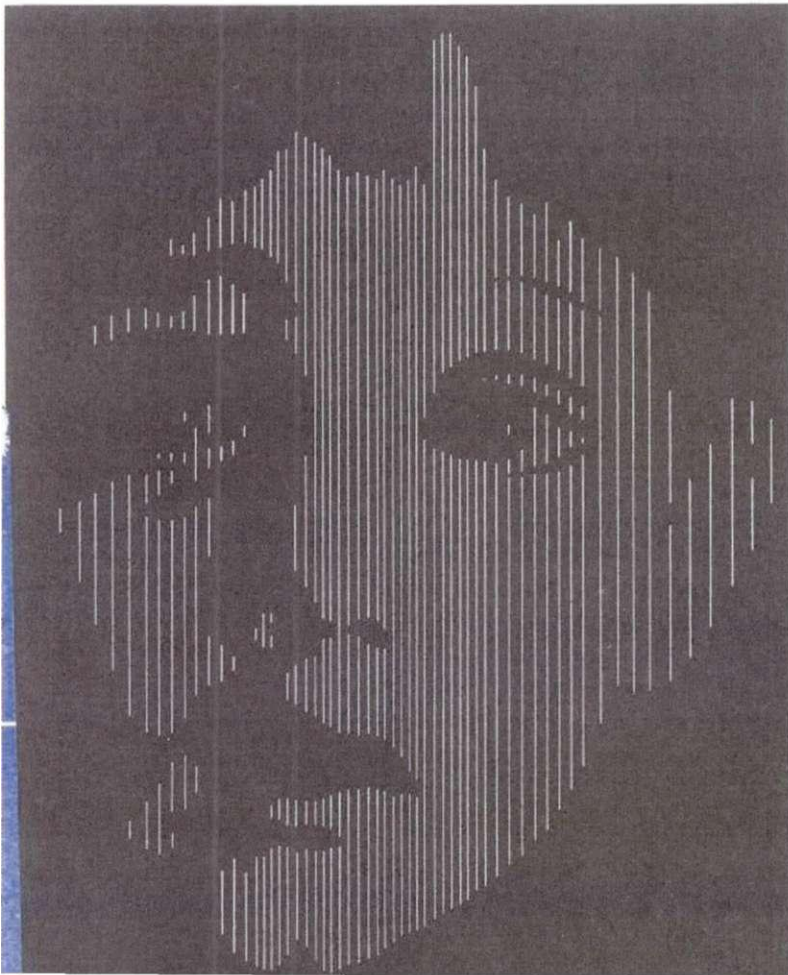




# State Government

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**Mental  
Disabilities:  
The  
State  
Role**

# State Developmental Disabilities Planning Councils

Assistance for the developmentally disabled is a relative newcomer to the governmental scene. Growing out of a legislative alliance in 1969 among several organizations working on behalf of handicapped persons, the concept of developmental disability came into use as including all children and adults with a substantial, continuing disability originating in childhood. Epilepsy, learning disorders of disabling proportions, and autism were later incorporated in the legislative mandate. Developmental disabilities councils are part of the system—established as state planning and advisory groups to be made up of representatives of state and local agencies, advocate groups, and consumers. Their mission is to advise state agencies on the administration of federal monies for planning the delivery of services to the disabled, and providing a formal process for citizen input to the state program. The councils were also created because the existing client/advocate groups (mentally retarded, cerebral palsy, etc.) needed a common basis or vehicle for taking their positions to state government. The two articles that follow provide commentary on the success of the councils in achieving these objectives and describe other factors useful in assessing the impact of developmental disabilities councils.

# Are They Worth Their Keep?

*by Elizabeth M. Boggs\**

ASKING WHETHER developmental disabilities (DD) councils have been a success is a little like asking whether the Class of 1960 at New Missolimia University is a success. One alumnus is a member of Congress, two are in jail, one is a professional golfer, and three are "address unknown." Who defines success, and when? How does one score a collective success when individual experiences are so diverse? To what extent is success a product of that which they have in common (a certain student experience at the university or, in the case of DD councils, a statutory base in federal law)? To what extent is success a function of the opportunities which came their way and which they utilized or did not utilize to good advantage?

The basic commonality of the developmentally disabled population is severe chronic disability originating in childhood. The hard core of this population does not exceed 2 million; however, if all handicapping conditions originating in childhood are counted, some 10 to 15 million would probably qualify. The principal component disabilities are mental retardation, cerebral palsy, epilepsy, and autism. Early onset of disability brings with it different life experiences and outcomes than disability experienced after the achievement of maturity and normal adult status. The "generic" service systems frequently show discontinuities

between services for handicapped children and disabled adults, yet developmentally disabled persons must make this transition. There is a real message for policymakers in the fact that between one fourth and one third of our severely disabled adults under 65 have been disabled since childhood, usually since preschool years.

In a Council of State Governments' study, 13 "target groups" most frequently in need of human services were identified. Among them are "mentally retarded" and "handicapped." The population currently designated "developmentally disabled" clusters the most vulnerable of the retarded with persons having certain other handicaps of early onset (e.g., cerebral palsy, uncontrolled epilepsy, autism) which carry grave risk of long-term social and economic dependence.

As federal programs go, the developmental disability program is very modestly funded. Total appropriations have never exceeded \$60 million a year, and a little over one half of that reaches the states in the form of formula grants. Eleven states receive the minimum allotment of \$150,000 (the territories get \$50,000), but even California receives only \$2.3 million. Members of the target population of the DD act are the beneficiaries of some \$3 to \$5 billion in federal funds (including Social Security, Supplemental Security Income, Education for the Handicapped, Vocational Rehabilitation, Social Services, and the like), as well as even larger sums invested by state and local governments, of which the most visible are the costs of special education and of institutional care for the mentally retarded. At both state and federal

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\*Dr. Boggs, a long-time advocate for the retarded and handicapped, currently is vice chairman of the New Jersey Developmental Disabilities Council. She was the first chairperson of the National Advisory Council on Services and Facilities for the Developmentally Disabled (1971-74). She headed the coalition which drafted and pressed for passage of the 1970 act which created the council.

levels, some eight to 10 major agencies are involved.

At the federal level, the administering agency for the DD act is the Developmental Disabilities Office (DDO)—a component of the new Administration for Handicapped Individuals within the Office of Human Development Services (OHDS). The old Office of Human Development, which under President Nixon was an aggregate of advocacy agencies for special target groups, has now become an operating agency with a multibillion-dollar budget. As of 1977, OHDS encompasses the Public Service Administration which is responsible for social services under Title XX, the Administration on Families and Children (subsuming Child Development), and the Administration on Aging, as well as the Rehabilitation Services Administration.

### THE FEDERAL OBJECTIVES

#### **How does DDO see the program?' It listed among its major objectives for 1977:**

To enhance the effectiveness of the State Developmental Disabilities Planning Councils in planning, evaluating, coordinating and filling gaps in services for persons with developmental disabilities and in supervising the development of comprehensive data-based planning systems which articulate the needs of the state's developmentally disabled population and describe the distribution of strategies for developing the state's service resources to meet those needs.

#### **This objective is in support of a long-range goal stated as follows:**

To enable states to increase the provision of quality services to persons with developmental disabilities through the design and implementation of a comprehensive and continuing state plan which makes optimal use of federal, state, local, and private resources.

Thus, the federal agency clearly stands on two principles: (1) the states are to be assisted, not directed, towards a target, and (2) the councils are a major instrument for achieving the program goal.

To understand the role of councils, one must look at their evolution both in the statutes and in practice. The DD formula grant program enacted in 1970 replaced the community facilities construction component of the Mental Retardation Facilities Construction Act of 1963, a part of the Kennedy mental retardation package.<sup>4</sup> This in turn was modeled after the Hill-Burton hospital construction act, which authorized federal project grants against priorities established in state plans approved by state advisory councils. The council model was

translated from one act to another substantially unchanged until 1975, except that in 1970 a requirement was added that the councils (rather than the state agencies) submit the plan to the secretary of HEW. This deliberate modification was introduced to assure that the state agencies had to go through (rather than around) councils, which in 1970 had no staff of their own. The actual effect of this relatively simple change has been much greater than was anticipated at the time.

Greater impact is, however, also the result of the broadened scope of activities for which the formula grant may be used, as well as the devolution of decisionmaking to the state level. As the 1970 act was originally written—and even today after the introduction of some strictures during the 1975 extension—the DD formula money is open to a wider range of state-level discretion than has been generally exercised. In particular, the distribution of the funds between the objectives of planning and services is not specified in the federal statute, unlike (for example) funding under the Public Health Act. That such options are helpful is illustrated by the shift in utilization. In the first year of the new act (fiscal 1971), states spent 14 percent of their formula funding on planning, 55 percent on services, 22 percent on construction, and 9 percent on administration; in 1977, the ratios were 19 percent, 72 percent, 1 percent, and 8 percent respectively. Of even greater significance is the wide variation among states in any one year, indicative that, indeed, mandating percentage allocations among such functions from the federal level based on preconceptions, however derived, can straightjacket the individual states.

### ROLE OF THE COUNCILS

What is the role of councils and their staffs? The councils are not "operating" units; indeed, the tension between them and the cognate "administering agencies" is one source of differences in perception as to their value. Yet, the concept of the council has moved in 15 years from that of a relatively ancillary instrument of "sunshine" in 1963 to that of a "systems advocate" in 1977. In that period, their title has changed from "advisory" (1963-70) to "planning-and advisory" (1970-75) to "planning" (1975 to date).

Concurrently, the term "state plan" has also taken on new meanings in this and other

contexts. A Council of State Governments' study in 1969 classified "state plans" responsive to federal requirements as falling into three classifications:

1. Planning dealing with facility construction or other physical improvements.
2. "Plans" which represent administrative control agreements and program work plans.
3. Multiyear functional program planning in which both policy discretion and long-term incentives are vested.<sup>5</sup>

Clearly, P.L. 88-164, as enacted in 1963, called for facilities planning. In fact, under that act, as in Hill-Burton, the actual administration was federal, based on state-specified criteria for rank ordering construction project applications from within each state. The 1970 legislation contemplated the generation of longer-range functional planning at the state level but did not require evidence of its characteristics within the annual work plan submitted as part of the state's application for funding under the DD act. More recently, states are being mandated to search out relevant data (from other agencies within the state) and to report this compilation as part of the annual submission to the federal agency. The assumption is that the required data will assist the council in its comprehensive functional planning and will also give the federal DDO some agreeable data nationwide. In addition, the council's annual state plan is expected to present long-range goals and short-term objectives within a five-year planning cycle.<sup>6</sup>

In some states, planning was displaced at the outset by an exercise in gamesmanship as non-profit private organizations speaking for private providers or for "consumers" jockeyed for position on grant review committees set up under the general auspices of the councils. (As of 1975, 21 councils had such committees.)<sup>7</sup> A General Accounting Office unpublished study commissioned by the Subcommittee on the Handicapped of the Senate Committee on Labor and Public Welfare (now the Senate Committee on Human Resources) picked up complaints about this phenomenon which were taken seriously by the subcommittee in writing the 1975 amendments. The Senate made it clear that it did not want the councils involved in the day-to-day administration and grant review, and that the state-administering agencies should devise the "designs for implementation," subject to approval by the state councils.

## THE MATURING PROCESS

It is not clear how much this new mandate has actually changed the way council business is currently being conducted, inasmuch as the councils themselves have been and are still evolving and developing a more mature life-style. In this, they have been assisted by a communication network of their own—the National Conference on Developmental Disabilities—and by the Developmental Disabilities Technical Assistance System (DD/TAS), based at the University of North Carolina, and funded directly by a federal grant as part of the DDO capacitation strategy.

Just as important has been the acquisition and stabilization of staff. Cross-agency planning on behalf of a target group is a skill not widely available. Council staffs have had to learn on the job. Most councils (50) now have a staff director and, on the average, one other professional employee, who is often designated as a planner.<sup>8</sup>

The planner's major visible product is the annual state plan submitted to the federal agency in support of the application for the formula grant.

Since the clientele served by DD/TAS includes all councils and their staffs, the technical assistance group has had a unique opportunity to study their behavior. Two men who have served as directors of DD/TAS, Donald J. Stedman and Ronald Wiegerink, have provided some analyses and insights into the evolution of council roles.<sup>9</sup> Stedman has noted that critical factors include effective internal structure and operation (including adequate staff assistance), adequate communication linkages with other structures in the state, and good organizational placement, both for the council itself and for the agency or agencies designated to administer the plan. These administering agencies now usually have assigned DD staff separate from the council's staff.

Members of councils are appointed by governors, but only a few councils are integral parts of the executive office. As to organizational locus in state government, Stedman identified six alternative placements for councils which have been used in practice, with their respective potentials and pitfalls. He has also schematized the "developmental stages of state DD councils" (Figure 1). At the time he wrote (1973), many councils were at Stage 2; today a significant

proportion are at Stage 3, and the rest are scattered throughout all three stages, including a few still at the primitive level.

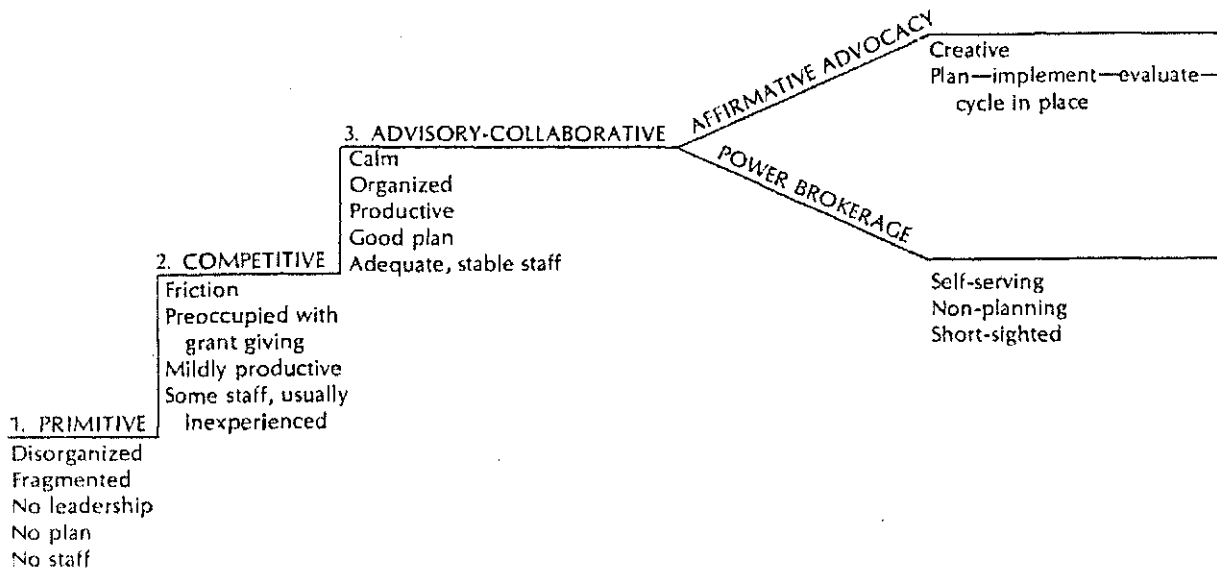
But, what can a council—even a Stage 3 council—do that is not superfluous? Isn't it enough for state agencies to do their own planning? To understand the rationale for councils, one has to review the organizational facts of state and federal life as they affect populations with multiple special needs. As Etzioni has pointed out, complex tasks require division of labor which, in turn, requires organization according to some rational principles.<sup>10</sup> In government, as in business, the rationales most frequently apparent are purpose, process, target group, and territory (region). Most large organizations display a mixture, with purpose and process more apparent in the upper echelons, while target group and territory show up in the middle and lower tiers."

If promotion of human well-being is the purpose which animates the so-called human services agencies, exemplified by the Department of Health, Education, and Welfare (HEW) at the federal level, then the traditional disciplinary groupings of health, social services, education and mental health represent the processes (skill clusters) which traditionally have identified the

major organizational subunits under the human services umbrella. Somewhere below this level, one can begin to see units defined by region and target population. The disabled, like children, the elderly, minorities, and the poor, have more specialized needs in the respective areas of health, education, social services, rehabilitation, housing, employment, and income maintenance, and less ability to put it all together than other citizens. To say that health care of the disabled can be dealt with apart from the health of the rest of the population is clearly absurd, but it is equally untenable to say that if health care is assured for the general population, the special needs of the disabled will automatically be accommodated. Thus, focal points of special expertise must be inserted.

The drafters of the DD legislation recognized that at both the federal and state levels such foci on its target population would be scattered among major agencies. Thus, lateral linkages are necessary at the lower echelons where the special populations are first identified. Figure 2 is a schematic diagram showing where concerns for the chronically handicapped become visible in the HEW table of organization. Comparable charts could be drawn for each state.<sup>12</sup>

**Figure 1**  
**STAGES IN THE DEVELOPMENT OF STATE COUNCILS ON DEVELOPMENTAL DISABILITIES\***



\*Source: Adapted from Donald J. Stedman, "The State Planning and Advisory Council on Developmental Disabilities," *Mental Retardation*, vol. xxiii, no. 3 (1975).

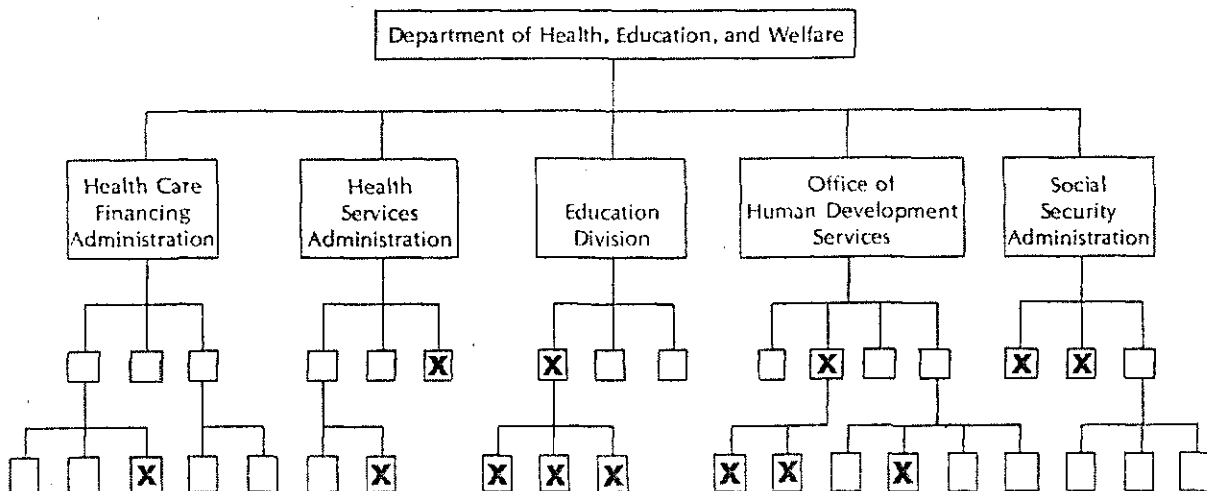
Although President Carter recently told the delegates to the White House Conference on Handicapped Individuals that he is about to assemble the 100 federal programs affecting the handicapped under one administration, many political scientists believe that such a move is not only impractical but that it would be counter-productive and undemocratic. Segregating the handicapped in their own small service enclaves, however "comprehensive," is definitely out of style. At any rate, one premise underlying the DD act is that the various generic systems must be assisted to become more responsive, within their respective missions, to the diverse needs of atypical persons. Needed specialized services can then be identified and designed to fill the gaps. Some effective mechanism must crosscut the traditional agency structure to bring this about.

When President Kennedy set up his President's Panel on Mental Retardation in 1961, one of the five major task forces was devoted entirely to "coordination."<sup>14</sup> It confirmed a concept previously put forward by a governors'

## COUNCIL FUNCTIONS

It is customary to list planning and coordination as the chief functions of the councils; in 1975 Congress added collective advocacy (not to be confused with the protection and advocacy systems for individuals separately mandated) as an explicit responsibility. Less is said about an implicit function, that of convenor. There is a mandated mix on the council of consumers and providers, public and private, state and local. Meetings, whether of the council or its task forces and committees, bring together, around one table, representatives of anywhere from three to six principal state departments, along with spokesmen from "categorical" groups and other consumers, and operators of a variety of agencies rendering direct community services. These are people with diverse interests, people whose pieces of power can be used either competitively or cooperatively. In the ordinary

Schematic representation of the distribution of target group focused services for the handicapped within selected operating agencies, defined by process, as found in the Department of Health, Education, and Welfare in late 1977.





course of events, many of these individuals, even those in government, would not be brought face-to-face.

Stedman has remarked especially on the consumer role:

**The involvement of consumers, especially the handicapped, is an absolute necessity to improve the quality, timeliness and propriety of the service needed as well as to guarantee that an appropriate and objective evaluation can be derived in the face of mounting service program costs.**

He also observed that:

**While consumerism has increased at a dramatic rate since the middle 1960s, the Developmental Disabilities Act is the only major piece of federal legislation currently being implemented at the state and local level that requires consumer involvement and input into the planning, program development and service delivery activity for handicapped individuals.<sup>17</sup>**

Some of the most important transactions that occur during or as a result of council meetings are not recorded in the minutes. Foreexample, an astute administrator can frequently pick up a "distant early warning" of potential political trouble and use this information to head off the heat. Concurrently, the consumer representatives often develop a more accurate picture of the intricacies of the bureaucracy and can better pinpoint the bureaucratic bottlenecks. This saves harassment of the innocent.

#### INDICATORS OF IMPACT

Other examples can be cited. In the early days of Title XX, one midwest state council meeting was the forum for a discussion of the need for protective services for adults disabled in childhood. As a result of this discussion, the representative of the social services agency understood for the first time the relevance of this activity to the Title XX goals. She volunteered to explore the allotment of available Title XX funding for that purpose.

In still another state, two state agencies concerned with foster family placements of handicapped children had been engaged in guerrilla warfare for 10 years. An interagency agreement was concluded between the two agencies within the past year, shortly after the state council completed a planning study related to these activities (using an outside contractor). During the course of the study, key middle-management figures in each agency for the first time had to meet each other in the presence of third parties.

A somewhat more objective indicator of impact is the rate at which the term

"developmental disabilities" is moving into state statutes. This, in turn, reflects the degree to which the DD program in general, and the convening of councils in particular, has influenced the formation of coalitions of consumer groups, thus encouraging cooperation rather than competition among them. DD councils provide a forum for working through resolvable differences when a community services bill or rights bill is being proposed. For example, a major administration bill introduced in the Alaska legislature in 1977 was drafted under council auspices.

Another function of the DD program is "gap filling." That part of the state plan which deals with the expenditure of federal funds (plus the 25 percent nonfederal match) directs these very limited dollars into support (usually temporary) for specific activities which cannot be immediately adduced from other sources. As an example of a state-level "gap-filling" activity, one state funded a statewide computerized information and referral system which lists all facilities and agencies in the state that provide an identifiable service specific to one or more handicapping conditions (not limited to developmental disabilities). Although designed to produce rapid up-to-date selective information to meet the need of a particular client at a particular time, it is capable of producing information in a form useful for planning whether on a local, regional, or statewide basis. The design of the system is readily adaptable to a broader use and it could become the nucleus of a human services referral system.

Even without computer glamour, the systematic search for the data now required for the plan has opened up channels of communication between heretofore closed agency-based data systems and increased the sensitivity toward the need for multiuse designs in many states.

Who can measure the indirect benefits of these interventions in the very complex human services support systems? Thus, council planners have a lot of hassle and few tangible results for which they can publicly claim credit.

What of the administering agencies? Of the state agencies designated to administer the plan—i.e., spend the DD allotment in accordance with plan priorities—about one half are state mental retardation or mental health agencies.<sup>18</sup> Had the state formula authority under the DD act been funded at the levels originally contemplated in 1969 (reaching \$130 million in



1973), it might have moved these agencies toward the big leagues. As it is, the developmental disabilities funding represents about 1 percent of what they spend. Most are parceled out to private, nonprofit providers in grants or contracts. Directors of state mental retardation agencies, if we are to believe their spokesmen,<sup>19</sup> are at best ambivalent and at worse cynical about the DD program and about councils. Curiously, they are asking for more federal direction rather than less. After all, who wants all those consumers looking over your shoulder when you do not have any suitable federal regulation with which to silence them? That money takes so much time and you cannot even slide much of it around to cover your deficits or overhead.

just before enactment of the 1975 amendments, Stedman wrote:

Much of the aforementioned material is debatable. One reason for this is that the federal legislation as written is deliberately non-specific in its interpretation. This vagueness can be seen either as ambiguity leading to no action and consequent requests by council members for outside guidance and direction or it can be interpreted as a golden opportunity for mature people to use the flexibility available to take the initiative in developing a unique council organization and activity pattern necessary to perform the advisory and planning function within a given state.

Curiously, it is this very flexibility which has been subject to such attrition through underutilization by councils and demands by special interest groups for mandated targeting. Stedman continues:

In the long run, the proof of whether or not the developmental disabilities councils are effective and productive will not depend on whether the federal legislation was definitively written or interpreted. It will depend on the extent to which state councils and state agencies accept the responsibility and challenge and use the flexibility available in order to initiate and implement a unique, comprehensive services plan within their own state."

## CONCLUSION

In extending the act in 1975, the Senate committee prevailed on the House to include a number of directives and specifications, thus limiting that flexibility. More circumscriptions are being proposed from every side, as several days of "oversight hearings" in 1977 demonstrated. Those interested in the outcomes of the act—consumers, categorical agencies, nonprofit providers, professionals, and state agencies—are each inclined toward persuading Congress to control more vigorously the activities of the others.

The present act comes up for renewal early in 1978. Whether any useful state-level flexibility

will survive the next round of amendments is now becoming a critical issue.

## Footnotes

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2. The Council of State Governments, *Human Services: A Framework for Decision-Making* (Lexington, Ky.: The Council of State Governments, 1975).

3. Office of Human Development, *Implementation Plan for the Developmental Disabilities Services and Facilities Construction Act, Amended by the Developmentally Disabled Assistance and Bill of Rights Act, P.L. 94-103*, Department of Health, Education and Welfare, April 2, 1976 (internal management document).

4. Elizabeth M. Boggs, "Federal Legislation, 1966-71," in Joseph Wortis, ed., *Mental Retardation, An Annual Review*, vol. iv (New York, N.Y.: Grune and Stratton, 1972), pp. 165-206; and "federal Legislation," in Joseph Wortis, ed., *Mental Retardation, An Annual Review*, vol. III (New York, N.Y.: Grune and Stratton, 1971), pp. 103-27.

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6. Massachusetts Developmental Disabilities Council, *A Guide to Federal/State Plan Review, under the Provisions of the Developmental Disabilities Services and Facilities Construction Act* (Washington, D.C.: Council for Exceptional Children, 1972).

7. Roy Bruninghaus and Ronald Wiegink, *Profiles of Developmental Disabilities Councils* (Chapel Hill, N.C.: Developmental Disabilities Technical Assistance System, 1976), p. 9.

8. Ibid., p. 8.

9. Ibid., and Donald J. Stedman, "The State Planning and Advisory Council on Developmental Disabilities," *Mental Retardation*, vol. XXIII, no. 3 (1975), pp. 4-8.

10. Amitai Etzioni, *Modern Organizations* (Englewood Cliffs, N.J.: Prentice Hall, 1964).

11. See also, Herbert Kaufman, "Reflections on Administrative Reorganization," in J. A. Pechman, ed., *The 1978 Budget: Setting National Priorities* (Washington, D.C.: The Brookings Institution, 1977).

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14. President's Panel on Mental Retardation, *Report of the Task Force on Coordination* (Washington, D.C.: U.S. Department of Health, Education, and Welfare, 1963).

15. The Council of State Governments, *Report and Recommendations of the Conference on Mental Retardation* (Lexington, Ky.: 1959).

16. Twenty-nine state-level coordinators of programs for the mentally retarded out of 48 queried in 1974 responded affirmatively to a question about the productivity of interagency relationships. They credited the following factors: informal relationships with top-level administrators in other agencies (17), interagency coordinating council (10), developmental disabilities council (7), and consolidated human services agency (3). See, President's Committee on Mental Retardation, *Mental Retardation: Trends in State Services* (Washington, D.C.: U.S. Government Printing Office, 1976).

17. Donald J. Stedman, "Service Delivery Systems," in

*White House Conference on Handicapped Individuals: Awareness Papers*, vol. 1 (Washington, D.C.: 1977).

18. Bruninghaus and Wiegerink, *Profiles of DD Councils*

19. Maurice G. Kott, *Oversight on the Developmentally Disabled Assistance and Bill of Rights Act, 1977: Hearing before the Subcommittee on the Handicapped of the Committee on Human Resources, U.S. Senate, March 31, 1977* (Washington, D.C.: U.S. Government Printing Office, 1977).

20. Stedman, "State Planning and Advisory Council," *Mental Retardation*

# Some Criticisms

by Charles E. Acuff\*

A REVIEW of selected mandates to and functions of developmental disabilities planning councils discloses present and potential barriers to effective council functioning. Revealing these barriers is a step toward assisting in their removal, thus allowing the council to fulfill more adequately its role as a group advocate for developmentally disabled citizens.

In 1970, Congress enacted P.L. 91-517, the Developmental Disabilities Services and Facilities Construction Act. This legislation was heralded as the catalyst needed to mold into a cohesive, coordinated effort the vast array of generic and special services that impact on the needs of developmentally disabled citizens. Funding of the legislation was intended basically to support planning and coordination activities, and to provide seed money for services and facilities that would fill gaps in services. To provide coordination, this act required the governor of each state to appoint a "Planning and Advisory Council on Developmental Disabilities" to develop a state plan for comprehen-

sive services and to administer the grant-in-aid program.

The act had limited success both in achieving the important objectives underlying its development and in fulfilling the high expectations held for it. Recognizing this, Congress sought a remedy by enacting P.L. 94-103, The Developmentally Disabled Assistance and Bill of Rights Act of 1975. While alleviating some of the problems, the amendments in P.L. 94-103 have not proved to be panaceas. Among the problems remaining in current developmental disabilities (DD) legislation, regulations, and interpretations, those relevant to developmental disabilities planning councils serve as examples. The focus here will be necessarily limited to a few major issues.

## COMPOSITION OF STATE COUNCILS

Each state receiving assistance under P.L. 94-103 must establish a state planning council representative of nine major services drawn from state agencies, local agencies, non-governmental agencies, groups concerned with services to developmentally disabled persons, and consumer representatives. The consumer representatives, who must comprise at least one

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third of the council membership, may not be officers or employees of a group which receives funds or provides services under this act. Herein lies a concern. Although service providers are mandated to membership on councils and can theoretically represent two thirds of the membership, officers or employees of a group eligible (as interpreted) to receive funds or provide services under this act may not serve as consumer representatives. If this limitation is intended to prevent conflicts of interest, it seems ironic for the other two thirds of the membership not to experience the same restrictions. The governor is placed in the position of selecting consumers who are not officers or employees of a service provider agency. The result is that, at least in the more rural or less populous states, those who have been the most active and dedicated advocates are prohibited from serving as consumer representatives on the council because so many are officers providing needed leadership to community programs. A number serve on boards of groups not seeking funds under this act; but, the interpretation has been that since their group is eligible for funds, they cannot serve except by filling a nonconsumer position. If a "qualified" consumer becomes more active and elects to contribute by becoming an officer on a service provider board, the interpretation of the law in effect means that the governor must replace that consumer on the council with a "qualified" consumer who is not on a board. This constraint constitutes a form of discrimination against proven leaders, chiefly parents, who must make a choice of the role in which they will serve even though others on the council represent agencies and groups eligible for and receiving DD funds.

#### AUTONOMOUS COUNCIL PLACEMENT

Council members are to be appointed by and to report to the governor. Even though they may be attached to an agency for "housekeeping" purposes, they must be free and independent of that agency. In theory, such mandated association with the governor's office would suggest that a state council has considerable influence in directing attention to its concerns. In practice, there is no effective way a governor can directly relate to all of the separate entities which have emerged with rapidly growing governmental bureaucracies. Many states have reorganized or are undergoing that process in an effort to develop a more viable management system. For

example, in Arkansas, before reorganization, there were approximately 185 departments, commissions, agencies, and boards presumably reporting directly to the governor. Obviously, contact by smaller groups was most often with an assistant to the governor who had limited information about, and possibly even less interest in, the concerns of the group.

It may be of questionable wisdom, therefore, to mandate organizational placement of the council in a position having potentially limited impact, instead of giving states the option of placing it with the agency having major responsibility for developmental disabilities services. The visibility of council concerns and recommendations could be enhanced in some states through such efforts. Accountability would, of course, have to be ensured. A meeting might be held at least annually with the governor for the council to present a capsule report and to make recommendations.

Another possible undesirable result of the mandated autonomous placement of the council is the breach that can develop between the council and the designated agency responsible for services to developmentally disabled persons. Absence does not necessarily make the heart grow fonder; neither does the separation of groups with common concerns. Enforced separation can conceivably be the gap that results in mutual suspicion. Cooperation, fundamental to the purpose of the act, may become strained despite the fact that some council members are also representatives of other state agencies. Communication between council and other state agencies having generic services which are, or should be, available to developmentally disabled individuals is difficult to sustain without such cooperation.

#### STAFF FOR COUNCIL

The act requires: "Each state receiving assistance under this part shall provide for the assignment to its State Planning Council of personnel adequate to ensure that the council has the capacity to fulfill its responsibilities under subsection (b)" [Section 141 (b)]. The Rules and Regulations further state, "and that staff shall be responsible to the State Council" (Subpart B, Section 1386.62).<sup>1</sup> Verbal interpretations expanded on this by attempting to dictate certain staff who will be employed. The case of the state plan is an example. The council is required to supervise the development of and

to approve the state plan, while the designated agency is required to develop it. An initial interpretation was that the planner had to be on council staff. A concession was made allowing this person to be on agency staff, if specifically identified as the DD planner even though he or she was one of several staff members in a mental retardation/developmental disabilities planning section.

In sparsely populated states, with minimum or near minimum allotments, either a substantial percentage of the state's allotment goes for adequate staff, or the staff must function within an existing agency where they receive housekeeping, administrative supervision, and other support services. In some states it is even questionable whether staff can legally be attached solely to a council. In a number of states, councils are not in a position to provide the ongoing supervision for which they must be held accountable if staff reports only to them. Why create another crevice between agency and council when the act mandates only that the council shall be adequately staffed to carry out its assignments?

#### THE STATE PLAN

Probably the major assignment given the council relates to planning. The council must supervise the development of the state plan for DD and monitor and evaluate its implementation. To the maximum extent feasible, the council must also review and comment on all state plans relating to programs affecting persons with developmental disabilities in the state. This assignment differs little from that mandated in the 1970 act. Council staff, or that specified in a contractual arrangement with the designated agency, still performs the basic information gathering and assimilating activities in accord with council-established objectives and priorities. Since the 1975 legislation, the council may reenter the process at a later phase for review and approval.

The mandated planning process and content of the plan, the interpretation given to planning procedures and staffing, and the patent format provided for the state plan sometimes result in a duplication of efforts and the development of additional state plans. In the case of Arkansas, an administrative board and our agency are responsible for ongoing DD planning, implementation, and service delivery. Our needs do not necessarily parallel those mandated by the act

and by the Department of Health, Education, and Welfare (HEW). Despite many areas and activities common to the efforts of both planning activities, enough differences exist to necessitate dual planning.

In Arkansas we experience good to excellent relations with other state agencies providing the services mandated to be covered in the plan by the act. These agencies have expressed concern, however, that information requested by the council is different from that required in their plan, or that routinely collected. Although they desire to cooperate by providing any available information, they cannot reconstruct their information collection system just to provide data to satisfy the needs of the format given us for the plan. Since there is as yet no effort at comparative analysis of one state's plan with another, and since state agencies implement the plans, it would seem practical for HEW to provide a statement of minimum contents, and helpful to allow flexibility to expand on this in a format most suitable to the individual state's needs.

Reviewing plans of other state agencies is not always a clear-cut assignment. The greatest impact on services required by developmentally disabled persons has to come from numerous agencies making available, without discrimination, the generic services of that agency, or new special services that agency can best provide. Compliance with a comprehensive state plan for the developmentally disabled population by the designated state agency cannot be compelled because that agency receives only a small DD allotment of which most is to be passed on to other groups and agencies. Further, the plans of those groups and agencies compositely providing the vast majority of services must be reviewed only "to the maximum extent feasible" by the DD planning council. The review process under these circumstances can become perfunctory.

#### THE PENALTY FOR NONCOMPLIANCE

Funding problems handicap both the council and the designated state agency. If the statewide advocacy system falters, the agency loses its state DD allotment. If the planning council, which is to function independent of any state agency with a staff solely responsible to it, fails to perform its duties, the agency loses its DD allotment. What does the state DD allotment mean? In Arkansas it means forfeiting a sum of money equal to about 1 percent of our own

agency's budget for services to the developmentally disabled population, and a small fraction of 1 percent of the total expenditure of all state agencies for this population. Since the designated agency serves as a "pass-through" agency for these funds, the impact on our budget is such that we would actually regain the administrative costs we supply, which is the vast majority of such costs, considering the volume of time spent by agency staff on council-related activities.

If other state agencies providing federally designated services choose not to cooperate, they currently suffer no penalty.

#### NEED FOR SPECIFIC OBJECTIVES

National objectives under this act are quite general and all-encompassing. The appropriation is not intended to fund all additional services required by developmentally disabled citizens. This, coupled with the limited impact the act has on generic services of other agencies, results in less accomplishment toward these national objectives than desired or anticipated.

A number of people suggest a more effective approach might be to target a few specific objectives requiring the cooperative efforts of two or three agencies each, and then utilize the available funds to support the accomplishment of these objectives. Should this be done, it would seem appropriate for HEW to promulgate specific, measurable objectives to which its own department can subscribe, and cooperative intra-and inter-departmental directives around which its own department can coalesce in order to develop a prototype for states to emulate. Concurrently, there must be more incentives than now exist for agencies with generic services to take affirmative measures to assure the availability of these services to developmentally

disabled individuals. Some changes in the statutes may be needed, but much can be accomplished under the present act.

#### CONCLUSION

More could be added about problems relative to a council's responsibility for monitoring and evaluating the implementation of state plans, the statewide advocacy plan and council involvement in it, the differing interpretations of the act and regulations by various federal staff, and the technical assistance program for council members and its staff.

Individually, the problems discussed and additional ones in the areas mentioned above may not appear significant; collectively, they create unnecessary barriers to a council's effectiveness. Any revisions in the act should demonstrate an awareness of problems such as those discussed. In the meantime, revised regulations and their interpretation, within the flexibility already permitted by the act, can enhance the functioning of planning councils. Furthermore, cooperative intradepartmental efforts can demonstrate to their state-level counterparts the unity required to progress toward a comprehensive program providing a continuum of appropriate services for developmentally disabled citizens of all ages.

Nevertheless, in Arkansas, the cooperation and understanding of council members and of sister state agencies have made success possible. Councils can and do make a most valuable contribution. Clarifying the legislation, regulations, and interpretations governing the activities of developmental disabilities planning councils, as indicated, can only augment that contribution.

#### Footnote

1. *Federal Register*, January 27, 1977, Part II.