

Treatment of the Dually Diagnosed Slowly Moving Into the Mainstream

Rosemary Frei

A new adaptation of the *Diagnostic and Statistical Manual of Mental Disorders*, for the intellectually disabled is being released next year.

In treating people with both mental illness and intellectual disability, considerable patience and skill are required to penetrate the veil of developmental delay that obscures the patient's psychiatric strengths and deficits. Unfortunately, these skills are rarely taught during medical school, residency or fellowship.

That may explain why fewer than 20 psychiatrists in the United States specialize in the treatment of these individuals, despite the fact that approximately 33% of the intellectually delayed also have mental illness and the dually diagnosed comprise 1% to 2% of all psychiatric inpatients.

Those 20 psychiatrists and others like them over the last several decades have had to overcome considerable barriers. They have done so because they recognize the enormous need, and had the skills, heart and drive to help these patients. Robert Fletcher, DSW, is typical of the handful of people who have dedicated themselves to the dually diagnosed.

"I was working in a day-treatment program in 1976 or 1977, and I had three or four patients with mental retardation," he recalled. "The director of the program found those people to be bothersome and always wanting attention, and he asked me to do something with them because I had a background in both mental health and mental retardation. So I started a group, pejoratively known as 'Rob's retarded group.' I began to read more on the subject, got a music and art therapist involved and expanded the program."

The overwhelmingly positive results had Dr. Fletcher hooked. In 1983, he founded the National Association of the Dually Diagnosed (NADD), and in 1993 obtained a doctorate in social work.

Changing the Treatment Landscape

At the time Dr. Fletcher's group was formed, only a handful of programs focused on the dually diagnosed. Fortunately, things have begun to change.

"When I started in the 1970s, people denied there was a problem, and now we've gained a small amount of recognition of the problem," said Steven Reiss, PhD, director of the Nisonger Center at Ohio State University in Columbus, and the creator of the Reiss Screen for Maladaptive Behavior and the Reiss Profile, diagnostic tools

for the dually diagnosed. "But we don't have research on the dually diagnosed, and we're not training professionals, especially in the medical area. And I think fixing those things, more than anything else, would go a long way to rectifying the situation."

Another positive change is the decreased use of the term *mental retardation*. Emblematic of this, the American Association on Mental Retardation changed its name this year to the American Association on Intellectual and Developmental Disabilities.

Now there is about to be another leap forward: An adaptation of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* modified for dually diagnosed individuals began field testing in July. It was developed over the last six years by NADD in association with the American Psychiatric Association. It is being assessed by 130 psychiatrists in the United States, Canada, Australia and Europe working with approximately 2,000 patients. Release of the *Diagnostic Manual for Persons With Intellectual Disability (DM-ID)* early next year will likely help significantly increase interest in this area.

"The manual has been designed to be used by clinicians who are working with people who have intellectual disabilities, and will be most useful for clinicians working with people with limited or no verbal skills," Dr. Fletcher explained. "There's still a lot more to be done. To my knowledge, there are virtually no rotations in medical school internship programs focusing on the dually diagnosed, and in the majority of psychiatry programs, there's still no exposure to these patients. We think this will be the most important development in the field of dual diagnosis thus far."

Opening the Door to the *DM-ID*

Dr. Fletcher is the lead editor of the manual, which was completed with four years of financial backing from the Joseph P. Kennedy Jr. Foundation. Each section—in which specific adaptations of the *DSM-IV-TR* are laid out for individuals with mild, moderate and severe intellectual disability—comprises a consensus on best practices. The other members of the editorial board are Chrissoula Stavrakaki, MD, PhD, Earl Loschen, MD and Michael First, MD, who is also the chief editor of the *DSM-IV-TR*. Dr. Reiss is a member of the *DM-ID* advisory board. Perhaps the most valuable part of the *DM-ID* covers assessment and diagnostic procedures. Emphasis is placed on the obvious but frequently misunderstood tenet that clinicians should use language that is comprehensible to the patient. Even more important, clinicians should be aware of processes that affect the diagnostic process in people with intellectual disability:

Baseline exaggeration—misinterpretation of a behavior as a mental disorder when it is simply an exacerbation of a preexisting and nonpathological state

Intellectual distortion—misinterpretation of unusual speech or thought processes as psychosis or emotional disturbance when they are due to poor cognitive or communication skills

Psychosis masking—misunderstanding of the true symptoms of a mental disorder due to a lack of awareness of the world of those with intellectual disability

Cognitive disintegration—the misinterpretation of a patient's extreme reaction to stress as a psychosis or other severe disturbance.

The third chapter covers behavioral phenotypes of genetic disorders. For example, the section on Down syndrome notes that children with this disorder can have oppositional and defiant behavior, as well as attention-deficit/hyperactivity disorder, while adults can suffer from depressive disorders, obsessive-compulsive and other anxiety disorders, Alzheimer's-type dementia and mental disorders associated with hypothyroidism.

The balance of the manual covers the two major categories of mental disorders—those diagnosed early in life and adult disorders.

"This is a bit like the *DSM-III* was 25 years ago," commented Jarrett Barnhill, MD, a member of the *DM-ID* editorial advisory board and a professor of psychiatry at the University of North Carolina at Chapel Hill. "It opened the door for much more systematic research, and gave a common language that people could use in research and in clinical management."

Jason M. Noel, PharmD, BCPP, one of few U.S. pharmacists working full time in the treatment of the dually diagnosed, said he welcomes the imminent arrival of the *DM-ID* but cautioned that if its use results in more routine diagnoses of psychiatric illnesses in the intellectually disabled, payers may respond by developing an approach to coverage that does not take into account the unique needs of these individuals.

"I work in a residential facility where the psychiatrists aren't pressured to give a diagnosis in order to provide their services, whereas in almost all other settings, there has to be some diagnosis given in order to provide psychiatric services," Dr. Noel explained. "So there is the potential problem of the assumption developing among payers that 'diagnosis x equals billing amount y,' where 'y' is the amount paid" for all patients regardless of intellectual disability, he said. "But dually diagnosed individuals require much more intensive therapy and management, and also their needs can vary significantly from person to person."

—Rosemary Frei, MSc