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STRATEGIES FOR ACTION

Developmental Disabilities
and
State Government

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Developmental Disabilities
and
State Government

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INTRODUCTION

This monograph has both an academic goal and a policy goal. On the academic side, it is an attempt to analyze the legal and organizational factors that facilitate and constrain the ability of State Developmental Disabilities Planning Councils ("DD Councils") to be effective advocates in the DD system. On the policy side, it is an attempt to outline advocacy strategies that can be successful within the constraints outlined.

The DD system, a network of public and private organizations and of individuals providing services to persons with developmental disabilities, is a success story in human services delivery systems. The story began in the 1950's, when parents of mentally retarded children and health professionals began to ask that national attention be given the plight of severely handicapped children. By 1960, the issue had become a plank in the Kennedy presidential campaign platform. By 1963, the President's Panel on Mental Retardation had developed several of the themes which have been part of the federal developmental disabilities effort ever since. Specifically, the Panel called for coordinated, community-based services and a focus on the diversity of needs of the persons requiring services.

Two laws passed in 1963 anchor our current notion of a developmental disabilities system, clearly identifying persons with mental retardation as a unique group entitled to special rights and public privileges. Subsequent laws passed in 1970, 1975 and 1978 successively broadened this original entitlement so that now, under the most recent legislation, most persons with a chronic, severe handicap having a neurological basis and first manifesting itself before age 22 are included in the target group. Although the new, broader definition of developmental disability makes it more difficult to identify the members of this group, it reiterates the basic fact that government structures and programs do exist specifically to deal with the "developmentally disabled."

The 1963 legislation contained a section promising federal aid to states to develop comprehensive mental retardation planning at the state level. Actually, comprehensive

DD planning at that level did not become a prerequisite for federal funding until the DD Act of 1970, but the 1963 legislation did establish the basic structure of the DD system. It considered the states to be the primary units of DD planning and service delivery. It also obligated the federal government to provide considerable funding and direction to each state to help it coordinate its planning and delivery efforts. The most recent federal legislation mandates priority service areas, but it still depends on the states to provide and administer the services in these areas.

The developmental disabilities system is a coordinated network of federal, state and local agencies and organizations. Under the federal and complementary state laws discussed in this monograph, these agencies and organizations, along with individuals working in the DD system, are obligated by their use of public funds to plan and deliver services and guarantee rights to persons with developmental disabilities. This obligation has several characteristics requiring comment.

First, the term "developmental disabilities" as employed in federal and state legislation has a political and not a physiological significance. That is, it is something of a legislative catch-all. For example, many persons with epilepsy have virtually none of the symptoms or physical limitations common among persons with Down's Syndrome. Similarly, the therapeutic and public service needs of autistic children differ profoundly from those of persons with cerebral palsy. Nevertheless, persons with these and the full spectrum of other conditions now legally classified as developmental disabilities do share several key characteristics. They all have physical or mental conditions which substantially impair their capacities in a number of major life areas. More specifically, they all are beneficiaries of the actions Congress has taken to ameliorate their circumstances through public efforts.

To be effective, these efforts require independent public actors and programs designed especially for the developmental disabilities population. This federal legislative determination reflects an historic observation that existing public programs and policies have not adequately served persons in this population.

This emphasis on entitlements created through the political process introduces the second key characteristic of the DD system, its incredible complexity. Public policy on developmental disabilities is shaped through the interaction of federal, state and local agencies.

While the DD system relies on public-sector resources for its basic activities, it flourishes only with considerable private investment of time, effort and money. Given our political system, we can expect public resources for developmental disabilities to be maximized only if such private effort is promoted. Thus, the DD system includes federal and state legislatures which create entitlements and provide public funds for developmental disabilities programs; federal, state and local agencies which plan and implement these programs; persons with developmental disabilities, their families, friends and advocates; and, at times, the general public.

Third, no single, ultimate authority exists in the DD system. Even though federal law defines developmental disability in the first place, and mandates that the basic rights of persons with developmental disabilities be protected, the DD system mirrors the federal structure of the country. Thus, while states must comply with the 1975 Act and the 1978 Amendments, they may choose to augment the entitlements this legislation guarantees. Furthermore, states determine precisely how federal and state goals will be implemented, and state agencies or their subordinate local counterparts actually provide developmental disabilities services.

Fourth, the public policy environment in which the DD system exists is even more complex than the system is. Other groups of persons seek or have obtained entitlements from governments, obligating public institutions to meet their needs. The resulting competition for funds and personal resources means that developmental disabilities plans and programs are not self-generating, self-implementing or self-perpetuating. Consequently, there is a need for advocacy, the assertion of claims to entitlements or to enforcement of rights before institutions having the potential to satisfy these claims. The very complexity of the system

means that this advocacy must be undertaken by many actors in many arenas.

This advocacy task is made harder in the DD system because in most states the DD system is grafted onto a larger human services system. State agencies which administer DD services generally administer other human services, so they have responsibilities beyond providing for persons with developmental disabilities. In short, many agency actors in the DD system have divided loyalties, for they must allot resources among DD and other task areas. This need to balance competing interests is even more encumbering on action in the legislature. Yet, persons with developmental disabilities or their advocates generally cannot devote full time to maintaining the system.

The fact that the DD system is grafted onto a pre-existing state human services system is important for still another reason. To the present, the focus of the DD system has been on planning and coordinating the delivery of services funded primarily but not exclusively by the federal government. For the most part, the state agencies charged with delivering these services both pre-existed the developmental disabilities system of public programs and continue to retain considerable autonomy in administering their programs, even with the strings that come attached to federal aid dollars. Thus, authority in the DD system is split not only between the federal and state governments, but between planning units such as the DD Council and state implementing agencies.

At the center of the DD system is the state DD Council. The basic task of the Council is to translate federal and state legislation, the demands of developmental disabilities interests and the capacities of state and local organizations into a coordinated program which ensures that persons with developmental disabilities receive the care, treatment and other services they need to achieve their maximum potential. The Council performs this task by coordinating and monitoring other actors in the DD system, by developing service-delivery plans, and by otherwise advocating for the interests of the developmental disabilities population. The Council is therefore both a place where groups meet to formulate developmental disabilities policy and an institution

which links federal and state programs and private and public developmental disabilities activities.

In summary, this monograph illustrates how the DD Council, as a critical element in the developmental disabilities policy system, can work to maximize the public and private investments made to ensure that persons with developmental disabilities function to their full potential in society. The DD system is the network of laws, agencies, programs and persons working to meet this goal. Since all of the necessary resources are limited, and since the loyalties of many actors in the DD system are divided, the system requires effective advocacy on behalf of those persons needing the system if the system is to work well at all.

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CHAPTER 1

THE EMERGENCE OF AN ADVOCACY ROLE FOR THE DD COUNCIL

ORIGINS AND EARLY DEVELOPMENT OF THE STATE COUNCIL CONCEPT

Federal concern with developmental disabilities developed out of a more specific concern with mental retardation which, in turn, dates from the Kennedy administration. In 1961, President Kennedy convened a Panel on Mental Retardation which he asked to submit recommendations that would facilitate "a comprehensive and coordinated attack on the problem of mental retardation."¹ In the Panel's Report we see the beginning of the State Planning Council concept. The Panel concluded:

[T]he problems of the mentally retarded are not and cannot be the responsibility of any one department of state government. They are important concerns of several departments and require a multiple, but coordinated attack.²

It therefore recommended that the Secretary of Health, Education and Welfare (HEW) be authorized to make grants to the states for comprehensive planning in mental retardation. It further advised that each state make arrangements through an interdepartmental committee, council, or board for the planning and coordination of state services for the mentally retarded.³

One of the first pieces of legislation enacted in response to the findings of the President's Panel was the *Maternal and Child Health and Mental Retardation Planning Amendments of 1963* (P.L. 88-156). Title XVII of the bill authorized the appropriation of \$2.2 million for one-time grants over the 1964 and 1965 fiscal years "to assist states in developing plans for comprehensive state and community action to combat mental retardation."⁴ While the focus of P.L. 88-156 was on planning and coordination, three addi-

tional objectives that would later become important were also clearly present in the Senate Report on the bill. These objectives were education of the public to the needs of mentally retarded people, influence on general social programs not specifically concerned with retarded people, and public advocacy of the rights of retarded people. Thus, the Senate Report on the bill argued that:

[The grants] would enhance public awareness and understanding of the massiveness of the problem, and foster the development of the mental retardation aspects of programs of education, rehabilitation, welfare, employment, health, recreation, and protection of legal rights of the mentally retarded.⁵

In the Sixties, however, it was the planning function that received the greatest attention. Title II, Part 2 of the *Social Security Amendments of 1965* (P.L. 89-97) extended the planning money under P.L. 88-156 for an additional two years and increased the amount to \$5.5 million,⁶ and besides this money being made available directly, additional planning money was tied to substantive programs. During the Sixties, the dominant social policy for dealing with mental retardation was still institutionalization. "National action to combat mental retardation" therefore largely meant the construction of facilities. The *Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963* (P.L. 88-164),⁷ in making available \$70 million over three fiscal years, required that each state wanting funds submit a state plan for a program of construction of mental retardation facilities.⁸ The plan had to designate a state agency "as the sole agency for the administration of the plan . . ."⁹ and this agency had duties similar to those now delegated to the DD Council.¹⁰ The state plan also provided for the designation of a state advisory council including:

representatives of state agencies concerned with planning, operation, or utilization of facilities for the mentally retarded and of nongovernmental organizations or groups concerned with education, employment, rehabilitation, welfare, and health, and including representatives of consumers of the services provided by such facilities . . .¹¹

While the composition of this council was similar to that of the present-day DD Council, in its original form the advisory council had no listed function. Notably absent was the function assigned to its counterpart under another title of the same bill, authorizing money for construction of community mental health centers, which was "to consult with the state agency in carrying out such a plan...."¹² The *Mental Retardation Amendments of 1967* (P.L. 90-170) extended the money under P.L. 88-164 through June 30, 1970, and increased the amount to \$19 million in 1968, \$63.5 million in 1969, and \$161.5 million in 1970, although some of the money was earmarked for programs other than construction.¹³

THE EMERGENCE OF COMPREHENSIVE PLANNING FOR DEVELOPMENTAL DISABILITIES

In 1970, mental retardation programs were expanded to include all developmentally disabled people, i.e., those suffering from:

a disability attributable to mental retardation, cerebral palsy, epilepsy, or another neurological condition of an individual found by the Secretary [of HEW] to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains the age of eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual.¹⁴

The *Developmental Disabilities Services and Facilities Construction Amendments of 1970* (P.L. 91-517), which we will refer to as the 1970 Act, and the 1972 federal regulations supporting it¹⁵ required each state to create, as a condition for receipt of its share of funds for federally sponsored developmental disabilities programs, a state council to oversee all federal and, ultimately, all state DD activity.¹⁶

Under the 1970 Act, the DD Council, then known as the "State Planning and Advisory Council,"¹⁷ had a broad charge to plan and coordinate state efforts on behalf of developmentally disabled people. The 1970 Act required the Council to "review and evaluate its state plan" at least an-

nually and to "submit appropriate modifications to the Secretary [of HEW]...."¹⁸ The 1972 supporting regulations required that the state council be responsible for planning and coordinating activities on behalf of the developmentally disabled people in the state and for obtaining information on the accomplishments and effectiveness of programs operating in the state.¹⁹

The 1970 Act and 1972 supporting regulations were concerned with setting minimum levels of compliance. It was originally intended that, through its lack of specificity, this legislation would allow each council the flexibility to develop the kind of organization and activities most appropriate to the needs of its state.²⁰ However, an extensive study conducted by the General Accounting Office found that, under the 1970 Act, much variability of programs existed across states and that programs within a single state were frequently uncoordinated and had differing goals.²¹

The Senate Committee on Labor and Public Welfare, in its discussion of subsequent legislation, credited this study with bringing to its attention the fact that in most states the planning function, which Congress had intended to be the primary duty of the state councils, had been neglected.²² Although the House preferred to continue the vague and flexible approach,²³ the Senate pressed for a very specific Act which would more effectively implement the intent of Congress. The resulting legislation was the *Developmentally Disabled Assistance and Bill of Rights Act* (P L 94-103), which we will refer to as the 1975 Act. This Act greatly increased the council's role in the planning process and more generally laid the groundwork for the council to be an advocate for the interests of people with developmental disabilities during all facets of the development and implementation of state programs.

THE DD COUNCIL AS AN ADVOCATE

Neither the 1970 and 1975 Acts nor their respective supporting regulations are fully explicit as to the role the DD Council is to have in state government. Much of the ambiguity is no doubt intentional. Congress and HEW have hoped to maximize diversity among the states in their de-

velopment of programs and have required adherence only to broad guidelines. Nonetheless, comparison of the 1970 Act and its regulations with the 1975 Act and regulations indicates substantial change in what might be called the "working concept" of the DD Council that was informing the pronouncements of Congress and HEW.

The 1975 Act and its 1977 supporting regulations²⁴ imply a shift from a concept of the DD Council as a relatively unobtrusive planning and coordinating body, embedded in the state administrative apparatus, to a concept of the Council as a forceful advocate, using a broad range of strategies in a variety of arenas to represent the interests of people with developmental disabilities wherever they are not being heard. While the Council is definitely conceived as a body with a commitment to working cooperatively with other state agencies, it nonetheless has a status independent of those agencies. It is to be equal, if not above, other state agencies and it is to have at least the potential to challenge the decisions of other agencies.

Since neither Congress nor HEW has been fully explicit on the intended role of the DD Council, interpretations other than the one offered here are certainly possible. However, it is our position that many of the changes in the structure and mandate of the Council make sense only if it was intended to have an aggressive and broad-ranging role.

Changes Giving the DD Council More Independence and Responsiveness

The 1975 Act and its supporting regulations make several changes apparently intended to make the DD Council structurally independent of other state agencies and to facilitate the expression of disagreements with them.

Under the earlier Act, the Council, as a body having to be accounted for in the state plan but having no existence apart from the plan, had an ambiguous relationship to the planning process. Moreover, its role was clearly designated as "advisory." Under the 1975 Act, the term "advisory" was dropped from the designation, and it became the "State Planning Council."²⁵ In addition, the supporting regulations required that the DD Council be formally independent

of other agencies. A previously existing council or agency cannot serve as the DD Council.²⁶ Under the 1975 Act the Council's mandate was made separate from that of the state plan, and the Council was made responsible for the plan, which outlines the way in which the state will carry out its federally mandated duties in the DD area.²⁷ The Council was given the tasks of supervising the development of the plan, of approving it, of monitoring and evaluating performance under it, and of submitting, through the governor, periodic reports and revisions to the Secretary of HEW.²⁸

While under the 1975 Act the Council sets the goals of and approves the state plan and monitors state action under the plan, it actually neither prepares the plan nor administers it on a day-to-day basis. These functions are performed by a state agency designated in the plan.²⁹ Under the 1977 supporting regulations, the Designated State Agency is responsible for selecting from alternative strategies the best methods for achieving the goals and objectives the DD Council develops.³⁰ The design for implementation must be submitted annually as part of the state plan, and the Designated State Agency can revise the design as necessary, subject to the Council's approval.³¹

The Senate Committee Report on its version of the 1975 Act gives an idea of the kind of DD Council/Designated State Agency relationship Congress contemplated:

The Committee . . . has designed a system which provides for cooperation and complementary functions between the State Planning Council and the State agency which administers the program. The State Planning Council is to act in a leadership and advocacy role: to be responsible for the State Plan, for the general direction and goals of the program, for the identification of gaps and of needs, and to provide the uniform planning authority that is needed for the maximum effective utilization of the available resources....

Neither the State Planning Council nor the implementing State agency alone can do the job. While the Council has the prime responsibility for the development and updating of the comprehensive State plan,

the agency has the equally critical responsibility to select from alternative strategies those best methods of actually implementing the plan through its program development and program evaluation procedures. The Committee stresses that bringing needed services to persons with developmental disabilities can occur only if this partnership succeeds.³²

Thus, the Senate Committee Report articulates a somewhat idealized vision of the relationship between the DD Council and the state agency. In reality, however, there are many potential sources of friction between the two. In many states, the administering agency is more powerful than the Council, in which case the Council's authority may be more limited than Congress contemplated.

Besides directly establishing the DD Council as an independent entity, the 1975 Act made at least three other changes in an attempt to enhance the Council's independence and its ability to advocate effectively. The first of these changes was to establish a method of appointment of Council members. The 1970 Act left the method of appointment unspecified; the 1975 Act mandated appointment by the governor.³³ The purpose of this was to "place the Council in an administrative position above that of State agencies providing services"³⁴ It was anticipated that gubernatorial appointment would give the Council the prestige and authority to carry out its mandate. However, as the next chapter will show, Congress did not entirely succeed in this goal, because there are many state agencies that are independent of the governor, and because many local agencies have control over DD programs. In addition, since Council members often serve at the pleasure of the governor, Councils can be subject to the caprice of state politics.³⁵

The second change was an attempt to restructure the Council's relationship to its staff. The 1970 Act required only that each Council be "adequately staffed,"³⁶ and the 1972 supporting regulations interpreted this requirement to mean a full-time or part-time planning director.³⁷ Because staff was often provided by state agencies, conflicts in staff loyalties were not uncommon.³⁸ The 1975 Act thus required

"personnel adequate to insure that the Council has the capacity to fulfill its responsibilities. . . ."39 Although the Act contains no hard and fast definition of "adequate " and although all of the states have not carried through on this requirement, the Conference Report makes it clear that the intent of Congress was that the councils have an independent and capable staff:

The conferees, intend . . . that adequate funds from the state allotments shall be expended to provide qualified staff solely for purposes of assisting the state councils in carrying out their responsibilities and that such staff shall not have joint responsibilities to the state council and to any state agencies, but shall be responsible only to the state council.⁴⁰

The final change involved the composition of the Council. Under the 1975 Act, as under the earlier one, the Council was to be made up of representatives of state agencies concerned with developmental disabilities;⁴¹ representatives of local agencies and nongovernmental organizations and groups concerned with services for people with developmental disabilities (sometimes referred to as "private providers" of services); and "consumers" of such services.⁴² The 1975 Act made a subtle, but significant, change in the definition of consumers, who are to constitute one-third of the Council's membership. Consumers were defined restrictively as "persons with developmental disabilities, or their parents or guardians, who are not officers of any entity, or employees of any state agency or of any other entity, which receives funds or provides services under this part."⁴³ In making the consumer representative on the Council independent of any providers of services, the legislation took a step consistent with an increased advocacy role for the Council. This step was reaffirmed with the expansion of consumer representation in the 1978 Amendments.⁴⁴

New Duties Consistent With Broad Advocacy

At a minimum, the changes discussed above imply a more assertive role for the DD Council in the planning process. Under the 1970 Act and supporting regulations the Council's structure, staff, and composition were sufficient

for a passive planning role in which the Council could coordinate the diverse interest groups involved in the DD System. The 1975 Act and supporting regulations imply that the Council is to have a more active role and a variety of resources sufficient to allow it to take issue with those institutions it perceives as being insufficiently attentive to planning. However, in addition to facilitating a more assertive posture in planning, the 1975 Act and 1977 regulations introduced several new mandates that significantly broaden the advocacy strategies available to the Council. But just as the original planning mandate was not fully developed in the earlier Act, neither were these new mandates developed in the 1975 Act.

The first of these mandates requires the DD Council to monitor state action under the plan, strengthening the Council's role as overseer.⁴⁵ The Council must review the plan at least annually to determine whether the state is complying with its requirements.⁴⁶ The Council may notify the Secretary of HEW of its review findings, but is not required to do so.⁴⁷ The supporting regulations require HEW to hold hearings, if there is a question of noncompliance,⁴⁸ and ultimately to terminate funds as a penalty for noncompliance.⁴⁹

The second mandate involves the DD Council in the program planning of any state agency that could have an impact on people with developmental disabilities, regardless of whether they are presently being served. The Council is to "review and comment on all state plans in the state which relate to programs affecting persons with developmental disabilities."⁵⁰ This includes agencies such as corrections, which could have inmates with developmental disabilities, or transportation, whose plans for highway rest stops or for aid to mass transit could affect people with developmental disabilities. The purpose of this review is to give the DD Council "the capacity for getting cross-agency cooperation in carrying out its duties."⁵¹ Moreover, the term "plan" is to be understood broadly as *any program*—no matter how it is funded, and no matter whether its plan is formal or informal—that *affects or has the potential to affect people with developmental disabilities*.⁵² However, there is no requirement that each agency submit its plan to the Council as a matter of course.⁵³

The third mandate concerns the DD Council's relationship to the newly established "Protection and Advocacy [P&A] System" in each state. The same 1975 Act that strengthened the Council also required, as a condition for receiving continued federal aid, that each state establish a P&A System independent of any state agency providing treatment, services, or habilitation to persons with developmental disabilities. This system is to have "the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the state. . . ." ⁵⁴ The purpose of the P&A System is set out in the Senate Committee Report on its version of the 1975 Act:

This newly established agency shall have the authority to review all complaints regarding infringement of human rights, denial of benefits, and any other complaint on the part of an individual Such a protective and personal advocacy is needed to provide a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his [sic] rights as an individual citizen may be being violated. ⁵⁵

Since the Protection and Advocacy System is to be independent of other state agencies concerned with developmental disabilities, it may appear that Congress meant to limit the DD Council's advocacy role. However, the HEW guidelines for the P&A System ⁵⁶ suggest instead that there is a division of labor between the DD Council and the P&A System. The Council is to be an *internal* advocate, using to greatest advantage its position within state government, and an *interest* advocate, representing developmentally disabled people *as a group*. The P&A System is to function as an *external* advocate, working outside of the DD delivery system (giving up some resources and contacts, but gaining more flexibility to challenge the system), and as advocate of *individual* rather than of group interests.

The advocacy role of the Council includes a concern for effective functioning of the P&A System. For example, in

the HEW guidelines there was a restriction on the agency designated to *implement* the P&A System, but not on the agency to plan it:

It is the opinion of the HEW Office of the General Counsel that the State DD Planning Council could *not* serve as the implementing agency for the protection and advocacy system, since the participation on the council by representatives of the state agencies providing treatment, service, and habilitation would conflict with the requirements of Section 113(a)(2)(B). However, this Section does not preclude the State Planning Council from serving as the body for *planning* the P&A System.⁵⁷

In addition, in those states where the designated agency for the P&A System is a non-public one, the guidelines recommend that the governor appoint a state official to serve as a liaison between the governor's office and the advocacy agency. "This liaison official might be the executive director of the State DD Council. . . ." ⁵⁸

The division of labor between the DD Council and the P&A System is explicitly set out in various subsections of the HEW guidelines:

Council members should be ardent advocates in program development through identification of the resources available to the developmentally disabled population of their state from other federally supported state programs. *The Council is a vehicle for collective advocacy*

[The council's duties include:]

Maintaining close liaison and providing back-up support to the advocacy agency . . . and commenting on the [P&A] plan being submitted to the Governor
[and]

Evaluating annually, the ongoing protection and advocacy system on the basis of the established goals of the system and recommending necessary changes to the system and to the Developmental Disabilities Office [of HEW].⁵⁹

Thus, rather than being excluded from a role in protection and advocacy, the Council was given an important role as overseer.

A final mandate relates to what might be termed "general advocacy." The HEW guidelines for the P&A System include a variety of requirements that, taken together, are best interpreted as a list of the kinds of action the DD Council can and should undertake in addition to whatever activities the P&A System may be engaged in. These actions include requirements that the DD Council:

- Provide "leadership to all State agencies in promoting a viable advocacy system in the State."
- Use "media, conferences and other approaches to make the public more aware of rights issues."
- Encourage state agencies concerned with vocational rehabilitation and related services to increase both the amount and quality of their services.
- Identify "state level and intrastate, regional level mechanisms for effecting planned change."
- Collaborate "with other official or volunteer efforts related to improving the quality of life for the handicapped"
- Propose or critique legislative bills.⁶⁰

TITLE V: HOW DOES IT AFFECT THE DD SYSTEM?

Title V of the Comprehensive Rehabilitation Services Amendments of 1978 (P.L. 95-602) makes a variety of changes in the DD system and in the structure and role of the DD Council. But on the basis of information available at this time, none of these changes would seem to alter the analysis presented in the previous part of this chapter. The easiest way to review the changes Title V made is to go through the legislation systematically, which we do in this section.

Title V reflects Congressional interest in integrating developmental disabilities policy with a developing compre-

hensive policy for all persons with handicapping conditions. Thus, unlike the earlier DD Acts, which originally pertained only to persons with mental retardation and later only to persons with developmental disabilities, the 1978 Amendments to the Acts were included in a new Act having the primary purpose of amending the Rehabilitation Act of 1973.⁶¹ As a result, there is some concern that developmental disabilities planning and programming will now come under the administrative ambit of state vocational services agencies, that developmental disabilities will disappear as a unique interest entitled to its own programs, and that as a consequence the Council's bargaining power will suffer. Subsuming developmental disabilities under vocational services would change the DD system in most states, since most developmental disabilities programs are currently administered by an umbrella state planning agency or a human services agency which also deals with severely disabled persons.

It is as yet too early to tell what the impact of such a change will be or whether, in fact, it is even intended. Congressman Paul Rogers (D.-Fla.), a leading congressional proponent of developmental disabilities legislation, has argued that Congress did not intend to link the DD system with vocational services, and that the DD Amendments were tied to the educational-vocational rehabilitation bill for purely strategic reasons. Neither the DD Amendments bill, H.R. 11764 (95th Cong., 2nd Sess.), nor the Rehabilitation Services Bill, H.R. 12467 (95th Cong., 2nd Sess.), had passed by early fall. To beat the fall recess of Congress, the bills were combined, voted on and passed.⁶²

However, other observers are not quite so sure that this marriage was purely for convenience. There was more opposition to the DD Amendments in 1978 than in 1975, when P.L. 94-103 was passed.⁶³ While the opposition attacked many portions of the 1978 bill, the biggest objection was that Congress should combine all programs for handicapped citizens into a "comprehensive" program, particularly one emphasizing rehabilitation-job training programs.⁶⁴ Indeed, at least one state vocational rehabilitation administrator believes that the 1978 Act brings the developmental disabilities population into his purview *far more so*

than before.⁶⁵ Thus, while Title V retains the existing "autonomous" character of the DD system at least through 1981, the area is clearly one in which change may come.

Part A of Title V contains several modifications of pre-existing developmental disabilities law; perhaps the most important of these is a new definition of a developmental disability. Whereas prior definitions were based on specific conditions or symptoms, e.g., Down's Syndrome, epilepsy or cerebral palsy, the Title V definition includes any person having a handicap which restricts his or her functioning independently in society.⁶⁶ DD advocates have long championed this "functional" approach to developmental disabilities.⁶⁷ Many developmental disabilities have diverse or complex origins and treatments, so that they frustrate etiological classifications and public programs based on them. As a result, many persons have been left unserved. By seeking to identify those persons having disabilities which substantially handicap their capacities in at least three major life-activity areas, the new definition looks more to the effects of handicapping conditions than to their particular symptoms or causes.

Nevertheless, for all its advantages this new definition may cause some administrative problems within the DD system, though not necessarily for the DD Council itself. At least for a time there are likely to be problems in determining eligibility for developmental disabilities benefits. State legislators fearing "Proposition Thirteen fever" already are asking developmental disabilities service agencies to hold the line on programs for persons with the disabilities covered under the 1975 law.⁶⁸ While the estimates necessarily vary with the interpretation and the application of the new definition to individuals, it has been argued that persons having any one or more of 30 to 40 conditions not previously covered explicitly in DD law will now be classified as developmentally disabled.

Complicating this definitional problem is the fact that the law does not define a key phrase, "substantial functional limitation." Another clause in Part A, the one establishing a service priority "to those persons whose needs cannot be covered or otherwise met under the Education for all Handi-

capped Children Act, the Rehabilitation Act of 1973 or other health, education or welfare programs," may further complicate administrative problems.⁶⁹ This clause could turn developmental disabilities into a catch-all category in which persons denied services under other programs seek developmental disabilities aid as a last resort.

The new definition and the identification of priority services (discussed below) will not impact on the DD Council itself as directly, but might make the Council's advocacy tasks more difficult in the short run. The state legislature, public agencies, potential service recipients and the general public will need to be re-educated about developmental disabilities and the DD system. It may be harder to get segments of the more diverse developmental disabilities group to work together to protect and advance their interests, and the Council may have to work harder to coordinate actors in the DD system. Nevertheless, the new definition will in the long run make the DD Council more successful in its efforts to advocate the interests of all persons with developmental disabilities, because it will no longer be limited by artificial distinctions.

Part A of Title V also identifies four priority services and ties their provision to the provision of federal funds. These services include case management services, child development services, alternative community living arrangement services and nonvocational social-developmental services.⁷⁰ Case management services are basically those which assist persons with developmental disabilities to gain access to general therapeutic services. Child development services stress prevention, identification and early evaluation of developmental disabilities. Alternative community living arrangements have been a goal under the 1975 Act's mandate for deinstitutionalization, and this new, direct federal mandate may assist state developmental disabilities advocates who have had limited success in this area.⁷¹ Social developmental services are those which assist a person in performing daily living and working activities. Under previous legislation, states had much more leeway in determining priority services within their jurisdictions, but these same four areas were nevertheless predominant.

While the changes Part A made are noteworthy, equally if not more important are the Title V continuities with previous legislation. Most significantly, the mission of the DD Council does not change. The new law restates Congressional intention to establish a federal-state DD system based on comprehensive planning, coordinated service delivery and the protection of individual rights.⁷² It also continues to see the DD Council as focusing primarily on internal advocacy in the federal-state DD system, while the P&A System retains an independent mandate for external advocacy. Similarly, the new law affirms the DD Bill of Rights articulated in the 1975 Act⁷⁴ and makes it clear that these rights are *in addition to* the constitutional and other legal rights afforded all citizens.

Parts B and C of Title V deal directly with the DD Council and the State Plan. The Council and the Designated State Agency now must "jointly develop" the State Plan.⁷⁵ The new law is vague as to precisely which institution is responsible for actually writing the Plan.⁷⁶ While several technical requirements for the State Plan remain intact, the Plan must now include more information than was required previously. The foremost data here are descriptions of the extent and scope of services being provided to developmental disabilities clients under other state plans for federally-assisted state programs and of how developmental disabilities funds will be used to complement funds other programs provide.⁷⁷

In addition, the Plan must indicate which priority service(s) the state wishes to pursue. By the second year of the Plan, 65% or \$100,000 of the federal funds, whichever is greater, must be committed to the priority service(s) named.⁷⁸ The Plan must also provide for the assessment of the adequacy of skills of persons serving persons with developmental disabilities and the adequacy of state programs for training these professionals and paraprofessionals.⁷⁹ The overall impact of the State Plan amendments is to give the federal government somewhat more control of the content of the State Plan and, hence, of state developmental disabilities programs.

Besides modifying the workload required in preparing the State Plan, the Title V amendments make the DD Coun-

cil's advocacy through the Plan more directed. The Council helps coordinate the DD system and acts as an internal advocate by identifying priorities in the Plan and by seeing that state agencies implement the Plan. The specificity with which Title V describes the content of the State Plan limits the discretion the DD Council formerly had in identifying priorities and specific uses for developmental disabilities funds. However, it remains to be seen just how much impact that this modest "federalization" of the State Plan will have.

Two other changes in Parts B and C of Title V seem directly to enhance the DD Council's capability for advocacy. First, the states are now mandated to staff the DD Councils according to provisions HEW sets out,⁸⁰ a requirement that could increase the Council's independence from the state agency to which it is attached. Second, whereas the 1975 Act directed that developmental disabilities consumers, service providers and agency representatives be represented in equal proportions on the Council, Title V requires that one-half of the Council membership be persons with developmental disabilities or their close relatives or guardians; i.e., be persons representing consumer interests.⁸¹

One-third of these consumers must be persons with developmental disabilities; another one-third must be immediate relatives or guardians of persons with mentally impairing disabilities of which at least one is a near relative or guardian of a person living in an institution; additionally, the Council must include a representative of a higher education training facility.⁸² During the Congressional hearings and debates, the increase in the percentage of consumer representatives on the Council was interpreted in many ways. However, it seems that Congress decided consumer representation would be effective only with an amplification of the consumer voice on the Council, and that this voice was necessary to help insure an advocacy role for the Council.

CONCLUSION

Review of the development and content of developmental disabilities legislation and regulations finds much to support and little to contradict the position that the DD Coun-

cil is intended to be the key agent of advocacy in the DD system. Over the years the duties of the Council have been greatly expanded, giving it a potential role as watchdog and intervenor in all state activity that could in any way affect persons with developmental disabilities.

Although some of the Council's new responsibilities, such as its relationship to the Protection and Advocacy System, have been clearly spelled out, others, such as its obligation to review and comment on agency plans and its role in general advocacy, have been only mentioned. It remains for each state to develop these duties within the context of its own needs. The task of this monograph is to present a plausible program for carrying out these advocacy responsibilities in a manner that is consistent with existing law and with what is known about the social conditions of successful advocacy.

FOOTNOTES

1. The President's Panel on Mental Retardation, *National Action to Combat Mental Retardation*, p. 201.
2. *Ibid.*, p. 165.
3. *Ibid.*, p. 164-167.
4. S. Rep. No. 551, 88th Cong., 1st Sess. 3 (1963).
5. *Ibid.*
6. P.L. 89-97 (1965), §211(a).
7. Note that until recently mental retardation was widely viewed as a type of mental illness. This view has changed, but many states still administer programs for mentally retarded people and mentally ill people out of the same "Mental Health and Retardation" agency.
8. P.L. 88-164 (1963), §134(a)(4).
9. *Ibid.*, §134(a)(1).
10. *Ibid.*, §134(a)(9)-(10).
11. *Ibid.*, §134(a)(3).
12. *Ibid.*, §204(a)(3).
13. S. Rep. No. 725, 90th Cong., 1st Sess. 7 (1967).

14. P.L. 91-517 (1970), §102(b)(5). The definition of developmental disability was later expanded to include autism and dyslexia. See P.L. 94-103 (1975), §102(7).
15. 37 CFR 18. 424-31 (1972).
16. Although the Council directly administers only a small part of the federal DD money going to the state, receipt of the total federal allocation is contingent on the existence and functioning of the Council.
17. P.L. 91-517 (1970), §134(b)(1)(A).
18. *Ibid.*, §134(b)(9).
19. 37 CFR 18. 429 (1972), §416.53-54.
20. Hammer and Richman, *The Orientation Notebook*, 3-2, 1.
21. Comptroller General of the United States, *Federal Programs for Education of the Handicapped*, pp. 24-37.
22. S. Rep. No. 160, 94th Cong., 1st Sess. 18-19 (1975).
23. See H. R. Rep. No. 473, 94th Cong., 1st Sess. 25-44 (1975).
24. 42 CFR 5272-5292 (1977).
25. P.L. 94-103 (1975), §137(a).
26. 42 CFR 5284 (1977), §1386.61(a).
27. P.L. 94-103 (1975), §137(a) (b)(1).
28. *Ibid.*, §137(b)(1), (2), (4). The Regulations elaborate on the role of the DD Council. See 42 CFR 5284 (1977), §1386.60.
29. H. R. Rep. No. 473, 94th Cong., 1st Sess. 33 (1975). S. Rep. No. 160, 94th Cong., 1st Sess. 19 (1975).
30. 42 CFR 5284 (1977), §1386.50(b).
31. *Ibid.*, §1386.50(c).
32. S. Rep. No. 160, 94th Cong., 1st Sess. 19 (1975).
33. P.L. 94-103 (1975), §137(a).
34. S. Rep. No. 160, 94th Cong., 1st Sess. 15 (1975).
35. Hammer and Richmar, *The Orientation Notebook*, 3-2, 4. Neither the legislation nor the regulations say anything about members' terms of service on Councils. In practice, length of service is set by the governor, by state laws or by the Council's own bylaws.

36. P.L. 94-517 (1976) §134(b)(8)
37. 37 CFR 18.429 (1972) §416.50(c)
38. Litvin and Chavan, *Developmental Disabilities: A Legislative Overview*, p. 16
39. P.L. 94-103 (1975) §137(c)
40. H. R. Rep. No. 473, 94th Cong., 1st Sess. 36 (1975)
41. Under the most recent regulations, 42 CFR 5284 (1977) §1386.61(b), "In minimum, the following Federal/State programs must be represented by the State agency membership on the Council: Education of the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, comprehensive health planning, and mental health."
42. P.L. 94-103 (1975) §137(c)
43. *Ibid.* Cf. 37 CFR 18.429 (1972) §416.50(b): "A consumer may not include a person whose major occupation is either the administration of activities or the provision of services, and may include developmentally disabled persons or representation of a parent group."
44. See discussion below.
45. P.L. 94-103 (1975), §137(b)(2)
46. 42 CFR 5282 (1977) §1386.16(b)
47. *Ibid.*
48. *Ibid.*, 5284-5287, §1386.80-112
49. *Ibid.*, 5282, §1386.16(a). HEW would be unlikely to invoke this procedure, however (telephone conversation between James Jacks, Director of Program Operations for the Developmental Disabilities Office, and Lynn Malchow, DD project assistant, 6-14-77)
50. P.L. 94-103 (1975), §137(a)(3). Both the legislation and the Regulations make clear that the review and comment is to be prior to the submission of the plans. See P.L. 94-103 (1975) §133(b)(28) and 42 CFR 5283 (1977) §1386.30
51. 42 CFR 5290 (1977)
52. Telephone conversation between Terry Lynch, staff member of the National Advisory Council on Services and Facilities for the Developmentally Disabled (NACSFDD), and Lynn Malchow, DD project assistant, 6-22-77. Mr. Lynch based his broad interpretation of the scope of review and comment on a provision in the Explanatory Statement of the Joint Conference Committee which accompanied the House version of the 1975 Act. The

Report points out that in regard to the State Plan's requirements concerning the DD Council, the Conference substitute conforms to the Senate amendment: that is, that the State Plan "(4) must provide that all relevant information concerning any programs which affect the developmentally disabled shall be made available by project and State agencies to the Council." See H. R. Rep. No. 473, 94th Cong., 1st Sess. 35 (1975).

53. 42 CFR 5278 (1977)
54. P.L. 94-103 (1975) §113(c)(A)
55. S. Rep. No. 160, 94th Cong., 1st Sess. 38 (1975)
56. *Interim Guidelines* (for Development and Implementation of a System for Protection of the Individual Rights of and Advocacy for Persons with Developmental Disabilities) FY 1978. Revised 11-1-76, hereafter referred to as the HEW *Interim Guidelines*
57. *Ibid.*, p. 8
58. *Ibid.*, p. 10
59. *Ibid.*, p. 19
60. *Ibid.*, pp. 19-20.
61. P.L. 93-142 (1973)
62. Videotaped program, Media Project, Region V Consortium, UAF Coordination Project
63. Comment made by a Senate staff member in an interview September 27, 1978.
64. See Hearings Before the Subcommittee on Health and the Environment of the Committee on Interstate and Foreign Commerce, 95th Cong., 2nd Sess., Developmental Disabilities Act Amendments of 1978, Part I
65. Madison, Wisconsin *The Capital Times*, November 13, 1978
66. A developmental disability is now defined as
"a severe, chronic disability of a person, which is attributable to a mental or physical impairment or combination of mental and physical impairments which is manifested before the person attains age twenty-two [and] is likely to continue indefinitely [and] results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency; *and* reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated."

- 67 See generally Boggs, "Federal Legislation, 1967-71" in J. Wortis (ed.) *Mental Retardation, An Annual Review IV* (1972)
- 68 See *Hearings*, *supra* note 64, at 134-136
- 69 P.L. 95-602 (1978), amending P.L. 94-103 §101(b)(2)(A)
70. P.L. 95-602 (1978), Title V §503(2)(c)(B)-(D)
- 71 Alternative community living arrangements, particularly residential group homes, have run into stiff opposition from the local communities in which they were to be located
- 72 P.L. 95-602 (1978) Title V §101
- 73 P.L. 95-602 (1978), Title V §§113, 508
- 74 P.L. 95-602 (1978), Title V §111
- 75 P.L. 95-602 (1978), Title V §512
- 76 Under P.L. 94-103 the designated state agency drafts the plan and the Council approves it. See above
- 77 P.L. 95-602 (1978), Title V §511
- 78 *Ibid*
79. *Ibid*.
- 80 *Ibid*
- 81 P.L. 95-602 (1978), Title V §512
- 82 *Ibid*

CHAPTER 2

THE DD COUNCIL AND THE STRUCTURE OF STATE GOVERNMENT

As we have shown in the previous chapter, federal law creates the opportunity for the DD Council to advocate in state and local government on behalf of persons who are developmentally disabled. But this opportunity does not exist in a vacuum; rather it is shaped by the governmental structure in which the Council is embedded. In this chapter we discuss that structure and the decision-making process within it.

GOVERNMENT STRUCTURE

United States government is commonly described as being based on the principle of separation of powers among the legislative, executive and judicial branches. The legislative branch makes basic policy choices by enacting laws and by providing the funds to put those policy choices into effect. The executive branch is responsible for implementing the policy choices, while the judicial branch authoritatively construes the law when disputes arise.

State governments also are based on the principle of separation of powers. At the state level, however, the concept of three branches provides an incomplete understanding of the structure of government; it is more useful to view state government as including two additional branches: the local branch and the independent administrative branch.

The constitution and laws of each state delegate many important decision-making functions to units of local government. Local government decision-makers are almost always directly elected by local constituencies and are therefore largely independent of state control. Local school boards, city councils and village and county boards are all elected. Their decision-making powers, which may be very significant to developmentally disabled people, are exercised independently of the other branches of government.

State government structure also includes important state-level decision-makers who, because of their direct election or the nature of their appointment, are essentially independent of other branches of government. Elected officials such as an attorney general, superintendent of public instruction or state auditor all exercise significant executive or administrative functions but cannot properly be considered a part of the executive branch under the governor. An appointed state board of education, university board of regents or board of health and social services whose members serve long terms with staggered expiration dates exercise such a degree of independence that they are usefully distinguished from executive branch agencies whose heads are appointed by and serve at the pleasure of the governor.

Executive, Administrative and Local

What we have called the executive, administrative and local branches of government are all engaged in the same type of activity. Each has as either its sole function or as one of its functions the implementation of legislative policy. These branches combine to carry on functions that are performed in the federal government by the executive branch. While it is useful to consider the structure of these three branches together, it is also important to distinguish among them for at least two reasons.

First, such a distinction reveals a basic flaw in the DD System Congress created. As noted in Chapter 1, Congress hoped to vest the Council with the prestige and the authority to carry out its mandate by requiring that Council members be gubernatorial appointees. However, while this method of appointment can give the Council added leverage, there is no guarantee that it will. There are a variety of other variables that can affect the Council's ability to influence other agencies. Perhaps the most important of these is the Council's location in state government. In some states the Council reports directly to the governor. In others it is located within a division of a department with at least two layers of bureaucracy between it and the chief executive. Regardless of the Council's location, the fact that persons who are not gubernatorial appointees head many

state agencies and all local governments affects the Council's relationship to other agencies. Such agencies are not part of the same executive hierarchy as the Council. They have their own constituencies and, since they do not serve at the pleasure of the governor, are more likely to be responsive to those constituencies than to the governor or to agencies whose status and authority derive from gubernatorial appointment.

A second reason for keeping in mind the distinctions between the executive, administrative, and local branches of government is the relevance of these distinctions for the strategy and tactics of the advocate. From the standpoint of someone concerned with influencing policy perhaps the most striking structural characteristic of state and local government is the diffusion of policy-making power. At the state level the structure is in large part designed to prevent not only the concentration of governmental power in general, but the concentration of executive power in particular. The structure of state and local government, as we have seen, carries the concept of divided power at least two steps further than the federal model by dividing power between the state and local units of government and by dividing executive power at the state level.

Where this diffusion of policy-making authority is most striking is in the field of education. For example, in none of the six states (Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin) in the Central administrative division of HEW does the governor exercise control over education. Either an elected Superintendent of Public Instruction¹ or an independent Board of Education² has executive responsibility for elementary and secondary education. These state-level entities in turn share this power with local boards of education.³ In higher education, independent boards of regents or similar bodies make executive policy.

In Michigan, for example, the state education department is headed by an eight-member elected State Board of Education. Indiana combines an appointed State Board of Education and an elected Superintendent of Public Instruction. In Wisconsin the State Superintendent is elected to a four-year term and heads the State Department of Public Instruction. In each state, the state education agency is insulated in

substantial degree from gubernatorial control and has significant program responsibility affecting persons who are developmentally disabled. The people responsible for these programs are answerable to an independent public officer who in most cases is in turn answerable directly to the electorate.

Each of the six states in the Central region also has a system of substantial local autonomy in public education. Local school districts, headed by elected boards of education, are directly responsible for most of the administration of education programs. Decisions concerning such important matters as construction of facilities, employment of teachers and selection of teaching materials are made at the local level. Local school districts also levy the taxes that provide a substantial portion of the funding for elementary and secondary education. These decisions, many of them having obvious implications for developmentally disabled people, are made by officials directly responsible to a local electorate and removed from the control of the states' chief executives.

Illinois provides a good example of the consequences of this diffusion of responsibility in education. In Illinois the Division of Specialized Educational Services of the Office of Education administers special education services for developmentally disabled children in public schools. Although local school districts are required by statute to provide "a comprehensive program of special education for exceptional children,"⁴ they are given wide discretion in determining the content of those programs. Local school boards are elected in each school district; they are responsible to the Office of Education (*not* directly to the deputy director for Specialized Educational Services), primarily through a series of performance reports. Considerable funding for local school activities is beyond the Office of Education's control. It is difficult, then, for special education goals determined by state agencies to be enforced in this structure without substantial local cooperation.

To complicate the picture, the Division of Specialized Educational Services does not plan these services. If the deputy director finds that compliance with vocational training or psychological services goals is impossible given

the funding structure in the school districts, he or she must alert planning officials elsewhere to adjust the program. These institutions include the Education Planning Office, the Office of Education Advisory Council on Education of Handicapped Children, and the Superintendent of Education's administrative assistant for planning.⁵ The Office of Education must then consult the Division of Developmental Disabilities in the Department of Mental Health and Developmental Disabilities (the designated state agency for developmental disabilities in Illinois). In the case of vocational rehabilitation, the independent Illinois Board of Vocational Rehabilitation should also participate in planning changes in strategy. Although not *required* to participate in the policy-planning process, the Commission on Mental Health and Developmental Disabilities, consisting of six state senators, six representatives and seven citizens, has been influential in stimulating the legislature to provide more funds. So they should be consulted about any special education problem as well.

Outside the field of education, state and local governmental structure continues, in varying degree, the pattern of diffuse power. The original state constitutions in each of the six states we are considering provided for the direct election of all of the principal officers of the executive branch. In addition to the governor, a secretary of state, state treasurer, attorney general and, in some cases, a state auditor were elected to head their respective executive departments. Each of these departments was therefore structurally insulated from gubernatorial control. Although some of these offices have lost much of their status over the years through allocation of their functions to executive branch agencies, others retain important duties. As the chief legal officer in each state, the attorney general may significantly influence the implementation of programs. If a question of legal authority arises, the attorney general's pronouncement on the matter may effectively be final.⁶ If a program requires prompt and adequate legal services for its success, the attorney general's allocation of the resources under his or her control may determine the program's success or failure.

In the early years of state government elected officials headed each of the "executive" or administrative agencies.

As the years passed and the needs of government changed, however, new state departments were created. In most cases these departments, like the federal executive department, are now headed by officials appointed by and serving at the pleasure of the governor. In some instances, however, the pattern of divided executive power has been continued by placing the department under the control of an independent board or of a department head appointed for a fixed term. For example, Indiana and Minnesota each have State Boards of Health with some degree of autonomy over programs their agencies administer.

Much the same situation exists in local government. In each of the states, units of local government—counties, towns, cities and villages—have been delegated the police power or certain aspects of it. The power is generally defined as the power to legislate for the public health, safety and general welfare. In the exercise of this broad power, local governments can have much to say about the success or failure of programs affecting persons who are developmentally disabled. For example, local zoning, housing or building codes may determine whether community-based residential facilities for persons with disabilities will succeed. Local officials may zone to keep such facilities out of residential areas, or they may impose building or housing code requirements which make construction or operation impossible. These decisions are made by local elected officials, who are responsible to local electorates and are not answerable to the governor or any other state-level official.

Units of local government may also control expenditures of funds for programs affecting developmentally disabled persons either through general expenditures or through special taxing powers. Local taxes build, remodel and staff schools, hospitals, vocational and technical training programs, and a variety of other relevant programs.

Overall, then, much of the decision-making process that the DD Council seeks to influence is insulated from the executive branch and from the influence of gubernatorial appointees. This is a fact the Council cannot ignore, but it does not mean the Council is incapable of affecting such decisions. Indeed the fact that it is located within the state government structure may help to make it the most effec-

tive advocate in the DD system. Non-governmental advocates and advocacy groups are unlikely to have the degree of access to information or to decision-makers that the Council has. By taking full advantage of this access, the Council may be quite effective as an inside advocate on some issues. It is apparent, however, that limitations imposed by structural factors must lead to modest expectations of the Council's ability to affect some executive and administrative policy decisions.

Legislative

The state legislature is technically the ultimate policy-making authority in the state developmental disabilities system. Indeed state and federal constitutions combine to make the state legislature the repository of all legislative powers not specifically delegated to Congress or to local governments. Legislatures allocate funds, determine general policy outlines, oversee administrative activities, and in some cases, provide direct, private assistance to individuals or groups.

Judicial

While state-level courts ordinarily do not create entitlements, and while the ability of any court to implement new rights is tenuous,⁷ in recent years there nonetheless have been efforts to create or enforce a broad array of entitlements through state court action, and lower court judges and lawyers have been put under close scrutiny for violating or incompletely serving rights.⁸ Developmentally disabled persons are being given broader due process protections regarding classification⁹ and commitment proceedings. Rights to free public education and full educational opportunity are being vindicated.¹⁰ However, most judicial action of broad-ranging consequence is still likely to take place at the federal level, in part because of state court reluctance to scrutinize state agency activities regarding civil matters, and in part because many DD entitlements are based on federal, not state, laws. As more states adopt comprehensive DD Bills of Rights, state courts should become more involved in the DD cause.

Once entitlements are established through legislative or judicial action, state courts are the body that most often vindicates the individual rights created.

GOVERNMENT DECISIONS

Decisions of concern to people with developmental disabilities tend to fall into three categories: policy planning, policy implementation and funding or budgeting. The following discussion will utilize these three categories to demonstrate the role each branch of government plays and how the DD Council as an advocate may influence decision-making.

Policy Planning

The importance of policy planning is recognized by the federal legislation which assigns to the DD Council the responsibility for supervising the development of a state DD plan and for reviewing and commenting on any state agency plans affecting persons with developmental disabilities. Policy planning of concern to the DD Council is largely the province of state executive and administrative agencies. Local government planning also may affect people with developmental disabilities, but the extent to which it occurs and the means by which it is carried out vary so widely, and information about it is so difficult to obtain, that useful generalizations are impossible.

Policy planning is essentially an informal process governed by a few rules of procedure. There is seldom any requirement that anyone other than agency people be informed of or allowed to participate in the process.¹¹ Federal law and policy, however, place the DD Council in a unique position to influence state planning by requiring that the Council supervise the state planning process. The importance of the Council's access to the planning process should not be underestimated. One frustration of many advocates is that plans are often solidified and decisions irrevocably made before the advocate knows that the process is going on.

The effectiveness of the DD Council's advocacy in the planning process depends on its ability to persuade or coerce those agencies having legal authority to make decisions regarding planning. The Council's authority is limited to supervising the development of and approving the state DD plan and to reviewing and commenting on other state plans relating to programs affecting persons with developmental disabilities. To get what it needs from the planning process, the Council must be able to get others to do what it wants.

While its status as a gubernatorially appointed body is not in itself sufficient to guarantee an impact, the Council has additional authority deriving from its federal mandate. Unless DD Councils exist and perform mandated functions, states run afoul of HEW funding requirements for developmental disabilities projects.¹² This fact gives the DD Council additional leverage affirmatively to plan, monitor, evaluate, and advocate within the DD system, even though state agencies would otherwise resist incursions on their authority or the subjecting of their operations to review by others. Council members have noticed this trend:

Although agencies would just as soon not be bothered by the Council . . . [the Council] has been successful in influencing agency policies and programs somewhat since [agencies] realize the Council is here to stay.¹³

Policy Implementation

Of course policy planning is only a first step. To reap the benefits of planning it is necessary to implement policy. Implementation may require action on the part of the state legislature, of one or more state agencies, of one or more units of local government or of any combination of these bodies. The means by which an advocate may influence policy implementation depends in the first instance upon which governmental agency is making the decision.

If a change in state statutory law is required, the only body constitutionally authorized to act is the state legislature. Such a change would be required if, for example, it were necessary to confer legal authority or impose legal obligations on a state agency or a local government.¹⁴

State legislatures, like Congress, operate on a committee system. In many instances the real decision-maker is the legislative committee, a fact of considerable relevance to any advocate seeking to influence a legislative decision and of particular importance to the DD Council. Restrictions on lobbying activities may limit the ability of the DD Council directly to influence legislative decisions. However, legislative committees often engage in fact-finding and investigations through the use of hearings and more informal methods in which the DD Council can participate.

Most policy implementation does not require new state legislation. State legislatures have delegated substantial decision-making authority to state agencies such as State Departments of Public Instruction, Health or Welfare. In most cases the legislature will establish broad policy and delegate to an agency the power to fill in the policy details and to administer the program on a day-to-day basis. An agency may be empowered, for example, to set standards for eligibility for special education programs and to decide whether a particular individual meets these standards. Decisions by executive and administrative agencies are made through processes established in part by state Administrative Procedure Acts.¹⁵ These laws are generally patterned after the same prototype legislation and create two types of procedure, "Rule-Making" and "Adjudication." A third residual category of decision follows a procedure usually called "informal decision-making."

Rule-making is the process whereby an agency adopts a general regulation, standard or policy to implement or interpret legislation it enforces or administers. A State Department of Public Instruction's adoption of standards of eligibility for special education programs would be an example of rule-making. Rule-making procedure generally requires an agency to publish notice of its intent to adopt rules and to provide an opportunity for public participation in the process. Public participation may be by an appearance at a rule-making hearing or by filing written comments on the proposed rules, and any interested person may participate in this manner. However, despite an agency's best efforts, the nature of published notice is such that few people are able to spend time scanning the columns of

sometimes obscure publications to determine whether an agency is proposing adoption of a rule of interest. Moreover, even if an interested person does become aware of such a proceeding, the costs of preparing testimony may be prohibitive. Accordingly, the DD Council as advocate may serve an important function by participating in rule-making hearings and by assisting other individuals and groups in their participation.

An adjudication or "contested case" is a proceeding in which an agency holds a hearing to settle a dispute; for example, a proceeding in which an agency decides whether a person denied benefits under a particular statute is entitled to a reversal of that decision. Participation in such proceedings is not ordinarily open to the general public.¹⁶ But under certain circumstances a DD advocate might have an interest in the outcome and may be allowed to intervene.

The vast majority of governmental decisions are neither rule-making nor adjudication but informal decisions made without hearing or any formal opportunity for anyone outside the agency to participate.¹⁷ Most decisions about the allocation of benefits, the construction of facilities, the employment of personnel and the like are made by a process which does not provide for notice, hearing or written comment. However, the lack of a formal procedure does not mean that there is no opportunity to influence the decision-maker. Advice and information often may be accepted and even solicited before a decision is made. Even after an initial decision it may be possible through informal discussion or other means to persuade the decision-maker to change his or her mind. The DD Council in particular may be in a position to use informal means of persuasion to good effect. Its existence as a part of state government, its access to information, its ability to mobilize public support and its ability to seek assistance from other governmental agencies and officials may enable it to be a highly successful participant in the informal decision-making process.

In dealing with governmental agencies at the level of informal decision-making it is important to understand that policy issues are identified and resolved at top levels but implemented at lower levels. To maximize their production of benefits, advocates must understand agencies in terms of

their constituent units. The major task here is to unmask the real lines of authority; for example, if field staff actually determine how much vocational training is available, advocates should work there.

Budgeting

No agency can continue to function without funds and no program can be implemented unless it is funded. It is important, therefore, that an advocate be aware of the budget process and the potential for participation in it.

Some states have initiated a system of "program budgeting" that identifies in the budget which funds are for which programs. The budget documents also may contain explicit criteria allowing decision-makers in the budget process to evaluate the performance of each program.

The budget process varies from state to state, but in each state there is some stage at which public participation is invited through appearance at public hearings. In most states an omnibus budget is prepared to cover the funding for all state operations for a specified period.¹⁸ The executive branch prepares a proposed budget on the basis of requests from the individual state departments and agencies. The heads of these departments or agencies usually prepare their requests on the basis of requests from their sub-units. An advocate may discern advantageous times and places for influencing budget proposals at any stage of this process—in general, the earlier the better.

When a budget proposal reaches the legislature it is referred to one or more committees. Information an advocate provides to the committee or its staff may be both appropriate and influential at this stage. When the legislative committees have acted on the budget, it goes to the legislature for adoption, amendment or rejection. If the budget bill is adopted, it goes to the governor for signature or veto. In some states the governor has item or partial veto powers permitting approval of those parts of the budget which he or she finds acceptable and rejection of the rest. The governor's veto can be overridden only by an extraordinary majority of both houses. To an advocate such gubernatorial

prerogatives mean that the potential for influencing the budget-making process continues until the governor signs the final document.

REVIEW AND OVERSIGHT

Every state has various means of review and oversight of policy implementation. Judicial review is available, as we have seen, to define and vindicate individual rights. Each state has other mechanisms available to help ensure that policy is carried out. Program audits by legislative or executive audit agencies are designed to determine if an established program is being properly implemented. Legislative committees often engage in legislative oversight of executive and administrative activity. Finally, officials charged with providing legal advice to executive and administrative agencies exercise a kind of review and oversight function as well.

Program Auditors

Some states have elected state auditors with authority to review the expenditure of funds and the implementation of programs by other state and local agencies. Some have instead—or in addition—a legislative audit bureau. Still others have a state department of administration or budget with powers that include some form of program audit. Sometimes these agencies can be persuaded to take on the evaluation of a program that the advocate would like to have investigated.

Legislative Overseers

A traditional legislative function, in addition to policy-making, is oversight. Congress has been more active in this phase of legislative activity than state legislatures have, but the potential exists at the state level as well. Legislative oversight usually occurs at the state level in two ways, both involving legislative committees. The standing legislative committee created to handle legislation in a particular subject area may oversee the activities of state and local agen-

cies in that area. For example, the Education Committee may conduct hearings on the implementation of special education programs; or the Labor Committee, on the administration of fair employment practices legislation. In addition, some states have standing committees charged with reviewing and receiving complaints about administrative rules. Rules may be brought before the committee for approval or disapproval or the committee may act when it becomes aware of a problem with particular rules.

Legislative oversight can be an important ally of the DD advocate. By calling a problem in program implementation to the attention of the appropriate legislative committee, the advocate may initiate a process leading to substantial benefits.

Legal Advisors

State legal advisors, such as the attorney general, are an often overlooked but potentially helpful source of assistance to an advocate. Legal advisors have an interest in seeing that the agencies they advise operate according to law. If they do not, it means additional work, inconvenience and perhaps embarrassment to the advisor. Moreover, some legal advisors, including the state attorney general, are elected officials who may feel a direct obligation to the public as well as to the agencies. If instances of non-compliance with the law by state or even local agencies are called to the attorney general's attention, the result may be informal action to bring them into compliance. The attorney general's advice is not ordinarily binding on an agency, but there are compelling reasons why an agency will give it serious consideration and ordinarily follow it. Among other strategies, the attorney general may refuse, if an agency fails to follow the advice it receives, to represent it in any ensuing litigation.

At the local level district attorneys, city attorneys and corporation counsels act also as legal advisors to governmental agencies. They have a similar interest in seeing that the agencies they advise comply with the law and they may be most helpful to the advocate.

CONCLUSION

The DD Council carries out its advocacy function within a complex and diffuse system of state and local decision-making. The complexity and diffusion results from a structure which includes local governments and independent state executive and administrative officials as important decision-makers. The nature of this structure is such that a governor does not control the executive functions of government in the way the president does in the federal government. Consequently gubernatorial appointment does not carry with it the status in an executive hierarchy that presidential appointment does. Therefore, reliance on such status to give the Council the necessary influence within state and local government may be misplaced.

The DD Council nevertheless has the potential to be an effective advocate. The fact that it is located within state government and is entitled to participate in the state planning process gives it the kind of access to planning decisions that no other actor in the DD system has. Not only does this permit participation in the planning process, but it also enables the Council to identify issues and problems at an early stage, making effective advocacy at a later point more likely.

A sophisticated understanding of the decision-making process within the state and local government structure is essential. An advocate must know who makes the important decisions, the process by which they are made, and the opportunities for access. Knowledge of this kind is not easy to acquire. DD Councils, however, being a part of the system and having advantages of proximity and access, are better able to acquire it than others might be.

The decision-making system includes the state legislature and the judiciary as well as state and local executive and administrative agencies. An advocate may find it necessary to participate in any or all of these arenas. The legislature alone can create new state programs and fund them. The judiciary can define and vindicate individual rights under these programs. The executive and administrative agencies must implement the programs. Precisely what agencies of government participate in what way will vary from state to

state. The message of this chapter is that a good working knowledge of the statutory and constitutional authority of each agency is essential to effective advocacy. Of course, there is no substitute for experience, and the roles the agencies play may differ substantially from those the law assigns them. Nevertheless, knowledge of the formal structure is essential as a starting point and, in some instances, as a tool an advocate may use to compel agencies to do what they might otherwise choose not to do.

FOOTNOTES

- 1 As is the case in Wisconsin (*Wis. Const.*, Art. X, §1) and in Indiana (*Ind. Const.*, Art. 8, §: §20-1-11-3, *Ind. Stats.*)
- 2 As is the case in Ohio (*Ohio Const.*, Art. VI, §4) and in Michigan (*Mich. Const.*, Art. VIII, §3). In Minnesota and Illinois the chief administrators of education, respectively the Commissioner of Education and the State Superintendent, are appointed by state boards of education, which in turn are appointed by the state governors (§§121.02 and 121.08, *Minn. Stats.* and Ch. 122, §§1A-1 and 1A-4(b), *Ill. Rev. Stats.*) (*Ill. Const.*, Art. 10, §2, gives the legislature an option in providing for either an appointed or an elected board of education, which is here designated as the appointer of the State Superintendent.) In these two states the governor's authority over the appointment of the chief administrator of education is made remote.
- 3 Wisconsin: §§120.40-120.12-13, *Wis. Stats.*
Ohio: §3313.01 *et seq.*, *Ohio Stats.*
Minnesota: §§123.12, 123.33, 123.521 and 123.56, *Minn. Stats.*
Michigan: See generally Ch. 340, *Mich. Stats.*
Indiana: §§20-5-2-1 through 20-5-2-3, *Ind. Stats.*
Illinois: Ch. 122, §§10-20 and 10-20.5, *Ill. Rev. Stats.*
4. *Ill. Rev. Stats.*, Ch. 122, Art. 5-01
5. The Illinois Office of Education is headed by the State Board of Education, a panel of 17 persons appointed to six-year terms by the governor (*Ill. Rev. Stats.*, Ch. 122, Art. 1-A-1). The Board determines general educational policy for the state and selects the State Superintendent of Education to administer public education programs (Ch. 122, Art. 1B). Officers of the Education Planning Office report directly to the State Superintendent. The Advisory Council, however, is composed of seven citizens and includes non-education personnel, the Director of the Department of Children and Family Services and the Director of Mental Health and Developmental Disabilities are ex-officio members. The Superintendent is required by statute to consult the Advisory Council regarding all rules and regulations affecting children with developmental disabilities and must submit to the Advisory Council for approval all comprehensive plans or amendments to

them. While an officer of the Office of Education serves as the secretary for the Advisory Council, the unit is not merely an arm of the Office of Education (Ill. Rev. Stats., Ch. 122, Art. 14-3.01). Thus, while the Office of Education through its planning office is charged with developing specific programs within the Department of Education, both the Board of Education and the Advisory Council exert independent influences on policy and program changes.

6. There are several reasons for the practical finality of opinions of the attorney general. Chief among them may be the lack of incentive to carry the matter to higher authority; that is, to the courts. See Christenson, "The State Attorney General," pp. 326-333.
7. A good statement of the limited capacity of courts to do any more than threaten sanction or promise a remedy is found in Wasby, *The Impact of the Supreme Court* Chapter 1. A particularly trenchant view of the litigation process and its uses and limitations in social action is found in Friedman, *The Legal System*, pp. 56-115. For the clearest statement of the value of litigating entitlements (rights), see Scheingold, *The Politics of Rights*, pp. 3-6, 83-95.
8. *State of Wisconsin ex rel. David Memmel and Judith Pagels v. Edwin A. Mundy*, Case No. 441-417 (Cir. Ct. Milwaukee County, Wis., Sept. 7, 1976), appeal dismissed and rights declared by Wisconsin Supreme Court on January 18, 1977, *Linda Sparkman and Leo Sparkman v. Ora E. McFarlen et al.* No. 76-1706 (7th Cir., March 23, 1977) review of Indiana case.
9. *In the Matter of Donald Lang*, No. 76 Crim. .064 (Cir. Ct. Cook County, Ill., Dec. 8, 1976).
10. *In the Matter of Tracy Ann Cox*, Civil No. H4721-75 (N.Y. Family Court, Queens County, April 8, 1976).
11. There are exceptions to this rule, the most notable being federal and state environmental protection legislation. At the federal level the Council on Environmental Policy, established to set national policy on environmental issues (42 USC 4344), is required "to gather timely and authoritative information concerning the conditions and trends in the quality of the environment" (42 USC 4344). The Council has opened policy-making to the public by promulgating interpretive guidelines to 42 USC 4332, which requires federal agencies to include a statement of environmental impact with recommendations "on proposals for legislation and other major Federal actions significantly affecting the quality of the human environment." One of these guidelines, 40 CFR §1500.7(d), published 38 FR 20550, August 1, 1973, states: "... Agency procedures shall also specifically include provisions for public hearings on major actions with environmental impact and for providing the public with relevant information, including information on alternative courses of action." Similarly, §1-11(d), Wis. Stats., provides for public hearings on the impact of proposed actions of state agencies. State law does not require public hearings on legislation proposed by state agencies.

12. See, for example, 1977 Regulations compiled by the Department of Health Education and Welfare, CFR 1386.29 (Councils must exist and be adequately staffed) and CFR 1386.30-31 (Councils must review and comment on all agency plans and must evaluate State Plans annually). See also 42 USC 06067 requiring the establishment of a State Council as a condition for receiving federal DD assistance.
13. Confidential interview with a state Council member conducted by John Martin, Center for Public Representation research associate, summer, 1977 (transcript available on request).
14. Of course the courts in interpreting legislation bring their own sense of policy to bear on what the law should be. A court's interpretation of a statute can be as decisive as a statutory amendment. However, state constitutions generally respect the doctrine of separation of powers, vesting the making of laws only in the legislature.
15. Wisconsin, §§227.01-.26, Wis. Stats.
Ohio: Ch. 119, Ohio Stats.
Minnesota, §§15.0411-.0422, Minn. Stats.
Michigan, §§24.101-.110, Mich. Stats.
Indiana §§4-22-1-1 through 4-22-1-30, Ind. Stats.
Illinois: Ch. 127, §§1003-1021, Ill. Rev. Stats.
17. For a discussion of the phenomenon of informal decision-making and its importance see generally, Davis, *Discretionary Justice*.
18. Among the six states we considered, the only exception appears to be Illinois, which does not follow the practice of adopting an omnibus budget bill.

CHAPTER 3

THE DD COUNCIL AND THE PROCESS OF ADVOCACY

Government provides special benefits, rights and assistance to people who are developmentally disabled because of a belief that they are entitled to services they cannot provide for themselves. The DD system has been established to ensure that these benefits, rights and assistance are effectively provided.

An essential part of the DD system is a process of advocacy.¹ In a competitive system of public policy creation and implementation, the needs of people with developmental disabilities cannot be met merely by passing a law or by authorizing specific expenditures. These steps are essential, but alone they will not guarantee that benefits will be provided and rights enforced. To do that, DD groups inside and outside government must engage in advocacy for their interests.² They must see that DD interests are articulated in all appropriate decision-making arenas and enforced by all implementing agencies.

DD advocacy takes place in a complex system consisting of several levels and branches of government, a wide variety of programs and services, and a number of particular groups and interests. The advocacy process must therefore take many forms and be carried out by diverse groups. Moreover, this advocacy must be sustained, systematic and coordinated if it is to be effective. The DD Council has the responsibility to ensure that such advocacy is available, although it may not necessarily provide the advocacy itself.

THE NEED FOR SUSTAINED MULTI-ARENA ADVOCACY

American government has been described as a pluralist process in which many interests contend for a limited supply of public benefits.³ When this process degenerates into "pork barrel" politics or corruption, it is widely and prop-

erly criticized.⁴ But the struggle of legitimate interest groups for governmental recognition and support is otherwise an important and valuable part of the American political process. Government is so complex and is pressed by the demands of so many groups that the process depends on interest groups to inform public institutions precisely which needs require the immediate attention and concerted efforts of government agencies.⁵ In so many words, interest groups provide the information public agencies use to make decisions. Groups failing to speak up or neglecting to provide such information may find that government does not consider their needs.

Developmentally disabled persons can be seen as an interest group, as they and their partisans form a small but significant group within the overall population. Persons with developmental disabilities have a wide variety of individual needs, but they share collective interests as well. They all have conditions which substantially hinder their capacities to function independently in society and require assistance with which to reach their productive potentials in society. Thus, they are united by a common interest, their need to overcome physical and mental handicaps. They also share a need for public assistance or support of various types to help them in this task. Toward this end, the federal government created a developmental disabilities system. The existence of the DD system, reaffirmed by the 1978 Rehabilitation Amendments, is proof that government has recognized that interest and responded to that need.

Legitimate interest groups in the American political process have learned that they must work constantly to ensure their fair treatment by government.⁶ Public policy-making and implementation processes are competitive struggles. Among groups these struggles are for limited public resources; within government they are to sort out incessant demands. Basic lessons are that government allocates many resources in our society, and that the demand for these resources exceeds the supply.

In addition, government actors have limited time, personnel and funds to process demands, establish priorities and implement programs. Every public agency, whether judicial, legislative or administrative, must cope with these

two pressures: the need to consider conflicting demands from a wide variety of groups and the limited capacity of public agencies to process these demands and implement programs.⁷

Other things being equal, interest groups win shares of public resources when they make their voices clearly and unambiguously heard above the voices of others, and when they articulate their demands through procedures public agencies handle. Thus, interest group representatives must be articulate and know the "rules of the game" government action imposes.

Advocacy is the overall process whereby a group attempts to secure its share of limited public resources. The twin aims of advocacy are to sustain a stream of articulate demands to relevant government agencies and to facilitate policy-making and implementation processes by exploiting the "rules of the game."⁸

Most effective advocates are large or well-organized groups. They are effective for several reasons. To begin with, their organization allows them to aggregate individual needs, interests and ideas. Persons with similar interests can decide collectively which issues are most important and which arguments are likely to sway public officials. This aggregation process permits advocates to identify issues and organize them into a coherent platform for action. The development of the interest group also provides resources for articulating this platform.

Some persons can specialize in collecting information, others can contribute the time and money necessary to advance the cause. Perhaps most importantly, group organization turns an interest into an institution which can develop its own history and its own sense of identity. Furthermore, as a group matures and acts, it learns more and more about the rules of the game. The group thus becomes a "repeat player," one which other actors in the policy-making process recognize, and one which knows how to play—and to win.

Some interests are advanced by organized groups. Business interests command substantial resources and have highly organized associations to protect their interests in the political process. Organized labor also has effective mechan-

isms for advocacy through systems of mandatory membership, dues requirements and political action committees.⁹ Other groups with equally valid claims may be less well organized. For example, consumers are frequently unorganized. While there are many people who are harmed by anti-consumer behavior, it is hard to organize "consumers" to act as advocates in the policy-making process. These people may not perceive themselves as members of a single "consumer" group, the costs of organization itself can be extremely high, and it may be difficult to develop a coherent list of particular demands to make upon government agencies.¹⁰ Organized groups which overcome these problems can secure a larger share of public resources than can unorganized interests, as we have suggested. The reasons are obvious. Organization permits sustained, coherent advocacy. Organized groups provide government agencies with a stream of information which can be used to design programs. Organization allows groups to marshal resources to allow them to operate in multiple arenas, influencing the many separate decision-makers whose individual decisions are all necessary to ensure enforcement of rights and provisions of real benefits.¹¹

This sustained and multi-arena advocacy is the only way to ensure that government will protect a group's interests. Very few laws or programs are self-executing. Legislatures may create rights or benefits, but these may become mere paper rights unless they are implemented by administrative officials. Often these officials have conflicting demands on their time and resources, so that rights secured in the legislature can be lost in the halls of bureaucracy. A congressional mandate to deinstitutionalize care for persons who are developmentally disabled may be difficult to implement, for example, in a state which uses all of its DLJ funds to upgrade total care institutions or by an agency that is staffed by persons skilled in institutional care. Moreover, policy-making involves constant readjustments and revisions, and few decisions are permanent. Budgets change, resource availabilities fluctuate, priorities shift. Policies take a long time to effectuate, and unless a group can work at all levels over long periods of time, it may find its interests ignored by those officials who daily make the decisions that determine the effective level of support.¹²

DEVELOPMENTALLY DISABLED PERSONS AS AN INTEREST GROUP

As an interest group, persons with developmental disabilities should be able to benefit from the kind of sustained, multi-arena advocacy that all organized interests employ in the policy process. People with developmental disabilities constitute, however, what has been termed a "suboptimally" or underorganized group, a group that lacks the degree of organization appropriate to the size of the group or to the intensity of its need.¹³ The reasons for this underorganization are complex, but the most obvious are the nature of the people in the group, i.e., the handicaps they suffer, and the physical and social dispersion characterizing them and their families. Further, this interest group represents people with a variety of disabilities, and hence a variety of needs. This fact has sometimes made it difficult to develop a coherent stream of demands for the DD population as a whole. This may be particularly true under the 1978 Act, which substantially broadens the definition of "developmental disability."¹⁴

ADVOCACY ASSISTANCE AS A NECESSARY COMPLEMENT OF GOVERNMENT PROGRAMS BENEFITING UNDERORGANIZED GROUPS

Because people with developmental disabilities are underorganized, any program of government assistance for them must include support for interest group advocacy. We have seen that government programs do not work automatically. Benefits may be allocated at top levels of government but defeated at lower levels. Agencies with multiple missions may find other groups competing for the resources of time and money that DD groups believe they should have. Formal entitlements may be established but rights may be ignored by government decisionmakers.¹⁵ For these reasons one of the essential elements in the supply of public benefits to any group is a sustained, multi-arena advocacy for that group.

If government programs are established to provide benefits for *organized* groups, the groups themselves can

provide the necessary advocacy. But if the groups are not organized, then resources for advocacy must be part of the overall government package of rights and benefits. Otherwise, there is substantial risk that the package will not be fully implemented.

The necessary complement between subsidized benefits and subsidized advocacy has been recognized in various public policy areas. For example, some programs for the aged have provided subsidized legal services, and the state of Wisconsin has established the Office of the Public Intervenor, an agency charged exclusively with advocating on behalf of the conservation of the natural environment.¹⁶ As Chapter 1 has demonstrated, Congress and HEW have recognized the need to include support for advocacy as an integral part of the overall program of assistance for people with developmental disabilities. The DD Council is charged with advocacy, as well as with planning and monitoring functions, and a Protection and Advocacy (P&A) System has been established to provide certain types of advocacy.¹⁷

However, the federal laws and regulations sketch out only the broadest outlines of the system of interest group advocacy that is necessary for effective operation of a program of assistance to persons who are developmentally disabled. The Council and the P&A system are given certain advocacy responsibilities, but these responsibilities are very general, and there is little guidance on how the advocacy functions of the two agencies are to be coordinated.¹⁸ Moreover, there are no guidelines on how the DD Council and the P&A System should relate their efforts to those of other groups whose actions may be essential for effective DD advocacy. These groups include private groups who represent DD interests and general purpose governmental agencies who may have an interest in DD issues.¹⁹

THE DD COUNCIL AS THE COORDINATOR FOR GOVERNMENT SUPPORT OF DD ADVOCACY

The DD Council has overall responsibility for planning, coordinating and monitoring all state efforts to assist persons with developmental disabilities.²⁰ Since advocacy has been recognized as a necessary part of such assistance, the

advocacy coordination responsibilities naturally fall to the Council. While the Council must include advocacy in its program, it is free to develop approaches appropriate to the needs, processes and resources of its state.²¹ The Council must work out the appropriate advocacy role for itself, for the P&A Systems and for other governmental bodies and private groups.

ELEMENTS OF THE ADVOCACY PROCESS

Before a DD Council can fulfill its responsibilities as coordinator of DD advocacy in its state, it must fully understand the advocacy process. This process has three basic elements: actors, arenas, and modes of advocacy.²²

Actors

An integrated process of advocacy for people with developmental disabilities involves four types of advocates. The first is the DD Council itself. The Council's role includes both direct advocacy and advocacy coordination.²³ The second actor is the Protection and Advocacy system, which is charged with protecting the rights of individuals.²⁴ In the third class of advocates are the various governmental bodies having general responsibilities which include protection of the interests of people with developmental disabilities. These include, for example, consumer advocates within state agencies, who are charged with responsibilities for assisting all groups receiving benefits from that agency, and agency-specific ombudsmen or other officers who review and monitor agency compliance with rules and regulations. Other general governmental offices which can perform advocacy roles are the attorney general's office, state-wide ombudsmen and governmentally-supported legal services programs.²⁵ The fourth actor is the private group, such as the Association for Retarded Citizens, which represents the interests of people with developmental disabilities.

DD advocacy occurs in the many arenas where policy is made or influenced.²⁶ These arenas include the planning and implementation activities of state and local agencies, the legislature, the courts, the federal government and the media. Issues relating to developmental disabilities will arise in all of these arenas, and DD advocates will find each of them appropriate for certain problems and certain types of advocacy. Frequently, the same issue must be pursued in several different arenas.

Each arena has unique characteristics. Advocacy must be tailored to these characteristics so that the flow of coherent DD information in each arena and the operation of the arena's decision-making processes can be facilitated. As noted in Chapter 2, for example, different agencies are responsive to different constituencies. Local boards of education may respond more directly to the demands of the general electorate or, in some cases, to the governor or nominating commission. Similarly, local boards are most concerned with policies affecting the daily operation of their particular schools, given the level of resources available through property taxes at the local level, while state boards spend more time determining general standards of education. Thus, DD advocates hoping to see a new special education program implemented statewide first may have to lobby for the rights, or entitlement, to that program at the state level by mounting an educational publicity campaign stressing the need for the program and the state's obligation to provide it. At the local level, however, advocacy may have to take the form of helping school boards search for part-time special education teachers or of establishing a volunteer program.

Modes of Advocacy

The techniques of advocacy necessarily vary with the particular characteristics of the advocates, the issues and the arenas involved. However, we can identify four general modes of advocacy which vary along two dimensions.²⁷

The first dimension identifies the location of the advocates, whether they are part of the normal process of government decision-making or operate outside it. This dimension is the internal-external dimension of advocacy.

The second dimension defines the scope of the advocacy objective. In this dimension, advocacy is individual or collective. Individual advocacy seeks as its goal the satisfaction of the particular needs of a particular individual. Collective advocacy, on the other hand, attempts to secure public benefits for the DD population as a whole.²⁸

Anyone familiar with government will recognize the importance of distinguishing internal from external advocacy.²⁹ Internal advocacy is conducted inside the government process. It is a way that people who actually make government decisions influence each other. It may be formal or informal. Much internal advocacy is informal, consisting of individual contacts and discussions and of input in meetings designed to plan programs and allocate budgets. However, internal advocacy may be more formal. When the DD Council formally comments on an agency's policies or its implementation of the DD plan, it is engaged in formal internal advocacy.

External advocacy involves pressure on government from the outside, from groups who are not bound by government's existing policy and operating agendas. The most obvious forms of external advocacy are conducted by non-governmental groups, but some government bodies—for example the Public Intervenor in Wisconsin—are charged with playing the role of an external advocate.

Advocacy may be for the interests of all members of a group or for specific individuals. Efforts designed to increase budget allocations for developmentally disabled people are an example of collective advocacy. An effort to secure a specific benefit for one or a few persons is an example of individual advocacy.

Within a dimension, the line between the modes of advocacy is not hard and fast. For example, much individual advocacy also will have a collective impact. The "test case" law suit, establishing a right to treatment for an individual, for example, will establish entitlements benefiting a large group of persons. An effort to ensure that an agency pro-

vides benefits mandated by law to one individual may identify a pattern of non-compliance that has an impact on many. In fact, what seems like pure individual advocacy will often prove to be the most effective way to further collective interests.

COORDINATING THE ELEMENTS IN THE DD ADVOCACY PROCESS

The DD advocacy system must operate in many arenas continually, from the earliest planning stages through program implementation, and must make these diverse advocacy efforts as coherent and as coordinated as possible. Since the DD advocacy system itself faces many constraints—severe limits on funds, personnel, communication, and other resources—and consists itself of actors with differing goals and capabilities, the planning and coordination of this advocacy process is a considerable task, and is itself an important form of DD advocacy. As we have noted, Congress has delegated this responsibility to the DD Council.

The DD Council must consider a wide array of variables in designing an advocacy system for its state. The precise “advocacy formula” for each state is best discussed in training sessions tailored to the particular characteristics and needs of the state DD system. We can offer, however, some general guidelines for allocating the DD advocacy burden by evaluating the characteristics of our four advocacy modes and by identifying which of these modes the primary DD actors—the DD Council, the Protection and Advocacy System, the other governmental agencies and the private groups—are best suited to employ.

Internal Versus External Advocacy

Compared to external advocacy, internal advocacy generally insures greater access to particular public decision-makers in the DD system, a broader range of communications to these particular public decision-makers, lower overall organizational costs and a greater capacity to accrue benefits as a “repeat player.”

Channels between internal advocates and representatives of other agencies are formalized by law and frequently by organizational linkages between advocates and agency personnel. Although these formal rules may seem to limit the nature of the contact between advocate and agency representative, they insure that advocates have some guaranteed level of access to at least some decision-makers. Internal advocates are frequently able to develop comprehensive, long-term relationships with agency representatives, thus enhancing their overall ability to persuade and otherwise facilitating the process of communication.³⁰

Since the state pays the organizational expenses of internal advocacy, resources can be directed more to advocacy activity itself, and less to maintaining the organization. Furthermore, state support for internal advocates can enhance their legitimacy in the eyes of other government agencies.

Guaranteed access, the development of long-term relationships, and a legitimate position in the DD system help internal advocates sustain a program of advocacy in the DD system. This sustained activity, in turn, makes the internal advocate a "repeat player," a member of the system who has learned the ropes and can spend increasingly large proportions of resources on actual advocacy rather than on discovering how to be an advocate.

Internal advocacy has its disadvantages, however. While formal channels of access guarantee certain modes of access to decision-makers, they may prohibit others. For example, internal advocates may have ready access to particular agencies, but will not enjoy the same level and quality of access to agencies with whom they have no formal tie. Thus, the internal advocate's legitimate range of activity may be limited to a rather small part of the DD system. Similarly, the long-standing relationships which develop between internal advocates and other agency representatives may work against the requirements of a particular situation.³¹ At times, advocacy must take the form of a contest between opponents. Persons who have worked together daily, and must continue to do so, may be unwilling to engage in adversary procedures. Finally, the internal advocate's freedom to select issue, strategy and target is limited by the organizational placement of the advocate and the

formal rules governing the interactions of government personnel and institutions.

External advocates, on the other hand, are freer to choose issue, strategy and target. However, external advocates, at least early in their efforts, must allocate a considerable portion of their resources to organizing and sustaining the group itself, before advocacy activities can take place. Similarly, external advocates must fight for access to decision-makers. First, they must discover who are the appropriate decision-makers to contact, given a particular issue. Second, they must find some means of legitimizing access to that decision-maker. Finally, even when access is formalized through public hearings or administrative, legislative or judicial proceedings, its effective use requires considerable effort, time and other resources.³²

Since external advocates are free to address any unit in the DD policy system, they are capable, given adequate resources, to engage in many arenas of advocacy. They play several roles in these activities: adversaries, negotiators, communicators of information. More so than internal advocates, external advocates can carry the fight to whatever part of the DD system they feel is necessary. Finally, external advocates are generally freer from political constraints than are internal ones. Since government does not control the personnel, operating or funding procedures of external advocates (at least, not completely), external advocates may be able to select advocacy approaches which would be inappropriate for an internal advocate.

Individual Versus Collective Advocacy

Individual advocacy concerns itself with seeing that particular individuals' needs are satisfied by the DD system. For this reason, individual advocates should locate themselves as close as possible to the service delivery system and to persons with developmental disabilities. Individual advocates must be geared to monitor service systems, receive information from service providers and recipients, and have access to institutions—service agencies, courts, and administrative agencies—that can provide particular benefits for individuals. Individual advocates

then, must have the following skills and capabilities: ready communication with individuals who have developmental disabilities; knowledge of the particular operations of service programs and institutions; command of legal, argumentative, and representational skills to secure or restore benefits to individuals; and the willingness and the ability to use whatever arena is required to obtain or restore these benefits.

Collective advocacy is concerned with general entitlements: rights or privileges granted to groups of persons by virtue of their identification with a particular group.¹³ Unlike individual advocacy, collective advocacy must focus on policy-making institutions which have the capacity to create entitlements and on agencies that develop programs to implement the benefits resulting from these entitlements. Legislatures and policy-making units of executive or administrative agencies at the national, state and local levels of government are included in this category. Courts, too, have played an important role in creating or affirming the rights of persons with developmental disabilities.

Although the kinds of skills collective advocacy requires resemble those individual advocacy requires, they are employed differently and in different arenas. For individual advocates legal battles generally focus upon breaches of established duties of institutions' agencies vis-a-vis individuals with developmental disabilities, while legal battles at the collective level are more likely to emphasize the presence of a general constitutional right. Individual advocates generally deal with local administrators; collective advocates usually bargain with higher-level policy-makers. While in individual advocacy the link between the advocate and the individual to receive the benefit is direct, in collective advocacy it is less direct, and the advocate must take care not to lose touch with the needs and interests of the group.

PLACING DD ACTORS IN THE ADVOCACY SCHEME

No single actor in the DD system is in a position effectively to use all of the modes of advocacy. This section shows how the various actors—the Councils, the Protection and Advocacy system, other state agencies, and private groups—must be used together to provide the optimal mix of advocacy strategies and to have the maximum impact upon the DD system.

DD Councils

We have already suggested that the DD Council plays the central role in the DD system. By virtue of its location in the system, its composition and its powers, the Council is the institution best situated to control, plan and coordinate the DD advocacy process. In the next chapter, we show *how* the DD Council can act as advocate; here we suggest *why* it should perform the advocacy tasks we attribute to it.

Basically, the Council has three advocacy tasks. First, it acts directly as an internal collective advocate. Second, it coordinates internal and external DD advocacy, regardless of which actors perform these tasks. And finally, it facilitates external individual and collective advocacy by the P&A System and by private groups.

The DD Council has a unique role in the DD advocacy process, and one that is rare in governmentally-supported advocacy systems. Most government approaches to supporting advocacy create either internal or external advocates. Moreover, when both types of advocates are present, they are frequently independent of one another.¹⁴ However, the DD Council really stands on the borderline between internal and external advocacy. In its own direct advocacy roles it is basically an internal actor (but half of its members represent primary groups and consumer groups) and has responsibilities to coordinate with other government advocates, including the P&A system. Thus, the Council has the potential for creating linkages between state agencies and external advocacy entities. To the extent that these linkages are well developed and maintained, the Council has the capacity to make all forms of DD advocacy more effective.

The Council includes members of relevant state agencies, service providers, and consumer representatives.³⁵ Thus, it is in a unique position to obtain, assimilate and act upon information from these primary sectors of the DD system. Either through these various representatives or else directly the Council can identify advocacy goals, strategies and persons or institutions to carry out advocacy tasks. By virtue of the consumer membership on the Council and the Council's ability to communicate with citizen DD groups, the Council also can organize and/or promote the activities of the public DD constituency. Persons representing university-affiliated facilities and state agencies, two other key constituencies, are also present on the Council. In short, the Council is in a position to see the whole range of activity in the DD system and to ensure that the DD advocacy process is adequate for the needs of the system.

Given the special needs of people with developmental disabilities as an underorganized interest group, these capabilities of the Council could be of great value. Underorganized groups suffer from a lack of information, high organization and coordination costs, and the inability to aggregate interests into a coherent agenda of demands. The Council can offset all these disadvantages at relatively low cost. It can assist external groups by forwarding necessary information through consumer representatives, by publicizing issues in the media or by conducting or facilitating membership campaigns for DD-oriented groups. By identifying gaps in existing services, the Council can direct Protection and Advocacy units to the individuals and programs most likely to be in need of assistance, and vice versa.

These coordination and facilitation activities help the Council perform its direct advocacy tasks. First of all, by stimulating external advocacy, the Council can create another source of data about the operation of the DD system. Needs, gaps, and alternative proposals these external groups articulate need not be filtered through various layers of the bureaucracy, but may be communicated directly to the Council, to the public, or to the other arenas in the DD system.³⁶ Second, these external groups may act as allies to the Council by assisting it in communicating

needs to appropriate arenas or by generating money, personnel, or other resources needed to promote new or existing DD programs. Third, these external advocates may help develop a political constituency for the Council outside the governmental structure.³⁷ The Council may lack substantial political "clout," and may depend upon the designated state agency for much of its supporting staff, basic information, and communication with other government agencies. If the Council can develop visible, active and articulate constituencies, however, its dependence upon other governmental institutions can be reduced, at least somewhat. One scholar even suggests that the development of an outside constituency is *the* key to survival and success for a government agency.³⁸ Finally, the Council may use external advocates to supplement its own activities or to provide for a broader, more flexible base for advocacy.

The Protection and Advocacy System

Although the Protection and Advocacy System in each state is established and supported by government, we characterize all Protection and Advocacy systems as external advocates. We do so because the P&A System is an independent entity in the DD system.³⁹ Furthermore, P&A systems react to activities of relevant state agencies as interested third parties, not as insiders.

Each state is free to develop its own P&A System,⁴⁰ as long as it is consonant with the HEW guidelines promulgated pursuant to P.L. 94-103 and the mandates of the 1978 Rehabilitation Amendments. Under the HEW guidelines, P&A systems must:

- a. represent individuals and organizations without otherwise adequate representational resources on matters relevant to the protection of legal and human rights of the developmentally disabled;
- b. provide information and advice about these rights
- c. negotiate with relevant agencies to maximize the application of these rights;
- d. receive and investigate complaints about the DD system;

- e. refer developmentally disabled persons to other advocates;
- f. provide legal and other back-up resources;
- g. educate the public on DD rights;
- h. lobby on behalf of DD interests;
- i. participate in formal administrative rulemaking and other processes;
- j. prepare reports on DD conditions;
- k. cooperate with other DD actors, including State Councils, to facilitate optimal operation of the DD system;
- l. perform other needed tasks.⁴¹

As we can see, some of these tasks overlap or complement the tasks of the DD Council. Furthermore, the P&A System may engage in both individual and collective advocacy.⁴² The mix of these particular functions will depend on the level of funding, the quality of personnel, the particular needs of the DD population, and the location of the P&A unit in the state. As external advocates, the persons in the P&A unit are limited only by their own skills, resources and political considerations and are, therefore, free to select target, strategy and issue. We can also see, however, that the P&A System will not be able to perform a large number of tasks without help. Particularly, the costs of collecting *and evaluating* the information necessary for many of the above tasks are extremely high. P&A Systems, given a tendency toward an adversary stance vis-a-vis governmental agencies, may have severe problems of access. Similarly, although P&A units may seek to identify or affirm collective rights through litigation, this route is extremely costly, time consuming and uncertain.

Government Oversight Agencies

Independent government agencies charged with monitoring and/or policing government agency activities—legislative oversight committees, ombudsmen, public intervenors, auditors, states attorneys general—work, by and large, outside the DD system. This is at once an advantage and a disadvantage. Controlling for unknown political pressures,

these agencies are free to prosecute violations or promote new objectives in the DD system as these institutions become aware of the need. Frequently, then, these agencies may escape the pressures to compromise or the need to accommodate which the Council or the P&A Systems may face.

On the other hand, independent government agencies, including agency-specific ombudsmen, cannot devote all of their time to DD activities. They therefore lack comprehensive information about DD needs and system capabilities. These agencies may also lack the capacity and/or desire to enter into the DD system at all. As with all government institutions, independent agencies have numerous, competing demands made on their time. Although these institutions may have enforcement powers lacking in the DD Council, they too may lack the full range, or even the appropriate power, for any given situations.⁴³

Outside, Private Groups

It should be remembered that before there was a DD system, there were private, voluntary organizations pressing for the rights of persons with mental retardation, cerebral palsy, autism, dyslexia and other developmental disabilities. In large measure, the concerted efforts of these state and national organizations are responsible for the creation of the DD system itself.⁴⁴

These organizations draw their memberships from persons involved with or extremely interested in developmental disabilities. As a result, they often can provide first-hand information about the day-to-day operation of the DD system. Moreover, as partisans of the DD cause, they often are able to provide a pool of volunteer and expert personnel to develop, staff and operate private or public projects aiding people who are developmentally disabled. Private organizations are a source of private money and other resources which expand the total pool of resources available to the DD system for the development and implementation of DD programs. This is particularly useful in states which provide relatively small public budgets for DD activities. Finally, since these groups are the core of the

political constituency pressing for public action on behalf of people with developmental disabilities, they can serve as an external source of pressure on other actors in the DD system.⁴⁵

As with other external advocates, private groups are limited in selecting targets for advocacy only by their resources and interests. While the limitations on these resources may be considerable, this freedom to select the precise issue in question and to pick the target arena of advocacy and the strategy to be employed—political, legal, a media campaign, direct contribution, self-help—add considerable flexibility and force to the overall DD advocacy process. The active participation of private groups also rounds out the DD system of data production and communication by providing still more sources of information about the operation of the DD system and ideas for improvement and further action. Finally, the activity of private groups provides a pool of prospective recruits to other elements of the DD system—especially for the DD Council and the P&A System.

CONCLUSION

We have seen that these various actors, by employing a variety of advocacy modes in a variety of arenas, more likely can make a sustained, comprehensive and coordinated DD advocacy process. Because there is a great deal of variety in the responsibilities and capabilities of the various actors in the process, it is essential if the advocacy process is to be successful, that the actors work to complement each other.

In this context, the advocacy task of the DD Councils is large. It must conduct internal advocacy, coordinate all internal and external advocacy and facilitate external advocacy by the P&A systems and private groups. In the following chapter we explore ways these roles can be performed.

FOOTNOTES

- 1 See P.L. 94-103 (1975), §113, Chapter 1.
- 2 For a concise explanation of why rights are not self-executing, and an illustration of the practical problems resulting from this "myth of rights," see Scheingold, *The Politics of Rights*, Chapter 2, and the later discussion in this chapter.
- 3 See, for example, Dahl, *A Preface to Democratic Theory*.
- 4 See, for example, Sherrill, *Why They Call It Politics*, Chapter 2; Lowi, *The End of Liberalism*, especially pp. 41-68; and Seidman, "Politics: Position and Power," Chapter 1.
- 5 Both supporters and critics of pluralist theory agree that public institutions do rely on information from pressure groups as an indicator of the demand for public goods (Lundblom, *The Intelligence of Democracy*, p. 49), as feedback to help agencies evaluate or produce programs (Simon, *Administrative Behavior*, Chapter 5), or for political support (Sabatier, *Social Movements and Regulatory Agencies*, pp. 304-310).
- 6 For interesting statements to this effect by interest group participants, see Zisk, *Interest Groups in American Politics*, *passim*.
- 7 This particular formulation is our own, but it parallels similar statements elsewhere. See, for example, Sabatier, *Social Movements and Regulatory Agencies*, pp. 303-310; Woll, *American Bureaucracy*, pp. 124-131; and Niskanen, *Bureaucracy and Representative Government*, *passim*.
- 8 See Trubek, "Public Advocacy," pp. 3-9.
Although "advocacy" traditionally has been used to describe the task lawyers perform for their clients, our use of the term is broader, encompassing a wide range of extra-legal tactics. Similarly, the advocate's relationship to his or her client need not resemble the attorney-client relationship, most certainly attorney-client privileges and rules proscribing limits between legal advocates and their clients need not apply in our advocacy scheme. However, the notion of the advocate as a skilled representative is retained in the theory, practice and debate concerning general advocacy. See Public Interest Law Institute, *Balancing the Scales of Justice*, Chapter 1, and Nader, "Consumerism and Legal Services . . ." for examples illustrating this point. The Nader article and Trubek's "Public Advocacy," pp. 1-25, explain the general issues and problems of advocacy as we have defined it.
- 9 For an analysis of how businesses and labor create and sustain organized activity, see Olson, *The Logic of Collective Action*, Chapter 4, and Greenstone, *Labor in American Politics*, pp. 86-203.
The analysis in this section is the result of the author's syntheses of a wide range of literature discussing (1) the political or social importance of interest groups, (2) the problems of forming effective groups and (3) the characteristics of group or collective action. Readers interested in exploring

these issues in greater detail should see Wilson, *Political Organizations*; Olson, *The Logic of Collective Action*; Frohlich, et al., *Political Leadership and Collective Goods*, Simon, *Administrative Behavior*; and Trubek, "Public Advocacy."

- 10 For a detailed analysis, see Olson, *The Logic of Collective Action*, Chapter 3; Cox, Fellneth and Schulz describe some of the problems of identifying and advancing the consumer interest in *The Consumer and the Federal Trade Commission*, Chapters 1-3.
This analysis of the difficulty of organizing diffuse groups is the basic justification behind the public interest law movement, Ralph Nader's activism and President Carter's proposed (now defeated) Consumer Advocacy Agency. Trubek discusses the problem of group action in detail in "Public Advocacy," especially in pp 10-14, 41-42, 50-54, and in Notes 9, 81-85.
- 11 See Wilson, *Political Organizations*, Chapter 6-9, and Trubek, "Public Advocacy," pp 30-56
- 12 For a concise, clear and witty overview of the tenuous nature of the policy-making process, see Wildavsky and Pressman, *Implementation*.
- 13 See Olson, *The Logic of Collective Action*, Chapter 2. See also Frohlich, Oppenheimer and Young, *Political Leadership and Collective Goods*, pp 12-13.
- 14 See Chapter 1, note 60
- 15 Indeed, these problems helped stimulate the congressional interest which led to the latest changes in the DD system: the enhancement of the Council role as advocate and the creation of the Protection and Advocacy System. See Chapter 1.
- 16 See Wis. Stat., §165.07 (1975) for the description of the Public Intervenor.
- 17 Chapter 1, pp. 16-18.
- 18 *Ibid*, pp. 10-11, 16 and 21.
- 19 Although several persons testifying in congressional hearings on what was to become of the Developmental Disabilities Assistance and Bill of Rights Act were representatives of private DD advocacy groups, the discussions were aimed generally at insuring that some government agency be created to provide developmentally disabled people a voice in government. See, for example, U.S. Senate Committee on Labor and Public Welfare, *Hearings*, March 18, 1975.
- 20 42 USC §6067(b).
- 21 See Regulations requiring the Council to include proposals to these effects in the State Plan. The Council is free to determine the means and forms through which advocacy resources are provided, however (1977 CFR 1386.45 and HEW *Interim Guidelines*, pp. 5-17).

- 22 The authors developed the following analysis after reviewing general literature in the areas of public organizational behavior, legal advocacy, interest group politics and citizen participation in government. In addition to sources cited in Note 9 above, see Center for Public Representation, *Toward a Fairer and More Responsive Administration*; Christenson and DuBois, *The Public Intervenor in Wisconsin*; and Zisk, *Interest Groups in American Politics*.
23. 42 USC §6067(b).
- 24 42 USC §6071(a)
- 25 See generally Chapter 2
- 26 The "arenas" notion is developed more fully in Trubek, "Public Advocacy," pp. 20-24, in Lowi, "The Public Philosophy," pp. 5-20, and in Lowi, *The End of Liberalism*, Chapter 2
- 27 See generally Christenson and Trubek, *Toward a Fairer and More Responsive Administration*, Chapter 1, and Center for Public Representation, *A Handbook on Public Advocacy*, "Introduction."
- 28 "Individual" versus "collective" advocacy has long been the primary distinction between advocacy forms. This is the primary distinction used in the HEW *Interim Guidelines* in 1976, when that agency attempted to describe the advocacy roles of the Councils and of the Protection and Advocacy systems. We note, as did HEW, that both the Councils and Protection and Advocacy systems can perform individual and collective advocacy functions, though the Council is better suited as a collective advocate. Similarly, one should remember that this individual-collective distinction is at best a matter of degree, and that the ultimate results of individual and collective advocacy may be the same. See this chapter, pp. 58-59 and Trubek, "Public Advocacy," pp. 7-27
- 29 "Internal" and "external" advocacies are terms the authors developed. Considerable literature discusses the concepts embodied in "internal advocacy" and "external advocacy" particularly in the research areas of ombudsmen and citizen participation in administrative proceedings. See, for example, Gellhorn, *When Americans Complain*, and Anderson, *Ombudsmen Papers*, pp. 3-26, for descriptions of the range of ombudsmen abilities within the government structure; Verbuil, "The Ombudsman and the Limits of the Adversary System," for a discussion of the limits imposed on various ombudsmen by virtue of their positions within the governmental apparatus. See also, Trubek, "Public Advocacy," pp. 27-29, and Center for Public Representation, *Ombudsman Access and Accountability in Government*
30. These observations were reported in interviews the Center staff conducted in 1977 with DD Council staff members. The interviews are confidential but are on file at the Center for Public Representation, Madison, WI
- 31 *Ibid*

- 32 This is the argument many observers associated with external advocacy movements have posed. See generally Nader, "Consumerism and Legal Services," Nadel, *The Politics of Consumer Protection*, Chapters 1 and 2; Senate Committee on Governmental Affairs, *Hearings*; and Ebbin and Kasper, *Citizen Groups and the Nuclear Power Controversy*, Chapter 4.
- 33 Scheingold develops the notion of entitlements more fully in *The Politics of Rights*, Chapters 2 and 3. While the creation of entitlements is an important initial task in advocacy (since the entitlement establishes a legitimate right to demand a good, service or even recognition as a member of a benefitted class), it is not the only aim of advocacy. See Note 2 above.
- 34 Recent studies the Center for Public Representation conducted of ombudsmen, advocate and similar institutions created to facilitate citizen input or advocacy in governmental processes reveal these trends. See the Center's *A Handbook on Public Advocacy and Ombudsman. Access and Accountability in Government* and Cunningham, et al., *Strengthening Citizen Access and Government Accountability*.
- 35 This is required by federal law, 42 USC §6067 Under P.L. 95-612, at least half of the Council membership must be developmentally disabled persons or their representatives.
- 36 See U.S. Senate Committee on Governmental Affairs, *Hearings*, pp. 127-145, for statements corroborating this view. see also the HEW *Interim Guidelines* (1976), pp. 1⁰-20
37. See Sabatier, *Social Movements and Regulatory Agencies*, pp. 305-330, and Wilson, *Political Organizations*, Chapter 6.
- 38 Sabatier *Ibid*
- 39 P.L. 95-602 demands that P&A units be administratively autonomous, not tied directly to any other government agency in the DD system.
- 40 42 USC §6012.
- 41 HEW *Interim Guidelines*, pp. 7-10.
- 42 *Ibid* See also Chapter 1
- 43 Interesting statements regarding the capacities and limitations of government oversight committees focus on the attorney general's office, but there are other studies available. See generally Center for Public Representation, *A Handbook for Public Advocacy and Toward a Fairer and More Responsive Administration*; DuBois and Christenson, *Public Advocacy and Environmental Decisionmaking*; and *Michigan Law Review*, "The Role of the Michigan Attorney General in Consumer and Environmental Protection."
- 44 Turnbull, "Through and Beyond the History of the Mentally Retarded."
- 45 See the Wilson, Zisk and Sabatier articles noted above for general discussions of the role of citizen pressure groups. See also Lowi, *The End of Liberalism*, Chapter 4, for a discussion of the pitfalls of pressure group politics.

CHAPTER 4

ADVOCACY STRATEGIES FOR THE DD COUNCIL

In light of the analysis offered in the previous chapters, this chapter offers some concrete suggestions on advocacy strategies that the DD Council could profitably use.¹

As we have seen, advocacy is a complex process, varying in terms of who is served through the advocacy and where the advocacy originates. Thus, advocacy may be intended directly to aid a particular developmentally disabled individual or it may be directed toward establishing rights or benefits for an entire group of developmentally disabled people. Similarly, agencies within government—the DD Council, the Designated State Agency, the legislature—may initiate proposals for DD service reform, as may citizen groups external to the government structure.

The distinctions between individual and collective advocacy and between internal and external advocacy frequently blur, and it is more correct to view advocacy strategies as a continuum rather than as a collection of distinct or mutually exclusive styles. For example, individual advocacy may yield collective benefits: a lawsuit a private attorney files to obtain benefits for an institutionalized child may result in a new definition of what rights are due such children or stimulate the legislature to redefine and expand its activities vis-a-vis institutionalized children. Similarly, the Council, which is primarily an internal advocate, may serve an important role as coordinator for or communicator to external advocacy groups. In this chapter we illustrate how the Council may act along this advocacy continuum.

First, let us briefly consider Council advocacy on behalf of individuals. Although the Protection and Advocacy System has the primary responsibility for this form of advocacy in the DD system, the Council will still have occasion to do some individual advocacy on an *ad hoc* basis.²

In one state, the Council established an information and referral service for DD individuals after it found that it itself could no longer intercede on behalf of individuals who contacted the Council.³ (Creation of the P&A System should eliminate this need in most states.) There is evidence that Council members in several states have interceded on behalf of individuals to expedite state or local agency action. This is typically an informal activity of Council members, not a formal activity of the Council as a whole.⁴

While the possibility of individual advocacy should not be neglected, the activities of the Council will be directed by and large toward collective advocacy. Most collective advocacy, in turn, will be internal, directed toward using the Council's position as a state agency to affect the extent to which other agencies provide entitlements and services to people with developmental disabilities. But as we shall argue in the second half of the chapter, there are important steps the Council can take to support external advocacy as well.

Of course Councils will vary in the extent to which they can effectively use the strategies of internal and external collective advocacy. State laws vary widely in the amount of authority and resources they grant to Councils and in the locations they specify for Councils in state government. Clearly, no Council has the power directly to coerce other agencies to comply with its mandates (but then few, if any, state agencies have this power).⁵ Moreover, because of the Council's representative character, it is particularly unlikely to sue or invoke other severe sanctions against agencies or officers in the DD system. But, given adequate staff support, the Council is ideally suited for several other important advocacy tasks. Since the Council is an amalgam of interests in the DD system, it serves as a forum for debate and compromise and as a communication link between these diverse interests.⁶ It serves well as a visible location where information about the DD system can be collected, digested and disseminated.⁷ Since the Council is directed to review the plans of state agencies to whatever degree feasible, it is also in a position to urge other agencies to advocate for DD issues, policies and programs.⁸

STRATEGIES OF INTERNAL ADVOCACY

Advocacy Through Affecting Information Flow

Since the Council is often in the best position to both accumulate and disseminate information of vital importance to effective operation of the DD system, it can perform a variety of important functions that broadly have to do with communication of information.

A. Collecting Information on the Operation and Needs of the DD System

The DD Council is the forum in which the interests of a relatively diffuse group are heard and translated into proposals for government action which are, in turn, implemented by state agencies. At a minimum, effective advocacy in this regard requires communicating to the Council the needs of individuals and the performance of state agencies in meeting those needs.

As we suggest through these chapters, the Council cannot overestimate the need to stay in close contact with DD service consumers and interested citizens. As with many government programs, there are very few formal means through which the DD service system actually can measure consumer satisfaction with existing programs and services; consumer knowledge of programs, services, and service delivery problems; or the adequacy of supply of DD goods and services. Holding periodic local or regional meetings where interested persons can share their experiences with the DD system can enhance the amount and the quality of information in all these areas. Some Councils have formalized such a system by subdividing into regional councils.⁹ Several Councils with active information networks of this type have noted that they produce valuable information at low cost, and that the Council's position in the planning process has thereby been enhanced.¹⁰

The tactics for obtaining planning information from agencies depend to a large degree on the organizational placement of the agencies in the service structure, the personal style and persuasive abilities of Council appointees,

and the closeness of the relationship between the Council and the agency in question. Some Councils have improved the level of information input for planning purposes by adding officials of particularly bothersome agencies to the Council. In one state the State Office of Public Instruction infrequently communicated its programs to the Council and did not participate in the preparation of the State Plan. The Council added the director of policy planning from the recalcitrant agency to the Council and apparently has been receiving more adequate information and participation from that agency.¹¹

Finally, national citizen organizations collect data and determine priorities as well. United Cerebral Palsy, the National Association for Retarded Citizens and the Epilepsy League, among others, can provide a great deal of valuable information.

B. Dissemination of Information as a Means of Influencing State Agencies.

The Council is directed by federal law simultaneously to track the myriad federal programs which provide benefits directly to developmentally disabled persons and to monitor numerous state and local programs.¹² Some of the most impressive gains DD Councils have made have resulted from their efforts to educate administrators of state and local programs about each other and to tell both how they could use federal programs to maximize their goals.

One example illustrates both the complexity of information in the DD system and the way the Council can improve the operation of the DD system by organizing and disseminating this information. A major, long-time goal of the DD system has been deinstitutionalization. This process involves a wide range of programs, activities and institutions. For many people with developmental disabilities who do not have families, deinstitutionalization means the loss of shelter. In 1974, Congress passed the Housing and Community Development Act which provided funds to local housing authorities,¹³ and many authorities subsequently built housing under the program. Further, the Council, following the lead of another state, obtained a

state-funded program to provide transportation from the new homes to state training or outpatient facilities.¹⁴ It seems unlikely that this system of care would have been provided without the Council's having provided the information and having coordinated the subsequent efforts.¹⁵

DD Councils have also provided information to state agencies simply by identifying needs in the DD system and then establishing systems to monitor and communicate those needs. We noted earlier the establishment of an information and referral service for DD individuals in one state. In at least one other state the Council funded a program for processing group home complaints to appropriate agencies.¹⁶ In another, the DD Council established regional placement centers around the state to identify training needs and job opportunities available to people with developmental disabilities.¹⁷ Information gathered from these centers was not only useful in job placement, but provided a means of collecting and evaluating data which the State Office of Special Education could use in designing DD vocational education programs.

Advocacy through dissemination also can mean making state agencies aware of their obligations under federal law. For example, several DD Councils have circulated information on the Rehabilitation Act of 1973 (requiring nondiscrimination in vocational educational opportunities and employment of handicapped people). These actions identified and emphasized the need for state and local compliance with its provisions.

C. Influence Through Informing the Legislature

Although it is the state agency that draws the budget for and administers DD programs, the Council should not forget that the legislature ultimately must approve all programs and expenditures for state activities. Thus, it is important for the Council to educate and inform the legislature, particularly appropriate committees of the legislature, about DD programs and policies. Several Councils have created legislative liaison committees for this purpose, and many Councils report that legislative liaison is one of

their best advocacy tools.¹⁸ In at least one state the Council has had sympathetic legislators read proposals and policy statements in the legislature in response to routine review of DD funding allocations.¹⁹ In this way, the Council can make the legislature more aware of the DD system generally or of particular DD problems for which the Council wishes to gain support. In some states there are laws preventing Council members from lobbying as individuals or as representatives of the Council. In those states, the Council can encourage other persons to lobby for DD interests.²⁰

Finally, activity in the legislature is also a source of information for the Council. Through legislative liaison, the Council may learn of programs in scattered agencies that may be relevant to people with developmental disabilities. Good liaison also can generate feedback useful for further lobbying efforts.

Advocacy through Liaison and Coordination of Efforts

In addition to informing other agencies of opportunities and needs in the DD system, Councils have acted as coordinators of agencies' efforts. In one state, where the Council is attached to the State Department of Health Planning, the Council screens the programs of several agencies and offices and recommends to the Department more efficient means of providing services. Some DD Councils have spent substantial funds to establish and support a system of local service coordinators, who see that service providers fully provide benefits to developmentally disabled persons, and that there are no inconsistencies or gaps among the services available.

Another way to improve the Council's ability to make the DD system more effective is to have Council members serve as ex-officio, advisory or actual members of related committees or organizations. In one state, for example, Council members advise the State's Title XX committee.²¹ Frequently, DD interests will coincide with those of other persons, groups or institutions in the human services area. This is particularly true in public education, health, mental health and family assistance programs. Much useful information can be obtained from institutions or organizations

working in these service systems. Conversely, such organizations will probably welcome any additional information about programs of interest to them which the Council could provide.

Besides its informal efforts at coordination and liaison, the Council also has a formal mandate to review the plans of all state agencies that may have some impact on people with developmental disabilities.²² Technically, any state program could fall under this mandate and be subject to review. (This would be a most onerous task.) Congress and the HEW relations have countered this problem by stating that the Council is to review and comment on agency plans only to the maximum extent feasible.²³ But what does Congress mean here by "review and comment"? First, Congress means that the Council should, whenever possible, look over agency plans prior to enactment. If DD needs are not met, or if the proposal conflicts with DD objectives (as would a plan by the Department of Corrections to build special facilities to house mentally incompetent persons convicted of crimes), the Council is to use whatever means available to convince the agency to modify or drop the plan. Just what these means are is never defined, but they appear to include such strategies as informal administrative lobbying, participation in agency proceedings, attempts to get other agencies (attorneys general or legislative oversight committees) to intervene, and whistle blowing about inconsistencies and illegalities.²⁴ The real purpose of the review and comment process seems, in light of congressional vagueness as to the actual powers and procedures involved, to be the coordination of efforts rather than the enforcement of program compliance.²⁵

Our interviews indicate that DD Councils have not used review and comment very much, due to their lack of staff, their own timidity and the lack of cooperation from other agencies.²⁶ Yet, as Council staffs grow in size and competence, and as other agencies accept the position of the Council (as evidence suggests agencies in several states are), review and comment can come to serve a vital coordinating function.²⁷

The State Plan As An Advocacy Tool

Much of the Council's time is spent planning or reviewing the State Plan. While a Council may not have the time or the resources to act as an advocate in many of the ways we suggest in this chapter, the planning process is one point at which its advocacy role can be greatly enhanced without markedly increasing its commitment of time or resources.

The State Plan is the central document outlining the state's commitment to DD.²⁸ In a sense, it is a contract between several parties. First, it is an agreement, between state agencies and the state legislature, which identifies just what the legislature will get in return for its money. Second, the Plan is a contract, between the state and the federal government, which obligates the state to provide particular services in return for matching federal monies. Finally, the Plan is a commitment the government makes to people with developmental disabilities and to the public as a whole. These various obligations, though they limit the scope of the State Plan, are sources of leverage for the Council vis-à-vis other actors in the DD system. The Council can use various strategies to advocate DD interests during the planning, implementation and review processes associated with the State Plan.

There are at least two senses in which the planning process can be used as a tool for advocacy. The first is obvious, in setting objectives for the DD system, the Council enhances the chance that increased or improved benefits will flow to developmentally disabled people. But while its general statements of goals are important, the Council can be a more effective advocate by specifying goals precisely (e.g., "to reduce the institutionalized population at X Center by 20%"), and by specifying or providing the means to achieve those goals. For example, to support the goal of deinstitutionalization, one DD Council engaged the state Department of Social Services to provide funds for transporting developmentally disabled persons from their homes to sheltered workshops in several cities. This was done merely by suggesting that the Department could get funds for such a project if it would submit a proposal for the project for the Plan.²⁹

The second way the Council advocates during the planning process is more subtle. Since the Council includes representatives from the relevant state agencies, it is in a position to affect system priorities through internal negotiations among representatives on the Council. This is, of course, a variation of the coordination and liaison function, but with its firm integration in the planning process it takes on more significance. The need to formulate a Plan can force agencies to take DD issues more seriously and to integrate current DD needs more fully into their internal program planning. Although DD Councils have not always been very successful in their efforts to promote such "meetings of the minds," the recently enhanced position of the Council should help in these efforts.³⁰

While the Council may act with some independence on implementing state agencies during the early planning process, in most states it is dependent on those agencies once DD programs are in progress. These implementing agencies control the distribution of DD benefits and programs, collect most of the available information about program performance, and control the personnel who supervise and implement DD programs. Many general goals for the DD program may "lose something in the translation" to program implementation. This makes reliance upon the Plan as a contract that much more important. Through its agency representatives the Council should convey to state implementing agencies its interpretation of general policy goals. It also should send its memos and position statements or make its oral comments through appropriate channels. The latter tactic the Council should use even if it seems initially that such communications are not having much impact on agency behavior. This information can be forwarded to other state agencies, particularly state legislative oversight committees, when the Council's version of the Plan and agencies' views expressed in program allocations differ. The task is to build a record interpreting the Council's understanding of the Plan. The objective is to make the Council's view as clear as possible not only to the implementing agencies, but to other, superior institutions which may be called to construe the State Plan "contract." As we already have noted, the more specific the goals the easier it will be to determine whether they have been properly implemented.³¹

Finally, the 1978 Amendments clearly make the State Plan a joint effort between the Council and the designated state agency.³² While the terms of this partnership are not detailed, the Council may use its weight to block objectionable plans state agencies develop. In most states this blocking may be politically inefficacious. Still, the new law gives the Council the duty of reporting to HEW on the progress of the Plan. These reports may call on the federal government to bring appropriate pressure to bear on agencies failing to develop adequate plans.³³

Even more important is the review of the Plan in action. Using both formal and informal means, the Council can obtain information about performance from the agencies themselves, from recipients of services or from interested citizens. The Council may require periodic performance reports from the agencies;³⁴ it may ask state budget or auditing agencies to monitor program spending and performance;³⁵ or it may contract for evaluation with a state agency or outside organization specializing in such tasks. Regular input from service consumers, through periodic polls or surveys or routinized service-satisfaction forms (which could be distributed through service institutions or through an office for citizen feedback) could provide strong quantitative and qualitative data to balance information from other sources. The 1978 Amendments make program evaluation a major focus of state DD agencies' activities.³⁶ Thus this review function is clearly mandated and is important for the Council to consider.

Advocacy Through the Use of Leverage

Depending on where the DD Council is located in its state's administrative structure, it will have different opportunities to use leverage to establish or enhance its influence in the DD system. The most common organizational forms are attachment to the Designated State Agency, attachment to the governor's office and attachment to a state-level umbrella agency charged with general administrative, budgeting or enforcement functions. Each form has characteristic strengths and limitations.³⁷

DD Councils more closely tied to the governor's office have been more successful in getting the governor to intervene in the DD system. Some Councils have asked governors to scrutinize State Plans or to use gubernatorial influence to see that some DD goal was adequately provided for in the final State Plan.³⁸ Although the power of the office varies, the governor is often in a central position to influence DD policy. First, those agency heads who are political appointees will be responsive to the governor and may be persuaded to take an active role in the DD planning or implementing processes. Second, the governor may have considerable power over the state budget. Third, the governor is a highly visible political entity who, if willing, can carry the cause of DD to the citizens of the state.³⁹

Close attachment to the governor's office can backfire, however. In one state a Council member leaked some of the goals of the State Plan to the press and noted that several state agencies were lax in enforcing and implementing the Plan. Unfortunately, the governor was more sympathetic to the heads of the agencies involved and very sensitive to press attacks about developmental disabilities. He fired the Council member.⁴⁰

DD Councils attached directly to the Designated State Agency have noted that their biggest successes have come after they have developed a positive working relationship with key agency personnel.⁴¹ Since these persons have regular contact with each other (their offices may be down the hall from one another), such goodwill can be an effective leverage tool. People hate to say "no" to a friend or regular associate. Similarly, those friends know which questions to ask, and when.

Some Councils attached to umbrella agencies have been able to use their positions to obtain high levels of compliance with the State Plan. The source of leverage here is the umbrella agency's capacity to audit the agency in question and to compel compliance through administrative or legal means.⁴²

A different type of leverage comes about through the Council's authority over certain HEW grants to its state. HEW, after consulting with the National Advisory Council, may make project grants to public or non-profit entities for

a wide variety of projects, such as experimental treatment programs, public awareness projects or legal advocacy offices.⁴³ It appears that the DD Council can itself apply for such grants, but, more importantly, the Council is to review all applications its state submits to HEW.⁴⁴ Furthermore, the Council may encourage individuals, groups or agencies to apply for such funds by promoting specific programs in the State Plan or by other means of communication and project support. Thus, when state agencies fail fully to accommodate the Council's goals in the Plan, the Council may more or less advertise 'project grants for sale' to see that unmet needs are given some attention.

Some Councils have encouraged this type of grant for the purpose of critically evaluating the DD system in their home state. Others have used this limited grant-approval authority to seek an independent description of the operation of their particular DD system.⁴⁵ The leverage here stems from the Council's ability to seek out independent sources of information. As we have suggested, information is a very necessary and valuable commodity in human services systems. By generating information through project grants, the Council can enhance its stature in the DD system.

Finally, seeing that all other state actors in the DD system implement the State Plan is itself a form of leverage. In this capacity the Council acts as the official state monitor of the State DD system. The Council has direct ties to the administering federal bureaucracy.⁴⁶ Once agency actors recognize the Council-HEW link, the Council may enhance its overall leverage in the DD system.

Advocacy Through General Articulation and Legitimation of DD Interests.

While our point here is only a brief one, it deserves consideration. A general advocacy strategy is simply to articulate and legitimate the DD issue in state government. The fact that an executive-level institution exists to provide information, press demands and actively coordinate state efforts for DD activities is significant. Several DD Councils have been most successful merely by going out and contact-

ing, formally through resolutions of the Council or informally through phone calls or lunches, the "right" person about a DD problem that that person's agency affects.⁴⁷

STRATEGIES OF EXTERNAL ADVOCACY

Advocacy Through Affecting Information Flow.

The DD Council can easily play the same informational role for private groups as for state agencies. By regularly communicating information about programs available and benefits to which developmentally disabled persons are entitled, the Council can provide necessary material at relatively low cost. This particular task could be accomplished by holding news conferences, establishing a DD newsletter, conducting regional meetings, establishing regional dissemination centers or using the broadcast media.⁴⁸

These tactics also could be used to stimulate external advocacy when it does not yet exist or when it does exist but is sluggish. Several states, in concert with the National Advisory Council and several national foundations for particular developmental disabilities (most notably, the National Association for Retarded Citizens), have developed general "consciousness raising" campaigns aimed at the public and at legislators and promoted fundraising and membership campaigns (by providing press releases, holding conferences, announcing "Retarded Citizens Rights Day" through the Governor's Office, etc., or by lending other support—such as by providing lists of active persons in the state).⁴⁹ Some Councils also have sponsored training for agency personnel, lay volunteers, developmentally disabled individuals or interested citizens. Such training can provide information on the operation of the DD system, rights and remedies available to developmentally disabled individuals, techniques and procedures for providing services and benefits, and methods of providing information for the State Plan planning process. Training by the Council or a contracting organization can improve the performance of existing DD system actors and add new actors to the system.⁵⁰

Advocacy Through Liaison and Coordination Efforts

Councils frequently have been used as “broker” institutions between DD service consumers and state providers. The very existence of the Council in part performs this function. Representatives of the agencies, consumer groups and other service providers meet head-to-head in Council meetings, activities and committees. In one state, the Council’s Governmental Affairs Committee includes members from state organizations of retarded citizens; of persons with epilepsy, cerebral palsy and autism; and a few others. Through the committee these groups can review rules, regulations and laws about DD in the state and lobby informally before the legislature.⁵¹

Again, Councils can and in many states have acted as a referral service for outside advocacy groups by showing these groups precisely where to go in the DD system to obtain information, press for benefits or present a particular policy proposal. In practice, this referral service has worked better for groups seeking collective or system goals than for the processing of individual complaints.

Advocacy Through Support of the Protection and Advocacy System

As we indicated in Chapter 3, the Protection and Advocacy System in each state also was given a broad mandate to act as an advocate for developmentally disabled people. Although in a few states there has been friction or considerable distance between the DD Council and the P&A System, we suggest that the advocacy roles of each of these institutions complement each other.⁵² The Council stresses collective advocacy, while the P&A System concentrates on individual advocacy; the Council acts as an internal advocate, while the P&A System is an external advocate. Finally, the Council is best suited by structure and location in the DD system to identify goals, problems and priorities at the general policy level. The P&A System is geared more to vindicating established rights, enforcing compliance and seeing that individuals’ needs are met.⁵³

Even in the gray area between these institutions, though, we can see how their functions complement each other. The Council relies on its control over the State Plan, its relationship with the Designated and other state agencies, the diverse composition of the Council itself and its location atop the DD policy-making structure to enable it to develop a coherent set of goals, priorities and programs. The Council relies on information, informal influence and some approval authority to enhance its role as advocate. The P&A System, however, tends not to rely on these advocacy tools. Rather, the P&A System is supposed to use the full panoply of legal, administrative and political rights and remedies—including individual support services—to attack imperfections in the DD system from the outside.⁵⁴ Thus, the Council may act from a relatively high position of authority with a relatively high level of information and ability to coordinate, but the P&A System is freer to use a wider variety of tactics to address particular problems.

For example, DD Councils were instrumental, along with the national associations for specific developmental disabilities, in adding the Developmental Disabilities Bill of Rights to the DD Act of 1975.⁵⁵ At the state level, the Councils translated this statement of entitlements into policy outlines that for the most part have been incorporated into all State Plans. Subsequently, a series of court cases initiated by public legal service agencies and P&A units has further defined and elaborated the rights outlined in the 1975 Act. Also, the enforcement of the 1975 DD Bill of Rights generally has been left to the P&A systems. Thus, the Councils have helped to provide the basis and authority on which the P&A Systems have been able to vindicate individual rights. The P&A Systems in turn have assured the Councils that hard-fought-for entitlements will in fact be implemented.

What overlap exists between the DD Council and the Protection and Advocacy System is a strength, not a duplication of services. As we indicated earlier, the most effective groups have been those able to articulate a coherent stream of demands in many arenas and across large spans of time. Yet, it sometimes is desirable to attack a single arena from two angles. For example, state and local agen-

cies implement virtually all DD policy. State agencies establish rules of procedure and agency conduct in formal or informal rule-making proceedings. These rules have substantial effect on the level and quality of services which eventually reach developmentally disabled people. As such, these rule-making hearings are important advocacy targets. P&A advocates can appear in all such proceedings to offer testimony, make suggestions or formally challenge the actions of the agency.⁵⁶ In some states legislation also permits the DD Council to appear in some capacity at these administrative proceedings.⁵⁷ Instead of one voice, developmentally disabled people then have two, as the Council and P&A unit influence the agency from the "inside" and from the "outside."

To enhance the level of cooperation between the Council and P&A, the Council can serve as liaison between the P&A unit and state agencies, even to the point of becoming an informal or formal arbitrator or negotiator, suggest priorities for P&A advocacy; provide information and coordination services for individual P&A units; and speak for the P&A System in relevant forums, providing moral, financial, political or other support. The latter includes formal or informal agency and legislative lobbying on behalf of the P&A system, requests for P&A funding in the State Plan and linkage of the P&A system with private groups.⁵⁸

Promoting Citizen Advocacy

The focus on formally organized external advocacy, such as that of the P&A System, should not detract attention from the important role citizen advocacy can play in the DD system. Citizen advocacy includes self-advocacy by persons with the developmental disabilities, advocacy by individual citizens acting on behalf of a developmentally disabled person and advocacy by representation of voluntary organizations.

Self-advocacy or self-help is in many ways the best type of advocacy, and programs providing professional or lay advocacy should encourage developmentally disabled people to speak and act on their own behalf to the maximum extent feasible. Self-advocacy can be fostered and

strengthened through a program of citizen advocacy in which developmentally disabled citizens are paired with other citizens. Each then learns from the other. If the person with the developmental disability needs assistance, his or her partner helps attend to that need or suggests means by which the need may be satisfied. This individualized advocacy provides services directly to developmentally disabled people, allows them to participate in directing their lives and at the same time sensitizes the general public to the circumstances and needs of citizens who do have developmental disabilities. The DD Council can support citizen advocacy as part of its support of outside advocacy groups, as discussed in the following section, or it can encourage and support efforts of the P&A System to develop such a program.⁵⁹

Advocacy Through Support of Outside Advocacy Groups

Full-scale advocacy requires considerable time, effort and expenditure of resources. Moreover, the DD Council is in a very difficult position from which to embark upon certain advocacy endeavors. Because of its sensitive relationships with other state agencies, for example, the Council sometimes may have to rely on outside groups to perform the advocate's task. Private, external advocates, like voluntary organizations or other citizens' groups concerned with DD, are freer to take more controversial positions than is the Council, which must try to balance all interests in the DD system.⁶⁰

However, private, external advocates can effectively challenge ongoing activities of state agencies. (Of course, these advocates have important cooperative roles as well, as when they serve as sources of information about consumer desires or when they help agencies distribute information to consumers.) They have the ability to select from a wide array of advocacy tactics, ranging from citizen advocacy to lobbying to court action.⁶¹ Since citizens in these groups generally are volunteers, and work when called, they constitute an advocacy labor pool which can be acti-

vated when needed. Similarly, private advocates are able to provide some of the funds needed to maintain advocacy. Overall, then, private advocacy groups are an important resource in the DD system, one that the Council should draw on whenever necessary.⁶²

But private, external advocacy groups often have difficulty forming and existing on their own, because of the substantial organizational efforts required. The Council can assist in these efforts, usually at a relatively small cost to itself. By publicizing the availability of new benefits, identifying a particularly salient policy issue or pointing out citizen groups or agency programs available for citizens to obtain information or articulate their interests, the Council can provide the seed information which may stimulate private activity. The Council press conference, the regional Council "town meeting" or the Council's publication of informational literature serves these ends well.⁶³ Specialized training in the art of advocacy or the operation of the DD system particularly enhances the capacity of private advocates to use the system. First, Council-sponsored training means that the private groups will not have to exhaust their resources just to learn what the DD system looks like or how to work within it; second, the Council can direct the private efforts to especially useful areas, preventing the waste of private advocacy resources.

Working to provide access for citizen representation at agency rule-making proceedings, facilitating access to agency decision-makers and coordinating information flow among private organizations are three means by which the Council can reduce the costs of getting together and of developing a private advocacy program. By reducing these costs, the barriers to private group formation are lowered, and the possibilities of successful advocacy increased. The Council facilitates access to agency decision-makers by telling citizens which decision-makers should be contacted for what purposes, and by persuading these officials to listen. The Council may act in a clearinghouse capacity by encouraging citizens to inform the Council of their interests and organizations. By collecting this information in a central library, and by making the information available to all

other interested citizens, the Council both obtains information about DD activities in the state and makes it easier for individuals and groups to get together to act.

ADVOCACY IN STATE AND LOCAL ARENAS

As we noted in Chapter 2, a five-part diffusion of authority characterizes state and local government. Single agencies or actors rarely hold all the power and means to design and implement programs. As a general rule, then, the DD Council must expect to advocate in several arenas for any given program. Since the targets of advocacy may be at different levels of government—state or local—and have different sources of authority—legislative, executive, administrative or judicial, the Council will have to use a variety of tactics and engage in both internal and external advocacy.

The Council perhaps is best able to advocate for DD interests through its ability to coordinate activities and to act as a liaison between the various public agencies in the state system. Given the diffusion of authority in state government, this coordinating function is extremely important. Much of the coordination at the state level results from the fact that DD Council members represent various state interests in the DD system. Agency, consumer and provider representatives carry information and assistance between the Council and their home groups. Similarly, Council representation on or communication with other state level advisory commissions is facilitated by the fact that such bodies often share similar functions or assignments.

The lack of clout the Council has at the local level is caused by the state focus of the Council, the distance between the Council and the localities, and the fact that these two institutions are responsive to different constituencies.⁶⁴ This gap can be narrowed if the Council can mobilize local constituencies to its cause. Advocacy training, combined with other techniques to augment information flow to interested parties at the local level, makes it possible to have persons and organizations who are closer to these decision-makers join the process of advocating for DD interests. This collaboration is particularly important when the target

of the advocacy is a financially-strapped agency—such as a local school board—that is likely to be responsive only to grass roots lobbying.⁶⁵

Advocacy Through Process Reform

Governing DD allocations, reforms and advocacy are general rules and procedures which apply to all forms of public advocacy and government activity. For this reason, the DD Council should study and support general proposals for advocacy which may be beneficial to the DD system. For example, several states have proposed various kinds of ombudsmen to process citizen complaints about the performance of state agencies affecting them. In New Jersey, there is a “general advocate” who has the capacity to investigate complaints in a number of issue areas and is empowered, upon finding an agency at fault, to settle the dispute by negotiating or by suing the infringing agency.⁶⁶ In Minnesota, there is an ombudsman in the Department of Health who has the power to investigate alleged abuses and to suggest legal or administrative corrective action.⁶⁷ DD Councils in states without such institutions could support such proposals when made or initiate such proposals themselves.

Similarly, the DD Council could suggest changes in agency rule-making procedures which would make it easier for service recipients to participate in those proceedings. The list of potential Council activities and proposals in this area is very lengthy, but the message is simple.⁶⁸ The Council should use its voice to advocate wherever something which could make the DD system more effective appears. This advocacy may include Council support for general government reform as well as DD system reform, because the DD system must work within the general structure of government.

FOOTNOTES

- 1 Statutory footnotes are to P.L. 94-103. Changes made under P.L. 95-602 are noted where appropriate.
2. Several Council members from states in HEW's Central administrative region have indicated that they or other Council members have interceded before appropriate state agency officials on behalf of developmentally disabled persons. One agency representative interviewed believed that such persistency by individual Council members seeking particular ends is the single most effective tool the Council has.

During the summer of 1977 the Center interviewed an agency, a provider and a consumer representative of the DD Council in Indiana, in Ohio and in Minnesota. These interviews, including the one referred to in the paragraph above, were conducted by John Martin, Center staff consultant to the DD Project. Howard Erlanger, assistant project director, conducted similar interviews in Wisconsin during the winter of 1977.

Martin, Erlanger and the Center project staff developed a survey instrument for these oral interviews that was designed (1) to solicit responses about the operation of the DD Council and about the respondent's impression of the relationship between the Council and his or her constituency and (2) to evaluate the respondent's knowledge of the DD system. Interviewees were told that their identities would not be revealed. Accordingly, survey responses were coded only by the state, the respondent's classification (agency, provider or consumer representative) and a number. The same code has been used to identify the interviews cited in this text. As indicated earlier, transcripts of the interviews are on file at the Center for Public Representation.
- 3 This program was initiated in Nebraska. See Government Accounting Office, *Task Force Report: Developmental Disabilities* (hereafter referred to as the *GAO Task Force Report*). The 1978 California State Plan provides that the State Protection and Advocacy Agency for Persons with Developmental Disabilities (CPAA) provide local information and referral services (California State Developmental Disabilities Council, "Federal Preprint of the State Protection and Advocacy Plan for Fiscal Year 1978," pp. 2-4).
- 4 See field interviews 2A1 and 2P1.
- 5 Interviewees almost unanimously endorsed this view. Similarly, no such provision exists in any federal or local act.
- 6 This role was again emphasized in the interviews. See interviews 5P1 and 2A1 for representative statements. In some states the chief executive of the DD Council serves as the primary broker between interests within the Council by insuring that professional provider, agency and consumer representatives participate equally in group discussions and decisions. See interviews 5P1, p. 1, and 5C1, p. 3. There is considerable authority which suggests that the Congress intended to composition of the Council to create precisely this amalgm of interests (Conference Report, H. R. 4005, *Developmentally Disabled Assistance and Bill of Rights Act*, p. 36).

- 7 See Chapter 3, pp. 58 and 62 and notes therein.
- 8 P.L. 94-103, §141(b)(3). 94th Cong., 42 USC §6067. See also HEW *Interim Guidelines*, pp. 6-9.
- 9 Minnesota has regional councils which perform much as the model proposed (Minnesota Governor's Planning Council on Developmental Disabilities, "Policy Statement: The Role and Responsibilities of Regional Developmental Disabilities Programs," pp. 5-13-17).
- 10 This was reported in Oregon and Nebraska in the GAO *Task Force Report*, pp. 46-48, 51-55. Several interviewees viewed the Councils as meeting places where various interests could exchange information (See interviews 2C1, 4P1 and 4C1.) The information costs are low because much information is volunteered freely as incidental to duties and desires of participants in the DD system. In short, the various actors in this system shoulder a portion of the cost required to produce needed information.
- 11 Reported in Stedman, "The Role of the State Planning Council," p. 14.
- 12 Cf. P.L. 94-103, §§114(3)(b), 111 and 141(b).
13. 42 CFR 5049.
14. Often Council action leads diverse agencies to see that they have common interests in problems such as education of the severely mentally retarded person. See, for example, interview 4C1.
15. See the GAO *Task Force Report*, pp. 56-59, for an elaboration of this narrative.
16. Oregon *State Plan*, fiscal year 1976, pp. 108-110.
17. Nebraska *State Plan*, fiscal year 1975, pp. 84-90 (cited in Stedman, "The Role of the State Planning Council," p. 15).
18. See, for example, Wisconsin State Council Bylaws, Article VII. §7CC. DD Councils have not been uniformly successful in this regard, particularly where they are dominated by agency representatives. These persons frequently are under orders from their supervisors not to engage in legislative influencing activities. See interviews 2P1, 2A1, 2C1, 4P1, 4C1 and 3A1.
19. Oregon, *State DD Newsletter*, p. 2.
20. The informal pressures suggested in Note 18 above are far more significant deterrents to direct Council lobbying. Councils as bodies may not wish to antagonize agency officials. See interviews 3P1 and 2C1. Weill, *Bureaucracy in America*, p. 146.
21. This happens in Wisconsin.

22. See Notes 8 and 12 above.
23. See Note 8 above. This general mandate to review other agencies' programs was not deleted under the 1978 Amendments.
24. This list the Center compiled from the interviews it conducted in the summer of 1977, from the construction of the developmental disabilities legislation (See Chapter 1), from the H. R. Conference Report, No. 94-473, and from the analysis in Trubek, "Public Advocacy."
25. See HEW *Interim Guidelines*, pp. 9-14, Regulations 42 CFR 1386.
26. See interviews 2A1, 2C1 and 4A1 and the GAO *Task Force Report*, pp. 86-87.
27. See Chapter 2, p. 36, and interviews 4P1, 4C1 and 1A1.
28. P.L. 94-103, §11. The precise content required of the State Plan has changed, but the purpose remains the same.
29. Michigan, as reported in the GAO *Task Force Report*, pp. 59-60.
30. See generally Chapter 1. The intent of Congress to upgrade the status of the DD Council is particularly evident in the Senate Report accompanying S. 462, Report No. 94-160, pp. 15-19. The provisions regarding the Council in S. 462 were embodied in P.L. 94-103.
31. See this chapter, p. 77.
32. P.L. 94-103, §137(b), 42 USC 6063, as amended, P.L. 95-602, §513.
33. P.L. 94-103, §137(b)(4), as amended, P.L. 95-602, §513.
34. See Chapter 2, pp. 40-41.
35. The DD Council could insist that requirements for reporting systems be included in the State Plan.
36. P.L. 94-103, §137(b)(2), as amended, P.L. 95-602, §513.
37. Although each DD Council can be seen as having a unique position in the state bureaucracy, the six forms Stedman suggests in "The State Planning Council on Developmental Disabilities" illustrate well the basic differences in form. These six forms are governor-attached with agency liaison, designated state agency-attached, umbrella agency-attached, designated state agency remote, agency-isolated and governor-isolated.
In the first model the DD Council is a state-executive-level body, but by law maintains formal communication and other links with the designated state agency. The second model places the DD Council as an institution on a par in the state bureaucracy with the designated state agency, while the third attaches the Council to an agency designed specifically to monitor state programs. In the fourth model the Council is linked to the designated state agency, but both are buried at relatively low levels in the

bureaucracy. In the agency-isolated model the Council is linked to an agency other than the designated state agency, the umbrella agency or the governor. In the governor-isolated model the Council is linked to the governor, but has no formal links to the DD bureaucracy.

For advocacy purposes the first three models are generally preferable to the last three. The cardinal rule is to situate the Council at a level equal to or greater than that of the designated state agency, but in no case to isolate it, in terms of lines of authority, from the designated state agency. This statement follows from what we have said generally in Chapters 2 and 3. The Council needs to work with the designated state agency, which is usually charged with drafting the State Plan and with directing the administration of state and federal DD programs. If the Council is located too distantly from the designated state agency in formal lines of authority, it will lose some of its capacity to marshal information through the designated state agency or to influence the agency's activities. Similarly, if the Council is placed below the designated state agency in the DD chain of command, it loses some of its bargaining and control capacities vis-à-vis the agency, since the latter will have the last word on policy decisions.

- 38 The California Council used this tactic to influence the design of the California Protection and Advocacy System, according to a report in the *Los Angeles Times*, September 21, 1977, p. 4.
- 39 For good discussions of the role and influence of governors in state politics, see Jacob and Vines, *State Government and Politics*, Chapter 5, and Wolf, *The Governor in American Politics*, pp. 11-36.
- 40 This incident was reported in the *Cleveland Plain Dealer*, December 17, 1977, p. 6. Interviewees have also suggested that gubernatorial support for Council activities vacillates considerably, although several respondents noted that a direct attachment to the governor's office might pique the governor's interest.
- 41 This is predicted in the general argument developed in Chapter 3. Several interviewees corroborated this thinking. "The Council has made its biggest impact just working with agency personnel," said one (2A1). "Communication makes the agency realize we're here," said another (5C1).
- 42 See Chapter 2.
- 43 P.L. 94-103, §127 and also 42 CFR 1387 (1977). This capacity has been retained under the 1978 Amendments.
- 44 42 CFR 1387.12, 42 CFR 1387.23(b) (1977), which establishes the DD Council as the state review agency for project and special project grants. The Secretary of HEW will review grant proposals only after the appropriate DD Council has done so.
- 45 This project is in part the result of one such attempt by the Wisconsin DD Council.
- 46 See generally Chapter 1 and P.L. 94-103, §§11, 141.

- 47 See Note 39 above and consider the following comment: "State agencies and the legislature are beginning to come around. They know we [the Council] are here to stay, so they are starting to cooperate with us" (Interview 2C1, p. 3). Compare also Edelman, *The Symbolic Uses of Politics*, pp. 20-21, and Trubek, "Public Advocacy," pp. 46-53, on the utility of creating institutions around which citizen interests can rally
- 48 At least a dozen Councils produce DD newsletters. According to our hour-long interviews, however Councils are very reluctant to use the broadcast media.
- 49 For an example of possible programs, see the excellent *Perspectives on Public Awareness*, edited by Richman and Trohanis, which outlines strategies for increasing public awareness. Possible targets for a publicity campaign include:
 - Radio and Television* news features stories, straight news, documentary programs, public service announcements, talk shows;
 - Newspapers* display advertising news stories, news features, columns, editorials, letters to the editor;
 - Other Printed Materials* magazines, brochures, annual reports, quarterlies, professional journals, fliers, pamphlets, newsletters, press kits;
 - Visual Materials* slide/sound shows, mobile displays/exhibits, motion pictures,
 - Outdoor Advertising/Public Service Announcements*, billboards, bus placards, city property,
 - Other* speaker's bureau, printed advertising items, lapel buttons, letter campaigns, seminars, personal rapport, bumper stickers.
50. This project introduces a training format for the DD system.
- 51 This strategy is used in Wisconsin.
52. See Chapter 3, pp. 62-63, and Chapter 1, Conclusion.
53. In addition to material cited in Note 50 above see "Conference Report," pp. 37-39.
54. *Ibid* See also HEW *Interim Guidelines*, pp. 7-19.
- 55 See generally Congressional *Hearings*, S. 427.
- 56 Though the precise structures and capabilities of P&A systems vary from state to state, these capabilities are universally mandated. See Senate Committee Report, No. 94-160, pp. 37-38.
- 57 Council members we interviewed indicated, however, that Councils do not use this advocacy tool.
- 58 See generally Chapter 3.
- 59 In California, for example, citizen advocacy is the responsibility of the P&A System. See the *California Protection and Advocacy Plan*, 1978, pp. 2-4.

- 60 In selecting influence strategies, interest groups are limited only by their resources and by lobbying laws. Consequently, they have wide latitude in selecting tactics and targets. See generally Zisk, *Interest Groups in American Politics*.
- 61 In some states volunteer organizations also are the foundation for local or regional protection and advocacy units. In Wisconsin, for example, the State P&A office organizes regional centers, but turns over the training, monitoring, and service functions to local voluntary organizations (Interview with Betty Halgren, Wisconsin Coalition for Advocacy [a P&A unit], conducted by Don Hermanson, 6-26-78).
- 62 Indeed, up to one-half of the Council membership comes from such groups in the form of consumer representatives, and often the provider representatives are linked to these groups as well. Local organizations often develop comprehensive citizen advocacy programs, as is the case in Madison, Wisconsin.
- 63 See Notes 46 and 47 above.
- 64 *Ibid*.
- 65 See Dye, *State and Local Politics*, Chapter 4.
- 66 See New Jersey Laws 1975, Chapter 27, Department of Public Advocate.
- 67 The State of Minnesota has a complex advocacy/ombudsman system for human services. In addition to the State DD Council, the State Council on the Handicapped and the State Hospital Patient Advocate system of the Department of Public Welfare act as advocates to monitor and stimulate change in the state service system. The state maintains several ombudsman organizations as well, including a Vocational Rehabilitation Ombudsman, an Office of Health Facilities Complaints and State Hospital Review Boards. For an excellent summary of Minnesota's advocacy and ombudsman system in the human services, see the Minnesota Office of Human Services, "Advocacy/Ombudsman Study." Note also the Minnesota Developmental Disabilities Advocacy Project.
- 68 The Council could promote the creation of agencies similar to those noted in Notes 66 and 67 above or programs to pay legal fees for persons representing DD groups at agency rule-making hearings. Nursing home or other institutional ombudsmen could be promoted as means of increasing the level of information in the DD system, the level of access to the system for interested persons or the quality of services.

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