

# REPORT OF THE INTERNATIONAL SUMMIT ON INTELLECTUAL DISABILITY AND DEMENTIA



# Report of the International Summit on Intellectual Disability and Dementia

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**Note:**

This summative report with recommendations was developed as an output from the 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland, 13-14 October 2016, and hosted by the University of Stirling and University of the West of Scotland, funded by the RS MacDonald Trust, the Scottish Government, and Alzheimer Scotland. Collaborating sponsors included the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States and the University of Illinois at Chicago. The Summit was co-chaired by Karen Watchman, Ph.D., and Matthew P. Janicki, Ph.D., and composed of individuals and representatives of many international and national organizations, with a stake in issues related to adults with intellectual disability affected by dementia. The contents of this statement were partially developed under a grant from the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT5020-03-00. However, those contents do not necessarily represent the policy of the US Department of Health and Human Services, nor the endorsement by the US Federal Government. The opinions expressed represent those of the Summit participants and of the NTG.

**Suggested citation:**

Watchman, K., Janicki, M. & members of the International Summit on Intellectual Disability and Dementia, (June, 2017). Report of the International Summit on Intellectual Disability and Dementia. Accessed from: <http://www.learningdisabilityanddementia.org/id-dementia-summit.html>

Date of publication: June 2017, version 1.0

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## INTRODUCTION

The International Summit on Intellectual Disability and Dementia held in Glasgow, Scotland (October 13-14, 2016) was hosted by the University of Stirling and co-sponsored by National Task Group on Intellectual Disabilities and Dementia Practices (NTG). Participants were individuals and representatives of numerous international and national organizations and universities with a stake in issues related to adults with intellectual disability affected by dementia. The summit's process was a discussion-based consensus dialogue designed to produce individual and summative reports examining notable issues, along with recommendations for public policy, practice, and further research. The issue topics encompassed 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 intellectual disability), (2) individualized services and clinical supports (advancing and advanced dementia, post-diagnostic support community, dementia-capable care practice, and end-of-life care practices), and (3) advocacy, public impact, family caregiver issues (nomenclature/terminology, inclusion of persons with Intellectual disability in national plans, and family caregiver issues). Outcomes, including published papers and topical summary bulletins have been produced and disseminated. The outputs were designed to be international resources, guidance for practice, and the impetus for planning and advocacy with, and on behalf of, people with intellectual disability affected by dementia, as well as their families.

## BACKGROUND

Many nations are continuing to experience significant increases in the proportion of aging persons in their populations along with corresponding increases in the prevalence and incidence of aging-related conditions, including dementia stemming from neurodegenerative diseases such as Alzheimer's disease. These demographics and disease factors apply also to aging adults with lifelong intellectual disability. Currently, some 46 million adults are projected to be affected by dementia worldwide (Alzheimer's Disease International, 2015); including an estimated 225,000 older adults with an intellectual disability (ADI, 2003). Due to their high risk for Alzheimer's disease, adults with Down syndrome represent a significant segment of these adults who may be affected. Adults with Down syndrome also tend to have early-age onset dementia and experience shorter disease trajectories. Notwithstanding, adults with intellectual disability have rarely been included in national dementia planning efforts and only recently been targeted for specialized services by third sector organizations. The WHO recognized these factors and included people with intellectual disability among those who should be specifically addressed by nations when designing and implementing their national dementia plans (WHO, 2012). Given this, more attention is now being given to the nature of dementia and how it presents and affects adults with intellectual disability.

Historical interest in the relationship between dementia and intellectual disability, and particularly in Down syndrome, dates back to 1876 when the first article appeared discussing "pre-senile dementia" in adults with Down syndrome (Fraser & Mitchell, 1876). Interest re-

emerged following an article that appeared in 1948, which discussed three cases of adults with Down syndrome showing symptoms of Alzheimer's disease (Jervis, 1948). However, it wasn't until the 1970s, when progressively more articles began to appear noting the genetic relationship between Alzheimer's and Down syndrome (see, for example, Holland & Oliver, 1995; Owens, Dawson, & Losin, 1971; Reid & Aungle, 1974; Wisniewski, Howe, Williams, & Wisniewski, 1978; Zigman et al., 2008), that interest expanded and became more marked. While articles on this topic stimulated progressively more nuanced research into the brain neuropathology of persons with Down syndrome (with application to Alzheimer's in general), issues related to dementia among persons with other etiologies of intellectual disability and the area of social care only began to be more fully explored in the 1980s.

By the 1990s there was sufficient critical mass of interest in the non-biologic aspects to lead researchers concerned with dementia and intellectual disability to converge and exchange information. This led to the convening in 1996 of a National Institute of Health (NIH)-underwritten scientific meeting in Minneapolis, Minnesota, of international researchers interested in epidemiological, assessment, and social care aspects. The meeting was held in association with an international Alzheimer's conference (one of the early iterations of the current Alzheimer Association International Conference [AAIC]) and it focused on the state of the science in assessment, epidemiology, and community care. The resulting outputs included consensus publications as well as the formation of an informal international network of researchers interested in the clinical and social care aspects of intellectual disability and dementia. Three papers emanated from the meeting focusing on practice guidelines (Janicki et al. 1996), epidemiology (Zigman et al., 1996), and research and assessment protocols and instruments (Alyward et al., 1996).

Research into the biological and genetic basis of Alzheimer's disease and Down syndrome was progressively more sustained and provided value to the overall study of the biogenesis of Alzheimer's (Head, Powell, Gold, & Schmitt, 2012). Consequently, increasingly meetings were also bringing together researchers interested in the neuro-biology of Alzheimer's disease and Down syndrome from across the world. Such research received substantial attention primarily due to the high risk for Alzheimer's among adults with Down and has progressively branched out into a variety of areas – including the pathogenesis of Alzheimer's and discovery of biomarkers which may lead to the early identification of affected individuals. This growth of interest has been notable and included major international efforts, including a summit on Down syndrome and dementia held under auspice of the NIH in the United States (Eunice Kennedy Shriver National Institute, 2014), and scientific meetings under the auspice of a variety of groups, including the Cambridge Intellectual and Developmental Disabilities Research Group and the Royal College of Psychiatrists in the UK and the T21 Research Society (T21RS, 2015). Such meetings have sustained an interest among national funding bodies to underwrite research on Down syndrome and Alzheimer's disease, including a recently funded (by the NIH in the USA) multi-site study of biomarkers which is examining the genesis of Alzheimer's disease in persons with Down syndrome (NIH, 2015).

Concurrent international efforts to address dementia and social care issues, family caregiving concerns, and the nature and impact of dementia upon adults with intellectual

disability have also been undertaken. Social care and related issues were discussed at a 3-day meeting held in Edinburgh, Scotland, in February 2001, where participants were charged with producing a set of principles outlining the rights and needs of people with intellectual disability and dementia, and defining service practices which would enhance the care supports available to them. The outcome became the Edinburgh Principles, seven statements that structured equity in the design and support of services to people with intellectual disability affected by dementia, and their carers. An accompanying four-point approach proposed: (1) adopting a workable philosophy of care; (2) adapting practices at the point of service delivery; (3) working out the coordination of diverse systems; and (4) promoting relevant research (Wilkinson et al., 2002). In 2008, an interest group on aging attached to the International Association for the Scientific Study of Intellectual Disability met in Cape Town, South Africa, and produced several publications assessing and updating the extant research literature on caregiving (Courteney et al., 2010) and epidemiology (Strydom et al., 2010).

Subsequently, the work and interest by various sectors with respect to care and clinical practice issues had become sufficiently nuanced to justify another meeting being held. Thus, in 2016 an International summit on intellectual disability and dementia was convened in Glasgow, Scotland, with the explicit purpose of examining the state of the science in dementia and intellectual disability and producing information relevant to new findings and practices. The charge was to include under-researched or nuanced topics, such as advanced dementia and end of life care, structures for post diagnostic supports, planning issues, and subjective perspectives on care and impact of dementia. Such topics had been gaining interest and momentum in the general population, but had not yet received sufficient attention among workers or research in intellectual disability. What was needed was a synthesis of these topics and coverage in seminal publications useful for practitioners, services planners, and third sector organizations, as well as potentially influencing the next generation of research endeavors. Thus, the Summit was held to examine several cross-cutting issues facing adults with intellectual disability at risk of, or affected by dementia, as well as to review support needs and issues relevant to public policy. The aim of this paper is to provide a summative report encapsulating the key discourse areas and outcomes of that meeting and a summary of 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 used an advance preparation and on-site discussion-based model, with the goal of producing a summative report encapsulating issues discussed and recommendations derived. It was anticipated that outputs would contain recommendations for public policy and practice development, as well as a framework for future research. To obtain a variety of perspectives, Summit participants were recruited from among researchers with publications on the topic, as well as clinical practitioners and other representatives actively involved with research, policy, advocacy, or practice in dementia among persons with intellectual disability. Outreach was undertaken with numerous international organizations

with interest in this topic from both the Alzheimer's and other dementias sector (e.g., Alzheimer's Disease International; Alzheimer's Europe) and the intellectual and developmental disabilities sector (e.g., European Association of Providers for Persons with Disabilities [EASPD]; National Task Group on Intellectual Disabilities and Dementia Practices [NTG]). Academic institutions involved in this topic were also invited to send participants. In all some 32 participants were involved from Europe and North/South America; Summit participants represented numerous international and national dementia and intellectual disability non-governmental or third sector organizations, families, government officials, and academic institutions (see Appendix A for delegate list). Perspectives of persons with intellectual disability, sought in advance as the preferred option of individuals, were inserted at salient points across the two days. Funding was provided by grants from the Scottish government, Alzheimer's Scotland, private foundations, several universities and provider organizations.<sup>1</sup> The focus of the discussions was on intellectual disability as broadly defined by the WHO<sup>2</sup> (2017a) and not solely on Down syndrome.

**Meeting methodology.** Once participation had been confirmed for the two-day event, a list of discussion topics was secured and the participants were assigned *a priori* to topic workgroups. Topics chosen were those with clinical or policy ambiguity or lack of consensus in the literature. The workgroups were asked to prepare background briefs and other matter examining their topic and provide a synopsis of germane issues. They were also encouraged to develop a position, if warranted, and propose potential recommendations. The meeting in Glasgow ran for two days to enable continuing discussions and networking. Using a topic working group process, the Summit participants worked through a general discussion and examination of 10 salient issues (noted below), based upon the discussion briefs produced. These permitted a more efficient and productive discussion by Summit participants and enabled cross-cutting input and suggestions for combining recommendations.

**Discussion areas.** Working groups were assigned a number of topics, encompassed three main conceptual areas, 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 intellectual disability), (2) *Individualized services and clinical supports* (advancing and advanced dementia, post-diagnostic support community, 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 Intellectual disability in national plans, and support for family caregivers).

**Outputs.** Following the Summit, select participants volunteered to chair writing teams and to produce papers that would be used for the Summit report and would lead to publication

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<sup>1</sup> The Summit was hosted by the University of Stirling and University of the West of Scotland with funding from the RS MacDonal Trust, the Scottish Government, and Alzheimer Scotland. Collaborating sponsors included the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States and the University of Illinois at Chicago with support funding from the US National Institute on Disability, Independent Living, and Rehabilitation Research.

<sup>2</sup> Intellectual disability means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development.



submission-ready articles. This process enabled clusters of participants with similar interests to develop thematic papers delving deeply into an issue and produce recommendations for policy, practice, and/or research. These papers, once developed by a writing team, were then vetted by the Summit participants to obtain consensus on the positions taken and the recommendations derived (see Appendix B for list of publications).

### Summary of Summit Areas Discussed

The Summit's discussion topics encompassed three main conceptual areas, focusing on (a) human rights and personal resources (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, perspectives of persons with intellectual disability), (b) individualized services and clinical supports (advancing and advanced dementia, post-diagnostic support community, dementia-capable care practice, end-of-life care practices), and (c) advocacy, public impact and family caregiver issues (nomenclature/terminology and the use of language, inclusion of persons with Intellectual disability in national plans, and support for family caregivers). What follow is a précis of each of the conceptual areas, their main findings or consensus outputs, and recommendations (see Table 1).

**Table 1: Key Recommendations from Summit by Area of Focus**

Area of focus	Recommendations		
<b>A. Human Rights and Personal Resources</b>	<b>Recommendation 1</b>	<b>Recommendation 2</b>	<b>Recommendation 3</b>
<i>A.1 Human Rights</i>	Promote consistency with the Convention of the Rights of Persons with Disabilities (CRPD) by enabling persons with intellectual disability affected by dementia to be able to continue to exercise their rights and be able 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 an intellectual disability 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 intellectual disability 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 intellectual disability and pose recommendations of solutions for international adoption.	Conduct research to better understand and address issues experienced by people with intellectual disability who find themselves providing support to someone else with dementia, typically either a parent in a family home context or a peer in group home environment.
<b>B. Individualized Services and Clinical Supports</b>	<b>Recommendation 1</b>	<b>Recommendation 2</b>	<b>Recommendation 3</b>
<i>B.1 Advanced Dementia</i>	Continue attention to systematic baseline screening, assessment and follow up of people with Down syndrome and other intellectual disability using agreed standardized instruments.	Undertake research to develop more valid and reliable instruments for assessing advanced dementia-related cognitive and physical deterioration among adults with intellectual disability, including adults with Down syndrome.	Develop practice guidelines and provide widespread related training and education to support quality care when adults with an intellectual disability 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 intellectual disability and dementia.	Examine the effects on carers and support staff of different models of support after diagnosis, in particular looking at issues such as resilience, emotional labour, staff turnover.	Examine the prevalence and nature of behavioural and psychiatric symptoms of dementia in adults with intellectual disability, and whether there is a difference in prevalence and nature related to

			the cause of the person’s intellectual disability or by the type of dementia.
<b>B.3 Community Dementia Capable Supports</b>	Develop standards of care and organizational policy for community based services that provide housing and other supports for persons with intellectual disability and dementia and encourage their application across provision sectors.	Recognizing 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 be cognizant of the differences among countries concerning funding systems and living circumstances.	Recognize that a ‘care partner’ may not always be a relative. This person may be a friend or partner in which case there will be relationship implications should a move or other changes be instigated for the person with dementia.
<b>B.4 End-of-Life Supports</b>	Collaborate by intellectual disability, dementia, and palliative care organizations and associations to create a universal practice guideline on end - stage care and support practices for persons with intellectual disability 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 intellectual disability is dying and dies.	Promote the notion that ‘home’ as place of death may differ; in acknowledging variations among countries, this may be community-based with family members or friends who have their own different health or social care needs, or an out-of-home setting.
<b>C. Advocacy, Public Impact, and Caregiver Issues</b>	<b>Recommendation 1</b>	<b>Recommendation 2</b>	<b>Recommendation 3</b>
<b>C.1 Nomenclature</b>	Promote a common understanding of the meaning of terms used to describe services and conditions related to dementia and intellectual disability, and adopt a standardized list or taxonomy for general use by providers and researchers.	Standardize reporting so as to harmonize data that addresses different types of dementia, behavioural 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 intellectual disability, 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 intellectual disability affected by dementia and avoiding language that stigmatizes.
<b>C.2 Inclusion in National Plans and Strategies</b>	Ensure that forums, meetings, and consultations held in advance of national plans being developed or modified include appropriate representation by	Draw into the process, government representatives who are requested to provide demographic, services, and financial data related to	Involve self-advocates or persons authorized to speak on behalf of adults with an intellectual disability, in the development or review of documents produced

	persons with intellectual disability and dementia or their advocates; such forums, meetings and consultations should include alternate and accessible methods of communication as required to ensure inclusion of people with intellectual disability and their families or advocates	intellectual disability (and in particular 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 facilitate the inclusion of intellectual disability in national dementia strategies or plans.	related to a national dementia strategy and make available the documents in accessible formats.
<b>C.3 Family Carers</b>	Ensure that effective supports offered to families are timely, appropriate, and tailored to the individual family’s values, beliefs, ethnicity, and circumstances.	Aid carers in establishing stepped plans to manage every single phase of a dementia as a degenerative disease, including the possibility to have to decide about sharing the caregiver activity with others, if necessary.	Enable carers 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 their own physical and mental health.

## HUMAN RIGHTS AND PERSONAL RESOURCES

**Human Rights and the Convention for Rights of Persons with Disabilities.** People with intellectual disability fall within the framework of disability as adopted by the Convention of Rights for Persons with Disabilities (CRPD) and as such have certain rights. Currently, there is a movement among some dementia advocates to have dementia also fall within the framework of the CRPD and enabling these rights. The recent *Draft Global Action Plan on The Public Health Response to Dementia* (WHO, 2017b) appears to support this position by noting that “Policies, plans, legislation, programmes, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the Convention on the

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*How can provisions of the Convention for Rights of People with Disabilities be optimally utilized to support people with intellectual disability affected by dementia?*

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Rights of Persons with Disabilities and other international and regional human rights instruments.” As dementia is included among the conditions defining disability within this document; there remains a question of reciprocity, as it appears the even with such pressure for inclusion within CRPD structures (Shakespeare et al., 2017), there is

little evidence within the dementia advocacy effort that inclusion of adults with intellectual disability and dementia occurs (Mittler, 2017 [personal communication]).

Although adults with intellectual disability do fall within framework of the CRPD because of the nature of the condition, when dementia is a factor in their lives they enter a grey area. Summit participants pondered “*how can provisions of the Convention for Rights of People with Disabilities be optimally utilized to support people with intellectual disability affected by dementia?*” Now that the WHO has proposed including people with dementia among those who have a disability, the provision may apply; how it will be structured is yet to be defined. The value of a ‘dual designation’ under the CRPD was raised and it lead to a varied discourse.

At issue is whether the dementia advocacy sector would also accept persons with life-long cognitive impairments as part of their group. However, if resolved, the formal consideration of dementia as a condition under CRPD may offer adults with intellectual disability so affected with additional resources and merits further attention. There is also the issue of how much cross-cultivation occurs between the two systems. Within the intellectual disability sector there is call for a greater cross-over and shared learning between intellectual disability and dementia care services (whether within or outside of the CRPD). Such a unified approach has the potential to offer more options for dealing with the issues facing people with intellectual disability and those affected by dementia, even when this may lead to multiple discriminations or greater stigma. It was proposed that this issue warrants further enquiry and additional dialogue among international advocacy organizations.

The Summit proposed three general recommendations (See table 1, Section A.1) which would support a human rights approach to self-determination when a person with intellectual disability is affected by dementia, and proposed increased dialogue and cooperation among the intellectual disability services, dementia advocacy, and dementia care sectors.

**Perspectives of Persons with Intellectual Disability.** There is a history of exclusion and marginalization of people with intellectual disability by others and often their wishes or wants are not considered when decisions concerning them are made. Professionals, who serve as decision makers, may be fleetingly in and out of their lives and their impressions may be drawn only from what they see at that moment or are told about sporadically – which may not reflect the wishes or support needs of the individual. Without firsthand knowledge drawn from persons with an intellectual disability, decisions may be made on their behalf that may adversely affect them. Further, with respect to decision-making, there may be tensions over who is the primary person deciding: the person with intellectual disability, the parent or caregiver, or a professional who may be tangentially involved. Another influencing factor is the legal framework in the jurisdiction that may cover personal decision-making (that is, whether it encourages autonomy or stifles self-determination). In some areas, there is a legal basis for giving prominence to the voice of the person with intellectual disability, in others this basis is absent. Although a cultural change has taken place in intellectual disability services over the past years, with a range of supports, tools, and resources now available to support people and address their wants, some of this change has not risen in situations when dementia is present. The relevant question raised at the Summit, was *“What are the priority areas identified by persons with intellectual disability in relation to dementia care for themselves or their friends at different stages of dementia?”* 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 – nor does the literature provide sufficient data in this area (see Watchman et al., 2017).

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*What are the priority areas identified by persons with intellectual disability in relation to dementia care for themselves or their friends at different stages of dementia?*

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We know about the perspectives of people with dementia in general because of increasing self-advocacy among persons with dementia, but this extent of self-advocacy is not yet prevalent among people with intellectual disability and dementia or among their families (see Davis, 1999). Omission of the perspectives of persons with intellectual disability limits understanding of the experience of dementia whether the diagnosis is their own or in their peers, leading to an overreliance on proxy reporting; something considered by the Summit to be a backwards step in person-centered work. Further, as has been noted by Gove et al. (2017) about insufficiencies and difficulties related to undertaking research with people with dementia in general, a similar lack of focus exists within research on personal perspectives limits understanding of the lived experience of dementia among adults with intellectual disability. One constraint on exacting more related research is the position of some research review boards that tend to believe that persons with intellectual disability are incapable of participating in research and creating a morass of consent barriers that often stymie such research. The Summit raised concerns about these omissions.

The Summit proposed three main recommendations (See Table 1, Section A.2 ) on this topic, which call for more research to be undertaken in care determination situations to better understand and engage persons with intellectual disability so that perspectives on needs, wants, and involvement are ascertained, and the greater involvement of self-advocacy groups in dialogues with providers, and an increased effort on breaking down bias by research and ethical review boards on the involvement of people with intellectual disability and dementia as informants.

## INDIVIDUALIZED SERVICES AND CLINICAL SUPPORTS

**Advanced Dementia.** Diagnosing advanced dementia in people with intellectual disability 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 dementia (see McCallion et al., 2017). Staging of dementia in people with an intellectual disability is also more challenging as functional decline may be compressed, of shorter duration, and confounded by behavioral factors. To help get at this issue, the Summit addressed this question: *“What are the characteristics of advanced dementia in adults with intellectual disability and what are the similarities and differences from advanced dementia in adults in the general population without intellectual disability across care settings?”* Although in general clinical features of advanced dementia in people with intellectual disability are like those of the general population, there are some exceptions. Inherent features of intellectual disability may confound or mask presentation of change and loss of function. Also, among adults with Down syndrome late-onset seizures may be present and initial symptoms may differ from those with other intellectual disability and affect function trajectories.

Knowing when an individual transitions into advanced dementia is necessary as care needs and responses will differ from those present in earlier stages and call upon services more associated with end-of-life. Also, many adults with intellectual disability with advanced dementia may be in care environments or care relationship that differ from the general population and staff or family caregiver skills need to be responsive to these changing care requirements as dementia progresses. Summit participants acknowledged that the need to identify signs signaling the transition to advanced dementia and proposed a scheme for determining the transition, noting that current instruments in use with the general population may offer false positives due to nature of intellectual disability. Specialized instruments were called for along with research examining the many facets used in assessing advance dementia. Understanding this transition to advanced dementia is necessary as program changes and care adaptations may be in order and may need to reflect different regimens of personal care and preparation for end-of-life – including initiation of palliative care (if this has not begun at point of diagnosis as is recommended by the World Health Organization (2017c), or involving hospice. 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 was suggested.

*What are the characteristics of advanced dementia in adults with intellectual disability and what are the similarities and differences from advanced dementia in adults in the general population without intellectual disability across care settings?*

The Summit proposed 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 practice guidelines for care practices with advanced dementia.

**Post-Diagnostic Support.** Differences in policies and practices exist among countries regarding what constitutes the post-diagnostic period and debates as to the value of pharmacological versus non-pharmacological supports for dementia. The Summit defined the post-diagnostic support timeline as the period from the point where the diagnosis is confirmed to when the person reaches end of life (see Dodd et al., 2017). Post diagnostic supports (PDS) should start with sharing the diagnosis, or talking about health changes if this is more appropriate, with the persons with intellectual disability facilitating their inclusion in making decisions about future support and care as far as is possible. The Summit adopted a working model of PDS that could be applied to people with intellectual disability and dementia and their carers/ support staff as identified in Table 2.

Table 2 Summit model of post-diagnostic support	
Stage in relation to diagnosis	Key factors in implementing PDS model
Immediately post-diagnosis	<ul style="list-style-type: none"> <li>Post-diagnostic counselling/ support and education offered to the person and carers/ 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/trajjectory</li> </ul>

	<ul style="list-style-type: none"> <li>• Early identification of behavioural and psychological symptoms of dementia in the individual and reviews of care practices and supports undertaken when such symptoms are present.</li> </ul>
<b>Ongoing</b>	<ul style="list-style-type: none"> <li>• 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-centred care</li> <li>• Supports and education offered to carers/ support staff on an ongoing basis, from both specialist and mainstream services, with continuing provision of information</li> <li>• Quality of life evaluations at regular intervals from both the perspective of the person with intellectual disability and their proxies, across the course of the person's journey</li> <li>• Psychological and medical surveillance carried out throughout the course of decline to address dementia-related needs and conditions (e.g. epilepsy in Down syndrome) and non-dementia comorbid conditions, irrespective of whether they impact directly on the course of dementia</li> </ul>
<b>Advanced dementia</b>	<ul style="list-style-type: none"> <li>• 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</li> </ul>

Source: Dodd et al., 2017

With respect to this topic, Summit participants were asked '*To what degree and intent does PDS with respect to people with intellectual disability mirror generic models and practices?*' The Summit noted that there were similarities, albeit also differences (see Dodd et al., in submission). It also recognized that there is limited research evidence for interventions (whether pharmacological or non-pharmacological) for adults with intellectual disability affected by dementia; however, it supported existing resources and guidelines that describe appropriate approaches drawn from clinical practice and that PDS should encompass all supports after diagnosis. The Summit's position is consistent with other organizations in recognizing that defining what composes PDS is necessary in the support and care of adults with intellectual disability affected by dementia.

The Summit proposed three main recommendations (see Table 1, Section B.2), including studying the effectiveness of different non-pharmacological interventions and their effects on carers and support staff, as well as researching the prevalence and nature of BPSDs in adults with intellectual disability who develop dementia.



**Community Dementia Capable Supports.** The Summit recognized that typical places of care and cultures differ widely across the world, based on historic or general societal practice, ranging from living alone or living with family or with friends, in small group homes, or in larger group community settings or, in some parts of the world, larger care facilities or institutions. It was further recognized that positive supports, environmental adaptation, response to individualized needs, a focus on quality of care, person-centred approaches and community integration should be possible regardless of the accommodation setting, with a requirement for ongoing staff training. Access to a range of dementia capable/adapted community services is often more difficult for persons with an intellectual disability affected by dementia for several reasons, including limited options for dementia-capable care, having to modify staff thinking from promoting autonomy over a lifetime to providing dependency-oriented care, and continued engagement of peers and other significant persons as a means of support.

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*What are the required services and supports needed to maintain or improve quality of life for persons with intellectual disability residing in the community at early, middle and advanced stages of dementia?*

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The Summit participants were asked to consider: *“What are the required services and supports needed to maintain or improve quality of life for persons with intellectual disability residing in the community at early, middle and advanced stages of dementia?”* The Summit noted that often intellectual disability 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 affected by dementia. Referral and transfer of the individual to a different service may be initiated, in some instances disrupting established routines and social relationships as well as a loss of a familiar environment. In some jurisdictions, this involves a move from a small scale or individual community setting to a larger generic congregate care facility. Such moves may at times be a function of governmental policies, enacted because of reductions in community-based social care funding, as remaining in place would require additional financing to provide awake night and other support staff in their existing residence to accommodate specialized dementia care needs. Similarly, community services and supports for persons in the general population affected by dementia may be unfamiliar with intellectual disability and be reluctant to include persons with intellectual disability.

With progressive dementia, behavioral changes may alienate peers and advocates, and lessen that circle of persons in meaningful relationships with the person with dementia. The Summit acknowledged that to accommodate dementia care related needs of adults with intellectual disability, community care systems need to have available a range of alternatives for both living care settings, and involvement in daily activities in settings that promote dignity and autonomy. Standards of care and protocols for dealing with progressive dementia in care settings are needed in specialty programs and can serve to both enhance program operations, staff orientation and capabilities, and have a positive effect on outcomes of care.

The Summit proposed three main recommendations (see Table 1, Section B.3), including developing standards of care for community based services that provide housing and other supports for persons with intellectual disability and dementia, promoting dementia capable living environments in all places called ‘home’, and involving family members and other invested friends or persons in supporting meaningful relationships.

**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 intellectual disability. Physical care can be standardized and focus on pain management, comfort, and relief from coincident conditions. In discussions related to end-of-life support practices, the Summit examined these questions: *“What are the required or recommended approaches to providing and sustaining end-of-life care for adults with intellectual disability affected by dementia? What are the specific elements that can be undertaken by family carers and professional staff/agency personnel and in what care setting - where do people die?”*

At end-of-life a difference set of care practices are called upon and usually are tailored to the adults and their situation (see McCarron et al., 2017; Service et al., 2017). With dementia as the causal factor, certain practices are becoming common. The Summit recognized that mainstream services,

including palliative and hospice services, do not receive referrals proportionate to the numbers of people with intellectual disability, and may be challenged to effectively include adults with intellectual disability and their families and other carers in decision-making. To prepare, discussions around goals and expectations around end of life should start early in the disease process (or ideally before) so that the individual may indicate choices about specific treatments, preferred intensity for medical interventions, and end-of-life preferences. Such advanced care planning remains an area for development in some countries and systems with variation existing in views of consent and legal status of advance care planning.

The Summit recognized that providers need to understand the implications of this process, even though different levels of intellectual disability may influence their ability to understand and participate in such planning. The Summit also recognized the value of involving available palliative/hospice services and posited that agreements be arranged between these services and intellectual disability services providers and families. On a personhood level, adults with intellectual disability affected by dementia bring their own life stories, their own relationships, and their own service or care history with them to the end of life, so this phase is also about the person living his or her last days as desired and with their family, friends, and paid carers. Even with the advent of death, person-centered approaches that have improved lives of adults with intellectual disability should be extended to end of life.

The Summit proposed three main recommendations (see Table 1, section B.4) which include creating a universal practice guideline on end-of-life supports, providing supports for

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*What are the required or recommended approaches to providing and sustaining end-of-life care for adults with intellectual disability affected by dementia? What are the specific elements that can be undertaken by family carers and professional staff/agency personnel and in what care setting - where do people die?*

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end-of-life care in home settings, and recognizing variations in what ‘home’ may like with respect to end-of-life care.

## ADVOCACY, PUBLIC IMPACT, AND FAMILY CAREGIVER ISSUES

**Nomenclature and the Use of Language.** As with research on dementia in the general population, language related to dementia in the intellectual disability field often lacks precision and leads to a misunderstanding of the condition(s) under discussion. This is becoming an increasingly crucial issue given the increased global attention dementia is receiving among people who have an intellectual disability (see Janicki et al., 2017). The question, *“How might we harmonize and standardize the terminology used in research papers, practice guidance and policy documents when referring to people with intellectual disability/Down syndrome and dementia?”*, drove the discussion of this issue at the Summit. Most articles related to intellectually disability and dementia reporting clinical or medical research generally provide a structured definition of dementia or related terms; social care articles tend toward term usage without definitions. Some of this imprecision and confusion may be 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. Further, lack of precision in language affects the understanding of any condition under discussion and confusion is further increased by a lack of agreement on common terminology.

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*How might we harmonize and standardize the terminology used in research papers, practice guidance and policy documents when referring to people with intellectual disability/Down syndrome and dementia?*

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Terminology standardization should be undertaken within studies/reports on dementia and intellectual disability. Efforts need to be undertaken to promote a familiarity with dementia-related diagnostic, condition-specific, and social care terms, as well as guidance documents produced that help structure accurate definitions and presentations of information about individuals or groups referenced. Such efforts can help when raising awareness of dementia in public campaigns, in advocating for inclusion in generic services and in planning and policy documents (and in services), and when enabling discussions across professions. Consistent use of terminology can aid in harmonizing protocols and cross-study communications of procedures and results. The Summit recommended that in research reports on dementia or cognitive decline or impairment, definitions used and data included should note subjects' ages, sex, level of intellectual disability, 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. Lastly, as language usage also reflects attitudes or biases, descriptive terms used to describe persons affected by dementia need to be measured so as not stigmatize.

The Summit proposed three main recommendations (see Table 1, Section C.1) which include adopting a standardized list or taxonomy of terms for general use by providers and

researchers, standardizing reporting so as 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 intellectual disability. Inclusion of this group is important as adults with Down syndrome are at high risk for early-onset dementia and adults with other intellectual disability may have specific needs for dementia-related care that, if unmet, can lead to diminished quality of old age. The Summit debated this query: *“What are the best practices in public policy advocacy and what constitutes meaningful inclusion of adults with intellectual disability in national plans on Alzheimer’s disease and related dementias, and in national plans for intellectual disability?”* The Summit proposed that national and sub-national dementia plans or strategies should include specifics of issues, needs, and responses to support adults with intellectual disability and such inclusion must go beyond just description and noting relevance (see Watchman et al., 2017).

The Summit noted that countries which were working towards their second or subsequent national plans or strategies were gaining momentum in the degree of inclusion of persons with intellectual disability and other previously excluded groups. Persons with intellectual disability should be included in consultation processes and greater advocacy is required from national organizations on behalf of families, with need for an infrastructure in health and social care that supports quality care in older life. The Summit posited that core needs 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. It is incumbent upon planning authorities to actively consider and include this group of adults in any government documents produced to promote awareness of dementia, plan for service provision, and allocate resources.

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*“What are the best practices in public policy advocacy and what constitutes meaningful inclusion of adults with intellectual disability in national plans on Alzheimer’s disease and related dementias, and in national plans for intellectual disability?”*

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The Summit proposed three main recommendations (see Table 1, Section C.2), which includes assuring the representation of adults with intellectual disability in processes that create national plans, advocating that governments provide supportive data related to intellectual disability for plan development, and involving self-advocates in the development or review of policy documents and plans.

**Family Caregivers.** With the onset of new challenges posed by cognitive decline and behavioral changes, and losses in self-care abilities, 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 countries offer a range of accommodation, information materials and care settings, as well as have organizations

targeting caregivers of persons with dementia, in general. With respect to living arrangements, in some localities, many older people with intellectual disability live at home with their families – usually with one or both parents or a sibling. In other localities, the prevailing norm is for adults to live independently or in supervised living with direct support needs organized by a service provider. Elsewhere, there continues to be housing based on large group living or in many cases no services at all. Yet family, regardless of living circumstance, often continues to play an important role supporting the relative aging with intellectual disability.

Participants at the Summit were asked to examine this query, *“Of the many services identified as being useful for family caregivers, what are most helpful for caregivers of adults with intellectual disability affected by dementia to support care at home at early, middle and advanced stages of dementia?”* As dementia becomes a factor, families are challenged to understand what is happening and how to best cope with new care demands. Families may experience similar demands and face similar stressors to those experienced by caregivers of persons with dementia generally, although as lifelong caregivers for their relative with intellectual disability they may have adapted and developed coping mechanisms over the years. The Summit recognized that lifelong caregiving, or resumption of parental or sibling caregiving in later age, is prevalent in the field of intellectual disability. Conversely, it also recognized that spousal or offspring caregiving is more typical than in the general population. Professionals who work in generic dementia or disability services may not have specialized knowledge or experience to support people with intellectual disability and dementia who live with their families. The complexities involved with home-based supports were recognized along with the new demands in providing increased care following a diagnosis of dementia. The Summit debated how typical family supports can be adapted 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 intellectual disability. These would apply irrespective of the presence of formalized structures and public policies present in a country or geographical area.

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*“Of the many services identified as being useful for family caregivers, what are most helpful for caregivers of adults with intellectual disability affected by dementia to support care at home at early, middle and advanced stages of dementia?”*

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The Summit proposed three main recommendations (see Table 1, Section C.3) which include 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 a range of issues related to the presence of dementia among adults with intellectual disability, each with a progressively nuanced agenda. This meeting with representatives from some 12 countries brought together workers experienced with social care and medical issues, as well as having experience with neurobiological research. The significance

of this effort is marked by its 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 fields relevant to workers in intellectual disability, geriatrics, dementia, and social care.

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 intellectual disability – and thus the exercise employed by this Summit can be applied to many other ‘special’ populations where dementia is a concern. Given the increases in the expected numbers of persons 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 more interest in nuanced research. The dementia related information and technology in intellectual disability 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 possess different cultures and family expectations, there is commonality in the need for a common information and a highly trained workforce to ensure the best possible supports are provided wherever persons with intellectual disability and dementia call home.

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*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 intellectual disability – and thus the exercise employed by this Summit can be applied to many other ‘special’ populations where dementia is a concern.*

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Some key public policy implications that can be gleaned from this exercise include more attention to groups of persons with high risk factors for dementia, inclusion of significant ‘target’ groups within national planning for dementia, careful reviews of extant program and services to determine what barriers may be present for continued community living when dementia is present, more focus on training and education of personnel who work with people affected by dementia, increased and better communication with people who have intellectual disability and are affected by dementia, and the creation of options for functional community care of persons with dementia.

The Summit model or another variant is something that warrants periodic reconvening to review the outputs from the 2016 summit, , ascertain whether recommendations have produced new instruments and affected practices, and identify areas un- or under-studied or evolving as new interests. As concerns about dementia care practices reach further across the globe, it is expected that future such meetings will involve even more representation from countries where dementia among adults with intellectual disability is gaining traction as a critical public health challenge. Such meetings will see the continued involvement of self-advocates with intellectual disability who are active in ensuring that people affected by dementia are included in a way that is relevant and meaningful to them.

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## Appendix A: Summit membership

Members of the Summit Workgroups included Cathy Asante (Scotland), Anna Berankova (Czech Republic), Kathleen Bishop (USA), Nicole Cadovius (USA), Sally-Ann Cooper (Scotland), Tonni Coppus (the Netherlands), Jim Crowe (Wales), Karen Dodd (UK), Juan Fortea (Spain), Claudia Gaertner (Germany), Kiran Haksar (Scotland), Flavia Heloisa Santos (Brazil), Mary Hogan (USA), Matthew P. Janicki (USA), Nancy Jokinen (Canada), Seth Keller (USA), Frode Larsen (Norway), Ronald Lucchino (USA), Philip McCallion (USA), Mary McCarron (Ireland), Peter Mittler (UK), Jim Pearson (UK), Sam Quinn (Scotland), Anne-Sophie Rebillat (France), Evelyn Reilly (Ireland), Kathy Service (USA), Michael Splaine (USA), Sandy Stemp (Canada), Andre Strydom (UK), Gomiero Tiziano (Italy), Leslie Udell (Canada), Karen Watchman (Scotland).

## Appendix B Publication list:

### Articles:

Janicki M, McCallion P, Splaine M, Santos FH, Keller S & Watchman K (2017). Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature. *Intellectual and Developmental Disabilities*, in press.

McCallion P, Hogan M, Santos F, McCarron M, Service K, Stemp S, Keller S, Fortea J, Bishop K, Watchman K & Janicki M (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 Disabilities*, in press.

Service KP, Watchman K, Hogan M, Cadovius N, Janicki M & Berankova A (2017). Dying well with an intellectual disability and dementia? *Journal of Dementia Care*, in press.

Watchman K, Janicki M, Splaine M, Larsen FK, Lucchino R & Gomiero T (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.

### Bulletin summary reports:

Report 1: Nomenclature

Report 2: Perspectives of persons with intellectual disability

Report 3: Advanced dementia

Report 4: Human rights

Report 5: Inclusion in national dementia plans and strategies

Report 6: Post-diagnostic support

Report 7: Community dementia capable supports

Report 8: Family caregivers

Report 9: End of life care

All reports can be sourced at <http://www.learningdisabilityanddementia.org/id-dementia-summit.html>