Dear Colleague:

As you may know, support for building and sustaining strong and active self-advocacy organizations in the States and Territories is a top priority for the National Association of Councils on Developmental Disabilities (NACDD). To this end, the NACDD has formed a Self-Advocacy Committee to both investigate the current status of Self-Advocacy organizations across the nation and to engage in important discussions about what makes a self-advocacy organization successful and sustainable.

Attached, please find an executive summary of a comprehensive survey that was sent to all 56 Councils on Developmental Disabilities along with a document of best practices. The "Nothing About Us without Us" Best Practices for Supporting Statewide Self-Advocacy Organizations was developed by NACDD's Self-Advocacy Committee with expert input from numerous self-advocate leaders from advocacy organizations around the country.

NACDD is continuing to engage through its Self-Advocacy Committee, Self-Advocate Leadership Circle and all of you to gather resources and tools that will help all of us support state and territorial based self-advocacy efforts. Over time, we will share these resources and tools on NACDD's website and through a new project on self-advocacy at http://startyourjourney.org.

We welcome your thoughts and feedback!

Best,

Molly Cole, President
NACDD Board of Directors

Nancy Cronin. Chair
NACDD Self-Advocacy Committee

Executive Summary of Self-Advocacy Survey Results
February 9, 2015

In 2014, NACDD sent out a survey on self-advocacy for the Councils to complete. This survey asked Councils to report on the state of self-advocacy in their states, including barriers and issues for sustainability. Fifty of the fifty-six Councils (89%) responded to this survey. Forty-eight (94%) of the fifty-one State Councils (including the D.C. Council) and two of the five (40%) Territory Councils filled out this survey.

This executive summary shares what NACDD has learned from the Councils' responses to the survey on self-advocacy. For the purposes of this summary, this summary uses the term *states* to refer to both U.S. states (plus D.C.) and territories.

Changes in Self-Advocacy in the States over Time

Most of the 48 Councils (73%) reported that their states had seen noticeable changes in the self-advocacy movement during the past five years. These changes involved shifts in recruitment of members, collaborations with other groups, age of participation, and other factors. Some states have seen progress in the growth of self-advocacy, where other states have experienced major declines.

The current trends in self-advocacy spanned a mix of positive and negative factors. Forty percent or more of Councils indicated that self-advocacy groups are not well organized (43%) or that youth with disabilities do not relate to them (40%). However, more than one third of Councils indicated several positive trends in self-advocacy in their states. These trends included: the emergence of statewide chapters (40%) or new leadership for groups (40%), attainment of 501(c)(3) status (35%), and participation in policymaking (37%).

Demographics and Diversity of Self-Advocacy Groups

The responding Councils (49) generally agreed that involvement in self-advocacy groups in their states ranged from 0-2,500 people with disabilities. (One Council indicated that 10,000 or more people with disabilities participate in self-advocacy groups.) More than half of these Councils indicated that 0-500 people with disabilities participate in self-advocacy groups in their states.)

Less than one quarter of Councils indicated that 500-900 (22%) or 1,000-2,499 (10%) people with disabilities participated in self-advocacy groups. Fourteen percent of Councils were unsure how many people with disabilities participate in self-advocacy groups in their states.

Most of the 48 responding Councils (56%) agreed that a cross-disability self-advocacy movement exists in their states. (The remaining 44% indicated that the self-advocacy movement in their states only involves people with intellectual and developmental disabilities.) About half of these Councils (27) identified groups that make up this cross-disability self-advocacy movement in their states. The vast majority of these 27 Councils reported that self-advocacy groups included people with I/DD (96%), physical disabilities (96%), and mental health disabilities (70%). A third of Councils indicated that self-advocacy groups included the aging population.

Sustainability of Self-Advocacy Groups

The Councils (35) evenly split on whether they considered self-advocacy groups sustainable in their states. Thirty-three Councils identified ways in which self-advocacy groups promote sustainability. Most of these Councils (60%) identified state funding (69%) or federal funding (56%) as the key way used to maintain sustainability of self-advocacy groups. Half of Councils identified fundraisers or in-kind staff time from other organizations as the way used to maintain sustainability. Fewer than half of Councils indicated that part-time staff (44%), full-time staff (33%), or private funding (11%) support sustainability of self-advocacy groups. No Councils indicated that local, municipal funding supports self-advocacy groups.

Barriers to Self-Advocacy

The Councils (49) identified several significant barriers that hinder the growth of self-advocacy in their states. Councils most frequently identified transportation access (61%) and recruitment of new members (55%) as the significant barriers to development of self-advocacy groups. More than a third of responding Councils (37%) reported three other significant barriers: administrative support, organizational leadership, and skills/equipment. Less than one third of responding Councils identified these factors as a significant barrier: unclear mission (31%), allies/advisors overshadowing (31%), providers overshadowing (27%), and advocacy training (22%).

Major Themes and Concerns

The Councils provided open-ended comments that showed a diversity of experience and history in facilitating self-advocacy in their states. These comments help illustrate that Councils and their state partners have approached self-advocacy from different ways that reflect the differences in their states. The state of self-advocacy thus looks unique to each state. However, some common themes underlie the open-ended comments sent in by Councils that completed the survey:

Successes and Weaknesses of the Self-Advocacy Movement

- +/- Cross-disability support: successful in some states but not working well in others
- +/- Policy initiatives: some self-advocacy groups pursuing policy change but others not
- +/- Age diversity support: mixed success in developing youth and young adults in self-advocacy and collaborating with the aging community (on shared concerns)
- - Funding challenges: persistent budget cuts constrain the growth of self-advocacy
- - Membership growth: hard to ensure sustainability in membership growth

Council Roles in Supporting Self-Advocacy (varies widely by state)

- Leadership training—in self-advocacy and conference participation support
- Dedicated staff support—to facilitate growth of self-advocacy groups
- Network brokering—connecting with DD Network partners (UCEDDs and P&As)
- Funding—in some cases targeted (w/ outcomes) and in other cases broad
- Advisory/TA—guidance with navigating development of an organization
- Meeting facilitation—help facilitate meetings of the self-advocacy group

P&A Roles in Supporting Self-Advocacy (varies widely by state)

- Legal services—including legal interpretation supports
- Funding—although it can be inconsistent
- Training and TA—including shared conference on self-advocacy
- Advisory support
- Dedicated staff support—sometimes available for self-advocacy

UCEED Roles in Supporting Self-Advocacy (varies widely by state)

- Funding—self-advocacy support staff and sometimes seed grants
- Dedicated staff support—for trainings
- Training and TA—including w/ administrative activity for groups and conferences
- 501(C)(3) attainment for self-advocacy groups

Recommendations for NACDD Support Roles Nationally

- Standards for self-advocacy and a unified vision (including for training)
- Best practices—continued innovation and resource exchange
- Represent self-advocacy interest w/ AIDD and other federal partners
- Collaborations (new) w/ DD Network Partners
- Outreach on ongoing trends in self-advocacy and outcomes
- Guidance on the role of advisors (including trainings)

Recommendations for NACDD Support Roles in States

- TA on geography—outreach on reaching statewide and rural areas (best practices)
- Cross-state connections—Learning from other states and implementing their success
- Shared resources—materials developed in other states to use
- Educational tools and resources—to assist training and TA by the Council

Summary of Findings and Recommendations

The NACDD survey of 51 Councils yielded extensive recommendations on challenges facing self-advocacy and suggestions for solutions to address these challenges. The Self-Advocacy Committee will support the work of NACDD to implement these recommendations. Namely, the committee will help NACDD develop a unified vision for best practices and approaches to outreach and development of inter-state collaborations for self-advocacy. The committee will also develop recommendations for DD Councils and AIDD on how to proceed in establishing a strong and diverse national network of statewide self-advocacy organizations that exemplify best practices for legislative advocacy, public awareness and capacity building.

"Nothing About Us Without Us"
Best Practices for Supporting Statewide Self-Advocacy Organizations

*NACDD's Self-Advocacy Committee, in collaboration with self-advocates from across the country, leaders of national disability organizations and State and Territorial Developmental Disability Councils, has developed a list of best and promising practices that we believe will result in the growth and sustainability of effective self-advocacy organizations. It is the opinion of its developers that these practices should be implemented to the greatest extent possible in advocacy organizations of all size and scope. ***

1. People with intellectual and developmental disabilities should participate in all decisions of the organization, including but not limited to being a member, being a leader and helping to define its vision, mission and activities.

2. Use people first and plain language. People first language puts the person first not the disability. Plain language uses the clearest words possible to describe actions, objects and people. Organizations must also respect that the meaning of words change and use language that best meets the needs of its members. For example, some advocates may choose to refer to themselves as "Autistic self-advocates."

3. Maintain a diverse membership by including people of all ages, including youth and people with different religions, race, ethnicity, and sexual orientation in learning and practicing leadership.

4. Support access for all people, including access to buildings, printed materials, transportation, and other areas of life to make sure all people with intellectual and developmental have the chance to be fully included and have meaningful participation in self-advocacy activities.

5. Recognize that advocacy is practiced in many different ways and all have value. Self-advocacy can be talking about disability to help others understand or working on policies and laws that make changes to help people with intellectual and developmental

disabilities and their families.

6. People with intellectual and developmental disabilities develop job descriptions and roles and responsibilities to choose and/or hire staff to support self-advocacy organizations. People with intellectual and developmental disabilities have the training and support they need to also serve as the statewide self-advocacy organization staff, which could include paid staff and leadership positions.

7. Work to become an independent organization with money to support the work of the organization. Some self-advocacy organizations may choose to become a non-profit organization.

8. Share information and provide skill building opportunities to people with intellectual and developmental disabilities to work on key policy issues that support the mission of the self-advocacy organization.

9. When possible, work together with other groups both disability and non-disability, which share the same issues and concerns.

10. Use current technology, such as social media, to help people learn about the work of self-advocacy organizations, increase membership and share information.

* This document is available in Word and accessible PDF versions so self-advocates and Self-Advocacy organizations can change its content to fit the unique needs of their state.

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