# **FIELD NOTES, AUGUST 2020**

## COMPLIANCE CORNER

Developmental Disabilities or Disabilities?

In 1999, Congress found that people whose disabilities occurred during the developmental period, frequently have severe disabilities that are likely to continue indefinitely. They are likely to encounter discrimination in the provision of critical services, are at greater risk for abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights. They lack access to appropriate supports and services and often require lifelong, individualized supports that are coordinated and culturally competent. There are other findings in Section 101 of the DD Act as well as the purpose of the Act, and the Policy of the United States for all programs funded under the DD Act.

 From time to time, the question is asked if Council work must be focused specifically on people with developmental disabilities. The simple answer is YES! Council projects, activities, initiatives, and other efforts should be focused on people with developmental disabilities and their families. If a Council initiative benefits other people in society, that is an additional benefit but the initial focus of DD Council work must be on people with developmental disabilities and their families.

During one of the recent TA Institute online sessions, the question was asked if data collection efforts should be focused on people with developmental disabilities and their families or could data be collected from all people with disabilities. The answer is people with developmental disabilities and family members of people with developmental disabilities.

However, if you capture other numbers, they can be reported in the narrative progress reports, and if a system change effort, the performance measure (SC 1.4) is for “people trained” – and does not include people with developmental disabilities or family members of people with developmental disabilities. Council staff should ensure the data collection instruments are designed in a way that will capture the number of people with developmental disabilities and family members of people with developmental disabilities (for federal performance measure purposes) but also capture the overall participation of people in Council funded activities – this will give you data that can inform your work and your “reach”.

# WEBSITE UPDATES

﻿
FIVE-YEAR STATE PLAN PAGE
FIELD NOTES AND OTHER RESOURCES

All of the accessible PowerPoint presentations from the 2020 TAI are now posted at the top of the Technical Assistance Institute & Other Resources page for your use.

To access webinar recordings from the TAI, contact info@nacdd.org with your request.

# 2022-2026 State Plan Development

*The plan is due on August 15, 2021,* *in the ACL reporting system for all DD Councils.*

**RESOURCE REMINDER!**

For multiple resources to support your Council's state plan development process, be sure to access the Five Year State Plan page for the important resources listed below.

* [State Plan Development Resource](http://r20.rs6.net/tn.jsp?f=001merW7B0boBpD3ijxCFYUQZNJAB7ySgwT1JTIlS5pM_E5UJExSdpgUsmr9dyfr3HkYpzjEeUB_qIwMM8lgFzLQLUfSQxZfSPx5H_QCSFds1zNfMT1SZlWu72OapusWKi6tKHZqQIU4iGUaR939yxWLBmV9PB47dJQf0rKdzukCQXuWFCzTas-UQDl1RmYR1DUQYwnKCvhuFasp21Q30TRftpgQYV7U1nTH6x_GHZ02XiL3hzr7bG7IKxA7d_LsR24&c=TrjtvsYi1K-AdFD7bcOtI8SZ7IROYVNoPK3m--WI7ZlzVs0zAdg_Ag==&ch=s7SL9Vjbr6n3eUBRTyWjnDFnLWT7yo6C7sNUQ7AWyNc2k1y4Dckhfg==)
* [Five Year State Plan Goals and Objectives Brief](http://r20.rs6.net/tn.jsp?f=001merW7B0boBpD3ijxCFYUQZNJAB7ySgwT1JTIlS5pM_E5UJExSdpgUsmr9dyfr3HkxPQHIFHgVhSibGWhpqBzdtHc8ECGyi6DIFU4i6l0lMGCrKqbuZT0UkxSRYYTj8p9H26qGGQuHRhvodr5_gi4DMJeoQYafnXk9YYmXaVeFcyVLKtEhKKr_kBmhx_R4q09CvYbjqqLcvAgg9EW6NRj3Zs84rmIxWl6WZU79iiVcyo6kBAyknYs4BFmCbdtOTXGw2e0IHxL09o=&c=TrjtvsYi1K-AdFD7bcOtI8SZ7IROYVNoPK3m--WI7ZlzVs0zAdg_Ag==&ch=s7SL9Vjbr6n3eUBRTyWjnDFnLWT7yo6C7sNUQ7AWyNc2k1y4Dckhfg==) and [WEBINAR PowerPoint](http://r20.rs6.net/tn.jsp?f=001merW7B0boBpD3ijxCFYUQZNJAB7ySgwT1JTIlS5pM_E5UJExSdpgUhoaDimDpKW-eJOTUtJM558uRUbrfoSXhZ3pSXfA1Ku3zPysmAYUgzy5fLkmv2-iJ2sLpMg2tGj3cFpwSVUqSDkjI0ec1_9Gl53hOY3iFm51A-O0-g4a75bACSFnaUE1u35ob2KnE2MK_Snwfz1vgO-T90bGaLWI9j4RlqIexpSwpQRtP97nZm0VdB3HhHAMsrv-8Mt9Yl6-&c=TrjtvsYi1K-AdFD7bcOtI8SZ7IROYVNoPK3m--WI7ZlzVs0zAdg_Ag==&ch=s7SL9Vjbr6n3eUBRTyWjnDFnLWT7yo6C7sNUQ7AWyNc2k1y4Dckhfg==)
* [Annual Work Plan Template with Guidance](http://r20.rs6.net/tn.jsp?f=001merW7B0boBpD3ijxCFYUQZNJAB7ySgwT1JTIlS5pM_E5UJExSdpgUguUTEABQhtg4khtzI1IYGivVjdbE-s5FhRrQJGDaAYpimBZkKoPAAi5dL1jGtsLkHVlmycqcpRmfMw6bCbSj9YHd5DAgBVzATOnYWkLzF-eox2p1_ZkLRqaWaNH2aUscdo5DUljvh347gx2JByegL4j3-Q-O7tWGp-MqSy5YfilxaI0-YSN-jk=&c=TrjtvsYi1K-AdFD7bcOtI8SZ7IROYVNoPK3m--WI7ZlzVs0zAdg_Ag==&ch=s7SL9Vjbr6n3eUBRTyWjnDFnLWT7yo6C7sNUQ7AWyNc2k1y4Dckhfg==)
* [NEW Public Input Strategies Resource for 2022-2026](http://r20.rs6.net/tn.jsp?f=001merW7B0boBpD3ijxCFYUQZNJAB7ySgwT1JTIlS5pM_E5UJExSdpgUhoaDimDpKW-ZxdCP6Z5diWpvfTPG-EHt0bnWMSjmKQo3fWy9gnmZsHAaprbJjx5SiuzRCxgHGSLFYuOrnFgAp5ylFg8r8qWuT2RbffapvN1xbWf-EDqiVKB-3W5p7pjIlYUWEdwEbWutw93SWt5-taf7mINBqldXqUEtkYxIX8rf30CSTFotmfYuGio0SVSYhp4QmnOhJbM&c=TrjtvsYi1K-AdFD7bcOtI8SZ7IROYVNoPK3m--WI7ZlzVs0zAdg_Ag==&ch=s7SL9Vjbr6n3eUBRTyWjnDFnLWT7yo6C7sNUQ7AWyNc2k1y4Dckhfg==)

If you are looking for a resource and cannot find it on the page, contact Angela at acastillo-epps@nacdd.org or call 202-506-5813, ext. 100.

# DICLC

DD Councils and addressing the "isms"

The “Isms” is an umbrella term used by the National Center for Cultural Competence to refer to a range of attitudes and behaviors that involve perceived superiority, oppression, prejudice, and discrimination based on such factors as race, national origin, ethnicity, language, class, disability, sexual orientation, and gender identity and expression.

Though the DD Act includes provisions for supporting unserved and underserved populations, cultural competencies with regard to services and supports and representation of a diverse Council membership (racial, ethnic and geographic), recent events around systemic racism and other inequities has evoked a time for reflection. This has led some Councils to contemplate the work they do every day. Councils may be asking and trying to answer some difficult questions.

• Does my Council have policies and procedures in place that maximize full inclusion and provide opportunities for all? Or do our procedures inadvertently exclude certain communities?

• Is my Council educating a wide array of potential grantees to ensure an equitable process for consideration and approval?

• Are our DD Council members and staff truly diverse?

Before the internal and external operations of a DD Council can be addressed, it is good practice for the members and staff to first look within.

The goal is to reflect on your personal world-view of diverse individuals and cultures. Think about how you perceive the way people are treated not only you, but by society as a whole.

• Do you recognize the disparities that existed long before the recent advocacy movements and health inequities brought about by COVID-19?

• How do you interpret or justify the disproportionate distribution of wealth, opportunities and privileges?

Other reflective questions could include, "How might I be contributing to the inequities?" "What are my implicit biases and how do they impact my personal and professional relationships?"

There are first steps in this reflective process and resources to help!

• First, call it what it is!

• Create a climate of intolerance

• Offer a safe refuge for authentic discussions

• Use conflict management and resolution

• Invoke legal interventions when necessary

(Georgetown University, National Center for Cultural Competence)

To call it what it is and facilitate those difficult conversations, see the resources listed below from the Georgetown University, National Center for Cultural Competence. Try starting with a framework for Addressing the "isms:

Learning and Reflection Forums

The NCCC defines "isms" as an umbrella term to refer to a range of attitudes and behaviors that involve perceived superiority, oppression, prejudice, and discrimination based on such factors as race, national origin, ethnicity, language, class, disability, sexual orientation, and gender identity and expression.

What Organizations can do to Address the "isms" PowerPoint presentation

Webinar Recording

Self-Assessments

In addition, there is wealth of information gained through organizational self-assessment. Though the literature typically refers to the health care field, the concepts are easily transferable to Council mission and functions.

The Cultural and Linguistic Competence Assessment for Disability Organizations (CLCADO)

For even more information, visit the [NCCC website](https://nccc.georgetown.edu).

# NCI’s COVID-19 BULLETIN

# Crisis, Respite and Emergency Planning

The Data on Family Experiences

Understanding the emergency preparedness, crisis and respite services for children and adults with intellectual and developmental disabilities (IDD) and their families during the COVID-19 pandemic

...Because of COVID-19 guidelines for social distancing and states’ executive orders, adults with IDD and their families may have temporarily lost access to regular respite and support services such as daytime activities and crisis supports. This bulletin examines NCI data on family emergency preparedness and access to crisis and respite services. Although these data were collected prior to the pandemic, they can help inform states about potential gaps in access to these services—gaps that are likely more dramatic now due to the pandemic. (NCI COVID-19 Bulletin)

CRISIS SERVICES: Prior to the pandemic, only 53% of families of adults with IDD living at home who responded to the National Core Indicators Adult Family Survey (2018-2019) said that they were able to get the crisis services they needed when they were needed. Of families with children with IDD living at home responding to the NCI Child Family Survey (2018-2019), 45% said they were able to get crisis services (IDD) when needed. These responses suggest that prior to the current crisis, only half of families with adults with IDD and over half of families with children with IDD had access to crisis services when they needed them.

RESPITE SERVICES: In the 2018-2019 Adult Family Survey, collected prior to the pandemic, 61% of families said they could always or usually get respite when needed; in the Child Family Survey, 66% of families said they could always or usually get respite when they needed it. That means that about one third of families don’t always get the respite services they need when they need them.

EMERGENCY SERVICES: In the last data cycle collected prior to the pandemic, 62% of Adult Family Survey respondents said that emergency planning was discussed at their last planning meeting, and 42% of Child Family Survey respondents said emergency planning was discussed at their planning meeting.

Possible uses for this data

Use the statistics to educate and inform policymakers about the increase in need for these vital services due to the COVID-19 pandemic. The bulletin can be shared with advocates and families to mobilize advocacy efforts to develop crisis teams and increase access to clinic-based therapy, and tele-health services.

Advocate for the expansion of Home and Community-Based Services HCBS waivers to provide families with respite services at home. Educate families on respite resources available to them during the COVID-19 pandemic, such as clearinghouses, Parent Training and Information Centers and local community resources and supports.

Due to the unique needs of supporting individuals and families during a health related crisis, consider how your Council might support these needs in the next Five Year State Plan cycle. If there is already a focus on emergency preparedness, think about objectives or activities that could be added to continue to support the aftermath of COVID-19 or for other potential pandemics.

For additional innovative approaches to supporting individuals and families during the COVID-19 pandemic and links to multiple resources, click on [Bulletin](https://files.constantcontact.com/66a22ea8401/e42e0b78-a7d7-47cc-ba1d-43286ebb937c.pdf) to access and share the full report.

*National Core Indicators is a collaborative effort between the National Association of State Directors of Developmental Disabilities and the Human Services Research Institute.*

# **DD ACT EDUCATION**

Foundations of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)

DEVELOPMENTAL DISABILITIES Subtitle A—General Provisions 42 USC 15001. SEC. 101. FINDINGS, PURPOSES, AND POLICY.

Summary: This section of the DD Act includes critical information on the reasons behind its creation, an outline of what the DD Act is intended to accomplish and principles to be followed as the DD Act is implemented by its programs. Every council member and staff should be trained on the law's content and purpose and refer to it whenever considering official Council action.

The FINDINGS section covers the philosophy of the DD Act, an acknowledgement of discrimination of people with developmental disabilities, the importance of families, culturally competent services and supports and much more.

The PURPOSES section outlines how Councils will use advocacy, capacity building and systemic change activities that support coordinated care, or the deliberate sharing of all information connected to an individual's care. This process should center around the individual and their family and result in self-determination for all.

The POLICY section sets the expectation that programs will promote activities that support individual and community services that facilitate full access to the community for all individuals with developmental disabilities, specifically individuals from minority populations and individuals with significant developmental disabilities. The policies ensure that individuals and families have the same opportunities afforded to others to be included in all facets of community life including but not limited to child care, employment, healthcare, transportation, and recreational/social activities.

Practical application:

This section is the foundation of DD Council work. Share its content with new Council staff and members to help introduce them to the DD Act program's role with regard to promoting community inclusion. Experienced members and Council staff should refer to this section often when considering five year state plan activities the consideration of proposals for DD Council funding to confirm they comply with the DD Act's original intent.

This section can also be reviewed with members and staff to guide policy work. For example, does congregate living align with the purposes section of the DD Act? Probably not, because congregate living is not promoting individuals to live in the community which by definition includes people both with and without disabilities. In contrast, does work to help sheltered workshops transition to competitive and integrated employment? Could be, because the DD Act policy is to promote all access to community, including employment.

Questions for consideration:

Does your Council's mission and purpose align with the findings, purposes and policy section?

Can you draw connections between your Council’s five-year goals, objectives, expected outcomes and the foundations of the DD Act?

To read these sections in their entirety, click on the [DD Act link](https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf).

# **DD COUNCIL HIGHLIGHT – PENNSLYVANIA DD Council**

THE POWER OF COALITIONS

Written by Lisa Tessler, Executive Director of the Pennsylvania Developmental Disabilities Council

Bringing organizations and stakeholders together for a shared purpose can be powerful and effective. Pennsylvania’s Developmental Disabilities Council has pulled together coalitions for specific issues and has supported long-standing coalitions to address issues in the disability community.

Coalitions are effective in PA when they:

Foster positive relationships between stakeholder groups who have a shared purpose and mission

Elevate, coordinate and amplify messages on important advocacy issues

Provide opportunities for members to share information with one another

Share responsibilities and ask each member of the coalition to contribute their skills toward collective action

Last year, the Department of Human Services announced plans to close two State Centers. State Centers are public Intermediate Care Facilities for people with Intellectual Disabilities. Pennsylvania operates four State Centers housing approximately 700 people. The announcement ignited a firestorm of political activity. Some state employees and their unions, family groups, and community leaders lobbied the legislature to prevent the closures. A coalition of community advocacy organizations came together to form the Coalition for Inclusive Community as a voice to support the administration’s decision to move hundreds of individuals with developmental disabilities into the community. Planned activities included joint press conferences, legislative visits and social media campaigns. This coalition was effective. The governor vetoed the legislation and the process to close the institutions moves forward. The coalition went dormant in January; mission accomplished.

When the pandemic happened in March, the PADDC pulled these community advocates back together to address the emerging challenges. Again, this group was effective, but it was only one part of ongoing efforts by multiple groups and coalitions. We communicated quickly on pressing issues, worked in concert with other stakeholders, and some members engaged in targeted lobbying efforts. The result was the allocation of significant funding for the intellectual and developmental disability service system and improvements in policies and practices.

However, there were some challenges and lessons learned in the process, such as:

It is important to have agreement around the purpose – some members of the group that formed to support institutional closure were not engaged in the new work

Coalitions need structure for decision-making and may not be suited for situations that require quick action – such as an immediate health crisis

Bigger is not always better – reaching consensus on a course of action or tactic is more challenging with larger groups

Respecting individual member autonomy and handling disagreement can be challenging

Here are some suggestions for councils as they form and support coalitions:

Carefully consider who to invite – consider mission, skills, capacity, and efficacy

Cultivate and foster trust and respect within the group

Assure accessibility and equity for all member

Come to agreement around purpose and mission at the outset

Develop structure to outline roles, responsibilities and decision-making

Use a logic model or strategic planning process to guide the work of the group

In closing, my best advice is to invest time, resources and energy in your coalition work. Coalitions may appear to be simple. It is easy to underestimate the level of engagement and support required. An outsider may only see the letter or position paper that is the result or output. Behind the scenes, there are complex organizational activities and relationships at work to create that product. I recommend Councils develop the capacity to provide the administrative, strategic, technical and management support necessary to support effective coalitions.

A resource I found helpful and refer to often is:

[What Makes an Effective Coalition? Evidence-Based Indicators of Success](http://www.pointk.org/resources/files/What_Makes_an_Effective_Coalition_by_TCC_Group.pdf)

[By Jared Raynor, TCC Group March 2011](http://www.pointk.org/resources/files/What_Makes_an_Effective_Coalition_by_TCC_Group.pdf)

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