



# ENVISIONING THE FUTURE: ALLIES IN SELF-ADVOCACY FINAL REPORT



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# ENVISIONING THE FUTURE: ALLIES IN SELF-ADVOCACY

## FINAL REPORT

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## I. INTRODUCTION

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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 indicated 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 the movement's initial formation. 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 with 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 individuals. 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, and some have taken more of a regional approach. Some approaches have promoted broad cross-disability organizing, while 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 is a need 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 Intellectual and Developmental Disabilities (AIDD) (for additional info please see Appendix A) 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 (including Councils on Developmental Disabilities [DD Councils], Protection and Advocacy [P&A] entities, and University Centers for Excellence in Developmental Disabilities [UCEDDs]), self-advocates, and allies, a series of regional summits were held across the country from the spring of 2011 through the spring of 2012 to promote collaboration, planning, and recommendations at the state and national levels.

“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.”



## 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, ASAN, National Association of State Directors of Developmental Disabilities Services (NASDDDS), and Human Services Research Institute (HSRI).

Two rounds of summits were held, and every state and US territory participated . In 2011, five regional summits were conducted with 30 states. In 2012, four additional regional summits were conducted with 26 states and U.S. territories.

First Round of Summits:

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

## Second Round of Summits:

- Baltimore, MD (March 19-20, 2012)
  - Connecticut, Delaware, District of Columbia, Maryland, New Hampshire, Puerto Rico, Virgin Islands, West Virginia
- Honolulu, HI (March 28-29, 2012)
  - American Samoa, Guam, Hawaii, Commonwealth of the Northern Mariana Islands
- Chicago, IL (April 19-20, 2012)
  - Illinois, Iowa, Kentucky, Louisiana, Nebraska, South Carolina, Texas
- Seattle, WA (May 10-11, 2012)
  - Alaska, Colorado, Idaho, Montana, North Dakota, Washington, Wyoming

Each state/territory developed a team of approximately 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:

- Self-advocacy leadership (adult + youth) (2-3 people)
- DD Council (1 person)
- P&A (1 person)
- UCEDD (1 person)
- DD State 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 28) 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 their state/territory. 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 in ensuring the greatest possible accessibility, including:

- 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

States were all at 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.

- 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 Providence and Seattle summits, graphic note taking was used and the visuals and pictures helped assist with understanding

Summit materials are available at <http://alliesinselfadvocacy.org>. The summits were held over two days. On the first day, state teams used the PowerPoints they prepared in advance to provide background about the movement in their state. Peer breakout sessions were held, providing 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 national recommendations for actions and policy recommendations. 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 Intellectual and Developmental Disabilities (AIDD) was prepared and additional time on the agenda was devoted to help individuals understand AIDD’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.
- Continuous improvements were made to provide accommodations and improve accessibility based on feedback from participants.

Changes were also made between the first and second round of summits. One key difference was that participants in the second round of summits were provided with a summary report of national recommendations from the first round of summits. Participants were able to review recommendations from the first round to build upon or make additional recommendations.

“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 THIS 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:

- Members of the research team attended the majority of regional self-advocacy summits 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, notes, and interviews with summit facilitators and planning committee members were used to summarize the findings.
- Following each summit, members of the research team met to discuss initial themes, which were then expanded and refined as subsequent summits took place.
- 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) The State of Self-advocacy in the States and Territories; 2) Plans to Strengthen Self-advocacy in the State and Territories; and 3) Recommendations for National Actions and Policy.

## II. FINDINGS

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### A. THE STATE OF SELF-ADVOCACY IN THE STATES AND TERRITORIES

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 slides and brief presentations. 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. Over one-third of states (20 states) reported that they received some level of funding through their state developmental disability services agency. Five states reported they received funds from the Administration on Intellectual and Developmental Disabilities through partnerships on other grants. Eight states indicated receiving funding and support from a Center for Independent Living. Eight states also indicated receiving funding and support from their state or local Arc chapters. As required in the DD Act, the majority of states indicated their Developmental Disabilities Council supported self-advocacy. UCEDDs and P&As provided support in various ways, including serving as a financial agent, and providing indirect financial support such as meeting space, office space and supplies, and travel support. Other sources of funding included donations, fundraising, and membership fees. Self-advocacy organizations also indicated getting in-kind support for grant writing, obtaining and maintaining nonprofit status, and advisement.

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, transitioning people from institutions to the community, and bullying. Transition after high school was also a major area of advocacy for most states. One state advocated on alternatives to guardianship, particularly for transition-age individuals. Self-advocates were involved in legislative advocacy in many states and participated in Advocacy Days at their Capitol as well as other meetings with legislators. Many states educated self-advocates through Partners in Policymaking <http://www.partnersinpolicymaking.com/>. Self-advocacy organizations in a number of states participated in voting initiatives. Many states also indicated having 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. One state has two paid youth leaders who organize monthly meetings. 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. One state created Self-Advocate Coordinator positions funded by the state DD agency to work with self-advocacy groups around the state and promote leadership development.

### ***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 number of states had laws passed related to People First Language and/or respectful language. 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. One state passed a law requiring disability history to be taught in schools. Another state created a speakers bureau for people with disabilities to present on disability awareness across the state. Some states were proud of materials they had developed to highlight their work and issues. Many states were using social media to reach out to and include more people around the state.

### ***d. Cross Disability Advocacy, Partnership and Allies***

Some states said that partnerships and collaboration with other organizations had worked well for their self-advocacy organizations. Types of partnerships included state agencies, businesses, and allies. Self-advocacy coalitions were also created through partnerships, which developed common goals and messages for advocacy and shared information and resources. One state created partnerships with organizations in the public and private sector that provide funding from multiple sources.

## **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. One state reported that funding sources often supported the old way of doing things and limited options for people with disabilities. Also, budget cuts in states compounded the challenge of finding funding for self-advocacy. 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. Another state

said their top challenge is finding “consistent well-trained staff who empower and don’t impede self-advocates.” Two states expressed a concern with the top-down approach to building self-advocacy in their state and the need to do more grassroots work to grow the movement. One state wanted people with disabilities who are paid as Directors to lead the self-advocacy organizations. For some of the territories, self-advocacy was a newer concept. For example, American Samoa does not have a self-advocacy organization though there is currently an organization for parents. They hope to establish one through their UCEDD. A challenge specific to territories was their feeling of isolation from the mainland and others.

***b. Community Services and Supports***

Many states indicated challenges related to lack of broader community services and supports. Over half of states (29 states) reported lack of transportation as a major challenge for people to get to meetings and gatherings. Territories especially had a challenge to connect across islands. Other challenges included lack of employment opportunities and dependence on sheltered workshops as well as lack of individualized housing options. Additional challenges expressed by states include long waiting lists for services as well as the need for money follows the person services where people can self-direct their own funds.

***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. One state expressed the need for intergenerational advocacy where people work together instead of being segmented by age. Expanding self-advocacy to rural areas, racial and ethnic minority communities, individuals with limited communication, and autism groups were a challenge for states. A number of states felt work needed to be done to enhance communication among self-advocacy organizations within the state to better coordinate efforts. Some states were not aware of or connected with all the different self-advocacy organizations in their states.

***d. Public Perceptions***

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. Many teams expressed the fact that self-advocates still face significant discrimination and feel they are not listened to.





## B. PLANS TO STRENGTHEN SELF-ADVOCACY IN THE STATES AND TERRITORIES

On the first day of the summits, state teams met to develop plans to strengthen and enhance the movement within their state. The number of goals developed by states and territories ranged from 1 to 5; the majority chose to focus on 2 or 3 goals. State teams outlined specific action steps including how the goal would be achieved, who would be responsible for each step and when each step would be completed. This information was compiled into 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 steam plan goals is contained in the appendix. While each state plan was unique to their own state or territory, 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, CT, IN, MI, MO, NV, and SD). Some states had existing curriculum in use within their state that they wished to expand, while others were interested in finding and adopting curricula. Some states focused on basic self-advocacy skills and choice-making, while 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 (CT, DC, MI, MO, and NV). This often included specific outreach to youth with disabilities.

#### c. Leadership Opportunities

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

### 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. Ohio and Utah mentioned providing information and technical assistance to local self-advocacy groups across the state.

**b. Statewide**

Many states developed goals to increase statewide capacity (AK, AS, DE, FL, GU, IA, CNMI, MT, NC, NH, NV, OK). There was a lot of diversity. Some states including Florida did not have statewide organizations, and they and many of the US territories included goals to develop self-advocacy organizations. Some states developed goals to organize statewide conferences or summits; Oklahoma included a goal to host a future national self-advocacy conference. Idaho included a goal to increase its advocacy and political presence at the state level. Several states expressed desires to do statewide assessments, surveys, and mappings of needs and resources. Alaska proposed exploring its current bylaws and possibly reorganizing its current structure. Maryland included an action to formally incorporate its statewide self-advocacy organizations as a non-profit 501(c)3.

**c. Funding**

Several states developed goals to secure funding and resources (AR, DC, LA, 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. The District of Columbia included an action to reach out to other states to explore how they have funded self-advocacy.

**3. CROSS DISABILITY COALITIONS, PARTNERSHIPS, AND ALLIES**

**a. Cross Disability Coalitions**

Many states developed goals that included broad cross-disability coalition building (AZ, CT, CO, FL, HI, MA, NC, OH, OR, OK, PA, SC, TN, TX, and VA). Some states were interested in creating formal cross-disability coalition organizations, and Virginia provided one 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 conduct outreach to individuals about self-advocacy (AK, AS, CA, DC, FL, GA, GU, LA, MA, MD, ME, MI, NC, NE, NJ, OK, SD, and UT). Some states planned to develop brochures, hold membership rallies, and do outreach through the radio, television, internet, and social and print media. Some specifically identified needs to reach out to ethnic minority and non-English speaking populations. Many of the states with outreach goals specifically included a focus on outreach to youth with disabilities. Strategies included establishing youth forums, presenting at schools and transition conferences, and working to get self-advocacy training and groups organized within schools. Some states also included goals to conduct outreach to racial and ethnic minority populations and other underrepresented groups.

### b. Communication

Many states also developed goals to improve communications within their self-advocacy organizations (AK, CA, CO, FL, GA, NC, NE, 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, Skype, 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, CT, FL, MA, ND, NV, OK, VI, VT, and WI). Some states identified focusing on schools and churches. Others focused on schools, service providers, and medical professionals. Several states included goals to train parents and families about self-advocacy, “letting go,” and “letting people lead their own lives.” Some states, including Oklahoma, developed legislative strategies to get rid of the “R” word and promote respectful language. The Virgin Islands included a goal to reduce the cultural stigma of disability in the territory through public service announcements and arts education.

### 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

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. The three most common areas were employment, transportation, and community living. States developed goals in the following areas:

- a. *Employment (AK, CT, ID, KS, ME, NJ, NV, and WY)*
- b. *Transportation (CT, ME, MS, ND, NJ, PR, RI and WV)*
- c. *Community Living (DE, GA, KY, NM, NY, and TX)*
- d. *Education and Transition (MO and NV)*
- e. *Housing (NJ)*
- f. *ADA Accessibility (CNMI)*

## 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 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 during the first round of summits (both categories were combined for the second round of summits). 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 Intellectual and Developmental Disabilities (AIDD) could consider undertaking to strengthen self-advocacy. Four major themes emerged:

#### a. *Support to Strengthen Self-Advocacy*

A major theme across recommendations for national actions was for AIDD 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 AIDD could consider piloting such centers as Projects of National Significance (PNS). If piloted as demonstrations, it was recommended that they be evaluated so that best practices and successes could be shared. 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 national center should similarly be led by self-advocates. AIDD could consider establishing such a center as a Project of National Significance. Suggestions of what a national center might do included:

- Assist with grant writing (or provide technical assistance on how to do it) and securing funding for self-advocacy.
- Support self-advocacy groups to develop by-laws and become incorporated as formal non-profit 501(c)3 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 technical assistance on getting rid of the “R-word” and promoting respectful language.
- Provide technical assistance on building partnerships with other organizations.
- Provide a central hub for self-advocacy groups to come together and share thoughts, ideas, and information.
- Develop a web-based blog or online community to promote communication and sharing of resources.
- Support a national newsletter by and for self-advocates.
- 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.
- Provide training on self-advocacy and leadership development.
- Provide technical assistance to the U.S. territories to assist with development of self-advocacy.

### **(3) *Provide Technical Assistance through DD Network Partners***

A third path suggested by state teams was for AIDD 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:

- Encourage DD network partners to devote part of their websites to self-advocacy.
- Require DD network to work together on a plan to strengthen self-advocacy.
- Include self-advocacy organizations in all DD network partners' national technical assistance conferences annually.
- Draw upon the expertise of UCEDDs 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 Self-Advocacy within the DD Network and at the Federal Level***

A second major theme was for AIDD 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 AIDD 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 AIDD, similar to some positions within state government agencies. A specific role for these coordinators might be to promote self-advocacy within AIDD, the DD Network, and in collaboration with other federal agencies and states.
- Support the hiring of self-advocates by the DD network partners.
- Continue to promote leadership opportunities for self-advocates, such as internship opportunities and inclusion on national boards and committees with necessary supports.
- Consider forming an AIDD self-advocate advisory board or task force to meet regularly and have input into AIDD'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.

***(2) Accessibility and Respectful Language***

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

- Improve the AIDD website to be more user-friendly and serve as a model for other agencies.

“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

- Ensure that all AIDD programs and materials support cultural and linguistic differences and multiple learning and communication styles.
- Work across agencies to improve accessibility and understandability of materials and resources. Work towards requiring universal design and accessibility in all government information.
- Work with other federal agencies to get rid of hurtful words such as the “R” word and “handicapped.”
- Hold a national conversation led by self-advocates about wording used to describe or refer to people with DD.

### ***(3) Raising Expectations***

Some state teams also suggested that AIDD 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.
- Promote participation of self-advocates on grant review panels.
- Promote transparency of DD network partners’ support of self-advocacy.
- Encourage the DD network to work together on plans to strengthen self-advocacy.
- Embed youth and underrepresented populations of self-advocates throughout all AIDD activities and initiatives, including racial/ethnic minorities, individuals with significant communication and behavioral challenges, low incidence disabilities, and LGBT populations.
- Set standards for AIDD grantees to ensure the inclusion of paid self-advocates in shaping policies that impact people with DD.
- Take on a government-wide advocacy and training role on the competencies of individuals with DD.

### ***c. Outreach and Public Education About Self-Advocacy***

A third major theme suggested by state teams was for AIDD 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.
- Outreach to the private sector to support funding for self-advocacy.
- Outreach to Governors to communicate the importance of increasing the number of self-advocates on advisory boards, councils, and commissions.
- Educate the public about the DD Act and how self-advocacy has improved the lives of individuals with disabilities. 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.
- Launch a national media campaign to improve public perceptions of disability and reduce stigma. Promote people with disabilities as people of value, that have competencies and are sexual beings. Promote possibilities for people with disabilities.
- 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 the disability rights movement.



#### **d. Collaboration with Federal Partners**

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

##### **(1) Department of Education**

- Introduce self-advocacy to youth at a young age and include it as a topic in transition planning.
- Work with school districts to allow self-advocates to go into schools to provide information, resources, and training. Training could include areas such as self-advocacy, being involved in IEPs and transition plans, and the prevention of bullying.
- Expand opportunities for postsecondary 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.
- Require self-advocacy training for teacher certification.
- Ensure that a proportion of Vocational Rehabilitation funding includes finding real jobs and other employment opportunities for people with intellectual and developmental disabilities.
- Promote collaboration between Centers for Independent Living and the Administration for Community Living on self-advocacy for individuals with intellectual and developmental disabilities.
- Work with NIDRR, other agencies, and UCEDDs to expand research on self-advocacy.

##### **(2) Centers for Medicare and Medicaid (CMS)**

- Provide guidance 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 the 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.
- Provide information to self-advocates about how the systems can work for individuals with disabilities.

##### **(4) Department of Labor**

- Promote best practices in employment of individuals with developmental disabilities.
- Work to eliminate subminimum wage policies.

##### **(5) Department of Transportation**

- Draw attention to the lack of transportation for self-advocates.
- Pull federal agencies together to talk about improving transportation for people with disabilities, especially in rural areas.

**(6) Department of Housing and Urban Development**

- Renovate unused housing and improve access to affordable and accessible housing.

**(7) Other relevant federal agencies**

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

**2. RECOMMENDATIONS FOR NATIONAL POLICY**

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

**a. Recommendations for the 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 a new Title to the DD Act, complementing the other three major components: DD Councils, UCEDDs, and P&As. One self-advocate provided a drawing (see right) 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.
- 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 collaboration of DD network partners on plans to strengthen self-advocacy at the state level. Put UCEDDs, P&As, and DD Councils on the same planning cycle to promote collaboration on network priorities and goals.
- Require collaboration of the DD network on a national plan to strengthen self-advocacy informed by self-advocates and state plans.
- Require youth with developmental disabilities on DD Councils. Encourage shadowing and mentoring for youth under 18.
- Add language to the DD Act on self-advocacy to promote inclusion of



people with the most significant disabilities and individuals from under-represented communities in self-advocacy.

- Explore the possibility of promoting self-advocacy through revising regulations for the DD Act.
- Improve the probability for U.S. territories to attain funding for Projects of National Significance by giving more weight (more points) to territories during the grant application process.

#### ***b. Recommendations for Other Federal Policy***

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

- Make Employment First a national policy and end subminimum wage policy.
- Get rid of the SSI federal benefits marriage penalty. Get rid of employment penalties, raise the SSI resource limits, and reduce the amount of time it takes to get through SSI.
- Provide SSI to Puerto Rico, Guam, the Virgin Islands, and American Samoa. Lift the cap and lower the match on Medicaid in the territories.
- 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).
- End the Medicaid institutional bias.

### **III. EVALUATION AND FEEDBACK**

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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:

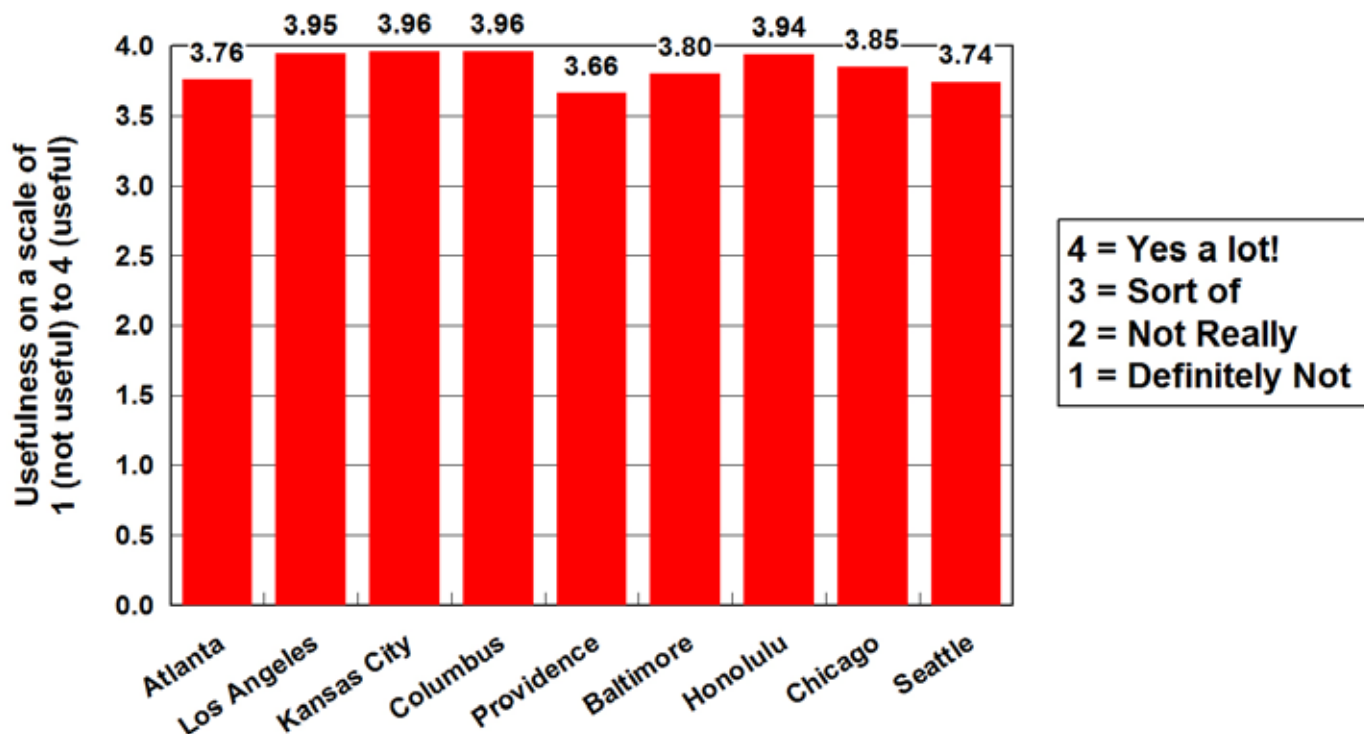
1. What did you learn?
2. After you leave, what will you do with what you learned?
3. What did you like the most?
4. What did you like the least?
5. How can we make the meeting better?

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?**

Many common themes emerged when participants were asked this question. 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.”

## Overall, was the meeting useful?



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 recognized 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 AIDD and the DD Act they obtained by attending the summits. They gained a better understanding of what AIDD is responsible for and gained a better sense of what AIDD 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. Many participants commented on the Commissioner of AIDD and her willingness to work with self-advocates. “AIDD 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.”



During the second round of summits, one new theme emerged. Participants noted that there were different understandings of what self-advocacy meant across the states and territories. “I learn[ed] that not every state has the same way of understanding self-advocacy.” “[I learned] how diverse the general understanding of self-advocacy among the states [was].” Some participants felt this was especially true for some of the territories, “I learned that some more isolated places may not have a good grasp on what self-advocacy is.”

Many participants were also surprised by the different service structure in the territories. Many commented that they were unaware that self-advocates in the territories (with the exception of the Northern Mariana Islands) did not receive SSI.

## **B. WHAT WILL YOU DO WITH WHAT YOU’VE LEARNED?**

Participants reported that with the information 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. During the Honolulu summit multiple participants went so far as saying they would return home and start a new self-advocacy group. One participant specified his/her advocacy group would be led by youth.
5. Share information from the summit with others, including self-advocates, DD Network Partners, and government officials.
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.”*

During the second round of summits, there was much more discussion about applying what was learned at the summits to self-advocates’ own lives. This personal self-advocacy includes getting jobs, helping friends get services, and speaking up more for themselves.

### **C. WHAT DID YOU LIKE THE MOST?**

Respondents indicated they liked the time spent with peers (including peer mentoring); meeting people in-person that they had previously only known online, the involvement of AIDD 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 liked] connecting with people of [state] I didn’t know and should have connected with a long time ago.”*

*“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 plans at the summit and felt rushed or forced by facilitators. More preparation or work as a state team prior to the summit might have been helpful. There was also confusion regarding the definition of self-advocacy. “[We] need a clearer definition or division between individual self-advocacy & self-advocacy organizations.” Other respondents specified their concern that parents were attending the summits as “self-advocates.” One respondent noted, “we don’t want our voice to be mixed with families because our opinion may be different from our family members.”

Additional comments also centered on a perceived 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. During the second round of summits, some participants felt there was a need for more cultural awareness

and “being mindful and educated about cultures/customs of islands/territories and integrating [this awareness] into sessions.”

Some felt the summit could benefit from expanded participation including more youth, parents/supporters/allies (though some clarified that parent-run groups should not be classified as “self-advocacy” groups), advocates outside the DD Network, state DD directors, and federal representatives beyond AIDD. 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, 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

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### A. OUTCOMES FROM THE SUMMITS

The nine regional summits, and the 56 states and territories that participated, produced a number of outcomes. First, the summits “injected new life into the movement.” 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.

Second, the summits produced recommendations for moving the movement forward at the national level. These included both short-term and long-term actions for AIDD to consider. While AIDD has limited resources and cannot pursue every recommendation, they highlight areas of importance and suggest possible directions. The summits also produced policy recommendations for strengthening the movement through reauthorization of the DD Act as well as broader policy recommendations in areas that impact the lives of self-advocates.

Finally, the summits provided a model for promoting collaborative leadership to strengthen self-advocacy. Self-advocates and professionals said they benefited from coming together and working as a team. However, particularly during the first round of summits, occasions arose where self-advocates felt their voice was not the primary voice. Advisors, allies, and other state team members at times dominated conversations. The planning committee made continuous improvements throughout the summits. Similarly, while accommodation issues did arise, the planning committee put in place a process of continual improvement to address diverse needs of individuals. The process, as well as materials from the summit, can provide a model for other conferences and summits, particularly on the accessibility needs of individuals 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.”*

### B. DIFFERENCES BETWEEN THE FIRST AND SECOND ROUNDS OF SUMMITS

Differences were seen between the states participating in the first round and second round of summits. Because it was uncertain whether funding would be available for every state and territory to participate, states selected for the first round of summits were seen to have more established self-advocacy movements. Therefore, more states in the second round were learning about self-advocacy and beginning to form movements. This was particularly true in the territories. They identified goals to strengthen their statewide infrastructure and form formal statewide organizations. The territories presented a number of unique challenges. For example, some territories share cultural differences in public perceptions and visibility of disability. They also receive considerably less funding for services and supports through such programs as Medicaid and Social Security and have less formal infrastructure. None of the territories currently have formal organizations that are members of SABE, ASAN, or NYLN. However, through the summits the territories generated a number of actions; in particular, many territories expressed

interest in working together with other territories and self-advocates in other states that have more established movements.

Other differences were seen between the two rounds of summits. More emphasis was placed on cross-disability collaboration and involvement of youth with disabilities in the second round. In general, members of the planning committee and facilitators

involved in both rounds of summits felt the second round went more smoothly. Facilitators got better at facilitating. States and territories in the second round of summits were provided with a summary of the national recommendations that came from the first round, allowing them to react to and build on the recommendations. Some states and territories added additional details to recommendations while other came up with new ideas. Many states and territories seemed to converge around recommendations to add a new self-advocacy Title to the DD Act and a resource center to serve as a central “hub” and provide technical assistance.

“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.”

## C. NEXT STEPS

The summits showed an unprecedented commitment by AIDD to strengthening the movement. The challenge going forward will be to keep the momentum going, particularly in difficult budget circumstances. Webinars and conference presentations are planned to share information from the summits and continue the conversation. An online community has also been created for summit participants from state and territory teams to promote sharing of information and assistance. The listserv is available at <http://alliesinselfadvocacy.org> and all are welcome to participate. The summits were made possible through the collective technical assistance efforts of AUCD, NDRN, and NACDD. In the near future, a similar model likely holds the most promising way to act upon recommendations for additional resources and technical assistance related to self-advocacy.

As AIDD continues to promote self-advocacy at the national level, real action and next steps will take place in the states and territories. In the words of Commissioner Lewis:

*“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 connections and fostered 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.”*

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“This was...

a Life Changing Event,

an Eye Opener,

Truly Inspiring,

Motivating,

and gives me more self-determination to make  
amazing changes in my state.”



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