

# Viability of a Dementia Advocacy Effort for Adults with Intellectual Disability: Using a National Task Group Approach

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**Abstract** The World Health Organization's report, *Dementia: A Public Health Priority*, noted that the number of people worldwide affected by dementia is significant and will continue to increase. The report called on nations to address dementia by developing national plans and undertaking public health initiatives. Special mention was made of the situation of people with intellectual disability, some of who manifest high risk for dementias. In the United States, the National Task Group on Intellectual Disabilities and Dementia Practices (the "NTG") was created to ensure that the needs and interests of adults with intellectual and developmental disability who are affected by Alzheimer's disease and related dementias—as well as their families and friends—are taken into account as part of general-population dementia health and public policy efforts, particularly as noted in the U.S. National Plan to Address Alzheimer's Disease. To this end, the NTG's multifaceted advocacy efforts have included (1) identifying best practices for providing care and services to affected adults with intellectual disability; (2) developing and identifying a functional workable administrative dementia early detection and screening instrument; (3) producing educational materials useful to families, adults with intellectual disability, and nongovernmental organizations; and (4) furthering public policy initiatives on dementia as they affect adults with intellectual disability. This article describes the origins of this group, its functions and accomplishments, as well its role with respect to national dementia advocacy, as a prototype for other national efforts that can be used to promote the interests of adults with intellectual disability affected by dementia and improve the quality of their lives. Suggested are means for replication of such an effort in other national environments.

**Keywords:** advocacy, community care, dementia, intellectual disability, national plans

## INTRODUCTION

Among all of the older age-associated conditions, dementia is the most insidious, as it affects and diminishes quality of life and robs affected individuals of their minds, capability to be independent, and often their dignity. The World Health Organization

(WHO, 2012) in its report, *Dementia: A Public Health Priority*, noted that prevalence and incidence projections indicate that the number of people with dementia will continue to grow, particularly among the oldest old. The total number of people with dementia worldwide in 2010 was estimated at 35.6 million and projected to nearly double every 20 years to 65.7 million in 2030 and 115.4 million in 2050. To begin to delay or mitigate the onset of dementia, the WHO called on primary prevention activities that should focus on countering risk factors for vascular disease, including diabetes, midlife hypertension, midlife obesity, smoking, and physical inactivity. The WHO also called on the individual states to address dementia prevention and reduction by developing national plans and public health initiatives to benefit their populations (Public Health Planning, 2012).

The WHO has called for countries to adopt national plans that would address such diverse issues as encouraging research into the causes and eventual prevention of dementia, promoting the support of treatment strategies and managing supports for carers, setting up public education programs, and enhancing the capabilities of workers to care and support adults affected by dementia. Alzheimer's Disease International (2013; Wortmann, 2013) has noted that a comprehensive government

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<sup>1</sup>The authors are the coauthors of the National Task Group on Intellectual Disabilities and Dementia Practices in the United States. (<http://www.aadmd.org/ntg>).

plan should address the needs of people with dementia and have targets promoting broad public awareness of Alzheimer's and combating stigma, identifying dementia-capable support services at all stages of the disease, quantifying the number of individuals with dementia, assessing and improving the quality of healthcare, social care, and long-term care support and services, assessing availability and access to diagnostic services, and undertaking public health efforts to conduct surveillance and promote brain health.

National plans should also focus on the social and healthcare aspects of helping people with dementia (Alzheimer Europe, 2014; Rosow et al., 2011). To date, upwards of 20 national plans that address dementia have been created or are in process throughout the world (Alzheimer's Disease International, 2013). Some trends are evident. For example, the public policy targets include delaying institutionalization, enabling individuals to remain at home as long as possible, supporting carers in order to delay the move of individuals living with dementia to long-term care, giving individuals living with dementia as much control over their care as possible while recognizing limitations due to cognitive impairment (e.g., in relation to having the capacity to make informed choices), equating service provision with need, promoting early diagnosis, coordinating services at the local level (where possible), and making long-term care, when required, as home-like as possible (Alzheimer Society of Canada, 2010; Wortmann, 2013). National plans should also explicate various pathways to achieving targets and accommodations for dementia-related challenges (Nakanishiemi & Nakashima, 2014).

In the United States, the national plan came about after the United States Congress passed the National Alzheimer's Project Act in 2010 (PL 111-375, which was signed into law by President Obama in January 2011). As a result of this law, the national government was mandated to develop an Alzheimer's plan—beginning in 2012—with annual updates continuing through to 2025 (DHHS, 2012; 2013; 2014). The law also provided for the creation of a joint citizen-based and government agency Advisory Council on Alzheimer's Research, Care, and Services and mandated that the Council be representative of a broad segment of constituencies that would guide the development of the plan. The first iteration of the U.S. plan in 2012 was a comprehensive document that spanned issues from basic research on Alzheimer's disease and related dementias to a focus on caregiver supports, and to publication education, workforce enhancement, and developing structures for quality care. The U.S. plan recognized people with intellectual disabilities as one of the specific populations that needed special attention.

In most countries, however, the dementia plans are directed toward the general population and often omit mention of specific needs groups, such as persons with lifelong disability who may be at higher risk of dementia.<sup>1</sup> The WHO (2012) noted this and called for national plans to subsume people with specific needs within their plans. Special mention was made of the situation of people with intellectual disability,<sup>2</sup> in particular those adults with Down syndrome who manifest high risk for

Alzheimer's disease. Recognizing that care pathways for populations with specific needs (such as adults with intellectual disability) have some common elements, the WHO (p. 57) noted, "Some groups have additional needs arising from having dementia or being a caregiver of a person with dementia." The WHO cited as an example of such specific groups people with intellectual disabilities. It is known that with respect to the aging of people with some intellectual disabilities, a differentiating feature is the high risk of manifesting certain neurodegenerative conditions, including dementia (Janicki & Dalton, 1999; Prasher, 2005).

It has been well established that one of the major risk factors for Alzheimer's disease is having Down syndrome (Bush & Beail, 2004; Prasher, 2005; Schupf, 2002). The WHO (2012) recognized this and included people with Down syndrome among all those who are at a significant risk of developing Alzheimer's disease. Studies suggest that in excess of 50% of adults with Down syndrome will be affected by dementia after the age of 60 years (Holland, Hon, Huppert, & Stevens, 2000; Janicki & Dalton, 1999; Ness et al., 2012; Prasher, 2005; Zigman, Silverman, & Wisniewski, 1996). As a result, many adults with Down syndrome (and some adults with other forms of intellectual disability) are particularly at risk for early-onset dementia leading to a shortened life and diminished quality of old age (Janicki & Dalton, 1999; Watchman, 2014). The WHO (2012) also noted that the onset of dementia in people with Down syndrome is also likely to occur at a younger age than the sporadic form that generally affects other older people. Thus, a primary consideration is recognizing dementia early, compensating for its effects, and providing services that improve quality of life and enhance quality of care. A secondary consideration is enabling lifelong changes to lifestyle, nutrition, healthy activities, and other preventive practices that could mitigate the risks for dementia.

The WHO report further noted that "Some of the barriers to access include a lack of understanding or recognition of the dementia in their population group, language or cultural barriers, and a lack of appropriate information resources and services" (p. 57). Many reports have documented the challenges faced by carers in trying to understand why age-associated changes are occurring, which are later linked to dementia, and learning how to best accommodate them (Watchman, 2014). The WHO's report also made mention of the efforts in the American plan to specifically target people with intellectual disability: "In the USA, a national task force of experts on intellectual disability and Alzheimer's disease has developed a comprehensive report with policy and practice recommendations on detection, care, and support for this population. The aim of the report is to enable adults with intellectual disability who are affected by dementia to remain living in the community with quality support." The WHO was referencing the work of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) (WHO, 2012, p. 59).

This international public policy concern stems from a recognition that people with intellectual disability are surviving

lectual limitations that significantly limit their ability to successfully participate in normal day-to-day activities such as self-care, communication, or work; (2) have developed the intellectual limitation during the "developmental period"; and (3) have a limitation that is anticipated to result in long-term adaptive or functional support needs.

<sup>1</sup>Although the U.S. plan is titled the "National Plan to Address Alzheimer's Disease," the document covers all forms of dementia and the term "dementia" is used generically, without attribution to etiology.

<sup>2</sup>Generally, adults with an intellectual disability are those who: (1) have intel-

longer and experiencing the challenges of old age, much like other age peers. They experience problems that are age related, including medical complications stemming from the interaction of aging and lifelong disability. For those adults affected by dementia, there are challenges to provide appropriate “dementia-capable” housing and services, as well as ensure that reliable screening and diagnostic resources are available and used. There are also situations when they begin to experience cognitive decline and are later diagnosed with dementia. As the general needs of older adults with intellectual disability with dementia mirror those of persons in the general population affected by dementia, they call for dementia awareness, diagnostic, and care practices undertaken by national and local groups for the general population to be inclusive of people with disabilities. However, such inclusion will not occur organically without special advocacy efforts being undertaken by associations, non-governmental organizations (NGOs), and families on behalf of people with intellectual disability.

Thus, this paper examines the work of an American task force designed to be a vehicle for advocacy on behalf of people with intellectual disability affected by dementia and their carers and provides insights into its functions and how its work and practices might be applied in other countries.<sup>3</sup>

## THE NATIONAL TASK GROUP

### *The Starting Point (2010–12)*

The NTG, the task force cited in the WHO report, is a coalition of interested persons and organizations that are working toward ensuring that the needs and interests of adults with intellectual and developmental disability who are affected by Alzheimer’s disease and related dementia—as well as their families and friends—are taken into account as part of the United States’ National Plan to Address Alzheimer’s Disease (DHHS, 2012). The NTG is a voluntary membership organization composed of families, association and organization representatives, clinicians, practitioners, academics, and others who contribute time and effort to its activities. Members represent a range of disciplines and educational backgrounds and serve on the NTG as volunteers. The NTG’s original support came from the American Academy of Developmental Medicine and Dentistry (AADMD), the American Association on Intellectual and Developmental Disabilities, and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago, as well as a number of other university aging and disability centers and organizations. Currently, additional support is derived from income produced by conducting educational activities and from grants from various foundations and organizations. At latest count, the membership of the NTG is made up of over 150 persons with varying levels of

involvement, with about 25 serving as core members. In framing its functions, it was important for the NTG to have a “heart”; we needed to ensure that the effort was about people, their families, and all of those who were personally affected by this devastating condition. We ensured that advocates were directly involved in any of the NTG’s efforts as each aspect of our work was based upon this belief.

The NTG’s genesis evolved from numerous discussions among key leaders in the area of intellectual disability and dementia, who were concerned that there was no single focal point for information and direction in the United States related to the needs of people with intellectual disability affected by dementia. From these discussions, it was decided to enlist the involvement of others who were concerned with the issue and to form an informal interest group. However, during these preliminary discussions, it became evident that an interest group format would be insufficiently robust to affect change and the decision was made to upgrade the initiative to the level of a national task group. Thus, the NTG came into being.

In 2010, when the NTG was originally being set up, its organizing committee decided that it needed to first define its mission and goals. Thus, the committee undertook a process of fact finding; that is, collecting information related to the dementia-related challenges faced by people with intellectual disabilities. The task was to determine the problems faced by families, the extent of general care needs, and the current state of dementia-related services provision in the United States. One significant concern identified was meeting the needs of aging carers who were still providing primary supports for their adult children and other relatives with intellectual disability who may be beginning to show or exhibiting the signs of dementia. Indeed, the first public effort undertaken by the organizing committee was providing testimony on behalf of family caregiver needs before a national series of “listening sessions” undertaken by the new administrator of the federal agency responsible for intellectual and developmental disabilities (cf. <http://www.aadmd.org/ntg>). Another concern identified was the need for some type of functional (i.e., easily applied) early detection and screening instrument that could be used by families and NGOs. The fact finding process also revealed that many NGOs were vexed by the lack of guidance or information available on how to develop and carry out programs and supports that aid people with dementia.

This information gathering process as well as the intuitive contributions of the organizing committee helped frame the mission and define a series of goals. It was agreed that its mission was to evaluate and recommend actions directed at improving the nature and quality of community services for people with intellectual and developmental disabilities affected by dementia, as well as their families; and promote greater cooperation among various sectors responsible for providing community supports, health and social care, and public education. With respect to its initial goals, it was decided to include the following: (1) define best practices that can be used by NGOs in delivering supports and services to adults with intellectual disability affected by various dementias; (2) identify a workable, national “first-instance” early detection/screening instrument; (3) produce educational materials of use to families, people with intellectual disability, and NGOs; and (4) further public policy

<sup>3</sup>A brief version of this paper appeared as Janicki, M. P. (2013). Skuteczność akcji orędowniczej na rzecz wspierania dorosłych osób z niepełnosprawnością intelektualną dotkniętych demencją. Wykorzystanie podejścia Krajowej Grupy Roboczej [Viability of a dementia services advocacy effort for adults with intellectual disability using a National Task Group approach]. *Człowiek-Niepełnosprawność-Społeczeństwo*, 4, 25–36.

with respect to dementia as it affects adults with intellectual disability. As time passed, the NTG adopted additional longer duration goals, including (1) advising and advocating before the Advisory Council on Alzheimer's Research, Care, and Services to focus attention of matters of concern to people with intellectual disability and their families; (2) creating a national education curriculum to enhance the skills and capabilities of staff working with people with intellectual disability affected by dementia; and (3) advocating for national standards for "dementia-capable" community care programs for people with intellectual disability.

In large part, the impetus for creating the NTG in 2010 was that there were no systemic and cross-cutting national-level or state-level plans in the United States that specifically addressed the needs of adults with intellectual disability affected by dementia. Given that the U.S. Congress was moving toward enacting a new federal law (i.e., the National Alzheimer's Project Act) calling for a "national action plan" for dementia, it was important to ensure that intellectual disability was considered in that national plan. However, even though the U.S. Congress was moving to set up a national entity to examine and address Alzheimer's disease, it did not provide any financial aid for ancillary efforts to cover specific needs populations.<sup>4,5</sup> Within the NTG, there was a debate as to how to underwrite its activities and maintain an active presence within Washington (where much of the activity on the National Plan took place). Absent a formal funding base, the NTG organizing committee decided to use a "voluntary involvement model" (based on the notion of "civic volunteerism"; Verba, Schlozman, & Brady, 1995). This process employed a four-step development strategy: (1) obtaining support for the formation of a national working group; (2) drawing on volunteer-based membership from across the country and various constituencies; (3) getting support for pro bono work and other contributions for its working groups' efforts; and (4) drawing in key governmental and national organizational officials to support its efforts and implement its recommendations (Janicki & Keller, 2012).

As the preliminary activities of the NTG gained attention and began to produce interest, the NTG organizing committee began the process of formalizing its processes and structure. To accomplish its primary goals, the NTG designated several "working groups," each charged with examining one of the key goal areas and providing a road map for the NTG to complete its work in that specific goal. The working group volunteers examined their assigned issues (i.e., create a national plan on dementia and intellectual disability, identify a workable administrative screening instrument, produce health/screening practice guidelines for the medical and allied health community, and define "best practices" for community social care of adults with intellectual disability and dementia), prepared reports, and reported back at the NTG's first plenary meeting in June 2011.<sup>6</sup> At this

meeting, a process of debate and consensus was used to review and accept the recommendations of each group, vote to give the groups the charge to develop further their products associated with their recommendations, and request that the groups report their progress at a second NTG plenary meeting in December 2011.<sup>7</sup> At this second meeting, the NTG reviewed the work of the three main working groups and used the results to produce its seminal report issued in January 2012—"My Thinker's Not Working": A National Strategy for Enabling Adults with Intellectual Disability Affected by Dementia to Remain in Their Community and Receive Quality Supports (National Task Group, 2012; see Table 1). This report, in essence, became a national intellectual disabilities and dementia action framework as it laid out the relevant issues, spoke to the interface of the NTG to the work of the Advisory Council on Alzheimer's Research, Care, and Services, proposed the issuance of a national dementia detection and screening instrument and sets of practice guidelines, and outlined a 20-point national action plan for improving dementia support services in the United States.

During 2012, the "My Thinker's Not Working" report was distributed broadly throughout the United States (and other countries) mostly via the Internet, although a limited number of print copies of the report were made available for distribution to governmental and other key public policy officials. The overall outcome was the placement of the table of issues related to people with intellectual disability at many settings where discussions about Alzheimer's disease and related dementias were being held. Thus, the NTG delivered a plan for carrying forth on dementia-related advocacy in parallel with the activities being undertaken under the National Plan to Address Alzheimer's Disease.

Following the issuance of "My Thinker's Not Working," the NTG organizing committee transitioned and formed a formal Steering Committee made up of the main working group leaders and others with vested interest in managing the activities of the NTG. It also engaged the services of a graphic artist to design a unique logo (see Figure 1) and a brochure so as to provide for brand recognition. Administratively, the Steering Committee began a series of monthly conference calls using an Internet-based meeting service and the NTG undertook to formalize its relationship with the AADMD, which helped underwrite and provide material support for the NTG's activities. A formal agreement was enacted in 2013 through which the NTG became a "committee" within the AADMD under its bylaws and in 2014, it gained ex-officio status on the AADMD's Board of Directors. The agreement permitted the AADMD to act as the NTG's fiduciary agent so that the NTG gained access to its banking operations for receiving funds and paying bills, formalized the use of

<sup>4</sup>During this period, the U.S. Congress was preoccupied with political maneuvering to control governmental spending and reshaping the national budget; this led to a curtailment of funding for a variety of governmental programs and public initiatives and general retrenchment of governmental activities.

<sup>5</sup>The "specific needs populations" cited in the National Plan included minority groups, and adults with early onset dementia and those with intellectual disability.

<sup>6</sup>This first on-site gathering of NTG members and other interested parties

occurred in St. Paul, Minnesota, in conjunction with the annual meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD). While NTG members covered their own expenses to attend, the AAIDD provided material support for the meeting.

<sup>7</sup>This second on-site gathering of NTG members and national association and governmental officials occurred in Arlington, Virginia, in conjunction with the annual meeting of the Association of University Centers on Disabilities (AUCD). Again, while NTG members and other attendees covered their own expenses, the AUCD provided material support for the meeting.

TABLE 1  
Products of the National Task Group (NTG)

Product	Format	Description	Comments	Tips for replication
“My Thinker’s Not Working”: A National Strategy for Enabling Adults with Intellectual Disability Affected by Dementia to Remain in Their Community and Receive Quality Supports	Report	A 36-page report summarizing the state of play with respect to dementia and how it affects adults with intellectual disability and laying out a public policy agenda and action plan	Available from <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a>	Seminal document to coalesce public policy and practice issues; helps initialize thinking and amalgamate diverse perspectives; energizes volunteers. Best way to produce document is to invite diverse actors to workgroup and encourage creativity in its construction while investigating available resources and barriers to outcomes. Important to set timeline and final product date, linking it to some significant nationally relevant launch.
Guidelines for Structuring Community Care and Supports for People with Intellectual Disability Affected by Dementia	Journal publication and booklet	A consensus statement with protocols outline suggested best practices in a range of activities supporting adults with intellectual disability residing in the community, structured around a stage-based approach	Available from Jokinen et al. (2013). Guidelines for structuring community care and supports for people with intellectual disability affected by dementia. <i>Journal of Policy and Practice in Intellectual Disability</i> , 10, 1–28. Also available as a handbook; can be retrieved from <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a>	Best way to produce document is to compose work group of various professional associations, services organizations, government representatives, and other interested persons. Set goal to adapt international products to national use. Define purpose and outcome and set timelines.
NTG-Early Detection Screen for Dementia and Manual	Publication and booklet	A six-page administrative screen for collating pertinent behavior, function, health status, and other relevant information useful for pre-assessment of dementia. Versions: English, German, Italian, Greek, Spanish, French, Dutch, Japanese	Available from Esralew et al. (2013). National Task Group Early Detection Screen for Dementia (NTG-EDSD) Manual. <i>NADD Bulletin</i> , 16, 47–54.	Best way to produce document is to compose work group of various professional associations, services organizations, government representatives, and other interested persons. Adapt process to national needs. Define purpose and outcome and set timelines.

TABLE 1 Continued

Product	Format	Description	Comments	Tips for replication
The National Task Group on Intellectual Disability and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults with Intellectual Disability	Journal publication	A consensus statement on suggested practices by medical personnel when assessing an adult with intellectual disability presenting with possible dementia	Available from Moran et al. (2013). The National Task Group on Intellectual Disability and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disability. <i>Mayo Clinic Proceedings</i> , 88, 831–840.	Best way to produce document is to compose work group of various professional associations, services organizations, government representatives, and other interested persons. Process documented should reflect desired national practice. Define purpose and outcome and set timelines.
Guidelines for Dementia-Related Health Advocacy for Adults with Intellectual Disability and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices	Web resource	Guidelines designed to enable carers, whether family members or paid staff, to prepare for and advocate during health visits, and to assist NGOs when they are aiding family members and staff with interacting with health professionals	Available from Bishop et al. (2014). Guidelines for dementia-related health advocacy for adults with intellectual disabilities and dementia of the National Task Group on Intellectual Disabilities and Dementia Practices. Available from <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a>	Depending upon the national healthcare scheme, this type of guide can be adapted to help carers become more adept at accessing health services and knowing what to discuss related to dementia when seeking help from health professionals.
Frequently Asked Questions (FAQs)	Internet webpages	A listing of some 55 frequently asked questions and answers related to dementia and intellectual disability.	Available from <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a>	Translate and adapt existing NTG FAQ.
NTG workshops	Workshops	Format defined for state or regional workshop to help mobilize planning and organizing services at state level		Organize work group to set schedule for and provide training throughout the country.
NTG webinars	Webinars	International webinar services on dementia and related issues underwritten by private foundation		Organize work group to provide webinars on topics of interest to country.
NTG brochure	Publication	A two-sided tri-fold pamphlet that outlines what the NTG is and its mission and goals, and provides some basic information on dementia and people with intellectual disabilities	Available from <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a>	Public document issued for branding and name recognition

NGO, nongovernmental organization.



FIGURE 1

NTG logo designed for branding.

the AADMD website for NTG matters, and, through the Board function, gave it a voice on matters of pertinence to the NTG.<sup>8</sup>

### Continuing Work

During the period 2012–14, the NTG was active in identifying select issues that warranted greater attention. In some instances, the NTG encouraged other national organizations to address these issues, and in some instances its workgroups were charged with developing the products (see Table 1). So far, the NTG has engaged in the following activities:

- *Promotion of early detection.* To help families and NGOs begin to identify adults at risk or showing symptoms of dementia, the NTG developed an early detection and screening administrative instrument, applicable particularly to adults with intellectual disability (Esralew et al., 2013). The instrument, the NTG-Early Detection Screen for Dementia (NTG-EDSD; National Task Group, 2013), was developed in response to requests by family carers and NGOs for a tool useful to record changes in health, behavior, and function. The NTG-EDSD is available for use by NGO personnel to collate signal health and function data and to help organize symptom presentations for clinical personnel and administrative determination as to whether staff or family caregiver observations merit more explicit assessment for mild cognitive impairment or possible dementia or—alternatively—whether the signal behaviors may be attributable to other causes and amenable to intervention and remediation (Zeilinger, Gartner, Maxian & Weber, 2014; Zeilinger, Janicki, Esralew, & Gartner, 2014). The NTG-EDSD has been incorporated into the assessment regimen of many NGOs in the United States and elsewhere. It is available in several language versions at <http://www.aadmd.org/ntg/screening> (see Table 1).<sup>9</sup>
- *Educational activities.* Beginning in 2011, the NTG organized educational webinars on the topic of dementia and intellectual disability held across the United States. In 2012, it began its series of “NTG Workshops” across the United States as well as in Canada. Initially, the workshops were held in conjunction with the annual meeting of several national partner organizations, but later there were free-standing and help upon requests from state or local organizations. Also, during this initial period, the NTG received a modest grant from the Special Hope Foundation to underwrite a webinar series, which involved two 4-week series of webinars on various topics associated with dementia. To complement its workshops and webinars, the NTG produced a Frequently Asked Questions document that it posted on its website and made available nationally and is working on developing a series of fact sheets to be used by the federal government as part of its dementia education and public awareness initiative. The NTG is also working in concert with a national association to produce an informational booklet for carers of adults with Down syndrome and dementia. In 2014, the NTG organized a joint national conference with the AADMD and Special Olympics (held in Princeton, New Jersey) that included sessions devoted to topics related to dementia and a plenary session on public policy involving several leaders from governmental agencies and national associations. Given the successful reaction to this conference, it was decided to hold similar conferences in subsequent years. NTG members have also been involved in presentations at the annual meetings of various national and international associations and organizations with the intent to raise awareness and further information exchanges.
- *Guidelines development.* The NTG’s working groups took on the task of developing evidence and consensus-based practice guidelines. One effort drew from the original practice guidelines developed and issued under the auspice of the former AAMR and IASSID<sup>10</sup> (Janicki, Heller, Seltzer, & Hogg, 1996). The contemporary community care guidelines version expanded that original work and added a staging framework for constructing supports and guiding service delivery (Jokinen, Janicki, Keller, McCallion, & Force, 2013). Another effort drew from medical practice and evidence and provided guidance for medical practitioners when conducting assessments and formulating diagnoses (Moran, Rafii, Keller, Singh, & Janicki, 2013). A third set of guidelines were directed toward health advocacy for use by carers and agency personnel (Bishop et al., 2014). All of these have appeared in professional journals or as widely distributed web-based publications.
- *Quality promotion.* The NTG participated in efforts by standards bodies to promote quality among NGOs when

<sup>8</sup>The AADMD had formal non-for-profit organization status under the rules of the U.S. Internal Revenue Service, while the NTG was an unincorporated entity. The affiliation agreement enabled the Academy to handle the NTG’s financial affairs under American tax laws.

<sup>9</sup>We acknowledge the contributions of Tiziano Gomiero of the ANFFAS Trentino Onlus in Italy for the Italian version, Sandy Stemp of the Reena Foundation in Toronto, Canada, for the French-Canadian version, Miguel Angel Verdugo of the University of Salamanca in Spain for the Spanish version, Angeliki Tsapanou of the National and Kapodistrian University for

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<sup>10</sup>The AAMR is now the American Association on Intellectual and Developmental Disabilities and the IASSID is now the International Association for the Scientific Study of Intellectual and Developmental Disabilities.

delivering services to people with developmental disabilities. One international certification organization subsequently produced a new set of standards, titled “Older Adults and Older Adults/Dementia Care Specific Population Designations,” that were designed to assess individually tailored services supporting adaptive aging and compensating for aging-related decline, such as seen in adults with intellectual disability and dementia (CARF, 2014). NGOs providing dementia-related services and programs can now apply to be assessed and potentially receive certification as dementia services providers. The NTG was also represented on a national quality organization workgroup commissioned by the federal government to define the characteristics and parameters of quality with respect to services being provided for all people with dementia (NQF, 2014). One task that the NTG has set for itself is the definition of a framework for core program standards for community care services and supports for adults with intellectual disabilities affected by dementia.

- *Workforce enhancement.* Responding to an identified need to define core competencies for workforce personnel who work with intellectual disabilities affected by dementia, the NTG identified critical topics for a training and education curriculum. As a follow-up, the NTG also developed a national curriculum for training personnel who work for NGOs and organizations that provide services to adults with intellectual disability affected by dementia. Several levels of training materials were developed, including an intensive curriculum for personnel working directly with adults with dementia, and ancillary materials for personnel who are “new hires” or who are already employed and work with adults with intellectual disability yet unaffected by dementia, or who might be at risk. The curriculum was designed for use by geriatric education centers, university aging and disability centers, and NGOs conducting staff education. The curriculum also contains a “train-the-trainer” component, which enables the NTG, via its education component, to provide direct training to personnel involved with training others.
- *Research support.* A significant focus of the U.S. National Plan is around research support and efforts to determine the etiology of the various dementias as well as study explicit treatment and outcomes. Although the NTG did not assume the mantle of advocacy for basic research, it has worked to support initiatives undertaken by the National Institutes for Health in the area of Down syndrome and other intellectual disabilities as well as coordinating with other NGO and university-based research efforts. One area of cross-focus is the NTG’s participation on the Down Syndrome Biomarker Initiative, which is working to create an international collaborative of studies related to identifying indicators of Alzheimer’s disease and study progression of the disease, with the ultimate goal of better understanding brain aging in adults with Down syndrome (Rafii, 2013). The NTG has also participated in activities focused on research stemming from cooperative endeavors spearheaded by the Alzheimer’s Association, including participation in the Down Syndrome and Alzheimer’s Disease professional interest area

associated with Association’s International Society to Advance Alzheimer’s Research and Treatment (ISTAART).

- *Advocacy.* The NTG has acknowledged that dementia has a devastating impact on all people one way or another—including people with intellectual disability and the many families, friends, and staff involved with them—and thus has advocated before the Advisory Council on Alzheimer’s Research, Care, and Services that it include concerns and considerations for people with lifelong intellectual disability in any and all of its documents, plans, and recommendations. The Task Group has also maintained liaison meetings with federal government officials charged with implementing select parts of the U.S. National Plan to Address Alzheimer’s Disease and is a member of a Washington-based national consortium of dementia advocacy and services provision groups (i.e., Leaders Engaged on Alzheimer’s Disease). Advocacy is also a feature of cooperative and collaborative relationships, such as those with various national groups in the United States, including the National Down Syndrome Society, the Arc of the United States, and the Alzheimer’s Association.

The NTG has acknowledged that Alzheimer’s disease and other dementias affect adults with lifelong intellectual disability in similar ways as they do other people, but sometimes have a more profound impact due to particular risk factors—including genetics, neurological injury, life history, and deprivation. Underlying its efforts is the belief that adults with intellectual disability require the same early and periodic diagnostic services, community education, and community-based supports for themselves, their carers, and the organizations responsible for them, as do other adults with dementia in the general population. The challenge was how to transform existing supports and services provided to work-age adults with lifelong intellectual disability to those more appropriate to older age adults with intellectual disability and now affected by cognitive decline and functional impairment associated with the various dementias. As part of its organizing principle, the NTG adopted the Edinburgh Principles (Wilkinson & Janicki, 2002) and believes strongly that community supports are to be given priority consideration when planning long-term care. Given this, the NTG has recommended that NGOs and local governmental authorities invest in increased home-based supports for persons who remain the primary carers for adults affected by dementia and that small-group community care models be employed via investments enabling NGOs to develop and maintain small community-based specialized “dementia-capable” group homes.

#### WHAT IS THE VIABILITY OF THE MODEL?

Although the model employed by the NTG is not unique and is often found to be functional at a local level—that is, the grouping of workers who have similar interests centered on a common issue—its application did break some new ground. The uniqueness was based on the application of a “ground-roots emergence and evolution process” and a “free-form advocacy effort,” which resulted in an organized volunteer- and



constituent-based movement and a progressive broadening of the scope of influence. Its functionality was vested in a number of factors, including the devotion of its members and their willingness to offer pro bono services, the linkages to a sympathetic and supportive formal professional organization (i.e., the AADMD), support from a nationally recognized university-based center on disability, and the concurrent legislatively mandated development of activities to address dementia by the national government. The model, thus, via its cumulative successes, permitted the effort to become progressively more self-sustaining and enabled the functions undertaken to take more prominence and kept active the mechanisms that motivated the agents. Its essence is reflected in this axiom: "The more the successes, the more the motivation." The individual members were often able to be more successful in creating and implementing a specific project and plan by being engaged in the task group. Working together as a team enabled projects to be completed by a number of colleagues and group members working informally and in concert. The effort was vetted and given added gravitas under the banner of the NTG. The group members who were active participants in the task force achieved additional prestige and credibility as experts and leaders in their area of expertise related to intellectual disability and dementia.

Under this model, the beginning is seen as both active and reactive; *active* as it begins to gain momentum as the result of the initiation of some common actions (advocating for supports for carers faced with caring at home of someone affected by dementia), and *reactive* as there are gains and more momentum through association with a greater task (i.e., a national dementia plan). Once going, it is sustained by its own successes. It also benefits from timeliness and opportunity, for contemporary demographics predict a significant increase in the number of older people; the topic of dementia and its impact in general is gaining traction in the public discourse. That there may be a transition from absence of dysfunction among some people with intellectual disability to progressive debility due to dementia in later life is also gaining recognition among families and NGOs tasked with providing supports and care. The model's timeline is dictated by some terminal outcome; in this case, the goal is to keep up the activities until 2025—the terminal point for activities under the national dementia plan in the United States.

The application of this model has permitted the NTG to function by virtue of being able to tap into its organic resources and resolve. This has led to successes in many arenas, mostly in areas directly under its control, such as its products and liaison efforts. It was able to mobilize the contributions of a wide range of family members, professionals, academics, and NGO personnel to provide volunteer time and expertise to attain its ends. The democratic participatory process it used enabled the NTG to fulfill many of its goals, define its activities by consensus, and draw together its members to coalesce around strategies to address key issues. Administratively, the NTG has evolved from a free form entity to one with more structure and process. It now has a leadership structure of two senior cochairs, a recording secretary, Steering Committee members, leaders for working groups, and functional structure of meeting minutes and an ex-officio seat on the board of the AADMD. It has access to information technology resources and help, a means for financial transactions, and recognized brand-

ing. It holds scheduled administrative meetings, communicates with its broader membership, and encourages the enlistment of new members. It is held together by the interest and willingness of its members to contribute their time and experience and a democratic, inclusive decision-making process that encourages initiative and innovation.

Analyses of the NTG's successes indicate initially more progress related to efforts undertaken within the private sector, with recognition of the group's value within the national dementia advocacy system growing incrementally. Work over the past 3 years is beginning to show promise as intellectual disability as an included population has become increasingly more receptive in the national conversation. National training initiatives now include intellectual disability among professional education topics, and the leadership of the NTG is increasingly consulted on matters related to disability and dementia with respect to recognition within the federal sector. More difficult was initially affecting immediate change at the national government level as legislative and budget-planning timelines, barriers posed by political wrangling, and administrative conditions (often outside the control of advocacy efforts) combined in the early years pose a tardiness in defining targeted initiatives for the inclusion of people with disabilities and dementia in all dementia-related services, gaining a fair share of funds appropriated for research and services, and being recognized as more than being a self-interest group. However, a recent shift in support from national governmental entities has mitigated these early challenges. The most recent iteration of the National Plan update (DHHS, 2014) contains significantly more direct mention of intellectual disability and specifically targets a number of governmental actions to bring about change and more services (see Table 2).

In measuring long-term impact, it is evident that over the past 4 years, the NTG has gained recognition as the central group with which to confer and work with when there is a concern with services and supports for people with intellectual disability affected by dementia. It is expected that its lifespan, begun in 2010, ostensibly will mirror that of the Advisory Council on Alzheimer's Research, Care, and Services and continue through to 2025. The NTG has helped various advocacy organizations acknowledge that the devastating impact dementia has on all people also includes people with intellectual disability and the many families, friends, and staff involved as parents, siblings, advocates, and carers. Also, its advocacy efforts before the national advisory council to include concerns and considerations for people with lifelong intellectual disability in any and all documents, plans, and recommendations submitted to the government have had an effect.

However, its successes to date are tempered by its limitations. As the NTG is restricted in its scope and ability to do everything it set out in its original document and action plan, the means to immediately address those needs identified have to be tempered by its resources. Without a stable financial base for its activities, the NTG has to place select products and activities on a graduated timeline for future attention. Ideally, having the resources for staff and facilities would enhance its productivity. However, if the NTG was to transition to a personnel-based organization, it might be led to compromise its native structures and dependency on volunteerism—which has given it much of its vitality, credibility, and viability. Even though, as it continues to function as a

TABLE 2

U.S. National Plan to Address Alzheimer’s Disease progression of mention and inclusion of activities directly referencing Down syndrome and intellectual disabilities (2012, 2013, and 2014)

U.S. plan version	References to		Activity or action
	Down syndrome	Intellectual disability	
<i>2012 National Plan to Address Alzheimer’s Disease</i>			
Page	5		Notes that “A significant number of people with Down syndrome also develop dementia in their 50s.”
		20	Notes that adults with ID are “unequally burdened” by dementia.
	20		Notes “people with Down syndrome almost always develop AD as they age.”
	21	21	Notes the DHHS will convene a taskforce regarding “specific populations” including people with “Down syndrome and other intellectual disabilities” with a focus on how to improve accurate and timely diagnosis, access to care, education on AD for practitioners who do not normally specialize in care for people with AD, and special considerations for these populations. (Action 2.H.1)
	21	21	Notes that AoA, OD, and ADD will “work together to address access to long-term services and supports . . . for . . . people with Down syndrome and other intellectual disabilities” and will identify barriers to these supports and make recommendations to the Advisory Council and DHHS on ways to address these barriers. (Action 2.H.2)
<i>2013 Update National Plan to Address Alzheimer’s Disease</i>			
Page	5		Notes meeting held in April 2013 to “advance a research agenda aimed at developing successful interventions to address Alzheimer’s disease for people with Down syndrome.”
		5	Notes DHHS convened a “Special Populations Task Force” for groups unequally burdened by AD, including people with intellectual disabilities.
	7		Notes “significant number of people with DS develop dementia in their 50s.”
		17	Notes trainings funded by HRSA via the GECs address the unique needs of special populations including individuals with intellectual disabilities. (Action 2.A.1)
		19	Notes that DHHS will develop and disseminate a unitary primary care AD curriculum, including “recognition of risk factors and signs and symptoms . . . among those with ID.” (Action 2.A.7)
	24		Notes “people with DS always develop AD as they age” under commentary on improving care for populations disproportionately affected by AD and facing care challenges.
		24	Notes “Some populations are unequally burdened by Alzheimer’s disease, including racial and ethnic minorities and people with intellectual disabilities.”
		29	Notes DHHS “will enhance knowledge about respite care for people with dementia and their caregivers . . . [and] develop and disseminate information on respite care considerations in dementia situations . . . among persons with intellectual disabilities.” (Action 3.B.8)
<i>2014 Update National Plan to Address Alzheimer’s Disease</i>			
Page	8		Notes “A significant number of people with Down syndrome develop dementia in their 50s.”
	12		Notes “NIH supported the <i>Advancing Treatment for Alzheimer Disease in Individuals with Down Syndrome</i> workshop in April 2013 to identify research recommendations and priorities for this population . . . [which] resulted in a set of recommendations including short-term goals such as sharing existing data and development of new data sets that follow study participants with Down syndrome as they age as well as longer term goals such as the development of a Down Syndrome-Alzheimer’s Disease consortium.”

TABLE 2 Continued

U.S. plan version	References to		Activity or action
	Down syndrome	Intellectual disability	
		17	Notes “Trainings also address the unique needs of . . . special populations including . . . individuals with intellectual disabilities.”
		19	Notes “The [unified curriculum for primary care practitioner] curriculum will include topics such as the recognition of risk factors and signs and symptoms, as well as AD among specific diverse populations and those with intellectual disabilities.” (Action 2.A.7)
		24	Notes that ACL/AIDD will “educate family and service providers of persons with intellectual disabilities about changes that may indicate the onset of dementia” by developing fact sheets and tools for family and service providers to use in identifying whether an individual with intellectual or developmental disabilities may be developing AD. (Action 2.B.3)
	29		Notes “People with Down syndrome almost always develop AD as they age.”
		29	Notes “Some populations are unequally burdened by Alzheimer’s disease, including racial and ethnic minorities and people with intellectual disabilities.”
		30	Notes that DHHS will explore promising models of family support and “Enhance understanding of models of family support for people with intellectual disabilities as they age” . . . and the “project will include a focus on issues related to aging of both family caregivers and people with intellectual disabilities, such as stressors related to Alzheimer’s disease.” (Action 2.H.4)
		33	Notes “ACL/AoA will develop and disseminate information on respite care considerations in dementia situations, as well as younger-onset and dementia among persons with intellectual disabilities.” (Action 3.B.8)

ACL, Administration on Community Living; AD, Alzheimer’s disease; ADD, Administration on Developmental Disabilities; Advisory Council, Advisory Council on Alzheimer’s Research, Care, and Services; AIDD, Administration on Intellectual and Developmental Disabilities; AoA, Administration on Aging; DHHS, Department of Health and Human Services; DS, Down syndrome; GEC, Geriatric Education Centers; HRSA, Human Resources and Services Administration; ID, intellectual disability; NIH, National Institutes of Health; OD, Office for Disability.

voluntary association, the NTG has been successful in leveraging and keeping up with the constant tracking of federal activities related to the American National Plan to Address Alzheimer’s Disease and promoting activities about intellectual disability within the Alzheimer’s Association in the United States, aiding national disability organizations to heighten awareness of Alzheimer’s disease, and gaining greater acknowledgment from national professional groups. Its promotion of greater emphasis on providing community-based supports and programs, and efforts given toward improving services have helped enhance an understanding of dementia, alerting to risk and early signs, adapting living environments, helping with future planning (health and social care), aiding families who are carers, enhancing staff skills training with respect to dementia, establishing quality checks in services, and providing stage-related services.

Its impact can also be measured by the heightened recognition of intellectual disability as a factor in the increase of older people affected by dementia. The special needs of families, often who have been lifelong caregivers, have gained attention, as have the challenges faced by NGOs who now do and will later bear the burden of care when families “age out” of caregiver capabilities, or when adults, who gained autonomy and live in our com-

munities, fall back upon dependency as a result of dementia and require specialized supports. The shift in emphasis on intellectual disability issues and actions in the U.S. National Plan over the period 2012–14 shows a notable increase in focus and mention. Table 2 illustrates the progressive shift from cursory mention of people with intellectual disability and their issues to stated plan actions that commit efforts by the federal government to address problems that have been raised by the NTG at the quarterly meetings of the Advisory Council and in discussions with federal authorities and leaders of the NGOs involved with intellectual disability. As the U.S. National Plan has an ultimate timeline of 2025, the fact that each year more attention is progressively being paid to intellectual disability concerns is encouraging, as is the fact that the mentions have shifted from cursory notations to specific actions that will draw resources from federal programs.

REPLICATION

With respect to replicating the model, several efforts have been undertaken in other countries, the most prominent has

been the work of the Anffas Trentino Onlus in the Trentino region of Italy (Gomiero & De Vreese, 2012). Others have begun to explore how they might introduce more focus on intellectual disability within their national dementia plans, or how to raise awareness of intellectual disability and dementia in general.

Replication of social advocacy is always reflective or driven by local conditions, including how much value is ascribed to an issue or the groups representing that issue by the central government. A lot will depend on whether there already exists a national dementia plan, or if efforts have to be undertaken to help establish one. With respect to either situation, we propose that like efforts could be undertaken in other countries or geographic areas to heighten focus on intellectual disability. Some strategies that might be undertaken by nascent groups to tag onto a generic national effort to address dementia might include the following: (1) start with creating a core group of advocates and representatives from various sectors to agree on the need for a national voice on behalf of older people with intellectual disability affected by dementia; (2) look to affiliating with the national Alzheimer's advocacy group (but exercising care so as to avoid getting subsumed by it, as this may diminish the group's potential voice and impact); and (3) mobilize a regional or national group to have a voice at any national discussions or actions. If there is a national plan, efforts might be undertaken to mirror the NTG's experience—that is, develop a group that will advocate in parallel for the greater inclusion of issues and actions related to adults with intellectual disability and their families and other carers. If there is no national plan, the efforts may be directed toward either creating a national intellectual disability and dementia plan or helping the Alzheimer's and related dementias community in creating a generic dementia national plan and thus ensuring the incorporation of intellectual disability concerns.

In either case, any efforts undertaken can follow several trajectories or employ varied strategies. One strategy is designing the process of how to get people involved. For example, it may include soliciting volunteers from a broad base to ensure that many sectors of interest and concern are represented (while realizing that not everyone will be prepared to devote a great deal of time, but may want to be affiliated with the group and help periodically). It may also include internal processing, such that once a distinct identity is established, the nascent group should agree on a message and what will be the course of action. This calls for a sound communication strategy and the means to explicate mission, process, and end points. One such means is to ensure that governmental policy makers and politicians are well briefed as to the nature of dementia and how it affects people with intellectual disability and what is needed with respect to change or provision of services. It also means conveying information about the existence of the group and developing a presence at events and meetings. Another strategy may involve engaging support from like-minded organizations and utilizing a process that helps educate provider organizations and gets a "buy-in" from administrators and governance bodies. In many instances, there may be a like-minded or sympathetic administrator or board member who may help bring up the issue within the organization or provide a means for securing an invitation by the nascent group to meet with the administration or board.

Table 3 outlines and illustrates some of the mechanics of organizing and maintaining such an advocacy group. The lessons learned noted in the table can be used to help frame actions and activities that can be undertaken. Options are not limited to those on Table 3, but what we have listed can help frame any strategic planning to undertake when evolving a national group. A summary of the lessons we have learned in developing and maintaining the NTG follows:

*Lesson 1 (Financing):* What is helpful to know is that generally such an effort can be undertaken without a great deal of money. Much can be done initially via contributions of time and effort by the persons involved. Yet, some financial support eventually will become crucial, if the activities undertaken come with a cost (e.g., travel to attend meetings, expense related to producing materials, etc.). Obtaining financial support would certainly help lessen the impact on the members who are contributing their time and effort. However, if attempting to first secure underwriting becomes a barrier to undertaking the effort, then reliance on a voluntary-based process will be necessary.

*Lesson 2 (Initiating):* A key to effective start-up is finding "sparks" (i.e., activists) to lead the effort and get acceptance by one or more key national associations or other established and respected bodies. This method was used successfully in the Italian effort, where a group of professionals and family members from a variety of organizations coalesced and formed a group to promote interest in this topic (De Vreese et al., 2012). They were able to build off efforts begun by the NTG and a cost saving for them was to translate and use already developed materials produced by the NTG. They paired this effort with a modest study they were conducting that was underwritten by a local foundation. This pairing helped gain attention and draw in other interested persons.

*Lesson 3 (Organizing):* In organizing, it is good to quickly identify the issue and make it broadly known. Critical to this effort is having committed leaders with time and foresight to help lead the effort and mobilize volunteers to become involved and who are familiar and comfortable with the actors on the main stage—the people involved with the National Plan or who could be called upon to aid this effort in the absence of a national plan. As much of the work may be political, the key people within the group should have a grasp of national politics and the ear of some key people at the national level. Also, the involvement of self-advocates and applications of family advocacy methods help with gaining credibility. The leaders of the group need to continually be sensitive to their members' time constraints, work ethics, personal motivations and goals, as well providing a sense of a groupthink and camaraderie throughout the group and its core leadership. A further critical lesson is to bring attention to the issue of dementia and intellectual disability. To gain attention, the group and its colleagues should make sufficient noise to get noticed, energize affected people (families, staff, self-advocates), and work to get recognized as a force in defining the direction government and national organizations should take in addressing Alzheimer's disease as it affects people with intellectual disability. It helps to have something to offer, such as a "white paper" or a plan, or at minimum a listing of the "asks"—that is, those things needed to be gotten or gained, or what needs to be accomplished and a designation of who might do it. It also

TABLE 3  
Mechanics of running a National Task Group (NTG)

Function	Source	Comments
Financial supports	Originally, the NTG was supported by goodwill and the contributions of the host organizations setting it up, as well as self-funding by members or their work organizations.	The NTG currently generates some income from running workshops and webinars, and receives some contributions from friendly organizations and funds from grants. Funds are used to defray meeting costs, printing, and support some members to provide comments and participate in government meetings.
Communications	Although the NTG held two plenary site meetings (these were underwritten by organizations hosting the meetings and by self-funding by members), most communication is via Internet using a web-based conferencing system.	An Internet conferencing system is used as members are dispersed across a large area and it is not practical to hold monthly face-to-face meetings.
Production	Materials produced by the NTG by its work groups are produced to be able to be posted in its website and then downloaded. Some costs for print versions were covered by the universities participating in the NTG.	All matter produced is available on the NTG's website— <a href="http://www.aadmd.org/ntg">http://www.aadmd.org/ntg</a> . The costs of maintaining the website are covered by the American Academy of Developmental Medicine and Dentistry.
Functional activities	The NTG uses a “working group” model whereby members volunteer to help with a product or task, a leader or leaders direct the effort and ensure that work is produced in due course and working drafts are circulated within the Steering Committee first and then the full NTG.	Working groups permit a focus on a specific task by those members most knowledgeable and experienced with topic; supports are provided when needed (funds for meetings and production work) and access is provided to Internet conferencing; leaders report back to the Steering Committee on progress and content.
Member time	No members are paid by the NTG for their time; all efforts are pro bono.	Members donate their time to the extent allowed or possible as per their NGOs or organizations.
Governance	The NTG is led by a Steering Committee composed of 2 cochairs and about 25 core members; new members are added on a consensus basis.	The Steering Committee meets once a month via Internet conferencing. NTG activities and products are reviewed and decisions are made related to any new efforts. Any major policy efforts or products in development are sent to the full NTG membership for input and comment.

NGO, nongovernmental organization.

is helpful to “put a face” on the issues, by providing illustrations of specific problems faced by carers with whom the public can identify.

*Lesson 4 (Auspice):* Sometimes such groups may be formed from an edict or initiative stimulant offered by a governmental entity or a national NGO. For example, a governmental agency or ministry may recognize this as a public health or public policy issue and seek out a nongovernmental means of raising the issues and increasing its visibility within the country, either to help with gaining consensus for action or to influence the legislative process. Such efforts also would be highly functional and usually have the same end point. The difference may be the nature of the support provided or the access to the governmental entity that may help speed along any actions that may be undertaken. One instance where this may occur is when the mainstream Alzheimer's community is

already engaged in a national plan development process and the governmental entity recognizes that the disability and dementia agenda warrant inclusion through a more organic and public process.

*Lesson 5 (Flexibility):* When constructing such a national effort, all work should be considered evolutionary and the means employed to get things done must be flexible and fluid. This means that strategies and tactics need to be malleable and easily adapted to new demands or opportunities (which in reality are always changing). It also means that being inclusive can go further as problems inherent in territoriality are minimized. It does not mean losing sight of the goals and objectives and letting the focus of the activities be muddled by pitfalls and the occasional failures; but it does mean knowing how to be political and knowing when to best deploy resources and with whom to correspond and collaborate.

*Lesson 6 (Evaluating):* Having an integrated evaluation method to measure the effort's progress and outcomes is crucial. Defining the outcomes and impact is important and will eventually be the measure of the success of the effort. One way to do this is to consider what questions may be asked and who to go about how they could be answered. The questions might include: (1) Have lives been improved? (2) Have NGOs been able to deliver more appropriate and worthy services? (3) Are families better off? (4) Has a standard been set for how people with intellectual disability affected by dementia should be seen and treated? (5) Has there been a shift in thinking and an actual change in services? and (6) Has there been more attention paid to intellectual disability issues within and by the various Alzheimer's communities (researchers, advocates, public policy people, etc.)? Most important, however, is having a good understanding of the end point—that is, mitigating the impact of dementia and making life better for those persons affected by it. Insight into the metrics that might be employed with respect to the outcomes generally come about organically and will become evident as the effort progresses or has hit crucial delimiters in the timelines.

Our experience has shown that in developing an organic group, some aspects of these processes cited above might be appropriate, depending on local/national politics and support from the national Alzheimer's group and national intellectual disability groups, and at other times, the natural evolution comes from the family and professional provider sector. With either approach, we suggest that there may be a natural ebb and flow of activities that can help such a group get mobilized and work toward attaining its goals (Janicki, Keller, Lucchino, & Watchman, 2014). Such activities might include: (1) defining the basis and purpose for a national group (e.g., is there a general dementia national plan to correspond to or is the purpose to raise activism on behalf of people with intellectual disability?); (2) agreeing upon the political development process that can be used to mobilize a national cadre of volunteers (is there a receptive climate, does one have to be created?); (3) setting mission and goals for attainment; (4) obtaining investments (or buying in) (i.e., who and what to connect with to build strength and credibility?); (5) dealing with financing (will there be underwriting, institutional support, or will this be a "scratch" operation?); (6) building a cadre of volunteers and keeping them engaged over the short and long term; (7) deciding where to put resources (public events, production work, meetings, etc.); (8) agreeing on what doors to knock on in pressing your case (e.g., what ministries or government entities need to be "educated" and what NGOs need to be seconded); (9) administering the work of the group in meeting goals, motivating volunteers, keeping abreast of national events and policies (e.g., securing good people to lead efforts, setting dates for deadlines, going public); and (10) networking, getting endorsements, and continually building credibility to build greater support and attain goals.

## CONCLUSION

Alzheimer's Disease International (2014) has noted that a comprehensive government plan should address the needs of

people with dementia and have targets that promote broad public awareness of Alzheimer's and combating stigma; identifying dementia-capable support services at all stages of the disease; quantifying the number of individuals with dementia; assessing and improving the quality of healthcare, social care and long-term care support and services; assessing availability and access to diagnostic services; and undertaking public health efforts to conduct surveillance and promote brain health. It is important to keep in mind these fine points with respect to the process and that the same points apply to any specific population of concern. Yet, it is also important to remember the nature of competitiveness. Various constituencies will be competing for whatever limited resources are being provided under a national plan process. Carving out the resources and public policy commitment to this segment of the national population will not be easy, but nonetheless should be undertaken. When it comes to seeking attention to issues particularly germane to people with intellectual disabilities, universality on knowing where things need to begin is not always the case (i.e., from a clean slate, as in many countries, or as an add-on on some form of services and supports already existent), so it is a question of adapting and adding to, which should prove easier to do and be less costly.

Thus, national Alzheimer's disease targeting efforts, whether formal plans or governmental and/or national organization initiatives, are effective devices in improving awareness of this insidious disease and providing needed services to affected persons and their carers. As some persons with intellectual disability are at elevated risk for this disease (in particular, adults with Down syndrome), it is important that any national dementia efforts contain provisions for this group of adults. In addition, as recent research is pointing to the genesis of the neuropathology of Alzheimer's disease occurring several decades prior to the observance of dementia, early preventive strategies involving lifestyle factors such exercise, diet, and other behavioral changes that have been demonstrated to improve cognitive functioning can be employed by families and NGOs providing supports to adults with intellectual disabilities. As reported by Norton et al. (2014), one-third of the occurrence of Alzheimer's disease is related to risk factors that can be potentially changed, and thus forestalling the appearance of dementia symptoms could have a significant impact on the quality of life of older adults with intellectual disabilities. Given this, a focus on prevention and a greater awareness of what lifestyle factors can aggravate or mitigate later life cognitive decline gives urgency to the creation of national dementia plans and advocacy efforts on behalf of adults with intellectual disabilities.

The lessons learned from the efforts in the United States to create and maintain a national task group advocating for people with intellectual disability show that low-cost and earnest organized advocacy efforts have viability and can have an impact and potentially improve the quality of lives of persons with intellectual disability affected by dementia.

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## REFERENCES

- Alzheimer Europe. (2014). *National dementia plans: A snapshot of the status of national dementia strategies around Europe*. Retrieved from <http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans>
- Alzheimer Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society*. Retrieved from <http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Rising-Tide>
- Alzheimer's Disease International. (2013). National dementia plans update. *ADI Global Perspectives*, 23, 4.
- Bishop, K. M., Hogan, M., Janicki, M. P., Keller, S. M., Lucchino, R., Mughal, D. T., . . . Wolfson, S. & the Health Planning Work Group of the National Task Group on Intellectual Disabilities and Dementia Practices. (2014). *Guidelines for dementia-related health advocacy for adults with intellectual disabilities and dementia of the National Task Group on Intellectual Disabilities and Dementia Practices*. Retrieved from <http://www.aadmd.org/ntg>
- Bush, A., & Beail, N. (2004). Risk factors for dementia in people with Down syndrome: Issues in assessment and diagnosis. *American Journal of Mental Retardation*, 109, 83–97.
- CARF. (2014). *Accreditation standards: Quality individualized services and supports (H. older adults and older adults/dementia care specific population designations)*. Tucson, Arizona: CARF International.
- De Vreese, L.P., Mantesso, U., De Bastiani, E., Weger, E., Marangoni, A. C., & Gomiero, T. (2012). Impact of dementia-derived nonpharmacological intervention procedures on cognition and behavior in older adults with intellectual disabilities: A 3-year follow-up study. *Journal of Policy and Practice in Intellectual Disabilities*, 9, 92–102.
- DHHS. (2012). *National plan to address Alzheimer's disease*. Washington, DC: US Department of Health and Human Services.
- DHHS. (2013). *2013 Update to the national plan to address Alzheimer's disease*. Washington, DC: US Department of Health and Human Services.
- DHHS. (2014). *2014 Update to the national plan to address Alzheimer's disease*. Washington, DC: US Department of Health and Human Services.
- Esralev, L., Janicki, M. P., DiSipio, M., Jokinen, J., Keller, S. M., & Members of the National Task Group Section on Early Detection and Screening. (2013). National Task Group Early Detection Screen for Dementia (NTG-EDSD) Manual. *NADD Bulletin*, 16, 47–54.
- Gomiero, T., & De Vreese, L. P. (2012). *Dimentica la disabilità e guarda alla persona: Una strategia nazionale per permettere agli adulti con Disabilità Intellettiva, affetti da Demenza, di rimanere nella propria Comunità, ricevendo sostegni di qualità* [Forget the disability and see the person: A strategy to be left to adults with intellectual disabilities, suffering from dementia, to remain in own community, receiving quality support]. Retrieved from <http://www.anffas.tn.it> and <http://www.validazione.eu/dad>
- Holland, A. J., Hon, J., Huppert, F. A., & Stevens, F. (2000). Incidence and course of dementia in people with Down's syndrome: Findings from a population-based study. *Journal of Intellectual Disability Research*, 44, 138–146.
- Janicki, M.P. & Dalton, A.J. (Eds.). (1999). *Dementia, Aging, and Intellectual Disabilities: A Handbook*. Philadelphia, PA: Brunner-Mazel.
- Janicki, M. P., Heller, T., Seltzer, G., & Hogg, J. (1996). Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability. *Journal of Intellectual Disability Research*, 40, 374–382.
- Janicki, M. P., & Keller, S. M. (September, 2012). *National planning for dementia-related supports and community care for adults with intellectual disability*. Poster presented at the 6th International Forum on Disability Management, London, UK.
- Janicki, M. P., Keller, S. M., Lucchino, R., & Watchman, K. (July 2014). *Strategies for implementing a national plan for dementia care for people with developmental disabilities*. Workshop provided as part of the IASSIDD Academy on Education, Teaching and Research Program at the 4th Quadrennial Conference of IASSIDD-Europe, Vienna, Austria.
- Jokinen, J., Janicki, M. P., Keller, S. M., McCallion, P., & Force, L. T., the National Task Group on Intellectual Disabilities and Dementia Practices. (2013). Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia. *Journal of Policy and Practice in Intellectual Disabilities*, 10, 1–28.
- Moran, J. A., Rafii, M. S., Keller, S. M., Singh, B. K., & Janicki, M. P. (2013). The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clinic Proceedings*, 88, 831–840.
- Nakanishiemi, M., & Nakashima, T. (2014). Features of the Japanese national dementia strategy in comparison with international dementia policies: How should a national dementia policy interact with the public health- and social-care systems? *Alzheimer's & Dementia*, 10, 468–476.
- National Quality Forum. (2014). Prioritizing measure gaps: Alzheimer's disease and related dementias. Retrieved from [http://www.qualityforum.org/Prioritizing\\_Measure\\_Gaps\\_-\\_Alzheimers\\_Disease\\_and\\_Related\\_Dementias.aspx](http://www.qualityforum.org/Prioritizing_Measure_Gaps_-_Alzheimers_Disease_and_Related_Dementias.aspx)
- National Task Group. (2012). "My thinker's not working": A national strategy for enabling adults with intellectual disability affected by dementia to remain in their community and receive quality supports. Retrieved from <http://www.aadmd.org/ntg>
- National Task Group. (2013). *National task group early detection screen for dementia*. Retrieved from <http://www.aadmd.org/ntg/screening>
- Ness, S., Rafii, M., Aisen, P., Krams, M., Silverman, W., & Manji, H. (2012). Down's syndrome and Alzheimer's disease: Towards secondary prevention. *Nature Reviews Drug Discovery*, 11, 655–656.
- Norton, S., Matthews, F. E., Barnes, D. E., Yaffe, K., & Brayne, C. (2014). Potential for primary prevention of Alzheimer's disease: An analysis of population-based data. *Lancet Neurology*, 13, 788–794. doi: 10.1016/S1474-4422(14)70136-X
- Prasher, V. P. (2005). *Alzheimer's disease and dementia in Down's syndrome and intellectual disabilities*. Oxford, UK: Radcliffe Publishing.
- Public Health Planning. (2012). Public health planning for dementia must start now. *The Lancet Neurology*, 11(6), 477. doi:10.1016/S1474-4422(12)70120-5
- Rafii, M. (2013). *The Alzheimer's disease Down syndrome connection*. Retrieved from [http://www.adcs.org/research/eNewsletter/ADIN\\_E-Newsletter\\_March\\_2013.pdf](http://www.adcs.org/research/eNewsletter/ADIN_E-Newsletter_March_2013.pdf)
- Rosow, K., Holzapfel, A., Karlawish, J.H., Baumgart, M., Bain, L.J. & Khachaturian, A.S. (2011). Countrywide strategic plans on Alzheimer's disease: Developing the framework for the international battle against Alzheimer's disease. *Alzheimers & Dementia*, 7(6), 615–621. doi: 10.1016/j.jalz.2011.09.226.
- Schupf, N. (2002). Genetic and host factors for dementia in Down's syndrome. *British Journal of Psychiatry*, 180, 404–410. doi: 10.1192/bjp.180.5.405
- Verba, S., Schlozman, K. L., & Brady, H. E. (1995). *Voice and equality: Civic volunteerism in American politics*. Cambridge, MA: Harvard University Press.
- Watchman, K. (2014). *Intellectual disability and dementia: Research into practice*. London, UK: Jessica Kingsley.

- Wilkinson, H. A., & Janicki, M. P. (2002). The Edinburgh principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46, 279–284.
- World Health Organization (WHO). (2012). *Dementia: A public health priority*. Geneva, Switzerland: Author. Retrieved from [http://www.who.int/mental\\_health/publications/dementia\\_report\\_2012/en/index.html](http://www.who.int/mental_health/publications/dementia_report_2012/en/index.html)
- Wortmann, M. (2013). Importance of national plans for Alzheimer's disease and dementia. *Alzheimer's Research & Therapy*, 5(5), 40.
- Zeilinger, E. L., Gartner, C., Maxian, S., & Weber, G. (2014). Screening for dementia: A feasibility study of the NTG-EDSD in German-language. *Journal of Applied Research in Intellectual Disabilities*, 27, 357.
- Zeilinger, E. L., Janicki, M. P., Esralew, L., & Gartner, C. (2014). Practical applications of the NTG-EDSD for screening adults with intellectual disability for dementia: A German-language version feasibility study. University of Vienna, Austria. [In Submission].
- Zigman, W., Silverman, W., & Wisniewski, H. M. (1996). Aging and Alzheimer's disease in Down syndrome: Clinical and pathological changes. *Mental Retardation and Developmental Disabilities Research Reviews*, 2, 73–79.