2023

Longitudinal Dynamics in the Ageing of People with an Intellectual Disability

Evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

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The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Longitudinal Dynamics in the Ageing of People with an Intellectual Disability

Evidence from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

Wave 5 IDS-TILDA

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The Intellectual Disability Supplement to TILDA

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Contents

List of Tables

Social Determinants of Health: Choice, Interpersonal Relationships and Community Participation

Multimorbidity and Physical Health Trajectories in People with Intellectual Disability

Behavioural Lifestyles

Psychological Well-being and Cognitive Health

Healthcare Utilisation

Family Carers

Methodology

List of Figures

Social Determinants of Health: Choice, Interpersonal Relationships and Community Participation

Multimorbidity and Physical Health Trajectories in People with Intellectual Disability

Behavioural Lifestyles

Psychological Well-being and Cognitive Health

Healthcare Utilisation

Oral Health

Methodology

Executive Summary

Social Determinants of Health: Choice, Interpersonal Relationships and Community Participation

Key Findings

Choice and decision supports

- Between Wave 2 and Wave 5, self-choice increased in every age category with the most notable increase in those less than 50 years of age.
- Younger men and women living independently / with family with a mild/moderate level of intellectual disability had the highest level of personal choice in all aspects of daily living.
- At Wave 5, one-third of the sample had a formal written decision agreement plan in place and a further 18.7% had an agreement under development.
- Thirteen people reported having an advanced care directive.

Interpersonal relationships

- Almost all participants had family (96.2%), with siblings being the most common, and there was an increase in the number of participants who lived close to family (29.3%); but still at Wave 5 very few marry or have their own children (<1%), with only a slight increase among the under-50s (1.6%).
- The proportion of participants with severe-profound intellectual disability living close to family (15.2%) was less than half that of participants with mild (37.7%) and moderate (33%) intellectual disability.
- The vast majority of participants also had friends (93.8%), and 60.5% had a best friend – both increased since previous waves. Nine in ten self-reporting participants had at least one close family member (88.4%), and one close friend (90.8%). Co-resident friends were most common (60.5%), and highest among participants living in residential care (75.2%) and group homes (73.5%). Peers with an intellectual disability were by far the most common type of best friend (62.6%), followed by support staff (18.1%).
- Individuals living independently or with family were more likely to have non-resident friends (79.8%) and to have a best friend (75.1%). Their best friends were also more likely to be family members, work colleagues and non-staff.
- Regular (weekly) contact with non-resident family has increased from 45.9% in Wave 1 to well over half (57%) in Wave 5, with another 21% having monthly contact.
- Regular contact with non-resident friends also increased over this period – three-quarters (76.6%) with these friends had weekly contact and a further 13.1% had monthly contact.

- The number who self-reported reporting that they had a confidant rose to 94.9% from 83.8% in earlier waves, with keyworker/support worker still the most common confidant (83.1%). Nearly one in four participants in Wave 5 (23.1%) provided help to their friends/ neighbours in the preceding two years, a substantial increase from 13.1% in Wave 1.

Community participation

- The mean number of regular community activities was 5.6 per month (SD = 3.1), with an increase across all age groups compared to Wave 3. Community activity decreased with increasing age; people in residential care were less active than others; people with severe-profound intellectual disability were less active than those with mild or moderate intellectual disability; and men were more active than women.
- Just one in 10 participants (10.9%) were in paid employment, a slight increase since Wave 4 (8.4%). Employment increased more significantly for the under-50s, from 20.4% in Wave 4 to 27.1%. Day service or day activation remained the most common daily activity (81.4%), but the number who reported doing nothing during the day almost doubled, from 6.9% in Wave 4 to 12.3% in Wave 5. In addition, 19.4% (n = 144) reported spending the majority of the week (four or more days) at home, with 5% (n = 37) not leaving their house in the past week. One in five (20.9%, n = 94) reported staying home due to lack of staff and resources.
- Mobile phone ownership at 44.7% in Wave 5 doubled from Wave 1 at 23%; but remains low by comparison with the general population at 96%. Access to and use of the internet at home also increased considerably over time, with nine out of ten participants (89.6%) now having access, and over half of all participants (53.7%, n = 409) reporting they used the internet at home, compared to 7.3% in Wave 1.
- Tablets (46.9%), smartphones (20.7%), and computers/ laptops (13.3%) were the smart devices most commonly used. Most older adults with an intellectual disability remain dependent on others to use technology.
- At Wave 1, 47.3% of participants lived in residential care, 35.6% in community group homes and 17.1% independent/with family. By Wave 5 the percentages were 28.5% in residential care, 49.0% in community group homes and 22.6% independent/with family.
- At Wave 1 44.8% of participants aged under 50 years lived in residential care, 34.0% in community group homes and 21.2% independent/with family. By Wave 5 the percentages were 7.7% in residential care, 45.9% in community group homes and 46.4% independent/with family.
- More people moved residence in Wave 5 compared with previous waves and moves to the same type of residence continue to be the largest proportion of these moves. Change in physical health status was the most commonly reported reason (25%) for moving to more supported settings, as well as the most commonly reported (12.5%) and ‘most important’ reason for moving to community based homes; and lack of nursing and twenty-four hour support the most significant contributor to such moves.
- A large proportion of those who moved noted that the move was talked about or included in their personal plan (86.8%), almost 80% reported that they wanted to move; yet only one-fifth of those who moved were included in viewing alternative accommodation before moving. Two-thirds of those who moved were not involved in the decision to move. However, 87% reported being happy now that they had moved with 6.1% still adapting to the change.
- Over half of participants had difficulty getting around their community (53.1%), down from 57.9% in Wave 1, with difficulty highest among the over-65 group (60.6%) and those with severe to profound intellectual disability (70.9%). Most participants rated the quality of their neighbourhood highly citing free/low-cost recreation facilities (78.9%), footpaths (77%), places to buy things (72.3%), transit (71.6%), and facilities to bicycle (58.1); however, almost half (46.7%) felt unsafe walking their neighbourhood at night.

Multimorbidity and Physical Health Trajectories in People with Intellectual Disability

Key Findings

- The physical health of participants aged under 50 improved over the last 10 years with 55.2% in Wave 5 reporting no chronic health condition compared to 36.7% in Wave 2. In addition, numbers reporting three or more chronic health conditions more than halved from 23.3% in Wave 2 to 11.9% in Wave 5.
- Despite the prevalence of chronic health conditions, the majority of adults (88.5%) appraised their health as excellent, very good or good.
- Prevalence for those aged 50 and over was 44.6% for hypertension and 44.7% for high cholesterol which was less than findings for the TILDA population at 52% (hypertension) and 59% (high cholesterol).
- Women with an intellectual disability had a significantly greater prevalence of arthritis than men.
- Doctor's diagnosis of osteoporosis for those aged 65 and over and the 50–64-year-olds increased from 24.7% in Wave 2 to 34.3% in Wave 5 and from 13.4% to 18.5% respectively. Whereas objective measurement found that 40.3% of the 50–64-year-olds had osteoporosis in Wave 2 and 36.4% in Wave 5.
- Individuals with severe/profound intellectual disabilities, regardless of sex, exhibited worrisome trends in poor bone health.
- Fragility fracture levels were higher in people aged 65 and over with intellectual disability (17.8%) than in TILDA participants aged 65 and over (9%).
- Women who have had fragility fractures exhibited notably elevated rates of osteopenia (47.8% versus 37.5% in men) whereas rates of osteoporosis remained similar for both (34.8% in women versus 37.5% in men).
- Fear of falling in people with intellectual disabilities was double that reported by TILDA for the general population aged 50 and over at 46.8% versus 21.8% respectively.
- Pain levels overall were similar to the general population aged 50 and over but pain reported by women under 50 rose from 24.5% in Wave 1 to 37.8% in Wave 5.
- Most frequently reported pain sites were knees (24%), stomach (21.1%) and back (15.2%).
- Across the waves of IDS-TILDA there has been a considerable and steady increase in GERD for all age groups. This was particularly evident among those aged 50-64 years where prevalence more than doubled from 7.3% in Wave 1 to 16.5% in Wave 5. Also, in individuals with severe or profound intellectual disability increases were from 15.9% to 28.6% in men, and from 10% to 30.7% in women.
- For all age groups constipation increased across the waves rising from 17.3% at Wave 1 to 42.8% at Wave 5. In the younger age groups (under 50 years) rates rose from 14.6% at Wave 1 to 34.4% at Wave 5, and prevalence in people with severe/profound intellectual disability was 70%.
- A newly introduced objective hearing screening at Wave 5 found a hearing deficit of (28.7%) among persons with mild and moderate intellectual disability versus self-report at (17.6%).
- Mean age at menopause was approximately 48 years for those without Down syndrome and approximately 44 years for those with Down syndrome.
- Just 41.6% of menopausal women in IDS-TILDA reported symptoms of the menopause whereas women in the general population report upwards of 90%.

- Only 48.8% of women were aware of menopausal transition; 37.9% of women said they discussed the menopause with someone and 16.2% received easy read materials on the topic.
- Foot health was self-rated as excellent/very/good by 89.8% of participants whereas 83.9% on objective measures were found with either moderate or high-risk foot problems with their feet, ranging from corns to infected ulcers. Measured rates for people with Down syndrome were 97.4%.

Behavioural Lifestyles

Key Findings

- Those with moderate intensity activity had the best quality of life scores and were least likely to experience loneliness.
- People in all age categories improved their levels of physical activity from Wave 2 to Wave 5. In some subgroups the percentages engaged in activity more than doubled.
- Despite these achievements half of participants (50.9%) were not engaging in the minimum amount of activity as recommended by the WHO (WHO, 2020).
- Those aged under 50 showed the greatest increase in the proportion doing vigorous physical activity since Wave 2 (3.6% to 11.8%)
- A smaller proportion of people with an intellectual disability engaged in high levels of activity than among TILDA general population participants over age 50 years (6% vs 33%).
- Walking was the most common physical pastime.
- Health considerations were most common reason for not doing more physical activity.
- Participants understood the health benefits of physical activity.
- Participants with low activity levels were more likely to be depressed.
- Activity intensity was positively related to mental health scores.
- Half of all participants reported their diet as excellent or good.
- Over 40% of participants reported watching 1-3 hours TV per day.
- Smoking levels decreased from Wave 1 to Wave 5 especially in younger age groups.

Psychological Well-Being and Cognitive Health

Key Findings

- The overall prevalence of mental health diagnoses at Wave 5 (44.4%) was lower than that seen in Wave 1 (49.9%), with anxiety the most prevalent reported condition at 24.1% which was much higher than that reported by TILDA for the general population over 50 years old.
- Depression also remained an important concern with 13.0% reporting a doctor’s diagnosis much higher than that reported by TILDA for the general population over age 50 years (5%), and much higher for those in community settings.
- Those aged 65 and over reported a greater overall prevalence for mental health diagnoses.

- Prevalence of mental health concerns remained highest among those with severe or profound intellectual disability.
- For those with Down syndrome, prevalence of mental health concerns at 15.2% was markedly lower than reports in Wave 1 at 24.1% and were 50% less than that reported for people with an intellectual disability from other aetiologies.
- Despite the high prevalence of mental health conditions reported, more than 80% rated their overall emotional and mental health as either excellent/very good/good.
- Self-reported loneliness declined from 50.5% at Wave 1 to 40% at Wave 5. This was especially notable among the under-50s, with 34.9% reporting feeling lonely at Wave 5 compared with 51.3% in Wave 1; and among participants living in residential settings, whose rates fell from 53.8% to 32.4% from Wave 1 to Waves 5 respectively.
- The mean score of Energy and Vitality levels at 68.9 were high regardless of age, setting or level of intellectual disability, and higher than those reported in the wider Irish population at 62.4% (Government of Ireland, 2021).
- Nearly two-thirds of respondents (77.1%) reported experiencing more than one life event over the previous year.
- In Wave 5, prevalence of dementia in people with Down syndrome was 22.7% ($n = 32$). The majority of people with Down syndrome and dementia were aged 50-64 at 84.3% ($n = 27$), and only 3% of those with Down syndrome and dementia in the 65 and over age group, perhaps suggesting earlier mortality for those with Down syndrome.
- Dementia was much higher in people with Down syndrome than those with an intellectual disability from other aetiologies with a mean age of onset in those with Down syndrome of 53 years compared to 67.5 for those with intellectual disability from other aetiologies.
- Dementia screening rose for those with Down syndrome, from 13.9% ($n = 28$) in Wave 1 to 66.4% ($n = 83$) in Wave 5. However, in Wave 5, 42.7% ($n = 41$) of those with Down syndrome who did not have dementia had never had a dementia assessment despite being over the age of risk.

Healthcare Utilisation

Key Findings

- Private health insurance cover increased for people with intellectual disability from less than 5% at Wave 1 to over 11% at Wave 5, similar to the general population. However, adults who lived in residential care had the lowest level of private medical cover.
- Older people with intellectual disability attended the GP and emergency department more often than the average for others, but they attended fewer outpatient appointments and spent fewer nights in hospital per year.
- Over the five waves of IDS-TILDA there was a trend for increased utilisation of specialist health (e.g., optician, dental, hearing) services for older adults with an intellectual disability.
- Wave 5 participants aged 40 - 49 years were less likely to use the public health nurse and therapy services than those aged 50 and above but more likely to use dental and pharmacy services.

- Adults with intellectual disability continued to have high uptake levels of flu and COVID-19 vaccinations with 95.1% of participants receiving the flu vaccine. COVID-19 vaccination rates were at 99.1% of participants and a further 98.1% received a follow up COVID-19 booster.
- Of 156 people who were eligible for bowel screening in the previous two years, 68.1% had a bowel screen. This is higher than the national reported average ranging from of 41.9% to 46.6%.
- Thirty-seven percent of eligible participants reported that they were invited for a cervical screen in the previous two years. Of those who were invited, only 30.6% attended. Fear was cited as a predominant reason for not attending.
- Medication use remained high at Wave 5, with 695 participants (94.7%) reporting medication use.
- The most frequently reported therapeutic classes were the same between Wave 1 and Wave 5 – psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives), drugs for constipation, analgesics, antiepileptics and psychoanaleptics (including antidepressants, psychostimulants and anti-dementia drugs). In contrast, most frequently reported medications in TILDA participants were medication for cardiovascular disease, acid related disorders and respiratory conditions.
- While psycholeptics remained the most prescribed medication class at Wave 5, (49% of participants), there was increased reporting of drug use for constipation (43.7%).
- There was a 20% decrease in psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives) use in those aged 40 - 49 years (56.3% to 33.9%) from Wave 1 to Wave 5.
- Calcium use increased from 17.8% at Wave 1 to 36.5% at Wave 5. Vitamin D use increased from 2.9% at Wave 1 to 25.2% at Wave 5. While at Wave 1, vitamin D use was predominantly reported by female participants (72.7%), 49% of vitamin D users were male at Wave 5.

Oral Health

Key Findings

- When asked, one in every five participants had no teeth at all. This increased to two in five for those aged 65 and over. This is still much higher than for older adults in the general population, where only one in eight were found to be edentulous in Wave 6 of the TILDA study. Nevertheless, this is a significant reduction from the one in three with total tooth loss in IDS-TILDA Wave 1.
- Seven out of ten (72.1%, *n* = 106) IDS-TILDA participants who were edentulous reported that they did not have dentures. This compares to just one in twenty (5.2%, *n* = 30) edentulous participants in TILDA.
- From clinical measurements, over 70% of IDS-TILDA participants who participated in the oral health assessment (*n* = 469) did not possess a functional dentition; rising to over 95% among those with severe to profound intellectual disability.
- Oral disease was common: Almost half of dentate participants (*n* = 144) were found to have at least one cavitated tooth and almost two thirds (*n* = 219) had unhealthy guMs. Only 27.3% (*n* = 118) of participants had a clean mouth and almost 8% (*n* = 35) reported recent oral pain.
- Dental anxiety was common: Over 41% of participants (*n* = 175) reported high/severe dental anxiety which is many times more than that reported for the general population.

- Oral Health services: RWithin the last two years, (84.2%; *n* = 602) reported attending a dentist or dental hygienist. This indicates that poor oral outcomes occur, despite access to dental services. Most visits deliver assessment only.
- Regular tooth brushing was very common (89.8%; *n* = 680). This indicates that poor oral outcomes arise despite oral home care, indicating that this care is ineffective.

Family Carers

Key Findings

- Thirty-Eight (52.1%) participating carers in Wave 5 were parents, all of whom were aged over 66 years of age and four of whom were aged over 86 years.
- Thirty-two (43.8%) participating carers were a sibling of the older person with intellectual disabilities.
- Three-quarters of the carers reported that they chose to take on the care responsibility.
- Fourteen (43.8%) sibling carers reported that they also provide care for another person.
- Most carers were very satisfied or satisfied with their own health (all: 69.9%, *n* = 51; parents: 57.9%, *n* = 22; siblings: 84.4%, *n* = 27).
- Just under 20% of carers reported that their health had been negatively impacted by their care responsibilities. There was no percentage difference between parents and siblings in Wave 5 - (parents 18.4%, *n* = 7; siblings: 18.8%, *n* = 6).
- Twenty-one carers reported that they experienced stress/nervous tension (parents: 36.8%, *n* = 14; siblings: 21.9%, n = 7). Twenty carers (27.4%) reported experiencing anxiety (parents: 34.2%, *n* = 13; siblings: 18.8%, *n* = 6). Nineteen carers (26%) reported experiencing back pain (parents: 31.6%, *n* = 12; siblings: 18.8%, *n* = 6).
- Over one-third of carers were “just about getting by” or finding it difficult or very difficult to manage financially. Just over half the carers were in receipt of the Carer’s Allowance or the Half Carer’s Allowance.
- Carers most frequently cited being constantly on call, stress and emotional strain as the most difficult aspects of caring.
- More than half of carers reported that their care responsibilities are confining, and almost 40% reported feeling completely overwhelmed by their care responsibilities.
- Just under half of carers reported changes in their own personal plans as a result of their caring role.
- Carers most frequently ‘strongly agreed’ or ‘agreed’ that providing care: “makes me feel needed”, “makes me feel useful” and “enables me to appreciate life more”.
- Talking to friends is the most common coping strategy, and few carers receive support from support groups.
- High levels of satisfaction with GP services and with Day Services were reported. However, a low level of satisfaction with respite services was reported, particularly among the sibling carers.
- Most carers expected that they would still be providing care to their family member in five years’ time, and most reported that they expected to be providing the same amount of care in five years as they are currently providing.
- Whereas most carers have thought about where their family member will be living in five years’ time, only a minority have discussed the issue with a professional individual or group.

Methodology

Key Findings

- A total of 762 participants completed the Computer Assisted Personal Interview (CAPI) at Wave 5, consisting of 621 participants who had previously taken part in Wave 4 and 141 newly recruited participants.
- Among the Wave 4 respondents who were alive at Wave 5, the response rate was 94.2%.
- A total of 755 Pre-Interview Questionnaires (PIQ) were returned, a response rate of 99.1%.
- The retention rate for Wave 5 was 84% (621/739). Almost 70% of the attrition was due to deaths.
- There were 506 participants who took part in the Health Fair.
- Interviews continued to be a mix of self-report and proxy interviews. Proxy interviews were completed by family or staff.

Introduction

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

The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) examines ageing among people with an intellectual disability aged 40 years and over in the Republic of Ireland. The first of its kind in Europe, IDS-TILDA, through alignment with The Irish Longitudinal Study on Ageing (TILDA), remains the only study able to directly compare ageing among people with an intellectual disability with ageing among the general population. IDS-TILDA completed its fifth Wave of data collection in 2023. There are now more than 12 years of follow-up data to compare to the original baseline Wave 1 data collection for the study.

Several important developments have enriched and challenged the study across those years. Undoubtedly, the most dramatic was the occurrence of COVID-19 which disrupted the lives of our participants, just as it did for everyone else in the population and impacted our own data collection efforts during Wave 4. This fifth Wave of data collection has enabled us to examine how former lived lives have been restored, as well as continuing issues from COVID-19. A repeat of the Wave 2 Health Fair was originally planned for Wave 4 but was interrupted by COVID-19. Now in Wave 5, we have successfully completed the Health Fair with objective physical measures previously undertaken in Wave 2 repeated, and a number of new measures added, including a comprehensive dental screening and a hearing screening.

Also initiated in Wave 4, and completed in Wave 5, was a refresh of the sample. Representativeness concerns, largely arising from deaths of participants across the waves, were addressed. Equally important, the advance of time has meant that there were no longer 40-49 years olds in the sample as they had aged; and in Wave 5 this cohort was replaced. Lives in 2023 are likely very different for forty-year-olds than was true for our forty-year-olds in 2010-2011 and the refreshment completed for Wave 5 has allowed us to examine those new lives in detail.

Change in the lives of people with intellectual disabilities has been an important theme in Wave 5. As has been noted in the reports of previous waves, there have been a number of policy initiatives, such as the De-Congregation Report, that had been expected to change the lives of adults with intellectual disabilities. One of IDS-TILDA's purposes has been to monitor the implementation and impact of such policy changes. We can report that at Wave 1, 47.3% of participants lived in residential care. By Wave 5, this had reduced to 28.5% overall. The change is even more dramatic when we compare our two groups under 50 years of age. In Wave 1, 44.8% were in residential care and in Wave 5 it was 7.7%. Much of what we provide in this report documents other changes in the lives of persons with intellectual disabilities, often for the better. But the report also provides information on concerns that still need to be addressed.

The potential for IDS-TILDA to monitor success and challenges in the implementation of desired policy change continues. The Wave 5 report includes the first information on implementation of the Assisted Decision-Making (Capacity) Act which began during data collection. Futures waves will monitor how this continues to be implemented and will examine how the resulting support plans better support ageing lives.

The chapters in this report cover health and mental health status and morbidity improvements and concerns; the daily lived lives of people with intellectual disabilities, including where they live, relationships and social engagement; and changing patterns of medication use and healthcare utilisation.

IDS-TILDA data collection

Data collection consisted of a Pre-Interview Questionnaire (PIQ) and a Computer-Assisted Personal Interview (CAPI). Topics covered in the PIQ included medications, health service use and frequency, how free time is spent and reported challenging behaviour. The CAPI protocol included questions on health, social and family circumstances, quality of life, and inter-personal relationships. As with previous IDS-TILDA waves, the CAPI/PIQ could be completed in one of three ways – independently by the participant, as a self-report with support, or by a proxy known well to the participant and responding on their behalf.

A total of 762 participants completed the CAPI at Wave 5. CAPI Interviews were a mix of self-report and proxy interviews. The majority of the 762 CAPI participants completed the interview independently or with support (64.7%, 493/762). The remaining interviews (35.3%, 269/762) were completed by proxy. Of those who completed a CAPI, 99.1% (n = 755) returned the previously forwarded PIQ. The overall retention rate for continuing participants was 84% (621/739).

In the Health Fair, a suite of 27 objective measures included neuro-psychological, cardiovascular, mobility, muscular skeletal assessments, anthropometric measures, oral health assessment, dietary assessment, sensory assessment and audiology assessments. A total of 506 participants took part in the Health Fair, of whom 50 completed all 27 assessments and the remainder engaged in at least one assessment.

Improved lives but continuing challenges

There were increases as compared to Wave 1 in the proportion of participants who had regular contact with both their family and friends and in giving and receiving help to/from neighbours and friends. There was also a decrease across waves in loneliness reported, which was especially evident among participants aged under 50 years. Between Wave 1 and Wave 5, there were increases in life choice opportunities with the most notable increases again for those less than 50 years old with mild intellectual disability and living independently or with family. Our findings also confirmed that many older adults with intellectual disabilities in Ireland live full social lives, with rich interpersonal relationships, and engaged in their communities.

Many barriers still remain. People with more severe intellectual disabilities, and those living in residential care, remained dependent on staff support. This continued importance of familiar staff clashes with ongoing difficulties with recruitment and retention of staff as reported by many providers, and has implications for the security, dignity and rights of people with intellectual disability. One in five participants reported not leaving the house due to staff/resource issues.

Health improvements and persistent health concerns

There were positive indications over time of reduced or stable incidence of some conditions and of multimorbidity overall, and there was an increased likelihood of screenings and diagnoses, such as for osteoporosis (although more vigilance is needed). Conversely, increasing prevalence of musculoskeletal, endocrine, and gastrointestinal conditions, and emerging eye health concerns and auditory impairments, underscored continuing pressing needs for tailored healthcare approaches and specialized interventions.

For everyone with an intellectual disability, across all age groups, there was a steady increase over time in GERD and constipation diagnoses that must be better addressed. Reports of pain have also increased in the younger groups, while use of pain medications declined. Arthritis, in particular, illustrated that there were both improving and concerning pictures of health mediated by advancing age, level of intellectual disability and sex.

Overall, women with intellectual disabilities had poorer health than men; but there were also important findings of underdiagnosis of osteoporosis and hearing difficulties for men and other declines as men age. Similarly, for those with severe to profound intellectual disabilities, there was a greater likelihood of conditions being under-recognised and reported.

Changing where I receive my healthcare and what services I receive

Differences were found in patterns of where healthcare was received, particularly among participants aged under 50 who appeared to be receiving more outpatient care rather than the reliance upon frequent GP visits found earlier and still likely for some others. It remains to be established if this represents a movement towards community-based and outpatient care or alternately a trend towards less care. In terms of preventive health, there were high levels of vaccination reported, but a lower uptake of breast screening in comparison to TILDA, and rates of cervical screening were much lower than the national average. Given distinct patterns of poorer health for women, screening and health service options for women were highlighted as needing further attention.

Medication use patterns continued to differ substantially from those observed in the older population in TILDA. For people with intellectual disabilities, patterns remained consistent with findings in Wave 1. However, there was a decrease over time in the use of psycholeptics (including antipsychotics, anxiolytics, hypnotics, and sedatives) in those aged under 50. Increases in constipation medicines use particularly stood out. Patterns in supplement use changed and, by Wave 5, a greater proportion of participants in IDS-TILDA were reporting calcium and vitamin D use. Greater attention to bone health and guidelines on Vitamin D supplementation appear to have changed levels of use.

Breaking new ground

Oral health concerns

Research nurses in the Health Fair were specifically trained and supported by a PhD student specifically trained as a gold standard in the methods of data collection. It was found that, on average, older people with intellectual disabilities in Ireland had four fewer teeth than other older adults. When an adult with an intellectual disability lost a tooth, it was rare that rehabilitation occurred. When teeth were present, oral disease was common. Yet there was a high level of toothbrushing and attendance at dental services. This is a critical disparity for people with intellectual disabilities; dental care requires procedures beyond assessment in the dental service and greater use of specialised toothbrushes and flossing.

Women’s health

Throughout the waves of IDS TILDA, a consistent finding has been that women with intellectual disabilities have poorer health, greater risk factors and higher rates of a number of chronic conditions than men with intellectual disabilities or compared to women in the general population.

In particular, Wave 5 confirmed that compared to women in the general population, menopause occurs at earlier age in women with an intellectual disability and even earlier for women with Down syndrome. Yet many were unaware of the menopausal transition and had never discussed the menopause with anyone or received easy read material.

Healthier lifestyles

People in all age categories improved their levels of physical activity from Wave 2 to Wave 5 with the percentage of active younger participants more than doubling. Those with moderately intensive activity also reported the best quality of life scores and were least likely to experience loneliness. Overall, health behaviours in Wave 5 appeared to be trending in a positive direction. There were also lower levels of smoking and alcohol consumption. However, approximately half of participants had low levels of activity, and few engaged in vigorous activity.

Improving mental health and continuing cognitive concerns

Older adults with intellectual disability continued to experience poorer mental health than those without identified disabilities, but there were trends for reductions in diagnosis prevalence over the waves. Energy and Vitality level rates at 68.9% were high regardless of age, setting, or level of intellectual disability, and were higher than those reported in the wider Irish population.

Dementia remained a significant concern, particularly for people with Down syndrome. Dementia screening increased, which is positive, and may be related to the development of the National Intellectual Disability Memory Service (NIDMS), established in 2020, which gives access to memory screening and assessment to everyone with an intellectual disability in Ireland.

Carers – changing family members and growing needs

The family care provision landscape in Ireland continues to change. De-congregation and more reliance on family carers is challenged by smaller family sizes, progressing age for parent carers and people with intellectual disability and, to some extent, siblings. This raises serious questions regarding the sustainability of care for people with intellectual disability in the coming decades. A Carer's Study is nested within the IDS-TILDA study and seeks to understand the experiences of family carers of older people with an intellectual disability. Participants in the Carer's Study may change between waves as different family members assume the primary responsibility for providing care. Of particular note by Wave 5, was a clear generational transfer of care from parent to sibling of the person with intellectual disability who participated in multiple waves. Although most carers frequently 'strongly agreed' or 'agreed' that providing care: "makes me feel needed", "makes me feel useful" and "enables me to appreciate life more", they frequently cited being constantly on call, stress, and emotional strain as difficult. Many found the role confining and expected to be still providing at least the same level of care to their family member in five years' time.

Conclusion

There has been an ever-evolving policy and service landscape within the intellectual disabilities sector. Through its comprehensive multi-domain theoretical framework and longitudinal design, IDS-TILDA has provided, and will continue to provide, essential evidence for the success and challenges in current policy and practice. Where policy and practice need to continue to improve is also highlighted through the findings.

The data in Wave 5 demonstrates that lives of people with intellectual disabilities have improved, sometimes dramatically, in many areas and over time. This is particularly true for those with mild and moderate levels of intellectual disability and those not living in residential care. Conversely, Wave 5 highlighted that more work is needed, in particular to address preventable and treatable mortality for women with an intellectual disability.

For the first time, Wave 5 is also pointing at generational improvements. The lives of those aged 40-49 years today are very different, healthier and more community-based than was true for the group in Wave 1. More needs to be done, particularly vigilance that health screening leads to care, more community-based access supports engagement and better health, and that the promise of assisted decision-making is realized. IDS-TILDA is documenting changes in lives and continuing challenges in ways that no other survey can or does. As planning for future waves progresses, it will continue to do so for Ireland and in ways that offer insights on healthy happy ageing for the world.

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CHAPTER 1

Social Determinants of Health: Choice, Interpersonal Relationships and Community Participation

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HEALTHY
HAPPY
AGEING

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

1.1: Key findings

Choice and decision supports

- Between Wave 2 and Wave 5, self-choice increased in every age category with the most notable increase in those less than 50 years of age.
- Younger men and women living independently / with family with a mild/moderate level of intellectual disability had the highest level of personal choice in all aspects of daily living.
- At Wave 5, one-third of the sample had a formal written decision agreement plan in place and a further 18.7% had an agreement under development.
- Thirteen people reported having an advanced care directive.

Interpersonal relationships

- Almost all participants had family (96.2%), with siblings being the most common, and there was an increase in the number of participants who lived close to family (29.3%); but still at Wave 5 very few marry or have their own children (<1%), with only a slight increase among the under-50s (1.6%).
- The proportion of participants with severe-profound intellectual disability living close to family (15.2%) was less than half that of participants with mild (37.7%) and moderate (33%) intellectual disability.
- The vast majority of participants also had friends (93.8%), and 60.5% had a best friend – both increased since previous waves. Nine in ten self-reporting participants had at least one close family member (88.4%), and one close friend (90.8%). Co-resident friends were most common (60.5%), and highest among participants living in residential care (75.2%) and group homes (73.5%). Peers with an intellectual disability were by far the most common type of best friend (62.6%), followed by support staff (18.1%).
- Individuals living independently or with family were more likely to have non-resident friends (79.8%) and to have a best friend (75.1%). Their best friends were also more likely to be family members, work colleagues and non-staff.
- Regular (weekly) contact with non-resident family has increased from 45.9% in Wave 1 to well over half (57%) in Wave 5, with another 21% having monthly contact.
- Regular contact with non-resident friends also increased over this period – three-quarters (76.6%) with these friends had weekly contact and a further 13.1% had monthly contact.
- The number who self-reported reporting that they had a confidant rose to 94.9% from 83.8% in earlier waves, with keyworker/support worker still the most common confidant (83.1%). Nearly one in four participants in Wave 5 (23.1%) provided help to their friends/ neighbours in the preceding two years, a substantial increase from 13.1% in Wave 1.

Community participation

- The mean number of regular community activities was 5.6 per month (SD = 3.1), with an increase across all age groups compared to Wave 3. Community activity decreased with increasing age; people in residential care were less active than others; people with severe-profound intellectual disability were less active than those with mild or moderate intellectual disability; and men were more active than women.
- Just one in 10 participants (10.9%) were in paid employment, a slight increase since Wave 4 (8.4%). Employment increased more significantly for the under-50s, from 20.4% in Wave 4 to 27.1%. Day service or day activation remained the most common daily activity (81.4%), but the number who reported doing nothing during the day almost doubled, from 6.9% in Wave 4 to 12.3% in Wave 5. In addition, 19.4% ($n = 144$) reported spending the majority of the week (four or more days) at home, with 5% ($n = 37$) not leaving their house in the past week. One in five (20.9%, $n = 94$) reported staying home due to lack of staff and resources.
- Mobile phone ownership at 44.7% in Wave 5 doubled from Wave 1 at 23%; but remains low by comparison with the general population at 96%. Access to and use of the internet at home also increased considerably over time, with nine out of ten participants (89.6%) now having access, and over half of all participants (53.7%, $n = 409$) reporting they used the internet at home, compared to 7.3% in Wave 1.
- Tablets (46.9%), smartphones (20.7%), and computers/ laptops (13.3%) were the smart devices most commonly used. Most older adults with an intellectual disability remain dependent on others to use technology.
- At Wave 1, 47.3% of participants lived in residential care, 35.6% in community group homes and 17.1% independent/with family. By Wave 5 the percentages were 28.5% in residential care, 49.0% in community group homes and 22.6% independent/with family.
- At Wave 1 44.8% of participants aged under 50 years lived in residential care, 34.0% in community group homes and 21.2% independent/with family. By Wave 5 the percentages were 7.7% in residential care, 45.9% in community group homes and 46.4% independent/with family.
- More people moved residence in Wave 5 compared with previous waves and moves to the same type of residence continue to be the largest proportion of these moves. Change in physical health status was the most commonly reported reason (25%) for moving to more supported settings, as well as the most commonly reported (12.5%) and ‘most important’ reason for moving to community based homes; and lack of nursing and twenty-four hour support the most significant contributor to such moves.
- A large proportion of those who moved noted that the move was talked about or included in their personal plan (86.8%), almost 80% reported that they wanted to move; yet only one-fifth of those who moved were included in viewing alternative accommodation before moving. Two-thirds of those who moved were not involved in the decision to move. However, 87% reported being happy now that they had moved with 6.1% still adapting to the change.
- Over half of participants had difficulty getting around their community (53.1%), down from 57.9% in Wave 1, with difficulty highest among the over-65 group (60.6%) and those with severe to profound intellectual disability (70.9%). Most participants rated the quality of their neighbourhood highly citing free/low-cost recreation facilities (78.9%), footpaths (77%), places to buy things (72.3%), transit (71.6%), and facilities to bicycle (58.1); however, almost half (46.7%) felt unsafe walking their neighbourhood at night.

1.2: Introduction

There is a well-established connection between social factors at various levels, from personal to macro, and an individual's health status (Brunner & Marmot, 2006; Kelly, Bonnefoy, Morgan, & Florenzano, 2006; Raphael, 2006). To fully appreciate the health status of people with intellectual disabilities, we must therefore account for the impact of these social determinants of their health (McCausland, McCallion, & McCarron, 2021). For five waves IDS-TILDA has explored social determinants of health for older adults with intellectual disability in Ireland, observing patterns over time, identifying key factors associated with differences within the population, and comparing outcomes with the general older population. An aspect unique to IDS-TILDA has been to understand how the role of people with intellectual disabilities themselves, in deciding major milestones in their lives including decisions to move where they live, has evolved across the waves of IDS-TILDA. Such opportunities for self-determination have been both theoretically and practically demonstrated to enhance health and quality of life for people with intellectual disabilities (Wehmeyer, 2020).

IDS-TILDA has also shown that many older adults with intellectual disability are very socially active with important networks and relationships, yet this population continues to have fewer social resources than the general older population, and those with the highest support needs and who are the least independent are the most socially excluded. Perhaps more so than for other populations, quality and extensiveness of personal relationship and opportunities for community participation are both inter-related and independent contributors to wellness and health. Past longitudinal data has shown that community residence, as compared to residential care, usually improves social inclusion, but residence is only one factor; multiple variables combine to shape social inclusion. Individualised, person-centred approaches appear to be a critical route to addressing social exclusion for this population and has been a key concern in data collection by IDS-TILDA.

This chapter reports on measures of social determinants conducted in Wave 5. It continues to explore choice and social outcomes longitudinally through repeated measures, and by comparison where possible with TILDA general older population data. Comparison was enhanced by the introduction of new measures in Wave 5, including additional questions about access to and use of technology, and questions assessing neighbourhood characteristics and quality.

There was continued follow-up on the exercise of choice and on the individual's role in planning for their care and future including where they lived. Additional questions addressed how decisions were being supported given the launch of processes to support the Assisted Decision-making (Capacity) Act.

In 2015, Ireland established the Assisted Decision-making (Capacity) Act establishing new decision-making agreements and a framework to provide people, who require it, with appropriate supports to make decisions. A functional approach to capacity underpins the Act. This means that "capacity is considered fluid, time and decision specific" (Rogers et al, 2020). Although the Act was established in 2015, it was not until 2023 that it was fully commenced (Casey et al, 2023).

Supported decision making consists of relationships, supportive action and explicit agreements. There is also a recognised need for people accessing these supports as well as people providing such supports to receive training. The Health Service Executive (HSE) has recently launched a training programme targeting health care workers (https://www.hse.ie/eng/about/who/national-office-human-rights-equality-policy/assisted-decision-making-capacity-act/).

The chapter is then structured in line with the ecological model of social inclusion proposed by Simplican, Leader, Kosciulek, and Leahy (2015), broadly identifying social inclusion as being comprised of two inter-related spheres – interpersonal relationships and community participation. Regarding interpersonal relationships, we report findings on participants' social networks, connections with family and friends, the quality of their relationships, and reported loneliness. Regarding community participation, we examine findings on social activities in the community, work and daily occupation, access to and use of technology, housing and movement since previous waves, and the characteristics of neighbourhoods in which participants live.

1.3: Choice profile

Choice in everyday and key life decisions for people ageing with intellectual disability was examined using the adapted daily choice inventory scale (Heller et al, 2000). Level of choice across key life and everyday domains at Wave 1 and Wave 5 are displayed in Table 1.1. The sample in Wave 5 shows increased self and supported choices in all domains and these differences between Wave 1 and Wave 5 (using McNemar Bowker test for paired samples) proved significant.

Table 1.1: Level of choice across key life and everyday domains at Wave 1 and Wave 5

In general, who chooses…?	Response Type	Wave 1		Wave 5	
		n	%	n	%
The food you eat	Self	241	32.2	338	44.6
	Supported	279	37.2	380	50.1
	Someone else	229	30.6	40	5.3
The food that is cooked in your home	Self	101	14.6	168	22.2
	Supported	229	33.2	495	65.5
	Someone else	360	52.2	93	12.3
The clothes you wear	Self	369	49.1	465	61.0
	Supported	177	23.5	243	31.9
	Someone else	206	27.4	54	7.1
Who you spend your free time with?	Self	296	40.0	366	48.7
	Supported	197	26.6	329	43.8
	Someone else	247	33.4	56	7.5
Where you go in your free time?	Self	246	33.1	291	38.5
	Supported	248	33.4	403	53.4
	Someone else	249	33.5	61	8.1
How you spend your money?	Self	170	22.8	245	32.5
	Supported	246	32.9	405	53.8
	Someone else	331	44.3	103	13.7
What time you go to bed?	Self	548	73.1	632	83.4
	Supported	86	11.5	104	13.7
	Someone else	116	15.5	22	2.9
What job you have? (of those who have a job)	Self	147	32.5	159	37.9
	Supported	120	26.5	211	50.4
	Someone else	186	41.1	49	11.7
Where you live?	Self	98	13.2	150	22.1
	Supported	85	11.5	174	25.6
	Someone else	559	75.3	355	52.3
Who you live with?	Self	53	7.3	116	17.9
	Supported	48	6.6	155	24.0
	Someone else	627	86.1	376	58.1
What support you may receive?	Self	65	8.8	97	13.5
	Supported	99	13.5	309	43.1
	Someone else	572	77.7	311	43.4
How you decorate your room?	Self	255	34.6	358	47.7
	Supported	192	26.1	328	43.7
	Someone else	290	39.3	64	8.5
Where you keep your money?	Self	105	14.3	191	25.7
	Supported	135	18.4	308	41.4
	Someone else	495	67.3	245	32.9

Note: Responses for "watch TV shows" and "training activation" were not provided since they were not asked in both Waves 1 and 5.

A mean self-choice score was calculated for 13 domains. As may be seen in Table 1.2, between Wave 1 and Wave 5, there was an increase in mean self-choice scores overall and for each age category.

The most notable increase was in the less than 50 years of age group. We found that all personal choices had significant associations with level of intellectual disability and residence type in both Wave 1 and Wave 5. Also, most choices had significant associations with age in Wave 5.

Table 1.2: Differences in mean self-choice at Wave 1 and Wave 5 by age group

Age category	Mean self-choice score in Wave 1	Mean self-choice score in Wave 5
<50	3.34	5.79
50-64	3.61	4.58
65+	3.16	3.95

People with mild intellectual disability had the greatest mean self-choice score (7.45 vs 4.24 (moderate) and 1.56 (severe/profound) in Wave 5 and 6.11 vs 3.35 (moderate) and 1.19 (severe/profound) in Wave 1).

Independent/family living arrangements provided the most choice with mean score 7.27 vs 4.57 (community group home) and 2.86 (residential care). This is a similar pattern to the Wave 1 scores (6.20, 3.95 and 2.05 for independent/family, community group home and residential care respectively).

The differences in level of personal choice were significant in all aspects of choice in daily life depending on a participant's residential circumstances and level of intellectual disability.

There was no significant difference between level of choice reported by men and women in any domain (mean self-choice score 4.56 and 4.81 respectively in Wave 5 and 3.38 and 3.48 in Wave 1).

1.4: Decision-making support

1.4.1: Formal planning

Although implementation has only recently commenced, participants were asked if they had completed a formal decision-support agreement or were working on one. The nature of the plan and the participant's nominated decision-supporters were recorded.

At Wave 5, one-third of the sample had a formal written decision agreement plan in place and a further 18.7% had an agreement under development.

There are a considerable percentage whose decision support plan are in progress. Differences were significant for level of intellectual disability, age, and type of residence. See Table 1.3.

Table 1.3: Proportion of participants who reported having a formal written plan in place

	In-progress		Full / complete		None	
	n	%	n	%	n	%
Male	56	17.5	97	30.3	167	52.2
Female	70	19.8	111	31.4	173	48.9
< 50	24	15.0	39	24.2	97	60.6
50-64	66	20.3	93	28.6	166	51.1
65+	36	19.0	76	40.2	77	40.7
Mild	35	20.1	40	23.0	99	56.0
Moderate	57	20.7	100	36.4	118	42.9
Severe/profound	24	14.9	53	32.9	84	52.2
Independent / family	22	14.6	20	13.2	109	72.2
Community group home	61	18.7	129	39.6	136	41.7
Residential	43	21.8	59	29.9	95	48.2

Of those with a decision support arrangement in place, half had a decision-making assistance agreement and just under a third a co-decision-making agreement. Thirteen people had an advanced health care directive. See Table 1.4.

Table 1.4: Type of decision support arrangement

Type of decision support arrangement	n	%
Decision-making assistance agreement	168	50.3
Co-decision making agreement	99	29.6
A decision-making representation order	2	0.6
Enduring power of attorney	5	1.5
Advanced healthcare directive with designated healthcare representative	11	3.3
Advanced healthcare directive without designated healthcare representative	2	0.6
Unclear or don’t know	47	14.1

A further 9.7% reported their intent to make a legal decision support agreement. A greater proportion of this group were women (57.5%), and people aged 50-64 years (57.5%), with moderate intellectual disability (51.5%) living in community group homes (51.5%). A quarter of people living independently/with family or in residential services stated an intent to make a legal support agreement. However, no differences between groups were statistically significant.

Respondents were asked to identify who in their circle provided support with decision making and were nominated decision supporters. For those with decision supporters in place, staff were the most common decision supporter. See Table 1.5.

Table 1.5: Type of decision supporter relationship

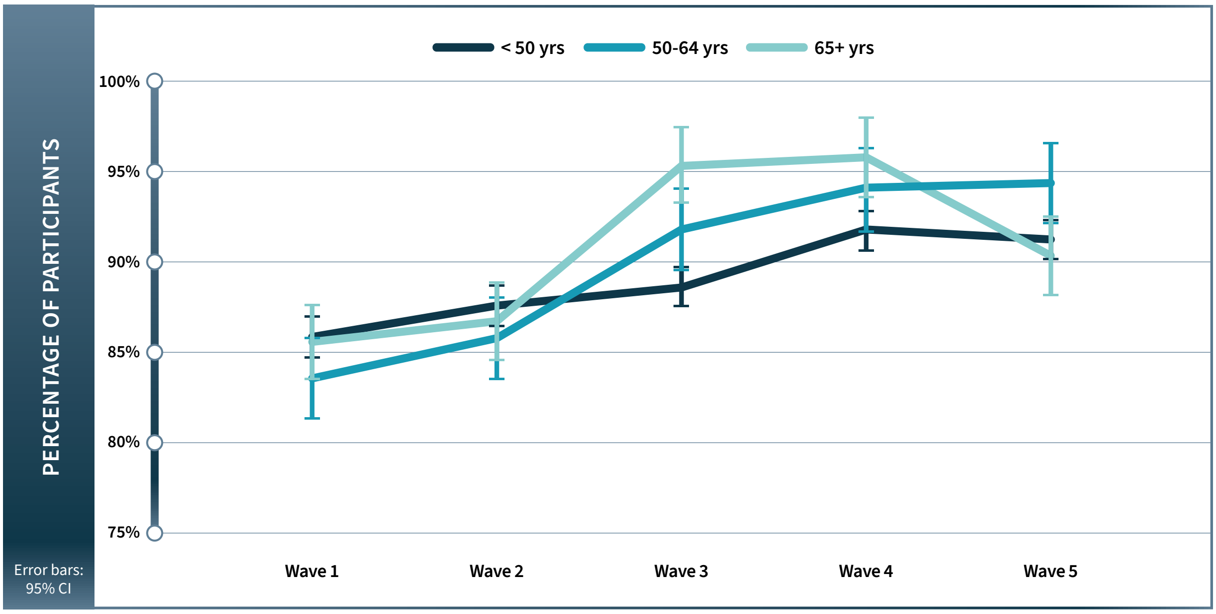
Relationship of decision supporter	n	%
Family	186	55.7
Friend	8	2.4
Staff	310	92.8
Other	19	5.7

1.4.2: Informal planning and supports

Besides formal individual agreements and identified decision supporters, respondents also reported on whether overall decision support protocols were in place within their provider organisation and a third (32.4%) confirmed there was a service organisation protocol in place.

Informal support plans and arrangements were more commonly in place (54.1%), compared with the more formal decision support plans and there was an increasing trend for informal support plans over the waves. See Figure 1.1.

Figure 1.1: Proportion of participants with informal support plans, Wave 1 to Wave 5



1.5: Interpersonal relationships

1.5.1: Social networks

1.5.1.1: Family networks

The vast majority of older adults with intellectual disability have family networks, with just 3.8% (*n* = 29) of participants having no family, although this increases with age to 7.9% for those aged 65 and over (Table 1.6). The structure of family networks has changed very little since first examined in Wave 1 of IDS-TILDA (McCarron et al., 2011), with siblings and nieces/nephews still the most common family members. However, the profile for the youngest cohort is somewhat different – with two-thirds still having their mother (66.7%), and almost half having their father (48.1%).

Very few older adults with intellectual disabilities had a spouse/partner (0.9%) or a child (0.7%), again changing little over time. Among the youngest participants, having a spouse/partner (1.6%) or child (1.6%) was marginally higher than for older participants confirming the continuance of a critical difference in the family networks of older adults with intellectual disabilities compared to the general older population, the vast majority of whom marry and have children and grandchildren (Kamiya & Sofroniou, 2011; Nolan et al., 2014).

Adults with intellectual disabilities have smaller, less intimate family networks and remain largely dependent on their siblings and extended family for family connection, particularly as they age and lose their own parents later in life (McCausland, McCallion, Brennan, & McCarron, 2018).

9/10
participants had close family and close friends

Table 1.6: Family of older adults with an intellectual disability (%)

		Spouse / Partner	Child	Mother	Father	Brother	Sister	Aunt / Uncle	Niece / Nephew	Cousin	Other Family	No Family
Sex	Male (*n* = 355)	1.7	0.6	30.7	20.8	70.7	72.1	17.2	42.3	20.6	4.8	3.9
	Female (*n* = 407)	0.2	0.7	24.1	12.8	70.8	77.6	16.0	50.4	22.9	3.7	3.7
Age	40-49 (*n* = 183)	1.6	1.6	66.7	48.1	72.7	78.7	31.7	51.4	26.2	3.3	0.5
	50-64 (*n* = 363)	0.6	0.6	22.0	10.5	77.1	78.5	15.2	46.6	20.7	3.3	3.0
	65+ (*n* = 216)	0.9	0.0	2.3	0.0	58.3	66.2	6.0	42.6	19.9	6.5	7.9
Level of ID	Mild (*n* = 205)	2.0	1.0	36.6	18.0	74.6	75.6	23.4	57.1	30.7	5.4	2.0
	Moderate (*n* = 312)	1.0	0.6	23.7	17.3	70.8	73.1	16.0	45.5	18.6	4.2	5.8
	Severe-profound (*n* = 172)	0.0	0.0	23.8	15.1	64.0	73.8	8.1	32.6	10.5	2.3	3.5
Residence type	Independent / family (*n* = 172)	1.7	2.3	51.7	33.1	79.7	83.1	32.6	66.9	35.5	5.2	0.0
	Group home (*n* = 373)	0.8	0.3	22.5	14.2	70.0	72.9	14.5	41.0	19.6	4.3	4.3
	Residential care (*n* = 217)	0.5	0.0	15.7	7.4	65.0	72.4	7.4	40.1	14.7	3.2	6.0
Total	**(n = 762)**	**0.9**	**0.7**	**27.2**	**16.5**	**70.7**	**75.1**	**16.5**	**46.6**	**21.8**	**4.2**	**3.8**

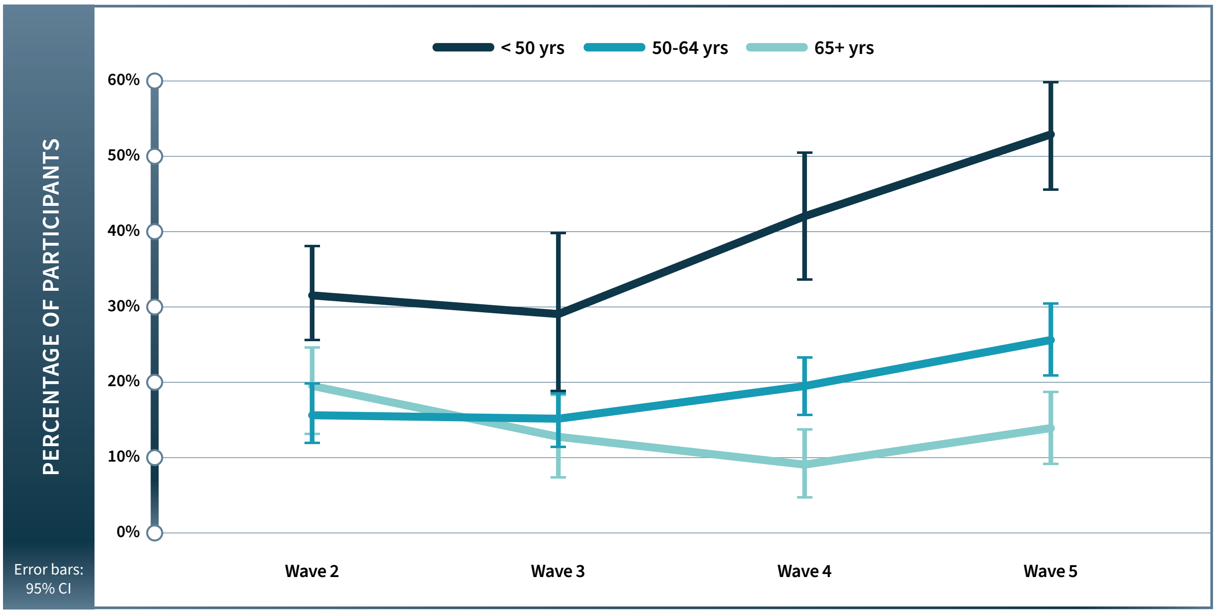
1.5.1.2: Family proximity

Living close to family is important because family proximity was previously associated with increased family contact and better social inclusion generally for this population (McCausland et al., 2018). At Wave 5, around three in ten participants (29.3%, *n* = 213) lived close to a family member – either living with them or in the same neighbourhood. This compares unfavourably with the general older population in Ireland; 36% of whom share housing with their children while also having other family nearby (Kamiya & Timonen, 2011).

There were significant differences in family proximity among IDS-TILDA participants based on age, residence type, and level of intellectual disability. Over three-quarters of those in independent/family settings lived close to family (79.1%), compared with just 16.9% and 12.2% for those in residential care and community group homes respectively. Proximity to family decreased sharply with age, from over half of those aged under 50 years (53%, *n* = 96), to a quarter of those aged 50-64, and just 13.6% of those aged 65 and over. The proportion of participants with severe-profound intellectual disability living close to family (15.2%) was less than half that of participants with mild (37.7%) and moderate (33%) intellectual disability.

Longitudinal examination found that the proportion of participants who lived close to their family had increased from 20.3% at Wave 2 to 29.3% at Wave 5. Most of this increase was due to changes in the under-50 cohort, where proximity increased from 31.6% in Wave 2 to 53% in Wave 5 (Figure 1.2). There was also an upward trend for the 50–64-year-old group, from 15.7% to 25.9%. However, the trend was reversed for participants aged 65 and over, with fewer living close to a family member at Wave 5 (13.6%) compared with Wave 2 (19.5%).

Figure 1.2: Proportion of participants who lived close to family stratified by age, Wave 2 to Wave 5



1.5.1.3: Friends

Overall, the vast majority of older adults with intellectual disabilities had friends (93.8%), and most of these (61.8%) also had a 'best friend' (Table 1.7) – an increase on Wave 3 figures of 92.4% and 56.6% respectively (McCausland, McCallion, Carroll, & McCarron, 2021). Co-resident friends were the most common type of friend (60.5%), with around half also reporting non-resident friends (56.2%) and staff friends (50.4%). Another person with an intellectual disability was by far the most common type of best friend (62.6%), but service provider was the second most common (18.1%). Just over a third (35.8%) of those with a best friend identified their best friend as someone who they lived with.

Women (95.8%) were more likely than men (91.5%) to have friends, but there were no other significant differences in sex regarding having a best friend or types of friends/best friends. Participants living in independent/family residences were significantly more likely to have friends outside their home (79.8%), and less likely to have co-resident friends (14.7%) or staff friends (39.3%).

This group were also more likely to have a best friend (75.1%) compared with participants in group homes (64.8%) and residential care (46%). Those in independent/family residences were more likely to have a best friend who was a work colleague (9.2%), and less likely to have a best friend who was another person with intellectual disability (53.8%) or a service provider (10.1%). This group was also far less likely to have a co-resident best friend (14.2%), compared with participants in group homes (43.1%) and residential care (47.3%). Participants living in group homes were least likely to have a family best friend (3.7%), and most likely to have a best friend with an intellectual disability (68.5%).

Regarding age, while there was no significant difference for having friends, participants aged under 50 years were significantly less likely to have co-resident friends (46%). Those aged under 50 years were most likely to have a best friend (69.6%) and were far less likely to live with their best friend (19.7%). People with mild intellectual disability were more likely to have friends (97.6%), a best friend (72.6%), and friends outside their home (73.5%), and were less likely than others to have co-resident friends (47.5%).

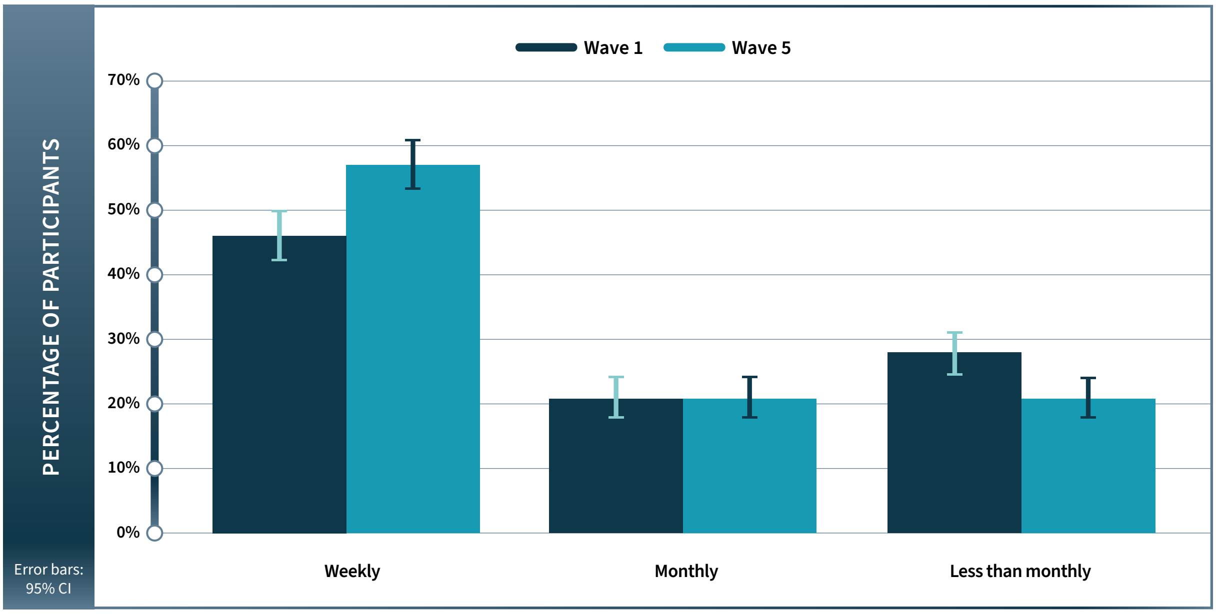
Table 1.7: Friends of older adults with an intellectual disability (%)

		Has Friends (n=759)	Type of Friends (*n* = 712)			Has a Best Friend (n=697)	Type of Best Friend (*n* = 425)				
			Co-Resident	Non-Resident	Support Staff		Family	Work Colleague	Friend with ID	Carer / Service Provider	Other
Sex	Male	91.5	59.6	58.0	52.2	59.5	7.0	5.3	59.9	18.7	9.1
	Female	95.8	61.3	54.6	49.0	63.7	5.0	1.7	64.7	17.6	10.9
Age	40-49	95.1	46.0	63.8	42.5	69.6	4.3	6.0	59.0	17.1	13.7
	50-64	93.4	61.5	54.4	53.8	61.7	6.9	3.5	64.9	18.3	6.4
	65+	92.5	71.7	52.5	51.5	55.2	5.7	0.0	62.3	18.9	13.2
Level of ID	Mild	97.6	47.5	73.5	44.5	72.6	5.7	3.5	65.2	12.1	13.5
	Moderate	93.6	61.9	57.0	53.6	65.8	5.3	3.2	59.4	23.0	9.1
	Severe-profound	87.7	77.3	30.0	50.7	33.3	10.6	0.0	68.1	19.1	2.1
Residence type	Independent / family	95.4	14.7	79.8	39.3	75.1	8.4	9.2	53.8	10.1	18.5
	Group home	93.4	73.5	53.9	52.2	64.8	3.7	0.9	68.5	20.8	6.0
	Residential care	93.5	75.2	41.1	56.4	46.0	7.8	1.1	60.0	22.2	8.9
Total		**93.8**	**60.5**	**56.2**	**50.4**	**61.8**	**5.9**	**3.3**	**62.6**	**18.1**	**10.1**

1.5.2: Social connections

Social connections were measured in Wave 5 by three types of contact those participants had with non-resident family and friends – meeting up face-to-face, speaking on the phone including video calls and voice memos, and written contact including text messages and social media. All three types of contact were combined to examine the frequency of social contact with family. Over half of all participants (57%, *n* = 407) had contact with a family member at least once a week, a further 21% (*n* = 150) had monthly contact, and 22% (*n* = 157) had less than monthly contact. This represented an increase in regular contact with family compared with Wave 1, when just 45.9% (*n* = 338) had weekly family contact (Figure 1.3).

Figure 1.3: Frequency of social contact with non-resident family at Wave 1 and Wave 5



Frequency of social contact with family varied between different groups within the sample. Participants living in independent/family settings were far more likely to have weekly contact with family (82.5%, *n* = 132) compared with those in community group homes (51.8%, *n* = 183) and residential care (45.8%, *n* = 82). Weekly family contact declined as age increased, from 76.6% (*n* = 131) for those aged under 50, to 54.3% (*n* = 188) for those aged 50-64, and less than half (44.7%, *n* = 88) for those aged 65 and over. The highest weekly contact was for participants with mild (74.7%, *n* = 145) compared to those with moderate (58%, *n* = 166) and severe-profound intellectual disabilities (27.6%, *n* = 45).

Of the 398 participants who had friends outside their home, three-quarters (76.6%, *n* = 305) had contact with these friends at least once a week, a further 13.1% (*n* = 52) had monthly contact, while 10.3% (*n* = 41) had less frequent contact. There was an increase in regular contact with friends since Wave 2, when 72.8% reported weekly contact, 10.8% had monthly contact, and 16.4% had contact less than monthly.

Frequency of contact with non-resident friends at Wave 5 varied according to age and residence type. Participants aged under 50 years were more likely to have weekly contact with friends (90.9%, *n* = 100), compared with participants aged 50-64 (69.2%, *n* = 128) and those aged 65 and over (74.8%, *n* = 77). People living in independent/family residences had the highest rate of weekly contact with friends (89.2%, *n* = 116), compared with those living in community group homes (71%, *n* = 132) and residential care (69.5%, *n* = 57).

1.5.3: Relationship quality

Measures of the quality of participants relationships included having family and friends they felt close to, having confidants, feelings of social isolation and community belonging, and reciprocity in relationships including support provided to family, and support given to and received from friends and neighbours.

Self-reporting participants were also asked new questions in Wave 5 about how many family members they felt close to (*n* = 449) and how many close friends they had (*n* = 435). Around nine in ten respondents said they had at least one close family member (88.4%, *n* = 397), and one close friend (90.8%, *n* = 395). Participants living in independent/family settings were most likely to have a close family member (95.4%), compared with those living in community group homes (85.5%) and residential care (82.9%) (p<0.001).

The vast majority of self-reporting participants said they had someone they could confide in (94.9%) – an increase from 83.8% recorded in Wave 2 (McCausland et al., 2018). The identity of who participants confided in did not change in that period – with keyworker/support worker still the most common confidant (83.1%), followed by sibling (35.8%), friend (17.6%), parent (17.2%), and spouse/partner (3.3%) which increased from 1.5% in 2014.

Reciprocity is an important dimension of interpersonal relationships, and IDS-TILDA examined this through the amount of support that participants provide to their family, friends and neighbours. Just over one in five participants provided support to a family member (20.2%), a small increase from 17% in Wave 2 (McCausland et al., 2018). However, this remains low compared to the general older population in Ireland, 47% of whom provided care to grandchildren, and 36% of whom gave non-financial help to non-resident children (Barrett, Savva, Timonen, & Kenny, 2011).

Participants living with family or independently were significantly more likely to support a family member (51.5%) compared with those living in community group homes (14.9%) and residential care (2.9%). Participants aged under 50 years were significantly more likely to support family (38.3%) than those aged 50-64 (15%) and over 65 (12.4%); and participants with mild intellectual disability were more likely (33.5%) than those with moderate (19.7%) or severe-profound intellectual disability (0.6%). The family members most commonly supported by participants were: sibling (53.1%); mother (49.7%), father (22.8%); and other (4.8%) including two participants who supported their children.

Nearly one in four participants in Wave 5 (23.1%, *n* = 174) provided help to their friends/neighbours in the preceding two years, a substantial increase from 13.1% in Wave 1. Similarly, just under a third of participants (30.3%, *n* = 229) said they received help from friends/neighbours in Wave 5, which was more than double the rate in Wave 1 (14.7%). These increases indicate that the IDS-TILDA population has surpassed rates for the general older population in Ireland of giving help to (23%) and receiving help from (17%) friends/neighbours previously reported by TILDA (Barrett et al., 2011).

Participants living in independent/family settings were the most likely to give help to their friends/neighbours (39.2%, *n* = 67), compared with those in residential care (30.6%, *n* = 66) and community group homes (25.9%, *n* = 96) (p<0.01, *n* = 757). Participants living in independent/family settings were also far more likely to receive help from friends/neighbours (39.2%, *n* = 67), compared with people in community group homes (21.4%, *n* = 78) and residential care (13.4%, *n* = 29). Giving help to friends/neighbours was significantly associated with age (p<0.001, *n* = 752).

Participants aged under 50 years were more likely to give help (33%, *n* = 60) than participants aged 50-64 (22.3%, *n* = 80) and those aged 65 and above (16%, *n* = 34). Both giving help (p<0.001, *n* = 679) and receiving help (p<0.01, *n* = 684) from friends/neighbours was associated with level of intellectual disability. Participants with mild intellectual disability (34%, *n* = 69) were more likely to give help than those with a moderate (20.9%, *n* = 64) and severe-profound level (11.8%, *n* = 20). Those with mild intellectual disability were also more likely to receive help (38.9%, *n* = 79) compared with participants with a moderate (26.1%, *n* = 81) or severe-profound (28.1%, *n* = 48) intellectual disability.

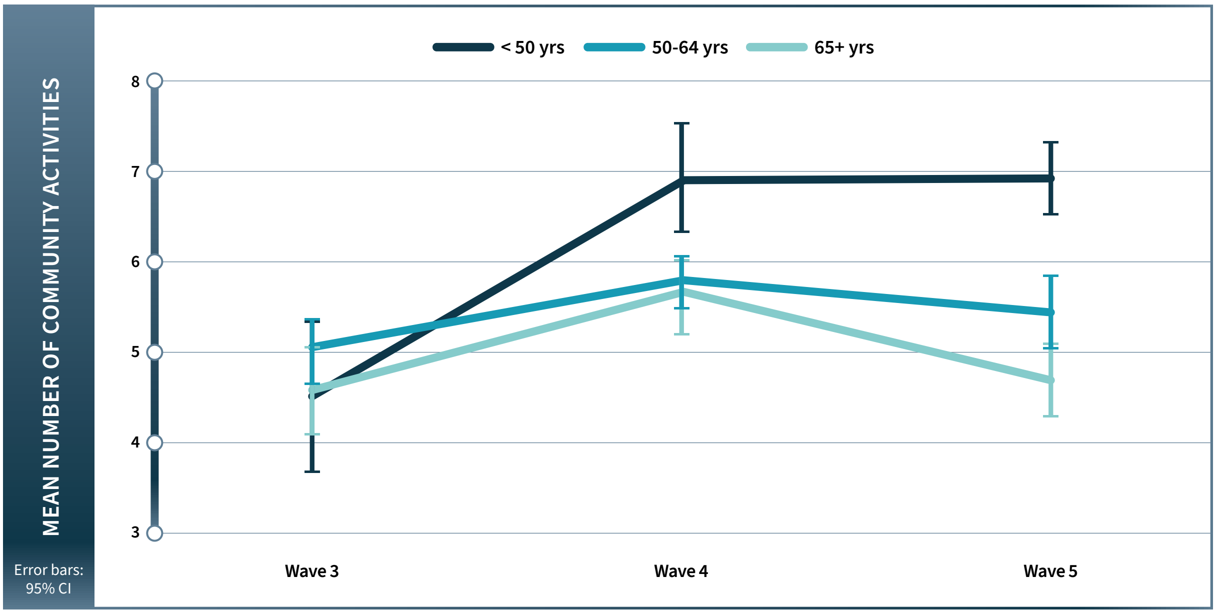
Rates of volunteering among participants in Wave 5 remained relatively low at 14.2% overall; and even lower (10.7%) in those aged 50 years and older – compared with 55% of men and 51% of women reported by TILDA for the general older population in Ireland (McGarrigle, Ward, Scarlett, & Kenny, 2020).

1.6: Community participation

1.6.1: Social activities in the community

Participants in Wave 5 were again asked about the social activities they engaged in, and whether or not they did these activities within community settings. Across 19 different social activities, the average number of activities was 5.6 (SD = 3.1). There was an increase in activities between Wave 3 and Wave 5 for all age groups, although the mean number for the two older groups fell back slightly from Wave 4 peaks (Figure 1.4).

Figure 1.4: Average number of regular community activities, Wave 3 to Wave 5



At Wave 5, on average, male participants did slightly more activities in the community (M = 5.9, SD = 3.1) than female participants (M = 5.3, SD = 3.1). Regular activities were highest for those under-50 years (M = 7.0, SD = 2.9) and falling for those aged 50-64 years (M = 5.5, SD = 3.0) and aged 65 and over (M = 4.7, SD = 2.9). Participants living in residential care (M = 4.3, SD = 2.9) did significantly fewer activities than those group home settings (M = 6.0, SD = 2.9) and in independent/family (M = 6.3, SD = 2.9). Participants with severe-profound intellectual disability did significantly fewer community activities (M = 4.0, SD = 2.6) than those with moderate (M = 5.8, SD = 3.1) and with mild intellectual disability (M = 6.4, SD = 3.1).

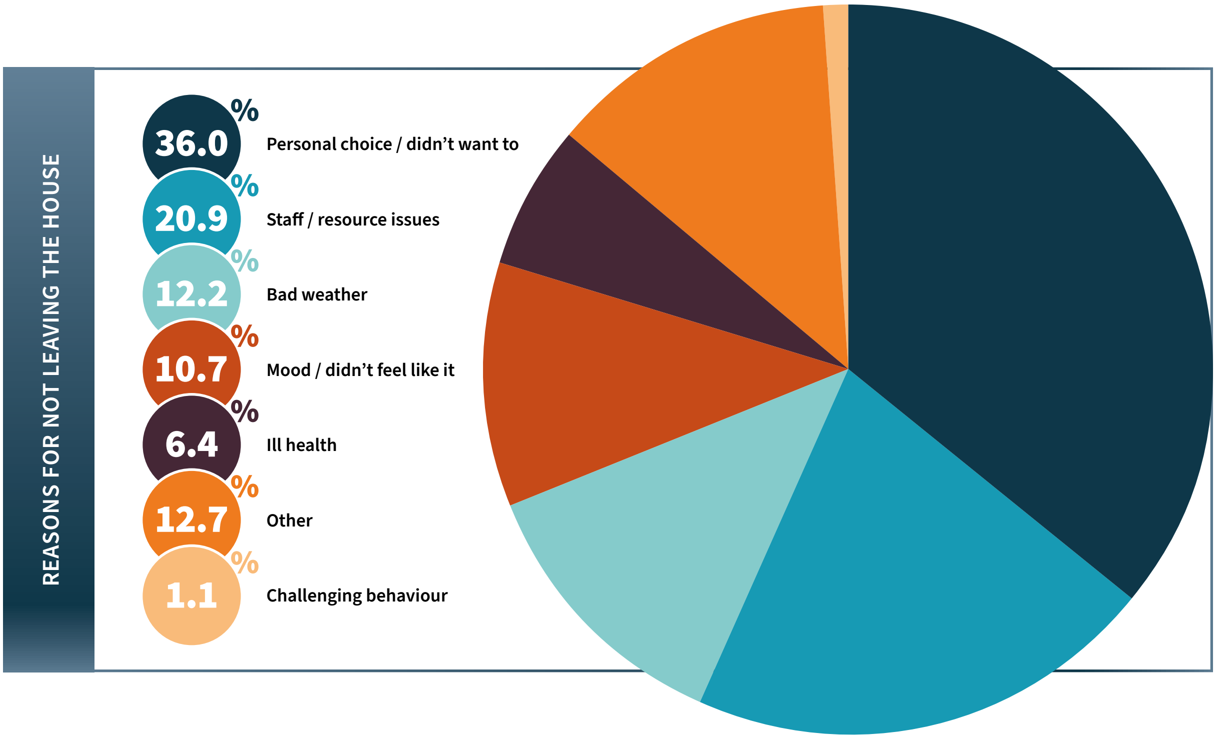
1.6.2: Work and daily occupation

Just one in ten participants (10.9%, *n* = 82) reported engaging in paid employment, although this was a slight increase from 8.4% (*n* = 62) in Wave 4. Most of this increase can be attributed to the participants under 50, as their rate of employment rose from 20.4% (*n* = 28) in Wave 4 to 27.1% (*n* = 49) in Wave 5. However, there remains a stark contrast with the general population with recent figures from the Central Statistics Office (2021b) reporting that 66.4% of adults aged 45-64 were currently in paid employment, compared to 11.8% (*n* = 55) in the same age group for IDS-TILDA Wave 5.

A large majority of participants (81.4%, *n* = 620) attended a day service or received day activation in their homes. However, 12.3% (*n* = 94) reported they did not do anything specific during the day, almost double the amount in Wave 4 (6.9%, *n* = 51).

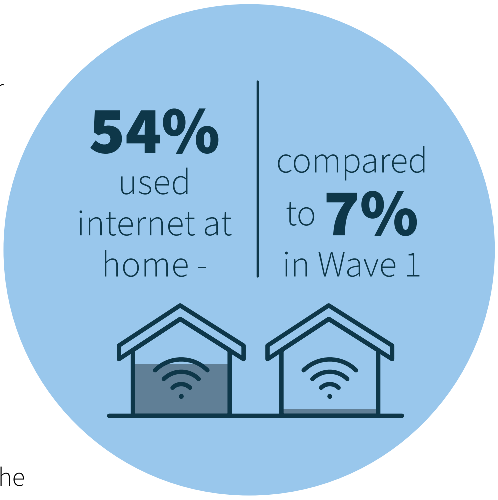
Fewer than half of participants (38.9%, *n* = 289) had left the house every day of the previous week. Most participants (70.8%, *n* = 526) reported spending at most two full days at home, but 19.4% reported spending the majority of the week (four or more days) at home, with 5% (*n* = 37) not leaving. The main reason for not leaving the house was personal choice (Figure 1.5). However, 20.9% (*n* = 94) of participants reported lack of staff and resources. Other reasons limiting daily outings can be seen in Figure 1.5.

Figure 1.5: Reasons for not leaving the house



1.6.3: Technology access and use

Fewer than half (44.7%, *n* = 340) of Wave 5 participants owned a mobile phone, but a large majority (88.8%, *n* = 300) said they used their phone. While lower in comparison to 96% mobile phone ownership amongst the general population (Pope, 2019), Wave 5 represents an almost doubling of ownership since Wave 1 (23%, *n* = 172).



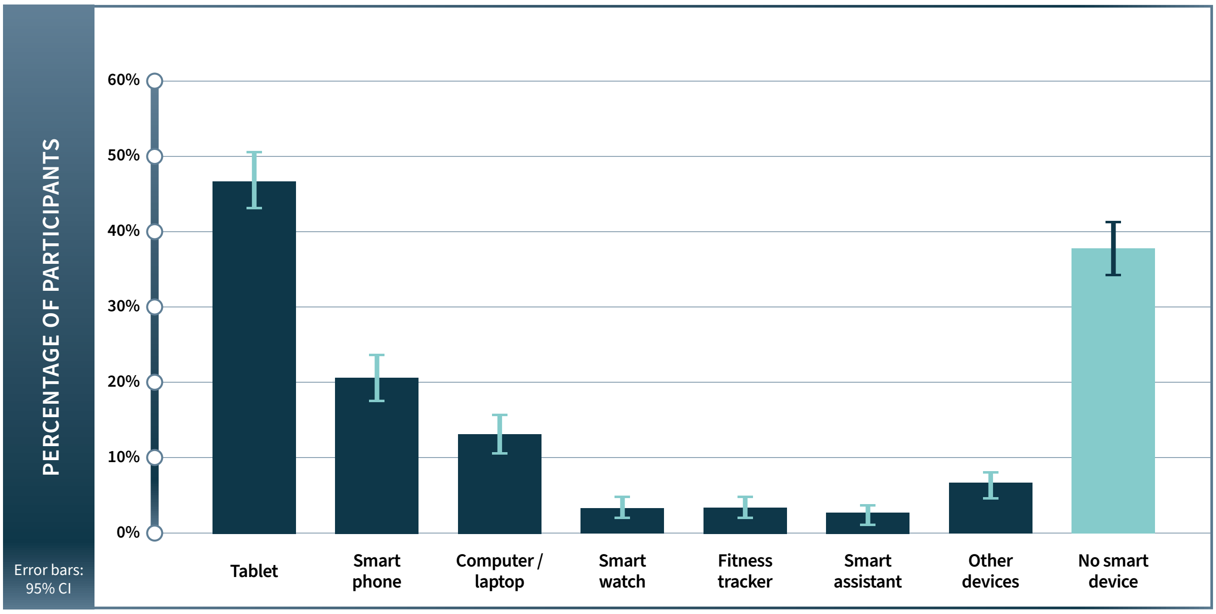
Access to and use of the internet at home also increased considerably over time, with nine out of ten participants (89.6%, *n* = 675) now having access, and over half of all participants (53.7%, *n* = 409) reporting they used the internet at home, compared to 7.3% in Wave 1 (McCarron et al., 2011). While positive, use is still lower than the 90% internet use among the general population (Central Statistics Office, 2021a), and 70% daily and 87% weekly usage among the general older population reported by TILDA just prior to COVID-19 (Kenny, Scarlett, & Mahoney, 2020).

Fewer individuals living in independent/family residences had access to the internet at home (84.7% compared with 93.2% and 87.4% for those in community group homes and residential care respectively), but they had the highest use of the internet at home (73.4% compared with 60.5% in community group homes and 51.6% in residential care).

Participants aged 65 and over were the least likely to have access to the internet at home (85.4% compared with 90.1% for under 50s, and 91.9% for those aged 50-64); and were less likely to use the internet at home (45.3% compared with 79.1% and 60.2% for participants under 50 and between 50-64 respectively). Participants with Down syndrome were more likely to use the internet at home (69.3%, *n* = 88), than those who did not have Down syndrome (58.8%, *n* = 321). Internet use at home was highest for participants with mild (72.6%, *n* = 130) compared with individuals with moderate (60.4%, *n* = 174) and severe-profound disability (46.9%, *n* = 69).

As shown in Figure 1.6, the most commonly used smart devices were tablets (46.9%, *n* = 357), smart phones (20.7%, *n* = 158), and computer/laptops (13.3%, *n* = 101), while more than a third of participants (37.9%, *n* = 289) said they did not use any such devices.

Figure 1.6: Smart devices used



Around half of participants living in residential care (49.3%, *n* = 107) did not use any smart device, compared with around a third of those in community group homes (36.7%, *n* = 137) and just a quarter in independent/family residences (26.2%, *n* = 45). Most participants aged 65 and over reported not using any smart devices (56.5%, *n* = 122), with a lower proportion of non-users among the under 50s (20.8%, *n* = 38) and 50–64-year-olds (35.5%, *n* = 129). Fewer participants with Down syndrome used no smart devices (27%, *n* = 38) compared with those without Down syndrome (40.4%, *n* = 251).

Figure 1.7 shows that 61.4% of smartphone users, 42.6% of computer/laptop users, and 30% of tablet users used devices without any support. When needed, the most common support by support staff was for two-thirds (63.9%) of tablet users, half (50.5%) of computer/laptop users, and around a third (34.8%) of smartphone users.

Figure 1.7: What helps/enables use of smart devices

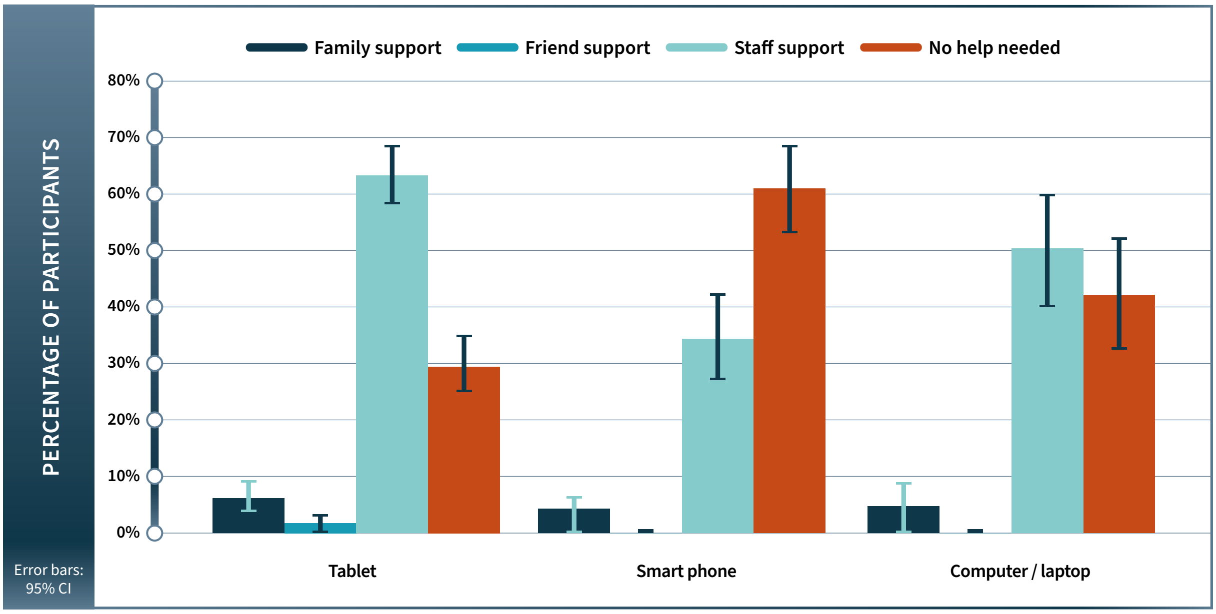


Figure 1.8 shows leisure, entertainment and gaming was by far the most common use reported for tablets and computers/laptops (72.5% of tablet users; 60.4% of computer/laptop users), followed by connect with family (31.7% of tablet users; 20.8% of computer/laptop users); some participants connected with friends and for social purposes, and use of computers/laptops was more diverse than tablets, including education (15.8%) and information (15.8%) purposes.

The profile of usage for smartphones was somewhat different. Primary uses were connecting with family (88.6%) and with friends (60.8%) with additional uses for leisure, entertainment, and gaming (35.4%) and for social purposes (29.7%).

Figure 1.8: What smart devices were used for

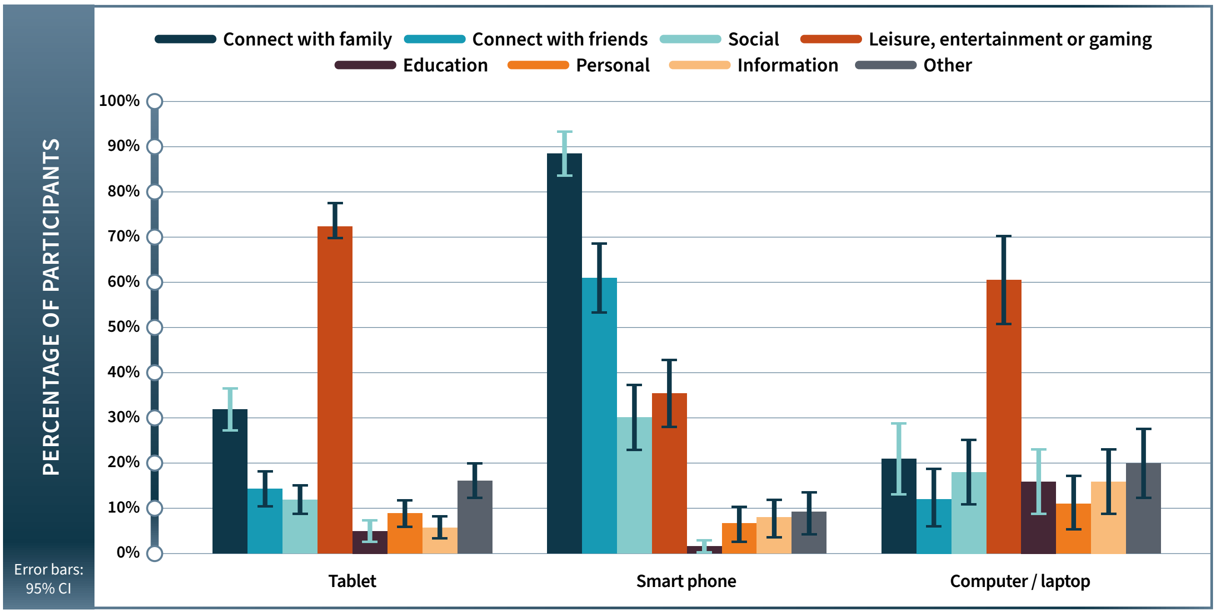


Figure 1.9 shows that most older adults with intellectual disabilities remain dependent on others to use technology, with a minority of participants able to perform specific skills even with assistance.

Figure 1.9: Skills and abilities to use technology

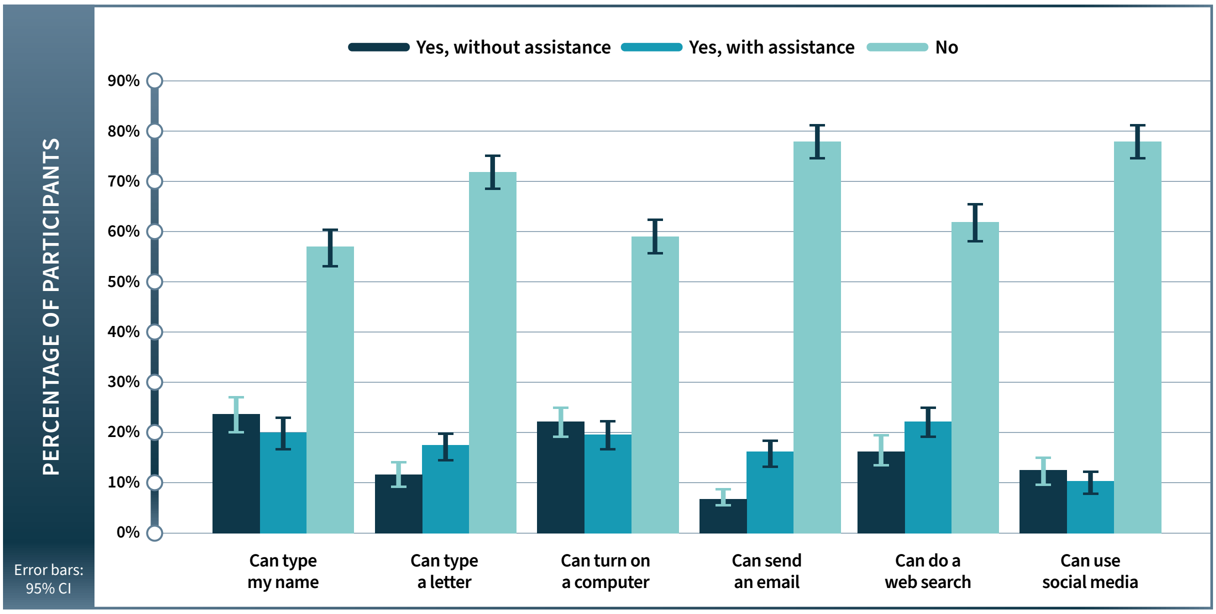
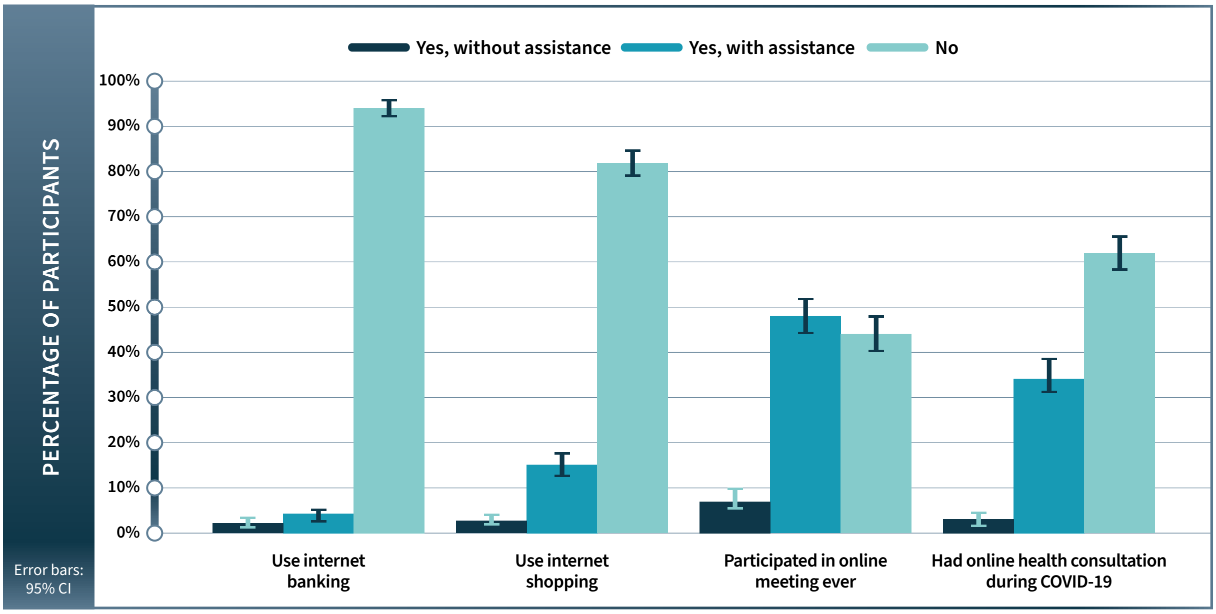


Figure 1.10 shows very little engagement in internet banking or shopping, with more than nine in ten participants not using internet banking and more than eight in ten not using internet shopping, even with assistance. More reported participating in online meetings (e.g., using Zoom, Skype, or Team) generally and for health purposes during COVID-19. However, many more required assistance to use technology for these purposes (48.3% and 34.9%) than used independently (7.4% and 2.9%). By comparison, TILDA reported higher rates of internet usage by the general older population prior to COVID-19, including information searches (81%), using email (73%), finance (59%), news (58%), audio/video calls (44%), and social media (40%) (Kenny et al., 2020).

Figure 1.10: Participation using technology



1.6.4: Housing and moving residence

1.6.4.1: Where participants live as they age

Where one lives impacts on health and health outcomes. This ranges from environmental and geo-spatial factors to structural and location (for example, closeness to services and amenities) as well as adequacy, accessibility, appropriateness of housing and the level of autonomy and choice an individual has over where and who they live with. This choice is a fundamental human right as outlined in The United Nations Convention on The Rights of Persons with Disabilities, Article 19. The extent to which people ageing with an intellectual disability moved to different living arrangements and the choice they exercised in those later life transitions is presented and discussed.

1.6.4.2: Housing mobility and motivations

Just under a quarter (22.6%) of people lived with family or independently. A greater proportion were living in community group homes or residential settings. There was a notable change in where people lived between Wave 1 to Wave 5. The figures are displayed in Table 1.8.

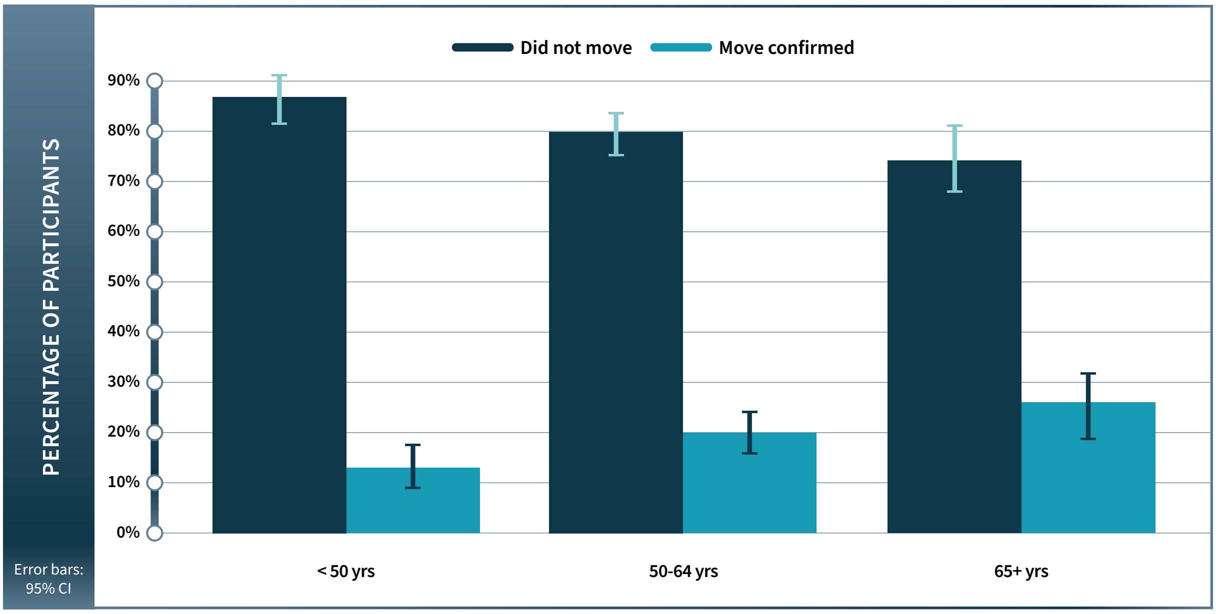
Table 1.8: Residential circumstances of IDS-TILDA participants at Wave 1 and Wave 5

	Wave 1		Wave 5	
	n	%	n	%
Independent / family	129	17.1	172	22.6
Community group home	268	35.6	373	49.0
Residential	356	47.3	217	28.5

These differences are particularly notable for the groups aged 40-49. At Wave 1 the percentages were 44.8% in residential care, 34.0% in community group homes and 21.2% independent/with family. By Wave 5 the percentages were 7.7% in residential care, 45.9% in community group homes and 46.4% independent/with family.

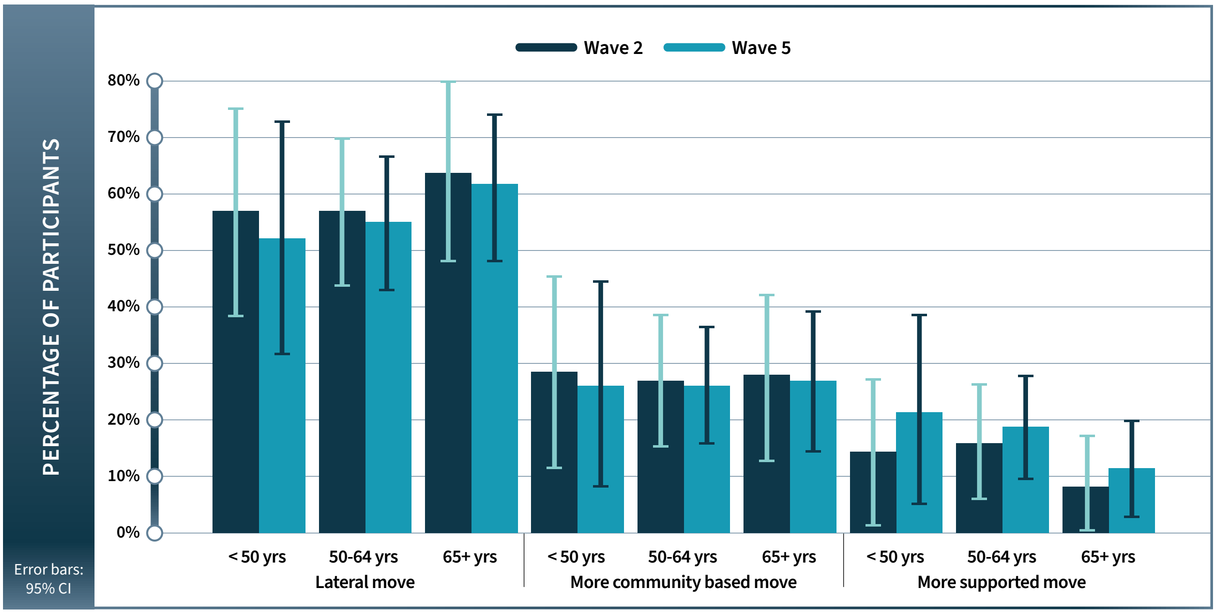
One hundred and forty-six people (19.8%) moved in the 3-year period prior to their Wave 5 interview, compared to (17.1%) at Wave 2. Age was the only demographic factor significantly associated with moving (Figure 1.11).

Figure 1.11: Moving residence and not moving by age group



Almost a quarter of moves were to community-based residences, with lateral moves (i.e., movement to a similar residence type) accounting for 56.9%, and 16.7% were moves to more supported settings. Comparing moves at Waves 2 and 5, there was a slight decrease in the proportion of community-based moves and a slight increase in the proportion of more supported moves (see, Fig 1.12). Reasons for moving were variable dependent on type of move, but change in physical health status was the most commonly reported reason (25%) for moving to more supported settings, as well as the most commonly reported (12.5%) and 'most important' reason for moving to community based homes.

Figure 1.12: Moving residence by age group at Wave 2 and Wave 5



'Lack of nursing supports' and 'lack of 24-hour support' were the only reasons for moving where a significant association was found, but numbers were small. Some respondents provided 'other' reason for moves – landlord selling the property, behaviours of neighbours or other residents, and HIQA stipulating move from congregate setting was required.

Those that reported a HIQA recommended move accounted for 19.7% of moves.

Lack of social housing, high private rental market and landlord instability have been previously noted as reasons for people with intellectual disability and autism and their family's experiencing homelessness or being at risk of homelessness (O'Donovan et al, 2020). Loss of primary carer (12%) has also been reported as a reason for a return to residential care (O'Donovan et al, 2020). Future waves of IDS-TILDA will track trends in risk of homelessness and increased re-institutionalisation.

1.6.4.3: Are people ageing in a place of their choosing?

For the general population, a move to a congregate setting/nursing home is not unusual but ageing in place is reported to have important health and well-being consequences (WHO, 2015). The debate over what ageing in place means for people with intellectual disability is underdeveloped and has been reframed in terms of ageing in a place of one's choosing. 4.3% of participants reported personal choice as their core motivation for moving, usually among those who moved laterally. No one who reported personal choice as the reason for a move, made a move to a more supported environment and only one of the participants who made a move to community-based residence reported personal choice as the reason to move.

Two-thirds of people who moved were not involved in the decision to move but those who were involved also demonstrated greater self-choice in other areas of life. People who moved to more community-based settings demonstrated greater mean self-choice in other areas of life compared with lateral and more supported moves.

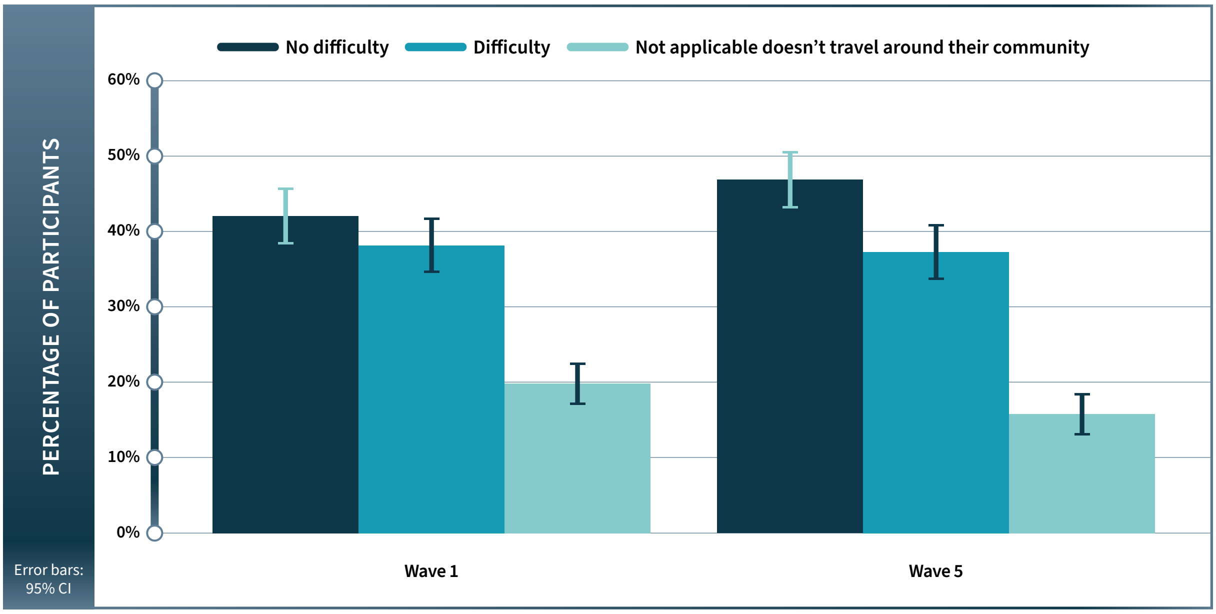
Although more females moved, a slightly higher proportion of those who were involved in the decision to move were male (51.2%). Only one-third of the women who moved were involved in that decision. A large proportion of those who moved noted that the move was talked about or included in their personal plan (86.8%), yet only one-fifth of those who moved viewed alternative accommodation before moving. Out of 97 responses, 79.4% stated that they had wanted to move. A higher proportion of participants who moved laterally reported not wanting to move, when compared with participants who moved to community and to more supported residences; however, this difference was not significant.

Overwhelmingly, those who moved reported that their current housing met their needs (94%) and most people were happy now that they have moved (87%) with 6.1% of people still adapting to the change. An additional indication of autonomy within the home and living space, is whether people had a key to their own home. Just under half of those who moved had a key to their own home (49.1%). This is comparable to the 50.8% with a key in the wider sample and reports of approximately one third having a key in Wave 3.

1.6.5: Neighbourhood quality/characteristics

There was little change in the proportion of participants who experienced difficulty getting around their community from 38.2% in Wave 1 to 37.3% in Wave 5, and a slight increase in those reporting no difficulty (from 42.1% to 46.9%), and a decrease in the proportion who said they were unable to travel around their community at all (from 19.7% at Wave 1 to 15.8% at Wave 5).

Figure 1.13: Difficulty getting around my community at Wave 1 and Wave 5



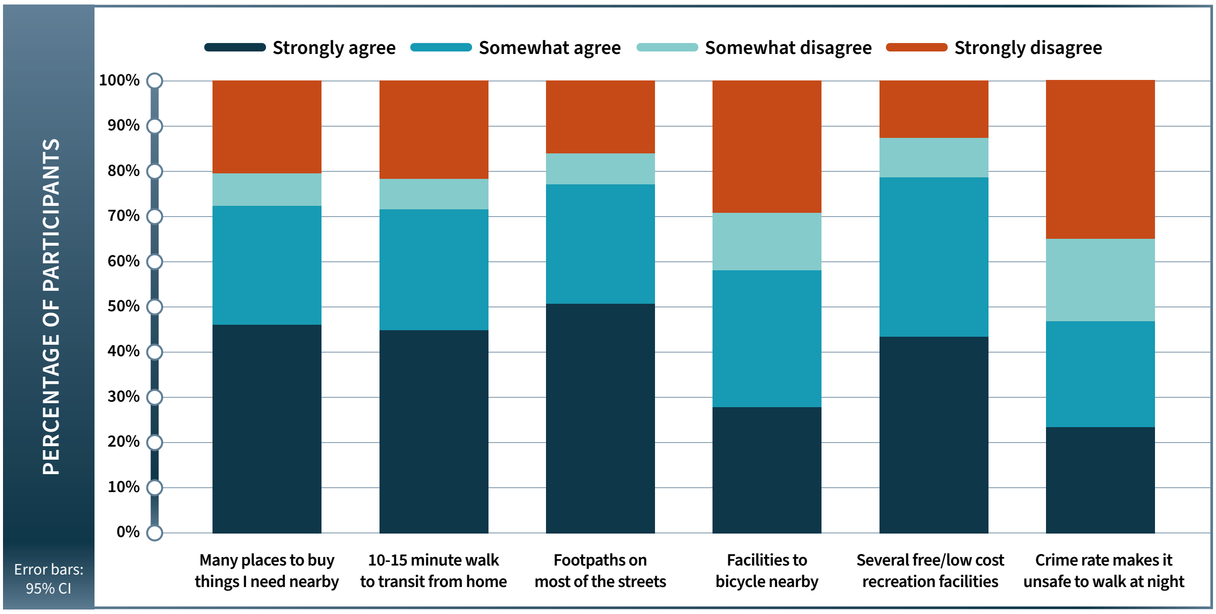
Difficulty getting around one's community was strongly associated with residence type. Participants living in independent/family settings were far more likely to have no difficulty (70.9%, *n* = 122) than participants living in community group homes (40.6%, *n* = 151) and residential care (38.7%, *n* = 84). Participants living in residential care were almost five times more likely than those in independent/family settings to be unable to travel around their community at all (23.5% versus 5.2%).

Difficulty travelling around the community was also strongly associated with age. Well over half of the under-50s (59.9%, *n* = 109) reported no difficulty, compared with 44.9% (*n* = 163) of the 50–64-year-olds, and 39.4% (*n* = 85) of the 65 and over group. A quarter of the oldest group (25%, *n* = 54) were unable to travel around their community at all, compared with 15.2% (*n* = 55) of the 50–64-year-olds, and just 6% (*n* = 11) of the under-50s.

There were stark differences between groups according to level of intellectual disability. Far more participants with mild intellectual disability had no difficulty getting around their community (70.6%, *n* = 144) than participants with moderate (40.4%, *n* = 126) and severe-profound intellectual disability (29.1%, *n* = 50). Those with mild intellectual disability were also less likely to be unable to get around their community at all (8.8%, *n* = 18) as compared with individuals with moderate (15.7%, *n* = 49) and severe-profound (26.7%, *n* = 46).

A new set of questions about the characteristics or quality of participants' neighbourhoods was introduced in Wave 5. Figure 1.14 shows that most participants rated the quality of their neighbourhoods positively agreeing there were several free/low-cost recreation facilities (78.9%), footpaths on most streets (77%), many places to buy things they need (72.3%), transit within 10-15 minutes' walk from home (71.6%), and facilities to bicycle nearby (58.1%). Additionally, a slight majority (53.3%) did not feel the crime rate made it unsafe to walk in their neighbourhood at night. However, this meant that almost half of participants (46.7%) felt unsafe walking their neighbourhood at night, with almost a quarter (23.5%) strongly agreeing they had this concern.

Figure 1.14: Participants ratings of neighbourhood quality



1.7: Conclusion

Choice or lack thereof, has a direct impact on health and well-being, i.e., is a critical social determinant, with people who experience greater choice and control in their lives more likely to experience greater quality of life. People with intellectual disability can learn choice making skills, even into older age (Heller et al, 2000). With implementation commencing during the data collection period, Wave 5 of IDS-TILDA represented the first opportunity to observe how implementation of the Assisted Decision-making (Capacity) Act was proceeding and the changes that were occurring. It was already impressive that one-third of the sample had a formal written decision agreement plan in place and a further 18.7% had an agreement under development. Future data collection waves will examine if there is further progress. Currently staff were the most common decision supporter designated in those plans. Perhaps just as important was that 54.1% of participants had Informal support plans by Wave 5 and this reflected an increasing trend for informal support plans over the IDS-TILDA waves. More work is needed in building formal plans. A quarter of people living independently/with family or in residential services stated an intent to make a legal support agreement meaning it is also likely that there will be growth in non-staff decision supporters. Again, data collection in future waves will monitor changes in these trends.

Between Wave 1 and Wave 5, there was an increase in mean self-choice scores overall and for each age category with the most notable increase in the less than 50 years of age group, those with mild intellectual disability and those living independently or with family. Progress continues but steps continue to be needed to ensure that choice is a feature for all lives and in all settings.

Fundamental differences remain between the social networks of older adults with an intellectual disability and the general older population in Ireland. While Wave 5 saw a very slight increase in the number who were married or had children, this was still very small by comparison to TILDA data. This has a real impact on quality of life, which is associated with being married and providing support to children and grandchildren (McCrory, Leahy, & McGarrigle, 2014). Staff friendships are debated in the literature for issues such as lack of reciprocity, power imbalance, and instability and turnover (Bigby, 2008; Cummins & Lau, 2003; Forrester-Jones et al., 2006; Friedman & Rizzolo, 2018). Nevertheless they remained common and a significant social support for many older people with an intellectual disability as did reliance by those living in grouped service accommodation on people they live with for friendships (McCausland, McCallion, Carroll, et al., 2021).

Wave 5 indicates that those living independently or with family continue to have greater opportunities to develop a broader range of friendships. However, people with more severe intellectual disabilities, including increased communication and behavioural difficulties, and those living in residential care, remained at most risk of exclusion and with greater dependence on staff support. Given the potential precariousness of staff relationships (McCausland, McCallion, Carroll, et al., 2021), the importance of familiar staff (McCausland, Murphy, McCarron, & McCallion, 2021), and the current context of a crisis in recruitment and retention of staff across many services, these factors pose a risk to the feeling of security, dignity and rights of people with intellectual disability (United Nations, 2006). Staff recruitment and retention challenges may also be apparent in the finding here that one in five participants reported not leaving the house due to staff/resource issues.

There was a notable increase in internet use between waves. While positive, overall engagement still lags behind 90% internet use among the general population (Central Statistics Office, 2021a), confirming the persistence of a digital divide for people with intellectual disabilities (Chadwick & Wesson, 2016; McCausland, McCarron, & McCallion, 2023). While digital skills are associated with individual ability and level of intellectual disability, previous IDS-TILDA analysis also identified that people living independently or with family, who may have less formal supports, may be at particular risk of digital exclusion (McCausland, Luus, McCallion, Murphy, & McCarron, 2021). It was notable in Wave 5 that support staff were the biggest help/enabler of smart device use for participants. Further research and analysis is needed.

There were other positive signs in the patterns of inclusion and participation at Wave 5 when compared to previous waves. There were increases as compared to Wave 1 in the proportion of participants who had regular contact with both their family and friends and in giving and receiving help to/from neighbours and friends. There was a slight increase in the proportion in paid employment between Waves 4 and 5 with the biggest if still modest increase among younger IDS-TILDA participants, which may signify a degree of generational change and the impact of more inclusive policies. Overall, it continues to be the case that many more adults with intellectual disabilities attend day services than are in paid employment. While employment is the type of activity associated with the best mental health outcomes, in terms of occupational activity, other regular daily activity including day services are also associated with improved mental health (Bigby, Beadle-Brown, & Bould, 2015; McCausland, McCallion, Brennan, & McCarron, 2020).

Analysis of new measures of neighbourhood characteristics and quality indicated that the majority of participants were satisfied with the quality of their local environments. However, a sizeable proportion of participants were not satisfied, and further analysis must seek to understand associated factors and how the finding that almost half of participants felt unsafe walking their neighbourhood at night might be addressed. It was also positive that fewer people reported difficulty getting around their community, although age remained a factor as highlighted in previous analyses (McCausland, McCallion, Carroll, & McCarron, 2023), and highlighting the need to support the oldest with intellectual disabilities and to address mobility issues associated with ageing.

Changing where one lives may be difficult and stressful at any time in life, but later years may bring additional complexity. The intersection of choice and need, particularly the need for services and support, and a housing market that is difficult to access and navigate, makes it unsurprising that the majority of people ageing with intellectual disability are more likely to be moving laterally between similar settings, often within the same provider network.

Levels of involvement of people with intellectual disability in the decision and process of moving is less than desirable, with two-thirds of participants who moved effectively excluded. Given the enactment of the Assisted Decision (Capacity) Act, an increase in involvement, choice and autonomy should be evident in future waves.

In conclusion, our findings confirm that many older adults in Ireland live full social lives, are connected to their networks through rich interpersonal relationships, and engaged in their communities and for many there have been improvements in these areas of life. Early analyses suggest that some of the structural issues previously identified remain present, in particular persistence of greater degrees of exclusion compared with the general older population. Further research is needed to fully understand the emerging data and to translate findings into actionable steps to improve policy, practice, and quality of life for adults ageing with an intellectual disability within their communities.

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CHAPTER 2

Multimorbidity and Physical Health Trajectories in People with Intellectual Disability

Eilish Burke, Pavithra Pavithra, Frances O'Brien, Darren Fitzpatrick, Stephanie Corrigan, Caitríona Ryan, Margaret Haigh, Philip McCallion and Mary McCarron.

2.1: Key findings

- The physical health of participants aged under 50 improved over the last 10 years with 55.2% in Wave 5 reporting no chronic health condition compared to 36.7% in Wave 2. In addition, numbers reporting three or more chronic health conditions more than halved from 23.3% in Wave 2 to 11.9% in Wave 5.
- Despite the prevalence of chronic health conditions, the majority of adults (88.5%) appraised their health as excellent, very good or good.
- Prevalence for those aged 50 and over was 44.6% for hypertension and 44.7% for high cholesterol which was less than findings for the TILDA population at 52% (hypertension) and 59% (high cholesterol).
- Women with an intellectual disability had a significantly greater prevalence of arthritis than men.
- Doctor's diagnosis of osteoporosis for those aged 65 and over and the 50–64-year-olds increased from 24.7% in Wave 2 to 34.3% in Wave 5 and from 13.4% to 18.5% respectively. Whereas objective measurement found that 40.3% of the 50–64-year-olds had osteoporosis in Wave 2 and 36.4% in Wave 5.
- Individuals with severe/profound intellectual disabilities, regardless of sex, exhibited worrisome trends in poor bone health.
- Fragility fracture levels were higher in people aged 65 and over with intellectual disability (17.8%) than in TILDA participants aged 65 and over (9%).
- Women who have had fragility fractures exhibited notably elevated rates of osteopenia (47.8% versus 37.5% in men) whereas rates of osteoporosis remained similar for both (34.8% in women versus 37.5% in men).
- Fear of falling in people with intellectual disabilities was double that reported by TILDA for the general population aged 50 and over at 46.8% versus 21.8% respectively.
- Pain levels overall were similar to the general population aged 50 and over but pain reported by women under 50 rose from 24.5% in Wave 1 to 37.8% in Wave 5.
- Most frequently reported pain sites were knees (24%), stomach (21.1%) and back (15.2%).
- Across the waves of IDS-TILDA there has been a considerable and steady increase in GERD across all age groups. This was particularly evident among those aged 50-64 years where prevalence more than doubled from 7.3% in Wave 1 to 16.5% in Wave 5. Also, in individuals with severe or profound intellectual disability increases were from 15.9% to 28.6% in men, and from 10% to 30.7% in women.
- For all age groups constipation increased for the waves rising from 17.3% at Wave 1 to 42.8% at Wave 5. In the younger age groups (under 50 years) rates rose from 14.6% at Wave 1 to 34.4% at Wave 5, and prevalence in people with severe/profound intellectual disability was 70%.
- A newly introduced objective hearing screening at Wave 5 found a hearing deficit of (28.7%) among persons with mild and moderate intellectual disability versus self-report at (17.6%).
- Mean age at menopause was approximately 48 years for those without Down syndrome and approximately 44 years for those with Down syndrome; younger than age 51 years for the general population.
- Just 41.6% of menopausal women in IDS-TILDA reported symptoms of the menopause whereas women in the general population report upwards of 90%.
- Only 48.8% of women were aware of menopausal transition; 37.9% of women said they discussed the menopause with someone and 16.2% received easy read materials on the topic.
- Foot health was self-rated as excellent/very/good by 89.8% of participants whereas 83.9% on objective measures were found with either moderate or high-risk foot problems with their feet, ranging from corns to infected ulcers. Measured rates for people with Down syndrome were 97.4%.

2.2: Introduction

The last decade has seen unprecedented changes for people with intellectual disability. From changes to their living circumstance emanating from the Congregated Settings report (HSE, 2011) to the worldwide pandemic in 2020. The IDS-TILDA study has collected data throughout this era which provides the opportunity to explore some of the greatest health challenges facing those with intellectual disability as they grow older in Ireland (McCarron et al 2011, Burke et al 2014, McCarron et al 2017, McCarron et al 2020). In the context of improving healthcare and increasing life expectancies, substantial disparities as compared to other older adults have existed among individuals with intellectual disabilities. Despite now experiencing longer lifespans, an unsettling reality endures.

On average their lifespan falls short by nearly two decades compared to those without intellectual disabilities (McCarron et al 2015, Doyle et al 2020). This striking divergence underscores the imperative to comprehensively address the unique health and wellbeing challenges faced by this population, including elevated prevalence of epilepsy, chronic constipation, gastrointestinal disorders, endocrine abnormalities, and mental health conditions.

Concurrently, auditory, visual, and musculoskeletal impairments often remain undiagnosed and untreated. Contemporary health policy agendas, Healthy Ireland and Sláintecare, emphasise personal responsibility for health management and ageing well (HSE 2013, GoI 2021). However, for individuals with intellectual disabilities, achieving these goals presents distinctive complexities, necessitating extensive support to navigate the intricacies of their healthcare needs.

This chapter seeks to explore the prevalence of chronic health conditions among older adults with intellectual disability and the changes that have occurred in their health over time. Examining potential intergenerational differences in the health status of individuals in their forties today, to those from a decade or more ago, will provide empirical insights that may inform enhanced health promotion strategies and clinical practices. Where possible, findings will be compared with data from the general population study 'The Irish Longitudinal Study on Ageing (TILDA).' Health data collected within IDS-TILDA includes a suite of 24 health measures, see chapter 8 for a full description, and as part of this chapter objective health measures from Wave 2 [2013] are compared with Wave 5 [2023].

2.3: Multimorbidity and chronic health

Multimorbidity, defined as the coexistence of two or more chronic health conditions (CHC) in an individual, presents unique challenges when it intersects with intellectual disabilities (Hussain et al 2020). The prevalence among those with intellectual disability continued to be high with 72.4% presenting with multimorbidity at Wave 5, similar to 10 years earlier at Wave 2 (71.6%).

The patterns of chronic health conditions in older adults with an intellectual disability continue to differ to those reported by TILDA for the general population. The most prevalent conditions in IDS-TILDA were gastrointestinal, endocrine and neurological diseases versus cardiovascular and respiratory disease reported by TILDA (Hernández et al 2021). There was increased prevalence noted in Wave 5 compared to Wave 2 for musculoskeletal, endocrine and gastrointestinal conditions and a decrease in psychiatric conditions (Figure 2.1).

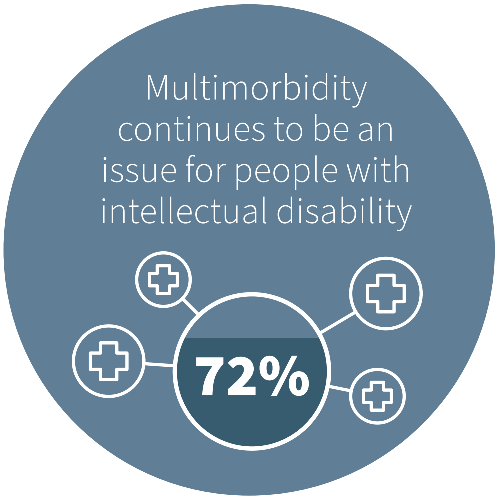
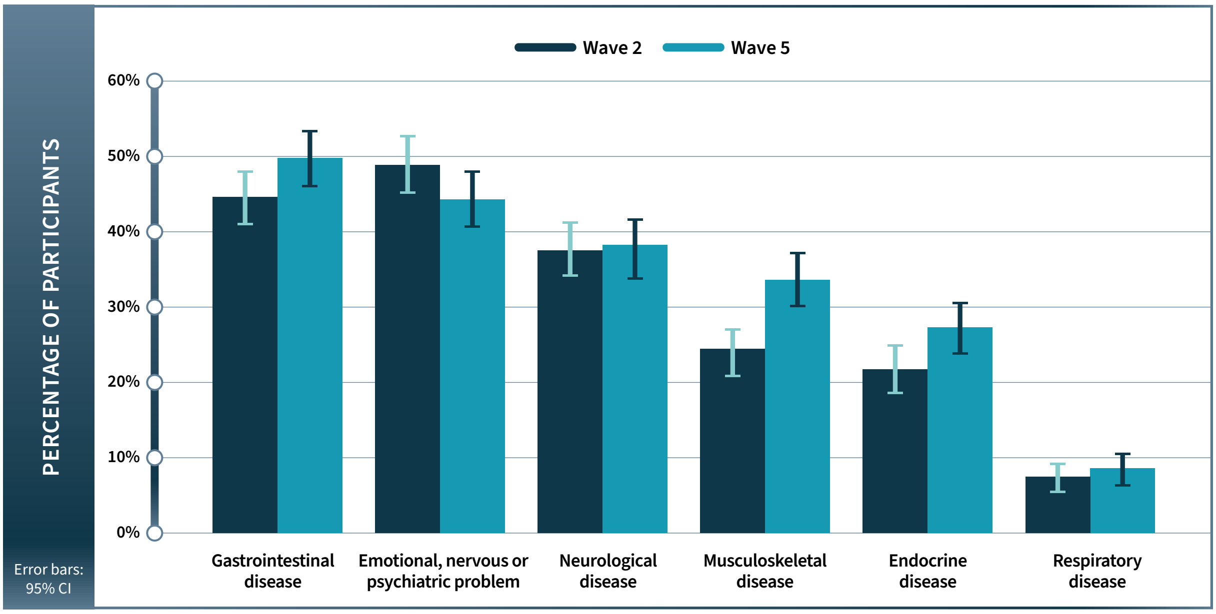


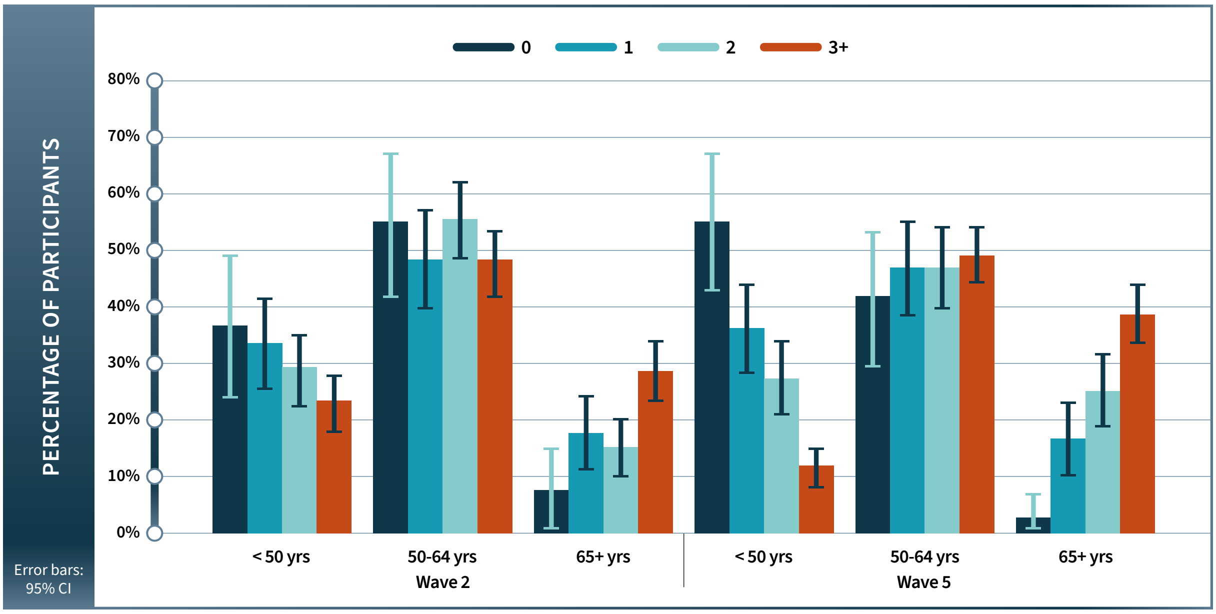
Figure 2.1: Chronic health classification at Wave 2 and Wave 5



Those in the older age group (65 and over) demonstrate the greatest increase in the number of conditions from Wave 2 to Wave 5 with 25.4% reporting two conditions and 38.8% reporting three or more conditions at Wave 5 compared to 15.3% and 28.9% at Wave 2. Similarly, for those in the middle age group an increase in three or more conditions are observed between the two time points from 47.9% to 49.3% respectively.

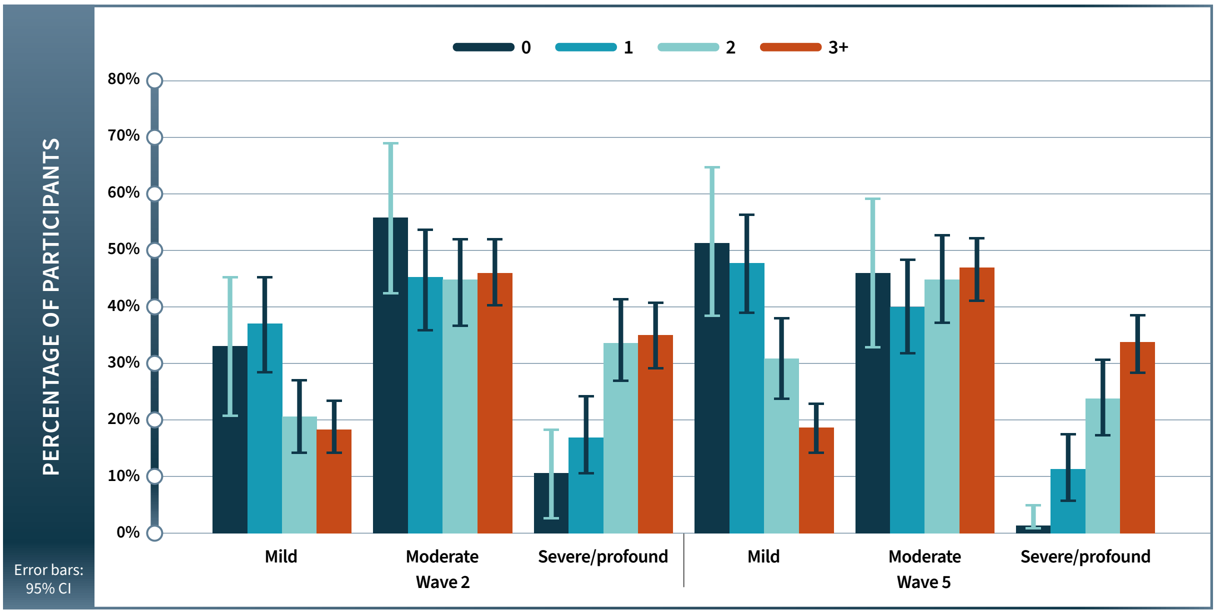
Overall, the physical health of participants under the age of 50 has improved over the last 10 years with 55.2% reporting no chronic health condition (CHC) compared to 36.7% in Wave 2. In addition, those reporting three or more chronic health conditions has more than halved from 23.3% in Wave 2 to 11.9% in Wave 5 (Figure 2.2).

Figure 2.2: Comparing the number of chronic health conditions by age at Wave 2 and Wave 5



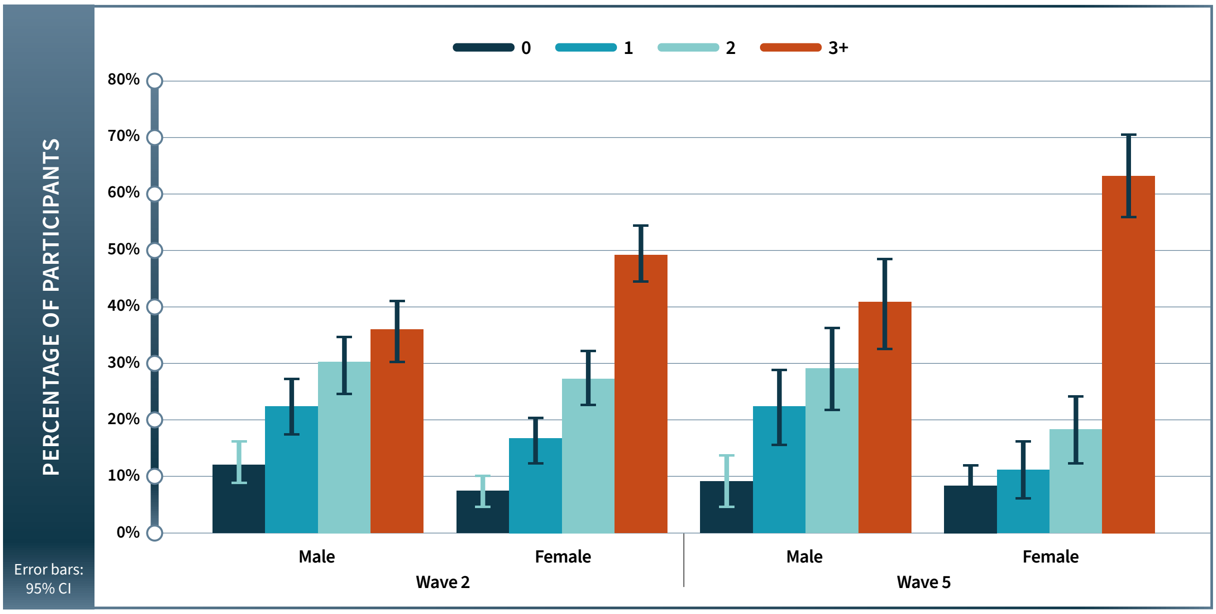
Those with mild intellectual disability showed a substantial increase in the percentage of people with no chronic health conditions reported, 33.3% in Wave 2 and 51.8% in Wave 5. Whereas those who reported 3 or more chronic health conditions remained stable (18.8% in Wave 2 and 18.9% in Wave 5). Similar trends were reported by those with moderate and severe/profound intellectual disability (Figure 2.3).

Figure 2.3: Number of chronic health conditions by level of intellectual disability at Wave 2 and Wave 5



Women's health remains disproportionately poorer than men's, with a notable increase in the prevalence of three or more conditions observed in Wave 5. Women's rates rose from 49% to 62.6%, while men saw a less substantial increase from 35.6% to 40.3%. Nevertheless, rates for men with no chronic health conditions decreased from 12.2% at Wave 2 to 8.7% by Wave 5. In contrast, women's rates remained relatively stable at 7.3% at Wave 2 and 8.0% at Wave 5. The prevalence of one or two conditions in men has remained consistent since Wave 2 (one CHC: 22.1% at Wave 2 and 5; two CHC: 30.1% versus 28.9%). Conversely, women have experienced notable drops in these categories (one CHC: 16.4% versus 11%; two CHC: 27.3% versus 18.4%). (See Figure 2.4).

Figure 2.4: Number of chronic health conditions by sex at Wave 2 and Wave 5



2.4: Self-reported health

Despite the prevalence of chronic health conditions, the majority of adults appraised their health as excellent, very good or good at 88.5%. For those aged 50 and over, this statistic is 91.4% which is higher than that reported by TILDA for the general population at 81% (Hennelly et al 2013).

2.5: Cardiovascular conditions

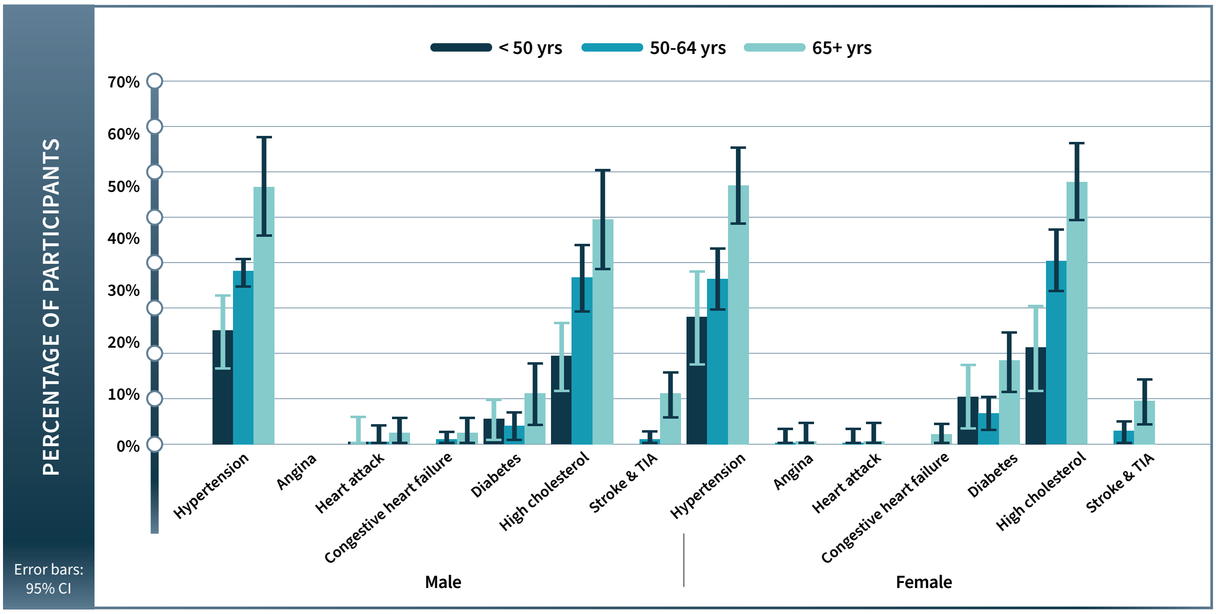
Cardiovascular Disease (CVD), which includes all diseases of the heart and circulation, remain a prominent contributor to mortality and morbidity in Ireland (Irish Heart Foundation 2023). Given that CVD risk increases with age (Visseren et al. 2022) and life expectancy continues to rise among individuals with intellectual disabilities (O' Leary et al. 2018), CVD is potentially a formidable health challenge for this population.

The prevalence rate for hypertension and high cholesterol in the full sample was 40.2% and 38.8% respectively. When limited to those aged 50 and over, prevalence increased to 44.6% for hypertension and to 44.7% for high cholesterol. This is less than the findings for the age-matched TILDA population at 52% (hypertension) and 59% (high cholesterol) (Hernández et al 2021). Despite these known risk factors for cardiovascular disease, the prevalence of heart attack, angina, and heart failure (<1% each), stroke/ministroke/TIA (3.9%), in people with an intellectual disability was low. When stratified by age and sex, the prevalence of all cardiovascular risks and conditions increased with age, with the highest prevalence reported in those 65 and over, and this was consistent for males and females. (See Figure 2.5).

The prevalence of hypertension for those over 50 was lower than that reported in the general population

45% **(IDS-TILDA)** | **52%** **(TILDA)**

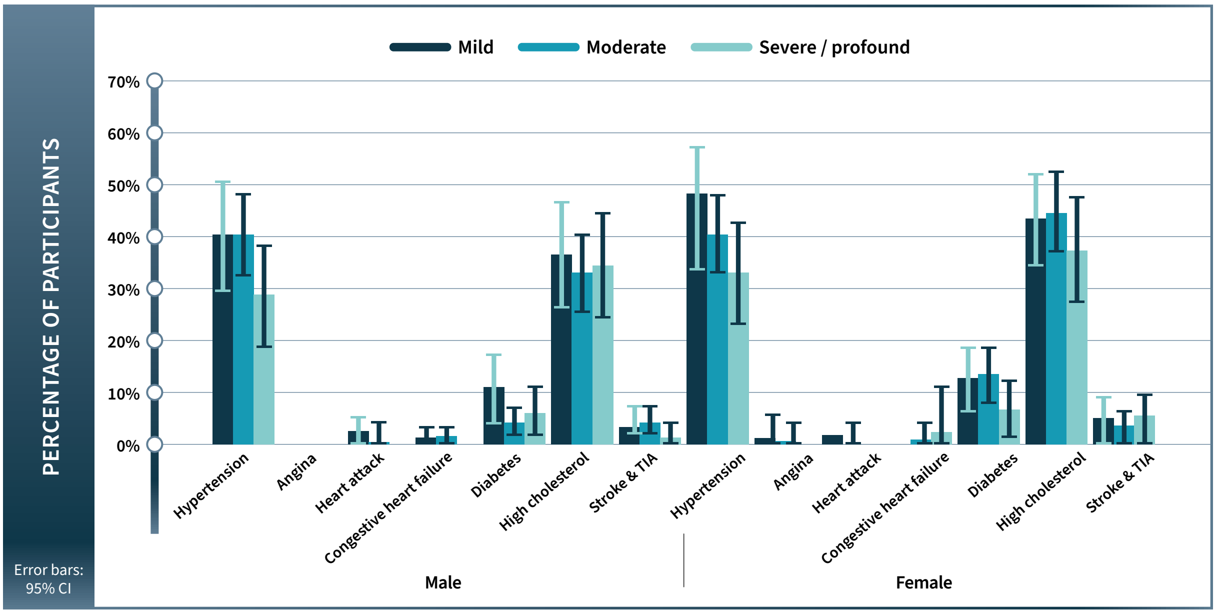
Figure 2.5: Comparing the prevalence of CVD and related risks by age and sex



Of all participants in the sample, more females than males had hypertension (41.8% v 38.3%), high cholesterol (42.8% v 34.4%), diabetes (11.5% v 6.2%) and stroke/TIA (4.7% v 3.1%), respectively. Awareness of these sex-related differences is important for the prevention and management of CVD and risks in women with an intellectual disability.

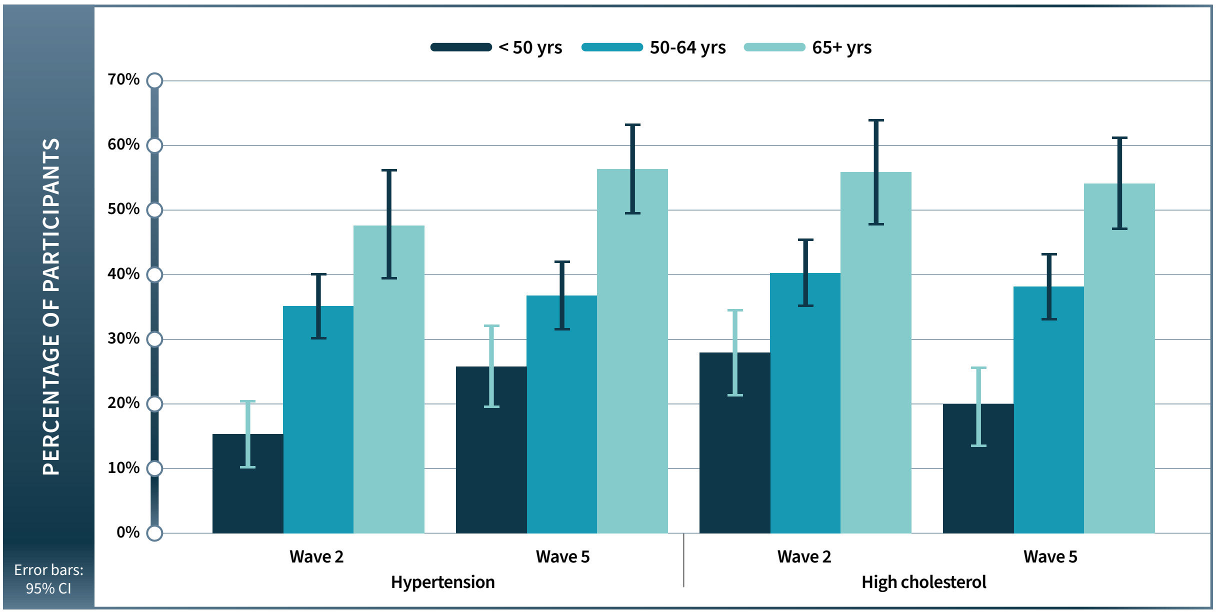
When examining CVD and risk prevalence by level of intellectual disability, greater prevalence of hypertension, high cholesterol, diabetes, stroke, heart failure and heart attack were observed in those with a mild or moderate disability (Figure 2.6).

Figure 2.6: Comparing CVD and risk prevalence by level of intellectual disability



The overall prevalence of hypertension increased by 7.3%, between Wave 2 (32.9%) and Wave 5 (40.2%), with the greatest increase evident in the under 50 age group (from 15.7% to 26.2%), followed by those aged 65 and over (48% to 56.9%) as illustrated in Figure 2.7. Conversely, hypertension in the general population has decreased over time, from 63.7% (Murphy et al. 2016) to 52% (Hernández et al. 2021).

Figure 2.7: Hypertension and high cholesterol prevalence at Wave 2 and Wave 5 stratified by age



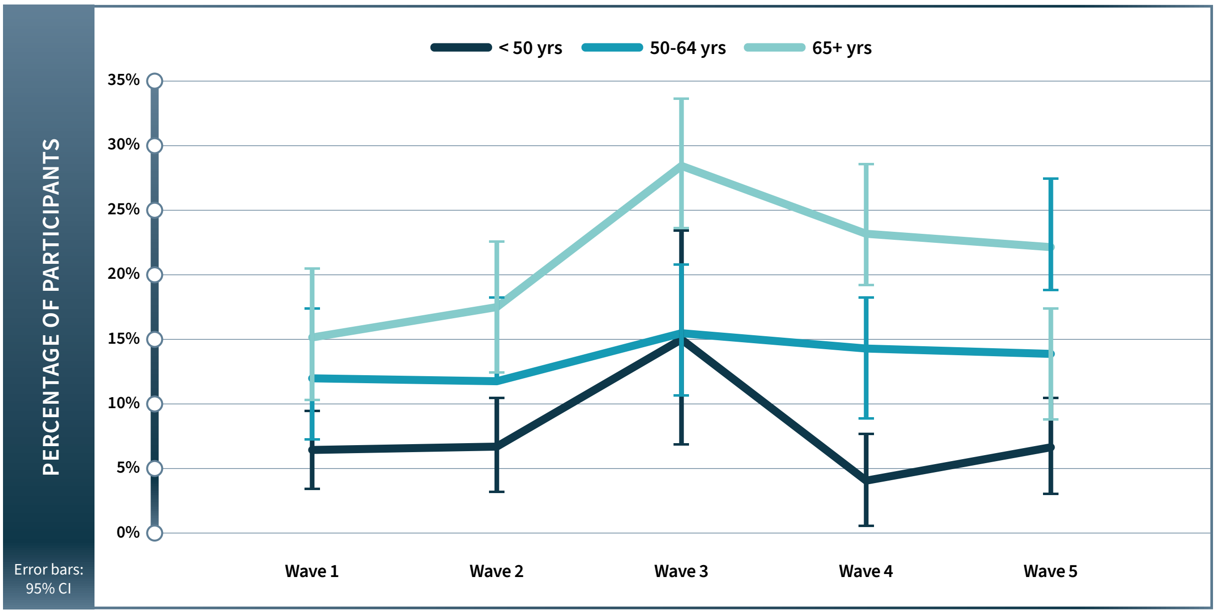
2.6: Musculoskeletal health

Musculoskeletal diseases (MSK), particularly arthritis and osteoporosis, account for a large part of global disease burden and are often conditions not recognised among those with intellectual disability (Hussain et al 2020, Burke et al 2019).

2.6.1: Arthritis

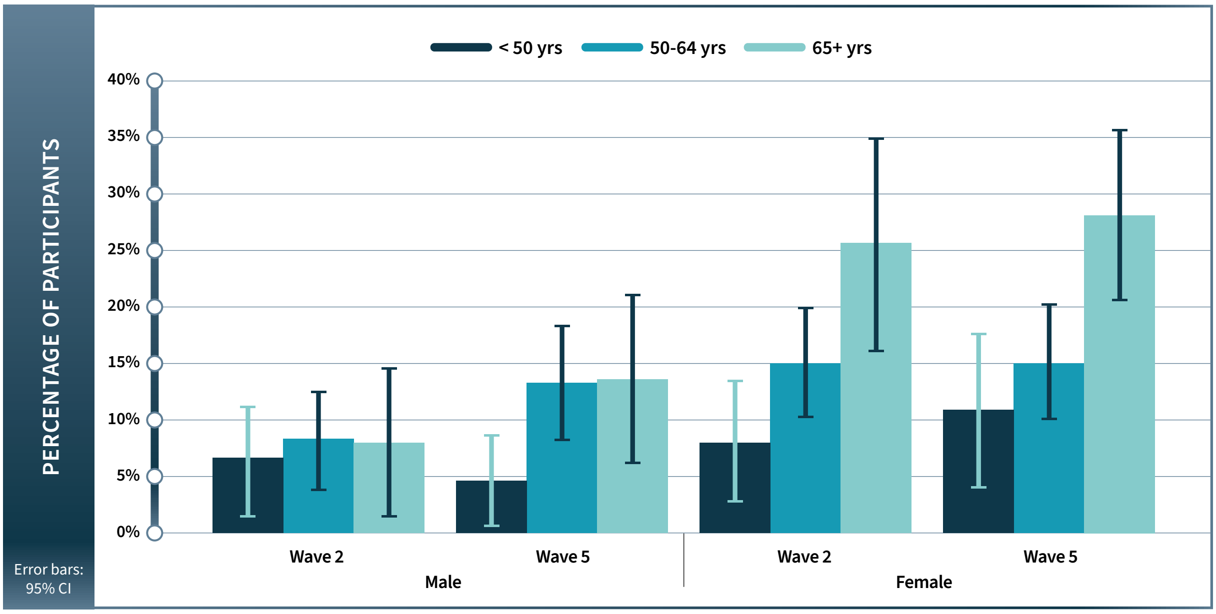
Arthritis, a debilitating and painful condition, has increased across the lifetime of IDS-TILDA from 11% at Wave 1, 12.2% at Wave 2 to 15% at Wave 5. Of those who reported a doctor's diagnosis of arthritis at Wave 5 in the older age group (65 and over), there is a notable increase (15.6% at Wave 1 to 22.7% at Wave 5). The middle age group show a slight increase of two percentage points. However, for the younger cohort (aged under 50) the prevalence is similar at Wave 5 as Wave 1 at 7.1%. (See Figure 2.8).

Figure 2.8: Prevalence of arthritis across IDS-TILDA stratified by age, Wave 1 to Wave 5



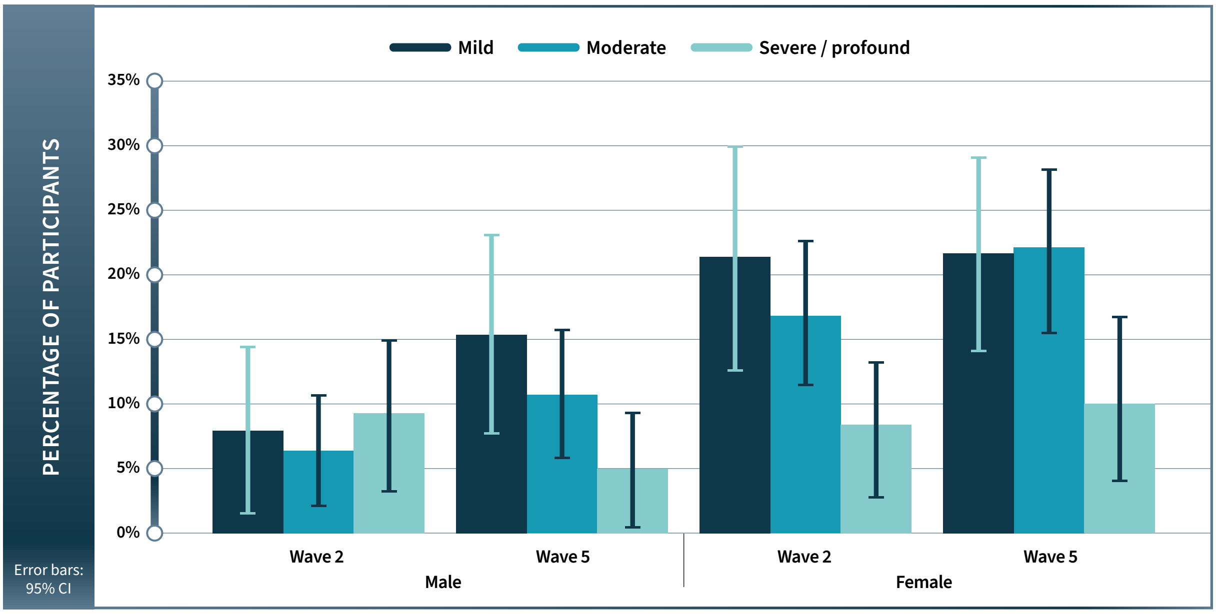
Sex analysis reveals that women with intellectual disabilities, particularly those aged 65 and above, exhibit a significantly greater prevalence of arthritis compared to their male counterparts, at 25.6% at Wave 2 and 28.1% at Wave 5 compared to 7.9% and 13.6% observed for men at Wave 2 and Wave 5 respectively. At Wave 5, in the under 50 age group, the prevalence for females was more than double that reported for males at 10.7% versus 4.6% respectively (Figure 2.9).

Figure 2.9: Comparing arthritis stratified by age and sex at Wave 2 and Wave 5



Among women, regardless of their level of intellectual disability, higher rates of arthritis have been consistently observed since Wave 2. The most substantial increase is noticeable among women classified as having a moderate level of intellectual disability, with a prevalence of 22.1% at Wave 5, up from 17% at Wave 2. Conversely, men with a mild level of intellectual disability have experienced a doubling in arthritis prevalence over the past decade, with rates rising from 7.7% to 15.3%. Notably, men with severe or profound intellectual disability have witnessed a significant decrease in arthritis, from 9% Wave 2 to 4.8% in Wave 5. This data is illustrated in Figure 2.10.

Figure 2.10: Comparing arthritis stratified by level of intellectual disability and sex at Wave 2 and Wave 5



2.6.2: Osteoporosis and osteopenia

Osteoporosis and osteopenia are reflective of deterioration of bone quality and density, increasing an individuals' risk of fracture. Reported doctor's diagnosis of osteoporosis initially at Wave 1 was 8% rising to 19.8% by Wave 5.

Among older adults (65 and over) prevalence of doctor's diagnosis of osteoporosis increased from 16.4% to 34.4% and for those aged 50-64 years osteoporosis prevalence increased from 9.3% to 18.5%. Meanwhile, for those under 50 years prevalence has only slightly increased from 3.1% to 5.5% in doctor's diagnosis. Refer to Figure 2.11 for visualisation.

Similar to Wave 2, bone health (osteoporosis and osteopenia) was objectively measured using the GE lunar Achilles ultrasound (QUS) at Wave 5. As in Wave 2, a greater prevalence of detection of osteoporosis is observed in Wave 5 in comparison to the doctor's diagnosis, 32% versus 19.8% with a further 29.4% within the osteopenic range. Dashed lines in Figure 2.11 provide an age stratified comparison of doctor's diagnosis of osteoporosis versus objectively measured osteoporosis. In a large Irish study, which examined older adults (60 and over) without an intellectual disability and without a diagnosis of osteoporosis, 15% were found to have osteoporosis and 47% osteopenia (Fitzpatrick et al 2023) emphasising the insidious nature of the disease.

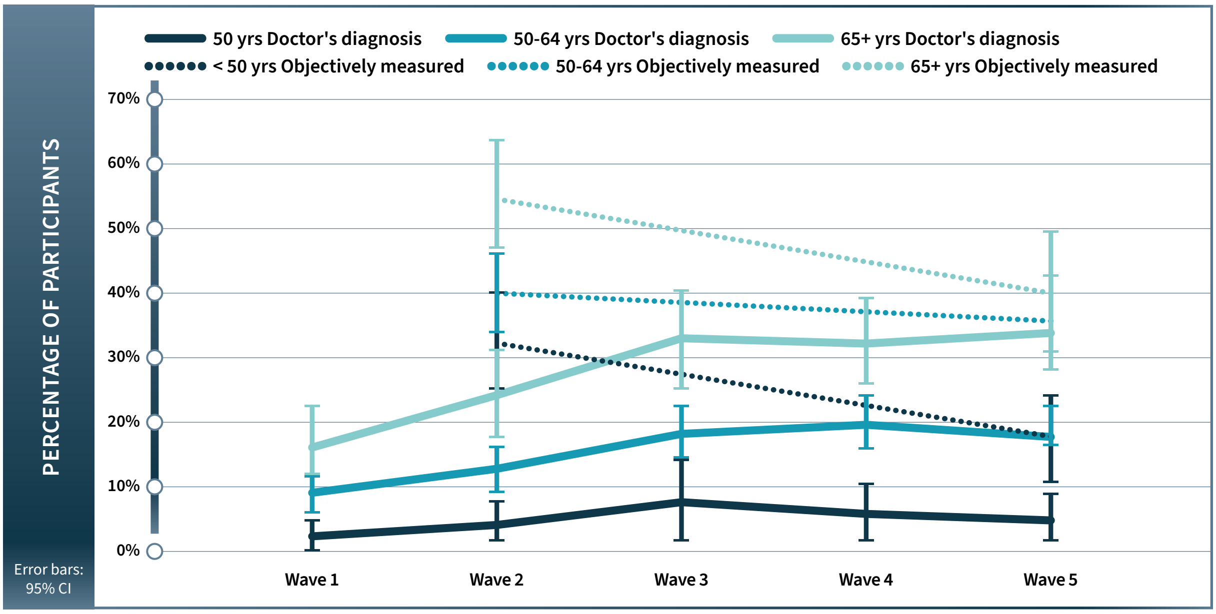
Doctor's diagnosis was lower than objectively measured osteoporosis

VS

objectively measured osteoporosis
32%

doctor's diagnosed osteoporosis
19%

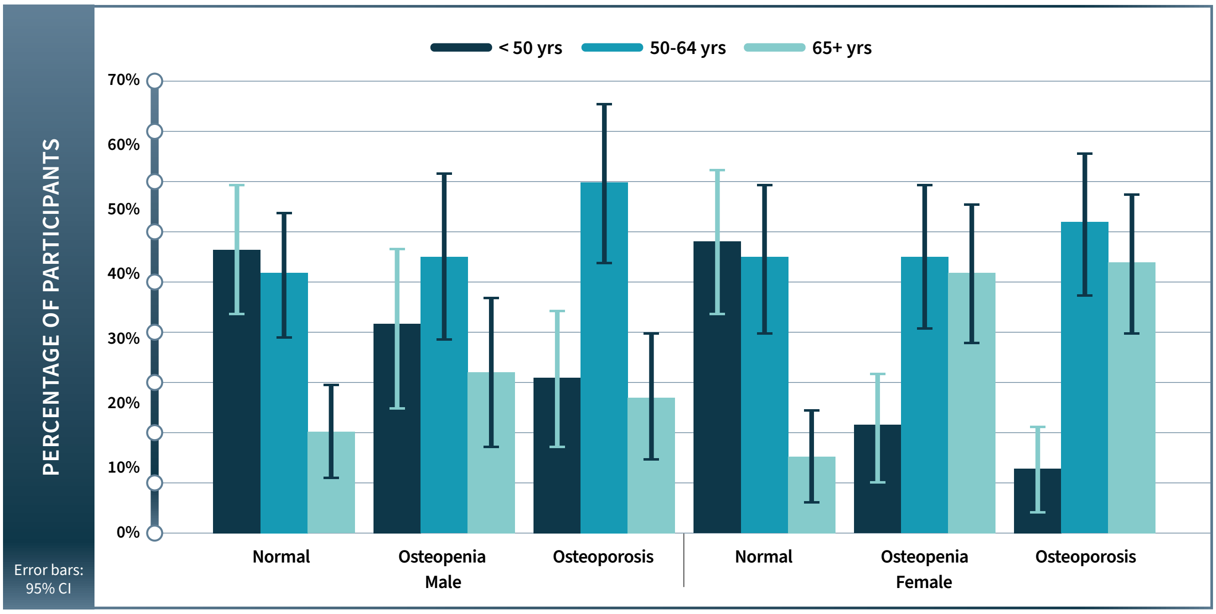
Figure 2.11: Changes in doctor's diagnosis of osteoporosis stratified by age versus objectively measured osteoporosis, Wave 1 to Wave 5



In Wave 5, objectively measured osteoporosis was higher among women in the older age group (65 and over) at 42% with an equally high detected prevalence of osteopenia at 40.5%. Whereas, 21.2% of men in the same age group were found to have osteoporosis and 25% had prevalence of osteopenia. On the other hand, men in the middle age group (50-64 years) presented with prevalence at 54.5% versus 48.1% for women.

A smaller proportion of younger women (aged under 50) were categorised within the osteopenic (16.5%) or osteoporosis (9.9%) range compared to men at 32.1% osteopenia and 24.2% osteoporosis respectively. This is concerning as there are no recommendations to investigate poor bone health among this younger cohort particularly for men. (See Figure 2.12).

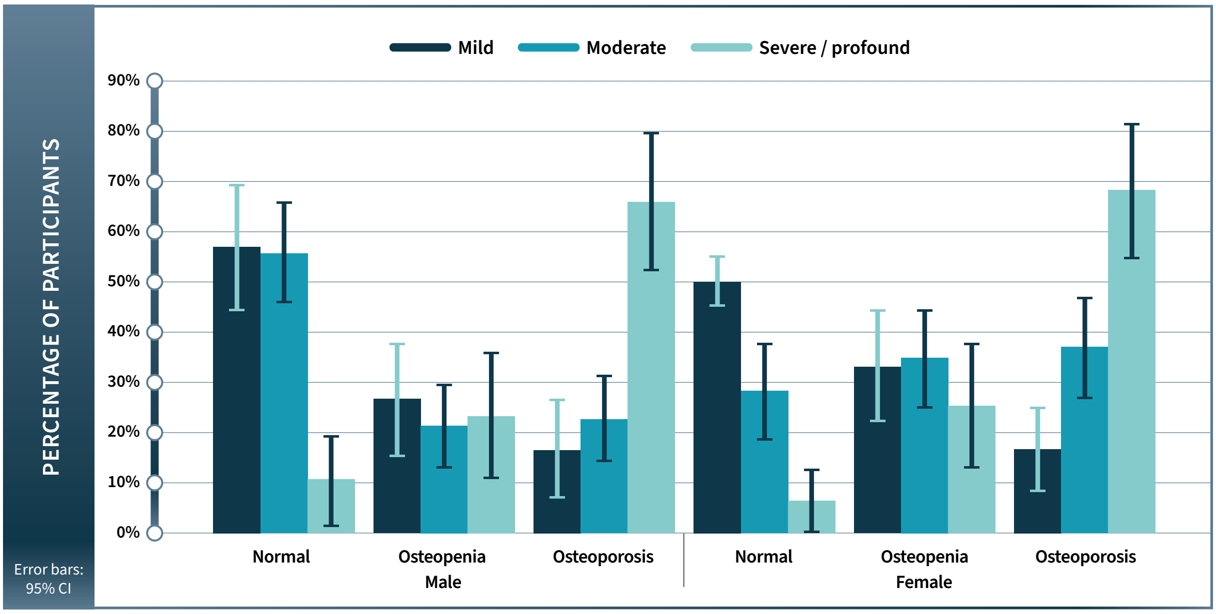
Figure 2.12: Objectively measured bone health stratified by sex and age



Considering level of intellectual disability (see Figure 2.13) the findings indicate that individuals with severe/profound intellectual disabilities, regardless of sex, exhibit worrisome trends in poor bone health.

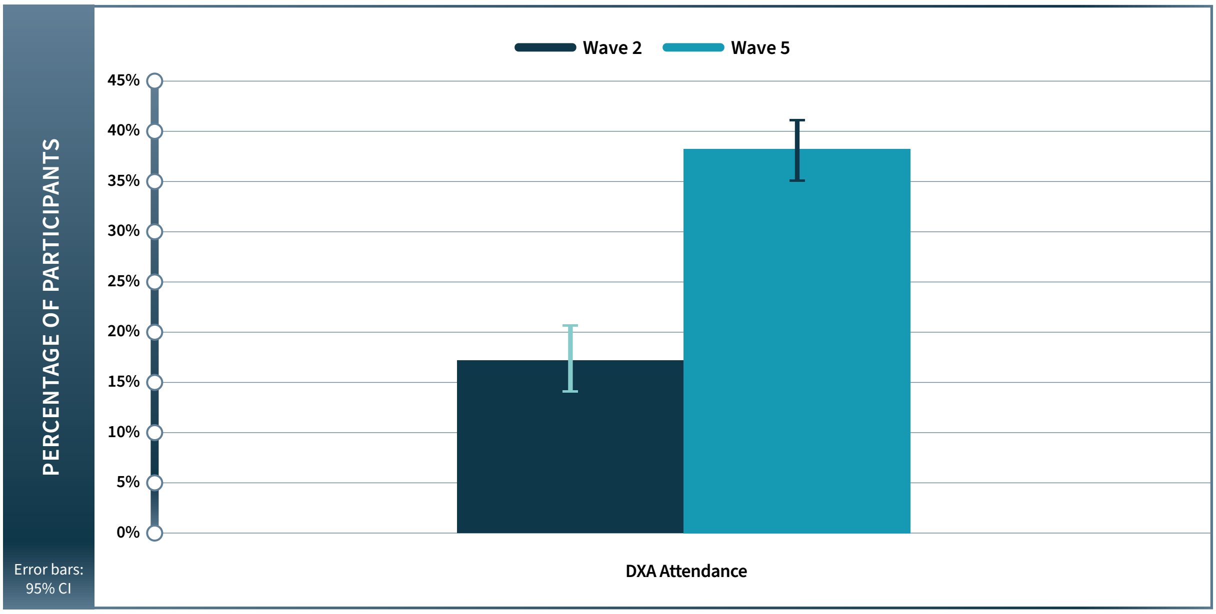
Women with moderate and severe/profound levels of intellectual disability also exhibited higher prevalence compared to men. Individuals with a mild level of intellectual disability, regardless of sex, were identified with similar levels of osteoporosis at a rate of 16.7%. Overall, these levels of poor bone quality imply compromised bone integrity and an increased risk of fracture.

Figure 2.13: Objectively measured bone health stratified by sex and level of intellectual disability



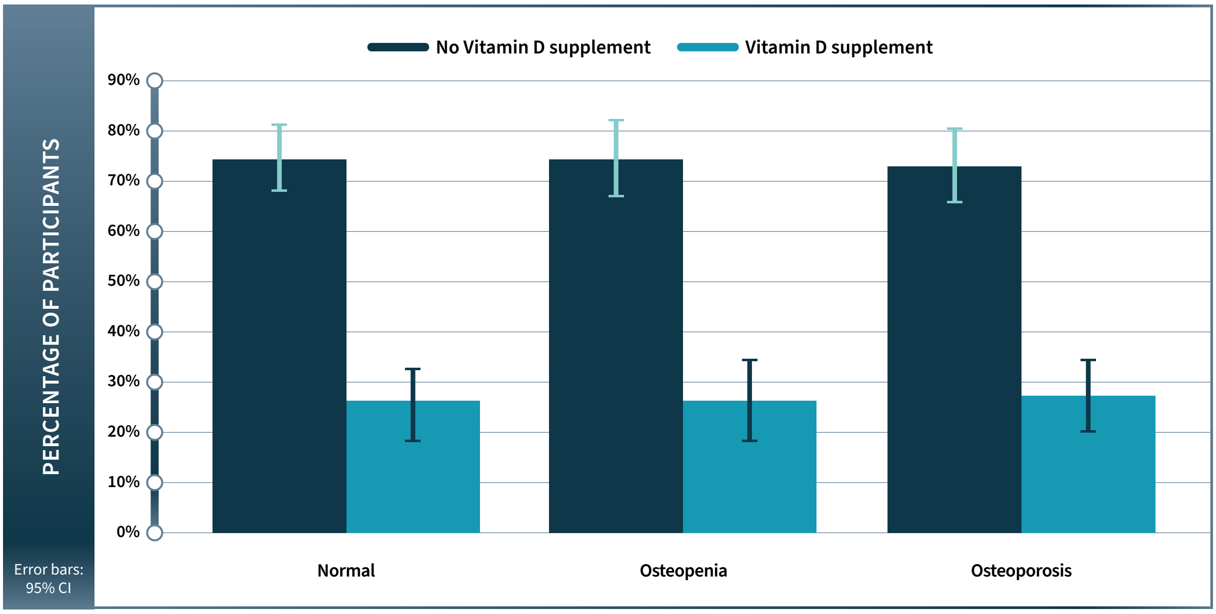
Dual-energy X-ray absorptiometry (DXA) serves as the gold standard for osteoporosis diagnosis. Over the past two years, an increase in DXA attendance has been noted, surpassing the rates observed at Wave 2, as depicted in Figure 2.14.

Figure 2.14: Attendance at DXA at Wave 2 and Wave 5



Vitamin D supplementation is suggested for all adults in Ireland as deficiency is common in Ireland (Food Safety Authority Ireland (FSAI), 2023). This vitamin is essential for bone integrity as well as normal functioning of the immune system and for good inflammatory response. Notably, when considering objectively measured bone health and vitamin D supplementation at Wave 5, only 27.1% of individuals within the osteoporotic range and 25.8% within the osteopenic range are receiving vitamin D supplementation (figure 2.15). Of the people who received a doctor's diagnosis of osteoporosis, only 22.8% of individuals are receiving vitamin D supplementation.

Figure 2.15: Vitamin D supplementation stratified by objectively measured bone health



2.7: Foot health

2.7.1: Self-reported

When asked about the condition of their feet, the vast majority (89.8%) of participants self-rated their foot health as excellent/very good/good. Fewer than one fifth of participants (16.3%) reported having pain in their feet, of whom half (55.6%) said foot pain impacted their ability to walk, meaning 17.0% of participants experienced pain that could compromise their mobility.

2.7.2: Objective assessment of foot health

The Brunswick Foot Risk Assessment Tool was used to objectively assess participants' foot health. It has seven categories: skin, nails, structure/anatomy, sensation, vascular, footcare and footwear. Both feet were risk-assessed based on specific criteria and rated as low, medium, high or urgent. In the skin category, which includes problems such as blisters, corns and ulcers; 41.6% of participants were assessed as low, 56.7% as moderate and 1.7% as high risk. As can be seen in Table 1, high risk was under 6.0% in each category and no participants presented as urgent risk. However, in the skin, nails and structure categories, a concerning percentage of participants were classed as moderate risk with problems such as cracks, fissures, deformed toenails and fallen arches.

Table 2.1: Participants' objective levels of foot risk measured using the Brunswick Foot Risk Assessment Form

	Low	Moderate	High	Urgent
Skin ($n = 473$)	41.6%	56.7%	1.7%	0%
Nails ($n = 472$)	64.6%	33.9%	1.5%	0%
Structure/anatomy (n = 473)	62.6%	37.2%	0.2%	0%
Sensation ($n = 364$)	99.2%	0.8%	0.0%	0%
Vascular ($n = 469$)	88.5%	6.4%	5.1%	0%
Footcare ($n = 473$)	91.1%	7.8%	1.0%	0%
Footwear ($n = 473$)	96.2%	3.0%	0.2%	0%

Only 16.1% of participants were classed as low risk across all categories. 75.5% of participants were classed as moderate risk, and 8.4% as high risk, in at least one category. The number with moderate and high risk was concerning considering 74% reported chiropody utilisation in Wave 5.

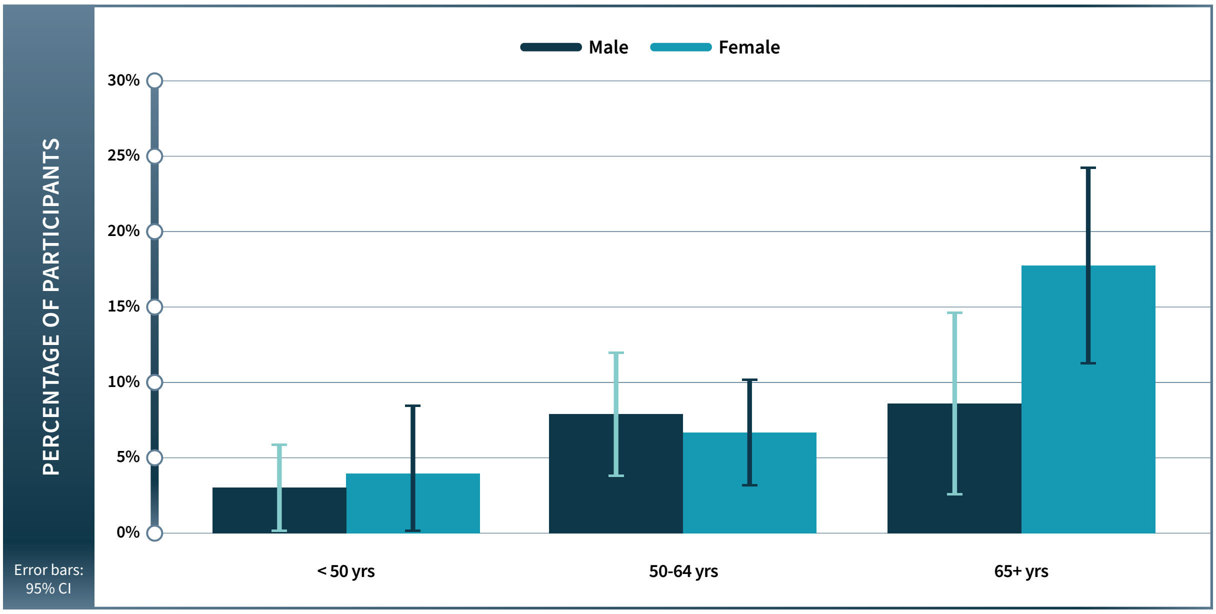
Levels of foot risk were similar across the different demographic variables such as age, sex, level of intellectual disability and residence. However, 97.4% of participants with Down syndrome presented with at least a moderate risk in one category, with only two people presenting with low risk in all categories. This higher level of challenges is consistent with reports that foot health issues start at an early age (Mik et al., 2008).

2.8: Fracture, falls and fear of falling

The extent of fractures among those with intellectual disabilities suggests higher levels of poor bone health with the body of current evidence pointing toward osteoporosis as the key determinant of fracture particularly in the presence of a fall (Frighi et al 2022). Fractures have been reported across the data waves.

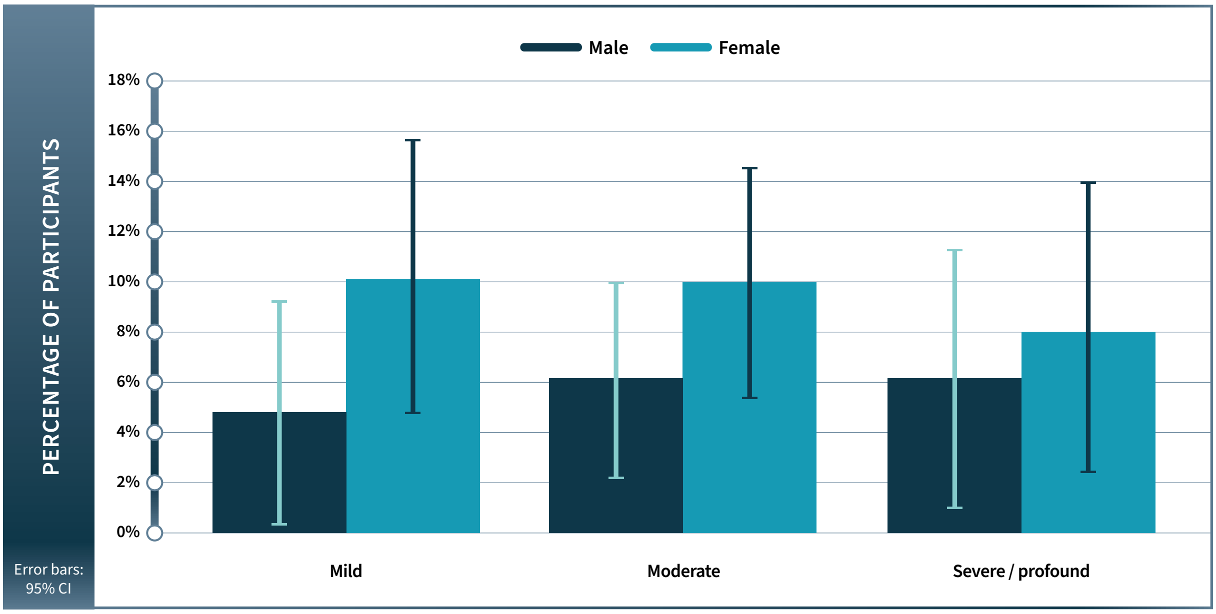
However, considering fragility fractures only - wrist, vertebra and hip - the prevalence observed increases considerably as people age, particularly for women, from 4% for those under 50 to 6.6% for those aged 50–64 years rising to 17.8% for those over the age of 65 years, see Figure 2.16; almost double the 1 in 10 of those 65 and over reported by TILDA (Donnell et al 2023).

Figure 2.16: Fragility fractures stratified by age and sex



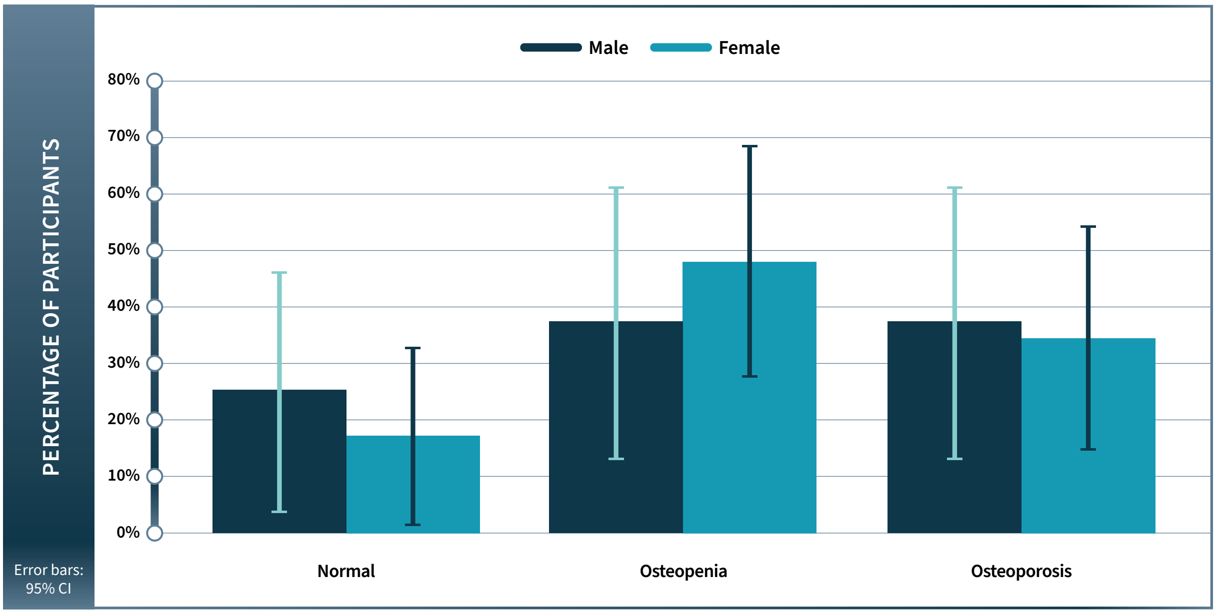
Interestingly, there is an intriguing trend wherein females with a mild intellectual disability exhibit higher rates of fragility fractures (10%) than those with more severe or profound intellectual disabilities (8%). Refer to Figure 2.17 for visual representation.

Figure 2.17: Fragility fractures stratified by sex and level of intellectual disability



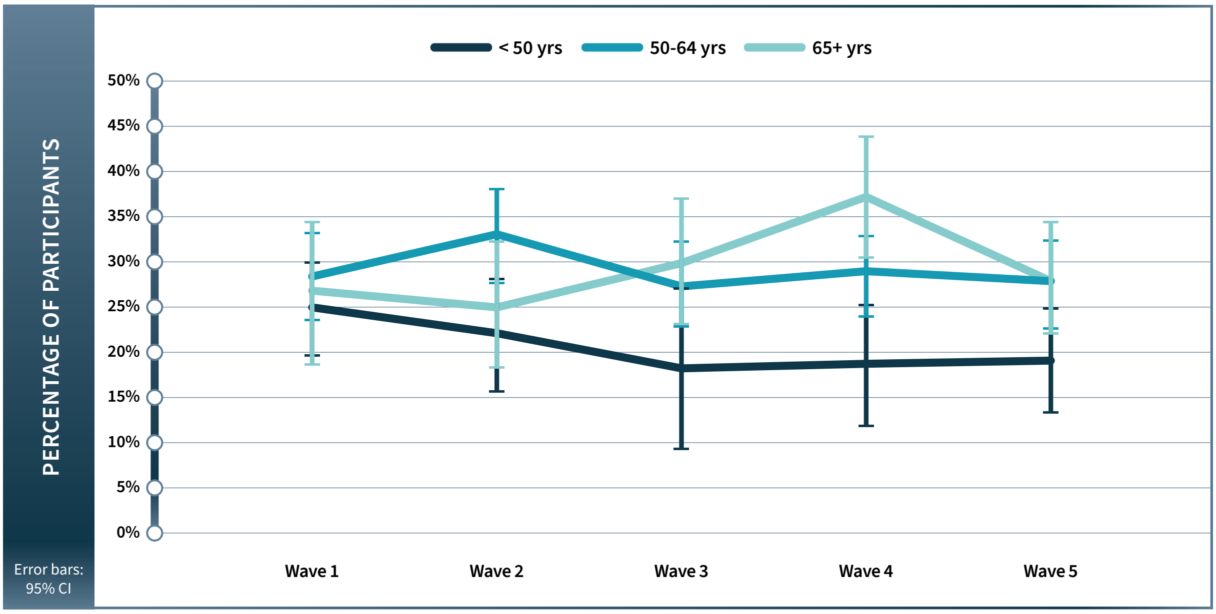
Women who have had fragility fractures exhibited notably elevated rates of osteopenia (47.8% versus 37.5% in men) whereas rates of osteoporosis remained similar for both (34.8% in women versus 37.5% in men). This association underscores the importance of monitoring and addressing bone health in individuals who have experienced fragility fractures, particularly in the context of osteoporosis risk assessment and management. Please refer to Figure 2.18 for graphical representation.

Figure 2.18: Fragility fractures by sex & objectively measured bone health



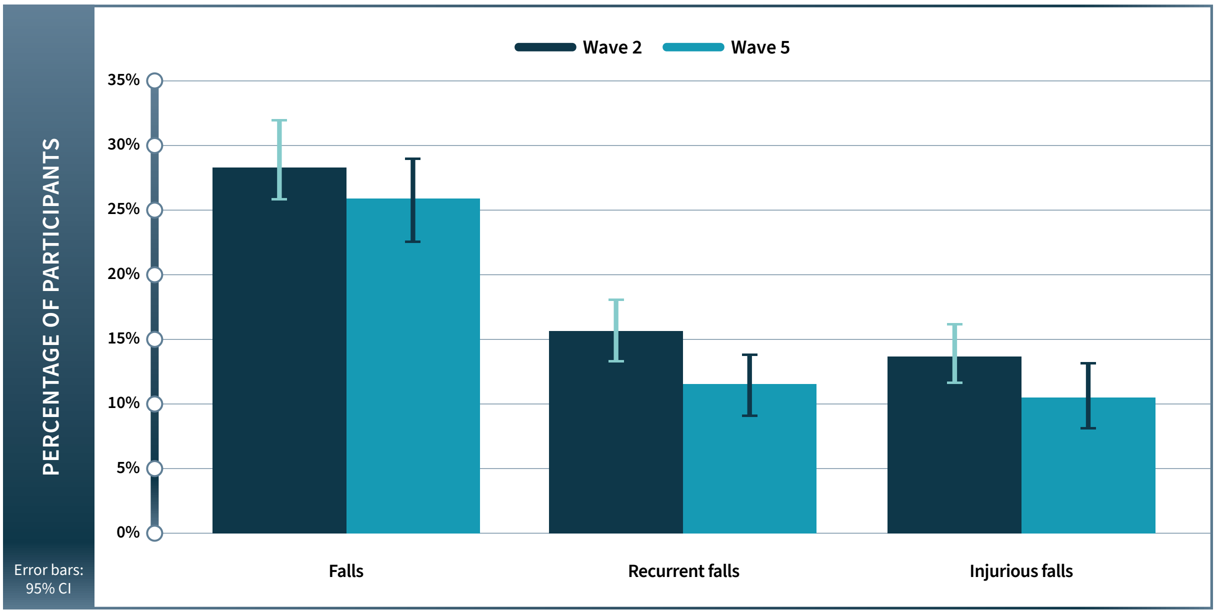
Falls are a common occurrence among older adults with intellectual disabilities, and the resulting injuries can lead to hospitalization, disability, and even death (Ho et al., 2019). Among those who reported experiencing a fall, the younger age group (under 50) presented a decrease from 24.8% at Wave 1 to 18.3% at Wave 3, followed by a slight increase to 19.2% by Wave 5. For the middle age group (50-64 years), the reported fall rate remained similar (28.4% at Wave 1 versus 27.6% at Wave 5). Conversely, the older age group (65 and over) experienced a substantial increase up to Wave 4, rising from 26.7% to 37.1%, but this was followed by a marked decrease to 28.4% at Wave 5, which may be indicative of mortality trends. Figure 2.19 illustrates these trends visually.

Figure 2.19: Prevalence of falls, Wave 1 to Wave 5



There is a slight decrease in reported falls since Wave 2 from 28.3% to 25.8% at Wave 5. Of the fallers, recurrent fallers and injurious falls have decreased since Wave 2. As illustrated in Figure 2.20, recurrent fallers (defined as experiencing more than two falls in the last month) decreased by four percentage points to 11.3%.

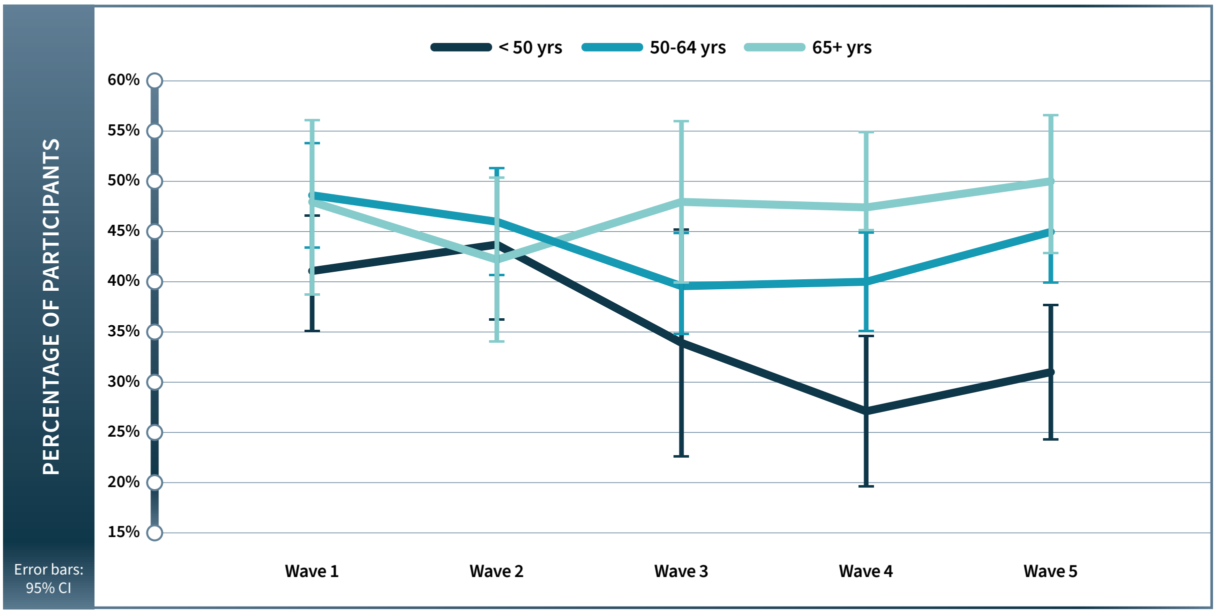
Figure 2.20: Changes in the prevalence of falls, recurrent falls, and injurious falls at Wave 2 and Wave 5



2.8.1: Fear of falling

Fear related to falling directly impacts on the quality of life of older adults and can contribute to actually falling (Schoene et al 2019). Fear of falling (FOF) is frequently associated with activity restriction, particularly for those who have experienced an injurious fall, and can have a significant impact on their social and physical wellbeing (Ho et al 2021). Fear of Falling was reported by 43% of IDS-TILDA participants at Wave 5. In those aged 50 and over, a prevalence of 46.8% was reported which is more than double reports in TILDA (Yao et al 2021). Refer to Figure 2.21 for visualisation.

Figure 2.21: Fear of falling, Wave 1 to Wave 5

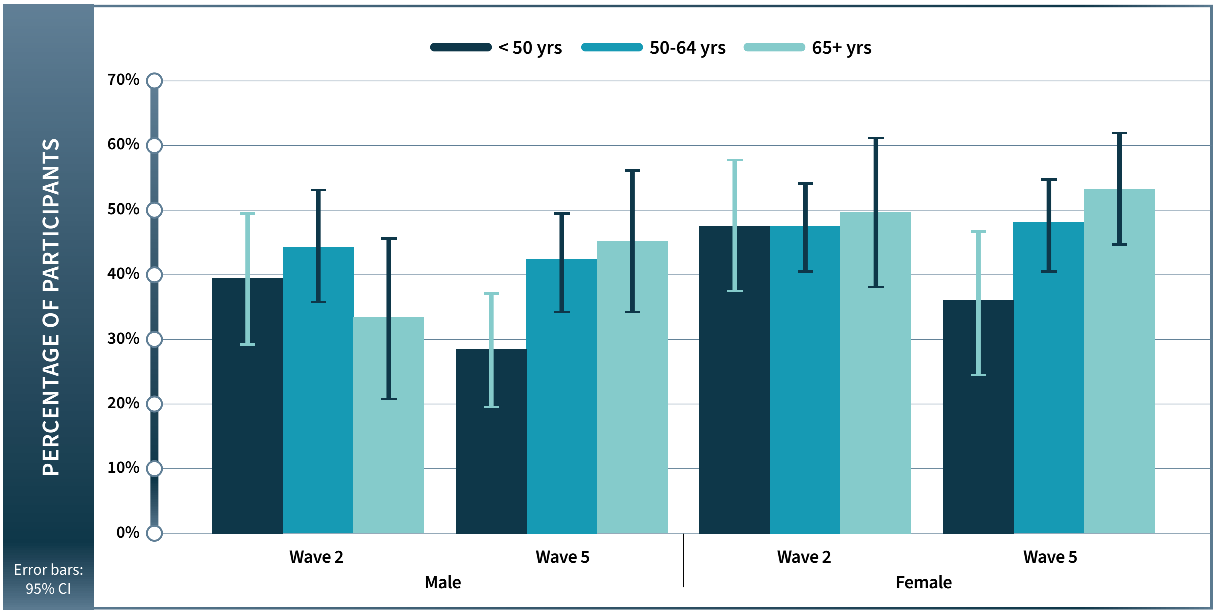


Significant changes in the perception of FOF are discernible. Notably, men, particularly within the older age group (65 and over), experienced a substantial FOF increase, from 33.3% at Wave 2 to 45% at Wave 5. Women, across all age groups, exhibited higher levels of FOF, increasing in the older age group (65 and over) from 49.4% at Wave 2 to 53% at Wave 5. Encouragingly, there was a reduction in FOF for both men and women in the younger age group (under 50) at 28% at Wave 2 and 35.6% at Wave 5, with the greater decrease experienced by men. Please see Figure 2.22 for graphical representation.

25.8%
of people reported a fall

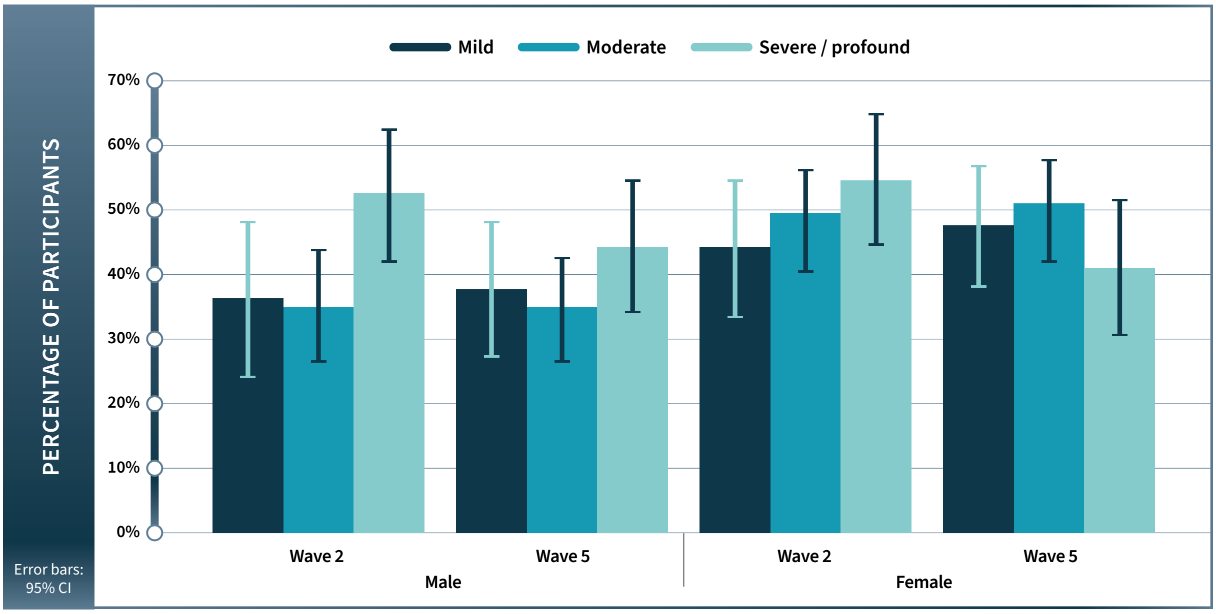
21% reported fear of falling over, **x2** that reported by TILDA

Figure 2.22: FOF stratified by sex and age at Wave 2 and Wave 5



There was a significant overall FOF decrease among individuals with a more severe/profound level of intellectual disability. For men with severe/profound level of intellectual disability, proxy and/or self-report FOF decreased from 52.6% to 44.4%; similarly for women there was an almost 15-percentage point decrease (54.9% to 41%). Conversely, slight increases in FOF are observed among those with other levels of intellectual disability, particularly among men and women with mild and women with moderate levels of intellectual disability. See Figure 2.23.

Figure 2.23: FOF stratified by sex and LOID at Wave 2 and Wave 5

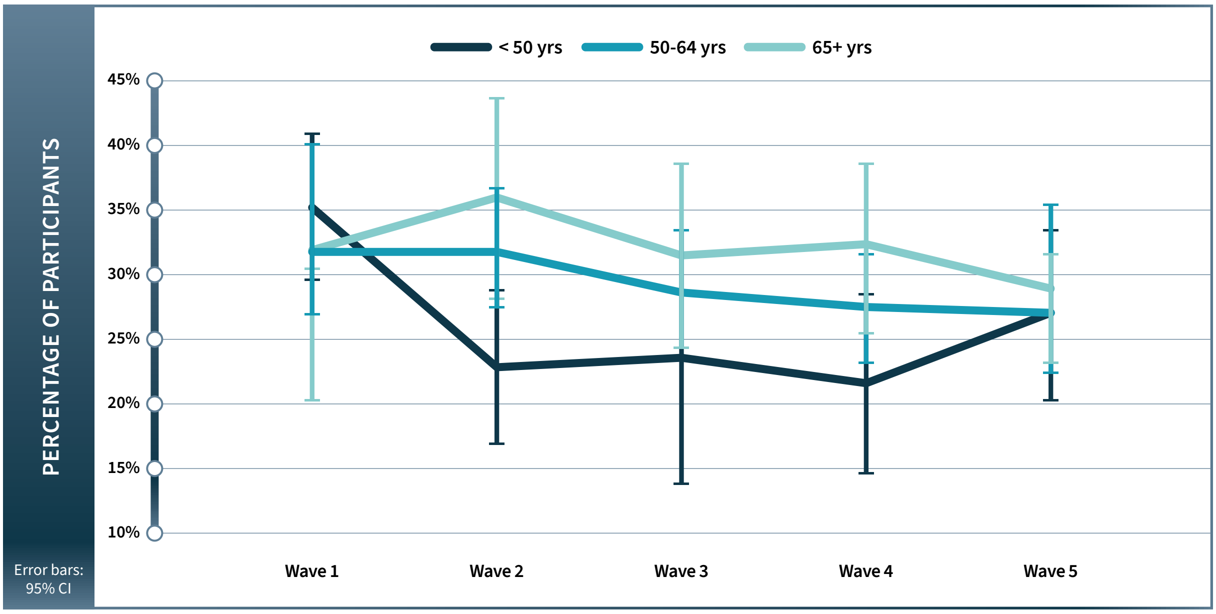


2.9: Pain

Chronic pain impacts between 13-36% of the Irish population (Purcell et al 2022). In the IDS-TILDA study, 27.5% reported experiencing pain at Wave 5 with 27.8% of those aged 50 and over in comparison to TILDA reports of 34% (O'Neill et al 2021). Across the lifetime of this study, reported pain has decreased somewhat in older adults (65 and over) from 31.9% at Wave 1 to 29.2% at Wave 5.

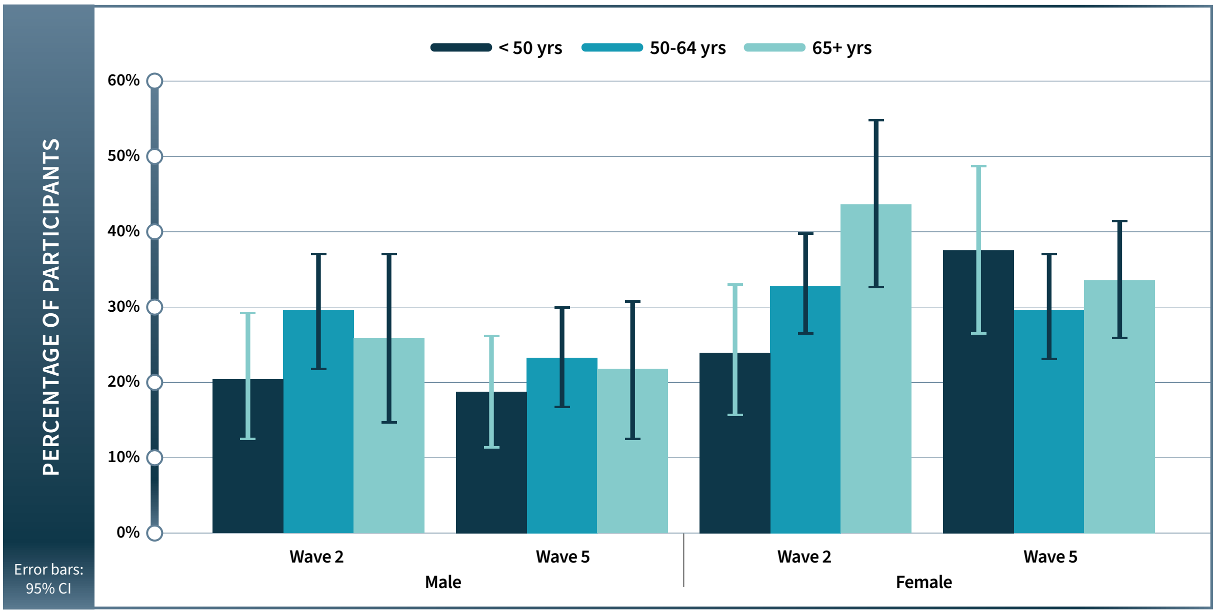
A similar decline in reported pain is observed for those in middle aged (50-64 years) from 31.8% to 27%. Reported pain for the younger cohort (under 50) dropped from Wave 1 but after Wave 4 increased from 21.5% to 26.7% at Wave 5. See Figure 2.24.

Figure 2.24: Changes in pain experience stratified by age, Wave 1 to Wave 5



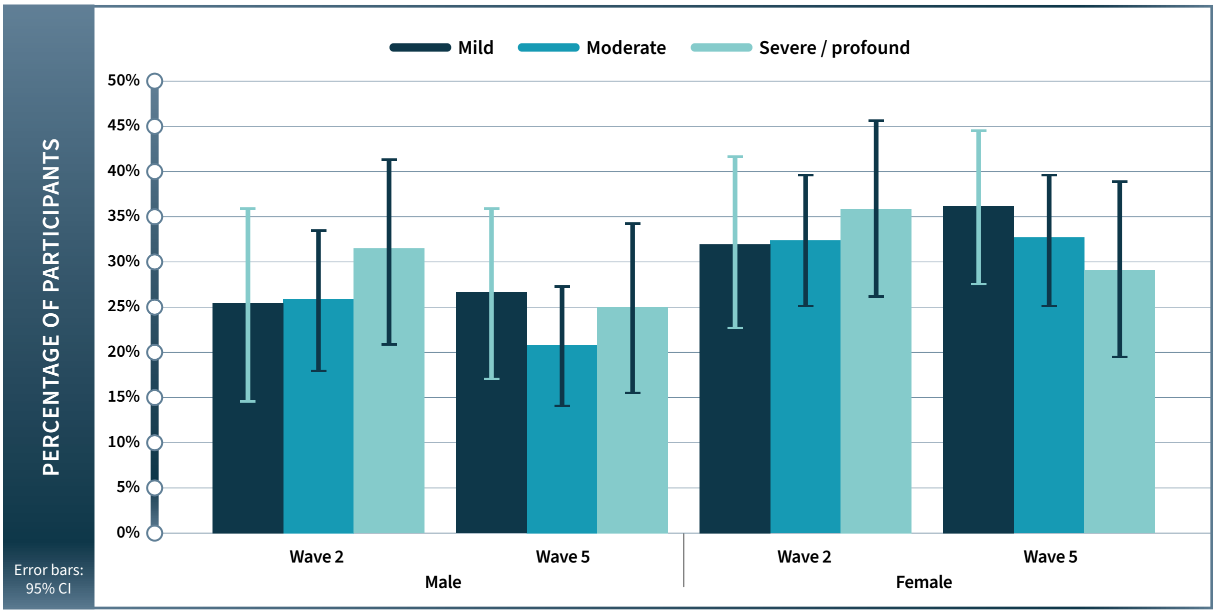
Women generally had higher reported pain prevalence. However, older and middle-aged individuals, both men and women, reported reduced pain prevalence. For older women (65 and over) reported pain dropped from 43.8% at Wave 2 to just over a third and older men saw a slight decrease from 25.8% to 21.8%. The most significant change for men was observed in the middle-age group (50-64 years), with pain prevalence decreasing from 29.7% to 23.8%. There was substantial increase in pain reporting among younger women, rising from 24.5% to 37.8%, as depicted in Figure 2.25.

Figure 2.25: Pain comparison stratified by age and sex at Wave 2 and Wave 5



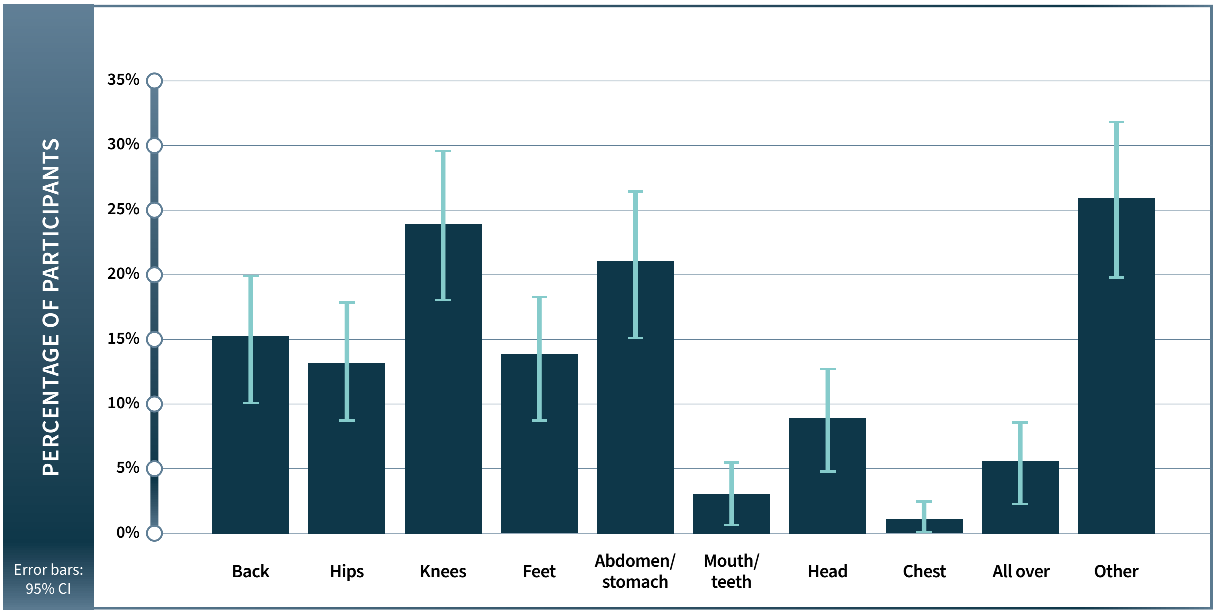
There was a slight increase in reported pain among individuals with mild intellectual disability, both in men (25% to 26.2%) and women (31.8% to 35.8%). However, a decrease in reported pain was observed among among men with a moderate level of intellectual disability, and men and women with severe/profound levels of intellectual disability between Waves 2 and 5, affecting both men (30.9% to 24.7%) and women (35.5% to 28.9%). See Figure 2.26.

Figure 2.26: Pain comparison stratified by age and level of intellectual disability at Wave 2 and Wave 5



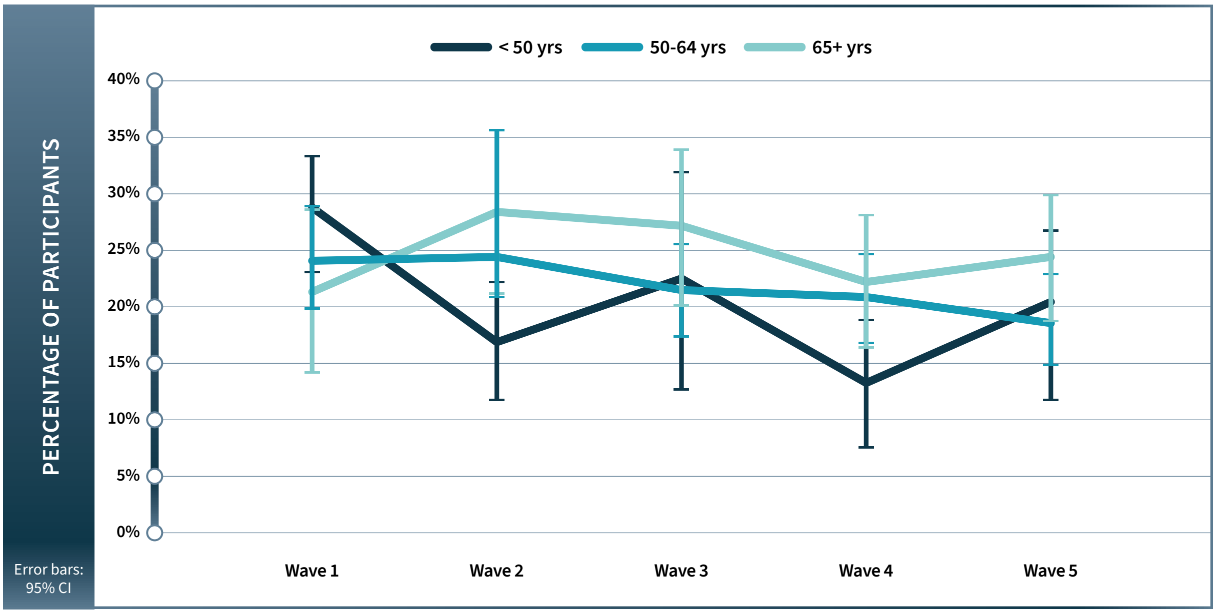
Of those who reported pain at Wave 5, the most frequently reported sites included knees (24%), stomach (21.1%), and back (15.2%) unlike those in a European survey where the most common site for reported pain was chronic back pain (Breivik et al 2013), but similar to reports of chronic joint pain becoming more common with increasing age, especially in older women (Mullins et al 2022). See Figure 2.27 for a visual representation and note that participant responses for 'Other' type of pain included arm, ankle, elbow, leg, hand and shoulder pain.

Figure 2.27: Sites of reported pain



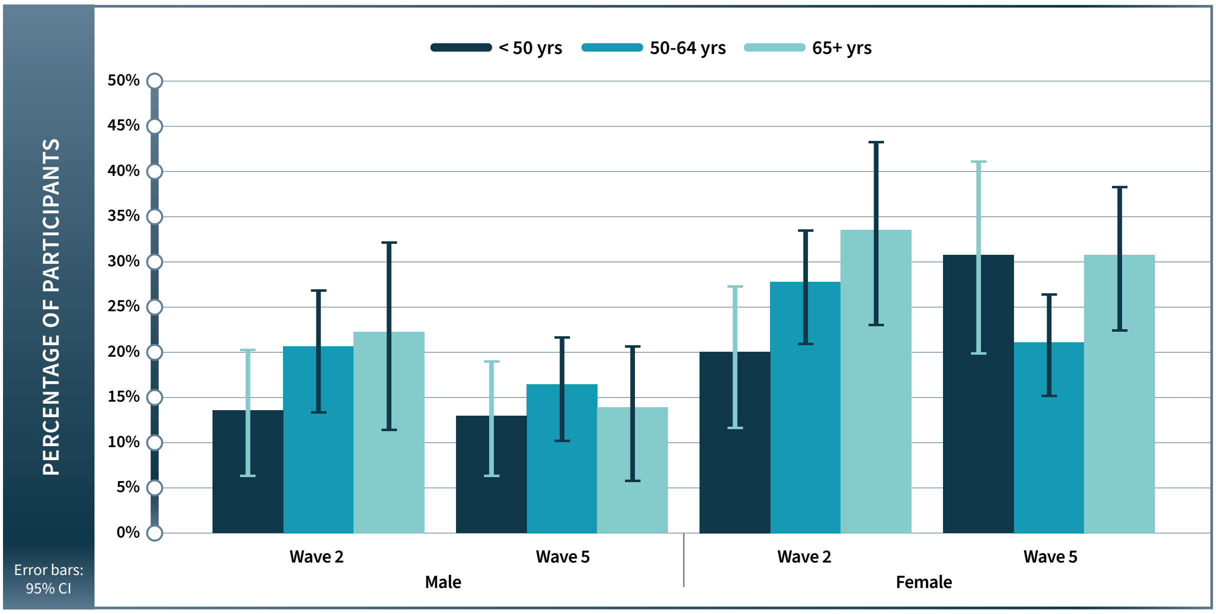
The prescription of pain medication for those in the younger age group varied from 28.1% in Wave 1 to 13.1% at Wave 4, and back to 20.2% at Wave 5. Among those in the older age group (65 and over), there was an initial increase at Wave 2 (28.4%), but this trend has also been steadily declining, with a slight upturn noted between Wave 4 (22.2%) and Wave 5 (24.2%). Conversely, the middle-age group exhibited a consistent decrease across all IDS-TILDA data waves (24.2%, 24.5%, 21.4%, 20.6%, 18.8%, respectively). See Figure 2.28 for a visual representation.

Figure 2.28: Changes in reported pain medication, Wave 1 to Wave 5



Notably, there has been an increase in prescribed analgesia for younger women (under 50) since Wave 2, rising from 19.8% to 30.7%. There is a notable decrease for middle-aged women (50-64 years) from 27.4% to 20.9%, and a similar decrease for middle-aged men (50-64 years) from 20.4% to 16.3%. In the older age group, analgesia prescription has declined for both men (21.9% to 13.6%) and women (33.3% to 30.6%) aged 65 and above. See Figure 2.29 for visual representation.

Figure 2.29: Comparison of changes in pain medication stratified by age and sex at Wave 2 and Wave 5



Across all levels of intellectual disability, there was a decrease in analgesia prescribing for women, with prescriptions among those with more severe or profound levels of intellectual disability dropping from 30.1% to 25%. Similarly, for men with severe or profound intellectual disability there were decreases from 23.6% to 20.2%. The only observed increase (25.6% to 28%) pertained to women with a moderate level of intellectual disability.

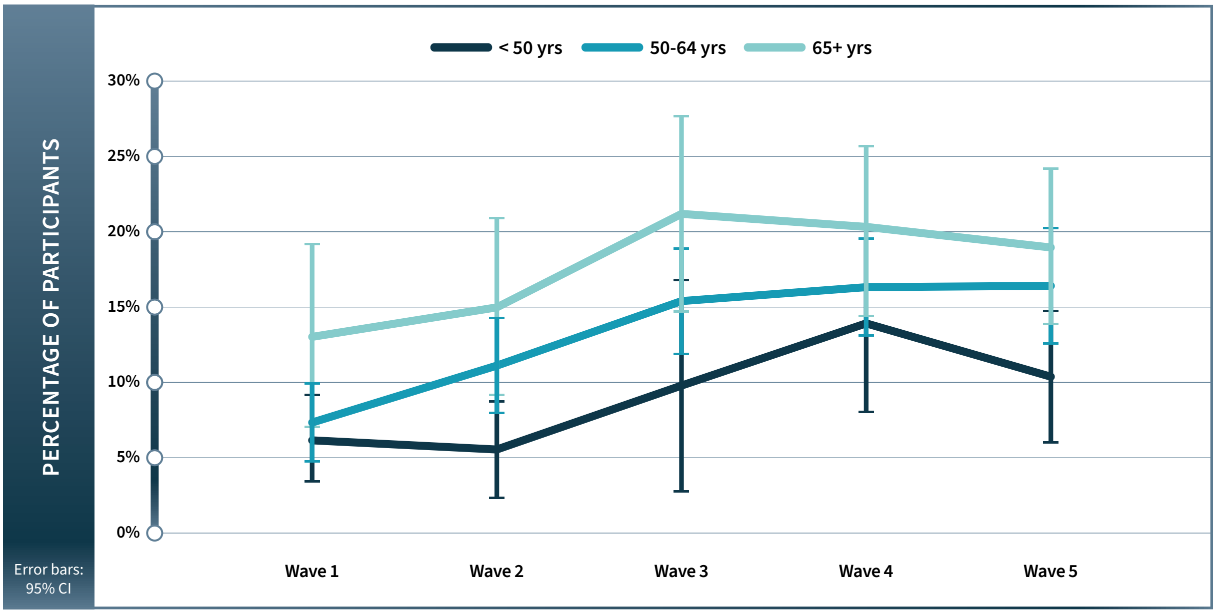
2.10: Gastric reflux (GERD)

Across the Waves of IDS-TILDA, and as can be seen in Figure 2.30, there has been a steady increase in GERD in all age groups, particularly evident among the middle and older age groups. For those aged 50-64 years, the prevalence of GERD has increased from 7.3% to 16.5%, and from 13.1% to 19% for the oldest age group (65 and over). For the younger age group (under 50) rates rose from 6.3% at Wave 1 to 14% at Wave 4 but dropped to 10.4% in Wave 5.

Gastrointestinal reflux has seen a continuous increase particularly for older **women**

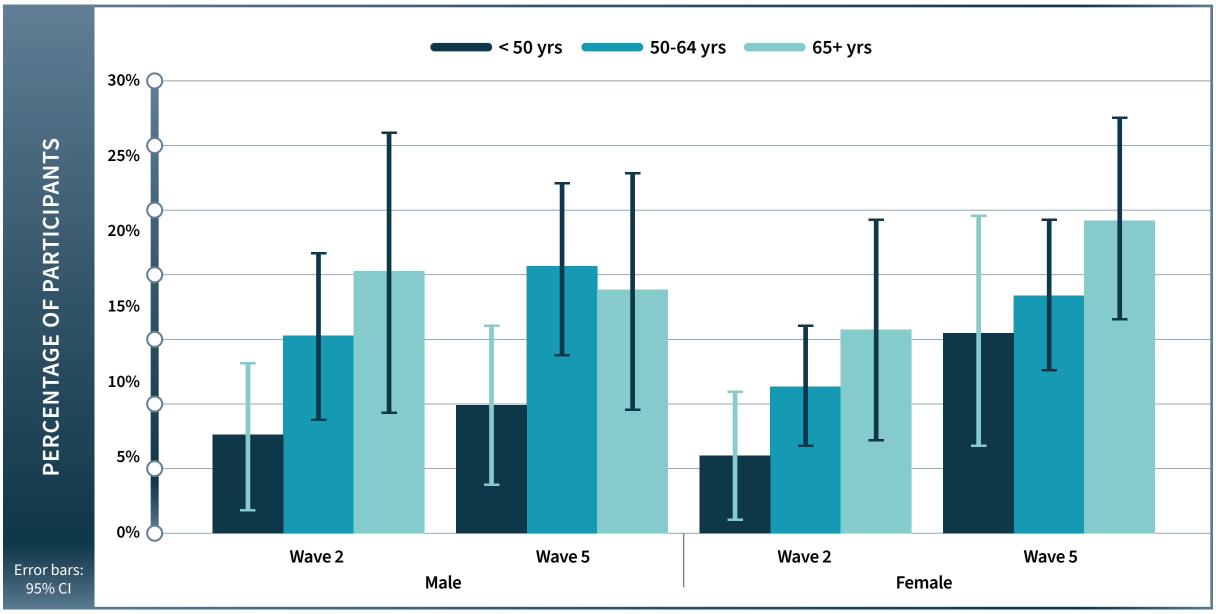
13.4% in Wave 2 | **20.7%** in Wave 5

Figure 2.30: Prevalence of GERD, Wave 1 to Wave 5



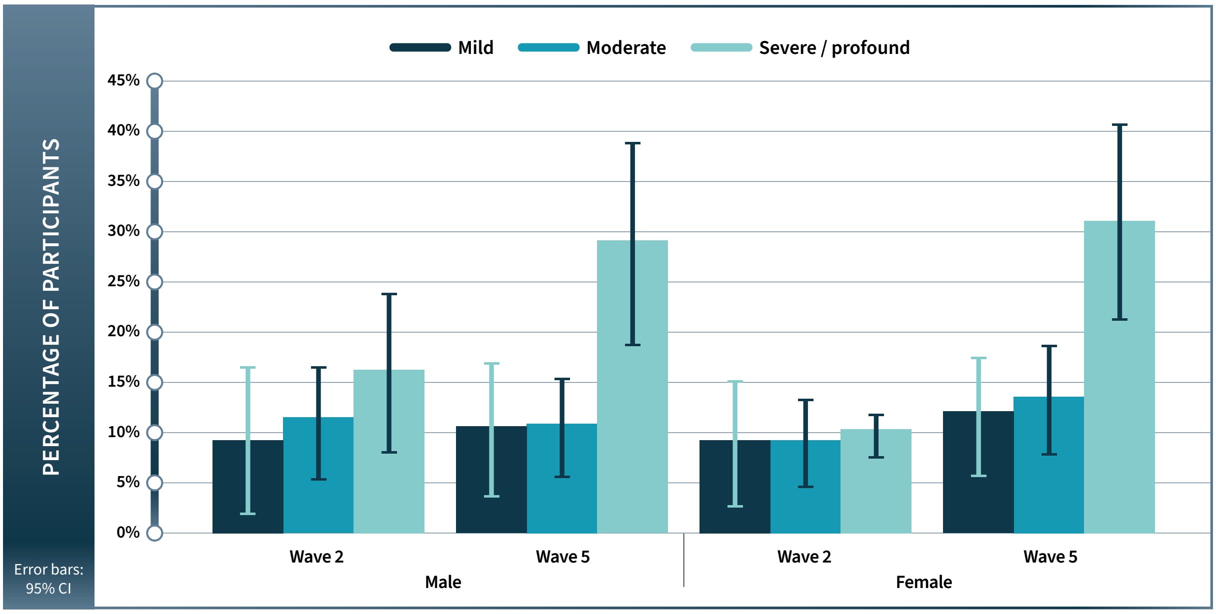
GERD prevalence has risen significantly for older women, from 13.4% at Wave 2 to 20.7% at Wave 5. There were similar trends for men in the younger and middle-age groups, but a minor decline among older men, from 17.2% to 16% at Wave 5. See Figure 2.31.

Figure 2.31: Comparing GERD stratified by age and sex at Wave 2 and Wave 5



While slight increases over time were observed among those with mild and moderate levels of intellectual disability, there were substantial increases among individuals with severe or profound intellectual disability. For men, the increase was from 15.9% to 28.6%, and for women from 10% to 30.7%. See Figure 2.32.

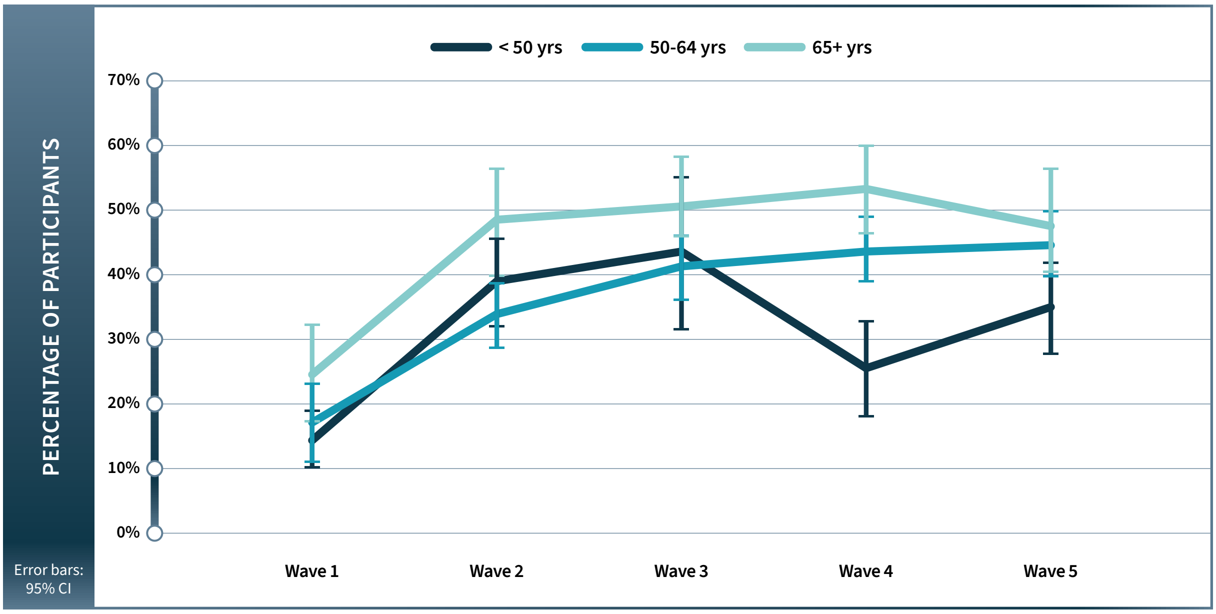
Figure 2.32: Comparing GERD stratified by age and level of intellectual disability at Wave 2 and Wave 5



2.11: Constipation

Constipation continued to be highly prevalent with prevalence rising from 17.3% at Wave 1 to 42.8% at Wave 5, across all age groups. In the younger age groups (under 50) the prevalence rose from 14.6% at Wave 1 to 34.4% at Wave 5. Similar trends were observed for those in the middle age group (50-64 years) rising from 16.9% to 44.4% and the older age group (65 and over) from 24.6% to 47.2%. See Figure 2.33.

Figure 2.33: Constipation stratified by age, Wave 1 to Wave 5



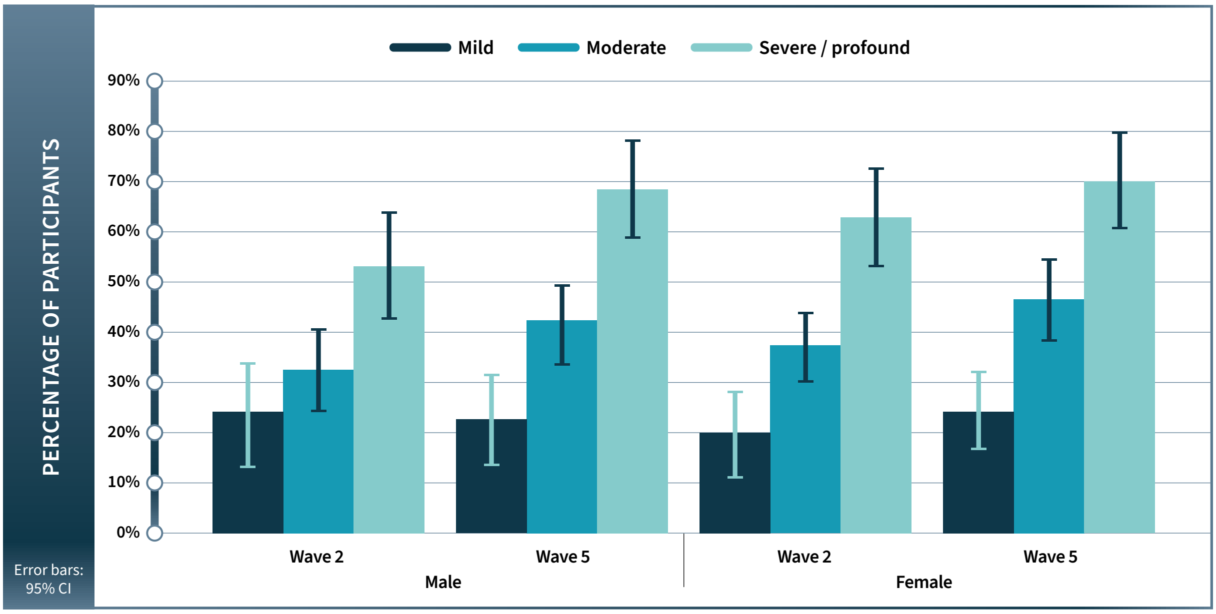
Constipation
is highly prevalent and
has increased considerably
over the lifetime of IDS-TILDA

17.3% to **42.8%**
in Wave 1 in Wave 5

Notable rises in constipation prevalence among women from Wave 2 to Wave 5, were from 46.3% to 51.9% among those over 65, and from 35.4% to 42.1% among the middle-aged group. Conversely, younger women (under 50) moved from 41% to 34.7% in Wave 5. In contrast, for men, constipation rates declined among the oldest and youngest age groups, but there was a substantial increase in the middle age group (50–64 years), rising from 30.8% to 47%.

Constipation remains a noteworthy concern among individuals classified within the severe/profound intellectual disability category. Specifically, for men, prevalence increased from 53.4% to 69%, while for women, rates increased from 63% in Wave 2 to 70.5% in Wave 5. Similarly, for individuals with a moderate level of intellectual disability, rates for men increased from 32.5% to 41.6%, and for women, from 36.8% to 46.6%. In contrast, among those classified in the mild category, women experienced a relatively modest increase in prevalence (from 19.3% to 24.2%), while men exhibited a slight decrease (from 23.4% to 22.4%) by Wave 5. See Figure 2.34.

Figure 2.34: Constipation prevalence stratified by age and level of intellectual disability at Wave 2 and Wave 5

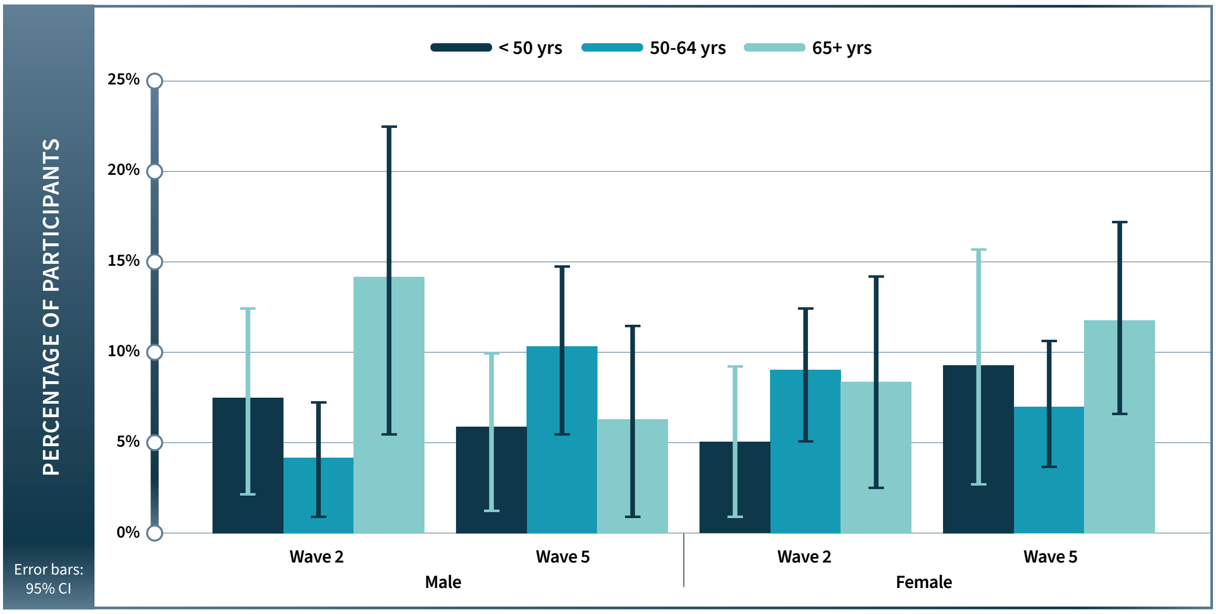


2.12: Respiratory conditions

For the purposes of reporting, respiratory disease is defined as all doctor's reported diagnosis of lung disease, including chronic bronchitis or emphysema, and asthma. Figure 2.35 illustrates a significant decline among older men, decreasing from 14.1% to 6.2% since Wave 2. Conversely, there was a notable increase among the middle-age group (50-64 years), rising from 4.1% to 10.2%.

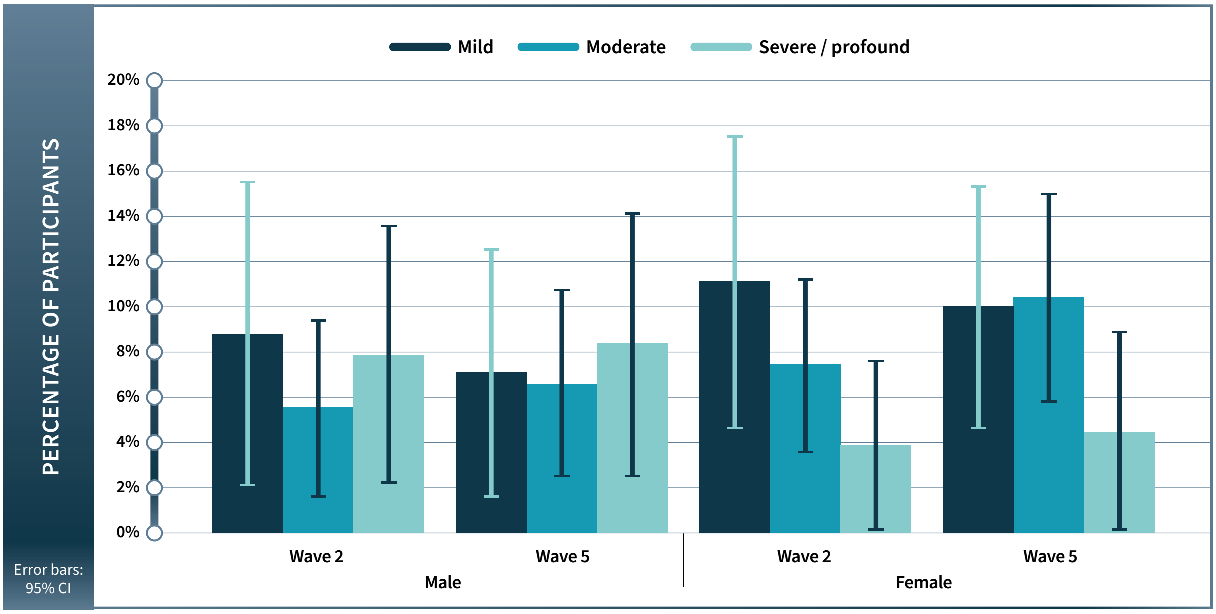
Among women, with prevalence rates comparatively lower than for men, rates in the younger cohort (under 50), increased from 5% at Wave 2 to 9.3% by Wave 5. Similar to men, the highest rates were among the oldest age group (65 and over), rising from 8.3% to 11.9%.

Figure 2.35: Respiratory conditions stratified by age and sex at Wave 2 and Wave 5



Women with mild or moderate intellectual disabilities reported a higher prevalence of these conditions compared to those with severe to profound intellectual disabilities (10% and 10.4% respectively versus 4.5% at Wave 5). Respiratory conditions have decreased in the mild category from 11.1% at Wave 2 to 10% at Wave 5; and increased from 7.4% at Wave 2 to 10.4% at Wave 5 in the moderate category. Conversely, among men, prevalence rates for severe/profound intellectual disability increased from 7.9% at Wave 2 to 8.3% at Wave 5. Refer to Figure 2.36 for visual representation.

Figure 2.36: Respiratory conditions stratified by sex and level of intellectual disability at Wave 2 and Wave 5



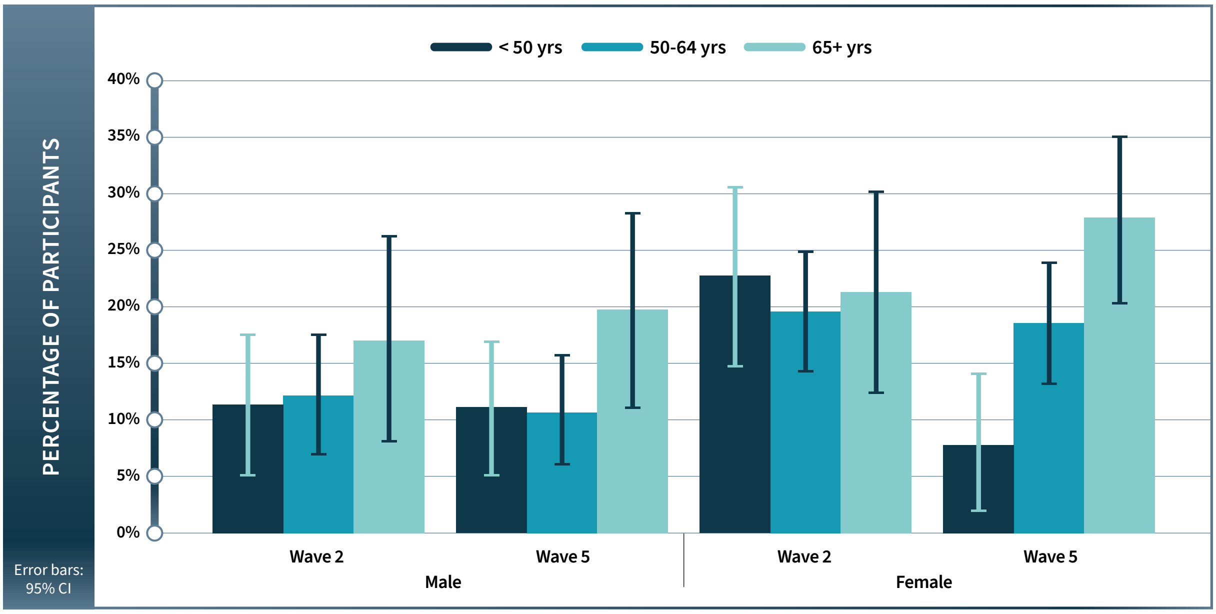
2.13: Sensory impairments

2.13.1: Eye health

Overall, 80% of participants self-reported their eyesight as excellent/very good/good. When eye conditions, such as cataracts, macular degeneration, glaucoma and keratoconus are considered, only minor changes were reported; those in the oldest age group remained the same at 24.6% and 25%, as did the middle age group at 16% and 15.2%, with a small decrease in the youngest age group (under 50) from 12.2% to 9.8%.

As anticipated, the highest reported prevalence of eye conditions was among the older age cohorts (65 and over) for both men and women, with rates rising from 17.2% to 19.8% for men and from 21.4% to 28.1% for women. The most notable decrease was among younger women with rates declining from 22.8% to 8%. Refer to Figure 2.37 for a visual representation of these trends.

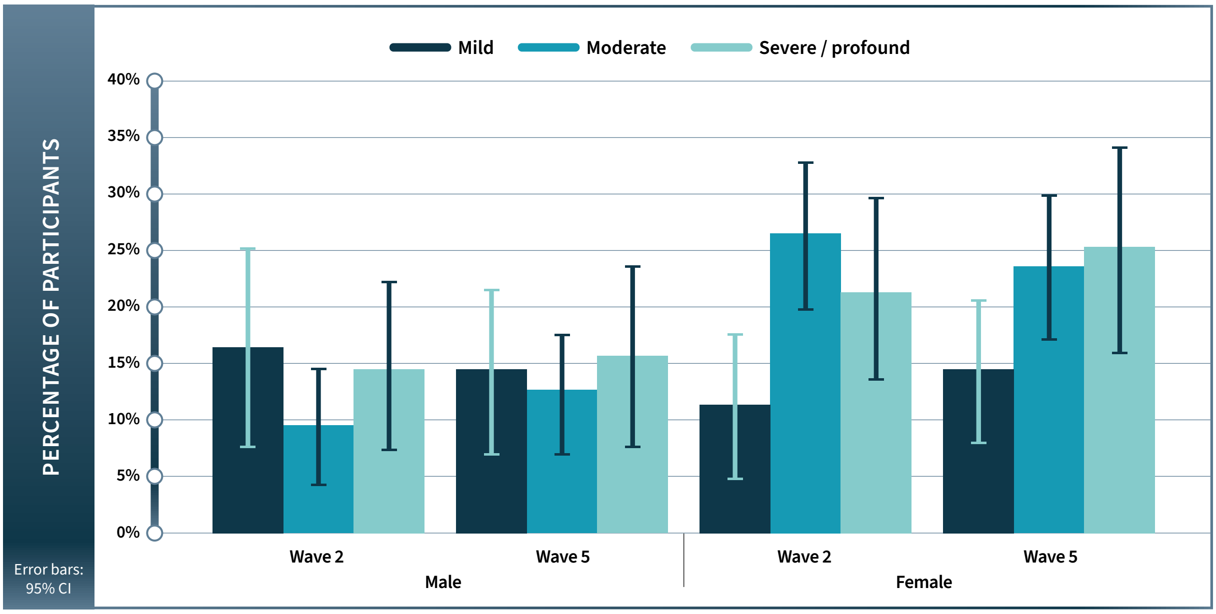
Figure 2.37: Eye disease stratified by age and sex at Wave 2 and Wave 5



Increases in eye disease were reported in women with mild intellectual disability, rising from 11.1% at Wave 2 to 14.2% at Wave 5. This was more prevalent in those with severe/profound intellectual disability, increasing from 21.4% to 25% from Wave 1 to Wave 5 respectively.

For men, among those with a moderate level of intellectual disability, reports of eye disease increased from 9.4% at Wave 2 to 12.1% at Wave 5. Please refer to Figure 2.38 for a visual representation of these trends.

Figure 2.38: Eye disease stratified by sex and level of intellectual disability at Wave 2 and Wave 5



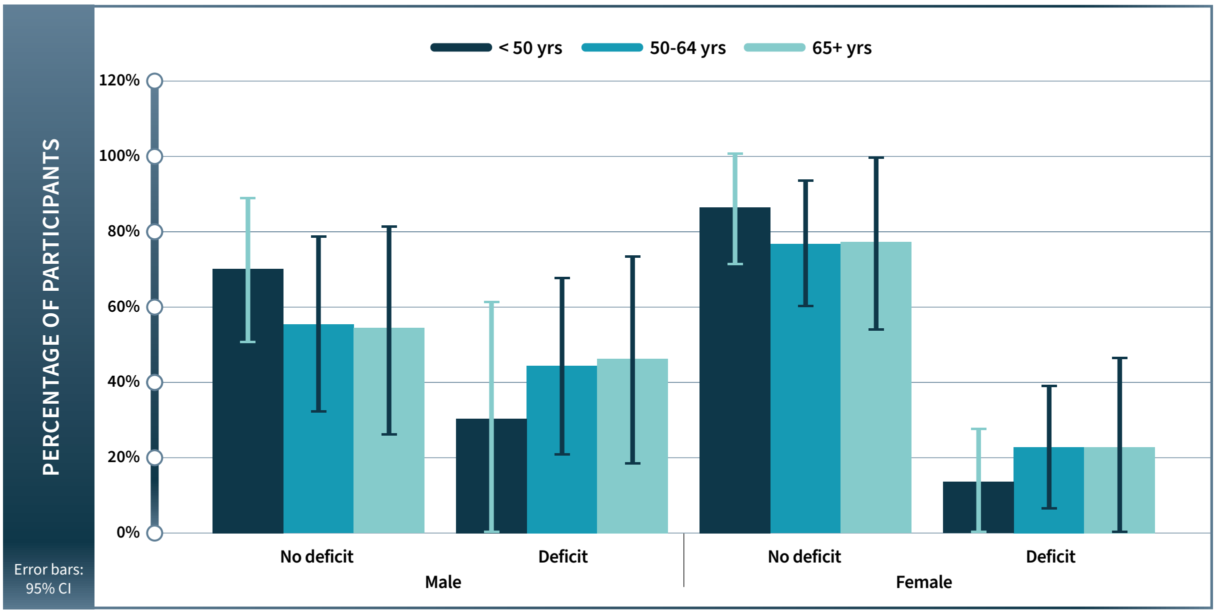
2.13.1.1: Auditory health

In the IDS-TILDA study, 87.5% of participants reported they had excellent, very good or good hearing. Generally, hearing loss and related issues are reported to be more prevalent among individuals with intellectual disabilities as compared to the general population (Willems et al 2021). Hearing loss also often goes unnoticed and untreated (Herer, 2012). With this in mind, an objective auditory screening assessment was introduced at Wave 5 of IDS-TILDA. This straightforward screening involved participants sitting in a quiet room, wearing headphones, and raising their hand upon hearing a beep at varying hertz and decibel levels. Individuals with mild or moderate intellectual disabilities successfully completed this assessment with 28.7% identified as having a hearing deficit.

This is almost double compared with the 14% of participants who reported having hearing loss. Of these 14%, 62.5% also reported wearing hearing aids. For those with more severe to profound intellectual disabilities, 7.1% reported hearing loss but they were not able to complete the objective auditory screening primarily due to difficulties in understanding or adhering to instructions.

Objectively established hearing deficits were higher in men across all age groups, particularly in younger individuals, 30.4% of men compared to 13.6% of women. This trend persisted as age increased, with 44.4% of men versus 23.1% of women and 46.2% of the oldest men compared to 23.1% of women. Refer to Figure 2.39 for visualisation.

Figure 2.39: Objectively established hearing deficits stratified by sex and age



Men with a mild level of intellectual disability were found to have greater hearing deficits than those with a moderate level (39.1% compared with 36.5%). Conversely, deficits were found more among women with moderate intellectual disability compared with mild levels of intellectual disability (21.1% versus 16.2%).

Despite the fact that the majority of participants reported their hearing as excellent, very good or good, there are differences when objective measurement is considered. Considering that those with more severe to profound level of intellectual disability did not engage in the auditory assessment it is possible that the prevalence of deficit could be much higher. Considering that this cohort can be the 'hard to reach' group when it comes to assessment, special consideration needs to be attributed to them and alternative screening with reasonable adjustments needs to be instigated.

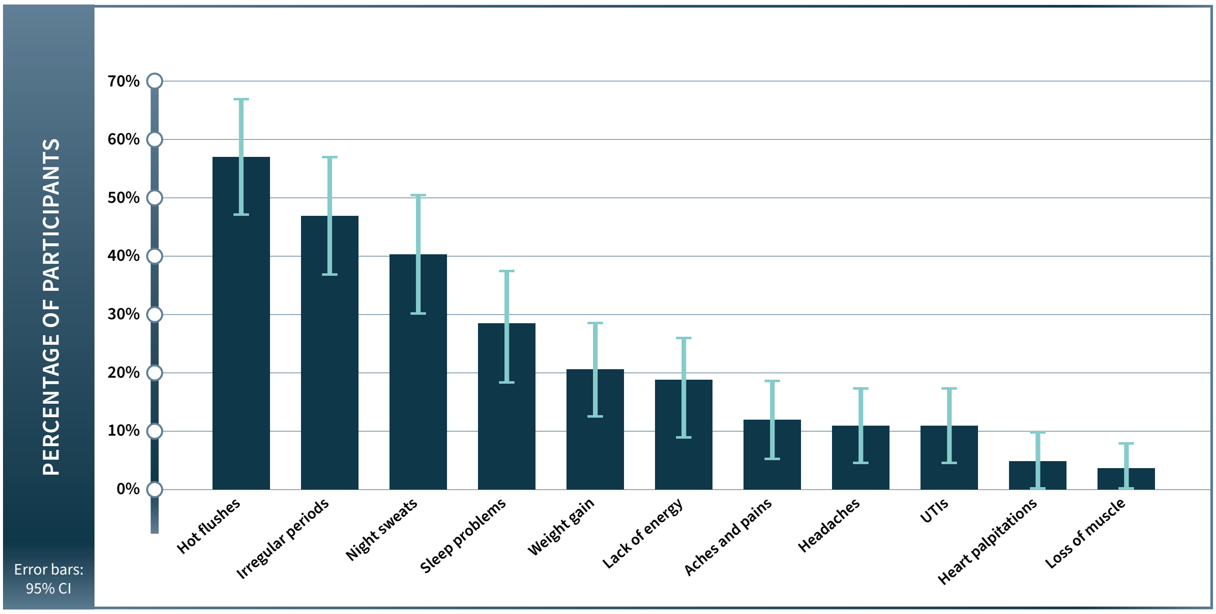
2.14: The menopause

2.14.1: Symptoms

The menopause can be defined as the period of time at least 12 months after a woman has finished menstruating (WHO, 2022). It can be a distressing and demanding time for all women, with many uncomfortable symptoms to contend with, such as hot flashes. Women with intellectual disabilities are often neglected when it comes to women's health education (Powell et al., 2020), and little is known about their experiences of the menopause. Having an intellectual disability could add yet another layer of complexity to this stressful time.

In IDS-TILDA Wave 5, 61.6% of women were currently going through, or had already gone through the menopause. Of these, 41.6% reported menopausal symptoms. The most common physical symptoms mentioned, aside from irregular periods, were vasomotor symptoms, with 56.7% experiencing hot flushes, and 40.4% experiencing night sweats (see Figure 2.40). This is consistent with hot flushes being the most commonly reported symptom in other studies in women with intellectual disabilities (Willis et al., 2010).

Figure 2.40: Physical symptoms of the menopause



2.14.2: Age at menopause

Women with intellectual disabilities experience the menopause at a younger age than the general population (Cosgrave et al 1999; Schupf et al., 2018; Schupf et al., 2003; Schupf et al., 2006; Seltzer et al., 2001). In the current study, the mean age at menopause of the sample was 47.7 (SD = 6.5) which is lower than the general population, with 51 being the most commonly reported average age (Sarri et al., 2015). Furthermore, it is suggested that women with Down syndrome often experience the menopause at an even earlier age that women with intellectual disabilities from other aetiologies (Willis et al., 2010). This was corroborated in Wave 5 with the mean age at menopause of women with Down syndrome being 43.9 years (SD = 6.9) and 47.9 years (SD = 6.0) for other intellectual disabilities. Earlier literature suggests strong links between early age at menopause and early onset dementia in women with Down syndrome (Cosgrave et al 1999., Schupf et al., 2003; Schupf et al., 2006). Further research into the potential implications of early age of onset is overdue.

2.14.3: Awareness

As mentioned, just 41.6% of menopausal women in Wave 5 reported symptoms of the menopause. This level of reporting is significantly lower than the general population with upwards of 90% of women reporting symptoms (Obermeyer et al., 2007). In Wave 5, only 48.8% of women were aware of the menopausal transition, only 37.9% of women reported discussing the menopause with someone, and just 16.2% had received easy read materials on the topic.

Of those who had talked to someone, 83.1% stated they were aware of the menopause, and of those who received easy-read material, over 84.8% were familiar with the concept. This suggests that education surrounding the topic of menopause could be beneficial to women with an intellectual disability in helping them to identify menopausal symptoms to ensure appropriate treatments are provided.

2.15: Conclusion

Across the waves of IDS-TILDA there is evidence of health improvement as well as concerns. Generally, self-reports of health by people with intellectual disabilities are positive. Conversely, this chapter does illustrate a changing and complex health picture as individuals with intellectual disabilities progress through the ageing process. Older adults with intellectual disabilities are susceptible to developing some chronic health conditions at an earlier age than their counterparts without identified disabilities, they present with different patterns of multimorbidity, and have distinctive healthcare requirements and challenges.

Differing patterns and prevalence, some higher and some lower, of multimorbidity, cardiovascular disease, musculoskeletal conditions, pain, respiratory ailments, foot ill-health and sensory deficits among individuals with intellectual disabilities have been reported and this includes changes in these patterns over time. But they do contend with complex health issues. Arthritis, in particular, illustrates that there are both improving and concerning pictures of health mediated by advancing age, level of intellectual disability and sex.

Overall, through doctor's diagnosis and objective measures it was confirmed that as they age, women with intellectual disabilities have poorer health than men; but there are also important findings of underdiagnosis of osteoporosis and hearing difficulties for men and other declines as men age. Similarly, for those with severe to profound intellectual disabilities there is a greater likelihood of conditions being under-recognised and reported.

For everyone with an intellectual disability, and for all age groups, there is a steady increase over time in GERD and constipation that must be better addressed. Reports of pain have also increased in the younger groups, while use of pain medications declined; this too deserves further investigation. Increases found in hypertension among younger participants is also concerning.

There are positive indications over time of reduced or stable incidence of some conditions and multimorbidity overall, and increased likelihood of screenings and diagnoses, such as for osteoporosis (although more vigilance is needed). Conversely, the increasing prevalence of musculoskeletal, endocrine and gastrointestinal conditions, and emerging eye health concerns and auditory impairments, underscores continuing pressing needs for tailored healthcare approaches and specialised interventions.

The health challenges experienced by people with intellectual disabilities are intricate and this chapter advances our understanding of their specific needs, signposts where we can promote overall well-being, inform policy development, and support the building of a healthcare system that is inclusive, equitable, and responsive to the diverse needs of all individuals. These will be the tools to ensure that as years are added to the lives of people with intellectual disability, they also live a healthy life of their choosing for those years.

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CHAPTER 3

Behavioural Lifestyles

Andrew Wormald, Louise Lynch, Caitríona Ryan, Margaret Haigh, Philip McCallion and Mary McCarron.

3.1: Key findings

- Those with moderate intensity activity had the best quality of life scores and were least likely to experience loneliness.
- People in all age categories improved their levels of physical activity from Wave 2 to Wave 5. In some subgroups the percentages engaged in activity more than doubled.
- Despite these achievements half of participants (50.9%) were not engaging in the minimum amount of activity as recommended by the WHO (WHO, 2020).
- Those aged under 50 showed the greatest increase in the proportion doing vigorous physical activity since Wave 2 (3.6% to 11.8%)
- A smaller proportion of people with an intellectual disability engaged in high levels of activity than among TILDA general population participants over age 50 years (6% vs 33%).
- Walking was the most common physical pastime.
- Health considerations were most common reason for not doing more physical activity.
- Participants understood the health benefits of physical activity.
- Participants with low activity levels were more likely to be depressed.
- Activity intensity was positively related to mental health scores.
- Half of all participants reported their diet as excellent or good.
- Over 40% of participants reported watching 1-3 hours TV per day.
- Smoking levels decreased from Wave 1 to Wave 5 especially in younger age groups.

3.2: Introduction

It is widely reported that healthy lifestyles lead to a better quality of life (Donoghue, O'Connell, & Kenny, 2016). This chapter looks at physical activity and nutrition and the associations between physical activity and measures of well-being among IDS-TILDA participants in Wave 5. Comparisons are drawn with previous IDS-TILDA reports and with wider population TILDA reports.

The available research suggests people with an intellectual disability are less physically active and more sedentary than the wider population (Hsieh, Hilgenkamp, Murthy, Heller, & Rimmer, 2017). It has been recently suggested that the health behaviours of people with an intellectual disability and their health literacy are negatively affected by inaccessible health promotion (Martin et al., 2021).

Conversely, other research suggests that people with an intellectual disability understand what constitutes a healthy lifestyle, and are aware of the consequences of an unhealthy lifestyle and of the need for moderation (Caton et al., 2012). Data from previous IDS-TILDA waves has demonstrated that people with an intellectual disability smoke less and drink less alcohol than the wider population (McCarron, 2011).

Within this report we use the International Physical Activity Questionnaire (IPAQ) to measure physical activity as it allows a direct comparison with multiple waves of IDS-TILDA data and direct comparison with the wider Irish population measured in the TILDA study.

3.2.1: Physical activity

Physical activity improves all-cause mortality, risk of cardiovascular disease, the incidence of site specific cancers, incidence of type-2 diabetes, quality of life, mental health, and feelings of loneliness (Donoghue et al., 2016; WHO, 2020). However, findings by the World Health Organisation (WHO) are that a quarter of the world's population are insufficiently active (WHO, 2020) and findings in Ireland suggest one third of Irish adults are insufficiently active (Donoghue et al., 2016). The WHO recommends that people living with disability should undertake between 150-300 minutes of moderate exercise per week or 75 to 150 minutes of vigorous exercise (WHO, 2020).

Participants in all age categories improved their levels of physical activity from Wave 2 to Wave 5

In some subgroups activity **more than doubled.**

People with an intellectual disability are reported as having inactive lifestyles that significantly contribute to health problems and health care needs (Hsieh, Heller, Bershadsky, & Taub, 2015), including low levels of physical activity and high levels of sedentary behaviour (Hsieh et al., 2017) with females having lower levels of physical activity than men (Westrop, Melville, Muirhead, & McGarty, 2019). However, a recent systematic review of physical activity programs for adults with an intellectual disability did not confirm the positive benefits for this group of physical activity and has called for further data to be made available (Jacob, Pillay, Johnson, Omoya, & Adedokun, 2023).

3.2.1.1: International Physical Activity Questionnaire (IPAQ)

The short version of the IPAQ has been tested extensively and is used in many international studies (IPAQ Research Committee, 2005). Participants were asked to indicate over the last week the number of days and typical time per day spent walking and doing physical activities of vigorous (heavy lifting, digging, aerobics or fast cycling) or moderate (carrying light loads, cycling at regular pace or doubles tennis) intensity.

Total time spent in each activity was weighted based on the energy requirements of the activity giving a metabolic equivalent of task (MET) score in MET-minutes/week for each respondent. They were then classified as having High, Moderate or Low Activity levels based on the criteria in Table 3.1.

The total METs were calculated as follows: (daily minutes of walking x days per week with walking x 3.3) + (daily minutes of moderate-intensity activity x days per week with moderate-intensity activity x 4.0) + (daily minutes of vigorous activity x days per week with vigorous activity x 8.0). A full description of IPAQ scoring can be found in the Guidelines for Data Processing and Analysis of the International Physical Activity Questionnaire (IPAQ Research Committee, 2005).

Table: 3.1: IPAQ category rules

Category	IPAQ category rules
High Activity: At least one hour per day or more, of moderate-intensity activity above the basal level of physical activity	Any one of the following 2 criteria: a. vigorous-intensity activity on at least 3 days achieving a minimum Total physical activity of at least 1500 MET-minutes/week OR b. 7 or more days of any combination of walking, moderate-intensity or vigorous-intensity activities achieving a minimum total physical activity of at least 3000 MET-minutes/week.
Moderate Activity: Equivalent to half an hour of at least moderate-intensity physical activity on most days	Any one of the following 3 criteria: a. 3 or more days of vigorous-intensity activity of at least 20 minutes per day OR b. 5 or more days of moderate-intensity activity and/or walking of at least 30 minutes per day OR c. 5 or more days of any combination of walking, moderate-intensity or vigorous intensity activities achieving a minimum Total physical activity of at least 600 MET-minutes/week.
Low Activity: Not meeting any of the criteria for either of the previous categories	Meeting none of the criteria for high or moderate activity

3.2.1.2: IDS-TILDA participant activity levels

In total, 538 participants answered the IPAQ scale. Table 3.2 shows that males were more active than females with 43.0% of males moderately active and 10.7% highly active, whereas 39.8% of females were moderately active and only 4.5% were highly active. When the moderate and high categories are combined shows that younger people were more active than older people, 62.8% of participants under the age of 50 were at least moderately active compared to 27.7% of participants aged 65 and over. People with a mild intellectual disability were more active than those with a severe profound ID, 54.7% of participants classified as having a mild intellectual disability undertook either moderate or high levels of activity and 41.5% of those living with severe or profound intellectual disability.

Those who live independently or with family were more active than those who lived in residential care or community group homes, 63.1% of participants living with family or independently undertake moderate or high levels of physical activity compared to 39.4% of those living in residential care. Overall, the majority of people with an intellectual disability (50.9%) were not engaging in the minimum amount of activity as recommended by the WHO (WHO, 2020).

Table: 3.2: Participant levels of activity as reported using the IPAQ scale

		Low		Moderate		High	
		%	95% CI	%	95% CI	%	95% CI
Sex	Male	46.3	40.5-52.3	43.0	37.2-48.9	10.7	7.4-14.7
	Female	55.6	49.6-61.5	39.8	34.1-45.8	4.5	2.5-7.5
Age	<50	37.3	29.9-45.1	51.0	43.1-58.8	11.8	7.4-17.6
	50-64	49.2	43.3-55.2	43.2	37.4-49.2	7.5	4.8-11.2
	65+	72.3	63.8-79.7	25.2	18.1-33.5	2.5	0.7-6.6
Level of ID	Mild	45.3	37.9-52.8	48.2	40.8-55.7	6.5	3.5-10.9
	Moderate	53.0	46.3-59.6	38.1	31.8-44.8	8.8	5.6-13.2
	Severe/profound	58.5	48.4-68.1	33.0	24.1-42.9	8.5	4.1-15.4
Residence	Independent / family	36.9	29.5-44.9	51.0	43.0-58.9	12.1	7.6-18.0
	Community group home	54.3	48.3-60.2	40.1	34.3-46.0	5.6	3.3-8.9
	Residential Care	60.7	51.8-69.0	32.8	24.9-41.4	6.6	3.1-12.0
Total		**50.9**	**46.7-55.1**	**41.4**	**37.3-45.6**	**7.6**	**5.6-10.1**

3.2.1.3: IDS-TILDA participants as compared to TILDA participants

The TILDA data for this comparison were extracted from the TILDA "Walking to Wellbeing" report which also utilised the IPAQ scale (Donoghue et al., 2016). Table 3.3 compares the percentages of males and females aged 50 upwards, for both IDS-TILDA and TILDA. TILDA reported one-third of participants completing low activity, one third moderate activity and one third high activity, whereas 56% of the IDS-TILDA participants recorded low activity levels, and 39% undertook either moderate or high activity levels.

In all comparable age categories for both males and females, a lower proportion of IDS-TILDA participants were likely to do high levels of physical activity and no IDS-TILDA participant aged 75 or older was recorded as undertaking high levels of activity; however, 25% did moderate physical activity.

Table: 3.3: Levels of activity as measured by the IPAQ scale compared to TILDA

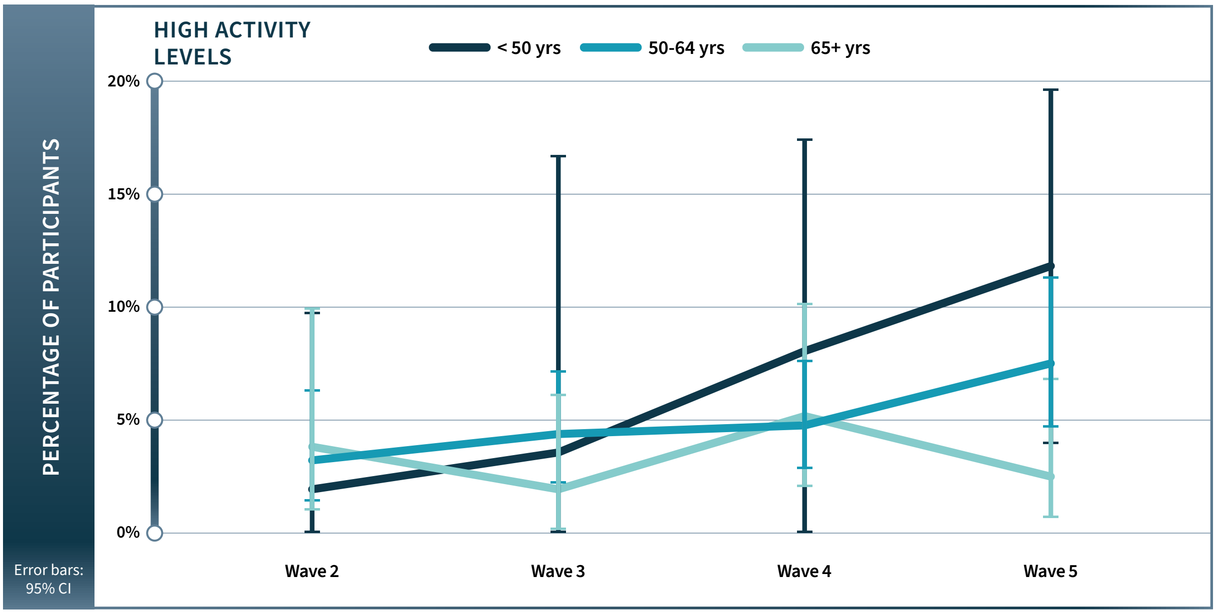
		Low Activity		Moderate Activity		High Activity	
		IDS-TILDA %	TILDA %	IDS-TILDA %	TILDA %	IDS-TILDA %	TILDA %
Male	50-64	44	23	47	29	9	48
	65-74	68	24	26	39	5	37
	75+	81	42	19	31	0	27
Male Total		**53**	**27**	**40**	**32**	**8**	**41**
Female	50-65	54	27	40	37	6	31
	65-74	74	32	25	35	2	26
	75+	69	51	31	29	0	11
Female Total		**60**	**40**	**36**	**35**	**4**	**26**
Total		**56**	**33**	**38**	**33**	**6**	**33**

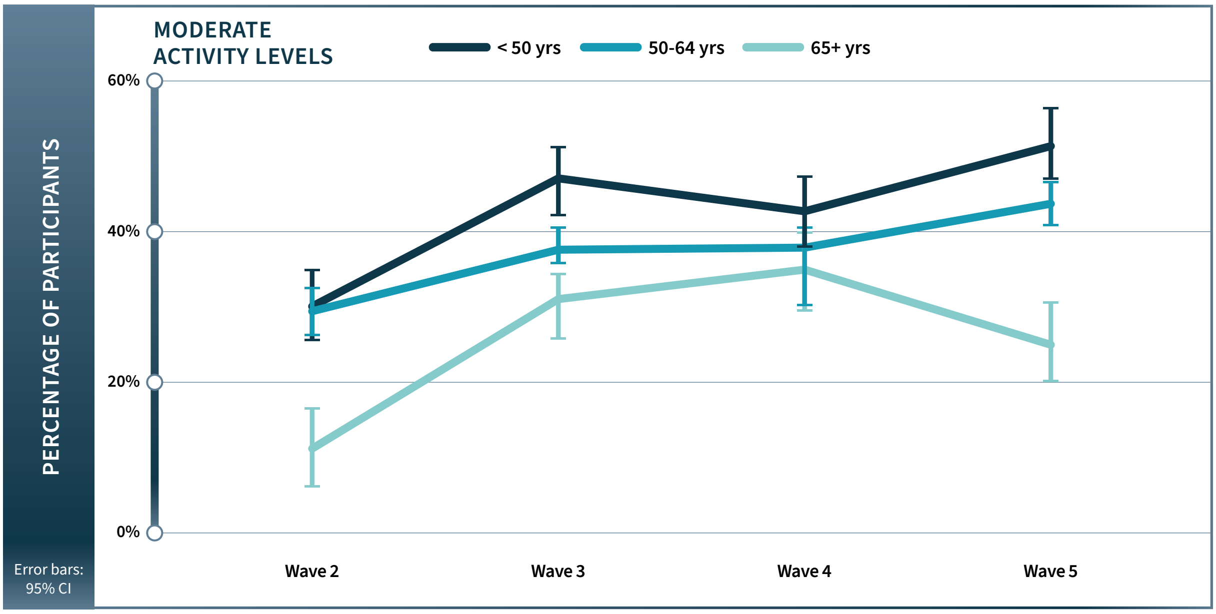
3.2.1.4: IDS-TILDA participants' physical activity changes over time

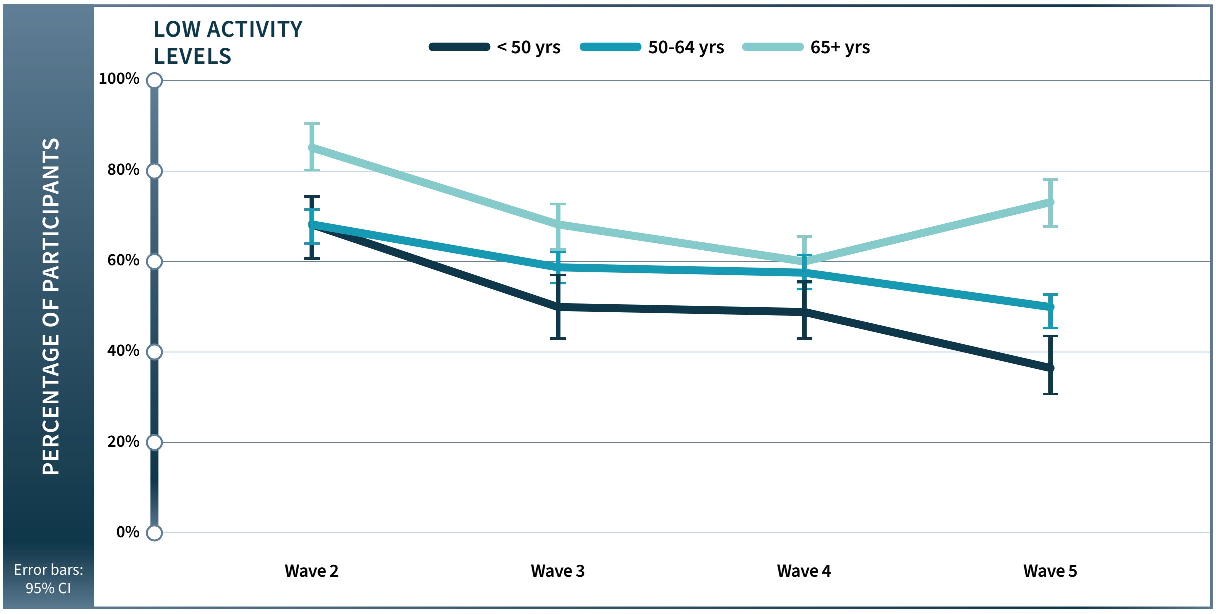
Whilst the IPAQ-reported activity levels compared to the TILDA population were lower, Figure 3.1 shows that in general, when comparing across all IDS-TILDA participants, by Wave 5 more people with intellectual disabilities were undertaking high and moderate levels of activity and fewer were classified as doing low levels of activity. The changes were even more pronounced in the younger age category (under 50 years) where a higher percentage of participants in Wave 5 were doing high activity levels than were the same age group in Wave 2 (11.8% vs 2%) as was also found for moderate activity (51.0% vs 30.4%).

Likewise, a greater percentage of the 50- to 64-year-old group were engaging in high levels of activity in Wave 5 than was reported in Wave 2 (7.5% vs 3.3%) and in moderate exercise (43.2% vs 29.5%). Those aged 65 and over were less likely to be doing high levels of physical activity in Wave 5 (2.5% vs 3.9%) but more moderate activity (25.2% vs 11.7%) reducing the numbers of those doing low levels of activity (72.3% vs 84.4%).

Figure 3.1: Participant activity levels by age group using the IPAQ scale, Wave 2 to Wave 5





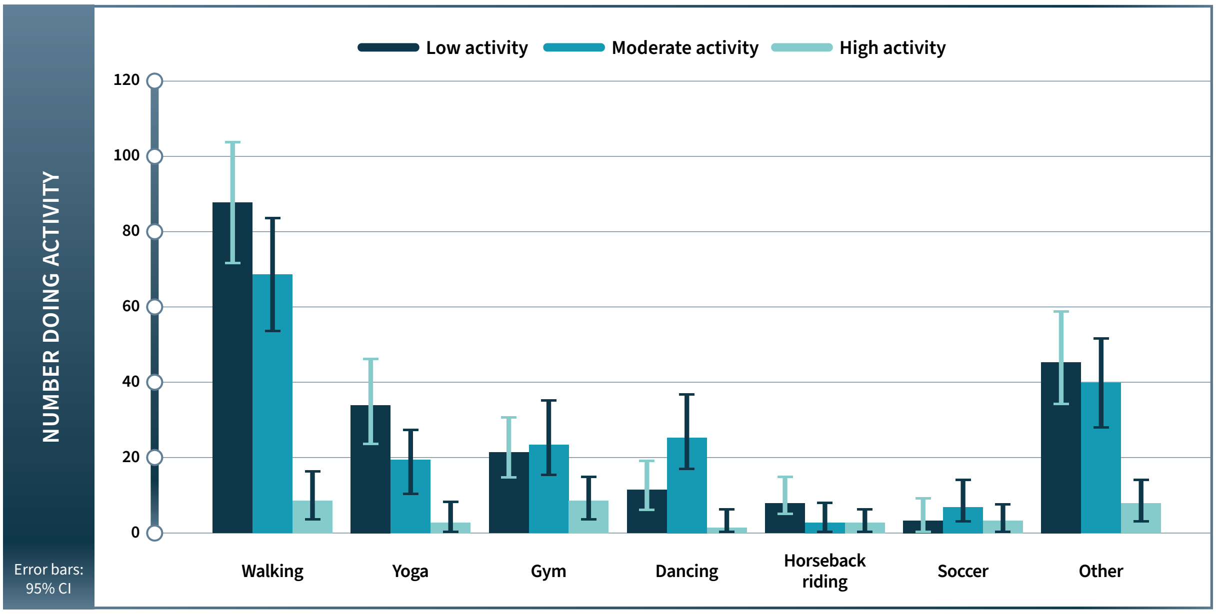


3.2.2: Physical pastimes

Participants were asked to select from a list of physical pastimes the activities they took part in including walking, tai chi and athletics. On average, participants were involved in between one and two physical pastimes weekly (M = 1.6, SD = 1.6, range 0 to 13).

The most common pastimes were walking (30.6%), other pastimes (21.2%), and Yoga (10.6%) (Figure 3.2). The three most common other pastimes were chair exercises (*n* = 29), exercise classes (*n* = 18) and attending a physiotherapist delivered programme (*n* = 18).

Figure 3.2: Leading physical pastimes undertaken by participants



3.2.2.1: Difficulties preventing physical activity participation.

Participants were asked “What difficulties might stop you doing physical activity?”. The most common responses were health considerations (*n* = 261, 33.6%), Don’t like exercise (*n* = 135, 17.4%), Wheelchair user (*n* = 115, 14.8%) and other (*n* = 110, 14.2%) which included being physically unable (*n* = 32), personal choice (*n* = 31) and staffing issues (*n* = 15).

The comments section included what prevented physical activities and perhaps explained lower levels of physical activity:

> ***Participant is in a wheelchair for two hours at a time then bed and then is back up and repeat.***
> ***Her physical health has deteriorated, she is now in a wheelchair unable to partake in physical activity.***

3.2.3: Sedentary behaviour

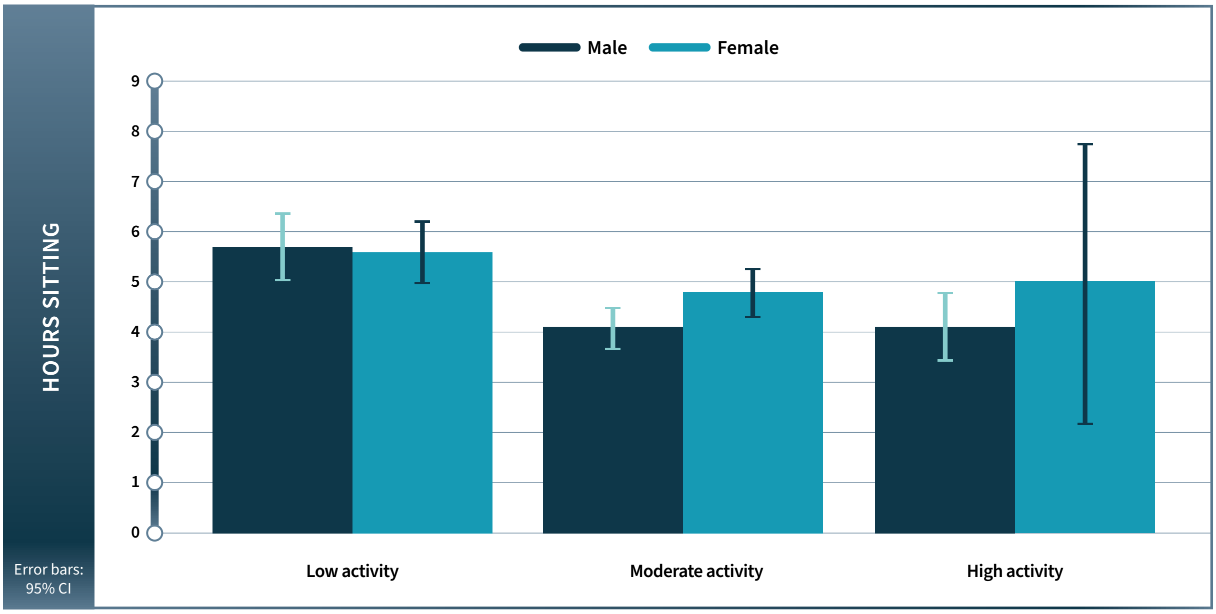
To understand the sedentary behaviour of participants they were asked about how much time they spent sitting, how much time they spent watching television and how much time they spent using electronic devices.

3.2.3.1: Sitting

The average sitting time was 5.7 hours (*n* = 633, SD = 3.41) ranging from 1 hours to 17 hours. Females (M =5.9 hours, SD = 3.6) reported sitting for more hours than males (M = 5.3 hours, SD = 3.19). Sitting was related to low activity levels, with those who reported the lowest activity levels sitting for the longest time (M = 5.7 hours, SD = 3.32) compared to those who did moderate activity levels (M = 4.4 hours, SD = 2.34) and high levels of activity (M = 4.4 hours SD = 2.41).

There was only a small difference in sitting between males and females in the low activity category, however, females in the moderate activity (4.8 hours) and high activity (5 hours) categories spent more time sitting than males (moderate = 4.1 hours, high= 4.2 hours) (Figure 3.3). Time sitting was also somewhat related to age with those aged 65 and over (M = 6.5 hours, SD = 3.92) sitting for more hours than those aged between 50 and 64 (M = 5.5 hours, SD = 3.18) and those aged under 50 (M = 5.1 hours, SD = 3.08).

Figure 3.3: Hours sitting for males and females

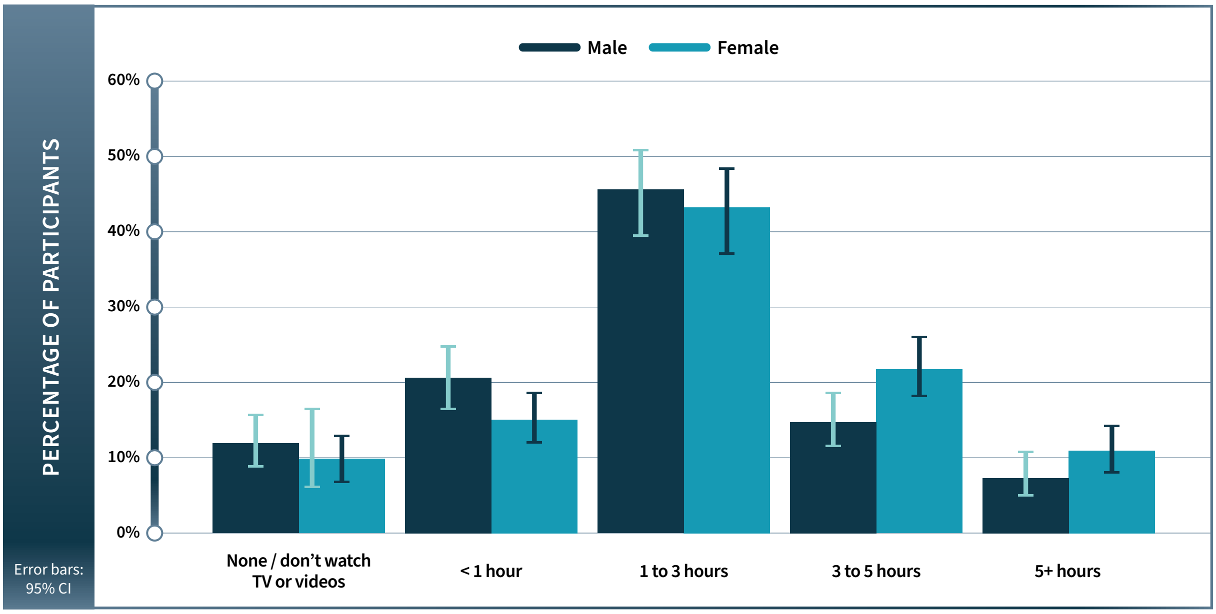


3.2.3.2: Watching TV

Participants were asked how much time they spent watching television each day, and over 44% of participants (*n* = 333) said they watched more than one hour television per day, but less than three hours. Women were more likely than men to watch TV for more than three hours in a day (32.6% vs 22.1%) (Figure 3.4).

Nearly half of participants did not own an iPad or electronic device (48.9%) and only 9.4% (*n* = 36) of those who owned one used it for more than three hours per day. There was no difference in screen time on electronic devices between males and females. The time people spent on electronic devices was not related to any group's levels of physical activity.

Figure 3.4: Number of hours watching TV for participants



3.2.4: Perception of physical activity

To understand participants' thoughts on the benefits of physical activity a nine item perceptions of physical activity scale was completed. Each item had a yes/no response. Scores ranged from 0 to 9 with a high score indicating a good understanding of the benefits of physical activity. Overall, participants' understanding of the benefits was high with a mean score of 7.59 (SD = 2.80) and there was no difference in scores between males (M = 7.67, SD = 2.76) and females (*n* = 7.53, SD = 2.84) or between the different age groups. On average, 84.4% of participants agreed with each question; the question with the highest proportion of agreement (87.3%) was "Does physical activity help you maintain and/or improve your health?". However, no association was found between positive responses and levels of activity. Many participant comments also reflected that understanding health benefits does not always lead to improvement in physical activity.

> ***Participant does not engage in physical activity and would not consider the benefits of such for health.***

3.3: Diet and health behaviour

Whilst poor diet may lead to people with an intellectual disability having a higher prevalence of obesity and morbid obesity than the wider population (Hsieh, Rimmer, & Heller, 2014), the effects of diet go beyond BMI and have been found to influence sleep quality (Harper, Ooms, & Tuffrey Wijne, 2021), mental health disorders (Głąbska, Guzek, Groele, & Gutkowska, 2020) and longevity (Longo & Anderson, 2022).

In a recent observational study of daily diet in a small sample of 33 adults with intellectual disabilities living in a residential or a group home, Hamzaid, O'Connor, and Flood (2020) reported that their diets were both poor in quality and nutrient deficient. Findings in the Netherlands were also of a lower quality diet (from a health recommendation perspective)and for participants a higher BMI was reported compared to a group from the wider population (Gast et al., 2022).

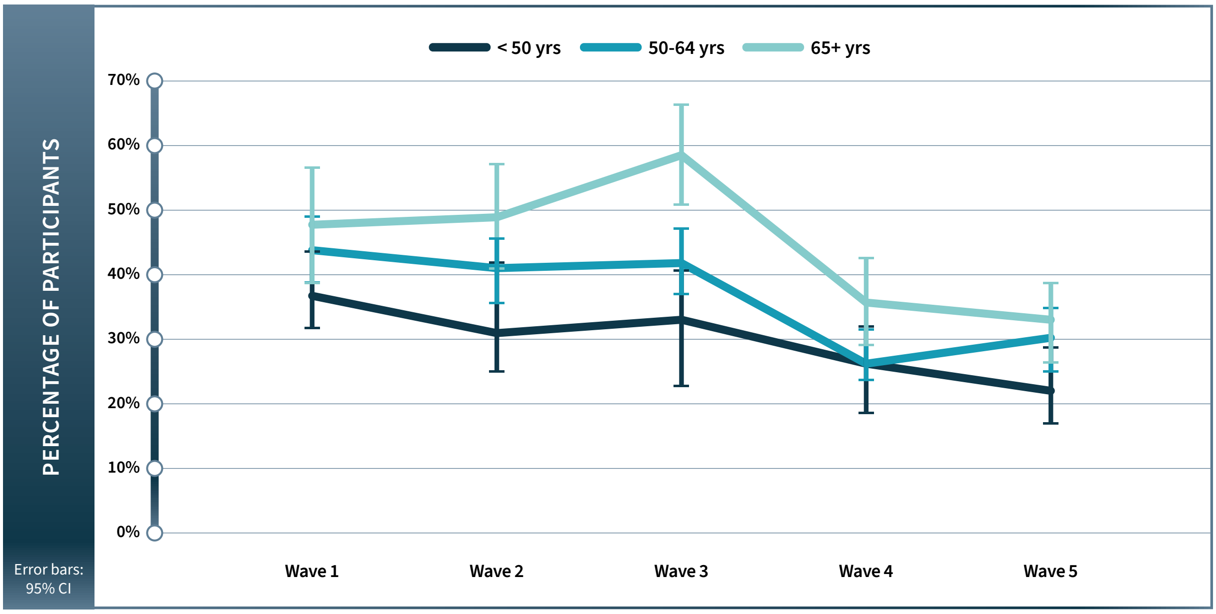
3.3.1: Perceptions of diet

Participants were asked about their dietary habits, whether they considered their meals healthy, what they drank and whether they found their meals enjoyable. Over 50% of participants reported their diet as excellent or very good and 75% rated their meals as very enjoyable as reflected in the following comment:

> ***Participant loves her food, choices are always respected, and healthy diet encouraged.***

Participants were asked, are you on any special diet? In total, 28.9% (*n* = 220) of participants at Wave 5 as compared to 48.1% (*n* = 314) at Wave 1 reported being on a special diet (Figure 3.5). This reduction in reporting of special diets was reflected across all age groups and special diets appeared to have particularly decreased since Wave 3.

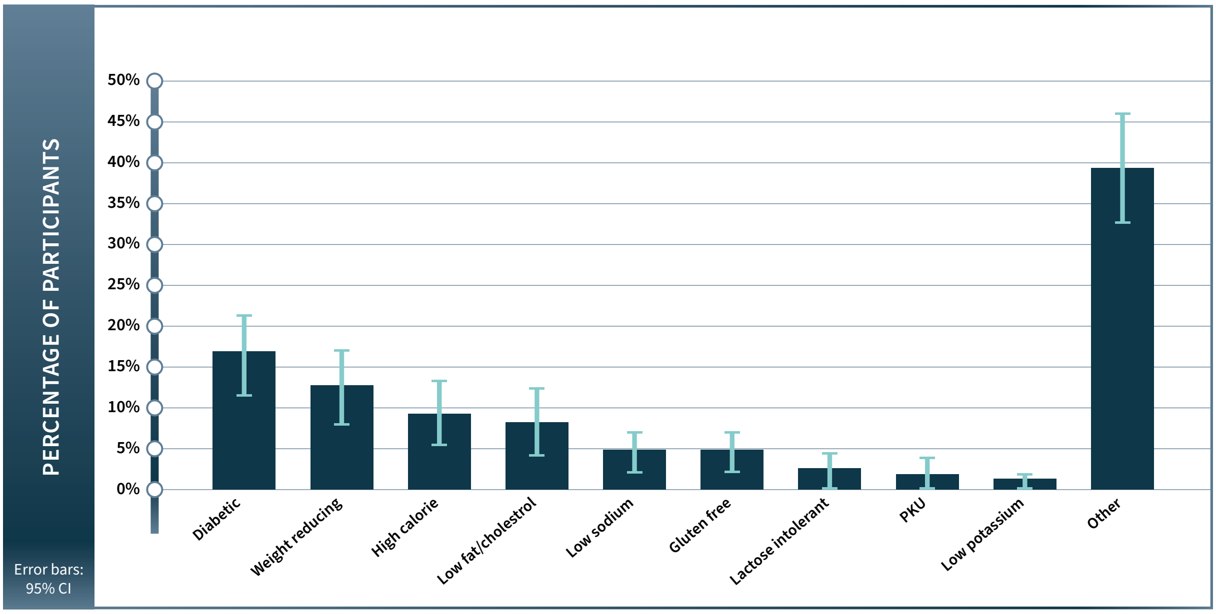
Figure 3.5: Participants reporting being on a special diet by age category, Wave1 to Wave 5



The most common diet types (Figure 3.6) were diabetic diet (16.6%), weight reducing (12.4%) and high calorie (9.2%). Most people on a special diet received advice from either a dietician (34.9%), doctor (26.1%), or speech and language therapist (25.7%). In addition, approximately half of the "other diet" category (50.5%), were from participants whose food was modified by being chopped, smoothed, or softened. Other diet types included supplements (*n* = 11), high fibre (*n* = 9) and kidney (*n* = 3). A high level of monitoring and reviewing of participants believed to be at a risk of choking was also flagged in the comments section:

> ***Participant is closely monitored at meals times. Has no history of choking however inclined to eat quickly.***

Figure 3.6: Reported diet types of participants on special diets



3.3.2: Smoking and drinking

Participants were asked about whether they smoke or have ever smoked, and the amount they smoke in a day. They were also asked about alcohol consumption.

In Wave 5, 56 (7.3%) participants reported having ever smoked, and of these only 26 still smoked which was a reduction on Wave 1 where 116 (15.4%) participants reported having ever smoked and 61 reported that they still smoked. The reduction in smoking was most notable in the under 50 age group where in Wave 1, 20.7% (*n* = 24) of participants reported having smoked and in Wave 5 only 4.4% (*n* = 8) report having ever smoked.

In Wave 5, 34.1% (*n* = 259) of participants reported drinking alcohol which was a reduction from Wave 1 where it was 40.3% (*n* = 303). Of those who drank alcohol in Wave 5, 39.9% (*n* = 101) reported drinking at least once a week. Typically, participants' comments reflected the types of drinks, their attitude towards alcoholic drinks and the risk of drinking in combination with medications:

> ***Likes a pint of Guinness or Heineken.***
> ***Used to have two drinks at the weekend but cut it down to one.***
> ***Not allowed to drink because of tablets.***

3.4: Behavioural health and well-being indicators

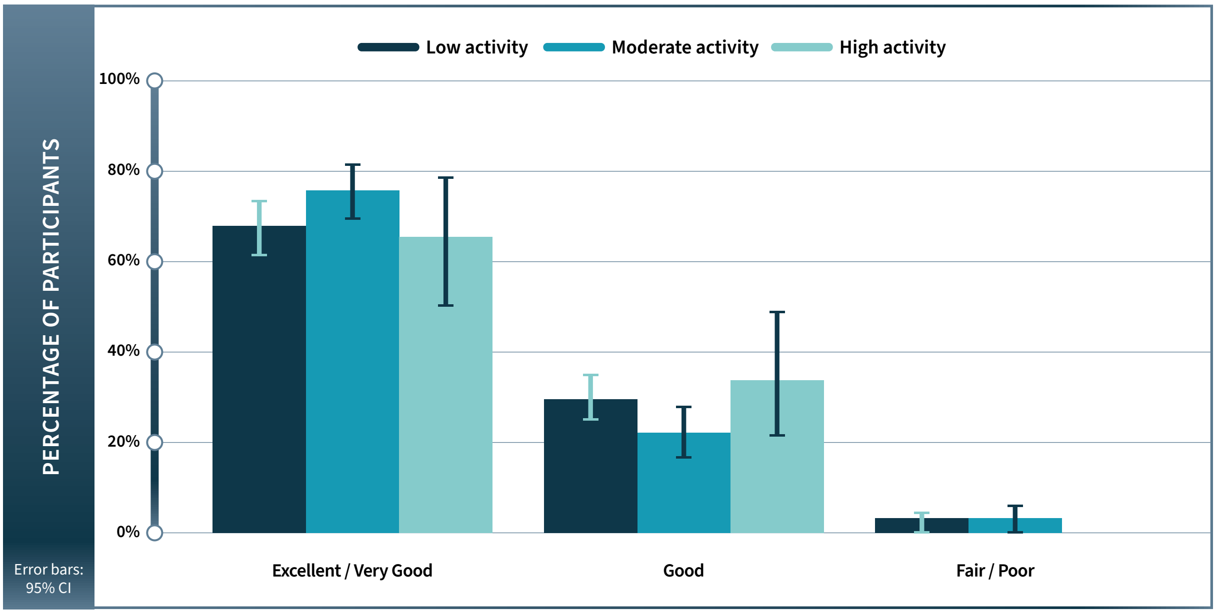
In the general population, researchers have found connections between physical activity and aspects of well-being such as quality of life, depression, and loneliness (Donoghue et al., 2016). In the population of people with intellectual disabilities, it has been observed that those who engage in more physical activity tend to report a better quality of life (Blick, Saad, Goreczny, Roman, & Sorensen, 2015).

In Wave 5, participants were asked two single item well-being questions "Would you say your quality of life is?", and "Would you say your emotional or mental health is?", with the response options "excellent, very good, good, fair and poor". Loneliness was measured with a single question, "do you ever feel lonely?", with a "yes/no" response item.

3.4.1: Self-reported well-being and physical activity

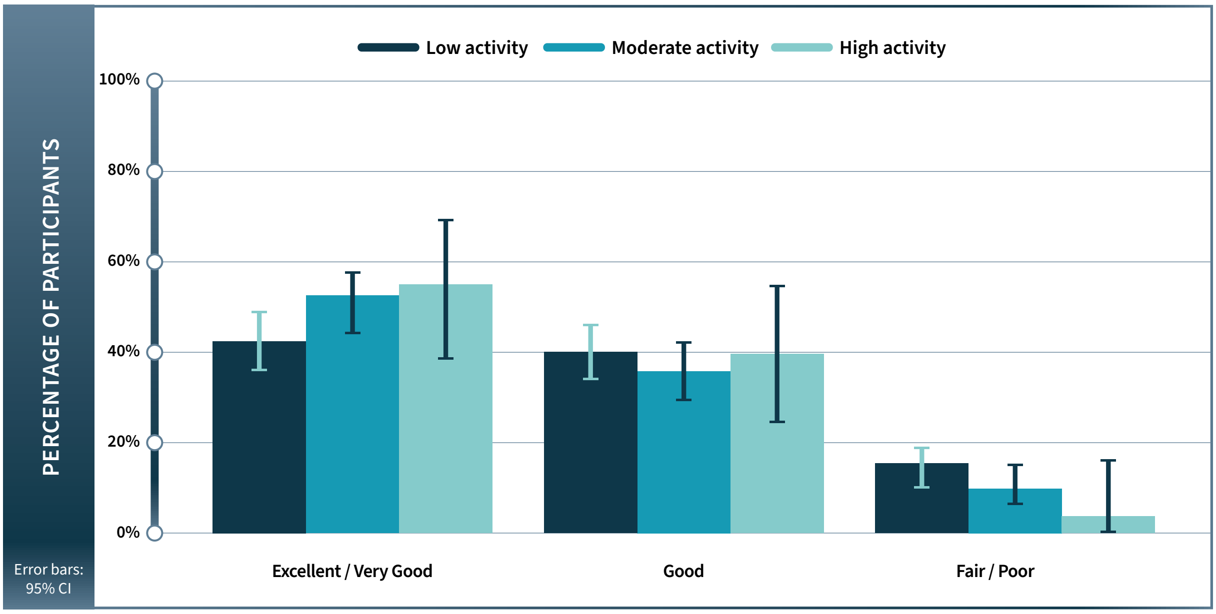
Reports using The IPAQ scale (Figure 3.7) found that a higher proportion of participants who did moderate activity (75.6%) were likely to report having an excellent or very good quality of life than the proportions of those that did either high or low levels of activity.

Figure 3.7: The effects of physical activity on quality of life as measured by the IPAQ scale



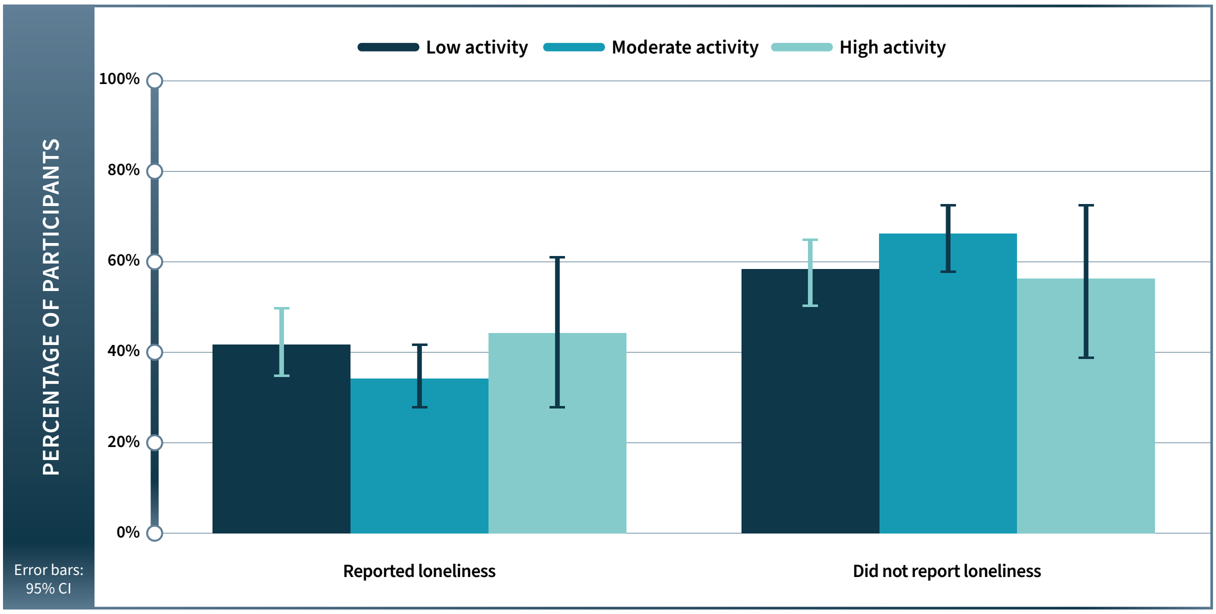
For self-reported mental health, and again using IPAQ scale scores (Figure 3.8), 55.0% of participants classified as having high activity levels reported excellent/very good mental health as did 52% of those with moderate activity levels and 43.1% of those with low activity levels.

Figure 3.8: The effects of physical activity on reported mental health as measured by the IPAQ scale



Those most likely to experience feelings of loneliness were those with high activity levels (43.8%) and those least likely to experience feelings of loneliness were those doing moderate activity levels (34.1%), again based on IPAQ scores.

Figure 3.9: The effects of physical activity on reported loneliness as measured by the IPAQ scale

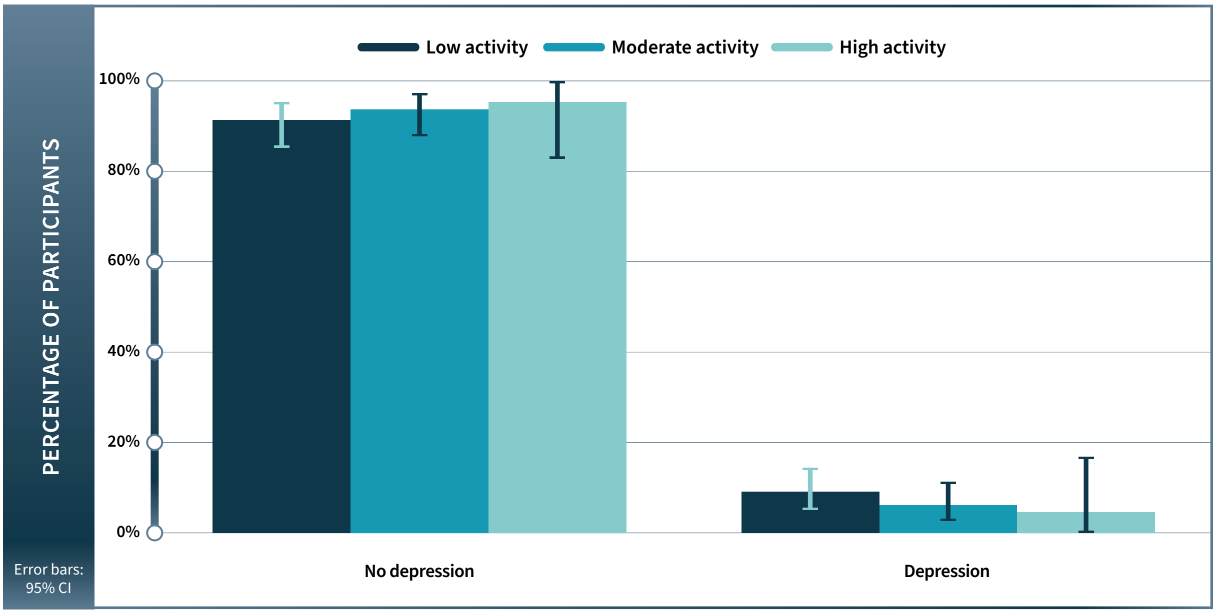


3.4.2: Measured depression and physical activity

The Glasgow Depression Scale (GDS) was used to assess symptoms of depression, with a score of 13 or higher indicating clinical depression. Results were divided into those who scored less than 13, classified as no depression and greater than 13 as depression.

Participants with IPAQ scores of low levels of activity (8.8%) were more likely to be depressed than those who did high levels of activity (3.8%) and conversely those who did high levels of activity were more likely to experience less depression (96.2% vs 91.2%). Moderate activity scores were similar to high activity and there were no statistically significant differences among the three activity level groups.

Figure 3.10: Depression and physical activity as measured by the IPAQ scale



The results suggest activity levels influence some aspects of well-being in older adults with an intellectual disability, and are in keeping with the reported TILDA research on other older adults (Donoghue et al., 2016).

3.5: Conclusion

In this chapter we have described the Wave 5 IDS-TILDA data on health behaviours, physical activity, self-reported diet, smoking and we have looked at the relationship between physical activity and well-being. The results were compared to findings from previous waves of the IDS-TILDA and to those reported on the general population by TILDA.

The use of the IPAQ scale to assess physical activity allowed both for comparison with TILDA, and comparison with previous waves of IDS-TILDA. The IPAQ is a frequently used measure despite the reported high rates of missing data (Mehta, MacDermid, Richardson, MacIntyre, & Grewal, 2015).

The findings suggest that males were more likely to be active than females, that younger participants were more active than older participants, people with a mild intellectual disability were more active than those with a moderate or severe/profound activity, and that participants who live with family or independently were more likely to be active than those who live in residential care.

The results here generally reflect the findings from other research with participants reporting lower levels of activity and higher levels of sedentary behaviour but with definite trends for improvement over time. Many participants perceived the benefits of physical activity and those in Wave 5 under age 50 did more physical activity than their Wave 2 counterparts. Those aged under 50 were also less likely to have smoked, and to drink alcohol as compared to Wave 1 and they were less likely to be on a special diet. It remains to be established if such differences reflect better reach of accessible health promotion for this younger group and this will be explored in future waves.

There were relationships between well-being and physical activity, with those who were more active being more likely to report better mental health. These results support the findings from the wider population about the benefits of physical exercise (Kapsal et al., 2019), particularly those reported for TILDA participants (Donoghue et al. (2016). Given that high activity levels were less frequent in the IDS-TILDA findings as compared to TILDA reports, it is an important finding that moderate intensity activity was associated in people with intellectual disabilities with better quality of life scores and being less likely to experience loneliness.

Overall, health behaviours in Wave 5 appeared to be trending in a positive direction with more physical activity and less smoking and drinking of alcohol being reported.

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CHAPTER 4

Psychological Well-being and Cognitive Health

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HEALTHY HAPPY AGEING

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

4.1: Key findings

- The overall prevalence of mental health diagnoses at Wave 5 (44.4%) was lower than that seen in Wave 1 (49.9%), with anxiety the most prevalent reported condition at 24.1% which was much higher than that reported by TILDA for the general population over 50 years old.
- Depression also remained an important concern with 13.0% reporting a doctor's diagnosis much higher than that reported by TILDA for the general population over age 50 years (5%), and much higher for those in community settings.
- Those aged 65 and over reported a greater overall prevalence for mental health diagnoses.
- Prevalence of mental health concerns remained highest among those with severe or profound intellectual disability.
- For those with Down syndrome, prevalence of mental health concerns at 15.2% was markedly lower than reports in Wave 1 at 24.1% and were 50% less than that reported for people with an intellectual disability from other aetiologies.
- Despite the high prevalence of mental health conditions reported, more than 80% rated their overall emotional and mental health as either excellent/very good/good.
- Self-reported loneliness declined from 50.5% at Wave 1 to 40% at Wave 5. This was especially notable among the under-50s, with 34.9% reporting feeling lonely at Wave 5 compared with 51.3% in Wave 1; and among participants living in residential settings, whose rates fell from 53.8% to 32.4% from Wave 1 to Waves 5 respectively.
- The mean score of Energy and Vitality levels at 68.9 were high regardless of age, setting or level of intellectual disability, and higher than those reported in the wider Irish population at 62.4% (Government of Ireland, 2021).
- Nearly two-thirds of respondents (77.1%) reported experiencing more than one life event over the previous year.
- In Wave 5, prevalence of dementia in people with Down syndrome was 22.7% (*n* = 32). The majority of people with Down syndrome and dementia were aged 50-64 at 84.3% (*n* = 27), and only 3% of those with Down syndrome and dementia in the 65 and over age group, perhaps suggesting earlier mortality for those with Down syndrome.
- Dementia was much higher in people with Down syndrome than those with an intellectual disability from other aetiologies with a mean age of onset in those with Down syndrome of 53 years compared to 67.5 for those with intellectual disability from other aetiologies.
- Dementia screening rose for those with Down syndrome, from 13.9% (*n* = 28) in Wave 1 to 66.4% (*n* = 83) in Wave 5. However, in Wave 5, 42.7% (*n* = 41) of those with Down syndrome who did not have dementia had never had a dementia assessment despite being over the age of risk.

4.2: Introduction

This chapter presents findings on mental health, well-being, vitality, life events and cognitive health in Wave 5. The same methods and measures were used as in previous IDS-TILDA waves and data is presented in a descriptive manner with comparisons to findings from those previous waves and from other studies of older adults with and without intellectual disabilities.

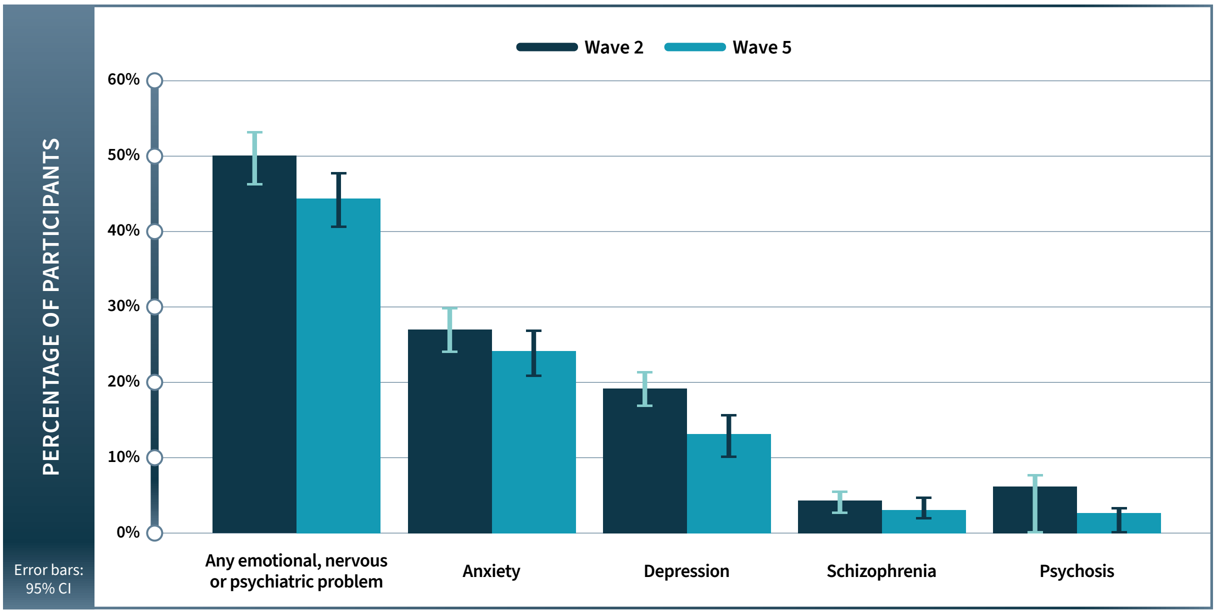
4.3: Mental health

Respondents who reported in previous waves that they had received a diagnosis from a doctor of an emotional, nervous, or mental health condition were asked in Wave 5 if they still had this condition. Participants were also asked if they had received a new diagnosis since the previous interview. Doctor's diagnosis was therefore a proxy for lifelong prevalence or a new diagnosis within a specific period of time.

4.3.1: Reported diagnoses

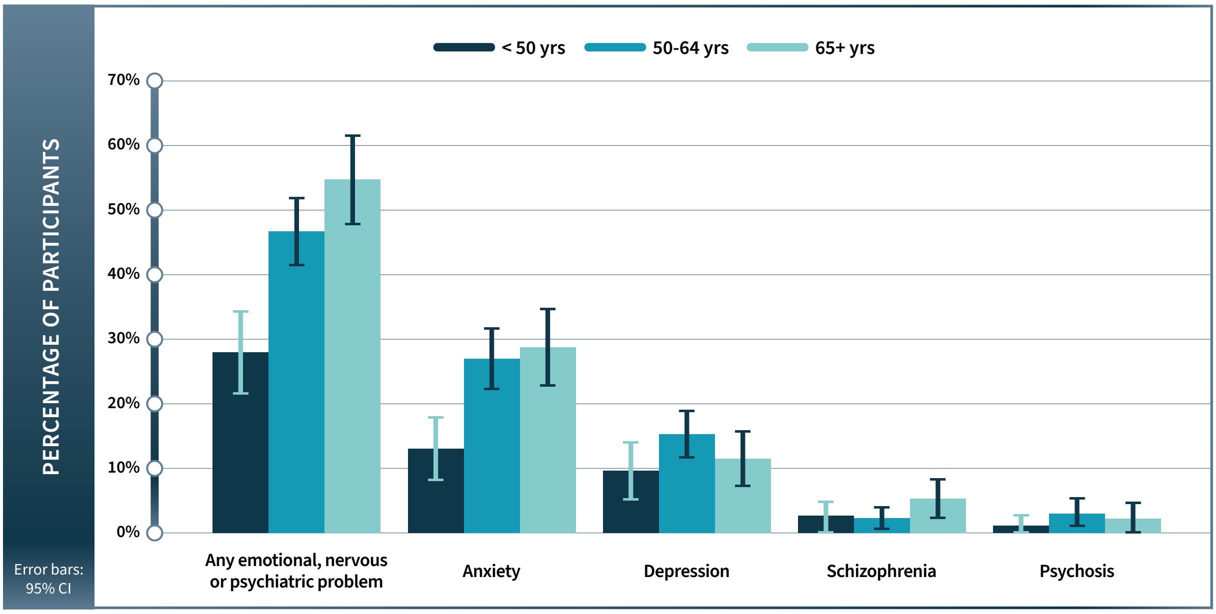
The overall prevalence of mental health diagnoses in IDS-TILDA Wave 5 (44.4%) was lower than that seen in Wave 1 (49.9%). There were similar decreases in the frequency of specific diagnoses. Anxiety remained the most prevalent reported condition, but at 24.1% in Wave 5, rates decreased from Wave 1: 26.8% This compares with TILDA findings for the general older population over age 50 years that 13% of people experienced 'case-level' symptoms for anxiety (O'Regan et al., 2011). The second most prevalent condition, depression, also decreased (Wave 1: 19.3%; Wave 5: 13%). As did schizophrenia (Wave 1: 4.2%; Wave 5: 3.4%) and psychosis (Wave 1: 6.0%; Wave 5: 2.4%) (Figure 4.1)

Figure 4.1: Prevalence of emotional and psychiatric conditions at Wave 1 and Wave 5



All diagnoses, except anxiety, were more prevalent in women. Those aged 65 and over reported a greater overall prevalence for mental health diagnoses (54.6%) than participants aged 50-64 years (46.6%) and under 50 years (27.9%) respectively (Figure 4.2). Prevalence remained highest among those with severe or profound intellectual disability (58.7%). Participants living in residential settings reported a higher overall prevalence of mental health diagnoses compared to those in community group homes, with participants living independently or with family having the lowest prevalence.

Figure 4.2: Prevalence of emotional and psychiatric conditions by age



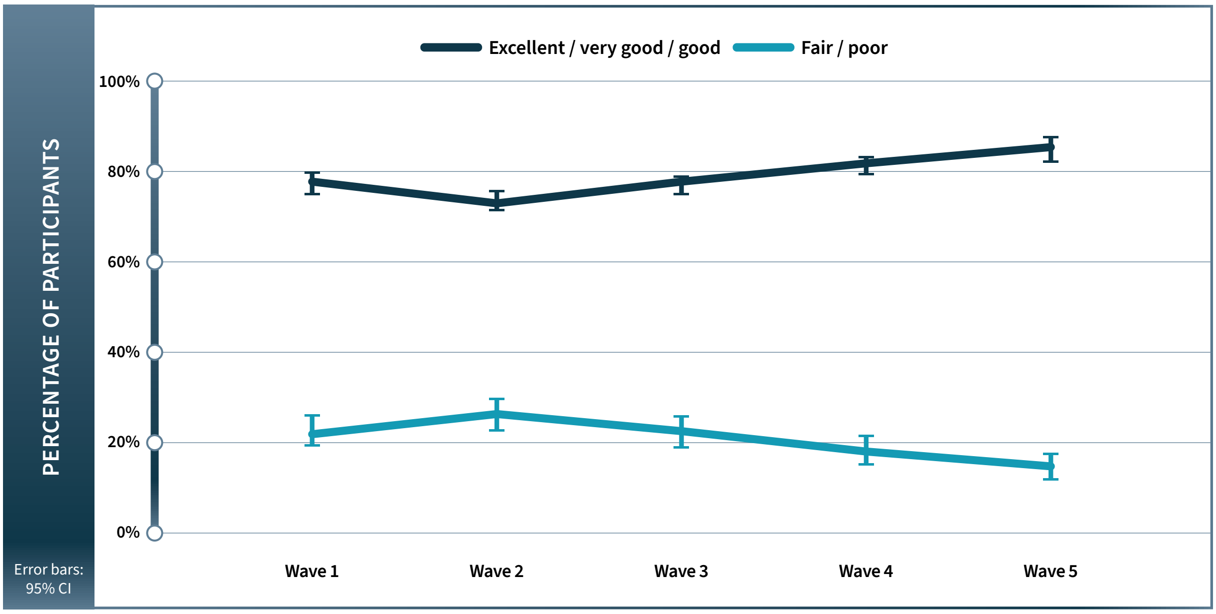
4.3.2: Self/proxy rated emotional and mental health

Respondents and/or their proxies were asked to rate their perceived mental and emotional health with five-point Likert options ranging from poor to excellent. Of the 744 valid responses, 212 were self-reports and, of these, more than 80% rated their overall emotional and mental health as either excellent/very good (41.9%), or good (43.3%). These figures were more positive than those reported in Wave 3 (33.3% and 44.3% respectively), a trend that has been noted since Wave 2 (Figure 4.3). These trends continued when the replenishment of the sample for Wave 4 and Wave 5 was accounted for.

92%

of participants rated their own mental health as excellent/very good/good

Figure 4.3: Rating of mental and emotional health, Wave 1 to Wave 5



The percentages of participants who rated their mental and emotional health as excellent/very good/good was comparable across self (92.0%) and joint self/proxy reporters (91.7%), with 76.8% of pure proxies reporting this rating. This is the highest concurrence in rates of self and self/proxy rating of positive mental health across the waves.

Favourable mental health ratings were regardless of age, with 89.5% of those aged under 50 years, 83.5% aged 50-64 years and 84.4% aged 65 and over. Participants living independently or with family were also more likely to report positive mental health (92.3%) than those living in community group homes (84.4%) and those in residential settings (80.2%), all marginal increases on Wave 3 reports.

4.3.3: Persons with Down syndrome

The overall prevalence of mental health conditions reported in Wave 5 amongst those with Down syndrome was (15.2%) markedly lower than that reported in Wave 1 (24.1%). This rate is less than half of reports for IDS-TILDA participants without Down syndrome, and consistent with what was reported in the earlier waves.

Also, in line with reported trends, the overall prevalence of reported mental health conditions was greatest among those participants with Down syndrome who lived in residential settings (40%) followed by community group homes (32.4%) and independently/with family (12.5%).

4.4: Depression

In Wave 5, 13.0% (*n* = 99) of participants indicated that they had received a diagnosis of depression, significantly higher than the pre-COVID figure of 5.0% reported by TILDA for the general population over age 50 years (Canney et al., 2017).

Depression remains a concern with **13%** reporting a doctor's diagnosis

4.4.1: The Glasgow Depression Scale

The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) devised by Cuthill et al. (2003) supports the assessment of depressive symptomatology in individuals with mild to moderate intellectual disability. A score of 13 or greater indicates depression on the self-report GDS-LD (Cuthill et al., 2003). The Glasgow Depression Scale was asked for the first time of IDS-TILDA participants in Wave 3 and comparisons will be drawn with Wave 5 data.

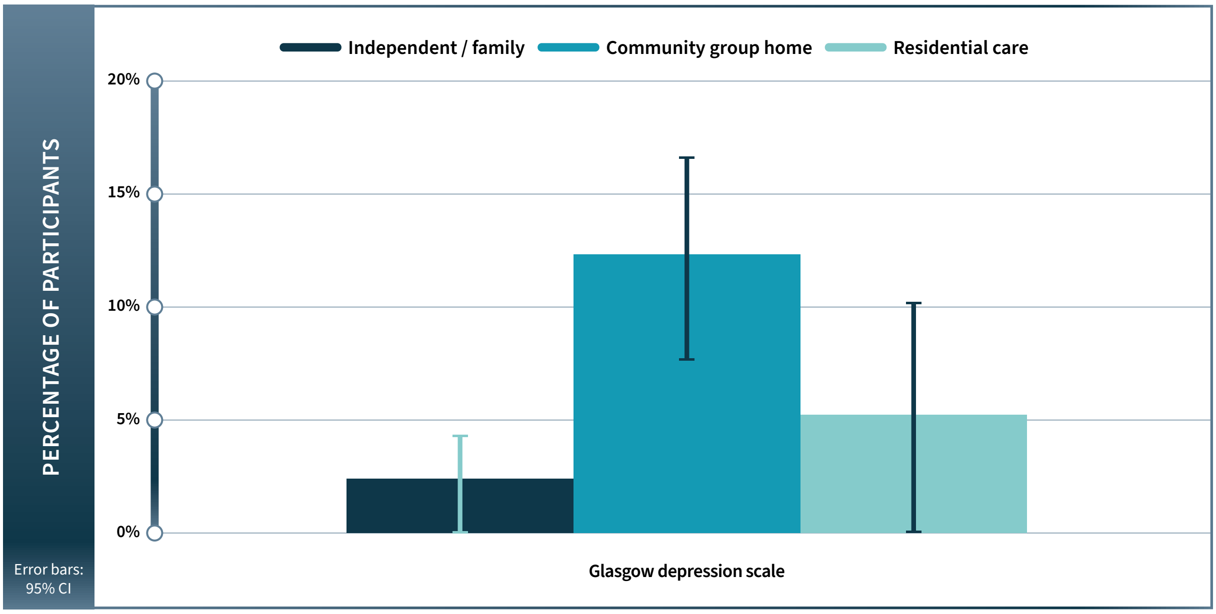
Rates of anxiety and depression continued to decrease from Wave 1 to Wave 5

For the 370 participants in Wave 5 who either self-responded (with/without support) or responded with the assistance of a proxy, 7.8% (*n* = 29) scored at or above the cut-off of 13, indicating the presence of depressive symptoms. This was slightly higher than the prevalence reported in Wave 4 (7.2%) and lower than in Wave 3 (10.0%) but remains higher than that found by TILDA in the general population over age 50 years with similar screening instruments with a cut-off score (Canney et al., 2017).

More women with an intellectual disability reported depressive symptoms (10.6%) than men (4.3%) which is lower than the finding of 26.0% reported in Cooper et al.'s (2015) study but similar to the 11% found by Sheehan et al. (2015). Furthermore, whereas the prevalence for women was unchanged between Wave 3 and Wave 5, rates for men reduced from the 9.1% found in Wave 3. More participants with moderate intellectual disability reported depressive symptoms (8.6%; Wave 3: 9.4%) than those with mild (7.1%; Wave 3: 10.8%) intellectual disability, though this association was not significant. Only 2.2% of participants living independently/with family had depressive symptoms, a reduction on the 6.4% found in Wave 3. There was a significant difference between those at home (2.2%), in residential care (5.1%) and those in community group homes (12.2%) (Figure 4.4).

Participants with Down syndrome had similar rates of scored depression (6.8%, 5/73) to other participants (7.8%, 29/370).

Figure 4.4: Glasgow Depression Scale and living situation



4.5: Anxiety

Anxiety is the most prevalent diagnosed mental health concern for older adults with intellectual disability with 24.1% (*n* = 184) reporting a diagnosis of anxiety in Wave 5 which was lower than reports in Wave 3 (32.4%).

4.5.1: The Glasgow Anxiety Scale

The Glasgow Anxiety Scale for people with a Learning Disability (GAS-LD) was developed by Mindham and Espie (2003) to facilitate assessment of anxiety in individuals with an intellectual disability. The 27 item self-rated scale covers domains of worries, specific fears and physiological symptoms. Each item is scored as (0) - 'never', (1) - 'sometimes' and (2) - 'always'. A cut-off score of 15 indicating presence of anxiety. An easy-read version using symbols to assist interpretation was available to respondents to support self-completion.

4.5.1.1: GAS-LD results – Wave 5 and longitudinal

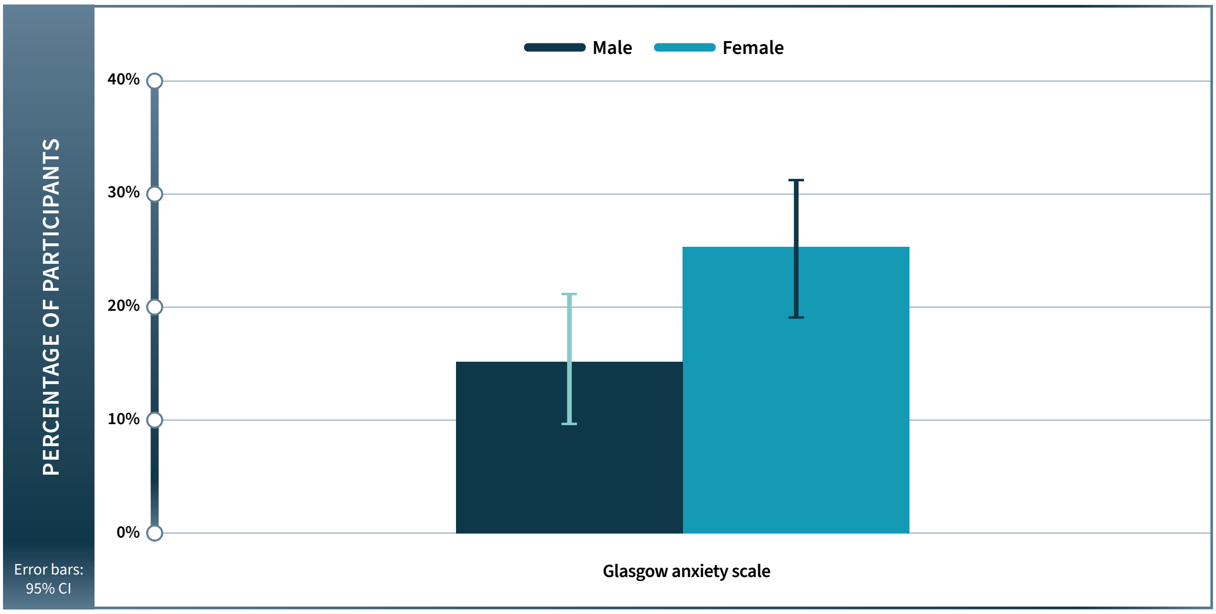
Total scores on the GAS-LD were obtained for 342 participants who either self-responded or responded with the assistance of a proxy, with 21.1% (*n* = 72) of those participants scoring above the cut-off of 15. This is slightly lower than the reported doctor's diagnosis prevalence of anxiety (24.1%) and is markedly less than the 41.9% reported in Wave 3.

Within the 50–64-year age group, 20.3% (Wave 3: 16.0%) had anxiety related symptoms as did 18.1% (15.3%) of those in the 65 and older age group and 23.8% (Wave 3: 9.4%) of those under the age of 50 years. 25.3% (Wave 3: 16.5%) of women and 15.5% (Wave 3: 13.2%) of men reported symptoms (Figure 4.5) as did 21.3% (Wave 3: 18.8%) of people with mild intellectual disability and 19.4% (Wave 3: 13.0%) of those with moderate intellectual disability.

None of the participants with severe/profound intellectual disability scored above the cut-off score. Participants living in community group homes were also more likely to experience anxiety related symptoms (Wave 5: 23.1% *n* = 40; Wave 3:17.7% *n* = 25) than those living independently (Wave 5: 11.4% *n* = 4; Wave 3: 15.4% *n* = 12) or in residential care (Wave 5: 20.9% *n* = 28; Wave 3: 9.7% *n* = 7).

Levels of anxiety for participants with Down syndrome (21.1%, 12/57) matched those of other participants (21.1%, 72/342).

Figure 4.5: Glasgow Anxiety Scale by sex

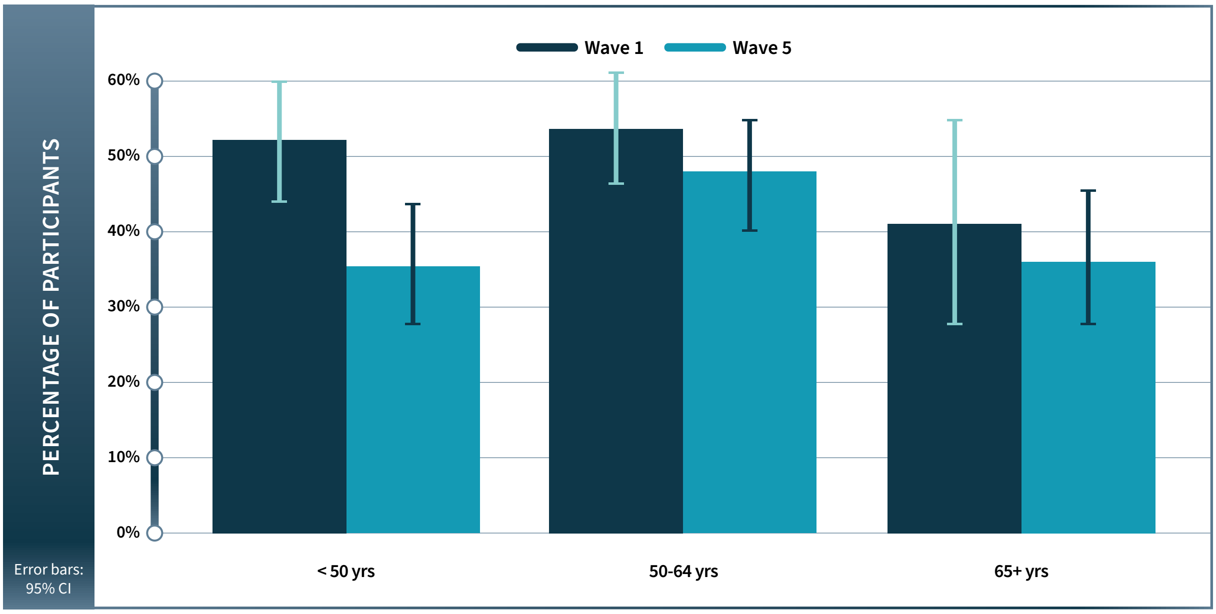


4.6: Loneliness

In Wave 5, 40% of participants self-reported feelings of loneliness. This was a drop from Wave 1, when half of all participants (50.5%) reported feelings of loneliness. Whilst a drop in reported loneliness was seen in all age categories, Figure 4.6 clearly highlights that this drop was largely associated with the youngest participants where 51.3% of those aged between 40 and 49 in Wave 1 reported feelings of loneliness and only 34.9% did in Wave 5.

Females remained more likely to report feelings of loneliness in Wave 5, however rates for females (55.3% to 45.2%) and males (44.4% to 33.7%) have declined equally. Declines are also noted across the levels of ID; Mild 53.1% to 41.3%, and moderate 50.5% to 39.7%. However, declines in reported loneliness across residency types were highest in residential settings (53.8% to 32.4%).

Figure 4.6: Reported feelings of loneliness by age group at Wave 1 and Wave 5



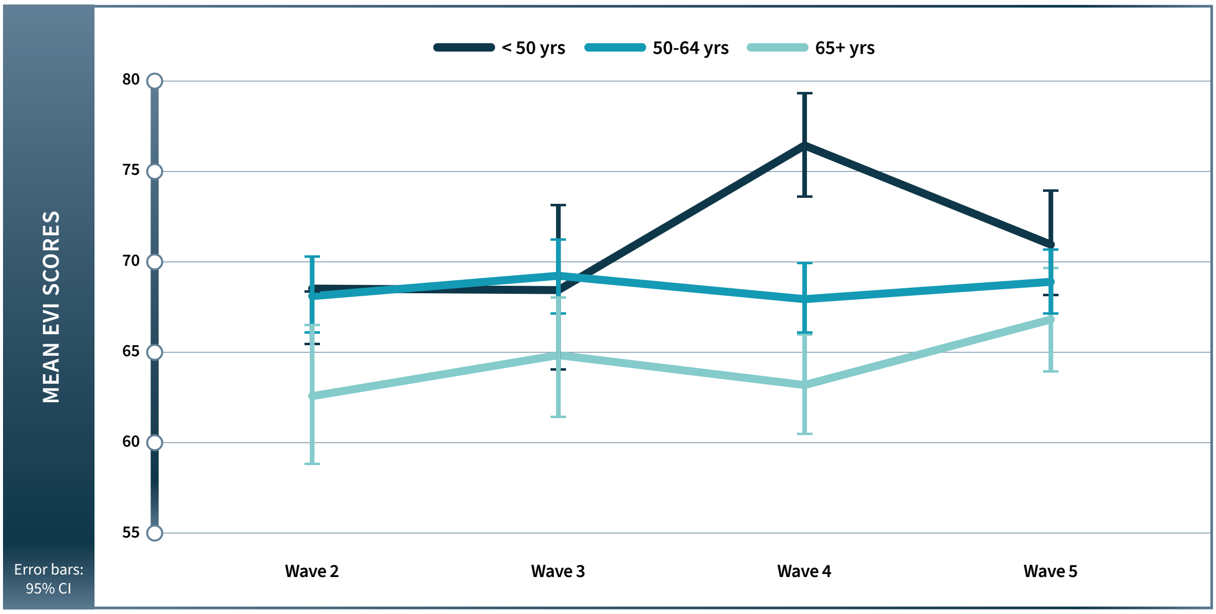
4.7: Energy and Vitality Index

As in Wave 2 and Wave 3, an Energy and Vitality Index was employed, comprising four Energy and Vitality Index (EVI) questions drawn from the 36-item Short Form Health Survey (SF36) (Burke et al., 2014, Ware et al., 1994) exploring respondent/proxy rated energy and vitality over the preceding four weeks. Responses were recorded using a 6-point Likert scale from 'All of the time' to 'None of the time'.

The EVI was completed by 727 participants. The mean score for all participants was 68.9 with a slightly higher score for males (70.58) than females (67.43). Scores were also higher for younger respondents (under 50 years: 71.0; 50-65 years: 69.0; 65 and above: 66.8) and were comparable to findings reported in previous waves (Figure 4.7).

They were also higher among those with less severe levels of intellectual disability (moderate: 70.5; mild: 70.4) as compared to severe/profound (63.6) and for those living independently or with family (71.7), as compared to in community group homes (69.4) or in residential settings (65.7).

Figure 4.7: Mean Energy and Vitality Index by age, Wave 2 to Wave 5



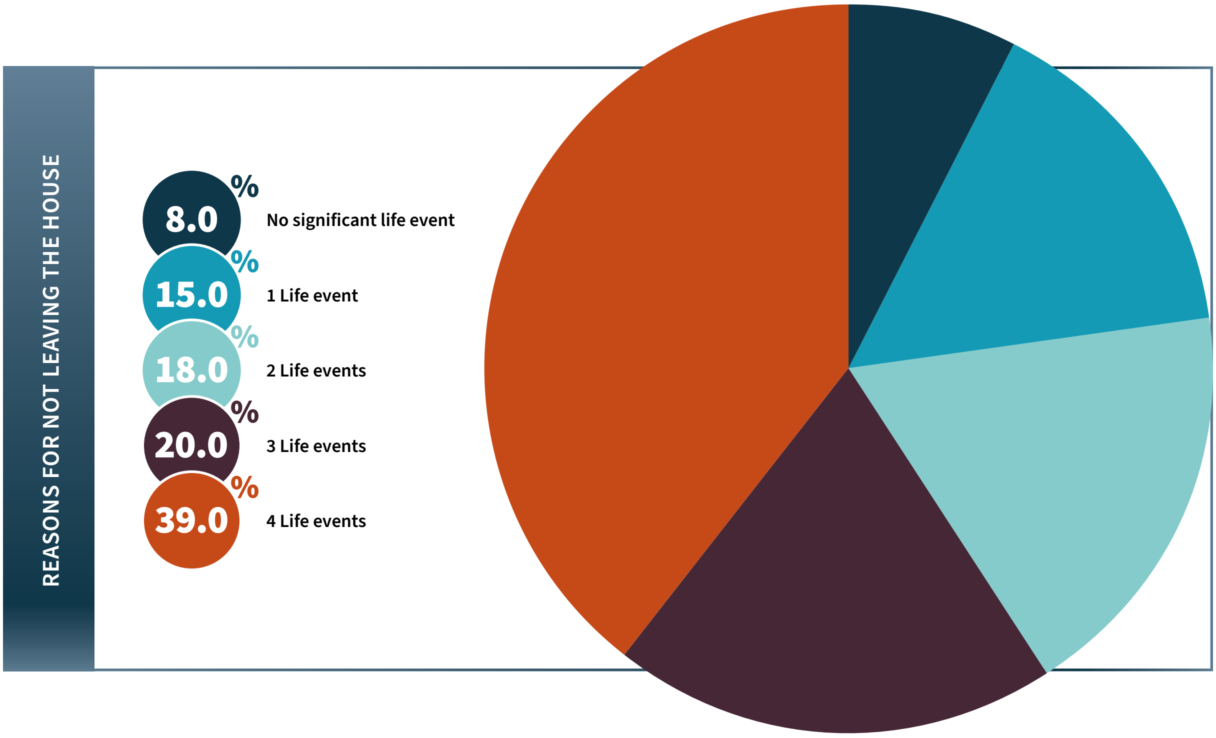
The mean EVI score mirrored closely those at Wave 2 (67.2) and Wave 3 (68.3) but were higher than those reported for the wider Irish population (62.4) in the 2021 Healthy Ireland Survey Report (Government of Ireland, 2021). In Wave 2, it was noted (citing Ball et al. 2011) that vitality reports by proxies, tend to be lower. This pattern was repeated in Wave 5, with a self-report vitality mean of 71.3, a self-report assisted by proxy mean of 72.8 and a proxy-report mean of 65.0.

4.8: Life events

People with intellectual disability are likely to experience more negative and a greater number of life events than those without intellectual disability (Hermans & Evenhuis, 2012). The number of such events in the preceding 12 months has also been proposed to be associated with clinical diagnoses of mental ill health (Cooper et al., 2007). Life events were assessed using a 31-item life event checklist, based on Herman and Evenhuis's (2012) Life Events Scale which looks back over the previous 12 months, and includes items on relationships, living arrangements and bereavements. The Life Events Scale was introduced in Wave 2 of IDS-TILDA. In Waves 2 and 3, participants were asked a shorter 18-item life event checklist.

Over two-thirds of respondents (77.1%) reported more than one life event over the previous year. There was an increase in the number of respondents who experienced four or more life events (Wave 5: 39.2%; Wave 2: 13.2%) although the longer scale used in Wave 5 may have contributed to this.

Figure 4.8: Number of life events



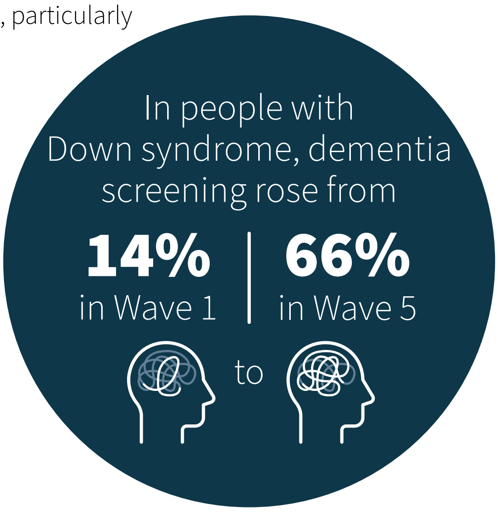
There were differences as compared to Wave 2 in some of the most frequently reported events but change of staff remained to the fore (60.1%). Other events included holidays (43.1%), minor illness (28.8%), change in key worker (25.3%), death of a friend (18.2%), problems with another resident (17.4%), new resident moved in (16%), decline in mobility (15.4%), change in frequency of visits (12.9%), and change at or from work (12.8%).

4.9: Cognitive health and prevalence of dementia

Cognitive health, as distinct from mental health, encompasses an individual's overall state of cognitive function including memory, perception, problem solving and decision-making abilities. Several factors can influence cognitive health including, genetic factors, age and lifestyle factors. Cognitive health can also have an impact on many areas of a person's life, such as overall well-being, interpersonal relationships and plays a role in everyday functioning. Dementia is an important and significant driver of cognitive decline with Alzheimer's disease the most prevalent cause of dementia for people with an intellectual disability, particularly for people with Down syndrome.

4.9.1: Prevalence of dementia

In all five waves of IDS-TILDA, participants were asked if they had received a doctor's diagnosis of dementia or Alzheimer's disease. In Wave 1, prevalence was 5.8% (*n* = 23) and remained similar in Wave 5 at 6.3% (*n* = 48). Due to a refresh of the sample in Wave 5 (as described in the Methods chapter) the age distribution of participants was similar between Wave 1 and 5, which may account for the relatively stable prevalence rate across the two waves.



In Wave 5, prevalence of dementia in people with Down syndrome was 22.7% (*n* = 32). Dementia was much higher in people with Down syndrome than those with intellectual disabilities from other aetiologies. Of those with dementia, 66.6% had Down syndrome. Risk of dementia increased with age, with a clear age-related trajectory both for people with Down syndrome and those with intellectual disability from other aetiologies. In people with Down syndrome, the majority of those with dementia were in the age group 50-64 at 84.3% (*n* = 27), with only 3% of those with Down syndrome and dementia in the 65 and above age group, perhaps suggesting earlier mortality for those with Down syndrome. The average age of diagnosis of dementia for those with Down syndrome was 53 years compared to 67.5 for those with intellectual disability from other aetiologies.

Table 4.1: Age breakdown of dementia prevalence for those with Down syndrome and intellectual disability from other aetiologies

Age	Down syndrome (*n* = 32)		ID from other aetiology (*n* = 16)	
	%	n	%	n
<50	12.5%	4	0%	0
50-64	84.3%	27	31%	5
65+	3%	1	68.7	11

4.9.2: Dementia assessment

A positive finding in Wave 5 was that dementia assessment rose for those with Down syndrome, from 13.9% (*n* = 28) in Wave 1 to 66.4% (*n* = 83) in Wave 5. However, in Wave 5,42.7% (*n* = 41) of those with Down syndrome who did not have dementia had never had a dementia assessment despite being over the age of risk.

4.10: Conclusion

In this chapter an overview has been provided of the mental and cognitive health of older adults with intellectual disability in Ireland. It has presented findings on the prevalence and incidence of reported mental health diagnoses and dementia often in light of data from previous waves of the IDS-TILDA study. Furthermore, it has explored the demographic, social and living contexts within which people experience mental and cognitive health and has compared their mental and cognitive health with that of other older Irish adults in general society.

Older adults with intellectual disability continue to experience poorer mental health than those without identified disabilities, but there are trends for reductions in diagnosis prevalence over waves that will be monitored in future waves. Moreover, in Wave 5 COVID and its associated restrictions and their consequences may have had continuing implications for the mental health and well-being of older people with intellectual disabilities. This will be explored further in the next wave of data collection.

Anxiety and depression remained prevalent in the lives of older people with intellectual disabilities but those living independently and with family rates continued to have lower rates than those living in other types of accommodation, particularly community group home settings. There was a decrease across waves in loneliness reported, which was especially evident among participants aged under 50 years.

Dementia remains a significant condition, particularly for people with Down syndrome, not surprisingly as age is the biggest driver of dementia presentation. Dementia screening has increased, which is positive, and may be related to the development of the National Intellectual Disability Memory Service (NIDMS), which was established in 2020, giving access to everyone with an intellectual disability in Ireland to memory screening and assessment, regardless of geographic location or attachment to services.

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CHAPTER 5

Healthcare Utilisation

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5.1: Key findings

- Private health insurance cover increased for people with intellectual disability from less than 5% at Wave 1 to over 11% at Wave 5, similar to the general population. However, adults who lived in residential care had the lowest level of private medical cover.
- Older people with intellectual disability attended the GP and emergency department more often than the average for others, but they attended fewer outpatient appointments and spent fewer nights in hospital per year.
- Over the five waves of IDS-TILDA there was a trend for increased utilisation of specialist health (e.g., optician, dental, hearing) services for older adults with an intellectual disability.
- Wave 5 participants aged 40 - 49 years were less likely to use the public health nurse and therapy services than those aged 50 and above but more likely to use dental and pharmacy services.
- Adults with intellectual disability continued to have high uptake levels of flu and COVID-19 vaccinations with 95.1% of participants receiving the flu vaccine. COVID-19 vaccination rates were at 99.1% of participants and a further 98.1% received a follow up COVID-19 booster.
- Of 156 people who were eligible for bowel screening in the previous two years, 68.1% had a bowel screen. This is higher than the national reported average ranging from of 41.9% to 46.6%.
- Thirty-seven percent of eligible participants reported that they were invited for a cervical screen in the previous two years. Of those who were invited, only 30.6% attended. Fear was cited as a predominant reason for not attending.
- Medication use remained high at Wave 5, with 695 participants (94.7%) reporting medication use.
- The most frequently reported therapeutic classes were the same between Wave 1 and Wave 5 – psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives), drugs for constipation, analgesics, antiepileptics and psychoanaleptics (including antidepressants, psychostimulants and anti-dementia drugs). In contrast, most frequently reported medications in TILDA participants were medication for cardiovascular disease, acid related disorders and respiratory conditions.
- While psycholeptics remained the most prescribed medication class at Wave 5, (49% of participants), there was increased reporting of drug use for constipation (43.7%).
- There was a 20% decrease in psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives) use in those aged 40 - 49 years (56.3% to 33.9%) from Wave 1 to Wave 5.
- Calcium use increased from 17.8% at Wave 1 to 36.5% at Wave 5. Vitamin D use increased from 2.9% at Wave 1 to 25.2% at Wave 5. While at Wave 1, vitamin D use was predominantly reported by female participants (72.7%), 49% of vitamin D users were male at Wave 5.

5.2: Introduction

Ageing people with intellectual disability typically present with greater health needs than the general population (McMahon & Hatton, 2021) requiring them to use more health services (McCarron et al., 2017; Sandberg et al., 2023). However, with difficulties identifying the health needs of this population (Doherty et al., 2020), attention for people with intellectual disabilities to better understand patterns of healthcare utilisation will provide direction for promoting better health and the lengthening of life expectancy (McCarron et al., 2017).

This chapter reports on health care utilisation by IDS-TILDA participants at Wave 5 and draws upon data from previous IDS-TILDA Waves 1 - 4 for longitudinal comparisons. Where appropriate, TILDA and other national comparisons are presented as well as 15-year trends.

5.3: Medical cover

Most participants reported having a full medical card or equivalent at 96.9% in Wave 1 and 98.3% in Wave 5. Conversely, prior waves reported that access to private health insurance was almost non-existent (less than 5% at Wave 1 and less than 1% at Wave 3) in contrast to the one-third of the general population of older people who reported holding such insurance (McCarron et al., 2017a). Reported rates increased in Wave 5 (11.6%). In terms of associations with sex, age and residence, as can be seen from Table 5.1, those living in residential care and aged 65 and older have the lowest levels of private health insurance cover.

Table 5.1: Private medical cover and its association with sex, residence, and age

		Covered by private medical insurance		Not covered by private medical insurance		Total	
		n	%	n	%	n	%
Sex	Male	34	10.2	298	89.8	332	46.5
	Female	49	12.8	333	87.2	382	53.5
Residence	Independent / family	32	20.0	128	80.0	160	22.4
	Community group home	38	10.8	314	89.2	352	49.3
	Residential care	13	6.4	189	93.6	202	28.3
Age	<50	27	16.0	142	84.0	169	23.7
	50-64	43	12.7	296	87.3	339	47.5
	65+	13	6.3	193	93.7	206	28.9

Note: Wave 5 n = 755

5.4: Healthcare utilisation - comparison with Wave 5 TILDA data

Table 5.2 compares health service use of older adults with intellectual disability with the over age 50 years TILDA general population (Roe et al., 2020)[1]. As compared to the estimated weighted average of adults aged ≥50years who used a service (GP, emergency department, outpatient clinic and hospital stay) in the previous 12 months in the general population (*n* = 1,446,460), IDS-TILDA participants aged 50 and above (*n* = 572) had higher mean use of general practitioner and emergency departments, but a lower mean use of Outpatient clinics and a lower mean number of nights spent in hospital.

International studies suggest that people with intellectual disability are hospitalised more often and have longer admission rates than the general population (Balogh et al., 2010; Glover & Evison, 2013). There is a need for further investigation of these trends in Ireland.

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[1] At Wave 5 TILDA used weights to make estimates relevant to the general population of over 50s in Ireland.

Table 5.2: Mean use of healthcare services in the previous 12 months in the general population and IDS-TILDA population aged ≥50

	TILDA Aged ≥50 years Mean	IDS-TILDA Aged ≥50 years Mean
General practitioner	3.88	5.57
Emergency department	0.27	0.45
Outpatient clinic	1.67	1.08
Nights spent in hospital	1.92	0.96

For those aged 40 - 49 years (*n* = 183) IDS-TILDA participants at Wave 5 general practitioner (M = 4.25, SD = 5.21), emergency department (M = 0.38, SD = 1.03) and nights spent in hospital (M = 0.48, SD = 1.96) was even lower, but their number of outpatients clinic appointments attended (M = 1.98, SD = 12.28) was higher.

This finding may reflect that younger age cohorts present with lower levels of morbidity, but higher outpatient use may also be influenced by higher levels of private medical cover and growing living in the community and reliance on community-based delivery of healthcare where outpatient use is growing. These trends will be investigated further and in more detail in future waves.

5.5: Wave 5 IDS-TILDA use of specialist health and other services

Table 5.3 reports on the use of specialist services across Waves 1 and 5 of IDS-TILDA. Binary variables (yes/no) were created to determine attendance in the previous 12 months. As can be seen, there was no change in level of GP use from Wave 1 to Wave 5 (92.1% vs 91.4%).

There were increases in the utilisation of optician services with an increase from 41.4% in Wave 1 to 57.2% at Wave 5; dental services (63.2% in Wave 1 to 69.2% in Wave 5); hearing services (11.6% in Wave 1 to 19.6% in Wave 5); speech and language services (20.9% at Wave 1 to 33.1% at Wave 5). Dietician services slightly increased from Wave 1 to Wave 5 from 26.5% to 28.7% respectively. Social work service use reduced from Wave 1 to Wave 5 from 23% to 10.3% respectively.

Table 5.3: Service use at Wave 1 and Wave 5

		Wave 1 (*n* = 753)		Wave 5 (*n* = 755)	
		n	%	n	%
In the last year have you received services from:					
General practitioner	Yes	692	92.1	639	91.4
	No	59	7.9	60	8.6
Public health nurse	Yes	80	10.7	112	15.7
	No	671	89.3	600	84.3
Occupational therapy	Yes	166	22.1	208	29.3
	No	585	77.9	502	70.7
Chiropody	Yes	469	62.5	525	74.3
	No	282	37.5	182	25.7
Physiotherapy	Yes	197	26.2	240	33.9
	No	554	73.8	467	66.1
Social work	Yes	173	23.0	73	10.3
	No	578	77.0	636	89.7
Psychology / counselling	Yes	151	20.1	140	19.7
	No	600	79.9	569	80.3
Home help	Yes	25	3.3	19	2.7
	No	726	96.7	694	97.3
Personal care attendant	Yes	91	12.1	-	-
	No	660	97.9	-	-
Meals-on-wheels	Yes	6	0.8	-	-
	No	745	99.2	-	-
Optician services	Yes	311	41.4	408	57.2
	No	440	58.6	305	42.8
Dental services	Yes	475	63.2	490	69.2
	No	276	36.8	218	30.8
Pharmacy services	Yes	-	-	237	33.8
	No	-	-	465	66.2
Hearing services	Yes	87	11.6	140	19.6
	No	664	88.4	573	80.4
Dietician services	Yes	199	26.5	204	28.7
	No	552	73.5	507	71.3
Speech and language services	Yes	157	20.9	235	33.1
	No	593	79.1	476	66.9
Day centre services	Yes	432	57.5	-	-
	No	319	42.5	-	-
Respite service	Yes	52	6.9	57	8.0
	No	699	93.1	654	92.0
Residential services	Yes	462	61.5	-	-
	No	289	38.5	-	-
Psychiatry services	Yes	293	39	-	-
	No	458	61.0	-	-
Neurological services	Yes	69	9.2	102	14.3
	No	682	90.8	610	85.7
Geriatrician services	Yes	19	2.5	-	-
	No	731	97.5	-	-
Endocrinology services	Yes	30	4.0	26	3.7
	No	721	96.0	686	96.3
Dermatological services	Yes	32	4.3	47	6.6
	No	719	95.7	666	93.4
Palliative care services	Yes	9	1.2	5	0.7
	No	742	98.8	708	99.3

5.6: Use of specialist health services – associations with people aged 40-49 and over 50 years

Differences in specialist health service utilisation were explored using two age categories (aged 40-49 and 50 and over) and odds ratios (OR) with 95% CIs across Wave 1 and Wave 5. Odds ratios are used to quantify the strength of association between age and healthcare utilisation. Odds ratios between 0 and 0.99 denote lower risk, odds ratios between 1 and infinity denote higher risk, and odds ratios of 1 denote no correlation between two variables.

At Wave 1, participants aged 40 - 49 years were less likely to use the general practitioner (OR = 0.57, 95% CI [0.33, 0.97]), chiropody services (OR = 0.57, 95% CI [0.42, 0.77]), optician services (OR = 0.55, 95% CI [0.40, 0.74]), residential services (OR = 0.74, 95% CI [0.54, 0.99]), and geriatrician services (OR = 0.19, 95% CI [0.04, 0.80]). At Wave 5 there was no difference observed with general practitioner use between age categories. However, at Wave 5, participants aged 40 - 49 years were less likely to use the public health nurse (OR = 0.53, 95% CI [0.30, 0.91]), occupational therapy (OR = 0.29, 95% CI [0.17, 0.46]), chiropody services (OR = 0.61, 95% CI [0.42, 0.90]), physiotherapy (OR = 0.41, 95% CI [0.27, 0.62]), dietician services (OR = 0.41, 95% CI [0.26, 0.64]), speech and language services (OR = 0.35, 95% CI [0.23, 0.54]) than those aged 50 and above, but more likely to use dental (OR = 1.51, 95% CI [1.01, 2.24]) and pharmacy services (OR = 1.76, 95% CI [1.23, 2.51]). Increasing age was associated with greater use of many therapy services which is similar to findings in the TILDA general population data (Roe et al., 2020).

5.7: Health screening

Influenza (flu) vaccine uptake in older adults with intellectual disability continued to be consistently high with 95.1% of participants receiving the vaccine, up from 93.5% in Wave 1 and higher than the general population at 49.9% of those over 50 years in Wave 1 of TILDA (Nolan et al., 2014) and 59% of adults aged over 60 between 2016 and 2019 (DeLooze et al., 2021).

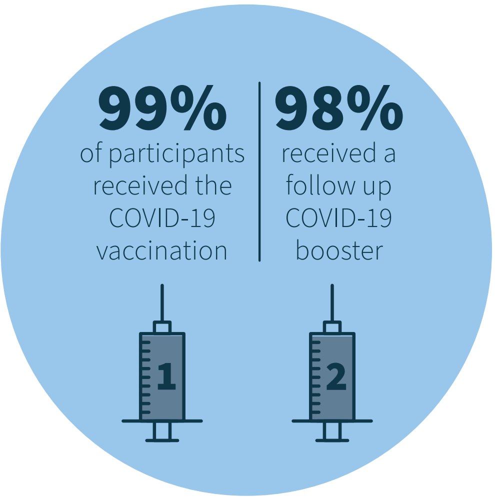
COVID-19 vaccination rates and booster rates at Wave 5 for people with intellectual disability were at 99.1% of participants and a further 98.1% received a follow up COVID-19 booster. There is data that suggests that high COVID-19 vaccination uptake was positively associated with low levels of mortality (Cuypers et al., 2020; Hatton et al., 2021).

In Ireland there are four national population screening programmes: three that screen for cancer, and one that screens for diabetic retinopathy.

Bowel screening is available to all adults aged 60 - 69 in Ireland using a Faecal Occult Blood Test. At Wave 5, out of 156 people who were eligible for screening in the previous two years (those aged 62 - 69), 68.1% (*n* = 96) had a bowel screen. Overall, this is significantly higher than previously reported in Wave 3 of TILDA (8%) for their at-risk population (Moore et al. 2017) and greater than other reports for the general adult population of 41.9% (Health Service Executive (NSS), 2019) and 46.6% (National Screening Service (NSS), personal communication, 2nd October 2023).

95%
of participants received the flu vaccine

Cervical screening is available for all people aged between 25 to 65 with a cervix. At Wave 5, of those aged 40 - 65 years of age, 272 participants were eligible to be screened. Thirty-seven percent (*n* = 88) reported that they were invited for a cervical screen, meaning 63% (*n* = 150) reported they were not. Of those invited, 30.6% attended (*n* = 26). In the general population 73% of those eligible were screened in the most recent reporting period (NSS, personal communication, 2nd October 2023).



Those with a mild intellectual disability were more likely to attend (54.2% of all attendees). Of those with an intellectual disability who did not attend, environmental, staffing levels, lack of transport, attendance timings or cost were not reported as a barrier to attendance; instead, fear was reported in over 25% of responses and 16.9% did not know why they did not attend. Narrative responses frequently highlighted that people with an intellectual disability were advised against being screened as they were not sexually active, or because the procedure was too invasive.

The Health Service Executive (2022) guidance states that if a person has never had sex or sexual contact, the risk of developing cervical cancer is very low and therefore cervical screening is discretionary, but there should be a discussion with a person's GP before opting out of cervical screening. Such informed decision-making cannot be assumed. There will be more work in future waves to understand barriers to and reasons for reduced cancer screening uptake in people with intellectual disabilities (Heslop et al., 2022).

Breast screening involves taking a mammogram (x-ray) of breasts and is undertaken between the ages of 50 - 69. At Wave 5, 71.1% (*n* = 165) people of eligible individuals were invited for a mammogram in the previous two years. Of these, 77.9% (*n* = 127) attended. This is a lower rate than in Wave 3 reports from TILDA where 86 - 88% of eligible participants had a mammogram in the previous two years (Moore et al., 2017); but higher than the national average of 62% (NSS, personal communication, 2nd October 2023). Here too, some (11.1%) cited environmental reasons while 27.8% reported being afraid. Cost and staffing were not reported as barriers restricting attendance.

At Wave 5, 65 participants (male *n* = 21, female *n* = 44) had a diabetes diagnosis. Diabetic retinopathy is a complication of diabetes caused by high blood glucose levels that damage the retina causing blindness if left untreated. At Wave 5, 55.4% (*n* = 36) of those eligible were invited for diabetic retinotopy screening with 94.4% of these attending (*n* = 34). If retinopathy has not been identified in the previous two screenings, the next screening invitation will be two years from the time of the last screen which may have reduced the number invited for screening at Wave 5.

5.8: Medications

Across IDS-TILDA Waves 1 - 5 participants were asked to record the medications that they take on a regular basis, every day or every week, including prescription and non-prescription medications, and vitamins and herbal supplements. Medications were coded according to the World Health Organisation (WHO) Anatomical Therapeutic Chemical (ATC) classification system: drugs for constipation, A06; analgesics, N02; antiepileptics, N03; psycholeptics, N05; psychoanaleptics, N06; calcium, A12A; folic acid, B03BB; glucosamine, M01AX05; iron, B03A; multivitamins, A11A and A11B; omega 3, C10AX06; vitamin B, A11D, A11E and B03BA; vitamin C, A11GA01; vitamin D, A11CC and M05BB; zinc, A12CB.

5.9: Prevalence of medication use

At Wave 1, 736 participants provided medication information. Of these participants, 91.7% (*n* = 675) reported regular medication use and fewer than 1% reported supplement only use. At Wave 5, 734 participants provided medication information, with 94.7% (*n* = 695) reporting use of at least one medication and less than 1% of participants reporting supplement use only.

5.9.1: Top five therapeutic classes

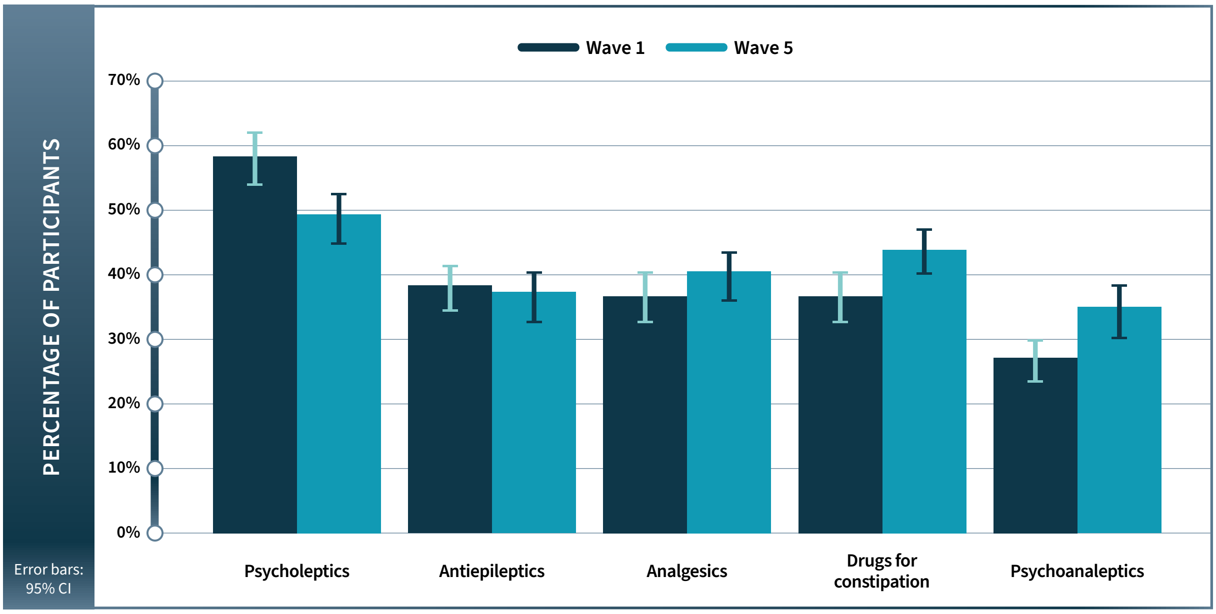
Psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives) were the most commonly prescribed therapeutic class at Wave 1, taken by 57.8% of participants, followed by antiepileptics (38.1%), analgesics (36.8%), drugs for constipation (36.7%), and psychoanaleptics (including antidepressants, psychostimulants and anti-dementia drugs, 27%).

At Wave 5, the top five reported therapeutic classes remained unchanged; however, the ranking of these classes did change slightly. While psycholeptics remained the most prescribed medication class at Wave 5, reported by 49% of participants, there was an increase in the number of participants reporting drugs for constipation (43.7%). Analgesics were reported by 40% of participants, antiepileptics by 37% and psychoanaleptics by 35%.

Figure 5.1 compares the top five therapeutic classes in Wave 1 and Wave 5. Patterns of prescribing are in sharp contrast to the general population data reported by TILDA with none of these classes appearing in the top 10 therapeutic classes.

The top classes reported by TILDA participants previously included lipid modifying agents, anti-thrombotic drugs, agents acting on the renin-angiotensin system, drugs for acid related disorders, beta blocking agents, and drugs for obstructive airways diseases (Peklar et al., 2017; Richardson et al., 2012).

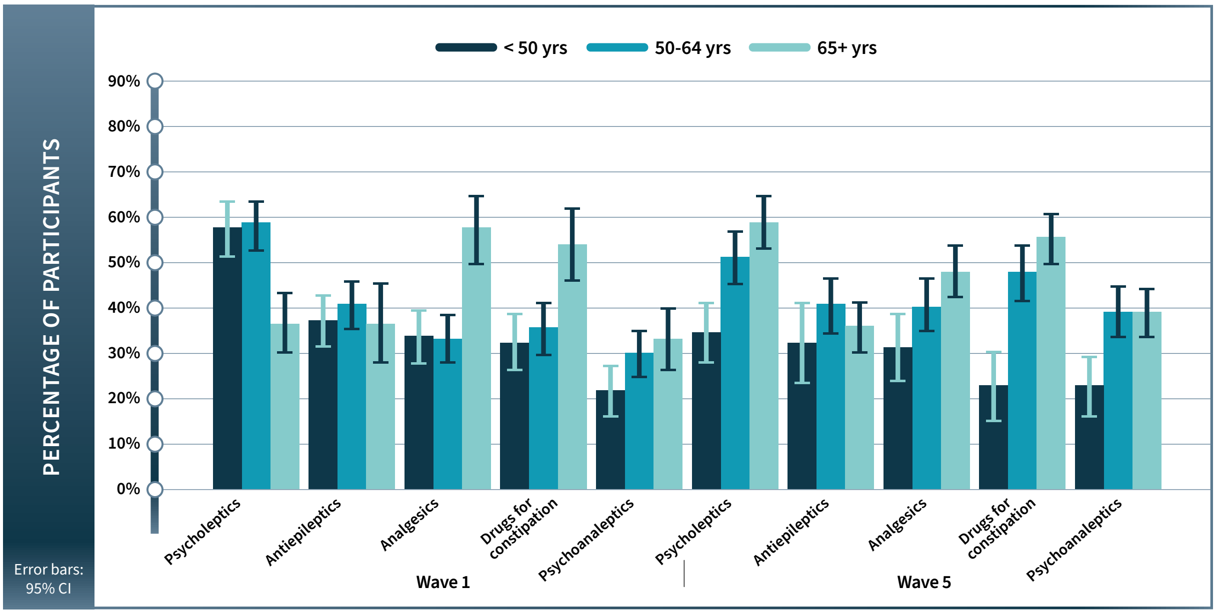
Figure 5.1: Comparison of top five therapeutic classes at Wave 1 and Wave 5



The prevalence of the top five therapeutic classes (psycholeptics, antiepileptics, drugs for constipation, analgesics and psychoanaleptics) by age are shown below. Here, there has been a decrease in participants reporting psycholeptic use across the age categories. The largest decrease at 20% was in those aged 40 - 49 years (56.3% to 33.9%) from Wave 1 to Wave 5. The percentage of participants reporting antiepileptic use has stayed relatively constant across the age categories. While the number of participants reporting drugs for constipation aged 65 and above was similar at both Waves, a decrease of nearly 10% was seen for participants aged under 50 years between Wave 1 (31.9%) and Wave 5 (22.4%).

Use of drugs for constipation increased in participants aged 50 - 64 between the two timepoints from 34.7% to 47.1%. The biggest change in reporting of analgesics was in participants aged 65 and above, which saw a decrease from 56.6% in Wave 1 to 47.2% in Wave 5. The number of participants under 50 years reporting psychoanaleptics was similar at Wave 1 and Wave 5. There was an increase in the number of participants aged between 50-64 years and those aged 65 and above reporting use of psychoanaleptics. Figure 5.2 shows the prevalence of the top five therapeutic classes by age at Wave 1 and Wave 5.

Figure 5.2: Prevalence of top five therapeutic classes by age at Wave 1 and Wave 5



5.10: Supplement usage

Table 5.4 reports and compares supplement use at Wave 5 to Wave 1 and to recent TILDA data for those over 50 years (Ward et al., 2021). At both Wave 1 and Wave 5, the most common supplement reported by participants was calcium, with increased use between Waves (17.8% and 36.5% respectively).

Vitamin D was the second most common supplement at Wave 5; at 25.2%, a substantial increase when compared to only 2.9% of participants in Wave 1.

Table 5.4: Comparison of supplement usage at Wave 5 versus Wave 1 and TILDA

Supplement	Wave 5		Wave 1		TILDA (Ward et al., 2021)	
	%	Rank	%	Rank	%	Rank
Calcium	36.5	1	17.8	1	-	-
Vitamin D	25.2	2	2.9	5	14.0	1
Iron	8.8	3	9.7	2	2.0	5
Folic acid	7.9	4	4.9	3	1.0	6
Multivitamins	7.0	5	3.6	4	8.0	3
Omega 3	3.0	6	1.7	6	-	-
Vitamin C	1.8	7	0.9	8	11.0	2
Vitamin B	1.8	7	1.5	7	-	-
Glucosamine	0.4	9	0.8	9	-	-
Zinc	0.1	10	0.0	-	4.0	4

While at Wave 1, vitamin D use was predominantly reported by female participants (72.7%), 49% of vitamin D users were male at Wave 5 (as shown in Figure 5.3). A similar trend in calcium usage by sex was seen between Wave 1 and Wave 5; male participant use increased from 25.4% to 39.2%. At Wave 1, 62.7% participants reporting calcium use lived in residential care, and this decreased to 39.6% at Wave 5. By Wave 5, there were higher levels of vitamin D, iron and folic acid use in IDS-TILDA as compared to TILDA reports for those over 50 years but higher rates in TILDA of vitamin C, multivitamins and zinc in TILDA.

Vitamin D use
increased from

3%
in Wave 1

25%
in Wave 5

to

Figure 5.3: Prevalence of vitamin D by sex at Wave 1 and Wave 5

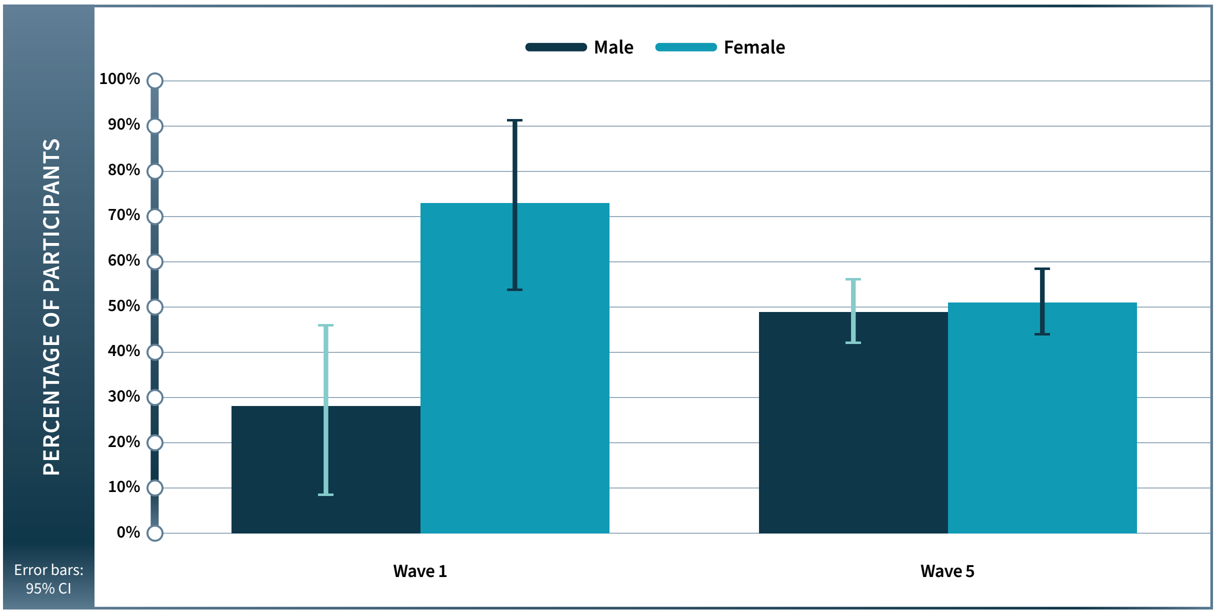


Table 5.5: Demographics of participants reporting calcium at Wave 1 and Wave 5

	Wave 1		Wave 5	
	n	%	n	%
Sex				
Male	34	25.4	109	39.2
Female	100	74.6	169	60.8
Age category				
<50	31	23.1	34	12.2
50-64	68	50.7	137	49.3
65+	35	26.1	107	38.5
Residence				
Independent / family	9	6.7	27	9.7
Community group home	41	30.6	141	50.7
Residential	84	62.7	110	39.6
Level of ID				
Mild	24	18.9	53	20.9
Moderate	66	52.0	114	45.1
Severe/profound	37	29.1	86	34.0

5.11: Conclusion

This chapter has reported on the levels of healthcare utilisation in Wave 5. People with intellectual disability as they age had a reported higher mean average attendance at the GP and emergency department than the general population. In a noticeable difference from previous waves there was an increase in private medical cover for older people with intellectual disability, which also occurred in this period in the general population.

In terms of preventive health there were high-levels of vaccination reported at Wave 5 (flu and COVID-19); however, for health screenings there was a lower uptake of breast screening in comparison to TILDA, but higher than the national average, while cervical screening was much lower than the national average with fear and beliefs that such screening was not needed being cited as prominent issues preventing attendance. Women's health is an under-researched area in this population and poor uptake in screening that result in negative health outcomes and additional risks deserves additional research.

Overall, medication use patterns continued to differ substantially from those observed in the older population in TILDA. While the top five therapeutic classes reported at Wave 5 remained consistent with findings in Wave 1, there were changes in the rank order and in prevalence of use.

Increases in constipation medicines use particularly stand out. Increased supplement use was observed at Wave 5, with greater proportion of participants in IDS-TILDA reporting calcium and vitamin D use than TILDA participants. There was a decrease in psycholeptics (including antipsychotics, anxiolytics, hypnotics and sedatives) use in those aged 40 - 49 years from Wave 1 to Wave 5.

Findings of emerging differences in patterns of where healthcare is received, particularly among those 40 - 49 years, and the reasons for those differences need additional attention to determine if this represents a movement more towards community-based and outpatient care or a trend towards less care.

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CHAPTER 6

Oral Health

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HEALTHY
HAPPY
AGEING

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

6.1: Key findings

- When asked, one in every five participants had no teeth at all. This increased to two in five for those aged 65 and over. This is still much higher than for older adults in the general population, where only one in eight were found to be edentulous in Wave 6 of the TILDA study. Nevertheless, this is a significant reduction from the one in three with total tooth loss in IDS-TILDA Wave 1.
- Seven out of ten (72.1%, *n* = 106) IDS-TILDA participants who were edentulous reported that they did not have dentures. This compares to just one in twenty (5.2%, *n* = 30) edentulous participants in TILDA.
- From clinical measurements, over 70% of IDS-TILDA participants who participated in the oral health assessment (*n* = 469) did not possess a functional dentition; rising to over 95% among those with severe to profound intellectual disability.
- Oral disease was common: Almost half of dentate participants (*n* = 144) were found to have at least one cavitated tooth and almost two thirds (*n* = 219) had unhealthy gums. Only 27.3% (*n* = 118) of participants had a clean mouth and almost 8% (*n* = 35) reported recent oral pain.
- Dental anxiety was common: Over 41% of participants (*n* = 175) reported high/severe dental anxiety which is many times more than that reported for the general population.
- Oral Health services: Within the last two years, (84.2%; *n* = 602) reported attending a dentist or dental hygienist. This indicates that poor oral outcomes occur, despite access to dental services. Most visits deliver assessment only.
- Regular tooth brushing was very common (89.8%; *n* = 680). This indicates that poor oral outcomes arise despite oral home care, indicating that this care is ineffective.

6.2: Introduction

All people have a right to a healthy mouth, as part of their right to health and access to healthcare (United Nations, 2006). A healthy mouth allows us to speak, smile, smell, taste, touch, chew, swallow and express a range of emotions with facial expressions with confidence and without pain, discomfort, and disease. Oral health is also an essential component of general health and mental wellbeing (Glick et al., 2016).

IDS-TILDA has previously reported that people with an intellectual disability are consistently found to have poorer outcomes from oral disease than the general population (Mac Giolla Phadraig et al., 2015). IDS-TILDA offers a unique opportunity to include people with intellectual disabilities who are routinely excluded from national surveys of oral health in Ireland and further afield. This exclusion has left a blind spot in service planning. Reasons for this systematic exclusion from research include issues around training, cost, consent, perceptions around difficulty in data collection and a lack of appropriate data collection tools. Wave 5 of IDS-TILDA addressed this systematic exclusion by inviting all participants to undergo a simple assessment of oral health status. This health evaluation survey was co-constructed with people with intellectually disabilities for use in IDS-TILDA (Mac Giolla Phadraig et al., 2021).

For Wave 5 of IDS-TILDA, *n* = 469 participants underwent an oral assessment as part of their data collection. Research nurses were specifically trained and supported by a specialist dentist and specifically trained PhD student as gold standard, to objectively measure oral health status of participants for the first time. Oral status covers both oral function and indicators and experience of oral disease.

Oral function is objectively measured by tooth count, assessment of the aesthetically important front twelve teeth, pairs of biting premolars and the presence of occlusal posterior contacts (biting back teeth). Indicators of oral disease included counts of cavitated teeth, oral cleanliness and assessment of gum health. Oral pain was assessed by self-report or changes in behaviour. Details of oral health behaviours and oral healthcare service use are also reported to facilitate planning of preventive and restorative oral healthcare services. All Wave 5 participants (*n* = 762) were asked questions about oral health behaviours, for example who brushed teeth, how often and how. Oral health service included frequency of dental visits, type of treatment received, type of dental provider and barriers to care.

Throughout the chapter, comparisons are made with Wave 6 TILDA data, representative of the corresponding community-dwelling older adult population in Ireland without intellectual disabilities but who were aged 50 years and over. This comparison is vital to understanding the IDS-TILDA results as it offers a comparison between those with and without intellectual disability in Ireland. It should be noted that comparisons between the IDS-TILDA sample, where participants are aged over 40, and the TILDA sample, where participants are aged over 50, may make the differences more pronounced. Moreover, small differences in the distributions of other demographic characteristics, as well as differences in sampling and data collection methods, mean that comparisons must be considered in the context of these methodological differences.

6.3: Oral health status

6.3.1: Self-reported oral health and status

When asked to rate their oral health, 38.1% (*n* = 298) of Wave 5 participants reported that their oral health was very good or excellent. This is slightly less than the self-report oral health status reported in TILDA Wave 6 (*n* = 4,330), where 40.6% (*n* = 1,757) reported a very good or excellent status.

6.3.1.1: Total tooth loss (edentulism)

There are stark differences in edentulism rates when comparing participants in IDS-TILDA and TILDA. When asked to describe their dentition as either having teeth, or having no teeth[2], 19.3% (*n* = 147) of IDS-TILDA participants reported that they had no teeth at all. This compared to 13.2% (*n* = 572) in TILDA. A reduction in total tooth loss (edentulism) is observed across waves (see Figure 6.1), particularly in older adults. This reduction in edentulism over time reflects a global decline in edentulism rates.

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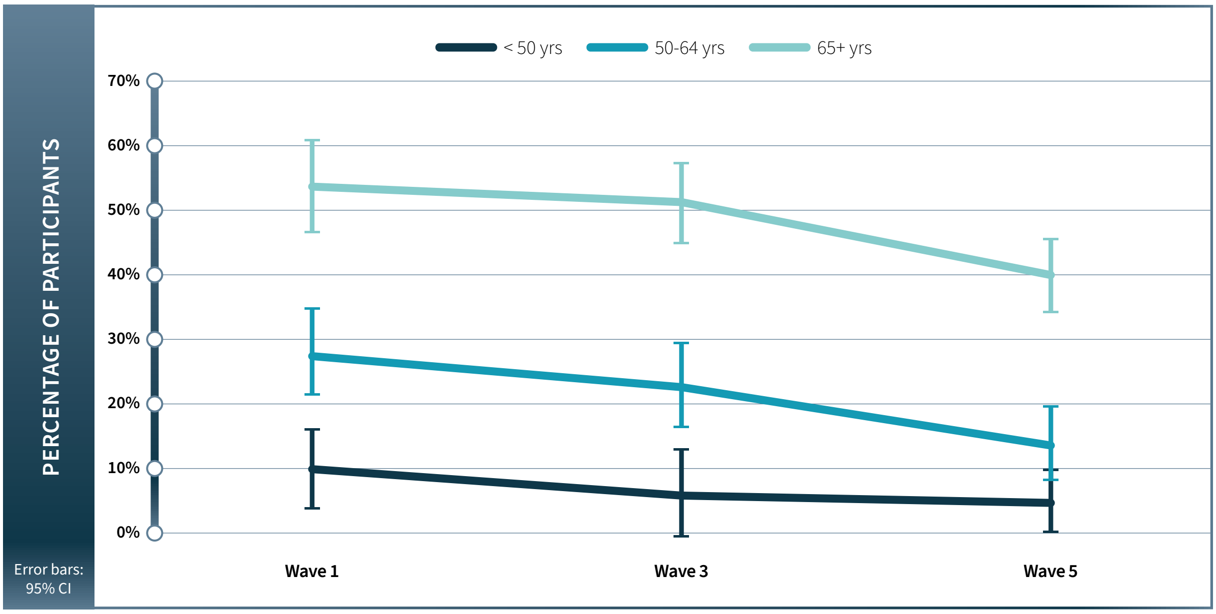
[2] “Edentulous” was calculated by combining “I have full dentures” and “no teeth or dentures”, whereas “Dentate” included the following answers: “I have all my own natural teeth; “own teeth but some missing”; “dentures and some of their own teeth”; This correlated well with the 19.3% (n = 79) who had no teeth when counted through direct observation.

Figure 6.1: Proportion of participants reporting no teeth by age at Wave 1, Wave 3 and Wave 5

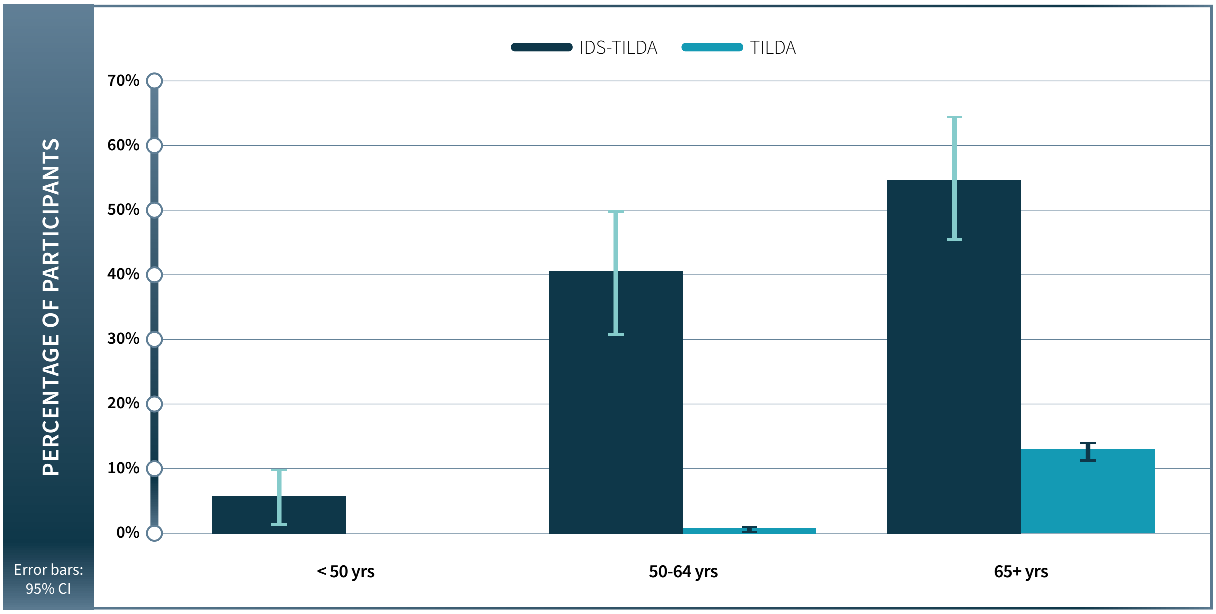


6.3.1.2: Untreated total tooth loss (unrestored edentulism)

Typically, total tooth loss is followed by rehabilitation with false teeth (dentures) to restore function and aesthetics. However, this is not the case for IDS-TILDA participants. Considering the subgroup who reported no teeth at all 19.3% (*n* = 147), 72.1% (*n* = 106) reported not having dentures either. This is not seen in the general population where only 5.2% (*n* = 30) of edentulous respondents 13.2% (*n* = 572) reported lack of functional functional replacement of complete tooth loss (Source: TILDA Wave 6 Self-Report Data).

For further breakdown of edentulism across age groups and across study, see Figure 6.2. The lack of functional rehabilitation continues an increasing trend for unrestored oral disability among IDS-TILDA participants, with an increase of 4.3% since Wave 3.

Figure 6.2: Comparison of unrestored edentulism by age between IDS-TILDA Wave 5 and TILDA Wave 6

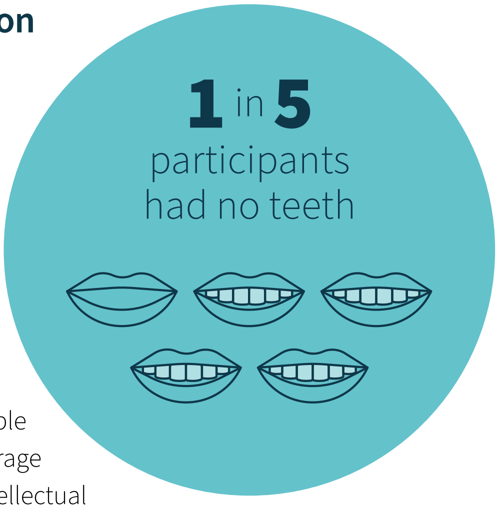


6.3.2: Objectively observed indicators of oral function

Data in this section relate to the subsample (*n* = 469) of IDS-TILDA participants who took part in the oral health aspect of the Health Fair in this study.

6.3.2.1: Average number of teeth (*n* = 409)

IDS-TILDA Health fair participants, who had their teeth counted (*n* = 409), had an average of 16.6 teeth (M = 16.6, SD = 13.8) compared to an average of (M = 20.4 teeth (SD = 7.8) in the general population of older adults in Ireland (Wave 6 of TILDA *n* = 1,090). This means that on average, older people in Ireland have four fewer teeth if they have intellectual disability. This average conceals a wide variation in the actual number of teeth for people with intellectual disabilities, probably due to the high number reporting no teeth at all.



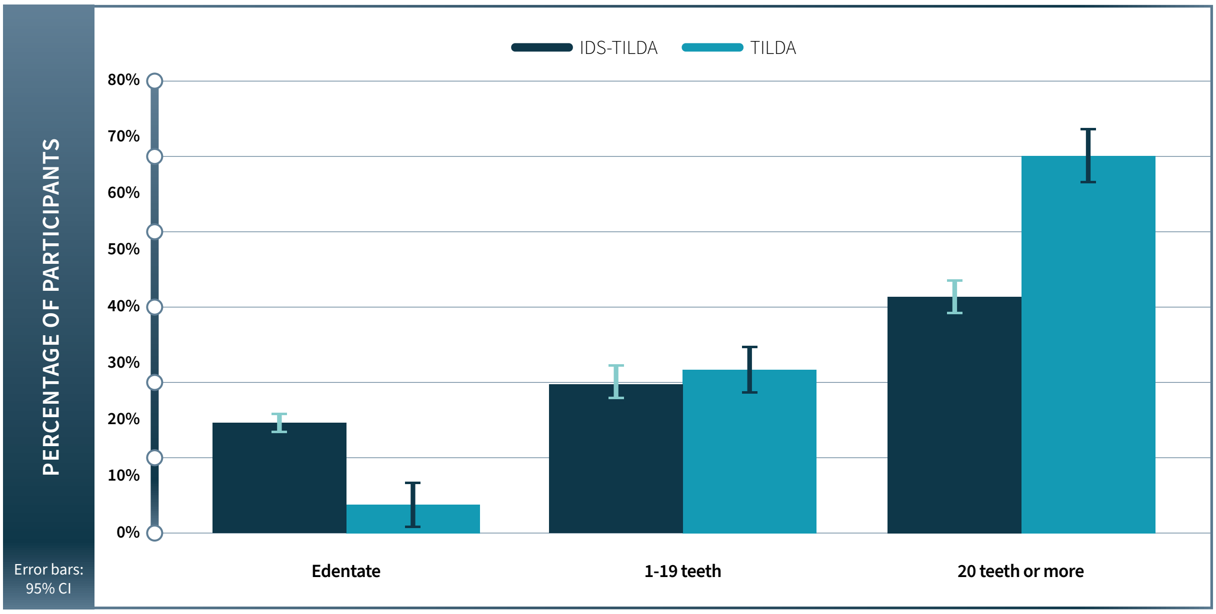
1 in **5**
participants
had no teeth

The mean number of teeth was lowest for those over the age of 65 (M = 10 teeth, SD = 13), for those who had a severe to profound intellectual disability with (M = 14, SD = 23), and for those who live in residential care facilities (M = 15, SD = 19).

6.3.2.2: Tooth count (*n* = 409)

A useful way of understanding the total number of teeth that people have is to categorise according to those with no teeth (0), some teeth (1-19) and a lot of teeth (20 or more). Among IDS-TILDA Health Fair participants who had their teeth counted (*n* = 409), 19.3% (*n* = 79) were found to have no teeth, 26.8% (*n* = 137) had between 1-19 teeth, and 41.1% (*n* = 193) had 20 or more teeth. This compares poorly to Wave 6 of TILDA (*n* = 1,090) (see Figure 6.3), where 5.1% (*n* = 56) had no teeth, 28.9% (*n* = 315) had between 1-19 teeth and 65.9% (*n* = 719) had 20 teeth or more. This means that on average, older people in Ireland are far more likely to have no teeth and less likely to have a lot of teeth if they have intellectual disabilities.

Figure 6.3: Number of teeth: comparison between IDS-TILDA Wave 5 and TILDA Wave 6



6.3.2.3: Denture wear (*n* = 465)

Full denture wear (upper and lower) was observed for 3.6% (*n* = 17) of IDS-TILDA participants in comparison to 4.9% in TILDA Wave 6 participants. This means that only 21.5% (*n* = 17) of people objectively measured to have no teeth in IDS-TILDA had full denture (upper and lower) replacement, compared to 96.6% (*n* = 54) of edentulous TILDA Wave 6 participants. Partial denture wear (including any other combination of denture wear) was observed in 10.9% (*n* = 51) of IDS-TILDA participants compared to 28.3% of TILDA Wave 6 participants. The above highlights a massive discrepancy for functional replacement of lost teeth for people with intellectual disabilities as compared to the general older population.

6.3.2.4: Functional dentition (*n* = 409)

A functional dentition is important for one's comfort, nutrition, aesthetics and wellbeing. While there is debate about how to quantify function, a dentition may be considered functional if three conditions are met : Firstly, there are at least twenty teeth; secondly, the front twelve teeth are present, and thirdly that there are at least three pairs of premolars meeting to allow for a stable and efficient bite (Nguyen, Witter, Bronkhorst, Gerritsen, & Creugers, 2011). Based on these three conditions, only 29.5% (*n* = 120) of Health fair participants were found to have a functional dentition. Of those with severe to profound intellectual disability, it was especially low at 4.7% (*n* = 3) see Figure 6.4.

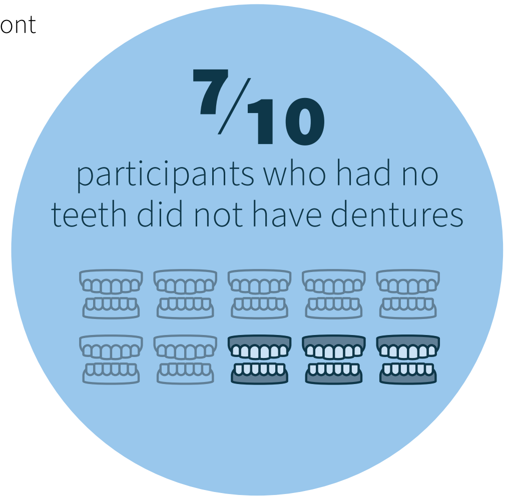
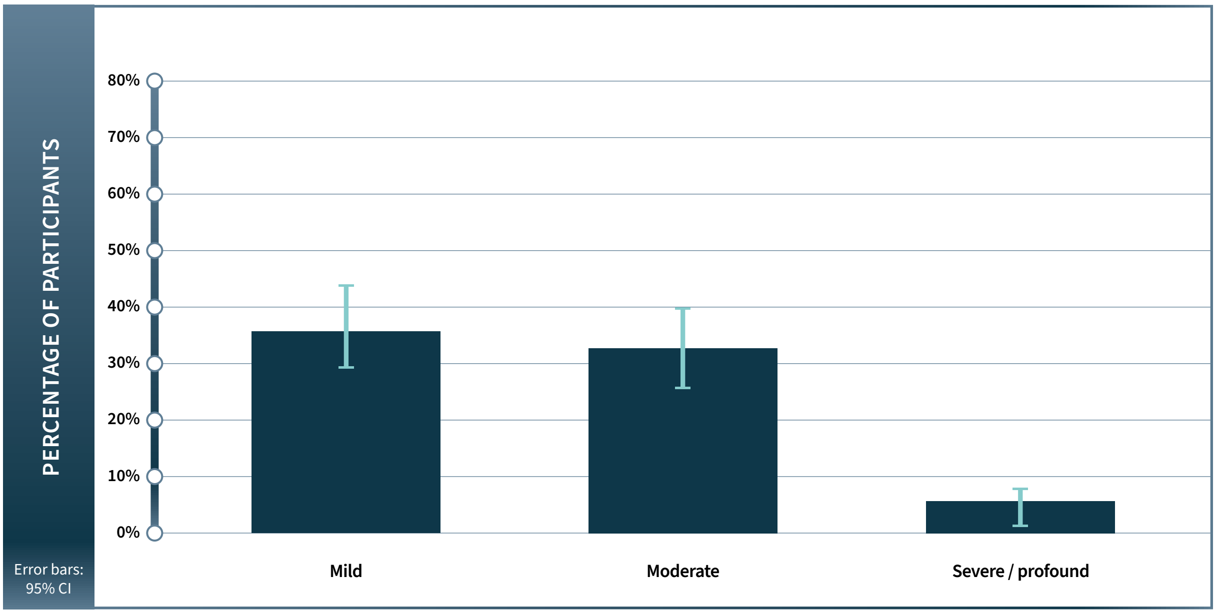


Figure 6.4: Functional dentition stratified by level of intellectual disability



6.3.2.5: Factors influenced by functional dentition

Having good oral function is important for being able to enjoy food and multiple types of food. When participants were asked if they experienced issues with chewing food (*n* = 234) 33.2% reported issues chewing food and 85.8% (*n* = 654) reported they enjoy their meals. Of those with no teeth, 57.7% (*n* = 45) reported difficulty with chewing food.

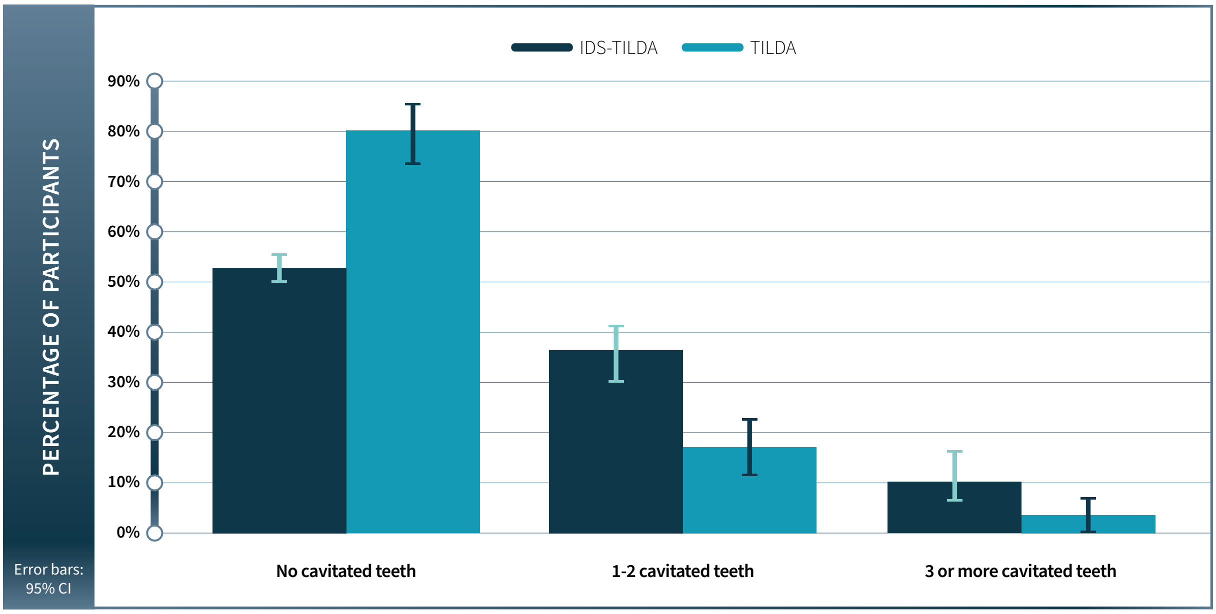
6.3.3: Indicators of oral disease

6.3.3.1: Dental cavities (*n* = 306)

Almost half of dentate participants were found to have at least one cavitated tooth: 36.1% (*n* = 112) had one or two cavitated teeth; 10.3% (*n* = 32) had three or more cavitated teeth. A comparison with TILDA shows that participants from IDS-TILDA have more cavitated teeth than TILDA participants (Figure 6.5).

In the TILDA Wave 6 Oral Health Assessment (*n* = 1090), 17% of participants had 1-2 cavities, and 3.4% had three or more cavities. IDS-TILDA participants who live in a residential care had higher prevalence of cavities, with 55.4% (*n* = 30) having at least one cavitated tooth.

Figure 6.5: Cavitated teeth comparison between IDS-TILDA Wave 5 and TILDA Wave 6



6.3.3.2: Oral pain (*n* = 460)

When asked was oral pain communicated or displayed behaviourally in the last week, 7.8% (*n* = 54) of participants reported pain.

6.3.3.3: Oral cleanliness (*n* = 433)

Only 27.3% (*n* = 118) of participants in Wave 5 were observed to have a clean mouth . Having an unclean mouth was associated with gum condition, with 72.1% (*n* = 204) of participants with an unclean mouth found to have unhealthy gums. No comparison between TILDA and IDS-TILDA was possible regarding oral cleanliness.

6.3.3.4: Gum health (*n* = 352)

Of IDS-TILDA participants who had at least one tooth (*n* = 352), 62.2% (*n* = 219) had unhealthy gums. This was most prevalent in those with severe to profound intellectual disabilities, where 83% (*n* = 44) did not have healthy gums. Differences in data collection methods did not allow for comparison with TILDA data.

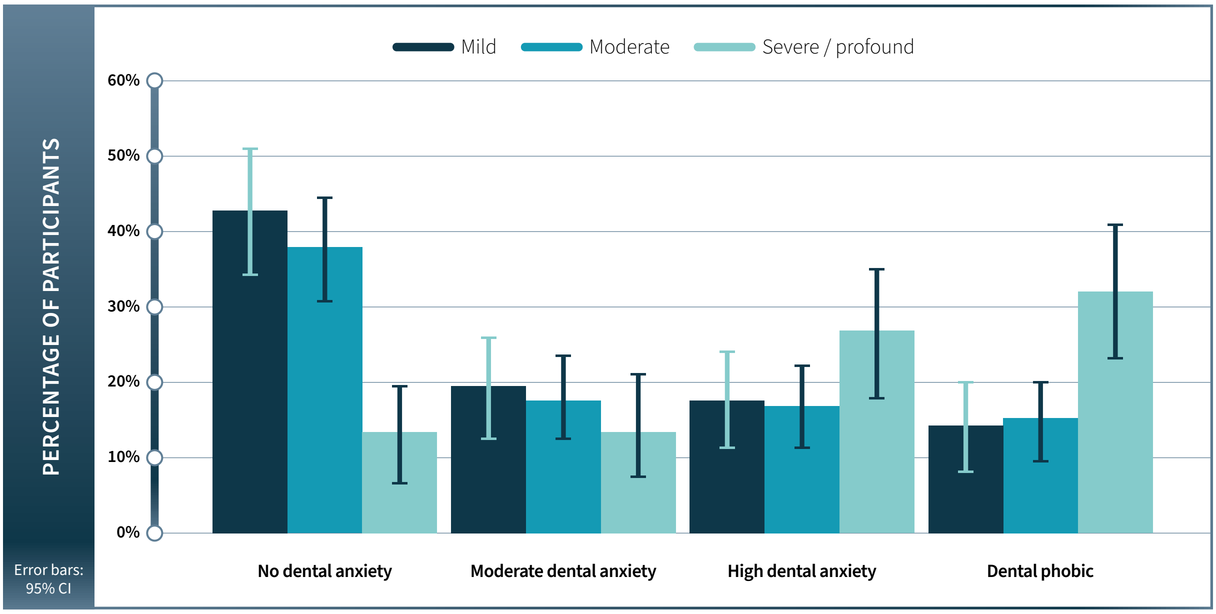
6.4: Dental anxiety

Dental anxiety can act as a barrier to accessing essential mouthcare, makes the experience of mouthcare much worse, and is associated with negative oral health and psychosocial outcomes. In this section, we report the use of the Modified Dental Anxiety Scale (MDAS) to rate dental anxiety from low anxiety to severely anxious/dentally phobic (Humphris, Morrison, & Lindsay, 1995).

6.4.1: Modified Dental Anxiety Scale Scores

Of those who completed the MDAS (*n* = 419), four out of ten had high dental anxiety or phobia: 20.3% (*n* = 85) were classified as severely dentally anxious or phobic, and 21.5% (*n* = 90) scored high dental anxiety. Together, this represents four out of ten as highly dentally anxious or phobic. This is about three times higher than that published for the general population (Silveira, Cademartori, Schuch, Armfield, & Demarco, 2021). Similar to the general population, females were more likely to be categorised as severely dentally anxious/dentally phobic than men. Those with a severe to profound intellectual disability had the highest prevalence of severe dental anxiety/dental phobia at 32.1% (*n* = 34). Figure 6.6 shows dental anxiety levels stratified by level of intellectual disability.

Figure 6.6: Dental anxiety stratified by level of intellectual disability



6.5: Oral health behaviours

Oral diseases are preventable (Peres et al., 2019) by adopting simple healthy behaviours like effective tooth brushing, eating a healthy diet, avoiding smoking and regular visits to oral healthcare services.

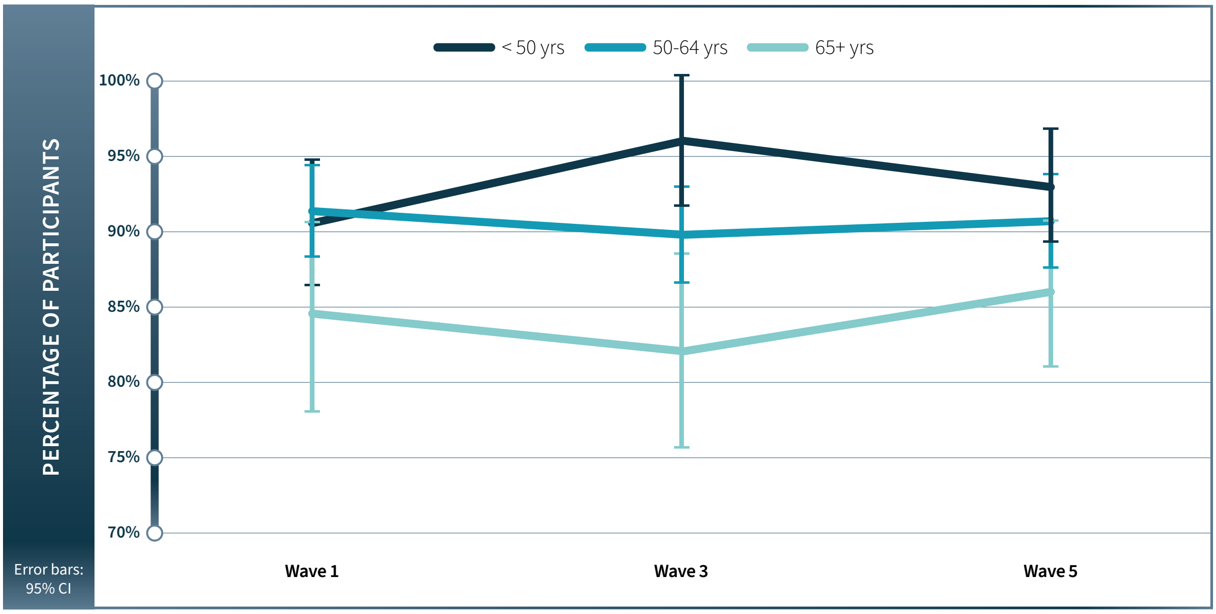
In this section, we use CAPI data to explore homecare behaviours like tooth brushing and oral healthcare service use behaviours like dental attendance, that together influence oral diseases and their outcomes.

6.5.1: Frequency of tooth brushing

Given the high prevalence of oral disease seen among people with intellectual disability, data are needed to understand behaviours like tooth brushing habits, that ought to prevent oral disease.

In Wave 5, 89.8% (*n* = 680) of participants brushed their teeth or cleaned their dentures once or more a day, whereas 10.2% (*n* = 77) reported brushing less frequently than once daily. Frequent brushing was less likely in older participants across waves (Figure 6.7).

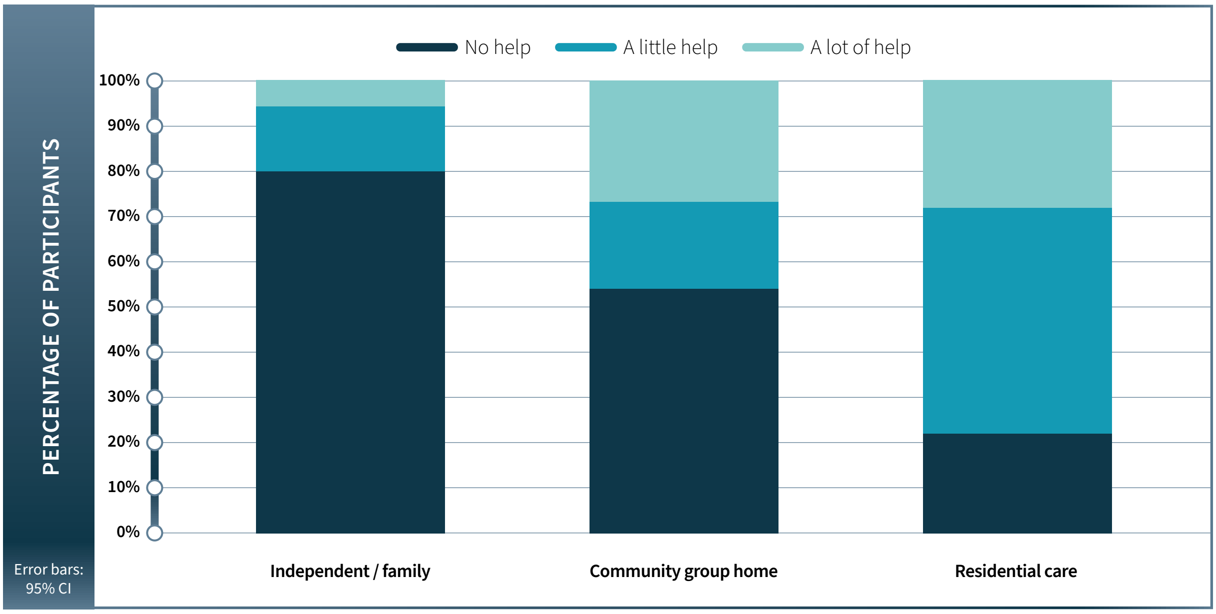
Figure 6.7: Reported tooth brushing at least daily, stratified by age at Wave 1, Wave 3 and Wave 5



6.5.2: Support for tooth brushing

Physical assistance to clean their teeth was reported by 42.1% (*n* = 321) of participants who reported tooth brushing. This corresponds with the level of intellectual disability: almost 60% (*n* = 103) of participants with severe or profound intellectual disabilities reported a lot of help with tooth brushing, whereas only 5.9% (*n* = 12) of those with mild intellectual disability. The level of physical support varied across type of residence: 86.5% (*n* = 135) of those living independently or with family reported cleaning their teeth without help, while a total of 77.1% (*n* = 152) of those living in residential care reported a little and a lot of physical support to brush their teeth (Figure 6.8). It is important to note that the proportion receiving support does not necessarily represent the proportion actually requiring support in mouthcare, which is likely to be much higher.

Figure 6.8: Level of physical assistance reported for tooth brushing



6.5.3: Type of toothbrush, flossing and mouthcare plans

The most common type of toothbrush used by Wave 5 participants was the regular toothbrush, as reported by 63.9% (*n* = 487) of respondents, followed by 17.7% (*n* = 135) reporting use of electric brushes; 6.3% (*n* = 48) using no toothbrushes; 6.0% (*n* = 46) reporting modified brushes like Super brushes, and 4.5% (*n* = 34) reporting other cleaning aides such as foam gauzes and mouth washes.

This is despite evidence that multi-headed toothbrushes, like the Super brush, are preferred for people with complex disabilities (Kalf-Scholte, Van der Weijden, Bakker, & Slot, 2018; Waldron et al., 2019). The proportion reporting different types of toothbrushes is stable across waves. Only 8.4% (*n* = 63) of participants reported using floss or interdental cleaners regularly, similar to previous waves.

6.5.3.1: Mouthcare plans

Mouthcare plans are written plans to clarify how a person can be supported to maintain oral health. More than half (61.2%, *n* = 428) reported that they have a mouthcare plan, essential tools for oral health needs assessment, goal setting, action planning and outcome assessment for people who receive help for oral hygiene.

Notably, there was no significant difference in oral cleanliness, cavitation, or gum health when comparing across type of toothbrush, type of physical support brushing or whether participants had mouthcare plans or not. This highlights how difficult it is to make a meaningful difference to oral health using current methods.

6.6: Oral health service use

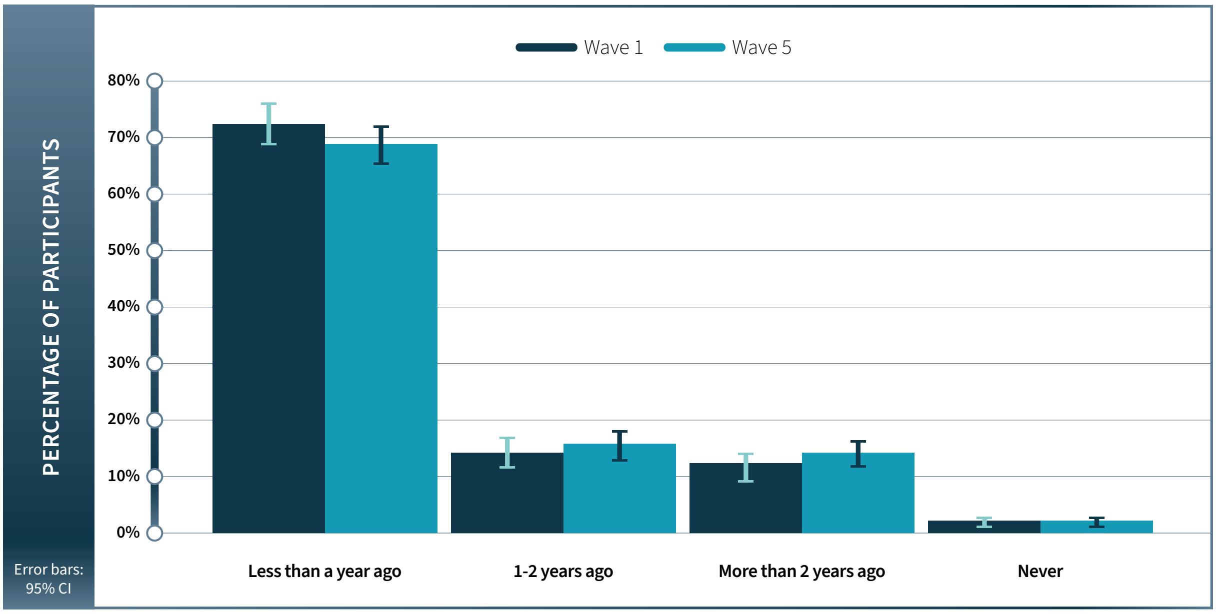
Regular dental visits are essential to maintain oral health, prevent disease, pain and infection, and identify and manage problems early. Data on oral healthcare service use is essential to understand how people with intellectual disabilities use services and how policy can be planned to improve the design of dental services to meet the needs of people with intellectual disability as they age in Ireland.

6.6.1: Last dental visit

In Wave 5, 68.8% (*n* = 492) of participants reported attending a dentist or dental hygienist within the last 12 months, and 84.2% (*n* = 602) during the last two years. This was similar throughout waves. A comparison between Wave 1 and Wave 5 is illustrated in Figure 6.9.

When stratified by age, the highest proportion of recent dental visits was in the younger age cohort of under 50 years old (89.6%, *n* = 155), 86.6% (*n* = 298) among 50 to 64 years, and a drop to 75.3% (*n* = 149) for those aged 65 years and above.

Figure 6.9: Last dental visit at Wave 1 and Wave 5



6.6.2: Regular dental visits

Regular dental attendance is recommended as an essential behaviour to support oral health. Considering regular dental attendance as attendance within the last two years and irregular attendance as less often than this, 84.2% (*n* = 602) of participants can be classified as regular dental attendees. This is in stark contrast to the general population, where 56.4% (*n* = 2,435) of Wave 6 TILDA participants reported attending more frequently than every two years, and 43.6% (*n* = 1,885) less frequently than every two years (Figure 6.10).

Figure 6.11 shows that 87.6% (*n* = 304) of those living in community group homes reported regular dental service use, compared to 83.3% (*n* = 170) of those living in residential care and 78.0% (*n* = 128) living independently or with family.

Regular dental attendance was very common at

84%

Figure 6.10: Comparison of regular dental service attendance and irregular dental service attendance between Wave 5 IDS-TILDA and Wave 6 TILDA

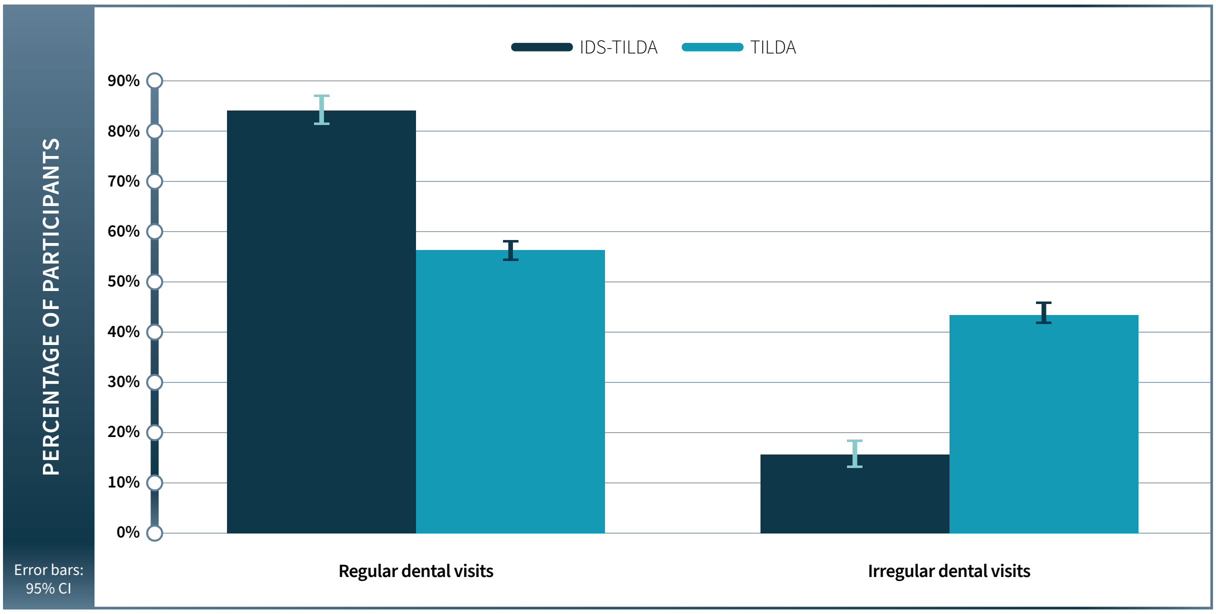
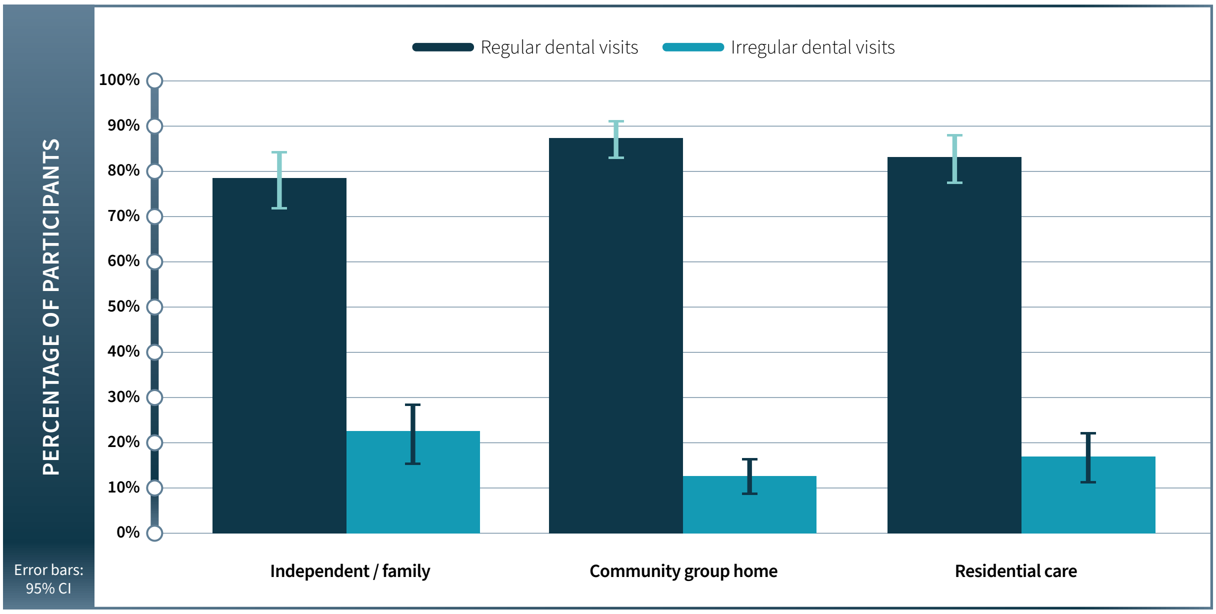


Figure 6.11: Comparison of regular dental service attendance and irregular dental service attendance by type of residence



6.6.3: Type of dental treatment

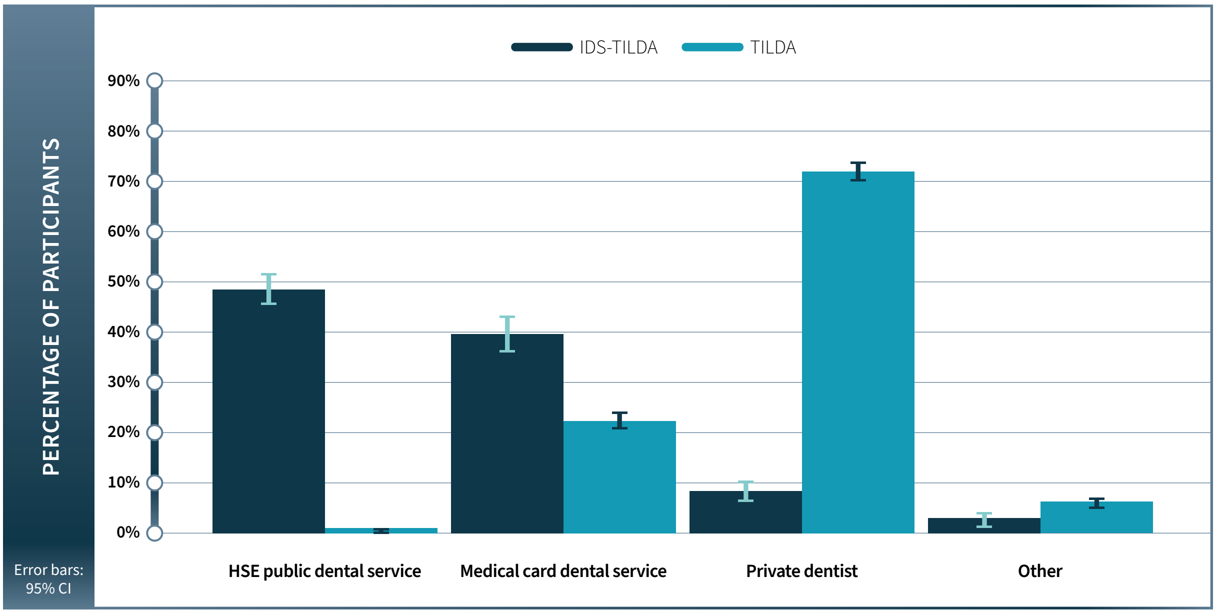
Participants were asked about their dental treatment in Wave 3, 4 and 5. The majority of participants (76.0% *n* = 579) received dental check-ups during their dental visits in Wave 5. Apart from check-ups, the most commonly reported dental treatment was scaling and polishing (29.5% *n* = 225).

This is surprisingly low, given that check-ups are routinely paired with scale and polish for most people receiving dental check-ups. This is followed by extraction, with 6.4% (*n* = 49), followed by 4.7% (*n* = 36) reporting dental fillings, 5.5% (*n* = 42) reporting other treatments (mainly denture work); with the least often reported treatment coming as preventive dental care, such as advice brushing, applying varnish, fissure sealants, with only 2.7% (*n* = 21) reporting this.

6.6.4: Preferred dental service provider

Dental services in Ireland are broadly delivered according to three major schemes: Private care, where patients pay out of pocket in general practice (with or without PRSI contributions); Medical card, a means tested public funding scheme delivered in general practice providing limited free care to specific targeted populations; and Public Dental Services, a targeted service provided by salaried public dentists through the Health Service Executive (HSE), which focuses primarily on children and other target groups. Almost half (47.9%, *n* = 348) of the participants in Wave 5 reported that they attend a HSE dental professional for their dental visits; 39.4% (*n* = 300) reported they attend a medical card dental provider, and only a small percentage (8.3%, *n* = 60) reported that they visit a private general dentist or dental hygienist. This can be compared to TILDA Wave 6 (*n* = 4,330) where only 0.7% (*n* = 29) reported that they attend an HSE dental professional; 22.0% (*n* = 951) reported they attend a general dental practice medical-card provider; and the majority, 71.4% (*n* = 3,093), reported that they attended a general dental practice as a private patient (Figure 6.12).

Figure 6.12: Comparison of dental service use between IDS-TILDA Wave 5 and TILDA Wave 6



6.6.5: Barriers accessing dental services

In Wave 5, 14.6% (*n* = 100) reported that they found it hard to access the dentist within the last year. This was most often seen among those with severe or profound intellectual disabilities (36.7%; *n* = 33), and those living in community group homes (44.0%; *n* = 44). Of note, 49.5% (*n* = 49) of those who found it hard to access to the dentist reported using a general dentist or dental hygienist on the medical card scheme. When asked if accessing dental care was recently becoming harder, 14.8% (*n* = 98) responded that it was: of these, 46.4% (*n* = 45) used medical card scheme, 34.0% (*n* = 33) used HSE and 12.4% (*n* = 12) used private dental services.

When asked to describe the problems they face accessing care, a range of responses were given, including issues with long waiting lists, previous dentist no longer willing to see them and their dentists no longer accepting medical cards. Together, an impression of participants unable to find a dentist or waiting on a dentist emerged:

> ***On waiting list for a long time for appointment.***
> ***No access to dentist, previous dentist in HSE not available anymore. Staff would like to highlight this as an area of importance for participant as it is an area they find difficult to participate in.***
> ***Many local dentists no longer accept medical card patients.***

6.7: Conclusion

Oral health is very poor for people with intellectual disabilities in Ireland. Older people with intellectual disabilities are still more likely to have no teeth at all than the general public, though the difference between IDS-TILDA and TILDA has reduced over ten years. However, when people with intellectual disabilities lose their teeth, they tend to be left orally disabled, while people without intellectual disabilities tend to receive rehabilitation.

On average, older people in Ireland have four fewer teeth in their mouths if they have an intellectual disability. When teeth are present, oral disease is common: Almost half of dentate participants were found to have at least one cavitated tooth; less than three in ten had a clean mouth and less than four in ten had healthy gums; One in twelve reported oral pain in the last week.

This report illustrates stark health inequalities and portrays an uneven distribution of disease burden. For this reason, oral function eludes many people with intellectual disabilities in Ireland, particularly older and more severely disabled people. The proportion without a minimum functional dentition was unexpectedly high. Many lacked sufficient front teeth for aesthetic reasons and many lacked sufficient posterior contacts for chewing.

Counterintuitively, the population with intellectual disabilities report frequent healthful homecare behaviours like tooth brushing. It is likely that the tooth brushing that is done is ineffective. Flossing, and specialised toothbrushes are underutilised. Interventions are needed to improve the effectiveness of daily oral homecare and prevent the oral diseases that have such negative outcomes for people with intellectual disabilities in Ireland.

Concerningly, the poor health outcomes observed in this chapter occur despite reportedly frequent attendance at dental services. One would expect better outcomes for a population who reportedly engage with health services so frequently. Most visits reportedly deliver assessment only. For those who attended, there was little report of preventive treatment. An unacceptable proportion of participants reported difficulty in attending dental services. Reasons given include patients being placed on waiting lists, being discharged out of HSE dental services without transfer of care, and, unable to find medical card dentists. Dental anxiety was also extremely common among people with intellectual disabilities in Ireland, meaning that appropriate services must plan for anxiolytic adjuncts, such as skilled dental teams, sedation and anaesthesia.

Service use is largely split between HSE and Medical Card dentists, which is very different to the oral healthcare utilisation trends of people without intellectual disabilities. Both schemes are publicly funded and therefore potentially modifiable through policy implementation.

The United Nations Convention on The Rights of Persons with Disabilities demands that people with disabilities are not further disadvantaged based on their disability regarding health and access to healthcare. This report illustrates a failure to deliver equal health outcomes. The National Oral Health Policy was published in 2019. It offers great hope to modify the outcomes observed. If implemented, health and equality should follow.

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CHAPTER 7

Family Carers

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HEALTHY HAPPY AGEING

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

7.1: Key findings

- Thirty-Eight (52.1%) participating carers in Wave 5 were parents, all of whom were aged over 66 years of age and four of whom were aged over 86 years.
- Thirty-two (43.8%) participating carers were a sibling of the older person with intellectual disabilities.
- Three-quarters of the carers reported that they chose to take on the care responsibility.
- Fourteen (43.8%) sibling carers reported that they also provide care for another person.
- Most carers were very satisfied or satisfied with their own health (all: 69.9%, $n = 51$; parents: 57.9%, $n = 22$; siblings: 84.4%, $n = 27$).
- Just under 20% of carers reported that their health had been negatively impacted by their care responsibilities. There was no percentage difference between parents and siblings in Wave 5 - parents 18.4%, $n = 7$; siblings: 18.8%, $n = 6$.
- Twenty-one carers reported that they experienced stress/nervous tension (parents: 36.8%, $n = 14$; siblings: 21.9%, ($n = 7$). Twenty carers (27.4%) reported experiencing anxiety (parents: 34.2%, $n = 13$; siblings: 18.8%, $n = 6$). Nineteen carers (26%) reported experiencing back pain (parents: 31.6%, $n = 12$; siblings: 18.8%, $n = 6$).
- Over one-third of carers were “just about getting by” or finding it difficult or very difficult to manage financially. Just over half the carers were in receipt of the Carer’s Allowance or the Half Carer’s Allowance.
- Carers most frequently cited being constantly on call, stress and emotional strain as the most difficult aspects of caring.
- More than half of carers reported that their care responsibilities are confining, and almost 40% reported feeling completely overwhelmed by their care responsibilities.
- Just under half of carers reported changes in their own personal plans as a result of their caring role.
- Carers most frequently ‘strongly agreed’ or ‘agreed’ that providing care: “makes me feel needed”, “makes me feel useful” and “enables me to appreciate life more”.
- Talking to friends is the most common coping strategy, and few carers receive support from support groups.
- High levels of satisfaction with GP services and with Day Services were reported. However, a low level of satisfaction with respite services was reported, particularly among the sibling carers.
- Most carers expected that they would still be providing care to their family member in five years’ time, and most reported that they expected to be providing the same amount of care in five years as they are currently providing.
- Whereas most carers have thought about where their family member will be living in five years’ time, only a minority have discussed the issue with a professional individual or group.

7.2: Introduction

The Carer’s Study is nested within the IDS-TILDA study and seeks to understand the experiences of family carers of older people with an intellectual disability. Unlike the study involving the older people themselves, the participants in the Carer’s Study may change between waves as different family members assume the primary responsibility for providing care. Of particular note was a clear generational transfer of care from parent to sibling of the person with intellectual disability between Waves 1 and 3 as parents aged (Wave 1: 58%, $n = 26$; Wave 3: 76.7%, $n = 33$). The refresh of the sample prior to Wave 4 resulted in the inclusion of younger parents and hence a reduction in the percentage of sibling carers.

The study itself has progressed to build on data in each wave in order to build a comprehensive picture of the lives and views of the participating family carers. Core questions have remained consistent across all waves. However, building on the insights gleaned from each wave, the questionnaire has also evolved including the amendment, addition and removal of a number of questions. A specific innovation in Wave 5 was the implementation of personal IDs for each carer which will identify carers as individuals rather than in relation to the person they care for, which will enhance the longitudinal analysis of individual carer experience across time.

This chapter reports on some key findings from Wave 5 of the Carer's Study and makes reference to findings in other waves where relevant. A profile of the participating carers is firstly presented followed by data under the following themes - tasks and level of care; finances; health of carers; the experience of the carers; support and coping; services and the future.

7.3: Profile of Wave 5 carers

7.3.1: Relationship to the person with intellectual disabilities.

Thirty-eight (52.1%) participating carers were a parent of the person with intellectual disabilities; thirty-two (43.8%) were a sibling and three (4.1%) were classified as "other". One of the "other" carers was a sister-in-law of the person with intellectual disabilities, one was a niece and one was a neighbour.

Table 7.1 below illustrates the extent to which a generational transfer of responsibility took place between Waves 1 and 3. The percentage of parent carers increased following the sample refresh, however high numbers of siblings are involved in the care of their family member.

Table 7.1: Relationship to older person with intellectual disabilities

Relationship	Parent		Sibling		Other	
	n	%	n	%	n	%
Wave 5	38	52.1	32	43.8	3	4.1
Wave 4	39	52	33	44.0	3	4.0
Wave 3	10	23.3	33	76.7	0	0.0
Wave 2	21	32.8	43	67.2	0	0.0
Wave 1	12	26.7	26	57.8	7	15.5

7.3.2: Sex of carer

Most carers were female although one-quarter of the sibling carers were male.

Table 7.2: Sex of carer

All	All		Parent		Sibling		Other	
	n	%	n	%	n	%	n	%
Male	15	20.5	6	15.8	8	25.0	1	33.3
Female	58	79.5	32	84.2	24	75.0	2	66.7

7.3.3: Age of carers

More than 60% (62.9%, *n* = 44) of the carers were over 66 years of age; including all the parent carers. Four parent carers were over the age of 86. Three (9.7%) sibling carers were aged under 45 years.

Table 7.3: Age groups

Age Group	All (*n* = 70)		Parents (*n* = 36)		Siblings (*n* = 31)		Other (*n* = 3)	
	n	%	n	%	n	%	n	%
36-45 years	3	4.3	0	0.0	3	9.7	0	0.0
46-55 years	7	10.0	0	0.0	6	19.4	1	33.3
56-65 years	16	22.9	0	0.0	15	48.4	1	33.3
66-75 years	24	34.3	17	47.2	6	19.4	1	33.3
76-85 years	16	22.9	15	41.7	1	3.2	0	0.0
86+	4	5.7	4	11.1	0	0.0	0	0.0

7.3.4: Employment status

None of the parent carers were employed outside the home; more than two-thirds (68.4%, *n* = 26) reported that they were retired and 31.6% (*n* = 12) reported that they were looking after home or family. Although more than three-quarters of the sibling carers were of traditional working age, the employment or self-employment rate for this cohort of carers was less than 60% (56.3%, *n* = 18).

Table 7.4: Employment status

Employment status	All (*n* = 73)		Parents (*n* = 38)		Siblings (*n* = 32)		Other (*n* = 3)	
	n	%	n	%	n	%	n	%
Employed	12	16.4	0	0.0	12	37.5	0	0.0
Self employed	7	9.6	0	0.0	6	18.8	1	33.3
Looking after home or family	20	27.4	12	31.6	7	21.9	1	33.3
Retired	32	43.8	26	68.4	5	15.6	1	33.3
Permanently sick or disabled	1	1.4	0	0.0	1	3.1	0	0.0
Other	1	1.4	0	0.0	1	3.1	0	0.0

Four siblings reported that they had given up work because of their care responsibilities and a further four reported that they had cut down on the hours that they work outside the home. To qualify for the Carer's Allowance, carers may not engage in more than 18.5 hours per week paid employment and one sibling identified that they reduced their hours to meet this criterion. Others withdrew from the workforce or reduced their hours in order to provide the necessary care.

> ***To care full time was required consequently left work to become a carer. (Sibling)***
> ***Wouldn't get all I need to do at home done if I worked more hours. (Sibling)***

7.3.5: Number of years caring

Given the relationship, parent carers reported most years spent caring. Two widowed parent carers dated their number of years caring from the time they became the primary carer. Most sibling carers (82.8%, *n* = 24) reported that they had been caring for up to 20 years.

Table 7.5: Number of years caring

Number of years caring	All (*n* = 70)		Parents (*n* = 38)		Siblings (*n* = 29)		Other (*n* = 3)	
	n	%	n	%	n	%	n	%
Up to 10 years	12	18.6	0	0.0	12	41.4	1	33.3
11-20 years	14	20.0	2	5.3	12	41.4	0	0.0
21-30 years	6	8.6	0	0.0	4	13.8	2	66.6
31-40 years	5	7.1	4	10.5	1	3.4	0	0.0
41-50 years	27	38.6	27	71.1	0	0.0	0	0.0
51-60 years	3	4.3	3	7.8	0	0.0	0	0.0
60+	2	2.9	2	5.2	0	0.0	0	0.0

7.3.6: Other care responsibilities

Four parents reported that they also provide care for another person; two noted:

> *I have to support my wife as she has been in failing health for the past few years (Parent)*
> *My husband [for] most of our family life (Parent)*

Fourteen (43.8%) sibling carers reported that they also provide care for another person. Most siblings who elaborated specified that they care for a parent, one provides care for a second sibling and two specified that they cared for their children.

7.3.7: Reasons for providing support

Whereas parents more frequently reported that they provided support because they "had always done so", siblings most frequently reported that they provided support because they are needed. 'Lack of services' was the least frequently cited reason in Wave 5 which is consistent with the responses in Waves 3 and 4. Carers were invited to indicate all the statements that were applicable to their experience and the responses to the question are presented in Table 7.6 below.

Table 7.6: Reasons for providing support

All		Parents		Siblings		Other	
n	%	n	%	n	%	n	%
Because I am the parent							
36	49.3	36	100	n/a	n/a	n/a	n/a
Because I've always done so							
31	42.5	20	52.6	11	34.4	0	0.0
Because I am needed							
34	46.6	16	42.1	17	53.1	1	33.3
Because I feel obliged to							
13	17.3	6	15.8	7	21.9	0	0.0
Because services are not available							
8	11.0	4	10.5	4	12.5	0	0.0
Because I enjoy and want to							
21	28.8	8	21.1	11	34.4	2	66.6

Despite that fewer than 30% of carers reported that they provide support to their family member because they "enjoy and want to", almost three-quarters (74%, *n* = 54) reported that they chose to take on the care responsibility. A number of parents identified care as an automatic role of a parent:

> ***Automatically as a loving parent (Parent)***
> ***Because he is my son. He needed to be cared for (Parent)***

Similarly, for some siblings, the provision of care was a consequence of the relationship between them and their family member and/or the expectation of their parents:

> ***He is my brother (Sibling)***
> ***My sister is very important to me and my parent would have wanted me to look after him (Sibling)***
> ***As an unmarried sibling living at home following the death of my parents it was expected of me (Sibling)***
> ***I live in the same house, so it happened organically (Sibling)***
> ***I promised my mother and father I would take care of my sister for the rest of her life or mine! (Sibling)***

7.4: Tasks and level of care

Carers most frequently reported giving partial or full physical support with managing money and bills 71.4% (*n* = 50), preparing hot meals (70.4%, *n* = 50) and shopping for groceries (59.2%, *n* = 42

most 40% (38.6%, *n* = 27) of carers fully or partial physically support their family member with bathing or showering and a slightly smaller percentage (36.6%, *n* = 26) gave full or partial physical support with medication.

Table 7.7: Tasks and levels of care

Level of support	All		Parents		Siblings		Other	
	n	%	n	%	n	%	n	%
Medication								
None	16	22.5	10	27.0	6	19.4	0	0.0
Monitoring/ gesturing	29	40.8	14	37.8	13	41.9	2	66.7
Full/partial physical assistance	26	36.6	13	35.1	12	38.7	1	33.1
Dressing								
None	35	52.9	18	50.0	17	53.1	2	66.7
Monitoring/ gesturing	18	25.4	10	27.8	7	21.9	1	33.3
Full/partial physical assistance	16	22.5	8	22.2	8	25.0	0	0.0
Walking								
None	51	75.0	27	71.1	22	73.3	2	66.7
Monitoring/ gesturing	8	11.8	3	8.6	4	13.3	1	33.3
Full/partial physical assistance	9	13.2	5	14.3	4	13.3	0	0.0
Bathing/showering								
None	28	40.0	13	36.1	14	45.2	1	33.3
Monitoring/ gesturing	15	21.4	7	19.4	7	22.6	1	33.3
Full/partial physical assistance	27	38.6	16	44.4	10	32.3	1	33.3
Cleaning teeth/taking care of dentures								
None	34	47.9	18	48.6	14	45.2	2	66.7
Monitoring/ gesturing	23	32.4	27	27.0	12	38.7	1	33.3
Full/partial physical assistance	14	19.7	9	24.3	5	16.1	0	0.0
Eating								
None	48	68.6	29	82.9	18	56.3	1	33.3
Monitoring/ gesturing	16	22.9	4	11.4	10	31.3	2	66.7
Full/partial physical assistance	6	8.6	2	5.7	4	12.5	0	0.0
Getting in and out of bed								
None	57	82.6	30	85.7	25	80.6	2	66.7
Monitoring/ gesturing	8	11.6	4	11.4	3	9.7	1	33.3
Full/partial physical assistance	4	5.8	1	2.9	3	9.7	0	0.0
Using the toilet								
None	57	75.7	28	77.8	25	71	3	100
Monitoring/ gesturing	8	11.4	4	11.1	4	12.9	0	0.0
Full/partial physical assistance	9	12.9	4	11.1	5	16.1	0	0.0
Socialising and activities within the home								
None	31	43.7	20	52.6	9	30.0	2	66.7
Monitoring/ gesturing	31	43.7	13	34.2	17	56.7	1	33.3
Full/partial physical assistance	9	12.7	5	13.5	4	13.3	0	0.0
Behavioural needs								
None	44	64.7	28	75.7	15	53.6	1	33.3
Monitoring/ gesturing	21	30.9	7	18.9	13	46.4	1	33.3
Full/partial physical assistance	3	4.4	2	5.4	0	0.0	1	33.3
Preparing a hot meal								
None	6	8.5	2	5.3	4	13.3	0	0.0
Monitoring/ gesturing	15	21.1	7	18.4	7	23.3	1	33.3
Full/partial physical assistance	50	70.4	29	76.3	19	63.3	2	66.7
Shopping for groceries								
None	12	16.9	9	25.0	3	9.4	0	0.0
Monitoring/ gesturing	17	23.9	7	19.4	8	25.0	2	66.7
Full/partial physical assistance	42	59.2	20	55.6	21	65.6	1	33.3
Telephone calls								
None	26	37.1	15	40.5	11	36.7	0	0.0
Monitoring/ gesturing	14	20.0	9	24.3	3	10.0	2	66.7
Full/partial physical assistance	30	42.9	13	35.1	16	53.3	1	33.3
Managing money and bills								
None	5	7.1	3	8.6	2	6.3	0	0.0
Monitoring/ gesturing	15	21.4	9	25.7	5	15.6	1	33.3
Full/partial physical assistance	50	71.4	23	65.7	25	78.1	2	66.7

7.5: Finances

Just under one-quarter of carers reported that they received the Carer's Allowance (24.7%, *n* = 18) and a further 23.3% (*n* = 17) reported that they received the Half Carer's Allowance from the State to support their caring. This represented a slight increase in the percentage of Wave 4 carers reporting that they received either allowance (46.7%, *n* = 35) and a decrease in the percentage of Wave 3 carers (54.6%, *n* = 24).

Whereas 64.4% (*n* = 47) of carers were "living comfortably" or "doing alright" on their current income, over one-third (34.9%, *n* = 26) were "just about getting by" or finding it difficult or very difficult to manage financially. Siblings were slightly less likely to report that they were "living comfortably" or "doing alright" than parents (parents: 65.8%, *n* = 25; siblings: 62.5%, *n* = 20) and slightly more likely to report that they were "just about getting by" or finding it difficult or very difficult to manage financially (parents: 34.2%, *n* = 13; siblings: 37.5%, *n* = 12).

A higher percentage of Wave 4 carers (78.7%, *n* = 59) and a lower percentage of Wave 3 carers (57.8%, *n* = 26) reported that were "living comfortably" or "doing alright" on their current income. Conversely, a lower percentage of Wave 4 carers (20%, *n* = 15) and a higher percentage of Wave 3 carers (40.9%, *n* = 18) reported that they were "just about getting by" or finding it difficult or very difficult to manage financially.

7.6: Health of carers

7.6.1: Health, satisfaction with health and comparative health

In Wave 3, more than half the carers (52.2%) rated their health as excellent or very good; in Wave 4 the percentage was 50.7%. In Wave 5, twenty-four carers (32.9%) rated their health during the previous four weeks as "excellent" or "very good". However, just 15.8% (*n* = 6) of parents reported health at this level compared to 50% (*n* = 16) of siblings.

Most carers were very satisfied or satisfied with their own health, although the parent carers were less likely to so report. Parent carers in Wave 5 were less positive about their health than parent carers in either Wave 3 (80%, *n* = 8) or Wave 4 (74.4%, *n* = 29).

Table 7.8: Satisfaction with own health

All (*n* = 73)		Parents (*n* = 38)		Sibling (*n* = 32)		Other (*n* = 3)	
n	%	n	%	n	%	n	%
51	69.9	22	57.9	27	84.4	2	67.7

Despite the overall satisfaction levels with their own health, a smaller percentage of carers rated their health, compared to others their own age, as excellent or very good. Parents were less likely than siblings or "other" carers to rate their comparative health highly.

Table 7.9: Comparative health

All (*n* = 73)		Parents (*n* = 38)		Sibling (*n* = 32)		Other (*n* = 3)	
n	%	n	%	n	%	n	%
35	47.9	15	39.5	18	56.3	2	66.7

Just under 20% of Wave 5 carers reported that their health had been negatively impacted by their care responsibilities. In Waves 3 and 4, this percentage was 23.8% and 16.4% respectively.

Table 7.10: Negative health impact

All (*n* = 70)		Parents (*n* = 36)		Sibling (*n* = 31)		Other (*n* = 3)	
n	%	n	%	n	%	n	%
13	17.8	7	18.4	6	18.8	0	0.0

A number of Wave 5 carers whose health has been impacted described the effect:

> ***Caring is a full-time job. 24/7 days a week. No respite and no help. The government don't care (Parent)***
> ***Stress, pain, loneliness (Parent)***
> ***Mainly mental health … Overthinking and head exploding due to lack of help and understanding with so called professionals I come across daily. (Sibling)***
> ***Lack of support has impacted severely on my health (Sibling)***

7.6.2: Health conditions

Consistent with earlier waves, the most frequently reported health conditions were back pain, anxiety, aching joints and stress and nervous tension. Parents experienced these and all other health conditions more frequently than did the other carers. Overall, 17.8% (*n* = 13) of carers reported that their health had suffered as a result of caregiving representing a decrease in the percentage from Wave 3 (23.8%, *n* = 10) and Wave 4 (16.4%, *n* = 12). There was no percentage difference between parents and siblings in Wave 5 - parents 18.4%, *n* = 7; siblings: 18.8%, *n* = 6.

Table 7.11: Health conditions

Health condition	All		Parents		Siblings		Other	
	n	%	n	%	n	%	n	%
Back pain	19	26.0	12	36.1	6	18.8	1	33.3
Anxiety	20	27.4	13	34.2	6	18.8	1	33.3
Aching joints	24	32.9	16	42.1	8	25.0	0	0.0
Stress/nervous tension	21	28.8	14	36.8	7	21.9	0	0.0

Almost 70% of the participating carers rated their quality of life as good or very good. However, a smaller percentage of parent carers reported this level of quality of life than did sibling or "other" carers.

Table 7.12: Good or very good quality of life

All (*n* = 72)		Parents (*n* = 37)		Sibling (*n* = 32)		Other (*n* = 3)	
n	%	n	%	n	%	n	%
50	68.5	23	60.5	25	78.1	2	66.7

Likewise, fewer parent carers reported having a lot or quite a lot of energy during the previous four weeks, and more parent carers experienced moderate, severe or very severe pain and/or emotional problems during the same period.

Table 7.13: Experience of pain, emotional problems and energy levels over previous four weeks

All		Parents		Siblings		Other	
n	%	n	%	n	%	n	%
Experienced moderate, severe or very severe pain during previous 4 weeks							
24	32.9	17	44.7	6	18.8	1	33.3
Extremely/moderately or extremely bothered by emotional problems during previous 4 weeks							
22	30.1	14	36.9	7	21.9	1	33.3
Had a lot or quite a lot of energy during previous 4 weeks							
31	42.5	8	21	21	65.6	2	66.7

7.7: The experience of providing care

7.7.1: Difficulties associated with providing care

Carers were asked whether they experienced any of a range of difficulties that have been associated with caregiving and were also asked to identify the most difficult aspects of providing care. The most frequently cited difficulty was that caregiving was confining (56.3%, *n* = 40) and, consistently, the most difficult aspect was reported to be being constantly on call (57.6%, *n* = 38).

More than 60% (61.5%, *n* = 32) of carers reported stress as a difficulty of providing care and just under 60% (56.9%, *n* = 33) reported emotional strain. Siblings (65.6%, *n* = 21) more frequently cited changes in personal plans than did the parent carers (36.1%, *n* = 13). The complete responses to these questions are presented in Table 7.14.

The difficulties cited by the carers is Wave 5 were consistent with those cited in all previous waves indicating the pervasive and enduring nature of these difficulties.

Carers cited the following as the most difficult aspects of caring

58% Being constantly on call

62% Stress

57% Emotional strain

57% Responsibilities are confining

38% Feeling completely overwhelmed

49% Causes changes to own personal plans

Table 7.14: Difficult and most difficult aspects of providing care

	All		Parents		Siblings		Other	
Difficulties	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Sleep is disturbed	12	17.7	4	12.1	7	21.9	1	3.3
It is inconvenient	11	16.4	3	9.1	8	25.8	0	0.0
It is a physical strain	9	13.4	5	14.7	4	13.3	0	0.0
It is confining	40	56.3	20	55.6	20	62.5	0	0.0
There have been family adjustments	23	34.3	10	29.4	13	43.3	0	0.0
Changes in personal plans	35	49.3	13	36.1	21	65.6	1	33.1
Emotional adjustments	18	26.1	7	20.0	10	32.2	1	33.3
Some behaviour is upsetting	18	26.9	9	27.3	9	29.0	0	0.0
It is upsetting to find the person you support has changed so much from his/her former self	14	20.6	8	22.9	5	16.7	1	33.3
Work adjustments	10	14.5	1	2.9	9	28.1	0	0.0
Financial strain	13	21.7	5	16.1	7	24.1	1	33.3
Feeling completely overwhelmed	26	37.7	12	34.3	12	38.7	2	66.7
Most difficult								
Lack of sleep	12	26.7	7	20.6	4	17.4	1	33.3
Isolation	14	31.8	8	24.2	6	26.1	0	0.0
Stress	32	61.5	16	47.1	15	57.7	1	33.3
Emotional strain	33	56.9	18	52.9	14	50.0	1	33.3
Being constantly on call	38	57.6	18	51.4	18	64.3	2	66.7
Frustration	23	37.1	13	37.1	10	38.5	0	0.0
Sadness for the person I care for	34	54.0	18	52.9	13	48.1	3	100
Guilt	18	31.0	6	18.8	11	47.8	1	33.3

7.7.2: Benefits of providing care

When asked to consider the benefits which they derive from providing care, carers most frequently strongly agreed or agreed that providing care: “makes me feel needed” (56.5%, *n* = 39); “makes me feel useful” (50.1%, *n* = 35); “enables me to appreciate life more” (53.6%, *n* = 37) and makes me feel good about myself 49.3% (*n* = 34).

Table 7.15: Benefits derived from providing care

	All		Parents		Siblings		Other	
	n	%	n	%	n	%	n	%
Makes me feel useful								
Agree / strongly agree	35	50.1	17	47.2	15	50.0	3	100
Disagree / strongly disagree	11	15.9	8	22.2	3	10.0	0	0.0
Makes me feel good about myself								
Agree / strongly agree	34	49.3	15	41.7	17	56.7	2	66.7
Disagree / strongly disagree	11	15.9	8	22.0	3	10.0	0	0.0
Makes me feel needed								
Agree / strongly agree	39	56.5	20	55.6	17	56.7	2	66.7
Disagree / strongly disagree	11	15.9	8	22.2	3	10.0	0	0.0
Makes me feel appreciated								
Agree / strongly agree	34	49.3	15	50.0	17	56.7	2	66.7
Disagree / strongly disagree	18	26.1	10	27.8	8	26.7	0	0.0
Makes me feel strong & confident								
Agree / strongly agree	23	33.4	12	33.4	10	33.3	1	33.3
Disagree / strongly disagree	14	20.3	9	25.0	5	16.3	0	0.0
Enabled me to appreciate life more								
Agree / strongly agree	37	53.6	19	52.3	16	53.3	2	66.7
Disagree / strongly disagree	11	15.9	8	22.2	3	10.0	0.0	0.0
Enabled me to develop a more positive attitude towards life								
Agree / strongly agree	31	44.9	17	47.2	12	40	2	66.7
Disagree / strongly disagree	12	17.4	7	19.4	5	16.8	0	0.0
Has strengthened my relationships with others								
Agree / strongly agree	28	40.6	14	38.9	11	36.7	3	100
Disagree / strongly disagree	10	14.5	6	16.7	4	13.3	0	0.0

Some carers took the opportunity to identify particular benefits they derived from providing care:

> *I have made some long-lasting friendships with other carers. In getting very involved with special Olympics I got to travel and meet some of the most amazing caring people (Parent)*
>
> *Her companionship. We have to go on trips in the car, just the two of us (Parent)*
>
> *We have made many friends in the clubs we are involved in for special needs and there is always something happening (Parent)*
>
> *Has made me a stronger person. Has helped in any job I do. You are not a selfless person. You always think of others. There are always worse cases than you. (Sibling)*
>
> *When I put her to bed at night and she sometimes says I love you! (Sibling)*

7.8: Support and coping

7.8.1: Sources of support

Parents most frequently reported receiving a lot or some support from their spouse and their children where applicable and from friends. Siblings most frequently reported receiving this level of support from their spouse and other close relatives.

Table 7.16: Sources of support

	All		Parents		Siblings		Other	
	n	%	n	%	n	%	n	%
From spouse / partner								
A lot of support / some support	38	52.8	20	54.1	17	53.1	1	33.3
Very little support / so-so support	3	4.2	2	5.4	1	3.1	0	0.0
NA	31	43.1	15	40.7	14	43.8	2	66.7
From parents								
A lot of support / some support	7	11.9	0	0.0	6	22.2	1	33.3
Very little support / so-so support	1	1.7	0	0.0	1	3.7	0	0.0
NA	51	86.4	30	78.9	20	74.1	1	33.1
From children								
A lot of support / some support	37	55.2	25	69.4	10	35.7	2	66.7
Very little support / so-so support	9	13.4	5	13.9	4	14.3	0	0.0
NA	21	33.3	6	16.7	14	50.0	1	33.3
From other close relatives								
A lot of support / some support	31	45.6	13	40.6	18	60.0	0	0.0
Very little support / so-so support	22	33.8	11	34.4	10	33.3	1	33.3
NA	12	18.5	8	25.0	2	6.7	2	66.7
From friends								
A lot of support / some support	22	36.1	14	45.2	7	25.9	1	33.3
Very little support / so-so support	16	26.2	7	22.6	9	33.3	0	0.0
NA	23	37.7	10	32.3	11	40.7	2	66.7
From employer / boss								
A lot of support / some support	9	15.3	3	10.0	6	22.2	0	0.0
Very little support / so-so support	6	10.2	0	0.0	5	18.5	1	33.3
NA	44	74.6	27	90.0	16	59.3	1	33.3
From others in the workplace								
A lot of support / some support	6	10.3	2	6.6	3	11.5	1	33.3
Very little support / so-so support	5	8.6	0	0.0	5	19.2	0	0.0
NA	47	83.9	28	93.3	18	75	1	33.3

No carer in the “other” category reported that other relatives or friends regularly support or assist them in caring for the person they support. Sixteen parents (42.1%) reported that they received such support as did seventeen (53.1%) sibling carers. A number of parent carers added a comment that they had as much support as they need at present, however three identified a need for more respite and one specified a need for night-time assistance. Respite was also the key support need identified by sibling carers and one wrote of the importance of adequate support:

> ***Having the HSE package in place (30 hrs per week) and respite for 1 night twice a month is priceless. I do not feel like I could manage the care without these supports in place. (Sibling)***

Apart from other family members, carers most frequently reported that further support and assistance should come from the intellectual disability service providers. However, a number also placed the responsibility for adequate support with the State and the HSE:

> ***The service provider and the HSE should willingly offer these supports to families in need and not have the families battle and beg for help/support which is what I had to do after my parents died (Sibling)***
>
> ***The government should be providing funding for respite services all over the country- it’s vital for many family members whose caring roles are huge- much, much bigger than mine may ever be. It’s extremely unhealthy for human beings not to have time (regularly) to switch off from caring (Sibling)***

7.8.2: Coping strategies

Talking to friends was the most frequently reported coping strategy (68.5%, *n* = 50) in Wave 5 as it was in previous waves (Wave 3: 70%, *n* = 28; Wave 4: 64%, *n* = 48). A higher percentage of parents (78.9%, *n* = 30) cited this strategy than did either sibling (59.4%, *n* = 19) or “other” carers (33.3%, *n* = 1).

Likewise, parents (55.3%, *n* = 21) more frequently identified watching TV as a coping strategy than did sibling (34.4%, *n* = 11) or “other” carers (0%) whereas sibling and “other” carers more frequently identified exercise than did the parent carers (28.9%, *n* = 11).

Fewer than 30% of carers (27.4%, *n* = 20) identified respite as a coping strategy (Wave 3: 35.7%, *n* = 15; Wave 4: 29.3%, *n* = 22). A greater percentage of parent carers (34.2%, *n* = 13) than sibling carers (15.6%, *n* = 6) identified respite as a coping strategy in Wave 5 (Wave 3: parents 10%, *n* = 1; siblings: 54.2%, *n* = 14; Wave 4: parents 35.9%, *n* = 14, siblings 21.2%, *n* = 7).

Across all the Waves, very few carers reported that they attended a support group (Wave 5: 5.5%, *n* = 4; Wave 4: 0%; Wave 3: 0%) or used phone support (Wave 5: 5.5%, *n* = 4; Wave 4: 1.3%, *n* = 1; Wave 3: 2.3%, *n* = 1).

Table 7.17: Support strategies

All		Parents		Siblings		Other	
n	%	n	%	n	%	n	%
Talking to friends							
50	68.5	30	78.9	19	59.4	1	33.3
Watching TV							
32	43.3	21	55.3	11	34.4	0	0.0
Exercise							
30	41.1	11	28.9	17	53.1	2	66.7
Drink alcohol							
3	4.1	2	5.3	1	3.1	0	0.0
Smoke							
1	1.4	1	2.6	0	0	0	0.0
Take medication							
4	5.5	4	10.5	0	0.0	0	0.0
Use respite							
20	27.4	13	34.2	6	15.6	1	33.3
Attend support group							
4	5.5	3	7.9	1	3.1	0	0.0
Use phone support							
4	5.5	2	5.3	2	6.3	0	0.0
Alternative medicine							
0	0.0	0	0.0	0	0.0	0	0.0
Faith / prayer							
22	30.1	13	34.2	7	21.9	2	66.7

7.9: Services

7.9.1: Satisfaction with services

High levels of satisfaction with GP services and with Day Services were reported. However, carers were less satisfied with the support to access community received by their family member and both parent and sibling carers reported paying for this support.

Table 7.18: Satisfaction with services

All		Parents		Siblings		Other	
n	%	n	%	n	%	n	%
Very satisfied or satisfied with GP service							
65	90.3	32	86.5	30	93.8	3	100
Very satisfied or satisfied with day service							
62	88.6	32	88.9	27	93.1	3	100
Very satisfied or satisfied with support to access the community							
22	51.2	12	52.2	7	41.2	3	100
Paying for support for family member to access the community							
12	21.8	8	21.1	4	12.5	0	0.0
Very satisfied or satisfied							
18	25.4	12	31.6	5	16.7	1	33.3

7.9.2: Respite

A low level of satisfaction with respite services was reported particularly among the sibling carers.

Table 7.19: Satisfaction with respite service

All		Parents		Siblings		Other	
n	%	n	%	n	%	n	%
Very satisfied or satisfied							
18	25.4	12	31.6	5	16.7	1	33.3

Fewer than 40% (all: 38.6%, *n* = 22; parents: 41.2%, *n* = 14; siblings: 33.3%, *n* = 7; other: 50%, *n* = 1) of responding carers (*n* = 57; parents: *n* = 34; siblings: *n* = 21; other: *n* = 2) reported that their family members respite service had returned to at least pre-Covid level. Almost 30% (29.8%, *n* = 17; parent: 23.5%, *n* = 8; sibling: 42.9%, *n* = 9) reported that it had not. The question was reported to be not applicable by 31.6% (*n* = 18) of responding carers.

A number of carers noted that respite was a very positive experience for their family member:

> ***Participant enjoys respite, he enjoys "living" with his friends (Parent)***
> ***She loves it and it is great for her to mix with her friends (Parent)***

However, whereas some carers stated that their family member does not need or use respite, others reported that their family member would not use it:

> ***My sister will not use respite as she had a bad experience in 2017 (Sibling)***
>
> ***… refuses to go to respite. She has some bad experiences when she was a child and was always brought home during the night, so I just don't try anymore (Parent)***

Most comments in response to this question, focussed on the lack of respite and its importance for carers:

> ***As we age, we realise that our son needs more respite then the two nights a month, currently available. This is to help prepare him for the future without us. (Parent)***
>
> ***Respite is very inconsistent. Families very disappointed with this service. HSE takes control of respite houses for crisis situations which creates crisis for the parents and clients (Parent)***
>
> ***During COVID it was extremely difficult. We were offered nothing and participant was at home 24/7 with no extra home support only 11 hours which was deplorable. No health professionals even may contact to know how we or [name] was coping (Sibling)***
>
> ***Respite is crucial for any family to receive who has a person they care for (Sibling)***
>
> ***It would be nice to have a date well in advance to be able to make plans/or book a holiday (Sibling)***

The need for more respite recurred repeatedly as a response to questions about services needed by the carer or by the service user and in response to the question about an ideal service package. Similarly, another frequently identified need was for social support outside day centre or respite hours:

> ***Regular outreach service in the company of groups of his peers (Parent)***
>
> ***2-3 hrs/day motivation when not day service or respite (Other)***
>
> ***Take participant for a coffee. Treat her with respect. Be nice to her (Sibling)***

7.10: The future

7.10.1: Expectation of future care

Most carers expected that they would still be providing care to their family member in five years' time: parents 76.3% (*n* = 29); siblings 87.5% (*n* = 28); others 100% (*n* = 3).

Whereas a number of parents expressed doubt because of their age:

> ***At 80 years of age now I will probably be dead (Parent)***

Others were more confident about their longevity and health:

> ***Age is a concern, but I am currently very healthy and will continue to care as I am (Parent)***

The response from some carers indicated that they did not consider that continuing to care was a matter about which they have a choice:

> ***I would love to see him settled in a forever home, but think it is highly unlikely. The services are forced to wait for a crisis (Parent)***

Likewise, some siblings did not expect that the future would differ from the present:

> ***Intellectual disability does not disappear with age (Sibling)***
> ***I don't expect the situation to change (Sibling)***

Whereas others expressed a hope that they would still be providing care:

> ***Participant and I are in good health, so we wish to be around for many years yet (Sibling)***
> ***Hopefully this will be possible (Sibling)***

Parents and siblings most frequently reported that they expected to be providing the same amount of care in five years as they were currently providing. Whereas almost one third (31.6%, *n* = 12) of parents expected to be providing less care, few siblings or "other" carers had the same expectation. Sibling and "other" carers were more inclined to expect that they would be providing more care.

Table 7.20: Expected level of care in five years' time

Level of care	All (*n* = 66)		Parent (*n* = 34)		Sibling (*n* = 29)		Other (*n* = 3)	
	n	%	n	%	n	%	n	%
Same	36	49.3	19	50.0	16	51.6	1	33.3
Less	14	19.2	12	31.6	2	6.5	0	0.0
More	16	21.9	3	7.9	11	35.5	2	66.7

7.10.2: Living arrangements in five years' time

Most carers reported that they had thought about where their family member would be living in five years' time although a higher percentage of parents rather than siblings did so (parents 71.1% vs siblings 56.3%).

Likewise, a higher percentage of parents reported that they had discussed the issue with a professional (parents 55.6% vs siblings 25%).

Table 7.21: Living arrangements in five years' time

	All		Parent		Sibling		Other	
	n	%	n	%	n	%	n	%
Has thought about where their family member will be living in five years								
Yes	47	64.4	27	71.1	18	56.3	2	66.7
Has discussed the issue with a professional individual or group								
Yes	27	37.0	20	55.6	7	25.0	0	0.0

A number of parents elaborated that they expected that their family member would be supported by their intellectual disability service in residential settings:

> ***I have met with participants social worker that [service provider] would take her into one of their residential houses if she would go (Parent)***

Others have made arrangements within the family:

> ***The plan for participant is- when I die- his brother and wife are taking in participant to live with them, they live near me (Parent)***
>
> ***My daughter will move into the family home and take over the carer role (Parent)***

One sibling carer wrote that they were working with a social worker to secure an arrangement for the future whereas other were clearly frustrated by the process:

> ***No plan. It is no good talking to anybody. I am told you are going nowhere (Sibling)***

Another recorded the difficulty that can arise when the responsibility for care is shared among family members who have a different perspective on the issue:

> ***No because it is very touchy subject with my mother, she does not want participant to go into residential. I worry about if I got sick and my mother is not here anymore what happens to participant. (Sibling)***

7.10.3: Responsibility for care

A question about perceived primary responsibility for providing care was included for the first time in Wave 5. Two thirds of carers (66.2%, *n* = 45) assigned the responsibility to themselves although parents more frequently did so. Conversely, siblings more frequently reported that the primary responsibility lay with the wider family than did parents. Very few carers considered that the primary responsibility lay with the State.

Table 7.22: Primary responsibility for providing care

Locus of responsibility	All (*n* = 68)		Parent (*n* = 36)		Sibling (*n* = 30)		Other (*n* = 2)	
	n	%	n	%	n	%	n	%
The carer	45	66.2	26	72.2	17	56.7	2	66.7
The wider family	18	26.5	5	13.9	13	43.3	0	0.0
The State	5	7.4	5	13.9	0	0.0	0	0.0

The overwhelming majority of carers (95.8%, *n* = 6) reported that this responsibility was a lifelong one:

> *I have a responsibility to care for my daughter (Parent)*
>
> *Yes, caring for a member of your family with an intellectual disability is a lifelong responsibility as she/he did not choose to be different or unable to cope with life, but they deserve the empathy and love they already miss out on in life! (Sibling)*

Family care was described as incomparable to care that would be provided by others:

> *No one will be able to care for her as I do, and I worry what will happen if my health or something happened to me (Parent)*
>
> *I know my sibling is happy and safe at home. This is not any judgement on the services provided by the state which are very good but can never equal the family setting (Sibling)*

Others, while accepting the primary responsibility, identified that they should be supported to provide support:

> *We have provided loving care and support to our son since he was born over 42 years ago. It has equally been a privilege and a responsibility. However, there needs to be a recognition by support services that as carers (parents) age, the level of support from those services must increase correspondingly (Parent)*
>
> *Yes, but the state needs to play a very significant role (Parent)*
>
> *Yes, life-long responsibility but carers need more help in doing so and more longer breaks for many reasons (Sibling)*
>
> *Once you are in a caring role it can be very hard not to do this. I would hope that there will be supports available to participant and myself as we age together (Sibling)*

7.11: Conclusion

Now in in its fifth wave, the IDS-TILDA Carer's study provides valuable and detailed insights into the lived experiences of care givers for older people with an intellectual disability. The longitudinal approach adopted makes this study unique in the international field of research relating to intellectual disability. The findings of the carer component of the overall study are of particular importance to understanding, planning for and overcoming some emerging challenges to sustaining care provision for people with intellectual disability as they age in Ireland.

Several specific dynamics are changing the care provision landscape in Ireland. In particular, the social policy drive towards de-congregation, the renewed societal prioritisation of the family as the key mechanism of care provision, smaller family sizes and the reality of progressing age, for parent carers and people with intellectual disability and to some extent siblings, raises serious questions regarding the sustainability of care for people with intellectual disability in the coming decades (Doyle et al, 2023; Brennan et al, 2020).

The capacity of the 'family' to provide long term care should not be taken for granted, and increasing health concerns for caregivers, declines in provision of services such as respite, a failure to understand both enduring difficulties and specific challenges in family care provision will lead to unplanned for and unwelcome crises points in care provision (Brennan at al, 2022; McCausland et al, 2019; Brennan et al, 2018). The detailed and quality longitudinal data provided by the IDS-TILDA Carer's study offers directions to inform government, policy makers and service providers in their work in supporting families as they provide care.

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METHODOLOGY

CHAPTER 8

Methodology

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HEALTHY HAPPY AGEING

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

8.1: Key findings

- A total of 762 participants completed the Computer Assisted Personal Interview (CAPI) at Wave 5, consisting of 621 participants who had previously taken part in Wave 4 and 141 newly recruited participants.
- Among the Wave 4 respondents who were alive at Wave 5, the response rate was 94.2%.
- A total of 755 Pre-Interview Questionnaires (PIQ) were returned, a response rate of 99.1%.
- The retention rate for Wave 5 was 84% (621/739). Almost 70% of the attrition was due to deaths.
- There were 506 participants who took part in the Health Fair.
- Interviews continued to be a mix of self-report and proxy interviews. Proxy interviews were completed by family or staff.

8.2: Wave 5 survey methodology

At Wave 5, respondents who took part in Wave 4 and who agreed to be contacted again were approached to be re-interviewed. In addition, a refreshment of the sample took place in Wave 5 to address sample attrition experienced during the first four waves which was largely accounted for by participant deaths.

The refreshment addressed losses likely to impact the representativeness of the sample and replaced the age 40-50 years cohort who, by Wave 5, had aged to older than 50 years. This was the second such refreshment of the sample (previous was in Wave 4).

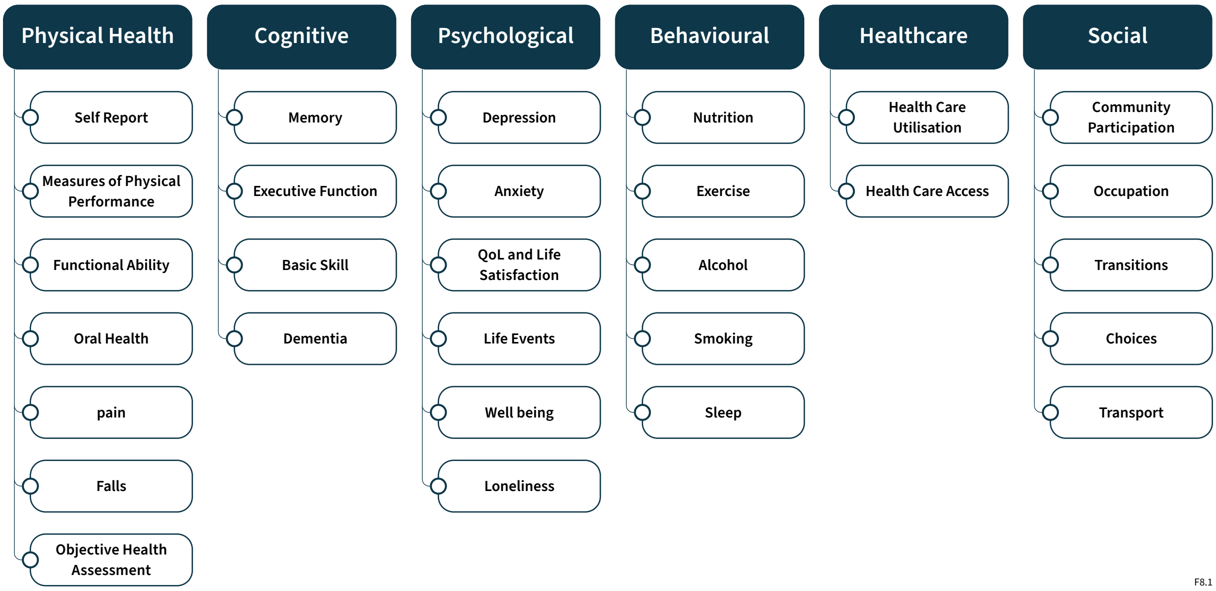
A targeted drive successfully recruited 141 new participants, 100 of whom were aged 40-49. A sample size of 762 was achieved which improved the representativeness of the sample in terms of age, level of intellectual disability and residential circumstances of people with an intellectual disability in Ireland as reported in the NASS Intellectual Disability Report 2020 (Casey et al. 2020). The demographic profile for all five waves is provided in Table 8.1.

Table 8.1: Demographic profile of IDS-TILDA participants, Wave 1 to Wave 5

	Wave 1 (*n* = 753)	Wave 2 (*n* = 701)	Wave 3 (*n* = 609)	Wave 4 (*n* = 739)	Wave 5 (*n* = 762)
	%	%	%	%	%
Sex					
Male	44.9	44.5	44.2	46.5	46.6
Female	55.1	55.5	55.8	53.5	53.4
Age					
<50	38.2	28.1	11.8	18.3	24
50-64	45.6	51	62.6	55.1	47.6
65+	16.2	20.9	25.5	26.7	28.3
Level of ID					
Mild	23.9	24	24.8	29.6	29.8
Moderate	46.5	46.5	46.2	42.5	45.3
Severe/ profound	29.6	29.5	29.1	27.9	25
Residence					
Independent / family	17.1	16.3	15.6	17.3	22.6
Community group home	35.6	43.5	40.4	49	49
Residential care	47.3	40.2	44	33.7	28.5

Data collection consisted of a Pre-Interview Questionnaire (PIQ) and a Computer-Assisted Personal Interview (CAPI) which together covered each of the topics set out in the IDS-TILDA Conceptual Framework (Figure 8.1).

Figure 8.1: IDS-TILDA Conceptual Framework



The PIQ was sent a minimum of seven days prior to the interview. Topics covered in the PIQ included medications, health service use and frequency, how free time is spent and reported challenging behaviour.

The CAPI protocol included questions on health, social and family circumstances, quality of life, and inter-personal relationships. This protocol was administered by a trained interviewer and was completed in person at the location of the respondent's choice, usually a day service or home setting. The option of carrying out the interview remotely, via telephone or video call, was also offered.

Consistent with previous waves, interviews were carried out by field researchers selected from across the country who had experience in the field of intellectual disability, and who attended in full a three-day comprehensive training programme. Twenty-eight field researchers completed training, with nine experienced field researchers returning from previous waves. The training included a review by a panel of people with an intellectual disability of reviewer competencies and skills in gaining consent and administering the protocol.

As with previous IDS-TILDA waves, the CAPI/PIQ could be completed in one of three ways – independently by the participant, as a self-report with support, or by a proxy known well to the participant and responding on their behalf.

The IDS-TILDA Carers Study also continued into Wave 5. This consisted of a self-complete questionnaire filled out at the time of CAPI interview by consenting family carers of IDS-TILDA participants living in their family home.

8.3: New PIQ and CAPI items in Wave 5

The Wave 5 protocols remained largely unchanged from Wave 4 to support the longitudinal integrity of the study. Any changes made were developed in consultation with PPI Contributors, people with an intellectual disability. Feedback was also sought from representatives of the Health Service Executive, the Department of Health and the IDS-TILDA governing committees - the International Scientific Advisory Committee and the Steering Committee.

Minor amendments were made to a small number of questions to obtain further detail and to reduce participant burden. New items were introduced to ensure that opportunities for comparisons with TILDA data were enhanced. In addition, some new questions were added to address increasingly prominent issues since Wave 4, for example long COVID and menopause and to consider over time the impact of the implementation of new policy directions, for example the Assisted Decision Making (Capacity) Act.

There were also additional new questions addressing physical activity and sedentary behaviour levels, neighbourhood facilities, relationships with family/friends, decision support plans, health care decision making, technology use, communication and diet.

In terms of protocol changes, 87 new questions were added, 34 questions were modified and 30 were rested/removed (see Table 8.2 for further details of amendments made).

Table 8.2: Amendments to Wave 5 protocols

Questions	Rationale	Number in PIQ	Number in CAPI
New questions	- To improve comparability with TILDA. - To extend and build on data gathered in previous waves. - To reflect policy changes. - To capture data from new participants. - To replicate government recommendations and health promotion.	16	71
Modified questions	- To improve flow of questions. - To improve understanding. - To reduce participant burden. - To clarify for analysis purposes. - To accommodate new participants.	6	28
Moved questions	- To improve flow of questions. - To reduce participant burden. - To ensure questions are being asked in the most appropriate manner/setting.	3	0
Rested/removed questions	- To exclude questions not relevant for this wave. - To reduce participant burden. - To account for questions which have been amalgamated.	3	27

8.4: Response rates and causes of attrition

A total of 762 participants completed the CAPI at Wave 5. CAPI Interviews were a mix of self-report and proxy interviews. The majority of the 762 CAPI participants completed the interview independently or with support (64.7%, 493/762). The remaining interviews (35.3%, 269/762) were completed by proxy. Proxy interviews were completed by family or staff members who were well-known to the participant.

Of those who completed a CAPI, 99.1% (*n* = 755) returned the previously forwarded PIQ.

The overall retention rate for continuing participants was 84.0% (621/739). This consisted of 621 of the 762 Wave 5 participants, who had taken part previously in Wave 4 from an overall Wave 4 sample of 739. Response rates for Wave 5, based on the 739 Wave 4 participants, were not significantly different for males and females, 83.1% (286/344) versus 84.8% (335/395). There was also no significant difference in response rates according to age group (based on age at Wave 4); 85.4% (117/137) (40-49 years); 85.3% (348/408) (50-64 years) and 80.4% (156/194) (65 and over) respectively.

Table 8.3 summarises the main reasons for non-participation of 118 individuals at Wave 5 who had previously participated in Wave 4. The most common reason was death which accounted for 67.8% of the attrition. Indeed, of the surviving 659 Wave 4 participants, 621 individuals took part in Wave 5. This represents a more specific retention rate of 94.2% (621/659) for surviving Wave 4 participants. A further 21.2% of the overall attrition were refusals (for example due to illness or personal reasons, or time constraints during the period of Wave 5 data collection). It should be noted that participants who decline to participate in a certain wave do not necessarily withdraw from the study permanently. They remain eligible for follow-up at future waves.

Table 8.3: Reasons for attrition

Reason		
	n	%
Deaths	80	67.8
Refusals	25	21.2
Withdrawn	13	11.0
Lost to follow up	0	0
Total	**118**	**100**

8.5: Health Fair measures and methods

8.5.1: The Health Fair

In response to findings from the IDS-TILDA study indicating elevated levels of inactivity, sedentary behaviour, health risk factors such as obesity, and mental health conditions among participants, Wave 2 introduced physical assessments termed the 'Health Fair.' This terminology was chosen to mitigate any negative connotations associated with measurement or testing, fostering participant engagement and contribution. The design and implementation of the Health

Fair prioritised a person-centred approach, inspired by an emancipatory philosophy (Barnes 2014) and ethos consistent with the inclusive values of IDS-TILDA. The intricate nature of the health assessment process necessitates meticulous planning and thoughtful consideration, characterised by a rigorous design process that includes pilot studies, independent advocate reviews, expert evaluations, and collaboration with the IDS-TILDA Scientific Advisory Board (Burke et al 2020). A methodology replicated in Wave 5.

8.5.2: Research nurse training

The assessments were conducted by experienced and trained research nurses who undertook specific training on each of the objective measures over a week-long comprehensive training programme. Each element was supported by subject specific experts. For example, the oral health assessment was supported by special care dentistry and a PhD student in oral health" with "and a research nurse, trained as a gold standard in the Modified oral status Survey tool. Training here involved theory and practical sessions with an intellectual disabilities trained dentist and with dentist-supervised baseline and final calibration of the research nurses' skills, with the Modified Oral Status Survey Tool (MOSST) protocol and its indices. The intense programme involved theory and practical sessions with baseline and final calibration of the research nurses' skills over the two days. The training involved using a blended teaching approach where each concept was explored and the use of pictures and numerous Kahoots quizzes were used to build the research nurses' skills on each Item of the MOSST. Inter-rater reliability scores were initially used in the MOSST training to calibrate the research nurses against a gold standard in preparation for using the tool in the health fair. Volunteer participants, who were people with intellectual disabilities, came to day two of the training to assist the research nurses in their training and give feedback on the MOSST and Modified Dental Anxiety Scale (MDAS).

8.5.3: The assessments

The suite of objective measures comprised 27 different assessments including neuro-psychological, cardiovascular, mobility, muscular skeletal assessments, anthropometric measures, oral health assessment, dietary assessment sensory assessment and audiology. The full suite can be review in Table 8.4.

Table 8.4: Suite of objective measures

Domain	Measurement	
Neuro-psychological	Test for severe impairment [TSI] Brief Praxis DSQIID	
Cardiovascular	Mobilograph - Pulse Wave Velocity - Central Blood Pressure	
Mobility and muscular skeletal	Sitting and standing blood pressure Kardia ECG Pulse Oximeter ActivPal	Sit to stand test 2-minute step test Timed up and go test Balance assessment
Anthropometric	Height Weight Ulna length Mid Upper Arm Circumference (MUAC) Waist & hip circumference	Foot assessment – Brunswick Quantitative heel ultrasound Calf measurement Grip strength
Oral health	Modified Oral Status Survey Modified Dental Anxiety Scale	
Other	Adult eating behaviour scale Computer proficiency assessment	Audiology Adult/Adolescent Sensory Profile

A total of 506 participants (69.9%, 506/723) took part in the Health Fair of whom 50 completed all 27 assessments and the remainder engaged in at least one assessment. Reasons for non-completion included health reasons, death or withdrawal of the participant before appointment was scheduled, difficulty with transport or own choice to decline. Invitations were not sent to the remaining 39 participants due to time constraints.

Assessments were conducted over three stations at one site and on the same day. Each measurement was purposely positioned to reduce participant stress potential for a negative impact on assessment readings and minimisation of inconvenience and burden for the participant. The majority of assessments occurred at the IDS-TILDA health fair clinic site within the Trinity Centre for Ageing and Intellectual Disability. Where transportation to Dublin proved difficult, temporary regional sites were established and utilised to reach additional participants.

8.6: Statistical methods

This report provides a high-level summary of the data gathered in the Wave 5 interviews. Estimates provided throughout the report are typically the percentages (or proportions) of participants in the IDS-TILDA Wave 5 sample who answered questions on the topic of interest. These responses are cross-tabulated by specific demographic variables of interest such as age group, residential situation, sex, level of intellectual disability and other analysis criteria relevant to each chapter. Means of specific continuously measured quantities are also reported where appropriate.

Corresponding figures in prior waves for IDS-TILDA may be reported as may comparisons with TILDA reports with the proviso that TILDA figures for the general population are for those over 50 years only. Comparisons are also made between those aged 40-49 in Wave 1 and the newly added 40–49-year-olds in Wave 5 as a measure of generational change noted, if any.

Changes across the five waves of data have been depicted using line graphs of summary statistics stratified by age group to illustrate longitudinal trends and generational differences over time such as: How has life changed over the past 12 years for the over 65s? Are the 40–50-year-olds experiencing better health, well-being and a more inclusive society in the 2020s compared to the 2010s? These preliminary findings with five waves of data will begin processes of applying sophisticated longitudinal modelling to provide a deep understanding of the health and well-being of this population as they age, given societal and policy changes.

As IDS-TILDA sampled approximately 8% of the population of registered individuals with an intellectual disability over 40 years of age, there is an inherent uncertainty in the derived estimates reported here. This is represented, where appropriate, by 95% confidence intervals (CI) and error bars in the graphs. These confidence intervals/error bars can be interpreted as an indication of confidence, based on our sample, that the true unknown statistic for the population lies within this range.

Causal relationships between health and well-being factors and the statistical significance of any differences will require further in-depth analysis. Future publications will explore statistical comparisons between sub-groups within the population with an intellectual disability as well as formal comparisons with the general population.

All analyses in this report were conducted using SPSS V28.0 statistical software.

References

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