



Comments of Dr. Seth M. Keller to Federal Advisory Council on Alzheimer's Research, Care, and Services on November 9, 2020

My name is Seth Keller. I am an adult neurologist with a private practice neurology group in southern New Jersey. We are affiliated with the University of Pennsylvania as well as with the Virtua Health System. I am the co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (the 'NTG'), past president and a Board member of the American Academy of Developmental Medicine and Dentistry, and chair of the Adults with Intellectual and Developmental Disabilities Section within the American Academy of Neurology. I specialize in the neurologic care of adults with intellectual and developmental disabilities.

Today, I want to provide the Council with vital information and insights on a major issue in the healthcare of those aging with intellectual disability. As the Council knows the number of people in the United States who are aging and at risk of cognitive decline is growing, this is particularly alarming for people with Down syndrome, a major intellectual disability, who are at a very high risk of developing early onset Alzheimer's disease.

There are a number of unique issues relevant to the population of persons with intellectual and developmental disabilities which make their healthcare needs particularly challenging. These include having a lifelong disability and a higher rate of comorbidities, aging family caregivers, high turnover of direct support professional staff, traditionally poor reimbursements for healthcare, and a lack of education and training on lifelong disabilities and aging/dementia in medical schools and residency and fellowship programs, and a lack of curriculum and formalized care guidelines.

The long-term care for individuals with dementia requires the integration of a multidisciplinary care approach which does not exist in most areas of the United States for individuals with intellectual and developmental disabilities. The lack of coordinated and quality services often leads to poorer outcomes of care in later life, including great levels of frustration, fear of the fear and tremendous stress upon the people delivering the care (which often may include aging parents and direct support professionals) who all too often are not prepared and supported to take care of this complex and sadly progressive disease.

Access to quality services will require:

- Appropriate assessments and diagnostics
- Reimbursements commensurate with time spent with complex-needs patients
- Tertiary dementia care center supports for second opinions and complex cases
- Development of education and training of Nurse Practitioners, Primary care physicians, and specialty care and behavioral health services
- Healthy aging programs to help mitigate age related cognitive decline
- Community based support services to include care coordination, physical and occupational therapy, speech and cognitive therapy, nursing services, behavioral care services, primary and specialty care services.
- Diagnostic services within easy reach of families for the accurate diagnosis of dementia in adults with intellectual disability

As people with intellectual and developmental disabilities are more prone to survive to older age, the dread of Alzheimer's disease and other dementias is ever increasing and the needs for care and supports will only continue to grow. The newly funded five-year grant projects by the Centers for Disease Control and the Administration for Community Living focusing on addressing some of these issues are a start, but our hope is that more will follow. The NTG, together with several partner organizations, plans to issue a VISION 2021 document outlining how some of these dementia education, care, and diagnostic deficiencies can be addressed.

In closing, I greatly appreciate the effort that the NAPA council has taken in its recognition that people with intellectual and developmental disabilities and have to be taken into consideration especially those with Down syndrome, but access to quality and reliable long term care services still remain pathetically absent. Support from the Council to help address these needed services is warranted and appreciated.

Thank you.

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