6 Methodology

Rachael Carroll, Eilish Burke, Philip McCallion and Mary McCarron.

Contents

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6.1 Key Findings

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

6.2 Target population at Wave 2

The IDS-TILDA sample was originally drawn from The National Intellectual Disability Database (NIDD) which collates information on all people with an ID in the Republic of Ireland eligible for or receiving services (Kelly & Kelly, 2007). The population included persons with all levels of ID, and the full range of residential circumstances age 40 years and over were selected, as opposed to TILDA who selected those age 50 and over. This reflects the fact that people with ID present with older age conditions at a much younger age, accounts for the lower longevity of people with ID, and ensures that there would be sufficient subjects for future waves of data collection, thus providing opportunities for insights into ageing for those who may age prematurely. The completed Wave 1 sample was 753 persons with an ID, aged 40 and older; which

represented 46% from the drawn sample, comprising 8.9% of the total population of persons aged 40 and over registered on the 2008 NIDD database. Comparison with the published demographics of the 2008 NIDD cohort confirmed that the IDS-TILDA sample was also representative of the larger sample. In Wave 2, considering the impact of deaths and those lost to follow-up, the continued representativeness of the sample was also assessed (see section 6.2 for greater detail) and it was determined that the sample continued to be representative.

6.2.1 Recruitment

In 2013, IDS-TILDA interviewers contacted each of the living original 753 first wave participants, 719 individuals in all, and invited them to take part in the next Wave of the study. No active recruitment of new respondents was carried out at Wave 2.

6.3 Refinement of Protocol

Before completing the CAPI, each respondent received and completed a pre-interview questionnaire (PIQ). This questionnaire repeated a range of questions covering demographics, health status, healthcare utilisation and medicine usage with some additional detail such as gathering more complete data on dosage and frequency of medications.

Each respondent or a proxy then completed a computer-assisted personal interview (CAPI) in their own residence which included detailed questions regarding socio-demographic characteristics, physical health, behavioural health, mental and cognitive health, social participation and social connectedness, health care utilisation, employment, income and life-long learning.

The CAPI questions in Wave 2 were largely a repeat of the questions asked in Wave 1. However, reflecting input from the scientific advisory committee, Wave 1 questions unlikely to change were not repeated. Such questions included aetiology of ID, and date of birth. A number of other questions were amended to obtain further detail. A number of new questions were added to obtain greater insight into issues which emerged from Wave 1 findings, and to better ensure an ability to consider over time the impact of the implementation of strategies related to new policy directions emerging from congregated settings report, the disability strategy, and changes contemplated in the changing structure of health care delivery. In particular there has been an interest to align IDS-TILDA in ways to measure how well the lives of people with ID are reflecting the priorities of *Healthy Ireland; A framework for Improved Health and Wellbeing 2013-2025* (DoH, 2013). Some examples of new questions were supplemental questions on emerging health concerns such as constipation, dental concerns and obesity; a life events questionnaire and questions

on numeracy and literacy competence, as well as questions designed to track transitions in living situations.

Throughout this process the research team also worked to ensure that opportunities for comparisons with TILDA data were not lost but rather enhanced. A total of 77 new questions were added, 16 questions were modified and a further 98 were removed (see table 6.1 for details on rationale of amendments). Prior to conducting Wave 2 interviews, all new and amended questions were then examined by focus groups of people with ID who assessed and offered insights on the most effective wording. The research team then finalized the protocol and arranged for its development as a CAPI.

Table 6.1: Amendments to Wave 2 protocol, items removed or modified and rationale.

Instrument: Pre-Interview Questionnaire		
New Questions	15	• To improve comparability with TILDA. • To extend and build on data gathered in Wave 1. • To reflect policy changes.
Modified Questions	9	• To improve flow of questions & understanding • To reduce participant burden • To clarify for analysis purposes • Some questions have been amalgamated as an extra option in other questions
Removed Questions	12	• Data already collected and will not change for Wave 2. • To reduce participant burden
Instrument: Main Questionnaire		
New Questions	62	• To improve comparability with TILDA. • To extend and build on data gathered in Wave 1. • To reflect policy changes. • To replicate government recommendations and health promotion.
	7 Objective measures	• To support the accuracy of self-report data ensure comparable analysis • To improve comparability with TILDA. • To pioneer instrument development to improve health markers for people with intellectual disability and so assist with confirming levels of both frailty and of independence. • To develop objective baseline health markers for PWID therefore enabling the identification of critical concerns in the advance of ageing.
Modified Questions	7	• To improve flow & understanding of questions • To clarify for analysis purposes
Removed Questions	86 (Which includes 2 instruments IDS-TILDA did not administer in Wave 2)	• To reduce the participant burden • Not necessary to gather a second time e.g. DOB. • Too soon to identify any significant change -may be reintroduced in subsequent waves.

An additional interview on end of life issues to be completed by carers on those who had died since Wave 1 and a health assessment were introduced at Wave 2. The carer end of life interviews are carried out for deceased participants within 6 – 12 months of death. Services notified IDS-TILDA of a death and the end of life interview was completed with a primary care giver/key worker who cared for the participant in the final stages of life.

6.4 Response rates

Of the original 753 Wave 1 respondents, 708 completed at least one element of Wave 2. As may be seen in Table 6.1, 595 participants completed all elements of PIQ, CAPI and health assessment, 104 completed the PIQ and CAPI only, 7 completed the health assessment only and 2 completed the PIQ only.

Table 6.2: Wave 2 participation.

		Frequency	Wave 1 Percent	Wave 2 Percent
Wave 2	PIQ, CAPI and Health Assessment	595	79.02	84.04
	PIQ and CAPI only	104	13.81	14.69
	Health assessment only	7	0.93	0.99
	PIQ only	2	0.27	0.28
	Total	708	94.02	100
Missing	No element of Wave 2	45	6.0	
Total		753	100	

The Wave 2 response rate is calculated as the number who completed at least one element of the Wave 2 data collection as a percentage of the original Wave 1 respondents. This yielded an overall response rate of 94.02%. The number of respondents (*N* = 708) by age, gender and level of ID is provided in Table 6.2 (a) as are the corresponding number of registrations on the NIDD in 2008 (*N* = 7381) from which the sample was originally selected. The corresponding proportions are then given in Table 6.2 (b). Although there are some differences in individual proportions the sample remains largely representative of overall NIDD figures.

Table 6.2 (a): Wave 2 response rates by age, gender and level of ID and corresponding NIDD registrations.

Level of Intellectual Disability											
		Unknown/Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age		Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	IDS-TILDA	6	3	2	3	17	19	45	47	29	30
43 -49	NIDD	37	33	26	22	373	384	592	527	451	329
50-64	IDS-TILDA	10	10	2	4	38	56	55	86	44	54
50-64	NIDD	54	24	44	25	481	483	742	822	463	422
65+	IDS-TILDA	2	6	5	1	14	13	28	43	16	20
65+	NIDD	16	13	15	10	116	148	226	280	110	113
Total	IDS-TILDA	18	19	9	8	69	88	128	176	89	104
	NIDD	107	70	85	57	970	1015	1560	1629	1024	864

Table 6.2 (b): Wave 2 response rates by age, gender and level of ID and corresponding NIDD registrations proportions.

Level of Intellectual Disability											
		Unknown/Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age		Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	IDS-TILDA	0.85	0.42	0.28	0.42	2.4	2.68	6.36	6.64	4.1	4.24
43 -49	NIDD	0.5	0.45	0.35	0.3	5.05	5.2	8.02	7.14	6.11	4.46
50-64	IDS-TILDA	1.41	1.41	0.28	0.56	5.37	7.91	7.77	12.15	6.21	7.63
50-64	NIDD	0.73	0.33	0.6	0.34	6.52	6.54	10.05	11.14	6.27	5.72
65+	IDS-TILDA	0.28	0.85	0.71	0.14	1.98	1.84	3.95	6.07	2.26	2.82
65+	NIDD	0.22	0.18	0.2	0.14	1.57	2.01	3.06	3.79	1.49	1.53
Total	IDS-TILDA	2.54	2.68	1.27	1.13	9.75	12.43	18.08	24.86	12.57	14.69
	NIDD	1.45	0.95	1.15	0.77	13.14	13.75	21.14	22.07	13.87	11.71

Table 6.2 (c) does show that there was a decrease in Wave 2 in the percentage of respondents in the youngest age group. This decrease was not unexpected as the sample was not replenished at Wave 2. A corresponding increase was also observed in the older age groups in line with the aging of the sample. Gender and levels of ID were largely unchanged.

Table 6.2 (c): Wave 1 and Wave 2 response rates by age, gender and level of ID.

	Wave 1 %	Wave 2 %
Age at Wave 1:		
40-49	38.2	28.1
50-64	45.6	51.0
65+	16.2	20.9
Gender:		
Male	44.9	44.5
Female	55.1	55.5
Level of ID:		
Mild	23.9	24.0
Moderate	46.5	46.5
Severe/Profound	29.6	29.5

6.4.1 Reasons for non-response and attrition at Wave 2

A total of 45 Wave 1 respondents did not participate in Wave 2. See tables 6.3 (a) and 6.3(b). Of these 76% (*n*= 34) had died and 24% (*n*= 11) refused to take part in at least one element of Wave 2.

Table 6.3 (a): Reasons for non-response.

Reasons for Attrition	Number	Percent
Deceased	34	76
Refusal	11	24
Total	45	100

Table 6.3 (b) examines Wave 2 attrition by age, gender and level of ID. The highest proportion (61%) of those who refused had a mild ID.

Table 6.3 (b): Attrition at Wave 2 by age, gender and level of ID.

		Level of Intellectual Disability								
		Not Verified		Mild		Moderate		Severe/Profound		
Age at Wave 1		Male	Female	Male	Female	Male	Female	Male	Female	Total
40-49	**Refusal**	0	0	1	2	0	0	0	0	3
	Deaths	0	0	0	0	2	1	3	0	6
50-64	**Refusal**	0	0	1	3	0	0	0	0	4
	Deaths	1	0	0	0	2	4	4	3	14
65+	**Refusal**	0	2	0	1	0	0	0	0	3
	Deaths	0	0	1	0	7	3	0	3	14
Total	**Refusal**	1	2	4	7	2	1	0	1	11
	Deaths	1	0	1	0	11	8	7	6	34

Note: For one participant who refused their age and level of ID were unknown

The strong retention rate achieved by IDS-TILDA may be at least partially attributed to a comprehensive post-Wave 1"keeping in touch" strategy used by IDS-TILDA which included sending greeting cards to mark all holiday occasions, organizing occasional competitions, mailing regular newsletters and providing regular updates on the IDS-TILDA website.

6.5 Field researcher training

Consistent with the approach in Wave 1, all field researchers recruited for this Wave (*n*=22) were required to have experience with people with ID and field researchers were selected from across the country to ease the process of completing interviews in a timely manner.

Attendance at three days of a standardized training was required for all field researchers and the topics covered included: 1) effective scheduling and interviewing, 2) confirming assent, 3) administering the CAPI protocol, the Test for Severe Impairment, and the mental health tools, 4) maintenance of quality and 5) confidentiality in all protocol administrations. Researchers were also trained to upload all CAPI materials to a secure share drive to be completed immediately after interviews.

6.6 Dataset

The results provided in this report are based on the IDS-TILDA dataset version 2.0.0 which comprises PIQ, CAPI and Health Assessment data from all 708 Wave 2

respondents. Various subsamples reported throughout this report are defined in the relevant sections. End of life and health assessment data will be reported separately.

6.7 Objective physical health measures

The physical health measures were comparable to those used in TILDA and included grip strength, waist to hip measurement, height, weight, Ulna length and Mid upper arm circumference, blood pressure, timed up and go, and Quantitative Ultrasound (QUS). The assessments, measures used, related equipment and rationale for their use are summarized in Table 6.4.

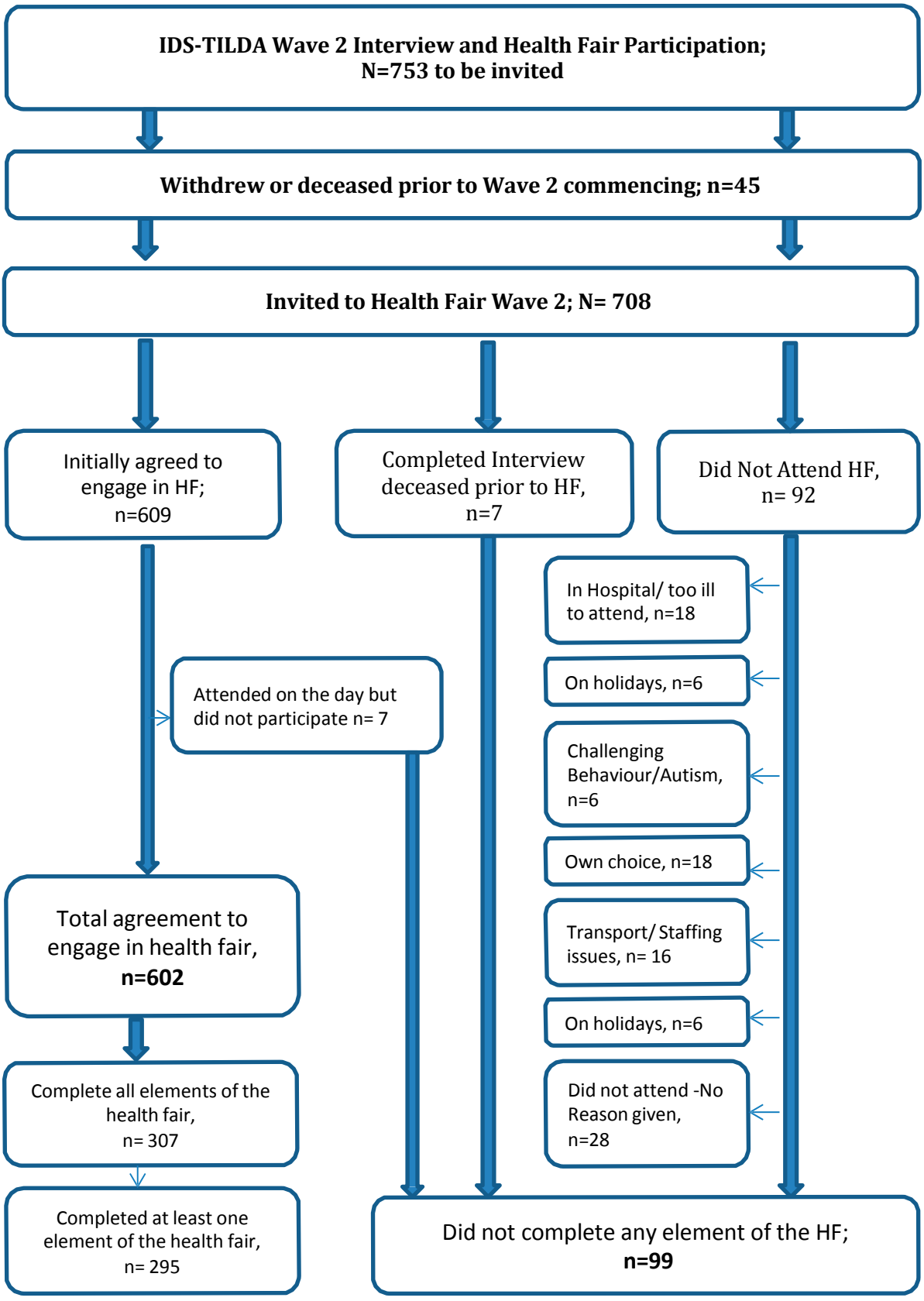
Table 6.4: Summary of assessments included in the Health Fair.

Assessment	Measurement	Equipment used	Rationale
Grip Strength	2 (alternately on each hand)	Hydraulic hand dynamometer	Diminished handgrip is associated with premature mortality, disability and other health risks of older adults.
Blood Pressure	4 (Two sitting & two standing)	Digital automated oscillometric blood pressure monitor (Omron M10-IT)	Hypertension is an important risk factor for cardiovascular disorders such as stroke, angina or myocardial infarction. Orthostatic hypotension can be indicative of unexplained falls in the elderly.
Waist size	2	SECCA tape measure	Central obesity is an indicator of the risk of diabetes and heart disease. Waist to hip ratio provides vital information on body fat distribution
Hip size	2	SECCA tape measure	Waist to hip ratio provides vital information on body fat distribution
Timed up and go (TUG test)	1	Standardised chair, tape, measuring tape and stopwatch	Assess proximal muscle strength, balance and gait speed which reflects general health and functional status.
Height	1	SECCA wall mounted standiometer	Used to calculate Body Mass Index (BMI)
Weight	1	SECCA digital floor scales	Used to calculate BMI
Bone Mineral Density	2 (right heel and left heel)	GE Achilles Quantitative Ultrasound (QUS)	Osteoporosis increases with age QUS method of assessing bone strength and osteoporotic fracture risk

Note: Not all of these measures are reported on in this report as analyses are continuing.

The scientific advisory committee, field experts and self-advocacy groups advised on effective completion of each specific measure and reviewed the accessible materials intended to promote engagement and participation. Similar to the main questionnaire focus groups of people with ID reviewed the materials and administration also.

Figure 6.1: Health Fair Attendance Flow Chart (Burke *et al.*, 2014).



All participants in IDS-TILDA Wave 2 (*N*=708) were invited to participate in the objective health assessments. In total, 609 participants agreed to take part with 7 participants changing their minds on the day (*n*=602). Of those who took part, 51% (*n*=307) completed the objective measures in their entirety and 49% (*n*=295) completed at least one measure (see *figure 6.2*).

The difficulties encountered by the participants who were unable to complete the health assessments included immobility, challenging behaviour and poor comprehension of the assessment or technique needed to complete the assessment, for example understanding the concept of the grip strength posed some of the greatest challenges for a number of participants.

Quality of assessments was influenced by location, experience of the assessor and the supportiveness of the assessment environment. Again, informed by the Scientific Advisory Committee and focus groups conducted with people with ID:

- Assessments were conducted in familiar service provider environments
- A Health Fair format was developed designed to be non-threatening and encouraging of participation
- All assessments were supported with easy read pictorial description which the health assessor used to explain and demonstrate the procedure
- Augmented and alternate communication was utilised such as 'hand over hand' modelling or Lamh to ensure clear understanding and promote participation
- All assessments were performed by the same assessor, someone with considerable experience in working with people with ID, using practiced standardized assessment approaches
- A preliminary feasibility study established the value of procedures and any adaptations to support participant engagement.

6.8 Analytical methods employed in this report

6.8.1 Confidence intervals and statistical significance

The majority of the estimates in this report are the percentage (or proportions) of older people with ID who fall into various groups and/or averages (mean or median) of the responses. The IDS-TILDA sample is a representative sample of the population of interest, but there is uncertainty in these estimates due to the sampling process. To reflect this uncertainty 95% confidence intervals including continuity correction are provided where appropriate. The confidence interval can be interpreted to mean in 95% of the confidence intervals in repeated sampling the true population mean will be included. Smaller confidence intervals indicate more precise estimates.

6.8.2 Weighting

Weighting was not applied in Wave 1 or Wave 2 of IDS-TILDA analyses. Table 6.5 includes the p-values for the results of a z test for significant difference between proportions of the various levels of ID in IDS-TILDA as compared to NIDD. The majority of sub categories by age, gender and level of ID did not differ significantly from the population (NIDD) from which the IDS-TILDA sample was drawn. There were, therefore, no systematic differences to be accounted for in Wave 2 estimates.

Table 6.5: P-values for test for significant difference in proportions between Wave 2 participants and corresponding NIDD proportions in 2008.

	Level of Intellectual Disability									
	Unknown/ Missing		Not Verified		Mild		Moderate		Severe/Profound	
Age	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
43-49	0.23	0.93	0.76	0.56	<0.001	<0.001	0.12	0.62	0.03	0.79
50-64	0.05	<0.001	0.29	0.34	0.23	0.16	0.05	0.42	0.95	0.04
65+	0.73	<0.001	0.01	0.97	0.41	0.76	0.19	<0.001	0.11	0.01
Total	0.02	<0.001	0.78	0.31	0.01	0.33	0.06	0.09	0.34	0.02

6.8.3 Software

All analysis presented in this report was conducted using SPSS 21.0.

6.9 Limitations of this report and future analysis

Although the IDS-TILDA sample is representative of the NIDD, it may not be fully representative of all those with an intellectual disability in Ireland as some may be unknown to NIDD data collection mechanisms which rely heavily on provider services.

The report has described the health and well-being of persons with ID as they age in Ireland. These analyses are preliminary and of a descriptive nature. Future analysis using the dataset will include more complex statistical modelling to provide in depth explorations that are outside the scope of this report.

This is the first report to document changes over time in the IDS-TILDA population. However, changes presented in this report are over a relatively short period of three years and for many measures and questions this has not been a long enough period to observe substantive change. Additional objective measures of health were introduced in Wave 2 to enhance the opportunities to better understand health status and opportunities for change consistent with the Healthy Ireland policy

document desire for everyone including health disparity populations such as people with ID to enjoy the fullest physical and mental health and wellbeing. As the study matures and the numbers of waves increases, the opportunities to compare with TILDA are sustained and key policy concerns continue to be tracked, change will be measured more precisely, enabling a greater understanding of the key determinants of health and well-being of older adults with an intellectual disability in Ireland.

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