

**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>
<b>A.1 Human Rights</b>	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.
<b>A.2 Perspectives of person with intellectual disability</b>	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>
<b>B.1 Advanced Dementia</b>	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.

<b>B.2 Post-Diagnostic Supports</b>	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 labor, staff turnover.	Examine the prevalence and nature of behavioral 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, 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 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 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	Draw into the process, government representatives who are requested to provide demographic, services, and financial data related to 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.	Involve self-advocates or persons authorized to speak on behalf of adults with an intellectual disability, in the development or review of documents produced 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 physical and mental health.

Source: 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. doi: 10.1093/geront/gnx160.DOI:10.1093/geront/gnx160