Welcome to NCCDD’s New Chair, Alexandra McArthur

Governor Roy Cooper appointed Alexandra “Alex” Cline McArthur as the new chairperson of the North Carolina Council on Developmental Disabilities (NCCDD). McArthur is a consultant in Advisory Services for the Taproot Foundation, an organization that drives social change by leading, mobilizing and engaging professionals in pro bono service. She was formerly the national director of Young Adult and Community Engagement for the Muscular Dystrophy Association (MDA).

NCCDD Partners

Under the general provisions of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (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.*

*The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (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.”

She also serves as the chairperson of the Board of Directors of the National Disability Institute, an organization that drives social impact to build a better economic future for people with disabilities and their families.

McArthur graduated from Davidson College, in Davidson, NC where she majored in History and also studied Spanish and Communications.

Administation 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 intellectual and other developmental disabilities (I/DD) and their families can fully participate in and contribute to all aspects of community life.

NC DEVELOPMENTAL DISABILITIES
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 is a non-profit 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.
The North Carolina Council on Developmental Disabilities (NCCDD) kicked off the year with great momentum and a mission to bring action to our new Five-Year Plan. With its implementation, the work of the Council is well underway to build partnerships that move forward a more fully inclusive and integrated North Carolina for people with intellectual and other developmental disabilities (I/DD).

With the support of NCCDD Council members, legislators, advocates, the community at-large and staff, we kicked off the year with a highly focused plan, specific goals and achievable outcomes. Our work and mission are closely tied with our three goals: 

- Increase financial security through asset development
- Increase community living
- Increase advocacy development

Supporting those goals, our community charged ahead. From hosting training sessions and seminars around the State in asset building, to attending the National Disability Policy Seminar in Washington, DC and NC Council of Community Programs’ Spring Policy Forum, to learning about state and federal policy changes within Medicaid, our Council members and self-advocates brought meaning to our work.

Multiple grassroots advocacy groups made big impacts by advocating for signage for accessible parking as well as lighter-weight accessible bathroom doors. Council members spoke on panels at the Carolina Institute for Developmental Disabilities community talks while NC Sibs hosted the State’s first-ever conference for siblings of individuals with I/DD.

We continued advocating for and recognizing avenues for inclusion and integration. NCCDD celebrated the 27th Anniversary of the Americans with Disabilities Act at the new Sassafras All Children’s Playground in Raleigh.

The year also welcomed a host of changes to the Council. Six members fulfilled their terms and NCCDD thanks them for dedicating their time, energy and resources to move our mission forward. Longtime chair, Ron Reeve, also announced his retirement. Their collective impact helped the Council become more innovative in its work for people with I/DD.

With those changes, we also welcomed new Council chair, Alexandra McArthur, and 10 new members to the Council.

It has been a year of focus and impactful accomplishments thanks to our members, partners and staff who uphold the Council’s mission to work collaboratively to assure that people 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 and inclusion in all areas of community life.

We look forward to continuing our partnership in advocacy into 2018, and the important work ahead of us.
To support the goals, NCCDD continued funding initiatives, while investing in new ones focusing on employment, natural supports and transportation.

The plan outlines goals, objectives and specific activities that are being implemented to bring about change. The State Plan also guides the Council regarding how fiscal resources are allocated. The Council’s State Plan is developed in accordance with the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

The Five-Year Plan (2017-2021) was adopted by the 40-member Council and was approved by the Administration on Intellectual and Developmental Disabilities (AIDD). Implementation began on October 1, 2016.

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 of 2000 (DD Act) for all North Carolinians with I/DD and their families.
Jack B. Hefner Memorial Award – Debra J. Burgess

Named after former NCCDD Council member and advocate for people with intellectual and other developmental disabilities (I/DD), the Jack B. Hefner Memorial Award recognizes advocates whose actions have improved the quality of life for people with I/DD across North Carolina.

In 2016, the award was given to Debra J. Burgess, a passionate parent advocate from Mebane, NC, who has been advocating for 25 years to bring awareness to Fragile X syndrome.

Burgess serves as the president of the North Carolina Fragile X Foundation and assists with the group's fundraisers to support the chapter and overall national efforts. She began her path of advocacy after her son, John David, was diagnosed with Fragile X syndrome.

Helen C. “Holly” Riddle Distinguished Service Award – Dr. Patricia Burns Porter

Awarded to professionals who have made lasting contributions towards improving opportunities, breaking down barriers and promoting increased quality of life for people with intellectual and other developmental disabilities (I/DD), the Helen C. “Holly” Riddle Distinguished Service Award was given to Dr. Patricia Burns Porter of Chapel Hill, NC.

A former NCCDD Council member, Dr. Porter is a consultant to the Joint Legislative Oversight Committee on Health and Human Services, NC General Assembly.

Formerly, she was the chief of developmental disabilities at the North Carolina Division of Mental Health/Developmental Disabilities/Substance Abuse Services (MH/DD/SAS). Under her leadership, the State experienced the greatest growth in community services for people with I/DD. She directed her efforts to moving people with I/DD into the community, and with NCCDD, she was instrumental in forming the DD Consortium and Consumer Advisory Committee.

The North Carolina Council on Developmental Disabilities (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 in honor of two leaders in the disability community who passionately worked and continue to work to build a better North Carolina for people with intellectual and other developmental disabilities (I/DD).

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

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

Expansion of Employment Opportunities for People with I/DD
This new in-house initiative establishes apprenticeships for individuals with I/DD, continues to support the expansion of Project SEARCH and form a coalition/partnership tasked with increasing employment opportunities for people with I/DD in North Carolina. In September 2017 this initiative hosted a mini-conference with more than 50 participants in Cary.

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. Through this initiative, NCCDD expanded Project SEARCH from two to 15 sites across the state. NC DHHS is the first in the nation to serve as a Project SEARCH site.

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 hosted four Train-The-Trainer programs during Developmental Disabilities Awareness Month in March 2017 with approximately 100 attendees across four cities.

COMMUNITY LIVING

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. Through the work of this initiative, a permanent Disability Integration Coordinator position was created.

From Planning to Action: Integrated, Collaborative Care for People with I/DD
The Arc of North Carolina in partnership with Easter Seals UCP and the Autism Society of NC
This new partnered initiative transitions the systems-change planning groundwork of the Medical Health Home Initiative into actionable demonstrations that advance innovation and access to quality healthcare for people with I/DD. This initiative piloted two actionable demonstrations with Duke University and TEACCH to increase primary care provider capacity.

Rethinking Guardianship: Building A Case For Less Restrictive Alternatives
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 alternatives to guardianship that advance productivity, independence, integration, inclusion and self-determination for people with I/DD. This year, the initiative launched a resource website: http://ssw.unc.edu/rethinking/home; built a knowledge base of best practices; introduced Restoration to Competency forms; and developed the Understanding Guardianship video.

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 developed intervention and primary prevention training addressing issues of sexual and domestic violence among the I/DD population. The training packages, targeted toward I/DD service providers and sexual assault service providers, includes a DVD of the training with an ASL interpreter and closed captioning. Direct support professionals and domestic violence support staff now have tools to meet the needs of victims with I/DD.

Supported Living: Making the Difference
Vaya Health
Joint effort between NCCDD and NC’s Money Follows the Person. This new initiative facilitated a learning collaborative of interested I/DD providers to examine how to better facilitate the practice of individuals with I/DD to live in their own homes and provide technical assistance to providers and direct support staff on supported living practices. Because of this initiative,
more than 15 people have moved into their own homes, nine from group living arrangements.

**ADVOCACY DEVELOPMENT**

**Inclusive Advocacy Leadership Development (IALD)**
This in-house initiative involves several important areas of advocacy and leadership development. The focus is on strengthening the visibility of self-advocacy in North Carolina. A new self-advocacy organization has formed as the NC Empowerment Network (NCEN). This is a collaborative effort with all of the North Carolina DD Network partners. This initiative also focuses on leadership development education and training for self-advocates, parents, professionals and other stakeholders.

**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 Affiliate Group ADA initiatives and participant travel/training expenses. 580 individuals with I/DD participated in these activities this year.

**North Carolina Chapter of the National Alliance for 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. Approximately 200 DSPs were interested in signing up to become members of the state chapter.

**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 to provide support and information specific to the unique aspects of the adult sibling relationship. On March 25, 2017, over 50 siblings throughout North Carolina gathered in Carrboro for the first ever NC Sibs conference which was designed for adult siblings, by adult siblings.

NCCDD and NC Treasurer Host ABLE Launch Event

With the assistance of NCCDD, the NC Department of State Treasurer’s office hosted an official launch of the NC ABLE (Achieving a Better Life Experience) program on April 2, 2017 at The Enrichment Center in Winston-Salem, NC. Treasurer Dale Folwell spoke to families and individuals with disabilities about the ABLE program, which will allow people with disabilities to save money without losing their Medicaid or SSI benefits.

The ABLE Program provides affordable, tax-advantaged accounts that allow eligible individuals with disabilities to build financial assets and live more independent lives.

Upward To Financial Stability Trains the Trainers

Upward to Financial Stability, an NCCDD initiative, hosted four Train-the-Trainer programs across North Carolina during Developmental Disabilities Awareness Month in March.

The National Disability Institute and The Collaborative held the two-day workshop to provide practitioners, service professionals and self-advocates an understanding of how individuals with disabilities can become more self-sufficient, less dependent on benefits and build a better financial future that promotes choice and greater community participation.

The events were held in Charlotte, Boone, Fayetteville and Raleigh and had approximately 100 attendees across all four cities.
NC Sibs Conference Welcomes Siblings

In March 2017, NC Sibs hosted the first ever NC Sibs conference in Carrboro, NC. The conference aimed to connect siblings with one another and provide support and information specific to the unique aspects of the adult sibling relationship. Supporting the Council’s Five-Year Plan goal of increased advocacy for people with I/DD, NC Sibs is funded through the Sibling Support initiative.

NCCDD hosted an ADA 27th Anniversary celebration event at the Sassafras All Children’s Playground in Raleigh, NC on July 23, 2017. The event welcomed families, advocates and children for a fun day in the park, celebrating the landmark law that promotes equal access for people with disabilities. The playground has been remodeled and designed to be a place for kids of all abilities to come together and play while promoting inclusion and integration for all members of the community.

Council Members in Action

Spring Policy Forum

Sessions at the NC Council of Community Programs Spring Policy Forum held in Raleigh on June 4-5, 2017 revolved around how to implement key business and clinical practices to ensure the ability to compete in a changing healthcare environment.

Represented by Council member I. Azell Reeves, former Council member Jonathan Ellis, Council staff Melissa Swartz and Philip C. Woodward, and NCCDD’s Executive Director Chris Egan, the Council learned about the proposed potential changes to Medicaid, federal advocacy goals and the NC Department of Health and Human Services’ (DHHS’) three areas of priority: the opioid crisis, Medicaid reform and investing in early childhood intervention and health.

UNC-CIDD Community Talk Series

NCCDD Council members Cheryl Powell and Bryan Dooley spoke on a panel hosted by the Carolina Institute for Developmental Disabilities (CIDD) Community Talk Series “Variations of a Full Life: A Panel Discussion with Disability Rights Advocates.” The talk included discussions on employment, marriage, disability rights and issues, as well as passions, for the disability community.
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
- Provider and Local Management Entities/Managed Care Organization Representatives

**COUNCIL MEMBERS**

- **Karen Armstrong**, Public at Large
- **Dr. 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 Disabilities Authority (DHHS) (Alternate – Teresa Strom)
- **Katherine Boeck**, Person with a Developmental Disability
- **Eric Chavis**, Person with a Developmental Disability
- **NaKima Clark**, Parent of a Child with a Developmental Disability
- **Anna Cunningham, NCCDD Secretary**, Parent of a Child with a Developmental Disability
- **Bryan Dooley**, Person with a Developmental Disability
- **Christina Dupuch**, Representative of Nonprofit Group Concerned with Services to People with I/DD (Alternate – Andrea Misenheimer)
- **Kerri Bennett Eaker, NCCDD Committee Chair**, Parent of a Person with a Developmental Disability, Residing in, or Having Resided 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
- **Sen. Valerie Foushee**, Representative of the NC Senate
- **Myron Michelle Gavin**, Parent of a Child with a Developmental Disability
- **Dr. Joshua Gettinger**, Parent of a Child with a Developmental Disability
- **David Michael Groves**, Person with a Developmental Disability
- **Brendon Hildreth**, 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)
- **Dr. Kelly Kimple**, Chief, Women’s and Children’s Health Section, Div. of Public Health, Representative of Women’s and Children’s Health (DHHS) (Alternate – Danielle Matula)
- **Aldea LaParr**, Person with a Developmental Disability
- **Alexandra “Alex” McArthur, NCCDD Chair**, Person with a Developmental Disability
- **William Miller, Esq.**, Person with a Developmental Disability

**Indicates New Members**
FFY 2017 NCCDD ACTUAL & BUDGET REPORT as of Oct 2017

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For the Period of October 1, 2016 - September 30, 2017

North Carolina’s Department of Health and Human Services (DHHS) Secretary Mandy K. Cohen, MD with the NCCDD Council at the May 2017 meeting.

- **Tara Myers**, Division of Vocational Rehabilitation Services; Representative of the Division of Vocational Rehabilitation Services (DHHS) (Alternate – Jim Swain)
- **Dr. Wing K. Ng**, NCCDD Vice Chair, Parent of a Child 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
- **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)
- **Daniel Smith, Esq.**, Parent of a Child with a Developmental Disability
- **Vicki Smith**, Executive Director, Disability Rights NC (DRNC), Representative of the State Protection and Advocacy Agency
- **James Stephenson, Esq.**, Parent of a Child with a Developmental Disability
- **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)
- **Dr. Jason Vogler**, Interim Senior Director, Division of Mental Health, Developmental Disabilities and Substance Abuse Services (Alternate – Mya Lewis)
- **Kelly Woodall**, Person with a Developmental Disability
- **Paula J. Woodhouse**, Parent of a Child with a Developmental Disability
Former NCCDD Chair Ron Reeve received the Order of the Long Leaf Pine for his service as chairman of NCCDD in February 2017. During his reception, Reeve reminded the Council to focus on high expectations, full inclusion and collaboration. The Order of the Long Leaf Pine is one of North Carolina’s highest civilian honors and is awarded for exemplary service to the State of North Carolina and their communities.

NCCDD Executive Director Chris Egan was presented with the Arc of North Carolina’s Deborah Greenblatt Distinguished Service Award for extraordinary contributions within the community of intellectual and developmental disabilities. The award honors an individual or organization that has contributed in a distinguished manner to the promotion of rights and/or services to North Carolina citizens with developmental disabilities.

NCCDD Systems Change Manager Philip C. Woodward received the Raleigh Mayor’s Committee for Persons with Disabilities’ 2016 James E. Meekins Award. The award honors an individual with a disability who is recognized for his/her outstanding achievement in the workplace and for significant contributions that increase public awareness of individuals with disabilities.