

CENTURY OF
DECISION
SERIES

YEAR 2000

MENTAL RETARDATION

... the known and the unknown



Statements by the Last Two Presidents of the United States:

"I invite all Americans to join me in commitment to two major national goals:

- To reduce by half the occurrence of mental retardation in the United States before the end of this century
- To enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community."

November 16, 1971

"There is urgent need to chart a concerted effort to minimize the occurrence of retardation and to assure humane services and full citizenship for those who are retarded. I encourage this Committee to pursue to completion its report on the directions that effort should take over the next quarter century."

October 11, 1974

This book is part of a projected "Century of Decision" series that may include the following:

Mental Retardation: The Known and the Unknown

Mental Retardation: A Century of Decision: Report to the President

Mental Retardation: Report of the States

Information as of February 1, 1975

PRESIDENTS COMMITTEE ON MENTAL RETARDATION

Washington, D.C. 20201

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Mental Retardation is a condition with which we have been living since civilization began. Although in recent years much has been accomplished to identify, treat, and sometimes eliminate certain causes of mental retardation, we are continually learning that its effects go far beyond present knowledge. There is an urgent need to determine and present what is known about mental retardation today. There is a parallel need to identify and acknowledge those areas where true knowledge does not exist, and only opinion prevails.

In this book we attempt to identify what is known, and to present it in such a manner that anyone associated with or interested in mental retardation will find it readily useable. This work deals with the nature and extent of mental retardation and its social implications. It presents information related to three goals of the President's Committee on Mental Retardation: minimum occurrence of the disability, adequate and humane service systems, and assurance of full citizenship for those who are mentally retarded.

It is hoped that this book will be first of all informative and authoritative, and that the manifest absence of knowledge in many areas will prove an incentive to seek facts that are presently lacking. The book should be a platform of present knowledge on which future directions can be charted. It is an essential prelude to the Committee's forthcoming report to the President on the future outlook for those who are mentally retarded.

I wish to acknowledge the generous contributions of members, consultants, advisers and staff of the President's Committee. The task group of Dr. Cecil Jacobson, Aris Mallas, Alfred Weissberg, Dennis Haggerty, and William Wilsnack are especially recognized.

James N. Juliana Chairman of the Task
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The nation has been given a mandate by its President ". . . to chart a concerted effort to minimize the occurrence of [mental] retardation and to assure humane services and full citizenship for those who are retarded."

The President's Committee on Mental Retardation is charged, on the eve of the Bicentennial, to make a major report to the President, advising him on the best methods for achieving these goals.

This book is one part of that report. It describes for each of the three major goals mentioned above what can and what cannot be reported about the level of methodology and accomplishment in the United States, in the year 1975.

It is stated now, and will be repeatedly emphasized, that there are many gaps in available information. While recommendations are not within the scope of the book, the need for information to be readily available is stated as a truism. Effective programs cannot be operated if major questions go unanswered.

It would be inaccurate to state that the highlighted gaps always represent the unknown or the unknowable. Each piece of information presented here represents the best of what could be obtained from what are called, in today's language, "information retrieval systems." Those in the field have done much more than can be reported here, but documentation of these facts has not been collected in a central reporting system.

Apart from the three specific areas of occurrence, services, and citizenship, each of which is discussed in a separate chapter, two other questions are discussed: what is mental retardation and what are the costs of mental retardation? The first question serves as an introduction. The second, although placed at the end, is not a summary, but raises questions that must be answered as the nation works to meet its objectives.

The information presented in this book should serve as a baseline for monitoring present circumstances and as a departure point, indicating future change.

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How Has the Definition of Mental Retardation Evolved?

Mental retardation refers to significantly sub-average general intellectual functioning (two standard deviations below the normal) existing concurrently with deficits in adaptive behavior, and manifested during the developmental period.

This is the definition adopted by the American Association on Mental Deficiency (AAMD) on advice of its Task Force on Classification and Terminology headed by Herbert Grossman in 1973. It is the latest in a series of efforts to define mental retardation. These efforts are certain to continue.

In 1846 Samuel Gridley Howe defined "feeble-minded" persons who ranged in level of incapacity from those with reason enough for simple individual guidance plus normal powers of locomotion and animal action, to "mere organisms."

In 1914 Henry Goddard subdivided the "feeble-minded," again by degree of incapacity, into "morons, imbeciles and idiots."

In 1941 Edgar Doll defined "mental deficiency" as "(1) social incompetence, (2) due to mental sub normality, (3) which has been developmentally arrested, (4) which obtains at maturity, (5) is of constitutional origin, and (6) is essentially incurable."

In 1958 Seymour Sarason and Thomas Gladwin accepted Doll's definition for those persons with brain damage but proposed another which applied to "individuals . . . who almost invariably come from the lowest social classes and whose low [intelligence] test scores cannot be considered a reflection of intellectual potential."

In 1959 Rick Heber prepared for the American Association on Mental Deficiency (AAMD) a definition which received wide use: "Mental retardation refers to sub average general intellectual functioning which originates during the developmental period and is associated with impairment of adaptive behavior." Sub average functioning was defined in the language of statisticians to mean anyone more than one standard deviation below the normal (IQ approximately 84 and below). It included a group called "borderline retarded," and labeled successive degrees of impairment as mild, moderate, severe, and profound mental retardation.

In 1973 Jane Mercer tried to define mental retardation in a different way, from what she called the "social systems perspective" rather than the "clinical perspective." She considered mental retardation an "achieved status in a social system and the role played by persons holding that status." One could, therefore, be considered mentally retarded and labeled as such even though not meeting all the criteria required by the AAMD definition.

Two Views of Mental Retardation

Clinical Perspective		Social Systems Perspective
Intelligence is an entity that exists independent of cultural setting.	M E N T A L R E T A R D A T I O N	"Intelligence" is relative to the requirements of the particular social system.
If one is retarded according to standard statistical or medical tools, he is retarded.		One can be "retarded" for some systems (e.g., school) and "normal" for others (e.g., family life).
A clinician can detect abnormalities not apparent to laymen. These unseen abnormalities can be proof of retardation.		Retardation cannot be "undetected," since an individual _is_ retarded only by virtue of being labeled as such in a particular setting.
The real number of retarded people in an area can be scientifically determined without considering the area's social structure.		The number of people labeled retarded in an area is determined by the social structure of that area (i.e., what is expected of persons; how much, or how well, is difference tolerated?)

Adapted from: Mercer, J.R. Labeling the Mentally Retarded. Berkeley, California: University of California Press, 1973.

Also in 1973, the Grossman committee modified the earlier AAMD definition, this time eliminating the category of borderline retardation and placing the upper IQ limit of mental retardation at approximately 70 (depending on which intelligence test is used).

This definition is not fully applied. As a consequence, practice follows a variety of definitions, some of them different from the formally established ones. This is particularly true in the areas of regulation and service.

See references 50, 77

How Has the Definition of Mental Retardation Been Approached?

Underlying the differences in definition presented here are approaches from different scientific frameworks.

From the biological or medical viewpoint, mental retardation has been seen in terms of pathology, or sickness, which differentiates individuals in their physical make-up and function from the characteristics of the "normal" individual.

From the educator's viewpoint, the mentally retarded individual is of concern when he does not respond to the usually successful methods of instruction in use in the schools. This has led to the statistical focus, which attempts to classify individuals according to intellectual potential and thereby predict the limits of future success or achievement.

As important as scientific concerns are, societal attitudes have been just as important in the developing definition of mental retardation. As evidence mounted that more retarded persons were "found" in certain ethnic or income groups and in certain geographical areas, pressure was exerted to re-examine definitions of retardation to determine whether the consequences of deprivation were being confused with constitutional disability.

There remain unresolved definitional questions that are under continuing inquiry.

See reference 22 4

What Is Subnormal Intellectual Functioning? How Is It Detected?

It is the inability to use one's mind for thinking, reasoning, figuring, or remembering as well as someone who is "normal," as a result of a developmental problem. "Normal" means average, and is determined by responses to intelligence tests.

The first attempts to measure intelligence in children by Binet and Simon in France in 1905 were brought to the United States and extended. Around 1915, Stern and Terman proposed the "intelligence quotient" (IQ), to compare a child's "mental age" as revealed on the tests, with his chronological age. By dividing mental age by chronological age and multiplying by 100, a number is achieved: the individual's IQ. Subsequently, a wide range of other tests for measuring intelligence have been developed, using other methods for obtaining an IQ. The most widely used is the Wechsler Series, applicable to both children and adults. The average score on intelligence tests is 100. How far above or below this number a person's score falls determines whether he or she is psychometrically "bright" or mentally retarded.

The following chart shows the major levels of mental retardation and the IQ ranges that apply to each level, from two widely used intelligence tests.

Level of Mental Retardation	Obtained Intelligence Quotient	
	Stanford-Binet	Wechsler
(Borderline)*	(69-84)	(70-84)
Mild	52-68	55-69
Moderate	36-51	40-54
Severe	20-35	25-39
Profound	19 and below	24 and below

***"Borderline" figures are given here for comparison. Since the American Association on Mental Deficiency adopted its 1973 definition, persons scoring in this range are not considered mentally retarded.*

There are a number of prevailing criticisms of intelligence tests today:

- They are based on the values of white, middle-class persons and are therefore not pertinent to persons of other cultures.
- They measure achievement based on differences in opportunity to learn, rather than native intelligence.
- They are used arbitrarily as a means for excluding persons of minority cultures from opportunities to learn.
- They are over-simplified reflectors of complex and unique human characteristics.

See references 30, 50, 77

Measured?

Although measurement of mental retardation was first concerned with intelligence, especially with more severe forms of retardation, deficits in adaptive behavior are the first indications of a problem. Simply stated, adaptive behavior refers to the way an individual performs those tasks expected of someone his age in his culture. For very young children, expected behaviors are dressing, eating with utensils, and acceptable toilet training. Older children are usually expected to go to school and advance in grade, be able to handle money, and take some responsibility for household chores. Adolescents are expected to develop independent social relationships, cope with their sexual development, and begin to earn money. Adults are expected to be capable of adequate performance in a job or the management of a household.

Since Heber's definition of mental retardation was adopted by the American Association on Mental Deficiency in 1959, attempts have increased to develop an accurate assessment of adaptive behavior.

Some well known measures in use today are the Apgar test for newborn infants, the Vineland Social Maturity Scale, the Gesell Developmental Scales, the AAMD Adaptive Behavior Scales, and the Denver Developmental Screening Test. In Europe, the Gunzburg Progress Assessment Chart is very widely used.

Measures of adaptive behavior typically depend on the judgments of people who know the individual being tested or on direct observation by the tester. Because the behaviors to be

rated often cannot be seen under "laboratory conditions" (for example, a person's ability to use public transportation), tests are often time consuming.

Some persons have criticized the available tests, saying that they do not adequately account for cultural or geographic differences that would make for differing expectations of "normal behavior."

With the exception of the child development clinics sponsored by the Maternal and Child Health Service of the U.S. Public Health Service, adaptive behavior measurement has not yet spread far beyond the institutions, where much of its development took place. Most children referred to these clinics for evaluation are rated for both intelligence and adaptive behavior, and both scales are considered in any diagnosis of mental retardation.

See references 50, 77, 118

How Are Ratings of Intellectual Functioning and Adaptive Behavior Related?

Is low IQ predictive of adaptive behavior failures? The answer is indefinite. We do not know.

New Patients in Maternal and Child Health Mental Retardation Clinics by Intelligence and Adaptive Behavior Levels, Fiscal Year 1972

Intelligence Level			Adaptive Behavior Level		
	Number	%*		Number	%
Total Determined	22,728	100.0	Total Determined	18,485	100.0
No Retardation	9,026	39.7	No Retardation	7,100	38.4
Borderline	4,886	21.5			
Mild Retardation	3,955	17.4	Level—1 (Mild)	4,152	22.5
Moderate Retardation	2,621	11.5	Level-2 (Moderate)	3,272	17.7
Severe Retardation	1,508	6.6	Level-3 (Severe)	2,348	12.7
Profound Retardation	732	3.2	Level-4 (Profound)	1,613	8.7

**Does not total 100% due to rounding.*

Adapted from: U.S. Department of Health, Education, and Welfare. Children Served in Mental Retardation Clinics - Fiscal Years 1970-1972. Rockville, Maryland: Maternal and Child Health Service, 1973.

The last year for which data represented in the above table were available from the Maternal and Child Health Service is 1972, when the pre-1973 AAMD definition of mental retardation was in use. For that reason, borderline retardation is still listed as a category. Since different numbers of persons were given the different tests, comparisons between scores cannot be drawn.

There is no available information on the distribution of mentally retarded individuals who have been identified on the basis of using IQ and behavior tests combined.

See reference 108

How Are the Numbers of Mentally Retarded People Determined?









This is a question of epidemiology, the science of determining the amount and distribution of a condition or disease in a given population. Mental retardation is a condition, not a disease. Two measures are used:

- Incidence refers to the frequency of occurrence of new cases of mental retardation in a population during a designated time interval. Questions concerning incidence usually are related to prevention.
- Prevalence refers to the proportion of persons in a population who are considered mentally retarded at a given time. Prevalence is important in determining the need for services.

What Is the Connection Between Incidence and Prevalence?

The incidence of mental retardation ultimately determines the prevalence of retardation. The following table shows the effect of incidence on prevalence under different conditions. This table illustrates that even if occurrence of mental retardation were to be prevented within the next ten years, there would still be need to provide increasing amounts of service in the immediate future.

An Illustration of the Effect of Incidence on Prevalence

Persons Leaving the Population	<div>Year 1 Incidence – 10 Per Year</div> <div></div>	<div>Year 5 Incidence – 5 Per Year</div> <div></div>	<div>Year 10 Incidence – 0</div> <div></div>	<div>Year 20 Incidence – 0</div> <div></div>
	<div>Prevalence = 10 – 2 = 8</div>	<div>Prevalence = 45 – 10 = 35</div>	<div>Prevalence = 65 – 20 = 45</div>	<div>Prevalence = 65 – 40 = 25</div>
Two Per Year	<div>Year 1 Incidence – 10 Per Year</div> <div></div>	<div>Year 5 Incidence – 5 Per Year</div> <div></div>	<div>Year 10 Incidence – 0</div> <div></div>	<div>Year 20 Incidence – 0</div> <div></div>
One Per Year	<div>Prevalence = 10 – 1 = 9</div>	<div>Prevalence = 45 – 5 = 40</div>	<div>Prevalence = 65 – 10 = 55</div>	<div>Prevalence = 65 – 20 = 45</div>

Retardation?

There are no methods currently available to determine the true incidence of mental retardation. And it is incorrect to speak of "the incidence" as if it were a fixed, unchangeable rate. The number of persons who will suffer impairments in adaptive behavior and demonstrate significantly subaverage intelligence is highly dependent on such factors as circumstances of heredity and birth, adequacy of health care, economic conditions, and family circumstances. Consequently, questions about incidence are related to prevention of mental retardation.

Obviously, incidence and prevalence will be significantly determined by the way in which mental retardation is defined.

Some factors that contribute to difficulty in determining the incidence of mental retardation are these:

- It is not possible to identify in every case the cause of mental retardation. Therefore, incidence cannot be determined at its source.
- In only the minority of cases can it be determined at birth that a person is, or ever will be, mentally retarded, or that, having been identified as retarded, he or she may not at some time cease to be so regarded.
- Most mentally retarded persons are first identified at five or six years of age when they enter (or attempt to enter) school and are subject to intelligence tests.
- Many children, classified socio-culturally mentally retarded, are not mentally retarded at birth, but begin to show deficits in functioning after they begin school.

What Is the Prevalence of Mental Retardation?

We are now at a point of being unable to establish the prevalence of mental retardation. This is one of the serious lacks of information since prevalence determines the need for service.

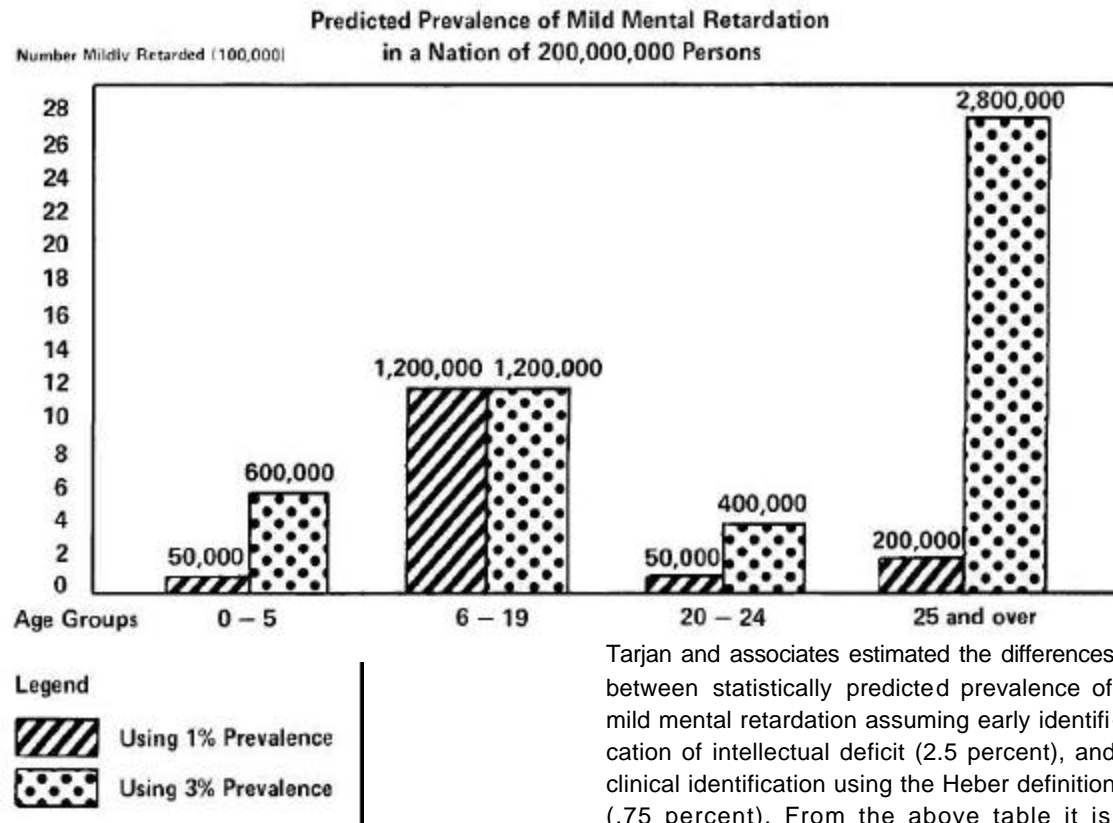
The answer to this question really has two parts: one fairly well agreed upon, the other shrouded in controversy.

A recent summary of epidemiological surveys that were conducted in the United States concluded that the prevalence rate is 0.3 percent for "severe" (actually moderate, severe, and profound) retardation. For the most part, the diagnosis of mental retardation for these individuals can be confirmed medically (through detection of physical signs associated with mental retardation), psychometrically, and through deficits in adaptive behavior. They are obviously retarded, and usually obviously handicapped as well. Epidemiological studies in other countries tend to converge on similar findings.

When mild mental retardation is added, consensus completely breaks down. The widely quoted three percent total prevalence figure used over the years is now being shown to be affected by many factors, including:

- changes in definition of mental retardation
- ways of identifying mildly retarded individuals
- confusion with respect to what constitutes socio-cultural retardation.

It is pointed out that at any given time only one percent (including all levels) are so identified. The discrepancy between a statistically



Adapted from: Tarjan, G., et al. "Natural History of Mental Retardation: Some Aspects of Epidemiology." *American Journal of Mental Deficiency*, 77 (January, 1973).

See reference **100**

predicted three percent and the actual one percent identifiable is demonstrated by the accompanying diagram.

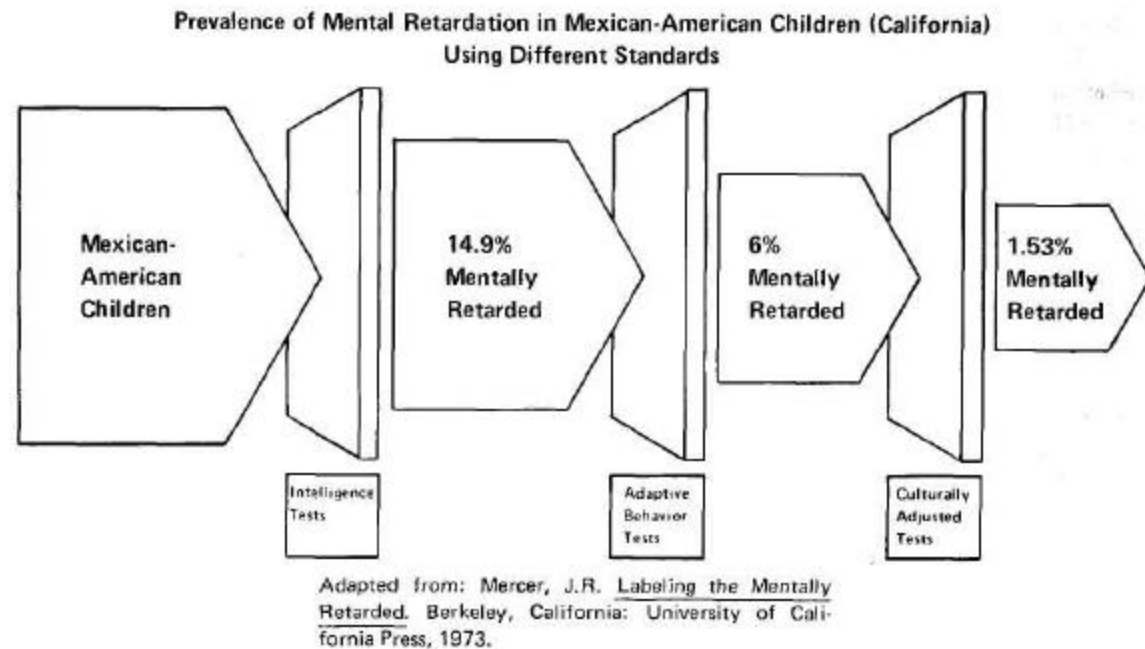
Tarjan and associates estimated the differences between statistically predicted prevalence of mild mental retardation assuming early identification of intellectual deficit (2.5 percent), and clinical identification using the Heber definition (.75 percent). From the above table it is manifest that the majority of difference in the estimates is accounted for by the adult population. The estimates for the school age population are identical.

Among possibilities suggested for such discrepancy are that persons identified as mildly retarded in childhood cease to be retarded as adults, or that such persons remain a large unidentified group in need of services. Further epidemiological study is required to explain the "disappearing retarded" in the adult age range.

How Has the Prevalence of Mental Retardation Been Studied?

A six-year long survey by Connecticut's Seaside Regional Center, using the Heber-AAMD definition of mental retardation, supports the one percent estimate. Of about 338,000 people in that region, only 2,587 persons, or 0.8 percent Of the population, were diagnosed or had ever been diagnosed mentally retarded.

Additional support comes from the Grossman-AAMD definition of mental retardation (1973). The changes resulting from this new definition were shown in a Riverside, California study. Using the pre-1973 definition of Heber, prevalence among school age children was 3.47 percent. Using the new definition, it was 0.97 percent. Differences were especially striking when tests for Mexican-Americans in the area were changed to reflect cultural and social class differences.



Those children who were actually classified retarded in schools (and not all who scored retarded in the clinical survey were labeled) were much more likely to come from poor families than those who were eligible but escaped the label.

It should be borne in mind that while the Grossman-AAMD definition excluded the former "borderline" classification from the definition of mental retardation, it does not mean that such individuals are free from problems of learning and social adaptation or that they do not require appropriate supporting service.

See references 24, 50, 77

How Has the Prevalence of Mental Retardation Been Calculated?

On the assumption that an IQ below 70 is sufficient indication of the possibility of adaptive failure, Conley, from his analysis of over 20 epidemiological studies, estimates an overall prevalence of mental retardation very close to three percent so that in 1970, 5.6 million persons were mildly retarded. (His definition of mild retardation, IQ 51—69, is very slightly different from the IQ range according to the current AAMD definition.) He also stresses, however, the differences in prevalence for differing populations. Indications are that mild retardation is:

- six to seven times more prevalent among non-whites than whites;
- thirteen times more prevalent among poor than middle or upper income groups; and
- found most frequently in rural, isolated areas and inner city ghettos.

To speak of "the" prevalence of mental retardation, then, is really to lose sight of the significant differences that occur among different regions, ethnic and income groups, and, as shown earlier, different age groups.

The foregoing material points up again the current lack of information concerning the prevalence of those with degrees of functional deficit less than that of "obviously" (moderately, severely, and profoundly) mentally retarded persons.

See reference 23

There is no clearcut agreement among professionals as to what constitutes a handicap. Different agencies define the term according to their needs: the Social Security Administration concentrates on employability; schools concentrate on educational performance.

The recently formed Office for Handicapped Individuals (OHI) of the Department of Health, Education, and Welfare defines a handicapped person as: "... an individual who, because of a physical or mental disability, is at a disadvantage in performing one or more major life activities (including communication, movement, employment, education, socialization, and self-care)."

Each of these major life activities is viewed relative to the abilities of a non-handicapped person, and each must be taken separately. For example, someone might be unable to communicate well, but be perfectly mobile.

Mental retardation, when diagnosed, is by definition a handicapping condition. Much more frequently than in the general population, retarded persons have additional physical or emotional problems severe enough to constitute handicapping conditions by themselves.

See references 6, 122

What Is the Prevalence of Associated Handicapping Conditions in Mentally Retarded Persons?

In a 1971 nationwide survey of persons (both in community settings and residential facilities) labeled mentally retarded, the following handicaps were found.

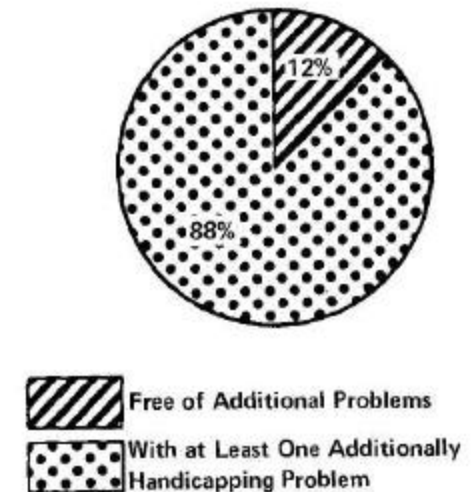
Prevalence of Other Handicaps (%) in Mentally Retarded Persons

Function	No Handicap	Partial Handicap	Severe Handicap	Description of Severe Handicap
Ambulation	57.8	32.4	9.9	Able to take few steps with help or totally unable to walk
Upper limbs, gross motor control	57.5	34.2	8.2	Unable to hold large objects or complete lack of muscle control
Upper limbs, fine motor control	56.1	34.9	9.0	Minimal use of hands, cannot use eating utensils
Speech	45.1	33.4	21.5	Can possibly communicate needs or wants, but uses few or no words
Hearing	85.0	11.5	3.4	Functionally or totally deaf, hearing aid partial or no help
Vision	73.3	20.9	5.9	Minimally sighted (uncorrectable) or legally blind
Seizures (epilepsy, convulsions)	82.3	15.1	2.7	Severe seizures partially controlled or uncontrollable
Behavior, emotional disorders	58.1	35.7	6.3	Adjustment not possible in home environment, abnormal behavior, dangerous to self or others
Toilet training	77.5	10.2	12.3	Dependent on others, slightly toilet trained, or not trained

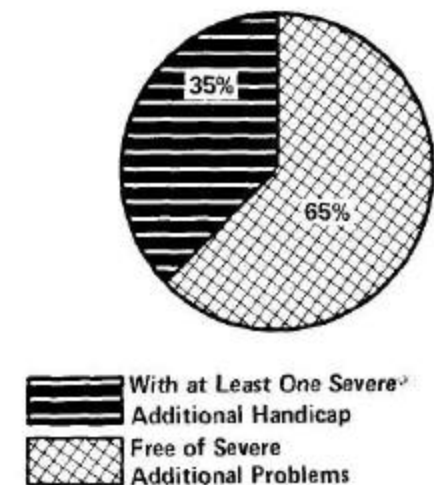
Percentages may not add to 100 due to rounding.

Adapted from: Conroy, J.W., and Derr, K.E. "Survey and Analysis of the Habitation and Rehabilitation Status of the Mentally Retarded with Associated Handicapping Conditions." Washington, D.C.: Department of Health, Education, and Welfare, 1971.

Additional Handicaps of Any Kind



Additional Severe Handicaps



Prevalence of Chronic Organic Conditions (%) in Mentally Retarded Persons

Percent	Chronic Organic Condition
68.9	No chronic organic condition
6.5	Chronic upper respiratory problems
0.8	Diabetes
3.4	Heart disease
4.9	Extreme obesity or severe chronic anemia
2.1	Cosmetic handicap (facial disfigurement)
5.4	Dental or orthodontic conditions
1.7	Cleft palate or oral deformity
3.4	Metabolic and endocrine disorders
2.9	Skin disorders

Percentage does not equal **100** because persons sometimes had more than one condition.

The sample included 14,086 individuals. Some persons called "borderline mentally retarded" were included.

See reference 25

What Effect Do These Additional Handicaps Have?

Handicapping conditions act cumulatively, i.e., the inability to do one major activity may limit participation in others. For example, the mentally retarded child who is not toilet trained is often excluded from special education classes.

In part because of this, the Developmental Disabilities Act was passed in 1969. It was recognized that similarities and overlaps exist among mental retardation, epilepsy, cerebral palsy, and other neurological handicaps. Support for projects for all of these conditions was brought under the same funding mechanism.

We have only estimates of the number of persons with two or more developmental disabilities, and they vary widely, e.g., estimates of the presence of mental retardation among cerebral palsied children have ranged from 15 to 70 percent. Again, information is lacking in this extremely important area.

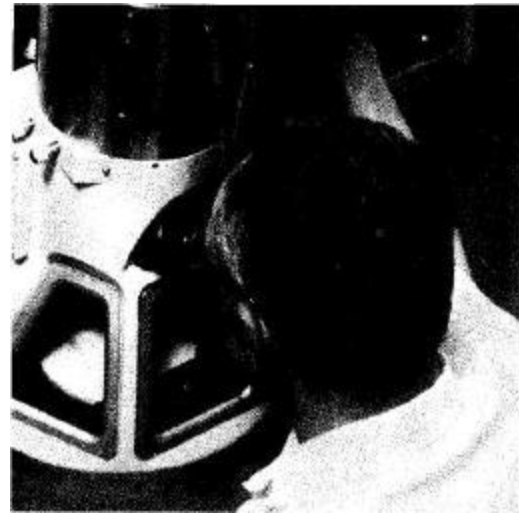
What About the Abilities of Mentally Retarded Persons?

Studies such as the one on the previous page show the prevalence and effect of additional handicaps.

No definitive studies showing the effects of positive and offsetting assets of retarded individuals have been found. Yet there is clinical evidence that many mentally retarded persons have average or superior abilities in different areas. There is also evidence that most retarded persons have highly variable "profiles," being proficient in some areas, deficient in others.

The absence of information on the capabilities of mentally retarded persons represents a major gap in current knowledge.

See references 6, 22, 25



What Is the Goal of Minimum Occurrence of Mental Retardation?

Simply defined, minimum occurrence of mental retardation means the reduction of the incidence of mental retardation, and the resultant prevalence, to the absolute minimum.

Stated as an objective for the nation it has been said:

"To reduce by half the occurrence of mental retardation in the United States before the end of this century."

—Presidential Statement,
November 16, 1971

What Are the Issues Involved in Minimum Occurrence of Mental Retardation?

There are two major issues: the discovery of causation and the application of preventive measures.

With respect to causation (etiology), if circumstances leading to mental retardation are known, remedies can be sought and preventive strategies developed. There are more than 250 known causes of mental retardation, or diseases and conditions so associated with the later development of retardation as to be considered probable causes.

The causes cover the range of hereditary, biological, psychological, and sociological determinants of life conditions and development. They include chromosomal-genetic influences derived from heredity or physiology. They include diseases, infections, accidents, and the physical neglect and mistreatment of children. And they include the slow, sometimes subtle, influences of the physical, psychological, and social environment which may influence the development of mental retardation through deprivation.

Because of the problems in estimating the incidence of mental retardation stated earlier, that portion of incidence attributable to identified causes is not yet known.

Prevention depends on known etiology or empirical discovery and its application.

Where knowledge is relatively clear-cut, as will be shown in the instances of rubella and the Rh factor, retardation attributable to such causes can be reduced or nearly eliminated by developing widespread availability and use of effective preventive technology.

Since there is difficulty in measuring the occurrence of mental retardation, progress toward the goal of reducing it by half in this century cannot yet be assessed.

See reference 50

What Research Is Being Attempted on Causes of Mental Retardation?

Twelve Mental Retardation Research Centers sponsored by the National Institute of Child Health and Human Development (NICHD) through its Mental Retardation Branch, devote their full effort to seeking causes and remedies for mental retardation. NICHD also supports independent research not affiliated with these centers, and the training of research scientists.

Various other government agencies — the Maternal and Child Health Service (MCHS), the Division of Developmental Disabilities (DDD), the Bureau of Education for the Handicapped (BEH), and the National Institute on Neurological Diseases and Stroke (NINDS), among others, help fund research on mental retardation.

University departments of genetics, obstetrics, pediatrics, education, psychology, and sociology contribute regularly to the search for causes.

The range and volume of the research effort, and the amounts of public, philanthropic, university, and other funds spent on research are not known.

See references 31, 44, 50, 52, 93

What Means Are Available to Prevent Mental Retardation?

They can be grouped according to time of application.

Pre-Conception

- Genetic assessment to determine potential chromosomal-genetic risks in pregnancy;
- Timing and spacing of pregnancies through family planning strategies;
- Adequate nutrition for women of child-bearing age; and
- Immunization.

During Pregnancy

- Protection of mother **and fetus against** disease;
- Proper nutrition;
- Monitoring pregnancy through medical supervision;
- Use of amniocentesis to determine the condition of the fetus in high risk mothers; and
- Parental choice of termination of pregnancy when amniocentesis confirms that the fetus is defective.

At Delivery

Medical supervision of delivery in a hospital, including:

- Screening for conditions causing mental retardation to determine newborn children at risk, and taking indicated remedial action;
- Protection of Rh— mothers with gamma globulin within 72 hours of delivery; and
- Intensive care of children who are born ill or premature.

In Early Childhood

- Proper nutrition for nursing mothers **and for** infants and very young children;
- Dietary management of metabolic conditions leading to mental retardation;
- Removal of environmental hazards such as lead-based paint; and
- Early social stimulation and education for infants and young children who are at risk of developing mental retardation (for prevention) and for children who exhibit early mental retardation (to lessen handicap).

This chapter discusses selected diseases and conditions associated with mental retardation, and what is being done, or can be done, to lessen their occurrence.

See references 54, 93, 101

What Is Meant by Chromosomal-Genetic Causes of Mental Retardation?

Each cell in the body contains 23 pairs of chromosomes containing the genes which are the biological elements that transmit characteristics from one generation to the next. The chromosomes and their genes are inherited equally from each parent and, when combined in the cells of the child, constitute what the child has inherited from his or her parents. The chromosomes and genes plus the influences of the environment determine how one looks, feels and behaves.

The chromosomal composition of a typical cell is referred to as a karyotype which is illustrated by the accompanying diagram. Microscopic examination of chromosomes in a specific cell of a living person, when the chromosomes are arranged in a specific order as illustrated by the karyotype, permit determination of differences from the normal, or so-called chromosomal anomalies.

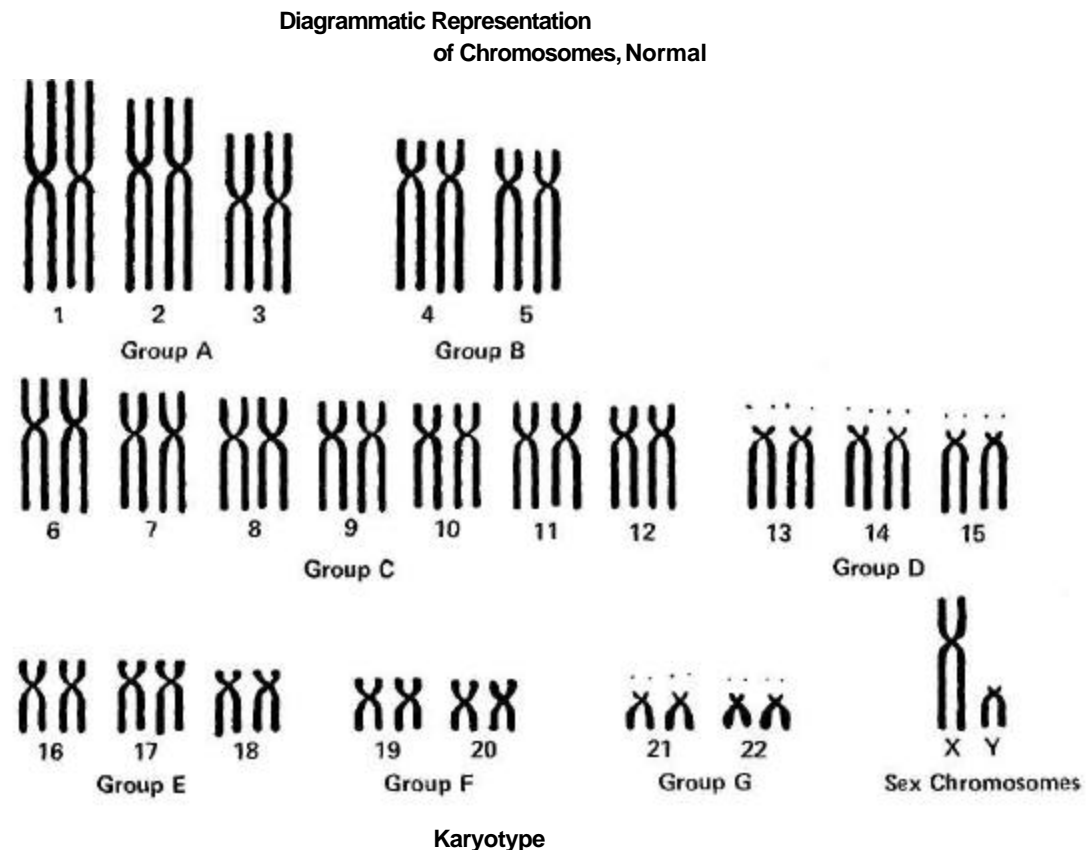
These errors may be the absence of part of a chromosome or an entire chromosome, the presence of more than the normal number of chromosomes, or the exchange of parts of chromosomes from different pairs. Occasionally, normal individuals are found to have an exchange (translocation) of material between two chromosomes. This anomaly is a clue to defects which may occur in children born to such individuals, and forms the basis of genetic predictions of problems such as mental retardation.

Genetic changes can occur during one's lifetime. They help account, for example, for differences in children born to a mother at different ages of her life. However, most

parents of children with chromosomal abnormalities show normal karyotypes in every respect. It is estimated that in the United States one child in every 150 to 200 live births has a major single gene or polygenic anomaly, and a larger number have minor anomalies. The relationship of these anomalies to mental retardation is not clearly understood.

Defects attributable to chromosomes and genes range from those based on a single gene to those that are polygenic (many genes involved). Only chromosomal disorders can be diagnosed from analysis using karyotypes.

See references 31, 59, 60, 74, 78, 102, 106, 113



Source: U.S. Department of Health, Education, and Welfare. "Antenatal Diagnosis and Down's Syndrome." Bethesda, Maryland: National Institute of Child Health and Human Development, April, 1974.

Down's syndrome was discovered in 1844 by Sequin and is named after Langdon Down, who reported in 1866 on a number of mentally retarded children who had a characteristic facial appearance. Not until 1959 did Lejeune demonstrate that Down's syndrome is associated with the presence of an extra chromosome. Since then, other chromosomal rearrangements some hereditary resulting in Down's syn-

drome have been identified, but by far the most common form (trisomy 21) is rarely inherited.

More than 50 signs of Down's syndrome have been identified. Not all signs appear in all cases.

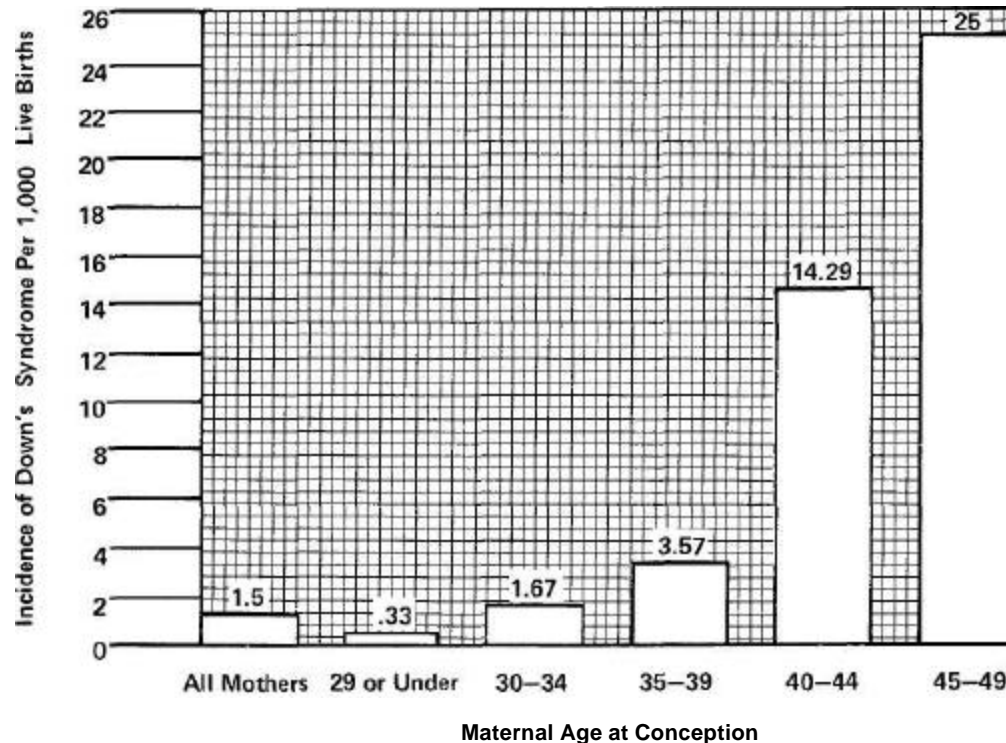
The major characteristics of the syndrome are moderate to severe mental retardation, poor muscle tone, characteristic facial appearance (upward slanting eyes, small round head, small low-bridged nose, protruding tongue), frequent abnormalities of the heart and the eyes, and upper respiratory infections.

See references 60, 66, 88, 106, 120

How Many Children are Born with Down's Syndrome?

A child with Down's syndrome is born once in every 600 to 700 live births. Of the major types of Down's syndrome, by far the most common is trisomy 21, or the presence of three instead of the expected two #21 chromosomes. For trisomy 21 the most important associated factor is mother's age at conception, as shown in the following chart.

**Increasing Risk of Down's Syndrome,
in Live Births, by Maternal Age
(Trisomy 21)**



Adapted from: Koch, R., and Dobson, J. The Mentally Retarded Child and His Family: A Multi-Disciplinary Approach. New York: Brunner-Mazel, Inc., 1971.

The number of newborn infants with Down's syndrome reflects only a small percentage of the number of trisomic children conceived. Most are spontaneously aborted.

A suggested reason for the greatly increasing risk of Down's syndrome with increased maternal age is the increasing susceptibility to damage of egg cells in the mother. The total number of eggs are present at the mother's birth, and over a period of years are reduced in number and exposed to physical and chemical effects that may cause chromosomal damage.

Some other factors that have been associated with increased risk of Down's syndrome are pre-ovulation exposure to radiation and other causes of mutation, repeated abortions, and poor spacing of pregnancies; but no causative influence has been demonstrated. Risk may be somewhat increased for mothers who have already borne one Down's syndrome child, regardless of maternal age.

See references 60, 66, 88, 106

How Can Genetic Counseling Help Prevent Mental Retardation?

Genetic counseling is a recent and increasing approach to prevention of mental retardation and related defects. Although occasionally offered by a physician acting alone, it usually involves a multi-disciplinary team, including research scientists, psychologists, social workers, and public health nurses as well as physicians.

Chromosomal analysis and other examinations (including taking a family history) help determine if there are increased risks; that is, if either or both parents carry the abnormal genes for a severe problem, or if environmental factors pose an increased risk.

A larger number of defects can be determined during pregnancy through amniocentesis. This is a procedure, which was developed in the late nineteenth century, but has had extensive use only in the last ten years.

A needle is inserted in the amniotic sac that surrounds the developing fetus and a small amount of fluid is obtained. Fetal cells in the fluid can then be analyzed to determine the chromosomal make-up of the fetus. In about 95 percent of the cases where amniocentesis is used it serves to detect chromosomal errors.

In addition, about 60 genetic-metabolic errors can be diagnosed by this procedure, combined with appropriate testing of the cultured amniotic cells. These disorders are individually and collectively rare, and account for well below 0.1 percent of diseases of newborns.

See references 31, 39, 66, 93, 106, 120

Genetic counselors usually review diagnostic and historical information with prospective parents and estimate the risks of their having a defective child. They attempt to help parents understand the probabilities and the alternatives facing them.

Amniocentesis is of special value to the counselor and the parents. For most high-risk parents the examination can provide confirmation that the fetus is normal. Without such confirmation, parents might undergo a termination of pregnancy for fear of having a retarded child when in truth the child would be normal. Others discovering through amniocentesis that their child will be defective may elect to have and keep the baby or they may begin considering alternative plans after birth, such as placement for adoption. Still others may elect to terminate the pregnancy. They may decide to have other children, with a good chance of their being normal.

Funding for genetic counseling is provided by government programs including family planning programs and CHAMPUS, the medical services program for Army families, by Health Maintenance Organizations and by some medical insurance plans.

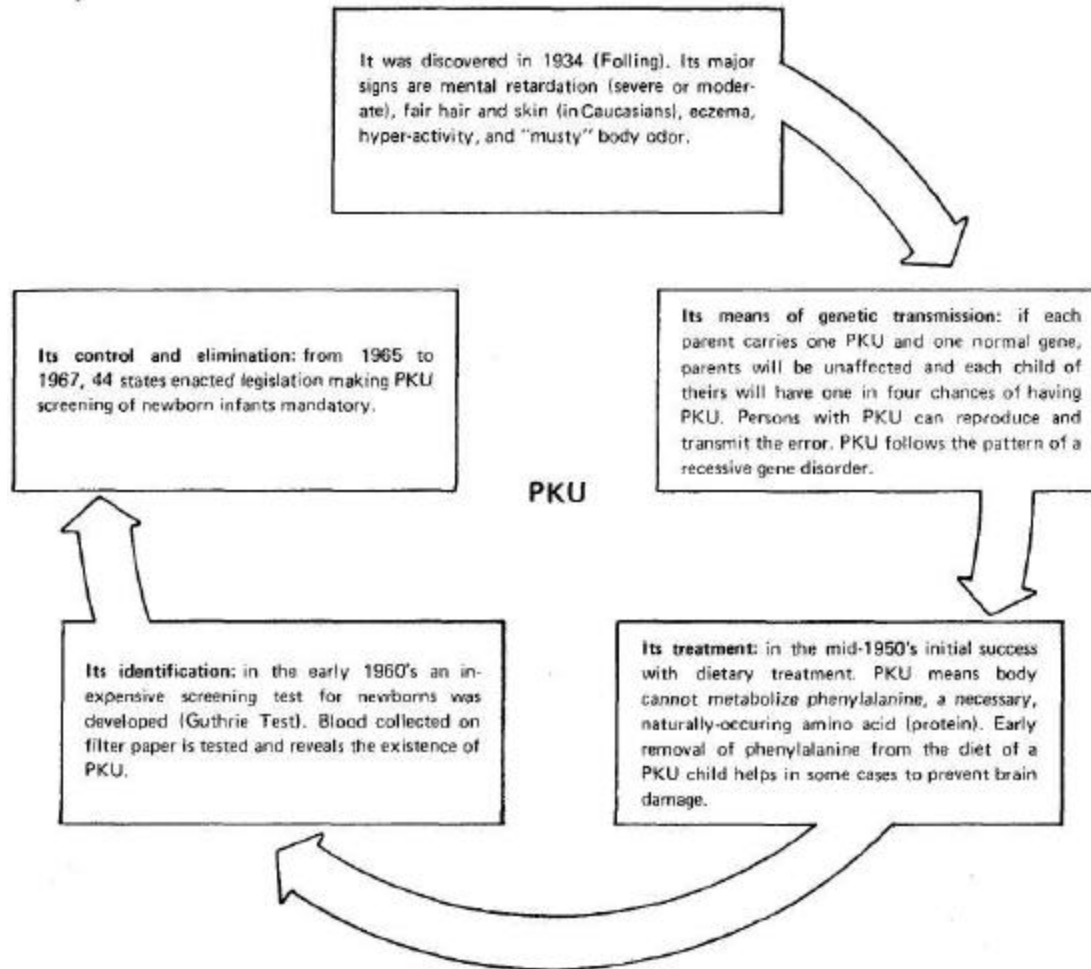
As of March, 1974, there were 274 centers across the United States providing genetic counseling. As of August, 1974, four Blue Shield (medical insurance) plans covered genetic counseling: California, Richmond, Virginia, Washington, D.C., and Florida.

See references **31, 45, 84** 24

Some MR-Related Conditions Detectable by Amniocentesis

Tay-Sachs disease
Maple Sugar
Urine disease
Glycogen Storage
disease
Gangliosidosis
Hurler's
syndrome
Sanfilippo syndrome
Lesch-Nyhan syndrome
Galactosemia

What Are the Inborn Errors of Metabolism?



Phenylketonuria (PKU) is the prototype of these genetically-based diseases. Its incidence is estimated as one in every 14,000 live births in the Caucasian population. Its history is described in the figure to the left.

In the eleven years from 1964 through 1974, Texas performed 1,433,386 tests in its PKU Screening Program, found 387 suspected cases, and confirmed PKU in 72 of these suspected cases. The total cost of the program during this period was \$707,650.

Despite some risks, dietary treatment of newborn infants with confirmed PKU has prevented brain damage which could result in lifetime care costs far greater than the costs of screening.

Screening may produce some "false positives," i.e., a child without the disease may show positive results on the test. Persons who do not have PKU can be harmed by the rigid, carefully regulated diet, and some children develop poorly despite good dietary regimens. It is still not known precisely how long a child should be kept on his diet.

In 1970, 69 percent of infants through the United States and Canada four days old and younger were screened for PKU.

See references 29, 44, 55, 64, 66, 93, 101, 103, 108

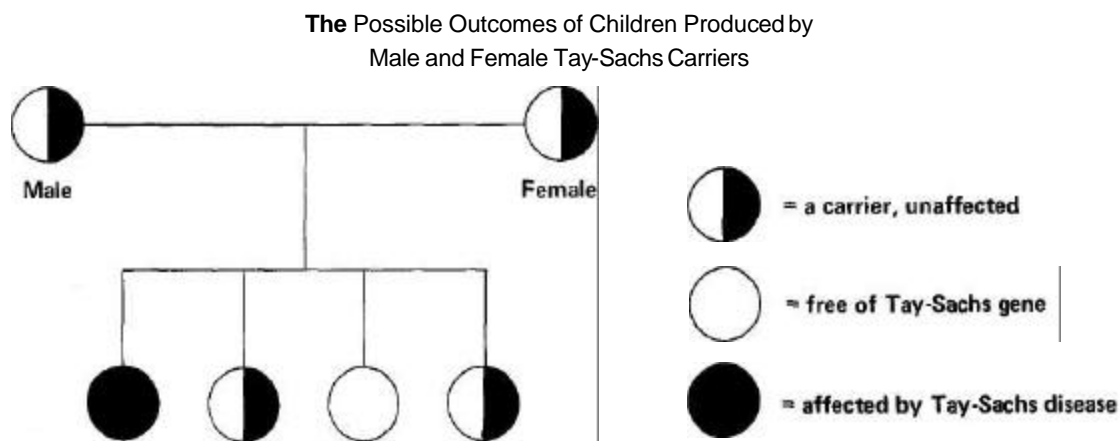
How Is Tay-Sachs Disease Related to Mental Retardation? Is It Preventable?

Tay-Sachs disease, another inborn error of metabolism, is the early infantile form of a class of diseases known as sphingolipoidoses. This means that the body cannot assimilate certain fats. The disorder was identified in 1881, when it was called "early amaurotic idiocy."

Tay-Sachs disease can be avoided if, after genetic studies, there is prevention of pregnancy or termination of pregnancy where the fetus is found defective.

For a child born with Tay-Sachs the disease is universally fatal, usually by the third year of life.

The genetic transmission of Tay-Sachs disease follows the same pattern as PKU. The only time Tay-Sachs is transmitted is when two carriers have children. The possible genetic makeup of their children is shown by the following diagram.



- Adult carriers of Tay-Sachs genes can be detected through a blood test for a specific enzyme (Hexosaminidase-A).
- Tay-Sachs occurs almost exclusively in families of East-European, Jewish background. About one Jewish couple in 900 is at risk of having a Tay-Sachs child.
- Tay-Sachs can be detected in the fetus by amniocentesis.
- If each parent has one Tay-Sachs and one normal gene, chances of their child's having the disease are one in four.

A voluntary screening program in Washington, D.C. and Baltimore, reported in 1974, demonstrated the possibility of reaching thousands of persons to screen them for this defect.

Results of Voluntary Screening Program for Tay-Sachs

Population	Findings
Subjects Tested	6,938
Carriers Identified	315
"At Risk Couples" Identified	11

Adapted from: Kaback, M., et al. "Approaches to the Control and Prevention of Tay-Sachs Disease." In *Progress in Medical Genetics*. Edited by A.G. Beam and A.G. Steinberg. New York: Grune and Stratton, 1974.

The cost for screening averaged a little over \$4.00 per person.

See references 44, 62

Mental Retardation?

Hemolytic disease, destruction of the red blood cells, was first noted in the newborn in 1609. Now, over 350 years later, scientists refer to it as erythroblastosis fetalis. Among its signs and symptoms are dropsy (hydrops), jaundice (icterus) and anemia. Kernicterus, a severe form of erythroblastosis marked by brain damage due to yellow jaundice, leads to death in early infancy or results in mild to severe mental retardation, seizures, spastic or involuntary muscle movements and deafness. About 75 percent of infants with kernicterus die in the neonatal period.

In 1940 a cause of this disease was found with the discovery of the Rh factor which causes some mothers to form antibodies and destroy the red blood cells of their later children. The antibodies are transferred to the fetuses in the mother's subsequent pregnancies via the placenta. The hemolytic disease occurs in the fetal and early neonatal period.

A number of remedies for erythroblastosis have been tried:

- heavy doses of oxygen during and after labor,
- early induction of labor,
- injections of Rh Hapten, a substance hoped to prevent antibody formation,
- partial or complete transfusions of blood to the newborn baby, and
- in recent years partial or complete transfusions of blood before birth.

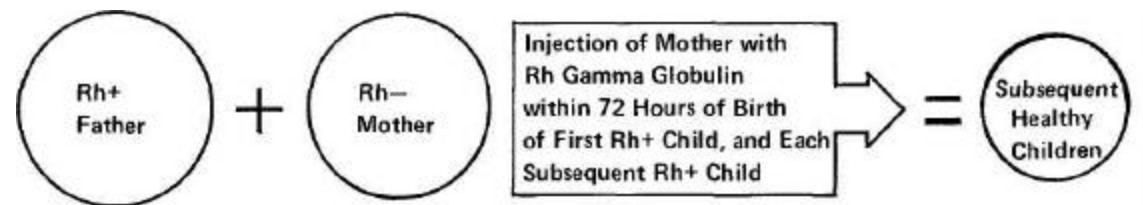
In most cases the complete transfusions were successful in treating erythroblastosis.

Finally, it was found that Rh gamma globulin injections for the mother were most effective since it was possible to prevent erythroblastosis in this manner. Postnatal injection of the mother after birth of her first child prevents initial sensitization and the formation of the dangerous antibodies. The timing of the injection is critical; it is possible to miss immunization of some mothers, and unrecognized abortions may result in formation of antibodies.

See references 4,18, 35, 124

How Is Rh Factor-Related Mental Retardation Prevented?

About 85 percent of the population is Rh positive (Rh+). This genetic factor is dominant. If an Rh+ male and an Rh negative (Rh-) female conceive a child (and this is the only time that the Rh factor creates problems), there is either a 50 percent or **100** percent chance that the child will be Rh+, depending on the genetic constitution of the father. The antibodies formed against this factor may cause death or severe brain damage to the children of later pregnancies. The injection of Rh gamma globulin prevents this possibility.



It is estimated that in 1970, before the preventive injection was available, 20,000 infants a year were affected by diseases stemming from the Rh factor.

In 1973, it has been estimated that 80 percent of women at risk were protected after delivery. The percentage of protection was much lower in cases of abortion, where the risks to future children remain the same.

See references 4, 18, 118, 124

How Is Rubella Related to Mental Retardation?

Although rubella (German measles), a viral disease, has been known since 1815, it was not until 1941 that the dangerous effects of maternal infection during the first months of pregnancy were described by Norman Gregg, an Australian ophthalmologist.

He found varied and unpredictable consequences of congenital rubella. Children of affected mothers might be stillborn, or born alive with multiple defects, or, on the other hand, be unaffected. In the first nine weeks of pregnancy, however, risk of damage to the developing child was estimated at over 50 percent.

Frequently occurring signs in children affected by congenital rubella are:

- microcephaly and/or mental retardation
- congenital heart disease
- low birth weight
- deafness or hearing impairment
- cataracts
- glaucoma
- enlarged liver and/or spleen
- "blueberry muffin" rash

When present, the severity of mental retardation can range from mild to profound.

See **references 26, 44, 118**

How Is Rubella-Related Mental Retardation Prevented?

Since 1969, when the rubella vaccine was licensed, it has been possible practically to eradicate the effects of this disease.

It has been estimated that during the last major epidemic of rubella in 1964, 20,000 to 30,000 infants were born with multiple defects of congenital rubella, many of them mentally retarded. However, during 1970, a non-epidemic year in Los Angeles County, California, the incidence of congenital rubella was one in 10,000 live births. Since only a portion of those affected suffered neonatal death or handicap, this record indicates that rubella as a cause of mental retardation can be kept very low.

The national Center for Disease Control of the Public Health Service has recommended that in order to prevent another major epidemic, all children under the age of puberty should be immunized, or have a history of the infection which creates its own immunity.

Percent of Population Protected Against Rubella, 1973

Age Group	History of Infection	History of Vaccine	Infection and/or Vaccine
1-4	12.8	55.6	62.4
5-9	25.1	64.9	77.9

Adapted from: U.S. Department of Health, Education, and Welfare. U.S. Immunization Survey, 1973. Atlanta, Georgia: Public Health Service, Center for Disease Control, 1974.

Women of child-bearing age are not at the most suitable age for vaccination, since the vaccine may cause harm if they are pregnant at the time. To take account of this, the level of vaccination of children would need to increase in order to protect the nation against another major rubella epidemic. Three major outbreaks of rubella were reported in Colorado during 1973.

See references 93, 118, 120

How Are Prematurity and Low Birth Weight Related to Mental Retardation?

Prematurity and low birth weight are by far the most important obstetrical problems in the etiology of mental retardation and are regarded as serious threats to a favorable prognosis for the child.

A study in Denver of low birth weight and premature children, reported in 1972, demonstrates the increasing risk of handicaps with decreased gestation time and/or decreased birth weight.

Incidence of Moderate to Severe Handicap in Relation to Gestational Age

Gestational Age (Weeks)	No. Examined	No. with Handicap	%
28	33	21	64
29-31	35	19	54
32-34	23	7	30
Total	91		

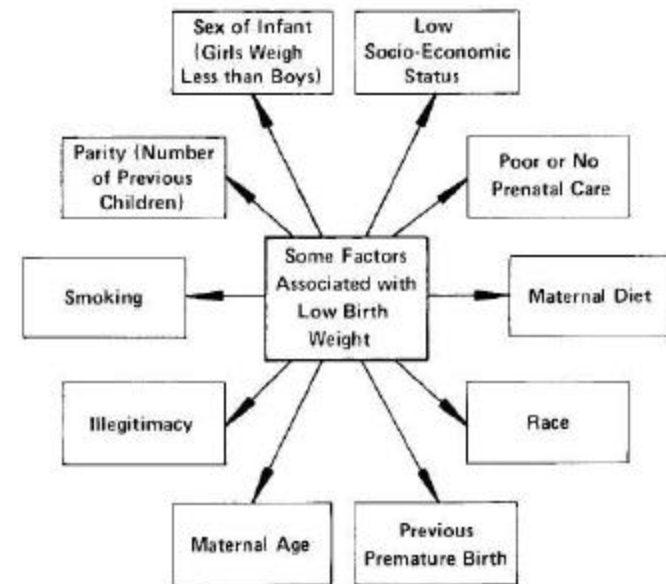
Incidence of Moderate to Severe Handicap in Relation to Birth Weight

Birth Weight (Gm.)	No. Examined	No. with Handicap	%
950	13	11	85
950-1,150	20	14	70
1,150-1,350	32	13	41
1,350-1,500	26	9	35
Total	91		

Adapted from: Lubchenco, L.O., Delivoria-Papadapolous, M., and Searls, D. "Long-term Follow-Up of Premature Infants, II." The Journal of Pediatrics, 80 (March, 1972).

Studies of premature and low birth weight children show that risk of severe handicapping conditions increases sharply when gestation time is reduced or when birth weight is much less than **2,500** grams (five pounds, eight ounces). The children studied here had many different handicapping conditions. Cerebral palsy and mental retardation were frequently found.

The factors below help determine "high risk" mothers.



Prematurity: Gestation time of less than 37 weeks.

Low Birth Weight: Weight at birth equal to or less than 2,500grams.

See references 71, 102

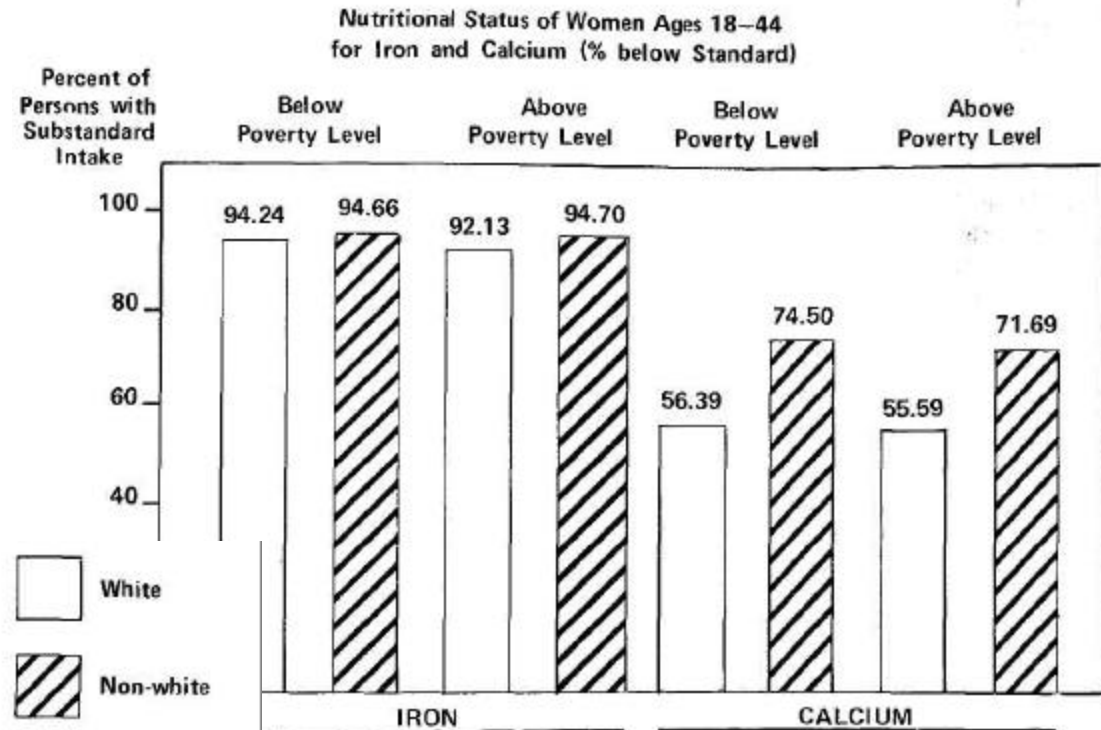
How Does Maternal Nutrition Affect the Occurrence of Mental Retardation?

There is only informed opinion on this subject at this time, but no conclusive information. For example, the following statements were presented in testimony to the Select Committee on Nutrition and Human Needs of the United States Senate in 1973:

"An association exists between maternal nutritional status prior to pregnancy and birth weight in poor populations."

"The larger the number of smaller infants, the greater the chance of mental retardation."

"Feeding a better diet during pregnancy increases maternal weight gain, birth weight, and, therefore, should decrease mortality and the incidence of retardation."



Adapted from: U.S. Public Health Service. First Health and Nutrition Examination Survey, United States, 1971-1972: Dietary Intake and Biochemical Findings. Washington, D.C.: Health Resources Administration, 1974.

Iron deficiency is a problem for many women of child bearing age. Calcium deficiencies, while not as prevalent, still occur in more than half of all women, and are greater among non-whites, regardless of income level.

The United States Department of Agriculture operates a Supplemental Food Program, still in the pilot stage, and a special Women, Infants, and Children (WIC) Program aimed at supplementing the diets of poor families. Of the 4.6 million women and children potentially eligible for assistance from these programs, less than half a million are being helped.

See references 105, 117, 126.

What Do Infant Mortality Rates Tell Us About the Occurrence of Mental Retardation?

Infant mortality is an indicator of a population's reproductive health and the number of persons who can be expected to have congenital anomalies. As indicated in the table below, the nation has made progress in reducing infant mortality rates, but the rate for non-whites is still almost double that for whites. The rate in the United States is substantially above that of some other countries.

Maternity and Infant Care Projects of the Maternal and Child Health Service have helped to reduce infant mortality rates: in Baltimore, from 30.0 (1964) to 20.4 (1972); in Denver, from 28.1 (1965) to 17.3 (1971); in Augusta, Georgia, from 38.8 (1964) to 22.8 (1970). These rates were achieved through providing prenatal care to expectant mothers at high risk.

There are urban and rural areas in the United States today where 30 percent of pregnant women never see a physician until delivery.

In Oregon, in 1973, the death rate among infants was 53.4 for those born outside hospitals, and 18.4 for those delivered in hospitals.

See references **118, 121**

**Infant Mortality, by Race, in the
United States per 1,000 Live Births**

Year	Total	White	All Other
1950	29.2	26.8	44.5
1960	26.0	22.9	43.2
1970	20.0	17.8	30.9
1973*	17.6	15.2	28.8

**1973 infant mortality figures are based on a 10 percent sample.*

Adapted from: World Health Organization. *World Health Statistics Report*. Vol. 27, nos. 3-4. Washington, D.C.: World Health Organization, n.d.

**Infant Mortality in Some Other Countries,
1972**

Some other countries have significantly lower rates.	Country	Rate
	Finland	11.3
	Iceland	11.6
	Sweden	10.8
	Netherlands	11.7

Does Malnutrition in Children Cause Mental Retardation?

While there is no clear cut proof that malnutrition by itself causes mental retardation, the available evidence, from areas with severe malnutrition, provides strong indication that this may be the case.

Malnutrition is thought by many to be just as much a problem for children as it is for their mothers. Although the recently conducted Health and Nutrition Examination Survey has not completed its analysis, preliminary findings show that among children aged one through five, the intake of four major nutrients is very low.

Nutrition levels are not always consistently related to either race or poverty.

Low Nutrient Intake in Children, by Race, Ages 1–5, 1971–1972

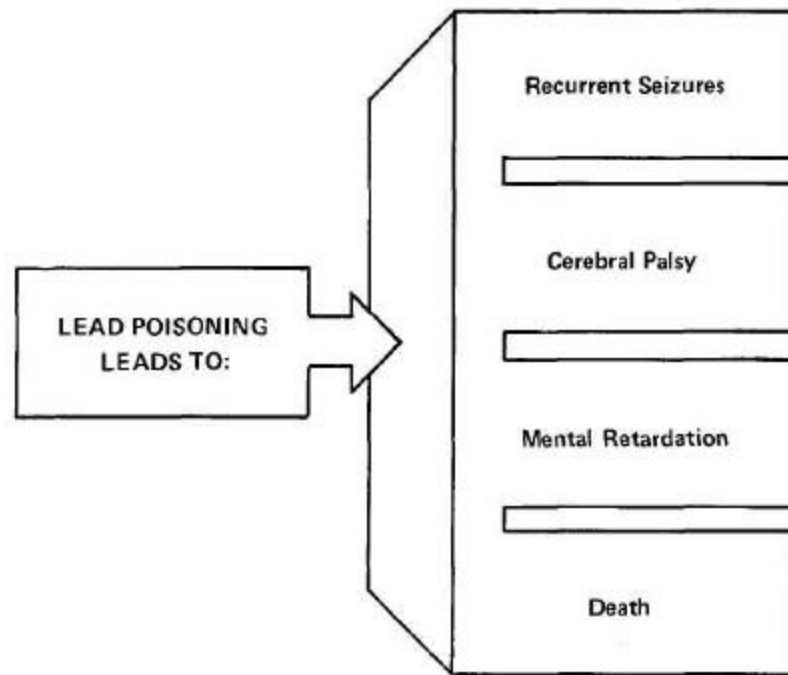
Nutrient	Percent of Persons Below Standard			
	Below Poverty Level		Above Poverty Level	
	White	Black	White	Black
Calcium	14.42	35.26	12.14	24.96
Iron	94.46	93.61	94.88	95.29
Vitamin A	51.51	46.07	36.91	51.01
Vitamin C	58.23	48.54	42.82	52.91

Adapted from: U.S. Public Health Service, First Health and Nutrition Examination Survey, United States, 1971-1972: Dietary Intake and Biochemical Findings. Washington, D.C.: Health Resources Administration, 1974.

Intake of less than 1,000 calories in the previous 24-hour period was reported for more black than white children in that age group.

Evidence also indicates that poor nutrition in youth adversely affects later reproductive performance.

See references 105, 117, 126



What Is the Relation Between Lead Poisoning and Mental Retardation?

Young children often put inedible things in their mouths. In older residences where lead based paint remains on walls, children eating flakes of paint are in danger of suffering irreversible brain damage.

There is growing evidence that lead poisoning, long thought to be a problem mainly in urban slums, may be a danger to middle class children as well.

- In a survey of 14 Illinois communities, more than one in six children ages one through six, from all socio-economic levels, had elevated blood lead levels. Fifty-one of the 6,100 children studied had definite cases of lead poisoning.
- A recent report from Boston showed that in certain neighborhoods which receive their water through lead pipes, there are noticeable quantities of lead in the drinking water supply.

There is conclusive proof that lead poisoning is a major health hazard in urban areas.

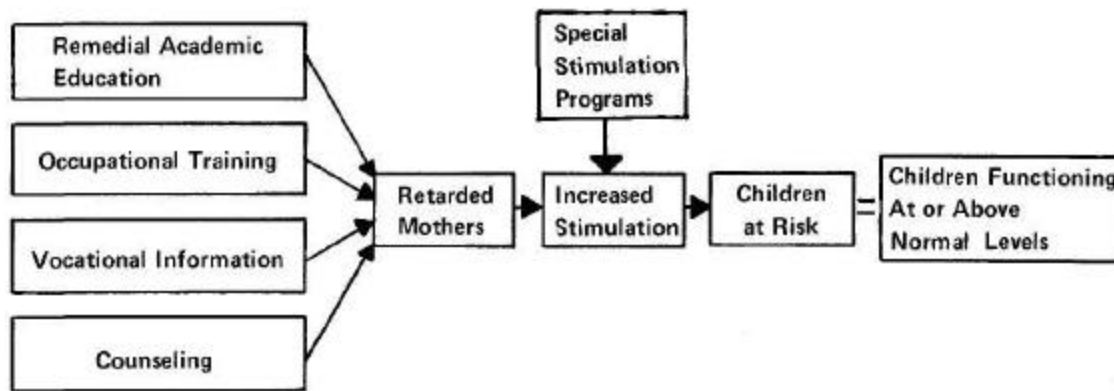
- During a four month screening period in 1972, about 50 percent of newly screened children in Washington, D.C.'s lead poisoning screening program, based at Children's Hospital, had blood lead levels in the abnormal range.

See reference 118

What Is Meant by Socio-Cultural Mental Retardation?

Observations that mild mental retardation occurs more frequently among poor and disadvantaged families led to study of cultural factors. It has been suggested that circumstances of poverty, lack of developmental stimulation, and differing cultural values combine to produce this form of mild retardation, characterized by recurrence in families and no physical or medical signs. An unidentified polygenic hereditary factor is not ruled out.

See references 30, 50, 51, 53, 54 36



What Can Be Done to Prevent Socio-Cultural Mental Retardation?

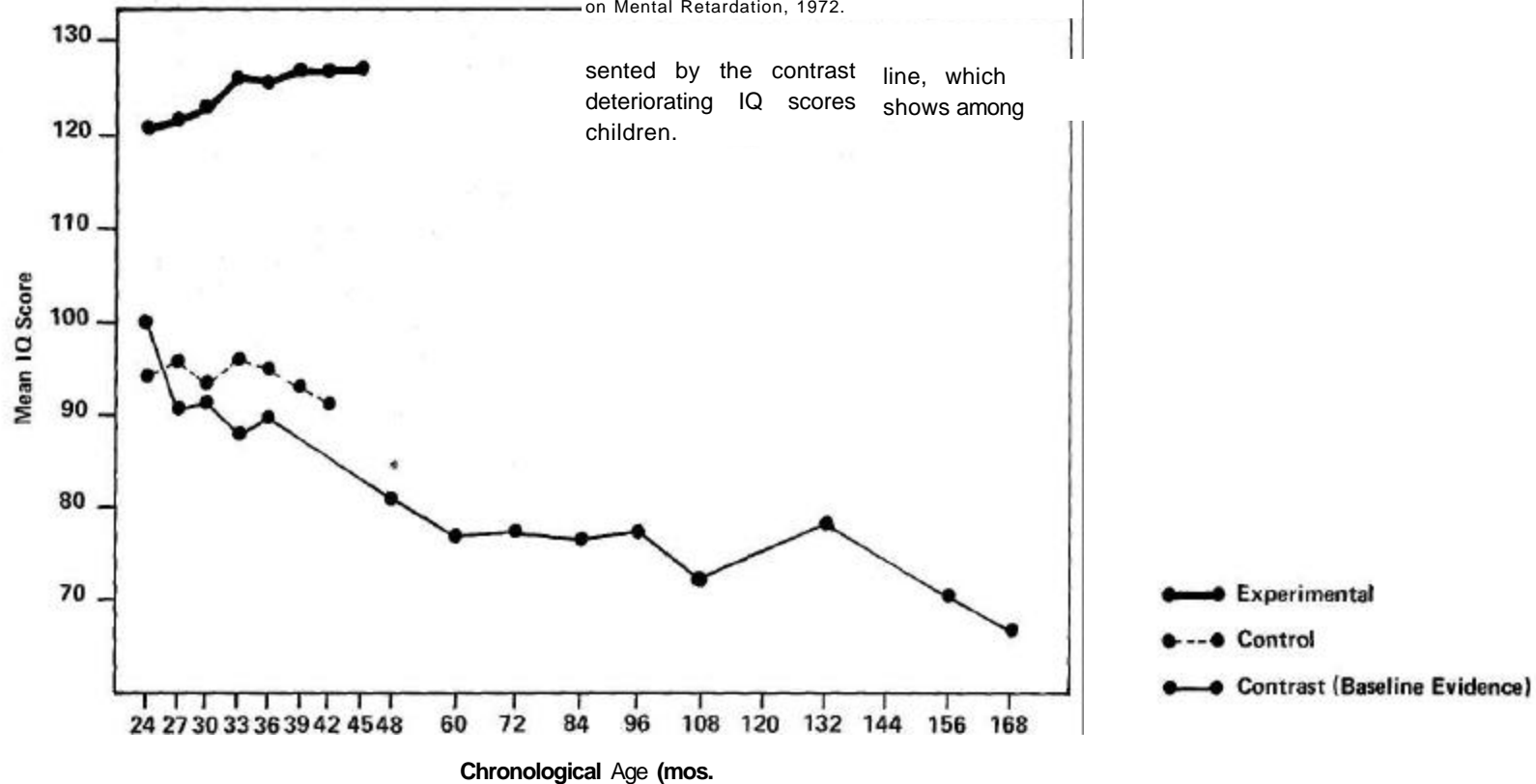
In the Milwaukee Project, begun in 1967, Rick Heber and his associates began by identifying, among the mothers of new-born infants, those who were "mentally retarded" (those having an IQ under 80). They worked intensively with these parents and their newborn children in hopes of preventing intellectual deterioration, relying heavily on methods of social stimulation.

By 1974, results clearly exceeded expectations. The project reports that the children in the experimental group are functioning significantly above their age norms. Children in the control group, whose parents have not participated in the program, have begun to show signs of mental retardation.

See references 53, 54

Experimental, Control and Contrast Group IQ Scores from the Milwaukee

Adapted from: "MR 71: Entering the Era of Human Ecology." Washington, D.C.: President's Committee on Mental Retardation, 1972.



All children initially had the same I.Q. level. The above chart reflects the findings after 24 months in the project. The experimental group is the group of children involved in the program. Control group children have begun to show declining intelligence scores, a result which follows the traditional pattern in the Milwaukee area being studied. This is repre-

See references 53, 54, 131.



Introduction

One of the goals of the President's Committee on Mental Retardation is adequate, humane service systems.

- Services are activities designed to meet human needs.
- Systems are arrangements of policies, resources, and processes by which services are provided to consumers in a systematic fashion. The systems concept includes not only the detailed procedures for providing services, but also the complex network of interrelationships among private and public resources that make service delivery possible. Further, it includes a definition of the measures that will be used to evaluate services and provision for maintaining standards of quality.
- Adequate refers to the extent to which service systems:
 - Substantially fulfill the needs of individuals who seek help from them.
 - Provide for the aggregate of human needs expressed by consumers and service providers in the community.
- Humane service systems embrace the following qualities as expressed by the President's Committee:
 - Respect for the dignity of the individual.
 - Freedom of choice among adequate services.
 - Assurance of the individual's right to have and keep personal belongings.
 - Encouragement of the individual to be active, rather than inactive or passive.

- Support for every individual's need to belong to (be interdependent with) some one else.
- Help to the individual so that he may feel his life has meaning and purpose.

Information on adequate, humane service systems can be presented in many ways. For the purposes of this publication, it is classified according to the diagram on this page. The diagram suggests that as a handicapped person moves from dependence to independence, he moves through a hierarchy of needs — physical, social, educational, economic, residential — and within each need area, from a more to a less dependent status. The requirement of care (represented by the area to the left of the dotted line) implies dependence and is most manifest in the need **area** of residence as the diagram indicates.

Dependence

This hierarchy refers to needs felt by all people and, thus, reflects services that can be provided around those needs. Every person, at some time in his or her life, requires assistance in meeting these needs. The steps in the diagram imply that certain needs must be met before a person will be able to acquire the skills needed to move upward in the process of achieving independence in living.

Data on the pages in this section reflect what is now known and not known about services to meet the physical, social-educational, economic, and residential needs of persons who are mentally retarded.



Adapted from: Santamour, M., and Ross, K. "Defining the Problem of Mental Retardation: A Functional Model." Paper presented at Region X AAMD Meeting, 1969.

about services:

In a discussion of services, one fact is paramount. There is a serious dearth of valid and reliable information through which to present an accurate picture of the state of services for mentally retarded people.

Some problems with available information arise from the confusion over the definition of mental retardation. Some agencies still use the old AAMD definition, some the new one, and still others do not define mental retardation at all. For the most part, statistics lack comparability.

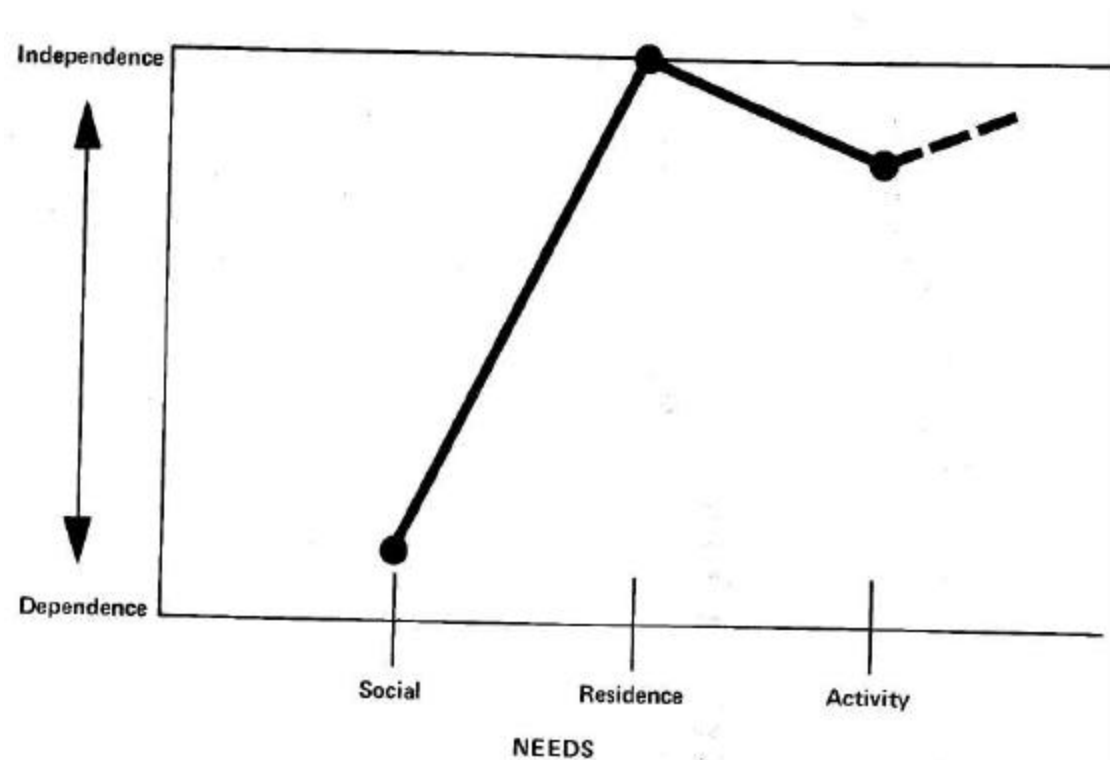
In many instances, persons served are not identified according to disability (e.g., mental retardation, cerebral palsy), and available data are merely estimates, based on varying opinions. This brings into question the validity of the information. For example, the number of mentally retarded persons in public assistance programs can only be estimated. A related problem is reliability of information. Do different persons in an agency, using the same criteria, report the same information? Subjective factors often interfere.

Perhaps most critical among these problems is the fact that current statistics are rarely available on a national, regional, or even statewide basis. In Fiscal Year 1975 many agencies are still analyzing information from 1971 or before, if they keep information at all. Lack of up to date information is a problem.

Concern with services for mentally retarded persons centers on two elements: those services that all people, including retarded people, require (generic services) and those special services designed to meet the special needs of individuals who are mentally retarded and have related handicapping conditions.

Not all mentally retarded persons require special services. On the other hand, "normal" persons often cannot get by with "normal" services alone. An individual's ability to meet his or her needs is dependent on many factors. Among them are age, socioeconomic status, geographic location, ability to get to needed services, and ability to enunciate one's needs, or have this done by a qualified spokesman.

Taking these and other factors into account, it is possible to plot the relative dependence or independence of a particular person in meeting a particular need.



For example, take the situation of a child who is mentally retarded, attends special education classes in public school, and spends most of his spare time at home watching television. He is in a relatively "normal" residential setting, has the opportunity to participate in an age-appropriate (although "special") activity by going to school, but is not having his social needs (friendships, etc.) met adequately. His greatest need for services would appear to be in the social area. Such needs profiles can be extended to other needs such as health, income, family relations, employment, etc.

The theory of normalization, developed in Scandinavia, is a cluster of ideas, methods, and experiences for providing the mentally retarded person with a pattern of life as close as possible to that which would be expected if the person did not have a handicap. A related idea is mainstreaming, which means the integration of handicapped and non-handicapped persons in the same service structures whenever possible. Both normalization and mainstreaming principles have been vigorously championed or attacked. Research on success or failure in their application is limited. Nevertheless, there appears to be a definite trend toward integration of handicapped persons with others, especially in public schools. Both ideas center on the provision of special assistance in the least restrictive setting, in the least stigmatizing manner possible. Both aim for maximum independence of the individual.

See references 9, 133.

What Services Are Required to Meet the Health Needs of Mentally Retarded Individuals?

Health services are of major importance for persons who are retarded because many of them also have other handicapping conditions. Health care is provided through the following types of program or funding:

- Public mental retardation or mental health agencies — such as residential institutions, community mental health centers, and day care centers
- Medicaid — Federally assisted State programs for financing health care of public assistance recipients and certain others
- Medicare — Federal Social Security medical care programs for persons 65 years of age and older or their children permanently handicapped prior to age 22
- Head Start - Federally supported preschool educational, health, nutrition, and parent education program
- Follow Through — early school follow-up of Head Start children
- Public Schools — health services for children and youth with special needs
- Maternal and Child Health Service Clinics — Federally supported local "well-baby" clinics
- Crippled Children's Services - Federally supported State-operated clinics for children and youth with a wide range of physical and mental impairments
- Maternal and Infant Care Projects — Federally financed pre-natal care, delivery, and post-partum services for women in high-risk groups, such as the poor and uneducated
- Children and Youth Projects — Federally financed comprehensive health care for children and youth in high risk groups
- Developmental and Evaluation Clinics — Federally financed special projects for the diagnosis and evaluation of mentally retarded persons
- Private practitioners — such as physicians, dentists, psychologists, social workers, nurses, counselors, and physical therapists.

The health strategy with the most impact on costs and benefits is the prevention of mental retardation, which was discussed in the previous section.

One of the most important factors leading to institutionalization of mentally retarded persons is the accompaniment of additional physical and medical handicaps. The need for long-term management of these conditions has not generally been available in outpatient facilities, and community hospitals are not equipped for long-term patients. Frequently, there is denial of remedial, corrective medical and dental services because of the belief that mentally retarded persons do not benefit.

No national data are available on the types of medical services, extent of coverage or the cost of providing medical services in public and private residential facilities for mentally retarded persons. These facilities are responsible for health care to the largest identifiable group of mentally retarded citizens. This health care has been shown to be seriously compromised by lack of sufficient adequately trained personnel, unsanitary conditions, disease of epidemic proportions, and medical experimentation on residents in many institutions, so that residence in some institutions has been called a health hazard.

See references 40, 118

**Federally Supported Health Services for Mothers and Children
through the Maternal and Child Health and Crippled Children's Programs**

Authorization Social Security Act Title V	Program	Funding Level Fiscal Year 1973	Special Focus	Known Gaps	Number Served
Section 501	Formula Grants to States to Improve Health Services for Mothers, Children	\$60,778,000	Children in Rural Areas	15 States Had No Physician Services Under Program	N.A.
Section 501	State Crippled Children's Services	\$64,900,000	All Crippling Con- ditions in Children		512,881 (Provisional)
Section 508	Maternity and Infant Care Projects	\$42,940,000	High Risk Pregnancies	Located Only in Major Medical Centers	133,000 New Maternity Admissions
Section 508	Intensive Care of Infants	\$ 753,000	Infants at High Risk	Located Only in Major Medical Centers, Low Funding Level	N.A.
Section 509	Comprehensive Health Care of Pre-school and School Age Children	\$43,151,000	Low-Income Populations	Only 1 of 6 Eligible Children Served	538,000
Section 510	Dental Health for Children	\$ 1,180,000	Rural and Urban Low-Income Areas	Only 18 Projects Operating	N.A.
Section 511	Training of Health Manpower	315,882,000	Manpower for Developmental Disabilities (University Affiliated Facilities)		N.A.
Section 512	Research in Comprehensive Health Care	\$ 6,035,000	Use of Different Levels of Health Personnel		N.A.
Total: All Programs		\$235,619,000			

N.A.: Not Available

Among highlights of these programs, 156 mental retardation clinics (child development clinics) were supported totally or in part under the Crippled Children's and Maternal and Child Health Programs. In 1972, 316,407 children were seen. The major service provided, which was diagnosis and evaluation of suspected mental retardation, resulted in a confirmed "diagnosis" in about 70 percent of new patients, but removed the label of retardation from 31.4 percent of all children seen.

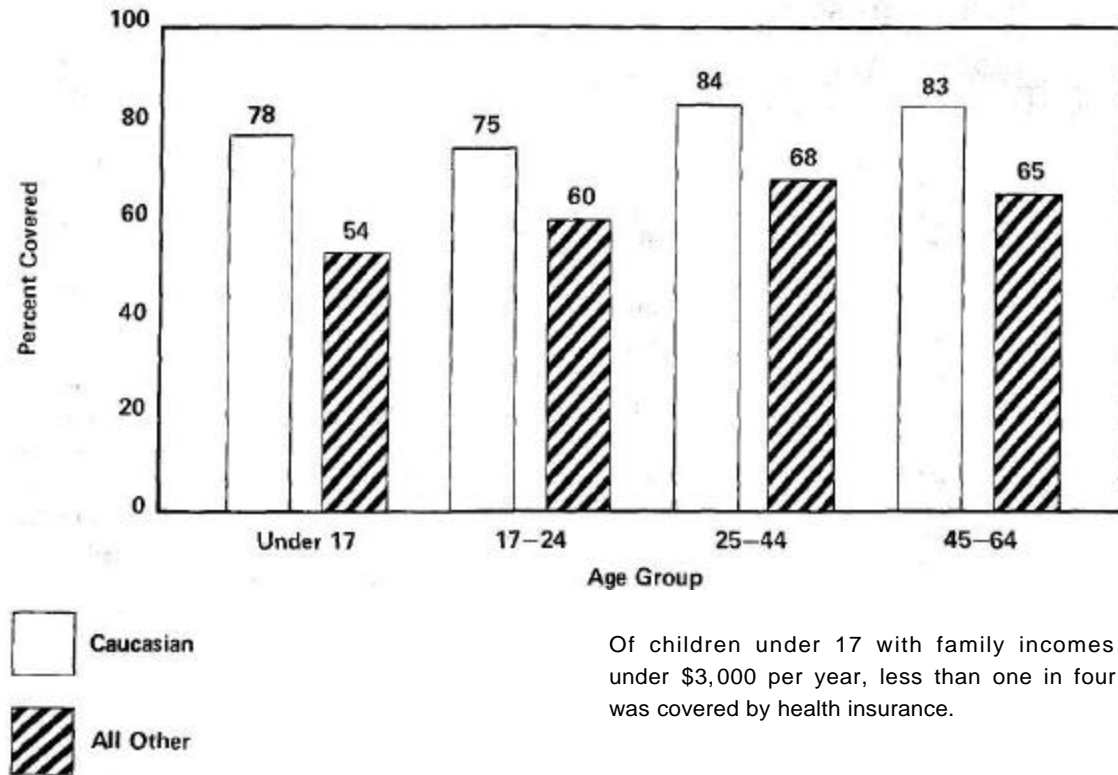
The most prevalent health problem among children is dental disease. There are no exact data available on the extent of the problem or the availability of dental services for mentally retarded children and adults.

See references 108, 118

Home-health services and public health nursing services are two significant health measures which, in enabling families to deal with special medical or management problems, can minimize the need for residential care outside of their homes. More States are moving to the "purchase of service" concept, which enables mental retardation, developmental disabilities, public health, or public welfare agencies to provide these specialized services in lieu of care in large state institutions for retarded persons.

Since insurance guarantees the financial means for securing service, one indication of the adequacy of health services is the extent of insurance coverage in the population. It was shown earlier that mental retardation is most prevalent among low income and minority groups. These same groups have a record of the lowest health insurance coverage.

Percent of Persons Under 65 Years Old with Health Insurance, by Race and Age, 1970



Of children under 17 with family incomes under \$3,000 per year, less than one in four was covered by health insurance.

See reference 118

What Services Provide Mentally Retarded Persons with Social Relationships?

Opportunities for social relationships are provided by the following types of services:

- Pre-school and public school — general socialization.
- Group residences — generally for adults who are moving toward more independent living.
- Membership in youth activity groups — The Boy and Girl Scouts of America have special troops for mentally retarded individuals. Handicapped persons have joined the YMCA and YWCA with full membership privileges.
- Membership in churches and church schools — Some are making an outreach effort to locate retarded persons in their congregations. Some provide special church school classes.
- Federally sponsored Volunteer Programs — A number of Federally sponsored programs encourage volunteers to work with the mentally retarded. The most notable is Foster Grandparents (FGP) which enables senior citizens to work on a one-to-one basis with approximately 15,000 mentally retarded children.

Other significant programs include:

Retired Senior Volunteer Persons (RSVP)
Volunteers in Service to America (VISTA)
University Year for ACTION (UYA) Program
for Local Service (PLS)

- Special social clubs for the mentally retarded
 - They exist or are being formed now in many communities.

- Public and private recreation agencies, including the Federal Parks system — Some provide special programs for retarded citizens.
- Attendance at summer camps — Some regular camps are physically designed to accommodate handicapped persons. Other camps specifically for retarded children and adults have been established.
- Youth NARC (a branch of the National Association for Retarded Citizens) - 40,000 teenagers and young adults befriend retarded persons their age through a variety of service programs.
- Places of employment — Jobs bring many retarded people into contact with others.
- Citizen advocacy programs — volunteer programs which stress socialization as well as representation for mentally retarded persons.

Although some programs for socialization of retarded citizens are available, there are many gaps. There are transportation and other physical barriers which often prevent access to services.

A further problem, as shown by the following information, is that many existing agencies do not yet accept responsibility for making their services available to a handicapped population.

See references 3, 19, 80

Three kinds of generic agencies were surveyed in 1970 to see if they served mentally retarded persons. The results, although from too small an area to present a generalized pattern, indicated that "mainstream" services are significantly limited for retarded persons.

Agencies	Do you serve mentally retarded persons?				What problems would you have in serving mentally retarded persons?				
	Yes	No	Don't Know	No Response	None	Management	Time Required to Serve	Acceptance By Others	
Guidance and Counseling Clinics	44%	53%	3%	6%	100%	0%	0%	0%	18%
Religious Programs	38%	47%	11%	9%	48%	0%	8%	0%	
Social or Recreational Agencies	22%	63%		4%	93%	7%	0%		

(Problems were primary ones; since some others were mentioned, percentages do not always add up to 100%.)

Adapted from: Scheerenberger, R.C. "Generic Services for the Mentally Retarded and Their Families." Mental Retardation, 8 (December, 1970).

At the Institute for the Study of Mental Retardation and Related Disabilities at the University of Michigan, the staff for the last two years has been working intensively to orient staffs of generic agencies as well as public officials (county commissioners, law enforcement officers from throughout the State), to the special needs of the developmentally disabled. One important component of the program is the Institute's work with churches and religious groups to develop outreach programs to help retarded citizens and their families participate in religious services.

See reference 95

Human Sexuality and the Mentally Retarded Person

Mentally retarded persons, especially of mild degree, have normal (not exaggerated) sex needs. The traditional social policy has been to deny normal expression of these needs by segregation or sterilization. Currently there is a tendency toward increasing normalization of contact between the sexes, but sterilization remains highly controversial. Sterilization means any procedure or operation intended to make a person incapable of reproducing. The right to sterilize or to refuse sterilization has become an issue in the courts.

On January 29, 1974 the Secretary of the Department of Health, Education, and Welfare approved regulations governing sterilization of persons in programs regulated by the Department. These regulations introduced a requirement of "informed consent" of the person to be sterilized which, in general, requires that he or she voluntarily and knowingly consent to the sterilization after having been given a fair explanation of the procedure, a description of its discomforts and risks, a description of its expected benefits, an explanation of alternative methods of family planning, assurance of answers to questions and assurance of the person's freedom to change his or her mind at any time prior to the sterilization.

A nation-wide attitudinal survey on the subject of marriage and sterilization for the mentally retarded has recently been conducted with parent and non-parent members of the National Association for Retarded Citizens. Some of the findings are these:

- * The majority (60 percent) of both parents and non-parents felt that mentally retarded persons as a group should be allowed to marry.
- * As their child's age increased, parents tended to be progressively: (1) more resistant to the idea of marriage for their child, (2) more inclined to believe that their child would not be capable of rearing his or her own child, and (3) more in favor of sterilization for their child should he or she eventually marry.
- * Thirty-three percent of all respondents approved of the concept of legislation making sterilization required for the most retarded individuals. An additional 29 percent approved of mandatory sterilization for those who are severely and moderately retarded. However, 86 percent of all respondents favored an individual determination as to whether sterilization is appropriate.

The ability to develop and sustain a meaningful marital relationship may be possible, while the ability of retarded individuals to function as parents may not be present.

See references 32, 41,70

What Services Provide Mentally Retarded Persons with Programs of Daily Activity?

Activities take the form of:

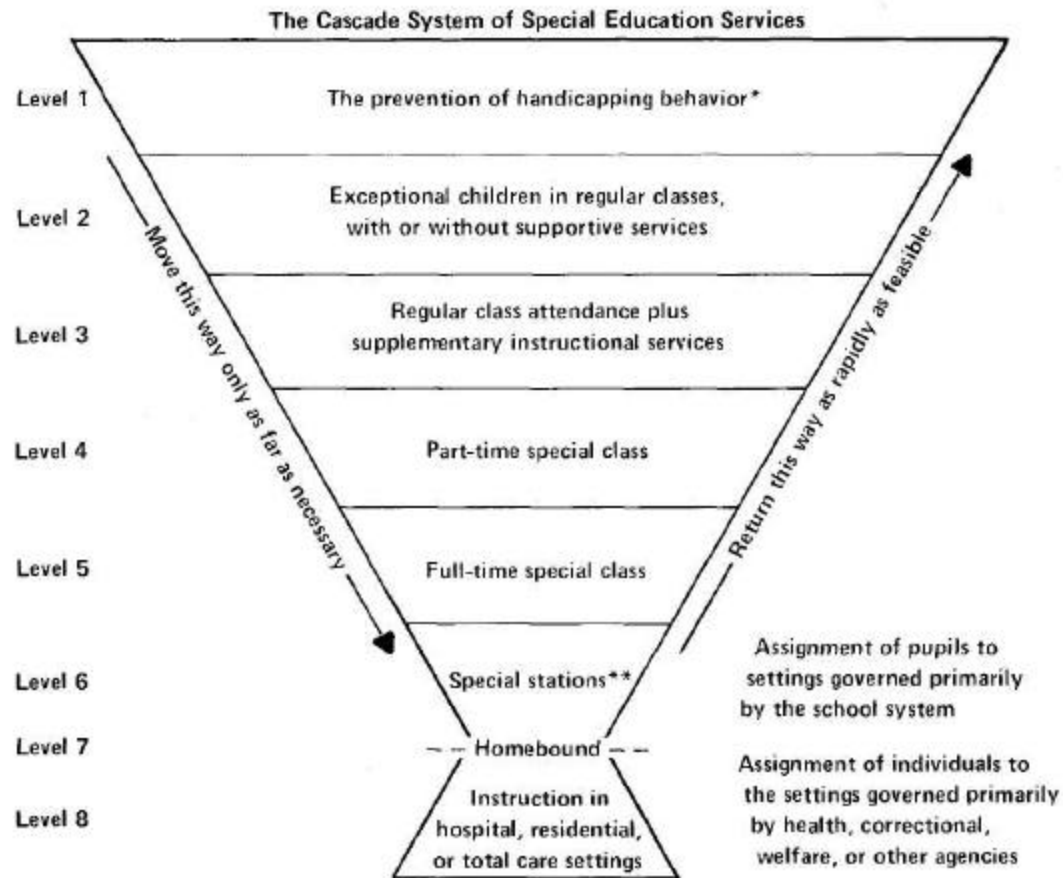
- Education — attending regular or special classes in public schools, private schools, Head Start and Home Start programs, pre school and adult and continuing education programs, special developmental programs, vocational training programs, and activity centers.
- Vocational Training and Employment — working in sheltered employment, on-the-job training, and employment in competitive industry.
- Recreation — physical recreation, cultural events, participation in arts and crafts, spectator entertainment, and neighborhood and community activities.

Services also include access to these programs: transportation, escorts, outreach helpers. The pages following give some of the known facts about these activities.

What Are Some Trends in Education for Mentally Retarded Persons?

Illustrated in the following chart is a current concept. The "least restrictive alternative" may be applied not only to residential services but to all specialized or restrictive circumstances possible. forms of service.

**This means the development of positive cognitive,*



affective, and psychomotor skills in all pupils that will reduce or prevent the frequency of handicapping behavior.

***Special schools in public school systems.*

Adapted from: Deno, E. Cited in Maynard Reynolds, "Two Policy Statements Approved by CEC Delegate Assembly." *Exceptional Children*, September, 1973.

What Pre-School Educational Programs are Provided for Mentally Retarded Children?

Early intervention has been shown to prevent some handicaps and lessen the impact of others. In the area of education this takes the form of infant stimulation and early childhood education.

The 1972 amendments to the Economic Opportunity Act require that at least 10 percent of children enrolled in Head Start programs be handicapped. In its second annual report, the Office of Child Development claims to have surpassed this goal: "... a total of 29,000 of approximately 287,100 enrolled children in Full Year Programs" had been diagnosed as handicapped as of December, 1973.

By Head Start estimates, 7.4 percent of the handicapped pre-school children it served were mentally retarded, 0.74 percent of the total children served.

Day training programs for severely retarded children serve pre-school children in 31 of 42 States responding to a recent national survey. There is a wide variation among States as to kinds of programs offered, standards for programming, and number of children served. The actual number of pre-school children enrolled in these programs is not available.

See references 33,111

What Public School Educational Programs Are Provided for Mentally Retarded Children and Youth?

The Bureau of Education for the Handicapped (BEH) estimates that in school year 1971-1972, 723,747 "educable" (able to learn academic subjects) and 148,466 "trainable" (able to learn self-care) mentally retarded students were served by the nation's public schools and public education agencies. Although the "educable" and "trainable" classifications are considered by many professionals as no longer acceptable terminology, information is still reported in this manner. BEH also estimates that there were 3.7 million handicapped children ages 0—21 not served by public educational agencies. Of this number, an unspecified number may be assumed to be mentally retarded children and youth.

A survey by the National Association of Retarded Citizens shows enrollment of mentally retarded students in the public schools has increased from 711,467 in the 1970-71 school year to 826,177 in the 1972-73 year. As a percentage of the total school enrollment, mentally retarded students increased from 1.43 percent in 1970—71 to 1.87 percent in 1972-73.

Among 49 States reporting, a decline in enrollment occurred in 10 states, while an increase was seen in 39 states. Although this report shows a significant increase, the nation is still substantially far from achieving the Commissioner of Education's goal of free public education for every child by 1980.

For less severely impaired retarded children, one trend in special education is toward "main-streaming" and away from separated special classes. Research in special education has never conclusively demonstrated that separate classes for educable mentally retarded students are superior to inclusion in regular classes with special assistance. Conversely, the main-streaming trend is so recent that there is as yet no completed research by which it can be judged effective. Other variations were reported for many states, making it difficult to compare their programs. Although much statistical information on public school programs is acquired and published by the Bureau of Education for the Handicapped, no data have been acquired by any Federal agency on the number of retarded adults in adult educational programs or in continuing education programs.

Day training services, mentioned earlier, have been a traditional resource for children and young adults excluded from public schools. In a recently completed survey it was found that 42 of 46 States responding provided such services. While the courts have established the principle of the right to education for retarded persons, there are many gaps between the determination of the right and the actual provision of service.

- One State had six centers serving 96 clients.
- One State had 163 centers serving 12,000 clients.

The wide variation can be seen in the following comparison.

A Comparison of Day Training Programs in Two States

State	Enrollees per 100,000 Pop.		Expenditures per Client	
	Number	Rank Among States Reporting	Amount	Rank Among States Reporting
West Virginia	5.5	35	\$3,333.33	1
Wisconsin	270.7	1	137.50	33

Adapted from: National Association of Coordinators of State Programs for the Mentally Retarded, "Day Training Services for Mentally Retarded Children: A State by State Survey," Arlington, Virginia: National Association of Coordinators of State Programs for the Mentally Retarded, Inc., May, 1974.

See references 9, 28, 33, 79, 82, 107

What Vocational Training and Employment Services Are Provided Mentally Retarded Persons?

Federal-State Vocational Rehabilitation services, available to the physically handicapped since 1920, were authorized for mentally retarded persons in 1943. Only since the 1960's have an appreciable percentage of Vocational Rehabilitation clients who were "rehabilitated" represented mentally retarded persons. "Rehabilitation," as used here, means placement in a job for sixty days or longer at the end of training. In 1972, it was estimated that 36,043 mentally retarded persons were rehabilitated, in this meaning of the term, representing **11.6** percent of the total number of clients rehabilitated.

- In 1971 it was estimated that 52,520 mentally retarded persons were served by the Vocational Rehabilitation program.
 - 32,980 were mildly retarded,
 - 14,600 moderately retarded, and
 - 4,940 severely retarded.
- Of this total, 29,744 persons were rehabilitated (56.6 percent).

This was a lower percentage of success than in previous years. One possible reason given for the lower success record was the emphasis placed on service to the severely handicapped in 1971. Program growth since that time is not known.

The Grossman-AAMD definition of the condition of mental retardation affects eligibility for Vocational Rehabilitation services. Prior to 1973, the old AAMD definition was used. Abolishing "borderline retardation," makes many persons ineligible for rehabilitation services who

formerly would have been eligible. Because of this problem, AAMD's Grossman Task Force has been reappointed and will soon issue a supplement to the 1973 Manual on Terminology and Classification in Mental Retardation, discussing the need of formerly "borderline retarded" persons to be eligible for services.

Sheltered Workshops

Special workshops which offer market-based employment opportunities for the handicapped in protected work stations provide a large proportion of the rehabilitation training for mentally retarded individuals. Generally, employees in workshops perform piece-work under contract with local industries.

There is no current, comprehensive information on sheltered workshops serving mentally retarded individuals. Of workshops in general there were 1,029 identified in a 1968 national survey, and approximately 2,500 in another national survey undertaken in 1973. Of the nearly 2,000 workshops which provided data for this 1973 survey, the proportion which were serving mentally retarded persons has not yet been determined.

In 1973, Suazo, in a survey of workshops serving the mentally retarded, found that most of the 110 workshops responding to the survey needed immediate help in many areas, especially in placing clients in jobs, providing financial support to those clients who could not produce at a high enough rate for competitive employment, and providing better training for workshop staff.

Activity Centers

While sheltered workshops serve primarily mildly and moderately retarded citizens, activity centers serve more severely handicapped individuals who are not yet ready for sheltered work. Training in basic activities (grooming, personal adjustment, traveling) and social programs are provided with the hope that individuals will become less dependent on others.

In 1971, a survey sponsored by the President's Committee on Mental Retardation located 706 activity centers throughout the nation. Based on the survey, it was estimated that 18,000 persons, ranging in ages from 14 to 65, were being served.

Although the programs had many different methods of operation, the two most often mentioned goals were:

- Work preparation — 85 percent
- Social development — 80 percent

See references 67, 92, 99, 128

What Is the Employment Potential of Mentally Retarded Persons?

Various surveys estimate the number of employed mentally retarded citizens in a given community. Conley summarizes these studies and estimates that at any given time, 90 percent of mildly retarded persons will be self-supporting and that "about two-thirds will maintain that status continuously."

Publicity campaigns over the last decade have tried to demonstrate that "employing the mentally retarded is good business." Retarded citizens themselves have established that, given proper training, they can perform well in competitive employment.

- Through a special examination waiver of the Federal Civil Service Commission, more than 7,000 mentally retarded persons have been employed since 1966. Most succeeded (over half are still working) and the reason for failure was, in most cases, not inability to do the work, but personal adjustment problems.
- An on-the-job training program, funded by the Federal government and administered by the National Association for Retarded Citizens, has placed retarded men and women in private industry. Reports in 1973 show 1,360 persons trained. Funding increases in 1974 raised the projected number to be served to 2,254.
- Major corporations, such as the W.T. Grant Company, have employed large numbers of mentally retarded workers — and would like to employ more.

A list of jobs that mentally retarded persons have performed successfully includes:

**Animal Caretaker
Key Punch Operator
Carpenter Medical
Technician
Dishwasher
Office Machine Operator Food Service
Worker Radio Repair Telephone Operator
Vehicle Maintenance Photocopy Operator
Ward Attendant (sometimes in the same
institution where he or she once lived)**

The employment potential of mentally retarded persons depends on government, industry, and organized labor's willingness to provide the training and restructuring of jobs necessary to take advantage of each individual's talents.

In general, persons identified as mildly retarded in school years tend to disappear into the adult population. There is evidence also that continued identification as "retarded" can be a barrier to employment.

See references 23, 80, 81, 104.

What Physical Education and Recreation Activities Are Provided Mentally Retarded Persons?

Leisure time accounts for one-third of an adult's day and more of a child's. Yet, traditionally most attention has been given to a retarded individual's deficiencies in work or education-related areas. Recreation takes place throughout an individual's life. Although for many years there have been recreation activities in institutions and the community for mentally retarded individuals, there is almost no information available on the extent of these programs for retarded persons at any age level.

A two-year training project at the University of Bridgeport (Connecticut) for physical education students centered on the special recreation needs of mentally retarded persons. Other such programs are becoming more common around the nation. An evaluation of accomplishments of the retarded persons in the project concluded with the following statement: "The most important development observed was the self-confidence they had in themselves and in what they could accomplish through physical activity; they demonstrated this new self-assurance at home with their families and later at the workshop."

A well-known recreation program for mentally retarded youth is the Special Olympics sponsored by The Joseph P. Kennedy Jr. Foundation. Operating in every State and every province in Canada, in Puerto Rico and in France, the Special Olympics had more than 250,000 participants in 1972. In addition to providing healthy exercise and fun for many children, the Special Olympics emphasizes the abilities, not the deficiencies, of mentally retarded youngsters.

This program has shown that children with intellectual deficits can and do compete in physically demanding sports, and that many mentally retarded persons can and do surpass the physical accomplishments of their intellectually average and superior counterparts. A later program sponsored by The Joseph P. Kennedy Jr. Foundation is "Families Play to Grow," a family recreation pattern adaptable to various circumstances, which offers a retarded individual a progressive opportunity for physical recreation, achievement and recognition. In its first year of operation, 1974-1975, the program served 18,000 individuals of whom 5 000 qualified for awards of achievement. Although essentially a family approach, the program has been adapted by residential care facilities, schools rehabilitation agencies and recreation departments.

Character-building organizations with major recreational programs for young people including the YMCA, YWCA, Boys Clubs of America, Camp Fire Girls, Boy Scouts and Girl Scouts, either through local units or on a national basis provide recreation services for handicapped youth, including mentally retarded persons. The Boy Scouts of America has undertaken national programming for mentally retarded members for many years, including a waiver of the usual age limit for membership. By 1973 it had 2,500 Scout units for retarded members.

Special camps for retarded persons have been developed and are operated on various patterns of funding and sponsorship, some by public residential facilities themselves, some by as-

sociations for retarded citizens and some by service organizations such as the Junior Chamber of Commerce (Jaycees).

The American National Red Cross supports a swimming program for the handicapped. In 1973 there were 126 chapters offering swimming programs for mildly and moderately retarded persons, with two of them also serving severely retarded children.

See references 63, 68, 73, 125

No comprehensive study specifically concerned with recreation services for mentally retarded individuals has been identified. The following information is from a 1970 nationwide study of 616 agencies such as commercial establishments, libraries, museums, public recreation agencies, fraternal and service organizations, community and youth service agencies, 4-H Clubs, and public, parochial, and private day schools concerning their services to handicapped citizens in general, including mentally retarded persons.

- No recreation services for handicapped children and youth were reported by 74 agencies. Of these, one-half of the commercial establishments and over one-third of the churches, libraries, and museums reported they had never been asked to provide such services.
- Over half of the churches, libraries, and museums believed there were no handicapped children or youth in their service area.

Types of problems agencies thought they might have in starting service programs:

- Over half felt an additional or specially-trained staff would be necessary.
- Over a third were concerned about physical and mental limitations of handicapped children.

Of the 542 agencies providing some recreation services, 457 had increased their services from 1965 to 1970:

- to serve additional disabilities

children

- to increase variety of activities

Reduced services had occurred in 11 percent of the 542 agencies since 1965 because of:

- lack of trained staff
- insufficient funds
- poor attendance
- lack of parental interest

Recreation activities provided by **all reporting** agencies:

- 82 percent had parties, socials, and special events
- 72 percent had active games and physical fitness activities
- nearly two-thirds provided arts and crafts
- 61 percent offered team sports
- about one-half offered individual sports, including swimming

Education levels of full-time personnel in all reporting agencies:

- 19 percent had graduate degrees
- 64 percent had bachelor degrees
- 9 percent had some college
- 8 percent had high school diplomas **or** less

See references 57, 89

What Services Provide Mentally Retarded Persons with a Source of Income?

Income support may be provided through the following types of services:

Continuing support from:

- Supplemental Security Income, Federal and State financial assistance on the basis of need for persons who are permanently and totally disabled, blind or aged.
- Public Welfare, general assistance available in some States, and the Federal Aid to Families with Dependent Children program which exists in all States, granted on the basis of need.
- Social Security and Railroad Retirement, Federal retirement income guarantee programs based on contributions by employees and employers, covering retired and disabled persons and survivors of the beneficiary.
- Veterans benefits
- Food Stamps, School Lunch and School Breakfast Programs of the United States Department of Agriculture, for recipients of public assistance and other low income persons.
- Medical Assistance (Medicaid), Federal/State payment for residents of hospitals, skilled nursing facilities (SNF) and intermediate care facilities (ICF and ICF-MR)
- Medicare, Social Security program to pay costs of hospital and nursing home care for Social Security beneficiaries.
- Federal black lung disease benefits, which provide for survivors of the disease.

- Public mental retardation or mental health residential institutions, where total care is provided.
- Public mental retardation programs in the community.
- Guardianship management of the retarded persons's own income and resources.

Interim support, or the provision of special needs, may be provided from the foregoing, as well as the following:

- Private voluntary agencies which provide a variety of specific benefits for which the retarded person may be eligible.
- Vocational Rehabilitation Service agencies, Federally and State supported, which may provide subsistence payment during vocational training.
- Emergency assistance grants provided by public or private agencies in such forms as allotments for food, temporary housing, and cash for other living expenses.

Some information is available regarding mentally retarded persons who receive continuing support through public programs administered by the Federal government or State agencies. Almost no information is available regarding mentally retarded persons who receive interim support until they qualify for assistance under a continuing major program.

Two Major National Studies of Income
Maintenance Programs for Mentally
Retarded Persons Took Place in 1967 and 1970.

**Aid to Families with Dependent Children (AFDC) for
Children Judged to have Mental Retardation, 1967**

	Total Recipients	Professional Opinion		Opinion of Others		Unknown
		M.R.	Not M.R.	M.R.	Not M.R.	
Number	3,922,719	89,472	646,555	64,044	2,548,639	574,009
Percent	100.0	2.3	16.5	1.6	65.0	14.6

Professional judgments were made by those competent to diagnose mental retardation. The combined 3.9 percent estimate of recipients judged to be mentally retarded children is probably quite low. Almost 15 percent of the children had no opinion expressed about them, and the reluctance on the part of family members or others probably contributed to "non-diagnosis."

This public assistance program has been operating since 1935. There are no minimum payment levels for the States, and payments vary widely in amount from State to State.

**Aid to the Permanently and Totally Disabled (APTD). 1970
Recipients with Mental Retardation as Primary or
Secondary Disabling Condition**

	All Recipients	M.R. Primary Condition	M.R. Secondary Condition
		138,163	28,610 3.3
Number	865,894		
Percent	100.0	16.0	

Until January 1, 1974, this State administered program provided for the disabled, blind, and aged. The figures in the above chart are based on a minimum sample of two percent of the caseload in each state or 500 persons, whichever was higher. Guam and Arizona did not participate, and Nevada did not have an APTD program.

See references 109, 110

What Is the Supplemental Security Income Program (SSI)?

As of January 1, 1974, income maintenance programs for the aged, blind, and permanently and totally disabled are combined under a new Supplemental Security Income Program. For the first time, the Federal government guarantees a minimum income to persons who have insufficient resources or income. The program is administered by the Federal Social Security Administration. The base in February **1975** is **\$146** per month for each eligible individual, with certain exceptions. In addition, 38 states and the District of Columbia supplement payments. The amount of an individual's SSI check is affected by earned or unearned income. States may ask the Federal government to administer any supplements to the Federal payment they may make or States may make this payment directly to individuals.

An important feature of SSI is that children who are "permanently and totally disabled" (a category that includes some mentally retarded children) may be eligible for income maintenance payments under certain circumstances, depending on their family finances. By November, **1974**, there were approximately **65,000** children receiving SSI.

The change over from State to Federal administration caused problems in reaching all persons eligible for payments. Information on the number of persons who are mentally retarded and receiving SSI payments is not currently available.

In October, 1974, 1,581,663 persons classified as disabled received federally administered payments (including Federal payments and State supplements) of \$230,383,000.

As services are provided to meet the needs previously discussed: physical, social, educational, and economic, it is possible for the individual to move toward independence in the place where he or she lives.

Where Do Mentally Retarded Persons Live? Who Cares for Them?

All children cannot live with their families nor can all adults find their own living arrangements. Residential services are needed for many mentally retarded persons at some time in their lives, and for some, throughout their lives. Residential services are the fulcrum around which many other services for retarded persons are balanced. This is especially true of personal care and management for the more severely handicapped.

Residential facilities are usually classified into two types: institutions and community care. The traditional residential facility was institutional in nature; that is, marked by isolation from the community, large congregations of disabled residents, and the type of daily regimen that characterizes hospitals and prisons. Institutions are being modified to accommodate to the new philosophies of normalization and maximum self-development. Institutions are becoming smaller, and tending to use cottage-type housing and care, are attempting to approximate a home-like environment, and are encouraging development of the resident and his or her access to adjacent community services and opportunities.

Community care facilities have been created not only to achieve the benefits of normalization and continuing development for the resident but also to achieve fiscal economies. The economies may actually represent shifts in fiscal responsibility; for example, transfer of funding as a total State responsibility (public institution) to a shared State-Federal-Local responsibility (group home in the community). The goal of deinstitutionalization is to replace the unnatural patterns of living in traditional

settings with the values of normalization, maximum self development, and community living.

What are Some Community Residential Services?

Prevailing philosophy holds that residential services follow a developmental model — providing attention to specific problems and needs of individual residents until they can be corrected or met. Thereafter, the individual progresses to an improved level of independent functioning. This viewpoint has spurred emergence of a growing array of residential alternatives to institutional care, each geared to specific needs of specific individuals. Among them are:

- Group homes, hostels, boarding homes, and half-way houses for adults. Although called by these different names, these facilities are generally defined as any community-based residential facility which operates 24 hours a day to provide services to a small group of mentally retarded or otherwise developmentally disabled persons who are presently or potentially capable of functioning in the community with some degree of independence.
- Foster care — for children and increasingly for adults who are dependent and cannot live, for whatever reason, with their own families.
- Natural home — living with one's parents as a child or as an adult, living alone or living with one's own family.
- Long-term sheltered living including nursing homes — an environment for adults incapable of independent living, based on normalization principles.

- Respite care - very short-term residence care for retarded individuals, both children and adults, to allow them and their families a "vacation" from one another and to alleviate a family crisis.
- Vocationally oriented residential services — to help young adults adapt to the world of work.

It is emphasized that much of the above terminology is just beginning to appear in the literature. Definitions are often vague and names of community facilities and programs are used, at times, without clarity as to meaning.

Institutions

An institution is "...a public or private facility or building(s) providing a constellation of professional services... on a 24-hour residential basis including those directed toward the care, treatment, habilitation, and rehabilitation of the mentally retarded and has been traditionally separated from the general population."

There are three major categories of facilities serving retarded persons which are classified as institutions: public facilities for mentally retarded persons, public facilities for the mentally ill that have some retarded persons among their resident populations, and private (proprietary and non-profit) residential facilities for mentally retarded individuals.

See references 50, 83, 85, 86

**Recent Trends in Public Institutions for
Mentally Retarded Persons**

	1963	1967	1971
All Admissions	15,151	15,714	15,370
Net Releases	8,156	11,665	17,079
Deaths in Institutions	3,498	3,635	3,183
Resident Patients at End of Year	176,516	193,188	181,009
Personnel (full time) at End of Year	69,494	94,900	118,909
Maintenance Expenditures	\$353,574,833	\$576,620,954	\$1,002,557,588
*Per Resident Patient			
Per Year	1,984.00	2,965.33	5,537.05
Per Day	5.44	8.12	15.17
tPer Patient under Treatment			
Per Year	1,879.43	2,774.10	4,982.25
Per Day	5.14	7.60	13.65
* Based on average daily population			
tBased on census at beginning of year			

Adapted from: U.S. Department of Health, Education, and Welfare. "Mental Retardation Source Book of the Department of Health, Education, and Welfare." Washington, D.C.: Office of Mental Retardation Coordination, 1973 (Mimeographed).

In recent years, persons being newly admitted to public institutions have been younger, have been more severely retarded, and have more physical disabilities than in the past. Information on age is available. While information on sex generally is not available, there has been an increasingly larger proportion of male new admissions noted.

To What Extent are Mentally Retarded Persons Placed in Public Hospitals for the Mentally III?

In 1971, there were 29,272 persons diagnosed as mentally retarded in State mental hospitals; 81 percent of them were over 24 years of age.

Information on the number of persons in each level of retardation is unavailable, but of new admissions to State mental hospitals in 1967, 71.5 percent were mildly or moderately retarded. For the same year, 48.8 percent of [persons newly admitted to mental retardation facilities were mildly or moderately retarded.

What are Some Characteristics of Persons Who are Residents in Institutions for Mentally Retarded Persons?

Two States, Florida and California, have collected detailed information on residents in their institutions. Such information can be used to design individualized treatment plans to enable each retarded person to come closer to the goal of self-sufficiency and self support.

See references 40, 112

The information from California clearly shows that from 1970 to 1974 over three-quarters of all residents remain retarded at the severe or profound levels. Sex distribution continues to remain about the same. There has been a slight increase in percentage of residents who have no hearing or no vision.

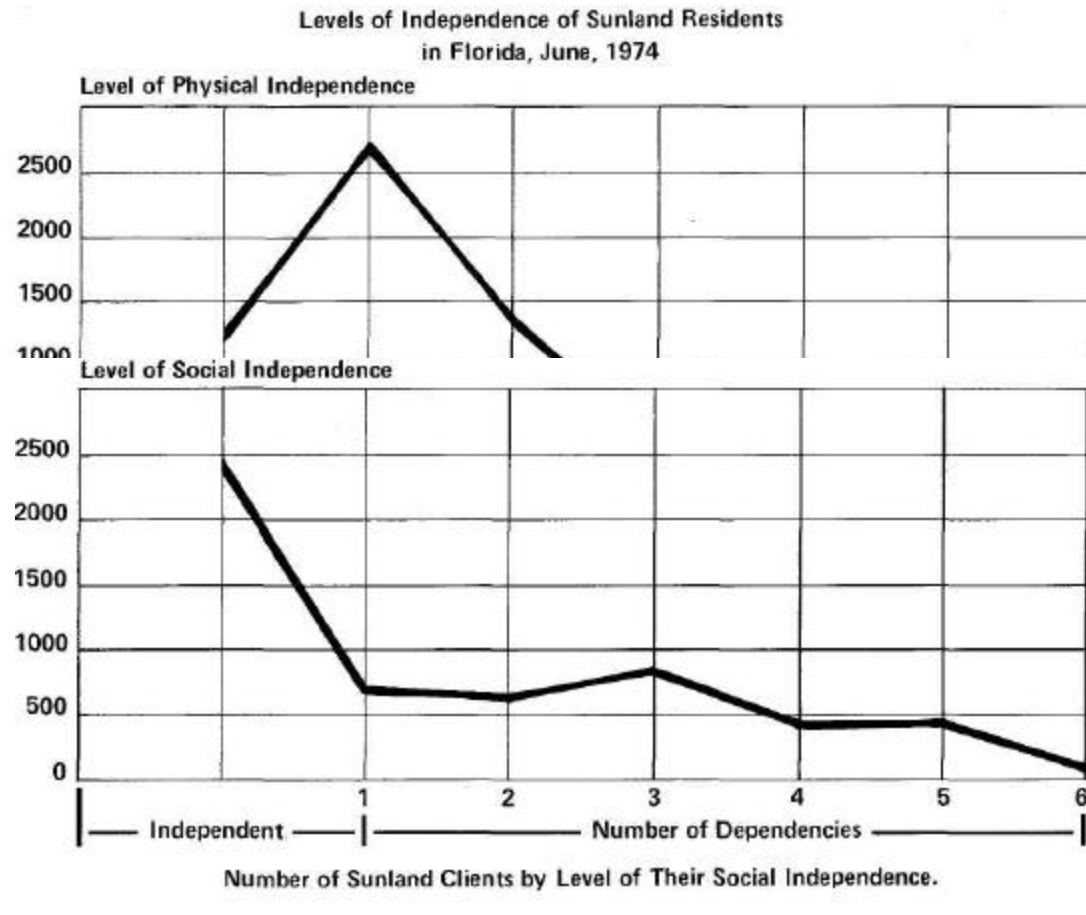
**Selected Findings of Annual Census of Characteristics
of Residents in Public Institutions for Mentally Retarded Persons
California, 1970 and 1974**

		1974 1970	
Census — Number		11616	10002
Degree (Level) of Retardation, by Percent	Profound	46.05	48.93
	Severe	30.35	29.21
	Moderate	15.39	14.45
	Mild	6.55	6.06
	Borderline	1.59	1.30
	Normal	0.10	0.07
	Total	100.03	100.02
Sex, by Percent	Male	58.41	58.79
	Female	41.60	41.22
	Total	100.01	100.01
Seizures, by Percent	None, no history	60.35	55.11
	None, has history	16.13	22.74
	Less than 1/mo.	15.67	12.03
	More than 1/mo.	7.86	10.14
	Total	100.01	100.02
Vision, by Percent	No usable vision	5.52	8.39
	Limited vision	13.34	9.58
	Impairment suspected	— — —	10.56
	No difficulty	81.15	71.48
	Total	100.01	100.01
Hearing, by Percent	No hearing	2.71	4.59
	Limited hearing	7.89	3.88
	Impairment suspected	— — —	7.41
	No difficulty	89.42	84.14
	Total	100.02	100.02
Mobility/ Locomotion, by Percent	Bed support/moved in crib	11.17	16.71
	Wheel chair, push	11.18	13.68
	Wheel chair, self	6.21	2.09
	Walks, led	8.44	67.54
	Walks, not led	63.03	
	Total	100.03	100.02

Note: Totals exceed 100.00 percent due to rounding.

See reference 15

The study in Florida was the first assessment ever undertaken of all 5,444 clients in its six Sunland Centers. Information on each resident was collected in June, 1974, using a Client Assessment Instrument specially designed for this survey. Levels of independence were noted for many skills, including: ambulation, self-care, social, communications, housekeeping, education, and work. Findings on these and other variables were grouped to form the following two graphs.



See reference 42

What Are Some Characteristics of Residents of Public Institutions for Mentally Retarded Persons in the United States?

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded has recently completed a nationwide survey of its own facilities. Information on this and the following page are from the results of that survey.

The following table presents information from 177 public institutions in the United States as of July 1, 1974. This represents 75 percent of all public institutions.

Distribution of Residents in Public Institutions for Mentally Retarded Persons, by Level of Disability, July 1, 1974

<u>Level of Disability</u>	<u>Percent</u>
Profound	41.2
Severe	30.0
Moderate	17.9
Mild	8.1
(Borderline-Normal)	2.8
Total	100.0

The following table presents the results of 177 public institutions reporting on 27,276 residents classified according to the 1973 AAMD etiology.

Distribution of Residents in Public Institutions for Mentally Retarded Persons, by Primary Cause of Disability, July 1, 1974

<u>Primary Cause of Disability</u>	<u>Percent</u>
Infections and Intoxications	14.3
Trauma or Physical Agent	15.4
Metabolism or Nutrition	2.8
Gross Brain Disease, Post-Natal	4.1
Unknown Pre-Natal Influence	30.6
Chromosomal Abnormality	10.8
Gestational Disorders	5.5
Following Psychiatric Disorder	1.6
Environmental Influence	15.0
Total	100.0

Of the 105,442 residents reported to have mental retardation, 53,265 or 50.5 percent had at least one additional handicapping condition and 34 percent had more than one. For example, 671 persons were both blind and deaf, in addition to the major handicapping condition of mental retardation. The distribution of the primary additional handicap is as follows:

<u>Additional Handicap</u>	<u>Number</u>	<u>Percent</u>
Blindness	3,825	7.2
Deafness	2,226	4.2
Emotional Disturbance	8,020	15.1
Cerebral Palsy or Other		
Neurological Handicap	19,448	36.5
Epilepsy	19,746	37.0
Total	53,265	100.0

Another finding was that 40 percent of new admissions and 40 percent of readmissions to public institutions during Fiscal Year 1973—74 represented mildly or moderately retarded persons and borderline persons.

See reference 94

What Does the Term Deinstitutionalization Mean?

In 1971, the President of the United States adopted as a national goal the return to useful lives in the community of one third of the more than 200,000 mentally retarded persons who were living in public institutions. Most of these persons live in special institutions for mental retardation. There are some who are cared for in State hospitals for the mentally ill. Deinstitutionalization requires reeducation and retraining of the residents of these facilities for them to be able to adapt to community living.

How Much Progress Has Been Made, toward Deinstitutionalization?

The recently completed study of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded mentioned on the preceding page provides some answers to this question. Data for the survey were acquired from 207 residential facilities of 250 queried. Of the 207, 15 facilities were not in operation at the time of the survey. Information was collected as of July 1, 1974.

Some Findings:

- Of 106 facilities in use during the nine-year period, 1965 to 1974, the population declined from 151,873 to 127,696 - 15.9 percent.
- Of 176 facilities in use during the four-year period, 1970 to 1974, the population declined at an accelerating rate of 1.7 percent in the first year to 3.6 percent in the fourth year. A trend may be seen in the table.

Population Changes in a Total of 176 Public Institutions for Mentally Retarded Persons, 1970 to 1974

Fiscal Year	Population at End of Year	Numerical Population		Percent Population	
		Decline from Preceding Year		Decline from Preceding Year	
1970	155,920				
1971	153,343	2,577		1.7	
1972	151,204	2,139		1.4	
1973	147,050	3,154		2.1	
1974	141,972	5,078		3.5	

If the survey results are generalized to the entire group of public institutions, estimates show a nine-year decline of 14,000 residents from 190,000 in 1969 to 176,000 in 1974. During the same period, the population has declined in older, larger facilities and has been offset by growth in newer, smaller facilities. Older facilities declined in median resident population from 1,146 in 1965 to 956 in 1974. In 1974, the median population of new facilities, those in operation subsequent to 1969, was 198.

There is no information available on average length of stay of a resident in a public facility. There is also no information to show that persons discharged from public institutions do not move to other types of institutions such as State hospitals for mentally ill persons or private institutions.

See reference 94

What Are Some Alternatives to Institutional Care?

The words "private residential facility" are used to describe other types of residential settings outside of public institutions where mentally retarded persons reside, including private institutions. The most frequently used settings are group homes, nursing homes, and foster care or family care homes. While such residential settings are private, governments may purchase care in them for residents considered to be a public responsibility. There is limited national information on private residential facilities. Information is not currently available by type of facility, such as group home, nursing home, etc.

**Characteristics of Private Residential Facilities,
1971, by Ownership**

Type of Facility	Profit	Non-Profit	All
Number of Facilities	745	286	1,031
Accept Both Sexes	435	199	634
Accept Only Females	164	43	207
Accept Only Males	146	44	190
Ages of Clients			
Under 21	332	125	457
21 +	34	4	38
Other Restrictions	226	124	350
AM Ages	153	33	186
Number of Residents	13,443	14,581	28,024

Number of Facilities with Programs Offered

Program		
	232	799
For Educable Children For Trainable		
Children For Profoundly	316	715
Retarded Children For Adults	188	843
Vocational Rehabilitation Occupational		
Therapy Physical Therapy Other Programs	127	904
<i>Four facilities offered all programs; 336</i>	184	847
<i>facilities offered no programs.</i>	158	873
	100	871
	132	899

See reference 112

A 1973 survey of group homes for developmentally disabled, the large majority of which served mentally retarded individuals, found 474 homes in operation. An additional 112 facilities were identified, but information was unavailable for the survey. Forty-six percent of those reporting were operating for less than two years, and more than 75 percent were formed since 1968. Of 7,753 residents reported, 60 percent were male and 40 percent female. The group homes varied widely in services provided. Over half relied on public residential facilities for one or more supportive services.

A significant result of this survey was reporting of difficulties encountered by the administrators of the group homes. Such problems may affect future development of community alternatives.

Family care or foster care is one of the oldest forms of planned community residential services for mentally retarded persons. Examples of the number of persons served in California and Indiana show that foster care serves significant numbers of retarded persons.

<u>State</u>	<u>Number of Residents Served</u>	<u>Date of Information</u>
California	Approximately 5,000	December, 1974
Indiana	1,348	June, 1972

**Most Serious Problem Areas in
Establishing and Operating Group Home Facilities**

<u>Area of Concern</u>	<u>Total Number of Facilities</u>	<u>Percent of Administrators Ranking the Variable</u>
Inadequate Funds	294	62
Difficulty of Finding Qualified Staff	174	37
Developing Individualized Client Programming	135	29
Lack of Community Supportive Services	113	24
Certification and/or Licensing	95	20
Attitude of Community Toward Residents	97	20
Staff Training and Development	88	19
Reducing Parental Fears	69	15
Difficulty of Maintaining the Staff	67	14
Zoning Restrictions	56	12
Meeting Fire Regulations	49	10
Meeting Building Safety Standards	29	6
Other	64	14

A recent trend has been the utilization of nursing homes to serve developmentally disabled persons. The State of California has made extensive use of nursing homes. As of December, 1974, 2,448 beds were available for developmentally disabled persons in separate buildings or separate wings of nursing homes or intermediate care facilities. Intermediate care facilities do not provide as intensive a level of nursing care.

See **references** 19, 58, 86.

What Was Found in a 1974 Kansas Study of Facilities and Homes for the Developmentally Disabled?

The Kansas Department of Social and Rehabilitation Services surveyed 330 facilities serving 1,900 developmentally disabled persons.

The study found that there is no common definition of different types of residential facilities. Almost half of the respondents were unable to identify their category. The following definitions were used in the study.

- Nursing home — a nursing facility providing both short- and long-term care for semi-independent residents over age 21 — (228 respondents)
- Foster home — a family type home providing either short- or long-term care, serving individuals ranging from dependent to almost independent, under age 21, and covering all resident needs — (74 respondents)
- Children's facility — a group residential facility offering short-term transitional care for independent and semi-independent persons under age 21, and providing most resident needs — (14 respondents)
- Boarding homes — a group living arrangement, providing both short- and long-term care for semi-independent persons over age 21, with the facility covering all resident needs — (14 respondents)

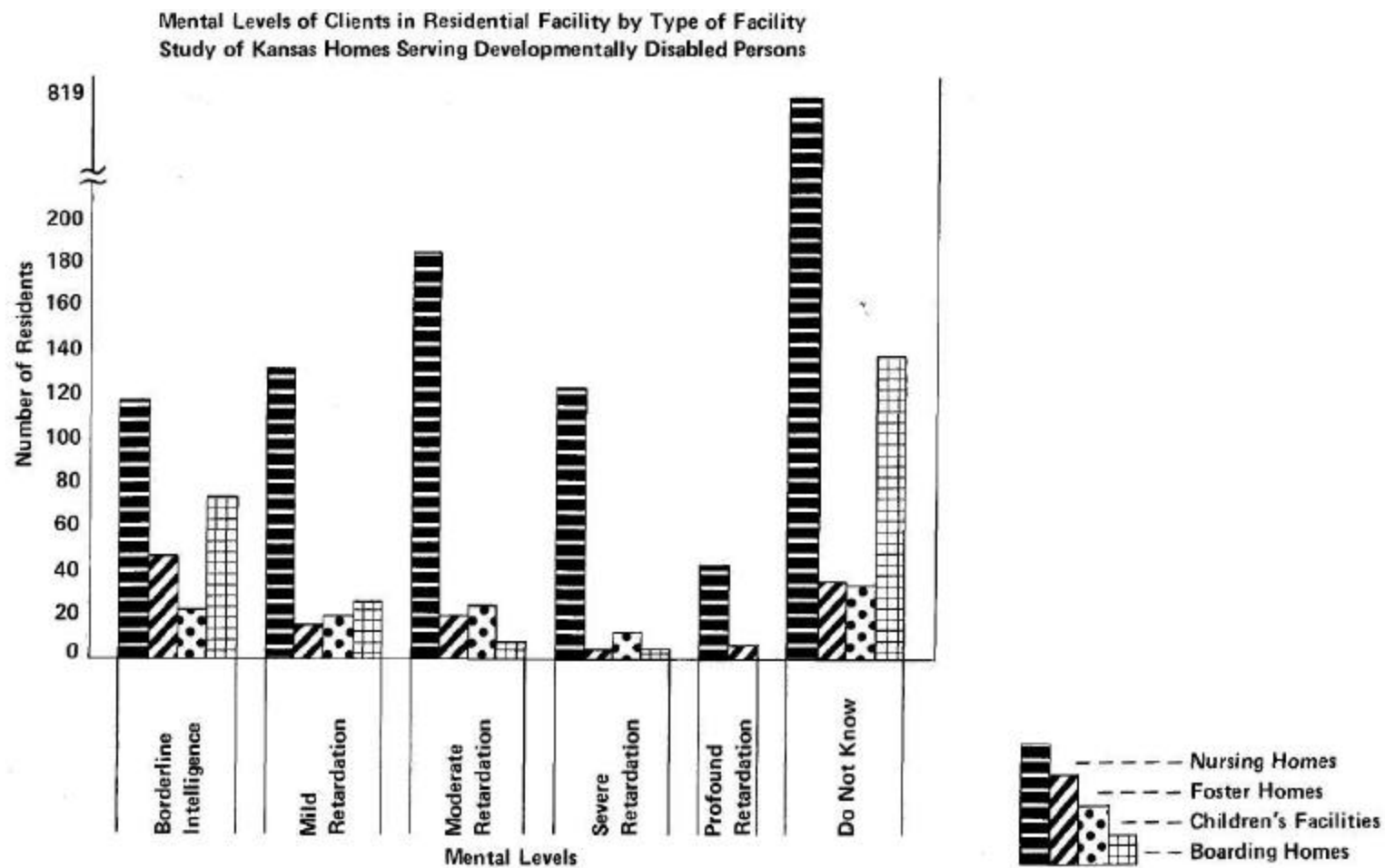
Further confusion of definitions may be seen in the table below where distribution of facilities by types and related characteristics is shown. Several different categories apply to a number of the reporting facilities.

Study of Kansas Homes Serving Developmentally Disabled Persons

	Number of Facilities				
Description	Nursing Homes	Foster Homes	Children's Facilities	Boarding Homes	Total
Pattern of Care					
Family type	24	72	6	0	102
Group	13	0	6	8	27
Residential	17	1	5	1	24
Nursing	205	0	0	0	205
Agency operated	3	2	3	0	8
Duration of Care					
Temporary respite	3	5	0	0	8
Short-term transitional	114	20	6	6	146
Long-term indefinite	176	35	2	7	220
Disability Level of Resident					
Almost independent	24	14	6	2	46
Semi-independent	175	22	5	7	209
Totally dependent	46	19	0	1	66
Age of Residents					
Under 21	20	72	14	2	108
Over 21	184	5	0	8	197
Service to Residents					
Five-day week residence only	1	1	4	0	6
Covers all resident needs	57	41	7	8	113
Board, room & guidance only	9	5	4	0	18

See reference 96

The study found "... that most facilities were unable to identify the mental levels of their developmentally disabled clients." As the graph shows, over one-half of all persons identified were shown in the "Do Not Know" category of mental levels.



How Accessible Are Services for Persons Who Are Retarded?

As recently as 1968, a report on employment, transportation, and the handicapped, prepared for the Social and Rehabilitation Service, made no mention of the special transportation needs of the mentally retarded. A 1973 planning document, prepared by the Urban Mass Transit Advisory Council, makes only passing references to mentally retarded persons in discussing travel barriers for handicapped persons.

In addition to the high prevalence of physical disabilities among retarded citizens, the inability of many to read instructions makes them less able to use public transportation.

In a survey among elderly and handicapped persons in Washington, D.C., the potential increase in trips for various purposes, if there were a barrier-free transit system, was given.

Trip Purpose	Potential % Increase
Work/School	14%
Shopping	82%
Medical/Dental	50%
Social/Recreational	111%
Church	85%
Combined Total	72%

In August, 1973, the President's Committee on Employment of the Handicapped issued "A Survey of State Laws to Remove Barriers." Only one State, Kentucky, had no law requiring some action to remove physical barriers in housing, governmental buildings, walkways, etc. No information is available regarding the extent to which these laws have been implemented in all States.

While there are continuing local efforts to employ such strategies, no information was found on the extent to which services are being offered to mentally retarded persons through outreach efforts, or provided by means of service "brokers," neighborhood service delivery points such as "store-front" centers, or special transportation arrangements.

See reference 119

What Manpower Is Needed to Provide Services for Mentally Retarded Persons?

Two recent publications of conferences on manpower, one held in Canada in 1969, the other in Philadelphia in 1973, produced remarkably similar recommendations.

- There is a need to employ different kinds and levels of professional personnel in working with mentally retarded and developmentally disabled persons.
- Training in the special needs of handicapped persons must become an integral part of training in all fields. Only in this way can mentally retarded individuals make extensive use of generic services (those available to everyone).

Federal government efforts in training personnel to work with mentally retarded and other developmentally disabled persons began in 1963 with legislation authorizing University Affiliated Facilities (UAFs) and Mental Retardation Research Centers. Funds for construction of both were appropriated in Fiscal Years 1965, 1966, and 1967.

In 1972, more than 52,000 persons from more than 60 separate fields were trained in the 32 operating UAFs.

The Bureau of Education for the Handicapped (BEH) reported there were 73,400 teachers for the mentally retarded employed in the 1971-1972 school year, estimated to be two-thirds of the number needed. Federally-supported training of special education teachers

See references 34, 127

reached an annual level of 6,000 new special education teachers a year in 1970.

The National Institute of Child Health and Human Development (NICHD), Mental Retardation Branch, operates 12 Mental Retardation Research Centers. As a by-product of research conducted by the Centers in the causes and prevention of mental retardation, manpower with scientific investigative skills is trained.

What Is Accountability for Mental Retardation?

Accountability means provision of evidence of:

- the extent of the problem
- the amount of effort expended to meet the problem
- the maintenance of service quality to meet established standards
- the actual meeting of individual needs
- the extent to which the effort has had impact on the general problem, and has reduced it

Accounting for the extent of the mental retardation problem and the effort made to deal with it is found in limited form in the management records of serving agencies — their case records, statistics, budgets and financial reports. Accounting for the excellence of service is based on licensing or voluntary standards, and periodic assessments by independent judges of how well those standards have been met. Accounting for effects of services on individuals and their problems, or for their impact on the community problem of mental retardation is called evaluation and is relatively rare and usually inconclusive.

What Are Currently Existing Mechanisms for Program Evaluation?

There are two types of mechanisms: regulatory and voluntary. The regulatory means is through licensure; the voluntary mechanism is through: (1) accreditation, (2) PASS, a new procedure now in use in two States, and (3) consumer evaluation. These processes are described below.

Licensing

Each State has legal minimum standards of health, sanitation, building safety, fire safety, etc. In addition, each State requires at least some of its programs for mentally retarded persons to meet certain standards in terms of qualifications of staff, services offered, number of persons served, etc. Licensing laws provide for minimum standards.

Enforcement of licensure laws is limited. Licensing is most often effective at the time of initial application for the license and is rarely subject to judicial review.

Accreditation

In order to measure the quality of service, it is necessary to know how well the program is equipped to help recipients achieve stated goals. Two methods of program evaluation recognized today attempt to do this. One is administered by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals. The Council has eight member agencies:

American Academy of Pediatrics American
Association on Mental Deficiency American
Nurses' Association American Psychiatric
Association American Psychological
Association National Association for Retarded
Citizens National Association of Private
Residential

Facilities for the Mentally Retarded
United Cerebral Palsy Association

Two sets of standards have been established, one for residential facilities and one for community agencies serving mentally retarded individuals.

The accreditation program is voluntary. An agency applies for evaluation. Once evaluation is undertaken, a range of program components is evaluated. The Accreditation Council began its program in 1973 and identified the principle underlying its standards as normalization. Because of the recency of the program, no information is available on the extent of coverage or results.

See reference 2

Program Analysis of Service Systems (PASS)

A system first devised in Nebraska to evaluate applications for new community programs, Program Analysis of Service Systems (PASS), has been expanded to include evaluation of existing services. A feature that makes PASS different from other methods of evaluation is that it allows for negative as well as positive evaluations of each program component. Central to the system is the principle that services are adequate to the extent that they promote integration of handicapped persons into the mainstream of society. Services are rated successful to the extent that they employ the principle of normalization. At least two states, Nebraska and Pennsylvania, currently use PASS as a formal evaluation tool.

Consumer Evaluation

Increasing attention is being paid to consumer evaluation of services, either by retarded citizens themselves, or by their advocates. One approach is a formal contract between the provider and consumer of the service. Weintraub and Abeson discussed the special education contract thus: "The contract would specify the obligations of all parties, the educational objectives to be achieved, criteria for assessing their achievement, a timetable for evaluation, and procedures for renegotiating the contract."

See **references** 1, 122



The United Nations Declaration on the Rights of Mentally Retarded Persons, 1971

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation, and guidance as will enable him to develop his ability and maximum potential.
3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest extent of his capabilities.
4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
5. The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interests.
6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offense, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.
7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

See reference 48

What Are the Issues in Full Citizenship for Mentally Retarded Persons?

Fundamentally, the issue is whether a person who is retarded can live under all the implications of citizenship — the exercise of his rights, acceptance on equal footing by the community, and the opportunity to exercise choice among options affecting his life and happiness.

Rights can be classified as human rights (those that most people feel exist and should not be denied to anyone), and legal rights (those that have been enacted by legislators or for which precedent has been established by the courts).

In a democratic society, human rights are supported by three general principles: positive presumption (no right may be denied an individual without proof that society's needs require this be done); due process (even when an individual's right must be denied, it can only be done through a formal process, thereby safeguarding the person's chance to retain or, once denied, regain his rights); and instrumental protection (society's obligation to provide for its members the special assistance they might need to exercise their rights).

The rights on the following page are those of all citizens. Mentally retarded citizens are presumed to have all the same rights as any other citizen.

This section describes some specific deficiencies in the citizen status of mentally retarded persons, identifies some barriers to the improvement of their status and explores the vehicles being used to remove these barriers.

See **reference 21**

How Can Rights Be Classified?

Although a good bit of overlapping is inevitable, one can group many of the components of full citizenship under the three fundamental principles mentioned on the previous page.

Positive Presumption	Due Process	Instrumental Protection
Right to education Right to manage one's own affairs Right to life and survival Right to vote Right to worship Right to develop one's sexual and social identity <ul style="list-style-type: none">• Right to marry• Right to procreate Right to be paid for work Right to dignity Right to fail	Right not to be labeled for exclusionary or discriminatory reasons Right to legal access to the courts <ul style="list-style-type: none">• To sue• To contract Right to the least restrictive or drastic alternative (in any setting)	Right to treatment Right to a developmental opportunity, including: <ul style="list-style-type: none">• Early intervention• Family or family-like home Right to physical access to all facilities Right to have an advocate when needed Right to reasonable protection from harm

It should be recognized that rights by their exercise may be in conflict. There may be conflict between rights of two persons, or among rights affecting the same person. As an example of the former, there may be conflicts between the rights of parents and of their retarded child. An example of the latter is the essential conflict between the right to reasonable protection from harm and the right to manage one's own affairs.

This list of rights is neither exhaustive nor static. Developments occur so rapidly that today's realities may be replaced by new ones tomorrow.

Adapted from: Cobb, H.V. "Citizen Advocacy and the Rights of the Handicapped." In Wolfensberger, W., and Zauha, H., eds. Citizen Advocacy and Protective Services for the Impaired and Handicapped. Toronto. National Institute on Mental Retardation, 1973.

See reference 20

How Has Litigation Affected the Citizenship of Mentally Retarded Persons?

The following table shows that litigation on behalf of retarded persons is essentially a phenomenon of the 1970's. Data show that lawsuits have been brought in all sections of the country, approximately according to population. 1974 data were available only for ten months. It is likely that information for the full year would show more legal activity than in any previous year.

See reference 129.

A Profile of Lawsuits Establishing the Legal Rights of Mentally Retarded Citizens, As of October 31, 1974.

Type of Lawsuit	Number Filed by Year								Total	Decision For or Against Plaintiff		Pending Decision
	1957	1968	1969	1970	1971	1972	1973	1974 [†]		For	Against	
Right to Equal Educational Opportunity	0	0	1	3	1	11	20	15	51	29	0	22
Right to Be Free From Inappropriate Educational Classification, Labeling and Placement	0	0	0	2	2	3	1	0	8	3	0	5
Right to Community Services and the Right to Treatment in the Least Restrictive Environment	0	0	0	1	1	5	5	8	20	10	2	8*
Right to Be Free from Peonage and Involuntary Servitude	0	0	0	0	0	2	4	2	8	5	0	3
Right to Be Free from Restrictive Zoning Ordinances	1	0	0	1	0	0	4	2	8	7	1	0
Right of Free Access to Buildings and Transportation Systems	0	0	0	0	0	2	0	2	4	2	0	2
Right to Be Free From Unconstitutional Commitment Practices	0	0	0	1	0	4	3	4	12	8	0	4
Right to Procreate	0	0	0	0	1	1	3	4	9	4	1	4
Right of Equal Access to Adequate Medical Services	0	0	0	1	0	0	0	1	2	2	0	0
TOTAL	1	0	1	9	5	28	40	38	122	70	4	48

*At the time table was drawn, only one appeal was pending in a community services decision.

[†]Through 10/31/74

Adapted from: Legal Rights Work Group. Compendium of Law Suits Establishing the Legal Rights of Mentally Retarded Citizens. Washington, D.C.: President's Committee on Mental Retardation, October, 1974.

What Is the Right to Education?

A class action lawsuit is an appeal for relief brought on behalf of one or more named individuals and all persons in the same jurisdiction suffering the same abuses. It is a new tool for advocates of the mentally retarded, but has been used so dramatically and often that legal action has dominated the scene in the 1970's.

Although free public education is taken for granted by most Americans, large numbers of mentally retarded children have been denied this right. Four major, or landmark, cases have begun to establish the requirement that public education be made available to all.

Attorneys for the Pennsylvania Association for Retarded Children (PARC) argued that equal protection under the law, guaranteed by the Fourteenth Amendment to the Constitution, required that all children have equal access to public education and that they also have the right to due process of law. They based many of their arguments on the Supreme Court's ruling in Brown v. Board of Education in 1954, that separate educational systems do not provide equal educational opportunity.

1971: Pennsylvania Association for Retarded Children (PARC) et al. v. David H. Kurtzman, et al.

1972; Mills, et al. v. Board of Education of the District of Columbia

1974: In re G. H. (North Dakota)

1974: Colorado ARC v. State of Colorado

"It is ordered . . . that the Commonwealth of Pennsylvania . . . provide as soon as possible, but in no event later than September 1, 1972, to every retarded person between the ages of six and twenty-one years as of the date of this order and thereafter, access to a free public program of education and training appropriate to his learning capacities."

PARC v. Kurtzman
May 5, 1972

Some Traditional Arguments for Exclusion

We cannot educate children who are not toilet trained.

We cannot handle children who are not ambulatory.

We do not have enough money to provide classes for retarded children. We will excuse your child — he cannot benefit further from our program. We do not accept children with a mental age under five.

Some Expert Testimony in the PARC Case

Due process must be made a part of the educational system.

Every child can be educated.

The school is responsible for responding to the needs of the child.

IQ does not determine absolute ability.

Education is vitally important in every child's development.

See references 1, 17,48

Pennsylvania did not contest the arguments of the experts and finally signed a consent decree that resulted in the order presented on page 80. The Commonwealth agreed to search for every mentally retarded child in Pennsylvania and offer each a public education. In order to make its decree effective, the court appointed two "masters" or experts in mental retardation, one with a background in education and the other with a legal background, to oversee administration of the program and report on progress. Pennsylvania also set up a Right to Education office to handle special problems and, especially, to conduct due process hearings.

Pennsylvania's Right to Education office estimates that between May, 1972, and June, 1973, 10,000 children were placed for the first time in public schools. Of these, 2,551 were severely or profoundly retarded and 200 new classes for severely handicapped children were started. New children are still being identified and enrolled in schools as this is being written.

The Mills decision came shortly after the PARC consent decree and significantly expanded the concept of "zero reject." PARC had been concerned only with mentally retarded children and Mills sought public education for all mentally or physically handicapped children. The defendants in PARC did not contest the decision of the court; in Mills they did.

In Mills, Judge Waddy held that not only did all handicapped persons have a right to equal access to an educational opportunity in public schools but that they also had a right to a due process hearing before being placed outside the

normal classroom setting. Judge Waddy ordered the Washington, D.C. School Board, on Constitutional grounds, to include all children in their educational planning and develop immediately "due process" procedures so that parents of children could question decisions about their school placement. Lack of money was not considered a valid excuse: "If sufficient funds are not available to finance all of the services and programs that are needed in the system, then the available funds must be expended equitably in such a manner that no child is entirely excluded from a publicly supported education consistent with his needs and ability to benefit therefrom."

In re G. H. is the only decision on equal education opportunity from a State supreme court. In Colorado ARC a three judge Federal court held that a State's responsibility extended beyond the passage of a mandatory special education law to the actual provision of education to all.

See references 17, 48, 75

Documentation on inhuman, non-stimulating, and dangerous conditions in many public institutions for mentally retarded persons can now be found in hundreds of volumes. Following are highlights from some of the most significant lawsuits on behalf of institutional residents.

Wyatt v. Aderholt (formerly Wyatt v. Stickney)
Alabama, 1972

Burnham v. Department of Public Health
(Georgia), 1972

New York State Association for Retarded
Children, et al. v. Nelson Rockefeller, 1972

Patricia Parisi, et al. v. Nelson Rockefeller,
1972

Welsch v. Likins, Minnesota, 1973

Horacek v. Exon, Nebraska, 1973

On November 8, 1974, the United States Court of Appeals, Fifth Circuit, affirmed the decision of the Federal District Court that there is a Constitutional right to treatment on behalf of persons confined in mental hospitals and State schools.

The court was hearing two cases: Wyatt v. Aderholt and Burnham v. Georgia. In the former the principle had been upheld; in the latter, it had been denied. The Burnham case was remanded for trial in Georgia, but the State of Georgia is asking the United States Supreme Court to hear it on appeal.

By its decision in Wyatt, the court affirmed a series of orders that have thus far been issued in in Wyatt case, but overruled in Burnham. The following are the orders and requirements:

- Minimum standards of safety at Partlow State School
- Minimum staffing ratios for professional and non-professional personnel
- Prohibition of unpaid resident labor
- Individualized treatment plans, periodically reviewed
- Standards for sterilization (four residents were "voluntarily" sterilized at Partlow during the course of the trial)
- Limits on behavior modification and behavior modifying drugs
- Prohibition of human experimentation
- Release to the community with proper transitional services of persons capable of such a move
- Treatment of all persons in "the least restrictive habilitation setting"

The Wyatt case has served as the basis for many suits that have since been filed against institutions around the country.

In the Wyatt and other cases, the United States Department of Justice played an active role, acting as a "friend of the court" (amicus curiae) in some suits and starting action as plaintiff in cases of alleged violation of the rights of mentally retarded persons, (e.g., United States v. Solomon, 1974, a case involving Rosewood Center in Maryland).

See reference 75, 130.

The two New York cases (New York State ARC and Parisi) both centered on Willowbrook State School, which was, at the time action was brought, the nation's largest residential facility for mentally retarded persons, housing more than 5,000 persons.

As in the Wyatt decision, minimal standards of care were set down for Willowbrook. Central to the argument of the plaintiffs was the need to use the least drastic alternative method of treatment. To that end, seclusion in isolated rooms and the arbitrary and unsupervised use of physical (straitjackets) or chemical (drugs) restraints was prohibited. Judgment was still withheld on the right to treatment (although the Fifth Circuit decision in Wyatt might have some effect). The case is still in litigation.

In their testimony, defendants agreed to reduce Willowbrook's population by transferring residents to smaller facilities. As of December, 1974, the population was below 3,000, but many transferred residents had been moved to other institutions operated by New York State.

In Welsch the court expanded the Wyatt holding by finding that the State has an affirmative duty to develop and provide appropriate community services. In Horacek Judge Urbom declared that interests of parents and children may be inconsistent, and that parental commitment of their children to institutions may violate the children's right to treatment in the least restrictive setting and could not be called a voluntary commitment.

In at least one case in Florida involving a person confined to a hospital for the mentally ill, a

jury verdict (upheld on appeal) has awarded damages to a person who did not receive "adequate habilitation and treatment." The case, Donaldson v. O'Connor (1972, appealed in 1974) may serve as precedent for individuals seeking personal freedom after years of confinement without an adequate developmental opportunity. On January 15, 1975, the Donaldson case was argued before the United States Supreme Court. It is the first case involving the right to treatment to have reached the nation's highest court.

See references 76, 114

What Is the Right to Payment for Work?

It has been estimated that in 1970 the value of unpaid resident labor in facilities for mentally retarded persons and by mentally retarded residents of public mental institutions was 1.25 million dollars. This labor was often essential to the operation of these facilities, including housekeeping, laundry, repair work and even care of other residents. A series of rulings have found this to be unconstitutional under the Twelfth Amendment to the Constitution, which prohibits involuntary servitude (peonage).

1973: Souder, et al. v. Brennan, et al. Washington, D.C.

1973: Brennan v. Iowa

1974: Jortburg v. U.S. Department of Labor, Maine

Prohibition of resident labor without compensation has posed a dilemma. Many States have stopped using resident help, but this has deprived these individuals of what, to them, was their most meaningful activity. In many cases institutions have failed to provide individualized treatment programs with vocational training to replace resident labor. One of the principal arguments that remains unanswered is why anyone capable of working in an institution cannot be gainfully employed, at least in a sheltered setting.

At least two states, New York and New Jersey, have employed significant numbers of former residents at institutions, while providing transitional living arrangements elsewhere. This has

not always been the case. Many persons have been made idle by these rulings and have not always moved into the community. Another strategy in protecting the rights of retarded persons is legislation.

Right to Education

See references 23, 76

Lack of uniformity in legal requirements for education is apparent from the following table.

State Statutory Responsibilities for the Education of Retarded Children

State	Type of Mandation	Date of Passage	Compliance Date	Ages of Eligibility
Alabama	Full Planning and Programming	1971	1977	6-21
Alaska	Full Program	1974		From age 3
Arizona	Selective Planning and Programming	1973	9/1/76	5-21
Arkansas	Full Planning and Programming	1973	1979-80	6-21
California	Selective			6-21
Colorado	Full Planning and Programming	1973	7/1/75	5-21
Connecticut	Full Planning and Programming	1966		4-21
Delaware	Full Program "Wherever Possible"			4-21
District of Columbia	No Statute			
Florida	Court Order: Full Program	1972	1972	From age 6
	Full Program		1973	3-no maximum (13 yrs. guaranteed)
Georgia	Full Planning and Programming	1968	1975-76	3-20
Hawaii	Full Program	1949		5-20
Idaho	Full Program	1972		6-21
Illinois	Full Program	1965	7/1/69	3-21
Indiana	Full Planning and Programming	1969	1973	6-18
	Full Program	1974		Birth-21
Iowa	"If Reasonably Possible"			
	Full Planning and Programming	1974	1979	Developmentally Disabled: Birth-21
Kansas	Planning and Programming Petition (Trainable Mentally Retarded Only)	1970	1974	6-21
Kentucky	Court Order — Orleans Parish only: Selective for Mentally Retarded. Otherwise, Permissive Full Planning and Programming	1962	1973	6-21
Maine	Full Planning and Programming	1973	1975	5-20
Maryland	Full Planning and Programming	1973	1979	
Massachusetts	Full Planning and Programming	1972	9/1/74	3-21
Michigan	Full Planning and Programming	1971	1973-74	Birth-25
Minnesota	Full Program Permissive		7/2/72	
Mississippi				

Missouri	Full Planning and Programming	1973		5-21
Montana	Full Program	1974	7/1/79	6-21
Nebraska	Full Planning and Programming	1973	10/1/76	5-18
Nevada	Full Program	1973		5-18
New Hampshire	Full Program			Birth-21
New Jersey	Full Program	1954		5-20
New Mexico	Full Planning and Programming	1972	1976-77	6-21
New York	Court Order: Full Program (N.Y.C. only) Conditional: 10 or more children who can be grouped homogeneously in same class.	1973	1973	5-21
North Carolina	Full Planning	1974		Birth-Adulthood
North Dakota	Full Planning and Programming	1973	7/1/80	6-21
Ohio	Selective, by Petition (18 or more crippled or Educable Mentally Retarded Children in district)	1972	1973	From age 5 6-18
Oklahoma	Full Program	1971	9/1/70	4-21
Oregon	Full Program	1973		EMR: 6-21 Others: Birth-21
Pennsylvania	Court Order: Selective (Mentally Retarded Only)	1971-72	9/72	6-21
	Full Planning and Programming	1956	1956	6-21
Rhode Island	Full Program		1964	3-21
South Carolina	Full Planning and Programming	1972	1977	6-21
South Dakota	Full Program	1972		Birth-21
Tennessee	Full Planning and Programming	1972	1974-75	4-21
Texas	Full Program	1969	1976-77	3-21
Utah	Full Program	1969		5-18
Vermont	Full Program	1972		Birth-21
Virginia	Full Program	1972		2-21
Washington	Full Program	1971		6-21
West Virginia	Full Program	1974	1974	5-23
Wisconsin	Full Planning and Programming	1973	8/74	3-21
Wyoming	Full Program	1969		6-21

See reference 27

There are many mandates that carry conditions that effectively eliminate some students from education. The compliance dates are those required by law or court order and they do not guarantee that requirements have been met. More and more. States are moving to the concept of comprehensive programs for all handicapped children (Texas and Massachusetts are examples) and away from categorical labels, e.g., educable mentally retarded, cerebral palsy, etc. These are the first examples of statutory "mainstreaming."

What Effect Does Legislation Have in Other Areas?

One can point to many pieces of legislation that have been enacted, but for which enforcement programs are largely undeveloped.

The Right to Be Trained, to Be Employed, and to Be Paid

- Fair Labor Standards Act, 1966, Public Law 89—601. Following the decision in Souder v. Brennan, 1973, the United States Department of **Labor** has issued regulations on the application of this act to persons in institutions for the mentally retarded.
- Rehabilitation Act of **1973, Public Law 93—112**. This requires that severely disabled persons be given preference in rehabilitation and requires "affirmative action" in hiring handicapped workers by certain employers.

Right to Physical Access

- Public Law **90-480. All** new Federal construction must be accessible to handicapped persons.
- Public Law 93—383, Community Development Act of 1974. This makes provision for removal of architectural barriers in public housing.

Right to Be Free from Discrimination

- The Civil Rights Act of 1964, Public Law 88-352, and related Executive Orders of the President prohibit discrimination because of race, religion, age, or sex. In addition, the 1973 Rehabilitation Act prohibits discrimination because of mental or physical handicaps.

How Do Questions of Competency Affect the Citizenship of Mentally Retarded Persons?

Civil Law

The discussion until now has been of rights. An equally important component of citizenship is responsibility. The table below shows the wide variation in State regulation of some different activities of retarded persons.

A problem that has not yet been resolved is that of partial competence, or competence for one task and incompetence for another. The judgment that a retarded individual could not marry, for example, has often been generalized to exclude him or her from other responsible activities.

States Regulating Right to Contract, Drive, Vote, Marry and Allowing Involuntary Sterilization for Mentally Retarded Persons

Kind of Regulation	Regulate Right to Get Drivers License (As of 1970)	Regulate Right to Vote (As of 1974)	Regulate Right to Marry (As of 1972)	Regulate Right to Contract (As of 1970)	Allow Involuntary Sterilization (As of 1972)
Prohibition	22	5	12	0	
Allow for Adjudication of Incompetence	12	20	0*	27	
Authorized by Law					24**

Blank boxes: not applicable

**No information on 16 States ** (In at least one State, Alabama, the law has been changed due to the judge's decision in the Wyatt case.)*

Some of this information is undoubtedly out of date, but the picture remains far from uniform across the United States. Regulations differ widely in definition and application or enforcement among States.

See references 12, 69, 87

Criminal Law

In a study of Georgia's criminal justice system, it was found that while only five percent of the estimated 140,000 mentally retarded citizens in the State ever come in contact with law enforcement authorities, 28 percent of the adult inmates of Georgia's penal institutions were mentally retarded.

In a nationwide survey of penal institutions in 1963 it was found that 9.5 percent of 90,000 tested prisoners were mentally retarded. (There were sharp differences among regions. The percentages for a group of Southern states was 24.3; for the Mountain States it was 2.6.)

The classification of mental retardation here is based on an IQ below 70.

Studies have shown that retarded persons are not necessarily more likely to commit crimes, but if they do, they are more likely to be arrested.

Legal authorities are divided over how much responsibility must be attached to the anti-social or criminal behavior of retarded persons. Questions center on the degree to which mental retardation interferes with the ability to act responsibly. There are three major rules of criminal responsibility in use by the courts:

- M'Naghten Rule: A person is not criminally responsible if he is unable to distinguish between right and wrong.
- Durham or Product Rule: The accused is not responsible for a criminal act if such act was the product of a mental disease or mental defect.

- Diminished Responsibility, the American Law Institute's Model Penal Code: A person is not responsible for an act, if, at the time, he cannot appreciate its criminality, or conform his actions to the requirements of law; the terms "mental disease or defect" do not include an abnormality manifested only by repeated criminal or otherwise anti-social conduct. The terms . . . shall include congenital and traumatic mental conditions as well as disease.

Mitigating circumstances are often helpful in averting harsh punishment for "naive offenders," but incompetency is a two-edged judgment. It has resulted in commitment "until cured," which could mean for life. In the 1972 case of Jackson v. Indiana, the United States Supreme Court held that indefinite commitment of a criminal defendant solely because of incompetency to stand trial (in this case due to mental retardation) violates the Constitutional right of due process. It ordered Indiana either to release Jackson, or start civil commitment proceedings (to an institution).

See references 7, 12, 13, 76

How Can Full Citizenship of Retarded Persons be Assured Other Than Through Law?

Two mechanisms are paramount in providing mentally retarded and handicapped persons with what we referred to above as "instrumental protection." One is public: protective services; the other is voluntary: citizen advocacy. Protective services are undertaken as a public responsibility, usually by a governmental agency, whereby handicapped or other disadvantaged persons receive protective help both on their behalf and that of the general community.

Citizen advocacy is a program of volunteer assistance by mature, competent citizens who represent the interests of the handicapped person entirely on his own merits, notwithstanding the expectations of the general community.

Protective services were begun by social agencies to protect disadvantaged children from abuse or neglect. (Their underlying principle is parens patriae — the state as parent.) In a sense, protective services became the voice defending those who could not defend themselves. They have existed for about 100 years and, in addition to traditional social casework practices, include adoption, foster care, and guardianship.

Key Elements of Protective Services

- Professionalism
- Legal authorization necessary
- Assignment of "cases"
- Legal action authorized to protect client interests
- Potential conflict of interests between citizen and public agency
- Concentration on instrumental needs of client

Common to Both

- Out-reach (seeking persons in need of assistance)

Key Elements of Citizen Advocacy

- Voluntarism
 - Legal authorization unnecessary
 - Matching of advocate and "protege"
 - Legal action possible, depending on resources of citizen advocacy office
 - Public education
 - Freedom from conflict of interest
 - Concentration on needs of client and his expressive need for friendship or for a confidant
-

Citizen advocacy for mentally retarded persons was started in response to what were felt to be deficiencies in protective services, most notably the potential conflict of interest. It was felt that persons receiving a salary from a governmental agency could not use all their efforts to provide services to their clients. At some point, their interests (keeping their job) would conflict with those of their client (receiving services). Another dimension of citizen advocacy, one for which the need has been documented, is that the expressive needs of the handicapped person (the need for friendship or someone to talk to) are given equal weight with his instrumental needs (those economic or legal functions necessary to his welfare, that the individual might need assistance in performing).

Protective services exist in all States, but special provisions for handicapped persons are missing in many of them. For example, guardianship laws, relating to the intervention of an interested person (relative or designated friend) to administer the property and/or protect the well-being of a child or person in need of assistance, have special provisions for handicapped (including retarded) persons in only nine states. Of these nine, only four (California, Minnesota, New Jersey, and Ohio) have a protective service system accompanying the law.

The first citizen advocacy project for mentally retarded persons began in 1970 in Lincoln, Nebraska. Between that time and mid-1973, 46 offices were functioning in the United States and Canada. Other cities have expressed interest

in acquiring the necessary resources and attracting enough persons to serve as citizen advocates.

Citizen advocacy programs have not been evaluated in terms of impact. This represents a gap in knowledge.

See references 97, 122

How Do Attitudes Affect the Rights of Mentally Retarded Persons?

It is widely believed that attitudes toward mentally retarded persons determine the way in which they are treated. Because of this, many attitudinal studies have been undertaken. Attitudes have been studied with regard to different activities (school, work, marriage, institutionalization) and among different groups (peers, teachers, parents, men, women).

Different theories have been tested, e.g., that experience with mentally retarded persons improves attitudes toward them, or that children in special classes are seen more positively than children in regular classes, or vice versa.

The results of attitude studies are generally inconclusive and leave a major gap in current knowledge. Most of them do show an unwillingness to allow mentally retarded persons the same freedoms expected for other citizens. And it has been pointed out that two important things have usually been ignored:

- Most attitude surveys have asked people to respond to stereotypes of retarded people. By describing subjects as "eternal children," or "unable to develop past a mental age of nine," researchers may have been predetermining the kind of response they received, thereby reducing the validity of findings.
- Evidence is mixed on whether expressed attitudes determine people's behavior. There have been some studies which showed that people harbored negative attitudes toward mentally retarded persons, but in their dealings with individuals who were mentally retarded they acted positively.

The President's Committee on Mental Retardation recently sponsored a nationwide poll, conducted by the Gallup Organization, to investigate how Americans accept the presence of mildly and moderately retarded people in normal residential and work environments.

Some of the results are these:

- Only five percent of respondents would object to working alongside a properly trained, mildly or moderately retarded person.
- Only nine percent would object to having a group of six mildly or moderately retarded persons who have been trained for community life occupying a home on their block.
- Fourteen percent think there is reason to fear mentally retarded people.

The poll presents results of what people say they would do or believe. Their statements may not always be reflected in their subsequent actions.

See references 43, 49, 91

What Do Mentally Retarded Persons Have to Say?

In 1970 in Malmo, Sweden, a group of fifty mentally retarded young adults met to discuss their needs and whether they were met or unmet.

Here are some of their ideas, as reported by a group leader.

On Leisure Time

- We want to be together in small groups during our leisure time.
- There should be more possibilities for sports and exercises.
- We want to have leisure time together with other youngsters of the same ages.
- We have all agreed that we want more power of participation in decision-making, especially in planning and implementation of leisure time activities.

On Living Conditions

- We wish to have an apartment of our own and not be coddled by personnel; therefore, we want courses in cooking, budgeting, etc.
- We want the right to move together with the other sex when we feel ready for it, and we also want the right to marry when we ourselves feel the time is right.
- We who live in institutions found that:
 - The homes should be small;
 - We will absolutely not have specific hours to follow in terms of going out, returning, etc.; and
 - Even in institutions, we want to be able to go steady and live together with the other sex without having the personnel interfering with our private lives.

On Education

- We think that the name "separate school" is degrading.
- There should be student councils which can take part in decisions about the curriculum, the choice of books, leisure-time activities in school, etc.

On Work

- We demand more interesting jobs.
- We do not want to be used on our jobs by doing the worst and the most boring tasks we do at present.
- We want that when we are working in the open market, our fellow workers should be informed about our handicap.

Recently, in California, eight mentally retarded adolescents discussed what it means to be called retarded.

- It's more the way it is said. It's not that word. It could be any word, really.
- Let the kid go out and make his own mistakes and learn from them.
- They'll grow out of some [of the mental retardation], but if the mother protects them, they'll never grow out of it.
- You gotta evaluate the youngster on an individual basis. Not compare one to another, like a tennis match.

See references 10, 132,133.

Are There Organizations Working for Full Citizenship for Mentally- Retarded Persons?

Many of the developments in the field of mental retardation have been brought about through the efforts of a group that called itself, in 1950, "Parents and Friends of Mentally Retarded Children," in 1951, "The National Association for Retarded Children (NARC), and, in 1974, "The National Association for Retarded Citizens." The Association has grown to include more than **250,000** members in more than **1,500** State and local member units. Each local unit has significant autonomy in the NARC.

Although NARC is a major group advocating for mentally retarded persons, there are many others. In the following listing are the names and addresses of some organizations that make up the leading edge of the rights movement for mentally retarded citizens. As is becoming increasingly more common, many of these groups deal not just with one classification of handicaps, but with groups of handicapped persons, such as developmentally disabled, or with handicapped persons in general.

National Association for Retarded
Citizens (NARC) 2709
Avenue E East P.O. Box
6109 Arlington, Texas
76011

The Council for Exceptional
Children (CEC) State-Federal
Clearinghouse 1920 Association
Drive Reston, Virginia 22091

American Association on Mental
Deficiency (AAMD) 5201
Connecticut Avenue, N.W.
Washington, D.C. 20015

National Information Center for the
Handicapped (Closer Look) Box
1492 Washington, D.C. 20013

National Center for Law and the
Handicapped 1235 North
Eddy Street South Bend,
Indiana 46617

Mental Health Law Project
84 Fifth Avenue
New York, New York 10011
and

1751 N Street, N.W.
Washington, D.C. 20036

The Center on Human Policy 216
Ostrom Avenue Syracuse, New
York 13210

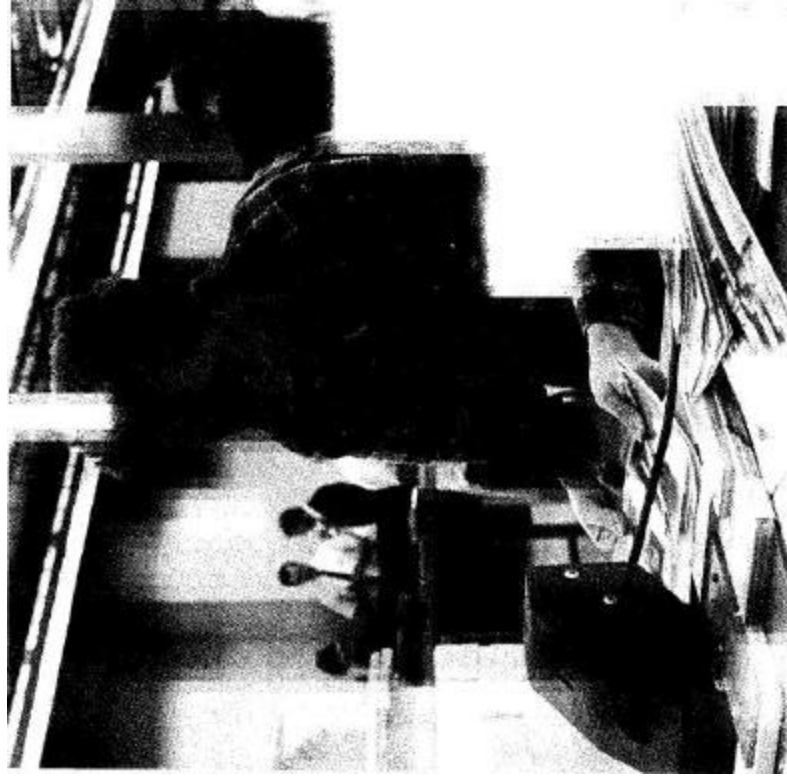
American Civil Liberties Union
85 Fifth Avenue
New York, New York **10011**

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See reference 80



Where Do Funds for Mental Retardation Programs Come From? How Much Is Spent?

A major factor in public policy is fiscal support. At most, ten percent of mentally retarded persons live in public residential facilities, but a significantly higher proportion of public, private, and personal funds is used to support these facilities. In 1970, for example, it is estimated that over 40 percent of all mental retardation funds were spent on persons living in these public care facilities.

Estimated Funding of Direct Service Mental Retardation Programs 1968 and 1970, by Source (in millions)

	Total	Federal	State & Local 1968	Client Fees	Insurance & Philanthropy
Public Residential care Community care	\$1,004 1,391	\$110 121	\$ 768 1,207	\$ 89 44	\$ 37 19
Total	\$2,395	\$231	\$1,975	\$133	\$ 56
% Distribution	100.0%	9.6%	82.5%	5.6%	2.3%
			1970		
Public Residential care Community care	\$1,307 1,868	\$196 192	\$ 937 1,580	\$123 64	\$ 51 32
Total	\$3,175	\$388	\$2,517	\$187	\$ 83
% Distribution	100.0%	12.2%	79.3%	5.9%	2.6%

Source: Conley, R. The Economics of Mental Retardation. Baltimore: Johns Hopkins Press, 1973.

Recent developments, including inflation and court decisions, are forcing the cost of institutional care to rise dramatically. For example, in one large facility it was recently reported that operating expenses per resident per day in 1974 were about \$41.00. This compares with approximately \$16.50 per resident per day in the same institution in 1972, only two years earlier.

See references 23, 85, 114

What Are the Economic Benefits of Preventing or Ameliorating Mental Retardation?

The following three pages discuss the economic factors of specific forms of prevention and direct service. They are based on the best financial and case service information available to the analysts who made the cost-benefit calculations. The evidence presented by the figures clearly points out that it is economically sound to provide these measures, unsound not to do so. This economic viewpoint does not, of course, cover questions of right and wrong, of social justice, or other motivating values that lead society to expend resources on mentally retarded persons.

The right hand figures refer to gains that would be made by avoiding the cost of special services to deal with handicapping needs of mentally retarded persons if they were not born. The left hand figures refer to those gains plus the added gains to society if the birth of a relatively "non-productive" person was prevented and replaced by the birth of a relatively "productive" person. Discounting means adjusting future benefits to current prices, in this case, 1970. The discount rate used was seven percent per year.

Estimated Economic Value of Preventing Mental Retardation
Among Persons Bom in 1952, Using 1970 Prices

	Prevention of Brain Damage or Replacement Birth				Prevent Birth without Replacement			
	Not Discounted		Discounted		Not Discounted		Discounted	
	Male	Female	Male	Female	Male	Female	Male	Female
IQ below 40 Includes earnings gain but not values of housekeeping and other unpaid work	\$739,000	\$291,000	\$202,000	\$107,000				
Includes total productivity gain	891,000	505,000	235,000	152,000	\$246,000	\$254,000	\$135,000	\$136,000
IQ 40 to 49 Includes earnings gain but not values of housekeeping and other unpaid work	654,000	258,000	179,000	95,000				
Includes total productivity gain	790,000	442,000	209,000	133,000	193,000	198,000	118,000	118,000
IQ 50 to 69 Includes earnings gain but not values of housekeeping and other unpaid work	118,000	70,000	25,000	17,000				
Includes total productivity gain	144,000	94,000	30,000	22,000	20,000	21,000	22,000	22,000

Source: Conley, R. The Economics of Mental Retardation. A large portion of this would be in reduced infant mortality and morbidity. Based on a summary of nutritional studies, the author estimated that proper nutrition would account for a 10 to 30 percent improved performance, both mental and physical, among children. If malnutrition contributes to mental retardation biologically or functionally, improved nutrition may significantly reduce its costs.

In a study done in 1969 for the United States Senate Committee on Nutrition and Human Needs, it was estimated that elimination of malnutrition would provide economic benefits to this country of between 14 and 50 billion dollars.

See references 23, 90

What Is the Economic Impact of Vocational Rehabilitation of Mentally Retarded Persons?

If one assumes that a successful vocational rehabilitation of a mentally retarded person, as defined by the Federal Vocational Rehabilitation program — placement in a job following rehabilitation services for at least sixty days — leads to enduring employment, the following cost-benefit relationships can be attributable to the rehabilitation effort.

Value of Future Earnings Generated by Each Dollar Spent on the Vocational Rehabilitation of the Retarded at Different Ages Discounted by 7%, 1970

	Ages of Retarded Persons When Rehabilitated				
	18yrs.	20yrs.	25 yrs.	35 yrs.	45 yrs.
Mildly Retarded Male	\$14.2	\$14.8	\$14.8	\$13.5	\$10.7
Female	8.3	8.4	7.8	6.9	5.7
Moderately Retarded (IQ 40 to 49)					
Male					
Female	2.2	2.3	2.3	2.1	1.7
	1.3	1.3	1.2	1.1	0.9

Source: Conley, R. The Economics of Mental Retardation. Baltimore: Johns Hopkins Press, 1973.

See reference 23

What Is the Economic Impact of Education of Mentally Retarded persons?

A similar analysis and comparison can be made for different forms of education and future productivity of mentally retarded persons. Differences are shown by sex, degree of retardation and type of education.

Ratio of Future Earnings of Retarded Workers to Costs of Their Public Education, Discounted at 7%, 1970

	Adjusted for Percentage Employed		Assuming Continuous Employment	
	Earnings Only	Earnings Plus Unpaid Work Other Than Homemaking	Earnings Only	Earnings Plus Unpaid Work Other Than Homemaking
Mildly retarded				
Males				
All regular education	8.3	10.4	9.7	12.1
All special education	4.3	5.4	5.1	6.4
Combination	5.9	7.4	6.9	8.6
Females				
All regular education	1.8	2.5	5.7	7.8
All special education	1.0	1.3	3.0	4.1
Combination	1.3	1.8	4.0	5.6
Moderately retarded				
Males	0.3	0.4	0.8	1.0
Females	0.1	0.1	0.4	0.6

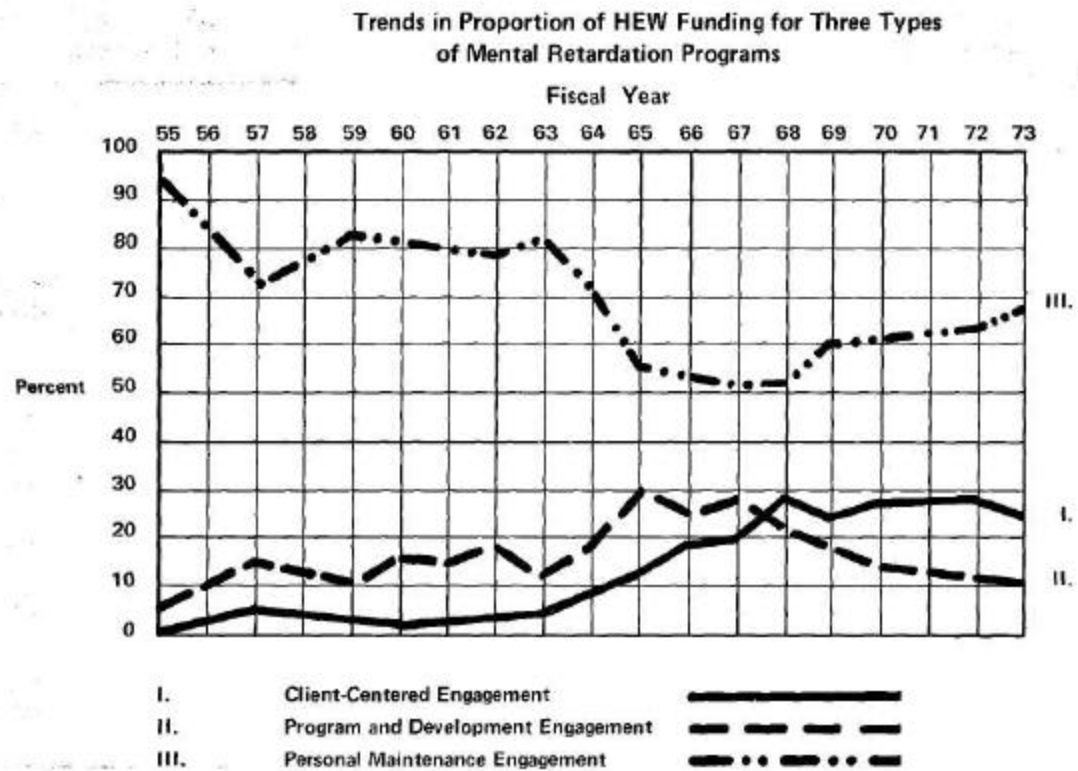
Source: Conley, R. The Economics of Mental Retardation. Baltimore: Johns Hopkins Press, 1973.

See reference 23

What Are the Trends in Federal Spending on Mental Retardation Programs?

With the wave of legislation and programs passed in the early 1960's, the Federal government began playing a major role in services for the mentally retarded. Federal expenditures rose from 15.79 million dollars in Fiscal Year 1955 to an estimate of 932.8 million dollars in Fiscal Year 1973.

In the chart at right, Braddock compares the relative importance of Department of Health, Education, and Welfare expenditures over time in three types of "engagements" (I. "Client-Centered," or funding of direct services for mentally retarded persons; II. "Program and Development," or training of personnel, research, construction, and coordinating agencies; and III. "Personal Maintenance," or funds for income maintenance and medical insurance).



Note: For each Fiscal Year funds obligated for these three object-classifications equal 100 percent of HEW mental retardation engagements.

HEW: The Department of Health, Education, and Welfare

Adapted from: Braddock, D. "Mental Retardation Funds: An Analysis of Federal Policy." Doctoral dissertation. University of Texas at Austin, 1973.

Braddock found that although the mental retardation budget was escalating rapidly, most of the increases in spending were attributable to Federal funds for personal maintenance. In recent years this has affected the proportion of funds available for client services and program administration.

Braddock reported fragmentation among HEW mental retardation programs, listing 46 separate program elements that made up HEW's effort for mentally retarded persons in **1973**. This fragmentation complicated comprehensive planning because so many different agencies, with different funding patterns and different regulations, were serving mentally retarded persons.

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