



CROSS-DISABILITY AND CULTURALLY DIVERSE LEADERSHIP COALITIONS

Strategies and resources for DD Councils

Background

There are 56 Councils on Developmental Disabilities in the United States and select territories. The Councils are funded through grants authorized under Subtitle B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. (DD Act). NACDD/ITACC provides technical assistance to all DD Councils to support the implementation of the DD Act.

The DD Act self-advocacy mandate has three components. One component is to

"Support and expand participation of individuals with developmental disabilities in cross disability and culturally diverse leadership coalitions." DD Act, Section 124 (c)(4)(ii)(III)

DD Councils support this component of the mandate in many ways. To share some of the strategies used by DD Councils, the ITACC SA work group in collaboration with the NACDD Self-Advocacy Committee (SAC) conducted a survey to gather additional information.

Responses were gathered from 43 people representing 29 states and 2 territories. The purpose of the survey was to identify DD Councils' needs in relation to supporting the mandate and gather successful strategies and resources to share.

Survey Summary

Question: How does your Council support and expand the participation of individuals with developmental disabilities in cross disability and culturally diverse leadership coalitions?
[Leadership coalitions may include advocacy and/or policy boards, advisory committees, and other governing bodies.]



Support training and education to advocates on skills necessary for participating on cross-disability and culturally diverse leadership coalitions.



Identify cross-disability and culturally diverse leadership coalitions and inform people with developmental disabilities of the opportunities to participate.



Fund small grants etc. to provide resources, access and opportunities for advocates to participate in cross disability and culturally diverse coalitions, committees and other meetings.



Support training and education to community members who organize cross-disability and culturally diverse leadership coalitions on how to create and support the meaningful participation of people with developmental disabilities.



Utilize cultural brokers in any way to support advocates in cross disability and culturally diverse leadership coalitions.

Training and Education.

Councils reported various ways they support training, including but not limited to...

- Partners In Policymaking programs
- Collaborations with DD Network partners
- Statewide and local self-advocacy organizations
- Non-profit organizations, such as [Toastmasters](#)
- Self-advocacy summits and conferences
- Adult/youth leadership training grants and initiatives
- Speaker networks

Additional Takeaways.

DD Councils are identifying opportunities for participation by utilizing DD Council staff, engaging with self-advocacy organizations, accessing list serves from DD Network partners and offices such as the Department of Human Resources, connecting with grantees and meeting with the Governor's office.

Although the mandate does not specify that coalitions must have a disability focus, the majority of those reported by Councils were solely focused on disability.

Once identified, DD Councils use the following methods to inform advocates and families about opportunities to participate: phone calls, emails, Facebook postings and other social media platforms, newsletters, and cultural brokers/community organizers that can reach diverse populations.

How can Council members and staff support the mandate?

Make Connections. DD Council members have potential connections with a wide range of local, state and national level committees and workgroups. Below are some suggestions for leveraging these connections.

Suggestion 1: Gather a master list from Council members that lists contacts they have to coalitions, work groups, boards etc. If possible, include a point person and links for more information. Be sure to redistribute the lists to each Council member throughout the year for updates.

Suggestion 2: Join list serves for organizations throughout the state/territory so alerts are received when there is an opening for a board or commission.

Suggestion 3: Maintain a database of graduates from leadership trainings and programs. Include advocacy interests, such as transportation or health care for each graduate.

Suggestion 4: Encourage Council members to alert Council staff when an opening becomes available. Council staff disseminate available opportunities widely through a database, Statewide and local self-advocacy organization list serves, DD Network partners (UCEDDs and P&As), local Arcs, service providers, and other collaborative partners, including grantees.

Think Broad. In the spirit of full inclusion; Councils should seek to foster the representation of people with developmental disabilities on boards, advisory committees, and other governing bodies not only with a disability focus but on other bodies at the local, state and national level.

Suggestion 5: In addition to a workgroup with a focus on medically fragile adults and children, *consider an advisory committee role at a local hospital.*

Suggestion 6: In addition to serving on The Arc board, *consider a state advisory committee on civil rights.* (<https://www.usccr.gov/about/sac.php>)

Suggestion 7: In addition to mobility transportation work groups for accessible transportation, *consider a role on a Federal Transit Board.*

Think Diversity, Inclusion and Cultural and Linguistic Competence. When identifying opportunities, engage culturally diverse coalitions in your state or territory, include community development organizations, and grassroots and civil rights organizations that support unserved/underserved populations across your state or territory. When funding initiatives to support this mandate, ensure trainings and resources address cultural and linguistic competence.

Resources and Information

The work on this mandate is a “two way street.” All advocates and stakeholders need education and support. The list below provides additional information and some examples of leadership training and opportunities that your Council may use or model. Read the summary and click on the links provided in blue.

(1) Beyond Tokenism, Executive Summary (Michigan DD Council)

Over the past twenty years, organizations focused on addressing the needs of individuals with complex disabilities have embraced multiple strategies to increase the number of self-advocates on boards and decision-making bodies. Similar to efforts by other marginalized groups to gain influence, individuals with intellectual and developmental disabilities have had to confront tokenism and the lack of commitment to their inclusion.

As such, the purpose of the Beyond Tokenism: People with Complex Needs in Leadership Roles national study was to determine how far individuals with complex and/or high support needs have moved "beyond tokenism" and into authentic leadership roles along with those factors or activities that have contributed to their ascent.

<http://www.beyondtokenism.com/wp-content/uploads/2016/05/BeyondTokenismExecutiveSummary-final.pdf>

(2) SELF-ADVOCACY RESOURCE AND TECHNICAL ASSISTANCE CENTER (SARTAC)

Sartac offers resources and one on one assistance for organizing and supporting self-advocacy groups, fellowships and more.

<https://selfadvocacyinfo.org/>

(3) ITACC Resource: Understanding Advocacy through the DD Council Lens

The “Understanding Advocacy through the DD Council Lens” provides Councils with clear information on the three mandated self-advocacy requirements in the DD Act, outlines examples of the many ways that Councils impact advocacy, and offers a complimentary glossary and resources list.

[English version](#) | [Spanish version](#)

(4) Americans with Disabilities Act (ADA) Trainer/Leadership Network

Training advocates to be trained disability specialists

The ADA Trainer/Leadership Network is a national initiative involving more than 500 disability specialists including people with disabilities, vocational rehabilitation professionals, community rehabilitation providers, businesses and employers, state and local government representatives, and others. The program uses a curriculum, designed by the Northeast ADA Center at Cornell University on behalf of the ADA National Network, to provide basic training on the Americans with Disabilities Act (ADA). In addition to learning about the ADA, members are provided training on community needs assessment, consulting, and relationship building so they can work with local ADA stakeholders to effect change in their communities.

<https://adata.org/project/ada-trainer-network>

(5) Webinar resources developed in partnership between Temple University and the PA DD Council

The three-part webinar series “[Diversity Includes Disability](#)” is designed to promote meaningful connections and leadership opportunities between individuals with disabilities and your Board of Directors.

Part 1: “*Considering Individuals with Disabilities as Members of Your Board of Directors*”

- Examine the value of diversity on decision making bodies
- Learn how to include individuals with disabilities on your decision making bodies
- Understand the benefits to your organization of having a diverse group of decision makers

<https://www.temple.edu/instituteondisabilities/programs/leadership/ilia-2015seriesPt1.shtml>

Part 2: “*How to Accommodate Individuals with Disabilities as Members of Your Board of Directors*”

- Discover a variety of accommodations for individual experiencing different types of disabilities
- Learn how individuals with disabilities are accommodated in ways that benefit other board members
- Hear from presenters as they share their personal experience of being accommodated as Board members
<https://www.temple.edu/instituteondisabilities/programs/leadership/ilia-2015seriesPt2.shtml>

Part 3: “*Creating a Successful Group Culture on Your Boards of Directors*”

- Learn how to build a culture of close listening
- Discover tools and processes to support equal participation
- Understand how to share knowledge effectively among board members
<https://www.temple.edu/instituteondisabilities/programs/leadership/ilia-2015seriesPt3.shtml>

(6) ABLE South Carolina and COMMUNITY LEADERSHIP ACADEMY

Professional Trainings: <https://www.able-sc.org/community-trainings/>

Community Leadership Academy is an effort funded by the USC School of Public Health to increase participation of individuals with disabilities on boards, committees, and councils. In its commitment to ensure that individuals have the tools and resources necessary to effectively participate in a leadership role, the CLA course teaches skills such as professional dress, ethical and legal responsibilities, and Robert’s Rules of Order.

The program helps graduates find leadership roles in their local communities that are in line with their passions and put their new skills to good use.

YouTube video (About the Community Leadership Academy)

<https://youtu.be/33C1uLDSUUC>

Website

<https://www.able-sc.org/community-leadership-academy/>

(7) Youth Leadership EQUIP

EQUIP is an inclusive, educational group designed to teach young adults (ages 13-28) with disabilities the value of self-advocacy, disability pride, youth empowerment, and professional

skills. EQUIP is comprised of young adults with disabilities who are passionate about reaching their full potential and empowering others to do so as well!

<https://www.able-sc.org/equip/> | [EQUP Brochure in Spanish](#)

(8) Youth Leadership Forum

The SC Youth Leadership is a four day, three-night leadership-intensive experience. Juniors, seniors, and recent high school graduates have the opportunity to stay overnight on a college campus, learn about independent living and advocacy in a safe and supportive setting, and collaborate with other young adults from around the state.

<https://www.able-sc.org/scylf/>

If you would like to add resources to this document, have difficulty with any of the links or need this information in an alternative format, contact ITACC staff, Angela Castillo-Epps, acastillo-epps@nacdd.org or call 202-506-5813, ext. 100
