

**HOW DEVELOPMENTAL DISABILITIES  
COUNCILS ARE USING  
GRANTS STRATEGICALLY**

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April 1995

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Development of this report was supported in part by  
The Administration on Developmental Disabilities  
Contract Number 105-94-7010

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## I. OVERVIEW

Most Developmental Disabilities (DD) Councils have moved away from using grants and contracts to help DD service system providers meet their budget deficits - away from a "United Way" approach, as described by one executive director, to an approach that uses grants and contracts strategically to promote desired changes in the system. Systems change and advocacy strategies may include using Council grants and contracts to:

- Stimulate innovation;
- Demonstrate effective services and approaches;
- Support legislative advocacy, including initiatives to support coalitions;
- Promote Americans with Disabilities Act (ADA) implementation;
- Support implementation of state family support legislation and other initiatives led by the Council;
- Evaluate Council-funded demonstrations;
- Conduct research on the effectiveness of existing services, including consumer satisfaction surveys;
- Support public education activities;
- Target initiatives to members of minority groups and other unserved or underserved populations;
- Provide training and technical assistance, such as training of self-advocates and family members;
- Support participation of individuals with developmental disabilities and family members through stipends;
- Promote reforms in DD quality assurance systems; and
- Meet a host of other specific systems change objectives defined by individual DD Councils.

A previous resource, *Developmental Disabilities Council Grant Programs: Building Quality in Monitoring and Evaluation Practices* (Jaskulski, 1994a) on suggested "best practices" for Councils in administering their grant and contract programs, focused on the contracts made with grantees and requirements for project implementation and Council procedures for monitoring grantee activities. A companion resource, *Developmental Disabilities Councils and Grants Administration: Suggestions for Best Practices* (Jaskulski, 1994b), focused on administration from the Request for Proposal (RFP) process through the proposal evaluation and selection process. This monograph, the third in the National Association of Developmental Disabilities Councils' series, will focus on how Councils use grants and contracts strategically in advocacy and systems change activities.

The concepts of grants administration and using grants strategically also are linked by the need for Councils to administer their grants program in ways that support their systems change objectives. For example, grants can produce information on findings that the Council can use effectively in educating legislators and other policymakers; these kinds of considerations are being reflected in Council's reporting requirements and other monitoring activities.

### A. GENERAL TRENDS IN COUNCIL GRANTS PROGRAMS

Although there is great variety in the ways Councils use grants and contracts, and, in many cases, variety within individual Council grants programs, there are a few general trends that can be noted:

- Council grants and contracts are being used more as systems change activities, and less and less to fill gaps in the service system, throughout the DD Council network;
- Grants and contracts are increasingly being tailored to meet specific purposes; many Councils are moving away from a single RFP and set of proposal review criteria, in favor of RFPs and review criteria that are unique to a particular set of objectives;
- Councils are more often specifying the objectives and outcomes to be implemented, rather than leaving it up to the grantees to propose objectives and outcomes from their perspective;
- The use of three-year grant projects is declining, with more and more Councils primarily funding projects for shorter time periods, as well as closely examining multi-year projects each year to see if they warrant continuation;
- There is an emerging trend for Councils to fund only a few large initiatives, rather than several small and medium size projects; and
- Grants and contracts are increasingly linked to Councils' public policy initiatives.

These trends are reflected in the approaches used by the WYOMING DD Council. During the 1992-1994 period, the Council used grants to accomplish goals in each of the 4 federal priority areas. RFPs have become more targeted, which the Council has found generally works better than asking potential grantees to "give us your good ideas."

One example of this approach was targeted to the state's shortage of paraprofessionals. The Wyoming Council provided a grant to a community college to develop a human service delivery Associates of Arts degree program, with particular focus on direct contact staff in the developmental disabilities service system. The program is now on-going and self-supporting. Similarly, to address the shortage of physical therapists, the Council funded a grant to a community college to develop a physical therapy assistant program.

The Wyoming Council used grants in conjunction with its public policy initiatives, including a "hands-on" project to keep children out of the state institution. The Council collaborated with the institution on a project to support individual families in avoiding institutionalization, with the Council providing most of the funds and the institution providing outreach workers. The Council's analysis of the results determined that the biggest need was for respite care.

The analysis was parlayed with the involvement of the Council-funded Family Support Network, leading to successful passage of legislation during the 1993 session that created a state-funded respite care program. The Family Support Network, while not supported by a grant, does include two local coordinators who are under contract on a part-time basis and who coordinate quarterly training for families provided by the Council. The coordinators work with families to help them network at the local level, identify resources, and participate in grassroots advocacy. The training agenda is family-driven. At families' request, training has included sessions on stress management, training from the Protection and Advocacy organization (P&A) on the Individualized Education Plan (IEP) process, and role-playing in IEP negotiations. The Network has been in operation since 1989.

The Wyoming Council's 1995-1997 plan includes promoting entrepreneurship in supported employment through Council funding for a job coach project focused on self-employment for individuals with marketable skills, such as a stained glassworker. A community advisory group will include a small business incubator program and representatives of the Chamber of Commerce. The initiative includes planning for ongoing support to the individuals as supported entrepreneurs. The Council also expects the project to help change people's attitudes toward individuals with developmental disabilities, especially because it will include people with mental retardation.

A major systems change issue being addressed by the Council is the switch to a consumer-driven/consumer-focused system rather than one that is funding stream and provider-driven. The Council is using grants to fund "inclusion aides" in day care centers and in recreation and leisure activities, to promote inclusion. The grants require documentation of project findings, which the Council will disseminate through the Family Support Network. Capacity building through the physical therapy assistants program also will promote consumer-focused services, especially in rural areas.

Wyoming Council's Executive Director Rose Kor sees the Council moving toward larger and fewer grants, coupled with ongoing emphasis on empowerment and "bottom-up" approaches. She notes that the only way to develop and sustain and change is to focus on the local level, and "bubble up" to the state level. The Council therefore focuses on strengthening family members and People First groups across the state.

The Wyoming Council also is looking at its initiatives more strategically, coupled with an overall increase in the Council's focus on systems change. During the 1990 Report process, the Council did a lot of vision development and long range planning, which were in turn used to begin development of strategic planning. The Council now takes time every two or three years to review the visions, make any changes needed, and identify the "real world" steps needed to make the visions a reality. This process is gradually reinforcing the systems change focus for grants and other Council activities.

Reviewing Three Year Plans provides a major opportunity to look at differences in approach within and across DD Councils, and emerging trends in using grants and contracts. This monograph is a preliminary look at current and emerging trends, based on examples from Councils' Three Year Plans for FY 1992 - 1994, a cross-section of Three Year Plans for FY 1995 - 1997, and recent RFPs. Along with some conversations with individual Councils, this information has been used to provide examples of different approaches to using grants and contracts strategically. These illustrations are preceded by brief overviews of relevant provisions in the Developmental Disabilities Act and the Quality Indicators that relate to planning and use of grant funds.

## **II. THE DEVELOPMENTAL DISABILITIES ACT**

The purpose of the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 103-230) is to assure that individuals with developmental disabilities and their families have a part in the design of and access to culturally competent services, support, and other assistance and opportunities that promote independence, productivity, and integration and inclusion into the community. In this capacity, the DD Act gives state Councils the authority to use a portion of allotted monies for the planning, coordination, administration, and implementation of priority area activities, and other activities relating to systemic change, capacity building, and advocacy to implement the responsibilities of the Council. Councils use these funds to provide grants to accomplish these activities. Federal allotments to Councils are like

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block grants in that Councils are given the flexibility to use the funds according to the differing needs of the States.

The DD Act provides the following ideas for systemic change, capacity building, and advocacy activities for which funds can be used:

- Demonstration of new approaches
- Outreach
- Training
- Supporting communities
- Interagency collaboration and coordination
- Coordination with related councils, committees and programs
- Barrier elimination, systems design, and citizen participation
- Public education and coalition development
- Informing policymakers
- Prevention
- Other activities

Councils must develop and submit an annual report each year that provides a description of the trends and progress made in the State concerning systemic change, advocacy activities, and a summary of actions taken to improve access and services for unserved and underserved people. Councils must also submit a State Plan to be reviewed annually in which specific requirements and assurances must be addressed.

### **III. THE QUALITY INDICATORS**

Principles and quality indicators for Developmental Disabilities Councils were prepared by a work group of Council executive directors and members from around the country, including a representative of Councils who are not members of NADDC (i.e., the Quality Indicators (QI) Work Group). The Work Group was assisted by the Human Services Research Institute (HSRI). The principles, indicators, and related probe questions are summarized in *Values, Principles, Quality Indicators and Probe Questions for Self Assessment*, July 1994, following the final meeting of the Work Group in April 1994. The document was prepared based on the following assumptions:

1. Council activities and characteristics are diverse and reflect the specific circumstances of a state or territory. Quality enhancement activities, therefore, should take into account these important differences.
2. Use of the principles and quality indicators by Councils will be voluntary and will be applied through a peer support or self-assessment process.
3. Principles and quality indicators should reflect ideals and best practice and should not be merely a reflection of what exists.
4. Principles and quality indicators should be used by each Council to determine the necessity for technical assistance, organizational reform or other quality enhancement intervention.

5. Principles and quality indicators should be updated on a regular basis to ensure that they continue to reflect the values of people with disabilities and their families as well as best practice.
6. The final set of principles and quality indicators represents widespread agreement among Councils across the system (HSRI & the QI Work Group, 1994).

The Developmental Disabilities Assistance and Bill of Rights Act expresses the values and philosophy that guide the Basic State Grant Program as well as the role and responsibilities of DD Councils.

Quality indicators build on the law's mandates by delineating the *operational* foundation for Council effectiveness and establishing criteria for excellence. Specifically, the principles reflect Councils' systems change mandate to work for change within the system, creating internal and external incentives for change, organizing people with developmental disabilities and their families to advocate for change, and to communicate and advocate with policymakers in state agencies, in the not-for-profit and for-profit services business sector, and in the general community.

The quality indicators are organized into 12 principles. Each principle is also a quality enhancement category, with specific quality indicators and probe questions that Councils can use for self-assessment, external evaluation or peer review in the following areas:

- Mission;
- Commitment and Leadership Development;
- Planning;
- Community Competence;
- Systems Advocacy;
- Public Awareness;
- Interagency Collaboration;
- Governance;
- Operational Policies;
- Budget and Finance;
- Staff; and
- Evaluation.

Principles, indicators and probe questions relevant to using grants and contracts strategically are found in eight of the 12 areas, and particularly under Planning, Community Competence, and Systems Advocacy, as illustrated in the following pages.

Although these indicators provide guidance to DD Councils in designing an effective grants program, they do not prescribe any particular way that grants should be used. The range of approaches to using grants strategically is highlighted in the following section.

## A. QUALITY INDICATORS RELEVANT TO USING GRANTS STRATEGICALLY

### **Mission**

The Council develops goals, activities and objectives that are consistent with [its]mission statement.

### **Planning**

Principle: State priorities, Council activities and advocacy efforts reflect the Council's mission, the expressed needs of people with developmental disabilities and their families in the state or territory, and the specific legal, political and financial context within which the Council functions.

The Council engages in needed research and analysis prior to developing the state plan and conducts ongoing policy analyses covering various issues using information obtained from a variety of sources, including consumer surveys and input, demonstration projects, and research conducted by professional entities, the Council and others.

The Council carries out systematic planning activities that link current state priorities to objectives, funding, policy initiatives and implementation time lines.

Council projects and activities are derived from the approved state plan. Probes:

- How are strategies developed on a short term and long term basis to implement priorities in the state plan?
- How does the Council ensure the relevance of its activities to state plan priorities and objectives to the needs of your state or territory?

The Council's plan is a working document and a blue-print for systems change, and plan priorities are reassessed every three years and updated annually as the state context changes.

### **Community Competence**

Principle: A Council promotes the grass roots development of those values and innovative practices that enhance independence, productivity, integration and inclusion of people with developmental disabilities.

The Council sponsors training, demonstration projects and other activities that support best practices and their replication. The Council translates the outcomes of projects exemplifying best practices into policy positions and initiatives.

### **Systems Advocacy**

Principle: A Council engages in systems advocacy and policy development and reform to further independence, productivity, integration and inclusion and to improve the quality of life for people with developmental disabilities and their families by influencing public policy and educating policy makers.

The Council pursues a range of strategies to meet its systems advocacy goals, including such things as development and support of legislation, community organizing, regulatory reform and education of federal, state or territorial, and local policy makers.



The Council uses policy and other analyses to develop its systems advocacy objectives. The Council presents information, strategies, findings and recommendations to federal, state or territorial, and local policy makers.

### **Public Awareness**

Principle: A Council engages in activities that illustrate and promote valued social roles for people with developmental disabilities as well as enhance independence, productivity, integration and inclusion.

Council activities enhance the opportunities for people with developmental disabilities to assume valued roles in their communities.

### **Interagency Collaboration**

The Council mounts specific interagency initiatives with state or territorial, local and federal agencies.

### **Budget and Finance**

Activities funded by the Council are consistent with the Council's priorities and its mission and values.

Activities funded by the Council do not replace or supplant activities of other state agencies or non-federal funds.

The Council follows federal guidelines in the allocation of its funds. (The Council allots 65% of Basic State Grant funds for priority areas, analysis and addressing issues in the Three Year Plan, no more than 5% or \$50,000, whichever is less, for expenses for functions of the designated state or territorial agency and the remainder for planning, coordination and operations.)

If the Council funds direct services (i.e., model demonstrations), it does so only as part of a short term strategy for systems change leading to funding from other sources.

### **Evaluation**

There are internal quality assurance practices to assess the consistency of activities with the Council's mission and priorities and legal mandates. There is a system for measuring the progress of Council-funded activities and the extent to which they succeed in meeting the Council's mission, goals and objectives. The Council evaluates its grant activities based on outcomes of increased independence, productivity, integration and inclusion of people supported by the activities.

## **IV. USING GRANTS STRATEGICALLY**

DD Councils are using grants and contracts as strategies for systems change and advocacy in many different ways. These strategies are focused on one or more of the following:

- Demonstrating new approaches/stimulating innovation;
- Capacity-building/system enhancement;
- Empowerment;
- Other "bottoms up" approaches;
- Major systems change;
- Evaluation and documentation; and

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- Legislative advocacy/coalition support.

Examples of these focuses are described in the following sections.

#### A. FOCUS: DEMONSTRATING NEW APPROACHES/STIMULATING INNOVATION

Some Developmental Disabilities Councils have focused on innovation in describing the purpose of their grant program:

To provide funding to local and statewide agencies and organizations to focus upon progressive approaches for enabling persons with developmental disabilities to achieve their maximum potential through increased independence, productivity and integration into the community. Projects are sought that will provide model demonstrations, research, training or advocacy in ways that are new, unique and do not supplant current programs. Projects should increase the opportunity for positive systemic systems change in service delivery systems and communities, thereby enhancing the options and opportunities for individuals with developmental disabilities. (*Solicitation of Proposals*, KENTUCKY DD Planning Council, December 1,1992)

A major responsibility of the Council is to be an innovator in disability policy and practice in **MICHIGAN**. Much innovation occurs through the annual grant program to plan, implement and monitor innovative projects, studies and evaluations. It is in this capacity that the Michigan Council has been particularly effective in effecting permanent changes in the way services and supports are provided to people with disabilities and their families. (*Michigan 1995-97 Developmental Disabilities State Plan*, p. 10.)

Developmental Disabilities Councils have led the way for many years in funding demonstrations and innovations as a systems change strategy, and in stimulating major systems change. This has led to widespread development in areas such as supported employment, family supports, personal assistance services, and supported living.

Councils also use grants and contracts to stimulate innovations for further enhancement of systems change, by focusing on special populations or by supporting innovation in a particular aspect of systems change:

The **NEW YORK** Council has used several grants and contracts to develop innovations in meeting the needs of culturally diverse populations. Activities funded include: outreach and resources targeted to recent Caribbean immigrants; bilingual materials on prevention; a bilingual/cultural early intervention program; and a Native American Forum. (See *Building Cultural Competence in the Disability Community*, Jaskulski 1993, for additional information on these and other activities designed to expand systems change to new populations).

The **IDAHO** Council has funded a family support demonstration project, providing information and referral, service coordination, and cash assistance to families, through a system model developed in proposed family support legislation.

As described above, the **WYOMING** Council has funded a grant to develop job coaches for people with developmental disabilities who want to become entrepreneurs.

## Using Grants Strategically

### B. FOCUS: CAPACITY-BUILDING/SYSTEM ENHANCEMENT

A related strategy in grants and contracts focuses on supports to the state or territory and the service system as systems change is being implemented. Specific strategies include training activities, technical assistance, research support, and leadership in interagency collaboration.

The **ARIZONA** Council funded a program of extensive technical assistance to the state on reforming the quality assurance system for developmental disabilities services. The technical assistance provided by the Human Services Research Institute (HSRI) has been instrumental in helping the legislature and service system focus on choices and outcomes important to people with developmental disabilities. (See *Promoting Quality in Developmental Disabilities Services: Considerations for State Legislators*, Jaskulski 1994c, for additional information.)

The **MICHIGAN** Council has co-funded a training initiative, "Facilitating Inclusion through Case Management: A Curriculum for Change." The first year supported development of a curriculum by the Wayne State University Developmental Disabilities Institute. Up to 20 interagency training sessions per year will reach 2,000 adult services workers, case managers, people with disabilities, family members, and others who perform case management functions.

The **OREGON** Council funded a one-year contract (June 1994 - June 1995) to provide health policy analysis, assist in policy development, and monitor implementation of the Oregon Health Plan from the perspective of its impact on people with developmental disabilities and their families. The contractor also is developing information and training to help consumers and family members make informed decisions in accessing and using the Oregon Health Plan.

The **DELAWARE** Council is using a series of contracts to influence the state's health care reform debate. One contract will fund a study of Delaware's current Medicaid program and coverage, followed by assessment and recommendations regarding adoption of other Medicaid options. Another contract will support a survey, focus groups, review of data collected by the state's Health Care Commission and related analysis. These findings will be used in a third contract to conduct a statewide health care reform education project. The educational program will present disability perspectives on health care reform in multi-faceted policy maker and public education activities. The campaign also will make use of findings from the previously conducted Single Payer Health Care Study funded by the Council.

Several Councils, including **CALIFORNIA, ILLINOIS, MASSACHUSETTS, MISSOURI, NEW YORK,** and **SOUTH CAROLINA,** have funded training, technical assistance, and interagency policy development activities to enhance the cultural competence of the service system (see *Building Cultural Competence in the Disability Community* for more information).

Some Councils also target resources to promoting replication of successful demonstrations. The **ALABAMA** Council, for example, collaborated with three state agencies to support model transition-from-school-to-work projects. During the 1995-1997 period, the Council will support refinement of the best of the model projects and replicate in up to ten additional locations. The Council also is continuing its support of training on Personal Future Planning to providers.

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Many Councils also have used grants and contracts to develop resource materials and provide training and technical assistance on ADA implementation:

- The **KANSAS** Council funded the Business Development and Consultation Program of the Occupational Center of Central Kansas, Inc. The program provides information, referral and consultation on issues such as physical plant accessibility, work station modification, and reasonable accommodations;
- In **TENNESSEE**, the Council funded the Coalition for Tennesseans with Disabilities to produce the *ADA Resource Directory*; and
- The **OHIO** Council produced the *Ohio Accessibility Guidelines*, a compilation of various statutes, regulations and guidelines governing access and use of building and related facilities for people with developmental disabilities.

These and several additional examples are described in *The Americans with Disabilities Act: Developmental Disabilities Councils Implementation Activities* (Musheno, 1994).

### C. FOCUS: EMPOWERMENT

Most Councils use grants and contracts to fund activities to empower individuals with developmental disabilities and their families. As a systems change strategy, Councils see increases in empowerment as critical in building long-range systems change and advocacy capacity.

Many Councils have funded Partners in Policymaking programs as part of their empowerment initiatives. Originally developed by the **MINNESOTA** Council in 1987, it has now been expanded and replicated throughout the DD Council network. Some Councils have funded "advanced" Partners in Policymaking programs, to further promote empowerment.

The **IOWA** Council focused its FY 1995-1997 Plan on the strategies it will use to further 11 objectives. Strategies include ongoing support to more than 125 Partners in Policymaking graduates in their continuing involvement in systems advocacy activities, including advanced leadership training, as well as training for 30-35 people each year. For example, Partners graduates are receiving advanced training and support in serving on policymaking boards in state and local government. Funding includes \$140,000 per year in contracts and \$25,000 for mini-grants supporting ongoing advocacy activities by Partners and an annual Partners conference.

In its State Plan, *Systemic Change, Empowerment: A Plan for Iowa, 1995-1997*, the Council states that it "fulfills its role with a commitment to empowerment of people with developmental disabilities. The Council believes that effective advocacy and system change can only occur when people with developmental disabilities and their families lead the change process. Through information, training, and support for involvement in the development of policy that affect their lives, the Council strives to fulfill its planning and advocacy role in a manner that maximizes the personal power of people with developmental disabilities."

The Full Citizenship Initiative (FCI) has been a statewide public awareness project of the **WISCONSIN** Council since February 1987. FCI's overall goal is the passage of state legislation which will guarantee

that people with disabilities receive the supports and services they need to become fully participating members of their communities. The Council contracts with Local Area Advocacy Coordinators across the state who work on activities to raise public awareness and strengthen and broaden the base of support for FCI goals.

By spring 1988 FCI was in full force, with extensive public awareness activities at the local level and strategic planning for legislative advocacy at the state level. Second year activities included marketing and wide dissemination of FCI videotapes. FCI Coordinators were instrumental in bringing hundreds of consumers, family members, advocates and service providers to the Capitol to meet with legislators and show support for disability issues in the state budget. They also stimulated additional coalition-building and legislative advocacy at the local level. These activities were instrumental in getting increased community aid funding and expanded Family Support Programs in all 72 counties, as well as budget increases for community-based supports.

An evaluation of FCI during its second year led to clarification of its scope and enhanced networking among local FCI Coordinators. As FCI passed through its third year and on into its fourth, even greater emphasis was placed on building grassroots support for local, state and federal initiatives consistent with the policy goals of the FCI Vision Statement. Although several pieces of FCI-supported legislation were passed by the legislature, most were subsequently vetoed by the governor. Birth to Three program legislation was enacted successfully during this period with strong FCI support.

Throughout the FCI, a great many public awareness activities have been conducted at the local level by the FCI Coordinators. Typical activities include: FCI booths at county fairs; Organizing disability awareness activities with Scout groups and schools; Convening meetings between parents and educators; Recruiting people to participate in Disability Awareness Week activities locally and in the state capital; preparing and distributing newsletters on disability issues; presentations on disabilities at civic organizations; coalition building on disability advocacy; promoting ADA implementation, such as distribution of public service ads to local media and other public education activities; organizing contacts between consumers, family members and their state legislators; disseminating information on biennial budgets, on FCI-supported legislative initiatives, and legislative directories throughout the community; and generating testimony and postcards to the governor, legislators and key legislative committees.

The Local Area Advocacy Coordinators work in their own communities with minimal supervision, however, they do not work in isolation. The Wisconsin Council provides technical assistance through training about specific issues, facilitating the sharing of ideas and information between Coordinators through teleconferences and meetings, and other activities as needed. Council staff also are available to brainstorm about any obstacles Coordinators encounter.

A major focus of the activities for the current State Plan is increasing positive media coverage of disability issues to strengthen a base of support among the public and policy-makers. The Council is involved in the 1995-97 State Biennial Budget process, and FCI will help educate the public and legislators about the benefits of inclusive communities which support people with disabilities.

The Full Citizenship Initiative has evolved over time into a vital source of information for Wisconsin citizens about developmental disabilities. FCI began with one goal: passage of entitlement legislation. However, FCI has grown into a force enabling people with disabilities and their families and friends to support issues that affect their lives by providing them with information and support. Raising awareness of

the general public and decision-makers is a long term project, yet it is necessary to making communities better places for people with disabilities to be independent, productive, integrated and valued members of society.

Additional information summarizing the history of the Full Citizenship Initiative and the position description for Local Area Coordinators are provided in Appendix A.

Some Councils are targeting specific populations for empowerment. For example, the **NEW YORK** Council has funded six projects focused on leadership development of adolescents with disabilities.

#### D. FOCUS: "BOTTOM-UP" APPROACHES

A related focus in using grants and contracts strategically is on "bottom-up" approaches, funding projects that work with one individual at a time or small groups of individuals and families. Strategically, such approaches are designed to promote systems change from the bottom up, by changing the ways services are delivered, changing people's expectations about services and supports, and enhancing the skills of those involved, including consumers. On a long range basis, the combined effect of these changes at the individual and community level can create momentum for policy changes at the larger system level.

The **PENNSYLVANIA** Council's *Request for Grant Proposals: Issue #2, 1993-1995* describes its grant strategy as follows:

"The Pennsylvania Developmental Disabilities Planning Council, in its efforts to address the issues facing people with developmental disabilities, fosters capacity-building and community-building strategies. The mandate to ensure the maximum integration, independence and productivity of people with developmental disabilities is seen by the Council as best fulfilled when it is an advocate over the long term. The Council knows that genuine social change takes significant time. Recognizing this, and the fact that traditional human services regularly contend with shrinking resources, the Council's approach to stimulating and creating change usually proceeds from the bottom up; from individuals, families and local neighborhoods and communities upward to the wide array of persons in decision-making and policy setting positions within the Commonwealth."

Therefore, the activities selected by the Council for its 1993-1995 State Plan are those projects which make extensive use of locally-based demonstration methods, person-to-person relationships, grass roots advocacy and community organizing techniques. The Council believes its role is to demonstrate that true social integration of people with developmental disabilities, including those with the most severe disabilities, promotes fundamental community regeneration which will benefit all the citizens of Pennsylvania.

Many Councils also use a "bottom up" strategy in combination with other approaches, in particular demonstrating innovations, or as part of a repertoire of strategies. In combination with other kinds of strategies, for example, the **UTAH** Council is funding the "Best Buddies Citizens" program to create friendships between people with developmental disabilities and citizen volunteers in local communities.

In **NEW HAMPSHIRE**, the Council created a physician mentor project, supporting mobile training and technical assistance to local primary care physicians provided by specialists. The project is now referred to as Accessing Developmental and Psychological Training (ADaPT). The Council is only one of several

agencies which collaborated to fund this project. This project originated with Dr. Carl Cooley, Developmental Pediatrician at Dartmouth Medical Center in an attempt to develop community capacity among pediatricians and general practitioners to serve the developmental needs of children with disabilities.

#### E. FOCUS: MAJOR SYSTEMS CHANGE

Some Councils have identified a particular major systems change as the focus for most of their grant and contract activity. Grants and related activities are used to support the Council's public policy priorities. Typically, these initiatives encompass multi-faceted approaches and extend beyond a single three-year planning period.

Like many Councils, the **WEST VIRGINIA** Council has mounted a major initiative to expand employment opportunities for people with developmental disabilities. In 1993, for example, the Council funded five employment projects, including three that were jointly funded with the state offices of vocational rehabilitation, special education and developmental disabilities. To assure ongoing funds for these projects, the Council convened the West Virginia Jobs Campaign, a coalition that was successful in advocating for supported employment legislation and for state funding. The Council also co-sponsors an annual supported employment symposium to provide training in best practices.

In some states and territories, a focus on major systems change is coupled with a shift toward concentration of resources on a particular initiative. In Louisiana, for example, the Council has moved away from providing much "seed money" to innovative service projects. The bulk of Council funding now goes toward projects that help implement plans written as a result of Council-backed legislation, as well as training and technical assistance to private service providers.

The **LOUISIANA** Council's family support initiative built a legislative advocacy coalition, LACAN, which succeeded in obtaining passage of family support legislation. The Council then turned to strategies to implement the legislation, including *Families Helping Families*, a statewide network of family-directed family resource centers. The Council began funding the family resource centers in 1992, committing approximately \$1 million over a three year period. A state advisory committee oversees the initiative, with representatives from each of the state's ten Families Helping Families regions which include parents of children with special needs and professionals; the Council's administrator for program development also attends meetings of the advisory committee and other interagency committees related to Council grant activities. The Council also contracts with Human Services Research Institute (HSRI) to provide training and technical assistance on family support, building on their previous role in supporting the Council's successful legislative advocacy for family support.

#### F. FOCUS: EVALUATION AND DOCUMENTATION

The **NEW YORK** Council's 1995-1997 plan summarizes its growing interest in evaluation and documentation as follows:

Over the last decade the Council has developed an increasing emphasis on documenting the outcomes of its efforts. This was a difficult process because the consumer membership of the

Council has historically desired that Council funds support more direct services to individuals with developmental disabilities and their families rather than research and evaluation type activities. While evaluative information has improved during that time period, recent concerns about the impact of all State Developmental Disabilities Councils has provided the impetus for an even greater emphasis on evaluating and documenting Council systems change efforts in a more rigorous manner. Initially, the Council will be establishing an ad hoc committee on evaluation to design a program evaluation process and to oversee that evaluation.

Concomitantly, the Council has also recognized that more time and resources need to be devoted to sharing the lessons learned from their endeavors with consumers, policy makers, and the provider community. The New York Council has a wealth of information from its various activities which has not always been shared with various stake holder groups in the most effective manner. Recently, the Council and each of its Standing Committees have begun to encourage more deliberate and effective dissemination of timely and relevant information in a manner which will facilitate public policy debate and provide information on best practice.

Several Councils, including the **ILLINOIS** and **MICHIGAN** Councils, have used cross-project evaluations as a way to look across projects with similar objectives, both regarding outcomes/lessons learned and as formative evaluations, to help projects learn from each other and to guide the Council in enhancing project activities. As summarized in *Developmental Disabilities Councils Grants and Contracts: Building Quality in Monitoring and Evaluation Practices* (Jaskulski, 1994b), Michigan describes its strategy as follows:

The Michigan Developmental Disabilities Council has a small budget to influence a large, complex system. Grant products must include:

- **Concrete outcomes** for people with developmental disabilities: improved independence, productivity, integration and inclusion in the community;
- **Hard data** that illustrate, to decision-makers and the public, how the systems change demonstrated affected the people with disabilities, their families and their communities; and
- **Reports** that explain *how* the change was effected, and *why* the change should be replicated.

The Michigan Council has carried out evaluation from the systems perspective through policy studies, baseline surveys, organizational efforts, task forces and other means, and through formal evaluation of specific priorities and activities. The FY 1992-1994 State Plan noted that "evaluations help shape activities that move the services system toward better enabling people with developmental disabilities to achieve independence, productivity and integration. Impact evaluation involves judgments about the outcomes and sets of activities and about their effect on the system as it influences the lives of people with developmental disabilities. Major studies of the system effects of particular initiatives (e.g., the Statewide Evaluation of Supported Employment) contribute to forming the Council's judgments in this arena."

The **ILLINOIS** Council has funded evaluations of several initiatives, including an evaluation and systems analysis of family support pilots and of the state's supported living program. In addition, summary final reports on grant activities, prepared by Council staff with monitoring responsibilities, highlight lessons learned and systems change implications as well as project accomplishments. A sample summary report is



provided in Appendix L of *Developmental Disabilities Councils Grants and Contracts: Building Quality in Monitoring and Evaluation Practices*.

#### G. FOCUS: LEGISLATIVE ADVOCACY/COALITION SUPPORT

Many Councils participate in disability coalitions to help advance their legislative agendas. Some Councils specifically use grants and contracts to support coalitions.

During the 1992-1994 grant cycle, the **TENNESSEE** Council funded the Coalition of Tennesseans with Disabilities, a statewide consortium of organizations supporting legislative advocacy, as well as a grant to Arc/Tennessee to publish a newsletter on state legislative issues affecting people with developmental disabilities.

The **VERMONT** Council sponsors the Vermont Coalition for Disability Rights. Through the Coalition, the Council has been able to effect statutory and budgetary changes that have strengthened the service system and helped protect consumer and family member rights.

The **UTAH** Council has funded the Legislative Coalition for People with Disabilities to provide ongoing information, education, and advocacy to the Utah State Legislature on pending legislation and on agency appropriation requests which affect people with disabilities.

Many Councils also combine empowerment strategies with coalition support and legislative advocacy. For example, the **WISCONSIN** Council encourages its network of approximately 40 local Full Citizenship Initiative coordinators to form and participate in coalitions at the local level. The Council provides ongoing support to the network, including training and information for legislative advocacy. Training and technical assistance to regional family support coordinators and the Families Helping Families initiative funded by the **LOUISIANA** Council similarly include coalition building at the state and local levels that includes legislative advocacy.

#### H. SPECIAL TYPES OF GRANTS

Other grant strategies being used by Councils include:

- Grants and stipends to individuals and family members, (1) to support empowerment, and (2) to support participation in Council activities;
- Mini-grants; and
- "Challenge" grants.

Examples of these special types of grants include the following:

Several Councils have sponsored family member participation in *Fiesta Educativa*, an empowerment and support group for Latino parents of special education students. (See *Building Cultural Competence in the Disability Community*.)

As part of their ADA implementation efforts, Councils have provided stipends to individuals to attend ADA training programs, so that they can provide training and technical assistance to others.

(See *The Americans with Disabilities Act: Developmental Disabilities Councils Implementation Activities.*)

The **PENNSYLVANIA** Council is developing a "DD Fellowship" to finance an individual with developmental disabilities in a leadership development year.

The **GEORGIA** Council has used "challenge grants" to stimulate innovations at the community level.

The **DELAWARE** Council is using mini-grants (maximum of \$1,500) to fund six-month projects that foster independence, productivity, inclusion and integration in the community.

The **MICHIGAN** Council provides basic funding (up to \$3,000 per year) to Regional Interagency Coordinating Councils (RICCs), to enhance Council efforts throughout the state. In addition, RICCs can compete for supplementary mini-grants for local capacity-building and coordination projects and to increase RICC participation among culturally distinct populations.

These and other specialized grant strategies, such as the wide range of "one-time" grants and contracts for specific products, are available to Councils to use flexibly in meeting their systems change and advocacy responsibilities.

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