



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 October 31, 2016 (HHH Building, Washington, DC)**

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

**Subject: Nomenclature**

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](http://www.aadmd.org/ntg)). The NTG is an affiliate of the American Academy of Developmental Medicine and Dentistry and is associated with the RRTC on Developmental Disabilities and Health at the University of Illinois at Chicago.

The issue we wish to raise today concerns the issue of nomenclature related to dementia as it applies to intellectual disability. Reviews of publications (whether journal articles, book chapters, or reports and plans) involving intellectual disability show mixed uses of terms that generally relate to dementia or the diseases associated with it. Terms in use (including dementia, Alzheimer's, and other similar descriptors) lack precision or consistency when applied inappropriately. Some of this may be attributed to a lack of understanding of the distinction in the terms, the nuances involved with neuropathologies, or inconsistent use of language as well as absence of or inconsistency in an agreed upon core group of methods used in diagnosis. However, in the intellectual disability field this lack of precision in language in and of itself affects the understanding of the condition under discussion and confusion is further increased by a lack of agreement on common terminology in the domain of 'dementia'.

This lack of precision is not solely found in the intellectual disability field, as witnessed by recent efforts in the mainstream Alzheimer's and dementia field to address the same issue and in discussions held by the Council. The concern over coherency and lack of agreement on terminology within the intellectual disability field was recently discussed at the International Summit on Intellectual Disability and Dementia, held at the University of the West of Scotland (nr. Glasgow, Scotland) on October 13-14<sup>th</sup> – which was co-sponsored by the NTG. Many of the same issues raised by the Council were echoed at the Summit, with the added concern that much needs to be done to reinforce and emphasize terminological precision and clarity among

workers in the field of intellectual disability as the distinctions between the diseases associated with dementia and the expressions of dementia are often confused.

We recognized that the precision in terminology benefits reporting and communicating among researchers and enables the furtherance of scientific goals and findings. With this in mind, the Summit draft report recommended that scientific reports in the field of intellectual disability carry more precision with respect to terms employed and the final Summit report contain a taxonomy of terms typically found in dementia reports and documents, so as to provide guidance and a resource for researchers, administrators, clinicians, paid carers, and others who need to understand and use more precise terminology.

However, with particular acknowledgement of the use of descriptors when employed in general applications, the participants at the Summit noted that it would be beneficial to avoid ‘high science language’ in documents directed toward general readership audiences so as to facilitate understanding. Yet, we recognized that terms and definitions that are in common usage can help to ensure the communication of messages, but may add to the lack of precision. Further, creating or using definitions that minimize the seriousness, course, and eventuality of brain changes leading to dementia – which may lead the public to believe that dementia is no more impairing than a minor aging-related discomfort and thus not worthy of concern – can leave conditions untreated and eventualities devoid of planning. This is a conundrum in the field of intellectual disability, as communicating the definition and process of dementia to people with intellectual disability often creates a challenge. With this in mind, we suggest that to enable understanding, language and phrasing needs to be at a word-level that persons communicating with self-advocates or adults affected by dementia can effectively convey concepts associated with dementia. Further, the concepts need to be communicated in a manner so as to convey the seriousness of the condition, while not creating confusion or undue anxiety.

Given the concerns raised, **the NTG supports**, with two caveats, **recommendation #4 in the 2016 US National Plan Update**, which states that *“Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.”* The Update further recommends that *“an integrated conference should be convened to develop consistent language for cognitive disorders among the scientists, care providers and the public... [and there is a need to] engage all of the stakeholders around these issues to reach a consensus for the benefit of persons with dementia, their family members and caregivers, and the scientific and service communities.”* We support this recommendation with two caveats: First, that the discussions around standardization recognize varied comprehension levels and produce variations in standardized definitions that reflect the varied educational and intellectual levels of the readers. Second, that representatives of the field of intellectual disability be invited to be participants at the ‘integrated conference’.

Thank you.

Matthew P. Janicki, Ph.D.

Co-Chair, National Task Group on Intellectual Disabilities and Dementia Practices  
University of Illinois at Chicago (RRTC/DDH)  
[www.aadmd.org/ntg](http://www.aadmd.org/ntg)  
[mjanicki@uic.edu](mailto:mjanicki@uic.edu)

Seth M. Keller, M.D.  
Co-Chair, National Task Group on Intellectual Disabilities and Dementia Practices  
President Emeritus, American Academy of Developmental Medicine and Dentistry  
[www.aadmd.org/ntg](http://www.aadmd.org/ntg)  
[sethkeller@aol.com](mailto:sethkeller@aol.com)

## Public Comment

Advisory Council on Alzheimer's Research, Care and Services

October 31, 2016

by

Mary Hogan, Family Advocate

NTG

Thank you for this opportunity to once again address the Council. As you may know I have a vested interest in people with Down syndrome (DS) who are at an increased risk to develop Alzheimer's disease at a much earlier age.

People with ID are specifically included in **Strategy 2 H: Improve care for populations disproportionately affected by Alzheimer's disease and populations facing care challenges**. Today we heard about the Gaps and Barriers to reaching and treating racial and ethnic groups referred to in Strategy 2 H. I am hopeful that we can continue to address and discuss the Barriers and Gaps in reaching and treating those with Intellectual Disabilities including DS, as part of **Strategy 2 H**.

In August 2016 I was at the Advisory Council meeting and heard the presentations from Indiana University and UCLA on their Aging Brain and Dementia care programs. We heard also about Team Integration and Home Based Workforce and lastly about the Value of Palliative Care. Since our public comments in August were limited to what was previously submitted, I would like to briefly to return to two of these topics.

The Aging Brain and Dementia care programs included specific goals that were directed at the general population and caregivers. The UCLA program included a dyad approach, recognition of the ADRD journey, comprehensive community based care with direct services to patients and families and a co-management model of care utilizing the services of a NP Dementia Care Manager. It included workforce development and family training. The outcome reflected patient, caregiver and physician outcomes that were all very favorable.

This type of support system would be most beneficial for individuals with ID, their family members, care partners, along with attending physicians.

- How can we create opportunities to experiment with this model for those disproportionately affected by AD, including those with ID/DS?
- How can we better integrate effective models of care to be inclusive of all of our diverse populations affected by ADRD?
- When we have separate service delivery models, we often do not have equal service delivery. How can we reduce the gaps in reaching and treating **all of those** referred to in Strategy 2 H?

- How can we create confidence and foster dialogue and inclusion across providers, i.e. Aging, Dementia, Healthcare?

The presentation on Palliative Care resonated strongly for me. Like many individuals with DS and ID, my brother Bill had numerous co-occurring conditions that resulted in pain. With the diagnosis of AD, there was little regard for the impact that these conditions continued to have on him. In the presence of a diagnosis of AD, all was attributed to this disease process. As a result he suffered greatly for the last year and a half of his life, despite our best efforts to advocate for pain management.

Individuals with ID have a history of marginalization in health care. Individuals with AD have experienced this same marginalization in the past, especially in the area of palliative care. It is encouraging to see the increased awareness and availability of palliative care for those in the general population diagnosed with ADRD. It is time to expand palliative care to include those with DS and other forms of ID.

The World Alzheimer's Report 2016 points out the importance of palliative care. In essence it states in part:

- Every person with a progressive illness has a right to palliative care.
- That good dementia care implicitly reflects a palliative care approach

In small nations like the UK, Scotland and Ireland, there appears to be both a greater discussion of and improved system of delivery of dementia care, including palliative care. We have much to learn from these countries.

In an effort to enhance awareness of issues related to pain for those with ID and dementia, I have attached material from the UK.

- How can replicate/disseminate this information in the US?
- How can we raise awareness of behavior as communication of an unmet need even in those with ID and ADRD?
- Lastly, how do we eliminate the possibility that those with ID and dementia will be left to suffer needlessly?

Thank you once again for your willingness to listen, reflect and act on behalf of this underserved population.