

Self-Advocacy Report

July 2004

The information contained in this report was collected by NACDD with funding from ADD as required in their Technical Assistance contract. The information was solicited from all DD State Councils from December 2003-March 2004. Thirty-one Councils responded with information requested on self-advocacy that is categorized into 4 main areas. It is summarized alphabetically by State within the following areas: Council Strategies and Descriptions of State Self-Advocacy programs (pages 1-15), Leadership Opportunities and Participation of P/W/DD in Leadership Coalitions (pages 15-20), Collaboration and Coordination Efforts (pages 20-22) and Other Activities (pages 22-23).

Council Strategies and Descriptions of State Self-Advocacy Programs

Arizona: The Council Quality Assurance/Self-Advocacy goal is to support self-advocates in developing and implementing a statewide, self-advocate led, cross-disability advocacy coalition. Additionally, the District Advisory Councils are supporting persons with developmental disabilities to fully participate in cross-disability advocacy coalitions. The Council implemented the aforementioned activities in order to provide individuals with the skills and opportunities that would provide them experience in order to organize a statewide, self-advocate led, cross-disability advocacy coalition. The Council has researched best practices with other Planning Councils and has decided to begin the development and implementation of a coalition through 3 phases. The project will be implemented through the identification of self-advocates willing to organize and participate in the coalition, host a summit in which the self-advocates will formulate the development of their organization and determine their policy agenda and support the self-advocates to form local coalitions that will advocate on local issues and send representatives to the statewide coalition. The Council will dedicate a staff person to facilitate the project phases.

Colorado: Report on Self-Advocacy (This is part of Section III of the 2003 PPR)

Narrative: Includes following questions on self-advocacy:

- A. Is there a self-advocacy organization(s) in the state led by individual with developmental disabilities that receives direct funding from a private or public source? YES
- B. Does the Council directly or indirectly fund a self-advocacy organization in the state led by individuals with developmental disabilities? Yes
- C. If yes, how much? \$24,195
- D. Dollars leveraged in CO for org(s) led by pwd: \$125,000

The Council has supported the development of a self-advocacy group of facilitated communication users, now called Watch Our Words (WOW). A family member whose child has a developmental disability currently facilitates the group. A person with a developmental disability, as the group coalesces and identifies its goals, will eventually lead the group. WOW participated in the conference planning for the annual conference of the Autism National Committee. Council funding also supported training for police departments throughout the state, as well as supporting the attendance at the national Self-Determination Conference by policy makers from Pueblo, Colorado. The Council also amended its Five-Year Plan to include specific objectives to the goal to monitor the States implementation of seclusion and restraint legislation. The Spring 2003 and Summer 2003 newsletters featured articles on self-determination.

Connecticut: The Council started-up, and has been supporting in-house, CT Kids As Self-Advocates (KASA.) In addition to staff support, the Council has made \$12,000 available to support KASA. In a memorandum of agreement (MOA), the State Department of Education (SDE) transferred \$10,000 to the Council to support KASA. The Council is currently negotiating with the CT Youth Leadership Project, Inc., and the SDE, for a grant to the Council for \$18,410 for future KASA's support. While two CT Council staff provided technical assistance and support to CT KASA, two CT KASA members are paid stipends to serve as organizers of CT KASA events and meetings. CT KASA has about 30 members, including one Council member. Another member of CT KASA has been recommended to the Governor for appointment to the Council. CT KASA members are between the ages of 12 and 22 and live in 18 different towns. Two (2) Youth Organizers each work in the CT Council office more than 13 hours per month arranging transportation, copying, mailings, contacting members and handling meeting logistics. Monthly Saturday meetings began with 8 consistent participants and grew to 20 consistent participants per month. Five (5) teleconferences were also held. A CT KASA website is in development via a link from the Council web page on the state server (www.state.ct.us/ctcdd/kasa/) but CT KASA is looking for a new server. A CT KASA listserve was posted during the summer of 2003. CT KASA also developed a recruitment brochure.

CT KASA presented in Salt Lake City, Utah, at the annual conference of the National Association of Councils on Developmental Disabilities, at a CT Council meeting, at the CT Family Support, Self-Determination and People First Conference and at the monthly meeting of transition coordinators and specialists from Fairfield County public schools and the regional education service center. CT KASA presented on public school inclusion to CT state legislators on March 23, 2004 in the Legislative Office Building at a Forum for Legislators sponsored by the DD Network. Later in the year, CT KASA will be making four (4) presentations to public school personnel on the topic of transition. Three (3) Council members are members of People First and the President of People First has been recommended to the Governor for appointment to the Council. Self-Advocates Chair the Council's Membership Committee. Not-for-profit non-governmental agencies are represented on the Council by a local center for independent living. A Council grant to the statewide association of centers for independent living supports the CT Olmstead

Coalition. With P&A, the Council supported a member of ADAPT of CT to participate in a march from Philadelphia to Washington, DC, in support of MiCASSA.

Council members who are self-advocates form an *ad hoc* Council Member Support Committee. The Council contracted with an outside consultant to work with the Committee. Their recommendations have resulted in numerous improvements in the Council process that is enabling better participation by self-advocates. The Council is establishing an "advocacy, education and empowerment" fund to enable self-advocates, and others, to attend state and national events. CT KASA and a local center for independent living are hosting DD Network Public Forums. Finally, a Council staff person is a person with developmental disabilities and has been serving as a full-time Disability Policy Specialist since 2000.

District of Columbia: We have begun putting in place structural needs to accommodate the growth of a State-wide self advocacy coalition. As two of our program initiatives are focused on training individuals with developmental disabilities, we plan to utilize, as a start, these individuals as part of our resources pool. Also, we have begun collaboration with DCPS to incorporate Special Education students at the Jr. and Senior high levels, as well as existing organizations such as Independent Living Council, individual consumers serving on Advisory boards, etc., and we are working with a consultant to design the forum for self determination training.

Florida: Florida's second self-determination conference on August 22-24, 2003, can only be described as bigger and better. The conference was hosted by the Southern Movement for Independence (SMI). It is estimated that 750 people attended the conference this year.

The conference was funded by the Florida Developmental Disabilities Council, Inc. (Council). The funding included financial assistance for 430 individuals with a family member or their personal care attendant to attend. Other major contributors were The Advocacy Center for Person with Disabilities, Inc., The Department of Children and Families Developmental Disabilities Program Office, The Florida Department of Education, the Florida Association of Support Coordinators and the ARC/Florida.

Nila Benito, chair of the Council, welcomed everyone and spoke of the Council's and her personal commitment to the self-determination movement. Then the honorable Pam Iorio, Mayor of Tampa, welcomed everyone to Tampa and spoke on her efforts to ensure everyone could vote and of creating a city that cared. John Satterwhite, president of SMI, added his welcome.



left to right: Kathy Burton, Pam Iorio, Leslie Wilson, John Satterwhite, Carl Suter
Nila Benito (speaking), Shelly Brantley, Michele Polland, Maria Risco

The theme of the opening session was employment. Carl Suter, Executive Director, Council of State of Administrators of Vocational Rehabilitation, provided an overview of national rehabilitation issues. He was followed by a panel presentation on the state of Florida's Employment Services. Panel representatives included Shelly Brantley for the Developmental Disabilities Program, Michele Polland for the Department of Education and Maria Risco for the Division of Vocational Rehabilitation.

This conference was unique in that the SMI Board of Directors collaborated with the Florida Association for Support Coordinators, Florida Association of Persons in Supported Employment and Florida AAMR to ensure networking and cross training on self-determination for all the stakeholders. Educational opportunities abounded with seven tracks and 24 exhibit tables being available to conference participants. The seven tracks included - Support Coordination and Self-Determination, Support Staff and the Self-Determination Movement, Speak Up for Yourself, Self-Determination and Families, Employment with Florida APSE, Self-Determination and Transition, and FL-AAMR.

After dinner, Josh Leibowitz, secretary for SMI, announced that SMI was beginning the process of advertising for an executive director. Sue Suter, from the Center for International Rehabilitation in Washington, D.C., then facilitated a panel discussion of national and state self-advocates on how self-determination had changed their lives. Joe Meadours, from The Meadours Firm, in Montgomery, Alabama; Tracy Rackensperger, Vice-President of SMI and member of the Council; and Martha Sheldon from the University of Miami and Treasurer of SMI were the panel members. Tia Nelis, with the Research and Training Center



Chris Drummond & Idelio Valdes, Jr

on Aging and Developmental Disabilities from Chicago, Illinois, came back this year and roused the crowd to chanting "Free my people." The evening panel discussions ended with Shelly Brantley speaking briefly about the Independence Plus program and introducing self-advocate Ashlie Wiegel to tell her story about self-determination and being a part of the Independence Plus program. Ashlie captivated the audience with her newly-developed Power Point presentation.

Then the dancing began with Total Entertainment from Boca Raton, Florida, providing the music. Conference participants partied late into the night and still managed to get up in the morning for breakfast and another panel discussion.



Sunday morning, the session was about the state of self-determination. James Conroy, President, The Center for Outcome Analysis, confirmed that

Ashlie Wiegel with her assistant

self-determination was unfolding in the United States.

He noted that Florida was the leader in the movement for several reasons, including having a network of support coordinators and an expanding Independence Plus program, but more importantly, Florida was unique because of the leadership being presented through SMI. Joe Meadours and Tia Nelis were part of the panel. Ms. Nelis spoke on the strength in numbers and reminded the audience that they were not alone. She let them know as they continued their efforts toward self-determination that others are with them, if not physically, then in spirit. She made a rallying call for everyone to bring at least one more person to the next conference. When she comes back she wants to see 1500 people in the audience. John Satterwhite spoke of the beginning of SMI -- a time when there was only a dream of a self-determination organization in Florida. He closed by reminding the audience that today SMI is searching for an executive director. Last but not least, conference participants gathered by their home districts to begin thinking about the future. Fourteen districts were represented in the strategic planning session. Leslie Wilson of Wilson Resources, Inc. read the various ideas for future activities and informed the group that SMI would incorporate their input into a strategic plan document to share with the group in the near future.

SMI is a Florida-based organization of self-advocates promoting the self-determination of individuals with developmental disabilities. SMI is currently sponsored by the Council. For more information about SMI, visit their website: www.southernmovement.org.

A special thanks is owed to the Hyatt Regency Tampa Center staff who participated in training before the conference and did a superb job during the conference. There were a number of compliments received on the courtesy of the staff. Numerous of compliments were also received on the great job Wilson Resources, Inc.'s staff did in organizing the conference and keeping things running smoothly during the course of the conference.

Georgia: One of the goals of the Governor's Council on Developmental Disabilities is that: People with developmental disabilities and their families will have opportunities to exercise leadership in organizations and in the disabilities rights movement. It is our expectation that through Council support we can increase the number of people with developmental disabilities and family members that have the information and skills to exercise leadership, self-advocacy and self-determination.

Hawaii: The Council's strategies for supporting self-advocacy includes:

1. Sponsoring trainings on person-centered planning with focus on the principles of self-determination and how to incorporate those principles in the Individual Service Plan process.

2. Sponsoring individuals with DD and families to participate in the Annual Pac Rim and Can Do Self-Determination Conferences. Participants have the opportunity to learn about best practices in DD, share their experiences with others through panel presentations, and networking with other self-advocates and families.
3. Sponsoring and hosting the Annual Direct Support Workers Conference. Participants at this conference learn innovative ways of supporting individuals with DD and their families.
4. Coordinating and sponsoring the Partners in Policymaking (PIP) Leadership Academy. PIP provides participants with knowledge about the current issues and best practices in disabilities and the service system in Hawaii. Participants develop skills in advocacy and policymaking. They learn about the legislative process and strategies for legislative advocacy. Partners have contributed to their community by:
 - a. Running for political office
 - b. Being appointed to councils, boards and advisory groups
 - c. Establishing support groups
 - d. Advocating before the legislature, governor and other state and county departments
 - e. Leading the development of accessible programs and facilities

The Council has sponsored this event for the last 10 years and there are 161 graduates.

Idaho Council's plans for supporting self advocates include:

- a) Financial support for self-advocates, particularly Council members, to attend conferences and trainings to enhance their leadership skills and abilities;
- b) Regular evaluation of Council materials for "user friendliness"
- c) Plans to provide a one-day pre-conference track for self-advocates in October; parallel to that will be a workshop on facilitation for support staff
- d) The support and enhancement of People First chapters; this has been

done over the last three years through a contract with Washington People First and has resulted in the development of 6 fledgling People First chapters in north Idaho; since progress toward contract goals has been uneven and slow, that contract has not been renewed; instead, after further analysis, it has been determined that the lack of trained and available advisors is a major obstacle to further organizational development, so the Council is developing an RFP to provide training and payment to a cadre of advisors statewide. The recruitment, training (through a contract with HSRI consultants), and development of two teams of self-advocates to conduct regional awareness and informational training on the principles of self determination; these individuals, the *Self-Advocate*

Leadership Network, have already made presentations to the Idaho Legislature and the statewide Parents Conference; three of the six will accompany our Council Chair (also a self-advocate) to the SABE convention. May do a similar presentation there.

- e) Including self-advocates on the Self-Determination Task Force and encouraging their leadership in that effort; one self-advocate is chairing the subcommittee on Fiscal Intermediary services and helped present a report on the Task Force to a legislative committee; another self-advocate presented with the Council Director at a statewide health care summit on a panel led by Former House Speaker Newt Gingrich; the two of them will be part of a panel presentation at a conference in Seattle in April with the UCEDD and P&A Directors.
- f) A Council self-advocate and staff member are making presentations to secondary students and their parents and teachers at transition fairs in southwest Idaho.
- g) The Council Chair is heading up Idaho's Project VOTE team that will attend training in Chicago in May and then provide training to a variety of groups across Idaho on voting accessibility.

Illinois: Council was instrumental in establishing People First of Illinois in the early 1990s. Financial support for the organization continued for over 10 years. As the partnership developed, self sufficiency of the organization was a topic of great concern for People First of Illinois. In 2002 the board of People First of Illinois informed the Council that financial support from the Council was no longer needed.

Three years ago Illinois CDD invested in Illinois Lifespan. This is a project developed as a information and advocacy coordination system. The vision of this project is to have one place where people with developmental disabilities and their families can go to get information and the advocacy support they need. One piece of this project involves working with existing advocacy organizations within Illinois to help them get better and thus, provide better customer service related to advocacy. The Illinois Lifespan project is working to help People First of Illinois address issues related to the advocacy services they provide.

Iowa: The Council supports the availability of accurate, timely policy information with the distribution of InfoNet to 2050 Iowans with disabilities, family members, advocates, providers and others. ID Action, the Council's campaign to empower Iowans with disabilities has grown to 1429 registrants, 1118 of whom are persons with disabilities. This year ID Action, with the help of two new outreach staff, recruited Iowans to the campaign, and assisted them to register to vote, discuss issues with candidates, and access the information and resources needed to maximize their participation in critical decision-making arenas.

The ID Action project encouraged greater participation in democratic decision-making by providing information and training resources to 1400 registrants. ID Action Town

Meetings, held to gain a broader perspective on the civic and political involvement of Iowans w/ disabilities, attracted the 319 participants in the following locations:

Atlantic	55
Dubuque	85
Waterloo	47
Burlington	65
Rock Valley	67

The Council continues to provide technical assistance and other resources as needed to a group who is working to establish a State-wide People First Organization. There are now 110 members who are beginning to articulate their needs for assistance with organizational development. The Council will continue to be responsive to the needs of this group as they build the organization; the only of its kind in Iowa.

Kansas: See PPR

Kentucky: We have created a self-advocacy organization through our "Self-Advocate Facilitator" project. This organization is made up of and run by self-advocates. They have elected to call themselves "Kentucky Self-Advocates for Freedom". This project is roughly two years old and we currently have 6 local chapters 3 pending and a statewide board of directors.

Louisiana: Two years ago the Council provided funding for and initiated the creation of a statewide self-advocacy organization that the Council continues to fund. The organization has grown to over 300 members and 21 local chapters. Members elect officers for the organization, develop legislative agendas and prepare position papers.

Maine: The Council provides significant funding for the state's self advocate's group and provides technical assistance. The SA group is partnering on a grant that is awaiting funding approval. Additionally, the SA group has a permanent seat as a fourth "Network Partner" on the Council.

Maryland Developmental Disabilities Council supports leadership opportunities for people with disabilities in many ways. In general, we support individuals with developmental disabilities and family members to be involved at the policy/systems level and work to increase opportunities for advocacy, leadership, and active participation by people with developmental disabilities and their families.

- The **Family NetWorks Project** offers opportunities for supporting, networking, and connecting families through an interactive and family friendly website. Originally developed under a grant from the Administration on Developmental Disabilities family support initiative, the website is a comprehensive online resource for disability-related information and supports specific to the needs of Maryland families that include a member with a

disability. Users access information and community resources and, under a section called “Creating Change,” learn about ways to become involved in policy issues that promote self-determination, choice and full inclusion. We have had as many as 85,000 hits/month on the website.

- The Family NetWorks project sponsors diverse support groups throughout Maryland to develop their advocacy and leadership skills and build their influence. Groups have widened outreach and dissemination about community resources, and increased access to services for families previously unserved or under-served. Those reached included families whose child was recently diagnosed; military families; Latino, Korean and other cultural and linguistic minority families; and families in the urban Empowerment Zone and rural areas of the state. At a Council retreat focused on the topic of self-advocacy, self advocates representing groups from around the state made it clear that youth and young adults are vital resources for the self-advocacy movement and interested youth must be mentored and supported to develop skills so they can become actively involved.
- As a result, the Council recently announced a Request for Concept Papers on **Youth Self-Advocacy**. The Council is soliciting proposals that will support and encourage adults with disabilities to outreach, educate, mentor, and support youth and young adults with developmental disabilities to improve their individual advocacy skills and then to take collective action on an issue they deem important for themselves and other youth with disabilities. This project will identify strategies to reach youth and young adults with disabilities and find creative ways to educate them about issues that have direct and present impact on their lives. Throughout the project, activities will promote and support the development of self-advocacy skills and networking, and maintain the active involvement of participating youth in pertinent systemic issues.
- The **Maryland Council website** publicizes opportunities for participation in public policy issues and has information on how individuals can become involved. Self-advocacy and leadership development continue to be a major priority for the Council and are incorporated in much of the Council’s advocacy and grant making on a range of issues, including employment, housing, and transportation. Council funded initiatives are required to include cross disability and culturally diverse representation on their advisory committees. The Council also requires the inclusion of people with disabilities and family members in all Council collaborative activities.

Minnesota: A survey was undertaken in January 2004 and there are 36 local self advocacy groups operating in Minnesota. New self advocacy groups have begun as a result of People First Minnesota efforts funded by the Council. Other activities include People First Minnesota working with the Arc of Minnesota, Advocating Change Together, and Centers for Independent Living.

Mississippi: The Council directly funds a group of individuals with developmental disabilities supporting their effort to become leaders and train other individuals with developmental disabilities to become leaders. This project is funded through the ARC of Mississippi. In our state the ARC stands for The Association for the Rights of Citizens with Developmental Disabilities. The self-advocates selected a program entitled “My Voice, My Choice” as their primary tool for training purposes.

Missouri graduated 25 individuals from the 9th Partners in Policymaking class. We maintain a listserv to offer ongoing support and encouragement in advocacy and leadership efforts by our 150 Partners graduates and invite active Partners to a biannual conference and biannual Partners Graduate program. The Planning Council also supports People First, our statewide self-advocacy organization. Members of the 42 chapters take active leadership roles in local, regional and state legislative and policy issues. They collaborate with our Regional Advisory Councils to assure grass roots input into the state service system.

Nebraska Council provides direct support to the state’s self-advocacy organization, People First of Nebraska. This organization continues to grow and their leadership is being asked to participate on a number of statewide committees. A small grant in western Nebraska supported 32 students to start a student chapter of People First in their area with the outcome being improved social skills and self-advocacy. Council staff continues to work with the state’s Real Choice grant that is changing the service system to one that supports self-direction. The Council is also supporting the efforts of HHS with the Community Supports Pilot. The model with 20 people is letting people change from specialized service providers and contracting for their own selected services under a capitated amount.

New York State DDPC (DDPC) has supported the self-advocacy movement from its beginning. In 1988, the Self-Advocacy Association of NYS (SANYS) was founded with the financial support of the DDPC. Our financial support continued until they were fiscally sound and had established a Statewide and regional organization. During that time, we provided technical assistance (where necessary) on topics including organizational development and fund management.

Over the past few years, we have co-sponsored the annual SANYS conference as well as funded self-advocates travel, registration and other costs of attendance at events at the State, federal and local levels. In addition, the DDPC has worked hand-in-hand with self-advocates and SANYS on programmatic improvements such as the “Creating Opportunities for Self-Determinations”. This project, administered by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), laid the groundwork for the self-determination program that is being refined today.

Currently

New York is currently working under its 2002-06 State Plan. Several areas of the Plan have direct application to self-advocacy.

<p>II. <i>From our State Plan 2002-06</i></p> <p>III. Objective CS 3.6</p> <p>IV. To engage in at least 4 activities that move the developmental disabilities service system towards use of a self-determination program and/or funding model(s).</p>	<p>5 activities are underway</p> <ul style="list-style-type: none"> ◆ OMRDD/SAA Self Determination Projects (have been undertaken) ◆ OMRDD & SAANYS training projects ◆ OMRDD Statewide Conference in 11/'02 ◆ National Self-Advocacy Conference in 9/'02 ◆ Multi-Cluster SD Summit <p>Other activities are:</p> <ul style="list-style-type: none"> ◆ Possible changes to policy and regulation ◆ Issue identification & model clarification activities
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The DDPC is funding initiatives with OMRDD and SANYS in Self-Determination that are supporting the self-advocacy movement. The Self-Determination projects are laying the infrastructure for a service system built on self-determination by increasing awareness of self-determination, encouraging individuals to think outside the normal service parameters and training self-advocates in deciding if self-determination is right for them. These projects include:

- SANYS' "Helping People Achieve their Dreams," which is developing curricula and providing training to self-advocates to develop their circles of support, create person-centered plans, develop individualized budgets and supervise their own staff. This grant also funds internships that enable self-advocates to work within OMRDD.
- OMRDD's Self-Determination pilot is providing comprehensive training and technical assistance to self-advocates and their families. The project is being undertaken in partnership with SANYS and is establishing self-determination learning environments in the Rochester and Westchester Universities Centers for Excellence and Developmental Disabilities.
- SANYS is working in collaboration with OMRDD in the newly-developed New Options Institute that is developing training opportunities for support brokers who will provide support to self-advocates.

<p>V. <i>From our State Plan 2002-06</i></p> <p>VI. Objective QA 3.1</p> <p>VII. To train at least 40 persons annually through the Partners-In-Policymaking Training Program by 2006.</p>	<p>2 activities are being undertaken:</p> <ul style="list-style-type: none"> ◆ PIPM Training. ◆ Partners Planning Focus Group. <p>Additional activity identified:</p> <ul style="list-style-type: none"> ◆ Ongoing evaluation activities.
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Over the last four years, our Partners-in-Policymaking (PIPM) grant has trained approximately 150 individuals about 45 of whom are self-advocates. These self-advocates serve on the boards of the SANYS, Board of Education, Americorp, DDPC and other local entities. Additionally, some of the self-advocates participating in PIPM serve in various leadership capacities including Board of Directors, as Director of Parent Advocacy Organization and members of a Town Boards.

North Dakota: Refer to our 2003 PPR where these activities are already described.

Oklahoma: The Council’s major commitment to self-advocacy is the support of the Partners in Policymaking program. For the past nine years, the Council has actively recruited and trained self-advocates with this national curriculum. To assure active participation, self-advocates are offered the assistance of a graduate mentor – a person who will assist in any way asked – from taking notes to assisting with homework assignments, or simply providing moral support during the class. These mentor relationships have provided companionship opportunities and great relationships. For the past nine years, the Council has actively recruited and trained self-advocates with this national curriculum.

Oregon: Since 2001, the Council has provided financial support for the administration of Self-Advocates As Leaders (SAAL), a statewide organization dedicated to leadership development and influencing public policy through the involvement of self-advocates in policy making. The Council dollars are used to leverage State dollars to support training activities of SAAL. SAAL’s organizational structure includes an Executive Director, support staff and several standing committees that meet regularly.

Rhode Island: In this past year, we explored the kinds and methods of self-advocacy that are practiced in Rhode Island. We interviewed people with developmental disabilities, to find out what makes them feel good about themselves, and what they need from their supports. We also talked with folks who could give us a “systems” picture. We looked to “broaden the scope” of self-advocacy with what we found.

We found in general, that support staff need to learn to be more of a shadow. They need to be sensitized about when they are over-assisting, and when their assistance is really needed. We also found that there is a good bit of active advocacy for supports and services (primarily for funding purposes), but that there is a gap between truly personal concerns and what is being funded. It was felt that an initiative which focused on internal strengths and feelings of self-esteem fostered ability to manage problem-

solving, and promoted overall health (feeling good, and feeling good about yourself, makes you a good self-advocate) would be beneficial.

South Carolina - During the 2002-03 fiscal year, 19 people (5 self-advocates and 14 parents) completed the sixth Partners In Policymaking class. The participants gained knowledge in: History of Disabilities; People First Language; Disability Rights and Law; Inclusive Education; Transition into and out of school; Positive Behavior Supports; Independent Living; Supported Living; Supportive Employment; Assistive Technology; State Legislative Process; Federal Legislative Process; Disability Benefits; Parliamentary Procedures; How to Run an effective Meeting; Accessible Meetings; Freedom of Information Act; HIPPA; Service Coordination; Personal Outcome Measures; and Person Centered Planning. 1,214.15 hours were spent by PIP participants on education and awareness. It is estimated that 607 people were reached.

In January 2004, the South Carolina Council is helping to sponsor the Spirit of Self-Advocacy, the third Carolinas' Self-Advocacy Conference hosted by Our Voices Count Too, which is a Self-Advocacy Group served by Florence County Disabilities and Special Needs Board. The People On the Go Self Advocacy Group received a grant from the DD Council. The group's goals are: 1.) training session on how to be a better public speaker. 11 self advocates learned how to be better public speakers. 2.) Get training on rights. 43 self advocates received training on rights. 3.) Produce a newsletter. 65 self advocates on mailing list receive newsletter. 4.) Go to conferences to learn how to be better self advocates. 10 self advocates went to the NC Self Advocate Conference. 6 self advocates went to the Arc of SC and Arc of NC conferences. 5.) Have a consumer review committee to look at accessibility. 10 advocates conducted two reviews. 6.) There were 7 meetings of the People on the Go officers. There were 12 meetings of the group and about 45 people in attendance at each meeting.

South Dakota: The Council initially issued a Request for Funding (RFF) for someone to re-energize the statewide Self-Advocacy Organization and to include leadership training for individuals with DD. After 2 years of funding, and not seeing the leadership results that were hoped, the Council chose not to fund the original project and issued a new RFF. The proposals in response to the 2nd RFF were not funded and the Council at its January meeting issued a new RFF specifically for "Leadership Development for Adults with DD". This new RFF specifies the number of individuals that must participate in leadership development training - based on a national curriculum - and the follow-up that is expected.

Tennessee: Support to People First of Tennessee to produce a book, Success Stories, about sixteen people who left institutions and now live in the community.

- a. Support of People First of Tennessee to attend various self-determination, self-advocacy meetings.
- b. Requiring inclusion of individuals with disabilities on advisory committees for specific grants.
- c. Partners in Policymaking is in its 10th year and YLF is in its 4th.
- d. Consumer Education Fund supports self-advocates to attend meetings,

conferences and workshops around the country this year. These opportunities generate information that individuals with disabilities and their families use to advocate for themselves and to take control by exercising choice and decision-making in the services and supports they receive.

- e. Funded expansion of Middle Tennessee Center for Independent Living in the form of two satellite offices.

Texas: TCDD requires that all projects have Project Advisory Committees and that they include self-advocates and family members, and encourages grantees to ensure that self-advocates are involved in planning and implementation of projects. TCDD is currently developing activities to further encourage advocacy training provided by self-advocates for self-advocates.

Vermont: One of our current sub-grantees is the Green Mountain Self-Advocates. This is an extremely active organization with state-wide membership.

In FY 2003, Council funding assisted about 75 self-advocates and family members to attend trainings and conferences to increase their knowledge and skills about self-advocacy and substantive disability issues. The Council also provided support for several conferences and events that support self-advocacy, and further rights and supports for people with disabilities and their families, including Disability Awareness Day, Developmental Services Legislative Breakfast, Community Developmental Services Communication Conference, Voices and Choices, and Parent to Parent of Vermont's "Partners in Care" Conference.

FY 2003 was the first year in which substantial support was provided to Green Mountain Self-Advocates (GMSA), GMSA made significant strides in setting up a website; developing a five-year plan; developing the infrastructure for a quarterly newsletter; holding workshops using a SABE toolkit to develop local self-advocacy groups, including groups with high school students; developing a self-advocacy curriculum; working with the Real Choices Project to develop best practices for including people with developmental disabilities on boards; and working with the Vermont Center for Independent Living on best practices for supporting people with developmental disabilities. GMSA also developed and produced a wonderful video on the Bill of Rights for People with Disabilities, using actors with developmental disabilities.

Virginia's DD Council has several initiatives reflecting a bold strategy for supporting self-advocacy requirements of the DD Act. In the context of the State Plan, the Council includes in its Quality Assurance (QA) activities -- i.e. those designed to enhance the skills and impact of consumer self-advocacy initiatives -- the Partners in Policymaking Program, (PIP) the Youth Leadership Forum, (YLF) and its recent initiative, "New Voices." The Council's three Quality Assurance Goals, met in these projects, are

distributed among the three areas of emphasis, or life goal areas, in the State Plan for FY '03.

Wisconsin

1. WCDD supports self-advocates to build a statewide organization governed by people with disabilities:
 - WCDD awards an annual grant (\$70,000 in 2003-2004 contract period) to People First Wisconsin to maintain a statewide office, toll-free telephone line, website, and newsletter through which people with disabilities and others can access information, resources, and technical assistance from People First Wisconsin staff.
 - This core grant enables People First Wisconsin to build membership (650 statewide) and develop local self-advocacy groups. In the last year, People First increased the number of local groups affiliated with People First Wisconsin from 12 to 18.
 - The core grant also supports the People First Wisconsin Board of Directors to meet six times yearly to set policy priorities and govern the organization. The board membership consists of representatives from local affiliates.
 - People First Wisconsin has a staff of six part time workers. People with disabilities comprise 85% of the staff.
2. WCDD supports leadership training to emerging self-advocacy leaders.
 - People First uses its board meetings as a training ground and incubator for self-advocacy leadership.
 - People First presents self-advocacy and leadership trainings to local self-advocacy groups and local and statewide conferences. Topics include self-advocacy, self-determination, legislative advocacy, health, relationships, and voting.
 - People First staff offer support to students and teachers around the state in regard to self-advocacy and transition, conducting workshops, providing written materials, presenting at statewide special education conferences, and participating in a statewide transition consortium.
 - People First offers a two-part board training to organizations interested in including self-advocates on their boards of directors. One part is aimed at self-advocates learning the roles and duties of board members. The other part is aimed at current board leadership on methods of incorporating the contribution of a self-advocate in a meaningful way.
 - People First staff developed and facilitated a leadership group for women with disabilities who live in Milwaukee.
 - People First staff and WCDD staff support the participation of self-advocacy leaders on the Council and in Survival Coalition, a statewide, cross-disability advocacy coalition.
3. WCDD assists self-advocates to participate in cross-disability coalitions.

- With help from WCDD, People First has taken the lead on advocacy to close state-operated institutions and private ICFs/MR. People First and WCDD co-sponsored a State Centers Work Group that advised the state on its plan to significantly downsize one of the state's three DD Centers.
- Self-advocates from People First and Adapt participate in the cross-disability Survival Coalition and co-lead the Survival Coalition workgroup on institutions
- WCDD's DAWN cross-disability advocacy initiative has provided small grants to People First leaders and other self-advocates to carry out advocacy events.
- WCDD assisted hundreds of self-advocates to participate in a cross-disability rally at the state Capitol. People First created the "Faces of Freedom" poster displayed at the Capitol for two weeks around the time of the rally.

Leadership Opportunities and Participation of P/W/DD in Leadership Coalitions

Arizona: The Council has initiated support efforts to achieve this goal through leadership training and providing people leadership opportunities. The Council has hosted 2 leadership trainings, funded Partner's in Policymaking and provided scholarships for consumers to attend non-Council related leadership training. Furthermore, the District Advisory Councils have provided technical assistance to leadership development programs on how to incorporate persons with developmental disabilities.

Colorado: The Council funded advocacy and civil rights training conducted by self-advocacy groups ADAPT and the Colorado Cross Disability Coalition.

Georgia: The Council is supporting two projects that promote leadership and innovative learning for self-advocates within Georgia. The first is the Georgia Voices that Count project. Developed and led by self-advocates, it is an innovative learning and leadership development program for people with disabilities. Each year 15 people with disabilities are chosen and given scholarships to participate in the program whose goal is to build strong leaders in self-advocacy who can work for change in our communities, in our state and in our nation. Advocates and community leaders gather four times throughout the year in different areas of the state to learn about Self-Determination, civil rights, community living, employment, and advocacy. After a year of work and learning, graduates celebrate commencement at the Council sponsored DD Day at the Capitol. (See 2nd Project under "Other" category at the end of this report)

Illinois: Support continues to be provided in a number of ways. The Council's Consumer Stipend project is a vehicle by which self-advocates and family members can apply for money to attend conferences of their choice. This very popular project has benefited numerous participants for the annual People First of Illinois conference. As part of its Five Year State Plan ICDD has a leadership development performance target.

The Council released a Call For Investment and funded two projects to help meet the target of 10 individuals with developmental disabilities being identified and trained, and then having them lead others in a policy issue related to disabilities.

Iowa: The Secretary of States civic outreach project with the Council trained 300 Iowans with disabilities as policy advocates, introduced 440 young Iowans to disability policy and the role of government in policy-making and with a voter registration drive that registered 1100 new voters, increased public awareness of the under-representation of people with disabilities in political processes.

Kentucky: We also have two Projects to train consumers, parents and professionals in self-advocacy.

Louisiana: The Council funds leadership training academies for self-advocates aspiring to leadership positions on the local, regional, or state levels.

Maryland: Many efforts supported by the Council identify and involve new and emerging leaders, including youth and young adults. These efforts identify, promote and support opportunities for training new leaders. **Partners In Policymaking** provides leadership training for parents of young children with severe disabilities and people with developmental disabilities so that they become skilled systems change advocates. The purpose of Partners in Policymaking is to provide education and training in the five key areas: inclusion, integration, productivity, self-determination, and independence. For the eight years that the Council has provided funding to the Partners in Policymaking program, approximately 30 parents and self-advocates from around the state were trained each year to work for individual and systemic change. In FY04 the focus of program activities were to re-franchise the group of Maryland Partner Graduates – approximately 250 individuals. The approach taken provided additional support to Partners that are currently involved at a productive level, and gave support and addressed needs to reactivate Partners who are less active. Staff undertook a variety of activities to assist graduates of all previous Partners in Policymaking classes to increase their involvement in, and impact on, systemic issues of interest to them.

- **The Maryland Youth Leadership Forum** (Independence Now) works to identify students with all types of disabilities, entering one of their final two years of high school, who have exhibited leadership skills. Participants apply for this weeklong sleep over training where they are able to become leaders by example. YLF students expand their knowledge of the culture of disability, learn about all types of disabilities, and meet adults who are living successfully with disabilities. Each year, YLF trains approximately 25 students with a range of disabilities from around the state. Two graduate sessions were held in FY03: one for students who were transitioning out of school and one on the ADA and knowing your rights. These graduate sessions provided specific high-level information to encourage continued growth of personal knowledge and networking and were attended by a total of 35 YLF graduates.

- **The Family Networks project** also awarded a grant to People On the Go, a statewide self-advocacy group, to support “Becoming Effective Leaders” training.
- The MD Council sponsored, as part of the Campaign for Freedom, an internship by a person with significant disabilities in a state senator’s office. This **Legislative Internship** involved reviewing budgets and bills that deal with disability issues and subsequently educating policymakers on bills that affect people with disabilities. Examples of legislation that were a focus in 2003 were bills regarding: the DDA budget; hate crimes, custody issues; Money Follows the Individual; and a Medical Assistance Program for Employed Persons with Disabilities. The internship was such a success that the Developmental Disabilities Council decided to sponsor the internship again for the 2004 legislative session.
- The MD Council established its **Legislative Advocacy Support Fund** in 2001, which has been instrumental in assisting approximately 45 people with disabilities each year to educate and inform their state legislators. The Fund supports people with disabilities and family members to be involved in advocacy activities in Annapolis by assisting with costs related to transportation, personal assistance services, and child care.
- **Living Free: The Campaign for Freedom**, is a project led by people with developmental disabilities. For three years this group has educated and influenced legislators about deinstitutionalization while they trained self-advocates and helped organize them around this issue. Through this project, People on the Go of Maryland assisted self-advocates to increase their advocacy skills to help people move out of institutions and live in the community. Project activities included a Statewide Self-Advocacy Conference and Legislative Activities such as a State Governmental Affairs Seminar, Developmental Disabilities Day at the Legislature, on-going Focus Groups, and a Legislative Internship in the Maryland General Assembly. The group also coordinated Quarterly Leadership Meetings and Federal Legislator Visits to describe the Campaign for Freedom and urge their support to help states implement Olmstead.

Minnesota: Fourteen self advocates provided leadership training in 2003.

Mississippi: The Council directly funds a group of individuals with developmental disabilities supporting their effort to become leaders and train other individuals with developmental disabilities to become leaders.

Missouri: The Council assisted numerous members of People First in participating at the national level to strengthen their leadership in Missouri. We supported and assisted the Missouri Advocates for Individuals with Developmental Disabilities (MOAIDD) by

recruiting and training additional volunteers. This program provides volunteers to visit group homes and ISL residents to assure that residents have quality services.

Nebraska: In addition to supporting the state organization, the DD Regional Council’s provide funds to local chapters to increase leadership opportunities for local members.

New York: Additionally, we continue to support self-advocates participation at events throughout the State and perennially support SANYS Annual Conference (including the National Self-Advocacy Conference which was held in New York State in 2002).

Four years ago, the NYDDPC began a cluster of projects entitled “Promoting Leadership Opportunities” that sought to train self-advocates for leadership positions on community service boards as well as provide the supports once their board service begins. In 2003, 46 self-advocates participating in this program assumed leadership positions on public and private community boards.

<p>VIII. From our State Plan 2002-06</p> <p>IX. Objective QA 3.4</p> <p>To identify at least 12 effective models for training individuals with developmental disabilities to become members of community boards of director/planning bodies that result in 60 individuals becoming members of such community boards/bodies by 2006.</p>	<p>2 activities are being undertaken</p> <ul style="list-style-type: none"> ◆ Leadership Opportunities projects. ◆ Syracuse Univ. TA & Evaluation. <p>Additional identified activity:</p> <ul style="list-style-type: none"> ◆ Conduct on outreach campaign to state and local agencies and service systems serving persons with developmental disabilities to recruit, train and support self-advocates and organizational leadership positions
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Oklahoma: In addition to the Partners class, the Council offers Partners in Policymaking participants an annual Legislative Day, at which pending Oklahoma legislation is discussed; and Graduate Academy, a bi-annual “brush-up” course on advocacy issues.

Self-advocates are further supported by the Council through the Consumer Involvement Fund, Justin A. McCurry Resource Library, and AccessNet Computer programs. The Consumer Involvement Fund (which has a very high user rate and satisfaction rate for self-advocates) provides financial assistance for persons with disabilities and their family members to attend in-state and out-of-state conferences related to developmental disabilities. Annually the Council sends the leadership of Oklahoma People First to their national/international conference. The Justin A. McCurry Resource Library is a research and lending library inside the Council office. Included in the library are print, audio and video materials on specific disability types, broader disability issues, and management and leadership topics. AccessNet is a project of the Council that places and supports

accessible public-use computers in local libraries. There are 55 such computers throughout Oklahoma equipped with accessible hardware and software

In FY 2003, the OK Council, working with the Oklahoma Disability Law Center and Center for Learning and Leadership, promoted a concept of a luncheon round table for leaders and emerging leaders in Oklahoma self-advocacy. We invited persons with disabilities to meet for a free lunch (and transportation and attendant care would have been provided) to discuss leadership topics. We announced this program both through Oklahoma People First and Oklahoma Partners in Policymaking, but received no response to our offer.

Oregon: SAAL leaders participate on all the major statewide advisory groups and advocacy coalitions, as well as on many local and regional policy-making bodies. The Council and SAAL have collaborated on many trainings, including Partners in Policy Making and legislative advocacy trainings.

South Carolina - The Council awarded funding to sponsor a Leadership Forum in conjunction with DDSN. The forum was to help self-advocates realize their empowerment by providing information and building on the skills they already have. Also, the council partnered with the ARC of the Midlands to provide People On the Go, a group of self-advocates who meet to learn how to be better advocates by learning how to speak up for themselves and also learn about rights.

South Dakota: Beyond our initial training project, the Council would hope to utilize the local "leaders" to train others on a regular basis and see what develops as far as a statewide advocacy organization.

Participation of individuals with DD on other leadership coalitions, etc., has mainly involved graduates of Partners in Policymaking and participants in Youth Leadership Forums. Both these avenues have added enthusiastic participants to the possible member's for many organizations such as Board of Vocational Rehabilitation, P&A boards, the DD Council, the SD Coalition of Citizens with Disabilities, Special Education Advisory Panel, and others.

Texas: TCDD directly funds self-advocacy training through grants, including Partners in Policymaking, the Youth Leadership Forum, an advocacy training program conducted in Spanish, and several smaller projects designed to develop networks of self-advocates and family members.

Wisconsin: CDD supports leadership training to emerging self-advocacy leaders. Through its core grant to People First Wisconsin and other grants, WCDD supports leadership training and experiential opportunities for emerging and established self-advocacy leaders. The Council's core grant enabled development efforts that resulted in People First securing a grant from the National Catholic Campaign for Human Development to train 70 self-advocates on leadership development. Participants will bring what they learn back to their local groups and apply their skills in local advocacy

efforts. WCDD sponsored three Advocacy Odyssey cross-disability advocacy training workshops. Self-advocates participated as learners and session leaders in each.

Collaboration and Coordination Efforts

Colorado: The Council voted in February to contribute \$20,000 to the Native American Self-Advocacy training program, a cooperative effort among the New Mexico, Utah and Colorado Developmental Disabilities Councils. The Council has directly funded other self-advocacy organizations in the state: Atlantis/ADAPT, the Center for People with Disabilities, and the Colorado Cross-Disability Coalition. The dollars leveraged for organizations led by people with disabilities by Council activities have gone to Speaking for Ourselves and People First groups in the Denver and Colorado Springs areas. The Council also funded advocacy and civil rights training conducted by self-advocacy groups ADAPT and the Colorado Cross Disability Coalition.

Illinois - ICDD sponsored a two day summit between state and national leaders of the Independent Living Movement and Self Advocates. The purpose of this summit, facilitated by an independent moderator, was to work through details of how the Independent Living and Self Advocacy movements can work together. They created a set of principles for collaboration and agreed to use them as they work together on issues.

Iowa: ID Action co-sponsored, with People First of Iowa and the Secretary of State, trainings on elections and public policy advocacy.. ID action is also pursuing strategies to increase the presence of Iowans with DD and parents in decision-making capacities (boards, commissions, task forces) at all levels of government.

Maryland: The Council continues to actively support self advocacy, to encourage active participation of families and individuals in policy making, as well as to collaborate with groups throughout Maryland. Collaboration between and among groups focused on specific issues and disabilities has increased in the past two years, particularly with efforts around national and state MiCASSA and Olmstead. Several Council initiatives support self-advocacy groups, including:

- In FY03 the MD Council awarded funds for a project where partnering groups would work together to identify shared issues and develop an action plan that will lead to long-term change. **The Cross-Disability Rights Coalition (CDRC)** is a cross-disability effort led by advocates from People On the Go of Maryland and Maryland ADAPT. CDRC's focus is on two issues: 1) getting people out of state residential centers (SCR) and nursing facilities (NF) into the community in the most integrated setting, and 2) assuring self-determination for people with disabilities who are transitioning from SRC/NFs. CDRC's priority is "to make a significant change in Medicaid's long-term care funding, and to shift the institutional bias to one that is more community oriented." CDRC members will benefit from each other's support and training by individuals with developmental disabilities who are considered leaders. Collaborative work

toward systems change will benefit from each other's support and training by individuals with developmental disabilities who are considered leaders. Collaborative work toward systems change will continue through outreach to other self-advocacy groups and close work with key legislators. The purpose of the project is to build on the successes of advocacy groups led by people with disabilities and further support individuals with disabilities to continue to expand their influence on issues that are important to them. The project has demonstrated that there is some difficulty in different types of advocacy groups with different styles coming together to work on common issues, but has also demonstrated that these issues can be addressed and efforts can be strengthened as a result.

Minnesota: Other activities include People First Minnesota working with the Arc of Minnesota, Advocating Change Together, and Centers for Independent Living.

Missouri: We partnered with the UCE and the DSA to support the Missouri Consumer Advocacy Network which provides public awareness training on self-determination and self-advocacy to family members, consumers, professionals, and the general public. They presented to over 3829 Missourians last year.

The Oklahoma Developmental Disabilities Council has extended many offers to Oklahoma People First to provide assistance beyond travel assistance to the national SABE Conference. Other than helping us to recruit potential Partners in Policymaking, we have been relatively unsuccessful in our outreach attempts.

South Dakota: The current People First chapters have not requested anything more than an annual conference.

Texas: TCDD supports and collaborates with several self-advocacy organizations including NAMI and Texas Advocates.

Other Activities

Georgia: The second project is "Creating One Community" which was funded through a Project of National Significance. This project is working with schools to develop teams of kids with and without disabilities to develop self-advocacy skills and create People First chapters. The Council has contracted with a self-advocate to organize this project. There are 8 projects underway in Valdosta, Flowery Branch, Madison County, Seminole County, Henry County, Athens, Dalton and Gwinnett County.

Illinois: Three years ago ICDD invested in Illinois Lifespan. This is a project developed as an information and advocacy coordination system. The vision of this project is to have one place where people with developmental disabilities and their families can go to get information and the advocacy support they need. One piece of this project involves working with existing advocacy organizations within Illinois to help them get better and thus, provide better customer service related to advocacy. The Illinois Lifespan project is working to help People First of Illinois address issues related to the advocacy services they provide.

New York: While not awarded yet, a cluster of grants under Object HE 1.5 will ask self-advocates to take a more active in their own health care as well as their own wellness. Projects under this cluster will self-advocacy to better document, prepare for visits and advocate for themselves with health care professionals.

<p><i>X. From our State Plan 2002-06</i></p> <p>XI. Objective HE 1.5</p> <p>XII. To establish at least 5 effective and replicable health promotion and wellness programs for people with developmental disabilities by 2006.</p> <p>XIII.</p>	<ul style="list-style-type: none"> ◆ Health and wellness demonstration projects ◆ Technical assistance for health and wellness projects. ◆ DOH’s 2004 Health Promotion Conference <p>Other identified activities:</p> <ul style="list-style-type: none"> ◆ Demonstration projects that include nutrition, wellness, substance abuse, prevention and socialization components. ◆ Consumer & family training. ◆ Consumer & provider training. ◆ Review NYSARC Monograph on aging for relevance. ◆ Public education materials and resource centers. ◆ Cross-committee work.
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Rhode Island: We found Healthy Lifestyles, a wellness curriculum for persons with developmental disabilities. It was located through a web search concerning itself with the health of persons with disabilities. It borrows from the Centers for Disease Control research, Living Well with a Disability. Personal goal setting and the steps to problem-solving are at the core. An advisory panel formation is underway.

