

INTERNATIONAL SUMMIT ON INTELLECTUAL DISABILITY AND DEMENTIA: **NOMENCLATURE**

POLICY & PRACTICE BULLETIN 1

 THE
RS MACDONALD
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 Alzheimer
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Action on Dementia

 ntg
National Task Group
on Intellectual Disabilities
and Dementia Practices

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Policy & Practice Bulletin 1 of the Summit Working Group on Dementia and Intellectual Disability: Nomenclature

Nomenclature pre-summit question for delegates

How might we harmonize and standardize the terminology used in research papers, practice guidance and policy documents when referring to dementia and people with intellectual disability/Down syndrome?

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 as the preferred option of individuals, 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

Nomenclature is a system of names or terms, or the rules for forming these terms in a particular field of arts or sciences. A review by the Summit group of publications (including journal articles, book chapters, reports and plans) involving people with intellectual disability found dementia-related terms that lacked precise definition and contained inconsistency in the use of terms, sometimes within the same document. As with dementia research in the non-intellectually disability population, language related to dementia in the intellectually disability field often lacks precision and could lead to a misunderstanding of the condition(s) under discussion; an increasingly crucial issue given the increased global attention dementia is receiving in that field. Most articles related to intellectually disability and dementia reporting clinical or medical research generally provide a structured definition of dementia or related terms; social care articles tend toward term use without definition. Some of this imprecision and confusion may be due to a lack of understanding of the distinction in the different types of dementia, inconsistent use of language and/or the result of an absence of agreed core methods and criteria in diagnosis. Yet, lack of precision in language affects the understanding of any condition under discussion and confusion is further increased by a lack of agreement on common terminology.

The Summit recommends terminology standardization within studies/reports on dementia and intellectual disability and that a consistent approach is taken. This is to ensure: (a) growing familiarity with dementia-related diagnostic, condition-specific, and social care terms (b) creating a guidance document on accurately defining and presenting information about individuals or groups referenced, and (c) that in reports on dementia or cognitive decline or impairment, definitions are used and data include subjects' ages, sex, level of intellectual disability, residential situation, basis for dementia diagnosis, presence of Down syndrome (or other risk conditions), years from diagnosis, and if available, scores on objective measures of changing function.

The discussions at the Glasgow summit showed consensus in recommendation:

- Promotion of positive imagery that organizations, researchers, educators, and practitioners adopt image enhancing language when describing persons with intellectual disability affected by dementia and avoid language that stigmatizes;
- Promotion of a common understanding of the meaning of terms used to describe services and conditions related to dementia and intellectual disability, with a standardized list or taxonomy adopted for general use.
- To help with reporting events or research related to intellectual disability and dementia, that information be included that accurately defines and presents detail about individuals or the group being referenced. This should include both formal diagnostic criteria and general definitions of various dementias.

- To standardize reporting that there is a consistent approach to harmonizing data in that addresses different types of dementia, behavioral and functional changes, and cognitive decline or impairment. Such reports should use recommended definitions and at a minimum include the subjects' ages, sex, level of intellectual disability, residential situation, co-morbidities, basis for dementia diagnosis, presence of Down syndrome (or other risk condition), years from diagnosis, and if available, scores on an objective measure of changing function from a recognized and validated dementia scale.

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, Brazil / 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>