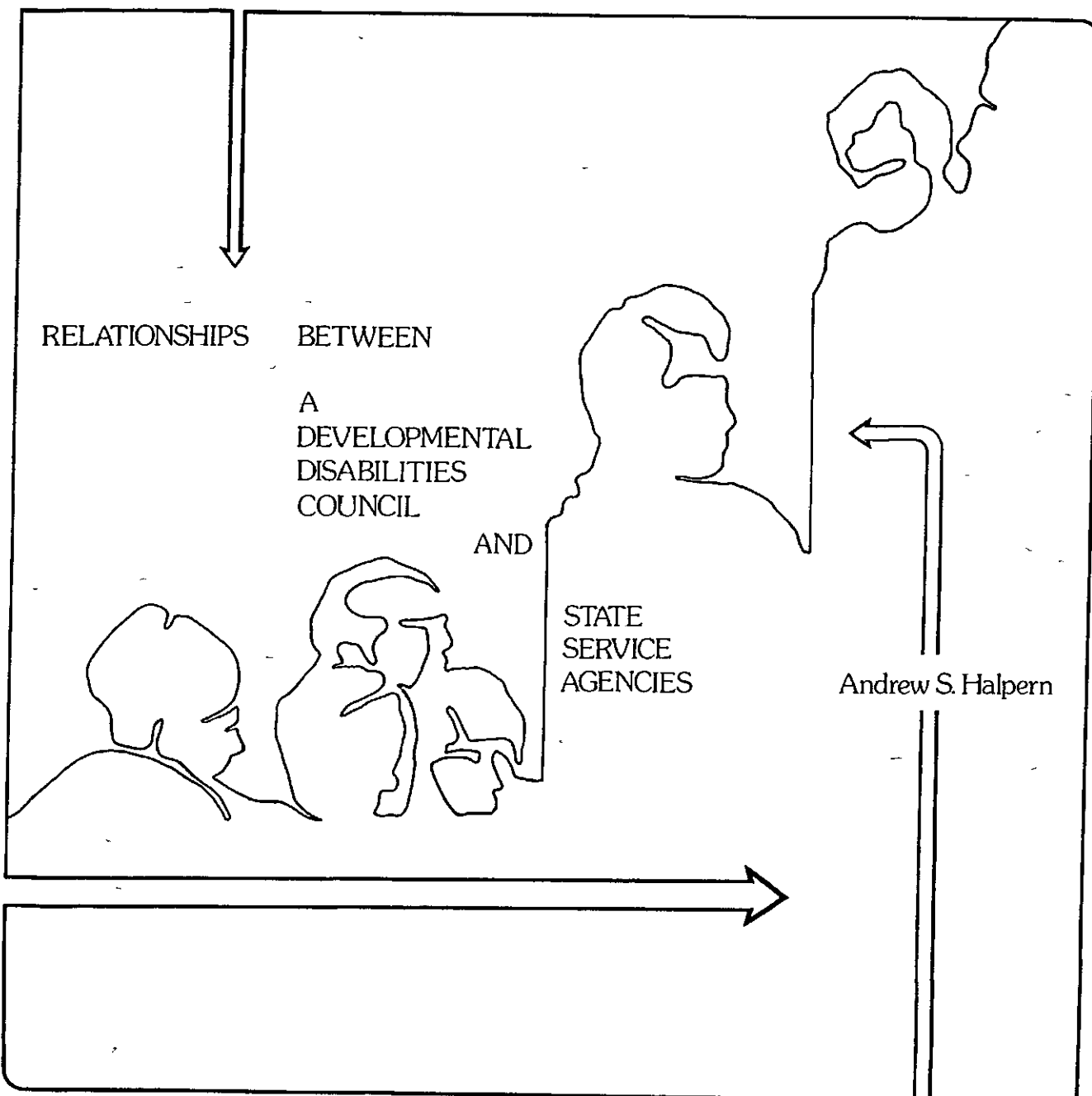




themes & issues

A Series of Topical Papers on Developmental Disabilities



Series Editors: James L. Paul, Pascal L. Trohanis

Number 2

ABOUT THE AUTHOR



Andrew S. Halpern, Ph.D. (University of Wisconsin, Madison) is Project Director for the Rehabilitation Research and Training Center on Mental Retardation at the University of Oregon in Eugene and is Associate Professor in the Department of Special Education. Dr. Halpern has had extensive experience in education and in program planning and evaluation, and has provided much valuable assistance to state Developmental Disabilities Councils in these areas.

CONTRIBUTING STAFF

Printing Coordinator
Editorial Assistant
Artist
Typist

Zena Harvley
Ann Ramsbotham
Doris Mahaffey
Lynn Harmon

DD Themes and Issues is a series of topical papers for this nation's Planning and Advisory Councils on Developmental Disabilities. Each participating state, territorial, and District of Columbia Council develops and implements a comprehensive State Plan for the coordination of comprehensive services for citizens who are developmentally disabled.

This series is published by the Developmental Disabilities Technical Assistance System (DD/TAS), which is a consultative and assistance system for the Councils. DD/TAS is a division of the Frank Porter Graham Child Development Center, the University of North Carolina at Chapel Hill.

This series was prepared pursuant to a grant from the Division of Developmental Disabilities, U. S. Department of Health, Education, and Welfare. Grantees undertaking such projects under government sponsorship are encouraged to express freely their judgement in professional and technical matters. Points of view or opinions do not, therefore, necessarily represent official DDD position or policy.

Published in July of 1975

RELATIONSHIPS BETWEEN A DEVELOPMENTAL DISABILITIES COUNCIL AND STATE SERVICE AGENCIES

Andrew S. Halpern

The Developmental Disabilities Services and Facilities Construction Act was designed to provide states with a broad responsibility for planning and implementing a comprehensive program of services for developmentally disabled people. The Act also authorizes the provision of formula-grant funds to stimulate the development of facilities and services that are not adequately provided within the existing network of public and private agencies.

In order to accomplish this mandate, each state and territory is expected to create a Developmental Disabilities Council. The legislation requires that membership for such Councils be drawn from three different groups: state agency personnel, consumer representatives, and "interested third parties." The rationale for such membership requirements is to facilitate dialogue between the providers and consumers of services in the process of developing a plan for comprehensive service delivery.

Since a DD Council must include representatives from a variety of public service agencies, it becomes an intriguing and complex problem to identify and implement appropriate relationships between the Council and the state agencies which provide a part of its membership. Before examining the problem directly and suggesting some possible solutions, it will be useful to review briefly the major roles and responsibilities of a DD Council.

Major DD Council Responsibilities

The primary responsibility of a state DD Council is to prepare annually a comprehensive plan for meeting the needs of the state's developmentally disabled citizens. In order to accomplish this task effectively, a Council must be aware of both the demand and availability of services throughout the state. Where gaps exist between need and resources, the Council's annual plan should be directed toward narrowing the discrepancy.

The annual cycle of developing a state plan can be further described in terms of three interrelated activities: planning, influencing, and evaluating. Planning involves the establishment of goals, the assessment of needs and resources, the identification of gaps in service delivery, and the selection of objectives which are aimed toward the achievement of the goals. Influencing is the vehicle through which a council implements its objectives. Lacking direct control over most agency programs, the Council engages in activities that will encourage the responsible agencies to improve the delivery of services in accord with the goals and objectives of the state plan. Evaluation involves an assessment of the extent to which the objectives of the state plan have been accomplished. Evaluative information leads to the selection of new objectives, and the cycle begins again.

A DD Council will be successful in attaining its objectives only to the extent that it is able to establish and maintain effective relationships with the state service delivery agencies. What does this mean when one-third of the members of a DD Council are also employees of the very state agencies that the Council is attempting to influence?

A Conceptual Dilemma

This ambiguity with respect to the roles of individual Council members leads to an organizational ambiguity as well. Is a DD Council advisory to or in some sense a part of the state agency structure? There are many facets of this apparently symbiotic relationship. Each of these facets has the potential for weakening the identity and diminishing the effectiveness of a DD Council.

The administration of DD Councils has taken a variety of forms in different states around the country (Stedman, 1973). In some states the Council has been designated as either, part of a single state agency, such as the health division, or as part of an umbrella agency, such as a department of human resources. In some states, the administration of the DD Council has been assigned to one agency, and the administration of the DD formula-grant program to another. In other states, the administration of the Council has been assigned directly to the governor's office.

Each of these administrative alignments offers the potential for conflict of interest. Does the Council's staff work only for the Council, or are there pressures to conform to the policies and demands of the administering agency or office? To what extent can the Council advocate for the policies and programs of agencies if these are in conflict with the governor's attempt to balance his budget? Are the state agency members of the Council free to vote their minds, or is their function to protect the interests and policies of their agencies?

There are no clear and unequivocal answers to these questions, and the resulting ambiguity has made it difficult to delineate clearly the relationships between DD Councils and state service agencies. Perhaps as a result, in part, of this dilemma, there has been an unfortunate tendency of many DD Councils to view themselves simply as a state agency, concentrating all or nearly all of their efforts on the administration of the formula-grant program. When this happens, it is frequently accompanied by a neglect of the major resources that are available within any state for developmentally disabled citizens--namely, the resources and programs of the major state agencies.

Some Possibilities for Meaningful Relationships

The potential for conflict of interest within members of a DD Council will be alleviated if the Council focuses attention upon its true mandate—the state's total delivery system. If and when this occurs, it becomes even more essential to es-

establish good working relationships between the Council and the various state agencies. Assuming that such relationships can be established, there are a number of specific activities that should be considered by DD Councils as they develop their work plans.

Service Objectives. More than 50 distinct services are provided to developmentally disabled citizens by various agencies, both public and private, within a state (Halpern and Farah, 1974). Each of these services can be evaluated on three different dimensions: Quantity, quality, and effectiveness.

The quantity of any service is adequate when it can be obtained by those who need it without undue difficulty or delay. Achieving this goal is very difficult because it involves the coordination of efforts among various agencies, the accurate assessment of need for any given service, and success in the competition for limited resources.

The quality of any service is measured by the adequacy of standards which are adopted for that service, and the degree of compliance which agencies show with respect to the adopted standards. The effectiveness of any service should follow whenever quality is high. Effectiveness is, however, more difficult to assess since it involves the specification of expected client gains and subsequent measurement to ascertain whether or not the gains have been realized.

DD Councils can play an important role in helping to conceptualize what is needed to improve the quantity, quality, and effectiveness of services that are provided by the state agencies. If a careful analysis of the service delivery system is made along these three dimensions, the DD Council can propose specific objectives for the agencies to adopt in their own future planning. If these objectives are realistic, timely, and built upon a foundation of the best available information, there is a chance that the agencies will view them as an asset rather than a liability to their own process of planning.

Agency Budgets. In most instances, the only way that service objectives can be accomplished is through their incorporation into appropriate agency budgets. Each state agency has a distinct set of procedures that it must follow in the development and implementation of its budget. Although these budgets can be monitored and influenced at several points throughout the fiscal year, the potential impact is greatest during the time that the agencies are formulating their budget for presentation to an umbrella agency, the legislature, or the governor. If a DD Council can influence state agency budgets during this critical formulation stage, the potential impact should greatly exceed the total value of the DD formula-grant allocations.

New Legislation. Agencies are frequently unable to improve or extend services to developmentally disabled citizens because of restrictions or inadequacies in existing state legislation. DD Councils should study this legislation carefully, and be prepared to support the introduction and passage of new laws that would improve the service delivery system for developmentally disabled clients. Such support

can be more effective than an agency advocating for its own programs, since the Council is less vulnerable to an accusation of self-serving advocacy.

Service Standards. For better or for worse, service standards are frequently imposed upon state agencies in the form of either suggested guidelines or enforced regulations. Such standards can greatly improve services when they are well formulated and, conversely, can lull people into a false sense of security when they are poorly formulated. For example, the standards that are developed by various states for the operation of community residential facilities are likely to contain health and safety regulations since these are probably familiar to most people and have already been implemented effectively within some agency structure. But unless standards for client training are also introduced, the full expectations for community residential facilities are not likely to be realized.

There are many instances in which the development of service standards within generic agencies could fall short of what is needed for developmentally disabled clients. DD Councils should monitor this activity closely, and work with the state agencies toward the development of more appropriate service standards.

Client Data Banks. Neither the quantity nor the effectiveness of services can be accurately monitored without the assistance of well functioning client data banks. Such data banks must be capable of storing and retrieving information about the services that clients need and receive, as well as the outcomes of these services. Only this kind of information will permit DD Councils to accomplish accurate planning and evaluation.

Although there is a project of national scope currently in progress which addresses the problem of developing an appropriate format for client data banks (Eyman, 1975), the management of information in any given state will depend ultimately upon motives, constraints, and resources of the state agencies that collect and use the information. Since DD Councils will need this information, they must establish and maintain cooperative agreements with the appropriate state agencies.

Most state agencies at this point in time do not have well functioning client data banks or highly sophisticated management information systems for processing the data they do possess. DD Councils might benefit greatly by assisting relevant agencies in the development of these tools, perhaps even utilizing some of the DD formula-grant funds for this purpose. With the utilization of DD funds to provide some of the impetus in this area, it is likely that the end product will not neglect the information needs of the DD Council. Furthermore, the goodwill generated by such a gesture might increase the willingness of the agencies to share information candidly with the Council. A word of caution is in order here to balance the enthusiasm that can be engendered when considering the potential of technical data systems. That caution has to do with protecting the individual from either data mismanagement and/or abuse. For example, citizens must be protected against an invasion of privacy or being trapped in a data system track which bears a label that endures for a time after the needs for services cease. While it is beyond the

scope of this paper there are good resources that address these issues. (Pascal, 1973 and Secretary's Advisory Committee, 1973).

Applied Research. There are numerous problems within the service delivery system for developmentally disabled citizens that do not stem from a lack of motivation, legislative authority, or resources to do the job well. The basic problem is ignorance of how to provide services most effectively.

This ignorance is not necessarily abstract or theoretical in nature. There are many concrete and practical questions that should receive at least tentative answers through research before launching major revisions in the service delivery system. Once again, the current movement toward deinstitutionalization provides us with a useful example.

It is likely that a great deal of money will be spent during the next decade for the purchase and staffing of community residential facilities for developmentally disabled citizens. If we are to insure that this money is being well spent, we need answers to a number of important questions. What is the smallest number of residents that can be placed in a single home if that home is to remain economically solvent? Is this number constant, or does it vary as a function of geography, client age, or level of client disability? What kind of personnel are needed to staff these homes, and how can they best be trained?

In seeking the answers to these and many similar questions, a DD Council could be in the position of assuming a leadership role. One aspect of this role might be the identification of the most urgent problems that need to be resolved to improve the delivery of services to DD clients within a given state at a given time. The Council might also solicit and endorse research proposals which address the critical questions, perhaps using DD formula-grant funds to support those that are most important. If the Council works closely with relevant agencies throughout this process, another bond of mutual trust and appreciation should be added to their relationship.

Summary

There is little doubt that DD Councils have been established, in part, to provide a check and balance mechanism for the state agencies that provide services to developmentally disabled citizens. The relationship between the Council and the agencies is complicated, however, by the fact that many Councils are administered by a state agency, all the DD formula-grant funds must be administered by a state agency, and at least one-third of every Council's membership consists of representatives of the state agencies that are to be monitored by the Council.

This organizational symbiosis makes it extremely difficult for a DD Council to establish a clear and separate identity. The monitoring of state agencies should be attempted in the role of collaborator rather than adversary, for if the lines of

battle are drawn, then the agencies will probably, attempt to frustrate if not smother the independence and creativity of the Council. At this point in time, the agencies appear to have sufficient political power to accomplish such a task.

In spite of these somewhat unusual organizational and political realities, there are a number of ways that a DD Council can relate effectively to the state service agencies, if the foundation of this relationship is trust and collaboration. Several aspects of such a relationship have been identified and described.

Reference List

Eyman, Richard. Individualized Data Base Interim Report of Progress and Future Plans. Pamona, California: UCLA/NPI State Hospital, 1975.

Halpern, A. & Farah, J. A Planning and Evaluation Strategy for State Developmental Disabilities Councils: Volume II. Working Paper No. 79. Research and Training Center in Mental Retardation, University of Oregon, August, 1974.

Pascal, C. A Statement on the Policy Considerations Inherent in the Use of Case Registry and Tracking Systems. Unpublished manuscript, 1973.

Secretary's Advisory Committee on Automated Personal Data Systems. Records, Computers and the Rights of Citizens. U.S. Department of Health, Education; and Welfare. July 1, 1973.

Stedman, D. The State Planning and Advisory Council on Developmental Disabilities. A Conference Paper published through the Developmental Disabilities Technical Assistance System. University of North Carolina, 1973.

themes & issues

DD/TAS

Suite 300 NCNB Plaza

Chapel Hill, North Carolina 27514

BULK RATE
MAILING
U.S. POSTAGE
PAID
CARRBORO, N.C.
PERMIT NO. 12

310-00429000
ROGER STRAND
8TH FLOOR 802 CAP SQ BLDG
550 CEDAR ST
ST PAUL, MN
55101

DD/TAS is a division of the Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill