A Newsletter from the North Carolina Council on Developmental Disabilities

September 2016



NCCDD Executive Director Chris Egan

A Message from the Executive Director

September has presented many ways our community can get involved in pushing NCCDD's mission forward to make North Carolina a more inclusive and integrated state for people with intellectual and other developmental disabilities (I/DD).

Self-advocates, advocates and professionals who work and advocate on behalf of the disability community here in North Carolina are integral to the progress we have made and continue to make. And it is important for us to recognize the hard work and passion of these individuals who continue to speak up and speak out for the I/DD community. The deadline to nominate these individuals for the Jack B. Hefner Memorial Award and Helen C. "Holly" Riddle Distinguished Service Award is fast approaching on Monday, Sept. 26, so get your nominations in!

As I mentioned, our work isn't complete without the professionals and advocates who have made this their life's work. To support its new Five Year Plan, NCCDD is seeking a Systems Change Manager who will lead and manage initiatives that will make our goals a success in North Carolina. Additionally, the Council has opened an RFA for programs that support its Community Living goal under the new plan.

October will celebrate National Disability Employment Awareness Month, and what better way to start the month than with The Sixth Annual WNC Regional Transition into Adulthood Fair, A Journey Toward Independence: Positive Outcomes for Youth with Disabilities in Asheville, NC. There will be great resources for families to learn about early transition planning so all students with disabilities can have a successful adulthood.

There are a lot of activities and ways to get involved to support the I/DD community and we hope you join us as we pave the way to make NC a more inclusive and integrated state.

Public Policy Update

NCCDD's public policy team continues to deliver local, state and federal updates on public policy that affects people with I/DD. Highlights of these updates include:

STATE POLICY

Voting: Information you can use!

Many people have questions about voting requirements. Disability Rights North Carolina has created a great resource — www.accessthevotenc.org. Learn more about voter registration and voting, candidate information, reporting a violation, and an email listserv to be kept up-to-date on any further changes. Remember: Voter ID is not required.

IMPORTANT DATES:

10/11/16: Last day to register to vote from home

10/20 -11/5/16: Early voting period – contact your local County Board of Elections for times and locations. Same day voter registration is allowed during early voting.

11/8/16: **ELECTION DAY**



FEDERAL POLICY

The Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities delivered their final report to US Secretary of Labor Thomas E. Perez on September 15, 2016. Created by the Workforce Innovation and Opportunity Act (WIOA) of 2014, this committee was charged with developing recommendations to improve the employment participation rate of individuals with disabilities across the nation. The recommendations are intended to increase opportunities

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Highlights & Hot Topics

Chris Egan Receives Honor from The Arc of North Carolina

Chris Egan, executive director of the North Carolina Council on Developmental Disabilities, received the 2016 Deborah Greenblatt Distinguished Service Award from The Arc of North Carolina. The award was presented at the organization's statewide conference held from Sept. 8-9, 2016 in Charlotte, NC.

The award honors an individual or organization that has contributed in a distinguished manner to the promotion of rights and/or services to North Carolina citizens with developmental disabilities.

It is named for Deborah Greenblatt, a North Carolina attorney, who was a passionate advocate for children and adults with mental disabilities and the executive director of Carolina Legal Assistance for 23 years. She was primarily responsible

for bringing
together the
diverse coalition
of disability
advocates
and education
stakeholders
who drafted
the current
bill promoting
the safe use
of seclusion and
restraint in public



Chris Egan (c), accepts the Greenblatt award from The Arc of North Carolina.

schools, now known as the Greenblatt Act.

Family Support Network Hosts Transition Fair

The Sixth Annual WNC Regional Transition into Adulthood Fair, A Journey toward Independence: Positive Outcomes for Youth with Disabilities will be held on Saturday, October 1, 2016 from 11:00am to 5:00pm at Mission Health/A-B Tech Conference Center, 340 Victoria Rd. Asheville, NC 28801.

This year, there will be four educational sessions provided for attendees. Participants will have the chance to meet with exhibitors/agencies that provide services related to housing options, employment, post-secondary education and community engagement programs. Chris Egan, NCCDD's executive director, will also be the event's keynote speaker. He will highlight high expectations and that a person's disability is not a limiting factor to building and leading a successful, meaningful life.

The nature of this event appeals to parents of children with special needs as well as developmental disability specialists, special educators, service/care coordinators, mental health professionals, allied health professionals, teachers, school nurses/counselor and other interested health and human services professionals. It offers a great opportunity to meet and network with other providers.

Please contact Kerri Eaker, Family Support Outreach Coordinator, for the Family Support NetworkTM of WNC at 828-213-0047, or by email at *kerri.eaker@msj.org* for more information.

NCCDD Seeks Systems Change Manager

NCCDD is hiring a systems change manager to join its team! The Systems Change Manager will coordinate, plan and guide the Council's investment in initiatives to accomplish goals set forth in the Council's Five Year Plan. This includes research, analysis, administration and management, budget and finance, relationship building with other state, federal, and local agencies in the promotion of independence, productivity, integration and inclusion of people with intellectual and other developmental disabilities (I/DD) into the community. For more details and how to apply: http://bit.ly/SystemsChangeManager

Public Policy Update (continued from front page)

for competitive integrated employment for individuals with intellectual and developmental disabilities (I/DD) and other disabilities. Ensuring that employment is the first option for people with I/DD or other significant disabilities will increase their employment participation rate and lead to a significant reduction in segregated work and non-work programs and in the use of Section 14(c) certificates for paying subminimum wages. With a work force participation rate of less than a third that of the general population, people with disabilities must be included in efforts to develop the skills and experiences necessary to successfully enter the workforce.

Highlights & Hot Topics



Taking Initiative: First In Families Brings Together Adult Siblings of People with Disabilities

On her birthday, when her cake with flaming candles was placed in front of her, Kelly Mellage would close her eyes and wish for the same thing year after year – that her big sister Angela would talk. Kelly didn't care what Angela would say, she just wanted to hear her sister's voice. Then she would blow out the candles.

That wish hasn't come true, yet. Forty-seven years ago, Kelly's older sister Angela was born with intellectual and developmental disabilities (I/DD) that impacted her independence profoundly. She is non-speaking, lives with seizures and requires constant supervision. Although Angela walked as a child, she now uses a wheelchair and requires the support of multiple caregivers to help meet many needs such as personal care, and learning new skills.

Angela, Kelly and their younger brother, Brian grew up in New Jersey where friends and family took Angela's physical and mental challenges in stride. But a move to Raleigh, North Carolina when Kelly was high school age meant she had to start all over 'explaining' to her peers about Angela. Growing up, Kelly never knew a single person who was a sibling of a person with I/DD like she was.

Enter the North Carolina Council on Developmental Disabilities (NCCDD) Sibling Support Initiative, managed by First In Families of NC (FIFNC), which address the various needs and barriers that adult siblings of a person with an intellectual or other developmental disabilities face. But the initiative also lets us all hear the dreams and interests held by these adult siblings.

"As an adult, I do talk about Angela easily and I thank God that He gave her to us. What I have found with the Sibling Support initiative (NC Sibs) is that it gives us permission to openly talk about our siblings – the good, the bad, the ugly – with others who truly get it," explains Kelly. "There is power in sharing our stories and being truly understood and validated."

Across the State, in Boone, NC, is Allison Dodson, the middle sister of three. "Jennifer is the oldest in our family. She was born with a rare genetic disorder, Tuberous Sclerosis, which can affect people in a spectrum of severity. Her disability causes seizures, impairs intellectual development and has created some physical disabilities due to the location of tumors in her brain and other areas of her body," explains Allison.

Allison and Kelly found each other through NC Sibs. They both share the knowledge that one day, as their parents age beyond the ability to care for their siblings with disabilities, Kelly and

Allison will need to step into that role.

"I'm just now beginning to learn about the systems in place that provide support resources to Jennifer, and I feel overwhelmed at trying to absorb all of the information available. I'm grateful to have NC Sibs as



The Mellage Family

a credible and empathetic network of support as I prepare to eventually move into a more active "caretaker" role in my older sister's life," says Allison.

Connecting with others who have brothers and sisters with I/DD has allowed the group, including Kelly and Allison, to talk about what they have lived through. They also get the chance to talk about the person their sibling is, beyond whatever challenges they may experience.

Jennifer "is tenacious and passionate, and isn't afraid to challenge systems to get her point across. She loves music, M&Ms, hugs, and Oprah," shares Allison.

Plus, the group reminds each other that they each have lives, too, outside their sibling relationships. "As a sibling, much of the family's attention is always focused on the child with special needs," explains Kelly.

While understandable, other siblings often get lost in the shuffle. NC Sibs provides a chance to recognize the members as unique individuals, too. They talk about their careers, their pets, their hobbies- relaxing in an important way among peers who understand them well.

The initiative offers a variety of opportunities to brothers and sisters of people with disabilities. Sibling events, monthly calls and both public and private Facebook groups help these siblings

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Highlights & Hot Topics

NCCDD Seeks Nominations for Advocacy and Leadership Awards

The deadline to submit nominations for NCCDD's Advocacy and Leadership Awards is Monday, Sept. 26. Please nominate and share in your network to recognize those individuals for the Jack B. Hefner Memorial Award and Helen C. "Holly" Riddle Distinguished Service Award.

The Advocacy and Leadership Awards highlight two of the most important qualities that the namesakes - former NCCDD Council member Jack B. Hefner and former NCCDD Executive Director Holly Riddle - presented and continue to present in their work

for people with intellectual and other developmental disabilities (I/DD).



Read more about the awards and the applications are available here: http://bit.ly/
AdvocacyLeadershipAwards

NCCDD Requests Applications for Supported Living Initiative

In its State plan, NCCDD set out the goal that the Council will increase community living for individuals with intellectual and other developmental disabilities (I/DD). To reach this goal, NCCDD has committed its funds to expand and strengthen North Carolina's capacity to support people with I/DD, who may have traditionally been excluded from living according to supported living principles. Deadline to apply is October 10, 2016.

For more details and how to apply, visit http://nccdd.org/news-media/blog/54-initiatives/428-nccdd-announces-rfa-for-support-living-initiative.html.

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meet each other. In addition, FIFNC provides help in understanding and navigating the system of services and supports for their brother or sister with I/DD.

"Being the sibling of a person with disabilities is such a unique experience. The challenges, milestones, and successes are often powerful moments that



Allison with Jennifer (I)

shape our relationship with our family and our own personal development. I'm grateful to be connected to a network of people who have similar experiences and understand the scope of what it means to be a sibling," adds Allison.

To provide ongoing support and connection for even more siblings of people with I/DD, North Carolina started its very own chapter of National Sibling Leadership Network called NC Sibs. NC Sibs is a statewide group of adult siblings of individuals with developmental disabilities, and it hopes to continue beyond the Council funding to connect siblings with one another to provide support and information specific to the unique aspects of the adult sibling relationship.

Connecting to others who have similar circumstances, finding resources to help support their sibling and family, and gathering information on planning for the future are common needs expressed by siblings.

As a part of NC Sibs efforts to engage more siblings, caregivers, parents, and professionals, the chapter's leaders together with FIFNC staff will be traveling across the state in September 2016 to share resources, provide information about the network, and gather feedback about what siblings need. Get more details

on the NC Sibs Statewide Sibling Tour, http://ncsibs. org/assets/files/nc-sibsevents-flyer.pdf



This publication is produced by the North Carolina Council on Developmental Disabilities, established by the Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402) to promote interdependence, contribution, self-determination, integration and inclusion into the community for citizens with developmental disabilities. The NC Department of Health and Human Services does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services. Hard copies of this publication are available on request at a cost to the Council of \$2.58 per copy.