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Introduction

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1.1 Introduction

In September 2011, a summary report on initial findings from a major landmark study, the *“Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing”* (IDS-TILDA) was published. This study was not only the first of its kind in Europe but it was also the only study with potential to compare the ageing of people with intellectual disability directly with the general ageing population.

1.2 Rationale for an Intellectual Disability Supplement

Ageing in ID is a relatively new phenomenon and there is a substantial gap in our knowledge as to how this increasingly at risk and vulnerable population age (McCarron *et al.,* 2011). International cross-sectional studies do provide some clues and suggest that as a group, individuals with intellectual disabilities (ID) have a greater variety and number of health care needs compared to those of the same age and gender in the general population (see Haveman *et al.,* 2010 for a detailed review). The Haveman *et al.,* review (2010) also draws attention to the lack of longitudinal and incidence studies on the health of elderly people with ID. Reasons cited include difficulties in securing the needed financial resources to conduct studies, difficulty in securing needed samples sizes, recruitment and retention challenges and consent and ethical issues. Yet, similar to the general population, longitudinal studies are likely a critical element in the evidence base for understanding the key determinants of health and well being of people with an ID as they age (McCarron & McCallion, 2007). They have a particular advantage in their ability to examine multiple exposures, determinants and outcomes, and to measure relationships between variables over time.

One solution would be to ensure the inclusion of people with ID in general population longitudinal studies but there is a dearth of examples where this has occurred. Often the sampling frame or the mechanisms for data collection reduce the likelihood of such inclusion, but a question arises is the issue simply a lack of attention. *The Irish Longitudinal Study on Ageing in Ireland* (TILDA) (Kenny *et al.,* 2010) recognised that inclusion of a supplement which would purposefully include persons with an ID would not only improve understanding of how people with an ID age in their own right but support direct comparison with data from other groups of older adults to understand differences in ageing experiences. A supplement would also help illuminate the roles of disability, education, lifestyle, living situations, social networks, health concerns, health service utilisation and environmental factors in supporting or thwarting successful ageing for people with ID. The Intellectual Disability Supplement to TILDA (McCarron *et al.,* 2011) closely harmonised questions with the general ageing study TILDA to ensure that (1) differences and similarities between the population groups would be systematically ascertained, and (2) data collected inform the development of future policies, services, and resources that better address the needs of both groups as they age in Ireland.

IDS-TILDA was also designed to explore unique issues for people with ID, e.g., their ageing profile, health, health service needs, psychological health, social networks, living situations and community participation including employment. In addition the experience of family carers has been captured.

In the general ageing field there is a long-standing awareness that longitudinal studies have played a major role in understanding many health concerns in older adults, their natural history and the complex interplay between biological, genetic, environmental, psychological and social factors on health and well-being (Newman, 2010, Stanziano *et al.,* 2010). Despite this awareness, we have little understanding of similar or different interplays of these factors on health and well-being of persons with ID as they age. The Intellectual Disability Supplement to TILDA has been launched as a program of research and a platform to investigate risk and protective factors, and increase our understanding of the trajectories of healthy ageing in persons with ID as compared to those for the general population.

1.3 First Wave Findings

First wave data was collected on a random sample of 753 people with ID aged 40 years and over, drawn from Ireland's National Intellectual Disability Database (Kelly *et al.,* 2010). Preliminary results from Wave I highlighted the reality of health disparities for people with intellectual disability as they age (McCarron *et al.,* 2011), including higher levels of mental health problems, increased risk factors for cardiovascular disease, obesity and polypharmacy, coupled with lower levels of physical activity, access to health information, and health care screenings. Additional findings that people with intellectual disability were also usually unemployed, had lower levels of education and access to life-long learning, and had more limited social networks and friendships and high levels of loneliness further highlighted their difficulties in accessing community supports, integrating within their communities and perhaps placed them at greater vulnerability in terms of the social determinants of health as one ages. A particular concern from the data was that despite decades of efforts to move people with an ID from segregated into community-based accommodation, some still lived in large segregated settings and many living at addresses in the community continued to remain poorly connected with those communities.

1.4 Understanding the link to public policy

The pursuit of longitudinal answers to ageing questions for people with intellectual disability at a research level is similar to the same questions within the general population and must now be mirrored in policy responses to the data gathered. As Rimmer (2011) suggests, inclusion 'merely gives us (people with ID and their advocates) entrance into the vast 'mall' of public health; ... Getting into the mall is one thing, getting into the reports, documents and policy recommendations is a totally different thing'. As a supplement to mainstream efforts to understand ageing, IDS-TILDA is intended to promote such inclusion and not separate consideration of older adults with ID. There is little to be gained for people with ID if they, their families and their advocates discuss these issues only with each other; policy makers and health professionals with an interest in ageing but limited knowledge of intellectual disability must be reached to ensure that issues for persons with ID are at the table when policies are formulated on health care reform, health promotion, the built environment, combating obesity, and strategies to prevent the development of additional secondary disability.

As Ireland launches its health reform policy agenda, its key policy documents including the *Healthy Ireland – A Framework for Improved Health and Well-Being 2013-2025* and *Move from Congregated Settings* (DoH, 2013; HSE 2011) have set forth opportunities and challenges associated with ageing, particularly ageing for people with an ID (see *figure 1.1*). Just as *The Irish Longitudinal Study on Ageing* (TILDA) is gathering and presenting general population data to inform these efforts, so too IDS-TILDA is ensuring that there is high quality data on people with an ID to assist our understanding and support both the implementation and evaluation of the important goals set out in these documents. The data available will also support the integration of this population group into future national health and social care policies, and services, better ensuring a healthy and happy life span for all people in Ireland. Perhaps, however, the most important role for IDS-TILDA is to be a launching pad to raise visibility of the needs and experiences of persons with ID as they age and to encourage the cross-walking of that information between specialised ID services and general public health environments.

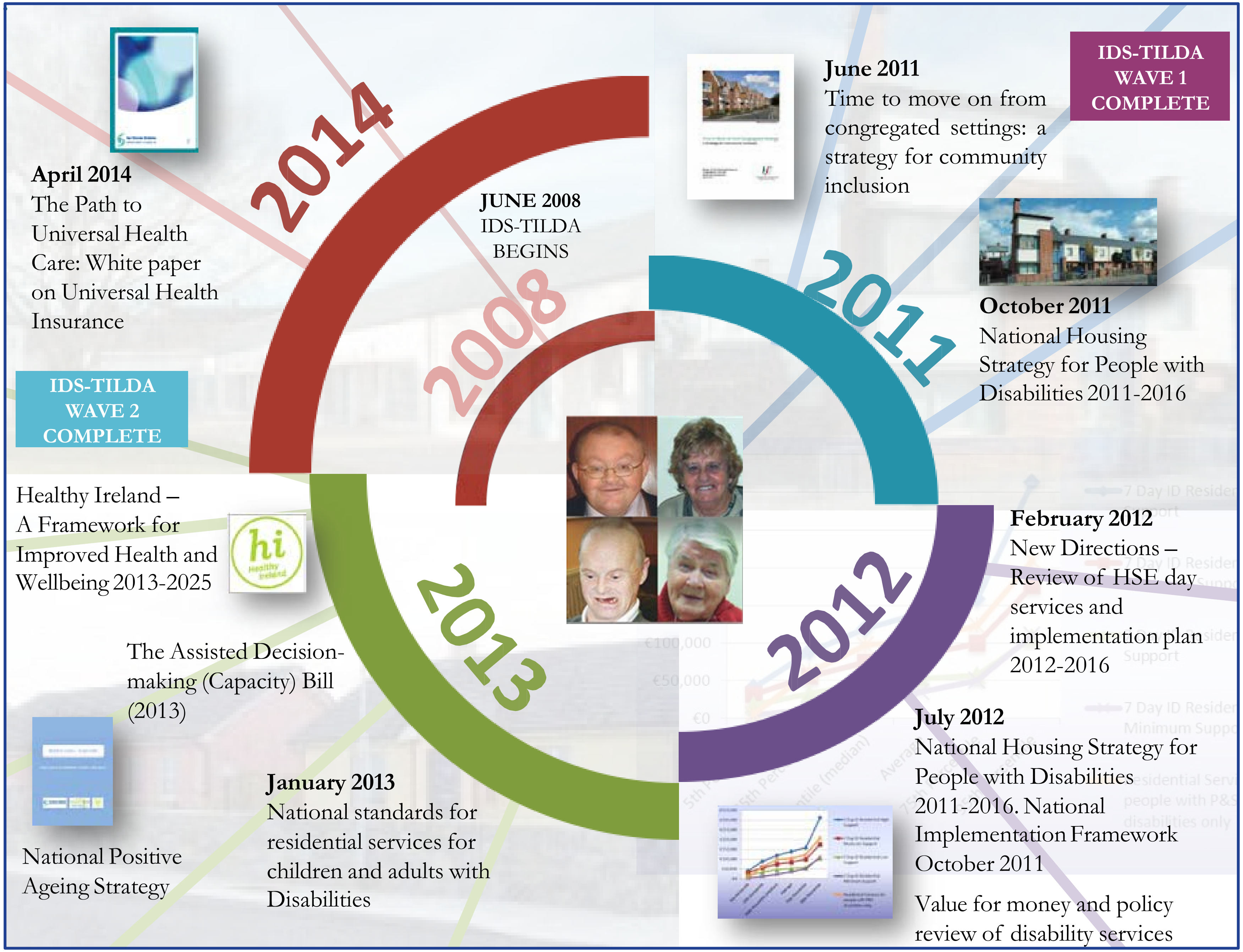
There are also ID-specific issues and over time IDS-TILDA will assist in identifying key issues in the prevention of disease and secondary disability in people with ID and improve understanding of the roles of pre-existing disability, social and living circumstances, education, wealth and social connectedness. There is also a need for similar intellectual disability supplements to longitudinal studies in other countries which will only occur when there are ID researcher advocates and openness by other researchers, funders and governments to support them. Such a commitment will ‘bear fruit’ in the implementation of evidence based policies that not only ‘add years to life, but life to years’ for people with intellectual disability as they age.

1.5 Wave 2 of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).

IDS-TILDA is now ready to report the results of its second wave of data collection. As can been seen in *figure 1.1* the period since IDS-TILDA began in 2008 has seen considerable social and economic change. In this second summary report, we document how the lives of people with an intellectual disability over 40 years in Ireland has changed over this intervening period, document the point prevalence and incidence of health conditions, and compare their ageing to that of the general population as documented in data yielded by TILDA (Nolan *et al.,* 2014). The report will focus particularly on physical and behavioural health, mental health, social participation and connectedness, and health care utilisation including the transitions of people into more community based settings. A more detailed and in-depth analysis of all these areas will be dealt with in forthcoming reports, papers and PhD theses from members of the research team. Additional domains not discussed here such as family caregiving, dealing with chronic illness and end of life will be addressed in forthcoming PhD thesis reports and publications.

Details of IDS-TILDA methodology, sampling and study population are described in the Wave I summary report (McCarron *et al.,* 2011). Chapter 6 of this report contains a detailed description of methodology for Wave 2 including a summary of amendments to the original protocol from Wave 1 and a detailed description of objective measures. The recruitment and data collection approaches for Wave 2 are illustrated in *figure 1.2.*

Figure 1.1 Positioning IDS-TILDA among the policy change affecting the field of intellectual disability in Ireland 2008 – 2013.



April 2014
The Path to Universal Health Care: White paper on Universal Health Insurance

JUNE 2008
IDS-TILDA BEGINS

June 2011
Time to move on from congregated settings: a strategy for community inclusion

IDS-TILDA WAVE 1 COMPLETE

October 2011
National Housing Strategy for People with Disabilities 2011-2016

IDS-TILDA WAVE 2 COMPLETE

Healthy Ireland – A Framework for Improved Health and Wellbeing 2013-2025

February 2012
New Directions – Review of HSE day services and implementation plan 2012-2016

The Assisted Decision-making (Capacity) Bill (2013)

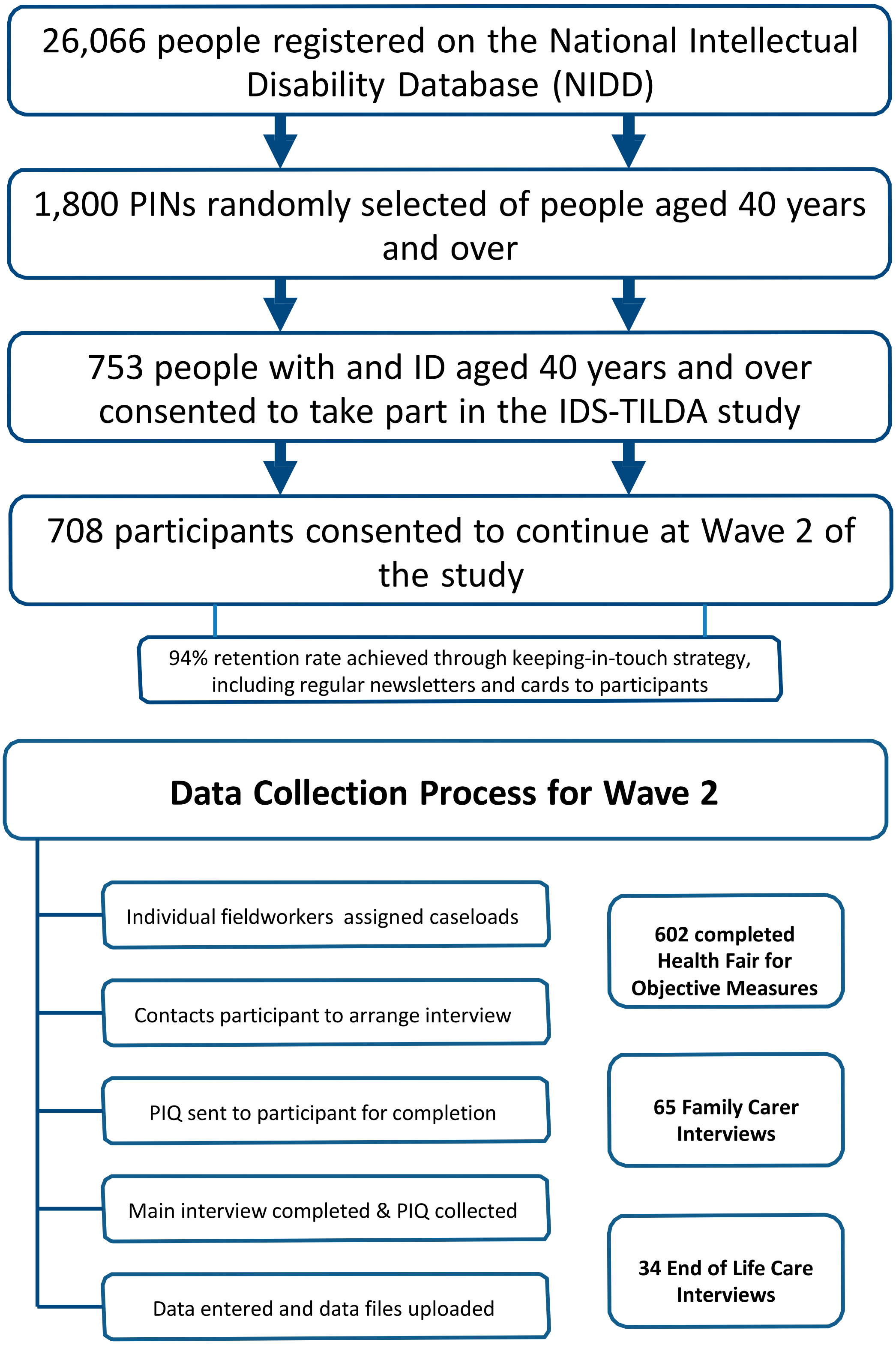
National Positive Ageing Strategy

January 2013
National standards for residential services for children and adults with Disabilities

July 2012
National Housing Strategy for People with Disabilities 2011-2016. National Implementation Framework October 2011

Value for money and policy review of disability services

Figure 1.2: Recruitment and data collection process for IDS-TILDA



1.6 Key Aspects of Wave 2

- At Wave 1, the National Intellectual Disability Database (NIDD) provided the sampling frame for the study and a nationally representative group of 753 respondents with an ID over the age of 40 years were successfully enrolled in the study.
- At Wave 2, all living Wave 1 respondents were invited to complete a pre-interview questionnaire (PIQ) and also undertake an extensive face-to-face computer assisted personal interview (CAPI).
- The overall response rate to Wave 2 of the study was 94%. Of those not participating 34 had died.
- Two new data collection elements were added to Wave 2 consisting of a health assessment and an end of life (EoL) interview conducted with carers of Wave 1 participants who had died.
- Strategic harmonisation of questions with The Irish Longitudinal Study on Ageing (TILDA) have ensured that there are opportunities to compare the experiences of people with ID with experiences of the general population as they too age.
- Attention to key policy documents in Ireland have ensured that there are questions and data available to assess how the implementation of key policies are influencing over time the ageing experience of people with ID.

1.7 Structure of the Report

We begin in Chapter 2 by describing how social participation and social connectedness changes over time by comparing relevant data from Wave 1 to Wave 2. We examine levels and types of social connections, engagement in social life, facilitators and barriers of social participation, and changes in residential status since Wave 1. Where possible comparisons will be made with the general population with data yielded from TILDA and/other identified sources. This descriptive and comparative approach is repeated in chapter 3 through 5. Chapter 3 focuses on the changes in physical and behavioural health. Point prevalence and incidence of health conditions will be presented and comparisons will be shown with the general population using reported data from TILDA (Finucane *et al.,* 2014; Leahy *et al.,* 2014). Chapter 4 focuses on changes in mental health including consideration of cognitive decline and the impact of life events. Chapter 5 focuses on health care utilisation and how it changes as people with ID move between living situations. Finally, Chapter 6 documents the methodological approach utilised for Wave 2 of IDS-TILDA, and describes the sample and new elements of data collection.

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Appendix 1: IDS-TILDA Reports and Publication

IDS-TILDA Reports and Accessible Material

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2. McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S and McCallion, Philip. (2011). Growing Older with an Intellectual disability in Ireland 2011: First Results from The Intellectual Disability Supplement to The Irish Longitudinal Study of Ageing: School of Nursing & Midwifery, Trinity College Dublin.
3. McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S and McCallion, Philip. (2011). Growing Older with an Intellectual disability in Ireland 2011: First Results from The Intellectual Disability Supplement to The Irish Longitudinal Study of Ageing: An Accessible Report. School of Nursing & Midwifery, Trinity College Dublin.
4. IDS-TILDA The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (2014). Retrieved on July 31, 2014 from http://www.idstilda.tcd.ie/
5. IDS-TILDA (McCarron, M. & McCallion, P.). (2012). IDS-TILDA: *Scenes from Our Lives* [DVD].

Peer-Reviewed Journal Articles 2014

1. Burke, E., McCarron, M., Carroll, R., McGlinchey, E. & McCallion, P. (2014)What it's like to grow older: The aging perceptions of people with an intellectual disability in Ireland. *Intellectual and Developmental Disabilities,52*(3), 205 – 219.
2. Mac Giolla Phadraig C., McGlinchey E., McCarron M., el-Helaali R, Burke, E., McCallion., and Nunn J.H.(2014). National levels of reported difficulty in tooth and denture cleaning among an ageing population with intellectual disabilities. *Journal of Dentistry and Oral Hygiene 15*(2), 20 – 25.
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4. McCarron, M., O'Dwyer, M., Burke, E., McGlinchey, E., & McCallion, P. (2014). Epidemiology of Epilepsy in Older Adults with an Intellectual Disability in Ireland: Associations and Service Implications. *American journal on intellectual and developmental disabilities, 119*(3), 253-260.

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2. McCausland D., McCallion P., McCarron M. Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA. *Journal of Applied Research in Intellectual Disability.*

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1. Burke E., McCallion, P., Walsh JB., and McCarron M. Structured Feedback from Older Adults with an Intellectual Disability on their Experience of Attending for a Health Assessment – Results from a Feasibility Study.
2. Burke E., McCarron M., Walsh JB., and McCallion, P. Osteoporosis and People with Down Syndrome; A preliminary Descriptive Examination of the IDS-TILDA Wave 1 Results.
3. Burke, E., McCarron, M., Walsh, JB. & McCallion, P. Supporting Older Adults with ID to Engage in Health Screening: Lessons Learned from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).
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PhD Thesis in Progress and Completed*

Ms. Janet Swinburne*: Feasibility of Anthropometric Measurements for Large-scale Application in the Irish Longitudinal Study on Ageing among People with an Intellectual Disability (IDS-TILDA): An Exploratory Study. Trinity College Dublin 2014.

Ms. Sinead Foran: The prevalence and predictors of falls and falls related injuries in older adults with intellectual disabilities in Ireland.

Dr. Niamh Mulryan (MD student): Mental health and associated factors in a national sample of persons with an intellectual disability aged 40 and over.

Ms. Maire O’Dwyer: Prevalence, Patterns and Indications for Medicine Use in an Ageing Population with Intellectual Disability.

Ms. Ann Belton: Changing patterns of medication use in an ageing population with an intellectual disability.

Ms. Mary Ann O’Donovan: Changes in living arrangements in later life: implications for health services and the health of the older person with an intellectual disability.

Ms. Marianne Griffiths: An exploratory study measuring changing experiences of carers of older people with an Intellectual Disability and investigating their support service requirements in the context of continued caregiving.

Mr. Darren McCausland: A study of social participation for older people with intellectual disabilities.

Ms. Janet Clare O’Farrell: Understanding equality and inclusion in Palliative Care: Identifying and addressing the needs of people with an Intellectual Disability.

Ms. Eilish Burke: An exploratory study to measure bone health and the prevalence of osteoporosis in older people with an intellectual disability in Ireland.