D—RIC

Disabilities Research and Information Coalition
3530 Stone Way North
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FINAL REPORT

LEADERSHIP PROJECT
MAY - 1988

Prepared by

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Project Coordinator

This study and report was prepared under the sponsorship of a grant from the Washington State Developmental Disabilities Planning Council to the Disabilities Reseasrch and Information Coalition with funds provided by the Developmental Disabilities Act (P.L. 98-527).

Brenda

Final billing & financial report for last quarterly report to coming. Rob Bellflower has not been available for 2 wks ([illegible] [illegible] out of town)

Steve

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INTRODUCTION

From 1984 through 1986, the Washington State Developmental Disabilities Planning Council (DDPC) funded a leadership development project administered jointly by the Disabilities Research and Information Coalition (D-RIC) and the Washington Assembly for Citizens with Disabilities (The Assembly). The focus of this three year project was to support current and emerging leadership at the community level to strengthen local leadership and networking efforts on behalf of persons with developmental disabilities. This grant focused its efforts on leadership development through the implementation of a leaderhip workshop and follow-up support.

Part of this effort was continued with additional grant funds provided to People First of Washington which subcontracted with D-RIC to continue to provide leadership development workshops. These workshops were conducted in the Fall of 1987.

The DDPC undertook efforts to develop a new Request for Proposal in the Spring and Summer of 1987 to refund this effort for another three years. This new three year project would not be underway until Oct of 1987 and wouldn't really be full staff until at least January. An interim or mini grant was therefore provided to D-RIC to begin in August of 1987 and to run through December of 1987. This "mini grant" was not completed, however, until March of 1988.

The leadership development mini grant four major goals:

1. Provide ongoing assistance to core groups by conducting an initial assessment of the strengths and weaknesses of existing core groups.

2. Provide ongoing assistance to core groups through monthly liaison contacts with approximately 30 core groups and organizations.

3. Conduct two study tours with legislative staff of model programs serving persons with developmental disabilities.

4. Conduct an assessment of the developmental disabilities community education efforts with legislative staff in Olympia.

CORE GROUP ASSESSMENT

The assessment of thirty core groups was conducted primarily in January and March of 1988. The assessment was accomplished through interviews with the core group representative using a questionnaire developed for the project.

The questionnaire solicited information in the following major categories:

1. Existing core group network and phone trees
2. Information sources for core group representatives
3. Local meetings and training events
4. Individual and group community players
5. Networking efforts
6. Level of interest and commitment to core network
7. How the leadership project can help

The core group assessment report which includes a copy of the assessment form, a definition of a core group network and its possible functions and information on the telephone tree network is included in this final report. Major findings and some recommendations are included here.

Findings:

1. Core group representatives are interested in continuing to assist in providing local leadership in developing and strenthening core group networks.

2. Most core groups do not fint the "model core group composition" which has a representative from many different interest areas (see core group assessment report appendix). Instead, they are composed of some interested individuals or are formed around an existing parent group.

3. Core group representatives are wanting assistance in expanding their understanding of how to develop local networks, the role of local networks in both legislative and non-legislative activities, the functions of core groups including minimum requirements to the range of possibilities.

4. Core group representatives want and need assistance in including more individuals and groups in their core group network.

5. Core group representatives vary in their knowledge and understanding of issues and organizational relationships. Information and assistance needs to be provided in these areas.

6. Flexibility needs to be quarded to support the differences in preferences and styles represented by core group representatives. People do not appear to want core groups to develop into highly formalized structured groups.

7. There is little interconnectedness between parents and parent groups and local service providers and primary consumer self-advocacy groups. Ties between these sectors need to be strengthened in the core group networks. Individuals and groups not directly involved in issues affecting persons with disabilities need to be more involved.

Recommendations:

1. The concept of core groups needs to remain a flexible one. Continued project support must be careful not to create a highly bureacratic strucutured set of formalized groups imposed from "the outside" on local communities. Core groups need to thought of more in terms of mini networks within a given community. These mini networks are composed of individuals who have a personal network of friends and associates with whom they communicate and work, informally organized groups of individuals (often parents) who meet to talk about common concerns, as well as formally structured service provider and advocacy organizations.

2. Future assessments of core group networks should be for the purpose of assisting people in a local community to improve their networking and establishing their own agenda. Such assessments should involve several people who are interested in these efforts.

3. The model core group network with representation from all of the different possible interest areas can still serve as one model. It can also be incorporated into a more inclusive associational map to assist local leaders in identifying who they want to include in their natural network.

4. The DDPC should continue to fund efforts to strenthen local networking efforts. Many communities lack the more traditional parent and consumer self-advocacy organizations around which individuals traditionally received both information and personal support.

5. Information about core group networks should be shared among various groups and organizations. These networks can be of value to several organizations and avoids unnecessary duplication. Most important is the concept that no organization can own these networks. Rather, they are an integral part of community and have their own independent status.

ON-GOING ASSISTANCE TO CORE GROUP NETWORKS

On-going support was provided to 39 core group and organization representatives on a monthly basis. This is an important kind of support that should be continued, with some modifications. Below are some quotes from letters documenting the monthly contacts and the outcomes of this activity:

1. "For the past eight months, I have relied on your well-informed advice and incomparable skills at networking when making instrumental decisions regarding my organization .... you facilitated the matchup of United Cerebral Palsy with a group I now refer to as "Choices," a committed group of parents who have teenage children with cerebral palsy .... through your guidance and encouragement, I am taking on the task of trying to bring a myriad of groups to concensus regarding the needs of those individuals with neurological impairments." G.G. Reimer, Executive Director, United Cerebral Palsy Association of Washington.

2. "Thank you for all the information you were able to garner in reference to foster care issues and disabled persons ... you're quite a resource." Maxine M Siegel, Executive Director, Merrywood School.

3. "I feel we have come a long way in developing the network of individuals and organizations through which all persons with disabilities can find service and avenues where they can serve others." Caroly Blair Brown, Community Education Coordinator, Washington Coalition of Citizens with Disabilities.

4. "I do appreciate all your assistance in making our Forums such a success." Jon W Halvorson, Supervisor, Division of Developmental Disabilities.

5. "I just wanted to let you know how much I appreciate the monthly contact that we have had since last August. The information sharing and coordination functions that our conversations have produced has been of help to me and the organizations that I work with." Paul Wysocki, Chair, Governors Committee on Disability and Employment Issues.

6. "I truly appreciate your quick responses to my calls. The several meetins and conversations we have had since last fall have been very helpful to me and other citizen volunteers as we help people who have deaf-blindness to increase their participation in our communities. You seem to always know who I need to contact, where to reach them, and how best to approach them." Bonnie Larson, Parent.

Recommendations:

1. Ongoing support to core group representatives and organizations should continue based upon the comments received.

2. Modifications should be undertaken regarding the on-going support to core group representatives and organizations. Where possible, calls should be regionalized, using local or regional coordinators. This will reduce dependence on a "central office" disspensing all information and will increase local and regional independence.

3. In addition to direct phone calls and in-person contacts, a newsletter should be used to disseminate information on issues and topics and events of interest to the local networks.

Comment: The renewed leadership project has three coordinators. Each is responsible for a regional area. These areas are Spokane County, Pierce County, and King County. These three individuals will assume more of the local phone networking. In addition, the new project has initiated a brief newsletter called <u>Network Action News</u> which calls to major organizations and core group representatives on a monthly basis. The new project will also facilitate getting core group network representatives on the mailing lists of several other organizations.

LEGISLATIVE STUDY TOURS

Two very successful study tours with legislative staff were conducted, the first in August of 1987 and the second at the end of March, 1988.

Tour One:

Jonnell Anderson - Research Analyst, Senate Republican Caucus
John Welsh - House Human Services Committee
Debra Okre - Aide to Senator Ann Anderson
Jan Sharar - Senate Ways and Means Committee
Keith Long - Office of Financial Managaement
Barbara Shelton - Parent
Carol Simkins - Parent

Tour Two:

Jean Wesman - House Human Service Committee
Jane Beyer - House Democratic Policy Unit
Carol Pedigo - Senate Health and Corrections Committee
Bill Wegeleben - Office of Financial Management
Mary McKnew - Office of Financial Management

Both tours were conducted in a similar manner. They began with an orientation at the Washington Supported Employment Initiative Office for an overview of supported work which included the use of videiotapes and slides. Programs visited included:

1. Physio Control - Enclave and individual competitive work in a high technology environment.
2. Associated Grocers - Recycling operation.
3. King County Parks Crew - First local government funded employment program in Washington State.
4. Food Training Service Program at CDMRC - first non-sheltered employment training program in Washington.
5. Supported Work Program at Fred Meyers - one individual who recently left Rainier School.
6. Puget Sound Personnel Services - model competitive placement program focusing on large businesses.
7. Morgan Child Designer Soaps - small business.
8. Mobile Crew - operates three small crews doing janitorial work.
9. King County Human Services - Presentation on history of employment program development and data presentation.
10. People First of Washington - Presentation by persons with developmental disabilities on self-advocacy.
11. Kataro House - HUD build and state operated Title 19 funded group home
12. Community Home Health Care - Intensive Tenant Support.
13. Puget Sound Residential Services - Intensive Tenant Support for persons with deaf-blindness and for persons who recently lived at Rainier School.

The tours were organized with assistance from two staff persons at King County Human Services. Discussions with these staff helped to identify new model programs. In addition, once the programs to be visited are identified, the King County staff do all of the phone calling to confirm availability, times and dates.

On both tours the project coordinator was assisted by a Ray Jensen who is employed by the King County Human Services Department. This arrangement worked well in that Ray had a good history of the development of these programs as well as where the county was going. On the second tour, King County provided a van so that all tour participants could travel in the same vehicle.

The focus of the tour is to showcase the best programs available. The tours are conducted in King County because it provides the largest array of different model programs in one geographical area. King County also has excellent data on all of its employment and community integration programs.

The study tour has been a very successful event. Legislative staff have encouraged their peers to participate in future tours.

Recommendations:

1. The DDPC should continue to fund this activity. The majority of staff have only visited a limited number of programs, and these tend to include the state operated institutions and community IMRs.

2. Tours groups need to remain small to allow for discussion and interaction as well as not overwhelming any one program being visited. Each tour team should attempt to include a parent as well as a person with a developmental disability. Inclusion of a county coordinator might also be helpful.

3. While the tours have only visited with employment programs and residential supports considered to be model programs, staff have also indicated they would like to visit some "typical" programs. This should be considered in future tours or be part of a follow-up.

4. Legislators need to be encouraged and assisted in touring model programs as well as visiting programs in their own districts. Tours could be conducted by local core group representatives. This could be assisted by the local county coordinator. Some of this is already happening in communities where individual parents, parent groups or service providers are having legislators visit programs. This is very important since there is a 20 percent turnover in legislators every two years.

5. A short overview of programs, values, and directions pertinent to Washington State would be useful, similar to that produced by the Minnesota DDPC.

LEGISLATIVE STUDY

A study was conducted in January through March with 26 "legislative staff." Its intent was to gain information on the extent to which legislative staff were informed about issues facing the developmental disabilities community and their assessment of current programs and future policy issues.

To this end, questions were included to ascertain the primary sources of information for staff, their level of satisfaction and concerns about Department of Social and Health Services Programs and Special Education Programs serving persons with developmental disabilities. Also included was their assessment of what consituted the major public policy issues facing persons with disabilities, their assessment of how effective the issues have been presented to the legislature, information gaps, Their interest in visiting programs was also assessed.

The findings and recommendations are detailed in the enclosed Legislative Study Report. Only some of the findings and recomdations are stated in this portion of the final report.

Findihgs:

1. Advocates within the developmental disabiilties community are an important and vital source of information for both legislative staff and legislators. Mentioned most often was The Assembly followed by the Developmental Disabilities Planning Council.

2. Most legislative staff receive and review publications provided by The Assembly and D-RIC. To a lesser degree, they review other newsletters.

3. Personal contacts and informal discussions remains the most used method of staying informed for legislative staff followed by reading reports.

4. Legislative staff are obviously most knowledgeable about the area of interest covered by their committee. However, most non-education staff knew little about special education programs.

5. There is a fairly solid base of support for those programs attempting to serve persons in ways which increase their being part of a community (E.g. supported employment, tenant support). However, reservations are still expressed regarding efforts to integrate severely handicapped persons in public school programs. Most staff still see a need for institutionalization.

6. There was widespread concern regarding the lack of new funds to serve the growing number of unserved persons. Staff expressed the hope that the DDPC and advocates would explore alternative ways to do more with less.

7. Many staff expressed concern over high costs in serving severely handicapped persons in state operated institutions and community programs funded with Title 19 dollars. They doubt that increased funding for these same indiividuals results in increased and cost effective programs and see these rising costs as detracting needed funds from community programs for unserved persons.

8. Long term care and lack of opportunties for high school special education graduates were two additionally strong themes mentioned by legislative staff as critical concerns.

9. Failure to resolve the financial responsibility or parent pay issue is viewed as potentially harmful to the developmental disabilities community by a significant number of the staff interviewed.

10. In all, staff believed the developmental disabilities community has done a good job in presenting its issues to the legislature. However, they are concerned by the fractioning of groups and would like to see more data.

Recommendations:

1. The DDPC should be more visible and active in providing orientations and briefings for legislative staff and legislators. This includes orientations for new staff and legislators as well as addressing major issues.

2. The DDPC should insure that legislative staff and legislators as well as the Executive Branch know that it is an important source of information about issues, trends and directions in service development as well as actual programs and that it is available to provide such information to the legislature and Executive branch. Insuring that reports and issue papers are provided to these groups is also important.

3. The DDPC needs to assist the developmental disabilities community in having access to information and n tying specific issues to generic themes and services (e.g. chore and attendent care program as important to the issue of long term care).

4. The DDPC could be instrumental in developing consensus within the developmental disabiities community through the development of policy positions that advocates could rally around.

5. The DDPC should continue and increase its internal advocacy role as well as working closely with the advocacy community.

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REPORT

ASSESSMENT OF CORE GROUP NETWORKS

MARCH - 1988

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INTRODUCTION

The assessment of core group networks was conducted during the months of January through March. Individual interviews were conducted by three persons with representatives from 30 core group networks around the state by telephone.

The questionnaire used during the interview attempted to gain information in the following major areas:

Existing Core Group Network & Phone Trees
Sources of Information
Local Meetings and Training Events
Community Players (Individuals and Groups)
Networking Efforts
Level of Interest & Commitment
How the Leadership Project Can Help

FINDINGS

1. Core group representatives are interested in continuing to assist in providing local leadership in developing and strenthening core group networks.

2. Most core groups do no fit the "model core group composition" which has a representative from many different interest areas. Instead, they are composed of some interested individuals or are formed around an existing parent group.

3. Core group representatives are wanting assistance in expanding their understanding of how to develop local networks, the role of local networks in both legislative and non-legislative activities, the functions of core groups including minimum requirements to the range of possibilities.

4. Core group representatives want and need assistance in including more individuals and groups in their core group network.

5. Core group representatives vary in their knowledge and understanding of issues and organizational relationships. Information and assistance needs to be provided in these areas.

6. Flexibility needs to be guarded to support the differences in preferences and styles represented by core group representatives. People do not appear to want core groups to develop into highly formalized structured groups.

7. There is little interconnectedness between parents and parent groups and local service providers and primary consumer self-advocacy groups. Ties between these sectors need to be strengthened in the core group networks. Individuals and groups not directly involved in issues affecting persons with disabilities need to be more involved.

CORE GROUP NETWORK ASSESSMENT

FINDINGS & RECOMMENDATIONS

MARCH - 1988

The information provided here was obtained in the interviews with core group representatives. They are presented in a summary form first and they followed with a narrative explanation. They represent the ideas, feelings, and understandings of those persons who were interviewed.

BARRIERS TO NETWORKING:

Proximity to meetings and events
Urban - Rural splits within legislative district
Groups not understanding one anothers functions
No clearing house for information
Not enough structure
Individuals and groups not seeing interconnectedness
Interest, knowledge and time
Information on disabilities

IMPROVING NETWORKING EFFORTS:

Strengthen core groups
Build phone trees
Accurate phone lists
Education on differences
Personal contact outside of legislative session
Contact with legislators
Community meetings
Common cause
Back up
Follow through
Assistance in planning and goal setting
Communication across groups

THINGS TO EXPAND UPON:

Phone trees
Core groups
Help of DDD Case Managers in Informing and Bringing Together
DRIC as central information clearing house
Legislative reception
Use of ESDs

THINGS THE LEADERSHIP PROJECT CAN DO TO HELP

INFORMATION:

Specific bills
Specific activites for core groups
Core group sharing of information
How to deal with legislators
Information on who is doing what
Networking
How to hold meetings

WORKSHOPS:

Running a core group
What should a core group do - possibility and necessities
How to get people involved
Self-empowerment
Self-advocacy
Leadership
Available childcare

TECHNICAL ASSISTANCE:

Fact papers
Setting goals
Setting priorities
Knowing where to start
How to use core groups for non-legislative activities
Finding new people to be involved
Sharing responsibilities in network development & maintenance

OTHER:

Financial assistance to get to meetings
Formation of model core group(s)
Establishing consistent meetings
Common meeting place
Updated computer mailing/phone lists
More feedback

BARRIERS TO NETWORKING

1. Insufficient Number of Local Meetings and Events

More local events were requested. Travel to statewide and regional meetings presents problems to a number of individuals. Issues such as child care, transportation costs, and time were some issues identified. Many felt that local, community based workshops would attract local interest.

2. Accomodating Urban - Rural Splits Within Legislative Districts

Some legislative districts, particularly those outside of the state's metropolitan areas, cover a large geographical area. This can and does present communications problems within the district. Different population clusters within the district often represent significant community differences in terms of how things work and what are considered primary problems. Ways need to be explored to develop a network within each community within a district as well as methods to have those population centers communicate and work together on issues that affect the entire district or region.

3. Lack of Understanding of Group & Organization Roles

Respondents were confused by the large number of organizations that exist. This included statewide as well as local groups along with organizations that exist by Executive Order. It is not clear to network representatives how they can or could or even should related to these organizations. It may also be unclear to these organizations as well.

4. Lack of Clearing House for Information

While there are a number of organizations with newsletters or information referral services, respondents said they often did not no where to go for information and would like a central clearing house type concept to be in place so they would at least know where to start. Some suggested that the Disabilities Research and Information Coalition take on this role.

5. Insufficient Structure to Core Group Networking

Some respondents indicated they did not have a good understanding of the core group concept or of core group networking. This lack of understanding centered on what is a core group, who should be in it, how does such an informal network really work, how do you know when its really working, how much is enough, etc. Most indicated they wanted more support from someone who knew as well as help from others in their community.

6. Individuals and Groups Not See Interconnectedness of Efforts

Individuals often felt isolated as well as overwhelmed by all of the issues and potential "work" of a core group. They did not understand how different efforts by different people and groups elated to one another either within their own community or tatewide.

. Lack of Interest, Knowledge and Time

ll core group respondents indicated an interest in continuing in heir efforts with The Assembly and the networking project. owever, they expressed the frustration of not having enough upport from others in their community. Usually this was expresed n terms of their stating that people lacked interest because hey were tired and overwhelmed with their job or with the care hey have to provide to a disabled son or daughter, or, they did ot know where the people who might be willing to work with them ere. Many expressed the frustration of fealing that they did not ave enough information about the various issues that The ssembly and others were addressing. Time conflicts were also a roblem, with those people who were involved be extremely busy ith many advocacy related activities or not having enough time ue to family and work demands.

. Hard to Reach People in the Telephone Networks

ome people indicated it was hard to get a hold of people when hey called. Often they had to call several times before they ctually reach the individual. Obviously this took more time than naticipated or people wanted to spend and resulted in feeling rustrated.

. State Legislative Hotline Always Busy

eople indicated that using the state toll-free legislative otline was often next to impossible as it was always busy. alling legislators on their office phones was a problem for some ue to the expense of long distance calling.

IMPROVING NETWORKING EFFORTS

. Strengthening Core Groups has Broad Support

esponsdents were supportive of the core group concept. They ndicated it was often one of their few links to getting nformation. Most also agreed that it had a good deal of otential even though they were unclear about its structure and peration. A number of individuals requested specific workshops n how to form and maintain a core group, how to keep peoples nterest high, how to increanse participation, and clarification n what core groups could do and how they could do it.

THINGS THE LEADERSHIP PROJECT CAN DO TO HELP

INFORMATION

1. Information on Specific Bills and Issues

Respondents indicated they wanted more in-depth information explaining proposed legislatiion and issues facing the disabiities community.

2. Specific Activities for Core Groups

Some core group respondents wanted assistance in defining the core acitivities appropriapriate for core groups. This could include specific things that core group members could do on a volunteer basis.

3. Sharing Information Among Core Groups

People want to know what other core groups are doing and whats working for these core group networks. Dissemination of this information in the form of a Network Action Newsletter would be helpful. This newsletter should include specific information on examples in which others are effectively networking in our state. People also wanted to know who is doing what. This information could be a good resource to others as well as appropriate role models.

4. Effective Strategies in Dealing with Legislators and other Key Players.

Most people have had limited experience in working with legislators or other key decision makers such as county commissioners, special education directors, DSHS administrators etc. Respondents indicated they would like assistance in developing strategies and methods of dealing with individuals in these positions.

WORKSHOPS

Respondents indicated they wanted workshops to be conducted on the following topics:

1. Core Group Development

    - How to form a core group
    - How to run a core group
    - How to get people involved in the network
    - What should a core group do
    - Possibilities and necessities for core group action

2. Self-empowerment

3. Self-Advocacy

4. Leadership Development

5. Planning and Goal Setting

6. Ways to Network

7. Motivation and Involving Others

TECHNICAL ASSISTANCE TO CORE GROUPS

1. Fact Papers

Respondents wanted short papers that included basic information about services and issues.

2. Setting Goals and Priorities

To assist local core groups, core group leaders wanted help in identifying strategies to be used in getting people to agree to goals and setting a limited number of priorities that people could focus on.

3. Planning and Implementation

People often expressed a feeling of being overwhelmed or not knowing where to start with their core group in its development or in addressing a specific issue in their community. Help in knowing where to start was requested.

4. How to Use Core Groups for Non-Legislative Activities

People expressed an interest in using the core group network for a variety of activites other than legislative. These networks and groups can be an important support network for people. This is especially true in communities lacking in formal groups and structures.

5. Finding People to Be Involved

Most core group respondents indicated they needed help in finding people to participate in the core group networking activities. Many did not know where to go to find such people. Those that are involved often seem to be the same persons who are always active.

6. Sharing Responsibilities in Network Development and Its Maintenance.

Too often, one or two key people feel they carry the major responsibilities for developing and maintaining the core group network. Expanding involvement to other people and groups and getting others to agree to share in the responsibility for this effort is an issue of importance to many core group representatives.

7. Formation of Model Core Groups

People want to know what and how people in other areas of the state (and probably outside the state as well) are developing their core groups. They recognize in this request that core group networks can vary in how they are formed and operate.

8. Establishing Consistent Meetings in Common Meeting Place

In many communities there is no consistent place and time in which people gather to discuss issues of concern to the disabilities community. While some formal structures such as county boards exist that could serve in this function, they are not related to. Respondents discussed the possibilities of establishing a way in which to bring people together in some consistent way and place to provide the forum or context in which people could cooperate on agreed upon issues.

OTHER AREAS OF HELP REQUESTED OF THE LEADERSHIP PROJECT

1. Financial Assistance in Getting to Meetings

Many core group representatives (and others) would like to participate in meetings and workshops but can't because of expenses. The inability to find respite care workers also is a problems for many who want to participate but can't because they can't find child care. Many are also uncomfortable in bring their disabled child or son or daughter with them. In some cases its not practicable. In other cases, people feel uncomfortable doing so.

2. Updated Computer Mailing/Phone Lists

People requested periodic updated lists from The Assembly that they could use in developing their core group networks

3. More Feedback Requested

People want to know that what they are doing is making a difference and achieving some benefit. Often, they felt they had insufficient or no feedback that their actions counted. Ways need to be developed to provide this kind of feedback to people.

OTHER RECOMMENDATIONS

1. Provide updated accurate phone lists from The Assembly to local groups. Local core group networks should be asked to assist in this updating and expanding of the list.

2. Build core group (local network) on existing groups as well as reaching out to persons who do not belong to any formal organization and to groups and organizations that have not typically been involved. People currently actively involved should be assisted in identifying the people and groups that they know. School distric personnel and Division of Developmental Disabilities case managers should also be asked to assist. Statewide and regional groups should also be contacted to identify people who are members of their organizations who could become part of the network.

3. The present "model" core group composition form should be reviewed by the new advisory committee to the leadership project and amended as needed to serve as a guide in developing core group networks (see attachment). It can be used as an "associational map" to help local core group leaders identify people who could become part of the local network. Consideration should also be given to expanding this list to include citizens not currently involved in disability issues (see attachment entitled "an associational map developed by John McKnight).

4. More persons with disabilities should be involved in the core group networks. Statewide organizations (e.g. People First) and regional groups (e.g. COHO in Vancouver; Washington Coalition of Citizens with Disabilities in Seattle) should be asked to assist in this effort.

5. Core group networks should include representation from major areas of interest.

6. The new leadership project should consider developing videotapes on the topics of interest in organizing network and core group activities.

7. Core group network leaders should be provided assistance in developing team building skills that can help in expanding the sharing of responsibilities in developing and maintaining an effective local network.

8. Core group leaders should be provided basic skills and information regarding how to do some of the activities included in the description of core group network activities. This includes (a) setting up and running a community meeting, (b) how to insure participation in a local meeting of elected officials, (c) how to communicate with elected officials, etc.

9. Core groups leaders and participants should be encouraged and assisted to attend meetings of The Assembly, DDPC, GCDE and other

groups to expand their personal networking contacts and knowledge of issues.

10. Core group leaders and participants need additional information on issues in which they are interested. Habilitation News and Network Action News are two vehicles that could be used. Core group leaders should be assisted in getting newsletters from other organizations. People need assistance in understanding the interconnectedness of issues and how and how these issues affect individuals and groups. Information on what happens with a legislative issue after it fails and/or passes also needs to be disseminted.

11. Core groups need assistance in how to increase the dissemination of information locally.

12. Core group leaders and participants want more feedback - people want and need to know they make a difference. This is important for maintaining interest and motivating people to stay involved.

13. People involved in local core group efforts need a better explanation of the responsibilities involved in being an active participant in a core group and how this may differ from just being part of a phone tree.

14. Models for core group networks need to be explored, tried, and shared with other local core group network leaders. Models should reflect the uniqueness of communities and the varied interests of those involved.

15. The support and structure for developing, maintaining, and strengthening core group networks needs improvement. Implementation of regional coordinators through the new leadership grant should be a significant help. Other areas need to be explored as well.

16. Core groups should help facilitate sponsoring a series of community forums that will provide information on basic issues and concerns to parents and professionals. Where possible, this should be in cooperation with an existing organization. Too many communities no longer have this kind of activity available to them.

APPENDIX

CORE GROUPS

DEFINITION: A group of citizens responsible for organizing and maintaining a communications network for a specific region for the purpose of sharing information and uniting for action around a common need.

GOALS:

1. Develop local networking system which brings together parents, consumers, service providers, professionals and advocacy groups.
2. Provide the leadership and structure for development of a potent community force shich empowers citizens and leads to the development of competent communities.
3. Provide input on important local issues to The Assembly (& other groups / e.g. DRIC, DDPC, etc.) in the development of a statewide legislative agenda representing consensus.
4. Provide the mechanism to help local citizens meet with their own legislators to discuss and gain support for The Assembly's legislative agenda as well as local issues.

PRIMARY FUNCTIONS:

1. Organize self and maintain structure including delegate and alternate delegate to The Assembly Board of Directors.
2. Organize a "Telephone Tree" in the Legislative District which will generate a minimum of 25 phone calls in several hours.
3. Organize and host at least one meeting each fall with local legislators to discuss The Assembly legislative agenda and local concerns.
4. Foster communications and trust through agreed upon additional activities.

CORE GROUP ACTIVITIES

ACTIVITIES	COMMMENTS
CORE GROUP ORGANIZATION (CG) Form CG Steering Committee Form CG for ___ Legislative District Select CG Prime Contact Complete 6 or 12 month work plan Prepare monthly progress report Solicit individual memberships to The Assembly Develop CG meeting schedule Select representative to The Assembly	
COMMUNICATIONS NETWORKING Complete service/advocacy directory Develop Telephone Tree Publisize Hotline Publisize CG members' numbers News Media Letters to Editor TV Talk Show Radio Talk Show Develop contact(s) with non-disability groups	
ISSUE SHARING : Planning & Advocacy / Info. Dissemination CG with services & advocacy organizational reps CG with services & advocacy reps plus legislators CG with County Board CG liason with regional program administrators CG with ___________	
MONITORING & EVALUATION CG visit(s) to service programs CG sponsers "visit a program week"	
LEGISLATIVE CONTACTS CG with legislators in home district CG with legislators in Olympia CG lead "tour or services / schools / homes" CG sponser legislators meeting consumers CG / others attend coffee hours with legislators CG follow-up with Assembly Rating questionaires CG help with DRIC Issue Analysis Papers	

POSSIBLE CORE GROUP COMPOSITION

(10/9/87 Draft)

EARLY INTERVENTION - PRESCHOOL:

(a) ECDAW (Early Childhood Dev. Assoc of WA): ____________
(b) Generic Early Childhood Group: ____________
(c) Specific Disability Group: ____________

SPECIAL EDUCATION:

(a) Council for Exceptional Children (CEC): ____________
(b) Special Education Advisory Council(s) (SEPAC):
____________ ____________
____________ ____________

(c) Special Education Coalition: ____________

EMPLOYMENT:
(a) Existing Local Program:
____________ ____________
____________ ____________

(b) Rehabilitation Enterprises of WA (REW): ____________

COMMUNITY RESIDENTIAL SERVICES:

(a) Organized Residential Programs:

Tenant Support/Alternative Living: ____________
Group Home: ____________ ____________
Independent Living Center: ____________
Organizations:
DDRSA: ____________
CRSC: ____________
WRAPS: ____________
Generic Housing Advocacy Group: ____________

SELF-ADVOCACY GROUPS:

(a) People First of WA: ____________
(b) WA Coalition of Citizens with Disabilities: ____________
(c) Others: ____________ ____________

ADVOCACY & SYSTEMS PLANNING GROUPS:

(a) WA P & A SYSTEM: ____________
(b) DDPC: ____________
(b) GCDIE: ____________
(d) Guardianship: ____________
(e) Client Assistance Program: ____________
(f) Others: ____________ ____________

FAMILY SUPPORT:

(a) Home Aid Coalition: ____________
(b) Other: ____________

ACCESSIBIITY: ____________

HEALTH SERVICES: ____________ ____________

AN ASSOCIATIONAL MAP

ARTISTIC ORGANIZATIONS:	choral, theatrical, writing
BUSINESS ORGANIZATIONS:	Chamber of Commerce, neighborhood business associations, trade groups
CHARITABLE GROUPS AND DRIVES:	Red Cross, Cancer Society, United Way
CHURCH GROUPS:	service, prayer, maintenance, stewardship, acolytes, mens, womens, youth, seniors
CIVIC EVENTS:	July 4th, art fair, Halloween
COLLECTORS GROUPS:	stamp collectors, flower dryers, antiques
COMMUNITY SUPPORT GROUPS:	"friends" of the library, nursing home, hospital
ELDERLY GROUPS:	Senior citizens
ETHNIC ASSOCIATIONS:	Sons of Norway, Black Heritage Club, Hibernians
HEALTH AND FITNESS GROUPS:	bicycling, jogging, exercise
INTEREST CLUBS:	poodle owners, old car owners
LOCAL GOVERNMENT:	town, township, electoral units, fire department, emergency units
LOCAL MEDIA:	radio, newspaper, local access cable TV
MEN'S GROUPS:	cultural, political, social, educational, vocational
MUTUAL SUPPORT (SELF-HELP) GROUPS:	Alcoholics Anonymous, Epilepsy self-help, La Leche League
NEIGHBORHOOD AND BLOCK CLUBS:	crime watch, beautification, Christmas decorations
OUTDOOR GROUPS:	garden clubs, Audubon Society, conservation clubs
POLITICAL ORGANIZATIONS:	Democrats, Republicans, caucuses
SCHOOL GROUPS:	printing club, PTA, child care

SERVICE CLUBS:	Zonta, Kiwanis, Rotary, American Association of University Women
SOCIAL CAUSE GROUPS:	peace, rights, advocacy, service
SPORTS LEAGUES:	bowling, swimming, baseball, fishing, volleyball
STUDY GROUPS:	literary clubs, bible study groups
VETERANS GROUPS:	American Legion, Amvets, Veterans of Foreign Wars, their Auxiliaries
WOMEN'S GROUPS:	cultural, political, social, educational, vocational
YOUTH GROUPS:	4H, Future Farmers, Scouts, YWMCA

° Additional copies may be obtained by contacting John L. McKnight, Center for Urban Affairs and Policy Research, 2040 Sheridan Road, Evanston, IL, 60201.

INITIAL CORE GROUP ASSESSMENT FORM

MINI GRANT 1/88

LEGISLATIVE DISTRICT NUMBER: **DATE:**

CORE GROUP (City or Area):

Core Group Contact(s):

	Name	Address	Phone
Delegate:			
Alternate:			
Other:			

TABLE OF CONTENTS

PART ONE: EXISTING CORE GROUP

1. Describe your Core Group Network: Use (Attached) Core Group Composition Form)

2. Do You Have a Phone Tree?

2.1 ___ Yes ___ No Number of Individuals in Tree: ___

Number of Organizations in Tree: ___

2.2 How does your phone tree work? Describe in general terms:

2.3 Is it ___ formalized or ___ informal ?

2.4 Do you call everyone ___ Yes ___ No ?

2.5 How many people help you call: ___ ?

2.6 Are you part of anyone else's phone tree ___ Yes ___ No ?

Specify:

	Purpose/Use of Phone Tree	# of Times Used in 1987
___	Call legislators	___
___	Local Issues for County Board	___
___	Local Issues for SEPAC	___
___	Forums (DDD, DVR, GCDE)	___
___	Conferences	___
___	Other Local Issues Specify:	___
___	Other Specify:	

: SOURCES OF INFORMATION

viduals) are your best sources of information about issues affecting persons with
es. Indicate if information relates to local, state, or national issues.

year and which

s	Affiliation	LOCAL	STATE	NATL

ty

anizations, newsletters, and hotlines are your best source of information?

Organizations & Newsletters	Helpful ? Yes	Somewhat	No
ssembly			
mbly Legislative Action News Bulletin	___	___	___
mbly Legislative Hotline 1-800-638-LAWS	___	___	___
rnors Committee on Disability & Employment Issues (GCDE)	___	___	___
E Legislative Connections	___	___	___
E Connections	___	___	___
ilities Research & Info. Coalition (DRIC)	___	___	___
Habilitation News	___	___	___
TREN *For Your Information*	___	___	___
Issue Analysis	___	___	___
	___	___	___
Pipeline	___	___	___
nt Community Relations Project (PCR)	___	___	___
Networking Newsletter	___	___	___
Hotline (1-800- 422-GOAL)	___	___	___
ation Law Project	___	___	___
ilities Law Project	___	___	___
lopmental Disabilities Planning Council	___	___	___
ction & Advocacy System Troubleshooters)			
Reports (formerly *The Inside Scoop*)	___	___	___
Hotline (1-800-562-2702)	___	___	___
of Washington	___	___	___
ARC	___	___	___
County ARC (KCARC)	___	___	___
RC *The Advocate* (newsletter)	___	___	___
le First of Washington	___	___	___
le First Newsletter	___	___	___
	___	___	___
LD	___	___	___
ssional Association	___	___	___
r (Specify):	___	___	___

2. Who offered training opportunities in your community and did you attend any?

Held		Local	City
___	Assembly Leadership Workshop	___	___
___	PAVE	___	___
___	PCR	___	___
___	ARC Parent-to-Parent	___	___
___	WACLD Parent Advisor Training	___	___
___	Other (Specify):	___	___

3. Were you aware of any of the statewide training events listed below and did you attend?

Held	Event	Local	City
___	Residential Ellensburg	___	___
___	Employment Ellensburg	___	___
___	You Are the Expert	___	___
___	ARC Convention	___	___
___	Autism Conference	___	___
___	WA Supported Employment Workshops	___	___
___	DDD Sponsored Training	___	___
___	WACLD Conference	___	___
___	Sp. Ed. and The Law Conference	___	___
___	Other (Specify):		
	______________________	___	___

4. List any disability organizations or groups that you are a member of, or work with:

PART FOUR: COMMUNITY PLAYERS (INDIVIDUALS AND GROUPS)

1. **List the groups in your community that are interested in services and support to people with disabilities and their families.**

    a. leadership development opportunities (e.g. United Way, Junior League)

    b. local networks (informal groups)

    c. special education advisory council, committee, group etc.

    d. county DD advisory board

    e. parent support / advocacy organizations

    f. consumer and self-advocacy

    g. protection and advocacy organization

    h. local access to information (training opportunities, model services, information & referral programs, hotlines, etc.)

    i. mechanisms / efforts for participating in local planning (e.g. "independent" planning group)

    k. opportunity to participate in case management (individual programs)

    l. mechanisms to decrease isolation, identify role models (e.g. YMCA or YWCA, religious groups, social groups, etc.)

    m. structures to link individuals and planning

    n. service organizations

    o. service organization coalitions

    p. other (specify)

2. **Who do you view as key members and players of your community related to disability issues and services?**

Name	**Interest Area**	**Phone**

T FIVE: HOW ARE PLAYERS NETWORKING TOGETHER?

escribe how well the constituency groups and key players are working together. n or

hat are the major barriers to networking in your community?

hat would help to improve networking in your community?

hat current networking efforts exist which could be expanded upon?

PART EIGHT: NETWORK / CORE GROUP ANALYSIS

Major Strengths:

Major Weaknesses:

Planning Suggestions & Strategies:

OTHER COMMENTS and Information that doesn't fit anywhere else:

INTERVIEWERS COMMENTS:

D-RIC

DISABILITIES RESEARCH AND
INFORMATION COALITION

LEGISLATIVE STUDY:
FINDINGS AND RECOMMENDATIONS

Prepared By
Stephen Schain
Project Director

April, 1988

This research study and report was prepared under the sponsorship of a grant from the Washington State Developmental Disabilities Planning Council with funds provided by the Developmental Disabilities Act (P.L. 98-527).

INTRODUCTION

This study was conducted during the months of January, February and March of 1988. Its intent was to gain information on the extent to which legislative staff were informed about issues facing the developmental disabilities community and their assessment of current programs and future policy issues.

To this end, questions were included to ascertain the primary sources of information for staff, their level of satisfaction and concerns about Department of Social and Health Services Programs and Special Education programs serving persons with developmental disabilities, their assessment of what constituted the major public policy issues facing persons with disabilities, and their assessment of how effective the disabilities community representatives have presented their issues to the legislature. Information was also sought on the information gap of legislative staff and their level of interest in visiting programs serving persons with disabilities and their families.

The study was conducted in the form of questionnaire. Each staff persons was provided with a written and verbal introduction along with a copy of the survey questionnaire which they were to complete over a several week period. Follow up interviews were conducted with all of the respondents.

Twenty six staff were interviewed. This included House and Senate staff working for the health and social services committees, judiciary committees, education committees, and ways and means committees. Senate Republican and Democratic Caucus staff and House Democratic Caucus Policy Staff were also interviewed. Further, staff in the Governors Office of Financial Management and Department of Social and Health Services were interviewed.

All respondents were assured that their specific comments would be regarded as confidential.

A complete compilation of responses are provided. The narrative statements are close approximations to the actual verbatim comments made and have not been edited except for the purpose of brevity.

SOURCES OF INFORMATION

FINDINGS

1. A significant number of respondents indicated that their information came from all categories presented on a list of standard sources but varied in their intensity depending on the specific issue. Reports and informal discussions with key players ranked a close first and second in that order for the two primary sources of information. The following sources were used to a much lesser degree in the following order of preference: other legislative staff, briefings, testimony, letters, and tours of service programs. Several staff indicated they relied heavily on information from DDD staff and DSHS staff in general and that this was the first place they went when seeking information (See Questionnaire, Section 1.11).

2. Seven of the respondents indicated they used other legislative staff on a regular basis for information. Five indicated they did on a limited basis. Only one key staff person indicted he tried to involve every. Another key staff indicated that a team approach was easiest on DD issues (See Questionnaire, Section 1.12).

3. Committee staff all indicated that they did not utilize caucus staff for information.

4. Lobbyists and citizen advocates were identified as an important source of information. The Washington Assembly for Citizens with Disabilities director (14) lobbyist (13) and legislative chair (11) was mentioned most often followed by the Developmental Disabilities Planning Council director (5) and lobbyist for the Rehabilitative Enterprises of Washington (4). Institutional parent advocates were identified (8) and King County Human Service Board staff names were also identified (4).

The Division of Developmental Disabilities director was mentioned a number of times as having high credibility and being extremely helpful.

The Office of Superintendent of Public Instruction was also identified as an important source of information (See Questionnaire, Section 1.16).

5. The materials most routinely received and reviewed in order were the Assembly Legislative Action News Bulletin (23), Legislative Budget Committee Reports (15), DSHS reports (14), DRIC Habilitation News (14) and DRIC Issue Analysis (11). (See Questionnaire, Section 1.2).

6. Three groups were mentioned most often as sources of reliable information. In priority order, these were The Assembly (22), DSHS (19) and the DDPC (17). SPI was also mentioned (8) by staff with direct connections to education issues. A number of other organizations and interest groups were mentioned to a

significantly lesser degree (See Questionnaire, Section 1.3).

7. The Assembly was mentioned most often (14) as the organization most heard from on disability related issues. The DDPC was second (5) (See Questionnaire, Section 1.4).

8. Individuals identified as most helpful in obtaining information were Steve Schain (12), Sue Elliot (12), and Jeff Larsen (9). A total of 25 individuals were named. DDD staff were mentioned as helpful when the Division of Developmental Disabilities Director (Sue Elliot) was mentioned. SPI staff were also mentioned as a helpful as a group.

PROGRAM INFORMATION - SPECIAL EDUCATION

FINDINGS

1. Opinion supported efforts of local districts to provide access and participation (See Questionnaire, Section 2.1A).

2. Greatest concerns were expressed about not knowing whether blending ("merging"), pull-out, self-contained categorical programs or mainstreaming was the most appropriate approach or when each approach should be employed. A second major concern was the cost for individuals who were more severely handicapped pupils (See Questionnaire, Section 2.2A).

3. There was no voiced opposition to continued support for special education programs, although the state's responsibility was noted as being continually defined and refined (See Questionnaire, Section 2.3A).

4. Little was identified as outstanding in Special Education programs when staff were asked what they were most satisfied. Several staff indicated they didn't have criteria to judge and that with local control, it was hard to tell. Being "out of the closet" was mentioned as a significant step, along with what is being taught about differences to non-handicapped students (See Questionnaire, Section 2.4A).

5. Program approaches (mainstreaming, pull-out etc) and costs for severly handicapped pupils were two issues repeatedly identified when staff were asked what their greatest concerns were about special education as well as when asked other questions. Over-classification of students in LD and BD programs along with minority students were also identified as a concern by several staff (See. Questionnaire, Section 2.5A).

6. When asked for a general opinion about special education programs, non education related staff almost uniformly expressed the opinion that they had no opinion (14) or knowledge (15) about school programs. Costs were identified again as a concern along with a general feeling that school programs were not as well managed as state agency programs.

PROGRAM INFORMATION - DEVELOPMENTAL DISABILITIES PROGRAMS

FINDINGS

1. Overall opinion about DSHS programs serving persons with developmental disabilities was good, especially when compared to mental health. Potential for greater effectiveness and support was also identified given staff dedication, model programs, historical achievements, underutilization of private sector efforts, current in-fighting, and DDD's more recent responsiveness to legislative direction (See Questionnaire, Section 2.1B).

2. Several themes were expressed when staff were asked to identify their greatest concerns. The need for advocates and DSHS to do more with less, including the reexamination of some current programs (Title 19) in light of the projections for a flat budget over the next several bienniums was most prominent. The lack of parity across programs and hence the need for addressing the issue of financial responsibility was a second major theme. A third theme was the institutional bias in addressing the long term care needs (residential services) of people. A fourth theme was the need for a more coordinated and comprehensive approach rather than trying to fix the problems piecemeal (See Questionnaire, Section 2.2B).

3. General support was expressed for continued support for DD programs, especially for programs helping families to maintain children and helping people to become part of a community. However, rising costs and a state economy not generating increased revenue will requires a change in strategy by the DD community. The DDPC should take a lead role in identifying ways to reduce reliance on government programs, increasing private sector initiative, and in altering ways in which funds are currently spent (See Questionnaire, Section 2.3B).

4. Community residential programs were identified as the programs staff were most satisfied with (See Questionnaire, Section 2.4B).

5. Two dominant themes emerged when staff were asked to identify their greatest concerns regarding DSHS/DDD programs. The first was the high cost for serving severely handicapped individuals with limited potential and the resulting inequity of where DDD spends its money. This issue was linked to the large issue of long term care and the large and growing numbers of individuals needed residential services. Suggestions including closing the IMR-C and IMR-D programs were made. The second major theme was concern over the lack of opportunities and options for high school special education graduates. Lack of leadership within the executive branch to identify priorities and direction was cited by many staff as a critical problem (See Questionnaire, Section 2.5B).

PUBLIC POLICY ISSUES

FINDINGS

1. The three major policy issues identified were financial responsibility (13), unserved persons needing residential and/or employment services (19), and long term care in combination with the concern over the use of Title 19 funds for institutional care and its potential role for community options such as chore services (12).

Four other issues were identified by four or five respondents. These included residential placement policy, state responsibility for long term care, early intervention and special education opportunities.

Another six issues were identified by two or three staff as concerns including family support and transition while another 12 issues were identified by one staff person (See Questionnaire, Section 3.1).

2. At least 10 staff thought that the disabilities community had done a good to well and even excellent job presenting its issues to the legislature. Proof was cited including the DD advocates reputation for political effectiveness and in its integrity. These individuals thought that a better job still needed to be done in getting legislators to know disabled people and visit exemplary programs, get more focused, and bolster our use of hard data.

Several staff felt the DD lobby could do better even though it was better organized than most other lobbies. One criticism was of its perceived piecemeal approach to the problems with certain issues not getting much attention at all, such as transportation, housing, and vocational education. Recommendations were made to put less emphasis on money and more emphasis on what should be happening and the similarities of need with other groups (e.g. elderly and non-elderly handicapped needs for long term care including chore services).

No one identified or was aware of the up-coming issue of a birth to three mandate.

Several staff emphasized the need for disability advocates to recognize that Washington State and the country as a whole was in a "diminishing resource economy." This requires a reexamination of how funds are currently spent and making some hard decisions about change. Furthermore, parent pay came up repeatedly in this context. While most staff are of the opinion that parents should pay for certain services on a sliding scale basis, many felt that regardless of what happens, there needs to be a resolution of this issue.

Several staff also discussed the absence of new and influential "champions" within the legislature on developmental disability issues. Too much reliance has been placed on "old friends" and not on expanding a base of support (See Questionnaire, Section 3.2).

3. There was not much disagreement (14) with the following list of priorities presented to staff:

Family Support
Unserved Persons - Employment
Unserved Persons - Day Programs
Unserved Persons - Residential
Community Workers - Staff Salaries & Benefits
Special Education - Full Funding
Tax Supported Services - Elimination of Parent Pay
Health Care - Prenatal, Medical, Dental
Birth to Three - Mandate

The issue of parent pay was the one single issue that repeated itself when asked this question (See Questionnaire, Section 3.3).

4. There was no one area in which the experienced staff interviewed admitted an information gap. Several new staff did indicate a need for general information. A number of requests for specific information were identified by individual staff (See Questionnaire, Section 3.4).

5. Staff generally felt that the issues facing the DD community were similar to other social service groups - money for new programs. Long term care was the one issue most often mentioned as a common problem along with how the issue of parent pay separates the DD community from other groups. Several staff stressed the value of cooperating with other constituencies.

6. Fifteen staff indicated they thought legislative interest in disability issues was either constant, the same or static. When asked this question, staff indicated they thought DD services did better than other groups on a consistent basis. Staff also talked about the need for fresh approaches. Most agreed that The Assembly had done a good job of maintaining the visibility of the needs of the DD community.

Two staff thought interest in disability issues was declining in relation to other social service needs (children, homeless) or that we were too well organized.

Four staff thought interest was rising or remained high. Some frustration was expressed by several staff who felt unnecessarily bombarded by phone calls when they understood the issue. Some felt this actually had a negative impact, particularly the phone calling by institutional parents (See Questionnaire, Section 3.6).

FUTURE FOLLOW UP

FINDINGS

1. Ten staff indicated they had visited many (8), some (2), few (1), none recently (2) or no programs (9) serving persons with disabilities. Of those visiting programs, the majority had visited one or more state institutions.

2. The majority of persons interviewed indicated a willingness and even desire to visit programs serving persons with disabilities (20). Only six said no.

3. Only seven (7) staff indicated they had visited families who had sons or daughters with a disability. Of the eighteen (18) who had not visited with families, ten (10) said they were willing to while eight (8) were not sure or said no.

4. Several staff indicated they were glad they had participated in the interview in that they had learned allot. Several indicated their interest had been peaked and would follow up on some of the things discussed during the interview process.

RECOMMENDATIONS

SOURCES OF INFORMATION

1. The DDPC should coordinate efforts with The Assembly, the Governors Committee on Disabilities and Employment Issues and other groups to insure that legislative staff are kept informed on issues effecting the different constituencies within the developmental disabilities community. An orientation package should be prepared for new legislative staff.

2. The DDPC, in cooperation with DDD should conduct an annual briefing for legislative staff on critical issues facing the developmental disabilities community. Consideration should also be given to doing the same with legislators.

3. The DDPC should include legislative staff on its mailing list being sure that legislative staff receive copies of DDPC reports and reports from DDPC funded projects.

4. The DDPC should prepare a list of projects it funds which produce reports. These reports should be forwarded to appropriate legislative staff.

5. The DDPC should inform legislative staff of its capabilities in producing and sharing information, positioning itself in the role of dispenser of critical intormation. This includes information on how other states are addressing problems similar to those in Washington.

6. The DDPC should consider preparing an annual report or issues paper which focuses on a particular subject of interest to the legislature similar to that done by the Minnesota Developmental Disabilities Planning Council.

7. There should be improved coordination between the DDPC and other advocacy groups to insure that legislative staff are receiving information that will assist legislative staff and legislators in understanding issues of consequence to the developmental disabilities community.

PROGRAM INFORMATION - SPECIAL EDUCATION

1. The DDPC should work with the Office of Superintendent of Public Instruction in presenting information to legislative staff of the House and Senate Education Committees information on effective programs serving students with developmental disabilities in the least restrictive environment.

2. The DDPC should work with the Office of Superintendent of Public Instruction and other advocacy groups in providing information to legislative staff and legislators on the efficacy and effectiveness and legal rights of severely handicapped students to broaden the base of support for these programs.

3. Legislative staff working on issues effecting persons with disabilities need a general orientation to how special education programs are preparing students to enter the adult world.

PROGRAM INFORMATION - DEVELOPMENTAL DISABILITIES PROGRAMS

1. The DDPC should provide information to legislative staff on innovative programs and alternatives in addressing the long term care needs of persons with developmental disabilities.

2. The DDPC should prepare position papers on alternative ways to meet the needs of persons with developmental disabilities with the assumption that increases in state dollars will be limited and possibly non-existent.

3. The DDPC should initiate efforts to brief the Executive Branch of Government on critical needs facing the developmental disabilities community and advocate for the Governor's office taking a more visible leadership role in addressing these problems.

4. The DDPC should initiate efforts to examine alternatives to current state service strategies that could lead to more effective support systems that are cost effective.

PUBLIC POLICY ISSUES

1. The DDPC should take an active role in presenting federal initiatves to legislative staff, such as Medicaid reform.

2. The DDPC state plan, and other documents, should focus on real needs, costs, and ideal services in order to help set a direction in thinking about meeting the needs of the developmental disabilities population.

3. The DDPC and other advocacy groups need to find ways to tie their issues to more generic themes in order to broaden its support base (e.g. long term care, foster care, prevention).

4. The DDPC and The Assembly need to take steps to assist legislators in developing a greater understanding and appreciation of persons with developmental disabilities through direct contact and interaction with these individuals and their families. Such interaction with people and observation of programs need to occur on a regular basis since there is close to a 20 % turnover in legislators every two years.

5. The developmental disabilities interest groups need to continue working towards building a consensus and presenting as united a front as possible when addressing legislative issues. The DDPC should explore how it can assist in this area.

Disabilities Research and Information Coalition
Washington Assembly for Citizens with Disabilities

Leadership Grant Legislative Questionnaire

Person Being Interviewed: ____
Position: ________________________________ Work Phone: __________

This study is being conducted by The Assembly and D-RIC under a grant sponsored by the Washington State DDPC. Its purpose is to obtain your assessment of the major issues facing persons with developmental disabilities, how well these issues and related information has been presented to you, and what is needed to make progress in resolving some of these issues.

In Washington a "developmental disability" means a disability attributable to mental retardation, cerebal palsy, epilepsy, autism, or another neurological or other condition of an individual found by the secretary to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, which disability originates before the individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to the individual.

The Developmental Disabilities Act (PL 98-527) defines a developmental disability as a severe, chronic disability of a person which is attributable to a mental or physical impairment or combination of mental and physical impairments, is manifested before the person attains age twenty-two, is likely to continue indefinitely, results in substantial functional limitations in three or more of the following areas of major life activity: self care, receptive and expressive language, mobility, self-direction, capacity for independent living, and economic self-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.

In our state persons with Developmental Disabilities, if identified as infants can be served in early intervention programs until the age of three through county funded programs. During the school years (ages 3-21), these individuals are in public schools. The Division of Developmental Disabilities provides major support to many families in the form of respite and therapy services. Upon graduation from public school, these individuals would be eventually supported in work or day programs. Eventually these individuals will need a residential service. Of DDD's 13,000 clients, 1,900 reside in RHCs which includes only 180 individuals under age 21. Case management services are operated through DDD regional offices. Of course, other services are used in DSHS and individuals contribute their SSI payments to the cost of services.

I would like to ask you a few specific questions as well as some general ones in order to get your assessment of where we are today and what we can expect in the future regarding services and support to persons with disabilities in Washington State.

PART ONE: SOURCES OF INFORMATION

1.1 What are your primary sources of information on disability issues? How much (rough % basis) do you get from each source?

1.11 DSHS or SPI:			Percentages Assigned by Respondents						
1	Reports	Yes (5)	50(2)	35(1)	30(4)	20(4)	15(2)	10(3)	5(2)
5	Testimony	Yes (4)	30(1)	20(2)	15(1)	10(3)	5(5)		
4	Briefings	Yes (4)	30(1)	20(5)	15(2)	10(1)	5(1)		
6	Letters	Yes (4)	40(1)	30(1)	20(1)	15(1)	10(1)	5(2)	
7	Tours of Services	Yes (4)	30(1)	20(1)	10(2)	5(1)			
2	Informal Talks	Yes (6)	75(2)	50(2)	40(2)	30(3)	25(2)	20(2)	10(1)
3	Legislative Staff	Yes (5)	40(1)	30(1)	25(2)	20(3)	10(2)		
8	DDD Staff		60(1)	50(1)					

1.12 Committee Staff	Comments
	Yes (7) Some (5) Try to involve them in everything we do. I work with everybody. Staff director (from other policy committee alerts me to policy issues). Easier to do team approach with DD issues.

1.13 Caucus Staff	Comments
	Not used by any committee staff.

1.14 Legislators	Comments
	Not primary source of information to staff.

1.15 Professional Groups:	Percentages Assigned by Respondents			
Reports	50(1)	15(1)	10(2)	
Testimony	50(2)	15(1)	10(1)	5(1)
Meetings	50(1)	30(1)	15(1)	5(1)
Tours of Services	20(1)	15(1)		
Informal Discussions	50(1)	35(1)	25(1)	

1.16 Lobbyist(s) or Other Citizens:

Washington Assembly for Citizens with Disabilities:
- 11 - Cecile Lindquist (Legislative Chair)
- 13 - Jeff Larsen (Lobbyist)
- 14 - Steve Schain (Director)

DDPC:
- 5 - Sharon Hansen (Director)
- 1 - Bruce Treichler & Ed Holen

Rehabilitative Enterprises of Washington:
- 4 - Michael Doctor (Lobbyist)

Governors Committee on Disability and Employment Issues:
- 2 - Toby Olson (Executive Secretary)

Institution Parents:
- 2 - Jackie McRae (Friends of State Schools)
- 1 - Tom Dean (Friends of Rainier)
- 2 - Delores Hayes (Friends of Rainier)
- 1 - Chris Mangini (Frances Haddon Morgan Center)
- 1 - Rhodella Haugen (Interlake)
- 1 - Unnammed

Social Welfare:
- 4 - Phil Kaplan (Poverty Advocates)
- 4 - Tony Lee (Peace and Justice Center)
- 4 - Margaret Casey (Catholic Community Conference)
- 1 - Ed Whedbee (Evergreen Legal Services)

County Human Service Boards:
- 4 - King County (Carol Greenough & Ralph Larsen)
- 1 - County Coordinators

Other Social Service Representatives:
- 1 - Frank Winslow (Alzheimers Society)
- 1 - Shirley Nodell (Washington State Head Injury Foundation)
- 1 - Mary Margaret Cornish (Community Residential Services Coalition)
- 2 - Pat Thiebido (Community Mental Health Centers)

DSHS:
- 4 - Sue Elliot (Division of Developmental Disabilities)
- 1 - Aaron Lowin (Division of Developmental Disabilities)
- 1 - Sharon Stewart Johnson (Division of Vocational Rehabilitation)
- 1 - Thelma Struck (DSHS Assistant Secretary)

Special Education:
- 4 - Judy Schrag (Assistant Superintendent - SPI)
- 1 - Judy Hartman (Legislative Affairs - SPI)
- 2 - Bruce Mrkvicka (SPI Budget Office)
- 1 - Joan Gaetz (SPI)
- 2 - John Pearson (Special Education Director - Tacoma)
- 1 - Kateri Brow (Issaquah School District)
- 2 - Steve Fink (Edmonds School District)

1.2 What materials do you routinely review:

Ranking	Number	Source
1	23	The Assembly Legislative Bulletin
2	15	Legislative Budget Committee Reports
3	14	DSHS Reports
3	14	DRIC Habilitation News
4	11	DRIC Issue Analysis
5	5	GCDE Leg Connections
5	5	SPI Bulletins & Reports
6	3	Protection & Advocacy Reports
7	2	Washington Health
7	2	Fair Budget Action Coalition
8	1	DDPC
8	1	Networking
8	1	Washington Fair Share
8	1	Aging

1.3 Which groups do you look to for reliable information:

Ranking	Number	Source
1	22	The Assembly
2	19	DSHS
3	17	DDPC
4	8	SPI Staff
5	7	County Coordinators
5	7	DRIC
6	6	GCDE
6	6	ARC-WA
7	4	Special Education Coalition
7	4	Unions
8	3	Residential Service Groups
8	3	RHC Parent Groups
9	2	United Cerebal Palsy
10	2	Rehabilitation Enterprises of WA
10	1	Other - Legislative Budget Committee - Fair Budget Action Coalition - WA Coalition of Citizens with Disabilities - Human Relations Commission - Independent Living Centers

1.4 What groups have you heard from:

- ALL (1)
- Alzheimers Society (1)
- WA Assembly for Citizens with Disabilities (14)
- Association for Retarded Citizens of Washington (2)
- Developmental Disabilities Planning Council (5)
- Disability Research & Information Coalition (1)
- Governors Committee on Disability & Employment Issues (1)
- Head Injury Foundation (1)
- IMR Facilities (2)
- King County Board 2
- Poverty Law Advocates (1)
- Rehabilitation Enterprises of Washington (02
- RHC Parents 2
- Special Education Coalition (2)
- Special Education Directors (1)
- United Cerebal Palsy (3)
- WA Coalition of Citizens with Disabilities (1)

1.5 Individuals Most Helpful To You in Obtaining Information on DD Issues:

Organization	Individuals
Assembly	Cecile Lindquist (5)
	Jeff Larsen (9)
	Steve Schain (12)
Physical Disabilities	Sue Ammeter (1)
	Barbara Allan (1)
	Carolyn Brown (1)
DD Service Providers	Michael Doctor (3)
DSHS & DDD Staff	Sue Elliot (12)
	Aaron Lowin (1)
	Corki Hirsch (2)
	Bev Wilson (1)
	Linda Rolfe (2)
	Noel Hagens (1)
	Thelma Struck (1)
	Dick Dorsett (1)
County Coordinators	General (1)
	Carol Greenough (1)
	Ralph Larsen (1)
DDPC	Sharon Hansen (4)
	Bruce Treichler
SPI Staff & Others	Judy Schrag (3)
	Bruce Mrkvicka (3)
	Staff (2)
	Judy Hartman (1)
	John Pearson (1)

PART TWO

A. SPECIAL EDUCATION

2.1A <u>What is your general opinion about the Special Education programs serving persons with developmental disabilities:</u>

1. Opportunities for access and participation protected.
2. School districts provide excellent special education & institutional education programs.
3. More accepted than in earlier years.
4. With local control, don't know if overall good job being done.
5. Overall, doing pretty good job.

2.2A <u>What are your greatest concerns about these programs:</u>

1. Allocation formula for education makes it hard for legislature to affect local programs.
2. Coordination of institutional education programs with DSHS services.
3. Overidentification of minority students for special education.
4. Costs of paperwork and administration.
5. Backlash - too much money on one kid who may not be productive.
6. Pull-out versus merging - don't know what's best for child and not sure anyone knows yet.
7. Influence of local levy on program quality.
8. Insuring services providing as program blending increases and categorical programs less clearly identifiable.

2.3A <u>Are Special Education programs are successful and worth supporting:</u>

1. State's paramount duty to provide for education of all children, including children with handicapping conditions continues to be defined and refined.
2. Yes (2).

2.4A <u>Which Special Education programs are you most satisfied with:</u>

1. Transition programs to assist 17-21 year old DD students.
2. Don't have enough contact to distinguish.
3. Fact that we special education is out of the closet.
4. Special education has taught important stuff to non-handicapped kids.

2.5A <u>Which Special Education programs do you have greatest concerns about:</u>

1. Transportation and related services.
2. Special education overrated. Too many students classified LD & ED. Learning specialists not the answer and technology not the issue. Missed boat in connecting mental health and special education for these two groups.
3. Mainstreaming - not sure how helpful it is to keep kids in public school. Lack objective outcomes. Need compromise between good intent and outcomes.
4. Stigma of pull-out program model.

5. Possible and real backlash to programs costs for severely multiply handicapped kids. We are not selling these programs well. 6. ED/BD programs have horrible reputations with legislators ("junk programs").
7. Real "fear" of DD Advocacy Groups.
8. Need to change how school psychologists are funded - need core program funding rather than paying based on number of assessments performed.

2.6A <u>What is your opinion about special education programs:</u>

1. Don't know anything about them.
2. Heard some horror stories about some local districts.
3. If parent not assertive schools get away with not doing stuff.
4. Don't know...yet.
5. Uniformed or don't know (14).
6. No opinion.
7. Not enough effort & emphasis by SPI to integrate persons of disability.
8. Making efforts for individualized plans, services and supports, and keeping more kids in local district.
9. Doing a pretty good job in this state.
10. State provides adequate resources - quality dependent on district utilization and distribution of resources.
13. Ideology beyond what's reasonable or realistic - need to restructure. some kids just getting babysitting - money may not be issue.
14. Not as well managed as DD programs. Special Education programs don't receive same scrutiny as executive agency (state) programs. Lacking in centralized accountability. Not as cost effective as state programs.
15. Don't have any information. (15)