

We are glad to share this article which appeared in the January/February 2017 issue of the NADD Bulletin.

An Introduction to Recently Published NADD Press Books

Edward Seliger, M.A., Project Coordinator, NADD

For a small publishing house such as the NADD Press, the output we have seen over the past year and a half as well as the variety of topics and approaches to the material has been astonishing. Over this period of time, we have published our first book for Direct Support Professionals by a DSP, a comprehensive manual on dual diagnosis using a train-the-trainer model, an examination of systems, regulations and fiscal impacts on supports and services to individuals with a dual diagnosis and their families, a look at some common

and some lesser known syndromes that are associated with persons with developmental disabilities and coexisting mental or behavioral challenges, a manual for caregivers of people with intellectual disability and behavioral issues, an investigation into deinstitutionalization and the impact it has had on the lives of persons with intellectual disabilities and their families, and the long-awaited revision of the DM-ID. This article will share an introduction to this remarkable output.

Mental Health Approaches to Intellectual/Developmental Disability: A Resource for Trainers

Robert J. Fletcher, Daniel Baker, Juanita St Croix, and Melissa Cheplic have provided a comprehensive training manual, using a train-the-trainer model, in *Mental Health Approaches to Intellectual/Developmental Disability: A Resource for Trainers*. The book is arranged in ten modules:

Module I: What Is a Dual Diagnosis?

Module II: Building on the Basics: Understanding Assessment Practices in Dual Diagnosis

Module III: Mental Health Evaluations: Mental Status Examinations (MSE)

Module IV: Signs and Symptoms of Mental Illness of Mental Illness

Module V: From DM-ID to DM-ID-2

Module VI: Support Strategies

Module VII: Adapting Therapy for People with IDD

Module VIII: Childhood and Adolescence

Module IX: Aging

Module X: Inter-Systems Collaboration

Learning objectives are identified for each module. Within the module, materials are presented in Microsoft PowerPoint, with slides and Speaker's Notes. The book comes with a flash drive containing the PowerPoint slides for use in training on this material. The book is designed for use in a variety of ways: for trainers to train others for professional development; for individual study; and as a reference guide.

A workbook intended to be used by participants in trainings is also available. *Trainee Workbook for Mental Health Approaches to Intellectual/Developmental Disability* contains the slides (without Speaker's Notes) and space for the participant to write his or her own notes. The workbook contains pre-and post-tests for each module to measure and assist in learning.

Since its publication, Robert Fletcher, NADD Founder and CEO and one of the book's authors, has provided several multi-day trainings across the country using *Mental Health Approaches to Intellectual/Developmental Disability: A Resource for Trainers* as the basis of the training.

The Way of the Support Worker

Kevin Alexander shows a great deal of fondness for the individuals he provides support to, as he shares lessons he has learned over the twenty years he has worked as a Direct Support Professional. *The Way of the Support Worker* is less a how-to manual about providing support than a look at building a strong and healthy community,

and relationship with the people to whom support is provided. "I have learned such lessons as tolerance, patience, understanding, and sense of community from my time as a support worker," Mr. Alexander writes. "I have a depth of understanding of such topics that I do not believe I could have gained from anyone else other than the people that I support every day."

He writes of the importance of humility and gratitude, of building community, of respecting and listening to the individual who is receiving support. He writes of the power of setting a clear intention. He highlights the value of giving everyone the opportunity to create the life of his or her dreams regardless of perceived ability.

A whole chapter is devoted to "survival tips." In a profession with high rates of turnover and burnout, Mr. Alexander emphasizes the importance of taking care of yourself so that you are able to take care of someone else. He offers tips on relaxation and when to seek professional help.

Demystifying Syndromes II: Clinical and Educational Implications of Common Syndromes Associated with Persons with Intellectual Disability

Edited by Shelley L. Watson and Dorothy Griffiths, *Demystifying Syndromes II* is a revision and updating of the 2004 *Demystifying Syndromes*. The book is intended to provide a holistic understanding of the biopsychosocial implications of various syndromes for the lives of individuals with developmental disabilities. The audience for this book is (1) current professionals working in the field; (2) community college or university students who are studying developmental disabilities; and (3) parents, family members, and/or other interested persons who wish to learn more about this area. There are separate chapters about each of the following syndromes.

- Fragile X Syndrome
- Down Syndrome
- Williams Syndrome
- Smith-Magenis Syndrome
- Autism Spectrum Disorder
- 22 Q Deletion Syndrome
- Angelman Syndrome
- Smith-Lemli-Opitz Syndrome

The chapters examine characteristics of the syndrome, physical findings and medical issues, biomedical features, genetics, development, psychological features, cognitive effects, and behavioral phenotype. Resources are provided to assist the reader to explore the syndromes further. For each syndrome, there is a table (in both the introductory chapter and the appendix) which

lists physical characteristics, behavioral characteristics, common medical vulnerabilities and strategies, and cognitive and language strengths, weaknesses, and strategies.

A new chapter, “When Syndromes Demystify: Family and Professional Perspectives,” has been added in this edition to provide the reader with the perspectives of family and various professionals as to why syndrome identification is important. This concluding chapter features the words of family members, speaking to why syndromic identification was important to their family.

A Difficult Dream: Ending Institutionalization for Persons with Intellectual Disabilities with Complex Needs

While deinstitutionalization for individuals who were considered “community ready” or “easy to place” in the community began in the 1970s, for individuals with complex needs including medical, physical, and/or mental health/behavioral challenges the opportunity to live in the community has been much more restricted. *A Difficult Dream: Ending Institutionalization for Persons with Intellectual Disabilities with Complex Needs*, edited by Dorothy M. Griffiths, Frances Owen, and Rosemary A. Condillac, looks at the challenges involved in deinstitutionalizing this most challenging population.

The book is divided into three parts, (1) History: Deinstitutionalization, (2) Research Studies on the Facilities Initiative in Ontario: The End of an Era, and (3) Applying Strategies for Success for Individuals with Intellectual Disabilities and Complex Needs. In the history section, a general background of institutionalization is provided, followed by discussion of the impact of deinstitutionalization on the lives of individuals with an intellectual disability and complex needs. Critiques and concerns are discussed. Emerging changes in the deinstitutionalization process are reviewed, as well as attitudes, experiences, and impacts on families during and after deinstitutionalization. The research section focuses on the experience in Ontario, Canada of closing the last three government-operated institutions for persons with intellectual disabilities, and the end of a 35-year process of phasing out institutionalization in Ontario. Research evaluates this process, including impact on agencies and family. The practice section focuses on transitional planning, principles of transitional planning, special considerations for communication when planning transitions, gathering and integrating transitional planning information, and developing an

integrated transition plan to address complex needs. Best practice guidelines for transition of individuals with intellectual disabilities and behavioral/mental health needs are discussed.

What’s Going On? How to Tell When They Can’t Tell You. A Manual for Caregivers of People with Intellectual Disability and Behavioral Issues

What’s Going On?, by Marie Hartwell-Walker, is an ambitious book. It provides a holistic, multi-modal approach for analyzing why an individual with intellectual disability is in distress and what can be done about it. In looking at the whole person, the workbook recognizes that the cause of troublesome behaviors may lie within the individual’s body (syndromes, seizures, medical issues, mental illness) or outside the individual’s body (attitudes of others, environmental issues, and life challenges). Dr. Hartwell-Walker offers a handy, although unpronounceable mnemonic to insure that all possible causes of the behavior are considered: S.S.-MMMEFSAP (“envision yourself on a big ship navigating through a sea of data”).

S – List the **S**ymptoms

S – Identify **S**trengths

M – **M**ap the system

M – Rule out **M**edical issues

M – Rule out **M**edication issues

E – Check for **E**nvironmental changes or issues

F – Check for a **F**unctional cause

S – Check for **S**ubstance use, misuse or abuse

A – Rule out **A**buse/neglect

P – Check for **P**sychiatric issues

There is a lot of content in this manual. In Part I, “Analysis: Understanding Challenging Behavior,” there is a chapter on each of the above considerations. The Symptoms chapter includes sections on observation of behavior, syndromes, challenging behaviors: aggression, property destruction and self-injurious behavior, and factitious disorders and somatic symptom disorders. The Medical Issues chapter includes sections on seizure disorders, sleep disorders, eating disorders, and elimination disorders. A chapter on Common Clinical Diagnoses has sections on bereavement, anxiety disorders, trauma and stress-related disorders, paraphilias, dissociative disorders, obsessive compulsive disorder, affective (mood) disorders, attention deficit hyperactivity disorder, impulse control disorders, intermittent explosive disorder, oppositional defiant disorder, conduct disorder, pyromania, kleptomania, schizophrenia and other psychotic disorder.

ders, dementia, autism spectrum disorders, and personality disorders. The manual is full of case examples, and as Dr. Hartwell-Walker introduces each new area for consideration, she asks the learner to speculate on what might be going on and then provides possible answers. Part II provides a “Toolbox of Interventions,” and Part III addresses “Treatment Planning.”

Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID-2)

Improved outcomes for individuals with co-occurring intellectual/developmental disability and mental illness depend upon effective psychiatric treatment. Effective treatment requires an accurate psychiatric diagnosis. Obtaining that accurate psychiatric diagnosis for individuals with IDD has been, and remains, very challenging, especially for individuals with limited receptive and expressive language. This book was written to address this challenge.

More than 100 experts from around the world, under the leadership of editors Robert J. Fletcher, Jarrett Barnhill, and Sally-Ann Cooper, have now adapted the DSM-5 for use with individuals who have IDD. The DM-ID-2 was developed to facilitate an accurate psychiatric diagnosis in persons who have intellectual disabilities and to provide a thorough discussion of the issues involved in reaching an accurate diagnosis.

The DM-ID-2 provides state-of-the-art information concerning mental disorders in persons with intellectual disabilities. Grounded in evidence based methods and supported by the expert-consensus model, DM-ID-2 offers a broad examination of the issues involved in applying diagnostic criteria for psychiatric disorders to persons with intellectual disabilities.

Chapters in the *DM-ID-2* cover special issues (i.e., assessment and diagnostic procedures and presentations of behavioral phenotypes of genetic disorders) as well as the full range of psychiatric disorders. Grounded in evidence-based methods and supported by the expert-consensus model, the *DM-ID-2* offers a comprehensive approach to each diagnostic category.

For each disorder, descriptive text and details of how to apply diagnostic criteria, as well as tables of adapted diagnostic criteria, are included. Each diagnostic chapter has a comprehensive review of the research literature. Additionally, each diagnostic chapter has a section on etiology and pathogenesis covering risk factors, biological factors, psychosocial factors, and genetic syndromes. In addition to adapting the *DSM-5* diagnostic criteria where appropriate, the *DM-ID-2* provides advice about and considerations for assessing and diagnosing individuals with ID and coexisting mental health needs. In some cases, it is not so much that the criteria need to be adapted, as that a different method of eliciting the necessary information must be used. Information is provided in recognizing common behaviors of individuals with intellectual disabilities and in how to differentiate these behaviors from psychiatric disorders.

The *DM-ID-2* is designed to help clinicians better understand complex behaviors and guides the clinicians to better comprehend the difference between problem behaviors as compared to the expression of specific psychiatric disorders. Furthermore, the *DM-ID-2* provides a wealth of information on the presentation of psychiatric disorders manifested in adults as compared to children and adolescents.

For further information contact Ed Seliger at eseliger@thenadd.org.