

Summary of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults With Mental Retardation and Comorbid Mental Disorders

ABSTRACT

This summary provides an overview of the assessment and treatment recommendations contained in the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults With Mental Retardation and Comorbid Mental Disorders. The parameters were written to aid clinicians in the assessment and treatment of children, adolescents, and adults with symptoms of mental retardation (MR) and comorbid mental disorders. MR is a heterogeneous condition defined by significantly subaverage intellectual and adaptive functioning and onset before age 18 years. With an approach underscored by principles of normalization and the availability of appropriate education and habilitation, persons with MR generally live, are educated, and work in the community. Mental disorders occur more commonly in persons with MR than in the general population. However, the disorders themselves are essentially the same. Clinical presentations can be modified by poor language skills and by life circumstances, so a diagnosis might hinge more heavily on observable behavioral symptoms. The diagnostic assessment considers and synthesizes the biological, psychological, and psychosocial context of mental disorders. Comprehensive treatment integrating various approaches, including family counseling, pharmacological, educational, habilitative, and milieu interventions is the rule. *J. Am. Acad. Child Adolesc. Psychiatry*, 1999, 38(12):1606–1610. **Key Words:** dual diagnosis, developmental disabilities, mental illness, psychiatry, mental health, practice parameters, guidelines, children, adolescents, adults.

These parameters give the clinician direction in diagnosing and treating children, adolescents, and adults with mental retardation and comorbid mental disorders. Recommendations are based on extensive review of the scientific literature and clinical consensus among experts in the subject. These parameters are not intended to define the standard of care, nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results. The ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all the circumstances presented by the patient and his or her family, the diagnostic and

treatment options available, and available resources. The literature review, including references, and the rationale for specific recommendations are contained in the complete document (American Academy of Child and Adolescent Psychiatry, 1999).

INTRODUCTION

In the past several decades, the patterns of service delivery for persons with mental retardation (MR) have changed dramatically. At present, an overwhelming majority live in the community and are expected to use community-based medical services. Yet barriers to successful community living exist. Mental disorders are more prevalent in persons with MR than in the general population and are a primary reason for failure to adapt to community living. Furthermore, relatively few mental health clinicians receive training specific to the needs of this population. The goal of these parameters is to aid clinicians who are called upon to provide mental health services to persons who have mental disorders comorbid with MR.

The primary focus of these practice parameters is on children, adolescents, and young adults up to 21 to 22 years of age, an upper age limit of eligibility for public special education and related services in some states. Issues related to older individuals with MR are also highlighted to provide an understanding of the natural history of MR.

Mental retardation is not a single entity, but includes a heterogeneous group of individuals with a broad spectrum of levels

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This summary and the full text of the Practice Parameters for the Assessment and Treatment of Children, Adolescents, and Adults With Mental Retardation and Comorbid Mental Disorders is available to Academy members on the World Wide Web (www.aacap.org) and appears in the 1999 supplement to the Journal. The full text of these parameters was reviewed at the 1998 Annual Meeting of the American Academy of Child and Adolescent Psychiatry. Both the full text and this Summary were approved by the AACAP Council on June 25, 1999.

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of functioning, disabilities, and strengths. Therefore, these parameters are general in nature and have to be adapted to a particular person's needs.

These parameters consist of 2 major sections:

Part I: Review of General Knowledge on MR. Mental health clinicians usually are not the primary professionals responsible for the diagnosis and treatment of MR. However, the understanding of the biological basis and nature of the MR, its natural history, and the availability of and entitlement for services is necessary for every mental health clinician working with these individuals.

Part II: Mental Disorders Comorbid With MR. This section describes the modifications of psychiatric diagnostic and treatment techniques that may be necessary for patients with significant cognitive impairment. It also details some variations in the clinical presentation of major mental disorders in this population and the principles of psychiatric interventions including general treatment and habilitation programs.

EXECUTIVE SUMMARY

GENERAL ASPECTS OF MENTAL RETARDATION

The diagnosis of MR requires the finding of significantly sub-average current intellectual functioning, for example, IQ below 70 to 75 on a standardized, individually administered test; significant impairment in present adaptive functioning; and onset prior to age 18 years. Its presence is noted on Axis II in the multiaxial classification scheme. MR is not a single disorder but a heterogeneous condition defined by a person's functioning. Its prevalence is estimated at about 1% of the population, and about 85% of those with this condition have IQs within the mild MR range. In about 35% a genetic causation is found, and in fewer than 10% a malformation syndrome of unknown origin may be identified. External, prenatal, perinatal, or postnatal factors including infections, trauma, toxins, delivery problems, and prematurity account for about one third. In the remainder the etiology is unknown.

The cause of the MR should be identified if possible, as it may clarify the prognosis, sometimes suggest treatment, or alert the clinician to possible medical and behavioral complications that may be more common in certain conditions.

Assessment of Mental Retardation

The assessment of a person with MR is typically multidisciplinary. Increasingly, developmental disorders clinics are established in which psychologists may perform cognitive assessment, developmental pediatricians and clinical geneticists may complete physical diagnostic evaluations, and psychiatrists and behavioral psychologists may assess psychological and behavioral function. University-Affiliated Programs have been established throughout the United States to bring together such expertise, but available resources will influence the roles of various clinicians in the evaluation process. The comprehensive assessment includes:

- Diagnosis of MR using standardized intelligence testing and evaluation of adaptive skills through testing or clinical evaluation.
- Biomedical evaluation, including family, pregnancy, perinatal, developmental, health, social, and educational history; physical and neurodevelopmental examination; and laboratory tests. Laboratory tests are usually indicated by the findings in the history and physical examination and may include chromosomal analysis (including fragile X by DNA analysis), brain imaging (computed tomography, magnetic resonance imaging), EEG, urinary amino acids, blood organic acids and lead level, and appropriate biochemical tests for inborn errors of metabolism.
- Assessment of psychological and behavioral functioning.

Habilitation and Treatment of Persons With Mental Retardation

The habilitation of persons with MR is based on the principles of normalization and community-based care, with additional supports as needed. Federal legislation, for example, the Individuals With Disabilities Education Act (IDEA), entitles disabled children and adolescents to a full range of diagnostic, educational, and support services from birth to age 21 years. Specialized treatments are also provided if necessary, as is done for persons with severe visual and auditory impairment. Additional entitlements may be provided by state laws. The parents of children and adolescents with MR are entitled by these laws to receive support services and to be active participants in treatment planning. Some parents and older patients are not aware of their rights to obtain services. The clinician has an important role in such instances to educate and, if needed, to refer to a "patient advocate" or "educational advocate." In recent practice, children and adolescents are educated in special classes in regular school or in inclusionary programs (in age-appropriate regular classes, with additional supports as needed). In the United States, children with MR are now rarely (if ever) placed in residential institutions and separate schools. Adults with MR of all levels live in the community, in settings varying from their own apartments with supports as needed, to small (4–8 residents) group homes. They are employed in specialized settings or, increasingly, in the competitive job market. Habilitation and treatment include:

- Specific treatment of the underlying condition, if known, to prevent or to minimize brain insults that result in MR (e.g., shunting in the case of hydrocephalus).
- Early intervention, education, and ancillary therapies (such as physical, occupational, and language therapies), family support, and other services, as needed.
- Treatment of comorbid physical conditions, such as hypothyroidism, congenital cataracts or heart defects in children with Down syndrome, treatment of seizures in persons with tuberous sclerosis, etc.
- Treatment of comorbid mental disorders.

ASSESSMENT OF MENTAL ILLNESS IN PERSONS WITH MENTAL RETARDATION

Mental illness is frequently comorbid with MR, with prevalence estimates ranging from 30% to 70%. Virtually all categories of mental disorders have been reported in this population. An accurate psychiatric diagnosis provides the foundation for understanding the patient and for treatment planning.

The psychiatric diagnostic evaluation of persons who have MR is in principle the same as for persons who do not have retardation. The diagnostic approaches are modified, depending on the patient's cognitive level and especially communication skills. For persons who have mild MR and good verbal skills the approach does not differ much from diagnosing persons with average cognitive skills. The poorer the communication skills, the more one has to depend on information provided by caregivers familiar with the patient and on direct behavioral observations.

The assessment includes the following components.

Comprehensive History

The history taken from the patient and from several caregivers in different settings covers:

- Presenting symptoms including concrete descriptions of specific behaviors in various situations and settings, their change over time, antecedent events, and the way the various caregivers handle the behaviors.
- Psychiatric review of systems including premorbid and current behavioral and personality patterns, adaptive functioning, self-care, communication, and social functioning.
- Details of previous psychiatric treatment, with particular emphasis on medication side effects that could cause the presenting symptoms.
- Past and present educational and habilitative interventions, work programs, and living situation: their quality, consistency, and appropriateness; availability of supportive services; and long-term plans for the patient's care.
- Parents'/caregivers' attitudes toward the patient, their understanding of his/her disability, and support for growth versus overprotection.
- Review of past cognitive tests and evaluations or request for new ones if needed.

Patient Interview

Ample time must be allotted for the patient interview, which typically takes longer than with patients without MR. Sufficient time is needed to put the patient at ease.

The verbal examination should be adapted to the patient's communication skills and should use clear and concrete language, structure, reassurance, and support. Leading questions and questions requiring yes or no answers should be avoided, and the interviewer should ensure that questions are understood.

Patients with sensory impairments such as blindness or deafness must be approached in a manner that recognizes their

needs through the use of appropriate interpreters or communication devices.

Mental status may be assessed in the context of conversation, rather than in a formal examination. It is often helpful to start the interview with a discussion of a patient's strengths and interests, rather than problems, and later focus on the patient's understanding of disability, limitations, and reasons for the referral.

Nonverbal aspects of the interview include observations of performance on selected tasks, relatedness, expression of affect, impulse control, attention span, activity level, and the presence of unusual behaviors or seizures.

Medical Review

This review should include developmental and medical history, past etiological assessments, and coexisting general medical disorders and their treatments. The latter is particularly important, since undiagnosed medical conditions are frequent in this population and may lead to behavioral symptoms.

Diagnostic Formulation

Data from the assessments should be interpreted in light of developmental level, communication skills, associated handicaps, life experiences, education, and family and sociocultural factors. A particular behavior may suggest an underlying mental disorder if it is part of a pattern of a defined mental disorder syndrome. The possibility of sexual or other abuse that the patient cannot report should be considered. A *DSM-IV* diagnosis (in addition to MR) should be made if the appropriate criteria are met. The diagnostic statement should include a description of the person's strengths, deficiencies, and needs including intellectual, adaptive behavior, communication, health, and psychosocial domains. A comprehensive assessment should yield a multiaxial diagnostic formulation with appropriate differential, and supporting evidence for diagnoses should be highlighted.

SPECIFIC DIAGNOSIS OF COMMON COMORBID MENTAL DISORDERS

Pervasive Developmental Disorders

The majority of children with pervasive developmental disorders (PDDs) also have MR. However, children with MR alone do not have significant impairments in reciprocal social interaction and can engage in social communication, verbal or nonverbal (such as gestures and eye contact), appropriate to their developmental level.

Attention-Deficit/Hyperactivity Disorder

The diagnostic criteria for attention-deficit/hyperactivity disorder (ADHD) are based on observable behavior as reported by multiple informants and thus can be applied to nonverbal children. ADHD should be differentiated from situation-specific inattentiveness, such as at school if the academic expectations

are too high, and medication side effects. In assessing "non-compliance"—not following commands of caregivers—one should consider the child's ability to understand social rules and the presence of sufficient skills to communicate opposition.

Tic Disorders and Stereotypic Movement Disorder

In Tourette's disorder, the movements, as opposed to self-stimulatory stereotypies seen in persons with severe MR, are less complex and appear involuntary. For the latter, the diagnosis of stereotypic movement disorder may be used if other mental disorders are excluded. The specifier "with self-injurious behavior," is added if bodily damage results. Self-injurious behavior is common in certain MR syndromes, especially Lesch-Nyhan syndrome.

Mental Disorders Due to a General Medical Condition

MR, in and of itself, does not constitute a medical condition to which aberrant behavior or emotional disturbance should be ascribed. The attribution of behavioral or emotional disturbance to a general medical condition should be used only when there is evidence from history, physical examination, or laboratory findings that the disturbance is a direct consequence of a specific medical condition. For example, in the case of Down syndrome, hypothyroidism may present as symptoms of depression. In such cases, the medical disorder to which the depression should be attributed is hypothyroidism, not Down syndrome.

Schizophrenia and Other Psychotic Disorders

Schizophrenia can be diagnosed in the usual manner in verbal persons with mild MR, but rarely if at all in persons with more severe retardation. For the latter, the less specific diagnosis of psychotic disorder not otherwise specified (NOS) may be made, if behavioral features such as grossly disorganized behavior and negative signs are present, but were absent in the pre-morbid period. Conversation with an imaginary friend should not be confused with hallucinations.

Mood Disorders

Mood disorders, especially depressive disorders, are quite common in persons with MR. In verbal persons with mild MR the complaints are simple and concrete. History obtained from caregivers and evidence of neurovegetative signs help in assessing the mood change. Depression may also be manifest by aggressive behavior. Environmental events, such as a precipitous move to a new setting or change in care provider, may trigger a depressive episode. Medication side effects should be considered, for example, depression resulting from β -blockers or agitation associated with akathisia from a neuroleptic drug.

Anxiety Disorders

Verbal persons with mild MR can report on subjective feelings of anxiety; in nonverbal ones symptoms such as avoidance behaviors and agitation might suggest the diagnosis. The

tendency toward anxiety and social avoidance is also a part of the behavioral phenotype of fragile X syndrome.

Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) in persons with MR might be quite frequent and should be routinely considered in the differential diagnosis. These individuals are vulnerable to abuse because of difficulties in reporting it and a tendency to want to please others.

Obsessive-Compulsive Disorder

The diagnosis of obsessive-compulsive disorder (OCD) may be difficult in nonverbal persons who cannot report on obsessional thoughts underlying their compulsions. Some repetitive behaviors, for example, hoarding objects, flicking lights on and off, and tidying and arranging, all have been suggested as indications of OCD in persons with MR. Self-restraint, for example, insistence upon wearing a helmet or other protective device, is a behavior that has been described in persons who also exhibit self-injurious behavior and might suggest the ego-dystonic nature of self-injury. A connection between some self-injurious behaviors and OCD has thus been postulated.

Eating Disorders

Anorexia and bulimia nervosa are relatively rare in the context of MR, particularly moderate to severe MR, but MR is a predisposing factor for other eating disorders such as pica and rumination. The ingestion of nonnutritive substances, pica, and the regurgitation and rechewing of food, rumination, occur with greater frequency as the severity of cognitive disability increases. When these behaviors are a focus of clinical attention, the diagnoses should be indicated.

TREATMENT

The principles of psychiatric treatment are the same as for persons without MR, but modification of techniques may be necessary according to the individual patient's developmental level, especially communication skills. Medical, habilitative, and educational interventions should be coordinated within an overall treatment program. The mental health clinicians should actively participate with other professionals in the development of the various treatment interventions.

The Behavioral Emergency

When the clinician is called to assist with a behavioral emergency, the first task is generally to ensure the safety of the patient and others. For example, in the case of severe self-injurious or aggressive behavior, if the usual attempts at redirection fail and the patient continues to pose an imminent risk, it may be necessary to temporarily use physical restraint. In some instances this may require admission to a psychiatric hospital. The use of emergency medication may also be considered after adequate diagnostic assessment. Medical causes for an acute behavioral

exacerbation must always be considered. It is not uncommon for even simple problems such as constipation, infection, or even occult injury to set the stage for behavioral problems. Medication side effects such as akathisia from neuroleptics or disinhibition from sedative-hypnotic agents can be expressed in aggressive and self-injurious behaviors. When a temporizing measure is necessary, it is generally advisable to use a drug with which the patient has had a positive experience, typically a neuroleptic or benzodiazepine. The need for emergency treatment should prompt a comprehensive diagnostic assessment including the evaluation of environmental influences. Approaches should also be considered to prevent recurrence of such emergency situations for a given individual.

Psychosocial Interventions

Persons with MR may benefit from group, individual, and family psychotherapy. Concrete goals should be established, with the overall aim to achieve a maximally feasible quality of life. Disruptive behaviors should not merely be suppressed, but they should be replaced with constructive, adaptive behaviors and skills. Patients should learn to understand their own disability, focus on strengths, and develop a positive self-image, a realistic striving for independence, and age-appropriate social skills. The treatment techniques include focus on current reality, directiveness and structure to maintain focus, and activities adapted to chronological age. A therapist with training in developmental disorders is best equipped to accomplish these goals and to guide the patient to develop his or her own understanding. Therapists should be active, directive, and flexible, perhaps using themselves as examples, and should be prepared to give concrete advice.

Family therapy typically focuses on the parents' identification and support of their child's strengths and independence and the provision of opportunities for success. Parents of recently diagnosed children need careful explanation of their child's condition. Concrete advice in management and resource finding is important, as is help in obtaining educational supports to which the child is entitled under federal and local laws. Parents of adolescents and young adults need help in coming to terms with emergent sexuality and in emotionally separating and preparing them to move to out-of-family living in the community.

Pharmacotherapy

Medication effects generally are not different from those expected in the absence of MR. The adage, "start low, go slow," reflects the observation that shifts in dose-response in certain contexts are far more likely than changes in the mechanism of action of a compound; for example, persons with Down syndrome may be exquisitely sensitive to anticholinergic drugs, and some persons with MR may be more sensitive to the disinhibiting effects of sedative-hypnotic agents.

Several problems with pharmacotherapy are frequently encountered with persons with MR:

- Some clinicians appear to prescribe medication with inadequate information, aiming, for example, for symptom suppression seemingly without consideration of the potential negative impact on habilitative function or overall quality of life. Risks/benefits for medication appear not to be fully considered (e.g., drugs that adversely affect cognition, either directly or through sedation, appear to be used without clear justification and careful monitoring).
- There is no evidence of informed consent to support the prescription or administration of psychotropic medication.
- Medication appears not to be integrated as part of a comprehensive treatment plan (e.g., there is no evidence of a behavior plan; there is no evidence of communication between prescribing physician and other therapists; behavioral data are not collected).
- Medication may not appear to be appropriate for the diagnosis of record (e.g., a patient with a diagnosis of a mood disorder is receiving only thioridazine).
- Drug exposure appears to be excessive or poorly justified. Medication appears to be prescribed for extended periods for nonspecific indications for which other active treatments or environmental supports are needed. Multiple representatives from the same medication class and other complex polypharmacy regimens are used or no attempt can be seen over time to adjust medication doses to document ongoing need or the minimum dose at which a medication remains effective. In some cases treatment effectiveness is never clearly established.
- No evidence can be found for the active monitoring for emergent side effects, particularly in nonverbal patients.

Treatment Follow-up

A common problem in the treatment of persons with MR is assessing its effectiveness, which may be viewed differently by various caregivers. Therefore, discrete treatment goals should be agreed upon by the clinician and caregivers, as well as target or "index" symptoms. Interdisciplinary collaboration of professionals and caregivers is essential. Various mental health clinicians might function in the team as direct care providers, team leaders, or consultants to other professionals. Among them, clinicians with medically and psychologically oriented training are often prepared to function as synthesizers of treatment modalities of various disciplines. Follow-up includes patient interview/observation and obtaining comprehensive interim information. If the patient is not experiencing improvement, the accuracy and completeness of the biopsychosocial diagnosis should be reviewed, as well as the consistency of implementation of treatment by the caregivers.

REFERENCE

- American Academy of Child and Adolescent Psychiatry (1999), Practice parameters for the assessment and treatment of children, adolescents, and adults with mental retardation and comorbid mental disorders. *J Am Acad Child Adolesc Psychiatry* 38(suppl):5S-31S