

Mental Retardation

Also called Developmental Disability (DD), Static Encephalopathy

Description of the Disability

Mental Retardation (MR) is an umbrella term that covers a variety of similar cognitive disorders that occur during childhood or young adulthood. It is important to remember that mental retardation is literally a slowing down (retarding) of a person's cognition - these individuals learn and think much like everyone else, only more slowly. There are two major differences in their learning compared to the rest of the population. The first is a tendency to focus on concrete concepts (how to use a computer, for example) and a consequent difficulty with abstract concepts (how the monster movies of the 1950s were really about anxiety over communism, for example). The second difference is a difficulty generalizing information or skills from one setting to another (applying classroom math skills to figuring out how much cloth you need to make a shirt, for example). Individuals with mental retardation can think, feel, do, and learn most of the same things as anyone else, but it may take them longer to do it. Their development as a person will go through the same basic stages as everyone else, but it may take them longer to reach the same milestones. In employment situations, once trained, individuals with MR can be very effective workers.

Clinically, an individual is considered to have MR if:

- Their intelligence functioning is below average (usually interpreted as an IQ below 70-75)
- And they have deficits in (usually) 2 or more of the following adaptive skill areas: communication, leisure, health and safety, self-care, home living, self-direction, functional academics, community use, and work
- And the characteristics above started before age 18

(A person with low IQ who does not have limits in adaptive skills would not have MR.)

There is great diversity among individuals with MR in personality, learning, intelligence, interests, dislikes, talents, humor, attitudes, and aptitudes. Although there are always some intellectual challenges, this varies greatly from person to person. Specific skills and assets must be individually assessed.

There are two major ways to classify individuals with MR. The first classification system includes three levels:

- Severe – Unable to care for basic needs (2% of all MR)

- Moderate – Trainable for basic skills in selected vocational areas (13% of all MR)
- Mild – With training can live independently and work (85% of all MR)

The severe category is sometimes broken down to include ‘profound’ MR (IQ below 50). In vocational rehabilitation the term ‘borderline’ has been used for individuals with IQs between 70 and 80.

Many rehabilitation experts prefer another set of categories based on a person’s functional skills and how much support he or she needs in each skill area. This system also has four levels of support intensity:

Intermittent Support Needs: Support is provided "as needed", but most of the time the individual functions well on their own.

Limited Support Needs: Support provided regularly for a period of weeks or months and then transitioned out. Like intermittent support, limited support is provided as needed, but it lasts longer.

Extensive Support Needs: These are supports provided continuously, long term, but only in one or two aspects of their lives.

Pervasive Support Needs: These are supports provided continuously in several aspects of the person's life, such as work, home, and community involvement.

Under this system of classification, a person with MR will have different levels of intensity of support in different adaptive skill areas, rather than a single rating. A particular person may need pervasive “environmental” support for traveling around town, only need intermittent support at work, and need limited health support as he recovers from injuring his back last month. The documents describing this person will look more like a profile chart than like a single label. Because there is no single “condition” of mental retardation, each individual will be different and have a different pattern of support needs.

Some older literature used a third classification system that assigned a "mental age" rating to a person based on their IQ score, but that classification system is no longer considered useful. Other literature of that period also classified individuals as educable or non-educable, another classification system that professionals no longer use.

Limited life experience and work history can be a significant source of functional challenges for individuals with MR. Understanding all the different rules of behavior involved in the work setting may initially be a major task for the person. Teaching them how to fit in at a job can be much harder than teaching the different job tasks.

Many different things can cause mental retardation. Three major causes (described below) are **Fragile X Syndrome**, **Down Syndrome**, and **Fetal Alcohol Syndrome**. Other possible causes include

- Trauma (prenatal or postnatal) (Anoxia, Fetal Alcohol Syndrome, etc.)
- Infections (congenital rubella, meningitis, encephalitis, HIV, etc.),

- Chromosome abnormalities (involving a physical problem with a chromosome rather than a specific gene code) (Downs, Fragile X, Klinefelter's, Prader-Willi, Cri du chat syndromes, etc)
- Genetic abnormalities (involving a specific gene) (Hunter syndrome, Tay-Sachs disease, Adrenoleukodystrophy, Rett's disorder, etc.)
- Metabolic disorders (Reye's syndrome, Hypoglycemia, etc.)
- Toxic chemicals (lead poisoning, etc.)
- Nutritional deficits
- Environmental issues (poverty, pollution, etc.)
- NOS -For some individuals, the specific cause is unknown.

Fragile X Syndrome (also called Martin-Bell Syndrome):

This genetic disorder is the most common form of inherited MR. It is called Fragile X because there is a gap in the normal gene sequence of the X chromosome. The gap is composed of multiple copies of the same gene, which codes for a protein involved with brain function (FMRP - Fragile X Mental Retardation Protein). The extra copies of the gene scramble the protein and cripple the protein production.

The severity of symptoms is different for men than for women. Men with Fragile X typically have a moderate to severe form of mental retardation, among other symptoms. Women can be affected but generally have milder symptoms because, genetically, women are XX, so typically only one of the two X chromosomes is affected. One third of women with Fragile X Syndrome will not show any symptoms. Others may experience only a learning disability or they may have a set of symptoms similar to those of men with the syndrome.

In addition to mental retardation, other behavioral and physical symptoms are associated with Fragile X. Approximately one fifth of people with Fragile X show behaviors similar to autism, including as poor eye contact, hand flapping, or hand biting. They often have distinctive physical features, including large ears, a long narrow face, loose joints, and Lazy Eye (Strabismus). Some individuals have a Seizure Disorder (see entry), although it is usually mild. Many also have Learning Disorders (see entry). The individuals are sometimes shy and may have difficulty with social skills. These individuals may also show "hyperarousal", which means they can be easily over-stimulated, causing them to become agitated or to over-react to changes in their surroundings. Because of this, the individual may have an undeserved reputation for behavior problems. It may be useful to minimize stimulation and distractions in the workplace for a client with Fragile X Syndrome. The hyperarousal and distractibility are similar in many ways to ADHD (see entry).

Individuals with Fragile X Syndrome may also show Tactile Defensiveness - an extreme sensitivity to touch and textures. People with tactile defensiveness may avoid physical contact with other people (especially light touches - firm handshakes may be OK), may avoid crowds, and may prefer clothes with certain kinds of fabrics. This can also lead to reluctance about shaving, getting haircuts, or going to the dentist.

Down Syndrome:

Down Syndrome is caused by an extra 21st chromosome, providing the individual with a total chromosome count of 47 in each cell, rather than the usual 46. The presence of this duplicate chromosome appears to cause the characteristics associated with Down Syndrome. No one knows why this genetic change happens, but it is not due to prenatal factors or anything the mother has done - although the odds of having a child with the syndrome increase with the age of the mother.

People with Down Syndrome usually have some level of mental retardation. They may also have problems with hearing, vision, and congenital heart conditions. The distinctive physical traits often associated with the syndrome include slanted eyes; a small/short head which is somewhat flattened at the back and front; a flattened bridge of the nose; a thick tongue; stout hands, feet, and limbs; and reduced muscle tone. Many individuals with Down Syndrome have significant hearing loss. Life expectancy for someone with Down Syndrome is 10 to 20 years less than for the rest of the population, often because of congenital heart conditions.

People with Down Syndrome show a great diversity in personality, learning, interests, dislikes, talents, humor, attitudes, and aptitudes. They are often stereotyped as loving, trusting, out-going, and almost childlike people, but this stereotype is inaccurate.

Fetal Alcohol Syndrome (FAS):

FAS is a set of congenital disabilities, both mental and physical, that are caused by a child's mother drinking alcohol while carrying the fetus. Even small amounts of alcohol can cause trouble for the fetus because the alcohol can cross the placental barrier into the child's blood and the child's developing liver cannot process and remove the toxin quickly. FAS is the most common form of preventable MR.

Individuals with FAS may have brain damage, growth abnormalities, heart defects, kidney defects, bone and joint abnormalities, and long-term behavioral problems. Reasoning, judgment, and impulse control may be significant challenges for a person with FAS. They may also have a Learning Disability (see LD entry). Distinctive physical characteristics associated with FAS include a small head, a low nasal bridge, a short nose, small eyes, a flattened midface, and a thick upper lip.

Fetal Alcohol Effects is a milder version of Fetal Alcohol Syndrome, with the same cause and similar consequences.

Possible coexisting conditions for mental retardation (all types)

- Vision impairment
- Hearing impairment
- Musculoskeletal impairment
- Autism

- Mental Illness (mood disorder or schizophrenia)
- Personality Disorder
- Learning Disorder (Technically, LD requires an IQ above 85, so the official definition would not apply. However, in a sense, MR is similar to LD (see above on cognition), so similar issues of learning and patterns of strengths and weaknesses will apply.)

Incidence Statistics

- 1-3% of the general population has MR (7 - 8 million people in the US).
- There are more than 500 genetic diseases associated with MR.
- MR is 12 times more common than cerebral palsy and 100 times more common than total blindness.
- MR cuts across all racial, ethnic, educational, social and economic lines.
- About 85% of people with MR are mildly affected. 13% have serious functional limitations, and 2% are profoundly affected.
- 0.1% of the population has Fragile X Syndrome.
- 15% of children with Fragile X Syndrome are diagnosed with Autism as well.
- Among women who abuse alcohol, 30% of births show FAS.
- 0.1% of the population has Down Syndrome.
- About 1 in 800 of all babies born worldwide are born with Down syndrome.
- The odds of having a child with Down Syndrome increase dramatically with the age of the mother, especially after age 35. Surprisingly, most children with Down Syndrome are born to women in their late 20s - there are just more people having children at that age.
- There are 10-12 thousand new cases of Fetal Alcohol Syndrome in the U.S. each year.
- Studies of employees with MR show they are identical to other employees in regard to performance, attendance and turnover. Employers do not consider them a safety risk.
- 60-80% of individuals with MR are not employed. Between 7% and 20% are employed full-time, and between 9% and 20% are employed part-time.

Common Treatments, Medications, and Side Effects

There are no medications for treating Down Syndrome, Fragile X Syndrome, Fetal Alcohol Syndrome, or for mental retardation in general. In some cases surgery can correct specific physical abnormalities. Other specific symptoms (such as seizures or attention problems) may be treated with appropriate drugs. In particular, Carbatrol (Carbamazepine) is sometimes used to treat seizures, behavioral issues, and psychiatric disorders associated with Fragile X Syndrome

(See Drug Entry). Phenobarbital and Dilantin may also be prescribed for control of seizures. (See entry on Seizure Disorder)

Possible Functional Issues

Because there are so many different kinds of mental retardation, the possible functional issues are quite diverse. Some of the common ones include:

- Difficulty generalizing skills and experiences from one environment to another
- Difficulty structuring work time
- Reduced problem solving strategies
- Impulsive behavior
- Attention seeking behavior
- Reduced coordination
- Reduced dexterity
- Expressive language (speaking, etc.) skills better than comprehension skills
- Reduced reading skills
- Reduced math skills (counting, adding, etc.)
- Inappropriate habits or rituals
- Short attention span/distractibility
- Limited social judgment
- Limited interpersonal skills
- Memory deficits
- Hyperactivity
- Difficulty learning from consequences
- Emotional outbursts when frustrated or over stimulated
- Difficulty handling money
- Transportation issues (driving or using public transportation)

Initial Interview Considerations

Initial Questions

Although questions should be directed to the individual, it may be helpful to have family members or other persons who know the individual (service providers, friends, etc.) present.

Always direct your questions to the individual and allow them to seek assistance from others. Break down concepts into small, easy to understand components. Keep in mind that because persons with MR often try to please others they may say what they think you want to hear. Try to avoid prompting them or steering them. Also they may act as though they understand a concept when in fact they do not - try to ask questions to confirm their understanding.

- What is their living situation?
- Which self-care issues do they handle themselves? Dressing, bathing, or cooking?
- Have them describe their past work- what they did, how they liked it, how successful they were, how they got along with others at work (a chance to discuss work history and workplace social skills).
- How well do they handle their own money?
- At what grade level do they read? Can they recognize their own name written out, for example?
- How well can they follow written instructions, such as a cooking recipe?
- What kinds of transportation do they use? (Car, Public Transportation...)
- How often if ever have they had seizures? What medication if any are they taking for it if they have?
- What problems if any do they have with hearing or vision?
- How physically active are they? Have they ever participated in any sports?
- What do they do for fun?
- What is a typical week like for the person? What do they do on weekends?
- How often, if every, have they been hospitalized? Why?
- How do they feel about working around groups of people? What sized group would feel comfortable to them?
- Would it be OK with the person if you talk with other people who know them, so you can learn more about their abilities and preferences?

Initial Observations

- How is their attention span?
- Do they have any difficulty sitting still?
- How are their communications and social skills?
- How is their grooming?
- Do they have any difficulty seeing or hearing?
- Do they seem able to read and understand documents?

- Do they avoid physical contact? (see Tactile Defensiveness under Fragile X discussion above)
- Do they have any difficulty with coordination, dexterity, or balance?

Interview Accommodations (if any)

- Hold the interview in a room with minimal distractions
- Have a family member or close friend present
- Break down information into short, easy to understand concepts.

Possible Accommodations and Assistive Technology

Pre-employment Assistance

- Provide instructions in a slow, simple and concrete manner. (Some individuals have difficulty learning through verbal instructions and do better with visual cues.)
- During training, place the individual close to the instructor.
- Train or teach in short segments with breaks to avoid attention deficit problems.
- Provide visual cues such as illustrations, color-coding, numbering, and arrows to organize tasks (see entry on learning disability)
- Job seeking skills training and support (interpreting want ads, filling out applications, etc.)
- Job trials instead of traditional verbal interviews

Workplace Accommodations

- A workplace with minimal distractions
- Limited amount of written information to process.
- Demonstrations to accompany instructions about tasks and performance.
- Regular routines
- Advance warning when duties or tasks will change
- Job coaching
- Co-worker as mentor
- Alternative transportation if necessary for training or work. Service needs might include training to use a bus, arranging rides with neighbors, relatives, friends or co-workers, or locating a job site within walking distance of home.
- Training on appropriate workplace behavior, including

- The importance of work and earning money.
- The job must be done correctly.
- The amount of work done and speed are important.
- Workers must continue to work even when their boss is not around.
- Some talking is OK, but too much may interfere with your work.
- It is important to be on time to work and back to work after break times.
- Workers must stay in their work area and keep working during work hours.

Career Planning Issues

- A “place and train” model seems to work better than a “train and place” model. In the train and place model the person learns work skills in a classroom setting, and often these do not transfer to the actual work site. In the place and train model, they learn work skills on the worksite and in the context of the working environment
- Although the person may learn appropriate work behaviors, the skills may deteriorate after time on the job. Often, because of past work in sheltered environments and living in group homes, these individuals have conflicting experiences upon which to draw. Older, less appropriate work habits (such as taking frequent, long breaks) may interfere with newly learned work habits (taking fewer, brief breaks). Follow-up and on-going support can be very important for workplace behavior.
- Other areas to assess and possibly provide training include:
 - Self-control.
 - Grooming and hygiene.
 - Social skills (especially regarding co-workers and bosses).
 - Independent living skills (including money management).
- Making decisions about careers may be difficult for individuals with MR and they may have limited work experiences to guide them. Tours, job shadowing, career exploration activities and trial work experiences while still in high school can be useful.
- People with MR whose lives are well rounded appear to do better at work. It is appropriate to pay attention to the person’s physical fitness and social activities.
- Individuals with MR may need extensive instruction in job seeking skills (interviewing and completing applications). They may need applications completed for them if they can’t read or write.
- For some individuals, traditional verbal interviews may not be appropriate or even possible. A job tryout may be a better approach than an interview.
- Explore the job goal carefully with the individual. The individual may agree with things just to please you or because they don’t understand, leading to jobs they do not like or

want. Help them thoroughly think about their job choices. In the end persons with MR want what everyone wants - a job they like and decent pay in return for hard work.

- Address any coexisting disabilities, such as epilepsy, depression, alcoholism, learning disabilities, hearing problems, visual problems, and heart/kidney problems.

Emerging Issues

- Community integration
- School inclusion and transition issues
- Independent living
- Home and community based services
- Implications of Medicaid waiver for funding of community supports
- Equivalence (or non-equivalence) of sheltered employment and competitive employment
- Rights regarding marriage and having children
- Legal responsibilities in terms of crimes, accidents, etc.

Additional Information Resources

- The ARC (formerly the Association of Retarded Citizens): www.thearc.org
- National Organization on Fetal Alcohol Syndrome: www.nofas.org/what.htm
- National Down Syndrome Congress: www.ndscenter.org
- National Down Syndrome Society: www.ndss.org
- National Fragile X Foundation: www.nfxf.org
- The 11q Network (Jacobson's Syndrome): web.ukonline.co.uk/c.jones/11q/contents.htm
- The Prader-Willi Syndrome Association: www.pwsausa.org
- Chromosome Deletion Outreach (rare chromosome disorders): www.chromodisorder.org