

INTERNATIONAL SUMMIT ON
INTELLECTUAL DISABILITY AND
DEMENTIA:
**PERSPECTIVES OF PERSONS WITH
INTELLECTUAL DISABILITY AND
DEMENTIA**

POLICY & PRACTICE BULLETIN 2



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Policy & Practice Bulletin 2 of the Summit Working Group on Dementia and Intellectual Disability: Perspectives of persons with intellectual disability and dementia

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Pre-summit question for delegates

How can we determine the priority areas identified by persons with intellectual disability in relation to dementia care for themselves, or their friends, at different stages of dementia?

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

The Summit representatives recognize that the existing evidence base that includes people with intellectual disability has been drawn from adults in early stages of dementia, and has focused primarily on adults with Down syndrome which may bias interpretations of findings noted in the literature. However, there remains a recurring theme of not hearing or seeking the perspective of the person with intellectual disability and dementia; not knowing how to do so, and not recognising the potential for naturally occurring activities that may facilitate conversation. Whilst this is not unique to people with intellectual disability; it is also prevalent in the general population and in dementia literature, it perhaps has more meaning within the intellectual disability field. This is due to the historical exclusion and marginalisation of people with intellectual disability by others. Professionals may be in and out of lives very fleetingly and rely on what they see or are told on the day, which again may not reflect the wishes or support needs of the individual. This can lead to a tension between who is the primary person: the parent or carer, or the person with intellectual disability, or a professional who may have guardianship – with consideration needed of the legal frameworks that exist to respect and give prominence to the voice of the person with intellectual disability.

A culture change has taken place in intellectual disability services over the past decades with a range of supports, tools and resources available to support people and a rise in self-advocacy by individuals and organizations. Similarly, we know about the perspectives of people with dementia who do not have an intellectual disability, again because of increasing self-advocacy. This extent of self-advocacy is not yet representative of the population of people with intellectual disability and dementia or their families. Omission of the perspectives of persons with intellectual disability limits understanding of the experience of dementia, leading to an overreliance on proxy reporting; something considered by the Summit to be a backwards step in person-centered work over recent decades.

Part of the difficulty in determining perspectives of people with an intellectual disability is the lack of awareness of their diagnosis of dementia with a limited range of information, mostly in English, available to explain dementia to people with intellectual disabilities.

The discussions at the Glasgow summit showed consensus in recommendation:

- People with intellectual disability should be invited to participate in planning groups charged with establishing services and supports for dementia care.
- Commit to equality of access to supports and services offered within the community
- Expand peer support efforts when helping persons with intellectual disability who are affected by dementia (either directly or indirectly).

- Undertake consultation for future dementia plans and strategies, and reviews of current iterations, that are inclusive of people with an intellectual disability affected by dementia.
- Support for existing self-advocacy groups for people with an intellectual disability to forge partnerships with dementia advocacy organizations, recognizing the significant experience of the self-advocacy movement.
- Develop and test a quality of life tool or measure for people with intellectual disability and dementia that includes self-report, in addition to carer perspective. This may be drawn and adapted from available measures and tools already existing in the general dementia field.
- Establish an international review group to examine the barriers to inclusion in research studies posed by research and ethics review boards that don't actively support the presence and perspectives of participants with intellectual disability.
- 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.

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>