

INTERNATIONAL SUMMIT ON INTELLECTUAL DISABILITY AND DEMENTIA POST-DIAGNOSTIC SUPPORT

POLICY & PRACTICE BULLETIN 6



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Policy & Practice Bulletin 6 of the Summit Working Group on Dementia and Intellectual Disability: Post diagnostic support

Policy & Practice Bulletin 6 of the Summit Working Group on Dementia and Intellectual Disability: Post-diagnostic Support

Pre-summit question for delegates

How far does post diagnostic support in people with intellectual disability mirror generic models and practices, and what are the critical components that should make up post diagnostic support when applied to people with intellectual disability?

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 discussions at the Glasgow summit showed consensus in principle that post-diagnostic support is essential for people with intellectual disabilities. However, it is clear that there are differences in policies and practices between countries regarding what constitutes the post-diagnostic period, and if time constraints should be applied. Nor is it apparent that there is international agreement on what constitutes effective interventions for people with intellectual disabilities. Non-pharmacological and pharmacological interventions post-diagnosis necessitate both the funding and the personnel to deliver, monitor and evaluate both, and to ensure that they are making a difference to the quality of life for the person.

In relation to pharmacological interventions, the two major classes of medications to reduce the symptoms of dementia are acetylcholine esterase inhibitors such as Aricept which increases acetylcholine concentration in the brain, and N-methyl-D-aspartate (NMDA) antagonist (Memantine). Whilst neither are used to prevent the long-term progression of dementia, both have been shown to slow clinical deterioration in the short/medium term in the general population. These drugs are therefore recommended for treatment of dementia (particularly Alzheimer's disease), through guidance such as the UK's NICE guideline (NICE 2012). The guidance explicitly includes individuals with intellectual disabilities and Down's syndrome in their recommendations. However, it is clear from Summit representation that dementia medication for people with intellectual disability is not routinely considered and/or funded in all countries.

Post diagnostic support should start with sharing the diagnosis with the person with intellectual disabilities wherever possible. It is important that professionals should take an individualized person-centered approach to share information with the person with intellectual disabilities as early as possible, and at all stages, so that they can be supported to understand and cope with changing experiences. To support this, the summit has committed to the translation of Jenny's Diary into a range of languages (see Further Reading). This approach supports the inclusion of the person with intellectual disability as far as possible in decisions about their future support and care, and are supported to describe and have recorded their views and preferences about future care.

The Summit explored what might comprise a working model of post-diagnostic support that could be applied to people with intellectual disability and dementia and their carers/ support staff. This was developed from a consensus that the timeline for post-diagnostic support is from the point where the diagnosis is confirmed to when the person reaches the end of life stage of dementia. The proposed Glasgow Summit model supposes that in concert with national dementia care policies, family, ethnic and cultural values, and the preferences of the adult, provision of post diagnostic support is within a community-based framework. It is therefore designed to preclude inappropriate change of

accommodation or day services. The components of the proposed Glasgow Summit model include:

- Post-diagnostic counselling and/or support for the person and their carer in relation to the diagnosis, its implications, and the probable progression, as well as information about sources of support.
- Ongoing medical and psychological monitoring throughout the progression to address dementia-related needs and conditions (e.g. epilepsy) and non-dementia comorbid conditions, irrespective of whether they are known to impact directly on the course of dementia.
- Periodic, but regular, reviews of the person's care plan to identify significant changes in health, behaviour, function and quality of life and make adjustments in activities and support.
- Review of care practices and support when advanced dementia is reached.
- Provision of supports to family and paid carers, from diagnosis through the progression of dementia recognising that change may at times be rapid.
- Evaluation of quality of life at regular intervals using self-report where possible.
- Review of care practices and support when the condition of the individual changes considerably so as to introduce presumption of approaching death.

Appendix A: Summit Participants

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| 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>