

Catalyst for Change

WINTER 2009

NEWS OF THE NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES



Council co-sponsors international self determination conference

Hundreds expected to attend May event in Winston-Salem

The spotlight will be on Winston-Salem, N.C. on May 3 as people from across the U.S. and around the world gather for the International Conference on Self-Determination at the Benton Convention Center. The NCCDD is proud to join the national Center for Self-Determination as co-host and co-sponsor of this important event, which will feature presentations on self-advocacy, direct support workforce development, emerging approaches to employment and other income sources, and innovations in creating inclusive communities and personalized supports, among others.

The cost of the three-day conference is \$189 for early registrations, but goes to \$239 after April 24. A pre-conference program will also be held, with fees of \$75 for early registration and \$100 after April 24. Scholarships are available. Those interested are asked to go to www.self-determination.com to register.

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Growing tomorrow's I/DD policy leaders is goal of new initiative

Electronic applications due February 23

The future, it is said, is what one is working on today. In that spirit, the North Carolina Council on Developmental Disabilities is moving now to ensure strong leaders in the field of intellectual and other developmental disabilities

(I/DD) for the decades to come. The NCCDD is funding the new Advancing Strong Leadership in Developmental Disabilities initiative, a three-year effort to identify and prepare the next generation of people who will lead North Carolina's programs for people with I/DD.

"This is an especially significant initiative since an estimated 60 percent of the leadership of nonprofit and governmental organizations will be retiring in the next five years. We need to have high caliber leadership ready to step up to the plate," said Holly Riddle, NCCDD Executive Director.

The leadership development program for young professionals is

modeled after a successful project at the University of Delaware: the National Leadership Consortium on Developmental Disabilities. This program, in partnership with the Community Resource Alliance, will present the North Carolina program.

The initiative will be led by Nancy Weiss and Steve Eidelman (former director of The Arc of the U.S.). Its faculty will also benefit from the expertise of Derrick Dufresne, Mike Mayer and Duncan Munn, acknowledged leaders in the field and well known to many in North Carolina.

"By focusing on one state over a multi-year period, we believe that the results for people with intellectual and other developmental disabilities will be significant," said Eidelman. "We are hopeful that other states will follow North Carolina's lead."

The immediate task is selecting 25

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Nancy Weiss, University of Delaware, co-leader of Advancing Strong Leadership in Developmental Disabilities Initiative

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NCCDD member Monica Foster speaks at forum, as husband, Bryan, and facilitator Trish Farnham look on.

Sexuality, meaningful relationships and disabilities: Meeting the right person -- safely

Sexuality in the context of meaningful relationships between people with disabilities: it's a topic that is usually skirted, but the NCCDD addressed it head-on at its November meeting with a guided panel discussion on developing relationships and the risks associated with them.

Connecting with other people in a romantic way largely involves getting

people to look beyond the wheelchair or the disability to see the person.

Several Council members took part in the discussion and shared their own experiences. Vice-Chair Monica Foster and her husband, Bryan, along with Executive Committee members Rusty Bradstock and Jonathan Ellis were among those taking part. They were

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2 MANAGING FOR QUALITY

An organization committed to quality is John McCallum's legacy at the NCCDD

Though John McCallum has retired from the NCCDD after several decades of dedicated service, he leaves a valuable legacy: a deep-seated concern for quality. As assistant director for quality management, this skilled administrator



John McCallum, NCCDD assistant director for quality management, retires

created policies and practices aimed at monitoring and enhancing the quality of the Council's operations with its grantees, as well as interactions among members and other key stakeholders.

Though he always underplayed his contributions, McCallum's insights and experience have contributed greatly to the accomplishments of the Council.

"While John will be much missed, we will continue to reap the benefits of his years of work behind the scenes to ensure that the Council operates effectively, efficiently, ethically and always with its mission of member-driven change front and center," said Holly Riddle, NCCDD executive director. "We wish John a rewarding and well deserved retirement."

Sexuality, from page 1

joined by NCCDD Communications Manager Barton Cutter, his wife, Megan, and facilitator Trish Farnham.

Monica Foster said that locating the right partner for a relationship may take some time, but that the outcome can be very rewarding. She first connected with Bryan via the Internet. They exchanged messages for months as their fondness for each other continued to grow—all before they actually met.

Bradstock and Ellis said they had not yet found long-term partners but both are still doing the work it takes to meet and get to know someone. They observed that transportation can be a barrier to dating and that living with roommates or in group settings can prompt privacy concerns. Both men have had significant relationships, however.

Common interests can be the key to some connections, as the Cutters can attest. Megan met Barton while both were training in martial arts. A common interest helped spark a relationship that grew from there. Family members on both sides can raise concerns, the Cutters noted, especially when the subject of

marriage arises. Some family members may fear that a disability will add stress to a relationship. Keeping the channels of communication open with families can often overcome this, they said, agreeing that it is well worth the effort.

While encouraging social contacts is important, so too is understanding risks. Tina McNeill of the North Carolina Coalition Against Sexual Assault and Pam Dickens of the NC Office on



NCCDD Communications Manager Barton Cutter, his wife, Megan, and Council Member Jonathan Ellis.

Disability and Health reported on the incidence of sexual victimization of people with disabilities, known to be well above

that of the general public. These presenters addressed concerns about the threats of sexual assault with tips for staying safe and avoiding harm.

People with I/DD need to set boundaries, they explained, know the people around them and know where to turn for help when needed.

If uncomfortable, people should say "no," distance themselves from the person and tell someone what happened. Community rape crisis centers are helpful, McNeill and Dickens noted. They also shared the NC Coalition Against Sexual Assault's toll-free number: 1-888-737-2272.

Future leaders, from page 1

qualified individuals, under the age of 40, to participate in the first leadership institute in April. Those applying need to have the backing of their organizations, since both the person and the agency will be expected to commit to the initiative over the course of the three years. The selected, future leaders will be expected to participate in all three days of the April 14-17 institute, plus monthly webinars and teleconferences.

Over the three years, young leaders will learn to navigate successfully common systems barriers; to challenge the status quo effectively; and to promote progressive public policy. All will be expected to also challenge themselves and their organizations with ambitious goals that foster a positive organizational culture and outcomes meaningful to people and families.

Applications are due February 23, 2009 and are available at www.nccdd.org. The NCCDD looks forward to supporting leadership development for the field's next generation.

Conference, from page 1

The NCCDD sees the conferences as an opportunity for participants to learn about the national and international approaches to building welcoming communities that offer a better quality of life for everyone.

New staff additions

NCCDD welcomes two new staff members, Lynell Tucker Otto and Cora Gibson. Otto, whose background includes parenting a child with I/DD, leadership roles in the Maryland DD system and doctoral studies in Public Policy, will be a program manager.



Cora Gibson has broad experience in administrative support and will work with the Council and its staff to help ensure that the organization has the support it needs to run smoothly.



Summit findings go to Governor Perdue

A new governor and state administration need time to chart policies across all areas of government. In North Carolina, the mental health, developmental disabilities, and substance abuse system presents perhaps the greatest challenge for establishing clear, cohesive direction. This was the motivation for the "Looking Forward" Summit on North Carolina's Developmental Disabilities System. The Summit brought together some of the state's finest expertise, including policymakers, professional advocates, people with I/DD and families, and providers. Organized by the NC Council on Developmental Disabilities, the Summit initiative produced a technical report, supporting the Summit participants' recommendations, and presented these to Governor Beverly Perdue.

The goal of the Summit was to reach consensus among a group of experts on

the policies that should guide North Carolina's delivery of services and supports for people with intellectual and other developmental disabilities. "The Summit is unprecedented in the history of this state," said NCCDD Chair Robert J. (Bob) Rickelman, Ph.D., who together with Senator Katie Dorsett and Representative Verla Insko, co-chaired the Summit.

Recommendations for the new administration include reinstating the waiting list for services to meet a growing demand driven by aging "baby boomers," implementing workforce development strategies



From left, Holly Riddle with crowd, Derrick Dufresne, Council members Senator Katie Dorsett and Vicki Smith. Below, Holly Riddle opens presentation.

to build competencies and address recruitment and retention among direct support workers; strengthening case management to enhance accountability and coordination between case management entities and the Local Management Entities (LMEs); and developing state and LME leadership, specific to I/DD.

Other recommendations concern the development of an individual funding allocation model that corresponds to the intensity and complexity of a person's needs and matches these to funding levels; creating incentives that assist LMEs and providers to transition people from congregate settings to real homes in the community; and identifying individuals with I/DD living in adult care and nursing facilities and working to ensure they receive needed support in the most integrated setting possible.

The report also makes a series of recommendations that reaffirm self-determination and individual freedoms for all people with I/DD.

ELLEN PERRY WINS HEFNER AWARD

The NCCDD recognized more than 25 years of dedication, persistence and accomplishment when it presented the 2008 Jack B. Hefner Award to Elizabeth Ellen Perry of Carrboro.

Known as a forceful advocate for people with disabilities, Perry began her campaign for change by pressing for the installation of automatic doors to improve access at Carrboro City Hall. She later served on the Carrboro Transportation Advisory Board. Then she shifted her focus to Raleigh and work on statewide policies. She was subsequently credited as being the key figure in advancing a



Former NCCDD member Ellen Perry of Carrboro holds the 2008 Jack B. Hefner Award she received at the fall meeting.

resolution in support of self-determination at the North Carolina General Assembly. Ms. Perry currently leads an initiative on health and wellness and continues her work with Real Advocates Now Emerging (RANE), a self-advocacy group based in the Chapel-Hill/Carrboro communities.

Ellen Perry served two terms on the North Carolina Council on Development Disabilities. "Everyone who knows Ellen has witnessed her passion and commitment to improving the lives of people with disabilities and their families," said Executive Director Holly Riddle.

Applications for the 2009 Hefner Award

The Hefner Award is named in honor of Jack B. Hefner, the father of a son with intellectual disabilities. "Big Jack" served on the NCCDD from 1982 until his death in 1994. A man willing to do whatever it took to enhance the lives of North Carolinians with disabilities, Hefner was an inspiration to others who work for full inclusion for all.

The NCCDD welcomes nominations for the 2009 Hefner Award, to be presented to an individual with I/DD or a family member who has made significant contributions to enhancing the quality of life for North Carolinians with developmental disabilities. Nominees are those individuals whose leadership, achievements, lives and advocacy advance a shared, contemporary vision of life for people with developmental disabilities.

For more information call (919) 420-7901 or 1-800-357-6916 or go to www.nccdd.org.

4 An era of change, state and federal

An atmosphere of change fills the air in both Washington, D.C. and Raleigh as new administrations seek to lead and to serve our communities, state and nation. The many people who are deeply concerned about those policies, pursued at both capitals, affecting people with I/DD and their families will be watching carefully and, we hope, taking action together to support positive change. We at the NC Council on Developmental Disabilities offer Governor Perdue and her administration our best, with renewed hopes of advancing those systems change, advocacy and capacity building efforts that move us forward together.

The Council's Summit on Developmental Disabilities, held this past summer, provided specific recommendations for Governor Perdue, Secretary of DHHS Lanier Cansler and other policy makers to consider as we begin these next four years. The Summit recommendations promise a stronger, more cost-effective,

coordinated system of personalized services and supports, aimed ultimately at offering all people with I/DD and their families full lives in welcoming communities across North Carolina.

We are pleased to have advanced innovation on several key fronts in the past year. Among these are direct support workforce development; asset development; health and wellness; and grassroots organizing and networking. I invite you to review our annual report for the 2007-2008 year. The report outlines our priority areas and the tangible steps being taken to achieve the Council's goals. Whether we are funding innovation, supporting grantees, building grassroots or professional leadership, or acting as a statewide catalyst for change, the membership of the NCCDD—60% of whom are people with I/DD and their families—seeks to promote those policies and practices that offer people rewarding lives in the community.

The NCCDD is particularly proud to have been invited to co-sponsor

the International Conference on Self-Determination to be held in Winston-Salem, May 3-5. It is sure to give the self-determination movement the extra push it must have in these difficult times.

Working with and through an impressive group of grantees, the North Carolina Council on Developmental Disabilities anticipates making strong progress in the months ahead on its core goals. Your support is appreciated as the Council and its grantees strive to empower North Carolinians with intellectual and other developmental disabilities, along with their families, to achieve the life goals that we all so value.

Sincerely,



Holly Riddle, J.D., M.Ed.
Executive Director



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If you would like a name to be added or removed from this mailing list, contact Cora Gibson at (919) 420-7901, or e-mail newsletter@nccdd.org.

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