



North Carolina Council on Developmental Disabilities

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Aging, Dementia, and Intellectual and Developmental Disabilities

Issues associated with aging continue to garner major public attention, largely due to the burgeoning senior population, but evidence is emerging now that broad brush conclusions affecting all groups of people are ill-advised; that not all follow the same path. This is particularly true when it comes to people with intellectual and developmental disabilities.

Globally, the number of people with dementia is projected to rise from a level of just under 40 million in 2010 to nearly 120 million by 2050. As people with intellectual and developmental disabilities live longer, they are also becoming increasingly susceptible to these issues. Yet, until recently, little has been done to address the matter.

The World Health Organization is among those who see this as an international health priority, and the issues surrounding dementia, its diagnosis, and treatment are of particular concern for those with intellectual and developmental disabilities (I/DD) and those in the field.

To address these issues, the American Association on Intellectual and Developmental Disabilities and its partners convened a National Task Group on Aging, Dementia, and DD. The group's consensus document, "My Thinker's Not Working," contains key recommendations to address the specific needs of those with intellectual and developmental disabilities. The task group has been engaged in efforts to educate providers and families on the topic, including national workshops, the second of which was recently held in Charlotte, N.C. under the sponsorship of the North Carolina Council on Developmental Disabilities (NCCDD). The workshop touched on a variety of components for addressing the challenges of dementia and intellectual and developmental disabilities from basic indicators and health concerns to screening and diagnosis, housing, and supports.

Throughout the day, workshop leaders stressed the need for screening tools for families and caregivers as well as early assessment. “Generally, there is little information on this issue and much needs to be done to make people more aware of it,” said Dr. Matthew P. Janicki, of the University of Illinois at Chicago, Co-Chair of the National Task Group and the workshop’s facilitator.

The standing recommendation for people with intellectual and developmental disabilities calls for monitoring to begin at age 40 for those with Down syndrome, as they are at high risk for early onset dementia and 50 for those with intellectual and other developmental disabilities, or I/DD.

To support early monitoring, a standardized assessment tool is now being developed through a workgroup headed by Lucille Esralew, Ph.D., of Trinitas Regional Medical Center in Elizabeth, New Jersey. In the meantime, task group members emphasize the need for families and providers alike to familiarize themselves with the 10 warning signs of Alzheimer’s: memory loss, difficulty performing familiar tasks, issues with language, distortions to time and place, decreased judgment, difficulty with abstract thinking, misplacing items, changes in mood or behavior, changes in personality, and loss of motivation.

Due to the range of challenges faced by people with intellectual and developmental disabilities, it is further recommended that those who provide supports pay particular attention to changes observed in mood, personality, and motivation, as these indicators may be the most recognizable in a person with intellectual or developmental disabilities. In a similar vein it is also stressed that any decrease in function, be it memory loss or disorientation, should be measured in relationship to the individual’s typical performance, allowing them to better distinguish between a developmental disability and an age-related disability.

Crystal Bowe, a physician and member of the North Carolina Council on Developmental Disabilities, is a co-guardian of two aging relatives with intellectual disabilities and has had a front row seat to concerns over dementia and other age related disabilities. As her aunt and uncle age, Dr. Bowe and her husband are acutely aware of how Alzheimer's and dementia impact those with intellectual and developmental disabilities.

Dr. Bowe, a Greenville physician, said too many in the medical community have little understanding of the issues concerning intellectual and developmental disabilities. "As people with intellectual and developmental disabilities age out of pediatric care, it seems that many feel they have nowhere to go, there is nobody available who is comfortable dealing with these people as adults with disabilities...so there is nobody comfortable or even prepared to deal with their developmental disabilities and their aging issues."

That concern led the Mountain Area Health Education Center in Asheville to launch an initiative to develop a mini-fellowship in adult developmental medicine, an effort to educate physicians about differences that should be recognized in the treatment of people with intellectual and developmental disabilities. Supported by a grant from the NCCDD, these education programs are slated to grow.

The Task Group, in addition to calling for educating family members and caregivers around recognizing and assessing dementia for people with I/DD, proposed identifying safe and supportive housing options that maintain the least restrictive environments. Two popular models that are now being explored involve using small group homes, each with three to five beds, to incorporate the supports that are needed in the various stages of dementia. In the first model, one group home simultaneously serves individuals who are in various stages of dementia. The second model uses multiple group homes, each geared toward serving individuals in a specific stage of the disease. As the dementia progresses, people move from one group home to the next.

The second housing model has some drawbacks since it involves moving people regularly and displacing them from a living site they know to be home. However, one study found some positive outcomes. Within a cluster of five group homes, three of which were geared toward each of the stages and two that housed people in all stages, the people residing in the houses with specialized activities for early dementia, stayed in the early stages for longer periods of time than those who lived among people in various stages.

The costs for the two models were equivalent, with the average annual cost to support someone in one of these specialized group homes reported to be \$53,000, as compared with \$52,000 for more typical nursing home care. This was presented as a significant benefit, in that the care received was more specialized for maintaining a person's maximum independence compared to congregate housing.

The workshop closed with a panel discussion that brought together professionals from North Carolina's Department of Aging and the Division of Mental Health, Developmental Disabilities and Substance Abuse, and individuals from the disability community. The discussion of current realities regarding intellectual and developmental disabilities and dementia within North Carolina provided a rather bleak perspective, but there are additional resources available.

Those impacted by Alzheimer's and dementia and their families can receive supports and help through the Department of Aging. Among these, Project C.A.R.E. (Caregiver Alternatives to Running on Empty) was highlighted as a top resource for family members needing individualized, family-centered respite care. Additionally, North Carolina's Caregiver Support Program, another service to assist family caregivers, is available statewide for those who support someone 60 or over who has Alzheimer's or, alternatively, someone who has another disability and is younger than 55.

The conclusion that is evident is that there is still much to do to fully understand how Alzheimer's and dementia have special impacts on those with I/DD, as well as informing physicians and other health care providers of appropriate treatment modes for these individuals. The National Task Group on Aging, Dementia and DD and the physician mini-scholarships in developmental medicine can make major contributions to improving the care provided to people with intellectual and developmental disabilities, and their quality of life.

Some hospital residency programs, such as the one at East Carolina University, in which Dr. Bowe is involved, are making concerted efforts to bring their physicians up to speed on the needs of those with I/DD. In her contacts with colleagues, Dr. Bowe emphasizes the positive impact of preventative care.

“As my grandmother ages and care for my aunt and uncle increasingly falls to my husband and me,” said Bowe, “I see the need for preventative care as crucial in addressing issues of aging.”

Growing understanding of the importance of these issues among those in the field, the disabilities community and public policy leaders can help drive progress in the future.

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