

INTERNATIONAL SUMMIT ON
INTELLECTUAL DISABILITY AND
DEMENTIA:
ADVANCED DEMENTIA
POLICY & PRACTICE BULLETIN 3



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Policy & Practice Bulletin 3 of the Summit Working Group on Dementia and Intellectual Disability: Advanced dementia

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Advanced dementia pre-summit question for delegates

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

Background

This summary policy and practice bulletin was developed as an output from the 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland, 13-14 October 2016. The event was hosted by the University of Stirling and University of the West of Scotland with funding from 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 two-day Summit was composed of individuals and representatives of many international and national organizations, family members and policy officers with a stake in issues related to adults with intellectual disability affected by dementia. Perspectives of persons with intellectual disability were sought in advance and were inserted at salient points across the Summit. The contents of this bulletin 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 contributors and of the NTG.

Summary statement

Diagnosing dementia in people with intellectual disability has proven more complex than in the general population due to varying levels of pre-existing intellectual impairment and increased risk of other health conditions which often mimic dementia (such as, hypothyroidism, sensory impairments, sleep apnoea, B₁₂ and folate deficiency, and depression). Staging of dementia in people with an intellectual disability is also more challenging because for some decline is often compressed and of shorter duration. Clinical features of advanced dementia in people with intellectual disability are similar to those of the general population with the exception that among adults with DS new-onset seizure activity is an additional clinical feature

Similarly, care needs are different across the continuum of dementia and the care environment and staff skills with will need to be responsive to the changing care requirements as dementia progresses. Many people with intellectual disability may already have significant difficulties in day to day activities of living and language, which are accepted as fundamental clinical features of dementia in the general population. These symptoms can be considered characterise of underlying intellectual disability and has implications for the staging of dementia if using instruments validated for the use in the general population. To increase diagnostic accuracy, it is important to have a reliable baseline measure of functioning and a key informant who has known the individual over an extended period of time. Unfortunately, baseline measurement of functioning is more often an exception rather than the norm, with frequent staff changes in out-of-home placements and lack of regular assessment in family situations often meaning that there is poor knowledge, understanding, or measurement of decline or change. This often results in the individual progressing to a more advanced stage of dementia before any diagnosis is made, further confounding difficulties in the staging of dementia. Moreover, dementia may present differentially within various syndromes or aetiologies of intellectual disability.

The discussions at the Glasgow summit showed consensus in recommendation:

- Continue attention to systematic baseline screening, assessment and follow up of people with Down syndrome and other intellectual disabilities using agreed standardized instruments
- Compare the trajectory of dementia in people with Down syndrome to trajectories in people with intellectual disability from other aetiologies
- Undertake research to develop more valid and reliable instruments for assessing advanced dementia-related cognitive and physical deterioration among adults with Down syndrome and people with intellectual disability.

- Develop practice guidelines and widespread related training and education to support quality care when adults with an intellectual disability have advanced dementia.
- Utilizing life story strategies early in the dementia process (if not before) to develop a record of the person's preferences and wishes, likes and dislikes to inform later discussions of care when the person is no longer able to participate in care decisions
- Understanding the person's attempts at communication, responding appropriately when the person gives a clue, asking questions and listening to concerns or worries.
- Compile a formal record of expressed wishes that is kept, and reviewed on an ongoing basis, ensuring that all person engaged in care know those wishes.

Appendix A: Summit Participants

Cathy Asante	Solicitor and Legal Officer at the Scottish Human Rights Commission, Scotland
Anna Berankova	Researcher, Centre of expertise in Longevity and Long-term care, Charles University, Prague
Kathleen Bishop	Intellectual disability and dementia consultant, National Task Group on Intellectual Disabilities and Dementia Practice, USA
Nicole Cadovius	National Task Group on Intellectual Disabilities and dementia Practice, USA
Jim Crowe	Director of Learning Disability Wales / Vice President of the European Association of Service Providers for People with Disabilities, Wales
Sally-Ann Cooper	Chair of Learning Disabilities / Director, Scottish learning Disability Observatory, Glasgow, Scotland
Antonio Coppus	Head of Raboud University Down Syndrome Centre, Netherlands
Karen Dodd	Consultant Clinical Psychologist for Surrey and Borders Partnership NHS Foundation Trust, England
Juan Fortea	Adult Medical Director, Down Medical Centre, Catalan Foundation for Down Syndrome, Barcelona, Spain
Claudia Gaetner	Head of Department of Science and Research, Theodore Fliedner Foundation, Dusseldorf, Germany
Tiziano Gomiero	Researcher and Coordinator, DADS of ANFFAS, Trentino, Italy
Kiran Haksar	Policy Officer, Scottish Government's Dementia Innovations Unit, Scotland
Mary Hogan	National Task Group on Intellectual Disabilities and dementia Practice, USA
Nancy Jokinen	Associate Professor, School of Social Work, University of Northern British Columbia
Matthew Janicki	Research Associate Professor, Department of Disability and Human Development, University of Illinois at Chicago/ Co-chair of National Task Group on Intellectual Disabilities and Dementia Practice, USA
Seth Keller	Neurologist, Advocare Neurology, South Jersey, USA
Frode Larsen	Special advisor in the unit Intellectual Disabilities and Ageing at the Norwegian National Advisory Unit on Ageing and Health, Norway
Ron Lucchino	Retired Director of Institute of Gerontology, University of New Mexico, Albuquerque, USA
Peter Mittler	Human Rights Adviser to Dementia Alliance International, England
Philip McCallion	Professor, School, of Social welfare / Co-director of Centre for Excellence in Aging and Community Wellness, University at Albany, New York, USA
Mary McCarron	Dean of Faculty of health Sciences / professor of Ageing and Intellectual Disability, Trinity College, Dublin
Jim Pearson	Alzheimer Scotland's Director of Policy and Research, Scotland
Sam Quinn	Research Assistant / PhD student, Scotland
Anne-Sophie Rebillat	Director, Geriatric Outpatient Clinic, Lejeune Institute, Paris, France
Evelyn Reilly	Clinical Nurse Specialist in Intellectual Disability and Dementia, Trinity College, Dublin, Ireland
Flavia H Santos	Professor, UNESP, Sao Paulo State University / University of Minho, Portugal
Kathy Service	National Task Group on Intellectual Disabilities and dementia Practice, USA
Michael Splaine	Policy Advisor, Alzheimer's Disease International , USA
Sandy Stemp	Chief Operations Officer, Reena, Toronto, Canada
Andre Strydom	Reader, Intellectual Disabilities, University College London, England
Lesley Udell	Director, Winnserv, Manitoba, Canada
Karen Watchman	Senior Lecturer, Ageing, Frailty and Dementia, University of Stirling, Scotland

Appendix B: Policy & Practice Bulletin Series

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