2 SD |
| Visual impaired | | No domain or skill areas <2 SD |

*Note*: Table indicates adaptive behavior composites, domains, and skill areas scores that fall greater than two standard deviations below the mean for each disability on the ABAS-3 and Vineland-3 compared to typically developing peer samples

*ABC* adaptive behavior composite, *ADHD* attention deficit/hyperactivity disorder, *GAC* general adaptive composite

### 3.10.4 Attention Deficit/Hyperactivity Disorder

On the ABAS-3, children with ADHD displayed profiles similar to those displayed by children with emotional and behavioral disorders. Children with ADHD displayed greatest impairment in self-direction skills, underscoring their general difficulty with maintaining attention and regulating impulsivity, which impacts the ability to start and complete tasks, maintain a schedule, follow directions, and make choices (Harrison & Oakland, 2015). The Vineland-3 manual does not provide a sample of children diagnosed with ADHD and defers to the previous edition (Sparrow et al., 2016). On the Vineland-2, those diagnosed with ADHD showed impairment in adaptive communication and socialization behaviors as well as elevated maladaptive behaviors (Sparrow et al., 2005). These deficits may lead to impairment in educational settings in which students with ADHD must display independent responsibility for the organization and thoroughness of their work.

In contrast to more flexible home settings, structured educational settings are most difficult for children with ADHD, as demonstrated by differences in adaptive behavior ratings made by parents and teachers. Parent ratings generally are higher than matched teacher ratings. Thus, in contrast to their impairments at home, children with ADHD at school may display greater impairments in adaptive communication, self-direction, and socialization skills and display greater difficulty in classrooms in which self-control, rule-governed behavior, and attention to detailed academic tasks are required.

### 3.10.5 Learning Disabilities

On the ABAS-3, children with learning disabilities displayed significantly lower general adaptive behavior when compared to a matched control group. Their communication, functional academics, and self-direction skills were most impaired (Harrison & Oakland, 2015). Twenty-six students with learning disabilities (mean age 8.1) displayed below average conceptual adaptive behaviors (Ditterline et al., 2008). Their impairments were most evident in functional academics, communication, and self-direction skills. The Vineland-3 deferred to the second edition for those with learning disabilities (Sparrow et al., 2016). On the Vineland-2, individuals with learning disabilities exhibited deficits in adaptive communication and writing skills (Sparrow et al., 2005). Thus, although academic problems may be most common for individuals with learning disabilities, they also tend to display impairment in important adaptive skill areas.

Three distinct groups emerged when relationships among adaptive behavior, processing speed, academic achievement, and intellectual ability were examined in 112 students with learning disabilities (ages 8–11) (Strawser & Weller, 1985). Group 1 displayed average intellectual ability, mild-to-moderate deficiencies in adaptive behavior, and discrepancies between intellectual ability and academic achievement. Group 2 displayed average levels of intellectual ability, severe deficiencies in adaptive behavior, and significantly greater discrepancies among intellectual ability, academic achievement, and processing speed. Group 3 displayed below average intellectual ability, moderate deficiencies in adaptive behavior, and no discrepancies between intellectual ability and academic achievement or processing speed. Results suggest that students with learning disabilities present with heterogeneous conditions, and their adaptive behavior deficiencies may range from mild to severe. The most severe levels of adaptive behavior deficits were found in those students who displayed the greatest discrepancies among intellectual ability, academic achievement, and processing speed. Thus, prior to placement and programming decisions, consideration of adaptive behavior may aid in determining the severity of a particular learning disability subtype and the impact the learning disability may have on a child's adaptive functioning.

Adaptive self-care, communication, social, academic, and occupation skills of 114 students with learning disabilities (66 elementary-level participants with a mean age of 9.1 and 48 secondary-level participants with a mean age of 13.4) were compared with same-age peers with normal intelligence or with intellectual disability who comprised the norm group of the Adaptive Behavior Inventory (Leigh, 1987). The adaptive skills of students with learning disabilities were more impaired than students with normal intelligence and less impaired than students with intellectual disability.

Students with learning disabilities generally displayed their highest skills in self-care and lowest skills in academic areas. Further, adaptive behavior was considerably lower in adolescents than in children, suggesting that adaptive behavior deficits may be more prevalent in adolescence than in childhood.

Students receiving special education services for multiple or more severe disorders (e.g., emotional disturbance in combination with specific learning disability or ASD) display more severe impairment in adaptive behavior than students receiving services for singular disorders (e.g., emotional disturbance) (Ditterline et al., 2008). The general adaptive behavior as well as the adaptive conceptual, social, and practical behaviors were below average for 20 students receiving services for both emotional handicap and specific learning disabilities (mean age 8.5). These students displayed their greatest impairment in social, self-direction, school living, leisure, health, safety, and communication skills (Ditterline et al., 2008). The presence of an emotional and behavioral disturbance together with a specific learning disability may lead to impairment in general adaptive behavior as well as impairment in multiple skill areas.

Thus, research illustrates impairment in the adaptive behavior and skills of individuals with various disabilities. Those with intellectual disability display deficits in general adaptive behavior as well as in various skill areas. Individuals diagnosed with ASD tend to display deficits in adaptive communication and socialization. Those with emotional and behavioral disturbance tend to display deficits in socialization, while deficits in other skill areas such as communication and daily living are less predictable. Individuals diagnosed with learning disabilities tend to display deficits in conceptual adaptive behaviors (i.e., qualities related to academic skills).

### 3.10.6 Hearing/Visually Impaired

On the ABAS-3 a sample of those diagnosed with deaf or hard of hearing did not significantly differ from the general adaptive composite mean (Harrison & Oakland, 2015). Additionally, significant differences were not found in domain or skill areas. The Vineland-3 found those diagnosed with a hearing-impairment had significantly lower scores on the three communication domains when compared to matched controls (Sparrow et al., 2016). No statistically significant differences were found on the other domains or the maladaptive scales. Also on the Vineland-3 with a sample of individuals with visual impairment, the adaptive behavior composite and all domain scores fell in the low average range.

## 3.11 Conclusion

Adaptive behavior refers to one's ability to meet daily living responsibilities and respond to the needs of others, including the conceptual, practical, and social skills that people need to function in their everyday lives. The assessment of adaptive behavior traditionally has been associated with diagnosing developmental disabilities. Intellectual disability is generally characterized by significant impairments in adaptive behavior and intellectual functioning (AAIDD, 2010).

The assessment of adaptive behavior increasingly is being used for diagnosis and classification together with treatment planning and evaluation for individuals with various disabilities. Adaptive skills should be assessed routinely for any individuals who have difficulties and disorders that may impair their daily functioning. For example, individuals with attention disorders, ASD, developmental disabilities, emotional and behavioral disturbance, and learning disabilities generally exhibit impairments in daily living skills as well as patterns of strength and weakness in discrete adaptive skill areas. The assessment of adaptive behavior provides useful information for diagnosis, functional assessment, and treatment planning and evaluation for these and other individuals.

The WHO, AAIDD, and APA emphasize the importance of adaptive behavior and skills. The assessment of adaptive behavior is necessary for the diagnosis of intellectual disabilities under AAIDD and APA guidelines. Also, the evaluation of adaptive behavior yields information that is useful to professionals using the *WHODAS 2.0* (APA, 2013). The WHO's *ICF* provides a framework that professionals may find useful for gathering information about clients' functional status. The Activities and Participation portions of the *ICF* emphasize the acquisition of knowledge about skills used in daily life. Measures of adaptive behavior help provide this information, thus assisting professionals to describe clients more comprehensively.

Further, qualification for services under federal programs often requires information from measures of adaptive behavior. Information from adaptive skills assessments informs eligibility decisions under programs such as the Individuals with Disabilities Education Act, Supplemental Security Income, and Social Security disability.

This information may be required to establish stable daily functional limitations—information that often is necessary for the receipt of services. Thus, information from adaptive behavior assessments aids professionals in developing, monitoring, and ameliorating individual and family service, education, and transition services for people with various disabilities. The information also is helpful in the creation of programs for those entering prevocational training or vocational activities and in the evaluation of the needs of the elderly for assisted living and other forms of support. Professionals can select from several well-developed norm-referenced measures of adaptive behavior. Information on three scales reviewed in this chapter is intended to help professionals in the selection of one or more measures that best meet their needs. The use of these measures provides information that assists professionals in completing more comprehensive assessments for individuals, identifying specific areas of impairment, and developing, implementing, and monitoring intervention services. Professionals often find measures of adaptive behavior to be valuable because results provide data useful for clinical assessment and individual evaluation, assisting in differential diagnosis, establishing eligibility for special services, informing program planning, and identifying changes over time in the skills used by individuals to effectively function in their daily lives.

## References

American Association on Intellectual and Developmental Disorders. (2010). *Intellectual disability: Definitions, classifications, and systems of supports* (11th ed.). Washington, DC: Author.

American Bar Association. Task Force on Mental Disability and the Death Penalty. (2006). Recommendations and report on the death penalty and persons with mental disabilities. *Mental and Physical Disability Law Reporter, 30*, 668–677.

American Educational Research Association, American Psychological Association, and National Council on Measurement in Education. (2014). *The standards for educational and psychological testing*. Washington, DC: American Educational Research Association.

American Psychiatric Association. (1995). *Diagnostic and statistical manual of mental disorders* (4th ed., international version with ICD-10 codes). Washington, DC: Author.

American Psychiatric Association (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

American Psychological Association. (2002, amended 2010). *Ethical principles of psychologists and code of conduct*. Washington, DC: Author.

Apling, R. N., & Jones, N. L. (2005). *Congressional Research Service report for Congress, Individuals with Disabilities Education Act (IDEA): Analysis of changes made by P. L. 108–446*. Washington, DC: Library of Congress.

*Atkins v Virginia*. (2002). 536 U.S. 304.

Bölte, S., & Poustka, F. (2002). The relation between general cognitive level and adaptive behavior domains in individuals with autism with and without co-morbid mental retardation. *Child Psychiatry and Human Development, 33*, 165–172.

Bonnie, R. J. (2004). The American Psychiatric Association's resource document on mental retardation and capital sentencing: Implementing *Atkins v Virginia. Journal of the American Association of Psychiatry and the Law, 32*, 304–308.

Bonnie, R. J., & Gustafson, K. (2007). The challenges of implementing Atkins v Virginia: How legislatures and courts can promote accurate assessments and adjudications of mental retardation in death penalty cases. *University of Richmond Law Review, 41*, 810–860.

Bruininks, R., Woodcock, R., Weatherman, R., & Hill, B. (1996). *Scales of independent behavior—Revised*. Chicago: Riverside.

Clark, C., Prior, M., & Kinsella, G. (2002). The relationship between executive function abilities, adaptive behaviour, and academic achievement in children with externalizing behaviour problems. *Journal of Child Psychology and Psychiatry, 43*, 785–796.

Council for Exceptional Children. (2004). *The new IDEA: CEC's summary of significant issues*. Arlington, VA: Council for Exceptional Children

Ditterline, J., Banner, D., Oakland, T., & Becton, D. (2008). Adaptive behavior profiles of students with disabilities. *Journal of Applied School Psychology, 24*, 191–208.

Duvall, J. C., & Morris, R. J. (2006). Assessing mental retardation in death penalty cases: Critical issues for psychology and psychological practice. *Professional Psychology: Research and Practice, 37*, 658–665.

Ellis, J. W. (2003). Mental retardation and the death penalty: A guide to legislative issues. *Mental and Physical Disability Law Reporter, 27*(1), 11–24.

Endicott, J., Spitzer, R. L., Fleiss, J. L., & Cohen, J. (1976). The global assessment scale. *Archives of General Psychiatry, 33*, 766–771.

Fisch, G. S., Simensen, R. J., & Schroer, R. J. (2002). Longitudinal changes in cognitive and adaptive behavior scores in children and adolescents with the fragile X mutation or autism. *Journal of Autism and Developmental Disorders, 32*, 107–114.

Freeman, B. J., Del'Homme, M., Guthrie, D., & Zhang, F. (1999). Vineland adaptive behavior scale scores as a function of age and initial IQ in 210 autistic children. *Journal of Autism and Developmental Disorders, 29*, 379–384.

Gilotty, L., Kenworthy, L., Sirian, L., Black, D. O., & Wagner, A. E. (2002). Adaptive skills and executive function in autism spectrum disorders. *Child Neuropsychology, 8*, 241–248.

*Hall v. Florida*. (2014). 572 U.S.

Harrison, P. (1990). Mental retardation, adaptive behavior assessment, and giftedness. In A. S. Kaufman (Ed.), *Assessing adolescent and adult intelligence* (pp. 533–585). Boston: Allyn and Bacon.

Harrison, P., & Oakland, T. (2003). *Technical report: Adaptive behavior assessment system* (2nd ed.). San Antonio, TX: Psychological Corporation.

Harrison, P., & Oakland, T. (2015). *Adaptive behavior assessment system* (3rd ed.). San Antonio, TX: Harcourt Assessment.

Kostanjsek, T. B., Chatterji, S., & Rehm, J. (2010). *Measuring health and disability: Manual for WHO disability assessment schedule WHODAS 2.0.*. Geneva: World Health Organization.

Leigh, J. (1987). Adaptive behavior of children with learning disabilities. *Journal of Learning Disabilities, 9*, 557–562.

Liss, M., Harel, B., Fein, D., Allen, D., Dunn, M., Feinstein, C., et al. (2001). Predictors and correlates of adaptive functioning in children with developmental disorders. *Journal of Autism and Developmental Disorders, 31*, 219–230.

Maccow, G., & Zlomke, L. (2001). Review of the scales of independent behavior—Revised. In B. Plake & J. Impara (Eds.), *The fourteenth mental measurements yearbook*. Lincoln, NE: Buros Institute of Mental Measurements.

Olley, J. G., & Cox, A. W. (2008). Assessment of adaptive behavior in adult forensic cases: The use of the Adaptive Behavior Assessment System-II. In T. Oakland & P. Harrison (Eds.), *Adaptive Behavior Assessment System-II: Use, interpretation, and application in assessment practice* (pp. 198–214). New York: Elsevier.

Olley, J. G., Greenspan, S., & Switzky, H. (2006). Division 33 Ad Hoc Committee on mental retardation and the death penalty. *Psychology in Mental Retardation and Developmental Disabilities, 31*(2), 11–13.

Organisation for Economic Co-operation and Development. (2004). Equity in education: Students with disabilities, learning difficulties, and disadvantages. Paris: Author.

Reschly, D. J. (1990). Best practices in adaptive behavior. In A. Thomas & J. Grimes (Eds.), *Best practices in school psychology* (2nd ed., pp. 29–42). Washington, DC: National Association of School Psychologists.

Schatz, J., & Hamdan-Allen, G. (1995). Effects of age and IQ on adaptive behavior domains for children with autism. *Journal of Autism and Developmental Disorders, 25*, 51–60.

Social Security Administration. (2015). Disability evaluation under social security. SSA Publication Number 64-039 ICN 468600. Retrieved March 30, 2015, from http://www.ssa.gov/disability/professionals/bluebook/

Sparrow, S. S., & Cicchetti, D. V. (1987). Adaptive behavior and the psychologically disturbed child. *Journal of Special Education, 21*, 89–100.

Sparrow, S., Cicchetti, D., & Balla, D. (2005). *Vineland adaptive behavior scales* (2nd ed.). Circle Pines, MN: AGS.

Sparrow, S., Cicchetti, D., & Balla, D. (2016). *Vineland adaptive behavior scales* (3rd ed.). Bloomington, MN: NCS, Pearson.

Strawser, S., & Weller, C. (1985). Use of adaptive behavior and discrepancy criteria to determine learning disabilities severity subtypes. *Journal of Learning Disabilities, 18*, 205–212.

U.S. Code Service. (2007). *20 USCS* Section *1400: Individuals with Disabilities Education Act*. Retrieved June 12, 2007, from http://web.lexisnexis.com/universe/document?_m=6af9d78cf01c007d8151e26c38f4192dand_docnum=1andwchp=dGLbVlzzSkVband_md5=412bb646231d76b75426f221f837233a

U.S. Department of Education. (2006). *The Individuals with Disabilities Education Improvement Act of 2004*. Retrieved June 13, 2007, from http://www.ed.gov/about/offices/list/osers/osep/index.html

Weller, C., & Strawser, S. (1987). Adaptive behavior of subtypes of learning disabled individuals. *Journal of Special Education, 21*, 102–115.

World Health Organization. (1992a). *The international classification of diseases and related health problems* (10th ed.). Geneva: Author.

World Health Organization. (1992b). *International statistical classification of disease and related health problems* (10th rev.). Geneva: Author.

World Health Organization. (2001). *International classification of functioning and disability*. Geneva: Author.

# Impairment in Children

# 4

Gregory A. Fabiano and William E. Pelham Jr.

For children with mental health problems, impairment results in a diminished ability to perform at developmentally expected levels. Impairment in daily life activities can include dysfunction or an absence of adaptation in social, emotional, psychological, or occupational/academic domains, and it is a core component of nearly all childhood and adolescent mental health disorders. Currently, the American Psychiatric Association's (APA's) *Diagnostic and Statistical Manual of Mental Health Disorders, Fourth Edition, Text Revision* (*DSM-IV-TR*, 2000) requires impairment in daily life functioning for the diagnosis of the externalizing (e.g., attention deficit/hyperactivity disorder [ADHD], oppositional defiant disorder [ODD], and conduct disorder [CD]) and internalizing (e.g., anxiety and mood-related) disorders, and impairment in social or academic functioning is a cardinal feature of other disorders of childhood and adolescence (e.g., autism, learning disabilities, substance abuse).

## 4.1 Importance of Impairment for Child and Adolescent Disorders

With the advent of the *DSM*, substantial research and professional attention has been devoted toward developing and implementing *DSM* symptom-related assessments (e.g., Pelham, Fabiano, & Massetti, 2005), and *DSM* symptoms have been

---

G.A. Fabiano, Ph.D. (✉)
University at Buffalo, State University of New York, 334 Diefendorf Hall,
Buffalo, NY 14214, USA
e-mail: Fabiano@buffalo.edu

W.E. Pelham Jr., Ph.D.
Department of Psychology, Florida International University, AHC 1 Room 248B,
Miami, FL 33199, USA
e-mail: wpelham@fiu.edu

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_4

used as primary outcome measures in large treatment outcome studies (e.g., MTA Cooperative Group, 1999; Treatment for Adolescents with Depression Study [TADS] Team, 2004). Relative to symptoms, however, attention devoted toward impairment in daily life functioning has lagged. As described in this chapter, there is considerable justification for emphasizing impairment in evaluations and interventions; as it is a key contributor to referral for intervention, it should be the major outcome evaluated during and after intervention, and it is the best predictor of long-term outcomes for children and adolescents.

Importantly, it is impairment in daily life functioning, not putative *DSM* symptoms, that typically results in referral for treatment or services (e.g., Angold, Costello, Farmer, Burns, & Erkanli, 1999; Lavigne et al., 1998). For example, (Angold et al., 1999) reported that children who had evidence of psychosocial impairment, whether or not they met criteria for a *DSM* disorder, were typically involved in clinical treatment setting efforts. Further, children who met symptom criteria for a *DSM* disorder but did not have impaired functioning were generally not receiving clinical services. Costello & Shugart, 1992 investigated rates of *DSM* symptoms in pediatric and psychiatric settings and reported that there were a considerable number of children who did not meet symptom count criteria for *DSM* externalizing disorders but were nonetheless experiencing significant psychosocial impairment. Intensity of service use is also related to severity of impairment, with more restrictive and costly treatments generally implemented for more impaired children and adolescents (McDermott, McKelvey, Roberts, & Davies, 2002).

Second, impaired domains of functioning, and not *DSM* symptoms, are one aspect of the social validity of a treatment. Social validity relates to the "meaningfulness" of the goals of treatment, intervention procedures, and the way outcomes of the treatment are defined and evaluated (Foster & Mash, 1999; Kazdin, 1977; Wolf, 1978). For instance, referring problems as reported by parents and teachers rarely include *DSM* symptoms such as "fidgeting" or "psychomotor agitation or retardation nearly every day." Rather, parents and teachers report that the child is actively rejected by peers, is failing academic classes in school, disrupts family and classroom routines, and does not get along with adults. These latter areas are those that are the socially valid targets of intervention; it is these areas of impairment that should receive the attention of intervention efforts, and whether treatment improves functioning in these domains is the primary means for assessing treatment outcome (Foster & Mash, 1999).

Third, with an eye toward treatment planning, the identification and evaluation of impaired functional domains is a critical task because the putative *DSM* symptoms do not provide information on the function of problematic behavior (Scotti, Morris, McNeil, & Hawkins, 1996). Take, for example, the symptom of "distractibility." A child who has this item endorsed on a structured interview or rating scale as occurring at least "pretty much" would have the item count toward a *DSM* diagnosis. However, the item in and of itself provides no information on the extent to which this behavior is a problem for the child and what causes, maintains, or exacerbates the behavior. Even worse, a perusal of the *DSM* illustrates that this symptom could be part of inattention related to ADHD, a mood disorder (either depressed or elevated mood), a generalized anxiety disorder, or a post-traumatic stress disorder. For one child, the function of the behavior could be to avoid tasks he or she dislikes, and the behavior is limited to situations in which a demand is placed on the child. For another child, he or she may appear distractible because of an attempt to avoid intrusive thoughts. A third child may not have psychological problems at all and instead have auditory problems that impair his or her ability to follow a conversation effectively. Obviously, effective interventions for this behavior will require different approaches depending on the function of the behavior and the nature of the impairment; in this example, the intervention for the first child may focus on increasing motivation, for the second child, a cognitive-behavioral approach that includes exposure to the feared thought, and for the third child accommodations for hearing impairment. The negative *impact* of the symptom on the child's functioning is what is conceptualized as impairment—in all three cases, we suspect the child would experience negative outcomes related to the symptom of distractibility. However, rather than spending valuable clinician and patient time establishing whether the child is distractible "just a little" or "pretty much," assessment efforts should be devoted toward determining the function, extent, and impact of the behavior on functioning and how to reduce the negative impact of the behavior in functional life domains.

Fourth, and perhaps most important, impairment in functional domains during childhood are the best predictors of negative short-term and long-term outcomes, and improvement in impaired domains must be achieved to avoid continued problems throughout development. Longitudinal studies have demonstrated functional impairment in childhood is predictive of future adolescent problems (Costello, Angold, & Keeler, 1999). For example, poor peer relationships in childhood, inconsistent and ineffective parenting, and academic underachievement all predict a host of negative outcomes in adolescence and adulthood (Chamberlain & Patterson, 1995; Christle, Jolivette, & Nelson, 2005; Coie & Dodge, 1998; Dishion, Nelson, & Yasui, 2005; LaGreca & Harrison, 2005), whereas to our knowledge, the symptoms of *DSM* disorders are *not* strong predictors of adolescent or adult outcomes (e.g., Mannuzza & Klein, 1999). Thus, improvement in functioning in the areas of impairment is necessary to divert the child's developmental trajectory from these negative outcomes.

It is also worth noting that symptoms of a *DSM* disorder typically do not provide any information on the child's current levels of adaptive functioning or strengths, which may also predict long-term outcomes. In addition to reducing impaired areas of functioning, treatment efforts also focus on promoting the development of positive behaviors and competencies. A comprehensive assessment of impairment will include a consideration of adaptive abilities and behavioral competencies, and these behaviors will also be monitored and targeted in treatment.

## 4.2 Domains of Child and Adolescent Impairment

A prototypical child from a family who seeks services will present with problems across functional domains, including in his or her relationships with peers and siblings; relationships with parents, teachers, and other adults; academic progress in school; and disruption in family and classroom functioning or routines. For many children, these difficulties will be apparent across domains of functioning, meaning treatments will need to address impairment in the home, school, and peer group settings.

Peer relationship problems are often impaired in children and adolescents referred for psychological services (Bukowski & Adams, 2005). For example, researchers have long known that children with ADHD (e.g., Pelham & Bender, 1982) or conduct problems (Coie & Dodge, 1998) have problems in peer relationships. Problems may range from simply being ignored by other children (e.g., not being picked to play in recess activities, being the only child not invited to a classmate's birthday party) to being actively rejected by other children (e.g., being bullied during recess). A child with ADHD or CD may also tease and be teased by peers, get into fights with other children, and exhibit inappropriate social skills (e.g., is a poor sport during games).

Adult relationships may also be an area of impaired functioning. Problems include noncompliance to adult commands and instructions and argumentative behavior. Furthermore, the negative behavior exhibited by children with disruptive behavior disorders seriously affects family and classroom functioning (e.g., Fischer, 1990). It is not uncommon for parents to report that they no longer go out to dinner at a restaurant, attend Sunday worship services, or attend family parties and social gatherings as a direct result of their child's behavior. Similarly, teachers may observe impaired children in their classrooms require constant one-to-one attention to complete even the simplest of tasks, require extra attention during field trips or other activities outside the classroom (e.g., music class), or fail to complete academic assignments accurately and in a timely manner. Children with internalizing disorders might have comparable impacts on family or classroom functioning. For example, a child with depression may spend large portions of the school day in the nurse's office with somatic complaints.

An additional area of impairment is in the domain of academic achievement. The primary feature of the specific learning disabilities is impairment in academic functioning. Other disorders may also result in impaired academics. For example, a child with school phobia may fail to attend classes and therefore may experience a lag in academic achievement or with social development. Children with ADHD may perform poorly due to failing to hand in completed homework or long-term projects. Furthermore, behaviors that may be relatively easy for most students, such as completing independent seatwork assignments, remembering to bring home all needed materials for homework, and note taking, may be extremely difficult for children with ADHD.

Notably, these problems in important domains of daily life functioning are rarely included in the behavioral symptoms in the *DSM*. In addition, any evaluation of impairment typically measures a child's strengths, skills, and abilities. Eventual treatment efforts will work not only to reduce the occurrence of problematic behaviors but also to increase competencies in these areas of adaptive functioning.

## 4.3 Impairment Measures

Below we briefly review an impairment measure for children and adolescents not discussed elsewhere in this volume. Since the publication of the first edition of this volume, a number of nationally standardized measures designed to assess impairment have been published (Barkley, 2016; Goldstein & Naglieri, 2015). Perhaps because impairment has been *implicit* but not *explicit* in previous versions of the *DSM*, few practical means of measuring impairment across functional domains have been developed. Some impairment-rating procedures have been developed to quantify a child's overall level of functional impairment. In clinical and research settings, commonly used global impairment scales include Axis V of the *DSM* (American Psychiatric Association, 2000), which is a modified version of the Global Assessment Scale (Endicott, Spitzer, Fleiss, & Cohen, 1976). The version most commonly used with children and adolescents is the Children's Global Assessment Scale (CGAS; Setterberg, Bird, & Gould, 1992).

Respondents on the CGAS rate the child's current level of functioning on a scale from 1 to 100, with scores of 1 relating to the most serious impairment in functioning and 100 relating to the best level of functioning. Raters refer to a behavioral descriptor for every ten points on the scale and can make a rating anywhere in the range from 1 to 100. The CGAS has been used in epidemiological, research, and clinical settings, and it evinces good reliability and validity. Advantages of the CGAS include its good psychometric properties and its ability to be completed quickly and over repeated administrations.

However, global measures of impairment have limitations. They provide no information on specific impaired areas of functioning, which is critical for treatment planning, monitoring, and evaluation. Therefore, many other scales have been developed to assess functional impairment in specific domains. For example, a portion of the widely used Child Behavior Checklist (CBCL) and Teacher Report Form (TRF; Achenbach & Rescorla, 2001) asks parents about adaptive functioning, such as the child's participation and proficiency in social activities, academic achievement, and receipt of special services in school. Measures such as the Teacher Assessment of Social Behavior (TASB; Cassidy & Asher, 1992), the Social Skills Rating Scale (SSRS; Gresham & Elliott, 1990), and peer sociometric ratings may be used to evaluate impairment in children's peer interactions. The effects of a child's behavior problems on the family may be measured by the Impact on Family Scale (IFS; Sheeber & Johnson, 1992) or the Daily Hassles Scale (Crnic & Greenberg, 1990). In addition, a child's impairment in academic functioning may be determined through standardized intelligence and academic achievement tests or school report cards.

Although these measures, and others, may be used to measure specific domains of impairment, they have limitations. For example, some require the rater to answer a large number of questions (e.g., the SSRS), some require multiple raters (e.g., sociometrics, which requires a group of children to make negative or positive nominations of peers), and others require the use of lengthy and therefore expensive psychological tests (e.g., intelligence and academic achievement testing) or observation for a lengthy time period (e.g., academic grades). Finally, most focus on a single domain of impairment, which means that a battery of measures such as these must be administered to obtain a comprehensive assessment of impairment (see Lahey et al., 1998, for an example of such an approach). This means that raters and clinicians must invest significant time to evaluate impairment, which is impractical for large-scale screenings or repeated assessments in clinical or applied research settings.

Due to these limitations, other researchers have worked to develop multidimensional measures of impaired functioning. Table 4.1 lists commonly used multidimensional measures of impairment, a brief description of each, and a general review of the psychometric properties of each measure. We briefly review each of these measures next.

### 4.3.1 Columbia Impairment Scale

The Columbia Impairment Scale (CIS; Bird et al., 1993, 1996) is a 13-item measure that assesses multiple areas of psychosocial functioning, including interpersonal relationships, occupational, or academic functioning, and use of leisure time, in addition to some questions on broad areas of psychopathology (e.g., feeling sad or unhappy). Respondents are instructed to rate each item on a scale from zero (no problem) to four (very big problem), and the measure can be completed by a parent or other adult informant as well as a child/adolescent. The parent CIS evinces good indices of reliability (Bird et al., 1993) and validity (e.g., correlates with measures of functioning such as whether the youth was in treatment or had been expelled/suspended from school; Bird et al., 1996).

### 4.3.2 Child and Adolescent Functional Assessment Scale

The Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, Doucette-Gates, & Liao, 1999; Hodges & Kim, 2000; Hodges & Wong, 1996) is a multidimensional measure of impairment. Following a clinical interaction that includes an interview, record review, or consultation with treatment providers or other professionals, the CAFAS asks an interviewer to rate the child across eight domains (e.g., behavior toward self and others) and to rate the caregiver (i.e., the environment) on two domains. Psychometric studies of the CAFAS indicate that the measure demonstrates good internal consistency and the measure is consistent across raters (Hodges & Wong, 1996). Furthermore, the CAFAS is sensitive to changes in functioning due to treatment efforts (Hodges et al., 1999).

**Table 4.1** Multidimensional measures of impairment

| Impairment measure | Description | Reliability | Validity |
|---|---|---|---|
| Columbia Impairment Scale (CIS; Bird et al., 1993, 1996) | • Completed by lay interviewer or parent | • Evidence of internal consistency ($r = .82$ to .89) and test-retest reliability for the parent version ($r = .89$) | • Evidence of concurrent validity when compared to parent CGAS |
| | • 13-item scale that asks about functioning across functional domains | | • Mean scores higher in clinical participants compared to community respondents |
| | • Respondents rate each domain on a scale from 0 to 4 | • Less internal consistency ($r = .70$ to .78) and test-retest reliability for child raters ($r = .69$) | • Correlates with other psychosocial measures of dysfunction; parent version exhibited more evidence of validity than child-rated version |
| Children's Global Assessment of Functioning (CGAS; Bird, Canino, Rubio-Stipec, & Ribera, 1987, 1990; Shaffer et al., 1983) | • Adapted from adult Global Assessment Scale | • Evidence of test-retest reliability when completed by a clinician ($r = .74$ to .84) | • Correlates highly with other global measures of impairment ($r = .80$ to .92) |
| | • Scores range from 0 to 100 with descriptions of behavior and functioning for every ten points | • Evidence of interrater reliability for clinicians ($r = .69$ to .87) | • Scores related to service use and severity of behavior problem ratings |
| | • Typically completed by a clinician after interview/records review | | |
| | • Nonclinician version may be completed by parents | | |
| Impairment Rating Scale (IRS; Evans et al., 2005; Fabiano et al., 2006) | • Completed by a parent and teacher | • Evidence of temporal stability over 4 months and 1 year for parent and teacher version | • Correlates moderately with parent and teacher CGAS |
| | • Items ask raters to report on functioning across important domains | | • Correlates moderately with objective measures of problematic behavior |
| | • Includes space for a rater to provide a narrative of problematic behaviors | • Moderate to high interrater reliability between parents and teachers | • Predicts use of mental health and school services |

(continued)

**Table 4.1** (continued)

| Impairment measure | Description | Reliability | Validity |
|---|---|---|---|
| Child and Adolescent Psychiatric Assessment (CAPA; Angold & Costello, 1995; Angold et al., 1995, 1999) | • Built into a psychiatric diagnostic interview | • Evidence of temporal stability on the child version | • Children with impaired functioning rated on the CAPA more likely to be receiving services |
| | • Symptoms counted only if impairing | • Kappa coefficients rage from .55 (conduct disorder) to 1.0 (substance abuse/dependence) | |
| | • After disorder-specific symptom questions are completed, interviewer also rates incapacities across important life domains | | |
| Child and Adolescent Functional Assessment Scale (CAFAS; Hodges et al., 1999; Hodges & Kim, 2000; Hodges & Wong, 1996) | • Includes eight scales to assess child behavior and two scales for the child's environment | • Internal consistency ($r = .73$ to .78) | • Higher ratings of impairment obtained for children with more "severe" disorders and behavioral indices of impairment such as academic grades, school attendance, contact with the police |
| | • Completed by a rater after a review of records, interviews with relevant respondents, and discussions with others involved in the case | • Interrater reliability for total score ($r = .92$ to .96) | • Sensitive to treatment effects |
| | • Yields a score for each subscale and a total score | | |
| | • Training manual available for completing the measure | | |

### 4.3.3 Child and Adolescent Psychiatric Assessment

The Child and Adolescent Psychiatric Assessment (CAPA) integrates the assessment of impairment with a structured diagnostic interview, asking the informant to rate impairment specific to each symptom group (e.g., ADHD, depression, etc.; Angold et al., 1995). The CAPA is a structured psychiatric interview administered by an interviewer to both children and parents. Interviewers are trained to ask about the presence, frequency, and intensity of diagnostic symptoms. Then, interviewers rate the degree to which the symptoms have incapacitated the individual across a number of important functional domains (e.g., family life and relationships). The CAPA has demonstrated acceptable indices of reliability and good indicators of validity, and it has been used in epidemiological as well as clinical settings.

### 4.3.4 Impairment Rating Scale

The Impairment Rating Scale (IRS; Evans, Allen, Moore, & Strauss, 2005; Fabiano et al., 2006) is a multidimensional measure that assesses functioning across domains developed for children with ADHD. The IRS asks the rater to place an “X” on a continuum from “no problem; definitely does not need treatment or special services” to “extreme problem; definitely needs treatment or special services.” There is also space for the rater to describe in a narrative fashion his or her reasoning for the rating or to provide additional information or examples regarding the extent of the impairment. Because the IRS can be completed by a parent or teacher without clinician involvement, the only clinical cost is the time spent to review and score it. It is unique in that it is a rating scale completed by the child’s parent and teacher, making it a quick and low-cost alternative to assessments that require an interviewer. The IRS exhibits concurrent, discriminant, and convergent validity and acceptable levels of temporal stability. The IRS is also sensitive to changes in behavior modification or pharmacological interventions (e.g., Fabiano et al., 2007). Research indicates a score of three or greater on the measure reliably identifies children with ADHD and does not identify those without the disorder.

As Table 4.1 indicates, there are a number of well-studied, psychometrically sound instruments for assessment of impairment. Depending on the explicit goal of a particular assessment, one measure may be preferred over another. Clinicians/researchers must decide on the best approach to assessing impairment given their needs.

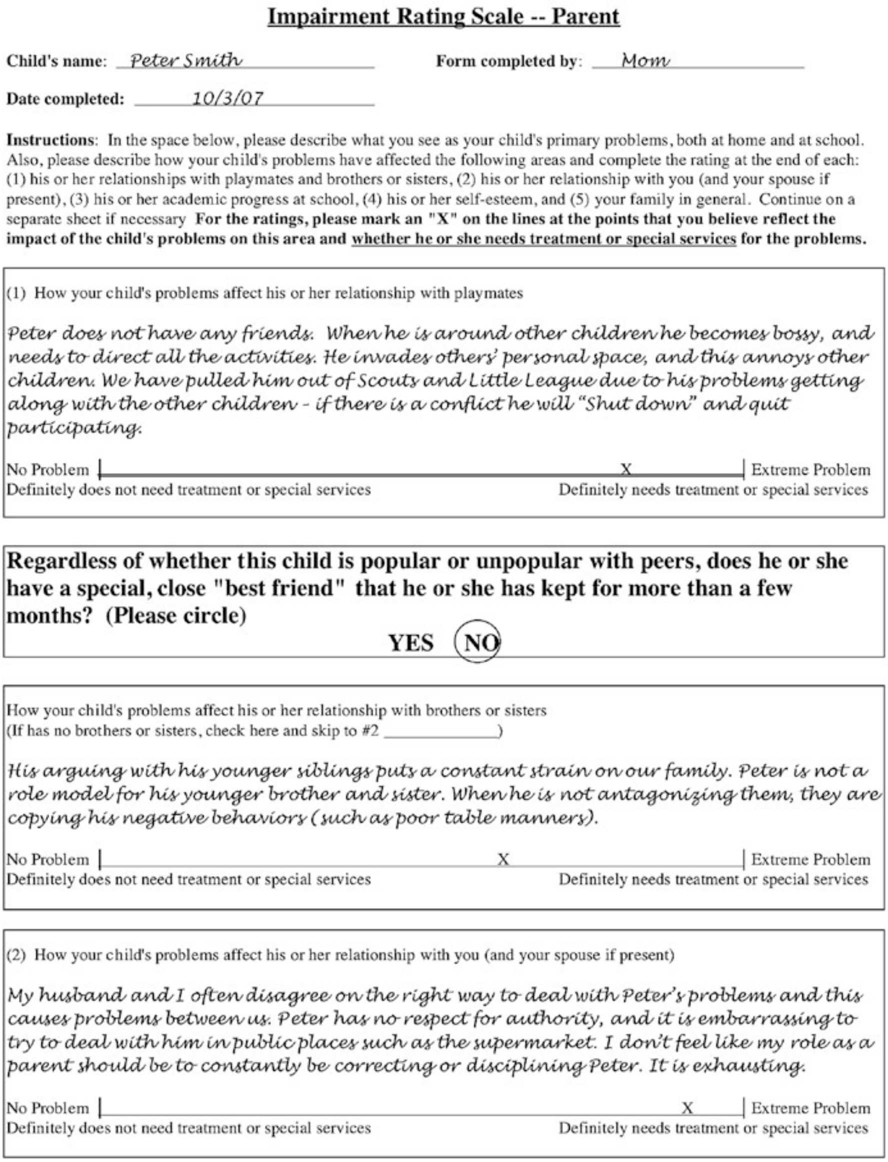
### 4.3.5 Illustrative Case

In an effort to describe a practical approach to measuring impairment in a child client, we describe a prototypical case in our clinic for children with ADHD and then walk through the steps included in the assessment, beginning with the initial referral, meetings with the parents, the approach to treatment, and the strategies for assessing treatment outcomes. Following this, we present general guidelines for the assessment of impairment in children and adolescents.

Peter Smith is a 9-year-old boy who lives with his parents, John and Jane Smith, and his younger brother and sister. He attends third grade at the local public elementary school. He has had long-standing behavior problems dating back to preschool, and he was referred to the clinic in October of the current school year due to parent and teacher concerns about behavior. Before the initial clinic intake, his parent and teacher were mailed the IRS to complete. Figure 4.1 displays the responses on the parent IRS, and Fig. 4.2 displays the teacher IRS responses.

Before the initial meeting with the parents, the clinician should review and score the IRS. The IRS is scored by placing a transparency over the line where the rater placed an “X”. The line is divided into seven equal segments labeled 0 (no problem) to 6 (extreme problem). The segment within which the “X” is placed constitutes the score. Research indicates any score greater than or equal to three is within the clinically impaired range for a child Peter’s age (Fabiano et al., 2006). Thus, with the exception of self-esteem (not surprising given the literature on positive illusory bias in children with ADHD; Hoza, Pelham, Dobbs, Owens, & Pillow, 2002), Peter’s parent and teacher agree that he is impaired across all major functional domains in both the home and school setting. The narrative information provided on the parent and teacher IRS provides additional explanatory and contextual information on impairment, and this information naturally leads to follow-up questions that may be asked during the clinical interview.

Figure 4.3 illustrates a portion of an initial intake interview. In clinical practice, the majority of intake time should be devoted to identifying, operationalizing, and understanding the child’s areas of impairment. This portion of the assessment is where the clinician collects more detailed information on the nature and extent of impairment, and this information should be collected in a manner that is integrated with treatment planning. As Fig. 4.3 illustrates, the clinician reviews intake ratings and the parent report of presenting problems and then works with the parent to operationalize and review the antecedents, consequences, and setting events of the targeted behavior. For example, for the targeted behavior of completing homework in the specified time, the parents described antecedents that encompassed tasks that included writing and situations for which they were feeling time pressure. The clinician also obtains information on consequences; for the child, these include escape/avoidance of an aversive task, and for the parents these consequences include their own feelings of frustration. Behavior modification strategies such as time-out have not been effective consequences according to the parent. Clinicians also obtain information during this interview on the child’s strengths and competencies and ask the parent about the impact of the targeted behavior for the child in the short and long term. Similar to other global ratings of impairment (e.g., Shaffer et al., 1983), the clinician also provides an overall global rating of the impact of the behavior using IRS methodology (Fabiano et al., 2006). If this procedure is repeated for the child’s main presenting problems, the result of the initial assessment should be a list of target behaviors and parent-generated information on the nature, severity, and function of each.



**Impairment Rating Scale -- Parent**

**Child's name:** Peter Smith **Form completed by:** Mom

**Date completed:** 10/3/07

**Instructions**: In the space below, please describe what you see as your child's primary problems, both at home and at school. Also, please describe how your child's problems have affected the following areas and complete the rating at the end of each: (1) his or her relationships with playmates and brothers or sisters, (2) his or her relationship with you (and your spouse if present), (3) his or her academic progress at school, (4) his or her self-esteem, and (5) your family in general. Continue on a separate sheet if necessary **For the ratings, please mark an "X" on the lines at the points that you believe reflect the impact of the child's problems on this area and <u>whether he or she needs treatment or special services</u> for the problems.**

(1) How your child's problems affect his or her relationship with playmates

Peter does not have any friends. When he is around other children he becomes bossy, and needs to direct all the activities. He invades others' personal space, and this annoys other children. We have pulled him out of Scouts and Little League due to his problems getting along with the other children - if there is a conflict he will "Shut down" and quit participating.

No Problem |______________________________________________X______| Extreme Problem
Definitely does not need treatment or special services — Definitely needs treatment or special services

**Regardless of whether this child is popular or unpopular with peers, does he or she have a special, close "best friend" that he or she has kept for more than a few months? (Please circle)**

**YES [✓ NO]**

How your child's problems affect his or her relationship with brothers or sisters
(If has no brothers or sisters, check here and skip to #2 ____________)

His arguing with his younger siblings puts a constant strain on our family. Peter is not a role model for his younger brother and sister. When he is not antagonizing them, they are copying his negative behaviors (such as poor table manners).

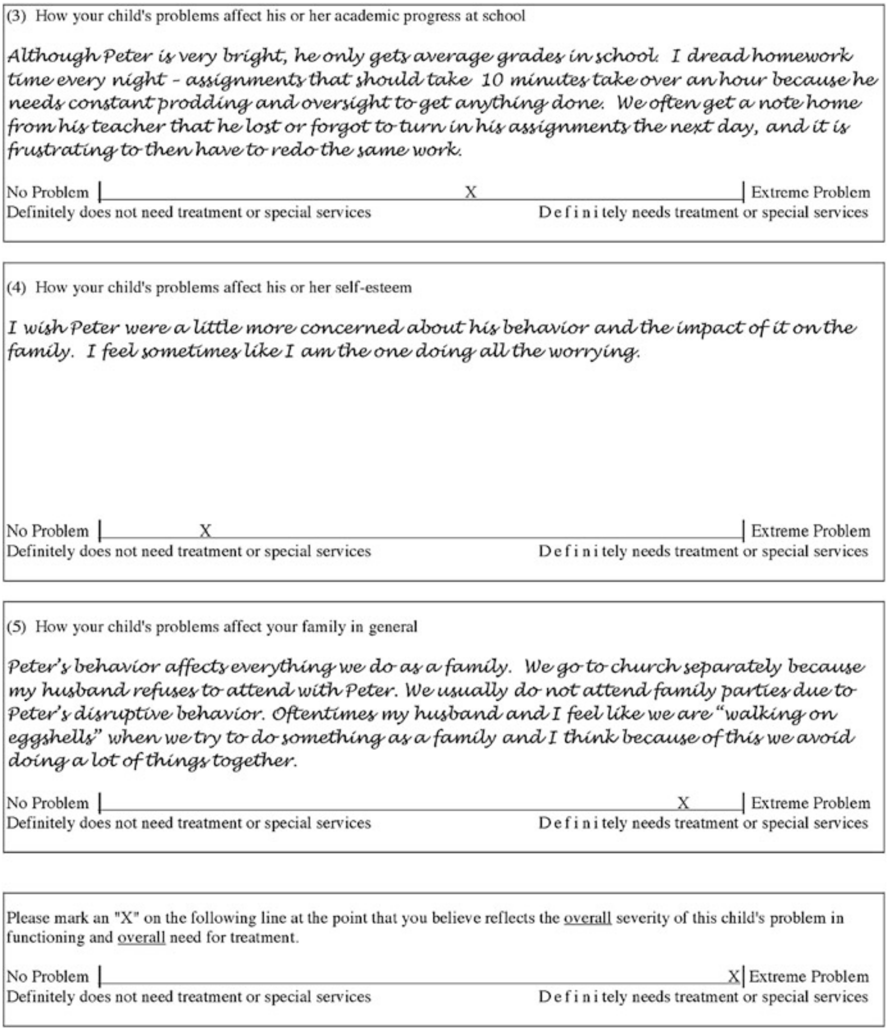
No Problem |______________________________X________________________| Extreme Problem
Definitely does not need treatment or special services — Definitely needs treatment or special services

(2) How your child's problems affect his or her relationship with you (and your spouse if present)

My husband and I often disagree on the right way to deal with Peter's problems and this causes problems between us. Peter has no respect for authority, and it is embarrassing to try to deal with him in public places such as the supermarket. I don't feel like my role as a parent should be to constantly be correcting or disciplining Peter. It is exhausting.

No Problem |________________________________________________X_____| Extreme Problem
Definitely does not need treatment or special services — Definitely needs treatment or special services

**Fig. 4.1** Sample parent impairment rating scale



(3) How your child's problems affect his or her academic progress at school

Although Peter is very bright, he only gets average grades in school. I dread homework time every night - assignments that should take 10 minutes take over an hour because he needs constant prodding and oversight to get anything done. We often get a note home from his teacher that he lost or forgot to turn in his assignments the next day, and it is frustrating to then have to redo the same work.

No Problem |______________________X______________________| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

(4) How your child's problems affect his or her self-esteem

I wish Peter were a little more concerned about his behavior and the impact of it on the family. I feel sometimes like I am the one doing all the worrying.

No Problem |______X_______________________________________| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

(5) How your child's problems affect your family in general

Peter's behavior affects everything we do as a family. We go to church separately because my husband refuses to attend with Peter. We usually do not attend family parties due to Peter's disruptive behavior. Oftentimes my husband and I feel like we are "walking on eggshells" when we try to do something as a family and I think because of this we avoid doing a lot of things together.

No Problem |_____________________________________X____| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

Please mark an "X" on the following line at the point that you believe reflects the overall severity of this child's problem in functioning and overall need for treatment.

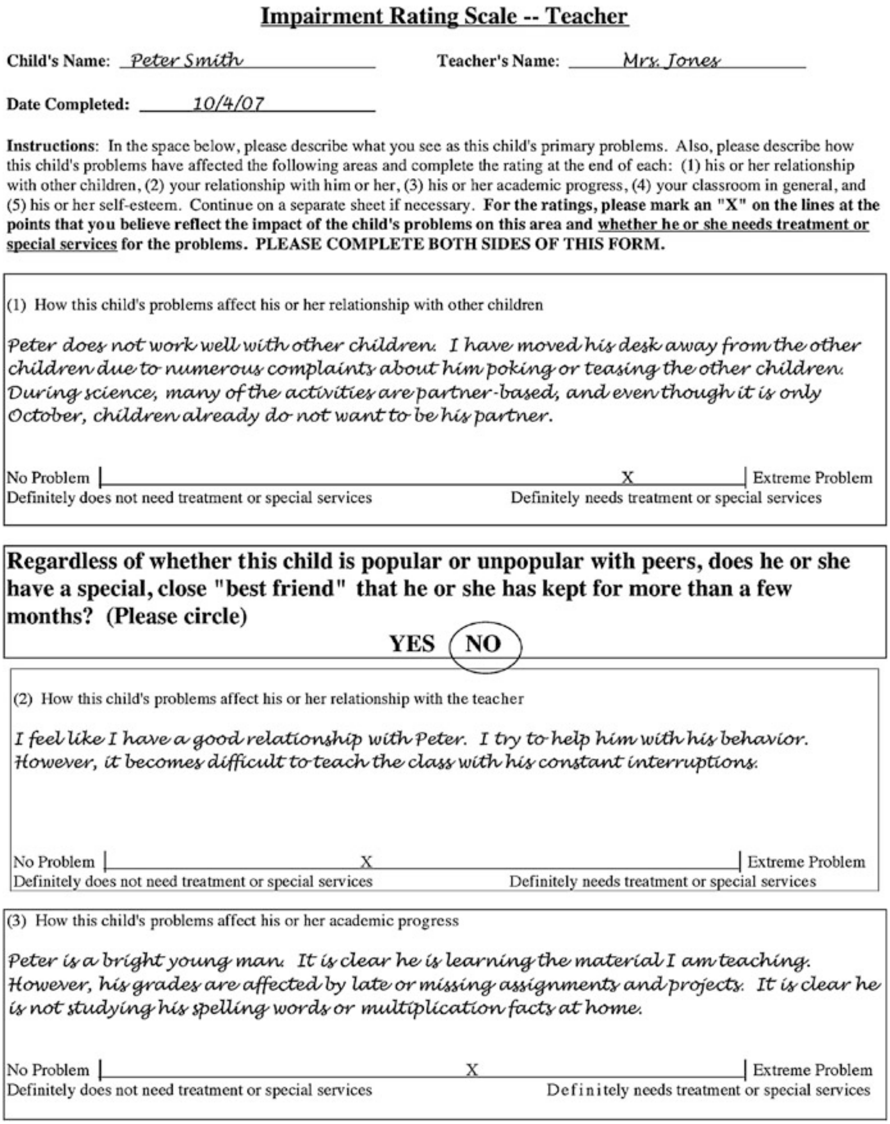
No Problem |____________________________________________X| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

**Fig. 4.1** (continued)

Using the information gathered on impaired areas of functioning as part of the assessment, the clinician is now armed with sufficient information to begin treatment planning, with a focus on the child's main areas of functional impairment. For a child such as Peter, intervention should focus on reducing problematic behaviors and increasing adaptive ones. An efficient and effective means of meeting this goal is to establish a daily report card (DRC; http://ccf.buffalo.edu/pdf/school_daily_report_card.pdf). The DRC has long been used effectively to treat ADHD, monitor outcomes, and open a daily line of communication between teachers and the child's parent (DuPaul & Eckert, 1997; DuPaul & Stoner, 2004; Kelley, 1990; O'Leary & Pelham, 1978; O'Leary, Pelham, Rosenbaum, & Price, 1976; Pelham, Wheeler, &

Chronis, 1998); Pelham et al., 2001, 2002, 2005, and it is a procedure aligned with a long tradition of using contingency management with children with disruptive behavior in clinical and educational settings (e.g., Hops & Walker, 1988).

In addition to being an effective treatment for ADHD, the DRC is also an efficient and effective procedure for monitoring outcomes in the child's important areas of psychosocial functioning (Pelham et al., 2005). It is sensitive to environmental



**Impairment Rating Scale -- Teacher**

**Child's Name:** Peter Smith **Teacher's Name:** Mrs. Jones

**Date Completed:** 10/4/07

**Instructions**: In the space below, please describe what you see as this child's primary problems. Also, please describe how this child's problems have affected the following areas and complete the rating at the end of each: (1) his or her relationship with other children, (2) your relationship with him or her, (3) his or her academic progress, (4) your classroom in general, and (5) his or her self-esteem. Continue on a separate sheet if necessary. **For the ratings, please mark an "X" on the lines at the points that you believe reflect the impact of the child's problems on this area and whether he or she needs treatment or special services for the problems. PLEASE COMPLETE BOTH SIDES OF THIS FORM.**

(1) How this child's problems affect his or her relationship with other children

Peter does not work well with other children. I have moved his desk away from the other children due to numerous complaints about him poking or teasing the other children. During science, many of the activities are partner-based, and even though it is only October, children already do not want to be his partner.

No Problem | X | Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

**Regardless of whether this child is popular or unpopular with peers, does he or she have a special, close "best friend" that he or she has kept for more than a few months? (Please circle)**

**YES [✓ NO]**

(2) How this child's problems affect his or her relationship with the teacher

I feel like I have a good relationship with Peter. I try to help him with his behavior. However, it becomes difficult to teach the class with his constant interruptions.

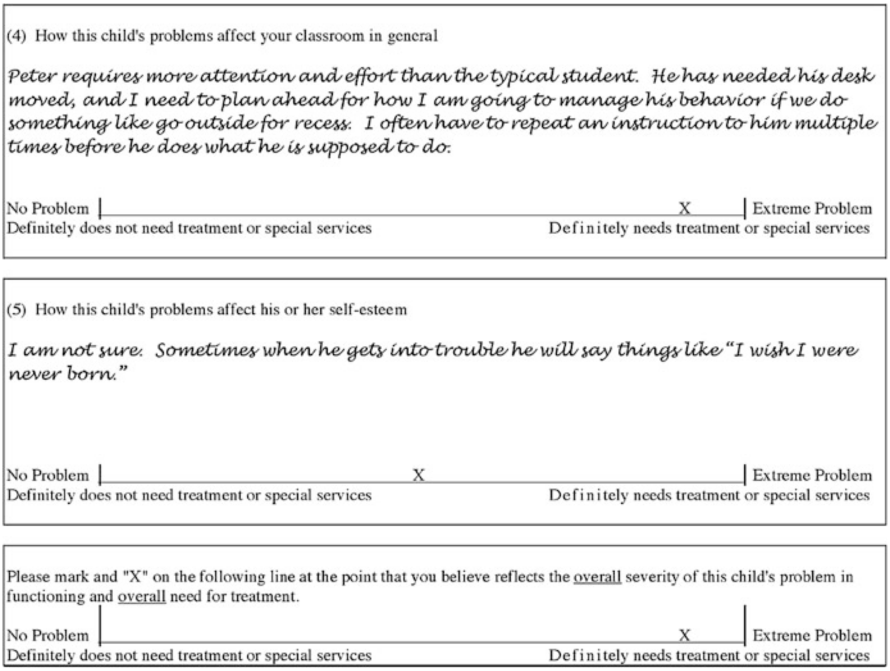
No Problem | X | Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

(3) How this child's problems affect his or her academic progress

Peter is a bright young man. It is clear he is learning the material I am teaching. However, his grades are affected by late or missing assignments and projects. It is clear he is not studying his spelling words or multiplication facts at home.

No Problem | X | Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

**Fig. 4.2** Sample teacher impairment rating scale



(4) How this child's problems affect your classroom in general

Peter requires more attention and effort than the typical student. He has needed his desk moved, and I need to plan ahead for how I am going to manage his behavior if we do something like go outside for recess. I often have to repeat an instruction to him multiple times before he does what he is supposed to do.

No Problem |________________________________________X| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

(5) How this child's problems affect his or her self-esteem

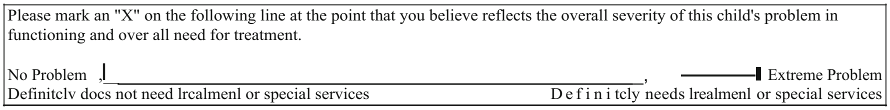
I am not sure. Sometimes when he gets into trouble he will say things like "I wish I were never born."

No Problem |____________________X____________________| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

Please mark and "X" on the following line at the point that you believe reflects the overall severity of this child's problem in functioning and overall need for treatment.

No Problem |________________________________________X| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

**Fig. 4.2** (continued)



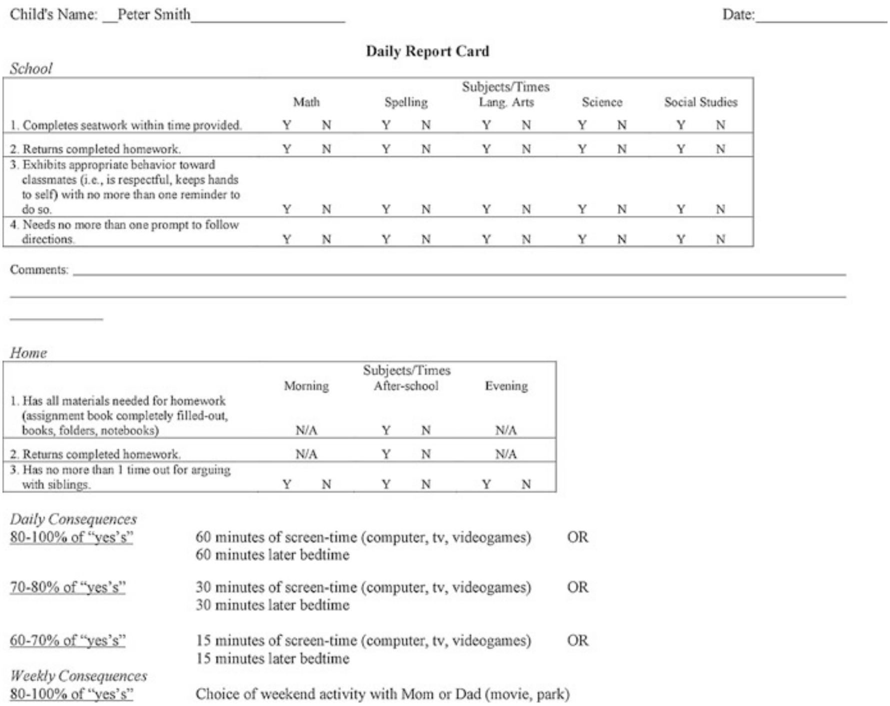
Please mark an "X" on the following line at the point that you believe reflects the overall severity of this child's problem in functioning and over all need for treatment.

No Problem |________________________________________| Extreme Problem
Definitely does not need treatment or special services Definitely needs treatment or special services

**Fig. 4.3** Sample clinician-completed target behavior evaluation

modifications, and it is also a useful device for communicating with parents regarding the child's behavior in school. The DRC is sensitive to pharmacological (e.g., Pelham et al., 2001) and behavioral treatment effects (e.g., Pelham et al., 2005). Teacher feedback to the child regarding progress toward DRC goals and explicit feedback regarding whether goals are met may also serve as an antecedent to future appropriate behavior as well as be used as a data-driven monitoring device for schools to use to evaluate the progress of children in general and special education programs. Importantly, the targets on the DRC are the impaired areas of functioning that constitute the socially valid targets of treatment.

For Peter, impaired areas of functioning are clearly present in the home and school settings. A clinician should synthesize the information gathered through the IRS and clinical interview and use it to establish target behaviors. These targeted behaviors then become the means of monitoring progress and measuring the



Child's Name: __Peter Smith__________________ Date:__________

Daily Report Card

*School*

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | Subjects/Times | | | | | |
| | Math | | Spelling | | Lang. Arts | | Science | | Social Studies | |
| 1. Completes seatwork within time provided. | Y | N | Y | N | Y | N | Y | N | Y | N |
| 2. Returns completed homework. | Y | N | Y | N | Y | N | Y | N | Y | N |
| 3. Exhibits appropriate behavior toward classmates (i.e., is respectful, keeps hands to self) with no more than one reminder to do so. | Y | N | Y | N | Y | N | Y | N | Y | N |
| 4. Needs no more than one prompt to follow directions. | Y | N | Y | N | Y | N | Y | N | Y | N |

Comments: ____________________________________________

*Home*

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | Subjects/Times | | | |
| | Morning | | After-school | | Evening | |
| 1. Has all materials needed for homework (assignment book completely filled-out, books, folders, notebooks) | N/A | | Y | N | N/A | |
| 2. Returns completed homework. | N/A | | Y | N | N/A | |
| 3. Has no more than 1 time out for arguing with siblings. | Y | N | Y | N | Y | N |

*Daily Consequences*

| | | |
|---|---|---|
| 80-100% of "yes's" | 60 minutes of screen-time (computer, tv, videogames)<br>60 minutes later bedtime | OR |
| 70-80% of "yes's" | 30 minutes of screen-time (computer, tv, videogames)<br>30 minutes later bedtime | OR |
| 60-70% of "yes's" | 15 minutes of screen-time (computer, tv, videogames)<br>15 minutes later bedtime | OR |

*Weekly Consequences*

| | |
|---|---|
| 80-100% of "yes's" | Choice of weekend activity with Mom or Dad (movie, park) |

**Fig. 4.4** Sample daily report card (DRC) for the school and home setting

outcome of treatment efforts. Based on the information presented in Figs. 4.1, 4.2 and 4.3, a clinician may choose to focus on academic-related targets such as seatwork and homework completion. Further, Peter appears to have difficulty negotiating peer interactions at home and at school. Figure 4.4 illustrates a sample DRC that might be constructed initially to target Peter's impaired areas of functioning at home and at school. Importantly, many of the goals are phrased in a positive way to promote Peter's development of adaptive behavioral skills. Because the targets selected are clinically meaningful, the DRC can also double as an individualized target behavior evaluation (ITBE; Pelham et al., 2005). As such, the percentage of targets that earn a "yes" before consequences are introduced, as consequences are added, and as additional treatment modifications occur (e.g., Peter is made to complete homework immediately after school before he can engage in other activities) will yield information on the effectiveness of treatment in an ongoing fashion. Clinicians can also be confident this progress monitoring is socially valid and clinically meaningful because the targets are directly linked from concerns at referral. The ITBE/DRC may also be modified as needed. For example, should Peter's parents decide to reintroduce him to a Little League activity, a goal that targets his active participation throughout the activity might be supportive of this transition.

## 4.4 Guidelines for Assessment

Based on this review of impairment rating scales, a few guidelines for assessment may be generated. First, assessment of impairment in daily life functioning should be a cornerstone of any psychological assessment. Second, these assessments should utilize multidimensional measures to adequately capture the topography of impaired functioning. Third, the measures utilized should lend themselves to efficient, reliable repeated assessments to permit the monitoring of treatment outcomes. Fourth, measures should provide useful information for treatment planning as clinically meaningful targets of treatment are those that are related to impaired functioning. We discuss each of these guidelines in turn.

As mentioned, the research literature on measures for assessing *DSM* symptoms dwarfs that of impairment measures. However, recent prominent publications have emphasized the importance of measuring functional outcomes. For example, the American Academy of Pediatrics (2000) clinical assessment guidelines for ADHD emphasize the assessment of impaired functioning by parents and teachers. The treatment guidelines for ADHD state “the primary goal of treatment should be to maximize function” (American Academy of Pediatrics, 2001, p. 1036). If these guidelines are followed, the assessment of impairment should be heavily emphasized in psychological assessments from the initial meeting through treatment.

Multidimensional measures of impairment have advantages over global measures in clinical settings. Global measures are useful for epidemiologic or research activities, but in clinical settings, specific information on impaired areas of functioning is needed. For instance, a clinician using a global rating that indicated impaired functioning would then have to proceed with an assessment to determine the specific behaviors that contributed to the negative rating. Collecting a multidimensional measure across domains (e.g., academic, family, peer relationships) has more practical clinical utility as it permits the clinician to obtain a comprehensive picture of the child’s current levels of functioning.

Once an initial diagnosis and functional assessment are obtained, clinician efforts should be dedicated to treatment planning, monitoring, and evaluation. For this reason, measures of functional impairment should be brief and efficient and lend themselves to repeated assessments (Pelham et al., 2005). Longer, expensive measures of functional impairment, such as those embedded in interviews administered by a clinician, are undesirable for these assessment goals. It is recommended that clinicians use assessment measures that are brief and easy to score. This permits repeated assessments that will promote an ongoing measure of the child’s functioning and feedback directly into treatment planning and modification.

Finally, clinicians should use measures of impairment that are directly related to intervention. Assessments of impairment should lead directly to the establishment of target outcomes that can be operationalized in intervention plans. For this reason, measures must go beyond classifying a child as impaired, or not, and instead document the specific problems the child is experiencing (e.g., failing academic classes; being rejected by peers). These target outcomes then become the yardstick that clinicians, parents, teachers, and the child use to measure progress related to treatment.

## 4.5 Conclusion

Many measures of impairment have been developed and validated of late. It is hoped that researchers and clinicians continue to emphasize the measurement of impairment in their work. Policy-makers and decision-makers should also begin to emphasize the importance of impairment, both as a means of identifying children in need of intervention and as the main means of evaluating treatment outcomes.

## References

Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for ASEBA school-age forms and profiles*. Burlington: University of Vermont, Research Center for Children, Youth, and Families.

American Academy of Pediatrics. (2000). Diagnosis and evaluation of the child with attention-deficit/hyperactivity disorder. *Pediatrics, 105*, 1158–1170.

American Academy of Pediatrics. (2001). Clinical practice guideline: Treatment of the school-aged child with attention-deficit/hyperactivity disorder. *Pediatrics, 108*, 1033–1044.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

Angold, A., & Costello, E. J. (1995). A test-retest reliability study of child-reported psychiatric symptoms and diagnoses using the child and adolescent psychiatric assessment (CAPA-C). *Psychological Medicine, 25*, 755–762.

Angold, A., Costello, E. J., Farmer, E. M. Z., Burns, B. J., & Erkanli, A. (1999). Impaired but undiagnosed. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 129–137.

Angold, A., Prendergast, M., Cox, A., Harrington, R., Simonoff, E., & Rutter, M. (1995). The child and adolescent psychiatric assessment (CAPA). *Psychological Medicine, 25*, 739–753.

Barkley, R. A. (2016). Measuring impairment with the Barkley functional impairment scales. In S. Goldstein & J. Naglieri (Eds.), *Assessing impairment: From theory to practice* (2nd ed.). New York, NY: Springer.

Bird, H. R., Andrews, H., Schwab-Stone, M., Goodman, S., Dulcan, M., Richters, J., et al. (1996). Global measures of impairment for epidemiologic and clinical use with children and adolescents. *International Journal of Methods in Psychiatric Research, 6*, 295–307.

Bird, H., Canino, G., Rubio-Stipec, M., & Ribera, J. (1987). Further measures of the psychometric properties of the children's global assessment scale (CGAS). *Archives of General Psychiatry, 44*, 821–824.

Bird, H. R., Shaffer, D., Fisher, P., Gould, M. S., Staghezza, B., Chen, J. Y., et al. (1993). The Columbia Impairment Scale (CIS): Pilot findings on a measure of global impairment for children and adolescents. *International Journal of Methods in Psychiatric Research, 3*, 167–176.

Bird, H., Yager, T., Staghezza, B., Gould, M., Canino, G., & Rubio-Stipec, M. (1990). Impairment in the epidemiological measurement of childhood psychopathology in the community. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 796–803.

Bukowski, W. M., & Adams, R. (2005). Peer relationships and psychopathology: Markers, moderators, mediators, mechanisms, and meanings. *Journal of Clinical Child and Adolescent Psychology, 34*, 3–10.

Cassidy, J., & Asher, S. R. (1992). Loneliness and peer relations in young children. *Child Development, 63*, 350–365.

Chamberlain, P., & Patterson, G. R. (1995). Discipline and child compliance in parenting. In M. Bornstein (Ed.), *Handbook of parenting: Vol. 4. Applied and practical parenting* (pp. 205–225). Mahwah, NJ: Erlbaum.

Christle, C. A., Jolivette, K., & Nelson, C. M. (2005). Breaking the school to prison pipeline: Identifying school risk and protective factors for youth delinquency. *Exceptionality, 13*, 69–88.

Coie, J. D., & Dodge, K. A. (1998). Aggression and antisocial behavior. In W. Damon (Series Ed.) & N. Eisenberg (Vol. Ed.), *Handbook of child psychology: Vol. 3. Social, emotional, and personality development* (5th ed., pp. 779–862). New York: Wiley.

Costello, E. J., Angold, A., & Keeler, G. P. (1999). Adolescent outcomes of childhood disorders: The consequences of severity and impairment. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 121–128.

Costello, E. J., & Shugart, M. A. (1992). Above and below the threshold: Severity of psychiatric symptoms and functional impairment in a pediatric sample. *Pediatrics, 90*, 359–368.

Crnic, K. A., & Greenberg, M. T. (1990). Minor parenting stresses with young children. *Child Development, 61*, 1628–1637.

Dishion, T. J., Nelson, S. E., & Yasui, M. (2005). Predicting early adolescent gang involvement from middle school adaptation. *Journal of Clinical Child and Adolescent Psychology, 34*, 62–73.

DuPaul, G. J., & Eckert, T. L. (1997). The effects of school-based interventions for attention deficit/hyperactivity disorder: A meta-analysis. *School Psychology Review, 26*, 5–27.

DuPaul, G. J., & Stoner, G. (2004). *ADHD in the schools: Assessment and intervention strategies*. New York: Guilford Press.

Endicott, J., Spitzer, R. L., Fleiss, J., & Cohen, J. (1976). The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry, 33*, 766–771.

Evans, S. W., Allen, J., Moore, S., & Strauss, V. (2005). Measuring symptoms and functioning of youth with ADHD in middle schools. *Journal of Abnormal Child Psychology, 33*, 695–706.

Fabiano, G. A., Pelham, W. E., Gnagy, E. M., Burrows-MacLean, L., Coles, E. K., Chacko, A., et al. (2007). The single and combined effects of multiple intensities of behavior modification and multiple intensities of methylphenidate in a classroom setting. *School Psychology Review, 36*, 195–216.

Fabiano, G. A., Pelham, W. E., Waschbusch, D. A., Gnagy, E. M., Lahey, B. B., Chronis, A. M., et al. (2006). A practical measure of impairment: Psychometric properties of the impairment rating scale in samples of children with attention-deficit/hyperactivity disorder and two school-based samples. *Journal of Clinical Child and Adolescent Psychology, 35*, 369–385.

Fischer, M. (1990). Parenting stress and the child with attention deficit hyperactivity disorder. *Journal of Clinical Child Psychology, 19*, 337–446.

Foster, S. L., & Mash, E. J. (1999). Assessing social validity in clinical treatment research: Issues and procedures. *Journal of Consulting and Clinical Psychology, 67*, 308–319.

Goldstein, S., & Naglieri, J. A. (2015). *Rating scale of impairment*. North Tonawanda, NY: Multi-Health Systems.

Gresham, F., & Elliott, S. (1990). *Social skills rating system*. Circle Pines, MN: American Guidance Service.

Hodges, K., Doucette-Gates, A., & Liao, Q. (1999). The relationship between the child and adolescent functional assessment scale (CAFAS) and indicators of functioning. *Journal of Child and Family Studies, 8*, 109–122.

Hodges, K., & Kim, C. (2000). Psychometric study of the child and adolescent functional assessment scale: Prediction of contact with the law and poor school attendance. *Journal of Abnormal Child Psychology, 28*, 287–297.

Hodges, K., & Wong, M. M. (1996). Psychometric characteristics of a multidimensional measure to assess impairment: The child and adolescent functional assessment scale. *Journal of Child and Family Studies, 5*, 445–467.

Hops, H., & Walker, H. M. (1988). *CLASS: Contingencies for learning and academic and social skills*. Seattle, WA: Educational Achievement Systems.

Hoza, B., Pelham, W. E., Dobbs, J., Owens, J. S., & Pillow, D. R. (2002). Do boys with attention-deficit/hyperactivity disorder have positive illusory self concepts? *Journal of Abnormal Psychology, 111*, 268–278.

Kazdin, A. E. (1977). Assessing the clinical or applied importance of behavior change through social validation. *Behavior Modification, 1*, 427–452.

Kelley, M. L. (1990). *School-home notes: Promoting children's classroom success*. New York: Guilford Press.

LaGreca, A. M., & Harrison, H. M. (2005). Adolescent peer relations, friendships, and romantic relationships: Do they predict social anxiety and depression? *Journal of Clinical Child and Adolescent Psychology, 34*, 49–61.

Lahey, B. B., Pelham, W. E., Stein, M. A., Loney, J., Trapani, C., Nugent, K., et al. (1998). Validity of DSM-IV attention-deficit/hyperactivity disorder for younger children. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 695–702.

Lavigne, J. V., Arend, R., Rosenbaum, D., Binns, H. J., Christoffel, K. K., Burns, A., et al. (1998). Mental health service use among young children receiving pediatric primary care. *Journal of the American Academy of Child and Adolescent Psychiatry, 37*, 1175–1183.

Mannuzza, S., & Klein, R. G. (1999). Adolescent and adult outcomes in attention-deficit/hyperactivity disorder. In H. C. Quay & A. E. Hogan (Eds.), *Handbook of disruptive behavior disorders* (pp. 279–294). New York: Kluwer Academic/Plenum.

McDermott, B. M., McKelvey, R., Roberts, L., & Davies, L. (2002). Severity of children's psychopathology and impairment and its relationship to treatment setting. *Psychiatric Services, 53*, 57–62.

MTA Cooperative Group. (1999). 14-Month randomized clinical trial of treatment strategies for attention deficit hyperactivity disorder. *Archives of General Psychiatry, 56*, 1073–1086.

O'Leary, S. G., & Pelham, W. E. (1978). Behavior therapy and withdrawal of stimulant medication in hyperactive children. *Pediatrics, 61*, 211–217.

O'Leary, K. D., Pelham, W. E., Rosenbaum, A., & Price, G. H. (1976). Behavioral treatment of hyperkinetic children. *Clinical Pediatrics, 15*, 510–515.

Pelham, W. E., & Bender, M. E. (1982). Peer relationships in hyperactive children: Description and treatment. In K. Gadow & E. Bialer (Eds.), *Advances in learning and behavioral disabilities* (Vol. 1, pp. 365–436). Greenwich, CT: JAI Press

Pelham, W. E., Fabiano, G. A., & Massetti, G. M. (2005). Evidence-based assessment for attention-deficit/hyperactivity disorder in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*, 449–476.

Pelham, W. E., Gnagy, E. M., Burrows-Maclean, L., Williams, A., Fabiano, G. A., Morrissey, S. M., et al. (2001). Once-a- day Concerta™ methylphenidate versus t.i.d. methylpheni- date in laboratory and natural settings. *Pediatrics, 107,* e105. Retrieved January 5, 2009, from http://www.pediatrics.org/cgi/content/full/107/6/e105.

Pelham, W. E., Hoza, B., Pillow, D. R., Gnagy, E. M., Kipp, H. L., Greiner, A. R., et al. (2002). Effects of methylphenidate and expectancy on children with ADHD: Behavior, academic performance, and attributions in a summer treatment program and regular classrooms. *Journal of Consulting and Clinical Psychology, 70*, 320–335.

Pelham, W. E., Wheeler, T., & Chronis, A. (1998). Empirically supported psychosocial treatments for attention deficit hyperactivity disorder. *Journal of Clinical Child Psychology, 27*, 190–205.

Scotti, J. L., Morris, T. L., McNeil, C. B., & Hawkins, R. P. (1996). DSM-IV and disorders of childhood and adolescence: Can structural criteria be functional? *Journal of Consulting and Clinical Psychology, 64*, 1177–1191.

Setterberg, S., Bird, H., & Gould, M. (1992). *Parent and interviewer version of the children's global assessment scale*. New York: Columbia University.

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., et al. (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry, 40*, 1228–1231.

Sheeber, L. B., & Johnson, J. H. (1992). Applicability of the impact on family scale for assessing families with behaviorally difficult children. *Psychological Reports, 71*, 155–159.

Treatment for Adolescents with Depression Study (TADS) Team. (2004). Fluoxetine, cognitive-behavioral therapy, and their combination for adolescents with depression: Treatment for adolescents with depression study (TADS) randomized controlled trial. *Journal of the American Medical Association, 292*, 807–820.

Wolf, M. M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis, 11*, 203–214.

# Impairment in the Geriatric Population

# 5

Holly Tuokko and Lesley Ritchie

## 5.1 Introduction

The aim of this chapter is to examine how the concept of impairment has been applied in geriatric populations. In so doing, we will focus on impairments in cognition and in the performance of everyday behaviors as they are known to be age associated and interrelated. Moreover, impairments in cognition and everyday behavior are some of the greatest challenges faced by this population. As people live longer, more are likely to be affected by age-associated neurodegenerative diseases (e.g., Alzheimer disease, AD) resulting in a substantial number of cognitively impaired people requiring support and assistance in performing everyday behaviors (Gruenberg, 1977; Kramer, 1980). For these reasons, it is important to consider how cognitive impairment has been conceptualized, as well as factors that influence its expression.

We have chosen to examine the cognitive and functional impairments associated with later life within the disablement process, a broad conceptual framework emerging from discussions and research on disability (Verbrugge & Jette, 1994). We have chosen to do this, rather than limiting ourselves to the concept of impairment alone,

---

H. Tuokko, Ph.D., R.Psych. (✉)
Department of Psychology, University of Victoria, PO Box 1700 STN CSC, Victoria, BC V8W 2Y2, Canada

Institute on Aging and Lifelong Health, University of Victoria, Hut R 103, on McKenzie Ave (between McGill and Finnerty), 3800 Finnerty Road, Victoria, BC V8P 5C2, Canada
e-mail: htuokko@uvic.ca

L. Ritchie, Ph.D., C.Psych.
Neuropsychology Service, Department of Clinical Health Psychology, College of Medicine, University of Manitoba, Health Sciences Centre, 771 Bannatyne Avenue, Winnipeg, MB R3E 3N4, Canada
e-mail: lritchie3@exchange.hsc.mb.ca

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_5

because research with geriatric populations has revealed that the conceptualization and identification of impairment is heavily influenced by a myriad of factors. These factors include characteristics of the individual (e.g., biological, psychosocial, socio-demographic) and actions that may be taken to reduce or accentuate impairment. These concepts are central to the disablement process and to understanding how behavioral interventions can be used to optimize functioning and well-being, minimize the risk of disability, and prevent the development of dysfunctional family or social functioning. We will address the concept of impairment, the many influences (e.g., lifestyle, psychosocial, compensatory) that may affect the consequences of impairment for an individual, and whether or not benefits from interventions are likely to be derived within the context of the conceptual framework of the disablement process.

The disablement process, a "sociopsychobiological" model of disability (Barberger-Gateau, Fabrigoule, Amieva, Helmer, & Dartigues, 2002), describes a pathway from pathology to various kinds of functional outcomes and incorporates psychological, social, and environmental factors that modify or alter the proposed pathway. According to Verbrugge and Jette (1994), "disablement" refers to impacts that chronic and acute conditions have on the functioning of specific body systems and on people's abilities to act in necessary, usual, expected and personally desired ways in their society" (p. 3). The term "process" is used to acknowledge the dynamic interplay of factors that affect the direction, pace, and patterns of change over time.

The main pathway of the disablement model consists of four interrelated components: pathology, functional impairments, functional limitations, and disability (see Fig. 5.1). In this context, pathology refers to the biological and physiological abnormalities medically labeled as disease or injury. Pathology leads to functional impairments, defined as dysfunctions and significant structural abnormalities in specific body systems (e.g., neurological, cardiovascular, musculoskeletal) that have consequences for mental, physical, or social functioning. These consequences are referred to as functional limitations and are defined as restrictions in physical actions, such as mobility, discrete motions and strength, and mental actions, such as cognitive and emotional functions (Verbrugge & Jette, 1994). The final consequence of the pathway is disability, or difficulty performing everyday activities of daily living (i.e., basic and instrumental) and work-related activities.

This main pathway, then, posits the sequence of events that lead from pathology to disability when medical factors are considered, and aids in distinguishing between constructs. For example, in the context of this model, "functional impairment" refers to dysfunctions or structural abnormalities in specific body systems (e.g., metabolic, cardiovascular, neurological, renal) that are identified through clinical examinations, laboratory tests, imaging procedures, and symptom reports. The term "functional limitation" is used to refer to restrictions in physical and mental activities (e.g., trouble seeing, short-term memory problems) that are frequently identified as "impairments" outside the context of this model. For example, the International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001) refers to impairment (or significant deviation or loss)

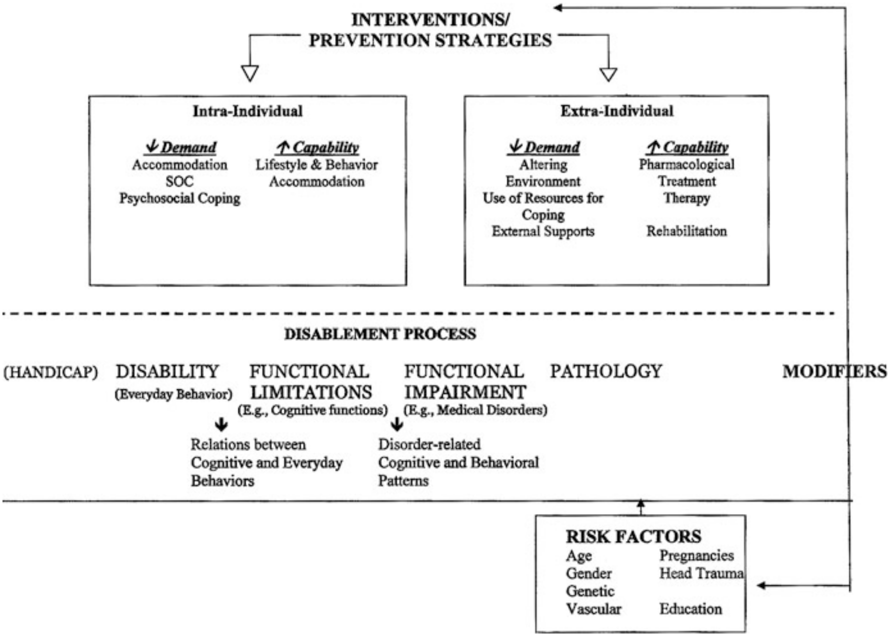


**Fig. 5.1** Extended Disablement Process model

of body functions (i.e., physiologic functions of body systems including psychological functions) and structures (i.e., anatomical parts of the body). Similarly, that described as disability in the disablement process model is often described as functional impairment or activity limitations in other contexts. To further extend the model, the social disadvantage resulting from an impairment and/or a disability has been referred to as restrictions of participation within the ICF (WHO, 2001). These distinctions begin to allow us to differentiate one set of consequences, resulting from an underlying pathology, from another.

However, it is well known that relations among pathology, impairments, limitations, and disability are not straightforward and are influenced by a myriad of other factors, many of which are psychosocial in nature. These include characteristics of the individual that affect the presence and severity of impairment, functional limitations, and disability (i.e., risk factors) (e.g., van Gool et al., 2005). In addition, actions or interventions may be taken in response to age-associated changes that mitigate or accentuate their impact. These may be internally generated (operate within a person) or may be dependent on others (external to the individual).

In practice, it is often disability and/or functional limitations that bring older adults to the attention of clinicians. The clinician's role often is to determine the underlying impairments, abnormalities in specific body systems that give rise to these limitations and/or disabilities. For example, it may be determined that an older adult who presents with mild memory impairment (functional limitation) and difficulty handling finances (disability) is in the early stages of dementia (impairment). Medical investigations and a detailed clinical history (risk factors) would ensure examining for reversible forms of dementia and clarify the differential diagnosis. If no identifiable medical foundation for the dementia was evident, a presumptive diagnosis of AD (pathology) may be given.

At this point, the clinical focus may shift from diagnosis to interventions aimed at minimizing functional limitations and, consequently, disability. An important consideration in many chronic disease conditions, such as AD, is that these interventions are taking place within the context of progressive underlying pathology that is associated with progressive functional decline. This should not deter intervention efforts, but emphasizes the need to be mindful of expected patterns of progressive decline associated with various disorders and the factors that may reduce or accentuate the speed of decline or the manifestation of functional limitations and/or disability. Disability greater than that warranted by existing impairment and functional limitations has been referred to as “excess disability” (Brody, Kleban, Lawton, & Silverman, 1971; Rogers et al., 2000) and carries with it the implication that vigilance is required to ensure all efforts are undertaken to maximize functional capabilities.

We have chosen to structure the remainder of this chapter in accordance with this clinical process (functional limitations/disability then impairment/pathology), in contrast to the sequence typically described in association with the disablement process model (pathology through to disability). As the focus of this chapter is on the functional limitations (i.e., cognitive impairments) and disability associated with later life, we will begin by examining key issues relevant to understanding the links between functional limitations and disability arising from the literature. We will focus on selected functional impairments (i.e., medical disorders) commonly seen in geriatric populations that differ with respect to expected patterns of progressive decline, risk factors that may influence the course of the disablement process or predispose an individual to cognitive impairment, and underlying pathology. We will then discuss intraindividual and extra-individual interventions that can be used to optimize functioning and well-being, minimize disability, and/or prevent the development of dysfunctional family or social functioning.

## 5.2 The Process

### 5.2.1 Functional Limitations/Disability

A number of different approaches may be taken to the identification of impairments in cognition (functional limitations) and everyday behaviors (disability) for older adults. In general, these are the same approaches to deficit measurement identified by Lezak, Howieson, and Loring (2004) that pertain to all age groups. However, some specific caveats need to be considered that are particular to this age group and the types of disorders commonly encountered.

#### 5.2.1.1 Identification of Cognitive Impairment

As is typical of clinical measurement across a number of fields and age groups, measures designed to assess relevant cognitive functions are administered and often the person' s performance during the test administration is observed to provide information about the individual's approach to the task, tolerance levels, personal style, and coping skills. In addition, characteristics of speech and language and abnormalities in movement that may be clinically significant can be observed. In addition, information is gathered through interviews with the older adult and/or a person familiar with this person's daily activities (e.g., family member or close friend). Standardized tests (i.e., tests administered and scored in a set and consistent manner) are used to gather objective data about a person's performance that permits meaningful comparisons with others (i.e., standardization samples), to assess change over time within an individual, or in relation to a "gold standard" or specific criterion of achievement (Lezak et al., 2004).

Measures of cognitive and everyday behaviors are most commonly interpreted in relation to the performance of a standardization sample, a representative group of people administered the measure in the standardized fashion. Where the scores on the measure are normally distributed in the adult population, an individual's performance can be evaluated in relation to norms based on the performance of the standardization sample. Many measures of cognitive functions are affected by age and education (or vocational achievement) and the effects of these variables need to be considered when generating norms, and in the interpretation of an individual's performance in relation to the norms. Although it has often been common practice to use norms adjusted for age and education, Sliwinski, Buschke, Stewart, Masur, and Lipton (1997) and Sliwinski, Hofer, Hall, Buschke, and Lipton (2003) question this approach in the context of dementia diagnosis. Because it has been repeatedly observed that age and education are risk factors for dementia (see section below on Impairment; Bachman et al., 1993; Braak et al., 1999; Canadian Study of Health & Aging Working Group, 1994; Canadian Study of Health & Aging Working Group, 2000; Shaji, Promodu, Abraham, Roy, & Verchese, 1996), Sliwinski et al. (2003) argue that using norms corrected for these factors would compromise diagnostic accuracy by removing predictive variance. They propose, instead, the use of uncorrected raw scores from the adult population as a whole taken in conjunction with demographically based dementia base-rates when seeking information relevant to the diagnosis of dementia (diagnostic norms). On the other hand, when the purpose of the assessment is to describe the cognitive strengths and weaknesses of the older individual, Sliwinski et al. (1997, 2003) support the use of demographically corrected scores (comparative norms).

Even taking these issues into account, the use of norms to identify impairment requires the selection of a cut-off point, such as defining scores ≥1.5 or 2.0 SD below the mean of a cognitively normal sample as being impaired. This approach assumes that impaired people show quantitative differences rather than differences of kind. An advantage to this approach is that no matter how difficult a cognitive measure is, roughly the same number of people will be identified and this will largely determine the prevalence of impairment in the population. The disadvantage is that there will almost always be an overlap in scores between the normal population and the group with cognitive impairment with a percentage of the normal population being falsely classified as impaired (e.g., approximately 7 % of normal sample will fall below −1.5 SD). A related issue is how many measures in a particular cognitive domain must be impairment before impairment is determined. Petersen (2004a), in discussing criterion for identifying mild cognitive impairment (MCI), a classification thought by some to capture those individuals likely to develop AD, notes that "multiple more challenging memory instruments are required to detect the subtle memory deficits seen in early MCI." Similarly, Blackford and La Rue (1989) definition of Late Life Forgetfulness requires a performance of 1–2 SDs below the mean established for age on 50 % of memory measures administered. However, in practice, few cognitive assessment batteries have been co-normed (i.e., simultaneous attainment of data on multiple tests for the same cohort; Smith & Ivnik, 2003) and when such norms have been developed, it is common for "normal" participants to show impaired performances on one or more measures within a battery (Tuokko & Woodward, 1996).

Another approach to the interpretation of scores on measures that are normally distributed in the adult population is to examine differences between scores obtained for an individual on the same standardized measure at different points in time. This information may be particularly relevant for older adults as (1) more normative change in cognitive functions is expected in older age groups than in younger samples, (2) inherent in the diagnosis of dementia is recognition that the individual's cognitive and behavior has changed over time, and (3) being able to demonstrate that interventions may alter the rate at which cognitive functions change in specific forms of dementia (e.g., AD) is an important goal. However, as yet, there is a lack of information about the appropriateness of different change measurement methods, the validity of neuropsychological measures for studying change in older adults, and information about the amount of test score change that can be considered normal (or abnormal) among older adults over clinically relevant intervals (Frerichs & Tuokko, 2005). Methods for measuring change have been discussed for over 50 years (e.g., Harris, 1963; Lord, 1957, 1958; McNemar, 1958; Payne & Jones, 1957) and continue topics of debate (e.g., Crawford & Howell, 1998; Hageman & Arrindell, 1999; Hsu, 1989; Jacobson & Truax, 1991). Our own research suggests that normal change in older adult's memory test performance can be accurately classified using change score methods (Frerichs & Tuokko, 2005). Moreover, diagnostic change was significantly associated with a number of different change score methods, but differed in strength of association depending on the memory measure under investigation. These findings stand in contrast to those of Ivnik et al. (2000) who concluded that reliable change in test scores did not contribute to dementia diagnosis in older adults beyond chance levels. Given that these studies differed markedly in the samples that were examined, the design of the study, and the measures used, additional research is needed to examine and validate change score methods in other samples of older adults to determine whether these methods can assist in the detection of particular neurodegenerative disorders.

Although many measures of cognitive functioning provide scores that are normally distributed in the adult population, this is not true for some domains of cognitive functioning. In some instances, an underlying assumption of the measure is that all persons of a certain age (e.g., adults) will manifest these capabilities as they are considered rudimentary components of behavior (e.g., following simple instructions). If the task cannot be performed, impairment is assumed. This is a form of criterion-referenced testing (Anastasi, 1988) where performance is evaluated in terms of achievement on the measure, not in relation other people. In criterion-referenced testing, a particular score on a reference test may be selected and designated as an indication of "significant" impairment. This is a more common approach used in the field of occupational therapy, where performance of everyday behavior is of particular concern (see below).

By definition, the identification of functional limitations (e.g., poor performance on measures of cognitive functions) and disabilities are central to criteria for cognitive disorders. For example, in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5, American Psychiatric Association, 2013), diagnoses of neurocognitive disorders are all based on changes in defined cognitive domains that impact everyday activities. Neurocognitive disorders are then further subclassified according to underlying pathology (e.g., AD, vascular). When cognitive impairment is evident but does not interfere with everyday activities, a variety of other sets of criteria may be employed. For example, the DSM-5 (American Psychiatric Association, 2013) provides categories such as "mild neurocognitive disorder" linked to underlying pathology or etiology, "multiple etiologies" or "unspecified." The International Classification Diseases-10 (ICD-10; World Health Organization, 1993) provides a classification for Mild Cognitive Disorder to capture objective evidence of decline in cognitive performance not attributable to other mental or behavioral disorders identified in ICD-10.

In 2004, Petersen (2004b) proposed an algorithm for identifying Mild Cognitive Impairment, a hypothesized interim state between normal and abnormal cognitive functioning indicative of incipient dementia. According to Petersen (2004b), MCI is identified when: (1) an individual presents with a cognitive complaint (either subjective or by proxy), (2) a determination of abnormal cognitive function in relation to age and education is established after clinical examination, (3) the individual's cognitive functioning represents a decline from previous function, and (4) the individual exhibits intact activities of daily living (ADLs). Once the presence of MCI has been established, the type of MCI can be further subdivided based on the presence or absence of memory impairment into amnestic MCI (aMCI) or non-amnestic MCI (naMCI). These types can be further subdivided into aMCI single domain (aMCIsd; memory impairment only), aMCI Multiple Domain (aMCImd, memory impairment plus other cognitive impairment), naMCI single domain (naMCIsd, impairment in a single non-memory domain), and naMCI multiple domain (naMCImd, impairments in multiple domains other than memory). MCI, then, is cognitively heterogeneous with subgroups that differ with respect to cognitive profiles. In addition, MCI appears to be etiologically heterogeneous and some promising work linking etiologic subtypes to cognitive subgroups using neuroimaging techniques and genetic markers (Smith, Machulda, & Kantarci, 2006; Wilson, Aggarwal, & Bennett, 2006; Wolf & Gertz, 2006).

Although the presence of these sets of criteria for cognitive disorders are useful, at least conceptually, few specify procedures for identifying cognitive impairment but instead involve the application of clinical judgment based on the overall impression (Petersen, 2004a). Criteria for Neurocognitive Disorders, as outlined in the DSM-5, give no specific direction as to the meaning of impairment beyond "modest" or "significant" cognitive decline from previous level of cognitive performance. The National Institute of Aging—Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease (McKhann et al., 2011) specify the presence deficits in two or more areas of cognition as established through a combination of history-taking from the affected person and a knowledgeable informant, and an objective cognitive assessment (i.e., mental status examination or neuropsychological testing). The major disadvantage of relying on clinical judgment is that a broad understanding of brain–behavior relations is required and a number of factors (e.g., risk and protective factors) need to be taken into consideration. This will affect the reliability with which cognitive impairment is identified (Tuokko, Gabriel, & The CSHA Neuropsychology Working Group, 2006).

Measures of everyday behavior vary in terms of *content* and *method*. Content refers to whether a measure is more global (i.e., fewer questions per domain, spanning a number of domains) or specific (i.e., many questions per domain, usually focusing on only one domain). Method refers to the manner in which information is collected from participants (i.e., whether data is collected in a subjective or objective manner). Most commonly employed measures of everyday behavior are subjective, relying on self-report or report of a knowledgeable informant, when there is reason to believe participants may not be able to accurately self-report (Diehl, 1998; Fillenbaum, 1985, 1987a, 1987b; Lawton & Brody, 1969). Moreover, most of these measures are global in nature, spanning a number of domains with few questions per domain. Typically, questions relevant to each domain are evaluated on a 3- or 4-point scale. For example, a question relevant to the ability to transport oneself outside of walking distance might read, "can you use public transportation: (a) without help, (b) with some help, (c) not at all?" (Willis, 1996). Self-report measures of everyday behavior tend to focus on *what* is happening rather than *why*. They provide minimal information on concomitants and causes of incapacities in particular domains. Asking an older adult whether they can transport themselves does not provide information as to why that may be the case. For example, the self-reported inability to transport oneself may be due to immobility, or a lack of knowledge of the local bus schedule.

Moreover, a distinction can be made between a person's ability to intrinsic ability (doing an activity without personal or equipment assistance) versus functional ability (doing activity with personal or equipment assistance). Many people with cognitive impairment can continue to perform many activities of daily living if provided with minimal support and assistance. For example, making use of direct deposit and automatic withdrawal banking functions can alleviate concerns about paying bills on time for people who may have memory difficulties. A final distinction can be made between a person's ability to perform everyday tasks and her/his understanding of her/his limitations and the consequences of these limitations. This distinction is central to compensatory and adaptive processes (see below-Intraindividual interventions).

#### 5.2.1.2 Relations Among Impairments in Cognitive and Everyday Functions

As noted earlier, impairments in both cognitive and everyday functions are central to the definition of dementia, and their co-occurrence is expected in this context. However, a number of studies have shown a clear co-occurrence of cognitive impairments and disabilities in samples of older adults without dementia (Barberger-Gateau, Fabrigoule, Rouch, Letenneur, & Dartigues, 1999; Black & Rush, 2002; Njegovan, Man-Son-Hing, Mitchell, & Molnar, 2001; Steen, Sonn, Hanson, & Steen, 2001). It appears that progressive cognitive decline is associated with a natural hierarchy of loss with instrumental activities of daily living (IADLs) (e.g., shopping, banking, and cooking) being lost at higher levels of cognitive functioning than basic ADLs (e.g., eating, dressing, and walking) (Njegovan et al., 2001). In addition, strong associations have been found between measures assessing a broad range of cognitive domains and dependency in four IADLs (i.e., telephone use, use of transportation, medication intake, and handling finances) (Barberger-Gateau et al., 1999). Processing speed was associated with performance on each IADL, whereas specific independent associations between cognitive domains and individual IADL were noted. For example, transportation was also related to visuospatial perception and attention; medication intake was also associated with memory; and handling of finances was the most heavily cognitively mediated being associated with conceptual abilities, orientation, and memory as well as processing speed.

In studies of people identified with MCI, it is clear that they experience difficulty with a number of household and other everyday activities (Albert et al., 1999; Bassett & Folstein, 1991). Artero, Touchon, and Ritchie (2001) found the overall prevalence of impairment in everyday activities for people with MCI to be 30.8 %. The domains with which MCI experienced the most difficulty were walking (18 %), bladder control (16.1 %), bathing (7.7 %), and use of telephone (7.5 %).

There remains controversy in the literature concerning the temporal relations between cognitive impairment and everyday functions. Some longitudinal studies suggest that cognitive impairment occurs first impairment (Greiner, Snowdon, & Schmitt, 1996; Moritz, Kasl, & Berkman, 1995; Steen et al., 2001), while others suggest that both cognitive impairment and disability may show roughly parallel progression (Barberger-Gateau, Dartigues, & Letenneur, 1993). For example, Artero et al. (2001) noted that, over a 3-year follow-up interval, decline in language and visuospatial skills corresponded to an overall drop in activity performance with visuospatial deficits being most strongly related to decline in a number of specific areas of decline on everyday tasks (i.e., dressing, going to bed, use of telephone, mobility, toileting-bladder and bowel, bathing, dental hygiene). Our own work in this area (Tuokko, Morris, & Ebert, 2005) suggests that cognitive impairment and disability may be seen independently, but the likelihood of developing disability after cognitive impairment is high.

## 5.2.2 Functional Impairment and Pathology

In the original model of the Disablement Process put forward by Verbrugge and Jette (1994), the development of disability is initiated by pathology. Diseases and disorders affecting many different body systems (e.g., pulmonary, renal, hepatic) can adversely influence cognitive functioning (e.g., Armstrong & Morrow, 2010; Butters, Beers, Tarter, Edwards, & van Thiel, 2001; Lehman, Pilich, & Andrews, 1993; Salmon, Butters, & Heindel, 1993). However, we have chosen to limit our discussion here to the pathological processes of diseases affecting the brain (e.g., abnormal biological or biochemical changes), many of which are often immeasurable until death (e.g., Poser et al., 1999). For instance, despite technological advances in the study of medicine, extracellular β-amyloid senile plaques and intracellular accumulations of neurofibrillary tangles, the neuropathological markers of AD, are only identified postmortem. As such, only presumptive diagnoses of Possible and Probable AD (based on NINCDS-ADRDA criteria) may be assigned premortem (McKhann et al., 2011). Given this substantial limitation, we have elected to focus on the disease processes that affect brain function resulting in measurable cognitive changes in the geriatric population. We have chosen to classify disorders leading to cognitive impairment in old age according to their progression (e.g., rapid deterioration, stepwise decline, maximal neurologic deficit at onset, progressive decline, reversible with intervention, variable; Tuokko & Hadjistavropoulos, 1998).

### 5.2.2.1 Rapid Deterioration

#### 5.2.2.1.1 Delirium

Delirium or Acute Confusional State (ACS) is an acute condition resulting from a general medical condition, substance intoxication or withdrawal, exposure to toxins, medication use, alone, or in combination. To receive a diagnosis of ACS, a person must not meet the criteria for dementia. ACS is especially prevalent among elderly persons: hospitalized (10–30 % point prevalence), 75+ year olds living in nursing homes (60 %), and terminally ill (80 %). In general, 20–25 % of elderly persons admitted to hospital are delirious upon arrival or develop ACS while hospitalized (Lipowski, 1994). ACS serves as a marker for serious illness in the elderly and necessitates emergent care. Although a full recovery is possible following treatment of the underlying condition, elderly persons typically continue to exhibit residual deficits. In the elderly, ACS due to a general medical condition is also associated with a high risk of mortality (15–30 % die within 30 days of hospitalization; Lipowski, 1994).

### 5.2.2.2 Maximal Neurologic Deficit at Onset

#### 5.2.2.2.1 Cerebrovascular Disease and Vascular Dementia

Cerebrovascular disease (CVD) is associated with significant cognitive and physical deficits. The cognitive deficits are often the result of an acquired dementia (i.e., Vascular dementia (VaD)) resulting from varied cerebrovascular incidents (e.g., stroke, cerebral hypoperfusion causing anoxia; Onyike, 2006). VaD accounts for approximately 13 % of the dementias in the Canadian population (Ebly, Parhad, Hogan, & Fung, 1994). The occurrence and development of VaD is dependent upon the type, severity, and location of the cerebral infarct. Moreover, VaD and Alzheimer's disease (AD) pathology often coexist, resulting in a diagnosis of mixed dementia. The severity of dementia is often higher in persons with mixed dementia. For example, data from the Nun Study reveal significantly poorer cognitive performance among Sisters whose brains at autopsy met the neuropathological criteria for AD and contained infarcts (Snowdon et al., 1997). In his review of CVD and dementia, Onyike (2006) suggests that AD may be a symptom of VaD, given arguments that sporadic AD is due to cerebral hypoperfusion (de la Torre, 2004). de la Torre argues that, despite its popularity, research does not support the amyloid hypothesis (i.e., deposits of amyloid-β-peptide and neurofibrillary tangles are the cause of progressive neurodegeneration in AD). Rather, he argues that evidence supports a vascular hypothesis wherein age and vascular risk factors create a condition of cerebral hypoperfusion, thereby affecting cellular energy and resulting in cognitive impairment, neurodegeneration, and ultimately, AD (de la Torre, 2004).

### 5.2.2.3 Progressive Decline

#### 5.2.2.3.1 Major Neurocognitive Disorders

The etiology of major neurocognitive disorders may be due to several neurologic diseases including Alzheimer's disease, Parkinson's disease, Lewy bodies, or Fronto-Temporal Lobar Dementia. The prevalence of dementia varies from 1.4–1.6 % in persons aged 65–69 and increases to 16–25 % in persons 85 years and older (American Psychiatric Association, 2013). In the Canadian Study of Health and Aging (CSHA, 2000), the prevalence of dementia was shown to increase from 2.4 %, to 11.1 %, to 34.5 % in persons aged 65–74, 75–84, and 85+ years, respectively. Dementia is defined as a progressive, stable, or remitting cognitive disorder that is not better accounted for by delirium. It is characterized by cognitive deficits including memory impairment, and at least one of executive dysfunction, aphasia, apraxia, or agnosia. The symptoms must represent a decline from premorbid functioning and cause clinically significant impairment in social and/or occupational functioning.

##### Alzheimer's Disease

AD is the most prevalent of the dementias accounting for approximately 60 % of all dementias (Terry, 2006). The prevalence of AD is positively correlated with increased age (i.e., 0.6 % in males aged 65 compared to 36 % in males aged 95 years). AD is a progressive dementia with an average survival time of 8–10 years (American Psychiatric Association, 2013). The neuropathological markers of AD, as seen at autopsy, include cerebral atrophy (especially in the temporal and parietal lobes), loss of cholinergic neurons in the Nucleus Basalis of Meynert, abnormal intracellular accumulations of tau protein in the form of neurofibrillary tangles (NFTs), abnormal accumulations of cellular debris and β-amyloid protein in the form of extracellular senile plaques (SPs), and amyloid deposits in the arteries and arterioles. NFTs are typically found in the hippocampus, entorhinal cortex, and neocortex of persons with AD. SPs are found in the neocortex and mesial temporal cortex. The severity of dementia is reported to increase with the distribution of NFTs and SPs (Terry, 2006).

#### Parkinson's Disease

Parkinson's disease (PD) is a movement disorder characterized by bradykinesia (slowed movement), rigidity, resting tremor, and postural instability. The neuropathological underpinning of Parkinson's disease is the degeneration of dopamine neurons in the pars compacta region of substantia nigra. The disease is also marked by neuronal Lewy body inclusions and adrenergic and cholinergic neuronal atrophy. Over 8 years, 78.2 % of persons with PD developed dementia (Aarsland et al., 2001). PD is estimated to affect 2 % of persons over 65 years of age, 20–40% of whom have comorbid depression (Lieberman, 2006).

#### Lewy Body Dementia

Lewy bodies, eosin inclusions in neuronal cytoplasm, were first identified in the brains of patients with Parkinson's disease. Compared to Parkinson's Dementia, where patients are diagnosed with PD more than 1 year before the onset of dementia symptoms, Lewy body dementia (LBD) is characterized by dementia early in the course with some features of PD (McKeith et al., 2005).

The distribution of alpha-synuclein Lewy bodies determines the type of pathology: brain stem-predominant, limbic, or diffuse neocortical (McKeith et al., 2005). LBD shares several neuropathological markers with other forms of dementia. Specifically, Lewy bodies are present in the cortex and basal ganglia of both PD and LBD; cortical and subcortical dopaminergic deficits due to atrophy of substantia nigra neurons are observed in both PD and LBD; and cholinergic deficits are observed in both LBD and AD (Selwa & Gelb, 2005).

## 5.2.2.4 Variable

### 5.2.2.4.1 Frontotemporal Lobar Dementia

Frontotemporal lobar dementia (FTD) is due to the degeneration of the frontal and temporal lobes of the brain. FTD accounts for approximately 5–15 % of all dementias (Selwa & Gelb, 2005) and is more rapidly progressing than AD (i.e., mean survivals time post-symptom onset of 8.7 ± 1.2 years and 11.8 ± 0.6 years, respectively; Robertson et al., 2005). The average age of onset for FTD is 40–60 years (Tuokko & Hadjistavropoulos, 1998). Although FTD is a progressive dementia, it is also described as having a variable course due to the fluctuating cognitive symptoms of the disorder (Tuokko & Hadjistavropoulos, 1998). FTD may present with personality, behavior, executive, or language (i.e., primary progressive aphasia) deficits. Four variants of FTD have been isolated: behavioral/dysexecutive FTD (a frontal lobe variant), semantic FTD (temporal lobe variant), progressive non-fluent aphasia (PNFA) (Boxer & Miller, 2005), and movement disorders (e.g., amyotrophic lateral sclerosis, parkinsonism, and other corticobasal syndromes (Boeve & Hutton, 2008; Warren, Rohrer, & Rossor, 2013).

#### 5.2.2.5 Reversible with Intervention

##### 5.2.2.5.1 Depression

Depressive disorders, identified as mood dysregulation (American Psychiatric Association, 2013), are common in the geriatric populations. Several depressive syndrome are described in the DSM-5 (American Psychiatric Association, 2013) including major depressive disorder and persistent depressive disorder (i.e., dysthymia). A common clinical referral question addresses whether an older adult's cognitive deficits are related to depression (i.e., pseudodementia) or dementia. Depression in the elderly is often accompanied by cognitive impairments (Lockwood, Alexopoulos, & van Gorp, 2002). Dementia and depression, however, do not necessarily occur in isolation. Rather, increasing depression is associated with the development of dementia. It is not clear whether dementia precedes depression, or vice versa (Barberger-Gateau et al., 2002).

### 5.2.3 Relations Between Disease/Disorder and Functional Limitations

The disorders described above differ with respect to underlying pathology and in how they manifest in terms of functional limitations (i.e., cognitive impairments) and associated disability (i.e., impairment in everyday behaviors). These disorders are perhaps best conceptualized as syndromes that may or may not be linked to specific etiologies. It has been proposed that these syndromes can often be distinguished based on key features of the presenting functional limitations (i.e., patterns of cognitive deficits) and associated disability (Tuokko & Hadjistavropoulos, 1998). Table 5.1 links the disease/disorder in question to the typical presenting functional limitations.

It is important to note that some of these disorders and their associated underlying pathology are degenerative and the cognitive or behavioral presentations may change or evolve over time. For example, in the AD literature, Reisberg et al. (1984) have proposed seven identifiable stages based on cognitive or behavioral presentation that are presumed reflective of the severity of the underlying pathological brain damage (see Table 5.2). In fact, despite differences in the initial symptoms of different forms of dementia (e.g., primary memory deficit in AD; behavioral and executive dysfunction in the frontal-variant of FTD), because of the progressive nature of most dementias, they are all characterized by severe functional limitations and disability at the end of the disease process (Schneck et al., 1984).

## 5.3 Modifying Factors

The Disablement Process is described as the natural process of disease. However, it is not a fixed process. Rather, several innate and developed personal characteristics, as well as intra- and extra-individual processes, occur along the continuum of the Disablement Process and impact the rate of progression and transition from one stage to the next. These modifiers include disease/impairment-specific risk factors, protective factors, and interventions to delay the progression of the disease.

**Table 5.1** Cognitive and behavioral symptoms of common disorders affecting older adults

| Domain | ACS | CVD and VaD | AD | PD | LBD | FTD | Depression |
|---|---|---|---|---|---|---|---|
| Awareness | Disorientation to time and place | | Progressive loss of awareness of deficit | | Confusion | Lack of awareness; no insight | |
| Memory | Impaired recent memory | Often preserved | Impaired recent and remote memory | Impaired recall | Impaired recall | Impaired memory for words; | Memory deficits due to lack of attention |
| Attention and Executive Function | Impaired ability to focus, shift, and/or sustain attention | | Difficulty sustaining attention | Executive dysfunction | Obvious deficits in attention and executive function | Disinhibition; socially inappropriate; perseveration; attention deficits; impulsive | Impaired selective and sustained attention; slow processing speed; indecisive |
| Language | Dysarthria, dysnomia, dysgraphia, aphasia | Dysarthria, dysphagia | Progressive aphasia | Dysarthria | | Paraphasia; impaired verbal fluency; pronunciation deficits | Limited spontaneous speech |
| Perception | Delusions, hallucinations, misinterpretations | | Progressive paranoia; visuospatial dysfunction | | Visuospatial dysfunction, visual hallucinations, delusions | | |
| Emotional | Fear, anxiety, depression, anger, euphoria, apathy | Pseudobulbar affect | Apathy; disinterest; personality change | Depression; apathy | Depression | Flat affect; apathy; personality change; irritability | Disinterest; apathy; loss of pleasure; lack of motivation |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Physical | Hypoactivity | Physical deficits dependent upon location of cerebral infarct | Apraxia; difficulty dressing | Bradykinesia<br>Rigidity<br>Resting tremor<br>Postural instability | Spontaneous parkinsonism (bradykinesia, rigidity, hypomimia, postural, gait abnormalities) | Increase in eating or drinking | Slowed movement |
| Other | Altered sleep-wake cycle | Focal neurological signs or symptoms | No loss of consciousness | Dementia symptoms at least one year after motor symptoms | Early-onset dementia<br>Extreme sensitivity to neuroleptics, REM sleep disturbance; loss of consciousness | Early-onset; fluctuating cognitive symptoms; lack of personal hygiene; changes in appetite | Poor performance on measures reliant on frontal lobe function |
| Course | Fluctuating | Stable or stepwise | Insidious onset progressive course | Insidious onset<br>Slowly progressive | Fluctuating | Insidious onset<br>Rapidly progressing and variable | Abrupt onset<br>Variable course |

**Table 5.2** Reisberg's functional assessment stages (FAST) in normal aging and AD

| Global deterioration scale | Clinical phase | FAST characteristics |
|---|---|---|
| 1. No cognitive decline | Normal | No functional decrement manifest, either subjectively or objectively |
| 2. Very mild cognitive decline | Forgetfulness | Complains of forgetting location of objects; subjective work difficulties |
| 3. Mild cognitive decline | Early confusional | Decreased functioning in demanding employment settings evident to co-workers; difficulty in traveling to new locations |
| 4. Moderate cognitive decline | Late confusional | Decreased ability to perform complex tasks such as planning dinner for guests, handling finances, and marketing. |
| 5. Moderately severe cognitive decline | Early dementia | Requires assistance in choosing proper clothing; may require coaxing to bathe properly |
| 6. Severe cognitive decline | Middle dementia | (a) Difficulty putting on clothing properly |
| | | (b) Requires assistance bathing; may develop fear of bathing |
| | | (c) Inability to handle mechanics of toileting |
| | | (d) Urinary incontinence |
| | | (e) Fecal incontinence |
| 7. Very severe cognitive decline | Late dementia | (a) Ability to speak limited to one to five words |
| | | (b) All intelligible vocabulary lost |
| | | (c) All motoric abilities lost |
| | | (d) Stupor |
| | | (e) Coma |

### 5.3.1 Risk Factors

According to the original model proposed by Verbrugge and Jette (1994), risk factors are those characteristics of a person that exist prior to the beginning of the disablement process. They include demographic, social, genetic/biological, environmental, educational, and recreational factors. In this chapter, we discuss risk factors that are preexisting personal characteristics associated with an increased incidence of cognitive decline. They predispose an individual to cognitive impairment or dementia and may also influence the course of the disablement process (Barberger-Gateau et al., 2004). A sample of risk factors for select diagnoses of cognitive impairment and associated supportive research follows.

#### 5.3.1.1 Age

With the lengthening of the human life span, there has been increased interest in the study of aging and dementia. The most prominent risk factor associated with cognitive decline is age. As noted earlier, the prevalence of dementia was shown to increase from 2.4 %, to 11.1 %, to 34.5 % in persons aged 65–74, 75–84, and 85+ years, respectively, in the Canadian population (Canadian Study of Health and

Aging, 2000). Increasing age is also a risk factor for cognitive impairment not meeting the criteria for dementia. For example, age was found to be risk factor for Cognitive Impairment No Dementia (CIND) in the older Italian population (Di Carlo et al., 2000), and the Australian population (Low et al., 2004), and for cognitive decline in the Canadian older population (Graham et al., 1997).

Positive correlations between incidence rates of dementia (i.e., the number of new dementia cases each year) and advancing age are also reported. For example, in persons up to 90 years of age, the incidence of dementia continues to increase with advancing age without reaching a plateau (Ravaglia et al., 2005). Similar findings were reported in the European Studies of Dementia (EURODEM), a pooled examination of dementia in the Netherlands, the United Kingdom, France, and Denmark. The incidence rate for dementia in persons aged 65 years was 2.5, compared to 85.6 in persons aged 90 years or older (Launer et al., 1999).

#### 5.3.1.2 Gender

The role of gender as a risk factor for cognitive decline differs according to diagnosis. Specifically, the female gender is associated with a greater risk for AD. In contrast, men have a higher risk of developing VaD. For example, Yamada et al. (1999) report AD prevalence rates of 3.8 and 2.0 % for women and men, respectively. In contrast, women had VaD prevalence rates of 1.8 % compared to 2.0 % for men.

#### 5.3.1.3 Genetic Risk

Having first-degree relatives with a history of dementia may be a risk for dementia. Launer et al. (1999) report a positive but insignificant risk for dementia in persons with two or more family members with a history of dementia. Family history of dementia occurs almost twice as frequently in persons with VaD and AD, compared to non-demented persons (Boston, Dennis, & Jagger, 1999).

Genetic risk factors associated with AD involve four genes: amyloid-precursor protein (APP), presenilin genes 1 and 2, and the apolipoprotein E (ApoE) gene. Unlike the first three genes, risk associated with the ApoE gene is not due to mutation of the gene. Rather, its presence is speculated to predispose individuals to AD (Hsiung, Sadovnick, & Feldman, 2004). ApoE is located on Chromosome 19 and consists of three alleles: $\epsilon2$, $\epsilon3$, and $\epsilon4$. The $\epsilon4$ allele is associated with an increased risk of dementia.

Results from the CSHA (Hsiung et al., 2004) reveal the prevalence of the ApoE $\epsilon4$ genotype to be significantly higher in those with AD and VaD. Similar findings were observed in persons who progressed from CIND to AD. New and non-progressing CIND cases and CIND cases who subsequently reverted to a diagnosis of No Cognitive Impairment (NCI) had distributions of ApoE $\epsilon4$ similar to control subjects. Additionally, an interaction between age and ApoE $\epsilon4$ genotype was noted in persons with AD. Specifically, age of onset of AD and age of progression from CIND to AD were significantly associated with the ApoE $\epsilon4$ genotype. The authors suggest that these interactions may account for the earlier onset of AD and earlier conversion to AD in persons with the ApoE $\epsilon4$ genotype.

Similar increase in risk was noted by Frikke-Schmidt, Nordestgaard, Thudium, Moes Grøholdt, and Tybjærg-Hansen (2001) in their sample of Danish participants. The Є44 and the Є43 genotypes were associated with tenfold and threefold increases in the risk of AD, compared to persons with the Є34 genotype. The increased risk associated with the ApoE Є4 allele was not limited to diagnoses of AD. Rather, a 2.5-fold increase in risk of "other dementia" was also noted in persons with the Є43 genotype. The authors report that, overall, the Є44 and the Є43 genotypes, respectively, accounted for 37 and 20 % of AD and the Є43 genotype accounted for 26 % of other dementias in the general population.

The risk of dementia associated with ApoE Є4 genotype has also been linked to vascular risk factors. Baum et al. (2006) found a significantly greater percentage of persons with VaD (23.6 %) compared to controls (15.1 %) who had the ApoE Є3/Є4 or Є4/Є4 genotype. The relationship between VaD and ApoE Є4 was significant only in patients with comorbid hypertension or diabetes.

#### 5.3.1.4 Vascular Risk Factors

Risk of cognitive decline associated with various cerebrovascular factors differs according to the type of dementia (i.e., VaD v. AD). Hayden et al. (2006) examined the differential risk of AD and VaD associated with cerebrovascular factors, using data from the Cache County Study of Memory Health and Aging. Overall, increased risk of dementia was associated with older age, female gender, ApoE genotype, history of stroke, and history of obesity. The following disease- and gender-specific risk factors were identified: (1) history of diabetes in men with AD; (2) history of diabetes in women with VaD; (3) obesity in women with AD; (4) hypertension in women with VaD.

While hypertension has been associated with VaD, hypotension has been identified as a risk factor for AD. Verghese, Lipton, Hall, Kullansky, and Katz (2003) report that in persons over 75 years of age, ongoing low diastolic blood increases the risk of developing AD. The authors hypothesize that hypotension may predispose a person to dementia and may also be an outcome of dementia.

Xu, Qiu, Wahlin, Winblad, and Fratiglioni (2004) investigated the role of diabetes as a risk factor for dementia using data from the Kungsholmen Project. Diabetes was identified as a significant risk factor for dementia, especially VaD. The risk of dementia associated with diabetes was further magnified with comorbid severe systolic hypertension and heart disease. The authors speculate that diabetes may increase the risk of dementia through both vascular and nonvascular effects. On its own, diabetes was not identified as a risk factor for AD. Hassing et al. (2002) report similar findings of significantly increased risk of VaD, but not AD, in persons with type 2 diabetes.

#### 5.3.1.5 Pregnancy

Women with a higher number of pregnancies have a higher risk of dementia than women with fewer pregnancies. In a study of 204 AD and 201 control Italian older women, Colucci et al. (2006) found that women with three or more pregnancies had an earlier age of onset of AD (71.7 ± 7 years), compared to women with less than three pregnancies (75.6 ± 6.7 years). Moreover, the risk of dementia was three times greater in women with three or more pregnancies. The authors hypothesize that the greater prevalence and earlier onset of AD in women with three or more pregnancies may be due to increased exposure to estrogen and progesterone.

#### 5.3.1.6 Head Trauma

There are mixed results in the literature regarding the role of head trauma as a risk factor for the development of dementia. For example, in the Rotterdam Study, none of head trauma with loss of consciousness (LOC), multiple head traumas, time since head trauma, or length of LOC were significant risk factors for dementia (Mehta et al., 1999). Similar results were observed in the European population-based study of dementia (EURODEM; Launer et al., 1999). In contrast, in a study examining the risk of dementia among war veterans with and without early closed head injury, Plassman et al. (2000) found moderate and severe early head trauma to be significant risk factors for the development of AD. In a recent review of 15 case-controlled studies, Fleminger, Oliver, Lovestone, Rabe-Hesketh, and Giora (2003) confirm that head injury is a significant risk factor for AD in males. These studies highlight the disparity of results of the risk of dementia among persons with head injury.

### 5.3.2 Protective Factors

Theoretically, protective factors modify the disablement process by delaying or preventing the onset and/or progression of cognitive decline. It can be difficult to identify the specific variables that serve to protect against cognitive decline. As discussed below, easily researched variables, such as education, may serve as a proxy for more remote variables, such as lifestyle, quality of education, access to healthcare, or socioeconomic status (McDowell, Xi, Lindsay, & Tuokko, 2004).

#### 5.3.2.1 Education

Head circumference and education have been identified as protective factors against the development of dementia. For example, in the Nun Study (Mortimer, Snowdon, & Markesbery, 2003) smaller head circumference and low education were associated with a fourfold increase in the development of dementia. These results are in concert with earlier findings that the clinical manifestation of dementia is delayed in persons with larger brains (Katzman et al., 1988). The “brain reserve capacity” (BRC) is a passive threshold model of cognitive impairment following damage to the brain (Stern, 2002). The BRC model hypothesizes that different clinical manifestations of similar brain damage is due to differences in the brain itself (e.g., number of synapses or neurons). In theory, persons with greater BRC can tolerate more damage to the brain before crossing the “threshold” for clinical expression of cognitive impairment (Satz, 1993). Thus, according to BRC model, sisters in the Nun Study with smaller head circumferences may be described as having lower BRC and, therefore, surpassed the threshold for clinical impairment earlier than those with larger head circumferences.

Some suggest that higher levels of education serve to protect against cognitive impairment by enhancing one’s cognitive reserve, thereby delaying the onset of cognitive decline (Cummings, Vinters, Cole, & Khachaturian, 1998). Cognitive reserve is based on the theory that differences in the clinical outcome of brain damage are due to individual differences in intellectual, educational, and occupational achievements. Persons with higher cognitive reserve can theoretically withstand

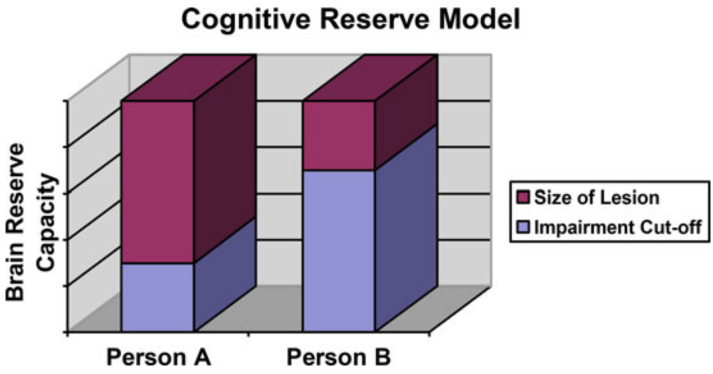


**Fig. 5.2** Cognitive reserve model

greater damage to the brain before exhibiting clinical symptoms of cognitive impairment because of proficient use of intact cognitive abilities. Unlike the BRC model, the cognitive reserve model is not a threshold model. It is not assumed that there is a predetermined threshold that, once surpassed, is associated with cognitive or functional impairment (Stern, 2002). Rather, the cognitive reserve model holds that individuals with the same BRC but differing levels of cognitive reserve will exhibit diverse clinical presentations following similar injury to the brain (Fig. 5.2-derived from Stern, 2002). When applied to dementia, Fig. 5.2 suggests that Person A, who has more cognitive reserve, can withstand greater synaptic degeneration before exhibiting symptoms of cognitive decline, compared to Person B, who has less cognitive reserve.

Cognitive reserve is described as an “active model” wherein there is an active attempt by the brain to compensate for damage (Stern, 2002). Le Carret et al. (2003) suggest that level of education supports and increases cognitive reserve by developing and maintaining two multifaceted cognitive functions: controlled processes and conceptual skills. In a population sample of normal, healthy French elderly persons, higher education was associated with higher neuropsychological performance, especially on attention-focused tasks. Together, controlled processes and conceptual skills are hypothesized to delay the clinical expression of cognitive decline through proficient cognitive functioning.

Classifying education as a protective factor that potentially delays the onset of cognitive decline or dementia is not without controversy. Several studies suggest that the protective effects of education are limited with respect to age. For example, data from the Canadian Study of Health and Aging suggest that education protects against cognitive decline in persons younger than age 80 years (McDowell et al., 2004). Similar findings were reported in the Framingham Study, a community-based study examining the role of education in the incidence of dementia (Cobb, Wolf, Au, & D’Agostino, 1995). The authors report an absence of education as a risk factor for dementia, when controlling for age. It has been proposed that the “protective effects” of education in delaying the onset of dementia may reflect an "ascertainment bias." For example, McDowell et al. (2004) suggest that highly educated individuals may be more adept at and familiar with testing practices similar to those utilized in neuropsychological assessments. Alternatively, given findings that higher functioning (HF) persons with incident dementia exhibit more rapid cognitive decline than lower functioning (LF) persons with incident dementia, Tuokko, Garrett, McDowell, Silverberg, and Kristjansson (2003) propose that the "ascertainment bias" reflects the use of inappropriate normative data for the detection of dementia in HF individuals. As such, cognitive decline is not identified in these individuals until the later stages of impairment. Moreover, education may serve as a proxy for other potentially protective factors such as socioeconomic status (i.e., better lifestyle, access to better healthcare) and occupation (i.e., mental stimulation, exposure to toxins). These possibilities, however, do not invalidate the role of education in the dementia process. Rather, the protective effect of education on the dementia process may be indirect instead of linear (McDowell, Xi, Lindsay, & Tierney, 2007).

#### 5.3.2.2 Physical Activity

Also reducing the risk of cognitive decline with aging is regular physical activity. For example, in a longitudinal study of the relation between cognitive function and regular physical activity in women aged 71–80 years, Weuve et al. (2004) identified a 20 % reduction in the risk of cognitive decline in the most physically active women. The authors describe the observed decline in risk as equivalent to being 3 years younger than their less active counterparts. The cognitive benefits of physical activity were not limited to extremely active women. Better cognitive functioning was observed in women who walked 90+ min per week, compared to those walking for less than 40 min per week. A meta-analysis of the effects of physical activity on risk of cognitive impairment reported that high levels of physical activity reduce the risk of Alzheimer's disease by 45 % and, more generally, dementia by 28 % (Hamer & Chida, 2009).

An active lifestyle among aged persons serves to promote cardiovascular and nervous system health, thereby delaying the onset of cognitive decline. In particular, cardiovascular exercise promotes cognitive functions associated with the frontal and parietal regions of the brain which are instrumental in promoting such functions as working memory and attention (Colcombe et al., 2003; Colcombe & Kramer, 2003). Research using magnetic resonance imaging (MRI) of the brain reveals significant increases in both gray and white matter volume in elderly (aged 60–79 years) persons following a 6-month aerobic exercise routine. The largest increase in gray matter is located in the frontal lobes, while white matter volume increases were largest in the anterior third of the corpus callosum (Colcombe et al., 2006). The benefits of short-term cardiovascular training appear to be restricted to specific brain regions and cognitive functions that are vulnerable to age-associated declines and, as with education, it is possible that some of the protective effects of education are due to factors associated with such as nutrition and lifestyle (Churchill et al., 2002).

Although beneficial to promoting both physical and cognitive health, the resulting neural effects of exercise may be enhanced by cognitively stimulating experiences. Human and animal studies have each contributed to the understanding of the complementary roles of exercise and experience in preserving neural and cognitive function in late life. Overall, aerobic exercise promotes neurogenesis into late life, while exposure to cognitively stimulating environments (i.e., learning) promotes the growth of synapses within the brain (Churchill et al., 2002). These results suggest that, in persons “destined” to develop dementia, physically active, well-educated, cognitively stimulated older persons should exhibit slower rates of cognitive decline, compared to sedentary, less educated persons with repetitive non-stimulating occupations or activities.

### 5.3.3 Interventions

In contrast to risk and protective factors, intervention practices are typically introduced following the discovery or identification of specific impairments to slow or prevent the progression of decline (Verbrugge & Jette, 1994). For example, following a left temporal lobe stroke, a patient may be enrolled in rehabilitative speech pathology to address issues of aphasia. Interventions can intervene at any level of the disablement process and are classified as either intraindividual or extra-individual. Intraindividual interventions are those processes that originate within the patient (e.g., self-efficacy), while extra-individual interventions are processes that are initiated or provided by sources outside of the patient (e.g., cognitive rehabilitation) (Verbrugge & Jette, 1994).

Interventions have been researched to both prevent and slow the progression of dementia. Using Caplan’s (1964) classifications of prevention, interventions designed to prevent the development of dementia in at-risk, but asymptomatic, persons are means of primary prevention. In the context of the current discussion of interventions implemented in response to the disablement process, the interventions of interest are secondary prevention mechanisms-interventions put into action by or for persons exhibiting symptoms of cognitive decline to prevent or slow further decline.

#### 5.3.3.1 Intraindividual Interventions

There are a number of actions a person may take to reduce the demands placed on them, thereby allowing them to maximize their functional capabilities. In describing the disablement process, Verbrugge and Jette (1994) make reference to activity accommodations (i.e., what people do or the activities they engage in, how they do it, for how long and how often) and psychosocial coping strategies (i.e., adjustment of the definition of self in the face of chronic conditions and dysfunctions). In describing behavior change associated with the aging process, Baltes and colleagues (Baltes & Baltes, 1990; Baltes & Lang, 1997) refer to selective optimization with compensation (SOC), whereby an older adult *selects* (actively or passively reduces the overall number of goals and pursuits to conserve energy for goals determined to be most important), *optimizes* (refines the means and resources necessary to reach a goal and/or to excel in a chosen domain), and *compensates* (searches for and makes use of alternate means to reach goals once old means are no longer available).

Although neither Verbrugge and Jette (1994) or the SOC model examines what motivates an older adult to compensate or select so as to maintain their level of everyday functioning, awareness has been identified as playing a key role in compensatory behavior, where those who are more aware of their own deficits are more likely to compensate for them and find alternative methods of completing desired tasks (e.g., Diehl, 1998). It is this understanding or awareness that promotes the use of compensatory or adaptive behavior that allows people to continue to function well despite difficulties performing specific activities.

Although many people with cognitive impairments are painfully aware of their deficits early in the course of the disorder, others are not. Awareness of deficits has been linked to executive functioning (e.g., Amanzio et al., 2013; Van Wielingen, Tuokko, Cramer, Mateer, & Hultsch, 2004) and executive functions, in turn, have been implicated in self-regulation and possibly to identity (Caddell & Clare, 2013). The onset of dementia, then, poses a threat to the self and people respond to this challenge in different ways (Clare, 2003). For some, the self-concept adjusts to incorporate the changes associated with the onset of dementia (i.e., self-adjusting) and others strive to maintain their prior sense of self to maximize continuity (i.e., self-maintaining). Those who do not adjust their behaviors to accommodate for cognitive changes may not engage in compensatory behaviors, thereby placing themselves and others at risk of harm. For example, there is substantial literature to suggest that some older adults with dementia continue to drive even in the face of significant impairment (e.g., Wild & Cotrell, 2003). Similarly, there is some evidence to suggest that dementia patients with insight make significantly greater gains in intervention programs addressing cognitive and affective functioning (Koltai, Welsh-Bohmer, & Schmechel, 2001) than those without insight.

#### 5.3.3.2 Extra-Individual Interventions

The Functional Transitions Model (FTM) was designed to improve clinical practice with AD patients by predicting and preparing for progressive functional decline associated with the disorder (Slaughter & Bankes, 2007). Recall that the progression of AD is reported to occur in seven stages. The goal of this staging was to allow clinicians to identify both disease-related progression and disability due to comorbid factors (Reisberg et al., 1984). Understanding the predicted transitions and identifying impairments due to comorbid conditions allows families and caregivers the opportunity to plan for probable declines in the patient's function (e.g., consider possible intervention strategies; establish the patient's care wishes [e.g., living will], power of attorney). Anticipating functional declines provides the opportunity to be better able to cope with progressive declines (Slaughter & Bankes, 2007).

Several interventions have been proposed as effective treatments (not cures) for dementia. From a medical perspective, pharmacological treatments, such as cholinesterase inhibitors (ChEIs), are the most researched extra-individual interventions for slowing the progression of dementia. Despite recent findings that persons in the early stages of AD do not exhibit diminished levels of the neurotransmitter acetylcholine, cholinesterase inhibitors are the most effective treatments for symptoms of AD (Chertkow, 2006). Meta-analysis of three approved ChEIs (donepezil, rivastigmine, and galantamine) revealed significant but modest increases on a global assessment score, compared to placebo (Lanctôt et al., 2003). Long-term treatment with donepezil (i.e., at least 2 years) has been found to reduce levels of annual cognitive decline in persons with AD, compared to non-donepezil-treated patients (annual declines of 1.2 and 2.8 points on the MMSE, respectively; Tomita, Ootsuki, Maruyama et al., 2007).

Positive results for the treatment of AD have been found with Memantine, an NMDA receptor antagonist. This drug is approved for the treatment of severe AD in Europe and the United States. It has also proven to be effective in the treatment of mild–moderate AD. In a 6-month, randomized, placebo-controlled study, mild AD patients receiving memantine treatment exhibited statistically significant better cognitive functioning than placebo-receiving mild AD participants. Statistically superior language and memory abilities were found in the memantine-treated group (Pomara, Ott, Peskind, & Resnick, 2007).

Other pharmaceutical interventions (both prescribed and over-the-counter products) have been utilized for the treatment of memory disorders in old age. Such products include ginko biloba, nootropics ("dietary supplements"), antioxidants, Vitamin E, estrogen, anti-inflammatory agents, to name a few. For a good review of existing and emerging pharmacological treatments for memory impairment, see Chertkow (2006). For a review of the pharmacological treatments available for non-AD, see Arlt and Jahn (2006).

From a clinical psychology perspective, cognitive rehabilitation has been identified as intervention for persons with Alzheimer's disease and vascular dementia. Clare and Woods (2004) have identified three cognitive interventions with different foci for use with people with dementia. Cognitive stimulation is typically conducted in a group format and, while encompassing a cognitive element, generally has an equal emphasis on social interaction. Cognitive training, designed to maintain current cognitive abilities and slow the progression of cognitive decline, is undertaken in group or individual format and consists of ongoing practice of exercises targeting specific cognitive domains (e.g., memory, attention, language, praxis). Improvement on cognitive tasks is believed to generalize to activities outside of the training regime. Cognitive rehabilitation programs are tailored to the individual patient and involve working with the patient and their caregiver(s) to design-specific strategies (e.g., use of memory aids) to compensate for cognitive deficits. Examples of cognitive rehabilitation techniques include spaced retrieval, errorless learning, and mnemonics. Cognitive stimulation and rehabilitation are reported to be effective treatments for persons diagnosed with early AD. There is limited research to support the utility of cognitive training for the treatment of dementia (Woods & Clare, 2006). Similar cognitive rehabilitation approaches are used to address cognitive deficits resulting from a cerebrovascular event (e.g., stroke, anoxia due to hypoperfusion, etc.), traumatic brain injury (e.g., from a fall), or illness/disease (e.g., diabetes).

The aim of pharmaceutical treatments, cognitive stimulation, and cognitive training is to increase the patient's cognitive capacity and, in turn, maintain or improve his/her current level of independence. Other interventions aim to decrease the environmental demand(s) that the patient is struggling. The implementation of memory aids in cognitive rehabilitation essentially modifies the memory demand of the task to meet the abilities of the person. Relocation to a care facility reduces the environmental demands for intact instrumental activities of daily living (IADLs; e.g., grocery shopping, cooking) and/or activities of daily living (ADLs; e.g., personal hygiene) by providing the necessary supports for the patient. Different levels of care are available and are dependent upon the patient's level of independence. Interventions that decrease environmental demand and those that increase personal capacity aim to create a better fit between the patient's environment and their abilities (Verbrugge & Jette, 1994).

Overall, the goal of implementing intervention programs is to slow the progression of the disablement process. However, interventions can have negative outcomes for the individual and serve to "exacerbate" the existing deficits (Verbrugge & Jette, 1994). For example, relocation to an institution is associated with increased levels of disability (Barberger-Gateau et al., 2004). Woods (1999) suggests that, in many care settings, dependence is encouraged over autonomy. This finding is consistent with Baltes (1982, 1988) theory of learned dependency, wherein dependent behavior among elderly persons is rewarded socially, while independent behavior is frequently ignored (Horgas, Wahl, & Baltes, 1996). Coping with feelings of loss (e.g., freedom, possessions, independence) is perhaps the biggest obstacle for persons entering a nursing home. Inability to do so can result in withdrawal (e.g., activities, meals, socializing) and depression (Harker, 1997). Depression in older adults is associated with impairment in executive functioning (Lockwood et al., 2002). Thus, although the goal of institutionalization is to improve the fit between the personal capacity and environmental demand, it is important to address and plan for the potential negative consequences associated with the transition.

## 5.4 Conclusion

The use of the disablement process clearly illustrates the complexities of identifying impairment in geriatric populations. Within the disablement process framework, functional impairments refer to abnormalities within specific body systems (here we have focused on disorders affecting brain function) whereas functional limitations refer to restrictions in physical and mental activities, often referred to as impairments outside the context of this model (e.g., cognitive impairments). In practice, it is often these functional limitations and/or the resulting disability (i.e., impairments in everyday functioning) that bring older adults to clinical attention. We discussed a number of different approaches to the identification of cognitive impairment (e.g., comparison to normative samples, to assess change over time, in relation to specific criterion for achievement) and sets of criteria for disorders of cognitive functions. In addition, we described common approaches to assessing for impairments in everyday functions (i.e., disability) and how these impairments relate to cognitive impairment. We described common underlying pathologies related to disorders of cognition in older adults, noting how differences in patterns and presentation of cognitive and behavioral impairments are often the basis from which inferences are drawn concerning the presence these pathologies. We identified modifying factors that impact emergence, rates of progression, and functional outcomes associated with the expression of these pathologies: risk factors, protective factors, and interventions. The inferences drawn about the nature of the underlying pathology are of primary importance for determining prognosis and selecting medical intervention options (e.g., pharmacologic agents to slow, arrest, or reverse the pathological process). On the other hand, it is the clarity with which functional limitations (i.e., cognitive and behavioral) are understood that lays the foundation for behavioral and psychosocial interventions intended to optimize functioning, minimize the risk of disability, and prevent dysfunctional social or family functioning (Woods & Clare, 2006). Particularly within the context of geriatric populations, where biological, psychological, and social changes are expected and highly interdependent, the disablement process framework offers a comprehensive view of the myriad of factors that need to be considered when assessing for and interpreting the meaning of impairment.

## References

Aarsland, D., Andersen, K., Larsen, J. P., Lolk, A., Neilsen, H., & Kragh-Sørensen, P. (2001). Risk of dementia in Parkinson's disease: A community-based, prospective study. *Neurology, 56*, 730–736.

Albert, S. M., Michaels, K., Padilla, M., Pelton, G., Bell, K., Marder, K., et al. (1999). Functional significance of mild cognitive impairment in elderly patients without a dementia diagnosis. *American Journal of Geriatric Psychiatry, 7*, 213–220.

Amanzio, M., Vase, L., Leotta, D., Miceli, R., Palermo, S., & Geminiani, G. (2013). Impaired awareness of deficits in Alzheimer's disease: The role of everyday executive dysfunction. *Journal of the International Neuropsychological Society, 19*(1), 63–72. doi:10.1017/S1355617712000896.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington: Author.

Anastasi, A. (1988). *Psychological testing* (6th ed.). Upper Saddle River, NJ: Prentice-Hall.

Arlt, S., & Jahn, H. (2006). Pharmacological treatment of non-Alzheimer dementias. *Current Opinion in Psychiatry, 19*, 642–648.

Armstrong, C. L., & Morrow, L. (2010). *Handbook of medical neuropsychology: Applications of cognitive neuroscience*. New York: Springer.

Artero, S., Touchon, J., & Ritchie, K. (2001). Disability and mild cognitive impairment: A longitudinal population-based study. *International Journal of Geriatric Psychiatry, 16*, 1092–1097.

Bachman, D. L., Wolf, P. A., Linn, R. T., Knoefel, J. E., Cobb, J. L., Belanger, A. J., et al. (1993). Incidence of dementia and probable Alzheimer's disease in a general population: The Framingham study. *Neurology, 43*, 515–519.

Baltes, M. M. (1982). Environmental factors in dependence among nursing home residents: A social ecology analysis. In T. A. Wills (Ed.), *Basic processes in helping relationships* (pp. 405–425). New York: Academic Press.

Baltes, M. M. (1988). The etiology and maintenance of dependency in the elderly: Three phases of operant research. *Behavior Therapy, 19*, 301–319.

Baltes, P. B., & Baltes, M. M. (1990). Psychological perspectives on successful aging: The model of selective optimization with compensation. In P. B. Baltes & M. M. Baltes (Eds.), *Successful aging: Perspectives from the behavioral sciences* (pp. 1–34). New York: Cambridge University Press.

Baltes, M. M., & Lang, F. R. (1997). Everyday functioning and successful aging: The impact of resources. *Psychology and Aging, 12*, 433–443.

Barberger-Gateau, P., Aliom, A., Pérès, K., Regnault, A., Farigoule, C., Nikulin, M., et al. (2004). The contribution of dementia to the disablement process and modifying factors. *Dementia and Geriatric Cognitive Disorders, 18*, 330–337.

Barberger-Gateau, P., Dartigues, J.-F., & Letenneur, L. (1993). Four instrumental activities of daily living score as a predictor of one-year incident dementia. *Age and Ageing, 22*, 457–463.

Barberger-Gateau, P., Fabrigoule, C., Amieva, H., Helmer, C., & Dartigues, J. F. (2002). The disablement process: A conceptual framework for dementia-associated disability. *Dementia and Geriatric Cognitive Disorders, 13*, 60–66.

Barberger-Gateau, P., Fabrigoule, C., Rouch, I., Letenneur, L., & Dartigues, J.-F. (1999). Neuropsychological correlates of self-reported performance in instrumental activities of daily living and prediction of dementia. *Journal of Gerontology, 54B*, P293–P303.

Bassett, S. S., & Folstein, M. F. (1991). Cognitive impairment and functional disability in the absence of psychiatric diagnosis. *Psychological Medicine, 21*, 77–84.

Baum, L., Lam, L. C. W., Lee, G., Chiu, H. F. K., Mok, V. C. T., Wong, A., et al. (2006). Apolipoprotein E ε4 allele is associated with vascular dementia. *Dementia and Geriatric Cognitive Disorders, 22*, 301–305.

Black, S. A., & Rush, R. D. (2002). Cognitive and functional decline in adults aged 75 and older. *Journal of the American Geriatrics Society, 50*, 1978–1986.

Blackford, R. C., & La Rue, A. (1989). Criteria for diagnosing age-associated memory impairment: Proposed improvements from the field. *Developmental Neuropsychology, 5*, 295–306.

Boeve, B. F., & Hutton, M. (2008). Refining frontotemporal dementia with parkinsonism linked to chromosome 17: Introducing FTDP-17 (MAPT) and FTDP-17 (PGRN). *Archives of Neurology, 65*(4), 460–464.

Boston, P. F., Dennis, M. S., & Jagger, C. (1999). Factors associated with vascular dementia in an elderly community population. *International Journal of Geriatric Psychiatry, 14*, 761–766.

Boxer, A. L., & Miller, B. L. (2005). Clinical features of frontotemporal dementia. *Alzheimer Disease & Associated Disorders, 19*, S3–S6.

Braak, E., Griffing, K., Arai, K., Bohl, J., Bratzke, H., & Braak, H. (1999). Neuropathology of Alzheimer's disease: What is new since A. Alzheimer? *European Archives of Psychiatry and Clinical Neuroscience, 24*, 14–22.

Brody, E. M., Kleban, M. H., Lawton, M. P., & Silverman, H. A. (1971). Excess disabilities of the mentally impaired aged: Impact of individualized treatment. *Gerontologist, 11*, 124–133.

Butters, M., Beers, S. R., Tarter, R. E., Edwards, K. L., & van Thiel, D. H. (2001). *Medical neuropsychology* (2nd ed.). New York: Springer.

Caddell, L. S., & Clare, L. (2013). How does identity relate to cognition and functional abilities in early-stage dementia? *Aging, Neuropsychology, and Cognition, 20*(1), 1–21. doi:10.1080/13825585.2012.656575.

Canadian Study of Health and Aging Working Group. (1994). Canadian study of health and aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*, 899–913.

Canadian Study of Health and Aging Working Group. (2000). The incidence of dementia in Canada. *Neurology, 55*, 66–73.

Caplan, G. (1964). *Principles of preventive psychiatry*. New York: Basic Books.

Chertkow, H. (2006). Emerging pharmacological therapies for mild cognitive impairment. In H. A. Tuokko & D. F. Hultsch (Eds.), *Mild cognitive impairment: International perspectives* (pp. 217–244). New York: Taylor & Francis.

Churchill, J. D., Galvez, R., Colcombe, S., Sain, R. A., Kramer, A. F., & Greenough, W. T. (2002). Exercise, experience and the aging brain. *Neurobiology of Aging, 23*, 941–955.

Clare, L. (2003). Managing threats to self-awareness in early stage Alzheimer's disease. *Social Science and Medicine, 57*(6), 1017–1029.

Clare, L., & Woods, B. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation, 14*, 385–401.

Cobb, J. L., Wolf, P. A., Au, R., & D'Agostino, R. B. (1995). The effect of education on the incidence of dementia and Alzheimer's disease in the Framingham study. *Neurology, 45*, 1707–1712.

Colcombe, S., Erickson, K. I., Raz, N., Webb, A. G., Cohen, M. J., McAuley, E., et al. (2003). Aerobic fitness reduces brain tissue loss in aging humans. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 58A*, 176–180.

Colcombe, S., Erickson, K. I., Scalf, P. E., Kim, J. S., Prakash, R., McAuley, E., et al. (2006). Aerobic exercise training increases brain volume in aging humans. *Journals of Gerontology. Series A, Biological Sciences and Medical Sciences, 61A*, 1166–1170.

Colcombe, S., & Kramer, A. F. (2003). Fitness effects on the cognitive function of older adults: A meta-analytic study. *Psychological Science, 14*, 125–130.

Colucci, M., Cammarata, S., Assini, A., Croce, R., Clerici, F., Novello, C., et al. (2006). The number of pregnancies is a risk factor for Alzheimer's disease. *European Journal of Neurology, 13*, 1374–1377.

Crawford, J. R., & Howell, D. C. (1998). Regression equations in clinical neuropsychology: An evaluation of statistical methods for comparing predicted and obtained scores. *Journal of Clinical and Experimental Neuropsychology, 20*, 755–762.

Cummings, J. L., Vinters, H. V., Cole, G. M., & Khachaturian, Z. S. (1998). Alzheimer's disease: Etiologies, pathophysiology, cognitive reserve, and treatment opportunities. *Neurology, 51*, S2–S17.

de la Torre, J. C. (2004). Is Alzheimer's disease a neurodegenerative or vascular disorder? Data, dogma, and dialectics. *Lancet Neurology, 3*, 184–190.

Di Carlo, A., Baldereschi, M., Amaducci, L., Maggi, S., Grigoletto, F., Scarlato, G., et al. (2000). Cognitive impairment without dementia in older people: Prevalence, vascular risk factors, impact on disability. The Italian longitudinal study on aging. *Journal of the American Geriatrics Society, 48*, 775–782.

Diehl, M. (1998). Everyday competence in later life: Current status and future directions. *Gerontologist, 38*, 422–433.

Ebly, E. M., Parhad, I. M., Hogan, D. B., & Fung, T. S. (1994). Prevalence and types of dementia in the very old: Results from the Canadian study of health and aging. *Neurology, 44*, 1593–1600.

Fillenbaum, G. G. (1985). Screening the elderly: A brief instrumental activities of daily living measure. *Journal of the American Geriatrics Society, 33*, 698–706.

Fillenbaum, G. G. (1987a). Activities of daily living. In G. L. Maddox (Ed.), *The encyclopedia of aging* (pp. 3–4). New York: Springer.

Fillenbaum, G. G. (1987b). Mulitdimensional functional assessment. In G. L. Maddox (Ed.), *The encyclopedia of aging* (pp. 460–462). New York: Springer.

Fleminger, S., Oliver, D. L., Lovestone, S., Rabe-Hesketh, S., & Giora, A. (2003). Head injury as a risk factor for Alzheimer's disease: The evidence 10 years on: A partial replication. *Journal of Neurology, Neurosurgery, and Psychiatry, 74*, 857–862.

Frerichs, R. J., & Tuokko, H. A. (2005). A comparison of methods for measuring cognitive change in older adults. *Archives of Clinical Neuropsychology, 20*, 321–333.

Frikke-Schmidt, R., Nordestgaard, B. G., Thudium, D., Moes Grøholdt, M.-L., & Tybjærg-Hansen, A. (2001). APOE genotype predicts AD and other dementia but not ischemic cerebrovascular disease. *Neurology, 56*, 194–200.

Graham, J. E., Rockwood, K., Beattie, B. L., Eastwood, R., Gauthier, S., Tuokko, H., et al. (1997). Prevalence and severity of cognitive impairment with and without dementia in an elderly population. *Lancet, 349*, 1793–1796.

Greiner, P. A., Snowdon, D. A., & Schmitt, F. A. (1996). The loss of independence in activities of daily living: The role of low normal cognitive function in elderly nuns. *American Journal of Public Health, 86*, 62–65.

Gruenberg, E. M. (1977). The failure of success. *Milbank Memorial Fund Quarterly. Health and Society, 55*, 3–24.

Hageman, W. J. J. M., & Arrindell, W. A. (1999). Establishing clinically significant change: Increment of precision and the distinction between individual and group level of analysis. *Behaviour Research and Therapy, 37*, 1169–1193.

Hamer, M., & Chida, Y. (2009). Physical activity and risk of neurodegenerative disease: A systematic review of prospective evidence. *Psychological Medicine, 39*(1), 3–11. doi:10.1017/s0033291708003681.

Harker, J. (1997). Help me: Coping with the nursing home decision. Retrieved July 29, 2007, from the World Wide Web: http://www.alharris.com/harker/helpme.htm

Harris, C. W. (Ed.). (1963). *Problems measuring change*. Madison: University of Wisconsin Press.

Hassing, L. B., Johansson, B., Nilsson, S. E., Berg, S., Pedersen, N. L., Gatz, M., et al. (2002). Diabetes mellitus is a risk factor for vascular dementia, but not for Alzheimer's disease: A population-based study of the oldest-old. *International Psychogeriatrics, 14*, 239–248.

Hayden, K. M., Zandi, P. P., Lyketsos, C. G., Khachaturian, A. S., Bastian, L. A., Charoonruk, G., et al. (2006). Vascular risk factors for incident Alzheimer disease and vascular dementia: The Cache County Study. *Alzheimer Disease and Associated Disorders, 20*, 93–100.

Horgas, A. L., Wahl, H.-W., & Baltes, M. (1996). Dependency in late life. In L. L. Carstensen, B. A. Edelstein, & L. Dornbrand (Eds.), *The practical handbook of clinical gerontology* (pp. 54–75). Thousand Oaks, CA: Sage.

Hsiung, G. R., Sadovnick, A. D., & Feldman, H. (2004). Apolipoprotein E epsilon 4 genotype as a risk factor for cognitive decline and dementia: Data from the Canadian Study of Health and Aging. *Canadian Medical Association Journal, 171*, 863–867.

Hsu, L. M. (1989). Reliable changes in psychotherapy: Taking into account regression toward the mean. *Behavioral Assessment, 11*, 459–467.

Ivnik, R. J., Smith, G. E., Petersen, R. C., Boeve, B. F., Kokmen, E., & Tangalos, E. G. (2000). Diagnostic accuracy of four approaches to interpreting neuropsychological test data. *Neuropsychology, 14*, 163–177.

Jacobson, N. S., & Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. *Journal of Consulting and Clinical Psychology, 59*, 12–19.

Katzman, R., Terry, R., DeTeresa, R., Brown, T., Davies, P., Fuld, P., et al. (1988). Clinical, pathological, and neurochemical changes in dementia: A subgroup with preserved mental status and numerous neocortical plaques. *Annals of Neurology, 23*, 138–144.

Koltai, D. C., Welsh-Bohmer, K. A., & Schmechel, D. E. (2001). Influence of anosagnosia on treatment outcome among dementia patients. In L. Clare & R. T. Woods (Eds.), *Cognitive rehabilitation in dementia* (pp. 455–476). New York: Taylor & Francis.

Kramer, M. (1980). The rising pandemic of mental disorders and associated chronic diseases and disabilities. *Acta Psychiatrica Scandinavica, 62*(Suppl.285), 382–397.

Lanctôt, K. L., Herrmann, N., Yau, K. K., Khan, L. R., Liu, B. A., LouLou, M. M., et al. (2003). Efficacy and safety of cholinesterase inhibitors in Alzheimer's disease: A meta-analysis. *Canadian Medical Association Journal, 169*, 557–564.

Launer, L. J., Andersen, K., Dewey, M. E., Letenneur, L., Ott, A., Amaducci, L. A., et al. (1999). Rates and risk factors for dementia and Alzheimer's disease: Results from EURODEM pooled analyses. *Neurology, 52*, 78–84.

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist, 9*, 179–185.

Le Carret, N., Lafont, S., Letenneur, L., Dartigues, J.-F., Mayo, W., & Fabrigoule, C. (2003). The effect of education on cognitive performances an its implication for the constitution of the cognitive reserve. *Developmental Neuropsychology, 23*, 317–337.

Lehman, L. B., Pilich, A., & Andrews, N. (1993). Neurological disorders resulting from alcoholism. *Alcohol Health and Research World, 17*, 305–309.

Lezak, M. D., Howieson, D. B., & Loring, D. W. (2004). *Neuropsychological assessment* (4th ed.). New York: Oxford University Press.

Lieberman, A. (2006). Depression in Parkinson's disease: A review. *Acta Neurologica Scandinavica, 113*, 1–8.

Lipowski, Z. J. (1994). Acute confusional states (delirium) in the elderly. In M. L. Albert & J. E. Knoefel (Eds.), *Clinical neurology of aging* (2nd ed., pp. 347–362). New York: Oxford University Press.

Lockwood, K. A., Alexopoulos, G. S., & van Gorp, W. G. (2002). Executive dysfunction in geriatric depression. *American Journal of Psychiatry, 159*, 1119–1126.

Lord, F. M. (1957). The measurement of growth. *Educational and Psychological Measurement, 16*, 421–437.

Lord, F. M. (1958). Further problems in the measurement of growth. *Educational and Psychological Measurement, 18*, 437–451.

Low, L.-F., Brodaty, H., Edwards, R., Kochan, N., Draper, B., Trollor, J., et al. (2004). The prevalence of 'cognitive impairment no dementia' in community-dwelling elderly: A pilot study. *Australian and New Zealand Journal of Psychiatry, 38*, 725–731.

McDowell, I., Xi, G., Lindsay, J., & Tierney, M. (2007). Mapping the connections between education and dementia. *Journal of Clinical and Experimental Psychology, 29*, 127–141.

McDowell, I., Xi, G., Lindsay, J., & Tuokko, H. (2004). Canadian Study of Health and Aging: Study description and patterns of early cognitive decline. *Aging, Neuropsychology, and Cognition, 11*, 149–168.

McKeith, I. G., Dickson, D. W., Lowe, J., Emre, M., O'Brien, J. T., Feldman, H., et al. (2005). Diagnosis and management of dementia with Lewy bodies: Third report of the DLB consortium. *Neurology, 65*, 1863–1872.

McKhann, G. M., Knopman, D. S., Chertkow, H., Hyman, B. T., Jack, C. R., Jr., Kawas, C. H., et al. (2011). The diagnosis of dementia due to Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia, 7*, 263–269.

McNemar, Q. (1958). On growth measurement. *Educational and Psychological Measurement, 18*, 47–55.

Mehta, K. M., Ott, A., Kalmijn, S., Slooter, A. J. C., van Duijn, C. M., Hofman, A., et al. (1999). Head trauma and risk of dementia and Alzheimer's disease: The Rotterdam Study. *Neurology, 53*, 1959–1962.

Moritz, D. J., Kasl, S. V., & Berkman, L. F. (1995). Cognitive functioning and the incidence of limitations in activities of daily living in an elderly community sample. *American Journal of Epidemiology, 141*, 41–49.

Mortimer, J. A., Snowdon, D. A., & Markesbery, W. R. (2003). Head circumference, education and risk of dementia: Findings from the Nun Study. *Journal of Clinical and Experimental Neuropsychology, 25*, 671–679.

Njegovan, V., Man-Son-Hing, M., Mitchell, S. L., & Molnar, F. J. (2001). The hierarchy of functional loss associated with cognitive decline in older persons. *Journal of Gerontology, 56A*, M638–M643.

Onyike, C. U. (2006). Cerebrovascular disease and dementia. *International Review of Psychiatry, 18*, 423–431.

Payne, R. W., & Jones, H. G. (1957). Statistics for the investigation of individual cases. *Journal of Clinical Psychology, 13*, 115–121.

Petersen, R. C. (2004a). Challenges of epidemiological studies of mild cognitive impairment. *Alzheimer Disease and Associated Disorders, 18*, 1–2.

Petersen, R. C. (2004b). Mild cognitive impairment as a diagnostic entity. *Journal of Internal Medicine, 256*, 183–194.

Plassman, B. L., Havlik, R. J., Steffens, D. C., Helms, M. J., Newman, T. N., Drosdick, D., et al. (2000). Documented head injury in early adulthood and risk of Alzheimer's disease and other dementias. *Neurology, 55*, 1158–1166.

Pomara, N., Ott, B. R., Peskind, E., & Resnick, E. M. (2007). Memantine treatment of cognitive symptoms in mild to moderate Alzheimer disease: Secondary analyses from a placebo-controlled randomized trial. *Alzheimer Disease & Associated Disorders, 21*, 60–64.

Poser, S., Mollenhauer, B., Krauß, A., Zerr, I., Steinhoff, B. J., Schroeder, A., et al. (1999). How to improve the clinical diagnosis of Creutzfeldt-Jacob disease. *Brain, 122*, 2345–2351.

Ravaglia, G., Forti, F., Maioli, F., Martellia, M., Servadei, L., Brunetti, N., et al. (2005). Incidence and etiology of dementia in a large elderly Italian population. *Neurology, 64*, 1525–1530.

Reisberg, B., Ferris, S. H., Anand, R., De Leon, M. J., Schneck, M. K., Buttinger, C., et al. (1984). Functional staging of dementia of the Alzheimer type. *Annals of the New York Academy of Sciences, 435*, 481–483.

Robertson, E. D., Hesse, J. H., Rose, K. D., Slama, H., Johnson, J. K., Forman, M. S., et al. (2005). Frontotemporal dementia progresses to death faster than Alzheimer disease. *Neurology, 65*, 719–725.

Rogers, J. C., Holm, M. B., Burgio, L. D., Hsu, C., Hardin, J. M., & McDowell, B. J. (2000). Excess disability during morning care in nursing home residents with dementia. *International Psychogeriatrics, 12*, 267–282.

Salmon, D. P., Butters, N., & Heindel, W. P. (1993). Alcoholic dementia and related disorders. In R. W. Parks, R. F. Zec, & R. S. Wilson (Eds.), *Neuropsychology of Alzheimer's disease and other dementias* (pp. 186–209). New York: Oxford University Press.

Satz, P. (1993). Brain reserve capacity on symptom onset after brain injury: A formulation and review of evidence for threshold theory. *Neuropsychology, 7*, 273–295.

Schneck, M. K., Buttinger, C., & Borenstein, J. (1984). Functional staging of dementia of the Alzheimer type. *Annals of the New York Academy of Sciences, 435*, 481–483.

Selwa, L. M., & Gelb, D. J. (2005). Dementing illnesses. In D. J. Gelb (Ed.), *Introduction to clinical neurology* (3rd ed., pp. 189–214). Philadelphia, PA: Elsevier Butterworth Heinemann.

Shaji, S., Promodu, K., Abraham, T., Roy, K. J., & Verchese, A. (1996). An epidemiological study of dementia in a rural community in Kerala, India. *British Journal of Psychiatry, 168*, 745–749.

Slaughter, S., & Bankes, J. (2007). The functional transitions model: Maximizing ability in the context of progressive disability associated with Alzheimer's disease. *Canadian Journal on Aging, 26*, 39–48.

Sliwinski, M., Buschke, H., Stewart, W. F., Masur, D., & Lipton, R. D. (1997). The effects dementia risk factors on comparative and diagnostic selective reminding norms. *Journal of the International Neuropsychological Society, 3*, 317–326.

Sliwinski, M., Hofer, S. M., Hall, C., Buschke, H., & Lipton, R. B. (2003). Optimizing cognitive test norms for detection. In R. Petersen (Ed.), *Mild cognitive impairment* (pp. 89–104). New York: Oxford Press.

Smith, G. E., & Ivnik, R. J. (2003). Normative neuropsychology. In R. Petersen (Ed.), *Mild cognitive impairment* (pp. 63–88). New York: Oxford Press.

Smith, G. E., Machulda, M., & Kantarci, K. (2006). A perspective from the Mayo Clinic. In H. A. Tuokko & D. F. Hultsch (Eds.), *Mild cognitive impairment: International perspectives* (pp. 131–162). New York: Taylor & Francis.

Snowdon, D. A., Greiner, L. H., Mortimer, J. A., Riley, K. P., Greiner, P. A., & Markesbery, W. R. (1997). Brain infarction and the clinical expression of Alzheimer disease: The Nun Study. *Journal of the American Medical Association, 277*, 813–817.

Steen, G., Sonn, U., Hanson, A. B., & Steen, B. (2001). Cognitive function and functional ability. A cross-sectional and longitudinal study at ages 85 and 95 in a non-demented population. *Aging Clinical and Experimental Research, 13*, 68–77.

Stern, Y. (2002). What is cognitive reserve? Theory and research application of the reserve concept. *Journal of the International Neuropsychological Society, 8*, 448–460.

Terry, R. D. (2006). Alzheimer's disease and the aging brain. *Journal of Geriatric Psychiatry and Neurology, 19*, 125–128.

Tomita, N., Ootsuki, M., Maruyama, M., et al. (2007). Long-term cognitive benefits of donepezil in Alzheimer's disease: A retrospective comparison between 1994–1999 and 2000–2004. *Geriatrics and Gerontology International, 7*, 41–47.

Tuokko, H., Gabriel, G., & The CSHA Neuropsychology Working Group. (2006). Neuropsychological detection of cognitive impairment: Inter-rater reliability and factors affecting clinical decision-making. *Journal of the International Neuropsychological Society, 12*, 72–79.

Tuokko, H., Garrett, D. D., McDowell, I., Silverberg, N., & Kristjansson, B. (2003). Cognitive decline in high functioning older adults: Reserve or ascertainment bias? *Aging & Mental Health, 7*, 259–270.

Tuokko, H., & Hadjistavropoulos, T. (1998). Age-associated conditions affecting cognition. In H. Tuokko & T. Hadjistavropoulos (Eds.), *An assessment guide to geriatric neuropsychology* (pp. 181–204). Mahwah, NJ: Lawrence Erlbaum Associates.

Tuokko, H., Morris, C., & Ebert, P. (2005). Mild cognitive impairment and everyday functioning in older adults. *Neurocase, 11*, 40–47.

Tuokko, H., & Woodward, T. (1996). Development and validation of a demographic correction system for neuropsychological measures used in the Canadian Study of Health and Aging. *Journal of Clinical and Experimental Neuropsychology, 18*, 479–616.

van Gool, C. H., Kempen, G. I. J. M., Penninx, B. W. J. H., Deeg, D. J. H., Beekman, A. T. F., & van Eijk, J. T. M. (2005). Impact of depression on disablement in late middle aged and older persons: Results from the Longitudinal Aging Study Amsterdam. *Social Science & Medicine, 60*, 25–36.

Van Wielingen, L. E., Tuokko, H. A., Cramer, K., Mateer, C. A., & Hultsch, D. F. (2004). Awareness of financial skills in dementia. *Aging & Mental Health, 8*(4), 374–380. doi:10.1080/13607860410001709728.

Verbrugge, L. M., & Jette, A. M. (1994). The disablement process. *Social Science & Medicine, 38*, 1–14.

Verghese, J., Lipton, R. B., Hall, C. B., Kullansky, G., & Katz, M. J. (2003). Low blood pressure and the risk of dementia in very old individuals. *Neurology, 61*, 1667–1672.

Warren, J. D., Rohrer, J. D., & Rossor, M. N. (2013). Frontotemporal dementia. *British Medical Journal, 347*, f4827. doi:10.1136/bmj.f4827.

Weuve, J., Kang, J. H., Manson, J. E., Breteler, M. M. B., Ware, J. H., & Grodstein, F. (2004). Physical activity, including walking, and cognitive function in older women. *Journal of the American Medical Association, 292*, 1454–1461.

Wild, K., & Cotrell, V. (2003). Identying driving impairment in Alzheimer disease: A comparison of self and observer reports versus driving evaluation. *Alzheimer Disease & Associated Disorders, 17*(1), 27–34.

Willis, S. L. (1996). Assessing everyday competence in the cognitively challenged elderly. In M. A. Smyer & K. W. Schaie (Eds.), *Older adults' decision-making and the law* (pp. 87–127). New York: Springer.

Wilson, R. S., Aggarwal, N. T., & Bennett, D. A. (2006). Mild cognitive impairment in the Religious Orders Study (pp. 117–130). In H. A. Tuokko & D. F. Hultsch (Eds.), *Mild cognitive impairment: International perspectives* (pp. 131–162). New York: Taylor & Francis.

Wolf, H., & Gertz, H.-J. (2006). Studies in the Leipiz Memory Clinic: Contributions to the concept of mild cognitive impairment. In H. A. Tuokko & D. F. Hultsch (Eds.), *Mild cognitive impairment: International perspectives* (pp. 131–162). New York: Taylor & Francis.

Woods, B. (1999). Promoting well-being and independence for people with dementia. *International Journal of Geriatric Psychiatry, 14*, 97–109.

Woods, R. T., & Clare, L. (2006). Cognition-based therapies and mild cognitive impairment. In H. A. Tuokko & D. F. Hultsch (Eds.), *Mild cognitive impairment: International perspectives* (pp. 245–264). New York, NY: Taylor & Francis.

World Health Organization. (1993). *International classification of diseases and related health problems* (10th ed.). Geneva: Author.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: Author.

Xu, W. L., Qiu, C. X., Wahlin, Å., Winblad, B., & Fratiglioni, L. (2004). Diabetes mellitus and risk of dementia in the Kungsholmen project: A 6-year follow-up study. *Neurology, 63*, 1181–1186.

Yamada, M., Sasaki, H., Mimori, Y., Kasagi, F., Sudoh, S., Ikeda, J., et al. (1999). Prevalence and risks of dementia in the Japanese population: RERF's Adult Health Study Hiroshima subjects. *Journal of the American Geriatrics Society, 47*, 189–195.

# Part II

# Modeling Impairment

# Legal Conceptions of Impairment: Implications for the Assessment of Psychiatric Disabilities

# 6

Benjamin J. Lovett, Michael Gordon,
and Lawrence J. Lewandowski

The measurement of functional impairment is hardly a mere academic enterprise, given the current demand for clinical evaluations of disability status. For instance, witness the recent controversies over US military veterans seeking benefits through certification of psychiatric disability (e.g., McNally & Frueh, 2012) or individuals convicted of murder who may feign intellectual disability to avoid the death penalty (e.g., Chafetz & Biondolillo, 2012). More generally, individuals seeking access to specialized accommodations and services in school or at work are pursuing assessments that establish their qualification as having a disability. To satisfy those requests, clinicians have to understand how the law defines disability and the level of documentation required to establish that an individual has a disability. These legal definitions of disability push clinicians to shift focus from the familiar terrain of symptom counts and psychological test scores to the less traveled path of assessing impairment in actual functioning.

The discrepancies between psychiatric and legal criteria pose challenges for the mental health practitioner. Although many sets of formal diagnostic criteria for psychiatric disorders include an impairment criterion, the standard for meeting this criterion is often very different from the relevant legal standard. In recognition of this reality, the recently revised *Diagnostic and Statistical Manual of Mental Disorders* (the DSM-5; American Psychiatric Association, 2013) clearly states:

B.J. Lovett, Ph.D. (✉)
Department of Psychology, SUNY Cortland, P.O. Box 2000, Cortland, NY 13045, USA
e-mail: Benjamin.Lovett@cortland.edu

M. Gordon, Ph.D.
Department of Psychiatry, SUNY Upstate, Syracuse, NY 13210, USA
e-mail: Gordonm301@gmail.com

L.J. Lewandowski, Ph.D.
Department of Psychology, Syracuse University, 430 Huntington Hall, Syracuse,
NY 13244, USA
e-mail: ljlewand@syr.edu

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_6

> In most situations, the clinical diagnosis of a DSM-5 mental disorder…does not imply that an individual with such a condition meets the legal criteria for the presence of a mental disorder or a specified legal standard (e.g., for competence, criminal responsibility, or disability). For the latter, additional information is usually required beyond that contained in the DSM-5 diagnosis, which might include information about the individual's functional impairments and how these impairments affect the particular abilities in question. It is precisely because impairments, abilities, and disabilities vary widely within each diagnostic category that assignment of a particular diagnosis does not imply a specific level of impairment or disability. (p. 25)

This chapter is predicated on the premise that, while the transition from clinical to legal criteria for impairment can be jarring, it can also be productive, provoking us to reconsider ideas that are central to the diagnostic enterprise: What constitutes a disorder? What standard should we use to consider someone as having a disability? Should we compare the examinee to the average person, to people of similar educational attainment or aspirations, or to the examinee's own array of strengths and weaknesses? How valid is psychological testing as a source of information about impairment? Should a person be considered to have a disability if the deficit is not so great as to lead to limitations in activities central to daily living? Might the legal method for establishing disability represent a fairer and more practical strategy than what prevails in psychiatry? Does the forensic construal of impairment have something to teach us about how we might reformulate diagnostic protocols?

This chapter reviews the essential elements of establishing impairment within a legal context. Given limitations of space, we focus on conceptions of impairment in disability discrimination law, with some additional consideration of special education law; these arenas have witnessed some of the most nuanced debates over impairment. For readers seeking detailed information about the place of impairment in other legal arenas (e.g., the laws governing someone's competence to stand trial for a crime), we recommend the chapters in a recent edited anthology (Drogin, Dattilio, Sadoff, & Gutheil, 2011).

## 6.1 Impairment in Special Education Law

The primary law governing special education is the Individuals with Disabilities Education Act (IDEA), most recently reauthorized in 2004. Students who qualify under IDEA receive an individualized education program (IEP), which includes separate educational goals and objectives, based on the students' unique needs. To qualify, students must have a condition that fits into one of 13 enumerated categories (e.g., autism, hearing impairment) *and* their disability condition must lead them to need special education services. It is this latter point that constitutes an impairment criterion under IDEA; if a student has a disability condition but is able to succeed in school without any special services, the student does not qualify. For instance, in one case (*Eric H. ex rel. Gary H. v. Judson Independent School District*; W.D. Tex. 2002), a court found that a student with a diagnosis of Asperger's syndrome did not qualify under IDEA merely because his parents worried that he would do poorly without special services. As the court noted, "The IDEA not only requires that a disability be shown, but also that the child demonstrate a *present* need for special education services and related services *because* of the disability" (p. 91, emphasis in original). Unfortunately, there are no detailed guidelines available to operationalize "need for special education services." Whether receiving passing grades in classes is sufficient to show a lack of impairment has been debated, but not resolved (Office of Special Education Programs, 1995).

Some students who have disability conditions but who are found to not need special education still qualify for certain protections at school, through Section 504 of the Rehabilitation Act of 1973. Schools must consider this potential eligibility after determining that IDEA does not apply (Yell, 2012). Section 504 does not typically provide special education per se, but it ensures that *public* schools do not discriminate against individuals with disabilities. Many students receive accommodations such as preferential seating in classrooms, scheduling adjustments, and testing accommodations under Section 504, without receiving any special education services (Lovett & Lewandowski, 2015). Section 504 has an impairment criterion as well. The student's disability must substantially limit one or more "major life activities," just as under the Americans with Disabilities Act (ADA). We will discuss the specifics of this definition in more detail below.

## 6.2 The Americans with Disabilities Act

The most important legislation that currently establishes the bounds of disability is the Americans with Disabilities Act (ADA). It encompasses the institutions that IDEA and Section 504 apply to, as well as other institutions. This law, designed to combat discrimination against individuals with disabilities, contains five sections, three of which impact daily life. Title I requires employers to treat qualified individuals with and without disabilities equally with regard to hiring, salary, promotion, and training opportunities. It also requires that "reasonable accommodations" be made so as to allow individuals with disabilities to perform their jobs. Title II deals with public services, requiring (for instance) public transportation authorities to ensure that individuals with disabilities have comparable access to the transit system. Finally, Title III requires that any facility open to the public (designated under the law as a "public accommodation") be accessible to individuals with disabilities. As proclaimed by the General Rule for this section: "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation."

Anti-discrimination laws do not guarantee success in life for individuals of groups that the laws combat discriminate against. In the same way that a law prohibiting racial discrimination in employment would not guarantee that any minority applicant applying for a particular job would be hired, the ADA does not guarantee that an individual with a disability will be hired or admitted to a particular educational program.

By definition, an anti-discrimination law such as the ADA is "outcome-neutral." While it establishes procedures for making certain decisions around hiring and test accommodations, it does not impose constraints on the decision itself. For instance, the ADA does not dictate that a student qualified as having a disability must succeed in every course or examination. It only guarantees that the student not be discriminated against because of limitations that are irrelevant to the essential functions inherent in being a student. The ADA would protect someone who was visually impaired from failing an examination because he could not see the text. It would not assure that that student received a high score on a version of the test he could access. Therefore, a clinician who writes, in a report supporting accommodations, that the student "must be allowed extra time so that he can pass the licensure examination for his profession" misreads the intent of the law and ensuing regulations. The ADA ensures that individuals who are otherwise qualified for jobs or educational programs are not denied participation *simply because they have disabilities*. The law therefore guarantees *access*, not *success*.

In educational settings, advocates for students with disabilities may be surprised to learn about ADA's outcome-neutral nature, especially if they are using special education laws (e.g., The Individuals with Disabilities Education Act and its revisions) as a model. Typically, these special education laws have aimed at improving performance of students with disabilities, rather than merely protecting students from discrimination (Yell, 2012). Even though these laws do not guarantee high achievement (or any *particular* outcome; Latham, Latham, & Mandlawitz, 2008), they are designed to promote it. The No Child Left Behind Act reinforces this goal by setting clear academic expectations for students and insisting that all students (including almost all students with disabilities) meet those expectations (Hess & Petrilli, 2006). These laws consider outcomes, while the ADA, again, only examines the *procedures* followed by institutions. This distinction may cause confusion when students transition from high school to college, since special education laws do not apply in the latter setting.

Evaluators charged with making objective decisions about disability status may also misconstrue the intent of the law. In a survey of 147 clinicians who prepared disability documentation to support testing accommodations on the Law School Admissions Test (LSAT), Gordon, Lewandowski, Murphy, and Dempsey (2002) found marked disagreement over the purpose of the ADA. Over 30 % of the clinicians (incorrectly) endorsed the statement that the ADA was intended to increase test scores and the academic performance of individuals with disabilities. Over 35 % of the clinicians (again, incorrectly) endorsed the statement that the ADA is violated if a testing organization or academic institution "fails to provide accommodations guaranteeing that the individual with a disability will perform at his or her best." A more recent study showed many of the same confusions present in Canada, where clinicians failed to appreciate the similar distinctions between education and human rights laws there (Harrison, Lovett, & Gordon, 2013).

### 6.2.1 ADA and the Average Person Standard

At the heart of the ADA is a fundamental question: “What defines a disability?” The law defines disability as follows: *The term disability means, with respect to an individual, a physical or mental impairment that substantially limits one or more of the major life activities of such individual, a record of such an impairment; or being regarded as having such an impairment* (P.L. 101–336, 1990). We note that the use of “impairment” here does *not* refer to functional impairment; instead, it refers to the disability condition (e.g., diabetes, ADHD). Throughout the rest of the chapter, we return to using “impairment” to mean functional impairment.

One governmental entity responsible for setting forth regulations regarding the ADA, the Equal Employment Opportunity Commission (EEOC), has noted that a substantial limitation must be gauged by determining if someone is limited “*compared with the abilities of the average person* [italics added].” The regulations illustrate this principle by stating that “an individual who had once been able to walk at an extraordinary speed would not be substantially limited in the major life activity of walking if, as a result of a physical impairment, he or she were only able to walk at an average speed, or even at moderately below average speed.” This statutory language was intended to ensure that the ADA covered serious disabilities but not those that were minor or trivial.

Establishing the general population as the norm against which to judge impairment has profound implications for determinations of disabilities in both postsecondary education and the workplace. By setting “average abilities of most persons” as the standard, Congress adopted a benchmark that departs from the educational tradition embodied by special education laws. For determining learning disabilities in elementary and secondary school students, many states use a discrepancy between aptitude and achievement as one way of establishing abnormality (Zirkel & Thomas, 2010). However, for ADA-type determinations, the government and courts have indicated that a discrepancy alone is not sufficient to warrant test accommodations and that impairment also must be considered. The obvious significance for clinicians is that one cannot justify someone as having a *legal* disability based on relative discrepancies or presumptions of “potential” based on scores from psychological testing. Furthermore, the law discourages the practice of using norms based on other than the general population (e.g., college graduates or students in professional programs). According to the ADA, a student cannot be considered to have a disability simply because he or she is not quite as talented as other very talented individuals.

Several concrete implications for the assessment of impairment follow from these points. First, assessment measures with population norms should be strongly preferred to criterion-referenced test scores. Norm-referenced scores are calculated by comparing each examinee’s performance to that of other examinees. IQ scores, T-scores from rating scales, and percentile scores are common examples of scores that show a relative comparison to the average person. Criterion-referenced scores are calculated by comparing the examinee’s performance to an absolute standard, rather than to other examinees’ performance. For instance, many state exams in

K-12 education classify students using terms such as "proficient" and "advanced" depending on what percentage of items they answer correctly. These scores do not gauge an individual's scores to the performance of most people (Sax, 1997).

Second, these norms should be based on the general population (typically, age-norms are appropriate here) rather than being based on "clinical groups" (e.g., samples of students with ADHD) or high functioning groups (e.g., college graduates, law students). As Hopkins (1998) points out, the key to making confident norm-referenced score interpretations is a representative norm group. Individually administered tests of ability and achievement are known for their careful selection of participants for standardization samples, stratified by relevant demographic variables, and consequently representative of the population at large. A new trend has been the creation of norms for certain population subgroups (e.g., performance of medical school students on the Nelson Denny Reading Test). However, while these norms may serve certain clinical goals well, they cannot be used for disability determinations because they directly violate the average person standard.

Finally, the assessment of impairment should not be based solely on self-reported comparisons to others in a particular peer group since those peers often function much better than the average person in the general population. For example, a professor at Harvard Law School who describes a student as having academic trouble might be tantamount to an Olympics coach describing an athlete as "the worst on the team." It is unlikely that a Harvard Law School student or an Olympian would function poorly when compared to the average person. Evaluators should be aware that high-functioning individuals frequently report that they perform less well than peers. Lewandowski, Lovett, Codding, and Goddon (2008) found that a sizable proportion of typical college students perceived themselves as slower readers and poorer test takers than other students. Thus, there is something inherently natural, albeit inaccurate, about reporting relative deficiencies, even among groups of individuals who perform better than most people.

Many clinicians are unaware of the ADA's basic tenets on these points. For example, the survey by Gordon et al. (2002) documented that 43 % of clinicians wrongly endorsed the practice of determining impairment by comparing a student to others at "similar educational levels," and 36 % wrongly endorsed examining "students in a similar college or professional program" to establish a standard. Even more surprisingly, over 50 % of clinicians wrongly endorsed making a diagnosis of "reading disability" for a hypothetical student with an IQ of 135 and a reading score of 100 (perfectly average) under the ADA. Clearly, to the extent that clinicians examine impairment, many compare examinees with standards other than the "average person" standard of the ADA.

### 6.2.2 Significant Impairment and Major Life Activities Under the ADA

To be qualified as disabled under the ADA, an individual must be substantially limited in one or more "major life activities." To justify accommodations for individuals in higher education, clinicians often claim that the substantial limitations are present, but latent. Typically, the evaluator accounts for high academic or occupational functioning by claiming that the individual was only successful because of hard work or high intelligence. For example, a clinician might write, "Susan was able to adjust because she was so motivated to achieve and worked much harder than her classmates. Now that she is in graduate school, she requires accommodations because the work is becoming so demanding, and her learning disability/ADHD is causing her to perform below average in the class."

Claiming that a person can become disabled because of heightened academic demands is problematic. First, both LD and ADHD are developmental problems which should surface and cause impairment during childhood (12–14 years of age, at the latest). Generally, if an individual is able to cope with the academic and social demands of a high school education without substantial assistance, he or she is neuropsychologically intact and therefore unimpaired relative to most people. While the person may encounter future academic difficulties, those shortcomings are often better understood as the consequences of a mismatch between individual aptitude and the requirements of a challenging educational program or career choice. A reading disability, then, should not be first identified when a law student begins to struggle with comprehension of a law textbook. By stretching the age of onset for symptom presentation until young adulthood or later, clinicians risk distorting the concept of disability to include anyone who reaches an academic level that outstrips his or her particular array of talents. Conceivably, people can "develop" a disability simply by matriculating in educational programs for which they are poorly suited. Thus, clinical impairment resulting from a developmental disorder should be documented early and throughout one's educational life.

A second problem with the clinician's report on Susan is that "being a graduate student" is not likely to be considered a major life activity. "School" may be a major life activity in elementary and even high school, but in postsecondary settings, the classification is less obvious. In graduate or professional school, the "major life activity" designation is incorrect, considering how many individuals discontinue formal education by this point. Similarly, an assistant district attorney who develops problems concentrating and other symptoms of inattention after taking a job directing the homicide division of a large city's district attorney's office is unlikely to be considered to have a disability under the ADA since success in that particular position is not a major life activity.

A third problem often seen in evaluation reports involves the clinician's use of "hard work" as an explanation for successful function in spite of a disability. In truth, most of us have to work hard to succeed, especially as expectations and demands mount over time. Lewandowski et al. (2008) found that over 40 % of a large sample of nondisabled students at a private university felt they worked harder than peers to get good grades. Over half of the students reported having to read material over and over again to understand it. Finding life's challenges to be challenging makes no sense as a marker of disability. Using that metric would result in classifying most individuals as having a disability in some area of life.

Yet another problem with the report on Susan involves identifying her high intelligence as an explanation for the late onset of her symptoms. Clinicians often make the argument that a particular student warrants a disability classification because he or she does not perform as one would expect given his or her IQ score. The logic behind this assertion seems to require that IQ is a perfect predictor of academic outcome. Actually, research indicates that, although IQ is a moderately strong predictor of academic or occupational achievement (Mackintosh, 2011), the prediction is far from perfect. A high IQ is simply not a precise indicator of how well someone should perform on the job or in higher education. A bright person can underperform for a universe of reasons unrelated to disability, from poor educational experiences to uneven motivation. The evidence is clear that a diagnosis of a learning problem based on a discrepancy between IQ and achievement should not be sufficient to document a learning disability (as indicated in the revised diagnostic guidelines in DSM-5; American Psychiatric Association, 2013).

### 6.2.3 Reasonable Accommodations Under the ADA

If it is determined that an individual is indeed qualified as having a disability under the ADA, the next step is to identify reasonable accommodations. Those accommodations must be justified based upon two considerations: (a) the specific nature of the person's functional impairment; and (b) the educational, occupational, or testing environment in which that individual will be functioning. The evaluator must provide a rationale for any recommended accommodations by explaining how those adjustments or technological aids would cancel or ease the impact of the impairment on the task in question.

Accommodations are task-specific and intended to eliminate or reduce the impact of the impairment on a particular activity. Thus, an individual who must dictate test answers to a scribe because of a limitation in the ability to write would not require that accommodation on an oral examination. Likewise, an individual who, because of problems walking, requires a ramp to enter a building would not need additional time to complete assignments or examinations, at least based on that disability. In essence, there must be a demonstrated match between the disability and task requirements.

Assignment of a diagnostic label does not mean that the individual is automatically entitled to accommodations, even though students (and their advocates) sometimes request accommodations that are not directly related to the impairment. To give an example: Roger submits documentation to a testing agency certifying that he suffers from ulcerative colitis. First, he wants to be seated near the restroom because he may need to use it often during the course of the day. The test organization has no problem granting this request. But Roger also wants double the allotted time to take the examination. Here, the ADA administrator balks. What are the functional impairments associated with ulcerative colitis that would require extra time to work on the test? While off-the-clock breaks may be justified, it is hard to provide a rationale for extended time working on the test itself.

Another key concept in justifying accommodations relates back to the outcome-neutral nature of these anti-discrimination laws. Under the ADA, the explanation that someone "would benefit from" a particular accommodation is not sufficient. As we have repeatedly indicated, the intent of the law is not to help people succeed. This stance is eloquently described in an opinion by the Office of Civil Rights (OCR) in the Golden Gate University (CA) case in 1996. In this instance, a student claimed to have the right to accommodations so that he could achieve a certain grade. OCR responded thus:

> "[The student] appears to be of the misapprehension that the duty to provide academic adjustments includes a responsibility to provide such adjustments until a certain outcome is achieved, e.g., a grade of A. This is not what was contemplated by the OCR regulations. The objective is to create equal opportunity, not equal outcomes. Tests are modified to achieve greater validity, not higher grades. Indeed, the regulation implementing Section 504 explicitly states that services provided by recipients, 'to be equally effective, are not required to produce the identical result or level of achievement for disabled and nondisabled persons, but must afford disabled persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement.'" (National Disability Law Reporter, 1996, §12)

The focus of an accommodation request should therefore not be on what would help the individual to do better or to pass the exam or course requirements. Instead, the focus should be on which accommodations would correct or circumvent functional impairments that might otherwise preclude a fair opportunity to access a course or a test.

By implication, an ADA-based accommodation, because it is designed to correct a deficit, should not represent a general benefit to anyone in the same situation. Such an accommodation would constitute an unfair advantage rather than an accommodation specifically aimed at reducing the impact of a disability. For example, a handicapped-accessible door allows someone in a wheelchair to gain access to that building. The accommodation would neither help nor hinder most individuals who did not use wheelchairs. Even if individuals who fell outside of ADA's protection benefited from it, they are, importantly, not excluded from using it. Similarly, while large print on a paper exam would be an appropriate accommodation for an individual with poor eyesight, it would not be of substantial benefit to most nondisabled individuals. It might actually slow such individuals down because it would require extra page turning. These accommodations lead to what has been described as a "differential boost" (Fuchs & Fuchs, 2001) for the individual with a disability since in each case, the accommodation provides more of a "boost" to the test scores of individuals with the disability than to nondisabled examinees.

Strictly speaking, accommodations for ADHD should also meet the "differential boost" criterion. Most examinees who apply for accommodations based on this disorder request extra time. However, because most high stakes examinations are at least in part speeded, additional time would likely help anyone (see Lovett, 2010, for a review of evidence on this point). There are a variety of reasons why extra time may not be particularly helpful for ADHD, some of which follow from the impulsiveness that is the hallmark of this disorder (Barkley, 1997). For instance, many individuals with ADHD report that extra time would be of little use because they tend to complete tests too quickly, failing to make wise use of the allotted time for checking answers and ensuring accuracy (Murphy & Gordon, 1997).

That reasonable accommodations are designed to correct for impairment rather than to increase performance is often a difficult distinction to make in practice. Indeed, many clinicians may not even be aware of the principle, as evidenced by the survey by Gordon et al. (2002). In this survey, 29 % of clinicians agreed with the statement that the "purpose of accommodations is to allow an individual with a disability to perform at his or her best," which presumes that all performance (and testing) environments should be *optimal* environments.

### 6.2.4 A Note on the 2008 ADA Amendments

Our coverage of the ADA has reflected the current version of the law, which involves significant changes from when we wrote the corresponding chapter for the first edition of this book (Lovett, Gordon, & Lewandowski, 2009). In 2008, the U.S. Congress passed the ADA Amendments Act (ADAAA; also known as the ADA Restoration Act). The ADAAA was passed in response to the conservative interpretation of the original ADA of 1990 on the part of the U.S. Supreme Court and the Equal Employment Opportunity Commission (EEOC). For instance, the Supreme Court had ruled that if "mitigating factors" such as medications and technology aids kept someone from being substantially limited, that person was no longer disabled under the law. The ADAAA explicitly takes issue with these interpretations and designates different standards, among its other changes (Joiner, 2010; Rozalski, Katsiyannis, Ryan, Collins, & Stewart, 2010; Scott, 2010). However, the changes should not be overstated; key features of the original ADA, such as the average person and general population standards, are still intact. Again, the foregoing discussion of the ADA was revised to make it consistent with the current ADA, as amended in 2008. Still, readers may find it useful to be aware of the changes, especially if they examine documentation—or case law—from before the ADAAA was passed.

## 6.3 A Special Legal Issue in Assessment: Malingered Impairment

One additional legal issue in the assessment of impairment concerns malingering, defined in the DSM-5 as "the intentional production of false or grossly exaggerated physical or psychological symptoms, motivated by external incentives such as avoiding military duty, avoiding work, obtaining financial compensation, evading criminal prosecution, or obtaining drugs" (APA, 2013, p. 726). Malingering has long been recognized as a problem in medical assessment (e.g., Jones & Llewellyn, 1918). Its import in psychological assessment is seen in the "validity scales" of personality tests and the "effort tests" developed by neuropsychologists. In assessing impairment, clinicians must be alert to the possibility of malingering whenever an external incentive exists. Individuals seeking evaluations to justify accommodations based on high-incidence disorders (such as LD and ADHD) may want to look impaired because they would like to benefit from extra time on tests, the availability of academic support services, accommodations on the job, medications that act as performance boosters, etc.

Technically, malingering is only one of a set of related threats to validity. Some clients may exaggerate their symptoms without consciously malingering (as when a client seeks attention). They may also simply put forth poor effort on cognitive and achievement measures due to apathy, boredom, or noncompliance. They may similarly exaggerate symptoms for a variety of reasons. Indeed, the DSM conceptualization of malingering is problematically narrow (Berry & Nelson, 2010). We use "malingering" as shorthand for this set of problems although we acknowledge that malingering, symptom exaggeration, and poor effort are distinct (if related) issues (Iverson, 2006).

Of the non-forensic subspecialties within the clinical realm, clinical neuropsychology has been most aware of the threat of malingering. In 2005, the National Academy of Neuropsychology issued a position paper (Bush et al., 2005) acknowledging that "Symptom exaggeration or fabrication occurs in a sizeable minority of neuropsychological examinations" (p. 419). The position paper insists that, "In order to place maximal confidence in the ability to interpret accurately results from cognitive measures and/or tests of personality or mood, a determination must be made that the examinee put forth appropriate effort on tasks and responded honestly to questions" (p. 421). Two years later, the American Academy of Clinical Neuropsychology, in their Practice Guidelines for Neuropsychological Assessment and Consultation (Board of Directors, 2007), were more specific. They recommended that "Clinicians utilize multiple indicators of effort, including *tasks and paradigms validated for this purpose*" (p. 222, emphasis added). Unfortunately, in other areas of clinical, counseling, and school psychology, these issues are not given much attention. The default assumption seems to be that clients are putting forth adequate effort and honestly reporting their symptoms and impairment under all circumstances. Clinicians even assert that they can use their clinical judgment to detect malingering and low motivation, despite research suggesting otherwise (e.g., Faust, Hart, Guilmette, & Arkes, 1988).

In the case of ADHD, only in the past decade or so has research established that many individuals being assessed for possible ADHD may be exaggerating their symptoms to some degree (e.g., Sullivan, May, & Galbally, 2007). Most ADHD rating scales make it easy to malinger for anyone with even a passing acquaintance with the symptoms of the disorder (Jachimowicz & Geiselman, 2004). In one recent study, Harrison, Edwards, and Parker (2007) compared university students who were asked to put forth full effort on a battery of tests with students who were asked to try to simulate symptoms of ADHD in an attempt to obtain a variety of accommodations. Both groups were then compared with a sample of students from the same university who had validated diagnoses of ADHD. The simulators exhibited performances closer to the legitimate ADHD group than to the other nondisabled students. A discriminant function analysis incorrectly classified over one third of the simulators as being in the ADHD group.

Until recently, most of the malingering literature has focused on more severe neuropsychological problems, especially traumatic brain injury (TBI; see e.g., Green, Rohling, Lees-Haley, & Allen, 2001). However, the concept clearly applies in any test or evaluative situation in which less than optimal effort can produce a desirable outcome. Recent research on learning disability assessments suggest that they exhibit a vulnerability to malingering similar to that of ADHD assessments although fewer examinees may attempt to malinger. Sullivan et al. (2007) used the Word Memory Test (WMT) to examine possible malingering in a sample of college students being assessed for LD/ADHD conditions. The WMT is a measure designed to detect malingering. It uses recognition measures of memory for paired-associate stimuli (e.g., dog/cat) that almost all cognitively intact, literate adults could manage quite well. Based on the number of students who "failed" the WMT, Sullivan and colleagues estimated that 25 % of students being assessed for comorbid LD-ADHD were exaggerating symptoms. A remarkable 48 % of students assessed solely for ADHD were found to exaggerate their symptoms.

To assess for possible malingering when examining impairment, clinicians should consider administering tests that have been shown to be easier for individuals with actual impairment than for those feigning impairment. The WMT meets this criterion for neuropsychological problems. For dyslexia, an even more specific test, the Word Reading Test, has been shown to effectively detect malingering (Osmon, Plambeck, Klein, & Mano, 2006). For schizophrenia and other psychiatric problems, a variety of personality test indices that have been shown detect malingering (Berry, Baer, Rinaldo, & Wetter, 2002). There are even effort tests to detect low effort in individuals being assessed for chronic pain disorders (Suhr & Spickard, 2007).

Finally, we note that a growing body of research is emerging on malingering and poor effort in children and adolescents, and on the utility of special tests to assess effort and symptom validity in this population (DeRight & Carone, 2015). In sum, psychologists and other professionals should be aware of these threats to validity when assessing impairment in both children and adults, and at least outside of neuropsychology, there is certainly a need for more education and training regarding this issue.

## 6.4 Conclusions

In this chapter, we have reviewed issues pertinent to the evaluation of disability status within a legal context. We have emphasized how laws such as the ADA have set standards that can be at odds with practices common to clinical and educational settings. At the heart of that tension are contrasting conceptions for what constitutes a disability or disorder. The legal standard hinges on the notion that an individual is disabled only if he or she is substantially impaired in a major life activity relative to the average person. Also, the ADA and its predecessors were designed to combat discrimination, not ensure a successful outcome. Clinicians, on the other hand, operate in a world where the lines are drawn less boldly. It is more common in such circumstances to identify a disorder even in the absence of absolute abnormality relative to most people. Clinicians are more apt to make diagnoses and recommend accommodations to help a client on the path to *success*, rather than to gain mere *access*.

While legal and clinical approaches to the identification of disability/disorder can collide, we conclude by wondering if clinicians might learn something from the standards of the legal world. The legal emphasis on impairment is consistent with the spirit of the frequently mentioned clinical criteria of dysfunction and disability when defining psychopathology (e.g., Maddux, Gosselin, & Winstead, 2012). Similarly, the educational reform movement known as Response-to-Intervention (RTI; Hughes & Dexter, 2011) also implicitly defines abnormality as impairment—a failure to acquire appropriate levels of important academic and social–behavioral skills (despite exposure to appropriate instruction and intervention)—rather than focusing on within-person discrepancies and skill profiles. One cannot help but wonder whether the clear lines established in a legal context are not appropriate for clinical settings. In refusing to lower thresholds for what constitutes a disability, courts aim to limit special protections to those who are truly impaired. That stance, while disheartening to some, has a basis in much clinical literature, and represents a reasonable effort at defining disability in ways that are most protective of those who are most in need.

## References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Americans with Disabilities Act Amendments Act, Pub. L. 110–325. (2008).

Barkley, R. A. (1997). Behavioral inhibition, sustained attention, and executive functions: Constructing a unified theory of ADHD. *Psychological Bulletin, 121*, 65–94.

Berry, D. T. R., Baer, R. A., Rinaldo, J. C., & Wetter, M. W. (2002). Assessment of malingering. In J. N. Butcher (Ed.), *Clinical personality assessment: Practical approaches* (2nd ed., pp. 269–302). New York: Oxford University Press.

Berry, D. T., & Nelson, N. W. (2010). DSM-5 and malingering: A modest proposal. *Psychological Injury and Law, 3*(4), 295–303.

Bush, S. S., Ruff, R. M., Tröster, A. I., Barth, J. T., Koffler, S. P., Pliskin, N. H., et al. (2005). Symptom validity assessment: Practice issues and medical necessity. *Archives of Clinical Neuropsychology, 20*, 419–426.

Chafetz, M. D., & Biondolillo, A. (2012). Validity issues in Atkins death cases. *The Clinical Neuropsychologist, 26*, 1358–1376.

DeRight, J., & Carone, D. A. (2015). Assessment of effort in children: A systematic review. *Child Neuropsychology, 21*(1), 1–24. doi:10.1080/09297049.2013.864383.

Drogin, E. Y., Dattilio, F. M., Sadoff, R. L., & Gutheil, T. G. (2011). *Handbook of forensic assessment: Psychological and psychiatric perspectives*. Hoboken, NJ: Wiley.

Faust, D., Hart, K. J., Guilmette, T. J., & Arkes, H. R. (1988). Neuropsychologists' capacity to detect adolescent malingerers. *Professional Psychology: Research and Practice, 19*(5), 508.

Fuchs, L., & Fuchs, D. (2001). Helping teachers formulate sound test accommodation decisions for students with learning disabilities. *Learning Disabilities Research & Practice, 16*, 174–181.

Gordon, M., Lewandowski, L., Murphy, K., & Dempsey, K. (2002). ADA-based accommodations in higher education: A survey of clinicians about documentation requirements and diagnostic standards. *Journal of Learning Disabilities, 35*, 357–363.

Green, P., Rohling, M. L., Lees-Haley, P. R., & Allen, L. M., III. (2001). Effort has a greater effect on test scores than severe brain injury in compensation claimants. *Brain Injury, 15*, 1045–1060.

Harrison, A. G., Edwards, M. J., & Parker, K. C. H. (2007). Identifying students faking ADHD: Preliminary findings and strategies for detection. *Archives of Clinical Neuropsychology, 22*, 577–588.

Harrison, A. G., Lovett, B. J., & Gordon, M. (2013). Documenting disabilities in postsecondary settings: Diagnosticians' understanding of legal regulations and diagnostic standards. *Canadian Journal of School Psychology, 28*, 303–322.

Hess, F. M., & Petrilli, M. J. (2006). *No child left behind primer*. New York: Peter Lang.

Hopkins, K. D. (1998). *Educational and psychological measurement and evaluation* (8th ed.). Boston, MA: Allyn & Bacon.

Hughes, C. A., & Dexter, D. D. (2011). Response to intervention: A research-based summary. *Theory Into Practice, 50*(1), 4–11.

Iverson, G. L. (2006). Ethical issues associated with the assessment of exaggeration, poor effort, and malingering. *Applied Neuropsychology, 13*(2), 77–90.

Jachimowicz, G., & Geiselman, R. E. (2004). Comparison of ease of falsification of attention deficit hyperactivity disorder diagnosis using standard behavioral rating scales. *Cognitive Science Online, 2*, 6–20.

Joiner, A. M. (2010). The ADAAA: Opening the floodgates. *San Diego Law Review, 47*(2), 331–370.

Jones, A. B., & Llewellyn, L. J. (1918). *Malingering, or the simulation of disease*. Philadelphia, PA: Blakiston's.

Latham, P. S., Latham, P. H., & Mandlawitz, M. R. (2008). *Special education law*. Boston: Pearson.

Lewandowski, L. J., Lovett, B. J., Codding, R. S., & Goddon, M. (2008). Symptoms of ADHD and academic concerns in college students with and without ADHD diagnoses. *Journal of Attention Disorders, 12*, 156–161.

Lovett, B. J. (2010). Extended time testing accommodations for students with disabilities: Answers to five fundamental questions. *Review of Educational Research, 80*, 611–638.

Lovett, B. J., Gordon, M., & Lewandowski, L. J. (2009). Measuring impairment in disability evaluations: Legal and ethical issues. In S. Goldstein & J. Naglieri (Eds.), *Assessment of impairment: From theory to practice* (pp. 93–103). New York: Springer.

Lovett, B. J., & Lewandowski, L. J. (2015). *Testing accommodations for students with disabilities: Research-based practice*. Washington, DC: American Psychological Association.

Mackintosh, N. J. (2011). *IQ and human intelligence* (2nd ed.). New York: Oxford University Press.

Maddux, J. E., Gosselin, J. T., & Winstead, B. A. (2012). Conceptions of psychopathology: A social constructionist perspective. In J. E. Maddux & B. A. Winstead (Eds.), *Psychopathology: Foundations for a contemporary understanding* (3rd ed., pp. 3–22). New York: Routledge.

McNally, R. J., & Frueh, B. C. (2012). Why we should worry about malingering in the VA system: Comment on Jackson et al. (2011). *Journal of Traumatic Stress, 25*, 454–456.

Murphy, K., & Gordon, M. (1997). ADHD as a basis for test accommodations: A primer for clinicians. *The ADHD Report, 5*(1), 10–11.

National Disability Law Reporter (1996, July 10). Golden Gate University (CA) Complaint No. 09-96-2088. *National Disability Law Reporter, 9*, 182ff.

Office of Special Education Programs. (1995). *Letter to Lillie/Felton*. Retrieved from http://www.wrightslaw.com/info/elig.sld.osep.felton.htm

Osmon, D. C., Plambeck, E. A., Klein, L., & Mano, Q. (2006). The Word Reading Test of effort in adult learning disability: A simulation study. *The Clinical Neuropsychologist, 20*, 315–324.

Rozalski, M., Katsiyannis, A., Ryan, J., Collins, T., & Stewart, A. (2010). Americans with Disabilities Act Amendments of 2008. *Journal of Disability Policy Studies, 21*(1), 22–28.

Sax, G. (1997). *Principles of educational and psychological measurement and evaluation* (4th ed.). Belmont, CA: Wadsworth.

Scott, C. L. (2010). The Americans with Disabilities Act Amendments Act of 2008: Implications for the forensic psychiatrist. *Journal of the American Academy of Psychiatry and the Law, 38*(1), 95–99.

Suhr, J., & Spickard, B. (2007). Including measures of effort in neuropsychological assessment of pain- and fatigue-related medical disorders. In K. B. Boone (Ed.), *Assessment of feigned cognitive impairment: A neuropsychological perspective* (pp. 259–280). New York: Guilford.

Sullivan, B. K., May, K., & Galbally, L. (2007). Symptom exaggeration by college adults in attention-deficit hyperactivity disorder and learning disorder assessments. *Applied Neuropsychology, 14*, 189–207.

Yell, M. L. (2012). *The law and special education* (3rd ed.). Upper Saddle River, NJ: Pearson.

Zirkel, P. A., & Thomas, L. B. (2010). State laws for RTI: An updated snapshot. *Teaching Exceptional Children, 42*(3), 56–63.

# The Medical Model of Impairment

# 7

Norma Leclair, Steven Leclair, and Christopher R. Brigham

## 7.1 Introduction

The principal medical model of impairment is the American Medical Association's (AMA's) *Guides to the Evaluation of Permanent Impairment* (2008). The sixth edition, published in December 2008, introduced new approaches to rating impairment, using methodology designed to enhance the relevancy of impairment ratings, improve internal consistency, promote greater precision, and simplify the rating process. The approach is based on a modification of the conceptual framework of the *International Classification of Functioning, Disability, and Health* [*ICF*] (World Health Organization, 2001), although the fundamental principles underlying the guides remain unchanged. In this chapter, we review the medical approach to assessing impairment, with focus on the underlying methodology and the evaluation of pain, nervous system, and mental and behavioral impairment.

## 7.2 Use of the Guides

The AMA *Guides to the Evaluation of Permanent Impairment* (2008) is used to define *impairment*, which is defined as "a significant deviation, loss, or loss of use of any body structure or function in an individual with a health condition, disorder or disease" (p. 5). The guides provide the basis for defining impairment in the vast majority of workers' compensation jurisdictions, and the use of the most recent edition will be required immediately by certain state jurisdictions and for Federal

---

N. Leclair, R.N., Ph.D. (✉) • S. Leclair, Ph.D., C.R.C.
Leclair Behavioral Health, 9 Callaway Drive, Gray, ME 04039, USA
e-mail: Normaleclair@me.com; Steveleclair@me.com

C.R. Brigham, M.D.
Brigham and Associates, Inc., 6 Golden Hind Drive, Hilton Head, SC 29926, USA
e-mail: cbrigham@cbrigham.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_7

and Longshore and Harbor Workers Act cases. The guides' impairment ratings are used in different ways, depending on the type of case and the jurisdiction.

Although impairment is a different concept from disability, some jurisdictions use impairment as a proxy for the latter, while others use the impairment-rating value in a formula that results in a disability rating.

The guides started in 1958 with publication by the AMA of the article, "A Guide to the Evaluation of Permanent Impairment of the Extremities and Back." This was followed by additional guides published in the *Journal of the American Medical Association*. In 1971, a compendium of 13 guides became the first edition (AMA, 1971). Thirteen years later in 1984, the second edition was published (AMA, 1984), and it provided numerical impairments for mental and behavioral impairments. Subsequent editions omitted numerical mental and behavioral ratings until the most current sixth edition.

## 7.3 Challenges and Criticisms of Prior Editions

There are many challenges associated with the use of the guides, including criticisms of the guides themselves, the use of impairment-rating numbers, and a high error rate (Burd, 1980; Clark et al., 1988; Hinderer, Rondinelli, & Katz, 2000; Pryor, 1990; Rondinelli et al., 1997; Rondinelli & Duncan, 2000; Rondinelli & Katz, 2002; Spieler, Barth, Burton, Himmelstein, & Rudolph, 2000). Previous criticisms include

Failure to provide a comprehensive, valid, reliable, unbiased, and evidence-based rating system.
Impairment ratings did not adequately or accurately reflect loss of function.
Numerical ratings were more the representation of "legal fiction than medical reality."

Therefore, the following changes were recommended:

Standardize assessment of activities of daily living (ADL) limitations associated with physical impairments.
Apply functional assessment tools to validate impairment-rating scales.
Include measures of functional loss in the impairment rating.
Improve overall intrarater and interrater reliability and internal consistency.

Studies have demonstrated poor interrater reliability and revealed that most impairment ratings are incorrect, more often rated significantly higher than appropriate (Brigham, Uejo, Dilbeck, & Walker, 2006). While treating physicians, who by definition are advocates for their patients, have been particularly prone to overrate impairment, physicians who have not been adequately trained in the use of the guides also commonly provide similarly erroneous ratings.

## 7.4 Sixth Edition Approaches and Developmental Process

The guides define the process for evaluating impairment. Clinical discussions among physician colleagues regarding potential severity of an illness or injury typically involve four basic points of consideration:

What is the problem (diagnosis)?
What symptoms and resulting functional difficulty do the patient report?
What are the physical findings pertaining to the problem?
What are the results of clinical studies?

In a similar manner, these same basic considerations are used by the physicians to evaluate and communicate about impairment, although given the use of ratings as the basis for monetary awards, physicians are always cognizant of the need to be certain that subjective and other objectively nonquantifiable aspects of the clinical presentation are consistent with both the diagnosis and the patient's objective findings. The sixth edition (AMA, 2008) expands the spectrum of diagnoses recognized in impairment rating, considers functional consequences of the impairment as a part of each physician's detailed history, refines the physical examination, and clarifies appropriate clinical testing.

### 7.4.1 International Classification of Functioning, Disability, and Health

The sixth edition of the guides (AMA, 2008) uses the framework based on the *ICF*, a comprehensive model of disablement developed by the World Health Organization. This framework, illustrated in Fig. 7.1, is intended for describing and measuring health and disability at the individual and population levels. The *ICF* is a classification of health and health-related domains that describe body functions and structures, activities, and participation. The domains are classified from body, individual, and societal perspectives. The *ICF* systematically groups different domains for a person in a given health condition (e.g., what a person with a disease or disorder does do or can do). *Functioning* is an umbrella term encompassing all body functions, activities, and participation; similarly, *disability* serves as an umbrella term for impairments, activity limitations, or participation restrictions. Since an individual's functioning and disability occur in a context, the *ICF* also includes a list of environmental factors.

The following definitions are presented in the guides (AMA, 2008) and are used in the *ICF* to facilitate communications and standardization:

*Body functions*: Physiological functions of body systems (including psychological functions)
*Body structures*: Anatomic parts of the body such as organs, limbs, and their components

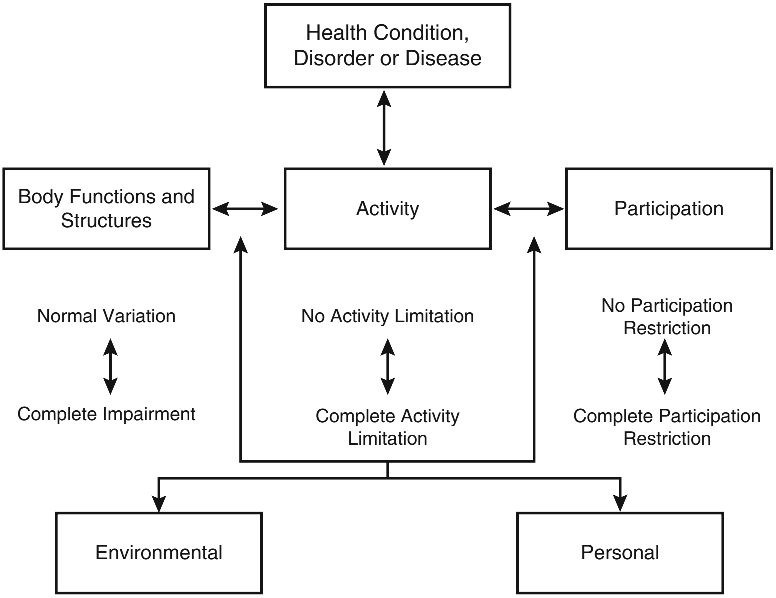


**Fig. 7.1** International Classification of Functioning, Disability, and Health (ICF) model of disablement

*Activity*: Execution of a task or action by an individual
*Participation*: Involvement in a life situation
*Impairments*: Problems in body function or structure such as a significant deviation or loss
*Activity limitations*: Difficulties an individual may have in executing activities
*Participation restrictions*: Problems an individual may experience in involvement in life situations

The *ICF* model reflects the dynamic interactions between an individual with a given health condition, the environment, and personal factors. Impairment, activity limitations, and limitations in participation are not synonymous; an individual may have impairment and significant limitations in most activities but be able to participate in a specific life situation of relevance, minor impairment and activity limitations with inability to participate in a specific life situation, or any permutation of these three factors.

Use of the *ICF* model does not indicate that the guides (AMA, 2008) will now be assessing disability rather than impairment. Rather, the incorporation of certain aspects of the *ICF* model into the impairment-rating process reflects efforts to place the impairment rating into a structure that promotes integration with the *ICF* constructs for activity limitations and limitations in participation, ultimately enhancing its applicability to situations in which the impairment rating is one component of the "disability evaluation process."

### 7.4.2 Impairment Classes and Diagnosis-Based Grids

The *ICF* classification uses five impairment classes, which permits rating of patients who range from having no problems to having significant problems. In the sixth edition of the guides (AMA, 2008), "diagnosis-based grids" were developed for each organ system. These grids use commonly accepted consensus-based criteria to classify most diagnoses relevant to a particular organ or body part into five classes of impairment severity ranging from Class 0, normal, to Class 5, very severe.

The final impairment is determined by adjusting the initial impairment rating given by factors that may include physical findings, the results of clinical tests, and functional reports by the patient. The basic template of the diagnosis-based grid is common to each organ system and chapter; therefore, although there is variation in the ancillary factors used to develop the impairment rating (depending on the body part), there is greater internal consistency between chapters than was seen formerly.

The preface to the sixth edition (AMA, 2008) states that the features of the new edition include

> A standardized approach across organ systems and chapters.
> The most contemporary evidence-based concepts and terminology of disablement from the ICF.
> The latest scientific research and evolving medical opinions provided by nationally and internationally recognized experts.
> Unified methodology that helps physicians calculate impairment ratings through a grid construct and promotes consistent scoring of impairment ratings.
> A more comprehensive and expanded diagnostic approach. Precise documentation of functional outcomes, physical findings, and clinical test results, as modifiers of impairment severity.
> Increased transparency and precision of the impairment ratings.
> Improved physician interrater reliability (p. iii).

The sixth edition (AMA, 2008) reflects movement toward these features; however, such change is not immediately achieved. Thus, it should be considered a step in the evolution of the guides rather than an end point in and of itself.

### 7.4.3 Development Process

The sixth edition (AMA, 2008) process involved many participants—including physicians who use the guides and the staff of the AMA, all of whom were tasked to develop the sixth edition in the context of the aforementioned principles. The process was guided by an editorial panel and an advisory committee and involved a tiered peer review process. The editorial process used an evidence-based foundation when possible, primarily as the basis for determining diagnostic criteria, and a Delphi panel approach to consensus building regarding the impairment ratings themselves. When there was not a compelling rationale to alter impairment ratings from what they had been previously, consistency of the ratings with those provided in prior editions was the default. An advisory committee was developed to provide ongoing discussion of items of mutual concern and current issues in impairment and disability.

## 7.5 Sixth Edition Structure

The sixth edition of the guides (AMA, 2008) is 634 pages long (the fifth edition was 613 pages; AMA, 2001) and comprises 17 chapters. Chapter 1, "Conceptual Foundations and Philosophy," and Chap. 2, "Practical Applications of the Guides," define the overall approaches to assessing impairment. Chapters 3 to 17 provide approaches for assessment of specific impairments, including Chap. 3, "Pain-Related Impairment"; Chap. 13, "The Central and Peripheral Nervous System"; and Chap. 14, "Mental and Behavioral Disorders."

### 7.5.1 Chapter 1:"Conceptual Foundations and Philosophy"

The sixth edition of the guides commences with section 1.1, "History of the Guides" (AMA, 2008, pp. 1–2), and describes a history of compensation for personal injury and disability that dates to antiquity. Section 1.2, "New Direction for the Sixth Edition" (p. 3), presents previous criticisms of the guides and five new axioms of the sixth edition, which include

The guides adopt the terminology and conceptual framework of disablement as put forward by the International Classification of Functioning, Disability, and Health (ICF).
The guides become more diagnosis based with these diagnoses being evidence based when possible.
Simplicity, ease-of-application, and following precedent, where applicable, are given high priority, with the goal of optimizing interrater and intrarater reliability.
Rating percentages derived according to the guides are functionally based, to the fullest practical extent possible.
The guides stress conceptual and methodological congruity within and between organ system ratings.

The contemporary model of disablement adopted by the sixth edition is the *ICF*, as explained in section 1.3 (AMA, 2008, pp. 3–6). The former model of disablement previously relied on the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) presented by the World Health Organization more than a quarter century ago. This approach was a simplistic model providing a unidirectional depiction of the relationship among pathology, impairment, disability, and handicap without recognizing the dynamic relationships among these factors or the role of important personal and environmental modifiers.

The sixth edition defines *impairment* as “a significant deviation, loss, or loss of use of any body structure or body function in an individual with a health condition, disorder, or disease” (AMA, 2008, p. 5). This is more refined than the definition in the fifth edition, which was “a loss, lose of use, or derangement of any body part, organ system, or organ function” (AMA, 2001, p. 601); the sixth edition includes the term *significant* and then adds the phrase “in an individual with a health condition, disorder, or disease.” *Disability* is defined as “activity limitations and/or participation restrictions in an individual with a health condition, disorder, or disease” (AMA, 2008, p. 5) reflective of the *ICF* terminology. The fifth edition definition of disability was “alteration of an individual’s capacity to meet personal, social or occupational demands, or statutory or regulatory requirements because of an impairment” (AMA, 2001, p. 600).

Impairment rating is a physician-provided process that attempts to link impairment with functional loss and continues to be defined as a “consensus-derived percentage estimate of loss of activity reflecting severity for a given health condition, and the degree of associated limitations in terms of activities of daily living (ADLs)” (AMA, 2008, p. 5). The sixth edition differs in stressing the importance of causation assessment in performing a rating as it is first necessary to determine if the health condition is related to an allegedly causal event or exposure. This represents a concerted attempt to prevent, or at least reduce, the common error of including factors that are not causally related to an injury in the rating (for example, rating spinal degenerative disease not caused by an injury).

Since impairment ratings may be used inappropriately as a direct correlate of disability, the sixth edition addresses this issue by explaining

> The relationship between impairment and disability remains both complex and difficult, if not impossible, to predict. In some conditions there is a strong association between level of injury and the degree of functional loss expected in one’s personal sphere of activity (mobility and ADLs). The same level of injury is in no way predictive of an affected individual’s ability to participate in major life functions (including work) when appropriate motivation, technology, and sufficient accommodations are available. Disability may be influenced by physical, psychological, and psychosocial factors that can change over time. (AMA, 2008, pp. 5–6)

The sixth edition specifically states, as did prior editions, “the *Guides* is not intended to be used for direct estimates of work participation restrictions. Impairment percentages derived according to the *Guides* criteria do not directly measure work participation restrictions” (AMA, 2008, p. 6). Instead, it stresses that “the intent of the *Guides* is to develop standardized impairment ratings which involves defining the diagnosis and associated loss at maximum medical improvement, enabling a patient with an impairment rating to exit from a system of temporary disablement, and provide diagnosis and taxonomic classification of impairment as a segue into other systems of long-term disability”( p. 6). In other words, the process of assigning an impairment rating requires the evaluator to clearly delineate the diagnostic criteria (based on the history, including prior clinical course), physical examination findings, current and prior diagnostic test results, and functional status that places

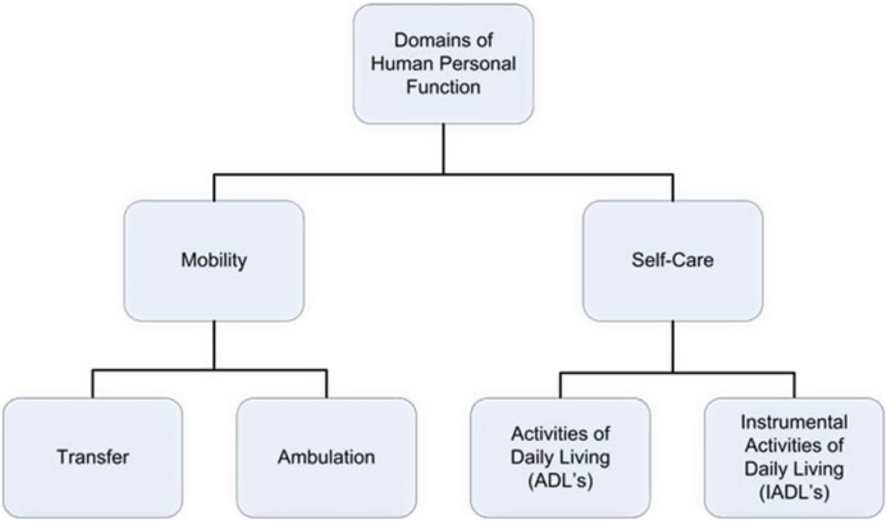


**Fig. 7.2** Domains of personal function

the patient in a given impairment class and warrants assignment of a specific number within the options for that class, with the understanding that the provision of an impairment rating does not directly equate to a permanent disability rating.

As assessment of the functional ramifications of a given diagnosis is used in assigning (or modifying) impairment ratings, the sixth edition (AMA, 2008) facilitates consideration of relevant factors by defining two domains of human personal function: mobility and self-care (illustrated in Fig. 7.2). This definition is new to the guides.

Mobility involves transfer (movement of one's body position while remaining at the same point in space) and ambulation (movement of one's body from one point in space to another). The sixth edition (AMA, 2008) differentiates ADLs that relate to self-care performed in one's personal sphere (e.g., bathing and showering, bowel and bladder management, dressing, eating, feeding, functional mobility, personal device care, personal hygiene and grooming, sexual activity, sleep/rest, and toilet hygiene) and "instrumented" ADLs that are complex self-care activities (e.g., financial management, medications, meal preparation), which may be delegated to others. Mobility and self-care activities may be performed independently or may require adaptive aids or helper assistance. The highest level of independence with which a given activity is consistently and safely performed is considered the functional level for that individual. This concept is critically important since function is a modifier of impairment in the sixth edition. It is therefore important that raters be more precise in asking questions (or using questionnaires) to assess the ability to perform activities relevant to an overall assessment of function.

Measurement issues are important factors in defining impairment and are discussed in section 1.4 (AMA, 2008, pp. 6–8). Previous studies examining the validity of musculoskeletal impairment ratings have revealed equivocal results between impairment rating and functional losses. The guides attempt to balance science and clinical judgment, as explained in section 1.5 (pp. 8–9). Impairment ratings continue to be based largely on consensus and expert opinion since there is not yet adequate methodology or data to relate these ratings to functional loss. The validity of impairment percentages defined in the sixth edition must await further empirical testing. As much as possible, the approaches in the sixth edition focus on simplicity and brevity (p. 9), although finding an appropriate balance between these goals and providing the information (often complex) required to increase the accuracy and reliability remains difficult.

The sixth edition provides greater weight to functional assessment than prior editions. The full impact of this approach is yet to be determined. Section 1.7 (AMA, 2008, pp. 9–11) discusses earlier approaches that have worked well (such as the New York Heart Association classification). Guidance is then provided on the use of self-report assessment tools and the need for empirical validation through in-office applications. The rating physician is to consider all available information; however, there is a clear mandate to evaluate the reliability of the information presented. The guides note that patients may underreport or overreport their difficulties. As the guides are often used in workers' compensation cases and other litigation settings as the basis for monetary awards, overreporting severity of problems is a common challenge. Therefore, the sixth edition states that "examiners must exercise their ability to observe the patient perform certain functional tasks to help determine if self-report is accurate" (p. 10). In other words, if the examinee reports loss of certain abilities on a questionnaire or during the clinical interview, the examiner should observe the patient to see if these losses are consistent with the physical examination, diagnostic tests, or functional limitations that are "usually" associated with a given disorder. Inconsistent and invalid data should not be used to define impairment. The use of functional assessment tools varies by chapter.

Section 1.8, "The Need for Internal Consistency and a Uniform Template" (AMA, 2008, p. 11–16), explains the process used to develop a generic template for impairment grids that could be used across various organ systems to enhance uniformity and consistency. The five-scale *ICF* taxonomy used by the guides is provided in Table 7.1.

Impairment percentage ranges are provided for each class; the impairment values are dependent on the organ system and structure. Diagnosis and other historical or clinical information typically serve as the key factor used to place a patient within a

**Table 7.1** Five-scale *ICF* taxonomy

| Class | Description |
|---|---|
| 1 | No problem |
| 2 | Mild problem |
| 3 | Moderate problem |
| 4 | Severe problem |
| 5 | Complete (very severe) problem |

*ICF* International Classification of Functioning, Disability, and Health

**Table 7.2** Diagnosis-based grid template

| Diagnostic criteria | Class 0 | Class 1 | Class 2 | Class 3 | Class 4 |
|---|---|---|---|---|---|
| Ranges | 0 % | Minimal % | Moderate % | Severe % | Very severe % |
| Grade | | A B C D E | A B C D E | A B C D E | A B C D E |
| History | No problem | Mild problem | Moderate problem | Severe problem | Very severe problem |
| Physical Findings | No problem | Mild problem | Moderate problem | Severe problem | Very severe problem |
| Test Results | No problem | Mild problem | Moderate problem | Severe problem | Very severe problem |

specific class, although there are some exceptions. Each class is associated with a corresponding range of available impairment ratings, typically defined into five impairment grades (A to E), with the midrange grade (C) serving as the default value. The grade may be modified by nonkey findings, which may include functional history, physical examination findings, and the results of clinical studies. Whether this modification occurs depends on whether these factors fall into the same class as did the initial key factor.

The structure of a typical diagnosis-based grid is presented in Table 7.2. Not all chapters use the same key factors, and some chapters use information other than the physical examination, test results, and functional limitations in assigning a specific rating (e.g., the endocrine chapter considers burden of treatment compliance) (AMA, 2008). Nonetheless, the system used in the sixth edition represents a dramatic change from prior editions, especially with regard to the non-musculoskeletal chapters, as the classes previously were listed as ranges of impairment ratings with little or no specific guidance given regarding how to choose a discrete numerical value to reflect a patient's impairment. This significantly contributed to the lack of interrater (and even intrarater) reliability seen with use of prior editions. This new method should improve interrater reliability. The generic system used as the basis for most of the non-musculoskeletal chapters, which was modified for use in rating the extremities and spine, is presented in Table 7.2, above.

Once the history is used to place a patient into a given impairment class (at the default level of Grade C), the class ratings for other relevant factors (which will differ between body parts or organ systems) will be used to shift the rating to a higher or lower grade. The degree to which this occurs will ordinarily be based on the number of classes by which the additional factor is classified as representing a higher or lower impairment than the key factor. For example, if the history is the key factor and places an individual in Class 2, Class 1 physical findings (one below the originally assigned class) will shift the rating down to Grade B, and then with Class 4 test results (two above the original class), a net change of + 1 (−1 + 2) results in a final rating in Class 2 of Grade D.

### 7.5.2 Chapter 2: "Practical Application of the Guides"

Chapter 2 outlines the key concepts, principles, and rationale underlying the application of the guides (AMA, 2008); therefore, it is essential that all participants understand this content. With prior editions, erroneous ratings often occurred as a result of physicians failing to follow rules defined in Chap. 2. Fourteen fundamental principles are defined, and many of these principles have a significant impact on the rating process. These principles are summarized in Table 7.3.

The wide use of the guides in workers' compensation and other disability systems is discussed in section 2.1 (AMA, 2008, pp. 20–21), with section 2.2 (pp. 21–23) explaining the concept of the whole-body approach to impairment ratings. Although most ratings are provided as whole-person permanent impairments, some jurisdictions require regional impairment values, and these continue to be supplied to serve the needs of these jurisdictions. The hierarchical relationship of extremity ratings to whole-person ratings remains with total loss of the upper extremity equaling 60 % whole-person permanent impairment and total loss of the lower extremity equaling 40 % whole-person permanent impairment. The approach to combining impairment values using the Combined Values Chart remains the same; however, specific guidance is now provided for circumstances when multiple impairments are combined, with it stated that the largest values must be combined first. This is consistent with

**Table 7.3** Summary of fundamental principles

| |
|---|
| Chapter 2 preempts everything in subsequent chapters that conflicts with or compromises the principles |
| No impairment may exceed 100 % whole-person permanent impairment nor may impairment extend the maximum assigned to an organ or extremity |
| All regional impairments are combined at the same level first and then regional impairments are combined at the whole-person level |
| Impairments must be rated per the chapter relevant to the organ or system where the injury primarily arose or where the greatest dysfunction remains |
| Only permanent impairment may be rated and only after maximum medical improvement is certified |
| A licensed physician must perform impairment evaluations |
| Valid impairment evaluation report must contain the three-step approach of clinical evaluation, analysis of findings, and discussion of how the impairment rating was calculated |
| The evaluating physician must use knowledge, skill, and ability generally accepted by the medical scientific community when evaluating an individual, to arrive at the correct impairment rating |
| The *Guides* are based on objective criteria and if findings conflict with established medical principles they cannot be used to justify an impairment rating |
| Motion and strength determinations should be assessed carefully for self-inhibition |
| Ratings of future impairment are not provided |
| If there is more than one method to define impairment, the method producing the higher rating must be used |
| Subjective complaints alone are generally not ratable |
| Impairment ratings are rounded to the nearest whole number |

*Source*: Based on AMA (2008), Table 2.1

the approach used in the California Schedule for Rating Permanent Disabilities, January (2005); however, it is a change from directives provided in the fifth edition in Chap. 16, "The Upper Extremities, in Section 16.1c Combining Impairment Ratings" (AMA, 2001, p. 438). Duplication or inflation of a rating by combining ratings that rely on a similar underlying factor is not permissible and is avoided by careful consideration of the underlying pathophysiology.

The use of the guides is explained in section 2.3 (AMA, 2008, pp. 23–24). As noted, the most important element is the physician's accurate diagnosis, particularly since this defines the class of impairment. Diagnosis by analogy is only permitted if there is no other method for rating objectively identifiable impairment. Although impairment ratings are performed by physicians, nonphysician evaluators may analyze an impairment evaluation to determine if it was performed appropriately. The physician's role is to provide an independent, unbiased assessment; treating physicians are not completely independent. They also may not necessarily have received adequate training in the use of the guides. Therefore, assessments by treating physicians may be subject to greater scrutiny than those provided by independent physicians or those with extensive training in the use of the guides. Impairment ratings are only performed at maximum medical improvement (MMI).

The rules of application for the guides presented in section 2.4 (AMA, 2008, pp. 24–25) are similar to those in prior editions and essentially reiterate the fundamental principles and the need to base ratings on consistent objective criteria. The guides indicate the impairment values may be rounded. It also notes that impairment ratings in the body organ system chapters make allowance for most of the functional losses accompanying the use of prosthetic and similar devices. The sixth edition explicitly advises the physician to assess if an individual must regularly use a prosthesis, orthosis, or other assistive device and then test and evaluate the organ system with that device. If the device is easily removed, the physician does have the option of reporting findings with and without the device.

Section 2.5 (AMA, 2008, pp. 25–27) presents concepts important to the independent medical examiner, including definitions of medical possibility versus probability, causation, exacerbation, aggravation, and apportionment. The process of apportionment is the same as previous editions; the examiner determines the current total impairment rating (all inclusive) and subtracts the baseline rating reflecting preexisting impairment. Apportionment requires careful analysis of the alleged causative factors and may be challenging when ratings have been performed using different editions. This may be particularly challenging with the sixth edition since the approaches used to define impairment may differ from earlier editions. If impairment was defined previously and there has been further injury of the same region, it may be appropriate to subtract that previous impairment number from the current rating by the sixth edition. In most circumstances, the most appropriate method is to rate both the current total impairment and the preexisting impairment (using clinical information about that condition prior to the more recent injury) by the sixth edition.

In this edition, MMI refers to "a status where patients are as good as they are going to be from the medical and surgical treatment available to them. It can also be conceptualized as a date from which further recovery or deterioration is not anticipated, although over time (beyond 12 months) there may be some expected change" (AMA, 2008, p. 26). With prior conditions, typically the factors that result in potentially ratable impairment decrease over time as the patient heals. Therefore, rating prematurely typically inflates ratings. With the sixth edition, diagnoses may be modified by the time the patient is at MMI; therefore, it is again necessary to ensure that the patient is at MMI prior to rating. The guides do not permit the rating of future impairment. This edition presents a brief new discussion of the significance of cultural differences that may have an impact on the evaluation process.

An impairment evaluation is a form of expert testimony, as explained in section 2.6, "Impairment Evaluation and the Law" (AMA, 2008, pp. 27–28). Therefore, ratings must be fully supportable. If findings or impairment estimates based on these findings conflict with established medical principles, they cannot be used to justify an impairment rating.

The standards for reports are provided in section 2.7 (AMA, 2008, pp. 28–29), including clinical evaluation, analysis of findings, and discussion of how the impairment rating was calculated. This continues to serve as an excellent basis to determine the quality of an impairment evaluation report.

### 7.5.3 Chapter 3: "Pain-Related Impairment"

Chapter 3, "Pain-Related Impairment" (AMA, 2008, pp. 31–46), discusses the challenges and controversies associated with assessing pain. If pain accompanies objective findings of injury or illness that permit rating using another chapter in the guides, then pain-related impairments are not permitted to serve as add-ons. The clear language to this effect should reduce a common problem of double-dipping seen with the fifth edition (i.e., rating for a musculoskeletal condition and then providing further impairment for pain) (AMA, 2001). Therefore, it is probable that impairment ratings for pain will be less frequent with the sixth edition.

Pain not accompanied by objective ratable findings may be ratable (AMA, 2008), resulting in a maximum of 3 % whole-person permanent impairment, the same limit assigned in the fifth edition (AMA, 2001). The actual impairment is based on the patient's self-reports on a Pain Disability Questionnaire (PDQ), with lowering of the impairment if the examiner questions the credibility of the patient. Due to the subjective nature of pain and differing theoretical perspectives, this chapter was one of the most controversial. There is limited empiric evidence to support a maximum impairment of only 3 %, but the evidence to increase the range of impairment attributable to pain is not widely accepted across the different specialties participating in the development of the guides. Although there was discussion of modifying the magnitude of the impairment due to pain, lacking compelling information to change from the precedence established in the fifth edition, the maximum rating of 3 % remains. It is probable that the approach to pain-related impairment will continue to evolve with the seventh edition.

### 7.5.4 Chapter 13: "Central and Peripheral Nervous System"

Although most chapters in the sixth edition perform impairment ratings by first assigning a class and then assigning a grade within that class, Chap. 13 "The Central and Peripheral Nervous System" (AMA, 2008, pp. 321–345) continues to use a methodology similar to that of the fifth edition (AMA, 2001). This is consistent with the stated goal in the introduction of being "evolutionary but not revolutionary," which has led to some important changes and additions to the chapter while leaving the overall format essentially intact. Although the introduction states that one of the goals is "to offer single values rather than range for impairment categories. Ranges implied a level of impairment rating validity that does not exist" (AMA, 2008, p. 321). Most of the tables provide ranges, however, without explanation of how a value is selected within a range.

The primary application of this chapter in previous editions has been for the rating of traumatic brain injuries and spinal cord injuries. This edition comments: "In contrast to previously held belief, the symptoms of mild traumatic brain injury generally resolves in days to weeks, and leave the patient with no impairment" (AMA, 2008, p. 330).

The fifth edition (AMA, 2001) was criticized for having duplication of materials in the central and peripheral nervous system chapter that was presented in other chapters, with some differences between the ratings assigned. Thus, stated goals for the sixth edition (AMA, 2008) included a collaborative decision of the editorial board of the sixth edition to maintain most ratings related to limbs in the upper and lower extremity chapters (Chaps 15 and 16, respectively), to refer visual disorder ratings to the visual disorders chapter (Chap. 12), and to provide most ratings of nerves of the head and neck in the ear, nose, and throat (ENT) chapter (Chap. 11), with complex regional pain syndrome (CRPS) rated only in the upper and lower extremities chapters. Attention was also paid to maintaining consistency between this chapter on neurology and the

Mental and behavioral disorders chapter (Chap. 14) in terms of ratings of higher cortical function
Upper and lower extremities chapters in terms of complete loss of limb function
Digestive system chapter (Chap. 6) in terms of loss of bowel control
Urinary and reproductive systems chapter (Chap. 7) in terms of bladder and sexual function

"Table 13.1 Summary of Chapters Used to Rate Various Neurologic Disorders" (AMA, 2008, p. 323) assists the reader in finding chapters that have been deferred in order to rate neurologic disorders such as radiculopathy and other disorders to the spinal roots, plexus injuries and other plexopathies, focal neuropathy or mononeuropathy relating to the limbs, CRPS, visual disorders, vestibular disorders, disorders of the cranial nerves other than trigeminal and glossopharyngeal neuralgia, dysarthria and dysphonia, and primary mood disorders, anxiety disorders, and psychotic disorders.

Section 13.1 (AMA, 2008, pp. 325–326) provides the principles of assessment. As many of the conditions discussed in this chapter, even if "permanent," can result in significantly less impairment when optimally treated, the clinician is instructed to assess response to treatment before providing an impairment rating. This is to include

History of the response to treatment, and a determination whether there has been an adequate treatment course
Determination of whether the treatment has been sufficiently aggressive and of adequate duration with improvement in patient function
Evaluation of whether a suitable number of treatment options have been applied, and both medication compliance and patient cooperation with treatment assessed
Documentation of the response to treatment (with it noted that treatment may result only in a partial remission)
Consideration of whether residual problems represent symptoms or medication side effects
Identification of objective evidence to support impairment when the condition is intermittent, including documentation regarding missed work or school days, examination of both medication records from pharmacies and medical records to establish medication use and corroborate symptoms

The approach in assessing central nervous system (CNS) impairment presented in section 13.2 (AMA, 2008, p. 326) and section 13.3 (pp. 326–333) is similar to the fifth edition (AMA, 2001); however, there are some changes in the values of impairment, in part resulting from the definition of five classes of impairment. With the fifth edition, the most common basis for rating CNS impairment was "Table 13.6 Criteria for Rating Impairment Related to Mental Status" (AMA, 2001, p. 320) or Table 13.8 (p. 525), with impairment classes based on interference in ADL. In the sixth edition (AMA, 2008), "Table 13.8 Criteria for Rating Neurologic Impairment Due to Alteration in Mental Status, Cognition, and Highest Integrative Function (MSCHIF)" bases classification of cognitive impairment on findings of an extended mental status exam, neuropsychological assessment and testing, and description of interference in ADL. Maximum impairment is 50 % whole-person permanent impairment; previously, it was 70 % whole-person permanent impairment. "Table 13.10, the Global Assessment of Functioning (GAF) Impairment Score" (p. 334) is provided to define emotional or behavioral impairment due to an objective CNS lesion. Conditions that are primarily psychological are rated by Chap. 14, "Mental and Behavioral Disorders." Maximum impairment for emotional and behavioral disorders is the same as MSCHIF impairment (i.e., 50 % whole-person permanent impairment; previously, it was 90 % whole-person permanent impairment). With the exception of consciousness and awareness (now 100 %, previously 90 %), maximum whole-person permanent impairment for other ratable CNS impairments is less: episodic loss of consciousness or awareness 50 % (previously 70 %) and sleep and arousal 50 % (previously 90 %).

Central nervous and spinal cord injuries that result in upper extremity impairment are rated per Section 13.5 "Criteria for Rating Impairments of Upper Extremities due to CNS Dysfunction" (AMA, 2008, p. 335); Section 13.6, "Criteria for Rating Impairments of Station, Gait and Motion Disorders" (p. 336); section 13.7, "Criteria for Rating Neurogenic Bowel, Bladder, and Sexual Dysfunction" (p. 336); and section 13.8, "Criteria for Rating Respiratory Dysfunction" (pp. 336–337). The number of classes of impairments ranges from four (sexual dysfunction) to six (respiratory dysfunction), rather than the five-class approach. Some maximum values have changed (i.e., bladder maximum of 30 % whole-person permanent impairment [previously 60 %], sexual 15 % [previously 20 %], and respiratory 65 % [previously 90 %+]).

Section 13.9 (AMA, 2008, pp. 339–341) provides criteria for rating peripheral neuropathy, neuromuscular junction disorders, and myopathies; however, ratings of peripheral nerve lesions are performed using Chap. 15, "The Upper Extremities," or Chap. 16, "The Lower Extremities."

Criteria for rating impairments related to chronic pain (fifth edition, section 13.8; AMA, 2001, pp. 343–344) have been replaced by "Table 13.17 Dysesthetic Pain Secondary to Peripheral Neuropathy or Spinal Cord Injury" (AMA, 2008, p. 339). The maximum impairment for dysesthetic pain is 10 % whole-person permanent impairment (Class 3, "severe dysesthetic pain"); the maximum impairment from the fifth edition for "Table 13.22 Criteria for Rating Impairment Related to Chronic Pain in One Upper Extremity" (AMA, 2001, p. 343) was 60 % whole-person permanent impairment (Class 4, dominant extremity, "individual cannot use the involved extremity for self-care or daily activities"). A brief description of complex regional pain syndrome is provided in section 13.10 (AMA, 2008, p. 341); however, these ratings are performed using Chaps 15 and 16.

Instructions for rating impairments due to migraines are provided in section 13.11, "Criteria for Rating Impairments Related to Craniocephalic Pain" (AMA, 2008, p. 341) and Table 13.18 (AMA, 2008, p. 342), with scores obtained from the MIDAS (Migraine Disability Assessment) Questionnaire. The maximum impairment for migraine headaches is 5 % whole-person permanent impairment; however, the maximum assigned for pain in Chap. 3, "Pain," is 3 % whole-person permanent impairment.

Miscellaneous peripheral nerves not ratable in the previous edition are discussed in section 13.12 (AMA, 2008, p. 343) and listed in Table 13.20 (p. 344).

### 7.5.5 Chapter 14: "Mental and Behavioral Disorders"

Chapter 14, "Mental and Behavioral Disorders" (AMA, 2008, pp. 347–382), discusses impairments due to mental disorders and considers mental and behavioral impairments that may result from these disorders. The authors stated that focus is on evaluating brain function and its effect on behavior in the absence of evident traumatic or disease-related objective CNS damage. The most significant change from the most recent editions of the guides is the provision of numeric ratings.

Earlier editions of the guides cited the lack of empiric evidence to support any method for assigning a percentage of impairment of the whole person for a mental and behavioral disorder. These editions classified impairment across four domains: ADL, social functioning, concentration, and adaptation. There were five classes of impairment ratings applied to each of the four domains, ranging from no impairment (Class 1) to extreme impairment (Class 5). The sixth edition of the guides is the first since the publication of the second edition in 1984 to provide numeric ratings for mental and behavioral disorders. It is important to note that this is a controversial decision because of the continued lack of clear, consistent empiric evidence to support the use of numeric ratings. It is the intention of the sixth edition, however, to increase the internal consistency of impairment evaluation and rating, and to accomplish this it was judged as important to provide numeric ratings for mental and behavioral impairments. In addition, since the guides are established to provide a uniform template to translate human trauma or disease into a percentage of the whole person, the delineation of numeric ratings in this chapter will minimize the highly inconsistent and idiosyncratic methodologies used by clinicians, adjudicators, and others in their attempt to apply numeric ratings without a standard template to guide them. While greater interrater reliability and internal consistency may be achieved by the methodology described as of this writing, the validity and usefulness of the impairment ratings will certainly be in question.

The guides sixth edition continues to emphasize the importance of following the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (*DSM-IV*; American Psychiatric Association [APA], 1994). For the purpose of this discussion, we make the assumption that the authors of the guides were referring to the most recent text revised version of the *DSM*, the *DSM- IV-TR* (APA, 2000). Section 14.1b (AMA, 2008, p. 348) stresses strict adherence to the *DSM-IV-TR* criteria to determine an accurate diagnosis and notes the importance of using the multiaxial system referenced in Table 14.1 (p. 348). Axis I includes the major psychiatric syndromes and conditions, such as mood disorders or anxiety disorders. Axis II is reserved for personality and developmental disorders, while physical disorders and conditions relevant to the health and treatment of the patient are listed on Axis III. Axis IV conveys information about any psychosocial stressors experienced by the patient. The Global Assessment of Functioning (GAF) score is reported on Axis V and should reflect the effects of the psychiatric impairment. Identifying the GAF score is essential because this score is used as part of the procedure to determine the percentage of whole-person psychiatric impairment.

The guides (AMA, 2008) indicate that clinicians conducting an independent mental and behavioral evaluation using this procedure should be trained in psychiatry or psychology or have expertise in the use of the *DSM-IV-TR* (APA, 2000), be experienced in the psychiatric or psychological evaluation of patients, and have expertise in the diagnosis and treatment of mental and behavioral disorders.

The introduction to the "Mental and Behavioral Disorders" chapter states that only impairments for selected well-validated major mental illnesses are considered for an impairment rating. Section 14.1c (AMA, 2008, pp. 348–349) elaborates, stating that the purpose of the chapter is not to rate impairment in all persons who may fit a *DSM-IV-TR* (APA, 2000) diagnosis since many conditions are common in the general population and do not require an impairment rating. Given the use of the guides in medicolegal settings, impairment rating in the sixth edition is specifically limited to mood disorders (including major depressive disorder and bipolar disorder), anxiety disorders, and psychotic disorders (including schizophrenia). Section 14.1c further provides a list of disorders that are *not* ratable in this chapter, including psychiatric reaction to pain, somatoform disorders, dissociative disorders, personality disorders, psychosexual disorders, factitious disorders, substance use disorders, sleep disorders, dementia and delirium, mental retardation, and psychiatric manifestations of traumatic brain injury. While the inclusion and exclusion of diagnostic categories is stated clearly in the chapter, the explanation and rationale are stated with less clarity. It is probable that the inclusion and exclusion criteria for medicolegal purposes will be determined by regulatory bodies, contractual wording, or the court systems in specific jurisdictions.

Specific rules for the use of this chapter are delineated in section 14.1, "Principles of Assessment" (AMA, 2008, p. 349). This methodology is used when

There is a mental and behavioral disorder without a physical impairment or pain impairment.

A mental and behavioral disorder exists that is judged independently compensable by the jurisdiction involved. In such an instance, the mental and behavioral disorder impairment is combined with the physical impairment. There is a specific requirement of the compensation system.

The sixth edition of the guides also states, "In most cases of a mental and behavioral disorder accompanying a physical impairment, the psychological issues are encompassed within the rating for the physical impairment, and the mental and behavioral disorder chapter should not be used" (AMA, 2008, p. 349). This statement is somewhat confusing and may be an over-statement. The focus of the consensus building among participating clinicians to establish numeric impairment ratings for physical disorders described in the other chapters typically did not include a discussion of or any emphasis on related or co-occurring mental and behavioral disorders. It is also important to note that if at least one of the first three statements is true, then the impairment may be ratable under this chapter. If none are true, then the impairment is not ratable. Therefore, the fourth statement may not be relevant and can probably be disregarded.

Section 14.2,"Psychiatric/PsychologicalEvaluation" (AMA, 2008, pp. 349–351), provides only minimal detail about what constitutes an appropriate mental and behavioral disorders independent medical examination (IME). The guides state, "The general psychiatric or psychological evaluation involves soliciting a history, review of appropriate records, and a mental status examination" (p. 349). Key areas addressed in a mental status examination include the patients' appearance, activity level, mood and affect, speech and language, thought content and organization, perceptual disturbances, insight and judgment, and neuropsychiatric functions such as sensorium, cognitive functions, memory, attention and concentration, and level of intelligence. Another area typically included in a mental status examination involves somatic functions and concerns such as a change in appetite and weight, alterations in energy level and libido, and alterations in sleep patterns. The evaluator usually describes the person's attitude toward the examiner, quality of cooperation during the examination, and the reliability of information provided.

An effective independent psychiatric evaluation typically begins with a thorough psychiatric and medical history that elicits information about the onset of clinical signs and symptoms of the psychological disturbance as well as any relevant medical information that may contribute to the development of the mental and behavioral disorder. The evaluator notes the various health care and mental health care providers the person has consulted to address the reported symptoms. The treatment history is a critical element of this evaluation as it documents interventions used to alleviate the symptoms of the psychological disorder and whether these interventions have been effective. The evaluator should also solicit information about the person's level of stress or dissatisfaction with the work environment, work relationships, or personal relationships.

Other relevant historical data include the identification of previous episodes of mental or behavioral disorders and the response to any treatment the person might have received to address these disorders. The evaluator should note whether there is a positive family history for any psychiatric disorder. The evaluator should also solicit information about the person's childhood and adolescent development and whether there was a history for abuse or trauma. School functioning, level of education, and work history provide context for understanding the person's ability to function in the community. Personal habits like the use of caffeine, nicotine, alcohol, or illicit drugs are included in the history section of the report.

Section 14.2 includes a brief and inadequate discussion of the utility of psychological testing as part of the assessment process. The guides sixth edition states: "The use of well-standardized psychological tests, such as the Wechsler Adult Intelligence Scale [we assume the authors are actually referring to the 3rd edition, the WAIS-III] and the Minnesota Multiphasic Personality Inventory-2 (MMPI-2), may improve diagnostic accuracy and support the existence of a mental disorder" (AMA, 2008, p. 351). The guides provide a list of selected psychological assessment tools in adults in Table 14.3 (AMA, 2008, p. 350). This list is broken down into four categories: personality and symptoms assessment, intellectual assessment, academic assessment, and neuropsychological evaluation. Self-report inventories such as the Beck Depression Inventory are described by the guides as "purely subjective" and viewed as having limited value in the independent medical evaluation setting. The guides reiterate: "Despite the wide range of available psychological tests, the patient interview, review of records, and the mental status exam remain the foundation for the evaluation of the patient and determination of the impairment rating" (p. 351). This appears to minimize the use of psychological assessment as one essential component of the evaluation process. This perspective is also inconsistent with the guides' stated intention of relying on objective clinical data as a basis for establishing a diagnosis as well as the type and degree of impairment experienced by a patient.

Section 14.3, “Special Features of the Mental and Behavioral Disorders Independent Medical Examination” (AMA, 2008, pp. 351–353), addresses the physician alliance and source materials. This section points out how a mental and behavioral disorders IME conducted in a medicolegal setting differs from a standard psychiatric or psychological evaluation. The guides primary purpose is “to rate impairment to assist adjudicators and others in determining the financial compensation to be awarded to individuals who, as a result of injury or illness, have suffered measurable physical and/or psychological loss” (p. 20). Table 14.4 (p. 352) lists a number of specific suggestions to address when conducting a mental and behavioral disorders IME. Examples of these recommendations include the following:

Screen individuals for past and current substance abuse to determine whether symptoms of substance abuse better account for psychiatric symptoms manifested by the person.
Evaluate the legal history, especially concerning prior lawsuits, work-related injuries, bankruptcies, incarcerations, driving while intoxicated, restraining orders and courts ordered child support.
Obtain military history, overseas service, adjustment to service, discharge history, pay grade, military arrests, and disability pension.
Note whether there is a pattern of over-endorsing symptoms during the psychiatric interview.
Assess the patient’s motivation vis-a-vis returning to work.
Determine if symptom exaggeration or malingering is present.
Ask about the patient’s attitude to the third-party payer (employer, insurance company, etc.).
Assess the influence of the litigation process on return to work.
Determine whether adequate pharmacologic and biologic treatment has been provided, including whether the patient has accepted and complied with reasonable treatment.

The guides (AMA, 2008) stress that mental health professionals conducting an independent psychiatric or psychological evaluation are expected to maintain a neutral, unbiased position regarding the patient. This perspective differs from the role of a treating mental health professional, in which patient advocacy may play an important role in treatment intervention. Treating mental health professionals are cautioned that the therapeutic relationship can be compromised when the mental health provider serves as an expert witness.

While the guides sixth edition (AMA, 2008) places emphasis on the use of objective data in determining the presence of a psychiatric impairment, it is still important to assess how the person describes his or her psychological symptoms and the impact these symptoms have on functioning. Six areas of functional impairment are particularly relevant in this evaluation process: self-care and personal hygiene; social and recreational activities; the capacity for travel, including driving and using public transportation; interpersonal relationships; the capacity for concentration, persistence, and pace; and employability. The evaluator should review information from other reliable sources, such as records from inpatient hospitalization, outpatient treatment, day treatment programs, occupational therapy, work evaluations, and disability assessments. Information gathered from these sources, the patient's self-report of symptoms, and impact on the six functional areas as well as the findings from the objective clinical assessment are analyzed by the evaluator to determine how consistent this information is. Any widely inconsistent findings between the patient's self-reports and the other sources of information, including the clinical evaluation, should be examined in detail to determine the reasons for this discrepancy.

Section 14.4 of the guides sixth edition discusses the importance of determining whether the person has reached MMI (AMA, 2008). This edition continues to instruct the evaluator to follow the general principle that a condition is ratable when the person has reached MMI. This level of improvement implies the condition is not expected to change significantly over the next 12 months. This principle poses somewhat of a challenge when assessing impairment for mental disorders because a degree of variability exists for many mental disorders, like recurrent major depression or schizophrenia. Persons with these chronic conditions are likely to experience a series of relapses and remissions. Personal life stressors, new or chronic health conditions, and workplace stressors can exacerbate stress and lead to a resurgence of psychological symptoms.

The establishment of MMI is a highly controversial area in the mental health field. True MMI implies a relatively rare state for someone with a psychiatric disorder, yet many people are judged to have reached that point in the medicolegal environment. This is not consistent with the literature and may be more of a function of the system within which the disorder is being evaluated (medicolegal system) than a general psychiatric population. Individuals with psychiatric diagnoses may experience a complete resolution of their disorder even after an extended period of time. They may also experience a relapse/remission pattern. For example, many individuals have a single episode of major depression that resolves over time, while others experience recurrent episodes of depression.

Investigating the treatment history is essential in determining whether the person has reached MMI and is likely to remain so over the next 12 months. The guides direct the evaluator to determine how the person has responded to the prescribed treatment (both medication and psychotherapy) and whether the treatment has been adequate and appropriate according to best practice standards (AMA, 2008). Patient compliance to treatment may be an issue requiring further investigation. Barriers to treatment compliance include poor insight about the importance of treatment compliance, timely and consistent access to mental health services, and the experience of significant side effects of medications. Partial response to treatment can indicate the need to reassess medication intervention or adjust the psychotherapeutic approach. Other comorbid factors such as substance abuse, a personality disorder, or perceptions of involvement in the medicolegal system may affect treatment response.

Since the evaluation of permanent impairment is the basis for defining impairment in the vast majority of workers' compensation jurisdictions, vocational issues are relevant to the evaluation process. Many people diagnosed with psychiatric disorders continue to work successfully by meeting the essential requirements and demands of the job. Others are unable to meet these demands because their psychiatric symptoms significantly affect their work capacity. All editions of the guides have consistently stated that the purpose of the impairment rating is not to provide direct estimates of work participation restrictions. The guides are intended to identify impairments such as limitations in concentration, persistence, and pace; disturbances in memory and recall; difficulty with emotional stability; challenges in interpersonal relationships at the work site; or diminished capacity to adapt to work-like settings. Permanent impairment in any of these areas may ultimately affect the person's ability to perform his or her specific job, but an employer's capacity to modify the particular requirements of a job on a temporary or permanent basis can also influence whether a person with a psychiatric condition can return to work.

## 7.6 The Impairment Rating Process

In determining impairment rating, the guides rely on measurements of the severity of psychiatric symptoms, global functioning, and more specific areas of functional impairment. Specific considerations are offered to provide guidance in the overall impairment rating process (AMA, 2008, pp. 355–356):

Psychiatric impairment is based on Axis I pathology only and in cases where multiple diagnoses exist, only one impairment rating is derived.

Underlying aspects of the personality, borderline intellectual functioning and personality disorders are not rated.

Compromise of ADLs that is caused by financial constraints, the lack of transportation, or the lack of opportunity (e.g., employment) is not rated.

The assessment is not limited to the number of activities that are restricted but the overall degree of restriction or combination of restrictions.

The assessment is not limited to a one-time interview. The evaluation of a patient's abilities and functional limitations may also rely on documented collateral sources of information that reflect the patient's behavior in other settings.

Functional limitations across the following areas: Self-care and personal hygiene; social and recreational activity; travel; interpersonal relationships; concentration, persistence, and pace; and employability that are related to physical impairment should not be included in the impairment rating in this chapter.

The percentage of impairment associated with the current accident or event (final impairment rating) is what remains when the level impairment associated with a preexisting condition is subtracted from the current total impairment.

The impairment rating score is not necessarily indicative of whether or not a person can work.

The mental and behavioral disorders impairment rating is based on consideration of three specific scales—the Brief Psychiatric Rating Scale (BPRS), the GAF, and the Psychiatric Impairment Rating Scale (PIRS)—as explained in section 14.5, "Concepts for Impairment Ratings" (AMA, 2008, pp. 355–356), and section 14.6, "Methods of Impairment Rating" (pp. 356–360). These scales are provided either in the chapter or in its appendix.

The guides identify the BPRS as a measure of "major psychotic and nonpsychotic symptoms in patients with major psychiatric illnesses" (AMA, 2008, p. 352). The authors also indicate it has shown excellent reliability in clinical trails, and "it is probably the most researched instrument in psychiatry (p. 352)." However, there are selected examples and some are abbreviated. A 7-point scale is used, ranging from 1 (not present) to 7 (extremely severe). The BPRS summed score is grouped in ranges reflecting various percentages of impairment from 0 % to a maximum of 50 %.

Unfortunately, the BPRS was not designed for a general outpatient psychiatric population, and it was not developed for the purpose of impairment rating (and has not undergone any validation studies to support its use for this purpose with this type of population). The reader should note that the Corrections and Clarifications for the Guides sixth edition, published in August, 2008, corrects the scoring process described in the first printing. Because a score of "1" is used for "not present," a rating of "2" (very mild) on a single item results in a summed score of 25. The range of summed scores resulting in an impairment score of 5 % was 25–30 in the original printing. The entire rating scale was shifted up five raw score points, so a score of 24–30 now represents an impairment score of 0 %, a score of 31–35 represents an impairment score of 5 %, and so on. There have been very few studies exploring the clinical implications of specific scores on the BPRS. One such study (Leucht et al., 2005) identified "mildly ill" as the descriptor for a range of scores beginning at 31. In the future, it may be prudent and very worthwhile for the guides to review and revise the scoring methodology it has used to attribute impairment ratings for BPRS score ranges. It may also be very desirable to explore the use of alternative scales for the purpose of establishing the severity of psychiatric symptoms. An example of one alternative could be the DPRS (Derogatis Psychiatric Rating Scale), which is coupled with either the Brief Symptoms Inventory or the Symptom Checklist 90-Revised (SCL-90-R). This alternative has the advantage of combining professional rating (DPRS) with the results of a structured self-report instrument rather than relying on professional rating alone (as is the case for the BPRS). From a measurement point of view alone, the use of the BPRS and the methodology used to derive impairment ratings from BPRS scores is questionable and ambiguous. While reliability may be adequate, the validity of this instrument as a measure of impairment in a population of people with psychiatric disorders in the medicolegal system is very weak.

The second scale used is the GAF, formerly Axis V of the DSM-IV and now a separate notation of disability for the DSM 5. This is a well-known scale that rates a combination of overall psychological symptoms, occupational functioning, and social functioning. Like the BPRS, the guides (AMA, 2008) established a series of score ranges that translate to percentage of impairment from 0 % to a maximum of 50 %. The GAF was routinely used as part of the multiaxial assessment and has both undergone significant psychometric assessment and been demonstrated to have satisfactory interrater reliability. Its use in formulating an impairment rating appeared obvious to the guides authors, although the assignment of impairment ratings to GAF score ranges is not based on empiric evidence. Section 14.5 also notes some of the limitations of the GAF, which is one of the reasons for combining its use with that of the BPRS and PIRS.

The PIRS is the final scale used as a measure of impairment. It evaluates the behavioral consequences of psychiatric disorders and, while expanded to rate impairment, is similar in construction to the GAF. This scale was developed for the New South Wales Motor Accidents Authority in Australia and is in use in a variety of other Australian states. It is a relatively new scale, and its validity and coverage as a measure of impairment associated with psychiatric disorders have been questioned by Australian mental health professionals (Australian Psychological Association, 2003). The PIRS is made up of six scales, each designed to evaluate a specific area of functional impairment. The six functional impairment scales are scored using a 5-point, anchored scale. The two *middle* scores (of the six) are summed and translated to percentage of impairment from 0 % to a maximum of 50 %. While this scale has high "content" validity, it lacks empiric evidence to support its use as a measure of impairment.

The *total impairment* rating from the sixth edition of the AMA guides (2008) is the middle score of the three impairment ratings derived from the BPRS, GAF, and PIRS. The authors chose to use the "median" as a measure of central tendency to avoid the influence of outliers. While this may be true, it is generally accepted that the mean is a more effective reflection of central tendency for very small distributions of scores and is much more appropriate when the scores are not necessarily drawn from a single distribution. While these scores were designed to reflect a similar scoring approach for level of impairment, they clearly are not from the same distribution. While it may be more appropriate to use the mean as the measure of central tendency, this is not the method that will be used in the guides at this point in time.

When there is documented evidence of a preexisting condition, the base rate (impairment rating prior to the current accident or event that has triggered the impairment rating) is subtracted from the total impairment rating documented in the process outlined. The result is a *final* impairment rating for the mental and behavioral impairment.

## 7.7 Challenges Existing in the Use of Chap. 14

The stated purpose of including all three of these scales is "to provide a broad assessment of the patient with M&BD" (AMA, 2008, p. 355). The goal is to "arrive at a strongly supportable impairment rating" (p. 355). As the approach used in the Mental and Behavioral Disorders chapter is a dramatic departure from what was used previously (especially since numerical psychiatric ratings have not been used since the second edition), its impact and reliability are yet to be determined. Several critical challenges exist that greatly complicate the use of this particular chapter in the guides. Many of these challenges have been discussed in this section.

Briefly, there are problems with the conceptualization and definition of impairment associated with mental and behavioral disorders, with the process used to identify certain diagnoses as “ratable” and others as “nonratable,” with the establishment of the very difficult concept of MMI, and with the identification of what information will be used as the foundation for impairment assessment and how that information should be gained. Most importantly, there are significant problems and flaws associated with instrumentation, measurement, statistical analysis, and validity of the tools and methods chosen to derive the actual impairment ratings. It is clear that this chapter, while it provides a methodology that will increase the reliability of impairment ratings, faces major challenges *as it currently exists* in terms of its validity and usefulness in medicolegal settings.

## 7.8 Conclusion

The AMA *Guides to the Evaluation of Permanent Impairment* serves as the standard for assessing medical impairment. The new sixth edition (AMA, 2008) reflects a change in the process of assessing impairment by defining most impairments on the basis of a methodology derived from the *ICF*. The process of defining impairment or the complexities of human function is not perfect; however, the vast majority of the sixth edition should simplify the rating process, increase intra- and interrater reliability, improve accuracy, and provide a solid basis for future editions of the guides.

## References

American Medical Association. (1958). A guide to the evaluation of permanent impairment of the extremities and back. *Journal of the American Medical Association, 166*(supplemental), 1–122.

American Medical Association. (1971). *Guides to the evaluation of permanent impairment*. Chicago: Author.

American Medical Association. (1984). *Guides to the evaluation of permanent impairment* (2nd ed.). Chicago: Author.

American Medical Association. (2001). *Guides to the evaluation of permanent impairment* (5th ed.). Chicago: Author.

American Medical Association. (2008). Guides to the evaluation of permanent impairment. In *Corrections and clarifications* (6th ed.). Chicago: Author.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

Australian Psychological Association. (2003). *Supplementary submission to the productivity commission’s inquiry into national Workers’ Compensation and Occupational Health and Safety frameworks.* Retrieved February 18, 2008, from http://www.pc.gov.au/__data/assets/pdf_file/0014/20345/ sub165.pdf

Brigham, C., Uejo, C., Dilbeck, J., & Walker, P. (2006). Errors in impairment rating: Challenges and opportunities. *Journal of Workers Compensation, 15*(4), 19–42.

Burd, J. (1980). The educated guess: Doctors and permanent partial disability percentage. *Journal of the Tennessee Medical Association, 783*, 441.

Clark, W. L., Haldeman, S., Johnson, P., Morris, J., Schulenberger, C., Trauner, D., et al. (1988). Back impairment and disability determination: Another attempt at objective, reliable rating. *Spine, 3*, 332–341.

Hinderer, S., Rondinelli, R., & Katz, R. (2000). Measurement issues in impairment rating and disability evaluation. In R. Rondinelli & R. Katz (Eds.), *Impairment rating and disability evaluation* (pp. 35–52). Philadelphia, PA: Saunders.

Leucht, S., Kane, J., Kissling, W., Hamann, J., Etschel, E., & Engel, R. (2005). Clinical implications of the Brief Psychiatric Rating Scale. *British Journal of Psychiatry, 187*, 366–371.

Pryor, E. (1990). Flawed promises: Critical evaluation of the AMA Guides to the Evaluation of Permanent Impairment. *Harvard Law Review, 103*, 964–976.

Rondinelli, R., & Duncan, P. (2000). The concepts of impairment and disability. In R. Rondinelli & R. Katz (Eds.), *Impairment rating and disability evaluation* (pp. 17–33). Philadelphia, PA: Saunders.

Rondinelli, R., Dunn, W., Hassanein, K., Keesling, C., Meredith, S., Schulz, T., et al. (1997). Simulation of hand impairments: Effects on upper extremity function and implications toward medical impairment rating and disability determination. *Archives of Physical Medicine and Rehabilitation, 78*, 1358–1563.

Rondinelli, R., & Katz, R. (2002). Merits and shortcomings of the American Medical Association *Guides to the Evaluation of Permanent Impairment*, fifth edition: A psychiatric perspective. *Physical Medicine and Rehabilitation Clinics of North America, 13*, 355–370.

Spieler, E., Barth, P., Burton, J., Himmelstein, J., & Rudolph, L. (2000). Recommendations to guide revision of the Guides to the Evaluation of Permanent Impairment. *Journal of the American Medical Association, 83*, 51–53.

State of California, Schedule for rating permanent disabilities, labor and workforce development agency, Department of Industrial Relations, Division of Workers, Compensation. (2005). Retrieved January, 2005, from http://www.dr.ca.gov/dwc/PDR.pdf

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: Author.

# The Diagnostic and Statistical Manual of Mental Disorders: Fifth Edition (DSM-5) Model of Impairment

# 8

Diana Joyce-Beaulieu and Michael L. Sulkowski

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the leading reference within the United States for establishing accurate diagnosis of mental health syndromes and is considered a medical classification system (American Psychiatric Association [APA], 2013, p. xli, 10). A wide variety of professionals including counselors, forensic specialists, nurses, physicians, psychiatrists, psychologists, rehabilitation therapists, and social workers utilize the DSM to facilitate assessment of symptoms within their clinical practice. The manual also crosses multiple disciplines including biological, behavioral, cognitive, and psychodynamic orientations in understanding mental health. By design, the DSM is intended to provide a common nomenclature for researchers, practitioners, and public health agencies serving the needs of individuals with mental health diagnoses across a range of settings from inpatient hospital treatment to outpatient clinics and private practice.

The stated goals of this manual include providing an education reference, a guide for practice, and a mechanism for epidemiological studies as well as national morbidity data collection (APA, xii). The DSM acknowledges that disorders can have overlapping symptomology and variation is evident between individuals' manifestations of symptoms even for the same disorder, thus notes that boundaries between

---

D. Joyce-Beaulieu, Ph.D. (✉)
School of Special Education, School Psychology, and Early Childhood Studies,
College of Education, University of Florida, 1403 Norman Hall, PO Box 117047,
Gainesville, FL 32611-7047, USA
e-mail: djoyce@coe.ufl.edu

M.L. Sulkowski, Ph.D.
Department of Disability and Psychoeducational Studies, School Psychology Program,
College of Education, University of Arizona, Room 421, East 2nd Street, P.O. Box 210069,
Tucson, AZ 85721-0069, USA
e-mail: sulkowski@email.arizona.edu

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_8

disorders may be porous (p. 6). The operating DSM definition for a mental disorder is:

> A mental disorder is a syndrome characterized by clinically significant disturbance in an individual's cognition, emotion regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behavior (e.g., political, religious, or sexual) and conflict that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above (p. 20).

The DSM's ability to establish a common taxonomy for research has both national and international implications for identifying early risk factors, understanding prognosis, and validating the efficacy of treatments. The organizers of the DSM manual have sought to achieve these purposes by a rigorous effort to provide clear and explicit criteria for diagnosis (APA, 2013). The goals of this chapter include a brief review of the 60-year development of the DSM as it has evolved in addressing these directives and discussion of important applied clinical implications for the assessment of impairment. In addition, limitations in the DSM criteria for diagnosing are considered. Lastly, an overview of the World Health Organization (WHO) family of international classifications is provided. The WHO international classification system predates the DSM and the two are used in tandem for tracking national mental health data. In fact, there has been an increasing alignment between the two systems overtime. The WHO also provides a model of integrating three classification systems that distinctly addresses diagnosis, functioning, and intervention relevant to ameliorating impairment.

## 8.1 History of the Development of the DSM

### 8.1.1 DSM-I (APA, 1952) and DSM-II (APA, 1968) Editions

An early impetus for the establishment of the DSM as a classification system was the need to collect statistical data on mental illness in America (APA, 2000). This need dates back to as early as 1840 when the United States government first included the category of insanity/idiocy on the national census. Over the following decades, a more detailed categorization system was established. In 1917, the forerunner of the American Psychiatric Association collaborated with the New York Academy of Medicine to develop a nomenclature system. The system would not only be used for the purpose of statistical collection, but also for diagnosing severe psychiatric and neurological disorders in inpatient populations. After World Wars I and II, the need for a broader classification system that could be utilized in diagnosing less debilitating psychiatric illnesses in outpatient populations became evident. This was a result of the prevalence of veterans and other service members who demonstrated manifestations of exposure to trauma, such as acute stress, and psychosomatic or personality disorders. A need existed to develop a common language to diagnose these disorders and also to maintain accountability records that documented types of impairments treated and frequency and duration of services required.

In 1952, the American Psychiatric Association responded to this need by establishing the first version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-I; APA, 1952), a variation of a similar system that had been utilized internationally (the International Statistical Classification of Diseases and Related Health Problems—6th Edition [ICD-6]; World Health Organization [WHO], 1948). The DSM-I was unique in that it was the first official manual developed with the primary purpose of clinical diagnostics, as opposed to a sole focus on statistical utility, hence leading to the terms *diagnostic* and *statistical* in the name of the manual. The original version of the DSM largely reflected a psychobiological view of mental disorders, in which mental illnesses were perceived as *reactions* to internal and external factors. The manual contained descriptions of various psychiatric categories of illness for adults, but described few categories of illness specific to children. The DSM was organized into three categories (i.e., organic brain syndromes, functional disorders, and mental deficiency) with 106 subcategories (Kessler, 1971). Although the manual made an important contribution to acknowledging mental health syndromes, it was criticized for providing vague criteria for disorders that made diagnosis assessment unreliable. This lack of specificity resulted in only moderate agreement rates among diagnosticians (Ward, Beck, Mendelson, Mock, & Erbaugh, 1962).

The DSM-II was published in 1968 and corresponded with the publication of the eighth version of the ICD (WHO, 1968). The major deviation in the second manual from the first was the elimination of the term *reaction* throughout the manual, thus demonstrating a theoretical change in the basis of the classification system. Symptoms were presented in a narrative form and clinicians had the option of diagnosing based on the client's current symptoms or the client's perceived unconscious processes. The emphasis on unconscious processes was a result of influences from psychoanalytic theory (Mash & Barkley, 2003). Unfortunately, given the wide range of clinicians' interpretations of patients' *perceived* unconscious processes, the manual did not improve upon the vague diagnostic definitions and failed to lead to increased consistency in diagnoses among clinicians (Spitzer & Fleiss, 1974).

### 8.1.2 DSM-III (APA, 1980) and DSM-III-R, (APA, 1987) Editions

In 1974, APA undertook the arduous process of developing a major revision of the second manual. The DSM-I and DSM-II were short and more closely resembled pamphlets than manuals; the third edition of the DSM was increasingly complex and more closely resembled a text. The third edition of the manual, published in 1980, also improved upon the earlier versions by providing diagnostic criteria symptom lists for specific mental illnesses. Thus, a more neutral approach to describing the development and manifestations of syndromes was adopted. Following much criticism of the DSM-II's narrow assessment perspective, a

**Table 8.1** Multiaxial assessment system-DSM—III

| Axis | Information reported |
|---|---|
| Axis I | Clinical disorders and disorders usually first diagnosed in infancy, childhood, or adolescence (i.e., delirium, dementia, amnestic, and other cognitive disorders; mental disorders due to a general medical condition; anxiety, somatoform, factitious, dissociative, sexual and gender identity, eating, sleep, adjustment, and impulse-control disorders not elsewhere classified; and other conditions that may be a focus of clinical attention) |
| Axis II | Personality disorders (i.e., paranoid, schizoid, schizotypal, antisocial, borderline, narcissistic, avoidant, dependent, obsessive-compulsive, and personality disorder not otherwise specified) and mental retardation |
| Axis III | General medical conditions (e.g., infectious/parasitic diseases, neoplasms, diseases of the nervous system and sense organs, complications of pregnancy, childbirth, and the puerperium, injury and poisoning) |
| Axis IV | Psychosocial and environmental problems (i.e., problems with primary support group, problems related to the social environment, educational, occupational, housing, economic, problems with access to health care services, problems related to interaction with the legal system/crime, and other psychosocial and environmental problems) |
| Axis V | Global Assessment of Functioning |

multiaxial diagnostic system was introduced in the third edition (DSM-III) and remained in place for the fourth edition of the DSM as well.

***Multiaxial assessment system***. The multiaxial diagnostic system contained five axes (listed in Table 8.1) that were each associated with an independent domain of functioning for the individual. The overall goal of the multiaxial system was to provide a useful format for organizing multiple components of the patient's condition. This approach allowed for the inclusion of psychosocial, environmental, and daily functioning domains that may be overlooked or minimized if the diagnostician is only concerned with just reviewing a symptom list. The multiaxial system also prompted clinicians to consider the individual differences between persons within the same diagnostic categories (APA, 1987). The domains were considered useful when matching treatment options to impairment domains.

Axis I was utilized to report both the name and code number for any clinical disorder(s) or other condition(s) requiring clinical intervention in the classification system (except for mental retardation and personality disorders). Personality Disorders and Mental Retardation were reported under Axis II (see Table 8.1). On both Axes I and II, it was acceptable to list more than one disorder when comorbidities were present. If an Axis II disorder was the primary diagnosis for the person, that was indicated after the listing for the diagnosis by denoting "principal diagnosis" in parenthesis. In cases where there was no Axis II diagnosis, the clinician listed the appropriate code to indicate no diagnosis or deferment of a diagnostic decision.

The patient's general medical status was reported along Axis III. Only medical conditions that were relevant to the person's current functioning in relation to the mental illness(es) were listed in Axis III. The purpose of inclusion of medical factors was to promote communication among health care providers and to encourage clinicians to conduct a thorough assessment recognizing that there is a bi-directional relationship between psychological and physiological functioning (APA, 1987). In many patients, the presence of a medical illness can impair psychological functioning (for a review see Boekaerts & Röder, 1999) and, conversely, a mental illness can contribute to complications with medical conditions (for a review see Balon, 2006). The documentation of dual medical/mental health diagnoses is particularly important for prognosis and treatment decisions in neuropathological disorders that may include degeneration characteristics (e.g., Alzheimer's Disease, Parkinson's Disease). This is also true for neurodevelopmental disorders of children (Goldstein & Reynolds, 1999; Lezak, 1995). In situations when a patient's medical condition or injury is the underlying mechanism for the development of a mental illness (e.g., Traumatic Brain Injury or when a seizure disorder causes neurological damage that results in amnesia), the primary diagnosis was listed in Axis I (Mental Disorder due to a General Medical Condition) and the medical condition was specified in both Axis I and Axis III.

Axis IV was reserved for recording environmental and psychosocial events that may negatively impact a person's functioning, treatment, or prognosis (see Table 8.1). Multiple events could be listed in that domain, but usually only those that had relevance within the past year were included (e.g., helping a client process the loss of a friend). Finally, the patient's overall level of functioning during a given time period was recorded on Axis V. On this axis, the clinician used clinical judgment to provide an indication of the patient's symptom severity and impairment of functioning utilizing the Global Assessment of Functioning (GAF) scale provided in the DSM for coding (APA, 1987; Yamauchi, Ono, Baba, & Ikegami, 2001). The GAF ratings were an estimate of the degree to which the patient's diagnoses along the previous four axes impaired the ability to engage in skills and behaviors necessary for daily living across three domains (psychological, social, and occupational/educational). The predominant purpose of the GAF was to consider the patient's symptom severity and functioning to provide an indication of the need for treatment intensity and as a measure of progress monitoring (Endicott, Spitzer, Fleiss, & Cohen, 1976; First, 2004; Gamst, Dana, Der-Karabetian, & Kramer, 2004; Woldolf, 2005).

The DSM-III multiaxial structure changes led to a significant overall increase in interrater diagnostic agreement for adult disorders (Spitzer, Forman, & Nee, 1979). Another advancement provided by the DSM-III was the inclusion of more childhood and adolescent diagnostic categories than the DSM-II. However, unlike the adult categories, the child/adolescent criteria were not as well-established, and therefore, did not lead to a significant improvement in diagnostic agreement between clinicians at that time (Mattison, Cantwell, Russell, & Will, 1979).

Descriptions of each diagnostic disorder in the DSM-III also included information on age of symptom onset, etiology, course, sex differences, associated features, and differential diagnoses. Most notably, behavioral and cognitive manifestations of the symptoms of each illness were described. This allowed clinicians to make more objective, yes-or-no decisions regarding patient diagnoses. The third edition (DSM-III-R) was revised in 1987 to clarify inconsistencies and errors in the DSM-III (APA, 1987).

### 8.1.3 DSM-IV (APA, 1994) and DSM-IV-TR, (APA, 2000) Editions

It has been widely argued that the publication of the DSM-III revolutionized clinical diagnosis of mental illnesses (McBurnett, 1996). However, the manual still had criticisms regarding the vague criteria of some categories of psychopathology and thus a fourth edition of the manual was necessary and preparation began in 1987. The resulting manual was formed utilizing the input of over 1000 professionals in various professions and 13 distinct work groups (APA, 2000) and published in 1994. The DSM-IV carried forward the multiaxial tradition of the DSM-III and retained the GAF scale with scores ranging from 0 to 100.

Each diagnostic category in the DSM-IV contained detailed and specific information to guide the diagnosis and educate the reader about the etiology and course of the diagnosis. Several broad categories of information were systematically included for each diagnostic category including Diagnostic Features, Associated Features and Disorders, Specific Age, Gender, and Culture Features, Prevalence, Course, Familial Patterns, and Differential Diagnoses. In addition, some categories also included information about subtypes and specifiers and the procedures for recording that information.

Subsequently, the DSM-IV-Text Revision (DSM-IV-TR; APA, 2000) was published in 2000 to correct some factual errors in the DSM-IV and to add more current research for the listed conditions. The DSM-IV-TR contained the same disorders and symptoms lists in the DSM-IV as well as an appendix of the October 2000 updated International Statistical Classification of Diseases and Related Health Problems—9th Edition, Clinical Modification (ICD-9-CM) codes (National Center for Health Statistics, 1989). The ICD-9-CM is a clinical modification of the International Classification of Diseases: Ninth Revision (ICD-9). It was adapted by the United States National Center for Health Statistics to record additional morbidity data for US hospitals that was not represented in the ICD-9 system (APA, 2000; WHO, 1977). These codes were important as they could be utilized on Axis III of the DSM-IV-TR to note medical disorders that affect mental health issues, thus acknowledging the reciprocal interactive nature of some physical and mental health disorders. ICD codes are also important because they are required in some settings by agencies and insurance companies to acquire financial reimbursement for some services, including evaluation or rehabilitation. The codes for the tenth edition of the ICD (ICD-10) also were noted in a DSM-IV-TR appendix, although they were not yet implemented in the US (WHO, 1992). Finally, the DSM-IV-TR listed several mental conditions that were gathering increasing attention and research; therefore, might appear in the next DSM, edition five.

### 8.1.4 DSM-5 (APA, 2013) Edition

The publication of the DSM-5 in 2013 represents more than half a century of efforts since its first edition in 1952 to refine the definitions, characteristics, and diagnostic criteria of mental illness. The development process began in 1999 with efforts to organize the procedures. In 2007, multiple scholars formed the DSM task force and set about the process of formulating 13 work groups to address proposed DSM-5 revisions over the next 2 years. In 2010, field trials began in large academic medical centers as well as routine clinical practices. Following the input and work of 400 professionals, as well as public comment opportunities, a final draft of the manual was approved by the APA Board of Trustees in 2012 and published in 2013 (APA, 2013; Kupfer, Kuhl, & Regier, 2013).

As with prior versions, the DSM-5 discusses the manual's basic format in Section I. However, Section II advances significant changes in both the structure of the manual and parameters for some specific diagnoses. Among the more salient changes is a move away from the multiaxial systems of classification utilized for the DSM-III and DSM-IV editions as prior critique of these versions had brought into question both the reliability and the validity of the multiaxial approach (Hilsenroth et al., 2000; Moos, McCoy, & Moos, 2000; Moos, Nichol, & Moos, 2002; Startup, Jackson, & Bendix, 2002). Additionally, the use of the GAF received significant negative reviews, thus also was dropped from the DSM-5 version (Moos et al., 2002; Pearsma & Boes, 1997; Söderberg, Tungström, & Armelius, 2005; Swartz, 2007). In contrast to DSM-IV, the DSM-5, Section II, arranges 22 chapters (see Table 8.2) based on a lifespan approach, thus keeping disorders that emerge in childhood in the beginning chapters with a neurodevelopmental perspective and organizing disorders that appear in adulthood toward the end of the manual with a neurocognitive perspective (APA, 2013, p. xlii). A second purpose of the reorganization of disorders is to better correspond with the pending publication of the ICD-11 (p. xli, 11).

**Table 8.2** DSM-5 Section II—diagnostic criteria and codes

| |
|---|
| Neurodevelopmental disorders |
| Schizophrenia spectrum and other psychotic disorders |
| Bipolar and related disorders |
| Depressive disorders |
| Anxiety disorders |
| Obsessive-compulsive and related disorders |
| Trauma- and stressor-related disorders |
| Dissociative disorders |
| Somatic symptom and related disorders |
| Feeding and eating disorders |
| Elimination disorder's |
| Sleep-wake disorders |
| Sexual dysfunctions |
| Gender dysphoria |
| Disruptive, impulse-control, and conduct disorders |
| Substance-related and addictive disorders |
| Neurocognitive disorders |
| Personality disorders |
| Paraphilic disorders |
| Other mental disorders |
| Mediation-induced movement disorders and other adverse effect of medication |
| Other conditions that may be a focus of clinical attention |

Section III of the text includes discussion of emerging assessment measures, cultural formation considerations, an alternative DSM-5 model for personality disorders, and conditions for further study. The assessment measures discussed (pp. 733–736) note that there are limitations to categorical approaches to diagnosis given that individuals may not present with symptom clusters that exactly match a DSM-provided criteria, symptoms present in differing severity/frequency across individuals with the same syndrome, and overlap or comorbid symptomology is not rare. The authors also note that this lack of specificity may result in over-usage of the not-otherwise-specified (NOS) diagnoses found in prior versions of the DSM. Therefore, measurements are discussed in lieu of a dimensional perspective to diagnosis.

Dimensional measurement often utilizes self-reported descriptions of symptoms, but also can use ratings or surveys. The DSM-5 discusses cross-cutting symptom measures that review important pathology by domains and offers two levels of forms; adult and child versions that can be used by practitioners. A self-report measure of disability offered through the World Health Organization also is reviewed and a sample protocol is provided. All of the forms for the measures discussed in this section are publically available at www.psychiatry.org/dsm5 for download. The cultural formation portion of section III provides a definition of culture, race, and ethnicity as well as outlines of cultural identity of the individual, cultural conceptualization of distress, psychosocial stressors and cultural features of vulnerability and resilience, cultural features of the relationship between the individual and the clinician, and an overall cultural assessment (pp. 749–759). Additionally, a detailed description of a cultural formation interview (CFI) is provided. Although Section II of the DSM-5 presented chapters on specific current criteria for personality disorders, Section III also discusses a new approach for diagnosis of several of these including antisocial, avoidant, borderline, narcissistic, OCD, and schizotypal (pp. 761–781), which acknowledges a functioning and pathological traits perspective. A new diagnosis of personality disorder that is trait-specified (PD-TS) is presented. The final portion of Section III provides proposed diagnostic criteria, for several new syndromes that are being researched and under consideration (e.g., attenuated psychosis syndrome, persistent complex bereavement disorder, caffeine use disorder, internet gaming disorder, nonsuicidal self-injury). These disorders may appear in subsequent revisions of the DSM if research establishes their validity (pp. 783–806).

The appendices offer listings of the ICD-9-CM and ICD-10-CM codes corresponding with DSM-5 diagnoses and are often used for insurance billing purposes as well as statistical data collection by hospitals. US reporting standards require changing the use of the ICD-10-CM codes as of October 1, 2014 (APA, 2013, p.839). Additionally, there is an appendix of cultural concepts of distress to make clinicians aware of syndromes that may be expressed by clients from diverse backgrounds. As an example, Kufungisisa translated as “thinking too much” reflects distress associated with headache and dizziness when thoughts are preoccupied with life stressors. This syndrome and similar components are found in Shona and

Nigerian cultures. Thus, practitioners serving individuals from these cultures may find this information enhances clinical understanding of these patients' perceptions and expressions of distress. This section coupled with the cultural formation portion of Section III of the DSM-5 offers additional resources in promoting professional considerations for cultural factors in diagnoses.

**Diagnostic criteria and codes**. Although there is some variation, the diagnostic criteria chapters within Section II are generally formatted similarly. They start with a Diagnostic Criteria box that delineates specific symptoms, sometimes including the age of onset, as well as duration and frequency of symptoms. This box also may contain coding notes and specifier codes. For example, the Diagnostic Criteria for Intellectual Disability (APA, 2013, p. 33) indicates onset must occur during the developmental period and both intellectual functioning and adaptive functioning deficits must be present. Additionally, the criteria include coding notes for the ICD-9-CM and alerts practitioners to the fact that the ICD-10-CM code requires new specifiers (i.e., mild, moderate, severe, profound). When specifiers for severity are indicated, the DSM-5 provides detailed descriptors to assist examiners in determining which code is most appropriate.

*Diagnostic features.* The Diagnostic Features text is found in each chapter following the Diagnostic Criteria and provides information about the defining characteristics of a disorder and describes the features that are usually consistent with the disorder. Symptoms described in this section are essential for making the diagnosis. In addition, illustrative examples are often provided. Again using the example of Intellectual Disability, the diagnostic features portion indicates the exact score ranges that meet criteria for a deficit in intellectual functioning (i.e., approximately two standard deviations below the mean, APA, 2013, p. 38).

*Associated features supporting diagnosis.* The associated features section includes information related to the descriptive clinical features of a disorder that are nonessential for diagnosis. For example, the Associated Features and Disorders section under Intellectual Disability diagnosis lists possible difficulties with self-management of behavior and interpersonal relationship, although this is not a symptom that must be present for diagnosis. Also reported in this section are any associated physiological and/or anatomical laboratory findings that can be (a) used for diagnosis; (b) associated with the disorder, but not necessary for diagnosis; or (c) are related to complications with the disorder. For example, under the diagnostic criteria for Alcohol Intoxication it is noted that the presence of "very high blood alcohol levels (e.g., 200/300 mg/dL) can cause inhibition of respiration and pulse and even death (p. 498).

*Prevalence.* One of the purposes of the manual is to provide a forum by which to communicate statistical information regarding the prevalence of mental disorders. This section meets this goal by presenting statistical information related to the prevalence of the specific diagnostic disorder and is included for all diagnostic categories. Increasing trends in national identification rates as well as differing gender and age manifestations also may be noted.

*Development and course.* The information included in the Development and Course section under each diagnostic category describes the lifetime patterns and prognosis related to the mental disorder. The typical age and nature of onset is depicted, as is the recurring nature of the disorder. For example, this section will describe whether a specific diagnosis is episodic (it occurs occasionally and is marked by periodic absence of symptoms) or continuous (untreated symptoms remain present). The length of each duration of episodes and likelihood for recurrence are also recorded. Additionally, the section may discuss differing trajectories based on associations with genetic syndromes or other factors.

*Risk and prognostic factors.* Finally, the prognosis of symptom severity (e.g., worsening, alleviating) over time is also indicated. Information on genetic, physiological, and environmental influences may be provided depending on the disorder. This knowledge is valuable in treatment planning as well as educating the patient or guardians on the long-range implications for managing symptoms.

*Culture-related diagnostic issues.* Information included in this section communicates the variability of the diagnostic features and prevalence of the disorder that may be due to demographic and cultural differences among patients. This section also reminds professionals of the importance of cultural formation knowledge and sensitivity during any assessment.

*Gender-related diagnostic issue.* The manual also indicates any gender differences in prevalence or diagnostic features (or the lack of gender differences), when relevant. For example, under Separation Anxiety Disorder, it is noted that girls have higher rates of school avoidance than boys, although indirect fear characteristics may be more prevalent for boys with the disorder (APA, 2013, p. 193).

*Diagnostic markers.* The required components of a thorough assessment are mentioned in this section and may include intelligence, adaptive, academic, or personality measures as well as known metabolic screening or neuroimaging evaluation methods.

*Differential diagnosis.* Some disorders have overlapping symptoms or yield similar symptoms to one another. In addition, some symptoms are a result of physical health conditions rather than mental health diagnoses. Therefore, this section is included to provide the clinician with information regarding how to make decisions about diagnosis that rule-out disorders with shared symptomology. Typically, specific examples of differentiating diagnoses are provided. As an example, the Differential Diagnosis section of the criteria for Attention-Deficit/Hyperactivity Disorder (ADHD) discusses 16 different diagnoses that can be misidentified as ADHD and therefore alerts examiners to distinguishing factors (APA, 2013, pp. 63–64). The process of differentiating disorders is essential to avoiding misdiagnosis as well as increasing treatment efficacy. Some diagnoses also may have a section on Comorbidity, which specifies prevalence rates of diagnoses that often coexist.

**DSM-5 Important diagnoses changes.** Although many of the mental health diagnoses have long been established and continue to garner support (e.g., anxiety, depression), some have been changed from the DSM-IV to the new DSM-5 to reflect emerging research. The following list provides some of the changes highlighted by authors of the DSM-5 (APA, 2013, pp. 809–816). This listing is not intended to be comprehensive as the DSM-5 has 947 pages of complex diagnoses information.

- Mental Retardation was renamed Intellectual Disability adhering to the new common nomenclature addressed in public law and advocacy since the last publication of DSM (e.g., American Association of Intellectual and Developmental Disabilities, 2014).
- Communication Disorders were renamed (i.e., Language Disorder, Speech Sound Disorder, Social [Pragmatic] Communication Disorder)
- Autism Spectrum Disorder incorporates and replaces prior diagnoses of Asperger's Disorder, Childhood Disintegrative Disorder, Rett's Disorder, and Pervasive Developmental Disorder
- ADHD age of onset was changed to prior to age 12 and *subtypes* were replaced with "presentation" specifier terminology
- SLD combines the prior terms of *reading disorder, mathematics disorder, disorder of written expression, and learning disorder NOS* for specific learning disorder and a discrepancy between intelligence and achievement is not required for diagnosis
- Under the Depressive Disorders, a new diagnosis of Disruptive Mood Dysregulation Disorder is included, what used to be called dysthymia is now under Persistent Depressive Disorder, and the bereavement exclusion is removed from Major Depressive Episode.
- Under Anxiety Disorders, Specific Phobia and Social Anxiety remove the requirement that persons over 18 recognize that the anxiety is excessive
- The use of *not-otherwise-specified* (NOS) disorders are replaced with new terminology (e.g., other specified disorder and unspecified disorder)
- In addition to core review of Personality Disorders diagnoses, an alternative approach to some of these diagnoses is provided in the appendices
- Additionally, some criteria changes also are reflected in specific diagnostic categories (e.g., Schizophrenia [eliminated all subtypes—paranoid, disorganized, catatonic, undifferentiated, and residual], Obsessive-Compulsive and Related Disorders, Bipolar and Related Disorders, Trauma- and Stressor-Related Disorders [two former subtypes: Reactive Attachment Disorder and Disinhibited Social Engagement Disorder became diagnoses], Dissociative Disorders, Somatic Symptom and Related Disorders, Feeding and Eating Disorders, Elimination Disorders, Sleep-Wake Disorders, Sexual Dysfunctions, Gender

Dysphoria; Disruptive, Impulse-Control, and Conduct Disorders, Substance-Related and Addictive Disorders, Neurocognitive Disorders, and Paraphilic Disorders)

The new DSM-5 has made significant changes that many scholars consider advancements in mental health diagnoses (APA, 2013; Kupfer et al., 2013). To summarize, those include a developmental lifespan organization strategy for chapters that emphasizes the genetic and biological origins of many disorders emerging in childhood as compared to those emerging later in life and reflecting a neurocognitive ethiology. This new strategy moves away from the problematic multiaxial system of classification as well as the use of the GAF. The inclusion of a section on measurement with multiple online tools (e.g., severity rating scales, disability measure) for general use by practitioners may also be considered innovative. Utilization of these scales has the potential to promote a more dimensional or quantitative approach to determining diagnosis in contrast to the prior categorical focus. Eliminating the NOS diagnosis is hoped to reduce overdiagnosing and new descriptors and tables of specifiers are perceived as improvements to clarifying severity of symptoms. The manual also offers additional resources when considering cultural factors through inclusion of an explanation for the cultural formation interview technique, availability of online cultural interview forms, and an updated Cultural Concepts of Distress appendix. Additionally, the text has offered revisions to diagnosis criteria across multiple diagnoses to better reflect emerging research findings.

### 8.1.5 DSM Limitations

As noted previously, the DSM has made advances in providing mental health professionals an important comprehensive guide to diagnoses. It has made significant changes with each edition and will continue to evolve as practice demands change and research informs treatment (Borstein, 1998; Watson, 2005; Widiger & Samuel, 2005). However, in looking forward to better serving the mental health needs for future patients, a number of limitations in the DSM structure also continue to be questioned (Greenberg, 2013).

*Categorical approach.* At this time, the new DSM-5 has introduced some dimensional measurement concepts, especially related to determining severity. This is evident in the new measurement section which offers cross-cutting symptom measures, access to the WHO Disability Assessment Schedule as well as more detailed descriptors of specifiers for some diagnoses including a few matrix examples (e.g., Intellectual Disabilities). However, the manual is still primarily a categorical approach and some scholars argue this assumes a disorder is either present or not, rather than perceiving symptoms on a continuum (e.g., low, at-risk, clinically significant). Disorders are presumed to be distinct from each other and from normal functioning. The DSM also is based on a medical model of identifying pathology and assumes maladaptive functioning within the patient. Kupfer et al. (2013) note that in an age when medicine is able to define normal, at-risk, and high risk thresholds for disease (e.g., cholesterol, blood pressure), it stands to reason that the practice of psychiatry/psychology also has this capability. In fact, many norm-reference rating scales (e.g., Behavioral Assessment of Children [BASC], Reynolds & Kamphaus, 2004) exist that can define the frequency of reporting common mental health symptoms such as depression or anxiety and distinguish pathological from nonpathological levels. The use of more objectively defined criteria may assist diagnosis accuracy.

*Comorbidities and symptom overlap.* Comorbidities are common and can further complicate the distinctions between diagnoses, especially when there are overlapping symptoms (Aragona, 2009). In addition, there is variability of the clustering of symptoms within a diagnostic category. Thus, two patients with the same diagnosis may exhibit markedly different behavioral patterns. As an example, in both the older versions and the new DSM-5, Oppositional Defiant Disorder lists eight symptoms, four of which are required for a diagnosis. In this particular case, it is possible for two clients to both have ODD and not share even one of the eight symptoms. This heterogeneity among many disorders, as defined by the DSM, does not provide strong discriminate validity for differential diagnosis or presumed divergent etiologies for some disorders.

Some authors have suggested viewing mental health issues in alternative paradigms that acknowledge there is not always a clear boundary between normal and pathological and describe mental health functioning on a multi-dimensional spectrum (Ball, 2001; First, 2005; Krueger, Markon, Patrick, & Iacono, 2005; Sirgiovanni, 2009). Considerations have included a continuum from healthy to maladaptive functioning, distinguishing internalizing from externalizing symptoms, as well as defining diagnosis in terms of protective and vulnerability factors (Achenbach, 1985; Mash & Barkley, 2003; Widiger & Trull, 2007). Other authors argue for organization of mental health disorders based on the common biological underpinnings of brain function that are related to specific disorders (Jabr, 2013). It is suggested that these changes would also enhance the DSM by creating a more direct link from diagnosis to treatment. Currently, the DSM model does not offer guidance on treatment which is yet another criticism.

*Traits versus states.* A long-standing concern for the utility of the DSM has been that many diagnoses are made based on traits treated as static and stable when in fact personality traits change over time even among persons without mental disorders (Widiger & Trull, 2007). Some diagnostic criteria of impairment are merely states and not enduring traits (e.g., loss of appetite). These types of trait symptoms remain in the current DSM-5. The transient nature of states and traits can lower consistency in ratings over time. This approach has little emphasis on an ecological perspective that would include documenting the mental health hospitalizations examinating the support networks of patients to better promote understanding of disabilities within a psychosocial context (Kerig, 2006; Mash & Barkley, 2003; Routh, 1990).

*Variability in diagnostic assessment methods and data.* Another issue inherent in DSM diagnosis is the variation among professionals in how they gather information to establish diagnostic criteria. In the absence of clear DSM guidance for types of data to collect, the type of assessment will depend on the orientation of the diagnostician. This results in considerable variation of testing measures and/or observation skills and the dependence on clinical judgment by the examiner. Not all patients within a diagnostic category will receive the same type of evaluation, thus decisions are being made with a wide variation in the rigor of diagnostic data. The assessment/diagnosis style of physicians, social workers, counselors, and psychologists as well as other mental health professionals may depend heavily on their particular training orientation. Kupfer et al. (2013) note that although the manual is written for psychiatrists and the new dimensional measures may assist them in moving toward less categorical and subjective diagnoses, a significant proportion of diagnoses are provided by other practitioners, often physicians. Patients generally first approach their primary care providers when experiencing distress and these professionals may not have training in the objective assessment of mental health disorders. Therefore, the inclusion of thresholds along a continuum from normal to pathology could improve the diagnostic accuracy for non-psychiatrists. Ultimately, a DSM with a strong emphasis on dimensional measurement could afford more accurate diagnoses across disciplines. The new DSM-5 does include some guidance on evaluation components on some diagnosis under the new Diagnostic Markers sections; however, this is generally quite brief, often one to two sentences, and broadly stated.

Best practices in psychological assessment require selection of instruments and methods that meet standards for reliability, validity, and fairness (American Educational Research Association, 1999). The DSM does not require this adherence through provision of guidance on assessment batteries or diagnoses techniques within its criteria for disorders. These choices are made by individual practitioners and therefore may vary across patients, settings, and disciplines. Training and credentialing standards address broad competencies in psychological services. In addition, there are a number of ethical and professional guidelines practitioners can reference for these decisions. They include *The Ethical Principles of Psychologists and Code of Conduct* (American Psychological Association, 2002a), *Code of Fair Testing Practices in Education* (American Psychological Association, 2003), *Professional Practice Guidelines for Psychotherapy with Lesbian, Gay and Bisexual Clients* (American Psychological Association, 2000), *Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists* (American Psychological Association, 2002b), *Responsibilities of Users of Standardized Tests* (Association of Assessment in Counseling, 2003), *and the Standards for Educational and Psychological Testing* (AERA, 1999). However, the DSM does not routinely and directly reference these standards in providing diagnostic guidance.

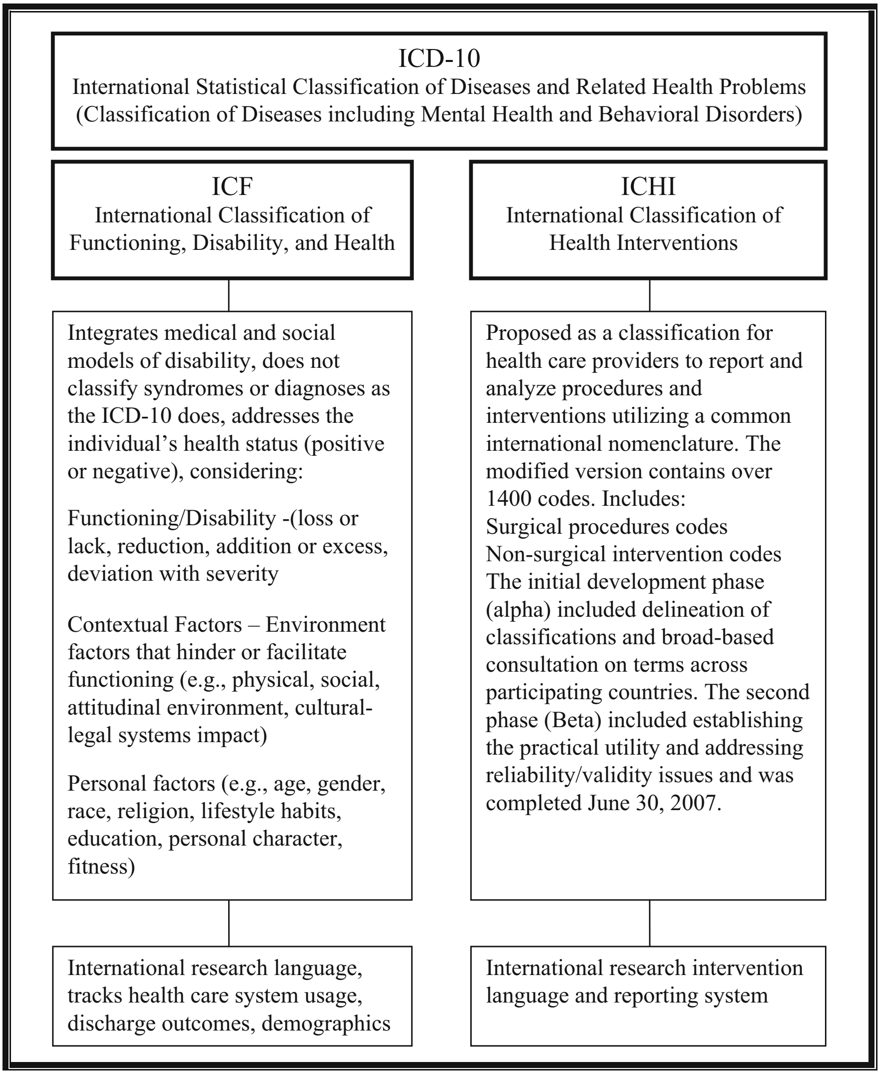
#### 8.1.5.1 DSM Diagnosis with Children and Adolescents

*Neglecting child and adolescent diagnosis.* Another limitation of the DSM is the focus on criteria in adult terms. There is a lack of discussion of developmental norms, trajectories, and early emerging risk factors that make the use of the DSM especially problematic in the diagnosis of children and adolescents. This may be particularly important as the prevalence estimates for DSM-IV disorders were 46.4 % with onset for half of the disorders before age 14 and 75 % by age 24 (Kessler et al., 2005). Given the majority of mental health needs will manifest symptoms during the childhood through postsecondary age range, the need for more information on these disorders is important to practitioners serving this age range. Wodrich, Pfeiffer, and Landau (2008) note that practitioners serving this age range particularly need enhanced DSM information on the epidemiology, progression, as well as causes and treatments for childhood disorders. In an effort to address this need, the *Diagnostic and Statistical Manual for Primary Care* (DSM-PC) was created, although it has not enjoyed wide usage (Wolraich, Felice, & Drotar, 1997). A second system, the DC: 0–3 written by the Diagnostic Classification Task Force for the Zero to Three/National Center for clinical Infant Programs, provides diagnostic guidelines for infants through toddlers age three. A multiaxial system was designed to include primary diagnosis, relationship disorder classifications, medical and developmental disorders and conditions, psychosocial stressors, and functional emotional development (Zero to Three/National Center for Clinical Infant Programs, 1994).

## 8.2 World Health Organization Family of International Classifications: ICD, ICF, and ICHI

The DSM is a well-respected and important diagnostic instrument within the US mental health care system; however, it is not utilized in many other countries. In the DSM-5, an effort has been made to further align with the International Classification of Diseases (ICD) tenth edition including a requirement that diagnoses be coded for ICD-10 after October 2014. The ICD ninth edition codes are currently utilized by the National Center for Health Statistics and Centers for Disease Control and Prevention to track national health care data including mental health hospitalizations. The International Statistical Classification of Diseases and Health Related Problems (ICD-10) provides a universal framework for the diagnostic classification of disorders, diseases, and health conditions (see Box 8.1). In addition, the World Health Organization has addressed some of the limitations of utilizing a diagnostic classification manual to fully assess impairment and inform intervention (Madden, Sykes, & Ustun, 2007). The system provides three separate comprehensive manuals each addressing a distinct area; classification of diseases, classification of functioning, and classification of interventions. This section will briefly review the development of the ICD, merging trends between the DSM and ICD, as well as implications for a common classification and statistical data system.

**Box 8.1: World Health Organization Family of International Classifications**



ICD-10
International Statistical Classification of Diseases and Related Health Problems
(Classification of Diseases including Mental Health and Behavioral Disorders)

ICF
International Classification of Functioning, Disability, and Health

Integrates medical and social models of disability, does not classify syndromes or diagnoses as the ICD-10 does, addresses the individual's health status (positive or negative), considering:

Functioning/Disability -(loss or lack, reduction, addition or excess, deviation with severity

Contextual Factors – Environment factors that hinder or facilitate functioning (e.g., physical, social, attitudinal environment, cultural-legal systems impact)

Personal factors (e.g., age, gender, race, religion, lifestyle habits, education, personal character, fitness)

International research language, tracks health care system usage, discharge outcomes, demographics

ICHI
International Classification of Health Interventions

Proposed as a classification for health care providers to report and analyze procedures and interventions utilizing a common international nomenclature. The modified version contains over 1400 codes. Includes:
Surgical procedures codes
Non-surgical intervention codes
The initial development phase (alpha) included delineation of classifications and broad-based consultation on terms across participating countries. The second phase (Beta) included establishing the practical utility and addressing reliability/validity issues and was completed June 30, 2007.

International research intervention language and reporting system

## 8.2.1 History of the ICD

Systematic attempts to classify diseases and causes of death may have begun as early as the 1500s. Recovered portions of the London Bills of Mortality indicate records by parishes of births, christenings, and burials from 1592. These documents were utilized to make primitive mortality estimates and determine longevity as well as prevalent types of death. Causes of death included accidents (e.g., bit by mad dog) and illness (e.g., scurvy, swinepox). In addition, a number of deaths were attributed to what may now be considered mental health issues (e.g., grief, lunatique). Rudimentary efforts were made to understand data patterns across groups and health issues for society as a whole. For example, a large number of abortive, stillborn, and childbed deaths noted the blight of young children. One particular record indicates only 64 out of 100 children remained alive at age six and only 25 still remained alive at age 26. Early pioneers in collecting and reviewing these data included John Graunt and Franciois Bossier de Lacroix (Stephan, 2007; WHO, 2007a, 2007b).

In 1853, the first International Statistical Congress initiated the preparation of a formal international classification system that could track morbidity data across countries. The work of William Farr and Marc d'Espine resulted in a rubric classification approach that was revised several times between 1864 and 1886. In 1893, the International Statistical Institute furthered this work by adopting Bertillon's Classification of Causes of Death, which included nomenclature from the English, German, and Swiss systems (see Table 8.3). The American Public Health Association later adopted Bertillon's classification in 1898 (WHO, 2007b).

The first international conference for the revision of Bertillon's classification, renamed the International List of Causes of Death (ICD-1), was held in 1900 with 26 countries participating. To acknowledge the importance of collecting data not just on death, but also illnesses and public health, a second classification system for diseases also was adopted. Subsequent conferences resulted in the second and third revisions (ICD-2 in 1909; ICD-3 in 1920). Fourth and fifth versions (ICD-4 in 1929; ICD-5, 1938) created more sophisticated statistical utility of the classifications and morbidity data system. In addition, the revisions included broader collaboration across experts and the International Statistical Institute shared responsibility for development with the Health Organization of the League of Nations.

Subsequent revisions have been completed under the oversight of the World Health Organization (ICD-6 in 1948; ICD-7, 1955; ICD-8, 1968; ICD-9, 1968; ICD-10, 2003) and the eleventh edition is pending with expected completion in 2015. Following publication of the ICD-9, the United States created a clinical modification (ICD-9-CM) of the codes (WHO, 1977) that was adapted by the United States National Center for Health Statistics to record additional morbidity data for US hospitals. The US Department of Health and Human Services directs all changes to the clinical modifications and updates are available annually (APA, 2000).

The DSM-5 appendices contain listings of both the ICD-9-CM and ICD-10 codes to facilitate hospital and agency data collection as well as some financial reimbursements. The inclusion of these general medical disorders permits DSM-5 diagnoses that acknowledge the interaction between some medical and mental health disabilities. The current DSM-5 codes and terminology were organized to correspond with Chap. 5 of the ICD-10, Mental and Behavioral Disorders, codes which are now utilized by many countries and will eventually be implemented in the US (APA, 2013).

**Table 8.3** Comparison ICD/ICF and DSM development

| ICD/ICF | | DSM | |
|---|---|---|---|
| Bertillon classification of causes of death adopted—International Statistical Institute | 1898 | Convergent development of the DSM, ICD, and ICF | |
| ICD-1 International List of Causes of Death (also parallel classification of diseases)—International Statistical Institute | 1900 | Diagnostic models | |
| ICD-2 International List of Causes of Sickness and Death (also parallel classification of diseases)—International Statistical Institute | 1910 | | |
| ICD-3 International List of Causes of Death—International Statistical Institute | 1920 | | |
| ICD-4 International List of Causes of Death—International Statistical Institute and the Health Organization of the League of Nations | 1929 | | |
| ICD-5 International List of Causes of Death—International Statistical Institute and the Health Organization of the League of Nations. | 1938 | | |
| ICD-6 International List of Diseases and Causes of Death—World Health Organization | 1948 | | |
| ICD-7 International Classification of Diseases—World Health Organization | 1955 | | |
| ICD-8 International Classification of Diseases—World Health Organization | 1968 | 1952 | DSM-I, vague criteria focused on psychological “reactions” |
| ICD-9 International Classification of Diseases—World Health Organization | 1975 | 1968 | DSM-II, dropped term “reactions”, add symptoms |
| ICD-9-CM International Classification of Diseases, Version 9, Clinical Modifications | 1977 | 1980 | DSM-III, explicit diagnostic criteria; multiaxial system |
| ICD-10 International Classification of Diseases—World Health Organization | 1992 | 1987 | DSM-III-R, clarified inconsistencies in DSM-III |
| ICF International Classification of Functioning, Disability and Health | 2001 | 1994 | DSM-IV, empirical support, data analysis, and field trials |
| ICD-10-CM | 2003 | 2000 | DSM-IV-TR, updated errors, ICD-9-CM/ICD-10 codes |
| ICF—World Health Assembly (2001) | | | |
| ICD-11 (anticipated 2018) | 2018 | 2013 | DSM-V |

### 8.2.2 Implications for ICF Framework in Assessing Function

Another important diagnostic tool, the International Classification of Functioning, Disability, and Health (ICF), is used in conjunction with the ICD-10 to identify health and health-related functioning levels. The ICF classifies functioning in the context of interactions between health characteristics or limitations and individual or environmental factors. This model suggests that a diagnosis or disability classification alone should not dictate the services provided and evaluation should directly inform treatment or intervention (Reed et al., 2005). In some ways, the ICF addresses limitation issues that have been presented regarding the DSM's lack of emphasis on specific functioning measurement and consideration for environmental context.

The ICF approach to determining treatment needs emphasizes a comprehensive analysis of the individual and his/her resources. The ICF coding provides a two-part evaluation documentation system that (1) considers components of body functions and structures with impact on activities and participation as well as (2) contextual factors. The emphasis on body functions delineates several aspects directly related to the work of psychologists. These include global mental functions, temperament, personality, attention, memory, and emotional functioning. In addition, body functions address sensory and neuromusculoskeletal functions related to physical impairments (e.g., vision). Atypical bodily functions may be considered impaired yet not problematic, if they do not diminish activities and participation in life functions. Analysis of activities and participation includes review of the individuals learning, knowledge application, communication, mobility, self-care, and interpersonal relationships. The ICF also requires practitioners to assess environmental factors that may impede or facilitate the individual's progress. This includes assistive products and technology, support relationships, attitudes, agency services, and public policies (Bruyere, Van Looy, & Peterson, 2005; Reed et al., 2005; WHO, 2001).

With the emphasis on simultaneous consideration for body function, activity level, and participation factors, the ICF model provides a synopsis of individual strengths and needs. The model acknowledges that a physical impairment may exist with or without a negative impact on performance depending on other facilitating factors. The model emphases that impairment's effect on performance is also subject to change over time. An understanding of this approach may enhance collaboration on treatment regimens for persons comorbid for both mental health and general medical disorders as it is used by many health professionals.

Recognition of the need to also classify and track intervention and treatment procedures has resulted in development of a third manual in the WHO classification systems. The International Classification of Health Interventions (ICHI) concept was first proposed in 1971 and field trials of a modified version were completed in June of 2007.

### 8.2.3 Integration of the DSM, ICD, and ICF

As the DSM and ICD codes become closer aligned and cross data systems are created, the utilization of a common international taxonomy has immense implications for understanding mental health issues across cultures, environments, and within differing medical systems. Analysis of these data has the potential to inform social policy, treatment, and research. Clinical implications include creating a common language for diagnosis and treatment that facilitates multidisciplinary collaboration. This is particularly important for persons with neurological impairments or comorbid disabilities as those cases require working in tandem with other service providers. Comparisons across differing health care systems in countries can serve to inform best practices in managed care. With the inclusion of the ICF emphasis on functional impact, issues such as the level of care, disability benefits, and work performance are also directly addressed in the diagnostic process. Research implications include creating a unified framework that permits an international database of mental health symptoms, treatment, and outcomes. Analyses of these data across nations can expand scientific knowledge to better inform etiology across the lifespan and across cultures.

## 8.3 Summary

The DSM provides a sophisticated and encompassing guide for the multifarious task of diagnosing mental disorders. It represents the combined expertise of a broad range of nationally and internationally recognized scholars and agencies. The metamorphosis from the original DSM-I with three major categories to the current DSM-5 with 22 categories reflects significant advances in mental health research. The relationship between the DSM and the assessment of impairment is important as most diagnoses are accompanied by some level of diminished functioning. Diagnostic categories also provide a plethora of information pertinent to projecting the course and prognosis for recovery. These data can be utilized in educating patients, as well as designing appropriate treatment supports to diminish impairment. However, as in the past, the DSM remains a work in progress and will no doubt continue to change. Revision issues of importance to the assessment of impairment include operationalizing behavioral descriptions of symptoms, as well as improved validity and reliability for measures of functioning. The inclusion of definitions of impairment that acknowledge severity, the role of culture, environmental factors or situational problems, adaptive behavior, and quality of life issues may also improve utility of the DSM. The progress of critique for the DSM-5 is well underway and no doubt will result in enhancements to the next version as science and policy continue to shape future understanding of mental health.

## References

Achenbach, T. M. (1985). *Assessment and taxonomy of child and adolescent psychopathology*. Beverly Hills, CA: Sage.

American Association of Intellectual and Developmental Disabilities. (2014). *AAIDD calls upon APA to revise proposed diagnosis of "intellectual developmental disorder"*. Retrieved from http://aaidd.org/news-policy/news/article/2012/05/17/aaidd

American Educational Research Association. (1999). *Standards for educational and psychological testing*. Washington, DC: Author.

American Psychiatric Association. (1952). *Diagnostic and statistical manual of mental disorders* (1st ed.). Washington, DC: Author.

American Psychiatric Association. (1968). *Diagnostic and statistical manual of mental disorders* (2nd ed.). Washington, DC: Author.

American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.

American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed., Rev.). Washington, DC: Author.

American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

American Psychological Association. (2000). Professional practice guidelines for psychotherapy with lesbian, gay and bisexual clients. *American Psychologist, 55*, 1440–1451.

American Psychological Association. (2002a). Ethical principles and code of conduct. *American Psychologist, 57*, 1060–1073.

American Psychological Association. (2002b). *Guidelines on multicultural education, training, research, practice, and organizational change for psychologists*. Washington, DC: Author.

American Psychological Association. (2003). *Code of fair testing practices in education*. Washington, DC: Author.

Aragona, M. (2009). The concept of mental disorder and the DSM-V. *Dialogues in Philosophy, Mental and Neuro Sciences, 2*, 1–14.

Association of Assessment in Counseling. (2003). *Responsibilities of users of standardized tests*. Greenboro, NC: Author.

Ball, S. A. (2001). Reconceptualizing personality disorder categories using personality trait dimension: Introduction to special section. *Journal of Personality, 69*, 147–153.

Balon, R. (2006). Mood, anxiety, and physical illness: Body and mind or mind and body? *Depression and Anxiety, 23*, 377–387.

Boekaerts, M., & Röder, I. (1999). Stress, coping, and adjustment in children with a chronic disease: A review of the literature. *Disability and Rehabilitation, 21*, 311–337.

Borstein, R. F. (1998). Reconceptualizing personality disorder diagnosis in the DSM-V: The discriminate validity challenge. *Clinical Psychology: Science and Practice, 5*, 333–343.

Bruyere, S. M., Van Looy, S. A., & Peterson, D. B. (2005). The international classification of functioning, disability, and health: Contemporary literature overview. *Rehabilitation Psychology, 50*(2), 113–121.

Endicott, J., Spitzer, F. L., Fleiss, J. L., & Cohen, J. (1976). The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry, 33*, 766–771.

First, M. B. (2004). *GAF report for Windows: The Global Assessment of Functioning Scale*. Cheektowaga, NY: Multi-Health Systems.

First, M. B. (2005). Clinical utility: A prerequisite for the adoption of a dimensional approach in DSM. *Journal of Abnormal Psychology, 114*, 560–564.

Gamst, G., Dana, R. H., Der-Karabetian, A., & Kramer, T. (2004). Ethnic match and treatment outcomes for child and adolescent mental health center clients. *Journal of Counseling and Development, 82*, 457–465.

Goldstein, S., & Reynolds, C. R. (1999). *Handbook of neurodevelopmental and genetic disorders in children*. New York: Guilford Press.

Greenberg, G. (2013). *The book of woe: The DSM and the unmaking of psychiatry*. New York: Blue Rider Press.

Hilsenroth, M. J., Ackerman, S. J., Blagys, M. D., Baumann, B. D., Baity, M. R., Smith, S. R., et al. (2000). Validity and reliability of the DSM-IV axis V. *American Journal of Psychiatry, 157*(11), 1858–1863.

Jabr, F. (2013). New DSM-5 ignores biology of mental illness. *Scientific American, 308*(5), doi:10.1038/scientificamerican0513-17.

Kerig, P. (2006). *Developmental psychopathology: From infancy through adolescence* (5th ed.). New York: McGraw Hill.

Kessler, J. W. (1971). Nosology in child psychopathology. In H. E. Ried (Ed.), *Perspectives in child psychopathology* (pp. 85–129). Chicago, IL: Aldine-Atherton.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*(6), 593–602.

Krueger, R. F., Markon, K. E., Patrick, C. J., & Iacono, W. G. (2005). Externalizing psychopathology in adulthood: A dimensional-spectrum conceptualization and its implication for DSM-V. *Journal of Abnormal Psychology, 114*, 537–550.

Kupfer, D. J., Kuhl, E. A., & Regier, K. L. (2013). DSM-5—The future arrived. *Journal of the American Medical Association, 309*(16), 1691–1692.

Lezak, M. D. (1995). *Neuropsychological assessment* (3rd ed.). New York: Oxford University Press.

Madden, R., Sykes, C., & Ustun, T. B. (2007). *World health organization family of international classifications: Definition, scope, and purpose*. Geneva, Switzerland: World Health Organization.

Mash, E. J., & Barkley, R. A. (2003). *Child psychopathology* (2nd ed.). New York: Guilford Press.

Mattison, R., Cantwell, D. P., Russell, A. T., & Will, R. (1979). A comparison of DSM-II and DSM-III in diagnosis of childhood psychiatric disorders: Interrater agreement. *Archives of General Psychiatry, 36*, 1208–1213.

McBurnett, K. (1996). Development of the DSM-IV: Validity and relevance for school psychologists. *School Psychology Review, 25*, 259–273.

Moos, R. H., McCoy, L., & Moos, B. S. (2000). Global Assessment of Functioning (GAF) ratings: Determinants and role as predictors of one-year treatment outcomes. *Journal of Clinical Psychology, 56*, 449–461.

Moos, R. H., Nichol, A., & Moos, B. S. (2002). Global Assessment of Functioning ratings and the allocation and outcomes of mental health services. *Psychiatric Services, 53*, 730–737.

National Center for Health Statistics. (1989). *The International Classification of Diseases, 9th revision: Clinical modification* (3rd ed., DHHS Publication No. PHS 89-1260). Washington, DC: Public Health Service, U.S. Government Printing Office.

Pearsma, H. L., & Boes, J. L. (1997). The GAF and psychiatric outcome: A descriptive report. *Community Mental Health Journal, 33*(1), 35–41.

Reed, G. M., Luz, J. B., Bufka, L. F., Trask, C., Peterson, D. B., Stark, S., et al. (2005). Operationalizing the international classification of functioning, disability, and health in clinical settings. *Rehabilitation Psychology, 50*(2), 122–131.

Reynolds, C. R., & Kamphaus, R. W. (2004). *Behavioral Assessment for Children System (BASC-2)* (2nd ed.). Bloomington, MN: Pearson.

Routh, D. K. (1990). Taxonomy in developmental psychopathology: Consider the source. In M. Lewis & S. M. Miller (Eds.), *Handbook of developmental psychopathology* (pp. 53–62). New York: Plenum Press.

Sirgiovanni, E. (2009). The mechanistic approach to psychiatric classification. *Dialogues in Philosophy, Mental and Neuro Sciences, 2*, 45–49.

Söderberg, P., Tungström, S., & Armelius, B. A. (2005). Reliability of global assessment of functioning ratings made by clinical psychiatric staff. *Psychiatric Services, 56*, 434–438.

Spitzer, R. L., & Fleiss, J. L. (1974). A re-analysis of the reliability of psychiatric diagnosis. *British Journal of Psychiatry, 125*, 341–347.

Spitzer, R. L., Forman, J. B., & Nee, J. (1979). DSM-III field trials: Initial interrater diagnostic reliability. *American Journal of Psychiatry, 136*, 815–817.

Startup, M., Jackson, M. C., & Bendix, S. (2002). The concurrent validity of the Global Assessment of Functioning. *British Journal of Clinical Psychology, 41*(4), 417–422.

Stephan, E. (2007). *John Graunt (1620-1674): Observations on the bills of mortality*. Retrieved September 17, 2007, from http://www.ac.wwu.edu/~stephan/Graunt/graunt.html

Swartz, R. C. (2007). Concurrent validity of the Global Assessment of Functioning scale for clients with schizophrenia. *Psychological Reports, 100*(2), 571–574.

Ward, C. H., Beck, A. T., Mendelson, M., Mock, J. E., & Erbaugh, J. K. (1962). The psychiatric nomenclature. Reasons for diagnostic disagreement. *Archives of General Psychiatry, 7*, 198–205.

Watson, D. (2005). Rethinking the mood and anxiety disorders: A quantitative hierarchical model for DSM-V. *Journal of Abnormal Psychology, 114*, 522–536.

Widiger, T. A., & Samuel, D. B. (2005). Diagnostic categories or dimensions: A question for DSM-V. *Journal of Abnormal Psychology, 114*, 494–504.

Widiger, T. A., & Trull, T. J. (2007). Plate tectonics in the classification of personality disorder. *American Psychologist, 62*(2), 71–83.

Wodrich, D. L., Pfeiffer, S. I., & Landau, S. (2008). Contemplating the new DSM-V: Considerations for psychologists who work with school children. *Professional Psychology: Research and Practice, 39*(6), 626–632.

Woldolf, S. B. (2005). Reliability of the Global Assessment of Functioning scale. *Dissertation Abstracts International: Section B, The Sciences and Engineering, 54*(9-B) (UMI No. AAI3148826).

Wolraich, M. L., Felice, M. E., & Drotar, D. (1997). *The classification of child and adolescent metal diagnoses in primary care: Diagnostic and statistical manual for primary care (DSM-PC): Child and adolescent version*. Elk Grove Village, IL: American Academy of Pediatrics.

World Health Organization. (1948). *Manual of the international statistical classification of diseases, injuries, and causes of death* (6th ed.). Geneva: Author.

World Health Organization. (1968). *Manual of the international statistical classification of diseases, injuries, and causes of death* (8th ed.). Geneva: Author.

World Health Organization. (1977). *Manual of international statistical classification of diseases, injuries, and causes of death* (9th ed.). Geneva: Author.

World Health Organization. (1992). *Manual of international statistical classification of diseases, injuries, and causes of death* (10th ed.). Geneva: Author.

World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: Author.

World Health Organization. (2007a). *Report of the 1st meeting of the international advisory group for the revision of the ICD-10 mental health and behavioral disorders*. Retrieved November 1, 2007, from http://www.who.int/mental_health/evidence/icd_advisory_group_meeting_jan_%202007_summary.pdf

World Health Organization. (2007b). *History of the development of the ICD*. Retrieved September 17, 2007, from www.who.int/classifications/idc/en/

Yamauchi, K., Ono, Y., Baba, K., & Ikegami, N. (2001). The actual process of rating the Global Assessment of Functioning Scale. *Comprehensive Psychiatry, 42*, 403–409.

Zero to Three/National Center for Clinical Infant Programs. (1994). *Diagnostic classification of mental health and developmental disorders of infancy and early childhood*. Washington, DC: Author.

# Impairment in Parenting

# 9

Keith D. McGoldrick

## 9.1 Introduction

Parenting can be a rewarding and joyful experience; effective parenting however requires a myriad of abilities and skills to perform. The Merriam-Webster Dictionary (2004) defines parenting as the process of taking care of children until they are old enough to take care of themselves. A more comprehensive definition provided by Davies (2000) notes parenting promotes and supports children physically, emotionally, socially, financially, and intellectually, from infancy to adulthood. From this second definition it is obvious parenting requires a broad skillset that fosters positive growth in children to make them prepared as adults to be resilient, psychologically stable, and intellectually capable to maintain their own care.

Studies on impairment have become more prevalent over the past decade. The American Psychiatric Association and World Health Organization have increasingly identified impairment within psychiatric disorders. Goldstein and Naglieri (2016) noted, "To be impaired means to be unable to perform whatever daily activities are required" (p. __). Identifying the level of impairment in psychiatric disorders is important, since these impairments can result in diminished quality of life and decreased functioning at home, work, or in the community. Impairments that affect parenting broadly encompass those skills that affect a parent's ability to promote and support the physical, emotional, social, financial, and intellectual development of a child or adolescent. Parents who suffer from psychiatric disorders are not only themselves adversely affected but can also additionally affect the family. Psychiatric disorders have been found to adversely impact parenting styles as well as responsiveness to a child's behaviors. Additionally, psychiatric disorders can

---

K.D. McGoldrick, Ph.D. (✉)
Neurology, Learning and Behavior Center,
230 South 500 East, Suite 100, Salt Lake City, UT 84102, USA
e-mail: keith@samgoldstein.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_9

impair cognitive functioning such as multitasking, planning, and organizing, which are critical skills in parenting.

It is important to understand how impairments affect one's daily activities and the ability to parent. Identification of impairments and understanding how they affect parenting is of the utmost importance since this allows for intervention strategies to be implemented as a means to assist the parent and provide the child the greatest opportunities to grow socially, emotionally, and academically. The majority of parents involved with termination of parental rights are affected by cognitive disorders and/or mental illness (Bogacki & Weiss, 2007; Jellinek et al., 1992; Schetky, Angell, Morrison, & Sack, 1979; Wattenberg, Kelley, & Kim, 2001). These cases are largely the result of neglect, not abuse (Lightfoot, Hill, & LaLiberte, 2010). It is hoped that better identification of specific impairments within parenting and supportive programs to assist parents can help decrease the causes of disruption to the parent and child that can result from removal of a child from the home.

This chapter focuses on identifying how psychiatric disorders can impair parenting abilities and subsequently affect children. This is followed by an outline of recommended assessment methods to identify impairments and how they are affecting parenting capabilities. Lastly, treatment recommendations to mitigate the effect of impairment on parenting are discussed with a focus on creating psychological well-being, increasing supports, and developing effective parenting.

## 9.2 Overview of Research

Impairments from psychiatric disorders can result in decreased effectiveness in parenting skills and abilities. Such impairments can result in child neglect, abuse, poor parent–child relationships, and inconsistent parenting practices, among other consequences. Understanding how specific psychiatric disorders can negatively affect parenting is important for prescribing intervention plans that target impaired areas. The following section outlines aspects of impaired parenting within common psychiatric disorder. Due to the dearth of research in specific areas, especially paternal parenting, further research is still needed.

### 9.2.1 Depressive Disorders

Mothers of young children experience depressive symptomatology at an estimated rate of 17–24 % (Mclennan, Kotelchuck, & Cho, 2001). In fathers, rates of depression range from five to 25 % (Areias, Kumar, Barros, & Figueiredo, 1996; Lee, Taylor, & Bellamy, 2012). This rate is significantly higher in parents with children who have an externalizing disorder, with 40 % of mothers who have children diagnosed with ADHD experiencing a history of major depression (Chronis et al., 2007).

Cognitive impairments associated with depression can affect attention, memory, executive functioning, motor, and language abilities (Christensen, Griffiths, Mackinnon, & Jacomb, 1997; Richards & Ruff, 1989; Taconnat et al., 2010;

Veiel, 1997). These have been shown to persist, following remission of depressed symptoms, albeit at a decreased level (Hasselbalch, Knorr, & Kessing, 2011). Impairments associated with depressed parents often include disengagement, inconstant and harsh parenting, intrusive parenting, and emotional withdrawal. Children of depressed parents can manifest a greater prevalence of externalizing and internalizing disorders as well as impaired cognitive functioning and decreased school readiness. Although parents may experience remission of depressive symptomatology, a history of depression can continue to negatively affect parenting styles.

Negative parenting behaviors associated with maternal depression include unresponsiveness, inattentiveness, and intrusiveness (Gelfand & Teti, 1990). Cox, Puckering, Pound, and Mills (1987) found one of the most prevalent behaviors associated with depression is disengagement, resulting in being emotionally unavailable, withdrawn, and lacking sensitivity to the child's needs. Decreased maternal engagement can manifest as decreased verbal and physical affection, limited positive facial expressions, and decreased responsiveness (Kam et al., 2011). As such, depressive symptoms interfere with the ability to display warmth and affection, which are critical for a child's emotional development.

Lovejoy, Graczyk, O'Hare, and Neuman (2000) noted maternal depression is associated with harsh or inconsistent parenting. These parenting traits can increase the prevalence of a child developing externalizing problems. Findings additionally suggest depressed mothers increasingly react in a more negative and less positive manner, as well as have greater difficulty in managing their child's behaviors. Goodman et al. (2011) indicated lax discipline and a lack of positive parenting may be a result of symptoms associated with depressive symptomatology such as fatigue, irritability, and low mood. As such, giving into a child's misbehavior, providing inadequate supervision, or using coercion may in part be related to a mother's fatigue and poor coping skills. Furthermore, longitudinal studies have shown that mothers with severe chronic depression tend to have children with higher rates of insecure attachment (Campbell, Cohn, & Meyers, 1995; Teti, Gelfand, Messinger, & Isabella, 1995), increased rates of impaired cognitive functioning and greater behavioral problems at 5 years of age (Brennan et al., 2000), lower comprehension and school readiness at 36 months (NICHD, Early Child Care Research Network, 1999). Consequently, maternal depression not only impairs the ability to foster emotional support that can result in internalizing and externalizing psychological problems in the child, but also impairs the mother's ability to cognitively and educationally prepare a child.

Studies have conversely found that some depressed parents may respond to a child in an overinvolved and intrusive manner. This can result in a tendency to control play, to change the focus of play without consideration of the child's interest, to physically manipulate, and to increase assertive verbal directives (Cox et al., 1987). Van der Bruggen, Bögels, and van Zeilst (2010) found such behaviors can inhibit a child from adequately developing self-initiated coping techniques, since intrusive parenting controls situations in which children may experience anxiety, limiting their ability to develop appropriate coping mechanisms. This may result in the development of depression and anxiety in children. Additionally, Field, Healy, Goldstein, and Guthertz (1990) found that children respond with increased dysphoria, social withdrawal, and reduced activity with depressive mothers who exhibit higher rates of intrusiveness and decreased warmth.

The earlier maternal depression occurs earlier in a child's life, the greater the impact on the child. In a meta-analytic review, Goodman et al. (2011) concluded that maternal depression exposure at an earlier age can increase vulnerability to development of psychopathology when compared to older children. This may in part be related to more years of healthy development in children exposed to maternal depression at a later age. Additionally, older children are less exclusively dependent on their mothers to the extent that other adults and peers become increasingly involved in their life. Since older children have increased cognitive maturity, they may better understand their mother's depressed symptomatology and mitigate its effects on them through increased emotion- and social-regulation skills.

Although there has been less research on paternal depression and parenting, studies have shown paternal depression can impair parenting that can result in poor outcomes for children, such as social and academic impairment and increased risk of psychopathological development. In a meta-analytic review, Wilson and Durbin (2010) found parental depressive symptoms created increased maladaptive behaviors in younger children. This may be a result of the difficult demands of young children, parenting inexperience, and/or contextual features of a father's age. Negative parenting behaviors that have been found in depressed fathers include intrusiveness, aggravation, rejection and invalidation, coerciveness and control, withdrawal, inconsistent and lax discipline, and over-reactive parenting (Cummings, Keller, & Davies, 2005; Gartstein & Fagot, 2003; Giallo et al., 2015).

Despite remission of depressive symptoms, mothers with a history of depression may continue to engage in a manner that is psychologically controlling relative to those without a history of depression, although they also show increased warmth when compared to currently depressed mothers (Foster et al., 2008). Murray, Halligan, Adams, Patterson, and Goodyer (2006) additionally found that mothers with a remission of depressive symptoms continue to exhibit less adaptive parenting. Moreover, a history of maternal depression can continue to adversely affect parents' responses to compliant and noncompliant behaviors exhibited by a child as well as create an increase in coercive parenting styles (Thomas, O'Brien, Clarke, Liu, & Chronis-Tuscano, 2015). Therefore, despite a remission of depressive symptoms, such parents may need continued assistance and support to mitigate the impairment caused by depression.

### 9.2.2 Anxiety Disorders

Anxiety disorders (e.g., generalized anxiety disorder, social anxiety disorder, specific phobia) share features of excessive fear and anxiety that differ from developmentally normal fear and anxiety that can lead to behavioral disturbances. Anxiety disorders tend to develop in childhood and persist into adulthood if not treated. Anxiety disorders are found in women with increased frequency when compared to men, approximately 2:1 ratio (American Psychiatric Association, 2013). Prevalence of anxiety disorders varies. In a 12-month community prevalence estimate in the United States, specific phobia was found in seven to nine percent of the general population, social anxiety disorder in approximately seven percent, panic disorder in two to three percent, and generalized anxiety disorder in almost three percent of adults (American Psychiatric Association, 2013).

Despite a high level of comorbidity among anxiety disorders, a significant number of individuals experience clinical levels of anxiety that result in impairment. Anxiety has been shown to impair attention, working memory, executive functioning, and memory (Airaksinen, Larsson, & Forsell, 2005; Berggren, Richards, Taylor, & Derakshan, 2013; Vytal, Cornwell, Arkin, & Grillon, 2012). The impact of anxiety disorders on parenting has been shown to impair a number of parenting abilities that can result in internalizing and externalizing disorders in their children. For example, clinically anxious parents have increased tendencies to be intrusive and less supportive than non-anxious parents (Drake & Ginsburg, 2011; Ginsburg, Grover, & Ialongo, 2005; Van der Bruggen et al., 2010). Additionally, parents with an anxiety disorder engage in greater levels of behavioral control that inhibits development of autonomy in children (Ginsburg et al., 2005; Lindhout et al., 2006). When engaging with their children, parents with social anxiety disorder tend to exhibit greater levels of negativity and less warmth than those without social anxiety disorder (Budinger, Drazdowski, & Ginsburg, 2013). Murray, Cooper, Creswell, Schofield, and Sack (2007) and Murray et al. (2012) additionally found socially anxious mothers are less encouraging of exploration in infants and express greater levels of anxiety when interacting with their preschoolers.

In a comparison of anxious behaviors exhibited by mother and fathers, Teetsel, Ginsburg, and Drake (2014) found both parents with anxiety to display similarities in the following: levels of negative and positive affect, number of anxious behaviors, level of autonomy granting, frequency of positive reinforcement, and modeling coping behaviors. Fathers were found to display greater levels of controlling behaviors than mothers, which were exhibited as intrusive and unsolicited help, overinvolvement in tasks, and overdirecting the child's behavior. Anxious mothers were found to exhibit greater levels of punishment (e.g., mild spanking, removing privileges or rewards), name calling, and negatively reinforcing a child's fear of harmless situations by allowing greater levels of avoidance.

The effect of anxiety-driven parental behaviors on children has been shown to increase the prevalence of anxiety disorders in children. Engagement with their children by anxious parents promoted greater levels of anxiety when compared to non-anxious parents (Whaley, Pinto, & Sigman, 1999; Woodruff-Borden, Morrow, Bourland, & Cambron, 2002). Additionally, relationships were found between parental controlling behaviors and anxiety in children during parent–child interactions (McLeod, Wood, & Weisz, 2007; Van der Bruggen, Stams, & Bögels, 2008). Specifically, maternal overprotection was found to promote social anxiety in children whereas paternal overprotection promoted general anxiety in children (Rork & Morris, 2009). As such, parental behaviors that result from anxiety promote intergenerational anxiety symptoms in children.

### 9.2.3 Bipolar Disorder

The 12-month prevalence estimate in the United States for bipolar I disorder is approximately 0.6 % whereas for bipolar II disorder it is approximately 0.8 % (American Psychiatric Association, 2013). Boyd, Joe, Michalopoulos, Davis, and Jackson (2011) found a 12-month prevalence of 1.6 % and lifetime prevalence of 2.5 % of bipolar disorders in mothers. Most individuals with bipolar disorder experience impairments in work, social, and family functioning (Judd et al., 2003). Some of these impairments are attributed to problems with attention, memory, and executive functioning, which can continue to occur when clinically stable (Burdick, Goldberg, & Harrow, 2010; Murphy et al., 1999; Schretlen et al., 2007). Latalova, Prasko, Diveky, and Velartova (2011) noted individuals with bipolar disorder and a history of psychosis have greater impairments in working and spatial memory and executive functioning, whereas those with a history of bipolar depression demonstrated impairment in all domains tested (e.g., attention, memory, motor, and executive functioning). Many of these areas that demonstrate cognitive impairment are critical in the role of parenting and appropriate decision-making.

Several studies have demonstrated children are at an increased risk of developing emotional and behavioral disturbances when growing up in a family with a parent diagnosed with bipolar disorder (Duffy, Alda, Crawford, Milin, & Grof, 2007; Hillegers et al., 2005; Jones, Tai, Evershed, Knowles, & Bentall, 2006). Parents with bipolar disorder have been found to exhibit a more negative communication style when compared to parents without bipolar disorder (Vance, Huntley, Espie, Bentall, & Tai, 2008). Additionally, parents with bipolar disorder have a greater tendency for poor organization and instability (Matheny, Wachs, Ludwig, & Phillips, 1995), which is in part a result of the associated cognitive impairments.

Calam, Jones, Sanders, Dempsey, and Sadhnani (2012) found parents with bipolar disorder rated themselves as having considerable difficulties in both attending to their own personal matters and raising their children. Few parents in this study were professionally engaged due to these difficulties. Children in this study also had greater levels of anxiety and depression, decreased adaptability for adjustment, and increased rates of conduct problems. Calam et al. (2012) attributed some of these emotional and behavioral problems in children with the parenting style, but also noted that these stressful environments coupled with genetic predisposition may increase the chance for the child to develop bipolar disorder. Therefore the combined chaotic and stressful environment coupled with genetic predisposition increases the likelihood of a child with a parent diagnosed with bipolar disorder to result develop bipolar or a related mood disorder.

### 9.2.4 Schizophrenia

The lifetime prevalence of schizophrenia is approximately 0.3–0.7 % (American Psychiatric Association, 2013). In a review of studies from 2000 to 2011, Seeman (2012) found approximately 50 % of mothers diagnosed with schizophrenia, either temporarily or permanently, lose custody of their children. As such, mothers diagnosed with schizophrenia have a high risk of losing child custody. Despite this, research on parenting with schizophrenia is limited. Research has demonstrated that cognitive impairments associated with schizophrenia include decline in memory, attention, motor skills, language, general intellectual functioning, and executive functioning (Fioravanti, Bianchi, & Cinti, 2012; Paulsen et al., 1995). O'Carroll (2000) noted that cognitive impairment often predates the first presentation of schizophrenic symptoms.

In a review of parenting in mothers diagnosed with schizophrenia, Bosanac, Buist, and Burrows (2003) identified several impairments that include decreased identification in picking up discordance between the mother and infant, limited eye contact, and lack of stimulation. These impairments are critical in early infant development and can result in emotional, cognitive, behavioral, and social consequences. Other research has demonstrated that mothers with schizophrenia are often less responsive and sensitive to an infant's needs as well as more intrusive and less stimulating in their parent–infant interactions (Steadman et al., 2007; Wan et al., 2007). Suspected reasons for these interaction difficulties are believed to result from attribution errors, poor empathy, reasoning biases, and/or positive symptoms associated with schizophrenia (Brüne, Abdel-Hamid, Lehmkämper, & Sonntag, 2007; Chandra, Bhargavaraman, Raghunandan, & Shaligram, 2006; Montag, Heinz, Kunz, & Gallinat, 2007).

Recent research has demonstrated impairment of affect recognition and theory of mind in those with schizophrenia (Mehta, Bhagyavathi, Kumar, Thirthalli, & Gangadhar, 2014), which is critical in recognizing infant cues. Healy, Lewin, Butler, Vaillancourt, and Seth-Smith (2015) found when interacting with their infant, mothers with schizophrenia display impairment in emotion regulation and affect discrimination. Additionally, these mothers demonstrated unusual verbal utterances and poor sensitivity to the child's needs. These findings suggest that social-cognition defect may contribute to unusual maternal behaviors often displayed by mothers with schizophrenia, since they have difficultly appropriately responding to an infant due to missing or misunderstanding cues.

Mothers with schizophrenia have also been found to be less sensitive, less responsive, and demonstrate less warmth when compared with nonschizophrenic mothers (Riordan, Appleby, & Faragher, 1999; Steadman et al., 2007; Wan et al., 2007). This may in part be a result of impaired affect recognition, but it is also likely a result of cognitive impairments and general symptomatology associated with schizophrenia. For example, negative schizophrenic symptoms result in decreased affect, mood, and energy that can impact how a parent interacts with his or her children. Additionally, positive symptoms can result in preoccupation with delusions or hallucinations that can detract from parent–child interaction and frequency and result in unusual interactions.

### 9.2.5 Attention-Deficit/Hyperactivity Disorder

Attention-Deficit/Hyperactivity Disorder (ADHD) occurs across the life span and affects 2.5 % of adults, with a more frequent presentation in males than females and can impair functioning in multiple domains (American Psychiatric Association, 2013). Core diagnostic features include hyperactivity (i.e., excessive motor activity or extreme restlessness), impulsivity (i.e., hasty actions that occur without forethought), and inattention (i.e., difficulty sustaining focus). In adults, areas of noted impairment include academic achievement, occupational history and attainment, and interpersonal relationships (Barkley, Murphy, & Fischer, 2008; Mannuzza et al., 2011). Adults with elevated levels of ADHD symptoms struggle with executive functioning that affect working memory, inhibitory control, and self-regulation. In addition, daily functions of time management, self-organization, problem-solving, self-motivation, and emotional self-regulation tend to be impaired (Barkley, 2011). These deficits related to executive functioning consequently impair parenting abilities.

Weiss, Hechtman, and Weiss (2000) note that parents with ADHD report difficulties with supervision and monitoring children due to the sustained attention required. They further reported increased procrastination as well as problems with planning and executing instrumental and organizational parental tasks. Inattentive symptoms associated with ADHD have been found to affect parental emotional responsiveness to a child. Maternal ADHD has been associated with decreased length of interactions with their infants, which is believed to result from an aversion towards repetitive and boring tasks that are associated with infants (Kryski, Mash, Ninowski, & Semple, 2010). In addition, levels of inattentive symptoms have been found to predict reduced sensitivity and increased intrusiveness of maternal interactions with their infants (Semple, Mash, Ninowski, & Benzies, 2011).

Parenting styles of those with ADHD tend to be inconsistent in discipline and create chaotic home environments (Mokrova, O'Brien, Calkins, & Keane, 2010). Consistency with discipline and emotional reactivity are highly variable in both mothers (Murray & Johnston, 2006) and fathers (Arnold, O'Leary, & Edwards, 1997) with ADHD. Inattentive symptoms are associated with inconsistent and lax discipline (Chen & Johnston, 2007), whereas hyperactive symptoms are associated with over-reactive parenting and increased arguments with children (Harvey, Danforth, McKee, Ulaszek, & Friedman, 2003). As such, symptoms of inattention that impair parenting organization and planning consequently affect consistency in discipline due to inability to remain attentive to a child's behaviors, while hyperactivity affects the ability to control emotional regulation when a child exhibits unwanted behaviors (Johnston, Mash, Miller, & Ninowski, 2012). Since inconsistent parenting inhibits a child's ability to learn rules and appropriate behaviors, there results a greater frequency of a child exhibiting unwanted behaviors. Such unwanted behaviors can elicit overreaction from a parent, resulting in a negative cycle of learned maladaptive behaviors that can result in increased anxiety in the child due to an inability to predict a parent's emotional state and reaction.

Research has demonstrated that ADHD is highly heritable (Thapar, Cooper, Jefferies, & Stergiakouli, 2012). Thus it is not uncommon for parents with ADHD to have children who develop ADHD. In a UK study, Agha, Zammit, Thapar, & Langley (2013) found that a parent with persistent/adult ADHD is associated with a more severe presentation of clinical ADHD symptoms in his or her children. Particularly, they found increased symptoms of inattention and conduct problems in children of such parents. This increase in severity is suspected to arise from gene-environment interplay (i.e., genetics and parenting style). Greater rates of persistent ADHD were found in children with maternal ADHD as well as increased severity of ADHD symptomatology especially in the presence of a maternal comorbid disorder (e.g., oppositional defiant, conduct, bipolar, and anxiety disorders) (Biederman, Petty, Clarke, Lomedico, & Faraone, 2011). As such, these children are at increased risk for intergenerational impairment, since adult ADHD is associated with underachievement, unemployment, underemployment, and problems with interpersonal relationships (Asherson, Chen, Craddock, & Taylor, 2007; Wilens, 2004), coupled with increased risk of developing comorbid psychiatric disorders.

### 9.2.6 Intellectual Impairment

Individuals with an Intellectual Disability (ID) possess deficits in intellectual functions (e.g., reason, problem-solving, planning, abstract thinking, judgment, academic learning, learning from experience), along with deficits in adaptive functioning that result in the failure to meet standards for personal independence and social responsibility (American Psychiatric Association, 2013). Studies have found parents with ID are at a high risk for their child being removed, with reported rates between 40 and 60 % (Booth & Booth, 2007; Taylor et al., 1991). Child removal in these cases is primarily a result of neglect, not physical abuse (Lightfoot et al., 2010).

A World Report on Disability found that those with disabilities are likely to be living in poor and disadvantaged circumstances, and possess significantly fewer resources for their healthcare (World Health Organization and World Bank, 2011). As such, those parents with ID are not only limited in their intellectual capacity, but access to services (e.g., healthcare, childcare, social supports) and assistance in caring for their child (Llewellyn, 2012). This is further complicated due to the difficulty this population has self-advocating for their needs and navigating the complex system to gain access to services. Additionally, those with ID suffer from high rates of institutional discriminatory beliefs and practices, especially with antenatal and infant care and parenting as well as are often negatively viewed by family members and the broader community (Aunos & Feldman, 2002). These complications may in part be why woman with ID has high rates of preeclampsia, delivers infants with low birth weights, and greater rates of neonatal intensive care admissions than woman without ID (McConnell, Mayes, & Llewellyn, 2008). In a Swedish study, mothers with ID were found to have higher risk for preterm birth, cesarean section, nonuse of nitrous oxide, and discharge of the infant from the hospital to a place other than the mother's home as well as four times as likely to be either stillborn or die within the first week of life (HöGlund, Lindgren, & Larsson, 2012). Unfortunately, this population is at a high risk for maternal biological factors and social-environmental factors that can result in negative antenatal and infant outcomes.

Inadequate childcare in parents with ID is largely believed to result from limitations in cognitive ability that impact generalizing care from one setting to another, adapting to changes in child development, providing cognitively stimulating play, and providing adequate supervision. Using the social information processing model (SIP), Azar, Stevenson, and Johnson (2012) identified areas in which parents with ID are at high risk of maladaptive parenting. SIP is based on evaluating a combination of simplistic, inappropriate, and ridged schema, along with poor executive functioning and biased appraisals. Azar et al. (2012) notes mothers with ID that perpetrated child neglect have difficulties across all domains when compared to those who have not. Greater instances of maladaptive parenting were found in mothers with lower intellectual functioning. These mothers have greater levels of disturbed schema regarding their child (i.e., unrealistic expectations), cognitive dysfunction (e.g., executive functioning, interpersonal planning and problem-solving, attention, memory), and negative misappropriations (i.e., attributing negative or incorrect intent of the child). They demonstrated greater levels of unrealistic expectations for their child coupled with poorer problem-solving abilities that placed the child in increased instances of danger through neglect. These mothers held unrealistic expectations and beliefs that their child was developmentally more capable of self-care and greater autonomy than the child was capable. Frustration intolerance in mothers due to their unrealistic expectations was also found, which often resulted in negative child–parent interactions as well as less warm interactions. The combination of factors identified in the SIP model was found to have greater instances of physical indicators of neglect that included the physical environment (e.g., home, neighborhood quality), belief that a child's injuries are a result of fate, and high levels of risk tolerance in supervision.

Llewellyn and Hindmarsh (2015) note that concerns over social isolation and poor and inappropriate support with parents who have ID have resulted in increased interventions targeted at developing greater social supports and community participation. Access to these social supports has shown greater child well-being (Wade, Llewellyn, & Matthews, 2008). Additionally, in combination to social supports, parenting skills training programs have demonstrated promising results in development of parenting abilities in those with ID (Booth & Booth, 2003; Darbyshire & Stenfert Kroese, 2012). Overall, despite many of the cognitive and social problems parents with ID possess in raising children, the use of training and social supports greatly increases these abilities and decreases child removal.

### 9.2.7 Comorbid Disorders

Psychiatric disorders rarely present as a single diagnosis. Often there is a complexity of comorbid conditions that can make treatment far more challenging. As previously noted, a mood disorder presents with accompanying cognitive impairment, while neurologically based disorders can have high rates of comorbid mood disorders. As a rule of thumb, greater severity of psychiatric symptoms results in increased impairment. Similarly, the more comorbid psychiatric disorders that are present the greater the impairment. Many studies on parenting often look at a singular diagnosis, often excluding those who may have more than one psychiatric disorder. Thus, those parents with a complex psychiatric presentation will likely demonstrate increased impairment of parenting abilities and present with greater parenting problems from multiple domains that have been discussed. These parents that have comorbid mental illness, cognitive disorders, learning disorders, and substance abuse have the highest representation of termination of parental rights cases (Bogacki, McGoldrick, & Gogineni, 2014) as well as present with the greatest challenges in providing adequate parenting. These parents will typically need the highest levels of intervention, which will likely require multiple service agencies (e.g., psychologist, psychiatrist, caseworker, in-home and community supports). Parents with these comorbid disorders would benefit from early identification, that could be conducted prior to birth if a severe mental health history is known, and be provided supports and services preemptively as a means to reduce maladaptive parenting behaviors.

## 9.3 Guidelines for Assessment

Conducting an assessment of parental abilities involves evaluating not only the parent's but also the child's needs, possible etiological causes of impairment, and environmental factors that are hindering parenting as well as possible supports. As parenting promotes and supports a child physically, emotionally, socially, financially, and intellectually, these factors must be included. It is important to evaluate not only the nature and degree of parenting abilities but also parenting strengths, since these can be utilized and built upon within treatment planning.

Psychological and neuropsychological testing assesses a parent's cognitive assets and weaknesses, ability to learn, and emotional stability. Understanding cognitive functioning is important since psychiatric disorders can result in cognitive impairment, as previously noted. Since cognitive dysfunction can impair parenting abilities, evaluation of cognitive functioning should be used as a means to understand potential underlying causes of impaired parenting. For example, parents with poor cognitive flexibility and attention may have difficulty attending to multiple tasks, such as simultaneously cooking and caring for a toddler, and parents with impulsive behaviors can react harshly to a child's behaviors or provide inconsistent discipline. Low intellectual functioning or low academic achievement can hinder a parent's ability to assist with schoolwork and learning. Changes in mood can result in inconsistent parenting that can result in erratic discipline and poor parent–child bonding. Since some parents may have difficulty evaluating their own abilities and skills, input from service providers (e.g., primary physician, social service agency, day care workers/teachers), family, and friends can offer additional information regarding a parent's strengths and weaknesses that affect their ability to parent. Once a full picture of a parent's functional and parenting impairment is identified, prescriptive interventions can be made, utilizing teaching techniques based on the parent's strongest abilities and simultaneously providing remedial work for weaknesses.

Evaluation of environmental and psychosocial stressors must include identifying areas that are hindering parenting but also areas that may be utilized as potential supports. Mental illness suffers experience higher rates of underemployment and unemployment than do healthy individuals. This can result in financial stressors that include decreased access to nutrition and healthcare, limited transportation, and an increase in overall stress. Financial stressors often include living in areas of low socioeconomic status where they may be higher rates of crime and negative influences on children and adolescents (e.g., drugs, gangs, crime). Additionally, such areas tend to offer less funding for schools and decreased access to educational services, leaving a greater burden for education on parents, who themselves may not be equipped to provide.

An important consideration is access to services. This includes not only specific resources in the area but also the ability to access those resources due to transportation availability, wait lists, the quality of services, and the parent's ability to manage multiple appointments and schedules. Bogacki and Weiss (2007) found in a sample of 300 parents involved in termination of parental rights in New Jersey that none possessed a vehicle. As such the ability of the parent to attend appointments is limited and access to those resources distant from public transportation is denied. In such circumstances, it is mandatory to conduct a conversation with a parent to understand from his or her perspective the factors that hinder their parenting ability and the ability and unique environmental factors, which present differently for each parent.

Many parents with psychiatric and cognitive disorders also have children with specific learning disorders, cognitive impairment, developmental disorders, serious medical conditions, and severe psychiatric and behavioral disorders. Understanding the needs of the child is important when developing a parenting plan. Although developed for family court, Pickar and Kaufman (2015) argue that professionals conducting these evaluations should possess specialized knowledge and understanding of childhood disorders and the parenting skills required to meet the needs of the child. This knowledge base allows for appropriate assessment of parenting skills and available resources to meet the child's needs, along with targeted recommendations for the child's mental-health maintenance. Pickar and Kaufman's (2015) model is based on three primary factors: child factors, parent factors, and parent–child factors. Within these three areas, there are eight domains that are broken into two continuous dimensions: those that are most likely to cause risk for harm and those most likely to protect from harm. The eight domains are (1) safety issues (physical safety/supervision and environmental safety); (2) parenting skills (parent/child temperament, structure and routine, discipline, time availably at home, acceptance or denial of the child's condition, and emotional attunement); (3) medical needs (openness to medical intervention, time availability for medical appointments); (4) educational needs (awareness of special educational needs, co-parenting and communication about special educational needs, takes steps to arrange for special education services); (5) therapeutic series (mental health therapy, occupational or physical therapy, parent participation in services); (6) advocacy, (7) parenting plan schedule considerations (transitions between home, predictability of schedule, parenting plans schedule consistent with child's developmental level); and (8) financial considerations.

Pickar and Kaufman (2015) provide a framework to translate these factors into a parenting plan. This plan is divided into child factors, parent factors, and parent–child factors. Child factors include basic temperament, the nature and severity of the disorder, and the nature and demands of the treatment plan. The parent factors include each parent's capacity to address the special circumstances and behaviors that arise from the child's disorder, parent's abilities, and parent participation in the treatment plan. Parent–child factors include parent insightfulness and empathy for the child, and the temperamental match between each parent and the child. The factor analysis used to create the parenting plans begins with evaluation of the following factors: severity of disorder, treatment plan, parent availably, safety and supervision, general parenting skills, special parenting requirements, co-parenting relations, level of conflict, quality of parent–child relationships, parent insightfulness and empathy, and parent–child temperament match. By evaluating these factors, decisions can be made to provide recommendations to those areas that the child is not obtaining.

## 9.4 Treatment Recommendations

Development of treatment recommendations for impaired parenting requires careful consideration to ensure a parent's ability to adequately provide an environment that promotes and supports children physically, emotionally, socially, financially, and intellectually. It should also address the underlying etiology that is causing the impairment. Although symptoms related to psychiatric disorders can be reduced with psychotherapeutic and psychopharmacological treatment, decreased symptoms do not necessarily reduce impairment related to parenting. Parents with a remission of depressive symptoms can continue to engage in controlling behaviors, show less warmth, employ less adaptive parenting methods, and engage in other negative parenting behaviors (Foster et al., 2008; Murray et al., 2006; Thomas et al., 2015). Likewise, parents who begin psychopharmacological treatment for ADHD symptoms can continue to exhibit negative parent–child interactions (Chronis-Tuscano et al., 2010). Despite remised symptoms, the continuation of negative parenting behaviors may in part be related to poor development of parenting skills, well-established negative parent–child interactions and family dynamics, and residual cognitive impairments. As such, to reduce impairment in parenting, multifaceted treatment is required. At minimum three areas should be addressed in treatment: (1) reduce psychiatric symptoms; (2) increase parenting skills; and (3) increase support systems. If cognitive impairments are additionally identified, these should also be targeted for treatment to mitigate the impact on parenting and functional impairment.

The use of psychotherapy and psychopharmacological treatment as a means to reduce symptoms associated with psychiatric disorders has been highly researched and is beyond the scope of this chapter. It is important when using these treatment modalities with parents that their capacity to parent is addressed. For example, when selecting specific medications, side effects should be considered, especially with medications that can be sedative and cause cognitive dulling. Parents who may experience sedation during the day and/or at night may possess difficulty reacting to their child's needs, especially parents of infants and young children. In psychotherapy, it is important to consider recommendations that will not impede parental duties and to incorporate components to enhance parents' ability to manage stress and exercise their parental duties. An example of this may be finding relaxing or pleasurable activities that include children or enhance their care. Additionally, when children trigger stressful reactions using methods to more effectively parent may help reduce the tension in such interactions.

Parental training can be defined as those programs in which parents acquire parenting skills. Such trainings are often comprised of classwork, practicing skills, role-playing, homework, and modeling. As outlined by the Center for Disease Control, effective training programs address multiple aspects of parenting (Wyatt Kaminski, Valle, Filene, & Boyle, 2008). Effective parental training includes: (1) education of child development and care, which entails learning developmentally appropriate physical care, typical child development and behavior, and methods to foster positive emotional development; (2) learning the importance of having positive interactions with a child through skills that permit positive parent–child interactions and positive attention; (3) responsiveness, sensitivity, and nurturing through appropriately responding to a child's psychological needs; (4) emotional communication by using relationship-building communication skills and helping children identify and express emotions appropriately; (5) disciplinary communication that is clear and developmentally appropriate, setting limits and rules, and providing clear behavioral expectations and consequences; (6) discipline and behavioral management that include discipline strategies, understanding a child's misbehavior, monitoring and supervision practice, reinforcement and punishment techniques, techniques to problem solve about child behaviors, and consistent responding; (7) promoting a child's social skills and prosocial behaviors; and (8) promoting a child's cognitive development and academic skills. Additionally, for parents who have a child with a psychiatric disorder, specialized training to develop a skillset that addresses the child's particular emotional, behavioral, and developmental needs may be necessary as an adjunct to basic parental training.

Bogacki et al. (2014) note that individuals with comorbid cognitive and psychiatric disorders may benefit from parenting plans tantamount to Individual Education Plans used in special education. Such plans would include concrete and measurable goals with objectives on how each service will help the parent reach their goal. Since many parents with severe mental health and/or intellectual disabilities have lower educational attainment, service providers should understand that they may need instruction approximately one or two grade levels below their academic test scores. McConnell and Llewellyn (2002) note specific elements should be incorporated into parent training for those who have intellectual disabilities and cognitive impairments. McConnell and Llewellyn additionally state that training programs should be designed to meet each parents' individual needs and learning style, areas of parental interest should be provided as this assists motivation to learn, and skills must be taught within the environments where the parents will utilize them and taught in a concrete and systematic manner. Additionally, education should include modeling and practice with feedback, including positive reinforcement. Lastly, periodic maintenance training sessions should be used that can also assist with teaching new skills that are required as a child grows.

Parents with comorbid psychiatric and cognitive disorders often have a limited support system when compared to control groups (Guinea, 2001; Llewellyn, 1997; O'Hara & Martin, 2003). Supports as defined by the American Association on Intellectual and Developmental Disabilities (Schalock, Borthwick-Duffy, Buntinx, Coulter, & Craig, 2010) include "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (p. 105). Formal supports can include day care, paid tutoring, take-out restaurants, housecleaning, whereas informal supports can include chore assistance from neighbors/friends (e.g., shoveling show, food shopping), respite care (e.g., night out for parents), and transportation services (car pooling) (Lightfoot & LaLiberte, 2011). Parents with specific impairments may also benefit from supports to meet the demands related to parenting (e.g., money management, adaptive technology, safety planning, nutrition planning).

Since children with developmental and psychiatric disorders can require more time and energy to care for and greater financial resources, supports to assist the needs of these children can greatly lessen the burden on parents. Such supports for these children can include specific parenting training for children with specific developmental and psychiatric disorders, adaptive technology, respite, tutoring, extended childcare, and psychotherapy for the child and/or family. These additional services can provide the parent time and resources to focus on increasing their parental skills while decreasing stress that may trigger a relapse of psychiatric symptoms.

## 9.5 Conclusion

Early identification of impairment in parenting and effective treatment that increases a parent's psychological well-being, increases parental skills, and develops ongoing supports are critical to enhancing the lives of families as well as reducing intergenerational impairment. Understanding how these impairments manifest and impact children and the family structure is critical in developing effective treatment. Although there has been an increase in the study of impairment, there is a dearth of research related to impaired parental abilities. Specifically, most research has focused on impairment within maternal parenting, with little research on paternal impairment. This may be a result of mothers being held to greater level of responsibility for the quality of childcare and developmental progress, antenatal care and postnatal support are primarily focused on mothers, and parenting programs typically focus on addressing parenting skill development for mothers (Llewellyn & Hindmarsh, 2015). High rates of single mother families may also account for the lack of paternal research. Additionally, there are large gaps in research, such as regarding parents with schizophrenia and bipolar disorder, parenting older children and adolescents, and preventive treatment (i.e., addressing potential impairment prior to childbirth). Lastly, effective treatments and resources to decrease impaired parenting are highly lacking. Research and subsequent availability of services are greatly needed since once these impairments have been identified, effective methods to provide assistance are needed.

## References

Agha, S. S., Zammit, S., Thapar, A., & Langley, K. (2013). Are parental ADHD problems associated with a more severe clinical presentation and greater family adversity in children with ADHD? *European Child & Adolescent Psychiatry, 22*(6), 369–377.

Airaksinen, E., Larsson, M., & Forsell, Y. (2005). Neuropsychological functions in anxiety disorders in population-based samples: Evidence of episodic memory dysfunction. *Journal of Psychiatric Research, 39*(2), 207–214.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Association.

Areias, M. E., Kumar, R., Barros, H., & Figueiredo, E. (1996). Correlates of postnatal depression in mothers and fathers. *The British Journal of Psychiatry: The Journal of Mental Science, 169*(1), 36–41.

Arnold, E. H., O'Leary, S. G., & Edwards, G. H. (1997). Father involvement and self-report parenting of children with attention deficit-hyperactivity disorder. *Journal of Consulting and Clinical Psychology, 65*(2), 337–342.

Asherson, P., Chen, W., Craddock, B., & Taylor, E. (2007). Adult attention-deficit hyperactivity disorder: Recognition and treatment in general adult psychiatry. *The British Journal of Psychiatry: The Journal of Mental Science, 190*, 4–5.

Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 285–296.

Azar, S. T., Stevenson, M. T., & Johnson, D. R. (2012). Intellectual disabilities and neglectful parenting: Preliminary findings on the role of cognition in parenting risk. *Journal of Mental Health Research in Intellectual Disabilities, 5*(2), 94–129.

Barkley, R. A. (2011). *Barkley functional impairment scale (BFIS)*. New York: Guilford Press.

Barkley, R. A., Murphy, K. R., & Fischer, M. (2008). *ADHD in adults: What the science says*. New York: Guilford Press.

Berggren, N., Richards, A., Taylor, J., & Derakshan, N. (2013). Affective attention under cognitive load: Reduced emotional biases but emergent anxiety-related costs to inhibitory control. *Frontiers in Human Neuroscience, 7*, 232–238.

Biederman, J., Petty, C. R., Clarke, A., Lomedico, A., & Faraone, S. V. (2011). Predictors of persistent ADHD: An 11-year follow-up study. *Journal of Psychiatric Research, 45*(2), 150–155.

Bogacki, D. F., McGoldrick, K., & Gogineni, R. (2014). Assessment of comorbid cognitive disorders in termination of parental rights cases: Conceptual formulation and treatment recommendations. *American Journal of Forensic Psychology, 32*(4), 5–22.

Bogacki, D. F., & Weiss, K. J. (2007). Termination of parental rights: Focus on defendants. *Journal of Psychiatry & Law, 35*(1), 25–46.

Booth, T., & Booth, W. (2003). Self-advocacy and supported learning for mothers with learning difficulties. *Journal of Intellectual Disabilities, 7*(2), 165–193.

Booth, T., & Booth, W. (2007). Parental adequacy, parenting failure and parents with learning difficulties. *Health & Social Care in the Community, 2*(3), 161–172.

Bosanac, P., Buist, A., & Burrows, G. (2003). Motherhood and schizophrenic illnesses: A review of the literature. *Australian and New Zealand Journal of Psychiatry, 37*(1), 24–30.

Boyd, R. C., Joe, S., Michalopoulos, L., Davis, E., & Jackson, J. S. (2011). Prevalence of mood disorders and service use among us mothers by race and ethnicity: Results from the national survey of American life. *The Journal of Clinical Psychiatry, 72*(11), 1538–1545.

Brennan, P. A., Hammen, C., Andersen, M. J., Bor, W., Najman, J. M., & Williams, G. M. (2000). Chronicity, severity, and timing of maternal depressive symptoms: Relationships with child outcomes at age 5. *Developmental Psychology, 36*(6), 759–766.

Brüne, M., Abdel-Hamid, M., Lehmkämper, C., & Sonntag, C. (2007). Mental state attribution, neurocognitive functioning, and psychopathology: What predicts poor social competence in schizophrenia best? *Schizophrenia Research, 92*(1–3), 151–159.

Budinger, M. C., Drazdowski, T. K., & Ginsburg, G. S. (2013). Anxiety-promoting parenting behaviors: A comparison of anxious parents with and without social anxiety disorder. *Child Psychiatry & Human Development, 44*(3), 412–418.

Burdick, K. E., Goldberg, J. F., & Harrow, M. (2010). Neurocognitive dysfunction and psychosocial outcome in patients with bipolar I disorder at 15-year follow-up: Neurocognition and bipolar outcome. *Acta Psychiatrica Scandinavica, 122*(6), 499–506.

Calam, R., Jones, S., Sanders, M. R., Dempsey, R., & Sadhnani, V. (2012). Parenting and the emotional and behavioural adjustment of young children in families with a parent with bipolar disorder. *Behavioural and Cognitive Psychotherapy, 40*(04), 425–437.

Campbell, S. B., Cohn, J. F., & Meyers, T. (1995). Depression in first-time mothers: Mother–infant interaction and depression chronicity. *Developmental Psychology, 31*(3), 349–357.

Chandra, P. S., Bhargavaraman, R. P., Raghunandan, V., & Shaligram, D. (2006). Delusions related to infant and their association with mother-infant interactions in postpartum psychotic disorders. *Archives of Women's Mental Health, 9*(5), 285–288.

Chen, M., & Johnston, C. (2007). Maternal inattention and impulsivity and parenting behaviors. *Journal of Clinical Child & Adolescent Psychology, 36*(3), 455–468.

Christensen, H., Griffiths, K., Mackinnon, A., & Jacomb, P. (1997). A quantitative review of cognitive deficits in depression and Alzheimer-type dementia. *Journal of the International Neuropsychological Society, 3*(6), 631–651.

Chronis, A. M., Lahey, B. B., Pelham, W. E., Williams, S. H., Baumann, B. L., Kipp, H., et al. (2007). Maternal depression and early positive parenting predict future conduct problems in young children with attention-deficit/hyperactivity disorder. *Developmental Psychology, 43*(1), 70–82.

Chronis-Tuscano, A., Rooney, M., Seymour, K. E., Lavin, H. J., Pian, J., Robb, A., et al. (2010). Effects of maternal stimulant medication on observed parenting in mother–child dyads with attention-deficit/hyperactivity disorder. *Journal of Clinical Child & Adolescent Psychology, 39*(4), 581–587.

Cox, A. D., Puckering, C., Pound, A., & Mills, M. (1987). The impact of maternal depression in young children. *Journal of Child Psychology and Psychiatry, 28*(6), 917–928.

Cummings, E., Keller, P. S., & Davies, P. T. (2005). Towards a family process model of maternal and paternal depressive symptoms: Exploring multiple relations with child and family functioning. *Journal of Child Psychology and Psychiatry, 46*(5), 479–489.

Darbyshire, L. V., & Stenfert Kroese, B. (2012). Psychological well-being and social support for parents with intellectual disabilities: Risk factors and interventions: Psychological well-being and social support. *Journal of Policy and Practice in Intellectual Disabilities, 9*(1), 40–52.

Davies, M. (2000). *The Blackwell encyclopedia of social work*. Oxford: Blackwell.

Drake, K. L., & Ginsburg, G. S. (2011). Parenting practices of anxious and nonanxious mothers: A multi-method, multi-informant approach. *Child & Family Behavior Therapy, 33*(4), 299–321.

Duffy, A., Alda, M., Crawford, L., Milin, R., & Grof, P. (2007). The early manifestations of bipolar disorder: A longitudinal prospective study of the offspring of bipolar parents: The early manifestations of bipolar disorder. *Bipolar Disorders, 9*(8), 828–838.

Field, T., Healy, B. T., Goldstein, S., & Guthertz, M. (1990). Behavior-state matching and synchrony in mother-infant interactions of nondepressed versus depressed dyads. *Developmental Psychology, 26*(1), 7–14.

Fioravanti, M., Bianchi, V., & Cinti, M. (2012). Cognitive deficits in schizophrenia: An updated metanalysis of the scientific evidence. *BMC Psychiatry, 12*(1), 64.

Foster, C. E., Webster, M. C., Weissman, M. M., Pilowsky, D. J., Wickramaratne, P. J., Talati, A., et al. (2008). Remission of maternal depression: Relations to family functioning and youth internalizing and externalizing symptoms. *Journal of Clinical Child & Adolescent Psychology, 37*(4), 714–724.

Gartstein, M. A., & Fagot, B. I. (2003). Parental depression, parenting and family adjustment, and child effortful control: Explaining externalizing behaviors for preschool children. *Journal of Applied Developmental Psychology, 24*(2), 143–177.

Gelfand, D., & Teti, D. (1990). The effects of maternal depression on children. *Clinical Psychology Review, 10*(3), 329–353.

Giallo, R., Cooklin, A., Brown, S., Christensen, D., Kingston, D., Liu, C. H., et al. (2015). Trajectories of fathers' psychological distress across the early parenting period: Implications for parenting. *Journal of Family Psychology, 29*(5), 766–776.

Ginsburg, G. S., Grover, R. L., & Ialongo, N. (2005). Parenting behaviors among anxious and non-anxious mothers: Relation with concurrent and long-term child outcomes. *Child & Family Behavior Therapy, 26*(4), 23–41.

Goldstein, S., & Naglieri, J. A. (2016). Defining the evolving concept of impairment. In S. Goldstein & J. A. Naglieri (Eds.), *Assessing impairment: From theory into practice* (2nd ed.). New York: Springer.

Goodman, S. H., Rouse, M. H., Connell, A. M., Broth, M. R., Hall, C. M., & Heyward, D. (2011). Maternal depression and child psychopathology: A meta-analytic review. *Clinical Child and Family Psychology Review, 14*(1), 1–27.

Guinea, S. M. (2001). Parents with a learning disability and their views on support received: A preliminary study. *Journal of Intellectual Disabilities, 5*(1), 43–56.

Harvey, E., Danforth, J. S., McKee, T. E., Ulaszek, W. R., & Friedman, J. L. (2003). Parenting of children with attention-deficit/hyperactivity disorder (ADHD): The role of parental ADHD symptomatology. *Journal of Attention Disorders, 7*(1), 31–42.

Hasselbalch, B. J., Knorr, U., & Kessing, L. V. (2011). Cognitive impairment in the remitted state of unipolar depressive disorder: A systematic review. *Journal of Affective Disorders, 134*(1–3), 20–31.

Healy, S. J., Lewin, J., Butler, S., Vaillancourt, K., & Seth-Smith, F. (2015). Affect recognition and the quality of mother-infant interaction: Understanding parenting difficulties in mothers with schizophrenia. *Archives of Women's Mental Health, 19*(1), 113–124.

Hillegers, M. H., Reichart, C. G., Wals, M., Verhulst, F. C., Ormel, J., & Nolen, W. A. (2005). Five-year prospective outcome of psychopathology in the adolescent offspring of bipolar parents. *Bipolar Disorders, 7*(4), 344–350.

HöGlund, B., Lindgren, P., & Larsson, M. (2012). Newborns of mothers with intellectual disability have a higher risk of perinatal death and being small for gestational age: Newborns of intellectually disabled mothers. *Acta Obstetricia et Gynecologica Scandinavica, 91*(12), 1409–1414.

Jellinek, M. S., Murphy, J. M., Poitrast, F., Quinn, D., Bishop, S. J., & Goshko, M. (1992). Serious child mistreatment in Massachusetts: The course of 206 children through the courts. *Child Abuse & Neglect, 16*(2), 179–185.

Johnston, C., Mash, E. J., Miller, N., & Ninowski, J. E. (2012). Parenting in adults with attention-deficit/hyperactivity disorder (ADHD). *Clinical Psychology Review, 32*(4), 215–228.

Jones, S. H., Tai, S., Evershed, K., Knowles, R., & Bentall, R. (2006). Early detection of bipolar disorder: A pilot familial high-risk study of parents with bipolar disorder and their adolescent children. *Bipolar Disorders, 8*(4), 362–372.

Judd, L. L., Akiskal, H. S., Schettler, P. J., Coryell, W., Maser, J., Rice, J. A., et al. (2003). The comparative clinical phenotype and long term longitudinal episode course of bipolar I and II: A clinical spectrum or distinct disorders? *Journal of Affective Disorders, 73*(1–2), 19–32.

Kam, C. M., Bierman, K. L., Coie, J. D., Dodge, K. A., Foster, M. E., Lochman, J. E., et al. (2011). Maternal depressive symptoms and child social preference during the early school years:

Mediation by maternal warmth and child emotion regulation. *Journal of Abnormal Child Psychology, 39*(3), 365–377.

Kryski, K. R., Mash, E. J., Ninowski, J. E., & Semple, D. L. (2010). Maternal symptoms of attention-deficit/hyperactivity disorder and maternal language: Implications for infant language development. *Journal of Child and Family Studies, 19*(3), 270–277.

Latalova, K., Prasko, J., Diveky, T., & Velartova, H. (2011). Cognitive impairment in bipolar disorder. *Biomedical Papers, 155*(1), 19–26.

Lee, S. J., Taylor, C. A., & Bellamy, J. L. (2012). Paternal depression and risk for child neglect in father-involved families of young children. *Child Abuse & Neglect, 36*(5), 461–469.

Lightfoot, E., Hill, K., & LaLiberte, T. (2010). The inclusion of disability as a condition for termination of parental rights. *Child Abuse & Neglect, 34*(12), 927–934.

Lightfoot, E., & LaLiberte, T. (2011). Parental supports for parents with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 49*(5), 388–391.

Lindhout, I., Markus, M., Hoogendijk, T., Borst, S., Maingay, R., Spinhoven, P., et al. (2006). Childrearing style of anxiety-disordered parents. *Child Psychiatry and Human Development, 37*(1), 89–102.

Llewellyn, G. (1997). Parents with intellectual disability learning to parent: The role of experience and informal learning. *International Journal of Disability, Development and Education, 44*(3), 243–261.

Llewellyn, G. (2012). Mothers with intellectual disability and their babies: A population warranting special consideration: Mothers with intellectual disability. *Acta Obstetricia et Gynecologica Scandinavica, 91*(12), 1353–1356.

Llewellyn, G., & Hindmarsh, G. (2015). Parents with intellectual disability in a population context. *Current Developmental Disorders Reports, 2*(2), 119–126.

Lovejoy, M. C., Graczyk, P. A., O'Hare, E., & Neuman, G. (2000). Maternal depression and parenting behavior. *Clinical Psychology Review, 20*(5), 561–592.

Mannuzza, S., Castellanos, F. X., Roizen, E. R., Hutchison, J. A., Lashua, E. C., & Klein, R. G. (2011). Impact of the impairment criterion in the diagnosis of adult ADHD: 33-year follow-up study of boys with ADHD. *Journal of Attention Disorders, 15*(2), 122–129.

Matheny, A. P., Wachs, T. D., Ludwig, J. L., & Phillips, K. (1995). Bringing order out of chaos: Psychometric characteristics of the confusion, hubbub, and order scale. *Journal of Applied Developmental Psychology, 16*(3), 429–444.

McConnell, D., & Llewellyn, G. (2002). Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law, 24*(3), 297–317.

McConnell, D., Mayes, R., & Llewellyn, G. (2008). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research, 52*(6), 529–535.

Mclennan, J. D., Kotelchuck, M., & Cho, H. (2001). Prevalence, persistence, and correlates of depressive symptoms in a national sample of mothers of toddlers. *Journal of the American Academy of Child & Adolescent Psychiatry, 40*(11), 1316–1323.

McLeod, B. D., Wood, J. J., & Weisz, J. R. (2007). Examining the association between parenting and childhood anxiety: A meta-analysis. *Clinical Psychology Review, 27*(2), 155–172.

Mehta, U. M., Bhagyavathi, H. D., Kumar, C. N., Thirthalli, J., & Gangadhar, B. N. (2014). Cognitive deconstruction of parenting in schizophrenia: The role of theory of mind. *Australian and New Zealand Journal of Psychiatry, 48*(3), 249–258.

Merriam-Webster, Inc. (2004). *The Merriam-Webster dictionary*. Springfield, MA: Merriam-Webster.

Mokrova, I., O'Brien, M., Calkins, S., & Keane, S. (2010). Parental ADHD symptomatology and ineffective parenting: The connecting link of home chaos. *Parenting, 10*(2), 119–135.

Montag, C., Heinz, A., Kunz, D., & Gallinat, J. (2007). Self-reported empathic abilities in schizophrenia. *Schizophrenia Research, 92*(1–3), 85–89.

Murphy, F. C., Sahakian, B. J., Rubinsztein, J. S., Michael, A., Rogers, R. D., Robbins, T. W., et al. (1999). Emotional bias and inhibitory control processes in mania and depression. *Psychological Medicine, 29*(6), 1307–1321.

Murray, L., Cooper, P., Creswell, C., Schofield, E., & Sack, C. (2007). The effects of maternal social phobia on mother: Infant interactions and infant social responsiveness. *Journal of Child Psychology and Psychiatry, 48*(1), 45–52.

Murray, L., Halligan, S. L., Adams, G., Patterson, P., & Goodyer, I. M. (2006). Socioemotional development in adolescents at risk for depression: The role of maternal depression and attachment style. *Development and Psychopathology, 18*(02), 489–516.

Murray, C., & Johnston, C. (2006). Parenting in mothers with and without attention-deficit/hyperactivity disorder. *Journal of Abnormal Psychology, 115*(1), 52–61.

Murray, L., Lau, P. Y., Arteche, A., Creswell, C., Russ, S., Zoppa, L. D., et al. (2012). Parenting by anxious mothers: Effects of disorder subtype, context and child characteristics. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 53*(2), 188–196.

National Institute of Child Health & Human Development, Early Child Care Research Network. (1999). Chronicity of maternal depressive symptoms, maternal sensitivity, and child functioning at 36 months. *Developmental Psychology, 35*(5), 1297–1310.

O'Carroll, R. (2000). Cognitive impairment in schizophrenia. *Advances in Psychiatric Treatment, 6*(3), 161–168.

O'Hara, J., & Martin, H. (2003). Parents with learning disabilities: A study of gender and cultural perspectives in East London. *British Journal of Learning Disabilities, 31*(1), 18–24.

Paulsen, J. S., Heaton, R. K., Sadek, J. R., Perry, W., Delis, D. C., Braff, D., et al. (1995). The nature of learning and memory impairments in schizophrenia. *Journal of the International Neuropsychological Society, 1*(01), 88–99.

Pickar, D. B., & Kaufman, R. L. (2015). Parenting plans for special needs children: Applying a risk-assessment model: Parenting plans for special needs children. *Family Court Review, 53*(1), 113–133.

Richards, P. M., & Ruff, R. M. (1989). Motivational effects on neuropsychological functioning: Comparison of depressed versus nondepressed individuals. *Journal of Consulting and Clinical Psychology, 57*(3), 396–402.

Riordan, D., Appleby, L., & Faragher, B. (1999). Mother-infant interaction in post-partum women with schizophrenia and affective disorders. *Psychological Medicine, 29*(4), 991–995.

Rork, K. E., & Morris, T. L. (2009). Influence of parenting factors on childhood social anxiety: Direct observation of parental warmth and control. *Child & Family Behavior Therapy, 31*(3), 220–235.

Schalock, R. L., Borthwick-Duffy, S. A., Buntinx, W. H. E., Coulter, D. L., & Craig, E. M. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schetky, D. H., Angell, R., Morrison, C. V., & Sack, W. H. (1979). Parents who fail: A study of 51 cases of termination of parental rights. *Journal of the American Academy of Child Psychiatry, 18*(2), 366–383.

Schretlen, D. J., Cascella, N. G., Meyer, S. M., Kingery, L. R., Testa, S. M., Munro, C. A., et al. (2007). Neuropsychological functioning in bipolar disorder and schizophrenia. *Biological Psychiatry, 62*(2), 179–186.

Seeman, M. V. (2012). Antipsychotic-induced somnolence in mothers with schizophrenia. *Psychiatric Quarterly, 83*(1), 83–89.

Semple, D. L., Mash, E. J., Ninowski, J. E., & Benzies, K. M. (2011). The relation between maternal symptoms of attention-deficit/hyperactivity disorder and mother–infant interaction. *Journal of Child and Family Studies, 20*(4), 460–472.

Steadman, J., Pawlby, S., Mayers, A., Bucks, R. S., Gregoire, A., Miele-Norton, M., et al. (2007). An exploratory study of the relationship between mother–infant interaction and maternal cognitive function in mothers with mental illness. *Journal of Reproductive and Infant Psychology, 25*(4), 255–269.

Taconnat, L., Baudouin, A., Fay, S., Raz, N., Bouazzaoui, B., El-Hage, W., et al. (2010). Episodic memory and organizational strategy in free recall in unipolar depression: The role of cognitive support and executive functions. *Journal of Clinical and Experimental Neuropsychology, 32*(7), 719–727.

Taylor, C. G., Norman, D. K., Murphy, J. M., Jellinek, M., Quinn, D., Poitrast, F. G., et al. (1991). Diagnosed intellectual and emotional impairment among parents who seriously mistreat their children: Prevalence, type, and outcome in a court sample. *Child Abuse & Neglect, 15*(4), 389–401.

Teetsel, R. N., Ginsburg, G. S., & Drake, K. L. (2014). Anxiety-promoting parenting behaviors: A comparison of anxious mothers and fathers. *Child Psychiatry & Human Development, 45*(2), 133–142.

Teti, D. M., Gelfand, D. M., Messinger, D. S., & Isabella, R. (1995). Maternal depression and the quality of early attachment: An examination of infants, preschoolers, and their mothers. *Developmental Psychology, 31*(3), 364–376.

Thapar, A., Cooper, M., Jefferies, R., & Stergiakouli, E. (2012). What causes attention deficit hyperactivity disorder? *Archives of Disease in Childhood, 97*(3), 260–265.

Thomas, S. R., O'Brien, K. A., Clarke, T. L., Liu, Y., & Chronis-Tuscano, A. (2015). Maternal depression history moderates parenting responses to compliant and noncompliant behaviors of children with ADHD. *Journal of Abnormal Child Psychology, 43*(7), 1257–1269.

Van der Bruggen, C. O., Bögels, S. M., & van Zeilst, N. (2010). What influences parental controlling behaviour? The role of parent and child trait anxiety. *Cognition & Emotion, 24*(1), 141–149.

Van der Bruggen, C. O., Stams, G. J. J. M., & Bögels, S. M. (2008). Research review: The relation between child and parent anxiety and parental control: A meta-analytic review. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 49*(12), 1257–1269.

Vance, Y. H., Huntley, S. J., Espie, J., Bentall, R., & Tai, S. (2008). Parental communication style and family relationships in children of bipolar parents. *British Journal of Clinical Psychology, 47*(3), 355–359.

Veiel, H. O. (1997). A preliminary profile of neuropsychological deficits associated with major depression. *Journal of Clinical and Experimental Neuropsychology, 19*(4), 587–603.

Vytal, K., Cornwell, B., Arkin, N., & Grillon, C. (2012). Describing the interplay between anxiety and cognition: From impaired performance under low cognitive load to reduced anxiety under high load. *Psychophysiology, 49*(6), 842–852.

Wade, C., Llewellyn, G., & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*(4), 351–366.

Wan, M. W., Salmon, M. P., Riordan, D. M., Appleby, L., Webb, R., & Abel, K. M. (2007). What predicts poor mother–infant interaction in schizophrenia? *Psychological Medicine, 37*(04), 537.

Wattenberg, E., Kelley, M., & Kim, H. (2001). When the rehabilitation ideal fails: A study of parental rights termination. *Child Welfare, 80*(4), 405–431.

Weiss, M., Hechtman, L., & Weiss, G. (2000). ADHD in Parents. *Journal of the American Academy of Child & Adolescent Psychiatry, 39*(8), 1059–1061.

Whaley, S. E., Pinto, A., & Sigman, M. (1999). Characterizing interactions between anxious mothers and their children. *Journal of Consulting and Clinical Psychology, 67*(6), 826–836.

Wilens, T. E. (2004). Attention-deficit/hyperactivity disorder in adults. *Journal of the American Medical Association, 292*(5), 619.

Wilson, S. & Durbin, C. E. (2010) Effects of paternal depression on fathers' parenting behaviors: A meta-analytic review. *Clinical Psychology Review, 30*, 167–180.

Woodruff-Borden, J., Morrow, C., Bourland, S., & Cambron, S. (2002). The behavior of anxious parents: Examining mechanisms of transmission of anxiety from parent to child. *Journal of Clinical Child and Adolescent Psychology, 31*(3), 364–374.

World Health Organization and World Bank. (2011). *World report on disability*. Geneva: WHO.

Wyatt Kaminski, J., Valle, L. A., Filene, J. H., & Boyle, C. L. (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology, 36*(4), 567–589.

# Part III

# Assessment and Reduction of Impairment

# Psychometric Issues in the Assessment of Impairment

# 10

Jack A. Naglieri and Keith D. McGoldrick

## 10.1 Introduction

One of the greatest contributions psychologists have made to society is the development of methods for quantifying the various constructs used in the field (see Anastasi & Urbina, 1997). In fact, without methods of quantification, little research could be conducted, and practitioners would be limited to subjective interpretations of informal data they obtain. The development of tools used to assess psychological constructs has greatly improved the reliability and validity of the field, perhaps the most obvious ones being personality and intelligence tests. It is important to recognize that the study of *any* psychological construct is very dependent on the quality and content of the tools used. And, the methods included in scientific research directly influence the results of any study and consequently what is learned about the topic. Importantly, we must recognize that what we learn from a test is completely determined by the content of the instruments and the specific information they provide. The quality of these tools, therefore, is directly proportional to the quality of the information obtained and based on the way in which test authors conceptualize and measure their constructs. The better the tool, the more reliable and valid our findings, and as validity increases, so does the quality of the information that is obtained and, ultimately, the better the services provided. In this chapter, the tools used for assessment of impairment are examined.

---

J.A. Naglieri, Ph.D. (✉)
Curry School of Education, University of Virginia,
Charlottesville, Virginia, USA
e-mail: jnaglieri@gmail.com

K.D. McGoldrick, Ph.D.
Neurology, Learning and Behavior Center,
230 South 500 East, Suite 100, Salt Lake City, UT 84102, USA
e-mail: keith@samgoldstein.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_10

The first purpose of this chapter is to review the important psychometric qualities of test reliability and validity. Special attention is given to the practical implications of psychometric concepts of reliability and validity and the influences these test attributes have on the decisions made by clinicians and researchers alike. The practical implications these psychometric issues have for the assessment of impairment and the implications they have for interpretation of results within and across instruments are stressed. Given that test quality is so dependent on the processes used to develop a scale and the methods used to develop derived scores, these issues are given close attention. The second section of this chapter focuses on the concept of impairment and how it is measured in research settings and how it should be measured when utilized in clinical practice. The intent of this chapter is to provide a discussion of the relevant psychometric issues and the characteristics researchers and clinicians should demand so that they can have confidence in any tool they use to assess impairment.

## 10.2 Reliability and Related Issues

### 10.2.1 Reliability

The reliability of any score has considerable implications for understanding research findings (e.g., reliability of two measures imposes a limit on the extent that they can reliably correlate) and is equally critical in clinical practice (e.g., reliability determines the amount of error of measurement). It is imperative that the reliability of any score be known so that its accuracy can be determined and used to calculate interpretive guides such as confidence intervals around obtained scores. High reliability is always desired because the higher the reliability the smaller the amount of error in the measurement of the construct and the smaller range of scores that represent the confidence interval around the estimated true score. The smaller the range, the more precision, and with precision comes greater confidence in interpretations of the results.

General guidelines about how much reliability is sufficient were suggested by Bracken (1987). He suggested that a test's total score should have an internal consistency reliability of .90 or greater, and individual scales (e.g., a subtest or subscale) should have a reliability of .80 or greater. These guidelines must, of course, be used in light of the reason for assessment and the importance of the decisions that are being made; the greater the importance, the greater the need for good reliability. For example, if a score is used for screening purposes for which overidentification is preferred to underidentification, a .80 reliability standard for a total score may be acceptable. If decisions are made, for example, about special educational placement, then a higher reliability (e.g., .95) would be more appropriate (Nunnally & Bernstein, 1994).

### 10.2.2 Recognizing Measurement Error

Every score has two components: the true score and measurement error (Crocker & Algina, 1986). The true score can only be estimated and is therefore best described on the basis of a range of values within which the person's true score falls at a specific level of certainty (e.g., 90 % probability). The standard error of measurement (SEM), which represents all possible obtained scores within plus or minus 1 standard deviation (SD) of the true score, is computed from the reliability coefficient and the SD of the scores using the following formula (Crocker & Algina, 1986):

$$SEM = SD\sqrt{1 - reliability}$$

The size of the SEM is directly related to the reliability in standardized tests that have a set mean. As is evident in Table 10.1, as the reliability of the measure goes down, the SEM goes up. This mathematical fact is very important to the researcher and especially the clinician when decisions about score differences are being made. One way to utilize the SEM in practice is to convert it to a range of scores that represents the true score, that is, a confidence interval.

When the SEM is multiplied by a *z* value of, for example, 1.96, we obtain a range of scores, called a *confidence interval*, at the 95 % level that includes the true score. Knowing the confidence interval allows us to say that there is a 95 % chance that the person's true score falls within a value added to and subtracted from the obtained score. For example, the confidence interval for an obtained score of 100 may be 95 (100 − 5) to 105 (100 + 5). Table 10.2 provides confidence intervals (95 % level of confidence) for a standard score of 100 that would be obtained for measures with reliability of .50 through .99. As would be expected, the range within which the true score is expected to fall varies considerably as a function of the reliability coefficient, and the lower the reliability, the wider the range of scores that can be expected to include the true score.

Although many professionals use confidence intervals by adding and subtracting a value from the obtained score, it is more correct that the range of scores should be centered around the estimated true score rather than the obtained score (Nunnally & Bernstein, 1994). These estimated true score-based confidence intervals are included

**Table 10.1** Various standard errors of measurement (SEMs) obtained from different reliability coefficients

| Reliability | SD | SEM |
|---|---|---|
| .99 | 15 | 1.5 |
| .89 | 15 | 5.0 |
| .79 | 15 | 6.9 |
| .69 | 15 | 8.4 |
| .59 | 15 | 9.6 |
| .49 | 15 | 10.7 |
| .39 | 15 | 11.7 |
| .29 | 15 | 12.6 |
| .19 | 15 | 13.5 |

*SD*, standard deviation

**Table 10.2** 95 % confidence intervals obtained from different reliability coefficients

| Reliability | Confidence interval | Score minus confidence interval | Score plus confidence interval |
|---|---|---|---|
| .99 | 2.9 | 97 | 103 |
| .95 | 6.6 | 93 | 107 |
| .90 | 9.3 | 91 | 109 |
| .85 | 11.4 | 89 | 111 |
| .80 | 13.1 | 87 | 113 |
| .75 | 14.7 | 85 | 115 |
| .70 | 16.1 | 84 | 116 |
| .65 | 17.4 | 83 | 117 |
| .60 | 18.6 | 81 | 119 |
| .55 | 19.7 | 80 | 120 |
| .50 | 20.8 | 79 | 121 |

**Table 10.3** Relationships among obtained standard scores, estimated true scores, and confidence intervals across the 40–160 range

| Obtained standard score | Estimated true score | True score minus obtained score | Lower confidence interval | Upper confidence interval | Upper minus lower confidence interval |
|---|---|---|---|---|---|
| 40 | 46 | 6 | 38 | 54 | 16 |
| 55 | 60 | 5 | 52 | 67 | 16 |
| 70 | 73 | 3 | 65 | 81 | 16 |
| 85 | 87 | 2 | 79 | 94 | 16 |
| 100 | 100 | 0 | 92 | 108 | 16 |
| 115 | 114 | –2 | 106 | 121 | 16 |
| 130 | 127 | –3 | 119 | 135 | 16 |
| 145 | 141 | –5 | 133 | 148 | 16 |
| 160 | 154 | –6 | 146 | 162 | 16 |

*Note*: This assumes a reliability coefficient of .90 and a 90 % confidence interval

in some test manuals, such as the *Wechsler Intelligence Scale for Children—Fifth Edition* (WISC-V; Wechsler, 2014) and the *Cognitive Assessment System* (Naglieri, Das, & Goldstein, 2014), for the user's convenience. The differences between these methods and the relationships among the various scores are illustrated in Table 10.3. This table provides several obtained scores and their associated estimated true scores, with the lower and upper ranges for the confidence intervals for standard scores having a normative mean of 100 and SD of 15 and a reliability of .90 at the 90 % level of confidence.

Table 10.3 values reveal that the confidence interval is equally distributed around a score of 100 (92 and 108 are both 8 points from the obtained score), but the interval becomes more asymmetrical as the obtained scores deviate from the mean. The result is that ranges for standard scores that are below the mean are mostly *higher* than the obtained score. For example, the range for a standard score of 70 is 65–81 (5 points below 70 and 11 points above 70). In contrast, scores for standard scores that are above the mean are *lower* than the obtained score. The range for a standard score of 130 is 119–135 (11 points below 130 and 5 points above 130). This difference is the result of centering the range of scores on the estimated true score rather than the obtained score even though the size of the confidence interval is constant (±8 points) in all instances.

Practitioners should routinely use confidence intervals when describing results regardless of how the confidence intervals are constructed. In either case, importance of measurement error must be made known and taken into consideration when scores from any measuring system are used. Confidence intervals, especially those that are based on the estimated true score, should be provided for all test scores, including rating scales.

The lower the reliability two scores have, the larger their respective SEMs and the more likely two scores will differ on the basis of chance. For example, when a score on an IQ test is compared to an achievement test score, the reliability of these measures will influence the size of the difference needed to reliably compare them. The lower the reliability, the more likely they will be different by chance alone. In fact, the formula for determining how different two scores need to be to have a significant difference includes the standard error of measurement of each score and the $z$ score associated with a specified level of significance. The formula is

$$\text{Difference} = Z\sqrt{\text{SEM1}^2 + \text{SEM2}^2}$$

### 10.2.3 Comparing Test Scores

Recognition of measurement imprecision is important when describing test scores and particularly important when comparing test scores (Crocker & Algina, 1986).

The relationships between SEM and the differences needed for significance are apparent in Table 10.4, which provides the values needed for significance when comparing two standard scores on an IQ metric (mean of 100, SD of 15). The data show that comparing two scores with reliabilities of .70 requires a difference of 23 points.

**Table 10.4** Differences required for significance when comparing two standardized scores with a mean of 100 and standard deviation of 15 at the $p = .05$ level

| Reliability | .99 | .95 | .90 | .85 | .80 | .75 | .70 | .65 | .60 | .55 | .50 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| .99 | 4 | 7 | 10 | 12 | 13 | 15 | 16 | 18 | 19 | 20 | 21 |
| .95 | 7 | 9 | 11 | 13 | 15 | 16 | 17 | 19 | 20 | 21 | 22 |
| .90 | 10 | 11 | 13 | 15 | 16 | 17 | 19 | 20 | 21 | 22 | 23 |
| .85 | 12 | 13 | 15 | 16 | 17 | 19 | 20 | 21 | 22 | 23 | 24 |
| .80 | 13 | 15 | 16 | 17 | 19 | 20 | 21 | 22 | 23 | 24 | 25 |
| .75 | 15 | 16 | 17 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 25 |
| .70 | 16 | 17 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 25 | 26 |
| .65 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 25 | 26 | 27 |
| .60 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 25 | 26 | 27 | 28 |
| .55 | 20 | 21 | 22 | 23 | 24 | 25 | 25 | 26 | 27 | 28 | 29 |
| .50 | 21 | 22 | 23 | 24 | 25 | 25 | 26 | 27 | 28 | 29 | 29 |

**Table 10.5** Differences required for significance when comparing two standardized scores with a mean of 50 and standard deviation of 10 at the $p = .05$ level

| Reliability | .99 | .95 | .90 | .85 | .80 | .75 | .70 | .65 | .60 | .55 | .50 |
|---|---|---|---|---|---|---|---|---|---|---|---|
| .99 | 3 | 5 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 13 | 14 |
| .95 | 5 | 6 | 8 | 9 | 10 | 11 | 12 | 12 | 13 | 14 | 15 |
| .90 | 7 | 8 | 9 | 10 | 11 | 12 | 12 | 13 | 14 | 15 | 15 |
| .85 | 8 | 9 | 10 | 11 | 12 | 12 | 13 | 14 | 15 | 15 | 16 |
| .80 | 9 | 10 | 11 | 12 | 12 | 13 | 14 | 15 | 15 | 16 | 16 |
| .75 | 10 | 11 | 12 | 12 | 13 | 14 | 15 | 15 | 16 | 16 | 17 |
| .70 | 11 | 12 | 12 | 13 | 14 | 15 | 15 | 16 | 16 | 17 | 18 |
| .65 | 12 | 12 | 13 | 14 | 15 | 15 | 16 | 16 | 17 | 18 | 18 |
| .60 | 13 | 13 | 14 | 15 | 15 | 16 | 16 | 17 | 18 | 18 | 19 |
| .55 | 13 | 14 | 15 | 15 | 16 | 16 | 17 | 18 | 18 | 19 | 19 |
| .50 | 14 | 15 | 15 | 16 | 16 | 17 | 18 | 18 | 19 | 19 | 20 |

Differences between such scores that were less than 23 points would be attributed to *measurement error alone*. Similarly, Table 10.5 provides the values needed when comparing two *T* scores that have a mean of 50 and SD of 10. If two test scores being compared have reliabilities of .90 and .75, the difference required for significance is 12 points. Clearly, in both research and clinical settings, variables with high reliability are particularly needed when scores will be compared.

Comparing pairs of test scores using the values in Tables 10.4 or 10.5 provides a way of determining when differences are likely due to measurement error and when the differences are reliable. These tables can be used to compare more than one pair of scores; however, doing so changes the actual level of significance in proportion to the number of comparisons made. For example, using a .05 level of significance six times makes the experimentwise error rate actually .265, not .05, because six pairwise increases error [the chance of a Type I error is obtained using the formula $1-(1-.05)\times 6$]. One way to control for inflation in the level of significance is by using the Bonferroni correction method. This procedure controls for the number of comparisons by setting the experimentwise error rate on the basis of making all six comparisons simultaneously (e.g., $.05/6 = .008$).

An alternative to the pairwise comparison approach that maintains the overall error rate and provides a more efficient way to examine intraindividual differences is termed an *ipsative approach* (Silverstein, 1982). The ipsative method provides the values needed to make comparisons between an individual's scores on separate scales within a test to the average of those scores (Davis, 1959; Silverstein, 1982). See the work of Naglieri and Paolitto (2005) for an example using the WISC-IV, for which this method is most applicable.

### 10.2.4 Conclusions Regarding Reliability

Researchers and clinicians who assess any construct should use measures that have a reliability coefficient of .80 for individual variables and .90 for variables that is a composite of several variables. If a rating scale or test does not meet these requirements, then its use in research should be questioned, especially because of the amount of error this will introduce into the results. Of course, this will be particularly important when the research involves many variables with low reliability as well as undocumented reliability. Moreover, clinicians are advised *not* to use measures that do not meet reliability standards because there will be too much error in the obtained scores to allow for reliable interpretation. This is especially important because the decisions clinicians make can have a significant and long-lasting impact on the life of an examinee.

## 10.3 Validity

Highly reliable psychological measurement is an important goal, but consistently measuring a construct that has insufficient validity accomplishes little for the clinician or researcher. The importance of validity is that it concerns the degree to which empirical evidence supports interpretation of scores that represent a construct of interest. For example, a measure of impairment should contain carefully crafted questions that reliably *and* validly reflect the individual's current state of functioning. Researchers who study impairment and authors who develop tools to assess impairment have the responsibility to carefully and clearly define the condition and ways to detect it. When there has been sufficient operationalization of those observable events that reflect impairment, then further development of the dimensions or factors that may comprise a complete examination of impairment can be obtained and used for research and clinical practice. This is, of course, all dependent on the extent to which the measures of impairment have acceptable levels of reliability.

At this time, there are only three nationally standardized measures of impairment, one for adults and two for children/adolescents. Given the fact that methods for evaluating impairment as well as our understanding of the underlying aspects of the disorder are evolving, developers of any measure of impairment have a responsibility to provide reliability and validity evidence and normative values based on a nationally representative sample, which has only occurred recently.

Demonstrating reliability is relatively easy, but validity is harder to demonstrate because of the complexity of the concept and the fact that validity is not determined by a single study. A body of literature that supports the interpretation of scores obtained from a measure of impairment must be obtained; this is a considerable undertaking with many challenges. For example, what standard can a measure of impairment be validated against? Any new tools designed to measure impairment will have to first demonstrate validity by showing that individuals who can be objectively agreed are impaired actually earn scores that reflect some level of diminished level of functioning. How such a group is defined and the extent to which that definition will be considered acceptable will be important. Similarly, research methodology is also especially important when comparing impaired individuals to those that are not. Special attention should be made to ensure that the methodology includes a sufficient number of control groups that vary on the basis of diagnosis.

It is important also to consider that our emerging definitions of impairment will influence the questions used in any test of this construct, which in turn will then define the condition. Tests and rating scales not only provide a tool for assessment, but also by the author's inclusion of particular content, they simultaneously define the construct. That is, the very nature of our understanding of impairment is determined by the selection of the variables used to build any scale, which in turn has profound influence on our understanding of the concept. In addition, the psychometric quality of the tests and rating scales used to study impairment will also influence both research and practice decisions. As the research is progressing, clinicians must be aware, however, that until there is sufficient maturity in the scope and quality of the instruments used to assess impairment, use of nonstandardized instruments with undocumented reliability and validity documentation and no nationally representative normative group should be avoided or used with considerable risk.

## 10.4 Development of Scales to Assess Impairment

There are several nonstandardized impairment methods that have evolved over the past 25 years, such as the *Children's Global Assessment Scale* (CGAS) (Shaffer et al., 1983); the *Child and Adolescent Functional Assessment Scale* (CAFAS); the *Columbia Impairment Scale* (CIS) (Bird, Shaffer, Fisher, Gould et al., 1993); the *Brief Impairment Scale* (BIS) (Bird et al., 2005); and the *Impairment Rating Scale* (Fabiano et al., 2006). Issues concerning the CGAS, CAFAS, and the CIS are that these measures are mostly unidimensional; many include measures of symptomatology into the measurement, some mix severity of psychopathology with functional impairment; others some involve subjective scoring systems and others are excessively lengthy, thus impractical for either clinical or research use (Bird et al., 2005). To address these issues, Bird et al. (2005) created the BIS, which has the advantages of being respondent based, short (23 items), and multidimensional, but it is limited in that it was assessed only within one ethnic group, is not applicable to preschool children, and does not provide an assessment in the direction of superior functioning. Similarly, the Impairment Rating Scale, like the others, is limited to a nonstandardized, nonnormed instrument with limited documentation of psychometric qualities.

Researchers and clinicians alike have a need for a measure of impairment that is appropriately standardized and normed, has sufficient documentation of reliability and validity, and has interpretative guidelines so that researchers and clinicians can assess impairment with confidence. Demonstrated reliability and validity are essential, as is a workable, user-friendly format. Because clinicians are required to demonstrate the impact psychological and psychiatric diagnoses have in daily functioning to make a clinical diagnosis, they have relied on imprecise tools to do so, such as the *Global Assessment of Functioning* included in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* [*DSM-IV-TR*] of the American Psychiatric Association [APA], 2000). As a result of the imprecise nature of this scale, the recent version of the DSM (DSM-5, APA, 2013) elected to use the

World Health Organization Disability Assessment Schedule (WHODAS) from the International Classification of Functioning (IFC). Although this measure of impairment is purported to be useful as a standardized measure of disability, research is still limited as well as there is no standardized sample. It is therefore clear that the field needs scales that are carefully developed using well-known procedures amply described by Crocker and Algina (1986) as well as Nunnally and Bernstein (1994). The essential ingredients of these methods are summarized next.

There have been three scales of impairment that have been standardized using a national sample. The *Barkley Functional Impairment Scale* (BFIS) (Barkley, 2011) and *Barkley Functional Impairment Scale—Children and Adolescents* (BFIS-CA) (Barkley, 2012). These scales were developed to match the 2000 U.S. Census. One of concerns with these two scales are the 15 domains that are represented, each domain is assessed with only one question each. As such these scales work well as screening measures for impairment. Recently, the *Rating Scale of Impairment* (RSI) (Goldstein & Naglieri, 2016) was published. The RSI is nationally standardized based on 2010 U.S. Census Data on children (age 5–12 years old) and adolescents (13–18 years old). It comprises of both parent and teacher forms that yield six scales (School, Social, Mobility, Domestic, Family, and Self-Care) and a Total Score. The use of parent and teacher forms provides measures of impairment at both school and home/community, allowing for a more comprehensive picture of impairment.

### 10.4.1 Step 1: Define the Construct

Initial test development should begin with a definition of *impairment*. Authors might define impairment as the outcome of any psychological disorder manifested by a constellation of symptoms. This might be defined as clear evidence of clinically significant impairment in social, academic, or occupational functioning, perhaps by restrictiveness of placement (day treatment vs. outpatient care). Functioning could be further categorized into interpersonal and community relations, occupational or school performance, and a range of self-care and other home activity dimensions. Impairment that might be indicated by poor performance in one or more of these dimensions goes beyond any diagnosis that may be causing them. Once the parameters of the definition have been defined, then items can be written.

### 10.4.2 Step 2: Operationalize the Definition

These behaviors and other defining characteristics must be written with sufficient clarity that they can be assessed reliably over time and across raters. Behaviors should be included that represent the characteristics that define as completely as possible individuals who have functional impairment. Definitional clarity is *required* for good item writing. The next step is to develop an initial pool of questions followed by a pilot test to evaluate the clarity of the instruction, items, as well as the structure of the form and other logistical issues. For instance, it is important to consider the way items are presented on the page, size of the fonts, clarity of the directions, position of the items on the paper, colors used on the form, and so on. The overall goal of pilot testing is to answer essential questions such as the following: Does the form seem to work? Do the users understand what they need to do? Are the items clear? Can the rater respond to each question? Can the items be answered in a reasonable amount of time?

### 10.4.3 Step 3: Assess Psychometric Qualities

Assessing the psychometric characteristics of a test or rating scale prior to collecting standardization data for norming is an important next step. Because of the cost of norming, in the next important step preliminary examinations of the instrument allow for an examination of the psychometric qualities of the items, the relationships between each item and any composite scale scores, and their correspondence to the constructs of interest. This effort is repeated until there is sufficient confidence that the items and the scales have been adequately operationalized. This is also the point at which decisions are made about the experimental evidence as well as the practical demands that application in the real world will involve. For example, research at this stage may yield a psychometrically strong scale that is impractical to give, in which case it might be discarded. What follows is a summary of the essential analyses that are typically conducted.

- Item means, SDs, and *p* values should be obtained for each item.
- Item total correlations should be computed to measure the extent to which each item correlates with a total score obtained from the sum of all those items designed to measure that same construct. If the correlations are low, then their inclusion on the scale should be questioned.
- The effect each item has on the reliability of the scales on which it is placed should be evaluated.
- Items designed to measure the same construct should correlate with other items designed to measure that same construct higher than items designed to measure different constructs. If this is not found, then the item may be eliminated.
- The factor structure of the set of items may be examined to test the extent to which items or scales form groups, or factors, whose validity can be examined.
- The internal reliability of those items organized to measure each construct should be computed, as should the reliability of a composite score.

The procedures used at this phase are repeated until the scale is ready for standardization. The number of research studies needed to complete this step will depend on the quality of the original concepts, the pool of items, and the quality of the samples used. The overall aim is to produce an experimental version of an instrument that is ready to be subjected to large-scale and more costly national standardization study. The normative sample should include a sufficient number of cases to obtain stability in the means and SDs across ages, gender, and so forth.

Standardization requires not only that the scale be administered in a consistent manner, but also that good data are obtained from the sample that represents the population of the country in which the scale will be used. This demands that all the conditions necessary for standardization are followed exactly so that normative values can be computed.

### 10.4.4 Step 4: Standardization Data Collection

A normative standardization sample is designed to obtain data that are representative of the normal population so that those who differ from the norm (50th percentile ± 1 SD) can be identified, and the extent to which they differ from the norm can be calibrated. Development of norms is an art as much as a science, and there are several ways in which this task can be accomplished (see Crocker & Algina, 1986; Nunnally & Bernstein, 1994; Thorndike, 1982). The second component of this stage is collection and analysis of data for establishing reliability (e.g., internal, test-retest, interrater, intrarater) and validity (e.g., construct, predictive, and content). Of these two, validity is more difficult to establish and should be examined using a number of different methodologies and to assess the extent to which there is empirical evidence for interpretation of the scores the scale yields.

Establishing validity of any psychological test requires an accumulation of evidence that examines the extent to which a test does what the authors intended. Because there are many different types of validity, it is not possible for validity to be determined by a single study. Evidence for validity supports the intended use of test scores and interpretation through existing evidence and theory as well as evidence collected prior to initial use as well as further data analysis as the test is in operational use (American Educational Research Association et al. [AERA], APA, and National Council on Measurement in Education [NCME], 2014). The standards regarding validity need to be addressed by authors and test development companies. Some of them that demonstrate the amount of evidence available should assess.

- Interpretations based on the scores the instrument yields
- The relationships between the new instrument with one or more relevant criterion variables
- The utility of the measure across a wide variety of demographic groups (gender, race, ethnicity, language, culture, and so forth)
- The utility of the test for differentiating groups as intended
- A rationale or empirical support for the alignment of the structure of the items or subtests with the scale configuration provided by the authors

There is wide variety in the way test authors construct a test manual that documents the development, standardization, reliability, and validity of their measure. Some manuals provide sufficient descriptions that bring out the strengths of the scale, whereas others provide limited details. Readers interested in illustrative manuals should examine those developed by the *Kaufman Assessment Battery for*

*Children—Second Edition* (Kaufman & Kaufman, 2004), Bracken and McCallum for their *Universal Nonverbal Intelligence Test—Second Edition* (Bracken & McCallum, 2016), and the *Cognitive Assessment System* (Naglieri et al., 2014). These manuals are illustrative of how to provide detailed discussion of the various phases of development, reliability, validity, and especially interpretation of scores the tests yield (AERA et al., 2014). This includes how test scores should be compared with one another and interpretive issues such as the values needed for significance when the various scores are compared. This information is critically important if clinicians are to be expected to interpret the scores from any instrument in a manner that is psychometrically defensible.

## 10.5 Conclusions

Authors of any published psychological measure have the responsibility to simultaneously publish a test manual that contains accurate information about the reliability, validity, and utility of any instrument they produce and distribute for use in clinical settings. Researchers and practicing clinicians have a responsibility to choose measures that have been developed using the highest standards available when important decisions will be made about individual clients or groups of subjects based on the information a measure may provide. It is best to choose scales for clinical practice that, in addition to being reliable, have a standardized administration and scoring format with norms developed based on a large sample that represents the country in which the scale is used. This should also include ample documentation of methods used to develop the measure, evidence of validity, and explicit instructions for interpretation of the scores that are obtained.

The information provided in this chapter is intended to provide researchers and clinicians with important criteria that could be used to evaluate a measure of impairment. Perhaps the most important characteristic of a measure of impairment is having norms based on a national sample. This provides a critical advantage for several reasons. First, a large representative sample allows for reliable calibration of derived scores. Second, comparison to that sample provides an understanding of how often and to what degree individuals within the normal population have functional impairment. Third, the comparison of an individual to a normative expectation of what is expected in the typically developing population provides for greater understanding of how far an individual may be from the norm. Fourth, having a well-normed score provides a means of calibrating how much response to intervention is needed to bring the person's level of impairment into a range that can be considered typical.

The most glaring shortcoming of most scales of impairment is that they do not provide a way of evaluating individuals in comparison to a representative sample. This poses considerable liability for those who choose to use these measures because it is imperative to know how far a person's level of impairment is from the norm and how much like those with functional impairment the individual may be. The only way to know adequate levels of impairment is to have a national standardization group and to build norms on that sample. Clinicians can then make defensible statements about how far an individual deviates from normality and the extent to which such data provide documentation for making a diagnosis. Those measures that do not have a national standardization sample and documented reliability and validity should be viewed with caution because interpretation of results may or may not be accurate.

The use of well-developed, psychometrically sound assessments greatly enhances the likelihood that reliable and valid information can be obtained about a person's level of impairment. Any and all efforts to advance the field in this area should closely follow the guidelines described in this chapter as well as other appropriate resources.

## References

American Educational Research Association, American Psychological Association, National Council on Measurement in Education. (2014). *Standards for educational and psychological testing* (2014th ed.). Washington, DC: Author.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Anastasi, A., & Urbina, S. (1997). *Psychological testing* (7th ed.). Upper Saddle River, NJ: Prentice Hall.

Barkley, R. A. (2011). *Barkley functional impairment scale*. New York: Guildford Press.

Barkley, R. A. (2012). *Barkley functional impairment scale—Children and adolescents*. New York: Guildford Press.

Bird, H. R., Canino, G. J., Davies, M., RamÍrez, R., Chávez, L., Duarte, C., et al. (2005). The brief impairment scale (BIS): A multidimensional scale of functional impairment for children and adolescents. *Journal of the American Academy of Child and Adolescent Psychiatry, 44*, 699–707.

Bird, H. R., Shaffer, D., Fisher, P., Gould, M. S., et al. (1993). The Columbia Impairment Scale (CIS): Pilot findings on a measure of global impairment for children and adolescents. *International Journal of Methods in Psychiatric Research, 3*, 167–176.

Bracken, B. A. (1987). Limitations of preschool instruments and standards for minimal levels of technical adequacy. *Journal of Psychoeducational Assessment, 5*, 313–326.

Bracken, B. A., & McCallum, R. S. (2016). *Universal nonverbal intelligence test* (2nd ed.). Itasca, IL: Riverside.

Crocker, L., & Algina, J. (1986). *Introduction to classical and modern test theory*. New York: Hold, Rinehart and Winston.

Davis, F. B. (1959). Interpretation of differences among averages and individual test scores. *Journal of Educational Psychology, 50*, 162–170.

Fabiano, G. A., Pelham, W. E., Waschbusch, D. A., Gnagy, E. M., Lahey, B. B., Chronis, A. M., et al. (2006). A practical measure of impairment: Psychometric properties of the impairment rating scale in samples of children with attention deficit hyperactivity disorder and two school-based samples. *Journal of Clinical Child and Adolescent Psychology, 35*, 369–385.

Goldstein, S., & Naglieri, J. A. (2016). *Rating scale of impairment*. Toronto: MHS.

Kaufman, A. S., & Kaufman, N. L. (2004). *Kaufman assessment battery for children second edition manual*. Circle Pines, MN: AGS.

Naglieri, J. A., Das, J. P., & Goldstein, S. (2014). *Cognitive assessment system interpretive handbook* (2nd ed.). Itasca, IL: Riverside.

Naglieri, J. A., & Paolitto, A. W. (2005). Ipsative comparisons of WISC-IV Index scores. *Applied Neuropsychology, 12*, 208–211.

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory*. New York: McGraw-Hill.

Shaffer, D., Gould, M. S., Brasic, J., Ambronsini, P., Fisher, P., Bird, H., et al. (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry, 40*, 1228–1231.

Silverstein, A. B. (1982). Pattern analysis as simultaneous statistical inference. *Journal of Consulting and Clinical Psychology, 50*, 234–240.

Thorndike, R. L. (1982). *Applied psychometrics*. Boston: Houghton-Mifflin.

Wechsler, D. (2014). *Wechsler intelligence scale for children* (5th ed.). San Antonio, TX: Psychological Corporation.

# Measurement of Symptom Severity and Impairment

# 11

Lawrence J. Lewandowski, Benjamin J. Lovett, and Michael Gordon

Maria, a fifth grader with a measured IQ in the gifted range (135), has reading skills that are only slightly above average (a standard score of 108). There is a significant discrepancy between her ability and her level of achievement. Does this mean that Brenda has a learning disability in the area of reading? Is a score of 108 a deficit in relation to most people? The reading score may be a relative weakness, but does Maria need special education services and test accommodations?

Alex, a law school graduate who cannot seem to pass the Bar Exam, has concerns about his attention and concentration abilities, reports this to his doctor, and receives a diagnosis of ADHD. He had no previous history of a disorder and performed well in high school and college. Is a diagnosis made in young adulthood and based on self-reported symptoms enough evidence to formulate such a diagnosis? Is a law school graduate likely to be impaired relative to most people, and should his recent diagnosis qualify him for testing accommodations the next time that he takes the Bar Exam?

Maria and Alex's cases raise many of the questions inherent in the definition of impairment and the relationship of symptoms to impairment. In this chapter, we will examine the relationship between measures of symptoms and impairment. In

---

L.J. Lewandowski, Ph.D. (✉)
Department of Psychology, Syracuse University, 430 Huntington Hall, Syracuse, NY 13244, USA
e-mail: ljlewand@syr.edu

B.J. Lovett, Ph.D.
Department of Psychology, SUNY Cortland, P.O. Box 2000, Cortland, NY 13045, USA
e-mail: Benjamin.Lovett@cortland.edu

M. Gordon, Ph.D.
Department of Psychiatry, SUNY Upstate, Syracuse, NY, USA
e-mail: Gordonm301@gmail.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_11

particular, we will review this relationship with regard to ADHD. We offer three reasons for focusing on this disorder. First, much recent research has examined symptom–impairment relationships here, so the empirical base is larger than it is elsewhere. Second, ADHD is a disorder for which impairment is especially important, due to the high frequency of symptoms in both people with and without the disorder (e.g., Lewandowski, Lovett, Gordon, & Codding, 2008). Finally, ADHD rarely occurs by itself (Barkley, 2006), and this high comorbidity leads the ADHD researcher to naturally examine groups of participants with many different psychiatric problems. Before turning to research on ADHD, however, we briefly review research in psychopathology more generally and discuss some of the general issues in the measurement of impairment.

## 11.1 Impairment as a Diagnostic Criterion

Since the publication of the DSM-III in 1980, clinicians and researchers have been made aware of the importance of impairment in addition to the number and severity of symptoms in considering a patient's psychiatric diagnosis. Since 1980, the DSM has been revised several times, but its focus on impairment has remained essentially the same. Specifically, impairment has remained a part of the diagnostic criteria for most mental disorders. The most recent revision (DSM-5; APA, 2013) includes a "clinical significance criterion" of impairment in a majority of the disorder definitions. DSM-5 recognizes that symptom presentation itself is not equivalent to pathology and may be present in individuals who do not have a mental disorder. "Therefore, a generic diagnostic criterion requiring distress or disability has been used to establish disorder thresholds, usually worded 'the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning'" (p. 21).

Despite this inclusion of an impairment criterion, whether clinicians adhere to it in practice is uncertain. Although little research has examined this, it appears that most clinicians rely primarily on the DSM descriptions of the *symptoms* of the various disorders, which are discussed in more detail than impairment (Gordon, Lewandowski, Murphy, & Dempsey, 2002). Even clinical scientists and other scholars sometimes overlook this important aspect of the DSM. Indeed, many critiques of DSM-based diagnostic systems (e.g., Eriksen & Kress, 2005; Kutchins & Kirk, 1997) accuse them of focusing exclusively on symptoms and neglecting the individual's life context. Unfortunately, the DSM-5 may lead to even more neglect of impairment, since the multiaxial system of DSM-IV has been removed, and with it the Global Assessment of Functioning (the GAF; Axis V)—the 100-point scale that integrated an assessment of symptom severity with an assessment of impairment (Smith et al., 2011).

Barkley et al. (2006) have distinguished between symptoms and impairment by defining the former as "the behavioral expressions associated with the disorder" and the latter as "the consequences that ensue for the individual as a result of these behaviors" (p. 2). If we take these definitions as being useful, we can think about the relationship between symptoms and impairment by asking whether individuals who have more behavioral manifestations of some type of psychopathology typically have more negative life consequences. If symptom severity and impairment are identical or correlate almost perfectly, assessing one is tantamount to assessing both, but if the relationship is contingent and far from perfect, each must be assessed separately. Also, it may be the case that treatment interventions need to be informed differentially by both symptoms and negative life consequences. Treating impulsivity and treating drunken driving may call for quite different interventions.

In the child psychiatric literature, there is now a fair amount of research examining the symptom–impairment relationship, and this research generally supports the need for examining impairment as distinct from symptoms. In one study, Angold, Costello, Farmer, Burns, and Erkanli (1999) examined 1015 children aged 9–13, comparing children who exhibited enough psychiatric symptoms to meet DSM-III-R criteria for at least one disorder to those who exhibited subclinical levels of symptoms. These investigators found that the lives of children who did not meet DSM symptom criteria were just as disrupted as the lives of children who met symptom criteria, and that a substantial number of children did meet DSM-III-R criteria for a diagnosis but were not impaired.

A study by Bird et al. (1996) also suggested that both symptoms and functional impairment need to be considered separately when making diagnostic decisions. Their study compared two global measures of impairment, the Children's Global Assessment Scale (CGAS; Shaffer et al., 1983) and the Columbia Impairment Scale (CIS; Bird et al., 1993). In the process of comparing these measures, the investigators found that each correlated only moderately with symptom counts, again indicating that symptoms and severity are related but distinct constructs.

Other researchers have examined the symptoms–impairment relationship by determining incidence estimates for a disorder based on symptoms and then investigating whether those estimates shrink significantly when an impairment criterion is added. In one study utilizing this analytic technique, Bird et al. (1988) found that 49.5 % of children in a community sample met DSM criteria for at least one disorder when symptoms alone were required for a diagnosis, but when an additional criterion of moderate impairment was applied, the prevalence went down to 17 %. Shaffer et al. (1996) found similar results in that 4.5 % of their large sample met ADHD criteria based on reports of symptoms, but only 2.8 % did when parent reports of impairment were considered in the diagnostic decision.

## 11.2 Measurement of Impairment

Before examining research on ADHD as an illustrative example of complex symptom–impairment relationships, we take a brief detour to consider the measures of impairment that are frequently used in this literature. Unlike the

DSM-based checklists used in the assessment of symptoms, there is no type of impairment measure that has become the standard. Instead, a wide variety of measures have been used to assess clinical impairment, including clinician ratings, parent and teacher reports, as well as counts of negative life events (e.g., number of arrests). Our overview of various impairment measures is not meant to be exhaustive, and we refer the reader to more comprehensive reviews of these instruments (Canino, Costello, & Angold, 1999; Costello, Angold, & Keeler, 1999; Winters, Collett, & Myers, 2005). Table 11.1 presents the major features of 11 different impairment instruments, showing both the availability and diversity of impairment measures.

Measures of impairment are typically divided into *unidimensional* (or *global*) scales, which yield a single score interpreted as the individual's overall level of impairment, and *multidimensional* (or *domain-specific*) measures, which yield several scores, each pertaining to a different domain of functioning. In general, unidimensional scales are more helpful for research purposes than in clinical practice, where scores that average across different areas (e.g., academic functioning and social functioning) can mask impairments that should serve as the focus of behavioral interventions (cf. Pelham & Fabiano, 2001). Moreover, Winters et al. (2005) noted that unidimensional scales are more likely than multidimensional scales to confound symptoms and impairment, since symptoms of psychopathology are more likely to overlap conceptually with a total impairment score than with any individual area of functioning.

One commonly used unidimensional measure is the Children's Global Assessment Scale (CGAS; Bird, 1999). Assessing a child using the CGAS requires first gathering a wide variety of data on the child, and then using this information to assign the child a score between 1 and 100, where higher scores indicate higher levels of functioning (and thus, lower levels of impairment). Paragraph-long descriptions are given for each range of 10 points (e.g., 31–40), and a degree of clinical judgment is used to assign the final score within each 10-point range. Despite this apparently somewhat subjective procedure, the CGAS exhibits good psychometric characteristics (Canino et al., 1999; Winters et al., 2005). Its interrater reliability is .84, and its test-retest reliability over a 19-day interval is .83. Moreover, validation studies have found substantial correlations between CGAS scores and DSM-IV Axis V (Global Assessment of Functioning) scores.

A relatively new unidimensional measure of impairment is the Barkley Functional Impairment Scale (BFIS). This scale of 15 items (domains of impairment) is implicitly targeted toward individuals with ADHD, but it may be used for anyone experiencing psychosocial impairment. The BFIS is a self- and other-report instrument that takes a few minutes to complete. Respondents rate the extent of difficulty (0 = not at all, to 9 = severe) that they or someone they know is having in various life activities (e.g., at work, in relationships, etc.). Normative score tables are available for three age groups (18–39, 40–59, and 60–89). There also is a quick screen version available that covers six domains (items). While one could treat each domain/item as a separate entity, at least for purposes of examining areas of change during treatment, such one-item clinical interpretations must be made cautiously because

**Table 11.1** Selected standardized measures of clinical impairment

| Instrument and source | Dimensionality | Procedure | Standardization |
|---|---|---|---|
| Adaptive Behavior Assessment System-Second Edition (Harrison & Oakland, 2003) | Multidimensional | Comprehensive rating scale indicating whether or not the individual is able to do certain behaviors and how frequently they are performed | Well standardized on nationally representative sample; for school-age children, the normative sample was over 1600 |
| ADHD-FX (Haack, Gerdes, Lawton, & Schneider, 2014) | Unidimensional | Parent rates child's functional impairment on 32 items across home, school, and peer domains | Culturally sensitive instrument available in English & Spanish. Not standardized yet. Offers a global impairment score |
| Brief Impairment Scale (Bird et al., 2005) | Multidimensional | Brief (23-item) rating scale yielding scores for three areas of functioning: interpersonal relations, school/work, and self-fulfillment | Several samples have been used, but none are meant to be nationally representative. Various cut scores are proposed based on the sample norms, but at the present time, criterion-referenced score interpretation is superior |
| Child Behavior Checklist Social Competence Scale (Achenbach 1991a, 1991b) | Multidimensional | Parent rates children's competence in the areas of school, sports/hobbies, and social relationships as above average, average, or below average | Excellent standardization on large nationally representative samples of clinically referred and nonreferred children |
| Children's Global Assessment Scale (Bird, 1999) | Unidimensional | Clinician uses other assessment data and back general information to make a judgment concerning overall functioning, assigning the child a score between 1 and 100 | No normative sample used in development, but cut scores are available based off of large-sample trials of the scale |
| Barkley Functional Impairment Scale (Barkley, 2011) | Unidimensional | Self- and other-report measure for adults that assesses15 domains (long form) of potential impairment (i.e., home life, work, education, relationships, driving, self-care). Also has short form (six domains) | Standardized on a sample of 1249 adults. Norms provided for age groups (18–39, 40–59, 60–89), and total |

(continued)

**Table 11.1** (continued)

| Instrument and source | Dimensionality | Procedure | Standardization |
|---|---|---|---|
| Home Situations Questionnaire (Barkley, 1997) | Unidimensional | Parent notes whether rule-breaking and oppositionality occurs in any of 16 settings and the degree to which each setting is a problem situation for the child. The number of problem situations and mean severity are calculated | Limited norms are available, but a criterion-referenced interpretation of scores is preferred |
| Impairment Rating Scale (Fabiano et al., 2006) | Multidimensional | For each of six (school) or seven (home) domains, teacher or parent places a mark along a line representing a continuum of impairment; an average score across domains can also be calculated | Normative data have not been reported, so criterion-referenced interpretation is required |
| School Situations Questionnaire (Barkley, 1997) | Unidimensional | Teacher notes whether child presents problems in any of 12 school settings and the degree to which each is a problem situation for the child. The number of problem situations and mean severity are calculated | Limited norms are available, but a criterion-referenced interpretation of scores is preferred |
| Social Adjustment Inventory for Children and Adolescents (John et al., 1987) | Multidimensional | 77-item scale administered in semi-structured interview format by trained clinician; covers four areas: school functioning, spare-time activities, peer functioning, & family functioning | Normative data have not been reported, so criterion-referenced interpretation is required |
| WHODAS 2.0 (World Health Organization, 2012) | Multidimensional | Long (36 items) and short (12 items) scales completed by structured interview or self-report for ages 18 & up; provides six domain scores and a summary score; offered in multiple languages | Standardized on samples across 19 countries; good psychometric properties; percentile scores provided on degree of disability |

Portions of this table are reprinted with permission from the ADHD Report these items are not reliable or sensitive enough to make clear distinctions. The Mean Impairment score and Percent Domains Impaired score provide global indices of impairment, and both show acceptable levels of reliability and validity.

There are at least as many multidimensional as unidimensional scales that measure impairment in some fashion; one representative measure is the Social Adjustment Inventory for Children and Adolescents (SAICA; John, Gammon, Prusoff, & Warner, 1987). The SAICA is a semi-structured interview administered by a clinician to either a parent or directly to the child. The 77 questions load on several subscales, including spare-time activities, peer problems, and sibling relationships. The internal consistency of the scale's total score is low, but given the heterogenous content, this is to be expected. The interrater agreement is considerably higher, and validation studies have included findings of a significant difference between children with and without ADHD. However, the clinical utility of the SAICA is limited by the lack of a normative sample (Winters et al., 2005); although scores can be used to track progress during an intervention, they are difficult to interpret when used in diagnosis.

Other multidimensional measures derive from Achenbach's (e.g., 2000) empirical assessment system, and the two most prominent impairment measures found in the system are the Child Behavior Checklist (CBCL) Competency scales (Achenbach, 1991a) and the corresponding Teacher Report Form (TRF) Adaptive Functioning scales (Achenbach, 1991b). Pelham, Fabiano, and Massetti (2005) concluded that measures as simple and as inexpensive as the Child Behavior Checklist and the Teacher Report Form are sufficiently correlated with more comprehensive measures such as achievement that have been used to measure impairment. Empirically derived scales such as the CBCL and TRF assess the symptoms of several childhood disorders (e.g. anxiety, depression, oppositional defiant, ADHD) in addition to impairment, making them more efficient than DSM-IV-based scales that only measure symptoms of a single disorder (Pelham et al.).

Another multidimensional measure that is worth describing in some detail is the Impairment Rating Scale (IRS; Fabiano et al., 2006). The IRS is unlike any of the other impairment measures reviewed here; for each of several domains, the respondent (a parent or teacher) places an "X" along a line that symbolizes a continuum of impairment severity, ranging from "no problem/definitely does not need treatment or special services" to "extreme problem/definitely needs treatment or special services." The parent version has different domains (e.g., relationship with siblings) than the teacher version (e.g., influence on classroom functioning). Although further research must be done, initial results are promising. Fabiano and colleagues reported good psychometric characteristics, including differentiation of children with and without ADHD.

One of the most widely accepted and utilized multidimensional measures of impairment is the World Health Organization Disability Assessment Schedule (WHODAS 2.0, 2012). This is the latest revision of earlier measures developed by the World Health Organization. The WHODAS 2.0 is intended to assess health and disability across a wide range of diseases and disorders in adults. It is linked conceptually to the International Classification of Functioning, Disability, and Health diagnostic system also developed by WHO. WHODAS 2.0 also has been incorporated into the DSM-5 manual (American Psychiatric Association, 2013, pp. 745–748). Although there are various versions of WHODAS 2.0 (long and short; self-report and structured interview) in many languages, the DSM-5 lists the most common version, the 36-item, self-report form. This version assesses seven areas of functioning (e.g., difficulty with self-care, or getting along with people, etc.) with multiple items (rated on a scale from 1 = none, to 5 = extreme or cannot do). The scale yields separate domain scores as well as a General Disability (impairment) Score. Normative data are available and the average domain and general scores are used to determine a person's degree of disability in a domain and overall. This instrument also allows a clinician to correct a patient's self-reported score if other information suggests a change; scores that are consistently elevated in a domain or, in general, typically indicate significant clinical impairment.

Standardized measures of impairment have psychometric characteristics comparable to those of symptom rating scales. Moreover, like symptom rating scales, there are many different kinds of impairment measures, each with its own advantages and disadvantages. Diagnosticians working with specific clinical issues (e.g., comorbidities, certain demographic groups, treatment planning) can search the available pool of measures for one that meets their needs. Similarly, researchers examining symptom–impairment relationships can select a measure of impairment that seems most relevant to the symptoms that they are interested in measuring. In the research reviewed below, a variety of impairment measures were utilized within ADHD populations.

## 11.3 Relationship of Symptoms and Impairment in ADHD

The inclusion of an impairment criterion in diagnosis is particularly important in the assessment of ADHD as compared to many other mental disorders. High functioning people who live apparently unimpaired lives may experience many of the symptoms of ADHD. As such, the relationship between symptoms and impairment merits special attention in the case of ADHD.

Gordon et al. (2006) conducted the most comprehensive analysis of the relationship between symptoms and impairment by reanalyzing data from four large-scale studies. The first study reviewed by Gordon and colleagues, the Massachusetts General Hospital (MGH) Longitudinal Families Study (Biederman et al., 1992, 1999), included 280 children with ADHD diagnoses (based on DSM-III-R criteria) and 240 non-ADHD controls; half of the participants in each group were girls, and all of the children were between 6 and 17 years of age. Children with ADHD were recruited from referrals to a pediatric psychopharmacology clinic at the MGH and from a local HMO, whereas control participants were selected from outpatients at pediatric medical clinics. The MGH Longitudinal Families Study used many different measurement instruments. However, in the Gordon and colleagues' reanalysis, data from the Attention subscale of the Child Behavior Checklist (CBCL; Achenbach & McConaughy, 1987) and the Schedule for Affective Disorders and Schizophrenia

Epidemiologic version for School-Age Children (K-SADS-E; Orvaschel & Puig-Antich, 1987) were selected as the symptom measurements, whereas the Social Adjustment Inventory for Children and Adolescents (SAICA; John et al., 1987) and the Competence subscales of the CBCL (Activities, Social, and School) were considered as the measures of impairment.

In this MGH dataset, the correlations between symptoms and impairment never exceeded $r = .43$, and therefore, symptom levels accounted for no more than 19 % of the variance in impairment levels. Additionally, based on impairment criteria established for the SAICA (having a score below 5th percentile of control group), Gordon et al. (2006) concluded that only 23 % of the ADHD sample was both symptomatic and impaired. Alternatively stated, more than three quarters of the children identified as having ADHD through the use of symptom counts would not have been diagnosed if the impairment criterion had been considered. It is noteworthy that these figures were derived using only a single measure of symptoms and a single measure of impairment; since, in clinical practice, multiple pieces of information from multiple informants are used, an even smaller proportion of the sample would likely to have been rated both symptomatic and impaired by *all* informants.

In another study reanalyzed by Gordon et al. (2006), the Vermont Family Genetics Study (Hudziak, Copeland, Stanger, & Wadsworth, 2004), very similar results were found regarding the relationship between symptoms and impairment. This study included 187 children with ADHD and 183 randomly selected siblings of the ADHD participants, all between 6 and 18 years of age. Families were recruited from local pediatricians and psychiatrists and through newspaper advertisements and posters placed throughout the county. In this study, the symptom measures consisted of the Predominantly Inattentive and Hyperactive-Impulsive Subscales of the Vermont Structured Diagnostic Interview (Hudziak et al., 2004), and the impairment measures again included the Competency Scales of the CBCL. The correlations between symptoms and impairment were higher than those in the MGH study, but still none of the correlations accounted for more than 25 % of the variance.

A third analysis described in Gordon et al. (2006) was conducted using patients from an outpatient mental health care center in Ontario, Canada, where the Brief Child and Family Phone Interview (BCFPI; Cunningham, Pettingill, & Boyle, 2004) was administered as part of a standard intake procedure for approximately 1900 consecutive referrals. Administration of this 30 min structured phone interview to parents and teachers of children aged 3–18 yielded information on both symptoms and impairment. The subscale of symptoms that was most closely related to ADHD was called "Regulating Attention, Impulsivity and Activity Level" and was composed of six items. Seven different subscales tapped impairment, and these included "Child's Social Participation," "Quality of the Child's Social Relationships," "School Participation and Achievement," and "Global Child/Youth Functioning." Similar to the results found in the previous two datasets, each of the correlations between the ADHD-related symptoms and the impairment subscales was below about 0.40. The impairment measures correlating the highest with the symptom measure were "Quality of the Child's Social Relationships" and "Global Family Situation," (each with a correlation of $r = 0.39$), and the "Global Family Situation" was not even a direct measure of the *child's* level of impairment. Admittedly, had the impairment measures been combined, the relationship with symptoms might have been stronger, but since impairment in more than one area is required for a proper ADHD diagnosis, aggregating the subscale scores would have resulted in a measure with less diagnostic utility.

The fourth and final reanalysis conducted in Gordon et al. (2006) was the only analysis on adults with ADHD, and it used data from the Milwaukee Longitudinal Study (Barkley, Fischer, Smallish, & Fletcher, 2004). Data from this study were gathered from individuals 19–25 years of age who were originally included in the study as young children and who had been followed for at least 13 years. There were originally 158 subjects diagnosed as hyperactive as children and 81 community controls included in the study. Ninety-one percent of these were male and 9 % were female. The hyperactive group had been recruited from consecutive referrals to a child psychology service specializing in the treatment of hyperactive children at Milwaukee Children's Hospital, whereas the community control children had been recruited using a 'snowball' technique (i.e., current participants help recruit new participants). Telephone interviews of both symptoms and impairment were conducted at three points in a subject's life. A DSM-IV-based structured interview to assess ADHD served as the measure of symptoms, while a structured interview of adaptive functioning served as the measure of impairment. Overall, the results extended the finding of a weak relationship between symptoms and impairment. The average correlation coefficient was only $r = .25$, and none of the correlations were above 0.50. Given that there was only a single measure of impairment, and that for adult participants, multiple measures of impairment across diverse life activities are even more important, the true relationship between symptoms and *clinical* levels of impairment is likely even weaker than the data reported here.

Based on these four secondary data analyses, Gordon et al. (2006) concluded that there appeared to be a weak relationship between ADHD symptoms and impairment in all four datasets reviewed. The largest correlation found between symptoms and any specific measure of impairment was $r = .65$ (accounting for about 42 % of the variance). However, the majority of the correlations were much smaller, accounting for no more than 10 % of the variance. Based on these data, Gordon et al. concluded that symptoms and impairment were distinct dimensions of ADHD that should be measured separately when making diagnostic decisions. However, as has been emphasized, all four of these datasets were analyzed with only a single measure of symptoms and a single measure of impairment, and the need to take a multidimensional approach to impairment measurement was recognized by the same research team in subsequent papers.

As a follow-up to Gordon et al. (2006), a study was conducted (Barkley et al., 2006) addressing this issue of the multidimensional nature of impairment. Three ADHD datasets were examined in this study; two of these had also been included in Gordon and colleagues' earlier paper: data from the Milwaukee Longitudinal Study (Barkley et al., 2004), and data from the outpatient mental health care center in Ontario, Canada. The third dataset was from the UMASS study conducted by

Barkley (reviewed in Barkley, Fischer, & Murphy, 2008), and included 146 adults with clinical diagnoses of ADHD, 97 adults referred to the same clinic who did not have ADHD (but did have other varieties of psychopathology, mainly anxiety and mood disorders), and 109 community control adults. The participants were all between 17 and 69 years of age ($M=35$), and 52% were male. Several ADHD symptom measures were used, including a clinical interview, self-report rating scales, scales completed by others who knew the participant well, employer ratings, and recall of childhood symptoms. The Various self-rated and other-rated impairment measures were also used. Examples of some of the impairment measures included: ever retained in school, difficulty keeping friends, car crashes, and low-grade point average (see Barkley, Murphy, & Fischer, 2008).

Whereas Gordon and colleagues considered each measure of impairment individually, Barkley et al. (2006) aggregated impairment across domains to create an omnibus index of impairment within each dataset. Impairment indices were determined using either dichotomously scored variables (e.g. "ever involved in a teenage pregnancy either as mother or father"), or cut-off criteria (e.g. more than seven citations on their official driving record). These investigators found that analyzing the datasets with the use of impairment indices significantly increased the correlations between symptoms and impairment. Previous correlations from the review by Gordon and colleagues had ranged between .01 and .65, but in Barkley and colleagues' analyses, the correlations ranged between .43 and .88, with the majority >.70. That is, when impairment was aggregated across multiple measures and domains, the relationship between symptoms and impairment was found to be approximately twice as strong.

A study conducted by Fabiano et al. (2006) also investigated the relationship between ADHD symptoms and impairment. This study was designed to test the psychometric properties of the Impairment Rating Scale (IRS; see above), specifically developed to assess ADHD impairment based on both parent and teacher report. A series of four analyses were conducted using over 3200 children from preschool to fifth grade recruited from various elementary schools as well as from a medication efficacy trial. The Diagnostic Interview Schedule for Children (DISC; Shaffer et al., 1996) and the Disruptive Behavior Disorders Rating Scale (DBD; Pelham, Gnagy, Greenslade, & Milich, 1992) were used as symptom measures, and the CGAS (Shaffer et al., 1983) was used as an impairment measure, in addition to the IRS. Children were labeled as having ADHD based on parent and teacher report, although the DSM-IV impairment criterion (Criterion D) was not included in the identification of these children.

Fabiano et al. (2006) found moderate to high correlations between symptoms and impairment ($r=.58$–$.93$) in clinical populations. However, when the same analyses were conducted with a random sample of children from various elementary schools, the correlations between symptoms and impairment were much lower ($r=.17$–$.53$). Although the IRS was found to be a valid and reliable measure to assess impairment in a child with ADHD, this series of studies demonstrated the variability with which symptoms and impairment are related, since the extent to which these variables were related was dependent on the sample and the source of the ratings (parent or teacher). Interestingly, the study also showed that the IRS added incremental validity beyond a diagnosis made based on symptoms alone. An $R^2 = .31$ was found using average teacher symptom ratings alone to predict CGAS scores. This increased to $R^2 = .38$ (a statistically significant increase) when teacher IRS ratings were added to the equation.

A study by Gathje, Lewandowski, and Gordon (2008) also examined the symptom–impairment relationship in a clinic-referred sample of 314 children (ages 5–17 years). These investigators found modest correlations (ranging from .26 to .32) between maternal reports of symptoms on an ADHD checklist and a composite impairment score (home, school, social, and recreational domains). The symptom–impairment relationship grew slightly stronger based on the cutoff score used to determine impairment (1, 1.5, 2 standard deviations above the mean). Correlations were higher between the Child Behavior Checklist (CBCL; Achenbach 1991a, 1991b), Attention scale score (maternal report), and the impairment cutoffs (.42–.47). They found that symptom count along with CBCL score, Peabody Picture Vocabulary Test (Dunn & Dunn, 1997) score, and gender all contributed significantly to the prediction of impairment. However, these variables collectively only accounted for 30 % of the variance in impairment score.

Next, Gathje et al. examined the effects of both symptom and impairment variables on diagnostic classifications of ADHD. Of the sample of 314 students referred to the ADHD clinic, 81 % met a liberal criterion for diagnosis based on maternal report on a DSM-IV checklist of ADHD symptoms. When additional criteria were added (Child Behavior Checklist Attention scale score greater than 65, and impairment measure scores of at least 1.5 standard deviations above the mean) the rate dropped to 19 %. When an even more stringent criterion on the impairment measure (2 standard deviations above the mean) was required, the classification rate dropped to 2 %.

Clearly, then, diagnostic classifications are very different when they are based on symptoms alone versus symptoms plus impairment. The research suggests that symptoms and impairment are related yet separate factors that both need to be part of the diagnostic equation.

## 11.4 Relationship of Symptoms and Impairment in Other Disorders

After examining the literature on ADHD, in which the correlations between symptoms and impairment were found to be far from perfect and often quite modest, it is reasonable to ask whether ADHD is a special case. Certainly, the nature of ADHD symptoms—specifically, their being so common in the general population (e.g., Lewandowski et al., 2008; Murphy & Barkley, 1996)—suggests that they may be especially poor in serving as a proxy for (or a predictor of) impairment. However, although the research base is currently small, it appears that symptoms and impairment are distinct in other forms of psychopathology as well.

Consider the case of posttraumatic stress disorder (PTSD). After undergoing a traumatic event (e.g., sexual assault, military combat, childhood physical abuse, etc.), many individuals develop a set of symptoms that includes avoidance of cues related to the event, mental re-experiencing of the event (through, e.g., dreams, flashbacks), and a persistent heightened level of arousal or vigilance (Resick & Calhoun, 2001). Intuitively, these symptoms would seem to necessarily lead to impairment, but research suggests otherwise. Breslau and Alvarado (2007) examined data from two large community-based samples (*N*s were 2181 and 1698), focusing on those participants who had been exposed to traumatic events (excluding military combat). These investigators found that when the clinical impairment criterion (which is present for PTSD in the DSM criteria) was applied, the conditional probability of developing PTSD was 30 % lower; that is, of those who had been exposed to trauma, the proportion who would be diagnosed with PTSD was 10.8 % without the application of the impairment criterion, but only 7.8 % with the impairment criterion applied. Even symptoms as serious as those associated with PTSD, then, may not always bring impairment along with them, necessitating a separate assessment of impairment.

Similarly, in schizophrenia, Fulford et al. (2013) found that positive, negative, and disorganized symptoms never correlated with measures of impairment above $r = .5$, and often the relationships were well below that value. The case of schizophrenia is an especially interesting one, in that common pharmacologic treatments do a better job of addressing positive symptoms, but negative symptoms are more strongly (but still only moderately) related to impairment. Impairment, then, should be measured continuously throughout treatment, in large part to document whether treatment is working.

The importance of impairment in assessment can even be seen in disorders for which “symptoms” are defined more broadly. Consider the case of learning disabilities, in which individuals, typically children, have trouble in specific academic skills, such as reading, writing, and mathematics. Even though the most common method of diagnosing learning disabilities over the years has involved looking for a discrepancy between a student’s ability (typically measured by an IQ test) and his or her achievement in some academic skill area, the DSM-5 guidelines for “specific learning disorders” include what amounts to an impairment criterion, insisting that “The affected academic skills are substantially and quantifiably below those expected for the individual’s chronological age, and cause significant interference with academic or occupational performance…” (p. 67). As noted by many critics, the IQ vs. achievement discrepancy criterion does not take into account the impairment guideline. For example, students with IQ scores in the above average range (>130), yet scoring in the average range in achievement, might have a discrepancy but not be impaired because they are performing at the typical level expected for their age and grade (Brody & Mills, 1997). These students, then, have the “symptoms” of a learning disability without the attendant impairment. Proposals to include impairment in the diagnosis of learning disorders (e.g., Dombrowski, Kamphaus, & Reynolds, 2004; Lovett & Lewandowski, 2006) have been met with criticism (e.g., Gregg, Coleman, Lindstrom, & Lee, 2007), as if a student's absolute level of academic functioning is unimportant when determining whether an academic problem exists.

To summarize, symptoms and impairment are related, but distinct constructs. Clearly, the intensity and frequency of symptoms are far from perfect predictors of a person's functional outcome. Research indicates that a person can be substantially impaired without manifesting high levels of symptoms, can display many symptoms and have little functional impairment, or can change over time in degree of symptomology and impairment (Sibley et al., 2012). This reality should encourage clinicians to move beyond simple symptom counts toward an evaluation that fully considers the extent of functional impairment. Clinicians should consider incorporating into their evaluations some of the impairment measures reviewed in this chapter.

The addition of impairment measures to one's diagnostic test battery is an important step. Yet the clinician must determine "how much impairment is required to rise to the level of a disorder or disability?" The legal definition of disability established for the ADA and other disability laws requires evidence of a substantial limitation in a major life activity (e.g., learning, speaking, reading, writing, concentrating, etc.). "Substantial" is typically operationalized as functioning that is significantly below that of the population average. Therefore, the legal realm establishes an "average person standard" as the basis from which a substantial limitation is determined. Clinicians have not always embraced the legal construal of disability as a key factor in assigning a diagnosis. In addition, professional diagnostic guidelines, such as the DSM-5, offer little guidance to diagnosticians regarding how to judge the extent of impairment for most disorders. The advice that the diagnostic criteria do provide is very general and inconsistent across diagnoses. Therefore, while the DSM-5 requires evidence of impairment, it is unclear with respect to degree of impairment required to warrant a diagnosis or how to measure that impairment.

We began this chapter by presenting two brief case studies about Maria and Alex. In light of our discussion, it should be apparent that Maria would not be likely to warrant a DSM-5 diagnosis of a Specific Learning Disorder, nor would she qualify for test accommodations under the ADA. While her reading test score falls below her IQ score, her reading skills are well within the average range. It seems implausible to claim that she has a disability when her lowest scores are nonetheless average. Because Maria is not substantially limited in reading relative to persons her age, she likely would not be considered to have a "disability" in the legal sense of the term.

While Alex's case may be less clear cut, his failure to pass a bar examination would not be sufficient to demonstrate impairment. Most people in the general population lack the skills to even consider sitting for such a challenging postgraduate test. That he was able to graduate from high school, college, and law school without any record of impairment or need for formal accommodations argues against the contention that he is impaired. Failing to pass a bar examination is not, by itself, even diagnostic of a disorder. (If it were considered pathognomonic, almost the entire population could fairly be deemed as disordered!) Furthermore, many non-psychiatric factors could easily account for Alex's struggle with this exam, including test anxiety, poor preparation, or skills that, while average, were not sufficient to allow for easy success on a highly demanding task. While he may not have ADHD, he might well benefit from attention to these other issues.

Cases such as these serve to highlight the importance of considering impairment when making a diagnosis and qualifying a person for treatment services and/or accommodations. Failure to take impairment into account lays the groundwork for misdiagnosis. The evidence is clear that, while a client's symptoms tell some of the diagnostic story, they represent only part of the tale. It is critical for clinicians to also ask questions (and use scales) that explore the impact of symptoms on the person's ability to manage routine real-world tasks normally. From our perspective, every evaluation should ask the question: "Precisely how have the problems you've told me about actually kept you from functioning as well as most other people?" If this fundamental question cannot be answered clearly, clinicians should consider explanations other than those associated with a mental disorder.

## References

Achenbach, T. M. (1991a). *Manual for the Child Behavior Checklist/4-18 and 1991 profile*. Burlington, VT: University of Vermont Department of Psychiatry.

Achenbach, T. M. (1991b). *Manual for the teacher's report form and 1991 profile*. Burlington, VT: University of Vermont Department of Psychiatry.

Achenbach, T. M. (2000). Assessment of psychopathology. In A. J. Sameroff, M. Lewis, & S. M. Miller (Eds.), *Handbook of developmental psychopathology* (2nd ed., pp. 41–56). New York: Kluwer.

Achenbach, T. M., & McConaughy, S. H. (1987). *Empirically based assessment of child and adolescent psychopathology: Practical applications*. Newbury Park: Sage.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Association.

Angold, A., Costello, E. J., Farmer, E. M., Burns, B. J., & Erkanli, A. (1999). Impaired but undiagnosed. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 129–137.

Barkley, R. A. (1997). Inhibition, sustained attention, and executive function: Constructing a unifying theory of ADHD. *Psychological Bulletin*, *121*, 65–94.

Barkley, R. A. (2006). *Attention deficit hyperactivity disorder: A handbook for diagnosis and treatment* (3rd ed.). New York: Guilford Press.

Barkley, R. A. (2011). *Barkley functional impairment scale*. New York: Guilford Press.

Barkley, R. A., Cunningham, C. E., Gordon, M., Faraone, S. V., Lewandowski, L., & Murphy, K. R. (2006). ADHD symptoms vs. impairment: Revisited. *The ADHD Report, 14*, 1–9.

Barkley, R. A., Fischer, M., Smallish, L., & Fletcher, K. (2004). Young adult follow-up of hyperactive children: Antisocial activities and drug use. *Journal of Child Psychology & Psychiatry, 45*, 195–211.

Barkley, R. A., Murphy, K. R., & Fischer, M. (2008). *ADHD in adults: What the science says*. New York: Guilford Press.

Biederman, J., Faraone, S. V., Keenan, K., Benjamin, J., Krifcher, B., Moore, C., et al. (1992). Further evidence for family-genetic risk factors in attention deficit hyperactivity disorder. Patterns of comorbidity in probands and relatives in psychiatrically and pediatrically referred samples. *Archives of General Psychiatry, 49*, 728–738.

Biederman, J., Faraone, S. V., Mick, E., Williamson, S., Wilens, T. E., Spencer, T. J., et al. (1999). Clinical correlates of ADHD in females: Findings from a large group of girls ascertained from pediatric and psychiatric referral sources. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 966–975.

Bird, H. R. (1999). The assessment of functional impairment. In D. Shaffer, C. P. Lucas, & J. E. Richters (Eds.), *Diagnostic assessment in child and adolescent psychopathology* (pp. 209–229). New York: Guilford.

Bird, H. R., Andrews, H., Schwab-Stone, M., Goodman, S., Dulcan, M., Richters, J., et al. (1996). Global measures of impairment for epidemiological and clinical use with children and adolescents. *International Journal of Methods in Psychiatric Research, 6*, 295–307.

Bird, H. R., Canino, G. J., Rubio-Stipec, M., Gould, M. S., Ribera, J., Sesman, M., et al. (1988). Estimates of the prevalence of childhood maladjustment in a community survey in Puerto Rico. *Archives of General Psychiatry, 45*, 1120–1126.

Bird, H. R., Shaffer, D., Fisher, P. W., Gould, M. S., Staghezza, B., Chen, J. Y., et al. (1993). The Columbia Impairment Scale (CIS): Pilot findings on a measure of global impairment for children and adolescents. *International Journal of Methods in Psychiatric Research, 3*, 167–176.

Bird, H. R., Canino, G. J., Davies, M., Ramirez, R., Chavez, L., Duarte, C., et al. (2005). The Brief Impairment Scale (BIS): A multidimensional scale of functional impairment for children and adolescents. *Journal of the American Academy of Child & Adolescent Psyciatry, 44*(7), 699–707.

Breslau, N., & Alvarado, G. F. (2007). The clinical significance criterion in DSM-IV post-traumatic stress disorder. *Psychological Medicine, 37*, 1437–1444.

Brody, L. E., & Mills, C. J. (1997). Gifted children with learning disabilities: A review of the issues. *Journal of Learning Disabilities, 30*, 282–296.

Canino, G., Costello, E. J., & Angold, A. (1999). Assessing functional impairment and social adaptation for child mental health services research: A review of measures. *Mental Health Services Research, 1*, 93–108.

Costello, E. J., Angold, A., & Keeler, G. (1999). Adolescent outcomes of childhood disorders: The consequences of severity and impairment. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*, 121–128.

Cunningham, C. E., Pettingill, P., & Boyle, M. H. (2004). *The brief child and family phone interview version 3: Interviewer's manual.* Retrieved February 25, 2006, from http://www.bcfpi.com/bcfpi/downloads/manual/en/ENIntMan.pdf

Dombrowski, S. C., Kamphaus, R. W., & Reynolds, C. R. (2004). After the demise of the discrepancy: Proposed learning disabilities diagnostic criteria. *Professional Psychology: Research and Practice, 35*(4), 364.

Dunn, L. M., & Dunn, L. M. (1997). *Peabody picture vocabulary test* (3rd ed.). Circle Pines, MN: AGS.

Eriksen, K., & Kress, V. E. (2005). *Beyond the DSM story: Ethical quandaries, challenges, and best practices*. Thousand Oaks, CA: Sage.

Fabiano, G. A., Pelham, W. E., Waschbusch, D. A., Gnagy, E. M., Lahey, B. B., Chronis, A. M., et al. (2006). A practical measure of impairment: Psychometric properties of the impairment rating scale in samples of children with attention deficit hyperactivity disorder and two school-based samples. *Journal of Clinical Child and Adolescent Psychology, 35*, 369–385.

Fulford, D., Niendam, T. A., Floyd, E. G., Carter, C. S., Mathalon, D. H., Vinogradov, S., et al. (2013). Symptom dimensions and functional impairment in early psychosis: More to the story than just negative symptoms. *Schizophrenia Research, 147*(1), 125–131.

Gathje, R., Lewandowski, L., & Gordon, M. (2008). The role of impairment in the diagnosis of attention deficit hyperactivity disorder. *Journal of Attention Disorders, 11*(5), 529–537.

Gordon, M., Antshel, K., Faraone, S., Barkley, R., Lewandowski, L., Hudziak, J. J., et al. (2006). Symptoms versus impairment: The case for respecting DSV-IV's criterion D. *Journal of Attention Disorders, 9*, 465–475.

Gordon, M., Lewandowski, L., Murphy, K., & Dempsey, K. (2002). ADA-based accommodations in higher education: A survey of clinicians about documentation requirements and diagnostic standards. *Journal of Learning Disabilities, 35*, 357–363.

Gregg, N., Coleman, C., Lindstrom, J., & Lee, C. (2007). Who are most, average, or high-functioning adults? *Learning Disabilities Research & Practice, 22*(4), 264–274.

Haack, L. M., Gerdes, A. C., Lawton, K. E., & Schneider, B. W. (2014). Understanding and measuring functional impairment in diverse children with ADHD: Development of the ADHD-FX scale with an at-risk, community sample. *Journal of Attention Disorders, 20*(6), 487–500. doi:10.1177/1087054714527791.

Hudziak, J. J., Copeland, W., Stanger, C., & Wadsworth, M. (2004). Screening for DSM-IV externalizing disorders with the Child Behavior Checklist: A receiver-operating characteristic analysis. *Journal of Child Psychology & Psychiatry, 45*, 1299–1307.

Harrison, P., & Oakland, T. (2003). *Adaptive behavior assessment system (ABAS-II)*. San Antonio, TX: The Psychological Corporation.

John, K., Gammon, G. D., Prusoff, B. A., & Warner, V. (1987). The Social Adjustment Inventory for Children and Adolescents (SAICA): Testing of a new semistructured interview. *Journal of the American Academy of Child and Adolescent Psychiatry, 26*, 898–911.

Kutchins, H., & Kirk, S. A. (1997). *Making us crazy: DSM: The psychiatric bible and the creation of mental disorders*. New York: Free Press.

Lewandowski, L., Lovett, B., Gordon, M., & Codding, R. (2008). Symptoms of ADHD and academic concerns in college students with and without ADHD diagnoses. *Journal of Attention Disorders, 12*, 156–161.

Lovett, B. J., & Lewandowski, L. J. (2006). Gifted students with learning disabilities: Who are they? *Journal of Learning Disabilities, 39*, 515–527.

Murphy, K., & Barkley, R. A. (1996). Prevalence of DSM-IV symptoms of ADHD in adult licensed drivers: Implications for clinical diagnosis. *Journal of Attention Disorders, 1*, 147–161.

Orvaschel, H., & Puig-Antich, J. (1987). *Schedule for affective disorder and schizophrenia for school-age children: Epidemiologic, 4th version*. Pittsburgh, PA: Western Psychiatric Institute and Clinic.

Pelham, W. E., & Fabiano, G. A. (2001). Treatment of attention-deficit hyperactivity disorder: The impact of comorbidity. *Clinical Psychology and Psychotherapy, 8*, 315–329.

Pelham, W. E., Fabiano, G. A., & Massetti, G. M. (2005). Evidence-based assessment of attention deficit hyperactivity disorder in children and adolescents. *Journal of Clinical Child and Adolescent Psychology, 34*, 449–476.

Pelham, W. E., Gnagy, E. M., Greenslade, K. E., & Milich, R. (1992). Teacher ratings of DSM-III—R symptoms for the disruptive behavior disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 31*, 210–218.

Resick, P. A., & Calhoun, K. S. (2001). Posttraumatic stress disorder. In D. H. Barlow (Ed.), *Clinical handbook of psychological disorders* (3rd ed., pp. 60–113). New York: Guilford.

Shaffer, D., Fisher, P., Dulcan, M. K., Davies, M., Piacentini, J., Schwab-Stone, M., et al. (1996). The NIMH Diagnostic Interview Schedule for Children Version 2.3: I. Description, acceptability, prevalence rates, and performance in the MECA study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 865–877.

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fischer, P., Bird, H., et al. (1983). A Children's Global Assessment Scale (CGAS). *Archives of General Psychiatry, 40*, 1228–1231.

Sibley, M. H., Pelham, W. E., Jr., Molina, B. S., Gnagy, E. M., Waxmonsky, J. G., Waschbusch, D. A., et al. (2012). When diagnosing ADHD in young adults emphasize informant reports, *DSM* items, and impairment. *Journal of Consulting and Clinical Psychology, 80*(6), 1052–1061.

Smith, G. N., Ehmann, T. S., Flynn, S. W., MacEwan, G. W., Tee, K., Kopala, L. C., et al. (2011). The assessment of symptom severity and functional impairment with DSM-IV Axis V. *Psychiatric Services, 62*(4), 411–417.

Winters, N. C., Collett, B. R., & Myers, K. M. (2005). Ten-year review of rating scales, VII: Scales assessing functional impairment. *Journal of the American Academy of Child and Adolescent Psychiatry, 44*, 309–338.

World Health Organization. (2012). *Measuring health and disability: Manual for WHO Disability Assessment Schedule* (WHODAS 2.0). Geneva: World Health Organization.

# Measuring Impairment with the Rating Scale of Impairment

## 12

Sam Goldstein and Jack A. Naglieri

The Rating Scale of Impairment (RSI) (Goldstein & Naglieri, 2016) was developed to measure functional limitations across a range of life areas for youth ages 5 through 18 years. The RSI meets the need for a measure of impairment that can be used with symptom-based diagnostic tools as part of a comprehensive assessment. The RSI can be completed by a parent or a teacher. It yields scales measuring functioning in the following areas: school or work, social, mobility, domestic, family, and self-care. The RSI was developed to the highest psychometric qualities to provide clinically meaningful information that aids in treatment planning.

## 12.1 Uses of the RSI

### 12.1.1 Assessing an Individual

The RSI can be used during the assessment and diagnostic process of mental health and medical conditions providing information about an individual's functional impairment in different life areas. Normative scores from the RSI allow the clinician to effectively compare an individual to a nationally representative group. Scores from the RSI can be integrated with other clinical, diagnostic, and medical information to provide a more complete understanding of a youth. When used in combination with other sources of information, results from the RSI help in guiding

---

S. Goldstein, Ph.D. (✉)
Neurology, Learning and Behavior Center, 230 South 500 East, Suite 100,
Salt Lake City, UT 84102, USA
e-mail: info@samgoldstein.com

J.A. Naglieri, Ph.D.
Curry School of Education, University of Virginia, 6622 White Post Road,
Centerville, VA 20121, USA
e-mail: jnaglieri@gmail.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_12

diagnostic decisions, developing treatment plans, and ongoing monitoring of treatment. The RSI can also be used to evaluate the effectiveness of treatment programs designed to improve a youth's level of functioning in the identified areas of impairment, independent of a clinical diagnosis.

### 12.1.2 Screening a Group of Individuals

In some instances, clinicians may wish to obtain information about a group. For example, the RSI can be used to screen children or youth to identify those who might require additional assessments, or alternatively might benefit from additional support. High scores on the RSI suggest problems with the youth's competence in meeting the demands of everyday functioning. Additional considerations are then required in this situation, such as a more thorough evaluation of the causes of the individual's impairment, and/or intervention/treatment to improve the youth's level of functioning.

### 12.1.3 Evaluating an Intervention Program

Results from the RSI can inform decisions about the effectiveness of a particular individual or group intervention. When used in a clinical setting, RSI results can be collected at the beginning of an intervention and at several points throughout the intervention in order to evaluate whether a particular program is associated with an improvement in the targeted area(s) of impairment. In research studies, group data from the RSI can be analyzed to determine whether change (pre- vs. posttreatment or experimental treatment vs. control group) is significant. Results from these types of evaluations can be helpful in supporting the continuation of a treatment program.

### 12.1.4 Use in a Research Context

The RSI can be used in a variety of settings for different research protocols. The RSI offers several advantages over other data collection methods. First, the scales were carefully developed to measure impairment across a comprehensive range of life areas, supported by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) guidelines for measuring impairment (WHO, 2001). Second, the scales provide scores based on a nationally representative normative sample (ages 5–18 years) of a diverse group of youth. Third, the RSI possesses strong, well-documented psychometric qualities. Finally, the RSI is easily comparable to other instruments due to the use of standard scores.

| RSI 5–12 Years Parent Form | RSI 5–12 Years Teacher Form | RSI 13–18 Years Parent Form | RSI 13–18 Years Teacher Form |
|---|---|---|---|
| Age Range: 5–12 Years | | Age Range: 13–18 Years | |
| Number of items: 41 | Number of items: 29 | Number of items: 49 | Number of items: 29 |
| Total Score | | Total Score | |
| RSI Scales<br>- School<br>- Social<br>- Mobility<br>- Domestic<br>- Family | RSI Scales<br>- School<br>- Social<br>- Mobility | RSI Scales<br>- School/Work<br>- Social<br>- Mobility<br>- Domestic<br>- Family<br>-Self-care | RSI Scales<br>- School<br>- Social<br>- Mobility |

**Fig. 12.1** Overview of the RSI components

## 12.2 RSI Form Options

The RSI can be used by parents and teachers of youth aged 5–18 years. For children (5–12 Years), the parent form (RSI [5–12 Years] Parent Form) includes 41 items, and a teacher form (RSI [5–12 Years] Teacher Form) includes 29 items. For adolescents (13–18 Years), the parent form (RSI [13–18 Years] Parent Form) includes 49 items, whereas the teacher form (RSI [5–18 Years] Teacher Form) includes 29 items. All scales are set to have a normative mean of 50 and a standard deviation of 10 (Fig. 12.1).

## 12.3 Administration and Scoring Options

### 12.3.1 Paper-and-Pencil

All of the RSI forms are available in the MHS QuikScore™ format. The rater writes on the external layers of the form, and the results transfer through to a hidden scoring grid within the internal layers. The examiner then uses the internal layers to tabulate results. Each RSI QuikScore form includes conversion tables, which are used to convert raw scores to *T*-scores, percentile ranks, and classifications. For individuals who wish to use the MHS Online Assessment Center, users can print paper forms that do not include scoring pages.

### 12.3.2 Online

The RSI can be completed and automatically scored online wherever an internet connection is available. Paper-and-pencil forms can also be scored online by entering responses from a completed paper-and-pencil administration into the online program.

### 12.3.3 Report Options

RSI reports can be generated using the online scoring option. Three report types are available for all RSI forms. The Interpretive Report provides detailed results from one administration. The Progress Monitoring and Treatment Effectiveness Report provides an evaluation of RSI score changes over time for up to four administrations from the same rater. The Comparative Report provides an analysis of scores from two to five different raters.

## 12.4 Users and User Qualifications

The RSI is intended for use by professionals such as clinical psychologists and neuropsychologists, school psychologists, clinical social workers, physicians, school and community counselors, psychiatrists, and pediatric/psychiatric nurses. Professionals interpreting the RSI must possess appropriate qualifications (which require that, at a minimum, the professional has completed graduate-level courses in tests and measurements at a university or has received equivalent documented training), and must be familiar with the RSI manual and the Standards for Educational and Psychological testing developed by the American Educational Association, the American Psychological Association, and the National Council on Measurement in Education (AERA, APA, & NCMA, 1999). Users of the RSI should be members of professional associations that endorse a set of standards for the ethical use of psychological or educational tests, or be licensed professionals in the areas of psychology, education, medicine, social work, or an allied field. Although individuals who do not have advanced formal training in clinical psychology or psychometrics can administer and score the RSI by following the procedures outlined in this manual, interpretation should be conducted only by individuals with those qualifications described above.

### 12.4.1 Development

The development of the RSI encompassed 6 years of effort (April 2007 to August 2014), and include the three phases of conceptualization: initial planning and item writing, pilot study, and final scale construction and standardization, including the normative, reliability, and validity studies. The preliminary content was determined by a comprehensive review of current research literature, as well as the authors' experience in the conceptualization and assessment of impairment. The content structure was then refined to correspond to key domains of functioning as identified by the World Health Organization's International Classification of Functioning, Disability and Health (ICF; WHO, 2001). Items were developed to measure functioning in the following areas: Academic, Communication, Interpersonal, Mobility, Domestic, Organization, Mental and Physical health, and Self-Care. Separate items were created for the 6–13-year-old children and 13–18-year-old adolescents to account for developmental differences. Moreover, items related to behaviors not typically observed by teachers were not included on the teacher forms (i.e., domestic functioning, family interactions, socializing with friends/peers outside of school, ability to get around on one's own). Where possible, items placed on both parent and teacher forms were identical.

Construction of the final scales began with the collection of the normative and clinical data. The normative samples include 2800 ratings—800 for each of the RSI (5–12 Years) Parent and Teacher Forms, and 600 for each of the RSI (13–18 Years) Parent and Teacher Forms. These samples included 50 males and 50 females at each age and are representative of the US population across several demographic variables. The clinical samples included 327 ratings of children/youths across the different normative samples, including 123 diagnosed with ADHD, 17 diagnosed with Autism Spectrum Disorder, 27 with a diagnosis of Depression or Anxiety Disorder, 24 diagnosed with Intellectual Disability Disorder, 96 with a diagnosis of Learning Disorder, and 40 with other disorders (e.g., Traumatic Brain Injury, Physical Disability [muscular-skeletal], and other disorders).

A series of factor analyses were performed on data from the normative and clinical samples for the demographic characteristics of the normative samples. Specifically, the normative and clinical samples were pooled together and split into two halves matched on age, sex, race/ethnic group, region, and clinical diagnosis, with the first half used for item-level exploratory factor analyses and the second half for parcel-level confirmatory factor analyses.

Exploratory and confirmatory factor analyses, based on this large epidemiologic sample, which include parent and teacher ratings, confirmed that the behaviors rated on the RSI represent a multidimensional construct resembling the structure of impairment proposed in the ICF (WHO, 2001). Specifically, a five-factor structure (School, Social, Mobility, Domestic, and Family) provided the best fit on the RSI (5–12 Years) Parent Form, six factors (School/Work, Social, Mobility, Domestic, Family, and Self-Care) for the RSI (13–18 Years) Parent Form, and three factors (School, Social, and Mobility) for the RSI (5–12 Years) Teacher and RSI (13–18 Years) Teacher Forms. The multidimensional factor solution of each RSI form persisted when tested across genders, age groups, race/ethnicities, and clinical status further supporting that the items on the RSI are best described as representing a multifaceted conceptualization of impairment.

Results of the factor analyses, coupled with practical considerations, guided the assignment of items to the RSI scales: School or School/Work (ten items), Social (ten items), Mobility (nine items), Domestic (seven items), Family (five items), and

Self-Care (eight items) and resulted in creation of the final RSI forms. Forty-one items are included on the RSI (5–12 Years) Parent Form, 49 items on the RSI (13–18 Years) Parent Form, and 29 items on each of the RSI Teacher Forms. Inter-item correlations and Cronbach's alpha values were calculated to evaluate the internal consistency of the RSI scales. The median inter-item correlation across scales on all forms was equal to .46, and Cronbach's alpha values all fell above .75, indicating good internal consistency of the final set of items retained for each of the RSI Scales.

## 12.5 Reliability

Measurement error must be taken into account when observations are made during the assessment of human behavior. In classical terms, any observed score is a reflection of the true score of the attribute being measured, plus measurement error (Lord & Novick, 1968). Reliability is the counterpart to measurement error, and is defined as the consistency of measurements obtained by the instrument across populations or groups of individuals (AERA, APA, & NCME, 2014).

Internal consistency estimates demonstrate that the RSI Scale scores have excellent internal reliability. For the RSI (5–12 Years) versions, the median alphas were .85 and .89 respectively for the Parent and Teacher Forms in the normative samples, and .85 and .92 in the clinical samples. For the RSI (13–18 Years) versions, median alphas were .85 and .91 for Parent and Teacher Forms respectively in the normative samples, and .88 and .92 in the clinical samples. Internal consistency for the Total Scores was also excellent. The reliability estimates for the Total Score in the normative and clinical samples were all .94 or higher. In summary, the RSI Scale scores and Total Score all showed excellent reliability.

The stability of the RSI *T*-scores was evaluated by calculating the differences between Time 1 (pretest) and Time 2 (posttest) ratings. Inter-rater reliability refers to the degree of agreement between two raters. The average time interval was 2.3 days (SD = 5.0) for the RSI Parent Form and 4.4 days (SD = 5.8) for the RSI Teacher Form (range across forms = 0–31 days). As was done for the test–retest findings, data from the child and youth forms were analyzed together.

Substantial to almost perfect inter-rater agreement, according to the classification of Cicchetti et al. (2006), were found across all RSI scales for parent raters (corrected $r$ ranged from .65 to .85), and moderate agreement was found across all RSI scales for teacher raters (corrected $r$ ranged from .56 to .59). The inter-rater reliability of the Total Score was $r = .87$ between parents, and $r = .77$ between teachers. These findings are comparable (and in the case of parent ratings, superior) to the average inter-rater reliability of .60 across studies reported by Achenbach and McConaughy (1987). The median values for Cohen's $d$ for the RSI scales among the parent and teacher inter-rater samples were 0.10 and 0.08, respectively, and the values of Cohen's $d$ for the Total Scores ranged from 0.11 to 0.13 across the inter-rater samples, showing negligible rater effects across administrations.

The consistency between raters was evaluated by calculating the difference between *T*-scores for Rater 1 and Rater 2. Results suggest that scores on the RSI possess good consistency between parent raters; for the RSI scales, between 70 and

89 % of the differences across scales fell within one standard deviation (i.e., +/− 10 *T*-scores). Good levels of consistency were also found for teacher raters, with 71–73 % of the differences falling within +/− 10 *T*-scores. For both parent and teacher ratings, the mean differences were close to 0, providing further evidence for inter-rater consistency. Further these results suggest that RSI scores have excellent stability; for the RSI scales and Total Score, over 89 % and 81 % of the differences on the Parent and Teacher Forms respectively fell within +/− 10 *T*-scores (i.e., one standard deviation). The mean differences were very close to zero, supporting the stability of the RSI across administrations.

## 12.6 Validity

Validity is described as "what the test measures and how well it does so" (Anastasi & Urbina, 1997, p. 113). The preliminary content structure of the RSI was determined through a comprehensive review of current research literature, as well as the authors' clinical experience on the conceptualization and assessment of functional impairment. The content of the RSI is also consistent with the structure of the World Health Organization's International Classification of Functioning (ICF; WHO, 2001). According to the ICF, a societal view of functioning refers to the individual's ability to participate in life activities, with major life areas broken down into several broad domains: education; learning and applying knowledge; communication; interpersonal interactions and relationships; community, social, and civic life; mobility; self-care; and domestic life. Multiple items were developed for the RSI to assess behaviors from the key domains of the ICF as they apply to impairment in youth. These items were organized into six scales. For example, the ICF education and knowledge domains are measured in the items from the RSI School/Work scale. Likewise, the ICF domains of communication, interpersonal interactions and relationships, and community and social life are reflected in the items of the RSI Social and Family scales. The remaining ICF domains correspond to the RSI scales of Mobility, Self-Care, and Domestic impairment. These six content areas measured by the RSI are intended to cover a wide range of observable indicators related to the general concept of impairment, as well as to more specific areas of impairment in everyday life functioning.

To evaluate the criterion-related validity of the RSI, mean differences in the RSI scores between the general population and samples of children/youths previously diagnosed with specific clinical disorders were examined. The mean differences between the general population and samples of children/youths with an increasing number of diagnoses were also examined. To further evaluate the criterion-related validity of the RSI scoring and interpretation methods, correlations between RSI scores and scores from other measures were examined. Overall, results from these analyses provide strong evidence for the criterion-related validity of the RSI.

The moderate correlations between raters, coupled with negligible effect sizes, provide support for the construct validity of the RSI. However, the correlations were only moderate suggests that ratings collected from different types of raters (i.e., parents and teachers) are not redundant. Instead, as Achenbach and

McConaughy (1987) point out, the moderate correlations between raters of different types indicate that each type of rater accounts for some unique variance that is not captured by other types of raters. Therefore, obtaining information from multiple sources is important.

### 12.6.1 Summary and Implications

The RSI operationalizes the construct of impairment. The RSI is strongly correlated with other measures of impairment such as the Barkley Functional Impairment Scale—Child and Adolescent (Barkley, 2012) and the Children's Global Assessment Scale (Shaffer et al., 1983). In addition, the RSI is correlated with scores from the Adaptive Behavior Assessment System—Third Edition (Harrison & Oakland, 2015). This suggests that there is some similarity, but also difference, in the behaviors assessed by these measures. Perhaps most importantly, the RSI correlates the greatest with the Comprehensive Executive Function Inventory (Naglieri & Goldstein, 2013) and the Devereux Student Strengths Assessment (LeBuffe, Shapiro, & Naglieri, 2014). Although these two rating scales may seem different, as noted by Goldberg (2009), the concept of executive function with its association with the frontal lobes is the foundation of social-emotional behaviors. Both of these rating scales, therefore, provide the means by which humans meet the demands of everyday life, especially the social demands—which the RSI also addresses. The low correlations between the RSI and intelligence, neurocognitive abilities, and achievement as well as the personality scales suggest that the RSI adds unique information that is not obtained from these measures. The lack of correlation between the RSI with the Wechsler Intelligence Scale for Children, Cognitive Assessment System-2 (Naglieri, Das, & Goldstein, 2014) and the Woodcock Johnson IV: Tests of Achievement (Schrank, McGrew, & Mather, 2014) illustrates that the constructs measured by these tests are independent. Perhaps most importantly, the modest correlation between the RSI and Conners Comprehensive Behavior Rating Scales (Conners, 2014) illustrates that symptoms and impairment are not strongly related, supporting the need to include measures of impairment in all assessment batteries. Similarly, the only modest correlations found between the RSI with informal evaluation of impairment by clinicians argue strongly for a psychometrically sound tool to evaluate impairment.

## References

Achenbach, T. M., & McConaughy, S. H. (1987). *Empirically based assessment of child and adolescent psychopathology: Practical applications*. Newbury Park: Sage.

American Educational Research Association (AERA). (1999). *Standards for educational and psychological testing*. Washington, DC: American Psychological Association, National Council on Measurement in Education.

American Educational Research Association (AERA). (2014). *Standards for educational and psychological testing*. Washington, DC: American Psychological Association, National Council on Measurement in Education.

Anastasi, A., & Urbina, S. (1997). *Psychological testing* (7th ed.). New York, NY: Prentice Hall.

Barkley, R. A. (2012). *Barkley functional impairment scale—Children and adolescents*. New York: Guilford Press. Copyright 2012 by Guilford Press. Reprinted with permission.

Dante C., Fred A. R., & Sheree L. T., (2006). Development and Psychopathology, 18, 623–649

Conners, C. K. (2014). *Conners comprehensive behavior rating scale*. Toronto, Canada: Multi-Health Systems.

Goldberg, E. (2009). *The New Executive Brain*. London: Oxford University Press.

Goldstein, S., & Naglieri, J. A. (2016). *Rating scale of impairment*. Toronto, Canada: Multi-Health Systems.

Harrison, P. L., & Oakland, T. (2015). *Adaptive behavior assessment system—Third edition (ABAS-3)*. Torrance, CA: Western Psychological Services.

LeBuffe, P. A., Shapiro, V. B., & Naglieri, J. A. (2014). *Devereux student strengths assessment (DESSA)*. Charlotte, NC: Apperson SEL.

Lord, F. M., & Novick, M. R. (1968). *Statistical theories of mental test scores*. Reading, MA: Addison.

Naglieri, J., Das, J. P., & Goldstein, S. (2014). *Cognitive assessment system - II*. Austin, TX: PRO-ED.

Naglieri, J., & Goldstein, S. (2013). *Comprehensive executive functioning inventory*. Toronto, Canada: Multi-Health Systems.

Schrank, F. A., McGrew, K. S., & Mather, N. (2014). *Woodcock-Johnson IV*. Itasca, IL: Houghton Mifflin Harcourt.

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H., et al. (1983). A children's global assessment scale (CGAS). *Archives of General Psychiatry, 40*, 1228–1231.

World Health Organization (WHO). (2001). *International classification of functioning, disability and health (ICF)*. Geneva: World Health Organization.

# Measuring Impairment with the Barkley Functional Impairment Scales

# 13

Russell A. Barkley

The evaluation of psychosocial impairment first requires that one has a relatively well-specified concept or construct of the term impairment that can guide the construction of instruments for its assessment. As earlier chapters have explained, there has been considerable variation and ambiguity in the concept of impairment even though the documentation of impairment is a requirement for the diagnosis of the vast majority of mental disorders not to mention various disability determinations for government and other entitlements. As I noted in the manuals associated with the *Barkley Functional Impairment Scale* for adults (BFIS; Barkley, 2011a), as well as that for children and adolescents (Barkley, 2012a), impairment has a variety of existing definitions both in dictionaries and in governmental regulations. Most definitions of the term include reference to diminished functioning; in the case of psychosocial impairment this of course would be in important domains of human major life activities. As I noted in the manuals for these impairment rating scales, it is useful to distinguish impairment from symptoms, as the earlier chapter by Lewandowski and colleagues stipulated. The distinction I have found useful is that a symptom is a physical, cognitive, or behavioral manifestation of a disorder (Barkley, 2011a, 2012a). By contrast, impairment refers to *the adverse consequences* that arise from *functioning ineffectively in a major life activity* due to the expression of those symptom(s) of a disorder. In short, symptoms may have consequences in major life activities by reducing functional effectiveness in those domains. To be impaired is to function so ineffectively from one's symptoms as to result in harm or adverse consequences to the individual—hence, disorders (sets of symptoms) begin where impairment (harm) arises as a consequence (Wakefield, 1992, 1997). This can help us to see why the severity of symptoms is only partially coupled to or correlated

---

R.A. Barkley, Ph.D. (✉)
Medical University of South Carolina, 2720 Fountain Head Way,
Mt. Pleasant, SC 29466, USA
e-mail: drbarkley6769@comcast.net

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_13

with the degree of impairment, sharing less than 50 % of their variance when rating scales are used to assess both and often less than 25 % when other methods are employed, such as archival records (Barkley, 2011a; Gordon et al., 2006; Lewandowski, Lovett, & Gordon, 2009). Other factors can intervene in the sequence from symptoms to functioning ineffectively and from there to the harm that befalls one from such functional ineffectiveness that can partially decouple the symptom from the harm (impairment) it might produce.

For example, to be inattentive often during class work in school (a symptom) can result in a person turning in an uncompleted work sheet (functional ineffectiveness) and so receive a failing grade on the assignment. The latter is a consequence of the former due to functioning ineffectively in school (impairment). But a teacher could so alter the classroom structure of curriculum, say by moving the child's desk nearer to her teaching area allowing greater supervision or giving the child much smaller work quotas to be done at one time, and so moderate the harm that results from a child being inattentive in this situation.

In the sense intended here impairment therefore represents *both* the functional ineffectiveness and the harmful consequences that may result. That is because one judges the severity of that functional ineffectiveness largely from the consequences arising from it. Functional ineffectiveness is viewed here as being typically dimensional, not categorical, in nature. There can be degrees of diminution in the functioning of most physical or mental adaptations as opposed to all-or-none effectiveness. When the ineffective functioning reaches such a magnitude that it begins to result in an inability to adapt (to solve) the problems or accomplish the demands that arise in any major domain of human life for the individual, adverse consequences arise for that individual (harm ensues). At that point or threshold, the functioning can be said to be ineffective and thus the person may be said to be impaired.

The BFIS scales focus on evaluating psychosocial functional ineffectiveness relative to others of the same age and sex regardless of the source or disorder, be it psychiatric, psychological, or medical. That is incredibly important as it permits the scales to be used across many medical, psychiatric, and psychological–educational disorders. That said, the evaluation of impairment cannot be done by the exclusive reliance on any single method, be it a rating scale, psychometric test, interview, or mere clinical observation. The information gathered on functional ineffectiveness in any given major life activity must be obtained across multiple sources and integrated into a judgment that harm (adverse consequences) is occurring to the individual related to such malfunctioning. A rating scale of functional ineffectiveness, however, can be a valuable tool in this protocol for various reasons not the least of which is the cost-effectiveness of this method and capacity for making comparisons to typically functioning individuals in the population. After all, if impairment is to be judged relative to the average person, as recommended by various government agencies and laws and their associated regulations and as implied or explicit in various definitions of the term (see Lewandowski et al., 2009; also chapter earlier in this volume), then some means of comparing the ratings of an individual's psychosocial functioning to those given by the general population is indispensable to the determination of impairment.

## 13.1 The BFIS-Children and Adolescents (BFIS-CA)

### 13.1.1 Construction

The BFIS-CA was developed from the earlier Home Situations Questionnaire (HSQ; Barkley, 1981; Barkley & Edelbrock, 1987; see Barkley & Murphy, 2006 for the scale). On the HSQ, parents rated the extent to which their children manifested behavioral problems across 16 home and public domains or situations using a ten-point (0–9) Likert scale. From this one could compute a score reflecting pervasiveness (number of problem settings) and another reflecting the mean severity across the problem areas. The scale proved very useful in research studies and clinical practice for evaluating both the pervasiveness of children's behavioral problems and the severity in each problem setting (as well as overall mean severity) (see Barkley, 2012a for research). As a measure of general psychosocial impairment, however, the HSQ suffers from some significant limitations. One is that the instructions make it clear that degree of functional difficulties in any given situation is to be based on externalizing types of behavioral problems. A more general and hence useful scale would not specify the types of symptoms that produced the difficulties with functioning in any situation but would simply ask parents to rate the degree of difficulties the child had functioning effectively in those situations generically. This would help to assess impairment independent of some specific disorder. In this way, the scale could be used to assess impairment in children having many different disorders besides externalizing ones. A further problem with the scale was the lack of nationally representative norms for the US childhood and adolescent population.

In order to create a scale assessing impairment that could be used without reference to any particular disorder or condition several changes were made to the HSQ. The instructions to the rater were altered to make it explicit that the child was being rated on their degree of problems functioning effectively in each setting without regard to any specific types of symptoms or disorders that may be causing the problems functioning in that situation. Moreover, some of the situations in the HSQ were removed from the scale, such as mealtimes, watching television, etc. and replaced with other domains of major life activities thought to be more important in evaluating psychosocial impairment, such as self-care and school performance. The number of situations on the BFIS-CA was therefore set at 15 domains, these being: interactions with the mother, interactions with the father, school performance, social interactions with brothers or sisters, playing with other children in the neighborhood, in the child's activities in the community (church, clubs, scouts, social groups, organizations), when the child is visiting other people's homes, when playing with other children at school, in managing any money they may earn or be given as an allowance, in daily self-care (dressing, bathing, and hygiene), in getting chores or other assigned work completed at home, in doing school homework, in their ability to follow rules, in interactions with other adults (visitors to the home, when visiting others, in other community settings) and in playing sports. The same range of item responses from the HSQ was retained, that being the 0–9 format but with more explicit descriptions of anchor points across the scale to be used to describe the child's degree of malfunctioning (0 = Not at all, 1-2 = Somewhat, 3-4 = Mild, 5–7 = Moderate, and 8-9 = Severe). Parents were also provided this time with a response option in which they could specify that the situation was not applicable to their child, in which case they circled the number 99 for Does Not Apply. Parents are asked to rate their child's degree of difficulty functioning effectively in each domain relative to other children of the same age. If a child is taking a psychiatric medication, parents are asked to rate the child as to how they function off of that medication. An interview version of the scale is also available for the clinician to collect specific information as to why the parent may have rated the child as not functioning well in each of the 15 domains.

### 13.1.2 Normative Sample

The 15-domain BFIS-CA was then given to a nationally representative sample of 1922 parents in the United States who had children between the ages of 6 and 17. An equal representation of males and females was to be obtained in each of 12 age groups for each of nine regions representing the United States. Knowledge Networks of Menlo Park, California (see web site knowledgenetworks.com for more information on the company) did so using the web-enabled Knowledge Panel®, a probability-based panel designed to be representative of the US population. Initially, participants were chosen scientifically by a random selection of telephone numbers and residential addresses. Persons in selected households were then invited by telephone or by mail to participate in the web-enabled Knowledge Panel®. For those who agreed to participate, but did not already have access, Knowledge Networks provides at no cost a laptop and ISP connection. This is very important as surveying only people who already have computers and Internet connections immediately biases the sample away from one that is representative of the US population. People who already have computers and Internet service are permitted to participate using their own equipment. Panelists then receive unique log-in information for accessing surveys online, and then are sent emails throughout each month inviting them to participate in research. Panelists were paid for their completion of the survey.

Ratings from 1922 parents were obtained with at least 80 boys and 80 girls at each of these years. Initial analyses of the demographic profile showed that the sample was slightly overrepresented with male respondents (fathers) (53 % vs. 47 % females). It was also somewhat overrepresented with ethnically white individuals (74 %) compared to the US 2000 Census (69.1 %). And it was overrepresented with college educated (Bachelor's degree or higher = 42 %) people compared to the US census (25 %). Consequently, the original sample was reduced by 6 % ($N = 122$) by removing White male parents having at least a Bachelor's degree or higher at random. The final sample used to create the norms reported here therefore consists of 1800 parents (and their children) with at least 75 boys and 75 girls at each age level from 6 to 17 years (901 males and 899 females). This slightly reduced sample is referred to henceforth as the *normative sample*. All further analyses reported here are based on this normative sample. Information on the age and sex of the parents completing the scales can be found in the manual. Important to note is that half were mothers and half were fathers. The parents' educational levels, marital status, employment status, and geographic region were a reasonable approximation of the US adult population according to the 2000 census. The sample slightly underrepresented blacks and had a slightly higher family income level than the US population based on that same census. Important to note is that the sample was not filtered so as to remove children with various psychiatric, learning, or other disorders or those receiving special education or medications as has been done with other rating scales. That is because such a practice thereby results in a super-normal sample not representative of the general population. In using a rating scale like the BFIS, one wishes to know the individual's placement within the general population and not just within an unimpaired, non-disordered, or untreated population.

### 13.1.3 Scale Structure

The child's age and sex were found in subsequent analyses not to have any significant relationship to the scores from the scale, suggesting that the scale domains are widely applicable across the age range of 6–17 years and to both sexes of children. The scores were submitted to a factor analysis with varimax rotation. Two factors emerged. The first factor (Eigenvalue = 9.85) accounted for 38 % of the variance after rotation and contained nine domains that were entirely related to home and school activities, largely work oriented in nature. It was therefore labeled as Home-School Domains and had its highest loadings from the domains related to doing chores and tasks at home, doing school homework, school performance, and following rules. It is largely a dimension of work or handling responsibilities and rules. The second factor (Eigenvalue = 1.05) accounted for 34 % of the variance after rotation and contained the six remaining domains that dealt with community and leisure activities. Its highest loadings came from the domains of when visiting others' homes, when playing with other children at school, and in community activities, such as church, scouts, and clubs, and when playing with other children in the neighborhood. It is largely a social-leisure activities dimension. It was therefore labeled as Community-Leisure Domains. The relationship of the two factors was moderate to high, $r = .68$, indicating approximately 46 % of shared variance between the two dimensions.

### 13.1.4 Scoring

The percentage of children rated with the most severe impairment scores (8 or 9) was less than 5 % across the 15 domain ratings. Less than 7 % had ratings of 6–7 on most domains. The score on each domain that represented the 93–95th percentile was chosen to represent significant impairment for purposes of calculating the score for the number of domains on which a child was rated as impaired. Other scores that can be computed from the scale are the individual domain ratings, a total mean impairment score (mean score across all domains rated as applicable to that child), a mean impairment score for the Home-School domains (factor 1 above), another for the Community-Leisure domains (factor 2 above), and a total number of impaired domains score (number of domains in which the child falls at or above the 93rd percentile). There are also eight secondary impairment questions on the scale, as noted previously, that deal with friends, community organizations, sports, and academic performance and adjustment. Because of a slight relationship of age to a few of the domain scores (accounting for less than 2 % of the variance in them), the norms on the scoring profiles are presented for two age ranges (6–11 and 12–17 years) for scoring purposes. And because of slight differences between males and females on several of the domain ratings, normative profiles are also presented within these age groups for each sex separately. Given the fact that the vast majority of domains involved no significant ethnic differences between any of the groups and the one comparison that was significant was trivial, the norms do not need to be portrayed for each ethnic group on the scoring forms. The region of the United States in which the children resided also had no relationship to the scores and so norms were presented without regard to this factor.

### 13.1.5 Reliability

The internal consistency of the BFIS-CA domain ratings (Chronbach's alpha) was found to be quite satisfactory (Alpha = .970). This was also the case for the nine domains forming the Home-School factor (.948) and the six domains comprising the Community-Leisure factor (.960). Test-retest reliability was assessed by having a subset of 86 parents in the original sample complete the scale on a second occasion 3–5 weeks after initially completing the scale with at least 5 children for each age level from 6 to 17 years (45 boys and 41 girls). Correlations ranged from .56 to .89 across the individual domains with the Home-School mean impairment score having a reliability of .86 and the Community-Leisure score having a reliability of .83. Reliability for the Number of Impaired Domains score was .87. Scores were not found to change significantly from the first to second administration.

### 13.1.6 Validity

Validity of the scale was evaluated using various approaches. The first and obvious approach is that of face validity. Does the scale content reflect the conceptual domain it is intended to assess? Earlier, impairment was defined as reflecting functional ineffectiveness that rises to a significant degree relative to others of the same age and sex and to a degree that results in harm (negative consequences) for the individual. Because parents are explicitly instructed to rate their child's functional ineffectiveness and because the scale provides normative data for making comparisons to other children of the same age and sex, the scale would seem to have satisfactory face validity. Evidence of high internal consistency above also indicates that the scale is evaluating a global construct (presumably that of functional ineffectiveness). The factor analysis suggests that it is worth deconstructing this global impairment construct into those domains reflecting home and school (largely work related) and those reflecting community and social-leisure activities although these two dimensions are substantially correlated with each other sharing 67 % of their variance.

The manual also presents evidence that shows that various subgroups of children who would be expected to have significantly higher scores of functional impairment because of their psychiatric disorders, receipt of special educational services, psychiatric medications, or psychological treatments in fact did so when compared to children without those disorders or services. For instance, Table 13.1 taken from the manual (Barkley, 2012a) shows a summation of various findings in the manual concerning comparisons of children who did and did not have a professional diagnosis of various psychiatric, learning, or developmental disorders (as reported by parents). It contains the effect sizes for these comparisons, the classification of the magnitude of that effect size (medium, large, X-large, etc.), and the percentage of the disordered children who were classified as being impaired on that score (greater than 93rd percentile). Because ADHD was found to be such an impairing disorder and because it can overlap with many of these other disorders, such comorbid cases were excluded from the analyses of all other disorders (except ADHD, of course). The results show marked variation across the disorders in the extent of impairment and magnitude of the differences among the groups, all of which provides evidence for the validity of the BFIS-CA.

Likewise, children who were rated as being impaired in various domains were also found to be more likely to have fewer friends, to be more unpopular, to have more academic difficulties (lower grade point averages, more likely to have a grade retention, etc.), to be receiving various educational, psychological, and psychiatric services, and to be more likely to have psychiatric, learning, or developmental disorders. Ratings of impairment were also significantly associated with parent rated deficits in various domains of executive functioning on both the Barkley Deficits in Executive Functioning Scale—Children and Adolescents (Barkley, 2012b) and the Behavior Rating Inventory of Executive Functioning (Gioia, Isquith, Guy, & Kenworthy, 2000), sharing between 36 and 79 % of their variance. Impairment scores were also highly associated with severity of symptoms of ADHD as rated by the same parents, sharing 31–53 % of their variance. Thus, there is ample evidence for the validity of the BFIS-CA as reported in the scale manual (Barkley, 2012a).

## 13.2 The BFIS (Adult Version)

The information that follows comes directly from the manual for the BFIS for adults (Barkley, 2011a). The BFIS began its development more than 16 years ago in our initial studies on the extent of impairment experienced by adults with ADHD at both the Medical College of Wisconsin (with Mariellen Fischer, Ph.D.) and University of Massachusetts Medical Center (with Kevin Murphy, Ph.D.). The scale began originally as a means (1) to quickly evaluate or screen for risk for psychosocial impairment secondary to ADHD in adults presenting to our ADHD clinics; (2) to

**Table 13.1** Effect sizes (Cohen's *d*), magnitude of effect sizes, and percentage of cases deemed clinically impaired on the three summary scores for the BFIS-CA for various developmental, learning, and psychiatric disorders when compared to the control group not having that disorder (with ADHD removed from all but its own comparisons)

| Disorder[a] [*N*] | | Home-school mean impairment | Community-leisure mean impairment | Number of impaired domains |
|---|---|---|---|---|
| ADHD [171] | ES | 1.51 | 1.13 | 1.07 |
| | Magnitude[b] | X-Large | Large | Large |
| | %Impaired[c] | 43.3 | 39.2 | 43.4 |
| | $X^2$ *p*-value | <.001 | <.001 | <.001 |
| ADHD (research) [124] | ES | 2.54 | 1.92 | 1.83 |
| | Magnitude | X-Large | X-Large | X-Large |
| | %Impaired | 64.5 | 61.3 | 69.6 |
| | $X^2$ *p*-value | <.001 | <.001 | <.001 |
| Speech/language [71] | ES | 0.28 | 0.34 | 0.27 |
| | Magnitude | Small | Small | Small |
| | %Impaired | 5.6 | 12.7 | 11.1 |
| | $X^2$ *p*-value | NS | .003 | .011 |
| DCD [36] | ES | 0.63 | 0.62 | 0.43 |
| | Magnitude | Medium | Medium | Small |
| | %Impaired | 5.6 | 16.7 | 10.0 |
| | $X^2$ *p*-value | NS | .002 | NS |
| DD/MR [9] | ES | 0.85 | 1.37 | 0.75 |
| | Magnitude | Medium | Large | Medium |
| | %Impaired | 0.0 | 33.3 | 22.2 |
| | $X^2$ *p*-value | NS | <.001 | .015 |
| Seizures/epilepsy [10] | ES | 0.92 | 0.80 | 0.56 |
| | Magnitude | Large | Large | Medium |
| | %Impaired | 10.0 | 20.0 | 8.3 |
| | $X^2$ *p*-value | NS | .033 | NS |
| Tic disorders/TS [8] | ES | 0.39 | 0.66 | 0.13 |
| | Magnitude | Small | Medium | X-Small |
| | %Impaired | 12.5 | 0.0 | 0.0 |
| | $X^2$ *p*-value | NS | NS | NS |
| Autism spectrum [19] | ES | 0.62 | 1.07 | 0.68 |
| | Magnitude | Medium | Large | Medium |
| | %Impaired | 10.5 | 15.8 | 26.3 |
| | $X^2$ *p*-value | NS | .035 | <.001 |
| Reading disorders [51] | ES | 0.56 | 0.35 | 0.40 |
| | Magnitude | Medium | Small | Small |
| | %Impaired | 11.8 | 11.8 | 13.0 |
| | $X^2$ *p*-value | .007 | .030 | .005 |
| Spelling disorders [32] | ES | 0.61 | 0.35 | 0.43 |
| | Magnitude | Medium | Small | Small |
| | %Impaired | 9.4 | 12.5 | 12.1 |
| | $X^2$ *p*-value | NS | NS | .049 |

(continued)

**Table 13.1** (continued)

| Disorder[a] [*N*] | | Home-school mean impairment | Community-leisure mean impairment | Number of impaired domains |
|---|---|---|---|---|
| Math disorders [28] | ES | 0.80 | 0.45 | 0.51 |
| | Magnitude | Large | Small | Medium |
| | %Impaired | 14.3 | 14.3 | 13.8 |
| | $X^2$ *p*-value | .008 | .027 | .024 |
| Writing disorders [27] | ES | 0.98 | 0.75 | 0.89 |
| | Magnitude | Large | Medium | Large |
| | %Impaired | 14.8 | 29.6 | 25.0 |
| | $X^2$ *p*-value | .006 | <.001 | <.001 |
| Anxiety disorders [33] | ES | 0.61 | 0.75 | 0.46 |
| | Magnitude | Medium | Medium | Small |
| | %Impaired | 12.1 | 18.2 | 11.8 |
| | $X^2$ *p*-value | .024 | .001 | NS |
| Depression [23] | ES | 1.16 | 0.97 | 0.76 |
| | Magnitude | Large | Large | Medium |
| | %Impaired | 30.4 | 26.1 | 26.1 |
| | $X^2$ *p*-value | <.001 | <.001 | <.001 |
| Oppositional defiant [11] | ES | 1.83 | 1.04 | 1.29 |
| | Magnitude | X-Large | Large | Large |
| | %Impaired | 27.3 | 36.4 | 36.4 |
| | $X^2$ *p*-value | <.001 | <.001 | <.001 |
| Bipolar disorder [7] | ES | 0.93 | 1.09 | 1.02 |
| | Magnitude | Large | Large | Large |
| | %Impaired | 42.9 | 28.6 | 42.9 |
| | $X^2$ *p*-value | <.001 | .005 | <.001 |

[a] All disorders are based on parent report that their child received a professional diagnosis of that disorder, except for ADHD (research) where it was also diagnosed by research criteria (see above). All disorders except ADHD have cases with comorbid ADHD (research) removed from their analyses

[b] Magnitude is graded as <0.20 = X-Small or extra small; 0.20+ = Small, 0.50+ = Medium, 0.80+ = Large (see Cohen, 1992), and 1.5+ = X-Large or extra large

[c] "%Impaired" means the percentage of children with this disorder who placed at or above the 92.5 percentile for the normative sample ($N = 1800$) for their age group (6–11 years, 12–17 years) and sex. $X^2$ *p* value = probability value for the chi-square test if $p < .05$ for comparison of this disorder to the remainder of the sample not having that disorder. *NS* Not Significant

From Barkley, R. A. (2012). *Barkley Functional Impairment Scale—Children and Adolescents*. New York: Guilford Press. Copyright 2012 by Guilford Press. Reprinted with permission

*N* sample size for disorder, *ES* Effect Size (Cohen's *d*), *BFIS-CA* Barkley Functional Impairment Scale-Children and Adolescents, *ADHD* Attention Deficit Hyperactivity Disorder, (research) = ADHD diagnosed by the research criteria reported in this manual (93rd percentile on ADHD symptom ratings and impairment in at least one domain), *DCD* Developmental Coordination or Other Motor Disorders, *DD*/*MR* Developmentally Disabled/Mental Retardation, *TS* Tourette's Syndrome measure self-rated psychosocial impairment as part of our large-scale federally funded research grants on the nature of comorbidity and impairment associated with the disorder (Barkley, Murphy, & Fischer, 2008); and (3) to evaluate self-rated psychosocial impairment in hyperactive (ADHD) children followed to adulthood (see also Barkley et al., 2008). The early prototype scale, the Impairment Rating Scale (IRS), was embedded as a section within a larger rating scale assessing symptoms of ADHD. That section evaluated ten domains of major life activities and provided a four-point Likert scale (0–3) for responding to each domain. Respondents were simply asked to rate the degree of functional impairment they believed they were experiencing in these ten domains from their ADHD symptoms. These ten domains were: home life, work, social interactions, community activities, educational activities, dating or marriage, money management, driving, leisure activities, and handling daily responsibilities. Each domain was a single item and to be rated as "Rarely or Not at All," "Sometimes," "Often," or "Very Often" (0–3, respectively). While each rating could be studied separately, typically these numerical responses were summed to create a total impairment index (see Chapter 6 in Barkley et al., 2008). The results could be compared to different control groups being used in these projects to determine degree of psychosocial impairment arising from ADHD. Much of the research validating the BFIS was done with this earlier ten-domain prototype, the IRS, discussed later in this chapter concerning reliability and validity information. But lacking until the present time was information on a nationally (the United States) representative normative sample that would permit use of these impairment ratings in clinical, research, or industrial settings. Control groups are not available in such settings as they are in research studies for making judgments of degree of statistical deviance of the ratings.

To meet this need, the original IRS was pulled from its place inside the ADHD rating scale, expanded to include ten additional domains initially, and given a wider 0–9 Likert scale for answering each domain. The same ascertainment window, however, was retained in that respondents were directed to consider their functioning during the prior 6 months in completing the scale items. Norms also needed to be collected on a large sample of adults in the general population that was representative of the United States. The manual presents those findings and norms based on 1240 adults 18–89 years of age representative of the United States, at least as based on the 2000 Census (www.census.gov).

The new version of the scale, the BFIS, initially included the ten domains from the IRS along with the following ten changes and additional domains. The Home domain was separated into three more specific domains, these being completing home chores and managing a household, self-care routines, and home life with family. The social domain was split into two separate more specific domains, these being social relations with friends and social interactions with strangers and acquaintances. And new domains were added for child-rearing, sexual behavior and relations, health maintenance, caring for one's major items of property, obeying the law, avoiding the use of illegal substances, and controlling the use of legal substances. The domain of marriage and dating was clarified and broadened to include other intimate co-habiting relationships. As noted above, the response format for each domain was also expanded to a ten-point (0–9) Likert scaling to permit the determination of a wider range of functional impairment than the original IRS. An option was added to the response format for the respondent to indicate that the particular domain does not apply to them (such as child-rearing for individuals who are not parents, driving for those individuals who do not drive). Finally, instead of the response format for each item reflecting frequency of problems (Rarely, Sometimes, etc.), the anchor points for the 0–9 item response scale were changed to reflect severity or degree of functional ineffectiveness or impairment in that domain (i.e., Not at All, Somewhat, Mild, Moderate, and Severe).

Further review of the domain content of the first draft of the BFIS along with statistical analyses indicated that the three new domains related to substance use (legal and illegal) as well as obeying the law formed a separate factor from that containing the other domains. And two other domains had loadings equally as high on this factor as on the first factor reflecting general impairment—driving and child-rearing. This is not surprising since both of those domains have elements of legal responsibilities and consequences associated with them. This result appeared to create a second factor concerning antisocial conduct (a form of psychopathology) besides the initial larger one of psychosocial impairment. And so the three domains related to legal substance use, illegal substance use, and obeying the law were removed from the final version of the BFIS. Also, discussions with colleagues suggested that two of the remaining 17 domains were clinically trivial and unlikely to be regarded by others as major domains of impairment in psychosocial activities. These domains were leisure activities and caring for one's own property. They were also among the weakest loading domains on the psychosocial impairment factor. Therefore, to avoid trivializing the item pool of the BFIS, these two domains were also removed from further consideration. This left a scale content of 15 domains believed to reflect the most important major life activities for most adults in the United States (and most developed countries).

As noted above, an important issue here is just how the term psychosocial impairment is to be defined. For the BFIS, similar instructions were used as for the BFIS-CA noted above—the following explicit instructions were given to respondents in the normative sample to guide them in making a judgment of how impaired they viewed themselves as being in each domain:

> "How much difficulty do you have functioning effectively in each of these major life activities? That is, to what degree do you see yourself as being impaired in each of these life domains? Please circle the number next to each item that best describes your difficulties in functioning **DURING THE PAST 6 MONTHS**. If that situation does not apply to you (for instance, you don't drive a car, don't have children, don't live with anyone, etc.) please circle the 99 in the last column (under Does Not Apply)."

As with the BFIS-CA described above, the *degree of impairment refers to degree of difficulty in functional effectiveness in a particular domain of major life activity*. It is *very* important to note here that the BFIS, like the children's version, contains instructions to rate the degree of functional impairment *without reference to any specific mental or medical disorder*. In this manner, degree of impairment can be established separately from such a specific disorder. This method permits such an impairment rating scale to be used as part of the evaluation of *any* medical or mental disorder that could lead to difficulties in psychosocial functioning in these 15 domains. Determining the cause(s) of the psychosocial impairment is a separate issue involving differential diagnosis. If a disorder were specified in the instructions of the rating scale, it would be applicable only to patients known to have that disorder, such as ADHD, depression, anxiety, bipolar disorder, or a neurological of general medical disorder. This would limit the applicability and value of such a scale as the patient may rate only the degree of impairment related to that disorder and not their overall degree of impairment generally.

### 13.2.1 The Normative Sample

The 15-domain BFIS was then given to a nationally representative sample of adults in the United States ages 18–70+. Efforts were made to obtain this national sample to insure that equal representation of males and females occurred in each of six age groups for each of nine regions representing the United States. Again, Knowledge Networks did so using the web-enabled Knowledge Panel®, a probability-based panel designed to be representative of the US population. The self-report version of the BFIS was provided to Knowledge Networks as a rating scale in which respondents were to answer each item using a ten-point Likert scale (0–9) with anchor points for rating degree of impairment or difficulties in functioning ranging from not at all (0) to somewhat (1, 2), then to mild (3, 4), moderate (5–7), and severe (8, 9). The scale was uploaded to an Internet site and members of the Knowledge Panel® were invited to complete them.

As discussed above, this sample was not subsequently filtered to remove individuals with a prior history of psychiatric diagnosis, being treated currently with psychiatric medications, or who may have learning, developmental, neurological, or medical disorders as has occurred in collecting normative information for other adult scales. Doing so creates a super-normal comparison group, not a general population sample, and can result in the determination of impairment being found to occur at far lower levels of deviance on the ratings than would be the case had a general population sample free of such filtering been used. The BFIS is based on just such an unfiltered general population sample so that comparisons of individual impairment scores on it can be compared to the average, typical, or normal person standard so important in the definition of the term impairment.

The company was contracted to obtain completed scales on at least 1200 adults broken down into six age groups (18–29, 30–39, 40–49, 50–59, 60–69, and 70+) with at least 100 males and 100 females in each age group. A final sample of 1249 adults was obtained. A total of 623 males ages 18–93 years (49.9%) and 626 females ages 18–96 years completed the rating sale. However, just seven participants were older than 90 years and so they were dropped from the normative sample portrayed in the scoring profiles. The mean age for males was 49.7 years (SD = 18.0) and for females was 49.8 years (SD = 18.0) which were not significantly different.

The sample was found to be representative of the US adult population with regard to age, sex, ethnicity, education, marital status, income, and region of residence relative to the 2000 US census.

### 13.2.2 Scale Construction

A factor analysis of the scale found that a single factor (Eigenvalue = 7.93) accounted for 52.9 % of the variance and contained all 15 domains having moderate to high loadings on this factor. All domains loaded at least .587 or higher. The factor could be called an Adaptive-Social Impairment factor because it received its highest loadings (≥.750) from the domains of (descending order): Organizing/Managing Daily Responsibilities (.842), Social Relations with Friends (.824), Completing Home Chores and Managing a Household (.785), Home Life with Family (.765), Marriage/Cohabiting/Dating (.759), Self-Care (.754), Social Activities with Acquaintances/Strangers (.750), and Community Activities (.750).

Results for the individual domain ratings showed that for the vast majority of domains, the vast majority of a general population sample endorsed most items at a severity of impairment of Not at all, Somewhat, or Mild. Answers reflecting Moderate to Severe Impairment (5–7, 8–9, respectively) were statistically unusual and even rare in the case of scores of 8 or 9. The latter ratings were endorsed by less than 2 % of the population. Less than 6–10 % in most cases gave answers of 5–7. How much difficulty (how high a rating) must an individual report to be considered statistically unusual or abnormal? Most rating scales consider the 93rd to 95th percentile as probably indicative of being statistically deviant in a population (which translates to 1 in 14 to 1 in 20 people, respectively). So if one wanted to identify a domain as being impaired to a degree that is statistically rare (top fifth to seventh percentile), then each domain can be examined for that score that signifies this threshold (93rd–95th percentile or higher). Overall, 64 % of participants had no scores that fell at or above these thresholds for abnormality (impairment). Twelve percent reported one impaired domain, another 7 % reported two domains, and 4 % reported three domains being impaired. Just 10 % had scores on 5 or more domains that were impaired. And just 6 % were impaired in 7 or more of the 15 domains. The mean number of domains falling in the impaired range was 1.3 (SD = 2.5).

Besides the score (rating) given on each of the 15 domains, a separate Mean Impairment Score can be computed for the scale. To do so, the scores for the domains in which a participant rated themselves (as opposed to indicating it Did Not Apply to them) were summed. This sum was divided by the number of domains rated as applying to them (the number of domains that contributed a score to the summation). A third score can be computed by just counting the number of individual domains in which a rating placed at or above the 93rd percentile divided by the total number of domains that were rated (Percent of Impaired Domains score). To summarize, the BFIS long form can be used to obtain 17 scores: 15 individual domain ratings, a Mean Impairment Score, and a Percent Domains Impaired score. A short form of this scale was also created for situations warranting just a quick screen of impairment. It contains those six domains believed to be the most important for making impairment and disability determinations in clinical settings. There is also a separate rating form on which the clinician can obtain the reports of someone who knows the patient well, but no norms are available for scoring this version of the scale. Although no norms were collected on it, a separate interview is provided for use as a follow-up to the completion of the rating scales. It is strongly encouraged that clinicians use this interview to gather more specific information as to the basis for any of the participant's ratings in any domains that were in the Moderate (6) or higher range. That rating would be at the 93rd to 95th percentile or higher for 13 of the 15 major life domains on the BFIS. This provides the clinician with an opportunity to determine the veracity or legitimacy of the individual's self-report of such high impairment by asking for specific details that led the participant to rate the domain this high or higher. The interview form contains the 15 domains from the BFIS. Clinicians do not need to interview the patient about all domains—just those on which the rating was sufficiently high to be abnormal or unusual relative to the general population. The interview is not scored but serves as a recording device for this important follow-up interview. On the basis of the participant's detailed explanations of any impaired domains, the clinician may elect to obtain official archival records for that domain, if available, to further corroborate these self-reports of impairment. Obtaining the reports of someone else who knows the patient well is also strongly encouraged. This provides yet further information to corroborate patient reports. And it gives the clinician a means of triangulating all sources of information against each other for the determination of an informed judgment about the extent and pervasiveness of the individual's impairments.

### 13.2.3 Demographic Findings

Age was found to correlate to a very low yet significant degree with many of the individual domain ratings, explaining less than 5 % of the variance. Inspection of all of the results for age along with the distributions for the scores on each scale indicated that three large age groupings could be made from the initial 7 discussed above. It made sense to keep the 18–39-year-olds as a separate group from those 60–80+-year-olds as most differences occurred between these two groupings where significant differences existed. While the 40–59-year-olds did not differ from the younger age group, they were joined here as a single and separate age grouping to create approximately equal sample sizes of middle-aged participants to those for the youngest and oldest age groupings. The 60+-year-olds would then serve as the final age group given that on no comparisons were the age groups in this 60–80+ range found to differ from each other. Only seven participants were 90 years of age and older. Given that this older age group was not well represented in the normative sample, they were excluded from further consideration. Thus, the normative information for the BFIS scales and Score Sheets were created for individuals between 18 and 89 years of age. The final three age groupings were 18–39 years, 40–59, and 60–89. These yielded sample sizes per age grouping of 412, 419, and 411, respectively, for a total sample of 1242. There were no significant differences across the domain ratings between the two sexes and very few for differences among the ethnic groups, with those few being of a very small magnitude. As a result, the norms for the scale are presented separately just for the three age groups noted above.

### 13.2.4 Reliability

The internal consistency of the BFIS domain ratings (Chronbach's alpha) was found to be quite satisfactory both for the long form (.969) and the quick screen version (.916). Test-retest reliability was assessed by having a subset of 62 adults complete the BFIS on a second occasion 2–3 weeks after initially completing the scale. Half of the participants at each age level were men and half were women. At least ten from each of the original six age groups participated. Correlations ranged from .40 to .72 with the Mean Impairment score being .71 and the Percent Domains score being .53. These results show moderate to high reliability across this time period with the most satisfactory reliabilities occurring for the specific domain scores of Social Relationships, Driving, Work, Marriage/Cohabiting/Dating, and Child-Rearing. Clearly, though, the most reliable score to use may be the Mean Impairment Score from either form rather than the individual domain ratings. When initial and retest scores were compared, most domain ratings did not change significantly over time. But three domain scores did decline significantly from pre- to post-testing, these being Social Relations with Strangers/Acquaintances, Social Relations with Friends, and Marriage/Cohabiting/Dating. Though significant, the declines in the individual domain impairment ratings were slight. As for the summary scores, the Mean Impairment Score for the BFIS long form showed a slight but significant decline from pre- to post-testing, but the changes in the Percent Domains Impaired score for this form did not change across time. For the BFIS Quick Screen, neither the Mean Impairment Score nor the Percent Domains Impaired score changed significantly from pre- to post-testing. These results suggest that there is satisfactory stability of the vast majority of BFIS scores over this period of assessment. Although agreement between self and other ratings was not available for the BFIS, such information had been collected on its earlier prototype, the IRS, and was found to be .68 (see manual, Barkley, 2011a).

### 13.2.5 Validity

As with the BFIS-CA, one approach to validity is face or construct validity—does the scale reflect the content of the construct it is intended to evaluate, in this case functional ineffectiveness. Given that the instructions explicitly direct the rater to rate their functional ineffectiveness in each domain, the scale would seem to have face validity. The finding that the scale consists of a single highly coherent factor, as reflected in the high internal consistency found above, this factor likely reflects global impairment. The earlier prototype of the scale (IRS) was highly correlated with clinician rated impairment in occupational and social functioning (.74).

Various subgroups of the normative sample were compared to examine further evidence of validity in which one group would be expected to be more impaired than the comparison group. For instance, adults who reported that they were disabled in their working status reported significantly greater impairment scores than those not so classified in their work status. Degree of educational attainment was also inversely related to the impairment ratings, with those having less education reporting higher impairment scores, especially in the education domain. Likewise, the level of annual income was significantly and negatively related to the degree of impairment reported in managing money and finances. Substantial evidence for the validity of the individual domain ratings was also reported in the manual for the prototype IRS scale from various prior research studies in which specific measures of the various domains were collected. And the impairment ratings were significantly associated with self-rated deficits in executive functioning on the Barkley Deficits in Executive Functioning Scale (Barkley, 2011b) and degree of ADHD symptoms in the normative sample on the Barkley Adult ADHD Rating Scale (Barkley, 2011c).

In summary, additional research on the BFIS is obviously needed on its reliability, validity, and other psychometric properties. What evidence exists to date, however, is enough to indicate quite satisfactory validity of the scale. It is certainly sufficient to recommend its use in clinical practice with adult patients, for studying impairment in research protocols, and for screening adults for possible psychosocial impairment in industry and other organizations. The scores from the BFIS are significantly related to difficulties in numerous domains of major life activities. These include a greater likelihood of impairment or adversity in education, occupational functioning, income, driving, and marital/cohabiting relationships among others as well as symptoms of ADHD in adults and extent of EF deficits in daily life.

## 13.3 Conclusion

The BFIS rating scales for children and adults provide a convenient, cost-effective means for obtaining ratings of a patient's degree of functional ineffectiveness across a variety of domains of major life activities. These ratings can then be compared to those for general population samples for determination of the degree of functional ineffectiveness of a patient relative to the patient's age and sex. Although such ratings are not to be used as the sole determinant of impairment in a patient, they do provide one valuable component for doing so given their ability to compare the individual's rated functioning to others representative of the general population. When combined with other sources of information on impairment, such as interviews, psychological testing, and archival records, these ratings permit a more rigorous determination of impairment than has heretofore been the case in clinical practice that relies merely on un-normed clinician judgments of degree of global impairment.

## References

Barkley, R. A. (1981). *Hyperactive children: A handbook for diagnosis and treatment*. New York: Guilford.

Barkley, R. A. (2011a). *Barkley functional impairment scale*. New York: Guilford Press.

Barkley, R. A. (2011b). *Barkley deficits in executive functioning scale*. New York: Guilford.

Barkley, R. A. (2011c). *Barkley adult ADHD rating scale—IV*. New York: Guilford.

Barkley, R. A. (2012a). *Barkley functional impairment scale—Children and adolescents*. New York: Guilford Press.

Barkley, R. A. (2012b). *The Barkley deficits in executive functioning scale—Children and adolescents*. New York: Guilford.

Barkley, R. A., & Edelbrock, C. S. (1987). Assessing situational variation in children's problem behaviors: The Home and School Situations Questionnaire. In R. J. Prinz (Ed.), *Advances in behavioral assessment of children and families* (Vol. 3, pp. 157–176). Greenwich, CT: JAI Press.

Barkley, R. A., & Murphy, K. (2006). *Attention deficit hyperactivity disorder: A clinical workbook* (3rd ed.). New York: Guilford.

Barkley, R. A., Murphy, K. R., & Fischer, M. (2008). *ADHD in adults: What the sciences says*. New York: Guilford.

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112*, 155–159.

Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2000). *BRIEF: Behavior rating inventory of executive function—Professional manual*. Odessa, FL: Psychological Assessment Resources, Inc.

Gordon, M., Antshel, K., Faraone, S., Barkley, R., Lewandowski, L., Hudziak, J., et al. (2006). Symptoms versus impairment: The case for respecting DSM-IV's Criterion D. *Journal of Attention Disorders, 9*, 465–475.

Lewandowski, L. J., Lovett, B. J., & Gordon, M. (2009). Measurement of symptom severity and impairment. In S. Goldstein & J. A. Naglieri (Eds.), *Assessment of impairment: From theory to practice*. New York: Springer.

Wakefield, J. C. (1992). The concept of mental disorder: On the boundary between biological facts and social values. *American Psychologist, 47*, 373–388.

Wakefield, J. C. (1997). Normal inability versus pathological disability: Why Ossorio's definition of mental disorder is not sufficient. *Clinical Psychology: Science and Practice, 4*, 249–258.

# Measuring Impairment with the Neuropsychological Impairment Scale

# 14

Tammy L. Stephens-Pisecco

## 14.1 Overview

The *Neuropsychological Impairment Scale* (NIS; 2009) is a screening instrument designed to serve as an "early warning system" (Lezak, 1983, p. 135), which can be used to identify areas of neuropsychological weakness, focus treatment efforts, or to determine service efficiency. Many times, and for a variety of reasons, individuals do not report symptoms or medical histories that may be diagnostically relevant. Further, the routine clinical examination may overlook or fail to elicit pertinent information pertaining to neuropsychological impairment. The structured, efficiently administered NIS inventory addresses both global impairment and the following specific symptom areas: attention, memory, and linguistic functioning (Robins, 1980).

The NIS consists of three forms: Self-Report form, Observer Report form, and Senior Interview form. When scored, the NIS provides three summary measures: the Global Measure of Impairment (GMI), the Total Items Circled (TIC), and the Symptom Intensity Measure (SIM). Additionally, subscale scores are provided in seven areas of impairment: Critical Items (CRIT), Cognitive Efficiency (COG), Attention (ATT), Memory (MEM), Frustration Tolerance (FRU), Learning-Verbal (L-V), and Academic Skills (ACD). Validity checks are also provided: Defensiveness (DEF), Affective Disturbance (AFF), and Response Inconsistency (INC). Finally, a Subjective Distortion Index (SDI) can be computed. All of these components of the NIS will be explained in depth in the Sect. 14.3 of this chapter.

Results on the NIS should always be viewed as subjective information and verified using objective information. While the NIS can be used as a single, efficient introductory measure of an individual's experience or neuropsychological symptoms, it should never be considered the final or definite estimate of neuropsychological impairment (O'Donnell, DeSoto, DeSoto, & Reynolds, 2009). As with any comprehensive

---

T.L. Stephens-Pisecco, Ph.D. (✉)
Midwestern State University, 1930 Dunstan Rd., Houston, TX 77005, USA
e-mail: Doctammy7@gmail.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_14

assessment, a variety of measures should be used to obtain the most accurate measure of functioning. Consequently, in a clinical setting, the NIS is best used in combination with neuropsychological measures.

## 14.2 Normative Sample

The NIS was normed using a nonclinical standardization sample and a neuropsychological sample. The following presents a breakdown of the norming samples:

### 14.2.1 Nonclinical Standardization Sample

The nonclinical standardization sample consists of data obtained from 1000 community-dwelling adults representing 48 separate groups: Churches ($n=27$), Community Activities ($n=7$), Public Activities/Events ($n=7$), Schools ($n=4$), and Work Settings ($n=3$). Maryland was the primary location for data collection; data was collected in urban, suburban, and rural areas. In an effort to counteract systematic selection patterns arising from the migration of healthy older individuals, some of the 65-and-older sample was recruited from Florida. Participation was voluntary, and anonymous if desired.

The nonclinical sample is cross-stratified according to gender and age. The 1995 projections from the U.S. Bureau of the Census provided the basis for the stratification. The mean education for the sample, 13.5 years, is comparable to the national median educational level of 12.7 years for people 25 years and older (Bureau of the Census, 1988). Means and standard deviations of the NIS raw scores observed for each age grouping in the nonclinical standardization sample are provided in the testing manual (O'Donnell et al., 2009). Differences in responses to some specific items were found when comparing men to women. However, none of the differences were significant enough to warrant age- and gender-specific Profile Sheets.

### 14.2.2 Neuropsychological Sample

Several outpatient rehabilitation settings were used to collect neuropsychiatric data. The neuropsychiatric sample was made up of 534 participants. The sample is predominately male (318 males and 216 females) with an average age of 33.2 years (SD=11.8). The average education level of the neuropsychological sample is 12.0 (SD=2.1). Additionally, the sample includes the following patient categories: Neurological ($n=215$), Alcohol/Drug Abuse ($n=97$), Learning Disability ($n=43$), Psychiatric Disorder ($n=155$), and Physical Trauma ($n=24$). The neurological patients were well beyond the acute phase of illness (205 of the 215 neurological patients reported a mean length of 2.5 years (SD=2.2) since illness onset; the median time since illness onset was approximately 1.9 years (O'Donnell et al., 2009). Specific diagnoses for the neurological and psychiatric patients as well as means and standard deviations of NIS raw scores can be found within the testing manual.

## 14.3 Scale Structure

The NIS is composed of 95 items; 80 describe neuropsychological symptoms, 10 measure affective disturbance, and 5 gauge test-taking attitudes. A five-point scale is utilized to rate each item, ranging from 0 (Not At All) to 4 (Extremely). The NIS can be completed in 15–20 min and is intended for use with individuals aged 18 and older, and who are able to read at a fifth-grade level or higher and cooperate with testing. The NIS can be administered by a trained technician; however, the interpretation of the resulting scores should be conducted by a professional with advanced clinical training. While the NIS can be used as a screening measure in nonclinical settings, the most optimal use within the clinical setting would be as an intake measure, or as a measure to supplement comprehensive psychological or neuropsychological assessment batteries (O'Donnell et al., 2009).

The NIS comprises three forms: Self-Report, Observer Report, and the Senior Interview Form. Each of the forms is described below:

- The *NIS Self-Report form* is composed of statements to which the individual is asked to indicate whether the statement describes their experience or applies to them. Items contained on the self-report refer to experiences during the past few days or weeks, while others refer to experiences at any time during the past.
- The *NIS Observer Report* form is a non-standardized way to allow family members or other individuals familiar with the patient to describe how they perceive him or her in terms of neuropsychological symptoms or cognitive impairment. Consisting of essentially the same items as those on the Self-Report form, the observer's perceptions can be directly compared to the patient's own report.
- The *NIS Senior Interview* form is available for use with older patients who experience difficulty completing the self-report form.

When scored, the NIS provides a variety of scores: three summary measures, seven subscale scores in seven areas of impairment, and validity checks. A brief description of each measure is presented below; however, more in-depth descriptions can be found within the NIS examiner's manual (O'Donnell et al., 2009).

## 14.4 Three Summary Measures

- *Global Measure of Impairment* (*GMI*): Made up of the total score (the sum of the responses to the 80 neuropsychological items on the NIS), is the best general index of neuropsychological functioning on the NIS. High GMI scores (above 70 T) indicate a strong likelihood of neuropsychological impairment, whereas excessively high GMI scores (above 80 T) suggest extreme neuropsychological impairment. Low GMI scores (below 60 T) indicate neuropsychological functioning in the normal range.
- *Total Items Circled* (*TIC*): Represents the number of neuropsychological items (excluding DEF and AFF items) with a nonzero score. TIC helps to distinguish between individuals who report many symptoms of low intensity from those who

report a few symptoms of high intensity. The TIC score is especially useful for comparing responses over repeated NIS administrations, since the number of endorsed items may remain the same, whereas the intensity rating of the items may change.

- *Symptoms Intensity Measure* (*SIM*): Represents the ratio of the GMI score divided by the TIC score. The SIM provides useful clinical information by reporting the average subjective severity of reported neuropsychological symptoms. Elevated SIM scores (above 70 T) along with high scores on the AFF and FRU may indicate an Organic Personality Disorder. Low SIM scale score (below 40 T) are often found for individuals with diminished affective experience (AFF), and especially for individuals with poor awareness of impairments. Further, low scores on SIM also suggest defensiveness due to a patient's reluctance to report symptoms at high levels.

## 14.5 Subscale Scores for Seven Areas of Impairment

- *Critical Items* (*CRIT*): Include items that are frequently associated with a history of neurological illness or injury. Results of CRIT indicate a history of neuropathology (e.g., head injury) or the residual symptoms of neuropathology (e.g., seizure disorder).
- *Cognitive Efficiency* (*COG*): Provides information about the number of general symptoms of neuropsychological impairment, such as slowness of mediation or praxis, fatigue, confusion, and mental efficiency. An obtained score on COG (above 60 T) is considered moderate whereas above 70 T is considered severe.
- *Attention* (*ATT*): Consists of items that indicate difficulty with attention and concentration.
- *Memory* (*MEM*): Includes items that reflect memory dysfunction which include long-term memory and memory for names and faces.
- *Frustration Tolerance* (*FRU*): Used to assist in identifying symptoms of Organic Personality Disorder, such as irritability, anger, or temper.
- *Learning-Verbal* (*L-V*): Consists of items which measure difficulty with learning and with expressive speech.
- *Academic Skills* (*ACD*): A measure of difficulties with academic skills such as making change, reading the newspaper, or spelling words.

### 14.5.1 NIS Observer Report Form

Obtaining information from patient relatives and other individuals familiar with the patient provides an additional snapshot of behaviors. Such information also provides additional perspectives on patient symptoms, resulting in a more comprehensive evaluation. The NIS Observer form consists of the NIS items, which are restated in the third person. After completing the NIS and NIS Observer form, results can be compared to determine if any discrepancies exist. Such discrepancies should be further investigated by the examiner.

## 14.6 Validity Check

The NIS has several informal techniques and formal scales that measure the validity of the scores obtained. Initially, item responses should be reviewed. Consider and investigate the number of items left unanswered (e.g., was it due to visual problems, forgetfulness, or general attitude towards testing). Also, when all responses have the same value (e.g., all 0's or all 4's), the individual's general attitude and approach to the test should be considered. The formal scales that should be considered include the following:

- *Defensiveness* (*DEF*) *Scale*: Provides an indication of test-taking attitude and distortion of social judgment. Unusually high and unusually low scores on this scale suggest an atypical test-taking attitude that may reflect personality issues, cultural background, or impaired social judgment. High scores (above 60 T) may suggest severe cognitive impairment or rigidly inflexible or moralistic in attitude. Low DEF scores (below 40 T) may reflect cynicism, independence, cultural differences, or a noncompliant approach to the test.
- *Affective Disturbance* (*AFF*) *Scale*: Provides an estimation of the presence of affective disturbance (e.g., anxiety, depression, or poor stress tolerance), often resulting from overreporting of neuropsychological symptoms. When a patient's AFF score exceeds 70 T, it should be assumed that there is an affective contribution to responses on the neuropsychological items. A low AFF scale score (below 40 T) is associated with the diminished affective range and expression is often described as "flat affect" or apathy.
- *Response Inconsistency* (*INC*) *Scale*: Provides a useful measure of the individual's ability to respond in a consistent, coherent manner. The INC is determined by using pairs of items in which the members of each pair have similar content and are expected to elicit responses that are usually highly correlated. A low INC scale score (40 T or below) indicates no difference between responses on the paired items. Whereas, a high score (above 70 T) on the INC scale reflects inconsistency that may be a result of inadequate orientation, inattention, a reading problem, or haphazard responding (results should be interpreted with caution).
- *Subject Distortion Index* (*SDI*): Provides a way of evaluating an individual's tendencies to exaggerate or downplay symptoms when responding to the NIS items. The SDI addresses the extent to which the obtained GMI score based on the individual's report of symptoms differs from the predicted GMI score based on his or her actual performance on other neuropsychological measures. If a patient's SDI is less than 40 T, the obtained GMI score is well below the predicted GMI score. This suggests the patient is underestimating the nature and extent of his or her cognitive deficits. This underestimation may be due to unawareness, general defensiveness, psychologically motivated denial, or depression. On the other hand, if the SDI is greater than 60 T, the patient's obtained GMI score is well above the predicted GMI, suggesting he or she is overestimating his or her cognitive deficiency. Such exaggeration of symptoms could be due to affective disturbance or poor personal judgment (O'Donnell et al., 2009).

## 14.7 Scoring

Administration and scoring of the NIS is straightforward and the procedures are the same regardless of whether the NIS Self-Report or the NIS Observer Report form is being administered. The Self-Report should be the primary tool used; the Observer Report should be used as a supplemental. The NIS Senior Interview form can be used with patients who have difficulty completing the written self-report form.

Prior to administration, establish rapport with the patient. Ensure the testing environment is comfortable and quiet, free from distractions. To complete the assessment, the patient should be provided with the appropriate report form and a pencil. The administrator should review the directions with the patient to ensure understanding and answer any questions. For completion of the Self-Report and the Observer Report forms, the individual completing the form is instructed to read each item and circle the response that best corresponds with his/her answer, ranging from 0 (Not at all) to 4 (Extremely). For completion of the NIS Senior Interview form, the examiner should read each item aloud to the patient. The examiner should instruct the patient to rate each item using the following rating scale: 0 (Not at All) to 2 (Quite a Bit).

Scoring of the NIS may be conducted by hand or using the scoring CD. If the examiner is going to hand score the test, the examiner should remove the perforated strip from the side of the report form and discard it along with the carbonized tissue insert. Inside the AutoScore™ form, the examiner will find the NIS Profile Sheet, a scoring page, and reproductions for Tables 2, 3, and 4. Additional step-by-step scoring instructions are provided within the form (O'Donnell et al., 2009). To score using the scoring CD, scores should be entered into the scoring system and the system will compute the scores.

## 14.8 Reliability

Reliability of the NIS is examined through an analysis of split-half reliability, internal consistency, test–retest reliability, and profile stability. Results of the reliability analysis are presented below:

- *Split-Half Reliability* for the NIS was conducted by comparing the first 40 with the last 40 neuropsychological items. The correlation between the first and second half was .87; when corrected for attenuation, the resulting correlation was .93.
- *Internal Consistency* alpha coefficients for the NIS scales were conducted for nonclinical and neuropsychiatric patient samples. The alpha values of the two samples are high, with median values of .79 and .86 for each group, respectively.
- *Test–Retest Reliability* was examined across four groups of individuals:
  - *25 College students*: The average test–retest correlation for this group's obtained NIS scores was .90 and ranged from .64 for DEF scores and .98 for GMI scores.

  - *25 Outpatient Rehabilitation Patients*: The average retest correlation for this group's obtained NIS scores was .91 and ranged from .78 for DEF scores to .97 for TIC and CRIT scores.
  - *25 Neurological Patients*: The average retest correlation for this group was .84.
  - *25 Outpatient Rehabilitation Patients*: The average test–retest correlation observed for the NIS subscale scores was .83 and ranged from .72 for SIM scores to .88 for COG and GMI scores.
- *Profile Stability*: Determined by analyzing the consistency of high point elevations over time. Comparisons were made in scores obtained between the first and second administrations of the test–retest sessions; results found that 19 subjects (76 %) had the same high point, and 11 subjects (44 %) had the same first and second high points. Results demonstrate that the high point elevation for the NIS profile is fairly stable over time.

## 14.9 Validity

Validity of the NIS is examined through the investigation of questions relating to construct validity (internal structure), its concurrent validity, its effectiveness as a screening device, and its ability to discriminate between clinical groups. Results of the validity studies are presented below:

- *Construct Validity*: Detailed construct validity information is provided in the NIS Examiner's Manual (O'Donnell et al., 2009). Construct validity analysis was conducted for nonclinical and neuropsychiatric standardization samples. The patterns of relationships are similar for both groups. The GMI correlates highest with most of the remaining scores for both groups. For the clinical scales, COG correlates highest with GMI for both groups. Refer to chapter 5 of the NIS Examiner's Manual for a list of detailed validity correlates.
- *Criterion Validity*: Several investigations of criterion validity were conducted by comparing the NIS to convergent measures, determine screening effectiveness, and discriminant analysis. A complete list of correlations is presented in chapter 5 of the NIS Examiner's Manual (O'Donnell et al., 2009).

## 14.10 Conclusion

The *Neuropsychological Impairment Scale* (NIS) is a screening instrument that provides a quick, accurate picture of neuropsychological symptoms, by eliciting relevant diagnostic information that might otherwise go unreported. The NIS consists of a Self-Report form, an Observer Report form, and a Senior Interview form. Administration and scoring of the instrument is easy. Scoring can be conducted by hand or via a scoring software program. Seven areas of impairment can be identified through the use of the NIS. Reliability and validity studies have been conducted and detailed results are presented in the NIS Examiner's Manual. Results of the NIS should be used with other neuropsychological assessments to plan treatment.

## References

Lezak, M. D. (1983). *Neuropsychological assessment* (2nd ed.). New York: Oxford University Press.

O'Donnell, W., DeSoto, C., DeSoto, J., & Reynolds, D. (2009). *The neuropsychological impairment scale*. Los Angeles, CA: Western Psychological Services.

Robins, L. N. (1980). *The N.I.M.H. diagnostic interview schedule: Version 2* (DHHS Publication No. 68-S79050). Washington, DC: U.S. Government Printing Office.

# Assessing Occupational Disability Following Trauma and Impairment

# 15

Jasen M. Walker and Stacey A. Krauss

Rehabilitation professionals have come to recognize the importance of comprehensive assessment in evaluating the employability of individuals who may have acquired occupational disability secondary to trauma. Disability evaluation and rehabilitation professionals do not always agree on nomenclature and specific methodologies, and as a result, both the meaning and practice of assessing disability following trauma vary. For many years, however, occupational disability assessment and vocational rehabilitation following trauma have been considered comprehensive, intradisciplinary processes of evaluating an individual's physical, mental, and emotional abilities; limitations from identifiable medical impairment; and residual functional capacities in order to help the injured person experience optimal restoration (Power, 1991). We endorse a biopsychosocial model of disability evaluation adopted by the *International Classification of Functioning*, *Disability and Health* of the World Health Organization (WHO, 2002). However, we wish to make what we believe are important distinctions among trauma, impairment, and disability, particularly in the assessment of occupational disability.

The National Institute on Disability and Research (1992) summarizes the role of assessment and measurement in rehabilitation as follows: "Consumers are measured to establish their eligibility for benefits or services, to determine which services are appropriate, to assess their needs, to ascertain their current level of functioning, and to estimate their potential" (p. 1). Cushman and Scherer (1995) note that Anne Anastasi presented three definitions of assessment during her 1993 Master Lecture at the 100th American Psychological Association Annual Meeting: (a) testing as a whole; (b) any information-gathering technique regarding individual behavior; and (c) the clinical

---

J.M. Walker, Ed.D. (✉)
CEC Associates, Inc., 1220 Valley Forge Road, Unit 9, PO Box 987,
Valley Forge, PA 19482, USA
e-mail: jasen@cecassoc.com

S.A. Krauss, Ph.D.
Employee of CEC Associates, Inc.

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_15

and intensive study of an individual in which test scores are considered together with all of the relevant data and information. Cushman and Scherer declare that they prefer the third definition, and we concur.

Disability assessment integrates medical, psychological, social, cultural, educational, vocational, and psychometric data into an evaluation process that explains the effects of medical impairment on an individual's occupational capabilities. Despite the recognition that comprehensive assessment is fundamental to disability evaluation and occupational rehabilitation, the practice of disability evaluation following the onset of impairment remains highly eclectic. Moreover, notwithstanding the growing appreciation for the difference between medical impairment and occupational disability (Holmes, 2007), many physicians are asked to determine or feel compelled to comment on vocational capacity and employability.

In this chapter, we will define the lexicon of vocational/disability evaluation and occupational rehabilitation, trace its origin, briefly review relevant literature related to assessment of impairment and evaluation of disability following trauma, and proceed to describe a biopsychosocial model of vocational disability assessment following trauma. We will make our bias known. Physicians diagnose disease and attempt to ameliorate the effects of impairment. Vocational evaluators trained in a variety of disciplines, generally allied with medicine, and yet outside its scope, assess occupational disability.

Accurate assessment of vocational disability following injury or trauma should be a concern for healthcare professionals, employers, public policymakers, and society in general. If for no other reason, human injury is expensive. Direct medical costs and indirect costs, such as lost productivity due to traumatic brain injury (TBI) alone, for example, totaled an estimated $76.5 billion in the United States in 2000 (Finkelstein, Corso, & Miller, 2006). In 2011, approximately three million workers in private industry and 821,000 workers in state and local government experienced a nonfatal occupational injury or illness, according to the Centers for Disease Control and Prevention (CDC, 2013a). The CDC also reports that nonfatal workplace injuries and illnesses are estimated to cost the US economy approximately $200 billion annually. The National Safety Council (NSC) references research that shows work-related injuries cost the US economy $250 billion in 2007. In 2010, there were an estimated five million "medically consulted injuries" and 3,783 deaths that occurred in the workplace (2012). Traumatic injury and associated occupational disability are costly to individuals, families, social agencies, and work organizations. Precision and accuracy in disability assessments can only benefit the individual being evaluated, employers, and society in general, as inaccurate evaluations are likely to be the subject of scrutiny and result in further inquiry, misguided treatment, and additional loss. Precise assessment begins conceptually with differentiating among the phenomena of trauma, impairment, and disability.

## 15.1 Trauma

People arrive at the disability evaluation process most often following trauma. The term "trauma" originates from the Greek word meaning "wound." Bodily trauma can take place in many ways. Slip and falls, motor vehicle collisions, work accidents, physical assaults, shootings, and surgeries can cause trauma. Mild physical trauma does not always cause damage. For example, striking one's elbow or ulnar nerve on the arm of a chair (hitting the "funnybone") is a mild form of trauma that seldom causes damage to the organism, and if it does, the injury is not necessarily permanent. However, ulnar nerve injuries can cause permanent damage, and when irreversible damage occurs, the trauma has caused anatomic and/or physiologic change, which is described in this chapter as impairment.

Definitions of trauma are myriad and too diverse to adequately summarize here. Classen and Koopman (1993) describe trauma as "an abrupt physical disruption in ordinary daily experience, often with loss of control over the body" (p. 178). Courtois (2004) speaks to complex trauma as "a type of trauma that occurs repeatedly and cumulatively, usually over a period of time and within specific relationships and contexts" (p. 412). The American Psychological Association's *Dictionary of Psychology* (VandenBos, 2007) defines trauma as a physical injury or event in which a person witnesses or experiences a threat to his or her own life or physical safety or that of others, and as a consequence, also experiences fear, terror, or helplessness.

The effects of trauma can be numerous. Trauma can be the result of a single event or repetitive exposures to environmental forces. Industrial explosions can cause trauma. Repetitive assembly operations can cause trauma and injury. Repetitive trauma often occurs because muscles are repeatedly stressed, tendons become inflamed, nerves get pinched, or blood flow becomes restricted (Van Fleet & Bates, 1995).

Psychological responses during and related to trauma include temporary psychophysiological reactions and development of permanent mental disorder. Dissociative symptoms concomitant to traumatic experiences include stupor, derealization, depersonalization, numbing, and amnesia for the event (Classen & Koopman, 1993). Survivors of automobile accidents often report a dulling of senses during the accident (Noyes, Hoenk, Kuperman & Slymen, 1977, as cited in Classen & Koopman, 1993). Traumas that are seen as being caused by others (e.g., rape, assault, toxic accidents) generally have more psychological effect on victims and their significant others than those caused by natural disasters (e.g., earthquakes) (VandenBos, 2007).

Acute stress disorder (ASD) was introduced into the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, *Fourth Edition, Text Revision* (DSM-IV-TR, 2000) as a diagnosis to describe acute stress reactions. The *Fifth Edition* of the *Manual* (DSM-5, 2013) states that ASD should resolve within 4 weeks after the conclusion of the traumatic event. However, psychological responses to trauma can be more enduring and pervasive.

Posttraumatic stress disorder (PTSD) is a diagnosis that grew from the observations and formulations of researchers concerned with the devastating effects of war trauma on individual soldiers, but according to the DSM-5, PTSD can occur at any age, including childhood. Survivors of rape, child abuse, domestic violence, and other traumatic experiences can develop PTSD. Chronic PTSD has been linked with diminished health and longevity of Vietnam War veterans (Boscarino, 2005), underscoring the validity of the biopsychosocial model of disability assessment. As the result of severe, cumulative, or complex trauma, maladaptive psychological responses can be chronic and debilitating.

According to Herman (Herman, 1992a, b, as cited in Courtois, 2004), symptoms associated with complex PTSD include alterations in the regulation of: affective impulses; attention and consciousness; self-perceptions; perception of the perpetrators; relationships with others; position and/or medical problems; and alterations in systems of meaning.

Not all traumatic injuries produce enduring psychological sequelae. When it does occur as a result of trauma, dissociation, for example, does not necessarily persist (Esposito & Mellman, 2005). Likewise, other psychological symptoms to trauma have been found to abate with time. Grunert et al. (1992) discovered that the majority of workers with injured hands assessed 5 days post-injury reported flashbacks and nightmares. At 3, 6, 12, and 18-month follow-ups, however, many of these non-exertional symptoms had diminished, although some, including flashbacks and avoidance behaviors, persisted.

Research on Adverse Childhood Experience (ACE) reveals that trauma can be the result of early childhood experiences resulting in social, emotional, and cognitive impairment that ultimately cause long-term effects, including adult chronic health problems and disability. The CDC (2013b) reports that ACE research findings suggest that certain developmental experiences, including various traumas, are major risk factors for the leading causes of adult illness and death as well as poor quality of life in the United States. Therefore, recognition that trauma can be acute, chronic, and/or repetitive is an important aspect of comprehensive, biopsychosocial disability evaluation.

Trauma may be described as being mild, moderate, or severe, but these vague scales in the evaluation process are qualitative at best and may provide little meaning in the assessment of impairment and disability. What is clear is that trauma can produce physical and/or mental damage to the individual. With time, the effects of trauma can abate, but the residuum from trauma may be permanent and may be measured in terms of impairment, physical and/or mental.

## 15.2 Impairment

Impairment is defined by the American Medical Association (Cocchiarella & Andersson, 2001) as the loss, loss of use, or derangement of any body part, system, or function. Impairments may be exertional or non-exertional in nature. The Social Security Administration (SSA) offers a Program Policy Statement (SSA, 1978) that clarifies the distinction between exertional and non-exertional impairments. Exertional impairment affects the performance of work activities involving strength and endurance, such as standing, walking, lifting, and otherwise performing the essential requirements of sedentary, light, medium, heavy, or very heavy work. A non-exertional impairment is one which is medically determinable and causes functional limitation generally unrelated to strength or environmental restriction.

For example, speech impairments or hearing disorders may be considered non-exertional impairments. Most mental disorders can be classified as non-exertional impairments. One would expect licensed clinical social workers, psychologists, and psychiatrists to diagnose a mental impairment and hopefully assess its effects on mental and emotional functioning.

Impairments may be exertional, non-exertional, or both. Impairment is evaluated in a variety of ways and is customarily the purview of healthcare providers with a particular expertise related to the type of injury, illness, or impairment. Therefore, orthopedic surgeons are concerned with trauma or impairment to the musculoskeletal system, including bones, joints, and muscles. Neurologists assess what is thought to be impairment of the central and peripheral nervous systems, and neuropsychologists generally assess cognitive deficits and other changes in brain behavior. Psychiatrists and psychologists diagnose and treat mental and emotional disorders.

The American Psychiatric Association relies upon the DSM-5 (2013) to categorize mental disorders and provide criteria for diagnosis. The previous version, the DSM-IV-TR (2000), reminds its readers that the term “mental disorder” implies an unfortunate distinction between “mental” and “physical,” as the compelling literature documents that the mind/body dualism is misleading: “…there is much ‘physical’ in ‘mental’ disorders and much ‘mental’ in ‘physical’ disorders” (p. xxx). The DSM-5 notes that the publication’s task force has made substantial effort to separate the concepts of mental disorder and disability.

Each healthcare specialist possesses more or less reliable methodologies to assess the nature and degree of impairment. When necessary, there may be attempts to determine the permanency of impairment. Diagnoses and defined impairments, however, are insufficient to provide a basis for disability. The critical link between impairment and disability may be functional capacity.

## 15.3 Functional Capacity: The Critical Link?

The critical link or keystone between impairment and disability seems to be functional capacity, and in disability evaluation, accurately assessing functional capacity can be of significant importance in evaluating disability and predicting employability. Nonetheless, the evaluation of an individual’s residual functional capacities following trauma remains a challenge for rehabilitation professionals. Among the primary issues are the validity and reliability of functional capacity assessments (King, 2004). Although thought to be a substantial improvement over the practice of a physician simply filling out a physical capacity checklist, solid empirical data with respect to the validity and reliability of the functional capacity evaluation (FCE) is still lacking. Randolph, Nguyen, and Osborne (as cited in Talmage & Melhorn, 2005) recommend that the FCE be used in conjunction with the practitioner’s thorough understanding of the examinee’s health problem and medical history. Still, the FCE appears to be an improvement over the so-called “educated guess” offered by most physicians in response to questions regarding the injured person’s post-injury physical capacities. In 2008, the American Medical Association published the *Guide to the Evaluation of Functional Ability: How to Request, Interpret and Apply Functional Capacity Evaluations*, an important text in assisting practitioners of medicine and rehabilitation on further appreciating the FCE in the disability assessment process.

Psychiatric and/or psychological statements regarding residual functional capacity are dubiously reliable in terms of predicting an individual's disability and employability. Knowing the diagnosis and Global Assessment of Functioning (GAF) of the individual with mental impairment has been insufficient in accurately assessing the degree of motivation, self-control, functional skills, and tolerance for stress that individuals bring to prospective employment. The GAF formed the fifth axis of the standardized diagnostic procedure followed in the DSM-IV-TR and sought to quantify psychological, social, and occupational functioning on a continuum of mental illness. The DSM-5 no longer endorses the GAF as an assessment scale but arguably provides no better a tool, the World Health Organization Disability Assessment Schedule 2.0 (WHO, 2007a).

Because trauma can result in permanent physical and/or mental impairment, and functional capacity assessments are currently designed only to investigate the impaired person's physical capacities, rehabilitation professionals must turn to other assessment tools and procedures to appreciate the examinee's residual employability following trauma that may have resulted in mental impairment and associated dysfunction. The SSA (2005) references limitations in concentration, persistence, or pace as representative of disabling mental impairment. Fortunately, significant attention has been paid to the validity and reliability of mental measurements, including standardized psychological and vocational tests that can measure an individual's concentration, persistence, and pace. Unfortunately, psychological and vocational testing in disability assessments is not always employed, and when utilized, vocational disability evaluation measures are often administered without the issue of ecological validity in mind.

Ecological validity refers to the real-world meaningfulness of data-gathering activities. The term "ecological validity" was coined by Egon Brunswik (Hammond, 1998), who was concerned with ergonomics, the application of human factors in the design of objects and systems in the environment. How a person behaves at the time of an FCE or disability assessment may not necessarily predict how the person will function in a work setting, and essentially that is the challenge to rehabilitation professionals—to determine the value of their collected data in terms of predicting workplace behaviors.

## 15.4 Disability

In describing the relationship of trauma and impairment to occupational disability, one must reiterate the important distinction between impairment and disability (Walker, 1993). The AMA *Guides* (Cocchiarella & Andersson, 2001) references the difference between impairment and disability. As noted above, impairment is defined as "a loss, loss of use, or derangement of any body part, organ system, or organ function" (p. 3) and is evaluated best by medical means. On the other hand, disability is "an alteration of an individual's capacity to meet personal, social, or occupational demands" (p. 3). The World Health Organization (2007b) defines disability as an activity limitation that creates a difficulty in the performance, accomplishment, or completion of an activity in a manner that is within the range considered normal for a human being. The Americans with Disabilities Act of 1990 (U.S. Department of Justice, 2007) speaks to disability as having a physical or mental impairment that substantially limits one or more of an individual's major life activities; having a record of impairment; or being regarded as having an impairment. In this chapter, we are concerned with the occupational consequences of medical impairment.

Occupational disability may be defined as an individual's loss or limitations in employment capabilities secondary to physical and/or mental impairment. Vocational disability can have a strong social component. Observations and research have shown that vocational disability can be induced by social dynamics, and disability can be ameliorated or managed through psychological and social interventions, transition-to-work, ergonomic assistance, or career change, to name a few (Walker & Heffner, 2006). Vocational or occupational disability is best assessed by qualified evaluators who possess an understanding of medical impairments and their effects on functionality. Through comprehensive assessment, vocational disability evaluators can develop an accurate prediction of how the individual's history of impairment will impact the essential functions of employment for which he or she is best qualified given the person's residual physical capabilities, age, education, work skills, potentials to benefit from retraining, and return-to-work possibilities through job re-engineering.

Scheer (1991) pointed out that society is accustomed to putting physicians in decision-making roles for assessing work capacity or vocational disability and expecting physicians to make disability determinations, often without collaborating with other assessment professionals. By training, however, physicians are ill-prepared to assess work disability, capability, and employability. Nonetheless, the family physician in particular is commonly called upon to serve as an occupational health physician and to assess vocational capacity. Walker (2007) and others (Growick, 2004) have described, in detail, the problems facing physicians and other healthcare professionals (i.e., physical and occupational therapists) in assessing an individual's functional capacity following physical injury or illness, and yet, assessing functional capacity is only part of the tripartite analysis (i.e., impairment, functionality, and residual employability) of disability. Following the occurrence of trauma, impairment and then functionality must be carefully investigated prior to determining the examinee's occupational disability and assessing his or her employability.

Rehabilitation professionals trained in vocational disability evaluation realize that assessment of occupational disability following trauma is a comprehensive, intradisciplinary process of evaluating an injured individual's physical, mental, and emotional capacities in an effort to identify an optimal vocational fit, and in most cases, a return to work (Power, 1991). Disability is a biopsychosocial phenomenon and requires investigation into all spheres, the biological, psychological, and social aspects of the examinee's life. In vocational disability assessments carried out for court purposes (forensic evaluations), rehabilitation is probably not the goal. Nonetheless, assessment is the same and involves the gathering and integration of data for purposes of making evaluations, decisions, or recommendations (VandenBos, 2007, p.751). Assessing vocational disability following trauma for any purpose is logically multidisciplinary, integrating information from a variety of sources, as accurate assessment requires reliable data from more than one specialty.

Assessment of disability and employability following trauma begins with appreciating the functional effects of impairment. The various assessment methodologies employed to determine functional capacity are dictated to some extent by the nature of the impairment(s). Assessment of occupational disability following brain injury resulting in both exertional or strength deficits (e.g., hemiplegia) and non-exertional impairments (i.e., cognitive and emotional deficits) will likely require physical capacity testing, neuropsychological investigation, and ultimately, vocational evaluation, the latter to determine if the individual with multiple impairments can still carry out work-related activities on a competitive level.

Assessment strategies for determining disability are therefore dictated to a large extent by the nature of the permanent impairments presented at the time of evaluation. An individual with a permanent impairment of the lumbar spine following a work-related trauma involving lifting may not demonstrate postaccident psychological problems and may require no more than physical capacity testing after reaching maximum medical improvement through physiotherapy.

Thorough assessment of disability following trauma, however, requires a comprehensive and detailed investigation of an individual's medical history and residual functional capacities. The examinee's social and family background, educational history, acquisition of vocational skills through experience, and potentials to acquire additional skills through post-injury training and/or job experience are critical areas of inquiry.

The more thorough the assessment, the more likely it is to carry ecological validity. The prediction of vocational functioning from laboratory or clinical diagnoses alone remains a concern. The rehabilitation professional wants to know how an examinee's performance on an FCE and scores on various tests compare to what is expected in a job description or in relation to those performances of unimpaired cohorts with whom the examinee will compete in the labor market.

In terms of assessing the occupational disability and residual employability of individuals experiencing psychiatric or psychological symptoms following trauma, the input from treating mental health professionals regarding the examinee's diagnosis and capacities for non-exertional work demands can be helpful. For example, whether the psychologically impaired person can communicate and cooperate with others in a workplace is essential in determining if a person is disabled from the essential function of teamwork. Moos, Nichol, and Moos (2002) conducted research that led them to conclude that GAF ratings were only minimally associated with treatment outcomes and were of questionable value in a program for predicting the allocation and outcomes of mental health care. As noted, the DSM-5 has eliminated the GAF scale and instead includes the World Health Organization Disability Assessment Schedule 2.0 (WHO, 2007a).

No consistent relationship has been identified between psychiatric symptoms and vocational performance, making diagnostic categories poor predictors of future work performance (Anthony & Jansen, 1984). On the other hand, a person's functional capabilities and occupational adjustment exhibited in a clinical setting and in response to work-like tasks, such as problems on psychological tests and work samples, may still be important observational data in assessing disability and residual employability. For example, whether the psychologically impaired person can communicate and cooperate effectively with others in an evaluation would seem to have merit in terms of predicting work behaviors. Likewise, because standardized tests are designed to measure behaviors, a person's performances on appropriately selected psychological and vocational measures would seem to have value in predicting work performance following the onset of impairment.

It is in light of the experience and research of others that we advocate multidisciplinary, comprehensive assessment to include documentation regarding the examinee's medical history and disabling impairment; careful observation during a detailed structured clinical interview; and analysis of relevant data from both functional capacity assessments and psychological/vocational testing. Assessing occupational disability is greatly enhanced through "clinical and intensive study of an individual in which test scores are considered together with all other relevant data and information" (Cushman & Scherer, 1995, p. 3). As stated above, we concur with Anastasi (as cited in Scherer, 1995) and propose a three-part model to disability assessment: (1) review of detailed documentation; (2) structured clinical interview data; and (3) results of ecologically valid psychovocational testing.

## 15.5 Assessing Disability: Practical Applications

Although there are many elements of investigation that have the potential to contribute to disability assessment, beginning with determination of physical or mental impairment, the findings of impairment alone should not be considered equivalent to disability. As stated, there is a, sometimes considerable, difference between impairment and disability. Walker and Heffner (2006) note that the presence of impairment alone does not determine an individual's capacity to meet social or occupational demands. Disability is more complex than a change in mental or physical functioning secondary to impairment; it is a multifaceted combination of physical, social, and psychological factors. Breeding (2005) recognizes that the impact of a medical impairment largely depends on the perception of the person affected, and he adds that the psychosocial impact on two people with identical impairments can be quite different.

A major objective of disability assessment is to determine an individual's capacity to meet social and occupational demands following the acquisition of impairment. The goal of the disability assessment process is to develop a detailed picture of the individual being evaluated, including, among other factors, medical impairments, residual functional capacities, post-injury aptitudes and skills, personality characteristics, the environments in which the individual might again live and work, and levels of functioning prior to impairment. The individual's entire medical history is often important in disability assessment. Disease entities and resultant limitations can be antecedent to and not necessarily a consequence of trauma, and these comorbidities, regardless of their etiology, may be occupationally significant. Due to the encompassing nature of disability, gathering the often interrelated biological, psychological, and social information needed to adequately assess disability and potential is challenging but nonetheless essential.

Although the methods for assessing disability in a forensic setting remain the same as for rehabilitation purposes, the goal of the former is often to answer a legal question. Typically, it is a question of whether an individual has incurred reduced employment capacity and/or lost potential to earn wages occupationally. Assessment for rehabilitation purposes generally produces recommendations, and forensic vocational disability evaluation aims to answer legal questions. Ideally, the initial assessment processes and methodologies remain the same.

It is important to consider the question of who is qualified to conduct disability assessments. Walker and Heffner (2006) indicate that it is a common misconception that members of the medical field are qualified to make determinations about disability. There are several concerns associated with this misconception, particularly as the determination of disability is reliant on many factors apart from medical expertise alone, and are therefore beyond the purview of physicians (Cocchiarella & Andersson, 2001; Scheer, 1991; Talmage & Melhorn, 2005). The assessment of disability also requires training in the nature and demands of multiple forms of work and what is required of individuals to successfully participate socially in a work setting. Sleister (2000) correctly notes that the reliance on physicians and economists to provide assessment of an individual's capacity to work following impairment is ineffective, as they do not have the expertise to speak to qualifications, physical requirements, or earnings for the more than 20,000 jobs in the US labor market.

Often, in cases of personal injury where disability assessment is required, vocational experts are the most qualified. Sleister (2000) provides a comprehensive discussion on the qualifications and abilities of vocational experts, which include knowledge of the psychosocial aspects of disability and a variety of occupational skills and characteristics. Weed and Field (2001) discuss the role of vocational or rehabilitation experts as professionals who are knowledgeable in vocational, educational, and psychological assessment practices. Weed and Field provide an overview of the forensic disability evaluation process. Ultimately, the disability assessor needs to be able to synthesize information from a variety of sources while maintaining a focus on ecological validity.

## 15.6 The Elements of a Disability Assessment

Although Thomas (1999) notes that some feel the present state of vocational evaluation has lost its utility and that the formal process associated with disability assessment should be altered to reflect more of a screening process driven by self-report, we argue that thorough and accurate assessment should consist of three main parts: a review of pertinent documentation, a clinical interview, and the administration of standardized testing. Berven (as cited in Bolton, 2001) similarly describes assessment for rehabilitative purposes as being constructed of a review of client records, clinical interviews, observations, examinations by other professionals, and formal testing.

Before presenting each of these data-gathering areas in some detail, it is noteworthy to mention that reliance on a clinical interview solely is fraught with potential for error. Meyer et al. (2001) highlight several possible errors, such as gathering data from poor or unreliable historians, using overly narrow interview formats, and having an inability to objectively determine exaggerated or biased self-reporting. It is also worth noting that through the use of testing in conjunction with interviews, the evaluator is able to measure a variety of features at the same time, compare individual performances to relevant norm groups, and follow standardized scoring and administration procedures, which lessen possible legal and ethical conflicts and likely increase the validity of the findings.

Sleister (2000) notes that throughout a disability assessment, a skilled evaluator must be able to observe and assess personal characteristics, educational potential, and related work histories, which would be difficult to complete accurately through reliance on self-report alone. Additionally, Breeding (2005) points out that in the research on disability, no link exists between the physical severity of an injury or illness and the psychosocial effects it has on a given individual and, therefore, disability cannot adequately be assessed through medical examination alone.

Many disability evaluators have traditionally relied on Transferability of Skills Analysis (TSA), a process of investigating the skills and traits a person has demonstrated during his or her working life in order to recommend alternative job placement or retraining options after the establishment of impairment. Despite its broad acceptance in the field of disability evaluation, we suggest that a TSA is not comprehensive enough to adequately assess disability and has several inherent flaws that lend against its use. In fact, findings suggest that little research, particularly empirical research, has been conducted to speak to the validity and usefulness of the practice (Dunn & Growick, 2000).

A major criticism of TSA is its rigidity, which often leads evaluators to overlook a range of alternate occupations available to a person simply because it falls outside of the description of his or her customary employment. TSAs actually evaluate the essential functions of job descriptions that the person reportedly carried out and intend to predict what skills the individual should be capable of doing with functional limitations. However, an individual's self-report of work history, job titles held, and specific work responsibilities is not a reliable method of assuring the individual had actually acquired skills delineated by government job descriptions, such as those promulgated by the U.S. Department of Labor (1991). Job titles alone vary from workplace to workplace. Even with a very careful inquiry regarding the individual's training, tools, materials, and methodologies used, considerable variation can exist from one worker's job responsibilities and experiences to another's.

The TSA method of disability assessment also assumes that an individual was well suited to prior employment, which may be untrue, and therefore not only presumes acquisition of work adjustment skills but also ignores potential vocational interests outside of previous modes of work (Dunn & Growick, 2000). Dunn and

Cain (2001) note that often a return to employment following the onset of impairment is dependent on extra-vocational circumstances and activities, and a disability assessment is likely to be ineffective if these variables are not considered. Dunn and Cain also conclude that many elements of TSA are not relevant to determining vocational outcome, and furthermore, TSA does not appear to be as sensitive in identifying alternate vocations when the individual in question has greater physical effects of impairment.

Power (1991) asserts that when assessing an impaired individual's current level of functioning, the use of standardized tests, such as aptitude and achievement tests, is warranted because specific knowledge of how an impaired individual's abilities or competencies compare with those of non-impaired individuals may be necessary for rehabilitation planning to be relevant. Neukrug and Fawcett (2010) conclude that assessment procedures include the clinical interview, ability testing, aptitude testing, personality testing, and informal methods such as observation and review of pertinent documents.

## 15.7 Review of Pertinent Documentation

The process of assessing disability is greatly enhanced by the review of critical documents, which can provide a wealth of information not typically available to an evaluator. It is not possible to gather all of the needed information for a disability assessment through a clinical interview and testing alone, particularly given the limited time allotted for those tasks. Through the review of additional records, the evaluator often has better access to the social environment in which the individual lives and works. For example, by reviewing employment records, it is possible to obtain information about how an individual typically performs at work through performance reviews, disciplinary actions, workplace injury reports, and attendance logs. Review of these records may also provide valuable insight into the employee–employer relationship, which may influence an individual's motivation to return to work following impairment. It can also serve to highlight supportive social environments that can be utilized to support a return to employment or avocational activities.

Medical documentation can be vital in a disability assessment and stands as a historical reflection of the individual's health. As mentioned earlier, some individuals can be unreliable historians or may intentionally distort or omit aspects of their health history that they feel will influence the outcome of a disability assessment. Reviewing documentation of medical treatment, both prior to and after an injury or illness, has the potential to provide a more complete body of information than some individuals may provide in an interview. Reviewing medical records is especially important if the individual in question had been diagnosed with particular conditions that could have interfered with his or her ability to participate in work prior to the issue in question, such as advanced heart disease or diabetes.

Apart from employment and medical records, in some cases, academic records can provide excellent information about an individual's baseline or premorbid performance for formal testing and his or her specific skill sets. At times, academic records identify a starting point in a long history of absenteeism or disciplinary issues. These types of records also have the potential to illustrate post-injury avenues for someone who must consider alternate work following the onset of impairment.

Ultimately, the review of records provides the evaluator with information about an individual as that person may be living from day to day as opposed to how that person presented in the assessment interview and performed during testing. Records provide a historical context to the disability assessment, a context that hopefully includes both pre-trauma and post-injury data.

## 15.8 Clinical Interview

The clinical interview is an essential element of a comprehensive disability assessment for several reasons. For one, it gives the individual being evaluated the opportunity to express his or her personal experience prior to and after sustaining an impairment. Breeding (2005) highlights the subjective nature of the impact of impairment and notes that information about an individual's lived experience is typically not available in documentation, testing, or general intake interviews. The clinical interview provides the examiner with the opportunity to ask an individual about a variety of areas in his or her life that may have been affected by impairment and also to gather information about the person's lifestyle.

Perhaps the most important reason to conduct a clinical interview, as opposed to simply reviewing records, is that more often than not, people are much different in person than they appear to be on paper. This point comes into sharp relief when one considers the many different professional perspectives that build a body of records regarding an individual's care. The type of qualitative information generated in a clinical interview helps to construct a context for the assessment and resultant findings by exploring and incorporating the unique features of the individual.

There are numerous texts devoted to specific techniques, styles, and goals of interviewing, so only select points will be briefly discussed here. Before conducting a clinical interview, the examiner should invest considerable time into practicing the required skills. Namely, data gathered from clinical interviews are greatly enhanced when the interviewer is a trained listener who recognizes and follows important leads instead of relying solely on the rather clerical nature of filling in a structured interview format. That is, though semi-structured, the interview should respond and adjust to the unique features each individual brings to an evaluation. This is also essential to building rapport with the person being interviewed and demonstrates that the examiner is listening. Berven (as cited in Bolton, 2001) suggests that during an interview, the communication of empathy, respect, and genuineness have the power to augment the relationship and encourage disclosure.

During the interview, the evaluator's main tool is that of questioning, so it is essential to practice phrasing questions tactfully though directly. At times, individuals are resistant to being interviewed, and the evaluator must effectively confront the person in order to generate quality information. One method is to simply point out the individual's behavior, such as appearing uncomfortable, and then engage the person in a dialogue directed to resolve the resistance and resume the interview. For example, it may be that the individual feels uncomfortable meeting new people and simply needs a few additional minutes to adjust to the task. In forensic settings, some individuals come to evaluations with the knowledge that the opposing legal party sent them and therefore have pre-existing notions of what the experience will entail. In any case, investing a few minutes to develop rapport with the individual and reduce resistance is worthwhile.

Another essential task of the clinical interviewer is to closely observe the person being interviewed. As mentioned, interviewing should not be considered a static clerical task, but rather an opportunity to gather important qualitative data about a person. Observations might include noting the way an individual is dressed, monitoring body language or complaints of physical discomfort, surveying the person's emotional responses to different questions, and any obvious abnormalities in thinking or information processing. The evaluator may also want to observe the individual's level of social appropriateness and sophistication, as the ability to be socially aware and accurately interpret social cues is essential to successful functioning in all but a select few vocational settings. Goleman (2006) explores the topic of social intelligence in detail.

The examiner should begin an interview by clearly stating the purpose of the evaluation. This includes stating any limitations to confidentiality, the source of the referral, and who will have access to the findings of the evaluation. The assessor should be prepared to answer any questions that the individual may have before beginning and should take care to ensure that the person has understood the purposes of the evaluation as stated.

When conducting a clinical interview as part of a disability assessment, it is important to structure the interview around the areas of the individual's life that generally have an effect on his or her productivity. This would include exploring the person's perceptions of his or her own abilities or disabilities, the role of work in the person's life as part of a detailed job history, and premorbid and unrelated post-morbid health issues. Berven (as cited in Bolton, 2001) suggests conducting an interview with at least a semi-structured format so that other professionals assessing the individual are likely to reach similar conclusions, or at least to understand how the conclusions of an interview are determined. During the clinical interview, the evaluator should take into account how the person spends a typical day, which, in some cases, has the potential to highlight new roles the individual has taken on that may reduce the likelihood of a return to full productivity. An example of this is when a person becomes the primary caretaker of the family almost by default while the spouse works.

There are certain concrete areas of an individual's experience that should be taken into account during a clinical interview as well, such as recording a list of any medications taken, including the dosage and frequency of use. Some medications can affect the speed or clarity of cognitive processing, thus affecting performance both on standardized testing and on general measures of productivity. It is also helpful to ask individuals to describe educational attainment, hobbies, and his or her family. This information further builds the context for a disability assessment.

If possible, it is helpful to interview other people who are significant in the life of the individual who is the focus of the evaluation. Often, significant others can offer valuable perspectives on the individual both prior to and after injury and can also speak to the person's residual abilities, activities, and interests. The need to interview significant others becomes evident when a child is the subject of evaluation, as it is essential to interview parents. This can also be the case if the subject of the evaluation is unable to participate in interviewing due to his or her physical or mental limitations.

## 15.9 Standardized Testing

The final area of the three-part model proposed for conducting a disability assessment is the administration of standardized testing. This area is frequently overlooked or is undertaken incompletely by examiners. As mentioned earlier, Meyer et al. (2001) point out the many benefits of using standardized testing as a valuable part of an assessment and even demonstrate that many published assessment measures are as reliable as medical tests like x-rays and CT scans. The use of standardized testing also provides unique information in that it can measure a person's aptitudes for retraining in a new vocation, for example. It is difficult to determine with any certainty a person's learning potentials based on self-report or historical documentation alone (Walker, 2004).

When designing a test battery to employ during a disability assessment, it is important to keep the concept of ecological validity in mind. That is, it is most logical to select measures that can provide information useful in the real world in which the person will be functioning. There is not much value in administering a test of manual speed and dexterity to a person who has suffered a major injury to his or her dominant hand, unless attempting to demonstrate that, in fact, the hand is impaired. It would be more informative, not to mention a better use of time, to select measures for that person that speak to the basic skill sets required in areas where he or she may be able to resume work or social activities. The availability of various workplace accommodations, such as voice-activated dictation, highlights the need to measure the basic, underlying skills a person has even if the person is impaired in using those skills via traditional methods. An individual who possesses skills associated with office work should not be considered excluded from that category of work simply because he or she lacks the capacity to type on a keyboard in a way that others do.

Typically, a test battery used for the purpose of disability assessment includes measures of achievement, intelligence, aptitudes, interests, personality dynamics, and, at times, measures of effort (Walker, 2004). Standardized testing should always include objective measures of personality or temperament as opposed to including only subjective self-report measures. The use of self-report measures raises the potential for biased responding and offers no means of objectively determining when biased responses are given. Although not directly related to vocational skill, personality measures offer valuable information about an individual's suitability for a certain vocation. Even if an individual had the requisite skills for a career in sales, the person would likely not be successful if extremely introverted or socially timid. Personality measures not only provide objective information on how suitable a person is for a specific job, but also how likely the individual is to be satisfied with that particular work.

In addition to administering an objective measure of personality, a test battery for disability assessment should also include measures of achievement to include basic academic skills, such as reading comprehension and mathematics. It is advisable to administer achievement testing early in a battery to ensure that later measures are appropriate for the individual's mathematic and reading abilities. There are also a variety of standardized measures that assess a range of work aptitudes, such as the Career Ability Placement Survey, the Differential Aptitude Test, or the Minnesota Clerical Test, that may be helpful.

When conducting disability assessment, it is important to incorporate the individual's personal and vocational interests, as an individual should not be expected to undertake an activity that they find repellent and, in fact, it is likely that the individual would not sustain unappealing activity even if able. Evaluators should devote special attention to the interest inventory they employ in order to ensure that it adequately covers a large range of occupational interests, including more modern vocations, such as computer-related activities, if possible.

Another aspect of the test battery for disability assessment is testing designed to measure effort. There are several available measures for assessing the validity of an individual's effort and response style during testing that are informative to the process, as sometimes individuals purposefully distort performance, particularly when secondary gain dynamics are present. Lynch (2004) offers some suggestions for identifying behaviors that indicate when validity testing is warranted, such as large discrepancies between subjective complaints and objective findings or a lack of cooperation during assessment efforts.

As with interviewing, test administration is a clinical process rather than a clerical task. The test administrator should make careful observations throughout the administration of standardized testing in order to gather qualitative data about how the person approached and organized each task. These observations should also include the individual's emotional response to particular activities, willingness to follow instructions, affect, and any signs of thought disorder. The examiner must be prepared to answer questions about not only the purpose of testing, but also specific questions about each test, and therefore, must be quite familiar with the measures. Frequently, it will fall to the examiner to help reduce anxiety associated with taking tests.

It is of great importance that the test battery and the examiner are responsive to the strengths, weaknesses, and needs of the individual being assessed. As data is gathered during the interview and test administration, it is the examiner's responsibility to integrate the information and adjust the assessment so that the most useful information is being collected.

The goal of medical and vocational rehabilitation is to maximize an individual's functioning following trauma and the onset of impairment, and when possible, restore that person's productivity. The comprehensive assessment initiates the disability evaluation and vocational rehabilitation processes, both of which are enhanced when practitioners fully appreciate the difference between impairment and disability.

## 15.10 Current and Future Assessment Considerations

Assessment of disability following trauma and impairment logically follows concepts associated with rehabilitation psychology and what we think we know about recovery. Current and growing concepts that appear to provide promise to the fields of occupational disability assessment and resultant rehabilitation flow from positive psychology. Positive psychology emphasizes the role of personal strengths and assets in human development, happiness, and well-being (Seligman & Csikszentmihalyi, 2000). The WHO asserts that health is "*A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" (WHO, 2004), and in keeping with the WHO advocacy of the psychosocial model of rehabilitation, it follows that response to and recovery from trauma and impairment will depend on one's positive strengths and attributes. Therefore, assessment of an individual's strengths and attributes is most certainly in order.

As we believe the biopsychosocial model of disability assessment remains valid, once an individual's biology has been compromised following trauma and impairment, psychosocial reserves that summon courage and resilience, for example, are the individual's means for recapturing productivity and citizenship. Methods of measuring courage, resilience, optimism, and gratitude among other strengths become relevant following trauma, particularly with regard to measuring and actualizing rehabilitation potentials. Many important questionnaires associated with positive psychology are being developed and validated, in part, through the *Authentic Happiness* website at the University of Pennsylvania (2006). Practitioners committed to assessing an individual's disability following trauma and impairment are encouraged to utilize these tools, meant as qualitative measures at least, and by doing so, consider the importance of positive psychology concepts in the assessment of vocational disability and rehabilitation following trauma and impairment.

## 15.11 Conclusion

The vocational disability assessment process is of substantial concern to rehabilitation professionals, employers, and society in general. In this chapter, we provide specific definitions of vocational disability assessment and its key concepts, look at relevant economic impact data, and continue by discussing the explicit methods used in disability assessment to evaluate the work potentials of individuals who are impaired physically and/or mentally. We advocate for adoption of a biopsychosocial model of assessment. After defining trauma, we make the crucial distinction between "impairment" and "disability." We describe the vital role of the functional capacity evaluation in the assessment process.

Vocational disability assessment is discussed in depth in terms of practical applications, the elements of an assessment, and the "three-part model" of assessment. The tripartite model, the heart of the assessment process, identifies the essential steps as: (1) a document review; (2) the clinical interview; and (3) standardized testing. Contributions from positive psychology are recognized as a potential "next stage" for providing disability assessment tools and rehabilitation methods. The thrust of this chapter is that the goal of vocational disability assessment is to develop a precise picture of the individual's capacity to function occupationally so that reliable decisions regarding the examinee's potentials and productivity can be made.

## References

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed. – text revision). Washington, DC: American Psychiatric.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric.

Anthony, W. A., & Jansen, M. A. (1984). Predicting the vocational capacity of the chronically mentally ill. *American Psychologist, 39*(5), 537–544.

Berven, N. L. (2001). Assessment interviewing. In B. F. Bolton (Ed.), *Handbook of measurement and evaluation in rehabilitation* (pp. 197–213). Austin, TX: Pro-ed.

Boscarino, J. A. (2005). Posttraumatic stress disorder and mortality among U.S. army veterans 30 years after military service. *Annals of Epidemiology, 16*, 1–9.

Breeding, R. R. (2005). Vocational rehabilitation and sudden onset disability: Advancing proprietary consumer involvement through improved vocational assessment. *Journal of Vocational Rehabilitation, 22*, 131–141.

Centers for Disease Control and Prevention. (2013). *Nonfatal work-related injuries and illnesses—United States, 2010*. Retrieved January 30, 2014, from http://www.cdc.gov/mmwr/preview/mmwrhtml/su6203a6.htm

Centers for Disease Control and Prevention. (2013). *Adverse childhood experiences (ACE) study*. Retrieved January 30, 2014, from http://www.cdc.gov/ace/index.htm

Classen, C., & Koopman, C. (1993). Trauma and dissociation. *Bulletin of the Menninger Clinic, 57*(2), 178–194.

Cocchiarella, L., & Andersson, G. B. J. (Eds.). (2001). *Guides to the evaluation of permanent impairment* (5th ed.). Chicago: AMA Press.

Courtois, C. A. (2004). Complex trauma, complex reactions: Assessment and treatment. *Psychotherapy: Theory, Research, Practice, Training, 41*(4), 412–425.

Cushman, L. A., & Scherer, M. J. (Eds.). (1995). *Psychological assessment in medical rehabilitation*. Washington, DC: American Psychological Association.

Dunn, P., & Cain, H. M. (2001). Comparisons of pre-injury characteristics of injured workers across levels of post-injury occupational congruence: Potential applications for Transferable Skills Analysis. *Journal of Forensic Vocational Analysis, 4*, 13–20.

Dunn, P. L., & Growick, B. S. (2000). Transferable skills analysis in vocational rehabilitation: Historical foundations, current status, and future trends. *Journal of Vocational Rehabilitation, 14*, 79–87.

Esposito, K., & Mellman, T. (2005). Stress disorder after traumatic injury. *The American Journal of Psychiatry, 162*, 629–630.

Finkelstein, E., Corso, P., & Miller, T. (2006). *The incidence and economic burden of injuries in the United States*. New York: Oxford University Press.

Genovese, E., & Galper, J. (2008). *Guide to the evaluation of functional ability: How to request, interpret and apply functional capacity evaluations*. Chicago, IL: American Medical Association.

Goleman, D. (2006). *Social intelligence: The new science of human relationships*. New York, NY: Bantam Books.

Growick, B. (Ed.). (2004). The use of functional capacity evaluations in vocational forensics. *Journal of Forensic Vocational Analysis, 7*(2).

Grunert, B. K., Devine, C. A., Matloub, H. S., Sanger, J. R., Yousef, N. J., Anderson, R. C., et al. (1992). Psychological adjustment following work-related hand injury: 18-month follow-up. *Annals of Plastic Surgery, 29*, 537–542.

Hammond, K. R. (1998). Ecological validity: Then and now. Retrieved October 1, 2007, from http://www.brunswik.org/notes/essay2.html

Holmes, E. B. (2007). Impairment rating and disability determination. Retrieved September 23, 2007, from http://www.emedicine.com/pmr/topic170.htm

King, P. M. (2004). Analysis of the reliability and validity supporting functional capacity evaluations. *Journal of Forensic Vocational Analysis, 7*, 75–82.

Lynch, W. J. (2004). Determination of effort level, exaggeration, and malingering in neurocognitive assessment. *Journal of Head Trauma Rehabilitation, 19*(3), 277–283.

Meyer, G. J., Finn, S. E., Eyde, L. D., Kay, G. G., Moreland, K. L., Dies, R. R., et al. (2001). Psychological testing and psychological assessment. *American Psychologist, 56*(2), 128–165.

Moos, R. H., Nichol, A. C., & Moos, B. S. (2002). Global assessment of functioning ratings and the allocation and outcomes of mental health services. *Psychiatric Services, 53*(6), 730–737.

National Institute on Disability and Rehabilitation Research. (1992). Human measurement in rehabilitation. Retrieved October 1, 2007, from http://www.empowermentzone.com/measure.txt

National Safety Council. (2007). Report on injuries in America. Retrieved October 1, 2007, from http://www.nsc.org/library/report_table_1.htm

National Safety Council. (2012). *Injury facts 2012 edition*. National Safety Council.

Neukrug, E. S., & Fawcett, R. C. (2010). *Essentials of testing & assessment* (2nd ed.). Belmont, CA: Brooks/Cole Cengage Learning.

Power, P. W. (1991). *A guide to vocational assessment* (2nd ed.). Austin, TX: PRO-ED.

Randolph, D. C., Nguyen, T. H., & Osborne, P. (2005). The functional capacity evaluation: Is it helpful? In J. B. Talmage & J. M. Melhorn (Eds.), *A physician's guide to return to work*. Chicago, IL: American Medical Association.

Scheer, S. J. (1991). *Medical perspectives in vocational assessment of impaired workers*. Gaithersburg, MD: Aspen.

Seligman, M. (2006). *Authentic happiness*. Retrieved February 7, 2014, from http://www.authentichappiness.sas.upenn.edu/Default.aspx

Seligman, M., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*(1), 5–14.

Sleister, S. L. (2000). Separating the wheat from the chaff: The role of the vocational expert in forensic vocational rehabilitation. *Journal of Vocational Rehabilitation, 14*, 119–129.

Social Security Administration. (1978). SSR 83-14: Titles II and XVI: Capability to do other work—The medical-vocational rules as a framework for evaluating a combination of exertional and nonexertional impairments. Retrieved September 29, 2007, from http://www.ssa.gov/OP_Home/rulings/di/02/SSR83-14-di-02.html

Social Security Administration. (2005). Disability evaluation under social security—Mental disorders—Adult. Retrieved October 1, 2007, from http://www.socialsecurity.gov/disability/professionals/bluebook/12.00-MentalDisorders-Adult.htm

Talmage, J. B., & Melhorn, J. M. (Eds.). (2005). *A physician's guide to return to work*. Chicago, IL: American Medical Association.

Thomas, S. W. (1999). Vocational evaluation in the 21st century: Diversification and independence. *Journal of Rehabilitation, 65*(1), 12–15.

U.S. Department of Justice. (2007). Americans with disabilities act. Retrieved October 1, 2007, from http://www.usdoj.gov/crt/ada/pubs/ada.htm

U.S. Department of Labor. (1991). *Dictionary of occupational titles—Volume II, fourth edition, revised 1991*. Washington, DC: U.S. Government Printing Office.

Van Fleet, E. L., & Bates, R. (1995). Ergonomics. *Facts & Resources, 1*(1), 1–2.

VandenBos, G. R. (Ed.). (2007). *APA dictionary of psychology*. Washington, DC: American Psychological Association.

Walker, J. M. (1993). The difference between disability and impairment: A distinction worth making. *Journal of Occupational Rehabilitation, 3*(3), 167–172.

Walker, J. M. (2004, June 3-4). *Forensic vocational assessments*. Paper presented at the 2004 Pennsylvania & New Jersey I.A.R.P. Conference.

Walker, J. M. (2007). *Application of the FCE by vocational experts.* Manuscript submitted for publication.

Walker, J. M., & Heffner, F. (2006). Disability, dysfunction, or deception: Explaining acquired occupational disability. *The Forensic Examiner, 15*(1), 12–23.

Weed, R. O., & Field, T. F. (2001). *Rehabilitation consultant's handbook—Revised*. Athens, GA: Elliott & Fitzpatrick.

World Health Organization. (2002). *Towards a common language for functioning, disability and health: International classification of functioning, disability and health*. Geneva, Switzerland.

World Health Organization. (2004). *Promoting mental health. Concepts, emerging evidence, practice*. Geneva, Switzerland.

World Health Organization. (2007). *Meeting of the international advisory group for the revision of ICD-10 mental and behavioral disorders*. Geneva, Switzerland.

World Health Organization. (2007b). *Disabilities*. Retrieved October 1, 2007, from http://www.who.int/topics/disabilities/en/

# Treatment Integrity in Interventions for Children Diagnosed with DSM-5 Disorders

# 16

Samantha Benevenuto Skolnik and Andrew Livanis

## 16.1 Introduction

*Treatment integrity* (also known as *treatment fidelity, procedural fidelity, or intervention integrity*) refers to the reliable and accurate implementation of an intervention. Treatment integrity (TI) is a term that refers to how the treatment which is actually administered is similar to the theoretical and procedural components of the intended treatment model (Dusenbury, Brannigan, Falco, & Hansen, 2003; Nezu & Nezu, 2008; Reed & Codding, 2011). Failing to control for treatment integrity can result in several issues (Livanis, Benvenuto, Mertturk, & Hanthorn, 2013). First, if a treatment is not implemented with fidelity, clinicians cannot reliably evaluate the effects of the independent variable upon the dependent variable (Cooper, Heron, & Heward, 2007; Kazdin, 2011). In these instances, the intervention takes on multiple "lives"—one which exists on paper and one which is actually implemented—both of which may be similar to one another but are not exactly the same (Livanis & Mercer, in press). Second, there is the potential lack of improvement among clients. When interventions are implemented with higher rates of treatment integrity, there is a stronger association with positive treatment outcomes (DiGennaro, Martens, & Kleinman, 2007; DiGennaro, Martens, & McIntyre, 2005; Erhardt, Barnett, Lentz, Stollar, & Raifin, 1996; Hogue et al., 2008). When well-designed interventions are implemented correctly, there tends to be positive effects on clients.

---

S.B. Skolnik, Psy.D.
Philadelphia College of Osteopathic Medicine, 226 Rector Street, Philadelphia, PA 19128, USA
e-mail: Samy.Skolnik@gmail.com

A. Livanis, Ph.D. (✉)
Long Island University - Brooklyn Campus, Dept. of Counseling and School Psychology, 9 Hanover Place, Brooklyn, NY 11217, USA
e-mail: Andrew.livanis@liu.edu

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_16

Lastly, interventions that are implemented without integrity can lead to related ethical and potential legal problems. Within the field of psychology, the push for evidence-based interventions (EBIs) has increased tremendously and a wide variety of governmental agencies and professional organizations have sought to define EBIs for children (Reichow & Volkmar, 2011). Failure to adhere to EBI, as in not implementing the intervention as intended, ceases to be an EBI. Various professional organizations address treatment integrity within their ethical codes or in collections of best practices for treatment implementation. The American Psychological Association's (APA) Policy Statement on Evidence-Based Practice in Psychology (APA, 2005) states to ensure the effectiveness and validity of intervention strategies, systematic review, and assessment is necessary; a lack of such evaluation would otherwise be viewed as unethical. The National Association of School Psychologists (NASP) Principles for Professional Ethics (2010a) states that, "school psychologists use assessment techniques and practices that the profession considers to be responsible, research-based practice" (p. 7). The NASP Model for Comprehensive and Integrated School Psychological Services (NASP, 2010b) urges school psychologists to use multisource data collection and assessment procedures to ensure effective implementation of EBIs.

Treatment integrity (TI) as a construct is not often effectively measured by clinicians or researchers (Dusenbury et al., 2003; McLeod, Southam-Gerow, & Weisz, 2009). To be fair, it is only recently that there has been some recognition of TI as an important construct that has implication on the nature of psychological therapy (Sanetti & Kratochwill, 2014). In some instances, it appears that practitioners have difficulties accessing the body of work that is based on treatment integrity (McIntyre, Gresham, DiGennaro, & Reed, 2007), but others have suggested that the measurement of treatment integrity might present as a greater challenge than the actual implementation of the intervention (Foxx, 1996).

Only 18 % of the studies of interventions for children actually assessed and reported treatment integrity data (Wheeler, Baggett, Fox, & Blevins, 2006), while Cochrane and Laux (2008) found that only 1–2 % of practicing school psychologists regularly measured rates of treatment integrity. This is a problem for clinicians because the treatments that are researched in the literature often fail to demonstrate that they were consistently implemented and calls into question whether these research-based interventions can be translated into practice (Allen & Warzak, 2000).

## 16.2 Dimensions of Treatment Integrity

TI is traditionally conceived as a multidimensional construct that comprises three dimensions or components (McLeod et al., 2009; Perepletchikova & Kazdin, 2005): treatment adherence, implementer competence, and treatment differentiation.

### 16.2.1 Treatment Adherence

Adherence refers to the clinician's implementation of procedures in a stable manner over time, which can improve with consistent contact with others with whom they can discuss the treatment application process. When treatment implementers are exposed to some form of consistent and ongoing training or supervision regarding the treatment, TI has been shown to improve dramatically and ultimately provides positive outcomes for the clients. For instance, it was found that weekly supervision to therapists increased fidelity to the manualized treatment protocols, which in turn led to significant decreases in problem behaviors in an outpatient setting (Hogue et al., 2008). It was also found that implementation of biweekly direct observations and immediate feedback increases the level of integrity to the treatment plan in a school setting (Codding, Feinberg, Dunn, & Pace, 2005).

A consideration of treatment adherence must take into consideration the setting of the intervention as well as the population served. Treatment protocols must be flexible to meet the needs of the client in various real-life settings: schools, clinics, hospitals, and offices. Some interventions, especially those that target psychopathological conditions in children actually require creative implementations of established interventions; in these conditions, therapist creativity can be considered a component of treatment adherence (Perepletchikova, 2014). In those cases, the treatment protocol or manual could specify which components of the treatments as well as the parameters of creativity that the therapist may apply. In other cases, more extreme psychiatric disorders may require the implementation of the same treatment protocol with increased magnitude or intensity (Dusenbury et al., 2003; Schulte, Easton, & Parker, 2009). In all of these instances, the "personalization" of the intervention should be overtly specified within the protocol to provide additional supervision on how to adhere the various components of the intervention (Barber et al., 2006; Perepletchikova & Kazdin, 2005).

### 16.2.2 Implementer Competence

Implementer competence refers to the experience, knowledge, and/or skill of the individuals that is implementing the treatment (Perepletchikova & Kazdin, 2005). The individual's competence could potentially be an important factor depending on the complexity of the intervention. Agent competence can be a combination of preservice and ongoing training and supervision. Some clinicians may not have received preservice training that prepared them for the implementation of a specific treatment protocol, or for specific components of an intervention, which would require additional in-service training. Corrective feedback, which is the observation of an implementer coupled with feedback, has been shown to be an effective and time-efficient method for in-service training opportunity to many implementers (Codding et al., 2005; Codding, Livanis, Pace, & Vaca, 2008; DiGennaro et al., 2005, 2007; DiGennaro-Reed, Codding, Catania, & MaGuire, 2010; Mortensen & Witt, 1998; Mouzakitis, 2010; Noell, Witt, Gilbertson, Ranier, & Freeland, 1997), thus improving implementer competence.

Competence also varies as a function of the level of communication between the treatment designers and implementers (Cowan & Sheridan, 2003). In many instances, especially when working with children, people other than the therapist may be called upon to deliver services. For example, parent implementation of key behavior procedures is a key component of treatment for children diagnosed with Attention Deficit Hyperactivity Disorder (Kazdin, 2015), and can greatly enhance and support the treatment of children diagnosed with developmental disorders as well (Skotarczak & Lee, 2015). Parent-based interventions are usually created or managed by the therapists, and training needs to factor in the use of psychological jargon, and use more practical and common sense terms to describe or define the intervention plan (Elliot, 1988; Witt, Moe, Gutkin, & Andrews, 1984).

### 16.2.3 Treatment Differentiation

Treatment differentiation refers to the extent that the treatment, intervention, or program that is implemented is "pure" and other treatments are not implemented in addition to or instead of the intervention (Perepletchikova & Kazdin, 2005). Differentiation is particularly important when two or more treatment programs are compared to one another in the research literature. Specifically, treatment protocols must be reliably distinguished from one another in order to ensure that potential differences in the dependent variable can be attributed to differences in the independent variable (Kazdin, 1986). Treatment differentiation can be effectively dealt with if operational definitions of the treatment has been well established. One must be cognizant of *therapist drift*, where implementers modify the treatment plan in minor ways over periods of time, which produces a significant shift in the independent variable over time, which can over- or underestimate treatment effects. Therapist drift is typically not intended but can happen due to decreased diligence, supervision, or boredom.

## 16.3 Associated Variables

There are factors that have been associated with difficulties in the maintenance of TI. The complexity of a treatment has been found to impact TI (Meichenbaum & Turk, 1987), and it is usually operationalized as the number of components or parts of an intervention. In general, more complex interventions are evaluated more negatively by potential treatment implementers (Yeaton & Sechrest, 1981) and are not implemented with integrity. Complexity may play a role when practitioners implement interventions across various settings (e.g., home, school, clinic) and with multiple implementers (e.g., parents, teacher, clinicians). Communication among all implementers is a critical dimension of complexity as is the varying degree of experience among the implementers (Gresham, 1996). For example, parents may experience certain procedures or components of interventions as difficult to manage over period of time in the home, which may cause them to stray away from the originally stated procedure (Allen & Warzak, 2000; Kazdin, 2015). This may be particularly evident when interventions target externalizing difficulties, such as explosive behaviors (Greene, 2001; Greene & Albon, 2006). In-service training could be provided to implementers who are not effectively trained. Usually these trainings involve a great deal of didactic instruction, which assumes that parents will develop adequate rules for program implementation based solely on instruction and follow them perfectly. However, this is an unrealistic assumption (Hayes & Wilson, 1993). It is for this reason that a fair amount of training programs for parents (and all treatment implementers) should include modelling, role-play, and rehearsal, both before they begin to implement the intervention and after the intervention has been in place for a while.

Time spent in the delivery of the intervention by treatment implementers may serve to obstruct treatment integrity. Interventions that are easy to learn tend to show better rates of TI (Gresham, 1996). Some interventions require ongoing supervision to maintain at effective levels, while some treatments need extended periods of administration (typically referred to as *dosage*) until an effect is witnessed, typically due to the severity of the targeted issues that are addressed (Happe, 1982). Interventions that require a great deal of materials or present major expenses to implementers (in time or finances) can also negatively impact treatment integrity (Gresham, 1996; Perepletchikova & Kazdin, 2005).

## 16.4 Measuring Treatment Integrity

### 16.4.1 Operational Definition of the Treatment and its Components

Psychological interventions for children are complex and include multiple components (Domitorvich et al., 2008). Therefore it will be often necessary for the practitioner to define her intervention vis-a-vis its components in order to ensure treatment integrity. A good operational definition should be clear and parsimonious and should include, when possible, exclusionary and inclusionary criteria (Cooper et al., 2007).

Ideally, an operational definition of a component should include four dimensions: verbal (descriptions of scripts to be presented at various times), physical (descriptions of what actions should be performed), spatial (the positioning of materials such as furniture and papers), and temporal (which actions should follow which environmental events in the program sequence). Referencing these four dimensions allows for an easy replication of the intervention, both in applied settings and in research studies. However, treatment integrity could potentially be affected by overspecifying treatments and its individual components as a treatment can be made to appear overly complex (Gresham, 1996).

### 16.4.2 Direct Assessment of Treatment Integrity

The direct assessment of TI is conducted in a similar fashion to traditional behavioral assessment—the presence or the absence of the operational definition documented over a period of time (Cooper et al., 2007), and often a final percentage is calculated to indicate how much integrity to the treatment the agent(s) has exhibited. Direct assessments can be conducted at the point of intervention (i.e., during the implementation of the treatment), at a later time possibly through video (Perepletchikova & Kazdin, 2005), or possibly via internet-based technologies.

The reliability of direct assessments of TI improves dramatically when multiple observations are conducted in single-case experiments (Kazdin, 2011). The literature generally suggests the need for multiple observational periods of sufficient length; however, there are debates as to the number and time frame of observations. Gresham (1996) suggests 20–30 min of three to five observational sessions. Leblanc, Ricciardi, and Luiselli (2005) and DiGennaro-Reed et al. (2010) observed treatment implementers for 10–15 min but Codding et al. (2005) observed treatment implementers for 55–60 min. There is also variability in the number of observations that are conducted as well, ranging from 3 sessions to 12 sessions (Codding et al., 2008; LeBlanc, Ricciardi, & Luiselli, 2005). Since most of these studies were conducted in non-laboratory settings, the variability was oftentimes a function of the conditions of the setting that the therapy was conducted. In controlled settings, the number of observation periods as well as the length of the average observation period seems to decrease, which may possibly be due to issues of increased agent competence as well as a heightened awareness and focus on treatment adherence (DiGennaro-Reed et al., 2010; LeBlanc et al., 2005).

An important consideration when TI is directly observed is that of observer reactivity, or the tendency for implementers to modify their behavior if they are aware that they are the subject of observation (Cooper et al., 2007; Foster & Cone, 1986; Gresham, 2014). However, there is some evidence to suggest that reactivity to the observer tends to dissipate as a function of time (Codding et al., 2008).

Most studies of TI focus on the assessment of treatment adherence (i.e., the implementation of the treatment as designed). Perepletchikova and Kazdin (2005) stress the importance of two other dimensions of treatment integrity that need to be assessed: agent competence and treatment differentiation. Measures of agent competence should assess the quality of the delivery, which include client or consumer comprehension of the purposes, goals, and procedures of the treatment, and the level of concordance between training and agent activities (Jones, Clark, & Power, 2008). Perepletchikova (2014) however warns that attempting to include client or consumer comprehension and/or appreciation may veer the assessment to include outcomes or possibly even measures of social validity (Cooper et al., 2007). Measures of treatment differentiation should focus on an assessment of procedures that are not prescribed, that are delivered in addition to or instead of the prescribed intervention (Perepletchikova & Kazdin, 2005).

### 16.4.3 Indirect Assessment of Treatment Integrity

Several authors have cautioned against the use of indirect assessments of TI, noting that at best, they can only supplement direct methods of assessment (Bergan & Kratochwill, 1990; Gresham, 1989). Indirect methods can include implementers' self-reports, an evaluation of permanent products which result from the treatment (e.g., client homework or worksheets jointly completed in therapy), rating scales, and self-monitoring (Perepletchikova & Kazdin, 2005). Self-monitoring has been found to be an effective assessment tool, as well as a method to help increase and improve treatment integrity (Burgio et al., 1990; Coyle & Cole, 2004; Petscher & Bailey, 2006; Richman, Riordan, Reiss, Piles, & Bailey, 1988). However, self-monitoring can be a laborious method of collecting data on TI—it requires that the agent stop the intervention, rate their own behavior, and then continue with the intervention. It may be extremely difficult to implement this moment-to-moment self-monitoring, even when interventions are being delivered in a 1:1 fashion (Gresham, 1996). Because of these concerns, it is possible that self-monitoring methods are not the most effective methods to collect data on adherence (Coyle & Cole, 2004; McLeod et al., 2009; Richman et al., 1988). There have been several recommendations suggested to make this process easier, specifically the addition of prompts (Petscher & Bailey, 2006) or visual representations of data (Burgio et al., 1990) to assess adherence.

Self-monitoring data create implementer awareness to of their own behaviors for better understanding and how it relates to treatment integrity; however, this avenue of research has not been extensively researched as of yet. Self-monitoring assessments and resulting data should be evaluated with caution due to a subtle demand characteristic that pulls for social approval and may cause treatment implementers to overreport treatment integrity (Perepletchikova & Kazdin, 2005).

### 16.4.4 Interpretation of Treatment Integrity Data

Measurements of treatment integrity are quantitative methods that identify how therapist drift affects the dependent variable (Gresham, 1996). Therapist drift, or low levels of treatment integrity, often calls into question whether or not the independent variable effected changes onto the dependent variable. Table 16.1 highlights some of the interpretative issues that can arise from differing levels of treatment integrity. Where there are high levels of TI, decisions regarding the effectiveness and efficacy of treatment can be made with the confidence that the treatment conditions that were specified were followed.

However, where there are conditions of low levels of TI (or none), the drift may actually serve to artificially improve outcomes, thus creating Type I error, a situation where the intervention is incorrectly deemed to be effective. To a large degree, most therapeutic interventions conducted with children or adults are the results of Type I errors: the therapist and the client may "feel good" about the "work" they have conducted, but in reality, there is no long-term benefit to the client.

Furthermore, low levels of treatment integrity in relation to no changes or undesired changes in the client could cause practitioners to conclude that the therapeutic intervention was not effective. While the authors agree that ineffective treatment procedures should clearly be suspended, in this instance, it is not clear whether the lack of client change was the function of an inappropriate intervention or an

**Table 16.1** Interpretative issues that can arise from effects of varying levels of treatment integrity on the dependent variable

| | Levels of integrity | |
|---|---|---|
| | *High* | *Low or none* |
| Outcome | | |
| Desired direction | Confidence that the treatment package has an effect | No confidence that the treatment package has any effect<br>Increased risk of making a Type I error (*False Positive*) if treatment integrity data are not collected |
| No change | Confidence that the treatment package has no effect | No confidence that the treatment package has any effect<br>Increased risk of making a Type II error (*False Negative*) if treatment integrity data are not collected |
| Undesired direction | Confidence that the treatment package has no effect and may even be potentially harmful | No confidence that the treatment package has any effect<br>Increased risk of making a Type II error (*False Negative*) if treatment integrity data are not collected |

inappropriately applied intervention. This is considered to be a Type II error, in which the therapist rejects an intervention that might actually be effective. A lack of TI in these conditions would hinder the identification of potentially effective treatments.

## 16.5 Methods to Increase Treatment Integrity

Performance feedback (PFB) is the most common reported method to increase TI (Codding et al., 2005, 2008; DiGennaro et al., 2005, 2007; DiGennaro-Reed et al., 2010; Mortensen & Witt, 1998; Mouzakitis, 2010; Noell et al., 1997). Performance feedback typically consists of a systematic method of delivering feedback to treatment implementers regarding their treatment adherence. Typically, this process includes a structured observation by someone other that the treatment implementer followed by a meeting (or some other means of communication) between the observer and the implementer where feedback regarding adherence is shared. A typical PFB observation session can last anywhere between 5 and 20 min (Reed & Codding, 2011), with initial PFB sessions lasting much longer than later sessions. Praise is typically delivered as a function of the amount of correctly implemented components, as well as aspects of a plan that were not followed or implemented correctly. Furthermore, training methods can be employed during PFB to ensure correct component implementation in the future.

PFB as a method can be used to address some of the threats to PFB. Specifically, the fluency or automaticity of treatment skills can be addressed with PFB. In other instances, the implementer may have forgotten components of the treatment which are important. PFB addresses these threats via the use of review, modelling, rehearsal, and role-play, if necessary.

While PFB has been demonstrated to increase TI, variations of the procedure have been examined in the literature. For example, Guercio et al. (2005) varied PFB private meetings with public postings of treatment integrity to train 30 staff members at a residential facility. Although the results of the study showed dramatic increases of integrity among all staff, it is unclear whether the private or public PFB was more successful. The delivery of PFB and the amount of time between the observation periods have also been investigated. Noell et al. (1997) delivered PFB immediately after observation, while Codding et al. (2005) delivered PFB every other week and others have examined varying lengths of time in between. PFB appears to work despite time delays, but ultimately more intense and steeper increases in treatment integrity were associated with shorter time lapses (Mortensen & Witt, 1998).

While PFB has been demonstrated to be effective method to increase treatment integrity, the removal of PFB demonstrates decreases in levels of treatment integrity (Noell et al., 1997; Witt, Noell, LaFleur, & Mortenson, 1997). The process of fading is recommended to work around this issue (DiGennaro et al., 2005; Noell et al., 2000; Reed & Codding, 2011). Fading refers to the gradual decrease in how often and how long PFB is delivered that is contingent upon the demonstration of treatment integrity at specified criterion levels. For example, if a treatment implementer received PFB once a day and she demonstrates TI rates of 90 % or better for three consecutive observation sessions, then the schedule might be *thinned* to once every other day.

There has been a fair amount of interest into conceptual systems that underlie the process of PFB (Noell & Gansle, 2014). An analysis of conceptual systems involves an evaluation of which principles underlie change processes when PFB is used effectively (Baer, Wolf, & Risley, 1968; Cooper et al., 2007). Ultimately, PFB may operate on different principles depending on contextual variables as well as observer and implementer characteristics. In many instances, the delivery of PFB may be experienced as a positive reinforcer (as it increases appropriate behaviors upon delivery; Codding et al., 2008). However, it is not so far-fetched to consider certain work conditions might make the delivery of PFB an aversive condition where treatment adherence behaviors are performed to remove the presence of the observer (DiGennaro et al., 2005). These discrepant experiences of PFB could be due to the setting (e.g., an inner city private school vs. a suburban mental health clinic), the person delivering PFB (e.g., a relaxed university faculty member vs. strict clinic supervisor), how PFB is used by the setting (e.g., as a teaching tool or as a way to evaluate staff dismissal), and perhaps even idiosyncratic characteristics of the individual delivering PFB.

Lastly, self-monitoring procedures have also been investigated to improve treatment integrity. Self-monitoring procedures would be enticing because it would decrease the reliance on other individuals observing and intervening with treatment implementers, thus saving time for staff and resources for the agency as a whole. Self-monitoring as an intervention to improve treatment integrity shows some good results (Coyle & Cole, 2004; Richman et al., 1988) and more rapid increases when paired with environmental prompts (Burgio et al., 1990; Petscher & Bailey, 2006); however, overall, these results do not approach the speed and total amount of improvement in treatment integrity that the PFB procedure offers.

## 16.6 Conclusion

The failure to engage in a process to consider evidence-based interventions can severely compromise the implementation of evidence-based interventions. A treatment designer must take time to evaluate if the intervention was implemented as was suggested in the literature so that she may rationally consider changes to treatment plans. Naturally, provisions are made with every intervention regarding the amount and quality of deviation that individual practitioners can apply, but core aspects of the intervention must be applied as was described initially in order to critically examine what should or should not be altered.

Such efforts impact not only the remediation or rehabilitation of psychological distress in clients, but also is a matter of public trust. If procedures are easily accessed through books or websites, and the psychological community fails to implement them correctly (and fails to show improvements in psychological functioning), then the public will lose their trust in our ability to effect positive change in behavioral and mental health outcomes.

## References

Allen, K. D., & Warzak, W. J. (2000). The problem of parental non-adherence in clinical behavior analysis: Effective treatment is not enough. *Journal of Applied Behavior Analysis, 33*(3), 373–391. doi:10.1901/jaba.2000.33-373.

American Psychological Association. (2005, August). *Policy statement on evidence-based practice in psychology.* Retrieved from http://www.apapracticecentral.org/ce/courses/ebpstatement.pdf

Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis, 1*(1), 91–97. doi:10.1901/jaba.1968.1-91.

Barber, J. P., Gallop, R., Crits-Chirstoph, P., Frank, A., Thase, M. E., Weiss, R. D., et al. (2006). The role of therapist adherence, therapist competence, and alliance in predicting outcome of individual drug counseling: Results from the National Institute Drug Abuse Collaborative Cocaine Treatment Study. *Psychotherapy Research, 16*, 229–240. doi:10.1080/10503300500288951.

Bergan, J. R., & Kratochwill, T. R. (1990). *Behavioral consultation and therapy*. New York: Plenum Press.

Burgio, L. D., Engel, B. T., Hawkins, A. M., McCormick, K., Schieve, A., & Jones, L. T. (1990). A staff management system for maintaining improvements in continence with elderly nursing home residents. *Journal of Applied Behavior Analysis, 23*, 111–118. doi:10.1901/jaba.1990.23-111.

Cochrane, W. S., & Laux, J. M. (2008). A survey investigating school psychologists' measurement of treatment integrity in school-based interventions and their beliefs in their importance. *Psychology in the Schools, 45*, 499–507. doi:10.1002/pits.20319.

Codding, R. S., Feinberg, A. B., Dunn, E. K., & Pace, G. M. (2005). Effects of immediate performance feedback on implementation of behavior support plans. *Journal of Applied Behavior Analysis, 38*, 205–219. doi:10.1901/jaba.2005.98-04.

Codding, R. S., Livanis, A., Pace, G., & Vaca, L. (2008). Using performance feedback to improve treatment integrity of classwide behavior plans: An investigation of observer reactivity. *Journal of Applied Behavior Analysis, 41*, 417–422. doi:10.1901/jaba.2008.41-417.

Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behavior analysis* (2nd ed.). Upper Saddle River, NJ: Merrill Prentice Hall.

Cowan, R. J., & Sheridan, S. M. (2003). Investigating the acceptability of behavioral interventions in applied conjoint behavioral consultation: Moving from analog conditions to naturalistic settings. *School Psychology Quarterly, 18*(1), 1–21.

Coyle, C., & Cole, P. (2004). A video-taped self-modeling and self-monitoring treatment program to decrease off-task behaviour in children with autism. *Journal of Intellectual and Developmental Disability, 29*, 3–15. doi:10.1080/08927020410001662642.

DiGennaro, F. D., Martens, B. K., & Kleinman, A. E. (2007). A comparison of performance feedback procedures on teachers' treatment implementation integrity and students' inappropriate behavior in special education classrooms. *Journal of Applied Behavior Analysis, 40*, 447–461. doi:10.1901/jaba.2007.40-447.

DiGennaro, F. D., Martens, B. K., & McIntyre, L. L. (2005). Increasing treatment integrity through negative reinforcement: Effects on teacher and student behavior. *School Psychology Review, 34*(2), 220–231.

DiGennaro-Reed, F. D., Codding, R., Catania, C. N., & MaGuire, H. (2010). Effects of video modeling on treatment integrity of behavioral interventions. *Journal of Applied Behavior Analysis, 43*, 291–295. doi:10.1901/jaba.2010.43-291.

Domitorvich, C. E., Bradshaw, C. P., Poduska, J. M., Hoagwood, K., Buckley, J. A., Olin, S., et al. (2008). Maximizing the implementation quality of evidence-based preventive interventions in schools: A conceptual framework. *Advances in School Mental Health Promotion, 1*(3), 6–28. doi:10.1080/1754730X.2008.9715730.

Dusenbury, L., Brannigan, R., Falco, M., & Hansen, W. B. (2003). A review of research on fidelity of implementation: Implications for drug abuse prevention in school settings. *Health Education Research: Theory and Practice, 18*(2), 237–256. doi:10.1093/her/18.2.237.

Elliot, S. N. (1988). Acceptability of behavioral treatments in educational settings. In J. C. Witt, S. N. Elliott, & F. M. Gresham (Eds.), *Handbook of behavior therapy* (pp. 121–150). New York: Plenum Press.

Erhardt, K. E., Barnett, D. W., Lentz, F. E., Stollar, S. A., & Raifin, L. H. (1996). Innovative methodology in ecological consultation: Use of scripts to promote treatment acceptability and integrity. *School Psychology Quarterly, 11*, 149–168. doi:10.1037/h0088926.

Foster, S., & Cone, J. (1986). Design and use of direct observation. In A. Ciminero, K. Calhoun, & H. Adams (Eds.), *Handbook of behavioral assessment* (2nd ed., pp. 253–324). New York: Wiley Interscience.

Foxx, R. M. (1996). Twenty years of applied behavior analysis in treating the most severe problem behavior: Lessons learned. *The Behavior Analyst, 19*(2), 225–235.

Greene, R. W. (2001). *The explosive child: A new approach for understanding and parenting easily frustrated, chronically inflexible children*. New York: Perennial.

Greene, R. W., & Albon, J. S. (2006). *Treating explosive kids: The collaborative problem solving approach*. New York: Guilford Press.

Gresham, F. M. (1989). Assessment of treatment integrity in school consultation and prereferral intervention. *School Psychology Review, 18*, 37–50.

Gresham, F. M. (1996). Treatment integrity in single-subject research. In R. D. Franklin, D. B. Allison, & B. S. Gorman (Eds.), *Design and analysis of single-case research* (pp. 93–117). Mahwah, NJ: Lawrence Erlbaum Associates.

Gresham, F. M. (2014). Measuring and analyzing treatment integrity data in research. In L. M. Sanetti & T. R. Kratochwill (Eds.), *Treatment integrity: A foundation for evidence based practice in applied psychology*. Washington, DC: American Psychological Association.

Guercio, J. M., Dixon, M. R., Soldner, J., Shoemaker, Z., Zlomke, K., Root, S., et al. (2005). Enhancing staff performance measures in an acquired brain injury setting: Combating the habituation to organizational behavioral interventions. *Behavioral Interventions, 20*, 91–99. doi:10.1002/bin.174.

Happe, D. (1982). Behavior intervention: It doesn't do any good in your briefcase. In J. Grimes (Ed.), *Psychological approaches to problems of children and adolescents* (pp. 15–41). Des Moines, IA: Iowa Department of Public Instruction.

Hayes, S. C., & Wilson, K. G. (1993). Some applied implications of a contemporary behavior-analytic account of verbal events. *The Behavior Analyst, 16*(2), 283–301.

Hogue, A., Henderson, C. E., Dauber, S., Barajas, P. C., Fried, A., & Liddle, H. A. (2008). Treatment adherence, competence, and outcome in individual and family therapy for adolescent behavior problems. *Journal of Consulting and Clinical Psychology, 76*(4), 544–555. doi:10.1037/0022-006X.76.4.544.

Jones, H. A., Clark, A. T., & Power, T. J. (2008). Expanding the concept of intervention integrity: A multidimensional model of participant engagement. *Balance, 23*(1), 4–5.

Kazdin, A. E. (1986). Comparative outcome studies of psychotherapy: Methodological issues and strategies. *Journal of Consulting and Clinical Psychology, 54*, 95–105. doi:10.1037/0022-006X.54.1.95.

Kazdin, A. E. (2011). *Single-case research designs*. New York: Oxford University Press.

Kazdin, A. E. (2015). Clinical dysfunction and psychosocial interventions: The interplay of research, methods, and conceptualization of challenges. *Annual Review of Clinical Psychology, 11*, 25–52.

LeBlanc, M., Ricciardi, J. N., & Luiselli, J. K. (2005). Improving discrete trial instruction by paraprofessional staff through an abbreviated performance feedback intervention. *Education and Treatment of Children, 28*(1), 76–82.

Livanis, A., Benvenuto, S., Mertturk, A., & Hanthorn, C. A. (2013). Treatment integrity in autism spectrum disorder interventions. In S. Goldstein & J. A. Naglieri (Eds.), *Interventions for autism spectrum disorders: Translating science into practice* (pp. 19–37). New York: Springer.

Livanis, A., & Mercer, S. H. (in press). The effects of graduated treatment introduction and performance feedback on treatment integrity for complex behavior intervention plans. Unpublished manuscript.

McIntyre, L. L., Gresham, F. M., DiGennaro, F. D., & Reed, D. D. (2007). Treatment integrity of school-based interventions with children in the journal of applied behavior analysis 1991–2005. *Journal of Applied Behavior Analysis, 40*(4), 659–672.

McLeod, B. D., Southam-Gerow, M. A., & Weisz, J. R. (2009). Conceptual and methodological issues in treatment integrity measurement. *School Psychology Review, 38*(4), 541–546.

Meichenbaum, D., & Turk, D. C. (1987). *Facilitating treatment adherence: A practitioner's guidebook*. New York: Plenum Press.

Mortensen, B. P., & Witt, J. C. (1998). The use of weekly performance feedback to increase teacher implementation of a prereferral intervention. *School Psychology Review, 27*, 613–627.

Mouzakitis, A. (2010). *The effects of self-monitoring training and performance feedback on the treatment integrity of behavior support plans for children with autism*. Unpublished doctoral dissertation, The Graduate Center of the City University of New York, New York.

National Association of School Psychologists. (2010a). *Principles for professional ethics.* Retrieved from http://www.nasponline.org/standards/2010standards/1_%20Ethical%20Principles.pdf

National Association of School Psychologists. (2010b). *Model for comprehensive and integrated school psychological services.* Retrieved from http://www.nasponline.org/standards/2010standards/2_PracticeModel.pdf

Nezu, A. M., & Nezu, C. M. (2008). Treatment integrity. In D. McKay (Ed.), *Handbook of research methods in abnormal and clinical psychology* (pp. 351–363). New York: Sage.

Noell, G. H., & Gansle, K. A. (2014). The use of performance feedback to improve intervention implementation in schools. In L. M. Sanetti & T. R. Kratochwill (Eds.), *Treatment integrity: A foundation for evidence-based practice in applied psychology*. Washington, DC: American Psychological Association.

Noell, G. H., Witt, J. C., Gilbertson, D. N., Ranier, D. D., & Freeland, J. T. (1997). Increasing teacher interventions implementation in general education settings through consultation and performance feedback. *School Psychology Quarterly, 12*, 77–88.

Noell, G. H., Witt, J. C., LaFleur, L. H., Mortenson, B. P., Ranier, D. D., & LeVelle, J. (2000). Increasing intervention implementation in general education following consultation: A comparison of two follow-up strategies. *Journal of Applied Behavior Analysis, 33*, 271–284. doi:10.1901/jaba.2000.33-271.

Perepletchikova, F. (2014). Assessment of treatment integrity in psychotherapy research. In L. M. Sanetti & T. R. Kratochwill (Eds.), *Treatment integrity: A foundation for evidence based practice in applied psychology*. Washington, DC: American Psychological Association.

Perepletchikova, F., & Kazdin, A. E. (2005). Treatment integrity and therapeutic change: Issues and research recommendations. *Clinical Psychology: Science and Practice, 12*(4), 365–383. doi:10.1093/clipsy/bpi045.

Petscher, E. S., & Bailey, J. S. (2006). Effects of training, prompting and self-monitoring on staff behavior in a classroom for students with disabilities. *Journal of Applied Behavior Analysis, 39*, 215–226. doi:10.1901/jaba.2006.02-05.

Reed, F. D., & Codding, R. S. (2011). Intervention integrity assessment. In J. K. Luiselli (Ed.), *Teaching and behavior support for children and adults with autism spectrum disorder* (pp. 38–47). New York: Oxford University Press.

Reichow, B., & Volkmar, F. R. (2011). Evidence-based practices in autism: Where we started. In B. Reichow, P. Doehring, D. V. Cicchetti, & F. R. Volkmar (Eds.), *Evidence-based practices and treatments for children with autism* (pp. 3–24). New York: Springer.

Richman, G. S., Riordan, M. R., Reiss, M. L., Piles, D. A. M., & Bailey, J. S. (1988). The effects of self-monitoring and supervisor feedback on staff performance in a residential setting. *Journal of Applied Behavior Analysis, 21*, 401–409. doi:10.1901/jaba.1988.21-401.

Sanetti, L. M., & Kratochwill, T. R. (2014). Introduction: Treatment integrity in psychological research and practice. In L. M. Sanetti & T. R. Kratochwill (Eds.), *Treatment integrity: A foundation for evidence-based practice in applied psychology*. Washington, DC: American Psychological Association.

Schulte, A. C., Easton, J. E., & Parker, J. (2009). Advances in treatment integrity research: Multidisciplinary perspectives on the conceptualization, measurement, and enhancement of treatment integrity. *School Psychology Review, 38*(4), 460–475.

Skotarczak, L., & Lee, G. K. (2015). Effects of parent management training programs on disruptive behavior for children with a developmental disability: A meta-analysis. *Research in Developmental Disabilities, 38*, 272–287.

Wheeler, J. J., Baggett, B. A., Fox, J., & Blevins, L. (2006). Treatment integrity: A review of intervention studies conducted with children with autism. *Focus on Autism and Other Developmental Disabilities, 21*(1), 45–54. doi:10.1177/10883576060210010601.

Witt, J. C., Moe, G., Gutkin, T. B., & Andrews, L. (1984). The effect of saying the same thing in different ways: The problem of language and jargon in school-based consultation. *Journal of School Psychology, 22*, 361–367. doi:10.1016/0022-4405(84)90023-2.

Witt, J. C., Noell, G. H., LaFleur, L. H., & Mortenson, B. P. (1997). Teacher use of interventions in general education: Measurement and analysis of the independent variable. *Journal of Applied Behavior Analysis, 30*, 693–696. doi:10.1901/jaba.1997.30-693.

Yeaton, W. H., & Sechrest, L. (1981). Critical dimensions in the choice and maintenance of successful treatments: Strength, integrity, and effectiveness. Journal of Consulting and Clinical Psychology, 49(2), 156.

# Conclusions

# 17

Sam Goldstein

Functional impairment is a key factor of clinical importance of not only mental health problems but overall quality of life in our society. As this second edition volume can attest, the nature of and variables contributing to impairment and the criteria for defining and evaluating impairment are still in its infancy. It is now understood and appreciated that diagnoses and their accompanying level of symptom severity contributes to but falls far short of painting a complete picture of impairment within a specific individual. In 2011, the DSM-5 Impairment and Disability Assessment Study Group suggested that the symptoms of a disorder be very clearly separated from their consequences (Gold, 2014). This recommendation has already been implemented by the International Classification of Disease through its publication in 2007 of the International Classification of Functioning, Disability and Health (Stucki, Cieza, & Melvin, 2007). This framework was designed to provide a comprehensive means of classifying the functional effects of diseases (Lollar, 2008).

Rapee, Bogels, van der Sluis, Craske, and Ollendick (2012) acknowledge the often variable and interchangeable use of terminology for disability such as distress, impairment, and quality of life. The authors point out that quality of life is a global, subjective construct extending well beyond distress or impairment. They point out that each of these three constructs represents slightly different aspects of the possible effects of symptoms or other life stresses.

In 2006, the National Institute of Disability and Rehabilitation reported a prevalence of disability in the United States for persons 5 years and older as 15 % (Disability Status Report, 2006). Disability was reported to be greater among females, lower in Asians, and higher in African-Americans and Native Americans than Caucasians. Disability in this survey was based on the following definition:

---

S. Goldstein, Ph.D. (✉)
Neurology, Learning and Behavior Center, 230 South 500 East, Suite 100,
Salt Lake City, UT 84102, USA
e-mail: info@samgoldstein.com

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4_17

> "*Disability and Disability Types*: The ACS definition of disability is based on three questions. (1) Does this person have any of the following long-lasting conditions: (a) blindness, deafness, or a severe vision or hearing impairment? [Sensory Disability]; (b) a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying? [Physical Disability] (2) Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have difficulty in doing any of the following activities: (a) learning, remembering, or concentrating? [Mental Disability]; (b) dressing, bathing, or getting around inside the home? [Self-Care Disability] (3) Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: (a) going outside the home alone to shop or visit a doctor's office? [Go Outside-Home Disability]; (b) working at a job or business? [Employment Disability]. A person is coded as having a disability if he or she or a proxy respondent answers affirmatively for one or more of these six categories" (Disability Status Report 2006, p. 42).

A recent study completed by the Center for Disease Control (Courtney-Long et al., 2015) found that 22.2 % of US adults alone (over 53 million people) reported any disability. Disability and mobility was the most frequent reported type at 13 %, followed by disability and cognition (10.6 %), independent living (6.5 %), vision (4.6 %), and self-care (3.6 %). As definitions of disability and impairment are better refined and research methods broadened, a better appreciation of impairment in the population has emerged over the past 10 years. Understanding the prevalence and incidence of disability and impairment continues to be critically important for public health programs to address the needs of a large percentage of the population. In this survey, a higher prevalence of any disability was seen among adults living in states in the south and among women (24.4 %) compared with men (19.8 %). Prevalence of any disability and disability in mobility were higher among older age groups. This study represented the first data on functional disability types available in a state-based health survey.

Disability and impairment in everyday functioning very clearly go hand-in-hand. Based upon this study in 2013, approximately one in five US adults reported any disability. These findings are consistent with earlier reports. Previous research has found that lower educational levels among adults with a disability compared with those without were also noted. In this study, approximately 40 % of those who did not complete high school reported a disability. The need to appreciate, understand, and define disability and functional impairment continues to increase. Census Bureau data from 2010 demonstrated that the seniors were increasing faster than younger populations, raising the nations median age from 35.3 in 2007 to 37.2 in 2010 with seven states having a median age of 40 or older. In the year, people 65 years or older represents 12.4 % of the population, a number expected to swell to 19 % of the population by 2030. Between 2000 and 2010, the 45 to 64-year-old population grew 31.5 % to 81.5 million and now makes up 26.4 % of the total US population. This rapid growth is in part due to aging of the baby boomer generation (Ortman, Velkoff, & Hogan, 2014). Despite these advances, it still remains the case that the primary survey of disability in the United States continues to not only fail to make a clear distinction between disability and impairment but also imply that disability is determined on the one hand by impairment (e.g., employment disability) and on the other hand by physical conditions (e.g., sensory disability). These large surveys still fail to take into account the emerging body of research that has been well documented in this volume demonstrated that equal disabilities do not lead to equal impairments in all individuals. In doing so, the broader fields of medical, mental health, and education remain shackled by antiquated ideas, unsupported by current literature.

As the authors of this second edition volume have amply demonstrated, impairment and ultimately quality of life are predicted by a set of biopsychosocial variables that likely have a unique impact on each individual. The central scientific challenge facing researchers and clinicians today is not only to develop an understanding and appreciation of impairment but also to create a workable system to assess risk in the face of disability, evaluate impairment in a reasoned and reasonable way and most importantly, intervene successfully to reduce impairment in disabled and nondisabled individuals. In doing so, quality of life is improved for everyone.

As multiple authors in this volume have demonstrated, the absence of pathology or diagnosis does not necessarily equate with psychological and physical wellness or the absence of impairment. This concept continues to represent a challenge that will have to be addressed in both research and clinical settings. Medical and mental health professionals have been trained to collect data through a variety of means to measure symptoms. Such symptoms have been equated with poor adaptation and adequate adjustment, distress, and life problems. Emphasis on the negative equates with the perception that symptom relief will ultimately lead to positive long-term outcome. However, the accepted nosology of all of these systems is a model that reflects assessment of symptoms and severity packaged into what at this point are weekly factor analyzed frameworks. Still unavailable, however, is a nosology and system to measure adaptation, stress hardiness, and the qualities necessary to deal successfully with and overcome adversity, the very qualities needed to live life free of impairment. Yet, in clinical practice, it is increasingly recognized that these phenomena, rather than relief of symptoms or the absence of certain risk factors, best predict adaptation, stress hardiness, positive adjustment, and freedom from impairment.

To move forward, we must expand beyond symptom-driven treatment interventions toward the development of a consensus set of definition, model, and applied theories. We must accurately define disability, disorder, diagnosis, impairment, and a host of other terms often used interchangeably. We must direct an increased focus on the ways of developing an understanding of those resilience factors within individuals as well as within the immediate and extended environment capable of not only insulating and preventing clinical and medical disorders but also reducing impairment in the face of such conditions. Understanding resilience is as important as developing "an understanding of the mechanisms and processes defining the etiological path by which disorders evolve and a theory of the solution, conceptual and empirically supported or supportable intervention that alters these mechanisms and processes in ways that normalize the underlying developmental trajectory" (Cowen, 1994, p. 172). As Werner and Smith (1992) pointed out, "beating the odds" is an obtainable goal. Such a goal must comprise a "science of prevention" (Coie et al., 1993) as well as scientifically demonstrated interventions to reduce impairment in those with disabilities and disorders. The concept of resilience as a process to reduce impairment in the face of adversity is fairly straightforward if one accepts the possibility of developing an understanding of the means by which members of our species thrive emotionally, behaviorally, academically, vocationally, and interpersonally in the face of risk and adversity or not. Such a model offers valuable insight into those qualities that likely insulate and protect in the face of wide and varied types of adversities. Although as noted, a focus on symptoms and symptom relief (assessing risk alone) may be satisfactory for identifying immediate needs, diagnoses, and disabilities within a pathology model. Such data, though necessary, are not sufficient to improve future functioning and reduce impairment. It has been well documented that not all individuals facing significant risk and adversity develop serious life problems. Risk factors also do not appear to be specific to particular outcomes but related more to broad developmental phenomena. It is likely that there is a complex, multidimensional interaction among risk factors, biological functioning, environmental issues, and protective factors that ultimately combine to predict an individual's level of impairment in the face of adversity. Within this framework, resilience can be defined as individual's achievement of positive outcomes and avoidance of maladaptive outcomes under adverse conditions.

In 1983, over 30 years ago, Bronfenbrenner and Crouter described a functional model that could very well lend itself today to building a foundation for a clinical psychology of impairment. This model contained four domains of influence: the acute stressor or challenge, the environmental context, the individual's characteristics, and the outcomes required. Although these authors were unable to address the exact mechanisms by which stressors or challenges interacted, such a model provides an interesting and workable foundation to begin addressing and applying the resilience theory to the concept of impairment measurement and reduction.

Finally, Werner and Johnson (1999) well demonstrated that protective factors include dispositional attributes of the individual, the individual's daily interactions with family and friends, and finally the broader support offered by the individual community. Such protective factors "moderate against the effects of a stressful or stress situation but the individual is able to adapt more successfully than they would have had the protective factors not been present" (Conrad & Hammen, 1993, p. 594). The concept of resilience has not traditionally encompassed the potential of individuals to survive risks should they arrive. Defining risks and protective factors relative to impairment is, as the authors of this second edition volume have demonstrated, not a simple process. These variables are likely broad in their presentation and impact on a specific individual. Reducing impairment must be conceptualized within a framework that defines and understands the multiple pathways by which outcome, good or bad, is achieved.

In this second edition volume, we have attempted with our coauthors to continue the discussion of many of the critical questions relative to impairment. As this second edition text goes to press, it remains the case that impairment secondary to medical, educational, and mental health disabilities and adversities represents a diverse and important set of myriad challenges facing our society. It is still the case that a significant percentage of the variance contributing to impairment is neither well understood nor defined. An increasing number of our citizens across the life span face lives influenced by medical, educational, and mental health disabilities leading to lives of pain, suffering, and adversity. In this second edition volume, we have continued our journey to appreciate that within the broader context of prevention we can and must develop a system to address impairment in the presence of adversity. Such a process will lead to a proactive, primary prevention model. Such a process, as Weisberg et al. (2003) noted, “Is a sound investment in society’s future” (p. 425).

## References

Bronfenbrenner, U., & Crouter, A. C. (1983). The evolution of environmental models in developmental research. In P. H. Mussen (Ed.), *Handbook of child psychology* (4th ed.). New York, NY: Wiley.

Coie, J. D., Watt, N. F., West, S. G., Hawkins, J. D., Asaranow, J. R., Markman, H. J., et al. (1993). The science of prevention: A conceptual framework and some directions for a national research program. *American Psychologist, 48*, 1013–1022.

Conrad, M., & Hammen, C. (1993). Protective and resource factors in high- and low-risk children: A comparison of children with unipolar, bipolar, medically ill, and normal mothers. *Developmental and Psychopathology, 5*, 593–607.

Courtney-Long, E. A., Carroll, D. D., Zhang, Q. C., Stevens, A. C., Griffin-Blake, S., Armour, B. S., et al. (2015). Prevalence of disability and disability types among adults—United States, 2013. *Morbidity and Mortality Weekly Report, 64*(29), 777–783.

Cowen, E. L. (1994). The enhancement of psychological wellness: Challenges and opportunities. *American Journal of Community Psychology, 22*, 149–179.

Disability Status Report. (2006). United States, Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics, U.S. Department of Education, National Institute of Disability and Rehabilitation. Research #H1338031111.

Gold, L. H. (2014). DSM-5 and the assessment of functioning: The World Health Organization Disability Assessment Schedule 2.0. *Journal of the American Academy of Psychiatry Law, 42*, 173–181.

Lollar, D. J. (2008). Function impairment and long term outcomes in children with ADHD and how to measure them. *Psychiatric Annals, 38*, 15–33.

Ortman, J. M., Velkoff, V. A., & Hogan, H. (2014). *An aging nation: The older population in the United States*. U.S. Department of Commerce, Economics and Statistic Administration, U.S. Census Bureau.

Rapee, R. M., Bogels, S. M., van der Sluis, C. M., Craske, M. G., & Ollendick, T. (2012). Annual research review: Conceptualising functional impairment in children and adolescents. *Journal of Child Psychology and Psychiatry, 53*(5), 454–468.

Stucki, G., Cieza, A., & Melvin, J. (2007). The International Classification of Functioning, Disability and Health (ICF): A unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine, 39*(4), 279–285.

Am Psychol. 2003 Jun-Jul;58(6-7):466-74.Enhancing school-based prevention and youth development through coordinated social, emotional, and academic learning.Greenberg MT, Weissberg RP, O’Brien MU, Zins JE, Fredericks L, Resnik H, Elias MJ.

Werner, E. E., & Johnson, J. L. (1999). Can we apply resilience? In M. D. Glantz & J. L. Johnson (Eds.), *Resilience in development: Positive life adaptations* (pp. 259–268). New York, NY: Kluwer/Academic/Plenum.

Werner, E. E., & Smith, R. S. (1992). *Overcoming the odds: High risk children from birth to adulthood*. Ithaca, NY: Cornell University Press.

# Index

S. Goldstein, J.A. Naglieri (eds.), *Assessing Impairment*,
DOI 10.1007/978-1-4899-7996-4