



**NCCDD Executive Director
Chris Egan**

A Message from the Executive Director

March was Developmental Disabilities Awareness Month, and NCCDD celebrated through state and federal advocacy, partnership and outreach. Recognizing the importance of North

Carolinians with intellectual and other developmental disabilities (I/DD), Governor Cooper offered a proclamation calling for deeper understanding and increased opportunities for our community. Shortly thereafter, the Governor's budget included 2,000 proposed new Innovations Waiver slots. At the federal level, we partnered with the National Association of Councils on Developmental Disabilities to raise awareness about I/DD by gathering and sharing stories of people who live with a disability, including the contributions they make and persistent barriers they face.

Advocacy development is a primary goal of the NCCDD. As such, Council members Bryan Dooley, Adonis Brown, Eric Chavis and Nessie Siler traveled with members of the NCCDD staff March 19-22 to Washington DC for the 2017 Disability Policy Seminar. In addition to learning and networking during the conference, scheduled visits were made to "The Hill" to educate our members of Congress about the primary goals of the NCCDD and to share information and stories. We highlighted two stories in particular - Tim Balogh and Bryan Dooley - which emphasized the importance of supports, both natural supports and optional Medicaid, as well as state funded services which increase engagement, contribution and independence. The Council maintained our commitment as a resource to answer questions and provide information about the impact of health care, waiver services and naturally occurring supports in the lives of individuals with I/DD and families, and the importance of the right balance of these supports.

In North Carolina, various events brought awareness to I/DD. Training sessions were held by the Upward to Financial Stability initiative - led by the National Disability Institute and The Collaborative - to outline tangible ways individuals with disabilities can become more self-sufficient and financially independent. We were overwhelmed

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Governor Cooper Adds Waivers to Budget

Roy Cooper announced an additional 2,000 developmental disability waiver slots in the budget released on March 2, 2017.

As part of the budget, Governor Cooper is proposing to fully fund an additional 1,000 North Carolina Innovations Waiver slots, effective January 1, 2018, to reduce the wait list for this program for individuals with intellectual and other developmental disabilities (I/DD). This is funded through the targeted reinvestment of community services funding in the base budget.

Additionally, the Governor has proposed to expand the DD Innovations Waiver with an additional 1,000 slots for "lower-acuity individuals," effective January 1, 2018, to be designed for individuals who do not need the full range or intensity of services offered under the current waiver, but who will benefit from service at their specific level of need.

Governor Cooper also proposed to:

- Expand Medicaid eligibility to cover an additional 624,000 individuals.
- Include expansion of the Children's Developmental Services Agencies (CDSAs).
- Invest \$1 million in state-of-the-art adaptive equipment and assistive technology to support inclusion and integration.
- Identify \$20 million for school system personnel, which may impact students with I/DD in terms of teaching assistants, behavioral support staff and nurses.

The budget process now moves to the Senate, then the House, followed by the Conference committee, with the goal of a final budget by the end of June. For more information on Governor Roy Cooper's budget, please visit <http://bit.ly/2mkPpmj>

Public Policy Update

FEDERAL:

Health insurance and long-term services and supports:

On March 24, 2017, House of Representatives Speaker Paul Ryan (R-WI) removed H.R.1628 (<https://www.congress.gov/bill/115th-congress/house-bill/1628>), the American Health Care Act, from the House floor prior to an expected vote. He cited lack of a sufficient number of votes to pass the bill. H.R. 1628 was intended to both repeal the Affordable Care Act and fundamentally alter the Medicaid program.

The President's budget and federal appropriations:

President Trump released a short version of his Fiscal Year 2018 budget on March 14. While the President's budget doesn't have the force of law, it paints a picture and provides insight into an administration's priorities. The short budget calls for significant cuts to discretionary programs, those programs to which Congress allocates funds each year, and increases to military spending. The Administration will be offering a full budget with additional detail in May. Congress is expected to provide its budget resolution after the President's full budget is released.

Education: The US Supreme Court ruled that school districts must give students with disabilities the chance to make

meaningful, "appropriately ambitious" progress. In *Endrew F. v. Douglas County School District RE-1*, the high court rejected the "merely more than de minimis" standard set by the US Court of Appeals for the 10th Circuit, in Denver.

Chief Justice Roberts, in his opinion wrote, "When all is said and done, a student offered an educational program providing 'merely more than de minimis' progress from year to year can hardly be said to have been offered an education at all. . . . The IDEA demands more," he continued. "It requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances."

For additional coverage, visit <http://www.npr.org/sections/ed/2017/03/22/521094752/the-supreme-court-rules-in-favor-of-a-special-education-student> for NPR's written and audio commentary, an article from *The Atlantic* (https://www.theatlantic.com/education/archive/2017/03/how-a-new-supreme-court-ruling-could-affect-special-education/520662/?utm_source=atfb) as well as a statement from The Arc (<https://blog.thearc.org/2017/03/23/arc-applauds-u-s-supreme-court-decision-special-education-case-idea-demands/>)

Council Member Spotlight: Dr. Joseph Piven



Dr. Joseph Piven

Joseph Piven, MD was appointed to the North Carolina Council on Developmental Disabilities (NCCDD) in 2013. He is the director of the Carolina Institute for Developmental Disabilities (CIDD), one of 67 University Centers for Excellence in Developmental Disabilities (UCEDD) in the US. UCEDDs serve as a resource for those involved in education, research and service working to

meet the needs of individuals with developmental disabilities and their families. Dr. Piven represents the North Carolina UCEDD on the Council.

Dr. Piven earned his medical degree from the University of Maryland School of Medicine and went to Johns Hopkins Hospital for his psychiatry residency. He completed a John Merck Research Fellowship in developmental disabilities at

Hopkins. He is the author of over 150 publications on a variety of topics including the causes and mechanisms underlying autism and Fragile X Syndrome. He is the founding editor-in-chief of the *Journal of Neurodevelopmental Disorders*.

In addition, he is the Thomas E. Castelloe Distinguished Professor of Psychiatry at the University of North Carolina (UNC) School of Medicine. Dr. Piven is a child/adolescent/adult psychiatrist specializing in the clinical care of individuals with autism and other neurodevelopmental disorders.

Prior to joining UNC in 1991, Dr. Piven was on the faculty at Johns Hopkins University and the University of Iowa.

Dr. Piven is most excited about the work NCCDD is doing on the Medical Health Homes initiative. This initiative works with stakeholders across the state to identify the needs and concerns of people with intellectual and developmental disabilities (I/DD) and their families, and gaps in the current systems of care, in order to develop recommendations that promote person-centered collaborative care in the right setting at the right time.

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by the participation! Approximately 100 providers, agency leaders, employers and other stakeholders attended sessions in Charlotte, Boone, Fayetteville and Raleigh. In fact, Council member Adonis Brown completed the requirements to be a master trainer!

As NCCDD focuses on increasing community living for individuals with I/DD, the NC Sibling Support initiative held its first statewide conference in Carrboro for sisters and brothers who have siblings with I/DD. Additionally, Vaya Health, which is managing the Money Follows the Person and NCCDD's Supported Living initiative, held a two-day conference on supported living in Greensboro.

At the time of this writing, plans were underway by NCCDD to celebrate access and inclusion on the final day of Developmental Disabilities Awareness Month with a family fun event at Sassafras All Children's Playground at Laurel Hills Park in Raleigh. The 3.5 acre site includes a playground for children of all abilities and provides a variety of play experiences. However due to poor weather predictions, we will postpone this event until July. As soon as we have a new date, we will let you know and hope you will come and join us!

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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