

## 4 The Road Ahead...

Change can be sudden, and sobering, as we learned with the passing of Steve Jordan, the head of the NC's Division of Mental Health, Developmental Disabilities and Substance Abuse Services. Change can also present a time to reflect. NCCDD looks back, with pride, at the many initiatives advanced under the chairmanship of former Chairman Bob Rickelman, Ph.D.; among these, the state's first four-year college experience for students with intellectual disabilities, "Beyond Academics"; the initiation of the National Curriculum Initiative in Developmental Medicine, the initiation of "Advancing Strong Leaders in Developmental Disabilities;" the introduction of the College of Direct Support; the dissemination of information about individual development accounts and other asset development strategies to people with disabilities; the development and the expansion of the Americans with Disabilities Act Network; "That All May

Worship;" the introduction of self-directed services ("self-determination") to NC; and the publication of a seminal gap analysis and action steps, "A Strategic Analysis for Change," to name but a few.

Change also leads us forward. The appointment of Ron Reeve as the new chairman and the 2011-2016 State Plan are likely to focus the Council's resources squarely on employment, along with the family support for aging families; the impact of the Affordable Care Act for people with I/DD; new approaches to housing, companionship, and support (e.g., shared living); and a renewed commitment to grassroots self-advocacy.

The Developmental Disabilities Bill of Rights and Assistance Act (PL 106-402) charges all 55 Councils on Developmental Disabilities with change of a particular type: systems change. Systems change comprises not only legislative advocacy, but also creating a policy and practice

environment, at the state and local level, that effectively and efficiently focuses resources on the outcomes that matter most to people with I/DD; among these, a place to live side-by-side with neighbors, friends and family; meaningful relationships; good health; a job with competitive wages and a career path, working alongside others in the community; and the opportunity to pursue post-secondary education.

The NC Council on Developmental Disabilities has a full agenda, investing in a future in which all people are welcomed into community and valued for their unique contributions. We are counting on all North Carolinians to be part of that change.



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

For NCCDD website, scan  
with mobile device.



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"Catalyst" - An instrument for change



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# Catalyst for Change

SUMMER 2012

NEWS OF THE NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES



## NCCDD Member Steve Jordan Passes Away

The NCCDD mourns the passing of Council Member Steve Jordan, 49, who served as director of the Division of Mental Health, Developmental Disabilities and Substance Abuse Services. An active bicyclist, Jordan was fatally struck as he pedaled along a Raleigh area highway.



In expressing sadness and sympathy for his family, friends and coworkers, Holly Riddle, the Council's executive director, said, "He approached his job with a passion that came from the heart, listening carefully to self-advocates and families; using a sense of humor and self-deprecation to put people at ease; and sharing his thoughts candidly and openly."

Noting that he stepped into a position that required that he lead North Carolina through a systems change of near monumental proportions, Riddle said he was pivotal in setting a new course for the state's community services for people with intellectual and other developmental disabilities (I/DD). This course sets a future where "all people with I/DD are respected, valued contributing members of their communities," she said.

"Steve was a passionate advocate for the citizens of North Carolina," said Al Delia, Acting Secretary of the Department of Health and Human Services. Citing his passion for life and work in the community, Delia said, "We have lost a friend, colleague, leader and a man of character in Steve Jordan."

## Reeve Named NCCDD Chair

Ronald Reeve, a parent-advocate and community leader from Charlotte, has been named to chair the North Carolina Council on Developmental Disabilities by Governor Beverly Perdue. He is the chair of the Mecklenburg Disability Action Collaborative and leads its "Employment First" group, which seeks to increase employment of people with disabilities.

"I'm looking forward to this assignment," said Reeve, noting that furthering employment prospects for those with intellectual and other developmental disabilities will be given a high priority.

Reeve's business career included service with IBM and American

Management Systems in marketing, business development and consulting.

He also brings a personal perspective to the issues, with his family's experience with developmental disabilities and mental illness.

Reeve serves as a director of the NC Business Leadership Network (NCBLN), which on a business-to-business basis works to expand employment opportunities for people with disabilities. He is a member of the NC Alliance for Full Participation, which was previously funded

by the NCCDD. In that capacity Reeve was instrumental in drafting the "Employment First" position statement that was the basis for the state policy now being pursued. *Reeve, see page 2*



Ron Reeve, NCCDD

## AAIDD Meets in Charlotte with Help from NC Council on DD

The American Association on Intellectual and Developmental Disabilities concluded its annual conference in Charlotte, N.C., in June and the NCCDD played a significant role in arrangements for the national meeting.

In addition to participating in planning the conference, the Council sponsored a pre-conference session on dementia in people with intellectual disabilities, featuring national authorities and state leadership.

Matthew Janicki, Ph.D, of the University of Chicago, led the presentation of the National Task Group on Intellectual Disability and Dementia Practices, supported by Jarrett Barnhill,

M.D., UNC School of Medicine, and Lucille Esralew, Ph.D., Trinitas Regional Medical Center, New Jersey. The Task Force report, "My Thinker's Not Working," outlined key findings and recommendations. Early screening is recommended for people with intellectual disabilities. People with AAIDD, see page 2



Mary Edwards, NC Div. of Aging & Adult Services and NCCDD alternate, Bob Konrad, Ph.D, UNC Institute on Aging, and Michael Lancaster, M.D., Behavioral Health and Community Care, DHHS, panelists at AAIDD session on aging and dementia.



Reeve is married and the father of three adult children. He and his wife, Janie, started an Arc in western Connecticut in 1973 and formed a special education PTA.

The family moved to Charlotte in 1989 and continued their advocacy of inclusion for people with developmental disabilities.

Robert J. (Bob) Rickelman, Ph.D, who has served as NCCDD chair since 2005,

and more than 10 years as a member, will step down from the Council at the end of August. Rickelman, a professor of reading at the University of North Carolina, Charlotte, has established a distinguished record as chair of the NCCDD, helping launch a number of creative initiatives.



Bob Rickelman, NCCDD

“Bob has been a dedicated and conscientious leader for the Council. His steady hand has maintained clear focus and produced noteworthy results,” said Holly Riddle, executive director of the Council. “We deeply appreciate his many contributions.”

## Sen. Mansfield, Carter Join Council

The newest member of the North Carolina Council on Developmental Disabilities, Senator Eric Mansfield, is both a legislator and a physician. The Fayetteville leader was appointed by the Governor to take the legislative seat held by former member of the Senate Katie Dorsett.



Senator Eric Mansfield



Christina Carter, NCCDD

“I am most pleased to welcome Senator Mansfield to the NCCDD,” said Holly Riddle, executive director. “We will benefit from his counsel and draw upon his background both in public policy and medicine.”

Senator Mansfield, who has an ear, nose and throat practice in Fayetteville, was elected to the State Senate in District 21. He also serves as a part-time minister.

Christina Carter, the chief operations

officer of the Smokey Mountain Local Management Entity/Managed Care Organization, will serve on the NCCDD as the representative of the NC Council of Community Programs (NCCCP). The NCCCP is the professional association for North Carolina’s local management entities and managed care organizations.

Carter previously served in the Division of Mental Health, Developmental Disabilities and Substance Abuse Services, where she was credited with playing a major role in the state’s “person-centered systems” initiative.

Down Syndrome are at high risk for early onset dementia, so screening is recommended beginning age 40; screening is recommended beginning at age 50 for people with other intellectual disabilities.

Two NCCDD Council members, Crystal Bowe, M.D., and Mary Edwards, of NC Division of Aging and Adult Services, were panelists at the daylong event, along with Michael Lancaster, M.D., Genny Pugh, and Bob Konrad, Ph.D. Dr. Bowe, a guardian for family members, was able to share both clinical and personal experiences, and noted that physicians, other service providers, and families all needed to become familiar with the symptoms of dementia in people with intellectual disabilities. “As

people with intellectual disabilities age out of pediatric care many feel they have nowhere to go for good health care...there are few health care professionals who are comfortable or prepared to address both intellectual disabilities and aging issues.”

Increasing housing options for people with intellectual disabilities and dementia is discussed in the Task Force report. The report looks at the characteristics needed in a setting, relative to the stage of a person’s dementia. Family members, the report urges, should be alert to the need for greater support as the disease advances and to available options.

NCCDD Executive Director Holly Riddle said the Council has long believed

that more attention should be given to the needs of people with intellectual and developmental disabilities as they age. “The work of the National Task Group has significant implications for service delivery and for the quality of life of older people with intellectual disabilities,” she said. Ms. Riddle observed that over the past 50 years, the average life span for people with I/DD has greatly increased. This has resulted in much new information in the field of health care. “Professionals, including those who do direct support, who are able to identify dementia in people with intellectual disabilities are key to better health care and family support.”

The Council will continue to provide support for initiatives and organizations

aimed at addressing issues impacting older people with intellectual and other developmental disabilities.

### Welcome Video for AAIDD Conference

With the theme of “What do I like about North Carolina?” Council members and representatives from across the state joined in greeting visitors for the AAIDD annual conference in Charlotte.

The colorful video illustrates North Carolina’s best practices in serving those with I/DD and points to emerging areas of change, while highlighting why people like calling North Carolina home. See it at [nccdd.org](http://nccdd.org)



## Partners Underway

The 2012 Partners in Policymaking® session is in full swing, with self-advocates and family members learning valuable skills on how to make their voices heard. The 20-member class met in June for the first of eight sessions, this one focused on the history of the field and I/DD policies. Future meetings cover the legislative process, learning to advocate with policymakers, and how to work in the community.

The program is led by Deborah Whitfield, J.D., CEO of Advocacy Institute Inc., the grantee responsible for the initiative.

The current class is diverse, with people from across the state and differing backgrounds. Graduates have become leaders in North Carolina, committed to bettering the lives of people with I/DD and their families.



### Partnering for People

The new NCCDD video, “Partnering for People,” reviews the life changing Partners in Policymaking® initiative in North Carolina, with the story told in the words of graduates.

Self-advocates and parents are featured, describing how the program impacted their lives and the changes they have made. with comments from the program director.

The video can be accessed on the Council website, [nccdd.org](http://nccdd.org).



## Washington DC = Advocacy in Action

North Carolina had strong representation at the Disability Policy Seminar in Washington, D.C. where there were opportunities to interact with policy leaders and learn about current issues in the field of I/DD. NCCDD members and staff were joined by leaders of Arc of NC, the Association of Self-Advocates of NC and others from across the state and nation at the three day session.



A highlight of the visit was a meeting with Senator Tom Harkin, Iowa, one of

the country’s most esteemed leaders on disability issues, together with sessions with other legislators and staff members to talk about issues of concern currently before the U.S. Congress.



At top U.S. Senator Kay Hagan, second from left, greets NCCDD at her office, including Beth Stalvey, Jonathan Ellis, Kelly Bohlander, Holly Riddle and Renate Macchirole.

At bottom, Commissioner of the Administration on Intellectual and Developmental Disabilities, Sharon Lewis, third from left, took time to meet with members of the NC delegation, from left Ellen Perry, Renate Macchirole, Kelly Bohlander, Jonathan Ellis and Beth Stalvey.



## Council Represented at Capitol Rally

Individuals from the NCCDD were among the hundreds of people who turned out for the Legislative Rally at the state capitol in Raleigh. Council Member Carrie Ambrose was on hand for the event, together with a new Council

member who appears regularly at the state capitol in Raleigh, Senator Eric Mansfield.

NCCDD Policy Analyst Beth Stalvey, Ph.D., had alerted the Council members and others of the event, which focused advocacy around issues important to people with I/DD and their families.



From left, NCCDD Policy Analyst Beth Stalvey, Council Member Carrie Ambrose and State Senator and Council Member Eric Mansfield.

