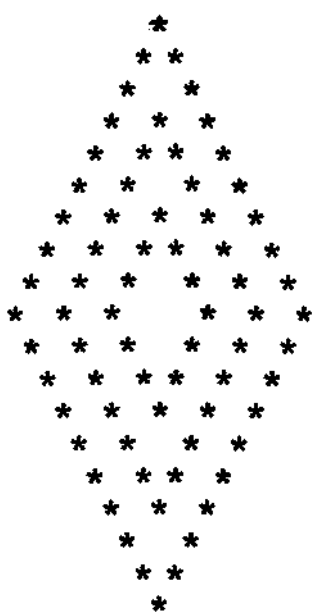
STATE PLANNING AND COORDINATION OF RESOURCES

FOR EXCEPTIONAL CHILDREN



STATE PLANNING AND COORDINATION OF RESOURCES FOR EXCEPTIONAL CHILDREN*

In talking about the topic you have given me I must say that I feel like I am bringing coals to Newcastle. Louisiana has shown vision and taken leadership in attacking some of the most complex problems of coordination of services to large numbers of handicapped children.

Much of what I shall say is drawn from experience within the Southern Regional Education Board where we find the problem of coordinating the resources of agencies and institutions constantly brought before us by legislators, administrators, and educators. Since last October, it has been my privilege to have been a member of the President's Panel on Mental Retardation, where as chairman of the Task Force on Coordination, I have been especially concerned with the coordination of resources and services for the mentally retarded. We canvassed the Nation for ideas and information about this problem of coordination. In several major efforts of national scope in which the focus was upon coordination, we called upon leaders in your State.

Before launching into a detailed discussion of our topic, I would like to lay down some assumptions about the goals of services for exceptional and handicapped children. The first is that a goal of service to the handicapped is continuity of care.

Continuity of Care

By continuity of care I mean that the individual in need of special services gets those services at a time and in a place appropriate to his needs. To use a medical paradigm, the goal is that the individual move from diagnosis and evaluation to treatment or training and then, into habilitation or rehabilitation as the case may be, without a significant gap occurring between any of these fundamental stages of care. Such continuity of care requires an array of services. You, who work in the field of handicapped children, know how numerous and how complex these services may have to be. Rarely is a handicap found in isolated form and frequently the handicapped individual must receive special assistance in areas other than the primary handicap. But to achieve the goal of continuity of care, an array of services alone will not suffice.

*Talk given by William P. Hurder, Ph.D., M.D., Associate Director for Mental Health Training and Research, Southern Regional Education Board, at the Annual Meeting of the Louisiana Council for Handicapped Children, October 11, 1962, Alexandria, Louisiana.

It is one of the real tragedies of our program efforts that we seem so often to be able to assemble an array of services, but so seldom are we able to so organize and so activate them that they constitute a continuum of care.

Continuum of Care

The second assumption is that continuity of care is dependent upon a continuum of care. By continuum of care, I mean that the elements that make up the array of services are so intimately related to one another, and so accessible to the handicapped person, that the patient is or client's needs are always in focus even though he may have to move from service to service or be the concern of more than one source of assistance.

Coordination

The third assumption is that coordination is a necessary condition for the existence of a continuum of care and the provision of continuity of care. Coordination is the process of bringing all necessary resources to bear in the appropriate sequence in order to accomplish a specific mission.

Before going on to a detailed discussion of coordination, I wish to emphasize something which is so obvious that it may be overlooked. The difficulties of coordination will vary with the number of resources needed, and with the extent of the sequence in which they must be assembled. For example, the mentally retarded present the greatest challenge to coordination both because as a group they require so many different kinds of specialized services and because on the average they will require this specialized help over a long segment of their life span.

Conditions for Coordination

In order to "bring all necessary resources to bear in the appropriate sequence in order to accomplish a specific mission," certain minimum conditions must be met. They are essential to the optimum utilization of our resources for direct service to the handicapped. These conditions, in order of their significance, are communication, cooperation, and authority.

Communication

It is an absolute essential that all participants in an enterprise as complex and diversified as we are discussing have, and use, means of communicating about their objectives and their activities. Such communication must be explicitly provided for—and it must be recognized that it takes energy and resource for its accomplishment. Just as physical systems require explicit provisions for communications, so do human systems of the type needed in the field of the handicapped.

Cooperation

When communication is effective, the groundwork for cooperation will have been laid. If cooperation is to be worthwhile, the "cooperants" must have needs and objectives in common and each must have some resource to contribute to the common effort. Adequate communication is the only means of assessing such common cause and shared potential.

It is often overlooked that the wish to cooperate is not a sufficient condition for joint or collective action. Individuals—even institutions, agencies, States, and Nations—must learn to cooperate. Principles and techniques must be wrought from experience and adapted through trial and error.

Finally, it needs emphasis that there is no magical conservation of energy inherent in cooperation. The gain in effective cooperation derives from the fact that the participants get more for their pooled energies than if each had spent his energy alone.

Authority

This is probably the most over-valued condition for coordination. It is true that coordination requires a measure of authority. This may be expressed or implied, clothed in logic—"the authority of ideas"—enforced by opinion or prestige, or made possible solely by the will to cooperate on a common endeavor. However, authority alone will not suffice as goad or guide for the coordination of complex human enterprises such as we are considering today. Authority must be coupled with and accompanied by realistic attention to the conditions of communication and cooperation.

In brief, coordination takes time and resources and those who would achieve it must possess special skills and understanding as well as whatever modicum of authority the situation requires.

Coordination: The Two Sides of the Coin

We have said that to prescribe for the individual, or to program for individuals in general, there must be an array of services. These services will be administered by, through, or within institutions which minister to the normal individual—the family, the professions, and the agencies, such as health, education, and welfare. We have said also that ideally, the elements of this array of services would be so intimately related to one another, and so readily accessible to the handicapped person, that they would function as a continuum of care. Such a continuum of care would permit fluidity of movement of the client from service to service, yet all the while maintaining a sharp focus on his needs as an individual. Unfortunately, this degree of coordination is a goal rarely achieved. But--and this is a major theme of this paper—if it is to be approximated, there must be explicit provisions for the integration and the coordination of services at each of two levels:

1. between the individual and the appropriate service, and
2. among the resources for service.

These are the two sides of the coin: one, coordination around a clinical objective; the other, coordination around an administrative objective. The first is sharply focused on the individual in need of specific service; the second is focused upon a class of individuals and their general needs. Failure to recognize and take account of these distinct but inseparable objectives may well be a source of failure in our efforts to provide for the handicapped.

Coordination Around the Clinical Objective

Integration and coordination with respect to the specific individual in need of a prescribed sequence of services may be said to have a clinical objective. For the child in our society, the law provides that his parents serve as the primary coordinators on his behalf; and education "for citizenship" includes, among other things, development of the capability to utilize the resources for education, health, safety, and the like on behalf of one's self and one's family. Most of us can usually, with respect to ordinary needs, negotiate a path to these resources with the informal assistance and advice of neighbors, relatives, etc., since such common

knowledge is widely diffused in the population. It is when the ordinary individual has extraordinary needs that self-coordination—self-guidance through the maze of less commonly understood, but nevertheless available services—may tax his capabilities. This is even more true when the individual himself has impaired ability for self-management.

Therefore, coordination of services to the handicapped individual begins with a capable parent or other adult willing, able, and obligated to concern himself about the coordination of services to meet the continuing and changing needs of the child. However, the most intelligent and dutiful parent or guardian cannot be expected to have, a priori, adequate knowledge of all of the extraordinary resources necessary to meet the clinical objective of integration and coordination of service to the handicapped. Furthermore, where the duration of handicap is lifelong—especially in those with more severe impairment of adaptive behavior—the natural parent or guardian may not be available for the child who survives to the expected "three score and ten,"

This leads to the suggestion that a first condition to meet the clinical objective of service to the individual is that there be in each community a "fixed point of referral and consultation" and, for the chronically handicapped, a "life counseling service," as the base from which service can be activated. An analogy can be drawn here to the field of medicine. We do not expect the most able of citizens, when ill, to choose for himself, on the basis of his symptoms, a specialist from such widely divergent fields as neurology, hematology, radiology, and surgery. Rather, we hold up the ideal of a general practitioner or a family physician who serves as a first line of guidance and defense in illness, a "fixed point of referral and consultation," and who may also provide a "life counseling service" with respect to one's health.

There is even greater need in some areas of handicap, and in mental retardation particularly, for the equivalent of a "general practitioner" who can both counsel and refer, thereby helping to keep the needs of the individual in adequate focus, and to maintain liaison between the individual and the numerous specialized services rendered by various professions and agencies. But such "general practitioners" can not work in a vacuum. They must have a local base for their operations and they must be backed up by the multiple services required to meet the needs of the handicapped. This brings us to a consideration of the second level—coordination around the administrative objective.

Coordination Around the Administrative Objective

Integration and coordination of the many resources for direct service may be said to have an administrative objective. The goal is to provide optimum administrative climate and mechanics for the coordination of the complex array of services needed for all handicapped—or, for the handicapped in general.

Pursuit of the administrative objective of coordinating resources for direct service must begin in the local community where we find individuals in need of such services. In other words, it is in the local community that we have the most intimate union of the clinical and administrative objectives of coordination. It is there, at the local level, that the analogy of the two sides of the coin is most applicable. Assuming that adequate provisions have been made to focus services upon specific individuals, it then becomes necessary to establish some means of planning, deploying, and evaluating the resources upon which the "general practitioner" or equivalent can draw in the interest of the individual handicapped person.

What are the nature of these resources? In our society whether at the local or national level we provide certain generic resources which are designed to meet the ordinary needs of all of our citizens. Whether they be publicly or privately sponsored and whether they be applied by an individual, as happens in the practice of medicine, or administered through agencies, they get at such society-wide needs as health, education, welfare, and justice. It needs emphasis that these broad categories of resources--generic resources—are provided to meet needs held in common by all citizens and that administrative mechanisms for their utilization have counterparts at the national, State, and local levels.

However, handicapped individuals, especially children, have extra ordinary needs. The resources for meeting these extraordinary needs must be drawn from the generic resources just described and, furthermore, they must be specially blended and coordinated in order to meet these extraordinary demands. It is this blending and this coordination with reference to both general and specific categories of the handicapped that I have called the administrative objective of coordination. Let us look at it first from the standpoint of action at the local leve

The Administrative Objective at the Local Level

At this local level there must be explicit provisions for planni deploying, and taking stock of resources needed to serve handicapped persons. From the standpoint of the administrative objective of

coordination, the term "local level" refers to the smallest or least divisible and most practicable unit of organization of generic resources from which special services to meet extraordinary needs can be drawn. This will vary with the geographic and the demographic characteristics of the area in question. An urban area might have one or more administrative bases for such activity while sparsely populated areas might require the pooled resources of several counties to achieve the same objective.

The administrative base may consist of a person, an office, or even an agency. However, responsibilities at this level of administrative concern are actually quite broad. They involve not only providing support for clinical or individual services to the handicapped within that area, but also, feeding information and conclusions to individuals and agencies who have administrative responsibility for services to the handicapped on a broader base, such as the State and the national level.

It should be abundantly clear that a most critical point in our efforts to provide services to the handicapped is at the point of union of the clinical and administrative objectives. This is at the local level. We will say more about this critical relationship later.

The Administrative Objective at State Level

It is a characteristic of our Nation that the organization and administration of our generic resources for direct service are accomplished largely at the State level of government. Thus, it is the State departments of health, mental health, and education to which we look for leadership and initiative in planning and evaluating resources and services and, to a lesser extent, for the deployment of these. It is at the State level that we reach the apex of our collective efforts to integrate and coordinate the resources from which we derive those special services required by the handicapped. Necessarily, the emphasis at the State level is upon the administrative objective and much less upon the clinical objective. The essence of the problem at the State level is how to parcel out, mobilize, and blend resources from such generic agencies as health, education, and welfare so that these can be funneled and focused to the local level where they become available for the pursuit of the clinical objective. There are several steps involved in this process.

A first step is the provision of special resources in generic agencies at the State level. For example, departments of health may provide a position, an office, or a division concerned with mental retardation or with orthopedic handicap. However done, the major purpose is the better utilization of the generic resource of the agency and, where necessary, to supplement these generic resources by special personnel and knowledge.

As you well know, it so often happens that the resources of a single agency are not sufficient to meet the extraordinary needs of the handicapped. Mentally ill children need education as well as psychotherapy. The mentally retarded may need specialized vocational and social training and supervision as well as special education. Accordingly, the second step in the mobilization of the State's resources for handicapped citizens is to provide for the channeling and focusing of resources which must be drawn from more than one agency. States attempt to do this by creating commissions, councils, or interdepartmental committees to serve all handicapped children, or children with specific handicaps such as mental retardation, emotional disorder, or physical handicap. The primary purpose of such administration devices is to provide a means of pooling and blending resources of multiple origin, so that they may ultimately be delivered to local communities. It is at this point—the deployment of State level resources to the local administrative level, and the retrieval of information needed for evaluation and further planning—that we can identify a second critical point in coordination. It is just as critical to success as is the point of union and merger of the administrative and clinical efforts on the local level.

The creation and maintenance of these special provisions, such as positions and offices within individual agencies, and such councils and committees across agencies, are administrative mirrors of unusual human needs. In fact, the whole system can be likened to a system of lenses and mirrors whose major reason for existence is to allow us to collect and focus resources for the ultimate purpose of delivering them to the local level where they must again be focused and blended with local resources for the benefit of the individual child.

Implications for Action

If the analysis of the problem of coordination of resources that has been presented in these remarks is accepted, then certain implications for action follow rather naturally. I would like to examine several of these. Although the topic assigned to me clearly indicates your concern with State level planning and action, I have found it necessary to go to the local level in order to present a complete analysis of my assigned topic. Similarly in these concluding remarks, I wish to consider implications at the local as well as the State level.

State Action

Clearly there needs to be at the State level of government explicit provisions to coordinate resources around the administrative objective of an appropriate supply and balance of services to meet the composite needs of handicapped children. These provisions are of the following nature:

1. A marshalling of resources for specific handicaps within these agencies which control and administer generic resources most relevant to the handicap of concern. For example, agencies such as health, mental health, institutions, education, and welfare should provide a position, office, division or other appropriate instrumentality to focus resources of the agency which are relevant to mental retardation.

2. From a super-agency position, such as the office of the governor, there needs to be created some means of fostering communication and setting the stage for cooperation among these agencies which administer generic resources with respect to their shared concern and responsibility for specific handicaps. This might take the form of inter-agency councils, commissions, or committees and would be comprised of members drawn from those instrumentalities referred to in 1 above. Thus, for example, a given State might have an interdepartmental committee concerned with emotional disorder; another with orthopedic handicap; and still another with mental retardation.

3. In addition to these coordinating mechanisms there is need for some sort of planning and evaluation body or office which draws membership and advice from all segments of the community which have a concern for the handicapped. Such a body would be representative of voluntary associations, parents groups, professional organizations, etc. If it is to be effective, it should have staff to serve it and funds to provide for data collection and analysis. If it takes the form of an office, it should be placed in the governmental hierarchy in such a way that the staff would report to the chief executive or the legislature or both and so the advisory body would have direct channels of communication with the appropriate authority. It seems to me to be especially important that this body draw its membership from outside of State government so that it would be able to discharge its responsibilities for planning and evaluation in an impartial manner.

Local Action

There is need at the local level for machinery for coordination around the administrative objective in much the same order as that described for the State level. The counterparts of agencies such as those described above exist at local levels although their pattern of organization, administration, and finance may vary considerably. However this may be, there is need at the local level to provide appropriate means of focusing resources relevant to specific areas of handicap and provide a means of facilitating communication and creating conditions for cooperation among these agencies with respect to their common concerns. There is just as much need for broad community participation in evaluation and planning locally as there is at the State level.

It is with respect to the achievement of the clinical objective of meeting the needs of specific individuals that coordination at the local level presents unique problems. Some needed actions at the local level are:

1. There should be provided a fixed point of counsel and referral for the individual and his family or guardian. This should take the form of a person or an office to which those in need can go for authoritative advice, or referral to more appropriate resources. It might be sponsored by local voluntary organizations, local health, welfare, or other governmental agencies. The major consideration is that such a "fixed point" be a source of authoritative information and that it have the resources of time and personnel necessary to meet this purpose.

2. Either as an integral part of the office described above, or in intimate association with it, there should be provided a life counseling service for those with chronic handicap. For example, such a life counseling service would be a local instrumentality for longitudinal coordination around the progressive life needs of the mentally retarded or perhaps of the severely orthopedically handicapped individual. In urban areas such a life counseling service would likely be available out of the office which served as the fixed point of referral and counsel. In rural areas it might be necessary to centralize this more specialized life counseling service and, consequently, to physically separate these two services. In such instances, the role of personnel in the most "local" office would be that of assisting the retarded and his family to make contact with the life counseling service. This life

counseling service would play something of the role of a broker and an expeditor in finding and making use of those resources which the local community and the State have to offer the handicapped.

It is in this office and through these personnel that the merger of the clinical and administrative objectives of coordination would take place. Both the office and the personnel would be strategically placed for the assessment of the needs of the handicapped and the effectiveness of coordination of available resources to meet these needs. The assignment of this office to specific agencies within local government would most likely vary from locale to locale. It would likely depend to a large extent upon the State agency with primary responsibility for the handicap in question. However, if it is intended that the services of this office are largely those of providing information and advice to those in need and serving as an agent for these clients in their search for services, then agency affiliation becomes of secondary importance.

State and Local Relationships

This is perhaps the most complex single aspect of the problem of coordination of the resources of a State. Obviously, the effectiveness of any State program for handicapped children will depend heavily upon effective State-local relationships. Success in meeting this problem begins with adequate communication between these two levels of government. It will depend also upon vigorous leadership, especially at the State level, and upon an enlightened leadership which takes cognizance of the necessity of a coordinated effort. Such leadership will take pains to establish the needed conditions for coordination, communication, and cooperation, and will assign responsibility and delegate authority as appropriate.

Throughout this paper, programming has been divided into three phases: planning, operations, and evaluation. State responsibilities and opportunities for leadership fall largely in the areas of planning and evaluation. Operations—the pursuit of the clinical objective-should in most instances be carried out in the local community with feedback of information from the local to the State level for use in planning and evaluation.

I would like to cite just one example of a way whereby State level concern for evaluation of the adequacy of coordination of services to the handicapped individual might be met. It should be possible to devise statistical procedures whereby services to individual handicapped children such as the mentally retarded could be evaluated through sampling procedures. To do this the appropriate State body or office would periodically select representative case files of individuals and examine them to see how well the clinical objective of coordination was being met in that area of handicap. The question asked of these data would be, "how near are we in our State to reaching the goal of continuity of care?" I feel certain that we have the know-how to establish such procedures.

I hope that if I have done nothing else in this talk I have made you acutely aware that the problem of coordination of resources for handicapped children is a very real one and one which is deserving of your attention—if this were not already so. I hope also to have gone at least one step beyond sensitizing you and to have suggested a useful way of looking at this problem. I believe that it will profit us if we only stop to analyze coordination according to the two objectives: the clinical and the administrative. Failure to make this differentiation may be a factor which creates dissension between clinicians and administrators, local and State level personnel those on the "firing line" and those in the "ivory towers"—and cause each to lose sight of the other's contribution to a common cause.