

INTERNATIONAL SUMMIT ON
INTELLECTUAL DISABILITY AND
DEMENTIA:
INCLUSION IN NATIONAL
DEMENTIA PLANS & STRATEGIES

POLICY & PRACTICE BULLETIN 5



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Policy & Practice Bulletin 5 of the Summit Working Group on Dementia and Intellectual Disability: Inclusion in national dementia plan and strategies

Policy & Practice Bulletin 5 of the Summit Working Group on Dementia and Intellectual Disability: Inclusion in National Dementia Plans and Strategies

Pre-summit question for delegates

What constitutes meaningful inclusion of adults with intellectual disability in national plans on Alzheimer's disease and related dementias?

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 importance of national plans or strategies in guiding public policy and research related to dementia is increasingly recognised along with the importance of 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 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.

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 suggested 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.

The discussions at the Glasgow summit showed consensus in recommendation:

- Forums, meetings, and consultations held in advance of national plans being developed or modified should include appropriate representation by persons with intellectual disability and dementia and/or their advocates; such forums, meetings and consultations should include alternate and accessible methods of communication as required to ensure meaningful inclusion.
- 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 advance and in accessible formats.
- Discussions should be held at an organisational level to determine what guidance may need to be instituted or altered/updated to support the inclusion of intellectual disability in national dementia strategy planning or evaluation meetings.
- Intellectual disability, and in particular, Down syndrome organisations, should actively seek to gather feedback from members with intellectual disabilities with a view to collective input into the development of new dementia strategy document.

- Government or policy representatives should be tasked with sourcing and providing demographic, and financial data related to people with intellectual disability (and in particular Down syndrome) for use in local and national plans.
- Dementia plans or strategies should not be seen as static documents and there should be ongoing work to contribute to future iterations.

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: International Summit 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>