

When is the diagnosis made?

The onset of mental retardation is in childhood, before 18 years of age. The diagnosis is generally made after infancy, between the preschool and school-age periods. Sometimes the diagnosis may be made later, at the time when a thorough assessment is performed.

What causes mental retardation?

Mental retardation has many different causes, and sometimes biological, social, behavioral, and educational factors interact to affect how a person functions. Events that may be associated with the diagnosis of mental retardation may occur before, during, or after birth. There may be genetic (inherited) conditions, serious infections, vascular (blood vessel) problems, trauma (injury) to the brain, metabolic (body chemistry) conditions, or exposure to toxins (like lead or alcohol) that can all cause or contribute to mental retardation. It also may be difficult or not possible to identify a specific cause.

Can a child with MR have other disabilities?

A child with mental retardation may or may not have other disabilities. Some common developmental disabilities associated with mental retardation are autism, cerebral palsy, epilepsy, and vision or hearing impairments.

Will my child need medical tests?

A number of factors are considered when making the decision to perform medical tests. Not all children require that many tests be done. Your child's presenting concerns, past medical history, family history, physical exam, and results of our evaluation or others will determine which tests, if any, are recommended. Some tests may affect the treatment of your child, while others may help in identifying a specific medical condition related to the diagnosis of mental retardation. In those instances, information may be available regarding future progress, the need for other medical monitoring, and the chance that family members may inherit a certain trait.

Is mental retardation the same as mental illness?

No. Mental illness, or psychiatric disability, has to do with emotional or behavioral problems. While children with mental retardation can have a psychiatric disability, the two conditions are separate and require different types of intervention.

Will medication help my child?

There is no medication to treat mental retardation. It is considered a disability, not a disease. Sometimes medication is used for other associated conditions or behavioral problems, such as difficulties with attention or mood.

Are there different types of mental retardation?

Yes. In general, a person with MR has an IQ lower than 70 (approximately two standard deviations below the mean), although this number may change based on how a person functions in his or her environment. A person with mental retardation functions below age expectation in his or her daily activities, and requires additional support by others compared to most children of the same age. There are different classifications of mental retardation.

- a) Mild retardation:** About 85% of children with mental retardation. Children with mild retardation can generally learn reading, writing, and math skills between the third- and sixth-grade levels. In adulthood, they may have jobs and live independently.
- b) Moderate mental retardation:** About 10% of children with mental retardation. Children with moderate mental retardation may be able to learn some basic reading and writing. They are able to learn functional skills, such as safety and self-help. Adults with moderate mental retardation usually require some type of oversight or supervision.
- c) Severe mental retardation:** About 5% of children with mental retardation. Children with severe retardation probably will not be able to read or write, although they may learn self-help skills and routines. They will require supervision in their daily activities and living environment.
- d) Profound mental retardation:** Affects about 1% of children. Children with profound retardation will need intensive support for the rest of their lives. They may be able to communicate by verbal or other means. Some children and adults have medical conditions that require ongoing nursing and therapy support.
- e) Mental Retardation, Not Otherwise Specified:** The exact level of functioning cannot be determined with certainty. Sometimes a child has not yet received the needed intensive supports and it is unclear how he or she will respond to these services. Other times, testing cannot be completed or is not felt to reflect a child's potential. In those instances, further testing is required at a future date to be able to better determine the level of functioning.

Are there other terms used to indicate mental retardation?

When a child is young, the term "delay" is sometimes used to describe developmental skills being at a lower level than expected for a child's age, in language, motor, cognition, play, or other areas. As a child becomes older, he or she may or may not "catch up" in all or some of the developmental skills.

The term "mental retardation" may later be used for some of these children, when it is felt that they will no longer totally catch up in their development, based on reliable tests of cognition (intelligence), adaptive skills (everyday functioning), interaction with the environment or surroundings, and supports needed within the community.

Other terms have been also used in place of "mental retardation," such as "intellectual disability" and "cognitive disability."

Where will my child receive his or her needed services?

Children generally live at home with their families providing for their needs, often with the assistance of workers from state agencies. Until your child reaches the age of three, services are provided through the Early Intervention system. A Services Coordinator (Case Manager) works with parents and/or guardians to develop an Individualized Family Services Plan (IFSP). Services for a child with developmental delay may include individual therapies, play groups, parent training, family counseling, or transportation services. Depending on your state, there may be a sliding-scale fee for these services, or they may be free of charge.

At three years of age, the school system begins to provide the needed school and therapy services. As noted in the Individuals with Disabilities Education Act (IDEA), children with mental retardation are entitled to a free and appropriate education based on their needs. School systems are required to work with parents to develop an Individualized Education Program (IEP). The IEP describes each child's own needs and how the school system will meet them. Both special education and other needed services are provided free of charge.

Ideally, children with mental retardation are enrolled in regular classrooms with children of the same age, with special supports as needed. They may be included in a regular classroom for all or part of the school day. Sometimes children may also attend specialized classrooms or schools, based on their individual needs.

PARENT INFO

How much help will my child need?

The amount of services that a child needs will vary for each individual based on the level of cognitive disability, adaptive skills, physical and emotional well-being, and resources at home and in the community. In addition to identifying areas in which a child needs help, it is also important to build on his or her areas of strength.

What can I do to help my child?

While different therapists, educators, and other specialists can provide special training, the best thing you can do is include your child in warm and lively family living. Have your child participate in a loving and active environment that celebrates life, including participation in social and recreational activities in your community. Assist your child to develop as much independence and functional skills as possible. It is important to have open and ongoing communication with your child's teachers and therapists in order to carry over tasks and activities in the home setting.

Where can I go for more help?

We have found that most families find joining a parents' support group to be very helpful. In addition to using developmental centers as a resource, such as the Developmental Medicine Center at Children's Hospital, you may also wish to learn about and take advantage of resources offered through some of the agencies listed on the back of this pamphlet.

References:

American Association on Mental Retardation. *Mental Retardation: Definitions, Classifications, and Systems of Supports*, www.aamr.org

American Association on Mental Retardation. *Mental Retardation Fact Sheet*, www.aamr.org

Batshaw, M.L. (Ed.). *Children with Disabilities* (5th ed.). Paul H. Brookes Publishing Co., Inc., www.brookespublishing.com

Keep Kids Healthy. *Mental Retardation in Children*, www.keepkidshealthy.com

National Center for Birth Defects and Developmental Disabilities. *Mental Retardation*, www.cdc.gov/ncbddd/ddmr.htm

National Dissemination Center for Children with Disabilities. *Disability Info: Mental Retardation*, www.nichcy.org

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Resources

New England State Agencies

Connecticut

Department of Mental Retardation
460 Capitol Avenue
Hartford, CT 06106
(860) 418-6000
www.dmr.state.ct.us

Maine

Mental Retardation Services
Department of Behavioral and
Developmental Services
40 State House Station
Augusta, ME 04333
(207) 287-4242; (207) 287-2000 (TTY)
www.maine.gov/bds

Massachusetts

Department of Mental Retardation
500 Harrison Avenue
Boston, MA 02118
(617) 727-5608
www.mass.gov/dmr

New Hampshire

Division of Developmental Services
105 Pleasant Street
Concord, NH 03301
(603) 271-5034
www.dhhs.state.nh.us

Rhode Island

Division of Developmental Disabilities
Department of Mental Health, Retardation
and Hospitals
14 Harrington Road, Barry Hall
Cranston, RI 02920
(401) 462-3234

Vermont

Division of Developmental Services
Department of Developmental and Mental
Health Services
103 S. Main Street, Weeks Building
Waterbury, VT 05671-2614
(802) 241-2648; (802) 241-2614
www.state.vt.us/dmh

Massachusetts Organization

Federation for Children with Special Needs
1138 Tremont Street, Suite 420
Boston, MA 02120
(617) 326-7210; (800) 331-0688 (in Mass.)
www.fcsn.org

National Organizations

American Association on Mental
Retardation
444 North Capitol St. NW, Suite 846
Washington, DC 20001-1512
(202) 387-1968, (800) 424-3688
www.aamr.org

The Arc of the United States
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
(301) 565-3842
www.thearc.org

Division on Developmental Disabilities
The Council for Exceptional Children
1110 North Glebe Road, Suite 300
Arlington, VA 22201-5704
(888) 232-7733; (703) 620-3660;
(866) 915-5000 (TTY)
www.dddcec.org

National Dissemination Center for
Children with Disabilities
P.O. Box 1492
Washington, DC 20013
(800) 695-0285
www.nichcy.org

National Down Syndrome Congress
666 Broadway, 8th Floor
New York, NY 10012
(800) 221-4602
www.ndss.org

National Fragile X Foundation
P.O. Box 190488
San Francisco, CA 94119
(800) 688-8765
www.fragilex.org

The Prader-Willi Syndrome Association
5700 Midnight Pass Road
Sarasota, FL 34242
(800) 926-4797
www.pwsusa.org

Supplemental Security Income (SSI)
Social Security Administration
Office of Public Inquiries
Windsor Park Building
6401 Security Blvd.
Baltimore, MD 21235
(800) 772-1213; TTY (800) 325-0778
www.socialsecurity.gov

TASH
29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
(410) 828-8274
www.tash.org

Answers To Parents' Questions On Mental Retardation



CHILDREN'S HOSPITAL BOSTON
INSTITUTE FOR COMMUNITY INCLUSION

What exactly is mental retardation (MR)?

The term "mental retardation" is used to indicate a person's intelligence and daily functioning, which are expected to be lower than other people of the same age. The diagnosis also reflects how a child interacts with his or her environment, and how much social and other supports are needed. Children with mental retardation are important and endearing youngsters with a special style of learning. Most are happy and healthy. Children with mental retardation learn and show developmental progress, although at a rate slower than others. They may take longer to learn to speak, walk, dress, or eat by themselves. With ongoing support to meet each individual's needs, the functioning of a person with mental retardation can be expected to improve over time.

How is the diagnosis made?

The diagnosis is made based on the results of testing cognitive abilities (intelligence) and adaptive skills (how a child functions in everyday activities). A psychologist generally administers the cognitive testing. The psychologist or developmental pediatrician may also use a test to determine adaptive skills. Consideration also needs to be given to the environment in which a person lives, and the manner in which he or she interacts with others on a daily basis.