



ENVISIONING THE FUTURE: ALLIES IN SELF-ADVOCACY REPORT



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I. INTRODUCTION

The self-advocacy movement is a human and civil rights movement led by individuals with intellectual and developmental disabilities. In the words of the national self-advocacy organization, Self Advocates Becoming Empowered (SABE):

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)

The movement started internationally over 35 years ago (Dybwad, 1996). Influenced by developments in Canada, both Oregon and Washington were among the first states in the U.S. to develop local and state organizations (People First of Washington, 1984). As the movement spread across the country during the 1980s, momentum grew to form a national organization. Planning began in 1990 at the first national self-advocacy conference held in Estes Park, Colorado and SABE was incorporated in 1996 (SABE, 2010).

SABE currently estimates that there are over 1,200 local self-advocacy chapters in the United States. While there is little detailed information about the state of the movement, the last estimate was that 31 states had formal state self-advocacy organizations and an additional 9 had state-level contacts (Hayden & Nelis, 2002). Internationally, at least 43 other countries have formed national organizations (Buchanan & Walmsley, 2006).

The movement has transformed the lives of millions of individuals with intellectual and developmental disabilities. It has empowered individuals to make choices in their lives, provided opportunities to speak up and have a voice, and opened pathways for leadership development (Caldwell, 2010). It has provided access to the disability community and for many it has contributed to development of a positive self-identity and sense of disability pride (Caldwell, 2011). Moreover, the movement has challenged negative attitudes about disability and achieved major advances in rights, full participation, and social justice (Goodley, 2000).

However, the movement has struggled within the U.S. to secure stable funding for infrastructure and necessary supports. While a handful of states have developed strong movements, the movements within other states have been weakened in recent years due to lost funding and supports. Other states are still in the early stages of organizing.



The movement has also changed over time. Opportunities for individuals with disabilities within the U.S. have improved since initial formation of the movement. The Rehabilitation Act, Individuals with Disabilities Education Act (IDEA), Americans with Disabilities Act, and U.S. Supreme Court Olmstead decision have provided a generation of self-advocates and their families greater opportunities, rights, and expectations for full inclusion. Yet while opportunities have risen, people continue to face discrimination and oppression. The movement continues to evolve and change as younger self-advocates enter and share their experiences.

Other national self-advocacy organizations have formed. The National Youth Leadership Network (NYLN), a cross-disability organization led by young people with disabilities between the ages of 16 and 28 years old, was formed in 1997 and became a non-profit in 2005. NYLN is open to individual members in all states and territories and has state affiliates in many states. More recently, the Autistic Self Advocacy Network (ASAN) has emerged as an advocacy organization run by and for Autistic individuals¹. ASAN provides a national voice on issues and has state chapters in about 11 states.

There have also been many different approaches taken to structure self-advocacy. Some states have more than one statewide self-advocacy organization. Some have taken more of a regional approach. Some approaches have promoted broad cross-disability organizing. Others have focused more narrowly on subgroups or particular issues. While approaches have been largely driven by funding streams, there have been varying degrees of success from different approaches. There are needs for better coordination of the wide range approaches to self-advocacy that have evolved at the local, state, and national levels.

Valuing the vital importance of the self-advocacy movement, the Administration on Developmental Disabilities (ADD) (for additional info please see the appendices) launched an unprecedented commitment to better understand the current state of the movement, promote state team planning, and develop suggestions for national actions and policy to support the movement.



In collaboration with the Developmental Disabilities network, self-advocates, and allies, a series of five regional summits across the country were held in the spring of 2011 to promote collaboration, planning, and recommendations at the state and national levels.

1 Some self-advocates prefer the term “Autistic individuals” to express personal identity and pride. Other self-advocates prefer people first language, such as “individuals with autism” to emphasize personhood and challenge hurtful labels.

A. REGIONAL SELF-ADVOCACY SUMMITS

The summits were organized around the following four goals:

1. Assess what is currently happening in the states in self-advocacy – the support structures, activities, accomplishments and challenges;
2. Plan steps we can take to strengthen and enhance current efforts at the state level;
3. Develop recommendations for actions that we can take at the national level; and
4. Develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country.

Funding for the summits was provided through the collective technical assistance contracts of the Association of University Centers on Disabilities (AUCD), National Association of Councils on Developmental Disabilities (NACDD), and National Disability Rights Network (NDRN). AUCD took the lead on organizing the summits.

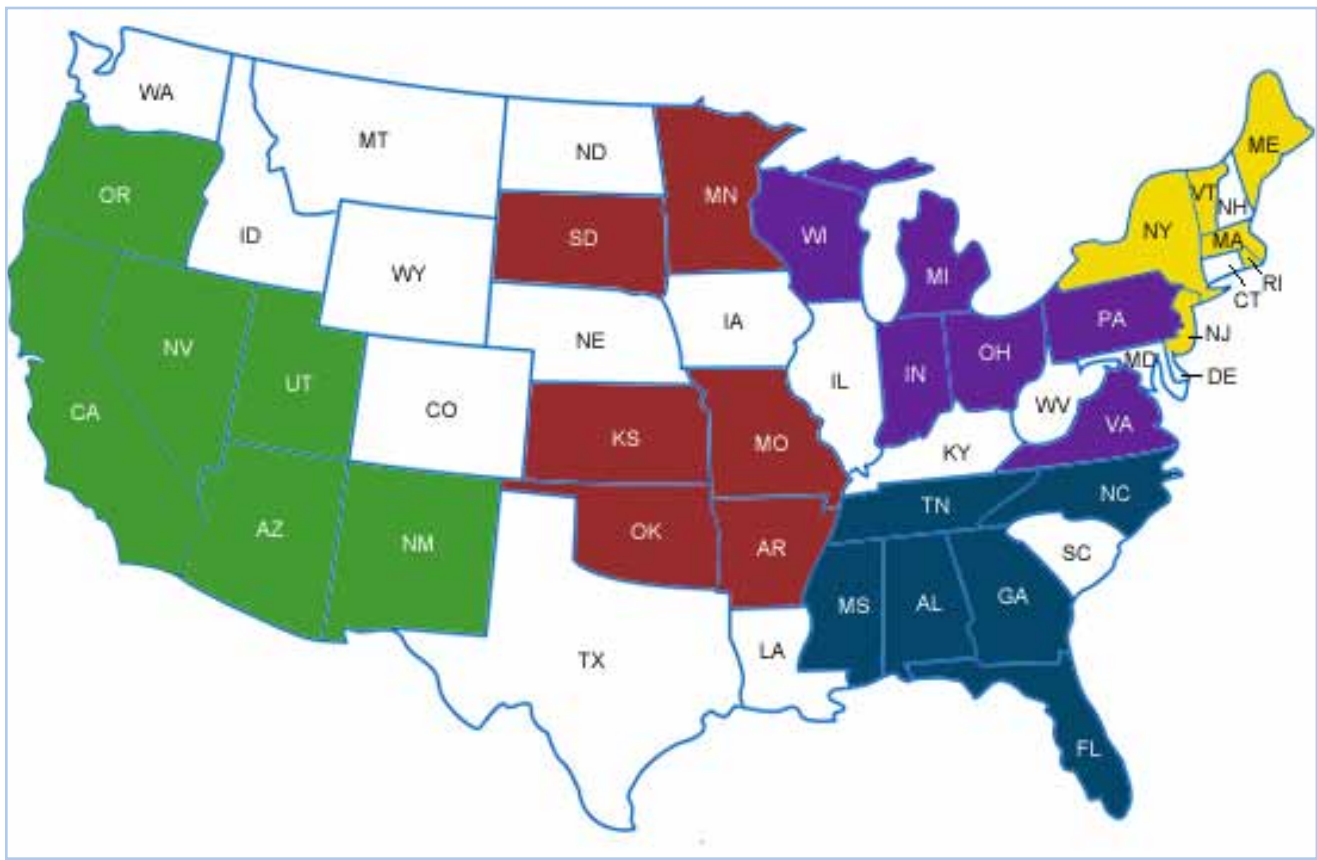
A planning committee was developed to guide the summits. The planning committee consisted of representatives from SABE, AUCD, NACDD, NDRN, NYLN, National Association of State Directors of Developmental Disabilities Services (NASDDDS), and Human Services Research Institute (HSRI).

Due to limited funding, it was not possible to include every state in the first round of summits. However, the Administration on Developmental Disabilities plans to conduct additional summits that would include the remaining states and territories. A total of 30 states were selected for the first round of summits. States were organized into five regional summits (with 6 states per region). States and regions are highlighted in the following map.

The five regional summits took place at the following locations and dates:

- Atlanta, GA (March 10-11, 2011)
 - States: Alabama, Florida, Georgia, Mississippi, North Carolina, Tennessee
- Los Angeles, CA (March 24-25, 2011)
 - States: Arizona, California, Nevada, New Mexico, Oregon, Utah
- Kansas City, MO (April 11-12, 2011)
 - States: Arkansas, Kansas, Minnesota, Missouri, Oklahoma, South Dakota
- Columbus OH (April 28-29, 2011)
 - States: Indiana, Michigan, Ohio, Pennsylvania, Virginia, Wisconsin
- Providence, RI (May 16-17, 2011)
 - States: Maine, Massachusetts, New Jersey, New York, Rhode Island, Vermont

“Our state is maybe a little bit behind some of you all in getting organized as a statewide advocacy movement. But, I think this conference has allowed us to bring some heads together and make a start towards making up for that and moving forward into the future.”



Each state developed a state team of 9-12 people, with an equal combination of self-advocates and professionals. The make-up of the teams is identified below.

The core team members included:

- DD Council (1 person)
- P&A (1 person)
- Self-advocacy leadership (adult + youth) (2-3 people)
- UCEDD (1 person per UCEDD)
- DD Services Agency (1 person)

Core state team members were asked to collaborate to determine the remaining team members from:

- National Youth Leadership Network (NYLN) or other youth self-advocacy leadership
- Autistic Self Advocacy Network (ASAN) or other autism self-advocacy leadership
- Other DD organization leaders in state
- At least one “youth” self-advocate (under the age of 30) was required to participate as a member of the state team.

Before coming to the summits, state teams were instructed to meet and develop an overview of activities, accomplishments, and challenges in self-advocacy for the state. A PowerPoint template was provided for state teams to complete prior to the summit.

A great deal of attention was paid to the accessibility of the summits and summit materials. AUCD hired a self-advocacy coordinator to assist. Examples of steps taken to ensure accessibility included:

- Accessible materials were prepared that used easy to understand language and pictures.

- Webinars were held in advance to help explain the purpose of the summits and prepare state team members.
- Self-advocates brought support persons.
- Opportunities were provided to ask questions.
- Quiet rooms were provided for individuals with sensory needs.
- Color coded interaction signal badges were used based on a system developed by the Autistic Network International (<http://www.autreat.com>).
- Requests were made for individuals to not wear scented perfumes, colognes, and toiletries.
- Individuals were asked not to use flash photography.
- At the last summit, graphic note taking was used and the visuals and pictures helped assist with understanding.

Summit materials are available at: <http://alliesinselfadvocacy.org>. The summit agenda is also available in the appendix. The summits were held over two days. On the first day, state teams used their PowerPoints prepared in advance to provide background about the movement in their state. Peer breakout sessions were held which provided an opportunity for individuals to network with their peers (i.e. self-advocates, DD Councils, P&As, UCEDDs, DD State Agencies, and Advisors and Allies). Finally, state teams met to develop state plans to strengthen the movement in their state. On the second day, state teams reported on their state plans. State teams then met to develop recommendations for national actions and policy recommendations and reported their recommendations to all summit participants. At the end of each day, time was provided for “open mic” sessions where participants provided reflections and feedback on the summits.

Members from the planning committee met during and following each summit to make continuous improvements. Examples of improvements that were made included:

- A background document about the Administration on Developmental Disabilities (ADD) was prepared and additional time on the agenda was devoted to help individuals understand ADD’s structure, role, and location within the federal government.
- Self-advocate facilitators were recruited to co-facilitate breakout sessions whenever possible.
- A self-advocate was recruited to lead the “open mic” sessions.
- Additional guidance and a template was provided to note-takers to improve the quality of notes.
- Questions and additional guidance were developed and provided to facilitators of the peer breakout sessions.

“I see self-advocacy as both speaking up for what we want but also getting in there and making things happen. And I think that is what this summit is all about, us taking part with the people who are allies and working together.”

B. PREPARATION OF THE REPORT

A research team from the University of Illinois at Chicago took the lead on developing the report. Highlighted below is an outline of the process:

- At least one member of the research team attended each regional self-advocacy summit to observe and take notes.
- All plenary sessions were recorded (opening session, state team presentations, and “open mic” sessions). Quotes were used from these sessions. However, names were not used.
- Note takers, recruited primarily from the UCEDDs in each region, took notes during all state breakout sessions.
- While members from the research team observed the peer/organizational breakout sessions, no notes or recordings were taken of these sessions in order to promote a safe place for confidential discussions.
- State team PowerPoint presentations, observations, and notes were used to summarize the findings.
- Following each summit, members of the research team met to discuss initial themes. Initial themes were expanded and refined as more summits occurred.
- The planning committee reviewed an initial draft of the report and provided feedback. This served as an important check based on their observations during the summits.
- Self-advocates from the planning committee assisted the research team with development of an accessible format of the report for individuals with intellectual and developmental disabilities.

The main findings of the report are organized into the following areas based on the goals of the summits: 1) State of the States in Self-advocacy; 2) State Team Plans to Strengthen Self-advocacy; and 3) National Recommendations for Actions and Policy.

States were at all different points in their commitment and capacity to support self-advocacy.

Some state teams were just getting to know each other and learning how to work together while other state teams had a long history of collaboration and support for self-advocacy.

II. FINDINGS

A. STATE OF THE STATES IN SELF-ADVOCACY

State teams worked together before the summit to develop an overview of self-advocacy in their state to share at the beginning of the summit. State team presentations were led by self-advocates. Information shared included organizations within the state, resources, activities, accomplishments, challenges, and dreams for the future. Below is a synthesis of some of the major themes within the state team presentations. It is limited to the information that was shared in the PowerPoint and brief presentation. State team PowerPoints can be found in the appendix (materials that go with this report) and online at: <http://alliesinselfadvocacy.org>.

States were all at different points in their commitment and support of self-advocacy. Some state teams were just getting to know each other and learning how to work together while other state teams had a long history of collaboration and support for self-advocacy.

1. RESOURCES TO SUPPORT SELF-ADVOCACY

States said that self-advocacy organizations received a wide range of financial and other supports. Sources of financial supports included state and federal agencies as well as some private foundations. Approximately one-third of states (11 states) reported that they received some level of funding through their state developmental disability services agency. Three states reported they received funds from the Administration on Developmental Disabilities through partnerships on other grants. Only one state indicated receiving funding and support from a Center for Independent Living. As required in the DD Act, the majority of states indicated their Developmental Disabilities Council² supported self-advocacy. UCEDDs and P&As provided support in various ways, including indirect financial support, serving as a financial agent, meeting space, office space and supplies, and travel support. Other sources of funding included donations, fundraising, and membership fees.

A few states provided a detailed breakdown of their funding for self-advocacy. However, it should be noted that even in the states with the highest level of funding, the total operating budgets of self-advocacy organizations were extremely low, often dependent on short-term funding streams, and vulnerable to cuts. Very few states indicated that they had secured enough funding for a paid executive director for the self-advocacy organization.

2. MAJOR ACTIVITIES AND ACCOMPLISHMENTS

a. Advocacy

States highlighted focusing advocacy on a variety of important issues, including increasing employment opportunities, affordable accessible housing, accessible transportation, postsecondary education opportunities, reducing waiting lists for services, and transitioning people from institutions to the community. Transition after high school was also a major area of advocacy for most states. Self-advocates were involved in legislative advocacy in many states. Many states also indicated a focus on participation on boards and committees of decision-making entities. One state received an apology from the Governor for forced sterilization of people with disabilities. Another state passed a self-directed support waiver.

b. Training and Leadership Development

Training and leadership development were also major activities identified by states. Training ranged from skill building workshops to conferences. Topics included rights, sexuality and relationships, guardianship, and voting. Leadership development included peer support and mentoring, youth leadership, and policy education. States indicated that a major role of self-advocacy organizations was to provide a supportive space for people with disabilities to discuss concerns, help each other solve problems and make decisions. Several states had projects focused on youth leadership. Many states highlighted successful leadership initiatives to get self-advocates on boards and committees as well as to support involvement in the national movement. Some states also had developed training for advisors.

2 The Developmental Disabilities Act requires DD Councils to include a goal in their state plans to: (I) establish or strengthen a program for the direct funding of a state self-advocacy organization led by individuals with developmental disabilities; (II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and (III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

c. Public Education and Outreach

Many states reported that they were focused on educating the public on disability awareness and accessibility. Many states had advocacy campaigns around respectful language and getting rid of the “R” word. A lot of self-advocacy organizations engaged self-advocates in activities to reach out to others in the community and tell their stories. Several states highlighted specific disability awareness initiatives. Some states were proud of materials they had developed to highlight their work and issues.

d. Cross Disability Advocacy, Partnership and Allies

Some states said that partnerships and collaboration with other organizations had worked well for self-advocacy organizations. Types of partnership included state agencies, businesses, and allies. Also, self-advocacy coalitions were created through partnerships, which developed common goals and messages for advocacy and shared information and resources.

3. CHALLENGES

a. Infrastructure to Support Self-Advocacy

Infrastructure means the foundation to support self-advocacy. The two most frequently mentioned challenges were lack of funding and support by advisors. Some states said they could use support to help them get grants. States report they have a hard time finding and keeping advisors as well as getting support that empowers versus controls. For example, one state reported that some of the advisors are not trained and some try to run the groups.

b. Community Services and Supports

Many states indicated challenges related to lack of broader community services and supports. Nearly half of states (13 states) reported lack of transportation as a major challenge for people to get to meetings and gatherings. Other challenges included lack of employment opportunities and lack of individualized housing options.

c. Outreach and Communication

Involving more self-advocates through communication and outreach was a challenge for many states. Recruiting and developing leaders as well as maintaining and engaging current membership was difficult. Finding meaningful ways to engage youth and develop youth-led advocacy work was an area where some states felt they were struggling. Expanding self-advocacy to rural areas, racial and ethnic minority communities, individuals with limited communication, and autism groups were a challenge for states.

d. Public Perceptions

Finally, a major challenge indicated by many states was negative public perceptions. Some states identified perceptions of service providers and families as major challenges. One state felt that many look at self-advocacy as a “program” rather than a movement. Also, some indicated struggles with public awareness and understanding about self-advocacy.



B. PLANS TO STRENGTHEN SELF-ADVOCACY IN STATES

On the first day of the summits, state teams met to develop state plans to strengthen and enhance the movement within their state. The number of goals developed by states ranged from 1 to 5. The majority of states chose to focus on 2 to 3 goals. State teams also outlined specific action steps including: 1) How the goal would be achieved; 2) Who would be responsible for each step; and 3) When each step would be completed. This information was compiled into powerpoint presentations that state teams used to report to the all summit participants on the second day of the summits.

Powerpoint presentations of the state team plans are available online at: <http://alliesinselfadvocacy.org>. A compiled copy of all state team plan goals is contained in the appendix. While each state plan was unique to their own state, there were six major themes outlined below.

1. TRAINING AND LEADERSHIP DEVELOPMENT

a. Training

Many states developed goals, which included providing some form of self-advocacy or leadership training for self-advocates (AL, AZ, CA, IN, MI, MO, NV, and SD). Some states had existing curriculums in use within their state that they wished to expand, while others were interested in finding and adopting curriculums. Some states focused on basic self-advocacy skills and choice-making. Others focused on more advanced leadership development skills. Some focused on trainings to support participation in voting and public policymaking.

b. Mentoring

Several states mentioned expanding peer mentoring opportunities for self-advocates (MI, MO, and NV).

c. Leadership Opportunities

Some states developed goals to provide a variety of other leadership opportunities, such as participation on state advisory boards and committees and promoting hiring of individuals with disabilities within agencies and organizations serving individuals with disabilities (AL, MI, and PA).



2. INFRASTRUCTURE TO SUPPORT SELF-ADVOCACY

a. Local and Regional

Some states developed goals to strengthen local and regional capacity of their self-advocacy movements. For example, California established a goal to create local summits to develop a strategy for each region. Massachusetts developed a goal to expand regional self-advocate coordinators throughout the state to support self-advocacy. Other states mentioned providing information and technical assistance to local self-advocacy groups across the state (OH and UT).

b. Statewide

There was a lot of diversity across states in terms of organizational capacity at the state level. Florida, which currently does not have a formal state self-advocacy organization, developed a goal to establish one. Oklahoma, which has long had a statewide organization, established a goal to explore its ability to host another national SABE conference. Other states expressed desire to do statewide assessments and strategic planning (NC and NV).

c. Funding

Several states developed goals to secure funding and resources (AR, MN, and NV). These included strategies such as grant writing, corporate and foundation roundtables, and donations. Minnesota developed a goal to establish a “think tank” to work on sustainable, long-term funding to support the movement.

3. CROSS DISABILITY COALITIONS, PARTNERSHIPS, AND ALLIES

a. Cross Disability Coalitions

Many states developed goals that included broad cross-disability coalition building (AZ, FL, MA, NC, OH, OR, OK, PA, TN, and VA). Some states were interested in creating formal cross-disability coalition organizations. Virginia provided a model for doing this. Others decided to work on communications among self-advocacy organizations, establishing informal networks, or partnering together on joint projects or initiatives.

b. Partnerships and Allies

Many states also established goals that included strengthening relationships with partners and allies (AR, AZ, GA, ME, MS, NM, OR, and UT). Some focused on “non-traditional” allies. Some mentioned partnerships with schools, youth organizations, hospitals, providers, community organizations, and policymakers. In addition, many of the state teams identified goals for the state team partners to continue meeting and planning following the summit.

4. OUTREACH AND COMMUNICATION

a. Outreach

Many states developed goals to outreach to individuals about self-advocacy (CA, FL, GA, MA, ME, MI, NC, NJ, OK, SD, and UT). Some states planned to develop brochures, hold membership rallies, and outreach through the radio, television, and print media. Some specifically identified needs to outreach to ethnic minority and non-English speaking populations. Many states also identified specific goals to outreach to youth and underrepresented communities. Strategies included establishing youth forums and presenting at schools and transition conferences.

b. Communication

Many states also developed goals to improve communications within their self-advocacy organizations (CA, FL, GA, NC, OK, SD, TN, and UT). Strategies included conferences, teleconferences, newsletters, mailings, forums, and home visits. Several states developed strategies to use social media and technology, such as Facebook, blogs, listservs, webinars, video conferencing, websites, and online resource libraries.

5. PUBLIC EDUCATION

a. Public Attitudes and Knowledge of Self-Advocacy

Many states developed goals to educate the general public about self-advocacy, promote positive attitudes and perceptions about disability, and celebrate diversity (AR, FL, MA, NV, OK, VT, and WI). Some states identified focusing on schools and churches. Others focused on parents, service providers, and medical professionals. Oklahoma developed a legislative strategy to get rid of the “R” word.

b. Employers

Several states also specifically emphasized the importance of educating employers and the business community within goals to increase employment (IN, ME, and NJ).

6. COMMUNITY SERVICES AND SUPPORTS

Finally, several states developed goals to improve community services and supports. These goals were central to the lives of individuals and their ability to participate in their communities and the movement. States developed goals in the following areas:

a. Education and Transition (MO and NV)

b. Employment (KS, ME, NJ, and NV)

c. Transportation (ME, MS, NJ, and RI)

d. Housing (NJ)

e. Community Living (GA, NM, and NY)

C. RECOMMENDATIONS FOR NATIONAL ACTIONS AND POLICY

State teams met on the morning of the second day of the summits to develop recommendations for national actions and policy recommendations to lead to a stronger, more effective, and long lasting self-advocacy movement across the country. Teams prioritized recommendations for national action and policy. These were compiled into PowerPoint presentations that state teams used to report to all the summit participants in the afternoon.

PowerPoint presentations of the state team plans are available at: <http://alliesinselfadvocacy.org>. A compiled copy of all recommendations by state is also included in the appendix. However, there was a great deal of overlap and inconsistency between what some teams reported as actions and some reported as policy recommendations. Therefore, in order to help communicate the main themes across all the summits, these categories were reorganized in this report. Below are the major themes that were identified.

1. RECOMMENDATIONS FOR NATIONAL ACTIONS

National actions included short and long-term recommendations for activities that the Administration on Developmental Disabilities (ADD) could consider undertaking to strengthen self-advocacy. There seemed to be four major themes:



a. Support to Strengthen Self-Advocacy

A major theme across recommendations for national actions was for ADD to strengthen support for self-advocacy. There seemed to be three possible paths for action.

(1) Statewide Information and Training Centers

The most frequently made national policy recommendation was to authorize self-advocacy and training centers as part of the Developmental Disabilities Act reauthorization. This is discussed in the next section as a policy goal. However, as a more immediate action, it was suggested that ADD could consider piloting such centers as Projects of National Significance. Self-advocates emphasized that these centers should be run by statewide self-advocacy organizations governed and led by individuals with developmental disabilities. They could help support many of the activities highlighted earlier in the report, such as:

- Peer advocacy and mentoring
- Training and leadership development
- Public education and outreach
- Assistance with accessing community services and supports

(2) National Technical Assistance and Resource Center on Self-Advocacy

Many state teams recommended establishing a national effort to support development and infrastructure of local and state self-advocacy organizations across the country. Similar to statewide information and training centers, self-advocates stressed that this center should similarly be led by self-advocates. ADD could consider establishing such a center as a Project of National Significance. Suggestions of what a national center might provide included:

- Assist with grant writing and securing funding for self-advocacy.
- Support self-advocacy groups to become non-profit organizations.
- Develop strategies for delivering state-to-state technical assistance.
- Teach the history of the self-advocacy movement and build pride in what has been achieved.
- Provide a central hub for self-advocacy groups to come together and share thoughts, ideas, and information.
- Develop a “one-stop shop,” “internet portal,” or clearinghouse to share information about self-advocacy organizations, training and leadership curriculums, best practices and resources across states.

(3) Provide Technical Assistance through DD Network Partners

A third path suggested by state teams was for ADD was to use existing technical assistance contracts with DD Network partners to support self-advocacy. This is similar to how the regional self-advocacy summits were made possible. Given limited funding for Projects of National Significance, this pathway might support some of the needs identified above. Additional suggestions included:

- Continue regional self-advocacy summits to reach states and territories that did not participate in the first round.
- Encourage DD network partners to devote part of their websites to self-advocacy.
- Include self-advocacy organizations in all DD network partners’ national technical assistance conferences annually.

- Draw upon the UCEDDs expertise to help develop measurement tools to collect data on outcomes of self-advocacy.
- Explore focused efforts with P&As to provide technical assistance to support self-advocacy around targeted issues such as community employment.

b. Promote Inclusion and Self-Advocacy at the Federal Level

A second major theme was for ADD to serve as a model agency and be a platform to promote self-advocacy at the federal level.

(1) Employment and Leadership Opportunities

Many state teams recommended that ADD continue to play a leadership role in modeling and promoting employment and leadership opportunities for self-advocates at the federal level and within the DD network.

Suggestions included:

- Consider hiring self-advocacy coordinators at ADD, similar to some positions within state government agencies. A specific charge of such positions might be to promote self-advocacy within ADD, the DD Network, and in collaboration with other federal agencies and states.
- Continue to promote leadership opportunities for self-advocates, such as internship opportunities and inclusion on national boards and committees with supports.
- Consider forming an ADD self-advocate advisory board or task force to meet regularly and guide ADD’s work.
- Assist with organizing a mock congressional legislative session, similar to what was done at the state level in Arkansas as a leadership training opportunity.

“We all know—whether we are talking about service providers, individuals who work for the government, family members, or individuals working for network entities—that we all benefit when self-advocates have an opportunity to design the policies, design the service systems, and most importantly, lead.”

-Commissioner Sharon Lewis

(2) Accessibility and Respectable Language

State teams also recommended several potential leadership roles for ADD to play in promoting accessibility for individuals with intellectual and developmental disabilities at the federal level. Suggestions included:

- Improve the ADD website to be more user-friendly and serve as a model for other agencies.
- Work across agencies to improve accessibility and understandability of materials and resources. Work towards requiring universal design and accessibility in all government information, so self-advocates can understand.
- Work with other federal agencies to get rid of hurtful words such as the “R” word and “handicapped.”

(3) Raising Expectations

Some state teams also suggested that ADD should continue to use its leadership platform to set expectations for DD network partners and the federal agencies. Suggestions included:

- Set expectations for shared responsibility to support self-advocacy across the DD network.
- Embed youth and underrepresented populations of self-advocates throughout all ADD's activities and initiatives.
- Set standards for ADD grantees to ensure the inclusion of paid self-advocates in shaping policies that impact people with DD.

c. Outreach and Education About Self-Advocacy

A third major theme suggested by state teams was for ADD to consider outreach and education activities about self-advocacy. Suggestions included:

- Outreach to un-served and underserved populations and families about self-advocacy.
- Dialogue with business community to increase employment opportunities for individuals with DD.
- Educate the public about the DD Act, how self-advocacy has improved the lives of individuals with disabilities, and public perceptions and disability. Some expressed that outside of the DD field few people know what "self-advocacy" is and there is a need to "re-brand" the term.
- Use social media (e.g. Facebook, MySpace, Twitter, and YouTube) and public service announcements to promote self-advocacy.
- Issue an annual proclamation of Disability Awareness Month and celebrate the history of self-advocacy and disability rights movement.

d. Collaboration with Federal Partners

Finally, a fourth major area of recommendations for ADD focused on communication and collaboration with other federal agencies on a wide range of issues impacting the lives of self-advocates. Specific agencies and suggested activities included:

(1) Department of Education

- Introduce self-advocacy to youth at a young age and include in transition planning.
- Expand opportunities for post-secondary education, scholarships, and internships.
- Promote inclusion of Disability history and rights in public school curriculum.
- Improve general education teacher training on the needs of students with visible and invisible disabilities.

(2) Centers for Medicare and Medicaid (CMS)

- Provide TA to states on funding of self-advocacy activities through Medicaid.
- Make sure self-advocates are at the table to provide input into planning and guidance of services at both the state and federal levels.
- Increase person-centered practices, community supports, and individualized budgeting.
- Improve training of doctors and health professionals – (led by self-advocates).

(3) Social Security Administration (SSA)

- Work with SSA to study, raise awareness, and assist with eliminating the marriage penalty and barriers to employment and asset accumulation.

(4) Department of Labor

- Promote best practices in employment of individuals with I/DD
- Work to eliminate subminimum wage policies.

(5) Department of Transportation

- Draw attention to the lack of transportation for self-advocates.

(6) Other relevant federal agencies

...including Administration on Aging, Substance Abuse and Mental Health Services Administration (SAMSHA), Health Resources and Services Administration (HRSA), and the Rehabilitation Services Administration (RSA).

2. RECOMMENDATIONS FOR NATIONAL POLICY

Policy recommendations were organized into two categories: 1) Recommendations for the Developmental Disabilities Act, and 2) Recommendations for other federal policies.

a. Developmental Disabilities Act

The following recommendations were made regarding reauthorization of the Developmental Disabilities Act (DD Act):

- As previously discussed, the most frequently made recommendation was to authorize self-advocacy information and training centers. This was discussed as an important step in acknowledging self-advocates as “equal and respected partners” within the DD network. Many referred to this as adding a “fourth leg,” or new title to the DD Act, to complement the other three major components: DD Councils, UCEDDs, and P&As. One self-advocate provided a drawing to illustrate that the new title would not merely “stand alone,” but would help bind the other three partners. It would serve as a check and support to strengthen the whole DD Act.
- Require collaboration of the DD network on a national plan for self-advocacy with goals informed by self-advocates and state plans.
- Add language to the DD Act to require the 3 sister agencies (UCEDDs, P&As, and DD Councils) to support the self-advocacy movement, similar to what is already in place for DD Councils.
- Require youth with developmental disabilities (under 28 years of age) on the DD Council.
- Add language to the DD Act on self-advocacy to promote inclusion of people with most significant disabilities and individuals from under-represented communities in self-advocacy.
- Explore the possibility of promoting self-advocacy through revising regulations for the Developmental Disabilities Act.



b. Other Federal Policy

The following broader policy recommendations impacting the lives of self-advocates were made:

- Get rid of the SSI federal benefits marriage penalty. This was the most frequently made recommendation.
- Get rid of employment penalties, raise the SSI resource limits, and reduce the amount of time to get through SSI.
- Support expanded and enhanced transition activities for youth with disabilities to include self-advocacy (e.g. TEAM Act).
- Allow working self-advocates to have savings accounts that do not disqualify them for other benefits (e.g. ABLE Act).
- Make Employment First a national policy and end subminimum wage policy.
- End the Medicaid institutional bias.

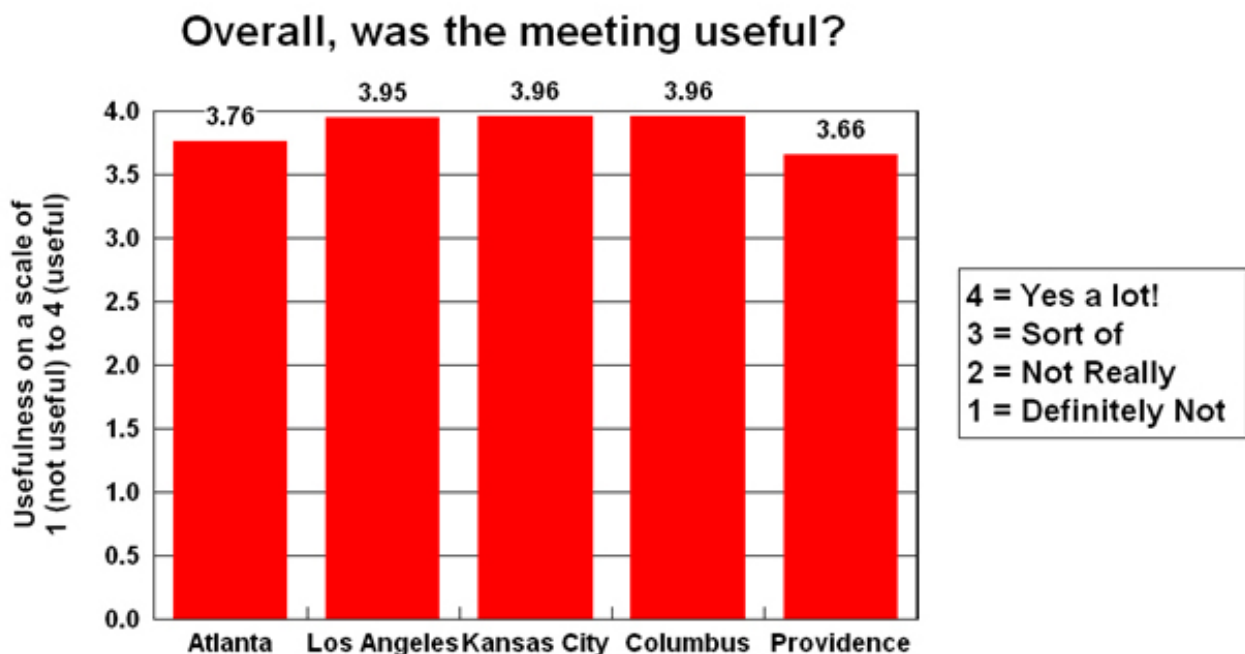
III. EVALUATION AND FEEDBACK

Summit participants were each given an evaluation form in their packets. They were asked to rate the usefulness of the meeting using a four-point scale (yes a lot, sort of, not really, definitely not). Overall, participants indicated overwhelmingly they felt the summits were useful.

Participants were also asked five open-ended questions:

1. What did you learn?
2. After you leave, what will you do with what you learned?
3. What did you like the most?
4. What did you like the least?
5. How can we make the meeting better?

In addition, summit participants provided feedback on many of these questions during the “open mic” periods at the end of each day of the summit. Major themes are highlighted below.



A. WHAT DID YOU LEARN?

Six themes emerged from the responses regarding what participants learned. The first theme was an increased awareness of the self-advocacy movement. One participant commented, "...there is this fantastic movement crossing the country" while another respondent stated, "the world of self-advocacy is bigger than I thought."

Another theme expressed by participants was that the self-advocacy movement benefits from working together and forming coalitions. They expressed enthusiasm for the inclusion of self-advocates from the autism community. Participants felt that collaborations were especially helpful when working on campaigns, such as removal of the "R" word.

Participants did recognize that barriers exist in the self-advocacy movement. "There are some hard conversations that may be uncomfortable, but VITAL to move forward in a manner that's productive and honors the voices of ALL self-advocates..." Others acknowledged limitations in their state that impeded progress..."Philosophically on board BUT most states are doing the best they can but have a lot of structured barriers to doing more."

Participants commented on the increased awareness and understanding of ADD and the DD Act they obtained by attending the summits. They gained a better understanding of what the ADD is responsible for, gained a better sense of what ADD was realistically capable of doing. For example, one participant stated, "I did not realize the DD Act has its roots in 1963—that tells me that real change doesn't happen overnight." Participants also gained a clearer understanding of the role of each of the DD Network partners [the DD Councils, Protection and Advocacy (P&As) agencies, and University Centers for Excellence in Developmental Disabilities (UCEDDs)]. Many participants commented on the Commissioner of ADD and her willingness to work with self-advocates. "...ADD wants to hear from self-advocates directly and that they are committed to continuing the conversation."

Responses indicated the benefit participants gained by learning what was occurring in other states. Many recognized the similar challenges self-advocates and allies faced regardless of which state they were from. "We have a lot of the same challenges so we can support each other and work together to find solutions. Many of us already have the same ideas." Others learned strategies that worked in other states to promote self-advocacy that they hoped might guide their own state efforts. "Our state is maybe a little bit behind some of you all in getting organized as a statewide advocacy movement. But, I think this conference has allowed us to bring some heads together and make a start towards making up for that and moving forward into the future."

Finally, many reported that the summit helped their state move forward on self-advocacy. "[I]... didn't really 'learn' anything but it did help motivate our team to organize." Some felt that the summit was a way of bringing the relevant players to the table together. "This summit really helped bring the players together to commit to a more collaborative effort."

B. WHAT WILL YOU DO WITH WHAT YOU'VE LEARNED?

Participants reported that with the information they learned they will: 1) continue to work on their state plans..." I will continue to be a leader on the team and make sure we all do the things we agreed to do." "I think one thing that went very well is working on actual things, really working on specific things, and we're going to do in our state plans. Because sometimes we just come together for broad discussions that we do over and over again all the time and don't

necessarily focus our efforts on some kind of really specific task.” 2) promote awareness of self-advocacy in their state, including to youth; 3) involve others in the movement and create cross-disability coalitions; 4) re-energize self-advocacy in the state; 5) share information from the summit with others, including self-advocates, DD Network Partners, and government officials; and 6) examine (and increase) what the DD Act partners are doing to promote self-advocacy in their state... “[We are going to] ...convene the state team, self-advocates, and the DD network to have a frank discussion about what self-advocacy is and how to best support it.” “I really learned a lot. It is hard work, but if you put the work in you get it done. Now I will go forward and teach my fellow self-advocates at home what I learned.”

C. WHAT DID YOU LIKE THE MOST?

Respondents indicated they liked the time spent with peers (including peer mentoring); the involvement of ADD and other federal representatives; diversity, respect, inclusion, and accessibility; networking opportunities; and the opportunity to work as state team. Some participants stated:

- “I would just like to say that it has been an awesome day all around. I learned a lot. I listened a lot. And I met new people today.”
- “It was a chance for our rural state to get together and feel more united in our self-advocacy movement and get the ball rolling.”
- “I learned that a diverse bunch of people can get together and it doesn’t have to end in a brawl.”
- “I am glad that autism got to come to the table because everybody always sees people who are on the other end and you hardly ever hear from mine. So I am glad we got to come and have our voice heard too.”



D. WHAT DID YOU LIKE THE LEAST?

Some concerns expressed by participants included logistical issues. There was limited time at the summits. Some participants felt there were too many breaks, while others expressed needing more time for breaks as an accommodation. Many participants felt there was limited time to prepare state plan at the summit and felt rushed or forced by facilitators. More preparation or work as a state team prior to the summit might assist. There was also confusion regarding the definition of self-advocacy... “[We] need a clearer definition or division between individual self-advocacy & self-advocacy organizations”; a lack of familiarity with DD Act (of the participants); and problems with facilitators (including inexperience of some facilitators, input into discussion beyond what participants felt was appropriate, too much facilitation, unfamiliarity with state, and commitment to filling in the charts versus promoting discussion). Some respondents suggested having additional training for facilitators prior to the summits.

Some felt the summit could benefit from expanded participation including more youth, input from parents/supporters/allies, and attendance by state DD directors. Although it varied a great

deal from state to state, some self-advocates expressed that they did not feel treated as “equals at the table” during state team discussions. Finally, many commented on their concerns regarding the future of their state plans and whether there would be any follow up after the summits.

E. HOW CAN WE MAKE THE MEETING BETTER?

Suggestions for improving future meetings largely addressed logistical issues (more time for networking); more information (on the DD Act, information for support staff); wider participation (a wider range of developmental disabilities, and an increased youth presence), and increased leadership roles for self-advocates during the summits. One respondent indicated a desire to have a session at future summits on the current and future roles of allies and advisors.

IV. CONCLUSION

The five regional summits, and the thirty states that participated in the first round, produced a number of outcomes. First, the summits “injected new life into the movement.” The feedback from participants was overwhelmingly positive and enthusiastic. State teams left with renewed energy and plans that will hopefully carry over into action when they return to their states. In the words of the Commissioner:

“We see this as a beginning, not an end. I really hope that if you take nothing else home from here that you have made some connections and fostered some relationships with the people in your state and that you now have a team of people and that we have started something with the development of a group of individuals that will take responsibility as a team collaboratively to strengthen self-advocacy.”

-Commissioner Lewis

ADD may want to consider following up with state teams in the future to see if they have moved forward on their state plans.

Second, the summits produced a number of creative recommendations for moving the movement forward at the national level. Some of these can build upon current short-term activities at ADD. Others may be possible actions for ADD to consider as it moves forward with long-term strategic planning. While ADD has limited resources and staffing, and cannot pursue every recommendation, they highlight areas of importance to self-advocates and can suggest major directions. In the case of policy recommendations for the DD Act and long-range federal disability policy goals, it will take much larger efforts from the disability community. As one self-advocate summed up:

“Commissioner, I know we have given you a lot to do. But if you need any help we will do whatever we can to help you do all those things.”

Third, the summits contributed to learning about how to work together as a team while ensuring the voice of self-advocates is the primary voice. The majority of comments from participants indicated that the summits “got a lot right” in terms of accessibility for people with intellectual and developmental disabilities. As one participant stated:

“I was really impressed with all the conference materials that were put together. I can tell that a lot of hard work went into them to make them accessible in all sorts of

ways and to prepare people to come to something that they have never been to before and explain what was going to happen by using pictures. I was excited to come here because they were paying attention to access stuff that a lot of other places don't."

However, some self-advocates expressed needs for improvements. For example, some self-advocates felt that more attention needs to be given to accommodations for individuals who do have difficulty understanding spoken language through use of sign language or real time captioning. There particularly seemed to be issues at the state team level. Self-advocates noted accessibility issues with state team planning calls and meetings. There also seemed to be issues for some self-advocates who needed assistance with transportation and other supports to participate. The planning committee might consider providing additional technical assistance and training to state teams on accessibility and accommodations.

Comments from both self-advocates and professionals suggested that they benefited from working together as a team and learned from the process. Yet, one area of need for ongoing improvement is ensuring that the primary voice is that of self-advocates. While this was the case with most state teams, there were instances during the course of the summits when advisors, allies, and other state team members dominated conversations and steered the recommendations. As some self-advocates reminded professionals during the summits:

"The summits are about having the power to do and change things. We need to be in the lead. Allies can suggest things to do but remember we are the advocates. This is time to speak up for what self-advocacy means and what the movement means to us."

The power of allies and professionals is at times unintentional and subtle. Perhaps this was best illustrated in observing the peer self-advocate break-out sessions. These sessions, which only included self-advocates, provided safe environments. They produced lively discussions where nearly every self-advocate shared ideas and perspectives. However, some of the same self-advocates who contributed the most during these sessions, were silent during the break-out sessions with other state team members. Also, at times some advisors and support persons seemed to overstep their roles, allowing their perspectives to overshadow their role in supporting self-advocates in sharing their views. These conflicts and tensions lie at the very heart of the self-advocacy movement. At its very core the movement is an ongoing struggle of an oppressed group for voice and control. While the summits helped to move us forward on this path, they occasionally reminded us of how much further we need to go.

The planning committee made continuous improvements throughout the first round of summits and will continue to do so for the remaining states and territories. This report suggests several areas to consider going forward. While maintaining the primary voice of self-advocates, additional clarity and space for advisors seems to be needed. While a peer break-out session was provided for this group, information was not documented and it was somewhat unclear as to whether their perspectives should be included in the state team discussions or not.

Greater clarity on the definition of "self-advocacy organization" and questions concerning recommendations for national recommendations is needed. There was a lot of variety in what states identified as self-advocacy organizations. Some organizations listed were advocacy organizations, but clearly not led by self-advocates. There was also inconsistency in how states approached their recommendations for national actions and policies. More clarity and guidance to facilitators might contribute to development of more specific recommendations to strengthen the self-advocacy movement.

The summits helped provide details about the self-advocacy movement within states. The power points developed and presentations developed by states teams are an excellent start. However, this continues to be an area where we know very little. More detailed information is needed – particularly concerning funding, resources, and organizational structure. This information could provide a baseline state-of-the-states and a platform on which to evaluate progress to strengthen the movement.

In closing, it is import to remember that this report has attempted to highlight the experiences of the thirty state teams that participated in the first round of summits and outcomes. While it hopefully provides useful and thought-provoking information, much more will be learned as ADD moves forward with another round of regional summits involving voices from additional states and US territories.

“As I travel across the country I am amazed by how much local and state self-advocacy organizations have accomplished with little if any resources. Imagine just how much more we could get done if we had access to resources and opportunities to develop a stronger structure.”

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