The Problem of Mental Retardation

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Office of the Secretary
Secretary's Committee on Mental Retardation
Washington, D.C. 20201

FOREWORD

Mental retardation is a problem with impact on the whole spectrum of domestic concerns confronting the nation today. Accordingly, there are few programs within the Department of Health, Education, and Welfare which fail to touch on mental retardation in one way or another.

The success or failure of such programs depends in large part upon the commitment of private citizens, working as individuals or in groups to bring about the changes in society needed to prevent or effectively treat this condition. Neither government nor private industry can do the job alone.

This booklet is presented as an introduction to mental retardation. It is designed to deepen the understanding of the problems faced by the mentally retarded and to strengthen our resolve to find solutions to them.

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The Mentally Retarded

. . . are children and adults who are limited in their ability to learn. They are generally socially immature and inadequate, and they are sometimes further handicapped by emotional and physical disabilities.

In more scientific terms, "Mental retardation refers to sub-average intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior." [1]

Mental retardation may be caused by defects in the developing embryo, by deprivation in early childhood, by disease of the nervous system, by toxins and poisons, or by brain injury early in life. It is also thought to be associated with prematurity.

Estimates reveal that about 6 million persons in the United States—or roughly 3 percent of the population—are mentally retarded. This condition causes more disability among children than any other physical or mental abnormality.

There are differences among the retarded, just as there are among the rest of the population.

Generally, those whose Intelligence Quotient (IQ) is 50 or above are capable of being educated for a relatively independent life. The retarded who measure below this level range from those with a potential for

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[1] Adapted from *A Manual on Terminology and Classification in Mental Retardation.* Monograph Supplement to the *American Journal of Mental Deficiency,* American Association on Mental Deficiency, Washington, D. C.

satisfactory work under sheltered conditions to those who are completely helpless.

However, all but a small percentage can gain some measure of independence if given adequate help. The amount of independence each achieves depends in large measure on the quality of care and understanding he receives and the degree to which these relate to his needs.

Estimated Distribution of Retardates in the United States by Age and Degree of Retardation [2]

Degree of Retardation	All Ages Number	All Ages Percent	Age by Years Under 20	Age by Years 20 and Over
Total	6,000,000	100.0	2,454,000	3,546,000
Mild (IQ 52-67)	5,340,000	89.0	2,136,000	3,204,000
Moderate (IQ 36-51)	360,000	6.0	154,000	206,000
Severe (IQ 20-35)	210,000	3.5	105,000	105,000
Profound (IQ 20-0)	90,000	1.5	52,900	37,100

[2] Adapted from data in *Facts on Mental Retardation*, p. 15, National Association for Retarded Children, Inc., New York City, 1963. See also Footnote 3.

This care must start in the earliest years. Studies indicate that approximately 50 percent of an individual's intellectual development takes place between conception and age 4; about 30 percent between ages 4 and 8. The period encompassing gestation and early childhood determines to a large extent the life adjustment potential for all individuals, on all intellectual levels.

Among the many factors playing a part in each child's development are heredity, nutrition, and his living conditions, emotions, physical factors, inter-personal relationships, and the interaction between the individual and his environment.

When something goes wrong—either through human neglect, an error of nature, or an environment which has failed to provide opportunities for healthy emotional and

mental growth—retardation can be the result.

Although this problem is found in families of all income levels, by far the largest number of mentally retarded children are born to parents in poverty. The type of retardation that results from social and cultural deprivation is often mild, or "borderline," and may not be readily recognizable until the child enters school. There, such children are seen to perform below the levels of achievement normally expected of youngsters their age. Achievement, however, is determined largely by the social, educational, and cultural standards of the community. Thus, a person with limited abilities may function adequately in menial work on a rural farm but not be able to meet the demands of crowded, complex, and competitive life in a highly urban setting.

Retarded children from deprived environments, if given adequate early help, often can improve their school performance. However, this improvement may not be sustained without follow-up. In the absence of early intervention and a continuous follow-up program, retarded children living in conditions that stunt mental and social growth tend to drop to even lower IQ levels as they grow older.

Many pre-school programs and projects such as Head Start are designed to provide such children with early stimulation to offset the negative environment. These programs are based on the belief that retardation due to deprivation is not only reversible, but preventable through changes in the society which contributes so heavily to its occurrence. They often do provide a real "head start" in life.

Unlike retardation due to deprivation, retardation due to biological or organic causes, generally may not be reversed. Identified causes include genetic or metabolic defects, diseases, injuries at birth or brain injury resulting from an accident later in life. Most of these children have physical as well as mental handicaps, and usually they are among the more seriously retarded.

Tests to Determine Mental Retardation

. . . range from laboratory studies for chromosomal analysis of parents, to intelligence and social adaption tests of school children.

Many States require screening tests for infants soon after birth to detect chemical and neurological abnormalities which can result in retardation. In these cases, immediate treatment often can prevent retardation from developing.

As the infant grows older, sensory and motor development, along with perception, can be measured even while the child is still very young.

Later, the so-called "IQ tests" are given. Intelligence is generally defined as problem-solving ability; ability to adapt appropriately to environmental demands, and ability to apprehend abstract interrelationships.[3]

Another important dimension in the determination of intelligence is adaptive behavior. Adaptive behavior refers primarily to the effectiveness with which the individual copes with the natural and social demands of his environment. (See table on page 5)

The result of an intelligence test alone is insufficient evidence of retardation, since intelligence is not constant, but relatively variable, and subject to emotional and environmental influences.

If considered along with other test results, however, the IQ can be an important factor in determining a child's potential for learning. If an IQ of 100 is considered as normal for the average person, then an IQ of 40 indicates that the individual at the time of testing shows a potential for performance of 40 percent of normal. (See chart on page 5)

[3] *Op. Cit. Manual on Terminology,* American Journal of Mental Deficiency.

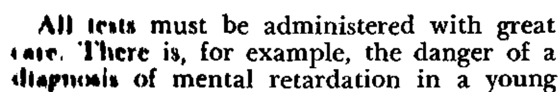
[4] *Op. Cit. Manual on Terminology,* American Journal of Mental Deficiency. Persons whose measured intelligence falls within these limits may be considered retarded if their adaptive behavior so indicates.

Adaptive behavior classification for the retarded are rated on the following basis:

Mild:	Development slow. Children capable of being educated ("educable") within limits. Adults, with training, can work in competitive employment. Able to live independent lives.
Moderate:	Slow in their development, but able to learn to care for themselves. Children capable of being trained (termed "trainable"). Adults need to work and live in sheltered environment.
Severe:	Motor development, speech and language are retarded. Not completely dependent. Often, but not always, physically handicapped.
Profound:	Need constant care or supervision for survival. Gross impairment in physical coordination and sensory development Often physically handicapped.

Today, much thought is being given to redesigning intelligence tests to insure that they make adequate allowance for cultural differences. This would permit a greater degree of accuracy in test results.

Consideration is also being given to development and standardization of tests of social competency—since this plays an equally important role in establishing the presence or absence of mental retardation.



All tests must be administered with great care. There is, for example, the danger of a diagnosis of mental retardation in a young

child whose only problem may be impaired hearing or vision.

Though the mentally retarded often have poor muscular coordination, speech and hearing problems, poor vision, difficulty in perception, extreme lethargy or hyperactivity, each of these conditions can be present without mental retardation.

Thus, diagnosis and evaluation is extremely difficult and should be conducted by a team of specialists in several disciplines. Most reliable is a comprehensive mental retardation clinic which offers medical, psychological, social and educational examinations.

The Deprived Child

. . . who is retarded due to non-organic causes may never receive the benefits of special education or rehabilitation. His problem may not be recognized until it becomes apparent that he cannot keep up with the rest of his class in school.

He may then fall into a cycle of failure which further limits his ability to learn. Dropping out of school at age 15 or 16, he faces a future with no skills and, too often, becomes a social problem.

On the other hand, if a transfer to a special education program is promptly arranged, he may be helped—through psychological, medical and social services—along the road to a productive life. Placement in a mental retardation category can often be his only avenue to this assistance. However, care must be taken to insure that no child is mislabeled and that no child is stigmatized.

In the mass migration to cities that has occurred in the last decade, thousands of

Those native to inner-city slums are crowded into even more unsatisfactory living conditions by the daily waves of new arrivals. They are often hungry, neglected and suffering from chronic anxiety.

Opinions vary widely on the causes and solutions to educational and social problems these children experience. It has been pointed out that many speak a different "language" from that of the usual textbook and classroom.

Increasingly, educators see the need for early childhood enrichment, specially trained teachers, and revised curricula to meet the unique needs of the deprived. In addition, they recommend changes in total life patterns for these children.

Mental Illness

. . . is not the same as mental retardation. They are separate and distinct conditions. Mental illness is often temporary and may strike at any time during the life of the individual. Mental illness can be treated and often cured.

Mental retardation, (which is not caused by economic and social deprivation) on the other hand, occurs during the period of development, or is present from birth or early childhood. It may be alleviated through medical treatment, special education, training, rehabilitation and proper care.

When the mentally retarded have difficulty adjusting to the demands of society, the problem is usually related to limited intellectual capacity, and an inability to understand what society expects of its members. When the mentally ill fail to adjust to society's demands, it is often because their mental disorders have caused them to lose touch with reality, or their emotions interfere with so-called normal responses.

However, the mentally retarded also may have emotional problems; they can become mentally ill through frustration born of repeated failures, the humiliation of being ridiculed and the fears that come from trying

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Developmental Characteristics of the Mentally Retarded

Degrees of Mental Retardation	Pre-School Age 0-5 Maturation and Development	School Age 6-20 Training and Education	Adult 21 and Over Social and Vocational Adequacy
Mild	Can develop social and communication skills; minimal retardation in sensorimotor areas; often not distinguished from normal until later age.	Can learn academic skills up to approximately sixth grade level by late teens. Can be guided toward social conformity. "Educable"	Can usually achieve social and vocational skills adequate to minimum self-support but may need guidance and assistance when under unusual social or economic stress.
Moderate	Can talk or learn to communicate; poor social awareness; fair motor development; profits from training in self-help; can be managed with moderate supervision.	Can profit from training in social and occupational skills; unlikely to progress beyond second grade level in academic subjects; may learn to travel alone in familiar places.	May achieve self-maintenance in unskilled or semi-skilled work under sheltered conditions; needs supervision and guidance when under mild social or economic stress.
Severe	Poor motor development; speech is minimal; generally unable to profit from training in self-help; little or no communication skills.	Can talk or learn to communicate; can be trained in elemental health habits; profits from systematic habit training.	May contribute partially to self-maintenance under complete supervision; can develop self-protection skills to a minimal useful level in controlled environment.
Profound	Gross retardation; minimal capacity for functioning in sensorimotor areas; needs nursing care.	Some motor development present; may respond to minimal or limited training in self-help.	Some motor and speech development; may achieve very limited self-care; needs nursing care.

to survive in a highly complex and somewhat impersonal world.

Parents can contribute to frustrations by overprotectiveness which keeps retarded children dependent. Or parents may be overambitious, pushing their children beyond their intellectual and emotional capacities.

Community Services

. . . can often eliminate the need for long-term residential care. Among such community services are: diagnostic and evaluation clinics; early childhood education facilities, training and enrichment programs; day-care centers; pre-school and Head Start projects with follow-through; special tutoring; quality special education; summer camps and recreational facilities; group living arrangements in the community; vocational training; rehabilitation programs; sheltered workshops; employment opportunities; and "surrogate parents" or guardianship arrangements for older retarded persons. The optimum is a complete plan of life-time protective services available as needed.

Sheltered homes or part-time residential care can be effective in giving temporary relief to parents of a retarded child who lives at home.

Parent counseling services are an additional aid, especially during crisis periods—the discovery of the condition, the beginning of schooling, adolescence, the first years of adulthood, and when the parents reach the age when they can no longer care for the child—either because of their advancing years or the condition of the child.

All of these services offer alternatives to institutional placement, or can be provided as part of the therapeutic program of residential facilities.

Whether at home or in residential care, the retarded do grow up. Their needs follow the pattern of all human beings, though in a different degree. For example, it is as natural for a retarded adolescent to want to cut

parental ties as it is for any other young person. Community group homes can provide this opportunity while still offering necessary protection and supervision.

The retarded need close personal friends outside the family; they need a group to belong to, outlets for their energies, and identity. Such community activities as Scouting, camping, competitive sports, religious affiliations, social groups, accessible shops, and transportation can contribute much toward a retarded person's sense of well being and belonging. Similarly, a job to go to and money to spend are as essential to the self-respect of the retarded adult as to any other.

The community can provide these opportunities—at a cost far less than that of a lifetime in an institution—if enough people care enough to make it possible. The American taxpayers contribute over a half-billion dollars a year to operate public facilities for the retarded.

In the long run it costs less to do it right —both in terms of human lives and tax dollars.

Manpower

. . . of both the professional and supportive type is in short supply. Despite Federal training grants, there is great need for more special education teachers, psychologists, social workers, physicians, therapists, counselors, recreation specialists, and capable administrators to direct programs for retarded children.

It is imperative to tap the vast resource of allied personnel who can be trained to relieve the professionals of many duties they now perform which do not require professional expertise.

There is also a growing awareness of the effectiveness of trained volunteers, especially young people. Volunteer work has served as a gateway to careers in this field for many of all ages.

Residential Care

. . . is often a necessity for the more severely retarded who need constant attention, and for older retarded persons left with no one to care for them. There are now approximately 200,000 residents of state institutions for the retarded in the U.S.

Some residential facilities are outstanding and offer good programs in special education and training, medical care, therapy and recreation—sometimes coordinated with community activities and services. Other residential facilities may be limited to providing little more than basic subsistence.

Even the most profoundly retarded respond favorably to pleasant, colorful, and personalized surroundings. Architecture and interior decor are important parts of the whole therapeutic program; of even greater importance is the healing effect of a person who cares.

Recently implemented behaviorial modification techniques are proving that nearly *all the retarded can be trained* to care for their personal needs, such as self-feeding, dressing and toileting. Many thought to be "hopeless cases" are now being trained in self-care and returned to their homes for visits—some are able to remain at home permanently.

The best kind of residential care seems to be that most closely resembling family life—a small group or unit, with "parents" to look after the residents, and professional help as a resource when needed.

Some very successful group homes are located in apartments or individual houses scattered throughout the community.

Special Education

. . . is one of the most important means to the goal of productive citizenship and self sufficiency for the retarded.

Although classes for the educable and trainable are now offered in every State and are

growing in number, there is a critical need for many more. Current estimates indicate that approximately only 40% of all retarded children are being provided special educational services.

Effective special education is oriented toward the practical goal of independent and productive living, so that the student can graduate into the kind of job he can do, with preparation for handling money, the ability to use public transportation, and a well developed level of social competency.

Most schools integrate the children from special education classes with those in the regular program for such subjects as art, music, physical education, industrial arts, and home economics, bringing them into the center of school life as far as feasible. However, physical integration alone does not guarantee acceptance by non-retarded youngsters. Psychological integration is also important and requires considerable planning by school officials and related personnel to be effective.

New Federal legislation enacted in 1968 provides authority for broadening efforts in vocational education of the handicapped to include the mentally retarded. This program should have a significant impact on vocational training of the mentally retarded within the school system.

Individually prescribed instruction is proving highly successful in those schools which have the facilities for it. This is programmed learning which allows each child to progress at his own pace while the teacher acts as a guide and resource person.

Rehabilitation

. . . for the retarded can be the passport to entrance into the life of the community.

The most effective rehabilitation services provide training in job skills as well as practical preparation for independent or semi-independent living.

In some cases, training is an extension of

a special education program geared to productive living from the start. In others, rehabilitation services make it possible for older, long-term residents of institutions to move out into the community and take jobs.

Coordination is needed in each of the steps along the way: special education, vocational training, rehabilitation, arrangements for community living, and employment. Employers need preparation for the kinds of supervision the retarded may require, the patience and understanding necessary, and they must be provided with a clear picture of the strengths as well as the weaknesses of their retarded employees.

Increasingly, employers are learning to appreciate the reliability of the retarded worker, his punctuality, his contentment with the kind of work that causes high turnover among more skilled employees.

There are thousanas of retarded who are being trained to fill the many jobs that require such attributes. There are just as many of these jobs that need to be filled— the biggest problem is getting the two together. There has been a great deal of progress in job placement of the retarded in the last ten years.

Preventive Measures

Measures to prevent retardation caused by deprivation include:

Availability of education and health services for every child from birth.

Expansion of maternal and child health programs.

Establishment of urban and rural community health and education centers for preventive health care and screening, plus early education, day care, and social services.

Expansion of career planning in supportive

health, education, and social services in low-income areas.

Formation of services groups to teach and demonstrate home and health skills in low-income neighborhoods.

Development of large-scale voluntary service programs especially for youth organizations in poverty areas.

Availability of family planning information to all who desire it.

Inclusion of the needs of the retarded in urban planning programs.

Stimulation of intensified research into the causes of mental retardation—those associated with social and cultural deprivation, as well as those of biological origin.[5]

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Prevention of biological causes of mental retardation, in addition to those cited above include:

Medical care throughout pregnancy to lessen the risk of untreated and unsuspected infections, diabetes, and other diseases, as well as to help prevent premature births—a major cause of mental retardation.

Genetic counseling before conception whenever possible, for both parents, particularly if the family history includes a history of abnormalities.

Avoidance of all drugs during pregnancy except those prescribed by a physician.

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[5] Adapted from *MR-68—The Edge of Change*, A Report to the President, President's Committee on Mental Retardation, Washington, D. C.

Vaccination against 10-day measles for each child.

Immediate treatment for venereal disease.

Prenatal tests for incompatible blood factors.

A balanced diet for children and adults.

Limitation of radiation exposure for both parents before conception and for mothers during pregnancy.

Thorough medical examination of the newborn.

Research has now produced a rubella vaccine which has the potential to protect against the 3-day German measles, a frequent cause of defects if contracted by the mother, especially during the first trimester of pregnancy.

The answers are yet to come on the prevention of certain infectious diseases and virus disorders that cause retardation, problems caused by prematurity or birth injury, prolonged high fever, and toxic agents.

Chromosomal abnormalities that cause Down's Syndrome (Mongolism) can be detected—but not eliminated—by blood samples taken from the parents. Progress is being made in molecular biology, which will help provide some of the answers to the causes of metabolic defects causing mental retardation.

Practical Application

. . . of all preventive and remedial measures known, however, is still a distant goal, especially for those who need it most.

Application of this knowledge could significantly reduce the incidence of mental retardation, and make life a more satisfying

experience for the majority of those who are retarded.

National Concern

As one would expect, the first to be concerned about the problem of mental retardation were the parents of afflicted children. The first counselors were the physicians attending these children and families. As the ranks of concerned people grew, they began to include others—from the professions, foundations (public and private), legislators and representatives of Government agencies who were becoming convinced of the urgent need for action in this area.

In 1961, a panel of experts was appointed by the President to study the problem and to draw up a plan of action. One year later the group published a comprehensive report entitled "A Proposed Program for National Action to Combat Mental Retardation." A followup White House Conference was held to acquaint the States with the proposals.

Significant Federal legislation enacted since the Report of the President's Panel on Mental Retardation reflects increased mental retardation programming in areas involving the provision of services, construction of facilities, research, training, and planning. Under this legislation, Federal resources stimulate action by State and local governments and private groups through a variety of grant-in-aid programs. The Federal Government also offers guidelines for communities. The major emphasis is on the local, community level, with the Government providing seed money and ideas to be adapted to community needs and potential.

In May 1966, the President's Committee on Mental Retardation was established to:

. . . advise the President on what is being done for the mentally retarded;

. . . recommend Federal action where needed;

. . . promote coordination and cooperation among public and private agencies;

. . . stimulate individual and group action;

. . . promote public understanding.

Coordinated national and local efforts as well as individual contributions are important in helping the mentally retarded take their rightful place in the world.

Such concerted efforts can improve the quality of life for approximately 6 million retarded persons and transform most into productive citizens. Concern for the retarded, then, clearly becomes an investment in human worth that pays dividends to every citizen of the nation.

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