Individuals with intellectual disability (ID) often present with behavioral symptoms complicated by limited expressive language skills and undiagnosed medical conditions. Many training programs do not include focused study of individuals with ID, despite the fact that such patients will be seen by virtually every mental health practitioner and that these patients can benefit from the full range of mental health services. In this book, the authors present a framework for competent assessment and treatment of psychiatric disorders in individuals with ID.

There are no evidence-based principles dedicated to psychotropic medication use in ID, but consensus guidelines address the high prevalence of poly-pharmacy. Altered diagnostic criteria have been published which accommodate less self-report and incorporate collateral information; this book reviews the literature on psychotropic medications, consensus guidelines, and population-specific diagnostic criteria sets.

Psychiatry of Intellectual Disability also includes:

- Interviewing techniques and assessment tips for all levels of communicative ability as well as for nonverbal individuals
- Assessment of aggression to determine etiology and formulate a treatment plan
- Overview of types of psychotherapy and suggested alterations for each to increase efficacy
- Relevant legal issues for caregivers and treatment providers

The detective work involved in mental health assessment of individuals with ID is challenging yet rewarding. The highest quality mental health treatment limits hospital days, improves quality of life and often allows individuals to live in the least restrictive environments. Psychiatry of Intellectual Disability is a must-have resource guide for psychiatrists, nurse practitioners, and other prescribers treating patients with ID. It is a supplemental text for psychiatry residents, medical students, psychology graduate students, psychotherapists, counselors, social workers, behavior support specialists, and nurses.

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Psychiatry of Intellectual Disability
Psychiatry of Intellectual Disability

A practical manual

Edited by

Julie P. Gentile, MD and Paulette M. Gillig, MD, PhD
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Dedications

Dr. Gentile would like to dedicate this book to her husband John for his extraordinary love and support; to her daughters Sarah and Jess and her son-in-law Sayre for being sources of inspiration and pride every day; and to her parents Charlie (RIP) and Patricia, who always believed the sky was the limit. She would like to thank her patients with intellectual disability, and the people who stand with them, for being true survivors.

Dr. Gillig would like to dedicate this book to the memory of Uncle Al Petre, Peter Reilly and Patty Whibbs, childhood friends with intellectual disabilities. We had some good times.
Editor Biographies

Julie P. Gentile, M.D. (jen-TILL-ee) is Associate Professor of Psychiatry at the Boonshoft School of Medicine, Wright State University, Dayton, Ohio and the Project Director/Primary Investigator for Ohio’s Coordinating Center of Excellence in Mental Illness/Intellectual Disability. She has been the Professor of Dual Diagnosis for the Ohio Department of Mental Health, the Ohio Department of Developmental Disability and the Ohio Developmental Disabilities Council since 2003, and the Medical Director for both the Montgomery County Board of Developmental Disabilities Mental Health Program and Consumer Advocacy Model (treating patients with traumatic brain injury, substance use, and mental illness). Dr. Gentile has evaluated more than 2,000 individuals with co-occurring mental illness and intellectual disability. She is the recipient of the American Psychiatric Association’s Frank J. Menolascino Award for Excellence in Psychiatric Services for Developmental Disabilities, the Excellence in Contributions to Clinical Practice Award from the National Association for the Dually Diagnosed, and she is a member of Alpha Omega Alpha Medical Honor Society. She is a recipient of the Faculty Mentor Award, the Golden Apple Teaching Award, the Career Achievement Award, the Outstanding Achievement in Medical Education and Research Award of the Academy of Medicine, and the Nancy Roeske Award in Medical Education from the American Psychiatric Association. Dr. Gentile has been awarded more than $3,000,000 in grants and contracts to support her work in dual diagnosis since 2003. She is the Director of Medical Student Mental Health Services at Wright State University, is a member of the editorial board for the journal Innovations in Clinical Neuroscience and has published articles and book chapters on various topics in the area of co-occurring mental illness/intellectual disability.

Paulette Marie Gillig, M.D., Ph.D. is Professor of Psychiatry at the Boonshoft School of Medicine, Wright State University, Dayton, Ohio and on the Faculty of the Graduate School. She has been Ohio Department of Mental Health Professor of Rural and Underserved Populations since 1998, is listed in Best Doctors in America, Who’s Who in America, Who’s Who in the World, is Distinguished Fellow of the American Psychiatric Association and is a member of Alpha Omega Alpha Medical Honor Society. She also is a member of the Society of Neuroscience and the Russell DeJong Society. She is a recipient of the Faculty Mentor Award and the Golden Apple Teaching Award, the Outstanding Achievement in Medical Education and Research Award of the Academy of Medicine, and the Nancy Roeske Award in Medical Education from the American Psychiatric Association. Dr. Gillig has published three books and over 60 articles and book chapters in the several areas of Community
(Public) Psychiatry, Psychotherapy, and the Interface between Psychiatry and Neurology. She is the Section Editor for the journal *Innovations in Clinical Neuroscience*. She has completed residencies in both neurology and in psychiatry and she also holds a doctorate in Social Psychology in the area of cognitive processes. She is the past Area 4 representative to the American Association of Community Psychiatrists and Chair of the Training Committee. She was the Chair of the Committee on Minorities and Under-represented Groups for the Ohio Psychiatric Association, and a member of the Committee on Poverty and Homelessness of the American Psychiatric Association.
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## List of Abbreviations

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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AOC</td>
<td>altered consciousness</td>
</tr>
<tr>
<td>APD</td>
<td>antisocial personality disorder</td>
</tr>
<tr>
<td>ARND</td>
<td>alcohol related neurodevelopmental disorder</td>
</tr>
<tr>
<td>BD</td>
<td>bipolar disorder</td>
</tr>
<tr>
<td>BPD</td>
<td>borderline personality disorder</td>
</tr>
<tr>
<td>BPS</td>
<td>biopsychosocial</td>
</tr>
<tr>
<td>CBT</td>
<td>cognitive behavioral therapy</td>
</tr>
<tr>
<td>CDC</td>
<td>Center for Disease Control</td>
</tr>
<tr>
<td>CT</td>
<td>computerized tomography</td>
</tr>
<tr>
<td>DBT</td>
<td>dialectical behavior therapy</td>
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<tr>
<td>DC LD</td>
<td>Diagnostic Criteria – Learning Disorders</td>
</tr>
<tr>
<td>DM-ID</td>
<td>Diagnostic Manual – Intellectual Disability</td>
</tr>
<tr>
<td>DS</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>DSM-IV-TR</td>
<td>Diagnostic and Statistical Manual, Fourth Edition Text Revision</td>
</tr>
<tr>
<td>DZ</td>
<td>dizygotic</td>
</tr>
<tr>
<td>ED</td>
<td>emergency department</td>
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<tr>
<td>EEG</td>
<td>electroencephalogram</td>
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<tr>
<td>EKG</td>
<td>electrocardiogram</td>
</tr>
<tr>
<td>EPS</td>
<td>extrapyramidal side effects</td>
</tr>
<tr>
<td>FAE</td>
<td>fetal alcohol effects</td>
</tr>
<tr>
<td>FAS</td>
<td>fetal alcohol syndrome</td>
</tr>
<tr>
<td>FASD</td>
<td>fetal alcohol syndrome disorders</td>
</tr>
<tr>
<td>FGA</td>
<td>first generation antipsychotic</td>
</tr>
<tr>
<td>FMR1</td>
<td>Fragile X Mental Retardation 1 gene</td>
</tr>
<tr>
<td>FXS</td>
<td>Fragile X syndrome</td>
</tr>
<tr>
<td>FXTAS</td>
<td>Fragile X tremor ataxia syndrome</td>
</tr>
<tr>
<td>GABA</td>
<td>gamma Aminobutyric acid</td>
</tr>
<tr>
<td>GAD</td>
<td>generalized anxiety disorder</td>
</tr>
<tr>
<td>GCS</td>
<td>Glasgow Coma Scale</td>
</tr>
<tr>
<td>GMC</td>
<td>general medication condition</td>
</tr>
<tr>
<td>HPD</td>
<td>histrionic personality disorder</td>
</tr>
<tr>
<td>ID</td>
<td>intellectual disability</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
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<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>IQ</td>
<td>intelligence quotient</td>
</tr>
<tr>
<td>LD</td>
<td>learning disorder</td>
</tr>
<tr>
<td>LOC</td>
<td>loss of consciousness</td>
</tr>
<tr>
<td>MDD</td>
<td>major depressive disorder</td>
</tr>
<tr>
<td>MI</td>
<td>motivational interviewing</td>
</tr>
<tr>
<td>MRI</td>
<td>magnetic resonance imaging</td>
</tr>
<tr>
<td>MZ</td>
<td>monozygotic</td>
</tr>
<tr>
<td>NADD</td>
<td>National Association for the Dually Diagnosed</td>
</tr>
<tr>
<td>NOS</td>
<td>not otherwise specified</td>
</tr>
<tr>
<td>OCD</td>
<td>obsessive compulsive disorder</td>
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<tr>
<td>ODD</td>
<td>oppositional defiant disorder</td>
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<td>PD</td>
<td>personality disorder</td>
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<tr>
<td>PDD</td>
<td>pervasive developmental disorder</td>
</tr>
<tr>
<td>pFAS</td>
<td>partial fetal alcohol syndrome</td>
</tr>
<tr>
<td>PTA</td>
<td>post-traumatic amnesia</td>
</tr>
<tr>
<td>PTSD</td>
<td>post-traumatic stress disorder</td>
</tr>
<tr>
<td>PWS</td>
<td>Prader-Willi syndrome</td>
</tr>
<tr>
<td>SAP</td>
<td>Structured Assessment of Personality</td>
</tr>
<tr>
<td>SGA</td>
<td>second generation antipsychotic</td>
</tr>
<tr>
<td>SIB</td>
<td>self-injurious behavior</td>
</tr>
<tr>
<td>SP</td>
<td>supportive therapy</td>
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<tr>
<td>SSI</td>
<td>supplemental security income</td>
</tr>
<tr>
<td>SSDI</td>
<td>social security disability income</td>
</tr>
<tr>
<td>SSR1</td>
<td>selective serotonin reuptake inhibitor</td>
</tr>
<tr>
<td>TBI</td>
<td>traumatic brain injury</td>
</tr>
<tr>
<td>WS</td>
<td>Williams syndrome</td>
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Foreword

The field of Intellectual Disabilities (ID) is expanding along many fronts. Over the last 20 years, community-based placement has come to replace large residential facilities in many states. This transformation accompanied changes in treatment models, especially the legal and ideological shifts away from custodial to more active treatment programs. During this era, increased demands for community programs required a major restructuring of services to deal with many of our most complicated and difficult to treat patients. Adequate staffing and integration of complex services needs proved to be one of our greatest challenges—especially the gaps between availability and access to quality care and sociocultural-bound beliefs and values that might hinder utilization by the target population.

In part, availability and access to adequate care is often limited by maldistribution of qualified professionals, fragmentation of health care systems and persistent problems merging mental health and intellectual disability services. These are especially thorny issues since many of these individuals have either major problems with co-existing medical/neurological disorders, severe challenging behaviors or mental disorders. When specialized services are not available, any combination of these variables may overwhelm community programs and in many situations circumstances may jeopardize community placement. These challenging individuals seriously tax community resources and as a result finish up with multiple psychotropic medications or with an excessive reliance on acute hospitalization. In many cases these individuals end up in a pattern of revolving door admissions to mental health facilities. As a result, we are in the midst of a second psycho-pharmacological revolution; this one is generated by the increased overuse of polypharmacy that is due in part to limited clinical and behavioral management resources.

Over 25 years ago, the idea that individuals with ID might also be at risk for psychiatric disorders was clouded by many layers of diagnostic overshadowing. In addition, it became apparent that many individuals with ID did not fit either the standard psychiatric models of etiology or descriptive phenomenology, and therefore required modifications in the standard psychiatric evaluation and assessment. In the mid 1980s, the National Association for the Dually Diagnosed in the US attempted to remedy this confusing situation by providing direct training and educational programs designed for clinicians and direct care personnel in the field. In 2007, this Association published the Diagnostic Manual-Intellectual Disabilities. This two-volume edition modified and adapted the already existing DSM-IV-TR diagnostic criteria (American Psychiatric Association, 2000). These modifications, along with the ICD-based Diagnostic Criteria-Learning Disability already available, promoted a modified descriptive and categorical classification system for the field of dual diagnosis.
The DM-ID provided a starting place for improvements in clinical treatment using evidence and best practice-based diagnostic criteria.

This book edited by Drs. Gentile and Gillig is grounded in our growing understanding of the complex neurodevelopmental and biopsychosocial substrates for challenging behaviors and mental disorders. The authors provide abundant evidence for the value of criteria-based diagnosis and treatment planning founded on scientific evidence and our growing integration of genetics, behavioral neurosciences and neuropharmacology with psychosocial/behavioral therapies. Our biggest challenge is to keep our assessment and treatment approaches in step with the rapidly changing scientific evidence. One example of this problem is the difficulty we all face dealing with the rapid pace of change in our understanding of neurobiology of major psychiatric disorders. We now confront molecular genetics, intracellular mechanisms that are replacing our previous reliance on neurotransmitter models, behavioral neuropharmacology and genomics of drug metabolism and mechanisms of action, developmental changes that point to gene-environmental and epigenetic interactions rather than our older over-simplified models of nature versus nurture, neuro-endocrinological and neuro-immunological factors that influence brain function and psychopathology. If this isn’t enough, we confront a second conundrum-dealing with the clinical heterogeneity and complex developmental neurobiology of ID.

The authors of this edition focus on integrating biopsychosocial models. In keeping with the medieval position taken by Bernard of Chartres and later borrowed by Isaac Newton: we make progress “by standing on the shoulders of giants” who came before us. This book is a testament to their vision and efforts. Their challenge to us is take the new knowledge gleaned from our marvelous technical and scientific research and integrate neurosciences into a person-centered, positive support program that provides humane care. This book reminds us how we might accomplish this.

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1
Overview

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The history of intellectual disability and mental illness

The history of individuals with mental illness and intellectual disability (ID) is profoundly intertwined. Due to a lack of effective treatments, both groups have long occupied a status of “otherness” and have been relegated to the fringes of society. Individuals with ID and those with mental illness had to rely on support from the community if their families were unable or unwilling to care for them. Throughout history, such individuals have been diagnosed together as “mental defectives,” have been treated or housed in asylums and have been singled out as somehow “less than human” or less deserving of the same rights and treatment as other individuals.

In more recent times, progress has been made in returning rights, choices and lives of their own making to individuals with ID and mental illness. There remains, however, a paucity of historical writings about people with a combination of both ID and mental illness. An overview of their separate histories and the subsequent development of the concept of dual diagnosis will serve as an appropriate starting point for Psychiatry of Intellectual Disability.

In prehistory, individuals with mental illness and ID were reliant on family and social structure. The earliest treatment of mental illness was likely through shamanism, spirituality and superstition, using herbs, rituals and amulets. From observations documented in the fossil record, other techniques were found, including psychosurgery.
For example, Neolithic humans used trepanation – the drilling of circular holes in the skull – to release evil spirits that were thought to cause mental illness. The practice of trepanation has been observed across varying cultures and geographical regions. For example, the Incans of Peru (Arnott et al., 2002) and the Native Americans of North America (Stone et al., 1990) performed trepanation, with most cases living long enough for the bones of the skull to heal. The great classical physicians Hippocrates and Galen used trepanation to treat phlegmatous lesions of the brain (Missios, 2007). There exists a painting by the Dutch Renaissance painter Hieronymus Bosch called “Extracting the Stone of Madness” that indicates that psychosurgery also was performed to alleviate mental illness.

The etiology of mental illness remains a mystery even now. The Judeo-Christian tradition teaches that disobedience to God will result in being cursed with madness, saying, “God will smite thee with madness” (The Holy Bible, King James Version, 1611). In the Hindu faith, a person suffering from schizophrenia would be treated by removing toxins presumed to be causing the illness in order to restore harmonious balance and mental health (Progler, 2008). Hippocrates also believed that mental illness resulted from an imbalance in the bodily humors, rather than a divine cause. He recommended that the body be allowed to restore itself, as opposed to using more invasive procedures and medicines.

Individuals with more severe intellectual or other disabilities historically did not survive into adulthood. In ancient times, infants who were considered “deformed” were often killed through what was called “exposure” (Bennett, 1923), in which the infant was abandoned outside, presumably to perish. Aristotle (Kraut, 1998) recommended, “Let there be a law against nourishing those [infants] that are deformed.” Sparta, a culture infamous for rates of infanticide, had a process wherein the infant was brought for official inspection for “defects” and was abandoned if found to be “defective.” Soranus of Ephesus, a 2nd Century C.E. physician, listed criteria that made an infant “worth rearing,” which included having a healthy mother, being full-term, crying with vigor, being perfect in all its parts and having the right size and shape (Patterson, 1985). Soranus did, however, advocate for the humane treatment of persons with mental illness, recommending rest, sympathy and reading (Scheerenberger, 1983). He wrote:

“They [physicians] compare their patients to ferocious beasts whom they would subdue by the deprivation of food and by the torments of thirst. Misled without doubly by this error, they advise that patients be cruelly chained, forgetting that their limbs might be injured or broken and that it is more suitable and much easier to restrain the sick by the hands of men than by the weights of often harmful iron. They even advise bodily violence, like the use of the whip, as if such measures could force a return to reason.”

Slowly, the classical civilizations began outlawing infant exposure. The newly emerging major world religions promoted gentle treatment of people with intellectual and other disabilities. The Koran, the New Testament of the Bible, Confucius and Buddha argued for mercy and kindness for those with ID.

During the Middle Ages and through the Renaissance period, people with ID and mental illness continued to be treated as other. Some people with ID were employed as “fools,” similar to court jesters, to provide a royal court or household with entertainment. The rights
of individuals with ID and mental illness were restricted during these times by law. In England in the 1700s, Brydall recapitulated the earlier scholars Fitzherbert (who described “idiocy” as “not being able to count to twenty”) and Swinbourne (who added that the definition should include not being able to do other activities like telling the days of the week or measuring fabric). A lunatick or “mad-man” was described by Brydall as “having sometime his Reason, and sometimes not” (Brydall, 1700).

When someone was pronounced an idiot, the individual’s property would revert to the king; however, if someone was declared a “lunatick” – or mentally ill – their heirs would retain the rights to the family property. There is considerably more written about the distinction between mental illness and ID compared with their overlap. John Locke wrote that individuals with ID “[seem] to proceed from want of quickness, activity, and motion in the intellectual Faculties, whereby they are deprived of Reason: whereas mad Men, on the other side, seem to suffer by the other Extrem. Or they do not appear to me to have lost the Faculty of Reasoning: but having joined together some Ideas very wrongly, they mistake them for Truths” (Locke, 1690).

While the rights of the individual were limited in the Middle Ages, there was also protection from prosecution; the insanity defense had been a viable defense in Roman and Greek times and made a return in the late 1500s. Richard Cosin wrote of the insane that “In which respects they are compared in lawe, to men absent, and utterly ignorant of any thing done by themselves, or in their presence” (Cosin, 1592).

The Middle Ages and the post-Reformation era were also times of great superstition. The Malleus Maleficarum, or “Hammer of Witches” (Kramer et al., 1487, translated in Summers, 1948) was published to outline the correct prosecution of people (usually women) accused of witchcraft. There is no specific mention of individuals with ID, although descriptions of “witches” who drove men to insanity may have been about individuals suffering from mental illness. In writing about the Salem Witch Trials of 1692, Kai Erikson noted that some accused witches “were witless persons with scarcely a clue as to what happened to them” (Erikson, 1966). St. Vincent de Paul crusaded against the prosecution of people with mental illness and ID as witches.

The reformers

Treatment and attitudes toward people with ID and mental illness varied throughout history. Well-off families could afford to provide the additional support needed, but poorer families could not. When family or friends could not care for an individual with ID, mental illness or both, some communities as a group either actively or passively supported the individual.

In rural communities, a person with ID might be the “town idiot” and given food and shelter. However, circumstances were not always so benign. Scheerenberger quotes William Tuke, a Quaker philanthropist, who described: “Hardly a parish of any considerable extent in which there might not be found some unfortunate human creature, who, if his ill-treatment had made him ‘frenetic,’ was chained in the cellar or garret of a workhouse, fastened to the leg of a table, tied to a post in an outhouse, or perhaps shut up in an uninhabited ruin; or, if his lunacy were inoffensive, was left to ramble, half-naked and half-starved, throughout the streets and highways” (Scheerenberger, 1983).

In more urban communities, a person with ID would rely on begging or would be placed in an institution like an asylum. Asylums began as a way to house individuals
with mental illness and ID. Treatment of people with mental illness and ID included cold baths, beatings and immobility, to calm what was thought to be demons or disturbed tempers. In some sections of the asylum, residents were not given clothes and were chained to walls without heat. During the time of the asylums, people with ID were still viewed as a form of entertainment, with the more famous asylums charging entrance fees to visitors.

Reformers like Tuke, who advocated for “moral treatment,” sought to improve the living conditions for people with ID. Philippe Pinel, a French physician who also encouraged the humane treatment of people with ID and mental illness, wrote: “The managers of those institutions [the asylums], who are frequently men of little knowledge and less humanity, have been permitted to exercise towards their innocent prisoners a most arbitrary system of cruelty and violence; while experience affords ample and daily proofs of the happier effect of a mild, conciliating treatment, rendered effective by steady and dispassionate firmness.”

Pinel is famous for removing the irons from the residents at Bicêtre upon taking charge at the facility. He and the superintendent of the hospital, Jean-Baptiste Pussin, worked closely in providing compassionate treatment to residents of the asylum (Gerard, 1997). Consistent with today’s ethos concerning patient care, Pinel advocated “to allow every maniac all the latitude of personal liberty consistent with safety; to proportion the degree of coercion to the demands upon it from his extravagance of behavior, to use mildness of manners or firmness as occasion may require” (Pinel, 1806). A well-known American reformer and scholar in the field of mental health care, Dorothea Dix, addressed the Massachusetts legislature regarding recommendations to reform the state institutions; and Eduoard Séguin of France advocated that individuals with ID be educated for their own “improvement” (Scheerenberger, 1983).

Starting in the middle 20th century, attempts were made to deinstitutionalize individuals with ID or mental illness and integrate them back into the community. The discovery of the first effective antipsychotic, chlorpromazine (Thorazine), allowed for symptoms to be treated outside of the institutional setting, with varying results.

Current treatment recommendations

It is important to maintain the human rights and dignity of the individual with ID. This includes informed consent to treatment, accurate diagnosis, and formulation of a biopsychosocial treatment plan. Allow individual choice in small and large decisions. The rise of self-advocacy groups like Autism Speaks and People First have been influential in allowing individuals a voice where the forum did not previously exist.

Prevalence and classification

Approximately two percent of the population have co-occurring mental illness and ID and these individuals will be encountered in virtually every practice setting (Hardan & Sahl, 1997, Larson et al., 2001, Silka & Hauser, 1997). There is a three to six times increased rate of psychiatric and behavior problems in individuals with ID compared to the general
population. There are many etiologies currently known for ID, obviously a highly heterogeneous condition. Most causes of ID fall into the categories of chromosomal abnormalities, other genetic factors, prenatal and perinatal factors, acquired childhood disorders, environmental factors and socio-cultural factors.

ID is usually classified as profound, severe, moderate or mild, which can often be an indicator of the level of dependency or expressive language capabilities of the individual. The designation is frequently correlated with the level of risk for certain medical and neurological conditions.

- Generally, individuals with mild cognitive deficits live independently in the community in supported residential situations and participate in life-long supported employment. Special vocational and community socialization training is often required for success and to attain the highest quality of life.
- Persons in the moderate category will most often need varying levels of support from their families or community agencies. Because their expressive language skills are typically more limited, they are at higher risk of being unable to communicate subjective complaints about mental health and medical illnesses.
- Individuals with severe and profound ID are more likely to have very high levels of dependence on outside supports and to have associated medical conditions, with many requiring intensive support to be able to master activities of daily living. Significant medical complications, such as seizure disorders, swallowing difficulties, speech impairments, ambulation limitations, sensory deficits and reduced life expectancies are more common for persons in the profound impairment category. Multiple physical disabilities increase risk for medical complications irrespective of the level of ID, so the use of the biopsychosocial formulation is therefore vital in the mental health assessment.

Current and proposed diagnostic criteria for ID

It has been argued that the existing diagnostic manuals for mental disorders (i.e. The American Psychiatric Association Diagnostic and Statistical Manual for Mental Disorders, 4th Edition Text Revision 2000, and International Classification of Diseases 10th Revision, Criteria for Mental Retardation, 1996) are not a good fit for use in individuals with ID (see Tables 1 and 2). Publications such as the Diagnostic Manual – Intellectual Disabilities (DM-ID 2007) and Diagnostic Criteria – Learning Disabilities (DC-LD 2001)

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Diagnostic criteria for mental retardation.</th>
</tr>
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<tbody>
<tr>
<td>Sub-average IQ</td>
<td>Decrease adaptive function in at least two areas</td>
</tr>
<tr>
<td>Mild MR</td>
<td>50/55 – ~70</td>
</tr>
<tr>
<td>Moderate MR</td>
<td>35/40 – 50/55</td>
</tr>
<tr>
<td>Severe MR</td>
<td>20/25 – 35/40</td>
</tr>
<tr>
<td>Profound MR</td>
<td>&lt;20/25</td>
</tr>
</tbody>
</table>

Table 2  International classification for diseases and other health-related conditions. Criteria for mental retardation.

<table>
<thead>
<tr>
<th>Code</th>
<th>Clinical description</th>
</tr>
</thead>
<tbody>
<tr>
<td>F70</td>
<td>Mild mental retardation</td>
</tr>
<tr>
<td></td>
<td>Mildly retarded people acquire language with some delay but most achieve the ability to use speech for everyday purposes, to hold conversations and to engage in the clinical interview. Most of them also achieve full independence in self-care (eating, washing, dressing, bowel and bladder control) and in practical and domestic skills, even if the rate of development is considerably slower than normal. The main difficulties are usually seen in academic school work, and many have particular problems in reading and writing. However, mildly retarded people can be greatly helped by education designed to develop their skills and compensate for their handicaps. Most of those in the higher ranges of mental retardation are potentially capable of work demanding practical rather than academic abilities, including unskilled or semiskilled manual labor. In a socio-cultural context requiring little academic achievement, some degree of mild retardation may not itself represent a problem. However, if there is also a noticeable emotional and social immaturity, the consequences of the handicap, e.g. inability to cope with the demands of marriage or child-rearing, or difficulty fitting in with cultural traditions and expectations, will be apparent. In general, the behavioral, emotional and social difficulties of the mildly mentally retarded, and the needs for treatment, are more closely akin to those found in people of normal intelligence than to the specific problems of the moderately and severely retarded. An organic etiology is being identified in increasing proportions of patients, although not yet in the majority.</td>
</tr>
<tr>
<td>F71</td>
<td>Moderate mental retardation</td>
</tr>
<tr>
<td></td>
<td>Individuals in this category are slow in developing comprehension and use of language, and their eventual achievement in this area is limited. Achievement of self-care and motor skills is also retarded, and some need supervision throughout life. Progress in school work is limited, but a proportion of these individuals learn the basic skills needed for reading, writing and counting. Educational programs can provide opportunities for them to develop their limited potential and to acquire</td>
</tr>
</tbody>
</table>

Diagnostic guidelines
If the proper standardized IQ tests are used, the range 50 to 69 is indicative of mild mental retardation. Understanding and use of language tend to be delayed to a varying degree, and executive speech problems that interfere with the development of independence may persist into adult life. An organic etiology is identifiable in only a minority of subjects. Associated conditions such as autism, other developmental disorders, epilepsy, conduct disorders or physical disability are found in varying proportion. If such disorders are present, they should be coded independently.

Includes: feeble-mindedness, mild mental subnormality.
some basic skills; such programs are appropriate for slow learners with a low ceiling of achievement. As adults, moderately retarded people are usually able to do simple practical work if the tasks are carefully structured and skilled supervision is provided. Completely independent living in adult life is rarely achieved. Generally, however, such people are fully mobile and physically active and the majority show evidence of social development in their ability to establish contact, to communicate with others, and, to engage in simple social activities.

**Diagnostic guidelines**

The IQ is usually in the range 35 to 49. Discrepant profiles of abilities are common in this group, with some individuals achieving higher levels in visuo-spatial skills than in tasks dependant on language, while others are markedly clumsy but enjoy social interaction and simple conversation. The level of development of language is variable; some of those affected can take part in simple conversations, while others have only enough language to communicate their basic needs. Some never learn language, though they may understand simple instructions and may learn to use manual signs to compensate to some extent for their speech disabilities. An organic etiology can be identified in the majority of moderately mentally retarded people. Childhood autism or other pervasive developmental disorders are present in a substantial minority and have a major effect upon the clinical picture and the type of management needed. Epilepsy and neurological and physical disabilities are also common, although most moderately retarded people are able to walk without assistance. It is sometimes possible to identify other psychiatric conditions, but the limited level of language development may make diagnosis difficult and dependent upon information obtained from others who are familiar with the individual. Any such associated disorders should be coded independently.

**Includes:** imbecility, moderate mental subnormality, moderate oligophrenia.

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**F72 Severe mental retardation**

**Clinical description**

This category is broadly similar to that of moderate mental retardation in terms of the clinical picture, the presence of an organic etiology and the associated conditions. The lower levels of achievement mentioned under F71 are also the most common in this group. Most people in this category suffer from a marked degree of motor impairment or other associated deficits, indicating the presence of clinically significant damage to or maldevelopment of the central nervous system.

**Diagnostic guidelines**

The IQ is usually in the range 20 to 34.

**Includes:** severe mental subnormality, severe oligophrenia

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**F73 Profound mental retardation**

**Clinical description**

The IQ in this category is estimated to be under 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. Most such...
individuals are immobile or severely restricted in mobility, incontinent and capable at most of only very rudimentary forms of nonverbal communication. They possess little or no ability to care for their own basic needs and they require constant help and supervision.

**Diagnostic guidelines**

The IQ is under 20. Comprehension and use of language is limited, at best, to understanding basic commands and making simple requests. The most basic and simple visuo-spatial skills of sorting and matching may be acquired and the affected person may be able, with appropriate supervision and guidance, to take a small part in domestic and practical tasks. An organic etiology can be identified in most cases. Severe neurological or other physical disabilities affecting mobility are common, as are epilepsy and visual and hearing impairments. Pervasive developmental disorders in their most severe form, especially atypical autism, are particularly frequent, especially in those who are mobile.

**Includes:** idiocy, profound mental subnormality, profound oligophrenia.

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are adaptations of diagnostic manuals utilized for the general population, and they address the unique needs and presentations of individuals with ID (DM-ID 2007, DC-LD 2001 (see Tables 3 and 4). These classification systems are grounded in evidence-based methods and supported by the expert consensus principles. The manuals include review of scientific literature and research, etiology and descriptions of various mental disorders and, when appropriate and supported by literature, proposed alterations of criterion for use in individuals with ID.

The proposed criteria for the *Diagnostic and Statistical Manual*, 5th Edition, to be published in 2012 can be found in Table 5.

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**Current trends in nomenclature**

For many years, the term ‘mental retardation’ has been used not only in diagnostic manuals, in writing and in reference to persons with ID, but has been used as a slang term and to ridicule persons with cognitive limitations. There has now been a shift to the use of either “intellectual” and/or “developmental” disabilities, with legislation in many regions to formally eliminate the term “mental retardation.”

In September 2010, the United States Congress passed legislation eliminating the term “mental retardation” from all federal laws and utilizing the terminology “an individual with intellectual disability” in all health, education and labor law. This legislation made the language in federal law consistent with language used by the Center for Disease Control and Prevention, the United Nations and the United States federal government. It also determined that all references to individuals with ID would be referred to in the People First Language format, described below (United States 111th Congress Bill S2781, 2010).
Table 3  American Association on Intellectual and Developmental Disabilities.

AAIDD definition: “a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18” (American Association of Mental Retardation, 2005). To this they add “five assumptions essential to the application of the definition”:

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. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

(American Association on Mental Retardation, 2005)

Degrees of severity
Mild: 50–55 to 70
Moderate: 35–40 to 50–55
Severe: 20–25 to 34–40
Profound: below 20–25

AAIDD categories
Intermittent support
Limited support
Extensive support
Pervasive support


Table 4  Diagnostic criteria for learning disabilities for use with adults (DC-LD).

• Diagnostic criteria: used synonymously with the ICD-10 term Mental Retardation. The diagnosis of Mental Retardation is dependent upon the person having an intelligence quotient below 70, together with continued impairment in adaptive behavior/social functioning, and with onset during the developmental phase (i.e. before the age 18 years). The term borderline learning disabilities is not included in the ICD-10, nor is it included in DC-LD. Within most European and North American cultures, ICD-10 recommends the use of the Vineland Adaptive Behavior Scales as an assessment tool.

• Severity of learning disabilities:
  o Mild learning disabilities: IQ range = 50–69; mental age 9 to under 12 years
  o Moderate learning disabilities: IQ range = 35–49; mental age 6 to under 9 years
  o Severe learning disabilities: IQ range = 20–34; mental age 3 to under 6 years
  o Profound learning disabilities: IQ range = 20; mental age <3 years
  o Other learning disabilities
  o Unspecified learning disabilities.

• An example of a clinical summary sheet (this relates DC-LD descriptive classification to etiology, using the four dimensions of biological, psychological, social and development, and provides an example of other summary information relevant to clinical practice).

• Diagrammatic presentation of the hierarchical approach to diagnosis which is adopted throughout DC-LD.

• The text of DC-LD provides additional information on psychiatric assessment of adults with learning [intellectual] disabilities.

Source: Adapted from Royal College of Psychiatrists. DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation). London: Gaskell, 2001, p. 18.
“People first” language

As Mark Twain once said, “The difference between the right word and the almost right word is the difference between lightning and the lightning bug.” The Sapir-Whorf hypothesis of language (Chandler, 1994) proposes that language use significantly shapes perceptions of the world and forms ideological preconceptions.

“People First” language is a linguistic style that is becoming more widely recognized and considers the persons or individuals first and their associated disability or condition as a secondary attribute as opposed to being defined by their disability (Snow, 2009). It entails using the term “individual” or “person” first, followed by the condition or mental health issue. The purpose is to avoid perceived or subconscious dehumanization and is considered “disability etiquette.”

For example, instead of “schizophrenic patient” or “intellectually disabled person,” it is preferred by groups advocating “people first” to state “patient with schizophrenia” or “person with intellectual disability.” In this sense, the person’s identity is separated from their disorder or condition or disability. Along the same lines, instead of “a deaf person,” People First Language recommends “person with a hearing impairment.” Although critics...
of People First language may claim that is it awkward and repetitive. Whether in written form or in oral presentation, it is significant that the aforementioned style is preferred by many individuals with disabilities and their advocates.

The interface between intellectual disability and mental illness

Patients with dual diagnosis often present to psychiatrists with behavioral problems. Because these patients often have communication difficulties, they may have medical conditions which are undiagnosed and that affect their behavior. Characteristics of ID may confound the usual procedures for psychiatric assessment and treatment. For example, it may be helpful to incorporate some child mental status examination techniques when assessing adult patients with ID. The psychiatric interview of patients with ID can be complicated by communication deficits or lack of verbal communication skills but, by utilizing certain question types and avoiding others and allowing sufficient time, one can yield a wealth of information as well as effectively develop rapport between mental health clinician and patient.

Most mental health (MH) care delivery systems have a different philosophy than most ID systems. For example, ID systems may meet the individual “where he is” without expecting significant change in functioning, and focus on habilitation. By contrast, MH systems typically focus on “cure” and are recovery-oriented, in that the expectation for mental illness is the achievement of clear short-term goals.

The ID professional relies on assessment of functioning, while the MH professional relies on diagnosis. When ID professionals refer individuals with ID to MH systems for assessment and care, they should request treatment for anxiety or mood instability or another appropriate MH diagnosis or symptom set, as opposed to services for “mild ID” or “Down syndrome,” for example. ID assessments view the entire person (living environment, employment, medical), while MH assessments utilize the medical model and pursue diagnosis of disorders and underlying causes.

In many MH settings, evidence-based practices are preferred. ID settings sometimes use consensus and tradition, but most have been moving toward evidence-based practices in recent years. In the end, both systems must work in collaboration in order to treat individuals with ID and mental illness effectively. The ID system offers involvement over the lifespan, holistic consideration of the person in the environment, housing and employment services and detailed account of skills and behavior; the MH system offers crisis support, treatment of emotional distress, behavior as a form of communication and knowledge of mental illnesses which may affect all areas of functioning.

This book covers a curriculum of topics for the multidisciplinary treatment of individuals with co-occurring ID and mental illness. Patients with ID may present with emotional, behavioral, interpersonal or adjustment problems and may benefit from psychiatric input even when there is lack of a diagnosable psychiatric disorder, while the individual also works closely with a multidisciplinary team that receives input from caregivers, family, and interested others. Patients with ID can absolutely benefit from the full range of mental health treatment, but there are important alterations necessary to ensure that mental health assessment, diagnosis and treatment interventions are effective and relevant. Individuals
with ID represent two to three percent of the general population, so it is reasonable to assume this specialized group will be integrated into virtually every practice setting.

Use of the biopsychosocial formulation is the key to determining the etiology and true meaning of the behavior in the person with ID. Patients with ID often function at higher levels when accurately diagnosed, when psychotropic medications are prescribed following best practices and evidence-based medicine principles, when polypharmacy is avoided, when medical conditions are appropriately treated, and when they have access to a full range of mental health treatments suitable to their developmental framework. Mental health care delivery systems can, and should, offer comprehensive treatment plans, including psychotherapy for patients with ID. Psychotherapy can be effective for patients with ID, and we discuss specific alterations and types of psychotherapy.

Patients with dual diagnoses are often medically fragile and often have co-occurring seizure disorders and other neurological conditions. These are described here, as are recommended modifications regarding the prescribing of psychotropic medications in this population. Best practices and evidence-based medicine principles formulated for the general population are recommended when there are no unique guidelines available for individuals with ID. Clinical vignettes created from composite cases are utilized to illustrate important practice points.

References


