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President's Panel on Mental Retardation, Washington, D.C.

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Professional Personnel, Program Development, *Residential Care

Significant changes in the diagnosis, study, and treatment of mental retardation are documented, and the long-range trend toward including mental retardation services in programs for all handicapped persons is described. Recommendations are made in three major need areas: residential care for the retarded, manpower for mental retardation programs, and mental retardation in poverty neighborhoods. Photographic illustrations, figures, and graphs are provided. (LE)









The Edge of Change

A REPORT TO THE PRESIDENT ON MENTAL RESERVATION PROGRAM TRENDS AND INNOVATIONS, WITH RECOMMENDATIONS ON RESIDENTIAL CARE, MANPOWER, AND DEPRIVATION

Highlights of the Second Report of The President's Committee on Mental Retardation

THE REPORT:

Documents significant changes in the field of mental retardation

Describes a long-range trend toward including mental retardation services in programs for all handicapped persons

Makes recommendations in three major need areas—residential care for the retarded, manpower for mental retardation programs and mental retardation in poverty neighborhoods.

AMONG THE RECOMMENDATIONS:

Residential Care (page 11)

- Improve standards and develop a national system of accreditation
- Expand the Hospital Improvement Program
- Establish a program to relocate and rebuild obsolete facilities
- Develop an insurance system to give parents a free choice in selecting residential services
- Bring mental health authorities into more active participation in developing programs for the retarded who are emotionally disturbed

Manpower (page 15)

- Increase grants and awards to attract top professionals into the mental retardation field
- Develop grants for the training of desperately needed supportive personnnel

- Make grants to develop statewide volunteer service programs
- Develop in-service training and education programs for employee improvement and advancement

Deprivation (page 19)

- Make health and education services available to every child from birth as his right
- Enact the proposed 1968 maternal and child health legislation
- Develop community and neighborhood health and education centers to give preventive health care and screening, early education and day care
- Develop fixed facility and mobile health, education and social service programs for rural areas
- Expand career planning in supportive health, education and social services in low income areas
- Form a service group to teach and demonstrate home and health skills in low income neighborhoods
- Urge youth organizations to undertake large-scale membership and voluntary service program development in poverty areas
- Extend voluntary family planning services to all Americans.
- Include the needs of the retarded in model cities planning
- Intensify research into the causes of mental retardation associated with social and cultural deprivation.



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The Edge of Change

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION





We cannot rest as long as there is one child who becomes retarded through our neglect, one individual who lacks the care he needs because of our indifference, one person who fails to reach his potential

... no matter how limited.

—Lyndon B. Johnson



President's Committee on Mental Retardation Washington, D.C. 20201

Dear Mr. President:

I have the honor to transmit the second report of the President's Committee on Mental Retardation. Although I have assumed the chairmanship of the Committee too recently to participate in the development of the report and the recommendations, I nevertheless urge fullest consideration for its recommendations on the part of all concerned government and private agencies.

During its second year, the Committee has continued its studies in the 10 priority need areas identified in its first report. Work has focused on three of those areas - residential care, manpower needs and mental retardation in poverty neighborhoods. Reports and recommendations in those three areas, together with an assessment of trends that are working basic change in mental retardation programs, make up this report.

Individual members of this Committee, Mr. President, are eminent in their fields and leaders of many years' standing in the Nation's endeavor to make progress in serving human and social service needs. We can look to the future with confidence as long as distinguished citizens such as the members of this Committee give of their experience, knowledge and vision to help the Nation chart its progress for the common good.

The Committee is deeply grateful for the encouragement and guidance that you have so fully and unstintingly given. Your informed, continuing interest in the problem of mental retardation inspires us in our belief that the national effort to deal more effectively with mental retardation will ultimately be achieved.

Respectfully yours,

Chairman Cohem

The President
The White House
Washington, D. C.







The Edge of Change

THE enduring change that brings new directions and meanings into life comes on like a new day: not all at once, but in a growing definition of shapes, a stirring as men awake, and finally a growing fullness of light and movement.

Thus has basic and meaningful change been coming into the lives of the

nation's millions of mentally retarded in this decade.

There is a long way to go and much to do before the new day for the retarded is full. But the dawn is now far enough advanced to distinguish much that is new and many of the directions that progress must take.

Three developments are bringing on the new day for the retarded:

- POPULAR AND PROFESSIONAL ACCEPTANCE of the mentally retarded as human beings who can grow and learn to make the most of their abilities.
- AGENCIES' REAPPRAISAL of their missions and methods in light of new and different human needs to be served. This reevaluation, often painful, is bringing new patterns of social action and citizen participation in community affairs.
- RECOGNITION OF MENTAL RETARDATION PROGRAM DE-VELOPMENT AS AN INESCAPABLE PART OF THE RESPONSE TO CRITICAL NATIONAL ISSUES such as poverty and deprivation, city planning and renewal, manpower training and use, education policy, population study and human resources planning.

Ushering in the new shape of life for the retarded are hundreds of programs and projects. Federal government programs grounded in landmark legislation enacted by Congress during your administration, President Johnson, have brought major program advances in a field of human need seriously neglected before. This federal action — such as construction of university-affiliated training facilities, mental retardation research centers and community mental retardation service facilities — has spurred important beginnings nationwide in meeting the evident needs of the mentally retarded.

As a result, social action, career and research possibilities never before

available have opened up.

And mental retardation has been brought into the mainstream of citizen concern as a national problem that every American can help meet in his own community.





Real change announces itself in new ways of tackling problems and needs at the grass-roots level. There are now hundreds of such new-look activities throughout the country. The following pages present a sampling.

Diagnosis, Study, Treatment: A Problem of Availability

Interest and expertise in mental retardation are still scarce in health, education, social work, psychology and other professions. As a result, competent, helpful guidance for retarded children and their families continues to be a desperate need.

Progress is coming as specialists recognize that mental retardation is a many-sided problem and that its "cure" comes only in the fullest possible development of individuals' particular abilities. Prevention demands massive public education and public involvement as well as top professional work. These needs are now producing such innovative programs as:

- DIAGNOSTIC, STUDY AND TREATMENT CENTERS. These bring together teams from many fields. The U.S. Children's Bureau has taken the lead in starting a national network of such centers. Some states are now building their own. The aim of these centers is to put comprehensive diagnostic and study centers within reach of every family.
- REGIONAL SERVICE PROGRAMS. Here the aim is to make care, education, training and other service programs for the retarded conveniently available to every family. A few states now have a network of such centers.
- COMMUNITY CENTERS. These are on the front line of community health and social services. Some serve only the retarded, but increasing numbers work with all handicapped conditions. Their sponsorship and patterns of operation differ. Some are under-one-roof cooperatives of community public and private agencies. Others coordinate the efforts of groups of agencies.
- SPECIAL MEDICAL AND ALLIED PROGRAMS. Of many kinds, these seek to meet specific needs that—usually—have been overlooked before. Examples:
- A southwestern city's mouth care training and dental treatment program for every retarded child in its area.
- Mobile unit diagnostic programs in some rural areas.
- Trained home health aides to relieve mothers of severely retarded children of their constant care.
- Homemaker services for families with a retarded infant.
- PUBLIC INFORMATION PROGRAMS. The great number and variety of these highlights the widespread public interest generated by the problem of retardation.

The 3-year public service campaign on mental retardation coordinated by the Advertising Council brought over \$30 million in contributed space and



time from newspapers, magazines, radio and television stations and display advertisers.

State and community campaigns to spur public awareness of retardation and its causes have been conducted in nearly every state by such groups as the U.S. Jaycees, Civitan International, United Commercial Travelers, women's club federations, service fraternities and sororities. These activities have often been tied to measles vaccination campaigns, better nutrition drives and other mental retardation efforts.

Residential Care: A Road to Main Street

Everybody's picture of the "bad old days" in mental retardation is the large warehouse giving custodial care to the forgotten retarded. That picture, tragically and disgracefully, is still true about many of the nation's public and private institutions for the retarded (see special report heginning on page 11).

At the same time, however, dedicated staffs, imaginative state leaders and federal encouragement for innovation are spurring the development of institutional analysis of the same time, however, dedicated staffs, imaginative state leaders and federal encouragement for innovation are spurring the development of institutional encouragement.

tutional programs of startling freshness and vision.

- COMMUNITY GROUP LIVING PROGRAMS. These are making it possible in some states to move significant numbers of people out of institutions and into community living. Making the move are two kinds of institution residents—trained workers starting on jobs in the community and semi-independent persons able with minimum supervision to live in the community. This trend has brought major growth in community foster care programs for the retarded.
- BEHAVIOR MODIFICATION. Improvement in the hyperactive, sometimes self-destructive behavior often found in the severely retarded has made learning and social growth possible for the first time for many retarded persons. These capabilities in the severely retarded were undreamed of even by most experts until recently.
- "SPECIAL PEOPLE" PROGRAMS. These bring the care, compassion and hope of concerned citizens into the lives of individual retarded persons. They are vitally important, effective programs that operate on small budgets.

The Foster Grandparents Program gives this service opportunity to the elderly. High school and college students take part through the Student Work Experience and Training (SWEAT) Program. (Unfortunately, both these programs have been curtailed by budget cuts this year.)

Some institutions give service-and-training opportunities to VISTA volunteers. At least one institution has formed a Neighborhood Youth Corps

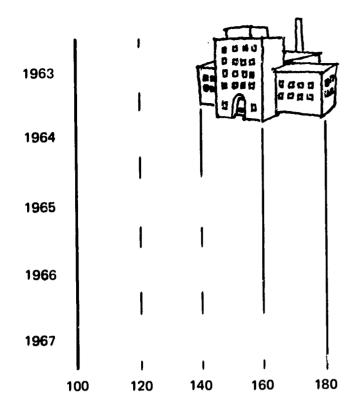
unit of retarded residents.

Nearly every institution in the country has a group of community volunteers. These groups increasingly include high school and college students.

• INNOVATIVE RESPONSE-TO-NEED PROGRAMS. These are of many kinds. For example: Residence ward nurses in a midwest institution learned speech and physical therapy techniques in order to supply steady reinforcement to therapists' work during residents' on-ward hours. . . . A southern institution fitted a bus as a mobile classroom so that field trip experiences could be discussed on the spot before returning. . . . A west coast insti-

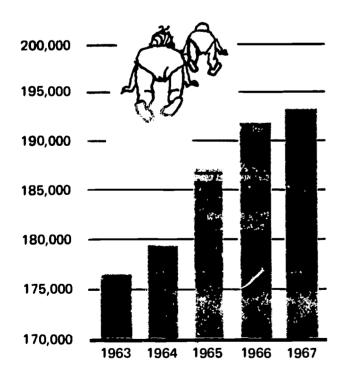


INCREASE IN NUMBER OF PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED 1963-1967



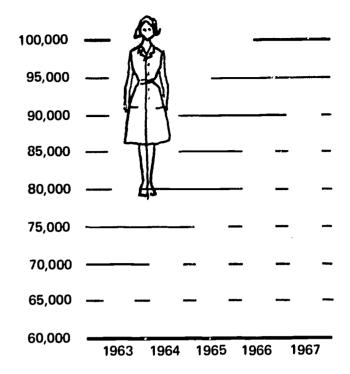
Approximately 50% have less than 1000 population; approximately 30% have more than 2000 population. Most institutions established since 1960 have less than 1000 population. Of the present 165 institutions, 33% have been constructed in the past ten years.¹

INCREASE IN NUMBER OF RESIDENTS IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED 1963-1967



Reports indicate a significant increase in the severely retarded and the emotionally disturbed mentally retarded among recently admitted residents of these institutions.³

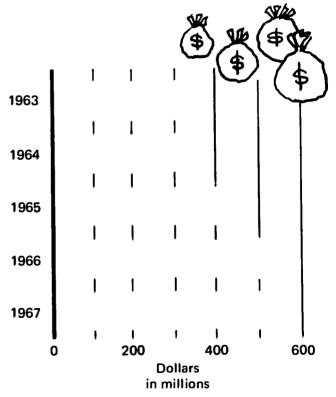
INCREASE IN NUMBER OF EMPLOYEES IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED 1963-1967



Although there was a 36.6% increase in number of employees during the period shown, the staff-to-resident ratio changed very little. There was still in 1967 a need for 50% more staff to meet the minimum ratios established by The American Association on Mental Deficiency.

Staff-to-resident ratio, 1963, was 1: $2\frac{1}{2}$; and staff-to-resident ratio, 1967, was 1: $2\frac{1}{3}$.

INCREASE IN OPERATING COSTS IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED 1963-67



Although operating costs increased by more than 63% in this period, staff increased by only 36%. There is presently a need for 50% more staff to meet minimum standards of The American Association on Mental Deficiency. Since wages and salaries are more than 70% of the institutional budget, it is apparent that total increase has not kept pace with need.4

tution uses behavior-modification to teach one group of residents how to work with another, more severely retarded group to improve the latter's behavior. . . . An occasional community is now developing programs to meet the special needs of the adult retarded, a group often overlooked. Also being tackled in some programs are the needs of the multiply handicapped retarded individual. . . . A community service group in one eastern state works with mentally retarded offenders committed to the state penitentiary. (A national sample of 90,000 prison inmates was recently found to include nearly 8,600 mentally retarded persons.)

Education and Day Care: More, Earlier, Better

Discoveries of far-reaching significance have been made in recent years in the field of learning.

Studies have found that the period of most rapid learning comes years before school begins. The range of an individual's intelligence is largely set in earliest childhood. It can be blunted in those same early years by a limiting, harsh, negative environment.

It has also been found that traditional education methods faced many children with problems that their special learning handicaps make difficult or

impossible for them to surmount.

Education and day care for the intellectually handicapped have thus grown up as innovation-minded, probing fields. Some of the new-look programs now under way in these fields include:

- PRE-SCHOOL CLASSES. These aim to give the retarded child a running start when his potential for learning is highest. Another goal is to prevent functional retardation. Programs range from infant stimulation projects to school-entrance readiness classes.
- MACHINES, SPECIAL MATERIALS AND TECHNIQUES. Samples:
- A multi-station electronic laboratory gives programmed instruction to varying-sized groups simultaneously. An aide supervises each group. Teachers concentrate on children needing individual attention.
- Audio-visual presentations and role-playing supplement field trips in a western program that helps retarded children build a sense of self-worth.
- A reading readiness program built on picture-word associations produces results even with severely retarded pupils.
- A community center produces film strips on personal hygiene and grooming for the trainable retarded.
- A state university produces an educational television series for the retarded in every primary and intermediate class in the state.
- A private organization center devised simple pre-primers which retarded children in a reading readiness program compiled from their personal experiences.
- SPECIAL INSTRUCTIONAL PROGRAMS. These are as varied as the needs that imaginative special educators see. A midwest public school system teaches concepts of language and systematic thinking to pre-school children





tion of long-time institution residents as nurse's aides, housekeepers and food service workers, finds homes for them in communities and places them in jobs.

• SPECIAL RESIDENTIAL TRAINING PROGRAMS. These programs offer Monday through Friday residential center training opportunities to retarded persons who cannot conveniently take training on a day basis.

Planning, Programming, Manpower Development: What Islakes the Action Go Forward

Until recently, the design and administration of programs for the mentally retarded was largely confined to programs in residential institutions.

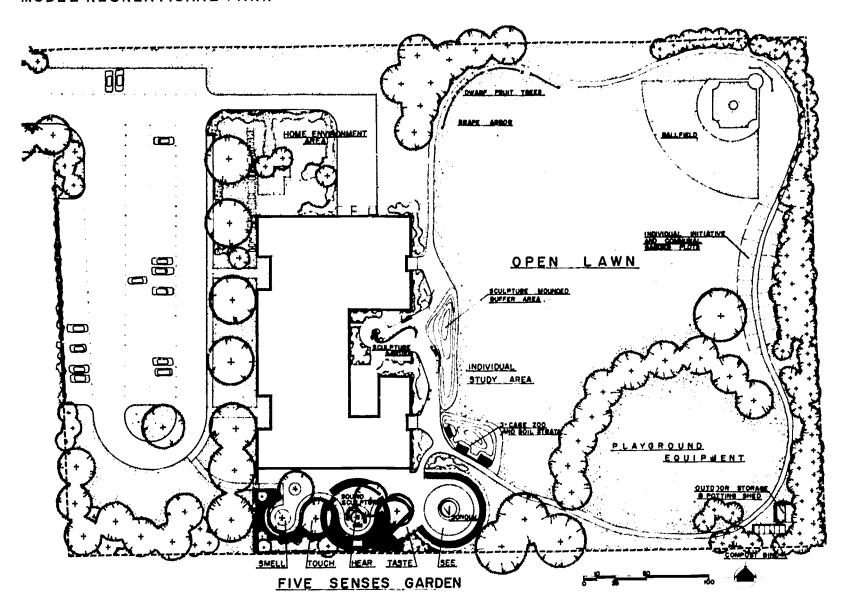
The emergence of community-based services during the past decade has radically altered old patterns. Today, the planning and administration of up-to-date programs for the retarded is a highly complex activity that reaches into every area of community endeavor. It joins many kinds of resources to bring better service to the retarded and is highly innovative.

Among examples of new-look program design, administration and resource development activities in the retardation field are:

• A midwest state's interagency case information service, tied into state university computer center.



MODEL RECREATIONAL PARK





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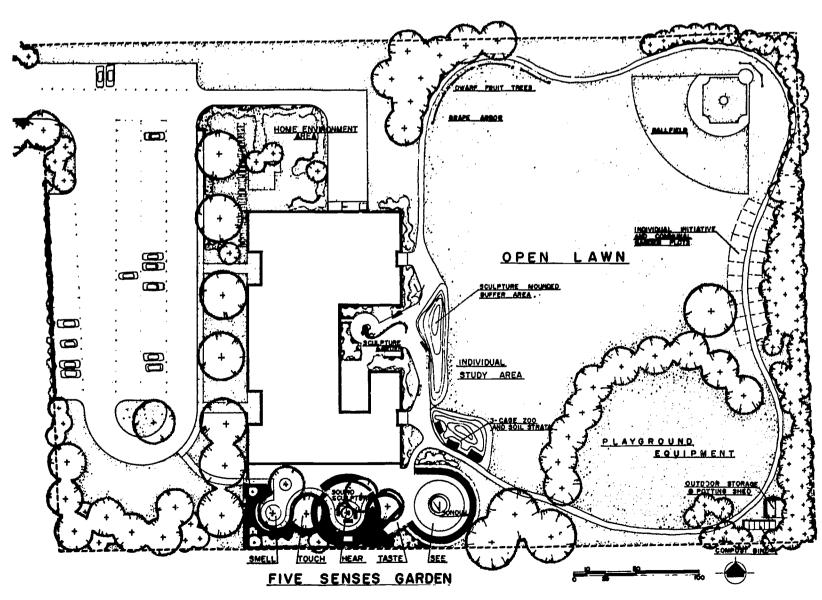
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MODEL RECREATIONAL PARK







- A cooperative planning and programming project for a sparsely settled area of thousands of square miles, being carried out by four western states. Communications heart of the program is a network of intensively trained citizens whose strategic locations make them logical referral and feedback resources.
- A central state's interagency retardation planning group has developed and begun implementing detailed service planning models for work with the socio-economically disadvantaged teenaged girl, the pregnant woman in a poverty area and the pre-school child in deprived areas.
- The National Association for Retarded Children established during the past year the first national organization of youth united to serve the retarded. State units are being organized rapidly.
- A midwest city's association for retarded children and anti-poverty program jointly planned and developed a center for handicapped children in low income neighborhoods.
- Workshops, training institutes, information exchange and other in-service developmental activities are becoming widespread. Growing numbers of programs use closed circuit television for staff training as well as case study. . . . A southern regionwide program spurs training and experience exchange among retardation specialists and institution staffs. . . . An eastern state institution offers a course to qualify attendants for high school equivalency certificates with resultant job advancement and increased pay.
- Aiming for one-to-one staff-patient ratios in programs for the retarded and other handicapped, an eastern state trains supportive workers to assist specialists, thereby freeing the specialists to concentrate on the major concerns their training has qualified them to handle.

What the New-Look Programs Mean

Citizen action to focus attention on a specific health or social problem has been a potent force behind dramatic advances in American health, education and social services.

Such action has led in two generations' span to almost total conquest in the United States of tuberculosis, polio, diphtheria and measles. It has spurred wide popular participation and technical progress in overcoming mental retardation, mental illness, heart and circulatory disorders, crippling neurological conditions and cancer. It is now awakening the nation to the profound interrelationships of man and his environment.

Almost everything we have been learning in this explosive century, how-

ever, has shown us that no problem exists in a vacuum.

Solutions to Problems A and B may be found in a study of apparently unrelated Problem C.

Effective diagnosis, study and treatment of any condition now requires the cooperative knowledge and skills of many people from many fields.

At the same time, our communities' health, education and social needs—particularly in low income areas—have become so great, and the resources to meet them so inadequate in their present applications, that fundamental

revision in the delivery of community services has become a critical necessity.

Leaders in the field of mental retardation must face up to this challenge. The campaign to prevent mental retardation and help the mentally retarded utilize their abilities fully is entering a new phase.

Because resources of money and people are short and because human needs are so deeply interrelated, people and organizations interested in specific handicapping conditions will need to work together increasingly.

The development of all-inclusive approaches to handicapping conditions will promote more effective services for retarded individuals than can be found in most communities today.

Such approaches would end the tragic limbo into which the emotionally disturbed retarded have so often fallen.

They would end the frequent neglect of individuals having unusual retardation-allied conditions such as autism.

Comprehensive approaches would particularly make it possible to tackle the awesome amount of mental retardation that has social and environmental causes. This retardation is frequently neglected in today's largely biomedically oriented research and treatment programs.

The time has come for workers with the retarded to surmount their fears of submergence and neglect in comprehensive programs for the handicapped. Substantial grounds have often existed for such fears... and still do in many programs. But important changes in knowledge and attitudes about the retarded are combining to make enlightened action possible.

The mistaken notion of retardation as an irreversible, unchangeable condition is at last giving way in a score of fields. Replacing this long-frozen view of retardation is a mounting involvement and excitement among scientists, health specialists, educators, psychologists, social workers and therapists.

This new attitude is bringing attention, respect, and action programs to the field of mental retardation. If wisely cultivated, it will assign retardation as important a priority in comprehensive service planning and programming as that given to any other handicapping condition.

The protection of the interest of the retarded over the next decade, then, will probably be a matter of two related endeavors.

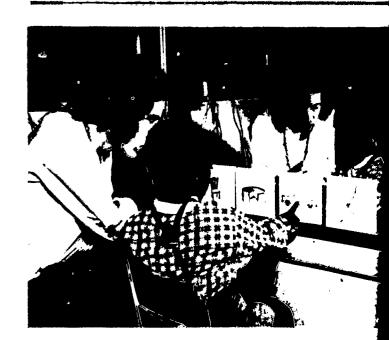
We will need to cultivate the excitement about the possibilities of making important progress in preventing and overcoming human functional disorders.

And all groups and individuals concerned about such disorders will need to insist that every handicapped individual get all of the help he needs to grow to the fullest realization of his own abilities and potential.

Last year, this Committee pointed out 10 areas in which major action in furthering the national campaign against mental retardation was needed. During the year since submitting its first report, the Committee has focused major effort on studies in three of those areas—residential care of the retarded, manpower for programs working with the retarded, and poverty-linked retardation. Reports with recommendations in these areas follow.











PRIORITY REPORT:

Residential Care for the Retarded

MANY of the nearly 200,000 residents in state institutions for the mentally retarded live in disgraceful conditions that the states' own regulatory agencies would not tolerate in privately operated facilities for anyone.

Moreover, the facilities in which these retarded persons live are in many cases in a state of decay.

The average age of institution buildings is 44 years. Some have reached the century mark. At least 50 percent are functionally inadequate for the care, growth, learning and rehabilitation programs that can be successfully carried out with the retarded.

The reasons are not hard to find.

Many states' institutions are administrative stepchildren. They are often located in remote places, far from population centers, according to a longprevailing view of the retarded as mistakes of nature to be put out of sight.

They are poorly budgeted: the national average expenditure per person per day—with *all* costs, both direct and indirect, figured in—is just \$7.60, and actual amounts range down to just over \$3.00 in some states.

Staffs are often underpaid, underqualified and without reasonable hope of having better working conditions or career advancement. Institution locations and pay scales make recruitment of trained manpower difficult. Archaic, uneconomical administrative practices, born of the low-budget necessity to "make do," have hardened into tradition at many institutions.

Seen in this perspective, the accomplishments of some institution administrators and staffs in developing fresh, innovative programs (see page 3) appear near-miraculous.

The closest approach to development of standards for residential facilities for the retarded has been made by the American Association on Mental

Deficiency with its institutional evaluation program. The AAMD effort, helpful though it has been in guiding many institutions' improvement activities, chiefly covers the traditional large, hospital-oriented type of residential program, however, and contains little guidance on day-to-day care.

Taxpayers pay over a half-billion dollars a year to operate these so-often-inadequate facilities for residential care of the retarded. In all too many cases, it is half a billion dollars paid to perpetuate outworn, inhumane warehousing of human beings.

The dilemma of how to improve the nation's institutions for the mentally retarded is a tough and tangled one. The essence of the problem is what to do about buildings, budgets, programs and populations that have existed in neglect and decay for many years with little or no thought being given to their needs by either state officials or the public.

Renovation of existing buildings is often too costly to undertake. But states hesitate to abandon such buildings because of the investment put into them. Finding another use for them is usually difficult because of their isolated location.

A look at institution budgets can be like an expedition into a hidden land that time forgot. Needs that were great in 1930 may not yet have been constructively studied and responded to. The hundred different ways of using residents' unpaid labor to flesh out penny-pinching personnel budgets would appall labor and management specialists.

Housed in inadequate buildings and chained by inadequate budgets, many institutions, moreover, cannot control the size or kind of population they must care for. Nationwide, there are thousands of mildly retarded individuals, "behavior problems" and "slow learners" in residential facilities for the retarded who should not be in these institutions.

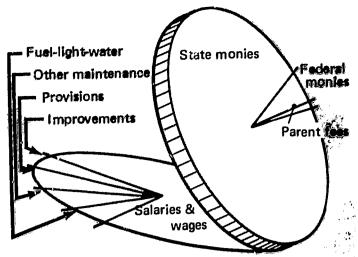


HE RESIDENTIAL CARE DOLLAR 5

IT IS SPENT:

res & Salaries: \$ rovements: visions: ntenance: i, Light, Water:

\$437,698,067 or 70% 62,528,295 or 10% 56,275,465 or 9% 50,022,636 or 8% 18,758,488 or 3%



WHERE IT COMES FROM:

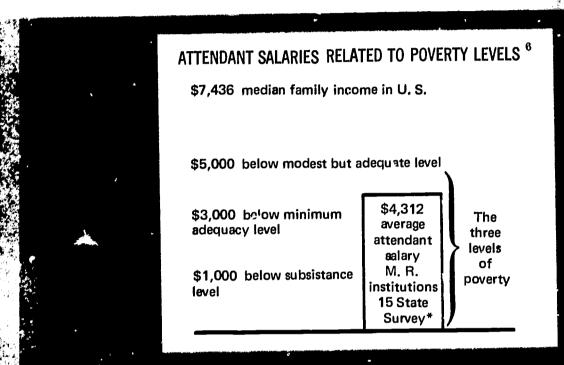
\$48,662,000 or 7.63% Federal Sources: Education of Handicapped Children 8,473,113 or 1.33% **Grants:** 6,790,053 or 1.06% 2,181,550 or .34% Hospital Improvement Awards: .34% Hospital Inservice Training Awards: Foster Grandparent Program: .72% 4,595,724 or Student Work Experience & Training 95,760 or .01% Program: Civilian Health and Medical Program of the Uniformed Services: 646,800 or .10%

Parent Fees: State and County Monies:

Title XIX; Social Security Act:

\$11,788,866 or 1.86% \$576,620,954 or 90.51%

25,880,000 or 4.06%

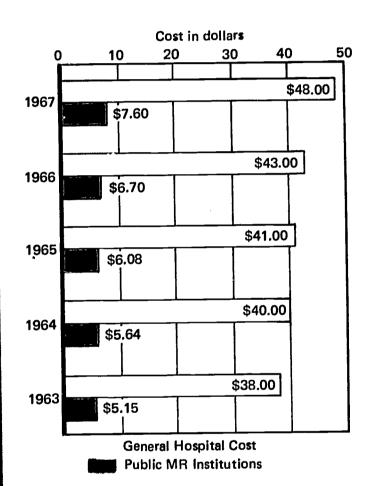


OVERCROWDING IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED

21% of the institutions serving 0-1000	40% of the institutions serving 1001–2000	72% of the institutions serving 2001-3000	75% of the institutions serving 3000 +
residents report overcrowding	residents report cvercrowding	residents report overcrowding	residents report overcrowding

The larger the institution, the more likely it is to be overcrowded. 8

COMPARISON OF COSTS:
GENERAL HOSPITALS VERSUS PUBLIC
INSTITUTIONS FOR MENTALLY RETARDED
PER DIEM COSTS 1963-1967



The cost of general hospital care increased \$10.00 during the 5-year report period, while the cost of residential care for the mentally retarded increased only \$2.45 during the same period.7



0

Thousands of severely retarded individuals are on waiting lists trying to get in. Institutions' budgets, administrative channels and ties with other agencies are too often insufficient.

The need is now too great and too long neglected to be solved by the states alone. Massive federal intervention to spur the improvement of present facilities and the development of new, up-to-date self-renewable systems for the residential care of the mentally retarded is imperative.

The recommendations that follow offer a program for beginning the job in a constructive way that will make as much use as possible of existing facilities and resources.

1. Control of the quality of public, non-profit and private residential care for the retarded is essential.

We recommend, therefore, that the appropriate professional and voluntary organizations, with support from the federal government, take immediate steps to improve the standards for residential care of the retarded and simultaneously develop a system of accreditation of residential care programs and facilities for the retarded.

2. The federal government's Hospital Improvement Program has elicited imaginative new approaches to delivering resident' ' care in state institutions.

We recommend that this program now be expanded to effect major change by:

- A. Greatly increasing funds, with the provision that every state institution for the retarded have opportunity to participate.
- B. Making awards on the basis of a state plan for bringing present institutions up to acceptable standards and the development of communitybased residences as alternatives to institutions.
- C. Relating awards to the size, budget, and needs of the institution.

Particular effort in this connection must be made to meet the unmet needs of the severely and profoundly retarded. Accommodations and care for them are inhuman in many institutions.

3. The use of outmoded, mass-housing buildings must be ended. Industry has rarely hesitated to abandon and replace obsolete plants; states should be no less firm in developing up-to-date facilities. A new geographic distribution of modes and forms of residential care services—including group homes, residential vocational training centers, nurseries and specialized nursing homes—is badly needed.

We recommend, therefore, that a new part be added to Public Law 88-164 to establish a construction program for relocating and rebuilding obsolete residential facilities.

Safeguards must be included to insure that future institutions do not perpetuate the mass housing and programming patterns of the past, and that the construction be planned for easy modification as new techniques and needs are found. The planning should be carried out in consultation with architects, urbanologists, demographers, community developers and other specialists in environmental sciences.

- 4. Hospital In-Service Training Program grants should be greatly increased to include significant training for both leadership and direct service personnel in residential care facilities.
- 5. Public and private social services for children and adults are related to residential care for the retarded in two ways: one, they can suggest alternatives to residential care; two, they have the competency to counsel families during their times of greatest stress—such as the time of deciding to seek a child's admission to an institution, or that of returning a retarded person to community living.

We recommend that federal, state and local welfare agencies, both public and private, clearly identify a portion of their resources for welfare services to the retarded and their families.

Such services include casework, adoption, homemaker services, foster care and day care.

Immediate strengthening of child welfare services to the retarded through expert staffing, consultation and training is an essential component of this recommendation.

6. We recommend that a federally supported insurance system be established to enable a free choice in selecting residential services.

The exercise of free choice in the selection of an institutional home for a retarded individual will bring to the residential care field the improvement motivation of free, competitive enterprise.

- 7. In order to provide a viable choice, we further recommend that a system of loans or grants be developed to assist private non-profit and proprietary organizations to establish alternative forms of residential care for the retarded, such as hostels, group homes, nurseries, residential vocational training centers, nursing homes and extended care facilities.
- 8. State and local mental health authorities and the National Institute of Mental Health should take active leadership in developing services and programs for emotionally disturbed retarded persons in residential care or community programs.





PRIORITY REPORT:

Manpower To Serve the Retarded

THE time has come for systematic action to overcome chronic shortages of trained persons to work with the mentally retarded.

The shortages are felt in every kind of program for the retarded.

There are too few physicians, nurses, social workers and psychologists to give needed diagnostic and evaluation services. There are too few teachers trained to work with the retarded in the schools, too few therapists to work with them in community and residential care programs.

Less heard about, but equally critical, there are too few attendants and cottage parents, too few foster grandparents and student workers, aides, too few volunteers.

Every kind of worker with the retarded is in short supply.

At the same time, however, there is too much hand-wringing in the mental retardation field about specialist shortages and too little being done to find and develop supportive staff members to assist specialists.

The manpower problem in mental retardation is thus a double-barreled one. More workers, both specialists and supportive personnel, are needed. But also needed are searching studies to develop ways of extending specialists' efforts through the imaginative use of trained supportive manpower in all program areas.

Long a neglected career area, the mental retardation field is now erupting with interest and challenge. Findings in human learning problems have pushed special education to prominence and challenged the interest of students and teachers. Discoveries in genetics and biochemistry are making retardation research one of the brightest new frontiers of scientific exploration. Work simplification and job redesign studies have been spurred by findings about the increasingly more significant jobs that trained retarded workers can handle.

Meantime, large numbers of unskilled or semiskilled persons are entering the U.S. work force and the mainstream of the nation's economic life for the first time. Supportive service occupations offer an ideal route for many such workers into prideful and important careers. The nation's service organizations and agencies, including those working with the retarded, should not lose the opportunity to tap this resource through bold new programs of training and neighborhood involvement.

In the broad context of a great need for the services of many people and great opportunity for career growth in work with the mentally retarded, we make the following recommendations directed to manpower planning, development and use.

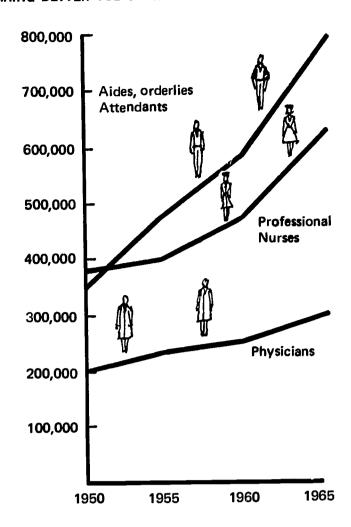
1. We recommend that increased effort be made to attract scientists and professional specialists in education, the medical and behavioral sciences and related fields into research and service in the field of mental retardation. U. S. Department of Health, Education, and Welfare grants, scholarships and awards should be greatly expanded in support of this effort.

Private organizations and foundation sources of support should also be sought and involved, particularly in researching and developing innovative uses of specialist manpower in serving the retarded and other handicapped persons.

2. To increase supportive service personnel in mental retardation programs, we recommend that existing grant programs such as the New Careers and

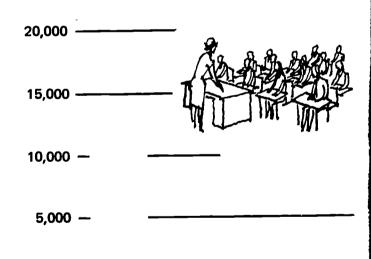
CURRENT NEEDS* VERSUS SUPPLY IN THREE PROFESSIONS® ional 2,300 more needed Presently 4,100 2,900 more needed Presently 8,500 5,100 more needed Presently 10,700 yorkers *Estimates for the 7,000 hospitals registered with the American Hospital Association and based on returns from 5,300. This is national data and depicts wider needs than just in the mental retardation field. RRENT STAFF SHORTAGES IN PUBLIC INSTITUTIONS FOR THE MENTALLY RETARDED 11 The services of 80,490 attendants are required The services of 9,659 registered nurses are required But only 2,651 are available The services of 1,931 social workers are required But only 921 are available The services of 965 psychologists are required But only 417 are available

MAKING BETTER USE OF MEDICAL MANPOWER



Supply of physicians has risen little in recent years, but increased use of aides, attendants and nurses has made medical services go further. 10

TEACHERS NEEDED* FOR SPECIAL EDUCATION IN THE SOUTH: AN EXAMPLE OF MANPOWER SHORTAGE



For mentally retarded 14,112	For deaf, blind, emotion, dist., najor learnir	For speech defects 3,232	For crippled 3,110
	disorders 3,869		

*Estimates by state directors of special education and supertendents of state residential schools or hospitals, projected 1968-69, with total of needs shown to be 24,323.

States are Alabama, Arkansas, Florida, Georgia, Kentuc Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, Sou Carclina, Tennessee, Texas, Virginia, West Virginia.¹² Teighborhood Youth Corps programs be exanded and new grant programs be made availble through the Departments of Labor and Iealth, Education, and Welfare to recruit, training place supportive workers such as teacher ides, nurse's aides, social casework and family ervice aides, and attendants in mental retardation ervices.

These grants should be administered primarily as work training and employment grants and should be nade particularly available to low income applicants. The place of training and employment should preferably be clinics, schools (including public school special education classes) and centers serving the needs of the retarded in the trainee's neighborhood.

We recommend a sustained effort on the part of all agencies operating programs for the rearded and other handicapped to attract into work with the retarded those qualified workers who may need only refresher training or slight retraining to return to work in service professions.

A great potential in this area exists in nurses, therapists, teachers and other professionals who are not working during their family-raising years.

4. To expand mental retardation services with existing and potential manpower resources, we recommend that professional groups recognize and extend professional acceptance to supportive personnel who work with their members.

We also recommend that professional specialists and their associations evaluate specialists' functions with a view to transferring as many of those functions as possible to trained supportive workers.

We further recommend that professional groups reassess in light of the preceding any restrictions which they now place on the use of nonprofessional support personnel and reduce those restrictions to a minimum.

We urge in this connection also that higher education institutions review curricula to assure that courses reflect current thought on specialist and supportive staff duties and responsibilities in services for the retarded.

5. To improve utilization of adult and youth volunteers and to develop volunteer service as a major mental retardation manpower resource, we recommend that a Department of Health, Education, and Welfare grant program be made available to each state to set up, expand or modify a volunteer

service program available to both tax-supported and private programs for the retarded.

6. We recommend that institutions, schools, centers and other facilities offering services to the retarded develop employee education and training programs for employee self-improvement and upgrading. The Departments of Labor and Health, Education, and Welfare should collaborate in helping make such programs possible through grants and development of training models.

We also urge that supportive occupations in service to the mentally retarded be recognized as career opportunities, with adequate remuneration, on-the-job and other opportunities for learning new skills, and predictable lines of advancement and promotion for qualified aspirants.

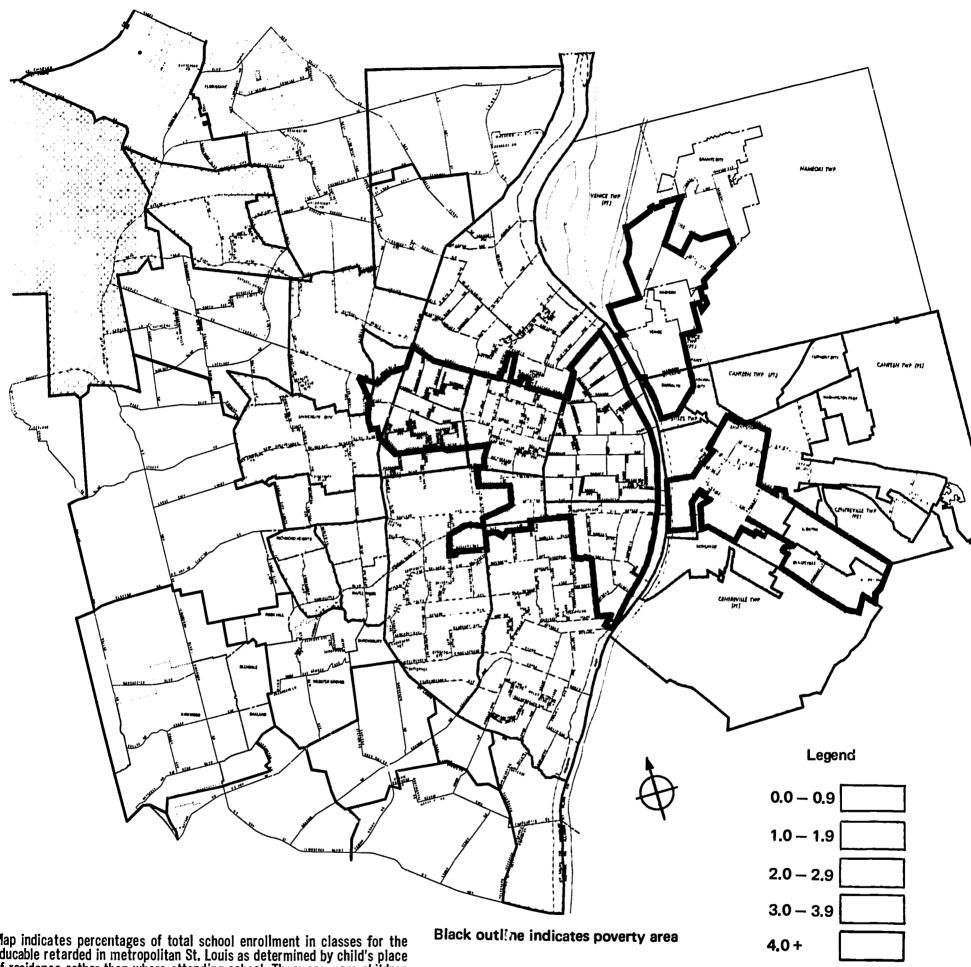
- 7. To permit a wider sharing of knowledge and experience in the field of service to the retarded, we recommend that the federal government develop and fund a program through which clinics, schools, residential care facilities and agencies could exchange specialist and supportive workers for mutual program benefit.
- 8. To establish a common terminology for jobs and positions in programs serving the retarded, we recommend that occupations serving the handicapped be defined in the Department of Labor's Dictionary of Occupational Titles and that the dictionsary's definitions then become standard reference for workers serving the mentally retarded.

In developing these definitions, the Department of Labor should also identify nonprofessional duties that have accumulated in the work of professional workers with the handicapped and suggest possible new service and support occupations in which these duties could be combined.





THE EDUCABLE MENTALLY RETARDED IN URBAN AND SUBURBAN AREAS



Map indicates percentages of total school enrollment in classes for the educable retarded in metropolitan St. Louis as determined by child's place of residence rather than where attending school. There are more children classified as educable mentally retarded living in urban poverty areas than there are living in the suburban sections. This pattern of poverty and mental retardation is repeated in map data prepared on Bridgeport, Los Angeles, Harrisburg and Seattle, and would be expected to be true of other major urban centers. 16

Map developed by President's Committee staff, using school enrollment data supplied by school systems, 1968.



PRIORITY REPORT:

The Retarded Victims of Poverty

FACT:

Three-fourths of the nation's mentally retarded are to be found in the isolated and impoverished urban and rural slums.

FACT:

Conservative estimates of the incidence of mental retardation in inner city neighborhoods begin at 7 percent.

FACT:

A child in a low income rural or urban family is 15 times more likely to be diagnosed as retarded than is a child from a higher income family.

FACT:

Forty-five percent of all women who have babies in public hospitals have received no prenatal care. Avoidable complications of pregnancy, which are often the harbingers of crippling conditions in children, soar in this group.

FACT:

Incidence of premature births (among whom neurological and physical disorders are 75 percent more frequent than in full-term babies) is almost 3 times as great among low income women as among other groups of women.

FACT:

The mortality rate of infants born to low income mothers is nearly double that of infants born to mothers in other income brackets.

FACT:

The children of low income families often arrive at school age with neither the experience nor the skills necessary for systematic learning. Many are found functionally retarded in language and in the ability to do the abstract thinking required to read, write and count. An appalling number of these children fall further behind with the passing of each school year.

FACT:

Students in the public schools of inner city low income areas have been found in numerous studies to be from 6 months to 3 years behind the national norm of achievement for their age and grade. About three times as many low income children as higher income children fail in school. The child whose father is an urban laborer has only one chance in 3,581,370 of being named a National Merit Scholar; but the child whose father has a professional or technical position has one chance in 12,672.

FACT:

The rate of Selective Service System rejections for intellectual underachievement is 23 percent nationally and soars to 60 percent and more among groups whose members are largely from low income areas.

Mounting evidence is pointing to an intimate relationship between diet and mental and nervous disorders. Low incomes, economic stagnation, high rates of malnutrition and high incidence of disease, health problems and mental retardation are all found together in the nation's poverty neighborhoods, and even though they cannot yet be directly linked, more than coincidence is obviously at work.

To those of us with responsibility to advise on measures to combat mental retardation, the meaning of the known and apparent facts is clear: the conditions of life in poverty—whether in an urban ghetto, the hollows of Appalachia, a prairie shacktown or on an Indian reservation—cause and nurture mental retardation. We believe that attack on the fester points of poverty will also hit the causes of retardation in the nation's rural and urban slums.





We therefore support and urge all speed in the war on poverty at all levels, by both the public and private sectors of American life. Within that framework, and with a focus on preventing mental retardation as well as other handicaps, we make the following specific recommendations.

1. Since mental handicaps afflicting millions of Americans stem from neglect, deprivation and lack of stimulation during infancy and early childhood, we recommend that all service agencies, both public and private, act now to make health and education services available as the right of every American child from birth.

The need for such action presents itself in every

part of our communities. It has reached crisis stage in the nation's low income areas.

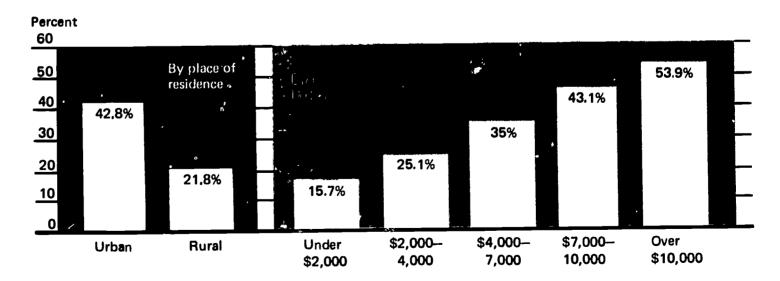
We recommend passage and full funding of the maternal and child health legislation which you, President Johnson, proposed in your 1968 State of the Union Address to assure prenatal care to mothers and first-year medical care to children in disadvantaged areas.

We also urge all necessary steps to assure systematic attention to the medical screening, health care and developmental education of children prior to school-entry age. In the absence of such attention today, nearly irreversible perceptual and learning handicaps become deeply rooted in great numbers of children.

We recommend that the needed services be made available in urban and suburban areas through community and neighborhood health and education centers located for convenient access by all. These centers would initially furnish three kinds of services:

- A. Preventive health care and systematic screening for health and developmental handicaps in children from birth to school-entry age; prenatal care and counseling for pregnant women.
- B. Early developmental education beginning in the child's first year.
- C. Day care for all children who need it, with the aim as in Project Head Start of promoting mental and social development from infancy onward and aiding parents to encourage each child's growth as an individual.

CHILDREN UNDER AGE 17 WHO HAD ROUTINE PHYSICAL EXAMINATION DURING A 12-MONTH PERIOD, 1962-63



Mental retardation and other handicapping conditions are often—found through physical examination in childhood, but the isolated rural child and the child in the impoverished family is likely to miss examination. Handicapping conditions will therefore go undetected. 13



These centers would be financed cooperatively by the federal government, states and localities.

We do not minimize the great practical problems involved, but we believe that a network of centers in the highest-need areas can be started quickly. First requirement is a wholehearted commitment by community leaders, public and private agencies, professional groups and civic organizations to provide health and education services to infants and children as a first-priority investment in the nation's long-term health.

Representatives of the population living in the area to be served should be involved in the planning and leadership of each center so that the program meets area needs and continues to do so.

2. The problems of the handicapped in rural America urgently require special attention.

In our preoccupation with urban needs and problems, we have overlooked a crisis in rural health, social service and education that has been steadily growing more acute. This crisis was documented recently in the report of the President's National Advisory Commission on Rural Poverty, The People Left Behind.

The basic fact is that people in most rural areas are too few, too scattered and often too poor to support adequate services.

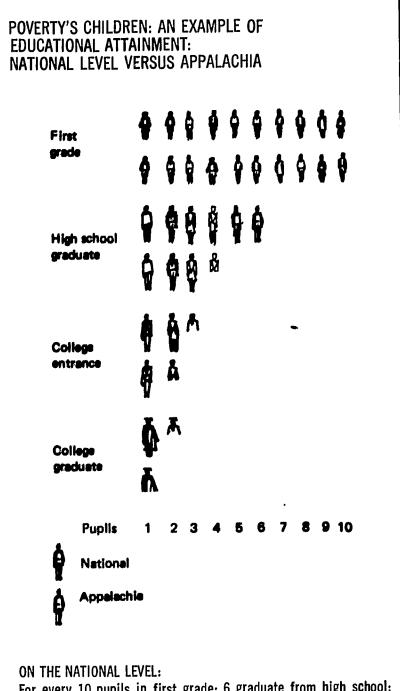
Thir problem needs to be attacked on a regional basis. As in the cities, existing resources should be brought together and applied.

We recommend that county governments, school districts, public health districts, medical and other professional societies and voluntary organizations (including such major rural forces as the American Farm Bureau Federation, the National Farmer's Union, the National Grange and other groups) pool their resources to plan regional health, special education and social service facilities and programs that can handle the unique problems of specific rural areas through a combination of fixed-facility and mobile services.

State and federal resources should be applied on a supplementary basis to assure adequate facilities and services in areas unable to finance or maintain them entirely.

We suggest that the United States Department of Agriculture's Extension Service, the Partnership for Health Program and the Comprehensive Rehabilitation Planning Program take leadership in promoting and coordinating the development of these regional programs. The population of each region to be





For every 10 pupils in first grade: 6 graduate from high school; more than 2 go to college; more than 1 finishes college.

BUT IN APPALACHIA:

For every 10 pupils in first grade: fewer than 4 graduate from high school; just over 1 goes on to college; fewer than 1 finishes college. Sources: Inside backcover





served should be represented in planning and operational groups.

3. The soaring incidence of mental retardation in the nation's disadvantaged areas calls for continued and intensified programs of education and rehabilitation for all persons whose skills and self-reliance could be improved.

We recommend, therefore, that federal assistance to state and local educational agencies for programs of education and rehabilitation serving those areas at all age levels be increased and significantly expanded.

4. The continuing national shortage of health, education and social service specialists makes the development of large numbers of supportive workers as "expanders" of specialists' efforts a crucial need.

We therefore urge that public and private agencies aggressively promote and develop career planning and opportunity in supportive health, educational and social services as an aid in supplying trained manpower for low income area programs, including those for the mentally retarded. Agencies' promotion of these opportunities should support adequate remuneration, on-the-job training activities and chances for advancement and

promotion as part of supportive service occupation planning.

Potential supportive manpower resources abound in the low income areas themselves. These resources should be tapped to the fullest possible extent.

As part of this effort, we urge agencies and private industry to devise and conduct work training programs through which low income area residents can conveniently acquire the skills to work in supportive service positions. U.S. Department of Labor, Department of Health, Education, and Welfare and Office of Economic Opportunity grants should be available to assist in the development of these programs.

Built into the training programs should be services that will help make it possible for interested persons to be trained. Temporary child care, for example, should be furnished.

We also urge the formation of a community living service modeled on the U.S. Agricultural Extension Service.

The job of this service would be to recruit, train, assign and supervise highly skilled men and women in instruction and demonstration activities in homemaker, community hygiene and personal health skills in low income neighborhoods. A significant propor-

tion of the service members should be from low income areas.

We suggest that the service be established as a federal government program so that uniform national standards and a pride in nationwide membership can be attained.

In addition, existing supplementary manpower programs that bring special groups into work with the handicapped should be expanded. Among these are the Student Work Experience and Training (SWEAT), the Foster Grandparent, and the Volunteers in Service to America (VISTA) programs. These low-budget projects have produced spectacular results both for those served and for their participants.

5. To help free young minds from the shackles of poverty and futility, we urge the nation's voluntary and service organizations for children, youth, students and young adults to come to the aid of young people in low income areas, both urban and rural.

Youth membership organizations such as the Boy Scouts and Girl Scouts, Campfire Girls, 4-H, Future Homemakers, Future Teachers, Future Farmers and religious youth groups might seek massive increase in members in low income neighborhoods. Leaders from those neighborhoods could be trained in hurry-up courses and modifications in membership qualifications and fees made as necessary to increase participation.

Volunteer service organizations for youth such as the newly formed and promising youth arm of the National Association for Retarded Children, Red Cross Youth and the various hospital youth auxiliaries could make major expansion of their activities into low income areas. These groups could make an especially critically needed contribution by furnishing the trained volunteer aides needed in neighborhood health and social welfare agencies, public health clinics, schools, day care centers and Head Start programs.

Such organizations should aggressively seek to involve civic and service organizations as co-sponsors



SUB-EMPLOYMENT RATE FOR SLUM SECTIONS FOR EIGHT METROPOLITAN AREAS

Mission-Fillmore
BedfordStuyvesant
New York
Harlem
East Harlem
Philadelphia
North Pa.
St. Louis
North side
Phoenix-Salt
River bed area

New Orleans sev. Contiguous areas San Antonio East & West side

Boston Roxbury area San Francisco 0 10 20 30 40 50
Percent of total number who are or should be workers

(Subemployment includes unemployment, underemployment and subminimum earnings.)
One out of every three slum residents who was already a worker, or who should and could become a worker with suitable help, was either jobless or not earning enough for living above the poverty level. The mentally retarded make up a significant proportion of the slum population, as demonstrated by the map on page 18. The mentally retarded are therefore strongly affected by such conditions as sub-employment and unemployment.¹⁵





in these activities, especially to assure that such program needs as volunteers' transportation, needed uniforms and meals are furnished.

We also suggest that the voluntary service organizations for youth redouble their efforts to recruit low income area young people into community volunteer work, and that these organizations further work with the schools to develop a system through which junior and senior high school students could receive educational credit for volunteer service in the community.

6. A key factor in the futility of life in poverty is the accumulation of mischance and unwanted event.

One of the points at which the treadmill of futility can be stopped is in helping low income men and women plan the size of their families.

We recommend that family planning services and voluntary birth control assistance be made available through poverty area and other community agencies to help lower the alarmingly high rates of unwanted children and infant mortality in low income areas. We support your 1968 Health Message proposals on this subject.

We also recommend that the nation's schools promptly develop and offer a top quality program of instruction, beginning in the early elementary grades, in human biology and education for parenthood.

Over-all goal of this instruction would be to raise the quality of child and family life as well as arm young people with mature views of their future roles as responsible individuals, parents and heads of families.

7. Among the most difficult problems facing U.S. communities today are the elimination of slums, the design and construction of attractive low cost housing, and the planning and delivery of community health. education and social services.

We recommend that responses to the needs of the mentally retarded be incorporated in model cities and other programs that seek to improve present communities and design the communities of the future.

We also recommend that labor, industry and commerce be involved on a larger scale in the development and redevelopment of our communities to assure adequate standards of living and community human services for all citizens.

8. Ninety-five percent of the existing community facilities for the mentally retarded constructed under Public Law 88-164, Part C, are located in middle income neighborhoods.

We recommend that Congress amend P.L. 88-164, Part C, to give the Secretary of Health, Education, and Welfare authority to see that the facilities are located for best service to all of a given community's mentally retarded.

Requirements for matching funds should be made more flexible so they can be related to a community's average income or ever eliminated in very deprived areas.

9. Results are now beginning to come in from early childhood research and education programs being conducted throughout the country by universities, foundations and research laboratories. Without exception, their findings are the bildhood programs can have long-term effect and any mental retardation linked to environment at the second s

We therefore recommend intensification of research in the social and other behavioral sciences with the aim of isolating and defining the so-far unidentified social, environmental and cultural factors that cause or contribute to mental retardation.

10. Not all of the answers needed about the bonds between deprivation and retardation can be found through studies of human beings, however.

There is in existence a national network of centers developed for the purpose of man-related research which cannot be carried out in studies directly involving human beings. We recommend that this network, the regional primate research centers, undertake major inquiries into the relationship to mental development of nutrition, infant stimulation, success-failure patterns and similar topics.



Mr. President:

DURING the coming year we shall continue our studies of the three critical program need areas on which we have made recommendations in this report: residential care for the retarded, manpower development and use in mental retardation programs, and the mentally retarded victims of poverty and deprivation.

We expect to have further recommendations in these areas as our studies of programs, needs and trends progress.

We plan also to launch a major inquiry into the area of education for the mentally retarded.

In addition, you will be receiving special reports and papers on progress and needs in research on mental retardation and on a national information center. The latter is planned to bring together research and program information in the mental retardation field and to make that information conveniently and uniformly available to researchers and program planners nationwide.

Also directed to your attention will be a comprehensive monograph on the history, development, status and needs in residential care of the retarded. This monograph is the chief supporting document for the recommendations on residential care made in this report.

We will report to you from time to time on progress in several continuing studies.

One of these studies is attempting to define the economic impact and cost of mental retardation. The aim of this study is to develop a body of economic information through which cost factors in mental retardation may be established for the guidance of agency planners, valid cost comparisons made, and viable program projections made.

Another study is developing guidelines for the use of model cities planners in incorporating designs for mentally retarded persons living and working in communities of the future.

All of these areas were identified in our 1967 report as having critical needs. Our work during the past year has carried forward from general de-



scription of those major need areas into the deep and detailed studies whose outcomes are reported in these pages or will reach you in later papers.

This 1968 report, as did its predecessor, suggests actions to combat mental retardation that can and should be taken at all levels of the nation by both public and private agencies. Retardation is a problem that can strike any family in the nation. Every individual, every agency can help to do something effective about the problem. Our fundamental belief is that the nation's ultimate success in the attack on mental retardation will be won by a broad cooperative effort in which professional specialists and citizen volunteers work together to combat retardation and its causes through programs in health, education, rehabilitation, community planning and organization, social service and research.

The field of mental retardation, with your steady support, President Johnson, has crossed the threshold of major change and advance. Some ways to foster growth and learning in even the most severely retarded have been found. The human cell's secrets of programming for the unborn are being pried out. The most critical period for learning has been found to be years before the time when formal education of children begins. Developing successful instruction for the retarded has enabled us to discover steps in the learning process that were unsuspected before. And analysis of work and work patterns in order to train retarded workers has shown that these workers can do more than previously thought and that the elements of even complex jobs can often be rearranged for effective performance by retarded workers.

It is crucial, therefore, that the momentum of interest and action developed in the problem of mental retardation in this decade be held and intensified.

We are grateful, Mr. President, for your continued personal inspiration and guidance to us and to the many others who are working on behalf of the retarded. The support of your Office is a key force in helping the nation bring on the new day when most mental retardation can be prevented and the remaining retarded individuals can be helped to be contributors to the common good.





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THE COMMITTEE IS GRATEFUL TO THE MANY INDIVIDUALS IN GOVERNMENT AT ALL LEVELS, IN THE VOLUNTARY ORGANIZATIONS AND IN PRIVATE LIFE WHO HAVE GIVEN THEIR INVALUABLE ASSISTANCE DURING THE PAST YEAR.