



**NCCDD Executive Director  
Chris Egan**

## A Message from the Executive Director

"Three weeks ago we celebrated our nation's Independence Day. Today, we're here to rejoice in and celebrate another "independence day," one that is long overdue. With today's signing of the landmark

Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom."

President George H. W. Bush said these very words as he signed into law the Americans with Disabilities Act in 1990, making equal opportunities and access a right for people with disabilities. We, at NCCDD, are excited to continue celebrating this landmark legislation and recognizing the progress that has been made and is continued to be made for the disability community.

Highlighting one of the ADA's key principles - access- NCCDD has partnered with The Adaptables Center for Independent Living, ACCESS North Carolina and Hanging Rock State Park in Danbury, NC to celebrate the opening of a new accessible picnic shelter on Sunday, July 24 - allowing families with and without disabilities to enjoy North Carolina's beautiful state parks. It is a great opportunity to showcase our great State's continued efforts towards accessibility for its disability community while celebrating a law that promotes equal opportunities, regardless of disability.

As we celebrate the ADA's current accomplishments, let us keep working towards creating more opportunities and access for individuals with I/DD through employment, financial security, housing, transportation and more.

Chris Egan  
Executive Director

## Public Policy Update

NCCDD's public policy team brings you the latest on the NC's final budget that was signed on July 14, 2016; updates on the NC Innovations Waiver; disability studies recaps; and the latest from Workforce Innovation and Opportunity Act.

### FINAL BUDGET IS SIGNED

Governor McCrory signed the \$22.3 billion state budget on July 14, 2016. While there continue to be gaps in our system and people on waiting lists, some items indicate that there are areas that need to be adjusted.

### Budget items related to I/DD include the following:

**Governor's Task Force Reserve Fund** – The initial recommendation from the Task Force was \$30 million to address several areas of need. One was case management for children with I/DD and complex needs. The final budget allocates \$10 million recurring funds and \$10 million non-recurring. These funds will be put in a reserve and spent with approval of Office of State Budget and Management. It is not clear how it will be allocated, so it may or may not address I/DD needs. Most likely, funds will be directed to Mental Health/Substance Use Disorders.

**Single Stream Funding** – Provides a partial restoration (\$30 million) for the current year from the \$110 million cut last year and \$152 million cut this year, so this is a small percentage of the cut. This funding allows for up to \$30 million next year if there is a surplus in the Medicaid budget. Both of these are non-recurring.

**Traumatic Brain Injury (TBI) Funding** – There is an allocation of \$2.37 million non-recurring funds for the Brain Injury Association of NC, residential supports and supports for individual consumer needs. This continues funding that was allocated last year and is in addition to the pilot TBI waiver in the area managed by Alliance.

**Innovations Waiver Slots** – There is an allocation of \$2.6 million recurring to add 250 new slots. This was not in the Senate or House budget and was a last-minute addition to the budget.



## NCCDD to Host Picnic in the Park to Celebrate ADA's 26th Anniversary



### New accessible picnic shelter in Hanging Rock State Park

Join NCCDD, The Adaptables, Inc. Center for Independent Living, ACCESS North Carolina and NC State Parks for Picnic in the Park at Hanging Rock State Park on July 24, 2016 from Noon – 3 PM to celebrate the opening of the shelter with an ADA training, lunch and also commemorate the 26th anniversary of the Americans with Disabilities Act (ADA).

A new accessible picnic shelter will welcome families with and without disabilities to enjoy a day at Hanging Rock State Park to further the mission of accessibility and inclusion for people with disabilities.

**What: Picnic in The Park!**

**When: Sunday, July 24, 2016**

**Where: Hanging Rock State Park, 1790 Hanging Rock Park Rd, Danbury, NC 27016**

**Time: Noon – 3 PM**

Why: Hanging Rock State Park will celebrate the anniversary of the signing of the Americans with Disabilities Act (ADA) at its new accessible picnic shelter. Activities will include an ADA training provided by the staff of The Adaptables Center for Independent Living and painting the Accessible Icon in accessible parking spaces led by Brendon Hildreth of New Bern, NC. Lunch will be provided at the accessible picnic shelter that the ACCESS North Carolina program built to increase accessible picnic opportunities in the park.

## NCCDD Attends Project SEARCH Statewide Meeting

On June 27 & 28, 2016, representatives from each Project SEARCH program in North Carolina gathered at Wake Tech's Community College's Beltline Education Center in Raleigh for a statewide meeting led by Linda Emery and Susie Rutkowski from the Cincinnati Children's Hospital Medical Center, where Project SEARCH started in 1996.

The meeting also attracted other key partners in our State and representatives from South Carolina involved in establishing Project SEARCH sites there. Project SEARCH provides three

ten-week internships at over 400 sites internationally designed to help high school students and young adults with I/DD develop the skills they need to obtain competitive employment.

Day One focused on Project SEARCH's Teaching and Coaching for Success Training



Project | SEARCH

that included discussions on partnerships, teaching strategies, employability skills, and communication and collaboration.

Day Two focused on Effective Strategies for Job Development and Program Sharing in the morning. In the afternoon, Jennifer White (pictured) of Able Opportunities, Inc. in Washington state discussed an Office of Disability Employment Policy (ODEP) technology project that will incorporate iPad technology to teach job skills to Project SEARCH interns at CONE HEALTH Alamance Regional Medical Center starting in the fall of 2016.

Day Two also featured program updates from all 12 of North Carolina's Project SEARCH programs and then a panel discussion with NCCDD Executive Director Chris Egan, NCCDD Systems Change Manager Philip Woodward, NC Division of Vocational Rehabilitation Services Interim Director Kenny Gibbs and NC Community Colleges Education Program Administrator Dr. Trudie Hughes. The panelists talked about ways that Project SEARCH in North Carolina can continue to expand and succeed and fielded questions from the audience.

## Wilkesboro Family Stays Active and Advocates for People with Disabilities

Merlie Hayslett Jackson of Wilkesboro, NC tossed out her Webster's Dictionary a long time ago. She learned when people approached her about her daughter, Jessie, using the words "can't" and "no" that she needed to rewrite the definitions so it reflected her attitude about life – "we just need to find a way to make this happen."

So during the 13 years Merlie and her husband David searched for the reason their daughter began to fall, to slow down, to stop walking and talking, Merlie made sure Jessie stayed active doing all the things Jessie loved to do from riding Harleys to horses to playing baseball and more.

Six years after being diagnosed with Gangliosidosis-1 (GM-1), a progressive neurological genetic disorder caused by the absence of a vital enzyme, and hearing their fill of "no" and "can't," Jessie and her parents are busier than ever! Although she cannot speak and uses a wheelchair, 24-year-old Jessie is ready for her first two-mile Harley ride coming up this summer. She just participated in a 68-motorcycle caravan taking a trip to Danville, VA, exploring the back roads of North Carolina while riding in her parents minivan. Then, this Harley gal switched her motorcycle gear for a sparkly, lavender prom dress and attended the Joy Prom with several of her friends, looking like the princess she truly is.

"If you just sit, and this is for anyone with or without disabilities, your mind is going to run away with you, and it'll eat you alive," explains Merlie as she lists the activities Jessie participates in throughout the year. Those activities also include learning as much as they can about GM-1 and meeting other families facing that challenge.

For the fourth time, Merlie and her husband, David, packed up and headed with Jessie to the annual National Tay-Sachs and Allied Diseases Association (NTSAD) conference with help from the North Carolina Council on Developmental Disabilities (NCCDD). Funds from the NCCDD's Jean Wolff-Rossi Fund for Participant Involvement (Rossi Fund) paid for the Jackson family's conference registration and travel costs via van to Florida, where this year's conference was held.

The Rossi Fund empowers people with intellectual and other developmental disabilities (I/DD) and their family members with

opportunities to actively participate in decisions that often impact them personally. Through the Rossi Fund, individuals with I/DD and their family

members can receive reimbursement for specific expenses for seminars and conferences designed to improve their knowledge, networking and skill levels for advocacy.

"Without the help of NCCDD, we're not sure we could have pulled off this year's conference," admits Merlie. Additional funds for lodging, food and outings at the conference came from a year-long fundraising process which included everything from a children's clothing sale to a Go Fund Me page.

Explaining the power of the conference, Merlie says, "You will love it, you will hate it, you will cry and then you'll count the days until the next one."

“ “  
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to make this happen.  
” ”

This year's conference had 334 attendees with 21 of those being children affected by GM-1. Families came from as far away as United Arab Emirates, the Philippines and Germany. Thirty-three researchers, clinicians and industry partners were also in attendance with a group gathering data to help with clinical trials. The clinical trials were the big news announced at the conference, and Jessie will be a part of the group being considered for trial participation.

While Jessie is the oldest known woman with GM-1 by the doctors at the National Institutes of Health in Washington, D.C., she much prefers her back-home notoriety in Wilkesboro, where she is the reigning princess at Crossroads Harley-Davidson.

Check out how much fun Jessie had during a her Ride to Bike Night at <https://www.youtube.com/watch?v=06jnPseGytE>



Jessi Hayslett

## Public Policy Update *(continued from front page)*

### **Community Alternatives Program for Children nursing rates**

– There was an allocation of \$2.3 million recurring to increase nursing rates in the CAP-C program.

**Health Analytics Pilot** – Funding of \$1.25 million non-recurring to continue pilot, which will examine LME/MCO encounter data.

### **STUDIES:**

**Strategic Plan for Behavioral Health Services** – The Department of Health and Human Services is directed to conduct a statewide assessment of behavioral health services, including identifying role, responsibilities and accountability of LME/MCOs. This report is due to The Health and Human Services Legislative Oversight Committee and the Medicaid and Health Choice Legislative Oversight Committee by Jan 1, 2018. This is an opportunity for input into the system. Since the study is being carried out by DHHS, it is expected that there will be public comment options and opportunities to be a part of committees or task forces. NCCDD will keep stakeholders informed as the process is developed.

**Study Innovations Waiver to Address Waitlist and Federal Changes** – The Medicaid and Health Choice Legislative Oversight Committee is directed to study and report to General Assembly by Jan 1, 2017 on the following: strategies for reducing the waitlist for the waiver, use of single stream funding, implications of Home and Community Based Settings federal mandate, and coverage of autism treatments. This is short turn-around but a great opportunity to highlight the gaps in the I/DD system of support and generate solutions.

### **INNOVATIONS WAIVER AMENDMENTS - NOVEMBER 1, 2016**

**Innovations Waiver** – The NC Innovations Waiver amendment has been approved by the Centers for Medicare and Medicaid Services (CMS) and will be implemented on November 1, 2016. As a reminder, there are several changes to existing services definitions and some new services. New services include Community Living and Supports, which combines current Personal Care, In-home Skill Building and In-home Intensive services. Another new definition is Supported Living, which allows 2 -3 people to receive supports in their own home

without having to license the site. This is a great change which will expand opportunities for increased independence and decision-making.

One of the biggest changes to the waiver is the implementation of individual budgeting. An Individual Budget Tool, which includes the Supports Intensity Scale, will be used to determine funding levels. There is some concern about how this process will affect current supports for individuals. The Due Process Case that was brought by Disability Rights North Carolina helps to ensure appeal rights and keeps services in place during an appeal.

### **FEDERAL LEGISLATION:**

#### **Workforce Innovation and Opportunity Act (WIOA) Final Regulations:**

On June 30th, the Department of Labor announced its final rules to implement the Workforce Innovation and Opportunity Act (WIOA). A detailed fact sheet of the final regs can be found here. Signed into law in July of 2014, WIOA impacts many focus areas and populations. Of particular interest to individuals with I/DD: competitive, integrated employment, transition services for youth with disabilities, coordination between VR and other agencies, extension of the initial time period for VR supported employment services (from 18 to 24 months), and emphasis on VR services for individuals with significant disabilities among others. Over the next few months, the Department of Labor will host regional meetings in Washington, D.C., Chicago and Sacramento to help orient states, advocates and others to the final regulations and next steps. We'll update Council members as detailed analyses of these regulations become available.

## **North Carolina Council on Developmental Disabilities**

3125 Poplarwood Court • Suite 200 • Raleigh, NC 27604

919-850-2901 (TTY) • Fax 919-850-2915

Toll Free 800-357-6916 (TTY)

[www.nccdd.org](http://www.nccdd.org)



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