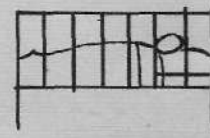
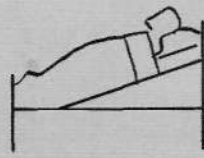
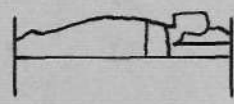
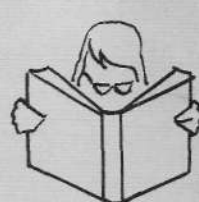
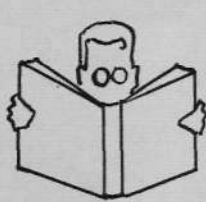
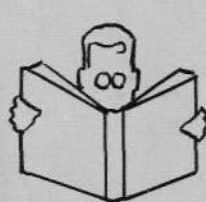
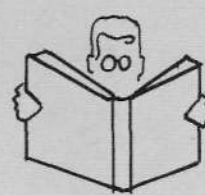
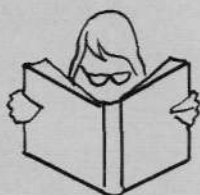
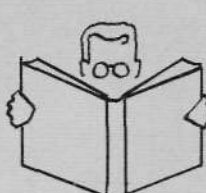
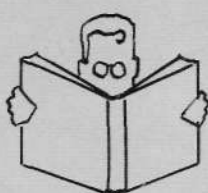
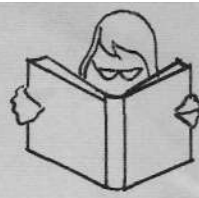
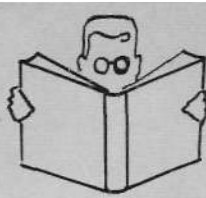
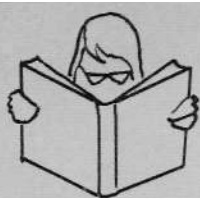


MR 67:
*A first report to the President
on the nation's progress
and remaining great needs
in the campaign to
combat mental retardation*





MR 67:

*a first report
to the President
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the campaign
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mental retardation*

MR. PRESIDENT:

THIS is a report about six million special Americans for whom—and for whose families—our national accomplishment has been great. . . and far too little.

THE six million are the nation's mentally retarded. They are as many as the combined populations of Maine, Oregon, Mississippi, North Dakota, and Wyoming. They are as many people as live in Los Angeles and Chicago together. Their number would make 12 Indianapolises, 24 Wichitas, 48 Winston-Salems.

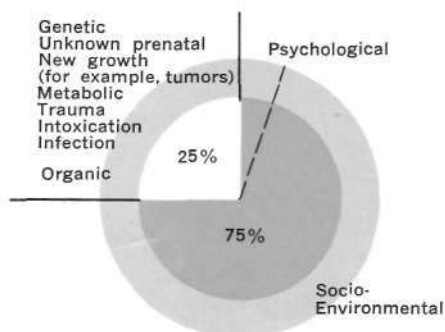
THESE special Americans are people who are limited in what they can do and understand and achieve.

THEY are slower to learn than most. They have greater difficulty in coping with swift change and life's growing complexity.

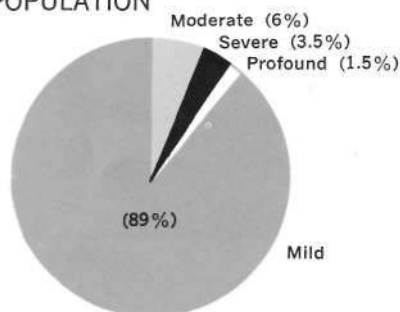
BUT they are not helpless or hopeless.

LIFE for them has taken on new promise since Congress, responding to popular and professional call, passed major legislation in their behalf not quite four years ago. Over \$400 million a year is now appropriated for federal programs benefiting the retarded. More than twice that amount is spent each year by the states, localities, and private citizen organizations. The result has been an extraordinary growth in the services which the mentally retarded and their families may call upon.

MENTAL RETARDATION
BY CAUSE



CLASSIFICATION OF THE
MENTALLY RETARDED
POPULATION



THE ACHIEVEMENT, HOWEVER, IS ONLY
A BEGINNING.

AMONG the major needs still facing us are:

- Half of the nation's 25,000 school districts offer no classes for pupils having special learning problems and needs. Many of the existing special education classes do not offer retarded students opportunity to learn and achieve to their full capacity.
- Three-quarters of the nation's 201,000 institutionalized mentally retarded live in buildings 50 years old or more—many of them "hand-me-down" mental or tuberculosis hospitals or abandoned military installations.
- The 81,000 full-time staff in public facilities for the mentally retarded must be almost doubled to reach *minimum adequacy*.
- The mentally retarded in disadvantaged neighborhoods often receive significantly less service from public and private agencies than do the retarded living in other neighborhoods.
- An estimated 2 million retarded persons capable of learning to support themselves need job training and placement services. Even at minimum wage, these individuals have a potential annual earning capacity of \$6 *billion*.
- The cause of three in every four cases of mental retardation remains unknown.

TRAINING PROGRAMS IN THE FIELD OF MENTAL RETARDATION Department of Labor		
Year	Mentally Retarded Persons Trained	Persons Trained To Work with Mentally Retarded
1963	160	12 90
1965	2,727	664
1966	1,740	281
1967	2,777	250

a OUR PROSPEROUS, OUTREACHING AMERICA MUST CONCERN ITSELF with this group of its least able citizens for practical as well as idealistic reasons.

FIRST, we have learned that problems ignored or neglected do not go away. On the contrary, they grow, both in urgency and cost, until at last we are forced to contend with them, often at enormous expense for measures that can only hold the line.

WE are confident that the causes of mental retardation will be found. Some already have been discovered. When we know more about the causes, we will be able to make significant advances in prevention of retardation.

AND we have learned that the clear-eyed compassion which helps the weak become stronger, the less able to achieve to their full ability, the dependent to become self-reliant is a necessity for people who have important work to do in the world. We Americans are such a people.

FOR the retarded and for ourselves we must continue and improve on the splendid beginnings that we as citizens of a great nation have made in meeting the national problem of mental retardation.

SPECIAL EDUCATION CLASSES FOR THE MENTALLY RETARDED

EDUCABLE

Year	Number of Classes	Number of Pupils
1953	—	108,903
1958	—	201,443
1963	22,500	363,000
1964	26,415	406,000
1965	31,277	459,442
1966	36,851	519,422
1967	43,525	587,722

TRAINABLE

Year	Number of Classes	Number of Pupils
1953	—	4,659
1958	—	16,779
1963	2,500	30,000
1964	3,490	40,035
1965	4,678	52,341
1966	6,329	68,322
1967	8,522	89,252

AT IS NEARLY FIVE YEARS SINCE a panel of the nation's leading authorities on mental retardation, appointed by President John F. Kennedy, made the first thorough survey of what was being done for the retarded and what needed to be done. It is now time to assess what has been accomplished since then and to set new goals.

The 1961-62 President's Panel on Mental Retardation made 95 action recommendations that sought progress in four critical areas. The nation, said the panel, could make significant progress against the problem of mental retardation if:

We as a nation confronted mental retardation as a major national social, educational, and health problem calling for legal and moral commitment at all levels;

The problem was exposed to the widest possible citizen awareness, interest, involvement and action, ceasing to be the concern solely of a closed, professional group;

- *We took the revolutionary step of treating mental retardation as a problem in national human resources, moving to narrow the research-and-service gap so that prevention programs could be launched and a significant percentage of the mentally retarded made self-sufficient contributing citizens;*

The national concern about the retarded was hacked in action by allocation of sufficient money and manpower to make real progress possible in all areas—research, prevention, planning, and services.

These recommendations were challenges put to the nation by a group of dedicated specialists who knew that the most effective and enduring works in the United States are those undertaken by an informed, aroused citizenry. The recommendations resulted in legislation that attacked the problem through research, professional training, programs of prevention, and state and community planning.

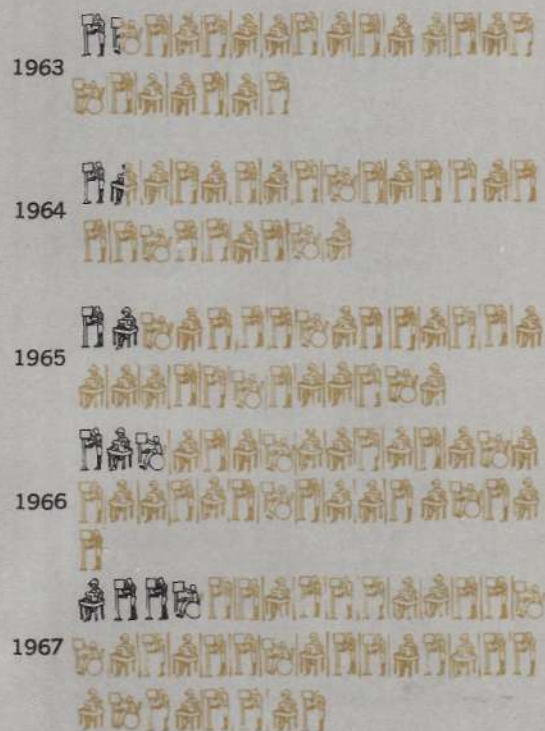
SINCE ITS APPOINTMENT A YEAR AGO, YOUR COMMITTEE ON MENTAL RETARDATION has carried on an intensive effort to learn and evaluate the nation's progress in combating retardation. The Committee has inquired into the status, trends, and needs of programs for the mentally retarded nationally, in the states, and locally. This inquiry has proceeded along several lines:

A survey that sought to learn the adequacy of present programs from a nationwide sample of 3,000 persons.

Field interviews with community mental retardation programmers, citizen and volunteer leaders, state planners and coordinators, training and manpower development experts, and residential facility superintendents and staffs. These interviews have been carried out in 15 states across the nation.

Forum meetings held in the field by the Committee's subcommittee on the state of the nation in mental retardation programs. These meetings have brought Committee members together with state, community, and private agency workers as well as interested citizens for an on-the-scene look at how the needs of the retarded are being met.

VOCATIONAL REHABILITATION

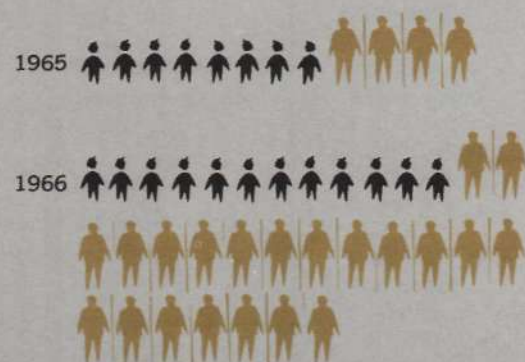


(Each symbol represents 5,000 individuals rehabilitated)



Number of Mentally Retarded Rehabilitated

THE FOSTER GRANDPARENT PROGRAM



(Each symbol represents 100 individuals)



Number of Retarded Children Served



Number of Foster Grandparents

Fact-finding meetings with key staff from the wide range of federal agencies operating programs or interested in the field of mental retardation. (Among these—and demonstrating the scope of federal involvement—have been the Department of Labor, Department of Defense, Department of Housing and Urban Development, Office of Economic Opportunity, Civil Service Commission, Veterans Administration, and the National Aeronautics and Space Administration, as well as several Department of Health, Education, and Welfare bureaus.) All federal agencies having programs are reporting data on their activity and experience.

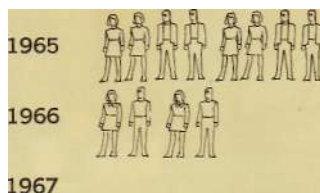
FROM these and other, special studies, *we can report that the last five years have seen an historic emergence of mental retardation and the mentally retarded from isolation and public indifference.*

MANY factors have contributed to this development, among them major federal involvement in programs for or benefiting the retarded, a reawakening in the states to their own social service needs, and a national information campaign by public and private agencies together to build public awareness and understanding of mental retardation and the mentally retarded.

Major successes include:

All 50 states (plus the District of Columbia, Puerto Rico, and the Virgin Islands) now have a written plan for providing comprehensive services for the retarded.

GOAL:
ELIMINATE
MEASLES
THIS YEAR



(Each figure represents 500,000 measles cases)

Privately sponsored day care and recreational programs for the retarded are now available in many parts of the nation. Local and state associations for retarded children alone sponsor over 300 day camps and 150 residential camps as well as more than 1,000 other recreational and social group programs.

WHILE THESE SUCCESSES HAVE BEEN BUILDING, HOWEVER, LONG-TERM NATIONAL TRENDS HAVE BEEN RAISING NEW CHALLENGES to which those concerned for the mentally retarded must address themselves.

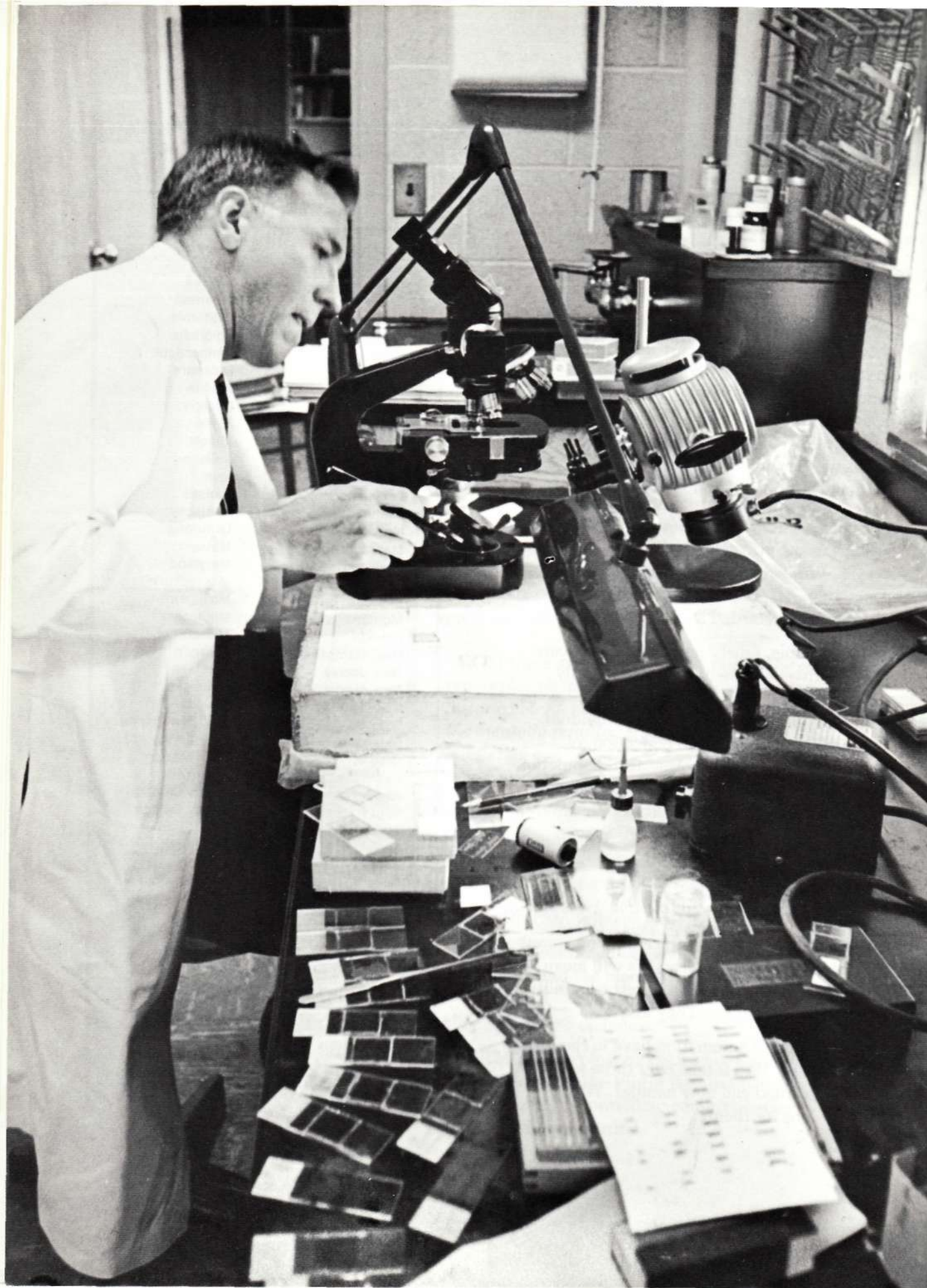
Soon, for example, ninety percent of Americans will be city-dwellers, their lives shaped daily by mass technologies. . . . Effective and meaningful living requires that the individual obtain more and more formal education... . The spiraling growth of the American population—some 70,000 babies are born each *week*—strains the already undermanned teaching and other social service professions to meet even the needs of the normal.

STATE AND LOCAL MENTAL RETARDATION AUTHORITIES ARE CONCERNED about what the galloping complexity and sophistication of American life will mean to the retarded, who have the lowest capability to adapt to swift change. They ask:

What effect will automation have in the lives of the retarded? Will it take over those jobs which the retarded can now handle? Will it create new jobs for them?

STATES WITH PHENYLKETONURIA SCREENING AND CHILD ABUSE REPORTING LAWS

PKU	Child Abuse
Alabama	Alabama
Alaska	Alaska
California	Arizona
Colorado	Arkansas
Connecticut	California
Florida	Colorado
Georgia	Connecticut
Hawaii	Delaware
Idaho	Florida
Illinois	Georgia
Indiana	Idaho
Iowa	Illinois
Kansas	Indiana
Kentucky	Iowa
Louisiana	Kansas
Maine	Kentucky
Maryland	Louisiana
Massachusetts	Maine
Michigan	Maryland
Minnesota	Massachusetts
Missouri	Michigan
Montana	Minnesota
Nevada	Mississippi
New Hampshire	Missouri
New Jersey	Montana
New Mexico	Nebraska
New York	Nevada
Ohio	New Hampshire
Oklahoma	New Jersey
Oregon	New Mexico
Pennsylvania	New York
Rhode Island	North Carolina
South Carolina	North Dakota
Texas	Ohio
Utah	Oklahoma
Virginia	Oregon
West Virginia	Pennsylvania
Wisconsin	Rhode Island
	South Carolina
	South Dakota
	Tennessee
	Texas
	Utah
	Vermont
	Virginia
	Washington
	West Virginia
	Wisconsin
	Wyoming
	Virgin Islands



1. Mental retardation services must be available to more of the nation's people.

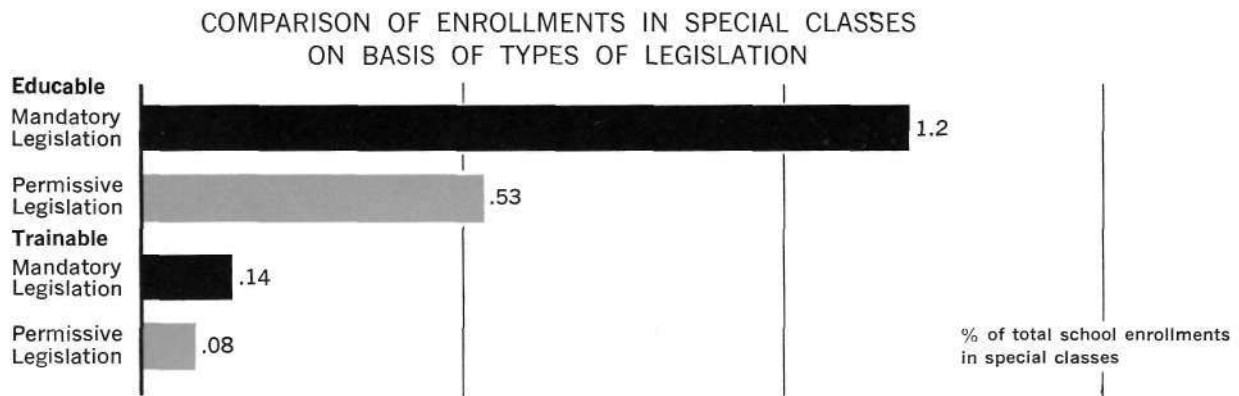
Particularly, ways must be found to bring these to low income, disadvantaged neighborhoods, both urban and rural.

Community public and private agencies working with the mentally retarded must move swiftly to assure that the retarded in lower income neighborhoods receive the same services as the retarded in other neighborhoods. Provision for the needs of the retarded must be included in the comprehensive "one-stop" community health care programs now being developed. In need of special attention are medical and social measures—such as parent and child health, family planning, and counseling programs—that give promise of reducing mental retardation in "high risk" areas now having an above average rate of incidence.

The nation's schools must plan both to improve their special classes for the mentally retarded and—because it can now be clearly shown that many children *become* retarded during their school years—to raise their over-all instructional quality, especially in those schools whose students live in a retardation-fostering environment. Pre-school programs—such as Project Head Start—need increased emphasis in this connection.

Private citizen organizations have especially meaningful challenges in these areas. That they have had success in stimulating and building public awareness and services in the field of mental retardation should not blind them to how much remains to be done.

The voluntary agencies are able to express the will and apply the strength of citizens banded together for cooperative action. They should, therefore, take the lead in developing new directions for social services, effective liaison among themselves for comprehensive action, and careful, objective analyses of need and resource to assist state and national legislators in writing pertinent, effective legislation for the mentally retarded.



2. More effective and extensive manpower recruitment and training programs for work with the mentally retarded are needed.

Acute shortages of professional specialists—especially teachers, therapists, physicians, social workers and nurses—continue to hamstring programs for the retarded in all parts of the nation.

Careers in work with the retarded must be brought to the attention of the nation's young people. And the incentives—financial, career developmental, intellectual and prestigious—that would stimulate youth interest and commitment in such careers need intensive build-up.

In addition, we must open up new career fields in mental retardation programs.

Trained, professionally recognized supportive workers can take on much of the work now done by physicians, nurses, social workers, psychologists, therapists and administrators. Here, in fact, is the most significant challenge and opportunity in the mental retardation manpower area. In such work, non-college and junior college graduates can meet great need and build satisfying careers.

Broader use of supportive workers in mental retardation programs could also tap major reservoirs of precious human resource that are presently little utilized. For example, students (through such activities as the Student Work Experience and Training program) and elderly persons (through such activities as the Foster Grandparent Program) have created valued places for themselves in work with the retarded. Programs of this kind need major expansion.

If, however, these opportunities are to be seized fully and the field's specialists freed to use their skills to maximum effect, many walls and barriers erected in the name of "professionalism" must be torn down.

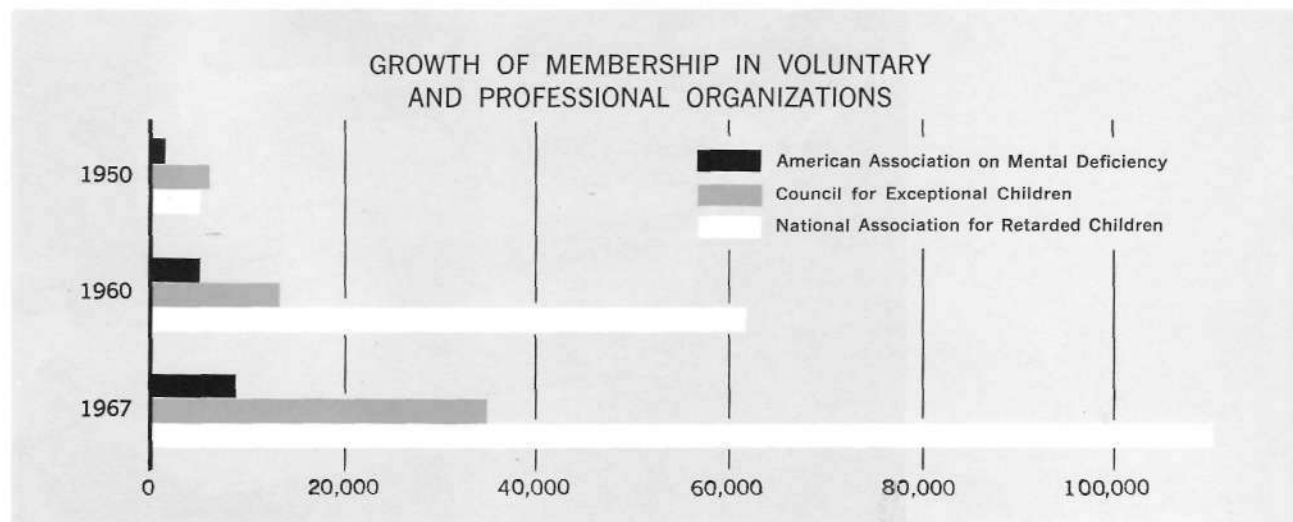
Information and citizen involvement are indispensable to success in this area. Governors' advisory groups on mental retardation services and state coordinating bodies should actively promote the formation of voluntary associations on behalf of the retarded in every community (or group of communities) in their states. Each citizen should have access to a directory of state services for the retarded. Particular attention must be given to measures by which the new parents of a retarded child may receive immediate assurance that they are not alone and that there is hope and help for their child and themselves.

Finally, families having mentally retarded children should be informed of and encouraged to make use of the casework, foster care, protection and medical services available through public and private welfare agencies.

Work at the service-giving local level, however, must be backed by effective coordination, cooperation, and leadership at state, regional and national levels. Great improvement could be effected in these areas.

4. More public-private partnerships in program development, services and research are needed.

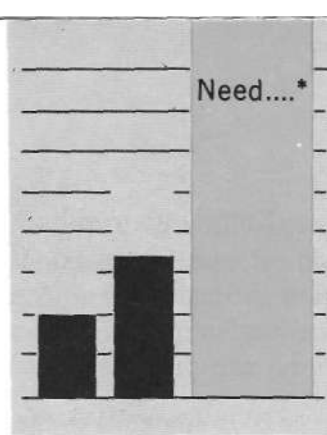
Such partnerships join citizen initiative and imagination with state and federal resources. They give all levels a stake in the solving of social service problems.



Among possible partnerships in the field of mental retardation: foundation-assisted demonstration projects in disadvantaged areas . . . cooperative labor-industry studies and experimental projects in employment and vocational rehabilitation of the mentally retarded . . . application of industry-developed systems management techniques to the meeting of local and state mental retardation needs . . . cooperative programs for improvement of public library resources in mental retardation materials . . . public grant assistance to voluntary organizations wishing to stimulate innovative services to the mentally retarded . . . a cooperative project of government, universities, and technical publishers to translate and make foreign-language mental retardation research and program reports available.

Local and state governments, especially, should promote and enter such partnerships as part of an enlightened public policy to foster long-range growth that is shaped, led and endorsed by the citizens concerned.





5. A national mental retardation information and resource center should be developed.

The center would serve as a central storage and dissemination point for information on mental retardation and mental retardation programs. It would gather, systematize and furnish information on research, studies, programs and services throughout the nation and in other countries, employing the most up-to-date facilities and techniques for information gathering, storage, evaluation, retrieval, exchange and dissemination.

Consultative services, too, would be made available through the center to mental retardation program planners and leaders at all levels, and to state and community planners of comprehensive health and social services. Also available through this center should be a basic directory that will enable any citizen to locate a contact in his state for mental retardation program and information assistance.

To develop broad national participation, the center might be a public-private partnership, with the federal government, state governments, and private organizations in the mental retardation field assisting in its financing and costs.

6. Basic research, training in application of research, and rapid translation of research results into service program uses need continuing encouragement.

Far too little, even now, is known about mental retardation, its causes, and ways to combat and prevent it.

Biomedical research has been able to identify 25 of every 100 cases of mental retardation as associated with faulty genetic constitution or resulting from virus infections, accidents and diseases before birth or in early infancy. The body processes bringing about mental retardation in the other 75 percent of cases are still unknown, although nutritional, intellectual and cultural-environmental factors are often clearly at work.

Knowledge resulting from scientific research now makes it possible to prevent a tantalizing one to two percent of mental retardation through tests and treatment beginning at or shortly after birth (phenylketonuria and some other conditions in which metabolic disorder can produce retardation) and through immunization (measles).

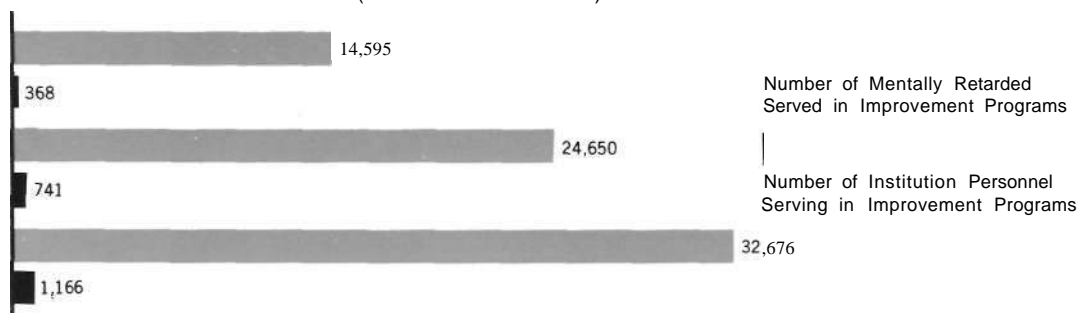
It is imperative that many more scientists engage in studies in areas (such as biochemistry, physiology, learning) related to or bearing on the field of mental retardation, and that these scientists multiply their own efforts through greatly expanded training activities for scientific researchers and supporting research personnel.

Better and wider use of modern technology (such as automation) will make possible the development of new or more widely applicable techniques for retardation study, treatment, and prevention. For example, automated procedures would enable the genetic study of larger numbers of people and the detection of subtle differences between normal individuals and those whose genetic make-up is such that they are "carriers" of genes associated with retardation. Progress in this area will in turn make genetic counseling more accurate.

A special effort should be made in the study of prenatal life from its cytogenetic and physiological aspects, utilizing all appropriate clinical experience as well as the resource afforded through the National Institutes of Health's primate research centers. Increased knowledge in this area will make prenatal diagnosis and, ultimately, prenatal therapy possible.

Research on factors leading to a higher incidence of mental retardation in low income areas must be expanded and special methods developed for reaching such "high risk" groups through intensive family counseling and planning services.

IMPROVEMENT OF INSTITUTION SERVICES (Under Federal Grants)



The important role that the clergy often has in family counseling should also be considered in this connection.

In addition, all schools readying students in the health, social service, community organization and related fields must move to make their instruction and training in the techniques of individual, family and group counseling the best possible. They should, indeed, assign as much importance to this area as to their professional subject matter areas.

All medical and social service agencies and facilities should give increased, major attention to measures that will reduce the impact of mental retardation on the family and the community. Such measures include well-baby care programs . . . early psychological screening and biological evaluation of children . . . close and continuing observation of the identified retarded child's growth, development and learning . . . comprehensive, coordinated medical and social services for the retarded . . . counseling and planning aids for the parents of a retarded child. Need for such measures as these was stirringly described in your Spring 1967 Message to Congress on Children and Youth.

8. Social and institutional planning for the coming decades must take into account the special needs of the mentally retarded.

It is estimated that some 2,100 children who are or will become mentally retarded will be born *every week* in 1968.

Until more ways are found to prevent mental retardation, we must expect that up to three percent of our annual baby population will be or will become mentally retarded.

Facilities and programs for the retarded, therefore, should be considered in the compilation of every state and community development, education and social service plan, as well as in such guidelines as may be developed for federally aided urban development, housing, and comprehensive health, rehabilitation, welfare and education programs. Specialists in mental retardation should be involved in the basic social service planning process.

Simultaneously, renewed attention must be given to public facilities and programs for the five percent of the mentally retarded who require full- or part-time residential care.

These have not kept pace with progress in community activities on behalf of the retarded. Some of the best residential programs

represent triumphs of resourceful staffs over cheerless facilities, penny-pinching budgets and general indifference. Many are plainly a disgrace to the nation and to the states that operate them.

The states must meet their responsibility to plan, construct and maintain modern residential facilities for those mentally retarded needing them. They should retain architects to design facilities that will be cheerful to live in as well as promote maximum effective use of staff and other resources, provide sufficient funds to staff and operate the facilities at adequate levels, and integrate the facilities' operation into the over-all state plan for health and welfare services.

studies indicate that *no* state adequately reflects in its laws what we know of the mentally retarded today. Outmoded classifications 50 or more years old are in common legal use.

The laws applicable to the retarded in most states deny them even the elementary rights of citizenship.

This situation can and must be remedied through forthright action to recognize in state guardianship laws, mandatory education laws, institutionalization procedures and (for retarded offenders) penal regulations, inheritance laws, court and police procedures, and **civil** rights statutes that the mentally retarded are variously limited individuals whose basic human rights are inalienable.

We particularly commend this question to the action of the legal profession through its national and state associations.

10. Lastly, we urge that everyone interested in helping the mentally retarded and combating retardation give thought to imaginative ideas and approaches that will make new advances possible.

New ideas and approaches are the catalysts that change problems into possibilities. They are needed in every phase of the nation's

effort against mental retardation. Among the questions on which bold, original thinking and ideas are needed are the following:

- What is the cost to the nation of mental retardation? That cost is known to be staggering in terms of service expenditure and undeveloped human resource. Its more precise determination and elaboration in terms of long-term national societal trends is a major planning need.
- With jobs being increasingly designed for people, what kinds of job engineering can and needs to be done for the retarded? What kind

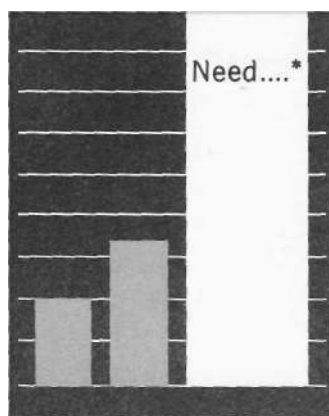
are its undiscovered potentials for bringing the retarded a greater share in the fullness of daily life? How shall we inspire young America to enter this critically important field, both as volunteers and as career workers?

- What job, personnel and career changes and innovations will be necessary to match available skills and resources to the meeting of ever-growing need in the mental retardation field?
- What are the moral and ethical implications of technological findings in the genetics and management of mental retardation? Should a discourse on these subjects be instituted among scientists, philosophers, theologians, social theorists, parents?

The widest possible attention to the problem of mental retardation is a national necessity. The problem affects all parts of American society. The best thinking and action of labor, industry, the professions, and government must be brought to bear on this problem. It is too significant a problem, too tough a challenge to be left to a comparatively few specialists and other interested persons.

MR. PRESIDENT, THIS REPORT PRESENTS ACTION AREAS in which concerted national, state and local effort by public agencies and private, voluntary organizations can produce significant progress in combating mental retardation and lessening its effects. This Committee has in progress a group of special reports which will present specific documentation and recommendations on many of the areas described in general terms in this report. Effective action, however, need not await the compilation of details, but can be taken at every level *now* on the basis of information already available.

We enlist your aid, Mr. President, in endorsing the release of this report to the public and in urging action at all levels for a continuing, effective national attack on the problem of mental retardation.



The endpapers of this report present an artistic portrait of the mentally retarded and an approximate tallying of the degrees of mental retardation of each 100 retarded individuals.

The mildly retarded—nearly 90 percent of all the retarded—are shown in dark brown or white outline. All of these can learn to do productive work, and most can learn school subjects.

The moderately retarded, shown in light brown outline, can learn to care for themselves and do simple, routine tasks.

The severely and profoundly retarded—who are the very small number requiring constant care—are shown in dark blue outline at the bottom of the chart.

PHOTOGRAPH CREDITS

IV, 9, 14, 16, 18, 22, 29—David Warren for the President's Committee on Mental Retardation; 2—Human Resources Center; 13—FRIENDS Magazine.



- Mildly retarded, able to learn school subjects and capable of doing productive work
- Mildly retarded with other handicaps
- Moderately retarded, able to do routine tasks
- Severely and profoundly retarded

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