

MENTAL RETARDATION

KEY FACTS

- Mental retardation (MR) affects approximately 1 percent of the U.S. population. In about 85 percent of individuals with MR, the level of retardation is classified as mild (King et al., 1999; McLaren and Bryson, 1987; Roeleveld et al., 1997, as cited in Szymanski and King, 1999).
- Down syndrome (the most common chromosomal abnormality), fragile X syndrome, and fetal alcohol syndrome (FAS) together are responsible for 30 percent of all identified cases of MR (Batshaw, 1993).
- The etiology of MR is unknown for about 60–80 percent of children and adolescents with mild MR and about 20–40 percent of children and adolescents with severe MR (McLaren and Bryson, 1987, as cited in Szymanski and King, 1999).

Mental retardation (MR) can result from a variety of causes: congenital malformations, genetic, teratogenic, infectious, toxic, and perinatal factors, and postnatal complications. It is often impossible to attribute a particular child's or adolescent's MR to a single cause; in half of the children and adolescents for whom causal factors are known, there is more than one such factor (e.g., early bacterial meningitis and lack of intellectual stimulation in the home). The milder the MR, the more difficult it typically is to identify a specific etiology.

MR is defined as a deficit in both intelligence and adaptive skills, with onset before age 18. MR is characterized by significantly sub-average intellectual functioning (an intelligence quotient [IQ] of approximately 70–75 or below), existing concurrently with related limitations as expected for age and by the individual's cultural group in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. Mental retardation reflects the "fit" between the capabilities of individuals and the structure and expectations of their environment. A valid assessment considers cultural and linguistic diversity as well as differences in communications and behavioral factors (American Association on Mental Retardation, 1997, 2001; American Psychiatric Association, 2000).

The life functioning of a child or adolescent with MR will generally improve if she has adequate and appropriate supports. To improve func-

tioning, a child or adolescent may need intermittent, limited, extensive, or pervasive support; the level of support needed varies from individual to individual and over time. In the past decade, there has been increased recognition of the potential of individuals with MR and greater understanding that limiting expectations of their abilities can be damaging. Primary care health professionals need to work together with children and adolescents with MR and their families to establish goals and to ensure that these children, adolescents, and families have the support they need to achieve these goals. The support needed may vary with the severity of MR as discussed below (King et al., 2000).

In about 85 percent of individuals with MR, the level of retardation is classified as mild. MR is best detected in infancy or early childhood so that early intervention strategies can be initiated; however, mild MR may not be recognized until the child enters preschool or elementary school. Individuals with mild MR can typically achieve at least fourth-grade-level to sixth-grade-level scholastic skills, and they can graduate from high school. As adults, they can hold jobs in the regular work force, marry, and raise families. If they encounter challenging life problems, they may need intermittent environmental supports.

In about 10 percent of individuals with MR, the level of retardation is classified as moderate. Moderate MR is usually identified during infancy or early childhood. School-age children with moderate MR frequently benefit from special education programs. With limited but consistent environmental supports, adults with moderate MR can thrive in neighborhoods and communities. Some function well in regular jobs, while others need more supportive job settings.



In about 3–4 percent of individuals with MR, the level of retardation is classified as severe. These individuals frequently have motor and neurological impairments as well as significant problems communicating. People with severe MR need extensive environmental supports and individualized help to maximize their adaptive skills. They can participate in their self-care. As adults, they may be able to work productively in structured work environments.

In 1–2 percent of individuals with MR, the level of retardation is classified as profound. These individuals also have pervasive problems in sensorimotor (both sensory and motor) and communicative functioning. Most children and adolescents with profound MR need pervasive or multiple environmental supports, including supports for self-care tasks such as grooming, toileting, and eating.

DESCRIPTION OF SYMPTOMS

Mental Retardation

(Diagnostic codes: 317, 318.x, 319)

Information below is from DSM-PC. Selected additional information from DSM-PC and DSM-IV-TR is available in the appendix. Refer to DSM-PC and DSM-IV/DSM-IV-TR for full psychiatric criteria and further description.

The diagnosis of mental retardation (MR) is coded as follows, based on level of cognitive functioning:

- V62.89 Borderline intellectual functioning (IQ level 71–84)
- 317 Mild MR (IQ level 50–55 to approximately 70)
- 318 Moderate MR (IQ level 35–40 to 50–55)
- 318.1 Severe MR (IQ level 20–25 to 35–40)
- 318.2 Profound MR (IQ level below 20 or 25)
- 319 MR severity unspecified is diagnosed when there is a strong presumption of mental retardation but the child's intelligence is untestable by standard intelligence tests

In addition, the child or adolescent shows concurrent deficits in the adaptive skills expected for his age and by his cultural group in at least two of the following areas: communication, self-care, home living, social

skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety. Onset is before age 18.

MR presents differently in infancy, early childhood, middle childhood, and adolescence. The following are examples of how MR may be manifested across developmental periods.

Infancy

- Significant limitations in emotional expressiveness, language, purposeful behavior, gross and fine motor skills, and apparent cognitive abilities
- Mild and moderate deficits may go undetected

Early Childhood

- Significant delays in communicating, walking, self-feeding, toilet learning, and social interaction
- Intellectual function is significantly below average

Middle Childhood and Adolescence

- Developmental delays are usually clear by this age
- Evaluation can identify strengths and weaknesses in cognitive and adaptive abilities

COMMONLY ASSOCIATED DISORDERS

Many children and adolescents with mental retardation (MR) (especially those with mild MR) are aware that they often cannot do what is expected of other children and adolescents their age and that they are different from their peers. They frequently have low self-esteem and are at high risk for emotional and behavioral difficulties. Children and adolescents with MR are also extremely vulnerable to exploitation by

both peers and adults (e.g., experiencing sexual abuse and assault, being led into unsafe behaviors).

Reported rates of the proportion of individuals with MR who have associated mental disorders vary from 10 to 60 percent (King et al., 1997). The psychiatric needs of individuals of all ages with MR remain largely unmet for several reasons, including the perceived difficulties in diagnosing mental disorders in

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COMMONLY ASSOCIATED DISORDERS (continued)

the presence of significant MR, a narrow focus on specific behavior issues, and the tendency to attribute symptoms of a mental disorder to MR rather than to a separate disorder (Reiss et al., 1982, as cited in Szymanski and King, 1999). Yet, co-occurring mental disorders are the primary factor preventing individuals with MR from adapting successfully to living in the community (Szymanski and King, 1999).

Commonly associated disorders in children and adolescents with MR include the following:

- Pervasive developmental disorders
- Attention deficit hyperactivity disorder
- Conduct disorder
- Anxiety disorders
- Mood disorders

INTERVENTIONS

Children and adolescents with MR require a multidisciplinary intervention approach that takes into account how to optimize functioning in each important area of a particular child's or adolescent's life. With appropriate supports over a sustained period, the life functioning of a person with MR will generally improve.

Child or Adolescent

1. Assess all infants, children, and adolescents for developmental delays at well-child visits. Pay particular attention to concerns parents might express about their child's or adolescent's development:

Infancy

- Unusual appearance (e.g., dysmorphic features, atypical head circumference)
- Failure to achieve developmental milestones (e.g., delays in sitting without support, delays in the development of babbling)

Early Childhood

- Not yet walking unassisted (> 18 months)

- Not yet talking (e.g., speaks fewer than 15 words by 18 months, does not use 2-word sentences by age 2)
- Pronounced lack of self-control (> 3 years)
- Delayed self-care skills (e.g., feeding, dressing and undressing)
- Little progress in toilet learning (> 3 years)

Middle Childhood and Adolescence

- Unable to do what is expected at home
- Forgets things
- Failing in school

Screening tools such as the Ages and Stages Questionnaires (ASQ) (Bricker and Squires, 1999), the Child Development Inventories (CDIs) (Ireton, 1992), and the Parents' Evaluation of Developmental Status (PEDS) (Glascoe, 1997) can help identify areas for further evaluation (Filipek et al., 1999). If an initial assessment indicates developmental delays, refer to an early intervention program, school, or assessment specialists as indicated. (See *Bright Futures Case Studies for Primary Care Clinicians: Using the Denver II: When to Watch, When to Refer, When to Reassure* [Davidson and Frazer, 2001]; Global Delay: Will

David Catch Up? [Deutch and Frazer, 2001]; Down Syndrome: Finding New Friends [Friedman and Knight, 2001] at <http://www.pedicases.org>, and information on screening tools in the Introduction to the *Mental Health Tool Kit*, p. vii.)

2. Assess and treat the child or adolescent for any associated medical concerns (e.g., seizures, poor visual acuity, or the medical problems associated with Down syndrome).
 3. Refer for therapeutic services (e.g., physical therapy, occupational therapy, speech therapy) as indicated.
 4. When talking with the child or adolescent, be aware of his level of cognitive development and communication skills. Use developmentally appropriate language to make requests or explain concepts. Language should be as clear and concrete as possible. When interviewing the child or adolescent, avoid leading questions and yes/no questions; children and adolescents with MR may choose the response they think will please and will often select the last option presented. Check repeatedly to make sure that the child or adolescent understands the questions you are asking (Szymanski and King, 1999).
 5. Recognize that children and adolescents with MR have strengths and capabilities, aside from their specific adaptive limitations. Help them identify their strengths, and support efforts to enhance these strengths. Focusing on strengths can increase self-esteem.
 6. Support children and adolescents with MR in achieving to the best of their ability. Work with each child or adolescent and family to identify goals and the supports needed to achieve their goals (e.g., classroom assistance, vocational train-
- ing, transportation assistance). Be aware of the child's or adolescent's developmental needs (e.g., for play and opportunities to make choices in early childhood, for friends and opportunities to make decisions in middle childhood, for increased independence and opportunities to work in adolescence).
7. Refer a child or adolescent who presents with persistent behavioral or emotional difficulties for a mental health assessment. Suggest positive behavioral support techniques to reinforce positive behaviors (Carr, 1999).
 8. Consult with a child psychiatrist or developmental-behavioral pediatrician about the use of psychopharmacologic agents to help with problems of attention, aggression, anxiety, and mood.

Family

1. Discuss the diagnosis of a child or adolescent with MR sensitively, honestly, and completely. Identify the child's or adolescent's areas of strength, offer emotional support, and provide opportunities for families to express their concerns and ask questions. The family will need to adjust, and they will need to support the child in ways they may not have expected. Help parents express and cope with their feelings and concerns (e.g., sense of loss, adjustment of expectations).
2. Encourage families to engage appropriate supports depending on the age, ability, and interests of their child or adolescent. Regular social, recreational, and physical activities are important for children and adolescents with MR.
3. Help families implement behavioral management plans to increase their child's or adolescent's adaptive behaviors (e.g., meeting household

- responsibilities) and decrease her maladaptive behaviors (e.g., temper tantrums, emotional lability, disruptive behavior).
4. Counsel families about developmental stages and tasks that may present particular challenges for children or adolescents with MR (e.g., toilet learning, development of friendships, school functioning). As children with MR enter adolescence, help families discuss and address issues such as social relationships, sexuality, increasing independence, and vocational training.
 5. Encourage families to work with their child or adolescent on decision-making and safety skills (e.g., learning how to recognize potentially dangerous situations, how to get help, and how to respond to pressure from peers).
 6. Work with adolescents and their families to engage supports that improve functioning and to plan for the adolescent's transition to adulthood, including the transition to employment and independent living. Provide information on community resources that can help adolescents make this transition (e.g., high school vocational planning programs, local rehabilitative agencies, local chapters of The Arc [an organization of and for people with mental retardation and related developmental disabilities and their families]).
 7. Refer families to national organizations or local, state, and federal agencies for further support. (See Resources for Families, p. 267.)

Friends

1. Recognize that a child or adolescent may need help in sustaining friendships because of communication problems and impairment of age-appropriate self-care and social skills.

2. Help identify year-round group activities in which the child or adolescent can participate.
3. Discuss arranging scheduled activities with supportive peers.
4. Consider activities such as Unified Sports or Special Olympics to help the child or adolescent meet a wider circle of peers, to boost his self-esteem, and to offer families an opportunity to network.

Community and School

1. Advocate for a comprehensive evaluation of the child's or adolescent's cognitive abilities and needs as soon as developmental delays are evident.
2. Refer the child or adolescent for additional services (e.g., early intervention services, speech and language services, occupational and physical therapy) after assessing her specific needs. Children and adolescents with MR are eligible for early intervention and special education services through the Individuals with Disabilities Education Act (IDEA). Offer to participate in the child's Individualized Family Service Plan (IFSP) (ages 0–3) or Individualized Education Program (IEP) (ages 3 and up). (See Tool for Families: Individualized Education Program [IEP] Meeting Checklist, *Mental Health Tool Kit*, p. 120.) The IEP and IFSP are required under the Individuals with Disabilities Education Act (IDEA), Part B, Assistance for Education of All Children with Disabilities, and Part C, Infants and Toddlers with Disabilities, respectively. The IFSP and IEP document the child's (and family's in the case of the IFSP) current level of functioning, establish goals, and delineate the services needed to meet those goals.



Children or adolescents with MR may also qualify for services under Section 504 of the Rehabilitation Act.

For further information about eligibility and services, families can consult the school's special education coordinator, the local school district, the state department of education's special education division, the U.S. Department of Education's Office of Special Education Programs (<http://www.ed.gov/offices/OSERS/OSEP>), the IDEA '97 Web site (<http://www.ed.gov/offices/OSERS/IDEA>), or the U.S. Justice Department's Civil Rights Division (<http://www.usdoj.gov/crt/edo>).

3. Pay special attention to the child's or adolescent's language abilities and level of social maturity when helping families and schools assess options for academic placement.
4. Encourage parents to develop an educational plan that allows the child or adolescent to develop strengths and interests (e.g., expressive vocabulary, visual memory, music, art). (See Tool for Families: Individualized Education Program [IEP] Meeting Checklist, *Mental Health Tool Kit*, p. 120.)
5. Continue to be available to children and adolescents with MR and their families to support and advocate for the child's or adolescent's academic and vocational needs as she progresses through school. Focus on interventions that can help maximize the child's or adolescent's scholastic achievement and adaptive functioning (e.g., vocational training, person-centered planning) (Falvey et al., 1994; Mount and Zwernik, 1988; Smull and Harrison, 1992; Turnbull and Turnbull, 1996).

Resources for Families

Academy for Educational Development, National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013
Phone: (800) 695-0285
Web site: <http://www.nichcy.org>

NICHCY is funded by the Office of Special Education Programs, U.S. Department of Education, and provides access to resources including state- and local-level agencies and resources.

Administration for Children and Families
 Administration on Developmental Disabilities
 U.S. Department of Health and Human Services
 Mail Stop HHH 300-F
 370 L'Enfant Promenade, S.W.
 Washington, DC 20447
 Phone: (202) 690-6590
 Web site: <http://www.acf.dhhs.gov/programs/add>

American Association of University Affiliated
 Programs for Persons with Developmental
 Disabilities (AAUAP)
 8630 Fenton Street, Suite 410
 Silver Spring, MD 20910
 Phone: (301) 588-8252
 Web site: <http://www.aauap.org>

American Association on Mental Retardation
 444 North Capitol Street, N.W., Suite 846
 Washington, DC 20001-1512
 Phone: (800) 424-3688
 Web site: <http://www.aamr.org>

The ARC
 1010 Wayne Avenue, Suite 650
 Silver Spring, MD 20910
 Phone: (301) 565-3842
 Web site: <http://www.thearc.org>

Di Lima SN, Niemeyer S, Carson JR. eds. 1998. *Caregiver Education Guide for Children with Developmental Disabilities*. Gaithersburg, MD: Aspen Publishers.

National Down Syndrome Society (NDSS)
 666 Broadway, Eighth Floor
 New York, NY 10012-2317
 Phone: (212) 460-9330, (800) 221-4602
 Fax: (212) 979-2873
 Web site: <http://www.ndss.org>

NDSS promotes public awareness and education about Down syndrome, supports research on this genetic disorder, and provides referral and information services for people with Down syndrome and their families.

National Fragile X Foundation (NFXF)
 1441 York Street, Suite 303
 Denver, CO 80206
 Phone: (303) 333-6155, (800) 688-8765
 Fax: (303) 333-4369
 Web site: <http://www.nfxf.org>

NFXF is a nonprofit organization that informs professionals, parents, and the public about the diagnosis and treatment of fragile X syndrome and other forms of X-linked MR.

National Library of Medicine
 FAS Web site: <http://www.nlm.nih.gov/medlineplus/fetalalcoholsyndrome.html>
 Down syndrome Web site: <http://www.nlm.nih.gov/medlineplus/downsyndrome.html>
 Genetic disorders Web site: <http://www.nichd.nih.gov/publications/pubs/Fragilex.htm>

The National Library of Medicine offers electronic resource guides for FAS, Down syndrome, and genetic disorders (including fragile X syndrome).

National Organization on Fetal Alcohol Syndrome (NOFAS)
 216 G Street, N.E.
 Washington, DC 20002
 Phone: (202) 785-4585, (800) 66-NOFAS (66327)
 Fax: (202) 466-6456
 Web site: <http://www.nofas.org>

NOFAS is a nonprofit organization dedicated exclusively to eliminating FAS and helping children and families touched by alcohol-related birth defects.

Office of Special Education and Rehabilitative Services
U.S. Department of Education
330 C Street, S.W., Room 3132
Washington, DC 20202-2524
Phone: (202) 205-8241
Web site: <http://www.ed.gov/offices/OSERS>

This office includes the Office of Special Education Programs and the Rehabilitative Services Administration.

Social Security Administration/Supplemental Security Income (SSI)

Phone: (800) 772-1213

Web site: <http://www.ssa.gov/pubs>

The Social Security Administration/Supplemental Security Income (SSI) can provide information on financial support for individuals with MR.

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