

The Road Ahead...

...leads to full inclusion of those with Intellectual and other Developmental Disabilities!

The Americans with Disabilities Act (ADA) of 1990 stated the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals. Yet, almost 25 years later, we are far from achieving these goals!

Most people with disabilities still live in dependency and poverty and are segregated in many ways. Unemployment is approximately 70%. Most are not living independently, and few have economic self-sufficiency. Segregated housing, employment, education and social activities are still very common.

Why?

I'd suggest the largest cause is our own attitudes and beliefs regarding the abilities and value of these individuals. Too often we believe that those with disabilities can't do things, must be protected from risk, must be taken care of and are better off in segregated facilities. These attitudes and beliefs create low expectations and fear among parents, teachers, employers and friends. We seek more money and services to "take care of them", rather than changing expectations and creating appropriate supports that help people toward a fully inclusive life. Even federal government policy states some with disabilities can be paid sub-minimum wages. If our government says that, how does that impact employers' beliefs and attitudes towards those with I/DD?

What can we do?

All people with disabilities have value and different abilities. NCCDD funds initiatives to support policies and practices that help people have truly meaningful and productive lives. The Council believes in the value of each person and supports systems change around education, employment, asset building, and transition from school to work. This belief is also reflected in the Stakeholder Engagement Group's Report regarding Medicaid reform. Join us as we pave the road ahead to foster better lives.

Sincerely,



Ron Reeve, NCCDD Chair



Catalyst for Change

SUMMER 2014

News of the North Carolina Council on Developmental Disabilities



Chris Egan Named New Executive Director for NCCDD

For the first time in over two decades, the North Carolina Council on Developmental Disabilities (NCCDD) has a new Executive Director. Chris Egan, formerly a Clinical Assistant Professor in the School of Social Work, UNC Chapel Hill, and Clinical Coordinator for the Developmental Disabilities Training Institute within the Jordan Institute for Families in the School of Social Work, became NCCDD's Executive Director on June 30.



CHRIS EGAN

"As Executive Director of the North Carolina Council on Developmental Disabilities, I am committed to collaborating with individuals, families, advocacy organizations, the Secretary of Department of Health and Human Services (DHHS) and various DHHS divisions, Managed Care Organizations (MCOs), and other stakeholders to promote choice, responsiveness, innovation and stability within our service system," said Egan.

With both undergraduate and graduate degrees in social work from East Carolina University (ECU), Egan's efforts are directed toward promoting

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The SEG Way to a Healthy North Carolina

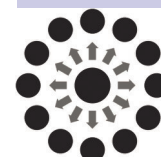
The North Carolina Stakeholder Engagement Group (SEG) is working to ensure decisions about people with disabilities have input from those with disabilities themselves. Having met for six months, the group has developed a consensus about what is wanted from a long term care system - the values, principles, needs, and outcomes important to those with disabilities. They plan now to communicate that consensus to key decision makers.

This 19-member unique group is comprised entirely of individuals receiving disability services as well as their family members. They are the only cross-disability stakeholder group representing intellectual and other developmental disabilities, mental health, addictive diseases, individuals with physical disabilities, and family caregivers in the state of North Carolina.

The Stakeholder Engagement Group worked to reach consensus on what is needed in the long-term support system rather than how to get there in terms of administration. The group very quickly defined five outcomes that are important to individuals and families from all disability groups which includes a system that helps those with disabilities be more independent—a system:

- 1) that has no waiting lists.
- 2) where individuals have jobs in integrated employment settings.

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"Catalyst" - An instrument for change

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SEG Way *-continued from page 1-*

- 3) where individuals live inclusively in their communities.
- 4) where people with disabilities have the ability to develop assets.
- 5) that is accountable for meaningful outcomes.

The Stakeholder Engagement group also spent time discussing their expectations of the system, such as:

- getting disability care services for the first time
- disability assessment
- support coordination
- assuring the availability of qualified providers
- protecting the rights of those with disabilities

SEG wants the leaders of the Department of Health and Human Services, at Medicaid and North Carolina state legislators to know what is important to people with disabilities.

“I Need To Make A Difference” Says 2013 Hefner Award Winner

Once on a path to a career as a zoologist, the birth of her daughter Nicole, who has a developmental disability, brought a new focus to Roxann Colwell’s life and a commitment to work as a volunteer and professional in human services. The accomplishments in her nearly 30 years of activity as an advocate and organizational leader led to her selection as the winner of the prestigious Hefner Award from NCCDD in November, 2013.



Now director of the Family Support Network of Western North Carolina in Asheville, Colwell is responsible for a Parent-to-Parent program serving 15 western North Carolina counties. This program matches new

parents of children with special needs with “mentor or support” parents who have raised children with disabilities. She also is director of the family resource center at Mission Children’s Hospital.

As a volunteer, she has been active in the WNC Down Syndrome Alliance, the Family Support Network, Leadership in Self-Determination, the NCCDD, The Mediation Center and The Blue Ridge Area Authority.

“I have been involved in tons of initiatives to change the system across the state. I need to make a difference,” she said.

The Jack B. Hefner Memorial Award, established in 1994, celebrates the leadership of a man whose work inspired a generation of advocates and people with developmental disabilities.

Shar’ron Williams Joins NCCDD Staff

NCCDD’s newest Business Service Coordinator, Shar’ron Williams, joined the NCCDD team in early June.

Shar’ron most recently worked as a Contract Coordinator for the Division of Public Health. She has a bachelor’s degree in Organizational Management from St. Augustine College. Her passions are meeting and helping people and traveling.



Egan *-continued from page 1-*

respect and positive outcomes for people with intellectual disabilities, developmental disabilities, and other co-occurring disabilities.

Egan and his wife, Lauren, are parents of twins, a boy and girl born in 2001. Their daughter was born with VATER Association resulting in numerous and significant medical complications, placing their daughter at significant risk of developmental delay. They engaged natural and formal supports including North Carolina’s Early Intervention services to provide supports for their daughter. “As a parent, I have a unique perspective of the powerful experiences associated with having a child born with a disability, and have benefited from the assistance of our service system,” Egan added.

Egan brings a multitude of skills and expertise to his new position with NCCDD including person-centered thinking and planning, a commitment to personal outcomes and supports for people with disabilities and volunteer leadership with The Arc of the US and of NC, the NC Developmental Disabilities Consortium and the ECU School of Social Work Board of Advisors.

“We continue to have much to do to enhance the array of responsive and stable community supports, and The North Carolina Council on Developmental Disabilities is strongly positioned to help promote a voice for individuals and families in advising and guiding NC’s DHHS and MCOs,” Egan said.

“Communities are stronger when all people are included. We will achieve the greatest success in supports for people with intellectual and other developmental disabilities by engaging the full range of community cohorts as vested partners,” he added.

Three New Members Bring Diverse Backgrounds to Council

Governor Pat McCrory recently appointed Amanda N. Bergen, Ph.D.; Wing Ng, M.D.; and David White to the North Carolina Council on Developmental Disabilities. The Council is a 40-member, governor-appointed body and 60 percent of its members are people with developmental disabilities or their family members.

AMANDA BERGEN

Amanda Bergen is a stay-at-home mother in Charlotte raising her two children who both have developmental disabilities. She applied to be a part of the Council in order to help give a voice to parents of younger children with developmental disabilities as they start advocating for a better tomorrow for their children. “Along with my fellow council members, I hope that we can make significant and measurable progress



in our state that benefits all citizens, but especially those with intellectual or developmental disabilities,” Bergen said.

DR. WING NG

Dr. Wing Ng is the Medical Director of the Brain Injury Program at WakeMed Rehabilitation Hospital in Raleigh, NC.

His oldest daughter was born with Down Syndrome and Dr. Ng’s hope is for her to grow up in a society that will not place limits on what she can achieve because of her diagnosis.



“I hope to use my perspective as a physician and a parent-advocate to help advance the direction towards better access to healthcare for those with intellectual and developmental disabilities,” he said about joining the Council.

DAVID WHITE

A Raleigh resident, David White is a Principal at Capital Planning Group, Inc. in Cary, NC. He feels serving on the Council as a parent of a child with developmental disabilities is a great opportunity to advocate for all with disabilities in this ever-changing world. “I hope we, as a Council, can continue to strive for even more dignity and an evolving understanding of people with developmental differences,” he added.



“The NCCDD is very fortunate to have these three new dedicated members appointed by Governor McCrory. Each is a parent of a child with developmental disabilities and brings personal knowledge and experience to help the Council foster better lives for all of those in the intellectual and developmental disabilities population,” said Ron Reeve, Council Chair.

TWO NEW INITIATIVES TO ADDRESS SIBLING SUPPORT AND FINANCIAL LITERACY

The NCCDD approved funding for two new initiatives during their May council meeting.

The Sibling Support initiative, through First in Families of North Carolina, will create a system of support for siblings of a person with an intellectual or other developmental disability which will prepare them in a variety of ways to meet their brother’s or sister’s needs.

The Financial Education initiative, through the National Disability Institute, will encourage and support the partnership of the public and private sectors in spreading financial awareness to people with intellectual and/or developmental disabilities and their families.



Applications for both the 2014 Hefner Award and the 2014 Holly Riddle Award are now available on our website on the “What We Do” page. Submissions are due September 26!

LEGENDARY LEADER J. IVERSON RIDDLE HONORED WITH FIRST NCCDD DISTINGUISHED PROFESSIONAL AWARD

Dr. J. Iverson Riddle received the first Helen C. “Holly” Riddle Award from the NCCDD. Dr. Riddle began his lengthy North Carolina career at Western Carolina Center in Morganton, an institution for people with intellectual disabilities that he headed from 1962—2006.

Dr. Riddle made the center a birthplace for original policy development, with a record of more than 40 innovations in developmental disabilities, including the establishment of the first advocacy program in an institution, creative arts programs and the first human rights committee within a state institution.

A graduate of the University of North Carolina at Chapel Hill Medical School, he went on to a residency in child psychiatry. He joined the Western Carolina Center after serving as a lieutenant commander in the U.S. Navy. The Center was renamed the J. Iverson Riddle Center in his honor.

The new NCCDD award is named for Holly Riddle, Dr. Riddle’s daughter, who served as executive director of the Council for more than two decades.

