Professional and Governmental Roles in Mental Retardation

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In the Security Council building of the United Nations hangs a large handwoven cloth, a gift from the people of Ghana. It is made of silk and took 10 weavers over three months to complete.

In Ghana such cloths are worn toga-fashion for ceremonial occasions. Each is woven with a different pattern and theme.

The theme of the cloth at the United Nations is "One Head Cannot Go Into Council," in memory of an Ashantic queen of the 18th century for her practice of seeking counsel before making decisions.

As a result of the dramatic growth of interest in mental retardation, there is now underway a re-examination of professional and governmental roles, and of ways to seek counsel and to secure the most effective collaboration of effort.

There has been a growing awareness for more than a decade that mental retardation is a problem calling for interagency and interprofessional collaboration of a high order. This awareness stems, in no small measure, from the ferment initiated by the Report of the President's Panel on Mental Retardation. *

**A Proposed Program for National Action to Combat Mental Retardation,* October 1962. Superintendent of Documents, Washington 25, D.C.

THE PRESIDENT'S PANEL STRESSES NEED FOR INTERDISCIPLINARY AND INTERAGENCY ACTION

Running through the Panel's entire Report, implicitly and explicitly, is the theme that mental retardation is a complex health, educational, social, and economic problem requiring multidisciplinary efforts in research and services and interagency coordination among programs of education, health, residential and day care, recreation, rehabilitation, employment, income maintenance, and protective services. One section of the report is devoted specifically to the "Organization of Services—Planning and Coordination."

The emphasis in the Panel's Report on interrelationships is illustrated in the presentation of the need for a "continuum of care," a phrase used to describe:

> ". . . the selection, blending and use, in proper sequence and relationship, of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his lifespan. Thus "care" is used in its broadest sense and the word 'continuum' underscores the many transitions and liaisons, within and among various services and professions, by which the community attempts to secure for the retarded the kind and variety of help and accommodation he requires."

In the section of the Report on the Organization of Services are two extremely important recommendations on the subject of State governmental roles and responsibilities, as follows:

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

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

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

In support of these recommendations, the President's Panel states that "planning should be directed to the development of a balanced arrangement of local, area, and State services." "The Governors of the respective States are urged to note," says the Report, "that there are functions and services which should properly be the concern of every State government, but to which adequate attention is not now being given. In most States, at least 3, and perhaps as many as 5 major divisions of State government have, or should have, a responsibility for some significant segment of the program for the mentally retarded."

MANY PROFESSIONS MUST CONTRIBUTE TO THE ATTACK ON MENTAL RETARDATION

To lend concreteness to these pleas for recognition of interdisciplinary and interagency responsibilities it will be helpful to review some of the specific programs and professions involved.

Prevention is one of the most important words in the vocabulary of mental retardation. To promote the goal of prevention requires the mobilization of those who are concerned with public health and with the biological and medical aspects of the quality of human reproduction. Here we turn to the obstetrician, gynecologist, and the other health

professions whose concern is with healthy mothers, fetuses, and babies. Their goals are to reduce those conditions in the reproductive process that give rise to abnormalities in the child. The post-natal causes of damage to the nervous system provide a still different arena of action for the pediatrician and neurologist. Also dedicated to the biological aspects are the laboratory scientists who are seeking to penetrate such mysteries as cell replication, metabolism, and the mechanisms of labor.

The cultural aspects of prevention impose demands upon another cluster of professions—the sociologist, anthropologist, social psychologist, economist, social worker, welfare administrator, and those leaders of government, business, and civic endeavor who are concerned with the blight that poverty and deprivation often bestows upon the developing mind and personality.

A second important word in the vocabulary of mental retardation is *amelioration,* by which we mean the greatest possible reduction, through proper diagnosis, therapy, and training, of the adverse effects of retardation. Amelioration is the responsibility of several clusters of talent and of programs of public and private agencies. In the medical area these needs make demands on the general practitioner, pediatrician, psychiatrist, neurologist, speech pathologist, physiatrist, otologist, oculist, and others who help the retarded person to function as well as possible. Diagnostic teams require as well the services of the clinical psychologist, social worker, and public health nurse.

Realization of the potential of mentally retarded persons requires, during the years of development, the support of specialists in education, vocational rehabilitation, and job placement. For those needing residential care it is important to draw, in addition, upon the dedication and abilities of institutional administrators, nurses, and attendants.

The fight to combat mental retardation involves still other needs and talents. A "continuum of care," to which I have previously referred, includes the services of those who will safeguard the legal rights of the retarded, tend to their religious nurture, plan recreational programs, and promote public understanding.

This enumeration of professional and agency roles in mental retardation, though incomplete, is sufficient to explain why the President's Panel subscribed to the principle that the attack on mental retardation requires the cooperative efforts of many professions and agencies.

IMPEDIMENTS TO COOPERATIVE AND COORDINATED EFFORTS

To the National Association for Retarded Children the soundness of this principle is unassailable and the logic upon which it is based cannot seriously be questioned. Yet we are witnessing some difficulty in getting the concept translated into practice in the States and communities.

1. There is some distance yet to be travelled before a number of disciplines are fully aware of what is expected of them, and how best they can respond, in the fight to combat mental retardation. In spite of the great increase in the last few years in public awareness, professional understanding in several fields still has some catching-up to do if each is to make a maximum contribution to interdisciplinary cooperative endeavor. When the various professions themselves have a better definition and understanding of their own roles, joint endeavors can be promoted without some of the indecision that now prevails.

There are hopeful signs that professional and voluntary health, education, and welfare organizations are striving to meet this problem. The American Medical Association has held a conference to promote greater understanding on the part of medical practitioners. The College of Obstetricians and Gynecologists has established a Mental Retardation Committee. The Committee on the Handicapped Child of the American Academy of

Pediatrics and the Committee on Mental Retardation of the American Academy of Neurology appear to be making progress within their own constituencies. We also are informed that an understanding of mental retardation is being promoted by special efforts within welfare, social work, recreation, and educational organizations.

The National Association for Retarded Children is gratified at this growing interest of many organizations in mental retardation. To promote this interest and to facilitate the exchange of information, the National Association for Retarded Children recently convened the first Inter-Organization Conference on Mental Retardation.

2. Among the agencies of government there is similarly a need for a further appreciation of program responsibilities and of the ways in which particular departments of government are needed in the struggle to prevent and ameliorate mental retardation. In the past, needed program support has not always been forthcoming from some of the agencies of government. This is changing. Within the executive and legislative branches of the Federal Government there has been a gratifying increase in activity. In addition to expanded and improved programs in the Department of Health, Education, and Welfare, there is underway an examination of possible activities by the Department of Labor, of the needs of service families by the Department of Defense, and a fostering of Federal employment possibilities by the Civil Service Commission.

Within a number of States there are promising developments. In some, the Departments of Health appreciate as never before that their programs of maternal and child health, crippled children's services, school health, nutrition, radiological health, and public health nursing are resources of great importance in this cause. In some of the Departments of Mental Health greater visibility is being given to mental retardation, as well as greater program emphasis. Within the Departments of Education special education seems to be receiving greater support, and the new Vocational Education Act should give further impetus to meeting the needs of handicapped persons. Voca-

tional rehabilitation agencies also are giving greater attention to services for the mentally retarded.

This growing interest both of the professional community and of the government agencies is to be commended. But we should not leave this subject with any false impressions. Some of the vacuums that existed in a former day in departments of health, mental health, welfare, and education are being slowly filled; but others still persist. While nature is said to abhor a vacuum, the same cannot be said for gaps in services needed by mentally retarded persons. As we all know, there is a great difference between knowing what should be done and translating that knowledge into services.

3. The third impediment to the goal of coordinated action is the lack of experience within government generally with cooperative techniques. We should appreciate the fact that most functions of government—such as education—are performed by a single agency with little dialogue between it and other agencies. The goal of joint endeavor thus is a major challenge to program administrators, since coordinated action almost always carries with it some subordination of independence.

The experience of State governments in mobilizing all of the resources of its various departments on a single objective has been limited. This has been true even though some problems, such as juvenile delinquency, economic dependency, and mental illness require the mobilization of the resources of many agencies and challenge the leadership of the chief executive. While in some States the departments and the Governor's office are not structured in a manner conducive to unified action, the difficulty usually can be traced to inexperience in establishing the necessary administrative mechanisms and the interagency rivalry that so often accompanies the processes of government.

4. A fourth impediment arises from the fact that there is both professional and public uncertainty about the relationship between mental retardation and mental illness and of the place that mental retardation should occupy in a total mental

health program. A reappraisal of these relationships is now taking place as a consequence of the gradual acceptance of responsibilities by other agencies of government and the resulting need to reach new understandings and agreements. We are gradually beginning to hear the statement that "mental retardation is a mental health problem" placed in a broader context that makes it clear also that mental retardation is a *health* problem; that mental retardation is an *education* problem; that mental retardation is a *welfare* problem; and that mental retardation is a *vocational rehabilitation* and *employment* problem.

FEDERAL GRANTS TO PROMOTE COMPREHENSIVE STATE PLANNING IN MENTAL RETARDATION

The further development of this broader approach has become of particular importance in view of the legislation of 1963 providing Federal grants for comprehensive planning in mental retardation.

The law authorizes a one-time Federal grant of $2.2 million, of which each State that makes an acceptable application will receive a minimum of $30,000. In order to be eligible for a grant, a State must submit an application that (1) designates or establishes a single State agency, which may be an interdepartmental agency, as the sole agency for carrying out the purposes of the planning grant, and (2) indicates the manner in which provision will be made to assure full consideration of all aspects of services essential to planning for comprehensive State and community action to combat mental retardation, including services in the fields of education, employment, rehabilitation, welfare, health, and the law, and services provided

through community programs for and institutions for the mentally retarded.

The mental retardation planning grants were originally proposed to accomplish four objectives:

1. To provide, through Federal action, a means for encouraging all of the States to initiate systematic follow-up action on the Report of the President's Panel.

2. To secure highly visible involvement of the Governors, top officials, and outstanding laymen in the many policy implications in the Panel's proposals.

3. To enhance public awareness and understanding of the problem.

4. To foster the development and coordination of the mental retardation aspects of programs of education, rehabilitation, welfare, employment, health, and the law.

In late 1962, when these grants initially were being considered as a part of President Kennedy's mental retardation program, Congress already had appropriated funds for mental health planning. The question was raised immediately, of course, as to whether the mental retardation planning might not be a part of, or an add-on to, the mental health planning grants.

This question of the relationship of the mental health and mental retardation planning grants was given careful consideration by policy officials in the Department of Health, Education, and Welfare, the Bureau of the Budget, and the White House. The conclusion was that the objectives of the mental retardation planning grants could not be achieved as effectively within the framework of mental health planning as by a separate grant specifically on mental retardation. It was decided, however, that the mental health planning should cover facilities for and services to persons who are *both* mentally ill *and* mentally retarded. Accordingly, the National Institute of Mental Health has provided that the mental health planning grants will include the mental illness aspects of mental retardation.

DIFFERENCES BETWEEN MENTAL RETARDATION AND MENTAL ILLNESS

The wisdom of the decision to have separate planning for mental retardation, which was accepted by Congress and is now embodied in Federal law and regulation, is still being debated and in some places the debate appears to have delayed progress. To clarify the Federal position the U. S. Department of Health, Education, and Welfare has issued an official statement on the distinction between mental retardation and mental illness. This statement was used at congressional hearings and appears in the Department's document on *New Approaches to Mental Retardation and Mental Illness.* This statement is as follows:

> "It should be emphasized that mental retardation and mental illness are in most instances separate problems. There has been much misunderstanding on this point among the general public. Mental retardation is usually a condition resulting from developmental abnormalities that start prenatally and manifest themselves during the newborn or early childhood period. Mental illness, on the other hand, includes problems of personality and behavioral disorders especially involving the emotions; it usually manifests itself in young and older adults after a period of relatively normal development.
>
> "There is always a deficit in intellectual function in mental retardation; mental illness may or may not involve such a defect. If there is an involvement of intellectual function, it is usually not of the nature and degree found in mental retardation.
>
> "The two problems are related in that they may occur in the same patient and frequently involve some of the same kinds of professional skills to diagnose or assist the

> patient. On the other hand, each problem does occur independently of the other and adequate professional skill to deal with one problem does not assure competency to deal with the other. The ability to distinguish clearly between these problems in a given patient and to deal with each appropriately is often the crux of good care." (U.S. Department of Health, Education, and Welfare, Office of the Secretary, November, 1963)

In recognition of the foregoing considerations the National Association for Retarded Children has insisted that mental retardation planning be carried forward separate from mental health planning and on a truly interagency basis. The end-product of the planning operation should be a "blueprint for action" based on an analysis of needs, existing programs, and gaps. The final report should contain policy recommendations on health, education, employment, welfare, residential care, the law, public awareness, and the other subjects specified in the legislation.

Our view is that such a plan can best be developed by an interagency body whose authority stems from the Governor's leadership and which includes or is advised by key officials, qualified professionals, and informed citizens. The designation of an agency that is "interdepartmental in character" is specifically authorized in the law and is preferable to the designation, also legally proper, of one of the agencies of government, such as the Department of Mental Health, as the planning agency.

The rationale for our position is straightforward. Those with experience in the administration of public programs know that one agency does not take kindly to direction from another agency on the *same* level of responsibility. I know of no instance in which a public health department has had any great influence on the programs of an education department, or of a welfare department having had any great influence on a department of mental health. On the other hand, there are numerous examples of the successful exertion of influence on education, *and* health *and* welfare programs from a higher authority, such as the *President's* Panel on Mental Retardation; the

Secretary's Committee on Mental Retardation in the U. S. Department of Health, Education, and Welfare; the *Governor's* Study Commission on Mental Retardation; and a *Legislative* Committee on the Handicapped. With all due respect to the good intentions of a single agency it cannot exert any great policy direction or play a decisive role in obtaining policy changes or in securing the development of new programs *in other agencies.*

In addition to realistic administration, there is also a problem of the most efficient use of manpower. There is today a shortage of professional persons in many areas. The shortage reportedly is very serious in such fields as obstetrics, neurology, and psychiatry. In view of these shortages it is not in our view reasonable or proper to expect these specialists to divert precious time and talent in an effort to mobilize the interests and energies of those in all of the other major areas of government. We do not see the psychiatrist, for example, as necessarily being the primary agent to secure the support of the legal, or dental, or educational fraternities in performing their appropriate roles. It is proper, however, for top elected officials, other key governmental personnel, and leaders outside of government to organize and direct policy reviews and to foster the planning of new programs.

OTHER PROGRAMS ALSO WILL AFFECT AGENCY ROLES

Although the comprehensive planning activity will be extremely significant for the future, we must not forget that coincidentally other activities will be moving forward, including those authorized in the 1963 mental retardation legislation and the previously authorized programs for which additional funds have been provided by Congress.

Among the activities that will affect the course of State programming are:

1. The new Federal grant program to assist the States in constructing and equipping public and other non-profit facilities for the mentally retarded. In carrying out this program, each State must submit a plan that sets forth a program that is based on a statewide inventory of existing facilities, a survey of needs, and an assignment of priorities.

2. The construction of university-affiliated facilities that will provide, as nearly as practicable, a full range of inpatient and outpatient services for the mentally retarded and facilities that will aid in demonstrating specialized services for the diagnosis and treatment, education, training, or care of the mentally retarded or in the clinical training of physicians and other specialized personnel needed for research, diagnostic treatment, education, training, or care of the mentally retarded.

3. Enlarged programs under the maternal and child health and crippled children's programs.

4. Project grants to assist States and communities to provide care to prospective mothers who are unlikely, because of economic circumstances, to receive all necessary health care. This care would be available particularly to mothers who have or are likely to have conditions associated with childbearing which increase the hazards to the health of the mothers or their babies, including those which may cause physical or mental defects in the infants.

5. Project grants to mental retardation institutions, through the hospital improvement and in-service training programs, for the purpose of up-grading the quality of care.

6. Various other programs that will expand research, training, and rehabilitation.

THE FUTURE PATTERNS OF ORGANIZATION

From the planning process and the other Federal-State programs we can expect great forward steps in defining goals and in strengthening programs of prevention, services, and care. Naturally, there will be differences among the States as they chart future courses of action and make decisions for continuing administration. In general, however, we can expect:

1. *Expanded programs of prevention by public health departments* through the promotion of maternal and child health, and other such public health activities as accident prevention, radiological health, and nutrition.

2. *Strengthened programs of services by public health departments,* including services in the fields of case finding, screening for metabolic disorders, diagnosis and evaluation, maternal and child health, crippled children, public health nursing, school health, and the referral and treatment of mentally retarded persons with associated physical handicaps.

3. *Additional services by departments of mental health,* with special emphasis on emotional disturbances that may accompany and accentuate retardation. The problem of pseudo-retardation is one area needing attention. To mental health departments we also will look for tangible and identifiable activities in behalf of mentally retarded persons and their families who need counseling on and treatment for emotional problems.

4. *Impetus toward residential care facilities that are smaller, more accessible and oriented toward community resources and interests.* Regardless of the agencies assigned administrative responsibilities, more attention will need to be given to modernization of structures, outpatient services and

the effective use of volunteers and professionals from outside the institution.

5. *Further development of classes, curricula, and teachers for both educable and trainable children within the framework of the public schools.* To the school administrators we also will look for the development of suitable relationships to programs of vocational education, vocational rehabilitation, and adult education.

6. *Additional special efforts to expand employment opportunities together with suitable training and placement programs.* To secure work for more retarded persons will require the combined efforts of the State and local agencies charged with employment, welfare, rehabilitation, and education.

7. *Greater attention to the problem of cultural deprivation,* which is now recognized as a major cause of mental retardation. Those responsible for programs of public assistance, social welfare, family services, education and urban renewal will need to collaborate in providing the preschool classes, the day care, and other community services needed to break the social perpetuation of intellectual subnormality.

8. *Additional programs for adult retardates,* made necessary by the increasing longevity of retarded persons. For example, there is a need for living centers where employed adults can live and secure recreation and guidance on money and other matters that will make the difference between institutionalization—at much greater expense to the taxpayer—or substantial independence.

These eight results are not all that should come from the present upsurge of interest in mental retardation. We also can expect a review of pertinent civil and criminal law, of State and community relationships, and of organizational provisions within the various departments. This enumeration is sufficient, however, to demonstrate that out of the new impetus will come better governmental

programs and a greater awareness of the relationships among the elements of the total effort.

As the new enlarged programs become a reality there will, of course, be continuing assignments of operating responsibility to individual agencies. Important tasks will be carried forward by education, health, welfare, labor, legal and other departments as a part of their regular functions. We can hope, in addition, that, as a result of the comprehensive planning, these particular roles will be performed with greater understanding of total needs and on a higher level of service.

BUT COLLABORATION MUST NOT CEASE!

The assignment of on-going responsibilities, even on a much higher level of performance, must not mean, on the other hand, that cooperative efforts can cease or that lessons in collaboration can be forgotten. Rather, out of the process of working together in planning should emerge habits of consultation and cooperation, with no retreat to the insulation and isolation of the smaller worlds of bureaucracy.

There is no sure way to accomplish the execution of individual program responsibilities in the framework of a larger whole, but some type of *interagency coordinating committee* appears to be one necessary ingredient. Such a committee has been successfully employed in the U. S. Department of Health, Education, and Welfare. Coordinating committees also have been established in a number of States.

The interagency committee will be a useful coordinating device, however, only if key persons are represented on it and they provide the insights and authority that can come only from those who are truly influential in the various agencies. Not much will be accomplished if the meetings of a coordinat-

ing committee are attended only by persons with little influence on policy decisions.

A second mechanism that can have future importance is that of a continuing advisory committee to which are named professional persons and influential citizens who will serve as "watch dogs" of civic, professional, and consumer interests. An important function of such a committee can be to press for the translation of the proposals developed during the planning cycle into actuality. Again, such a committee will succeed or fail depending upon the vitality with which the group performs its role and the continuing community interest that it can generate.

With reliance upon these devices we can direct and preserve the momentum that is now so heartening to all who wish to improve the quality of human reproduction, to promote the greater utilization of our human resources, and to help every individual develop to the maximum of his ability.