

# TOWARD ACCELERATED PROGRESS IN COMBATING MENTAL RETARDATION<sup>1, 2</sup>

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*Great strides have been made in dealing with mental retardation over the past 25 years. This article, based on an oral presentation by Dr. Tarjan, outlines the situation existing in the United States around the end of the Second World War and the changes that have occurred since that time. It then analyzes the current state of the fight against mental retardation and makes a list of general recommendations that the authors believe suitable for presentation to government leaders.*

## Introduction

During the past quarter-century I have had the privilege of caring for retarded children and adults as a physician and as a child psychiatrist; of being responsible for large programs; of teaching professionals, semiprofessionals, parents, and others about retardation; of participating in research, from the viewpoints of a number of disciplines; of learning about the retarded and their families; and, probably most importantly, of advising a host of planning

groups at the local, state, national, and international levels.

The reflections about the United States of America presented here will focus on the forces which, in my judgment, contributed to the unusually rapid progress made during the last decade. Obviously, the choice of events will be influenced by my personal biases. I started work in mental retardation shortly after the end of the Second World War. It is not surprising therefore that the place where I first became intimately acquainted with its problems was in a large residential institution, Pacific State Hospital (or Pacific Colony, as it was known at that time) in Pomona, California. In those days few retarded individuals received any special care while at home, and the traditional resource for "out-of-home" care was the large institution. Most such institutions were supported and managed by the individual states, as the Federal Government had set aside no special funds for this purpose. These state programs were highly independent of the Federal Government and of one another; the levels of care they provided varied greatly and generally ranged from poor to worse.

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## Problems with Institutional Care

During World War II the energies of the

United States were primarily directed toward the war effort. No new facilities for the retarded were planned or constructed. The end of the war found the existing institutions understaffed, underbudgeted, overcrowded, and in disrepair. In spite of the poor quality of institutional programs, however, there were long waiting lists for admission, their length governed only by the futility of waiting beyond a reasonable time.

Most retarded individuals were not institutionalized out of real necessity nor with a specific therapeutic goal in mind, but simply because no other alternatives were available, because institutionalization was convenient for the community, or because it coincided with parental desires. Two types of retarded people were obvious casualties of this system. The first was young children with severe retardation and superimposed physical handicaps. Institutional medical and nursing programs were inadequate and insufficient for them. Most institutions simply excluded them from admission, and when they were admitted they were apt to die early.

The second group was composed of mildly retarded adolescents who, in general, came from underprivileged social classes. They often entered as a consequence of some minor delinquency, or for purely educational reasons (since most communities offered no special schooling). For them the institutions' educational resources were inadequate, and they frequently spent much of their time caring for those who were more severely retarded than themselves.

Neither the overall goals of the institutions nor those of their program components were clearly defined, and attempts at program evaluation were practically nonexistent. Not even basic demographic or epidemiologic information was available, either on newly admitted patients or those in residence. The patients' development, their adjustment or lack of it, went unmonitored. No estimates were on hand for gauging the probability of such critical events as death or release from the institution. Discharges were few and turnover rates were low.

After the war the addition of new beds was thought to be the answer to all problems. Most states embarked on a program of institutional construction; and, since it was more economical to add beds to existing places, the enlargement of existing institutions was the primary result. Though quite a number of new facilities were started, even these followed traditional guidelines.

Community programs were generally unavailable. Public school education for the retarded existed only in a few communities, and then only at the discretion of the local boards. Alternatives for institutional care were unexplored. In spite of the well-recognized discouraging state of affairs in the traditional residential settings, the new beds did not cause the waiting lists to shrink. If anything they grew longer, because parents could at least hope for an earlier admission date. The key issue remained unanswered. As long as the retarded were housed out of sight and out of mind, they were also kept out of the social conscience.

These were the circumstances when I joined the staff of Pacific. Hundreds of children were kept idle, many in restraints, and very few received any intensive care. I can still recall my excitement as I searched for alternatives to institutional care—at least for those young adults who probably should never have been admitted to Pacific, but who had already spent many years there. In fact, my first major research project involved that problem. This generally grim picture carries with it a lesson against the notion that institutionalization can be a national solution for mental retardation.

### Development of Reform Programs

In the early 1950's general dissatisfaction with the level of institutional care began to mount among the parents of the retarded as well as among professional workers. Local parent organizations were spreading fast, and soon the National Association for Retarded Children came into being. I must add, with regret, that this movement did encounter the

occasional opposition of some of my colleagues who believed that parents were unable to participate effectively in planning programs for their own children.

Several of the early parent groups were rather militant. They began to search for facts, inquire about problems, seek alternatives to institutionalization, develop recommendations, and pressure for local as well as national improvements. They demanded both qualitative and quantitative progress. Their mission included both public education and forceful lobbying at the federal and state levels.

Soon many congressmen and state legislators joined their ranks. They in turn initiated public hearings and systematic inquiries. They wanted to know what had been accomplished, what was planned, and what was needed. Fortunately, they were willing to appropriate the funds necessary for innovative programs. Most professional leaders, both governmental and non-governmental, responded enthusiastically. With the aid of federal funds several significant early projects were started, such as a review of the status of research and the identification of promising leads; revitalization of the American Association on Mental Deficiency, the only interdisciplinary professional association devoted entirely to work in mental retardation; initiation of a research program systematically exploring the process of institutionalization; development of professional training in several relevant disciplines; and the establishment of a network of model diagnostic clinics.

By then the 1960's were approaching, and a number of far-reaching changes were about to occur. One of the first was spearheaded by the Joseph P. Kennedy, Jr., Foundation, which began concentrating its attention on research in mental retardation, and which established several university-based research centers. The Foundation's international awards program also brought timely recognition and respectability to the research field. Another event, and one with much more far-reaching consequences, was President Kennedy's appointment of a Special Panel on Mental Retardation in the early 1960's. The 27 members of this panel included

two Nobel laureates, several highly respected scientists within and outside the field of retardation, and equally competent clinicians and administrators. I had the privilege of serving as vice-chairman under the chairmanship of Dr. Leonard W. Mayo.

A number of arrangements were made to assure an immediate, direct, and constant flow of information between the President and the panel, which was assigned the task of evolving a basic plan for national action against mental retardation. The high degree of enthusiasm among the participants and the feverish pitch of their work is best reflected by the fact that the panel submitted its report in less than one year, on 16 October 1962.

That year was filled with excitement, success, and quite a few problems. Within the panel were represented various, at times even opposing, viewpoints. Some of these involved priorities and value judgments. An example of the former was the relative urgency of a major research effort as compared with service to the retarded, while opinions as to the likelihood of major contributions by biomedical research as compared to behavioral research was one example of the latter. It is to the credit of all panel members that critical decisions were arrived at quickly. It was agreed, for instance, that enough knowledge was at hand to outline an action program; that the panel could rely on the collective knowledge of its members and consultants; and that lengthy studies would only cause delays, unjustified by the probable results. Several task forces were established. All disagreements were debated and resolved, and a unanimous report including approximately 100 recommendations was submitted. The *Proposed Program for National Action to Combat Mental Retardation* became a blueprint for national action, and has remained the basic guide for progress in the United States ever since. It has also served as a model for several other countries.

Soon after the panel completed its work, the President appointed a Special Assistant for Mental Retardation, who was assigned the task of working with a select group of advisers and

monitoring implementation of the panel's recommendations. This arrangement continued until 1966, when the President appointed a Committee on Mental Retardation which assured uninterrupted high visibility for the fight against retardation at the White House level. The committee is still active as a review and advisory body.

President Kennedy's historic message to Congress in February 1963 on mental illness and retardation represented a milestone for implementation of the panel's recommendations. The resulting laws provided for construction of university-based Research Centers on Mental Retardation and Related Aspects of Human Development; for construction of University-Affiliated Facilities for the Retarded aimed at developing model clinical programs and at educating professionals; for construction of Community Facilities for the Mentally Retarded; for training teachers of retarded and other handicapped children; for expansion of services for maternal and child health, with emphasis on care of the retarded; and for planning comprehensive services for the retarded in each state. Institutional programs were strengthened through demonstration projects and inservice training. Probably the only major recommendation of the President's panel which was not implemented proposed establishment of a National Institute of Learning for the interdisciplinary study of basic learning processes by biological, behavioral, and pedagogical scientists.

A number of other developments, not directly focusing on retardation, also benefited the field. Creation of the National Institute of Child Health and Human Development, Head Start, and the Foster Grandparents Program are good examples. Professional associations as well as individuals, who in the past showed little or no interest in the field, soon joined the ranks of the involved. Unquestionably, some acted more out of opportunism than out of scholarly or compassionate interest, but on the whole all became members of the armada fighting for the benefit of the retarded. Parents' groups were joined by a number of citizens' organizations,

adding to the national voice, demanding a place under the sun for each retarded person.

### The Present Situation

Turning to the current scene, it should be stressed that mental retardation is a complex phenomenon which transcends any single human service system; therefore, adequate care must depend on several such systems—including those related to education, welfare, health, and employment. In the United States these systems function along independent lines, with some lodged primarily in the public domain and others in the private realm. Changes are on the horizon, but at the present time the need for coordination and collaboration, particularly in planning, is self-evident. The individual states in my country still differ greatly from one another—with most, if not all, strongly agreeing on only one relevant principle, namely that they wish to remain as autonomous as possible. It is therefore likely that any nationwide model evolved in the near future will have to be implemented with careful attention to local priorities and customs. Differences in program quantity and quality will continue. Such variability, though troublesome at times, also assures dynamic vitality and opportunities for comparison and experimentation.

The institutional programs in the United States are still far from ideal, but they are steadily improving. It is now possible to view them with greater calm and objectivity, and to readily acknowledge their many historical contributions. They have continued to serve as the backstops when community resources have failed. In many respects, they have served as the models for most of the newer clinical techniques. They have also been the first laboratories in both basic and clinical research, their patient populations having contributed immensely to studies ranging from epidemiology to genetics. And, last but not least, they have provided the training-grounds for most of today's workers, professionals, and leaders in the mental retardation field.

There is an accelerating trend toward emphasis on community-based programs. The traditional as well as the newer and smaller residential facilities are increasingly seen not as self-contained bastions of care, but as components of a more comprehensive system. This trend is clearly reflected by the fact that in 1968, for the first time, the number of persons residing in public institutions declined. I consider this development a major landmark in the history of the fight against retardation in the United States.

During the 1960's the prevailing idea was that if the retarded were to be given adequate care, such care had to be delivered through special programs designed and operated specifically for them. Currently, there is a trend toward incorporating the care of the retarded into more general programs. Sometimes the broad categories of these programs include people with any type of mental disorder, sometimes children in general, occasionally all people in a geographic area, and most recently the whole population defined as suffering from "developmental disabilities."

Public school education of retarded children in their local communities is now quite common. Though the program does not reach all educable or trainable mentally retarded students, most communities have classes for the majority of them. Sheltered work settings and opportunities for competitive employment are also on the rise. A good example of the latter is the program developed by the federal civil service system. A few years ago it set aside a number of jobs for the retarded and eliminated the requirement of written examinations so that applicants could be tested in a practical way. The results have been gratifying, with adequate work performance and low rates of turnover and absenteeism proving the program economically sound.

The present scene can probably best be described by emphasizing its highly transitional and changing nature. The retarded are cared for in a variety of settings ranging from their own homes to residential institutions. Involvement of the private sector is increasing, and in most



**Thirty years of experience have helped us realize that mental retardation must be taken out of the shadows, and that our goal should be a legitimate place in society for each retarded person.**

situations at least some special services are available. On the other hand, the stable nature of the old systems has not yet been replaced by similar stability in the new ones. Some programs—such as those involving foster care, day-care and developmental centers, and the rather small residential units—have not existed long enough to be systematically evaluated. As a consequence, there is a growing concern over the quality of care given in the mushrooming community programs, some of which operate with profit as a motive.

Almost all of the traditional approaches, including public school education and residential care, are under constant scrutiny. In state after state where services were believed to be qualitatively or quantitatively inadequate, class action suits have been filed in court to assure the rights of the retarded.

### Potential Problems

Though these advances are very encouraging, there are a number of concerns which merit attention.

One of these involves our lack of systematic data about the retarded as they disperse from a few settings to many. We have just about reached the point where a capacity to monitor the retarded in public institutions and to evolve systematic information has been developed. But the proportion residing in institutions is declining. We know little about those who leave or those who do not even enter; and we have practically no information concerning their adjustments and way of life in the communities.

A second concern involves our shift from specialized services to more general ones. This is a desirable trend, but it requires clear delineation of the roles of the general systems to be used and assurances that the retarded will not be shortchanged and forgotten when called upon to compete with others for services. Furthermore, an adequate supply of diversified manpower services is absolutely vital for success.

I am also concerned about two particular groups of patients. One of these, the moderately to profoundly retarded adults, are often forgotten, probably because it is easier to arouse community concern for severely handicapped children than for adults. As the focus shifts from institutional to community settings, these severely impaired adults are most likely to be left out when priorities are considered.

The other group is composed of our so-called "socioculturally" retarded. Many searching and justified questions are being raised about them. Should they continue to be included among the mentally retarded or should they be viewed as a basically different group? In my judgment, they resemble normal or average individuals much more than persons with organic or more severe impairments. Is the use of traditional intelligence tests justified in their case? Should their educational management continue to involve special classrooms? Ultimate solutions to their problems will come not from special programs for the retarded but from advances in social, economic, educational, and health activities for the impoverished. These advances are rather slow, but major

changes will undoubtedly occur; I can only hope that the people involved, i.e. the socio-culturally retarded, will not be lost during the transition from old to new approaches.

After many years of strong U.S. emphasis on research, it is customary today to assume that for the time being we have acquired enough new knowledge. Many say that what is needed is to make this knowledge available on a broad scale. I do not disagree that enormous benefits would result, but I do not agree that the time has come to shift our emphasis toward service at the expense of research. I believe that there are still too many unanswered questions. Though I advocate the expansion of service programs, I strongly favor our continued quest for new knowledge.

Finally, there is a concern that is less directly related to retardation. Our people are increasingly preoccupied with the problem of rapid population growth, and the rate of this growth is beginning to slow. At the same time, infant mortality is declining. Whether this decline will or will not result in the survival of an increasing number of damaged newborns, I expect that the quality of human reproduction will receive increasingly acute attention. Issues involving genetics, eugenics, prenatal diagnosis, abortion, biological engineering, concepts about the value of human life, and a host of other philosophical beliefs and ethical tenets will come to center stage. I can only hope that during this process the retarded will not again become the easy targets of hasty actions, as has often been the case in the past.

### Recommendations

I would now like to make a number of recommendations which are considered suitable for presentation to the leaders of any country concerning development of programs for the retarded. Though several of these are derived from my experiences in the United States, some have not yet been implemented even there. It should also be stressed that although progress in the United States has been enormous over the past 25 years, similar or even greater advances

have occurred elsewhere. In some respects other countries are in the lead, and we can learn as much from them as they can from us.

For the sake of brevity, the recommendations are listed here as 15 points; these are as follows:

1) Progress, particularly in the prevention of retardation, is highly dependent on advances in a host of general programs not directly related to mental retardation. For example, adequate general health care for children, adolescent girls, and pregnant women; improvement of early childhood education and general education; remedies for poverty through economic progress; and a national scheme of population planning can cut the incidence of mental retardation as readily as can any program devoted especially to caring for the retarded.

2) National and regional planning on a continuous basis should be given high priority. I would urge the appointment of commissions, panels, or committees charged with intermittent assessment of the current state of affairs and delineation of visionary yet practical action plans to combat mental retardation. It is recommended that these planning bodies be established on a long-term or permanent basis, with rotating memberships, and that arrangements be made for consultants, adequate staffs and budgets, and clear and easy access to the highest political officers and legislators in the land.

3) It is suggested that these planning bodies spend only a relatively small portion of their energies on pursuing their own studies, and that they spend most of their time gathering information from other agencies, engaging in hard thinking, crystallizing recommendations, and monitoring major programs. At each step they should take into account the political structure of their nation, and should avoid assuming that any plan conceived in a capital city can be imposed equally effectively and at the same speed in the various component states, or that a plan for metropolitan centers will do well in rural areas.

4) Before any national program is implemented, a series of demonstrations should be

carried out to test the efficacy of its underlying concepts in a variety of social and geographic settings.

5) Mental retardation is a complex phenomenon, so any national program must involve several human service systems. That is, retardation transcends the fields of medicine, education, employment, social welfare, or even all of these combined. No one of these alone can solve the problems of retardation. Therefore, from the start broad professional planning must involve all social service systems in full collaboration with parents and political decision-makers.

6) I would also caution against the notion that similarities between cases of "clinical" and "sociocultural" retardation are sufficient to justify lumping these two groups under one label and adopting one set of programs. In my judgment the differences between them are substantial enough to preclude across-the-board generalizations with respect to treatment concepts, diagnosis, prognosis, or management of the two groups.

7) Where there are no large residential institutions, none should be built. The mentally retarded should not be segregated. They belong in their communities, and their large-scale sequestration only removes them from the mainstream of human activities and the social conscience. Community-based programs hold the promise of the future because they are more humane and more economical than those of the large institutions.

8) Dispersed programs, however, require stronger emphasis on coordination, on rigidly enforced standards, and on continuous quality control. These goals cannot be accomplished without systematic evaluation of large as well as small programs, and such assessments are impossible without an adequate follow-up system. Current epidemiologic and computer science knowledge is adequate to maintain data on individuals and the population as a whole while thoroughly assuring privacy and confidentiality.

9) The mentally retarded should always be viewed first as human beings and only secondarily as individuals impaired by handicaps. As

far as possible their lives should approximate those of other people, and their care, whenever practical, should be provided via general human service channels. Even many of their highly specialized needs can be satisfied in this way.

10) On the other hand, as greater emphasis is placed on general resources, the need for an advocacy system becomes clearer. The retarded often prove to be poor competitors in the general marketplace and are apt to be excluded. At the national level the presidential commission can well serve as the advocate, but parallel bodies serving similar functions are also needed at other levels of government.

11) In the area of education, particularly for the mildly retarded, I would recommend development of a system that relies more on supplemental and enriched education than on establishment of segregated classrooms. Such an approach minimizes the tragic consequences of long-term labeling and assures that retarded students can return to the mainstream of educational activities at the earliest possible time.

12) In employment, I would suggest programs which assist the retarded person during his transition between school and job, and I would encourage public as well as private enterprise to employ him by offering special incentives. For those who cannot be absorbed by the competitive labor market, it is recommended that sheltered but productive work opportunity settings be established.

13) It is urged that as many retardation programs as possible be linked to institutions of higher learning such as medical schools, schools of education, schools of social welfare, etc. Only in this fashion will a possible solution to the manpower problem be found. This approach could produce the necessary number of mental retardation specialists and, even more important, could result in the exposure of virtually all human service professionals to the problems of retardation. This latter development would represent a vital step toward including the retarded in the general systems that provide care.

14) Each university-based unit should also serve as an experimental station in which new care and treatment modalities can be tried and assessed, and new professional and semiprofessional disciplines can be developed.

15) Finally, and most important, it should be emphasized that knowledge is an international blessing, ignorance an international tragedy, and research an international obligation. I would strongly urge every nation, whether economically advanced or disadvantaged, to allocate a portion of its resources to the acquisition of new knowledge. I would also urge that research centers dealing with retardation be set up, located in universities, and if possible tied in with programs of higher education in mental retardation.

### SUMMARY

The United States has made substantial progress in dealing with mental retardation over the past quarter-century. At the start of this period few retarded persons received any special care at home, and the traditional source of outside care was the large institution—which usually lacked sufficient funds, staff, facilities, and upkeep to provide for those inside its walls.

In the two decades following World War II, growing pressure for reform resulted in a number of significant achievements. Among these were review of the status of existing research, revitalization of the American Association on Mental Deficiency, and initiation of a research program that systematically explored the institutionalization process.



The climax to this movement came during the early 1960's following creation of the President's Panel on Mental Retardation. This panel's report, submitted in 1962, became a blueprint for national action that has served as the basic U.S. guide in this field ever since.

Virtually all of the panel's major recommendations were eventually implemented. Among the actions called for were construction of university-based research centers and university-affiliated facilities for the retarded, creation of community facilities, planning of comprehensive state services for the retarded, and expansion of maternal and child health services involved in dealing with retardation.

Today there is an accelerating trend toward community-based programs, and toward using more general programs to provide part of the care for retarded persons. Public school education of the retarded is now quite common, and opportunities for competitive employment are on the rise.

The present period, however, is clearly one of transition. The relatively new community-based systems cannot yet offer the stability of the old institutions, nor has sufficient experience accumulated for their systematic evaluation. As a result there is growing concern about the quality of care provided by them, while at the same time almost all the traditional programs are under constant public scrutiny.

During this transitional phase certain problems appear to deserve particular attention. Departure of retarded patients from institutions is apt to increase the difficulty of gathering adequate data. It is essential that the retarded not be forgotten in the shift away from special services exclusively devoted to them. Important questions remain regarding care for the so-called "socioculturally" retarded. And finally, continued emphasis needs to be placed on research, which should not be neglected in the drive to expand services currently being provided to those in need.

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