A Newsletter from the North Carolina Council on Developmental Disabilities

**April 2018** 







NCCDD Executive Director Chris Egan

# A Message from the Chair and Executive Director:

It has been an exciting April, as we spent the month getting ready for the Disability Policy Seminar, the annual must-attend policy event for advocating for people with disabilities.

It is the premier opportunity to cultivate champions on Capitol Hill and advance the grassroots movement for people with intellectual and developmental disabilities (I/DD). For 40 years, this unique platform has offered the opportunity to come together with passionate advocates, self-advocates, experts, and professionals in the field to learn about key issues.

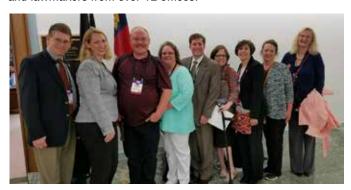
NCCDD was in full representation with our staff and Council members Kerri Eaker and Cheryl Powell. We had the opportunity to learn from experts in the field, and find opportunities to discuss key issues with others from our state. Next year's date is already set for April 8 - 10, 2019, so please think about joining us next year!

Big news also came down from Centers for Medicare and Medicaid Services (CMS)! NC Department of Health and Human Services (NC DHHS) has received approval from the Centers for Medicare & Medicaid Services to implement a NC Traumatic Brain Injury waiver as of May 1st. This is exciting, as these waivers will allow individuals with TBIs to receive the services and supports to help them succeed and integrate in the community.

## **Public Policy Update**

### **DISABILITY POLICY SEMINAR**

Council member Kerri Eaker and her son, Dakota, joined fellow Council member Cheryl Powell and her husband, Billy, at the 2018 Disability Policy Seminar in Washington, DC. NCCDD Executive Director Chris Egan, Systems Change Manager Melissa Swartz and Public Policy Specialist Erika Hagensen rounded out the NCCDD contingent – part of the 30+ attendees from North Carolina and over 900 advocates from across the US. Advocates from across North Carolina worked in partnership to educate and inform lawmakers about key issues facing individuals with I/DD here at home. Together, we met with staff and lawmakers from over 12 offices.



Conference presentations (http://disabilitypolicyseminar. org/)presentations/ and policy fact sheets (http://disabilitypolicyseminar.org/fact-sheets/) are available to view.

#### **Work Requirement proposals for government programs**

On April 10, President Donald Trump issued an Executive Order on "Economic Mobility." The order requires the Secretaries of the Treasury, Agriculture, Commerce, Labor, Health and Human Services, Housing and Urban Development, Transportation and Education to review their programs and identify steps and recommendations to establish or expand work requirements in their programs — within 90 days.

Ben Carson, the Secretary of Housing and Urban Development (HUD), <u>announced</u> a work requirements proposal for individuals receiving housing supports. Meanwhile, efforts are <u>underway</u> in Congress to insert work requirements into the Supplemental

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## NCCDD Council Member Spotlight - Nakima Clark



Nakima Clark with her daughters

New North Carolina Council on Developmental Disabilities (NCCDD) member, Nakima K. Clark, is the proud mother of two daughters, Nadeya, age 16 and Morgan, age 9. Morgan is her reason for serving on the Council - to represent and advocate for her.

Morgan was born at just 25 weeks and three

months later suffered a traumatic brain injury and was diagnosed with cerebral palsy. She is non-verbal and non-mobile and due to her chronic health issues, Morgan has a tracheotomy. "For this reason, I am her voice," says Clark.

"For those who are like my daughter Morgan, I am their voice. I have the pleasure of being that voice and letting people know that all people should be considered in everything we do in life. A lot of times people who have no idea or clue about certain situations are making decisions on things and issues and they are not aware the effect it will have on that particular population," she adds.

The Raleigh-native, Clark has a bachelor's degree in sociology from Shaw University and works at University of North Carolina (UNC) Physicians Network as a team leader/claims coding specialist. She and her husband of 11 years are busy with both daughters' active lives. Nadeya is a varsity cheerleader at Southwest Raleigh Magnet High School and Morgan cheers with the CFF Carolina Challengers, a Pop Warner flag football and cheer program for youth with disabilities ages five to 18.

Appointed to NCCDD in July 2017 by Governor Roy Cooper, Clark says, "I absolutely love the fact that this Council is built with those who are impacted directly. There is no better way to show what is need than for it to come from the ones who are actually experiencing these issues and needs in daily life."

Clark adds that outside of working 40-plus hours a week, being a "cheer mom" and volunteering at her daughters' schools, she is an avid sports lover. "I am a huge Carolina Panthers fan," she says. In addition, she loves swimming, vacations, shopping and spending time with her family.

"I am thrilled and honored to be a part of something so dear to me," Clark adds about her position on the Council and as a member of the Advocacy Development committee. "I hope that I am a great asset to NCCDD and that I bring a lot of exciting ideas with me.

## **EveryBody Works Comes to Asheville!**

Exploring the Possibilities with Everybody Works NC will take place on May 30 at 11 AM at the Biltmore Estate in Asheville, NC.

Secretary Cohen will introduce the *EveryBody Works NC* campaign to raise awareness of the value that people with disabilities bring to the workforce, as well as resources available from DHHS and other service providers that support employers who hire and retain qualified job-seekers with disabilities.

### **Featured Speaker**

Mandy K. Cohen, MD Secretary, North Carolina Department of Health and Human Services (DHHS)



Wednesday May 30, 2018 • 11:00 AM - 1:00 PM Lioncrest at Biltmore Estate • Asheville, NC

Please RSVP your name, email and number attending to ewnc@nccdd.org





### **Public Policy Update**

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Nutrition Assistance Program (SNAP) also known as food stamps. In a previous HHT, NCCDD outlined Medicaid work requirements now open to states.

Additional resources: <u>impact</u> of work requirements on SNAP and why Medicaid work requirements hurt people with disabilities.

Proposed cuts to Supplemental Nutrition Assistance Programs (SNAP): The House Agriculture Committee approved the Agriculture and Nutrition Assistance Act of 2018 (H.R.2), also known as the "Farm Bill," which includes the Supplemental Nutrition Assistance Program (SNAP). It's estimated 2 million people would lose their SNAP food assistance or see their benefits reduced, over 10 years. While the Committee vote clears a path for a future House vote on the floor, the Senate has not yet announced its Farm Bill reauthorization efforts.

Additional resources: how SNAP helps individuals with disabilities

## Report on Discipline Disparities for Black Students, Boys, and Students with Disabilities

The Government Accountability Office (GAO) has released a report showing that black students, boys, and students with disabilities are more likely to be disciplined. While students with disabilities accounted for 12% of public school students, they were 25% of students suspended out of school; 21% suspended in school; 28% of students referred to law enforcement; 24% of expelled students; 16% of students who received corporal punishment; and 28% of students arrested for school-related incidents. Read the highlights of the report here.

### **STATE POLICY**

The NC Legislature will reconvene for Short Session on May 16th. The Short Session is designed to address budget issues and any unfinished business from the Long Session. This session, we will be looking for legislative action that will allow the Department of Health and Human Services (DHHS) to include the Tailored Plan for people with I/DD into their proposed Medicaid managed care transformation. The plan to integrate physical health, behavioral health, and long term supports and services is moving forward for most people who receive their healthcare through Medicaid. But in order to include people with I/DD, the DHHS needs legislative approval.

The Legislative Research Committee on I/DD which met three times during February and March, has released recommendations addressing issues around employment. These include:

- Establishing a new position in DHHS which focuses on employment opportunities for people with IDD
- Focusing on using data to track employment outcomes,
- Allowing withdrawal of Parental Savings Trust Funds to be rolled over to ABLE accounts.



- Establishing the state as a model employer.
- Addressing the waiting list for university based, postsecondary education opportunities

There are some preliminary draft bills for the above recommendations but there are additional considerations for each of these and more work to be done. We will track these through the session. The Innovations Waiver will be posted on the Department of Medical Assistance website for comments in the next few days. We do not expect any substantial changes to the waiver. There may be some minor adjustments to employer of record processes which are designed to provide more support for this option.

## TBI Waiver comes to North Carolina!

The North Carolina Department of Health and Human Services has received approval from the Centers for Medicare & Medicaid Services to begin the long awaited NC TBI waiver as of May 1, 2018. The pilot project will begin in Cumberland, Durham, Johnston and Wake counties to offer rehabilitation services for adults who have suffered traumatic brain injury on or after their 22nd birthday.

To qualify, the adults must require the level of care for a nursing facility or specialty rehabilitation hospital. Up to 49 individuals may be served in the first year, expanding to 107 by the third year. The TBI pilot will be administered by Alliance Behavioral Healthcare. Alliance Behavioral Health will then have a 90 days start-up period with the TBI pilot program's implementation to take place on or around August 1, 2018.

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## NC Resident Chosen for National ABLE Board



After a nationwide search and call for entries, Cheryl Walfall-Flagg, resident of Raleigh, NC, was selected as one of the 10 advisors for the inaugural Achieving a Better Life Experience (ABLE) Act Advisory Group being led by ABLE National Resource Center (ANRC). The advisors will serve as national spokespersons for ABLE accounts.

The ABLE National Resource Center (ANRC) did a nationwide search to select advisors that represented a cross-section of ages, locations, disabilities, genders, race and ethnicities. family photo

After seeing a call for applications promoted in a North Carolina Council on Developmental Disabilities (NCCDD) "Highlights & Hot Topics" blog, Walfall-Flagg read the information provided and submitted her application.

Walfall-Flagg has been researching ABLE accounts since she heard about the possibility of having one in mid-2016. The day after the ABLE accounts went live in 2017, she opened one. She is a big ABLE supporter and shares with everyone the ease of opening and administering an account, the security of taking care of future needs for her boys, the debit card option so money can be used now and later as well as not having financial penalties for individuals who receive Social Security benefits.

The goal of each advisor is to put a face and voice to explaining the ease of opening an ABLE account themselves while sharing their stories of why. Through telling their experiences, the advisors' goal is to help as many people as possible learn about ABLE and open their own accounts for themselves or their children.

The advisory group members hail from Michigan to Texas and from Kansas to North Carolina and everywhere in between. Four of the six, including Walfall-Flagg, are parents of children with disabilities. Other advisors have a range of disabilities from blindness to Down Syndrome to various physical and mental disabilities. Each person shares their goals for their ABLE accounts from saving for transportation needs to home modifications to disability related equipment.

Walfall-Flagg is saving for the time when she and her husband are no longer around to care for their three boys, two of whom are on the Autism Spectrum. Walfall-Flagg and her husband, Terrance, are raising their 17-year-old son who is preparing to graduate high school along with their 16-year-old son and 11-year-old nephew who both have autism.

Walfall-Flagg, who works for North Carolina Head Start, says her role on the ABLE Advisory Group requires a commitment of six teleconferences among the 10 members to meet and talk about the ABLE accounts, to help the ANRC, to gather more information and help in sharing that information with individuals as well as with legislators. In addition, each group member is tasked with getting the word out about ABLE accounts to their community, state and region. "I told people what I was doing as I was opening my account. Telling others was a great responsibility," said Walfall-Flagg. She has already spread the word across the United States to all her family and friends. "If I can help one person make that change for a loved one, then it has been worth it," she added.

She offers two pieces of advice to anyone wanting more information about opening an ABLE account:

- The ABLE National Resource Center is a great source (http://ablenrc.org/), providing webinars and a comparison tool. "It gives you the power to educate yourself and to make the decision for an account at your own pace," Walfall-Flagg said.
- Start the process of getting an ABLE account sooner rather than later. Walfall-Flagg shares that one does not need a large amount of money to open an account. She advises people to start with a small amount and build from there. In North Carolina, the minimum amount to open an account is \$25.00.

Right now, Walfall-Flagg is developing a plan to help in spreading the word about ABLE accounts which includes talking to the members of NCCDD. She may develop a blog about ABLE accounts in the future. Walfall-Flagg is active with the Autism Society of North Carolina's parents group as well as the Re-Thinking Guardianship: Building a Case for Less Restrictive Alternatives initiative and the Family Support Network of the Greater Triangle Development Group.

For information specific to North Carolina's regulations for ABLE accounts, go to <a href="http://ablenrc.org/state-review/north-carolina">http://ablenrc.org/state-review/north-carolina</a>, to <a href="https://savewithable.com/nc/home.html">https://savewithable.com/nc/home.html</a>, as well as <a href="https://www.nccdd.org">www.nccdd.org</a>



### A Message from the Chair

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One of the biggest ways people with intellectual and other developmental disabilities (I/DD) can succeed in the community is through financial security. EveryBody Works NC, NCCDD's employment campaign, is heading to Asheville in May to bring attention to the importance of employment with NC Department of Health and Human Services (NC DHHS) Secretary Mandy Cohen. We are also very proud to see North Carolina represented at the national level with the appointment of Cheryl Walfall-Flagg to the ABLE Act Advisory Group being led by ABLE National Resource Center (ANRC). What a way to advocate!

As always, we want to hear from YOU. What are your ideas? Share them with us and join us on our social media spaces, attend our meetings and events, or connect with us.

With best wishes,

Alex McArthur, Chair

Chris Egan, Executive Director

### TBI Waiver

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The TBI waiver also includes extended occupational therapy, physical therapy and speech therapy; supportive services such as respite, home and vehicle modifications; and assistive technology, equipment and supplies.

The North Carolina Brain Injury Advisory Council and the Brain Injury Association of North Carolina will be working with DHHS and Alliance to assist in the implementation of this waiver and in efforts to expand access to these services beyond a single LME/MCO to all eligible state citizens.

People interested in learning more can contact Alliance Behavioral Healthcare's Access and Information line by calling 1-800-510-9132 or by sending an email to TBIInfo@alliancebhc.org



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