PC MR message

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CHALLENGE, ACCOMPLISHMENT AND NEED

This presentation was made by the President's Committee on Mental Retardation to a plenary session of the National Association for Retarded Children's national meeting, Portland, Oregon, October 19, 1967. Focus was on areas in which the Committee made major recommendations in its first report to the President in August 1967.

INTRODUCTION

Mr. Tucker

THOMAS TUCKER, **Moderator**

One of the roles of the President's Committee is that of a catalyst—to gather information, to make recommendations, to spur agencies to action. To actually get the job done, however, we have to turn to where the action is, among you people who represent the citizen effort to help the mentally retarded and prevent mental retardation. This is the context within which six members of the Committee and its executive director will talk with you this morning.

AN OVERVIEW-SERVICES FOR ALL RETARDED PERSONS

ROBERT A. ALDRICH, M.D.

Dr. Aldrich

Constantine Doxiadis, a well known city planner who lives in Athens, Greece, tells the story of a dancer who returned to his native country after traveling all over the world and decided to make a tour of his country's most famous temples. In the course of the tour, he came one day to the most magnificent of the temples. As the dancer climbed the hundreds of steps leading to the temple's top, he seemed to become increasingly distressed. At the top of the staircase, he met a priest and said to him, "If you will dig at the bottom of the staircase, you will find that there are two more steps." They dug, and the two steps were there. You see, the master, the dancer, could feel the rhythm of the structure.

It takes a masterful touch to appreciate the relationship between structure and function, and I would like to talk in this vein a little bit about cities and the people who live within them. Whitney Young *(see PCMR Message #7)* has done such an excellent job of telling you about the people that I will not go into as much detail as he did, but I would like to bring out some aspects of these human settlements that I think are important.

The mentally retarded are people, people who have been out of the mainstream of human affairs, and they must be returned. They are young and they are old. They are white, or black, or red, or yellow, and, in fact, all of the intermediate shades of man on

The President's Committee on Mental Retardation, Washington, D.C. 2O2O1

JOHN W. GARDNER, Chairman: ROBERT A. ALDRICH, M. D., Vice Chairman: DAVID B. RAY, JR., Executive Directo

this planet. The processes that can create mental retardation don't know political boundaries, nor do they recognize social classes or economic achievement. In effect, the mentally retarded are a segment or a slice of our society that seems to cut through all of the layers and the interrelationships, no matter what culture or what nation we examine.

Importance of Environment

The mentally retarded are born, as we all are, in human settlements, and when I use the term "human settlements," I may be talking of the small village in the rural area or a very large metropolitan complex, or a small residential institution, or a home, or an apartment. The mentally retarded are then shaped and influenced by their parents and their environment. There can be no doubt any longer that the exposure to the environmental stimulation or lack of it determines whether or not a young infant or child, otherwise biologically normal, will attain normal intellectual capabilities.

In an age of technology such as we have today, in which continuing learning is essential, those who do not develop this capability cannot compete successfully for professional training, education and jobs.

New industries and professions are constantly being created. Men and women who are displaced from obsolescent industry as it is phased out have to be reeducated with additional skills that will permit them to enter the work force of these new fields. There are almost unlimited opportunities around, if we will analyze the contemporary jobs and professions, for those parts which can be done as well by less skilled people. Thus, the strategy and many of the tactics necessary for advancing the isolated and disadvantaged anywhere are applicable to the mentally retarded.

The retarded must be identified early in life and channeled through good environmental learning experiences.

Now, let me return to my theme of human settlements. Let us look for a moment at the metropolitan complex, the cities of a million or more people. What are their major problems today? My list looks something like this: congested transportation, polluted air, danger, cars, crime, constricted freedom, ugliness, crowding, and isolated pockets of disadvantaged people. The mentally retarded are one of the products of the ghetto or poor areas. They are produced from cultural deprivation as well as by biological circumstances, although there are overlapping factors contributing to both sets of causes, such as poor housing, inadequate nutrition, ignorance, disease, fractured families.

The approach to resolving the problem of either one is not the same. Those who are culturally disadvantaged can be advanced through response to educational and environmental stimulation, while those who are retarded from biologic causes will need more, particularly the addition of medical knowledge. I think there is some reason to believe that the mentally retarded are an important perpetuating cause of urban ghettos. This is especially true of those in the culturally disadvantaged group.

The Mayor of St. Louis reported recently, "My office received from the St. Louis

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"/ hope you will . . . become a walking spokesman for those underprivileged—a walking spokesman for those who need attention, for those who need help, and for those who need direction—a walking spokesman to enlighten the other 200 million people in this country as to what good can flow from efforts in this direction."

—PRESIDENT LYNDON B. JOHNSON, on receiving the first PCMR Report, August 30, 1967

Evaluation Training Center a report providing a statistical survey of 1,300 clients served by a one-week diagnostic evaluation and a comprehensive manpower program that is the pride of our business and welfare community. Of these 1,300 unemployed who were seeking employment, it was found that 75 percent have less than an eighth grade literacy level; 88 percent have less than an eighth grade computational level; and 62 percent scored less than 90 in an I.Q. standardized test."

This interview is much longer and can be found in the October 9 issue of *U. S. News and World Report.* There is a possibility that it could serve as a model for agencies.

Obviously, St. Louis is looking at its constituency through the eyes of responsible civic officials and leaders of the business and commercial community. They are bringing their ideas and their talents to those who need help. They are facing disadvantaged men and women with a positive approach based on primary assessment of what capabilities the unemployed have and followed by very specific efforts that are known to produce rehabilitation and re-entry into the work force. Here is a method for reaching out into the community and into the attack on mental retardation in the poor areas. Government can exert leadership and provide some very important resources, but the task requires an enormous new input which must come from commerce, from industry, and from labor. It cannot come from anywhere else.

I believe that the link within the community between the mentally retarded and these new forces—commerce, industry and labor—can be brought about by such organizations as NARC and its chapters who are represented here.

Are we talking to ourselves too much? To whom shall we communicate the message of the mentally retarded in the ghetto in their plight? How many of us have been to the ghetto to work and have returned to bring others from our branches of society, so that they can consider their place in the efforts to improve the disadvantaged? Are we putting this viewpoint across to our youthful idealists and activists in our universities and high schools? In a few more years, these young people will be the managers of society and will have their opportunity to steer the progress of our civilization. Can we ignore them?

I want to recommend to them, then, if I may, that, in our metropolitan cities there be established a functional unit in every ghetto, representing the interests and the 'Ombudsman' know-how of those who are concerned with For Retarded the mentally retarded so that the mainstream of our efforts as a nation to improve the lot of the disadvantaged through some federal program such as the anti-poverty program, the model city program, and other health, education and social programs can incorporate the needs of the mentally retarded and the means of preventing mental retardation, whether it is from biological causes or from the environment itself.

Let these programs and the men and women involved learn that the problems of the ghettos, of the isolated and the disadvantaged, are the problems of the mentally retarded, and that without a solution to the latter, there will not be real progress for all. Here is a challenge for the volunteer and the part-time worker. Here is an opportunity for the three main areas of our nation—for the universities and higher education, government at all levels, and what is called the private sector. These three together can do this job in a uniquely American fashion.

The rural community attracts less attention than the metropolitan these days. Nevertheless, the rural community will continue to The Rural contain large numbers of people who con- Contribution tribute to the national advancement in varying unique ways. It might be interesting to some of you to examine the history and background of many of the great leaders of this nation from all walks of life. I was particularly intrigued, in looking into the background and early childhood of many of our captains of industry, that a disproportionate number of these men and women came from very small rural towns.

There is a message here, I think. Rural areas are also contiguous to metropolitan complexes. They are certainly going to be involved in the solution of urban problems through the available space there is in the rural area, and in the intermediate cities between the rural areas and the larger metropolitan towns. Mentally retarded individuals are born in small towns, too. Resources for their education and advancement are limited in almost every instance unless there happens to be some kind of a residential facility located nearby which has professional talent available. The precarious nature of the health and education resources in the rural regions makes almost any handicap a major disaster to the family, and mental retardation is certainly no exception.

Few Resources Available

I have known several outstanding business and professional people who lived in rural areas but moved away—at great loss to the town and the county—because the opportunities for their mentally retarded youngsters were greater elsewhere—usually in a much larger community. It takes the loss of only a few leaders of this sort to make a tremendous difference in the viability of the very small town, and their departure can in a very real way contribute to the decline of a previously viable rural community.

I would recommend that the large national volunteer agencies, such as NARC, take a look at the agricultural extension programs and how they are organized and how they distribute their activities in the rural areas. Is it possible that we could include more human elements in this type of mechanism? Is it possible that we can reach out to the rural areas through this type of mechanism and bring better resources for the mentally retarded to the places where they are born and where they live?

To summarize: The problem of mental retardation in a rural area stems partly from the form of the area's human settlements, and I think that the time will come very soon when our city planners, our architects and engineers will find it necessary to have knowledgeable people in the field of mental retardation consulting with them and on the boards of their national organizations. Secondly, I think we should look to models such as the agricultural extension services for guidelines on how to reach rural areas. In cities, we should look to commerce and industry and the models that they have developed for reaching all people in the city. I'll just mention milk distribution, utilities like gas and telephone, electricity; the grocery chains are a fascinating model to study. We have much to learn from this sector of our society.

Finally, if we are going to improve the quality of man, we must simultaneously address ourselves to the quality of human settlements.


Dr. Krim

THE PREVENTION OF MENTAL RETARDATION: TODAY AND TOMORROW

MATHILDE KRIM, PH.D.

Preventing mental retardation is something that we all ultimately want to achieve.

But there are several difficulties in the way of our doing this now.

First of all, mental retardation is by definition inborn, or appears very early in life. We must therefore find a way to deal with it very soon after birth, at a time when diagnosis is difficult; before birth; or perhaps even before conception.

Secondly, mental retardation is not a single pathological condition. It has a variety of known or suspected causes, both genetic and environmental. They are often at work at the same time, resulting in a wide variety of manifestations which makes accurate diagnosis difficult. Even after retardation has set in, an infinite number of interactions between the afflicted person, his family and his total environment modify the basic symptoms seen.

Thirdly, the basic causes of mental retardation, in too many instances, still remain unknown, and effective preventive measures must await the identification of those causes. Nevertheless, in some cases, causes *are* known and prevention can already be achieved by a variety of means, either by preventing conception on the basis of genetic counseling or by avoiding certain pathological manifestations even if the basic defect cannot be corrected.

Also, even when the precise causes are not known, the fact that we are aware of certain aggravating factors, even if only one among many, helps us to do something. I am thinking here particularly of the large number of mildly or moderately retarded people, whose condition appears to be so closely related to a deprived early childhood. Although the case can be made (as it had been by the English geneticist, Penrose) that there is at work even here some genetic factor—since many of the siblings of such people raised under similar circumstances do not become retarded, the fact remains that under more favorable conditions of social interaction and intellectual stimulation, they probably would not have become retarded.

We can prevent such cases by remedying the socio-economic structure, improving prenatal and post-natal health care, and early childhood training. I said purposefully *can* prevent and not *could* prevent because—although we are still largely ignorant of the precise mechanism that produces this type of retardation—we know quite well empirically what are good conditions in which to conceive and nurture a child. Prevention of such retardation, then, will involve an all-out effort by our society at large to upgrade the socio-economic status of the deprived groups within our population. This will require a considerable and costly effort but will repay us by an estimated 50 percent reduction in the total cases of mental retardation.

A completely different type of approach has to be applied to those cases of retardation that involve an organic defect, an inborn anomaly of genetic nature or a number of other causes like trauma at birth, virus infection, poisoning, radiation, and the like.

The first cases to prevent, obviously, are those caused by X-ray examinations during pregnancy, dangerous chemicals and vaccine-preventable virus infections such as measles.

However, abnormalities of the chromosomes are the major single factor causing wastage of life at birth and the largest single factor causing inborn cases of mental retardation. We know also that one death in each 150 births, 25 percent of spontaneous abortions during the first trimester of pregnancy, 10 percent of all institutionalized retarded, 50 percent of female sterility with primary amenorrhea and 20 percent of male sterility are due to chromosome defects.

Chromosome Analysis

We don't know at the moment how to prevent the spontaneous occurrence of chromosome abnormalities, but we can detect a number of them with new techniques for the study of human chromosomes developed over the last 10 years. As little as a single drop of blood is sufficient for obtaining dividing cells whose chromosomes can be analyzed. Among parents of mongoloid children, for example, such analysis can distinguish between those who are unlikely to give birth to a second mongoloid and those—much more rare, fortunately—who are very likely to produce more mongoloid offspring. Chromosome analysis is also valuable in many cases other than mongolism. It has what we call prognostic value, in that findings on the affected baby enable us to predict quite accurately the future course of his development and inborn potentialities.

Even more interesting, chromosome analysis can now also be performed on the cells found in a few drops of amniotic fluid that can be safely collected from the womb of a pregnant woman. This type of examination can predict quite accurately whether the expected child will be normal or defective. Since such examination can be done at 10 to 12 weeks after conception, it could, if personal ethics and law permitted, make it possible to avoid the birth of a defective child through therapeutic abortion.

However, whatever use society will

decide to make of this possibility at the present time, there is another way of using amniotic fluid which will offer even more interesting and promising possibilities in the future.

Test Costs Are Low

Advances in biochemical analysis applied to body fluids like blood, urine, etc., have made it possible to separate and to characterize, both qualitatively and quantitatively, a number of compounds like amino acids, lipids and purine and pyrimidine bases. Such tests can be done quite rapidly and cheaply today, the cost for an amino acid analysis on blood being now as low as 25 cents per sample. This has permitted the large scale screening programs for phenylketonuria, for example, that are now compulsory under the law in 39 states in this country.

PKU is not the only anomaly that such tests can detect. There are at least a dozen other metabolic anomalies, most of them -, leading to severe mental retardation, that we can now recognize very early in life, even a few days after birth, at a time when damage to the nervous system has not yet occurred or is minimal. Although these anomalies are rare and most of them as yet poorly understood, there is no doubt that in the very near future our understanding of these conditions as well as our capacity to detect others will increase greatly. When we become able to test for evidences of metabolic anomaly in the amniotic fluid, we will be able to perform a pre-natal diagnosis.

Possibilities For the Future

Since, ultimately, all genetic anomalies, whether point mutations or chromosomal abnormalities, must perforce be translated into chemical terms, into some change of the chemistry of the body, the day will undoubtedly come when we will recognize the subtle biochemical similarities that exist between organisms affected by the same accident in their genetic make-up, whether gene mutation or chromosomal anomaly. Once we know the difference between the chemistry and physiological processes of affected and normal individuals, therapy can be devised, either through special diet as is done now for PKU, in order to avoid the accumulation of a substance the body cannot metabolize, or through replacing one or more possibly missing chemical factors. Once we are able to do pre-natal diagnosis, we may also be able to do pre-natal therapy.

Even better, and much more important, in the future it might be possible completely to avoid the birth of certain types of defective children by means of the following methods: by obtaining what we may call a "biochemical profile" of healthy individuals, detecting those who are likely to give birth to defectives and advising them on the choice of their mates.

You may know that for every inherited character, each of us carries two genetic determinants, two genes: one coming from our father, and the other one coming from our mother. People who have a normal appearance for a certain genetic character are made of two kinds of people, really. There are those who have two normal genes determining this characteristic, and there is a minority of these people who carry one mutated or abnormal gene, whose harmful effect is not expressed because of the presence of a second, normal gene. The people who carry one normal and one abnormal gene, but who look normal, are called heterozygous for a certain character, or carriers of an anomaly. These people include, for example, the healthy-looking parents of the PKU child. They have a child who by bad luck happens to have received from each of his parents their bad gene instead of the good one.

Although PKU as a disease is a rare phenomenon (it affects only one in 20,000 children), it can be calculated that as many as one person out of every seventy is a carrier of one PKU gene. Since there are many other diseases inherited in the same fashion, it can also be calculated that every one of us is the carrier—and we don't know it most of the time—of anything from one to eight abnormal mutated genes.

Now, there are very good reasons to believe, on the basis of the latest developments in biochemical research, that carriers of such mutated genes have certain subtle peculiarities in their physiology that will soon be detectable by more refined tests than those available today, although even today we have some indication that in certain cases carriers can be recognized.

Establishing people's biochemical profile will therefore permit a precise evaluation of the risks incurred in choosing a mate for procreation, and both real prevention of mental retardation could be achieved and/or remedial therapeutic measures could be started at birth and probably even before that.

Provided that research goes on vigorously and automation is used to screen larger numbers of people, all this is not Utopian. These prospects are so well recognized by scientists today that geneticists have already raised the question as to what impact such advances will have on the genetic makeup of the human species once the cruel but effective mechanisms of natural selection have been bypassed by human ingenuity.

Will unfavorable genes, although not achieving full expression, accumulate in our population? Will they reach an incidence such as to finally be present in one hundred percent of all individuals and make any human couple a high-risk pair? This is possible, but only in the distant future.

But so far our technological and scientific progress moves at a rate that is so much faster than human evolution, that—provided we remain aware of the fact that with every step forward we take a little more of mankind's evolution in our own hands—we can confidently work at achieving prevention and meanwhile at giving everyone, even the most afflicted, the fullest life possible.

MENTAL RETARDATION AND THE LAW

ROBERT B. KUGEL, M.D.

Dr. Kugel

In *MR 67,* the Committee's first report to the President, one of the 10 items singled out for special need had to do with the legal status of the mentally retarded individual. The International League of Societies for the Mentally Handicapped at its Symposium in Stockholm in 1967 stated as a general conclusion that "the services provided for mentally retarded persons should in no way segregate them from the rest of the community; for example, classes, workshops, recreational facilities and living accommodations should be integrated, as far as possible into those provided for other members of the community." To what extent are there now provisions to be certain that such a recommendation can be carried out?

Apparently the legal aspects of mental retardation do not capture our imagination to the extent that some of the other facets do. Exciting advances in the biological sciences and the steady progress of educational services have all but eclipsed this more basic concern.

Professor Richard C. Allen of the Institute of Law, Psychiatry and Criminology at George Washington University is making a study, as many of you know, concerning the legal norms and practices applicable to the mentally retarded. His studies and those of the President's Committee on Mental Retardation suggest several questions about services for the retarded which I would like to share with you at this time.

Do services protect when legal proceedings become routinized and when the decision-makers lose sight of both the nature of the services available and the needs of the people to be served? Many individuals have recognized that institutionalization and legal incompetence are different though related in concept. In some states, however, the law declares that institutional commitment does not of itself constitute a finding of legal incompetency. Yet, other statutes and hospital regulations prohibit all residents of the institutions for the mentally retarded from holding a driver's license, making a will, marrying, executing a contract and from having any right of management of property.

Facilities, Staff Needed

Do services protect if there are outmoded physical facilities and a lack of adequate staff? All states have a greater need for more community facilities to serve as alternatives to residential care, including day care centers, sheltered workshops, recreational programs, job placements, group boarding facilities, etc. In some residential institutions there are no resident psychologists and physicians, and consequently the clients are never retested and reexamined. Vocational training has not been developed in several states, and work assignments are based more on institutional needs than on the habilitation requirements of the clients.

Lack Provisions For Guardians

Do services protect when important decision-makers are ignorant of the services or of their appropriate use? Many parents are unaware of the alternatives available to them in planning for their children's future. Few parents have given any thought to making provisions for their children when they reach the age of their majority. Guardianship is often not seen as an appropriate recourse. The Task Force on Law recommended that there be an outside guardian for every retarded person involuntarily admitted to an institution, to check on his treatment, care and release possibilities; and yet this guardianship arrangement rarely exists. In many states there are many hundreds of inmates in hospitals for the mentally ill with the primary considerations of mental retardation. Some seem to have been sent to these facilities as a matter of administrative convenience and others out of ignorance.

Do services protect when they impose coercive sanctions unnecessarily, or for longer periods than required or when more appropriate non-coercive measures are available? In some states certain services—for example, special education and vocational training—cannot be obtained without formal commitment procedures. Another illustration would be in the sterilization and eugenic practices. Twenty-six of the states have eugenic and sterilization laws, 23 of which are compulsory laws.

Do services protect when the legal provisions under which they may be rendered are phrased in terms which, because of their ambiguity or inappropriateness, make it difficult to identify the categories of persons eligible to receive them? The most confusing array of terms exists, including some rubrics such as feeble-minded, backward, inferior, slow learner, custodial, marginal dependent, and trainable. These terms are not defined in the statutes, and hence interpretation becomes highly variable. Even such terms as mentally deficient or mentally retarded are not defined equally and are used to imply different things in different parts of the country.

Do services protect when custodial care, because of its ease of application becomes a treatment of choice over other protective services more appropriate to the needs of the individual? Not only is institutional placement often used as a substitute for guardianship, in large part because of the inadequacies of the laws, but it is sometimes used as a kind of disposal for children with behavioral problems. Despite a growing trend of professional and lay thought that home life is to be preferred to institutional care unless gross physical anomalies or an impossible family situation makes institutional care necessary, there still are a number of institutions in the country which routinely accept children under six years of age, and medical staff members and key decision-makers to the physicians recommend that all retarded children be institutionalized as soon as possible after birth.

Do services protect when they are referred by a multiplicity of agencies with ambiguously defined and overlapping jurisdiction? There are instances when reasonable and effective help has not been forthcoming not because of failure to recognize need or even lack of facility, but because of uncertainty as to which bureaucratic domain has decision-making authority.

Do services protect when they do not respect the dignity and worth of the individual? The Task Force on Law pointed out that "every means should be sought to minimize the need for physical restraint and to scrutinize its use." Most institutions seem to employ seclusion and other restraints as means of protecting patients or controlling their behavior, and in most institutions they are applied humanely. In some, however, discretion to employ them is given to untrained ward attendants, and that discretion is often exercised less for the client's well-being than for the comfort of the staff. In some institutions, ward attendants have obtained prescriptions for tranquilizing drugs at one time or another for many of the clients in their wards, and once obtained, these prescriptions were refilled and administered by attendants with no medical control whatever. Courtless and Brown in 1964 studied the problems and treatment of retarded offenders in penal and correctional institutions. They found that about 9.5 percent of those in penal institutions had tested I.Q. scores below 70. As such, this problem as it relates to our laws deserves some special attention. Certain questions were raised such as at what point, if at all, was an attorney appointed to represent the accused? Was a confession or other statement to the police offered in evidence? Was the issue of his competency to stand trial raised? Was he referred for examination? Was the defense of lack of criminal responsibility asserted? Was there a pre-sentence investigation? What were the dispositional alternatives available to the judge? And at what point, if at all, did significant decision-making persons become aware of the fact of the defendant's mental retardation? These are all questions which must be considered. Although the number of defective delinquent individuals may be small, the problem posed is great, and our consideration of this group must not be overshadowed by large numbers.

Rights Are
Not Heeded

Let me end with a statement from the general principles of the 1967 Stockholm Symposium: "The mentally retarded person has the same rights as other citizens of the same country, same age, family status, working status, etc., unless a specific individual determination has been made, by appropriate procedures, that this exercise of some or all such rights will place his own interests or those of others in undue jeopardy. Among the rights to which the general principle may apply are: the right to choose a place to live, to engage in leisure time activities, to dispose of property, to preserve the physical and psychological integrity of his person, to vote, to marry, to have children, and to be given a fair trial for any alleged offense."

THE INFORMATION CENTER

JOSEPH A. BEIRNE


Mr Beirne

The subject on which I report to you, on behalf of the President's Committee, is a very simple one, and it more or less explains itself.

Most of us in this room have lived in one lifetime through several ages. We were born in the machine age, went into the atomic age, jumped from that into the electronic age, from there into the thermonuclear age, and we are now in the space age. But we do not even know the language of the atomic age yet.

For the human mind to comprehend what has happened in the five ages we have lived in the span of a single lifetime is more, perhaps, than any of us can accomplish. But we can at least try to organize all of the new discoveries and information in a way that will make these things available to help people when they need the benefit of them.

So, one of the things the President's Committee did was to say, "Let us try to establish an information center; let us take advantage of the fact that there are more scientists alive and working today than ever existed in the history of mankind up to this time. Let us collect their findings, let us use the transistors; let us use the electronic impulse; let us put the computer to work; let us have our own memory bank for the mentally retarded."

And so, this very simple proposal, one of the ten which we made to the President, is that we create a national information center to help in this great work. So that you, wherever you may be, whether your interest in mental retardation is a personal and family interest or stems from your community activities, will know where to write, will know where to go for information, for advice, for guidance. So that fewer and fewer people will experience that terrible moment of not knowing what mental retardation is or means, or where and how to find out.

PUBLIC AND PRIVATE PARTNERSHIP

Mr. Mayo

LEONARD W. MAYO

Talking to this group on the subject of public and private partnership is really bringing coals to Newcastle because, in the last decade, the standard of the National Association for Retarded Children has been raised high many times in the battle for effective partnership between the governmental and private sectors. How this happened makes a fascinating chapter in the development of health and welfare services and education in the United States. You began with a vision of changing the nation's attitude about the retarded, putting down your roots in the soil prepared by the American Association on Mental Deficiency, you mixed popular appeal and scientific knowledge with your own commitment and concern and created a thrust that has few parallels in our history.

Six Areas Of Concern

You have developed a relationship between the private sector and the public forces which has great leverage, but the full potential has not yet been realized. There are six areas of deep concern in the United States in which this partnership can be more effectively used than it has been in the past. I shall mention them very briefly.

I mention first the challenge of the conquest of decadent city areas, the slums, and ghettos. In most cases it is no longer possible to delineate a definitive division of labor between the function of the private sector and that of the public in mental retardation. There is scarcely a single function in the field of retardation which cannot and has not to some degree already been performed by both sectors.

But in attacking the problem of the ghetto, there is thus far a sharp division of labor which can only be described as unfortunate. Except for a relatively few concerned individuals and voluntary groups here and there, only the public sector is fully involved in the problems of poverty, illness and inequality that combine to plague the poor. In many cities, the private sector has almost given up any extensive and significant work in these areas.

Actually, the private sector has a critical responsibility to keep on working in the slum areas—to provide clinics and recreation facilities, to develop day care services, and to offer consultation and casework services.

I have never been sympathetic to the argument that, because a child cannot be in an adequate environment 24 hours a day, he should not be given some taste of a good environment for a few hours a day; because an individual cannot be in a warm bath 24 hours a day, he should not give up bathing.

The private sector must also exercise the ancient biblical injunction to bear witness. Evidence of need must be presented to the key groups—in government and out, in our communities, our states, and nationally. Most governmental groups want the testimony and witness of private individuals and organizations who are concerned about the individual in our society.

Secondly, legislative activity is a prime area for the joint forces of the public and the private sectors. You have established an effective relationship with the Congress for which you need the continuing support of those of us in the private sector.

Third, I am glad to note that NARC is addressing itself this year with renewed emphasis to raising the level of residential care of the retarded. Most of the large residential institutions in the country are under public auspices, but nearly all of them have advisory boards made up of private citizens. Here is an opportunity for the private sector to approach those private citizens on the boards, to approach state governors and state legislators bearing witness to the urgent need to raise residential care in this country not only to a decent but to a high level. Other countries have done it; so can we.

Fourth, the area of special education. We need more effective teamwork here than we now have. We need to draw in a powerful group within the private sector that has not yet been involved. With a few exceptions, of which the Joseph P. Kennedy, Jr., Foundation is the most notable, the private foundations have not yet made substantial investments in the prevention of mental retardation, in the education of mentally retarded children, or in research devoted to learning problems, all of which are essential to improving special education.

Role of
Private Business

Fifth, job training and preparation for employment. Here, we must draw in another portion of the private sector which is only beginning to make its presence felt in the field of mental retardation—private business and industry. The President's Committee is interested in this and wants to work closely with you in developing a greater interest on the part of private employers in rehabilitation and job training.

Finally, it is important that private dollars from foundations and business and industry and individuals be invested in all aspects of research; finding out more about the basic causes of mental retardation is essential if we are going to find some of the answers to questions that still haunt us.

A strong public-private partnership is essential to the further development of the mental retardation program. It needs and deserves our total investment and full support.

BETTER INSTITUTIONAL PLANNING

MRS. HUBERT H. HUMPHREY

It is a wonderful opportunity to appear with the members of our committee, who are from all walks of life, twenty-one members representing all segments of the nation, all devoting their time and energies to this very deep and perplexing problem we all are so personally close to.

My subject this morning is one that has been uppermost in our thinking and much of our discussion of the past few days. But it's not been uppermost in our minds only through those days. It is firmly a part of everything we do in thinking and planning and talking about the retarded person.

Better institutional planning and residential facilities present a real challenge at this time because we know so much, we have so much information, but where do we go with it at this point?

First of all, like a good student, I thought I would look into the background of institutions and see where we came from, where we got the idea, where we started first of all in the field of mental retardation. So, I'll start with "Once upon a time."

In 1836, a man by the name of Johann Guggenbuhl was passing through the village of Siedorf in his native Switzerland. He encountered a person he described as a dwarf, crippled, cretin, of stupid appearance, reciting the Lord's prayer at a wayside crossing. He followed the man to a nearby shack where the man's mother explained that she had taught the prayer to her son during his childhood without much difficulty. Since that time, he had prayed at the crossing every day at the same hour in any kind of weather. She also explained to Dr. Guggenbuhl that, because of their great poverty, there had been no further chance for education. Her only alternative had been to sit by and watch him deteriorate from year to year.

Dr. Guggenbuhl, because of his background and training, was inspired by the thought of the better chance at life that this man and others similarly handicapped might have had with regular and thorough training.

He gave up his small medical practice and concentrated on finding a cure for mentally defective people. With the backing of the Swiss Association for Natural Sciences and a donation of 40 acres of land near Interlaken, Dr. Guggenbuhl established what is known to be the first residential facility for the teaching of mentally defective children. It was called the Abendberg.

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A man of tremendous energy, Dr. Guggenbuhl traveled widely to learn all he could about retardation, at the same time explaining his own work in the institution of Abendberg. Many people came to visit at Abendberg, and they would return home with glowing reports and anxious to establish similar institutions for the retarded in their own countries. So, this was the beginning, the very first institution for the retarded in the world.

Dr. Guggenbuhl's fame, however, was short-lived, and there's a lesson to be learned here. It very soon became obvious to his followers that he could not cure retardation. Moreover, during his frequent and extended absences from the Abendberg on speechmaking tours, many abuses developed and became widely known. Nevertheless, his efforts had already resulted in inaugurating in Europe an institutional expansion which, in the following decade, was to encompass the civilized world.

A contemporary writer, assessing his contributions, stated: "Guggenbuhl seemed to sense that time was ripe for more than just founding a school. He thundered his message and started a movement."

The second half of the 1840's and the following decades witnessed the opening of one institution after another. As his counterpart, the French Sequen, put it once, at certain times a full race of men has contemplated the discovery of truth and seemed to arrive at once at a certain point.

I hope that we in the 1960's, some 120 years after the first institution for the retarded was established, are at the point at which the thundering of the message on the needs of the retarded in residential facilities will bring a response from the minds and hearts of our people and will result in improvements we all seek.

I find little controversy in the general philosophy of any such message conveyed. Many articles and pamphlets are coming through loud and clear. It is true we heatedly debate the number of persons to be served, location, the small versus the large facility, the terms that should be used to describe institutional activities, architectural standards, personnel ratios, and it is important that we do. But, basically, I find in our country and in other parts of the world that our common goal, on which there is negligible debate, is simply to eliminate the so-called institutional character from our facilities for the retarded. Perhaps in the process, we should eliminate, as many have recommended, even the word "institution" as well. "Institution" has always conveyed to me, and I find it does to others, a rather sterile, militant, isolated, crowded environment which is not conducive to preserving the cherished human personality or providing for its growth. I respond in the same manner to the use of the words "insane asylum" or "home for feebleminded and mentally ill." Thank goodness, they are seldom used now.

What we must remember, in contemplating the nature of residential facilities, is that we are providing for what may be a lifetime home for fellow human beings, and that home should provide as completely as possible an opportunity for fulfilling personal contacts, for the realization of individual potential.

The activities in that home should center, as frequently as practicable on the individual, rather than always on the group. The home should be built and planned not to separate, but to integrate the retarded into the community. It should not be just a human repository.

Simply summarized, then, our over-all goal is to create in institutions as normal a living pattern for the handicapped as possible. It has been reassuring to find in my travels here at home, as well as in other countries, that institutional living need not mean permanent separation from family. Facilities can be constructed in a manner which preserves parental and community contacts and encourages normal living and is flexible through life cycles of the patient.

The time is at hand for our President's Committee and for the National Association for Retarded Children to set in a dynamic and meaningful way the direction we must take in providing the care and training that are rightly due our retarded citizens. It is high time that we set more specific guidelines, particularly architectural guidelines for residential facilities. Architectural guidelines are absolutely necessary to begin. We start from there. I would even go so far as to recommend that we set down our goal and ideals in blueprint form. A home starts with a blueprint. The philosophy of the life of the people that goes into it comes alive in that form and then later takes fulfillment in discussions and changes that are made in it before it ever a becomes a building, but, of course, the actual form it takes and usage come from people who will live there and work there and play there.

There are two basic needs in considering residential facilities at this time. The first one is the one that is most fascinating to all of us—a new building. Any new construction requires especially careful consideration. Let us not ever repeat the bad habits of the old ones.

When I was in Europe to attend a meeting of the International Association for the Scientific Study of Mental Deficiency, in September, I made a special side trip to Denmark to see their residential homes. I asked particularly to visit the newest and the best of that country's facilities. The homes for the retarded that we visited there were closely accessible to metropolitan areas. They were generally in residential neighborhoods. They were smaller in size and enrollment than many of our facilities. They were clean, sparkling, and beautifully kept. They had succeeded in attracting many youthful employees. There was strong emphasis on individual privacy, on providing space which was regarded as belonging to one person alone. I haven't time today to go into detail because there were so many interesting things that we found.

Privacy And Space

My general impression, though, was that the homes had been planned for the maximum comfort and development of the occupant. Architects had clearly understood the unique requirements of the retarded and had attempted to meet their various needs in a creative manner.

I have seen facilities in the United States that are equally impressive.

Our second need is the big one and the tough one. We must take a long, hard look at the state institutions as they exist now and prepare recommendations for their conversion. Let us seek the most efficient and economic way to adapt them more successfully to current requirements, care and treatment of the retarded. If we had our choice, I know we would just bulldoze some of these old institutions down, do away with them; I'm sure that the states and the local communities would like to do that, would like to start fresh and new. Maybe this would be more economical in the long run. The question is one we need to find out.

Time Must Be Considered

In considering both the old and new facilities, it is vital that guidelines reflect our best study and thought. However, we must remember that building is proceeding and will not necessarily wait our findings. Therefore, time is a factor to be considered in our deliberations. Let's see to it that new facilities and buildings aren't obsolete before they come off the drawing boards.

While we must aim for perfection in preparing standards, we must also realize that it is easy to fall short of our ideals. Nevertheless, this doesn't mean we shouldn't go ahead.

We know that the President's Panel on Mental Retardation came up with specific suggestions on facilities that have perhaps been overlooked and not always fully utilized. NARC has also given us direction over the years, and I especially want to compliment you this year for inviting the architects to insist on better planning.

I should perhaps conclude my remarks with a statement that is sometimes flashed on the television screen at the beginning or end of a program, and this is exactly what I should have said perhaps in the beginning, that the views stated are my own and not necessarily reflecting those of the sponsor.

I've been reluctant to speak on the subject, realizing fully that to achieve the best facilities requires the thought and deliberations of many, many persons. I think what Dr. Aldrich referred to as structure and function is what we want to emphasize, though.

Doesn't it all boil down perhaps just to this: Isn't our real goal the happy and proper placement of each and every retarded person in a home, his own or perhaps a place somewhere else which is suited to his own individual needs and requirements? I think we ought to emphasize the finding of every retarded person and making sure that he is in a proper and happy home.

I do hope that I have challenged you to act. Let's get our ideals and goals off the pad.

THE FUTURE

DAVID B. RAY, JR.

Mr. Ray

In trying to sum up, I don't think any of us can look in a crystal ball and say that the future of the mental retardation movement is thus and so. We have tremendous resources over the country, but there are certain things we need to do to make the future bright.

Number one is to talk to others—and not just to retarded children association groups, not just to Jaycees, and not just to Clipped Wings chapters, but also to other groups such as business associations, labor groups, and civic groups throughout the country that we need to involve in helping solve the national problem of mental retardation.

Number two is to zero in on the problem of mental retardation in the nation's disadvantaged areas, both urban and rural.

Define the Target Areas

Number three, we must define the target areas for action and set up priorities. Many times we ask others' help on mental retardation needs, but don't say in simple and specific terms what we want them to do.

The Advertising Council's national public service project focusing on mental retardation terminates at the end of 1967. While mental retardation will be included in the succeeding Ad Council campaign on the handicapped, NARC and PCMR, together, along with other groups, will need to devise ways of keeping the public's specific awareness of the mental retardation program at the high pitch achieved during the past 3 years. We will need carefully thought-out help from many communications and information media specialists.

Number four, we must accelerate and improve our grassroots operations. This is where the retarded are located. This is where the action is.

Number five, we must gather and convey correct information on retardation incidence and needs to state legislators and U.S. congressman, to state governors, to mayors, to city council members, to school board members, to all the key people at strategic stations in our way of life.

Sixth, we are going to have to solve the manpower problem. It's number one throughout the country, and its solution demands bold, imagination thinking about jobs, functions and people resources.

Seventh, as Mr. Beirne has pointed out, we must devise methods of passing on information scientifically.

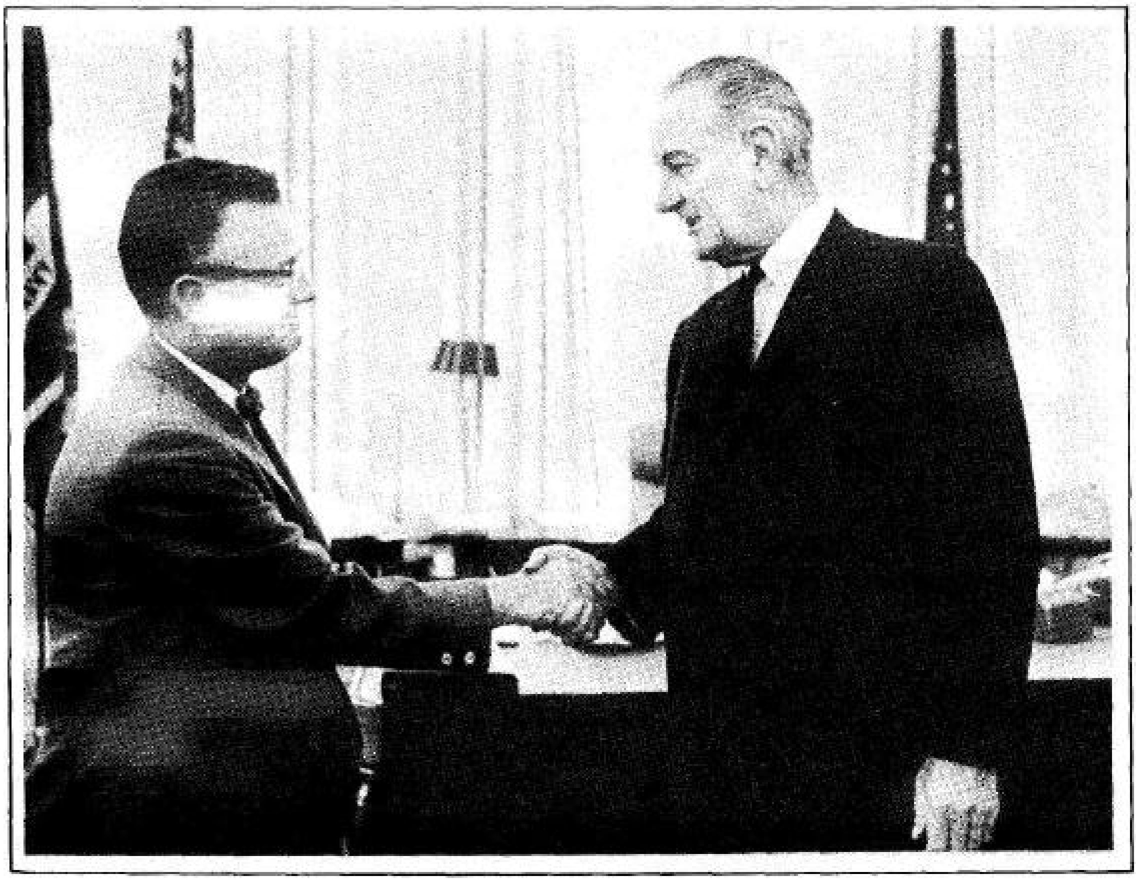
Lastly, we must keep up to date on the

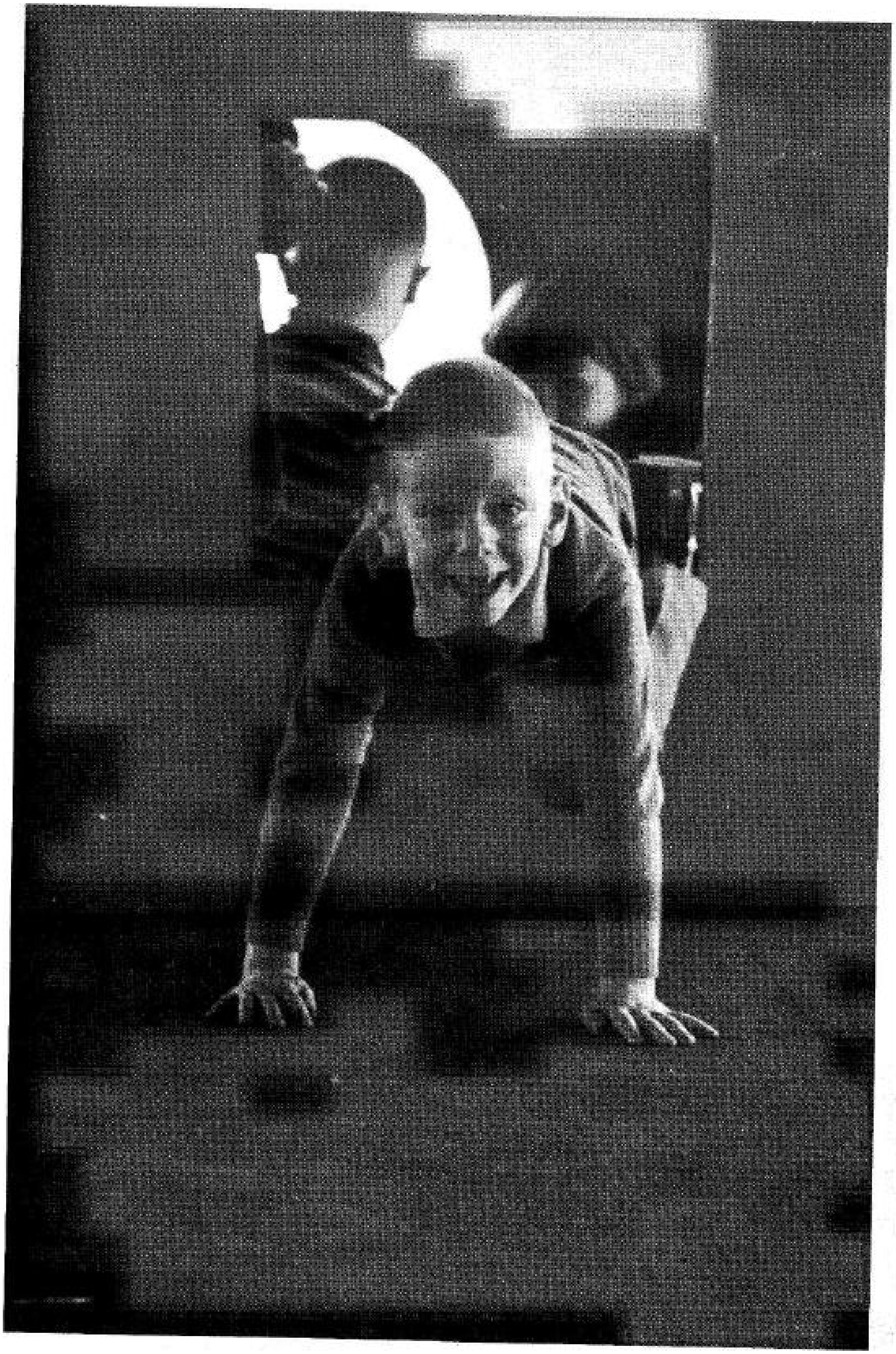
changing world, facing up to the tough questions in our field that have both moral and ethical implications, staying flexible, keeping our pioneering spirit, our enthusiasm, our dedication, keeping ever in view the real needs of the mentally retarded and how these can best be met.

The future is great. The President says so. NARC says so. The President's Committee on Mental Retardation says so. I think each of us would sav so. But to make it so, each of us has a challenge and a responsibility to fulfill regardless of his location, level or role. It might be the federal or state or local, or private or public; it might be big, it might be small; it might be fancy, it might be plain. But there's a place and there's a job for each of us to do. There are tools to use right now, and the time to start is now.

The reward of the future will unfold with rich dividend for the retarded as each new tomorrow is born.

The President pledges his support in the campaign against mental retardation to Dr. Robert A. Aldrich, PCMR vice chairman.





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