

# Partners in Policymaking: Empowering People

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*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, parent-professional 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 knowledgeable regarding available services, the kind of

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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 short-term 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 Characteristics

Factor	<i>n</i>	Percentage
Female participants	26	74.0
Male participants	9	26.0
Parents of children with disabilities	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 Pender, 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	Best practices in education	4.32
3	Policymaking at county and local level	4.66
4	Policymaking at federal level and national convention	4.18
5	Nonaversive behavior approaches and serving people with severe physical disabilities	4.28
6	Policymaking at the state level	4.36
7	State advocacy organizations 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	<i>n</i>	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 hearings	4	11.4
Served on committee or commission	28	80.0
Other advocacy efforts		
Published newspaper articles/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	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 self-confidence, 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, short-

term 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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