



‘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

Executive Summary to the
Report of the National Task Group on
Intellectual Disabilities and Dementia Practices

2012



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Executive Summary

'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, prepared by the National Task Group on Intellectual Disabilities and Dementia Practices, provides a summary of the challenges facing the nation as we observe an increasing rate of dementia found in older people with intellectual disabilities. The Report offers recommendations for the various stakeholders in the field of intellectual disabilities and anticipates that its findings and recommendations will be considered and integrated into the annual reports and plans developed by the federal Advisory Council on Alzheimer's Research, Care, and Services.

The National Task Group on Intellectual Disabilities and Dementia Practices first and foremost recognizes that the number of older adults with an intellectual disability affected by dementia is growing and this growth is posing a significant challenge to families and friends, provider agencies, and federal and state agencies concerned with supports and services to people with an intellectual disability. It also recognizes that although the research community is making significant strides in better understanding the causal and evolutionary factors leading to the onset of Alzheimer's disease and other dementing illnesses and is also making significant progress in identifying means for the early detection of the disease – all of which will benefit subsequent generations – the social care system still remains challenged with the 'here and now' of offering the best and most efficacious means of identification, daily supports, and long-term care.

The key findings of the National Task Group include:

- Most adults with an intellectual disability live in community settings, either independently or with support from families, friends and service providers; with advanced age, they may experience age-related conditions and diseases, including dementia.
- Epidemiological research has not arrived at reliable population counts of adults with an intellectual disability affected by mild cognitive impairment and dementia and more effort is needed to create a more reliable estimate of this population.
- Dementia has a devastating impact on adults with an intellectual disability as well as on their families, friends, housemates, and service provider staff who often provide key long-term support and care.
- Community services' providers are facing a 'graying' of their service population, many of whom are affected by cognitive decline and dementia, and are challenged to provide the most effective and financially viable daily supports and long-term care.
- Primary care and supports for adults with an intellectual disability affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization.
- Providers are beginning to adapt small group homes for specialized community care and supports for persons with an intellectual disability affected by dementia.
- Professional staff are often ill-equipped to help identify and support interventions that may be the most efficacious for adults with an intellectual disability affected by dementia.

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- There is a lack of background knowledge and training in late life problems of adults with an intellectual disability among primary care health providers (including physicians, physician assistants, and nurses) in community practice.
- Specialized assessment and diagnostic resources are needed to help more effectively identify adults with an intellectual disability and dementia.
- A common screening instrument would be useful for the cognitive impairment review that is part of the Affordable Care Act's annual wellness visit.
- Creating a national program of trainings using workshops, webinars, and other teaching methods, would advance the knowledge and skills among workers and clinicians working with adults with an intellectual disability affected by dementia.
- Creating a national information and education program for adults with an intellectual disability and family members would improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services.
- Access to appropriate professionals and supportive services outside major urban settings needs to be improved; technology may play an important role in achieving this goal.
- State and local developmental disabilities' authorities could more constructively forecast and budget for supporting in-community care of adults with an intellectual disability affected by dementia.

The Report concludes with a series of recommendations that comprise a **National Action Plan** (see page iv) for more effectively addressing needs and helping adults with an intellectual disability affected by dementia. Summarized below are some of the main areas that are covered by the recommendations.

Dementia often hits harder. Alzheimer's disease and other dementias generally affect adults with lifelong intellectual disabilities in similar ways as they do other people, but sometimes have a more profound impact due to particular risk factors – including genetics, neurological injury, and deprivation. While such illnesses generally follow a typical course in terms of impact and duration, some adults are profoundly and aggressively affected. Yet all need the typical types of supports and services usually associated with dementia-capable care. ***The National Task Group believes that adults with an intellectual disability require the same early and periodic diagnostic services, community education, and community-based supports for themselves, their caregivers, and the organizations working with them, as do other adults affected by dementia.***

Lifelong caregiving may create 'double jeopardy'. Many families are the primary lifetime caregivers for adults with an intellectual disability and when Alzheimer's disease and these dementias occur, they are particularly affected and need considerable supports. These families not only include parents, but also siblings and other relatives. Many such families are at a loss for providing extensive care at home once dementia becomes pronounced and care demands may overwhelm them. ***Thus, the National Task Group recommends that the nation's providers and federal and state aging and developmental disabilities authorities invest in increased home-based supports for caregivers who remain the primaries for support and care for adults affected by dementia.***

Providers are being challenged. Many intellectual disabilities' provider organizations that are the primary resources for residential and day supports are vexed by the increasing

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numbers of adults with an intellectual disability in their services showing signs of early decline and dementia with potentially more demanding care needs. In many cases, staff may be unfamiliar with the signs and symptoms of mild cognitive impairment (MCI) or dementia and may misrepresent or ignore these changes, when early identification and intervention could prove beneficial. **Thus, the National Task Group recommends that the nation's providers and federal and state aging and developmental disabilities authorities invest in increased education and training of personnel with respect to Alzheimer's disease and other dementias and invest in promoting best practices in models of community care of adults with an intellectual disability affected by dementia.**

Early identification is crucial. As it is important to recognize signs of dementia-related cognitive decline early on, the National Task Group has identified a potentially adaptable instrument, applicable particularly to adults with an intellectual disability, which can be utilized as a 'first-instance screen' and recommends adoption of such an instrument by providers and regulatory authorities to identify those adults at-risk due to early signs of mild cognitive impairment (MCI) or dementia. **Thus, the National Task Group recommends that the nation's providers and health authorities undertake a program of early identification – beginning at age 50 for adults with an intellectual disability and at age 40 for adults with Down syndrome and others at early risk – using a standard screening instrument.**

Commitment to living in the community. Research has shown that community-based models of care for adults with an intellectual disability and dementia including community-based options, such as support for living at home or in small group homes, are viable and gaining preference for all individuals affected by Alzheimer's disease and other dementias. The institutionalization of adults with an intellectual disability and dementia is anathema to the field's core beliefs and commitments to care practices; institutionalization (via use of long-term care facilities) can have an adverse effect on lifespan and quality of life. **Thus, the National Task Group recommends that the use of such community-care options be expanded and an investment be made in developing more small community-based specialized 'dementia capable' group homes.**

Education is what's missing. Information at all levels is needed to enhance the capabilities of staff, clinicians, community providers and administrators. Training of various sorts is necessary to raise awareness of dementia and how it affects adults with an intellectual disability. The National Task Group recognizes the need for more information related to age-associated cognitive decline and neuropathologies (such as dementia), particularly how they apply to people with an intellectual disability and impact their families, friends, advocates and caregivers. **The National Task Group recommends the institution of a national effort on training and education to prepare the workforce and eliminate disparities in dementia services provision for adults with an intellectual disability.**

A final word. Dementia has a devastating impact on all people – including people with an intellectual disability and their friends, families and the staff who may be involved with them as advocates and caregivers. **The National Task Group believes that the federal Advisory Council on Alzheimer's Research, Care, and Services should include concerns and considerations for people with lifelong intellectual disabilities in any and all documents, plans, and recommendations to Congress that are part of the work of the Council through to 2025.** To this end, the National Task Group stands ready to assist and contribute to such efforts.

What follows is a matrix listing the National Task Group's recommendations as to what should be undertaken and which organization or group could be involved.

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| National Dementia and Intellectual Disabilities Action Plan | | |
|---|---|---|
| Goal A: To better understand dementia and how it affects adults with an intellectual disability and their caregivers | | |
| Number | Recommendation | Who could do it? |
| #1 | Conduct nationwide epidemiologic studies or surveys of adults with intellectual disabilities that establish the prevalence and incidence of mild cognitive impairment and dementia. | Federal agencies and institutes (Administration on Developmental Disabilities, Administration on Aging, National Institute on Disability and Rehabilitation Research) |
| #2 | Conduct studies to identify and scientifically establish the risk factors associated with the occurrence of dementia among adults with an intellectual disability. | Universities' academic and research centers |
| #9 | Conduct studies on the impact of aging of family caregivers on the support and care of adults with intellectual disabilities residing in at-home settings. | Universities' academic and research centers |
| #11 | Conduct nationwide medico-economic studies on the financial impact of dementia among people with intellectual disabilities in various service provision settings. | Universities' academic and research centers |
| Goal B: To institute effective screening and assessment of adults with an intellectual disability at-risk, or showing the early effects of, dementia | | |
| #3 | Develop guidelines and instructional packages for use by families and caregivers in periodically screening for signs and symptoms of dementia. | American Academy of Developmental Medicine and Dentistry |
| #4 | Encourage provider agencies in the United States to implement screenings of their older-age clientele with an intellectual disability who are at-risk of or affected by dementia. | State developmental disabilities planning councils, State developmental disabilities authorities |
| #5 | Examine the utility of adopting an instrument such as an adapted Dementia Screening Questionnaire for Individuals with Intellectual Disabilities for use annually in preparation for the annual wellness visit. | Universities, Providers, American Academy of Developmental Medicine and Dentistry |
| #6 | Conduct an evaluation of a workable scoring scheme for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities that would help identify individuals in decline. | Universities' academic and research centers |
| #8 | Promote the exchange of information among clinicians regarding technical aspects of existing assessment and diagnostic instruments for confirming presence of dementia in persons with an intellectual disability. | American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Developmental Disabilities Nurses Association |
| Goal C: To promote health and function among adults with an intellectual disability | | |
| #15 | Develop and disseminate a set of nutritional and dietary guidelines appropriate for persons with an intellectual disability affected by dementia. | American Academy of Developmental Medicine and Dentistry |
| #16 | Develop and disseminate health practice guidelines to aid primary care physicians and related health practitioners address assessment and follow-up treatment of adults with an intellectual disability presenting with symptoms of dementia. | American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association |
| #17 | Conduct studies on the nature and extent of health compromises, conditions, and diseases found among adults with an intellectual disability and affected by dementia. | Universities' academic and research centers |
| Goal D: To produce appropriate community and social supports and care for adults with an intellectual disability affected by dementia | | |
| #10 | Enhance family support services to include efforts to help caregivers to identify and receive assistance for aiding adults with an intellectual disability affected by dementia. | State developmental disabilities authorities, State units on aging, Area agencies on aging, The Arc, National Down Syndrome Society |
| #12 | Plan for and develop more specialized group homes for dementia care as well as develop support capacities for helping adults affected by dementia still living on their own or with their family. | State developmental disabilities authorities |
| #13 | Plan and develop community-based dementia-capable supports to address the needs of those persons at-risk or affected by dementia. | State developmental disabilities authorities |
| #14 | Develop and disseminate social care practice guidelines to community agencies and professionals that address assessment, service development and life planning for adults with an intellectual disability presenting with symptoms of dementia. | American Association on Intellectual and Developmental Disabilities |
| Goal E: To produce a capable workforce and produce education and training materials | | |
| #7 | Establish undergraduate, graduate, and continuing education programs, using various modalities, to enhance the diagnostic skills of community practitioners. | American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Council of Deans of Medical Schools and Allied Health Colleges |
| #18 | Develop a universal curriculum, applicable nationwide, on dementia and an intellectual disability geared toward direct care staff, families, and other primary workers. | Administration on Developmental Disabilities, Universities, Developmental Disabilities Nurses Association |
| #19 | Organize and deliver a national program of training using workshops and webinars, as well as other means, for staff and families. | American Academy of Developmental Medicine and Dentistry, American Association on Intellectual and Developmental Disabilities, Developmental Disabilities Nurses Association, Universities' academic and research centers |
| #20 | Develop and produce an education and information package for adults with an intellectual disability to help them better understand dementia. | American Academy of Developmental Medicine and Dentistry, Developmental Disabilities Nurses Association, Universities' academic and research centers |

