

MODEL ROLES FOR DEVELOPMENTAL DISABILITIES COUNCILS

INTRODUCTION

In a time of great danger for the federal leadership and funding role in all human services, it becomes more important than ever that we, in the developmental disabilities field, clearly understand our roles and responsibilities; that we can conceptualize the actions we take within a clear framework; and that we can demonstrate to our colleagues in state government that the Developmental Disabilities Council can make a crucial contribution to state's analyses' of and planning for people in need.

In the ten year history of Developmental Disabilities Councils there has been great maturation of skills and abilities and, in many states, the Council is perceived as a valuable resource for advice, planning and demonstration. These states appear to use well their functions as coordinator, data gatherer and arbiter among varying interests. This high level of competence is now required in all fifty-four states and territories if the Council is to survive as an entity and if its mission and functions in behalf of people with developmental disabilities are to be achieved. The last ten years of growth and improvement have been impressive: but, in 1981 and beyond, it may not be enough.

It is in the spirit of creating an opportunity to hone our skills, to become more sophisticated advocates and to build a conceptual framework for our work that I offer these thoughts for you to consider.

"The State Planning Council Shall Serve As
An Advocate For Persons With Developmental
Disabilities"

The Council as advocate has been with us since developmental disabilities councils were first authorized in 1970. Advocacy, as an activity and as a service, has greatly expanded in this decade and many types of advocacy systems required the Council to be on the creative cutting edge, to have a vision of advocacy needs which help to pave the way for the entire system to operate more effectively.

The Developmental Disabilities Act specifies other functions for Developmental Disabilities Councils which serve the over-riding role of advocate. These functions are: coordinating, monitoring, planning and evaluation. All of these activities have required an increasing level of skill and sophistication by Council members and staff. These functions are in fact all planning activities.

There are implicit roles for Developmental Disabilities Councils which can greatly enhance our effectiveness as advocates. They are: giving advice to the Governor and State Legislature, negotiating with state agencies, and building the capacity of the public and private sectors to provide services to the developmentally disabled.

There is overlap among these roles. Most Councils implicitly use them in combination. Some have used only one - capacity building - and, thus may risk losing their clout, effectiveness and credibility as advocates due to their neglect of their other major roles within state government.

COUNCIL AS ADVISOR

Although Councils must be created in states by virtue of a state's acceptance of federal funds, Developmental Disabilities Planning Councils are, in fact, very much creatures of state government.

Initially many Governors would probably not have appointed Councils if there were no federal mandate to do so, although some planning or advisory mechanism possibly would have evolved. Since the federal law defines Council composition, leaving very little leeway for a governor to use Council appointments for great political gain, Councils must be useful to governors in other ways.

As we go through the elements of the role of Council as advisor, keep this question in the back of your mind: Does your Governor find your Council useful enough to him/her that the Council would be retained even without a federal mandate? This may in fact be a question you will have to answer if the current administration in Washington succeeds in consolidating Office of Human Development Services programs and simplifying state requirements for funds. It is the National Association of Developmental Disabilities Council's responsibility to assist you in becoming indispensable to your governor.

In general, Governor's need advice on:

- How to interpret data about developmental disabilities for purposes of policy development;
- The impact of state administrative procedures on programs affecting the disabled;
- The budget implications of serving this population and how to cut costs with the least toll on the citizens of your state;
- The political assets, liabilities and realities involved in serving the severely handicapped.

By providing good advice, Councils avoid a subtle or outright adversarial relationship with Governors. Although negotiation clearly comes into play when Councils work with Governor's Offices, the major role is one of advisor, particularly with respect to the policy impact of state and federal legislation on the Governor's Administration. Finally, Governors need advice on how to build political support for his/her policies. By helping him/her to serve the developmentally disabled who vote and whose parents, advocates and service providers vote, Councils can assist Governors in an important political arena.

It is in this advice-giving capacity that Councils currently have the responsibility to develop information for their Governors on the impact of block grants and budget cuts on services to the developmentally disabled.

As you know, the Governors have long been on record as supporting block grants. Many, however, are beginning to realize that block grants under New Federalism* represent not only a potential transfer of authority to the states, but a transfer of fiscal responsibility to the door of the Governor's mansion and state house. Although gubernatorial opposition to budget cuts is slowly mounting, Governors are in a ticklish position if they try to address the need for a federal responsibility in non-welfare programs. There is a great deal of money at stake if Medicaid and Aid to Families with Dependent Children would no longer be federal responsibilities. The Governors, therefore, are tending to focus their opposition to cuts in these welfare areas. They need the assistance of the Developmental Disabilities Council to understand that blocking and budget cuts in other human services areas will quickly influence the welfare system and increase indigence in the states, unless states and localities raise taxes to cover the loss in federal revenues.

Here's a way some states have developed a means to provide advice to their Governors on President Reagan's proposals. (These steps can be applied to any policy proposal).

STEP ONE: ANALYSIS OF PROPOSALS, INCLUDING CONGRESSIONAL
OPTIONS UNDER CONSIDERATION

This step can include narrative descriptions of options and charts on budget proposals. Councils can also include evaluative statements regarding impact on the developmentally disabled population. Data regarding eligibility changes and potential transfer of persons from one program to another should be provided and explained. There can also be a clear statement of the possible benefits which might occur. An objective, rather than self-serving, analysis of the continuum of policy proposals will greatly enhance the respect with which the Council is held within state government.

STEP TWO: EVALUATION OF BUDGET PROPOSALS ACROSS HUMAN
SERVICES PROGRAMS

By being a convenor or participant at meetings with state agencies responsible for other populations in need (such as juvenile, offenders, the elderly, unwed mothers, foster children, etc.), the Council will have access to the larger picture in its state; an appreciation of the difficulties being faced statewide; and, a chance to take advantage of opportunities otherwise unavailable to the disability community in isolation.

In addition to providing an opportunity to engage in statewide planning for human services, this approach offers future benefits for Council coordination efforts. It will enable you to see instances where developmentally disabled people can get "plugged in" to human services less traditionally directed to the developmentally disabled population and to influence the development of cross-cutting policies of benefit to the disabled. Advice to the Governor can then be in the form of over-arching issues, interagency coordination and non-duplication.

STEP THREE: PROVIDE THE GOVERNOR WITH POTENTIAL POSITIONS, WITH RATIONALES, FOR HIS CONSIDERATION OF THE VARIOUS OPTIONS.

At this point, the role of the Council and its value to the Governor, requires no justification. These steps point to a need for further coordination and joint efforts. Also, Council's ability to deliver support to the Governor's legislative initiatives by mobilizing consumers and advocates in the state, will add greatly to its value as an ally.

A final function vis-a-vis councils and their Governors' to be mentioned. There will be times when the Governor feels that in a conflict between groups in need, it is" the best interest of the entire state for him to make a decision with which the Council strongly disagrees. Councils should develop, with their Governor's office, an acceptable method to disagree. As advocates who are also creatures of the

Governor, it is incumbent on councils to find a way to agree to disagree - without embarrassing the Governor, while retaining Council integrity as an advocacy organization.

All of these steps also apply to advising your state legislature. This is an appropriate activity for Councils and must be done with the knowledge and consent of the Governor.

These activities which involve the Council as advisor are displayed below in terms of systems change activity versus direct services activity. The approach to Council as advocate I am offering holds that the funding of direct services is a secondary Council activity and that to truly have an impact on the state system of services, emphasis must be placed on systemic change. The funding of direct services should be at the service of systems change goals.

ADVISING THE GOVERNOR

Systems Change Activities

- Assess impact of administrative procedures
- Provide budget implications & suggestions on cutting costs
- Assess impact of federal & state legislative proposals & changes
- Identify problems of duplication & gaps
- Evaluate political impact of the above

Direct Services Activities

- Use aggregated data & case examples to illustrate systemic issues
- Data on consumers, parents & service providers illustrate potential support or opposition to state policies

You will notice that data from direct services is useful only in-so-far as it clarifies systemic issues and as it illustrates problem areas which need to be addressed.

The advisory role presupposes that the Council has a good working relationship with the Governor's office. It helps if the Chair has personal access to the Governor and/or if the Governor has assigned an effective staff liaison to the Developmental Disabilities Council.

COUNCIL AS NEGOTIATOR

Advocacy involves several elements which can be viewed along a continuum which includes gentle persuasion, negotiation, confrontation, adverse publicity and legal action. The adversarial advocacy role need never be used by Councils if the following things occur:

- Consumers and providers learn how to help state agencies to accomplish Council objectives, acknowledging the constraints under which the state agencies operate;
- Agency heads and Council staff take the time to inform Council members of agency objectives, planning cycles, political constraints and program and funding limitations;
- Council members take the time to learn about how the state system operates;
- All parties try to see the situation from the other's point of view while keeping the Council's mission ever in mind.

Negotiation Presumes:

- A set of common or complementary concerns or a problem requiring a solution;
- Differences of opinion on what needs to be done and how to do it;
- A willingness to compromise.

Some mechanisms by which Councils can consummate negotiations to achieve their goals are to:

Fund training projects for state agency personnel;

Use funds for a given priority service area to develop interagency agreements for service provision;

Really use the state planning process to appropriately review the plans of state agencies, coordinating agency objectives with the Developmental Disabilities State Plan and working cooperatively with agencies to find common objectives and future initiatives to meet the needs of both Council and agency and their target populations.

Too often in the past, Councils have reviewed an agency's public plan draft far too late in the planning cycle to substantively influence agency decisions at the option-development stage.

As I have attended Developmental Disabilities Council meetings during the past year, I have been quite struck by the general willingness to make a contribution to Council deliberations by state agency members of Councils. I have also picked up, on occasion, a feeling of "Well, this is only part of my job. There's nothing the Council can do for my agency; they just want more money for developmental disabilities." Some agency directors set themselves apart from the council, referring to the Council as "they" rather than "we". Sometimes I sense an adversarial relationship between agency and consumer Council members. In this political and economic environment, we need to do everything possible to find ways- to play on the same team. Since we can't all have the same goals, we must become top notch negotiators and find ways for both sides to win in order to obtain the most long-lasting positive effects for people with developmental disabilities.

The chart below displays the negotiating activities of the Council in terms of systems change activities and direct services activities.

Negotiating with State Agencies

Systems Change Activities_____	<u>Direct Services Activities</u>
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| <ul style="list-style-type: none">• Attendance at policy development meetings of state agencies• Review of policy option papers prior to public review process• Thorough review of and response to other state plans• Clarification of current and future initiatives common to DD state plan and other state plans• Development of projects to train agency staff | <ul style="list-style-type: none">• Grants to state agency to provide demonstration or gap-filling services to the developmentally disabled |
|--|---|

All negotiating activities should have, as their ultimate objectives, the provision of quality services to people with developmental disabilities. However, the expenditure of funds for direct services that do not become part of the ongoing service system is a waste of money. If a needed service stops after one to three years because an agency cannot or will not continue it, little is gained toward the long-term development of a comprehensive system of services. Negotiation with state agencies, therefore, represents the best way to cooperatively plan and implement the mission of the Developmental Disabilities Basic State Grant Program.

CAPACITY BUILDING

In addition to the capacity building activities that result from advising and negotiating, Councils also have a responsibility for determining priority service areas and developing or facilitating the development of RFP's which address those service areas.

There has been some controversy regarding the thrust of activities funded with Basic State Grant funds. Many Councils are divided on whether their "65% funds" should go to direct services or activities in support of direct services.

This issue has, I feel, caused some unfortunate misunderstanding in the past. If seen in light of Council roles, some of this misunderstanding may clear up.

The role of Council as capacity builder has often been viewed as the funding of gap-filling or demonstration direct services, rather than as an enhancement to monitoring, evaluating and planning. The model I am presenting assumes that the only reasons Developmental Disabilities funds should be used for direct services are:

- If no other source of funds exist for a service which fills an objectively demonstrable need;
- If a service is so specialized and/or innovative that it must first be demonstrated with Developmental Disabilities dollars;
- If the Council is willing to assist in identifying continuation funds for the grantee after a 1-3 year demonstration with Developmental Disabilities funds.

If these conditions do not exist, the limited funds under the Developmental Disabilities program should be focused on efforts which create an environment where services can improve and or expand.

The Developmental Disabilities Act defines service activities in priority service areas as follows:

"The term "service activities" includes, with respect to an area of services, provision of services in the area, model service programs in the area, activities to increase the capacity of institutions and agencies to provide services in the area, coordinating the provision of services in the area with the provision of other services, outreach to individuals for the provision of services in the area, the training of personnel to provide services in the area, and similar activities designed to expand the use and availability of services in the area." (Section 133(4)(CB)(iv)

Using our model of systems-change activities and direct services activities you will notice that in the chart below only two of the activities used in the definition address direct services.

CAPACITY BUILDING	
<u>Systems Change Activities</u>	<u>Direct Services Activities</u>
<ul style="list-style-type: none">• Activities to increase the capacity of institutions & agencies to provide services• Coordinating• Outreach• Training• Technical assistance to urban or rural poverty areas• Similar activities	<ul style="list-style-type: none">* Provision of services• Model service programs

Examples of systems change activities in support of services are:

parent and professional training;

training of state agency personnel;

studies of the provision of services to developmental disabilities under the jurisdiction of other Federal/State programs;

the development of interagency service agreements;

management training for service providers; and

outreach and public education activities and state legislative.

Both systems change activities and the funding of direct services aim to build the capacity of the service system. Direct services emphasize gaps and innovation, supportive activities emphasize longer term systemic improvement. Councils need to be clear about choices regarding their capacity building activities using 65% funds.

Skills Needed to Fulfill These Roles

Each of these models - Council as advisor, negotiator and capacity builder - requires Council members and staff to have skills and expertise in a number of areas and effective program implementation is enhanced if Council can structure themselves and their staff to accomplish specific tasks.

- Planning Skills - Management by Objective or similar structured process for determining goals, priorities, and strategies.
- Knowledge of federal/state programs and the criteria by which to assess their effectiveness for developmentally disabled people.
- Methodologies for gathering accurate data; for monitoring and evaluating grantees, state programs, legislative initiatives and administrative processes.

Organizing and Outreach Skills to mobilize support for and/or opposition to policies thru effective use of coalitions.

- Information Dissemination Skills to gain public awareness and acceptance of issues of concern to the Council.

And, for Council Directors:

- Management Skills to choreograph people, events and materials to do all of the above.

And finally, for Council Chairpersons:

- Leadership Skills to inspire others, to exert effective influence and follow-up and to establish and follow-through on the expectation that Council members will keep their agreements and act on their responsibilities.

Each of these skills defines a process by which Councils can become more effective advocates. Each of these areas generates policy statements which direct Council staff activity. Council staff acts at the direction of the Council.

. Without policy guidance, staff can frequently be placed in a position of having to make decisions without knowing the will of the Council* and be left without Council support and without an accountability mechanism for actions taken. It is an obligation of the Developmental Disabilities Council to create clear policies so that staff can develop procedures and a work plan by which all can be held accountable. This protects your staff, your Council and the Developmental Disabilities Program in your state.

CONCLUSION

The mission of the Developmental Disabilities Council - to advocate for people with developmental disabilities - is mandated by federal law. Methods for achieving that mission are delineated - sometimes very specifically, sometimes rather vaguely.

The Developmental Disabilities Act does not tell Councils how to achieve a comprehensive system of services for the developmentally disabled. It tells you to plan, monitor, and evaluate and-leaves the rest to you.

Systems change activities and service demonstration are techniques, action steps, within each model, which help to fulfill the Councils role as advocate. If we give reasoned advice and accurate information, if we negotiate in the spirit that both sides need to win and if we wisely spend Developmental Disabilities funds to build service capacities, Councils will become as invaluable to states as we know they already are to people with developmental disabilities.