

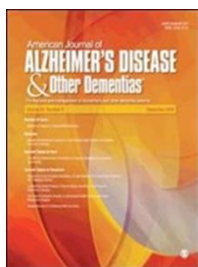
The International Summit on Intellectual Disability and Dementia



The 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland on October 13-14, involved 32 academics and international and national dementia and intellectual disability organization representatives from Europe and North and South America. Participants were charged with examining numerous

contemporary issues facing adults with intellectual disability at risk of, or affected by dementia, as well as reviewing family and personal support needs, and issues related to public policy. Working groups were assigned *a priori* tasks and produced discussion summaries on several topics for the main meeting, encompassing three main conceptual areas (and sub-topic areas): (1) 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), (2) personalized services and caregiver supports (advancing and advanced dementia, post-diagnostic support community, dementia-capable care practice, end-of-life care practices, support for family caregivers), and (3) advocacy and public impact (nomenclature/ terminology, and inclusion of persons with Intellectual disability in national plans). Topic output summaries were produced which subsequently resulted in a series of published articles (listed below).

International Summit Consensus Statement: Intellectual Disability Inclusion in National Dementia Plans



Abstract: The WHO 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. It called for distinct populations to be included within national plans, including adults with intellectual disability (ID). Inclusion of this group is important as having Down syndrome is a risk factor for early-onset dementia. Adults with other ID may have specific needs for dementia-related care that, if unmet, can lead to diminished quality of old age. The International Summit on Intellectual Disability and Dementia reviewed the inclusion of ID in national plans recommending that inclusion goes beyond just description and relevance of ID. Persons with ID 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.

American Journal of Alzheimer's Disease & Other Dementias, 2017, 32(4), 230-237.

Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Nomenclature



Abstract: A working group of the 2016 International Summit on Intellectual Disability and Dementia was charged to examine the terminology used to define and report on dementia in publications related to intellectual disability (ID). A review of related publications showed mixed uses of terms associated with dementia or causative diseases. Like general applications, language related to dementia in ID field often lacked precision and could lead to a misunderstanding of the condition(s) under discussion. Most articles related to ID and dementia reporting clinical or medical research generally provided a definition of dementia or related terms; social care articles tended toward term use without definition. Toward terminology standardization within studies/reports on dementia and ID, the Summit recommended (a) gaining familiarity with dementia-related diagnostic, condition-

specific, and social care terms (as identified in the working group's report), (b) creating a guidance document on accurately defining and presenting information about individuals or groups referenced, and (c) that in reports on neuropathologies or cognitive decline or impairment, definitions are used and

data include 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.

Intellectual and Developmental Disabilities, 2017, 55(5), 338-346.

Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to End-of-life Care in Advanced Dementia



Abstract: Adults with intellectual disability are affected by dementia at equivalent and elevated rates; many surviving into advanced age. End-of-life care and support considerations come into play among these individuals when most are in the advanced stage of dementia. The International Summit on Intellectual Disability and Dementia's report on end-of-life care in advanced dementia provides a synthesis statement which encompasses defining the state of advanced dementia, proposing use of palliative care services (including hospice), and recommending special efforts for enabling advanced directives and advance care planning prior to the extensive progression of dementia. The Summit recommended that when aiding adults with advanced dementia, the following be undertaken: integrative efforts between intellectual disability and palliative care providers, specialized training for carers on end-of-life care and supports, and involvement of adults with intellectual disability early on in their advance care planning.

Journal of Applied Research in Intellectual Disability, 2017, 30(6), 1160-1164; DOI: 10.1111/jar.12349

Dying Well with an Intellectual Disability and Dementia



Abstract: As more people with intellectual disabilities live into old age, the prevalence of dementia in this group is increasing. The authors examine the challenges to dementia practice presented by intellectual disability. Expertise in the field of intellectual disability and advanced dementia is rare and our summit offered a series of recommendations including ongoing exchange of experiences and skills across professions, development of tools and scales that facilitate understanding of the progression of dementia, and more equitable access to palliative care and hospice services with increased and timely referral. We also recommended that intellectual disability services increased understanding of the fundamental dementia related needs which complicate end-of-life care.

The Journal of Dementia Care, July/August 2017, 25(4), 28-31 &
Australian Journal of Dementia Care, Oct/Nov 2017, 6(5), 28-31.

Volume 59, Issue 3, June 2019, Pages 411–419, The Intersection of Intellectual Disability and Dementia: Report of the International Summit on Intellectual Disability and Dementia



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 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.

The Gerontologist, 2019, 59(3), 411–419, <https://doi.org/10.1093/geront/gnx160>

Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to Post-Diagnostic Support

Abstract: Post diagnostic support (PDS) has varied definitions within mainstream dementia services and by among different health and social care-oriented organizations, but generally it is recognized that it encompasses a range of supports that are offered to adults once diagnosed with dementia and extending of the condition, until death. An international summit on intellectual disability and dementia held in Glasgow, Scotland in 2016 identified how PDS applies to adults with who have an intellectual disability with dementia. The Summit proposed a model that encompassed eleven focal areas: post-diagnostic counseling; understanding the needs related to the intellectual disability; specific interventions and treatments; psychological and medical surveillance; early identification of behavior and psychological symptoms; periodic reviews of the dementia care plan; care during advanced dementia; care at end of life; supports for carers and regular evaluation of quality of life linked with reviews of the person's dementia care plan. It also explored current practices in providing PDS in intellectual disability services. The Summit concluded that although there is limited research evidence for interventions (whether pharmacological or non-pharmacological) for people with intellectual disability and dementia, there are viable resources and guidelines that describe practical approaches drawn from clinical practice. Post diagnostic support is essential, and the model components in place for the general population, and proposed here for use within the intellectual disability field, need to be individualized and adapted to the person's needs as dementia progresses. Recommendations for future research include examining the prevalence and nature of behavioral and psychological symptoms (BPSD) in adults with an intellectual disability who develop dementia, the effectiveness of different non-pharmacological interventions and the interaction between pharmacological and non-pharmacological interventions, and the utility of different models of support.



Aging & Mental Health, 2018 Nov;22(11):1406-1415. doi: 10.1080/13607863.2017.1373065. Epub 2017 Sep 7.

Supporting Advanced Dementia in People with Down Syndrome and Other Intellectual Disability: Consensus Statement of the International Summit on Intellectual Disability and Dementia.



Abstract: The International Summit on Intellectual Disability and Dementia (Glasgow, Scotland; October 2016) noted that advanced dementia can be categorized as that stage of dementia progression characterized by significant losses in cognitive and physical function, including a high probability of further deterioration and leading to death. The question before the Summit was whether there were similarities and differences in expressions of advanced dementia between adults with intellectual disability (ID) and adults in the general population. The Summit noted challenges in the staging of advanced dementia in people with ID with the criteria in measures designed to stage dementia in the general population heavily weighted on notable impairment in activities of daily living. For many people with an ID, there is already dependence in these domains generally related to the individuals pre-existing level of intellectual impairment, that is, totally unrelated to dementia. Hence, the Summit agreed that as was true in achieving diagnosis, it is also imperative in determining advanced dementia that change is measured from the person's prior functioning in combination with clinical impressions of continuing and marked decline and of increasing co-morbidity, including particular attention to late-onset epilepsy in people with Down syndrome. It was further noted that quality care planning must recognize the greater likelihood of physical symptoms, co-morbidities, immobility and neuropathological deterioration. The Summit recommended an investment in research to more clearly identify measures of person-specific additional decline for ascertaining advanced dementia, inform practice guidelines to aid clinicians and service providers and identify specific markers that signal such additional decline and progression into advanced dementia among people with various levels of pre-existing intellectual impairment.

Journal of Intellectual Disability Research, 2018, 62(7), 617-624. DOI:10.1111/jir.12500.

Quality care for people with intellectual disability and advanced dementia: Guidance on service provision.



Abstract: The International Summit on Intellectual Disability and Dementia (Glasgow, Scotland; October 2016) noted that advanced dementia can be categorized as that stage of dementia progression characterized by significant losses in cognitive and physical function, including a high probability of further deterioration and leading to death. The questions before the Summit were whether there were similarities and differences in expressions of advanced dementia between adults with intellectual disability and adults in the general population. The Summit noted challenges in the staging of advanced dementia in people with ID with the criteria in measures designed to stage dementia in the general population heavily weighted on notable impairment in activities of daily living. For many people with an intellectual disability (ID) there is already dependence in these domains generally related to the individuals pre-existing level of intellectual impairment, i.e., totally unrelated to dementia. Hence, the summit agreed that it is imperative that change is measured from the person's prior functioning in combination with clinical impressions of decline and of increasing co-morbidity including particular attention to late onset epilepsy in people with Down syndrome. It was further noted that quality care planning must recognize the greater likelihood of physical symptoms, comorbidities, immobility and neuropathological deterioration. The Summit recommended an investment in research to more clearly identify measures for ascertaining advanced dementia, inform practice guidelines to aid clinicians and service providers, and identify additional markers that may help signal decline and progression into advanced dementia among people with various levels of pre-existing intellectual impairment.

Journal of Palliative Medicine, 2018, 21(9), 1344-1352, DOI: 10.1089/jpm.2017.0442.

Perspectives on Family Caregiving of Ageing People with Intellectual Disability Affected by Dementia: Commentary from the International Summit on Intellectual Disability and Dementia



Abstract: This article, an output of the 2016 International Summit on Intellectual Disability and Dementia, examines familial caregiving situations within the context of a support-staging model for caregiving among adults with intellectual disability (ID) affected by dementia. Seven opportunistic narratives offer context for relating a support-staging model to interpretations of various situations in which caregivers find themselves. The multi-dimensional model has two fundamental aspects: (1) identifying the role and nature of caregiving as either primary (direct) or secondary (supportive); and (2) defining how caregiving is influenced by the stage of dementia. We propose that staging can affect caregiving via different expressions: (1) the 'diagnostic phase', (2) the 'explorative phase', (3) the 'adaptive phase', and (4) the 'closure phase'. The narratives illustrate both direct and indirect caregiving with a commonality the involvement of the caregivers

and their attention to the care needs of an adult with ID. We conclude that the model has utility and shows the variability of caregiving, and that caregivers have various needs and tend to use whatever works and look to outside help only when they need it. Furthermore, a support-staging model can be useful in constructing research, defining family-based support services, and setting public policy.

Journal of Gerontological Social Work, 2018, 61(4), 411-431. DOI: 10.1080/01634372.2018.1454563

Consensus Statement of the International Summit on Intellectual Disability and Dementia on Valuing the Perspectives of Persons with Intellectual Disability



Abstract: The International Summit on Intellectual Disability and Dementia held in Scotland in 2016 covered a range of issues related to dementia and intellectual disability, including the dearth of personal reflections of persons with intellectual disability affected by dementia. This paper reflects on this deficiency and explores some of the personal perspectives gleaned from the literature, from Summit attendees, and from the experiences of persons with intellectual disability recorded or scribed in advance of the two-day Summit meeting. Omission of the perspectives of persons with intellectual disability in both policy and practice limits understanding of the experience of dementia. It leads to an overreliance on proxy reporting; something considered by the Summit to be a backwards step in person-centered work. The Summit recognized that the perspectives of persons with intellectual disability must be considered

whenever interventions and supports are discussed with planning required at an earlier stage for advance directives that guide medical treatment, and for advice or counselling around relationships, the continuity of social networks, and when securing dementia-friendly housing. Systemic recommendations included reinforcing the value of the involvement of persons with intellectual disability in (a) research alongside removing barriers to inclusion posed by institutional/ ethics

review boards, (b) planning groups that establish services and supports for dementia, and (c) peer support efforts that help adults with intellectual disability who are affected by dementia (either directly or indirectly). Practice recommendations included (a) valuing personal perspectives in decision-making, (b) enabling peer-to-peer support models, (c) supporting choice in community dwelling arrangements, and (d) wider availability of materials for persons with intellectual disability that would promote understanding of dementia.

Journal of Intellectual Disabilities, Jan 1:1744629517751817. doi: 10.1177/1744629517751817. [Epub ahead of print]

Principales Conclusiones Acordadas Durante La Cumbre Sobre Discapacidad Intelectual y Demencia [Main conclusions agreed during the Summit on Intellectual Disability and Dementia]



Abstract: Durante la reunión internacional celebrada en Glasgow, Escocia, en 2016, se examinó la problemática asociada a la demencia en los adultos con discapacidad intelectual (DI). La temática abordada y los problemas estudiados incluyeron: (1) *los derechos humanos y recursos fundamentales de las personas* (aplicaciones de la convención de los derechos de las personas con discapacidad y del derecho a la inclusión social y perspectivas de las personas con DI); (2) *servicios individualizados y apoyo clínico* (a la progresión de la demencia y demencia avanzada, soporte humano tras el diagnóstico, ayudas sociales en el contexto comunitario y servicios, experiencia, capacidad y conocimiento acerca de personas que padecen de demencia, de los cuidados específicos que requieren, de la metodología de dichos cuidados y del acompañamiento al final de la vida), y (3) *amparo y defensa de las conclusiones consensuadas, impacto público, soporte al*

cuidador/familiar (nomenclatura/terminología, inclusión de la problemática de las personas con DI en los planes nacionales y cooperación con el cuidador/familiar). Los resultados incluyeron una serie de artículos con información y recomendaciones sobre las temáticas mencionadas. Estos artículos tienen como objetivo asistir a las diferentes organizaciones y agentes cuyo proyecto ofrece amparo y cuidados destinados a este grupo poblacional, como también a las administraciones gubernamentales en la planificación de estos cuidados específicos dirigidos a personas con DI, así como la protección, sostenimiento y difusión en favor, y en nombre, de las personas con DI afectadas por demencia y de sus familias.

Siglo Cero, 2018, 49(2), n.º 266, abril-junio, 115-122. DOI: <http://dx.doi.org/10.14201/scero2018492115122>

Highlights from the International Summit on Intellectual Disability and Dementia: Implications for Brazil [Síntese da Cúpula Internacional sobre Deficiência Intelectual e Demência: Implicações para o Brasil]



Abstract: In October of 2016, an interdisciplinary group representing North and South American and European countries met in Glasgow, Scotland, to scrutinize issues regarding adults with intellectual disability (ID) affected by dementia and to produce recommendations and guidelines for public policy, practice, and further research. The aim of this paper is to apprise relevant outcomes of the Summit targeting Brazilian researchers, clinicians, and nongovernmental organizations in the field of ageing and dementia with an eye to including ID within the Brazilian national dementia plan. Three core themes were covered by the Summit: i) human rights and personal resources, ii) personalized services and caregiver supports, and iii) advocacy and public impact. The exploration of the themes highlighted variations across countries, and revealed consensual views in matters, such as international networks, guidance for practices, and advocacy on behalf of both people with intellectual disability affected by dementia, and their

families. Implications for Brazilian efforts to organize a national dementia plan are discussed and the authors proffer a series of recommendations for targeted activities within Brazil to address the needs of adults with ID affected by dementia.

Dementia & Neuropsychologia, 2018 Oct-Dec; 12(4): 329–336. doi: <http://dx.doi.org/10.1590/1980-57642018dn12-040001>.

Information on these publications can be found at www.the-ntg.org

Bibliography

- 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.
- Janicki, M.P., McCallion, P., Splaine, M., Santos, F.H., Keller, S.M., & Watchman, K. (2017). **Consensus statement of the International Summit on Intellectual Disability and Dementia related to nomenclature.** *Intellectual and Developmental Disabilities*, 2017, 55(5), 338-346. DOI: 10.1352/1934-9556-55.5.338.
- 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*, 30(6), 977-1164; DOI: 10.1111/jar.12349.
- 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*, 25(4), July/August, 28-31.
- Watchman, K., & Janicki, M.P., and the members of the International Summit of Intellectual Disability and Dementia. (2017). **The intersection of intellectual disability and Dementia: Report of the International Summit on Intellectual Disability and Dementia.** *The Gerontologist*, 2019, 59(3), 411-419.
<https://doi.org/10.1093/geront/gnx160> DOI:10.1093/geront/gnx160
- Dodd, K., Watchman, K., Janicki, M.P., Coppus, A., Gaertner, C., Fortea, F., Santos, F.H., Keller, S.M., & Strydom, A. (2017). **Consensus Statement of the International Summit on Intellectual Disability and Dementia related to post-diagnostic support.** *Aging & Mental Health*, 2018 Nov;22(11):1406-1415. doi: 10.1080/13607863.2017.1373065. Epub 2017 Sep 7.
- McCarron, M., McCallion, P., Coppus, A., Fortea, J., Stemp, S., Janicki, M.P., & Watchman, K. (2018). **Supporting advanced dementia in people with Down syndrome and other intellectual disability: Consensus Statement of the International Summit on Intellectual Disability and Dementia.** *Journal of Intellectual Disability Research*, 62(7), 617-624. DOI:10.1111/jir.12500.
- McCarron, M., McCallion, P., Watchman, K., Janicki, M.P., Coppus, A., Service, K., Fortea, J., Hogan, M., Reilly, E., & Stemp, S. (2018). **Quality care for people with intellectual disability and advanced dementia: Guidance on service provision.** *Journal of Palliative Medicine*, 2018, 21(9), 1344-1352, DOI: 10.1089/jpm.2017.0442.
- Jokinen, N., Gomiero, T., Watchman, K., Janicki, M.P., Hogan, M., Larsen, F., Berankova, A., Santos, F.H., Service, K., & Crowe, J. (2018). **Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia.** *Journal of Gerontological Social Work*, 61(4), 411-431. DOI: 10.1080/01634372.2018.1454563.
- Watchman, K., Janicki, M.P., Hogan, H., Udell, L., Quinn, S., & Beránková, A. (2018). **Consensus statement of the international summit on intellectual disability and dementia on valuing the perspectives of persons with intellectual disability.** *Journal of Intellectual Disabilities*, 2019, 23(2), 266-280. doi: 10.1177/1744629517751817; 1744629517751817.
- Janicki, M.P., Watchman, K., & Fortea, J., (2018). **Principales Conclusiones Acordadas Durante La Cumbre Sobre Discapacidad Intelectual y Demencia [Main conclusions agreed during the Summit on Intellectual Disability and Dementia].** *Siglo Cero*, 49(2), n.º 266, abril-junio, 115-122. DOI: <http://dx.doi.org/10.14201/scero2018492115122>.
- Dos Santos, F. H., Janicki, M.P., & Watchman, K. (2018). **Highlights from the International Summit on Intellectual Disability and Dementia: Implications for Brazil.** *Dementia & Neuropsychologia*, Oct-Dec, 12(4), 329-336. doi: <http://dx.doi.org/10.1590/1980-57642018dn12-040001>.