# BOUT THE PARTNERS IN POLICYMAKING TRAINING PROGRAM

#### Governor's Planning Council on Developmental Disabilities

Minnesota State Planning Agency

300 Centennial Building 658 Cedar Street St. Paul, Minnesota 55155



We need to identify and empower the next generation of leadership.

Washington crossing the street

Partners in Policymaking is an innovative national model of leadership training for people with developmental and other disabilities,\* parents and family members. Partners in Policymaking is designed to provide state-of-the-art knowledge about issues related to disability and to develop participant competencies to become effective advocates in influencing public policy at all levels of government.

The program was developed in 1987 under the leadership of Colleen Wieck, Ph.D, Director, of the Minnesota Governor's Planning Council on Developmental Disabilities, and Ed Skarnulis, Ph.D, of the Minnesota Department of Human Services. Its original focus was to assist people with disabilities and families to get the

#### INTRODUCTION

<sup>\*</sup> See the definition of developmental disability on page 121.

best possible services and support. Partners in Policymaking has trained over 100 parents and people with disabilities in Minnesota with impressive results.

Partners in Policymaking became a part of The World Institute on Disability (WID) in 1989. WID has adopted the program in recognition of its potential as a national model for leadership training for people with disabilities of all ages. WID is managing the fourth year of Partners in Policymaking in Minnesota. With a grant from the Department of Health and Human Services, Administration on Developmental Disabilities, WID and the Minnesota Governor's Planning Council on Developmental Disabilities are conducting this national academy to train representatives of twelve Developmental Disabilities Planning Councils from all over the country to enable replication.

WID is a private, non-profit center for the study of public policy and disability issues. It is closely tied to the Independent Living Movement of people with disabilities and was established by leaders of the Movement. WID functions as a policy center and conducts research, analysis, and public education on issues of importance to people with disabilities. One of its major priorities is to support the efforts of unserved and underserved individuals with disabilities to improve the quality of their own lives.

Most people with disabilities grow up in a society that considers them powerless. These negative attitudes of others are frequently internalized, and people with disabilities are left doubting their ability to ever lead their own lives. Therefore the necessity for empowerment and self-determination exists if people with disabilities are to gain control over their own lives and fully participate in society. Leadership development and personal empowerment are at the core of all social movements. By preparing people with disabilities and their families to take the first step into self-advocacy, many will continue on to become group leaders, systems-change advocates, and eventually leaders of social change.

Over one hundred people have been trained in the Partners program and the results have dramatically increased individual empowerment, participation in state and regional policy commissions, interaction with public officials, and an increased role in the development of public policy.

The World Institute on Disability has collaborated with Minnesota Governor's Planning Council on this training manual. We hope it provides you with the necessary tools to replicate Partners in Policymaking in your home state.



Educating people to communicate with public officials using factual information and knowledge is the goal. Using deception and misleading information creates alienation.

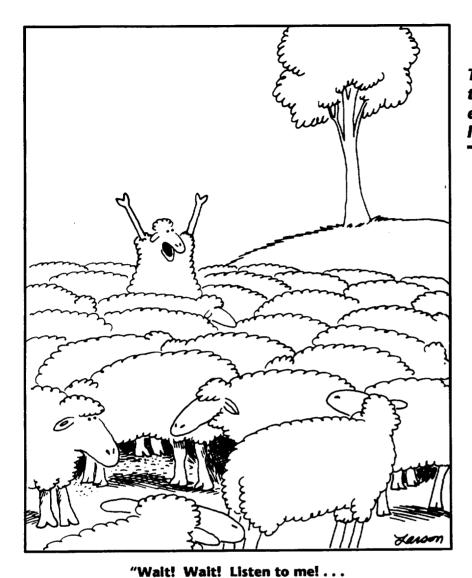
"And I like honesty in a relationship . . . I'm not into playing games."

Partners in Policymaking provides information, training, and skill building to individuals so that they may obtain state-of-the-art services for themselves and others. The program consists of 128 hours of instruction time delivered during eight weekends during a one year period. Each session begins on Friday shortly after noon and concludes Saturday late afternoon. During each of the Sessions, experts in specific areas present and interact with the participants in small groups or one on one.

Partners in Policymaking involves and empowers people with developmental disabilities and their families in the policymaking arena. It acquaints and connects people with organizations, opportunities, and possibilities in the area of developmental disabilities. It educates the participants about current issues. It familiarizes participants with the policymaking processes in local

#### **PROGRAM DESCRIPTION**

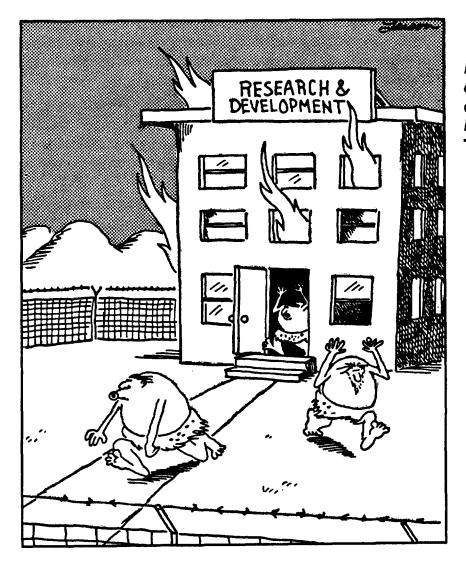
communities, at the state level and nationally. The overall intent is to achieve a productive partnership between people traditionally unserved and underserved needing and using services, and those in a position to make policy. The national replication of Partners presents each state with the challenge of establishing program goals which are applicable to the needs of your state while continuing to maintain the integrity of the Partners program. The exchange of information among participating states will no doubt enhance the quality and effectiveness of the replication process.



We don't HAVE to be just sheep!"

An equal number of adults with developmental disabilities (defined in PL. 100-146) and parents of young children with developmental disabilities are selected for the training. The total number of participants equals thirty with priority given to applicants not currently involved in advocacy organizations. Every effort is made to include a male/female balance, ethnic and racial minorities, low income families/individuals, single parent families, balanced representation from rural, urban and suburban communities, and a balanced representation of disabilities. Target Audience

The individuals selected to participate should exhibit desired leadership potentials.



It is important to have a creative and timely approach to critical issues in your states.

Fire is invented.

Historically, people with severe disabilities and their families have been socially and politically disenfranchised from society. The social welfare model delivered services but did not empower. The disability rights movement of the seventies and eighties has given voice to the issues still facing people with disabilities and their families.

 People with severe disabilities have traditionally been unserved and underserved. This has resulted in heavily segregated social, educational, habilitation, community support, medical and transportation services. Because of this isolation, people with severe disabilities have had limited opportunity to influence public policy. Over the past several years, many states have experienced an influx of ethnic populations. This has exposed a

#### **P**ROBLEM **S**TATEMENT

whole new unserved and underserved population of people with disabilities, compounded by cultural and language barriers. Members of these communities often rely on limited resources which are unable to reach the depth of the needs.

- People with severe disabilities who are also typically unserved and underserved, are attempting to establish homes in traditional community settings, significantly reducing the dependence on institutional housing, while increasing the need to improve the self-advocacy and empowerment skills.
- Parents of younger children are now guaranteed services for their children from birth to age 21 years. These individuals do not have to fight for accessing services like the parents during the 1950s, 1960s, and 1970s. The new fight is for quality and integration.
- The structure of the family is changing. There are more single heads of households. There is an increase in the number of single parents. There are more two-earner couples; and volunteer activity is declining.
- People with severe disabilities are expressing increased desire for full participation in employment and education opportunities.
- Self advocacy for individuals traditionally unserved or underserved has not been adequately supported.
- Education and training programs have not been developed to meet the needs of individuals with developmental disabilities who are unserved and underserved.
- Collaboration on public policy issues among various disabilityrelated consumer organizations have not been adequately developed, utilized, or encouraged.



Successful inclusion for people with disabilities and their families requires the combined efforts of <u>all</u> persons in the community.

"Barbara! I'm goin' for help - tread soup!"

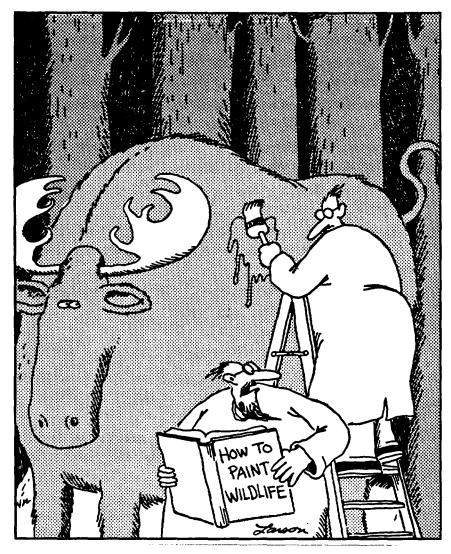
People with disabilities and their families need to be prepared to take the step into self advocacy. Once that is accomplished, they may choose to continue on to becoming group leaders, systems change advocates, and eventually agents for social change.

- There are few leadership development programs that prepare people who are unserved and underserved for positions of leadership in local, state, and national organizations. There is a need for new leadership to assume positions in these organizations.
- Grassroots advocacy leadership exists but needs systematic training in competencies of influencing public officials. There is a need to have an inclusion of people who are unserved or underserved in the grassroots advocacy movement in each

Impact of the Problem — The Need for Leadership community who can write, call, or meet with public officials when necessary or when requested through action alerts.

- The self advocacy movement does not have a shared vision. Individuals need an opportunity to share and develop a collective vision about the year 2000.
- There is no current mechanism for state and national leaders in the disabilities field to meet and discuss issues with people with disabilities who are traditional regarded as unserved or underserved.
- There is no centralized speakers' bureau which represents people regarded as unserved or underserved. There is a continued need to have spokespersons available who can speak on a wide range of issues at local meetings, university classes, conferences, public hearings, state events and national conventions.

# These problems are really opportunities for a creative program like Partners in Policymaking!



Each session is designed using a specific set of participant competencies.

"Hold on there, Dale. It says we should sand between coats."

Partners in Policymaking introduces participants to experts in the field of disability and local and state policymakers who provide them with state-of-the-art information on current issues. The following competencies are developed through the learning of this information and the practical experience which is a part of each session.

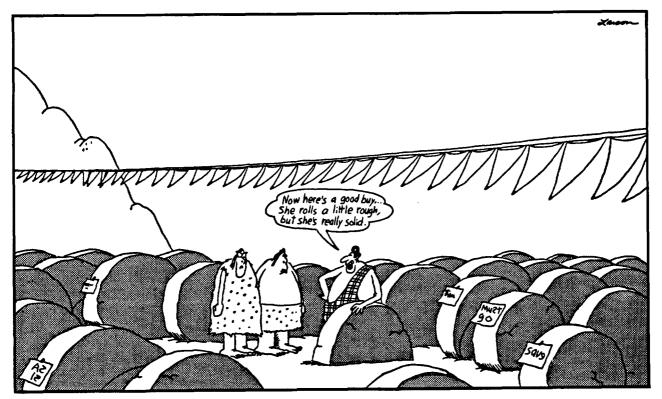
- Participants will be able to describe the history of the self advocacy and independent living movements.
- Participants will be able to describe the significant contributions of such organizations as the Association for Retarded Citizens, President's Committee on Mental Retardation, and The Association for Persons with Severe Handicaps.

#### COMPETENCIES

- Participants will be able to describe the history of services and perceptions of people with developmental disabilities.
- Participants will be able to describe the reasons for integrated education for people with developmental disabilities.
- Participants will be able to outline specific strategies to achieve integration and quality education and employment.
- Participants will be able to describe the importance of whole life planning for people with developmental disabilities.
- Participants will be able to describe state-of-the-art technologies for people with severe physical disabilities.
- Participants will be able to identify and describe their county CSSA plan, and the strategies utilized in the county planning process.
- Participants will be able to demonstrate their knowledge of the case management system and what services they, as self-advocates, will be able to utilize.
- Participants will be able to describe a vision for the year 2000.
- Participants will be able to identify types of supports necessary for creating a positive home environment for persons with developmental disabilities.
- Participants will be able to describe the importance of supported, competitive employment opportunities for people with developmental disabilities.
- Participants will be able to identify critical federal issues and the process by which they could personally address their concerns.
- Participants will be able to demonstrate appropriate skills and procedures for providing testimony to policymaking committees at the local, state, and national levels.
- Participants will be able to demonstrate how to draft testimony for legislative hearings.
- Participants will be able to describe the role of numerous statewide advocacy and service organizations related to issues of unserved and underserved people with developmental disabilities.
- Participants will be able to identify proper procedures of how to run a meeting according to Robert's Rules of Order.
- Participants will be able to demonstrate successful techniques of advocating for services to meet the needs of unserved and underserved individuals.

During the first three years, participants in the Partners Training served in various internships with public officials. Some participants met with officials in their homes, others shadowed an official for one day, while others spent longer periods of time with legislators. In the fourth year, an internship program has been established for at least 15 participants. These internships focus on developing relationships between individuals typically unserved and underserved, and officials in positions to affect public policy. The Governor, Lieutenant Governor and other key officials are invited to participate. The outcome is a greater understanding of the political and governing process for the participant. It also provides public officials with a greater connection to and appreciation of the genuine needs of citizens with disabilities.

Intensive and complete advocacy training is a big commitment and we need to avoid temporary solutions and quick fixes.



Early wheeler-dealers



Extensive mailings, word-of-mouth advertising, and face-to-face interviews are great recruitment tools.

"Listen — just take one of our brochures and see what we're about . . . In the meantime, you may wish to ask yourself, 'Am I a happy cow?'"

Individuals traditionally unserved or underserved should be targeted for recruitment by direct mailings, contacts with organizations serving people with disabilities and their families, and referrals from case management agencies. A variety of methods should be used to improve outreach to a broad spectrum of adults with disabilities (both cognitive and physical) to ethnic and racial minorities, low income families/individuals, and single parent families.

Contacts with advocacy, service, employment, and educational organizations which represent people with disabilities should be established via personal contact, phone calls and mailings. Every effort should be made to identify and provide the necessary support services (personal assistance, transportation, sign language inter-

#### RECRUITMENT

preters and translation of materials) needed by an individual to facilitate that individual's full participation in the sessions.

Contacts with advocacy organizations which represent various ethnic communities should be established via the same methods. These contacts should be for information sharing and to seek assistance in translating application materials. If translation assistance is not available, the language departments of local universities should be approached for assistance with translating application materials. Racial minorities should receive information via the identified neighborhood and local organizations.

Low income families should be reached by sharing information and application packages with the local and state social service agencies. Additionally, information should be shared with identified grassroots citizen advocacy organizations.



The following proposal was used to seek funds for the Minnesota Partners in Policymaking Project in Fiscal Year 1990. It is included here as a resource for you to use in developing a proposal for a similar project in your own state.

The materials include:

- Abstract
- Narrative
- Work Plan
- Assurances
- Application Packet
- Participant Contract
- Tables
- Examples of Letters of Support

# Application for Replication for PARTNERS IN POLICYMAKING

(October 1, 1989 — September 30, 1990)

Submitted to: Minnesota Governor's Planning Council on Developmental Disabilities

Prepared By: The World Institute on Disability Berkeley, California and Minneapolis, Minnesota

April 1989

#### Abstract

Partners in Policymaking is an innovative national model of leadership training for people with developmental disabilities who are unserved or underserved and self-advocates. Partners is designed to provide state-of-the-art knowledge about developmental disabilities issues and to provide competencies for becoming effective advocates through the influencing of public officials.

This application will replicate the current Partners program with slight content modifications. There will be special emphasis on people with developmental disabilities who are unserved and underserved. The topical schedule and competencies will remain the same. Ed Roberts, President of WID, has presented at six sessions of Partners, and he is very interested in widespread replication of this program.

The outcomes of the first and second years of Partners in Policymaking (May 1987 through March 1988 and May 1988 through February 1989) have been very dramatic:

- Individuals with disabilities are in integrated quality settings.
- Individuals with disabilities are receiving services they need such as family supports and case management.
- Graduates have succeeded in public education efforts including 50 news articles, 5 television and radio programs, 62 conference presentations, and 4 university presentations.
- Graduates have received 69 appointments to committees or commissions.
- Graduates have reached public officials through 500 letters, 100 visits, and 10 have testified at local, state, and federal hearings.
- Every effort will be made to ensure the integrity of the program to continue to build on these impressive results.

#### **Proposed Goal**

This proposal will respond to the Council's goal, "To increase accountability to individuals with developmental Disabilities of all ages by changing state policies to be more responsive to individuals who are unserved or underserved," and Council's objective number 2: "By September 1991, 60 young adults and adults with disabilities who represent the interests of unserved and underserved will have completed a one-year Partners in Policymaking program and 25 will have completed internship placements in government offices."

#### **Statement of Problem**

The 1987 Developmental Disabilities Act clearly directs DD Councils to address the issues and concerns of unserved and underserved populations. To empower individuals with disabilities and their families in seeking changes to public policy is a goal shared by the Developmental Disabilities Act, the Minnesota Governor's Planning Council on Developmental Disabilities, the Partners in Policymaking Program, and the applicant agency. These facts are known:

- People with severe disabilities have traditionally been unserved and underserved. This has resulted in heavily segregated social, educational, habilitation, community support, medical and transportation services. Because of this isolation, people with severe disabilities have had limited opportunity to influence public policy.
- Over the past several years, Minnesota has experienced an influx of ethnic populations. This has exposed a whole new unserved and underserved population of people with disabilities, compounded by cultural and language barriers. These language and cultural barriers result in "closed communities" whose members rely not on established service systems but the limited resources within their cultural communities. Often these resources are not able to reach the depth of the needs.
- People with severe disabilities who are also typically unserved and underserved, are attempting to establish homes in traditional community settings, significantly reducing the dependence on institutional housing, while increasing the need to improve self-advocacy and empowerment skills.
- Parents of younger children are now guaranteed services for their children from birth to age 21 years. These individuals do not have to fight for accessing services like the parents during the 1950s, 1960s, and 1970s. The new fight is for quality and integration
- The structure of the family is changing. There are more single heads of households. There is an increase in the number of single parents. There are more two-earner couples; and volunteer activity is declining.
- People with more severe disabilities are expressing increased desire for full participation in employment and education opportunities.
- Self-advocacy for individuals traditionally unserved and underserved has not been adequately supported in our state.

- Education and training programs have not been developed to meet the needs of individuals with developmental disabilities who are unserved and underserved and self-advocates.
- Collaboration on public policy issues among various disability related, consumer organizations have not been adequately developed, utilized, or encouraged.

These problems are really opportunities for a creative program like Partners in Policymaking.

#### Impact of the Problem

The impact of the leadership problems can be described in several ways:

- There are few leadership development programs that prepare people who are unserved and underserved for positions of leadership in local/state/national organizations. There is a need for new leadership to assume positions in these organizations.
- Grassroot advocacy leadership exists but needs systemic training in competencies of influencing public officials. There is a need to have an inclusion of people who are unserved or underserved in the grassroots advocacy movement in each community who can write, call, or meet with public officials when necessary or when requested through action alerts.
- The self-advocacy movement does not have a shared vision. Individuals need an opportunity to share and develop a collective vision. There is a need for motivated, well informed, active energetic volunteers who share a vision about the year 2000.
- There is no current mechanism for state and national leaders in the disabilities field to meet and discuss issues with people with disabilities traditionally regarded as unserved and underserved.
- There is no centralized speakers' bureau organized in Minnesota which represents people regarded as unserved and underserved. There is a continued need to have spokespersons available throughout the state who can speak on a wide range of issues at local meetings, university classes, conferences, state events, and national conventions.

The impact of the service problems can also be illustrated:

- Too often employment opportunities for unserved and underserved people with severe disabilities continues to be offered in isolated, self-contained settings or in segregated enclaves in community settings.
- Residential services for individuals with disabilities is often provided in traditional institutional settings, nursing home style environments, or community groups that do not promote individual lifestyle.
- Transportation in the metro areas continues to offer limited use and accessibility, often requiring individuals to make appointments far in advance for even the most routine activity. Spontaneous recreational travel using public transportation is unheard of, as is the availability of accessible public transportation in most of rural Minnesota.
- Lack of accessibility to many buildings (public and private), cultural events, shopping, recreation, and other facilities due to structural barriers causes exclusion for people with disabilities.

- There is a growing move for integration in public schools in Minnesota. Minnesota's schools are decreasing the levels of segregation of unserved or underserved people with developmental disabilities but not as rapidly as they could if more intensified attention was given to the issue. There is beginning interest for age-appropriate, community referenced, functional curricula in integrated settings. There is a need for additional supports for unserved or underserved parents and self-advocates to move from mediocrity to excellence in education.
- In order to advocate changes to match A New Way of Thinking, a new group of leaders is needed who:
  - share this vision;
  - are motivated;
  - are informed;
  - are skilled;
  - --- will speak up.

Partners in Policymaking is a proven solution for leadership building and service system problems resolution.

#### **Proposed Solutions**

Partners in Policymaking is a program designed to provide information, training, and skill building to individuals so that they may obtain the most appropriate state-of-the-art services for themselves and others. This education and training program is designed for a limited number of highly motivated, interested people.

Partners in Policymaking involves and empowers people with developmental disabilities and their families in the policymaking arena. It acquaints and connects people with organizations, opportunities, and possibilities in the area of developmental disabilities. It educates the participants about current issues and state-of-the-art approaches. It familiarizes participants with the policymaking and legislative processes in local communities, at the state level and nationally. The overall goal is to achieve a productive partnership between people traditionally unserved and underserved needing and using services and those in a position to make policy and law.

Each session is devoted to a specific service topic or level of government. Participants are expected to complete assignments between sessions. Participants will also be expected to complete a major assignment such as serving an internship.

The program is designed to give participants exposure to, and contact with, nationally known experts in the field of developmental disabilities. Participants attend two-day sessions, approximately eight times a year. During each of the sessions, experts in specific areas present and interact with the participants. Each session begins on Friday shortly after 12:00 noon and concludes Saturday late afternoon. This allows time for the participants to converse with the experts in small groups or on a one-to-one basis.

The proposed schedule for replicating Partners in Policymaking is illustrated in Table 1 (see Appendix). As a matter of reference, the three schedules discussed in Tables 2, 3, and 4 (see Appendix) were used in Years One through Three.

As a result of the first year's experience, a list of competencies was prepared for Years Two and Three. The following competencies will be used to achieve successful outcomes for replication of Partners in Policymaking in 1989-1990. Modifications have been made to respond to the needs of people with developmental disabilities traditionally regarded as unserved and underserved:

- Participants will be able to describe the history of the self-advocacy and independent living movements.
- Participants will be able to describe the significant contributions of such organizations as the Association for Retarded Citizens, President's Committee on Mental Retardation, and The Association for Persons with Severe Handicaps.
- Participants will be able to describe the history of services and perceptions of people with developmental disabilities.
- Participants will be able to describe the reasons for integrated education for people with developmental disabilities.
- Participants will be able to outline specific strategies to achieve integration and quality education and employment.
- Participants will be able to describe the importance of whole life planning for people with developmental disabilities traditionally unserved or underserved.
- Participants will be able to to describe state-of-the-art technologies for people with severe physical disabilities.
- Participants will be able to identify and describe their county CSSA plan, and the strategies utilized in the county planning process.
- Participants will be able to demonstrate their knowledge of the case management system and what services they, as self-advocates, will be able to utilize.
- Participants will be able to describe a vision for the year 2000.
- Participants will be able to identify types of supports necessary for creating a positive home environment for people with developmental disabilities.
- Participants will be able to describe the importance of supported, competitive employment opportunities for people with developmental disabilities.
- Participants will be able to describe critical federal issues and the process by which they could personally address their concerns.
- Participants will be able to describe critical state issues and the process by which they could personally address their concerns.
- Participants will be able to demonstrate appropriate skills and procedures for providing testimony to policymaking committees at the local, state, and national levels.
- Participants will be able to demonstrate how to draft testimony for legislative hearings.
- Participants will be able to describe the role and responsibility of numerous statewide advocacy and service organizations related to issues of unserved and underserved people with developmental disabilities.

- Participants will be able to identify proper procedures of how to run a meeting according to Robert's Rules of Order.
- Participants will be able to demonstrate successful techniques of advocating for services to meet the needs of unserved and underserved individuals.

In addition to this list of competencies, an internship program will be established for at least 15 participants. These internships will focus on developing relationships between individuals typically unserved and underserved, and officials in positions to affect public policy. The Governor, Lieutenant Governor, Legislators, appointed Commissioners, and other key officials will be invited to participate. The outcome will be a greater understanding of the political and governing process for the participant. It will also provide public officials with a greater connection to and appreciation of the genuine needs of Minnesota citizens with disabilities who are unserved and underserved. The World Institute on Disability is committed to maintaining the integrity of the original concept of Partners in Policymaking.

#### **Description of Population**

The primary focus of this program will be to involve a maximum of 35 people with developmental disabilities traditionally regarded as unserved or underserved. Among people traditionally unserved or underserved special emphasis will be placed on selecting people who represent racial and ethnic minorities, low income households, single-parent households, and a wide range of developmental disabilities. This replication would again seek appropriate gender and metro versus nonmetro representations. In addition, counties that have concentrations of people with disabilities who are unserved and underserved and few resources will be targeted for more intensive recruitment.

#### Methodology

Partners in Policymaking will use the following methodology:

- A maximum of 35 participants will be recruited by direct mailings, contacts with organizations, through previous year's graduates, and other appropriate means. Participants will be selected using a screening process that will attempt to obtain a ratio of participants that includes minorities, low income persons, single parents, persons with a variety of disabilities, males as well as females, and approximately 50 percent of the group from nonmetro areas.
- A minimum of eight two-day sessions will be held at locations in the Twin Cities metro area.
- Nationally known experts will be recruited to make presentations.
- Participants will be asked to sign a "Contract" (see copy of Participant Contract in attachments) that will obligate them to attend all sessions, do "homework" assignments, and complete an internship.
- Participants will be reimbursed for travel, lodging, meals, respite care, and child care.
- Sessions will include role playing and other experiential techniques compatible with adult learning theory. Extensive outside readings will be provided to participants to supplement presentations and exercises.
- Homework assignments will include personal contacts with local, state, and national policymakers; outside readings; presentations; and, attending meetings.

The sessions will be delivered in the Twin Cities metro area. Participants will be selected from the entire state with particular attention to attaining a geographic balance. In Year One, 49 percent of the participants were from the Twin Cities metro area and 51 percent were from the nonmetro areas of the state. In Year Two, 56 percent of the participants were from the Twin Cities metro area and 44 percent were from nonmetro areas of the state. In Year Three, 54 percent of the participants are from the Twin Cities metro area and 46 percent are from the nonmetro area.

The World Institute on Disability will use a variety of audiovisual and printed materials through its replication of Partners in Policymaking. The World Institute on Disability will use the previous resource list as a guide for materials. In addition, new materials will be developed specifically for individuals with disabilities.

Presentations on Partners in Policymaking will be made at state and national conferences. Replication of this program will continue to be promoted and alternate funding to enable continuation will be explored. Information on this program has been sent to over 20 states already. New York, Illinois, and Texas are planning to replicate the program while Maryland and New Hampshire have already begun separate replications.

#### Recruitment

Individuals traditionally unserved and underserved will be specifically targeted for recruitment. A variety of methods will be used to improve outreach to ethnic and racial minorities, low income families/individuals, and single parent families:

- Contact with advocacy organizations which represent various ethnic communities will be established via personal contact, phone calls, and mailings. These contacts will be for information sharing and to seek assistance in translating application materials. If translation assistance is not available, the project will seek resources at the University of Minnesota language departments.
- Racial minorities will receive information via the various neighborhood organizations in the Twin Cities.
- Native American communities will be contacted using the resources available through the tribal councils, support organizations, and school systems.
- Low income families will be reached by sharing information and application packages with local and state welfare systems. Additionally, information will be shared with identified grassroots citizen advocacy organizations.
- Information will be shared with the numerous advocacy organizations which represent people with disabilities and their families.

#### **Evaluation Procedure**

After each session, participants will be asked to complete an evaluation for that session. This format will provide immediate information about the perceived applicability of the session. As an example, Table 5 (see Appendix) illustrates participants' perceived applicability of the 1988-1989 (Year Two) session.

Table 6 (see Appendix) illustrates an example of the evaluation form we propose to use for the replicated Partners sessions. Summative evaluation forms from both Years One and Two have been

tallied and summaried in Tables 7 and 8 (see Appendix). A final and important part of the evaluation process was the collection of anecdotes from the participants (Table 9 in the Appendix).

#### Summary

In summary, the World Institute on Disability proposes to replicate Partners in Policymaking with close attention to the specifications, details, and integrity of the original program. Since its inception in 1983, WID has focused its energies on supporting unserved and underserved individuals with disabilities in their efforts to improve their individual quality of life. WID has established itself with a worldwide reputation for promoting grassroots advocacy efforts to influence public policy on housing, employment, community accessibility, and transportation.

GRANT PROPOSAL WORK PLAN

Pre	pjected Completion Date:	Budg	get for Task: \$2, (To	500 \$2,500 tal) (Federal)	\$ (Local
Sui	btasks:	Projected Completion Date:	Quarterly Repo 1st	rt: _ 2nd 3rd _	4ti
A.	Prepare announcement and application.	10/01/89			
3.	Disseminate announcement and application to approximately 600 organizations and individuals; follow up with personal contacts or by phone.	10/15/89			
С.	Revise existing criteria that will be used to select participants. Recruit a review panel of people with disabilities and family members.	11/15/89			
).	Receive and review applications for competencies. Convene review panel and apply selection criteria. Select approximately 35 participants.	12/15/89			
Ξ.	Notify all applicants regarding the results of the selection panel.	01/01/90			

Task: II. Develop and deliver a minimum of 8 two-day sessions on the following subjects: 1) History and Philosophy of the Advocacy and Independent Living Movement; 2) Best Practices in Education; 3) Nonaversive Behavior Approaches, Physical Disabilities, and Technologies; 4) Policymaking at the Local and County Levels; 5) Policymaking at the Federal Level and Best Practices in Employment; 6) Funding, Rules, Laws, and Policymaking at the State Level; 7) Organizations, Programs, and Opportunities; and 8) Advocacy

A. Select speakers, negotiate fee, contract regarding readings and presentations. The compl	etion Date: etion for these related to the sessions.	Quarterly 1st	-	_ 3rd	4th
B. Select locations for session, review facilities, determine audiovisual equipment. subtasks is date of the	related to the sessions.				
<ul> <li>C. Prepare agenda for each session, meet with speakers, presenters, and others as necessary.</li> <li>D. Review competencies for the session.</li> <li>E. Prepare homework assignments, accept and review assignments.</li> <li>F. Attend sessions, participate as speaker, moderator. Audio and videotape sessions for resource library and dissemination.</li> <li>G. Review and tabulate evaluation results.</li> </ul>	eks prior to Subtasks C and D 4 weeks prior to Subtask F to be ates of session; to be done 2 ar the session; to be ongoing;				

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Form IV — Budget Summary

(Instructions on Next Page)

#### 1. Applicant:

#### 2. Grant Funds:

Line Item	Acct.	Initial	For Budget Revisio	ns
	#	Budget	Revised Budget	Amt. of Change +/-
Personnel/Fringe	410	\$37,310.00		
Rent/Utilities	420	10,000.00		
Travel/Staff	430	4,000.00		
Supplies	440	5,000.00		
Equipment	450	0.00		
Communications	460	3,000.00		
Prof. Services	470	2,200.00		
Other: Participant Expenses	480	30,000.00		
Contract Services Faculty/Expenses	490	15,000.00		
Total		\$106,510.00		

#### 3. Local Match:

Line Item	Acct.	Initial	For Budget Revisions	
	#	Budget	Revised Budget Amt. of Chang	
Personnel/Fringe	510	\$58,000.00	(*This figure includes aproximately \$1,300.00)	pximately \$1,300.00 time
Rent/Utilities	520		match per each of the 36 Partners in Policymaki	artners in Policymaking
Travel/Staff	530		Participants; and an estimated time match of \$3,200.00 of nonfederally funded State Employe and approximately \$8,000.00 of time match from World Institute on Disability.)	funded State Employees;
Supplies540				
Equipment	550			······
Communications	560			
Prof. Services	570			
Other: Participant Expenses	580			
Contract Services Faculty/Expenses	590			
Total		\$58,000.00		

#### For office use only.

Initial application Budget revision request Approved By: \_\_\_\_\_ Comments: \_\_\_\_\_ Date: \_\_\_\_\_

1 Line Hem	2. Description of Expenditure Type 3. How Determined	3. How Determined	4. Grant	5. Local Match	tch
			Amount	a. Amount	b. Source
410	Refers to salary and fringe for Training Director and Support Staff (clerical).	Equals 50% of Training Director's salary and fringe, and 30% of Support Staff salary.	\$ 30,333.00		
	Fringe (at 23%)		\$ 6,977.00		
420	Refers to total of monthly rental and utilizes costs.	Based on \$833.00 per mo. available for rent and utilities	\$ 10,000.00		
430	Travel reimbursement allowances for staff in performance of duties.	Range of \$0.24-\$0.27 per mile and support for attendance at conferences and professional training.	\$ 4,000.00		
440	Office supplies and other materials for providing Partners in Policymaking.	Based on previous experience of costs.	\$ 5,000.00		
460	Communication costs such as mailing and long distance phone service.	Based on 250 per month on previous experience.	\$ 3,000.00		
470	Printing, reproductions, and other professional services as needed.	Based on previous experience.	\$ 2,200.00		
480	Reimbursement allowance for participant expenses such as travel, hotel, respite care, meals, instructional materials, site rental, and other costs associated with providing Partners in Policymaking	Based on previous year's amount and allowing for inflation.	\$ 30,000.00		
490	Honoraria, travel reimbursement, hotel accommodation, and other costs associated with securing contract services.	Based on previous year's amount and allowing for inflation.	\$ 15,000.00		
	Total		\$106,510.00		
510	Match generated by noncash hourly time contribution of Partners in Policymaking participants.	Approximately \$1,300.00 contribution per each participant.		\$ 58,000.00	Noncash volunteer time contribution.

#### Form V — Budget Detail (Instructions on next page)

### GRANT PROPOSAL: APPENDIX A

## Assurances: The World Institute on Disability

The World Institute of Disability (WID) is a public policy and research center founded in 1983 by leaders of the movement for independent living. It is acknowledged by the disability rights movement and by experts in rehabilitation as a national and international leader in public education, research, and policy related to independent living for people with disabilities.

WID has the personnel, the organization, the ties to the disabled community, and the experience in public education and public policy to efficiently and effectively administer the Partners in Policymaking program. Roberts has presented at six sessions of Partners — more than any other presenter. He has received the highest scores and has personally touched more participants.

WID acts as a national resource center for information on independent living and personal assistance; participates in national, state, and local hearings on issues affecting people with disabilities; sponsors national conferences; provides technical assistance to public and private agencies; and has designed training programs for a wide range of organizations.

WID has drafted model legislation on personal assistance services and is now educating legislators at the state and federal level about its significance.

WID is committed to the principles of unity and collaboration among people with different kinds of disabilities. It has a particular interest in working with people with mental disabilities and has recently taken on a new program, Supported Employment: Businesses with a Future, that trains and employs people with mental disabilities as personnel for a successful gourmet catering business.

WID maintains close ties with the National Independent Living Council (NILC), with state and regional councils on disability and independent living, and with many local independent living centers. It participates regularly in conferences attended by policymakers and disability rights activities. Its quarterly newsletter, *Attendant Services Network*, is widely circulated among organizations that serve people with disabilities.

The World Institute on Disability is a private, nonprofit 501 (c)(3) corporation focusing on major policy issues from the perspective of the disabled community. It functions as a research and advocacy center, and as a resource for information, training, public education, and technical assistance. WID opened an office in Minneapolis in 1989.

#### **Edward V. Roberts**

WID's cofounder and president is Edward V. Roberts, a man who is quadriplegic and uses a respirator and a motorized wheelchair, and who was once denied rehabilitation dollars from the state of California on the grounds that he was too disabled.

Mr. Roberts is the president and cofounder of The World Institute on Disability. He was the first person with severe disabilities to enter the University of California, Berkeley.

He led the movement to make the University accessible and cofounded the first Center for Independent Living. Mr. Roberts served as director of the California Department of Rehabilitation for eight years and was awarded the MacArthur fellowship. In 1988, he was featured on "60 Minutes." Mr. Roberts is a lecturer, a civil rights advocate, and the father of a ten-year-old son.

Roberts earned undergraduate and graduate degrees as the first full-time student with severe disabilities at the University of California at Berkeley. He became director of Rehabilitation for the state of California, founded the nation's first independent living center (ILC) in Berkeley, influenced the drafting and passage of the 1978 federal legislation that established ILCs across the country, and was named a MacArthur Fellow.

#### Director

Administration of the Partners in Policymaking program within Minnesota will be directed locally with consultant support. Duties of the local director will include logistics; participant contact, recruitment, and selection; scheduling; speaker/faculty facilitation; contract negotiations; and fiduciary and day-to-day management responsibilities.

### GRANT PROPOSAL: APPENDIX B

## **APPLICATION PACKET**

Please see the Sample Correspondence Section on page 105 for application materials.

### GRANT PROPOSAL: APPENDIX C

## **PARTICIPANT CONTRACT**

Please see the Administrative Forms Section on page 117 for Partners in Policymaking contract materials.

# GRANT PROPOSAL: APPENDIX D

# TABLES

### TABLE 1: 1990 PARTNERS IN POLICYMAKING PROGRAM TENTATIVE SCHEDULE

.

Dates	Topics	Presenters
Jan. 19-20	Values and History — Overview of Services	Gunnar Dybwad, Ph.D.; Ed Skarnulis, Ph.D.; Ed Roberts; and Colleen Wieck, Ph.D
Feb. 16-17	Education — Integration and Quality	Lou Brown, Ph.D.; Charlotte Des Jardins; and State Department of Education Officials
Mar. 23-24	State Legislative Issues	State Legislators
April 20-21	Nonaversive Approaches to Severe Behavior Problems, Severe Physical Disabilities, and Technology	Wade Hitzing, Ph.D.; Joan Bergman, Ph.D.; Robert Stack; and Richard Dodds
May 18-19	County Issues, Case Management, Promoting a Vision	Duane Shimpach, Fran Smith, Allan Bergman, and County Commissioners
June 23-24	Family Supports, Supported Living, Supported Employment, and Federal Issues	Hank Bersani, Ph.D.; Ian Pumpian, Ph.D.; Betty Pendler, and Congressional Staff
July	Accessing Advocacy Organizations	State and Local Advocacy Organizations
Sept. 21-22	Effective Meetings and Graduation	Ed Roberts and Donald Sikkink, Ph.D

### TABLE 2: 1989 PARTNERS IN POLICYMAKING PROGRAM TENTATIVE SCHEDULE — YEAR TWO

Dates	Topics	Presenters
Jan. 27-28	Values and History — Overview of Services	Gunnar Dybwad, Ph.D.; Ed Skarnulis, Ph.D.; Dolores Norley; Ed Roberts; and Colleen Wieck, Ph.D
Feb. 23-24	State Legislative Issues	State Legislators; and Hank Bersani, Ph.D
Mar. 16-17	Education — Integration and Quality	Lou Brown, Ph.D.; Charlotte Des Jardins; Larry Ringer; and State Department of Education Officials
April 18-19	County Issues, Case Management, Promoting a Vision	Duane Shimpach, Fran Smith, Allan Bergman, Ralph McQuarter, Toni Lippert, and County Commissioners
May 17-18	Federal Issues	United Cerebral Palsy Assn. Annual Conference
June 23-24	Nonaversive Approaches to Severe Behavior Problems, Severe Physical Disabilities, and Technology	Wade Hitzing, Ph.D.; Joan Bergman, Ph.D.; Robert Stack; and Richard Dodds
July 21-22	Family Supports, Supported Living, Supported Employment, and Federal Issues	Hank Bersani, Ph.D.; Ian Pumpian, Ph.D.; Betty Pendler, and Congressional Staff
Sept. 21-22	Effective Meetings Graduation Advanced Advocacy for Years 1, 2, and 3	Ed Roberts; Donald Sikkink, Ph.D.; and Dohn Hoyle

#### TABLE 3: 1988 — 1989 PARTNERS IN POLICYMAKING PROGRAM TENTATIVE SCHEDULE — YEAR TWO

Dates	Topics	Presenters
May 13-14, 1988	The History of the Parent Movement and the Independent Living Movement	Gunnar Dybwad, Ph.D.; Ed Skarnulis, Ph.D.; Dolores Norley; and Ed Roberts
June 24-25, 1988	Education — Integration and Quality	Anna Marie Ruttiman; Charlotte Des Jardins, Larry Ringer, Tim Moriarty, and Parents Panel
July 29-30	Nonaversive Approaches to Severe Behavior Problems, Severe Physical Disabilities, and Technology	Wade Hitzing, Ph.D.; Joan Bergman, Ph.D.; Robert Stack
Sept. 23-24, 1988	County Issues, Case Management, Promoting a Vision	Allan Bergman; Fran Smith; Duane Shimpach; Ed Skarnulis, Ph.D; Ralph McQuarter, Toni Lippert; and County Commissioners
Oct. 28-29, 1988	Family Supports, Supported Employment, Federal Issues Medicaid Reform	Hank Bersani, Ph.D.; Ian Pumpian, Ph.D.; Ed Roberts; Betty Pendler; and Congressional Staff
Nov. 6-7, 1988	Attend State Council on Disability Roundtable	All State Advocacy Organizations
Jan. 6-7, 1989	State Legislative Issues	State Legislators
Feb. 10-11, 1989	Graduation and Advanced Advocacy Efforts	Ed Roberts; Lou Brown, Ph.D., Dohn Hoyle; and Donald Sikkink, Ph.D

TABLE 4: 1987 — 1988 PARTNERS IN POLICYMAKING PROGRAM TENTATIVE SCHEDULE — YEAR TWO

Dates	Topics	Presenters
May 1-2, 1987	Historical Perspective	Gunnar Dybwad, Ph.D.; Dolores Norley; Lottie Moise; and Ed Roberts
June 5-7, 1987	Education	Linda Kjerland; Betty Pendler; Bob York, and Colleen Wieck, Ph.D
<sup>-</sup> uly 17-18, 1987	County Issues	Duane Shimpach; Dorothy Grotte, DHS Personnel; County Commissioners; Allan Bergman, and Fran Smith
Sept. 15-16,, 1987	Federal Issues	Hank Bersani, Ph.D.; Judge Miles Lord; Bill Malleris; and Congressional Staff
Oct. 15-16, 1987	Congressional Visits and ARC – U.S. Convention	Staff of Senator Weicker; Senator Chafee, and Representative Florio
Nov. 23-24, 1987	Nonaversive Behavior Approaches for Serving People with Behavior Problems and Providing Services for People with Severe Physical Handicaps	Karen Green-McGowan Wade Hitzing, Ph.D.; and Margot Imdieke
Jan. 15-16, 1988	State Legislative Issues	Lieutenant Governor Marlene Johnson, Legislators, and Mary O'Hara-Anderson
Feb. 26-27, 1988	Advocacy Organizations	Timothy Moriarty; James Fairley, Jr.; and Advocacy Organizations
Mar. 25-26, 1988	Integration and Advocacy	Lou Brown, Ph.D.; Donald Sikkink, Ph.D; Charlotte Des Jardins; and Ed Roberts

### TABLE 5: PARTNERS IN POLICYMAKING SESSION EVALUATION FORM

#### Session Speaker/Presenter:

#### Session Dates: \_\_\_\_\_

Please circle the number below from 1 to 5 that best reflects your feelings about each question. Please feel free to share additional comments below.

	Question	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1.	Speakers were prepared, organized, and effective.	5	4	3	2	2
2.	The material presented was relevant to my needs and this new knowledge will improve my advocacy skills.	5	4	3	2	1
3.	Questions were answered satisfactorily.	5	4	3	2	1
4.	I felt the speakers were sensitive to participants' individual situations.	5	4	3	2	1
5.	Written materials and handouts were useful.	5	4	3	2	1

6. How will you specifically attempt to use the information and experience gained from the activities presented this weekend?

#### 7. Comments:

### TABLE 6: AVERAGE SCORES FROM EVALUATIONS PER SESSION YEAR TWO

		A	verage	Score	/Stater	nent
_	Session	1	2	3	4	5
1.	May 13-14, 1988: History of the Parent Movement and the Independent Living Movement.	4.8	4.4	4.2	4.5	4.4
2.	June 24-25, 1988: Education — Integration and Integration and Quality	4.4	4.3	4.5	4.6	4.6
3.	July 29-30, 1988: Nonaversive Behavior Approaches, Severe Physical Handicaps, and Technology	4.5	3.8	4.2	4.2	4.1
4.	Sept. 23-24, 1988: County Issues, Case Management, and Promoting a Vision	4.6	4.6	4.5	4.5	4.6
5.	Oct. 28-29, 1988: Family Support, Supported Employment, Federal Issues, and Medicaid Reform	4.7	4.6	4.6	4.7	4.5
6.	Nov. 14, 1988: Attend State Council on Disability's Legislative Roundtable <sup>4</sup>					
7.	Jan. 13-14, 1989: State Legislative Issues	4.6	4.6	4.7	4.7	4.7
8.	Feb. 10-11, 1989: Graduation and Advanced Advocacy Efforts	4.7	4.7	4.6	4.6	4.4

**Note:** Statement = responses to a quesion in the evaluation form. The participants were asked to, "Please circle the number below from 1 to 5 that best reflects your feelings about each question." "Strongly disagree" was 1; "strongly agree" was 5. The statements were:

- 1. Speakers were prepared, organized, and effective.
- 2. The material presented was relevant to my needs and this new knowledge will improve my advocacy skills.
- 3. Questions were answered satisfactorily.
- 4. I felt the speakers were sensitive to participants' individual situations.
- 5. Written materials and handouts were useful.

\*Due to the nature of this session, evaluations were not distributed for comments.

### TABLE 7: AVERAGE SCORES FROM EVALUATIONS PER SESSION YEAR ONE

		Average Score /Statement				
	Session	1	2	3	4	5
1.	May 1-2, 1987: History, Philosophy, and Values	4.7	4.2	4.3	4.2	4.3
2.	June 5-6, 1987: Best Practices in Education	4.5	4.5	4.6	3.8	4.2
3.	July 17-18, 1987: Policymaking at the County and Local Level	4.8	4.8	4.7	4.6	4.4
4.	Sept. 17-18, 1987: Policymaking at the Federal Level	4.3	4.4	4.3	4.0	3.9
5.	Nov. 13-14, 1987: Severe Behavior Problems and Physical Disabilities	4.7	4.2	4.1	4.2	4.1
6.	Jan. 15-16, 1987: Policymaking at the State Level	4.5	4.6	4.4	4.0	4.3
7.	Feb. 26-27, 1988: State Legislative Issues	4.6	4.6	4.7	4.7	4.7
8.	Mar. 25-26, 1988: Integration, Advocacy, and Graduation	4.7	4.7	4.6	4.4	4.7

**Note:** Statement = responses to a quesion in the evaluation form. The participants were asked to, "Please circle the number below from 1 to 5 that best reflects your feelings about each question." "Strongly disagree" was 1; "strongly agree" was 5. The statements were:

- 1. Speakers were prepared, organized, and effective.
- 2. This session gave specific ideas which will be useful to me.
- 3. This session was relevant to my ideas/interests.
- 4. The material was presented in sufficient depth.
- 5. My questions on the topic were answered satisfactorily.

### TABLE 8: YEARS ONE AND TWO SUMMATIVE EVALUATION

- 50 News Articles—Profiles
- 5 Television and Radio Programs
- 69 Appointments to Commissions and Committees
- Over 500 Letters
- Over 100 Visits to Legislators, Petition of 120 Other Family Members
- 10 Testimony to Counties, State, and Federal Hearings
- 62 Presentations at National, State, and Local Conferences
- 4 University Class Invitations
- Children in Integrated Classes
- Children in Respite Care
- Children Receiving Case Management
- Individuals with disabilities and other participants have/are:
  - Returning to school;
  - Changing jobs;
  - Becoming competatively employed;
  - Interested in running for public office.

### TABLE 9: YEAR ONE AND TWO ANECDOTAL STATEMENTS

"Partners has provided me with more information, connections, support, and power than all I have experienced since our daughter's birth 10 years ago."

"Participation has helped me become a more independent, knowledgeable advocate for my child to work with public officials so that all people can benefit."

"A better ability to see the bigger picture."

"(I have) been able to help other parents."

"For the first time in four years our family is thriving, not just surviving."

"P in P is inspiring, wonderful, and exhausting."

"A side effect of this involvement is the wonderful friends we have made, people who have children with more labels and complications. People who are living their lives with dignity, style, and humor. For those friends we are deeply grateful."

"It has been a boon to our family."

"Your leadership and programming allows us to see the normal and good side of people with disabilities."

"It is a relief to have the information and tools to see our daughter in a new light."

"You are doing a wonderful job of empowering parents."

"P in P is needed throughout the country. Participating has helped me to become a more independent, knowledgeable advocate for my child to work with public officials so that all people can benefit."

"The last session helped me to think of new ways to resolve the greatest problem I see for my children and that is their loneliness."

"I have an exciting success story to share with you. The integration session last month was inspiring and helped me formulate goals. It led to further contact with Linda Kjerland and Larry Ringer. As a result of their information, support and talking with our special education cooperative, my daughter will be attending kindergarten in Sherburn this fall with appropriate nonhandicapped peers."

"The initial plan was for her to attend a special education preschool program in another town (16 miles away), in a building with third and fourth graders and no integration opportunities. We are now planning total integration with appropriate supports for her, a child with multiple severe disabilities, in a regular classroom."

"Another success I would like to share with you is my appointment to the Minnesota Special Education Advisory Council. It is another example of the Partners in Policy Making program impact."

"I am more assertive. The 'DC' trip proved to me that I can travel and even cross the streets by myself. A first!"

### TABLE 10: READING AND RESOURCES

These publications are available through the Minnesota Governor's Planning Council on Developmental Disabilities

Making an Issue of It: The Campaign Handbook In Counties We Trust How We Lived and Grew Together P.L. 99-457. The Education of the Handicapped Act (Amendments of 1986) MEDICAID: The Need for Reform in Long Term Care Services for Persons with Developmental Disabilities DHS Chapter 9550KcCSSA. A Guide for the Powerless and Those Who Don't Know Their Own Power Consumer Unity A Story I Heard 1987 Minnesota Income Tax Law - Before and After Consortium for Citizens with Developmental Disabilities (3/7/86). A Summary to Social Security and Supplementary Security Income Work Incentives for the Disabled and Blind Minnesota State Senate (Process) Brochures). Etiquette Tips (When Addressing Legislative Bodies) Recognizing Our Special Needs But Meeting Our Basic Needs Minnesota Monthly — The Importance of Family "For George, A House to Expand Vistas," New York Times, January 4, 1988. "Parents, No Longer Excluded, Just Ignored," Alan Gartner, Exceptional Parent, January-February, 1988. Defining Roles and Responsibilities for Transition Services Delivery Why Integration? --- Meyer Government Is for Everyone --- Be a Part of It Session Summary with Special Session Medicaid Home and Community Quality Services Act of 1987. Assessment of the Impact of the ICF/MR Moratorium. Read My Lips — MNGPCDD New Way of Thinking — MNGPCDD Never Too Late, Never Too Early --- Metro Council on Developmental Disabilities This Means War --- MNGPCDD How To Get Services By Being Aggressive — C. DesJardins How To Organize Effective Parent/Advocacy Group and Move Bureaucracies - C. DesJardins National Conference on Self-Determination (Monograph of recommendations) - University of Minnesota, Institute on Community Integration.

Test Your School's IO: Integration Quotient --- MNGPCDD Test Your IO: Integration Ouotient --- MNGPCDD Guidelines for Quality Individual Plans - MNGPCDD Guidelines for Meetings with Members of Congress --- UCDA The Key to Successful Meeting Planning — UCDA A New Way of Thinking about the "L" Word ... Lobbying — UCDA Know Your Legislature: How To Keep in Touch — Intern Minnesota Governor's Planning Council on Developmental Disabilities, Policy Analysis Series: Numbers 18, 20, 21, 24 In Counties We Trust --- MNGPCDD Assistance to States for Education of Handicapped Children, (34 Code of Federal Regulations, Part Two) Skills Transfer in Programs for Students with Severe Handicaps - L. Brown **Outline of Laws Regarding Special Education** Summary of Vocational Follow-Up Evaluation of the 1984-1986 Madison Metropolitan School District Graduates with Severe Intellectual Disabilities - L. Brown Providing Appropriate Educational Services in the Leest Restrictive Environment The "Why Question" in Instructional Programs for People Who Are Severely Intellectually Disabled -L. Brown, et al Ecological Inventory Strategies for Students with Severe Handicaps-L. Brown Minnesota Resource Guide to Public School Integration for Students with Severe Handicaps - R. McQuarter, T. Vandercook, J. York Minnesota Statutes, Section 120.17 — Handicapped Children The Care and Feeding of Legislators — D. Norley Case Management in Early Intervention - D. Bailey, Jr., Exceptional Parent The Rights of Physically Handicapped Persons - L. Rothstien, W. Virginia University Guidelines for Families: Improving Health Care for Childen with Chronic Conditions — A. Healy, M.D.; J.A. Lewis-Beck, Ph.D. Circle of Friends — Perski Beginnings and Endings: The Quality of Life for Young and Old - G. Dybwad Basic Principles of Seating Achieved Through the Use of Temporary Makeshift Equipment - J. Bergman, Ph.D, AAC: Journal of University of An. Augmentative Communication Association. Transition Services for Young Adults with Severe Disabilities: Defining Professional and Parental Roles and Responsibilities — J. Everson and M. Moon Disabilities and Technology: Executive Summary

#### These publications are available through the World Institute on Disability's California Office.

California Quality of Life Report on Developmental Disabilities Attending to America: Personal Assistance for Independent Living (Full Report) Executive Summary of Attending of America Ethics The Need for Personal Assistance Descriptive Analysis of the In-Home Supportive Services Program in California Swedish Attendant Care Programs for the Disabled and Elderly: Descriptions, Analysis, and Research Issues from a Consumer Perspective The Personal Assistance For Independent Living Act of 1989: (A Draft Bill) Access to Health Care, Vol. 1, No. 1 & 2 Access to Health Care, Vol. 1, No. 3 & 4 Ethical Issues in Disability and Rehabilitation: A Report on an International Conference

### TABLE 11: YEAR 3 EXPENDITURES

		Expenditures
	Personnel:	¢ 22 500 00
	1. Salary	\$ 22,500.00
	2. Fringe at 20 percent	4,500.00
	Total	\$ 27,000.00
I.	Supplies:	
	1. Publications	\$ 1,911.27
	2. Office supplies	576.62
	3. Xeroxing	815.61
	4. Space expenses	2,671.43
	(Xerox, UPS, FAX)	1 529 75
	5. Postage	1,528.75
	Total	\$ 7,503.78
I.	Equipment	\$ 901.12
v.	Participant Expenses:	
	1. Hotel	\$ 3,352.58
	2. Meals	10,252.84
	3. Meeting room rental	2,400.00
	4. Equipment rental	527.50
	5. Mileage and Travel reimbursement	17,781.96
	6. Respite care	3,921.02 1,071.72
	7. Child care	740.00
	<ol> <li>Personal care attendant</li> <li>Meal reimbursement</li> </ol>	236.76
		\$ 30,284.38
	Total	φ 50,204.50
7.	Faculty Expenses:	¢ 10 705 00
	1. Honorarium	\$ 10,705.00
	2. Travel	7,749.21
	3. Hotel	1,736.54
	Total	\$ 20,190.75
VI.	Professional Expenses	<b>\$</b> 370.52
VII.	Occupancy	<b>•</b> (110.00
	1. Space rental	\$ 4,119.98
	2. Janitorial	250.37
	3. Parking	335.48 1,132.11
	3. Phone	
	Total	\$ 15,773.79
VIII.	Washington Trip (34 individuals)	\$ 15,773.79
Tran	d Total	\$ 107,862.28

# GRANT PROPOSAL: APPENDIX E EXAMPLES OF LETTERS OF SUPPORT



### STATE OF MINNESOTA

OFFICE OF THE LIEUTENANT GOVERNOR

ST. PAUL 55155

MARLENE JOHNSON LIEUTENANT GOVERNOR

March 28, 1989

Mr. Ed Roberts, President World Institute on Disability 1313 W. 5th St., Suite 111 Minneapolis, MN 55414

Dear Mr. Roberts:

For the past three years, I have had the privilege of meeting with participants in the Partners in Policymaking Program initiated by the Minnesota Governor's Planning Council on Developmental Disabilities, and the University-affiliated Institute on community Integration for people with disabilities.

This program is unique in that it develops leadership and educates parents about the service system, and most importantly, trains people with disabilities to be self-advocates.

I strongly support the World Institute on Disability proposal to replicate this proven valuable program.

Warm regards,

mailendano

MARLENE JOHNSON

MJ/mk

AN EQUAL OPPORTUNITY EMPLOYER

Minnesota House of Representatives



**GLORIA SEGAL** 

DISTRICT 44B ST. LOUIS PARK

April 7, 1989

Edwards Roberts, President World Institute on Disability 1313 W. 5th Street S.E. Suite 111 Minneapolis, MN 555414

Dear Mr. Roberts:

This is in response to your request for an instrument of support for renewed funding for your organization's Partners in Policymaking Program. I am happy to oblige.

My interest in this program parallels my many years of involvement in the struggle for the rights of disabled people. As an elected official who participates in Partners in Policymaking, I have had the opportunity to witness firsthand its many successes.

Some of these achievements are highly visible, such as the 70 appointees to local and state policymaking bodies, that have come about because of the quality of instruction provided by Partners in Policymaking. Other accomplishments are much more intangible, but no less a contributor to a disabled person's sense of self-esteem. I am speaking here of the countless number of people who have had their spirits buoyed by their participation in Partners in Policymaking. It is unfortunate that we live in an era when little value is place on that which cannot be easily quantified, but I would be remiss both as a parent, and a legislator, if I failed to mention this contribution of your much-needed program.

I wish you all the best in your endeavor to renew the grant which has made Partners and Policymakers the reality that it has become for so many members of the disabled community. If you feel that I can of further assistance in this matter, please do not hesitate to call on me.

Sincerely, Gloria Segal State Representative

Reply to: 551 State Office Building - St. Paul, MN 555155 (612) 296-9889



STATE OF MINNESOTA DEPARTMENT OF HUMAN SERVICES CENTENNIAL OFFICE BUILDING ST. PAUL, MINNESOTA 55155

March 23, 1989

Mr. Edward V. Roberts, President World Institute on Disability 1313 W. Fifth Street Suite 111 Minneapolis, Minnesota 55414

Dear Mr. Roberts:

It is with pleasure that I offer this letter of support for your proposal to replicate the "Partners in Policymaking" program. The variation you propose, to focus education and training activities on individuals with developmental disabilities, or their parents, who have been traditionally unserved or underserved, is introduced a at time when the critical needs of these individuals are becoming increasingly apparent. an academy which can produce leaders, knowledgeable and well-tracked, will result in a better society for people with disabilities. Improved self-empowerment will enable unserved and underserved individuals to take a more active role in the influencing of public officials at the local, state and national level. The outcome will be an increased ability to set a direction in their lives and the lives of their family members.

The World Institute on Disability, with its mission of self-advocacy for people with disabilities, and your own involvement with Partners in Policymaking, qualifies the Institute to administer and influence a "Partners" replication of this nature. The World Institute on Disability is a leader in the fight for increased community-based, self directed services for people with severe disabilities.

Again, please accept this letter of support, and do not hesitate to call upon me for future endorsement or assistance. Should you have any questions or concerns, call me at (612) 296-9139.

Sincerely,

Edward R. Sharnulu

Edward R. Skarnulis, Ph.D., Director Division for Persons with Developmental Disabilities

AN EQUAL OPPORTUNITY EMPLOYER

DHS-825 (6-84



1619 Dayton Suite 303 ST. Paul MN 55104 612/646-8342 Voice or TDD

March 22, 1989

Mr. Ed Roberts 1313 West 5th St. #111 Minneapolis, MN 55414

Dear Ed:

Greetings! Good to hear from you and review your proposal for Partners in Policymaking. Several of MCIL board and staff are or have been involved in Partners and I certainly support its replication. Training is critical to independent living!

Let me know if I can help in any way!

Sincerely,

an

Dan Klint, Chairperson MCIL board of Directors

DK/cj



#### Minnesota Department of Education

Capitol Square

550 Cedar Street

Saint Paul Minnesota 55101

TY/TTD Number: (612) 297-2094 Phone: (612) 296-2012

April 3, 1989

Ed Roberts World Institute on Disability Suite 111 1313 W. 5th Street Minneapolis, MN 55414

Dear Ed:

It is with much pleasure and professional pride to write about the Partners in Policymaking project. I've always been a believer in training, especially those projects that offer more intensive work to maximize desired outcomes.

I've had the pleasure of meeting all three of Partners in Policymaking groups. These enthused parents and consumes gain critical knowledge and strategies to effect positive change in our delivery systems for people with disabilities. From my perspective in the Department of Education, we see these skilled people in local, regional and state activities as well as becoming more informed participants as part of the IEP process.

The World Institute on disabilities is clearly a natural choice for such a project. As an advocacy group with a fine reputation and network, the results would be far reaching.

Sincerely,

Barbara L. Trool:

Barbara L. Troolin, Manager Office of Monitoring and Compliance

BLT:cj

AN EQUAL OPPORTUNITY EMPLOYER



#### PARTNERS IN POLICYMAKING Session I: The History of the Parent Movement and the Independent Living Movement

#### January 26–27, 1990 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

#### Friday, January 26, 1990

Time of Activity	Activity	Location
11:45ам-12:15рм	Registration	Lobby/Depot
12:15рм-12:45рм	Introductions/Panel	Roundhouse
12:45рм-2:30рм	Ed Skarnulis, Ph.D., Director, Division of Services to People with Disabilities; Minnesota Department of Human Services	Roundhouse
	"History of Disabilities"	
2:30рм-2:45рм	Break	Depot
2:45рм-4:15рм	Ed Roberts, President, World Institute on Disability	Roundhouse
	"History of the Independent Living Movement"	
4:15рм-5:00рм	David Hancox, Director, Minnesota-WID	Roundhouse
	Explanation of the Contract and Ground Rules	
5:00рм-6:00рм	Refreshments/Social Time	Bandana Square
6:00рм-7:00рм	Dinner	Burlington
7:00рм-7:45рм	Colleen Wieck, Ph.D., Director, Minnesota Governor's Planning Council on Developmental Disabilities	
	"What is Partners in Policymaking?"	
7:45рм-9:00рм	Informal Discussions with Case Managers	Roundhouse

# Saturday, January 27, 1990

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ne of Activity	Activity	Location
8:00ам-8:45ам	Breakfast	Burlington
9:00ам-10:30ам	Gunnar Dybwad, Ph.D., Professor Emeritus Brandeis University	Roundhouse
	"The History of the Parent Movement"	
10:30рм-10:45рм	Break	Depot
10:45рм–12:00рм	Gunnar Dybwad (continued) "History of the Independent Living Movement"	
12:00рм-1:00рм	Lunch	Burlington
1:00рм-2:30рм	Dolores Norley, J.D. "A Personal Perspective"	Roundhouse
2:30рм-3:00рм	Wrap-up and Adjournment	Roundhouse

- 1. Participants will have an increased knowledge of the historical perspective of services for people with developmental disabilities.
- 2. Participants will be able to define and describe normalization, deinstitutionalization, and integration.
- 3. Participants will be able to describe the history and role of the parent movement and its impact on people with and families of, people with developmental disabilities.
- 4. Participants will be able to describe the history and role of the independent living movement and its impact on individuals with disabilities and their families.
- 5. Participants will know the procedures to complete local match forms to record their out-ofpocket expenses; the expense reimbursement forms for payment of refundable expenses; and the participant contract outlining responsibilities of participants and the Partners in Policymaking Project.
- 6. Participants will complete initial interviews with case managers to determine services received and those needed.

#### PARTNERS IN POLICYMAKING SESSION II: COUNTY PLANNING, COUNTY BUDGETING, CASE MANAGEMENT

February 16–17, 1990 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

#### Friday, February 16, 1990

Time of Activity	Activity	Location
11:45ам-12:15рм	Registration	Lobby/Depot
12:15рм-12:45рм	Introductions/Panel	Roundhouse
12:45рм-3:00рм	"County Planning and Budgeting"	Roundhouse
3:00рм-3:15рм	Break	Depot
3:15рм-4:30рм	Ed Skarnulis, Ph.D., MN Dept. of Human Servi "What is Case Management and Rule 185?"	ces Roundhouse
4:30рм-5:30рм	Fran Smith, Training Director United Cerebral Palsy Associations	Roundhouse
	"Creating a Vision for the Year 2000"	
5:30рм-6:30рм	Refreshments	Bandana Square
6:30рм7:30рм	Dinner	Burlington
7:30рм-9:00рм	Ms. June Kailes Issues of Transportation and Accessibility for Individuals with Disabilities	Burlington

## Saturday, February 17, 1990

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Time of Activity	Activity	Location
8:00am-8:45am	Breakfast	Burlington
9:00ам-12:00рм	Fran Smith (continued) Small Group Exercises: Preparing to Meet County Officials	Roundhouse
12:00рм-1:00рм	Lunch	Burlington
1:00рм-2:30рм	Role Play with County Officials	Roundhouse
2:30рм-3:00рм	Wrap-up and Evaluations	Roundhouse

#### COMPETENCIES FOR FEBRUARY 16 AND 17, 1990

- 1. Participants will understand the CSSA plan and process with respect to:
  - a. target groups;
  - b. timing of decisions;
  - c. plan requirements; and
  - d. how best to participate in the process.
- 2. Participants will locate and bring a copy of the most recent CSSA plan to this session.
- 3. Participants will be able to define case management and its functions.
- 4. Participants will be able to describe the process of case management as outlined in Rule 185.
- 5. Participants will be able to distinguish between an ISP, IHP, and IPP.
- 6. Participants will know how to apply for case management services.
- 7. Participants will work in a small group exercise to organize (role play) presentations for local public officials.
- 8. Participants will speak to a public official (during role play) about a critical issue regarding developmental disabilities.

#### PARTNERS IN POLICYMAKING Session III: Education—Integration and Quality

#### March 23–24, 1990 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

#### Friday, March 23, 1990

Time of Activity	Activity	Location
11:45ам-12:15рм	Registration	Lobby/Depot
12:15рм-12:45рм	Introductions/Panel	Roundhouse
12:45рм-2:30рм	Lou Brown, Ph.D., University of Wisconsin, Madison "Achieving Integrated Education"	Roundhouse
2:30рм-2:45рм	Break	Depot
2:45рм-5:00рм	Lou Brown, Ph.D. (continued)	Roundhouse
5:00рм-6:00рм	Refreshments/Social Time	Bandana Square
6:00рм-7:00рм	Dinner	Burlington
7:00рм-9:00рм	The State of Education in Minnesota: Early Education; K-12; Transition; Adult Educaton; and Post Secondary Education (State Department Education personnel) Small Group Meetings	Roundhouse

# Saturday, March 24, 1990

Time of Activity	Activity	Location
8:00am-8:45am	Breakfast and Announcements	Burlington
9:00ам-10:30ам	Charlotte Des Jardins, Director, Coordinating Council for Handicapped Children (Chicago)	Roundhouse
	"The How To's of Advocacy in Team Meetings"	
10:30рм-10:45рм	Break	Depot
10:45pm-12:00pm	Charlotte Des Jardins (continued)	
12:00рм-1:00рм	Lunch	Burlington
1:00рм-2:30рм	Judy Heumann, M.S., Co-Director World Institute on Disability	Roundhouse
	Post Secondary Education	
2:30рм-3:00рм	Wrap-up and Evaluation	Roundhouse

### Competencies for March 23 and 24, 1990

- 1. Participants will be able to define and identify characteristics of integrated educational settings.
- 2. Complete three brief evaluations entitled "Testing your School's IQ," "Guidelines for Quality Individual Plans," and "Guidelines for Quality Individual Education Plans."
- 3. Participants will demonstrate effective assertiveness and advocacy skills in public meetings.
- 4. Participants will be able to identify key education issues for all age groups.

### PARTNERS IN POLICYMAKING SESSION IV: STATE LEGISLATIVE ISSUES

April 20–21, 1990 Holiday Inn — State Capitol 161 Anthony Street St. Paul, Minnesota

#### Friday, April 20, 1990

Time of Activity	Activity	Location
11:30ам-12:00рм	Registration/Announcements	State Capitol Rotunda
12:00рт-1:00рм	Tour of the State Capitol	State Capitol
1:00рм-1:30рм	Greetings from Public Official	State Capitol Room
1:30pm-2:00рм	Break	Capitol Cafeteria
2:00рт-3:30рм	Scott Magnuson, Director Senate Information Office	State Office Building
	"How Bills Become Law"	
3:30pm-4:30рм	Michael Ehrlichman, Chair,	State Office Building
	Regional Transit Board "Some Important Tips about Interacting with Legislators"	
4:30рм-5:00рм	Mock Legislation Assignments	
5:00рм-6:00рм	Refreshments/Social Time	Holiday Inn
6:00рм-7:00рм	Dinner	Gilbert
7:00рм-9:00рм	Team Work Sessions;	Gilbert
	Prepare Testimony	Buffington

### Saturday, April 21, 1990

Time of Activity	Activity	Location
8:00ам-8:45ам	Breakfast	Gilbert
9:00ам-10:00ам	State of the Union	State Capitol House Chambers
10:00am-10:30am	Review testimony	State Office Building (SOB); Rooms 5 and 10
10:30рт-12:00 рм	Concurrent Hearings (Pro)	SOB, Rooms 5 and 10
12:00рт-1:00рм	Lunch	
1:00pm-2:30pm	Concurrent Hearings (Con)	SOB, Rooms 5 and 10
2:30pm-3:00рм	Wrap-up and Adjournment	SOB, Room 10

### PARTNERS IN POLICYMAKING SESSION V: Severe Physical Disabilities and Technology

#### June 29–30 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

#### Friday, June 29, 1990

Time of Activity	Activity	Location
11:45ам-12:15рм	Registration	Lobby/Depot
12:15рм-12:45рм	Announcements/Panel	Roundhouse
12:45рм-3:00рм	Joan Bergman, Ph.D. Sparks Center, University of Alabama, Birmingham "Severe Physical Disabilities"	Roundhouse
3:00рм-2:45рм	Break	Depot
3:15рм-5:00рм	Joan Bergman (continued)	Roundhouse
5:00рм-6:00рм	Refreshments/Social Time	Bandana Square
6:00рм-7:00рм	Dinner	Burlington
7:00рм-9:00рм	Ralph Hotchkiss, Senior Research Scientist San Francisco State University	Roundhouse
	"Mobility Technology"	

### Saturday, June 30, 1990

Time of Activity	Activity	Location
8:00am8:45am	Breakfast	Burlington
8:45ам-9:00ам	Announcements	Roundhouse
9:00ам-10:15ам	Robert Stack, New Jersey Department of Mental Retardation and Developmental Disabilities; and	Roundhouse
	Richard Dodds, United Cerebral Palsy Association	
	"Assessing Your Technology Needs and Demonstration of Technological Devices"	
10:15рм-10:30рм	Break	Depot
10:45рм-12:00рт	Robert Stack and Richard Dodds (continued)	
12:00рт-1:00рм	Lunch	Burlington/Northern
1:00рм-2:30рм	Richard Dodds (continued)	Roundhouse
2:30рм-3:00рм	Wrap-up and Adjournment	Roundhouse

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### COMPETENCIES FOR JUNE 29 AND 30, 1990

- 1. Participants will understand the need for correct positioning.
- 2. Participants will be able to identify debilitating effects of bad positioning.
- 3. Participants will understand new innovative approaches to positioning.
- 4. Participants will complete an individual technology assessment form to determine any specific needs.
- 5. Participants will be able to describe the importance of technological advances and the significant role they can play in the lives of individuals with disabilities.

### PARTNERS IN POLICYMAKING SESSION VI: SUPPORTED EMPLOYMENT, SUPPORTED LIVING, AND FAMILY SUPPORTS

#### July 20–21, 1990 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

#### Friday, July 20, 1990

Time of Activity	Activity	Location
11:45ам-12:15рм	Registration	Lobby/Depot
12:15рм-12:45рм	Announcements/Panel	Roundhouse
12:45рм-2:30рм	Ian Pumpian, Ph.D., University of San Diego "Supported Employment Begins in Schools"	Roundhouse
2:30рм-2:45рм	Break	Depot
2:45рм-5:00рм	Ian Pumpian (continued) "Issues of Adult Employment"	Roundhouse
5:00рм-6:00рм	Refreshments/Social Time	Bandana Square
6:00рм-7:00рм	Dinner	Burlington
7:00рм-9:00рм	Deborah Kaplan	Roundhouse
	"Americans with Disabilities Act (ADA)" Personal Care Attendant Services/Issues	

## Saturday, July 21, 1990

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Time of Activity	Activity	Location
д:00ам-8:45ам	Breakfast	Burlington
9:00ам-10:30ам	Hank Bersani, Ph.D. "The History of the Parent Movement"	Roundhouse
10:30рм-10:45рм	Break	Depot
10:45рм—12:00рт	Hank Bersani Preparing for Legislative Role Play	
12:00рт-1:00рм	Lunch	Burlington
1:00рм-2:30рм	Role Play with Legislative Staff "A Personal Perspective"	Roundhouse
2:30рм-3:00рм	Wrap-up and Adjournment	Roundhouse

# Competencies for July 20 and 21, 1990

- 1. Participants will be able to describe the values underlying supported employment.
- 2. Participants will be able to define supported employment.
- 3. Participants will be able to describe why supported employment is a better alternative to traditional programs.
- 4. Participants will understand the need to modify the environment to assure successful employment.
- 5. Participants will be able to identify key components of the critical federal legislation and the impacts on the lives of people with developmental disabilities.
- 6. Participants will be able to identify the process by which federal legislation is introduced and subsequently becomes law.
- 7. Participants will present to Congressional Staff.

### PARTNERS IN POLICYMAKING SESSION VII: SUPPORTED EMPLOYMENT, SUPPORTED LIVING, AND FAMILY SUPPORTS

August 17–18, 1990
Sunwood Inn — Bandana Square
1010 Bandana Boulevard, West
St. Paul, Minnesota

### Friday, August 17, 1990

Time of Activity	Activity	Location
12:15рм-12:45рм	Registration	Lobby/Depot
12:45рм-1:00рм	Announcements	Roundhouse
1:00рм-1:30рм	Introductions and Expectations	
	Richard Male Dan Lopp Community Resource Center, Denver, Colorado	Roundhouse
1:30рм-2:30рм	Martin Luther King, Jr., tape and Small Group Discussions	
2:30рм-2:45рм	Break	
2:45рм-3:45рм	<ul> <li>Basic Philosopy of Community Empowerment</li> <li>Why People Organize</li> <li>History of Organizing</li> <li>Different Approaches <ul> <li>Social Work</li> <li>Advocacy</li> <li>Organizing/Empowerment</li> </ul> </li> </ul>	
3:45рм-4:00рм	Break	
4:00рм-4:30рм	<ul><li>Power</li><li>What is it?</li><li>How to use it ?</li><li>Types of Power</li></ul>	
4:30рм-5:00рм	Neighborhood/Community Power Analysis Analyzing the Power in Your Community	
5:00рм-6:00рм	Dinner	
6:00рм-7:00рм	Community Organizing Process	
7:00рм-9:00рм	Panel Discussion	

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## Saturday, August 18, 1990

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Time of Activity	Activity	Location
8:00am-8:50am	Breakfast	Burlington
9:00ам-10:15ам	Detailed Look at the Organizing Process: Roundhouse Step I: Building Relationships	
10:15рм-11:15рм	Organizing Process: Step II: Leadership/Core Teams	
11:15рм-11:30рм	Break	
11:30рм-12:30pm	Organizing Process: Step III: Large Groups and Public Meetings Step IV: Negotiation	
12:30рт–1:30рм	Lunch	Burlington
1:30рм-2:30рм	Next Steps in Your Local Area	Roundhouse
2:30рм-3:00рм	Evaluation and Wrap-up	Roundhouse

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### Competencies for August 17 and 18, 1990

- 1. Participants will identify strategies for beginning "grassroots" level organizing which focuses on specific issues.
- 2. Participants will identify when and how to effectively use the media to promote their issues.
- 3. Participants will demonstrate effective ways to influence public officials in a public forum (as opposed to private meetings and correspondence), especially on subjects or disagreement.
- 4. Participants will identify strategies for effective involvement on boards, committees, and commissions, including how to promote themselves into positions of leadership, how to influence the "agenda" of the organization, and how to promote change within the organization.
- 5. Participants will identify mechanisms to promote cooperation and coalition building between separate disability organizations that will result in combined strength to more effectively influence public policy.
- 6. Participants will identify steps to develop and implement effective community information networks.

### PARTNERS IN POLICYMAKING SESSION VIII: GRADUATION AND CONDUCTING PUBLIC MEETINGS

#### September 14–15, 1990 Sunwood Inn — Bandana Square 1010 Bandana Boulevard, West St. Paul, Minnesota

### Friday, September 14, 1990

Time of Activity	Activity	Location
12:00рм-12:30рм	Registration	Depot
12:30рм-12:45рм	Announcements	Roundhouse
12:45рм-2:30рм	Donald Sikkink, Ph.D.	Roundhouse
	"Mastering Robert's Rules of Order"	
2:30рм-2:45рм	Break	Depot
2:45рм-5:00рм	Donald Sikkink (continued)	Roundhouse
5:00рм-6:00рм	Refreshments/Social Time	Bandana Square
6:00рм-7:00рм	Dinner	Burlington
7:00рм-9:00рм	Effective Meetings	Roundhouse
	"Meetings, Bloody Meetings" and "More Bloody Meetings"	

## Saturday, September 15, 1990

Time of Activity	Activity	Location
8:00am-9:00am	Breakfast	Burlington
9:00ам-10:00ам	To be announced	Roundhouse
10:00ам-12:00рм	Ms. Leah Walsh, Executive Director Independent Crossroads, Inc.	Roundhouse
	"Personal Care Attendant Issues"	
12:00рт-1:00рм	Lunch	Burlington
1:00рм-2:30рм	Ed Roberts, President, World Institute on Disability	Roundhouse
	Graduation	
2:30рм3:00рм	Wrap-up and Evaluation	

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# Competencies for September 14 and 15, 1990

- 1. Participants will demonstrate an understanding of the process and function of Robert's Rules of Order.
- 2. Participants will describe ways to influence public policy by engaging themselves with existing advocacy organizations.



### PARTNERS IN POLICYMAKING TIME/MATCH RECORD

The purpose of this form is to collect information about the amount of time that you spend working on Partners in Policymaking outside of the regularly scheduled sessions. This information will enable the Governor's Planning Council on Developmental Disabilities to use time that you have devoted to this project as match for the federal grant that is being used to support this project. Please estimate the time to the best of your ability and sign this form in the place provided. Thank you.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Since last completing one of these forms, I have spent approximately \_\_\_\_\_\_ hours on homework assignments, reading, phone calls, personal contacts, or other matters directly related to this program.

Signature

If you are employed, please indicate your hourly rate.

\$\_\_\_\_\_ (It is only necessary to provide this information once.)

Date	Time on Activity	Type of Activity	Tool for Activities (i.e. phone, letter
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## WORKSHOP/TRAINING EVALUATION

		Date	of Co	onferenc	e	<u> </u>		
	rticipant Information Title/Position/Relationship: Sel	ect one	•					
300	<ul> <li>Administrator</li> <li>Advocate</li> <li>Case Manager</li> <li>Social Worker</li> <li>Voc. Rehab. Counselor</li> </ul>	<ul> <li>Par</li> <li>Gu</li> <li>Gu</li> <li>Fri</li> <li>Par</li> <li>Re</li> </ul>	rent ardia end rent/l sider	Provider	vider	<ul> <li>Self A</li> <li>Consult</li> <li>Psych</li> <li>Rec.T</li> <li>Speec</li> <li>Other</li> </ul>	ologist herapy h Path.	
Yea	ars of School (circle highest):						Graduate 3	
Plea	ase circle your response to each s		ent. Igly	Agree	12		Strongly	
1.	The program met my expectations.	5		4	3	2	1	0
2.	I received new information.	5		4	3	2	1	0
3.	The information was helpful and relevant to my needs.	5		4	3	2	1	0
4.	The speaker(s) presented the information clearly.	5		4	3	2	1	0
5.	The speaker(s) encouraged audience participation.	5		4	3	2	1	0
6.	The exercises, if any, helped me apply the information presented.	5		4	3	2	1	0
7.	The handouts/materials, if any, were helpful.	5		4	3	2	1	0
8.	The audiovisual aids, if any, help clarify the information presented.			4	3	2	1	0
<del>9</del> .	My general reation to the program was positive.	5		4	3	2	1	0
10.	I would recommend this workshop to a colleague.	5		4	3	2	1	0

### Please respond briefly to each of the following:

- 1. What were the major strengths of the workshop?
- 2. The workshop would have been better if:
- 3. What did you expect to receive from attending this workshop?
- 4. Did the workshop meet your expectations?

5. What specfic skills, techniques, or knowledge did you obtain at this workshop that are relevant and applicable to your work setting?

6. In summarizing my reactions to this program, I would say:

### Participant Mileage, Travel, and Miscellaneous Expenses Reimbursement Claim Form

### Mileage Claim

Date	Destination		# of miles	_
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				-
		total miles		-
		_		_
		total due		\$
Travel C	laim			
Date(s) of	f trip:			_
Destinatio	on:			_
Purpose:				_
Air fa	re (ticket attached)		<u></u>	_
	/motel (room receipt attached)			
	(receipt attached) transportation receipts attached			
Other	(receipts attached)	·/		-
	-	total due		\$
Miscellar	neous Expenses			
Posta	ge (ticket attached)			_
	ng (room receipt attached)			-
	lies (receipt attached)			_
Oulei				-
				-
		total due		\$
(date)		(signature	;)	
		-		

510 Sixteenth Street, Suite 100 • Oakland, CA 94612 USA • (415) 763-4100, voice or TDD • (415) 763-4109, FAX 1313 5th Street, SE, Suite 103B • Minneapolis, MN 55414 • (612) 379-3969 • FAX (612) 379-3875

### Invoice

n consideration of payment in the amount of \$
hereby certify that I have performed the consulting duties as specified in the Memorandum of
Agreement dated
The dates such services were provided were:
Signature
Date
Social Security Number
Address:
Check approved by (authorized signature)
Date
Amount of Check Requested:
Payable to:
Purpose:
* Expense to Program/Account:

Please attach documentation (invoice, cover letter, etc.) \* Check will not be processed without expensing information!



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October 6, 1989

Dear Interested Persons:

The Minnesota Governor's Planning Council on Developmental Disabilities is currently seeking applications from interested **parents of young children** with developmental disabilities, or **persons with a disability**, to participate in Partners in Policymaking. This is a one-year leadership training program designed to improve the skills of participants to change the quality of life for people with developmental disabilities. The Council recognizes that well-informed parents and individuals with disabilities have historically had a powerful influence on policymaking by elected and appointed governmental officials.

This search actively seeks both males and females, members of minority communities, people who represent individuals with all types of disabilities which are severe, and participants from all areas of the state. Because of a desire to have as broad a participation as possible, we do not select husband-wife teams.

Expenses are paid for travel, lodging, meals, and respite care.

Selection will be made based on the quality of the applications. Applications are due on December 1, 1989. Final selection will be made by January 1, 1990. The first session will be held on January 27 and 28, 1990. Attendance at all sessions is mandatory.

Inquiries about this program can be directed to:

David Hancox, Director World Institute on Disability-Minnesota 1313 Fifth Street, SE, Suite 103B Minneapolis, Minnesota 55414

We would appreciate your assistance in identifying qualified applicants. Please share this information with other interested persons. Thank you in advance for your assistance in seeking qualified applicants.

Cordially,

Edward V. Roberts President

EVR/amc

Attachment

## PARTNERS IN POLICYMAKING Application for Participation

Name:
Address:
Zip Code
Telephone:         ( )         Daytime Number:         ( )
<ol> <li>Are you a parent of a son or daughter with a developmental disability? (Please indicate if you have more than one child with a disability. See attachment for definition of "developmental disabilities.")         Yes         No         Age     </li> </ol>
If yes: a. Describe the disability and how it affects the ability of your son/daughter to function in at least three (3) of the areas of major life activity ("D" of definition):
b. What services (school, respite care, case management, etc.) is your son/daughter currently receiving?
Describe the school placement:
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2.	Do you have other children?       Yes    No      a.    If yes, how many?      b.    What ages?
3.	Are you a person with a disability?
4.	Why are you interested in participating in the Partners in Policymaking project? Is there a specific issue, area of concern, or problem that encourages you to apply for this program?
5.	Will you make a time commitment of two days (Friday and Saturday) during the months of
	January, February, March, April, May, June, July, and September, 1989?
	a. Current employment:
6.	Will you travel to the metro area to attend the regularly scheduled meetings?
7.	Are there any special accommodations necessary for you to participate in this program? Yes No If yes, please describe (accessibility, interpreters, respite etc.):

8. Do you currently belong to any advocacy organizations? If so, please list and any offices. Membership in other organizations is **not a requirement**.

Please tell us a little about yourself and your family.

9.

10. Please list 2 to 3 references - names, addresses, and phone numbers.

11	Disass indicate how you learned shout the Derman in Delicymetring projects
11.	Please indicate how you learned about the Partners in Policymaking project:

Inquiries about this program can be directed to: David Hancox, Director World Institute on Disability-Minnesota 1313 Fifth Street, SE, Suite 103B Minneapolis, Minnesota 55414

## **DEVELOPMENTAL DISABILITIES DEFINITION**

The term "developmental disabilities" means a severe, chronic disability of a person which —

- a. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b. is manifested before the person attains age twenty-two;
- c. is likely to continue indefinitely;
- d. results in substantial functional limitations in three or more of the following areas of major life activity:
  - i. self-care
  - ii. receptive and expressive language
  - iii. learning
  - iv. mobility
  - v. self-direction
  - vi. capacity for independent living
  - vii. economic self-sufficiency
- e. 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.

Source: Developmental Disabilities Act of 1987 (P.L. 100-146).

510 Sixteenth Street, Suite 100 • Oakland, CA 94612 USA • (415) 763-4100, voice or TDD • (415) 763-4109, FAX 1313 5th Street, SE, Suite 103B • Minneapolis, MN 55414 • (612) 379-3969 • FAX (612) 379-3875

January 4, 1990

Dear Partners in Policymaking Participant:

We are pleased to inform you that you have been selected to be a participant in Year Four of **Partners** in **Policymaking**, sponsored by the World Institute on Disability, with funding from the Minnesota Governor's Planning Council on Developmental Disabilities. We received over 50 applications, and the selections were very difficult to make.

As you know, Partners in Policymaking is a nine-month program designed to increase empowerment and improve the self-advocacy skills of parents of young children with developmental disabilities and adults with disabilities. Enclosed with this letter is information related to this year's schedule of events, locations, dates, and other pertinent information. Please mark your calendars for our initial session to be held on **Friday and Saturday**, **January 26 and 27, 1990, at the Sunwood Inn at Bandana Square**. The January session will begin with registration at **noon** on Friday and adjourn at 3:00pm on Saturday. We will make arrangements for overnight accommodations for participants traveling from outside the seven county metro area. Please do not contact the hotel. consistent attendance is very important to a successful experience and we require that everyone be present at the first session.

Again, congratulations on being selected as a participant in this exciting program. Should you have any questions or concerns prior to the January 26 and 27, 1990, session, please feel free to contact David Hancox at (612) 379-3969.

See you January 26, 1990!

Sincerely,

David Hancox, Director

Enclosure

510 Sixteenth Street, Suite 100 • Oakland, CA 94612 USA • (415) 763-4100, voice or TDD • (415) 763-4109, FAX 1313 5th Street, SE, Suite 103B • Minneapolis, MN 55414 • (612) 379-3969 • FAX (612) 379-3875

January 4, 1990

Dear Partners in Policymaking Participant:

Thank you for submitting an application for year four of **Partners in Policymaking** to be sponsored by the World Institute on Disability, with funding from the Minnesota Planning Council on Developmental Disabilities. We are sorry to inform you that you were not selected to be a participant in this year's program.

We are pleased to say that we received over 50 applications from interested parents and individuals with disabilities. Each of the applications was compelling in their individual circumstances, and we genuinely wish we could have responded to the needs of all those who applied. five reviewers independently rated the applications on several criteria. we needed to assure a balance in terms of geography, gender, type of disability, and parent and primary consumer representation. However, because of our need to keep the participant group at 30 individuals, we had to make some very difficult choices.

Again, thank you for your interest. Should you have any questions or concerns, please feel free to contact David Hancox at the address or phone number listed above.

Sincerely,

David Hancox, Director World Institute on Disability — Minnesota

Enclosure



510 Sixteenth Street, Suite 100 • Oakland, CA 94612 USA • (415) 763-4100, voice or TDD • (415) 763-4109, FAX 1313 5th Street, SE, Suite 103B • Minneapolis, MN 55414 • (612) 379-3969 • FAX (612) 379-3875

January 24, 1989

TO: Partners in Policymaking Participants FROM: Edward V. Roberts, President REGARDING: Participant Contract

Some of the most crucial elements to ensuring a successful Partners in Policymaking program are a commitment to consistent attendance and quality communication from the very beginning. Because of these factors, we have found it to be beneficial to ask participants to sign "Participant Contract. "This serves to reaffirm their commitment, as well as, to spell out expectations and understandings related to how the program will proceed.

EVR/amc

Attachment

## PARTNERS IN POLICYMAKING — REPLICATION CONTRACT

As a participant in the Partners in Policymaking program, I understand and agree to the following:

- 1. I agree to attend all sessions. In the event of an emergency, I agree to contact and inform David Hancox.
- 2. I agree to arrive and depart from sessions at the prescribed times, i.e., arrive at 12:00 noon on Fridays and not leave before 3:00 p.m. on Saturdays, unless otherwise prescribed in the schedule.
- 3. I will not invite spouses, children, or other unexpected guests to Partners in Policymaking. Hotel accommodations are arranged on a roommate basis. If I desire to deviate from this arrangement, I will be expected to pay the additional room charges. Partners in Policymaking will not cover any of the additional costs.
- 4. Per diem rates are established for travel expenses and other costs that may be associated with participation. Participants agree to maintain these per diems:
- a. mileage reimbursement at \$0.24 per mile;
- b. meal costs; and
- c. respite care costs.
- 5. I agree to submit forms for expense reimbursement in a timely and complete manner. Meals, including tax and a reasonable gratuity, not to exceed \$6.00 for breakfast provided that the person leaves home before 6:00 a.m. or is away from home overnight; \$7.00 for lunch provided that the person is in travel status more than 35 miles from his/her home or is away from home overnight; and \$12.00 for dinner provided that the person cannot return home until after 7:00 p.m. or is away from home overnight. Partners in Policymaking will provide Friday dinner and Saturday breakfast and lunch.

Respite care costs will be reimbursed and based upon a preapproved mutually agreeable rate that is reasonable and consistent with the norm.

- 6. I will demonstrate competencies through action, i.e., letter writing, phone calls, attendance at local or state meetings, testimony before local or state bodies, news articles, and interaction with other participants. I will submit a "brief" report of monthly activities related to Partners in Policymaking.
- 7. I will choose one major assignment from the following list:
- □ a. Internship with Legislator/executive branch;
- □ b. Monitor hearings;
- □ c. Organize petitions/letter campaigns;
- $\Box$  d. Testify;
- □ e. Organize meetings/receptions with members of Minnesota Congressional Delegation;
- $\Box$  f. Other (please specify):

- 8. I agree to keep records and submit brief written monthly reports of contacts relative to, or as a result of, Partners in Policymaking with news media, public officials, action alerts, service organizations and/or community programs, phone calls, public presentations or speeches given, meetings attended, and organizations joined.
- 9. I agree to submit estimates of my time and out-of-pocket expenses as local match for the federal grant which sponsors Partners in Policymaking.

Date

Participant's Signature

### The Partners in Policymaking program agrees to:

- 1. Provide, face-to-face, the most up-to-date information available from national experts in the field of developmental disabilities.
- 2. Provide reading materials, suggestions, and resources to familiarize participants with a wide range of topics related to developmental disabilities and with information specific to identified areas of interest.
- 3. Provide both role play and direct experiences at the local, state, and federal levels to assist participants in their abilities to influence public policy.
- 4. Provide for and reimburse participant expenses generated by involvement to the fullest extent possible in return for complete participation.

Date

Project Director's Signature

# PARTNERS IN POLICYMAKING

### **INITIAL SURVEY**

I.D. Number: \_\_\_\_\_

This survey is an effort to measure your advocacy activities prior to your participation in the Partners in Policymaking program. Please answer the questions to the best of your ability providing estimates when necessary.

- 1. Prior to your participation in the partners in Policymaking program, did you ever contact local, state, or national public officials regarding your needs or the needs of a family member with a disability? (Check all that apply.)
  - □ Yes, National
  - □ Yes, State
  - 🗆 Yes, Local
- 2. If yes to Number 1, please indicate the type of contact, (letter, phone, or office visit) and estimate the number of contacts made. (Check all that apply.)
  - □ Letters: estimated number = \_\_\_\_\_
  - □ Phone calls: estimated number = \_\_\_\_\_
  - □ Office visits: estimated number = \_\_\_\_\_
- 3. What other opportunities have you had, prior to the Partners program, to advocate for yourself or other persons with disabilities or to educate the public regarding the rights or needs of persons with disabilities? (Check all that apply.)

Testified at a public hearing estimated number =	
Presentation to parent groups estimated number =	
Presentation at a conference estimated number =	
Service on a committee or commission estimated number =	
TV or radio appearances estimated number =	
Published newspaper articles/letters estimated number =	
□ Other:	

- 4. Please evaluate your advocacy skills, for yourself or a family member with a disability, prior to the Partners program.
  - □ My advocacy skills were excellent.
  - □ My advocacy skills were good.
  - □ My advocacy skills were fair.
  - □ My advocacy skills were poor.
- 5. Prior to your participation in the Partners program, were you able to receive appropriate services for yourself or family member with a disability?
  - $\Box$  Yes, most of the time.
  - $\Box$  Yes, some of the time.
  - □ No, have not been able to get appropriate services.
- 6. Do you expect to be better able to receive appropriate services as a result of the skills and information learned from the Partners program?
  - $\Box$  Definitely yes.
  - $\Box$  Yes, somewhat.
  - Probably not.
  - □ Definitely no.
- 7. As a result of your participation in the Partners program, what are your general expectations?

- 8. Place of residence:
  - 🗆 Urban
  - 🗆 Suburban
  - 🗆 Rural
- 9. Income:
  - □ Less than \$12,000
  - \$12,000-\$19,999
  - □ \$20,000-\$29,999
  - □ \$30,000-\$39,999
  - □ \$40,000**-**\$49,999
  - □ \$50,000+

#### 10. Level of Education:

- □ Less than High School
- □ High School Graduate
- $\Box$  Two Years of College
- □ Four Years of College
- □ Partial Graduate Work
- □ Master's Degree
- Doctoral Degree
- 11. Type of disability:
- 12. Race or Ethnicity:
  - □ Afro American
  - $\Box$  Native American
  - □ Hispanic
  - $\Box$  Caucasian
  - □ Other\_\_\_\_\_
- 13. 🗆 Female
  - □ Male
- 12. Age:
  - $\Box$  Under 20
  - □ 21–29
  - □ 31–39
  - □ 41-49
  - □ 50+

Thank you for your assistance.

## PARTNERS IN POLICYMAKING INITIAL SURVEY — SIX MONTH FOLLOW-UP

This survey is an effort to measure some outcomes of results of your participation in the Partners in Policymaking program. One way to evaluate the effectiveness of the Partners program is to collect information about how your participation in the program has helped you become a better self-advocate during the first six-month period after graduation. In this effort, please answer the questions below.

- 1. Please evaluate your advocacy skills, for yourself or a family member with a disability, prior to the Partners program.
  - □ a. Excellent
  - □ b. Very good
  - $\Box$  c. Good
  - 🗆 d. Fair
  - 🗆 e. Poor
- 2. Have you been in contact with local, state, or national public officials during the six-month period after graduation? (Check all that apply.)
  - $\Box$  a. Yes, national public officials
  - $\Box$  b. Yes, state national public officials
  - $\Box$  c. Yes, local national public officials
  - 🗆 d. No
- 3. If yes to Number 2, please indicate the type of contact, (letter, phone, or office visit) and estimate the number of contacts made. (Check all that apply.)

Estimated number

- $\Box$  a. Letters
- $\Box$  b. Phone calls
- $\Box$  c. Office visits
- 4. What other opportunities have you had to advocate for yourself or other persons with disabilities? (Check all that apply.)

Estimated number

□ a. Testified at a public hearing

b. Service on a committee/ commission

5. What other opportunities have you had to advocate for yourself or a family member with disabilities within a school or work setting? (Check all that apply.)

Estimated number

- $\Box$  a. School setting
- $\Box$  b. Work setting

- 6. If you responded to number 5, please indicate the degree to which your participation in the Partners program prepared you to be an effective advocate.
  - $\Box$  a. I was very prepared as a result of Partners.
  - b. I was somewhat prepared as a result of Partners.
  - $\Box$  c. I was not more prepared as a result of Partners.
  - $\Box$  d. I was less prepared as a result of Partners.
- 7. Have you participated in any public education efforts about persons with disabilities during the six-month period? (Check all that apply.)

		Estimated number	
a.	Published newspaper articles/letters		
b.	Conference presentation		
c.	TV appearances		
d.	Radio appearances		
e.	Other (please specify)	· · · · · · · · · · · · · · · · · · ·	

- 8. Did the information provided by the Partners program enable you to receive more appropriate services for yourself or a family member with a disability?
  - 🗆 a. Yes
  - 🗆 b. No
- 9. If "yes" to number 8, please provide specific examples here:

10.	Please outline any other benefits or outcomes you can attribute to your participation in the Partners
	program not mentioned above:

· · · · · · · · · · · · · · · · · · ·
· · · · ·

After you have completed this form, please return as soon as possible to:

Mr. David Hancox WID Minnesota 1313 5th Street, SE, Suite 103B Minneapolis, MN 55414

I.D. Number:



## Partners in Policymaking: Empowering People

Thomas J. Zirpoli College of St. Thomas

David Hancox and Colleen Wieck Minnesota Governor's Planning Council on Developmental Disabilities

Edward R. Skarnulis Minnesota Department of Human Services

Advocacy for people with disabilities and their families has evolved from the provision of public protective services to private and independent advocacy service groups, and finally to self-advocacy. This article describes one empowerment and self-advocacy training program for parents of young children and individuals with disabilities. An overview of the Partners in Policymaking program and the participants is provided along with Year 1 outcomes. The benefits of self-advocacy and the need for additional training programs are stressed.

DESCRIPTORS: advocacy, community services, developmental disabilities, families, legal rights, parentprofessional relations, parents, self-advocacy, special education

Advocacy services for people with developmental disabilities and their families have gone through significant changes over the years. In the past, protective services focused on the provision of basic care and services for people perceived as not able to effectively care for themselves. Protective services, usually provided by a state or local social agency, frequently placed people with disabilities in a passive role. In this role, people with disabilities and their families were seldom presented with choices or alternatives and typically had few opportunities to express their needs and make decisions regarding their own future.

As services for people with developmental disabilities increased, protective services became part of a growing public bureaucracy involved in the provision of social services. As part of the public bureaucracy, service agencies were forced to compete for limited public funds and in many ways became more concerned with the survival of the system than with fighting for the needs of people with disabilities (Vitello & Soskin, 1985). Independent organizations such as the Association for Retarded Citizens and The Association for Persons with Severe Handicaps began to provide advocacy services that focused on monitoring service providers and defending the legal rights of people with developmental disabilities and their families.

The availability of advocacy services for people with developmental disabilities and their families has never kept pace with the demand for these services (Herr, 1983; Vitello & Soskin, 1985). Advocacy services provided by federal and state agencies are subject to major problems. First, there is the uncertainty of funding. Second, government officials often are hesitant to support advocacy services likely to be critical of the government. Third, with the trend toward smaller, dispersed services, it is economically difficult for states to provide advocacy services for every residential, educational, and employment site. Fourth, the legal authority of many state public protection and advocacy systems is limited. Some states, for example, operate their protection and advocacy systems, originally mandated by the Developmental Disabled Assistance and Bill of Rights Act of 1975, without a legal staff (Vitello & Soskin, 1985). Although some public funding for advocacy services has been provided, the focus has been on providing information about the content of the law rather than on how to effectively access the system in order to receive services mandated by the law.

#### Self-Advocacy

Historically, the majority of people with disabilities and their families have depended upon others to advocate on their behalf. However, many have become more knowledgable regarding available services, the kind of

Requests for additional information on the Partners in Policymaking program should be directed to David Hancox, Minnesota Governor's Planning Council, 1313 Fifth Street Southeast, Suite 303, Box 80, Minneapolis, MN 55414.

We gratefully acknowledge the assistance of Karen Rogers and the reviewers for their suggestions during the preparation of this article.

Requests for reprints should be sent to Thomas J. Zirpoli, College of St. Thomas, P.O. Box 5017, 2115 Summit Ave., St. Paul, MN 55105.

services they need, and their legal rights to obtain appropriate services and to function in the mainstream of society. In addition, many publications teach people with disabilities and their families how to advocate for themselves. Some excellent examples include the workbook series by Haar (1984) and Freedman (1984) on power brokering in the community for families of children with disabilities, and the books by Des Jardins (1980a, 1980b) on how to organize advocacy groups and obtain services.

Public and private organizations that continue to provide advocacy services are now primary providers of empowerment and self-advocacy education and training. One objective of these programs is to teach people with disabilities how to be self-advocates by first learning how the system works and then learning how to effectively access the system. The People First movement, for example, challenges the stereotyped view that others always have to speak for people with disabilities because they cannot speak for themselves (Herr, 1983). As self-advocates, these consumers need not depend upon others to communicate their needs; they can represent themselves on issues affecting their own lives (Vitello & Soskin, 1985). These programs also seek to empower families of children with disabilities by providing information about state of the art services and how to effectively access the system so their children may be provided with appropriate services.

One aspect of advocacy is the ability to contact and communicate effectively with political representatives in order to have a direct influence on important decisions and policy development. Self-advocates and families that are empowered are no longer dependent upon others who serve on the boards of local, state, and national organizations; they are becoming board members themselves. Advocacy by, as well as for, people with disabilities is now a reality (Herr, 1983).

Several training programs serve as models for a new way of looking at advocacy and the provision of advocacy services (Massenzio, 1983; Wice & Fernandez, 1985). This article describes one such empowerment and self-advocacy training program, Partners in Policymaking, whose objectives have superseded previous attempts at self-advocacy training. This article discusses first-year activities, program evaluation data from participants, and both quantitative and qualitative shortterm outcome data collected from first-year graduates.

#### **Program Description**

Partners in Policymaking, a model empowerment and self-advocacy training program based in St. Paul, Minnesota, is a federally funded, three-year program with an annual operating budget of \$100,000. The program is under the direct supervision of the Minnesota Governor's Planning Council on Developmental Disabilities (GPCDD), with one GPCDD staffperson assigned half-time as director. Two other staff from the GPCDD and the Minnesota Department of Human Services (MDHS) provide additional program support, each allocating about one-third of their total workload to the program.

Partners in Policymaking was designed to provide information, training, and skill building in the area of developmental disabilities to individuals with disabilities, parents, and guardians so that they may obtain appropriate, state of the art services for themselves and others, develop their leadership potential, and impact public policy development. The program was designed to familiarize three cohort groups of participants (one year of training per cohort) with the policymaking and legislative processes at local, state, and national levels. Overall, Partners in Policymaking seeks to achieve a productive partnership between people needing and using services and those in a position to make policy and law regarding those services. In the process, the program was designed to introduce participants to nationally known experts in the field of developmental disabilities.

#### **Participants**

First-year applicants were recruited by direct mailings, contacts with organizations (including advocacy organizations), and referrals from local case management units. Fifty applications were received by the GPCDD.

Selection of 35 first-year participants was the responsibility of the selection committee, which included the Executive Director of the GPCDD, a staff member from the MDHS, and two individuals from the community (including one parent of a child with disabilities). The selection committee has since been reorganized to include three members of the GPCDD and four consumers from the community (three parents of children with disabilities and one adult with disabilities). Applicants not actively involved in existing advocacy organizations were given priority. Within that population, every effort was made to select people representing minorities, families with low incomes, people with disabilities, and a stratified sample of people from rural, suburban, and urban areas in the state.

The 35 participants represented 34 different family units; 30 were parents of children with disabilities and 5 were adults with disabilities. The mean age of the first cohort was 36 years, and the mean age of the parents' children in this cohort was 6.5 years. Unfortunately, only one minority applicant was received for the first year cohort; however, many minority applicants have been received and accepted into the second year cohort. Table 1 outlines the characteristics of Year 1 participants.

#### **Program Expenditures**

In order to encourage people to participate regardless of economic status, the program covered participants'

Table 1		
Year 1 Participant Ch	aracteristics	

Factor	n	Percentage
Female participants	26	74.0
Male participants	9	26.0
Parents of children with disa- bilities	30	85.7
Direct consumers	5	14.3
Participant income (\$)		
Less than 12,000	2	5.7
12,000-19,999	4	11.4
20,000-29,999	11	31.4
30,000-39,999	4	11.4
40,000-49,999	7	20.0
50,000+	7	20.0
Place of residence		
Urban	6	17.1
Suburban	20	57.1
Rural	9	25.7
Level of education		
High school graduate	8	22.9
Two years of college	7	20.0
Four years of college	5	14.3
Some graduate work	12	34.3
Master's degree	2	5.7
Doctoral degree	1	2.9

related travel, meals, lodging, respite care, and child care expenses. Only half of the first-year participants required overnight lodging during weekend training sessions; thus, the grant for the first year of operation (\$2,857 per participant) provided sufficient funds for 35 participants.

#### **Program** Activities

Participants were asked to sign a contract that obligated them to attend all training sessions and to complete homework assignments and other required projects during the year-long training program. The contract also outlined the responsibilities of Partners in Policymaking organizers.

There were three main training components: First, the core of the program consisted of eight 2-day training sessions (16 total days of training) with each session devoted to a specific service topic or level of government (local, state, or federal). Each training session began on Friday shortly after 12:00 p.m. and concluded in the late afternoon on Saturday. During each session, "experts" on specific topics such as Lou Brown, Charlotte Des Jardins, Gunnar Dybwad, Betty Pendler, and Ed Roberts were selected by the GPCDD to make presentations and talk with participants. A total of 14 presenters were recruited from outside Minnesota. Training sessions also included presentations by GPCDD staff, local and state legislators, and representatives from local and state advocacy organizations. In addition, during the cohort's visit to Washington, they heard presentations by the staffs of two U.S. senators (Senators Chafee and Weicker) and one congressional representative (Representative Florio).

The second training component involved supplemen-

tary study. Participants completed homework assignments between sessions which included (a) personal contacts with local, state, and national policymakers; (b) readings (e.g., about state guidelines for quality individual plans or a summary of existing legislation affecting people with disabilities); (c) attending community meetings (e.g., city council or school board meetings); and (d) making presentations (e.g., to parent groups, at PTA meetings, or at conferences) about the concerns of people with disabilities. The third training component required participants to complete a major project such as serving an internship or organizing a meeting with public officials.

The training sessions provided participants with information regarding local, state, and federal issues; advocacy organizations and advocacy skills; employment; nonaversive behavior management; severe physical disabilities; and specific educational issues regarding people with disabilities (e.g., IEP development, family participation, state of the art services, and educational integration). Participants received written materials on each topic for future resource and reference material and to facilitate ongoing learning between sessions. Visits to local, state, and federal elective officials helped participants learn how to seek out policymakers, prepare and deliver testimony before committees, and serve as effective self-advocates within government settings.

#### **Program Evaluation**

Participants were asked to complete an evaluation after each training session. This information provided immediate feedback to program organizers and was used to modify future training. Session topics and evaluation data are outlined in Table 2.

At the end of the program, participants were asked

Table 2           Session Topics and Participant Evaluations		
Session	Topic	Mean evaluation score (maximum score = 5)
1	History, philosophy, values	4.34
2 3	Best practices in education	4.32
3	Policymaking at county and local level	4.66
4	Policymaking at federal level and national con- vention	4.18
5	Nonaversive behavior ap- proaches and serving people with severe physi- cal disabilities	4.28
6	Policymaking at the state level	4.36
7	State advocacy organiza- tions and programs	4.44
8	Advocacy and integration	4.62
	Mean evaluation score for all sessions	4.40

to complete a comprehensive evaluation of the overall program and how well the objectives of the program were met. The evaluation provided important information as program organizers planned activities for Year 2 participants. Changes for Year 2 included a different sequence of training session topics and a decision to provide more information about supported employment and technology.

Short-term follow-up data also were collected from all graduates six months after graduation. All program graduates were mailed a survey consisting of two parts: (a) Participants again were asked several questions aimed at evaluating how well the program prepared them as self-advocates; (b), participants were asked to provide information regarding their own advocacy activities since graduation. For this second part, both quantitative and qualitative data were requested.

#### Results

When asked on the 6-month follow-up survey to "rate the program today in regards to improving your self-advocacy skills," 57% of the participants rated the program as "excellent," 37% as "very good," and 6% as "good." When asked if the program "enabled you to receive more appropriate services for yourself or a family member," 89% of the participants responded positively. When asked how "the Partners program prepared you to be an effective advocate," 82% responded "I was very prepared," and 17% responded "I was somewhat prepared."

Data collected on advocacy activities since graduation included the number of graduates serving on committees, the number of conference presentations, the amount of correspondence generated to public officials, and other quantitative measures of advocacy activities. A summary of advocacy activities is presented in Table 3.

Finally, the follow-up survey asked participants to "Indicate any other benefits or outcomes you can attribute to your participation in the Partners program." This was an important question because, based upon comments made by participants throughout the program, many important program outcomes could not be measured using quantitative methods. Responses to this survey question were categorized according to content, with the four highest categories being:

1. Fifty-four percent of the participants indicated that the program provided them with a strong support network. Most of these comments referred to new relationships that had developed among participants.

2. Thirty-one percent stated that they now had a better understanding of the system and how to access the system.

3. Twenty-three percent of the participants stated that they were able to obtain more appropriate services

 Table 3

 Advocacy Activities by Year 1 Participants During 6-Month

 Period After Graduation

Activity	n	Percentage
Level of contact		
With national officials	24	68.6
With state officials	29	82.9
With local officials	29	82.9
No contact with public officials	2	5.7
Type of contact with public officials		
Letters	24	68.6
Phone calls	32	91.4
Office visits	20	57.1
Testified at public hear- ings	4	11.4
Served on committee or commission	28	80.0
Other advocacy efforts		
Published newspaper ar- ticles/letters	15	42.9
Conference presentations	13	37.1
Presentations to parent groups	10	28.6
TV/radio appearances	3	8.6
Video presentation	3 3 3	8.6
On-the-job presentation	3	8.6

for themselves, their children, or someone else who sought their assistance.

4. Seventeen percent expressed an increase in selfconfidence, especially when interacting with legislators and educators.

#### Discussion

Several limitations to this study must be discussed. First, the methods of recruiting and selecting Year 1 participants may not have provided a representation of the population of parents and people with disabilities within the state. For example, only one minority participant and an inadequate number of low-income families were represented in the Year 1 cohort. Second, baseline data on participants' advocacy activities before training were not collected. These data would make analysis and comparisons between pre and posttraining data possible and increase the validity of the program. Future programs also may want to compare program evaluation and outcome data among participant subgroups (e.g., gender and age subgroups).

Partners in Policymaking is currently in its third year of operation. Over 80 applicants applied for the 35 positions available this year. Representatives from 13 other states have indicated an interest in replicating the Partners in Policymaking program in their home states. The number of applicants for the Partners program and the interest expressed by other states to establish similar programs are evidence of the growing demand and continuing need for self-advocacy and empowerment education and training. Future research for this project will include baseline data on the Year 3 cohort, shortterm follow-up studies on second and third-year participants, and long-term follow-up studies of all 3 groups.

Herr (1983) stated that the emergence of legal rights for people with disabilities has led to expectations that advocates will be available to defend those rights. Fortunately, advocacy for people with disabilities and their families is evolving from a service to a partnership of shared responsibility. The President's Committee on Mental Retardation (1973) once referred to people with mental retardation as a silent minority. Programs like Partners in Policymaking are teaching people how to speak out and be heard.

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February 21, 1990

Ms. Charlotte Des Jardins, Director Coordinating Council for Handicapped Children 20 East Jackson Boulevard, Suite 900 Chicago, Illinois 60604

Dear Charlotte:

Thank you again for your willingness to participate in Year 4 of Partners in Policymaking. It is always a pleasure to have you visit with us. This correspondence serves as your final confirmation.

I reserved your travel on February 20, 1990. You may have already received your tickets as you read this letter. You will depart Chicago Midway Airport at 9:00 a.m. on Friday, March 23, 1990 on Midway Airlines #333 arriving in Minneapolis/St. Paul at 10:15 a.m. Your return is scheduled for 5:55 p.m. on Saturday, March 24, 1990, on Midway Airlines #338 arriving Chicago at 7:15 p.m. I believe these arrangements are consistent with our last conversation. The Partners session will again be at the Sunwood Inn, 1010 Bandana Boulevard, West, St. Paul. I have enclosed a schedule for your convenience. Your presentation is scheduled for Saturday, March 24, 1990, from 9:00 a.m. until noon and should cover the "How To's of Advocacy in Team Meetings." My expectation is for you to share similar information as in the past three years. I will provide a standard lavalier microphone and any other audio-visual equipment you may wish to use.

I hope these arrangements meet with your approval. If you have any questions or concerns, please call me at (612) 379-3969. I will be in contact again just prior to the session to satisfy any last minute needs and to discuss a February homework assignment we would like you to follow up on in your presentation. I look forward to seeing you on March 23, 1990.

Regards,

David Hancox Director

To: Faculty, Partners in Policymaking

From: David Hancox, Director

Re: Audience Issues

We would like to take a moment to remind you about the composition of the audience of partners in policymaking We hope this information will be useful as you prepare your presentations.

- 1. The Year 4 participant group represents a wide variety of developmental disabilities. Please be sure to prepare materials which include references to all disabilities.
- 2. Nearly half of the participants in Year 4 are individuals with disabilities, and half are parents of young children with disabilities. This is a larger percentage of individuals with disabilities participating than in previous years. Please be sure to design your presentations to address all of the participants.
- 3. There will be a wide range of experiences represented in the group. Some of the participants may be very confident, while others may need some stretching. You may need to draw out the individuals who are quiet.
- 4. Please use references such as "he/she" whenever appropriate, and avoid sexist remarks. Please don't assume that everyone is a homemaker, or that everyone works out of the home.
- 5. The participants have information to share and will be expressing their need to share this information. Please be aware that there will be opportunities to do so during small group activities.
- 6. There may be some anger in some participants because of previous bad experience. While we try whenever possible to anticipate this, we are not always successful. Please be prepared to redirect anger into solutions or discussion whenever possible.
- 7. Finally, we are not condoning "professional bashing" during the Partners sessions. Our goal is to give individuals the tools they need to build effective partnerships to influence public policy. We feel it is essential to minimize adversarial feelings.

We are please and excited that you will be participating in Year 4 of Partners in Policymaking. We hope these reminders will help you as you prepare your presentation. Please let us know if we may be of service.

Thank you.