

**NCCDD**

North Carolina Council on  
Developmental Disabilities



2024 - 2025 Impact Report

# Building and Advocating

*for North Carolina's I/DD Community*





## A Year in Reflection

A conversation and reflection featuring  
Jon D'Angelo, Chair, NCCDD  
Marjorie Serralles-Russell, Vice Chair, NCCDD  
Talley Wells, Executive Director



Scan the  
QR code to  
watch the  
full video

## About the Council

The North Carolina Council on Developmental Disabilities (NCCDD), a 40-member body appointed by the Governor, is made up of:

- People with intellectual and/or other developmental disabilities (I/DD)
- Parents/Family members/Guardians
- Representatives of State agencies
- State legislators
- Representatives from Disability Rights NC and the Carolina Institute for Developmental Disabilities
- Provider and Local Management Entity/Managed Care Organization (LME/MCO) representatives

The Council represents people across North Carolina and is responsible for carrying out the provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). Staff make sure the Council is a member-driven, effective, efficient, and accountable organization. Sixty percent of the Council's members are people with intellectual or developmental disabilities (I/DD) or their family members. The rest are representatives from state agencies, nonprofits, and professional organizations.

Learn more  
about the  
Council:



NCCDD  
Council  
Members



NCCDD  
Staff



DD Network  
Partners

# Growing Voices Through Policy Education

NCCDD works to share information that supports people with I/DD, their families, and leaders to understand important issues. NCCDD supports policies that help people with I/DD be included in their communities and connect with the people who support them.

Each year, NCCDD determines public policy priorities for its policy education efforts. For 2025, the priorities were:



Eliminate the Waiting List for I/DD Medicaid waivers



Expand housing and transportation options



Ensure success of new I/DD services



Increase Direct Support Professional (DSP) rates



Increase Competitive Integrated Employment (CIE)

## Connecting Capitol & Community: Policy Education

Every second Thursday, NCCDD holds a monthly Policy Education Meeting via Zoom. Referred to as Capitol and Community, the meetings provide an opportunity for people with I/DD, family members, and leaders to engage in a 90-minute discussion on key policy issues impacting the I/DD community.

This year, 10 meetings were held with 571 total attendees. The largest attendance happened in June during the height of the federal budget resolution bill, called the One Big Beautiful Bill Act, that was outlining major changes to Medicaid. The bill was signed into law on July 4, 2025.



Additionally, NCCDD also provides a monthly Public Policy Update article on its Public Policy Blog and its monthly newsletter, Highlights & Hot Topics. It includes recent updates, bills to watch, and other announcements.

NCCDD worked to educate community members on how to get 1915(i) services for people with I/DD. 1915(i) is a new array of services enabling people with I/DD and other disabilities services similar to the Innovations Waiver. In 2025:



**11,251**  
people received 1915(i) services across the state.



**18,950**  
people were on the Innovations Waiver waiting list.\*



There are only **14,736** total waiver slots funded.



**1,702**  
people were approved for 1915(i) services.

\*7,492 of those individuals receiving some other services as reported by the North Carolina Department of Health and Human Services





## Wilmington Listening Session Brings Together Leaders and Advocates to Strengthen Disability Inclusion

On April 15, 2025, NCCDD held a community listening session in Wilmington, NC. The event featured guest presenters and gave time for people with I/DD, their families, advocates, and community leaders to share their ideas and concerns about making North Carolina more inclusive for everyone. People talked about what is working and what still needs to improve in education, independent living, and employment.



Read about  
the session

## Collaboration with Duke University Advances Comprehensive I/DD Data and Policy Insights

There are 18,950 people on the waiting list for the Innovations Waiver in North Carolina. Some have been waiting over 10 years. A big problem is the lack of clear, complete, and consistent data. Without good data, it's hard to make strong policies or advocate for better services.

To help fix this, NCCDD worked with Duke University to research and publish a report about the needs and services for people with I/DD in the state.

One key finding was that between 2013 and 2024, the waiting list for the Innovations Waiver nearly doubled—while the number of waiver slots only grew by 16%. For example, in 2014, there were 12,488 waiver slots and 9,278 people waiting. By 2024, there were 14,488 slots and 17,902 people waiting. As of September 2025, the waitlist has grown to 18,950 people.

To better understand the situation, the Duke team talked with over 45 experts and collected data from across the state and country.

The report found that many people with I/DD don't get formal services, so they aren't counted in public data. Also, different agencies use different terms and systems, which makes it hard to get a full picture.



Read the  
report

## Media Coverage on Policy Education

*NC does not provide enough support to people with disabilities, families tell legislators "NC Newsline"*



*OP-ED: Medicaid Innovations waiver can be difference between thriving and dying "The Carolina Journal"*





# Engaging and Empowering Advocates



Self-advocacy is people with disabilities speaking up for their rights, needs, and choices. This leads to more independence, a better quality of life, and a stronger voice in their communities. NCCDD provides several opportunities for people with I/DD to raise their voices and create change.

## Self-Advocate Discussion Series

The Self-Advocate Discussion Series is a monthly webinar hosted by NCCDD's Policy Education Coordinator, Chris Hendricks. The series aims to engage self-advocates by providing ways to build their advocacy skills and make connections with others who have similar experiences. Guest presenters cover topics such as transportation challenges, how to safely interact with police, and the

Register for  
a session



importance of planning for the future. During each meeting, time is set aside for open discussion and to share stories. Meetings are recorded and posted on NCCDD's YouTube page.



**12** sessions

**554** participants

**"Relationships are the foundation of advocacy. Advocacy can start anywhere at any time."** - Emmanuel Jenkins (guest speaker and Community Relations Officer of the Delaware Developmental Disabilities Council from the Organized Advocacy session held in March 2025)

## The Council Presents Webinar Series

In June 2025, NCCDD launched a monthly webinar series, The Council Presents, for self-advocates, families, providers, policymakers, and community members. Each session features timely topics, expert insights, Council updates, and practical strategies to support people with I/DD.

This year's webinars covered the Work Together NC Employment Toolkit, accessing assistive technology services, emergency preparation and planning, and an ADA National Network presentation in Spanish introducing a new Americans with Disabilities Act (ADA) Video Series for Spanish-speaking communities. All sessions are presented by experts on the topic being discussed.



**4** sessions **~250** attendees

## Advocacy & Leadership Awards

Each November, NCCDD honors individuals whose work has advanced opportunities and access for people with I/DD with its annual Advocacy and Leadership Awards. The 2024 award recipients were:

- **Kerri Eaker Mountain Mover Award:** Senator Jim Burgin and Department of Health and Human Services Secretary Kody Kinsley
- **North Carolina Leadership Achievement Award:** Cheryl Powell
- **Jack B. Hefner Memorial Award:** Jessica Aguilar
- **Helen C. “Holly” Riddle Distinguished Service Award:** Pam Shipman



Watch the  
awards video



Learn about  
2024 recipients



Cheryl Powell



Jessica Aguilar



DHHS Secretary  
Kody Kinsley (fmr.)



Pam Shipman



Senator Jim Burgin

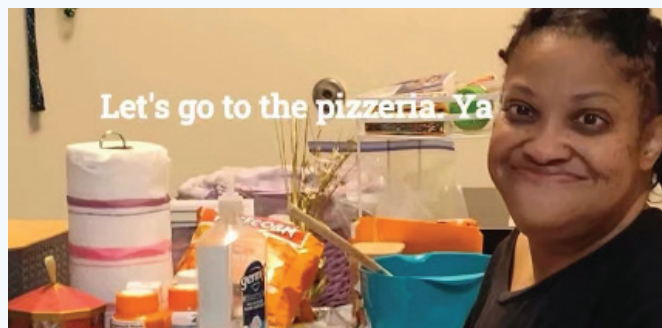
## Storytelling Makes a Difference



Tiffany Williams & her daughter, June - Boone, NC

NCCDD continued its **My Story Matters** campaign. The campaign encourages people with I/DD to submit their stories to give a first-person account of how cuts and changes to critical services would impact them. These stories are used to raise awareness among leaders, decision-makers, and the public of what's at stake when policy doesn't match what people need to live independently.

Also, NCCDD provided stories to the National Association of Councils on Developmental Disabilities (NACDD) for its Medicaid Matters campaign. The stories were added on NACDD's website, and several were highlighted during the Medicaid Vigil held at the National Mall in Washington, D.C. in July 2025.



Yvonne Bell - Charlotte, NC



Read the  
stories





## Unmet Film Engages Community Conversations

"Unmet: North Carolina's Two Developmental Disability Crises" is a film commissioned by NCCDD, sharing real stories of North Carolinians with I/DD whose needs are unmet. After several showings in theatres across North Carolina during 2023 and 2024, the film was released in July 2025 for the public to host watch parties with others within their community.

The watch parties intend to encourage people to watch the film together and engage in meaningful discussions on what happens when services and supports are missing or are not enough, and how this crisis might be solved.



Learn more about the Unmet film



Learn about hosting an Unmet film showing

"I feel that I'm fairly well versed in my advocacy for my family member, but I think the film helped me see that we're not a unicorn," said one viewer. "I often read the numbers, but seeing the faces and hearing the stories was impactful, not just for me, but for my husband."



**45** requests received



**19** viewing parties hosted



**644** participants



**102** identified as a person with I/DD or a family member

# Creating Positive Change Through Our Initiatives



## Training First Responders to Protect and Connect with the Autism and I/DD Community

NCCDD funded a pilot safety training in Buncombe County to improve interactions between first responders and people with I/DD and autism.

Led by Dustin Chandler of Interaction Advisory Group, 34 officers from 12 agencies learned communication and de-escalation skills through hands-on sessions with self-advocates. This initial year's work laid the groundwork for hundreds of officers to be trained in 2026.



The training helped officers understand real experiences, build empathy, and identify safer alternatives during crises. With plans to expand statewide and online, the initiative aims to equip all first responders with tools to protect and connect with individuals with I/DD—making communities across North Carolina safer and more inclusive.

Learn more about this initiative



## Supported Living Guidebook Promotes Choice



NCCDD contracted with FIRSTwnc to complete the Supported Living: How-to Guidebook in FFY 2024. In FFY 2025, the guidebook was promoted widely to reach North Carolina's I/DD community to provide step-by-step information for people with I/DD, family members, and provider agencies on how to make Supported Living work successfully. Designed to be easy to understand, it contains illustrations and information on topics such as learning how to self-direct services and identifying happiness triggers.



Read the Guidebook

## Ability Leadership Project of North Carolina Prepares Advocates to Become Leaders

The Advocacy Leadership Program of North Carolina (ALP-NC) was created to address key gaps in leadership training for the I/DD community. ALP-NC is unique and groundbreaking because it ensures that people with I/DD are facilitators and coordinators in each cohort. The initiative brings together people with I/DD, family members, professionals, and other stakeholders to develop and use advocacy skills to speak for themselves and to build relationships with key decision makers and lawmakers on a local, state, and federal level.



Learn more about ALP-NC





**112** applicants  
for cohorts 1 and 2

**12** leaders graduated  
from cohort 1

**51** leader candidates accepted  
for cohorts 1 and 2 (6 on waitlist)

### ALP-NC Graduate Takes Action

In September 2025, Gov. Josh Stein contacted Chelsea Grey before holding a press conference about the negative impact of impending Medicaid cuts. She did not hesitate to drive across the state to join him for this important press conference so she could share how the cuts would affect her daughter, who has daily seizures and depends on Medicaid for treatment. She shared, “Every day is already uncertain. We are barely staying afloat with the funds that Medicaid currently has.” Chelsea is a 2024 graduate of ALP-NC and will be certified as a facilitator after her internship during the fall of 2025.



Read about  
the press  
conference

## Strengthening Inclusive Education within North Carolina’s HBCU Community

In April 2025, Winston-Salem State University (WSSU), through NCCDD’s HBCU IPSE Program initiative, began developing PILLAR, an inclusive postsecondary education (IPSE) program. As one of North Carolina’s 11 historically Black colleges and universities (HBCU), WSSU aims for PILLAR to dismantle systemic barriers and serve as a model for inclusion across HBCUs. The program expands culturally competent services and supports that promote independence, integration, and inclusion for students with intellectual disabilities.

By fostering universal design and a more inclusive learning environment, WSSU seeks to enhance the college experience and create greater social connections for all students.



Learn more  
about this  
HBCU IPSE  
program

## NCCDD’s Current Initiatives

Through its Five-Year State Plan, NCCDD supports initiatives that help people with I/DD live better lives. These projects focus on building advocacy skills, supporting community living, and helping people become more financially independent. Currently, NCCDD funds several projects across the state working to advance services, supports, and systems for people with I/DD.



Learn more  
about the  
initiatives



**Goal 1:**  
Financial Asset  
Development



**Goal 2:**  
Community  
Living



**Goal 3:**  
Advocacy  
Development



**Cross  
Cutting**

# Planning for Future Initiatives

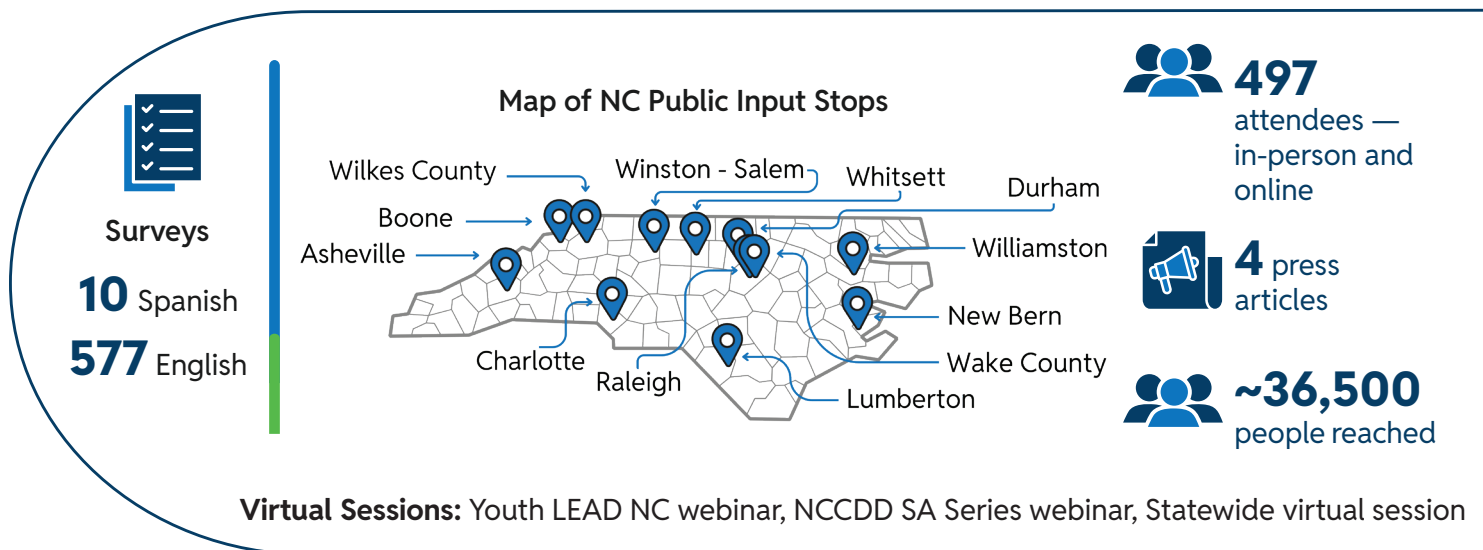


**Listen. Gather. Act.**

During 2025, NCCDD began planning for its next Five-Year State Plan for 2027-2031. This strategic plan, required by the federal DD Act, outlines goals, activities, and initiatives the Council will fund to ensure self-determination, independence, productivity, integration, and inclusion for North Carolinians with I/DD and their families.

The most important part of this process is to gather public input. A comprehensive survey, offered in English and Spanish, was launched in April. Public Input Sessions were held from July through September. Sessions were held in-person across North Carolina, along with two virtual sessions. These opportunities allowed self-advocates, families, and stakeholders to share what matters most to them.

The Council will now review the community feedback from the surveys and public input sessions to determine what its next Five-Year State Plan will include.



## NCCDD's Response During Hurricane Helene Aftermath

After the devastating impact of Hurricane Helene on Western North Carolina, NCCDD held daily virtual meetings for the first two weeks after the storm, focusing on the needs of the disability community impacted by the hurricane. 423 total attendees participated in the meetings, which included individuals with disabilities, family members, North Carolina Emergency Management, emergency responders, Federal Emergency Management Agency (FEMA), and NC Department of Health and Human Services (NC DHHS). NCCDD continued to participate and support daily meetings that were hosted by NC Emergency Management and NC DHHS.

The Council shared information alerts via email, social media, newsletter, and website. The Council's advocacy, along with the advocacy of many others, helped ensure all people with I/DD receiving services were contacted to respond to their needs.



[View website](#)

Since then, NCCDD then created a small project to collect stories from individuals with I/DD and families impacted by Hurricane Helene. These stories will be used to develop a report on ways to better prepare for future natural disasters.

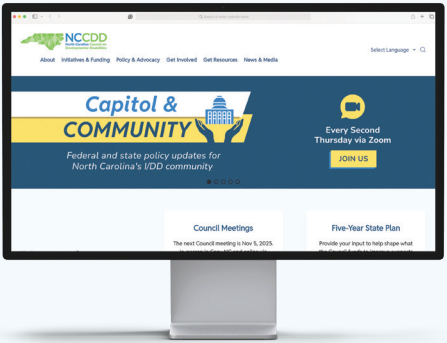


# Communications and Outreach

NCCDD shares news and updates with people in North Carolina’s I/DD community through its website, emails, social media, and news stories. This includes information about NCCDD projects, important I/DD news from other groups, and special campaigns like My Story Matters or public input sessions.

## Website

In August, NCCDD launched a new and improved website. The updated site makes it easier for visitors to find resources, events, and Council news. It also works better on phones and tablets and meets accessibility standards. All content was reviewed to be clear and easy to understand.



## Email Outreach



## Social Media

NCCDD is active on social media through its Facebook and Instagram pages, along with a YouTube channel. All social media channels are active, with nearly 5,000 followers combined on all channels.

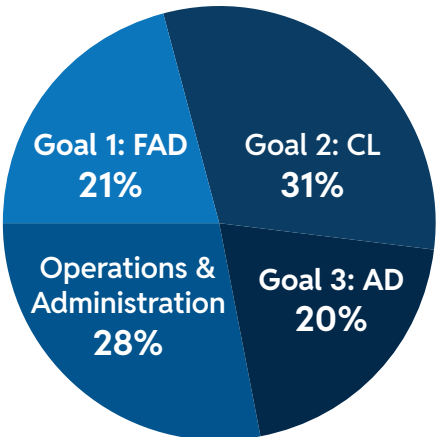


## Media Coverage



# Budget for FFY Oct. 1, 2024 - Sept. 30, 2025

| Budget                      | Amount          | %    |
|-----------------------------|-----------------|------|
| Goal 1: FAD                 | \$ 446,728.84   | 21%  |
| Goal 2: CL                  | \$ 679,465.25   | 31%  |
| Goal 3: AD                  | \$ 441,728.61   | 20%  |
| Operations & Administration | \$ 599,767.30   | 28%  |
| Total Budget                | \$ 2,167,690.00 | 100% |





Scan the QR  
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Report online.

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Funding Statement: This project is supported by grant number 2401NCSCDD (\$2,162,660.00), which is 100% federal funding, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.



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