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2019 THE YEAR IN REVIEW

OUR MISSION

The North Carolina Council on Developmental Disabilities (NCCDD) works collaboratively, across the state, to assure that people with intellectual or 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.



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FOCUS ON INCLUSION

The North Carolina Council on Developmental Disabilities (NCCDD) went into its third year of the current Five-Year Plan with an increased and dedicated focus. We continued championing partnerships that will help North Carolina become a more fully inclusive and integrated state for people with intellectual or other developmental disabilities (I/DD).

The hard work and support of NCCDD members, legislators, advocates, staff and the entire disability community-at-large continued into the new year with efforts focused on a continued plan with specific and strategic goals and achievable outcomes. The Council's work and mission are closely tied with our three goals:

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

Throughout the year, the Council and the community worked together to achieve those goals. From hosting Natural Support Network Development community conversations to painting the accessible icon in several Raleigh sites to hosting and participating in Guardianship, and Integrated Care and Sustainability Summits, advocates of all abilities and our Council members showcased their dedication to building an inclusive North Carolina.

This year, North Carolina officially became an Employment First State, making employment in the general workforce the first and preferred option for people with disabilities by Governor Roy Cooper signing Executive Order 92! A decade in the making, the efforts of NCCDD, NC Vocational Rehabilitation, NC Division of MH/DD/SAS and others brought this milestone to working-age North Carolinians with disabilities.

Building on our lasting partnerships, NCCDD met with NC disability organizations like Project SEARCH, Trillium Health, The Arc of North Carolina and others to get up-to-date information on disability services, discuss our mission and the direction of our work for the disability community going into 2020 and beyond.

Honoring the I/DD community and the efforts of advocates, we celebrated the 29th anniversary of the passing of the Americans with Disabilities Act (ADA) by being in the community! People from all over the state attended ADA anniversary events and learned how to highlight the progress the ADA has made with different themes throughout the year.

We are excited to see what 2020 brings as we continue to work diligently and collaboratively with the community and our statewide partners to build sustainable initiatives that will continue to increase financial security, community living and advocacy networks on behalf of the 1.3 million North Carolinians with disabilities and their families.

Sincerely,

Alexandra "Alex" McArthur, NCCDD Chair



THANK YOU. **CHRIS EGAN**

Chris Egan, who joined NCCDD as its Executive Director in June 2014, resigned his position in October 2018 to become the Senior Director of Employment Services for the North Carolina Department of Health and Human Services. There, he oversees the Division of Vocational Rehabilitation (DVR), Division of Services for the Deaf and Hard of Hearing (DSDHH), Disability Determination Services (DDS), the Division of Services for the Blind (DSB), and the NCCDD. NCCDD thanks Senior Director Egan for all his hard work focusing on systems change efforts for people with I/DD in North Carolina.



FIVE YEAR PLAN: YEAR THREE



Listen, Gather, Act.

In its third year of the Five-Year Plan (2017-2021), the North Carolina Council on Developmental Disabilities (NCCDD) is continuing to make an impact across the State towards its three goals of increasing:

- Financial Asset Development
- Community Living
- Advocacy Development

Throughout the year, NCCDD supported conferences, summits and gatherings in the community to further its goals of the Five Year Plan. The events focused on guardianship, employment, supports, advocacy, financial stability and community living.

NCCDD IN ACTION

NCCDD HOSTS RETHINKING GUARDIANSHIP SUMMIT

NCCDD's Rethinking Guardianship: A Person-Centered Approach initiative hosted the *Rethinking Guardianship Summit* in February 2019 in Raleigh, which focused on adult guardianship and North Carolina's laws and practices governing the removal of a person's right to make life decisions.

Nearly 280 people were in attendance at the Royal Banquet & Conference Center and heard messages of support from Senators Richard Burr and Thom Tillis, who contributed to the US Senate Special Committee on Aging's guardianship report.

CELEBRATING ADA 29

The Council celebrated the 29th Anniversary of the Americans with Disabilities Act (ADA) during ADA week at the end of July 2019 with celebrations in Raleigh, Carrboro, Durham and Charlotte. ADA Month was kicked off with an ADA Live! Podcast with chief ADA sponsor, Senator Tom Harkin.

FUN AT THE BEACH

In May 2019, NCCDD members held their May Council meeting at the Courtyard by Marriott in Carolina Beach. During their free time, they were able to access and enjoy the beach thanks to the Town of Carolina Beach and Ocean Cure. About 50 yards

50 BY

laid at Carolina Beach to make it more accessible for people with disabilities.

of rubberized material was laid connecting the beach to the boardwalk, creating an accessible surface for wheelchairs, walkers or strollers.

Council members Brendon Hildreth and Aldea LaParr enjoyed the sun, sand and water thanks to Ocean Cure's two reserved beach wheelchairs.



Rethinking Guardianship Summit



Celebrating the ADA



Accessible Icon Painting Project

ACCESSIBLE ICON PAINTING PROJECT

Celebrating Developmental Disabilities
Awareness Month, 25 people joined NCCDD
Council member Brendon Hildreth on March
30, 2019 in painting the new accessible icon
in six accessible parking spots at NCCDD's office.

Volunteers painted 25 total spaces around Raleigh and included former NCCDD Executive Director Chris Egan, Department of Health and Human Services (DHHS) Assistant Secretary of Public Health Mark Benton, DHHS Health Services Chief of Staff Matthew Herr, City of Raleigh Human Relations Commission Executive Director Dr. Audrea Caesar and NCCDD staff.

PATHWAYS TO INNOVATION SUMMIT

Six current Council members joined 89 other participants for the I/DD Medical Health Home initiative's *Pathways to Innovation, Integrated Care and Sustainability: What we are learning from North Carolina Consultation Projects* and Partnerships Summit in May 2019. Participants included people with I/DD, families, state government, LME/MCOs, MCOs, health care providers and others from across the state.

The Summit illustrated how collaboration is a critical element in removing barriers to care and promoting access to high quality, integrated, person-centered care.

EASTERN NC DISABILITY ORGANIZATIONS NETWORKING

During NCCDD's May 2019 meeting at Carolina Beach, NC, eight individuals representing eastern North Carolina disability organizations met Council members and shared information about their organizations. Representatives included Project SEARCH, NCVR, Robeson Community College, Trillium Health, disAbility Resource Center, The Arc of North Carolina, Brunswick Community College, Community Care of the Lower Cape Fear and New Hanover County Public Health.





Fun at the Beach

Eastern NC Disability Organizations



EMPLOYMENT FIRST COMES TO NC

On March 28, 2019, Governor Roy Cooper signed Executive Order 92: Employment First for North Carolinians with Disabilities, officially making North Carolina an Employment First state.

"North Carolina can be its best when all people have the opportunity to achieve their potential and live lives of purpose, including North Carolinians with disabilities," Gov.

Cooper said. "With this order, I'm establishing meaningful work as the first and preferred choice for all North Carolinians, regardless of disability, and directing state government to lead the way on including more people with disabilities in the workplace."

The principles of Employment First include working in integrated settings and earning competitive wages and benefits; securing employment with reasonable and appropriate placement and support; employees with and without disabilities are equally valued and that jobs should match an individual's work skills, abilities and career choices to the greatest extent possible.

The Employment First declaration builds on previous disability employment initiatives like the NC Job Ready initiative, the Hometown Strong initiative, and NCCDD's EveryBody Works NC campaign, which increased awareness of the skills and expertise in the untapped talent pool of North Carolinians with disabilities.

NCCDD was proud to be in attendance and among the speakers to celebrate this achievement.



NCCDD Chair Alex McArthur, Riddle award winner Duncan Munn, former NCCDD Executive Director Chris Egan, Leadership award winner Ellen Perry and Hefner award winner Merlie Jackson



Hefner award winner Merlie Jackson (center), with her daughter Jessie, and members of the Hefner family

2018 ADVOCACY & LEADERSHIP AWARDS

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 leaders in the disability community who passionately worked and continue to work to build a better North Carolina for people with intellectual or other developmental disabilities (I/DD).

In 2018, NCCDD added the North Carolina Leadership Achievement Award to recognize an outstanding North Carolina self-advocate whose work improved the quality of life for people with I/DD.

The awards ceremony was held during the November 2018 meeting in Cary, NC. Advocates, professionals and community members joined NCCDD to celebrate the year's work and to honor the recipients.



Jack B. Hefner Memorial Award – Merlie Jackson

Given to celebrate the vision and achievement of North Carolina's families and people with intellectual or other developmental disabilities (I/DD) and named after former NCCDD Council member and advocate, 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 2018, the award was given to Merlie Jackson of Wilkesboro, NC, for her work and support of the National Tay-Sachs & Allied Diseases Association (NTSAD), an organization that seeks cures for many diseases including Gangliosidosis GM-1. Her daughter, Jessie, is diagnosed with GM-1.

Jackson created and hosts an annual "Ride for Jessie" motorcycle ride in central North Carolina to raise money for a cure. She is also a key figure at the NTSAD Annual Family Conference where she offers assistance and advice to other parents whose children have GM-1.



Council member Aldea LaParr, Darcy Hildreth, Council member Brendon Hildreth and NCCDD Systems Change Manager Philip Woodward.



Riddle award winner Duncan Munn with his wife Marsha (I to r), his cousin Dr. Edward Newton and wife Karen

Helen C. "Holly" Riddle **Distinguished Service** Award - Duncan Munn

The Helen C. "Holly" Riddle Distinguished Service Award is named after NCCDD's former longtime Director and is given to professionals who have made lasting contributions towards improving opportunities, breaking down barriers and promoting increased quality of life for people with I/DD. The 2018 recipient was Duncan Munn of Raleigh, NC.

During his extensive work career, Munn developed a premier early intervention program (EIP) for infants and toddlers with I/DD, a first in North Carolina and the country. He was also employed as the chief of Community Support Services for the NC Division of Mental Health and Developmental Disabilities and for 25 years directed the NC Early Intervention Program.

Following his retirement, Munn also helped launch Beyond Academics, a program at UNC-Greensboro that supports students with I/DD in earning a four-year certificate of study that emphasizes life and career planning and self-determination.



Leadership award winner Ellen Perry (left) with former NCCDD Executive Director Helen C. "Holly" Riddle

North Carolina Leadership **Achievement Award –**

Ellen Perry

Presented for the first time in 2018, the NC Leadership Achievement Award is given to an outstanding North Carolina self-advocate whose work has improved the quality of life for people with I/DD.

Carrboro, NC resident and former Council member Ellen Perry was honored with the award for her instrumental work with the City of Carrboro's leadership in implementing beneficial navigational changes for people with I/DD.

Along with her work with the city, Perry also served on the state and national boards of the Association of People Supporting Employment First (APSE), on the NC Association of Self-Advocates, the Southern Collaborative, the Carrboro Transportation Advisory Board and state and local Consumer Family Advisory Committees.



Jill Hinton, Kelly Friedlander, Council member Christina Dupuch, Nancy Weiss and Council member Virginia Knowlton Marcus



Council member Katie Holler, DHHS Asst. Secretary of Public Health Mark Benton and Council member Tara Myers

TAKING THE INITIATIVE TOWARD SUCCESS

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 or other developmental disabilities (I/DD) in North Carolina.



NC ADA Network Train-the-Trainer workshop

NEW INITIATIVES



FINANCIAL ASSET DEVELOPMENT

NC EMPLOYMENT COLLABORATIVE Disability:IN

A new initiative that focuses on providing technical assistance, coordination and other support for the efforts of the Unified State Plan Committee, made up of the Community College System, Department of Commerce and the Department of Health and Human Services. As employment policy is recommended, this initiative will highlight innovative approaches to competitive integrated employment for people living with I/DD.

NCABLE PROJECT PROSPERITY The Collaborative

This new initiative aims to increase public awareness and expand outreach efforts through training and education about NCABLE accounts and other savings options available to people living with disabilities and their families. Participating partners include the Department of State Treasurer, NC Vocational Rehabilitation and trainers from Upward to Financial Stability for coordinated outreach efforts including live presentations or trainings, live and on demand webinars, literature and leave behinds, and overview vignettes.



COMMUNITY LIVING

RETHINKING GUARDIANSHIP: A PERSON-CENTERED APPROACH: UNC-Chapel Hill, Jordan Institute for Families

Building on the work of the Rethinking Guardianship: Building a Case for Less Restrictive Alternatives initiative, NCCDD developed this initiative to provide training, consultation and technical assistance to support the development of policies and practices, relative to guardianship and alternatives that advance productivity, independence, integration, inclusion and self-determination for people with I/DD.

CONTINUING INITIATIVES



COMMUNITY LIVING

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 partnered initiative transitions the systems change planning groundwork of the Medical Heath Home Initiative into actionable demonstrations that advance innovation and access to quality healthcare for people with I/DD.

This initiative completed two actionable cohorts with TEACCH, University of North Carolina – Chapel Hill, established the Duke NC Pediatric Access Line (NC PAL) to provide referral support for youth with I/DD and their families, and increased stakeholder engagement.

CROSS-SYSTEM NAVIGATION IN A MANAGED CARE ENVIRONMENT i2i Center for Integrative Health

A partnered initiative that studies the cross-system navigation components that accompanies the NC DHHS managed care system plans, integrating both physical and behavioral health and accesses the Medicaid options available to individuals with I/DD. Through this initiative, NCCDD plans to produce a future Workforce White Paper and Grant Recommendation Report to DHHS, state policymakers and other leadership. As of September 2019, a website has been developed and Cross-System Navigation Advisory Workgroup invitations were created.

NATURAL SUPPORT NETWORK DEVELOPMENT FIRST Resource Center

A natural support network initiative, which expands the capacity of North Carolinians with disabilities to develop non-paid relationships, foster opportunities for natural supports and train Network Facilitators and individuals with I/DD who want to develop their support networks. The initiative helped to host Community Conversations in Black Mountain and Goldsboro and as of July 2019, trained 23 people on the principles, values and practices of Personal Support Network Facilitation.

SUPPORTED LIVING: MAKING THE DIFFERENCE Vaya Health

NCCDD and NC's Money Follows the Person's joint effort that 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

People with disabilities who have moved into their own homes (11 from group living) because of Supported Living living practices. Three Virtual Stakeholder meetings were hosted in the fiscal year; two provider webinars were hosted in February and March 2019:

> and work continues on a Supported Living guidebook. Currently,

32 people have moved into their own homes, 11 from group living arrangements as a result of the initiative.



INROADS TO EMPLOYMENT: Disability:IN

NCCDD's initiative that expands on and creates new paid apprenticeships for individuals with I/DD, leading to integrated, competitive employment and career opportunities. As of August 2019, registered

apprenticeships have been established through the initiative in Burlington and Greensboro, NC and approximately **60 students** have received **Pre-Employment Transition Services** through the **READY program.**



Students with I/DD who have received Pre-Employment **Transition Services through** the READY program.

66 Employment First makes employment in the general workforce the first and preferred option for people with disabilities.



NC ADA NETWORK - FISCAL INTERMEDIARY Community Enterprise, LLC

The NC ADA Network supports grassroots groups, led by people with disabilities, to conduct projects that promote voluntary compliance with the Americans with Disabilities Act (ADA) in their local communities. The Fiscal Intermediary provides timely, accurate reimbursement for the funding of Network Affiliate Group ADA initiatives and participant travel/training expenses. Over 23 local

grassroots groups, led by people with disabilities, from across North Carolina are active members of the NC ADA Network.

These groups have provided ADA technical assistance to 819 people including people with disabilities, family members and business representatives. 819 F

People with disabilities who received ADA technical assistance from grassroots groups in NC ADA Network

INCLUSIVE LEADERSHIP DEVELOPMENT TRAINING Disability Rights North Carolina

Creating opportunities for Disability Rights North Carolina (DRNC) and the Center for Creative Leadership (CCL), this initiative created the partnership to design and implement an innovative and unique leadership development program for people with I/DD, family members and guardians, professionals and other stakeholders to support advocacy for systems change in North Carolina. The training curriculum was completed in October 2019 and aims to do pilot training with 12 advocates with the necessary skills to effectively advocate for themselves as well as train and mentor others.

North Carolina Council on Developmental Disabilities



THE COUNCIL

North Carolina Council on Developmental Disabilities (NCCDD), a 40-member body appointed by the Governor, is 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
- Provider and Local Management Entities/Managed Care Organization representatives

COUNCIL MEMBERS

- Dawn H. Allen, Public at Large
- Amanda N. Bergen, NCCDD Committee Chair, Parent of a Person with I/DD
- Katherine Boeck, Person with I/DD
- Eric Chavis. Person with I/DD
- NaKima Clark, Parent of a Person with I/DD
- Anna R. Cunningham, Parent of a Person with I/DD
- Alison S. Dodson, Sibling of a Person with I/DD
- Bryan Dooley, Person with I/DD
- Christina Dupuch, CEO, Vaya Health, Representative of Non-Profit group concerned w/ services to People with I/DD (Alt: Andrea Misenheimer)
- Kerri Bennett Eaker, NCCDD Committee Chair, Parent of a Person with I/DD Living in, or Having Lived in, an Institution
- Mary Edwards, Consumer Affairs Program Manager, Division of Aging and Adult Services, Representative of the NC Division of Aging = Older Americans Act (Alt: Joseph Breen)
- Jason Faircloth, Person with I/DD
- Myron Michelle Gavin, NCCDD Vice Chair, Parent of a Person with I/DD
- Dr. Joshua Gettinger, Parent of a Person with I/DD
- Brendon Hildreth, Person with I/DD

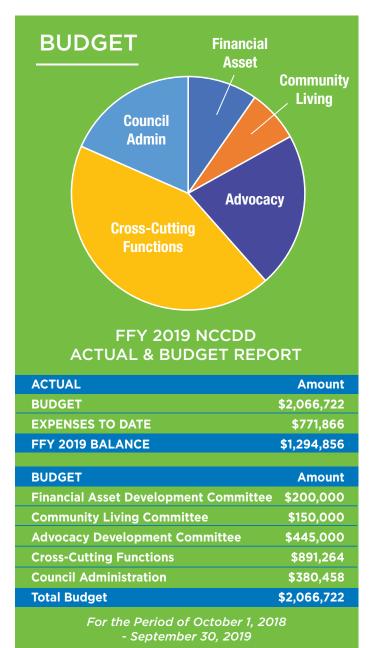
- Kathleen "Katie" Holler, Parent of a Person with I/DD
- Rep. Verla Insko, Representative of the NC House of Representatives
- Dr. Gary N. Junker, Representative of the State Department of Public Safety (Alt: Jamila Little)
- Dr. Kelly Kimple, Chief, Women's and Children's Health, Representative of Women's and Children's Health (DHHS) (Alt: Danielle Matula)
- Aldea LaParr, NCCDD Secretary, Person with I/DD
- Kristy Locklear, Parent of a Person with I/DD
- Alexandra McArthur, Chairperson, Person with I/DD
- William Miller, Person with I/DD
- Senator Mujtaba Mohammed, Representative of the NC Senate
- Dr. Wing K. Ng, Parent of a Person with I/DD
- Dr. Joseph Piven, Carolina Institute on Developmental Disabilities, University Center of Excellence (UCEDD) (Alt: Deb Zuver)
- Cheryl L. Powell, NCCDD Vice Chair, Person with I/DD
- Dave Richard, Deputy Sec. of Department of Health and Human Services, Representative of the Designated State Agency (DHHS)
- Ryan Rotundo, Sibling of a Person with I/DD
- Nessie Pruden Siler, NCCDD Committee Chair, Person with I/DD

- Virginia Knowlton Marcus,
 Executive Director, Disability
 Rights NC (P&A), Representative
 of the State Protection and
 Advocacy Agency-Disability
 Rights NC (DRNC)
- **Daniel Smith**, Parent of a Person with I/DD
- James Stephenson, Parent of a Person with I/DD
- Dr. Peggy Terhune, CEO, Monarch;
 Local Non-Governmental Agency
- Sandy Terrell, Director of Clinical Services, Division of Medical Assistance, Representative of the Division of Medical Assistance (DHHS) (Alt: Deb Goda)
- Sherry H. Thomas, State Director, Exceptional Children Division, NC Dept. Public Instruction, Representative of the NC Dept. of Public Instruction (Alt: Dreama McCoy)
- Kathie Trotter, Director of Vocational Rehabilitation, Representative of Vocational Rehabilitation (Alt: Jim Swain)
- Kelly Woodall, Person with I/DD
- VACANT Representative of the State Developmental Disabilities Authority (DHHS-MH/DD/ SAS); (Alt: Mya Lewis)
- VACANT Representative of the State Developmental Disabilities Authority (DHHS-DSS); (Alt: Teresa Strom)

Please Note: Green indicates a new Council Member









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 & 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."

OFFICE OF INTELLECTUAL AND **DEVELOPMENTAL DISABILITIES (OIDD),**

under the Administration on Disabilities (AOD), under the Administration for Community Living (ACL) is a federal agency dedicated to ensuring that individuals with developmental disabilities and their families are able to live with dignity, make their own choices, and fully participate in and contribute to all aspects of community life in the United States and its territories.

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 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.



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NCCDD STAFF

Chris Egan, Former Executive Director (position vacant since October 2018)

JoAnn Toomey,

Director of Operations

David Ingram,

Systems Change Manager

Melissa Swartz,

Systems Change Manager

Travis Williams,

Systems Change Manager

Philip C. Woodward,

Systems Change Manager

Yadira Vasquez,

Business Officer

Cora Gibson,

Administrative Specialist II

Letha Young,

Administrative Specialist I

Shar'ron Williams,

Business Services

Coordinator



NCCDD FIVE YEAR PLAN

GOAL 1: Increase Financial Security



NCCDD FIVE YEAR PLAN

GOAL 2: Increase Community Living



NCCDD FIVE YEAR PLAN

GOAL 3: Increase Advocacy

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