

# **THE ORIGINS OF SELF-ADVOCACY IN FLORIDA<sup>1</sup>**

The earliest indication of state policy support for the role of self-advocates as participants in planning and designing of services which affected their lives was in 1975 with the passage by the Florida State legislature of the “Bill of Rights for Retarded Persons.” This legislative action codified a requirement that individuals be involved in the planning process for their lives. The impact of this legislation was limited given the general beliefs associated with functional deficits and diminished capacity imbedded in early (ICF/MR) approaches. As such the influence and control of professionals, agency staff, and parents, continued to restrict meaningful participation by persons with developmental disabilities. However, this action by the state legislature played an important role in inspiring the establishment of Florida’s self-advocacy movement. The future development of self-advocacy would depend on pressure by persons with disabilities who asserted their right to independence, choice, and control, and a gradual recognition by policy makers and agency leaders that service design needed to support the role of all individuals in the choices and decisions which affected their lives.

## **An Overview of Self-Advocacy versus Self-Determination**

In reviewing the history of self-advocacy in Florida it is clear that, similar to other states, there has been an intermingling of both the terms and activities associated with two very distinct movements, self-

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<sup>1</sup>Materials in this section is excerpted from Self-Advocacy in Florida (Coile, Cohen, & Harter, n.d.), published by The Governor’s Commission on Advocacy for Persons with Developmental Disabilities.

advocacy and self-determination. For that reason it might be helpful to provide a definition for each and some explanation of the purpose and differences associated with these distinct movements.

According to *Self-Advocates Becoming Empowered*, “Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination” (*Self-Advocates Becoming Empowered*, 2000, p. 5). Self-advocacy refers to individuals advocating for themselves versus having someone else speak for them; and in the larger context describes a grassroots civil rights movement where individuals participate on their own and within self-advocate run organizations or associations in a variety of activities designed to influence public policy and practice as it relates to equal opportunity.

Self-determination, on the other hand, relates to shifting the dynamic between individuals with disabilities, families and the service system, so that individuals and families have control of decision making and resources. Self-determination has been defined in various ways. Most commonly, it has been defined based on a set of four principles: (1) freedom—individuals have the freedom to plan their own lives; (2) authority—individuals have authority or control over one’s own life, including control over resources; (3) support—individuals have access to the support they need and opportunity for increased community integration; and (4) responsibility—individuals take on the responsibility of living in interdependent communities (Nerney & Shumway, 1996). In recent years many states to varying extents have made changes in their service system in order to incorporate the principles of self-determination

Clearly, self-advocacy is an essential component of self-determination. However, self-advocacy goes beyond this, involving people with developmental or intellectual disabilities working together to advocate for equality, civil rights, and opportunity in all aspects of community life. The distinguishing characteristics of a grassroots self-advocacy group include:

- Self-advocacy groups are run by people with disabilities. Group leaders and members are people with disabilities. The leaders are selected by group members, not by advisors or service providers.
- Self-advocacy groups are independent of service provider agencies, which may provide material support to the group but not have any say over the group's activities and decisions.
- Advisors are selected by the group members and support, teach when needed, and advise the group, but do not control or lead the group in any way.

With this distinction in mind we can return to the origins of self-advocacy in Florida and its intersection with the evolution and increased opportunities for self-determination.

### **The First Self-Advocacy Groups**

The first self-advocacy group was formed in south Florida through the efforts of people with disabilities who worked with the Arc of Dade County to form People First of Dade County. The group received financial support from the Florida Justice Institute, the Technical Assistance for Self-Advocacy Project of the University of Kansas, and the Miami Dade Community College Continuing Education Program. The group was officially

formed in March, 1979 and campaigned with the slogan “We want to be treated like normal people, human beings. We do not want handouts. We want to live like everybody else.”

These founding self-advocacy group members quickly recognized that training was needed to prepare individuals with disabilities to become self-advocates. In May, 1979, the Arc of Dade County and the People First group addressed the Governor’s Commission on Advocacy for Persons with Developmental Disabilities to request funding for a pilot project to develop curriculum and provide self-advocacy training sessions to adults with developmental disabilities. This request was in accord with the Florida Plan for Protection and Advocacy of the Rights of Persons with Developmental Disabilities (P.L. 95-602), and funds were subsequently granted.

This grant supported 25 training sessions with an average attendance of 20 self-advocates at each training event. These training events provided many individuals with developmental disabilities the skill and knowledge to become effective self-advocates, and helped to expand the base of participation in the self-advocacy movement. As the People First group size and influence increased, they expanded their activities to include lobbying elected officials, giving presentations in the community, and engaging in media events. Several members of this original group also reached out and began to network with national self-advocates and attended national self-advocacy conferences.

Later, the Arc and People First of Dade County were awarded a grant from the Florida Developmental Disabilities Council to support the growth and expansion of self-advocacy in Florida. The project was entitled “Assisting Consumers in Coordinating and Establishing Self-Advocacy Services” (ACCESS). The goal of this

project was to provide technical assistance and training to individuals with disabilities, professionals, and others in Florida who had interest in forming self-advocacy groups.

The group that began as People First of Dade County has remained viable even though they have struggled with issues related to funding, finding advisors, and transportation. They are now called People First of South Florida, and have practicing groups in North Dade, South Dade, and Broward counties. The website of People First of South Florida can be found at: <http://www.encore4.net/peoplefirst/index.html>.

In 1988 the Arc of Florida published a document entitled We the People: A Self-Advocacy Guide for Floridians with Developmental Disabilities. This guide addressed issues that individuals with disabilities faced when working toward independence such as job searching, living arrangements, transportation, and post-high school education.

There was also an expansion of People First groups in Florida by the mid-1990s. According to the 1994-1995 Directory for North American Self-Advocacy Groups (Hayden & Senese, 1994), People First groups had expanded outside of Dade County. It was reported that there was a People First of Clearwater, Florida as well as a People First Special Gathering in Cocoa, Florida. However, there is no evidence that either of these groups is active today. There was one other attempt to form a group in Broward County (south Florida) which was not affiliated with People First. It was believed to be called Self-Advocates for Self-Determination. This group also disbanded because there was not enough support. This group, while in existence, spent a large amount of their time fundraising and recruiting members.

## **The Influence of “Consumer Conferences”<sup>2</sup>**

Another important contributor to the early development of self-advocacy in Florida was “consumer conferences.” The consumer conferences began in 1974, and were initially held in conjunction with the annual convention of the Florida Arc. They provided an opportunity for “consumers” to come together to discuss their rights as citizens. These conferences grew each year and by 1980, in order to more effectively conduct the conference, the Developmental Services Program Office contracted with a private nonprofit organization, the Florida Justice Institute, to plan and implement the conference. People First self-advocacy groups from south Florida were involved with these conferences which provided another opportunity to develop grassroots involvement in self-advocacy.

## **Self-Determination/Self-Advocacy in Florida**

As described earlier in this document, efforts to promote both self-advocacy and self-determination intersect. Self-advocates have advocated for self-determination; at the same time, initiatives that promote self-determination have benefited and strengthened the self-advocacy movement in Florida. In a document entitled Florida’s Self-Determination Initiative the early history of self-determination in Florida is described. A 10-year project (1994-2004), sponsored by the State Education Department, focused on transition from school to community. The goals included: increase awareness of self-determination; initiate and expand classroom

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instruction and information on self-determination; and improve students' school and post-school outcomes by knowledge of and use of self-determination skills.

In January of 2002 the first statewide self-determination conference was held in Orlando, Florida, organized by Wilson Resources Inc., with funding and other types of support provided by the Developmental Disabilities Council, the Advocacy Center for Persons with Disabilities, Inc. the Department of Education, the Department of Children and Families, and the Developmental Disabilities Program Office. Over 575 individuals attended this event and the agenda focused on both self-determination and self-advocacy.

On the final day of the conference, an 11 member board of directors was elected by conference participants which became a group known as the Southern Movement for Independence (SMI). The SMI is described as “an organization run by and for persons with developmental disabilities, and was dedicated to promoting the self-determination of individuals with developmental disabilities” (Southern Movement for Independence, 2003, p. 1). The SMI received technical assistance and support from a private consulting firm, Wilson Resources, Inc., with funds from a contract with the Florida Developmental Disabilities Council, Inc. The SMI was able to create 14 local self-determination chapters, one in every Department of Children and Families District. Some of the goals of the SMI included developing the leadership skills of board members, providing technical assistance to local self-determination/self-advocacy chapters, disseminating information on self-advocacy, creating a newsletter and website, engage in advocacy, and continue to seek grants (Southern Movement for Independence, Inc., 2003). The SMI hosted the second self-determination conference in August

of 2003 in Tampa (Wilson Resources, 2003) with support from the same sponsors as the previous year. The size of the conference grew, with an approximate 750 attendees. The focus of this conference included the following themes; Support Coordination and Self-Determination, Support Staff and the Self-Determination Movement, Speak Up for Yourself, Self-Determination and Families, Employment with Florida APSE, and Self-Determination and Transition.

According to the Wilson Resources report and meeting minutes, the SMI continued to meet through September of 2004. Prior to that point the technical assistance support the group received from their consultant was being transitioned to an Executive Director who was hired in the spring of 2004. The group's intention was to incorporate as a not for profit entity and secure continuation funding. However, SMI's administrative structure was insufficient at that point in its development to assume ongoing administrative responsibilities which resulted in a decision by the board to suspend operations. The effects, however, of the SMI have been continued and carried out in many ways throughout the state of Florida. Many of the chapters created and supported by the SMI are still active in promoting both self-advocacy and self-determination. The SMI also was able to raise general consciousness concerning self-determination and self-advocacy.

At the same time as there was growing participation by people with disabilities in efforts related to self-advocacy and self-determination, there was also increased support and funding from the state level which supported the empowerment of people with disabilities. In 1999 Governor Jeb Bush committed a \$210 million dollar increase in funding to persons with developmental disabilities. Governor Bush's stated intention with this

funding was to redesign Florida's service systems using the principles of self-determination. The Consumer Directed Care Plus waiver, begun as a three-year Cash and Counseling Demonstration with a grant from the Robert Wood Johnson Foundation in 1998, as well as the Florida Freedom Initiative (based on President Bush's New Freedom Initiative) offer increased choice and control. Additionally, the creation of the statewide Family Care Councils was a step in giving more voice to issues of families and individuals with disabilities. These initiatives have both been a response to and complemented the work of self-advocates in Florida who have been and continue advocating for increased independence, choice, and control.

Self-determination is emerging as a standard for person centered practice, and parents and self-advocates are seeking increasing control in the decisions related to service provision which affect their lives. The extensive efforts to provide self-determination training have provided many individuals with disabilities the opportunity to engage in self-advocacy and take on leadership roles in their own lives as well as within the larger civil rights arena. Incorporating the concepts of self-determination and self-advocacy in a statewide development plan for expanding a grassroots movement is an important component of a strategic process which encourages and promotes independence and self-direction for people with disabilities.

### **Youth Self-Advocacy in Florida**

In more recent years there have been several initiatives which have focused on the development of self-advocacy skills among youth. These opportunities have recognized the importance of preparing youth to take on increasing levels of responsibility for self direction in their lives and community. This attention to the

development of youth will impact the future growth of the self-advocacy movement and as such is an important part of a discussion about the state of the self-advocacy movement in Florida.

Department of Education. The Florida Department of Education, Bureau of Exceptional Education and Student Services in conjunction with the Career Development & Transition Project of The Transition Center at the University of Florida in 1999 sponsor Florida's Self-Determination Initiative. The Self-Determination Initiative is designed to provide training, technical assistance, and support to Florida's school districts wishing to implement self-determination activities within school settings. This program also focuses on the engagement of students in the IEP process, having students learn self-determination skills in the classroom, and have students assume an active role in the transition process from school to adult life.

Florida Youth Council. This organization is part of the National Consortium for Disability and Leadership for Youth (NCLD/Y). It is sponsored by the Florida Developmental Disabilities Council, Inc. and the Florida Agency for Persons with Disabilities. The Council is comprised of fifteen youth ages fifteen through seventeen and emerging young adult leaders aged eighteen through thirty. This is a diverse group of individuals from across the state. Youth Council members receive training in five core areas including learning, connecting, thriving, working, and leading with a focus on the development of foundation leadership skills that can be used within their own self-determined lives as well as in public policy activities on local and state levels.

In an interview with Rebecca Hare from NCLD/Y the individuals involved in this project from Florida have made exceptional headway. They are currently in the final stages of getting a law passed in Florida

which will integrate disability history into k-12 text books. They are also working to publish a book concerning transition out of high school by the use of personal narrative.

Florida Youth Leadership Forum. The first Florida Youth Leadership Forum was sponsored by ABLE TRUST in the year 2000. This is a four day program for high school juniors and seniors with disabilities. Students from around the state of Florida travel to Tallahassee and participate in training in the areas of leadership, citizenship, and social skills. Mentors and volunteers attend to guide the young students through a variety of workshops, working groups, speeches, and networking opportunities. Students also learn self-advocacy skills in this forum.

Family Network on Disabilities. The Family Network on Disabilities sponsors two programs which offer support for the development of parent and youth self-advocacy. The TILES project (Transition, Independent Living, Employment, and Support) provides training, resources and support for individuals with disabilities, parents, family members, guardians, advocates to more effectively participate with professionals in making important life choices. The project targets youth from ages 14-22 years of age receiving special education services, as well as adults with disabilities. The Family Network on Disabilities of Florida also sponsors the BRIDGES program. The BRIDGES program focuses on providing training and support to parents and youth living in rural areas of the state with particular attention to individuals and groups who may be more culturally or economically isolated, and may have less access to organized networking opportunities. The BRIDGES

program brings meetings to these areas, and helps families and individuals with disabilities learn self-advocacy and advocacy skills.

### **Other Contributing Advocacy Focused Initiatives in Florida**

There have also been many organizations, in addition to those already highlighted, within Florida which have influenced and will continue to contribute to the development of the self-advocacy movement. Some of these organizations are briefly described below.

Florida Independent Living Center (FICL). The Florida Independent Living Center is a statewide organization with a mission to promote independent living opportunities for individuals with disabilities. The services provided by the FICL are consumer directed. The voting members are comprised primarily of individuals with disabilities. The goals of this organization are in consistent with principles of self-advocacy and self-determination.

The Advocacy Center. The Advocacy Center is an organization dedicated to providing protection and advocacy services to individuals with disabilities in Florida. The mission of the Advocacy Center is to increase dignity, equality, and self-determination in the lives of persons with disabilities. Human and legal rights are protected through the dissemination of information and advocacy. The Advocacy Center provides a great deal of services which are in line with the ideas and concepts of self-advocacy and self-determination. The Advocacy Center has a self-determination team which promotes full participation and inclusion in the community.

Florida Governor's Working Group on the Americans with Disabilities Act (ADAWG). The ADAWG is a gubernatorial appointed board which focuses on issues and events which impact the rights of persons with disabilities in Florida. The goals of the ADAWG are to provide information, referrals, education, and compliance with the laws of the ADA.

Family Café. The Family Café began in 1999 in an attempt to respond to the need for information in the disability community. The organization's major features include serving as a clearinghouse for updated information, organizing and hosting an annual conference, and sponsoring leadership trainings. The conference has become a large event with 10,000 participants at the 8<sup>th</sup> annual conference (2006). The Family Café is strongly motivated by principles of self-advocacy and many self-advocates are involved in the workings of the organization.

Florida Institute for Family Involvement. This organization supports family and consumer involvement in developing responsive family centered, and community centered systems of care. This organization also works with private, state, and federal programs to develop resource and training information to allow individuals to advocate for appropriate services and make smart individualized service choices.

Partners in Policymaking. Partners in Policymaking is a program sponsored by the Florida Developmental Disabilities Council. The goal of the program is to train and inform individuals with disabilities and their family members about issues of leadership and advocacy. This program help's individuals develop self-advocacy skills to participate in activities which promote systems change. The participants of this program

attend six weekend training sessions over a six-month span. This program aims to help's individuals with disability improve advocacy and self-advocacy skills. More than 250 individuals have completed this training since the inception of the program in 1994.

## **Current Activity to Support and Expand the Grassroots Self-Advocacy**

### **Movement**

In the spring of 2006 the Community Living Task Force of the Florida Developmental Disabilities Council, Inc. issued a request for proposals to assess the current state of the grassroots self-advocacy movement in Florida, and to support the development of three self-advocacy groups. A grant was awarded to the Syracuse University Center on Human Policy, Law, and Disability Studies and the project was launched in the fall of 2006. In early December applications were solicited from interested individuals and groups located throughout Florida to participate in the self-advocacy group development training and technical assistance component of the project. A total of 24 applications were received from 18 different locations throughout the state. Based on the number of applications received, and the initial screening of the applicants it is clear that all of the previous efforts to support the development of self-advocacy skills and develop self-advocacy groups have resulted in a viable and active self-advocacy movement in Florida. This existing capacity provides a platform to build upon past efforts, as well as support, strengthen, and expand grassroots self-advocacy throughout the state. Efforts will be undertaken to engage all of the applicants who have shown interest in this initiative over the next three years.

Applicants for this project will be sorted into four groups as follows:

1. Three will be selected for the initial training and technical assistance activity which is scheduled to begin in the spring of 2007.
2. Four will be selected for phase two training and technical assistance tentatively schedule to begin in the fall of 2007.
3. Four will be scheduled for phase three training and technical assistance tentatively scheduled for the winter of 2008
4. Four will be scheduled for phase four training and technical assistance tentatively scheduled for the spring of 2008.

Other applicants who overlap geographically with anyone of the groups selected for the training and technical assistance sessions outlined above will be encouraged to join with the group in their area.

As each new group completes the initial training and technical assistance phase of the project they will continue to receive ongoing technical assistance and support targeted toward maintaining a sustained effort. The outcome of this project is intended to result in both the strengthening and expansion of the grassroots self-advocacy movement throughout the state of Florida over a three year period.

### **Assessment of the Current Status of the Self-Advocacy Movement in Florida**

This assessment of the current status of the self-advocacy movement in Florida is a result of information obtained from a review of the history, selected publications, web based material, and interviews

conducted with people in Florida who have been active in the movement. A complete list of these resources is contained in the final section of this narrative.

What is most evident is that the self-advocacy movement is alive and well in Florida. Past efforts to support the development and expansion of this movement have produced results which are evident today. There is awareness about the importance of self-advocacy, and evidence that significant attention has been given to developing foundation skills targeting both youth and adults resulting in activities on both the individual and systemic levels where self-advocates are actively engaged in meaningful leadership and participant roles which influence decisions about their own lives, public policy, and their civil rights. There have been fits and starts along the way, and some efforts to support the growth of the movement have faltered. However, even these circumstances seem to have energized self-advocates to overcome the circumstances that have contributed to these less than satisfactory results.

There has clearly been significant and growing support for the philosophy of self-advocacy among many stakeholder groups. Substantive resources have been committed to training and development of core skills targeting both youth and adults over many years. There are numerous graduates of these programs living throughout the state who are actively engaged in self-advocacy. There are existing self-advocacy groups in south Florida, as well as other locations as evidenced by the ongoing activities of the People First Groups, and the responses to the most recent solicitation for applications to participate in this project. Many of the people

involved are networked with others who are active in the self-advocacy movement including on a national level via attendance at conference events. All of this constitutes a strong foundation to the self-advocacy movement.

At the same time, there are a number of challenges to the strengthening and expansion of self-advocacy that have been identified based on interviews, as well as review of relevant documents and materials.

These include:

- Support for self-advocacy groups. Self-advocacy groups require ongoing support which does not compromise their independence. This type of support is intentionally targeted at developing the membership and group skills to operate independently. It is evident that groups have experienced difficulties in obtaining and maintaining the ongoing support of an advisor. All groups, regardless of their state of development require ongoing advisory support. Attention to the recruitment, training, and networking of advisors must be a part of an ongoing strategy in self-advocacy development. The temptation to compromise a group's independence by placing it under the control of an agency is not an option. However, accepting material support (transportation, meeting space, etc.) is acceptable.
- Focus of self-advocacy group efforts and energy. The goals of each group must be realistic and achievable. All groups want to experience success. This does not mean that a group should not confront the hard issues but these issues should be the ones that most affect their lives as opposed

- to those issues imposed upon them from outside sources or circumstances. External supports should contribute to enhance the group to focus its attention, time, and energy on self-advocacy.
- Financial support for self-advocacy groups. Financing is a problem, with some groups finding that they spend most of their time trying to raise money leaving little time for self-advocacy activities. Creative solutions to meeting financial needs which do not drain the energy of these groups need to be considered. While financial resources might be contributed from other entities, caution must be taken not to compromise the self-advocates' independence and mission.
  - Administrative/organizational issues. Decisions to incorporate and take on administrative responsibilities related to grant management can undermine the development of a group as shown in the experience of the SMI group. Although this decision has to be weighed against what many people identified as a need for financial support, solutions to that dilemma must take into account the fundamental purpose of a grassroots community organization, and all options for filling their financial support needs. Establishing a corporate structure which prematurely requires administrative capacity can also detract from the formative development of the group.
  - Transportation and other logistics. Meeting logistics, including location, transportation, and other related issues, have been a significant barrier to membership and participation.
  - Maintaining diverse participants as members and in leadership positions. Individuals with more severe developmental disabilities, particularly cognitive disabilities, appear to be underrepresented

as participants and as leaders in self-advocacy and self-determination initiatives. This observation is based on limited information and more a reflection of a lack of evidence to the contrary.

- Lack of a statewide network. Although there is some networking among individuals who are involved with the self-advocacy movement there is no formal statewide structure to support grassroots organizing and development efforts or activities.

None of these barriers is so overwhelming that solutions can not be found. In the section of this project that reports on practices used by successful groups from around the nation examples will be provided for approaches that Florida groups may want to consider. What is clear, however, is that future development efforts must take into consideration how these issues and barriers will be addressed as well as the lessons learned from previous efforts at expansion.

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## **Web Sites**

- The Advocacy Center for People With Disabilities: <http://www.advocacycenter.org/index.html>
- People First of South Florida: <http://www.encore4.net/peoplefirst/index.html>
- Family Café: <http://www.familycafe.net>
- Family Care Council: <http://www.fccflorida.org/>
- Family Network on Disabilities: <http://fndfl.org/>
- Arc Florida: <http://www.arcflorida.org/news.php>
- Florida Developmental Disabilities Council: <http://www.fddc.org/home/index.asp>
- Florida Department of Education: <http://www.fldoe.org/ese/>

- Florida Governor’s Working Group on the American’s with Disabilities Act:  
<http://www.abilityforum.com>
- Florida Independent Living Center: <http://www.flailc.org/index.htm>
- Florida Institute for Family Involvement: <http://www.fifionline.org/>
- Florida Youth Leadership Forum: <http://www.abletrust.org/yf/about/>
- Florida Youth Council: <http://www.nclid-youth.info/fyc.htm>
- Partners in Policymaking: <http://www.fddc.org/Announcements/orbpamphlet.pdf>

## **Interviews**

- Angress, Linda: Advisor of People First groups in S. Florida: [Langress@sunrisegroup.org](mailto:Langress@sunrisegroup.org)
- Chaney, Michael: Florida Housing Coalition: (850) 878 4219
- Drummond, Chris: Self-Advocate: (407) 332 9937
- Gosline, Molly: Executive Director at Florida Association for Independent Living: (850) 488 5624
- Hare, Rebecca: Project Coordinator for National Consortium on Leadership and Disability for Youth: (202) 822 8405 x127
- Houghland, Patty: Family Care Counsel: [weaverbgud@world.att.net](mailto:weaverbgud@world.att.net)
- La Rose-Aponte, Berthy: Family Care Council
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