



Aria Whaley
North Carolina

REPRESENTATIVE
**TERRY
BROWN**
CONGRESSMAN

Rep. Terry Brown

**UNMET: NORTH CAROLINA'S
DISABILITY CRISIS**



People with intellectual or other developmental disabilities, when receiving adequate supports and services, can be productive, engaged citizens in their communities, and we can contribute to our society.”

- Bryan Dooley, NCCDD Chairperson



The North Carolina Council on Developmental Disabilities (NCCDD) is a 40 member Governor-appointed Council. Sixty percent of those members are required to be people with intellectual or other developmental disabilities (I/DD) or their family members. Other members include state legislators, top state agency officials, representatives of Local Management Entities-Managed Care Organizations (LME-MCO), and service providers.

The Council meets quarterly to oversee the provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and to assure the Council continues to be member-driven, effective and efficient. NCCDD works on behalf of almost 200,000 North Carolinians with I/DD by creating more inclusive and accessible communities.

The Council works collaboratively across the state to assure that people with I/DD and their families have the opportunity to help design and maintain the programs and systems that impact their community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity and inclusion. The Council’s five-year planning process aims to identify the community’s challenges and opportunities while funding innovative projects and initiatives that promote the DD Act.



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A Year of Advocacy

A Message from NCCDD Council Chair & the Executive Director

The North Carolina Council on Developmental Disabilities (NCCDD) made FY 2023 a year of advocacy!

This year, the Council focused on the waiting list and the Direct Support Professional (DSP) workforce shortage. We made significant progress with the state increasing funding for DSP rates and launching 1915(i) Medicaid, which will provide new community living supports and employment services. At the same time, there are still thousands of people in our community who are without services due to the waiting list and the workforce shortage.

Our initiatives also made substantial strides. NCCDD had the opportunity to highlight much of this work in presentations at the National Association of Councils on Developmental Disabilities (NACDD) Conference in Orlando, Florida in July.



Council members and staff attended the NACDD Conference in Orlando.

The initiatives furthered the three goals of the Council's Five-Year State Plan: Financial Asset Development, Community Living, and Advocacy. NCCDD's policy education work was led by Council Chair Bryan Dooley. This included policy meetings with Governor Roy Cooper, NC Department of Health and Human Services (DHHS) Secretary Kody Kinsley, other DHHS leaders, and legislators. The Council's policy education was driven by its [five policy priorities](#).

NCCDD debuted a powerful film, "Unmet: North Carolina's Disability Crisis." The film brought viewers into the homes of individuals with I/DD and their families experiencing crises due to the workforce shortage and waiting list. NCCDD partnered with providers to do a DSP rate study that was necessary to determine the financial amount to increase wages.

In Community Living, NCCDD's "Making Alternatives to Guardianship a Reality in North Carolina" initiative successfully concluded its extraordinary work with a new law passing the General Assembly and with powerful education tools. NCCDD's "Justice: Release, Reentry, and Reintegration" initiative also concluded its successful work supporting people with I/DD to return to the community from prison. DHHS will continue this initiative for at least two more years. The "Supported Living: A How-to Guidebook" initiative introduced a practical guidebook on how to make the Supported Living service successful.

In Financial Asset Development, NCCDD worked with i2i Center for Integrative Health to prepare for a conference on how advocates can come together to increase competitive integrated employment. NCCDD continued its work to train leaders on benefits counseling, which is a critical component of employment for the I/DD community. The Council also supported a white paper on how individuals with I/DD and family members can work on Tailored Care Management teams as Care Extenders.

In Advocacy, NCCDD continued to support a pioneering Peer Mentor initiative that has gained national and state interest for individuals with I/DD to be employed as peer mentors. NCCDD's "Self-Advocate Discussion Series" continued its important work bringing together self-advocates to discuss critical topics from personal relationships to talking with legislators. NCCDD grew its Ability Leadership Project (ALP) initiative which trains self-advocates and family members to be leaders and includes self-advocate teachers.

To continue our work to reach wider communities, we welcomed Irlanda Ruiz, who joined as the Council's Hispanic Disability Advocate to build connections and provide public health education across the state.

NCCDD made a difference this year. But, we have much more work to do!



Bryan Dooley, Chairperson (left); Talley Wells, Executive Director (right)



Awards Recognize Influential Advocates and Leaders

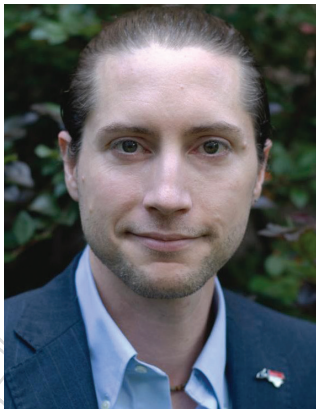
Each year, NCCDD honors the significant contributions made by advocates who are actively working to change attitudes and support greater choices for a more inclusive North Carolina. The Council established its [Advocacy and Leadership Awards](#) to recognize leaders in the I/DD community who help build a better North Carolina for all people with I/DD. The following are the award recipients:



Kerri Eaker

Jack B. Hefner Memorial Award: The Jack B. Hefner Memorial Award honors family members or volunteers who advocate for a more inclusive, understanding, and supportive local and state community for people with I/DD.

This year, the award was presented to **Kerri Eaker** of Asheville. Recently retired, Eaker served as the Family Support and Outreach Coordinator for Mission Health System. Among her many impactful roles, she was appointed chair of the North Carolina Council on Developmental Disabilities in 2012, a founding member of North Carolina Families United, and co-chair of the Cleveland County Children’s Collaborative. She is the mother of a son with disabilities and has traveled the state sharing her experience, knowledge, and ideas on disability advocacy.



Matt Herr

Helen C. “Holly” Riddle Distinguished Service Award: The Helen C. “Holly” Riddle Distinguished Service Award recognizes professionals who have made lasting contributions towards improving opportunities, breaking down barriers and promoting increased quality of life for people with I/DD in North Carolina.

This year, the award was given to **Matt Herr** of Raleigh, Assistant Division Director for System Performance for the North Carolina Department of Health and Human Services. A graduate of UNC Law School, Herr previously served as the policy attorney for Disability Rights NC. Herr designed, built, and launched the initial [acessthevote.org](https://www.accessthevote.org), which provides important resources for voters with disabilities. He also worked on the Rethinking Guardianship taskforce to reform the state’s guardianship law and assisted with the NC Empowerment Network — a group of people with disabilities who work together to advocate, empower, and affect change.



R.V. Kuser

NC Leadership Achievement Award: The North Carolina Leadership Achievement Award recognizes an outstanding North Carolina self-advocate whose work has improved the quality of life for people with I/DD.

This year, the award was given to **R.V. Kuser** of Winston-Salem. Having worked as a developmental specialist and autism coordinator, Kuser has traveled the state speaking about autism and schizophrenia. He is the author of two books: *Challenged But Not Defeated*, *Strategies for Coping with Autism and Schizophrenia*, and *Weight A Minute! Lessons a Family Learns Thru the Gift of Autism*. He is a board member on the Winston-Salem Mayor’s Council for Persons with Disabilities and Solutions for Independence.

**Meet the
2022 Advocacy
and Leadership
Awards recipients.**



Statewide Initiatives Make a Difference



Listen. Gather. Act.

This was the second year of NCCDD's [2022-2026 Five-Year State Plan](#).

The State Plan aims to advance the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) through its requirements of self-determination, independence,

productivity, integration, and inclusion for individuals with I/DD and their families. The plan's goals, to be achieved by 2026, include:

- 1) Increase financial security through asset development;
- 2) Increase community living; and,
- 3) Increase advocacy.



[Read about the current initiatives funded by NCCDD.](#)



PROJECT SPOTLIGHT

Project Succeeds in Helping Prisoners with Disabilities Find Sustainable, Meaningful Employment Upon Release

In 2020, the [Justice: Release, Reentry, and Reintegration](#) initiative launched with a focused mission to improve outcomes for individuals with I/DD when they transitioned back into the community after incarceration. The project's goals focused on reducing the rearrest, reconviction, or reincarceration of individuals with I/DD by implementing and expanding successful practices for reintegration into the community.

Aligned with its Five-Year State Plan Goal 2 that aims to increase Community Living, NCCDD funded this project because it recognized that incarcerated people with I/DD needed training in skills and making connections to resources to successfully reintegrate into society.

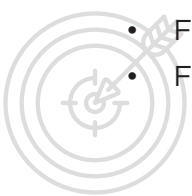
The grant recipient was the [Alliance of Disability Advocates \(ADA\)](#) located in Raleigh, NC. The grant was led by Sharif Brown, Re-entry Program Manager for ADA, who previously did reentry work at the Butner Federal Correctional Institute. He implemented the Individualized Reentry Plan (IRP) philosophy at Butner and assisted 200 inmates, of which only two reoffended.



Following his success, ADA was presented with a grant from NCCDD to implement the same IRP process in state prisons.

Activities of this initiative included:

- Culturally competent (inclusive, diverse) skill-building and support programming.
- Personal and service network building, including peer support.
- Continuity/seamless support of needed services and resources.
- Accessibility advocacy, advocacy to remove stigmas and reduce the barriers to successful reentry.
- Research supporting well-being and esteem-building strategies.
- Free General Educational Development (GED) training.
- Full wraparound services for individuals in the geographic area served by the ADA.





The IRP focuses on helping each inmate to identify and find the appropriate supports and services they need to become thriving citizens in their community. By doing so, it reduces the chance of the individual reoffending and ending up back in prison.

North Carolina’s state prison overall recidivism rate, or returning to prison, is 45%. After implementing the IRP process for this initiative, Brown reported that the success rate of not returning to prison was 88.9%.



88.9%
success rate of not returning to prison, after implementing the IRP process

“Each person has different situations and supports needed to help them succeed,” said Brown. “A person with I/DD may have even more supports they need for their daily life needs. These resources are essential for when they are released, to avoid reoffending.”

But it’s easier said than done. According to Brown, there are not enough resources once they are released. He cites lack of housing as a big issue, which can cause many to become immediately homeless after being released.

The IRP process is a way to avoid these situations. Brown also focuses on empowering individuals.

“I can’t stress enough how important it is for empowerment to begin while the individual is still in prison,” said Brown. Due to the strict structure of prison life, many lose their sense of self-direction.

“Empowerment means teaching them to take responsibility for their actions and to learn how to take care of themselves,” added Brown. “Many lose all of their family support when they are released. If they are completely on their own and without the proper resources, they will be more likely to reoffend so they can return to the structured environment of prison life. This helps them learn how to take care of their own plan and depend upon themselves to thrive.”

[Learn more about this initiative.](#)



“I can’t stress enough how important it is for empowerment to begin while the individual is still in prison,” Brown said.

Although the project with NCCDD is now completed, its success did not go unnoticed. The NC Division of Mental Health, Developmental Disabilities and Substance Use Services (DMH/DD/SUS) recognized the importance of this project and positive outcomes and will continue to fund this as a long-term program. Additionally, the program will expand to those who have been diagnosed with Traumatic Brain Injury (TBI).

The funding from DMH/DD/SUS will also allow the ADA to work longer with their clients, expanding their services from 90 days to one year.

“My hope is that this program will expand by using the success of the work we did with the NCCDD project by creating a model that will be implemented statewide and, most importantly, supported by the State budget,” said Brown.



[Read the NC Health News Article.](#)



*People leaving incarceration often feel directionless upon their reentry to society.
Photo Credit: Elizabeth Thompson*



Financial Asset Development



Expanding Competitive Integrated Employment

North Carolina has a goal of increasing Competitive Integrated Employment (CIE) for people with I/DD. CIE is employment in which individuals work in the community at a competitive wage.

In March 2019, Governor Cooper [issued an Executive Order](#) outlining North Carolina’s Employment First strategy. As a result, the North Carolina Department of Health and Human Services (DHHS) developed a Five-Year Strategic Plan to transition the State to CIE.

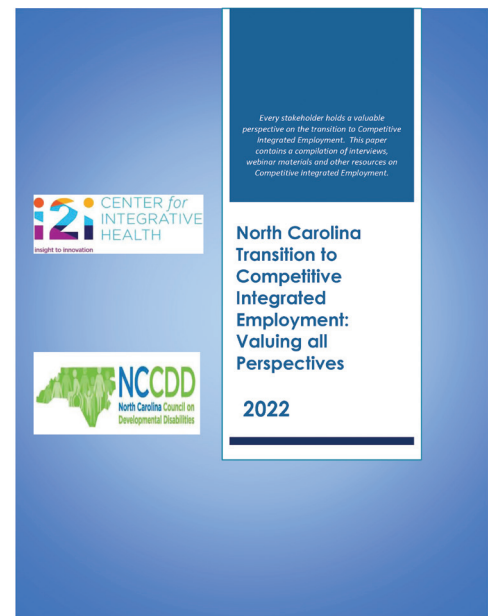
Some communities throughout North Carolina developed innovative models of integrated employment and vocational programming. In 2022 and 2023, NCDHHS entered into agreements with Disability Rights NC and the Center for Public Representation to increase CIE.



The I/DD community had important questions about CIE, so NCCDD provided funding to the [i2i Center for Integrated Health](#) to engage individuals within the I/DD community and other stakeholders to re-image what it would look like when North Carolina does this work.

In November 2022, the i2i hosted an information session. Individuals with I/DD, families, providers, and state representatives shared their knowledge and thoughts about the state’s transition to CIE, benefits counseling, family-driven approaches, and more. A panel of experts from state agencies and organizations, including a parent and a sibling of individuals with I/DD, answered questions and listened to the comments made by those attending.

Additionally, i2i published the [North Carolina Transition to Competitive Integrated Employment: Valuing all Perspectives](#), a white paper to help the I/DD community and all stakeholders better understand all perspectives on the transition to CIE. This white paper will be used to develop a summit in 2023 to give an additional opportunity to hear and learn from North Carolina stakeholders and other states that have transitioned to CIE. At the time of this writing, i2i is preparing a half-day conference on CIE to bring all stakeholders together in December 2023.

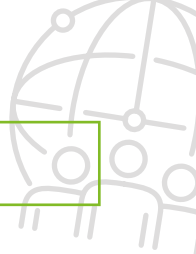


North Carolina Transition to Competitive Integrated Employment: Valuing all Perspectives, a white paper

Other Financial Asset Development Initiatives Funded by NCCDD:

- [North Carolina Benefits Counseling Services \(NCBCS\) Demonstration Project](#)
- [Care Extender White Paper](#)





Advocating for Supported Decision-Making



With a focus to promote less restrictive alternatives to guardianship and to advocate for supported decision-making, [Making Alternatives to Guardianship a Reality in North Carolina](#), also known as MAR-NC, was funded by NCCDD. This is important for individuals with I/DD and their families, specifically in allowing people with I/DD to choose the people they want to help them make choices and expand their freedom of how they choose to live.

This project builds upon the successes from a five-year Collective Impact initiative called [Rethinking Guardianship](#). Rethinking Guardianship is a statewide workgroup that has, with support from UNC Cares at the School of Social Work in Chapel Hill, established strong partnerships with individuals with I/DD, their families, leaders in the North Carolina State Bar, and other stakeholders.

Work on the MAR-NC project ended in 2023 and was a huge success. Over 1,400 individuals were reached through educational trainings and outreach; self-advocates, family, friends and professionals became more aware of the concept of supported decision-making; educational materials about supporting choice and self-determination were created in print and video formats (English and Spanish); and statutory guardianship reform is underway.

On the legislative front, MAR-NC’s coalition aimed to affect long-term changes in North Carolina’s guardianship system ([Chapter 35A reform of the North Carolina General Statute](#)) that would increase choice and self-direction for individuals. The coalition wrote a draft spelling out important reforms and then partnered with the Conference of Superior Clerks of Court, the UNC School of Government, and the Estate Planning & Fiduciary Law Sections of the state bar to finalize proposed statutory changes. The agreed upon changes are:

[Scan the QR Code for resources on Rethinking Guardianship.](#)



1. A mandate to consider alternatives that carry the least restrictions for the lives of people facing potential guardianship.
2. A need to make sure all parties are fully informed about relevant rights.
3. The ability of courts to monitor guardianships and call for hearings if needed.

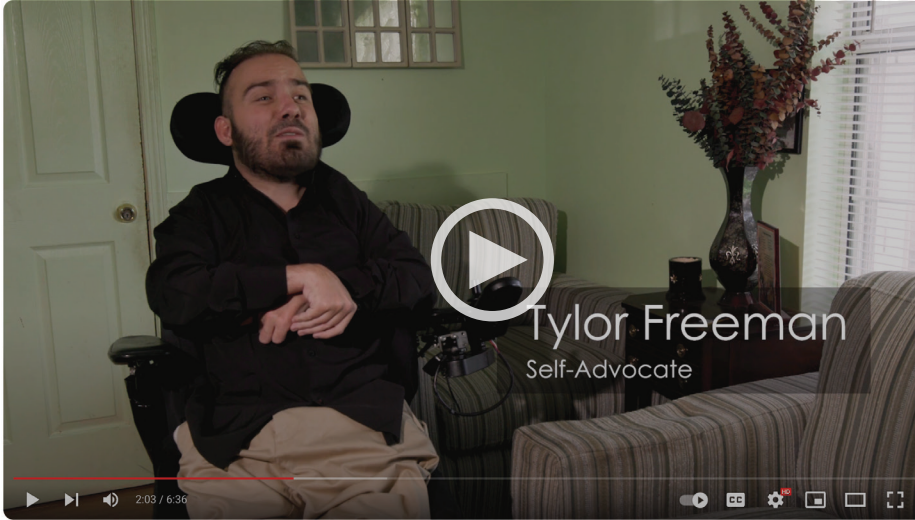
A consensus bill for guardianship reform was filed by the NC Bar Association during the 2023 long session of the NC General Assembly. [Senate Bill 308, otherwise known as the Guardianship Rights Bill](#), was passed unanimously in the Senate (74-0), later became Senate Bill 615, which passed in the Senate and the House, and Governor Roy Cooper signed it into law on September 28, 2023.

Other Community Living Initiatives Funded by NCCDD:

- [Natural Support Network Development](#)
- [Supported Living: A How-to Guidebook](#)



Rethinking Guardianship: Tylor Freeman's Story



[Watch the video series by scanning the QR Code.](#)



MAR-NC's final report to NCCDD

Making Alternatives a Reality in North Carolina



Final Report * July 1, 2020 to June 30, 2023

By All Indicators, a Resounding Success for Collective Impact

Rethinking Guardianship NC is a Collective Impact initiative that began in 2015. The Common Agenda is: To promote less restrictive alternatives to guardianship; and, to effect long-term changes in North Carolina's guardianship system. *Making Alternatives a Reality in North Carolina* (MAR-NC) was a three-year project (2020-2023) funded by the North Carolina Council on Developmental Disabilities (NCCDD). The goal of this project was to promote less restrictive alternatives to guardianship, especially supported decision-making. By all indicators, MAR-NC was a huge success. Over 1,400 individuals were reached through educational trainings and outreach; self-advocates, family, friends and professionals became more aware of the concept of supported decision-making; educational materials about supporting choice and self-determination were created in print and video formats and are available in English and Spanish, and statutory guardianship reform is underway. [Read on to learn more!](#)

Enhanced Website



You can find the following at Rethinking Guardianship's website:

- www.rethinkingguardianshipnc.org
- Our Common Agenda
- News & Reports about Rethinking Guardianship
- Educational materials in print and video, English & Spanish
- Stories and videos
- A blog
- Resources, including information about assessing capacity, restoration of rights, and guardianship in NC and the US.

Between October 2020 and June 2023, the website received 15,556 unique pageviews.

Educational Materials in English and Spanish

Educational materials created by MAR-NC include a video introducing supported decision-making, a downloadable, printable guide to SDM, and individual handouts, all available in English and Spanish. Topics include the importance of self-determination for well-being and how to get started using specific tools, including: Supported Decision-Making Formal and Informal; Power of Attorney; Healthcare Power of Attorney; Living Will; Living Trust; Special needs Trust; Simple Financial Tools; Foster Care 18-21; Representative Payee for Social Security Benefits; Fiduciary for Veterans Benefits; and Psychiatric Advance Directives.



[Read the MAR-NC Report by scanning the QR Code.](#)



MAR-NC: By The Numbers

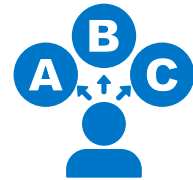


1,419

Individuals reached through trainings from July 2020 to June 2023



60 NC Clerks of Court trained on Supported Decision Making



6 Individuals with I/DD participating in MAR-NC

156 DSS social workers and public guardians enrolled in or completed Fundamentals of Guardianship training

28 Individuals who contributed to Senate Bill 308

12 Families advocates participating in MAR-NC





Unmet: Movie Debuts throughout the State



NCCDD hosted a screening of Unmet in Winston-Salem, NC at the ACE Theater Complex at the UNC School of Arts.

The film, “Unmet: North Carolina’s Disability Crisis,” is a 25-minute documentary commissioned by NCCDD. It debuted on March 9, 2023 at the ACE Theater Complex at the UNC School of Arts in Winston-Salem. The film shows the real-life situations of individuals with I/DD and what it looks like when their needs are unmet due to the workforce shortage and waiver waiting list. The event welcomed approximately 150 people to the showing, which was followed by a panel discussion about action steps to address these crises.

Many individuals with I/DD who qualify for services in the state are waiting for funding from the North Carolina General Assembly to become available. These individuals are placed on a waiting list called the Registry of Unmet Needs (RUN). There are approximately 17,000 people on the waitlist, and many have to wait for over 10 years for essential services. And, the list keeps growing.

In addition, many also need daily support such as physical assistance, bathing, cooking, and more to live in their homes and community safely. This assistance is provided by Direct Support Professionals (DSPs).

With DSPs earning an average of approximately \$13 an hour in the state, many North Carolinians with I/DD find it impossible to find the staff for necessary services. Nationally, a 2022 [report by ANCOR](#) found 63% of providers are discontinuing programs and services due to insufficient staffing.

“These are two long-simmering crises that we have to meet now,” stated Talley Wells, NCCDD Executive Director. “The Unmet film brings viewers inside the homes of North Carolina families and people with I/DD to see what our neighbors are experiencing due to the waitlist and workforce shortage.”



Attendees came to watch Unmet and share their experiences around the wait list.



Dave Owen featured in Unmet as Bryan’s DSP.

Winston-Salem native, Bryan Dooley, appointed to NCCDD by Governor Cooper and its current Chairperson, is among those featured in the film. “We hope that our state leaders will respond to these crises with bold action to support us. People with I/DD, when receiving adequate supports and services, can be productive, engaged citizens in their communities, and we can contribute to our society.”

Additional showings were held later in other North Carolina cities including Wingate, Greenville, and Asheville, along with a virtual screening. It was also shown to advocacy

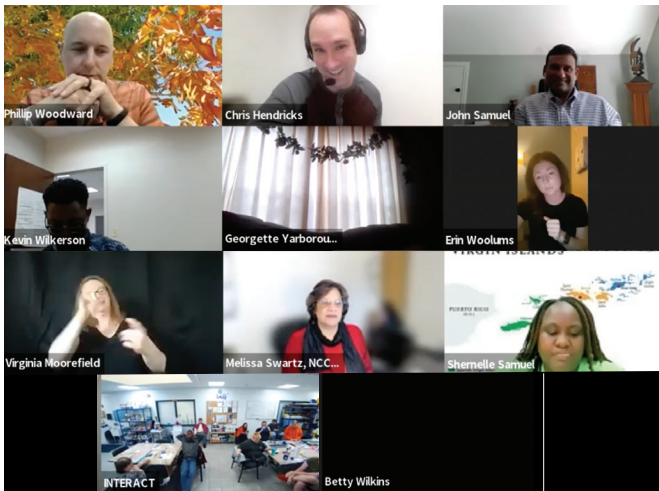
leaders across the country at the National Association of Councils on Development Disabilities (NACDD) Conference in Orlando, Florida in July.

The screenings include a film viewing, a panel discussion, and a call to action for what people can do to bring attention and solutions to issues facing the I/DD community in North Carolina.



Discussion Series Prepares Self-Advocates to Influence Change

In its second year, the [Self-Advocate Discussion Series](#) worked to attract, prepare, organize and mobilize North Carolina self-advocates to influence social and systems change. Facilitated by NCCDD Policy Education Coordinator Chris Hendricks and NCCDD self-advocate members, the Council held online monthly webinars throughout the year.



Self advocates join NCCDD's monthly webinar series.

Each session featured self-advocate leaders and presenters; engaging presentations; current and important topics; and community event announcements for self-advocates. Experts, trainers, and decision-makers offered approaches for accessing, speaking, and following up with legislators and policymakers. Topics included transportation, communications, housing, and more.

[Watch the Self-Advocate Discussion Series in English and Spanish on YouTube!](#)



develop relationships with NC legislators and decision-makers, while bridging connections and creating a network among NC self-advocates. Attendees develop their personal goal and topic-oriented story to share with others.

The series emphasized the value of people with I/DD by building on skills to meet and

[Learn more about the series here.](#) The Series is sponsored by NCCDD.

Other Advocacy Development Initiatives Funded by NCCDD:

- [Ability Leadership Project of North Carolina \(ALP-NC\)](#)
- [NC ADA Network Coordination, Technical Assistance & Fiscal Intermediary](#)
- [Peer Mentor Training for People with I/DD](#)





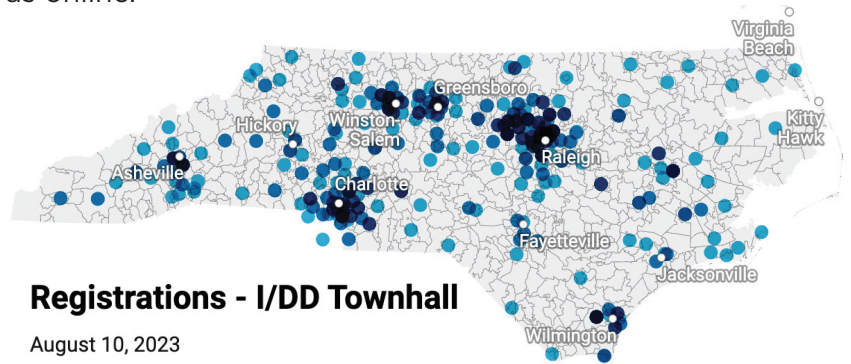
NCCDD Holds Statewide I/DD Town Hall Meeting



Over 300 people attended a statewide hybrid Town Hall Meeting on August 10, 2023 to discuss issues impacting people with I/DD living in North Carolina. The meeting was held in person at the site of NCCDD's quarterly Council meeting, Hilton Garden Inn in Cary, as well as online.

Secretary Kinsley and Director Crosbie spoke to a packed house at the I/DD Townhall in August in Cary, NC.

The event featured Kody Kinsley, Secretary of the Department of Health and Human Services (DHHS), and Kelly Crosbie, Division Director from the Division of Mental Health, Developmental Disabilities and Substance Use Services (DMH/DD/SUS). They provided updates and discussion on the state I/DD budget, 1915(i) Medicaid services, Medicaid Expansion, and more. Attendees had a chance to ask questions during the meeting.



Registrations - I/DD Townhall

August 10, 2023

Map: North Carolina • Source: Zoom • Map data: © Esri, TomTom North America, Inc., United States Postal Service • Get



Director Kelly Crosbie (left), NCCDD Chairperson Bryan Dooley (middle), and Secretary Kody Kinsley (right)

Bryan Dooley, Chair of NCCDD, opened the meeting by welcoming everyone and briefly sharing his own struggles with service and daily living disruptions due to the Direct Support Professionals (DSP) workforce shortage and the Innovations Waiver waitlist.

Dr. Charlrean Mapson, Chair of NCCDD's Community Living Committee and a parent of a child with I/DD, also spoke on how the workforce shortage is critical to the point that finding and keeping DSPs is nearly impossible.

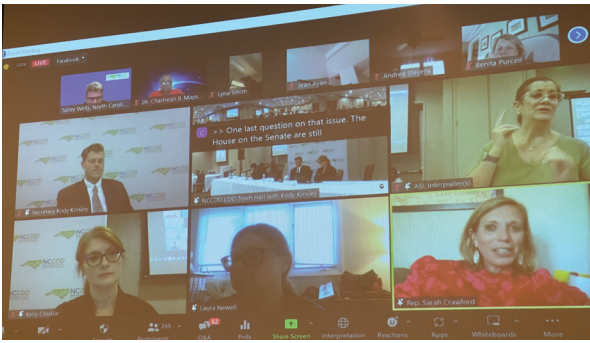
Secretary Kinsley started the Town Hall discussion by emphasizing that North Carolina is in a state of urgency like never before when it comes to waiting lists and the DSP workforce. He expressed his frustration with how these issues have escalated to the point where they are now. However, he feels that the state is heading on the right track.

"There is more traction and more of a sense of collective action and purpose than ever before," said Kinsley. "Governor Cooper understands the issue, and it is striking a chord and being heard by the General Assembly," he added.

In spite of obstacles to resolve the issues, the progress of the [1915\(i\) Medicaid services](#) and [Tailored Care Management](#) are gaining momentum to help bring the vision of "whole-person health" to reality.

Secretary Kinsley said he feels strongly that when we point fingers and cast blame, there is no way to move forward. Instead, we need to focus on building a continuum that provides choice for all people and builds opportunities to lead better lives. There is no one-size-fits-all for the I/DD community. Building a community involves meeting people where they are in their own lives.





The hybrid townhall included guests who joined online and shared their experiences around the wait list.

on community-based services, an explanation of 1915(i) entitlement services, the need to bring more psychiatrists and psychologists into the North Carolina public service sector, DSP wage disparity and more.

Director Kelly Crosbie spoke on the importance of being informed. She emphasized that she continues to meet with many families who don't understand the system – they don't know where to go or what to do or even what services are available to them. She feels there should be a stronger focus on helping people to learn about and navigate North Carolina's systems of services and supports.

[Watch the Town Hall Meeting on Facebook.](#)



A question-and-answer session was then opened to the audience. Secretary Kinsley and Director Crosbie fielded questions on several topics and issues, including the *Samantha R.* case and its potential impact

NCCDD Advocates on Behalf of I/DD Community at NC General Assembly



NCCDD members and staff met with North Carolina General Assembly legislators to educate them about issues that are important to the I/DD community.

In March, members and staff of NCCDD met with North Carolina General Assembly legislators to educate them about issues that are important to the I/DD community.

The issues included the dual crises — the DSP shortage and the Medicaid Innovations Waiver waiting list length.

hoping to receive services to help them live in the community instead of care facilities. The wait on this list for assistance is often more than 10 years.

The average pay rate for a DSP in North Carolina is just \$13 per hour. That low pay and high need has created a DSP crisis in this state. In addition, over 17,000 individuals with I/DD in North Carolina are on the Medicaid Innovations Waiver waiting list,

The group then attended the House Committee on Health hearing and then met with Senate Health Appropriations committee. Those members included Senators Michael Lee, Jim Burgin, Joyce Krawiec, Kevin Corbin, Mike Woodard, Sydney Batch as well as Representatives Zack Hawkins and John Bradford.



NCCDD Chair and Staff appear with Senator Joyce Krawiec after she receives an Advocacy Award from the I/DD Legislative Caucus.



The group at the I/DD Caucus meeting

Bryan Dooley, chair of NCCDD, said, "We tried to raise the profile of the Council in all areas including employment, the DSP crisis and the waiting list. I don't think we had any breakthroughs, but it was a productive meeting. Hopefully there will be a follow-up."

Additional time was given for the NCCDD attendees to meet individually or in small groups with other legislators. The NCCDD group displayed still photos from their film "Unmet" in a meeting room for legislators and visitors to view.

Meet the 2023 NCCDD Council Members



COUNCIL MEMBER SPOTLIGHT

Brendon Hildreth's Journey to Employment



Even before being appointed to the Council, Brendon Hildreth has been an impactful advocate across the state by finding success through opportunities.

One of his biggest achievements is the [Accessible Icon Project](#). The goal of the project is to advocate for the use of an updated version of the old, outdated accessibility symbol into a more active and engaging picture meant to show that people with disabilities can be active, engaged, and independent in their communities.

Through his advocacy efforts, he was successful getting the new accessible icon approved for use in North Carolina. And he was successful in getting his hometown of New Bern to be the first city in the state to adopt the icon.

Brendon Hildreth (second from left) hosted an Accessible Icon painting event at Hanging Rock State Park with other self advocates.



Old Icon

Updated Icon

Since then, many businesses, towns, schools and colleges in NC have adopted the icon and more importantly, its message. Just recently, East Carolina University (ECU), his alma mater, adopted the icon, and through the help of a graduate student, the icon made it to Miracle Field in Wilmington, NC and will be approaching the City of Greenville and other NC universities.

Hildreth was also able to get the City of New Bern to make its City Hall more accessible by having them add an accessible elevator because he couldn't get into the building using his wheelchair. The City is almost done installing an elevator, and rumor has it, he has been promised the first ride!

Hildreth was appointed to NCCDD in 2016, representing Craven County. Through his advocacy with NCCDD and other accessibility initiatives, Hildreth has proven that he has a gift to help advocate and not let himself be seen solely as a person with a disability. Instead, he prefers to be seen as a person who needs accommodations.

Driven to educate others and advocate on behalf of the disability community, Hildreth has a simple philosophy. "It's very easy to complain," he shared. "But I like to point out an issue and also try to come up with a solution."

And that passion has led him to a career in advocating for others with disabilities with the [North Carolina Department of Vocational Rehabilitation Services](#) (DVRS).



In 2022, Hildreth graduated from ECU. Around the same time, he was approached by Kathie (formerly Trotter) Smith, Division Director for DVRS about an internship position. He and Smith are both Council members. She was also familiar with his success as an advocate with the Accessible Icon Project.

He accepted the offer and began his responsibilities as an intern, which included educating about the Accessible Icon Project, helping with requests through DVRS' emails from people in need of services, assisting the Division Director on projects, and more.

In his work, he came up with a process to streamline the requests so that DVRS field offices would get to them quicker, so clients would get services quicker. The process was well received and adopted by DVRS.

Because of his accomplishments, Smith offered him a permanent position with DVRS as Disability Peer Consultant. His responsibilities include continuing to educate about the Accessible Icon Project, while working with each DVRS field office throughout the state to adopt the message of the new accessible icon.

"This role is new for me, so I'm still learning," he said. "I'm looking forward to showing people that I am capable and willing to do a job. I want to help others find jobs and most importantly, tell others what DVRS can offer."

Next, he will be trained to be a peer mentor and will work as a liaison between DVRS and people looking for a job and services.

When he started this process, Hildreth asked "a bazillion questions" while he was applying for services in the DVRS system. He experienced a lot of frustration along the way, and he wants to help others not to have to navigate the hard way.

When asked what he likes best about his job, Hildreth said, "I enjoy being seen and respected as a peer in my work environment. I enjoy meeting new workers and having them value and seek my input."

Darcy, Hildreth's mom, reflects on her son's success. "We believe as a family that everyone has a gift to share and you need to find yours and share it. He believes in equity, not equality. Everyone gets what they need, not the same."



Brendon Hildreth gets ready for a day of work at DVRS.



I enjoy being seen and respected as a peer in my work environment. I enjoy meeting new workers and having them value and seek my input."

- Brendon Hildreth





The NCCDD is a 40-member body appointed by the Governor and made up of:

- People with intellectual or other developmental disabilities (I/DD)
- Parent/Family member/Guardian
- Representatives of state agencies
- State legislators
- Representatives from Disability Rights NC and the Carolina Institute for Developmental Disabilities (CIDD)
- Provider and Local Management Entities/Managed Care Organization representatives (LME/MCO)

The Council represents all of North Carolina and is responsible for carrying out the provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and making sure that the Council is a member-driven, effective, efficient, and accountable organization. Serving up to two four-year terms, the membership is composed of 60 percent of people with intellectual or other developmental disabilities (I/DD) or family members, and the remainder with representatives from state agencies, nonprofit and professional organizations. The Council guides all initiatives and contracts.

Council members include:

BLADEN CO.

Tocarra E. Osborne
Parent

DARE CO.

Nessie Siler
Individual with DD

MECKLENBURG CO.

Representative Terry Brown
Legislative Representative

BUNCOMBE CO.

Rhonda Cox
Non-Profit Agency
Alternate: Judith Kirkman

DAVIDSON CO.

William Miller
Individual with DD

Marjorie Serralles-Russell
Parent

Joshua Gettinger, M.D.
Parent

DURHAM CO.

Representative Zack Hawkins
Parent

NEW HANOVER CO.

Charlrean Mapson, D. Min.
Parent

Rebecca Putnam, M.D.
Sibling

EDGECOMBE CO.

Katherine Boeck
Individual with DD

Cheryl Powell
Individual with DD

Ryan Rotundo
Sibling

ONSLow CO.

Donna Spears
Individual with DD

CARTERET CO.

Jonathan D'Angelo
Individual with DD

FORSYTH CO.

Bryan Dooley
Chairperson
Individual with DD

ORANGE CO.

Carol Ann Conway
Individual/Relative Institution

CRAVEN CO.

Myron Michelle Gavin
Parent

JOHNSTON CO.

Carla West
Agency: DHHS-Social Services
Alternate: Amy Eaton

Gary Junker, Ph.D.

Dept. of Public Safety
Alternate: Jamila Little

Brendon Hildreth
Individual with DD

Joe Piven, M.D.

Agency: Carolina
Institute on DD;
Alternate: Anna Ward



PENDER CO.

Keith B. Carney
Parent

PITT CO.

Bethany Dawn Smith
Individual with DD

RANDOLPH CO.

Peggy Terhune, Ph.D.
Local Non-Governmental
Agency

ROBESON CO.

Kristy Locklear
Parent

STANLY CO.

Dawn Allen
Public At Large

WAKE CO.

Senator Sydney Batch
Senate Representative

Yvonne Copeland

Agency: DHHS-W/C Health
Alternate: Danielle Matula

Kelly Crosbie (DMH/DD/SAS)

Agency: DHHS-MH/DD/SAS
Alternate: Ginger Yarbrough
Alternate: Vacant

Debra Farrington

Agency: DHHS

Tony Hall

Individual with DD

Carol Ann Hudgens, Ph.D.

Agency: Dept. Public Instruction
Alternate: Dreama McCoy

Virginia Knowlton Marcus

Agency: Disability Rights NC

Kayla McMillan

Individual with DD

Karey Perez

Agency: DHHS-Aging
& Adult Services
Alternate: Sarah Smith

Dale Stephenson

Parent

Sandra Terrell

Agency: DHHS-NC Medicaid
Alternate: Deb Goda

Kathie Smith

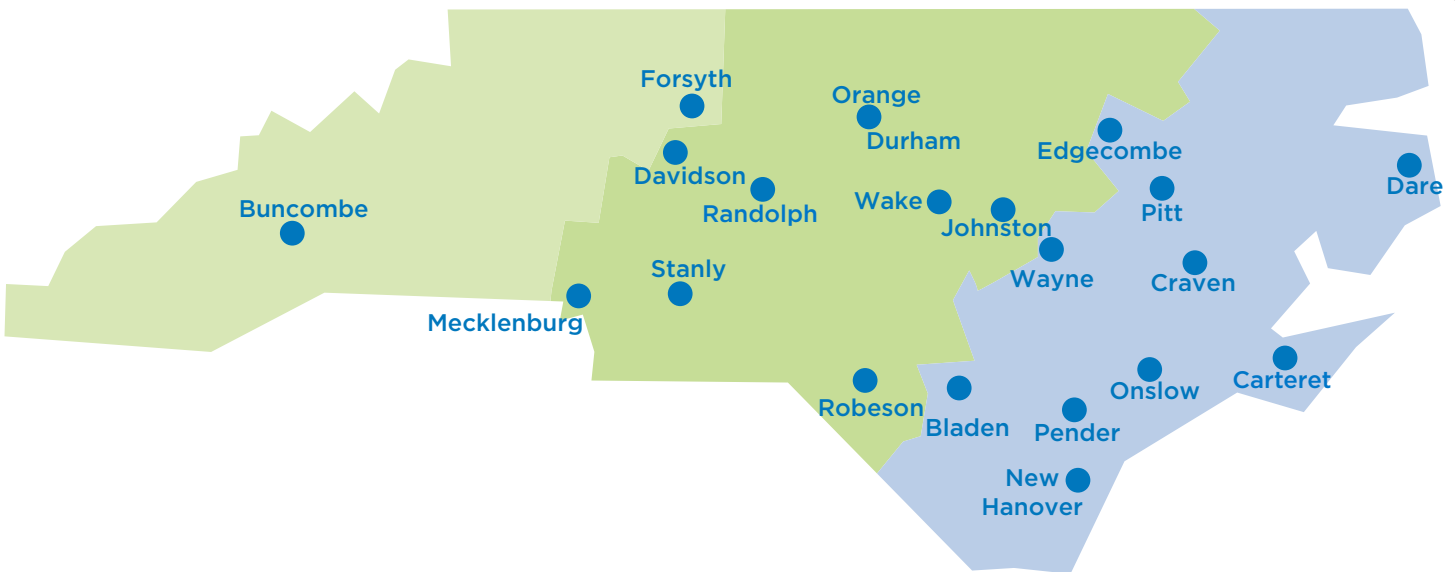
Agency: DHHS-Voc.
Rehabilitation
Alternate: Kenny Gibbs

WAYNE CO.

Aldea LaParr

Individual with DD

COUNTY MAP OF COUNCIL REPRESENTATION



Meet the NCCDD Staff



NCCDD's staff brings deep experience in human services and the field of I/DD. They work closely with Council members, state agencies and nonprofits to make a difference on individual, local, state and national levels to help better the lives of communities throughout North Carolina.



Talley Wells
Executive Director



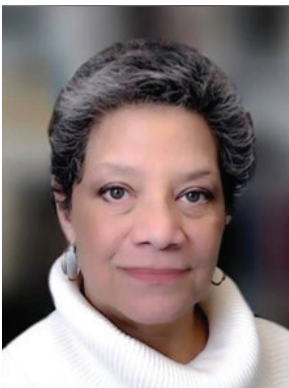
David Ingram
Director of Operations



Chris Hendricks
Public Policy Education Coordinator



Pam Hunter Dempsey
Systems Change Manager



Melissa Swartz, Ph.D.
Systems Change Manager



Tamira White, Ph.D.
Systems Change Manager



Philip C. Woodward
Systems Change Manager



Cora Gibson
Administrative Specialist II



Irlanda Ruiz
Hispanic Disability Advocate



La'Quadia Smith
Business Services Coordinator

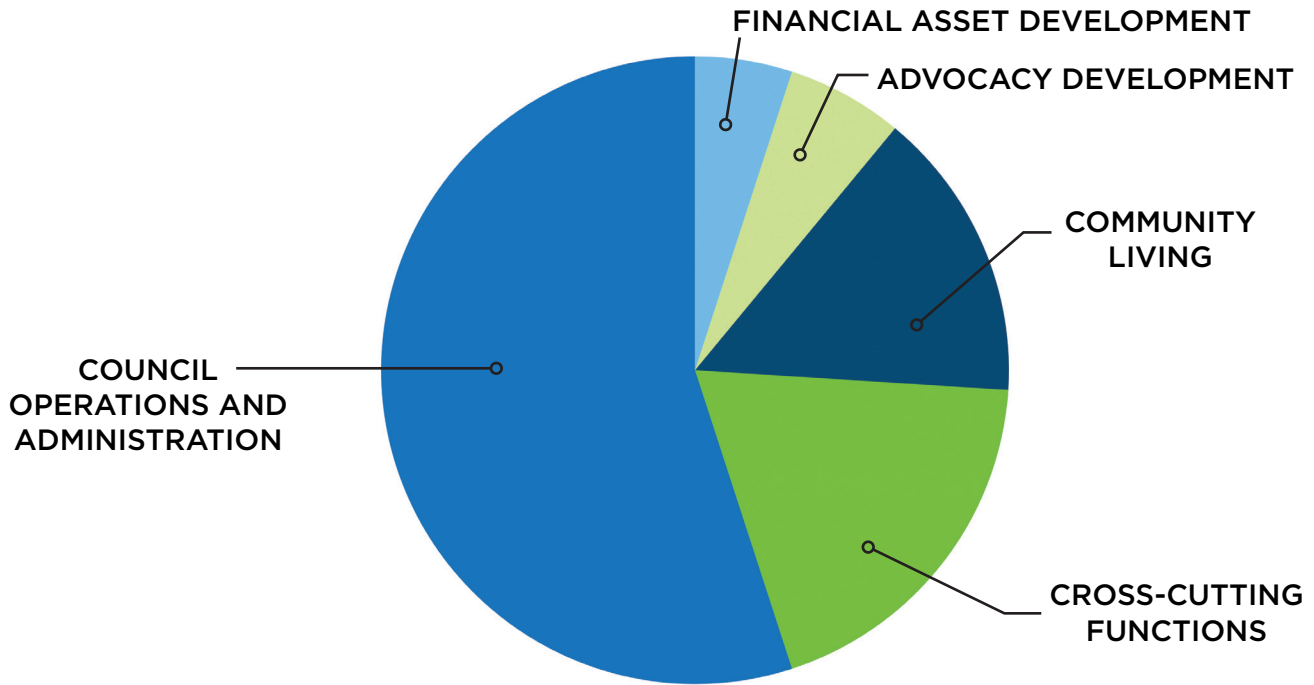


Shar'ron Williams
Business Officer



Letha Young
Administrative Specialist I

FFY 2022 - 2023 Budget



| Actual | Amount |
|--------------------------|-----------------------|
| Budget | \$2,155,429.00 |
| *EXPENSES TO DATE | \$2,140,018.00 |
| FFY 2022 BALANCE | \$15,411.00 |

| BUDGET | Amount |
|---------------------------------------|-----------------------|
| Financial Asset Development | \$90,000.00 |
| Advocacy Development | \$139,998.00 |
| Community Living | \$319,390.00 |
| Cross-Cutting Functions | \$407,699.00 |
| Council Operations and Administration | \$1,182,931.00 |
| Total Budget | \$2,140,018.00 |

For the Period of October 1, 2022 - September 30, 2023





NC DD NETWORK PARTNERS

CAROLINA INSTITUTE FOR DEVELOPMENTAL DISABILITIES (CIDD) is a comprehensive program for services, research and training relevant to individuals with I/DD and their families. It is the state's federally mandated University Center for Excellence in Developmental Disabilities (UCEDD).

DISABILITY RIGHTS NORTH CAROLINA (DRNC) is a nonprofit organization whose team of attorneys, advocates, paralegals and support staff provide advocacy and legal services for people with disabilities across NC. It is the state's federally mandated protection and advocacy agency.



3109 Poplarwood Court, Suite 105
Raleigh, NC 27604

1-800-357-6916 (TOLL FREE)
984-920-8200 (OFFICE/TTY)
984-920-8201 (FAX)

 /NCCouncilonDD

 nc_ddcouncil

 nccdd.org

