

INTERNATIONAL SUMMIT ON  
INTELLECTUAL DISABILITY AND  
DEMENTIA:  
**HUMAN RIGHTS & CONVENTION  
FOR RIGHTS OF PERSONS WITH  
DISABILITIES**

POLICY & PRACTICE BULLETIN 4



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*Policy & Practice Bulletin 4 of the Summit Working Group on Dementia and Intellectual Disability: Human rights and convention for rights of persons with disabilities*

# **Policy & Practice Bulletin 4 of the Summit Working Group on Dementia and Intellectual Disability: Human Rights & Convention of Rights for Persons with Disabilities**

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

How can provisions of the Convention of Rights for Persons with Disabilities be optimally utilised to support people with intellectual disabilities affected by 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

People with dementia and people with intellectual disabilities both fall within the conception of disability adopted by the Convention of Rights for Persons with Disabilities (CRPD). Adopted in 2008, it represents a paradigm shift for people recognized as having a disability from a medical model of disability to a social model. However, there is little evidence that persons with dementia are being included in its implementation at national level. Scotland provides a notable exception, where a Charter of Rights for People with Dementia was adopted by the Scottish Parliament to take a human rights based approach in the development of care services for people with dementia in Scotland. The subsequently developed Standards of Care for Dementia in Scotland relate to everyone with a diagnosis of dementia in Scotland regardless of where they live, their age, the supports they receive or the severity of their illness. The Standards of Care explicitly apply to people with intellectual disability in Scotland and there is a growing argument, particularly among dementia self-advocates, that dementia should be universally viewed as a disability.

Similar, there is a call from the intellectual disability sector for a greater crossover and shared learning between intellectual disability services and dementia care. This offers potential for a unified approach which appreciates the commonality of issues facing people with intellectual disabilities and those affected by dementia, and the multiple discrimination that may occur when a person is affected by both merits further attention. The Summit considered areas of divergence and overlap considering that a more strategic approach may be required that offers substantial opportunity for the improved implementation of the Convention on the Rights of Persons with Disabilities, in relation to people with intellectual disabilities affected by dementia.

Divergence occurs as people with an intellectual disability have already faced a lifetime of stigma and discrimination due to the perception of others even before a diagnosis of dementia. A diagnosis of dementia among the general population without an intellectual disability offers some insight into this world. A medical focus still prevalent in some countries, with barriers evident both socially and environmentally even prior to dementia.

The discussions at the Glasgow summit showed consensus in recommendation:

- That a human rights approach be adopted that ensures everyone with dementia including people with intellectual disability, are provided with information in an accessible format to make people aware of their rights.
- That intellectual disability organizations respond to a call for greater advocacy on behalf of their members with an intellectual disability and dementia.
- That intellectual disability organizations liaise with dementia organizations to share an advocacy role for families.

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- That all nations review laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person's autonomy, will and preferences.
- Consistent with the CRPD, deinstitutionalization should be achieved and legal capacity must be restored to all persons with intellectual disabilities, who must be able to choose where and with whom to live.

## **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>