A Newsletter from the North Carolina Council on Developmental Disabilities

November 2017



NCCDD Executive Director Chris Egan

# A Message from the Executive Director

November is the time of year when we are reminded to reflect on what we are thankful for. It is also the month of the annual meeting of the NC Council on Developmental Disabilities (NCCDD).

At the November meeting, members were updated about the accomplishments of recently completed initiatives such as our Emergency Preparedness collaboration with the NC Division of Emergency Management that includes the planned hiring of a full-time disability integration planner for North Carolina's Department of Emergency Management. Members also received an update about the Sibling Support initiative, a partnership with First in Families of NC that has connected 140 siblings of brothers and sisters with I/DD across the state of North Carolina who share ideas, offer support and provide resources.

During the meeting, we also recognize and celebrate leadership with the annual Advocacy and Leadership Awards event. In this newsletter, you will learn about Sherry Paul and Tony Dalton. They were the recipients of NCCDD's Jack B. Hefner Memorial Award and Helen C. "Holly" Riddle Award, respectively, for their work and advocacy for people with I/DD. In addition, we have posted videos highlighting each of these leaders on the NCCDD website and NCCDD YouTube channel!

We are underway in year two of our Five-Year Plan and are supporting important initiatives that help us implement the goals of the plan. As we continue to focus on our mission 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, we know that it's a collaborative effort.

We are taking all that we learned in the previous year and are applying lessons learned in our future investments to expand

### NCCDD Releases RFA for Improving Transportation Options

In its State plan, NCCDD set out the goal that the Council will increase community living for individuals with intellectual and other developmental disabilities (I/DD). Throughout their lifespan, more individuals with I/DD will be fully included, respected, valued and supported in their communities.

To reach this goal, the NCCDD has committed its funds to promote systems change innovations that will enable individuals with I/DD to have greater access to safe, reliable, affordable, and accessible transportation, thereby leading to greater independence and integration into their communities. This initiative will foster a mutual learning opportunity for public and private transportation services and individuals with I/DD to learn from each other and create solutions to transportation barriers and accessibility challenges using emerging transportation technologies and concepts that will benefit all citizens of North Carolina.

NCCDD seeks to foster a mutual learning opportunity for public and private transportation services and individuals with I/DD. It will aim to foster learning and creating solutions to transportation barriers and accessibility challenges using emerging transportation technologies and concepts benefiting all citizens of North Carolina. Details on this proposed initiative and RFA are available <a href="https://www.ddsuite.org/?nofa">https://www.ddsuite.org/?nofa</a> id=1417

### **Public Policy Update**

#### STATE UPDATE - 115 Waiver

In September 2015, the NC General Assembly enacted Session Law 2015-245, directing the transition of Medicaid from a fee-for-service structure to a managed care structure. On Nov. 20, 2017, North Carolina submitted an amended 1115 demonstration waiver application to the federal Centers for Medicare & Medicaid Services (CMS). This is a revised version of the 1115 waiver application that North Carolina submitted to CMS in June 2016. This 1115 submission focuses on the

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# Tony Dalton and Sherry Paul Honored at NCCDD Awards Reception

Byron Anthony "Tony" Dalton and Sherry Paul were honored for their outstanding contributions in advocacy and leadership in the North Carolina disability community at the North Carolina Council on Developmental Disabilities (NCCDD) Advocacy and Leadership Awards on Nov. 1 at the Hilton Garden Inn in Cary, NC.

Dalton, who worked for and led the Developmental Disabilities Training Institute (DDTI) at the University of North Carolina for 34 years, received the Helen C. "Holly" Riddle Distinguished Service Award that honors leadership by a professional in the field of intellectual and other developmental disabilities (I/DD).

Dalton began as a consultant in vocational services at DDTI in 1972, eventually becoming director in 2001. During that time, North Carolina shifted from an institutional system of services to a more individual and community-based system of supports and services. During his career, Dalton also traveled as a speaker and consultant, wrote training materials and grants, and participated in the governance of local, public and private I/DD agencies and professional organizations.

Paul, who most recently retired as a recreation supervisor at High Point Parks and Recreation, was awarded the coveted Jack B. Hefner Memorial Award which celebrates the vision and achievement of advocacy by North Carolina's families and people with I/DD.

While at High Point Parks and Recreation, Paul became active with Special Olympics of North Carolina, serving as a local program coordinator, board member, volunteer games director and coach. Her biggest impact with Special Olympics began



2017 Hefner Memorial Award Recipient Sherry Paul with her family



2017 Riddle Distinguished Service Award Recipient Tony Dalton with his family

in 1991 when she helped train the first class of Athletes for Outreach, a program allowing athletes to share their stories, voices and opinions. To this day, in retirement, she continues to train Special Olympics' athletes in that program, now known as Global Messengers, even traveling overseas with the athletes as they spread their message of life with disabilities and their participation in Special Olympics.

Chris Egan, executive director of NCCDD, said, "Our Council is very pleased to honor Tony Dalton and Sherry Paul as this this year's recipients of the Helen C. "Holly" Riddle Distinguished Service Award and Jack B. Hefner Memorial Award. Tony has been a strong mentor to so many of us, focusing on expanding choices and opportunities for individuals with I/DD. Meanwhile, Sherry's long-term commitment to supporting athletes to share their stories fosters leadership development and self-advocacy.

Both these leaders have done a tremendous amount of work to uplift and encourage communities about the capabilities of individuals with intellectual and other developmental disabilities," said Egan.





### Making Work WORK for Families and Guardians

NCCDD hosted a one-day mini-conference titled "Making Work WORK for Families and Guardians" on September 22 in Cary. More than 50 people participated in the event coordinated by Systems Change Managers Philip Woodward and Travis Williams and I/DD Employment Services Coordinator Pat Keul as a collaborative effort involving NCCDD's Expansion of Employment



Holly Stiles gave the keynote speech

Opportunities for People with I/DD and its Rethinking Guardianship: Building a Case for Less Restrictive Alternatives initiatives. This event aimed to

address the issue of how guardianship impacts employment options for people with I/DD and how families can best support individuals with I/DD in obtaining competitive, integrated employment.

Holly Stiles, Lead Attorney for the Community Access Team at Disability Rights North Carolina, provided the opening keynote "Great Expectations: Alternatives to Guardianship," discussing the numerous voluntary decision-making agreements that people with I/DD and their families can utilize.

Three panels gave participants the opportunity to hear from both service providers and individuals with I/DD who are successfully employed:

- How Finances Impact Working and Guardianship
- Understanding Guardianship and Families and How They Impact Work
- · Taking Guardianship to the Next Level with Employment

David Ingram, I/DD Employment Specialist at the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) provided the closing keynote "Employment and Guardianship," stating, "Research shows



Understanding Guardianship and Families and How They Impact Work panelists: Gerri Smith, Laura Newell, and Holly Stiles with moderator Philip Woodward (back)

that everyone can work" and sharing National Core Indicators statistics such as 50 percent of people with I/DD wanting to work, but only 14 percent having integrated employment.

Panelist presentations included NC Department of State

Treasurer staff providing information about the North Carolina ABLE Program; Laura Newell, a self-advocate and Administrative Peer Mentor at InReach, sharing the story of her journey through community college to employment; and Britton Scercy, an Office Assistant at the Autism Society of North Carolina's Greenville office, and his mother, Jill, describing how he has benefited from North Carolina's Medicaid Buy-In.

NCCDD wishes to thank all of its community partners who had an information table and contributed to the keynotes and panels and The Arc of North Carolina for providing exciting door prizes that

day. Access the mini-conference presentation and materials at: https://www.nccdd.org/expansion-of-employment-opportunities-for-people-with-i-dd.html



Philip Woodward, Pat Keul and Travis Williams





### Council Member Spotlight - Brendon Hildreth



**Brendon Hildreth** 

Brendon Hildreth has a life goal of seeing that everyone gets the same opportunity to do what they would like to do in this world.

"I strongly feel that all people belong in the real world and that all people should be given a chance to be the best and most successful person that they can be," explains Hildreth.

Hildreth is one of nine new members appointed

to the North Carolina Council on Developmental Disabilities (NCCDD) by Governor Roy Cooper.

He is the director of the Accessible Icon Project of North Carolina, which is ongoing work of what he calls "design activism." The project started when Hildreth lived in Boston. It's a redesign of the traditional accessible parking logo to be one that is a more "active" symbol, and to be placed on locales that were accessible to individuals with varying abilities.

Today, the new icon has gone global and is being used in hundreds of cities and towns, at private and public organizations, and by governments and individuals, including sites across the state of North Carolina. Hildreth is also a student at Craven Community College in New Bern, NC. He will receive two

associates' degrees next May, one in Manufacturing Technology-Composites and the second in Computer Aided Drafting (CAD).

Born with cerebral palsy, Hildreth explains that it affects his physical movements and speech. "I went through lots of physical therapies and braces and have learned how to make my body work best for me. For speech, I use a communication device which allows me to enter in my words and will speak for me. I can speak, but at times it may be a little hard to understand what I am saying. People with patience will often listen and understand what I am saying," he adds.

Hildreth hopes his time on the Council can be used to focus on guidelines for state agencies that assist people with disabilities so they all offer the same services. "I have found that the same agencies in different counties provide a different set of assistance, but do not meet what the State is saying they can do. All people in North Carolina should be treated the same, not based on what county they live in.

"I am still learning what the Council is working on. But, I liked that there are people and groups present in the meetings that can get things done. I feel like actions will be taken, not just listened to and forgotten," Hildreth said.

Currently a resident of New Bern, Hildreth is a fan of New England sports teams, specifically the Red Sox, Patriots and Boston Bruins. Hildreth himself is very active and likes to go to the gym, golf and play sports such as baseball and hockey.

### #EveryBodyWorksNC: The Rewards of Work

Ken Wease, former Chief Financial Officer (CFO) of Alliance of Disability Advocates, and Philip C. Woodward, Systems Change



Manager at NCCDD, share what they love about their work and why people with disabilities are assets to all organizations and companies. Watch their stories here: https://nccdd.org/general-content/543-employing-people-with-disabilities-in-their-own-words.html

### About EveryBody Works NC:

The Everybody Works NC campaign is increasing awareness of the untapped pool of talent found in the disability community and creating more and more job opportunities for people with disabilities. October was National Disability Employment Awareness Month (NDEAM), which kicked off the year-long EveryBody Works NC campaign with a statewide speaking tour, media relations programs, social media and a series of special events. The campaign is led by the North Carolina Council on Developmental Disabilities (NCCDD), the North Carolina Business Leadership Network (NCBLN) and the North Carolina Vocational Rehabilitation (NCVR) to promote and support inclusive workforce strategies.



### Public Policy Update (continued from page 1)

aspects of the managed care transformation that require CMS approval; the more comprehensive descriptions are found on the website and are documents the Council has reviewed and responded to in the past. This amendment is the next step in the transformation of North Carolina Medicaid and NC Health Choice programs to managed care.

The waiver application, as well as several other documents that are related to proposed changes, is found on the NC DHHS website. Two documents of particular interest are "Medicaid Managed Care Program Design" and "Behavioral Health I/DD Tailored Plan Concept Paper". The Council has reviewed and discussed these in the past, but following the submission of the waiver application to CMS, there is opportunity for more feedback and input.

"As the Department of Health and Human Services (the Department) prepares to launch Medicaid managed care in 2019, it will continue to work with stakeholders and experts to refine program details and ensure a transparent process."

Comments are welcome and encouraged, and will be accepted through Dec. 29, 2017. Submit comments through:

Email: Medicaid.Transformation@dhhs.nc.gov

**US Mail:** Dept. of Health and Human Services, Division of Health Benefits, 1950 Mail Service Center, Raleigh, NC 27699-1950 **Drop-off:** Dept. of Health and Human Services, Dorothea Dix Campus, Adams Building Reception, 101 Blair Drive, Raleigh, NC

#### Cardinal Innovations

Like many of you, we have been following the news about Cardinal Innovations. As of Monday November 27th, the NC Department of Health and Human Services (NC DHHS) has temporarily assumed leadership of Cardinal Innovations, an LME-MCO authorized under state law to provide essential behavioral health services using public funds. NC DHHS has also revoked approval of the current board composition effectively immediately, which means the prior board has no authority to take any further action. These actions are in response to many concerns, including the compensation and benefit packages of the CEO and other top leadership positions.

The following statement was sent out to the providers in the Cardinal catchment area:

Yesterday afternoon, the DHHS arrived at Cardinal Innovations unexpectedly and informed the Executive Leadership Team that

the Department is assuming control of Cardinal's governance. This enables the Department to remove the current Board of Directors and previously announced departing executives immediately.

This action by the state is strictly related to our governance, and is temporary as the state works closely with our leadership to manage and stabilize



operations as we transition both CEO and board leadership. This will not impact services to our members or our day-to-day operations, including regular and prompt payment to providers.

We are committed to a strong partnership with the Department and expect to work quickly and closely with them to address their outstanding concerns so that we can continue to take the best possible care of our members and their families.

We will continue to follow the developments related to Cardinal. Below are links to several of the news stories:

http://www.charlotteobserver.com/news/politics-government/ article186744443.html

http://www.wral.com/n-carolina-health-officials-taking-over-mental-health-agency/17144947/

http://wfae.org/post/topping-questions-states-authority-takeover-cardinal

#### **FEDERAL UPDATE - Tax Policy**

On November 29th, the US Senate passed a "motion to proceed" on its tax bill to remove \$1.5 trillion in tax revenue and repeal major components of the Affordable Care Act (ACA). This is the procedural hurdle, which allows limited debate (a maximum of 10 hours for the Republicans, and 10 hours for the Democrats), to begin prior to a series of fast-paced amendments referred to as "vote-a-rama," and a final vote. The Senate leadership only needs 50 votes to pass this bill. Once \$1.5 trillion is added to the deficit through tax cuts, House and Senate leadership have identified major cuts to Medicaid, Medicare and Social Security as well as discretionary programs (which includes education, housing, employment and more) to pay for these tax breaks.

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### Public Policy Update (continued from page 5)

This could impact individuals with disabilities in significant and long lasting ways. The bill includes:

- Dramatically cutting the revenue necessary to fund Medicaid, Medicare, Social Security, housing and other services that benefit people with disabilities.
- Eliminating tax deductions and credits that help people with disabilities work, access housing and get medication.
- Repealing the Affordable Care Act's requirement that everyone have health insurance. This will cause premiums for people with disabilities and pre-existing conditions to increase, leaving health insurance unaffordable for millions.
- The \$1.5 trillion cut to revenue is the "pay for" for tax cuts that disproportionately benefit the wealthiest Americans and large corporations.

Additional information can be found here:

A comparison of the House version of the bill passed November 16th and the Senate's current bill can be found here.

NCCDD will continue to update you on this critical issue.

#### **Government Funding**

The federal government is currently funded through December 8th. The US House and Senate will need to pass a continuing resolution to avoid a government shutdown.

#### Federal Policy Fellowship

The Joseph P. Kennedy, Jr. Foundation is currently accepting applications for its 2018 Public Policy Fellowship Program. Each

year the Foundation brings professionals, family members, and persons experiencing disability to Washington, D.C. for a one-year, full-time, intensive immersion experience. Throughout their time in the District, fellows actively participate in public policy development in the offices of a Member of Congress, Congressional committee, or federal agency. This experience is a unique chance to understand the intersection of public policy, disability advocacy, and the political process. Please see the full announcement for more details. Applications will be accepted until December 15.

#### Executive Director (continued from page 1)

opportunities for people with I/DD, their families and their support systems. To continue our impact, we are working on several new initiatives. We recently posted a Request for Applications (RFA) for improving transportation options for people with I/DD which we encourage you to review and share.

As we continue the work in year two of our Five-Year Plan, our focus stays on our three main goals to increase financial security, community living and advocacy.

As always, we love hearing from the community about your thoughts, events and even your ideas (https://nccdd.org/we-want-your-ideas) on what can make your community a more inclusive place to for people with I/DD to live, work and play. Contact us at https://nccdd.org/contact-us.html.







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