



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

2017 INTERNATIONAL SUMMIT ON AGEING WITH AN INTELLECTUAL DISABILITY

BEST PRACTICES IN POLICIES, SERVICES AND COMMUNITY
SUPPORTS TO ADVANCE HEALTH AND WELLBEING



20th September 2017

Trinity Centre for Ageing and Intellectual Disability
Trinity College Dublin

<https://www.tcd.ie/tcaid>
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08.30 - 09.00	Registration
09.00 - 09.05	Opening: Professor Martina Hennessy, Associate Dean of Research, Trinity College Dublin
09.05 - 09.15	Welcome Address: Ageing with an Intellectual Disability in Ireland – Mr. Finian McGrath, TD, Minister of State with Responsibilities for Disability Issues
09.15 - 10.45	Session 1: Ageing with an Intellectual Disability – The Irish Perspective Presents research findings from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) on morbidity, wellness, healthcare utilisation, social circumstances, family involvement, carer supports, and de-institutionalisation challenges and opportunities. This includes research on bone health, polypharmacy, transitions from congregated settings, social engagement, loneliness, end of life planning and palliative care. Policies, services and supports that improve the health, wellbeing and quality of life for individuals with an intellectual disability will be discussed. Title: Ageing, Health and Wellbeing in Adults with Intellectual Disability by Professor Mary McCarron, Principal Investigator, IDS-TILDA and Dean, Faculty of Health Sciences, Trinity College Dublin
10.45 - 11.15	Tea & Coffee Break
11.15 - 12.15	Session 2: Ageing with an Intellectual Disability – The UK Perspective Compares IDS-TILDA data to UK trends with presenters focusing on what is known about dementia and other health issues among people with intellectual disability. This includes how research databases are effectively mined to yield clinical recommendations and how research is changing healthcare practice, particularly for GPs, nurses and other health and social care providers. Title: Advances in Ageing and Dementia in People with Learning Disability by Professor Tony Holland, Health Foundation Chair in Learning Disabilities, Department of Psychiatry, University of Cambridge Title: Health Needs of Older Adults with Learning Disabilities in Primary Care by Professor Gyles Glover, Co-Director, Learning Disabilities Observatory Team, Public Health England
12.15 - 13.15	Lunch and Networking
13.15 - 14.30	Session 3: Ageing with an Intellectual Disability – Australian and American Perspectives Making comparisons with IDS-TILDA data and drawing upon Australian and American findings, this session presents emerging best practices in supporting community living for people with intellectual disability, their families and other carers, and discusses retirement planning within the context of changing public policies. Data from the United States will evaluate efforts to realise the “community imperative” by adapting ageing-focused, evidence-based health promotion and self-management approaches to genuinely include people with an intellectual disability in service planning and delivery. Title: Ageing with Intellectual Disability in Australia: Disability Funding, Retirement and End of Life by Professor Roger Stancliffe, Centre for Disability Research and Policy, University of Sydney Title: Evidence-Based Interventions for Addressing Health Concerns in Later Life by Professor Philip McCallion, Director, School of Social Work, Temple University and Adjunct Professor, Trinity College Dublin
14.30 - 15.00	Tea & Coffee Break
15.00 - 16.30	Panel Discussion: Best Practices in Policies, Services and Community Supports Speakers and other panelists from government, health and advocacy sectors will respond to participant questions and discuss findings which have emerged from all three sessions, with a focus on identifying best practices in policies, service provision and community supports relevant to the Irish context. A Policy Brief will be developed with recommendations to improve health, wellness and person-centred care for people with an intellectual disability which will be informed by participants during this engaging session.
16.30 - 17.00	Closing Remarks & Next Steps: Policy Brief
17.00 - 17.30	Networking Reception

01

Martina Hennessy

Professor Martina Hennessy is currently Associate Dean of Research in Trinity College where she represents Trinity nationally and internationally as well currently being involved in writing the first ever College Strategy for Research Excellence which articulates two highly relevant health research axes: Integrated Health & Ageing. In addition to that academic role, she is also a Clinical Pharmacologist and Consultant Physician at St. James's Hospital Dublin with clinical expertise in hypertension, cardiovascular risk and medication safety. The three main objectives of her research interests are i) that every patient should experience optimal therapeutic intervention, ii) that high quality healthcare should not be limited by poverty, iii) that we build sufficient talent development capacity to catalyse excellence within the Irish medical research and education ecosystem. Formally a Chair of Trinity's International Development Initiative, Martina's collaborative partnerships range from undergraduate medical education to international development projects. She is PI for the NOURISH project which is a Ugandan/Irish research cluster investigating the relationship between HIV and nutrition and currently Chairs/Co-Chairs several task-forces and committees both in Trinity College and St. James's Hospital.

02

Finian McGrath

Mr. Finian McGrath TD, is Minister of State at the Departments of Social Protection, Justice & Equality and Health with special responsibility for Disabilities. The Minister is accountable for developing and articulating Government policy on improving the lives of people with disabilities and their carers through three Government Departments: Health, Social Protection and Justice & Equality. The Minister is focusing on the Rights of Persons with Disabilities as well as their Equality of Opportunity, Access to Early Childhood Care and Educational needs. The Minister is committed to implementing in full, Ireland's first ever Carer's Strategy. Minister McGrath was elected to Dublin City Council in 1999. He was first elected to Dáil Eireann as an Independent in 2002 and was subsequently re-elected in 2007, 2011 and again in 2016 representing Dublin Bay North. In May 2016, as part of an Independent Alliance, Minister McGrath entered into a Partnership Government with an agreed programme including major Health and Disability Reforms.

03

Mary McCarron

Professor Mary McCarron, Principal Investigator, IDS-TILDA and Dean, Faculty of Health Sciences, Trinity College Dublin, PhD RNID, RGN, BNS. F.T.C.D, is Chair of Ageing and Intellectual Disability. Professor McCarron is an international expert in the fields of intellectual disability, ageing, dementia, and palliative care. She is the founder and Principal Investigator for the first ever longitudinal comparative study on ageing in persons with intellectual disability (IDS-TILDA) with the general population. With extensive experience in the area of dementia in people with Down syndrome, Professor McCarron has led large longitudinal cohort studies spanning over 25 years. Her special interest is on the early detection and presentation of dementia, and in the development of humane approaches to care and support. Her award-winning environmental designs and technology innovations for care homes are improving quality of life for people across the continuum of dementia.

04

Tony Holland

Professor Tony Holland, Health Foundation Chair in Learning Disabilities, Department of Psychiatry, University of Cambridge, leads interdisciplinary research on learning disabilities, intellectual disabilities and mental handicap. Research to date has had the following main themes. First, the relationship between specific genetically determined neurodevelopmental disorders and patterns of development and associated co-morbidities. Research projects have included investigations into the links between Down syndrome and the high risk for developing Alzheimer's disease. Secondly, Professor Holland investigates the interface between people with learning disabilities and the law. This has included research to inform the Mental Capacity Act 2005 and to investigate offending by people with learning disabilities. Thirdly, he focuses on sociological studies broadly on the theme of citizenship with respect to people with learning disabilities.

05

Gyles Glover

Professor Gyles Glover, Co-Director, Learning Disabilities Observatory Team, Public Health England, is a doctor with postgraduate training in psychiatry and public health. He has worked at Charing Cross Westminster Medical School, the Institute of Psychiatry, the Research unit of the Royal College of Psychiatrists, the Department of Health, and at Durham University, as the first professor of public mental health in England. He moved to the North East Public Health Observatory and with colleagues established the national Learning Disabilities Observatory in 2010. In 2013, this became a part of the new national Public Health agency, Public Health England.

06

Roger Stancliffe

Professor Roger Stancliffe, Centre for Disability Research and Policy, University of Sydney, is a researcher in the intellectual and developmental disability field with a special interest in community living. Professor Stancliffe's research focuses on making a difference in the lives of people with intellectual and developmental disability, ranging from research on transition to work to studies on ageing. He recently led the 3-year Transition to Retirement research project that demonstrated the benefits for older Australians with disabilities in developing an active, socially-inclusive retirement lifestyle. Currently, he is leading the 3-year Dying to Talk research project that examines understanding of end of life by adults with intellectual disability. This project also involves an intervention component to help improve understanding, based on everyday conversations about issues related to end of life. Professor Stancliffe has authored 175 academic publications on disability and has presented papers at research conferences in five continents. He edited the Journal of Intellectual & Developmental Disability from 2003 to 2008. He is a Fellow of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), and is the recipient of the 2011 AAIDD Research Award.

07

Phillip McCallion

Professor Philip McCallion, Director, School of Social Work, Temple University and Adjunct Professor, Trinity College Dublin, bridges scholarship on ageing populations and those with intellectual disabilities such as Down syndrome. He is co-principal investigator of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing, a visiting professor at Trinity College Dublin, a John A. Hartford Foundation Social Work Faculty Scholar and Mentor, and a member of the steering committee of the National Task Group on Intellectual Disabilities and Dementia. A renowned researcher, Professor McCallion has received more than \$30 million in research funding and published more than 140 articles on interventions with older adults with chronic conditions, caregivers of frail elderly persons with Alzheimer's disease, and persons with intellectual or developmental disabilities. Professor McCallion's research began with randomized control trials of psychosocial interventions for people with dementia and their caregivers. His interests have extended to creating ageing-prepared communities; evaluating non-pharmacological interventions; increasing the reach of palliative care programs; and developing community-oriented projects to assist ageing persons with intellectual disabilities.

08

Charles Normand

Professor Charles Normand, Chair, is an economist and the Edward Kennedy Professor of Health Policy and Management at Trinity College Dublin. From its inception, he has been a co-investigator on The Irish Longitudinal Study on Ageing (TILDA) and is a senior investigator in the All-Ireland Institute of Hospice and Palliative Care. His main research interests are on financing and delivery of health care, with a focus on the effects of ageing on health and social care. He has worked on planning and monitoring the effects of shifting care for people with mental health problems and intellectual disabilities from hospital to community settings since the late 1980s. More recently he has become involved in studies on palliative and end of life care, with a special focus on the roles and experiences of informal caregivers and the costs to patients and families near the end of life.

09

Mo Flynn

Mo Flynn, President, Irish Gerontological Society and CEO, Rehab, qualified from the New University of Ulster as a social worker and held positions in general and medical social work in Ireland, the UK and Australia, before progressing into senior social work and management positions. She completed a master's degree in gerontology at King's College, University of London, and worked with the NHS as a continuing care coordinator and with the Health Advisory Service in London as a service development advisor, specialising in older persons' services. Mo returned to Ireland in 2001 to work with the Eastern Regional Health Authority as a service planner for older people and people with intellectual disabilities and later as a senior commissioner, before taking on the role of national care group manager in the older people's directorate of the Health Service Executive. She was appointed chief executive of Our Lady's Hospice and Care Services in 2006 and led the organisation through a strategic planning and change process in a period of significant financial pressure. Mo became Group CEO of Rehab in January 2015, where she has developed a new strategy for the organisation across the spectrum of care, learning and employment for people with disabilities. She is a board member of CORU, the regulator for health and social care professionals, President of the Irish Gerontological Society and a council member of the International Association of Geriatrics and Gerontology.

10

**Breda Crehan
Roche**

Breda Crehan-Roche is Chairman of the National Federation of Voluntary Bodies and Chief Executive of Ability West, a non-statutory service provider in the intellectual disabilities sector. Breda worked in the Midland Health Board from 1996-2005 in the following positions; Project Specialist Disabilities; Continuous Quality Improvement Co-ordinator, for both Acute Care and Community Care Services; Director of Services for Persons with Disabilities: Assistant Chief Executive Officer/Programme Manager, Community Care Services. Breda was appointed the National Director Social Inclusion in the HSE in early 2005, a role which she covered until she joined Ability West formerly known as the Galway Association in September 2015. Breda's qualifications include MSc (Econ) Healthcare Management, MBS, Montessori Teaching, RNID.

11

Lisa Cogan

Dr Lisa Cogan is Consultant Geriatrician in St Vincent's University Hospital and The Royal Hospital Donnybrook. Since 2009, she has been the Medical Director in RHD which provides residential, respite and rehabilitation services to older and younger patients. Her specialty interests include orthogeriatric rehabilitation of older persons, management of patients with dementia and chronic complex disease, end of life symptom management and advanced care planning in residential care. She has experience in the management of younger patients who are minimally conscious following an acquired brain injury. Her other interests include quality improvement and clinical governance.

12

**Paddy
Connolly**

Paddy Connolly has been the CEO of Inclusion Ireland since 2012. Inclusion Ireland is a rights-based advocacy organisation that works in partnership with people with an intellectual disability and families of people with a disability to campaign for changes in services, supports and legislation which will improve the quality of life and participation of people with an intellectual disability in Irish society.

The Trinity Centre for Ageing and Intellectual Disability is the first dedicated Centre to investigate key issues in ageing, intellectual disability and the life course. Underpinned by the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA), the Centre advances world-leading research, scholarship and training to identify the determinants of health and wellbeing for adults with an intellectual disability. Through a transdisciplinary and cross-sectoral approach, we explore the individual and societal impacts associated with ageing, in order to address gaps in knowledge, inform clinical practice, improve service provision and evaluate the efficacy of policies over time.

Our regular engagement with diverse stakeholders and emphasis on collaborative enquiry is aimed at advancing healthy, happy ageing for people with an intellectual disability. To ensure Ireland is a great country for all ages and all abilities, consider whether you can make a difference by becoming a Friend of the Centre. By doing so, you will help us to deliver excellence in research, advance education and training initiatives, and ensure that people with an intellectual disability are involved in the decisions that affect them the most.

You can donate your time, champion a cause, or provide a financial investment. All donations go to funding research and training.

To learn more, please contact:

Dr Eilish Burke

Ussher Assistant Professor in Ageing and Intellectual Disability

Associate Director, Centre for Ageing and Intellectual Disability

T: +353 1 896 1749

Email: eburke7@tcd.ie



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