



ENVISIONING THE FUTURE: ALLIES IN SELF-ADVOCACY REPORT



INSTITUTE ON DISABILITY
AND HUMAN DEVELOPMENT
UNIVERSITY OF ILLINOIS AT CHICAGO

Envisioning the Future: Allies in Self-Advocacy Report

September 2011

by

Joe Caldwell
Katie Keiling Arnold
Mary Kay Rizzolo

Institute on Disability and Human Development
The University of Illinois at Chicago



The contents of this report were funded under a grant from the Association of University Centers on Disabilities (AUCD) and do not necessarily represent the views of AUCD or their funding sources.

Contents

I. INTRODUCTION.....	1
A. Regional Self-Advocacy Summits.....	3
B. Preparation of Report.....	6
II. FINDINGS	7
A. State of the States in Self-Advocacy.....	7
1. Resources to Support Self-Advocacy.....	7
2. Major Activities and Accomplishments	8
3. Challenges	9
B. Plans to Strengthen Self-Advocacy in States.....	10
1. Training and Leadership Development	10
2. Infrastructure to Support Self-Advocacy.....	10
3. Cross Disability Coalitions, Partnerships, and Allies.....	11
4. Outreach and Communication	12
5. Public Education.....	12
6. Community Services and Supports.....	12
C. Recommendations for National Actions and Policy.....	13
1. Recommendations for National Actions.....	13
2. Recommendations for National Policy.....	17
III. EVALUATION AND FEEDBACK	19
A. What did you learn?.....	19
B. What will you do with what you've learned?.....	20
C. What did you like the most?	21
D. What did you like the least?.....	21
E. How can we make the meeting better?	21
IV. CONCLUSION	22
V. REFERENCES	25
VI. APPENDICES.....	256

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 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, 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:

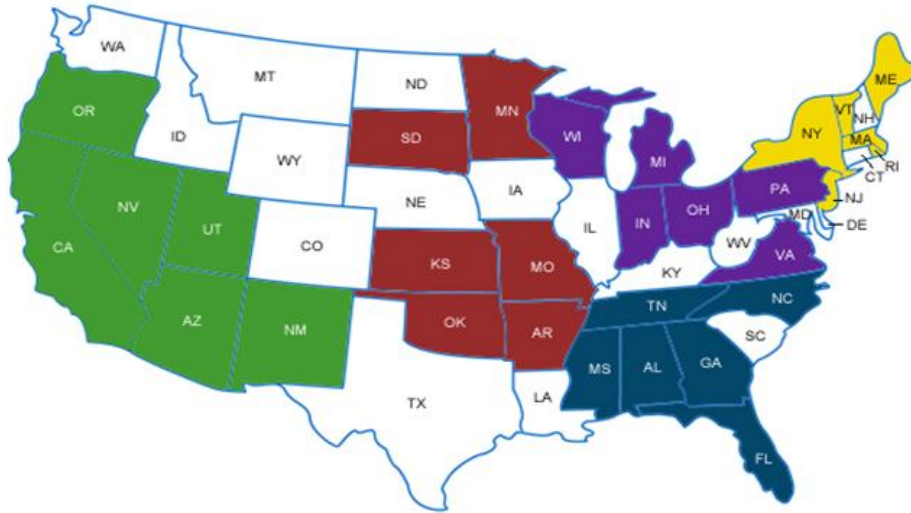
- 1) Assess what is currently happening in the states in self-advocacy – the support structures, activities, accomplishments and challenges;
- 2) Plan steps we can take to strengthen and enhance current efforts at the state level;
- 3) Develop recommendations for actions that we can take at the national 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 map on the next page.

“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.”



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

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.

B. Preparation of 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.

“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.”

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.

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.

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.

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.

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 steam 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 NY)

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

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.

(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.

"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

ADD's activities

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 (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.



- 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:

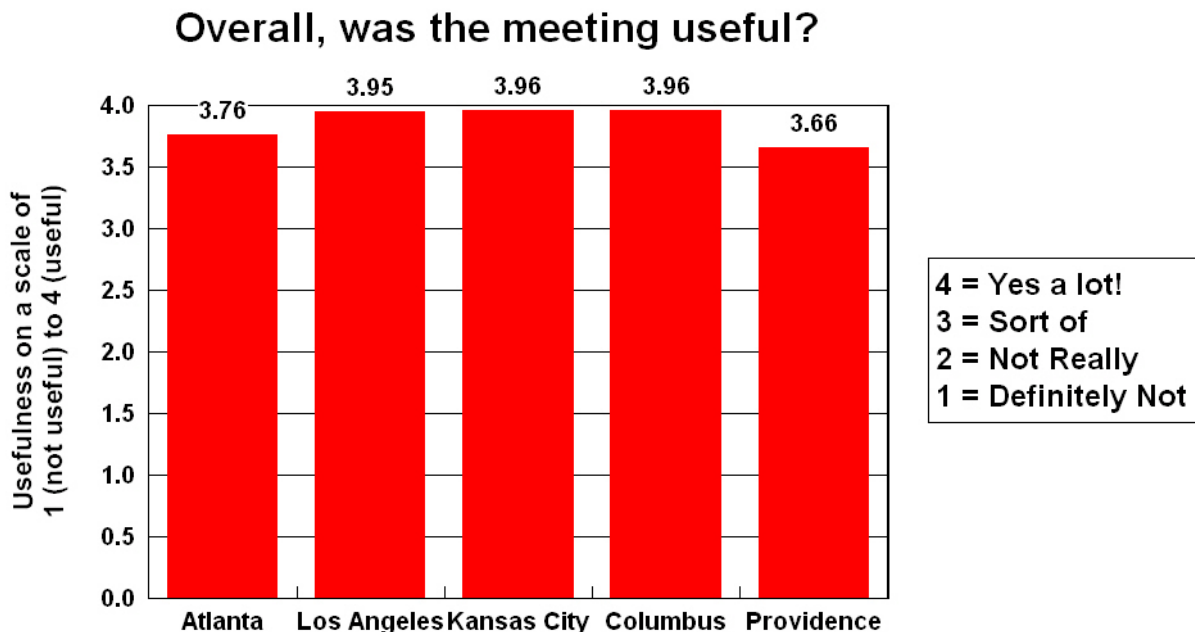
- Get rid of the SSI federal benefits marriage penalty. This was the most frequently made recommendation
- Get rid of employment penalties, raise the SSI resource limits, and reduce the amount of time to get through SSI.
- Support expanded and enhanced transition activities for youth with disabilities 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 manor

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.”

V. REFERENCES

- Buchanan, I. & Walmsley, J. (2006). Self-advocacy in historical perspective. *British Journal of Learning Disabilities*, 34, 133-138.
- Caldwell, J. (2010). Leadership development of individuals with developmental disabilities in the self-advocacy movement. *Journal of Intellectual Disability Research*, 54, 1004-1014.
- Caldwell, J. (2011). Disability identity development of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*.
- Dybwad, G. (1996). Setting the stage historically. In G. Dybwad and H. Bersani (Eds.), *New voices: Self-advocacy by people with disabilities* (pp. 1-17). Cambridge MA: Brookline Books, Inc.
- Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties*. Buckingham & Philadelphia: Open University Press.
- Hayden M., & Nelis, T. (2002). Self-Advocacy. In R.L. Schalock, P.C. Baker, * M.D. Croser (Eds.), *Embarking on a new century: Mental retardation at the end of the 20th Century* (pp. 221-233). Washington, CD: American Association on Mental retardation.
- People First of Washington (1984). *Speaking up and speaking out: A report on the international leadership conference*. Tacoma, Washington: People First of Washington and the University of Oregon.
- SABE (2010). Accomplishments of Self advocates Becoming Empowered. *Self Advocacy Nation, 20th Anniversary Issue*. Available at: <http://www.sabeusa.org/>

“The true definition of self-advocacy must include a more independent and more pure voice from self-advocates. Yes, from other partners but self-advocates must be the ones out front shaping their own voice and their own direction.”

Information About ADD

(Administration on Developmental Disabilities)

and the DD Network

(Developmental Disability Network)

What is the “DD Act”?

In 2000 the US government passed a law called The Developmental Disabilities Assistance and Bill of Rights Act of 2000. Most people call this law “The DD Act” for short. “Act” means law and “DD” stands for Developmental Disabilities.

What does The DD Act do?

The DD Act makes sure that people with developmental disabilities and their families are able to work together to come up with a plan for:

- community supports,
- person centered supports,
- and other supports that people with developmental disabilities may need.

The plan that is created must make sure that every person with a developmental disability:

- has self-determination,
- has independence,
- is included and valued as a member of the community.

**The Developmental Disabilities Assistance
and Bill of Rights Act of 2000 (The DD Act)**

Assures that individuals with DD
And their families

Participate in the design of
And have access to...
Needed community services
Individualized supports
Other assistance

Promotes
Self-determination,
Independence, Productivity,
Integration and Inclusion

In all facets of
Community life
Through culturally competent programs

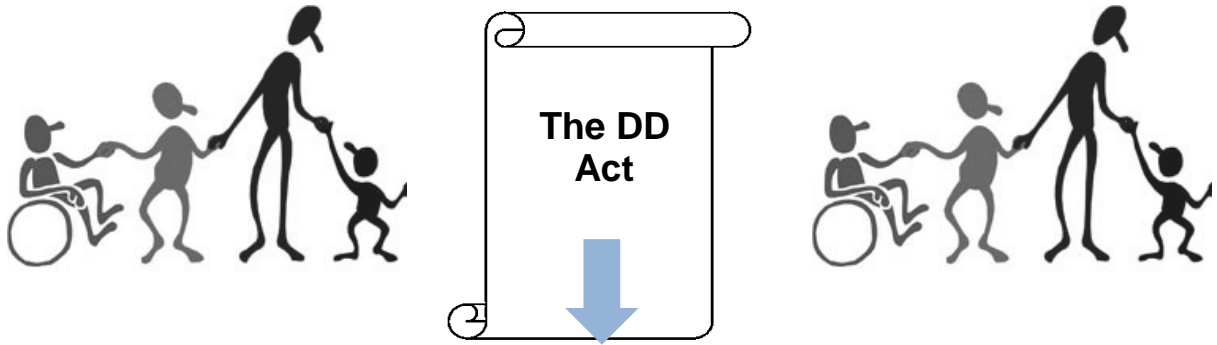
What is ADD?

The Administration on Developmental Disabilities (ADD) is a government agency that is in charge of making sure that The DD Act is followed. ADD also helps to create the plan which 4 different programs must follow. The programs that ADD oversees to help make sure that the plan is followed are:

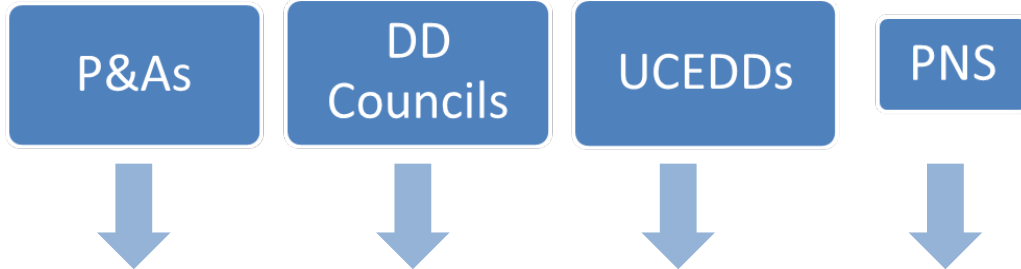
- **DD Councils** (State Councils on Developmental Disabilities are supported by NACDD)
- **P&As** (Protection and Advocacy systems are supported by NDRN)
- **UCEDDs** (University Centers for Excellence in Developmental Disabilities Education, Research and Service are supported by AUCD)
- **PNS** (Projects of National Significance)
 - PNS focus on a few of the most important issues affecting people with developmental disabilities and their families across the country. ADD awards grants and contracts to do these projects, however there is only a little amount of money that goes to PNS.

Many people call the DD Council, the P&A's, and the UCEDDs the "DD Network", because they are the programs that work together with ADD to follow all of the plans created from the DD Act.

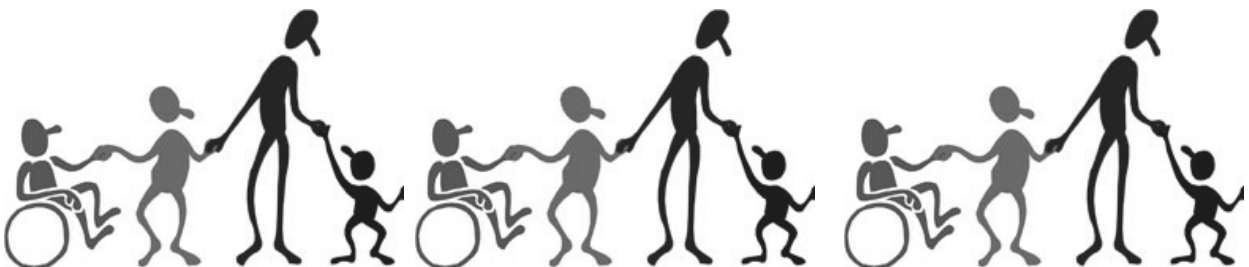
People with Disabilities and their Families



ADD



People with Disabilities and their Families



What does the “DD Network” do?







DD = Developmental Disabilities

- **DD Councils:** Councils carry out the DD Act and promote the interests and rights of people with developmental disabilities and their families by finding the most serious needs of people with developmental disabilities in their state or territory and participating in advocacy, changing the way things are done and supporting new projects and activities in order to help states meet those needs.
- **P&As:** Protection & Advocacy organizations work to protect the rights of people with disabilities and their families through legal support, advocacy, referral, and education.
- **UCEDDs:** University Centers for Excellence in Developmental Disabilities Education, Research and Service work with people with disabilities, members of their families, state and local government agencies, and community providers on projects that provide training, support, service, research, and information sharing, with a focus on strengthening communities and making sure everyone is involved.
- **State DD Agencies:** These state government agencies work to build person-centered systems of services and supports for people with developmental disabilities and their families. State DD Agencies are not funded by ADD.

VII. APPENDIX B
Envisioning the Future: Allies in Self-Advocacy
Summit Agenda – Day 1 (morning)

The purpose of the summits is four-fold:





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

	TIME	ACTIVITY
	7:30-8:30 am	Registration and Continental Breakfast with State Teams
	8:30-9:30 am	Welcome and Plenary Panel
	9:30-10:15 am	3 States Present their “State of the State” PowerPoints
	10:15-10:45 am	Break
	10:45-11:30 am	3 States Present their “State of the State” PowerPoints
	11:30 am- 12:00 pm	State Sharing Tables

**Envisioning the Future: Allies in Self-Advocacy
Summit Agenda – Day 1 (afternoon)**

	TIME	ACTIVITY
	12:00-1:00 pm	Lunch
	1:00-1:15 pm	Instructions for Organization/Peer Breakouts
	1:15-2:15 pm	Breakout Session: Organization/Peer
	2:15-2:45 pm	Break
	2:45-3:00 pm	Instructions for State Team Breakout: State Planning
	3:00-5:00 pm	State Team Breakout Session: State Planning
	5:00-5:30 pm	Open Mic: Feedback for Day 1
	5:30-7:00 pm	Reception

Envisioning the Future: Allies in Self-Advocacy Summit Agenda – Day 2

	TIME	ACTIVITY
	7:30-8:30 am	Continental Breakfast with State Teams
	8:30-8:45 am	Welcome
	8:45-9:30 am	State Teams Report Back to full group with State Plans
	9:30-9:45 am	Instructions for State Team Breakout Sessions: National Recommendations
	9:45-10:15 am	Break
	10:15-11:45 am	State Team Breakout Session: National Recommendations
	11:45 am- 12:15 pm	State Sharing Tables
	12:15-1:15 pm	Lunch
	1:15 -2:15 pm	State Teams Report Back to full group with National Recommendations
	2:15-2:45 pm	Open Mic: Feedback for Summit
	2:45-3:00 pm	Closing Comments
	3:00- 3:15 pm	Leave for home

**VIII. APPENDIX C
STATE TEAM PLANS**

ATLANTA SUMMIT		
Alabama		
Goal #1: People with disabilities are able to influence programs, policies and legislation at a state, local and national level.		
HOW?	WHO?	WHEN?
Have someone with a disability working everywhere that works with people with disabilities	AmeriCorps, Gov. Office on Disability (G.O.O.D.), DD Network (everyone on our team's organization), People First, legislative Offices	Start 3 months from today
EXPAND local and state advisory or leadership boards to have individuals with disabilities serving on team	Hospital, civic offices, everyone listed at G.O.O.D.	Now and on-going
Make sure supports are in place through: professional development and financial reallocation	Everyone previously mentioned	Start 3 months from today

Florida		
Goal #1: Create a state-wide DD self-advocacy network.		
HOW?	WHO?	WHEN?
Develop a strategy to develop a communication system to connect all the local self-advocacy organizations to each other.	The state team with Trish and Richard in the lead.	Bi-monthly calls to start within one month.
Goal #2: Increase participation of people with DD in the self-advocacy network.		
HOW?	WHO?	WHEN?
Create a strategy to increase participation through outreach.	This state team with Trish and Richard in the lead.	Bi-monthly calls to start within one month.

Goal #3: Create a cross disability self-advocacy network.		
HOW?	WHO?	WHEN?
Create a communication network such as list serves; a conference; other ideas to be generated by the state team.	The state team.	To follow several months after the first two goals are worked on.
Goal #4: Educate the Community about the importance of self-advocacy including providers, families, general community.		
HOW?	WHO?	WHEN?
Create training materials; build on what we have; reach the non-English speaking groups.	State teams and all disability organizations.	To be determined.
Georgia		
Goal #1: Find new ways to unite self-advocates across Georgia.		

HOW?	WHO?	WHE N?
Teleconferences, mailings, forums for self-advocates, and home visits	P&A--office space and phone, People First—funds, UCEDD—outreach help, email list, meeting space, DD Council—outreach	Take the first step by the end of July
Goal #2: Write a letter to the Governor and other elected officials about the continuation of the Olmstead Committee:		
HOW?	WHO?	WHE N?
People First and the P&A will collaborate to draft the letter and talk about specific people who have gotten out of institutions with the Long Road Home and ask legislators to keep the Committee going with self-advocates on the Committee; DD council will add it to their magazine; People First and UCEDD will distribute through email lists and post it on their website	Bernard of People First will draft the letter with Tracy and Jenny providing support	By the end of April
Goal #3: Create a Partners in Success chapter in southern Georgia.		
HOW?	WHO?	WHE N?
Josh a self advocate and Caitlin from the DD Council will have a planning call by the end of May with the	DD Council, UCEDD, and NYLN	By the end

person who coordinates the program; The UCEDD and NYLN will identify members in the southern area who can be a part of this chapter		of May
Goal #4: Create a forum around youth leadership.		
HOW?	WHO?	WHE N?
Key team members were identified to go back and talk with their organizations and make connections.	Key team members	Ongo ing
Goal #5: Have a follow up meeting on the plan created at the Summit.		
HOW?	WHO?	WHEN?
Cheri will email team about meeting.	Key team members	April 20th, 2011 11am- 2pm at People First meeting
Mississippi		
Goal #1: Create reliable and accessible transportation throughout the state.		
HOW?	WHO?	WHEN?

Look into working with MDOT transportation agency to begin an advocacy council on board.	Nickey & state team.	4/10/2011
Look into local transportation in the Gulf Coast area.	Cindy	4/10/2011
Look into local transportation in Central MS	Le'Ron	4/10/2011
Look into local transportation in Northern MS	Edie	4/10/2011
E-mail progress on research in above areas (e.g. who spoke to who about what) to Nickey	Nickey, Cindy, Le'Ron, & Edie	4/17/2011
Compile information about findings in report to share with group.	Nickey	4/24/2011
Goal #2: Explore the possibility of continuing this group after the summit.		
HOW?	WHO?	WHEN?
Share information about the Self Advocacy Summit with other stakeholders in MS	MS State Team	3/24/2011
Meet via phone call to start talking with one another about how to keep the group going.	Jerry, Nickey & Cindy	4/10/2011
North Carolina		
Goal #1: Inform, connect, and involve ALL self-advocates in taking a stand on important issues		
HOW?	WHO?	WHEN?
Increase people on mailing list to 10,000; use mailing list to share information about disability issues;	P&A to host mailing list, share information, help	Now and ongoing

help make connections and smaller interest groups.	make connections. All others on team to connect interested people to P&A.	
Work with HSRI on strategic planning for self-advocacy organization, pull in others in state.	ASARC, DD Council	Now and ongoing
Pull together ambassadors of different self-advocacy, disability, support, interest groups to identify issues and priorities in common, identify advocacy skills and develop curriculum.	T B D	TBD
Tennessee		
Goal #1: Develop self-advocacy resource center (SARC)		
HOW?	WHO?	WHEN?
Online database: Info for individuals, families, schools, employers; Tools self-advocates need to be effective	Today's team, The Arc & other disability-related organizations	12 months
Training, workshops – an actual learning center (i.e. offices regionally)	Today's team, The Arc & other disability-related organizations	12 months
Goal #2: Create network of self-advocates and organizations.		
HOW?	WHO?	WHEN?
More frequent communication and convening—possibly tie to the	State team and identify additional	3-6 months

mega-conference	partners	
Agency involvement	State team and identify additional partners	3-6 months
LOS ANGELES SUMMIT		
Arizona		
Goal #1: Recruit, connect, and empower self-advocacy groups in Arizona		
HOW?	WHO?	WHEN?
Invite all Arizona self-advocacy groups to connect online (yakkit?)	Arizona Team	Now
Teach people about technology and provide access	Arizona Team	Now
Develop register for funding to support goal	DDPS Self-Advocacy organizations	Now
DDPC state plan goal for self-advocacy	Team Arizona	Now
Identify non-traditional allies to support self-advocacy	Team Arizona	Now
Recruit members of disability community and build partnerships (schools, youth, hospitals, community)	Team Arizona	Now

Strengthen then the coalition of self-advocacy groups	Team Arizona	Now
Create a central place (physical) and virtual	Team Arizona	Now
Regular coalition meeting	Team Arizona	Now
Goal #2: Support self advocates to become a political voice.		
HOW?	WHO?	WHEN?
Encourage all groups to join AZDAC	Arizona Team	Now
Develop opportunities for self-advocates to get project vote training	Arizona Team	Now
Create support network within AZDAC so ALL can participate	Arizona Team	Now
Schedule first team teleconference to discuss next steps	Diane	By April 15th
California		
Goal #1: Create local summits of People First groups, self-advocacy groups, consumer advisory committees, federal partners, disability groups, minority groups, and other advocates to develop a strategy for each region.		
HOW?	WHO?	WHEN?
State DD Council has funding for self-advocacy. Our proposal is that much of that pot of money goes to 13 local area boards.	State team	To be determined

Some of that money could go to whatever priorities are decided at the local summit. Those could be things like: Leadership training Youth outreach Outreach to people of color	State team	To be determined
Some money would stay at the state level for things like: Bringing regions together in a coalition Statewide action alerts Developing outreach materials Creating a state self-advocacy resource library	State team	To be determined

Nevada

Goal #1: People First becomes self-sustaining forever.

HOW?	WHO?	WHEN?
Fundraising and grant writing	Community leaders Self-advocacy leaders	Launch: June 2011-2012
Forging better relationship with community leaders through outreach and education to other agencies	NCED, RAGE, Governor's Council PACE Events, Schools	

Paid, trained self-advocates leaders	People First	
Strategic plan for People First		June 2011
Goal #2: People with intellectual and developmental disabilities will have the expectation of and the ability to achieve meaningful, competitive career paths.		
HOW?	WHO?	WHEN?
Develop a model communicate real employment success stories by stories by self-advocates	DD Regional Centers *MIG, Youth Leadership Network	May 2011
Mentorship of self-advocates by self-advocates, peer mentoring.		
Educate the business community about the employability of people with disabilities.		
Develop a model communicate real employment success stories by stories by self-advocates	DD Regional Centers *MIG, Youth Leadership Network	May 2011
Goal #2: Before during and after high school youth will be provided with education, experience, and initiative, to be empowered leaders for their futures as well as mentors for others.		
HOW?	WHO?	WHEN?
Training self-advocates to go into schools	To be determined	To be determined

Foster better relationships with schools and school districts	Future Business Leaders of America	To be determined
New Mexico		
Goal #1: Statewide outreach and education on self-advocacy and disability issues, such as transportation, access and benefits		
HOW?	WHO?	WHEN?
Bring various groups across the state together to develop a common vision for self-advocacy in NM	Self-Advocates, State team, Cross disability organizations (Governor's commission on disability, Centers for Independent Living, Behavioral Health (NADR), DVR, NAACD (Native American Advisory Council on Disabilities))	At SW conference on Disability: Oct. 5 & 6, 2011
Collaborate with each other to develop common requests for resources and identify opportunities	(same as above) Also include other groups, e.g. housing authority, senior citizens, rehab programs	End of January 2012

Develop outreach strategies on why issues are important across the state and to diverse communities	Channel 27 & 26 State team and selected Committee members Community activists Other media outlets	Summer 2012
Goal #2: Improve and enhance New Mexico's benefit waivers to provide greater equity and increased self-direction and more streamlined administration.		
HOW?	WHO?	WHEN?
Gather information from pilot SIS (support intensity scale) in NM and other states who have used SIS	Joan Curtiss Tony Chavez Marilyn Martinez	August 2011
Share information to state stakeholders and gather feedback	State team and stakeholders	At South West Disability Conference
Come to consensus on what proposed amendments or modifications are needed and what they are	State team	January 2012
Oregon		
Goal #1: Hold an Oregon State Self-Advocacy Summit to identify areas to work on as a state.		

HOW?	WHO?	WHEN?
Develop and send a letter (from the state planning team) to each of the self-advocacy groups around the state inviting them to participate in a video conference to discuss interest in a Self-Advocacy Summit.	SAAL will draft initially (Eddie, Kristi, Hannah, Judi) and State Team will finalize	3 weeks
Make phone calls to self-advocacy groups around the state as a follow up to the letter.	Eddie & Hannah	2 weeks after letters go out
Hold a video conference (using video conference sites around the state) and get buy in from self-advocacy groups.	Cynthia will schedule/set up. Chuck will facilitate the video conference.	By the end of May
Summit planning group schedules regular planning meetings.	Judi, Eddie, Kristi, Jim, Josiah, Hannah, Robert, Teresa	At cocktail hour.
Goal #2: Create an Oregon State Coalition of Self-Advocacy Groups and Allies.		
HOW?	WHO?	WHEN?
Kick off the idea for the Coalition at the Self-Advocacy Summit. Present a powerpoint with background information on this Summit, explain coalitions, and share idea for the Coalition. (Facilitated by Laurie Powers)	Jim, Judi, Eddie, Josiah, Chuck, Teresa	By the Summit (date TBD)

Those interested in creating the Coalition, figure out the structure, develop a vision and purpose, and possibly a website and communication tools for the group.	SAAL Board help coordinate meeting for group to work toward this.	TBD
SAAL work to get non-profit status to possibly be umbrella group for Coalition	SALL Board	Hopefully by the end of the year
Identify resources to create and develop the Coalition.	Coalition Members	TBD

Utah

Goal #1: Increase information sharing about self-advocacy throughout Utah in the regions outside of the big cities (re-building local groups)

HOW?	WHO?	WHEN?
Contact other state organizations from this summits to see what they are doing	Alan & Andrew	April 15
Talk to other state teams at summit	Everyone	Now

Have paid bloggers to write for each established People First chapter	Mandy	July
Increase awareness through Media When People First meetings are Who People First is Publicize People First website Educate about what self-advocacy is	Brooke and Kelly talking to radio and giving story Brooke and Team summit picture and story about summit	For May April 8th
Have agency partners listing People First's website on their websites	Alan(State DD Agency) Andrew (P&A) Claire (DD Council) Tom (UCEDD) Andrew (Access Utah) Claire (CILs)	March 30
Get stories from all different regions to put on People First website to spread local awareness and news	Claire will ask for feedback from DD Council members at their monthly meetings and put it as an agenda item Self-Advocates from this summit will help find people to give stories or share their stories	On April's agenda On-going
Give the People First handout to families who are new to using state services Give the People First handout to other people with disabilities who may not be using state services	Eric (The Parent Center and the Autism Council Utah) James (National Ability Center) Mandy will give Alan People First brochures to distribute throughout the entire	Tonight Before May April 30

	state to every disability service coordinator	
Grassroots Advocacy Partnership Regional organizers participating in local People First chapters communicating disability issues/ legislation	Regional Organizers	End of April

KANSAS CITY SUMMIT

Arkansas

Goal #1: Determine and secure local resources to support local self-advocacy chapters that already exist.

HOW?	WHO?	WHEN?
Requests for donations	Businesses, organizations, legislators (Will Contact) AR State Team(Responsible)	3-6 months
Create corporate/philanthropic roundtable	AR State Team	9 months
Conduct awareness events and fundraisers	AR State Team	1 year
Goal #2: Promote positive attitudes and perceptions of Arkansans with DD.		
HOW?	WHO?	WHEN?
Use the “Believe Achieve” campaign already in place	CAN-Do Inc. (Coalition of DD partners)	June 30, 2011
Partner with Jr/Sr High Schools to promote positive attitudes and perceptions	AR People First members/Other individuals with disabilities	December 31, 2011

Increase awareness in local churches of needs and abilities of people with disabilities	Local churches with experience working/ministering to people with disabilities and invite other churches to participate	April 2012
Goal #3: Maintain this team to serve as a statewide alliance to further the efforts of self-advocacy in Arkansas.		
HOW?	WHO?	WHEN?
Alliance would meet every other month to plan forums, develop questionnaires, and establish a name.	Kansas City State Team Members	Every other month beginning in June
Conduct Public Forums in: Central Arkansas, Northwest Arkansas, Northeast Arkansas, Southwest Arkansas, Southeast Arkansas	DD Network Partners	Within the next 12 months
Send out a report from what happened in Kansas City	Send to DD, Interested Parties	Letter composed and posted, land mailed or emailed after each meeting
Develop website to be linked to : DD Network Partners ADD website	DD Network Partners ADD website	Within 12 months

Kansas

Goal #1: Provide training and technical assistance on community based employment (called Employment First in Kansas) for self-advocates

HOW?	WHO?	WHEN?
Have a monthly conference call with everyone on the Kansas summit team	SACK will schedule it	Within the month
Develop the training and then put it as part of the person centered planning training. SACK will pull together information from other organizations to develop a curriculum	SACK employees with... DD Partners Families Together Working Together	Bring up at the next Employment First meeting. Develop training by Sept. 2011
Do the training and apply for funding from the DD Council	SACK employees	On going
Teach Train the Trainer the Employment First trainings	SACK employees with... the 25 groups that currently exist Youth Empowerment Academy	On going
Follow-up with the self-advocates after the training to hold everyone accountable Provide technical assistance Track/Record data	SACK employees will provide technical assistance. UCEDD (Denise, Matt, and Sean)	On going

Minnesota

Goal #1: Develop Think Tank to work on sustainable long term funding

HOW?	WHO?	WHEN?
<p>Form a workgroup of stakeholders connected to the various funding issues. Could reconvene the advisory group, add members as necessary, and form a Funding Think Tank.</p> <p>SAM leadership circle, Community organizers, ICI, DHS, Council, Dept Ed, DEED, Disability Law Center, CILS, Providers association, ARC, DSPAM</p>	<p>SAM leadership circle will consider idea and convene group if approved</p>	<p>June 2011</p> <p>First Action Plan by October 1</p>
<p>Think Tank evaluates current ideas and develops more. Explore how the member organizations can best leverage their strengths and work together. Explore funding available for concrete items on the survey list of dreams.</p>	<p>Think Tank</p>	<p>Summer 2011</p>
<p>Detailed plan of first few action steps.</p> <p>Planning process will build relationships among members.</p>	<p>Think Tank</p>	<p>By September 2011</p>
<p>Missouri</p>		
<p>Goal #1: People with disabilities in larger numbers as participating/contributing citizens – including leadership training</p>		
HOW?	WHO?	WHEN?

<p>Identify examples of people with disabilities in leadership now as contributing citizens. Need clear demonstrations of people in leadership – profiles, examples, success stories.</p>	<p>DD Network (PF, UCEDD, P&A, DD Council, Division) agreed to flush out the questions in how – what</p>	<p>Establish the time and set a conference call and decide within the next 30 days.</p>
<p>Training and support for people with disabilities in order to get to greater leadership positions. Identify existing resources, etc.</p>	<p>specifically we need to make goals happen, resources, overcome barriers.</p>	<p>Perhaps: PF meets on May 21. Go to this meeting. P&A agreed to pay for call. Team members agreed to come on call.</p>
<p>Identify mentors – people with disabilities, without disabilities, parents, etc.</p>	<p>UCEDD: Laura SA (other than PF): Tiffany PF: Jason P&A: Shawn</p>	
<p>Identify and add partners to all efforts.</p>	<p>DD: Kyla & Vicky DD Council: Susan</p>	
<p>Goal #2: Stop the School to Prison Pipeline and Bullying in Schools, Make IEPs Work Better</p>		
<p>HOW?</p>	<p>WHO?</p>	<p>WHEN?</p>

To be developed by working group	DD Network (PF, UCEDD, P&A, DD Council, Division) agreed to flush out the questions in how – what specifically we need to make goals happen, resources, overcome barriers. UCEDD: Laura SA (other than PF): Tiffany PF: Jason P&A: Shawn DD: Kyla & Vicky DD Council: Susan	Establish the time and set a conference call and decide within the next 30 days. Perhaps: PF meets on May 21. Go to this meeting. P&A agreed to pay for call. Team members agreed to come on call.
----------------------------------	---	--

Oklahoma

Goal #1: Get rid of R-word in Oklahoma

HOW?	WHO?	WHEN?
Meet with legislators who will be key to introduction and passage of the bill.	Rose Ann & Nancy	June 2011
Get majority party Representative and Senator to write the bill.	Rose Ann & Nancy	November 2011

Get legislator (s) from House and Senate in both parties (Republican and Democrat) to support bill.	Rose Ann & Nancy	November 2011
Introduce the bill	House and Senate	January 2012
Advocate daily for passage/ inform other stakeholders and get them to advocate for passage of the bill.	State Teams	February 2012 until it gets passed.
Once the bill has passed the House and the Senate, educate Governor.	Team	As soon as bill is passed.
Celebrate passage and send thank you cards to Legislators	Team	May 2012
Goal #2: Host future SABE Conference		
HOW?	WHO?	WHEN?
Gather information from SABE conference and assess what additional information is needed.	Sent to Lance Nancy, Dee, Linda, Lance, Team	May 28, 2011
Meet as a state team to discuss information gathered and answer remaining questions about hosting the conference.	Nancy, Dee, Linda, Lance, Team	June 10, 2011

Determine what resources we need to pull together to write a strong proposal.	Partners , Team	August 1, 2011
Write a proposal to SABE and send to SABE board.	OK People First (with support as requested).	2011 SABE Fall/Winter Board Meeting
Get support from other self advocacy chapters in other states.	OK People First	Early 2012
Goal #3: Strengthen Oklahoma Self-Advocacy organizations/groups. "TEACH US TO DO IT OURSELVES"		
HOW?	WHO?	WHEN?
Identify what groups/organizations are working on disability issues in OK and who they represent (e.g. NAMI, autism group, TBI, youth groups, etc).	Nancy & Brian with Team	July 31, 2011
Do a needs assessment with each group/organization to determine needs for future growth.	Ann & Rose Ann	Dec 31, 2011
Plan and hold membership rallies across OK that include all self advocacy groups.	People First & NYLN	May 2012
Host a cross disability state wide training on voting.	Nancy & OK Disability Law Center	TBA

Develop a plan to deliver training on topics identified in needs assessments.	OK People First and the DD Council	April 2012
Media blitz (facebook, newsletters, etc.).	Brian	Fall 2012

South Dakota		
Goal #1: Train Self-Advocates to effectively advocate for what is important to them. Teach the skills that can be applied widely.		
HOW?	WHO?	WHEN?
Gather Curriculum options	Arlene and Kati Seymour.	July 6, 2011
Choose top options of curriculum(s) to meet South Dakota's needs. This may include customization process.	SDAC Leadership Team will identify the top two or three options.	September 30, 2011
Take these to core stakeholders team to give input about which curriculum to use.	SDAC State Coordinator, Chuck Henry.	January 2012
Make the final decision on which curriculum(s) to use.	SDAC Leadership Team	February 2012
Customize the Curriculum to meet the needs of SD self advocates	UCEDD and SDAC Leadership Team	to be determined

Provide training to implement the training. Provide consultant fees and stipends for the SA trainers and participants	UCEDD and the SDAC leadership team	to be determined
---	------------------------------------	------------------

Goal #2: Outreach to grow South Dakota Advocates for Change.

HOW?	WHO?	WHEN?
Create a fact sheet that describes People First Chapters and how it fits with SDAC and the Coalition as well as YLF. Include exciting "who's" and "what's"!	Arlene	Draft by May 31, 2011 for team review.
Identify groups to reach out to where we can find younger self advocates.	Team and DD Network.	May 31, 2011
Take to trainings, presentations, and conference booths.	SDAC	Always
Send out on email listservs, include in newsletters, facebook, and websites.	DD Network partners, SDAC	Get out by June 2011
Make a video for YouTube, CD/DVD. Put on Derek's website where people can comment on it as soon as they see it.	Derek, Brad, Kyle, K.D., and Mike	By Dare to Dream Conference in June, 2012

COLUMBUS SUMMIT

Indiana

Goal #1: Employment and self-advocacy: Self-advocacy organizations let businesses know that people with disabilities CAN and WANT TO work.

HOW?	WHO?	WHEN?
<p>Have a summit for businesses to come and learn about hiring people with disabilities</p>	<p>Step 1: go to SAI board and tell them how important it is to talk to businesses about employment Step 2: determine where to meet (DD agencies), contact partners to determine who to invite, ie chambers of commerce Step 3: Identify businesses to invite to meet with SAI</p>	
<p>Go to businesses to educate them; telling personal experience stories Get in touch with the businesses, flyers, advertisements</p>	<p>Step 4: Have a meeting. Tell reasons why employing people with disabilities is a good idea. Have self-advocates tell stories about what works.</p>	

	Tracy: Will look at contract opportunities David: Will help with training *Keep PoVA and council in the loop	
Goal #2: Self-Advocacy organizations teach people with disabilities that they have choices in employment and how to advocate for their choices (Goal #2 is going to be developed more back home in Indiana)		
Michigan		
Goal #1: Increase the ability of individuals to advocate for themselves.		
HOW?	WHO?	WHEN?
1) Leadership skills training and support so that individuals can advocate for themselves. Assertiveness training Skill development	1) MI Partners for Freedom, under DDC funding (limited), including UCEDD; however this prevents it from being state-wide. Will DDC direct funding toward this effort?	1) By June of 2011 at Local Leader's Summit - indefinite
2) Provide leadership opportunities for people to use skills	2) Community Mental Health Agencies (CMHs)	2) Now
3) Strategize how to sustain training over time	3) DDC; the network	3) Now
4) Expand peer mentoring program, paid and unpaid, statewide.	4) Council and Dept of Community	4) Now

5) Include self-advocacy program in secondary school curriculum: target individuals with complex needs	5) the Network; the lead would be from Michigan Dept of Education	5) October 2011
Goal #2: Increase systems self-advocacy for public policy		
HOW?	WHO?	WHEN?
1) Continue funding and training of Regional Interagency Consumer Committees (RICCs): training on how to have your voice heard in public policy	1) DD Council (funding for RICCs and training); UCEDD; DD Agency; ARC MI; P&A	1) Now (officially October 2011) until indefinitely
2) Create clear expectations of those trained that RICCs continue at the county level and become independent of the DDC	2) Self-advocate speaker to explain what SA means when you're independent from the council; how to have your voice heard in public policy	2) Now
3) Increase voting registration and political participation	3) P&A	
4) Maintain the MI Partners for Freedom: self-advocates should partner with this organization	4) Dept of community health	
5) Connect state leadership group to NYLN		
Ohio		

Goal #1: To generate a powerful civil rights movement across the state of Ohio		
HOW?	WHO?	WHEN?
<p>Create a broader coalition of SA orgs in Ohio</p> <p>Go back to our respective organizations and discuss participation in the coalition</p> <p>Seems that we want to identify and survey the various SA orgs in the state</p> <p>We must define what is a SA org – see notes above</p> <p>We must determine SA org commonalities and differences in what they do</p> <p>Increasing the number of self-advocates in the state</p>	<p>Outreach</p> <p>Caroline and Diana will follow-up with people to see where we are with the organizational commitment</p> <p>Connect with OSDA</p> <p>Everyone represented at table today would be part of coalition, at least to initiate the discussion</p> <p>People First</p>	2 months
Provide TA and support to SA orgs around the state that need it		For next 6 months
Pennsylvania		
Goal #1: Develop more communication, collaboration, and cooperation between all self-advocacy groups – by developing a long term (2 year+) plan for self-advocacy in PA.		
HOW?	WHO?	WHEN?
Get technology (and other supports) resources together so that people can start collaborating on the plan (Skype, FaceBook, mailing lists,	Scott and Chris. With support and resources from DRN (teleconference,	Can start on this now

teleconference, IM, etc)	website, other tools...etc)	
Use next 6 months to begin to work on the plan: share resources, gather information share information start talking		For next 6 months
Create and plan opportunities for self advocate groups to come together (not just summits)		In October
Goal #2: Create new and enhance current opportunities for self advocates to contribute. (Question we're answering: From what tables are self-advocates missing?)		
HOW?	WHO?	WHEN?
Explore boards and communities related to disability issues that do not have disability representation.		
Explore non DD specific disability boards and communities that do not have DD representation.		
Other Goal: Major discussion: Do we advocate to get the supports (for daily living as well as BIG events) we need? Or do we need the supports to advocate?		
Other Goal: In Pennsylvania, we are in a state of emergency. There is a lot going on – budgets, changes in the government... what are we going to do about it? How can we create unification to be sure everyone in the state is touched – we need to “pool” (collect) our resources.		
Virginia		

Goal #1: Develop communication among various self-advocacy (SA) groups/organizations		
HOW?	WHO?	WHEN?
Identify different SA groups and what they do	UCEDD already has a map on its website, but Jack needs updates (VirginiaSelfAdvocacy.org*)	May 15: Jack will send map to attendees.
	Ann to send info on other/more radical SA groups (Icarus, Mind Free), which have chapters in VA	June 6: Ann to send info
	Autism groups: ASA (Autism Society of America) can contribute information on their state chapter	July: Shawn to send info
	Aisha: send NYLN info and help open lines of communication between state and national	August (tentative): Aisha - NYLN info
Gather info to identify if CSB and providers support SA group (data collection can occur via a simple survey)	UCEDD with help of Office of Developmental Disabilities (ODD)	May 15: Survey is already developed; waiting to implement
Goal #2: Determine means of communicating among self-advocacy organizations		

Goal #3: Build a coalition (Lee to help name this coalition, if invited by self-advocates; perhaps use VAULT structure)

Goal #4: Identify topics of interest for policy impact by coalition

Wisconsin

Goal #1: Create more public awareness and respect of differences

HOW?	WHO?	WHEN?
Media campaign, including poster	Josh Disability Organizations Local Media Legislators Hope's Sister (teaches marketing)	August 1st committee meeting
Speaker's bureau	People first of WI Lawyers from P&A Facebook Waisman Center ARC Milwaukee	May
Celebrate diversity week	Fox Cities Autism Society Disability Mentoring Day organizers	2012
Involvement in civic life	Find a community that cares Find qualified people People in inclusive recreation Kiwanis	In process, immediately

PROVIDENCE SUMMIT

Maine

Goal #1: Develop an employment advocacy plan.

HOW?	WHO?	WHEN?
Educate employers, job coaches, vocational rehabilitation professionals on skills that people with disabilities have, as well as policies and employment practice related to PWD.	Team	Ongoing
Employment meeting with Chamber conference	Team	September 2011
Review employment policies; strengthen anti-retaliation efforts	Chris Powers and Disability Rights Center	November 2012

Goal #2: Strengthen the self-advocacy movement/network in Maine

HOW?	WHO?	WHEN?
Assess effective means of communication	Sandra Home	January 2012
Broaden representation in SA groups (include representation from different age groups and	Team	January 2012

disabilities)		
Strengthen SUFU membership	Team	May 2012
Goal #3: Develop for accessible transportation plan for advocates to attend local and statewide meetings and serve on councils, boards and committees		
HOW?	WHO?	WHEN?
Develop a proposal to do a transportation study	Team	June 2011
Assess transportation spending (by region)	Team	January 2012
Train local transportation authority on disability issues/concerns.	Team	May 2012
Goal #4: Engage policymakers and community organizations at the local level as active participants in efforts to achieve equal opportunities for self-determination and community inclusion.		
HOW?	WHO?	WHEN?
Develop a strategic plan	DD Council & Team	January 2012
Massachusetts		
Goal #1: Establish and expand collaboration among disability advocacy groups across disabilities to address common issues such as: employment, housing, transportation, transition and closing institutions.		
HOW?	WHO?	WHEN?

Form a coalition of cross disability organizations ensuring outreach and collaboration with current self advocacy groups in the state	Disability Law Center in collaboration with the DD council & DD network	On or before September 1st 2011
Identify common issues to address	Cross disability coalition	On or before January 1st 2012
Develop a workplan with expected outcomes, timetable and key activities	Staff of coalition	On or before June 1st 2012
Goal #2: Promote youth development by working to include self-advocacy and self determination training to adolescents and young adults with disabilities as preparation for the transition to adulthood (Draft Goal).		
Goal #3: Increase ability of health and service providers to listen to and feel comfortable with responding to the self-advocate needs, interests and wants (Draft Goal).		
Goal #4: Expand regional self advocate coordinators throughout the state to build and sustain self advocacy in MA. They would serve as point person for collaboration among self advocates and allies (Draft Goal).		
New Jersey		
Goal #1: People with disabilities in NJ will have affordable and accessible transportation to meet individual needs, (i.e. accessible taxis, buses, trains and Access link)		
HOW?	WHO?	WHEN?
Talk to the taxi /		

limousine commission (TLC). Find out why taxis are so expensive. Could there be a flat rate?		
Talk to the Dept. of Transportation		
Get more self-advocates on ADA Task Force – of NJ Transit – and involved in the meetings to speak to these issues		
Organize Self-advocacy groups at schools		
Goal #2: Get more youth involved in NJ Self-advocacy movement		
HOW?	WHO?	WHEN?
Go to elementary, middle & high schools (start early).	NJ State Team	
Present at Special education advisory councils	NJ State Team	
Use social media (Facebook, twitter, and the like)	NJ State Team	
Present at transition workshops and conferences, yearly coalition for inclusion conference	NJ State Team	
Goal #3: “Real jobs for real dough!” - Support people to get jobs they want to be more independent.		

HOW?	WHO?	WHEN?
Get self-advocates information about self-employment, job opportunities, supported employment services	NJ State Team	
Educate business community	NJ State Team	
Get support from Chambers of commerce, Business Leadership Networks, Better Business Bureaus	NJ State Team	
Meet with Alice Honeycut, Director Division of vocational rehabilitation (repair mis-information provided by DVR counselors)	NJ State Team	
Educate self-advocates how income affects benefits – learn about ways to protect benefits, benefits counselors, etc.	NJ State Team	
Find out information about the Equal Opportunities Commission	NJ State Team	
Invite more self-advocates to Alliance for Full Participation –	NJ State Team	

October employment conference		
Goal #4: More community options on affordable, accessible, individualized housing for people with disabilities in NJ. Options that allow freedom of choice.		
HOW?	WHO?	WHEN?
Look at natural resources (like shared living)	NJ State Team	
Close all institutions	NJ State Team	
Talk and write to legislators – Action alerts	NJ State Team	
Educate self-advocates to stand up for their rights – where to go when you are having a problem	NJ State Team	
Educate self-advocates and community about options	NJ State Team	
Promote “institutions are not a home” campaign	NJ State Team	
Workshops at annual conference	NJ State Team	
New York		

Goal #1: Increase individual and organizational supports.

HOW?	WHO?	WHEN?
Form a coalition of advocacy organizations	Network partners SANYS Others (Bill & David coordinates)	October 1, 2011 Quarterly thereafter
NY team provides technical support to the coalition of self advocates to strengthen and enhance individual supports.	<p>DDPC – follows state plan objective – 1500 people. (5 yrs)</p> <p>Finger Lakes Task Force – working on Person-Centered Planning (PCP).</p> <p>WIHD (2011 renewal)-This objective is at the core of its adult and transitional services</p> <p>Kennedy Ctr UCEDD committed to enhancing & expanding efforts (and will do so in regards to objective 1)</p> <p>P&A - Continue to pursue eligibility cases for individualized services</p>	Collaborative effort of all entities – done at quarterly call

Utilize outreach and education to accomplish objectives	All members of team	Quarterly call of coalition
Rhode Island		
Goal #1: Flexible transportation.		
HOW?	WHO?	WHEN?
Get stakeholders in the same room		Beginning of September
Get creative – use new resources in the community (not just through agency, friends, community organizations).	Emily & Committee	
Get movers and shakers (agencies/providers) and see what they'll give up (control in transportation) stakeholders in the room.		
Time bank hours to give/hours needed ("Bartering system").	Kevin & Deanne	
Compile a transportation menu of people and options (get stakeholders in the same room)		

Vermont

Goal #1: Educate the general public about self-advocacy.

HOW?	WHO?	WHEN?
<p>Go into High Schools and educate people about self-advocacy, using the transition tool kit. Also, have self-advocates go into the high schools and present to the entire school what self-advocacy is (create future allies).</p>	<p>DD Council has funding available for self-advocates to do the tool kit. Possibly not use toolkit – add to toolkit</p> <p>Secondary transition hire self-advocates to educate agencies through dept. of education, state director of Special Ed. Have Abby go with Susan.</p> <p>Discuss this at the next GMSA statewide monthly meeting.</p> <p>Deborah propose to state CIL to do training.</p> <p>Find out who has relationships with schools to help build relationship for advocacy.</p>	<p>By the end of the Summer.</p>

	UCEDD have university help find out which schools to work with. Collaborate with GMSA	
Educate parents about self-advocacy (this can be partially accomplished by speaking at the high schools due to people's dual roles, such as a teacher and a parent)	To be determined.	
Educate agency staff through workshops and presentations.	To be determined.	
Hold trainings about self-advocacy which anyone may attend.	To be determined.	

IX. APPENDIX D

NATIONAL RECOMMENDATIONS

ATLANTA SUMMIT
Alabama
National Action #1: Setting up a center for support information training center with self advocates running it. These will include: <ul style="list-style-type: none">a. professional developmentb. educator trainingc. less fragments including funding
National Action #2: National boards have a person with disabilities on it.
National Action #3: The Focus to be on the personalized employment meeting the needs of the individual; focus on the talent; not stuffing envelopes when you can work at NASA.
Policy Recommendation #1: Incentive to employ people with disabilities.
Policy Recommendation #2: Mandates the national DD network to have a joint plan/goal for self-advocacy for each year. This needs to be a recommendation from ADD: a priority with self-advocates in the conversation each year. States would let the national level know the plan and the federal plan will be informed by these state plans.
Policy Recommendation #3: Fund self advocacy directly in DD Act (4 th leg).

Florida

National Action #1: Support the creation of a national self advocacy organization or network by working closely with state level organizations. Help them connect with each other and the states will build it. ADD should support:

- Summits
- National conference
- National conference calls and webinars
- Training for self-advocacy with self-advocates in the lead
 - Training on how to run national and state self-advocacy organizations
 - Train self-advocates to be their own advisors
 - Training for self-advocates on how to write grants
- Training for advisors on their roles

National Action #2: Maintain mandate on DD Councils to support self-advocacy.

- Support a state self-advocacy organization
- Self advocates training other self advocates in leadership

National Action #3: (Modify third clause in DD Act): Self advocates having meaningful participation in coalitions, in the design of support and services, and full inclusion in community.

Policy Recommendation #1: Add a responsibility to DD network partners to reach out to people with developmental disabilities, including the unserved, underserved, inappropriately served and culturally and linguistically diverse populations to inform them of opportunities in self advocacy.

- Working with families, service organizations, etc. to reach them.

Policy Recommendation #2: Educate families about supporting self advocacy across the lifespan.

Policy Recommendation #3: Collaborate with Department of Education to require self advocacy as part of transition planning from the beginning and throughout the school years.

- Self-advocates should take the lead in providing training to younger self-advocates.

Policy Recommendation #4: Collaborate with Administration on Aging to require self advocacy training as part of planning.

- Self-advocates should take the lead in providing training to younger self-advocates.

Policy Recommendation #5: Through Administration for Children and Families (ACF), Department of Education and other appropriate agencies, promote self-advocacy with young children to show that "it can be done"...self-advocates as role models/mentors to young children.

- Self-advocates should take the lead in providing training to younger self-advocates.

Policy Recommendation #6: Report back to self-advocates after the summit series concludes, including proposed next steps.

Georgia

National Action #1: Fund Self Advocates directly to provide training & mentorship to other Self Advocates

National Action #2: Fund Self Advocates directly

National Action #3: Fund Self Advocates to do voter outreach to other people with disabilities

National Action #4: Fund Self Advocates to learn how to do legislative advocacy to close sheltered workshops

Policy Recommendation #1: Create a national training to build leadership positions of people with disabilities in the DD networks

Policy Recommendation #2: Create a mandate that 50% of DD network employees are people with disabilities

Policy Recommendation #3: ADD should work with the department of Labor to end segregated employment & sub minimum wage for people with disabilities

Mississippi

National Action and Policy Recommendation #1: Include more stories in reports instead of just numbers (more qualitative data).

National Action and Policy Recommendation #2: Include more youth on DD Councils (under 28).

National Action and Policy Recommendation #3: Define guidance and technical assistance to DD Network partners on promoting SA.

National Action and Policy Recommendation #4: Provide technical assistance to ensure projects are self advocacy driven.

National Action and Policy Recommendation #5: Prioritize Self-Advocacy within DD Network.

National Action and Policy Recommendation #6: Encourage more collaboration among disability groups.

North Carolina

National Action #1: Collaborate with Department of Education on funding scholarships for self-advocates to continue education beyond high school; provide technical assistance for common expectations for including self-advocacy skills in high school and post-secondary education curriculums.

National Action #2: Ensure states have road map for self-advocates to address issues to correct state agencies, follow up on federal level to collaborate with appropriate federal agencies to impact implementation.

National Action #3: Demonstrate commitment from ADD by employing self-advocate who has a specific charge to address self-advocacy topics within ADD, the DD Network, and in collaboration with other federal agencies.

Policy Recommendation #1: Fund national technical assistance entity to support development of infrastructure required to develop independent self-advocacy organizations including training for advisors and support staff, grant writing, etc.

Policy Recommendation #2: In any model chosen for TA or any other policy implemented, maintain non-interference and independence.

Policy Recommendation #3: Any funding for self-advocacy organizations must include allowing federal dollars to be used to educate policy-makers on issues impacting them.

Tennessee

National Action #1: Develop National Self-Advocate Resource Center.

National Action #2: Continue regional Self-Advocacy Summit meetings.
National Action #3: Emphasizing the importance of the self-advocacy voice to the DD networks.
Policy Recommendation #1: Don't let the DD Act get watered down.
Policy Recommendation #2: Mandate the UCEDDs and PNA to support self-advocacy movement.
Policy Recommendation #3: ADD to implement and model best practices with regard to supporting self advocates and self advocacy activities.
LOS ANGELES SUMMIT
Arizona
National Action #1: Provide TA to develop relationships (nontraditional) /partnerships to sustain movement.
National Action #2: Help states (us) spread word that people are not bound by state's narrow definition of DD.
National Action #3: Make the PAVA dollars more flexible in support of self-advocacy (P&As will help).
Policy Recommendation #1: Divert ADD funds to directly fund self-advocacy as fourth prong of DD network.
Policy Recommendation #2: Tie federal transportation dollars to expand state definitions of DD to reflect federation definition.
Policy Recommendation #3: Fund federal self-advocate coordinator(s) to work with state self-advocate coordinator(s) (<u>permanently</u> employed by DDCs) to establish how self-advocacy will be established.
California
National Action #1: ADD can develop a task force for self-advocates to guide its work; including but not limited to, keeping the momentum of self-advocates of progress after the summits to address the needs of under-represented groups.

National Action #2: Throughout all ADD’s activities, initiatives, etc, ADD’s leadership will promote & embed youth, rural/urban, people of color, LGBT.
National Action #3: ADD be more active in Public Awareness campaigns “use of multiple media (e.g. Facebook, Twitter, You-Tube) to address the discrimination and stigma by people with developmental disabilities especially when hot topics are in the news.
Policy Recommendation #1: Add “Dignity and Respect” to DD Act which will then require ADD to recommend implementation of Olmstead decision work with DOJ to close institutions, CMS to increase funds for community services and add self-advocacy as a waiver service, SSA to repeal the marriage penalty etc.
Policy Recommendation #2: Set standards for ADD grantees to ensure the inclusion of paid self-advocates in shaping policies which impact people with DD for example sustainable employment, post-secondary education, de-institutionalization, addressing disparities in accessing services for people with DD from underrepresented groups.
Policy Recommendation #3: ADD will charge the state DD network to provide technical assistance and core funding to support development of state coalitions; sustain self-advocacy groups, leadership training youth development towards the sustainability of infrastructure in states for self-advocacy.
Nevada
National Action #1: Conduct more webinars for the states on self-advocacy; what’s going on in Washington and the other states (e.g., SELN).
National Action #2: Develop strategies for state-to-state technical assistance.
National Action #3: Monthly video message from the Commissioner on ADD website to self-advocates, including updates.
National Action #4: Supporting people in their own life choices.
Policy Recommendation #1: Expand the role of network partners in supporting statewide self-advocacy.
Policy Recommendation #2: Work with the US Department of Education to make it easier to introduce self-advocacy to youth.
Policy Recommendation #3: Educate federal policymakers by conducting more presentations about policies related to disabilities.
New Mexico

National Action #1: Provide ways for state advocacy groups to learn what other states are doing by developing an internet portal.
National Action #2: Provide webinars or video conference on self advocacy with Q&A and state sharing.
National Action #3: More information and public education and marketing of the DD Act of 2000 and its provisions including stories on how self advocacy has improved lives of people with disabilities.
National Action #4: Develop a data collection system, that could be used by self advocacy organizations and provide technical assistance and training on outcome measures and data collection.
National Action #5: Have ADD strongly encourage P+A's, Councils and UCEDDs to devote part of their websites to self-advocacy efforts.
National Action #6: Use social media (ie: facebook, myspace, twitter, radio, youtube ect.) and PSA's to promote self-advocacy.
National Action #7: Develop a national e-magazine or e-newsletter on self advocacy with state stories and input.
Policy Recommendation #1: Eliminate the SSI federal benefits marriage penalty.
Policy Recommendation #2: Eliminate employment penalties and raise the SSI resource limits so that people with disabilities could work and maintain their benefits.
Policy Recommendation #3: Support expanded and enhanced transition activities for youth with disabilities to include self-advocacy. (TEAM Act)
Policy Recommendation #4: Promote Disability History and Rights inclusion in public school curriculum.
Policy Recommendation #5: Require additional training on the needs of students with visible and invisible disabilities for general educators, including benefits of universal designs.
Oregon
National Action #1: Support youth to learn about self-advocacy at a younger age (start in 4 th grade) and their families and peers.

National Action #2: Develop a library of resources online for self-advocacy such as a Clearinghouse.

National Action #3: A group of self-advocates from across the county meet regularly with commissioner to share ideas.

Policy Recommendation #1: Federal change in Social Security Regulations to allow working self-advocates to have retirement accounts and that the other benefits of self-advocates are not cut (such as food stamps, housing, etc.).

Policy Recommendation #2: Have specific training about how to be a self-advocate as part of IEP/ transition plan.

Policy Recommendation #3: Get rid of the marriage penalty.

Utah

National Action #1: Training of new self advocates.

National Action #2: Training of advisors.

National Action #3: Teaching parents and siblings when to let go and about self-advocacy.

Policy Recommendation #1: All DD service agencies must have self advocates advisory board.

Policy Recommendation #2: End institutional bias=Require waiver to go into nursing home. (Money follows the person).

Policy Recommendation #3: Educating congress about people with disabilities.

KANSAS CITY SUMMIT

Arkansas

National Action #1: Support a mock congressional legislative session to provide training about how to influence state policy.

National Action #2: Sponsor one activity per year to bring together state stakeholder teams with double attendance and double the number of states.
National Action #3: Develop a universal measurement tool to assess how states are doing in the area of self-advocacy.
National Action #4: Language in the DD Act: specifically the 3 sister agencies will give funding to further the efforts of self-advocacy in their states.
Policy Recommendation #1: ADD will set the expectation within federal agencies to omit negative terminology (ex: no longer using the "R" word, "handicapped" as in "handicapped parking").
Kansas
National Action #1: DD network partners be brought together for technical assistance and conversations around self-advocacy (not all separate efforts). Focused effort from P&As to provide TA around targeted SA issues.
National Action #2: UCEDDS help with expertise of determining measureable outcomes. This is essential for funding purposes. Also, assist states with being more data-driven (collecting information throughout the year).
National Action #3: Defining and setting national standards for outcomes advisors, quality supports DD organizations around SA – what are the outcomes of SA?
Policy Recommendation #1: Work with other non-DD specific federal organizations to create policy & practice around transition from school. Also emphasize post-secondary opportunities as a funding priority.
Policy Recommendation #2: Make employment first a national policy.
Policy Recommendation #3: Reduce the amount of time to get through SSI
Minnesota
National Action #1: Regional Self-Advocacy Meetings.
National Action #2: Self-Advocacy as” Funded 4th Leg of Stool”.
National Action #3: Help Self-Advocacy Movement Get Money from Council, UCEDD, and P & A.

Policy Recommendation #1: Self-Advocacy funding to be written into Medicaid Initiatives and Health Care Legislation.

Policy Recommendation #2: Involve Self-Advocates in policy maker education in DC (especially when the bill involves people with disabilities).

Policy Recommendation #3: Re-brand Self-Advocacy nationally.

Missouri

National Action #1: ADD could work with other federal agencies and general public to listen to individuals with developmental disabilities and address public perceptions.

- ADD can change perceptions by their own hiring practices and put individuals with developmental disabilities in leadership positions.
- Volunteer work – options to workshops are volunteerism because they put you in the community. Allow you to be a valuable member of the community.
- Get individuals with developmental disabilities involved in issues that affect everyone, not just individuals with developmental disabilities. Get our voices heard on larger issues – women’s rights, civil rights, employment, etc.

National Action #2: Support Advisor training. ADD can support advisor training through technical assistance, host statewide training.

National Action #3: Create dialogue with business community about how to increase employment/choice for individuals with developmental disabilities.

- Hold national conference/initiative or set up task force to address funding issues.
- Businesses have a social responsibility.
- ADD facilitates the inclusion of different funding sources (Federal and State) - Vocational Rehab, Senate Bill 40s, Governor’s Association, DOE, SAMSA, etc. ADD takes the responsibility of facilitating this initiative.
- Tie into AFP.
- Bring it to the President and ask him to weigh-in
- Promoting choice!
- Help people reach their dreams.
- Sub-minimum wage (214C of the Rehab Act)

National Action #4: ADD identify and share curriculum on self-advocacy and training across states.

- Connect to National Self-Determination resources.
- Connect to SABE resource collection.
- Connect to TA Centers that already exist.

National Action #5: National funding matrix associated with how S-A organizations are being funded. See nationally how much money we are talking about. Nationally and state – see all the pieces w/ all the funding.

- P: Provide for some flexibility in funding – percentage of funds that we can earmark for S-A. Right now there has to be a project, and then the project is funded. ADD establish that with this percentage of funds there is an unconditional piece. Management of dollars.

National Action #6: Measure outcomes and impact of self-advocacy.

Policy Recommendation #1: ADD change grant requirements

“We have a goal that the next Reauthorization of the DD Act will include a dedicated stream of funding for self advocacy. A goal that this Act will provide not only funding but also the recognition and acceptance that will enable self advocates to be equal and respected partners in shaping the decisions and events that will be our future.”

Oklahoma

National Action #1: Work across agencies. Work with other federal agencies to address barriers to community living ((Transportation/Department of Transportation (DOT), Benefits & Employment/SSA, R-word & language/Centers for Medicare & Medicaid Services (CMS) & 14C (Department of Labor (DOL)).

National Action #2: Include self-advocacy as leg in reauthorization of DD Act, until reauthorization include in a more meaningful way – Projects of National Significance (PNS).

National Action #3: Work across agencies to improve language accessibility (including cognitive accessibility) of policies & resources and in a location/organized where they can be easily retrieved. Assure that policy recommendations are implemented.

Policy Recommendation #1: Ensure that the R-word is out across systems – keep us informed of implementation of Rosa’s Law.

Policy Recommendation #2: All policies should be cognitively accessible and easy to find/organized.

Policy Recommendation #3: Develop a policy that includes self-advocacy (organization) across all DD Network partners’ national (TA) conferences annually.

South Dakota

National Action #1: Use TA providers (AUCD, NDRN, NACDD) to develop a resource bank of ideas for collaboration between state DD network and DD state agency to make sure the SA's voice is being reflected in the funding/budgeting decisions for DD services.

National Action #2: See the Dept. of Ed. be pushed a little to support earlier involvement of SA in schools, before the end of post-secondary transition. This includes inviting other entities into the school to be involved in transition planning and education, resources, etc.. Train SAs at a younger age about disabilities and possibilities.

National Action #3: Create a "project search" type program/model for people with DD who have completed post-secondary education / training and have trouble finding jobs.

Policy Recommendation #1: In the next reauthorization of the DD act require that self-advocates review and provide input on waiver for services. Work on this with CMS since they control the money. Get the SA voice even before this, include SA in development of state waivers. "A first thought, not an afterthought".

Policy Recommendation #2: To have an employment first policy in the next reauthorization of the DD Act. In next authorization, have the DD Act require all of DD network to support SA, not just DD councils.

Policy Recommendation #3: Work toward requiring universal design and accessibility in all government information, so self advocates can understand.

COLUMBUS SUMMIT

Indiana

National Action #1: Transportation- best practices, ADD draw attention to lack of transportation, build partnership with Dept of Transportation.

National Action #2: Educate doctors- have self advocates educate doctors.

National Action #3: ADD speaking about programs that are available- facebook, newsletters, phone calls.

Policy Recommendation #1: DD Act having a 4th leg.
Policy Recommendation #2: Require doctors to have more training.
Policy Recommendation #3: ABLE bill.
Michigan
National Action #1: Identify the common themes and gaps across the Summit events and follow-up
National Action #2: Convene national conferences so self-advocates can learn from each other
National Action #3: Bring mature and young self-advocates to discuss issues and ideas about what does and does not work to avoid backtracking/prior mistakes
National Action #4: Teach the history of the self advocacy movement. Build pride in what has been achieved. Know our heroes.
National Action #5: Establish (in collaboration with self-advocacy leaders) expectations for self advocacy. Define self advocacy; create standards; good/best practices; outcome measures.
National Action #6: Articulate some shared responsibility to support self advocacy across the ADD network.
Policy Recommendation #1: Promote self-determination...citizenship, employment, participation in community, community membership
Policy Recommendation #2: ADD needs to be part of the national discussion and communicate with federal agencies on issues such as health care, employment, graduation rates, social security specifically marriage, obesity, transportation, housing

Policy Recommendation #3: The paper on community living is a good model for partnership on a national issue

Ohio

National Action #1: Plain language that supports DD partner collaboration to address a specific issue brought to them by self advocates that could include 1) DD partners create a toolkit for self-advocates to be part of individual plans and 2) Create e-database for self-advocates for legal and other DD resources and national self-advocacy organizations—house toolkits to be a “one stop shop”.

National Action #2: Self-advocates should be at all tables. ADD should financially provide support for transportation assistance, technology, and e-meetings so everyone who wants to participate can and that self-advocates should be paid a fair wage and not expected to volunteer.

National Action #3: Create an advisory committee of self-advocates to advise UCEDDs on their research.

Policy Recommendation #1: Require that ADD advocates w/ CMS to have self advocates at the table when changes to healthcare coverage are being made.

Policy Recommendation #2: ADD should sponsor self-advocacy conferences where federal policy makers come to explain the laws that they are in charge of and listen to self-advocates share their stories and concerns about how cuts and changes affect their lives.

Policy Recommendation #3: ADD would advocate with Congress that self-advocates would become the 4th prong or the 4th branch of the DD network.

Pennsylvania

National Action #1: Fund self advocacy to collaborate/coordinate/communicate between all self advocacy groups.

National Action #2: Fund report on transition (similar to Keeping the Promise).

National Action #3: Continue to support and strengthen SA orgs that already exist.

National Action #4: Develop a formalized way in which to share all the info that comes out of state offices.
Policy Recommendation #1: Require UCEDDS and P&As to include a SA component.
Policy Recommendation #2: Emphasize SA in the DD Act so that it doesn't get lost or forgotten (assure that people with most sig disabilities are included in all SA activities).
Policy Recommendation #3: Amend the DD Act to emphasize the primary role of PWDs in directing their own lives and being empowered.
Virginia
National Action #1: Work with CMS to support increased person-centered practices, community support, and individualized budgeting.
National Action #2: Work with SAMHSA, RSA, Dept. of Labor/ODEP, etc. to identify what each [of these organizations] are doing to promote best practices for PWD (Persons With Disability).
National Action #3: Develop promotional/public relations statement that supports involvement in self-advocacy across different groups.
National Action #4: Fund study on how funds attached to SSI (Supplemental Security Income)/SSDI (Social Security Disability Insurance) impact people with disabilities.
National Action #5: Annual proclamation of Disability Awareness Month, to include history of disability movement.
National Action #6: PNS (Projects of National Significance) funds to establish "Beyond Tokenism" project nationally (for example, as has been done in Pennsylvania).
National Action #7: Target (more) funding toward communities of color, in poverty, in rural areas, that are culturally/linguistically marginalized (e.g., immigrants whose first language is not English).
Policy Recommendation #1: Work with CMS to infuse/combine ADD policies into CMS policies and guidance.
Policy Recommendation #2: Prior to reauthorization of DD Act: Explore definition of Disability (vs. DD/Developmental Disability) to determine whether focus should be on DD or D

<p>Re-evaluate functional limitations and age of onset criteria for eligibility, to promote inclusion of all individuals with disabilities, through formal discussions and public input from self-advocacy groups Overall: What benefits people with DD, benefits all.</p>
<p>Policy Recommendation #3: Work with SSA (Social Security Administration) and other departments of government (e.g., DOE/Department of Education) to allow people with disabilities to save money/funds but still maintain benefits that they receive.</p>
<p>Policy Recommendation #4: Work with DOE (Department of Education) to infuse ADD policies for educational guidance, with the goal of starting self-advocacy activities in early elementary school/at a younger age.</p>
<p>Policy Recommendation #5: Reauthorization of DD Act to include self-advocacy title (arm/branch).</p>
<p>Policy Recommendation #6: OVERALL THEME FROM VIRGINIA: AWARENESS!</p>
<p>Wisconsin</p>
<p>National Action #1: Encourage state government to involve SAs in public policy making.</p>
<p>National Action #2: Help connect SA individuals and organizations using technology (Facebook, etc), including making ADD website more user friendly.</p>
<p>National Action #3: Increase awareness of ADD (state/fed levels) as an influential agency.</p>
<p>Policy Recommendation #1: Give SA a 'line' in DD Act at same level as other Network Partners.</p>
<p>Policy Recommendation #2: Require DD Act Partners to work on joint SA goal(s) and commit to goals through their planning processes/reports (and include extension universities).</p>
<p>Policy Recommendation #3: UCEDDs, P&As, DDCs requirement to have staff dedicated to SA.</p>

PROVIDENCE SUMMIT

Maine

National Action #1: Work with other federal agencies on accessibility/accommodation to include all types of needs at all levels of the administration during policy discussions (explore all options) eg. Cognitively accessible, online).

National Action #2: TA support SA efforts at the state level (e.g. to follow up to this summit).

National Action #3: Model inclusion of all disability groups.

Policy Recommendation #1: Department of Education should be responsible for special ed advocacy related to IDEA (ADD is currently funding).

Policy Recommendation #2: Promote full inclusion in legislation.

Policy Recommendation #3: Require transition planning to include Human Services, correction, labor etc.

Massachusetts

National Action #1: ADD to work with federal agencies (Medicaid, Social Security Administration, etc.) and state network DD Partners to make available information on Medicaid, Social Security, Healthcare, Human Rights, and Civil Rights in an accessible and understandable format for self-advocates and support personnel.

National Action #2: Have ADD work with other federal agencies on transition issues (example, Department of Education, Post-Secondary Education Commission).

National Action #3: Have ADD collect from Self Advocates of different ages information on their perspectives on transition and make this disseminate it nationally.

National Action #4: Communicate problems & difficulties that self-advocates are having with Medicaid, Social Security and housing to federal agencies.
National Action #5: Develop an interactive online resource for best practices related to self advocacy.
Policy Recommendation #1: Have ADD work with other federal agencies to remove the Social Security marriage penalty for people with disabilities.
Policy Recommendation #2: Have ADD work to promote flexibility in waiver development at State and National levels.
Policy Recommendation #3: Have ADD work with other federal agencies to remove disincentives to independence and productivity for self-advocates such as income restrictions in housing, healthcare, and employment.
New Jersey
National Action and Policy Recommendation #1: Create a Centralized State/Nationalized Group to make sure voices are heard. A hub for all of the self-advocacy groups to come together and share thoughts, ideas, and information. Have a centralized website on federal policies.
National Action and Policy Recommendation #2: Use PNS funds to support a national public awareness campaign (similar to Autism Speaks). It could be called "People First"-We are people, not our labels, we want universal design, supports so that we can live independently. Discussing who we are, what we want ("I am, I can").
National Action and Policy Recommendation #3: A National TV show/campaign to make public services announcements or commercials to raise awareness for self-advocates, talk about issues.
National Action and Policy Recommendation #4: Support state self-advocacy groups to become non-profit organizations.
National Action and Policy Recommendation #5: Use Projects of National Significance (PNS) funds to support "An Institution is Not A Home" campaign.
National Action and Policy Recommendation #6: Hold ongoing summits on self-advocacy to hear voices, share ideas, and promote collaboration within states and with other states.
New York

National Action #1: Network with other federal partner agencies and highlight importance of self advocacy in every aspect of life for people with disabilities.
National Action #2: Communicate clear and consistent expectations in relation to self advocacy for the DD network partners.
National Action #3: Engage stakeholders on how to sustain the current service systems including other ways on how money should be spent differently – self advocate driven.
National Action #4: Focus on transition from school to adulthood. Ask national organizations to support local initiatives such as Project Search and include self advocates in that discussion.
Policy Recommendation #1: Advocate for an appeals process to the Medicaid caps to ensure services and supports in inclusive settings and that advocacy efforts are lead by self advocates.
Policy Recommendation #2: Include self advocacy as part of all DD network partners' work.
Policy Recommendation #3: ADD FIND a funding stream for self advocacy (not necessarily government).
Rhode Island
National Action #1: Self-advocacy needs to grow – influence the resources that grow the self-advocacy movement.
National Action #2: Support and require that everything is easy, accessible, and understandable for everyone.
National Action #3: ADD get our recommendations to Secretary Sebelius, the President, the White House, Disability Office, DD Network, Congress, Department of Education, Centers for Medicare and Medicaid Services (CMS), Social Security, private national associations.
Policy Recommendation #1: ADD should look at regulations and revise them to fit self-advocacy in. ADD can interpret the DD Act and clarify and update to promote the self-advocacy movement.
Vermont

National Action #1: Provide funding to support self-advocates running self-advocates groups. The commissioner can talk to other agencies that work with people with disabilities and suggest they do this as well (such as the Dept. of Education). Also, provide funding for both national and local self-advocacy organizations across the country, like SABE.

National Action #2: Commissioner needs to have a conversation and advocate for Voc. Rehab. To provide supports such as job coaches and identify more available jobs for people with disabilities (jobs that are a better fit for the person, not just the first job that Voc. Rehab. Finds available). Also, Voc. Rehab. Needs to support long-term employment (provides supports for as long as possible aka whenever the person needs the support!).

National Action #3: ADD should include the words "self-advocacy" in all materials created. Also, all ADD funded meetings should have a large percentage of self-advocates in attendance.

Policy Recommendation #1: Mandate (require) the UCEDDs and P&As to support self-advocacy organizations. [rith now the DD Councils are the primary supporters largely due to their legal mandate from the DD Act]

Policy Recommendation #2: Create and pass a national law to close ALL institutions.

Policy Recommendation #3: Create and pass a national law to close ALL segregated workshops and end sub-minimum wages (everyone should get minimum wage or more, regardless of their disability status).