



National Task Group on Intellectual Disabilities and Dementia Practices

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Comments to the Advisory Council on Alzheimer's Research, Care, and Services
September 27, 2011

By Matthew P. Janicki, Ph.D. on behalf of the National Task Group on Intellectual
Disabilities and Dementia Practices

I am the co-chair, along with Dr. Seth M. Keller, the President of the American Academy of Developmental Medicine and Dentistry, of the National Task Group on Intellectual Disabilities and Dementia Practices. The National Task Group was created in 2010 by the American Association on Intellectual and Developmental Disabilities (AAIDD), the American Academy of Developmental Medicine and Dentistry (AADMD), and my university center, the Rehabilitation Research and Training Center on Aging and Developmental Disabilities (Lifespan Health and Function) at the University of Illinois at Chicago. Our charge was to examine the state of practices related to dementia and people with lifelong intellectual disabilities, their families and caregivers, and the organizations that support them, and provide commentary on what needs to be done to further services and practices in the United States related to this population. Our charge also was to provide information and recommendations to the Advisory Council formed under the National Alzheimer's Project Act.

To this end, the National Task Group, composed of some 100 administrators, academics, providers, clinicians, families, and advocates, have coalesced with a number of national disability and family based organizations, federal agencies, and provider representatives to create a report on our findings and recommendations. The report, *"My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected By Dementia to Remain In Their Community and Receive Quality Supports "*, is currently in development and we anticipate having it launched at our next National Task Group meeting in November.

In advance of the release of our Report, it is timely to provide the Advisory Council with some key points from the Report for its use. We have prepared these comments, which I trust the Council members will find informative and helpful:

1. Alzheimer's disease and other dementias affects adults with lifelong intellectual disabilities in similar ways as it does other people, but sometimes has a more profound impact due to particular risk factors -- including genetics, neurological injury, and deprivation. While mostly the disease follows a typical course, at times some adults are profoundly and aggressively affected. Yet all need the typical types of supports and services usually associated with dementia-capable care. *We -- the National Task Group -- believe that adults with intellectual disabilities require the same early and periodic diagnostic services, community education, and community-based supports for themselves, their caregivers, and the organizations responsible for them, as do other adults with dementia in the general population.*

2. Many families are the primary lifetime caregivers for adults with intellectual disabilities and when Alzheimer's disease and dementia occurs, they are particularly affected and need considerable supports. These families not only include parents, but also siblings and other relatives. Many such families are at a loss for providing extensive care at home once dementia becomes progressive and care demands overwhelm them. *We -- the National Task Group -- recommend that the nation's providers and state disability authorities invest in increased home-based supports for caregivers who remain the primaries for care for adults affected by dementia.*

3. Many intellectual disabilities provider organizations that are the primary resources for residential and day supports are vexed by the emerging trend of increasing numbers of adults with intellectual disabilities in their services showing signs of early decline and dementia with potentially more demanding care needs. In such cases, staff may be unfamiliar with the signs and symptoms of mild cognitive impairment (MCI) or dementia and may misrepresent or ignore these changes, when early identification could prove beneficial. *We -- the National Task Group -- recommend that the nation's providers and state disability authorities invest in increased education and training of personnel with respect to Alzheimer's disease and other dementias and invest in promoting best practices in models of community care of adults with intellectual disabilities affected by dementia.*

4. As it is important to pick up signs of dementia-related cognitive decline early on, we -- the National Task Group -- recommend that the nation's providers and health authorities undertake a program of early identification screening - beginning at age 50 for adults with intellectual disabilities and at age 40 for adults with Down syndrome and others at early risk. We recognize that the Advisory Council may be debating the issue of early identification and screening in the general population. In this regard, *the*

National Task Group has identified a screening instrument, applicable particularly to adults with an intellectual disability, which seems to work as a first-instance screen and recommends adoption of such an instrument by providers and regulatory authorities to begin to identify those adults at risk due to early signs of mild cognitive impairment (MCI) or dementia.

5. Most adults with a lifelong intellectual disability live in community settings with support from families, friends and service providers. Research has shown that community-based models of care for adults with intellectual disabilities and dementia include community-based options, such as support for living at home or in small group homes, are viable and gaining preference for all individuals affected by Alzheimer's disease and other dementia. Institutionalization of adults with intellectual disabilities and dementia is anathema to the core beliefs and commitments to care practices in the intellectual disabilities field and such institutionalization (via use of long-term care facilities) has been shown to have an adverse affect on lifespan and quality of life. The group home model, where a handful of adults with intellectual disabilities and dementia live in a specialized care home, is becoming more prominent across the world. *We -- the National Task Group -- recommend that these models be expanded and an investment be made into enabling provider organizations to develop and maintain such care efforts, including developing more small community-based specialized 'dementia capable' group homes.*

6. Dementia has a devastating impact on all people one way or another -- including people with intellectual disabilities and the many families, friends, and staff involved as parents, siblings, advocates, and caregivers. *We -- the National Task Group -- wish to give emphasis to this point and ask the Advisory Council on Alzheimer's Research, Care, and Services to include concerns and considerations for people with lifelong intellectual disabilities in any and all documents, plans, and recommendations to Congress that are part of the work of the Council.* The National Task Group stands ready to assist and contribute to such efforts and is pleased that this Council recognizes Alzheimer's disease and other dementias as an ultimate public health issue and a problem to which we collectively need to attend.

Thank you.

Submitted by

Matthew P. Janicki, Ph.D.
Co-Chair of the National Task Group on Intellectual Disabilities and Dementia Practices, and
Research Associate Professor and Director for Technical Assistance
RRTC on Aging with Developmental Disabilities - Lifespan Health and Function
Department of Disability and Human Development
University of Illinois at Chicago
Chicago, Illinois
E/m: mjanicki@uic.edu