

# INTERNATIONAL SUMMIT ON INTELLECTUAL DISABILITY AND DEMENTIA:

## END OF LIFE CARE

POLICY & PRACTICE BULLETIN 9



## Contents

Pre-summit question for delegates .....	1
Background .....	1
Summary statement .....	2
Appendix A: Summit Participants .....	4
Appendix B: International Summit bulletin series .....	5

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*Policy & Practice Bulletin 9 of the Summit Working Group on Dementia and Intellectual Disability: End of life care*

# **Policy & Practice Bulletin 9 of the Summit Working Group on Dementia and Intellectual Disability: End of Life Care**

## **Pre-summit question for delegates**

What are the required or recommended approaches to providing and sustaining end of life care for adults with intellectual disability affected by dementia, and how does this differ from the population generally?

## **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 recognized that there are unique considerations when progressive dementia is a factor in the last days of life for a person with an intellectual disability. This provides a challenge for mainstream services, including palliative and hospice services, to effectively include adults with intellectual disability and their families and other carers in decision-making. The Summit recognizes that the focus should not be on primary medically-oriented end-of-life care. Adults with intellectual disability affected by dementia bring their own life stories, their own relationships, and their own service history with them to the end of life, this is not simply about procedures and interventions. Instead, it must be about the person living his or her last days as desired and their family, friends, and paid carers completing that journey with them. Person-centred approaches that have improved the lives of so many people with intellectual disability must be continued to the end of life. In the general population, it is recommended that discussion for goals and expectations around end of life should start early in the disease process having the individual indicate choices about specific treatments, such as resuscitation, preferred intensity for medical interventions or preferences for artificially administered nutrition (e.g., feeding tubes) and hydration. These preferences are often more complex for people with intellectual disability to determine. This remains an area for development in some countries and systems with variation existing in views of consent and legal status of advance care planning. There are also implications of different levels of intellectual disability on ability to understand and participate in planning and differences in palliative/hospice services available and agreements to work with intellectual disability services providers and families.

The discussions at the Glasgow summit showed consensus in recommendation:

- Intellectual disability, dementia, and palliative care organizations and associations collaborate to create a universal practice guideline on end - stage care and support practices for persons with intellectual disability and advanced dementia
- Understand the importance of previous communication methods utilised by the person with intellectual disability pre-dementia, particularly non-verbal.
- Recognise passive care as active care whilst being mindful of non-verbal cues that may indicate pain.
- Embrace a relationship-centred approach that recognises a wider range of existing or previous professional relationships for people with intellectual disability.
- Recognise the role that support staff often fulfil at end of life; the closest relationships that the person with intellectual disability and dementia has may not be with family.
- Recognise 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.

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- '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.
- People with intellectual disability are under-represented in hospice care; this should be considered as part of advanced care planning.

## **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>