



**NCCDD Executive Director
Chris Egan**

A Message from the Executive Director

Over the last several months, we have been intently following federal policy developments in the areas of Medicaid, long term service and supports, health care coverage and more.

North Carolina Council on Developmental Disabilities (NCCDD) Council members have truly represented our role to educate and inform on key issues impacting individuals with intellectual and other developmental disabilities (I/DD) and their families. I wanted to update you on some key developments in the program year 2018 federal budget discussion.

President Trump released his full 2018 budget, and while it doesn't have the force of law, it does represent the administration's policy priorities. In addition to large suggested cuts to both Medicaid and Social Security Disability Insurance (SSDI), the President's budget did not include funding for DD Councils in 2018. Instead, a new statewide structure combining Councils on Developmental Disabilities, Independent Living and Traumatic Brain Injury into a new "partnership for innovation, inclusion and independence" is planned. This proposed, cross-disability, statewide entity would come into existence with significant funding cuts.

As you know, DD Councils are a unique nonpartisan entity that effectively brings together stakeholders with diverse viewpoints and a unifying commitment to individuals with I/DD. Our efforts actively ensure individuals with I/DD and their families are at the table to help inform and strengthen key programs and efforts impacting individuals with I/DD across the lifespan: long-term services and supports, education, employment, health and other aspects of community living. In addition, we efficiently utilize modest grants informed by state trends and identified needs that are critical to the I/DD

continued on page 6

DHHS Secretary Mandy Cohen Meets NCCDD Council at Quarterly Meeting

North Carolina's Department of Health and Human Services (DHHS) Secretary Mandy K. Cohen, MD, visited the North Carolina Council on Developmental Disabilities (NCCDD) in May during its quarterly meeting. Dr. Cohen was appointed to her position in January of this year by Governor Roy Cooper.

Dr. Cohen led the discussion on Medicaid and how the department is looking at how to use levels of Medicaid payment to drive whole person care. She cited the state of Arizona as having a great plan and is looking to see if that would work for North Carolina.

Her work is also being driven by the State's health and social determinants to see what is contributing to good health and to poor health. In addition, Dr. Cohen hopes to use DHHS program money to further access health coverage throughout North Carolina. She also plans to continue to fight for more Innovation Waivers.

She applauded NCCDD for their efforts on workforce training and their new Five-year Plan and says she will be talking to Council members, employers, transportation heads and many others to

continued on page 6



North Carolina's Department of Health and Human Services (DHHS) Secretary Mandy K. Cohen, MD with the NCCDD Council at the May 2017 meeting.

Indian Affairs Director Addresses Need for Collaboration with NCCDD

The North Carolina Council on Developmental Disabilities (NCCDD) welcomed Greg Richardson, executive director of the Commission of Indian Affairs, at its quarterly meeting in Cary, NC earlier this month.

Richardson shared that 1.3% of North Carolina's population is American Indian, made up of eight tribes in the state. Among that population, 24% of them have disabilities. "This is why it is so important for us to be included in NCCDD's work," explained Richardson.

"I commend the NCCDD on the work of including the Indian population, and we would like to see that work expand," Richardson added. Specifically, Richardson hopes NCCDD would be open to collaboration with the Commission of Indian Affairs current work in employer training regarding people with disabilities the Commission offers, via community colleges.

In addition, Richardson shared the great medical needs of the NC American Indian population, with diabetes noted as the major killer. He explained many American Indians are coded as



Greg Richardson, NCCDD Council Member Michael Groves and Executive director Chris Egan

a different race when seeking medical attention. As a result, funding for American Indians' specific medical needs has no data to back up the need. "Many of our tribes have no services or programs to achieve help for the various needs of American Indians with disabilities," he added.

Disability Rights North Carolina files lawsuit against State and DHHS

According to a lawsuit filed on May 24, 2017, the State of North Carolina and the North Carolina Department of Health and Human Services (DHHS) fail North Carolina citizens with intellectual and/or developmental disabilities (I/DD) by forcing thousands of people with I/DD to remain in institutions or segregated from their families and communities because of a fractured and inefficient system of care. The case was filed on behalf of five plaintiffs with I/DD who are subject to improper segregation or are at risk of segregation.

The lawsuit identifies significant problems with North Carolina's system of services that rob people with I/DD of their right to live and participate in their communities by:

- Relying on institutional placements by failing to provide people with I/DD with the services they need to live in their communities.
- Identifying an insufficient number of providers to serve the needs of individuals with I/DD in the community.

- Inadequately planning to transition individuals with I/DD from institutional to community settings by failing to identify those who are ready for more independent living.
- Failing to provide for reliable long-term services and supports stemming from frequent changes and reductions in services, causing instability and making it harder for people with I/DD to remain in their communities.
- Maintaining a financing system that provides financial incentives to contractors who prioritize lowering costs over providing necessary services.

To learn more about the lawsuit, visit http://www.disabilityrightsnorthcarolina.org/news-and-alerts?utm_source=&utm_medium=&utm_campaign=#statecomplaint

DISABILITY RIGHTS
NORTH CAROLINA

Champions for Equality and Justice



Public Policy Update

NCCDD's public policy team brings a comprehensive update on federal and state public policies that affect people with disabilities and their families.

North Carolina's Bills in Play:

The crossover date for bills in the legislative session has passed. Bills that were being followed that met the crossover, and are still eligible to move through the process of final approval include the following:

- H84: DL/Deaf or Hard of Hearing Designation
- H591: Study/LEO Interaction with Disabled Drivers
- HB 478: Required Experience for MH/DD/SAS Qualified Professionals
- SB594/HB608: Family/Child Protection & Accountability Act
- HB 11: Handicap Parking Privilege Certification
- H307: Board Cert. Behavior Analyst/Autism Coverage
- H403: LME/MCO Claims Reporting/Mental

North Carolina's Bills in Play:

People First Bill – Rules Chair asked that it be taken care of through General Statutes. The intent of this bill was to change all language in statutes to person-first language, and this can happen without a legislative bill.

Handicap Placards – NC Department of Transportation asked to pull the bill to address international processes, but it will come back in the short session.

Guardianship Rights did not make crossover deadline.

NC General Assembly Budget

The biennial budget started in the Senate and after being approved in the Senate, the House will work on budget. Any discrepancies will be worked out in the Conference Committee.

Target Dates for Budget Approval are:

Senate Budget – May 11

House Budget – June 2

Conference Report – June 23

Senate Budget Highlights: The following is what is proposed in the Senate's biennial budget that will impact the disability community in North Carolina:

- 250 Innovations Waiver slots for 2017-18
- 250 Innovations Waiver slots for 2018-19
- Personal Care Services rate increase
- Disability Rights North Carolina settlement
- Traumatic Brain Injury Pilot
- Children's Developmental Services Agency (CDSAs) positions
- Reform State Child Welfare System

Ongoing State Issues: The following are ongoing policy issues that impact the I/DD community in North Carolina:

- Innovation Waivers - the renewal of the Innovations Waiver is coming up in the fall. Input on what is working and not working is being requested. Listening sessions are occurring around the state. Written comments will also be accepted.
- Resource Allocation - The Supports Intensity Scale (SIS), which is used as part of the Resource Allocation model for Innovations Waiver, continues to be used, but the ability to input SIS scores electronically had been on hold for several months. The contract which will allow the electronic input has been signed by the state. Over 1900 SIS evaluations have been conducted on paper, and these will need to be entered.
- Autism Services State Plan Amendment has been submitted to the Centers for Medicare and Medicaid Services (CMS)..
- Traumatic Brain Injury Waiver has been submitted to CMS.
- 1115 Demonstration Waiver listening sessions were held across the state to get input on the redesign of Medicaid managed care.
- Home and Community Based Settings – NC has been working on its plan to meet the new requirements for HCBS settings. Recently, a CMS bulletin came out, which allows states an additional three years, until March 2022, to ensure compliance with criteria of a home and community-based setting. However, the states still need to have their plan approved.

Special Needs Plans: Deputy Secretary Dave Richard of the North Carolina Department of Health and Human Services (DHHS) discussed Special Needs Plans to address a coordinated approach for habilitative, rehabilitative

continued on page 4

Public Policy *(continued from page 3)*

and medical supports for people with complex needs, including people with intellectual or other developmental disabilities (I/DD) at the NCCDD meeting in May. He described the importance of a stronger safety net and more specialized plan for people with complex needs.

- **Population:** Specialty plan population includes all people with I/DD identified through receipt of services such as the Waiver and those on the registry of unmet needs, people with SPMI (Severe and Persistent Mental Illness), and people with SUD (Substance Use Disorders) - people with SPMI and SUD would initially be determined by who has already accessed enhanced services. The Innovations Waiver would be coordinated under these plans. Automatic enrollment will occur for those meeting the criteria, however people could opt out.
- **Estimates:** The NC Department of Health and Human Services estimates the population to be 80,000 - 100,000 people who would be part of the special needs plan.
- **Geography of Plans:** Three or four regional plans will likely be the structure and one statewide plan (to create an option for people using Medicaid to choose).
- **Providers of Plan:** Nonprofit or government /public entity may bid to coordinate the plan (LME/MCOs could bid; commercial plans could partner with LME/MCOs). There would be an open bidding process.
- **Funding:** Regional Plans would include Medicaid, state funds, county funds and block grant funds. At this point, the thinking is that the statewide plan would only include Medicaid.
- **Quality:** There were questions by those participating on the call about ensuring quality services and treatment and a robust network of providers within the specialty plans as well as for people who remain outside the plans who have less intense needs or chose to be outside the specialty plans. Dave assured the group that they (DHHS) have learned much about contracting and would work to ensure this. He also emphasized the Secretary's commitment to integrated care. He stated that the intent behind this is "if you believe integration is important, the money has to be melded" and integration is clearly the priority of the Secretary.

Richards stated that the number belief behind this is "if you believe integration is important, the money has to be melded." And integration is clearly the priority of the Secretary.

Federal Policy Updates

The American Health Care Act (AHCA) – In early May, the US House of Representatives passed the American Health Care Act (AHCA, H.R. 1628) by a narrow margin (217-213). This legislation aims to repeal the Affordable Care Act (ACA), fundamentally alter the Medicaid program and end its 50+ year federal/state partnership. The AHCA will eliminate mandatory Medicaid eligibility and federal matching funds based on actual dollars spent on beneficiaries. Instead, states would receive capped funding (based on 2016 state spending rates), amounting to over an \$800 billion Medicaid cut over ten years. Faced with massive funding shortages, states would either need to raise significant revenue in an attempt to cover the cost shift, or reduce eligibility, types of services and the amount of services an individual can receive. Analysis of these deep cuts suggest that individuals with disabilities, especially those receiving Home and Community Based Services, will be at significant risk of service reduction or elimination. No other safety net is identified.

Additional components of the AHCA would offer states the option to modify key components of the Affordable Care Act. Previously mandatory components of health coverage (including habilitative services, mental health and prescription coverage, maternity care and more), known as Essential Health Benefits, would become optional. Insurers could charge significantly more based on health status and age. Preexisting conditions and yearly and lifetime caps also could return based on how states chose to structure their plans. States seeking to modify their program would need to reinstate high risk pools for individuals with costly and complex medical conditions. Subsidies to assist low income beneficiaries to buy insurance would be replaced with tax credits, and insurers would be allowed to charge 30% more in premiums for a year if an individual or family had a lapse in coverage for approximately two months.

You can compare proposals to replace the Affordable Care Act through the Kaiser Family Foundation [here](#). For more details on the Congressional Budget Office scoring of the bill which estimates 23 million people will lose coverage can be found [here](#).

AHCA has moved to the Senate where changes are expected, although what those changes might look like are still unknown. The Senate will aim to make changes compatible with "reconciliation instructions" rules which would allow a simple 51-vote majority vote, mandate discussion limits, and would not require bipartisan support for passage.

President Trump's Budget

On May 23, 2017, President Trump released his budget for 2018, and the implications for the disability community are significant. In addition to the more than \$800 billion cut to Medicaid passed by the US House's American Health Care Act, President Trump's budget would cut an additional \$610 billion from Medicaid for a total of well over \$1 trillion in cuts over ten years. This budget also calls for \$72.4 billion in cuts to the Social Security Disability Insurance (SSDI) program and hundreds of billions more in cuts to other programs vital to individuals with I/DD and their families. Notably, the President's budget omitted funding for DD Councils in 2018. Instead, the administration plan recommends a new statewide structure combining councils on developmental disabilities, independent living and traumatic brain injury into a new "partnership for innovation, inclusion and independence." This proposed cross-disability statewide entity would come into existence with significant funding cuts.

The President's budget lacks any force of law and is primarily a communication tool to showcase Administration priorities. Congress will next begin its work to solidify its funding priorities and levels for 2018. While this process typically offers many opportunities for bipartisan discussion and amendments, the Senate will use "reconciliation instructions" which limits discussion time and requires only a simple majority vote of 51 in the Senate.

CMS Announces Extension for States Under Medicaid Home- and Community-Based Settings Rule

The Centers for Medicare & Medicaid Services (CMS) announced a three-year extension for state Medicaid programs to meet the Home- and Community-Based (HCBS) settings requirements for settings operating before March 17, 2017. States now have until March 17, 2022 to demonstrate compliance for the final rule. See the announcement from CMS. This extension is in response to states' request for more time to demonstrate compliance with the regulatory requirements and ensure compliance activities are collaborative, transparent, and timely.

For more information, please visit: <http://www.medicare.gov/Federal-Policy-Guidance/Federal-Policy-Guidance.html>.



DHHS Hosts NC Innovations Waiver Listening Sessions

The NC Division of Medical Assistance and the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services are holding listening sessions on the NC Innovations Waiver as they prepare to renew the waiver.

June 5, 2017

5:30 – 7:30 p.m.
Chapel Hill Library
100 Library Drive, Room A
Chapel Hill, NC

June 13, 2017

5:30 – 7:30 p.m.
Partners Behavioral Health
901 S. New Hope Road
Gastonia, NC

June 6, 2017

5:30 – 7:30 p.m.
Guilford County DSS
1203 Maple St., Rm 123
Greensboro, NC

June 20, 2017

2:00 – 3:30 p.m.
Webinar

June 8, 2017

5:30 – 7:30 p.m.
Trillium Health Resources
165 Center Street
Jacksonville, NC

June 22, 2017

2:00 – 3:30 p.m.
Webinar

June 29, 2017

2:00 – 3:30 p.m.
Webinar

The goals of the listening sessions are to provide an overview of the Innovations Waiver; let you know what just happened; let you know what's coming up; and get feedback.

For additional information, please contact:
IDDLISTENINGSessions@dhhs.nc.gov or call (919) 855-4968



DD Awareness *(continued from front page)*

community - minimal investments that can leverage long-lasting solutions. To put it quite frankly, we have much to do, and we do it well. And while we actively engage with our partners who are focused on Independent Living and Traumatic Brain Injury, each entity has a specific and unique mission and purpose.

A few reminders about the federal budget process: as occurs with each administration, the President will put forth a budget highlighting the priorities of the administration. Congress can take this into account as they create their own budgets which typically requires a great deal of debate and conferencing to come to agreement, at which time various appropriations bills are sent to the President for signature.

Looking ahead, we may see changes. In the meantime, we continue to educate our community, lawmakers and other stakeholders of the unique role and capacity of DD Councils, and trust that Congress will not move forward with the massive reorganization proposed by President Trump. Our National Association of Council's on Developmental Disabilities (NACDD), along with many state and local partners, are focusing on this. My recommendation is to remain focused on our important work and to continue with strong advocacy and education efforts with policy makers. Right now, along with the priorities

of the NCCDD Five-Year Plan, the overall cuts to Medicaid and other safety net programs must be our primary focus.

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>

Secretary Cohen *(continued from front page)*

get up to speed on issues and needs for people with disabilities.

Of the 50 states, "North Carolina was the second hardest hit" by the US House of Representatives vote on the American Health Care Act (AHCA), she added. Dr. Cohen admits there are still many steps in the process of the passing of the AHCA, so now is the time to educate legislators from North Carolina about intellectual and developmental disability issues and concerns.

Dr. Cohen says Council members and advocates can maintain the partnership with DHHS and to address the legislators with data and stories that enhance the lives of people with disabilities to live in the community and have meaningful lives.



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