INTRODUCTION

This updated document provides technical assistance guidance on public input strategies, links to resources for more information and strategies being used by DD Councils to meet the public input requirements of the DD Act. The appendix section includes survey examples from DD Councils for advocates, families and other stakeholders.

What does the DD Act Say?

PUBLIC INPUT AND REVIEW -The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comment. Section 124(d)(1)

UNSERVED AND UNDERSERVED - an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly…(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;…Section 124 (c)

When developing the Five Year State Plan, DD Councils will want to ask for input from stakeholders in their State/Territory to identify needs and barriers. Stakeholders may include, people with developmental disabilities/IDD and family members (including representatives from culturally diverse groups), service providers, and other people concerned with services for people with developmental disabilities. Upon submitting the plan in the ACL Reporting System, DD Councils will also need to provide information on how the Council received and used public input in its plan.

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Commonly used strategies for collecting public input by DD Councils
Focus groups/town halls/community conversations to address barriers to services and supports; structured interviews (phone or in person); providing surveys in multiple formats and languages; webinars with targeted audiences (Providers, families, advocates, or other professionals) to obtain specific information; attending taskforces, workgroups, committees and other key meetings to share surveys and gather information and Utilizing electronic platforms to solicit public responses on DD Council priority areas.

TECHNICAL ASSISTANCE GUIDANCE/RECOMMENDATIONS

CULTURAL AND LINGUISTIC COMPETENCE: ENGAGING CULTURALLY DIVERSE GROUPS TO GATHER PUBLIC INPUT- WHAT COUNCILS SHOULD CONSIDER

Six Strategies and Approaches for Engaging Diverse Communities *(Georgetown University Center for Cultural Competence)*
1. Learn about communities.
2. Enter communities respectfully.
3. Elicit and consider the interests and needs of communities before declaring the goals of your organization, agency, or program.
4. Explore areas of mutual interests and benefits.
5. Foster relationships and partnerships that are built on mutual trust, reciprocity, and respect. 6. Commit to the long-haul.

Other guidance:
Provide materials in languages to meet your audience's needs. For more information on languages frequently spoken in your state or territory, visit the US Census website.

Check to see if your Council's Designated State or Territory Agency has language access procedures that can be adopted by the Council.

Consider partnering with DD Network partners who have bi-lingual staff or accessing professional translation services as needed.

Remember, not all people who use English as a second language are literate in their own native language. Ensure participants have more than just a written option to provide input.

To reach diverse communities, solicit the support of cultural brokers, community leaders and/or partners from your Council's targeted disparity work. Consider other groups not particularly associated with the disability network, such as, faith-based institutions, civil rights organizations, public health community outreach programs, and local groups that work specifically with diverse communities (I.e. Latinx, African American, Chinese American, and Jewish etc.)

Resource links for more information
Culturally and Linguistically Competent Strategies to Engage Diverse Communities
Ensure information is accessible both in language and reading level.
Readability Analyzer
American Translators Association

GATHERING INPUT WHEN IN-PERSON METHODS ARE PROHIBITED OR RESTRICTED – WHAT COUNCILS SHOULD CONSIDER

Due to social distancing restrictions, DD Councils are converting their public town halls, regional focus groups and in person interviews to alternative methods to collect vital public input.

Provide multiple formats to make the process accessible to a wide array of stakeholders. Electronic surveys, phone interviews, teleconferences and web-based platforms are among the common methods. However, due to many people experiencing the adverse effects of the digital divide, Councils should consider both low tech along with high tech methods to be fully inclusive of those without access to electronic or web-based platforms.

Hard copy/mail-in surveys: Utilize developmental disability service provider agencies, self-advocacy organizations, Council mailing lists etc. to access addresses for mail-in surveys and/or conduct surveys over the phone to gather information on barriers and needs. To support non-readers/visual learners, consider using icons and images to enhance accessibility. To vet surveys for accessibility, partner with Statewide or local self-advocacy groups to provide feedback on the materials. Materials should also include a contact person/information of someone who can support participants with other accommodation requests as needed upon request.

Electronic surveys: When developing surveys via on-line links, use 508 compliant standards to ensure content is accessible, for example, for those using screen readers for blindness/low vision. If using outside services for electronic surveys, such as Survey Monkey, check for accessibility standards as well. Electronic surveys can be linked and disseminated via email list serves, shared on DD Council and network partner's websites, social media pages and phone apps. (Be aware of restrictions related to personal information). *Remember, if you are converting an electronic survey to Word format, a simple*

copy and paste does not ensure accessibility. Double check to ensure reformatted surveys are fully accessible before disseminating.

Web-based platforms: To support access for devices for participation, explore partnering with assistive technology contacts, department of vocational rehabilitation or Independent Living Centers to provide or loan people with DD and family members the equipment needed to complete surveys and/or attend virtual public input meetings.

Training and support: The DD Council may need to provide training/provide access to resources on how to utilize the platforms and devices. This training and support is crucial for people with DD and family members to participate to their fullest potential. Provide directions for facilitators, caregivers, self-advocate leaders and others that may be supporting people with DD to collect the survey information.

Other questions to consider for web-based platforms: How many participants can take part in each session and will your platform accommodate the anticipated number? Can the meetings be recorded so Council staff can take notes on information gathered to develop a follow-up report for the full Council? Has your Council considered accessibility, staff capacity and pricing?

Examples of web-based platforms
Zoom video conferencing
GoTo Meeting
Microsoft Teams
Webex

Examples of electronic survey platforms
Survey Monkey (User friendly, Section 508 compliant survey system)
Qualtrics Survey Software (Expanded functionality and analysis options, works well for longer surveys and for building in logistics)

Resource links for more information (accessibility/readability)
WebAIM – Web accessibility in mind: Empowering organizations to make their web content accessible to people with disabilities.
508 Compliance and Colors Resource
Microsoft Disability Answer Desk
Checking accessibility in Word and Outlook

Note: ITACC does not recommend one web-bases platform over another. All links are provided for Council consideration.

STRATEGIES SUBMITTED BY DEVELOPMENTAL DISABILITY COUNCILS

ALABAMA – Using Multiple Methods
Prior to COVID-19, the Alabama DD Council attended a town hall meeting in early march and to gain vital input. Subsequent focus groups and meetings have been rescheduled. The Council has translated its surveys in other languages to be sent out via social media, web pages, Developmental Disabilities Network partners, through email, and phone interviews. Survey Monkey and Zoom meeting platforms are being purchased to solicit public responses. Additional information will be captured through Board Meetings when the full Council is able to meet in the future.

ALASKA – Targeted Weekly Webinars and Engaging the Unserved/Underserved
The Alaska Council is replacing local community forums throughout the state with focused outreach to regions and subgroups of stakeholders through weekly webinars. The webinar content is the same, with a break midway through to allow participants the chance to take a survey. The survey includes the opportunity to ascribe a level of need to areas of emphasis and to rank areas in a couple different ways. There is also an opportunity to write-in comments. The Council provides different survey links for each webinar to obtain feedback on methods of outreach. The demographic data from the surveys will inform future outreach efforts. A survey is also available on the Council's website (English and Spanish) for those who cannot attend a webinar. The link is promoted widely, including social media and through the Council's partners and committees, as well as through government delivery email lists.

To engage underrepresented groups and regions, the Council identifies contacts through survey responses and from past event registrations. The Council will make direct contact by phone to obtain public input from those who may not have the capacity to participate in other formats.

CONNECTICUT – Making use of Qualtrics and Advocacy Organizations
The Connecticut Council designed a survey using Qualtrics survey software. The Council works with a network of active advocacy organizations, including The Arc of Connecticut, the Down Syndrome Association of Connecticut, People First, SILC, PATH, KASA, and others to share the survey. The Qualtric survey is disseminated by asking participants to respond in the following ways, a) encourage their people to respond to the online survey as individuals; and b) respond to the survey offline as an organization, i.e. in a formal letter, representing their constituencies and adding any other comments they might have about gaps in services. In addition, the advocacy groups are asked for their input about gaps and barriers to services and supports.

MISSOURI – Gathering input on COVID – 19 and Engaging Self-Advocates
The Missouri Council is scheduled to conduct 11 listening sessions across the state in both rural and urban areas. One of the listening sessions will target Latinx families and individuals. A survey for families and individuals will be translated and distributed. A separate survey is developed for other stakeholders.

To engage people with DD, a new forum, "Coffee with Katheryne," is being used to gather information about gaps and barriers that self-advocates and families are currently facing. All information could be used to inform the new five year state plan, including those resulting from the COVID-19 pandemic (I.e. teachers figuring out how to provide accommodations for children who are now learning on a virtual

platform, the many children, self-advocates and families that do not have access to the internet, which isolates them further when sheltering at home, etc.).

NORTH CAROLINA – Webex Council Conversations

The North Carolina Council will transition in-person Council Conversations to Webex Council Conversations. Strategies for this transition are listed below. The meetings are organized regionally, with a conversational vs. webinar type atmosphere, questions are texted to call-in users, and questions are obtained in advance so the answers can occur during the meeting (Ideally, with the questioner's voice asking it).

Other methods:
Structured interviews (phone or in person);
- Follow-Up to Q&As, Listening Session(s), and Available for Call-In Survey Respondents (Five Year State Plan Survey)
- Providing surveys in multiple formats and languages;
  - English & Spanish by partnering with Ph.D. Psychologist and lead for NC on National Core Indicators for 5+ years. Results will be summarized and include NC Council member input.
  - COVID-19 Specific Open-Ended Survey

Webinars with targeted audiences (Providers, families, advocates, or other professionals) to obtain specific information;
  - Webinars on Telehealth and Life Planning due to COVID-19

Inclusion on meetings with taskforces, stakeholders, and committees to share surveys or gather information; and
  - Utilizing Council member contacts: Chair of the Five Year State Plan Ad Hoc Committee for the Council is 2nd in Command at NC Medicaid. Ad Hoc Committee also includes Chief of DD and Traumatic Brain Injury (TBI_ Services at NC's State DD Authority.
  - Request State of States and FISP/RISP information and additional information on the Registry of Unmet Needs
  - Use platform such as Survey Monkey to solicit public responses on DD Council priority areas.

APPENDIX

North Carolina Toolkit

To support North Carolina Council on Developmental Disabilities (NCCDD) Council members to "get the word out" about public input and be leaders in their regions, a Media Kit was developed and disseminated through its Media Relations Program.

NCCDD Five-Year Plan Virtual Road Tour Toolkit

NCCDD On-line Surveys (This is a comprehensive web page that explains the Council's public input process and links people to multiple ways to participate)

Tennessee – On-line Survey

The TN Council disseminates this survey widely to obtain public input from stakeholders. The survey is also translated and made available in alternative formats.

New York – On-line Survey

The NY Council is using the survey, linked below and in Word format, to collect public input for their 2022-2026 State Plan development. The NY Council also administers focus groups across the state (likely online/remote due to COVID-19) to gather further information from stakeholders not reflected as heavily in the survey responses (I.e. Self-advocates, youth, un/underserved ethnic/racial communities, rural communities, etc.).

 NY On-line Survey link (Survey Monkey Platform)

Word format of NY Survey

Key:
Black text is survey text
Blue text is direction/heading text built into the survey
Purple text represents where survey buttons would be
Red text was added by DDPC staff to explain the survey logic for this TA document (it is not included in the actual survey itself)

(Note: this is the English version of the NY survey. The NY council also disseminates the survey in three other languages (Spanish, Traditional Chinese, and Simplified Chinese). The translated surveys use the same formatting, but have some simplified language in place of technical terms and/or includes brief definitions to better reflect the communities and improve translation accuracy.))

2022-2026 STATE PLAN INPUT SURVEY

The New York State Developmental Disabilities Planning Council (NYS DDPC) is creating our 2022-2026 State Plan which outlines the direction of our work for the next five years. While the NYS DDPC does not provide direct services, we do pilot new programs across the state to try to positively impact the lives of people with intellectual and developmental disabilities and people that support them.

As part of this process we are seeking the valuable input of those most impacted by our work, including; individuals with intellectual and developmental disabilities, family members, caregivers, staff, advocates, and others.

We greatly appreciate your input in the following survey which asks what areas we should work in and what type of projects we should focus on in the coming years.

The survey should take about 5-10 minutes. Thank you for your participation.

(DDPC staff work with council members and a state plan workgroup to draft general areas for our state plan goals, prior to developing and disseminating a public input survey. The survey is then built with the goal areas in mind and they direct how it is organized. For ex. In the 2022-2026 State Plan, the NY council has pre-approved the preliminary goal framework of Goal 1: Individuals with DD, Goal 2: Family Members/Caregivers, Goal 3: Systems (disability and non-disability). Therefore the survey asks and organizes questions based on those targeted goal areas.)

The first set of questions asks you about areas you think the DDPC should focus on over the next five years. There are separate questions related to projects for (1) people with intellectual and developmental disabilities, (2) family members/caregivers, and (3) services, more generally.

1. What areas do you think need the most attention, to **support people with intellectual and developmental disabilities** to thrive in the community? (Please select your top three choices)
- Employment
- Housing
- Transportation
- Self-advocacy
- Health and safety
- Education
- Services, supports, and transitions
- Other (please specify)

2. What areas do you think need the most attention, to **support family members and caregivers** of people with intellectual and developmental disabilities? (Please select your top three choices)

- Employment
- Housing
- Family/Caregiver Advocacy
- Health and Safety
- Education
- Services, Supports, and Transitions
- Other (please specify)

3. What areas do you think need the most attention to **enhance and strengthen supports and services** provided to people with intellectual and developmental disabilities? (Please select your top five choices)

- Educating businesses and employers about hiring and supporting people with disabilities
- Educating transportation professionals on disability
- Increasing the use of trauma informed care
- Reducing gaps and inequality in health services provided to people with disabilities, especially in diverse racial and ethnic communities
- Improving access to Early Intervention services
- Exploring training, retention programs, creative hiring, and/or other options for support staff, professionals, and service providers
- Reducing language barriers to accessing information and services
- Improving supports to better reflect and account for different cultures

- Improving access to services and supports for individuals with complex health and/or mental health care needs
- Educating the public about intellectual and developmental disabilities
- Building collaborations and strengthening coordination between state, local, and community organizations
- Researching cost benefits of services, supports, and collecting data
- Other (please specify)

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(Based on selections chosen in the above 3 questions, survey participants are then directed to a subset of questions that allow them to provide more detailed selections on areas of need for the topics they selected as most important for each target group. This can be done using the survey software - logic, branching, etc. For example: If they selected housing, employment, and education as their top three choices in the above, they will only be asked to answer follow up questions on those three topics. They will not have to answer questions on other topics that they did not prioritize. *The benefit of this is a shorter survey, which increases response rates, but also still allows for the collection of more specific and detailed information/input.*)

(Follow up questions for question 1: people with DD)
Q#. **Employment:** You selected employment as a priority area, which of the below do you think is most important for the DDPC to focus on related to employment for **people with intellectual and developmental disabilities**: (pick up to two)

- Finding and getting jobs
- Managing benefits and employment
- Alternatives to workshops
- Creating Internship opportunities
- Learning skills needed to get and keep a job (resume writing, job interviews, interacting with coworkers, etc.)
- Other (please specify)

Q#. **Housing:** You selected Housing as a priority area, which of the below do you think is most important for the DDPC to focus on related to housing for **people with intellectual and developmental disabilities**: (pick up to two)

- Understanding different housing options
- Understanding community supports
- Managing benefits in housing
- Learning skills to live independently (cooking, cleaning, home safety, etc.) Using technology to support living independently
- Other (please specify)

Q#: **Transportation/Health/Safety/Education:** You selected Transportation, Health, Safety, and/or Education as a priority area, which of the below do you think is most important for the DDPC to focus on related to these topics for **people with intellectual and developmental disabilities**: (pick up to three)

- Learning how to navigate transportation options
- Trainings on managing emergency situations and crises

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- Abuse prevention education and activities
- Creating inclusive health and wellness programs
- Learning more life skills during K-12 schooling
- Participating more actively in education planning/IEP meetings
- Increasing access to college, internships, and higher education opportunities
- Other (please specify)

Q#: **Self-Advocacy:** You selected self-advocacy as a priority area, which of the below do you think is most important for the DDPC to focus on related to self-advocacy **for people with intellectual and developmental disabilities**: (pick up to two)

- Building relationships between existing advocacy groups
- Creating new advocacy groups
- Supporting advocacy groups to do outreach to certain areas of the state or specific populations (examples: rural areas, LGBTQ+, Self-advocates who identify as African- American, Latino (a), or Asian, etc.)
- Helping self-advocates learn how to better ask for what they want and need from their family, friends, and/or staff
- Training self-advocates on informing policymakers
- Other (please specify)

Q#: **Services, Supports, and Transitions:** You selected Services, Supports, and Transitions as a priority area, which of the below do you think is most important for the DDPC to focus on related to these topics f**or people with intellectual and developmental disabilities:** (pick up to two)
- Navigating self-direction
- Training on 'life plans 'and managed care
- Education on moving from one system (ex. school) to another (ex. adult services like OPWDD)
- Accessing non-disability services
- Connecting with community supports and programs
- Other (please specify)

(Next Button)
(Follow up questions for question 2: family members/caregivers of people with DD)

Q#: **Employment/Housing**: You selected employment and/or housing as a priority area, which of the below do you think is most important for the DDPC to focus on related to these topics for **family members/caregivers**: (pick up to three)

- Trainings on understanding benefits and employment
- Alternatives to workshops and other employment options
- Navigating (non-disability) employment services
- Understanding different housing options
- Navigating (non-disability) housing services
- Education on working with provider agencies to support employment opportunities and/or housing opportunities
- Understanding community supports
- Other (please specify)

Q#. **Health/Safety/Education:** You selected Health, Safety, and/or Education as a priority area, which of the below do you think is most important for the DDPC to focus on related to these topics **for family members/caregivers**: (pick up to two)

- Trainings on managing emergency situations and crises
- Abuse Prevention education and activities
- Creating Wellness and support programs for parents/caregivers
- Education and support for aging caregivers
- Navigating special education services
- Other (please specify)

Q#. **Family/Caregiver Advocacy:** You selected advocacy as a priority area, which of the below do you think is most important for the DDPC to focus on related to advocacy **for family members/caregivers**: (pick up to two)

- Building relationships between existing family/caregiver advocacy groups
- Creating new family/caregiver advocacy groups and/or peer support networks
- Increasing outreach of groups to certain areas of the state or specific populations (Families with diverse cultural or religious backgrounds, people who speak languages other than English, fathers, siblings, rural families/caregivers, etc.)
- Training on informing policymakers and/or educating communities about disabilities
- Supporting family members in their own self-advocacy
- Other (please specify)

Q#. **Services, Supports, and Transitions**: You selected Services, Supports, and Transitions as a priority area, which of the below do you think is most important for the DDPC to focus on related to these topics f**or family members/caregivers**: (pick up to two)
- Navigating self-direction services and options
- Training on "Life Plans ''and the transition to managed care
- Education on moving from one system (ex. school) to another (ex. OPWDD services for adults) across the lifespan (i.e. child to adult to senior)
- Improving access to supports for families from diverse cultural backgrounds
- Other (please specify)

(Next Button)
(The remaining questions are asked to all survey participants.)

Q#: Understanding all cultures, respecting diversity, and strengthening inclusion of all communities with intellectual and developmental disabilities will be key priorities for the next 5 years of DDPC's work. What areas related to serving diverse communities do you think need the most attention? (open-ended question)

Q#. Please share any other areas that were not listed that you think we should do work in during the next five years to support people with intellectual and developmental disabilities, family/caregivers, and/or to strengthen services and supports for all communities? (open-ended question)

(Next Button)

Q#. I am a:

- ■ Person with a disability
- ■ Family member/caregiver of a person with a disability
- ■ Support staff, provider, non-profit provider agency representative School personnel
- ■ State Agency representative (OPWDD, OCFS, SED, etc.)
- ■ Other (please specify)

Q#. Which best describes your Race and/or Ethnicity? (Check all that apply)

- ■ White/Caucasian
- ■ Black/African American
- ■ Hispanic, Latino(a),or Latinx
- ■ Asian (Chinese, Filipino, Japanese, Korean, Vietnamese, or other)
- ■ Middle Eastern
- ■ Native American, First Nation, or Alaskan Native
- ■ Native Hawaiian or other Pacific Islander
- ■ Race Unknown
- ■ Prefer not to answer
- ■ Other (please specify)

Q#. What is your gender identity?
- ■ I identify as a woman
- ■ I identify as a man
- ■ I identify as non-binary (for example: transgender, gender neutral, etc.)
- ■ I am unsure of my gender identity
- ■ I prefer not to answer
- ■ I prefer to identify myself as: (please specify)

Q#. Which of the following best describes the area where you live?
- ■ Rural - I live far from cities
- ■ Urban- I live in a city
- ■ Suburban - I live close to a city

(Next Button)
Thank you for telling us about yourself. The last question gives you an opportunity to share anything else you think would be helpful to us.

Q#. Please share any other information that you think the New York State Developmental Disabilities Planning Council needs to know for the creation of our next five-year state plan. (Examples: other areas of need, noteworthy and successful programs or projects already happening around NY State, etc.)
(open-ended question)

(End Button)
(Closing with hyperlinks)

Thank you for taking the time to fill out our survey. Your input is extremely important and valuable to us.

Sign up for our Listserv and follow us on social media: Facebook and Twitter to stay informed about the development of our 2022-2026 State Plan and to learn more about opportunities to participate in DDPC projects.

We hope you find the Public Input Strategies Resource helpful as you engage in the process of gathering information for the five year state plan. To that end, we encourage your feedback and input on information and strategies that would be useful to include. To submit content for consideration or if you need this resource in alternative format, please contact the NACDD office at 202-506-5813. For more information on State Plan Development, please contact NACDD/ITACC staff.