REPORT TO THE PRESIDENT

A PROPOSED PROGRAM FOR

National Action to Combat Mental Retardation

THE PRESIDENT'S PANEL ON MENTAL RETARDATION
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WASHINGTON 25, D.C.

October 16, 1962

Dear Mr. President:

I have the honor to submit herewith the Report of the President's Panel on Mental Retardation. The Panel was appointed by you on October 17, 1961, with the mandate to prepare on or before December 31, 1962, a "National Plan to Combat Mental Retardation." We have devoted the intervening months to carrying out this assignment and have prepared for your consideration recommendations concerning research and manpower, treatment and care, education and preparation for employment, legal protection and development of Federal, State and local programs.

The Panel gratefully acknowledges the cooperation of Federal and State officials and literally thousands of persons in every State who have responded enthusiastically to your leadership in bringing the needs of the retarded to the attention of the country. Members of the Panel appreciate the opportunity afforded them to be of service in this undertaking.

Respectfully yours,

Leonard W. Mayo
Chairman

The President The
White House Washington
25, D.C.

PRESIDENT'S PANEL ON MENTAL RETARDATION

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Section I

INTRODUCTION

The mentally retarded are children and adults who, as a result of inadequately developed intelligence, are significantly impaired in their ability to learn and to adapt to the demands of society. An estimated 3 percent of the population, or 5.4 million children and adults in the United States, are afflicted, some severely, most only mildly. Assuming this rate of prevalence, an estimated 126,000 babies born each year will be regarded as mentally retarded at some time in their lives.

Significance of the Problem

Mental retardation ranks as a major national health, social, and economic problem:

—It afflicts twice as many individuals as blindness, polio, cerebral palsy, and rheumatic heart disease, combined. Only 4 significant disabling conditions—mental illness, cardiac disease, arthritis, and cancer—have a higher prevalence, but they tend to come late in life while mental retardation comes early.

—About 400,000 of the persons affected are so retarded that they require constant care or supervision, or are severely limited in their ability to care for themselves and to engage in productive work; the remaining 5 million are individuals with mild disabilities.

—Over 200,000 adults and children, largely from the severe and profound mentally retarded groups, are cared for in residential institutions, mostly at public expense. States and localities spend $300 million a year in capital and operating expenses for their care. In addition, they spend perhaps $250 million for special education, welfare, rehabilitation, and other benefits and services for retarded individuals outside of public institutions. In the current fiscal year, the Federal Government will obligate an estimated $164 million for the mentally retarded, about three-fourths for income maintenance payments and the rest for research, training, and special services. Federal funds for this group have nearly doubled in 5 years.

-The Nation is denied several billion dollars of economic output because of the underachievement, underproduction, and/or the complete incapability of the mentally retarded.

-The untold human anguish and loss of happiness and well-being which result from mental retardation blight the future of millions of families in the United States. An estimated 15 to 20 million people live in families in which there is a mentally retarded individual. Economic costs cannot compare with the misery and frustration and realization that one's child will be incapable of living a normal life or fully contributing to the well-being of himself and to society in later life.

The Impact of Mental Retardation on the Public

Mental retardation does not respect station in life or geography. It may afflict the children of the rich or of the poor, in any part of the country. Yet there are extremely striking variations in its incidence by socioeconomic groups and by geographic areas which often mirror such differences. From the growing body of research information on mental retardation, the following points stand out:

—The more severe cases of mental retardation are likely to be associated with organic defects. However, in mild retardation, which constitutes the great bulk of the cases, specific physical or neurological defects are usually not diagnosable with present biomedical techniques.

—The occurrence of severely retarded children tends to be spread more evenly throughout the population regardless of the socioeconomic class of the family. The prevalence of children who are mildly retarded is heavily concentrated among the parents with poor education and low incomes.

- Selective Service statistics reveal an extremely wide variation geographically in the prevalence of mental retardation. During World War II, 716,000, or 4 percent, of the persons examined were rejected on grounds of "mental deficiency". The percentage rejected for this cause ranged from only one-half of 1 percent in some States to nearly 14 percent in others. Regional rejection rates ranged from 1 percent in the Far West to nearly 10 percent in the Southeast. Nationwide, 7 individuals were rejected for mental retardation for every 10 turned down for mental disease.
- The Selective Service statistics also show a much heavier prevalence of mental retardation among nonwhites than in the rest of the population. Draft rejection rates because of mental deficiency were 6 times as high for nonwhites as they were for whites. Of the total rejections of 716,000 for mental deficiency, 325,000 were nonwhites. In both categories there were substantial regional variations in the rejection rates. Among the whites, the rejections in the Southwest were 6 times as high for this cause as in the Far West. Among nonwhites, rejections in the Southwest were 4 times as high as in the Northwest. However, in every region the rejection rate for nonwhites was at least 3 times as high as that for whites; but the highest regional rejection rates for whites exceeded the lowest regional rejection rates for nonwhites. Modern science has indicated that such variations are due to lack of opportunity rather than hereditary or mental endowment.
- Data from a representative nationwide statistical sample on the basis of which the Stanford-Binet Intelligence Tests were standardized in 1937 confirm the geographic variations in intelligence. In addition, they highlight a significant variation in intelligence according to the socioeconomic level of the families. For example, children of fathers who were day laborers had a mean IQ of 93.6, while children of professionally employed fathers had an average IQ of 116.2. These tests also show an inverse relationship

between degrees of economic and social well-being and the rated intelligence in the intermediate ranges of vocations.

—Strikingly high concentrations of mental retardation in specific sections of metropolitan communities also point to a strong correlation between economic status and intellectual development. A 1952 study in Chicago, for instance, showed that 65 percent of the pupils in special classes for the retarded came from 11 slum-ridden areas out of the 75 areas comprising the metropolitan community. In these 11 communities, the rate of referral for mental retardation among school-age children ranged from 10 to 30 percent. However, children too severely mentally retarded for school were fairly evenly distributed throughout the entire city.

—Prevalence of mental retardation tends to be heavily associated with lack of prenatal care, prematurity, and high infant death rates. Women who do not have prenatal care are approximately three times as likely to give birth to premature babies as are women who receive adequate prenatal care, and very small premature babies are about 10 times more likely to be mentally retarded than are children of normal births. The study in Chicago'showed that infant mortality rates in the slum areas during the 2d through the 12th month of life were 3 times the rates in the best socioeconomic areas. In the United States in 1960, the infant mortality rate averaged 26 per 1,000 live births, but the State with the poorest record had a rate of 41.6, twice the rate of 19.6 in the State with the best record.

The Nature, the Causes, and the Effects of Mental Retardation

The term "mental retardation" is a simple designation for a group of complex phenomena stemming from many different causes, but one key common characteristic found in all cases is inadequately developed intelligence. Many synonyms for the term "mental retardation" have been used in the part and are still in use. They include amentia, feeblemindedness, mental deficiency, mental Subnormality, imbecility, and moronity.

Because mental retardation is a relative concept depending on the prevailing educational and cultural standards, there is no completely satisfactory measure for mental retardation. Current scientific usage favors groupings based on the intelligence quotient (IQ) and adaptive behavior of the person. Four groupings are commonly used—profound, severe, moderate, and mild. They range from the situation where evidence of human adaptation is almost totally absent to that where the degree of impairment is minimal and the difference from normality almost indistinct.

As designated under the 4 categories based on intelligence quotient, those individuals who are considered profoundly retarded (IQ usually below 20) and those designated as severely retarded (IQ from about 20 to 35) need constant care or supervision throughout their lives if they are to survive. In these groups are the anencephalics, human beings without cerebral cortexes, and the more seriously impaired Mongoloids. There are an estimated 60,000 to 90,000 persons, mostly children and adolescents, who are profoundly or severely retarded. It is estimated that 1 child out of every 1,000 born, or somewhat over 4,000 births a year, falls in these 2 groups.

The moderately retarded persons (IQ usually 35 to 50), of whom 300,000 to 350,000 individuals are so classified, are capable of developing self-protection skills and mastering limited skills for semiproductive effort so they can contribute partially to their self-support if given an adequately protected environment. An estimated 3 children per 1,000 births will become moderately retarded, unlikely to progress beyond a mental age of 7 years even in adulthood.

Finally, the mildly retarded (IQ usually 50 to 70, but sometimes including those of slightly higher IQ), comprising the largest group of approximately 5 million retarded persons, are usually not distinguishable from normal individuals until school age when they are often identified by an inability to learn general school subjects. Without special attention, they often become the problem members of our society, capable only of a marginal productive role. They are the workers who are the most frequently displaced by the economic adjustments in our competitive society. However, given timely supervision, guidance, and training early enough in life, many will be capable of complete assimilation into our society. Minimally retarded persons are more nearly comparable to the nonretarded than they are to the most profoundly retarded. It is estimated that about 26 out of every 1,000 children born will be mildly retarded at some time in their lives.

The manifestation of mental retardation varies significantly among different age groups and also among different types of retardation. Only a small proportion of infants is identified as mentally retarded, because only gross defects are apparent and intellectual deficits which may show up later in life are not yet obvious. Many of the causative physical and environmental factors have not as yet had a chance to adversely affect the infant. By far the heaviest prevalence comes during the school age when more exacting requirements of behavior and intellectual performance are imposed. Some surveys of school population have shown that in the age group of 10 to 14, as high as 8 to 10 percent of the children appear to be mentally retarded. Then as these retarded individuals approach adulthood there is a tendency for many of them to be assimilated into the population and the differences to disappear. This helps explain why studies have found varying rates of retardation, ranging to as low as 1 percent of the population. The age-group figures cited are only rough estimates because there are no authoritative survey statistics available.

The key to prevention and correction of mental retardation is an adequate understanding of its causes. Medical and social sciences have made a substantial beginning in this direction. Within the past decade several previously unknown causes have been identified and means for their prevention have been discovered. Rapidly growing interest in the problem of mental retardation is producing a growing accumulation of data on the general conditions with which mental retardation is associated, even though the specific causes may not yet be fully evident. But much of the long road to full understanding of the complex phenomena involved lies ahead and indeed is not clearly defined as to the directions it may lead.

With present knowledge regarding the causal factors in mental retardation, it is possible to identify precise causes in approximately 15 to 25 percent of the cases. In such cases organic pathology as a result of disease or injuries is often demonstrable, most readily in instances where the degree of retardation is severe and there has been gross brain damage. There are a great many diseases and conditions which affect the brain and result in retardation, including infections or poisons in the mother's system during pregnancy, infection of the central nervous system during infancy, injuries to the brain at birth, head injuries in childhood, metabolic disorders determined by heredity, and abnormal brain growths.

Where specific causes have been ascertained, in many instances it has been possible to devise effective preventive action. Familiar examples include German measles in the first 3 months of pregnancy, RH blood factor incompatability in new-born infants, lead poisoning, and dietary changes to overcome faulty body chemistry in such diseases as phenylketonuria and galactosemia.

Nevertheless, despite the recent progress made by medical science in identifying causes and developing preventive action for these specific causes, the hard fact is that the dramatic results flowing from new knowledge as yet apply only to part of the cases which can be specifically diagnosed and to only a small fraction of the total causes of mental retardation. For example, although medical science is now successful in averting brain damage in mental retardation due to RH blood factor incompatibility in practically all instances, the effect on the total situation is comparatively small because this cause accounted for about only 1 percent of the new admissions to institutions for the retarded. Phenylketonuria likewise accounts for only 1 of every 750 retarded, and galactosemia even less.

As matters stand, in from 75 percent to 85 percent of the cases of mental retardation, it is not yet possible to ascribe a specific diagnosis. This large group consists in the main of mildly retarded persons who show no gross abnormality of the brain.

But even here energetic research from many directions is casting light into the deep shadows. This research, from epidemiological surveys and other sources, strongly suggests that a variety of complex and interrelated factors in this category are definitely associated with the prevalance of mental retardation. It seems reasonable to believe that some members in this group are affect by operation of genetic and hereditary factors which are not clearly identifiable or understood. Similarly, a significant for biomedical causes is suggested by data which show clear that children born of mothers without prenatal care have incidence of retardation many times greater than children with proper maternal care. For example, a variety of unfamiliar able health factors, including lack of prenatal care, poor tion, deficient postnatal care, and similar unfavorable fact may produce damage to the brain or to the body which can be generally measured with present techniques but which constitute a drag on physical and neurological development Clearly, however, the incidence of mental retardation is hea\ correlated with a lack of proper maternal and perinatal health care, which in turn is closely associated with the unfavored socioeconomic status of families or whole neighborhoods groups in the population.

The majority of the mentally retarded are the children of the more disadvantaged classes of our society. This extraordinar heavy prevalance in certain deprived population groups suggest a major causative role, in some way not yet fully delineated, for adverse social, economic, and cultural factors. These condition may not only mean absence of the physical necessities of life, the lack of opportunity and of motivation. A number of experiments with the education of presumably retarded children from slum neighborhoods strongly suggest that a predominant cause of mental retardation may be the lack of learning opportunities or absence of "intellectual vitamins" under these adverse environmental conditions. Deprivation in childhood of opportunities for learning intellectual skills, childhood emotional disorder which interfere with learning, or obscure motivational factor appear somehow to stunt young people intellectually during their developmental period. Whether the causes of retardation in a specific individual may turn out to be biomedical or environ mental in character, there is highly suggestive evidence that the root causes of a great part of the problem of mental retardation are to be found in bad social and economic conditions as the) affect individuals and families, and that correction of these fundamental conditions is necessary to prevent mental retardation successfully on a truly significant scale.

Whatever the causes, the failure of mentally retarded individuals to adjust successfully to social and economic conditions of our society constitutes a severe and growing handicap for the individual, for his family, and for the society. Moreover, as our competitive society becomes more complex and fast moving, the demands for intellectual capacity and for adaptability increase. Thus in an age of automation, individuals with minimal skills and abilities become doubly handicapped. Not only do they face an increasingly competitive society, but, hampered as they are, they must keep pace with people of increasingly higher capacities. Thus they become more easily submerged by the vicissitudes which others can surmount.

The Prevention, Treatment, and Amelioration of Mental Retardation

From the available evidence on the prevalence and the causes of mental retardation, the Panel believes that the broad outlines and the directions in which action is needed can be determined with substantial assurance.

In the light of preceding discussion, a program of action must take account of the following facts: mental retardation is a complex phenomenon stemming from multiple causes. Many of the specific causes are known and can be prevented or their results can be treated. These are largely in the biomedical area.

For the great bulk of mental retardation cases, however, a specific cause cannot yet be ascribed with present knowledge. But epidemiological data from many reliable studies show a remarkably heavy correlation between the incidence of mental retardation, particularly in its milder manifestations, and the adverse social, economic, and cultural status of families and groups of our population. These are for the most part the low income groups—who often live in the slums and are frequently minority groups—where the mother and the children receive inadequate medical care, where family breakdown is common, where individuals are without motivation and opportunity and without adequate education. In short, the conditions which spawn many other health and social problems are to a large extent the same ones which generate the problem of mental retardation. To be successful in preventing mental retardation on a large scale, a broad attack on the fundamental adverse conditions will be necessary.

Another significant consideration in developing action programs is the lifelong character of mental retardation. Unlike other major afflictions, such as cancer or heart disease, which often come relatively late in life, mental retardation typical] appears in childhood and always before adulthood. And once incurred, it is essentially a permanent handicap, at least at the present stage of biomedical knowledge. In this light prevention—always desirable where illness is concerned—assumes an even higher priority both in terms of the standpoint of general community measures and also of measures which the individual should take.

Still a third consideration looms large. Unfortunately we do not yet know the causes or the means of preventing but a fraction of mental retardation cases through biomedical means. Prevention of the great bulk of mental retardation cases will require measures to eliminate causative factors embedded in our social, economic, and cultural environment, and this will obviously take time. For many years we will still have the retarded with us and we will have to provide care and rehabilitation for them—care which must contain an increasing component of restorative services.

From these basic considerations the fundamental strategy of our battle against mental retardation takes shape. Because its causes are complex, our attack will have to be "broad spectrum" in character. We must act on many fronts, not only against the specific cause of mental retardation but against the root problems in the social, economic, and cultural environment which nourish the specific causes and seem to have a major and direct causative influence of their own.

Essentially this means that our society will have to allocate more resources to basic services to the youth of the land—for health, for education and training, for community reconstruction and renewal, and for improved employment and social services. In these efforts we must particularly strive to improve opportunities and services for distressed groups in the population.

Our campaign will be costly, but we cannot afford inaction. On economic grounds alone, the costs of caring for mentally retarded persons in institutions are 3 or 4 times the cost of rearing and educating normal children. Moreover, improvements in opportunities and services for our youth are likely to have beneficial effects for solving other pressing social problems. The same preventive measures which strike at the basic causes of mental retardation will also help to overcome other problems such as juvenile delinquency, mental illness, and general poor health and lack of fitness. For example, maternal health measures which avert the birth of mentally retarded children will also pay dividends in improving the general health of mothers and children. Educational opportunities which prevent mental retardation from setting in will also be useful in preventing school dropouts or combating juvenile delinquency. Thus such basic preventive measures are not only likely to be less costly in the end than the treatment and care of the retarded, but they assume a larger importance because of the other desirable benefits that flow from them.

Many new social measures have been spurred by Government action and private initiative during this century. They include numerous diverse and useful actions, including minimum wage laws, public health measures, improved educational services, and social security insurance programs, which help to alleviate the economic burden of care for the dependent. Many of these measures have a preventive effect on the conditions which engender mental retardation, while others help provide the services or the financial support for which the mentally retarded benefit along with other people in the community. The continued existence of mental retardation on a vast scale, however, indicates that our society is still far from its goal of providing the essential conditions for normal healthy physical and intellectual development for this large segment of our children and youth. In this connection, it is significant that while Federal expenditures from budget and trust accounts for benefits and services for the aged are now on the order of $15 or $16 billion per year, the corresponding expenditures for children and youth are $4 $5 billion.

The National Action Program To Combat Mental Retardation

The Panel therefore urges high-priority consideration of necessary measures to improve and strengthen the health, the educational, and the social and community services for the you of our land, particularly in instances where large concentration of economically and culturally deprived families live. This a sound and necessary course of action, not just because services would directly benefit the mentally retarded, but because this is the only way which holds reasonable promise of preventir a large part of mental retardation from arising in the first in-stance. Increased outlays for the proper development of out human resources by giving all our children and youth a goo start in life would represent a high-return investment which would pay dividends throughout the rest of their lives.

To attack a problem as pervasive and intertwined with fundamental social conditions as mental retardation, we must thin and plan boldly. If, as it is apparent, the inadequate medics services available to large segments of our population during pregnancy and childhood play an important role in causing mental retardation, then we must remedy the basic situation of inadequate medical care. At a time when the infant mortality of some countries is reaching a new low, the infant mortality rate in the United States has leveled off at a relatively high rate. For example, it is now two-thirds higher than that of Sweden.

Likewise, we must have enough classrooms and teachers for all our students in order to provide adequate educational services to the mentally retarded. Although we have made excellent progress in providing increases in special educational facilities for the retarded, the shortages of classrooms and of teachers which are evident in education generally are even more aggravated in this area.

In addition to taking vigorous national action to improve the general programs, we must recognize that the mentally retarded who are in our population represent a group with extraordinary needs. Society's special responsibility to persons with extraordinary needs including the retarded is (1) to permit and actually foster the development of their maximum capacity and thus bring them as close to the main stream of independence and "normalcy" as possible; and (2) to provide some accommodation or adjustment in our society for those disabilities which cannot be overcome.

In the first of these two categories are such services as health care, guidance, special education, vocational rehabilitation, and the like, directed to groups especially prone to mental retardation or who are afflicted by it. Nowhere in our society are there more opportunities for constructive and useful innovation than in the development of improved techniques, better services, and improved institutional arrangements for the effective integration of such handicapped individuals into a self-reliant, productive, and happy life in our society.

The second part of the task concerns the provision of adequate and improved facilities for the care of the retarded individuals who must be maintained in institutions. Here, too, a positive and hopeful emphasis is possible and necessary, because improved methods and effective techniques can contribute immensely not only to the welfare of retarded persons as individuals but also can help them become at least partially self-maintaining.

Underlying effective action on all these fronts as they relate to retardation, there is the need for increased and more exact knowledge regarding the causes of retardation and the methods of prevention and care. More research support and capacity is therefore necessary not only specifically with respect to the mentally retarded but in the basic areas of health, learning processes, and other fundamental human processes which will apply to all people alike. The gaining of new fundamental knowledge can benefit not only the U.S. citizenry but all of mankind.

Thus, considering the problem of the mentally retarded in its broadest aspects, the Panel has addressed itself to both sides of the equation: (1) the necessary improvement of basic services to all people, and (2) to improved specific services to the mentally retarded. The Panel recognizes that extreme shortages c trained personnel and of funds will not make it possible to increase services and facilities greatly overnight. We must plan our campaign to combat mental retardation not for just next month or next year, but for the next decade. And we must move ahead vigorously and imaginatively. In this context, the main recommendations of the report are directed to—

1. *Research* in the causes of retardation and in method of care, rehabilitation, and learning.

2. *Preventive health measures* including *(a)* a greatly strengthened program of maternal and infant care directed first at the centers of population where prematurity and the rate of "damaged" children are high; *(b)* protection against such known hazards to pregnancy as radiation and harmful drugs; and *(c)* extended diagnostic and screening services

3. *Strengthened educational programs generally and extended and enriched programs of special education* in public and private schools closely coordinated with vocational guidance, vocational rehabilitation, and specific training and preparation for employment; education for the adult mentally retarded, and workshops geared to their needs.

4. *More comprehensive and improved clinical and social services.*

5. *Improved methods and facilities for care,* with emphasis on the home and the development of a wide range of local community facilities.

6. *A new legal, as well as social, concept of the retarded,* including protection of their civil rights: life guardianship provisions when needed; an enlightened attitude on the part of the law and the courts; and clarification of the theory of responsibility in criminal acts.

7. *Helping overcome the serious problems of manpower* as they affect the entire field of science and every type of service through extended programs of recruiting with fellowships, and increased opportunities for graduate students,

and those preparing for the professions to observe and learn at firsthand about the phenomenon of retardation. Because there will never be a fully adequate supply of personnel in this field and for other cogent reasons, the Panel has emphasized the need for more volunteers in health, recreation, and welfare activities, and for a domestic Peace Corps to stimulate voluntary service.

8. *Programs of education and information to increase public awareness* of the problem of mental retardation. In addition to a strong emphasis on *research* and *prevention*, the report recommends—

1. That programs for the retarded, including modern day care, recreation, residential services, and ample educational and vocational opportunities, be *comprehensive.*
2. That they operate in or close to the communities where the retarded live—that is, that they be *community centered.*
3. That services be so organized as to provide a central or fixed point for the guidance, assistance, and protection of retarded persons if and when needed, and to assure a sufficient array or *continuum* of services to meet different types of need.
4. That private agencies as well as public agencies at the local, State, and Federal level continue to provide resources and to increase them for this worthy purpose. While the Federal Government can assist, the principal responsibility for financing and improving services for the mentally retarded must continue to be borne by States and local communities.

One may well ask how these broad objectives for the retarded differ in kind or degree from desirable goals for others. They do not differ fundamentally, but the retarded do not presently receive either the attention or the services accorded to other groups with special needs. An effective way to achieve results beneficial to many is to seize the handle presented by an important segment of the population which has been neglected and lift that group to a higher level without losing sight of the needs of others. If, for example, research in learning is spurred by the urgent and specific needs of the retarded, the chances of gaining information of a generic nature applicable to all will most tainly be enhanced.

The Panel's Work and Its Report

In carrying out its mandate, the Panel has employed four m; methods of study and inquiry:

1. Task forces on specific subjects were appointed which all members of the Panel were assigned; special a visers were designated to work closely with them.
2. Public hearings were held in 7 major cities of the country to which public officials concerned with mental retardation, teachers, representatives of several professional parents, and others were invited not only to report on local and State programs and gaps in service but to make recommendations to the Panel.
3. Panel members and advisers visited England, Swedi and Denmark, Holland, and the Soviet Union to study methods of care and education of the retarded and to become acquainted with research in those countries.
4. A considerable body of literature and the results c recent studies were reviewed; and members of the Pan< visited and observed facilities and programs for the retarded in several States.

A report of this type must be regarded as only one step in a process. In this instance the "process" may be said to have started with a heightened activity within the American Association on Mental Deficiency dating from the close of World War II and the upsurge of interest among parents leading to the found ing of the National Association for Retarded Children. The support of the Congress and the subsequent emphasis on development of programs for the retarded in the Department of Health Education, and Welfare were additional steps of major importance.

In appointing the Panel on Mental Retardation, the President recognized the emergence of an idea "whose time had arrived" and gave impetus and visibility to a complex problem that had not yet been brought into the full view of the country.

The next steps beyond the submission of this report are, of course, the task of implementation, interpretation, and public education; and legislative activity and funding at the local, State, and Federal levels. Each of the several sections of the report presents some basic "State of the Nation" data and opinion as to the present status of the subject area under discussion, and makes both specific and general recommendations designed to fill in existing gaps, and to improve or extend an essential service or develop a new program. In each instance it is made clear where the responsibility for action lies, whether in the locality, in the State or Federal Government, with private agencies or in some combination of these, as is so often the case.

A *substantial number of problems discussed in the report* require further study and most of the recommendations call for a vigorous followup. Studies must be supported and a followup program set in motion but, in the meantime, we must go forward on the basis of past experience and with the tools at hand.

Robert Frost once defined wisdom as that quality which motivates man to act in spite of insufficient knowledge. We must move ahead in mental retardation, although we lack conclusive knowledge and all the tools we need; but we must continue to search, to learn, and to gain new insights if the decade ahead is to be one of steady progress and high achievement.

In acknowledging the cooperation of the personnel in the Department of Health, Education, and Welfare, the Panel wishes to record its appreciation of the progress made by the several agencies of the Department in developing programs of benefit to the mentally retarded. The staff and members of the National Association for Retarded Children and the American Association on Mental Deficiency have been untiring in their assistance to the Panel; State departments, private health and welfare agencies, professional organizations, parent groups, and countless individuals have cooperated both as private citizens and as formal advisers. All have contributed substantially to this enterprise and we are grateful to them. The knowledge that influential members of the Congress have had a long active interest in the field of mental retardation has been a soul of encouragement and inspiration to the Panel. Their lea< ship, moreover, has been a major factor in the constructive velopments that have taken place in the field to date.

Section II

RESEARCH AND SCIENTIFIC MANPOWER

In any consideration of research in mental retardation, we are inspired by the remarkable achievements of science and we are impelled by the poignant human and social losses that the problem itself induces. How can we accelerate research to illuminate the causes of this complex disorder and to create new and improved services and preventive measures? When the basic facts are known, we can define the most formidable social and medical challenges and then mobilize our resources more adequately to meet them. But at this stage we cannot mount the type of large-scale programs that were so effective in conquering malaria and polio; nor can we tackle research in mental retardation as we have the problem of nuclear armaments and the exploration of the solar system. Scientific discovery cannot be "programed" in the same way, and mental retardation is a phenomenon of such diversity and complexity that to impose a narrowly oriented plan of research upon it would be to stifle rather than encourage creativity and originality.

Probably the most creative advances in science have come from unpredictable insights, arising out of experience in basic investigations and clinical studies, and often from the junction of seemingly unrelated fields. Who would have guessed, for example, that studies on the chromosomes of wheat would lead directly to a better understanding of Mongolism? Or the metabolism of sugars by yeast to the recognition and treatment of galactosemia? Or the metamorphosis of tadpoles into frogs to knowledge of the pathogenesis of cretinism?

It is therefore essential to support the foundations of scientific research in all fields, and to stimulate the communication of both needs and solutions among investigators and clinicians working at every level and in all phases of the field, including education, treatment, and care of the retarded.

Because mental retardation is baffling, even in comparison with other scientific challenges, we must be aware of the following related facets of the problem: (1) mental retardation is not one, but many disorders; only a small fraction of the cases such as those of Mongolism, cretinism, phenylketonuria, and galactosemia, for example, are understood well enough to insure a meaningful diagnosis; (2) mental retardation, more than most phenomena, calls for knowledge from every branch of science; and (3) a deep understanding of it is dependent upon penetrating the most elusive secrets of the biological, social, and behavioral sciences, such as the development, structure, and functioning of the human brain, the complex process of learning, and of behavioral development, including the adaptation of the retarded to their enviroment.

We can point to many scientific enigmas whose resolution is patently needed for the ultimate solution of problems related to mental retardation; but it will be creative insight that will reveal new, unforeseen relationships between the fruits of basic research and their connection with the complex problem of mental retardation. The possibility of discerning a connection between the fruits of basic research and any clinical problem must depend to a considerable degree upon the investigator's knowledge of the problem itself and his interest in it. Hence, it is important that an adequate presentation of mental retardation in its several and different manifestations becomes an integral part of the education of students in appropriate university departments and professional schools.

This section mentions some obvious research challenges in mental retardation, and the report includes recommendations on prevention, treatment, and education. Progress in these areas is essential in view of the pressing problems of the retarded constantly facing the homes and communities of the Nation. These concerns, however, serve to accentuate our commitment to fundamental science, including an interest in fields seemingly distant from mental retardation itself. The further development of detailed suggestions to facilitate research in the biological and behavioral sciences should reflect the special outlook and experience of those acquainted with various aspects of the field.

It is not enough to accumulate new knowledge, for its effective application depends on communication and the dissemination of research information. Its recording, its retrieval, and especially its communication from one discipline to another, require more thoughtful and consistent attention, and a larger proportion of our resources than heretofore in view of the growing complexity of science. Improved communication is especially important in relation to a problem as pervasive as mental retardation, and warrants the special attention of the scientific community and the financial support of the public.

Research in this country has won the hard-earned support of the people and their representatives, and the mutual confidence that has developed between the scientist and the public is a vital factor in scientific progress. Any misunderstanding as to the relationship between basic research and its immediate application, such as pressures for quick and easy answers to complex problems, or moves to control research or determine its direction, will serve only to hamper rather than insure that freedom of inquiry recognized by both the scientist and the layman as essential to productive activity.

Since 1959, Federal funds for research on mental retardation have more than doubled, and in 1963 they will exceed $20 million. Beyond this are much larger sums for basic research. As this research effort broadens and deepens and as it attracts investigators in all applicable sciences, additional support will be needed from both public and private sources.

The Panel has developed recommendations in the field of research, which touch on the following major areas: (1) Federal leadership in research; (2) expanding the total research effort in the neural and behavioral sciences, including that which is specifically directed at mental retardation; (3) increasing the statistical information on the incidence, severity, and the sociocultural manifestations of mental retardation; (4) expanding the Federal support of research on the learning process; (5) better dissemination and application of the findings of research; and (6) increasing the supply of scientific manpower in this field.

Federal Leadership in Research

The Federal Government exercises its responsibility in research relating to the health aspects of mental retardation largely through the National Institutes of Health of the Department of Health, Education, and Welfare, by way of the intramural and extramural programs of those Institutes concerned with mental and neurological disorders. Over the past 20 years and especially in the last decade the Government has recognized its obligation to promote research related to the health of the people, and the Congress has appropriated substantial funds to carry out this mandate. Though substantial, these funds are not exorbitant in view of the magnitude of the problems; and they represent, as experience has shown, a prudent and profitable financial investment.

The Panel welcomes the establishment within the National Institutes of Health of a National Institute of Child Health and Human Development, and the elevation to institute status of the Division of General Medical Sciences.

The new Child Health Institute will provide a major focus for the conduct and support of research and research training in mental retardation, as well as the implementation of the other recommendations noted above. Complex factors which operate during the biological, psychological, and social development of the individual are central to the problem of mental retardation. The creation of the Institute of Child Health and Human Development will bring a new emphasis to the developmental sciences and facilitate an approach not only to mental retardation, but to other disorders. The new Institutes, recently approved by the Congress, will focus on studies of fetal, neonatal, infant and child development through all of the relevant disciplines, as well as on research concerning other aspects of human development.

The Division of General Medical Sciences has been a highly effective instrument in the National Institutes of Health in the development and support of basic and clinical research and training embracing several of the specialized fields. Many of the varied research and training activities of the National Institutes of Health, both extramural and intramural, are germane to mental retardation; for this reason the Panel has noted with satisfaction the elevation to Institute status of the Division of General Medical Sciences and believes it will be an aid to pertinent research in several fields and programs.

It is recommended that continuous evaluation of scientific personnel policies in Government be undertaken and that salary levels and career satisfactions commensurate with those in similar positions outside of Government be assured.

The development of new and expanded programs which this Panel has recommended and which will be essential in an effective attack upon the problem of mental retardation requires the most capable and effective leadership on the part of the several governmental agencies responsible. The recruitment, support, and retention of competent, scientific, professional, and administratrative staff is therefore imperative. There are serious difficulties in staffing the Government's present research programs—including those of the new Institutes mentioned above. The recently enacted pay reform bill will be of material assistance, but the President's pay reform proposals, particularly for the most highly trained scientific and executive personnel, require full implementation if the Government is to retain and attract high-caliber professional personnel.

Expansion of Research

In developing its proposals to expand the research effort, the Panel has been mindful of the significant advances in the attack on mental retardation which have taken place as a result of research findings. Such errors of inborn metabolism as phenylketonuria, "maple syrup urine" disease, and galactosemia have been intensively studied, and through the results of these studies, it has been possible to prevent many cases of mental retardation. The early findings of the collaborative perinatal project under the direction of the National Institute of Neurological Diseases and Blindness have pointed to some of the causes of prematurity, which is an important cause of brain damage and have focused on the association of oxygen deficiency at birth with abnormality of the offspring. Other important research findings have suggested how important it is that pregnant women be protected from both excessive X-rays of the fetus and German measles during the first few months of pregnancy.

These are merely illustrative of research findings which have led to the prevention of a significant number of cases of mental retardation. Other findings bear on the detection of brain disorders, such as electroencephalograms of newborn infants. Rapid progress has been made, and yet unfortunately it has unlocked the answers to perhaps only half of the 15 to 25 percent of the cases for which specific diagnoses can be attributed.

Research in the behavioral sciences is at present primarily addressed to therapeutic and rehabilitative possibilities. The most fertile unploughed area for further behavioral and social science research is indicated by the accumulating evidence that a host of social, economic, and environmental factors—often categorized as cultural deprivation—are correlated or associated to a high degree with the incidence of mental retardation, especially in its milder manifestations of low intellectual and social performance.

The Panel recommends that high priority should be given to developing research centers on mental retardation at strategically located universities and at institutions for the retarded.

The Panel believes that the importance of research in mental retardation and the very limited research resources now being devoted to this multifaceted problem require a special effort to create new centers of research competence. Such centers are needed for work in biomedical, behavioral, and social science, and in interdisciplinary areas. Support for them should be drawn from State and private sources as well as from the Federal Government through the National Institutes of Health and other appropriate Federal agencies. Three such centers are desirable in the near future, established on a pilot basis, and on the basis of experience with them, decisions should be made on proceeding toward an ultimate goal of as many as 10 centers. The estimated cost of a center might be about $1.5 million for facilities and about $0.5 million a year for operating expenses.

These centers might (1) conduct basic and applied research in the laboratory and the field; (2) serve as educational centers for the training of additional research and service manpower in this field; and (3) carry on experimentation in the application of new findings and techniques.

In the biological and medical research areas, these centers might undertake basic studies in the neurobiological sciences and in clinical aspects of the problem of mental retardation. The heterogeneity of the disorders resulting in intellectual deficit would provide a wide and fruitful area for basic and clinical research and training. Classical techniques of neuropathology have not yet been exhausted in the search for important clinical pathological correlations. For example, the sciences of microbiology, particularly virology, pharmacology, toxicology, and nutrition, can help provide answers to prenatal and postnatal factors which interfere with normal development. Particular disorders which contribute to mental retardation need to be differentiated and their etiology and pathology characterized at the biological, psychological, and clinical level. More information is needed regarding the relationship of psychological deficits to known biological abnormalities. Longitudinal and prospective studies are also desirable to clarify the workings of complex factors in the etiology of mental retardation.

Within the framework of these research centers, universities would be encouraged to establish clinical research programs through teaching hospitals, thereby permitting medical school and graduate departments to undertake research in mental retardation. In addition to providing an opportunity for clinical research, these clinical centers would also be important prototypes in stimulating the application of laboratory findings to clinical practice.

The majority of the mental retardation cases are undifferentiated, with failures in the field of adaptive behavioral and intellectual functioning. As has already been indicated, this suggests the need for expanding both basic and applied research in the behavioral and social sciences with respect to such substantive areas as deprivation and developmental and learning processes. While a balance between basicand clinical research is essential, the fact that millions of retarded persons in our society require improved care, services, and education indicates that a high degree of applied research is needed in the behavioral sciences.

Among the studies in the behavioral sciences which should be considered for special attention by the research centers are the following: the psychological and cultural factors in the etiology of mental retardation; the development of the behavioral processes of the retardate; studies on methods of measuring behavioral skills at all age and ability levels; the adjustment of the adult retardate in various community settings; comprehensive studies in learning, including intramural and extramural demonstrations; responses to stimulative and motivational factors at different ages from infancy to adulthood; and studies of the methods and programs of special education.

Some focuses for research will necessarily represent interfaces among the various sciences to such an extent that meaningful explanation of the whole problem is dependent upon a multidisciplinary approach. Because such a large proportion of mental retardation is presently undifferentiated, it would seem only prudent to have centers concerned with interdisciplinary approaches as well as the other two areas discussed above.

An important starting point for any specific study in the behavioral and even in certain of the biological areas is in comprehensive epidemiological study of deprived conditions—nationwide, statewide, and in particular communities—from which arise the vast majority of the retarded and their possible direct or indirect causal role. In this connection, both cross-sectional studies and longitudinal studies of the development of behavioral processes of retardation as related to possible causal environmental and biological factors would be most helpful. No less important are careful studies of the factors which affect or help the mental retardate in attaining and maintaining satisfactory adjustment in family, community, educational, and employment spheres.

Major national professional associations concerned with research in mental retardation should cooperate in formulating a statement of ethical standards to protect the interests of mentally retarded research subjects.

The need for such action has been evident for several years. With the present increase in research effort and activity, the necessary steps should now be taken to provide the protection that is the right of every citizen under similar circumstances.

The Panel believes that the Secretary of Health, Education, and Welfare should review the requirements for research facilities germane to his Department in the country over the next several years and should prepare a plan for meeting them.

On the basis of this review, consideration should be given to increasing the flexibility of the matching requirements and adjusting the total dollar levels in the existing research facilities matching construction grant program. With respect to mental retardation facilities, this should be done in cooperation with the review of other facilities recommended in Section VI, Residential Care, and in conjunction with the comprehensive planning recommended in Section IX, Organization of Services—Planning and Coordination.

The shortage of laboratory space, of facilities for research, and in some instances of equipment and materials, constitute major barriers to research progress in mental retardation as well as in other areas of scientific endeavor. It is now far easier to obtain support for research than it is to house it decently.

A considerable proportion of the research facilities now in use were built prior to this era and designed for other purposes, and thus frequently do not meet present-day needs. The continuous and successful effort of Federal agencies and private foundations to support research, especially in universities, has resulted in greatly increased support for the training of investigators and other scientific personnel, but, by comparison, has provided very little for the improvement and construction of research facilities.

The current construction rate of educational institutions, while meeting some deficits, has not satisfied the growing need for laboratory space. Either due to lack of full information as to the need or due to traditional policy reasons, most foundations decline requests for construction funds. As a result, few foundations are familiar with the actual cost of research facilities. For example, the cost of completely new facilities for the average research project in the country is estimated at only one to two times the annual budget of the project. Over a 10- to 20-year period, this would add only 10 percent to the funding of a research undertaking.

Experimental research findings should be tested in service agencies before widespread application. The Federal and State Governments and private foundations should assist in financing such studies.

As a consequence of the lag in publication and inadequate communication between the investigator and clinician, the results of research which could be put to profitable use are sometimes lost or their application seriously delayed. In some instances, dramatic research findings are accepted too promptly and applied without sufficient prior testing. Both situations are unfortunate and should be avoided if at all possible. Provisions should be made, therefore, to insure the prompt application of laboratory findings to clinical practice, and preliminary tests should be developed in the controlled environment of the laboratory to precede any widespread application of findings.

A step in this direction can be taken by allotting funds for the support of a series of well-controlled tests in schools, hospitals, and clinical settings. The service branches of the U.S. Department of Health, Education, and Welfare should be asked to make special provisions both in program and budget planning for such projects. The Office of Education, the Office of Vocational Rehabilitation, and the Children's Bureau, among others, would be involved.

Increased Statistical Information

The Federal Government should develop a comprehensive, continuing program for the collection and analysis of population statistics on the incidence, prevalence, and personal and socioeconomic characteristics of the mentally retarded.

In carrying out the mandate of the President to make a study of "the scope and dimensions of the various factors relevant to mental retardation," and to "appraise the adequacy of existing programs," the Panel has found that many needed data are not readily available in reliable and usable form. We know how many mentally retarded children were enrolled in special education classes in 1958, but internal delays have impeded publication of the details so long that much of their usefulness has been lost. Although about 70 percent of those now eligible for adult disabled child's benefits under the Social Security Act are mentally retarded, we have only rough estimates of the numbers receiving aid to the permanently and totally disabled. It is not even certain whether reliable data on survivorship in a defined clinical condition such as Mongolism can be adduced from the National Health Survey. No one knows what proportion of the Nation's unemployed out-of-school youth are mentally retarded or even how many were once enrolled in special classes. Of all aspects of the problem, that of provision in public residential institutions is the best documented by age, sex, degree of disability, and clinical diagnosis. Yet admissions to institutions, and hence their population characteristics, are usually on a replacement basis, and hence selective in favor of maintaining the prior population structure. Thus they do not fully reflect the changing needs. Data .are needed on a nationwide basis concerning mentally retarded persons who have been evaluated and referred for admission to residential care but refused for lack of space.

The present lack of adequate data on the mentally retarded population of the country makes it imperative to launch such a program as soon as possible. The selection and identification of the groups to be studied should be made by the Department of

Health, Education, and Welfare, with participation particularly from the Public Health Service, the Office of Education, and the Social Security Administration, and with assistance from the Bureau of the Census in order to assure that the groups are representative of the national population with respect to pertinent characteristics.

While these population studies would probably be supported largely by Federal funds, provisions should also be made for cooperation with universities capable of contributing to the program and availing themselves of the data collected for their own research purposes.

Serious problems beset statisticians because of difficulties in applying any precise criteria other than IQ to the identification and classification of the retarded. Continued support by the National Institute of Mental Health of efforts of the American Association on Mental Deficiency to formulate and secure wide use of a sound classification system will be an important factor in improving program analysis on a nationwide basis. Cooperation of all agencies in standardizing codes, where feasible, to permit the comparison of data from different programs and different States will require continuing attention.

It would be difficult for the Bureau of the Census to make a general enumeration of the mentally retarded in the course of the general Decennial Census. There are, however, areas suitable for special study by the Bureau which can be helpful. For example, the special Census report on institutional populations gives data not elsewhere available on the school attendance by age of children in institutions for the mentally handicapped. It is possible that the census operation could uncover the reason for nonenrollment among those children age 7 to 14 who are neither institutionalized nor attending school.

The data gathered by the national population studies, as an ultimate goal, should—

1. Permit the generalizations concerning characteristics of the mentally retarded which are necessary in the planning and activation of service and research programs. The data will be extremely useful in planning comprehensive

mental retardation programs in the States as envisaged in the recommendations of subsequent sections.

2. Provide sound estimates of incidence and prevalence of mental retardation, by degree of retardation.

3. Facilitate investigation of the effects of various environmental factors on mental retardation.

4. Provide a base for long-range studies, once the benchmarks are known; for example, studies of the effect of specified environmental manipulations, the effect of regulated diet on the prematurity rate, and the effect of communitywide rehabilitation services.

5. Make it possible for local health, education, and welfare authorities to conduct longitudinal studies through the maintenance of birth records and medical histories of retarded children in cooperation with universities in the area.

6. Furnish background information and provide an impetus for investigations of environmental and other influences affecting culturally deprived groups in our society.

Research on Learning Processes and Education

In view of the importance of research on basic learning to the achievement of our national goals—and to the special needs of the mentally retarded and those with other disabilities—it is proposed that here be established an Institute of Learning.

In the deliberations of the Panel, in testimony presented at the regional meetings, and in consultations with many authorities on higher education, the lack of exploration in depth of the learning process and educative techniques and procedures has been repeatedly cited as a major deficit in the scientific and other programs of the country.

There are no reliable statistics on the national effort in educational research. However, the Office of Education supports about $12 million annually in this field and other Federal agencies, principally the National Institutes of Health and the National Science Foundation, support at least an equal amount. Taking into account non-Federal sources, it can be concluded that the total effort is substantially under one-half of 1 percent of the Nation's expenditures for education. This stands in sharp contrast with the 4 to 5 percent spent for health research out of the national expenditures for health, and research by progressive industries costing 3 to 4 percent of their net sales.

The National Science Foundation, the U.S. Office of Education, the President's Science Advisory Committee, and private foundations have laid the groundwork and revealed the need for extensive and intensive research efforts concerning education. It is hoped and expected that the activities of these and other groups will continue. The enactment of the President's proposals for the improvement of educational quality would be a major step forward in this area. The Panel, however, believes that the magnitude, the universal character, and the urgency of the problems in learning and education call for a national effort of even bolder proportions.

An Institute of Learning would insure visibility and support for such a program and bear witness to the value that the Nation places on intellectual development at all levels of achievement. Moreover, as a matter of practical concern, the progress now being made in the physical and medical sciences cannot continue unabated without, on the one hand, the contribution of the behavioral sciences and, on the other, the full capitalization and utilization of the intellectual and creative capacity of all our people—a step which requires extensive support of investigation of how learning proceeds.

The major functions of an Institute of Learning would be to encourage and support studies of the structure, development, and function of intellective processes; characteristics of simple and complex learning; the extension of theories of learning and elaboration of these theories to include individual differences in human learning; and the neurological basis and biobehavioral correlates of learning. The development of methods of measurement and of training are essential as are further studies on creativity and programed instruction. The Institute would also be a center for the coordination and stimulation of research, for the initiation of programs to determine the conditions under which, and context within which laboratory findings can be applied to facilitate classroom learning.

The Institute should have a broad base involving several agencies within the Department of Health, Education, and Welfare. The National Science Foundation would have great interest in such an Institute and should be consulted in its planning and development. The administrative structure adapted should be conducive to research in such depth and breadth as the topics and problems under investigation require, unhampered by the orthodoxies of the field. It would be wise to defer decision on structure and relationships until the program is clearly delineated, as it is possible that a pattern somewhat different from any existing Federal research agency might emerge.

The Institute should include an intramural as well as an extramural research program and provide support for both. There are a number of universities in the country where there is an active interest in research in education and in other applied aspects of intellectual processes and functions, and it would be the purpose of an Institute of Learning to encourage and support such programs of competence and promise and, at the same time, to stimulate new activity and provide opportunities for the training of research personnel.

The conservation of human resources so essential for humanitarian, defense, and scientific reasons must now specifically include a new emphasis on the education and rehabilitation of the less capable as well as the typical and the talented. If all groups are to be effectively served and our national goals in education realized, comprehensive educational research must be given a high priority and go far beyond that presently underway in the country.

It is recommended that the research budget for exceptional children in the U.S. Office of Education be augmented in accordance with the provisions of legislation proposed in 1962.

If an Institute of Learning is established as recommended, the relation between its proposed program and the continuing research program of the Office of Education as presently constituted would require careful study. There is no inherent conflict between the two. however. In the case of the Children's Bureau and the new Institute of Child Health and Human Development, for example, it has been clearly stated that the Children's Bureau should continue and extend its program of research germane to the many problems of operation and development in the field; the Institute, on the other hand, would concern itself largely with basic research and developmental studies.

Funds are now available in the Office of Education, under its cooperative research program, for research in relation to exceptional children (including the mentally retarded). However, these funds have been drawn upon heavily by other research demands, and as a result, the proportion devoted to mental retardation has been sharply reduced. Support is required in the Office of Education for both intramural and extramural research, for short- and long-term studies, for demonstrations, and for facilities and equipment. In the context of the type of legislation proposed this year, appropriations in the magnitude of $1 million for the first year, and $1.5 million for the second, to support research for exceptional children are recommended, with the budget thereafter to be determined by need. It is strongly recommended that the proportion of such research funds devoted to the mentally retarded be substantially increased.

Scientific Communication

The phenomenal growth of research activity and consequent additions to knowledge that have taken place in the last 20 years have not been matched by significant innovations in the techniques of communication. The number of journals and other media now reporting the results of research make it impossible for investigators and practitioners to keep abreast of developments even within the spheres of their own immediate interest. By way of illustrating the significance of the national investment in new medical knowledge, the Nation has expended more than $19,000 in the last 10 years for medical research for each physician now in active practice. Little emphasis has been given to techniques of communicating this important knowledge. As a measure of the severity of the communications problem, in 1961 the Federal Government provided $623 million for the support of medical research and research facilities. But in this same period, the Public Health Service, the major medical research arm of the Federal Government, obligated less than $800,000—or only about one-eighth of 1 percent of its medical research outlays—for research in scientific communication.

Requirments of improved and accelerated communication across the boundaries not only of disciplinary lines but of nations can be met in part by vigorous exploitation of conventional methods as well as new methods and innovations. The Medical Literature Analysis and Retrieval Systems program of the National Library of Medicine will be a constructive step in unifying published medical literature. However, prompt exchange of unpublished scientific data and development of efficient, systematic retrieval of results of research is urgently needed.

Other efforts are now underway in the Government to improve exchange of scientific and professional information.

1. The Surgeon General has appointed a special asistant to work on problems of scientific information exchange.
2. A conference of specialists in scientific information exchange has been scheduled to discuss methods of disseminating scientific information.
3. The National Institute of Mental Health has established a national clearinghouse on mental health information for the collection, storage, retrieval, and dissemination of information in mental health and mental retardation among other fields.
4. The Science Information Exchange of the Smithsonian Institution has recently expanded its coverage of federally supported research to include the physical science and additional life sciences programs of a number of agencies.
5. The National Institutes of Health recently published an index of its research grants by subject matters.

The Panel commends the steps taken to date in this area and urges full backing to further organized activity in this direction. The needs of mental retardation are of sufficient importance and urgency to require specific program planning as part of the total program underway. The Panel recognizes that the storage and retrieval of mental retardation data are only a part of a vast program of improvement in scientific communication now under study by the Department of Health, Education, and Welfare and the President's Science Advisory Committee. It believes, however, that increased support for research in communication theory and technology must be provided if we are to make effective use of our scientific potential and translate new scientific knowledge into practice.

It is proposed that a number of highly specialized international conferences be organized by the Department of Health, Education, and Welfare to deal in depth with specific research problems underlying mental retardation.

These conferences, which should be planned by the National Institutes of Health and other appropriate agencies in the Department of Health, Education, and Welfare, can be financed jointly by funds of the Department and those of private foundations. They should include topics ranging from basic findings of contemporary research through application in practice. The conferences should facilitate communication among scientists in discrete fields of research, both at laboratory and clinical levels, and should include subjects of concern to both the biological and the behavioral sciences.

It is proposed that these conferences be continued at frequent intervals. Any list of suggested topics must reflect current predilections for some of the more pertinent areas; hence it would be futile to presume a definitive list, which would only prejudge the insights that the conferences themselves should help to generate and renew.

Any list of suggested topics must reflect current predilections as to the most pertinent areas. It would be futile to presume a definitive list which would only prejudge the insights that the conferences themselves should help to generate and renew.

In the biological sciences, topics should include the following among others: (1) early diagnosis; (2) neuroembryology; (3) elementary learning systems; (4) lipid metabolism; (5) neurohormones; (6) protein synthesis and metabolism in the brain; (7) virus diseases; (8) chromosome nondisjunction and hormonal influence on the ovum; (9) immunological reactions of the nervous system; (10) the blood-brain barrier and the cerebral circulation; (11) biochemical maturation in the perinatal period; (12) ultrastructure of the brain; and (13) energy metabolism of the central nervous system.

In the behavioral and social sciences, conferences are proposed on such topics as the following: (1) ability measurement in the young retardate; (2) the goals of special classes for the retarded; (3) research in vocational rehabilitation methods; (4) the structure of cognitive abilities in normal and retarded populations; (5) biobehavioral correlates of learning; (6) perception and perceptual deficit; (7) sociocultural factors which influence adult adjustment of the mentally retarded; (8) psychocultural deprivation and behavioral development; (9) personality development and measurement in mental retardation; (10) differential diagnosis between mental retardation, childhood schizophrenia, and autism; (11) learning and motivation; (12) promotion of public acceptance of the mentally retarded; (13) the role of the sociologist in mental retardation research; (14) imprinting, sensory deprivation, and behavioral development; (15) social class, communication skills, and intellectual development; and (16) residential facilities: size, purpose, staffing, and treatment effects.

The proceedings of such conferences should be published in order to constitute a dynamic encyclopedia of the biological and behavioral bases of mental retardation research. The above topics serve to illustrate the wide range of research areas germane to the basic problems underlying mental retardation. Research efforts in the ensuing decades in both the biological and behavioral sciences will, it is hoped, explore and probe these problems and areas among others, and thus subject the phenomenon of mental retardation in all its aspects to the full scrutiny of our scientific resources.

In such conferences and in other activities of an international character, it should be recognized that singular contributions to scientific knowledge have come from basic, clinical, behavioral, social, and educational research conducted outside the United States.

Current efforts to share research methods and findings in mental retardation among all interested countries should be expedited by the United Nations through such agencies as the

World Health Organization; the United Nations Educational, Scientific, and Cultural Organization; and the International Labor Organization. International scientific, professional, and voluntary organizations can also be of substantial assistance in this effort.

There is no organized method for exchange through annotated bibliographies of research efforts, methodologies, or findings in mental retardation.

Until recently the exchange of scientific and service personnel concerned with mental retardation has been very limited, and those that have taken place are largely related to research in the biological sciences. There is a great lack of exchange in the service and educational area. The most consistent efforts to foster and sustain exchange of information and communication to date among professional persons and parent groups concerned with service activities have been carried on by a volunteer in the National Associa'tion for Retarded Children.

Agencies authorized to conduct such activities appropriately related to their domestic functions include the National Institutes of Health, Office of Vocational Rehabilitation, Office of Education, Children's Bureau, and Social Security Administration. These and appropriate private organizations should develop both short- and long-range programs of cooperative research and exchange of service and educational, as well as research, personnel, and be given sufficient appropriations to finance such activities.

The current policies of the National Institutes of Health in the development of foreign grant programs are heartily commended. Scientific advancement in general, and the interests of mental retardation in particular, call for cooperative effort on an international scale.

There is also a need for additional foreign fellowships for study in this country and for specific exchange arangements in the service aspects of mental retardation as well as in the research area.

The importance of international activity in mental retardation in which our country should take the lead was well expressed in the President's charge to the Panel: "Our obligation is to search for the secrets of the human mind and to share our knowledge throughout the world."

Manpower and Training

Shortages of scientists and trained specialists are a severe, limiting factor on the present research effort. The supply must be substantially expanded if it is to meet the needs created by an expanding population and an increasingly technological civilization. The supply of scientific manpower depends on the recruitment and training of scientists for the medical, behavioral, and biological sciences, and in fact for all science generally. While it is impossible to estimate the precise number of scientists actually working in fields relevant to mental retardation, it is evident the number must be sharply increased.

The Panel endorses and assigns the highest priority to the President's proposals to assist in the contruction of academic facilities for higher education and to provide scholarships for students. There is a particularly urgent need for a program with Federal, State, community, and private support, designed to prevent the loss to science of large numbers of gifted youth financially unable to enter college.

The Panel recognizes that the strengthening of our institutions of higher learning and the equalization of opportunity for a college education among all elements in society are the cornerstones of scientific progress.

The following suggestions may also be helpful in interesting young people in scientific careers and developing an awareness of human disabilities:

1. The use of modern texts and teaching methods in science courses.
2. Organizing courses in developmental biology and psychology.
3. Providing opportunities for students to engage in scientific activities, to meet stimulating teachers and scientists, and to visit research centers and laboratories.

4. Presenting career opportunities in science to students in interesting ways, with the aid of films, special interviews, and "career days."

The efforts of the National Science Foundation, the American Institute for Biological Science Programs, and other groups in developing revised curricula and textbooks and other creative approaches to teaching are to be commended. Activities of this type and quality could be accelerated and extended by the proposed Institute of Learning. The teaching project in physics sparked by the President's Science Advisory Committee is a prime example of the kind of approach—both scholarly and dynamic—that is needed.

Colleges must give greater attention to the factors known to influence the selection of a science career. Studies have shown that the decision to enter a scientific field is influenced by such factors as acquaintance with an' outstanding science teacher, participation in a science program, visits to laboratories, summer work in a scientific activity, and the like. Little has been done, however, to develop such factors or to identify others. Studies of the whole range of factors influencing career choices - are needed from the sociological, economic, and psychological points of view. The National Science Foundation has made progress in this direction, but more should be known about the actual results of recruiting efforts if such activities are to be rendered more effective in the future.

The program whereby high school science teachers are enabled through financial assistance to obtain advanced training and degrees is highly constructive and should be encouraged and extended.

In addition to specific steps to interest undergraduate students in fields of science and action in support of higher education generally, the Panel has a number of recommendations directed specifically at manpower for work in the field of mental retardation.

Federal financial assistance is urgently needed to increase the capacity of medical schools and to enable capable students to study medicine. The Panel endorses the legislation proposed by the President for this purpose and urges its enactment by the Congress.

There is a serious and increasing deficit in the supply of physicians to serve our growing population. This deficit seriously handicaps our ability to strengthen our medical research effort and to expand essential public health programs. It is of particular concern to the Panel because mental retardation is a new field, which must attract new talent. The shortage will increase markedly for at least the next 8 years, because enlarged training efforts, even if started now, would take until after 1970 to graduate new physicians and provide postgraduate training for them.

The President's legislative proposals for medical school construction and for medical school scholarships seem particularly germane to solving this crucial manpower problem.

The Panel recommends that the Office of Education, the National Science Foundation, the National Institutes of Health, and private foundations provide an increased number of postdoctoral fellowships, research and career professorships, and awards in fields relevant to mental retardation.

Private foundations and national voluntary agencies are urged to increase support of training programs in academic, clinical, and research settings, and to plan with governmental agencies for a more adequate coverage of the need.

To increase and improve training programs, joint planning is needed between public and private groups. Further support for preservice and inservice training, summer workshops, and other proposed training programs is essential to further advances in the field. Direct allocation of funds to research units and provision of more academic and clinical facilities will hasten progress in training programs.

The research centers proposed above would offer training in the basic sciences and clinical training in mental retardation and would open up new career opportunities. Joint appointments in universities and clinics, with actual participation in both settings, would narrow the gap between clinician and researcher in respect to training, research activities, and communication. In addition, the new National Institute of Child Health and Human Development might well develop training programs designed particularly for motivating and preparing individuals for research in fields germane to mental retardation.

The expansion of the career investigator program of the National Institutes of Health in specific fields pertinent to mental retardation, such as in developmental biology and the behavioral sciences, should be seriously considered as a method of increasing the number as well as the prestige of academic research personnel. Such awards might be made to senior men in medical sciences and in graduate departments in the behavioral and social sciences who havr already achieved distinction in their field. The singling out of distinguished personnel for such awards would provide general stimulus to research.

It is recommended that the career investigator program, now restricted to persons who will spend their time primarily in research, be broadened to include a teacher-investigator program. This program would be confined to persons of demonstrated research competence, but who will spend a substantial portion of their time in *teaching* activities related to training of future scientists.

The Panel urges studies to determine what aspects of medical care can be provided by nonmedical personnel. The Children's Bureau is urged to expand its interest and support in this direction.

The existing shortage of scientific manpower and the prediction of an even greater shortage in the future necessitates every effort to make the best possible use of those men and women already trained and qualified for scientific careers. Unless some adjustments are made, our expanding population may well siphon off research manpower to satisfy ordinary medical requirements.

With the readily apparent shortage of medically qualified scientific manpower, there must be no waste of this portion of our scientific personnel. The Panel urges that consideration be given in the armed services to adequate utilization of the talents of those embarked on research careers in connection with the expanding research needs of the services.

The National Institutes of Health should be encouraged to continue the development of programs for the training of medical students for research careers. The National Institutes of Health should also develop a program of scholarships and fellowships to qualified individuals who choose to enter a career in medical research through medical education comparable to those which exist for Ph.D. training.

The biomedical sciences require for their adequate development a continuous interaction between the fundamental and clinical sciences, between biology as generally understood and human biology, including clinical practice and those areas of the behavioral and social sciences dealing with human adaptation and disorder. Yet, for special reasons, the recruitment and training of medically qualified investigators is rendered difficult and uncertain.

Less than 10 percent of the graduates of our best medical schools remain in a career of full-time teaching and research,[1] a situation which can be partially explained in terms of the great cost of a medical education, both in high tuition fees and loss of earnings, and the considerably greater financial returns from the private practice of medicine as compared with an academic and investigative career. This situation will become increasingly acute as the need for physicians grows and the cost of medical education continue to rise.

In establishing fellowships and stipends for graduate training leading to the Ph. D. degree, the Congress and many private foundations have recognized that research training is a national responsibility, the financial burden of which should not fall entirely on the individual. A similar provision is required for the student qualified and motivated to enter a career of biomedical research through the medical degree. In the field of mental retardation, as in dealing with many other clinical problems, such individuals are important, for in applying the knowledge acquired through basic research to clinical problems the

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[1] Stewart, W. H., and Pennell, M. Y.: *Health Manpower Source Book. Section II. Medical School Alumni.* Public Health Service Publication No. 263, Section 11. U.S. Government Printing Office, Washington 25, D.C., 1961.

individual trained as a physician and clinical investigator is among those who play a crucial role.

Medical schools should be encouraged and supported in offering not only research electives to the majority of students but in developing, for a selected number, special curricula designed to increase the number of medically trained scientists.

The unique opportunity which the intramural programs of the National Institutes of Health offer for postdoctoral training of investigators in the medical sciences represents an important national resource. The Institutes should be encouraged to increase their efforts and expand their facilities in this area.

The graduate fellowship program in the Office of Education should be extended to include provisions for the preparation of research specialists in the education of the mentally retarded.

Funds are currently available, under Public Law 85-926, for the preparation of administrators and college instructors in education of the mentally retarded. However, these funds exclude the participation of persons who wish to prepare for research careers. It is recommended that Public Law 85-926 be amended to include provisions for the training of research specialists in the education of the mentally retarded, or some other legislative mechanism to accomplish this end. The current requirement for eligibility of 1 year's teaching experience with the mentally retarded should be eliminated for those whose primary career objective is research.

Federal fellowship programs should be extended to provide opportunities for students to prepare for research careers in mental retardation in conjunction with training in one of the basic behavioral or social sciences.

The pool of competent behavioral scientists is limited; from among this pool, few select mental retardation as a principal concern. A major reason cited for the neglect of this field is that there is a longstanding disinterest in this area on the part of university departments despite the obvious relevance of mental retardation to the study of learning, developmental processes, social behavior and measurement. This can be attributed in large part to the paucity of research endeavors which until recently has characterized this field. As a consequence, graduate students are not exposed to ongoing research in mental retardation which could capture their interest and imagination. Thus, more university departments of psychology, sociology, and the other behavioral and social sciences need to develop opportunities for research careers in mental retardation. This can best be accomplished by combined training and research programs supported by Federal and private foundation grants. At the moment, only one department of psychology in the United States has a combined training and research program for research psychologists in mental retardation, and there is not a single comparable program in sociology in which a student in sociology could pursue a research career in mental retardation. As many as three to five centers are needed in the United States in these two disciplines alone.

It is recommended that universities offer opportunities for research training in more than one discipline.

Training plans of this kind should not clash with the classical avenues for obtaining the Ph. D. degree, but they should provide appropriate opportunities for those graduate students who have a broad interest in the developmental processes. Graduate students will usually specialize in one discipline such as psychology or biochemistry. However, to pursue a broad research concern in mental retardation, they need an orientation in educational, psychological, sociological, and physiological aspects of the problem. For example, persons studying psychophysiological aspects of mental retardation should pursue a double major in psychology and physiology. Other examples of an interdisciplinary approach to training could be cited.

The National Science Foundation, the National Institutes of Health, and private foundations are encouraged to stimulate and support increased research in the process of scientific creativity.

In spite of the substantial increase in research over the past decade, comparatively little attention has been given to studies of the research process itself in order to delineate and favorably in-

influence the important intrapersonal and environmental factors which contribute to it. A better understanding of the attributes of the creative scientists and the creative milieu would improve the reliability and effectiveness of selection procedures and training for research careers, and could greatly enhance research productivity.

Section III

PREVENTION

Measured in economic as well as human values, the inherent high cost of mental retardation that is currently borne by individuals, families, and society warrants a maximum effort for prevention—our great hope and ultimate goal. The considerable progress achieved to date and the new knowledge that will hopefully be available to us in the future are of minimal value unless the barriers to general application and utilization are removed. The full application and utilization of existing knowledge by action on a broad front encompassing measures to correct adverse community conditions as well as to take specific preventive measures would eliminate perhaps half or more of all new cases of mental retardation. Moreover, the application of such preventive knowledge would also reduce the incidence and impact of other health and social disabilities.

Prevention of a problem as complex as mental retardation therefore requires simultaneous action on all fronts—biological, psychological, and sociocultural. We must devise methods of applying old and new knowledge that will effectively reach our population. Thus, our knowledge must encompass not only the biochemical determinants of life itself as reflected in our knowledge of genetics, enzymes, and chromosomes, but must include a knowledge of people and how they interact with each other and with the society in which they live. Because such a large part of the problem of mental retardation is so closely interwoven with social, cultural, and economic conditions, we cannot hope, at least with our present knowledge, to prevent more than a small fraction of the new cases unless we deal with these fundamental factors.

Biological and Medical Preventive Measures

In the biomedical area, prevention increasingly offers opportunities for widespread application. The following are examples of effective preventive measures in several different fields:

The virtual elimination of congenital syphilis as a cause of mental retardation has been achieved by systematic use of blood tests during pregnancy, followed by the effective therapy now available.

Improved obstetrical practice has avoided a considerable amount of damage due to anoxia, mechanical, and other brain injuries during delivery. Encouraging results have also been achieved in avoiding brain damage associated with blood incompatibilities between mother and infant by use of routine prenatal blood tests for early identification of the condition and prompt exchange transfusions in the affected infant.

New preventive possibilities have appeared with the more precise understanding of a number of genetically determined enzymatic diseases and the assumption that others will be discovered. In these inborn errors of metabolism, there is a deficiency in the mechanism for dealing in normal fashion with certain common nutrients. As a result toxic substances accumulate within the body, causing severe brain damage. The progress made with respect to one of these conditions, phenylketonuria (PKU), has been widely publicized. The urine of infants is screened (starting at the second week and rechecking at about the sixth week) so that diagnostic laboratory blood tests may be made on suspected cases. When the diagnosis is established and the offending substance (phenylalanine) reduced in the infant's diet, the source of one severe but rather rare form of retardation is removed. A new and improved method of screening involving microanalysis of small amounts of blood before the infant is discharged from the hospital is now undergoing field study.

In another type, galactosemia, the problem is more complicated in that for best results the carrier state must be identified in both mother and father and the galactose-free diet started during pregnancy and continued in the infant after birth.

Another promising lead concerns maternal infection during pregnancy as a cause of retardation. A number of viruses and other infectious agents have already been identified or are strongly suspected of producing damage to the fetal brain when the mother is infected during pregnancy, especially in the first few months. The best known example of this is maternal infection with German measles (rubella) during the first trimester of pregnancy.

Other maternal infections known to be associated with mental retardation in the offspring include toxoplasmosis and cytomegalic inclusion body disease. Better management of thyroid disease and routine detection of subclinical urinary tract infections and diabetes in the expectant mother are examples of other possible preventive measures.

As there is a higher incidence of death and damage, including mental retardation, among premature infants, there is good reason to institute all of the preventive measures in this area that present knowledge suggests; hence the importance of adequate maternal care before and during the birth of the child, and postnatal care of both mother and child. Health hazards from which the newborn should be protected include anoxia, infection, diarrheal disease, inadequate diet, and physical trauma, any of which might contribute to the kind of damage that could lead to mental retardation.

Ionizing radiation is known to produce genetic mutations in the premarital and preconception period. This source of genetic defect may be reduced by strict enforcement of standards in the use of medical and nonmedical (X-ray and other) equipment which produces ionizing radiation.

Laboratory detection of particular types of chromosomal aberration helps to form the basis for prediction of reoccurrence of certain types of retardation as, for example, translocation Mongolism.

The effective delivery of the benefits derived from this hard-earned knowledge of preventive measures to all society depends on the social patterns from which the enlightened public of our democracy derive our cultural priorities. Federal, State, and local public health programs, the increasing public support of health research, and enacted health legislation reflect such priorities. By these, sufficient resources were allocated to the virtual elimination of syphilis as a cause of mental retardation, tuberculosis as a major killer, and poliomyelitis as the scourge of children and young adults. Similarly, the full utilization of improved obstetric and pediatric practice with its enormous potential for preventing mental retardation requires the assignment of a high cultural priority and sufficient resources.

The prevalence of mental retardation is significantly higher in those population groups where maternal care is frequently inadequate; therefore, a nationwide program should be launched by the Children's Bureau, the Public Health Service, and State and local health departments concentrating on these high-risk groups.

In order to reduce the incidence of disability among the newborn, particular attention must be focused on those women who have complications of pregnancy ranging from maternal malnutrition to premature labor. For these women it is of critical importance that good maternity care be provided during the prenatal period, labor and delivery, and the post partum period. Their babies, especially if premature, require intensive nursing care to minimize the incidence of health hazards. Such complications of pregnancy that increase the hazards of childbearing for both mother and child tend to be more prevalent among low-income families. It has been found, for example, that the incidence of toxemias of pregnancy among women in the higher income groups is about 3 percent, while among the lower income groups it is 15 percent.

The hazards of premature birth result in a significantly higher incidence of death and damage, including mental retardation, than occurs among full-term infants. Preliminary findings of a study of the development of premature infants, being conducted by the Johns Hopkins University School of Hygiene, indicate that:

—As the birth weight of the infant decreases, the amount of disability in a variety of aspects of growth and development increases.

—26.3 percent of those infants with a birth weight of 1,500 grams (3.3 pounds) or less have neurological abnormalities of sufficient degree to cause serious concern about their future development, while comparable figures for the remainder of the premature infants in the sample and for the full-term control groups are 8.2 percent and 1.6 percent, respectively.

—Corresponding figures relating to minimum cerebral damage, believed to be the precursor of subsequent learning and behavioral difficulties, are 22.8 percent, 16 percent, and 10 percent, respectively.

—17.6 percent of the smallest prematures have defective intellectual functioning.

—Premature infants have 2 or 3 times as many physical defects and 50 percent more illnesses than full-term infants.

—Prematurity generally has a deleterious effect, and 50 percent of these infants have handicaps ranging from minimum neurological damage to severe mental deficiencies and blindness.

Although other variables undoubtedly operate, there is sufficient evidence that the prematurity rate varies directly with the percent of women who receive little or no prenatal care. Dunham's study of 166,977 infants in New York City [1] demonstrates this relationship in the following manner:

1st prenatal visit	*Prematurity rate (percent)*
1st trimester	7.8
2d trimester	8.7
3d trimester	10.2
No prenatal visit	20.3

Similarly, a recent survey in the District of Columbia indicates that the prematurity rate is 22.7 percent among women with no prenatal care, as compared with 10.4 percent among those who had some prenatal care.

Large numbers of expectant mothers in the United States, particularly among the lower socioeconomic groups in both urban and rural areas, receive little or no prenatal care and suffer from extremely inadequate health supervision during the post-

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[1] Dunham, Ethel, *Premature Infants,* 3d edition, 1961.

natal period. This is becoming a serious problem especially in our larger cities and is directly related to the relative increase in the number of low-income families that has resulted largely from the middle-class exodus to suburban counties. In a large eastern seaboard city, 10,000 women who gave birth to children in 1962 received indifferent or no prenatal care. In the District of Columbia last year, one-half of the births at the city hospitals were without prenatal care, an increase from less than a third in 1952. In Baltimore the percentage of births with late or no prenatal care increased from 8.2 percent in 1951 to 21.4 percent by 1958. In New York City, it is reported that the number of births without prenatal care is increasing by 2 percent a year, and it is estimated [2] that by 1965, one-half of all deliveries in Manhattan will be medically indigent.

It is currently estimated that 35 percent of mothers in cities with over 100,000 population are indigent or medically indigent. This is supported by data from New York City which indicates that in 1960, 40 percent of all maternity deliveries in the city were general service deliveries (not private patients). In 1959, 60 percent of the deliveries in the District of Columbia were general service deliveries. A high percentage of such mothers are recipients of aid-to-dependent-children payments. The grants available to women and young children under this program are frequently so low that the diet is seriously inadequate, particularly in proteins. Although the specific effects of diet on prematurity, and hence fetal damage, have not yet been definitely established, there is evidence that general improvement in dietary habits of pregnant women reduces the incidence of prematurity.

All these problems are further aggravated by the great shortage of hospital beds in municipal or county hospitals that are available for maternity patients. The current widespread practice for voluntary hospitals to require payment of, or in behalf of, the patient upon admission has resulted in the general overcrowding of city and county hospitals. In addition to the relatively low priority assigned to maternity cases, this has resulted in an

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[2] New York Academy of Medicine.

average stay of only 24-48 hours for maternity patients in some hospitals. In contrast there are vacant obstetric beds in voluntary hospitals within the same cities, and private maternity patients in these hospitals spend an average of 5 days. Moreover, many hospitals now charge a daily fee, and indigent women who are hospitalized during the prenatal period for complications of pregnancy often sign out—against medical advice—because they cannot afford the daily rate. For these women and their babies this is a critical period; nevertheless, the management of their care is too often based on economics rather than on medicine.

To improve the present situation, State and local health departments, with the encouragement and assistance of the Federal Government, should move at once to extend comprehensive maternal and infant care to the mothers and children who are in the greatest need—those in the lower socioeconomic groups where the prematurity and infant death rates are high. To this end the Panel recommends that Federal funds be authorized on a project basis to assist State and local health departments to extend existing programs to meet the cost of comprehensive maternity and infant care for women who cannot afford private care and whose problems associated with childbearing greatly increase the hazards of pregnancy/for themselves and their infants.

Health departments would use these funds in behalf of mothers and infants to provide medical and hospital care, intensified public health nursing, and additional prenatal clinics. Health departments in the geographical areas selected would be enabled to develop maternity services for the neighborhoods or rural areas where the needs are greatest, as well as effective followup. Particular attention must be given to methods that make prenatal and post partum care more accessible by providing consultations and hospital care during the prenatal period as needed and during labor and delivery. Prenatal clinics should be brought closer to where patients live and, in cases where trained physicians are unavailable, qualified nurse midwives, under proper medical supervision, could be utilized to provide prenatal and obstetric care and to perform uncomplicated deliveries. Parents' classes, home visits, and other techniques to make prenatal care more meaningful should be extended.

For each of the first 3 years of the project, it is recommended that appropriations of $10 million, $15 million, and $20 million, respectively, be requested of the Federal Government to launch the program. After the 3-year developmental period, a total of approximately $30 million would be required annually from Federal, State, and local sources to sustain the program.

This estimate is based on the population in cities of 100,000 or more. There are 138 such cities in the country and they account for approximately 1,300,000 births per annum, or 30 percent of the annual births in the United States. It is conservatively estimated by the Children's Bureau that approximately 35 percent, or 455,000 mothers involved, are indigent or at least medically indigent. Within this population women with complications of pregnancy, poor previous medical and obstetric histories, and a portion of the young unmarried girls, constitute a *high-risk group* and total approximately 100,000 a year. This should be regarded as the minimum number of pregnant women for the program suggested here. The total cost to local health departments would be approximately $300 per patient, or $30 million a year, for medical and hospital care for mothers and infants and for public health nursing, not including the care of premature infants.

The program contemplated under this principal proposal differs from the existing maternal and child health program in two respects: (1) Under the existing program in only a few instances do large cities receive Federal maternal and chile[1] health grants. The proposal would insure such funds for the expansion of care currently financed primarily from State and local funds. (2) With the exception of 3 or 4 States, maternal and child health programs currently do not provide comprehensive medical care. The proposal would provide comprehensive care for indigent high-risk maternity patients.

Since many of the cities are now providing prenatal care an hospitalization at city or county hospitals financed primarily from State and local funds, the proposed project grants would be used to increase the number of prenatal clinics and bring them close to the needy population; to establish special clinic for the large number of high-risk patients where more time and professional services by obstetricians, nutritionists, medical social workers, and nurses can be provided; to provide consultation services; and to pay for hospital care as needed during the prenatal period and for delivery of high-risk patients in voluntary hospitals when city hospitals are crowded and inadequately staffed.

The accompanying table furnished by the Children's Bureau shows expenditures by 17 major cities for Maternal and Child Health and Crippled Children's Services. It must be emphasized that the additional Federal funds recommended here should not take the place of existing funds, but be made available only to assist the health departments to extend and improve their programs of maternal and infant care.

Expenditures by 17 Cities for Maternal and Child Health and Crippled Children's Services, Fiscal Year 1960

City	Expenditures		Source of funds			Total Federal MCH and CC grants paid to States within which cities are located
	Per capita	Total	Local	State	Federal	
Atlanta, Ga	$0.45	$225,000	$186,000	$39,000	....	$1,030,323
Baltimore, Md	.55	520,190	196,436	281,681	$42,073	788,929
Boston, Mass	.32	221,000	221,000	....	....	741,239
Buffalo, N.Y	1.49	797,000	398,500	398,500	....	1,474,574
New York, N.Y	1.64	12,739,163	6,369,581	6,369,581	....	
Dayton, Ohio	.32	84,765	84,765	....	....	1,233,431
Toledo, Ohio	.22	68,637	68,637	....	....	
Denver, Colo	.10	50,000	50,000	....	....	547,484
Los Angeles, Calif	.29	712,604	([1])	([1])	10,908	1,855,466
Louisville, Ky	.33	129,160	112,177	16,983	....	843,687
Milwaukee, Wis	.25	186,579	186,579	....	....	663,925
Newark, N.J	.57	232,875	232,875	....	....	510,192
New Orleans, La	.38	237,332	222,332	....	15,000	759,279
Philadelphia, Pa	.34	687,537	455,149	232,388	....	1,567,529
Richmond, Va	.23	50,442	38,442	12,000	....	951,319
St. Louis, Mo	.38	281,004	280,364	640	....	687,571
Seattle, Wash	.82	457,536	415,462	41,974	....	434,592

[1] Not distributed.

The unfavorable economic position of the cities in meeting their current health problems results from the population changes and related economic problems that have developed during the past 2 decades. These are marked increases in the proportion of families with low income, in the birth rates, and in the costs of medical care, especially hospital care. These facts are illustrated by the following figures from the city of Baltimore, Md.

Indices of Population Changes in Baltimore [1]

	Percent change, 1950-60
Public assistance clients	+39
Medically indigent families	+54
Population total	—1.1
Live births	+8.8
White	-15
Nonwhite	+56
Out-of-wedlock births	+41
Well-baby clinics: Infants registered	+59
Prenatal clinics: Women registered	+133
Infant mortality rate	+19

[1] "Urban Economics and Public Health," by M. Tayback and H. Wallace (to be published).

Although the above estimates are based on the number of medically indigent women in large cities, the program should not be restricted to these areas; indigent women in small towns and rural areas should be included. There are many mothers in the middle-income groups who do not receive adequate care during pregnancy. In some cases this is due to lack of concern or interest, and in others to the fact that a considerable number of families in the middle-income bracket do not have funds for medical care over and above the absolute essentials.

In connection with the proposed program in maternal care, it is suggested that in several selected geographical areas the Children's Bureau establish comprehensive demonstration programs in maternal and child health among economically deprived families. These programs should include provision for long-term periodic health supervision of infants and young children with the cooperation of child care clinics, public health nursing, nutrition instruction, and health education services. Special efforts should be made to reach apathetic, passive, and uncooperative families in the lower income groups.

Maternal and child care centers are such an essential part of every modern community that they should have a prominent part in city planning and urban redevelopment. The personnel of such centers should include obstetricians and pediatricians in training, nurse midwives, and public health nurses, as well as auxiliary nonprofessional personnel who might divide their time between the community maternal and child health center and the community hospital outpatient and inpatient services. Well-organized health education programs would help to bring these services to families who need them the most—that is, the low-income groups, where prematurity occurs at twice or even three times the rate found in the upper and middle income levels.

It is recommended (1) that State departments of health and university medical centers collaborate in the development of regional genetic counseling services [by groups of States where possible and appropriate) so that young married couples and expectant parents in all parts of the Nation may have access to such consultation; and (2) *that diagnostic laboratories for the performance of complex diagnostic procedures be developed on a regional basis by two or more States.*

These two types of service, both of which are of great importance to mental retardation, are in extremely short supply in this country.

Both are prohibitive for most individuals or even for many communities from the point of view of cost and scarcity of qualified personnel and equipment. However, they might be supported on a regional basis by Federal and State funds through State health departments. The diagnostic laboratories for such procedures as analysis of amino acids in blood and urine, which should be related to the central and regional laboratories of the U.S. Public Health Service, would be a boon to maternal and child health centers and hospitals, which frequently lack high-quality testing and other expensive services of particular value in modern diagnostic and evaluation procedures. Support of such laboratories should go hand in hand with the development of extended clinical services.

The Food and Drug Administration, the National Institutes of Health, and the pharmaceutical industry should develop and require the use of techniques for evaluating and assessing the effects of Pharmaceuticals on the fetus, infants, and young children.

The administration and the Congress have recently taken decisive and important steps in furtherance of more exacting and definitive testing requirements for drugs. The drug legislation proposed by the President in the consumer message and enacted by the Congress contains major provisions which will provide for safe drugs in both the clinical testing phase and the marketing phase. Furthermore, the Secretary of Health, Education, and Welfare has already proposed regulations which will provide for adequate Government surveillance of drugs being tested on human beings. Both the legislation and regulation which will be in effect soon will provide all American consumers, including women of childbearing age, with safer drugs.

These steps are essential. It has been known for many years that a number of drugs have a "teratogenic" effect on the fetus even though they may not be harmful to most adults, including women who are not of a childbearing age, or to every specie of animal. Ample data are available on the deleterious effect of certain drugs on the developing fetus[3] and the young child; and, in view of this, the Panel reiterates the need for maximum protection for all women of childbearing age and for young children.

The period of maximum risk in use of drugs is the first trimester of pregnancy, the last two trimesters presenting other hazards. During this period, however, many women are not aware of their pregnancy. Preventive measures should be based on this fact among others, and any restrictive measures covering women

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[3] A competent review of the literature is included in an article in *Pharmacological Reviews*, Vol. 12(1), March 1960, entitled "The Effects of Drugs on the Fetus," by J. B. E. Baker, Department of Pharmacology, Charing Cross Hospital Medical School, London, England.

whose pregnancy state is known should include all women of childbearing age. The risk involved in over-the-counter (proprietary) drugs taken with no direct physician supervision is also a matter of concern.

It is important that young women should be informed of this danger by family physicians and community clinics, and by means of health and hygiene courses in public and private schools. Physicians should consider the possibility of pregnancy in selecting medication, particularly new and relatively untested drugs.

Research on the effects of various chemical agents on all humans, particularly women of childbearing age and infants and young children, should be increased in universities and other research centers and in the intramural program of the National Institutes of Health.

While more stringent testing requirements of drugs will mean a larger expenditure by both the Government and the pharmaceutical industry and may possibly delay the advent of new and beneficial pharmaceutical products, this is a small price to pay for increased protection.

A few States have enacted laws or established regulations providing for the registration, inspection, calibration, and licensing of X-ray and fluoroscopic machines and other ionizing radiation sources; it is strongly recommended that all States establish such provisions and that the Public Health Service continue to expand its program for radiological health protection, with special emphasis on the provision of assistance to the States in establishing effective X-ray control programs.

The health hazards resulting from radiation exposure have become a matter of mounting public concern, and various public advisory bodies, including the National Advisory Committee on Radiation, have underlined the need for an intensified Public Health Service program to control this hazard. In response to this concern, the Public Health Service radiological program has grown rapidly from less than $1 million in 1958 to $11 million in 1962. The funds authorized by the Congress for 1963 would continue this rapid growth by providing almost $16 million for this program, an increase of nearly 45 percent over 1962. The Service should continue to be provided with funds adequate to its broad responsibilities in radiological health.

The Panel also urges that lifetime radiation records be developed in selected areas under the auspices of the Department of Health, Education, and Welfare for the recording and dating of diagnostic and therapeutic X-ray exposures. Even though it may not be possible to measure exposure doses accurately in each case, studies should be made to determine whether an extensive program of individual records should be mounted. To be of maximum value, a record of this type should cover the period from conception to 30 years of age.

Extreme caution is indicated in exposing patients to X-ray beyond the point actually necessary for effective diagnosis. Women are frequently X-rayed when they are not aware of their pregnancy, and hence at a time when the fetus is highly sensitive to radiation. It is therefore imperative that young girls and pregnant women be spared unnecessary X-ray exposure of any kind, and that full statements of menstrual history be obtained in advance of exposure from all women of childbearing age.

Hospitals are urged to adopt and use every known procedure for the prevention of prenatal and neonatal defect and brain damage: the joint hospital accreditation board should add criteria for prevention procedures to its present requirements for accreditation.

Criteria adopted by the Hospital Accreditation Board should include such items as: standardized techniques for the assessment of newborn distress; careful recording of such data together with important complications of pregnancy; use of records designed for immediate transmission to those responsible for postnatal health supervision; recording of neonatal statistics; and screening tests for metabolic disorders of the newborn.

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In view of the high percent of automobile and other accidents resulting in brain injury, it is recommended that the accident prevention activities of the U.S. Public Health Service be expanded and that it continue to encourage intensive research in the causes of accidents as a basis for more effective programs of prevention.

Brain injuries due to head trauma from automobile and other accidents are a source of growing concern to physicians and public officials. Accidents are now the leading cause of death in the age group 1 to 14, and include a high percent of head injuries. Further research should be encouraged in the causes and prevention of childhood accidents, particularly automobile accidents. Childhood accidents present a challenge of substantial proportions, and the field has hardly been touched in this or any other country from the point of view of a thoroughly scientific approach.

The U.S. Public Health Service has recently been granted additional funds for accident research, but additional financial support is needed to enable it to extend its influence and leadership throughout the country in encouraging further research and the development of programs of prevention based on research findings.' A far greater concern and commitment is needed at the local and State levels, and should involve safety councils and the research personnel and resources of universities.

Preventive Measures To Correct Adverse Environmental Conditions

Deprivation of adequate opportunities to learn and other environmental factors may adversely influence the intellectual development of children; therefore communities should undertake programs to modify these conditions.

Many of the mentally retarded are persons who have been reared under conditions in which they have been deprived of the stimulation and learning opportunities necessary to the development of adequate intelligence; they are the product of the urban and rural slums of the Nation. It is currently estimated that 28 million people, representing 16 percent of our noninstitutional population, are living in substandard housing units. These people are the inhabitants of our slum areas, which are found predominantly in our urban centers. These slum areas may be further identified by low family income, overcrowed schools, and an absence of community facilities. It is estimated that in 1960 more than one-fifth of the 45 million families in the United States had annual income of less than $3,000. These 9% million families included more than 12 1/2 million children under age 18. It is significant that 25 percent of these children live in families whose annual income is less than $ 1,000.

Conant[4] characterizes slum schools by overcrowding and by the expenditure per year per student of less than one-half that spent in the wealthy suburbs. In many cases teachers in the overcrowded slum area schools are required to instruct 75 percent more pupils than those in modern suburban schools.

The poor performance of slum area children is related to four broad influences in their development:

(1) Lack of motivation toward achievement and toward standards of high performance;

(2) A home environment that fails to develop the modes of thinking and perceiving common to the middle and upper class child;

(3) A family organization or structure that is emotionally crippling to the child;

(4) Lack of adequate social facilities in health, education, and welfare.

In slum areas, for example, the family structure is typically disorganized. These children enter school with a level of ability usually far below that of their middle-class peers. As the years pass they present a picture of retrogression, rather than gradual improvement.

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Significant evidence is found in the figures compiled by the armed services on rejection rates during World War II;[5] over 700,000 persons between the ages of 18 and 37 were rejected because of "mental deficiency" during the period from the start of Selective Service until the end of the war. There are heavy losses of manpower in those cities and regions where conditions of life depress intellectual performance.

The problem of the culturally deprived has been highlighted in the last decade by at least 3 important developments. The first is increasing school desegregation in the South. The Negro population includes a large number of children who have not had adequate learning opportunities, and with desegregation there is increasing recognition of the need for more adequate educational facilities. A second important change is the great influx of indigent families into the large cities. San Francisco—where a decade ago the socioeconomic level and school performance of pupils were high—now classifies nearly one-half of its citizens as culturally deprived. New York, Cleveland, Chicago, Detroit, and other large cities are facing similar situations. The third development or factor of importance is the large number of children in migrant families who literally have no home and no community roots.

A problem so massive, so embedded in our whole culture, will not respond to easy or quick solutions. There are at least 2 major approaches to it, however: (1) General measures to correct the fundamental social, economic, and cultural conditions with which mental retardation is so closely associated; and (2) specific measures directed at groups of children, among whom the incidence of mental retardation is heavy, to increase opportunities and provide experiences that will offset or alleviate the adverse factors in their environment.

The general measures must clearly be long range in character and must be designed to overcome the social and economic ills which plague the underprivileged in our society. These are our greatest hope for a major victory over mental retardation. The

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social security, public assistance, unemployment compensation, and other income replacement programs for people who cannot work or for families which have lost their wage earner are in this category, as are the more fundamental actions necessary to achieve sustained high employment in our economy.

Among the general measures, also, are a host of steps to equalize and increase opportunity for all our citizens. Included are the measures which are designed to give our children and youth a fair start in life by enabling them to have strong bodies and sound minds so that they can grasp the opportunities for self-development and achievement which will be available to them. In this sense, the maternal and child health measures discussed above, as well as the strengthening of health services generally, are of great importance, because human development is now recognized as beginning long before the child is born and as being substantially determined for better or for worse very early in life. Of high importance also is the strengthening of our educational system at all levels, and its supplementation through training programs which can provide for our youth the bridge between formal schooling and the world of employment. The Panel places great emphasis on enactment of the measures which the President has proposed for general aid to elementary and secondary education, for aid to higher education, and for new pilot programs to increase youth employment opportunities.

Still other programs, although of less general application, are the urban renewal and area redevelopment programs. They are designed to assist particular types of distressed communities—in which the incidence of mental retardation is extremely high.

The second group of measures is more specific in its application. It is directed not so much at the fundamental environmental conditions in which mental retardation arises, but rather at the groups of children in such adverse environments who may be retarded. The objective of these measures is to arrest the adverse effects of seriously deprived home or community environment by introducing through the schools, through guidance and employment services, and through other community activities, the kinds of opportunities and experiences which will stimulate and assist such children in their intellectual development. In this connection, available evidence suggests that the effects of cultural deprivation may be reversible, but to be most effective, action to offset such impoverishment must be set in motion before the typical age of school entrance. The Panel has a number of suggestions regarding such specific actions.

Centers for preschool children in rural and urban slum areas and the devising of similar enriching measures is one approach to be stressed. The centers should emphasize the acquiring of the attitudes and aptitudes which middle-class culture characteristically develops in children and which contribute to academic and vocational success. They should be concerned not merely with meeting the physical needs of the children, but much more with the development of their patterns of thought and motivation conducive to school and occupational success. The major focus of these programs should be on developing modes of learning, on communication, and on attitudes conducive to social adjustment. The centers might be a supplement to, or an extension of, day care centers operated for children of working mothers; they could be built in connection with low-cost public housing projects or they might become a part of the public school system in underprivileged areas, where children could start "school" at 3 rather than at 5 or 6.

Another fundamental part of any program designed to lift the level of the economic and social life of families is work with the parents. This may be done through many channels—the schools, social work agencies including settlements or neighborhood houses, and maternal and child health centers. Social workers and public health nurses, home economists, schoolteachers, and volunteers with special training can be effective with young mothers in introducing them to better childrearing practices.

A long-range approach is that of establishing courses and practical experiences in family life education in junior high schools. Under skillful leadership, nursery schools attached to junior and senior high schools could become "learning laboratories" for adolescents in some of the practical aspects of child care. Such procedures will be of no avail, however, unless the public schools are sufficiently reorganized—as they are beginning to be in many slum areas—to adapt educational opportunities to the needs and learning capacity of the children with whom they are working.[6]

Cultural deprivation of a serious nature produces a tragic loss of manpower, both to industry and the armed services; it constitutes a major problem of education in the schools; and, as Conant has pointed out in *Slums and Suburbs,* it is a source of accumulating "social dynamite" in our large cities. Large-scale research programs are needed to get at the roots of this complex problem; not enough is known about the specific origins of the patterns of performance and attitudes of the culturally deprived and how to change such patterns. Programs now underway in a number of cities including New York, Cleveland, Detroit, and Iowa City, and another soon to be launched in Milwaukee, Wis., should eventually illuminate these problems.

The contribution of the President's Committee on Juvenile Delinquency and Youth Crime through its emphasis and stimulation of improved coordination of community youth services and through its grants, which will amount to $5.8 million during the fiscal year 1963, has been a significant constructive influence in many community projects.

Infants in hospitals and residential facilities may suffer impaired intellectual development as a result of maternal deprivation and lack of stimulation. Officials responsible for such programs are urged to make provision for emotional support and intellectual stimulation as an essential element of care.

It is further recommended that accrediting agencies evaluate hospital and residential programs with respect to this important element of child care.

The effect on infants of institutional placement in early life has been studied more intensively than any similar environmental experience.[7] As a result of the findings, more infants are placed in foster homes in preference to institutions, and there have been some changes in the patterns of institutional care of young children to provide more individual attention.

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The separation of infants from their mothers or substitute mothers may affect the former adversely. Infants who react negatively to separation live a depressed existence with low physical and intellectual achievement.

Another category of mother-child distortions includes the so-called "unavailable mother"—the mother who is literally unavailable, such as a working mother, and the mother who is unable to supply the needs of her children because of difficulties within herself, and who is therefore emotionally unavailable. There are other mothers who cannot arouse themselves sufficiently from their passivity or lethargy to relate affectionately to their children, and there are deeply depressed and mentally ill mothers and those who reject their children for various reasons. In contrast, there are the overprotective mothers.

Still another cause of physical trauma is what has been called the "battered child syndrome." This refers to an almost incredible occurrence in our society—various injuries to young children, including brain damage, resulting from frequent or severe beatings on the head by parents or others who care for small children. Instances of this kind have occurred with sufficient frequency in the last 2 years to prompt the Children's Bureau to undertake an investigation of the circumstances surrounding such cases, and to discuss appropriate action with representatives of the medical and legal professions. The Bureau is urged to continue its study of this problem and to take appropriate action through publication of its findings and in providing consultation to local and State child welfare agencies and courts.

It is important in these days when a substantial body of data are available on mother-child relations and the effects of separation and rejection, that hospital and other staff dealing with "separated" children have adequate knowledge of it.

In addition to the deleterious effects on intellectual development of conditions associated with slums, mental retardation may be accentuated and perhaps even created by distortions in normal maternal-infant relationships occurring in families of any socioeconomic group. Institutional placement in infancy is one type of distortion in the usual pattern of childrearing which has been studied extensively. Generally, the findings of these studies are consistent in indicating that separation of infants from mothers and placement in institutions may adversely affect both emotional and intellectual development. While further study must be undertaken to identify the specific conditions of separation and institutionalization which operate to depress development, it is nevertheless of critical importance that groups accrediting hospitals and residential facilities direct attention to the adequacy of any environment in which young children receive 24-hour care.

As their contribution to a concerted effort of this kind, local and State health and welfare agencies should direct their attention to measures which offset the adverse effects of deprivation on children and youth.

State and local agencies can make specific contributions to the attack upon those particular adverse characteristics of the life of the culturally deprived which contribute to their lowered learning efficiency in school and in the world of employment. They should review their programs with a view to—

(1) Increasing the number of qualified boarding and foster homes;

(2) Increasing public health nursing and social case work services to deprived families;

(3) Establishing more day care centers for young children of working and otherwise "unavailable" mothers;

(4) Increasing guidance and employment services provided by the schools in order to build on the earlier help given and to aid transition of the child to adult status;

(5) Providing recreational opportunities for mentally retarded children by means of vacation camps and leisure time and other programs in the child's own neighborhood;

(6) Increasing parent counseling and education services;

(7) Providing homemakers and home economists to mothers who require help in family and child care;

(8) Experimenting in the training and use of volunteers and paid aides to assist professional personnel in work with mentally retarded children.

Joint planning among the appropriate Federal, National, whose pregnancy state is known should include all women of childbearing age. The risk involved in over-the-counter (proprietary) drugs taken with no direct physician supervision is also a matter of concern.

It is important that young women should be informed of this danger by family physicians and community clinics, and by means of health and hygiene courses in public and private schools. Physicians should consider the possibility of pregnancy in selecting medication, particularly new and relatively untested drugs.

Research on the effects of various chemical agents on all humans, particularly women of childbearing age and infants and young children, should be increased in universities and other research centers and in the intramural program of the National Institutes of Health.

While more stringent testing requirements of drugs will mean a larger expenditure by both the Government and the pharmaceutical industry and may possibly delay the advent of new and beneficial pharmaceutical products, this is a small price to pay for increased protection.

A few States have enacted laws or established regulations providing for the registration, inspection, calibration, and licensing of X-ray and fluoroscopic machines and other ionizing radiation sources; it is strongly recommended that all States establish such provisions and that the Public Health Service continue to expand its program for radiological health protection, with special emphasis on the provision of assistance to the States in establishing effective X-ray control programs.

The health hazards resulting from radiation exposure have become a matter of mounting public concern, and various public advisory bodies, including the National Advisory Committee on Radiation, have underlined the need for an intensified Public Health Service program to control this hazard. In response to this concern, the Public Health Service radiological program has grown rapidly from less than $1 million in 1958 to $11 million in 1962. The funds authorized by the Congress for 1963 would continue this rapid growth by providing almost $16 million for this program, an increase of nearly 45 percent over 1962. The Service should continue to be provided with funds adequate to its broad responsibilities in radiological health.

The Panel also urges that lifetime radiation records be developed in selected areas under the auspices of the Department of Health, Education, and Welfare for the recording and dating of diagnostic and therapeutic X-ray exposures. Even though it may not be possible to measure exposure doses accurately in each case, studies should be made to determine whether an extensive program of individual records should be mounted. To be of maximum value, a record of this type should cover the period from conception to 30 years of age.

Extreme caution is indicated in exposing patients to X-ray beyond the point actually necessary for effective diagnosis. Women are frequently X-rayed when they are not aware of their pregnancy, and hence at a time when the fetus is highly sensitive to radiation. It is therefore imperative that young girls and pregnant women be spared unnecessary X-ray exposure of any kind, and that full statements of menstrual history be obtained in advance of exposure from all women of childbearing age.

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(6) Increasing parent counseling and education services;

(7) Providing homemakers and home economists to mothers who require help in family and child care;

(8) Experimenting in the training and use of volunteers and paid aides to assist professional personnel in work with mentally retarded children.

Joint planning among the appropriate Federal, National, State, and local agencies, both public and private, is essential to insure the adequate development of preventive services in local communities. This is discussed at greater length in Section IX, Organization of Services—Planning and Coordination.

At the local level, for example, it is highly important that municipal zoning boards encourage the establishment of day care and other types of neighborhood centers in socially deprived areas for the benefit of normal, as well as disabled, children. A recent significant contribution to such development is embodied in the President's welfare legislation which, as enacted, provides Federal grants to States for the establishment of day care facilities for children. The initial authorization was $5 million for fiscal 1963 and $10 million annually thereafter. The need for development and expansion of these services is urgent since there are about 15 million children of mothers who are working or are otherwise unavailable, of which 4 million are under age 6 and 5 million are between the ages of 6 and 11. A 1958 survey indicated that there were no plans for 400,000 children under 12 and that they were expected to care for themselves while their mothers worked full time.

The greatest needs in the day care area as reflected by a recent Children's Bureau survey of the States are: Facilities for certain special groups of children such as the mentally retarded, subsidized low-fee facilities for those who cannot afford the full cost of care; and facilities in industrial or metropolitan areas to serve working mothers. It is highly important that local zoning boards encourage the establishment of day care centers in socially deprived areas for the benefit of normal as well as disabled children.

Neighborhood and day care centers can be bases for community health educational programs and for many related activities. The Panel has recommended elsewhere (Section II, Research and Scientific Manpower, and Section VI, Residential Care) that the Secretary of Health, Education, and Welfare review the need for construction of facilities for the mentally retarded. The facilities considered should include community health centers.

It is also recommended that the Department of Health, Education, and Welfare through its health and adult education programs, assist the States and localities in developing methods of motivating people in depressed areas to seek out and make use of the community services available to them.

Information services should utilize experts in the television industry, particularly in educational television, for the development of programing which may have some impact on those groups in the population which have a high prevalence of mental and social disorders. Sufficient funds should be provided from private sources to assist in the development of appropriate television scripts. This effort should involve both Federal and State agencies, since there are regional problems which differ in various parts of the country.

In view of the critical shortage of personnel and the need for volunteers in health, welfare, and education—particularly in areas of extreme deprivation—it is recommended that a domestic Peace Corps be organized to provide stimulus to volunteer community service groups.

A bold preventive approach is called for to interrupt, for at least one generation, the adverse cultural and social ailments which are the root of many of our health and social problems, including mental retardation, juvenile delinquency, and poor standards of physical and general fitness. These problems call for assistance to the passive and dependent or underprivileged families, many of whom are not reached by existing public or private community services. Their needs are great, but their financial and spiritual resources are meager. We must help them.

However, even if our capacity to finance services through public funds were of no consideration, there is one critical factor which constitutes an almost impassable barrier to the rapid expansion of necessary services. This is the lack of trained people to work with the children and the families in the disadvantaged communities. Yet, this shortage coexists paradoxically with a search on the part of large groups in our population for a meaningful and useful social outlet for their energies. Among the latter is a substantial proportion of our 17 million aged citizens, many of whom have been enabled to retire at comparatively early ages and who, with growing lifespans, can look forward to many years of life.

Voluntary service by citizens from all walks of life can help meet the needs for community service and also to provide useful outlets for people who want to serve. There is a long history of devoted and competent volunteer service in our country. The time has come, however, for a more extensive and intensive effort—on a National, State, and local basis—than we have ever undertaken. The experience to date in the field of mental retardation alone, in the constructive use of volunteers, is quite enough to justify such a move.

Many great volunteer service organizations are already rendering extremely useful service for many worthy causes at National, State, and local levels. We believe, however, that their efforts could be redoubled and millions of new volunteers could be recruited if voluntary service were given greater emphasis and recognition in our national life. We believe that this can be achieved by the creation of a domestic Peace Corps through which the President of the United States, together with outstanding leaders in public and private life, can provide leadership and stimulus for this high purpose. Such an organization can also assist existing voluntary organizations, and with appropriate State and local committees can reinvigorate and give new impetus to the volunteer spirit throughout the country.

Volunteers of all ages should be challenged to engage in a wide variety of community activities. We must learn to give not only our money but ourselves. Busy people should be asked to devote a portion of their time and talents. Scientists and mature social workers, experts in community organization, and other professional personnel should be called to lend their skills to the highly valuable purposes of organizing and conducting training programs for the new volunteers. Housewives should be encouraged to serve. The youth should be challenged to join. The retired people should be recruited to place their rich experience and special talents at the service of underprivileged youth.

Local activities in this spirit are already underway in Philadelphia, Washington, D.C., New York City, and in other portions of the country. But a movement on a national scale is not only essential from the point of view of helping to man community services, but as a meaningful and useful experience for thousands of capable people who would find it rewarding to engage in such activities. The young people of America, especially, need to be challenged and "stretched," and volunteer service in our own communities could be a wholesome and satisfying, as well as stabilizing experience for them.

In the development of a national domestic Peace Corps, special provision should be made to include services for the mentally retarded. In view of the acute need of the retarded present in many communities, it would be of great value if some members of the Corps were given special training in this field of work. Earlier in this report the needs of certain groups of people in our large cities and some rural areas were stressed. The importance of the environment in the development of children was pointed out, and a recommendation was made urging that schools and community agencies provide the personnel to assist in bringing to families and local neighborhoods some of the personal warmth and friendship that they need, educational and recreational activities and programs, instruction in childrearing and other constructive aids and influences. It is this kind of contribution that a domestic Peace Corps could make to our people, just as the Peace Corps has made in international service.

Section IV

CLINICAL AND SOCIAL SERVICES

In spite of extensive research and effective preventive measures, there will always be some children and adults in every stratum of society who will be handicapped to some degree by mental retardation. Sections IV, V, and VI of this report discuss the general and specific needs of the retarded, and the programs and services required to meet them.

The "richer" and the more easily available all general services become, the less need for special services for the retarded. Even if there were no need for economy the conviction that the retarded must be viewed as part *of,* rather than *apart* from, their fellow citizens would be sufficient reason to advocate that whereever a general setting or service or a general law can properly and effectively embrace the retarded person, it should do so. If there are barriers to his access—physical, psychological, social, legal, or administrative—they should be breached. This principle like many others is easier to articulate than to apply, but it must be kept before the American people as it has wide and general application.

A Comprehensive Program for the Retarded—"Continuum of Care"

Various ways by which the mentally retarded and their families may be helped to find and make the best use of the most suitable resources, whether general or specialized, are discussed in the following sections. Specialized medical, educational, or vocational services or whatever services are required should be readily available when and where they are needed. In range and variety, they should be capable of advancing the well-being of each retarded person regardless of his age and degree of disability.

Thus, in order to prescribe for an individual in particular at any given time, and for the retarded in general, there must be an inclusive array of services available. These are administered for the most part by, through, or within instrumentalities which administer to the nonretarded—that is, the family, the professions, and the health, education, welfare, and other agencies which society has created for these purposes. Ideally, the elements in this array should be so intimately related to one another, and so accessible as to be readily marshaled into a "continuum of care."

"Continuum of care" describes the selection, blending and use, in proper sequence and relationship, of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his lifespan. Thus "care" is used in its broadest sense and the word "continuum" underscores the many transitions and liaisons, within and among various services and professions, by which the community attempts to secure for the retarded the kind and variety of help and accommodation he requires. A "continuum of care" permits fluidity of movement of the individual from one type of service to another while maintaining a sharp focus on his unique requirements. The ongoing process of assuring that an individual receives the services he needs when he needs them and in the amount and variety he requires is the essence of planning and coordination.

The three basic elements in administration are germane to the process of proper planning for the individual retarded person; that is, *evaluation* (stating the problem, getting the facts, and assessing them) ; *planning;* and *implementation* (or execution), followed by reevaluation, revised planning, and further implementation. Most people engage in this process with respect to their own lives or those of their children in securing good health, education, and economic security. For the retarded these phases must be more consciously and expressly reinforced.

The process begins with identification of the retarded as a person with special or extraordinary needs. The first element in an adequate continuum therefore is that of "case finding," attuned to discovering the infant or child with suspected mental retardation and referring him to an agency having special professional competence for diagnosis and evaluation. Planning for the individual by, and with, the family must follow. This calls for parent counseling (initially intensive and continued as necessary), referral, parent education, and information. In some cases the retarded person himself may eventually be involved in his own reevaluation and planning. Finally, implementation depends on the accessibility of the services called for by the evaluation and plan.

Without enumerating the general services upon which the retarded may draw in common with the nonretarded, there is set forth here a representative array of services which should be made available for the retarded in some special form.

The accompanying chart includes only those services which should be rendered directly to the retarded person. Not included are the various diagnostic and evaluation services necessary at each stage, and those services designed primarily to sustain and reinforce the family. Clearly a wide variety of special services should be available to augment those rendered to the retarded child and adult by his immediate family and by the general agencies. The primary importance of the family in planning and caring for the mentally retarded person must nevertheless be emphasized. In the ongoing process of planning and care, the family should be advised, guided, and supported by qualified professional persons and agencies.

The various services that should be available in this array must be marshaled in different ways and in different combinations for different people in accordance with their needs at different times. Some of the services are rather closely related to one another and may be offered by the same agency, but in general one should free himself from any fixed preconception as to how the individual component services should be aggregated or grouped either physically or administratively.

*Array of Direct Services for the Retarded**

Life stage	Components of special need
	Physical & mental health - Shelter nurture protection - Intellectual development - Social development - Recreation - Work - Economic security
	Specialized medical follow-up Residential nursery
Infant	Special diets, drugs or surgery Sensory stimulation
	Child welfare services Home training
	Home nursing Environmental enrichment
Toddler	Correction of physical defects Foster care Nursery school
	Physical therapy Trained baby sitter
	Classes for slow learners Playground programs
Child	Psychiatric care Homemaker service Special classes—educable
	Special classes—trainable
	Dental care Day care Religious education Scouting
	Swimming
	Short stay home Work-school programs Day camps
	Residential camps
	Boarding school Speech training "Disabled child's" benefits
Youth	Psychotherapy Occupational training Youth groups
	Social clubs Health insurance
	Half-way house Vocational counseling—Personal adjustment training Selective job placement
Young adult	Facilities for retarded in conflict Guardianship of person Marriage counseling Sheltered employment
	Total disability assistance
	Long-term residential care Sheltered workshops
	Bowling Guardianship of property
Adult	Group homes Evening school Social supervision Life annuity or trust
	Evening recreation
	Boarding homes
Older adult	Medical attention to chronic conditions Old age assistance
	OASI benefits

*Not included are diagnostic and evaluation services, or services to the family; the array is set forth in an irregular pattern in order to represent the overlapping of areas of need and the interdigitation of services. Duration of services along the life span has not been indicated here.

Not only should all the major agencies, in health, education, and welfare (both public and private), play a conscious and conspicuous part in serving the retarded, but so also should those responsible for the administration of justice, for the use of natural and human resources, for the Nation's economic stability and security, and especially those concerned with the Nation's spiritual life.

Citizens must know and understand the needs of their handicapped fellows, for understanding will help to bring concern, and concern will prompt action. In like manner, in the public field all levels of government must be informed and involved. The next sections present recommendations on detection, diagnosis and evaluation, management, medical and social care, education, rehabilitation and training, recreation, and protection under the law. Recommendations on the organization, administration, and coordination of services at the various levels of government and participation of private citizens will be found in the last two sections of the report.

Detection, Evaluation, and Medical Care

Early Identification

Because adequate training and care are dependent upon early detection and evaluation, every child should receive continuous child health supervision. Every child should be examined for possible intellectual deviations; screening tests for the early detection of abnormalities should be established as part of the regular and routine service of well-baby and other child health clinics.

The importance of an adequate evaluation early in the life of every child suspected of mental retardation cannot be overestimated. Decisions based on erroneous expectations as to the child's capacity can lead to chronic failure with resulting emotional handicaps. Unfortunately, even among professional personnel, neither this nor the advantages of specialized treatment and care during infancy and childhood is fully appreciated. The responsibility for early identification of the mentally retarded child rests with the members of professions who see children at an early age, including the family physician, the public health nurse, or the child welfare worker. Diagnostic and treatment facilities, and social and health agencies, share this responsibility along with nursery schools and day care centers. Indeed, every individual and organization dealing with the preschool child in a professional capacity is involved.

Although severe forms of mental retardation are frequently recognizable at birth or in infancy, the majority of retarded children at first appear to be normal and are not readily distinguishable without periodic and meticulous scrutiny of their growth and development. If this is done consistently, slow development in one or more areas will identify the retarded child at an earlier age than is now occurring. Unless there are adequate facilities for discovery and identification, or at least some informed and alert professional personnel in a community, the mildly retarded may not be identified until after a period of school failure.

A few types of mental retardation such as that related to phenylketonuria may be prevented or ameliorated if the causative disease is identified promptly after birth and treated at once. It is possible that mental retardation associated with cultural deprivation may be reduced somewhat, but not unless it is detected early and radical changes made in the child's environment. (See Section III.)

Moreover, biological and cultural factors are often interdependent. For example, babies born to parents with little knowledge and marginal incomes are more likely to suffer also from prenatal and postnatal malnutrition. Conversely, undetected biological impairments, such as poor vision or hearing, may contribute to inadequate stimulation and thus aggravate the effects of a depriving environment.

To facilitate detection of a large number of children with incipient handicaps, a system of examination and observation of the newborn by physicians and nurses should be established in every general and maternity hospital.

The Children's Bureau, in cooperation with 32 health departments throughout the country, is sponsoring a screening program that will test 400,000 children in an attempt to detect phenylketonuria. It is hoped that if the blood test is successful, approximately 20 cases will be found and treatment begun. Allowing an estimated cost of $100,000 per person for lifetime care, a saving of $2 million will be possible. This does not include the potential contribution of these cases in terms of their normal income earning capacity.

An inclusive program of early detection should include the referral by the maternity hospital of high-risk newborn infants to physicians, child health clinics, or others who are responsible for continuing health supervision or care, followup by public health nurses, recording of the observations of physicians, and the use of special neurological and other screening procedures. The inclusion of suitable items on the "confidential medical data section" of birth certificates may be helpful as a mechanism for discovering cases of mental retardation.

The detection of infants subject to abnormalities depends to a very considerable degree on focusing attention on the "high-risk" groups—infants whose backgrounds, home, and parents give reason for special vigilance or those whose condition at birth merits special attention. The almost universal practice in this country of deliveries in the hospital gives an opportunity to evaluate the child himself and the capacity of the mother to care for him. Thus, many of the "high-risk" cases can be identified and registered for special care. The Panel's Mission to Great Britain found British innovations in this field worthy of study.

The advantage thus gained can be carried further if a sound relationship is established between the physician; the staff of the clinic, hospital, or public health agency; and the families of the infants. Public health nurses or other professional personnel can thus continue the observation of the child with the cooperation of the family and can keep the physician or the clinic informed of his progress and needs.

The 1930 White House Conference on Child Health under President Hoover guaranteed the right of every child to "adequate prenatal and maternity care and continuous medical health supervision after birth." while a great deal of progress has been made in the last 30 years toward compliance with this pledge, most communities in the country and particularly the large cities still have a long way to go in meeting it.

In the United States approximately 15 percent of babies are now estimated to receive care in their first year of life through health department "well baby" clinics. The trend has been upward from 12 percent since 1956 to 14.3 percent in 1960. These clinics most often serve underprivileged populations or "high-risk" groups and thus offer an important resource for early identification. Unfortunately, many of the "well baby" clinics have such limited resources in manpower and funds that they cannot offer services throughout childhood. In some cities the clinics limit themselves to the first 2 years of life. The role of the "well baby" clinic in serving as an important educational focus for the enrichment of environment in order to prevent mental retardation associated with cultural deprivation has been virtually untouched.

"Health Supervision of Young Children—A Guide for Practicing Physicians and Child Health Conference Personnel," published by the American Public Health Association, is an excellent blueprint on the content and standards of health supervision. It is absolutely essential that screening tests and physical and laboratory tests specifically include the neurological and sensory deviations as well as periodic appraisal of growth and development in physical, emotional, intellectual, and social functioning.

The importance of adequate child health supervision is apparent from some basic facts concerning the health status of children. More than 9 million children—17 percent of the population under 15 years—have one or more chronic conditions, and many more would have developing ailments. Of the number with chronic conditions, about 350,000 are unable to attend school or to play with other children. It is estimated that in the sensory area alone, an area of crucial importance to the problem of mental retardation, between one-third and two-thirds million children have a significant hearing loss and over 2 million a speech handicap. Several million children have eye conditions that may play a role in their adjustment or educability.

Physicians need special orientation with respect to the nature and implications of physical and intellectual disabilities. The whole process of early detection, case finding, diagnosis, and medical care of the disabled, particularly the mentally retarded, requires the full cooperation of knowledgeable and interested physicians and other professional personnel. It is essential for them to be familiar with normal expectancies so that significant deviations will be recognized as early as possible. By careful observation and recording of the growth and development of all children under their care, physicians have a unique opportunity to detect deviations from the normal range.

While the family physician is in a strategic position to identify and refer "suspect" infants and young children, he cannot be expected to detect *all* who are mentally retarded. As mentioned earlier, most retarded children are not identified as such until sometime after they enter school. The majority of mildly retarded children do not present organic deviations which can be detected by currently available techniques of medical examination; therefore, identification may often be achieved only through careful psychological examination. Unfortunately, intelligence tests are not now routinely administered to all children in the preschool years. Since success in rehabilitation is so contingent upon early detection of intellectual disabilities, it is imperative that effective methods be devised for mass intelligence screening of young children, particularly for those segments of the population where the prevalence of mental retardation is high. Research agencies are urged to support promising studies relevant to this problem.

It is important that the faculties of graduate schools in the health sciences, psychology, social work, and education have a comprehensive grasp of the modern knowledge concerning development of the human organism, and the origin and recognition of abnormalities and the place of this knowledge in the professional curriculum. Some universities are now giving students experience in well-child clinics, and in child welfare and family agencies and nursery schools. Training of this type is highly valuable in creating among young people, during their professional training, an awareness of the importance of early detection as well as an appreciation of the interdisciplinary cooperation necessary to accomplish it.

Schools of public health particularly should be encouraged to increase their research and training in selected aspects of mental retardation. These schools with their departments of biostatistics, epidemiology, maternal and child health, and mental hygiene are uniquely qualified to train people and to undertake large-scale epidemiological studies of environmental factors in intellectual development, the effect on other siblings of having a retarded child in the home, and the evaluation of community services for the retarded.

The seminars in a school of public health, with its emphasis on prevention and with its faculty and student body from clinical and community medicine, nursing, and the social sciences, can provide an excellent forum of discussion of clinical, administrative, and jurisdictional problems in improving services for the retarded. These services include screening programs, management of metabolic disorders, laboratory diagnostic services, special health department clinics, home visiting by public health nurses, and consultation by social workers and nutritionists. Faculty and senior fellows should be urged to accept joint appointments and responsibilities in the university and in a service agency for retarded children.

Clinical training in problems of behavior of children and adults should be made available to a greater degree than at present. A few traineeships are now offered by private foundations and the Children's Bureau. Increased support of this type of training through a variety of agencies in the country is strongly recommended.

Diagnosis

Every person suspected of mental retardation should have the benefit of expert comprehensive diagnosis and evaluation.

A comprehensive diagnostic evaluation provides the basis for all other services for the mentally retarded and his family. Neither short- nor long-term planning can be undertaken safely without an adequate evaluation of pertinent medical, psychological, and social characteristics and needs. It is essential that all case-finding efforts be backed fully by diagnostic laboratory services and the services of medical specialists and psychologists who can confirm or refute the presence of mental retardation.

To assure access, areas of low population density should be served by traveling clinics or by arrangements for transportation and lodging for parent and child at an area or regional facility.

Community clinics serving children with intellectual and neurological disabilities should extend their services to provide for additional patients and more professional training opportunities. A comprehensive diagnosis and evaluation of a mentally retarded child and his family in a community health clinic or an outpatient department requires the contributions and cooperation of several professions. (Hence, the term "interdisciplinary" or "multidisciplinary" frequently used to describe these clinics.) The physician, including the pediatrician, psychiatrist, neurologist, the psychologist, the nurse, the social worker, the special educator, the audiologist, the speech pathologist, and frequently others, all have important contributions to make. These services can be provided in many types of clinical settings.

One example of how these skills are brought into play is now being demonstrated in many of the 97 special clinics for retarded children in the United States, 64 of which are sponsored by the Children's Bureau. In total they served some 20,000 children in 1960. Some of the clinics furnish opportunities for training in more than one field which is of special value to professional personnel preparing for work with the mentally retarded.

Most of these clinics have been in operation for only a few years, but the demand for their services has already demonstrated their value and now far outstrips their capacity. Some, with long waiting lists, presently are able to function only on a part-time basis.

Another pattern is illustrated by the 1,400 outpatient psychiatric clinics in the United States. Nine out of 10 such clinics serve children, and about 15 percent of the children with disorders are diagnosed as being mentally retarded. A conservative estimate is that 40,000 mentally retarded children and adults were served by these facilities in 1960. Thus the current increased support and growth in strength of community mental health facilities have a direct bearing on improving services to the mentally retarded.

A third pattern which offers promise is the provision of such services through group health plans. The pending administration bill to provide financial assistance to such organizations through loan guarantees and direct loans should help speed the expansion and formation of such plans.

The U.S. Children's Bureau, the U.S. Public Health Service, State health departments, and State and local departments of education should support the extension and improvement of clinical services for the mentally retarded.

Resources should be made available to extend the patient load of clinical services for the mentally retarded and to enhance their professional training potential. Strong centrally located clinical services should be encouraged to extend their influence by offering fully staffed clinic days in outlying areas and smaller population centers on a regular basis.

All health services and facilities in the community should serve the retarded to the extent of their capability. Frequently pediatric, orthopedic, and mental health clinics, and other regular community agencies, offer only limited service to the retarded or exclude them altogether, thus increasing the demands made on special facilities. Child welfare and family agencies under private auspices, services for crippled children under State administration, mental health services, general clinics in hospitals and university centers, and the psychological and health services of the public schools are among those which can and should actively serve the retarded.

It is estimated that 90 percent of school systems attended by 95 percent of schoolchildren have some form of organized school health service. While we have no definitive information on the quality of service available, we know that the school health program is minimal in many school systems. In many instances it may consist only of annual screening examinations for gross defects or occasional public health nurse visits to schools for problems relating to limited concerns such as infectious disease. In contrast, some school systems have a carefully worked out case-finding and referral program. By virtue of the extent of coverage and the key age group involved, it is apparent that school health programs have an enormous potential for the diagnosis and supervision of many childhood diseases, including mental retardation. Where available, special clinics for the retarded should be looked to by the related agencies as a resource for consultation and for referral of the more difficult cases of diagnosis and treatment.

There are a number of reasons, over and above the problem of costs, why services for the retarded should be a part of existing services for other children. First, because of the difficulty that frequently arises in making a definite decision as to whether a child is or is not intellectually subnormal. Second, because the case-finding and diagnostic problems include the whole field of physical and mental health and education. Third, because the retarded have needs common to many children. And finally, because the retarded child has been isolated too long and should become an integral part of community life.

Medical Care

State governments should lift all present restrictions barring retarded children with physical handicaps from services available to other children. To increase the capability of the states to provide services for retarded children under the State crippled children's program, additional earmarked funds should be made available to that program.

The inclusion of retarded children in existing services applies to the public agencies perhaps even more than to private or voluntary services. Title V, Part 2, of the Social Security Act (Crippled Children) does not exclude the retarded child with physical handicaps from its benefits, but the demands for crippled children's funds in the States is heavy and retarded children have little or no priority. It is proposed therefore to increase the financial capabilities of the States to meet the needs of this group with the provision that retarded children be included.

During the fiscal years 1962 and 1963, the full authorization of $25 million each has been appropriated to cover the programs for crippled children and for maternal and child health. The latter program which spent no money specifically for the mentally retarded in 1952 has, within the past 5 years, quadrupled its expenditures for this purpose from $0.5 million in 1957 to over $2 million in 1962.

The official State crippled children agencies are a significant resource for the diagnosis, treatment, and aftercare for handicapped children. In 1960 they provided such service for over 350,000 children with a wide range of handicapping conditions.

To carry out this and other recommendations, it will be necessary to raise the statutory limits on the maternal and child health and crippled children's sections of Title V.

The physical and emotional needs of the retarded are neglected. Adequate treatment of these needs is essential to their total wellbeing.

All professional personnel should be oriented to the special needs of the retarded. Physical and emotional handicaps are common among the retarded and require early detection and competent treatment. The retarded child is subject to all of the diseases and health hazards to which the intellectually normal child is heir. In addition, his problems of retardation arc frequently complicated by such serious disorders as speech, hearing, sight, and dental defects.

The American Speech & Hearing Association has made a number of practical observations to the Panel on meeting problems of speech and hearing impairment among the retarded.[1] To provide dental care for those who are so severely handicapped that they cannot be treated in an office, it is suggested to the American Hospital Association and local boards of general and special hospitals and other community services that complete dental care facilities be made available in a hospital or conveniently located institution, where the dental needs of mentally retarded children could be incorporated into the general rehabilitation program of the patient.

The general medical approach to the retarded and the normal child should be basically the same. In many instances, a physician who is well informed in the field of retardation can serve in a liaison capacity between the family and child, on the one hand, and the several consultants and clinics required for the child's proper treatment and management, on the other. The

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[1] Obtained at the national headquarters of the Association, 1001 Connecticut Ave. NW, Washington, D.C.

physician should participate in planning a program of treatment and management for the child and should be involved in insuring that such plans are carried out, working closely with other professional people.

As in the case of physical handicaps, emotional maladjustment may compound retardation, producing a double handicap. Experience has shown that, with the proper approach, emotional difficulties among the retarded are as amenable to intervention as in the rest of the population within the limits imposed by the severity of the retardation. Even where there is relatively little ability to participate actively in the remedial process, it is possible to work with those components of personality makeup that are available.

As in the instance of the treatment of his physical disabilities, the retarded person has every right to expect that the same psychiatric treatment facilities and resources available to others will be open to him, if and when he needs them. In some instances this may necessitate the addition of a psychiatric consultant to the staff of a clinic. In others it may require that the present staff become much more knowledgeable in emotional aspects of mental retardation. The administrators of mental health services are urged to orient their personnel in the mental health problems of the mentally retarded and to provide such services for the retarded as their facilities allow.

When considering the total span of clinical needs of the retarded child, within his "continuum of care," the importance of case management can hardly be overestimated. Studies of etiology are essential, early case finding and detection are fundamental, adequate medical care is basic. But the broad objective in the field of retardation, in addition to gaining new knowledge through research, is to do everything that can possibly be done for the retarded individual medically, psychologically, and socially and vocationally, and thus improve his total functioning at every level, enhance his assets and compensate to some extent for his liabilities. In a *word, management, in* the best and most comprehensive sense of the term.

Role of the Family

Acceptance by the parents of the true nature of their child's handicap is essential if they are to be effective in helping him. Even though the diagnosis is carefully explained in simple terms to the parents during and after the examination, they are frequently reticent in the presence of a physician, or are so shocked by the implications of the diagnosis that the questions they should ask do not come out until days or even weeks later. Thus, responsibility for the family starts with the first meeting, and it should continue through the period when the family needs it most, and indeed in some form throughout the life of the retarded person, if and as required.

The physician and other professional people dealing with the family do not always appreciate the severe crisis through which its members pass during the weeks or months following the revelation of their child's affliction. It is a crisis, however, to which the physician need not and should not minister alone. The family should be able to turn to its minister, priest, or rabbi for help in finding the new strength they will need.

Today there are religious leaders and groups in each of the major faiths who are awake to the need for this new ministry and who are imparting their interest and concern to their colleagues and to lay leaders.

The clergy and their lay assistants are urged to intensify their efforts to meet the spiritual needs of families faced wih the problems of mental retardation. It is important that physicians and pastors meet to share their insights and experiences in helping families whose faith has been sorely tried and whose mental health may well be in jeopardy.

One of the pressing needs of parents in crisis is to be able to act, in self-defense, and even more in defense of their child. Here the constructive practical help of a physician, a nurse, a social worker, a teacher or other counselor can serve to sustain and carry both parent and child forward.

Whenever the mother has capabilities of understanding and cooperation, she should be regarded as a major resource. She usually possesses strong motivation to provide care—a motivation hard to duplicate in any "out of home" programs. Both parents as well as other members of the family should be involved wherever possible.

No mother can be expected to carry the responsibilities of a retarded child without outside support. Not only is relief from a feeling of aloneness and "no-enti-in-sightness" needed, but in addition, tangible help must come from the community. Through volunteers, public health nurses, homemaker services and other aids, assistance can be given in planning and carrying certain household activities for the retarded child, and in obtaining qualified babysitters for an evening or for a weekend away from home. Although day care centers for retarded children are being developed, transportation and other problems make it difficult for many families to utilize them and thus release the homebound mother during the day.

It is difficult to maintain a proper balance between overconcern and rejection or alternating cycles of each in the family of the retarded. An effective means of allaying concern is the provision of substitute care by others in the home, thereby demonstrating on home grounds the ability and interest of others in caring for the child. Meetings of parents in groups are valuable in releasing tensions and encouraging a free exchange of experience and the development of an esprit de corps. It is heartening to parents who have been "through the mill" to help others to face reality and meet the challenge of a handicapped child.

The families of today are subject to many stresses and the rate of family breakup is alarming. This is, of course, one of the conditions in which mental retardation and other social ills thrive.

A major counterforce to these adverse factors has been provided since 1935 through development of our social insurance and public welfare programs which now provide billions of dollars of benefits and services to help support and keep families together. The old-age survivors and disability insurance program, for example, is currently providing benefits of about $1.6 billion annually to 2.9 million widows and children. The Federal-State public assistance programs also play a major role. For example, the program for aid to families with dependent children provides monthly payments and services to an average of 3.9 million individuals annually, and it is estimated that in fiscal year

1963, $1.7 billion will be paid, of which the Federal Government will share 58 percent of cost.

It is significant that of the estimated total Federal funds of $164 million in fiscal year 1963 identified by the Panel as the amount for mental retardation, $127 million, or more than three-fourths, is for income maintenance benefits or related services for persons who are retarded. Of the total of the $127 million, the Bureau of Old-Age and Survivors Insurance provides $64 million in payments through the social security insurance program to children who are specifically identified as being mentally retarded, and the Bureau of Family Services provides an estimated $33 million in Federal public assistance grants to States and localities for payments which help individuals who are retarded. The Veterans' Administration, through its pension and compensation programs, provides an additional $30 million in payments. These figures are mostly broad estimates, because few precise statistics are available. The Federal Government also administers other income maintenance programs which make payments to individuals who are mentally retarded or to their families, although no data are available on the amounts. However, payments undoubtedly add up to many millions of dollars from such programs as Federal-State unemployment compensation, railroad retirement, and civil service retirement.

The Panel applauds the many constructive provisions in the public welfare amendments of 1962 which will help provide additional Federal resources for benefits and services to several million families who are in need. One of the most significant of these improvements is the new emphasis on the provision of increased social services to promote self-reliance. The availability of such services will be made a reality through the provisions for training of welfare workers. Likewise, the increase in the authorization for child welfare services from $25 million to $50 million by 1969 should be of material assistance to the several hundred thousand children who now receive child care and protection services from public welfare agencies. The importance of authorization for day care services has already been noted in Section III on prevention. Similarly the provisions authorizing protective payment plans and support for children in foster care institutions will be highly beneficial. Finally, the provisions extending benefits to families of the unemployed, authorizing community work training programs, and increasing welfare payments to several million individuals and families will be a great help to them.

Cooperative Planning for the Mentally Retarded Child and Adult

When the first round of initial adjustment is over, the "long haul" begins. Here *social* management assumes increasing importance.

Securing the proper "continuum of care" for each retarded person at successive life stages requires expert attention to planning on a long-range basis. The law provides that in our society, parents serve as the primary coordinators on behalf of their children. Education "for citizenship" includes learning to utilize the resources for education, health, safety, and the like on behalf of oneself and one's family. A citizen who is less than expert at this skill can usually negotiate a path to these resources to meet ordinary needs, with the informal advice of neighbors and relatives. It is when the ordinary individual has extraordinary needs that self-coordination-self-guidance through the maze of community services may tax his capabilities. This is even more true when the individual's ability for self-management is impaired.

Coordination of services for the individual retardate begins therefore with a capable parent or other adult willing, able, and obligated to concern himself with the retardate's continuing and changing needs. But the most intelligent and dutiful parent or guardian, let alone the retarded adult, cannot be expected to have adequate knowledge of the extraordinary resources necessary to secure the requisite "continuum of care" for the retarded person. Furthermore, the lifetime duration of mental handicap—especially in those, with more severe impairment of adaptive behavior—precludes the availability of the natural parent or guardian for the retardate who survives to the expected "three score and ten."

Experience has shown that barriers or breaks in the "continuum of care" often arise at points where the family of the retardate must find a new service and establish a relationship with it. At this point a "home base," a familiar face, a person to whom one does not have to rehearse once again one's "history," a person known and trusted from past experience, can make the difference between a referral which is accepted and one which is not.

There should be available in every community a "fixed point of referral and information" which provides a life consultation service for the retarded.

The "point" should be "fixed" in relation to the retardate and his ongoing needs. It could take the form of an office or a mobile service to which those in need of counsel could turn and return for authoritative advice and guidance, or for referral to appropriate general and special resources. Under favorable circumstances this service might be offered by a general community referral service, provided its staff has sufficient specific competence in this complex field.

To be truly effective, this service should have continuity and permanency, so that an ongoing relationship between the client and the agency, and more particularly a person in the agency, may be developed and used by the client on a recurring basis. To achieve the necessary continuity of care, this service should act both as broker and expediter in finding and making use of those resources which the community and State have to offer.

Where the volume of demand permits, consideration might well be given to developing such referral and consultation services for the potentially independent retardate apart from those for the more dependent person. Conversely, where needs are similar, the "point" might well accept and serve persons who have other closely related chronic handicaps with comparable social consequences. These two complementary services might be sponsored in any number of ways; for example, by a local voluntary social agency or by a State or local health or welfare department or other unit of government.

The modern concept of a community mental health center with its array of diagnostic services, outpatient and inpatient facilities, supervision of foster homes and other rehabilitation modalities, and community referral functions, might be one important locus for a life consultation service for the retarded. Cooperative planning for the mentally retarded child necessitates cooperation and coordination with the current planning and review of the national mental health program in which a large number of communty mental health centers is envisaged- These centers are seen as a locus for services to the mentally retarded as well as to the mentally ill. Section IX discusses in greater depth the organization and coordination of services.

The locus of service should be such, however, that the personnel therein have direct access to all resources their clients might need. In fact, it would be ideal if lifetime consultation service of this nature could be provided from an administrative base which was free of identification with any single type of service such as residential care or vocational guidance. From such a base the counselor might find it easier to be impartial in selecting and seeking services for the individual in need.

The person or persons staffing a life consultation service might come from a variety of professional backgrounds such as social work, nursing, rehabilitation, or education. Whatever their professional qualifications, personal characteristics would undoubtedly score heavily in their success or failure. They should be able to communicate with the retarded and with families from every walk of life, and capable of recognizing the links between counseling and referral, and the area of professional treatment into which they should not enter. They should also be flexible and perceptive in making use of the more intensive forms of counseling, such as are offered in clinics, by rehabilitation, counselors, or by schools. The counselor should have direct access to expert professional advice in meeting problems which require competence beyond his preparation.

Local or State agencies having a major responsibility for the retarded should test the continuity of counseling and referral by selecting identified cases at random ior checkout through, retrospective interviws with parents or through cumulative records.

Several services now being offered have shown the practicality of many of the features here proposed. The Special Services Office, under the direction of the Committee on Mental Retardation of the Community Council of Caddo-Bossier Parishes in Shreveport, La., is one example. This pilot program receives a State subsidy. The office provides for central recordkeeping, a central point of information and referral, and a life consultation service. It ties in closely with ongoing community planning based on gaps identified. The specialized counseling offered to parents and retardates in association with the unique guardianship program of the Minnesota Department of Welfare is another example. Similar functions will also be among those performed at some of the new regional centers, such as those being organized in Connecticut. The Parent Information and Counseling Service recently inaugurated in Rhode Island incorporates many useful features as does the Information and Referral Unit in Monroe County (Rochester), N.Y. The statewide traveling "home visitor" of Maine may demonstrate how these services can be brought to rural areas. A research and demonstration project in vocational rehabilitation just completed in Arkansas offers some insights into the effective use of professional and subprofessional personnel in one community setting. These may well be valid in the long-term service here proposed.

Information and referral units and other agencies dealing directly with the retarded should gather data systematically on the gaps and shortages in service and develop a means of communicating significant findings to those bodies responsible for planning and coordination. Such data should reflect any lack of service and the existence of real or perceived obstacles to reaching existing services. Such barriers may include lack of transportation, special eligibility or residence requirements, fee scales, and popular misconceptions about the service itself. Indeed, continuing interpretation to parents and others by the information and referral centers can contribute much to better use of all services.

Parent education and counseling are related but different; both are important. Skillful counseling always provides a certain amount of education, but it is usually aimed primarily at the specific personal problems presented by an individual parent. Education is a more formal procedure intended to convey information concerning the nature and implications of retardation and a wide range of suggestions that will be useful in dealing with children. Most parents need some help and a great deal of basic information.

Sound, up-to-date information convincingly conveyed to parents is one of the best bulwarks against the exploitation of their misfortune by quacks. As the American Medical Association leaders have pointed out, quackery flourishes most readily in respect to disorders for which science has no valid cure. Thus the families of the retarded are a vulnerable group, and should be given the best defenses available. Knowledge of the nature and source of their child's condition, and of the breadth and scope of research and other forces mobilized to aid him, will strengthen these defenses.

Parent education requires special knowledge and skills; it cannot be carried on successfully as an incidental function, nor by persons inexperienced in the art of "drawing out" people who face serious problems. It is, therefore, important for parent and other groups, clinics, and community agencies to give time and thought to the preparation and training of parent-education leaders. The Child Study Association of America has had a long and valuable experience in conducting parent-training programs and has prepared a practical study plan for the training of leaders for parent education groups.[2] It is suggested that demonstration programs be undertaken in several communities in the training of leaders.

Recreational Opportunities

The retarded child, like other children, needs opportunities for healthy growth-promoting play. The adolescent's vital need for successful social interaction and recreational experiences is frequently intensified by isolation resulting from parental overprotection, the numerous failure experiences in school and occupational pursuits, and by his exclusion by normal groups from their everyday play, group, and social activities. For the re-

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[2] Available at the offices of the association, 9 East 89th St., New York 28, N.Y.

tarded adult, opportunity in constructive use of leisure time may prove a major factor in maintaining community adjustment.

Pilot studies of recreational programs and resources for the retarded should be conducted and the results used as a basis for planning recreational and leisure time provisions for retarded children and adults.

Recreational programs for the retarded vary from well-organized activities in some communities to none in others. Since most mentally retarded individuals live at home, recreational activities are largely dependent upon the interests, skills, and available resources of their families and of the community. In many communities where organized recreational facilities are available, these facilities are seldom used by retarded persons. This limited usage may be partially due to a lack of public awareness concerning the retarded person's need for constructive leisure-time activities. Nevertheless, during the past decade new-opportunities have mushroomed. Playground programs, swimming instruction, day and overnight camping, bowling leagues, Scout troops, and social clubs have been organized for the retarded.

Greater public knowledge of current programs, utilization of facilities, and development of community resources are needed in order to achieve a comprehensive recreational program. Families having mentally retarded children need assistance in understanding the development and play activities of the retarded child. Agencies providing recreational programs and services should be encouraged to include the mentally retarded. Although the more capable retardate will be able to take advantage of the regular program if provided encouragement to participate, modified programs in which adaptation is made to the specific physical and psychological characteristics and needs of the retarded will be required for a large segment of the retarded population.

More trained leaders are needed at the National, State, and local level to plan, develop, and direct specialized recreational programs for this group. Information on recreation should be available to assist individuals and groups in developing programs.

Efforts need to be made to make the public more aware of the recreational needs of the mentally retarded.

As an aid in meeting these needs, it is recommended that pilot studies of programs and resources in selected communities for recreation for the mentally retarded be designed to develop and test guidelines for community planning and action. Such action should be planned as part of the comprehensive plan for which the planning grants recommended in subsequent sections would be used, and should be coordinated with other community facilities as outlined in Section IX. Such projects might be undertaken by an appropriate national group or by a university or college with particular interests and resources. The recommendations developed through such experiments should be implemented at State and community levels through the resources of the public and private agencies that have continuing program responsibilities.

Religion

Many retarded persons, especially those who live in institutions, are denied the fulfillment that comes through marriage and the rearing of children. It is a comfort for those retarded persons separated from their own family circles to experience a spiritual relationship with God through prayer and faith.

Religious organizations should take the initiative in supplying State and private institutions with services of a minister, rabbi, or priest (when such a plan is not already in effect) who would be responsible for conducting services of worship and providing religious instruction. A number of State and private institutions have established excellent programs of this kind.

It is also recommended that whenever possible the parents of children residing in institutions be allowed to take their children to local services of worship. It is the obligation of religious leaders in all faiths to provide whatever special opportunities for religious instruction and worship are needed for retarded persons living in the community.

Studies show that many parents of retarded "children depend on their minister, rabbi, or priest for advice and consolation. A clergyman can be of significant help to parents through spiritual counseling on their personal problems of anxiety and guilt. This could be another resource for parent counseling in State institutions. Clergymen conducting this work should participate in such programs as that conducted by the Council on Pastoral Clinical Training,[3] which has now been extended to include mental retardation; and, in addition, they should avail themselves of some of the current information on basic medical, psychological, educational, and recreational aspects of mental retardation.

The chaplains of institutions for the mentally retarded have recently started an organization to further the exchange of information in their field.[4]

Religious bodies should undertake surveys in cooperation with parents' associations to determine what religious training retarded children are receiving and what is necessary for their adequate instruction. Albany, N.Y., Hartford, Conn., Baltimore, Md., and St. Louis, Mo.—these are among the cities that have demonstrated how effectively Sunday school classes can be conducted for the retarded who cannot attend the regular church programs. Local churches are encouraged to work with parent groups in establishing such special classes and in introducing older children to religious services.

The National Council of Churches has been active in this field and has sought the advice and consultation of the National Association for Retarded Children in formulating its program. "The Mentally Retarded and the Church" is a useful pamphlet published by the council.

Several of the Protestant denominations have been active, particularly the Missouri Synod of the Lutheran Church, whose pamphlets "Organizing Religious Classes for Mentally Retarded Children" and "Serving the Mentally Retarded in Church and Community" have been extremely helpful. The National Lutheran Council leaflet "The Role of the Church in Serving the Mentally Retarded" is another practical guide.

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[3] Care of New York Academy of Medicine, 103d St. and 5th Ave., New York, N.Y.

[4] See *A Selected Bibliography on Religion and Religious Education,* National Association for Retarded Children, Inc., 386 Park Ave. South, New York 16, N.Y.

Several State and local councils of churches have been active in this field, including the New York State Council of Churches and the Connecticut and Philadelphia Councils.

Denominational colleges, including the College of Wooster in Ohio, Grove City College in Pennsylvania, and others, have cooperative programs with nearby institutions for the retarded, giving their students an opportunity to work in Christian education and recreation with young people in the institutions.

The National Conference of Catholic Charities published the brochure on "Planning for the Exceptional (Retarded) Child" as early as 1952; and the Redemptorist Fathers in Liguori, Mo., have taken a particularly keen interest, largely as result of the efforts of Father G. Breitenbeck, whose pamphlet "For Parents of Retarded Children" has been widely distributed. The National Catholic Education Association has also been active, as well as the Division of Special Education of the Archdiocese of St. Louis, under the direction of the Reverend Dr. E. H. Behrmann, who has written a useful guide in this field. Many Catholic journals carry articles on the religious training of the retarded.

The outstanding publication in the Jewish field is "Jewish Religious Education for the Retarded Child," published by the New York Federation of Reformed Synagogues, which also has a special prayer book for retarded children of the Jewish faith. Some excellent articles on religious education are also available for the Jewish retarded child.

Section V

EDUCATION, VOCATIONAL REHABILITATION, AND TRAINING

Every human being has potential for useful activity. Many individuals, ostensibly severely handicapped physically or mentally, possess considerable work potential. Modern science and action by our social institutions have demonstrated that many of them can become self-supporting and self-reliant if provided adequate education, rehabilitation, and training services, including counseling, guidance, and placement. Obviously it is a great economic gain when a handicapped individual is rehabilitated from a role of idleness and dependency to the status of a full-fledged wage earner and citizen.

There are many other handicapped individuals in whom the potential for useful work is more limited. In some instances the potential may be so limited that it is insignificant from the standpoint of economic gain. However, it is never insignificant from the standpoint of concern for the welfare and dignity of the individual. The true goal of education and rehabilitation of the handicapped is to help every individual to make the most of his potential for participation in all the affairs of our society, including work, no matter how great or small his potential may be.

The opportunity for adequate educational and rehabilitation services is being realized, however, by only a small proportion of the mentally retarded. Although special education and vocational rehabilitation programs are expanding rapidly, employment service offices are being strengthened, and new training and retraining programs are being initiated or are before the Congress, much more must be done to provide the timely and adequate services that are needed. There is a major challenge to provide these many services in an imaginative and integrated way. This will be a good investment not only in human but in economic terms, because the cost of such services will be returned many times in increased earnings and economic productivity.

Education

Only about 250,000 of the Nation's 1% million school-age retarded are enrolled in special education programs in public schools. Tremendous advances have been made in the past decade in both public and private programs of special education. Since 1948, the number of pupils enrolled in such programs has more than doubled, and the number of school systems offering these services has increased fourfold. Every State now has special legislation and makes some financial contribution to the education of the mentally retarded.

In spite of this progress a large majority of retarded children are still not provided with educational opportunities commensurate with their needs. It is the obligation of public and private education to provide appropriate educational opportunities for *all* mentally retarded children who can profit from education and training. There can no longer be doubt as to the need for, and desirability of, special classes for education of the mentally retarded.

If all retarded children are to receive adequate educational services, local communities and States must greatly extend specialized educational training in regular schools and in special schools, substantially increase the supply of teachers with specialized training, and more effectively coordinate the total resources of the community. Major deterrents to the realization of this objective are (1) the limited financial resources of most States and communities for support of costly specialized school services, and (2) the lack of sufficient numbers of teachers qualified to render the necessary specialized services. The needs are formidable because the total number of handicapped children, including the mentally retarded, is about 5 million. The expansion of special education programs will require leadership and financial assistance of the Federal Government and other national groups interested in education.

Leadership in the U.S. Office of Education

The U.S. Office of Education should exercise national leadership in the development of educational services for retarded children.

The administrative leadership and staff of the program for exceptional children within the U.S. Office of Education should be at a level commensurate with the importance of exceptional children in the Nation's program of public education.

The responsibilities of the Office of Education for the improvement of education generally are assuming a major significance as national needs in this area are recognized. In keeping with this increased role, the Office should expand its efforts devoted

(1) The extension of present programs for exceptional children. This would entail a review of proposed and current legislation and an analysis of present services of the Office of Education in the area of exceptional children as these relate to other Government agencies such as the National Institutes of Health, the Office of Vocational Rehabilitation, and the Children's Bureau.

(2) The development of new programs which would stimulate and assist State and local school systems in the extension of services for exceptional children.

(3) The administration of programs which provide funds to assist colleges and universities conducting programs for the preparation of special educational personnel.

(4) The administration of programs of intramural and extramural research on exceptional children.

Including all categories of physical and intellectual handicaps, there are more than 5 million school-age children who would profit from specialized educational services. They represent about 11 percent of the total school-age population. Education services for this group are provided in the home, in day and residential schools, and in treatment centers. They extend below and above the usual school-age range. Each specific program involves specially trained personnel, unique teaching materials and techniques, and curricular adaptations.

Although the Nation has long been committed to the objective of providing all children with opportunities for developing their potentials to the fullest, this goal has not yet been realized for those who are handicapped. Without visible, aggressive leadership at the Federal level, this gap between principle and practice will not be bridged. To bridge the gap, the program for exceptional children should have a position of importance in the Office of Education.

Extension and Improvement of Special Education

Specialized educational services must be extended and improved to provide appropriate educational opportunities for all retarded children.

The average cost of educating retarded children in special classes is estimated at about twice the cost of educating nonhandicapped pupils in regular classrooms. This has deterred States and communities with limited financial resources from extending their specialized programs to the level needed to provide adequate educational services for all retarded children. State and local school systems must now be expending in the neighborhood of $200 million for special education of the mentally retarded. At present, States usually assist local school systems by reimbursing them for a portion of the excess cost of providing special education services; however, the amount available for this purpose in the budget of the State departments of public instruction is usually limited and fixed. As a result, any new services that would substantially increase the number of retarded children receiving special education would dilute the proportion of the excess cost payment made available by State departments to local school systems. Because communities are not assured of increased subsidization when developing new specialized services, they are reluctant or unable to expand their programs. Therefore, any substantial extension of the specialized educational services for retarded children will require assistance and stimulation from sources beyond local and State school systems.

This assistance can be provided through a Federal extension and improvement program, administered so as to assure the use of available funds for expansion or development of new services rather than simply for financing of existing programs at current levels. Any proposal or a project to extend or improve special educational services for retarded children should be eligible for consideration for an extension and improvement grant. Proposals under the extension and improvement program should be evaluated on a competitive basis to assure the expenditure of funds only on programs of high quality and outstanding merit. Universities, State departments of public instruction, local and county school systems, and other educational agencies should all be eligible to submit applications for extension and improvement grants.

A group of experts on the education of the mentally retarded should be convened to help develop standards for special class teachers and for organization and operation of special classes. These standards would be of assistance in evaluating applications for extension and improvement grants. In addition, a professional advisory committee should be appointed to advise the Office of Education in the administration of the extension and improvement program. This committee would be responsible for reviewing and evaluating proposals for extension and improvement grants.

To accelerate the rate of extension and improvement and to assure continued operation of services beyond the period of Federal support, *each* extension or improvement project should be established on a declining-subsidy basis with a high initial level of Federal contribution and a low matching requirement. Over a period of 4 to 5 years, the Federal contribution could be reduced substantially or even terminated. The number of new projects will necessarily be limited by the availability of teachers. The teaching and research manpower program recommended later in this section will be the key to successful initiation of educational services under the extension and improvement program. Substantial financial assistance to education would also flow from the President's proposals for general aid for elementary and secondary education and for construction of college academic facilities. The bills in the 87 th Congress would provide annual Federal grants of $900 to $1,100 million for school construction, teacher salaries, and higher education facilities. The

Panel hopes that such aid will be enacted by the 88th Congress; the needs of special education will thus be alleviated along with the improvement in the status of education generally.

Of particular interest also to the Panel is the President's bill for improvement of educational quality (H.R. 10145 and S. 2826, 87th Congress), which included an experimental and pilot project program authorizing Federal assistance somewhat similar to that here proposed for mental retardation. Under that proposal, grants would be made to States which, in turn, would award funds for projects proposed by local school districts. Included in the specific list of types of projects which could be supported were *(a)* remedial or special instructional programs or services for pupils having language or other special educational problems, and (*b*) programs or services for adapting curriculums to the needs of deprived or disadvantaged pupils. These and other types of projects could be of material assistance to strengthening education for the mentally retarded, and the Panel urges the enactment of this legislation.

The 5 areas enumerated below represent particularly urgent needs for extended or new services which should be given emphasis and priority in awarding grants under the extension and improvement program and under the more general education aid programs proposea by the President:

1. Projects to enrich the learning opportunities of preschool children who live in homes where such opportunities are inadequate.

It is essential that adequate opportunities for learning of intellectual and social skills be provided such children through formal preschool education programs designed to facilitate adequate development of intellectual skills such as language development, abstract reasoning, problem solving, and other cognitive processes, and to effect desirable patterns of motivation and social values. This *program* of enrichment would necessarily include the formal participation of the parents.

The great majority of retarded children live in city slums or depressed rural environments. Research findings suggest that deprivation of adequate opportunities for learning contributes to and complicates the degree of mental retardation present in these children. Studies of attempts to add to the learning opportunities of deprived children through formal preschool programs have shown that such experiences may accelerate their development. Despite this knowledge, there are exceedingly few programs in which an effort is made to enrich the experiences of infants and preschool children who are deprived of adequate opportunities for learning.

Because of the potential importance of enrichment programs in reducing the extent and degree of mental retardation in this group, these services should be implemented on a research and demonstration basis to determine the range and types of procedures most effective in facilitating adequate intellectual and social development. A substantial portion of extension and improvement funds should be set aside for demonstrations of preschool training programs.

It should be noted that, under the cooperative research program authorized by Public Law 531, authority already resides within the U.S. Office of Education for the support of research projects in the education of the mentally retarded. Since the program began in 1957, the Federal Government has contributed nearly $6 million to research in education of the handicapped, of which about 70 percent has been in the area of mental retardation. The $6 million represents more than one-third of all cooperative research funds expended since initiation of the program. However, when viewed against the great magnitude of needs for research in education of the mentally retarded—particularly for projects designed to investigate the effectiveness of preschool enrichment as a means of facilitating development—it is clear that much more research must be undertaken. It is hoped that the funding of the cooperative research program will be increased with particular attention to the full exploration of methods of facilitating the learning capabilities of young children who live in slums or otherwise depressed circumstances.

2, *Instructional materials centers in the special education units of State departments of public instruction or in university departments of education.*

In order to provide teachers and other education personnel with competent consultation on instructional materials, it is recommended that State departments of public instruction and/or university departments of education establish instructional materials centers. These centers would distribute and loan instructional materials for the mentally retarded. The staffs of the centers would evaluate, distribute, and disseminate information concerning available instructional materials, and would consult with producers, or prospective producers, of special instructional materials for the retarded. Further, they could adapt and modify materials now available for use with normal children so as to be of maximum use in teaching retarded children. Instructional materials centers should be initiated on a demonstration basis under auspices of the extension and improvement program.

The unavailability of adequate instructional materials is cited by educators as one of the major barriers to efficient classroom instruction of retarded children. Teachers of special education receive little guidance in assembling and adapting material for use in their classrooms. While much has been done with children's books and with learning materials in social studies, language arts, mathematics, and science for normal children, almost no attention has been given to what adaptations can be made for those who are mentally retarded.

3. *State and local community leadership in the development, administration, and supervision of school services for retarded children.*

Extended and new programs of school services for the mentally retarded should not be initiated without leadership and personnel possessing special skills and experience in the education of the mentally retarded. The lack in many State and local school systems of staff experts in mental retardation is a major factor contributing to the general inadequacy of school services for retarded pupils. The employment of additional administrative and supervisory staff experts in mental retardation could be brought about by providing Federal incentive grants to State departments of education and local school systems to enable them to employ such personnel.

The President's bill for improvement of educational quality in the 87th Congress recognized the need for strengthening State departments of education by providing, in Title II, for up to $5 million per year in grants "for expansion or improvement of State educational agency supervision or related activities, including research, development, evaluation, and promotion of improved instructional practices. . . ." The Panel urges that the Congress enact a provision of this sort into law.

4. Specialized classroom services to provide for all mentally retarded children.

Between 1948 and 1958, the number of day and residential schools offering special education for the mentally retarded increased from 868 to 3,202, or about 270 percent. But the number of special classes in operation is still grossly inadequate. Additional special class services are required for all age levels for both educable and trainable retarded children.

However, it is doubtful that sound and comprehensive programs will be developed in most communities without the additional incentive of external financial support such as can be provided by the proposed extension and improvement program, the improvement of educational quality bill, or general Federal assistance to public schools. In addition to the need for new programs, existing services are often deficient. Many fail to accommodate the majority of children in the community needing this service, or are manned by persons inadequately trained to teach retarded pupils. Most programs fail to provide for the total age range or the full spectrum of intellectual abilities among the mentally retarded. Even though the need for preschool programs is generally recognized, few exist. Many communities do not extend their services beyond the legal age of compulsory school attendance, and practically no programs exist which aid the retarded adolescent or young adult in his transition from school to work and community living.

In the past, misconceptions about mental retardation and a restricted view of the objectives of public education led to a reluctance on the part of public schools to provide for the special needs of their retarded pupils. Increasing public awareness of the educational needs of the retarded and the success achieved by the few outstanding programs in present operation are increasing the receptivity of local school systems to proposals for the implementation of new and expanded services for the mentally retarded. Unfortunately, the high cost of providing such programs and the lack of funds in many communities are deterring school systems from developing comprehensive programs.

5. *Services of educational diagnosis and evaluation to provide for early detection of school learning disabilities and to enable appropriate school placement.*

Because success in training and rehabilitation of retarded children is contingent upon early detection and adequate evaluation, it is recommended that emphasis in the extension and improvement program be given to proposals which would serve to extend the services of educational diagnosis and evaluation available in schools. Many States, particularly in rural and sparsely populated areas, do not have available adequate services for the comprehensive psychological and educational evaluation and counseling of pupils with learning disabilities. As stated in Section III, the need for such services is evident when one considers that the great majority of retarded children are not detected until some time after they have entered school. This means that in many instances they are not placed in special classes until they have received 2 or 3 years of education in regular classes. As a result, they often develop behavior disorders which greatly complicate their fundamental problem of retardation.

The development and expansion of all community educational services will contribute to the strengthening of those special educational services required for the mentally retarded. The President's proposals to provide for "general assistance" to public schools and for improvement of educational quality would, as noted previously, be aimed at the broad range of community educational requirements and, hence, would assist in educational diagnostic and evaluation programs. In addition, specialized diagnostic services can be obtained from community resources such as clinics specializing in retardation and community mental health centers. In this sense, strengthening of the clinical and social services documented in Section IV will be of direct benefit to problems of the mentally retarded in the schools.

Few States or communities provide for adequate detection and evaluation of the learning disabilities in their school populations. Although field clinics and counseling service teams have been successful in reducing educational disabilities associated with groups such as the orthopedically handicapped and cardiac impaired, this type of service generally has not been sufficiently extended to the retarded.

In some sparsely populated areas, the problem of providing these services may be solved through use of traveling psychoeducational teams. Such teams would be designed to provide initial and continuing evaluation of learning disabilities, as well as educational counseling of retarded children and their families. When a more extensive medical and social evaluation is required for the child, the teams could make referrals to central diagnostic or treatment facilities. In addition to providing these services for retarded children, the staffs of professional traveling teams could serve as consultants to local professional personnel regarding the nature, needs, and problems of retarded children and their families.

Many existing techniques and tools used for educational diagnosis and evaluation are inadequate or inappropriate. For example, many of the devices used to measure intelligence, school achievement, and social adaptation are not designed for children who show extreme deviations from the average range of abilities. There is a particular need for devices to measure *specific* learning disabilities. Such instruments would be of great assistance to the teacher in planning individualized programs for retarded pupils. In addition, there is a need for tests which would measure the social adaptation of the adolescent retarded child. To remedy these deficiencies, it is recommended that research and demonstrations designed to evaluate the adequacy of new and existing measurement devices for use with retarded children be supported through the cooperative research program.

Manpower for Teaching

An additional 55,000 trained teachers of the mentally retarded are required. To meet this need, the States, communities, the Federal Government, and private foundations should undertake an extensive expansion of manpower training programs.

A critical barrier to rapid improvement of educational services for handicapped children, including the retarded, is the overwhelming shortage of special teachers. With only about one-fourth of all handicapped children enrolled in the Nation's special classes, the current total shortage of special teachers is in the order of 250,000. For the mentally retarded there are probably no more than 20,000 teachers in the Nation, and perhaps a fourth of these do not meet minimum certification requirements for their difficult and highly specialized teaching tasks.

It is estimated that in 1962 only about 500 new teachers will graduate from colleges and universities with adequate teacher-training programs in mental retardation. This number is scarcely sufficient to replace those teachers who will leave the field this year. It is estimated that 75,000 specially trained teachers are required to staff all the needed classrooms and to keep class sizes at a reasonable level to adequately educate the 1 1/4 million school-age retarded.

Many factors account for the serious shortage of trained teachers of the mentally retarded: a general insufficiency of adequately trained manpower in all of the teaching professions; the lack, until recently, of public awareness and understanding of the problem; the failure of universities to recognize the need and to develop appropriate training programs; the unavailability of opportunities for students to become acquainted with the challenge of a teaching career in mental retardation; and the inability of students to finance the additional specialized training required.

The precedent of special financial support for professional training in areas of great need is well established in Federal and

State Governments and within foundations and communities. The U.S. Office of Education currently finances the training of teachers of the deaf, and, to a limited extent, supervisors and college instructors for programs concerned with the mentally retarded. Limited though it is, this latter program, authorized by Public Law 85-926, has been a significant contribution to alleviation of the manpower shortage in this area. The first impact of the program has already been felt throughout the Nation. Approximately 340 specialists have been trained and are now acting in positions of leadership. A similar number are scheduled to receive training in academic years 1962-63 and 1963-64. However, the present law limits Federal funds to $1 million a year. The Office of Vocational Rehabilitation supports the training of a broad range of personnel engaged in rehabilitation programs (including, for example, speech and hearing specialists, clinical psychologists, and rehabilitation counselors), and the National Institute of Mental Health finances training in the mental health professions (including clinical psychologists, psychiatric social workers, psychiatric nurses, and psychiatrists). Many States now have grants available for training in mental health fields and a very few even support training for teachers of the retarded. In rare instances, foundations, service clubs, and other community organizations have provided a few scholarships for teachers wishing to obtain specialized preparation in mental retardation.

If the need for well-trained teachers for the mentally retarded is to be met, an estimated 6,000 new teachers must be added each year for a decade to the pool of well-trained, skilled teaching specialists in mental retardation. This is about 12 times the number of new teachers who will be graduated in 1962 with adequate training in teaching of mentally retardates. In view of severe limitations in the capacity of specialized teacher training institutions, it will take time to reach this level, but it must be our goal. In order to achieve it:

(1) The Federal Government and private foundations should provide increased funds for scholarships and for support of training programs.

The administration has recognized the compelling urgency to provide for training of additional teaching and research manpower in the area of exceptional children. In his February 6, 1962, message on education, the President recommended broadening the present limited training efforts in the areas of mental retardation and deafness to include assistance for the special training needed to help children afflicted with the whole range of physical and mental handicaps. On June 14, 1962, former Secretary Ribicoff transmitted to the Senate an expanded proposal to authorize $12 million a year for training of teachers, researchers, and other specialists required for educational services for the handicapped, as well as for conduct of research related to education of the handicapped. The Panel hopes that such legislation will be speedily enacted by the next Congress. It is suggested that private foundations set as their objective a contribution of $2 million toward meeting the total manpower training costs.

(2) Each State should make appropriate provision in its annual budget for special education funds to be used for training grants to experienced teachers who wish to obtain a teaching specialization in mental retardation.

(3) Local school systems (through the granting of leave of absence with pay), community agencies, civic and service organizations should also contribute to the preparation of the persons who will teach their retarded children. Concerted effort on the part of these local groups should enable them to achieve the reasonable objective of a contribution of $3 million annually. This figure would amount to a modest, average contribution of $1,000 from each of the 3,000 local school systems now operating programs for the mentally retarded.

On the basis of competitive application for support, Federal funds awarded under the administration's proposal should be allocated to universities for scholarships and support of the teaching program. University applications for participation in this program should be evaluated on the basis of the curriculum, the standards for selection of students taking part in the program, the competency of the staff conducting the program, the adequacy of the practicum facilities available for teaching and other experiences with the retarded, and the evidence of real commitment to training in this field on the part of the university requesting support.

Especially high priority should be given to training more college level instructors. Under Public Law 85-926, as noted above, $1 million a year has been provided for training administrators, supervisors, and college teachers of special education. Increased Federal funds should be authorized for grants to the State departments of public instruction and to colleges and universities for traineeships to experienced teachers of normal children who wish to return to universities for advanced training for teaching careers in mental retardation. State and local school systems should enable teachers to take a leave of absence to acquire this training without penalty in regard to promotions, salary increases, insurance or retirement programs. To assure competent preparation, teachers awarded traineeships should attend only those institutions with approved programs of teacher preparation.

This program of teacher training could suffer seriously from the present lack of concerted efforts to recruit prospective teachers for careers in mental retardation; young persons are not provided with programs or literature which would expose them to career opportunities in this field of teaching. Therefore, the U.S. Office of Education should initiate a national recruitment program to interest students in careers in the education of the mentally retarded and children with other handicaps.

Methods must be developed to provide for more effective training and use of personnel for teaching retarded pupils.

The number of teachers required to man education programs for the mentally retarded under the current teacher-pupil ratios is greater than the number we may realistically hope to recruit and prepare for teaching careers. Consequently, attention must be given to ways in which limited professional manpower may be most effectively utilized. As has been noted in the section on research, the level of ongoing research in education is most inadequate. Research and demonstration projects should be initiated to determine staffing patterns which would conserve teaching manpower.

In addition to the development of methods for more effective utilization of teachers, it is recommended that their training needs be more accurately determined. Some authorities have suggested, for example, that teacher-training programs be extended to 5 years of preparation. The additional year of training would enable teachers to receive the required specialized training and a greater depth in liberal education and related fields.

National standards of teacher qualifications and reciprocal certification agreements must be established.

Because of increased population mobility, it is important that teacher certification requirements be comparable in all States. Teachers certified in one State often find that their training does not meet certain specific requirements of other States. Consequently, when they move to another State they may assume positions in other fields. To facilitate the establishment of interstate reciprocity in the certification of teachers, national standards for the preparation of teachers of the mentally retarded should be established. Professional organizations, such as the Council for Exceptional Children and the American Association on Mental Deficiency, should work toward the establishment of common standards throughout the United States. Appropriate Federal agencies and national organizations should fully support this effort and encourage States to adopt common certification requirements. Responsible national certification agencies, such as the National Council on Accreditation of Teacher Education and regional groups such as the Southern Regional Education Board, the Western Interstate Commission on Higher Education, and the New England Board of Higher Education, should take measures to facilitate the implementation of interstate reciprocity agreements.

Vocational Rehabilitation and Training

The Federal-State vocational rehabilitation program offers a wide array of services for the disabled, including counseling and guidance, medical and related services, training, placement, and other rehabilitation services. The 1943 amendments to the Vocational Rehabilitation Act made the mentally retarded and the emotionally disabled eligible for rehabilitation services along with the physically handicapped.

Since 1954, the Office of Vocational Rehabilitation has supported research on all aspects of rehabilitation, including the social and occupational adjustment of the mentally disabled. Demonstrations of techniques for rehabilitating retarded persons have been undertaken in communities across the Nation as a result of the incentive of Federal aid. Community rehabilitation agencies have extended and strengthened their facilities and resources for serving the retarded with the financial assistance of the Office of Vocational Rehabilitation. The pool of skilled manpower available for service to the mentally retarded has increased steadily as a result of support by the Office of Vocational Rehabilitation of programs for training personnel in the rehabilitation professions.

The economic value of vocational rehabilitation for the retarded is clearly demonstrable. A study of 1,578 mental retardates who were rehabilitated in 1958 estimated that their total annual earnings rose from $70,000 before rehabilitation to $2.5 million after rehabilitation. Using $1,500 as the average individual cost for the rehabilitation services, the total one-time cost was estimated at under $2.4 million. The economic gain to the Nation and to the individual is thus clearly evident—aside from the savings in public and private assistance costs which were being incurred on behalf of these individuals before their rehabilitation. Only 3 percent of this group supported themselves, before rehabilitation, from their own earnings; 8 percent were supported by public assistance; and 89 percent by their families and other sources.

Rehabilitation is also achieved through facilities not financed by the Federal-State vocational rehabilitation system, but data on their activities are not available. The Federal-State system is the predominant resource. From 1954 through 1961, Federal funds for vocational rehabilitation increased threefold to $70 million. During this period the estimated funds for vocational rehabilitation of the mentally retarded increased 15-fold to $3.3

million. Analysis of the operations of the Federal-State system shows:

—A six fold increase in the number of mental retardates who were rehabilitated during the 8 years ending in fiscal year 1961, while the increase in total rehabilitations has been under 70 percent. In 1954, 561 rehabilitated mental retardates represented 1 percent of the total of 55,825; in 1961 they were 3,562, or 3.9 percent of the 92,501 rehabilitations.

—A more rapid growth of rehabilitation among the mentally retarded than of other disabled groups such as epileptics, mentally ill, and cardiacs, which also had a small number of rehabilitants in 1954.

—That in fiscal year 1961, the 10 States, with 42 percent of the Nation's population, which rehabilitated 49 percent of the national total, also produced 48 percent of all the mentally retardate rehabilitations. This indicates the critical importance of the need for growth in the total Federal-State rehabilitation program as a means to increase aid for particular selected disablements.

The Federal Government has recognized the need for growth in vocational rehabilitation programs, particularly through making available the full amount of Federal grants required to match available State funds. This is particularly evident in the 1963 budget—the President recommended, and the Congress approved, a level of Federal grants so that *all* State operating costs can be matched by Federal funds. In order to insure that the mentally retarded are adequately served and in view of the added cost of their rehabilitation, it may be advisable to appropriate funds specifically restricted to serve such persons.

There is need for increased State vocational rehabilitation appropriations which, with their matching Federal grants, will produce increased numbers of rehabilitated individuals—including those who were mentally retarded.

With respect to action towards new approaches, the Office of Vocational Rehabilitation has shown marked support for mental retardates. Over the past years about 12 percent of its budget, available for research grants, has been directed toward mental retardation.

Despite this progress in the vocational rehabilitation of the retarded, it is evident that the surface has only been scratched in assisting the retarded to prepare for jobs and to secure employment. It is estimated that about 75,000 retarded youths leave school each year who have a potential for self-support and independent living. While counseling and evaluation are useful for all students, it is particularly important that retarded youths in their final year of school receive prevocational counseling and evaluation, job placement assistance, and postplacement counseling.

Counseling programs in schools should be strengthened, the testing and employment counseling and placement facilities of the 1,900 employment service offices throughout the country should be full utilized, and training programs should be used and improved.

It is estimated that about three-fourths of the above group of retarded who leave school can be placed in competitive work if the counseling and placement services are provided effectively. The remaining one-fourth are likely to require other training along vocationally oriented lines in a classroom employment training program or in on-job training situations before regular placement in a competitive job is feasible. The opportunities for such training should be expanded through the Federal-State vocational rehabilitation program and through the regular vocational education courses. In addition, a significant new resource has been added recently with the enactment of the Manpower Development and Training Act of 1962 administered by the Department of Labor with assistance from the Department of Health, Education, and Welfare, which authorizes vocational and on-job training assistance for youths as well as unemployed adults. A great potential is also contained in the Youth Employment Opportunities Act, introduced in the 87th Congress, to authorize grants of $75 to $100 million a year for a 3-year pilot program for local work projects, on-the-job training, and youth camps.

Training and counseling services are of great importance under present conditions. In the future the demand for them will increase. Competition for jobs with which the retarded have been identified is becoming keener as unskilled workers, displaced by automation, seek these jobs. Adverse effects of recessions are likely to be felt more acutely by mentally retarded than by nonretarded workers.

If the productive capacities of the Nation's mentally retarded are to be realized, every retarded youth must have available appropriate vocational rehabilitation and related services prior to, during, and after termination of his formal education.

These services must include provisions for—

(1) Vocational evaluation, counseling, and job placement.

(2) Training courses in appropriate vocational areas.

(3.) Joint school-work-experience programs operated cooperatively by schools and vocational rehabilitation agencies.

(4) Clearly defined and adequately supervised programs for on-the-job training of retarded workers.

(5) Employment training facilities for those who require further vocational preparation after completion of the public school program.

(6) Sheltered workshops for retarded workers capable of productive work in a supervised, sheltered setting.

(7) Vocational rehabilitation services in conjunction with residential institutions.

(8) Counseling services to parents to provide them with an adequate understanding of the employment potentials of their children and to provide guidance which will enable them to participate more fully in the rehabilitation process.

(9) Coordination of vocational counseling with the entire school program.

The succeeding paragraphs set forth proposals which would eliminate the major barriers to the provision of improved vocational rehabilitation services for the mentally retarded. These barriers are: (1) the failure of many State agencies to assign the sheltered work program to a specific agency and to expand programs by using Federal-State funds for rehabilitation of the retarded; (2) a lag in the construction of facilities for sheltered workshops and other rehabilitation services; (3) the decline in work opportunities for retarded workers; (4) an insufficient number of specialists in retardation on rehabilitation agency staffs; and (5) the failure of public schools and rehabilitation and placement agencies to collaborate and work together toward their common objective.

Increasing Vocational Rehabilitation Services **for** *the Mentally Retarded*

Vocational rehabilitation services for retarded youth and adults should be expanded through special Federal expansion grants under the Federal-State program of vocational rehabilitation.

Bridging the great gap between available and needed services will require the joint efforts of Federal, State, and community agencies. Many States hesitate to use any substantial portion of the funds currently available under the Federal-State program of vocational rehabilitation to extend services for the mentally retarded, because they consider themselves committed to longstanding services in other areas of disability and because their communities may not have fully accepted the need to develop this area more fully. Moreover, a number of States still fail to provide the matching funds which would enable them to use all the Federal moneys for which they are eligible. A major increase in vocational rehabilitation services for the mentally retarded can be brought about under the incentive of a more substantial and directed program of Federal financial assistance.

This can be achieved by enactment of legislation proposed by the administration in 1962 to reactivate special expansion grants. Unlike the current Federal supporting grants, which require an average of about 40 percent matching State funds, these Federal expansion grants would be available to pay, for a specified period, all or nearly all of the costs. Being expansion grants, they would be utilized as "seed" to foster growth in selected fields, including services to the mentally retarded, and then would be most helpful in selected States where great gaps exist between the actual number of people served and the potential number who could be served. Once the period of incubation is completed, the programs initiated or stimulated by these expansion grants would be incorporated into the State regular program and be eligible for the regular Federal support grant.

Additional impetus to these rehabilitation services should be expected from the 1962 public welfare amendments. These amendments are designed to encourage services aimed at reducing dependency by providing Federal grants covering 75 percent rather than 50 percent of the cost of these services. The amendments require the State public welfare agencies which provide such services to utilize the facilities of the vocational rehabilitation agencies. The Secretary of Health, Education, and Welfare is directed to specify required services to be furnished to welfare clients. It is therefore recommended that his regulations specify as a minimum requirement for such contractual use those services that can be furnished by the State vocational rehabilitation agencies.

Establishing New Facilities

A Federal program should be established to provide financial support for construction, equipping, and initial staffing of sheltered workshops and other rehabilitation facilities.

The Office of Vocational Rehabilitation has available funds for support of a wide spectrum of rehabilitation services, such as training of professional personnel, extension and improvement projects, and demonstrations and research. Quite often rehabilitation services must be provided in rehabilitation facilities or workshops. The Office of Vocational Rehabilitation can provide grants to *convert or alter* existing buildings into facilities and workshops, and it can also grant funds for the initial staffing of rehabilitation facilities. However, Federal support for *direct construction* of facilities and workshops is possible only under the Hill-Burton Act and only if these buildings are associated with a hospital. Yet, rehabilitation services to help handicapped individuals are often provided by facilities or workshops which need not be medically oriented and associated with a hospital.

Workshops under Goodwill Industries, or those operated on behalf of the blind, are pertinent examples.

While construction of schools and medical institutions with State and local funds is firmly established in law and practice, no agency of State or local government has yet assumed this responsibility for non-hospital-related rehabilitation facilities such as sheltered workshops. As a result, the majority of rehabilitiation services for the mentally retarded are undertaken in grossly inadequate quarters, located in deteriorated and sometimes unsafe buildings. Frequently, services may not be extended to include more persons solely because of insufficient space.

Consequently, the Office of Vocational Rehabilitation should be authorized to initiate a program of Federal participation in the cost of constructing, equipping, and initial staffing of workshops and other types of rehabilitation facilities. Proposals made by this administration (S. 3320, 87th Congress) designed to improve and expand the vocational rehabilitation program include provisions for construction of rehabilitation facilities, and this legislation should be enacted. Expansion of special rehabilitation facilities for the mentally retarded should be encompassed in the comprehensive plan discussed in Sections VI and IX.

Other Work Opportunities for the Mentally Retarded

Sheltered work opportunities for the mentally retarded should be extended beyond the traditional workshop setting.

The limitations of many retarded persons prevent them from working in any place other than a sheltered environment. Traditionally, this sheltered environment has been a workshop. Many opportunities, however, for purposeful, productive work could be found outside the workshop through community and service activities carried on under the professional direction of community rehabilitation centers and programs.

Activities which could lend themselves to the development of sheltered work projects include conservation and maintenance of parks, recreational areas and grounds of public institutions, domestic service occupations, certain types of health service, and agricultural occupations.

These sheltered work programs could serve and benefit relatively large numbers of disabled persons and undertake a great variety of activities useful to the community. At the same time, they would require smaller capital investment in buildings and equipment than do other types of employment, including those of the workshop. The Office of Vocational Rehabilitation, particularly through its research and demonstration grants, should stimulate planning and development of such sheltered work programs. Furthermore, the President's proposed youth employment opportunities program was in part designed to meet the problem of youths who drop out of school or who otherwise enter the labor force and encounter difficulty in finding jobs. When enacted, this program will offer an excellent opportunity for joint effort by the Department of Labor and the Office of Vocational Rehabilitation. Small-scale pilot projects should be developed to be operated by voluntary and local public agencies. As experience is gained from these pilot projects, they could lead to the establishment of local sheltered work programs in every major urban community in the Nation.

The sheltered work program implemented nationally could strengthen the economy by helping to resolve the problem of unemployment, by reducing welfare costs of persons who would otherwise have to be supported by direct welfare payments, and by producing needed goods and services through the expedient tapping of manpower resources now being wasted.

Activity Centers for the Severely Handicapped

Methods of providing recreational and therapeutic activity centers to serve severely handicapped adults should be explored.

Currently Federal grants for vocational rehabilitation services are available only for services granted to individuals for whom there is a reasonably clear "potential for employment." In some cases the "potential" may be absent at the beginning, but may become reasonably clear after rehabilitation services have begun to work their change. The administration accordingly has recently recommended legislative revisions which would authorize Federal grants to provide services for up to 6 months prior to the determination of the employment potential. This legislation should be enacted because, as the vocational rehabilitation program continues to expand to include the more severely disabled, it will serve increasing numbers of individuals who at the beginning may not seem to have had a reasonable potential.

However, there is still a need to provide therapeutic and recreational services for those who cannot enter competitive or sheltered employment. The Federal public assistance program has recognized this need by authorizing Federal grants for "self-care" or "self-help" services provided to needy individuals even though there is no employment potential. Actual data on the extent or desirable methods for providing such services under the public welfare programs are spotty. Furthermore, such therapeutic or recreational services involve skills and contributions from health and rehabilitation agencies as well as the welfare agencies. Accordingly, it is recommended that the Secretary of Health, Education, and Welfare should explore the financial and administrative aspects of this problem, with the objective of developing suitable courses of action, insuring, however, that these therapeutic services do not dilute the effectiveness of the vocational rehabilitation program by dispersing its available resources over this new area. The pilot studies of recreational opportunities recommended in Section IV on Clinical and Social Services should help provide a basis for ascertaining the utility of recreational and therapeutic centers and their usefulness as a device for stimulating new and additional resources in a coordinated effort.

Coordinating Education and Vocational Rehabilitation Services

National, State, and local committees on the coordination of education, vocational rehabilitation, training, and placement services should be organized.

The average age for all individuals at the time they start receiving vocational rehabilitation services, under the Federal-State system, is about 36 years; for mental retardates the comparable average age is 19 years—with 59 percent falling within the 15- to 19-age bracket. Furthermore, experience with special grants (such as those made to Dallas, Detroit, and Minneapolis) by the Office of Vocational Rehabilitation on behalf of mental retardates has also highlighted the importance of providing services to these individuals while they are still in high school and before they reach the legally permissible age for leaving school.

Thus it is clear that the first line of attack is through the educational system, and that vocational rehabilitation for the mentally retarded must be coordinated with our secondary educational system. We must seek "habilitation" rather than "rehabilitation." What is needed for vocational preparation is a program starting during the teenage which coordinates special education, evaluation, and guidance with prevocational training and vocational training.

Such an approach will also require adaptation of, and coordination with, our vocational education system. Vocational education is a great untapped resource for assisting the disabled, including the mentally retarded. Yet many States have legislation which excludes the mentally retarded from the vocational education system.

At present, habilitative services for the mentally retarded are generally uncoordinated. A few States have interdepartmental committees, but these are typically without legislative direction or support. Mechanisms for coordinating special education and habilitation activities should be established at Federal, State, and community levels, as discussed at greater depth in Section IX.

At the Federal level there is need for mechanism to strengthen cooperative planning and joint efforts between the Office of Vocational Rehabilitation and the Office of Education in the Department of Health, Education, and Welfare, and the Department of Labor. The mechanism for obtaining coordination at the State and local levels will vary as a function of the administrative patterns of each State and community. Regardless of the particular mechanism, the group charged with this responsibility should be officially recognized by the State and provided with the financing necessary to fulfill its responsibility. In addition to the public agencies, all volunteer groups concerned with education and rehabilitation should participate in the statewide coordination of services.

The responsibility for coordination and cooperative planning also will pose the need for exploring the fundamental issue of the role of these various social institutions. Particularly in the area of vocational preparation and training, our society is in the midst of evolving new approaches and new institutional mechanisms. In the local communities, the public schools with their vocational education classes and their special classes for the handicapped are a basic resource. The vocational rehabilitation program and the various new manpower and work training programs provide important additional possibilities. Under the circumstances, it is clear that there is as yet no definitive answer to the best arrangements, and that we must continue to experiment and to evolve community programs which will provide timely and effective services to assist the mentally retarded to become employable and useful citizens.

Manning Programs of Vocational Rehabilitation

Staffs of State and private vocational rehabilitation agencies should be augmented by specialists in the rehabilitation of the mentally retarded.

Perhaps the most severe limiting factor on our capacity to mount a rapid expansion of effective rehabilitation and training programs is the shortage of specialists. The training program of the Office of Vocational Rehabilitation established in 1954 supports the preparation of personnel in the various professions related to rehabilitation. It provides teaching grants and traineeships in fields where shortages of qualified personnel are great and, in addition, sponsors short-term seminars designed to update training and orient professional personnel to the philosophy and practice of rehabilitation.

The vocational rehabilitation training program has proven to be an effective mechanism for increasing the available pool of skilled manpower, and it should be expanded to include—

(1) Increased emphasis on knowledge of the social and vocational adjustment of the mentally retarded in the curriculum for the training of rehabilitation counselors.

(2) *The training of personnel for workshops after studies to determine the competencies needed.*

(3) Preparation of personnel in rehabilitation and related professions for research careers.

Most vocational rehabilitation agencies do not have sufficient staff to meet longstanding obligations for service in other areas of disability and, at the same time, undertake to develop new services for the mentally retarded. Few agencies employ rehabilitation personnel with particular skills and compentencies in the field of mental retardation. If greater leadership is to be developed for services for the retarded, it is essential that specialists in mental retardation be recruited and the skills of existing staffs augmented.

Although some attempt has been made to give vocational rehabilitation counselors and counselor-trainees an orientation to mental retardation, these efforts have been minimal and require considerable strengthening. Since 1957, such short-term courses averaging 1 or 2 weeks have been given to 560 counselors. One long-term course, running for a full academic year, has been established at the University of Syracuse. This has trained 7 students in 1961 and 12 students in 1962. The Office of Vocational Rehabilitation should encourage universities to give vocational rehabilitation counselors a more adequate knowledge of retardation through specialized courses and practical experiences with the mentally retarded. The establishment of a few counselor-training programs which give particular emphasis to mental retardation would serve to create a pool of specialists needed by rehabilitation agencies but currently unavailable.

Most sheltered workshop personnel have had little or no orientation to those who are mentally retarded. Since workshops are a vital force in helping the mentally retarded to become productive, it is essential that they be well managed. Pilot studies under the auspices of the Office of Vocational Rehabilitation and other national groups should be initiated and supported by Federal funds in the form of teaching grants and traineeship awards. To expand and improve the quality of research on vocational rehabilitation of the mentally retarded, it is essential that the training programs of the Office of Vocational Rehabilitation be extended to include the preparation of personnel for careers of research in rehabilitation.

Employment

Help for mentally retarded persons in gaining employment is one of the most important services that can be rendered to the Nation and to those who are handicapped. Employment has both social and economic benefits, and few aspects of life in our society are more important to the individual.

Suitability for employment has its origins in health, family life, and relationships outside the family such as religion and education. When more significant progress has been made by the mentally retarded in these other areas, the problem of gaining and holding a job more frequently can be surmounted successfully.

The mentally retarded have a hard time finding and holding jobs—even ordinary jobs—for many reasons. The skill demands of most jobs are beyond their ability. The nonskill requirements of many tasks are difficult for them to meet because of their mental requirements and consistent application of effort, the need to travel to a workplace and arrive at a particular time, the need to accommodate to the demands of others, and so on. The mentally retarded person or his parents and friends do not know where to find a job that he can perform. The mentally retarded person does not know about the training he needs, the types of jobs he could perform, and the nonskill requirements of work (both before and during employment).

Employers generally do not know how to use the limited skill of the retarded person, nor how to supervise him in such a way as to bring out his full potential. Many employers and fellow workers are not sympathetic to the needs of the mentally retarded nor capable of meeting them; some employers furthermore do not believe they can afford economically to be concerned with the retarded.

In our complex industrial economy where technological progress and automation are eliminating more than 1 million unskilled jobs a year, the problem of employment for the retarded is accentuated. Automation is tending to throw the mentally retarded into competition with more capable persons who are displaced from ordinary jobs. It is fortunate that there is substantial expansion in some sectors of the economy (for example, the service industries) which can employ individuals with lesser skills.

Every effort must be made and all available services used to equip and train the retarded and assist them in finding suitable employment.

Employment assistance for the mentally retarded seeks to meet the problems of employment through private and public arrangements that:

—Relate the education and training of the mentally retarded to employment requirements, especially through expert evaluation and counseling.
—Advise the mentally retarded and their employer about the kinds of jobs they can perform and how jobs can be redesigned so that the mentally retarded can perform them.
—Refer the mentally retarded to jobs they can perform or to training opportunities.
—Advise the mentally retarded and their fellow workers and employers about the best ways for working together.
—Expose the mentally retarded to work in competitive situations and initiate them into the needs of competitive work situations.
—Provide the mentally retarded employment in noncompetitive situations if competitive employment is not possible.

We know, now, from the experience of public and private agencies that special efforts with the retarded can help them prepare for jobs, find jobs, and hold jobs. Many public and private institutions -axe. helping to provide these services. Among these are the Nation's educational systems, both through regular and special schools, which have been discussed above, and the Federal-State vocational rehabilitation system, as well as private rehabilitation agencies.

The Labor Department should review all of its employment services from the standpoint of the needs of the mentally retarded to assure that the needs of these people are receiving the appropriate attention and priority.

Many other existing and proposed institutions are providing employment services for various groups that include mentally retarded persons and are significant in the consideration of the ways in which to meet the needs of the mentally retarded. Of particular importance are the employment service and placement activities supported or administered by the Labor Department, which provide a link between the individual and the labor market. The most important of these is the Federal-State employment security system, which finances a large school counseling and testing program and through 1,900 local offices provides advice to the unemployed about job opportunities, advice to employers about available workers, and the advisability of redesigning jobs, and referral of workers to jobs or training opportunities. It is estimated that more than $1 million yearly is being spent for these special services to the retarded. In addition, while exact estimates are not available, millions of dollars of unemployment compensation are paid by the employment security offices to this group. Consideration should be given to providing more extensive placement services for the mentally retarded.

The Labor Department also carries on promotional efforts to encourage students not to drop out of school. The President's Committee on Youth Employment, headed by the Secretary of Labor, is exploring all avenues for gaining employment for youth. The President's Committee on Employment of the Handicapped also attempts to create an atmosphere of acceptance for the mentally retarded among workers and employers.

Section VI

RESIDENTIAL CARE

On any given day there are over 213,000 mentally retarded persons housed in residential institutions; they are 4 percent of the estimated 5.4 million mentally retarded persons in the United States. Based on 1960 data, approximately 160,000 are in 108 public residential institutions specifically designated for the mentally retarded, 10,000 are in 200 private institutions, and the remaining 43,000 retardates are cared for by the 279 public mental hospitals. This latter group comprises 8 percent of the approximately half million patients in public mental hospitals and constitutes 22 percent of the total number of retardates in State institutions for the mentally retarded and the State mental hospitals combined. In one State all institutionalized retardates are in residence in the public mental hospitals, for there is no institution specifically designated for the mentally retarded. In the remaining States, the percentage of retardates in State mental hospitals varies from 2 to 76 percent.

While the number of retarded in mental institutions has shown some decrease in the last decade, the number of persons in public institutions *specifically* for the retarded has been increasing steadily at the rate of 2.5 percent per year, from 113,000 in 1946 to over 160,000 in 1960. Over the past decade, the trend **of** admissions has been up, while the trend in releases has been down. Despite the trend toward admission of younger, more severely handicapped individuals, with a concomitant decrease in admissions of the mildly mentally retarded, the death rate has been held constant. The net result is that each day there are 8 more **retarded individuals** in **our public institutions for the** retarded.

One pertinent characteristic of the **approximately** 13,000 annual first admissions to public institutions for the retarded is their youth; the median age is about 11 years. In contrast, the 4,000 mentally retarded admitted to public mental hospitals are older; their median age at first admission is 29 years.

On only one-half of the patients in institutions can a definitive medical diagnosis be made; this is clear evidence of our lack of knowledge in the field of mental retardation.

The total cost of operating, maintaining, and making necessary capital improvements to the State institutions for the retarded was approximately $300 million in 1960. This represents a threefold increase over the past decade.

There is a wide range among the States in the cost per day spent for the care of the mentally retarded. Six States spent less than $2.50 a day per patient, while only 7 States spent over $5.50 per day. Nationally, the average is $4.55 per day, less than one-sixth of the amount spent for general hospital care. While obviously low, it is a gratifying increase when compared with the $2.05 national average in 1950.

Many types of personnel are necessary to care for the mentally retarded. In 1960 there were 51,000 full-time personnel employed by public residential institutions to care for the needs of the mentally retarded. Over half are attendants or aides. There are only about 500 physicians, many in administrative positions; more simply stated, each physician involved in clinical work averages over 400 patients—patients with complex medical, psychological, and social problems.

The quality of care furnished by State institutions varies widely, but from the standpoint of well-qualified and adequate personnel and the availability and use of professional services and modern, progressive programs, the general level must be regarded as low. In large State institutions the normal problems of administration and care are compounded by overcrowding, staff shortages, and frequently by inadequate budgets. In face of these difficulties, it is to the credit of State authorities and superintendents that there are a number of good, and a few first-rate, institutions. The population of State residential facilities runs the gamut from a few hundred to more than 5,000; but on the average, each institution is caring for 350 patients over stated capacity [1] and has a waiting list of better than 300.

Waiting lists are not a fair index of actual need, as analyses undertaken by several States in the last 2 years reveal that many parents whose children may need residential care have not requested admission as they have no hope of their being accepted in the foreseeable future. On the other hand, studies of some institution waiting lists show that 10 percent or more of those on the registers do not require residential placement or at least are good candidates for some other form of care.

It is difficult to make an accurate judgment as to the precise meaning of the waiting lists for another reason—namely, when new beds for the retarded are made available in a State, they are usually filled at once and the waiting list tends to remain at approximately the same figure as before. This would seem to confirm the claim that there may be many who need institutional care who are not on the lists. It is also true that an unknown number of retarded are being sent each year to the hospitals for the mentally ill, and these retarded persons could profit by some other form of care. If and when these persons are properly diagnosed and placed, the present picture will be changed to some extent.

States and local communities will not have an accurate picture of need until there are more adequate diagnostic and evaluation services, and more facilities of all types available. Analyses of waiting lists should continue, however, and become a regular procedure in every institution as they are at least a partial index of need.

In a number of States, attention has been given not only to a continuing analysis of waiting lists but to the establishment of priorities based on criteria worked out by the State.

Most private institutions are smaller than the majority of those under State auspices, ranging from under 50 to 600 or more in a single institution; however, many are crowded and a good number lack the resources to support the wide range of services and particularly the type of educational programs that the re-

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[1] In some cases this amounts to an overcrowding of 30 to 50 percent of the present population.

tarded child requires. In spite of this there are some institutions of unusual quality among the private group.

The private institution has been and remains an important factor in the national program of treatment and care. In earlier years it produced much of the research in the field, and today it has a valuable function as a pioneer in creative methods of care, in work with parents, and in providing both long- and short-term service with flexible policies of admission and discharge.

Both State and private institutions admit all classifications of the retarded. Some State institutions specialize in the care of certain groups and, by the same token, there are private institutions that do not admit children or adults below a given level of intelligence and capability.

The Role of Residential Care

Residential care has an important place among the various services required for the retarded, and for many years it was practically the only service of any importance in this country. The view that an institution is one of several rather than the main resource in the care of the retarded is not yet established in the United States as it is in the Scandinavian countries and in England, Holland, and other parts of Europe where significant community services are a part of their program. In this country institutions represent the greatest investment of manpower, buildings, and funds, and thus are highly visible. This is a consequence of the historical pattern of our concern for the retarded, and a coincidence of the physical nature of residential facilities which are very large in many cases and frequently at some distance from centers of population.

The challenge to State institutions is how to accelerate the change from large isolated facilities to smaller units close to the homes of the patients and to the health, education, and social resources of the community; and the challenge to both State and private residential facilities is how to replace the old concept of custodial care, wherever it still exists, with modern programs of therapy, education, and research.

Institutional care should be restricted to those whose specific needs can be met best by this type of service.

Institutions are one facet in a continuum of care. The decision to place a retarded person in residential care must be made on the basis of careful review of the diagnosis and symptoms of the individual, the needs of his family, and the other resources available in the community. Professional judgment and recommendations are indispensable, but the decision-making process must also include members of the family if they are at all competent to participate.

Because of the tremendous variations in the problem presented, it is unwise to generalize with respect to the desirability of keeping retarded children in their own homes. The attitude of parents on this matter ranges all the way from determination to retain a child whether or not it is wise for them to do so—to the despair that results from carrying an intolerable burden. The financial capability of families covers an equally wide range. Thus, what is "best" for the retarded child, his family, and the community can be properly determined only by adequate professional evaluation, skillful counseling, and an objective point of view on the part of local and State authorities.

There will always be some retarded individuals for whom a residential setting for a short or long period will be the treatment of choice. In making this decision, the emotional stability of the family and the degree of dependence of the retarded person involved are key factors. If the total well-being of the retarded person depends on the care of trained personnel, and if his presence in the home conflicts with the fulfillment of the needs of other members of the family, he probably should not remain at home. If a retarded person is to live at home, it is important to determine whether the community has the supplementary facilities he needs.

Age is an important and sometimes controlling factor. Studies have shown consistently that infants and even young children up to 6 and 7 years of age are usually better served in their own or in an adequate foster home or in boarding home group care.[2] The need for schooling alone rarely calls for admission to an institution today except in rural areas where facilities are scarce; most often admission is necessitated by unmet medical, nursing, or behavioral needs; by death of the parents; or by lack of stability in the family.

Many retarded people have a critical need not being met in the community; the need may be a foster home, an educational opportunity, or only routine medical and dental care. Every effort should be made to satisfy needs such as these through available or new resources rather than resorting in a routine fashion to institutional care.

The Biometrics Branch of the National Institute of Mental Health estimates that at the beginning of the year 1960, there were some 43,000 mentally retarded patients residing in hospitals for the mentally ill. It is generally agreed that a rather substantial number of these do not warrant such a placement and were probably committed because of a lack of other facilities or as the result of inadequate diagnostic evaluation. When figures on the number of retarded persons in institutions are cited, those residing in State hospitals for the mentally ill are frequently overlooked. As a matter of fact they should be kept constantly and actively in mind as communities move toward better diagnostic facilities and as new methods of care develop.

It is imperative that at regular intervals the appropriate authorities in each State determine the status of all mentally retarded persons in State hospitals for the mentally ill and remove those who can profit by some other form of care.

The following objectives for residential care should be considered by boards of private institutions, appropriate authorities of the States, and the Council of State Governments?

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[2] Ainsworth, Mary D.; Andry; Harlow; Lebovici; Mead; Prugh; and Wooten. *Deprivation of Maternal Care. A Reassessment of Its Effect.* Public Health Papers No. 14, World Health Organization, 1962.

Bowlby, John. *Maternal Care and Mental Health;* a report prepared on behalf of World Health Organization as a contribution to the United Nations program for welfare of homeless children. Geneva, 1951.

[3] See also the standards for institutions for the retarded prepared by a committee of the American Association on Mental Deficiency, 1601 West Broad St., Columbus, **Ohio.**

(1) Every such institution, including those that care for the seriously retarded, should be basically therapeutic in character and emphasis, and closely linked to appropriate medical, educational, and welfare programs in the community.

(2) Every institution has some unique quality or potential that can be developed for the benefit of the entire field. No institution should be regarded as merely "custodial"; those caring for the profoundly retarded offer unusual opportunities for the application of new methods of treatment and care, and for research.

(3) Diagnosis and evaluation should take place before admission and be followed promptly by treatment when the patient is received.

(4) The institution should extend its services beyond the traditional boundaries of its own campus and reach out to assist the patient and his family before his actual admission; this facilitates visits by parents and friends after admission and is an important factor in early adjustment.

(5) Flexible admission and release policies and outpatient programs similar to those of a hospital or school are essential in meeting the needs of the retarded and their families.

(6) The goal of every residential program should be the elimination or amelioration of as many symptoms as possible and the achievement of independent, semidependent, or even a sheltered extramural life for every person under care in accordance with his potential. This can be accomplished only by a devoted staff with a variety of professional skills and a competent administration. Both can be rendered impotent, however, without the support and leadership of a competent and interested State department or a board of trustees.

Indoor and outdoor recreation; social activities; programs of physical fitness; opportunities for self-expression through music, painting, worship; and other creative outlets are essential aspects of sound institutional programs.

(7) No child or adult should remain in residential care any longer than necessary. Regular and frequent reevaluations must be scheduled to reveal any possibilities that may have been developed in his community and to determine whether the in-

dividual himself has reached the point where he may profit by some other form of care.

(8) If and when the child or adult is ready for return to the community, adequate resources and services for his support should be made available. It may not be wise or possible for some to return to their own families, hence the importance of developing foster or boarding home placements, or homes for small groups similar to those in several European countries.

(9) Responsibility for the care of persons returned to the community should not be relinquished by the institution until assistance is assured from some other source; efforts should be made to see that community services are made available to him before he leaves.

(10) Many residential populations lend themselves to certain unique research undertakings, particularly of a clinical nature. Continued critical evaluation of the institution program itself requires personnel with a research point of view. It is important, therefore, when the size of the institution and the quality and experience of staff justify it, that research in some form be a part of the institution program.

(11) The future of residential care must be viewed in the context of State and regional needs and resources; i.e., more than one State should be included in planning in many instances, as the geographical characteristics and resources of some States are such that they cannot meet the needs alone. Joint planning and development of interstate facilities is particularly important in providing facilities for such combinations of handicap as the blind and the deaf mentally retarded. There is a precedent for such planning in other fields in the experience of the Southern Regional Education Board and the Western Interstate Commission for Higher Education.

(12) Residence laws offer one of the barriers to easy access to residential care. The Interstate Compact on Mental Health sponsored by the Council of State Governments offers a vehicle which can to some extent overcome this obstacle. Twenty-four States are now parties to the Compact which provides that residents of these States may be admitted or transferred to an institution in any other party State by common agreement, when-

ever in the judgment of the Compact administrator the patient's interest will be served thereby.

There are at least three kinds of situations affecting the mentally retarded which are favorably affected by the Compact: *(a)* retarded children of a serviceman may be admitted to residential care in the State institution which places him nearest to those relatives most likely to be able to visit him; *(b)* parents of retardates already institutionalized may arrange to transfer the latter to another State if the family moves; (c) the way is opened up for cooperative interstate programs in a special service in which the residents of several States who have some typical needs may be grouped in one special facility. For example, a small unit for aggressive behavior may serve such young people from several States. Although this latter possibility has not been implemented, it would be possible to do so. Other examples are services to the deaf or blind retardate who are relatively few in number and thus frequently constitute a difficult problem for a single State.

The Pattern of the Future

The keystone to the development of effective services for the mentally retarded is comprehensive planning that takes into account State and local requirements as well as the professional and voluntary resources of communities. In our Federal system such comprehensive planning is a major responsibility of the States. To encourage and help make possible effective planning, the Panel has recommended in Section IX that the Federal Government make grants to States for this purpose. The following recommendations are predicated upon the effective operation of the planning process in the States and localities so that the various components of care and services can be given appropriate priority.

The Panel is gratified to note that Congress has appropriated $4.2 million for comprehensive planning in mental health. This will make an excellent start in assuring comprehensive State and local planning for community health services for the related fields of mental illness and mental retardation.

Upon presentation of a plan meeting criteria established by the Secretary of Health, Education, and Welfare, it is recommended that project grants be provided to the State institutions to upgrade the quality of residential services by [a) augmenting and strengthening programs of residential care through demonstrations and pilot projects and other means designed to establish permanent improvement and change in institutional programs; (b) support of inservice training and education; and (c) support of research projects in institutional settings.

The upgrading of the quality of services in institutions caring for the mentally retarded to incorporate up-to-date methods and approaches is a major task which must be shouldered principally by the States. The 2 vital areas in which institutional services might be strengthened are in program and personnel. The Federal Government, however, can provide a major impetus to this objective through grants for stimulatory projects to strengthen, improve, and innovate in the areas of rehabilitation and care, with an emphasis on preparation for eventual return of the mentally retarded person to the community. Upgrading of staff by inservice training and education is a basic strategy in an era when there is a marked shortage of trained personnel.

Despite the enormous riches of clinical material available in our residential institutions, with only a few exceptions, there is little significant research carried out. The Panel believes that developing this area is of great importance. Moreover, this will also help improve the quality of care in the institution by the search for new knowledge, by additional manpower; and by a spirit of hope engendered through the research process.

The Secretary of Health, Education, and Welfare should review the requirements for construction of essential facilities for the mentally retarded under public and nonprofit auspices, including facilities which are not necessarily under direct medical supervision.

This review should be coordinated with the current review of the Hill-Burton program, and with the review of the national mental health program now underway in the executive branch.

It should provide a more definitive analysis of need in the light of desirable patterns of service outlined in this report and clarify the exact extent and character of facilities to be aided.

There is a shortage of physical facilities for many types of needed programs for the retarded, including classrooms, workshops, "activity centers," day care, halfway houses, and full-scale residential care. High priority should be given, however, to construction of facilities for day and residential care and related community programs designed to express the new program concepts recommended in other sections of this report. It is estimated that when the full potentials of day care are realized, facilities for some 50,000 seriously retarded children and adults will be needed. Residential facilities are currently required for at least another 50,000 children and adults now not served; replacement for overcrowded and obsolete quarters now in use would bring the total to over 100,000.

To assist it in developing its plans, and in preparing principles and guidelines for standards basic to Federal participation, the Public Health Service should be advised by an expert group composed of persons within the Department familiar with the program needs of the retarded, together with representative officials responsible for State programing in the various areas, and national agency consultants.

The Panel recommends that local communities, in cooperation with Federal and State agencies, undertake the development of community services for the retarded. These services should be developed in coordination with the State comprehensive plan for the retarded, and plans for them should be integrated with those for construction and improvement of services in residential facilities.

As the States and the boards of public and private institutions plan for the future, problems of the size of institutions, program, and personnel are paramount. Bringing the provision of services as close as possible to the local community is a basic tenet on which the Panel's recommendations rest. This would be consistent with the general movement of health and mental health services in this direction, in itself an important and key movement in developing new services of the retarded.

Size of Residential Institutions

The number of retarded persons cared for under a single administration, though not the only criterion of excellence, is a vital factor in furnishing a high level of care in residential facilities.

Certain basic principles obtain with respect to institutions now in existence and those that may be built or reconstructed in the future. Foremost among these are size and structure in relation to the main objectives of the institution.

In large institutions the problems of administration, staffing, and logistics are such that it is extremely difficult, if not impossible, for the management to give sufficient attention to individual needs and provide a constructive program of adequate and even quality for all members of the group.

Every individual in an institution should have a reasonable amount of privacy and the means of maintaining some of his own personal belongings. Single rooms or rooms for two are more desirable than even small dormitories, particularly when they are available to the occupants during the day and evening when privacy is even more important than at night. Patients of limited mobility, including the physically handicapped retarded, can be cared for effectively and economically in units of 8 or 10. Large institutions can be arranged to provide privacy and individual attention to some degree. For example, the superintendent of an institution housing over 2,000 persons wrote recently:

> A 2,400-bed institution could be built and organized to provide 12 areas or units of operation. Each unit could develop the typef of program which best meets the needs of about 200 residents; in effect, this would constitute a cluster of 12 "institutions" sharing ground, facilities, administration, and general staff.

It is frequently stated that the cost of furnishing professional services in small residential institutions is virtually prohibitive. However, if the facility is located in or near an urban area, and particularly close to a university, this problem may be mitigated to some extent due to the greater availability of certain services and professional personnel on a part- or full-time basis.

Per capita costs constitute another block to the acceptance of small facilities of 100 to 200, as compared with **institutions of** 1,500 to 2,000 or more. Cost analyses are being made in some States and are available in other countries. Per capita figures must always be subject to careful scrutiny, however, and comparisons between States, not to mention between countries, are generally misleading. Assuming that the cost of a high quality of care in small facilities might be somewhat higher, the value to the patient and his family may well be much greater. There is also the very good possibility that the attention accorded each individual in a small institution in relation to his possible return to the community could result in an earlier discharge than would otherwise be the case, thus providing both a social and economic gain.

If there is any virtue whatever in small institutions, and small living units within large facilities, moderate-sized institutions should at least be recognized as an essential objective for every State program even though they cannot be realized at once.

After nearly 200 years of orientation to the concept of congregate care for the mentally retarded and the mentally ill, it is difficult to change the pattern and adopt a new frame of reference. As long as we have major financial investments in large plants, it will be a temptation to some to defend them as satisfactory or even preferable.

The key factor, of course, is the progressive well-being of the individual patient. When that and other factors are taken into consideration, a reasonable conclusion is (1) that institutions for the retarded should not exceed 1,000 beds and those whose populations presently exceed this number should take steps as soon as possible to provide small living units within the facility to provide individual care; and (2) that residential facilities now being planned, and those to be built in the future, should not exceed 500 beds, in general, and for certain specific purposes any number under that might well be regarded as advantageous. Colorado is presently planning a special facility for 50 in the city of Denver; for example, adapting a building formerly used for other purposes.

The Program of Services in an Institution

The internal program of the institution should be developed in cooperation, or at least with a full knowledge of community resources in mind, but the institution itself must have a vital program of its own. When this transpires, the community can draw upon it, and the institution on the appropriate programs in the community, but each should be strong in its own right.

Intramural services should be supplemented by such extramural programs as outpatient services, part-time hospitalization, parent counseling, and other aids.

The community orientation of the institution should be increased through the cooperation of appropriate State personnel and the incorporation on the staff of community organization specialists capable of participating in surveys, evaluation of programs and their integration, and the stimulation and development of necessary local resources.

Community education (i.e., informing citizens of the needs of the retarded and the program of the institution) should also become an important part of this total responsibility.

Program planning and demonstrations of new modes of care should be initiated in each residential institution in cooperation with appropriate agencies in the community.

Personnel training programs should be implemented or initiated, with the objective of improving present personnel and training new employees, including selected patients who. may be assigned work in the institution as a prelude to obtaining positions in the community. Of special importance is the training of young students not yet committed to a vocation.

Special training programs of 6 or 8 weeks' duration for house parents and attendants should be inaugurated by each State in cooperation with a university and with the assistance of appropriate voluntary groups, to include lectures and discussions, visits to residential and other facilities for the retarded, and a period of supervised work followed by some form of certification, as a prerequisite to employment.

Volunteer programs should be established under professional leadership and a wide range of volunteers recruited from the community including young people, those in middle life, and others who have reached retirement age.

The qualifications of the chief administrative officer (superintendent or director) of both State and private institutions is a matter of importance. A competent person from any one of several disciplines involved in or related to mental retardation might be wisely selected, provided he has sound professional training, some orientation in the disciplines other than his own which are relevant to mental retardation, demonstrated administrative ability, and, last but not least, interest in the field of mental retardation and preferably some experience in it.

Private Institutions

Unique opportunities are open to the private institutions in the country. There are many ways in which they can serve as important links in a continuum of community services, and cogent reasons why they should become increasingly strong factors in programs for the retarded; first is the fact that our society believes in and profits by a fruitful partnership of public and private services in every area of endeavor; second, and more explicit, it is the opportunity that the high-quality institution offers to the States by way of a spearhead or vehicle for demonstration and experimentation in residential care. A great deal of value could accrue to both voluntary and public programs for the retarded if more States would apply in carefully selected instances "the purchase of care" plan whereby a private institution for the retarded is conducting, or can conduct for the State institution or other State programs, a unique service of special value. It is suggested that this possibility be thoroughly explored by those States which have not yet considered or used this resource. It is important that in any such plan the purchase of care should be made on a cost-accounting, rather than a flat, basis, and that the amount paid by the State in any year should not exceed the total amount of the budget of the institution for that year. Otherwise the institution would in a sense lose its private status and be subject to State control.

States have the responsibility to maintain effective licensing and inspection of all private facilities offering residential care for the retarded. Private institutions of appropriate standards and level of patient care that meet State requirements should be eligible for all support and subsidies outlined in these recommendations.

There are more than 300 public and private institutions for the mentally retarded in the country, and the question as to how they can most effectively serve now and in the future in relation to the plans for community services now developing in many parts of the country constitutes a challenge of substantial proportions. The funds which the State institutions alone now devote to building and reconstruction of facilities should be directed to some of the plans developed in other countries and to some of the most progressive examples available here at home.*

The mission to the Netherlands sponsored by the Panel made the following recommendations, among others, which are germane to the future of residential care in the United States.

> (1) Impetus should be given in the United States to the development of a wider range of diversified residential arrangements for those retarded persons who, for what ever reason, cannot live with their own or foster families; i.e., small units designed in program and structure to meet different needs.
>
> (2) Emphasis should be directed to the development of group homes in urban and suburban areas for small homogeneous groups of retarded persons who can use the various community opportunities for work, recreation, and education, and to the design, construction, staffing, and use of living units for 6 to 10 children within larger institutions.
>
> One of the best hopes for the improvement of both public and private institutions in the States may come from interdepartmental committees and equally strong citizens' committees, both appointed by the Governors and responsible to them.

If the membership of a citizens' committee includes knowledgeable and militant people who will acquaint themselves with the problems of the retarded in the State, and help to determine what is needed to improve and develop the program, there will be substantial progress; in fact, it is doubtful whether fundamental improvements in residential care where it is needed the most can take place without an organized and sustained citizen effort.

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[4] See papers by Gunnar Dybwad given at the Joseph H. Ladd School, Exeter, Rhode Island, Sunday, Apr. 29, 1962; and by Harvey Stevens in "Proceedings of London Conference on Mental Deficiency, 1960."

It is proposed that this section of the report, and others dealing with community facilities, be brought to the special attention of the Council of State Governments; and that steps be taken through the council to bring them to the official attention of the Governors and legislatures of the several States.

Section VII

THE LAW AND THE MENTALLY RETARDED

Justice in the Social Context

Growing understanding of a broad disability such as retardation usually sets in motion 3 altogether different processes, each of which affects the others, and has a bearing on practical decisions.

First, general understandings, the presumptions on which people operate every day, are altered so that human behavior comes to be seen in an often new and clearer light. This has occurred in relation to what we have learned both about mental disease and mental retardation. Second, important institutions such as school, church, and home alter their views, doctrines, and practices in the light of their interpretation of new knowledge. Lastly, new specialized institutions and services designed to deal with the problem are brought into being.

The laws and their administration influence the extent to which the mentally retarded will be permitted to benefit from these trends and advances.

"Equality before the law" is predicated on the assumption that everyone has roughly comparable capacities to invoke the law's protections and to abide by its proscriptions. This "minimum set of personal characteristics in the population," which the law ordinarily takes for granted, may not be totally present in the mentally retarded person, but neither will it be totally absent. He will have, in some measure, the inadequate intellectual development and degree of impairment in the ability to learn and adapt to the demands of society which we discussed in the first section of the report. The law must take into account the pervading chronic character of mental retardation, along with the disparities and divergencies in abilities and disabilities displayed by members of the group.

This variability has long been understood by those who work with the mentally retarded, and has been the subject of much specific investigation in the last half century. While legislators, lawyers, and judges have not been ignorant of this developing knowledge, the law itself has tended to deal in absolutes. Before it, the retardate is either competent or incompetent, committed or freed. The defendant is either responsible or not responsible, triable or not triable, punishable by ordinary standards or subject to exoneration.

With the development of *new* alternatives in treatment, our community and residential institutions are attempting to overcome certain rigidities of the law in the interests of giving the retarded individual the benefit of modern knowledge concerning his growth and development, and his ability to learn, and to modify his behavior in response to various social stresses and situations.

Responding to these trends and opportunities, we would minimize mandatory legal requirements wherever voluntary compliance can be obtained. The richer and better the services available to the retarded and those concerned with their welfare, the less need there is of coercive intervention to provide care. Indeed in dealing with problems that arise with the retarded in the community, formal legal intervention should be regarded as a residual resource and should not occur where social or personal interests can be adequately served without it.

Where the law must intervene, the community should look first to see whether laws of general application would be adequate. If they are not, the community should turn to law which protects the disabled as a group. Only in the last resort should the community rely on ad hoc legislation for a specific handicapped group.

The philosophy of minimizing reliance on the law depends for its success on the existence of adequate community, voluntary, and parental services for the retarded. Although formal, mandatory, and coercive legal action toward the retarded should be kept at a minimum, the law must, at the same time, protect the rights of the retarded; it cannot rely exclusively on the good intentions of those who manage institutions and other programs.

The Mentally Retarded Under Civil Law

Like other citizens, the mentally retarded must be assumed to have full human and legal rights and privileges. The mere fact of retardation should never be considered in and of itself sufficient to remove their rights. The circumstances which would justify any departure from these basic principles should be the subject of judicial review in each individual case.

On the other hand, it must be recognized that many of the retarded are at a disadvantage in recognizing and asserting their rights. For these people, society must provide additional protective services.

Each State should establish a protective service for the retarded in an appropriate State agency.

Among the functions of such a service would be consultation with the retarded, their families, employers, guardians, and others concerned with social and legal problems of the retarded. The State agency should supervise the private guardians of mentally retarded persons; it should interpret to the public the issues involved in protecting the rights of the retarded; it should be available to the courts to offer expert testimony on issues involving mental retardation.

The agency should also concern itself with scrutinizing the operation of any laws and administrative procedures which adversely affect the retarded. Among these may be the laws on adoption, marriage, sterilization, and mental incompetency.

Some laws operate to the detriment of retarded children by making difficult their adoption by willing and prospective parents aware of their handicap. These difficulties are neither desirable nor defensible. Parents who unwittingly adopt a retarded child may, under some laws, seek annulment of the adoption any time within 5 years. We doubt that the interests of the child are adequately protected by such laws.

Guardianship of the property of a retarded person should be clearly differentiated from guardianship of the person. There may well be a need for the former in cases where the latter is unnecessary, and vice versa.

Where guardianship of any kind is required, it should be carefully adapted to the specific requirements of the case. For some, a comprehensive guardianship will be needed, but it is urged that to the maximum feasible extent, mentally retarded adults should be allowed freedom—even freedom to make their own mistakes.

We recommend the development of a limited guardianship of the person, with the scope of the guardianship specified in the judicial order. Plenary guardianship of the person should be reserved for those mentally retarded who are judicially determined to be incapable of making adequate routine day-to-day decisions.

Where the court empowers the guardian to delegate formal custody of the ward as, for example, when arranging admission to a residential institution, the guardian should notify the court of changes in the ward's place of residence and the nature of the provisions made for him.

At the judicial hearing necessary to the appointment of a guardian, the person alleged to be retarded should be present unless he is excused by the judge for good cause. When this happens the judge should see the retarded person and the reason for nonattendance should be specified in the record. The proceedings should not as a rule take place in open court, but should be held in the judge's chambers or at some other appropriate place. Throughout the hearing, the allegedly retarded person should be represented by counsel—appointed by the court, if necessary.

The court must have at its command a comprehensive clinical evaluation by appropriate personnel drawn from the professions of medicine, psychology, education, and social work.

The rights of the retarded person will not be adequately protected unless the hearing is used as an instrument for genuine cooperation and exchange of ideas between the law and the various caretaking professions.

There should be periodic review by the courts of the need for continuation of any form of guardianship. In particular, the need for a continuance of guardianship should be reviewed when the ward reaches the age of 21.

In appointing guardians of the person, courts should look first to family members, though not necessarily in the order of formal kinship. Parents or other guardians should be encouraged to advise the court on choice of successor guardians by testamentary expression of preference.

The protection of guardianship should not be denied where there is no suitable relative to undertake it, or where the retarded person's financial assets are too small to compensate adequately a private guardian. Studies should be made to consider how best to deal with this problem. One possible solution is the establishment, perhaps through the State protective agency referred to earlier, of a program of public guardianship of the person. Although guardianship might then be formally vested in a State agency, duties would actually be carried out by individual staff members. The experience of Minnesota with such a program might well be studied by other States.

No special legislation is needed when a child is sent to a residential facility for the retarded by his parent or by a properly empowered guardian.

General laws governing parental neglect are usually adequate to insure the protection of the child. Additional protection could be provided by the State's careful examination of the administration of institutions caring for the mentally retarded. This, again, could be undertaken by the State protective agency, whose establishment we recommend above.

The judicial hearing now required for commitment to an institution over an adult's objection should also be required whenever a retarded adult is to be admitted to an institution without his clear, voluntary consent, unless a guardian has been appointed whose powers include discretion in this matter.

Admission procedures for adult retarded persons raise a number of complex problems. Our law has generally distinguished between "voluntary admissions" to mental institutions and "involuntary commitments"—with judicial intervention required only for the latter. As used here, "institution" refers to a recognized facility authorized to accept and exercise legal custody and control over persons committed for care. We must rely on the discretion and good faith of the superintendents of facilities for the retarded to accept as "voluntary" admissions only those retarded adults who are themselves capable of making such a decision in the same sense that a nonretarded person would make it.

The judicial hearing which should be held for all "nonvoluntary" admissions should have the same protections for the retarded person which we outlined in our recommendations on guardianship.

There should be judicial review every 2 years of the need for continued institutional care for all retarded adults, whatever their original type of admission. There should always be a review when a mentally retarded person reaches the age of 21.

Retarded persons living in institutions which they did not enter voluntarily should also have outside guardians who check on the ward's treatment and care and on the wisdom and possibility of his release from the institution.

The Mentally Retarded Under the Criminal Law

The possibility of doing justice, and thus fulfilling the function of the law, turns upon at least 2 conditions: *(a)* correct appreciation of facts—situations, acts, circumstances—and their meaning; and *(b)* a suitable range of disposition possibilities. Failing the first, justice is truly blind; failing the second, it is impotent. Justice is blind if it does not inquire into the significance of mental retardation as a "circumstance," and impotent if it has no dispositional variants suited to the differences it finds.

Confessions to crime by mentally retarded persons should be accepted only with the greatest caution—if at all.

Recent Supreme Court opinions have emphasized that mental retardation is an important factor in determining whether a confession is genuinely voluntary. And under the Constitution, only voluntary confessions may be used at the trial of the accused.

In those jurisdictions which consider silence in the face of an accusation as evidence of guilt, little or no probative weight should be given to the fact that a mentally retarded defendant remains silent when accused of a crime.

The police should be warned of the inherent unreliability of confessions by the mentally retarded. They should be urged to adopt strict standards in questioning people whom they have reason to believe may be mentally retarded.

It is recommended that procedures which result in automatic commitment to a mental institution of mentally retarded defendants found incompetent to stand trial should be critically reviewed.

The court should be able to choose from a range of dispositional alternatives depending on the facts brought out in each individual case. The type of further care or control required may range from full custody to normal life at home, with parents or guardians admonished concerning the need for supervision.

Following a finding of incompetence to stand trial, mentally retarded persons should be allowed, through an attorney, to raise at a hearing before a judge any defense on the facts or the law, other than a defense based on mental disease or defect precluding responsibility.

The indictment may be dismissed following the hearing on the basis either of the facts or the law. We endorse the recommendation of the American Law Institute's Model Penal Code on this point.

Rules of criminal responsibility should be designed, interpreted, and administered to reflect contemporary knowledge of the nature and effects of mental retardation.

The traditional tests of criminal responsibility have resulted in the conviction and punishment of many mentally retarded defendants. We urge lawyers, judges, lay and medical men in the different jurisdictions to reconsider the moral, social, and medical issues involved in assessing the criminal responsibility of the mentally retarded.

There is an urgent need for new approaches in the treatment of mentally retarded criminal defendants—those who have been found not criminally responsible because of mental retardation and those who have been convicted.

A mentally retarded defendant, whether convicted or found to be not criminally responsible because of his retardation, requires some form of therapeutic treatment or training. We recommend that the extent to which this is now available in prisons and in mental institutions be reexamined. For many, needed treatment should be made available under supervision in the open community. We recognize that the mentally retarded individual who exhibits persistent uncontrolled behavior which threatens the well-being of others requires particular attention. The type of control and treatment most appropriate to him requires further study since he seems unsuited to both the typical prison and the typical institution for the nonaggressive retarded.

Continuing Reform

The whole body of law that relates to the condition of mental retardation {whether specifically or by implication) should be reviewed from time to time in each jurisdiction.

The need for overhaul of State legislation pertaining to the mentally retarded in several different fields is now so overdue in most States that consistent attention to this need by the legislature over a period of several years may be required. The work of New York State's Joint Legislative Committee on Mental Retardation, and the Massachusetts Recess Commission, each active over a period of years, bears witness, among others, to the important role which can be played by the legislature in counterpoint to efforts of the executive branch of State government.

We do not believe it sufficient, however, that legislation and court procedure should be amended, or new legislation and court procedures introduced. These are crucial steps. But they are insufficient unless they are provided with a proper base in both professional and general education. There must be jurists, attorneys, physicians, and social scientists who understand what is required and there must be an educated and well-informed public to support their efforts and enter with understanding into the requirements of the new procedures and law.

Section VIII

PUBLIC AWARENESS

A public awareness program of the scope and content needed for mental retardation cannot and should not be the responsibility of any single existing organization, but should become the joint responsibility of several.

No one agency working in this field is in a position to discharge the full responsibility for this important work, because each is concerned only with special aspects of this program; and broad public awareness, as well as an effective approach to professional groups and other organizations, requires a broader concept and the use of different although related techniques.

The National Association for Retarded Children conducts a program of public education to the extent of its limited sources, but it cannot carry the full load. The American Association on Mental Deficiency, the Council on Exceptional Children, and the Department of Health, Education, and Welfare also contribute to *public* education in relation to mental retardation, but this is not a significant part of their total program.

An expanded program of information and education on mental retardation is essential for the general public and pertinent professional organizations.

It is recognized that filling the needs of various professional groups for information and education materials, and preparing and disseminating more general material for the benefit of special interest groups and lay publics, is a huge task.

It is essential, therefore, that carefully planned efforts in this direction be taken as promptly as possible and conducted over a period of time, if the recommendations of the Panel are to be backed up by better informed professional and lay groups.

Fulfilling this task is vital to any real progress in every aspect of the retardation problem because public awareness plays a key role in helping to shape the attitudes of legislators and potential workers in the field, as well as helping to stimulate community support and financial backing for the needed expansion and improvements necessary in the wide variety of programs discussed throughout this report.

Because no one of the specific agencies cited above can discharge this obligation alone, it is recommended that they work in close liaison through a planning and coordinating committee or similar device of their own choosing.

Information for Professional Groups

Information and education programs are needed to interpret the findings and recommendations of the Panel to pertinent professional organizations through articles in professional journals; participation in professional meetings, conferences, and seminars; and preparation of exhibits for display at professional and other meetings. Sponsorship and production of training films related to the aims of professional groups and designed to acquaint them with current data on mental retardation are also needed.

Information and materials on mental retardation should be distributed in a variety of forms to national and local groups.

To increase public awareness of the present status and potential of work with the retarded, there must be a wider distribution of material germane to mental retardation. The audiences for these materials should include religious, fraternal, and service organizations; women's groups; PTA's; youth organizations; voluntary health and welfare organizations; public and private schools; colleges and universities. Many such groups have a substantial influence both in local communities and in the country as a whole. They should, therefore, be fully aware of the problems and the challenge of mental retardation, and hence be in a position to support and improve programs and services.

The cooperation of mass communications media should be sought as a means of increasing public awareness of mental retardation.

As part of this effort, a press kit should be prepared, through the instrumentality of the planning and coordinating committee referred to above, for freelance writers, magazine and newspaper editors, television and radio writers and producers, including basic background data with "story," article, and program suggestions.

Films for lay audiences should be prepared to deal with such subjects concerning the retarded as—

A. The general "story" of the retarded and the need for increased and improved community services.
B. Special education—what it is and why we need an enriched and expanded program.
C. Vocational training and vocational rehabilitation.
D. Recreation for the retarded.

The above are recommended at this time as they are basic to helping communities throughout the country to understand the need for providing community services and facilities for the retarded. There is, at present, a dearth of first-rate films dealing with special education and vocational rehabilitation for the retarded.

These films, produced for showing to the special-interest audiences cited above and for public service television showings, would do much to increase public awareness of the mental retardation problem in general, as well as in the special education and rehabilitation areas where special needs for programs are greatest.

It is further recommended that filmstrips depicting the highlights of the Panel's recommendations be produced.

The basic needs for the first year of a public education program should include at least the following:

1. Three documentary films. Prints, promotion, and distribution.

2. Filmstrips, sound and color, including original art and photography. Prints, promotion, and distribution.
3. Exhibit for professional meetings (design, manufacture, rental of exhibit space, shipping, and storage).
4. Printing—reports, brochures, press kits, informational and other special materials.

The total cost of the above would be approximately $250,000, not including provisions for public relations services and consultation, which should be provided for in an overall operational budget.

The materials described above should be undertaken in conjunction with a planned program of work with the various mass media, such efforts to include the furnishing of story and program ideas and basic background data to such media people as science, education, and welfare writers, together with editors, radio and television producers, and others.

Such efforts, made concurrently and with planned continuity and coordination, represent a responsible approach to increasing public awareness of the retardation problem. Should budget permit, such efforts could be substantially expanded in many of the areas indicated so that the pace of public relations and public awareness could be materially quickened.

It is recommended that the planning and coordinating committee develop and conduct a national program of public education and interpretation.

It is suggested that the committee draw up a budget adequate to support a program of the scope and variety suggested here, and that grants from private sources be sought, if necessary, to supplement and complement the public funds and other resources available.

Section IX

ORGANIZATION OF SERVICES—PLANNING AND COORDINATION

The Role of Coordination

Coordination is the process of bringing all necessary resources to bear in the appropriate sequence to accomplish a specific mission. Coordination of some type and degree is a basic part of all human endeavor.

To achieve coordination, certain minimum conditions must be met. They are essential equally to the optimum utilization of resources for direct service to the retarded, for personnel training, and for research. In order of their significance those conditions are: *communication*, *cooperation*, and *authority*.

All participants in an enterprise as complex and diversified as the campaign against mental retardation must have, and use, means of *communicating* their objectives and their activities. Such communication must be explicitly provided for—and it must be recognized that it takes initiative and energy for its accomplishment. Just as physical systems require explicit provisions for communication, so do human systems of the type needed in the field of mental retardation.

When communication is made effective, the groundwork for *cooperation* has been laid. If cooperation is to be worth while, the participants must have some needs and objectives in common and each must have resources to contribute to the common effort. Through effective cooperation the participants get more for their pooled energies than if each spends his energy alone. Adequate communication is the only means of assessing such common cause and shared potential.

The *wish* to cooperate is not a sufficient condition for joint or collective action. Individuals—even institutions, agencies, States, and nations—must *learn* to cooperate. Principles and techniques must be wrought from experience and adapted through trial and error.

Authority is the most overvalued condition for coordination. Generally, it may be said that where formal authority is present, coordination merges with administration. Authority alone, however, will not suffice as goad or guide for the coordination of such complex and interdependent human enterprises as are involved in dealing with problems of the mentally retarded. Authority must be coupled with and accompanied by realistic attention to the conditions of communication and cooperation. Thus it is apparent that coordination takes time as well as resources, and those who would achieve it must possess special skills and understanding, as well as whatever modicum of authority the situation requires.

The major resources and services most necessary to promoting the well-being of the retarded, within the framework of existing knowledge and social progress, have already been described. A service does not exist in the abstract; it is a resource only to the extent that its purpose is relevant to the mission on which it is brought to bear. In relation to its defined contribution to that mission, a service must be: (1) wanted, (2) effective, (3) visible, (4) accessible, (5) efficient, and (6) related to others.

The grouping of services into physical or administrative complexes presents many critical problems. In general, the desirability of local responsibility is not to be denied, yet in determining the optimum size of an organizational unit or complex, conflicting factors must often be considered. For example, to make services more accessible, it may be desirable that they be dispersed into a number of small units, each of which serves only a relatively compact group of people. On the other hand, effectiveness may be impaired if this process is carried so far that manpower and physical facilities are not used to the best advantage.

This problem comes up in a variety of settings. For example, in the last 15 years efforts have been afoot across the Nation to increase the minimum population base for a "local" health service. Similarly, it has been recognized that a school district which can organize an adequate elementary school program may be too small to support and operate a sufficiently diversified high school program. The same forces are at work in respect to services for the mentally retarded, often in an accentuated form. For the effective organization of a sequence of special classes, for example, a certain minimum number of children must be assembled. The massive State institution grew up out of a similar thesis—which may have been overstated—that all essential services needed for all types of mentally retarded children and adults should be brought together in one place and the retarded person himself transported to that place as a resident to solve the problem of accessibility.

This report is predicated on a strong conviction that the mentally retarded person should be served with as little dislocation from his normal environment as is consistent with the special character of his needs. Those needs should be met as close to his home as possible and in such a way as to maintain his relation with his family and peers.

The thesis that services should be provided locally does not necessarily imply that all responsibility must be exclusively local. A study of the forces at work for the mentally retarded today suggests that, along with enrichment of the array of services available to him, a closer intermeshing of State and local and of official and voluntary activities on his behalf is developing.

In the public domain, of course, formal authority in these fields lies with the State, which by law may delegate some important functions and funds to public bodies at the municipal or county level. The State may also work through private agencies, informally through purchase of services, or more formally through grants-in-aid. In this manner some of the effectiveness and efficiencies of the State with its resources for planning, expert advice, and funding, can be combined with the accessibility *and relatedness of a more* localized service. The area *centers* and "dispersed services" discussed later provide examples.

Whether such possibilities are achieved in practice depends to a great extent on the effectiveness of State leadership. The

Panel believes that the role of the Federal Government, as the States and localities move toward improved programs of care, is to encourage planning and the change to new patterns, and whenever possible and feasible, furnish appropriate leadership and some financial assistance on a matching basis to these ends.

The Secretary of Health, Education, and Welfare should be authorized to make grants to States for comprehensive planning in mental retardation.

Planning should be directed to the development of a balanced arrangement of local, area, and State services, coupled with appropriate professional and subprofessional training and research in accordance with the needs of a particular State. The comprehensive plan will form the basis of other Federal grants pertaining to construction of various types of facilities recommended in Section VI, as well as research, education, rehabilitation, clinical, and training programs. It should be pointed out that comprehensive State planning will help the States to allocate more effectively their own present resources whether or not there are increased Federal funds.

It is paramount that the plans submitted by each State for the use of Federal funds should be developed by the departments and/or official committees responsible for statewide programs for the retarded, with the participation of the management of residential institutions. This will strengthen planning and coordination, and help to keep residential care in proper perspective in relation to other needs and developments.

Adequate planning will depend in part on the proper evaluation of adequate and relevant data which can be accumulated only through the establishment of good recordkeeping systems, the employment of personnel trained in biostatistics and social research, and carefully designed statewide and community studies. Furthermore, the selection of the data and the development of such record systems should be carried out with the objectives and requirements of good coordination in the forefront. Therefore all appropriate agencies should be involved in planning such record systems. In order to achieve this, Federal assistance may be necessary, and this may be supplied in part through the planning grant mechanism.

Planning will be aided by current efforts of Federal-State and voluntary agencies in gathering information in various mental retardation programs administered by or under the authority of the States. One example is the current activity in this area now being undertaken as part of the National Institutes of Mental Health Clearing House of Mental Health Information. Another important potential contributor would be the Council of State Governments, which is an authoritative source of information on State programs of all kinds. Although it convened a conference in 1958 and has given some additional attention to mental retardation, more recognition to this field is warranted in view of the initiative which States show and the size of their expenditures.

Organization of State Services to the Mentally Retarded

State responsibility, as outlined in 1958 by a conference of the Council of State Governments, must include "intensive efforts to prevent birth defects; other services, such as prenatal care, pediatric care, child health supervision, and safety provisions. The State program also includes diagnostic service for developmental evaluation, an extensive research effort, provisions for the training of professional personnel, and intensive programs for the care, training, and welfare of the mentally retarded."

The 1958 conference also agreed that "the problems of the mentally retarded are not and cannot be the responsibility of any one department of State government. They are important concerns of several departments and require a multiple, but coordinated attack." The Panel concurs.

Such a listing points up the need for an appropriate definitive assignment of functional responsibilities among the traditional departments of State governments.

The Governor of each State and his staff should review the array of major services outlined in this report; identify the branch of State government which is, or should be, discharging each re-

sponsibility noted; and assess the extent to which each function should be strengthened.

No single pattern will be equally applicable to all States. The Governors of the respective States are urged to note, however, that there are functions and services which should properly be the concern of every State government, but to which adequate attention is not now being given. In most States, at least 3, and perhaps as many as 5 major divisions of State government have, or should have, a responsibility for some significant segment of the program for the mentally retarded. The support for staff and program analysis to implement this recommendation and the following one may well come from the grants to States for comprehensive planning.

Each State should make arrangements through such means as an interdepartmental committee, council or board, for the pint planning and coordination of State services for the mentally retarded.

Any State program providing a comprehensive approach to the problems of the mentally retarded must also include provision for joint planning between State agencies and local government agencies.

The interagency body should be created or continued by the Governor, who should receive and act on its major recommendations from time to time. This pattern is already being followed to good effect in several States. For example, one Governor, having established a Governor's interagency committee on health, education, and welfare programs, set up within it an interagency subcommittee on mental retardation, composed of representatives from the department of public instruction, the department of institutions, the department of employment security, the department of health, and the department of public assistance. The division of vocational rehabilitation (in that State a division of the department of public instruction) was also represented because of its exceptional importance in this context.

In general, State agencies responsible for education, mental health, health, welfare, labor, employment services, and corrections, and State institutions of higher education, offer programs and services for the mentally retarded. Within a given State there may be other departments concerned.

In addition to interagency committees, public advisory committees broadly representative of interested lay and professional groups have proved valuable in helping to develop and advise on how to carry out comprehensive programs. A variety of organizations have been used, either to strengthen or to supplement interagency planning. For example, the Governor of South Dakota recently called a conference on mental retardation, modeled in part on the President's Panel, to make a comprehensive review of State programs and needs.

Within each State department with a major concern for mental retardation, there should be a division or bureau to administer services to the mentally retarded or. a special consultant with departmentwide responsibility for the development and coordination of these services.

The division, bureau, or special consultant should be so placed in the administrative structure as to command the attention and exercise the authority necessary to carry out whatever function is involved. A number of States now have specialists in education of the retarded in the bureaus of special education. Counselors who are specialists in rehabilitation of the retarded are receiving more recognition. Several States have major departmental divisions whose heads devote full time to administering clinical and social services and residential care for the retarded.

Adequate arrangements should be established within the State government to undertake responsibility for promotion of appropriate training and research activities, associated with the various services or in cooperation with universities. Some of the potential contributions are outlined in a later section.

Organization of Local and Area Services

In the local community explicit provisions for coordination are essential so as to achieve a balanced array of services and thus to meet the composite needs of the retarded. Through effective coordination, gaps in service will be identified which indicate the need for local, State, or national action; in some instances, action at intermediate levels also will be indicated. Machinery must be available and used systematically by local groups to transmit information, conclusions, and supporting documentation to appropriate agencies having responsibility for broader service areas. The personnel of the "fixed point of referral" and "life consultation service" in particular are strategically placed to pick out weaknesses in the "continuum of care" as it may affect the individual retardate.

The most desirable point for coordinating local services may well vary with the characteristics of "the local community." An urban center will afford a variety of governmental offices and agencies which may serve as the base for coordination and program evaluation. On the other hand, if "the local community" is a small settlement in a sparsely settled region of a State, it may be necessary to provide an administrative base on a county, intercounty, or other area basis. In any case the same general principles apply. Resources for mental retardation must be identified within those agencies which control and administer the health, education, and welfare services. Whenever the community has a multiplicity of locally sponsored services for the retarded, a coordinating committee or organization is needed. Except in the largest cities coordination is likely to emerge under voluntary auspices—for example, as a committee of the local community health and welfare council—although in Pennsylvania a mayor's committee for the handicapped has been established in a number of cities under the leadership of a Governor's committee. These broadly representative bodies should, if possible, have staff to serve them and funds to provide for data collection and program analysis.

The grouping of State and local responsibilities will reflect in part the philosophy favored in a particular State with respect to the appropriate grouping of services. Some States favor close administrative or physical aggregation, as in the area center; others find greater flexibility in dispersing the various functions. Several such types of programs are now being developed in different parts of the country which illustrate these contrasting approaches. These deserve careful study.

Area Centers

An area center, as the name implies, is a grouping of specialized resources intended to serve as a concentration point for services to the retarded of a specified geographical area. Characteristically, the center is located close to or in a population center and is made accessible to outlying districts by means of special transportation organized for the purpose. Such a center has the authority to deal, at least initially, with all calls for service from area residents. Usually it also uses other community resources, including public schools, and encourages volunteers to enrich its programs. In most cases, such centers should undoubtedly be planned and programed by State agencies, with administration of the centers in some communities handled by local political jurisdictions—particularly where those jurisdictions have successfully provided and can best supply the kind of services and the local leadership that is required.

Among the services which may be offered in an area center are: referral, diagnosis, counseling, day care, special medical care, recreation, short-term residential care with flexible admission procedures, halfway and self-government houses for the more able retarded youth, and workshops and adult activities in which both day and resident clients participate. Some facilities for long-term care may be included, depending on the place of the area center in the overall State plan.

Area centers may be organized and operated in relation to existing major residential facilities in a variety of ways:

(1) The area center may bring together an aggregate of services designed to serve all ages and classifications of retarded. Under such a plan some existing State institutions can be converted to area centers, gradually reducing their resident population to manageable proportions, while developing the flexibility and range of nonresident or extramural services envisaged for a comprehensive center program.

(2) A second type of area center might serve all but the most seriously retarded from the area. In this case, the central institution or institutions in the State would pre-

sumably specialize in the care and treatment of the most severely retarded or those with very unusual problems.

(3) A third approach would be for present State institutions to become area centers, but at the same time accept from other smaller, more localized centers the severe and atypical cases for special attention and research. State programs involving this approach have been launched in Connecticut and Colorado. In the latter the centers will be State-local projects under the direction of a local board, with supervision from the State coordinating agency. Each State and local agency will be responsible for providing those services to the retarded which are commonly assumed to belong to it, with the State coordinating agency filling in the gaps.

A number of communities, especially in the South, have moved toward the center idea, with emphasis on the day services needed by the moderately and severely retarded. One of the most complete is the MacDonald Training Center serving the Tampa, Fla., area. Its aggregate includes a nursery school, inaugurated with Junior League sponsorship, a day school for trainable children staffed by the county board of education, a sheltered workshop and vocational training center with a horticultural program, and a residence at the vocational center for trainees who live too far to commute.

A primary purpose of the area center is to provide services which are easily accessible to those it is designed to serve. Hence, the area should not be larger than necessary to include a sound population base. It is estimated that a center might well serve a total community of from 100,000 to 500,000 people, depending on the extent to which long-term residential care may be included in its program. There may be population clusters which straddle State boundaries, but which form a natural area for service in a single center. Interstate cooperation should be encouraged in such cases.

Advantages of the area center as a major component in statewide programing for the retarded arise from the ease of coordination and administrative supervision and of referral from service to service within the center. There are fewer opportunities for interruption of the "continuum of care." Qualified professional staff can easily give guidance to a number of different ongoing activities, no one of which would merit their full-time attention. By its high visibility the center fosters community awareness of the retarded and of the many positive things that can be done for them. Disadvantages lie in the tendency of generic agencies to "unload" cases they might properly serve, and the lowered level of community integration which results when services are less well distributed throughout the community structure. The high visibility may also militate against use of the center by the more mildly retarded and their families, who resist being associated with the more markedly retarded, both in their own and in the oublic's mind.

Dispersed Services With Centralized Local or State-Local Coordination

Although the coordinative effort may be more difficult, some communities and States have chosen a plan in which discrete services are dispersed throughout the accessible community, but these services are drawn upon through the "fixed point of information and referral" and the "life consultation services" to create the "continuum of care" for any one individual.

This plan may be best presented by examples. In discussing "Cooperative Planning for the Mentally Retarded Child and Adult," the demonstration program in Rochester, N.Y., and the pilot program in Shreveport, La., were cited. (See p. 94.) Under those programs special resources are developed or drawn from within a variety of State and local health, education, and welfare agencies to complete the necessary array. In Shreveport the special services office serves as the clearinghouse for information and for cumulative recording of the sequences of service offered to persons identified as mentally retarded and still in active need of service. Its director may convene interagency case conferences on occasion. Services which are distributed throughout the two-parish community but which are components of the available array include diagnosis and evaluation, counseling, a preschool nursery, local school board special classes, a sheltered workshop, vocational placement, an adult activity program, hospital-based medical services, and parent education programs. The office also maintains close contact with private and State residential facilities and assists with admission and placement procedures. The program is actively supported by the State through the coordinator of State services for the mentally retarded. The latter office was set up to implement the comprehensive interdepartmental program for the retarded authorized by the Louisiana Legislature.

The mission to the Netherlands observed a variant of this approach in operation in The Hague, where the retarded have access to a wide array of services.[1] Specialized service units are dispersed in natural settings throughout the city. The group homes for adults who need minimal sheltered living are in residential neighborhoods; the kindergarten classes are in the same buildings as normal kindergartens; the inpatient clinic is in the hospital; the sheltered workshops do not attempt to accommodate other services; evening recreational programs for retarded adults in open or sheltered employment are suitably located. A number of these services, which receive municipal and national subsidies, are sponsored by a single voluntary agency; the agency provides overall administration and supervision and also provides the "fixed point of information and referral" (an office not tied to any one service) through which the objectives of the "continuum of care" can constantly be pursued.

Coordination of Research, Training, and Service

Wherever there are good services, opportunities for professional training can be created. Wherever there are mentally retarded persons who have been carefully evaluated, there may be opportunities for research. Services cannot exist without a steady influx of trained personnel and steady assimilation of new knowledge gained from research. The possibilities for improved coordination among bodies having primary responsibilities in these 3 fields deserve more detailed exploration.

Many academic centers provide training and research relevant to mental retardation and, as a byproduct, offer certain services to retardates; service agencies in turn frequently contribute directly to training and research as a byproduct of their service

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[1] See also Section VI on Residential Care.

activities. Obviously, the academic and the service agencies can gain much from intermeshing their resources in appropriate ways to accomplish the ends set forth in this report. In addition, effective relationships are essential to the solution of many problems besetting the field of mental retardation.

The fundamental difference in the objectives of universities and service agencies must be taken into account in any consideration of joint university-agency enterprises. If a cooperative activity seriously disrupts or impairs the university's teaching program or the agency's service program, it not only fails, it destroys. If a medical school professor of pediatrics engages to work 2 days a week in diagnosis and treatment in the State institution for the retarded, and if rendering this service means that he does not have time to prepare his lectures and demonstrations properly or to supervise his clinical students sufficiently, the arrangement interferes with the primary mission of his university. If the chief psychologist in the institution for the retarded teaches a class 3 days a week at the university, and if this employment means that his testing program at the institution fails to give full value to the patients, the arrangement interferes with the primary mission of his agency. With proper planning and understanding of the processes involved, however, such shortcomings need not arise.

Relationships between academic and service enterprises can be successful if developed around problems important to both sides and if the roles required of each strengthen, rather than weaken or distort, the performance of the major functions of each institution. The most important common problems are these:

(1) Need to apply in actual practice the knowledge already developed through research.

(2) Need for "feedback" to professional education of what has been learned in clinical or service settings, as well as in research.

(3) Need to test research hypotheses in service settings.[2]

(4) Need to devise ways of making optimum use of scarce manpower skills.

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[2] See Section II on Research and Scientific Manpower.

As is true of all efforts at coordination, such joint activity requires a clear understanding by both parties of the responsibilities of each, lest the enterprise fall in between. They must agree on and spell out plainly the responsibilities of each institution for planning, conducting meetings, preparing materials, and defraying any costs. So far as possible, other potential barriers need to be worked out in advance. Geographical separation, and differences in institutional procedures, sources of financial support, and ultimate responsibility, are all possible sources of trouble which should be anticipated and dealt with as specifically as possible.

Because service facilities and academic institutions seldom look to the same source either for direction or for funds, coordination depends to an unusual degree upon cooperation, and to only a slight extent on authority.

It is especially important that grant-making bodies, public and private, foster cooperation and give priority to support of promising joint enterprises.

Various proposals for new institutional arrangements to provide improved coordination of research and training with service are being developed. New centers which bring together many disciplines afford a setting in which students from various fields can acquire a comprehensive understanding of mental retardation, and provide clinical, laboratory, and consultative services to the various State, area, and local agencies to an extent compatible with their primary research and teaching objectives. In addition to the diagnostic clinic, experimental day schools for residential units might be incorporated in centers. Experimentation along these lines should be encouraged.

Cultivation of cooperation and coordination between universities and States deserves particular attention. Many State departments and colleges of education already have established patterns of working together, but in other disciplines the processes by which curriculum and recruitment practices can be made to reflect changing needs identified in the major service programs of the State are less well developed. The universities and State agencies in North Carolina have addressed themselves to this need with particular vigor.

Increasingly, those responsible for State programing and comprehensive planning must be concerned with the range of disciplines needed in all service settings and by all State agencies. Cooperation to identify and meet such needs can be accelerated by assigning responsibility for liaison with State agencies and universities to a person associated with State interagency coordination. Such a liaison officer can interpret to university departments the needs identified in the service agencies, interpret to agencies the universities' requirements for supervision in field placements, suggest areas for attention through short courses and seminars, and enlist university consultants for programs of inservice training. Such a person can also serve as a point *of contact* in interstate relationships.

Regional Cooperation

The usefulness of interstate cooperation in research and professional training has been amply demonstrated by the various successful programs of the Southern Regional Education Board and the Western Interstate Commission on Higher Education. A number of the programs have been conducted in cooperation with State facilities for residential care of the retarded. The support given by the participating States and the Federal Government has provided critical impetus and permitted a much more rapid interchange of ideas than would otherwise have taken place. The resulting benefits reach beyond the regional boundaries. The next decade will undoubtedly uncover opportunities for other types of interstate cooperation on a regional basis in the interests of the retarded. It is suggested that, when statutes permit, regulations governing Federal grants-in-aid make clear the eligibility of interstate or regional bodies of this type.

Outstanding Models of Service for Teaching and Demonstration

Programs of interdisciplinary training centered on models of service should be developed with Federal, State, and private support.

Much of the success or failure in securing the "continuum of care" [3] depends upon individuals with different professional backgrounds and skills being able to relate their contributions effectively. In view of the confidence and enthusiasm so often expressed with respect to such teamwork in the field of the mentally handicapped, it is surprising how little systematic effort goes into preparation for such teamwork during professional training.

Ways should be explored whereby future participants may have an opportunity to learn to work together. At the minimum, ways should be sought to give the members of professional teams a better acquaintance with the unique contributions that each can make in such interdisciplinary settings. The critical time for such preparation probably is that point in training at which the trainee begins to practice the application of his knowledge, e.g., internship, residency, practicum, and fieldwork training.

It is an accepted principle of professional education that the student acquire his professional skills in settings which exemplify the most advanced practices of that profession. This principle is expressed in the enforcement of standards of practice by universities and professional organizations when they make a selection of services and institutions for placement of their trainees.

Models of practice and management which can serve as appropriate settings for professional training in the field of mental retardation are desperately needed in the United States. Such exemplary programs can also serve as a means of demonstrating truly adequate management and new concepts of service—such as the "continuum of care" approach—to leaders and potential leaders in other communities. "Seed personnel" are thus prepared who can extend the concept. In addition, with their emphasis upon quality, both in service and in professional training, they would surely promote the recruitment of desirable personnel for work in mental retardation.

It has been repeatedly emphasized in this report that adequate provisions for the mentally retarded require an extensive array of services which are so related to one another, and so readily ac-

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[1] See Section IV.

cessible to the retarded individual, that they can be characterized as offering a "continuum of care." Insofar as such a program is focused upon the creation and maintenance of a "continuum of care" for the retarded, and thereby gives comparable emphasis to the several professions involved in the management of this disorder, it would be a departure from the usual pattern of university sponsorship of such teaching facilities. If, at the same time, training needs received necessary emphasis and resources in the creation and operation of such a program, it would be quite unlike any existing programs sponsored by service agencies in the fields of mental health or mental retardation.

Models of this type might well be financed on a matching basis by communities, a host State, and the Federal Government. The State and Federal Governments would contribute to the cost of the service and training through grants-in-aid. Care should be taken, however, not to impair the initiative of community and State in identifying needs, working out solutions, and paying their share of the costs of service, since overendowment leads to an artificial and hence worthless "model" which would be unable to obtain comparable support and commitment from other communities.

When pilot demonstrations have proved successful, the tested models of management, coordinated with training and research, should be created in each of the regions served by the U.S. Department of Health, Education, and Welfare.

Regional distribution would not only permit the use of the regional office personnel of the Department in developing and demonstrating exemplary programs, but would encourage valuable natural variations in approach.

The Federal Role in Comprehensive Planning for the Retarded

Since its inception our National Government has had a mandate under the Constitution "to promote the general welfare." Out of respect for the principles of devolution and delegation cited earlier, as well as for the long tradition of voluntary effort, local initiative, and State primacy in domestic affairs, the Federal Government has seldom moved to do more than survey and report upon the health, education, and welfare problems of the Nation unless and until clearly called upon by the people to do more. It has become increasingly clear, however, that in certain matters the general welfare is most effectively served by vigorous initiative, followed by firmly sustained activity, on the part of the Federal Government in partnership with the States and local governments and the voluntary organizations and institutions which the people themselves have created outside the structure of governments.

The interests of the mentally retarded are bound up in some measure with the activities of most Federal departments. Among them the greatest leverage is exerted by the Department of Health, Education, and Welfare. That Department must assume major responsibility for leadership and action at the Federal level. It should also serve as a resource to the other departments.

Federal agencies, particularly the Departments of State, Defense, Justice, and Labor, should identify their activities affecting the mentally retarded and should seek from the Department of Health, Education, and Welfare whatever expert consultation is required.

The complex responsibilities of Federal agencies are illustrated by the problems posed in meeting the special problems of the estimated 75,000 mentally retarded children of servicemen, whether on oversea or home duty; in the handling of mentally retarded defendants or prisoners in the Federal courts and prisons; in the special interest in the mentally retarded of certain leaders from foreign countries brought to this country under State Department auspices; in the outdoor recreational needs of the mentally retarded; in the potential role of the Agricultural Extension Service; in the right of the mentally retarded individual to migrate with his family; and in many other problems which can be suitably resolved only by an enlightened approach within the respective Federal agencies having jurisdiction in each case.

The Department of Health, Education, and Welfare should be prepared to offer expert consultation on request to other departments through the Office of the Secretary or the most relevant operating constituent of the Department. In some cases the Department of Health, Education, and Welfare must act in concert with one or more sister departments. One such activity now under discussion between the Department of Defense and the Department of Health, Education, and Welfare relates to the special educational needs of children of servicemen.

Coordination and Action Within the Department of Health, Education, and Welfare

In the past 30 years the Federal Government has been called upon to inaugurate and extend a broad system of social security, to undergird an unprecedented expansion in biomedical research of all kinds, and to undertake a variety of grant-in-aid programs.

Grants-in-aid to States, universities, and other public and private bodies have proved especially effective in stimulating new attacks on old problems, and in supporting those approaches shown to be the most useful. Such grant programs are to be found in most of the major operating agencies of the Department of Health, Education, and Welfare and account for between 80 and 90 percent of the regular departmental budget. Their effect in generating and mobilizing community and State resources for service, training, and research multiplies their value many times.

A number of these general programs have had a salutary effect on the well-being of the retarded. With 1 or 2 significant exceptions, however, it is only in the last decade that the constituent agencies of the Department of Health, Education, and Welfare have begun to see the retarded as an important focus of their concern. At present 5 of the major operating agencies of the Department are making active contributions to the prevention and amelioration of mental retardation. In some, several subdivisions are involved. The programs of 4 of them have been well described in a recent departmental publication, "Mental Retardation Activities of the U.S. Department of Health, Education, and Welfare—May 1962."

Of the projected obligations in fiscal 1963 of $129 million by the Department, about $32 million would be for research, training, and preventive services. More than 80 percent of the $32 million would be for grants to States, universities, and other public and private agencies. In addition, the Bureau of Old-Age and Survivors Insurance will pay an estimated $64 million in benefits to persons over 18 who are substantially disabled by mental retardation. Those benefits are financed by contributions to the old-age, survivors and disability insurance trust funds, usually by insured persons on whom the beneficiaries were dependent. Finally, the Bureau of Family Services will pay about $33 million in grants to State-local public welfare agencies. Significant as they are, the total obligations nevertheless are but six-tenths of 1 percent of the total annual outlays of the Department of Health, Education, and Welfare from its regular budget and trust funds.

It is understandable that programs of research, training, and service related to mental retardation are an integral part of many branches of the Department of Health, Education, and Welfare. Some of the foci, present and potential, within the various agencies are identified on the accompanying organization chart.

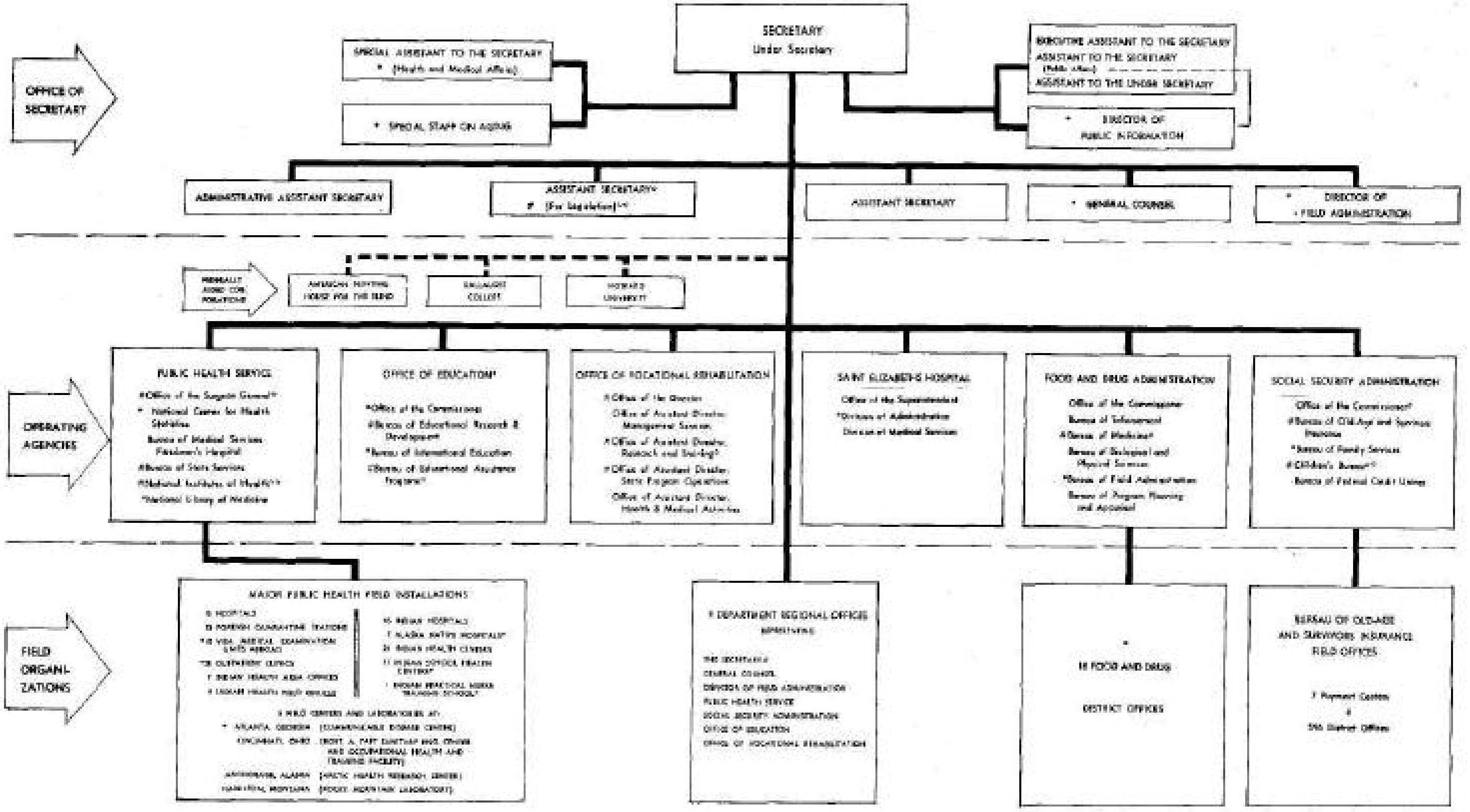
To provide a vehicle for communication between the major constituents involved, a Departmental Committee on Mental Retardation has recently been reconstituted. Among its responsibilities are the following:

(1) To serve the Secretary in an advisory capacity in consideration of departmentwide policies, programs, procedures, activities, and related matters.

(2) To serve in an advisory capacity for the Department as a whole with respect to interdepartmental programs and activities in the field of mental retardation.

The Assistant to the Assistant Secretary for Legislation presently chairs this Committee. The constituents represented on this Committee are indicated on the following chart.

Distribution of Responsibilities for Mental Retardation Programs in the Department of Health, Education, and Welfare, 1962



★ Member of Departmental Committee on Mental Retardation. # Significant program now underway. *Area of concern or potential contribution.

The Office of the Assistant Secretary for Legislation has been assigned responsibility for—

(1) Serving as the principal adviser to the Secretary for improving the programs and activities of the Department related to mental retardation.

(2) Providing staff coordination and direction to the staff offices of the Secretary, and to operating agencies relative to the planning, execution, coordination, reporting, and evaluation of mental retardation activities.

(3) Maintaining liaison on behalf of the Department with interested Federal agencies and with professional and other groups.

(4) Providing leadership to the Department's Committee on Mental Retardation.

Many of the recommendations made in previous sections of the report fall clearly in the purview of 1 of the existing branches, bureaus, or institutes; others do not. For example, the functions of the proposed Institute of Learning will interrelate with those of at least 3 distinct bureaus now functioning within the Department.

Other activities are required in a comprehensive program for the retarded for which no clear responsibility has yet been assigned in the Department. These include: Administration of residential facilities; housing for the semidependent adult, i.e., halfway houses (short-term) or group homes (long-term); recreation for the adult retarded; day care for the adult; legal problems of the dependent adult; problems of residence and immigration; and problems of retarded members in non-English-speaking families. The Office of the Secretary should consider how those activities should be viewed in the larger framework of the Department's responsibilities. Even if the Department does not contemplate offering active support in these areas, it would be well for it to gather some basic data on a nationwide basis and to provide well-identified, if minimal, resources for information and referral.

The distribution of responsibilities for the mentally retarded among several constituents of the Department requires constant emphasis on coordination and comprehensive planning. Coordination has been defined as the "process of bringing all necessary resources to bear in the appropriate sequence toward the accomplishment of a specific mission." To realize the recommendations which follow, and many others already made in this report, the Department must not only have a sense of mission and muster resources from several fronts; it must also see that the use of resources is skillfully coordinated. Full achievement of effective coordination is a matter of practice. The Panel hopes that, in taking the joint action necessary to implement the following recommendations, the leaders of the various organizational components within the Department of Health, Education, and Welfare will not only see but taste the fruits of coordination well accomplished.

The Department of Health, Education, and Welfare should assess its capabilities to stimulate and support the various relevant components of a comprehensive national program related to mental retardation.

The logistics of prevention and service require that each component of a comprehensive program be supported in proper proportion. In each of the major areas of clinical and social service, medical care, education, rehabilitation, child and family welfare, income maintenance, guardianship, and day and residential care, progress depends on the production and incorporation of new knowledge, on data for evaluation and planning, on qualified personnel, and on well-designed physical facilities. The Panel sees a need at this time for the Department, in cooperation with other agencies as appropriate, to review each of the broad program areas described in this report and to determine the extent of need within that field for each of the following activities:

(1) Basic research.
(2) Program research.
(3) Demonstration or pilot programs.
(4) Support for continuing service.
(5) Professional training for research.
(6) Professional training for service.
(7) Professional training for university teaching.
(8) Subprofessional training.

(9) Construction of physical facilities.

(10) Data-gathering mechanisms.

For example, in respect to day care, what basic research (e.g., on child development) ; what program research (e.g., on parental acceptance and use) ; what kinds of demonstration; what training for supervisory and caretaking roles; what physical facilities; what information on trends and needs are required for the sound development throughout the country of this promising form of service?

What role in stimulation and support would be appropriate to the Federal Government relative to each of the aspects of need and to what extent does the Department already have authority, funds, and skills? To what extent are its resources actually being directed to these ends? What arc the points at which improvement is needed and from what source? Comprehensive programing depends on continuing analysis and resynthesis of its components in some such detail.

Some matters may be beyond the scope of a particular department and may require interagency action, which the several agencies may undertake cooperatively or which may even require action at the Executive Office level.

The Panel suggests that particular attention be paid to interagency adjustments and concerted action in 4 fields; Professional training; data gathering and dissemination; construction of facilities; and cooperation between those who conduct research and those who can apply its findings.

An ad hoc advisory group representative of recipient colleges and universities should be convened to assist in identifying any self-defeating features of the Federal training assistance programs and to suggest measures which might contribute to improving the supply and utilization of manpower in mental retardation.

At least 8 programs of professional training, distributed among 4 of the main operating constituents, are being or can be applied to increase the supply of personnel qualified to conduct research or render service in the mental retardation field. A school of social work, for example, can now secure training funds from 3 different constituents of the Department. This is not undesirable in itself, but does suggest that the Departmental Committee should review and compare the standards and procedures in the various agencies for the purpose of identifying possible incompatibilities in standards, eligibility, stipends, and modes of payment in the training grant and fellowship programs relevant to mental retardation.

Balance should also be considered. For example, the Department can now make training grants for preparation of personnel to conduct research in biomedical science, psychology, and social science, but not in education. On the other hand, with the exception of the National Institute of Mental Health, the National Institutes of Health are basically restricted to research objectives in their professional training grants. This has tended to limit somewhat the availability of funds for specialist training of physicians in relevant clinical areas outside psychiatry. In some fields the funding formula may help students to attend established programs, but does not effectively stimulate the creation of strong new centers of training.

The Department should improve its resources for collecting coordinating, and distributing quantitative data on the mentally retarded and their'specific program needs.

A few agencies, such as the Biometrics Branch of the National Institute of Mental Health and the Section on Exceptional Children of the Office of Education, have for some years gathered such data on a nationwide basis above and beyond the requirements of immediate program analysis. There is still, however, a need for better interpretation, communication, and use within and among agencies in the Department. Activities of this nature should be coordinated with the collection of population statistics discussed in Section II.

The Department should give special attention to the use of professional and citizen advisory groups in relation to its program on mental retardation.

The Departmental Committee should plan to meet from time to time with representatives of the leading national professional and action groups concerned with the mentally retarded, and also with the major organization federations, such as the National Health Council, the National Social Welfare Assembly, the National Council on Aging, and the National Committee on Children and Youth.

Several constituents of the Department have made good use of technical or other advisory committees focused on particular problems and representing people actively engaged on the firing line of service, including grantees. It is suggested that the Department encourage this pattern for any of its programs for the mentally retarded which can benefit from informed reactions from the field.

The Department should consistently reinforce the principle and practice of comprehensive planning and coordination at the regional, State, and local levels.

As stressed earlier, coordination takes time and effort, but without it the retarded will suffer. The principle of Federal stimulation should therefore be applied in this area through precept, example, and support.

There are several specific ways in which reinforcement can be applied. These include a system of joint grants, including grants which foster statewide planning; emphasis on coordination at the level of the regional offices of the Department; and improved communication with the key persons in the various departments in each State who carry major responsibility for programs in mental retardation.

The Department should extend and develop the principle of pint review and programing, and when feasible joint financing, of grants-in-aid by the several Department of Health, Education, and Welfare agencies when this approach will result in a more comprehensive and unified program.

Such joint planning might encompass several areas of service or a combination of service, training, and research.

Examples of types of projects which might merit such joint support include:

(1) A university project for interdisciplinary professional training in mental retardation involving several of its departments and one or more service agencies.

(2) A proposal to coordinate training of personnel with an areawide "model of service" designed to assure "a continuum of care" for each retarded person.

(3) A project developed by a State or regional coordinating committee involving several different State agencies in an epidemiological survey, or a longitudinal study, or a coordinated interagency approach to one particular problem group, such as the retarded with sensory defects.

(4) A project to test the "continuum of care" through identification of gaps in prior service received by mentally retarded persons found in the course of a manpower retraining or unemployed, out-of-school youth program.

(5) A joint study by the appropriate local or State health, education, and welfare agencies to follow up children graduating from the perinatal study of the National Institute of Neurological Diseases and Blindness.

(6) A demonstration in programing, starring, and design of a functional unit for research and therapeutic care of grossly handicapped infants as an adjunct to an interdisciplinary university training program.

(7) A project to explore extension of the vocational educational program in practical nursing to prepare practical nurses for the mentally retarded as a means of recruiting and training personnel for day care centers, regional centers, or residential units.

Each of the projects suggested above, were they to be formulated and proposed by an appropriate sponsoring group, should be of interest to at least 3 major agencies within the Department of Health, Education, and Welfare. It would be useful to have the appropriate agencies in each case cooperate to offer combined support and commitment.

The principle of joint grants or sponsorship on a bilateral basis is not new. Examples include (1) the study of preparation of mentally retarded youth for gainful employment, sponsored by the Office of Vocational Rehabilitation, the Office of Education, and the American Association on Mental Deficiency; (2) the joint grant by the National Institute of Mental Health and the National Institute of Neurological Diseases and Blindness to the National Association for Retarded Children for its 3-year survey of research in mental retardation, completed in 1957; and recently (3) informal cooperation between the Children's Bureau, the Office of Vocational Rehabilitation, and the Division of Hospital and Medical Facilities in the Bureau of State Services of the Public Health Service, which contributed to the development of a comprehensive program for the retarded in northern Virginia. These precedents should be extended and improved.

Incompatibility between the authorities of the different agencies of the Department which would interfere with such a coordinated approach should be identified and eliminated wherever possible.

Coordination is, of course, not an end in itself but is justified by its results. The initial input of coordinative effort and planning does, however, take additional resources. This need should be recognized in the grant machinery with appropriate inducements.

The Department's increasing emphasis on comprehensive departmental planning should be reflected at the regional level.

Four of the operating agencies (Office of Vocational Rehabilitation, Office of Education, Public Health Service, and Social Security Administration) have representatives in each of the 9 regional offices of the Department. Those representatives should be involved in cooperative planning and coordination in concert with the Departmental Committee in Washington. As a means of firming up communication and clarifying the common mission, it is suggested that a visit to each regional office be planned, through which representatives of the Departmental Committee have an opportunity to meet with the 4 regional agency representatives as a group. The purpose of the meetings would be to review jointly the composite programing needs of the mentally retarded as they are manifest in each region.

Topics which might be placed on the agenda for the regional office meeting include—

(1) Assessment of the region's manpower needs and resources in the various areas of service to the mentally retarded.

(2) Review of the capabilities of the universities in the region to develop interdisciplinary demonstration programs.

(3) The potentialities for interstate programing or cooperation in special areas, such as service to the blind or deaf retarded, which might be accelerated by Federal stimulation through grants-in-aid or consultation.

(4) The problems confronting the States in supplying consistent and uniform data needed in national program projection.

It is recommended that the Secretary invite each Governor to designate several officers in each State with direct major responsibility for programs for the retarded to represent the State in periodic meetings with the Departmental Committee.

The success of the Surgeon General's annual meetings with the State health commissioners and, separately, with the heads of State mental health programs demonstrates the mutual value of such conferences. In mental retardation, however, from 3 to 5 key people from each State should be involved. Therefore, in order to keep the size of the conferences down to manageable proportions, it is suggested that approximately one-third of the States might be invited to participate each year in a triennial cycle of annual meetings.

The Department should extend and improve its efforts to interpret its own and the Nation s activities on behalf of the retarded.

There is an evident need for a departmentwide program of public information related to mental retardation.

The recent publication of the Department of Health, Education, and Welfare describing its mental retardation activities provides a good example of the type of public service which the Department should extend.

A list of the many excellent publications by the Public Health Service, the Children's Bureau, the Office of Vocational Rehabilitation, and the Office of Education relative to mental retardation should be issued as one of the Government Printing Office flyers.

A publication should be developed on careers in service to the mentally retarded. A handbook on major resources for professional training related to mental retardation in all parts of the country should be prepared and revised from time to time. Consideration might be given to securing these 2 publications through a grant or contract with the Health Careers Project of the National Health Council.

The Department should prepare, publish, and distribute widely a concise summary of the scope and purpose of those of its grant programs which can be invoked on behalf of the mentally retarded. This should be in such a form as to provide a ready reference for any agency desiring to determine the most likely sponsorship for a program of research, training, demonstration, or service which it desires to initiate, extend, or improve. The summary should indicate the sources of additional information and the point to which application should be made.

The annual Federal publications, "Grants-in-Aid and Other Financial Assistance Programs Administered by the U.S. Department of Health, Education, and Welfare," is a most useful document but does not clearly identify assistance available to programs for the retarded. Many investigators and program organizers with good ideas are not necessarily familiar with the most likely source of grants. Some misunderstandings and apparent rebuffs could be avoided if the Department would provide additional assistance to a potential grantee in selecting the program best designed to further his proper objectives.

The Department should secure production of additional films related to its program objectives. To augment the several excellent films produced recently with departmental support, the Department should consider a sequence of films covering in a consistent fashion the new knowledge and trends in the fields of research, prevention, professional training, and the various forms of service to the mentally retarded. Where production directly under the aegis of the Department itself or one of its own component agencies would be preferable to non-Federal sponsorship, the authority and encouragement to the agency should be forthcoming. Films for both public and professional audiences are needed. See also Section VIII on Public Awareness for more general discussion on how to disseminate information.

The services of the Department's educational television program should be invoked, and the subject of mental retardation should be responsibly presented through this medium as a matter of public interest.

The Department should improve the coordination of the international aspect of its programs for the retarded.

The recent reinforcement of the Department's international programs through the International Health Research Act of 1960 and the special foreign currency programs, as well as emphasis in programs of the Agency for International Development, should be reflected in an increased exchange of personnel and information between the United States and the foreign countries which are leaders in research and service to the retarded.

International seminars and institutes and exchange of research and other information on mental retardation lag behind exchanges in other fields. The number of international conferences on mental retardation has been limited, and those which have been held have not been truly global in their representation, nor have they covered the full scope of the field.

The very successful missions to 5 European countries undertaken on behalf of the Panel by Panel members and invited consultants during April and June 1962 and the visit of Dr. Osamu Kan to the United States at the invitation of the President in December 1961 have confirmed the convictions of many Panel members that approaches to research, professional training, and services in selected foreign countries are deserving of our careful study. It would also be advantageous to the retarded if certain findings and advances in this country were better known and interpreted abroad.

The Department is called upon from time to time to offer guidance to international visitors. For those with broad interests in mental retardation, there appears to be a need to present a more balanced picture, better advice, and improved tour planning. With growing international interest in mental retardation, the opportunities in this area will assume more critical importance. It is recommended that the Office of the Secretary assume a more active role in directing the reception and guidance of foreign visitors on official or sponsored exchange missions in order better to meet their individual interests and needs. In this the Department should work closely with voluntary and professional organizations having resources in depth in the specialized field of mental retardation. Cooperation with the Department of State in respect to programs it sponsors should be intensified.

The Vehicle for Coordination

The Panel believes that the Departmental Committee as now structured can serve as a major means of coordination around these and other objectives at the Federal level, *provided* that the following conditions are fulfilled:

(1) The Secretary himself should give clear indication, publicly and in ways recognized by his own staff, that the Department has a major commitment in this area, which he intends to implement.

(2) The Committee and its activities must be given a high degree of visibility in the Department's program.

(3) The members who represent the various agencies on the Committee must be both concerned and professionally knowledgeable about mental retardation and also in a position to influence their agencies' policies significantly.

(4) The Committee members must come to view the Committee not merely as a vehicle for advising the Secretary of the concerns of individual agencies but also as the major means to genuine coordination of the various components into a truly comprehensive and integrated program. The essential conditions for coordination—communication, cooperation, authority—along with a common commitment to a common goal must be more fully realized.

(5) The more urgent problems which cross agency lines should be presented to the Committee for discussion and

i joint study before responsibilities are assigned to one or more of the operating agencies.

(6) All proposed legislation affecting the retarded, either that to be presented to the Congress with administration sponsorship or that originating in the Congress, should be discussed in the Committee, and departmental policy should be clarified and made known as rapidly as possible.

(7) Mechanisms should be developed for securing appropriate participation and action from other agencies of the Department not directly represented on the Committee, such as the Division of Surplus Property Utilization.

(8) The chairmanship of the Committee should be continued as at present in the Office of the Secretary. The Chairman should be assisted by at least one full-time, professionally qualified senior staff person to carry forward the work of the Committee, to engage in broad evaluation and planning, and to provide impetus toward implementation at the operating levels within the Department. This staff position will require a person well versed in the complexities presented by mental retardation.

In asking for intensification of the Department's commitment to the mentally retarded at the present time, the Panel is not unmindful of what has been done, nor of the magnitude and importance of the many missions with which the Department is charged. However, in the Nation as a whole, as well as in the States and local communities, there are times when past neglect must be met by compensating emphasis. This is the time for such emphasis to be placed on the needs of the mentally retarded. The President and the Congress have each in their respective capacities made clear their intent that this be done.

It is not enough, however, that new labels be put on old doors or that mental retardation be inserted in the list of duties of some already overburdened branch or bureau. Specialized professional competence is required in key places. Analysis of program content must be carefully made without regard to traditional stereotypes. Major program needs which are identified at the local and State level must have their counterparts, even if only for data-gathering and consultation purposes, at the Federal level.

"Devolution down the line" is a principle applicable to the Department of Health, Education, and Welfare, as well as to community services, but there are decisions which cannot properly be delegated. Some must be made by the President himself. Many must be made by the Secretary. The Panel recognizes that, although the public has applauded the federation of many agencies into a single Department of Health, Education, and Welfare, the resulting aggregate is by no means as cohesive or monolithic as it appears from Independence Avenue. After all the discussion and advice has been concluded, there will be times when only the Secretary can act within the Department. It is our hope that when these moments arrive he will recognize them and act decisively.

While some problems are inherent in the size of the Department, yet as purposeful, consistent leadership is supplied and reinforced at all levels, better communication, fuller cooperation, and clearer authority will be achieved in relation to mental retardation programs.

Fundamentally, the Department must set the example for the Nation in comprehensive programing and must so structure itself as to support rather than distort the proper balance of service at the State and local levels. Thus it will make its great contribution to securing the necessary "continuum of care" for the retarded person whose welfare is the end objective and to preventing this misfortune for others in years to come.

BIBLIOGRAPHY

Shortly after its appointment, the Panel authorized the development of a bibliography on the world literature in the field of mental retardation. Work on this project is progressing and it is planned to have the bibliography published separately at a future date.

APPENDIX A

Statement by the President Regarding the Need for a National Plan in Mental Retardation, October 11, 1961

The manner in which our Nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. Yet, although we have made considerable progress in the treatment of physical handicaps, although we have attacked on a broad front the problems of mental illness, although we have made great strides in the battle against disease, we as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That **failure** should be corrected.

What Is Mental Retardation?

The term "mental retardation" itself is often misunderstood. It is confused with mental illness. Simply stated, mental retardation is a condition resulting from a basic abnormality of the human mind. It refers to the lack of intellectual ability resulting from arrested mental development. It interferes with the ability to adjust to the demands of environment. It manifests itself in poor learning, inadequate social adjustment, and delayed achievement. Usually this condition is either present at birth or begins during childhood. The causes are many and obscure. Some have already been determined and are easy to highlight; others are beyond our present knowledge and would yield only to research.

Mental retardation is not a disease. Rather, it is a symptom of a disease, of an injury, of some obscure failure of development, even of inadequate opportunity to learn. Just as a fever is a symptom of an infection, mental retardation is a symptom of Mongolism, birth injury, or infection, or even inadequate stimulation in early childhood. It can be so severe that the afflicted person never leaves protective care, or so mild that it is detected only under stress or through special tests.

In most instances, it can be clearly distinguished from mental illness, for mental illness strikes and incapacitates after there has been normal development up to the time of the affliction. The younger the child the more difficult it is to distinguish between the two. However, accurate diagnosis is an essential prelude to treatment. Unfortunately, **the** present limitations of our knowledge in this field make this diagnosis extremely difficult when the very young are involved.

I. *The Scope of the Problem*

The scope of the problem and its effect upon us is apparent in the large numbers affected by the condition. Approximately 5 million persons in this country are retarded. It strikes those least able to protect themselves—our children. It affects by its nature their relationships to all members of their families and their friends. Thus, mental retardation is a serious personal matter to at least 1 out of every 12 people. It disables 10 times as many as diabetes, 20 times as many as tuberculosis, 25 times as many as muscular dystrophy, and 600 times as many as infantile paralysis.

By 1970, at this rate we will have at least 1 million more retarded persons than there are at present. Over half will be children under 9, many of whom will suffer from both physical and mental handicaps. This growth in mental retardation is particularly anomalous in view of the advances in the medical sciences. Deaths at the time of birth have been reduced 75 percent in 20 years, tuberculosis 30 percent in 5 years, and such scourges as whooping cough, diphtheria, and scarlet fever have been almost completely eliminated. But the prevalence of mental retardation has steadily increased. Today, one out of four beds in State institutions is assigned to a mentally retarded person. Nevertheless, all public facilities have long waiting lists. Children needing service cannot obtain it. Our State institutions are overcrowded. The average State hospital has 367 patients more than its rated capacity. Its waiting list numbers 340.

Many retarded persons never reach a hospital. Their impairment, though mild, is a matter of serious concern. Over 700,000 draftees were rejected as unfit during World War II because they were mentally deficient or illiterate. The number of retarded who could not participate in the war effort was even greater. In many instances, illiteracy and mental retardation are indistinguishable.

Every year 126,000 babies are born who will be mentally retarded. Neither the rich nor the poor, the urban dweller or the farmer, the captain of industry or the manual laborer, or any other part of our society is exempt from the threat. It is a national problem and it requires a national solution.

There are no reliable estimates of the cost to each family for the care of the mentally retarded. Community costs of the 4 percent confined to institutions total approximately $300 million annually. The other 96 percent live in private homes. The financial strain of providing for them represents a staggering burden to each family that has this responsibility.

But the financial hardships are not the most serious aspect of the problem. It is the emotional strain, the problems of adjustment, training, schooling and vocation—the attempt to make possible a full life for the child, that represents the major impact of retardation. Our goal should be to prevent retardation. Failing this, we must provide for the retarded the same opportunity for full social development that is the birthright of every American child.

In addition to research, the current problems are those of diagnosis, evaluation, care, appropriate training and education, family guidance, the need for sympathetic environment, a lack of public understanding and a dearth of private and public facilities. There are difficult issues involving not only our social responsibility for adequate care of the retarded, but the extent of the responsibility of the retarded individual himself, as, for example, when he gets into trouble with the law. For a long time we chose to turn away from these problems. The standard treatment consisted of commitment to institutions, segregation from society, and silence about the affliction.

In this vast reservoir of children and adults who need various degrees of assistance to enable them to adjust to the demands of our complex society, we have a largely unused resource. As society becomes more complex, the problems will of necessity increase both in size and in seriousness.

It is just as important to integrate the mentally retarded within our modern society and make full use of their abilities as it is to make a special effort to do this for the physically handicapped. The grim struggle for survival does not allow us the luxury of wasting our human resources.

II. *Present Programs*

Some forms of mental retardation can be prevented; in others the degree of incapacity can be reduced; and in still others it may be possible to obtain a completely satisfactory adjustment. Steps taken thus far have concentrated upon improvements in environment and understanding. These are important and should be expanded. But real improvement will require a major effort along new lines.

Prior to 1950 relatively little attention was directed to the problem of mental retardation by either the Federal or State Governments or, in fact, by private groups. During the past decade, however, increased interest and activity have been stimulated by a few foundations, by the demands of parents, by interested lay and professional groups, and by members of legislative .bodies who have been convinced of the urgent need for progress in this field.

Until 1954, no State health department offered any special services for mentally retarded children or their families. The welfare services were directed largely to long-term institutional care. Today almost every State has a special demonstration, service or training project in mental retardation as a part of its maternal and child health service program. Last year the National Institute of Mental Health spent over $2.5 million on research, technical assistance, and grants in the mental retardation area, and the National Institute of Neurological Diseases and Blindness spent over $8 million on mental retardation. Next year's budget requests will double these figures. And the number of mentally retarded persons rehabilitated should also increase.

Today, the effort to help the mentally retarded takes six basic forms:

(1) Diagnostic and clinical services for the retarded are being expanded. There are over 80 clinics specializing in services to the retarded. Well over half were established within the past 5 years. These services need still greater expansion. The 20,000 children aided in 1960 represent only a small fraction of those who need the service.

(2) There has been an increase in the beds in residential institutions. Today there are over 200,000 mentally retarded patients in such institutions, approximately 10 percent more than there were 5 years ago. But the average waiting list continues to grow, and the quality of the service often suffers from limited budgets and salary levels. In the public institutions, there are less than 500 full-time physicians for 160,000 patients. The limited resources of the State institutions have been taxed beyond the breaking point. Additional increases in both facilities and manpower are necessary.

(3) The number of mentally retarded enrolled in special educational classes has been doubled over the past decade. In spite of this record, we are not yet meeting our existing requirements, and more such facilities must be provided. Less than 25 percent of our retarded children have access to special education. Moreover, the classes need teachers specially trained to meet the specialized needs of the retarded. To meet minimum standards, at least 75,000 such teachers are required. Today there are less than 20,000, and many of these have not fully met professional standards.

(4) Parent counseling is now being provided by private physicians, clinic staffs, social workers, nurses, psychologists, and school personnel. Although this service is still in an experimental stage of development, it offers bright prospects for helping parents to meet their social and emotional problems.

(5) Child welfare agencies are attempting to meet some of the needs of the mentally retarded. It is estimated that 10 percent of the 375,000 children brought to the attention of the agencies through such pathways as neglect, dependency, and delinquency are retarded. The social workers and other personnel tending to the needs of these children should be trained specifically in the area of retardation.

(6) Finally, the preparation of the mentally retarded for a useful role in society and industry must receive more attention. In the past 5 years the number of mentally retarded rehabilitated through State vocational agencies has more than tripled—going from 756 to 2,500—but in terms of potential, it is little more than a gesture. The problem

is complex. Neither special education nor special rehabilitation procedures furnish the complete answer to employment of the retarded. New knowledge and new techniques are needed, for over 25 percent of those coming out of the special classes still cannot be placed.

III. *Present Opportunities for New Scientific Solutions*

In terms of the enormity of the challenge, all these efforts represent only a modest approach along limited lines. The central problem remains unsolved, for the causes and treatment of mental retardation are largely untouched. An attack on these questions justifies the talents of our best minds.

A moonshot is not possible without prior discoveries in aerodynamics, propulsion physics, astronomy, and other sciences. A successful attack on a complex problem like mental retardation also requires a host of prior achievements, trained scientific personnel, tools and techniques, profound understanding of the behavioral sciences, a spirit of devotion to the underprivileged, and a free, democratic atmosphere of inquiry. Fortunately, ours is a country in which these ingredients abound. Our leadership in these fields is unchallenged.

Much of the world's population still struggles for mere survival; others for domination of the weaker. Our aim is individual and national dignity. Our fortune is scientific and technological ability. Our obligation is to search for the secrets of the human mind and to share our knowledge throughout the world.

Discoveries of the wheel, the internal combustion engine, and principles of thermodynamics have liberated mankind from much physical labor. Two hundred years ago man demonstrated, through the discoveries of Lavoisier and Harvey, that human life is governed by universal physical laws. Major progress in science and medicine can be measured from that date. Until the last two decades, however, little research was concentrated on the nature of the living cell and its reproduction. But great strides have been made in that direction through the understanding of the chemical basis of genes and chromosomes and their governing role in life itself.

The future belongs to those who can carry forward these achievements. It is now possible to attack the causes and prevention, as well as the treatment, of mental retardation. This will require new breakthroughs, but it will pay enormous dividends in knowledge about ourselves, for the functions of the brain represent an almost completely uncharted frontier. The basic research entailed in such an effort will probe the essence of human development, and its results may far exceed its objectives. Exploration and discovery in this field may uncover the secrets of life and man's capacities, and the answers to many mysteries of social behavior. Perhaps even more important, an understanding of the motivation and effect of human behavior offers the hope of fostering the rational behavior of nations.

Progress in the natural sciences during the past 15 years has been impressive, but achievements in the prevention and therapy of mental retardation can be even more spectacular and can bring important benefits to mankind.

IV. *The Task of the Panel*

We must undertake a comprehensive and coordinated attack on the problem of mental retardation. The large number of people involved, the great cost to the Nation, the striking need, the vast area of the unknown that beckons us to increased research efforts—all demand attention.

It is for that reason that I am calling together a Panel of outstanding physicians, scientists, educators, lawyers, psychologists, social scientists, and leaders in this field to prescribe the program of action. I am sure that the talent which has led to progress in other fields of medicine and the physical sciences can enlarge the frontiers of this largely ignored area.

It shall be the responsibility of this Panel to explore the possibilities and pathways to prevent and cure mental retardation. No relevant discipline and no fact that will help achieve this goal is to be neglected.

The Panel will also make a broad study of the scope and dimensions of the various factors that are relevant to mental retardation. These include biological, psychological, educational, vocational, and sociocultural aspects of the condition and their impact upon each state of development—marriage, pregnancy, delivery, childhood and adulthood.

The Panel will also appraise the adequacy of existing programs and the possibilities for greater utilization of current knowledge. There are already many devoted workers in this field, trained in diagnosis, treatment, care, education, and rehabilitation. The Panel should ascertain the gaps in programs and any failure in coordination of activities.

The Panel will review and make recommendations with regard to—

1. The personnel necessary to develop and apply the new knowledge. The present shortage of personnel is a major problem in our logistics. More physicians, nurses, social workers, educators, psychologists, and other trained workers are needed.
2. The major areas of concern that offer the most hope; and the means, the techniques, and the private and governmental structures necessary to encourage research in these areas.
3. The present programs of treatment, education, and rehabilitation.
4. The relationships between the Federal Government, the States, and private resources in their common efforts to eliminate mental retardation.

I am asking the Panel to report on or before December 31, 1962.

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