

THE FORGOTTEN RETARDED -

* in residential facilities

* in poverty

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THE FORGOTTEN RETARDED

Mr. Chairman, Ladies, and Gentlemen:

In 1967, the President's Committee on Mental Retardation took stock of the national effort being made to combat mental retardation. Two aspects stand out as needing special attention -- residential care and the retarded from disadvantaged areas, both urban and rural.

Residential Care

Some of what I have to say tonight will be an effort to discuss the reasons for this poor showing. Unfortunately I can bring you little good news when talking about residential facilities. I think it is important, however, to point out that in the United States considerable progress is being made in some areas of mental retardation, much of it outstanding, such as employment opportunity, sheltered workshops, public education, diagnostic centers, daytime activity programs, and research.

Why have the residential facilities in this country lagged so far behind these other areas in which advancement has been so prominent. What are some of the problems? In many places the public residential facility has been plagued by a triple problem --• overcrowding, understaffing, and underfinancing. Gradually a change in attitude has been occurring as various significant efforts have been made to enlighten lay and professional people alike. But despite these efforts, the residential facilities of this country have languished.

I would like to analyze briefly some of the reasons why public and private residential facilities throughout the country have fallen behind. Those persons responsible for planning facilities for the retarded were largely committed to locating them away from the population centers of the state. This unfortunate decision seems to have been motivated in part from the conviction that the mentally retarded person was best cared for in a more bucolic setting, in part out of fear that the retarded, being a scourge to society, should be removed as far from society as possible; and in part to satisfy the yearning to have a state facility in a certain town in order to provide additional revenue for that community.

One should further note something of the history of the development of residential facilities. In the late 19th century there was a wave of optimism about the care of the mentally retarded, with the general belief that through educational efforts the retarded could be helped, indeed cured. When this concept, so noble in its beginning, proved wrong, it was supplanted by the scourge notion promulgated by Goddard and derived from his poorly designed study of the Kallikaks. The mentally retarded were soon to overpopulate our society, according to Goddard, and segregating them from society was the most important service to be rendered. As a consequence, building programs for institutions in the 1915 - 1930 were really a continuation of the out-of-sight, out-of-mind concept. Still late institutions for the retarded began to be considered as colonies where the undesirable members of society would be segregated and separated. This concept also proved to be fallacious.

For whatever reason or combination of reasons, most of the nation's public residential facilities and also the private ones are located in out of the way communities. Being so located has meant an ever-increasing difficulty in obtaining highly qualified staff who frequently have preferred to live in larger communities. Similarly, the core of any institution, the ward or cottage personnel, have been increasingly difficult to recruit as people have moved to larger metropolitan areas.

When citizens become concerned about an issue such as where to locate a new highway or whether to build a new school, it has always been useful to be able to show these citizens, their legislators and others in decision making positions what the problem is all about by having ready access to an existing example. None of this is available to those trying to change the plight of the institution* Is there an exemplary model of care for the severe and profoundly retarded to be seen anywhere in this country? Many legislators have appropriated large sums of money to support their public facilities but have never visited a single institution for the retarded. There are physicians who refer patients to these residential facilities but who have never seen the facility and do not know the professional personnel caring for the clients whom they refer.

Patient help constitutes another problem, sometimes referred to as institutional peonage. Although some work placements may be indicated, the continued retention of patients in work situations has often been the only way the daily work could get done. Some important activities as the laundry, food service and ward service in the hospital would collapse if it were not for the continued reliance on patient help. In addition, the failure to have adequate community resources - workshops, group living facilities, and rest homes - has meant that even if patients were to be released, there is often no place for them to live and no job for them to have. To rehabilitate the retarded person who has lived most of his life in an institution becomes much more difficult since he is ill-prepared to cope with the social requirements of a normal community.

The underfinancing of most public institutions is a tremendous problem. The per diem costs over the country range from \$3.00 to \$12.00. .-. Five of the largest zoos spend an average of \$7.15 for their large animals on a per diem basis. The underfinancing pertains to all aspects of residential care. Many institutions have budgeted positions which are now vacant. On the basis of some rough calculations it is suggested that about 30% of all budgeted positions in residential facilities are now vacant. This can be partially explained by the fact that the attendant positions of many of our public institutions are at the level designated by our national government as poverty wages. Three thousand dollars a year will not provide, personnel of high caliber. Since the cottage life personnel and the ward personnel constitute the backbone of any residential program, it should not be surprising to find that the programs for rehabilitation are frequently seriously inadequate or lacking altogether. : 2

Underfinancing contributes, of course, to the understaffing. Many residential facilities do not have full-time physicians on their staff. Physical therapists are frequently lacking altogether. Speech therapists may consist only of untrained individuals. Occupational therapists may be totally unknown. While the clients '^ may be kept clean, they often have no programs for daily living other than the meaningless blare of a television set or the completely empty, fenced-in court.

A few years ago Burton Blatt and his colleagues put out a book called "Christmas in Purgatory". In this book Blatt described the deplorable state of some residential facilities, depicting this aspect in a most graphic fashion. Although criticized by some, I believe Blatt has performed a great and important service by pointing out this shocking problem. I have seen, for example, a man without legs condemned to walk on his stumps because he once ran away from the institution, got lost, froze his legs and had to have them amputated. Everyone was reluctant to provide him with rehabilitative services for fear that there might be a repetition of this behavior and furthermore it was a deserved punishment. There are too many places where patients sit naked, surrounded by their excreta. 3

Many Americans have the impression that poor residential facilities are something which must be endured along with other evils of our times. This situation need not be tolerated. One can visit several of the European countries, especially the Scandinavian countries, to find imaginative and unusual programs of care. Along with others I have been impressed by finding residential facilities in the Scandinavian countries which were located close to population centers. In Copenhagen I visited a facility, The Children's Hospital at Vangede, which is located well within the city limits. Many of these facilities have no more than 150 to 200 people. Staff ratios would be 1:1 and the care provided exemplary. In addition, the physical surroundings are attractive, abounding in bright colors. Fixtures and furnishings are attractively designed and not the clumsy prison industry furniture often found in this country. Everything is meant to be attractive and to have appeal to those who must reside in a residential facility. If one is to solve in some measure the problems of our overcrowded institutions, then corresponding attention must be given to community resources. It has been pointed out on many occasions that the galaxie of services needed should include day care centers, schools, diagnostic centers, vocational training centers, sheltered workshops, group living homes, etc., and the personnel to staff them. I would maintain that residential facilities will not be what we want them to be in the future unless simultaneous efforts are made to rectify the situation in the institution and in the community. As one major effort towards accomplishing the objectives which are desired, massive re-education is going to be required. There is nothing to be gained by hiding the fact that our residential facilities are in a deplorable state, their buildings crumbling, the staff overworked, underpaid and often undertrained and the programs available providing only minimal care and rehabilitation. Each state must develop an even greater public education effort to bring to the attention of their citizens. This blot on our escutcheon. It should be the wish and desire to try to rehabilitate patients to the community rather than to segregate them. This re-orientation in thinking will require considerable effort as public officials, administrators of institutions, professional people, and the lay public all come to understand that the physically handicapped and the mentally retarded do not need to be moved aside but rather should be a part of the ongoing programs of communities.

In addition, nursing homes, rest homes, and convalescent homes should all be part of the services available in the community. Even severely retarded individuals with extensive physical handicaps can be handled in the community. Great Britain some years ago pioneered with the idea that the physically handicapped as well as the person with other handicapping conditions can and should be maintained in the community, but to do this they developed a concept that even the most severe form of handicapping conditions which might require prolonged nursing care could be cared for in facilities in the community as part of a regular pediatric unit. Such services need not be separated, segregated and removed from society.

An attitude of helping should be inculcated into all of the helping professions. Mrs. Una Haynes, long associated with United Cerebral Palsy, has amply demonstrated the kind of things which can be done for the physically handicapped and the mentally retarded. Her type of enthusiasm will go a long way towards trying to promulgate far better ways of thinking about the mentally retarded. In brief, one should ask the question why couldn't all patients be maintained in the community? Why should they be removed? Should not society aim towards trying to help where the situation of mental retardation or physical handicap has occurred? One does not say to the parent of a child with leukemia that he should be "put away" even though everyone recognizes that the child will ultimately die. Rather, all forces are mobilized

to help and to sustain the child in the community even though he may need periodic hospitalizations. Surely the same approach should be used for the mentally retarded and the physically disabled.

The Foster Grandparent Program has been successful in helping to cope with the manpower problem. It takes cognizance, of not only the needs of the retarded and the handicapped persons, but also of the elderly who similarly are looking for places in our society where they can be of help and assistance and not relegated to a shelf. The SWEAT program has been another device used successfully in trying to attract people, in this instance young people, to have some exposure to mental retardation, thereby dispelling some of the fantasies they have had about the difficulties in working with the retarded and also giving them some knowledge about how rewarding such a career can be. But much more is needed and much greater effort will be required if the manpower problem is to be solved.

In thinking about solutions for residential care, one certainly must give thought to architecture and size. Many of you know from Dr. Gunnar Dybwad about the architectural barriers which exist in residential facilities. He and others would point out that if existing buildings are to be modified in order to make room for the clients, a loss in bed space is inevitable. The Scandinavian countries, again leading in the area of remodeling existing buildings, have deduced from their 10 to 15 years of experience that it is absolutely necessary to plan on reducing the number of beds by half if the former construction had been along the general open ward variety.

I realize it is still controversial as to the desirability or not of having large facilities of 1,000 or more. Many of our facilities are this size and some are now being constructed that will be of this size. The evidence is not convincing to suggest why large residential facilities need be built. The argument often runs that large facilities cost less to operate. I would suggest that this point has not been proven. Currently the President's Committee on Mental Retardation is in the process of making a study about what is known in reference to costs of running large versus small facilities. There is evidence to suggest that small facilities of 150 to 250 can be operated and constructed at no more than the cost now being utilized in the larger residential facility and perhaps even at less cost.

An additional point to be made about the size of an institution certainly relates to one's sense of human values. In today's world where many of us become numbers on an IBM card we all feel great reluctance to bid farewell to a more individualistic approach to the problems of human care. A return to small units, whether in a university, a city, or a residential facility, seems to be a matter of increasing concern to many people. These human values must not be permitted to be overshadowed by too much architectural efficiency and the engineering consideration of locating buildings at the point closest to the steam plant. Surely we have lived with problems of regimentation for too long and must be ever on guard in all sectors lest we perpetuate this problem.

Let me now turn to some thoughts about the disadvantaged. Poverty may be a leading cause of mental retardation. This may startle those of you here today who laboriously charted the family histories of the Jukes and the Kallikaks in your high school and college biology courses and came away believing that heredity was the leading factor in retardation. Perhaps only one quarter of the cases of mental retardation can be traced to faulty genes, virus infections, accidents and diseases causing brain damage before birth or in early infancy.

Today most agree that many in this group are the victims of urban and rural slums, social and psychological deprivation in which they live during their formative years and takes away from them the opportunity to develop fully their intelligence. Three of every four retardates come from homes in poverty areas. Relatively few of them seem to have been stunted intellectually by medical, physical or genetic problems, although poor nutrition and lack of adequate pre-natal and other medical services have contributed to this tragic statistic. Other figures further emphasize the problem. Three percent of the nation's total population is mentally retarded, yet conservative estimates of the prevalence of mental retardation in slum areas of the inner cities begin at seven percent. Poor families suffer mental illness, retardation and nervous disorders at a rate six times greater than the rest of the population.

It is estimated that 80 percent of all children who grow up in what we call disadvantaged homes will test out as borderline retardates by the time they enter school. The President's Committee on Mental Retardation, in its 1967 report to President Johnson, noted that many children from such homes become functionally retarded during their school years.

Whitney Young, Executive Director of the National Urban League, translated these disturbing figures into graphic human terms at the 1967 Annual Meeting of the National Association for Retarded Children. In describing the cycle of futility which faces residents of urban and rural ghettos, he said the poverty world of the ghettoized Negro, Mexican laborer, American Indian, Puerto Rican immigrant and poor white is "the breeding ground of as much as half of our mentally retarded people, the dull-eyed children, the juvenile delinquents, the dropouts and socially unadaptable youngsters who drive teachers, lawmakers and governments to despair."

Grim as all this may sound, new knowledge and techniques in educating and training the retarded give us the opportunity to change this unhappy pattern. Available evidence indicates that some of the effects of social-psychological deprivation may be reversible. This means that many of poverty's retarded victims can become productive members of the community. They can grow up to lead reasonably normal lives and to support themselves. Even more importantly, it means that we can do something now to prevent many future retardates, to reduce the retarded of tomorrow.

To accomplish these goals, we must understand how living in poverty contributes to mental retardation. If I may be candid, the fact that so many of us do not know what it is to live in poverty is a major stumbling block to the creation and implementation of the kinds of services that are needed. We go into the ghetto with our middle-class attitudes and our middle-class experiences and wonder why our good will and professional expertise is met with apathy, indifference or outright hostility.

Unfortunately, we do not talk the same language as the poor. We have not faced the cycle of futility, the terrible overcrowding and poor living which are all the ghetto resident can find. We have not been frustrated by exorbitant credit rates, higher prices in the ghetto stores than are charged elsewhere ... by second-rate schooling and lack of services more readily available in better neighborhoods. We have not lived with the growing bitterness that comes not only from grinding poverty and limited or total lack of job opportunities, but also from the knowledge that children from other neighborhoods are treated differently than ours when they get into trouble.

Frustration and anger are factors which overlies the poverty areas. But there are more specific factors which contribute directly to mental retardation. Most poverty area mothers have their babies in public hospitals, if they go to a hospital at all.

Yet, 4-5 percent of the women whose babies are delivered in public hospitals have had no pre-natal care. The lack of such care, along with poor health and ignorance of family planning, contributes to the high incidence of premature births among low-income women. They have three times more premature babies than other women. Prematurity is a major factor contributing to mental retardation.

Children born in poverty are often born to mothers who themselves are poorly nourished. The babies are often unwanted or born out of wedlock. They grow up in homes where there is frequently no father at all. If the mother is working, the child may be left alone all day, in a kind of solitary confinement to a crib.

It is not only the working mothers who are unavailable. There are those whose problems make them emotionally unavailable to their child, those so lethargic, depressed or just plain harrassed by life that they are incapable of providing the tender loving care which a child requires for healthy emotional and intellectual growth.

In such a home, the parent rarely reacts to the retardation of the child, even if intellectually able to recognize it. Such parents are usually so involved in their struggle to exist that they are unable to provide their children with any of the intellectual or cultural stimuli which are available to children of more affluent parents. Many simply cannot afford books, paints, records or toys. If they can afford a television set, it may become the child's intellectual parent.

When these children get to school, they are backward in language and in the ability to think abstractly. Too few teachers recognize this inability or are able to translate their classroom methods into a context which takes this into consideration. The borderline retardate, especially, becomes frustrated and if not helped, almost inevitably becomes a dropout.

Right now, the mentally retarded in such neighborhoods often receive less help from public and private agencies than do the retarded living elsewhere. Hospitals and health facilities are often located in other parts of the city. Day care centers and recreation programs for the retarded are generally in middle class : neighborhoods, while institutions for the retarded are even further away. Public transportation to such facilities is usually complicated and costs too much.

What is needed is to bring services to those people in the poverty areas. Services to the retarded must be integrated where possible into the total package of expanding health and social services which are being developed.

This means a massive re-education effort within the agencies and groups with whom the retarded and their families come into contact - the schools, the police, the public health services, the welfare department. Similarly, the welfare worker, encouraging a mother on relief to take a job, should know that there is a day care center in which she can place her retarded child while she is at work, so that the child does not suffer further from the lack of companionship and stimulus during , the mother's daily absence. In the area of preventive programs, there must be increased parent and child health services, family planning and counseling. It is now recognized that much of a child's intellect is developed between the 6th and 30th months of life, so programs comparable to Head Start need to be created for the very young, perhaps at day care centers or on a pre-school basis in neighborhood community center or library. Such programs are needed to fill in the gaps of intellectual and cultural stimulation which exist in so many low-income homes.

Schools in poverty areas usually have fewer special education facilities and the least-trained and least-experienced teachers. Both the over-all instructional level and the specialized training programs need improvement to reverse the drag downward for many children from retardation-fostering homes and to help those already blunted to make the most of their abilities.

The National Association for Retarded Children, the National Urban League and the Family Service Association of America are about to join forces to help achieve these goals by working together on a community level in several cities to pinpoint needs and provide the services – or see that they are provided. There is a demonstration program. All communities having ghetto areas should be doing something similar. A broad spectrum of voluntary groups and private and public agencies working together is needed. Groups such as yours have done a great deal to promote the services that now exist. Now, you need to help in the effort to broaden the services to provide an intensive preventive or reversal effort in poverty areas.

We will need to work closely with the community action groups, through which the poor are learning to communicate their needs and achieve some of the progress they hope for. Participation of the poor is essential, for they speak the same language, have shared the same frustrations, and can do more to spread the word that services are available than can traditional health and welfare agencies. They can enlist support, in terms of manpower and bring pressure for expansion of services.

Too many people in the health and welfare field think that by raising some money or getting an appropriation, opening the doors of a facility and announcing its presence in the press and on the air, they will bring service to the people who need it. They are frustrated when the people fail to flock to the new facility. They forget that they are dealing with families whose life experience has led them to expect that help really will not be given, even when it is publicly promised, or who are so frustrated by red tape and waiting lists that they have given up.

For example, in the South Bronx, a private agency established a group residence for eight retarded teenagers so they could live in the community while being retrained and beginning to work for a living. By dint of great persuasion, the agency was able to get a local Y to accept the boys in its swimming and recreation program. The next week brought more of the retarded into a needed recreation program which already existed, but also brought them out of the darkness into the light where the agencies with special services for them could make contact and begin helping them.

One key to providing service for the retarded in poverty areas is to establish facilities within the area and to utilize existing facilities – schools, Y's, libraries, and other available buildings – where they are visible to the people of the area. The grapevine will go to work and will help bring in families who need help. A community-based recreation program in an old hotel in Hartford, Connecticut, brought out a retarded woman who had been hidden away for thirty-two years of her life.

Another key is the utilization of personnel within the area for as many para-professional jobs as possible in the facilities. There are not enough specialists such as teachers, physicians, therapists, social workers and nurses to staff the needed programs for the retarded. Trained supportive workers can take on much of the work now being done by professionals. High school graduates and junior college students can be effectively utilized.

The parents of retarded children should be involved in the services insofar as possible. This can lead to strengthening the family, making the home more livable for the retarded individual and can be a means of lifting the level of the entire family. In a project I developed, a home economist joined the social worker who met with a parents' group in a retarded children's program. She helped them learn more about household activities such as sewing, decoration, and cleaning while, at the same time, they were learning together how to help their retarded children.

Right now there is a tremendous waste of people among the millions of retarded Americans for whom there are no educational or vocational training facilities. This is especially true in our poverty areas, where most of them live and too many of them will grow up without hope of a decent future.

By focusing our efforts on these people, we can achieve a great human triumph. It will take a lot of effort to sell public and private agencies on expanding their efforts, to garner public support for such expansion, and actually to provide the help. If it means, however, that the malignant, intellect-stunting results of poverty can be reversed and, perhaps, eliminated, it will be a magnificent achievement.