

<b>The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)</b>	
<b>Project Descriptor</b>	Established in 2007, IDS-TILDA is a longitudinal study investigating ageing in Ireland among people with an intellectual disability, aged 40 and over. It is the <b>first study in the world</b> to directly compare the ageing experience of people with an intellectual disability to the general population.
<b>Societal Challenge</b>	People with an intellectual disability are living longer, but continue to experience significant health disparities, with the average age of death 19 years younger than for the general population. Health problems often go unrecognised and unmet, as people with an intellectual disability are largely excluded from health screenings and targeted health promotions. They are often absent from the decisions that affect them the most, including financial and retirement planning, choice of residence and desired levels of care.
<b>Project Synopsis</b>	<p>Before the establishment of this study, only minimal information was available on the prevalence and incidence of disease, in addition to the economic and social well-being of adults with ID in Ireland. IDS-TILDA has four objectives:</p> <ul style="list-style-type: none"> <li>• To understand the health characteristics of people ageing with ID;</li> <li>• To examine the service needs and health service utilisation of people ageing with ID;</li> <li>• To identify disparities in the health status of adults with ID as compared to TILDA findings for the general population; and</li> <li>• To support evidence-informed policies, practices and evaluation.</li> </ul> <p>The underpinning conceptual framework for IDS-TILDA investigates physical health, cognitive health, mental health, behavioural choices, healthcare access and utilisation, as well as community participation, social connectedness and transitions across the life course. IDS-TILDA does not simply describe the lives of people with an intellectual disability; the study is leading the way in both engaged research and translational activities that support health, wellbeing and quality of life for people with ID, their families and carers. See: <a href="http://idstilda.tcd.ie/">http://idstilda.tcd.ie/</a>.</p>
<b>Principal Investigator</b>	Professor Mary McCarron Dean, Faculty of Health Sciences
<b>Higher Education Institution</b>	Trinity College Dublin
<b>Civic / civil society organisation or other</b>	<p>The IDS-TILDA Team collaborates with:</p> <ul style="list-style-type: none"> <li>• All Ireland Institute for Hospice and Palliative Care</li> <li>• Alzheimer's Society of Ireland</li> <li>• Care Alliance</li> <li>• Down Syndrome Ireland</li> <li>• Irish Cancer Society</li> <li>• Irish Hospice Foundation</li> <li>• National Disability Authority</li> <li>• National Federation of Voluntary Bodies</li> <li>• The Atlantic Philanthropies</li> <li>• 125+ Service Providers</li> </ul>

<p><b>Funding Sources</b></p>	<p><i>Core Funders:</i></p> <ul style="list-style-type: none"> <li>• Department of Health</li> <li>• Health Research Board</li> </ul> <p><i>Leveraged Funding:</i></p> <ul style="list-style-type: none"> <li>• All Ireland Institute for Hospice and Palliative Care</li> <li>• Alzheimer's Society of Ireland</li> <li>• An Bord Altranais</li> <li>• Care Alliance</li> <li>• Department of Health</li> <li>• Down Syndrome Ireland</li> <li>• Dunhill Medical Trust Grant</li> <li>• Genio Dementia Programme</li> <li>• Gay and Lesbian Equality Network (GLEN)</li> <li>• European Commission - Horizon 2020</li> <li>• European Commission - Marie Curie FP7</li> <li>• European Institute of Technology</li> <li>• Health Services Executive</li> <li>• Irish Cancer Society</li> <li>• Irish Hospice Foundation</li> <li>• Irish Research Council</li> <li>• National Disability Authority</li> <li>• Peamount Intellectual Disabilities Service</li> <li>• Stewarts Care Services</li> <li>• The Atlantic Philanthropies</li> <li>• Trinity College Dublin</li> </ul>
<p><b>Public Engagement &amp; Involvement</b></p>	<p>The IDS-TILDA Values Framework advances sustained public involvement through inclusion, promotion of best practices, and a person-centred approach which empowers people with ID to be visible partners in co-created research. This includes:</p> <ul style="list-style-type: none"> <li>• <i>Action-Oriented Research:</i> IDS-TILDA works with Government agencies, health and social care providers, advocacy organisations and people with ID to generate and translate knowledge to inform policies and evaluate services. This includes commissioned reports for Government departments, as well as public and private service providers.</li> <li>• <i>Community-University Partnerships:</i> IDS-TILDA collaborates with resident organisations and service providers to conceive, design and implement projects that address the health and social care disparities experienced by people with ID and their families.</li> <li>• <i>Delphi Method:</i> IDS-TILDA facilitates national and international research teams and topical experts in systematically refining professional opinions to arrive at consensual agreements that inform policies and refine guidelines. This method is currently being utilised by the <i>National Indicators for People with an Intellectual Disability</i> project which, using IDS-TILDA as the primary data source, is developing a set of national indicators of positive ageing for people with ID to mirror those collected</li> </ul>

	<p>for the non-ID population. These indicators will inform government departments' policy developments and implementation directly.</p> <ul style="list-style-type: none"> <li>• <i>Knowledge Democracy &amp; Exchange:</i> IDS-TILDA encourages participants and beneficiaries to implement research findings by democratising knowledge through accessible information in a broad spectrum of formats.</li> <li>• <i>Participatory Research:</i> IDS-TILDA involves people with ID, their carers, service providers and families who inform research priorities, co-create easy-read and accessible research materials (computer aided personal interview questionnaire, protocols, research reports and the programme website) and serve as research ambassadors.</li> <li>• <i>Science Cafe:</i> IDS-TILDA was selected as the national exemplar of public, patient involvement in research and included in the Horizon 2020-funded SPARKS Exhibition at Science Gallery Dublin, which includes a science café series that encourages citizens to inform research and innovation.</li> </ul> <p>At its <a href="#">10<sup>th</sup> Anniversary Celebration</a>, IDS-TILDA was recognised as the leader in engaged research by the Health Research Board.</p>
<b>Outputs to Date</b>	<p><b>Phase I outputs (2007-2017) are as follows:</b></p> <ul style="list-style-type: none"> <li>• <a href="#">44 peer reviewed journal articles</a> and <a href="#">6 topic reports</a></li> <li>• 8 book chapters and 1 <a href="#">book</a></li> <li>• Accessible and easy-read surveys, protocols, <a href="#">research reports</a> and <a href="#">website</a></li> <li>• Data protection protocols, operational protocols, committee terms of reference, and ethical approvals (Waves 1–3)</li> <li>• 10 IDS-TILDA <a href="#">newsletters</a></li> <li>• 13 IDS-TILDA <a href="#">infographics</a></li> <li>• <a href="#">A Guide for Carers</a></li> <li>• <a href="#">Accessible End of Life Tool</a> and <a href="#">How To Guide</a></li> <li>• IDS-TILDA <a href="#">SPARKS exhibition at Science Gallery Dublin</a></li> <li>• 100+ interviews, press releases and media engagements</li> <li>• 400+ conference presentations, seminars, posters and consultations</li> <li>• <a href="#">12 videos</a> (HRB-funded Knowledge Exchange and Dissemination Scheme)</li> <li>• 10 PhDs, 1 MD and 10 MScs (complete) and 5 PhDs, 1 MD and 3 MScs (in progress)</li> <li>• <a href="#">2016 EIT Health International Summer School</a></li> <li>• MSc: <a href="#">Ageing, Health and Wellbeing in Adults with Intellectual Disability</a></li> <li>• Massive Open Online Course: <a href="#">Improving Health Assessments for People with an Intellectual Disability</a> which has attracted 1,600+ learners from 100+ countries</li> <li>• <a href="#">2017 International Summit on Ageing with an Intellectual Disability</a></li> <li>• IDS-TILDA Keeping in Touch Strategy: annual certificates of appreciation for participants, as well as Christmas and Easter cards designed by participants</li> </ul>
<b>Outcomes</b>	<ul style="list-style-type: none"> <li>• <b>Professional and Public Services Outcomes:</b> IDS-TILDA has provided the evidence-base for external policy and strategy documents at national and international levels, including professional standards and guidelines such as the <i>National Dementia Strategy</i>.</li> </ul>

- **Capacity Building Outcomes:** IDS-TILDA has successfully attracted research funding to train 10 PhDs, 1 MD and 10 MScs (complete) and 5 PhDs, 1 MD and 3 MScs (in progress). Its MSc in [Ageing, Health and Wellbeing in Adults with Intellectual Disability](#) launches in 2018. Additionally, individuals with an intellectual disability are now involved in training field workers, undergraduate and graduate students at Trinity College.
- **Economic Outcomes:** IDS-TILDA has provided jobs and training for 34 field workers, 4 research project managers and 20 researchers.
- **Internationalisation Outcomes:** IDS-TILDA is harmonised with 13 international longitudinal studies and attracts researchers from all over the world, including researchers from Ireland, Australia, Saudi Arabia, the United Kingdom, the United States, Taiwan, Spain and the Netherlands.
- **Health and Wellbeing Outcomes:** Since 2007, IDS-TILDA has engaged more than 750 people with ID, their families, carers and service providers and among the 638 participants alive at Wave 3, the response rate was 95.5%. Recruitment of up to 300 additional participants is planned for Wave 4. Accessible health information provided to participants by IDS-TILDA has resulted in a number of documented health and wellbeing outcomes, however, significant disparities continue.
- **Product Development Outcomes:** The IDS-TILDA Team has informed technology outputs including the [WaytoB](#) smartphone and smartwatch prototype, which won the 2017 James Dyson Award. Data file algorithms and a custom hot desk access system with secure controls and accompanying access policies have also been created.
- **Social and Cultural Outcomes:** In collaboration with the European Institute of Technology and Future Learn, IDS-TILDA research was translated into a Massive Open Online Course, [Improving Health Assessments for People with an Intellectual Disability](#), which has attracted more than 1,600 registered learners from Ireland, the United Kingdom, Australia, the United States and India who posted more than 1,800 comments in Week 1 of the course.
- **Leadership and Empowerment Outcomes:** A further award EIT Health award received by IDS-TILDA funds the Physical Activity Leader Project (P-PALs). This programme encourages adults with an intellectual disability to take a leadership role in promoting physical activity among their peers, encouraging adults with ID to learn how to lead a group in physical activities and games and encouraging participants to become more physically active. This programme is in collaboration with colleagues from the Universitat de Barcelona and Age & Opportunity.
- **Environmental Outcomes:** The Daughters of Charity Service received the [2014 Specialist Care Centre of the Year and the Building Project of the Year](#) Irish Healthcare Centre Awards for Willow View and Meadow View House, a new build home for 14 people with intellectual disabilities and dementia

	<p>in Dublin. The IDS-TILDA Team was heavily involved in the research and guidance behind the development of the home, culminating in a <a href="#">book</a> which describes the philosophy and critical aspects of the home, including: failure-free enjoyment of life, maintaining self-identity and ordinary living, promoting meaningful opportunities for communication, welcoming family and community, providing dignity at end of life, and expressing care for staff.</p>
<p><b>Longer-Term Anticipated Impact</b></p>	<p>Building upon IDS-TILDA’s successes, the <a href="#">Trinity Centre for Ageing and Intellectual Disability</a> was launched, in 2017, and serves as an international and multi-disciplinary research centre at Trinity College Dublin, which examines key issues in ageing, intellectual disability and the life course. Underpinned by IDS-TILDA, the Centre advances world-leading inquiry, scholarship, and training to investigate the societal and individual impacts associated with ageing with ID and to address existing gaps in knowledge. It is anticipated that the multi-disciplinary and cross-sectoral approach will inform clinical practice, improve service provision and evaluate the efficacy of policies over time. The Centre welcomes students, researchers, policy-makers, industry leaders, healthcare professionals and members of the public to advance educational programming and launch co-created research. Regular engagement with diverse stakeholders and emphasis on collaborative inquiry is aimed at advancing healthy, happy ageing for people with ID – the anticipated and desired impact from IDS-TILDA, which continues with its Phase II activities.</p>