User Information Guide

An exploration of the consequences of, and coping with loneliness in an ageing intellectual disability population.

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

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1. 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.
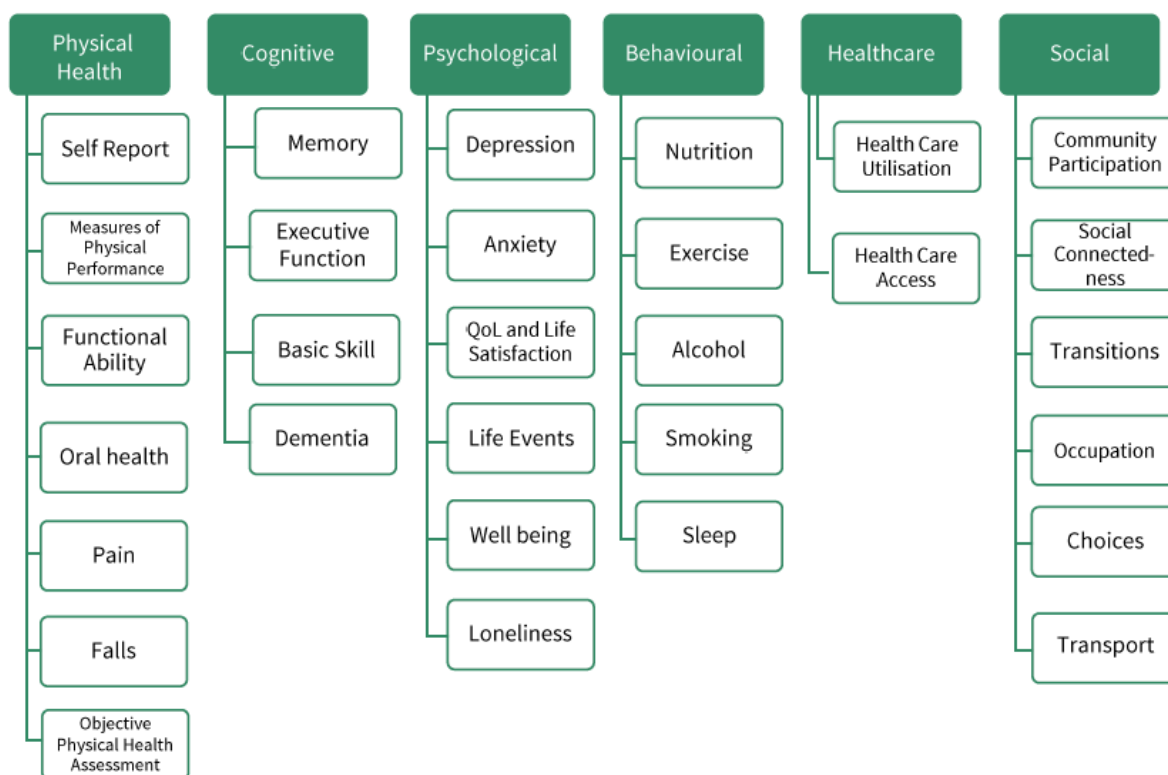

Figure 1: IDS-TILDA conceptual framework

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.

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 and randomly recruit adults with an intellectual disability aged 40 years and above in the Republic of Ireland. The final Wave 1 sample of 753 were 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 of those available to participate in Wave 2 of IDS-TILDA was 94%, with a final sample of 708 completing at least one element of the study and 699 completed the CAPI

Table 1: Demographics of wave 2 participants who completed the CAPI

Gender		n
Male	44.1%	308
Female	55.9%	391
Age		
< 50 years	28.0%	196
50-64	50.8%	355
65+	21.2%	148
Level of Intellectual Disability		
Mild	23.7%	153
Moderate	46.5%	300
Severe-profound	29.8%	192
Type of Residence		
Independent/Family	16.2%	113
Community House	43.3%	303
Institution	40.5%	283

The report on the initial findings from this representative sample of older adults with intellectual disability in Ireland was launched in September 2014 (McCarron, McCallion et al. 2014). It is hoped that the publication and availability of data through HRB Open Research will further contribute to our understanding of the impact of Loneliness on this population.

As part of the open publication process, the authors of this study have decided to make the data used in the study publicly available. The data from the original study is anonymised to make the data publicly available for future use. The details of the anonymisation process and rules used for anonymisation are described in the section below. The data set is saved as 'loneliness_consequences_anonvariables' in the ISSDA website. This is a subset of the Wave 2 dataset, used in the paper, entitled *'An exploration of the consequences of, and coping with loneliness in an ageing intellectual disability population'*. All variables in the dataset are created based on CAPI, PIQ and Health fair. Of note, the dataset does not comprise any personal identifiers such as name, address, or ID numbers. Any potentially identifiable data on its own, or in combination with others are either top coded, grouped or dropped completely. The resulting dataset has 18 partially or completely anonymised variables with 317 rows.
The dataset is available in SPSS version 26.

2. Data anonymisation process

IDS-TILDA 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, it may be possible for some users 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 due to personal identification concerns.

Only the variables that were used in the paper, entitled '*An exploration of the consequences of, and coping with loneliness in an ageing intellectual disability population*', were considered for release and hence, for anonymisation. The details of the variables included and excluded from the list of original variables used in the paper's analyses are given in the Excel file "List of variables used in original study".

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 anonymisation process that was carried out over several rounds of data analysis.

At each round the variables were assessed on a case-by-case basis. The variables which may lead to the potential identification of the participants, e.g. types of respondents, were omitted from the first round of anonymisation. Subsequently, each variable was summarised into category frequencies, where each frequency was compared to the cut-off of 20. Each variable was also cross tabulated with gender, age, ID level and residence type, and the resulting cell counts 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, top coding, or bottom coding. These steps formed part of consecutive rounds of data anonymisation.

2.1 List of original variables considered for anonymisation

The first round of anonymisation saw a number of the variables used in the paper's analyses removed from consideration as they either contained the participants' personal information or did not meet the minimum cell size cut-off of 20. This section contains the details of all remaining original variables considered for anonymisation. The details of the excluded variables are given in the Excel file named "List of variables used in original study". The list of variables considered for anonymisation is given in Table 2

Table 2: Variables considered for anonymisation

Variable Name	Description
LonMV	Loneliness scale score
LonMVDic	Dichotomised Loneliness based on quartiles
Q5Level_ID	Level of intellectual disability
Gender	Gender
NEWAGE	Age
FLScore	Functional limitations scale score
BH15bin	Binary coded vigorous activity
bh18bin	Binary coded moderate activity
bh20bin	Binary coded mild activity
BH_2	Do you smoke
BMIcat	BMI category
PH44exVG	How healthy is your diet dichotomised
MH8CountDic	Count of stressors dichotomised
MH8RelstrDic	Found in relationships stressful
MH8SocStrDic	Found Social changes stressful
MH8WrkStrDic	Found changes in work Stressful
Church2	Binary coded church attendance
sc16Fami	Confide in family
sc16Frnd	Confide in friend
sc16staf	Confide in staff
sc16othr	Confide in other
OM20dic	Blood pressure dichotomised
BH26Dic	Trouble falling asleep
BH28Dic	Sleep disruption
BH30Dic	Waking up too early
BH32Dic	Doze off
SleepScaleDic	Sleep scale

3. Description of variables included in the dataset

The variables listed then went through further rounds of anonymisation. As some of these variables again failed to meet the minimum cell-size cut-off of 20, especially after cross-tabulation, recoded versions of the variables were derived after regrouping of categories, combination with other variables, top coding, or bottom coding.

Variable Name	Description
CV_FLCat_Dic	Functional Limitations Categorised
CV_Gender	Gender
Dem_Age2Cats	Age Categories
LonMV	Loneliness scale scores
LonMVDic	Dichotomised Loneliness scores
P1HB_Act_Mod_Bin	Binary coded moderate activity
P1NotMod	Mild and vigorous combined
P1_HBUnhealth0	Smoking, obese and not excellent or very good diet
P2SE_MH8CountDic	Count of life events dichotomised
P2_SE_Change	Found relationship, service or social changes stressful
P3CP_Church	Attends church more than twice a month
P3CP_sc16staf	Confides in staff
P3_CP_NotStff	Confides in family, friends or other
P4HL_OM20dic	Blood pressure dichotomised
P5_SleepNightBin	Problems, getting to sleep, disturbed sleep or waking too early
P5RC_BH32Dic	Problem dozing during the day
P5RC_SleepScaleDic	Sleep scale

5 Disclaimer

There can be errors or inaccuracies in the dataset and documentation. The errors will be corrected in future upgrades. 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.

McCarron, M., et al. (2014). Advancing years, different challenges: Wave 2 IDS-TILDA. . Dublin, School of Nursing and Midwifery, Trinity College, Dublin.