

The Intersection of Intellectual Disability and Dementia: Report of The International Summit on Intellectual Disability and Dementia¹

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Abstract

An International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland (October 13-14, 2016) drew individuals and representatives of numerous international and national organizations and universities with a stake in issues affecting adults with intellectual disability (ID) affected by dementia. A discussion-based consensus process was used to examine and produce a series of topical reports examining three main conceptual areas: (1) *human rights and personal resources* (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, and perspectives of persons with ID), (2) *individualized services and clinical supports* (advancing and advanced dementia, post-diagnostic supports, community supports and services, dementia-capable care practice, and end-of-life care practices), and (3) *advocacy, public impact, family caregiver issues* (nomenclature/terminology, inclusion of persons with ID in national plans, and family caregiver issues). Outcomes included recommendations incorporated into a series of publications and topical summary bulletins designed to be international resources, practice guidelines, and the impetus for planning and advocacy with, and on behalf of, people with ID affected by dementia, as well as their families. The general themes of the conceptual areas are discussed and the main recommendations are associated with three primary concerns.

Introduction

Historical interest in the relationship between dementia and intellectual disability (ID), and particularly in Down syndrome, stems back to the late 1800s (Fraser & Mitchell, 1876). Interest in the neuropathological relationship intensified in the 1970s (see, for example, Holland & Oliver, 1995; Owens, Dawson, & Losin, 1971; Reid & Aungle, 1974; Wisniewski, Howe, Williams, & Wisniewski, 1978) and expanded to all forms of ID and to social care practices within ID services by the 1980s (e.g., Bauer & Shea, 1986; Newroth & Newroth, 1981). In 1996, a National Institute of Health-underwritten scientific meeting brought together international researchers interested in assessment and social care aspects (Janicki et al., 1996), followed by a 2001 meeting held in Edinburgh, Scotland, where a set of principles were promulgated outlining the rights and needs of people with ID and dementia (Wilkinson et al., 2002). These efforts reaffirmed the concerns within the ID field that dementia was a significant challenge among aging adults with ID, as many such adults were living to old age and experiencing aging-associated disorders.

For the most part, although persons with ID are affected by dementia to the same degree as other adults in the general population (Janicki & Dalton, 2000; Zigman et al., 2004), adults with Down syndrome show significantly elevated risk for dementia of the Alzheimer's type (Holland & Oliver, 1995). After age 60, about 6% of adults with ID will be affected by some form of dementia (with the percentage increasing with age) as will 50-70% of adults with Down syndrome (National Task Group, 2012). Adults with Down syndrome also show early onset dementia, (usually in the early 50s), while among adults with other ID age of onset is typically more like that of the general population. These factors, earlier onset and notable impact on ID

services, along with growing numbers of aging adults, combine to raise concerns within provider organizations and impact dementia plans (Watchman et al., 2017). With increased life expectancy and the demographic 'baby boom' effect, the resultant increasing number of aging adults with ID affected by neuropathologies has given relevance to the examination of emerging social care issues affecting this group.

Currently, some 46 million adults are projected to be affected by dementia worldwide (Alzheimer's Disease International, 2015); including an estimated 10% of older adults with ID worldwide. Although, the World Health Organization (WHO, 2012) has targeted dementia as a public health priority, adults with ID have rarely been included in national dementia planning efforts and only recently been targeted for specialized services by non-governmental or third sector organizations. The WHO recognized this deficit and included people with ID among those who should be specifically addressed by nations when designing and implementing their national dementia plans (WHO, 2012). Thus, more attention is being given to the nature of dementia and how it presents and affects adults with ID. Numerous international efforts have been undertaken to better understand the pathogenesis of various dementias in this group (Eunice Kennedy Shriver National Institute, 2014; NIH, 2015; T21RS, 2015), as well as explore best practices in social care of those adults affected (Wilkinson et al., 2002).

~~This was~~ The goal of a recent meeting, held in Glasgow, Scotland, ~~that examined and reported~~ was to examine and report on the state of the science on several under-researched or nuanced topics germane to dementia and ID, including defining advanced dementia and end of life care, structures for post-diagnostic supports, family caregiver needs and supports, proactive planning, and subjective perspectives on care and impact of dementia. The outputs of this

International Summit on Intellectual Disability and Dementia were designed to be useful to practitioners, service planners, advocates, and governmental and **non-governmental** or third sector organizations, and to influence the next generation of research endeavors. The WHO (2017a) definition of ID applied to the discussions: “... means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence) [which] results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.” This paper is a summative report of the Summit which encapsulates the key discourse areas and outcomes of the discussions and summarizes the key recommendations that may affect public policy, clinical practice, and research, as well as drive content for such future meetings.

The 2016 International Summit on Intellectual Disability and Dementia

The 2016 Summit process used an advance preparation and on-site discussion-based model, with the goal of producing individual topic reports and a summative report, encapsulating issues discussed and recommendations derived (see Watchman et al., 2017, for the full summit report). Three broad topic areas were examined, including (1) *Human rights and personal resources* (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, and perspectives of persons with ID), (2) *Individualized services and clinical supports* (advancing and advanced dementia, post-diagnostic supports, community supports and services, dementia-capable care practice, and end-of-life care practices), and (3) *Advocacy, public impact, and family caregiver issues* (Nomenclature/terminology and the use of language, inclusion of persons with ID in national plans, and support

for family caregivers). What follows is a **précis summary** of each of the conceptual areas, their main findings or consensus outputs, and recommendations (see Table 1).

Insert table 1 about here

Human Rights and Personal Resources

Human Rights and the Convention for Rights of Persons with Disabilities. People with ID fall within the framework of ‘disability’ as adopted by the United Nations Convention of Rights for Persons with Disabilities (CRPD) and thus are entitled to certain rights irrespective whether dementia is also present. Currently, the movement among some dementia advocates to have dementia also fall within this framework (Shakespeare et al., 2017) has received support in the WHO’s *Global Action Plan on The Public Health Response to Dementia* (WHO, 2017b). However, there remains the question of the value of a ‘dual designation’ under the CRPD for adults with ID and whether the dementia advocacy sector would also accept persons with *life-long* cognitive impairments as part of their efforts. There is also a question of how much cross-cultivation occurs between the two systems. Within the ID sector there is a call for a greater cross-over and shared learning between ID and dementia care services, as such a unified approach has the potential to offer more options for dealing with dementia-related issues facing people with ID, but it may also lead to multiple discriminations or greater stigma. It was proposed that this issue warrants further enquiry and additional dialogue among international advocacy organizations. Three general recommendations (See Table 1, Section A.1) supporting a human rights approach to self-determination when a person with ID is

affected by dementia and supporting increased dialogue and cooperation among the ID services, dementia advocacy, and dementia care sectors were proffered.

Perspectives of Persons with Intellectual Disability. Persons with ID have a history of exclusion and marginalization and often their wishes or wants are not considered in formative decision making. Without firsthand knowledge drawn from persons with ID, adverse decisions may be made on their behalf and there may be tensions over who is the primary decision maker: the person with ID, the parent or caregiver, or a professional who may be tangentially involved. Another factor is the legal framework that defines entitled decision-making. Although a cultural change has taken place in ID services over the years, some of this change has not occurred in situations when dementia is present. The perspectives of people with dementia in general are known because of their increasing self-advocacy, but the dearth of such perspectives in people with ID limits understanding of their experience of dementia, leading to an overreliance on proxy reporting. Even though there has been a rise in self-advocacy by individuals and organizations, the perspectives of persons with dementia have not been universally recognized or gathered – absent also are research data on this topic (see Watchman et al., 2017). Insufficiencies and difficulties related to undertaking research with people with dementia in general have been noted (Gove et al., 2017); similar problems exist within research in ID. A further constraint on exacting such research is the position of some institutional review boards that persons with ID are incapable of participating in research and thus create consent barriers that stymie such research. We suggested remedies for such exclusion and barriers, citing three main recommendations (See Table 1, Section A.2) that called for more research on care determination situations, greater involvement of self-advocacy

groups in dialogues with providers, and an increased effort on breaking down bias by research and ethics review boards on using persons with ID as informants.

Individualized Services and Clinical Supports

Advanced Dementia. Knowing when advanced dementia is present is necessary as care needs and responses will differ from those present in earlier stage care and reflect services more associated with end-of-life. Diagnosing advanced dementia in people with ID is often more complex than in the general population due to varying levels of pre-existing intellectual impairment and increased presence of health conditions or behaviors which often mimic symptoms of advanced dementia (see McCallion et al., 2017). Also, care environments or care relationships may differ and staff or family caregivers need to be responsive to these changes as dementia progresses. With the transition to advanced dementia, program changes and care adaptations may require preparation for end-of-life – including initiation of hospice, and palliative care if this has not already been begun. Further, as current instruments to identify progression of dementia in use with the general population may offer false positives due to the nature of ID, assessment may be difficult if using existing instruments. Thus, specialized instruments are needed as is research on ascertaining advanced dementia. Further, specialized training for staff that raises awareness of the signs of progression into this latter stage and care protocols augmented to reflect adaptations in care are also needed. We offered three main recommendations (see Table 1, Section B.1) directed at supporting continued assessment for changes in disease progression, encouraging research directed at identifying more sensitive clinical tools for identifying progression to late stage dementia, and developing training in and practice guidelines for care practices with advanced dementia.

Insert Table 2 about here

Post-Diagnostic Support. The nature and type of dementia-related supports following diagnosis for adults with ID often are similar to those in the general population, with some variations. **Post-diagnostic support (PDS)** should start with sharing the diagnosis, or talking about health changes if this is more appropriate, facilitating inclusion in making decisions about future support and care, and generally tailoring supports to the situation of each individual and the nature of the ID (see Dodd et al., 2017). We defined the post-diagnostic supports ~~(PDS)~~ timeline as the period from the point where the diagnosis is confirmed to when the person reaches end-of-life and adopted a working model of PDS that could be applied to specifically to people with ID and dementia and their caregivers/support staff (see Table 2.) The model follows the trajectories of dementia and posits interventions and supports in accord with noted changes, declines, and needs. We recognized that there is limited research evidence for interventions (whether pharmacological or non-pharmacological) for adults with ID affected by dementia, but supported continued use of practices that **had clinical utility worked** - a position consistent with other organizations concerned with dementia. We also recognized the need to identify more fully the nature of and interventions for idiosyncratic behavioral and psychological symptoms of dementia (BPSD). Three main recommendations (see Table 1, Section B.2), including studying the effectiveness of different non-pharmacological interventions and their effects on caregivers and support staff, as well as researching the prevalence and nature of BPSD in adults with ID who develop dementia were proffered.

Community Dementia Capable Supports. Housing and supports for people with ID often differ from those used by adults with dementia in the general population – and mostly

are an extension of specialty options available to younger age adults. Typical places of care for adults with ID may differ widely across the world, based on historic or general societal practice, ranging from living independently or with families, or under supervision in varied size community accommodations, or in large congregate care facilities. We recognized that positive supports, environmental adaptation, response to individualized needs, a focus on quality of care, person-centered approaches, and community integration should be possible regardless of the accommodation setting, along with a requirement for staff proficiency and ongoing training. Yet, barriers exist; ID social care staff may be unfamiliar with dementia, unsure how to adapt services, lack confidence or capacity to support the individual as dementia progresses, or are stymied by financial restrictions on providing the nature of care required for persons with ID affected by dementia. Referral and transfer to inappropriate options (often to nursing care facilities) may be initiated, disrupting established routines and social relationships, as well as affecting a loss of a familiar environment and compromise of meaningful relationships involving proximate family members and other invested friends. Such moves may be due to ill-conceived governmental policies, at times enacted because of reductions in funding for community-based social care. Accessing dementia capable/adapted community services are often more difficult for persons with ID and dementia due to limited options for dementia-capable care and disengagement from friends and family. Consequently, we called upon adoption of public policies that recognize the value and rights of persons with dementia to live in settings that are best suited for dementia supports and proposed that community care systems need to provide a range of dementia capable living settings which support activities that promote dignity and autonomy. We recognized the need to have standards of care and protocols for dealing with

progressive dementia in care settings and called for the adoption of practices that enhance program operations, staff capabilities, and have a positive effect on outcomes of care. We proposed three main recommendations (see Table 1, Section B.3), including the development of standards of care for community based services that provide housing and other supports for persons with ID and dementia, the promotion of dementia capable living environments in all places called ‘home’, and prevention of arbitrary changes in residence via fiat by government authorities.

End of Life Care. There are unique considerations when progressive dementia is the main factor in the last days of life for a person with an ID. While physical care can be standardized and focus on pain management, comfort, and relief from coincident conditions, care practices may need to be tailored to the adults and their situation (see McCarron et al., 2017a, b; Service et al., 2017). We recognized that palliative and hospice services often do not receive referrals proportionate to the numbers of people with ID, but also recognized the value of involving available palliative/hospice services and suggested that agreements be arranged among these services and ID service providers and families to increase their use. The nature of ‘active support’ in end-of-life needs to be clarified and providers enabled to provide sympathetic services by regulators even if they vary from the call to ‘maximize optimal functioning’. With the advent of death, person-centered approaches that have improved lives of adults with ID still should be applied. Additionally, advanced care planning remains an area for development in some countries and systems due to varying views of latter life rituals as well as consent and legal status enabling planning. Providers need to involve adults with ID in planning, even though different levels of ID may influence their ability to understand and

participate in this activity. We proposed three main recommendations related to this issue (see Table 1, section B.4) which include creating a universal practice guideline on end-of-life supports, encouraging the use of such supports for end-of-life care in home settings, and recognizing variations in what 'home' may be like with respect to end-of-life care.

Advocacy, Public Impact, and Family Caregiver Issues

Nomenclature and the Use of Language. As in research on dementia in the general population, language usage on ID and dementia often lacks precision (see Janicki et al., 2017). Clinical or medical research work related to ID and dementia mostly contains structured definitions of dementia or related terms; however, social care work tends toward less precise term usage. This imprecision is due to a lack of understanding of the distinction in the different types of dementia, inconsistent use of language, and/or the result of an absence of agreed core methods and criteria in diagnosis. We believe that terminology standardization should be the norm in studies/reports on dementia and ID and efforts be undertaken to promote a familiarity with dementia-related diagnostic, condition-specific, and social care terms. Guidance documents should be produced that help structure accurate definitions and presentations of information about individuals or groups referenced. Consistency in terminology can aid in harmonizing protocols and cross-study communications of procedures and results. We recommended that research data should note subjects' ages, sex, level of ID, residential situation, basis for dementia diagnosis, presence of Down syndrome (or other risk conditions), years from diagnosis, and if available, scores on objective measures of changing function. Also, as language usage reflects attitudes or biases, descriptive terms used to describe persons affected by dementia need to be measured so as to not stigmatize. We proposed three main

recommendations (see Table 1, Section C.1) which included adopting a standardized list of terms for general use by providers and researchers, standardizing reporting to include key demographic and subject factors, and promoting positive imagery via non-stigmatizing language.

Inclusion in National Dementia Plans and Strategies. The World Health Organization has called for the development and adoption of national plans or strategies to guide public policy and set goals for services, supports, and research related to dementia; this involves including distinct populations, including adults with ID. We proposed that national and sub-national dementia plans or strategies should include specifics of issues, needs, and responses to support adults with ID, and such inclusion must go beyond just description and noting relevance (see Watchman et al., 2017). To support plan development, governments should provide relevant statistics related to people with ID, their distribution and demographics, and any supportive information related to dementia. Also, persons with ID should be included in plan development consultation processes and greater involvement should be sought from national organizations on behalf of families. Planning considerations include provision of safe adapted housing, continued engagement, and safety monitoring, as well as assistance with personal care, the nature of which will be dependent upon the degree of ability experienced by the adult. Planning authorities should actively engage adults with ID in any documents produced to consider how concepts are expressed to promote awareness of dementia, and to help with planning service provision and allocating resources. We thus proposed three recommendations (see Table 1, Section C.2) to address these ends, such as including adults with ID in processes that create national plans, advocating that governments provide supportive data related to ID

for plan development, and involving self-advocates in the development or review of policy documents and plans.

Family Caregivers. Families are the primary source of housing and supports for many adults with ID. The onset of dementia may create new challenges for families due to cognitive decline and behavioral changes and losses in self-care abilities; consequently, many family members are unsure of what supports may be available or how to access information that is needed, particularly as dementia progresses (see Jokinen et al., 2017). Many such caregivers, usually parents, siblings, or other kin, may be challenged as to how to best cope with care demands that are continually changing and with local dementia care providers that are unprepared for advising on the care needs of adults with ID and dementia. Many home-based supports are already complex, and are complicated by new demands in providing increased care following a diagnosis of dementia. Core needs often focus on better information, relief from constant caregiving, medical advice on trajectories, and help with managing BPSD and daily care challenges. Debates exist on how to best adapt typical family supports for dementia-capable care and how inter-system collaborations might be leveraged to ensure that supports can be accessed throughout the course of dementia alongside the ‘typical’ aging of adults with ID – much of this is dependent upon local practices and service availability. Providers and others need to be aware of family caregiver needs and offer supports that can sustain caregiving or failing that, alternative care planning. We thus proposed three main recommendations (see Table 1, Section C.3) which included a focus on providing useful supports to families tailored to the family’s values, beliefs, ethnicity, and circumstances, helping with planning so that families

can decide best courses of actions, and enabling means of stress reduction to mitigate the negative aspects of caregiving.

Commentary

The 2016 Summit joins a succession of research and public policy convenings held over the past 30 years that explored issues related to dementia among adults with ID, each with a progressively nuanced agenda and contributions. The significance of this effort is marked by its timeliness, depth of discussions around currently relevant issues, its productivity, and its strategy of dissemination of outputs via reports, policy documents, and peer-reviewed publications easily accessible via the Internet, representing a diversity of topics relevant to workers in ID, aging, geriatrics, dementia, and social care, which can influence national planning, public policy, services development, and research.

The learning points from this exercise show us that while there is a common component to dementia and dementia care, specialty factors do come into play with respect to ID – and thus the exercise employed by this Summit can be applied to many other marginalized populations where dementia is a concern. Given the increases in the expected numbers of persons with ID affected by dementia over the coming years, the information gleaned from the Summit will have broad applications and expectations are that it will stimulate more conversations, a greater public policy reflection, and an uptick of interest in nuanced research. Some key public policy implications that can be gleaned from this exercise include more attention to groups of persons with a high risk for dementia, inclusion of significant ‘target’ groups within national planning for dementia, and careful reviews of extant program and

services to determine what barriers may be present for continued community living when dementia is present. We noted a need for a greater focus on training and education of personnel who work with people affected by dementia, increased and better communication with people who have ID and are affected by dementia, and the creation of viable options for community care of persons with dementia.

The Summit discussions revealed that dementia related information and technology in ID is growing, yet is still incomplete. It was evident from the discussions at the Summit that new areas of inquiries are constantly emerging and warrant additional convenings. Noted also was that although countries are working under different health and social systems and have different cultures and family life expectations, there is commonality in the need for common information and a highly trained workforce to ensure that the best possible supports are provided wherever persons with ID and dementia call home. The Summit was a productive exercise and should add value to the literature on dementia and ID, and aid in substantiating the need to include people with ID in dementia plans, services development, and research.

References

Alzheimer's Disease International. (2015). *World Alzheimer Report 2015: The global impact of dementia an analysis of prevalence, incidence, cost and trend*. Accessed from <https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf>

Bauer, A.M., & Shea, T.M. (1986). Alzheimer's disease and Down syndrome: A review and implications for adult services. *Education and Training of the Mentally Retarded*, 21(2), 144-150.

Report of the Intellectual Disability & Dementia Summit

Dodd, K., Watchman, K., Janicki, M.P., Coppus, A., Gaertner, C., Fortea, J., Santos, F.H., Keller, S.M., & Strydom, A. and the Post-Diagnostic Supports Working Group. (2017, in press). Consensus statement of the International Summit on Intellectual Disability and Dementia related to post-diagnostic support. *Aging and Mental Health*.

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). (2014). Down syndrome research plan revision promotes study of aging. Accessed from: https://www.nichd.nih.gov/about/overview/directors_corner/prev_updates/Pages/031914-down-syndrome.aspx.

Gove, D., Diaz-Ponce, A., Georges, H., Moniz-Cook, E., Mountain, G., Chattat, R., Øksnebjerg, L., & The European Working Group of People with Dementia. (2017). Alzheimer Europe's position on involving people with dementia in research through PPI (patient and public involvement). *Aging and Mental Health*, 17, 1-7. Epub ahead of print: 2017 May 17; doi: 10.1080/13607863.2017.1317334.

Holland A.J. & Oliver, C. (1995). Down's syndrome and the links with Alzheimer's disease. *Journal of Neurology, Neurosurgery, and Psychiatry*, 59(2), 111–114.

Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability service. *Mental Retardation*, 38(3), 276-288.

Janicki, M.P., McCallion, P., Splaine, M., Santos, F.H., Keller, S.M., & Watchman, K. (2017, In press). Consensus statement of the International Summit on Intellectual Disability and Dementia related to nomenclature. *Intellectual and Developmental Disabilities*.

Report of the Intellectual Disability & Dementia Summit

Jokinen, N.S., Gomiero, T., Hogan, M., Larsen, F., Beránková, A., Santos, F.H., Watchman, K.,

Janicki, M.P., Crow, J. (2017, in submission). Challenges and perspectives in the caregiving of ageing people with intellectual disability affected by dementia:

Commentary from the International Summit on Intellectual Disability and Dementia.

McCallion, P. Hogan, M., Santos, F H., McCarron, M., Service, K., Stemp, S., Keller, S., Fortea, J.,

Bishop, K., Watchman, K., Janicki, M.P. and the Working Group of the International

Summit on Intellectual Disability and Dementia. (2017). Consensus statement of the

international summit on intellectual disability and dementia related to end-of-life care in advanced dementia. *Journal of Applied Research in Intellectual Disability*. Epub ahead of

print: 9 May 2017; DOI: 10.1111/jar.12349

McCarron, M., McCallion, P., Watchman, K., Janicki, M.P., Coppus, A., Service, K., Fortea, J.,

Hogan, M., Reilly, E., & Stemp, S. (2017a; in submission). Quality care for people with intellectual disability and advanced dementia: guidance on service provision.

McCarron, M., Stemp, S., Coppus, A., Fortea, J., Janicki, M.P., Reilly, E., Watchman, K.,

McCallion, P. and the Summit Working Group on Advanced Dementia. (2017b; in

submission). Defining advanced dementia in people with Down syndrome and other

intellectual disabilities: consensus statement of the International Summit on Intellectual Disability and Dementia.

National Institute of Health. (2015). *NIH supports new studies to find Alzheimer's biomarkers in*

Down syndrome. Accessed from: nih.gov/news-events/news-releases/nih-supports-new-studies-find-alzheimers-biomarkers-down-syndrome

National Task Group on Intellectual Disabilities and Dementia Practice. (2012). *'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*. Accessed from www.aadmd.org/ntg/thinker

Newroth, S., & Newroth, A. (1981). *Coping with Alzheimer disease: a growing concern*. Downsview: Ontario: National Institute on Mental Retardation.

Owens D., Dawson J. C., Losin S. (1971). Alzheimer's disease in Down's Syndrome. *American Journal of Mental Deficiency*, 75(5), 606–612

Reid A. H., Aungle P. G. (1974). Dementia in ageing mental defectives: A clinical psychiatric study. *Journal of Mental Deficiency Research*, 18(1), 15–23.

Service, K.P., Hogan, M., Janicki, M.P., Cadovius, N., Watchman, K., & Beránková, A. (2017). Dying well with an intellectual disability and dementia. *Journal of Dementia Care*, 25(4), 22-25.

Trisomy 21 Research Society (T21RS). (2015). *1st International Conference of the Trisomy 21 Research Society*. Accessed from: http://www.t21rs.org/uploads/2015%20conference/Programme_T21RS_IC_Paris2015.pdf

Watchman, K., Janicki, M. & members of the International Summit on Intellectual Disability and Dementia. (2017). Summative report of the International Summit on Intellectual

Report of the Intellectual Disability & Dementia Summit

Disability and Dementia. Accessed from:

<http://www.learningdisabilityanddementia.org/id-dementia-summit.html>

Watchman, K., Janicki, M.P., Splaine, M., Larsen, F.K., Gomiero, T., & Lucchino, R. (2017).

International summit consensus statement: Intellectual disability inclusion in national dementia plans. *American Journal of Alzheimer's Disease and Other Dementias*, **32(4)**, 230-237.

Wilkinson, H., & Janicki, M.P., & Edinburgh Working Group on Dementia Care Practices

(EWGDCP). (2002). The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46(3), 279-284

Wisniewski K., Howe J., Williams D. G., Wisniewski H. M. (1978). Precocious aging and dementia in patients with Down's Syndrome. *Biological Psychiatry*, 13(5), 619–627.

World Health Organization (WHO). (2012). *Dementia: A public health priority*. Geneva, Switzerland: World Health Organization and Alzheimer's Disease International.

World Health Organization (WHO). (2017a). Definition: Intellectual disability. Accessed from:

<http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability>

World Health Organization (WHO). (2017b). *Draft global action plan on the public health response to dementia*. Accessed from:

http://www.who.int/mental_health/neurology/dementia/action_plan_consultation/en/

Zigman, W.B., Schupf, N., Devenny, D., Mizejeski, C., Ryan, R., Urv, T.K., Schubert, R., & Silverman, W. (2004). Incidence and prevalence of dementia in elderly adults with mental retardation without Down syndrome. *American Journal on Mental Retardation*, 109(2), 126-141.

Table 1: Key Recommendations from Summit by Area of Focus

| Area of focus | Recommendations | | |
|--|---|--|---|
| A. Human Rights and Personal Resources | Recommendation 1 | Recommendation 2 | Recommendation 3 |
| <i>A.1 Human Rights</i> | Promote consistency with the Convention of the Rights of Persons with Disabilities (CRPD) by enabling persons with ID affected by dementia to be able to continue to exercise their rights and to choose where and with whom to live. | Request that all nations review laws and policies and replace regimes of substitute decision-making by supported decision-making, which respects an individual’s autonomy, will, and preferences. | Request that intellectual disability organizations engage in greater advocacy on behalf of their members with ID and dementia, and that such organizations liaise with dementia organizations to share an advocacy role for families. |
| <i>A.2 Perspectives of person with intellectual disability</i> | Support ID self-advocacy groups to widen their reach to ensure perspectives of people who also have, or affected by, dementia are heard in policy or organizational review, using the model followed by dementia self-advocacy groups for ongoing development, discussion or collaboration. | Establish an international review group to examine the barriers to inclusion in research studies posed by research and ethics review boards that do not actively support the presence and perspectives of participants with ID and pose recommendations of solutions for international adoption. | Conduct research to better understand and address issues experienced by people with ID who find themselves providing support to someone else with dementia, typically either a parent in a family home context or a peer in a group home environment. |
| B. Individualized Services and Clinical Supports | Recommendation 1 | Recommendation 2 | Recommendation 3 |
| <i>B.1 Advanced Dementia</i> | Continue attention to systematic baseline screening, assessment and follow up of people with Down syndrome and other ID using agreed upon standardized instruments. | Undertake research to develop more valid and reliable instruments for assessing advanced dementia-related cognitive and physical deterioration among adults with ID, including adults with Down syndrome. | Develop practice guidelines and provide widespread related training and education to support quality care when adults with ID have advanced dementia. |
| <i>B.2 Post-Diagnostic Supports</i> | Examine the effectiveness of different non-pharmacological interventions, both singly and in combination, on the quality of life for people with ID and dementia. | Examine the effects on caregivers and support staff of different models of support after diagnosis, in particular looking at issues such as resilience, emotional labor, and staff turnover. | Examine the prevalence and nature of behavioral and psychiatric symptoms of dementia in adults with ID, and whether there is a difference in prevalence and nature related to the cause of the person’s ID or by the type of dementia. |

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| <i>B.3 Community Dementia Capable Supports</i> | Develop standards of care and organizational policy for community based services that provide housing and other supports for persons with ID and dementia and encourage their application across provision sectors. | Recognize that flexibility in supports and services is essential; service providers need to develop appropriate and least intrusive dementia capable settings that accommodate individual needs wherever the person lives, and are cognizant of the differences among jurisdictions as to funding systems and living circumstances. | Protect policies that prevent residential movement of adults with ID with dementia by fiat or for budgetary convenience, rather than for purposive therapeutic or personal- choice derived reasons. |
| <i>B.4 End-of-Life Supports</i> | Collaborate by ID, dementia, and palliative care organizations and associations to create a universal practice guideline on end - stage care and support practices for persons with ID and advanced dementia | Recognize that for family members, having a caring role did not begin with the onset of dementia, it has been lifelong; recognition and support for this should be provided when the person with ID is dying. | Promote the notion that ‘home’ as place of death may differ, ranging from a natural family home, a community-based accommodation, or other out-of-home setting, and that it need not be a health-care facility. |
| C. Advocacy, Public Impact, and Caregiver Issues | Recommendation 1 | Recommendation 2 | Recommendation 3 |
| <i>C.1 Nomenclature</i> | Promote a common understanding of the meaning of terms used to describe services and conditions related to dementia and ID, and adopt a standardized list or taxonomy for general use by providers and researchers. | Standardize reporting so as to harmonize data that address different types of dementia, behavioral and functional changes, and cognitive decline or impairment; in reports (whether research or practice) use recommended definitions and at a minimum include the subjects’ ages, sex, level of ID, residential situation, co-morbidities, basis for dementia diagnosis, presence of Down syndrome (or other risk condition), years from diagnosis, and if available, scores on an objective measure of changing function from a recognized and validated dementia scale. | Promote positive imagery so that organizations, researchers, educators, and practitioners can adopt image enhancing language when describing persons with ID affected by dementia and avoiding language that stigmatizes. |
| <i>C.2 Inclusion in National Plans and Strategies</i> | Ensure that forums, meetings, and consultations held in advance of national plans being developed or modified include appropriate representation by persons with ID and dementia or their advocates; such forums, meetings and consultations should include alternate and accessible methods of communication as required to ensure inclusion | Draw into the process, government representatives who are requested to provide demographic, service utilization, and financial data related to ID (including Down syndrome) for use in the plan and that discussions be held at a policy level to determine what laws or existing policies may need to be instituted or altered/updated to | Involve self-advocates or persons authorized to speak on behalf of adults with an ID, in the development or review of documents produced related to a national dementia strategy or plan and make available the documents in accessible formats. |

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| | of people with ID and their families or advocates | facilitate the inclusion of ID in national dementia strategies or plans. | |
| C.3 Family Caregivers | Ensure that effective supports offered to families are timely, appropriate, and tailored to the individual family’s values, beliefs, ethnicity, and circumstances. | Aid caregivers in establishing stepped plans to manage every single phase of dementia as a degenerative disease, including the possibility to have to decide about sharing the caregiver activity with others, if necessary. | Enable caregivers to strengthen their capacities for caregiving by learning strategies to minimize stress and managing other negative effects of long-term caregiving that may have on physical and mental health. |

ID: intellectual disability

Table 2: Post-diagnostic supports for persons with ID affected by dementia

| Stage in relation to diagnosis | Key factors in implementing PDS model |
|--------------------------------|--|
| Immediately post-diagnosis | <ul style="list-style-type: none"> • Post-diagnostic counselling/ support and education offered to the person and caregivers/ support staff to help empower them to deal with the condition in the most optimal way related to the diagnosis, its implications, and the probable course/trajectory. • Early identification of behavioral and psychological symptoms of dementia in the individual and reviews of care practices and supports undertaken when such symptoms are present. |
| Ongoing | <ul style="list-style-type: none"> • Periodic, but regular and planned, reviews undertaken of the person’s program / care plan to identify significant changes in health, function and quality of life, and adjustments made in activities and care practices to ensure that the person continues to receive quality person-centered care. • Supports and education offered to caregivers/support staff on an ongoing basis, from both specialist and mainstream services, with continuing provision of information. • Quality of life evaluations at regular intervals from both the perspective of the person with ID and their proxies, across the course of the person’s journey. • Psychological and medical surveillance carried out throughout the course of decline to address dementia-related needs and conditions (e.g., seizures in Down syndrome) and non-dementia comorbid conditions, irrespective of whether they impact directly on the course of dementia. |
| Advanced dementia | <ul style="list-style-type: none"> • Reviews undertaken of care practices and supports provided when advanced dementia is reached and when the condition of the individual changes and there is a presumption of approaching death. |

Source: Dodd et al., 2017; ID: