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## Positive ageing indicators for people with an intellectual disability

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**POSITIVE AGEING**  
INDICATORS  
**FOR PEOPLE WITH AN  
INTELLECTUAL DISABILITY**

2018

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# POSITIVE AGEING INDICATORS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY 2018

This report was produced by the Trinity Centre for Ageing and Intellectual Disability (TCAID) and funded by the Department of Health.

The team that worked on this report were Prof Mary McCarron (Principal Investigator), Dr Eimear McGlinchey, Prof Philip McCallion, Michael Foley, Sonia McDermott, Dr Éilish Burke, Dr Darren McCausland, Dr Mary-Ann O'Donovan, Dr Rachael Carroll, Margaret Haigh, Dr Sarah Gibney, Anne Doyle and the HaPAI team.

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An Roinn Sláinte  
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Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

Trinity Centre  
for Ageing and  
Intellectual  
Disability



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# FOREWORD

As a society, we are talking about ageing more than ever before. We are becoming more aware that what we do throughout our lifecourse will have an impact on our lives as older adults. Shifts are occurring in how we perceive ageing and in the perception and understanding of how older people can contribute to society. These are positive changes happening in our society today. We need to make sure that these positive changes are also reflected for members of our society ageing with an intellectual disability.

When the first report on positive ageing indicators was published, it was suggested that additional indicators should be developed for people with an intellectual disability. This report delivers this and represents an important step in ensuring that people with an intellectual disability are included in the conversation on ageing nationally. Over the coming years, changes that occur as a result of policies will be reflected in changes seen in these indicators. The information provided here also highlights areas where there is greatest disparity between the ageing experience for people with an intellectual disability and their peers in the general population. This knowledge can be used to inform future policies and to aid in the pursuit of optimal service provision for people with an intellectual disability.

It is important to note that while there are differences in the ageing experience of people with an intellectual disability compared to the general population, there are also similarities. Both people with an intellectual disability and in the general population report providing support to relatives. There was a similarity also between those with and without an intellectual disability in the proportion of people who reported having a supportive friend and someone they can confide in. Levels of social activity were also similar for both populations. This is of such great importance, as we know that social interactions play a vital role in successful ageing. It also reminds us that we need to promote these fundamental human connections across all of our society, and that we need to continue working to build a society that facilitates the inclusion of all.

This report also highlights areas in which people with an intellectual disability face additional challenges. With higher reporting of chronic conditions and higher medication use, the report emphasises areas where this population is more vulnerable than the general population and may require additional support.

I would like to thank the participants who took part in the Delphi process, and the participants, along with those who support them, who took part in the consultation groups. I would also like to thank Prof McCarron and the IDS-TILDA study which has provided much of the data in this report, and which has been working to promote successful ageing in a population with intellectual disability for the past ten years. Finally, we extend our thanks to all of those in the Department of Health and to everyone who has contributed to this report.

**Minister Finian McGrath TD**

Minister of State with special responsibility for Disability Issues



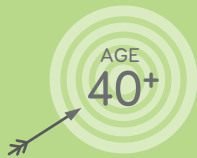
# GLOSSARY OF TERMS

<b>ADL</b>	Activities of Daily Living
<b>BMI</b>	Body Mass Index
<b>CES-D</b>	Centre for Epidemiological Studies - Depression
<b>DOH</b>	Department of Health
<b>EQLS</b>	European Quality of Life Survey
<b>EU-LFS</b>	European Labour Force Survey
<b>GP</b>	General Practitioner
<b>HADS</b>	Hospital Anxiety and Depression Scale
<b>HaPAI</b>	Healthy and Positive Ageing Initiative
<b>HSE</b>	Health Service Executive
<b>IDS-TILDA</b>	The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing
<b>IPAQ</b>	International Physical Activity Questionnaire
<b>NIDD</b>	National Intellectual Disability Database
<b>NPAS</b>	National Positive Ageing Strategy
<b>OECD</b>	Organisation for Economic Co-operation and Development
<b>PIACC</b>	Programme for the International Assessment of Adult Competencies
<b>QNHS</b>	Quarterly National Household Survey
<b>TILDA</b>	The Irish Longitudinal Study on Ageing
<b>WHO</b>	World Health Organisation


# KEY FINDINGS

## HEALTHY AGEING


**HEALTH SCREENING**  
WAS HIGH FOR PEOPLE WITH AN INTELLECTUAL DISABILITY




**57%**  
of eligible women had a mammogram



**91%**  
had the flu vaccine



**31%**  
have had a memory screening



FOUR OUT OF FIVE PEOPLE WITH AN INTELLECTUAL DISABILITY REPORT


**HIGH LIFE SATISFACTION**



**81%**  
AGE 40+



**86%**  
AGE 40+



of people with an intellectual disability rate their health as **GOOD, VERY GOOD, OR EXCELLENT**

MORE THAN SEVEN OUT OF TEN PEOPLE WITH AN INTELLECTUAL DISABILITY


**WERE TAKING 5 OR MORE MEDICATIONS**

**73%**  
AGE 40+




**HEALTH BEHAVIOURS** AGE 40+

**OVERWEIGHT OR OBESE** **80%**



**SMOKING** **7%**




**NEVER DRINK ALCOHOL** **62%**




OF PEOPLE WITH AN INTELLECTUAL DISABILITY

**WERE SEDENTARY OR UNDERACTIVE**


**85%**  
AGE 40+




**44%**  
have chronic constipation



**74%**  
have poor bone health



**28%**  
have no teeth or dentures



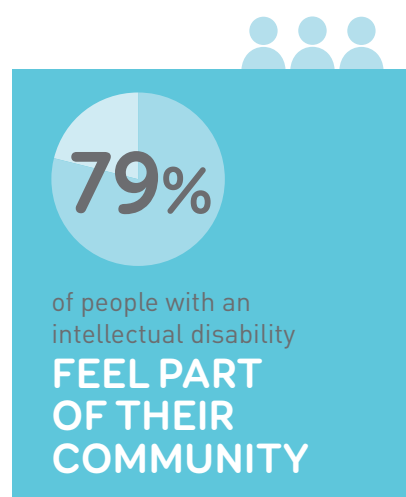
## HOUSING



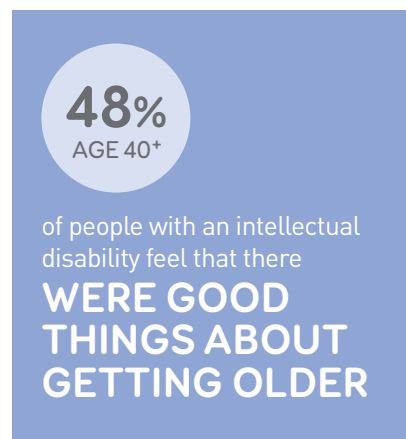
## TECHNOLOGY



## PARTICIPATION



## ATTITUDES TOWARDS AGEING



# SECTION 1: INTRODUCTION

## 1.1 THE NATIONAL POSITIVE AGEING STRATEGY

The National Positive Ageing Strategy outlines a vision for ageing in Ireland, where people are supported and enabled to enjoy physical and mental health and wellbeing to their full potential as they grow older. The strategy recognises that healthy ageing is not solely a health issue, but rather a set of interconnected factors, including social, economic and environmental factors, that all influence health and wellbeing. The focus on positive ageing aims to change the narrative of ageing away from one focused on decline towards one that highlights the contributions of older people to society and that sees later years as a time of new opportunities.

### THE STRATEGY SETS OUT **4** GOALS TO ACHIEVE THIS VISION:

- 1** Remove barriers to participation and provide more opportunities for the continued involvement of people as they age in all aspects of cultural, economic and social life in their communities according to their needs, preferences and capacities
- 2** Support people, as they age, to maintain, improve or manage their physical and mental health and wellbeing
- 3** Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible
- 4** Support and use research about people as they age to better inform policy responses to population ageing in Ireland

### The Healthy and Positive Ageing Initiative

The Healthy and Positive Ageing Initiative (HaPAI) was established in 2015 to address Goal 4 of the strategy: “Support and use research about people as they age to better inform policy responses to population ageing in Ireland”. HaPAI is a joint national programme led by the Department of Health, with Atlantic Philanthropies, the Health Service Executive (HSE) and the Age Friendly Ireland programme.

In order to monitor progress and to support good planning and policy development, HaPAI developed a set of National Positive Ageing Indicators. An indicator is something that can be used to measure changes or progress in a situation over time, or to compare groups. In particular, indicators can be used to assess progress in the goals or targets of a programme or policy. The set of indicators developed by HaPAI

covers a wide range of factors associated with positive ageing, from social, health, security and financial perspectives. These indicators will be monitored biennially, using data from existing research databases to examine whether there is any change at a population level, and to monitor whether changes in policy are having an impact on the lives of older people.

In 2016, the National Positive Ageing Indicators were developed for the general population using a collaborative approach (Gibney, Sexton & Shannon, 2018). A Delphi technique was used, where groups of experts engaged in an online survey process in order to gain a consensus opinion. Using this process and gaining consensus among experts, a set of 56 Positive Ageing Indicators was developed for the general population.

During the consensus process, the HaPAI team recommended the importance of developing specific Positive Ageing Indicators for several groups in Irish society who may not be represented in the national indicator set; one particular group was people with an intellectual disability (Healthy and Positive Ageing Initiative, 2018).

## **1.2 NATIONAL POSITIVE AGEING INDICATORS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY**

Previous research suggests that the ageing experience for people with an intellectual disability may differ from the general population, and that issues associated with ageing may occur for people with an intellectual disability at an earlier age than for the general population. Research has shown that not only is prevalence of certain conditions higher among a younger age group, but different patterns of disease are present for people with an intellectual disability compared to the general population. It is important also to recognise that there may be differences in the structure of social participation and family networks for people with an intellectual disability and to understand how these differences may have an effect on positive ageing.

## **1.3 THE INTELLECTUAL DISABILITY SUPPLEMENT TO THE IRISH LONGITUDINAL STUDY ON AGEING (IDS-TILDA)**

The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is the most comprehensive study on ageing in persons with intellectual disability ever carried out in Ireland (McCarron et al., 2011). IDS-TILDA provides data on the health, social, economic and environmental circumstances of 753 people with intellectual disability, as they grow older and on how their circumstances have changed over a ten-year period. Close harmonisation with the Irish Longitudinal Study on Ageing (TILDA study) ensures that similarities and differences between the populations may be systematically established, including for the national indicators. With three waves of data currently available, IDS-TILDA has become a rich data source for the study of the complex interrelationship between pre-existing impairment, physical, psychosocial and environmental factors, including the impact of living situations and changes in living situations, that may affect healthy ageing in persons with an intellectual disability.

# NATIONAL POSITIVE AGEING INDICATORS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

Figure 1: National positive ageing indicators for people with an intellectual disability



\*Additional indicators for people with an intellectual disability

# SECTION 2: DEVELOPMENT

## DEVELOPMENT OF NATIONAL POSITIVE AGEING INDICATORS FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

### 2.1 APPROACH

A systematic approach was undertaken to determine what additional indicators would be necessary in order to capture the important aspects of ageing for people with an intellectual disability. During that development process, there was a high level of agreement that certain important aspects related to ageing of people with an intellectual disability had not been included in the general indicator list, and that the ageing of people with an intellectual disability needed to be better represented.

The Delphi process for developing the National Positive Ageing Indicators for people with an intellectual disability closely resembled the process used in the general population.

**Figure 2:** Delphi process for reaching consensus



In addition, of great importance was the representation of the voices of people with an intellectual disability and, thus, consultation groups were added to promote greater inclusion, within the evaluation process.

### 2.2 EXPERT PANEL SELECTION

An invitation to participate was sent to individuals with an intellectual disability, family members and carers of people with an intellectual disability, researchers and academics working in the field of intellectual disability, intellectual disability service providers, advocacy services and Government departments. In Round One, 109 participants completed the online Delphi process, with 92 completing Round Two and 79 people completing Round Three. In addition to the online Delphi survey, 49 individuals with an intellectual disability took part in consultation groups which took place in tandem with the three rounds (see Table 1).

**Table 1:** Participation in the Delphi process

People with an Intellectual Disability	49 people took part in consultation groups across the three rounds of the process		
	ROUND 1	ROUND 2	ROUND 3
Academic / Research	33	27	28
Service Providers	30	29	29
State Sector / Advocacy	6	3	3
Family / Carer	40	33	26
<b>TOTAL</b>	<b>109</b>	<b>92</b>	<b>86</b>

## 2.3 EXPLORATION

The screening tool developed by the Healthy and Positive Ageing Initiative (HaPAI) team was used to review all existing (from the national indicators for the general population) and potential (from the literature) indicators prior to consideration in the Delphi process. Each domain was reviewed by a researcher with expertise in that specific domain using this tool. In total, 93 initial indicators were included in the long list to be reviewed. These indicators were chosen based on relevant literature on ageing and intellectual disability, and on research studies linking the indicator to ageing outcomes.

The screening identified indicators that:

- were needed and useful
- had technical merit
- were feasible items on which to collect data

After screening, 55 of the original 93 indicators remained and were utilised in the Delphi process.

## 2.4 EVALUATION

The online Delphi process modelled the approach used to develop the national indicators in the general population. An online survey process incorporated evaluation, re-evaluation and final consensus steps. Participants were asked to rate the indicators in terms of importance and ease of understanding and then were asked to also rank the indicators. Finally, participants indicated whether they thought the indicator set was balanced and coherent.

The evaluation criteria for each round is shown in Table 2 below.

**Table 2:** Delphi process evaluation criteria

EVALUATION CRITERIA	DELPHI ROUNDS		
	ROUND 1	ROUND 2	ROUND 3
Importance to positive ageing	✓	✓	
Easy to understand	✓	✓	
Ranking	✓	✓	
Indicators present a complete picture of the pillar	✓	✓	✓
Indicators present a complete picture of the domain			✓
Open-ended feedback	✓	✓	✓
Agreement with set of key indicators			✓

## 2.5 CONSULTATION WITH PEOPLE WITH AN INTELLECTUAL DISABILITY

Consultation groups were held with people with an intellectual disability, where members of the groups voted on the importance of the indicators. Prior to the consultation groups, an accessible information booklet was developed which explained the purpose of the consultation group, what was meant by an indicator, what we would be doing in the consultation group and what will happen after the indicators are chosen. Overall, 49 people with an intellectual disability took part in consultation groups which were held in Dublin, Kerry, Tipperary, Mayo and Louth. The consultation groups used accessible versions of the list of indicators using easy read language and pictures.

At the beginning of the consultation groups, the facilitators explained again the purpose of the meeting

and invited members to ask questions or any points that needed to be clarified. The indicators with accessible pictures were printed out, and then separated by pillar. The facilitator went through each indicator in the pillar and clarified what the indicator was, if needed. After each indicator, members of the consultation groups discussed the indicator and were given stickers with which to rate each indicator in order of importance. After each pillar, there was an open-ended discussion where people could recommend additional indicators, not yet included in the list, that they felt were important.

## 2.6 CONSENSUS (DELPHI AND CONSULTATION GROUPS)

Consensus was measured using level of agreement, where consensus was reached at 75%. This was the same measurement as was used for the development of the National Positive Ageing Indicators in the general population. In the Delphi groups where participants were asked to respond using a Likert scale from 1-5, the threshold was 2 or higher, with an interquartile range (IQR) of  $\geq 2$ . Ranking of indicators was also used, where there were more than two indicators in any section. Participants were asked to rank these in order of importance. We used the information on ranking of the indicators from both Delphi and consultation groups to help us to determine which indicators would remain and which should be removed. If an indicator was consistently ranked as of low importance by all participants and both sets of groups, it was excluded from the list.

At the end of each section, participants were asked if they had any other thoughts on that section, or if there were other indicators that they thought should be included. Every response was analysed and grouped into:

1. Suggestion for new indicator
2. Suggested change of indicator, or moving of indicator to different section
3. Rewording on indicator
4. General themes and concepts of ageing and intellectual disability

Throughout the rounds of the online consensus process and the consultation groups, indicators that were consistently ranked as being of low importance by the majority of people across all groups were then excluded. Twelve indicators were removed following Round One, and nine were removed following Round Two. In addition, eleven indicators from Round One were added for consideration in Round Two based on open-ended feedback. In addition, 13 indicators were changed or re-worded based on open-ended feedback. The result was that 33 Positive Ageing Indicators were added for people with an intellectual disability.

## 2.7 OUTCOMES OF THE CONSULTATION AND DELPHI PROCESSES

Table 3 below shows the results of the final consultation group with people with an intellectual disability, where participants were asked whether the indicators in each pillar gave a complete picture of that pillar. The same process was used for this as was used in the previous consultation groups, where participants were given stickers to indicate level of agreement from zero to five stickers.

**Table 3:** Rating of Completeness by final consultation group

	SCORE	%
Participation	4.25	85
Healthy Ageing	4.25	85
Security	4.13	77.6
Cross-Cutting Objectives	4.13	82.6

Table 4 below shows the results of the consensus across the three rounds of the online survey. By Round Three, there was 88% agreement that the indicators in the Participation pillar presented a complete picture, 89% for the Healthy Ageing pillar, 87% for the Security pillar and 83% for Cross-Cutting Objectives. The breakdown of consensus for individual domains for Round Three is also shown.

**Table 4:** Online Delphi consensus results

	ROUND 1	ROUND 2	ROUND 3
<b>PARTICIPATION</b>	<b>87</b>	<b>75</b>	<b>88</b>
Employment and Retirement	—	—	75
Education and Lifelong Learning	—	—	86
Active Citizenship and Volunteering	—	—	75
Social and Cultural Participation	—	—	89
Transport	—	—	88
Choice	—	—	89
<b>HEALTHY AGEING</b>	<b>87</b>	<b>84</b>	<b>89</b>
Physical Health	—	—	80
Brain Health	—	—	79
Adaptation to Illness	—	—	87
Health Behaviours	—	—	79
Mental Health	—	—	82
Healthcare	—	—	85
Social Care	—	—	79
<b>SECURITY</b>	<b>76</b>	<b>79</b>	<b>87</b>
Financial Security	—	—	81
Housing	—	—	85
<b>CROSS-CUTTING OBJECTIVES</b>	<b>81</b>	<b>83</b>	<b>83</b>
Attitudes towards Ageing	—	—	82
Technology	—	—	85

## 2.8 INDICATORS FROM THE GENERAL POPULATION NOT REPORTED FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

The list of indicators below were reported for the general population but are not reported here as published data was not available. Future reports may include these indicators.

<b>PARTICIPATION</b>	Percentage of people aged 50+ who provide care to children and/or grandchildren
<b>HEALTHY AGEING</b>	Healthy life expectancy at age 65
	Percentage of people aged 50+ whose ability to work or attend further education is reduced by disability
	Percentage of people aged 50+ who feel that they have control over their lives
	Percentage of people aged 50+ who experienced difficulty when seeing a doctor in the past twelve months
	Place of death
<b>SECURITY</b>	Consistent poverty rate among adults aged 65+
	Percentage of people aged 50+ who have housing facility problems
	Percentage of people aged 50+ who have housing condition problems
	Percentage of households with an adult aged 65+ who are unable to keep their house adequately warm
	Percentage of people aged 50+ who experience difficulty accessing essential services
	Percentage of people aged 50+ who experience difficulty accessing social facilities
	Percentage of people aged 50+ who experience difficulty accessing recreational or green spaces
	Percentage of people aged 50+ who report high levels of neighbourhood social capital
Percentage of safeguarding concerns with reasonable grounds for adults aged 65+	
<b>CROSS-CUTTING OBJECTIVES</b>	Percentage aged 50+ who reported that they felt discriminated against because of their age
	Percentage of people aged 50+ who perceive ageing as a time of personal growth

## SECTION 3: RESULTS

The report will detail results from each of the pillars – Participation, Healthy Ageing, Security and Cross-Cutting Objectives.

The results are set out in five sections.

### **SECTION 3.1: DEMOGRAPHICS**

This section provides information on the population of people with an intellectual disability from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) study.

### **SECTION 3.2: PARTICIPATION**

This section provides information on the participation of older people with an intellectual disability in society through employment, education and lifelong learning, active citizenship and volunteering, and on their participation in the social and cultural activities of their communities. It also includes data on transport as a facilitator or barrier to greater participation. Another domain 'Choice' was added for people with an intellectual disability.

### **SECTION 3.3: HEALTHY AGEING**

This section provides information on healthy ageing, including the domains of physical health and brain health, adaptation to disability and illness, health behaviours, mental health, healthcare and social care.

### **SECTION 3.4: SECURITY**

This section provides information on housing for people with an intellectual disability and on financial security.

### **SECTION 3.5: CROSS-CUTTING OBJECTIVES**

This section covers the two issues identified in the National Positive Ageing Strategy as having relevance for the achievement of objectives under each of the three pillars of Participation, Health and Security. They include information on attitudes towards ageing and technology.

## DATA SOURCES

Data for this report on people with an intellectual disability were taken from the IDS-TILDA study (McCarron et al., 2011, 2014, 2017) and the National Intellectual Disability Database (2017). IDS-TILDA is a longitudinal study that began in 2009 and currently has three waves of data. This means that the same people were interviewed three times over a ten-year period. When the study began, its participants with an intellectual disability were aged 40 and above.

For the indicators used in the general population, information was included from the general population National Positive Ageing Indicators Report 2018. Data from the general population came from The Irish Longitudinal Study on Ageing (TILDA), European Quality of Life Survey (EQLS), Organisation for Economic Co-operation and Development (OECD), Programme for the International Assessment of Adult Competencies (PIACC), Quarterly National Household Survey (QNHS) and European Labour Force Survey (EU-LFS).

## PRESENTATION OF THE INDICATORS

Throughout the report, indicators are reported as percentages (%), meaning the proportion of people of a specific age with a specific characteristic. Confidence intervals (CI : 95%) are used in graphs and tables. A confidence interval is a range of values within which you can be 95% certain the true mean of the population lies.

## DISAGGREGATION OF RESULTS AND AGE THRESHOLDS

Throughout the report, results are presented to show differences between age groups, level of intellectual disability, differences in residential settings and gender differences. Data for people with an intellectual disability is for those aged 40 and over. Age is broken into groups of 40-49, 50-64 and 65+. When data is reported for the general population, it is reported for those aged 50 and over.





SECTION

**3.1**

**DEMOGRAPHICS**

Table 5 below shows the demographics of the sample from IDS-TILDA across the three waves. In Wave 1, 753 people with an intellectual disability took part in IDS-TILDA, 701 in Wave 2 and 609 in Wave 3. The number of people in the 40-49 age category decreased over the three waves, as people aged into the 50-64 age bracket.

Overall, 56% of the sample were men and 44% were women. By Wave 3, 63% were in the 50-64 age range; 26% were over 65+ and 12% were under 50. The highest proportion had a moderate level of intellectual disability (46%), with 29% having a severe/profound level of intellectual disability and 25% a mild level of intellectual disability.

**Table 5:** Demographic breakdown of sample of people with an intellectual disability aged 40+

	WAVE 1 (2009-2011)		WAVE 2 (2012-2014)		WAVE 3 (2015-2017)	
AGE	%	CI (95%)	%	CI (95%)	%	CI (95%)
40-49	38.2	[34.8-41.8]	28.1	[25.0-31.7]	11.8	[9.5-14.6]
50-64	45.6	[42.0-49.1]	51.0	[46.9-54.3]	62.6	[58.7-66.3]
65+	16.2	[13.7-19.0]	20.9	[18.3-24.3]	25.5	[2.3-29.2]
GENDER	%		%		%	
Men	44.9	[41.0-48.1]	44.5	[44.1-49.5]	44.2	[40.3-48.1]
Women	55.1	[51.9-59.0]	55.5	[52.3-58.7]	55.8	[51.9-59.7]
LEVEL OF ID	%		%		%	
Mild	23.9	[20.9-27.2]	24.0	[20.7-27.2]	24.8	[21.4-28.5]
Moderate	46.5	[42.8-50.2]	46.5	[42.7-50.4]	46.2	[42.1-50.3]
Severe/Profound	29.6	[26.4-33.1]	29.5	[26.3-33.3]	29.1	[25.5-32.9]
TYPE OF RESIDENCE	%		%		%	
Independent/Family	17.1	[14.6-20.0]	16.3	[13.7-19.2]	15.6	[12.9-18.7]
Community Group Home	35.6	[32.3-39.1]	43.5	[39.9-47.2]	40.4	[36.6-44.3]
Residential	47.3	[43.7-50.8]	40.2	[36.7-43.9]	44.0	[40.1-48.0]
N=	753		701		609	

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Interval (95%)



SECTION

**3.2**

**PARTICIPATION**

## GOAL

## 1

Remove barriers to participation and provide more opportunities for the continued involvement of people as they age in all aspects of cultural, economic and social life in their communities according to their needs, preferences and capacities.

DOMAIN	KEY INDICATOR	% GENERAL POPULATION	
		AGE 40+	AGE 50+
EMPLOYMENT AND RETIREMENT	Employment rate in the population aged 50-64	7	64
	Percentage of people with an intellectual disability aged 40+ who were ever in paid employed	17	n/a
	Percentage of people with an intellectual disability aged 40+ who are engaged in day programmes	81	n/a
EDUCATION AND LIFELONG LEARNING	Level of education for people with an intellectual disability aged 40+	32% had no education	n/a
	Participation rate in formal education and training among people with an intellectual disability aged 40+	2	9
	Participation rate in informal education and training among people with an intellectual disability aged 40+	12	8*
	Percentage of people with an intellectual disability aged 40+ with low literacy	87	61*
	Percentage of people with an intellectual disability aged 40+ with low numeracy	81	64*
	Percentage of people with an intellectual disability aged 40+ who have difficulty using money	79	n/a

DOMAIN	KEY INDICATOR	% ID	% GENERAL POPULATION
		AGE 40+	AGE 50+
ACTIVE CITIZENSHIP AND VOLUNTEERING	Percentage of people with an intellectual disability aged 40+ who engaged in political activities in the past twelve months	0.7	24
	Percentage of people with an intellectual disability aged 40+ who did unpaid voluntary work in the past twelve months	10	41
	Percentage of people with an intellectual disability aged 40+ who provide care to a relative	12	10**
SOCIAL AND CULTURAL PARTICIPATION	Percentage of people with an intellectual disability aged 40+ who engage in one or more social leisure activity at least once a week	96	82
	Average self-reported loneliness among people with an intellectual disability aged 40+	8	5
	Percentage of people with an intellectual disability aged 40+ who have someone they can confide in	96	92***
	Percentage of people with an intellectual disability aged 40+ who participated in social or cultural activities in the past twelve months	96	85
	Percentage of people with an intellectual disability aged 40+ who feel part of their community	79	n/a
	Percentage of people with an intellectual disability aged 40+ who have contact with family on a weekly basis	61	n/a
	Percentage of people with an intellectual disability aged 40+ who report barriers to participation	56	n/a
TRANSPORT	Percentage of people with an intellectual disability aged 40+ who drive	0.5	72*
	Percentage of people with an intellectual disability aged 40+ who rate public transport in their area as good or excellent	70	49*
	Percentage of people with an intellectual disability aged 40+ who rate private transport in their area as good or excellent	91	59*
	Percentage of people with an intellectual disability aged 40+ who report lack of access to transport has affected social participation	11	n/a

DOMAIN	KEY INDICATOR	% ID	% GENERAL POPULATION
		AGE 40+	AGE 50+
CHOICE	Percentage of people with an intellectual disability aged 40+ with choice in day-to-day activities	69	n/a
	Percentage of people with an intellectual disability aged 40+ with choice in major life decisions	15	n/a
	Percentage of people with an intellectual disability aged 40+ with access to an advocacy service	72	n/a

\* Reported in the 2016 National Positive Ageing Indicators Report

\*\* Indicator for the general population specified providing care to an older relative

\*\*\* Indicator for the general population reported on percentage of people aged 50+ with a supportive relative or friend

**Note:** Generally n/a indicates that comparable data was not included in the National Positive Ageing Indicators Report as this is an additional indicator for people with an intellectual disability

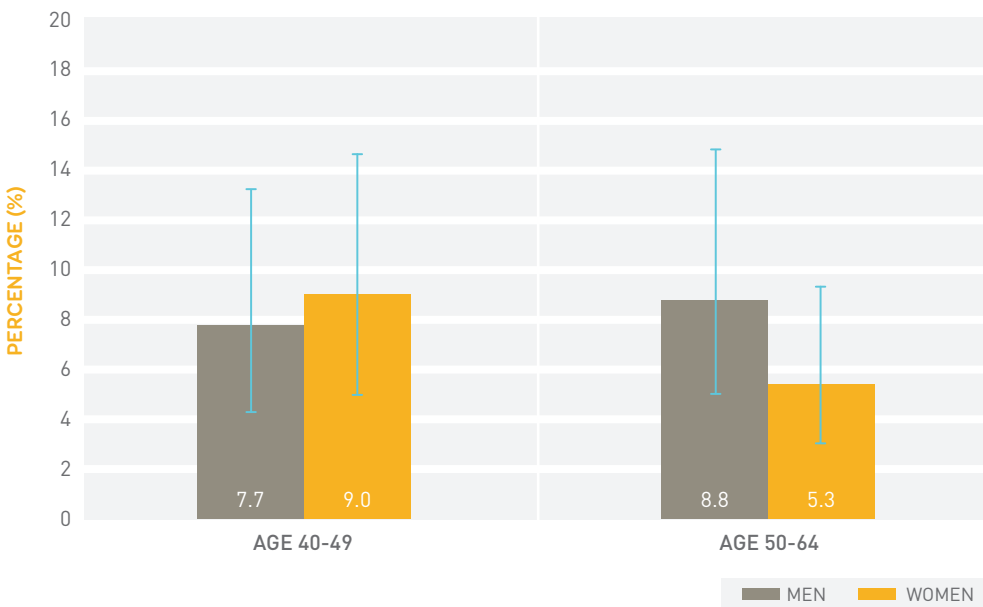
7% of people with an intellectual disability aged 40+ were in open paid employment

**INDICATOR:**  
EMPLOYMENT RATE  
IN THE POPULATION  
OF PEOPLE WITH  
AN INTELLECTUAL  
DISABILITY AGED  
40-64

In addition to the monetary gain, employment has been associated with numerous benefits, including higher self-esteem, confidence, social inclusion (Carew et al., 2010) and physical and mental health (Butterworth et al., 2011). Underemployment has been identified as a critical issue for people with an intellectual disability (McGlinchey et al., 2013). In order to address this issue, there needs to be a shift in government policies, workplace practices and vocational training (Lysaght et al., 2012).

This indicator shows the employment rate for people with an intellectual disability aged 40+. Employment is defined as 'in paid employment'. Data is also given on the percentage of those in sheltered employment and those who were attending a day service and perceived this as being in employment; this category is named 'perceived employment'.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 3:** Percentage of people with an intellectual disability aged 40+ in employment, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011). CI: Confidence Interval (95%).

**Key points**

- Employment rates in real paid employment were low across men and women at 7%
- 12% of people reported being in sheltered employment
- 7% were attending a day service and perceived this as employment
- Overall, 80% of people were attending a day service
- It was reported that 38% were unable to work due to having a disability
- Over half of those in paid employment did not know how much they received on a weekly/monthly basis

**EMPLOYMENT IN THE GENERAL POPULATION**

In 2017, the annual employment rate for people aged 50-64 was 64%

Source: EU – LFS 2015-2017

**PARTICIPATION: EMPLOYMENT AND RETIREMENT**

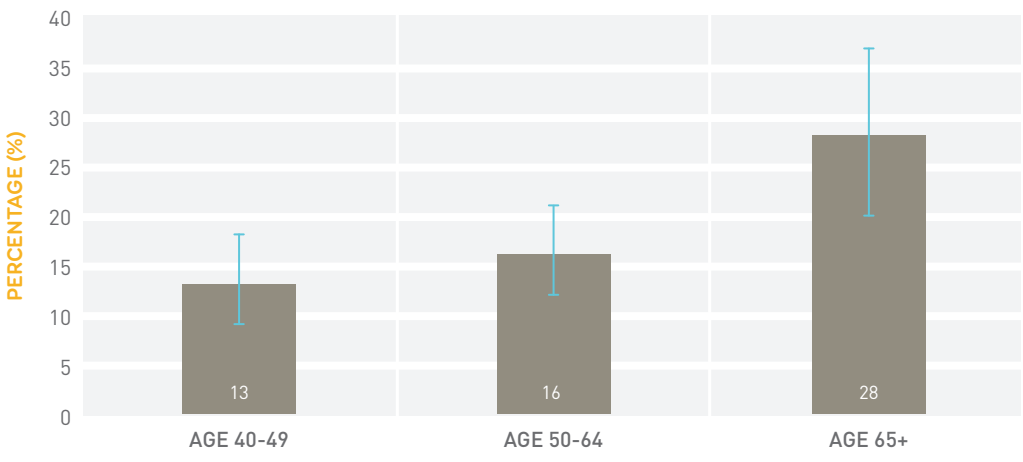
**17% of people with an intellectual disability aged 40+ have been in paid employment at some point**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO WERE EVER IN PAID EMPLOYMENT

The Comprehensive Employment Strategy for People with Disabilities (2015-2024) sets out a ten-year approach to ensure that people with disabilities who are able to and want to work are supported and enabled to do so. The strategy focuses not only on those who are 'job-ready' but also on those who, given the right supports, can work. Ensuring that people with an intellectual disability are supported to gain employment is a crucial issue.

This indicator shows the percentage of people with an intellectual disability who were ever in paid employment.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 4:** Percentage of people with an intellectual disability aged 40+ who were ever in paid employment, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011). CI: Confidence Intervals (95%)

**Key points**

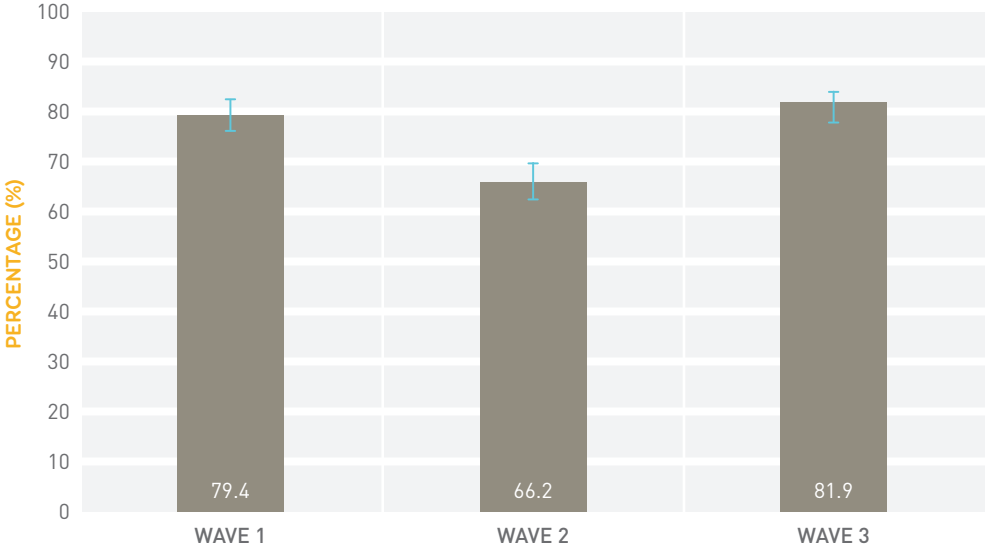
- 37% of people with a mild level of intellectual disability reported having been in paid work
- 20% of people with an intellectual disability who were living independently or with family had experience of paid work. This was also the case for people living in the community (20%), compared to 13% for people living in a residential setting

81% of people with an intellectual disability are engaged in day programmes

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WHO ARE  
 ENGAGED IN DAY  
 PROGRAMMES

Day programmes are essentially a day support and therapeutic service programme designed to meet the needs of people based on implementation of individual plans. The programmes range in skills and activities such as independent living skills, personal development, education classes, and social and leisure activities. The New Directions Report (2012) proposed a new approach to day service provision in Ireland, with a core focus on person-centeredness, community inclusion, active citizenship and quality (HSE, 2016).

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 5:** Percentage of people with an intellectual disability aged 40+ who are engaged in day programmes, by waves of IDS-TILDA

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Participation in day programmes were high across the three waves of IDS-TILDA
- 96% of respondents said that the day activity they described was what they wanted to do
- 50% reported that they had not spent any full days at home in the previous week, i.e. had been outside every day. 67% spent at most one entire day at home
- 16% reported that they had spent most of the week, i.e. four days or more, at home all day. Of those who spent most of the week at home, the most common reason was 'personal choice'. This was followed by 'staff/resource issues'

## PARTICIPATION: EDUCATION AND LIFELONG LEARNING

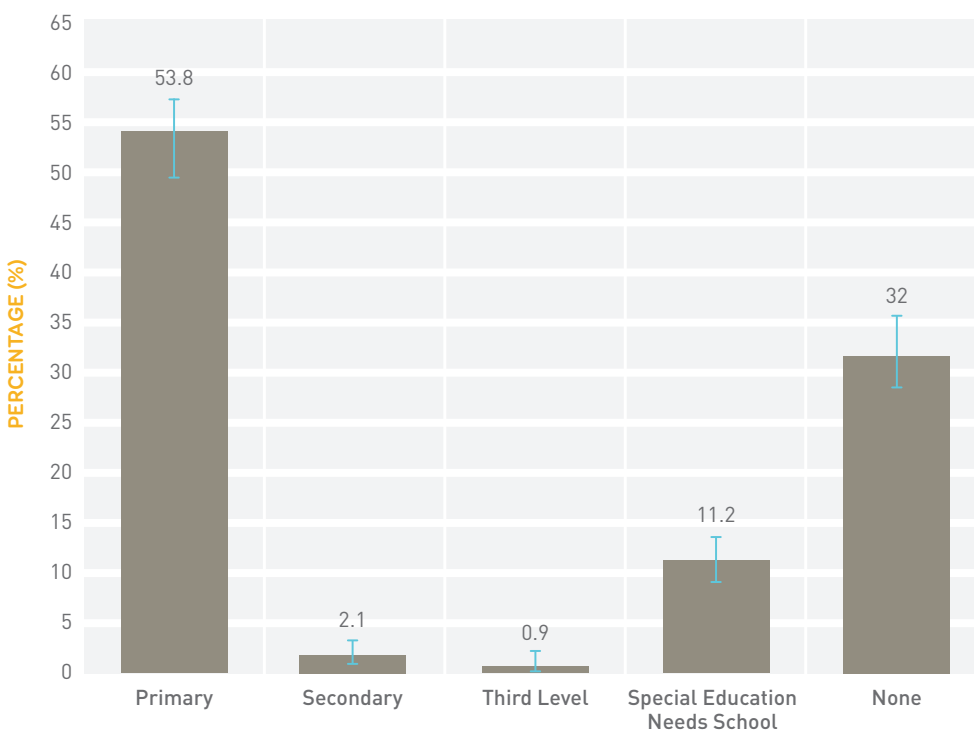
## 32% of people with an intellectual disability aged 40+ had never received any education

**INDICATOR:**  
LEVEL OF  
EDUCATION FOR  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED 40+

Level of education for people aged 40+ with an intellectual disability has a strong link with employment (Moni et al., 2018). A clear link has also been found between education levels, spending power, health and wellbeing (Lochner, 2011; Grundy & Holt, 2001).

This indicator examined the level of education of people with an intellectual disability aged 40+ by the response to the questions 'Have you attended education?' and 'Type of education'.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 6:**  
Level of education  
of people with  
an intellectual  
disability aged 40+

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011). CI: Confidence Intervals (95%)

### Key points

- Over half of people with an intellectual disability aged 40+ had attended primary school only
- Almost one-third had never had any education
- Level of intellectual disability influenced highest level of education:
  - 5% of people with a mild level of intellectual disability had no education
  - 25% of people with a moderate level of intellectual disability had no education
  - 71% of people with a severe/profound level of intellectual disability had no education

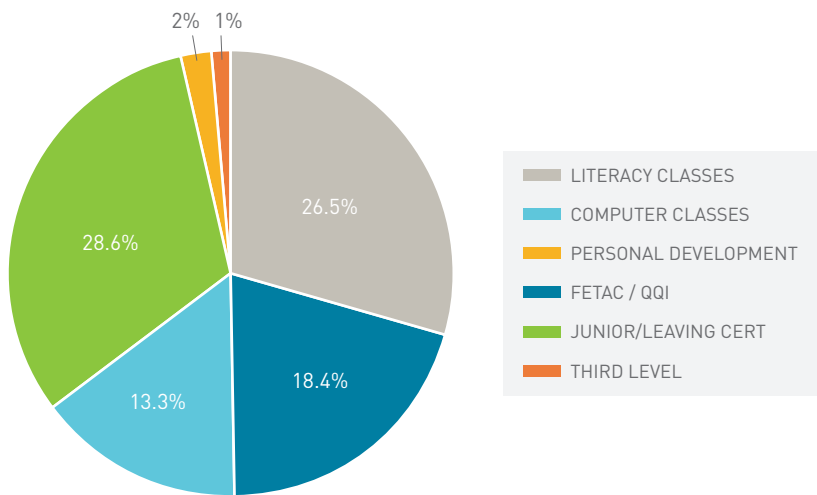
**2% of people with an intellectual disability aged 40+ are engaged in formal training. 12% are engaged in informal education**

**INDICATOR:**  
PARTICIPATION RATE IN FORMAL AND INFORMAL EDUCATION AND TRAINING AMONG PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+

Engagement in education and training has been shown to have many benefits including better attention to good health practices, health service access and usage (WHO 2008). Completion of an education course can also enhance quality of life and coping skills. It also increases social participation and connectedness (Simone & Sciuli, 2006).

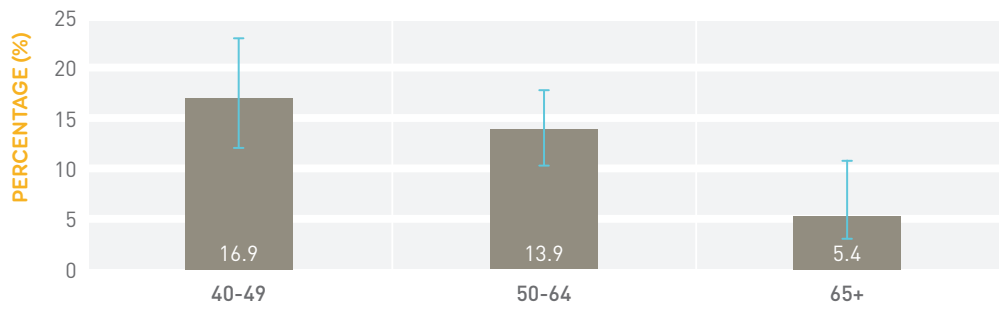
This indicator shows the percentage of people with an intellectual disability who engaged in courses, education or training in the previous year.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 7:** Of those attending a formal training course, percentage breakdown of type of training course attended

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI Confidence Intervals (95%)



**Figure 8:** Percentage of people with an intellectual disability aged 40+ engaged in informal training, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI Confidence Intervals (95%)

**Key points**

- 12% of people with an intellectual disability aged 40+ were engaged in informal education or training, with a further 2% engaged in formal education
- On average, people spent three hours per week in a training course
- Of those engaged in training, almost one-third were completing a FETAC/QQI course
- Just over one-quarter were completing a literacy course

**FORMAL TRAINING IN THE GENERAL POPULATION**

9% people aged 25-64 participated in formal education and training in 2017

Source: EU-LFS, Eurostat 2008-2017

PARTICIPATION: EDUCATION AND LIFELONG LEARNING

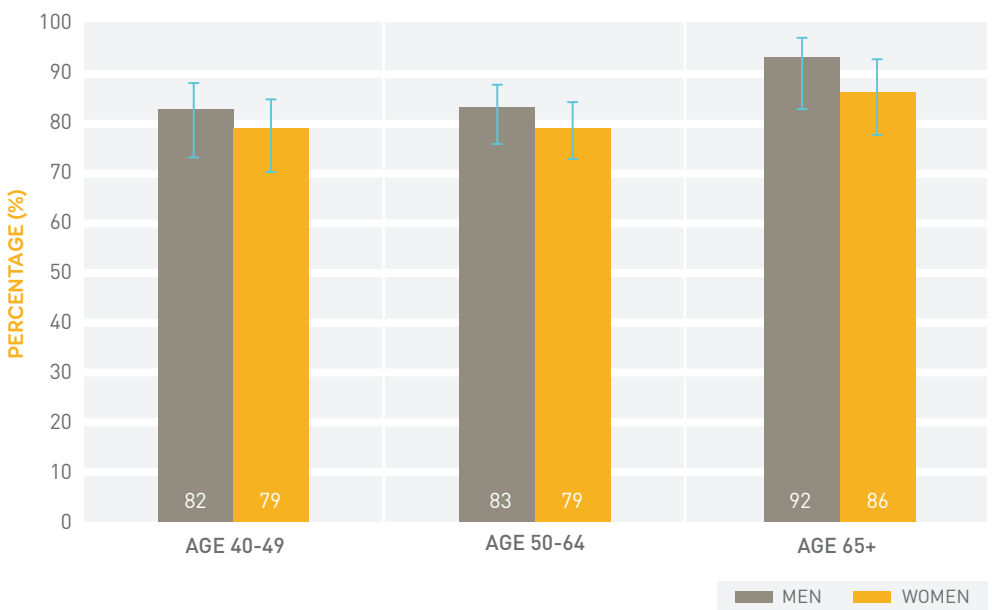
87% of people with an intellectual disability aged 40+ have literacy problems

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WITH LOW  
 LITERACY

The ultimate goal of literacy skills is to function as independently and in as integrated a way as possible (Griffen, 2017). Being literate empowers people to be engaged with society, whether in terms of being an effective consumer, being informed about lifestyle options, being able to make informed choices and increasing independence (Moni, 2018).

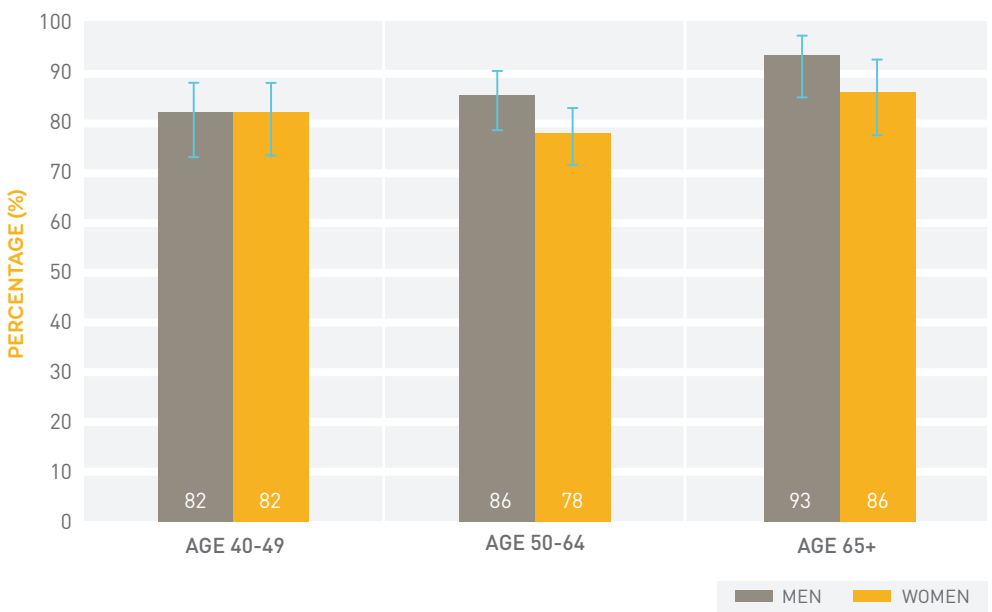
This indicator shows the percentage of people with an intellectual disability aged 40+ with difficulty reading or writing.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 9:**  
 Percentage of people with an intellectual disability aged 40+ who had difficulty with reading, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI Confidence Intervals (95%)



**Figure 10:**  
 Percentage of people with an intellectual disability aged 40+ who had difficulty with writing, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI Confidence Intervals (95%)

## PARTICIPATION: EDUCATION AND LIFELONG LEARNING

### Key points

- 82% of people had difficulty with reading
- 83% of people had difficulty with writing

The tables below give additional information in relation to difficulties with reading and writing.

**Table 6:** Difficulty with reading and writing among people with an intellectual disability aged 40+

	YES %	YES WITH ASSISTANCE %	NO %
I can read my own name	29.3	7.9	62.8
I can identify most letters of the alphabet	16.5	10.9	72.6
I can read easy read material	8.2	7.5	84.2
I can read environment signs, e.g. Stop, Exit	14.4	5.6	80
I can read instructions, e.g. on a medicine bottle	1.4	4.6	94
I can read newspaper articles	1.8	4	94.2

	YES %	YES WITH ASSISTANCE %	NO %
I can write most letters of the alphabet	13.2	13.7	73
I can write my own name	26.4	8.7	64.9
I can write notes and letters	5.2	14.4	80.3
I can fill out forms	0.7	5.2	94.1

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Interval (95%).

### Key points

- 90% of men reported difficulty with literacy compared to 85% of women
- Difficulty with literacy increased with increasing age and level of intellectual disability. 68% with a mild level of intellectual disability had literacy problems, compared to 90% with a moderate level of intellectual disability and 99% with a severe/profound level of intellectual disability

## LITERACY IN THE GENERAL POPULATION

61% of people aged 55-65 have low literacy skills

\* This indicator for the general population shows the percentage of adults aged 55-65 who have low literacy. This is based on the percentage of adults who were categorised as being at or below Level 1 in literacy skills proficiency (understanding and responding appropriately to written texts) following a comprehensive literacy skills test (PIAAC, OECD)

Source: PIAAC 2012

## PARTICIPATION: EDUCATION AND LIFELONG LEARNING

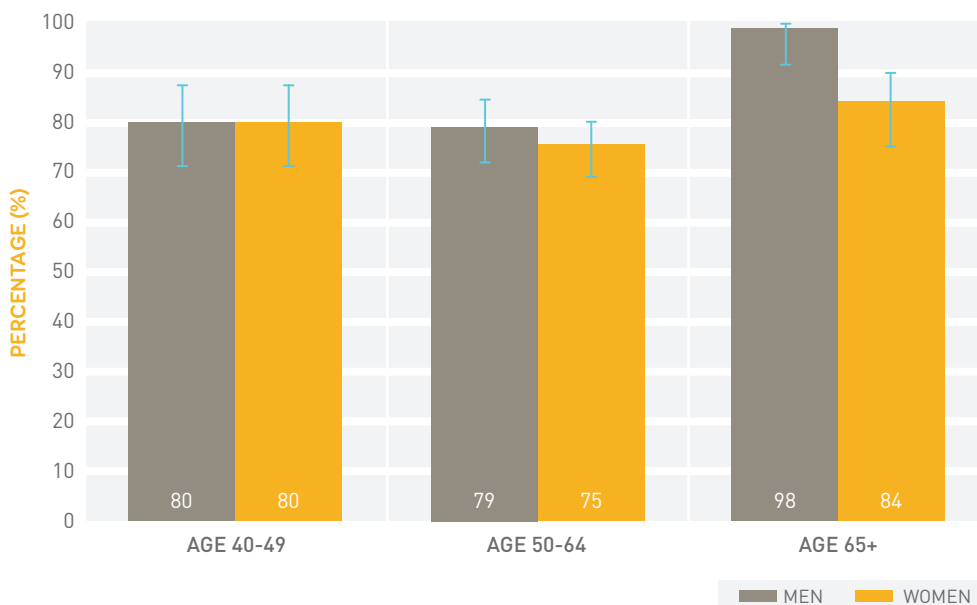
## 81% of people with an intellectual disability aged 40+ have difficulty with numeracy

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WITH LOW  
NUMERACY

Numeracy involves using mathematics to meet the general demands of life at home, in paid work, and for participation in community and civic life (AAMT 1997). Low numeracy can have an impact on employment opportunities, earning and social and political engagement (IAAPC, 2015). Low numeracy has been identified as a barrier to social inclusion for people with an intellectual disability (Abbot & McConkey, 2006).

This indicator shows the percentage of people with an intellectual disability who report difficulty with numeracy.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 11:** Percentage of people with an intellectual disability aged 40+ who had difficulty with numeracy, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Intervals (95%)

### Key points

- Over four-out-of-five people with an intellectual disability had difficulty with numeracy
- Difficulty with numeracy increased with age but was high across all age groups
- 57% of people with a mild level of intellectual disability had difficulty with numeracy
- 84% of people with a moderate level of intellectual disability had difficulty with numeracy

**Table 7:** Difficulty with numeracy among people with an intellectual disability aged 40+

	YES	YES, WITH ASSISTANCE	NO
	%	%	%
I can recognise numbers	24.7	10.6	64.8
I can locate numbers on a phone	9.8	7.9	82.3
I understand more-less relationships	7	5.9	87.1
I can do simple sums	4.1	5	90.9
I can tell the time on a clock	16.1	3.4	80.5

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Interval (95%).

### NUMERACY IN THE GENERAL POPULATION

63% of people aged 55-65 have low numeracy skills

\* This indicator focuses on the percentage of adults aged 50+ who have low numeracy. This is based on the percentage of adults who were categorised as being at or below Level 1 in numeracy skills proficiency (numerical and mathematical concepts) following a comprehensive numeracy skills test (PIAAC, OECD)

Source: PIAAC 2012

## PARTICIPATION: EDUCATION AND LIFELONG LEARNING

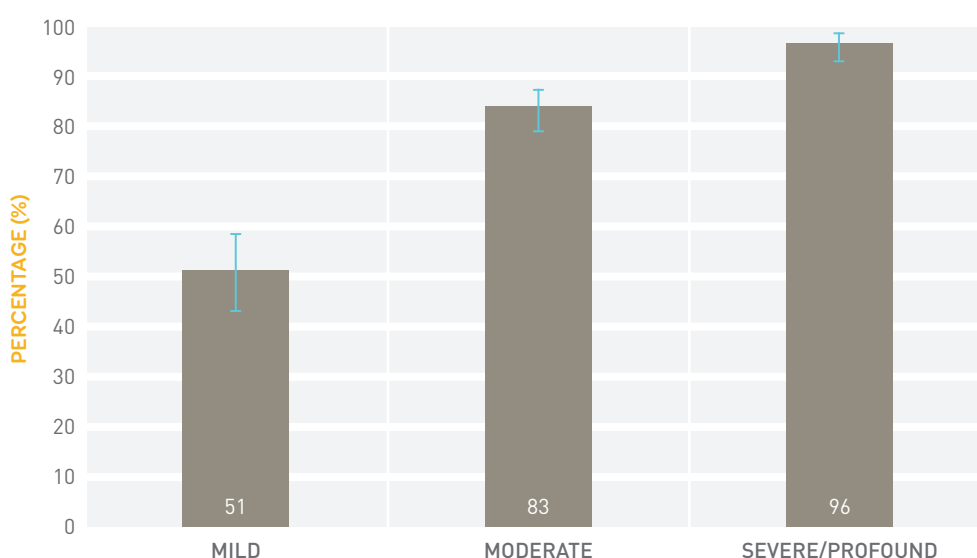
## 79% of people with an intellectual disability aged 40+ have difficulty with using money

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WHO HAVE  
 DIFFICULTY USING  
 MONEY

The UN Convention of the Rights of Persons with Disabilities (UNCRPD, 2006) aims to increase the equity between people with and without disabilities. In order to achieve this, there needs to be more opportunities for people with an intellectual disability to make their own decisions and for self-determination. Being able to use money supports autonomy and independence.

This indicator shows the percentage of people with an intellectual disability aged 40+ with difficulty using money.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 12:**  
 Percentage of people with an intellectual disability aged 40+ who had difficulty using money, by level of intellectual disability

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011). CI Confidence Intervals (95%)

### Key points

- 79% of people with an intellectual disability had difficulty with using money
- Money management was the IADL (Independent Activity of Daily Living) with the highest reported difficulty in each setting, with 49% of those living independently, 78% of those living in community group homes and 95% of those living in residential care reporting significant difficulty with this task
- 77% of people aged 40-49 and 50-64 had difficulty using money. This increased to 85% for those aged 65+

**Table 8:** Difficulty with using money among people with an intellectual disability aged 40+

	YES	YES, WITH ASSISTANCE	NO
	%	%	%
I can identify €5, €10, €20 notes	15	7.7	77.2
I can identify 1c, 2c, 5c, 10c, 20c, 50c coins	11.7	9.2	79.1
I can arrange notes in order	5.7	7	87.3
I can arrange coins in order	5.5	7.5	87
I understand more or less if I should be due change	4.6	5.5	89.9

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Interval (95%).

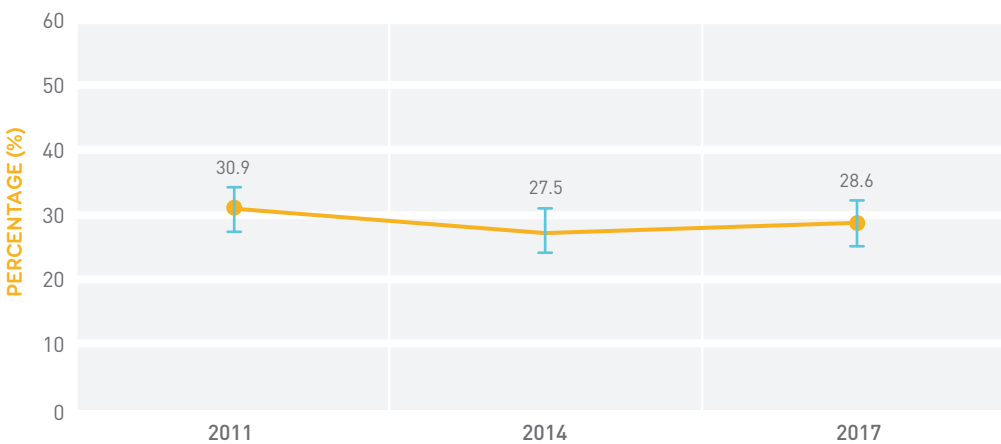
**0.7% of people with an intellectual disability aged 40+ engaged in political activity. 29% of people with an intellectual disability reported voting in a recent election in 2017**

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO ENGAGED IN POLITICAL ACTIVITIES IN THE PAST TWELVE MONTHS**

The UN Convention on the Rights of Persons with Disabilities was ratified in Ireland in 2018. This covers civil and political rights to equal treatment and freedom from discrimination. This indicator shows the percentage of people with an intellectual disability aged 40+ who engaged in any of the following political activities in the past twelve months: attended a meeting of a trade union, political, party or political action; attended a protest or demonstration; signed a petition; or contacted a political or public official.

Data is also shown below on the percentage of people who voted in the last election.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 13:** Percentage of people with an intellectual disability aged 40+ who voted in an election in 2011, 2014, 2017

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI Confidence Intervals (95%)

**Key points**

- Only 0.7% of people with an intellectual disability engaged in political activities
- The percentage of people who voted in an election remained steady over the three waves of data collection
- There was no significant difference between the age groups in terms of voting
- Over half (52%) of people with a mild level of intellectual disability voted in the last election
- This compared to 27% with a moderate level of intellectual disability
- 8 individuals (5%) with a severe/profound level of intellectual disability voted in the last election

**POLITICAL ACTIVITY IN THE GENERAL POPULATION**

24% of people aged 50+ engaged in political activities in the past twelve months

\* This indicator focuses on the percentage of people aged 50+ who engaged in any of the political activities in the past twelve months

Source: EQLS Fourth Round 2016

## PARTICIPATION: ACTIVE CITIZENSHIP AND VOLUNTEERING

## 10% of people with an intellectual disability aged 40+ volunteered in the past twelve months

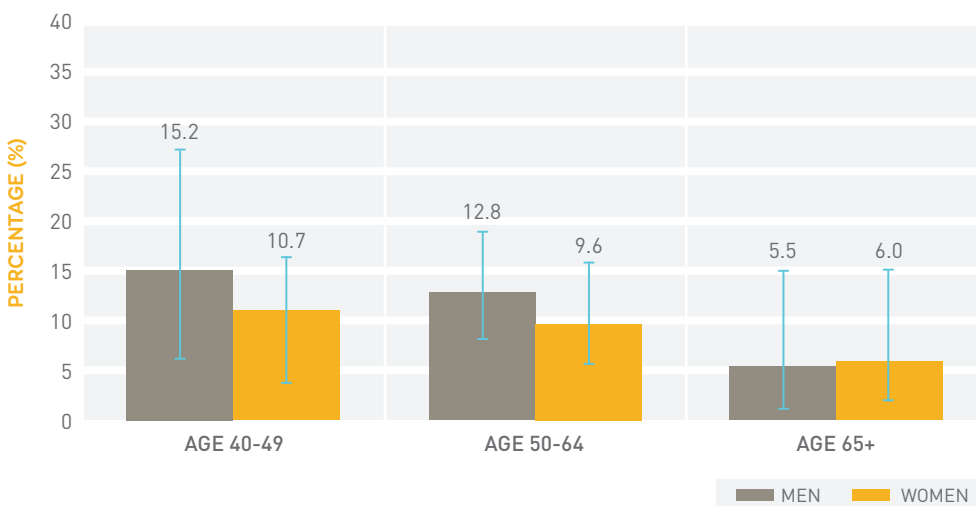
**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO DID  
UNPAID VOLUNTARY  
WORK IN THE PAST  
TWELVE MONTHS

Voluntary work has long been established as beneficial for life satisfaction and mental wellbeing. Voluntary work has been found to contribute to active ageing, to increased self-rated health and to social inclusion (Bechetti et al., 2018).

Research on volunteering with a population with an intellectual disability found that volunteering increased social networks, developed knowledge and skills and increased quality of life (Trembath et al., 2010). An added benefit found was that it gave people the opportunity to be providers, rather than recipients, of community services (Trembath et al., 2010).

This indicator shows the percentage of people with an intellectual disability aged 40+ who volunteered in the previous twelve months.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 14:** Percentage of people with an intellectual disability aged 40+ who volunteered in the past twelve months, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

### Key points

- 16% of people with a mild level of intellectual disability did unpaid voluntary work
- Of those who did unpaid voluntary work, 55% volunteered once a week or more
- The most common reasons given for volunteering included: enjoyment (60%); contributing something useful (55%); meeting other people (43%); because they needed to do it (30%); and a sense of achievement (27%)

### VOLUNTEERING IN THE GENERAL POPULATION

41% of people aged 50+ volunteered in the past twelve months

Source: EQLS Fourth Round 2016

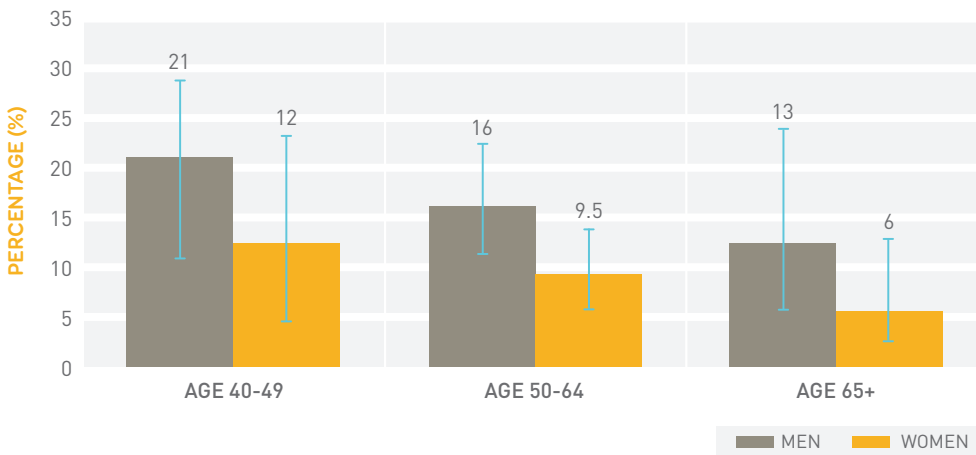
12% of people with an intellectual disability aged 40+ support a relative

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO PROVIDE  
CARE TO A RELATIVE

In the general population, family members often provide unpaid support to a spouse, parent or relative due to chronic illness or disability. A discussion paper from Care Alliance Ireland showed that people with an intellectual disability who are living at home are providing care to their parent (Care Alliance Ireland, 2015). This indicator shows the percentage of people with an intellectual disability who provide support to a relative.

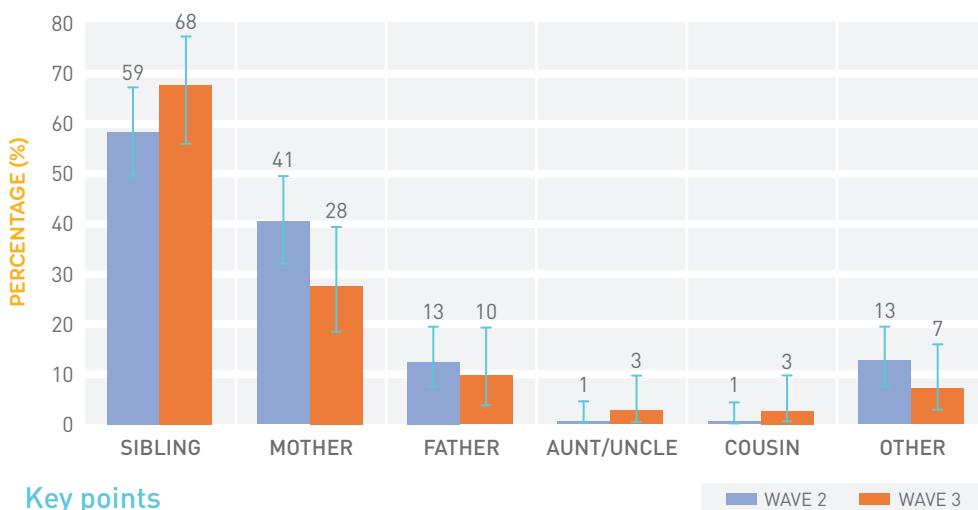
For the general population, the indicator shows data on care provided for an older or disabled relative in the previous month. The data for people with an intellectual disability does not include a timeframe.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 15:** Percentage of people with an intellectual disability aged 40+ who provided support to a relative, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)



**Figure 16:** Family members to whom people with an intellectual disability aged 40+ provide support

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Men provided more support for a relative across all age groups than women
- The percentage of people giving support to a relative dropped between Wave 2 and Wave 3 from 18% to 12%
- 23% of people with a mild level of intellectual disability supported a family member compared to 10% of people with a moderate level of intellectual disability
- 54% gave day-to-day support. 27% gave emotional support. 25% gave help with shopping

**SUPPORTING A RELATIVE IN THE GENERAL POPULATION**

10% of people in the general population support a relative or friend

Source: TILDA Wave 4 2016-2017

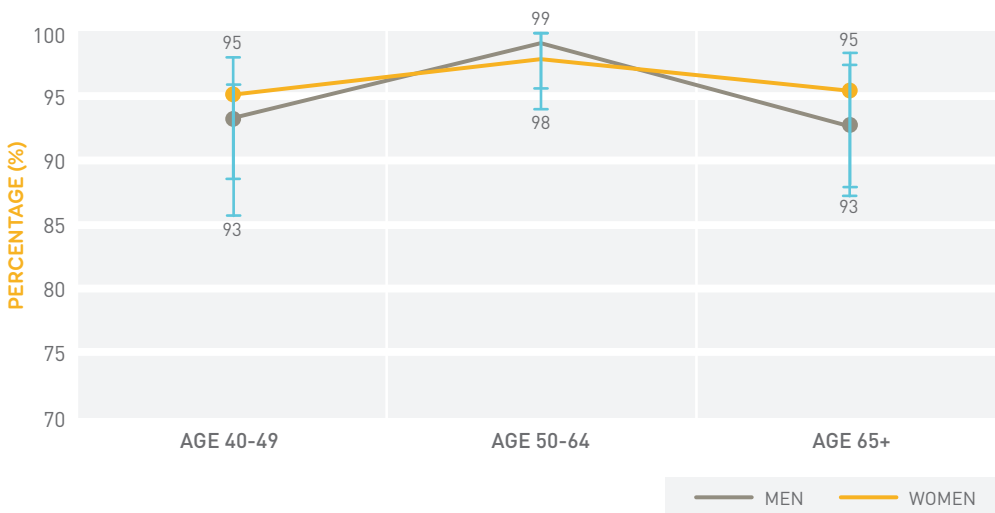
## PARTICIPATION: SOCIAL AND CULTURAL PARTICIPATION

**96% of people with an intellectual disability aged 40+ engage in one or more social leisure activity at least once a week****INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO ENGAGE IN ONE OR MORE SOCIAL LEISURE ACTIVITY AT LEAST ONCE A WEEK

Participation in community activities promotes friendship, skills and a sense of belonging (Merrells et al., 2017). Leisure activity refers to the 'freedom to do what one wants' (Retish & Reiter, 1999). The free choice of the individual is, therefore, essential for meaningful inclusion in a social or leisure activity (Merrells et al., 2017).

This indicator shows the percentage of people with an intellectual disability who engaged in one or more leisure activity at least once a week. Data is also shown for the type of activity in which people engaged.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



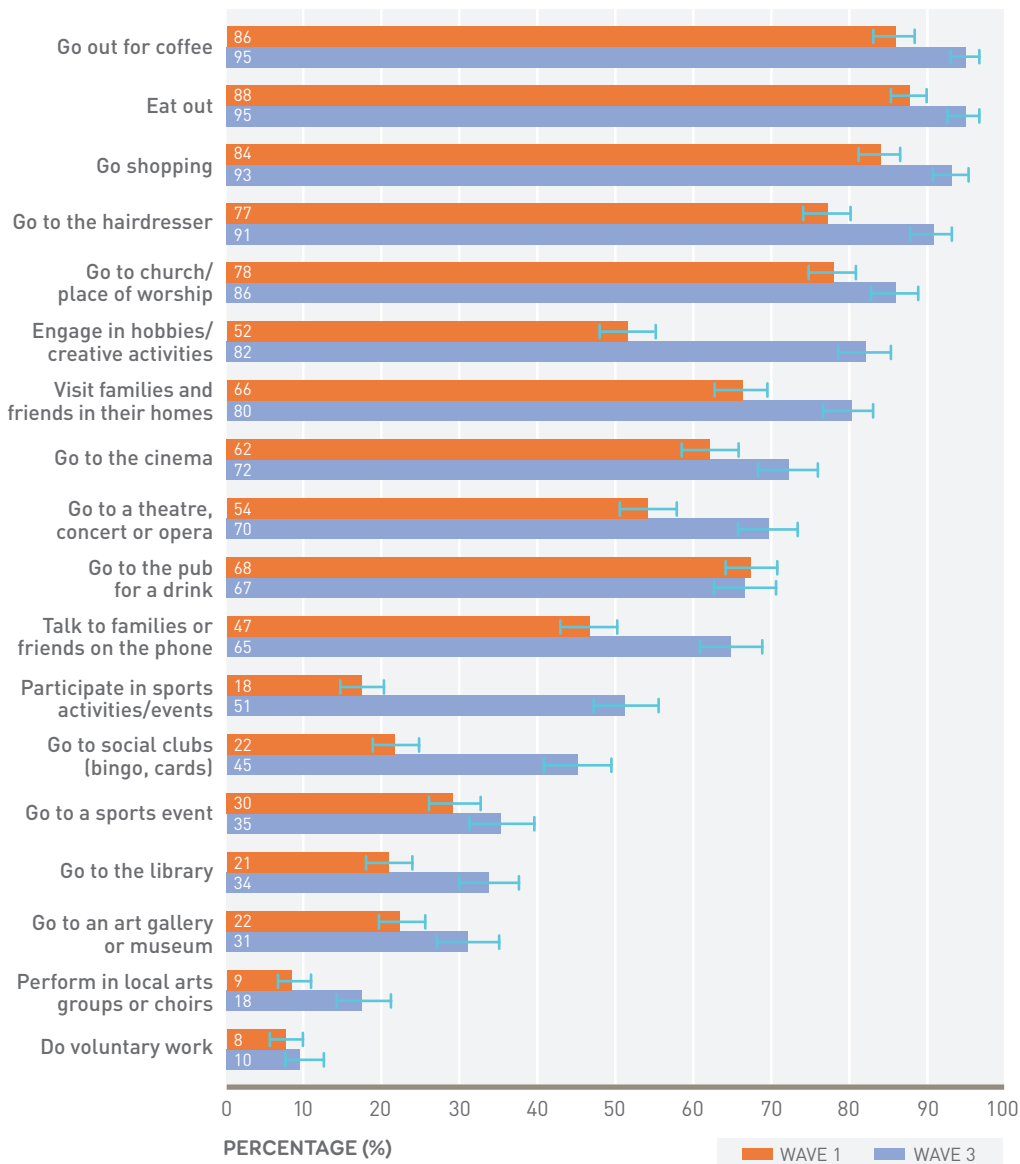
**Figure 17:** Percentage of people with an intellectual disability aged 40+ who engage in one or more social leisure activity at least once a week, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Both men and women were highly engaged in social activities at least once a week
- 99% of people with a mild level of intellectual disability were engaged in one or more social activity at least once a week. 92% of people with a severe/profound level of intellectual disability were engaged in one or more social activity at least once a week

**PARTICIPATION: SOCIAL AND CULTURAL PARTICIPATION**



**Figure 18:** Percentage of people with an intellectual disability aged 40+ engaged in social and leisure activities for Wave 1 (2011) and Wave 3 (2017), by social activity

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Rates for all but one activity increased from 2011 to 2017
- The most common activities were eating out, going out for coffee and going shopping

**SOCIAL ACTIVITY IN THE GENERAL POPULATION**

82% of people aged 56+ engage in at least one social leisure activity on a weekly basis

Source: TILDA Wave 4 2016-2017

**PARTICIPATION: SOCIAL AND CULTURAL PARTICIPATION**

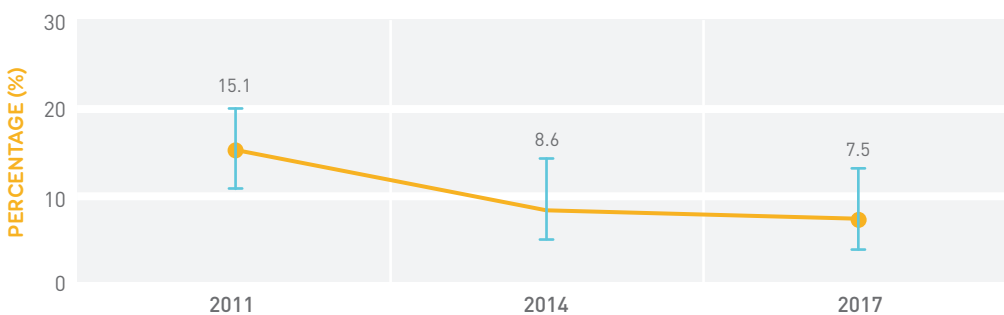
**8% of people with an intellectual disability aged 40+ often feel lonely**

**INDICATOR:**  
**AVERAGE**  
**SELF-REPORTED**  
**LONELINESS AMONG**  
**PEOPLE WITH AN**  
**INTELLECTUAL**  
**DISABILITY**  
**AGED 40+**

While social isolation is an objective phenomenon, loneliness is a subjective lack of social connectedness and can occur both in the presence or in the absence of social isolation (McHugh et al., 2018). Loneliness has a negative effect on physical, mental and cognitive wellbeing (Conroy et al., 2010). Up until recently, there has been little research into the causes, experiences and effects of loneliness in people with an intellectual disability (Wormald, 2018).

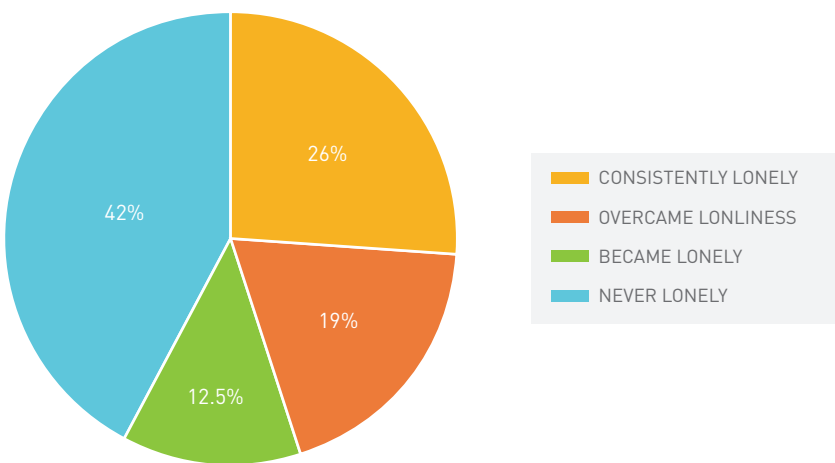
This indicator focuses on self-reported loneliness among people with an intellectual disability aged 40+.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 19:** Change in percentage who report feeling lonely most of the time from 2011-2017

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)



**Figure 20:** Changes in loneliness experienced between 2011 and 2014 for people with an intellectual disability aged 40+

Source: Wormald (2018)

**Key points**

- 26% of people were lonely in both Wave 1 and Wave 2
- 42% were never lonely

**LONELINESS IN THE GENERAL POPULATION**

5% of people aged 56+ often feel lonely

\*This was based on a five-item version of the UCLA Loneliness Scale

Source: TILDA Wave 4 2016-2017

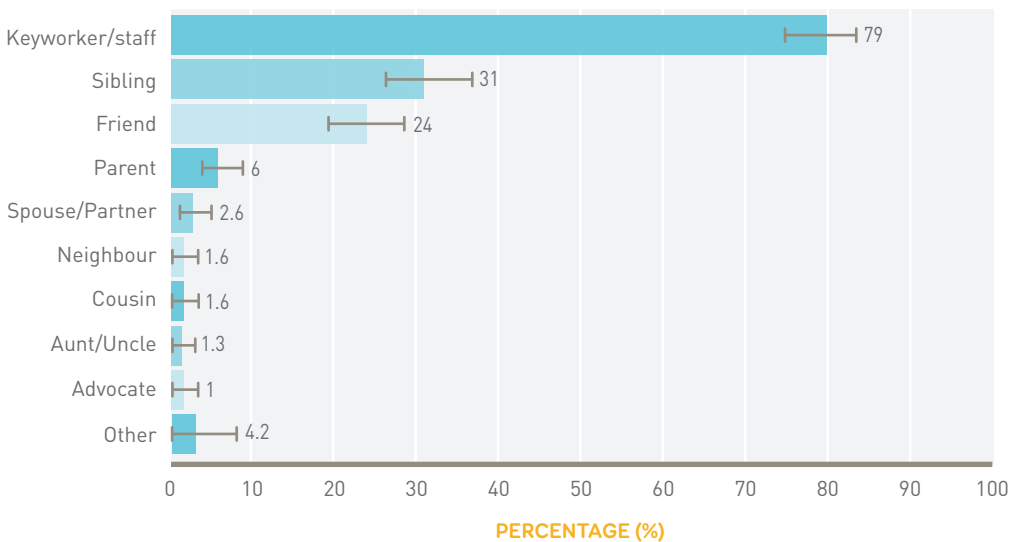
**96% of people with an intellectual disability aged 40+ said that they have someone to confide in**

**INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO HAVE  
SOMEONE THEY CAN  
CONFIDE IN**

Social connectedness is an important part of healthy ageing. Previous studies have found that people living independently or in the community were more likely to have someone to confide in, compared to those living in a residential setting. Having parents or siblings as a confidant was associated with age, with their availability as confidants reducing as the person with an intellectual disability grew older (McCausland, 2016).

This indicator measures the percentage of people with an intellectual disability aged 40+ who could self-report, who have someone to confide in. In the general population, this indicator reports on the percentage of people with at least one supportive relative or friend.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 21:** Identity of confidant for people with an intellectual disability aged 40+

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 79% of people who had a confidant reported a keyworker as their confidant
- Siblings (31%) and friends (24%) were also important confidants
- The number of people reporting keyworkers as confidants increased from Wave 1 to Wave 3
- The number of people reporting friends as confidants more than doubled between Wave 1 (11%) and Wave 3 (23%)
- Fewer people reported parents as confidants in Wave 3 than in Wave 1

**SUPPORTIVE FRIEND IN THE GENERAL POPULATION**

92% of people aged 56+ have at least one supportive relative or friend

Source: TILDA Wave 4 2016-2017

**PARTICIPATION: SOCIAL AND CULTURAL PARTICIPATION**

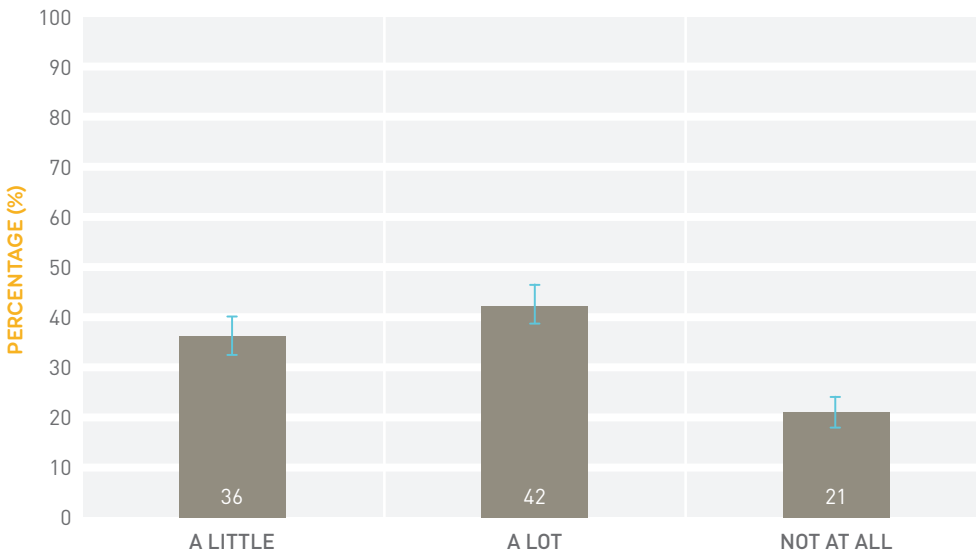
**79% of people with an intellectual disability feel part of their community**

**INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO FEEL  
PART OF THEIR  
COMMUNITY**

While more research is needed into the community participation of people with an intellectual disability, particularly due to policies on de-congregation, it has been found that people living in the community participate more than those in congregated settings do. Participation, however, is lower for those with an intellectual disability than for the general population or other disability groups (Verdonschot et al., 2009).

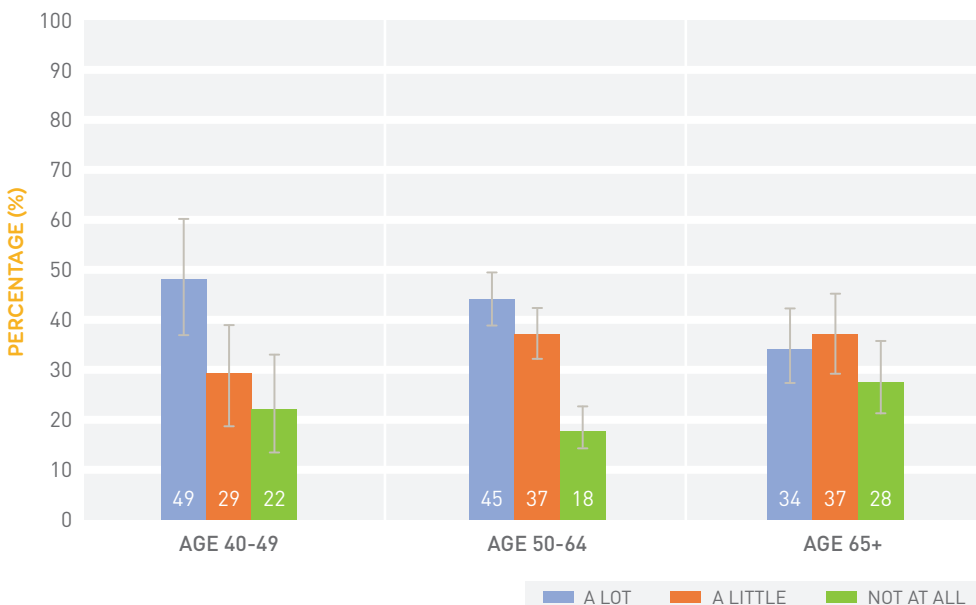
This indicator shows data on how many people with an intellectual disability aged 40+ who could self-report feel part of their community. Participants were asked to name their community and then were asked whether they felt part of that community.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 22:** Percentage of people with an intellectual disability aged 40+ who felt part of their community, by level of felt involvement

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)



**Figure 23:** Percentage of people with an intellectual disability aged 40+ who felt part of their community, by age and level of felt involvement

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 21% did not feel part of their community at all
- 78% of people aged 40-49 felt part of their community a little or a lot. This was slightly higher than for those aged 65+ (72%)
- 89% of people with mild level of intellectual disability felt part of their community compared to 68% with severe/profound level of intellectual disability

**Table 9:** Level of felt involvement by people with an intellectual disability aged 40+

	A LITTLE		A LOT		NOT AT ALL	
	%	CI	%	CI	%	CI
Mild	33.3	25.9-41	56.3	47.8-64.3	10.4	6.2-16.6
Moderate	35.6	29.9-41.7	42.9	36.8-49.1	21.5	16.8-27
Severe/Profound	40.5	33-48.4	27.5	21-35	32	25.1-39.7

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Interval (95%).

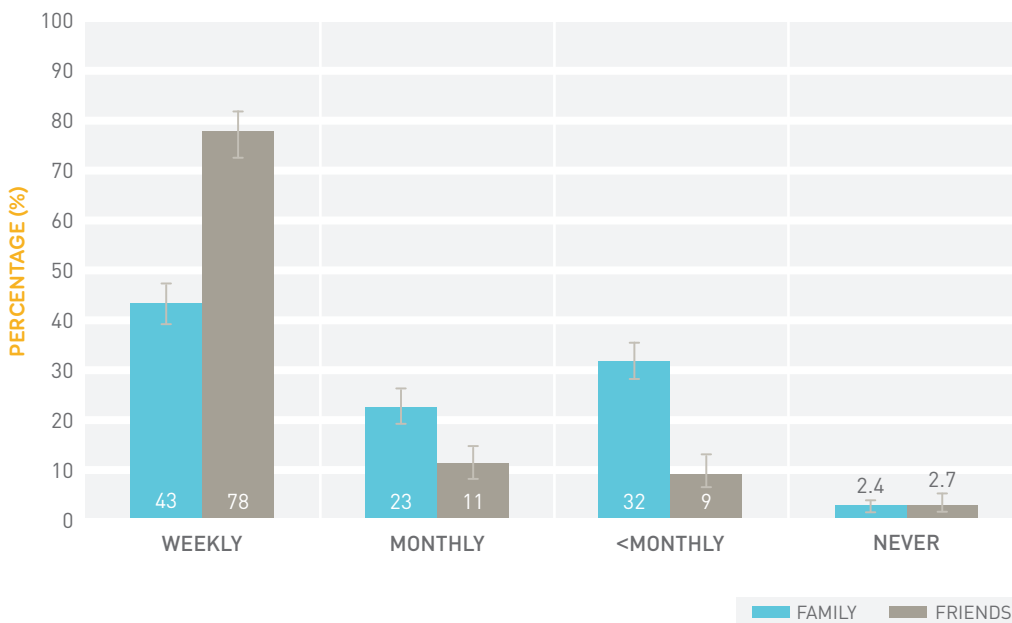
## PARTICIPATION: SOCIAL AND CULTURAL PARTICIPATION

**61% of people with an intellectual disability aged 40+ have contact with non-resident family or friends on a weekly basis****INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO HAVE CONTACT WITH FAMILY OR FRIENDS ON A WEEKLY BASIS

In the general population, quality of life is highest for those who were most integrated into social networks and lowest for those who are most isolated (Nolan et al., 2014). In Ireland, community-dwelling adults with an intellectual disability have greater social networks than those living in an institutional setting. Overall levels of social connectedness, however, are lower for people with an intellectual disability than is found for the general population (McCausland et al., 2016).

This indicator shows the frequency of contact people have with family or friends. This question is asked in relation to non-resident friends. People are asked about frequency of face-to-face contact, telephone contact and written contact.

This indicator is included only in the set of indicators for people with an intellectual disability.

**Figure 24:**

Level of contact with non-resident family and friends for people with an intellectual disability aged 40+, by frequency

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 78% of people had weekly contact with non-resident friends
- 43% of people had weekly contact with non-resident family
- The majority of people had infrequent (less than monthly) contact with family
- Younger males, with a mild level of intellectual disability, living independently or in the community, had the most frequent family contact
- People had the highest rates of frequent contact with their mother and father. Of concern for older people with an intellectual disability for the future is that they will lose the people with whom they have the most frequent contact
- People aged 65+ reported lower levels of frequent contact with friends compared to younger people
- There was a steady decline in very frequent contact as level of intellectual disability became more severe, with a difference of 15% between respondents with a mild level of intellectual disability and those with a severe/profound level of intellectual disability
- 79% of people did not live in the same neighbourhood as their family, rising to 86% for those with a severe/profound level of intellectual disability

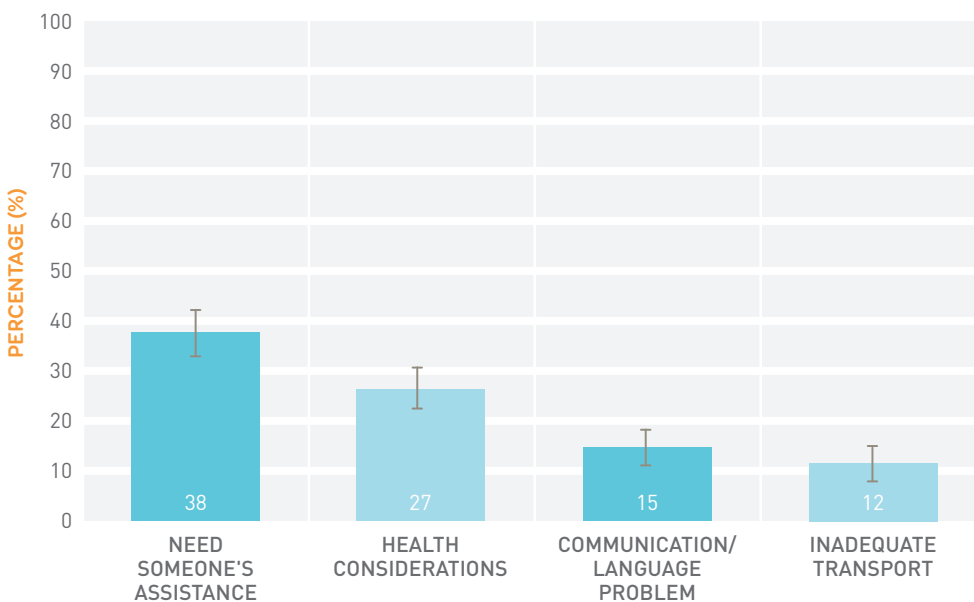
**56% of people with an intellectual disability aged 40+ have difficulty participating in social activities**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT BARRIERS TO PARTICIPATION

Social inclusion has been broadly defined as greater participation in community-based activities and wider social networks. Through a series of focus groups with people with an intellectual disability, it was found that four main barriers to social participation were identified: lack of knowledge and skills, role of support staff, location of house, and lack of facilities (Abbott & McConkey, 2002).

This indicator shows the number of participants who report difficulty participating in social activities outside the home. Participants were asked what specific barriers there were to participation.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 25:** Barriers to participation experienced by people with an intellectual disability aged 40+, by type of barrier

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Over half of people reported barriers to social participation
- The most common barrier to social participation was needing someone’s assistance in order to participate (38%)
- Over one-in-four people said that health considerations were a barrier to participation
- 38% of people with a mild level of intellectual disability experienced barriers to participation
- 73% of people with a severe/profound level of intellectual disability experienced barriers to participation
- There was little difference between the younger age group (63%) and the older age group (65%) in terms of barriers to participation experienced

**PARTICIPATION: TRANSPORT**

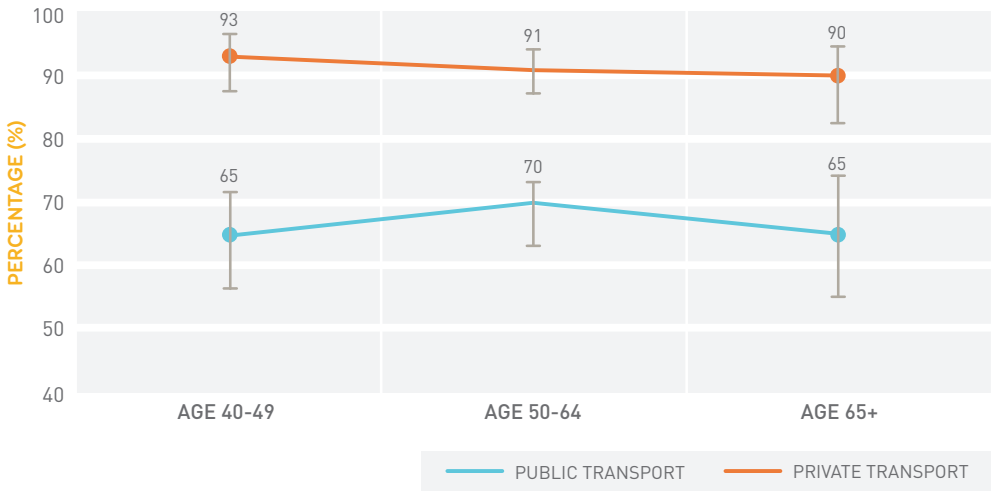
**70% of people with an intellectual disability aged 40+ rate public transport in their area as 'good' or 'excellent', and 91% rate their private transport as 'good' or 'excellent'**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO RATE THE PUBLIC AND PRIVATE TRANSPORT IN THEIR AREA AS GOOD OR EXCELLENT

Good transport options are essential in keeping people connected and in accessing health and social services. As the number of people with an intellectual disability who drive is low, transport is of great importance in allowing people with an intellectual disability to participate in social, cultural, sporting and other activities, as well as accessing healthcare.

This indicator shows the percentage of people who rate public and private transport as 'good', 'very good' or 'excellent'.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 26:** Percentage of people with an intellectual disability aged 40+ who rated their public transport and private transport as good or excellent, by age and type of transport

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Intervals (95%)

**Key points**

- The majority of people across all age groups rated both public and private transport as 'excellent', 'very good' or 'good'
- Private transport was rated higher than public transport
- 42% of people use public transport

**TRANSPORT RATING IN THE GENERAL POPULATION**

49% of people rate public transport as 'good' or 'excellent'  
 59% of people rate private transport as 'good' or 'excellent'

Source: TILDA Wave 1 2009-2011

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT LACK OF ACCESS TO TRANSPORT HAS AFFECTED SOCIAL PARTICIPATION

- 11% of people with an intellectual disability aged 40+ report that a lack of access to transport has affected their social participation
- 27% of people living independently reported that a lack of transport affected social participation, compared to 13% in a residential setting and 9% in a community setting

69% of people with an intellectual disability aged 40+ were involved in day-to-day choices

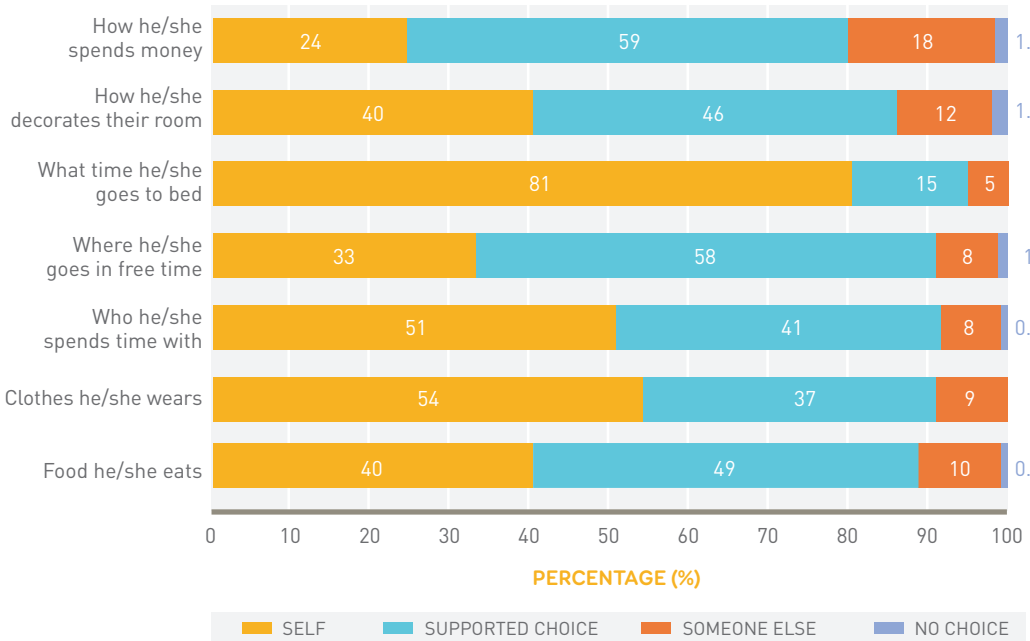
INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WITH CHOICE  
IN DAY-TO-DAY  
DECISIONS

For many people, making choices is an everyday occurrence. For people with an intellectual disability, however, these choices can often be restricted or absent (O’Donovan et al., 2017). While lack of choice-making skills in early life may affect ability for choice-making later in life (Smyth & Bell, 2006), it has been found that adults with an intellectual disability are able to learn choice-making skills (Heller et al., 2000).

This indicator focuses on the level of choice that people with an intellectual disability have in day-to-day decisions, such as: how he/she decorates their room; what time he/she goes to bed; where he/she goes in their free time; who he/she spends time with; what clothes he/she wears; what food he/she eats.

Response options were: ‘Self’, ‘Supported Choice’, ‘Someone Else Chooses’ or ‘No Choice’.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 27:** Level of choice in day-to-day decisions for people with an intellectual disability aged 40+, by type of choice

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Level of self-choice in day-to-day decisions ranged from 24% to 81% depending on the decision
- For nearly all day-to-day choices, nine-out-of-ten people with an intellectual disability were involved in the decision-making process
- Among the day-to-day decisions, people with an intellectual disability had the most choice regarding what time they went to bed

**PARTICIPATION: CHOICE**

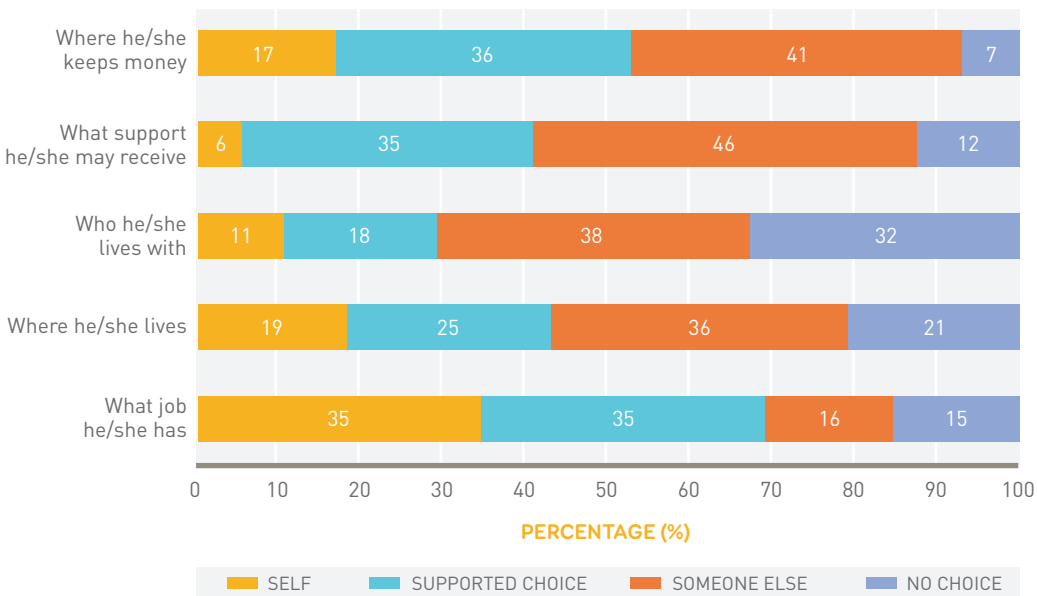
**15% of people with an intellectual disability aged 40+ were involved in key life decisions**

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH CHOICE IN KEY LIFE DECISIONS**

While choice has been identified in terms of health, quality of life, empowerment and self-determination (Smyth & Bell, 2006), these positive outcomes are only seen if the choice is 'real' or 'active'. Following a study on choice with people with an intellectual disability, type of choice was separated into 'day-to-day choices' and 'key life choices' (O'Donovan, 2017).

For this indicator, key life decisions included: where he/she keeps their money, what support he/she may receive, who he/she lives with; where he/she lives; what job he/she has; how he/she spends their money.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 28:** Level of choice in key life decisions for people with an intellectual disability aged 40+, by type of choice

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 21% of people with an intellectual disability had no choice of where they live
- 32% of people with an intellectual disability were involved in choosing who they live with
- 41% were involved in what support they receive

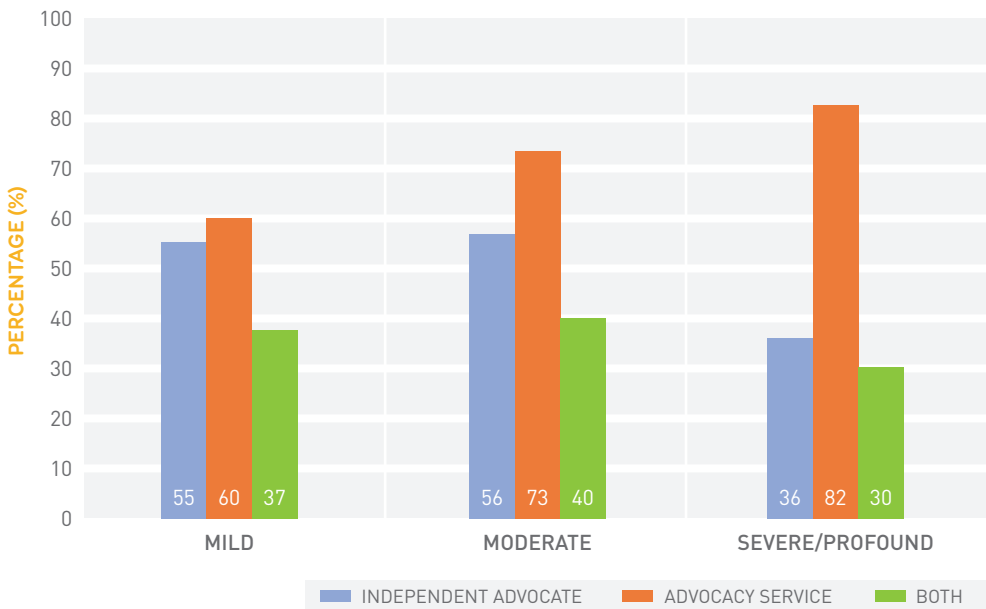
72% of people with an intellectual disability had access to a professional advocacy service

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH ACCESS TO AN ADVOCACY GROUP

Ensuring that people with an intellectual disability have the support to have their voice heard is an essential part of healthy ageing. Historically, people with an intellectual disability have been marginalised, and it is only in more recent times that the personhood of people with an intellectual disability has been acknowledged and, with it, the right for support and advocacy (Gray & Jackson, 2002).

This indicator shows the percentage of people with an intellectual disability with access to a professional advocacy service.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 29:** Advocacy type for people with an intellectual disability aged 40+, by level of intellectual disability

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 82% of people with a severe/profound level of intellectual disability had access to an advocacy service
- 54% of people with a mild level of intellectual disability and 56% with a moderate level of intellectual disability had an independent advocate
- 94% of people with an intellectual disability aged 40+ had a key worker
- 51% of people with an intellectual disability had an independent advocate
- 37% had access to both an independent advocate and a professional advocacy service





SECTION

**3.3**

**HEALTHY AGEING**

## GOAL

## 2

Support people as they age to maintain, improve or manage their physical and mental health and wellbeing.

DOMAIN	KEY INDICATORS	% GENERAL POPULATION	
		AGE 40+	AGE 50+
PHYSICAL HEALTH	Percentage of people with an intellectual disability aged 40+ with good (or better) self-rated health	86	80
	Percentage of people with an intellectual disability aged 40+ who have a chronic disease	83	65
	Percentage of people with an intellectual disability aged 40+ with two or more chronic conditions	56	n/a
	Percentage of people with an intellectual disability aged 40+ reporting a fall in the previous year	27	24*~
	Percentage of people with an intellectual disability aged 40+ who have a slow walking speed	81	48*
	Percentage of people with an intellectual disability aged 40+ who report severe or moderate pain most of the time	42	26
	Percentage of people with an intellectual disability aged 40+ with no teeth or dentures	28	n/a
	Percentage of people with an intellectual disability aged 40+ with poor bone health	74	n/a
	Percentage of people with an intellectual disability aged 40+ with sensory impairment even with corrective measures	28	n/a
	Percentage of people with an intellectual disability aged 40+ who experience incontinence where they were previously continent	38	n/a
	Percentage of people with an intellectual disability aged 40+ reporting chronic constipation in the previous two years	44	n/a

DOMAIN	KEY INDICATORS	% GENERAL POPULATION	
		AGE 40+	AGE 50+
BRAIN HEALTH	Percentage of people with an intellectual disability aged 40+ who have had a memory screening in the previous two years	31	n/a
	Percentage of people with Down syndrome aged 40+ who have a doctor's diagnosis of dementia	35	n/a
ADAPTATION TO DISABILITY AND ILLNESS	Percentage of people with an intellectual disability aged 40+ who have difficulty with activities of daily living	73	8
	Percentage of people with an intellectual disability aged 40+ who report difficulties with activities of daily living, who also receive help for those difficulties	96	n/a
	Percentage of people with an intellectual disability aged 40+ who limit their activities due to fear of falling	31	n/a
HEALTH BEHAVIOURS	Percentage of people with an intellectual disability aged 40+ who currently smoke	7	12
	Percentage of people with an intellectual disability aged 40+ who use alcohol	62% never drinking alcohol	12**
	Percentage of people with an intellectual disability aged 40+ who are sedentary or underactive	85	39
	Percentage of people with an intellectual disability aged 40+ who are underweight, overweight or obese	43% obese	33% obese
MENTAL HEALTH	Percentage of people with an intellectual disability aged 40+ with depression	10	11
	Percentage of people with an intellectual disability aged 40+ who report high levels of life satisfaction	81	86
	Percentage of people with an intellectual disability aged 40+ with moderate or severe levels of anxiety	15	4
	Percentage of people with an intellectual disability aged 40+ with emotional, nervous or psychiatric problems who are receiving treatment from a psychologist or psychiatrist	52	n/a

DOMAIN	KEY INDICATORS	% GENERAL POPULATION	
		AGE 40+	AGE 50+
HEALTHCARE	Percentage of people with an intellectual disability aged 40+ living in the community in receipt of home care services in the previous twelve months	14	11***
	Percentage of women eligible for screening who had a mammogram in the past two years	57% of eligible women who have ever had a mammogram	75
	Percentage of people with an intellectual disability aged 40+ who have had a flu vaccine in the previous two years	91	62*
	Percentage of people with an intellectual disability aged 40+ who are taking five or more medications	73	32
	Percentage of people with an intellectual disability aged 40+ who have had their cholesterol checked	93	n/a
	Percentage of people with an intellectual disability aged 40+ who have had their blood pressure checked	97	n/a
SOCIAL CARE	Percentage of people with an intellectual disability aged 40+ who report unmet need for a community care service	20	13
	Living situation of those people with an intellectual disability aged 40+	41% living independently or with family	n/a
CARERS' HEALTH	Percentage of carers aged 50+ who report high levels of stress or distress	25	27

\*Reported in the general population for those aged 65+

\*\*Indicator in the general population reports on problematic alcohol use

\*\*\*Reported in the general population for those aged 75+

~ Fall reported in the general population for prior two years

**Note:** Generally n/a indicates that comparable data was not included in the National Positive Ageing Indicators Report as this is an additional indicator for people with an intellectual disability

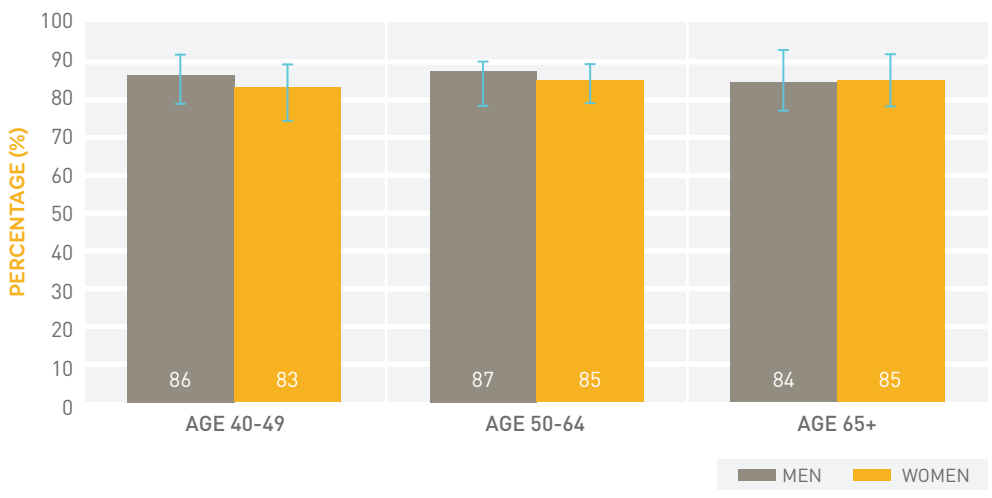
86% of people with an intellectual disability aged 40+ rate their health as 'good', 'very good' or 'excellent'

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH 'GOOD' OR BETTER SELF-RATED HEALTH

Self-rated health has been related to positive outcomes in morbidity and mortality. It is also commonly used as an indicator of health status (Del Salvo, 2006). It has been previously reported that people with an intellectual disability have lower self-rated health than their peers without an intellectual disability (Emerson et al., 2014).

This indicator shows the percentage of people with an intellectual disability aged 40+ who rated their health as 'excellent', 'very good' or 'good'.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 30:** Percentage of people with an intellectual disability aged 40+ who rate their health as good, very good or excellent, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- There was very little change across levels of self-rated health between Wave 1 and Wave 3 of IDS-TILDA (86%, 84%, 86% respectively)
- Self-rated health for people with an intellectual disability was comparable to that of the general population

**SELF-RATED HEALTH IN THE GENERAL POPULATION**

80% of people aged 56+ rate their health as 'good' or 'very good'

Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: PHYSICAL HEALTH

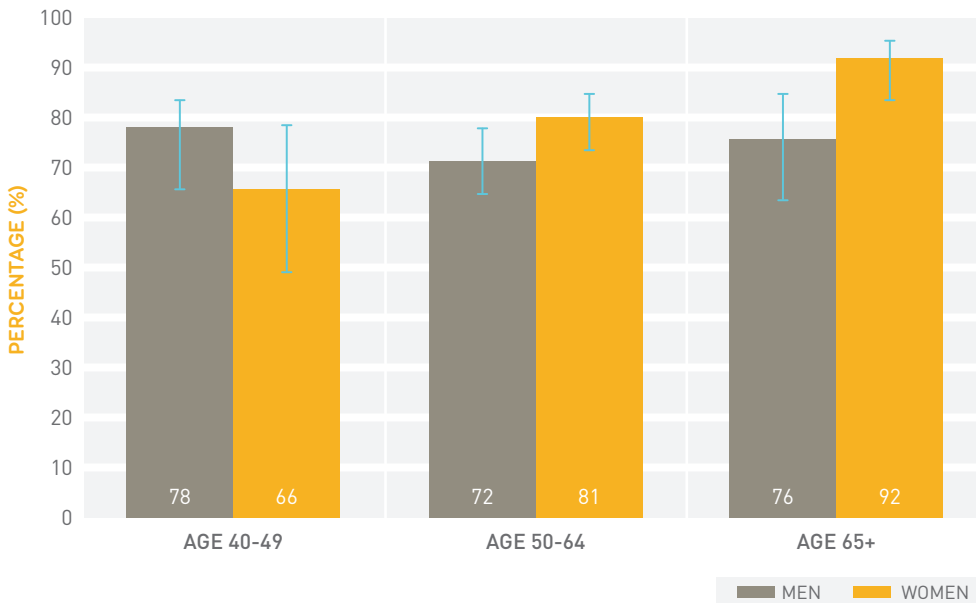
83% of people with an intellectual disability aged 40+ have a chronic disease

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO HAVE A  
CHRONIC DISEASE

People with an intellectual disability have a higher prevalence of chronic disease than is found in the general population (Carey et al., 2016; McCarron et al., 2013).

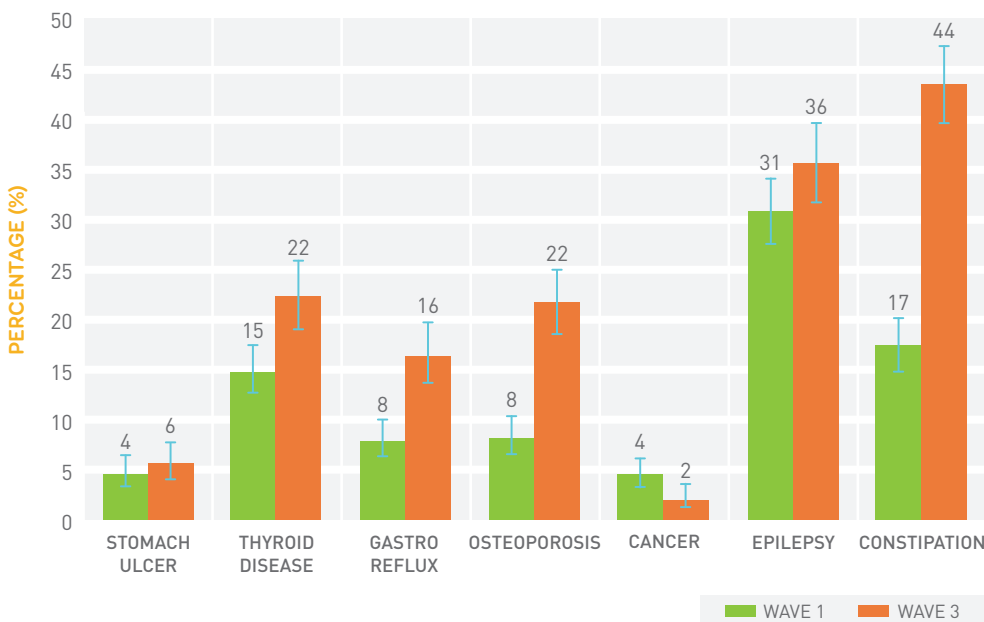
This indicator shows the percentage of people aged 40+ who have a chronic disease that has been diagnosed by a doctor. The following chronic conditions and diseases are included: arthritis; osteoporosis; angina; heart rhythm or murmur; heart attack; heart failure; stroke; transient ischaemic attack; asthma; chronic obstructive pulmonary disease; diabetes; epilepsy; constipation; thyroid disease; stomach ulcer; and cancer.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 31:** Percentage of people with an intellectual disability aged 40+ with a chronic disease, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)



**Figure 32:** Changes in chronic conditions for people with an intellectual disability aged 40+ between Wave 1 and Wave 3 of IDS-TILDA

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

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## Key points

- The prevalence of chronic disease increased from 81% in those aged 40-49 to 86% in those aged 65+
- In the older age group, women with an intellectual disability had a higher prevalence of chronic disease than men
- The prevalence of chronic conditions was higher for those with a severe/profound level of intellectual disability (90%) than for those with a mild level of intellectual disability (77%)
- In Wave 3, chronic constipation was the most common chronic condition
- The prevalence of epilepsy in people with an intellectual disability rose from 30% in Wave 1 to 35% in Wave 3 and was associated with new onset dementia in people with Down syndrome
- In Wave 3, 22% of people had a thyroid disease
- Different patterns of chronic diseases were seen for people with an intellectual disability compared to the general population

### CHRONIC DISEASE IN THE GENERAL POPULATION

65% of people aged 65+ have a chronic disease

Source: TILDA Wave 4 2016-2017

### INDICATOR: PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH TWO OR MORE CHRONIC CONDITIONS

- 56% of people with an intellectual disability had two or more chronic conditions

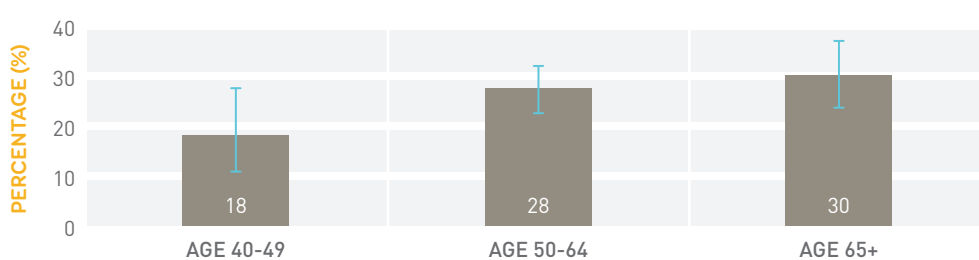
## HEALTHY AGEING: PHYSICAL HEALTH

## 27% of people with an intellectual disability aged 40+ have fallen in the past year

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED 40+  
 REPORTING A FALL IN  
 THE PAST YEAR

Falls are a major public health concern, affecting approximately a third of people aged 65+ per year (Stevens et al., 2008). Studies indicate that prevalence of falls is higher for people with an intellectual disability living in the community compared to the general population (Hsieh et al., 2012). Falls are a major cause of injury and hospitalisation, and they have longer term psychosocial effects, which can lead to decreased activity and more isolation (Hsieh et al., 2012).

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.


**Figure 33:**

Percentage of people with an intellectual disability aged 40+ who have had a fall in the past year, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

### Key points

- Falls remained high at 27%, with 29% of those reporting two or more falls
- Falls increase from 18% in those aged 40-49 to 30% in those aged 65+
- 13% reported injurious falls

**Table 10:** Falls reported in IDS-TILDA and TILDA

	IDS-TILDA WAVE 1	TILDA WAVE 1	IDS-TILDA WAVE 3	TILDA WAVE 3
Numbers	753	4788	608	4398
Any Fall (%)	26.7	21.1	27.2	25.8
Recurrent Fall (%)	14.6	7.7	15.9	11.1
Injurious Fall (%)	13.2	7.7	12.5	12.1

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011, 2017) and the Irish Longitudinal Study on Ageing (2011, 2017)

### FALLS IN THE GENERAL POPULATION

24% of people aged 65+ have fallen in the past two years

Source: TILDA Wave 4 2016-2017

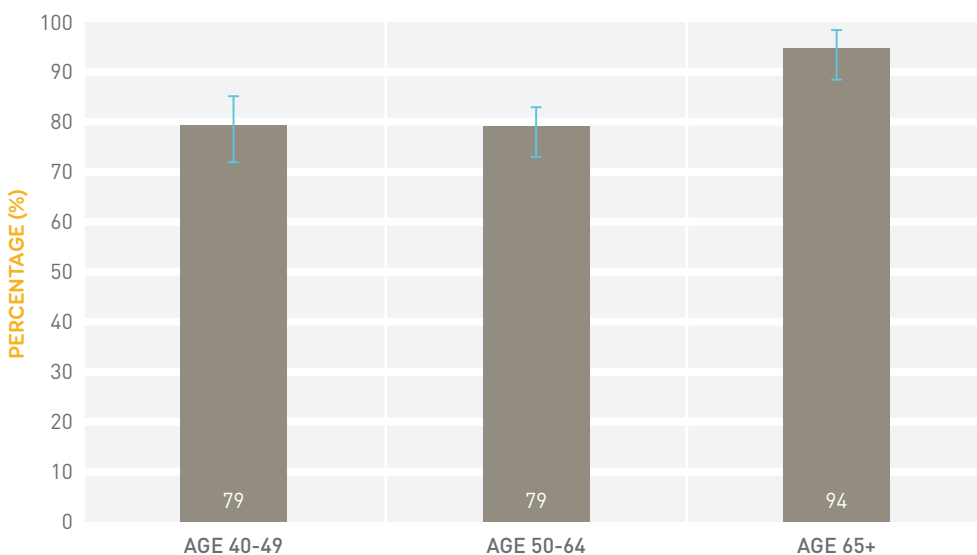
81% of people with an intellectual disability aged 40+ have a slow walking speed

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO HAVE A  
SLOW WALKING  
SPEED

Slow walking speed is identified as one of the indicators of frailty (Evenhuis et al., 2012). Frailty is a combination of symptoms and problems that can indicate an increase in vulnerability to stressors and a higher risk of adverse health and wellbeing outcomes, and is independent of any specific disease or disability (Fried et al., 2004).

This indicator shows the percentages of people aged 40+ who have a slow walking speed. A slow walking speed is defined as taking more than ten seconds to complete the following test: get up from a chair, walk three metres at usual pace, turn around and sit back down. This test is known as the 'Timed Up and Go' (TUG) test.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 34:** Percentage of people with an intellectual disability aged 40+ with a slow walking speed, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Intervals (95%)

**Key points**

- The percentage with a slow walking speed gradually increased as age increased
- 94% of people aged 65+ years were classified as 'slow walkers'
- 82% of women aged 50-64 years were slow walkers compared to 75% of men in the same age range
- 82% of those with a moderate level of intellectual disability had a slow walking speed

**WALKING SPEED IN THE GENERAL POPULATION**

48% of people aged 65+ have a slow walking speed

Source: TILDA Wave 3 2014-2015

HEALTHY AGEING: PHYSICAL HEALTH

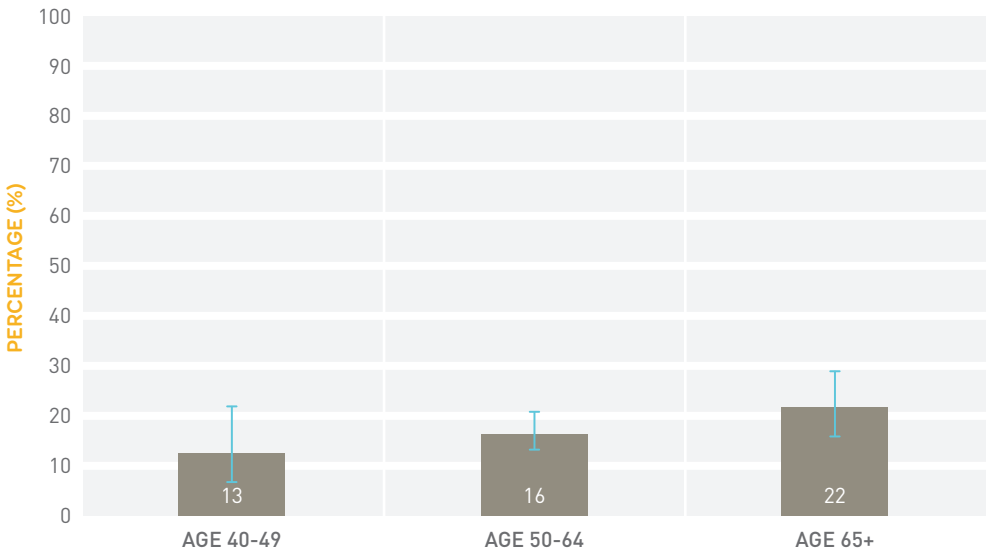
42% of people with an intellectual disability aged 40+ report moderate or severe pain most of the time

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT MODERATE OR SEVERE PAIN MOST OF THE TIME

Chronic pain impacts on quality of life and cognitive function, and it can limit everyday activities (Penny et al., 1999). This indicator shows the percentage of people aged 40+ who were often troubled with pain on a mild, moderate or severe level.

This indicator examines pain by asking people: 'Are you often troubled with pain?' and 'How bad is the pain most of the time?' on the scale of Mild - Moderate - Severe.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 35:** Percentage of people with an intellectual disability aged 40+ who report moderate or severe pain most of the time, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals [95%]

**Key points**

- As age increased, more people were troubled by pain
- 32% of women and 26% of men in Wave 2 reported having trouble with pain. Women were more likely than men to suffer with severe pain
- 61% of those aged 50- 64 years reported having trouble with pain
- 11% of people with a moderate level of intellectual disability reported having trouble with pain

**PAIN IN THE GENERAL POPULATION**

26% of people aged 56+ have moderate or severe pain most of the time

Source: TILDA Wave 4 2016-2017

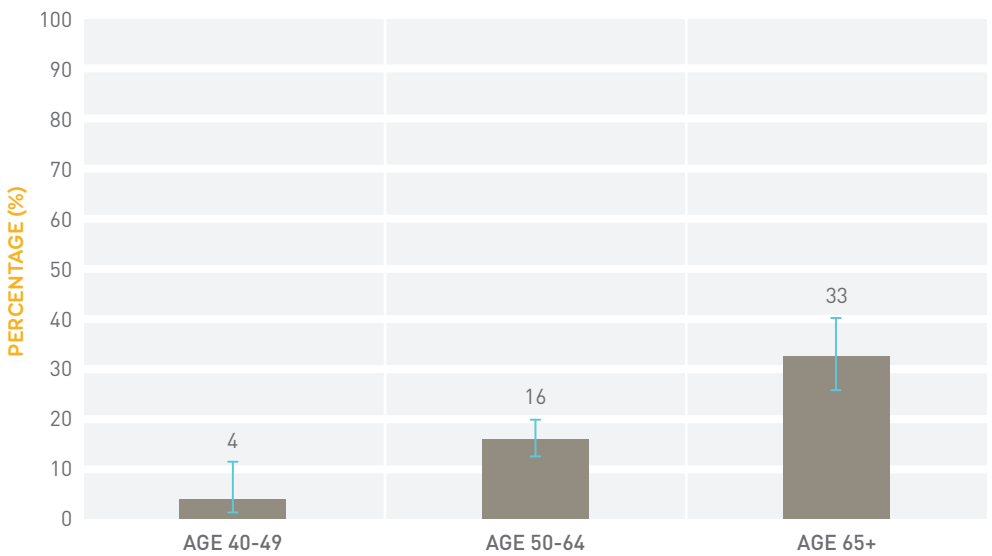
28% of people with an intellectual disability aged 40+ have no teeth or dentures

INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WITH NO TEETH  
OR DENTURES

Older people with an intellectual disability are more likely to have no teeth compared to their peers in the general population. Furthermore, when people with an intellectual disability lost their teeth, they are unlikely to use dentures (Mac Giolla Phadraig et al., 2015).

This indicator includes people who answered ‘yes’ to having ‘no teeth or dentures’.

This indicator is included in the set of indicators for people with an intellectual disability only.



**Figure 36:** Percentage of people with an intellectual disability aged 40+ with no teeth or dentures, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 19% of those aged 40+ years had no teeth or dentures
- 23% of men had no teeth or denture compared to 16% of women
- The prevalence of those with no teeth or dentures increased with age
- One-in-five of the people with a moderate level of intellectual disability had no teeth or dentures
- Of those with no teeth, 68% of people with an intellectual disability with tooth loss did not receive prosthetic denture compared with 5% of participants without teeth found in Wave 3 of TILDA

## HEALTHY AGEING: PHYSICAL HEALTH

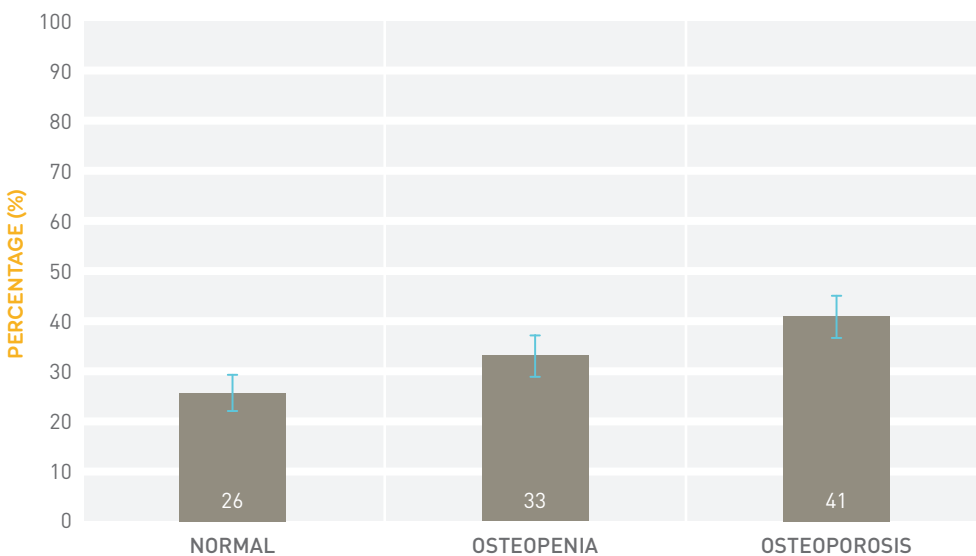
## 74% of people with an intellectual disability aged 40+ have poor bone health

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WITH POOR  
BONE HEALTH

Risk factors associated with poor bone health in the general population are age, gender and corticosteroid use. Risks may differ, however, for people with an intellectual disability. It has been shown that having epilepsy and taking anti-epileptic drugs are associated with having a doctor's diagnosis of osteoporosis. Levels of diagnostic screening were low for people with an intellectual disability, suggesting that a doctor's diagnosis of osteoporosis may underestimate prevalence of poor bone health in this population (Burke et al., 2017).

This indicator shows the objective measurement of bone health for people with an intellectual disability aged 40+.

This indicator is included in the set of indicators for people with an intellectual disability only.



**Figure 37:**  
Percentage of  
people with  
an intellectual  
disability aged 40+  
with poor bone  
health, by level of  
bone health

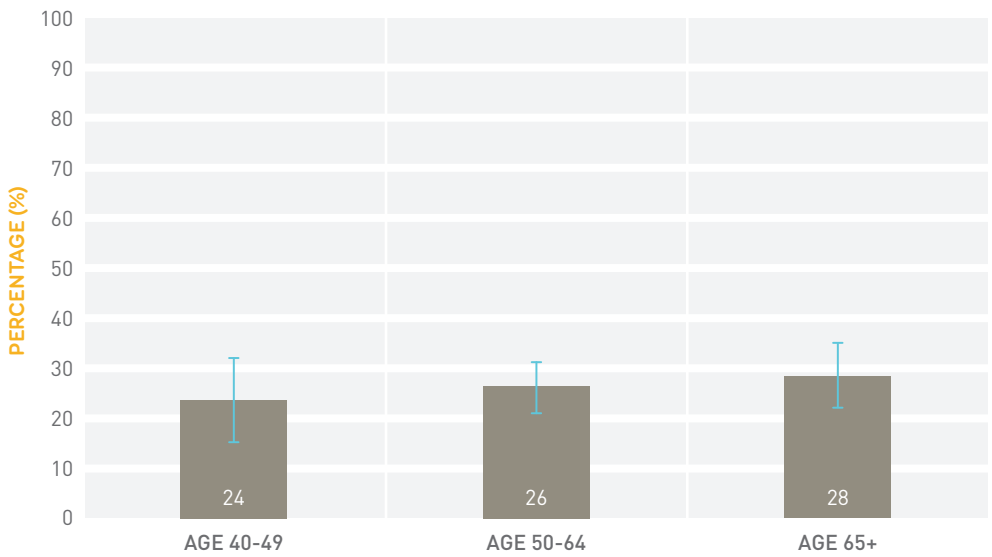
Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

### Key points

- Only 8% of people with an intellectual disability have a doctor's diagnosis of osteoporosis, but when this was objectively measured, using a quantitative heel ultrasound, 41% had osteoporosis and 33% had osteopenia
- 27% of people with a mild level of intellectual disability had osteoporosis compared to 35% with a moderate level of intellectual disability and 63% with a severe/profound level of intellectual disability
- The prevalence of osteoporosis increased with age from 32% of those aged 40-49 years to 40% for people aged 50-64 years to 54% in those aged 65+ years

**28% of people with an intellectual disability aged 40+ have a sensory impairment even with corrective measures**

<p><b>INDICATOR:</b> INDICATOR: PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH SENSORY IMPAIRMENT EVEN WITH CORRECTIVE MEASURES</p>	<p>The prevalence of sensory impairment is higher among those with intellectual disability compared to those in the general population (Evenhuis et al., 2001).</p> <p>This indicator shows the percentage of people aged 40+ who show evidence of sensory impairment, including vision and hearing. Participants were asked 'How good is your hearing/ vision?' with the responses 'excellent', 'very good', 'good', 'fair' or 'poor'. The indicator shows those who responded 'fair or poor'.</p> <p>This indicator is included only in the set of indicators for people with an intellectual disability only.</p>
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**Figure 38:** Sensory impairment among people with an intellectual disability aged 40+, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Vision impairment was more prevalent than hearing impairment, with 21% reporting poor vision, despite wearing glasses or contact lenses. This compared to 10% of people who reported poor hearing despite a hearing device
- Level of sensory impairment increased with age, from 24% in those aged 40-49 to 28% in those aged 65+
- 21% of people with a mild level of intellectual disability reported sensory impairment compared to 30% with a moderate or severe/profound level of intellectual disability
- No gender difference was observed in relation to sensory impairment

HEALTHY AGEING: PHYSICAL HEALTH

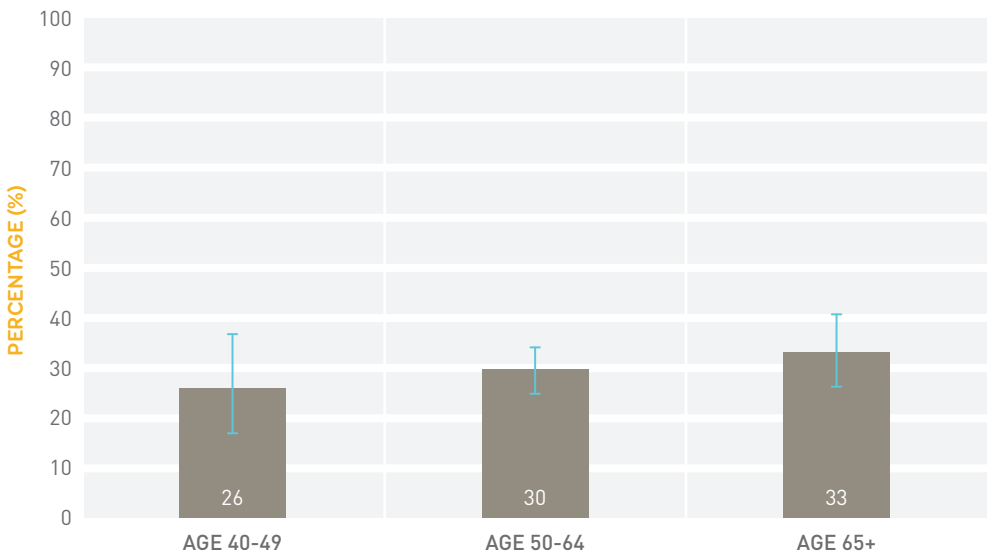
**38% of people with an intellectual disability aged 40+ experience incontinence where they had previously been continent**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO EXPERIENCE INCONTINENCE WHERE THEY WERE PREVIOUSLY CONTINENT

Incontinence is often a problem for people with an intellectual disability and is sometimes associated with pre-existing levels of intellectual disability and with impoverished care environments. In the general population, the development of urinary incontinence with increasing age is often associated with increased social isolation and depression (Nitti, 2001).

This indicator shows the number of people with an intellectual disability who report incontinence where they had previously been continent. People were asked ‘During the last 12 months, have you ever lost urine beyond your control?’ and ‘During the last 12 months, have you ever lost faeces beyond your control?’.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 39:** Percentage of people with an intellectual disability aged 40+ who report urinary or bowel incontinence, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Overall, three-in-ten reported bladder incontinence
- 20% reported bowel incontinence
- 32% of those with a mild level of intellectual disability reported some form of incontinence compared to 40% with a moderate level of intellectual disability and 44% with a severe/profound level of intellectual disability

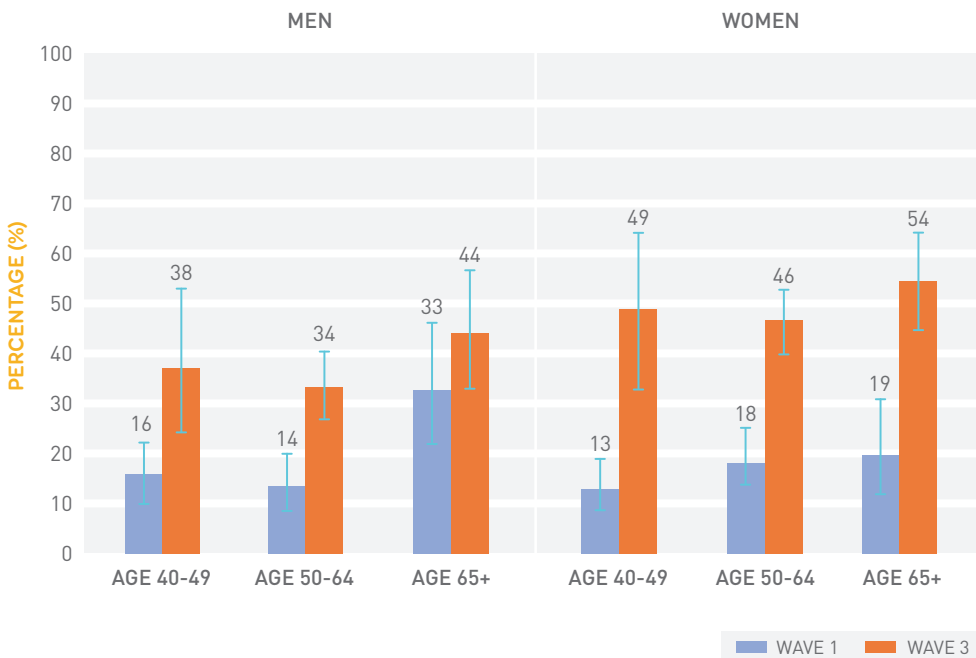
44% of people with an intellectual disability aged 40+ have chronic constipation

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WITH CHRONIC  
 CONSTIPATION IN  
 THE PREVIOUS TWO  
 YEARS

Constipation is a syndrome defined by bowel symptoms of difficult or infrequent passage of stool, hardness of stool or a feeling of incomplete evacuation (Bharucha et al., 2013). In a systematic review of constipation among people with an intellectual disability, it was found that constipation is a significant issue across the life course (Robertson et al., 2018).

This indicator shows the percentage of those with an intellectual disability with a doctor’s diagnosis of constipation.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 40:** Percentage of people with constipation in Wave 1 and Wave 3 of IDS-TILDA, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- The prevalence of constipation rose from 17% in Wave 1 to 44% in Wave 3
- Levels of constipation were also found to increase with severity of level of intellectual disability from 31% for those with a mild level of intellectual disability, 44% for those with a moderate level of intellectual disability to 58% for those with a severe/profound level of intellectual disability
- 75% were taking medication to manage the condition and 57% reported that they had made lifestyle changes to address the condition
- Of those with constipation, 38% reported never having a normal stool without the use of laxatives

HEALTHY AGEING: BRAIN HEALTH

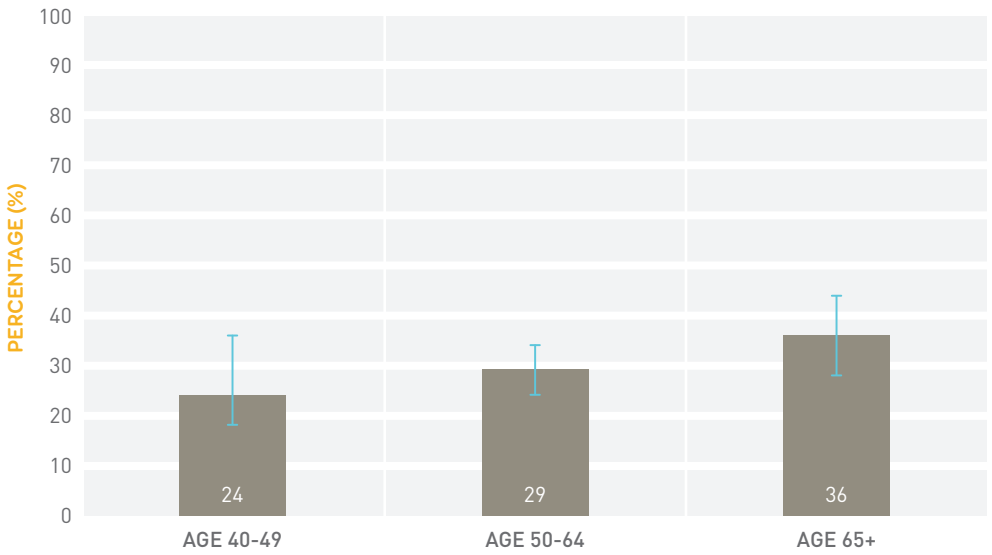
31% of people with an intellectual disability aged 40+ have received a memory screening

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO HAVE HAD A MEMORY SCREENING IN THE PREVIOUS TWO YEARS

An international consensus group developed a model of best practice for the screening of people with an intellectual disability for dementia (Burt & Aylward, 2000). This model of best practice recommends a baseline assessment for adults with Down syndrome by age 35, and for adults with intellectual disability from other aetiologies by age 55, with annual screening thereafter (Aylward et al., 1997).

This baseline screening is essential in order to detect a change from pre-morbid level of functioning. This indicator shows the percentage of people who had a memory screening in the previous two years.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 41:** Percentage of people with an intellectual disability aged 40+ who have had a memory screening, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Memory screening overall rose from 15% in Wave 1 to 31% in Wave 3
- The number of people with Down syndrome getting a memory screening rose from 14% in Wave 1 to 61% in Wave 3

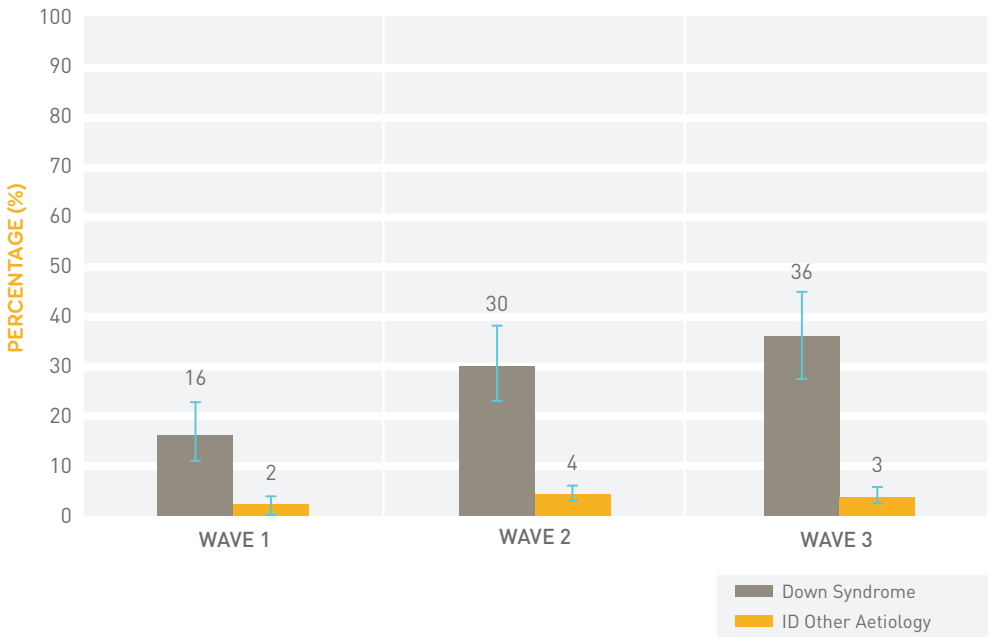
35% of people with Down syndrome aged 40+ have a diagnosis of dementia

INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH DOWN  
SYNDROME WHO  
HAVE A DIAGNOSIS  
OF DEMENTIA

Risk of dementia is higher for people with Down syndrome than for people from the general population or for people with an intellectual disability from other aetiologies. A longitudinal study conducted in Ireland over 20 years found the risk of dementia was 23% for those aged 50, 45% at age 55 and 88% at age 65 (McCarron et al., 2017).

The indicators below shows data for people with Down syndrome aged 40+ who had a doctor’s diagnosis of dementia from Wave 1 of IDS-TILDA (2009), Wave 2 (2014) and Wave 3 (2017).

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 42:** Percentage of people with an intellectual disability with a diagnosis of dementia, by waves of IDS-TILDA and aetiology of intellectual disability

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- The percentage of people with Down syndrome with a diagnosis of dementia increased from 16% in Wave 1 to 30% in Wave 2 to 35% in Wave 3 of IDS-TILDA
- The average age of dementia diagnosis for people with Down syndrome was 52.3 years
- Of those with Down syndrome who did not have a doctor’ diagnosis of dementia, 49% had never had a dementia assessment

HEALTHY AGEING: ADAPTATION TO DISABILITY AND ILLNESS

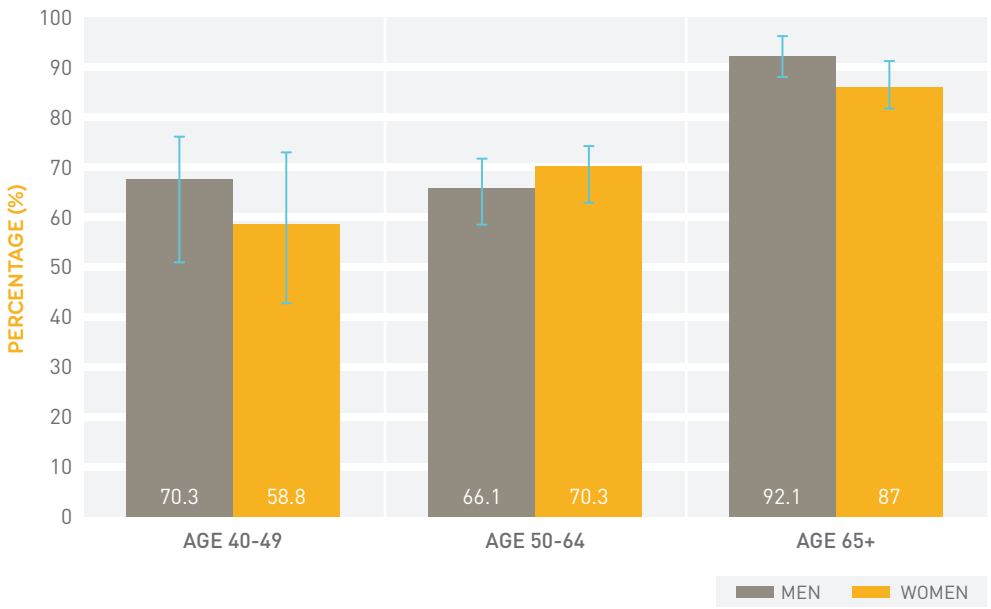
73% of people with an intellectual disability aged 40+ have difficulty with activities of daily living

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT DIFFICULTIES WITH ACTIVITIES OF DAILY LIVING**

Daily functioning predicts both hospital admissions and mortality in older adults. Level of daily functioning, along with ability for self-care, also determines level of independence (Hilgenkamp et al., 2011).

This indicator shows the percentage of people aged 40+ who reported having difficulty with the following activities of daily living (ADL): 'dressing', 'bathing', 'eating', 'getting in or out of bed', 'walking across a room' and 'using the toilet'.

This indicator is included in the Positive Ageing Indicator set for the general population and for people with an intellectual disability.



**Figure 43:** Percentage of people with an intellectual disability aged 40+ with difficulty with ADLs, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Men in the 65+ age group reported more difficulty with ADLs than women
- Difficulty with ADLs increased with age
- 39% of people living independently or with family reported difficulties with ADLs compared to 66% of people in community group homes and 92% in residential settings
- 49% of people with a mild level of intellectual disability reported some difficulty with ADLs. This increased to 72% for people with a moderate level of intellectual disability

**DIFFICULTY WITH ADLs IN THE GENERAL POPULATION**

8% of people aged 56+ have difficulty with ADLs

Source: TILDA Wave 4 2016-2017

## 96% of people with an intellectual disability who report difficulty with activities of daily living also receive help with those activities

### INDICATOR: PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT DIFFICULTIES WITH ACTIVITIES OF DAILY LIVING (ADLS) AND WHO ALSO RECEIVE HELP FOR THOSE DIFFICULTIES

By definition, intellectual disability is characterised by impaired intellectual functioning and adaptive behaviour, and these limitations impinge on everyday conceptual, practical and social skills (AAIDD, 2011). People with an intellectual disability, therefore, have a greater need for support and assistance than their peers in the general population.

The indicator below shows the percentage of people who reported difficulties with activities of daily living and who also received support for this.

This indicator is included only in the set of indicators for people with an intellectual disability.

**Table 11:** Percentage of people with an intellectual disability aged 40+ who have difficulty with ADL and who also receive help for that difficulty

ADL	%	CI (95%)
Receives help due to difficulty dressing	95.2	92.1 – 97.1
Receives help due to difficulty bathing	99.2	97.7 – 99.7
Receives help due to difficulty eating	60.4	54.3 – 66.1
Receives help due to difficulty toileting	90.4	85.1 – 94.0
Receives help due to difficulty getting in and out of bed	94.6	89.7 – 97.2
Receives help due to difficulty walking across a room	84.6	78.2 – 89.3

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

### Key points

- The majority of people received help and support with ADLs where help was needed
- Bathing was the activity where the highest proportion of people reported difficulty and also received help (99%)
- 60% of people reported that they received help with eating of those who needed help

## HEALTHY AGEING: ADAPTATION TO DISABILITY AND ILLNESS

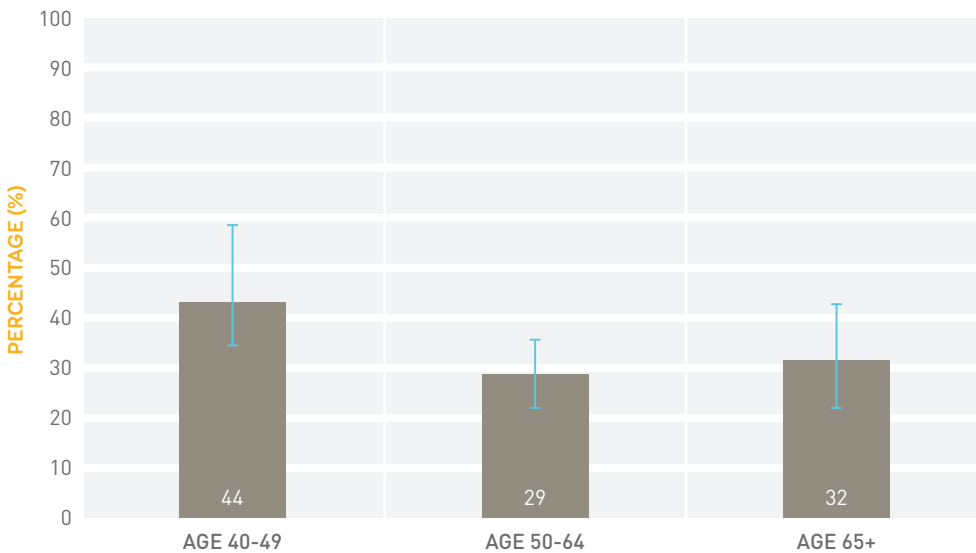
## 31% of people with an intellectual disability aged 40+ limit their activities due to their fear of falling

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO LIMIT  
ACTIVITIES DUE TO  
FEAR OF FALLING

Fear of falling has emerged as an important health concern in all older adults given its demonstrated association with restrictions in daily activity and, in many cases, activity avoidance (Foran et al., 2013; Zarkou et al., 2011).

This indicator shows the percentage of people aged 40+ who limit activities due to fear of falling. The indicator is measured using the questions 'Are you afraid of falling?' and 'Do you ever limit your activities due to fear of falling?'

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 44:**

Percentage of people with an intellectual disability aged 40+ who limit activities due to a fear of falling, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

### Key points

- The percentage of people who limited their activity due to fear of falling, at 44%, was higher in those aged 40-49 than in the older age groups, at 29% for those aged 50-64 and 32% for those aged 65+
- 22% of people with a mild level of intellectual disability were afraid of falling and limited their activities. This compared to 32% of people with a moderate level of intellectual disability and 31% of people with a severe/profound level of intellectual disability

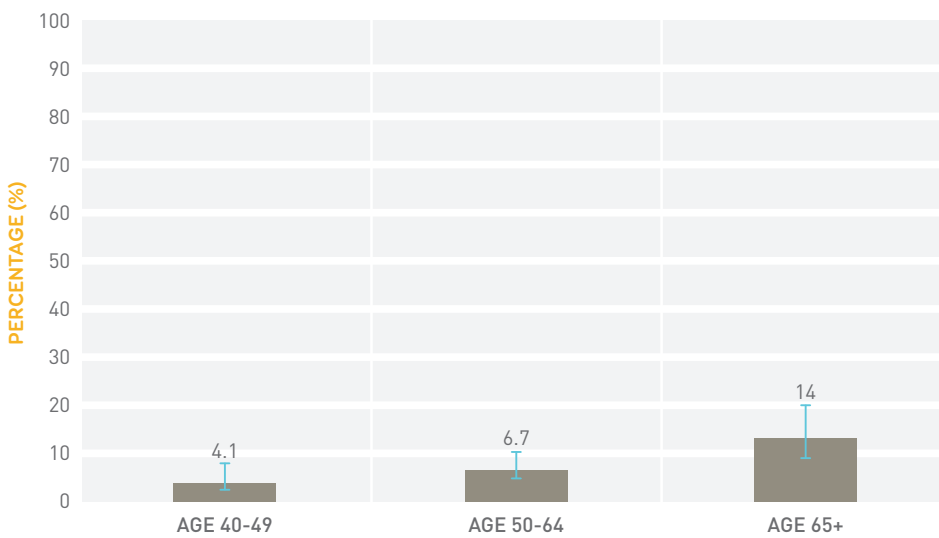
7% of people with an intellectual disability aged 40+ currently smoke

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO REPORT  
CURRENT SMOKING

Tobacco use is reportedly lower in a population of people with an intellectual disability compared to the general population (CDC, 2015). Tobacco use poses a greater threat to people with an intellectual disability as there is already an increased prevalence of chronic conditions known to be associated with tobacco use, including: arthritis, asthma, poor oral health, low bone density, respiratory conditions, diabetes (Eisenbaum et al., 2018).

This indicator shows the percentage of people who report currently smoking.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 45:**  
Percentage of  
people with  
an intellectual  
disability aged  
40+ who currently  
smoke, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Intervals (95%)

**Key points**

- A higher percentage of people in the older age group currently smoke
- 11% of people with a mild level of intellectual disability smoke compared to 2% with a severe level of intellectual disability
- Levels of smoking were slightly higher for those living independently or with family (10%) compared to those living in a community (7%) or in a residential setting (7%)

**SMOKING IN THE GENERAL POPULATION**

14% of people aged 56+ currently smoke

Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: HEALTH BEHAVIOURS

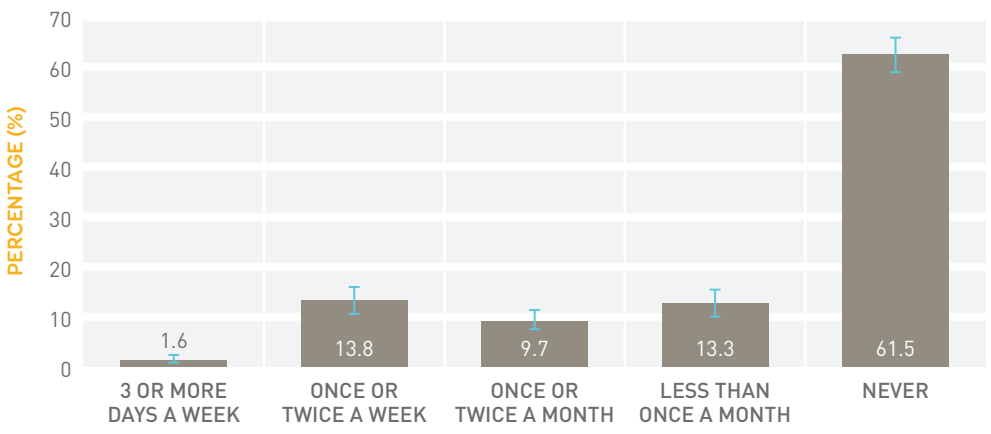
62% of people with an intellectual disability aged 40+ report never drinking alcohol

INDICATOR:  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO REPORT  
ALCOHOL USE

In Ireland, levels of alcohol consumption have been found to be lower for people with an intellectual disability than in the general population (McGuire et al., 2007).

This indicator shows how often people with an intellectual disability aged 40+ have consumed alcohol in the past year. Response categories include: 'almost every day', 'three-four days a week', 'once or twice a week', 'once or twice a month', 'less than once a month', 'not at all in the last 12 months' or 'never'. The indicator in the general population indicator set reports on problematic alcohol use. CAGE measure which captures whether a person has ever felt they should cut down on drinking (C), have been annoyed by others criticising their drinking (A), have felt guilty about their drinking (G), or taken a drink first thing in the morning to cure a hangover (eye-opener) (E). A point is assigned for each 'yes' answer, with  $\geq 2$  points indicating problematic alcohol use.

The indicator for people with an intellectual disability reports of level of alcohol use.



**Figure 46:** Percentage of people with an intellectual disability aged 40+, by frequency of alcohol consumed

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2014). CI: Confidence Intervals (95%)

Key points

- 39% reported drinking alcohol
- 43% of people with a mild level of intellectual disability reported drinking alcohol compared to 42% of people with a moderate level of intellectual disability and 29% of those with a severe/profound level of intellectual disability
- Overall, 14% of people drank alcohol once a week or more
- Of those who drank alcohol, 11% reported drinking more than two drinks in a day once a week or more

ALCOHOL USE IN THE GENERAL POPULATION

12% of people aged 56+ report problematic alcohol use

\*The indicator for the general population examined level of problematic alcohol use  
Source: TILDA Wave 4 2016-2017

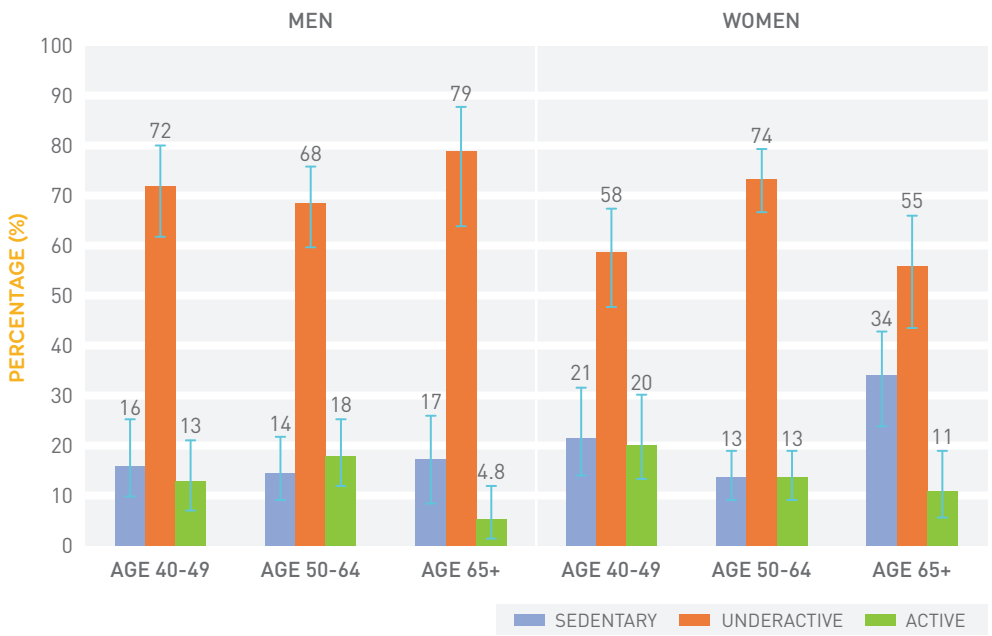
85% of people with an intellectual disability aged 40+ are underactive

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WHO WERE  
 SEDENTARY,  
 UNDERACTIVE AND  
 ACTIVE

Low levels of physical activity have been found in older adults with an intellectual disability (Temple, Frey, & Stanish, 2006). Increasing physical activity among the ageing population has been shown to have a positive effect both physically and psychologically on health outcomes (Hilgenkamp et al., 2012).

This indicator shows level of physical activity of people aged 40+. The indicator for people with an intellectual disability is measured using the RAPA (Rapid Assessment of Physical Activity) questionnaire and classified as 'sedentary', 'underactive' and 'active'. The indicator for the general population is measured with the IPAQ.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 47:** Percentage of people with an intellectual disability aged 40+ who were sedentary, underactive and active, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Table 12:** Level of activity among people with an intellectual disability aged 40+

ACTIVITY LEVEL	%	CI
Sedentary	17.6	14.6-20.8
Underactive	68.2	64.2-71.8
Active	14.3	11.6-17.3

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**LEVEL OF ACTIVITY IN THE GENERAL POPULATION**

39% of people aged 56+ report low levels of physical activity

\*This was measured by the IPAQ in the general population  
 Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: HEALTH BEHAVIOURS

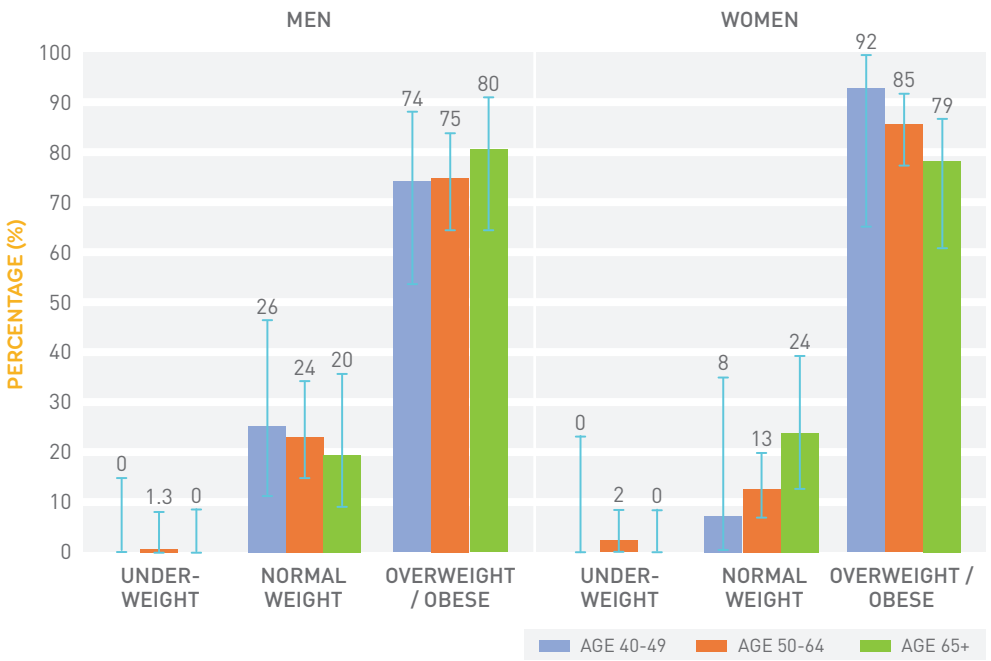
80% of people with an intellectual disability aged 40+ are overweight or obese

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO ARE UNDERWEIGHT, OVERWEIGHT AND OBESE**

This indicator shows the percentage of people overweight and obese in the 40+ age group. The levels of overweight and obesity in people with an intellectual disability are recognised as a major health concern by many researchers (Haveman et al., 2011).

This indicator shows the percentage of adults aged 40+ who are underweight, normal or overweight in relation to their BMI score.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 48:** Weight of people with an intellectual disability aged 40+, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Overall, 80% of people with an intellectual disability were overweight (36%) or obese (43%)
- 64% of people with an intellectual disability who were overweight or obese perceived themselves to be just about the right weight
- People aged 50-64 (81%) had higher levels of obesity than those aged 65+ (77%)
- People with a mild or moderate level of intellectual disability had greater levels of obesity at 88% versus 64% for those with a severe/profound level of intellectual disability
- Women had a higher prevalence of overweight and obesity compared to men at 83% versus 76% respectively

**WEIGHT IN THE GENERAL POPULATION**

33% of people aged 54+ are obese

Source: TILDA Wave 3 2014-2015

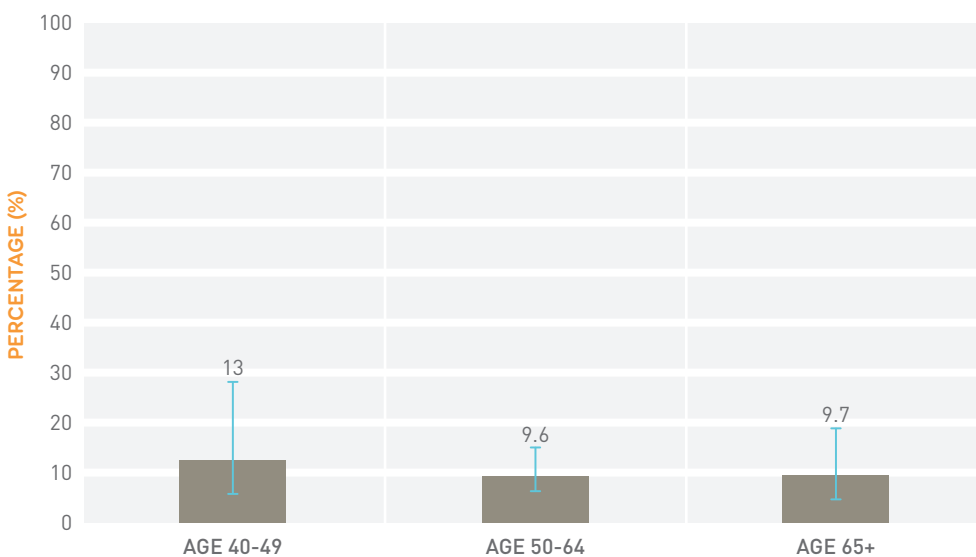
10% of people with an intellectual disability aged 40+ have depression

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY  
AGED 40+ WITH  
DEPRESSION

Mental health is one of the most important determinants of good quality of life in older people. Depression is one of the most common of mental health disorders and has a negative impact on quality of life (Moussavi et al., 2007).

This indicator shows the percentage of people aged 40+ with an intellectual disability that suffer from depression. People were asked to complete the Glasgow Depression Scale. The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) was devised by Cuthill et al. (2003) to support the assessment of depressive symptomatology in individuals with an intellectual disability. The scale focuses on symptoms, not a clinical diagnosis. This question was only answered by those who could self-report. While the GDS-LD was used to measure depressive symptoms for people with an intellectual disability, the CES-D was used in the general population.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 49:** Percentage of people with an intellectual disability aged 40+ with depression, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Note that these data show the percentage of people who have symptoms of depression that were above the cut-off point on the GDS-LD
- When asked about a doctor’s diagnosis, 16% reported that they had a doctor’s diagnosis of depression compared to 10% who showed depressive symptoms using this scale
- Slightly more women demonstrated depressive symptoms (11%) than men (9%)
- More participants with a mild level of intellectual disability had identified depressive symptoms (11%) than those with a moderate (9%) or a severe/profound (9%) level of intellectual disability

**DEPRESSION IN THE GENERAL POPULATION**

11% of people aged 56+ have depression

Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: MENTAL HEALTH

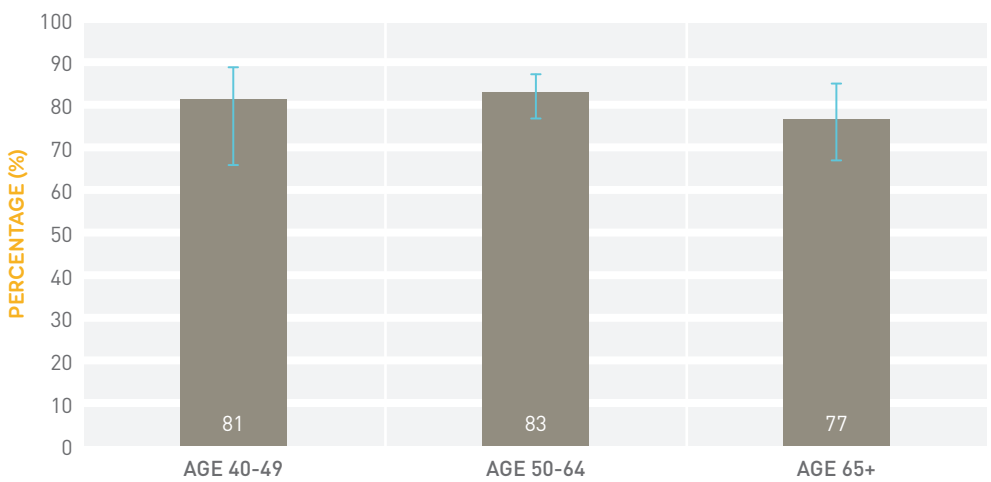
81% of people with an intellectual disability aged 40+ report high levels of life satisfaction

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY  
 AGED 40+  
 WHO REPORT  
 HIGH LIFE  
 SATISFACTION

Life satisfaction shows that people are happy overall with how their life is going. They may not be satisfied in every domain but feel that, on balance, they are satisfied with their lives. More research has been conducted on quality of life in people with an intellectual disability rather than on the subjective wellbeing and life satisfaction of the person with an intellectual disability (Lucas-Carrasco & Salvador-Carulla, 2012).

This question was only answered by those who could self-report.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 50:** Percentage of people with an intellectual disability aged 40+ who report high levels of life satisfaction, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

Key points

- 81% of people aged 40-49 reported high levels of life satisfaction compared to 77% of people aged 65+
- 86% of people with a mild level of intellectual disability reported high levels of life satisfaction, compared to 77% with a moderate level of intellectual disability
- 94% of people living independently or with family reported high levels of life satisfaction

LIFE SATISFACTION IN THE GENERAL POPULATION

86% of people aged 56+ report a high level of life satisfaction

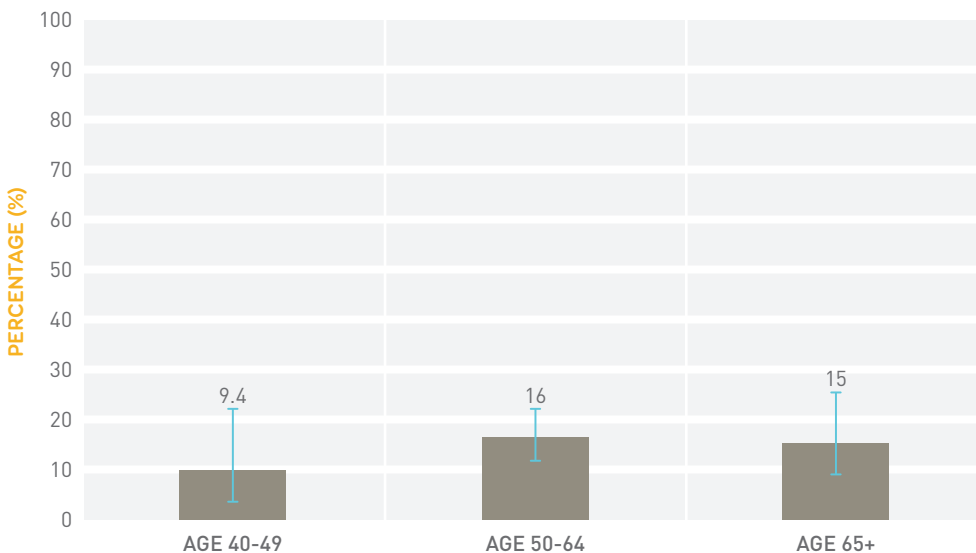
Source: TILDA Wave 4 2016-2017

15% of people with an intellectual disability aged 40+ have anxiety

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH ANXIETY**

Anxiety has been found to have a negative impact on the functioning and wellbeing of older people. It is associated with increased frailty and diminished wellbeing and increased use of health services (De Beurs et al., 1999). This indicator shows the results of an anxiety scale for people with an intellectual disability. The Glasgow Anxiety Scale for People with a Learning Disability (GAS-LD) was developed by Mindham and Espie (2003) to support the assessment of anxiety in individuals with an intellectual disability. The scale focuses on symptoms, not a clinical diagnosis. This question was only answered by those who could self-report.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 51:** Percentage of people with an intellectual disability aged 40+ with anxiety, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- These data show the percentage of people who showed symptoms of anxiety that were above the cut-off point on the GAS-AD
- When asked about a doctor’s diagnosis, 32% reported that they had a doctor’s diagnosis of anxiety compared to 15% who showed symptoms of anxiety using this scale
- 19% of people with a mild level of intellectual disability had anxiety symptoms compared to 13% of those with a moderate level of intellectual disability

**ANXIETY IN THE GENERAL POPULATION**

4% of people aged 56+ report having moderate or severe levels of anxiety

\*The indicator for people with an intellectual disability measures presence of anxiety symptoms rather than severity of anxiety  
 Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: MENTAL HEALTH

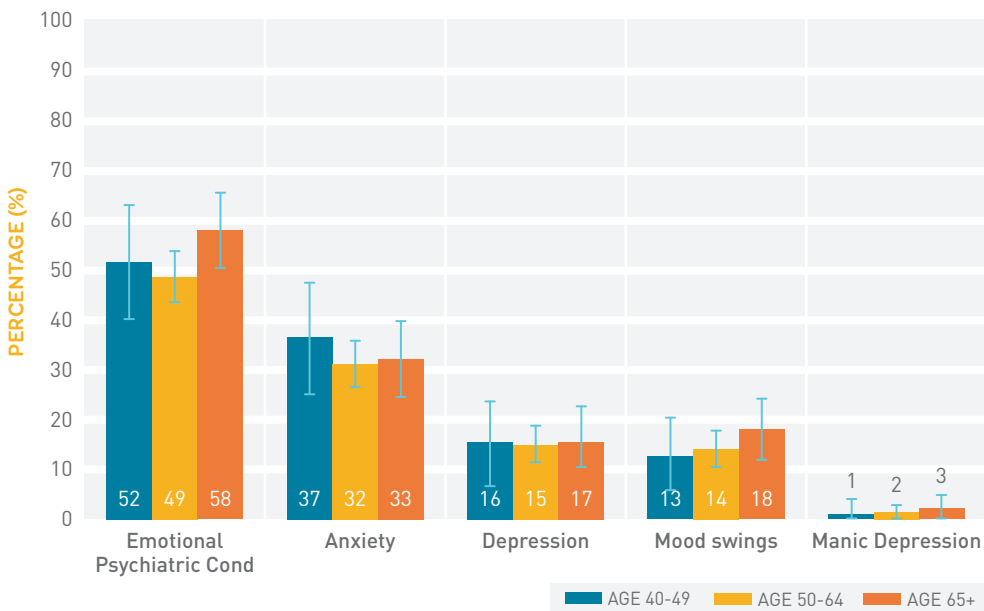
52% of people with an intellectual disability aged 40+ have an emotional, nervous or psychiatric condition

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WITH AN EMOTIONAL, NERVOUS OR PSYCHIATRIC CONDITION

Mental health is one of the most important determinants of good quality of life in older people. It is well recognised that mental health problems are common in people with an intellectual disability and have a significantly higher prevalence than in the general population (Cooper et al., 2007).

This indicator examined the prevalence of emotional, nervous or psychiatric problems of people aged 40+. Participants were asked 'Has a doctor ever told you that you have an emotional, nervous or psychiatric condition?'

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 52:** Prevalence of emotional and psychiatric conditions in people with an intellectual disability aged 40+, by age and type of condition

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- There was little change in the prevalence of mental health conditions from Wave 1 (50%) to Wave 3 (52%)
- The prevalence of emotional, nervous or psychiatric conditions were highest for those with a severe/profound level of intellectual disability (65%)
- Anxiety is the most common diagnosed condition, and slightly higher in the 40-49 age group. Overall, emotional and psychiatric conditions are higher for those aged 65+

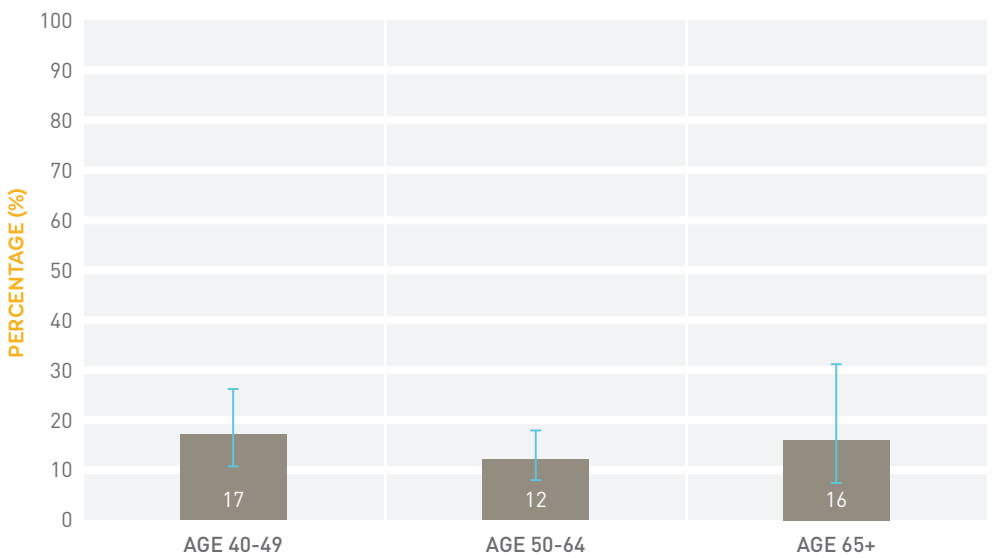
**14% of people with an intellectual disability aged 40+ and living in the community have received home care services in the past twelve months**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ AND LIVING IN THE COMMUNITY WHO HAVE RECEIVED HOME CARE SERVICES IN THE PREVIOUS TWELVE MONTHS

With the increased longevity of people with an intellectual disability, future housing beyond the family home is proving an increasing challenge as people with an intellectual disability are outliving their family carers. More research is needed into the supports required for those with an intellectual disability living in the community.

This indicator shows data for those living independently or with family or living in a community setting who were receiving home care services. Home care includes: home help; personal care attendant; and/or meals on wheels. This does not include staff working in disability services who may carry duties akin to this.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 53:** Percentage of people with an intellectual disability aged 40+ and living in the community who have received home care services in the past twelve months, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Personal care attendant was the most used service at 8%
- 7% of people received home help
- 20% of people with a mild level of intellectual disability received home help compared to 10% with a moderate level of intellectual disability

**HOME CARE SERVICES IN THE GENERAL POPULATION**

11% of people aged 70+ living in the community have received home care services in the previous twelve months

Source: TILDA Wave 4 2016-2017

## HEALTHY AGEING: HEALTHCARE

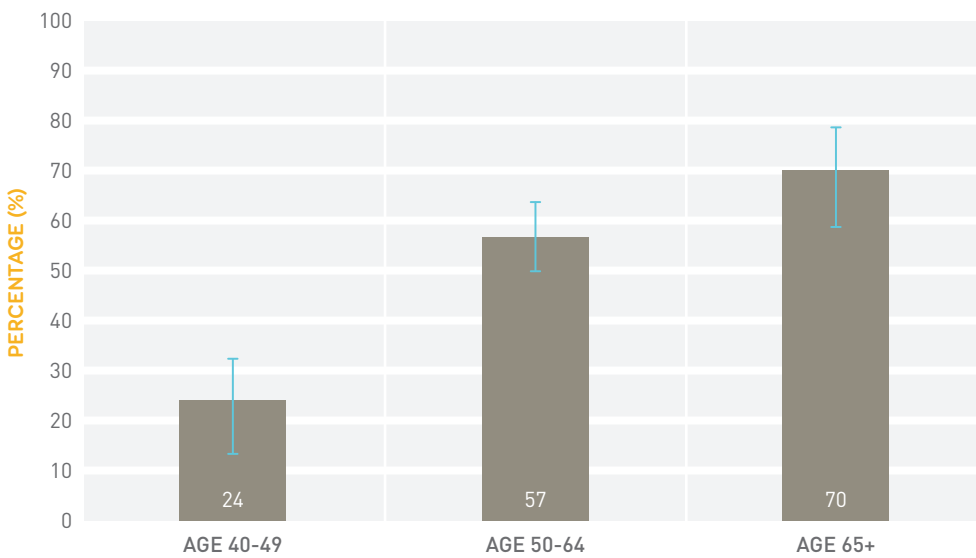
## 57% of eligible women with an intellectual disability have received a mammogram

**INDICATOR:**  
PERCENTAGE OF  
WOMEN WITH AN  
INTELLECTUAL  
DISABILITY AGED 40+  
WHO ARE ELIGIBLE  
FOR SCREENING  
WHO HAVE HAD A  
MAMMOGRAM IN  
THE PREVIOUS  
TWO YEARS

Many chronic conditions can be prevented, deferred or mitigated through good health promotion and preventative screening.

This indicator shows the percentage of women with an intellectual disability who have attended a BreastCheck screening service. BreastCheck Ireland helps to ensure that women with disabilities can use the service easily and have made efforts to ensure that simple, sensitive and easy to understand language is used in BreastCheck materials. This indicator presents data on women with an intellectual disability who have had a mammogram at some point.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 54:**  
Percentage of  
women with  
an intellectual  
disability aged  
40+ who have had  
a mammogram,  
by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

## Key points

- 70% of women with an intellectual disability over the age of 65 had a mammogram in the previous two years
- 63% of women living independently or with family had a mammogram, compared to 61% in a community group home and 51% living in a residential setting
- 70% of women with a mild level of intellectual disability had a mammogram
- 28% of women with a severe/profound level of intellectual disability had a mammogram
- There has been an increase in people receiving a mammogram screening from Wave 1 (48%) to Wave 3 (57%)

## WOMEN RECEIVING A MAMMOGRAM IN THE GENERAL POPULATION

75% of women eligible for screening in the general population have received a mammogram in the previous two years

Source: National Screening Service, Programme Report 2015-2016

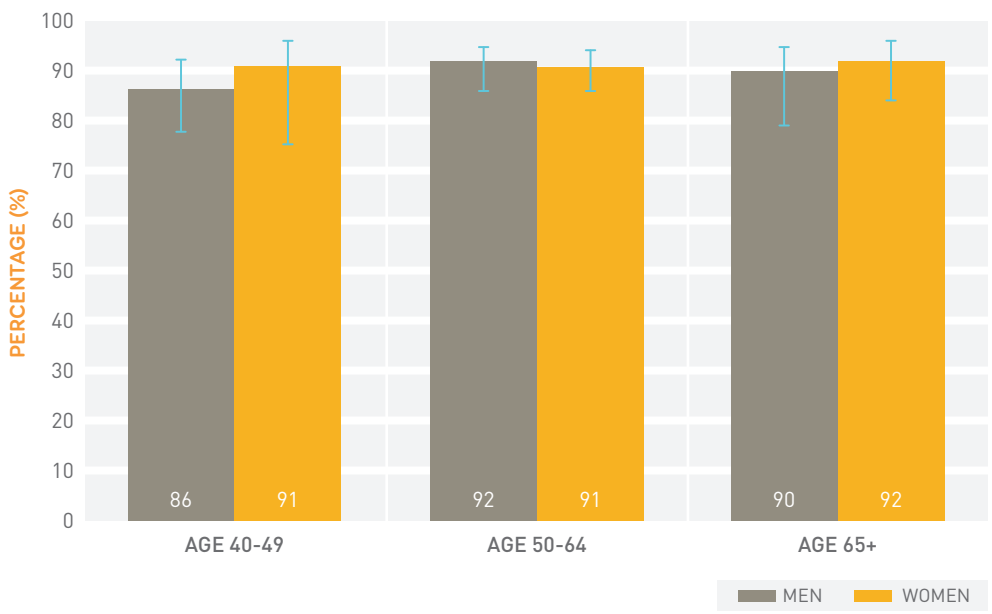
**91% of people with an intellectual disability aged 40+ have received a flu vaccine in the previous two years**

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO HAVE HAD THE FLU VACCINE IN THE PREVIOUS TWO YEARS

The seasonal flu is a highly infectious respiratory illness and spreads rapidly through droplets from the coughing and sneezing of infected people. The vaccine protects against flu strains. It is recommended that people in high-risk groups should receive the vaccine on an annual basis (HSE, 2011b).

This indicator presents the percentage of people with an intellectual disability who have received the flu vaccine.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 55:** Percentage of people with an intellectual disability aged 40+ who have had the flu vaccine in the previous two years, by gender and age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Men and women report similar levels for receiving the flu vaccine across all ages
- Percentage of people getting the flu vaccine remained high (over 90%) across all three waves
- 94% of people with severe/profound level of intellectual disability had the flu vaccine compared to 87% of those with a mild level of intellectual disability
- 93% of those living in a residential setting received the flu vaccine compared to 79% living with family or independently

**FLU VACCINE IN THE GENERAL POPULATION**

62% of people aged 65+ have received the flu vaccine in the previous two years

Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: HEALTHCARE

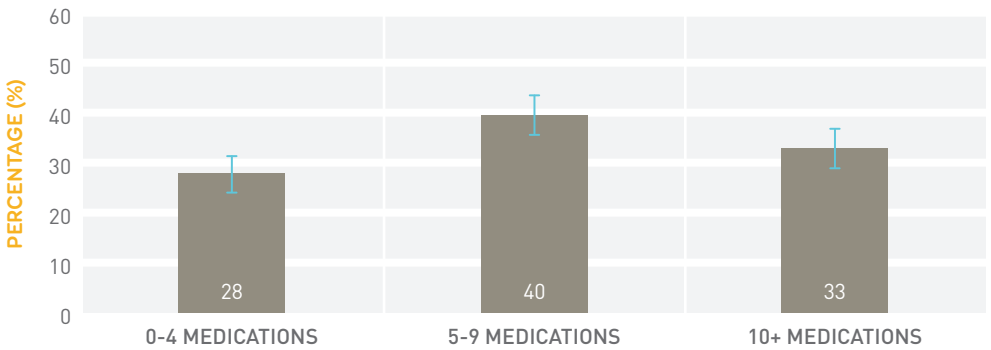
73% of people with an intellectual disability aged 40+ were taking five or more medications

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO ARE TAKING FIVE OR MORE MEDICATIONS**

In Wave 3 of IDS-TILDA, it was found that 97% of participants were taking medicines. Polypharmacy is defined as the use of 5-9 medications. Excessive polypharmacy is defined as 10+ medications. Polypharmacy was commonplace for older adults with an intellectual disability and may be partly explained by the high prevalence of multimorbidity reported. Review of appropriateness of medication use is essential, as polypharmacy places ageing people with an intellectual disability at risk of adverse effects (O'Dwyer, 2016).

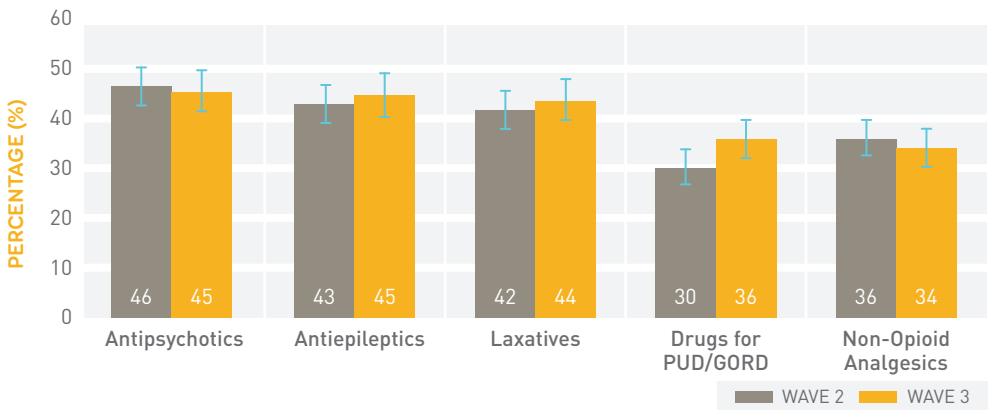
Participants were asked to list all of their current medications in a pre-interview questionnaire.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 56:** Percentage of people with an intellectual disability aged 40+ taking medications, by level of polypharmacy

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)



**Figure 57:** Levels of medication used by people with an intellectual disability aged 40+, by type of medication and waves of IDS-TILDA

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 40% of people reported polypharmacy
- 33% reported excessive polypharmacy
- The most frequent type of medication was antipsychotics, with 46% reporting use

**MEDICATION USE IN THE GENERAL POPULATION**

32% of people in the general population are taking five or more medications

Source: TILDA Wave 4 2016-2017

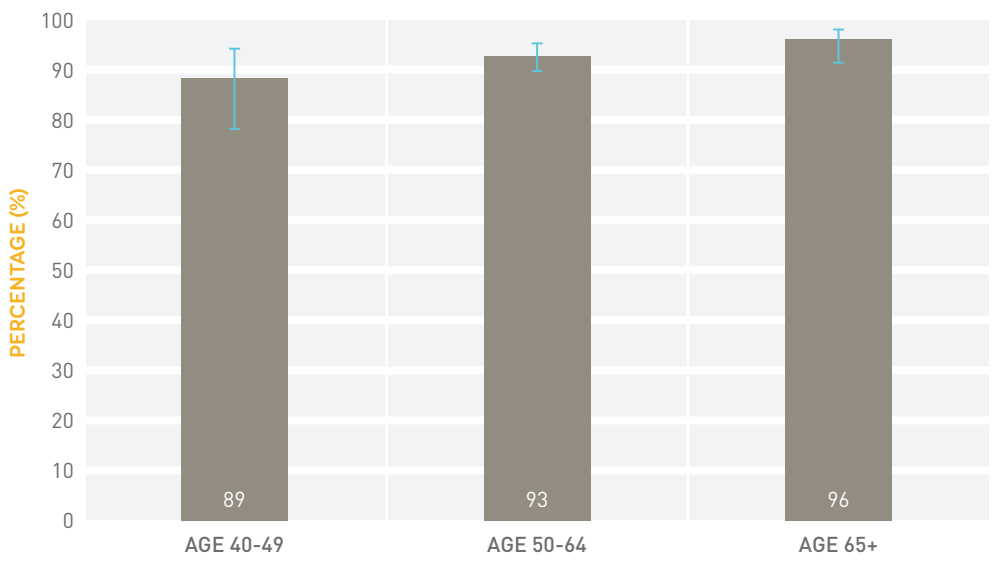
93% of people with an intellectual disability aged 40+ have had their cholesterol checked

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY  
 AGED 40+ WHO  
 HAVE HAD THEIR  
 CHOLESTEROL  
 CHECKED IN THE  
 PREVIOUS  
 TWO YEARS

High cholesterol is a common risk factor frequently associated with a subsequent cardiac event. Overall, prevalence of high cholesterol appears to be lower for people with an intellectual disability compared to the general population (McCarron et al., 2017; Janicki et al., 2002).

This indicator shows the percentage of people aged 40+ who have had a blood test for cholesterol.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 58:** Percentage of people with an intellectual disability aged 40+ who have had their cholesterol checked in the previous two years, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

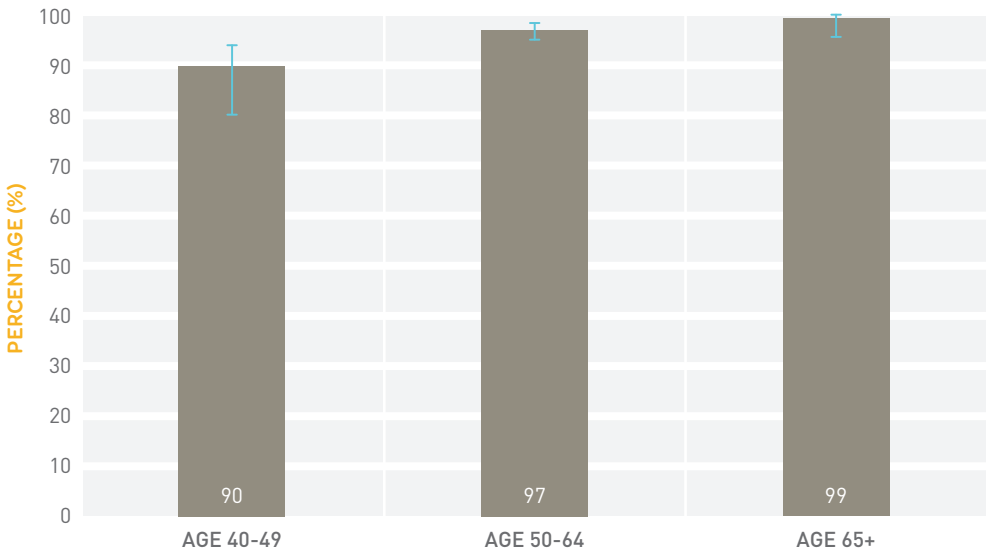
**Key points**

- There was an increase across the three waves of those who had their cholesterol checked, from 79% in Wave 1 to 82% in Wave 2 and 93% in Wave 3
- 96% of people aged 65+ have had their cholesterol checked
- 84% of people living independently or with family had a blood test for cholesterol compared to 94% of people living in a residential setting
- There is no notable difference between men and women in terms of cholesterol screening

HEALTHY AGEING: HEALTHCARE

**97% of people with an intellectual disability aged 40+ have had their blood pressure measured in the previous two years**

<p><b>INDICATOR:</b>                  PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO HAVE HAD THEIR BLOOD PRESSURE MEASURED IN THE PREVIOUS TWO YEARS</p>	<p>Treatment and prevention of disease is a high priority for people with an intellectual disability due to the health disparities compared to the general population, and greater prevalence of health conditions among people with intellectual disabilities (Iacono &amp; Sutherland, 2006). Comprehensive and proactive screening is, therefore, important for this population.</p> <p>This indicator shows the percentage of people with an intellectual disability aged 40+ who have had their blood pressure measured in the previous two years.</p> <p>This indicator is included only in the set of indicators for people with an intellectual disability.</p>
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**Figure 59:** Percentage of people aged 40+ with an intellectual disability who had had their blood pressure checked in the previous two years, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Screening was high across all levels of intellectual disability
- Screening increased from 94% in Wave 1 to 97% in Wave 3

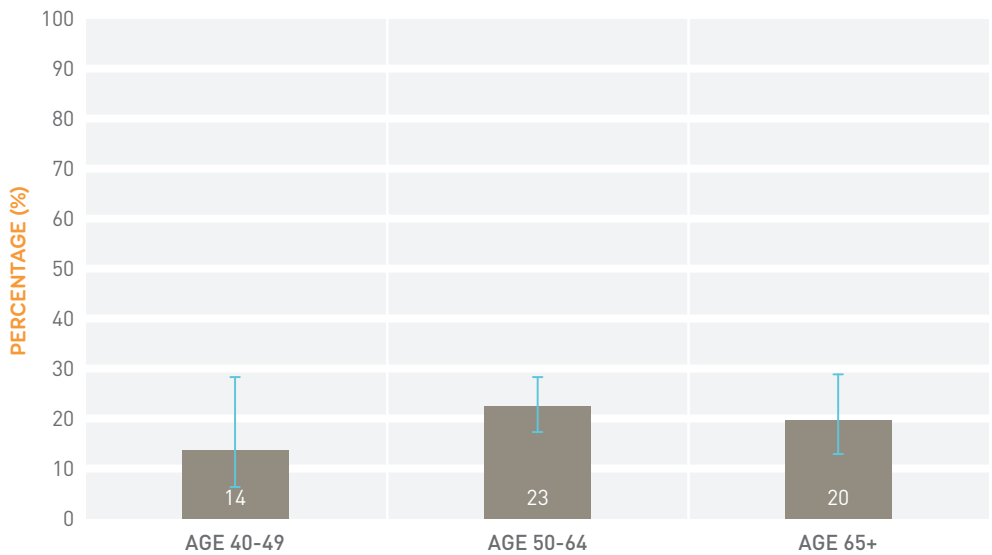
20% of people with an intellectual disability aged 40+ report an unmet need for community care service

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT UNMET NEED FOR A COMMUNITY CARE SERVICE

Unmet needs for services can lead to increased hospital or nursing home admissions. Unmet needs are also linked to weight loss, dehydration, falls and higher levels of hospital admission (La Plante et al., 2004).

Community care services include: Public Health Nurse; Occupational Therapy; Chiropractic; Physiotherapy; Speech and Language; Social Work; Psychology/Counselling; Home Help; Personal Care Attendant; Meals-on-Wheels; Day Centres; Optician; Dental; Hearing; Dietician; Respite Care. Reasons include: 'never heard of or did not know available'; 'transport difficulties'; 'cost'; 'reluctant/don't have time to apply'; 'not eligible'.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 60:** Percentage of people with an intellectual disability aged 40+ who report that there is a service from which they would benefit, that they are not receiving at present, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Unmet needs were higher in people aged 50-64 compared to other age groups
- Two-thirds of people with a severe/ profound level of intellectual disability answered 'yes' to services that they would benefit from but are not receiving
- 25% of men and 18% of women believe they would benefit from services they are currently not receiving

**UNMET NEED FOR COMMUNITY CARE IN THE GENERAL POPULATION**

13% of people aged 56+ report unmet need for a community care service

Source: TILDA Wave 4 2016-2017

HEALTHY AGEING: SOCIAL CARE

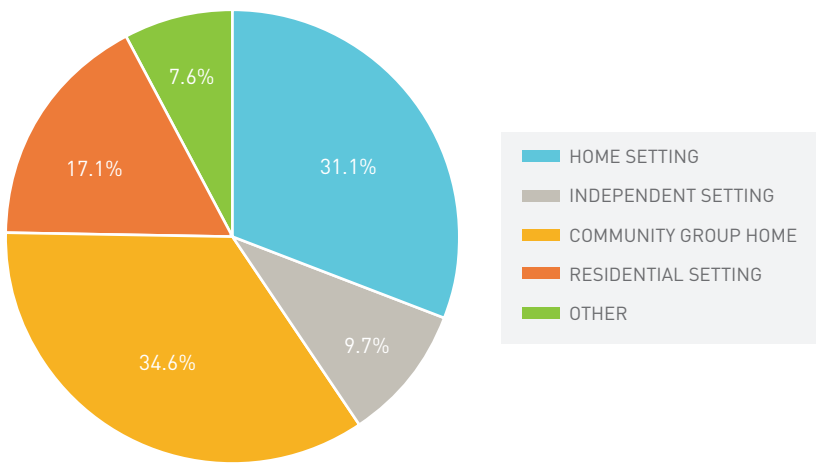
41% of people with an intellectual disability aged 40+ live independently or in a family home

INDICATOR:  
LIVING SITUATION  
OF PEOPLE WITH  
AN INTELLECTUAL  
DISABILITY AGED 40+

A change in where a person lives is a common key life event that most people will experience at some stage during their life. Typically for the general population, this event happens from adolescent to young adulthood (Sixsmith & Sixsmith, 2008). For someone with an intellectual disability, however, the concept of home is quite different; many people with an intellectual disability have historically been placed within segregated institutionalised spaces (Bigby, 2006) with others living in the family home throughout their life. With the increased longevity of people with an intellectual disability and a policy emphasis on community-based living (HSE, 2011), however, more people with an intellectual disability may live independently or with family over time.

This indicator shows data for the residential circumstances of those registered on the National Intellectual Disability Database in 2017. The NIDD is a service-planning tool to capture data on the usage of, and need for, specialist services for people with an intellectual disability.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 61:** Residential circumstance of people with an intellectual disability aged 40+

Source: National Intellectual Disability Database (2017).

**Key points**

- 31% of people aged 40+ were living with family. 10% were living independently. 35% were in a community group home. 17% were living in a residential setting

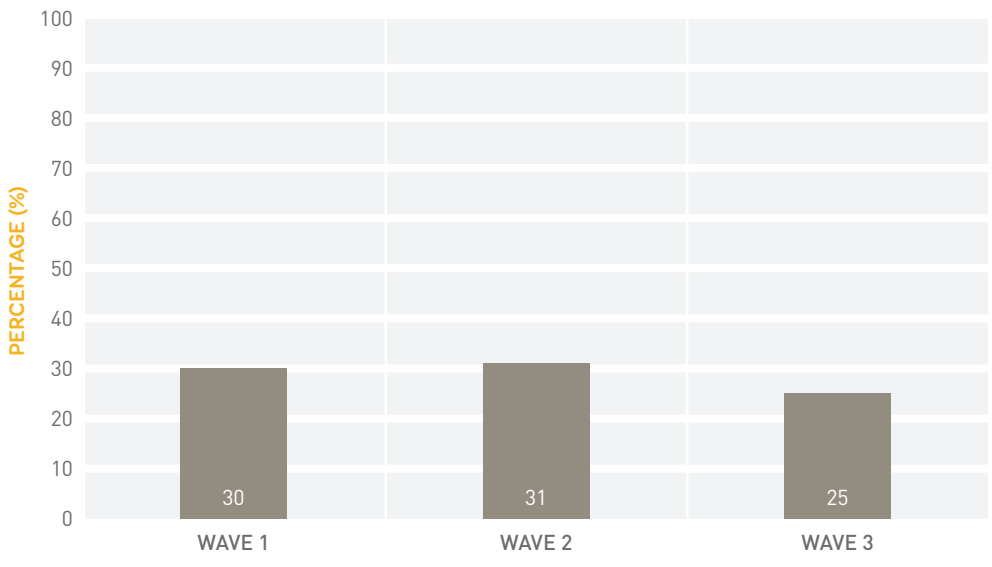
25% of carers report high levels of stress or tension

**INDICATOR:**  
**PERCENTAGE OF CARERS AGED 50+ WHO REPORT HIGH LEVELS OF STRESS OR DISTRESS**

Families are now the main providers of support for people with an intellectual disability, be they parents, siblings, relatives or foster parents (Kelly, 2015). While living in the family home offers significant advantages to a person with an intellectual disability as well as to the carers, negative effects include mental health, isolation, caregiver stress. The carer may be an ageing parent who may also have support needs or may be caring for a spouse, or may be a sibling who may be caring for a parent, a sibling and their own children.

This indicator shows occurrence of stress reported by family caregivers.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 62:** Percentage of carers experiencing stress, by waves of IDS-TILDA

Source: PhD in preparation using IDS-TILDA data

**Key points**

- 23% of carers said that their health had suffered due to caring responsibilities
- 62% of carers had been providing care for over ten years
- 61% of carers stated that constantly being on-call was the most difficult thing about caring

**CARER STRESS IN THE GENERAL POPULATION**

27% of carers aged 50+ report a high level of stress or distress

Source: QNHS Special Module on Carers, 2009





SECTION

**3.4**

**SECURITY**

## GOAL

## 3

Enable people to age with confidence, security and dignity in their own homes and communities for as long as possible.

DOMAIN	KEY INDICATORS	% ID	
		AGE 40+	AGE 50+
FINANCIAL SECURITY	Percentage of people with an intellectual disability aged 40+ who report that a shortage of money stops them from doing the things they want to do	5	14
	Percentage of people with an intellectual disability aged 40+ who are not living with family and who live with five or more people	66	n/a
HOUSING	Percentage of people with an intellectual disability aged 40+ who have a key to their own home	33	n/a

**Note:** Generally n/a indicates that comparable data was not included in the National Positive Ageing Indicators Report as this is an additional indicator for people with an intellectual disability

**5% of people with an intellectual disability aged 40+ report that a shortage of money stops them from doing what they want to do**

<p><b>INDICATOR:</b> PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO REPORT THAT A SHORTAGE OF MONEY STOPS THEM FROM DOING THE THINGS THEY WANT TO DO</p>	<p>In the general population, there is substantial evidence to suggest that people with lower income have poorer health, more chronic conditions and higher rates of disability (Wakabayashi &amp; Donato, 2006).</p> <p>This indicator shows the percentage of people with an intellectual disability aged 40+ who reported that having a shortage of money stopped them from doing what they want to do, e.g. food, heating, going out, visit pub, hobby, holiday.</p> <p>This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability</p>
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**Table 13:** Effect of shortage of money on people with an intellectual disability aged 40+

	I HAD THIS ITEM		I DID NOT HAVE AS I COULDN'T AFFORD		I DID NOT HAVE AS I DID NOT WANT	
	%	CI	%	CI	%	CI
New Clothes	99.4	98.4-99.8	0.2	0-1	0.4	0-1.3
Shoes	95.4	93.2-96.8	0.4	0-1.4	4.2	2.8-6.3
Food	99.8	98.9-99.9	0	0-0.7	0.02	0-1
Heating	98.8	97.3-99.4	0	0-0.7	0.4	0.1-1.4
Telephone Friends and Family	87	83.5-89.8	0.2	0-1.2	11.6	8.9-14.9
Going Out	97.1	95.3-98.2	0.4	0.1-1.3	2.3	1.3-3.9
Visit Pub	84.2	80.6-87.1	0.4	0.1-1.5	13.1	11.1-17.3
Hobby	75.9	71.6-79.6	0.2	0-1.3	21.6	17.9-25.7
Holiday	77.8	73.5-81.4	2.1	1.1-3.9	17.1	13.8-20.9

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- The vast majority of people reported that a shortage of money did not stop them from doing what they wanted to do

<b>SHORTAGE OF MONEY IN THE GENERAL POPULATION</b>
<p>14% of people aged 56+ report that a shortage of money stops them from doing the things they want to do</p> <p>Source: TILDA Wave 4 2016-2017</p>

## SECURITY: HOUSING

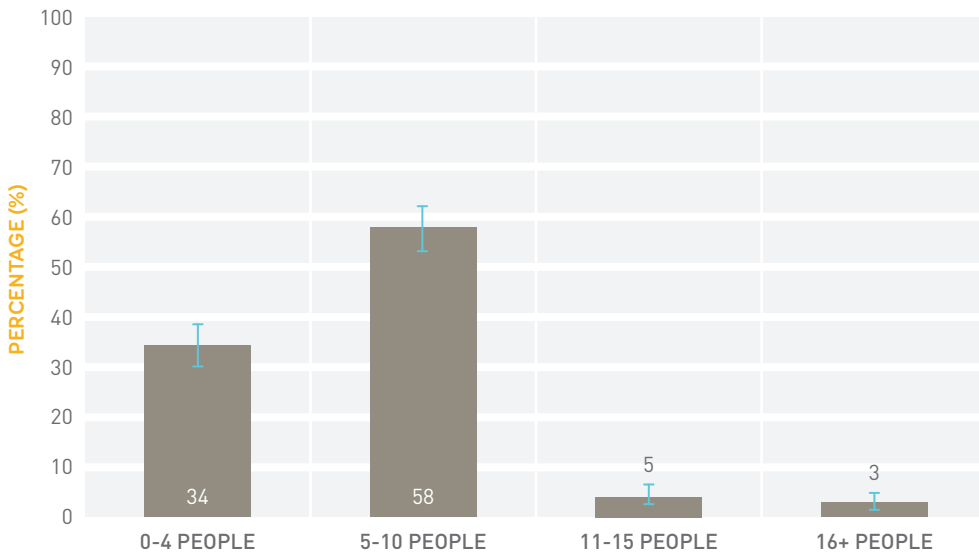
**66% of people with an intellectual disability who are not living with family live with five or more people**

**INDICATOR:**  
PERCENTAGE OF  
PEOPLE WITH AN  
INTELLECTUAL  
DISABILITY AGED  
40+ WHO ARE NOT  
LIVING WITH FAMILY  
AND WHO LIVE  
WITH FIVE OR MORE  
PEOPLE

The 'Time to Move On from Congregated Settings' (HSE, 2011a) report proposed that people moving from congregated settings should move to ordinary neighbourhoods in the community with individualised support designed to meet their individual needs. The report recommended that people moving from congregated settings should share their home with a maximum of four other people with a disability (HSE, 2011a).

This indicator shows the percentage of people who are not living with family or independently, i.e. living in the community or in a residential setting, and who live with five or more people.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 63:** Number of people either living in a house in a community or a residential setting with people with an intellectual disability aged 40+

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- The average number of people living in a house was 7
- Of those living in a community group home, 51% were living with five or more people
- Of those living in residential setting, 80% were living with five or more people

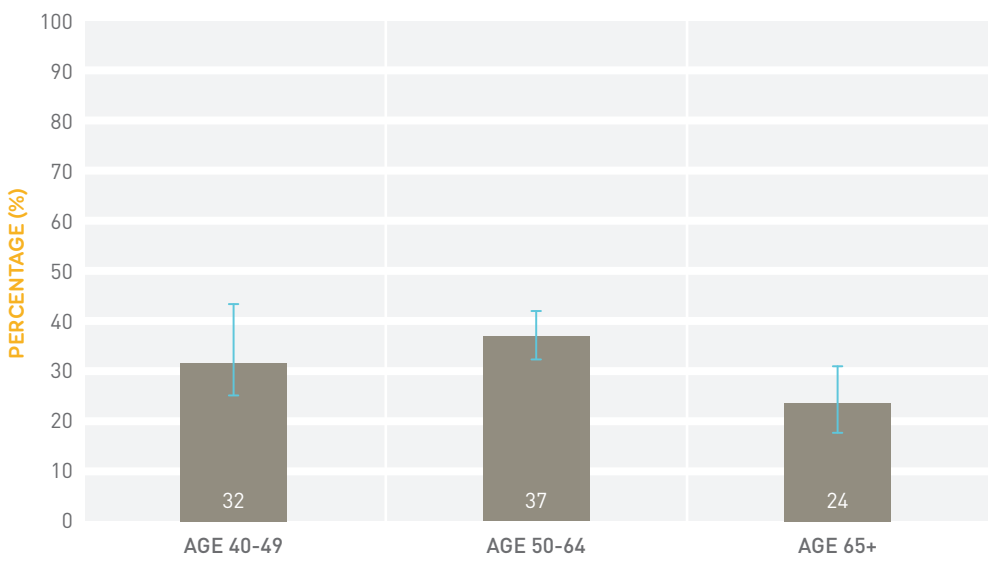
33% of people with an intellectual disability aged 40+ have a key to their own home

**INDICATOR:**  
 PERCENTAGE OF  
 PEOPLE WITH AN  
 INTELLECTUAL  
 DISABILITY AGED  
 40+ WHO HAVE A  
 KEY TO THEIR OWN  
 HOME

Generally, adults with intellectual disabilities have had little or no influence over service policies and planning that directly affect their lives. Having a key to their own home is a measure of independence (McConkey et al., 2004).

In this indicator, it is identified how many people have a key to their own home, in response to a 'yes' or 'no' question.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 64:** Percentage of people with an intellectual disability aged 40+ with a key to their own home, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Interestingly, of the 167 who had moved residence in the previous three years, a lower percentage, 28%, reported having a key to their own home
- 63% of people with a mild level of intellectual disability had a key to their own home
- 76% of people who are living independently or with family had a key





SECTION

**3.5**

**CROSS-CUTTING  
OBJECTIVES**

DOMAIN	KEY INDICATORS	% GENERAL POPULATION	
		AGE 40+	AGE 50+
ATTITUDES TOWARDS AGEING	Percentage of people with an intellectual disability aged 40+ who think there are good things about getting older	48	n/a
TECHNOLOGY	Percentage of people with an intellectual disability aged 40+ who use the internet	12	64
	Percentage of people with an intellectual disability aged 40+ who have access to and can use a computer or tablet	18	n/a
	Percentage of people with an intellectual disability aged 40+ who own and use a mobile phone	22	n/a

**Note:** Generally n/a indicates that comparable data was not included in the National Positive Ageing Indicators Report as this is an additional indicator for people with an intellectual disability

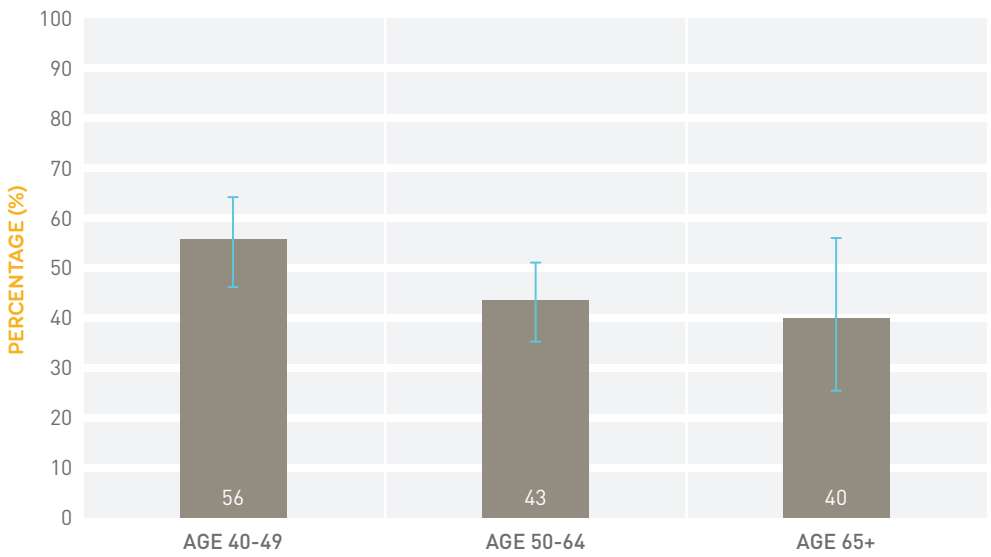
48% of people with an intellectual disability aged 40+ feel that there were good things about getting older

**INDICATOR:**  
PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO FEEL THAT THERE ARE GOOD THINGS ABOUT GETTING OLDER

Successful ageing is often about adapting to changes over time and having a positive view of the age at which one finds oneself. In Wave 1 of IDS-TILDA, it was found that 63% of people felt that older people can do most things that younger people can do, e.g. work, play sport or use a computer (McCarron et al., 2011). Challenging negative ageing concepts is essential to promote health and wellbeing (Burke et al., 2014).

This indicator shows the percentage of people with an intellectual disability aged 40+ who felt there are good things about getting older.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 65:** Percentage of people with an intellectual disability who feel there are good things about getting older, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2011). CI: Confidence Intervals (95%)

**Key points**

- 56% of people aged 40-49 felt that there were good things about getting older. This compared to 40% of people aged 65+
- 47% of people with a mild level of intellectual disability felt there were good things about getting older compared to 53% with a moderate level of intellectual disability

CROSS-CUTTING OBJECTIVE: TECHNOLOGY

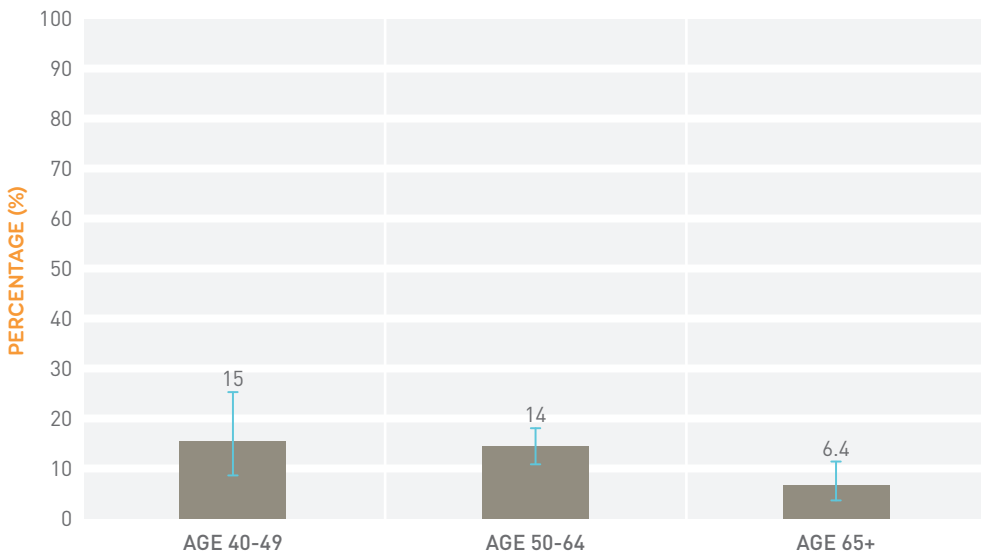
12% of people with an intellectual disability aged 40+ use the internet

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO USE THE INTERNET**

Internet and computer technologies have become a crucial part of participation and engagement. Technology is constantly offering new developments and opportunities for social interaction, knowledge and employment (Chadwick et al., 2013). People with an intellectual disability have lower rates of internet use than the general population. Training and support is necessary to ensure that people with an intellectual disability are not excluded from the opportunities available (Chiner et al., 2017).

This indicator shows the percentage of people who use the internet.

This indicator is included in the Positive Ageing Indicator set for both the general population and for people with an intellectual disability.



**Figure 66:** Percentage of people with an intellectual disability aged 40+ who use the internet, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- Rates of computer use was highest in those aged 40-49 and declined in the older age groups
- 17% of people living independently or with family used the internet compared to 16% living in a community group home and 8% living in a residential setting
- 22% of people with a mild level of intellectual disability reported using the internet

**INTERNET USE IN THE GENERAL POPULATION**

64% of people aged 50+ used the internet, other than for work

Source: EQLS Fourth Round 2016

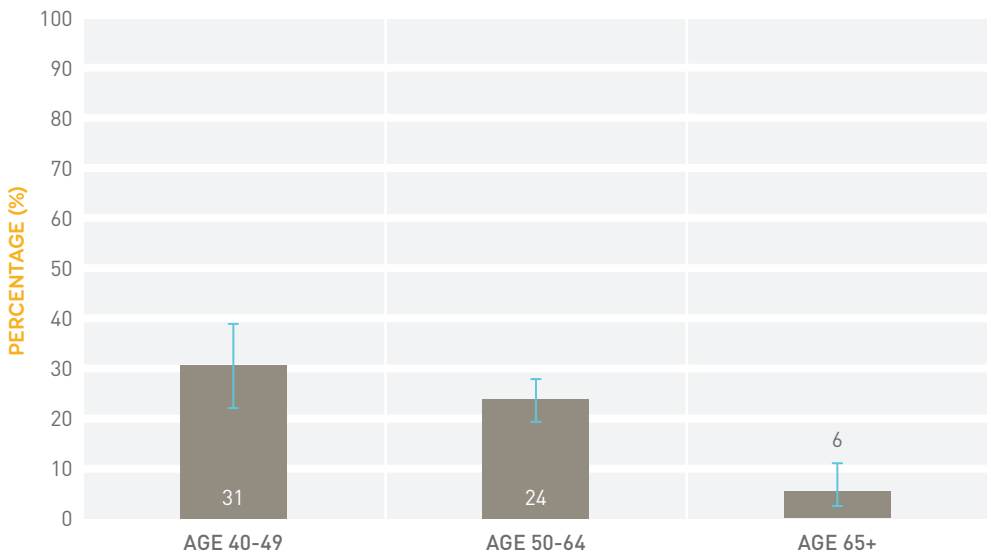
**18% of people with an intellectual disability aged 40+ have access to and use a computer or tablet**

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ HAVE ACCESS TO AND CAN USE A COMPUTER OR TABLET**

People with an intellectual disability have less access to a computer and the internet than their peers in the general population (Chadwick et al., 2013). Reasons given for this disparity include a lack of funding, lack of knowledge among caregivers and inadequate planning and lack of training (Li-Tsang et al., 2005).

This indicator shows the percentage of people who answered ‘yes’ to ‘Do you have access to a computer or tablet?’ and ‘How often do you use a computer or tablet?’.

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 67:** Percentage of people with an intellectual disability aged 40+ who have access to and use a computer or tablet, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals [95%]

**Key points**

- 31% of people aged 40-49 have access to and use a computer, compared to 6% of people aged 65+
- Of those who have access: 20% use it most of the time; 41% use it sometimes; 17% use it rarely; 22% never use it
- 39% of people living independently or with family have access to and use a computer compared to 22% living in the community and 12% living in a residential setting

CROSS-CUTTING OBJECTIVE: TECHNOLOGY

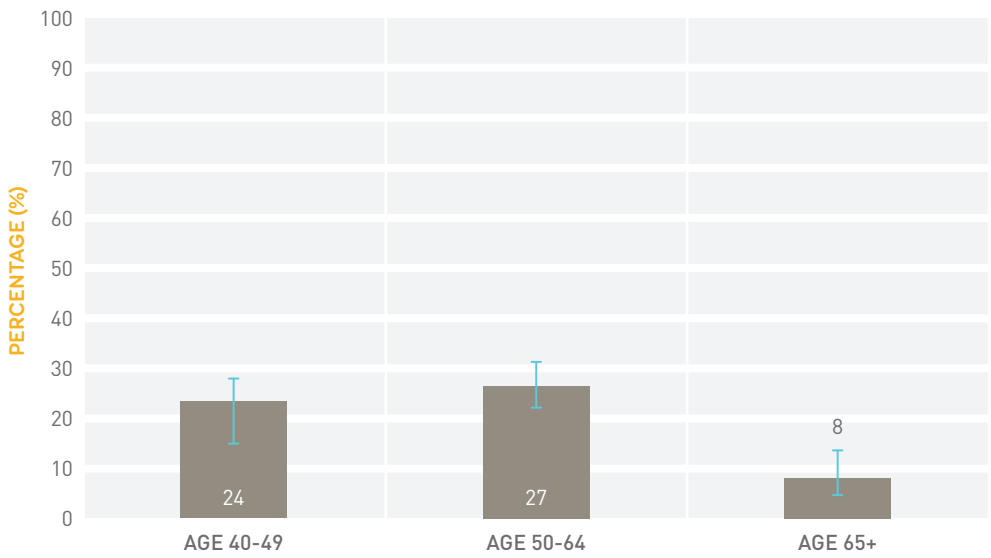
22% of people with an intellectual disability aged 40+ own and use a mobile phone

**INDICATOR:**  
**PERCENTAGE OF PEOPLE WITH AN INTELLECTUAL DISABILITY AGED 40+ WHO OWN AND USE A MOBILE PHONE**

Studies suggest that there is a gap between mobile phone use for people with an intellectual disability and the general population. The primary reasons given for this gap include cost, perception that it is not needed and a lack of accessibility (Bryen et al., 2007).

This indicator shows the percentage of people who answered 'yes' to 'Do you own a mobile phone?' and 'Do you use your mobile phone?'

This indicator is included only in the set of indicators for people with an intellectual disability.



**Figure 68:** Percentage of people with an intellectual disability aged 40+ who own and use a mobile phone, by age

Source: Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (2017). CI: Confidence Intervals (95%)

**Key points**

- 26% of people said that they own a mobile phone. Of those who own a mobile phone, 83% said they use it, 3% said that don't know how to use it and 14% said they don't use it
- 53% of people with a mild level of intellectual disability own and use a mobile phone with 17% of people with a moderate level of intellectual disability owning and using a mobile phone



# REFERENCES

1. AAMT (1997). Numeracy = Everyone's Business. The report of the Numeracy Education Strategy Development Conference. Canberra: Commonwealth of Australia.
2. Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10(3), 275-287.
3. Aylward, E., Burt, D., Thorpe, L. U., Lai, F. & Dalton, A. (1997). Diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 41, 152-164.
4. Becchetti, L., Conzo, P., & Di Febbraro, M. (2018). The Monetary-Equivalent Effect of Voluntary Work on Mental Wellbeing in Europe. *Kyklos*, 71(1), 3-27.
5. Bharucha, A. E., Dorn, S. D., Lembo, A., & Pressman, A. (2013). American Gastroenterological Association medical position statement on constipation. *Gastroenterology*, 144(1), 211-217.
6. Bigby, C. (2006). Shifting Models of Welfare: Issues in Relocation from an Institution and the Organization of Community Living. *Journal of Policy and Practice in Intellectual Disabilities*, 3(3), 147-154.
7. Bryen, D. N., Carey, A., & Friedman, M. (2007). Cell phone use by adults with intellectual disabilities. *Intellectual and Developmental Disabilities*, 45(1), 1-2.
8. Brownson, R. C. (2011). *Epidemiology in Public Health Practice: By A. Haveman-Nies, S.C. Jansen, J.A.M. van Oers and P. van 't Veer*. *American Journal of Epidemiology*, 174(7), 871-872.
9. Bryen, D. N., Carey, A., & Friedman, M. (2007). Cell phone use by adults with intellectual disabilities. *Intellectual and Developmental Disabilities*, 45(1), 1-2.
10. Burke, E. A., McCarron, M., Carroll, R., McGlinchey, E., & McCallion, P. (2014). What it's like to grow older: the aging perceptions of people with an intellectual disability in Ireland. *Mental Retardation*, 52(3), 205-219.
11. Burke, E. A., McCallion, P., Walsh, J. B., & McCarron, M. (2017). An exploration of the bone health of older adults with an intellectual disability in Ireland. *Journal of Intellectual Disability Research*, 61(2), 99-114.
12. Burt, D. B., & Aylward, E. H. (2000). Test battery for the diagnosis of dementia in individuals with intellectual disability. *Journal of Intellectual Disability Research*, 44(2), 175-180.
13. Butterworth, P., Leach, L. S., Strazdins, L., Olesen, S. C., Rodgers, B., & Broom, D. (2011). The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey. *Occupational and Environmental Medicine*, 68(11), 806-812.
14. Care Alliance Ireland (2015). *Family Caring in Ireland*. Dublin: Care Alliance Ireland.
15. Carew, D., Birkin, R., & Booth, D. (2010). Employment, policy and social inclusion. *The Psychologist*, 23, 28-31.
16. Centre for Disease Control Prevention (2015). *Smoking and Tobacco Use: Fast Facts*, Retrieved from [https://www.cdc.gov/tobacco/data\\_statistics/fact\\_sheets/health\\_effects/effects\\_cig\\_smoking/index.htm](https://www.cdc.gov/tobacco/data_statistics/fact_sheets/health_effects/effects_cig_smoking/index.htm)
17. Chadwick, D., Wesson, C., & Fullwood, C. (2013). Internet access by people with intellectual disabilities: Inequalities and opportunities. *Future Internet*, 5(3), 376-397.
18. Chiner, E., Gómez-Puerta, M., & Cardona-Moltó, M. C. (2017). Internet use, risks and online behaviour: The view of internet users with intellectual disabilities and their caregivers. *British Journal of Learning Disabilities*, 45(3), 190-197.
19. Conroy, R. M., Golden, J., Jeffares, I., O'Neill, D., & McGee, H. (2010). Boredom-proneness, loneliness, social engagement and depression and their association with cognitive function in older people: a population study. *Psychology, Health & Medicine*, 15(4), 463-473.
20. Cooper S. A., Smiley, E., Morrison, J., Williamson, A. & Allan, L., (2007). Mental ill-health in persons with ID: Prevalence and associated factors. *British Journal of Psychiatry*, 190(1), 27-35.

21. Cuthill, F. M., Espie, C. A., & Cooper, S. (2003). Development and psychometric properties of the Glasgow Depression Scale for people with a learning disability: Individual and carer supplement versions. *The British Journal of Psychiatry*, 182(4), 347-353.
22. Dawson, F., Shanahan, S., Fitzsimons, E., O'Malley, G., Mac Giollaibhui, N., & Bramham, J. (2016). The impact of caring for an adult with intellectual disability and psychiatric comorbidity on carer stress and psychological distress. *Journal of Intellectual Disability Research*, 60(6), 553-563.
23. De Beurs, E., Beekman, A. T. F., Van Balkom, A. J. L. M., Deeg, D. J. H., & Van Tilburg, W. (1999). Consequences of anxiety in older persons: its effect on disability, wellbeing and use of health services. *Psychological Medicine*, 29(3), 583-593.
24. De Winter, C. F., Hermans, H., Evenhuis, H. M., & Echteld, M. A. (2015). Associations of symptoms of anxiety and depression with diabetes and cardiovascular risk factors in older people with intellectual disability. *Journal of Intellectual Disability Research*, 59(2), 176-185.
25. DeSalvo, K. B., Bloser, N., Reynolds, K., He, J., & Muntner, P. (2006). Mortality prediction with a single general self-rated health question: a meta-analysis. *Journal of General Internal Medicine*, 21(3), 267-275.
26. Eisenbaum, E. (2018). Tobacco product use and smoking frequency among US adults with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 62(8), 709-718.
27. Emerson, E., Robertson, J., Baines, S., & Hatton, C. (2014). The self-rated health of British adults with intellectual disability. *Research in Developmental Disabilities*, 35(3), 591-596.
28. Evenhuis, H. M., Theunissen, M., Denkers, I., Verschuure, H., & Kemme, H. (2001). Prevalence of visual and hearing impairment in a Dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research*, 45(5), 457-464.
29. Evenhuis, H. M., Hermans, H., Hilgenkamp, T. I., Bastiaanse, L. P., & Echteld, M. A. (2012). Frailty and disability in older adults with intellectual disabilities: results from the healthy ageing and intellectual disability study. *Journal of the American Geriatrics Society*, 60(5), 934-938.
30. Foran, S., McCarron, M., & McCallion, P. (2013). Expanding assessment of fear of falling among older adults with an intellectual disability: A pilot study to assess the value of proxy responses. *ISRN Geriatrics*, 2013. DOI: 10.1155/2013/493042
31. Fried, L. P., Ferrucci, L., Darer, J., Williamson, J. D., & Anderson, G. (2004). Untangling the concepts of disability, frailty, and comorbidity: implications for improved targeting and care. *The Journals of Gerontology Series A: Biological Sciences and Medical Sciences*, 59(3), M255-M263.
32. Gibney, S., Sexton, E., & Shannon, S. (2018). Measuring What Matters: Achieving Consensus on a Positive Aging Indicator Set For Ireland. *Journal of Aging & Social Policy*, 31(3), 234-249.
33. Gray, B., & Jackson, R. (2002). *Advocacy and learning disability*. London: Jessica Kingsley Publishers.
34. Griffen, A. K. (2017). *Special Education Teachers, Literacy, and Students with Moderate and Severe Intellectual Disability: A Survey*. [PhD] Lexington: University of Kentucky.
35. Grundy, E., & Holt, G. (2001). Health inequalities in the older population. *Health Variations*, 7, 4-5.
36. Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P. N., Kerr, M., van Schroyensteen Lantman-de Valk, H., & Cara, A. C. (2011). Ageing and health status in adults with intellectual disabilities: results of the European POMONA II study. *Journal of Intellectual and Developmental Disability*, 36(1), 49-60.
37. Health Service Executive. (2011a). *Time to Move on from Congregated Settings. A Strategy for Community Inclusion. Report of the working group on congregated settings*. Dublin: Health Service Executive.
38. Health Service Executive. (2011b). *Flu vaccine, seasonal* [online]. Available at: <https://www.hse.ie/eng/health/az/f/flu-vaccine,-seasonal/who-should-have-the-seasonal-flu-jab-.html>
39. Health Service Executive. (2012). *New Directions: Review of HSE day services and implementation plan 2012 - 2016*. Dublin: The Stationery Office.
40. Health Service Executive National Screening Service. (2015). *BreastCheck – Programme Report 2014-2015*. Available at: <http://www.breastcheck.ie/sites/default/files/bcheck/documents/breastcheck-pr-2014-2015.pdf>
41. Heller, T., Miller, A. B., Hsieh, K., & Sterns, H. (2000). Later-life planning: Promoting knowledge of options and choice-making. *Mental Retardation*, 38(5), 395-406.

42. Hendricks, A. (2007). UN Convention on the Rights of Persons with Disabilities. *European Journal of Health Law*, 14, 273.
43. Hilgenkamp, T. I., Reis, D., van Wijck, R., & Evenhuis, H. M. (2012). Physical activity levels in older adults with intellectual disabilities are extremely low. *Research in Developmental Disabilities*, 33(2), 477-483.
44. Hilgenkamp, T. I., van Wijck, R., & Evenhuis, H. M. (2011). (Instrumental) activities of daily living in older adults with intellectual disabilities. *Research in Developmental Disabilities*, 32(5), 1977-1987.
45. Hourigan, S., Fanagan, S., & Kelly, C. (2018). Health Research Board Statistics Series 37, Annual Report of the National Intellectual Disability Database Committee 2017: Main Findings. Dublin: Health Research Board.
46. Hsieh, K., Rimmer, J., & Heller, T. (2012). Prevalence of falls and risk factors in adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 442-454.
47. Hunter, K. I., & Linn, M. W. (1981). Psychosocial differences between elderly volunteers and non-volunteers. *The International Journal of Aging and Human Development*, 12(3), 205-213.
48. Iacono, T., & Sutherland, G. (2006). Health screening and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 3(3), 155-163.
49. Janicki, M. P., Davidson, P. W., Henderson, C. M., McCallion, P., Taets, J. D., Force, L. T., Sulkes, S. B., Frangenberg, E., & Ladriagan, P. M. (2002). Health characteristics and health services utilization in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research*, 46(4), 287-298.
50. LaPlante, M. P., Kaye, H. S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: estimating the shortfall in hours of help and adverse consequences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(2), S98-S108.
51. LaPlante, M. P., Kaye, H. S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(2) S98-S108.
52. Li-Tsang, C., Yeung, S., Chan, C., & Hui-Chan, C. (2005). Factors affecting people with intellectual disabilities in learning to use computer technology. *International Journal of Rehabilitation Research*, 28(2), 127-133.
53. Lochner, L. (2011). Non-production benefits of education: Crime, health, and good citizenship (NBER Working Paper No. 16722). Massachusetts: National Bureau of Economic Research.
54. Lucas-Carrasco, R., & Salvador-Carulla, L. (2012). Life satisfaction in persons with intellectual disabilities. *Research in developmental disabilities*, 33(4), 1103-1109.
55. Lysaght, R., Ouellette-Kuntz, H., & Lin, C. J. (2012). Untapped potential: Perspectives on the employment of people with intellectual disability. *Work*, 41(4), 409-422.
56. Mac Giolla Phadraig, C., McCallion, P., Cleary, E., McGlinchey, E., Burke, E., McCarron, M., & Nunn, J. (2015). Total tooth loss and complete denture use in older adults with intellectual disabilities in Ireland. *Journal of Public Health Dentistry*, 75(2), 101-108.
57. 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). Dublin: School of Nursing and Midwifery, Trinity College Dublin.
58. McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013). Patterns of multimorbidity in an older population of persons with an intellectual disability: results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA). *Research in Developmental Disabilities*, 34(1), 521-527.
59. McCarron, M., McCallion, P., Carroll, R., Burke, E., Cleary, E., McCausland, D. & Shivers, C. (2014). Advancing years, Different challenges: Wave 2 IDS-TILDA: findings on the ageing of people with an intellectual disability: an intellectual disability supplement to the Irish Longitudinal Study on Ageing. Dublin: School of Nursing and Midwifery, Trinity College Dublin.
60. McCarron, M., Haigh, M., McCallion, P., McCallion, P., Carroll, R., Burke, E. A. & O'Dwyer, M. (2017). Health, Wellbeing and Social Inclusion: Ageing with an Intellectual Disability in Ireland. Dublin: School of Nursing and Midwifery, Trinity College Dublin.
61. McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*, 61(9), 843-852.

62. McCausland, D., McCallion, P., Cleary, E., & McCarron, M. (2016). Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA. *Journal of Applied Research in Intellectual Disabilities*, 29(1), 71-82.
63. McConkey, R., Sowney, M., Milligan, V., & Barr, O. (2004). Views of people with intellectual disabilities of their present and future living arrangements. *Journal of Policy and Practice in Intellectual Disabilities*, 1(3-4), 115-125.
64. McGlinchey, E., McCallion, P., Burke, E., Carroll, R., & McCarron, M. (2013). Exploring the Issue of Employment for Adults with an Intellectual Disability in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 26(4), 335-343.
65. McGuire, B. E., Daly, P., & Smyth, F. (2007). Lifestyle and health behaviours of adults with an intellectual disability. *Journal of Intellectual Disability Research*, 51(7), 497-510.
66. McHugh, J. E., Kenny, R. A., Lawlor, B. A., Steptoe, A., & Kee, F. (2017). The discrepancy between social isolation and loneliness as a clinically meaningful metric: findings from the Irish and English longitudinal studies of ageing (TILDA and ELSA). *International Journal of Geriatric Psychiatry*, 32(6), 664-674.
67. Merrells, J., Buchanan, A., & Waters, R. (2017). The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *Journal of Intellectual & Developmental Disability*, 43(4), 381-391.
68. Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): Development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research*, 47(1), 22-30.
69. Moni, K. B., & Jobling, A. (2000). LATCH-ON: A program to develop literacy in young adults with Down syndrome. *Journal of Adolescent & Adult Literacy*, 44(1), 40-49.
70. Moni, K., Jobling, A., & Baffour, B. (2018). Literacy Learning Outcomes in a Longitudinal Study of a Postschool Literacy Education Program for Young Adults With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 15(2), 155-165.
71. Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys. *The Lancet*, 370(9590), 851-858.
72. Nolan, A., O'Regan, C., Dooley, C., Wallace, D., Hever, A., Cronin, H., & Kenny, R. A. (2014). *The over 50s in a changing Ireland: economic circumstances, health and wellbeing*. Dublin: The Irish Longitudinal Study on Ageing.
73. O'Donovan, M. A., Byrne, E., McCallion, P., & McCarron, M. (2017). Measuring choice for adults with an intellectual disability—a factor analysis of the adapted daily choice inventory scale. *Journal of Intellectual Disability Research*, 61(5), 471-487.
74. O'Dwyer, M., Peklar, J., McCallion, P., McCarron, M., & Henman, M. C. (2016). Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study. *BMJ open*, 6(4), e010505.
75. Penny, K. I., Purves, A. M., Smith, B. H., Chambers, W. A., & Smith, W. C. (1999). Relationship between the chronic pain grade and measures of physical, social and psychological wellbeing. *Pain*, 79(2-3), 275-279.
76. Peplau, L. A., & Perlman, D. (1982). Perspective on loneliness. In L. A. Peplau & D. Perlman (eds.) *Loneliness: A Sourcebook of Current Theory, Research and Therapy*. New York: Wiley.
77. Retish, P., & Reiter, S. (1999). Leisure and persons with developmental disabilities: Empowering self-determination through inclusion. In P. Retish & S. Reiter (eds.) *Adults with Disabilities: International Perspectives in the Community*. New Jersey: Lawrence Erlbaum. (pp. 139-158)
78. Robertson, J., Baines, S., Emerson, E., & Hatton, C. (2018). Prevalence of constipation in people with intellectual disability: A systematic review. *Journal of Intellectual & Developmental Disability*, 43(4), 392-406.
79. Simone, P. M., & Scullin, M. (2006). Cognitive benefits of participation in lifelong learning institutes. *LLI Review*, 1, 44-51.
80. Sixsmith, A., & Sixsmith, J. (2008). Ageing in Place in the United Kingdom. *Ageing International*, 32, 219-35.

81. Smyth C. M. & Bell D. (2006). From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34, 227–36.
82. Stevens, J. A., Mack, K. A., Paulozzi, L. J., & Ballesteros, M. F. (2008). Self-reported falls and fall-related injuries among persons aged  $\geq 65$  years—United States, 2006. *Journal of Safety Research*, 39(3), 345-349.
83. Strydom, A., & Hassiotis, A. (2003). Diagnostic instruments for dementia in older people with intellectual disability in clinical practice. *Aging & Mental Health*, 7(6), 431-437.
84. Temple, V. A., Frey, G. C. & Stanish, H. I. (2006) Physical activity of adults with mental retardation: review and research needs. *American Journal of Health Promotion*, 21(1), 2-12.
85. Trembath, D., Balandin, S., Stancliffe, R. J., & Togher, L. (2010). Employment and volunteering for adults with intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 235-238.
86. Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303-318.
87. Wakabayashi, C., & Donato, K. M. (2006). Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement Survey. *Journal of Health and Social Behavior*, 47(3), 258-274.
88. World Health Organization. (2008). *Closing the gap in a generation*. Geneva: WHO.
89. Wormald, A. D. (2018). *Loneliness in Older People with an Intellectual Disability* (PhD), Dublin: Trinity College Dublin.
90. Zarkou, A., Aggelousis, N., Michalopoulou, M., & Tokmakidis, S. (2011). The impact of fear of falling, falls and gender on the quality of life in elderly people. *Physiotherapy Issues*, 7(1), 21–32.





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**POSITIVE AGEING**  
INDICATORS  
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2018

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