"Nothing About Us Without Us"
Best Practices to Support Statewide Self-Advocacy Organizations
User Feedback Survey Summary
August 2017

Dear DD Council Network,

In 2016, the "Nothing About Us Without Us" Best Practices for Supporting Statewide Self-Advocacy Organizations was developed by NACDD's Self-Advocacy Committee (SAC) and numerous self-advocate leaders from advocacy organizations around the country. The resource document includes an executive summary of the self-advocacy survey completed by DD Councils in 2014 and a list of best and promising practices that NACDD believes will result in the growth and sustainability of effective self-advocacy organizations.

If you have not reviewed the resource, it can be found on the NACDD website under the Advocacy/Self-Advocacy and Leadership tab and on ITACC website under the Other Resources tab.

In August of 2017, NACDD/ITACC disseminated a follow-up survey to assess the use and usefulness of the resource and compile recommendations to share on how it is being used. A brief update on the status on self-advocacy was also collected to assess the current statewide self-advocacy movement, determine how Council efforts are impacting advocacy, compile a list of self-advocacy organizations involved directly with Council work and offer suggestions for additional resources and topics of interest.

Please see the summary below as we hope it will inspire you and your Council to use the resource for the first time or provide ways to continue sharing it with Council members, colleagues and advocate leaders in your state and territory.

Resource User Feedback Survey Summary

1) The resource user portion of the survey was answered by 18 people representing 15 State/Territorial DD Councils. Half of the respondents did not know the resource was available. The remaining respondents stated that they use other resources and materials for self-advocacy or did not have enough time to address the issue.

Summary/recommendation:

To address the number of people who responded that they did not know about the resource, NACDD/ITACC may utilize social media announcements (FB & Twitter), website postings, events/trainings/teleconferences and "reminders" on list serves to advertise future resources. This will better inform the DD Council network and ensure that they know of the valuable resources that are being provided for their use.

2) **Below is a summary of how respondents used the resource.**

   – To support Council members who are self-advocates - 50.00% (3)
   – To support self-advocacy organizations - 83.33% (5)
   – To address self-advocacy through our RFP process - 16.67% (1)
   – We have shared and posted this information for others in our state/territory. - 16.67% (1)
   – We have disseminated this document via e-mail, or in hard copy at meetings & conferences. - 16.67% (1)
   – We have discussed this document at Council meetings. 16.67% (1)
   – Comments from respondents:
   – We will begin using this resource in upcoming trainings.
   – We will eventually use it to support self-advocacy organizations.
   – We anticipate sharing and using this resource with our SA organization training workshops.
   – Information in the resource supported the Councils approval for funding the initiation of a statewide self-advocacy group that included board and advisory members from the DD network…the group will review the recommendations of this report, acknowledge aligned activities and consider adding activities…

Summary/recommendation:

The responses suggest that the resource was mostly used to support self-advocates and self-advocacy organizations. NACDD/ITACC may forward this resource to other advocacy organization leaders across the states and territories for posting on their websites, list serves and social media. This added exposure will increase the usability of the resource and reach more advocates.

3) Of all the strategies listed in the resource, the following were the most helpful to respondents. Overall, the most helpful strategies centered around leadership and skill building of advocates and increasing diversity.

- Increase membership of self-advocates on the Council. 25.00% (2)
- Increase leadership of self-advocates in key Council roles. 75.00% (6)
- Use plain language in all documents. 62.50% (5)
- Use people first language and self-identification preferences of self-advocates. 50.00% (4)
- Increase diversity by including people of all ages, religions, races, ethnicity and sexual orientation in leadership development opportunities. 62.50% (5)
- Promote participation through addressing transportation needs of diverse members. 62.50% (5)
- Promote access and participation by making print materials accessible to diverse learner abilities. 37.50% (3)
- Promote access and participation by addressing accessibility issues including physical access and bus line/public transportation access. 25.00% (2)
- Provide people with intellectual and developmental disabilities the training and support they need to serve as paid staff/leaders in the statewide self-advocacy organization. 25.00% (2)
- Facilitate access to financial support so that the self-advocacy organization is an independent organization. 25.00% (2)
- Provide information, support and skill building to people with I/DD so that they can participate in addressing key policy issues. 62.50% (5)
- Build collaborations and partnerships with other groups that may share the same issues and concerns. 50.00% (4)
- Use technology and social media to help spread the word about the self-advocacy organizations, grow their membership and share information. 37.50% (3)

4) The following stats reflect whether or not NACDD's creation of the Nothing About Us Without Us Best Practices to Support Statewide Self-Advocacy Organizations resource was useful to states/territories in further developing and supporting self-advocacy.

Yes, 85.71% (6) – No, 14.29% (1)

Summary/recommendation:

The majority of the respondents found the resource useful within their state/territory to further leadership among self-advocates and to strengthen their support of self-advocacy organizations.

NACDD/ITACC will continue to explore the needs of states/territories with regard to supporting SA on many levels and provide training, technical assistance and tools that support those needs.

If you have any additional information to share about the resource or questions about its use, please contact Angela Castillo-Epps at acastilo-epps@nacdd.org or call 202-506-5813, ext. 100

Status of Self-Advocacy in Your State/Territory Feedback Survey Summary

The status on self-advocacy portion of the survey was answered by 10 respondents.

The following four questions provided NACDD with general feedback on the current status of self-advocacy in states and territories.

1) **As a result of your Council efforts, how has self-advocacy changed in your state/territory?**

Five respondents answered question one and all stated that the following changes have occurred due to Council efforts.

- The self-advocacy organization has grown in membership.
- Our state/territory offers more training and leadership opportunities for self-advocates.
- Our council has more self-advocate members. Our council has more self-advocates in leadership roles.
- The self-advocacy organization is now an independent organization.
- More self-advocates are active in policy discussions, public input and influencing policy decisions.

2) **What state or local self-advocacy group(s) is your DD Council most involved with?**

Twelve respondents answered question 2. See list.

- People First
- MA Advocates Standing Strong Statewide Independent Living Council
- Speaking for Ourselves of Colorado
- People First Wisconsin
- Self-Advocates in Action Organization
- NC Empowerment Network was established because of NCCDD involvement. Credit is shared with DD Network Partners: Carolina Institute for Developmental Disabilities and the Disability Rights of NC.
- Oklahoma Self-Advocacy Network (But we also have Oklahoma People First, lesser involvement, but still financial support provided.)
- The Statewide Self-Advocates Network
- Self-Advocates United as one; Speaking for Ourselves; Pennsylvania Autistic Self Advocacy Network, etc.
- People First of Alabama
- Peer Power Alaska statewide self-advocacy organization
- Advocates as Leaders Self-Advocacy Speakers Network and Next Chapter Book Club.

3) **How would you describe the current statewide self-advocacy movement presence within your state or territory?**

Twelve respondents answered question 3.

- Well organized 33.33% (4)
- Strong advisors empower self-advocates to lead 41.67% (5)
- New leaders are emerging 75% (9)

- Issues related to changing interests of younger advocates not relating to older advocate issues 33.33% (4)
- Not well organized 8.33% (1)
- Non-profit status (501c3) 58.33% (7)
- Participates/ is active in local or state policy making decisions 66.67% (8)
- Participates/ is active in the local or state political process 50.00% (6)
- Allies/ advisors (people without disabilities) are the leaders 16.67% (2)
- Maintains a system of statewide chapters 41.67% (5)
- Involved in local or state issues that are not disability related 8.33% (1)
- Involved with cross population advocacy (e.g. aging, LGBT, racial/ethnic minority populations) 33.33% (4)

Though the responses were limited, it appears that the majority of respondents feel strides are being made with regard to new leaders, people active in policy and policy making decisions, and self-advocacy organizations acquiring non-profit status.

4) Please share with us any additional resources for self-advocacy you would like NACDD to provide to the DD Council Network.

Three respondents answered question 4.

- More examples of what other states and territories have done.
- Resources on accessible language, fund raising and how to acquire in-kind resources.
- The last respondent offered to share trainings with Councils.

NACDD/ITACC will continue to keep an open dialogue with the DD Council Network and utilize a diverse set of strategies, which include but are not limited to list serves for information sharing, the Leadership Circle, the Self-Advocacy Committee (SAC), CEO Awards, resource page on nacdd.org website, DD Awareness Month Campaign, Civic Engagement, and Close UP to support the work of Councils, advocate leaders and self-advocacy organizations across each state and territory.