4

Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

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Contents

An Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing

4

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Key Findings

- Emotional, nervous or psychiatric disorders continued to be prevalent, nearly 60% of respondents reported receiving such a diagnosis from their doctor.
- The prevalence of reported mental health problems was higher in females and increased with age and level of disability.
- The mean annual incidence of receiving a diagnosis of mental ill health between Wave 1 and Wave 2 was 3.1% overall, 4.2% for anxiety and 2.8% for depressive disorder.
- The prevalence of mental health disorder reported by those with Down syndrome was 33.6% which is nearly half that for those without Down syndrome (DS) at 65.8%. The 3 year mental ill-health incidence for the Down syndrome cohort is 11.5% which is higher than the 9.6 % reported for the non-DS group.
- Those participants who self-reported were more likely to rate their emotional or mental health as excellent, very good or good than those who had proxy only replies, at 84.1% and 67.8% respectively.
- The mean annual depreciation in the perception of positive mental health is 5.1% in the group as a whole.
- 14.6% of those completing the CES-D reported case level depressive symptomatology with a further 30.5% reporting sub-threshold symptom burden.
- The point prevalence of case level depressive symptomatology increased by 3% since Wave 1.
- The mean score on the Energy and Vitality Index (EVI) was 67.2. This compares favourably with the reported national average of 68 for individuals without an intellectual disability.
- Males, those in the youngest age cohort and those living independently reported the highest EVI scores.
- Two-thirds of respondents had experienced at least one significant life event in

the previous year. Nearly one third experienced a change of staff and one in five had a change of key-worker in the previous year.

- At Wave 1, 15.8% of participants with Down syndrome reported a diagnosis of dementia which increased to 29.9% by the Wave 2. This group that are at most risk from dementia had a mean incidence of 4.7% per annum.
- Dementia screening for those with Down syndrome improved between Wave 1 and Wave 2. Over half (51.2%) of this cohort had memory screening in the previous 2 years, a considerable improvement from the 32.9% noted in Wave 1.

4.1 Introduction

This chapter reports the findings regarding mental health, well-being and cognitive function from Wave 2. In addition to revisiting the measures used in Wave 1 to assess levels of mental ill-health, in Wave 2 additional items enquiring into vitality and life events were added. Preliminary findings on the incidence of some disorders are also presented in the context of other similar studies in those with and without an intellectual disability.

4.2 Mental Health

Prevalence and incidence rates of mental health disorders may vary due to different populations, survey methods and diagnostic criteria. Similar methodological issues apply to studies in populations with ID, with the added complexity of aetiology and phenotype differences. Smiley *et al.,* (2007), reported a 2 year mental ill-health incidence rate of 12.6% when problem behaviours were excluded from the analysis. The 2 year incidence rate in those with Down syndrome is reported to be between 3.7% and 14.9% depending on the criteria used (Mantry *et al.,* 2008). Point prevalence rates of major depression (7.6%) and anxiety disorder (4.4%) have been reported from an older ID population, with the noted symptom prevalences of 16.8% and 16.3% respectively (Hermans et al., 2013).

4.2.1 Reported diagnosis

Respondents were asked if they had received a diagnosis from their doctor of an emotional, nervous or psychiatric condition. If so, a number of possible diagnoses were offered and the respondent was asked to indicate any or all that applied. See Appendix table 4.A.1 for overall mental health prevalence for Wave 2 for gender, age and level of ID.

The overall prevalence of diagnosed mental health disorders in IDS-TILDA Wave 2 was nearly 60% (Wave 1=49%), (see *figure 4.1*). Anxiety was the most prevalent (39.2%) followed by depression (26.7%) and manic depression (4.7%). All diagnoses tended to be more prevalent in women or with increasing age (see *figure 4.2*) and the overall prevalence was highest in those with severe or profound intellectual disability.

The 3 year incidence, from Wave 1 to Wave 2, of psychiatric conditions was 9.6%. The mean annual incidence of anxiety was the highest (4.2%), followed by depression (2.8%). The incidence tended to be lowest in males, younger age cohorts or those with a mild ID (see Appendix table 4.A.2).

Figure 4.1: Prevalence of doctor's diagnosis of emotional and psychiatric conditions Wave 1 & Wave 2.

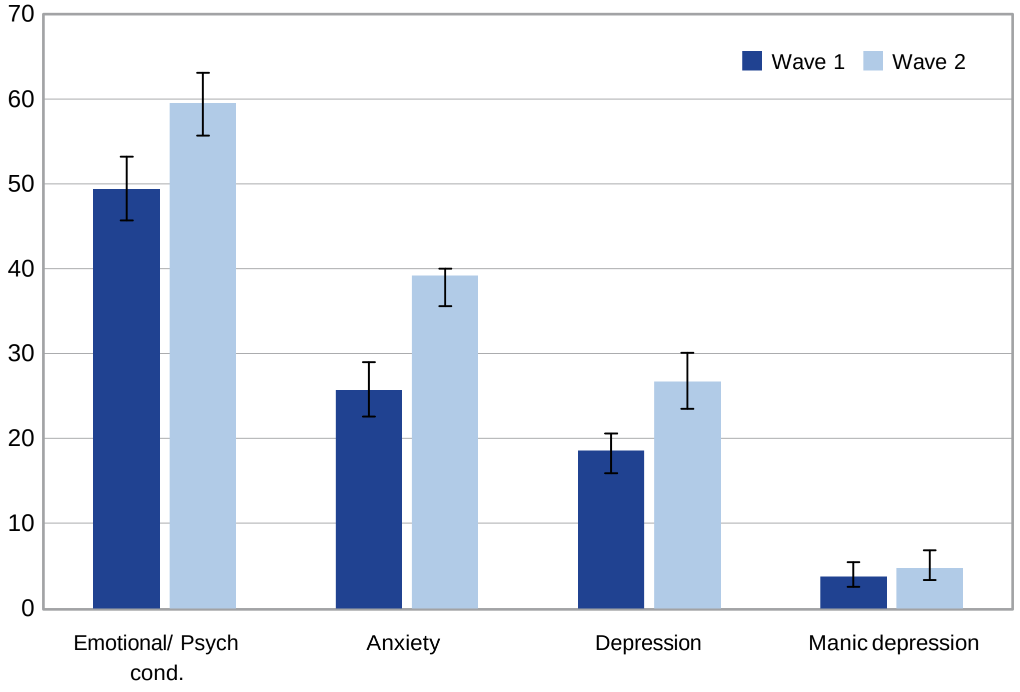
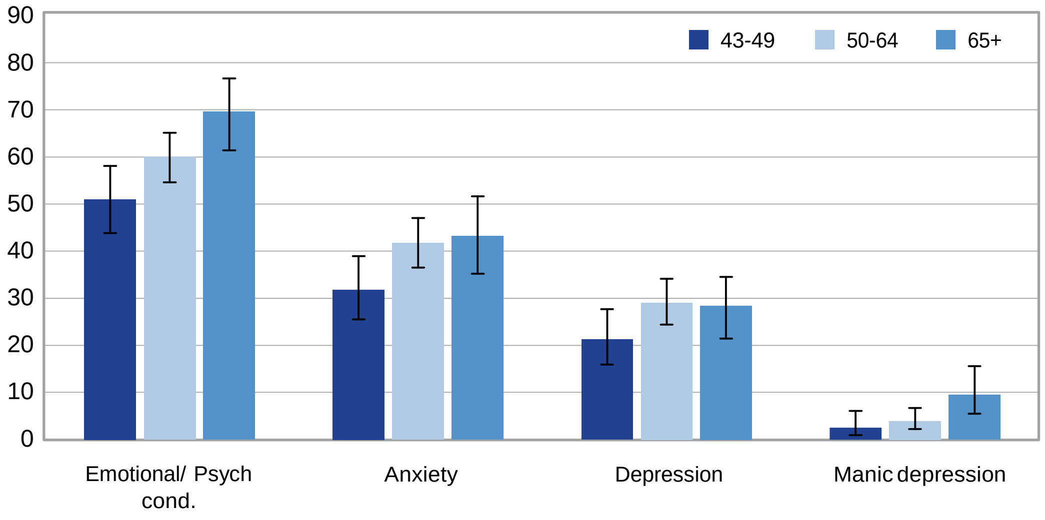


Figure 4.2: Mental health conditions by age.

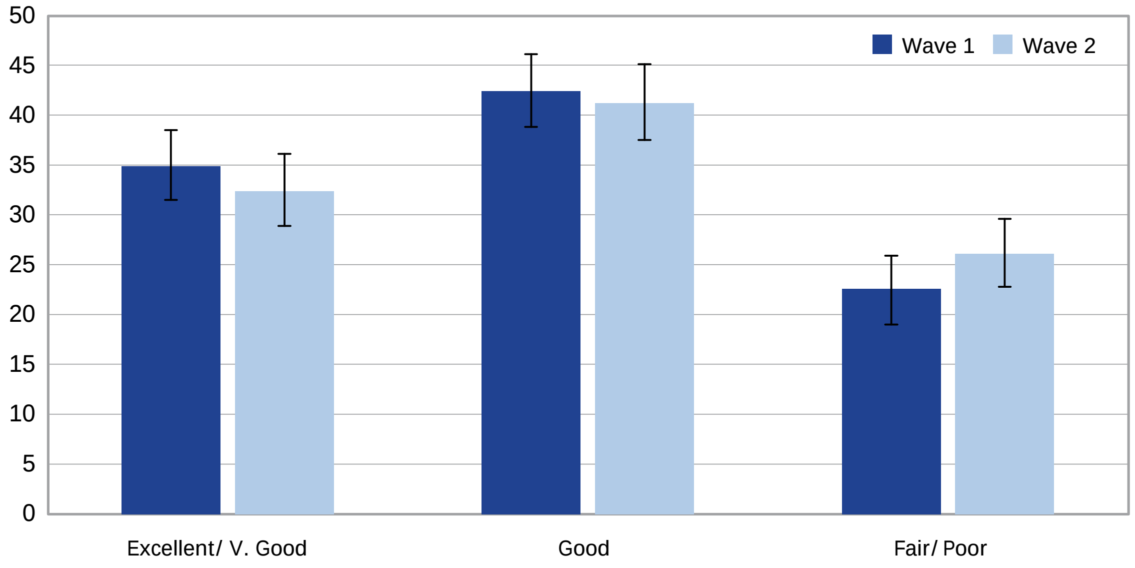


The prevalence of mental health disorder reported by those with Down syndrome was 33.6% which was nearly half that for those without Down syndrome (DS) at 65.8%. The 3 year mental ill-health incidence for the Down syndrome cohort is 11.5% which is higher than the 9.6 % reported for the non- DS group (see Appendix table 4.A.3).

4.2.2 Self/proxy rated emotional and mental health

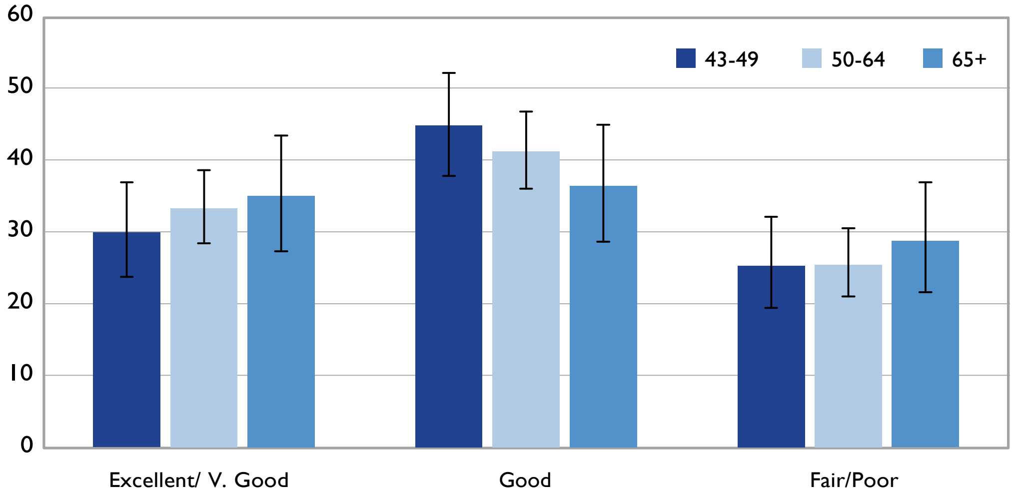
Respondents and/or their proxies were asked to rate their perception of the participant's mental and emotional health on a five point likert scale, with options ranging from excellent to poor. A total of 679 valid responses were collated of which 138 were entirely self-report. Despite the relatively high levels of reported mental health problems, almost three quarters (73.9%) rated their overall mental health favourably in Wave 2. Rating of overall positive emotional and mental health in people with intellectual disability was less than that reported for the general population at 73.9% versus 90% respectively.

Figure 4.3: Self-rated mental health Wave 1 & Wave 2.



Gender appeared to have little influence on the perception of mental health in Wave 2. Those with a mild ID reported a more positive appreciation of their mental health status as opposed to those with moderate or severe/ profound ID. Also the rates of those that regarded their mental health favourably (excellent, v. good or good), changed little across age groups. Rates of highly rated mental health are marginally lower in those aged 65 + years, at 74.7%, 74.5% and 70.7% respectively, see *figure 4.4*.

Figure 4.4: Self-rated mental health by age.



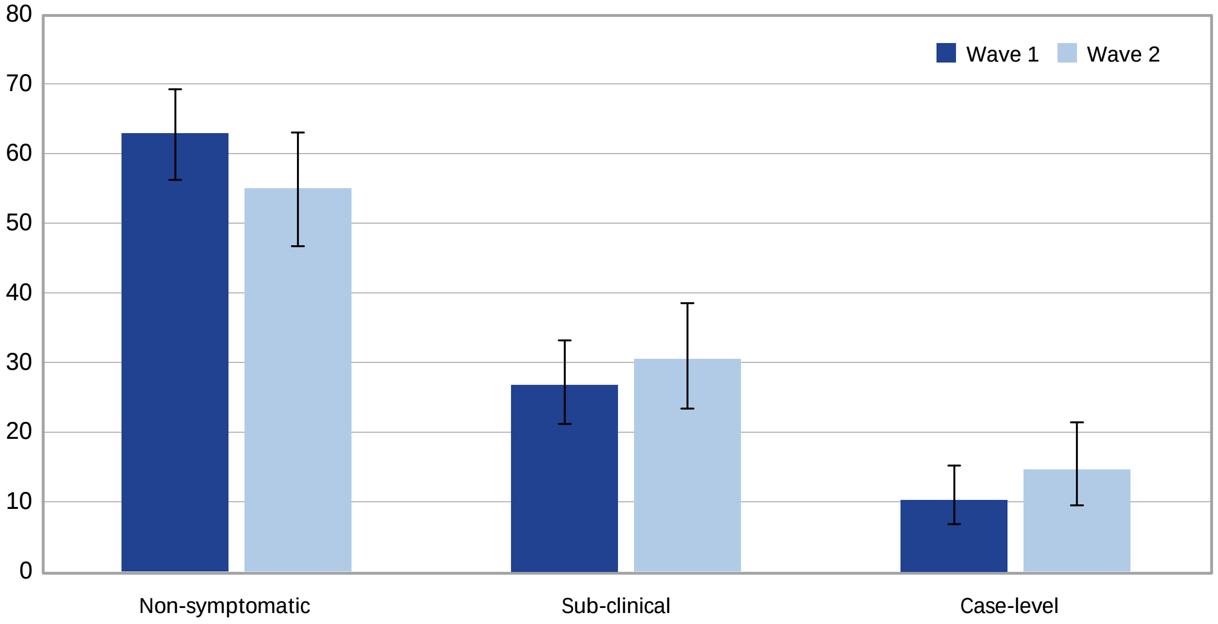
Those participants who self-reported were more likely to rate their emotional or mental health as excellent, very good or good than those who had proxy only replies, at 84.1% and 67.8% respectively. In addition, there has been attrition in perceived mental health wellbeing in the IDS-TILDA study population since Wave 1 in which 89.2% self-reported self-rated positive mental health (see Appendix table 4.A.5).

4.2.3 The Center for Epidemiological Studies Depression Scale (CES-D)

The CES-D is a self-report scale devised by Radloff, (1977) to assess depressive symptomatology in epidemiological studies. The scale consists of 20 items with four answer options; scored from zero to three. Four of the statements are positively framed, in which case the scoring schema is reversed. The maximum score is 60. Over the past few decades its use has been widely reported and the scale has been validated in many different populations. The cut off score of >16 was applied to indicate case level depressive symptomatology. Sub-threshold scores of 8-15 were also collated representing those who may have functional impairment due to their depressive symptom burden. Given the potential comprehension difficulties in this population, a score was considered valid if the scale was completed in its entirety or if one or two responses were absent. If data for individual items were missing, personal mean scores were imputed (Bono *et al.,* 2007) for those items. The CES-D instrument was completed as a self-report scale only (*n*=151).

The results from Wave 2 indicate a high level of depressive symptomatology, almost one third (30.5%) of the study population reported a significant sub-threshold depressive symptom burden. A further 14.6% had symptom levels above the cut off for a depressive disorder. In comparison to IDS-TILDA Wave 1 there was an increase in both sub-threshold (27.1%) and case level (11.6%) scores (see *figure 4.5*), representing a 3 year incidence rate of 3% for case level depression and 3.1% for sub-threshold symptomatology. Both waves of IDS-TILDA reported higher CES-D symptom scores than Wave 1 TILDA (Barrett *et al.,* 2011) where 10% of study participants had depression case scores and a further 18% reported sub-threshold symptomatology. For overall prevalence of depressive symptoms in Wave 2 measured by the CES-D see Appendix table 4.A.6

Figure 4.5: CESD – Wave 1 and Wave 2 Results



4.3 Energy and Vitality Index

Initially devised to support the Medical Outcomes Study (Wells *et al.,* 1989), the 36 item Short Form Health Survey (SF-36) has been widely utilised in monitoring outcomes in adult patients (Ware & Sherbourne, 1992). A subset of these items, the Energy and Vitality Index (EVI), assesses psychological wellbeing. It comprises 4 questions which enquire into aspects of psychological status over the previous 4 weeks. The response options are recorded on a 6 point likert scale from ‘None of the time’ to ‘All of the time’.

Offered for the first time in Wave 2, six hundred and eighty one individuals completed the EVI. The mean score for all participants was 67.2. The score was higher in males

(67.9) than females (66.6), in younger participants (43-49yrs=68.7, 50-64yrs=68.2, 65+yrs=62.3), those with milder levels of disability (mild=71.3, moderate=67.7, severe/profound=62.9) or those living independently (independent=73.5, community house=67.7, residential=64.2). However few of these differences were significant (see Appendix table 4.A.7).

The 2007 Survey of Lifestyle, Attitudes and Nutrition (SLAN) interviewed over 10,000 Irish adults and reported an overall mean EVI score of 68 (Morgan *et al.,* 2008). The score tended to be higher in males, younger individuals or those in higher social classes. These findings echoed an earlier Europe-wide study reporting comparative data from 11 EU countries (EORG 2003). This Eurobarometer 2002 study while noting similar gender and age trends additionally reported associations with social support, marital status and between country differences in EVI score (Lehtinen *et al.,* 2005). The study of positive mental wellbeing in those with an intellectual disability has received little attention to date. The EVI data reported by IDS-TILDA suggest that participants in this study experience energy and vitality levels favourably comparable with those in the general population. These findings are all the more interesting because 57.7% of the respondents to the vitality index items were completed by proxy. As reported by Ball *et al.,* (2001) proxies tend to under rather than over report vitality. Further work will be under taken to examine difference in vitality reports among self-report participants as compared to those for whom a proxy was used.

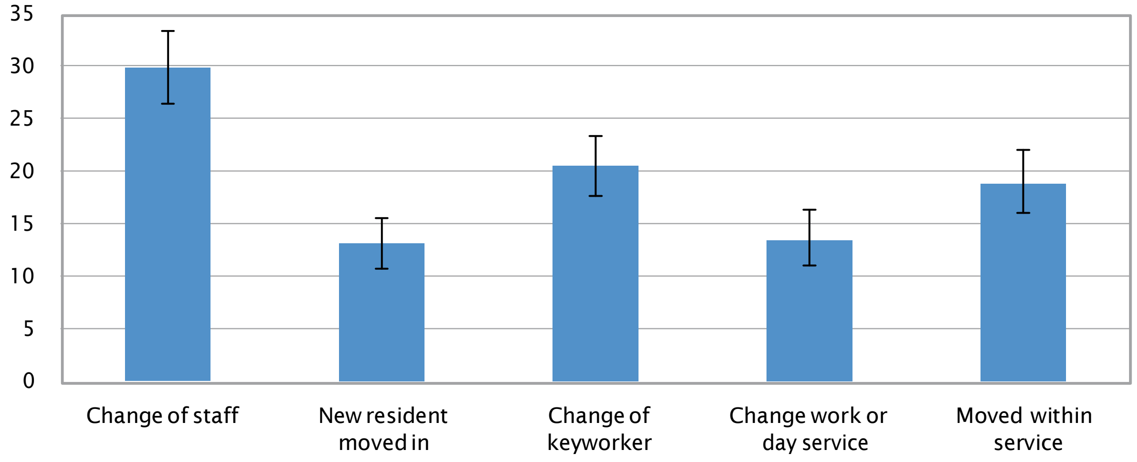
4.4 Life events

Life events are part of the human experience, for both individuals with and without an intellectual disability. There is evidence to support the viewpoint that persons with an intellectual disability have more frequent and negatively perceived life events (Tsakanikos *et al.,* 2007).

A 20 item checklist was devised to capture information regarding life events of participants over the previous year. The checklist included items on relationships, living arrangements and bereavements. The respondent was asked to attribute a positive, negative or neutral perception to each event.

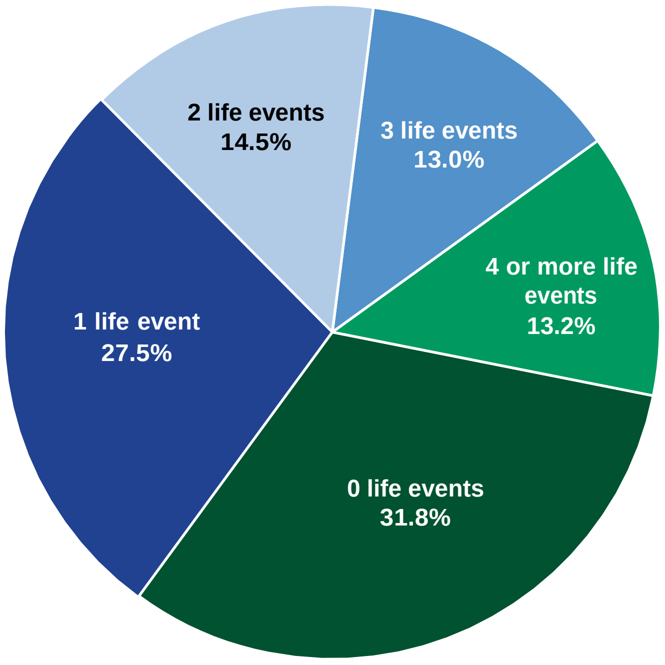
Two thirds of respondents reported multiple life events in the preceding 12 month period with over 13% experiencing 4 or more such events. The most frequently recorded changes related to a change of key-worker (20.5%) or other staff (29.8%) (See *figure 4.6* and *figure 4.7*)

Figure 4.6: Most prevalent life events



The occurrence of multiple life events in those with an intellectual disability may differ from the rest of the population due in part to the level of support needed, multiple carers and living arrangements which supports the findings from Tsakanikos *et al.,* 2007. The accumulation of these events has been associated with an increase in prevalence of depression and anxiety symptoms (Hermans & Evenhuis, 2012) and as a predictive risk factor for later psychological dysfunction (Hulbert-Williams *et al.,* 2014).

Figure 4.7: Number of life events



4.5 Cognitive findings

The increasing life expectancy of those with an ID is to be welcomed. Improved living circumstances, medical intervention and a better understanding of the pathological processes have allowed for more effective support of this vulnerable group. Unfortunately, ageing may introduce other challenges such as age related chronic diseases most notably dementia. The risk of developing dementia appears higher in those with an ID possibly due to decreased cognitive reserve or underlying genetic predisposition (Stern, 2012, Strydom *et al.,* 2010). The reported incidence is up to five times greater than the non-ID population (Strydom *et al.,* 2013).

A noted increase in life expectancy (Bittles & Glasson, 2004), in particular in those with Down syndrome, has unmasked a link with dementia (Oliver & Holland, 1986). Estimated prevalences vary but the risk of developing dementia is up to 80% at age 65 (McCarron *et al.,* 2014).

Assessment of cognitive function is a priority given the risk of illness and the potential to support the individual from an early stage of the disease. The advent of disease modifying medicines further increases the impetus to ensure adequate screening. International consensus recommends annual screening of individuals with DS from the age of 35 years and for others with ID from the age of 50 years (Aylward *et al.,* 1997). Screening tests for the non-ID population such as the Folstein Mini-Mental State Examination (Folstein *et al.,* 1975) are of not sensitive enough to indicate change in those with already compromised intellectual function (Deb & Braganza, 1999). Ideally, a screening battery should include instruments which can identify changes in memory, functional skills and cognition (Burt *et al.,* 2000).

4.5.1 Reported memory impairment

Respondents were asked if they had received a diagnosis of dementia or Alzheimer’s dementia. The overall prevalence had increased from 5.8% in Wave 1 to 9% in Wave 2 representing a 3 year incidence of 3.2%. There had been a notable increase in the Down syndrome (DS) sub-group in particular; at Wave 1, 15.8% reported a diagnosis which increased to 29.9% by the Wave 2 assessment. This group that are at most risk from dementia had a mean incidence of 4.7% per annum. Those participants without DS experienced a more modest increase in prevalence from 3.6% to 4%.

4.5.2 Dementia Screening

Dementia screening availability for those with DS improved between Wave 1 and Wave 2. Over half (51.2%) of the Wave 2 cohort had memory screening in the previous 2 years, a considerable improvement from the 32.9% noted in Wave 1.

The screening of those with an ID of other aetiology increased from 9.9% in Wave 1 to 16.5% in Wave 2. It is acknowledged that some proportion of those screened may have become eligible for local memory screening due to advancing age which they would not have been eligible for at Wave 1. However, the numbers involved are not sufficient to fully explain the increase in screening. It is likely that screening opportunities have improved across the country over the past 3 years as a result of local demand and increased awareness (see Appendix table 4.A.8).

4.6 Conclusion

This chapter reported on the mental health, wellbeing and cognitive function of the participants. As the second wave of a longitudinal study it is possible to make initial comments on incidence rates and also to compare the findings to those in the general population.

Mental health problems remained prevalent with nearly 60% of participants receiving a diagnosis of an emotional or psychiatric disorder at some point to date. On a positive note psychological wellbeing was assessed for the first time in this study using the EVI. Levels of vitality compare favourably with the general Irish population and Europe as a whole.

Mental and cognitive wellbeing are crucial to ensuring a good quality of life. The longitudinal study of ageing in individuals with an intellectual disability will enhance our evidence base to optimise support and care. By investigating mental and cognitive function and its associated factors and in particular mental wellbeing in an ageing population it will be possible to increase our knowledge-base. Derived from this it will be possible to optimise interventions and supports to enhance a positive life experience adding quality to the years gained by individuals with an intellectual disability.

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Appendix 4.A Tables from Mental Health, Well-being and Cognitive Function in Older Adults with an Intellectual Disability

Appendix 4.A.1: Doctor's diagnosis of mental health conditions prevalence Wave 2

	Emotional psychiatric condition	Anxiety	Depression	Manic Depression
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:				
Male	58.1 (52.3 - 63.6)	20.7 (16.4 – 25.7)	20.7 (16.4 – 25.7)	4.5 (2.6 – 7.7)
Female	60.6 (55.5 - 65.4)	31.4 (26.9 – 36.3)	31.4 (26.9 – 36.3)	4.8 (3.0 – 7.6)
Age:				
43-49	51.0 (43.8 - 58.1)	31.8 (25.5 – 38.9)	21.2 (15.9 – 27.7)	2.5 (0.9 – 6.1)
50-64	60.0 (54.6 - 65.1)	41.7 (36.5 – 47.0)	29.0 (24.4 – 34.1)	3.9 (2.2 – 6.7)
≥65	69.6 (61.4 - 76.7)	43.2 (35.2 - 51.6)	28.4 (21.4 – 36.5)	9.5 (5.5 – 15.6)
Level of ID:				
Mild	55.6 (47.3 - 63.5)	29.9 (22.9 – 37.9)	29.9 (22.9 – 37.9)	3.9 (1.6 – 8.7)
Moderate	57.0 (51.1 - 62.6)	24.9 (20.2 – 30.3)	24.9 (20.2 – 30.3)	5.6 (3.4 – 9.1)
Severe/Profound	67.7 (60.5 - 74.1)	27.6 (21.5 – 34.6)	27.6 (21.5 – 34.6)	4.2 (1.9 – 8.3)
Total	59.5 (55.7 – 63.1)	39.2 (35.6 – 43.0)	26.7 (23.5 – 30.1)	4.7 (3.3 – 6.6)

Appendix 4.A.2: Doctor's diagnosis of mental health conditions incidence Wave 2

	Emotional psychiatric condition	Anxiety	Depression	Manic Depression
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)
Gender:				
Male	9.2 (6.3 – 13.3)	12.3 (8.9 – 16.6)	8.4 (5.7 – 12.3)	0.6 (0.1 – 2.6)
Female	10.6 (7.8 – 14.3)	13.0 (9.9 – 16.9)	8.2 (5.7 – 11.5)	1.3 (0.5 – 3.2)
Age:				
43-49	9.5 (5.9 – 14.8)	9.1 (5.7 – 14.3)	6.1 (3.3 – 10.6)	0.0
50-64	10.2 (7.2 – 14.1)	15.5 (12.0 – 19.8)	9.0 (6.4 – 12.6)	0.8 (0.2 – 2.7)
≥65	10.3 (6.1 – 16.7)	10.8 (6.5 – 17.2)	9.5 (5.5 – 15.6)	2.7 (0.9 – 7.2)
Level of ID:				
Mild	9.7 (5.6 – 16.0)	13.0 (8.3 – 19.6)	8.4 (4.7 – 14.3)	0.6 (0.0 – 4.1)
Moderate	9.0 (6.0 – 13.0)	11.3 (8.1 – 15.6)	7.7 (5.0 – 11.5)	1.0 (0.3 – 3.2)
Severe/Profound	12.9 (8.6 – 18.8)	14.6 (10.1 – 20.6)	7.8 (4.6 – 12.8)	1.6 (0.4 – 4.9)
Total	9.6 (7.5 – 12.0)	12.7 (10.4 – 15.4)	8.3 (6.4 – 10.6)	1.0 (0.4 – 2.1)

Appendix Table 4.A.3: Mental Health Conditions Prevalence and Incidence Wave 2 Down Syndrome

	%	(95% CI)	Number in sample
Prevalence			
Down Syndrome	33.6	25.88-42.22	137
Not Down Syndrome	65.8	61.6-69.7	549
Total	59.3	55.54-63.02	686
Incidence			
Down Syndrome	11.5	6.77-18.48	131
Not Down Syndrome	9.6	7.24-12.49	523
Total	9.9	7.81-12.56	654

Appendix Table 4.A.4: Self-rated mental health Wave 2

	Excellent/ V. Good	Good	Fair/Poor
	% (95% CI)	% (95% CI)	% (95% CI)
Gender:			
Male	32.9 (27.7 – 38.5)	41.2 (35.6 – 47.0)	25.9 (21.1 – 31.3)
Female	32.5 (27.9 – 37.5)	41.3 (36.3 – 46.4)	26.2 (21.9 – 31.0)
Age:			
43-49	29.9 (23.7 – 36.9)	44.8 (37.8 – 52.1)	25.3 (19.4 – 32.1)
50-64	33.3 (28.4 – 38.6)	41.2 (36.0 – 46.7)	25.4 (21.0 – 30.5)
≥65	34.3 (26.7-42.7	36.4 (28.6 – 44.9)	28.7 (21.6 – 36.9)
Level of ID:			
Mild	38.4 (30.7 – 46.7)	40.4 (32.6 – 48.7)	21.2 (15.1 – 28.7)
Moderate	34.1 (28.8 – 39.9)	38.9 (33.3 – 44.8)	27.0 (22.0 – 32.5)
Severe/Profound	25.0 (19.0 – 32.0)	43.5 (36.3 – 51.0)	31.5 (25.0 – 38.8)
Total	32.7 (29.2 – 36.4)	41.2 (37.5 – 45.1)	26.1 (22.8 – 29.6)

Appendix Table 4.A.5: Self-reported favourable self-rated mental health, Comparison Wave 1 and Wave 2

	Wave 1			Wave 2		
	%	95% CI	Number in sample	%	95% CI	Number in sample
Self-report	89.2	82.54-93.63	139	85.6	78.27-90.71	138
Assisted interview	79.5	75.34-83.18	430	79.4	73.37-84.47	289
Proxy only	62.3	53.64-70.31	138	65.2	59.71-70.36	322
Total	77.4	74.11-80.3	733	73.9	70.42-77.16	679

Appendix Table 4.A.6: Prevalence of depressive symptoms at Wave 2 measured by the CES-D

	Non-symptomatic	Sub-clinical symptoms	Case level symptoms
	% (95% CI)	% (95% CI)	% (95% CI)
Gender:			
Male	54.0 (39.4 – 67.9)	24.0 (13.5 – 38.5)	22.0 (12.0 – 36.3)
Female	55.4 (45.2 – 65.2)	33.7 (24.7 – 43.8)	10.9 (5.8 – 19.0)
Age:			
43-49	56.2 (41.3 – 70.2)	31.2 (19.1 – 46.4)	12.5 (5.2 – 25.9)
50-64	51.8 (40.7 – 62.6)	32.9 (23.4 – 44.1)	15.3 (8.7 – 25.1)
≥65	66.7 (41.2 – 85.6)	16.7 (4.4 – 42.3)	16.7 (4.4 – 42.3)
Level of ID:			
Mild	57.4 (44.1 – 69.7)	21.3 (12.3 – 34.0)	21.3 (12.3 – 34.0)
Moderate	51.4 (39.3 – 63.4)	40.0 (28.7 – 52.4)	8.6 (3.5 – 18.3)
Severe/Profound	100 (0)	0	0
Total	55.0 (46.7 – 63.0)	30.5 (23.4 – 38.5)	14.6 (9.5 – 21.4)

Appendix Table 4.A.7: Vitality Score Index

	Mean Score	(95% CI)
Gender:		
Male	67.9	(65.3 – 70.5)
Female	66.6	(64.3 – 68.8)
Age:		
43-49	68.7	(65.6 – 71.9)
50-64	68.2	(65.9 – 70.6)
≥65	62.3	(58.2 – 66.3)
Level of ID:		
Mild	71.3	(68.1 – 74.5)
Moderate	67.7	(65.2 – 70.2)
Severe/Profound	62.9	(59.6 – 66.1)
Type of Residence:		
Indep/Family	73.5	(69.7-77.4)
Community group home	67.7	(65.1-70.0)
Residential Care	64.2	(61.7-66.9)
Total	67.2	(65.6 – 68.8)

Appendix Table 4.A.8: Dementia screening by ID aetiology Wave 1 & Wave 2

	Dementia Screening	
	Wave 1	**Wave 2**
	% (95% CI)	**% (95% CI)**
Within last two years		
Down Syndrome	32.9 (23.4 – 44.1)	51.2 (42.2 – 60.0)
Not Down Syndrome	9.9 (6.9 – 13.9)	16.5 (13.4 – 20.1)
Total	14.5 (11.3 – 18.5)	23.2 (20.5 – 26.7)
Before last two years		
Down Syndrome	8.2 (3.7 – 16.8)	8.5 (4.5 – 15.1)
Not Down Syndrome	2.6 (1.2 – 5.3)	3.8 (2.4 – 5.9)
Total	4.0 (2.4 – 6.6)	4.6 (3.2 – 6.6)