

Creating a New Self-Advocacy Organization - Imagine the Possibilities

A Discussion Brief

Jack M. Brandt

Partnership for People with Disabilities

Virginia Commonwealth University

Author Note

This paper is funded by grants to the Partnership for People with Disabilities from the Virginia Board for People with Disabilities and the Administration on Developmental Disabilities (Grant No. 90DD0656). The author would like to thank the Self-Advocates Leading Together steering committee for their guidance and peer support and Dr. Fred P. Orelove for his direction and editorial expertise.

Correspondence concerning this article manuscript should be addressed to Jack M. Brandt, Partnership for People with Disabilities, Virginia Commonwealth University, P.O. Box 843020, 700 E. Franklin St., Virginia Commonwealth University, Richmond, Virginia 23284-3020.

brandtj@vcu.edu

Abstract

The Virginia Board for People with Disabilities, Virginia's Developmental Disabilities Council, and the Partnership for People with Disabilities, Virginia's University Center for Excellence in Developmental Disabilities, are currently facilitating the formation of a statewide self-advocacy organization in Virginia. This paper explores two approaches disability advocacy groups have used to achieve a common goal. The paper also reviews the structure of nine national disability organizations that have grassroots affiliations in Virginia.

Creating a New Self-Advocacy Organization - Imagine the Possibilities

A Discussion Brief

Individuals who do not have a voice in the public debate over how they choose to live their lives often find opportunities to join together and create capacity to promote positive change in the public arena. The expression, “Nothing About Us Without Us,” has been a message of the disability rights movement to be involved in decisions that affect the lives of people with disabilities (Charlton, 1998). In 2000, Congress reauthorized the Developmental Disabilities (DD) Assistance and Bill of Rights Act, which required all DD Councils to “establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities” (Developmental Disabilities Assistance and Bill of Rights Act, 2000). Each state’s DD Council has chosen to fund self-advocacy organizations in a manner that supports the advocacy efforts of people with developmental and other disabilities.

The Virginia Board for People with Disabilities, Virginia’s Developmental Disabilities Council, and the Partnership for People with Disabilities, Virginia’s University Center for Excellence in Developmental Disabilities, have recognized the fragmented voice among the existing disability advocacy organizations and are in the process of initiating a statewide organization led by self-advocates. The organization will be led by and for people with disabilities to enter into systems advocacy to take action to make changes that impact their lives. As is true in other states, Virginia has a variety of advocacy groups that are led by and for people with disabilities. At this time, Virginia does not have a statewide self-advocacy organization led by people with disabilities that involves advocates at the grassroots level. This fact is reflected in the Virginia Board’s 2008 Biennial Assessment:

While Virginia’s public and private disability advocacy organizations cannot be expected to agree on all issues, it is essential that advocates come together when

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

they can to identify common concerns and pool their individually limited resources to advocate for systems change. VBPD... recommends continued expansion of coalition-building to identify and address areas of common concern (p. 353).

In forming this organization it is important to review what is meant by *self-advocacy* and *disability-led*.

Self-advocacy is difficult to define because of how it has been used by professionals and individuals with disabilities (Sutcliffe & Simons, 1993). *Individual* self-advocacy, as the term implies, is speaking or acting for oneself and deciding what is best for the individual and taking charge of one's life by standing up for oneself (Williams & Shoultz, 1982). *Group* self-advocacy is typically defined as individuals who join together to advocate for a common cause. Often these groups become a social outlet for people with disabilities; however, some groups focus on policies that may limit how people choose to lead their own lives. Typically, people without disabilities play an advisory role in the self-advocacy, which helps to facilitate the group's function (Dybwad, 1996).

Hayden (2004) laid out the framework of how self-advocacy is an unacknowledged civil rights movement. Dybwad (1996) described self-advocacy as being about independent groups of people with disabilities working together for justice by helping each other take charge of their lives to fight discrimination. The term self-advocacy perhaps is best captured by the organization, Self-Advocates Becoming Empowered, a national self-advocacy organization:

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. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us about our rights, but along with learning about our rights we learn responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other gain confidence in ourselves so we can speak out for what we believe in (Hayden & Nelis, 2002, p. 222).

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

The term self-advocacy is used primarily in the intellectual and developmental disability fields; however, recently self-advocacy principles have been applied to other organizations that value the voice of people with disabilities. The principles of self-advocacy in leading and directing one's own life are important to remember when starting a new organization in Virginia that is led by and for people with disabilities.

Disability-led organizations are generally referred to as consumer controlled or run. In the sparse information available about disability-led organizations, the accepted federal description of consumer controlled boards or organizations states that at least 51% of the governing board must be persons with disabilities or family members of persons with disabilities (Vocational Rehabilitation and Other Rehabilitation Services, 1998). Some organizations have adopted a more restrictive definition on consumer control, requiring that 100% of the board and staff have a disability. Other organizations have individuals without disabilities who serve as advisors or support staff to assist with the operations of the organization (Williams & Shoultz, 1982). For this paper, "disability-led" means the decision making process of an organization is controlled by a majority of people with disabilities.

Organizational Structures

People form into groups to promote their own interests and exert their influence over various areas such as environmental, social, or health care policies. Charlton (1998) developed a theory of disability oppression to explain the disability rights movement. People with disabilities experienced challenges and obstacles in society to participate fully in their communities, a phenomenon Charlton referred to as "disability oppression." This oppression leads people with disabilities to a consciousness to address issues by forming into various groups. Self-help groups

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

and self-determination have been cornerstones of the disability rights movement to empower and develop strategies to advocate for oneself and others.

Self-advocacy groups can follow one of four typologies: “autonomous,” “divisional,” “coalition,” or “service systems” models (Crawley, 1988; People First of Washington, 1984). The *autonomous* model refers to the self-advocacy groups that are independent from an outside influence. The *divisional* model is used among parent or professional organizations to promote the self-advocacy group within their structure. The *coalition* model embraces the cross disability philosophy and works with various disability advocacy groups. The *service system* model arose from the service providers supporting the self-advocacy groups. Most self-advocacy groups across the United States are “social clubs” with some engagement in system advocacy. Approximately half of the states have a statewide self-advocacy organization that coordinates groups and/or focuses on system change within their state. Each model has advantages and disadvantages, as Table 1 depicts.

Table 1

Advantages and disadvantages of self-advocacy organizational models

| Model | Advantages | Disadvantages |
|------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Autonomous | <ul style="list-style-type: none"> - Truly authentic self-advocacy voice - Leadership of the organization is self-advocates - Group recognition among policy makers | <ul style="list-style-type: none"> - Dependent on self-funding - Instability of leadership - Separation between executives and general membership |
| Divisional | <ul style="list-style-type: none"> - External support - Organization structure in place - Understanding of issues | <ul style="list-style-type: none"> - Self-advocacy voice gets lost - Decision making unclear - Funding unclear |
| Coalition | <ul style="list-style-type: none"> - Understanding of disability issues - Expertise of members | <ul style="list-style-type: none"> - Turf issues - Unclear leadership responsibilities |

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

| | | |
|----------------|--------------------------|------------------------------------------------|
| | - Shared resources | - Unable to reach consensus |
| | - Power in number | - Funding unclear |
| Service System | - External support | - Constrains development of real self-advocacy |
| | - Recruitment of members | - Few practical outcomes |
| | - Accommodations are met | - Staff takes over leadership |
| | | - Funding not controlled by self-advocates |
| | | - Priorities confusing |

Disability-led organizations fall primarily into two categories, a membership organization (autonomous model) or a coalition. Membership organizations are made up of individual members who receive specified benefits. The terms coalitions, alliances, and networks are used interchangeably but all are defined as organizations that use collaboration among independent groups for the advantage of all who enter into the relationship. Individuals join a membership group that has a particular identity and purpose. In contrast, coalitions are groups of organizations that retain their separate identities, but join together to achieve a common purpose.

Membership Organizations

Membership organizations have their own structure, by-laws, and leadership to work towards a common mission and vision. Membership organizations promote social and civic activities, the arts and sciences, political, religious, environmental, and other causes. Individuals can decide to join based on their belief system and the priorities of the organization. These organizations usually charge membership dues and provide some type of service or benefit to the individual members. Most of these organizations share information among their membership throughout a newsletter, and they offer benefits such as insurance plans, opportunities to connect with others who share the same interests, and a collective identity with a greater group of individuals. The challenge of membership organizations is getting individuals to join the cause of the group or motivating them to take action. The issues that the organization addresses should

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

appeal to a broad range of individuals so they can sustain momentum and interest among the members.

Membership organizations address the issue of sustainability by having chapters at a local level engage individuals within the organizational mission and vision. By having a chapter structure, some organizations, associations that connect these local chapters to have greater voice and influence (Brown, 2006). For example, the Lions Club has local, state, national, and international levels, and, while most of the activities happen at the local level, the state, national, and international levels support the local members to fulfill their mission.

Coalitions

“Coalition” comes from the Latin work *coalescere*, to grow together, and the term is used to describe organizations with diverse backgrounds that come together to pool resources to bring about a specific change that individual organizations would not be able to accomplish. Coalitions are defined as “a group of individuals representing diverse organizations, factions, or constituencies who agree to work together to achieve a common goal” (Feighery & Rogers, 1990, p. 8). In addition, coalitions are issue oriented and are structured to focus on specific goals that are external to the coalition with a diverse membership that have unique talents and resources (Allensworth & Patton, 1990; Boissevain, 1974; Stevenson, Pearce, & Porter, 1985). The reason organizations join coalitions is to increase influence in order to attain and maintain authority while retaining their separate identities.

Coalitions may be loose associations that join together to work on a short-term problem/issue; once the issue is resolved, the coalition disbands. Coalitions may, however, have a more formal, permanent structure by creating a stand-alone organization with by-laws, leadership, mission, and vision. Low power groups find more success in defending their interest when they

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

join together with other groups in a coalition. Coalitions allow the individual organizations to participate in the organization without assuming sole responsibility for the outcomes. The coalition increases the power for the organization by drawing from the diverse talents and experiences of individuals and groups that are a part of the collective action that has a stronger voice.

There are ten barriers to forming a coalition: turf issues, bad history, failure to act, dominance by professionals, poor links to the community, minimal organizational capacity, funding, the failure to provide and create leadership, the costs of working together, and the costs outweighing the benefits (Wolf, 2002). Acknowledging these barriers can help promote the creation and the sustainability of a coalition. Once a coalition is formed, the power relationship among organizations can become strained since each group is used to acting on its own and making its own decisions. To be successful the members of the coalition need to accept the equality of power among the organizations that are represented (Wolf, 2002).

In Virginia, various organizations encompass the principles of self-advocacy, working within a range of structures. Virginia has approximately five People First Chapters that are supported by local Arc chapters or Community Services Boards. Also, Virginia has 16 Centers for Independent Living (CIL), each being a separate non-profit, including four satellite locations, which are supported by a CIL. The 16 Centers for Independent Living have formed a membership organization that promotes the philosophy of Independent Living by advocating for policy change in Richmond. In addition, the various mental health consumer run/survivor organizations have formed a statewide coalition, Virginia Organization of Consumers Asserting Leadership (VOCAL), advocating for policy change in Richmond. The National Federation for the Blind (NFB) is active in Virginia with various affiliates across the state. The Virginia Association for

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

the DeafBlind has an organization that actively promotes the voice of the members of their association. The Virginia Association of the Blind advocates for rights of the blind apart from the NFB on issues that their members face. The Virginia Association for the Deaf and the Virginia Deaf and Hard of Hearing Association have worked on similar issues over the years; they collaborate on issues but respect their different philosophies. Also, a variety of Traumatic Brain Injury (TBI) Clubhouses teaches their members about the importance of advocating for oneself. Recently, a group of individuals with disabilities and supporters formed People for People to provide awareness and advocacy on issues that are important to people with disabilities in the Tidewater area. (See Appendix A for organizational models, activities, and dues for the above mentioned organizations.)

Disability-Led Organizations

Disability-led organizations take various structures. (Two examples were described above, i.e., membership organizations and coalitions.) The organizations described here provide a perspective of the disability-led organizations existing presently. This list is not a complete compilation of all of the disability-led organizations that currently exist, but rather provides examples of various organizational structures. Each of the organizations listed here has a national organization with state grassroots affiliations through either a chapter system or individual membership. Each of these organizations has members in Virginia that are affiliated with its national organization, and all promote the principles of self-advocacy. The brief descriptions of these organizations provide an overview of the structure of each organization, and applicable model, activities, and dues can be viewed in Appendix B.

National Federation of the Blind

The National Federation of the Blind (NFB) is a membership organization that promotes the sense of wellbeing of the blind. The Federation has over 50,000 members and 52 state affiliates. NFB develops policy statements and lobbies members of Congress as well as other federal agencies on the issues that affect the blind. The organization has various programs to promote youth, education, advocacy, technology, and research to encourage independence of its members. Membership is free at the state and local levels. Each state and local chapter coordinates events throughout the year, and chapters address issues that the blind face at the local level. Also, they have annual state and national meetings (National Federation of the Blind, 2010).

National Council on Independent Living

The Independent Living Movement with the formation of Centers for Independent Living started in the 1960's in California, and eventually Centers for Independent Living started to appear across the nation. Centers for Independent Living are grassroots organizations that are led by people with disabilities to maximize their independence. Also, the Rehabilitation Act of 1973 established Statewide Independent Living Councils (SILC) to develop a plan for independent living in the states. The National Council on Independent Living (NCIL), formed in 1982, describes itself as "the longest national cross-disability grassroots organization run by and for people with disabilities" (NCIL, 2010). This membership organization is made up of individuals, Centers for Independent Living, and statewide independent living councils. NCIL is the voice of its members in Washington, D.C. to advocate for policies that maximize the independence of people with disabilities. NCIL's national advocacy agenda is developed by various committees that are comprised of its members.

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

The NCIL Governing Board includes 22 individuals from its membership, five officers, ten regional representatives, and seven at large members. The committees develop recommendations to the board and the board conducts the business of the council between the annual meetings. During their annual meeting the membership votes on resolutions and other matters of the council. The Centers for Independent Living and the SILCs have a weighted vote compared to the individual members' vote (National Council on Independent Living, 2010).

ADAPT

ADAPT is a grassroots membership organization formed in 1983 to gain the rights of individuals with disabilities to access public transportation. ADAPT organizes disability activists to engage in non-violent civil disobedience in the pursuit of the freedom to live with their civil rights and freedom. Currently, ADAPT focuses its efforts in the deinstitutionalization of people with disabilities. ADAPT is a loose national network with state organizers that develop various non-violent actions that target key decision makers around the issue of deinstitutionalization of people with disabilities. Their membership is unique because acceptance as a member depends on the individual's involvement with ADAPT's actions and other activities of the chapters. The organization develops policy statements that unite the advocates at the grassroots level. The policy statements are direct and adhere to the tag line of their organizations, "Free Our People" (ADAPT, 2010).

American Association of People with Disabilities

The American Association of People with Disabilities (AAPD) describes itself as "the largest cross-disability membership organization, organizing the disability community to be a powerful voice for change: politically, economically, and socially" (AAPD, 2010). AAPD was founded in 1995 to help unite the diverse community of people with disabilities, including their

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

family, friends, and supporters; and to be a national voice for change in implementing the goals of the Americans with Disabilities Act (ADA). AAPD has a board of directors, which is elected by the board. AAPD has several programs, including the Justice for All List Serve, a U.S. Congressional internship program, a Disability Mentoring Project, and other programs that promote the leadership of people with disabilities (American Association of People with Disabilities, 2010).

Self-Advocates Becoming Empowered

Across the United States there are independent self-advocacy groups that take the form of People First and other groups that advocate for social justice by taking charge of their own lives. These groups, located at the local and state levels, are designed by and for people with intellectual and developmental disabilities. Self-Advocates Becoming Empowered (SABE) is a national grassroots group that formed in 1990. SABE, a non-profit membership organization, has individuals and organization members represented in all 50 states, divided into nine regions. The organization members are representatives from either statewide or local self-advocacy organizations. Each state has a volunteer state coordinator, who distributes the information to the membership. SABE actively participates with other organizations to promote policies that make positive changes in their members' lives. The membership and the board develop the priorities of the organizations (Self-Advocates Becoming Empowered, 2010).

National Coalition for Mental Health Recovery

National Coalition for Mental Health Recovery (NCMHR), formerly known as The National Coalition of Mental Health Consumer Survivor Organizations (NCMHCSO), is a coalition of consumer/survivor organizations that was formally organized in 2006 after 30 years of consumer/survivor advocacy. The focus of the organization is to give its members and the state

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

organizations a voice at the national level in Washington, D.C. The NCMHR receives funding and other support from the National Empowerment Center and the Technical Assistance Center. It has a 10-member steering committee that sets membership criteria for admitting statewide consumer-run organizations. Presently there are 36 member organizations within 32 states and four national Technical Assistance Centers. The steering committee is selected from state consumer run organizations (National Coalition for Mental Health Recovery, 2010).

Autistic Self-Advocacy Network

The Autistic Self-Advocacy Network (ASAN) seeks to advance the principles of the disability rights movement in the world of autism. ASAN is a non-profit membership organization run by and for Autistic individuals and utilizes only volunteers and a working board of directors. ASAN has no official membership, although the organization's bylaws give the board the option to establish two types of members within ASAN: voting members must identify as Autistic and nonvoting members who are parents or other allies who are not Autistic. ASAN is involved in policymaking initiatives at the national, state, and local level. Currently ASAN is actively setting up local chapters across the nation to build a grassroots support system that will organize Autistic adults and youth. ASAN also has a Speaker's Bureau to provide educational information, community living supports, and employment supports (Autistic Self-Advocacy Network, 2010).

National Disability Leadership Alliance

Justice for All Action Network (JFAAN) changed their name to the National Disability Leadership Alliance (NDLA) and adopted operational guidelines during the Martin Luther Holiday weekend in 2011. Also, they adopted the tagline "Nothing About Us Without Us" (National Disability Leadership Alliance, 2011). Prior to the 2008 presidential elections, the

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

disability-led organization for a national cross-disability coalition, Justice for All Action Network (JFAAN), committed itself to building a strong and unified cross-disability movement. The coalition does not have any formal by-laws and is not incorporated as a non-profit. All of the members of the NDLA have agreed that each organization brings a unique perspective that can support the issues that they share. Although some issues are disability specific, the network has agreed that if there is no conflict, then they will support the other organization's efforts. The membership of the network is open only to the national disability-led organizations. The 13 disability-led organizations that form the steering committee share the leadership responsibilities by rotating the role of chair among the organizations. All statements are distributed to each separate organization to disseminate to their members so the agreed upon agenda will have a grassroots action (A. Imparato, personal communication, March 15, 2010).

Disability Coalitions

Consortium for Citizens with Disabilities

The Consortium for Citizens with Disabilities (CCD) was created in 1973 as a national coalition of national consumer, advocacy, provider and professional organizations. The CCD identifies and researches public policy issues to develop policy recommendations, educate members of Congress, and to encourage people with disabilities to advocate for themselves. Also, the CCD educates members of Congress to improve public policy programs that foster independence of people with disabilities. The CCD is a non-profit whose members elect the board to decide on the activities of the Consortium. The CCD has various committees and task forces to develop recommendations that benefit people with disabilities that each organization supports. Each member organization contributes its time to serve on the task force in order to work with other organizations so they can consolidate their limited resources and share their expertise. The

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

task force reports are posted online. Membership includes approximately 100 organizations that support policy development that improves lives of people with disabilities (Consortium for Citizens with Disabilities, 2010).

State Disability-Led Organizations

The disability-led organizations described here were selected to provide a broad array of examples based on structure, mission, and funding streams. These organizations have a range of membership structures; some of them are membership organization, others coalitions, and still others, a combination of both structures. The state chapters of the national organizations are not mentioned below because they are representative of the national organizations in Virginia. The brief descriptions of these organizations provide an overview of the structure of each organization and applicable model, activities, and dues can be viewed in Appendix C.

People First of California, Inc.

People First of California (PFCA) originally began in 1982 but after several years the organization disbanded. It was restarted in 1991 and is funded by the California State Developmental Disabilities Council and other grants. PFCA's mission is to start, inform, and support local People First Chapters across California to enable the members to speak for themselves, and it serves all people in California with developmental disabilities to increase personal and economic independence and become valued, respected members of their communities. PFCA has a board of directors comprised of members with DD, other volunteers, and professional staff. In addition, the board is supported by a Professional Advisory Council that consists of organizational managers, the disabilities service field, and trained facilitators who assist the Board to carry out its mission. PFCA has a toolkit to help start local People First

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

chapters (People First of California, Inc., 2010). There is no national People First organization, but they align closely with SABE.

Association of Self-Advocates of North Carolina

Association of Self-Advocates of North Carolina (ASANC), a statewide network for self-advocates with developmental disabilities, established in 1987, became incorporated in 1995, and was established as a non-profit in 2000. The membership consists of the following levels: full members must have a developmental disability, associate members do not have a developmental disability or have a disability other than developmental, or they have a developmental disability and are between the ages of 16 and 18. Self-advocacy groups hold five member positions. Board members run the business of the organization with five officer slots, which are filled by members of longer than one year and who have a developmental disability (Association of Self-Advocates of North Carolina, 2010).

Self-Advocacy Association of New York State, Inc.

The Self-Advocacy Association of New York State (SANYS) is a non-profit organized in 1994 with the goal of creating a person-centered and person-directed system of supports. They are a strong voice for and by people with developmental disabilities promoting independence, empowerment, leading by example, communicating, networking and encouraging each other. SANYS administrates a project through AmeriCorps that includes people with and without disabilities to engage in volunteerism and they receive funding through New York Developmental Council. The association has an 18-member Board of Directors, which is representative of the populations of each of six regions across New York State. There are two types of members: voting members are people with developmental disabilities, and non-voting members are

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

affiliated with self-advocacy groups in New York (Self-Advocacy Association of New York State, Inc., 2010).

People on the Go of Maryland

The People on the Go of Maryland (PGM) organization is supported and operated through The Arc of Maryland and receives funding by the Maryland DD Council. There are 60 active members from 13 local self-advocacy groups around the state. Individual membership is free and open to anyone with a disability. People on the Go meets four times a year to discuss current issues. They work on increasing employment opportunities, improving transportation, eliminating discrimination against people with disabilities, training direct care staff, and protecting the rights of people with disabilities. People On the Go has joined forces with Maryland ADAPT to form the Cross-Disability Rights Coalition (CDRC), which is working to shift funding from institutions and nursing facilities to community supports for people with disabilities (The Arc of Maryland, 2010).

Kentucky Self-Advocates for Freedom, Inc.

Kentucky Self-Advocates for Freedom, (KYSAFF) was incorporated in 2003 and is the only state-wide non-profit organization led by and for people with developmental disabilities in Kentucky. They receive funding from the Kentucky Council on Developmental Disabilities and from the Kentucky Protection and Advocacy organization. KYSAFF is focused on development of the statewide organization to develop local chapters to promote equal rights, inclusion, self-advocacy support and education for members. KYSAFF is divided into six United States Congressional districts and the 15 Board of Director members and is representational from the six districts (Kentucky Self-Advocates for Freedom, Inc, 2010).

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

Cross-Disability Rights Coalition

The Cross-Disability Rights Coalition (CDRC) of Maryland was funded through the Maryland Developmental Disabilities Council. CDRC's Board of Leadership is made up of five individuals with a disability. Each of the five members on the Board of Leadership must fall into one of the following categories: be an active member of People on the Go of Maryland or an active member of ADAPT, have a developmental disability, have a cognitive disability, or be a person with any type of disability. The CDRC focuses on the following goals: "to get people out of State Residential Centers/Nursing Facilities (SRC/NF) with full funding for community services, to change the current system to one that ensures people who transition from SRC/NF's to do so with tools of self-determination, and to build CDRC into an influential and powerful group in the community, legislative and training empowerment" (Cross Disability Rights Commission, 2010). The coalition did not receive any additional funding from the Maryland Developmental Disabilities Council after the initial grant and is not currently active.

Self-Advocates of Minnesota

Self-Advocates of Minnesota (SAM) was launched in 2007 and is coordinated through Advocating Change Together (ACT) in Minnesota, which is a non-profit organization with a 30-year history of addressing disability rights in the fight against oppression for people with developmental disabilities. SAM is not a new non-profit but rather is a project to coordinate self-advocacy by offering technical assistance at a grassroots level in Minnesota. SAM is funded through the Minnesota Governor's Council on Developmental Disabilities. ACT addresses systems change by providing information, skill building, and leadership opportunities that include everyone. Members decide who is on the governing board of ACT and the board members must have a developmental disability. The Self-Advocates Minnesota network is supported by ACT

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

which supports local self-advocacy efforts to promote personal empowerment, disability awareness and systems change through leadership training. The network is divided into six regions in Minnesota and has a circle of leadership that includes a representative from each region. Self-advocacy organizations can be a part of the network and they promote the development of other local groups to form (Advocating for Change Together, 2010).

Massachusetts Advocates Standing Strong, Inc.

Massachusetts Advocates Standing Strong (MASS) is a statewide coalition that consists of local and regional self-advocacy organizations. They believe that people with disabilities are to be treated equally and they advocate for the opportunity to make their own decisions and choices, receive the support they need and for each person to have his or her own voice. MASS receives funding from the Massachusetts Developmental Disabilities Council. They have two categories of membership: voting members are people who have a disability and nonvoting members are people who do not have a disability, as defined by the Americans with Disabilities Act. The Board of Directors has 17 members who must be voting members with at least three members from each of the five regions. Each region has monthly meetings and develops its own action plan to address issues specific to the locality (Massachusetts Advocates Standing Strong, Inc., 2010)

Discussion

People with disabilities form various groups, organizations, associations, or coalitions to influence change, in order to lead and direct their own lives. In Virginia, there are multiple groups and organizations that encompass the principles and philosophies of self-advocacy. Currently, there is not a statewide organization that coordinates voices from people with disabilities who are self-advocates. Self-advocates in states around the nation have chosen to organize themselves in various structures in order to unite their voices at a statewide level to

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

impact systemic change. In other states, forming an organization that is disability-led has allowed individuals to educate and inform policymakers about how their decisions impact the lives of people with disabilities.

Typically, the self-advocacy movement has not been a part of the larger disability rights movement but recently it has joined with a broader range of groups to address issues that impede people in leading their lives the way they choose. In 2001, ADAPT, the National Council on Independent Living and Self-Advocates Becoming Empowered, issued a Statement on Solidarity that acknowledges that there is power in numbers and change will occur when people with disabilities come together and take direct action and that working together benefits all groups. This is the first formal attempt of people with disabilities to work together toward the common goals of living independently, participating in daily community living, and endeavoring to make decisions that lead to self-determination and the responsibility of their own lives.

Virginia is in a unique situation because the Virginia Board for People with Disabilities has provided funding for a statewide cross disability self-advocacy organization. The Developmental Disabilities Act requires the DD Planning Councils to fund a state-advocacy organization that is led by people with developmental disabilities. The definition of self-advocacy is an inclusive definition that is applicable to all disability groups. Advocates from each organization have to decide if they are willing to work to form a self-advocacy organization that promotes the principles of the self-advocacy movement in Virginia.

Based on the examples above of the national and state organizations, advocates have multiple avenues to form this new self-advocacy organization. One possibility is to develop a new grassroots organization based on social justice and the principles of self-advocacy. This could be a stand-alone organization with its own by-laws, mission, vision, and program. Another option

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

would be to form a coalition among the existing organizations that promotes the philosophy and principles of self-advocacy while maintaining the separate identities of each organization. Yet another option is to have the funding flow through an already existing organization to promote the self-advocacy activities in Virginia. All three of these basic structures are possibilities in forming a new self-advocacy organization in Virginia.

Some additional questions to be considered in deciding the structure of the new self-advocacy organization in Virginia. They include:

1. Will the structure of the new organization be a membership organization or a coalition or a combination?
2. Will the new organization incorporate as a non-profit or fall under an existing organization to receive funding?
3. Will the new organization support the existing priorities of other organizations or develop new priorities?
4. Will the new organization be an online association or an actual location with an address, phone number, etc?
5. Will there be membership fees?
6. Will the new organization have any programs or activities? If so, how will they support or complement existing programs of other organizations in Virginia?
7. How will the new organization carry out its mission of policy and systems change?

These seven questions will assist with formation of the organization and will be a guidepost for any future decisions about a self-advocacy organization in Virginia.

References

- ADAPT. (2010). *Home Page*. Retrieved March 4, 2010. www.adapt.org
- Advocating for Change Together. (2010). *Home Page*. Retrieved on March 5, 2010. www.selfadvocacy.com
- Allensworth, D., & Patton, W. (1990). Promoting school health through coalition building. *Eta Sigma Gamma Monograph Series*, 7.
- American Association of People with Disabilities. (2010). *Home Page*. Retrieved March 4, 2010. www.aapd.com
- Association of Self-Advocates of North Carolina. (2010). *Home Page*. Retrieved March 5, 2010. www.asa-nc.org
- Autistic Self-Advocacy Network. (2010). *Home Page*. Retrieved February 24, 2010. www.autisticadvocacy.org
- Barnartt, S., & Scotch, R. (2001). *Disability protests: Contentious politics 1970-1999*. Washington: Gallaudet University Press.
- Boissevain, J. (1974). *Friends of friends-Networks, manipulators, and coalitions*. Oxford, England: Basil Blackwell.
- Brown, M. J. (2004). *Building powerful community organizations: A personal guide to creating groups that can solve problems and change the world*. Arlington, MA: Long Haul Press.
- Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press.
- Crawley, B. (1988). *The growing voice: A survey of self-advocacy groups in adult training centers and hospitals in Great Britain*. London: Values into Action.

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

Consortium for Citizens with Disabilities. (2010). *Home Page*. Retrieved March 5, 2010.

www.ccd.org

Cross Disability Rights Coalition. (2010). *Home Page*. Retrieved February 25, 2010.

www.thecdrc.org

Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, § 114 Stat.1677 (2000).

Dybwad, G. (1996). Setting the stage historically. In G. Dybwad & H. J. Bersani (Eds), *New voices, self-advocacy by people with disabilities* (pp.1-17). Cambridge, MA: Brookline Books.

Feighery, E., & Rogers, T. (1990). *Building and maintaining effective coalitions*. (Guide No. 12). Palo Alto, CA: Health Promotion Resource Center, Stanford Center for Research in Disease Prevention.

Fleischer, D. Z., & Zames, F. (2001). *The disability rights movement: From charity to confrontation*. Philadelphia, PA: Temple University Press.

Hayden, M. F. (2004). *The self-advocacy movement: The unacknowledged civil rights movement*. Retrieved March 6, 2010, from REHABDATA database.

Hayden, M., & Nelis, T. (2002). Self-Advocacy. In R.L. Schalock, P.C. Baker, & M.D. Croser (Eds.), *Embarking on a new century: Mental retardation at the end of the 20th Century* (pp. 221-233). Washington, DC: American Association on Mental Retardation.

Kentucky Self-Advocacy for Freedom, Inc. (2010). *Home Page*. Retrieved June 8, 2010.

www.kyselfadvocates.com

Levin, E., & Denenberg, R.V. (1984). *Alliances and coalitions: How to gain influence and power by working with people*. New York: McGraw-Hill.

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

Massachusetts Advocates Standing Strong, Inc. (2010). *Home Page*. Retrieved June 8, 2010.

www.massadvocatesstandingstrong.org

National Coalition of Mental Health Recovery. (2010). *Home Page*. Retrieved March 6, 2010.

www.ncmhr.org

National Council of Independent Living. (2010). *Home Page*. Retrieved February 26, 2010.

www.ncil.org

National Disability Leadership Alliance. (2011). *Home Page*. Retrieved March 9, 2011.

www.disabilityleadership.net

National Federation of the Blind. (2010). *About the National Federation of the Blind*. Retrieved on May 15, 2010. www.nfb.org

People First of California, Inc. (2010). *Home Page*. Retrieved June 9, 2010.

www.peoplefirstca.org

People First of Washington (1984). *Speaking up and speaking out: A report on the international leadership conference*. Tacoma, WA: People First of Washington and the University of Oregon.

Roberts-DeGennaro, M. (1986). Factors contributing to coalition maintenance. *Journal of Sociology and Social Welfare*, 13, 248-264.

Self-Advocacy Association of New York, Inc. (2010). *Home Page*. Retrieved February 27, 2010.

www.sanys.org

Self-Advocates Becoming Empowered. (2010). *Home Page*. Retrieved March 1, 2010.

www.sabeusa.org

Stevenson, G. L., Pearce, J., & Porter, L. (1985). The concept of coalition in organizational theory and research. *Academy of Management Review*, 10, 256-268.

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

Sutcliffe, J., & Simons, K. (1993). *Self-advocacy and adults with learning difficulties:*

Contexts and debates. Leicester, England: National Institute of Adult Continuing Education.

The Arc of Maryland. (2010). *People on the Go Page*. Retrieved February 26, 2010.

www.thearcmd.org/programs/people_on_the_go.html

Virginia Board for People with Disabilities (2008). *Biennial assessment of the disability service system in Virginia*, Richmond, VA: Virginia Board for People with Disabilities.

Vocational Rehabilitation and Other Rehabilitation Services, 29 U.S.C. § 796a *et seq.* (1998).

Williams, P., & Shoultz, B. (1982). *We can speak for ourselves: Self-advocacy by mentally handicapped people*. Bloomington, IN: Indiana University Press.

Wolf, T. (2002). *From the ground up! A workbook on coalition building & community development*. Amherst, MA: United Book Press.

Appendix A Organizational models, activities and dues for Virginia

Table A1 represents organizations in Virginia based on self-advocacy organizational models.

Table A1

Virginia organizations based on the organizational models.

| Virginia Organizations | Autonomous | Divisional | Coalition | Service System |
|--------------------------------------------------------|------------|------------|-----------|----------------|
| Association of the DeafBlind | | | | X |
| Autistic Self Advocacy Network | X | | | |
| Brain Injury Association of Virginia | | | | X |
| Hearing Loss Association of Williamsburg | X | | | |
| National Federation for the Blind – VA | X | | | |
| People First Chapters | | X | | X |
| People 4 People | | X | | |
| Virginia Association of Centers for Independent Living | X | | | |
| VOCAL | X | | | |
| Youth Leadership Forum | | X | | |

Table A2 lists the organizations, the activities and programs, and the dues structures for each.

Table A2

Virginia organizations – activities, programs and dues

| Virginia Organizations | Activities | Dues |
|------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------|
| Association of the DeafBlind | <ul style="list-style-type: none"> - Advise service providers on the services - Meet quarterly to discuss issues that are pertinent | \$10/annually |

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

| | | |
|--------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| Autistic Self Advocacy Network | <ul style="list-style-type: none"> - There is not a state or local in Virginia - Beginning to form in Northern Virginia | National organization has a dues structure but not implemented |
| Brain Injury Association of Virginia | <ul style="list-style-type: none"> - Advocate for policy change that impacts individuals who experience brain injuries - Conduct Advocacy Academy and other events for individuals, families and professionals - Provide information and referral service - Have a database of support groups across the state | Membership: Basic \$35/ annually Professional \$75/ annually Corporate \$300/ annually |
| Hearing Loss Association (Williamsburg Chapter) | <ul style="list-style-type: none"> - Awareness campaigns - Educational programs in the areas of: cochlear implants, movie access, healthcare access, smoke alarm access, relationships, ASL basics - Advocate for assistive technology - Network with other community based organizations and government agencies | Individual \$35/ annually |
| National Federation for the Blind | <ul style="list-style-type: none"> - Coordinate the efforts of 15 local chapters - Advocate for complete integration of the blind into society on a basis of equality in Virginia - Distribute federal and state updates on blind issues | No dues |
| People First Chapters | <ul style="list-style-type: none"> - Conduct Toastmasters monthly - Discuss issues concerning the members - Take action when issues arise that impact members - Coordinate social outings for members | Dues are collected at local chapters |
| People 4 People | <ul style="list-style-type: none"> - Meet monthly to discuss issues that concern the members - Identify issues in their community and develop an action plan - Deliver presentations to various groups - Support each member | No dues |
| Virginia Association of Centers for Independent Living | <ul style="list-style-type: none"> - Statewide association of Centers for Independent Living (CIL) that advocates for the integration and inclusion of people with disabilities into all aspects of society. - Promotes the professional development, | Based upon the CIL's budget. Ranges from \$250-\$850 per quarter. |

| | | |
|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------|
| | <ul style="list-style-type: none"> improvement and expansion of community-based, consumer-controlled Centers for Independent Living and the community education throughout the Commonwealth. - Advocate for a community-based, consumer-directed service delivery system. | |
| VOCAL | <ul style="list-style-type: none"> - Operated by and for people in mental health recovery. - Work to create broad social change as well as in individual's lives. - Peer run programs that for people in mental health recovery. | <p>Individuals Free Peer run programs Free</p> |
| Youth Leadership Forum | <ul style="list-style-type: none"> - To empower Young Virginians with Disabilities to achieve their personal goals and to develop leadership skills. - To be self-reliant and to enhance self-esteem. - To participate fully in their community. | Not applicable |

Appendix B Organization models, activities and dues for National

Table B1 represents National disability-led organizations based on self-advocacy organizational models.

Table B1

National disability-led organizations based on the organizational models.

| National Disability-Led Organizations | Autonomous | Divisional | Coalition | Service System |
|------------------------------------------------------------|------------|------------|-----------|----------------|
| National Federation for the Blind | X | | | |
| National Council for Independent Living | X | | | |
| ADAPT | X | | | |
| American Association for People with Disabilities | X | | | |
| Self Advocates Becoming Empowered | X | | | |
| National Coalition for Mental Health Recovery ⁺ | X | | X | |
| Autistic Self Advocacy Network | X | | | |
| National Disability Leadership Alliance | X | | X | |
| Consortium for Citizens with Disabilities ⁺ | X | | X | |

⁺ NCMHR is a membership coalition of state mental health recovery groups

⁺ CCD has over 100 provider, advocacy and consumer national organizations

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

Table B2 lists the organizations, the activities and programs, and the dues structures for each.

Table B2

National disability-led organizations – activities, programs, and dues.

| National Disability-Led Organizations | Activities/Programs | Dues |
|---------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|
| National Federation for the Blind | <ul style="list-style-type: none"> - Develop policy statements regarding issues for the blind. - Host programs on developing youth leaders. - Enhance the use of Braille. - Disseminate the NFB-Newsline - digital talking newspaper. - Educate the Congress and federal agencies on their legislative priorities. | Dues are paid to the state and/or local chapters |
| National Council on Independent Living | <ul style="list-style-type: none"> - Support the Centers for Independent Living by coordinating training opportunities with other organizations for their members. - Develop legislative priorities through a committee system that is pursuant with the independent living philosophy. - Educate the Congress and federal agencies on their legislative priorities. | Individual \$35/ annually Youth \$10/ annually CILs Sliding scale based on annual budget |
| ADAPT | <ul style="list-style-type: none"> - Take direct action to enhance their agenda. - Train other state chapters on the basic organizing actions. - Develop policy statements that enhance their mission. - Offer various training opportunities in nonviolent direct action including civil disobedience. | Based on level of member's participation |
| American Association for People with Disabilities | <ul style="list-style-type: none"> - Host a Justice for All list serve regarding issues about the disability community. - Disability mentoring project. - Internship program for congressional interns and for information technology interns within federal agencies. - Interfaith Initiative to promote spiritual and religious access. | Individual \$15/ annually Student \$10/ annually |

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

| | | |
|-----------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| | <ul style="list-style-type: none"> - Educate the Congress and federal agencies on their legislative priorities. | |
| Self-Advocate Becoming Empowered | <ul style="list-style-type: none"> - Develop priorities from their membership. - Hold conference calls about self-advocacy. - Develop policy statements. - Promote People First language. - Work with other organizations to impact policy change. - Educate the Congress and federal agencies on their legislative priorities. | Person with a disability \$15/ annually Person without a disability \$10/ annually |
| National Coalition for Mental Health Recovery | <ul style="list-style-type: none"> - Develop policy statements. - Provide technical assistance to the state consumer run organizations. - Educate the Congress and federal agencies on their legislative priorities. | Individual \$25/ annually Group \$100/ annually |
| Autistic Self Advocacy Network | <ul style="list-style-type: none"> - Develop policy statements. - Work with other organizations. - Host a speaker bureau to educate the larger community about Autistic spectrum issues. - Educate the Congress and federal agencies on their legislative priorities. | No dues |
| National Disability Leadership Alliance | <ul style="list-style-type: none"> - Coordinate policy statements with the 13 disability led organizations. - Support a common agenda. - Educate the Congress and federal agencies on their legislative priorities. | No dues |
| Consortium for Citizens with Disabilities | <ul style="list-style-type: none"> - Develop policy statement and priorities in specific issues task forces. - Educate the Congress and federal agencies on their legislative priorities. | Based on size of organization |

Appendix C Organizational models, activities and dues for selected States

Table C1 represents State disability-led organizations based on self-advocacy organizational models.

Table C1

State disability-led organizations based on the organizational models.

| State Organizations | Autonomous | Divisional | Coalition | Service System |
|-------------------------------------------------|------------|------------|-----------|----------------|
| People First of California | X | | | |
| Association of Self Advocates of North Carolina | X | | | |
| Self Advocate Association of New York State | X | | X | |
| People on the Go Maryland | | X | | |
| Kentucky Self Advocates for Freedom | X | | | |
| Cross Disability Rights Coalition ⁺ | | X | X | |
| Self Advocates of Minnesota. | | X | | |
| Massachusetts Advocates Standing Strong | X | | X | |

Table C2 lists the organizations, the activities, and programs, and the dues structures for each.

Table C2

State disability-led organizations – activities, programs and dues

| State Organizations | Activities | Dues |
|----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------|
| People First of California | <ul style="list-style-type: none"> - Provide a toolkit to help start local People First Chapters. - Provide technical assistance to chapters. | Local chapters may have dues or fundraisers |

⁺ CDRC is a coalition that is operated under a umbrella organization

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

| | | |
|-------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------|
| | <ul style="list-style-type: none"> - Advocate for policy change. - Host an annual state conference. | |
| Association of Self Advocates of North Carolina | <ul style="list-style-type: none"> - Educate community, government leaders, families, guardians, and service delivery about self-advocacy. - Empower, encourage, and enable people with disabilities to become self-advocates. - Maintain a database of self-advocacy groups. - Advocate for policy change. - Host an annual state conference. | Person with a disability \$10/ annually Group \$35/ annually |
| Self Advocate Association of New York | <ul style="list-style-type: none"> - Administrate a project through AmeriCorps. - Educate members on how to contact their elected officials. - Coordinate the regional self-advocacy organizations. - Share their stories, poems, and other information in their voice on website. - Host an annual state conference. | No dues for voting members Non-voting individual members \$10/ annually Groups \$100/ annually |
| People on the Go Maryland | <ul style="list-style-type: none"> - Survey individuals about satisfaction of consumer direction. - Advocate for policy change at the state capitol. - Support 13 self-advocacy groups across the state. | No dues |
| Kentucky Self Advocates for Freedom | <ul style="list-style-type: none"> - Develop local chapters to promote equal rights, inclusion, and self-advocacy. - Encourage members to speak for themselves. - Educate community, lawmakers, and policy makers about rights of people with disabilities. | Individual \$20/ annually Family/support person. \$25/ annually Other Individual \$40/ annually Organization \$100/ annually |
| Cross Disability Rights Coalition | <ul style="list-style-type: none"> - Participate in policy activities involving getting people out of state residential centers/nursing facilities. - Facilitate an intern program for up and coming leaders. | No dues |

Running head: CREATING A NEW SELF-ADVOCACY ORGANIZATION

| | | |
|-----------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------|
| Self Advocates of Minnesota | <ul style="list-style-type: none"> - Support local self-advocate chapters. - Offer technical assistance. - Network with other self-advocacy organizations across the state. - Provide technical assistance. | No dues |
| Massachusetts Advocates Standing Strong | <ul style="list-style-type: none"> - Coordinate self-advocacy organizations across the state. - Develop policy statements. - Produce an online newsletter. - Host an annual state conference. | Member \$10/ annually Supporter \$30/ annually Organization \$300-\$1000/ annually |



The Partnership for People with Disabilities is a university center for excellence in developmental disabilities at Virginia Commonwealth University. VCU is an equal opportunity/affirmative action university providing access to education and employment without regard to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation or disability. If alternative formats of this document are needed, please contact the Partnership for People with Disabilities at (804) 828-3876 or (800) 828-1120 (TDD Relay).