



National Task Group on Intellectual
Disabilities and Dementia Practices

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National Alzheimer's Project Act
Office of the Assistant Secretary for Planning and Evaluation
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Ms. Brandt, Dr. Levey, Members of the Advisory Council:

My name is Kathryn Pears and I am Co-Vice President of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). I also co-chair the NTG's Training and Education Committee. Thank you for the opportunity to make these public comments. The NTG urges the Assistant Secretary for Planning and Evaluation (ASPE) and the Advisory Council to develop policies that will expand capacity to care for a group of individuals that has received little attention but who face significant challenges as they age and face the risk of developing Alzheimer's or a related dementia, aging individuals with autism spectrum disorder (ASD), a topic that one writer in 2016 described as a "black hole."

In fact, it is such a black hole that I am unable to even tell you how many adults with ASD there are over the age of 65, to say nothing of how many adults with ASD have Alzheimer's or a related dementia. If you embark on a Google search for 'adults with ASD over the age of 65' you will find no data at all. A 2018 report of The Interagency Autism Coordinating Committee (IACC) found that only about 3 percent (\$13.3 M) of funding for autism research supports studies on the lifespan needs of adults with the vast majority of those funds aimed at adolescents transitioning from the secondary education system to higher education and/or employment and vocational/job skills and social skills training for both transitional aged youth and adults.

In 2014 the NTG developed a national model training curriculum on dementia-capable care of adults with intellectual disabilities. To date, over 55 workshops have been held in 25 states across the country with over 3,000 participants. A consistent question at those workshops is, "what can you tell us about dementia in adults with ASD?" The answer, "very little."

What we do know is that the first individuals formally diagnosed with ASD were diagnosed in the 1940's and those individuals are now at the age of risk of developing dementia. It is likely that there are anywhere from tens of thousands to hundreds of thousands of adults with ASD over the age of 65.

We also know that people with ASD have a range of health conditions that place them at special risk of developing dementia, such as an increased risk of Parkinson's disease, depression, sedentary lifestyle, social isolation, long term antipsychotic medication use that can raise the risk of diabetes and heart

disease, and sleep apnea to name but a few. Additionally, we know that many people with ASD are being supported by aging family members and that when that family support system is lost, they will require alternative placements and support for the remainder of their years.

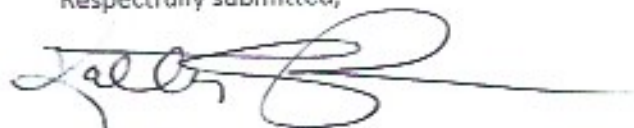
Finally, we know that the pre-existing sensory processing issues along with verbal communication and behavioral challenges that characterize ASD makes diagnosis of dementia challenging which can lead to inappropriate treatment.

Consistent with *Strategy 2.H: Improve Care for Populations Disproportionally Affected by Alzheimer's Disease and Related Dementias, and for Populations Facing Care Challenges* contained in the National Plan to Address Alzheimer's Disease we urge you to consider the following issues for inclusion in your deliberations:

- Research on aging with ASD and the specific risk of dementia
- Development of validated clinical interventions specific to aging adults with ASD and dementia
- Development of education and training curriculums for health care providers and community service providers who lack understanding of and expertise in the problems of aging with ASD
- Studies on the efficacy and safety of pharmacological interventions in aging adults with ASD, especially regarding cholinesterase inhibitors and antipsychotics.

Thank you for the opportunity to speak today about the challenges faced by aging adults with ASD who are at risk for or who have developed Alzheimer's disease or a related dementia. The NTG greatly appreciates the effort and actions that the Advisory Council has undertaken to date to raise the visibility of the needs of all aging adults with intellectual disabilities and respectfully asks that you add the challenges facing aging adults with ASD who are at risk of or who have developed a form of dementia to your work plan.

Respectfully submitted,



Kathryn G. Pears, MPPM
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