

# **Facts Mental on Retardation**



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## **What Is Mental Retardation?**

The modern definition accepted by the American Association on Mental Deficiency describes mental retardation as significant "subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior". In less technical terms the mentally retarded person is one who, from childhood, experiences unusual difficulty in learning and is relatively ineffective in applying whatever he has learned to the problems of ordinary living; he needs special training and guidance to make the most of his capacities, whatever they may be.

## **To What Extent Do the Mentally Retarded Differ From Other People?**

This depends on the degree of mental retardation. Those who are least retarded are scarcely distinguishable from the "dull normal" members of our population, but those whose handicap is extreme may never be able to master such tasks as feeding and dressing themselves.

Degrees of mental retardation are measured by considering both "measured intelligence" and "impairment in adaptive behavior". Since "measured intelligence" usually ties quite closely to learning ability, this factor assumes greatest importance in childhood, whereas "adaptive behavior" — the ability to make a living and to handle oneself and one's affairs with the prudence ordinarily expected of an adult in our society — is the more important determinant of the degree of retardation in an adult.

For descriptive convenience the range of mental retardation has been divided into four levels—mild, moderate, severe, and profound. Children who are classified as mildly retarded (frequently called "educable mentally retarded" by educators), although limited in their potentials for academic achievement, can usually be brought by special educational techniques to a state of self-sufficiency as adults. Moderately retarded children show a rate of mental development which is less than half of that normally expected, but can nevertheless learn to take care of their personal needs, to travel in their own neighborhood and to perform many useful tasks in the home or in a sheltered working situation. The severely retarded can learn self care, but their potential economic usefulness is extremely limited.

Most moderately and many severely retarded children are properly classified as "trainable" for educational purposes. The profoundly retarded also respond to training in habit formation, but usually cannot become independent even in eating and dressing. They have little sense of necessary safety measures and little or no speech.

## **How Prevalent is Mental Retardation in the United States?**

It is estimated that there are more than 5<sup>1/2</sup> million people in the United States (3% of the population) who should be identified as mentally retarded before they are 15 years old. Between 100,000 to 200,000 of the babies born each year are likely to join this group. By 1970, natural population growth is expected to increase the total to 6<sup>1/2</sup> million, unless far-reaching preventive measures can be introduced.

Of the total nearly 2<sup>1/2</sup> million are children and youth under 20 years of age. At least 2 million of these children are mildly retarded and many of them may not be singled out and identified until they have been in school for several years. Another 150,000 or more are estimated to fall in the moderately retarded category, with an additional 100,000 and 50,000 in the severe and profound categories respectively.

Although a significant number of moderate, severe and profoundly retarded children are found and given help in early childhood, many more are overlooked or not properly diagnosed. The mortality in this group is known to be high but is difficult to document since frequently a baby may not show his retardation definitively for months or even years after birth. Looking back however, we can see that the causes were acting from infancy.

Once he has lived to the age of 5 or 6 a retarded child has a good chance of growing up. In fact, the life expectancy of the mildly retarded is probably about the same as that of other people. For the profound and severely retarded it is substantially less, although profoundly retarded persons have been known to live to the age of 70 or 80 years. Because the retarded adults of today were born prior to the end of World War II, before the introduction of antibiotics and other modern life saving treatments, it is likely that the prevalence of moderate, severe and profound retardation among

adults will increase in the next 20 years. Statistics on survivorship among persons with Down's Syndrome (Mongolism), for example, indicate a much greater life expectancy for this group today than 20 or 30 years ago.

Even so, it is estimated that there are at least 35,000 adults alive today who are profoundly retarded, some 100,000 or more who are severely retarded, and some 200,000 or so who are moderately retarded.

Nearly 3 million adults were once mildly retarded children; these are handicapped members of our society but to the extent that they may have been helped to achieve a satisfactory degree of "adaptive behavior" and to attain economic and social independence, they will no longer be "spotted" as mentally retarded. For this reason they are often not identified and counted when community surveys are made, although most of them remain potentially vulnerable to adverse social or economic pressures. Thus, the number of adults who may require help because of varying degrees of mental retardation is probably no more than 1 million to 1<sup>1/2</sup> million. Many of these persons are receiving disability or general welfare assistance or are dependent on relatives.

Thus, as a cause of lifetime disability and as a medical, social, and educational problem of unique extent and complexity, mental retardation today presents an outstanding challenge to science and society in the United States and throughout the world.

## **What Are The Causes of Mental Retardation?**

Mental retardation can be caused by any condition that hinders or interferes with development before birth, during birth or in the early childhood

years. Well over 100 causes have already been identified, although these account for only about 1/4 of all identified cases of mental retardation.

Among the specific identified causes are: german measles (rubella) in the mother during the first 3 months of pregnancy, meningitis, toxoplasmosis, Rh-factor incompatibility between mother and infant, lead poisoning in young children, and chromosome abnormalities. Among the commonest and best known of the latter is Down's Syndrome (Mongolism) which occurs in 1 out of every 600 babies born and usually results in moderate to severe mental retardation. A number of in-born errors of metabolism have been identified which, if untreated, can cause damage to the nervous system and hence mental retardation. Physical malformations of the brain or other organs originating in prenatal life may also result in mental retardation directly or indirectly. Examples include hydrocephalus (a blocking of ducts resulting in an accumulation of fluid in the brain), and craniosynostosis (a premature closing of the sutures of the skull). Inflammation of the brain associated with childhood measles is another cause.

As time goes on more people who were originally placed in the "undifferentiated" category are found to have specific diagnosable causes of their mental retardation. Nevertheless even today, in the majority of cases, no clear diagnosis of cause can be made, and in most of these there is no demonstrable pathology of the nervous system. Undoubtedly among the mildly retarded there are many people whose development has been adversely affected by non-specific influences, such as inadequate diet, inadequate prenatal and perinatal care and lack of adequate stimulation towards growth and development through learning opportunities. Mental development, like physical development, is promoted by the right kind of activity and stimulation, and retarded when it is lacking. Indeed, the two tend to interact. In this process the years of early childhood, when the nervous system is maturing and language developing, are certainly very critical.

## **How Many Mentally Retarded Persons Are Actually Brain Damaged?**

The term "brain damage" has not been adequately defined and is used differently by different people. Destruction of brain tissue or interference with brain development in the infant or young child frequently produce mental retardation as well as cerebral palsy, convulsive seizures, hyperactivity, and perceptual problems. Such damage accounts for a substantial fraction of moderate, severe and profound mental retardation. Although it can not be definitely shown in most cases of mild mental retardation, the extent of its contribution is not known and expert opinion is divided. Several factors may be at work in the same individual. For example, the premature infant is more vulnerable to brain damage; prematurity is more common among mothers who receive inadequate prenatal care, and inadequate prenatal care in turn is more common in the underprivileged groups in our society; these same children are also more frequently exposed to inadequate postnatal opportunities for growth and development, and to other factors contributing to psychological and cultural deprivation.

The extent of psychomotor, perceptual and sensory handicaps among the retarded points to common causation in many cases. Most of the severely and profoundly retarded have pronounced motor handicaps or impairment of hearing, vision or speech, or a combination of several of these. Although the majority of the mildly retarded would not be readily identified as physically handicapped, their general level of motor coordination is below average, despite the occurrence among them of a few remarkable athletes.

## **Is Mental Retardation Preventable?**

Progress is being made in the prevention of mental retardation, but it is proceeding, as might be expected, through a succession of small advances across the broad front, rather than by any singular spectacular breakthrough. Each of the many contributing causes must be analyzed specifically and specific preventive measures devised when the cause has been found. Progress is being made against some of the more serious forms by such techniques as corrective surgery for malformations of the skull, and for the diversion of excess fluid in the brain. Children who have inadequate blood sugar in the first few critical days after birth are now more readily identified and given corrective treatment. Damage due to the Rh-factor incompatibility can be prevented by complete blood transfusion in the infant at time of birth. Quick treatment in cases of lead poisoning, or better yet, action to prevent children from eating lead-containing paint can also be effective in preventing some cases. The new measles vaccine can help if widely used. Some progress is being made in identifying the characteristics of mothers most likely to give birth prematurely, so that this indirect cause of mental retardation may be reduced. Thus far, however, all of these steps have been effective in eliminating only a relatively small fraction of mental retardation. Increased attention to relevant basic and applied research and to the prompt application of new discoveries are essential to carrying forward this initial progress. Moreover some of those forms of retardation which stem from physical, emotional or cultural deprivation will yield only to basic social reform.

## **What Can Be Done For Those Who Are Retarded?**

Where prevention has not been effective and retardation has already been established, specialized training and rehabilitation are necessary. Secondary handicaps, such as impairment of speech and hearing, seizures, emotional maladjustment and the like must be treated and reduced to the minimum. Special educational and vocational opportunities must be made available, and help and advice given to parents in managing day to day problems. All of these efforts must be based on accurate diagnosis at the earliest age level possible. Among the services which should be available are specialized diagnostic facilities, home nursing programs, parent counseling, specialized nursery and day care centers, special classes in public and other day schools, religious nurture, camping and other recreational programs, vocational training, sheltered workshops, specialized employment services, income maintenance where necessary, foster homes and boarding care, and specialized living arrangements or residential institutions.

## **What Provisions For The Mentally Retarded Exist In Residential Institutions?**

More than 200,000 mentally retarded children and adults now receive round the clock supervision, training, and care in residential institutions, most of them under state auspices, in the United States. Of the 50 States, 48 have one or more publicly

administered residential facilities but the quality of care, as well as the capacity, in relation to need, varies markedly from State to State. Some mentally retarded children and adults are also mentally ill and are therefore cared for in mental hospitals, but in some States admission of the mentally retarded to mental hospitals has been forced by the shortage of facilities especially designed for the retarded. This practice works a hardship not only on the retarded, but on the program of the mental hospital.

It is estimated that provision should be made for approximately 300,000 mentally retarded children and adults who are in need of specialized care outside their own homes.

## **What Other Specialized Services Are Being Offered To The Retarded?**

Special classes for the educable and trainable retarded are known to have increased since the last survey by the U.S. Office of Education in 1958. If we assume that enrollment in special classes for the educable in public, private, parochial, and residential schools has reached the quarter million mark, and that as many as 25,000 trainable children are enrolled in special classes, we must still conclude that only about 1/4 of those in need are being reached.

Vocational rehabilitation services to the retarded have been intensified in recent years and in 1962 a new record of 4,500 retarded adults were successfully placed in employment and thus converted from tax consumers to taxpayers.

About 250 sheltered workshops have been established in the last decade, providing opportunities for training and for long term sheltered employment which were virtually unavailable to the retarded before 1953. There are still many communities, however, where this service is unavailable.

Over 100 specialized diagnostic clinics have been established since 1949. The majority provide specialized diagnostic service using a team of specialists in child development. Most provide for continued parent counseling and some also have adjunctive nursery school and group programs for continued observation and optimal stimulation of the young child.

The provision of day care for children of school age and activity centers for adults who are too severely handicapped to fit into the special class programs or into competitive or sheltered employment are relatively new and promising developments.

### **What Urgent Steps Are Required Now To Meet The Needs?**

1. Research in biomedical fields relevant to prevention and treatment.
2. Research in the behavioral and social sciences relevant to prevention of socio-cultural forms of mental retardation, and relevant to techniques of training and management which will more effectively develop the fullest potentials of which each retarded individual is capable.
3. Orientation of physicians to the early diagnosis and positive management of mentally retarded youngsters in their care.
4. Extension of public health nursing services to provide practical assistance to mothers in the everyday problems of rearing a retarded child.
5. The extension of specialized diagnostic facilities so that they are reasonably accessible to all population groups in all parts of the country.
6. Extension of public school programs for the educable and trainable, especially in those States which have heretofore provided inadequate legislative and financial bases for these programs.
7. Recruitment and effective training of some 50,000 new teachers.

8. Development of improved techniques of selective placement of the mildly retarded youth and adult in gainful employment, tied with interpretation to employers of the assets and limitations of the retarded employee.
9. Extension and improvement of opportunities for sheltered employment of those incapable of entering the competitive employment market.
10. Modification of laws governing the civil status of the mentally retarded.
11. New approaches to protective services, guardianship, social guidance, and economic security for the retarded adult who cannot contribute substantially to his own support.
12. Development of diversified residential facilities close to the main stream of community life and professional service, and adapted to the various individual needs apparent among the retarded children and adults in need of residential care.
13. Effective planning and coordination of major public and private activities at national, regional, state and local levels.

## **How Much Is Being Spent On The Mentally Retarded Today In The U.S.?**

The direct cost to the taxpayer in support of schools, residential institutions, and related specialized services amounts to over half a billion dollars a year, a sum which is at least matched by the extra costs borne by the families of the retarded themselves. The indirect cost to the nation arising from lost productivity are estimated to approach \$5 billion a year. The direct services mentioned above do **not** include more than \$60 million in Permanent and Total Disability Assistance grants **and** related welfare costs paid by federal, state, and county governments, nor the \$64 million in payment to mentally retarded persons under the Old Age Survivors and Disability Insurance program,

popularly known as Social Security. These income maintenance costs, together with the heavy burden borne by the States in costs of operating residential institutions, point up the urgent need for more vigorous preventive measures and efforts to rehabilitate those of the retarded who are now dependent but who could be made more productive.

During 1963, under the stimulus of the Report of the President's Panel on Mental Retardation, additional amounts were invested by the federal government in research and professional training, in demonstration projects, and in stimulation grants to the States in the service areas. The total of \$31 million granted in these areas during the fiscal year 1963 was more than matched directly and indirectly by state, local and private funds.

During 1963, increasing interest has been shown by many of the Governors of the various States in improved planning and diversification of service, with participation by all major departments of State government, in collaboration with local government and with voluntary organizations.

## **What Was The President's Panel On Mental Retardation?**

In October 1961, President Kennedy appointed 27 professional and civic leaders to make recommendations concerning the scope of the problem of mental retardation in the United States, the major areas of concern that offer the most hope, the resources that must be mobilized, and the relationships between the Federal Government, the States, and private resources in promoting prevention and amelioration. In response to this mandate the Panel presented a report to the President in October 1962, entitled "A Proposed Program for National Action

to Combat Mental Retardation". (Copies are available from the U. S. Government Printing Office, Washington 25, D. C. at 65 cents per copy). The Report covers broadly the topics of research in scientific manpower, prevention, clinical and social services, education, vocational rehabilitation and training, recreation, residential care, planning and coordination, legal problems, and public attitudes.

**TABLE OF ESTIMATES OF RETARDATION BY AGE AND DEGREE — 1963**

(1963)	All Ages	Under 20 yrs.	20 yrs. & above
<b>General Population</b>	189 million	73 million	116 million
3% " "	5.7 million	2.2 million	3.5 million
1% " "	1.9 million	.7 million	1.2 million
<b>Retarded</b>			
<b>Profound (IQ - 20)</b> About 1½%	85 thousand	50 thousand	35 thousand
<b>Severe (IQ 20-35)</b> About 3½%	200 thousand	100 thousand	100 thousand
<b>Moderate (IQ 36-52)</b> About 6%	350 thousand	150 thousand	200 thousand
<b>Mild (IQ 53 +)</b> About 89%	5 million +	2 million +	3 million (1 million + needing help)
<b>Totals</b>	5.6 million	2.3 million	3.3 million

Note: These estimates give slightly more than 3% in the under 20 years of age group and slightly less in the adult population. This is within the margin of error and consistent with observation.