

# INTERNATIONAL SUMMIT ON INTELLECTUAL DISABILITY AND DEMENTIA:

## FAMILY CARERS

POLICY & PRACTICE BULLETIN 8



## Contents

Pre-summit question for delegates.....	1
Background.....	1
Summary statement .....	2
Appendix A: Summit Participants .....	4
Appendix B: Policy & Practice Bulletin Series .....	5

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*Policy & Practice Bulletin 8 of the Summit Working Group on Dementia and Intellectual Disability: Family carers*

# Policy & Practice Bulletin 8 of the Summit Working Group on Dementia and Intellectual Disability: Family Carers

## Pre-summit question for delegates

What are the key issues for caregivers of adults with intellectual disability at different stages of dementia affecting support and care at home?

## 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

Throughout the 21<sup>st</sup> century we have seen an expanding population of older parents who continue to care for their son or daughter with intellectual disability well into the older age of both generations. This often develops into a mutually caring relationship with at times no need or desire for professional intervention. However, this may also be because family members are unsure of the support available or where to access information as it is needed particularly as dementia progresses and behaviours change. In some countries, the majority of older people with intellectual disabilities live at home with families - usually with one or both parents or a sibling. Yet family, regardless of living circumstance, often continue to play an important role supporting their relative aging with intellectual disability.

Families face many challenges when caring for their relatives that share some similarities and differences to those faced by carers of persons with dementia generally. The Summit debated how typical family supports can be adapted for dementia-capable care and how inter-system collaborations might be leveraged to ensure that supports can be accessed throughout the course of dementia alongside the 'typical' aging of adults with intellectual disability. These would apply irrespective of the presence of formalized structures and public policies present in a country or geographical area.

The discussions at the Glasgow summit showed consensus in recommendations:

- Effective supports offered to families need to be timely, appropriate, and tailored to the individual family's values, beliefs, ethnicity, and circumstance.
- Supports for families should build on their strengths and abilities to enhance coping with challenges faced providing dementia care to their relative with intellectual disability.
- Whether living with, or separately from, their relative with intellectual disability family members affected by dementia require support to continue their familial roles.
- Similar to other groups of family caregivers, caregivers should learn strategies to minimize stress and other negative effects long term caregiving may have on their own physical and mental health.
- Family carers should be supported to develop plans to manage every phase of the progression of dementia, including the possibility to decide about being replaced as a carer or sharing the carer activity with others if necessary.
- Research and service evaluations need to be undertaken into the nuances of caregiving roles and responsibilities of families of adults with intellectual disabilities at different stages of dementia to translate the findings into more tailored support services.
- Coordination of cross system services is required for effective family support.
- There is a need to recognize that a 'care partner' is not always a relative but may be a paid carer and there will be relationship implications should a move be instigated

for the person with dementia. Paid carers become like family for some people or may even be substitute family members for persons who have lost contact with their family of origin.

## **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>