

User Information Guide
**The Intellectual Disability Supplement to The Irish Longitudinal
Study on Ageing (IDS-TILDA)**
2024

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

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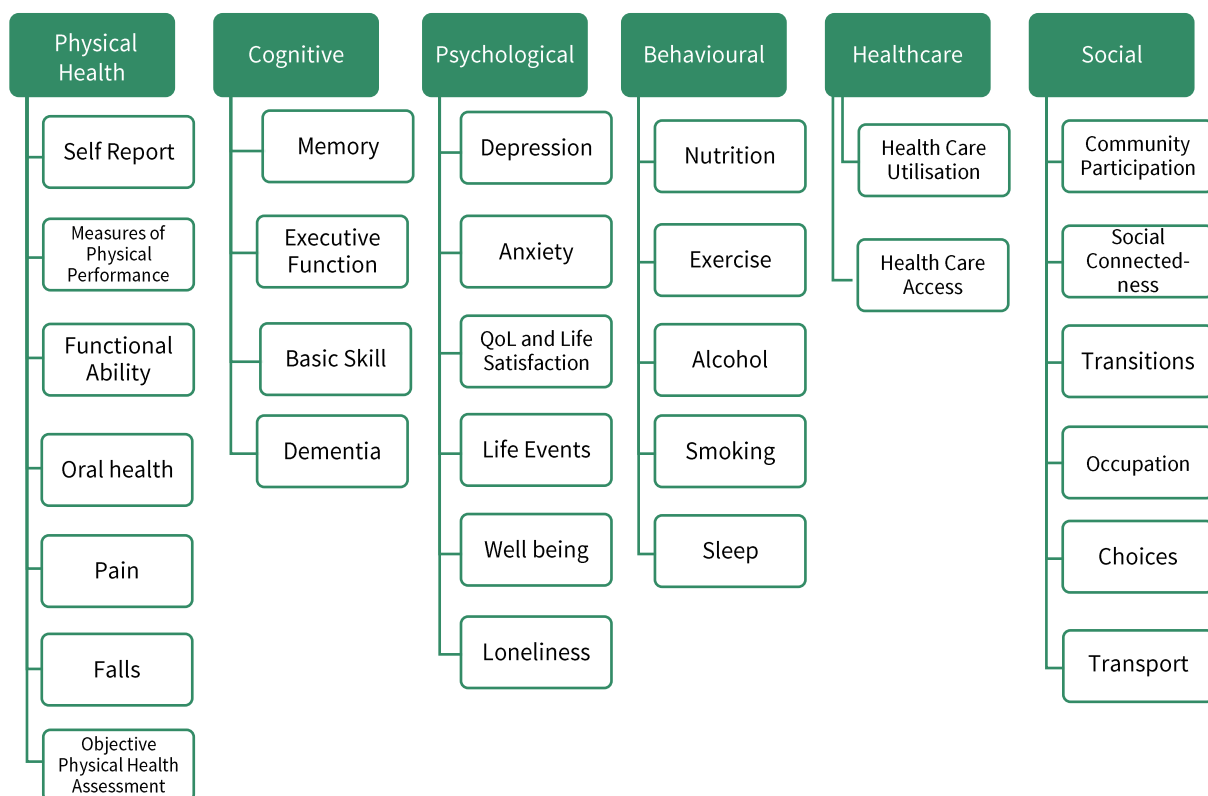
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The IDS-TILDA study

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) was established in 2008 with the aim to identify the principal influences on ageing in people with an intellectual disability in the Republic of Ireland aged 40 years and above. The study seeks to characterise and understand changes in ageing by examining healthy and successful ageing, determinants of health and longevity, and similarities or differences in ageing for those with and without intellectual disability using comparative data from the Irish Longitudinal Study on Ageing (TILDA) for the general population. IDS-TILDA was the first longitudinal study on ageing amongst the intellectual disability population worldwide to be implemented parallel to a study of ageing amongst the general population. The conceptual framework shown in Figure 1 illustrates the range of data collected by IDS-TILDA.

Figure 1. IDS-TILDA conceptual framework



The study is also underpinned by a set of core values including inclusion, empowerment, choice, person centeredness, best practice, promoting people with intellectual disability and making a positive impact on their lives. IDS-TILDA was developed in close cooperation with people with an intellectual disability, who have played an integral role throughout the development of the study.

Involvement of people with an intellectual disability began with the initial pilot study conducted to develop inclusive Wave 1 protocols and has continued through consultation on changes for each subsequent wave. A ‘keeping in touch’ strategy – for example using newsletters, cards and art competitions – is also integral to maintaining the voice of people with an intellectual disability as well as engaging people and preserving the study sample through multiple waves of data collection.

The first three waves of IDS-TILDA were reported in 2011 (McCarron et al., 2011), 2014 (Burke, McCallion, & McCarron, 2014) and 2017 (McCarron, Haigh, & McCallion, 2017). This established the study as a global leader in research on ageing among people with intellectual disability, contributing to policy and service development in Ireland, and supporting the establishment in 2018 of the Trinity Centre for Ageing and Intellectual Disability (TCAID) at Trinity College Dublin (TCD)¹. The fourth wave of the longitudinal study was interrupted in March 2020 by the outbreak of COVID-19 while data collection was ongoing. Adapting to the emerging crisis, and following ethical approval, the IDS-TILDA study resumed data collection in May 2020 using remote interviewing and with the addition of a survey of the impact of COVID-19 among IDS-TILDA participants. And finally, the fifth wave of the IDS-TILDA study was reported in 2023 (McCarron, Haigh, Dann, & McCallion, 2023).

For recruitment of the original study sample at Wave 1, the Health Research Board (HRB) supported use of the National Intellectual Disability Database (NIDD) to anonymously recruit adults with an intellectual disability aged 40 years and above in the Republic of Ireland. The final Wave 1 sample of 753 demographically and geographically representative of the target population within the NIDD, equating to 8.9% of the total eligible population at the time. The sample was 45% male and 55% female; aged 41 to 90 years (mean age 54.7 years); 24% had a mild ID, 46% moderate ID, 24% severe ID, and 5% profound ID (with 5% unverified). Around 40% lived in 52-week residential care centres, with a further 5.3% in other residential centres (i.e. 45.3% in ‘institutional’ or ‘congregated’ residential care settings); around one-third (34.1%) lived in community group homes with other individuals with intellectual disability; 5% lived independently or semi-independently; and 11% lived at home with their families (McCarron et al., 2011).

The retention rate for Wave 2 of IDS-TILDA was 94%, with a final sample of 708 completing at least one element of the study. At Wave 3, a surviving sample of 609 participants equated to 80.9% of the original Wave 1 sample. Of the 144 participants lost to the study by Wave 3, 105 had died and 39 had withdrawn.

To maintain adequate statistical power and ensure the representativeness of the study, additional recruitment was planned for Wave 4. As in Wave 1, HRB supported use of NIDD to anonymously recruit sufficient numbers of new participants to restore the sample to its Wave 1 size and representativeness. A targeted recruitment drive successfully addressed

¹ <https://www.tcd.ie/tcaid/>

underrepresented groupings including in the 40-49-year-old category. A final representative sample of 739 individuals was achieved for Wave 4 with 135 new participants in the new 40-49-year-old cohort.

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).

Data pseudonymisation process

The IDS-TILDA study collects sensitive information from a small representative sample of a relatively small population group, when compared to the size of the general ageing Irish population. IDS-TILDA information is often used by people who work within the intellectual disability (ID) sector, many of whom know the ID population well. Thus, for someone in such a position, it may be possible to determine the identity of a participant based on a few pieces of information viewed together. As such, it has always been the highest priority of IDS-TILDA to ensure that the participants' information remain protected and, by extension, access to the data is strictly controlled.

In order to make the data available, while making sure that the identities of the IDS-TILDA participants remain protected, an extensive data de-identification process was undertaken during which a number of variables had to be excluded from the dataset due to personal identification concerns.

As per McGrath and Hanan (2016), variable cell sizes of 20 or more ensure that data are sufficiently anonymised. This criterion was used as the basis of the pseudonymisation process that was carried out over several rounds of data analysis. It was decided that the cell size cut-off criteria would be 20 or more for frequencies of the variable itself, whereas the cell cut off criteria was decided to be 10 for crosstabs between variables. This decision was made because very few pairs of variables were fulfilling the criteria for 20 cell size. Retention of variables was decided with utmost scrutiny after having several discussions with the section leads. In some cases, variables with less than 10 cell size were retained due to the low identification nature of the variable but it was never retained if the cell size was less than 5.

At each round of de-identification, the variables were assessed on a case-by-case basis. Each variable was summarised by category, and the frequencies were compared to the cut-off of 20. Variables that did not meet the criteria were either removed or considered for regrouping, combination with other variables. Each variable was also cross tabulated with specific demographic variables, namely sex, age, ID aetiology, ID level and residence type, and the resulting cell counts were compared to the cut-off of 10. Cross tabulation results showed that there were very few people in the down syndrome category when cross tabulated with other variables therefore, aetiology as a variable was dropped from the dataset. Similarly, level of intellectual disability was dropped because there were cells less than 5 in the cross-tabulation result of level of intellectual disability with other variables. Due to similar reasons, age category variable was regrouped as '40+'.

Pseudonymised Datasets

There can be errors or inaccuracies in the dataset and documentation. We request you to contact the IDS-TILDA Project Manager via email, HAIGHM@tcd.ie, in the event of any errors or if you have any queries.

Wave 1

The version V1.0 pseudonymised dataset includes data from 753 IDS-TILDA participants interviewed at Wave 1. This includes data from the Computer Assisted Personal Interview (CAPI), Pre-Interview Questionnaire (PIQ) and other variables derived from these data. More information on these derived variables can be found in the 'Derived Variable Codebook_Wave1_IDS-TILDA_V1.0'.

Wave 2

The version V1.0 pseudonymised dataset includes data from 708 IDS-TILDA participants interviewed at Wave 2. This includes data from the Computer Assisted Personal Interview (CAPI), Pre-Interview Questionnaire (PIQ) and other variables derived from these data. More information on these derived variables can be found in the 'Derived Variable Codebook_Wave2_IDS-TILDA_V1.0'.

Wave 3

The version V1.0 pseudonymised dataset includes data from 609 IDS-TILDA participants interviewed at Wave 3. This includes data from the Computer Assisted Personal Interview (CAPI), Pre-Interview Questionnaire (PIQ) and other variables derived from these data. More information on these derived variables can be found in the 'Derived Variable Codebook_Wave3_IDS-TILDA_V1.0'.

More information on the findings is available on the IDS-TILDA website ([Reports - Trinity Centre for Ageing and Intellectual Disability - Trinity College Dublin \(tcd.ie\)](https://reports-trinitycentreforageingandintellectualdisability-trinitycollege.dublin.tcd.ie)).

Variable Naming

Variables from the Computer Assisted Personal Interview (CAPI) use a standard naming convention: the module code followed by a digital question code (e.g. PC_3).

For questions where multiple answers are possible or where questions are looped across a number of people or objects the root variable name is followed by an underscore and an additional number or word (e.g. PC_1_Eat_Recode).

All variables from the pre-interview questionnaire are prefixed with 'Q'.

Demographic variables and prevalence of health conditions have the prefix 'W1', 'W2', and 'W3'.

For more information, kindly refer to the variable codebooks.

Table 1: Variable codes

Variable Prefix	Research Area
CS	Cover screen
CH	Cognitive health
SP	Social participation
DR	Transport
SC	Social connectedness
PC	Personal choice
OC	Occupation
LE	Lifelong learning
DS	Day service
SI	Sources of income
PH	Physical health
BH	Behavioural health

Missing Codes

In this dataset, all the missingness was clubbed into one value as '999'. Missingness includes genuine missingness and as well as none, unclear response, don't know and refused to answer. If the question was skipped due to routing, it was assigned -1.

Citation and acknowledgement

When using the IDS-TILDA Wave 1 dataset, please cite the relevant publications from the following list:

- McCarron, M. (2011). *Growing older with an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)*. School of Nursing and Midwifery, Trinity College Dublin.

When using the IDS-TILDA Wave 2 dataset, please cite the relevant publications from the following list:

- McCarron, M., Carroll, R., Burke, E., Cleary, E., McCausland, D., McGlinchey, E., O'Donovan, M-A., Mulryan, N., Shivers, C. & McCallion, P. (2014) *Advancing Years, Different Challenges: Wave 2 IDS-TILDA – Findings on the ageing of people with an Intellectual Disability*. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

When using the IDS-TILDA Wave 3 dataset, please cite the relevant publications from the following list:

- McCarron, M., Haigh, M., Carroll, E., Burke, E., McGlinchey, E., O'Donovan, M-A., McCausland, D., Sheerin, F., O'Dwyer, M., Foran, S., MacGiolla Phadraig, C., Mulryan, N., O'Connell, J., Ryan, J. & McCallion, P. (2017) *Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland Evidence from the First Ten Years of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) Wave 3 IDS-TILDA*. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

Any publications using this IDS-TILDA data should include following information in acknowledgements:

Researchers interested in using IDS-TILDA data may access the data for free from the following sites: Irish Social Science Data Archive (ISSDA) at University College Dublin
http: <https://www.ucd.ie/issda/data/idstilda/>

Publications and presentations should include a reference to IDS-TILDA in the title. The recommended format is:

“[INSERT publication/presentation title]: results from The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).”