

INTERNATIONAL SUMMIT ON
INTELLECTUAL DISABILITY AND
DEMENTIA:
**COMMUNITY DEMENTIA CAPABLE
SUPPORTS**

POLICY & PRACTICE BULLETIN 7



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Policy & Practice Bulletin 7 of the Summit Working Group on Dementia and Intellectual Disability: Community dementia capable supports

Policy & Practice Bulletin 7 of the Summit Working Group on Dementia and Intellectual Disability: Community Dementia Capable Supports

Pre-summit question for delegates

What are the required services and supports needed to maintain or improve quality of life for persons with intellectual disability residing in the community at all 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

Access to a range of dementia capable community services is often more difficult for persons with an intellectual disability affected by dementia. Traditionally, intellectual disability service providers and family members have focused on skill building and facilitating independence necessitating change to become dementia capable. Staff may be unfamiliar with dementia, unsure how to adapt services, or lack confidence or capacity to support the individual as dementia progresses. Referral and transfer of the individual to a different service may be initiated, in some instances disrupting established routines and social relationships as well as resulting in a loss of familiar environment. In some jurisdictions, this involves a move from a small scale or individual community setting to a large group care facility. Community services and supports for persons in the general population affected by dementia may be unfamiliar with intellectual disabilities and reluctant to include persons with intellectual disability.

The discussions at the Glasgow summit showed consensus in recommendation:

- An organisational strategy or policy is needed by service providers in order to plan for additional and changing supports required for a person affected by dementia. Planning for anticipated need changes may reduce crisis-oriented reactions to changes in care and aid in building relations with other community services that might provide guidance and support.
- Recognizing that flexibility in supports and services is essential, service providers need to develop appropriate and least intrusive dementia capable settings that accommodate individual needs wherever the person lives, and be cognizant of the differences among countries concerning funding systems and living circumstances.
- Ageing in place may not always be the preferred option of the individual, however in order to know this, conversations are needed about health, dementia and longer-term planning.
- We need to avoid a “new” model of care being presented in the guise of a nursing home facility amid concerns of a return to institutional living under a different name.
- Acute care is not an appropriate medium or long-term option for dementia care.
- Life story work is an essential aspect that supports dementia capable settings to understand and support the individual throughout the changes experienced
- There is a need to acknowledge, but advise against, inappropriate moves between accommodation settings due to lack of availability of day staff when people can no longer attend day services, resources or employment sites.
- Recognition of the importance of waking night staff as dementia progresses in order to avoid unplanned moves due to lack of appropriate support.

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>