



NTG Response to National Institute on Aging Request for Information for the Second National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers

Background

The National Task Group on Intellectual Disabilities and Dementia Practices (the 'NTG') represents the interests of adults with intellectual disabilities and their caregivers and works in concert with other national groups and associations with an interest in general intellectual disability issues.ⁱ In this response, the NTG wishes to share its thoughts to the Request for Information (RFI) issued on April 15, 2019, in preparation for the designing of the Second National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers, to be held in 2020.

As background, the NTG was involved with previous NIH Summit efforts to examine caregiving and dementia. It supported a national expert working group which developed a pre-Summit working group report on issues related to intellectual disability and dementia to the first National Research Summit.ⁱⁱ That report was the basis for commentary on intellectual disability related issues presented at the first Summit by Prof. Tamar Heller of the Department of Disability and Human Development at the University of Illinois at Chicago. Following that Summit, the report was the genesis after further input, for a summary article published in *Alzheimer's & Dementia: Translational Research & Clinical Interventions*.ⁱⁱⁱ

The Family Caregiver Alliance has estimated that some 65 million people in the United States serve as caregivers to older family members or family members with a disability.^{iv} Among these is an important and often overlooked group, caregivers of older adults with intellectual disability and dementia. With an estimated 46.2 million adults ages 65 and older in the US^v, there are at least 180,000 older adults with intellectual disability and, at minimum, 11,000 of these adults will be affected by dementia.^{vi} As the population of older adults in the United States continues to increase this group will likely need additional services and supports.

Caregivers of adults with intellectual disability and dementia face many of the same challenges and stressors as caregivers of other older adults with dementia. However, research shows that they often experience different patterns of caregiving, face additional challenges and stressors, and may access different forms of support and education. What is uncertain is *to what degree* such caregivers face daily care challenges that may mirror or vary from other caregivers of older adults with dementia and whether the barriers they face in obtaining help to continue caregiving are at variance or equal to those faced by other caregivers.

The nature of the challenges associated with caregiving of adults with intellectual disability and dementia is relevant to the concerns and work of the various NIH Summits. Intellectual disability is one of

the designated ‘target populations’ under the *National Plan to Address Alzheimer’s Disease*^{vii}, and the NIH recognizes that many adults with intellectual disability face heightened genetic-based risk – particularly those adults with Down and certain other syndromes – or environmental and social deprivation-based risks for dementia.

Caregiving adaptations in later age has become a concern within the intellectual disability provider community, as many adults with Down syndrome and other intellectual disability continue to reside at home or with kin caregivers. Many others live on their own or under the aegis of provider agencies in community-based housing. Knowing more about the particular challenges encountered by home-based informal caregivers or formal community-living staff caregivers is a must, as state authorities that are funding, regulating, and overseeing supports to both types of caregivers can benefit from evidence-based research outcomes supporting targeted initiatives, funding, and ways to enhance home-based supports and minimize caregiver degradation.

Areas covered

In May 2019, the NTG held an open forum at the annual conference of the American Academy on Developmental Medicine and Dentistry for the purpose of obtaining input for this RFI.^{viii} Other input was gleaned from commentary provided by its members and from discussions with associated organizations. The issues gleaned from these various sources were then parsed into those most relevant to the charge of the RFI and of consequence for research considerations on caregiving and supports.

Based on these sources, the NTG reduced the main suggestions and recommendations into three inter-related topics which reflect both follow-up on areas considered in part within the First National Research Summit and concerns raised by parent-based associations and intellectual disability service providers. These reflect needs for further interest and translational applications to policy and practices in care and dementia management related to adults with intellectual disability and their caregivers.

The three areas are:

- (1) research into the prevalence of behavioral and psychological symptoms of dementia (BPSD) and their nature, frequency, and degree of adverse impact on continued home-based care;
- (2) research exploring key environmental factors that facilitate, mitigate, or aggravate extended caregiving at home or other community settings, with parsing on the nature of dementia, its stages, site design aspects, and beneficial interventions; and
- (3) research into problems experienced by families and other caregivers in seeking assistance for care and supports in community settings and the bases for those problems.

(1) Behavioral and psychological symptoms of dementia

The NTG was one of the co-sponsors of the *International Summit on Intellectual Disability and Dementia* held in Glasgow, Scotland, in 2016.^{ix} One of the topics considered at the Summit was the area of post-diagnostic supports and the presence of behavioral and psychological symptoms of dementia (BPSD).^x It was recognized that BPSD include a range of behaviors, including agitation, aberrant motor behavior, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes, which are present at one time or another in the majority of adults affected by dementia. With respect to terminology, although the term BPSD is more typically used with people with

dementia within the general population than in the intellectual disability field, its equivalent – ‘challenging behaviors’ – is in prevalent use and now more often also associated with dementia-related behaviors in individuals with intellectual disability. Thus, knowing whether such challenging behaviors are -- upon dementia diagnosis -- more exacting expressions of chronic behavior present earlier in the lifespan but masked or overshadowed by other mitigating health or behavioral factors, or new expressions of dementia symptoms can help with plotting trajectories of treatment and behavioral interventions. Epidemiological research on the prevalence of BPSD among adults with intellectual disability is needed, as is research that can discern whether these behavioral expressions are linked to dementia or aggravations of pre-existing behaviors.

In this vein, it has been noted that accurate recognition of BPSD may increase awareness and understanding of behavioral and psychological issues, thus enabling adaptive caregiving and provision of appropriate interventions.^{xi} Also noted is that although closely associated with advancing dementia, BPSD may be caused by factors other than dementia-related pathologies and some may have their genesis in the lifelong ‘maladaptive’ behaviors linked to the etiology of the intellectual disability and are aggravated by age, the environmental situation, or sensory/cognitive losses.

Adults with intellectual disability and dementia may have a range of comorbid conditions that are overlooked due to ‘diagnostic overshadowing’.^{xii} Some aging adults with intellectual disability and dementia may experience sleep disturbance, hyperactivity (including agitation and aggression), affective symptoms (such as anxiety and depression), and delusions and hallucinations that may be related to other causes. The report from the Glasgow Summit noted that caregivers and support staff may fail to recognize that some aging adults with intellectual disability and dementia experience pain or sensory confusion, and thus not offer timely treatment of symptoms or confuse the behavior resulting from pain or sensory losses as a BPSD. Given that various stimuli may set-off an incident of changed behavior, continuing to assess all physical and psychological causes is important and thus further research to examine the incidence of such presentations is warranted.

Long-term caregiving is often compromised by the existence of chronic ‘challenging behaviors’, but more specifically by new or increased intensity behaviors generally recognized as BPSD linked to the presentation of dementia. It is known, also, that BPSD can affect the quality of life of caregivers and be a compromising factor in caregiving duration and health.^{xiii} How these specifically may affect caregiving or compromise or shorten the capacity of dementia care management among families of adults with intellectual disability is unknown. Research undertaken that would ascertain the prevalence of BPSD and their type and intensity and their interactions with lifelong ‘challenging behaviors’ would be beneficial to help formulate strategies for non-pharmacological interventions and for assisting caregivers with care management.

(2) Environmental factors that mitigate or aggravate extended community-based caregiving

The National Task Group, in its seminal 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*”, noted that lifelong caregiving may create ‘double jeopardy’.^{xiv} Many parents are the primary lifetime caregivers for adults with an intellectual disability and when Alzheimer’s disease or other brain diseases or conditions are present, and dementia is recognized, they are particularly affected and need considerable supports. The make-up of such family caregivers includes not only

parents, but also siblings and other relatives. After adapting successfully to the day-to-day challenges of oversight and supports for a dependent adult, many such families are at a loss for providing continued extensive care at home once dementia becomes pronounced and care demands change and may overwhelm them. Dealing with the progression of dementia involves continually adapting care to address new challenges, and these often relate to increased time demands addressing a range of new needs and expanding caregiving responsibilities.

The National Task Group report cited estimates that some 75 percent of older-aged adults with an intellectual or developmental disability reside with their families. With increasing age, age-associated impairments and pathologies begin to take prominence and are amongst the challenges facing both family caregivers and adults with an intellectual disability. Information derived from the *State of the States in Developmental Disabilities Report*, issued by the University of Colorado's Coleman Institute for Cognitive Disabilities, indicates that there are approximately 2.88 million individuals of all ages with intellectual and developmental disabilities residing with their families.^{xv} Of these, approximately 731,000 adults reside with family caregivers age 60+ and another 1.0 million reside with family caregivers who are between age 41 and 59. Using average age of onset of dementia data (for adults with Down syndrome it is about 52 and for adults with other intellectual disability it is about 67) then it is easy to recognize that the impact on older caregivers will be considerable.

Given that it is estimated that about 33,000 adults currently living at home with older family caregivers may be also affected by mild cognitive impairment (MCI) or dementia and that in many cases, family caregivers are a generation removed, are aging themselves, and may be experiencing their own decline, the impact of any untoward challenges associated with dementia-caregiving can significantly affect continued in-home care. When caregiving for people with intellectual disability many families experience and have coped with a lifetime level of care that is functional, but the challenges of providing the add-on care needed for coping with dementia can become problematic and may often exceed family capacities.

Various trends or patterns have been observed about what the family caregivers need the most help with when coping with dementia care. In many situations, caregivers' physical and emotional health as well as family finances can often be compromised and stretched beyond capacities to continue to cope and care at home for someone affected by dementia. Thus, research directed toward exploring key environmental factors that facilitate, mitigate, or aggravate extended caregiving at home or other community settings, with parsing on the nature of dementia, its stages, site design aspects, and beneficial interventions, has a constructive purpose. Finding out more about what situational factors facilitate or compromise efficient in-home care can help with determining what can be done to aid caregivers, whether by offering targeted training, extending home modifications, or by providing respite or other relief sustaining strategies.

A working group paper on family caregiving emanating from the International Summit on Intellectual Disabilities and Dementia provided a useful staging schema for examining the dementia-related caregiving process and recognizes the complexity of caregiving progression once dementia becomes a factor in lifelong caregiving. This schema parsed dementia-related caregiving into (1) a "diagnostic phase" [i.e., seeking validation as to the cause of change in function early on with an assessment for dementia as well as later with the onset of other causes that change behavior]; (2) an

“*explorative phase*” [i.e., accepting the diagnosis and exploring support options as they apply to the dementia diagnosis as well as additional conditions that arise]; (3) an “*adaptive phase*” [i.e., managing the symptoms of dementia]; and (4) a “*closure phase*” [i.e., resolving caregiving issues and relief from responsibilities following end-of-life (where “decompression” occurs) or adapting to the loss and rebuilding lives and focus (where “reconstruction” occurs) – depending on the degree or nature of interpersonal investment of the caregivers].^{xvi} This construct helps to explain to some degree the nature of caregiving challenges and responses within a life-long caregiving context. It would be highly beneficial to support targeted research to examine this construct and test its applications to resilience, durability, coping, and care practices and outcomes.

(3) Challenges to obtaining outside assistance for home-based caregiving

The National Task Group’s 2012 report and plan noted that currently the numbers of older family caregivers still providing home-based supports and supervision of an adult with an intellectual disability are significant and provide a relief for the staggering costs that would otherwise be borne by governments. With the onset of dementia these caregivers are often taxed to continue to provide home-based care, and, like their peers in the general population caring for a spouse or parent (without an intellectual disability) affected by dementia, look for ways to continue to provide care while seeking outside assistance and support. Family caregivers living separately from their relative with an intellectual disability, who is beginning to be affected by dementia and who lives in an out-of-home care setting, also struggle to understand the disease, maintain their relationships, and ensure that appropriate quality supports are provided in a timely fashion. Research designed to produce more information about these caregivers and their challenges as advocates and overseers of services being provided would be most beneficial.

Historically, family caregivers have either borne the costs of care for a relative with intellectual disability or turned to the state developmental disabilities authority for assistance. Having access to this resource in many states differentiates lifelong caregivers from late-life caregivers (of persons with dementia in the general population). However, the nature and demands of caregiving for a person with dementia presents with new and unanticipated challenges for many of these families who have witnessed a lifetime of development, growth in skills, and movement toward autonomy in many adults with an intellectual disability. Dementia, as it does with adults in the general population, leads to losses of function, compromises normal expectations of self-direction and self-care, and introduces new challenges associated not with under-developed social and personal skills, but with behaviors that may compromise hard won established routines, shared household responsibilities, pace, and peace at home.

Questions arise as to what degree can adaptations take place and what outside services and supports might be accessed to help with adapting to the new and changing reality including care practices and the creation of a dementia-capable environment. Will this come from the system that has provided many years of support for developmental progression (i.e., the state developmental disabilities authority and its associated private provider network) or from a heretofore unknown and unfamiliar network to these families – that supports dementia caregiving? Certainly, research into aspects of these care systems would benefit both caregivers and the systems in place within the states to sustain and aid them to meet needs.

We recognize that state developmental disabilities authorities offer two main resources to enable families to maintain the care and supports that they are providing at home, as well as supporting similar efforts of provider agencies. The resources are funds provided by the Home and Community Based Waiver services via the Medicaid program and state appropriations to state developmental disabilities authorities. Additionally, some aspects of the Affordable Care Act, Medicaid long-term services and supports (LTSS) and Medicaid Advantage provisions may also provide the supports for those adults with chronic conditions being cared for at home. It has been noted that the Centers for Medicare and Medicaid Services (CMS) may play a more important role in these supports as State Plans' supplemental benefits related to caregiver support with respect to chronic conditions in general come into play.^{xvii} Research on beneficial methods of enabling support services for home-based caregiving of adults with intellectual disability is highly desirable and inclusion of application to adults with intellectual disability should be part of any cross-cutting studies on dementia support supplemental benefit packages.

We also recognize that some states have initiated special efforts to address the growing numbers of clientele in both public and private sector services affected by dementia. Some have authorized and are funding specialized group homes or other housing that is 'dementia capable'. Others have instituted family support programs to help caregivers facing home-based dementia-related care demands and have instituted training and education programs for provider agencies and families. However, these are not wholesale efforts and much that is needed by the provider sector in terms of additional financial and programmatic supports remains elusive. The reality is that many caregivers' physical and emotional health as well as family finances are often compromised and stretched beyond capacities to continue to cope and care at home for someone affected by dementia and the challenges of entering a new system that may offer supports can be overwhelming. Research commissioned to study these factors and to derive recommendations for state supports for dementia care is warranted and can translate not only to the disability care community but to the greater community of caregiving when dementia is involved.

Thus, research into problems experienced by families and other caregivers in seeking assistance for care and supports in community settings and the bases for those problems is important and can benefit public policy and state practices. If supported with evidence, states can use these findings to frame their dementia care services planning and use the information to expand constructive and cost-effective efforts to aid caregivers.

Commentary

Years before the behavioral onset of Alzheimer's disease is evident, felt, and most instances even considered, pathologic changes begin to occur in the brains of many adults with intellectual disability (and may particularly be evident in adults with Down syndrome in their 20s and 30s). Among persons with Down and other syndromes the high prevalence of early-onset Alzheimer's disease and the concern for eventual decline is a huge personal, social, and emotional issue that is not being discussed or planned by most families, nor among intellectual disability and aging provider agencies until the decline is evident. Current research funded by the NIH looking for biomarkers that can identify the changes consistent with Alzheimer's disease may prove beneficial. It is entirely probable that a wellness and health promotive program may be instrumental in changing the trajectory of underlying diseases or the impact of dementia upon an individual and his or her support systems. Research is needed, for example, to more explicitly

examine the time period between the beginning and conclusion of adolescence in adults with Down syndrome and what supports need to be proffered and what ‘brain health’ interventions or practices might be undertaken.

Therapeutic interventions also need to be considered, yet nothing is being done to investigate how individuals and families deal with the reality that their relative may surely one day develop a possibly rapidly progressive neurodegenerative disease and die. Further, given some eventualities, questions arise as to ‘What should be said?’ ‘When should it be discussed?’ and ‘What can be done years before any of the pathology manifests and decline ensues?’ Research examining the processes and implications of this sensitive area is necessary so that families, caregivers, and organizations can begin to prepare for eventualities or for the means of using the biomarker findings to develop new strategies for prophylactic approaches. *Further, given the approximate two million caregivers of adults with intellectual disability potentially touched by MCI and dementia in some manner, this is not an inconsequential number and this group of caregivers warrants inclusion in any discussions of and research on dementia caregiving.*

Lastly, there is a need to examine a cross-cutting issue that is related to these areas – i.e., the application of research to diverse populations, whether defined ethnically, culturally, or by socioeconomic status. The research is sparse with reference to any significant differences among many of America’s various cultural or ethnic groups and how dementia is recognized or managed when an intellectual disability is present. Most studies have focused on younger age families and the issues they face with accepting and managing disability among family members. Rare are studies that examine care practices across ethnic or cultural groups when aging-related pathologies are present in addition to intellectual disability, and socioeconomic status is rarely a parsing factor when caregiver data are presented. We recommend that cross-cultural or cross-ethnic group studies of family caregiving and dementia include families of individuals with an intellectual disability and that targeted studies of caregiving issues across diverse groups when an individual with an intellectual disability is involved should be undertaken. The same would apply to the influence of socio-economic condition/status upon care management and accessing available supports.

In each of these areas we have proposed focal attention with respect to underwriting new research that would both expand knowledge and provide the basis for public policy initiatives and programs affecting aging individuals with intellectual disability affected by neuropathologies. Even though we are speaking of some 1.7 million aging caregivers, the translational aspects of these areas of enquiry can be beneficial to a greater pool of caregivers and is not limited to only those involved with caregiving of adults with intellectual disability and dementia. However, these areas are for some the nub of the concerns that will either make or break continued caregiving in home situations or in agency provision and are of utmost import when assigning research to caregiving and intellectual disability and dementia.

Research Recommendations

1. Epidemiological research on the prevalence of BPSD among adults with intellectual disability and research discerning to what extent behavioral expressions are linked to dementia or aggravations of pre-existing behaviors.

2. Research on the type and intensity of BPSDs and their interactions with lifelong ‘challenging behaviors’ and the relation to formulating strategies for non-pharmacological interventions and for care management.
3. Research exploring key environmental factors that facilitate, mitigate, or aggravate extended caregiving at home or other community settings, with parsing on the nature of dementia, its stages, site design aspects, and beneficial interventions.
4. Research about what situational factors facilitate or compromise efficient in-home care (such as targeted training, extending home modifications, providing respite, or other relief sustaining strategies).
5. Research examining the application of the dementia caregiving staging construct to test its applications relative to resilience, durability, coping, and care outcomes.
6. Research to produce information about effective caregivers functioning as advocates and overseers of services provided.
7. Research examining best models for state-based care systems most beneficial to caregivers and the systems within the states.
8. Research on beneficial methods of enabling support services for home-based caregiving of adults with intellectual disability.
9. Research to derive recommendations for effective and beneficial state supports for dementia care for adults with intellectual disability.
10. Research to examine the time period from before to after adolescence of adults with Down syndrome as to what brain health initiatives may be most efficacious in mitigating the development of Alzheimer’s disease.
11. Research examining as what families, caregivers, and organizations can best prepare for eventualities of Alzheimer’s disease or for using biomarker research findings to develop new strategies for prophylactic approaches.

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ⁱ E.g., American Association on Intellectual and Developmental Disabilities, ANCOR, Down Syndrome-Medical Interest Group, DS-Connect, National Caregiving Alliance, National Down Syndrome Society, The ARC,

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