



National Task Group on Intellectual
Disabilities and Dementia Practices

**Comments to the NAPA Advisory Council on Alzheimer's
Research, Care and Services**

Council meeting of February 3, 2017 (HHH Building, Washington, DC)

Matthew P. Janicki, Ph.D., Co-Chair, NTG

I and Dr. Seth Keller are the co-chairs of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), a group formed in 2010 with a mission to advocate for people with intellectual disability and their families and other caregivers when an adult with intellectual disability is affected by dementia (www.aadmd.org/ntg). The NTG is an affiliate of the American Academy of Developmental Medicine and Dentistry and is associated with the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago.

Subject: NTG Activities on Information Development and Dissemination

The notion we wish to raise today concerns our efforts to create and disseminate transformative information related to dementia and intellectual disabilities. We recognize, as does the Council, that much of the general public, health care professionals, and even workers in the field of intellectual disability, are relatively uninformed about the nuances of dementia and how it affects adults with intellectual disability, as well as their spouses, friends, and caregivers. In concert with colleagues within the Alzheimer's and other dementias, intellectual disability, and university educational community, the NTG continues to develop materials in various media to inform and disseminate such information.

The basis for this notion is that many families have difficulties obtaining reliable information on recognizing dementia and how to best provide care and supports, in particular when their relative with intellectual disability is in the late or advanced stage of dementia and needing end-of-life specialized care. Further, we recognized that there are many nuanced issues that at time mirror those affecting adults with dementia in general, but also there are recognizable differences posed by lifelong intellectual disability. These differences can pose barriers to acceptance into generic services or add to confusion about how to provide specialized services. It is our hope at the NTG, as it is among our international colleagues in the intellectual disability and aging community, that this information will provide a basis for

increased understanding of how dementia affects people with intellectual disability (as it might among other recognized 'special populations') and constructively influence and affect state and local planning, public policies, and clinical and service practices.

This past October, the NTG partnered with colleagues at the University of the West of Scotland and the University of Stirling (near Glasgow, Scotland) and held an International Summit on Intellectual Disability and Dementia. Invitees from numerous countries within Europe and from the USA and Canada attended and discussed a number of topical issues and deliberated on the state of knowledge. From these discussions, a number of working groups were charged to produce background materials summarizing the issues and producing publishable reports. These reports encapsulate the key aspects of the issues and contain information and recommendations that can help expand knowledge, influence policy, and enhance services affecting adults with dementia and intellectual disability. The NTG's goal in this effort is to complement the activities of the Council and the various federal and organizational partners, and continue to make such information available and help transform policies and services so as to be more helpful to families and adults affected by dementia.

Thus, we are pleased to report that since October the participants of the Summit and their host organizations and associations have been busy on developing a series of summative reports. To date, one of the prepared reports, "Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature" has been accepted for publication by the American Association on Intellectual and Developmental Disabilities' journal, *Intellectual and Developmental Disabilities*. Another, "Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to End-of-life Care in Advanced Dementia" has been reviewed and is pending acceptance for a special issue on end-of-care topics, in the British journal, the *Journal of Applied Research in Intellectual Disability*. A third, "International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans" has been submitted to *the American Journal of Alzheimer's Disease and other Dementias* and is pending review. A fourth, "Defining Advanced Dementia in People with Down Syndrome and other Intellectual Disabilities: Consensus Statement of the International Summit on Intellectual Disability and Dementia" has been submitted to the *Journal of Intellectual Disability Research*, a British publication, and is also pending review.

Another grouping of reports and summative statements are in various states of preparation. These will attend to a variety of additional topics, including the needs of family caregivers, the perspectives toward dementia of people with intellectual disability, quality of life and dementia, post-diagnostic approaches to care, and dementia-capable services design for providers.

It is our hope that the Council will consider the substance and recommendations of these reports when constructing future updates of the National Plan to Address Alzheimer's Disease.

These reports and publications are available from us and also posted on the NTG website – www.aadmd.org/ntg.

Thank you.

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Comments to the NAPA Advisory Council
on
Alzheimer's Research, Care and Services

February 3, 2017
Submitted by Mary Hogan
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Once again, I appreciate the opportunity to address the Council this morning. In anticipation of the discussion of Clinical Trials, as I write these comments in advance, I am hopeful that issues related to those with Down Syndrome have been included in the morning discussion.

I understand that there are ethical considerations around consent and capacity for those with Down syndrome (DS) and other intellectual disability (ID) in regards to participation in clinical trials. However, I am hopeful that participation in the current DS Biomarker research is robust and that the outcome of these studies will provide very useful information for those with DS as well as the general population. I am also hopeful that there will be further efforts to include people with DS in preclinical medication trials in an attempt to delay the onset of Alzheimer's disease (AD).

I refer you an NIA/NIH document produced by the Alzheimer's Disease Education and Referral Center called: *Researchers seek Alzheimer's clues in people with Down Syndrome*, dated August 25, 2013 and updated in 2015. This may shed some light on the issue of DS and AD for those on the Council who remain under-informed about this topic.

Five years after the release of the first National Plan we continue to face many challenges for our family members with DS and other forms of ID. These include:

- Lack of adult clinics that specialize in care of individuals with Downs Syndrome.
- Lack of training for interns and residents in issues related to ID population at large.
- Limited proactive planning for those aging with DS/ID.
- Lack of access to appropriate diagnostic processes across settings and specialties.
- Potential misdiagnosis or missed diagnosis of AD in individuals with DS (we are now seeing diagnosis of young adults with DS in there mid to late 20's and early 30's which suggests that there is over-diagnosis of AD and missed opportunities to explore and define possible reversible conditions in these younger adults).
- An untrained work force with very limited information about healthy aging, how to support and care for those with a diagnosis of AD or other dementia

and how to interface with other specialties like Palliative Care to ensure that there is quality of life until end of life.

- Lack of attention to side effects of pharmacology, especially in those with Down syndrome who develop seizures concomitant with the onset of dementia. Thus, some individuals possibly remain grossly over-medicated and further compromised.
- Struggling caregivers, across generations, who are dedicated to supporting their family member with DS/ID and AD or other dementia at home or advocating for them in an alternative care setting.
- A limited voice at this table.

In an effort to provide medical information for this population, Dr. Seth Keller, NTG Co-Chair and Drs. Ira Lott, UC Irvine and Nicole Baumer of Boston Children's Hospital will address an upcoming 2017 American Academy of Neurology on "Neurologic Complications in Adults with I/DD". Dr. Keller has reached out to medical schools to determine the curriculum inclusion for this population. He will also address neurology residents at Brigham and Women's Hospital in Boston focusing on people with ID. Additionally, it is his hope to have a round table discussion to address issues related to the needs of adults with DS as they transition to adult neurology departments. In the meantime, a coterie of trainers from the NTG is providing seminars and webinars to agencies and professionals, including direct support professionals, across the US in an effort to expand knowledge, improve care and facilitate further development of local trainers. We are a small group taking on Herculean tasks.

In an effort to provide much needed information to families and other caregivers, including direct support professionals, the National Down Syndrome Society (NDSS), in conjunction with the NTG and the Alzheimer's Association, is in the process of preparing a companion document to its premier booklet, *Aging and Down Syndrome*. This new publication will focus on DS and Alzheimer's disease and will be released at the United Nations on March 21st, World Down Syndrome Day.

As Dr. Janicki has noted in his public comments, the NTG and colleagues in the US, Canada, the UK, and Europe are involved in the writing of a number of articles related to ID and dementia, with the focus on expanding the knowledge base and improving care outcomes for those with ID and dementia. This effort, resulting from a public and private supported meeting held in Scotland, is to be noted and commended with the sharing of rich ideas and significant efforts across borders.

The NTG has begun a fledging peer support group for family caregivers. We are grateful to the NDSS and Cure PSP who assisted us in our efforts. Response to this monthly group has been most positive with a growing number of participants from across the US. Included in this group is a number of parents of young adults facing extraordinary decline in function with no clearly defined cause.

Today we face looming issues with the Federal Budget and changes to the affordable Care Act that could potentially have a disastrous impact on individuals with dementia as well as their caregivers. These concerns, noted by Ian Kremer our colleague from the LEAD Coalition, demand the attention of all of us at this table and well beyond.

These noted activities reflect a dogged commitment to increasing attention to this special population. I assure you we will persist in our tireless effort to see that people with DS and other forms of ID will remain an integral part of the national discussion of Alzheimer's disease and other dementias. We look to you for continued support as we work to expand our public/private efforts.

Thanks, once again, for the opportunity to be here.

Mary Hogan
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