

Training Module

Introduction to Developmental Disabilities

Presented by

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Part I

Introduction to Developmental Disabilities

What is mental retardation?

Mental retardation is a developmental disability that can appear from birth through the age of 18. An individual is considered to have mental retardation based on the following three criteria:

- Intelligence quotient (IQ) is below 70-75
- Significant limitations exist in two or more adaptive skills
- The condition is present from childhood (defined as age 18 or less)

What are the adaptive skills essential for daily functioning?

Adaptive skills means how well a person can manage the tasks of everyday life including the daily living skills needed to live, work, and play in the community. These skills include the ability to speak and understand, self-care skills, home living skills, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic math), community use and work.

Adaptive skills are assessed in the person's typical environment across all aspects of an individual's life. A person with limits in intellectual functioning who does not have limits in adaptive skill areas may not be diagnosed as having mental retardation.

How many people are affected by mental retardation?

Approximately 2.5 to 3 percent of the total population has mental retardation. Mental retardation cuts across the lines of racial, ethnic, educational, social and economic backgrounds. It can occur in any family. One out of ten American families is directly affected by mental retardation.

How is mental retardation diagnosed?

The process for diagnosing and classifying a person as having mental retardation contains three steps and describes the system of supports a person needs to overcome limits in adaptive skills.

- **The first step in diagnosis** is to have a qualified person give one or more standardized intelligence tests and a standardized adaptive skills test, on an individual basis.
- **The second step** is to describe the person's strengths and weaknesses across four dimensions. The four dimensions are:
 - Intellectual and adaptive behavior skills
 - Psychological/emotional considerations
 - Physical/health/etiological considerations
 - Environmental considerations
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Strengths and weaknesses may be determined by formal testing, observations, interviewing key people in the individuals' life, interviewing the individual, interacting with the person in his or her

daily life or a combination of these approaches.

- **The third step** requires an interdisciplinary team to determine needed supports across the four dimensions. Each support identified is assigned one of four levels of intensity - intermittent, limited, extensive, or pervasive.

Intermittent Support

Refers to the support on an "as needed basis." An example would be support that is needed in order for a person to find a new job in the event of a job loss. Intermittent support may be needed occasionally by an individual over the lifespan, but not on a continuous basis.

Limited Support

This type of support may occur over a limited time span such as during transition from school to work, or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.

Extensive Support

This type of support offers assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work. Intermittent, limited and extensive supports may not be needed in all life areas for an individual.

Pervasive Support

Refers to constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas.

How does mental retardation affect the individuals?

The effects of mental retardation vary considerably among people. Mental retardation affects each individual differently. While some may need 24-hour care, others are able to live independently or with minimal supports. That is why it is so important for individuals and families to be able to choose flexible programs and services that best meet their needs. With early intervention, a functional education and appropriate supports as an adult, all can lead satisfying lives in the community. There are four levels of mental retardation: Mild, Moderate, Severe, and Profound.

Mild Mental Retardation

- IQ scores from 50- 75
- Includes about 85% of the mentally retarded population
- Individuals in this group can usually live on their own with intermittent or limited support
- As children, their mental retardation is not readily apparent and may not be identified until they enter school.

Moderate Mental Retardation

- IQ scores between 35-49
- Includes about 10% of the mentally retarded population
- Individuals in this group can lead relatively normal lives provided they receive some level of supervision to monitor primarily for safety and self-care.
- These individuals may require limited or extensive support

Severe Mental Retardation

- IQ scores between 20 and 34
- Includes about 3-4% of the mentally retarded population
- Individuals in this category can most often learn basic of self-care skills including cleaning and dressing themselves.
- These individuals can live in the community in group homes, with extensive or pervasive support staff

Profound Mental Retardation

- IQ scores of less than 20
- Includes about 1-2% of the mentally retarded population
- These individuals can often develop basic communication skills, as well as basic self-care skills
- These individuals can live in the community in group homes with extensive, pervasive support.

What does the term "mental age" mean when used to describe the person's functioning?

The term "mental age" is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample population. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life.

What are the causes of mental retardation?

Mental retardation is not a disease itself. It occurs when something injures the brain or a problem prevents the brain from developing normally. This can happen before birth, during birth, or after birth. The three most common causes of mental retardation are Down syndrome, Fragile X syndrome, and Fetal Alcohol syndrome.

In about 1/3 of all cases of mental retardation, the cause of the retardation is not known. The remaining 2/3 of all cases are thought to be caused on one of four possible factors: Genetic conditions (heredity), prenatal problems, childhood illnesses, and environment factors. The causes can be categorized as follows:

Genetic Conditions (Heredity) - About 5% of mental retardation cases are caused by genetic factors. Genes are chemical units found in our cells. These units carry instructions that tell our cells how to perform. These result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. More than 500 genetic diseases are associated with mental retardation. The most prevalent genetic conditions include Down syndrome, Fragile X syndrome, Williams syndrome, Prader-Willie syndrome, Neurofibromatosis, Hyperthyroidism, and McDermid syndrome.

Prenatal Problems - Use of alcohol or drugs by the pregnant mother can cause mental retardation. Recent research has implicated smoking in increasing the risk of mental retardation. Other risks include malnutrition, certain environmental contaminants, and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphilis. Pregnant women who are infected with HIV may pass the virus to the child, leading to future neurological damage. Fetal alcohol syndrome would be the most common prenatal problem that causes mental retardation.

Problems at Birth - Although any birth condition of unusual stress may injure the infant's brain, prematurely and low birth weight predict serious problems more often than any other conditions.

Problems After Birth - Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease which may lead to meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Lead, mercury, and other environmental toxins can cause irreparable damage to the brain and nervous system.

Poverty and Cultural Deprivation - Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and environmental health hazards. Also, children in disadvantaged areas may be deprived of many common cultural and day-to-day experience provided to other youngsters. Research suggests that such under stimulation can result in irreversible damage and can serve as a cause of mental retardation.

What is the treatment?

Treatment of mental retardation must be multi-faceted. The most effective treatment requires the development of an individualized plan based upon an individual's skills and needs. Early diagnosis is critical. A plan should be individualized from very early on, to plan for learning, and the gaining of life skills. Early intervention programs are available throughout the country. Some areas are more adept in programming for and educating these individuals. It is important for parents to research their own states, and specifically their school district, to determine the effectiveness of the programming. Many programs offer interventions for children even under the age of three. The federal government mandates that all children between the ages of 3 and 21, who are mentally retarded receive testing and individualized education and skills training within the public school system at no charge to the child's family.

The most essential component of any treatment program is the support of the family. Most families with a child with a developmental disability can strongly benefit from their own supports including family therapy, group support, and even skills trainings, and even individual therapy. That will help the family cope with the day to day struggles of raising a child with special needs.

Some good news:

During the past 30 years, significant advances in research have prevented many cases of mental retardation. For example, every year in the United State, we prevent:

- 250 cases of mental retardation due to phenylketonuria (PKU) by new born screening and dietary treatment.
- 1,000 cases of mental retardation due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy.
- 1,000 cases of mental retardation by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in new born infants.
- 5,000 cases of mental retardation caused by Hib diseases by using the Hib vaccine
- 4,000 cases of mental retardation due to measles encephalitis thanks to measles vaccine
- Untold number of cases of mental retardation caused by rubella during pregnancy thanks to rubella vaccine (Alexander, 1998).

Other interventions have reduced the chance of mental retardation. Removing lead from the environment reduces brain damage in children. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning.

Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing mental retardation. Pediatric AIDS is being reduced by AZT treatment of the mother during pregnancy, and dietary supplementation with folic acid reduces the risk of neural tube defects.

Research continues on new ways to prevent mental retardation, including research on the development and function of the nervous system, a wide variety of fetal treatment and gene therapy to correct the abnormality produced by defective genes.

Part 2

Community Living

What is community living?

Community living refers to the programs, services and other supports that enable children and adults with mental retardation and related disabilities to live much the same way that people without disabilities live. For children, this usually means living with their family in their own home and in their own communities. For adults, it usually means having opportunities and supports to live independently, or as independently as possible, in their own home or apartment, or perhaps in a small group home.

Community living may also include a variety of other supports and services. For example, a family that is caring for a child with mental retardation may need occasional respite services so that they can take a break from care giving or attend other needs. Or, an adult living in a small group home may require help finding a job through an employment program.

What types of community services are available?

Community services can take a number of different forms. Community programs in which adults with mental retardation live have different names, depending in the state or county of residences. Some different names for programs in the community are usually called supported living, community living arrangements/small group home programs.

Supported Living: Usually involves individuals living in homes or apartments of their own. The person may live alone or choose to live with a roommate versus being placed with others. Supported living often involved partnerships between individuals with disabilities, their families and professionals in making decision about where and how the person wishes to live. Focus is on giving the utmost attention to the desires of the person with the disability in how he or she would like to live, and to support the individual in having control over choices of lifestyle. People in supported living may need little or no services from professionals, or they may need 24-hour personal care. The kind and amount of supports are tailored to the individual's needs.

Community Living Arrangements/Small group homes: Small group homes are living environments where six or fewer individuals live, usually with 24-hour staff support. In 1996, Prouty and Lakin found that an average of 3.8 people with mental retardation and related developmental disabilities lived in each residential setting in the U.S. The average number was 22.5 people in 1977, and so has continued to drop since that time.

In the effort to assist families in keeping their child with a disability at home, there are supplement services for these individuals who live in the community. These include buy are not limited to:

- **Crisis intervention services:** on-call support to assist in dealing with crisis situation
- **Respite care:** Temporary relief for full-time, at home care providers
- **Other family support services:** States offer a variety of services, from cash subsidies to families so they can purchase their own services, to transportation that enables families to get to services
- **Service coordination (case management):** Professionals that service as coordinators or brokers between services, assisting families and individuals with accessing and benefiting from various programs
- **Employment programs:** Services which help adults with mental retardation find jobs

Why is it so important for people with mental retardation to be able to live in their own homes and/or communities?

Study after study has shown that community living enables people with disabilities to live happier, healthier and more productive lives. Giving people a real sense of home and community, along with a feeling of independence, is pertinent to helping individuals have a good sense of self-worth and well being. In many cases, community support enables people to live with or near their families. This is particularly important to maintaining a more stable and comforting environment.

Do people with mental retardation have the power to make decisions about institutionalization versus community living? Do their families decide? The state?

People with mental retardation and/or their families are, in theory, free to decide what type of living situation they desire and what is best for them. Adults with mental retardation, not under guardianship, are legally responsible for making decisions about and agreeing to participate in certain programs. In some cases, the state may involuntarily commit someone with mental retardation to a program if there is a life-threatening emergency, or similar situation. A family or individual's choice about certain community services is often severely hampered by the lack of availability of community programs in many states. If the services and supports an individual needs are not available, these options suddenly become very few.

Aren't there some people with mental retardation so severe that institutions provide the only real viable option?

Absolutely not. As with anything else, the degree of care needed varies from person to person. Some people with mental retardation manage very well on their own with minimal supports, while others may require more intense supports. There are community options to meet the needs of all individuals.

What are the economic benefits of community living alternatives?

Community support can save taxpayers a substantial amount of money. In 1996, the average annual cost for a person in a community setting served under the Home and Community Based

Services program (flexible Medicaid funding) was \$24,783. The average cost per resident in the large, state run institutions in 1996 averaged \$92,345. (Prouty & Lakin, 1997)

Won't increased funding for community programs and supports mean bigger government and higher spending?

Not at all. In fact, just the opposite is true. Community living programs represent an alternative to institutionalization, not an added expense. Further, community alternatives generally save money by providing more cost-effective care. And since the whole point of community support is allowing people with mental retardation to live more independently, either with their families or in small homes, it actually requires fewer state resources.

What about those states that have closed their institutions? How has it affected services for people with mental retardation?

Of the four New England states that have closed institutions, Maine, New Hampshire, and Vermont have reduced the size of their waiting lists. Rhode Island has no waiting list. In Connecticut and Massachusetts, states that maintain institutions, the waiting list has increased in numbers.

What are some of the trends that affect the availability and use of community services?

There are several trends that affect the availability and use of community services. Many of these trends inter-relate in how they impact individuals with mental retardation and their families. Perhaps the most significant trend is the increasing waiting list for community services. Hayden (1992) found an estimated 186,000 people in the U.S. waiting for residential, employment, and other services. As states either cap or cutback the number and kinds of services, more and more individuals end up on long waiting lists for necessary services. Many individuals with mental retardation do not receive the full array of services they need to increase their independence, and there are many who still reside with their families and receive no services whatsoever.

The number of adults with mental retardation still residing with their parents, especially aging parents or parent, is another area of concern. Many parents provide some or all care for an adult son or daughter with mental retardation, but these families increasingly recognize the need to plan for the time when the parents can no longer provide care. As these families begin to explore community residential and other services, they are finding waiting lists for services, sometimes up to several years long. Compounding this problem is the fact that some of these families do not even have access to a support system for providing information and assistance. A recent study in New York found that many of these families are neither in the aging service system or the mental retardation/developmental disabilities service system.

As individuals are discharged from institutional living to the community, this trend has increased the need for community services to service individuals with mental retardation

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