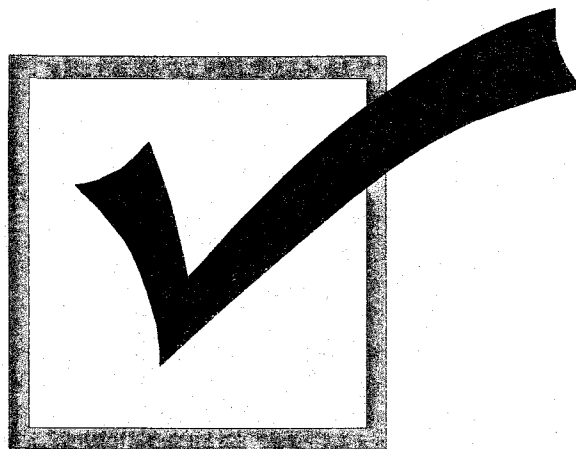


**A Survey of Leadership Opportunities for Individuals
with Disabilities and their Family Members within
Developmental Disabilities Councils**



**THE NATIONAL CENTER FOR SELF-DETERMINATION AND 21ST
CENTURY LEADERSHIP**

in partnership with

THE CONSORTIUM OF DEVELOPMENTAL DISABILITIES COUNCILS

and

**THE NATIONAL ASSOCIATION OF
DEVELOPMENTAL DISABILITIES COUNCILS**

Overview

In 1999, the National Center for Self-Determination & 21st Century Leadership, with the assistance of the National Association of Developmental Disabilities Councils and the Consortium of Developmental Disabilities Councils, sent a survey to the Directors of 56 Developmental Disabilities Councils (DDCs) who receive funding from the Administration on Developmental Disabilities. A similar survey was sent to the Directors of University Affiliated Programs.

The survey asked questions about the involvement of individuals with disabilities and their family members in DDCs and strategies DDCs use to involve individuals with disabilities and family members in their organizations. It also collected information on barriers that block the participation of individuals with disabilities and family members as well as ideas about ways to overcome them. DDCs that did not respond to the initial survey were sent two follow-up requests to participate.

A total of 30 surveys (approximately 54%) were returned. The DDCs that responded had the following general characteristics:

Average Budget:	\$788,279
Budget Range:	\$260,000 - \$4,200,000
Average Staff Size:	6.68
Staff Size Range:	1 - 24

This pamphlet presents a summary of the survey findings. Included on the final pages is a list of organizations that indicated they could provide technical assistance in specific areas related to promoting the participation of individuals with disabilities and family members in Developmental Disabilities Councils.

Individuals with Disabilities and Family Members Participation in DDC Activities

Of the 30 DDCs that responded, 193 individuals with disabilities and 208 family members of individuals with disabilities were reported to be directly involved in DDC activities. Eleven percent of individuals with disabilities were paid staff. Eighty-seven percent of individuals with disabilities were reported to participate as Council members. This is consistent with federal requirements for individuals with disabilities to participate on Developmental Disabilities Councils. Other persons with disabilities functioned as consultants, trainees, or had some other type of involvement.

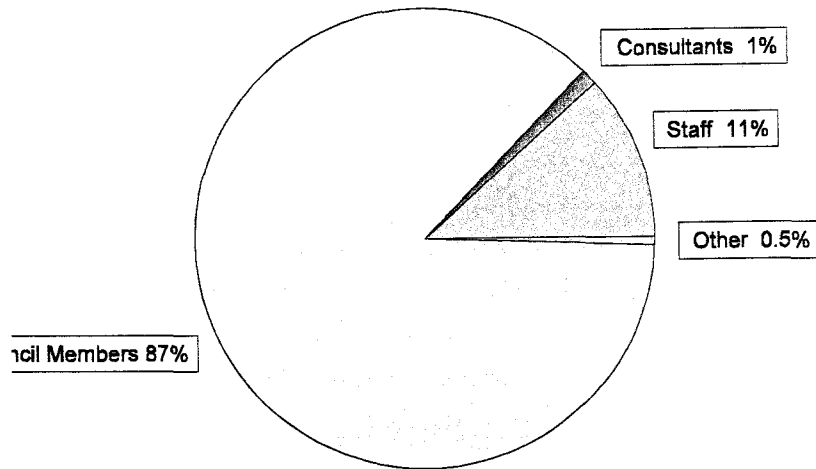
Seven percent of family members were paid staff. Ninety-two percent of family members served on Advisory Councils. Others were consultants or participated in training programs. Individuals with disabilities and family members were overwhelmingly involved in DDCs at an advisory level.

Internships for individuals with disabilities or family members were offered by 13 DDCs. Interest in starting an internship program was expressed by six organizations. Technical assistance in this area was offered by eleven DDCs, while six requested such assistance.

All of the respondents indicated that they somehow collaborate with self-advocacy groups. This ranged from donating office space, to disseminating information, providing training, and coordinating statewide networking.

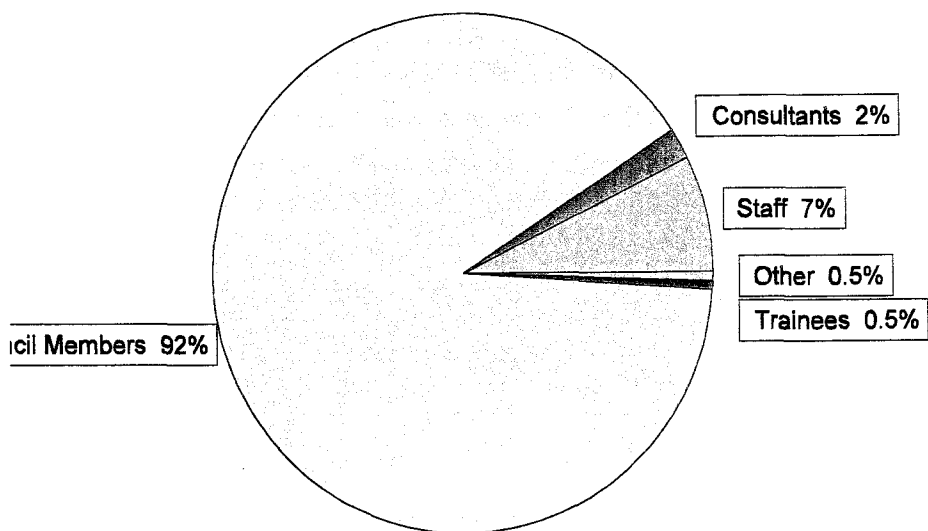
Individuals with Disabilities Involved in DDC Activities

Total: 193



Family Members Involved in DDC Activities

Total: 208

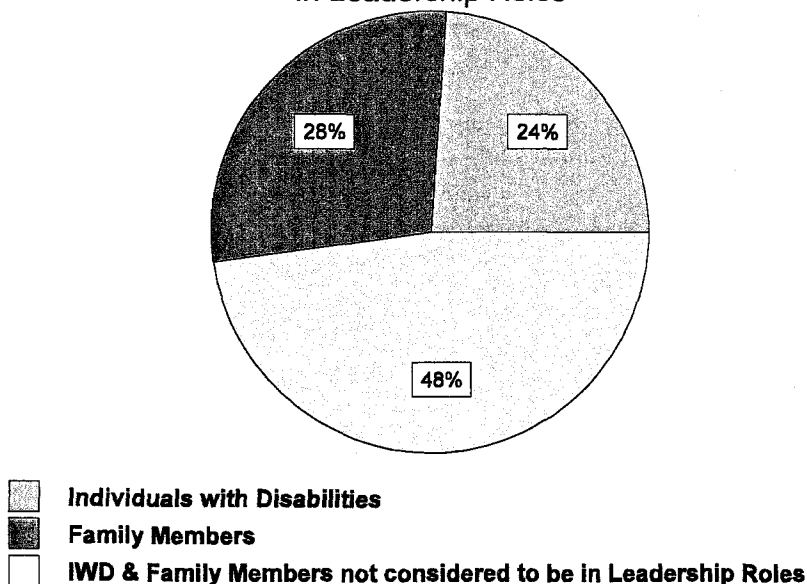


“Positions of Leadership”

Survey respondents were asked how many individuals with disabilities and family members were in “positions of leadership that could influence the policies or practices within their organizations.” Of the 401 individuals and family members identified, 52% were reported to be in leadership roles.

Interestingly, some DDCs indicated that individuals with disabilities serving on their Advisory Councils were not in positions of leadership that influence the policies and practices of their organization. However, they also indicated that the purpose of their Advisory Council was to help guide the policies of their organizations. It is possible that respondents thought they were being asked about the specific leadership activities of individual Council members (e.g., Chair) rather than the general leadership role of all the members of the Council. It is also possible that there is some difference of opinion across DDCs regarding the level of leadership that individuals with disabilities have as Council members.

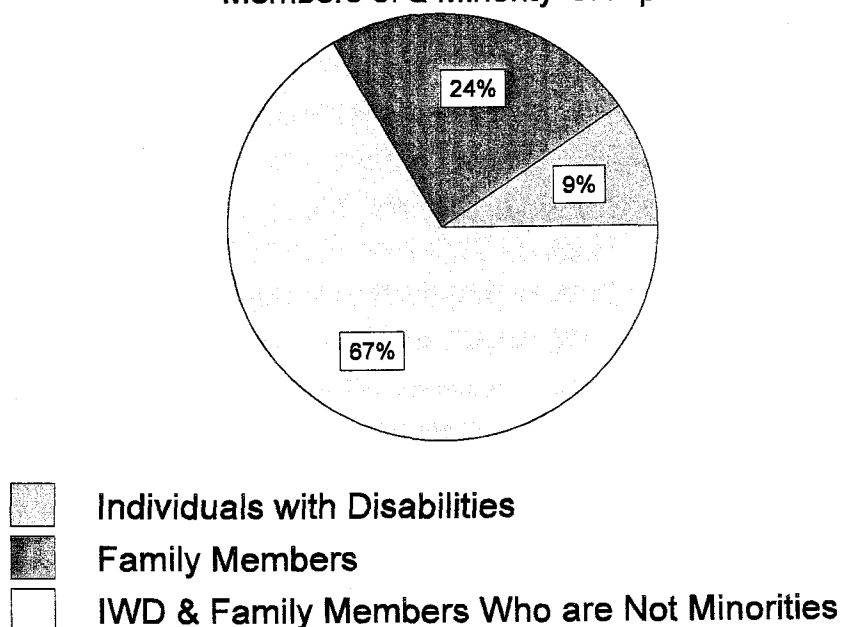
IWD & Family Members Considered to be
In Leadership Roles



Involvement of Ethnically and Culturally Diverse Individuals with Disabilities and Family Members

Of the 401 individuals with disabilities and family members, 9% of individuals and 24% of family members were identified as ethnically or culturally diverse. Many respondents said that recruiting ethnically and culturally diverse participants was difficult. However, they also identified a variety of strategies to increase the involvement of culturally diverse individuals and families, including providing materials in Spanish, creating community partnerships with minority advocates, using cultural diversity as a resource, and including minority recruitment in mission statements.

**Proportion of IWD and Family Members Who Are
Members of a Minority Group**

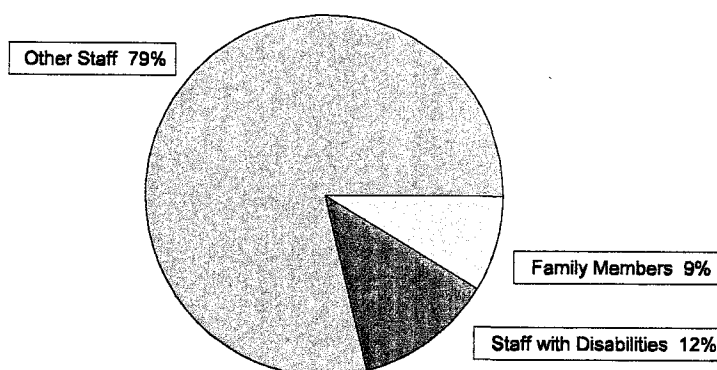


Compensation

As shown below, individuals with disabilities and family members made up about 21% of the DDC's total paid staff. There was a slightly higher percentage of paid staff with disabilities (12%) than paid staff who were family members (9%). All of the individuals with disabilities worked half-time to full-time.

DDC Paid Staff Ratio

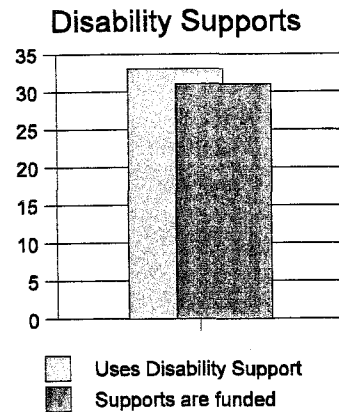
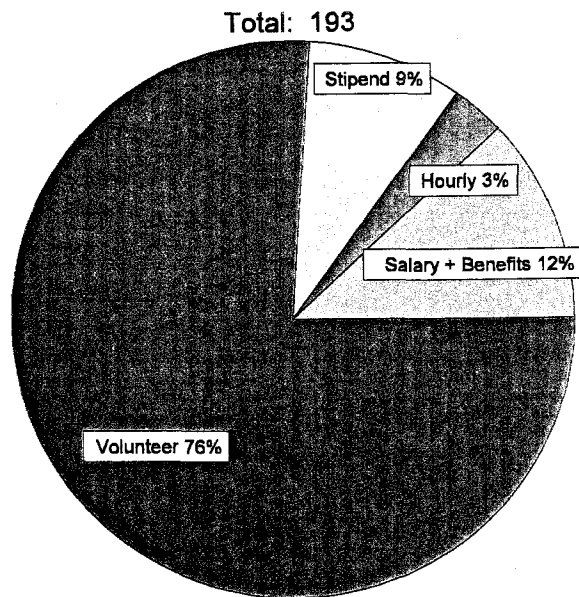
Total: 187



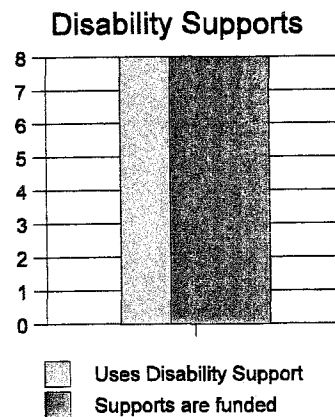
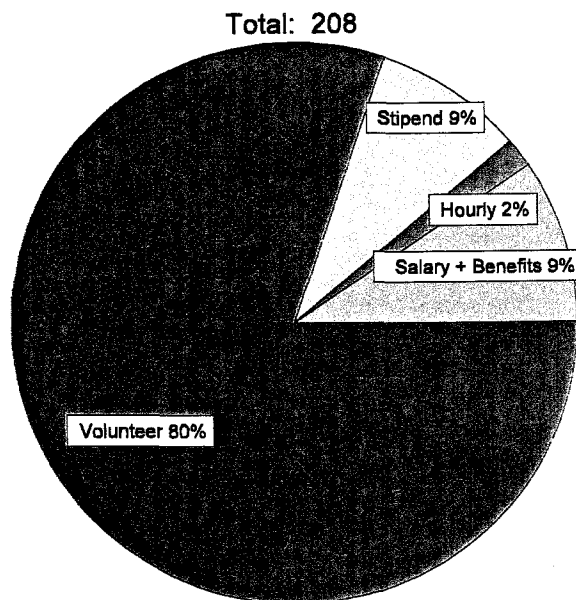
Most of the individuals and family members were volunteers, consistent with their participation as Council members. Seventy-six percent of individuals with disabilities and 80% of family members received no compensation for their participation. Eighteen percent of individuals and family members received stipends, 5% were paid hourly without benefits, and 21% were salaried with benefits. State rules for the reimbursement of Council members may have impacted these findings.

Support or accommodations were provided for 33% of individuals with disabilities. Some of these supports did not cost any money to provide. Eight families were provided with funded support. Respite care and flexible hours were listed as the most common supports provided.

Compensation for Individuals with Disabilities



Compensation for Family Members



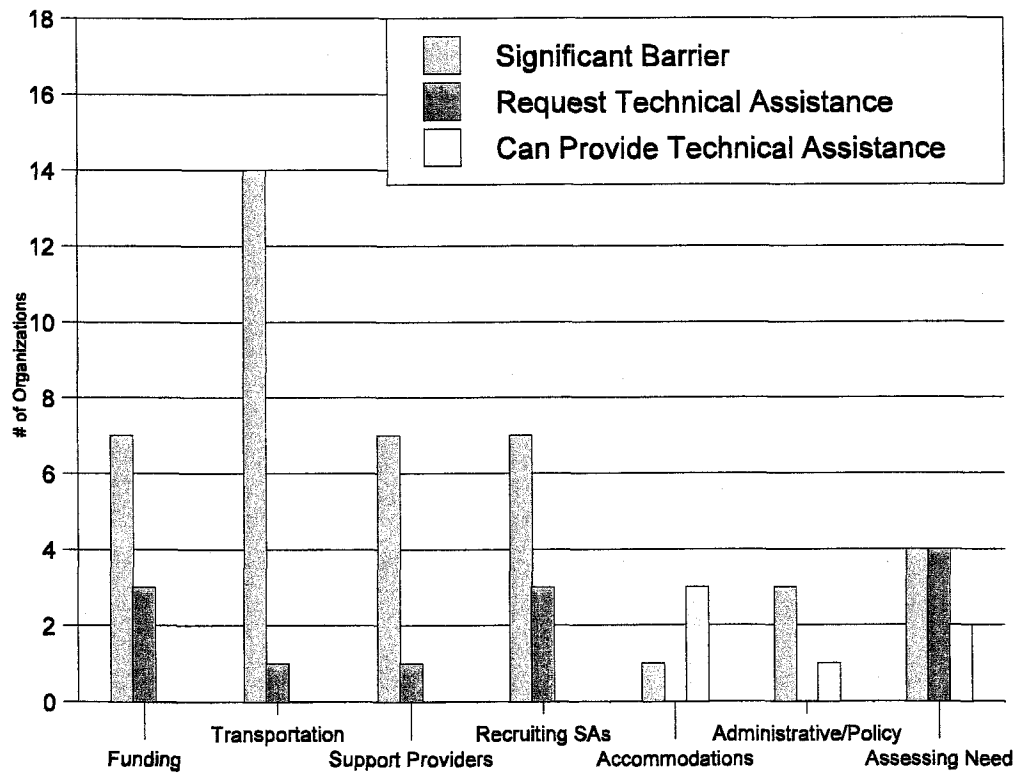
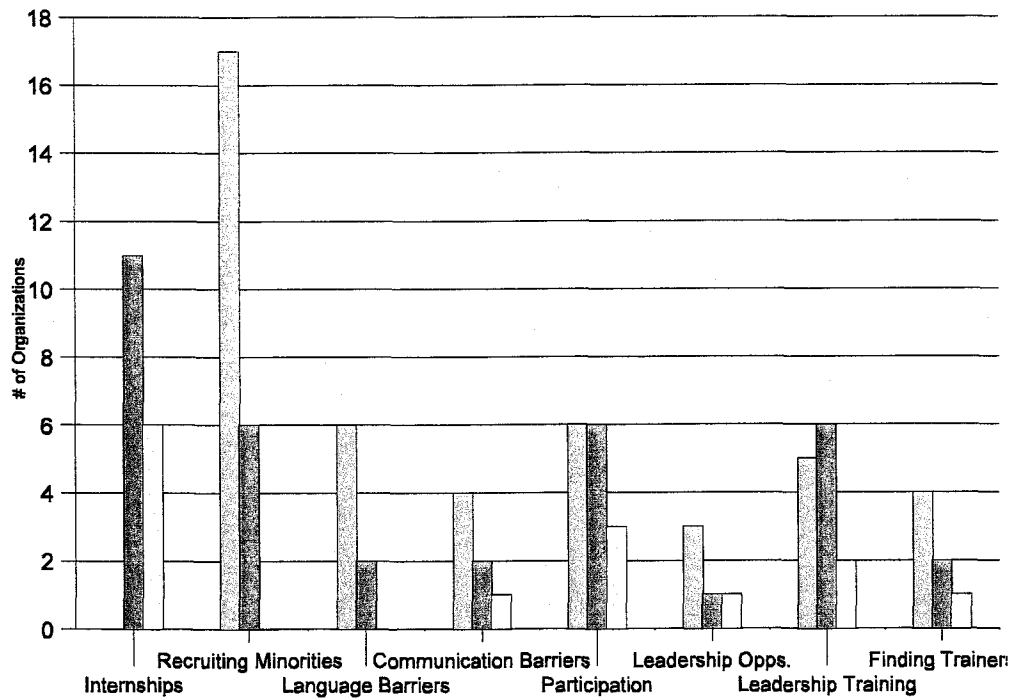
Barriers to Providing Leadership Opportunities

DDCs listed the following barriers to involving individuals and family members in leadership roles:

- Difficulty recruiting minorities
- Language barriers
- Communication barriers
- Difficulty providing support to individuals participating in meetings
- Lack of leadership opportunities
- Limited knowledge of leadership training approaches
- Lack of funding
- Lack of transportation
- Lack of support providers
- Difficulty recruiting individuals or family members for leadership roles
- Difficulty assessing individual support needs

Lack of transportation and difficulty recruiting minorities were identified more often than any other barrier.

Obstacles to Providing Leadership Opportunities



DDC Goals to Promote Leadership

Survey respondents shared their future goals for increasing leadership opportunities for persons with disabilities and their family members, including:

- Expanding training opportunities and programs.
- Funding more participants in Partners in Policymaking™ training.
- Increasing participation and effectiveness of advisory councils.
- Involving individuals and family members more directly in training, planning, and strategy development.
- Getting a more accessible, community based building.
- Improving and expand outreach to include more participants with disabilities.
- Hiring more people with disabilities and family members.
- Collaborate with other state agencies and groups.

Discussion and Implications

It is important to note that the results from this survey came from 30 of the 56 DDCs invited to participate. As such, we suggest caution in generalizing the findings to all DDCs. Given this limitation, the findings suggest that, although a significant number of persons with disabilities and family members are active in DDCs, there is much opportunity to increase their participation in leadership roles as well as the level of compensation and support provided for their activities.

Our findings are similar to those from a survey recently conducted by the NADDC Consumer Leadership Work Group. This survey asked Council Chairpersons of their 39 state membership to indicate how delegates to the national organization were selected and what leadership development opportunities were provided to individuals with disabilities and family members. Responses were received from nine states representing 23% of NADDC's membership.

Three of the respondents reported that they selected a person with disability to be their NADDC delegate, four did not, and two said it depended on who was the current chair and/or vice-chair. Eight respondents were willing to ask their Councils to consider appointing a person with disability as their NADDC delegate while one respondent was concerned about additional costs.

Respondents indicated that one to four people with disabilities were in a positions of leadership in their Councils. Seven respondents supported the participation of persons with disabilities in Partners in Policymaking or a similar leadership training program. The practices identified to promote the leadership of people of color included mentoring, recruitment into Partners in Policymaking, and assertiveness training. When asked about their specific goals for involving people with developmental disabilities and families members in leadership roles, five respondents indicated their Councils had either no reported goals, or goals that were not specific to individuals with disabilities or family members. The remaining four Councils identified goals such as working to get persons with disabilities viewed as equal partners in systems change efforts; recruiting more people with disabilities in leadership and self-determination activities; creating a two-level Council membership and making a top priority the increased involvement of individuals with disabilities.

When the two surveys are considered together, the findings suggest that some DDCs may have difficulty recruiting, placing and supporting individuals with disabilities and family members in true leadership roles. Furthermore, many of those who are members of advisory councils or participate in other DDC activities may not be perceived to be in leadership roles. Further study is needed to determine whether this is because these individuals lack skill or knowledge, their voices are not being heard, there is confusion about the leadership roles of Council members, or they are not viewed as leaders. A related follow-up activity would be to clarify what specific roles were held by the 48% of the individuals and family members not reported to be in positions of leadership. The identification of strategies to avoid tokenism of board members, staff members and consultants may also be an important next step.

Issues such as transportation, minority recruitment, compensation, training and support need to be addressed to pave the way for increased, meaningful participation of individuals and family members. Most important, building a foundation of leadership by individuals with disabilities and family members within DDCs must be perceived as a priority. It is clear that there are many opportunities available and strategies already identified to increase the opportunity for leadership by persons with disabilities and their family members in Developmental Disabilities Councils. Our challenge remains to mobilize the commitment and channel the resources required to make leadership by individuals and family members a stronger reality.

Technical Assistance

The following DDC and UAP organizations have self-identified that they have expertise in the areas listed below and would be willing to provide technical assistance.

A	Internships	I	Funding
B	Recruiting Minorities	J	Transportation
C	Language Barriers	K	Providing Support
D	Communication	L	Recruiting Self-Advocates
E	Participation Strategies	M	Providing Accommodations
F	Leadership Opportunities	N	Administration and Policy
G	Leadership Training	O	Assessing Support Needs
H	Leadership Trainers		

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Center for Disability Studies University of Delaware Theda M. Ellis (302) 831-4450	✓														
Mailman Center University of Miami Paula Lalinde (305) 243-6123		✓					✓								
Institute for the Study of Developmental Disabilities UAP of Indiana Sharon Ely (812) 855-6508	✓				✓							✓			✓

Technical Assistance

[illegible]

Technical Assistance

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
American Samoa DD Council Henry Seseapasara (684) 633-5908				✓											
ID Governor's DD Council Becky Harker (515) 281-9082					✓								✓		✓
KS Council on Developmental Disabilities Jane Rhyse (785) 296-2608												✓			
OK DD Council Ann Trudgeon (405) 528-4984					✓			✓							

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THE NATIONAL CENTER FOR SELF-DETERMINATION & 21ST CENTURY LEADERSHIP supports leadership among people with developmental disabilities to advance self-determination throughout the United States.

The Center is a partnership between several organizations, including Oklahoma People First, the Minnesota Governor's Council on Developmental Disabilities, the University of Illinois at Chicago, Special Kids, U.S.A., and the Oregon Institute on Disability and Development's Center on Self-Determination at Oregon Health Sciences University.

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