



**NCCDD Executive Director
Chris Egan**

A Message from the Executive Director

2016 opened on a great note! By the fall of this year, the North Carolina Department of State Treasurer expects to have the Achieving a Better Life Experience

(ABLE) Act available as a new savings option. Signed into law in 2015, the ABLE program allows people with disabilities to save money in a tax deferred account for some of their expenses related to health and wellness, employment supports, education, housing and other costs not covered by Medicaid.

Up to \$14,000 a year can be contributed to an ABLE account from various sources such as friends, family and employment earnings. In addition, up to \$100,000 saved to this account will not be counted toward a person's eligibility for federal means-tested programs.

This is great progress for highlighting the importance of financial security in the lives of individuals with intellectual or other developmental disabilities (I/DD) and their families.

As we look at what is ahead in 2016, many pieces of legislation affecting Medicaid and Home and Community Based Services are coming. That is why it is very important that we keep a close eye on legislation at both the state and national levels. NCCDD's public policy team will provide monthly updates to you about what is happening and how you can be involved.

We will be finalizing our Five Year Plan over the next few months. The importance of advocacy is not only highlighted in our Five Year Plan, but was clearly demonstrated by people with I/DD, their families, professional caregivers and other state citizens who gave us their thoughts and input on the goals and objectives of the plan. We thank everyone who took the time to provide this feedback! It is important to listen to what matters most to you as we settle on the goals and objectives of the Five Year Plan, to better serve the I/DD community across the State.

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Public Policy Update

TBI Waiver: DMA Seeks Public Comment on Application

The NC Department of Medical Assistance (DMA) is seeking input on its TBI (Traumatic Brain Injury) Waiver application to the Centers for Medicare and Medicaid Services (CMS). The TBI Waiver application can be accessed at bit.ly/1V4oxyX. The proposal to include the TBI Waiver in the state's (b) waiver update can be accessed at bit.ly/1Kcemru. The 30-day comment period closes on 12:01 AM on February 26, 2016. Feedback can be submitted by email to TBIfeedback@dhhs.nc.gov or by phone 919-855-4108.



NC DHHS Hosts Listening Sessions on Innovations Waiver

The Department of Health and Human Services' (DHHS) divisions will host listening sessions across North Carolina for input on the changes to the NC Innovations Waiver. The Division of Mental Health/Developmental Disabilities/Substance Abuse Services and the Division of Medical Assistance will facilitate the sessions. No registration will be required, but the community is encouraged to attend.

Find the event and location nearest you: <http://nccdd.org/news-media/blog/55-advocacy/297-nc-dhhs-divisions-to-host-listening-sessions-on-innovations-waiver.html>

The Achieving a Better Life Experience (ABLE) Act

The Achieving a Better Life Experience (ABLE) Act is a federal law (signed in December of 2014) that allows eligible individuals and their families to save money in a 529A account to be used for qualifying expenses while maintaining many benefits. You can find additional background information on here. In August of 2015, Governor McCrory signed legislation that directs the NC Department of State Treasury to oversee the program and creation of these accounts in our state. So what's new?

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Taking Initiative: Guardianship

To address innovative alternatives to guardianship, NCCDD has funded an initiative that is being managed through the Department of Health and Human Services (DHHS) Division of Aging and Adult Services. In its work, the group is exploring changes needed to the guardianship statutes, policies and practices; collecting relevant data to support innovative approaches to guardianship alternatives; and building a knowledgebase of best practices.

The initiative's purpose is to offer training, consultation and technical assistance to support the development of policies and practices, relative to guardianship and alternatives to guardianship, that advance integration, productivity, independence, inclusion and self-determination for people with I/DD.

At the completion of its first year, the division is working with the Jordan Institute to use a Collective Impact framework to effect change in guardianship.

A diverse and committed work group was gathered to broaden participation to a wider range of stakeholders to work toward sustainable change. The group began building a library of best practices in guardianship and its alternatives. In addition, they collected relevant data to support innovative approaches to guardianship alternatives.



As the group enters its second year of work, they plan to achieve the following goals:

LOCALLY

- Identify one or more local pilot programs.
- Provide technical support and some infrastructure support to these pilot programs.
- Appoint a subcommittee to act as a liaison between state and local levels.

STATEWIDE

- Conduct longitudinal analysis with Administrative Office of the Courts data.
- Refine a common agenda.
- Identify and begin to implement mutually reinforcing activities from the different sectors within the work group.

To learn more about the Guardianship initiative, email Nancy Warren at nancy.warren@dhhs.nc.gov



Philip Woodward

Philip Woodward Joins NCCDD as Systems Change Manager

Philip Woodward joined the North Carolina Council on Developmental Disabilities as a Systems Change Manager. In his role, Woodward will lead the Community Capacity Building initiatives, which include Project

SEARCH, Upward to Financial Stability, Emergency Preparedness and the NC ADA Network, including Fiscal Agent/Intermediary.

“As a person with a disability and an advocate for people with all types of disabilities, I hope to bring an awareness of the needs and talents of people with disabilities and build a strong network among agencies, organizations and people with disabilities across our State,” said Woodward, who is Hard of Hearing and knows American Sign Language.

Woodward previously worked as the access specialist for the NC Division of Vocational Rehabilitation Services (DVRS), where he wrote a new ACCESS North Carolina travel guide in 2012; administered North Carolina's voluntary service animal registration program and handled all service animal inquiries; and administered three American Recovery and Reinvestment Act (ARRA) contracts designed to provide employment opportunities for VR clients.

He also assumed a dual role as a communications project manager for the Department of Health and Human Services' Office of Communications, where he assisted DVRS, the NC Division of Services for the Deaf and the Hard of Hearing (DSDHH) and the NC Division of Services for the Blind (DSB) with their communications and outreach. In that role, he

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Council Member Spotlight: Amanda Bergen

Amanda Bergen is no stranger to advocacy. Her earliest memories are of supporting her younger brother to be fully included in the educational experience as early as kindergarten.

She remembers the standard lines from teachers as they pointed to lack of funds and resources as a main reason why this was not always possible. As a youngster, Bergen's response was limited to her own engagement with her brother, dismissing the adult reasons for why more could not be done.

Thirty years after those earliest memories, Bergen's children, ages five and seven and both on the spectrum, ventured to public schools for the first time.

Astonished to find that little had changed, Bergen found her passion for advocacy reignited. The standard line of insufficient resources was still standard fare, and yet with the insights gained in those intervening years, it rang far less true.



Amanda Bergen and family

Before the birth of her children in 2008 and 2010, Bergen had forged a successful career in the criminal justice field, most recently, teaching at Savannah State University and Columbia College.

Her research and work in the area of recidivism, and the urgency with which it is approached, soon came to

inform the advocacy work with her children. Bergen recognized this deep sense of urgency as a key difference between advocacy in the criminal justice system and advocacy within the intellectual and developmental disability (I/DD) community.

"In the criminal justice system, there is no time to waste because the longer we wait, the more young people will return to what they know as a means for getting by. The same urgency simply does not exist in the I/DD community at the moment, but I believe that once we change this, we'll begin to notice new doors opening."

In her own experience with her children, Bergen and her husband ultimately decided to home school them during the elementary school years. Her hope is that within the homeschooling environment, she will be better able to initiate the lessons of self-advocacy and personal responsibility that she sees as necessary for their personal independence as they grow older.

Bergen comments, "If kids are supposed to pick the high school that is best for them, they don't just need to be asked on the final day of eighth grade. The topic needs to be approached sooner and they need to be provided with the skills and the knowledge to understand and make the decision for themselves."

Certainly, Bergen expected her children to take on as much personal responsibility as they are capable of. She is also aware that the advocacy issues for people with I/DD are broad and deep.

She notes, "Just as I saw with my brother, transportation, I believe, is a major issue. If we as a community could get people to rally around this one issue, then I believe that we could see major change. We would see more inclusive churches and community organizations simply because people have a way to get there."

Eventually Bergen does intend to return to her career in criminal justice, and she is certain that her insights from the realm of disability advocacy will inform her return to the field.

Until then, however, her main focus is to continue fighting to empower her own children into ensuring that they are as well prepared for becoming adults as they possibly can be.

NCCDD Thanks Sam Miller for Service to Council



Dr. Sam Miller

On behalf of North Carolinians with intellectual and other developmental disabilities (I/DD) and their families, NCCDD thanks Dr. Sam Miller, PhD, for his contributions during his appointment as a member. Dr. Miller's knowledge and insight into the issues brought a thoughtful and committed voice to the Council.

Throughout his appointment, Dr. Miller was an active leader, in particular by serving as chair of the Systems Change Committee; being involved with Council funded initiatives; and through his service as a member of the Executive Committee.

Dr. Miller helped NCCDD to advance systems change in support of self-determination, self-advocacy, employment, productivity and community inclusion for people with I/DD. The Council greatly appreciates the commitment and action of Dr. Miller as a Council member and in his community.



Public Policy Update *(continued from front page)*

State Level: The North Carolina Department of State Treasurer continues to coordinate the set-up, administration and outreach of this important new program, with a goal to have NC ABLE accounts offered late in 2016. Updates can be found on its dedicated website.

Federal Level: Meanwhile, federal agencies continue to gather feedback and update regulations and guidance for the IRS, Social Security Administration and other agencies. The IRS has not yet finalized all of its regulations, but the accounts can be created and used in the interim. The Social Security Administration released guidance to its staff to assist with qualifying expenses and maintaining benefits while using ABLE accounts. (This guidance is very technical. The SSA plans to provide additional information geared for account holders and families soon.) Finally, Congress authorized a change to ABLE accounts making it possible to individual account holders to choose from any state's ABLE Account system.

State and federal entities continue to move ABLE accounts forward in a positive way. NCCDD will continue to keep you informed of changes that affect you.

SSA guidance:

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740>

Facts about the ABLE Act:

<http://www.thearc.org/document.doc?id=5009>

NC Department of State Treasurer:

<https://www.nctreasurer.com/able/Pages/default.aspx>

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A Message from the Executive Director *(continued from front page)*

Additionally, NC's Department of Health and Human Services (DHHS) is seeking input on the changes to the NC Innovations Waiver (listening sessions) and the TBI Waiver (public comment). The Division of Mental Health/Developmental Disabilities/Substance Abuse Services (MH/DD/SAS) and the Division of Medical Assistance (DMA) will be facilitating listening sessions across the State, and no registration is required. These Medicaid Waivers are truly essential to community living for people with I/DD, and it is important to voice your opinion to DHHS officials. DMA is seeking public comment on the TBI Waiver until Feb. 26, 2016.

2016 is off to a great start, and we look forward to what is ahead!

Philip Woodward Joins NCCDD as Systems Change Manager

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collaborated with NCCDD on various initiatives, including planning Raleigh's ADA 25th anniversary celebration.

He currently serves as a board member for Arts Access and as the public information chair for the Raleigh Mayor's Committee for Persons with Disabilities.

"We are very excited to have Philip join NCCDD and utilize his many talents in our work across the State," said Executive Director Chris Egan. "His enthusiasm and energy are a great addition to the Council and our initiatives."

A native of Richmond, VA, Woodward was diagnosed with a severe to profound hearing loss at age four, and was mainstreamed throughout his secondary education. He received his Bachelor Degree in English and his law degree from the College of William and Mary.