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Intergenerational Change in Health, Well-Being and Social Inclusion for Two Groups of Adults With Intellectual Disability Aged 40–49: Findings From a National Longitudinal Study

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ABSTRACT

Background: This paper examines differences in health, well-being and social inclusion between two generations of adults with intellectual disability in their 40s, measured 12 years apart.

Method: Data was drawn from Waves 1 and 5 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing. Descriptive statistics were calculated at Waves 1 and 5 and outcomes were analysed using CHAID (Chi Squared Automatic Interaction Detection) decision tree.

Results: Wave was the main predictor of increased weekly contact with friends ($p < 0.001$), internet use ($p < 0.001$) and alcohol consumption ($p < 0.001$). Mild exercise ($p < 0.001$) and moderate exercise decreased ($p < 0.001$). Self-rated health ($p < 0.001$) and mental health ratings ($p = 0.006$) improved, while loneliness declined ($p = 0.041$). Use of general practitioners ($p < 0.001$), social work ($p < 0.001$) and home help ($p = 0.020$) declined, whereas optician ($p = 0.001$) and dermatological services ($p = 0.048$) increased.

Conclusion: Intergenerational changes were observed, with improved social inclusion and health perceptions, alongside shifts in behaviour and healthcare use.

1 | Introduction

Historically, individuals with disabilities have faced poorer health outcomes (Van Schrojenstein Lantman-De Valk et al. 2000), higher mortality rates (McCarron et al. 2015) and significant social exclusion (Robertson et al. 2001; Verdonschot et al. 2009). The United Nations' adoption of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006 (United Nations 2006) has been identified as a significant milestone in the broader movement towards equality for people with disabilities. The CRPD, particularly for people with intellectual disabilities, serves as a reference framework in discussions of equality alongside those without disabilities. Recent research indicates some advancements in health, well-being and social inclusion for people with intellectual disabilities, yet it also highlights that progress towards achieving full equality remains limited in certain areas.

1.1 | Health and Mortality

The life expectancy of people with intellectual disabilities has improved over the decades; however, it remains much shorter than that of people without disabilities (McCarron et al. 2018).

Summary

- The study highlights intergenerational changes in a national cohort, reflecting policy and societal impacts on people with intellectual disabilities.
- Intergenerational changes were evident among people with intellectual disabilities, with improved social inclusion through greater friendship contact, digital engagement, better self-rated health and reduced loneliness.
- Healthcare utilisation patterns changed, with reduced engagement in generalist and support services but increased use of specialist services.

In the United States, the average life expectancy in 2017 for individuals without an intellectual or developmental disability was 72.5 years, an increase from 71.7 years in 2005. In contrast, people with an intellectual disability, but no co-occurring developmental disability, had an average life expectancy of 63.4 years. Age of death for individuals with developmental disabilities including Down syndrome (56.8 years), cerebral palsy (53.8 years) and rare developmental disabilities (46.8 years) was lower than persons with intellectual disability only (Landes et al. 2021). Data from Ireland comparing mortality rates between people with intellectual disabilities and the general population from 2001 to 2016 showed a narrowing of the gap in average age of death by 2 years. However, between 2009 and 2016, individuals with intellectual disabilities still had a significantly lower average life expectancy (54.0 years) compared to the general population (74.9 years), with a difference of around 20 years. Additionally, adults aged 20–64 with intellectual disabilities, particularly females, experienced a higher rate of premature deaths (Doyle et al. 2020). The increased mortality risk (Tyrer et al. 2022) and premature mortality risk may be related to the high prevalence of conditions such as hypertension, obesity (Ryan et al. 2021) and diabetes (McCarron et al. 2018; Hirvikoski et al. 2021).

1.2 | Mental Health and Wellbeing

People with intellectual disability are more vulnerable to mental ill-health for several complex reasons which range from biophysical to psychosocial (Whittle et al. 2018). In England, the proportion of people with a diagnosis of severe mental illness was considerably higher compared to those without intellectual disabilities (8.1% vs. 0.9%) (Perera et al. 2020). A meta-analysis shows that more than a third of people with an intellectual disability meet diagnostic criteria for a co-occurring psychiatric disorder (Mazza et al. 2020). A Swedish study found that 17% of older adults with intellectual disabilities (aged 55 and above) had a psychiatric diagnosis, compared to just 10% in a similarly aged general population sample (Axmon et al. 2018).

1.3 | Social Inclusion and Community Participation

In terms of social inclusion and community participation, research has consistently shown that individuals with intellectual disabilities encounter significant barriers when engaging in social activities, primarily due to the need for assistance and health/physical limitations (McCausland et al. 2022; Tatlow-Golden et al. 2014). As a result, people with intellectual disabilities are more prone to experiencing loneliness and social isolation (Emerson et al. 2021; Robinson et al. 2018; Wormald et al. 2019) and often face challenges in forming and maintaining interpersonal relationships (Friedman and Rizzolo 2018; Merrells et al. 2019; White and Forrester-Jones 2019). Although there have been advances in transitioning individuals from institutional settings to more integrated community environments, recent studies indicate that people with intellectual disabilities continue to experience a range of varied outcomes (Mihaila et al. 2022). For instance, Wang et al. (2024) has found that adults with borderline or mild intellectual disability often have strong family relationships but limited social connections outside the home, which may restrict their participation in broader community life and their ability to adapt to new social situations.

Over the past decade, the social and policy context for people with intellectual disabilities has evolved both internationally (United Nations 2006) and in Ireland (Government of Ireland 2024), with reforms promoting community-based living (Health Service Executive 2011; Government of Ireland 2015a) and person-centred supports (Health Service Executive 2012) aimed at enhancing inclusion and participation. In parallel, broader societal changes, including increased digitalisation and the disruptions associated with the COVID-19 pandemic, may also have influenced health, social participation and access to services. While shifting societal attitudes among younger generations may foster greater inclusion, there is a lack of longitudinal evidence on generational differences (Bredewold et al. 2020; McCarron et al. 2019; Wang et al. 2024). This gap underscores the need for longitudinal or cross-cohort analyses to assess whether the policies and societal changes over recent decades have translated into better outcomes for newer generations.

In this context, we aimed to examine whether any progress had been made for adults with intellectual disabilities in Ireland in their 40s over the past decade. This paper examines differences in health, well-being and social inclusion between two generations of adults with intellectual disability in their 40s, measured 12 years apart. It compares data for participants of a national longitudinal study aged 40–49 years at Wave 1 in 2011 ($n = 288$) with data for a new generation of 40–49-year-olds at Wave 5 in 2023 ($n = 183$).

2 | Method

Data was drawn from Waves 1 and 5 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). The approach focused on six key domains of measurement within IDS-TILDA—physical health, cognitive health, psychological health, behavioural health, healthcare and social inclusion.

Data collection was conducted in 2011 for Wave 1 and in 2023 for Wave 5 and it involved two components: a Pre-Interview

Questionnaire (PIQ) and a Computer-Assisted Personal Interview (CAPI). The PIQ focused on topics such as medication usage, frequency of health service visits, how free time is utilised and reported challenging behaviours. The CAPI included questions about health, social and family situations, quality of life and interpersonal relationships.

IDS-TILDA received ethical approval at Waves 1 and 5 from the Trinity College Dublin (TCD) Faculty of Health Sciences Research Ethics Committee and separately from all disability service providers who supported participants.

2.1 | Population and Sample

IDS-TILDA is a longitudinal study of adults with intellectual disability aged 40 years and above living in the Republic of Ireland. The original sample at Wave 1 ($n = 753$) was randomly selected from eligible individuals registered on the National Intellectual Disability Database (NIDD), with support from the Health Research Board (HRB) and was geographically and demographically representative of the target population in Ireland (McCarron et al. 2011). At Wave 1 there were 288 participants aged 40–49 years.

Prior to Wave 5 of the longitudinal study, a targeted sample refreshment was undertaken. Given that the original cohort of 40–49-year-olds had aged 12 years, recruitment of new participants at Wave 5 focused particularly on this age category, while also considering changing demographics of the population on the national database—now the National Ability Support System (NASS). All participants were selected using the same sampling framework and inclusion criteria as in Wave 1. The final Wave 5 sample of 762 remained demographically representative of Irish persons with intellectual and developmental disabilities and included 183 participants aged 40–49 years. Mean ages for the two groups were very similar (45.2 years wave 1 vs. 44.9 years for wave 5). The demographic profile of the two cohorts is outlined in Table 1 with *p*-values indicating the significance of differences between characteristics at Waves 1 and 5.

There were a number of significant differences between the two groups, notably in terms of gender, residential circumstances and level of intellectual disability; these were controlled for in the analyses.

2.2 | Measures

The selection of measures was guided by the six domains of measurement noted above. The research protocols were assessed to identify appropriate indicators that would provide consistent measure under each domain between Wave 1 and 5. In total, 19 measures fitting the selection criteria were selected from across the six domains (Table 2).

Different measures of quality of life were used in each of the waves; therefore, comparisons on measures of quality of life were not undertaken.

TABLE 1 | Demographic profiles of cohorts of 40–49-year-olds at Wave 1 ($n = 288$) and Wave 5 ($n = 183$).

Demographics	WAVE 1 (288)	WAVE 5 (183)	*p*
Gender			
Male	143 (49.7%)	108 (59.0%)	0.047
Female	145 (50.3%)	75 (41.0%)	0.047
Residential circumstances			
Independent/ Family	61 (21.2%)	85 (46.4%)	<0.001
Community Group Home	98 (34.0%)	84 (45.9%)	0.010
Residential	129 (44.8%)	14 (7.7%)	<0.001
Level of ID			
Severe/ Profound	86 (32.5%)	25 (15.2%)	<0.001
Moderate	119 (44.9%)	73 (44.5%)	0.937
Mild	60 (22.6%)	66 (40.2%)	<0.001
Cause of ID			
Down syndrome	85 (30.5%)	52 (33.1%)	0.566
Unknown	194 (69.5%)	105 (66.9%)	0.566
Occupation			
Employed	76 (26.4%)	49 (27.1%)	0.871
Unemployed	212 (73.6%)	132 (72.9%)	0.871

2.3 | Analysis

Descriptive statistics including frequencies and proportions were calculated for each measure at Waves 1 and 5. However, given the demographic differences between the two groups (see Table 1), an approach that took these differences into consideration was required to determine if differences between the two groups were significant. Given that the two groups were independent, they were combined into a single dataset with a wave identifier variable ('Wave') added to distinguish between Wave 1 and 5.

For multivariate analysis of each outcome measure, CHAID (Chi Squared Automatic Interaction Detection) decision tree analysis was selected as the best approach because, while the regression models only consider main effects, the classification trees consider all main effects and interactions between predictors and are recognised for not being influenced by outliers in the data or missing values. Table 3 outlines the categorical variables used as predictors in the analyses.

For the final decision trees, the *p*-value of the chi-square test at each significant split is reported as well as the predicted response (frequency) in each node.

TABLE 2 | Measures of generational change used.

Domain	Measure
Physical health	Self/proxy-rated physical health (excellent; very good; good; fair; poor)
	Multimorbidity—having two or more of the following health conditions: hypertension; eye disease; heart disease; endocrine disease; joint disease; lung disease; gastrointestinal disease; mental health condition; stroke; cancer; neurological disease; liver disease (McCarron et al. 2023)
Psychological	Self/proxy-rated mental health (excellent; very good; good; fair; poor)
	Do you ever feel lonely? (UCLA Loneliness Scale)
Behavioural	Exercise: Frequency of vigorous [and/or] moderate [and/or] mild exercise (> once a week, once a week, < once a week, rarely/never)
	Currently smoke
	Drink alcohol
	Are you on any special diet?
Social	Frequency of (in-person, phone or written) contact with non-resident family: 3+ times a week; once or twice a week; once or twice a month; every few months; once or twice a year; less than once a year; never.
	Frequency of (in-person, phone or written) contact with non-resident friends: 3+ times a week; once or twice a week; once or twice a month; every few months; once or twice a year; less than once a year; never.
	Number of regular (monthly) activities in community setting, from: Cinema; Eat out; Art gallery or museum; Theatre, concert or opera; Pub for a drink; Coffee shop for light refreshments; Shopping; Church or other place of worship; Go to sports events; Library; Social clubs; Hairdressers; Perform in local arts groups and choirs; Spend time on hobbies or creative activities; Visit family and friends in their home; Other activities outside your home (please specify).
	Own a mobile phone.
	Use the internet and/or email
	Self-choices: In general, who chooses ...?
	Help received in the last 2 years?
	Help given in the last 2 years?
Mainstream Healthcare Services	Healthcare utilisation within the last year: General Practitioner; Public Health Nurse; Occupation Therapy; Chiropody; Physiotherapy; Social Work; Psychological Counselling; Home Help; Optician; Dental; Hearing; Dietician; Speech & Language; Neurological; Endocrinology; Dermatological
	Are you covered by private medical insurance?

All analyses were carried out in IBM SPSS Statistics 28.0.

To ensure data confidentiality, cells with counts less than five were suppressed in accordance with data protection guidelines. Consequently, for variables such as self-choice score, vigorous exercise, public health nurse and speech and language therapy utilisation, analyses were restricted to descriptive statistics.

3 | Results

3.1 | Changes in Social Inclusion and Community Participation

The decision tree analysis found no significant differences between waves for contact with family (see Figure S1). Residential circumstances emerged as the main predictor ($p < 0.001$), with a higher proportion of weekly family contact among individuals living independently or with family (86.0%, $n = 117$).

In contrast, a substantial and significant increase in weekly contact with friends was observed across waves (Figure S2) ($p < 0.001$). In Wave 1, 47.3% ($n = 124$) of participants reported weekly contact with friends, which increased to 96.6% ($n = 141$) in Wave 5. In Wave 1, individuals living independently or with family reported higher levels of contact with friends (73.3%, $n = 44$; $p < 0.001$) compared to those in other residential settings (39.6%, $n = 80$).

In Wave 1, 16.0% reported receiving help from friends or neighbours, compared to 30.5% in Wave 5. Decision tree analysis showed that residential circumstances were the primary predictor of receiving help ($p < 0.001$), with participants living independently or with family more likely to report receiving help (35.9%, $n = 51$) (Figure S3). A significant difference between waves was observed only among those in community group homes ($p = 0.003$), with an increase from 12.2% ($n = 12$) in Wave 1 to 29.8% ($n = 25$) in Wave 5.

For help given, rates were 17.0% at Wave 1 and 33.0% at Wave 5. In the decision tree analysis (Figure S4) occupation emerged as the main predictor ($p < 0.001$). Employed participants were

TABLE 3 | Categorical predictor variables included in the analysis.

Variable	Categories
Gender	Male
	Female
Cause of intellectual disability	Down Syndrome
	Unknown
Level of intellectual disability	Mild
	Moderate
	Severe/Profound
Residence	Independent/Family
	Community group home
	Residential care
Wave	Wave 1
	Wave 5
Occupation	Employed
	Unemployed

more likely to give help (43.3%, $n=55$) compared to unemployed participants (15.7%, $n=53$). Between Waves, a significant increase in helping behaviour was observed only among unemployed individuals, rising from 10.1% ($n=21$) in Wave 1 to 24.4% ($n=32$) in Wave 5 ($p<0.001$).

There was no significant change in community activities between waves (Figure S5). Residential circumstances were the main predictor ($p<0.001$), with those who were living in community group homes, independently or with family (69.6%, $n=328$) most likely to engage in these activities (mean = 7.22, SD = 2.43) compared to those in residential care (30.4%, $n=143$) (mean = 5.61, SD = 2.85). Among individuals living in community group homes, independently or with family, level of intellectual disability emerged as the second most important predictor of regular community activities ($p=0.005$). Participants with a mild level of intellectual disability were the most likely to engage in these activities (mean = 7.72, SD = 2.45), compared to those with moderate or severe/profound levels (mean = 6.80, SD = 2.35). For individuals living in residential care, employment status was the second key predictor ($p=0.048$). Employed participants were more likely to take part in community activities (mean = 6.53, SD = 2.74) than those who were unemployed (mean = 5.08, SD = 2.80).

Internet use increased substantially during this period, from 10.8% ($n=31$) in Wave 1 to 79.1% ($n=129$) in Wave 5, with wave confirmed as the strongest predictor in the decision tree analysis (Figure S6) ($p<0.001$). For mobile phone ownership, residential circumstances were the main predictor in the decision tree analysis (Figure S7). Between waves, there were significant increases in mobile ownership for individuals living in independent/family residences and for individuals with moderate-profound intellectual disability living in community group homes. Among participants living independently or with family, ownership rose significantly from 52.5% ($n=32$) to 80.0% ($n=68$; $p<0.001$). In community group homes, mobile phone ownership was most common among those with mild intellectual disability (68.5%, $n=50$), while for other levels, ownership increased significantly from 15.3% ($n=9$) in Wave 1 to 42.0% ($n=21$) in Wave 5 ($p=0.002$).

3.2 | Changes in Behavioural Health

Between Wave 1 and Wave 5, there was a substantial increase in alcohol consumption from 2.4% ($n=7$) to 37.7% ($n=69$). Decision tree analysis confirmed a significant increase during this period, with wave identified as the only significant predictor ($p<0.001$) (Figure S8). There was no statistically significant change in smoking between waves (Figure S9). Occupation emerged as the main predictor ($p=0.001$), with a higher prevalence of smoking among employed individuals (13.6%, $n=17$) and unemployed participants with mild intellectual disability (9.1%, $n=9$; $p=0.042$). Similarly, there was no significant change over time in the proportion who were on a special diet (Figure S10). Residential circumstances were the main predictor, being highest among people in residential care (49.7%, $n=71$, $p=0.000$); while women living in community group homes were more likely to follow a special diet (38.5%, $n=30$; $p=0.008$).

Moderate exercise declined between Waves, with participation dropping from 50.9% ($n=146$) in Wave 1 to 16.9% ($n=31$) in Wave 5 and confirmed as the main predictor in the decision tree analysis ($p<0.001$) (Figure S11). Additionally, in Wave 1, employment was a significant predictor ($p<0.001$), with 80.3% ($n=61$) of employed participants engaging in moderate exercise. Among the unemployed group, individuals with mild or moderate intellectual disability were the most likely to practice moderate exercise (51.6%, $n=66$; $p<0.001$). Mild exercise was also more prevalent in Wave 1 (86.8%, $n=249$) than in Wave 5 (59.6%, $n=109$), with this significant decline between waves confirmed in the decision tree analysis ($p<0.001$) (Figure S12). Level of intellectual disability was also significant in the analysis—where individuals with mild or moderate levels were more likely to engage in mild exercise at Wave 1 (92.2%, $n=165$; $p=0.003$); while this was true for participants with mild level at Wave 5 (72.9%, $n=62$; $p=0.004$).

3.3 | Changes in Physical Health

Self/proxy-rated health improved significantly over the 12 years, with a high proportion of participants rating their health as good to excellent in Wave 1 (87.9%, $n=248$), increasing to 100% in Wave 5 ($n=182$). Decision tree analysis confirmed this significant increase between the Waves ($p<0.001$) (Figure S13); while at Wave 1 participants with mild–moderate intellectual disability had better rated health (91.4%, $n=180$) than those with severe-profound levels (80%, $n=68$, $p=0.050$). Multimorbidity showed no significant change between waves (Figure S14), where residential circumstances were the only significant predictor. Participants living in residential care or community group homes had a higher prevalence of multimorbidity (64.0%, $n=208$) compared to those in independent or family residences (47.9%, $n=70$; $p=0.003$).

3.4 | Changes in Psychological and Cognitive Health

In Wave 1, 79.7% ($n=224$) of participants (self or proxy) rated their mental health as at least good, compared to 89.5% ($n=162$) in Wave 5 and this increase was confirmed in the decision tree analysis, with Wave as the only significant predictor ($p=0.006$) (Figure S15). Feelings of loneliness decreased from 50.7% ($n=77$) in Wave 1 to 39.1% ($n=61$) in Wave 5, with Wave confirmed as the only significant predictor in the decision tree analysis ($p=0.041$) (Figure S16).

Table 4 provides a summary of the findings, outlining the independent rates for each indicator at Wave 1 and Wave 5 and the significance of differences identified in the multivariate analyses.

3.5 | Changes in Healthcare Utilisation

Changes in healthcare used within the past year are outlined in Table 5, showing the prevalence of use for each type of service at Wave 1 and 5, along with the decision tree findings for group/wave, indicating the significance of differences between Wave 1 and Wave 5 respondents after controlling for other variables.

Wave 5 participants were significantly less likely to visit a general practitioner (GP) (80.5%, $n=145$) compared to Wave 1 (94.5%, $n=240$), with this difference confirmed by decision tree analysis ($p<0.001$) (Figure S17). No significant change between waves was observed regarding public health nurses and speech & language. Residential setting emerged as the strongest predictor for receiving occupational therapy (OT) services in the decision tree analysis, being highest among those in residential care (34.5%, $n=49$, $p<0.001$) (Figure S18). Among all other residential types there was a significant drop in use of OT services between Waves, from 10.8% ($n=17$) in Wave 1 to 4.5% ($n=7$) in Wave 5 ($p=0.038$).

For physiotherapy services, there was no significant change between Waves in the decision tree analysis, where residential circumstances was the sole predictor ($p<0.001$) (Figure S19). Those living in residential settings were more likely to receive physiotherapy (33.1%, $n=47$).

A decline in use of social work services between Waves was confirmed as significant in the decision tree analysis, where fewer participants in Wave 5 (4.7%, $n=8$) used these services compared to Wave 1 (22.7%, $n=65$; $p<0.001$) (Figure S20). The analysis also identified occupation as the significant predictor in Wave 1, with employed individuals having the highest service usage (31.6%, $n=24$; $p=0.0032$). For chiropody services, there was not a significant change in the decision tree analysis between waves, where residential circumstances were the primary predictor, with individuals in residential settings most likely to access these services (68.3%, $n=97$, $p<0.001$) (Figure S21).

Residential circumstances were also the main predictor for psychological service use, being higher among people in residential care and community group homes (19%, $n=60$), compared to independent/family residents (8.6%, $n=12$, $p=0.016$) (Figure S22). A decline between waves was observed for those in residential and community group homes, from 23.3% ($n=53$) to 7.7% ($n=7$) ($p=0.001$).

For optician services, wave was the strongest predictor in the decision tree analysis ($p=0.001$), with an increase in usage from 32.5% ($n=93$) to 48.5% ($n=82$) in Wave 5 (Figure S23). Additionally, in Wave 1, a higher proportion of individuals in community group homes (43.3%, $n=42$) used optician services compared to other settings (27.0%, $n=51$; $p=0.016$). Regarding home help, no participants reported its use in Wave 5 compared to 3.1% ($n=9$) individuals in Wave 1. This difference was significant ($p=0.020$) in decision tree analysis (Figure S24).

For dental services, residential circumstances was the main predictor in the decision tree analysis, with a higher proportion of participants in residential and community group homes using these services (73.1%, $n=231$). However, within these groupings, there was a significant decrease in use of dental services from 76.4% ($n=172$) in Wave 1 to 64.8% ($n=59$) in Wave 5 ($p=0.035$) (Figure S25). Dietician services were predominantly accessed by participants in residential settings (33.1%, $n=47$; $p<0.001$), though a significant decrease between Waves was observed among those in community group homes, from 21.6% ($n=21$) in Wave 1 to 7.8% ($n=6$) in Wave 5 ($p=0.010$) (Figure S26). The decision tree analysis showed no difference between waves in hearing service use, identifying cause of intellectual disability as the only predictor ($p=0.001$) (Figure S27).

Neurological services were used more by participants living in residential care and community group homes (11.7%, $n=37$) compared to independent/family living (4.3%, $n=6$; $p=0.039$) (Figure S28). A significant wave difference was found only among those in independent/family settings, increasing from no users in Wave 1 to 7.7% in Wave 5 ($n=6$, $p=0.027$). Wave was the only predictor for dermatological services ($p=0.048$), with usage increasing slightly from 3.5% ($n=10$) in Wave 1 to 7.7% ($n=13$) in Wave 5 (Figure S29). No wave difference was observed in medical insurance coverage, but the level of intellectual disability was identified as the sole predictor and use highest among individuals with mild–moderate levels (16.7%, $n=56$, $p=0.013$) (Figure S30).

4 | Discussion

The United Nations (UN) Convention on the Rights of Persons with Disabilities (UNCRPD), adopted by the UN General Assembly in December 2006, is widely regarded as an important international framework for promoting and safeguarding the rights and dignity of persons with disabilities (United Nations 2006). In 2018, Ireland ratified the Convention, committing to its provisions and 6 years later marked a significant milestone by signing and acceding to the Optional Protocol of the UNCRPD (Government of Ireland 2024). This step allows individuals with intellectual and other disabilities to file individual complaints with the UN if they believe their rights are not being upheld by the government. The formal process of accession has now been completed and since November 30, 2024, the Optional Protocol to the UNCRPD has been in effect in Ireland (Government of Ireland 2024).

TABLE 4 | Summary of findings.

Domain	Measure	Wave 1%	Wave 5%	Difference between Wave 1 and Wave 5 groups (decision tree analysis)
Social	Self-choices	85 (30.9%)	89 (50.9%)	No wave difference.
	Help received	47 (16.0%)	56 (30.5%)	Significant increase among those living in community group home.
	Help given	48 (17.0%)	60 (33.0%)	Significant increase among those unemployed.
	Internet and/or email usage	31 (10.8%)	129 (79.1%)	Significant increase. Wave was the strongest predictor. Within Wave 1, the level of intellectual disability is the next important predictor. Occupation was the second predictor within Wave 5.
	Own a mobile phone.	71 (24.7%)	120 (65.6%)	Significant increase among participants living independently/family and those with moderate/severe level of intellectual disability living in community group home.
	Contact with family	154 (53.7%)	130 (76.0%)	No wave difference—residential circumstances was the main predictor.
	Contact with friends	124 (47.3%)	141 (96.6%)	Significant increase. Wave was the strongest predictor.
	Activities in community setting	153 (53.1%)	114 (62.3%)	No wave difference—residential circumstances was the main predictor.
Behavioural	Smoking	24 (8.3%%)	8 (4.4%)	No wave difference—Occupation was a strong predictor, followed by level of intellectual disability within unemployed group.
	Alcohol consumption	7 (2.4%)	69 (37.7%)	Significant increase. Wave was the only predictor.
	Diet	106 (37.1%)	41 (22.8%)	No wave difference—residential circumstances was a strong predictor. Within community group home, gender was a predictor.
	Vigorous exercise	59 (20.7%)	53 (29.0%)	No wave difference
	Mild exercise	249 (86.8%)	109 (59.6%)	Significant decrease. Wave was the main predictor.
	Moderate exercise	146 (50.9%)	31 (16.9%)	Significant decrease. Wave was the main predictor.
Physical health	Multimorbidity	184 (63.9%)	94 (51.4%)	No wave difference—residential circumstances was the only significant predictor
	Self/proxy-rated health (At least good)	248 (87.9%)	182 (100.0%)	Significant increase. Wave was the strongest predictor.
Psychological	Self/proxy-rated mental health (At least good)	224 (79.7%)	162 (89.5%)	Significant increase. Wave was the only predictor.
	Feeling of loneliness	77 (50.7%)	61 (39.1%)	Significant decrease. Wave was the only predictor.

TABLE 5 | Changes in healthcare utilisation.

Healthcare service	Wave 1 *n* (%)	Wave 5 *n* (%)	Difference between W1 & W5 Groups (decision tree analysis)
General practitioner	240 (94.5%)	145 (80.6%)	Significant decrease ($p = 0.000$)
Public health nurse	25 (8.7%)	13 (7.7%)	Not significant
Occupation therapy (OT)	61 (21.3%)	12 (7.1%)	Significant decrease among individuals residing independently/family and in community group homes ($p = 0.038$)
Chiropody	155 (54.2%)	83 (49.1%)	Not significant
Physiotherapy	71 (24.8%)	16 (9.5%)	Not significant
Social work	65 (22.7%)	8 (4.4%)	Significant decrease ($p = 0.000$)
Psychological/counselling	54 (18.9%)	18 (10.7%)	Significant decrease among those in residential and community group home ($p = 0.001$); Significant increase among those in independent/family residential circumstances ($p = 0.009$).
Optician	93 (32.5%)	82 (48.5%)	Significant increase ($p = 0.001$)
Home help	9 (3.1%)	0 (0.0%)	Significant decrease ($p = 0.020$)
Dental	203 (71.0%)	102 (60.7%)	Significant decrease among those living in residential and community group home ($p = 0.035$)
Hearing	26 (9.1%)	25 (14.8%)	Not significant
Dietician	73 (25.5%)	12 (7.1%)	Significant decrease for those living in community group home ($p = 0.010$)
Speech & language	59 (20.6%)	11 (6.5%)	Not significant
Neurological	26 (9.1%)	17 (10.1%)	Significant increase among participants who live independently/family ($p = 0.027$)
Dermatological	10 (3.5%)	13 (7.7%)	Significant increase ($p = 0.048$)
Medical insurance	34 (12.5%)	27 (16.0%)	Not significant

In addition, Ireland has made significant strides in improving legislation and policies that aim to influence the lives of people with intellectual disabilities. Notable changes include key reforms related to deinstitutionalisation and community living (Health Service Executive 2011), disability service provision (Department of Health 2012), person-centred day services (Health Service Executive 2012), supported decision-making (Government of Ireland 2015a) and employment (Government of Ireland 2015b, 2017). Within this evolving policy context, an important question concerns whether and to what extent, changes are evident in the lives of people with intellectual disabilities. These developments have implications across multiple domains, including living arrangements, access to technology, social participation and healthcare utilisation, which are reflected in the measures examined in this study. To assess these changes over the past decade, this paper compares a range of health, well-being and social inclusion measures for two generations of IDS-TILDA participants aged 40–49, with data collected in 2011 and 2023.

Regarding social measures, for internet use and mobile phone ownership, this study found a significant increase between waves, likely influenced by broader societal shift, particularly the rapid digitalisation prompted by the COVID 19 pandemic in Ireland (McCausland et al. 2021). The same pattern has been seen in other studies, with a higher proportion among those with mild level of intellectual disability (Kim and Lee 2020; Bakkum et al. 2021). The increased use of internet and mobile phones may improve work-related and leisure activities, enhance the feeling of independence, quality of life and develop digital skills (Cihak et al. 2015; Kim and Qian 2019; Kim and Lee 2020). Additionally, it may have improved the connectedness with friends and family (Martin et al. 2021). Despite this progress, digital inclusion among people with intellectual disability remains lower than that of the general population, where mobile phone ownership stands at approximately 96% (McCarron et al. 2023), underscoring the need for continued investment in equitable access.

Weekly contact with friends had considerably increased between waves and from findings in other studies, the use of technology may have played an important role in facilitating this change. For instance, there have been reports that digital inclusion and mobile technology have strengthened connections between individuals with intellectual disabilities and their friends (Martin et al. 2021; Caton et al. 2022) as well as enhanced engagement in social activities (Danker et al. 2023; Martin et al. 2021).

Significant wave differences were also seen regarding help given and received from friends or neighbours in the previous two years. For help given, a rise was seen among unemployed, while for help received, the increase occurred in the community group home. These results suggest a population more involved

in social relationships in Wave 5, which may reflect broader shifts towards community-based living and social inclusion, as promoted in national disability policies (Woodman et al. 2014). Giving and receiving help and their effect on well-being, have been studied over the last few decades. A systematic review and meta-analysis of the experimental kindness literature suggest that giving help improves the well-being of the actor (Curry et al. 2018) and increases feelings of trust and belonging in those who receive help (Gur and Bina 2022).

With respect to self/proxy-rated health, in Wave 5, 100% of individuals rating their health as at least good, a significant increase from Wave 1 (87.9%). A similar increase was observed for self/proxy-rated mental health, along with a decrease in feelings of loneliness. Improvements may, in part, be an outcome of the cumulative impact of the mentioned changes. Individuals with higher levels of independence, along with received and perceived support, typically report better scores for general health and well-being (Alonso-Sardón et al. 2019). While these findings suggest positive changes over time, they should be interpreted within the context of wider societal changes. Evidence from the general population indicates that levels of poor self-rated health and loneliness remain lower than those typically observed among people with intellectual disabilities. In the general population, self-perceived health is closely associated with factors such as social vulnerability and frailty (Orlandini et al. 2024). Among people with intellectual disabilities, the same outcome may also be influenced by societal expectations, disability-related limitations and reduced opportunities for independent social engagement (Stokes et al. 2025). Together, these findings highlight the role of systemic social and structural inequalities in shaping health and well-being for people with intellectual disabilities (Gilmore and Cuskelly 2014).

In terms of behavioural aspects, individuals with intellectual disabilities typically consume less alcohol and other substances compared to the general population (Salavert et al. 2018; Swerts et al. 2017). However, this study found a rise in alcohol consumption from 2.7% to 37.7% in Wave 5, although this increase was slightly lower than the 45.5% reported by Swerts et al. (2017) in Belgium. The reasons behind alcohol consumption among people with intellectual disability remain unclear. A qualitative study conducted in New Zealand found that individuals in this group tend to drink moderate amounts of alcohol when socialising with family, friends, or at celebratory events. The main influences on alcohol consumption were family, observing others in the community drinking and media portrayals (Gee et al. 2020). A population-based cohort study in Sweden indicated that individuals with mild intellectual disabilities face an increased risk of substance use-related problems, including alcohol use disorder and alcohol-related somatic disorders (Påhlsson-Notini et al. 2024).

While it is important to note that this study did not assess the frequency or amount of alcohol consumed, which may limit the interpretation of the results, greater attention should be given to understanding the factors influencing alcohol use among individuals with intellectual disabilities aged 40–49 years in Ireland. This is particularly relevant when considered in the context of broader population trends, where recent public health efforts have been associated with expectations of stabilisation or decline in alcohol use in the general population, especially in parts of Western Europe and North America (Shield et al. 2025), highlighting the role of policy and social norms. Further research is needed to determine whether these trends extend to people with intellectual disabilities and to inform tailored approaches to alcohol use in this population. In this study, there was an increase in the number of people engaging in vigorous exercise, though this change was not statistically significant. However, decision tree analyses revealed a significant decrease in participation in mild and moderate exercise between waves. The reasons for this decline are unclear, but there is evidence suggesting it may be linked to the pandemic lockdowns, which led to a general reduction in physical activity across both the general population and people with various disabilities (McCarron et al. 2021; McCausland et al. 2021; Murphy et al. 2020). This decline was particularly noticeable in activities that typically involve interaction in confined spaces (Cho et al. 2022). These changes may also reflect disruptions to structured supports and services that facilitate physical activity among people with intellectual disabilities.

Regarding healthcare utilisation, the decision tree analysis revealed a significant increase in visits to opticians, neurological services and dermatological services between waves. In contrast, there was a notable decrease in visits to GPs, occupational therapy (apart from those in community group homes), social work, home help, dental services and dietician consultations. For psychological services, an increase was observed among individuals living independently, while those in residential and community group homes experienced a decline. It remains to be explored whether these changes reflect improved monitoring and management of utilisation in Wave 5, as opposed to the earlier pattern in Wave 1 where appointments, particularly in residential settings, were scheduled routinely rather than based on identified needs.

People with intellectual disabilities have been reported to be at a higher risk of having limited or no access to healthcare professionals, particularly those with milder forms of intellectual disability, individuals living with family carers or independently and those associated with smaller provider agencies that do not employ healthcare professionals (Doyle et al. 2020). The literature indicates that healthcare professionals in Ireland tend to focus on individuals with more severe disabilities, particularly those in residential settings (McCarron et al. 2018). However, the analyses in these studies included demographic but did not include chronic condition variables in their analyses. Changes in residential settings may also have affected the continuity of care and healthcare delivery models, particularly in the context of the transition from institutional to community-based provision and the shift towards more needs-led approaches.

A national survey in Canada reported an association between individuals with intellectual disabilities living alone or with family and poorer access to health services compared to those in community settings (National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute 2019). However, Maltais et al. (2020) found that while people with intellectual disabilities accessed a wide range of health services, the presence of specific health

conditions was associated with increased access to the corresponding healthcare professionals. More work is needed to better understand the associations between demographics of persons with intellectual disabilities, places lived in and health conditions experienced.

The observed increases in social engagement and independence, alongside persistent inequalities in areas such as health and access to services, reflect the complex nature of inclusion for people with intellectual disabilities. While these outcomes may be influenced by policy and legislative developments, they are also shaped by societal attitudes and the extent to which individuals are recognised and accepted as equal members of the community (Lombardi et al. 2019; Mittler 2015; Parmenter 2024). In this context, policies and frameworks such as the Convention on the Rights of Persons with Disabilities provide an important foundation, although they are not sufficient on their own to reduce inequalities (Gomez et al. 2024). The translation of rights into lived experiences requires not only policy and legislative developments, but also adequate supports, inclusive practices, appropriate measurement and evaluation tools to monitor implementation and broader societal change (Gomez et al. 2024; Parmenter 2024; Morán et al. 2023). Within this context, the present findings illustrate how these broader processes are reflected in practice. Changes were observed among individuals aged 40–49 years over the past 12 years across health, healthcare utilisation and social inclusion. In general, the results suggest some improvements in terms of social inclusion and healthcare utilisation related to residential settings, which may be an impact of deinstitutionalisation and community living policy (Health Service Executive 2011). These trends may point to more positive experiences of daily life, including greater opportunities for participation, autonomy and access to support within the community. On the other hand, the prevalence of multimorbidity remained unchanged, highlighting the complexity of health outcomes in this age group across physical, cognitive, psychological and behavioural domains. Regardless of setting and wave of data collected there is still a need to understand and better address the multimorbidity people with intellectual disabilities experience.

Additionally, the shift to more independent living environments may positively impact access to healthcare services, an area that requires further investigation. Conversely, such transitions leading to greater autonomy appear from the data to be associated with increased alcohol consumption and other less healthy behaviours, pointing to emerging lifestyle challenges. These patterns suggest a complex interplay of social, emotional, environmental and educational factors, all of which should be considered in future evaluations.

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Ethics Statement

IDS-TILDA received ethical approval from the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee and from all participating disability service providers at both Waves 1 and 5.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Figure S1:** CHAID Decision tree for contact with family. **Figure S2:** CHAID Decision tree for contact with friends. **Figure S3:** CHAID Decision tree for help received in the last 2 years. **Figure S4:** CHAID Decision tree for help given in the last 2 years. **Figure S5:** CHAID Decision tree for regular community activities. **Figure S6:** CHAID Decision tree for use of internet and/or email. **Figure S7:** CHAID Decision tree for mobile phone ownership. **Figure S8:** CHAID Decision tree for alcohol consumption. **Figure S9:** CHAID Decision tree for smoking. **Figure S10:** CHAID Decision tree for being on a special diet. **Figure S11:** CHAID Decision tree for moderate exercise. **Figure S12:** CHAID Decision tree for mild exercise. **Figure S13:** CHAID Decision tree for self/proxy-rated health. **Figure S14:** CHAID Decision tree for multimorbidity. **Figure S15:** CHAID Decision tree for self/proxy-rated mental health. **Figure S16:** CHAID Decision tree for loneliness. **Figure S17:** CHAID Decision tree for GP visits in the last year. **Figure S18:** CHAID Decision tree for receiving occupational therapy services in the last year. **Figure S19:** CHAID Decision tree for receiving physiotherapy services in the last year. **Figure S20:** CHAID Decision tree for receiving social work services in the last year. **Figure S21:** CHAID Decision tree for receiving chiropody services in the last year. **Figure S22:** CHAID Decision tree for receiving psychological/counselling services in the last year. **Figure S23:** CHAID Decision tree for receiving optician services in the last year. **Figure S24:** CHAID Decision tree for receiving home help services in the last year. **Figure S25:** CHAID Decision tree for receiving dental services in the last year. **Figure S26:** CHAID Decision tree for receiving dietician services in the last year. **Figure S27:** CHAID Decision tree for receiving hearing services in the last year. **Figure S28:** CHAID Decision tree for receiving neurological services in the last year. **Figure S29:** CHAID Decision tree for receiving dermatological services in the last year. **Figure S30:** CHAID Decision tree for having medical insurance.