

# 2016 ANNUAL REPORT



Financial Asset Development • Community Living • Advocacy Development



**NCCDD**  
North Carolina Council on  
Developmental Disabilities

[www.nccdd.org](http://www.nccdd.org)



## Our Mission

The North Carolina Council on Developmental Disabilities (NCCDD) works collaboratively, across the state, to assure that people with intellectual and other developmental disabilities (I/DD) and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all areas of community life through culturally competent programs. The Council awards its funds to help communities become more inclusive of people with I/DD and to promote the goals of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) for all North Carolinians with I/DD and their families.

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“As NCCDD works to achieve our Five Year Plan Goals and Objectives, we are guided by the notion of high expectations for all North Carolinians with I/DD and their families across the lifespan.”

– Chris Egan, NCCDD Executive Director

## NCCDD 2016 – Reflecting on Our Accomplishments and Looking Ahead

As the NC Council on Developmental Disabilities (NCCDD) works with our members, self-advocates and other community leaders to engage in and implement our new Five Year Plan, we recognize that future goals to advance self-determination, productivity, true community integration, inclusion and independence are built upon our past and current efforts, and the direction set by our new Five Year Plan. Looking back on NCCDD’s previous year’s successes, I’m struck by the many faces of people all across our state that were a part of moving our shared mission and vision forward. A record number of North Carolinians joined together this year to accomplish goals that are truly touching the lives of individuals with intellectual and other developmental disabilities (I/DD) and making a difference.

We kicked off the year with input from many of you throughout our state to inform the NCCDD’s new Five Year Plan. Your guidance and ideas, shared at face-to-face community listening sessions throughout North Carolina and online, contributed to a strong and strategic plan that will guide NCCDD’s work from 2017 to 2021. We have important opportunities ahead.

This plan reflects a comprehensive review of major systems and issues impacting North Carolinians with I/DD, and it outlines three key systems change goals to:

- **Increase financial security through asset development for individuals with I/DD.**
- **Increase community living for individuals with I/DD.**
- **Increase advocacy for individuals with I/DD.**

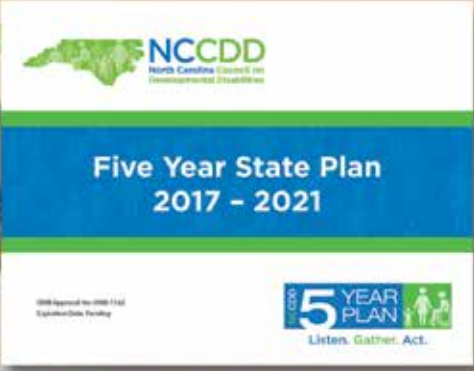
The impact of our work would not be possible without the leadership of the members of the Council. Three new members joined our governor-appointed, 40-member Council representing all regions of North Carolina. The Council guides all initiatives and contracts with a commitment to carry out the provisions

of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in meaningful ways.

Friendships are made and communities strengthened when we come together. Many people greeted us across the state as we celebrated increased accessibility in North Carolina and historic federal legislation. “Fun in the Sun” at Fort Macon State Park in Atlantic Beach, showcased four new Sand Rider beach wheelchairs donated by Access North Carolina to make North Carolina beaches accessible to all people. Hanging Rock State Park, in Danbury, hosted “Picnic in the Park” – an Americans with Disabilities Act’s (ADA) 26th anniversary event and showcased a new accessible picnic shelter which welcomes families with and without disabilities.

As NCCDD works across our state’s 100 counties to achieve our Five Year Plan Goals and Objectives, we are guided by the notion of high expectations for all North Carolinians with I/DD and their families across the lifespan. Partnerships and collaboration across the different sectors in local communities foster greater understanding, creative solutions and increased likelihood of sustainability of our initiatives. In fact, later in this report you will have a chance to review a summary of the many efforts in which we are fostering change. We will continue to seek out unique partnerships and collaborative efforts to ensure that people in North Carolina with I/DD and their families participate in the design of and have access to needed community services, individualized supports and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all areas of community life.





*NCCDD Executive Director Chris Egan, NC Department of Health and Human Services (NC DHHS) Deputy Secretary Sherry Bradsher (center) and NCCDD Chair Ron Reeve at the August Council meeting*

## New Five Year Plan

In 2015, North Carolina Council on Developmental Disabilities (NCCDD) launched its new Five Year Plan efforts to gather input from the intellectual and other developmental disabilities (I/DD) community in regards to their goals for the next five years (2017-2021).

The planning process for NCCDD's Five Year Plan included surveys and listening sessions that were organized and scheduled across the state during which stakeholders provided input to help identify the changes and priorities for individuals with I/DD and their families.

At the sessions, Council staff sought to listen and gather information about what is working for North Carolinians with I/DD, what needs to change, and how could it be changed.

Additionally, in partnership with the Carolina Institute on Developmental Disabilities (CIDD), the Council developed a community survey, which also gathered input from the I/DD community.

After community input, the Council synthesized the data collected and three major themes emerged that will become the goals for the next five years.

- **Financial Asset Development**
- **Community Living**
- **Advocacy Development**

The defined goals and objectives were endorsed by the Council at their quarterly meeting in May, and the final plan was adopted during the August meeting. The plan was then submitted to the Administration on Intellectual and Developmental Disabilities (AIDD).

The Five Year Plan is developed in accordance with the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).



**GOAL 1: Increase Financial Security**



**GOAL 2: Increase Community Living**



**GOAL 3: Increase Advocacy**





*Justice Robert H. Edmunds, Jr. (center) visits the Council at the May meeting*



*NC DHHS Secretary Rick Brajer (center) with NCCDD Chair Ron Reeve and NCCDD Executive Director Chris Egan*

## Meet the Influencers

The work of NCCDD requires a collaborative effort of the community, organizations and agencies.

During the annual meeting in November of the NCCDD, then newly appointed Secretary of the North Carolina Department of Health and Human Services (NC DHHS), Rick Brajer, joined the Council to introduce himself and also to learn what matters most for people with I/DD in North Carolina.

Secretary Brajer spent time listening and learning from the Council. He opened the floor to the Council members to provide input on three key questions:

- 1. What is DHHS currently doing well that incorporates the needs of people with I/DD?**
- 2. How should DHHS shift its focus to better serve the I/DD community?**
- 3. What are some new things DHHS should be doing in terms of funding, legislatively and more to support the I/DD community?**

In response, members of the Council raised concerns ranging from individuals potentially losing services, questions over managed care systems and crisis prevention. In addition, members discussed the importance of high expectations and strong transitions leading to productive choices such as employment.

The Secretary also spoke about the transition to a hybrid model of managed care organizations in Medicaid reform among many other topics. He joined DHHS after two decades of serving in leadership roles in the healthcare and medical technology industries.



*Council Member Paula Woodhouse (right) with Justice Robert H. Edmunds, Jr.*

*“So we think about providers who spend every day with families, who look them in the eye and support them, we want to give them every chance to win in this new model of healthcare reform.”*

*– Secretary Rick Brajer*

Robert H. Edmunds, Jr., Senior Associate Justice of the Supreme Court of North Carolina, attended the May Council meeting to welcome and reaffirm the Council members regarding their duty on the Council.



*NC DHHS Secretary Rick Brajer met with the Council in November 2015 to listen and learn what matters most for people with I/DD in North Carolina*





# community financial security advocacy

## Taking Initiative

North Carolina Council on Developmental Disabilities' (NCCDD) initiatives provide resources and training for community members and professionals in the field to become stronger advocates for services and supports for people with intellectual and other developmental disabilities (I/DD) in North Carolina.



### FINANCIAL ASSET DEVELOPMENT

#### Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with I/DD

*Western Carolina University*

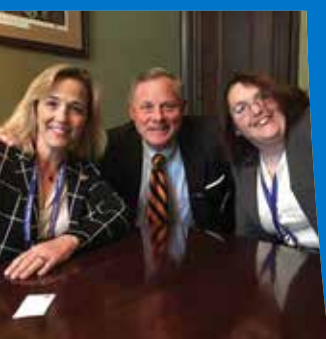
This initiative creates a sustainable approach to providing transition services and resources for students with I/DD, even for those with the most complex of these disabilities. See the resource matrix at [www.rtle.org](http://www.rtle.org).



#### Project SEARCH

*Cincinnati Children's Hospital Medical Center*

This high school transition initiative is a business-led, one-year, school-to-work program that combines classroom instruction, career exploration and relevant job skills training through strategically designed internships for students with I/DD. Sixty-nine young people with I/DD graduated in 2016.



#### Upward to Financial Stability

*National Disability Institute*

This initiative provides education and training to spread financial awareness and conduct financial literacy training for individuals, families and service providers to raise expectations for people with I/DD to develop financial assets. This initiative trained 61 people in train-the-trainer sessions with seven becoming Master Trainers.



### COMMUNITY LIVING

#### Bridging Practice and Policy: Transitions from Adult Care Homes

*Disability Rights North Carolina*

This initiative assists individuals with I/DD to transition from adult care homes to homes of their own, with the appropriate services and supports and a blueprint to support transition for others with I/DD living in adult care homes. As a pilot project, sixteen individuals transitioned from an adult care home into a community setting.



#### Emergency Preparedness

*North Carolina*

*Department of Public Safety*



This emergency preparedness initiative implements and maintains a program that is inclusive of people with I/DD and that builds capacity for disaster preparation, emergency response and related procedures and systems. Five North Carolinians participated in Functional Assessment Support Team (FAST) training for our state.

#### Guardianship

*NC DHHS Division of Aging and Adult Services*

NCCDD funds this initiative for training, consultation and technical assistance to support the development of policies and practices, relative to guardianship and alternative to guardianship that advance productivity, independence, integration, inclusion and self-determination for people with I/DD. Through the work of this initiative, NC passed an Act that will make it easier for family caregivers living across state lines to make important decisions for their loved ones.

#### Medical Health Homes

*Easter Seals UCP*

This initiative seeks to assure that people with I/DD receive the right care at the right time in the right setting. Simultaneously, efforts are occurring to help inform policymakers during transition to managed care in NC. The initiative has identified oral health as a critical component of wellness for people with I/DD and conducted two clinics to build capacity for more dentists to serve patients in rural areas.



#### Safety and Security: Addressing Domestic Violence and Sexual Violence Against People with I/DD

*The Rape Crisis Center of Coastal Horizons, Inc.*

The Safety and Security initiative increased the capacity and knowledge of domestic violence and/or sexual assault service providers about the needs of victims who have I/DD. Through the efforts of this initiative, a training with an American Sign



Language (ASL) interpreter and closed captioning has been developed to equip direct support professionals and domestic violence support staff with the tools to meet the needs of victims with I/DD.

## ADVOCACY DEVELOPMENT

### Advancing Strong Leadership in Intellectual and Developmental Disabilities (ASLiDD)

*University of Delaware*

This is a leadership development initiative for early career professionals in the I/DD field in North Carolina. ASLiDD offers participants to come together with a faculty of national experts on progressive supports for people with I/DD. The FFY 2016 ASLiDD Cohort included 25 participants and 28 mentors from 30 organizations.



### Medicaid Reform Stakeholder Engagement Group

*National Association of State Directors of Developmental Disabilities Services*

This is a cross-disability advocacy initiative focusing on shaping the long-term support and service systems. It is currently the only group in North Carolina that consists solely of individuals receiving services and their family members who are charged with systems change through meaningful engagement and dialog with policymakers at all levels.



### NC ADA Network

The NC ADA Network supports grassroots groups, led by people with I/DD, to conduct projects that promote voluntary compliance with the Americans with Disabilities Act (ADA) in their local communities. This year the initiative partnered with 23 grassroots groups.

### NC ADA Network – Fiscal Intermediary

*Alliance of Disability Advocates*

The NC ADA Network – Fiscal Intermediary supports the grassroots efforts of local ADA affiliates by providing timely, accurate reimbursement for the funding of Network



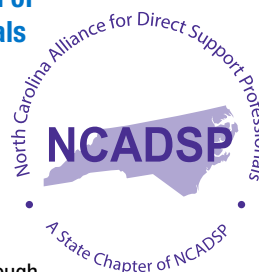
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Affiliate Group ADA initiatives and participant travel/training expenses. Five hundred and eighty individuals with I/DD participated in these activities this year.

### North Carolina Association of Direct Support Professionals

*Benchmarks, Inc.*

This initiative established a local chapter of the National Alliance for Direct Support Professionals to advance the quality of the workforce that supports individuals with I/DD through increased competency, professionalism and a voice in decision-making. Two hundred DSPs have signed up to become members of the state chapter.



### Partners in Policymaking®

*Advocacy Institute, Inc.*

Partners in Policymaking® is a nationally replicated and cutting-edge leadership and disability advocacy training program for parents of school-aged children with I/DD and self-advocates. In FFY 2016, the program graduated 24 members.



**Partners in  
Policymaking**

### Sibling Support

*First in Families of NC*

Sibling Support addresses the various needs and barriers that siblings of a person with I/DD face. The NC Chapter of the Sibling Leadership Network (NC Sibs) engages siblings, caregivers, professionals and stakeholders in order to provide support and information specific to the unique aspects of the adult sibling relationship. In FFY 2016, NC Sibling Support Network became an official chapter of the National Sibling Leadership Network. In two years of implementation, the NC Chapter of the SLN has 53 members.





## 2015 Hefner and Riddle Awards

The North Carolina Council on Developmental Disabilities (NCCDD) recognizes that the progress of disability rights is not complete or possible without tireless advocates and professionals. The Council's annual awards ceremony honors self-advocates or family members and professionals who work tirelessly in their efforts to make the state a more integrated and inclusive community for people with intellectual and other developmental disabilities (I/DD).



**“It’s not easy to speak up, but the payoff when you do is enormous.”**

– Donna Meltzer

The 2015 awards ceremony was held during the November Council meeting in Raleigh, NC, where advocates, professionals and community members joined NCCDD to celebrate the year’s work and to honor the recipients.

The event also welcomed Donna Meltzer, CEO of the National Association of Councils on Developmental Disabilities (NACDD), as its guest speaker.



She gave a stirring speech on leadership and inclusion of people with I/DD. The night honored advocacy, and Meltzer paraphrased from David Bornstein’s book, *How to Change the World*, about how ideas such as inclusion need good producers and promoters. Explaining that no matter how good an idea is – unless it moves to the mainstream – then it’s not going to lead to change.

### Jack B. Hefner Memorial Award – Becky Hopper

Named after former NCCDD Council member and tireless advocate for people with I/DD, the Jack B. Hefner Memorial Award recognizes community members who advocate for people with I/DD across the state of North Carolina.

In 2015, the award was given to parent advocate Becky Garland Hopper from Andrews, NC, who advocates for individuals with autism.



Becky Garland Hopper (center) with the Hefner family and NCCDD Executive Director Chris Egan (far left) and NCCDD Chair Ron Reeve (far right)

Hopper has been a determined advocate for her 26-year-old son David and many other individuals with I/DD. She has mentored many families within the University Participant program at Western Carolina University and actively gives presentations and participates in forums while working a full time job and pursuing her Master’s degree in Public Administration and Policy.

The mother and son team serve on the North Carolina TASH Board and have unified their efforts to show what possibilities exist for individuals with I/DD to live independent and meaningful lives. TASH is an organization that advocates for human rights and inclusion for people with significant disabilities and support needs.

**“I hope that we can continue this fight toward full inclusion where it’s not a special thing to be included, it’s just the way it is.”**

– Becky Garland Hopper





## Helen C. “Holly” Riddle Distinguished Service Award – Michael Mayer

The 2015 Helen C. “Holly” Riddle Award was given posthumously to Michael Mayer of Mebane, NC.

Mayer had been directly responsible for overseeing the development of community residential, vocational, and other support and treatment services for people with disabilities, specializing in individuals with more severe and/or complex disabilities. He had also overseen and consulted on the development, modification to or conversion of family and community services and supports.

His dedication to community supports had been a passion of his since he was a young adult, and he motivated emerging young leaders to embrace innovation and impact change for the disability community nationwide.



Joan Johnson (second, left) accepts the Riddle Award on behalf of the late Michael Mayer with NCCDD Executive Director Chris Egan (far left), Holly Riddle and NCCDD Chair Ron Reeve



The Council introduced the Helen C. “Holly” Riddle Distinguished Service Award in 2014 in honor of former Executive Director Holly Riddle, who served the Council for over 20 years. The 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.

Michael Mayer  
1958 – 2015



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## FFY 2016 NCCDD

### ACTUAL & BUDGET REPORT- As of Oct 2016

For the Period of October 1, 2015 - September 30, 2016

ACTUAL	Amount
BUDGET	\$2,063,970
EXPENSES TO DATE	\$1,230,239
FFY 2016 BALANCE	\$833,731

BUDGET	Amount
Financial Asset Development Committee	\$325,000
Community Living Committee	\$260,920
Advocacy Development Committee	\$334,988
Cross-Cutting Functions	\$593,062
Council Administration	\$550,000
<b>Total Budget</b>	<b>\$2,063,970</b>



# Statewide Events Promote Community Access, Advocacy and Employment

The North Carolina Council on Developmental Disabilities (NCCDD) promotes accessibility, inclusion and integration across the state. This year, the Council hosted three events that promoted community access, advocacy and employment, three major goals under NCCDD's new Five Year Plan (2017-2021).

## A Day at The Beach: Sun, Sand and Fun for All

New beach wheelchairs that provide beach access to individuals with mobility disabilities were showcased at *A Day at The Beach: Sun, Sand and Fun for All* at Fort Macon State Park at Atlantic Beach, NC on March 19, 2016. The event welcomed families with and without disabilities to participate and celebrate March as Developmental Disabilities Awareness Month.

## A Day at The Beach: Sun, Sand and Fun for All



## Picnic in the Park



## Picnic in the Park

NCCDD celebrated the opening of a new accessible picnic shelter at Hanging Rock State Park on July 24, 2016 in Danbury, NC. Attendees participated in an Americans with Disabilities Act (ADA) training and also painted accessible icons in the parking lot, courtesy of the Accessible Icon Project. J. Leon Inman, Stokes County Commissioner, read a proclamation honoring the ADA's 26th anniversary.

*The ADA: Making it Work* highlighted the area of employment. NCCDD partnered with the City of Raleigh Mayor's Committee for Persons with Disabilities and the Raleigh Wake Human Resources Management Association to host *The ADA: Making it Work*, an employer resource workshop to help hiring professionals learn about the ADA and hiring people with disabilities.

A panel including the CEO and Executive Chef of PG Werth's, Gregory Hamm; his employee Derrick; and Kenneth Kelty, a local advocate and staff member at The Arc of The Triangle, also discussed the values of competitive employment.

Deputy District Director Tim Colclough of the U.S. Equal Employment Opportunity Commission also shared tips and resources for ADA compliance with attendees.





NCCDD Council members with NC Department of Health and Human Services (NC DHHS) Deputy Secretary Sherry Bradsher at the August Council meeting

## New Council Members

In 2015-2016, Governor Pat McCrory appointed three new members to NCCDD.



**Bryan Dooley**, Person with a Developmental Disability



**Dr. Jason Vogler**, Division of Mental Health, Developmental Disabilities and Substance Abuse Services



**Paula Woodhouse**, Parent of a Child with a Developmental Disability

## NCCDD Council Members

NCCDD, a 40-member board appointed by the Governor, is made up of:

- People with I/DD
- Family Members
- Representatives of State Agencies
- State Legislators
- Public at Large
- Representatives from Disability Rights NC and the Carolina Institute for Developmental Disabilities (CIDD)
- Provider and Local Management Entities/Managed Care Organization Representatives

### Members

- **Karen Armstrong**, Public at Large
- **Amanda Bergen, NCCDD Committee Chair**, Parent of a Child with a Developmental Disability
- **Wayne Black**, Director, Division of Social Services; Representative of the State Developmental Disability Authority (DHHS) (Alternate – **Jack Rogers**)
- **Wendy Boyd**, Parent of a Child with a Developmental Disability
- **Caroline Bradstock**, Person with a Developmental Disability
- **Adonis Brown, NCCDD Vice Chair**, Person with a Developmental Disability
- **Lisa Byrd**, Person with a Developmental Disability
  - **Christina Carter**, Representative of Nonprofit Group Concerned with Services to People with I/DD (Alternate – **Andrea Misenheimer**)
  - **Eric Chavis**, Person with a Developmental Disability
- **Anna Cunningham, NCCDD Secretary**, Parent of a Child with a Developmental Disability

- **Bryan Dooley**, Person with a Developmental Disability
- **Kerri Bennett Eaker, NCCDD Committee Chair**, Parent of a Person with a Developmental Disability, Living in, or Having Lived in an Institution
- **Mary Edwards**, Consumer Affairs Program Manager, Division of Aging and Adult Services; Representative of the Division of Aging (DHHS) (Alternate – **Joseph Breen**)
- **Jason Faircloth**, Person with a Developmental Disability
- **Dr. Joshua Gettinger**, Parent of a Child with a Developmental Disability
- **David Michael Groves**, Person with a Developmental Disability
- **Kathleen “Katie” Holler, NCCDD Vice Chair**, Parent of a Child with a Developmental Disability
- **William Hussey**, Director, Exceptional Children Program, Dept. Public Instruction; Representative of the NC Dept. of Public Instruction (Alternate – **Dreama McCoy**)
- **Rep. Verla Insko**, Representative of the NC House of Representatives
- **Wing K. Ng**, Parent of a Child with a Developmental Disability
- **Desiree Peterson**, Person with a Developmental Disability
- **Dr. Joseph Piven**, Carolina Institute on Developmental Disabilities, University Center on Excellence (UCEDD) (Alternate – **Deborah Zuver**)
- **Cheryl L. Powell**, Person with a Developmental Disability
- **Ron Reeve, NCCDD Chair**, Parent of an Adult with a Developmental Disability
- **I. Azell Reeves**, Parent of a Child with a Developmental Disability
- **Clare Shocket**, Parent of a Child with a Developmental Disability
- **Nessie Pruden Siler, NCCDD Committee Chair**, Person with a Developmental Disability
- **Dave Richard**, Deputy Secretary for Medical Assistance, Representative of the Designated State Agency (DSA-DHHS)
- **Vicki Smith**, Executive Director, Disability Rights NC (DRNC), Representative of the State Protection and Advocacy Agency
- **Jim Swain**, Division of Vocational Rehabilitation Services; Representative of the Division of Vocational Rehabilitation Services (DHHS)
- **Dr. Peggy Terhune**, CEO, Monarch; Local Non-Governmental Agency
- **Sandra Terrell**, Director of Clinical Services, Division of Medical Assistance; Representative of the Division of Medical Assistance (DHHS) (Alternate – **Deb Goda**)
- **Sen. Tommy Tucker**, Representative of the NC Senate
- **Dr. Jason Vogler**, Interim Senior Director, Division of Mental Health, Developmental Disabilities and Substance Abuse Services (Alternate – **Mya Lewis**)



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## NCCDD Partners and Staff

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**Steve Strom,**  
Systems Change  
Manager

**Melissa Swartz,**  
Systems Change  
Manager

**JoAnn Toomey,**  
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**Yadira Vasquez,**  
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**Shar'ron Williams,**  
Business Services  
Coordinator

**Philip Woodward,**  
Systems Change Manager

**Letha Young,**  
Office Assistant

[www.nccdd.org](http://www.nccdd.org)

### Partners

Under the general provisions of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the DD Councils, the protection and advocacy (P&A) agencies, and the University Center for Excellence in Developmental Disabilities (UCEDD) coordinate and collaborate on projects, initiatives and activities they undertake to fulfill the purpose of the DD Act.\* In addition to the NCCDD, the following organizations are part of the developmental disabilities network in North Carolina:

#### 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

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 system.



**\*The Developmental Disabilities Assistance and Bill of Rights Act (DD Act)** intends to “assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity and integration and inclusion in all facets of community life.”

#### Administration on Intellectual and Developmental Disabilities (AIDD)

provides financial and leadership support to organizations in every state and territory in the United States to ensure that individuals with developmental disabilities and their families can fully participate in and contribute to all aspects of community life.

