



2011

## Growing Older with an Intellectual Disability in Ireland 2011

First results from the Intellectual Disability  
Supplement to the Irish Longitudinal Study on Ageing.



# **Growing Older with an Intellectual Disability in Ireland 2011**

**First results from the intellectual Disability  
supplement to the Irish Longitudinal Study on  
Ageing**

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## Acknowledgements

I am delighted to publish this report on behalf of the IDS to TILDA research team.

This report is about the IDS to TILDA study; what we learned from everyone who took part, how the study was carried out and what will happen next.

Without you, the participants, we would never have been able to get the information that will help everyone to understand what it is like growing older with an intellectual disability in Ireland. I would like to thank all of you who took part in the study. Also, big thank you to all of the people who helped you to take part, your families, friends and support workers.



Yours Sincerely

*Prof. Mary McCarron.*

Professor Mary McCarron  
Principal Investigator  
Intellectual Disability Supplement to TILDA

## Why are we doing this study?

This study is about people who are growing older with an intellectual disability in Ireland. This study will help us learn about people with an intellectual disability who are growing older. We asked questions about were

- Where people lived.
- Did they go to school?
- What people's health was like?
- What did they do every day?
- How often people see their family and friends.
- Did people work?
- Did they go to day service?
- Did they have a personal plan?
- Who supports them?
- What did they think about growing old?
- What would they like to do in the future?

With this information we can plan for the future together.

# 1

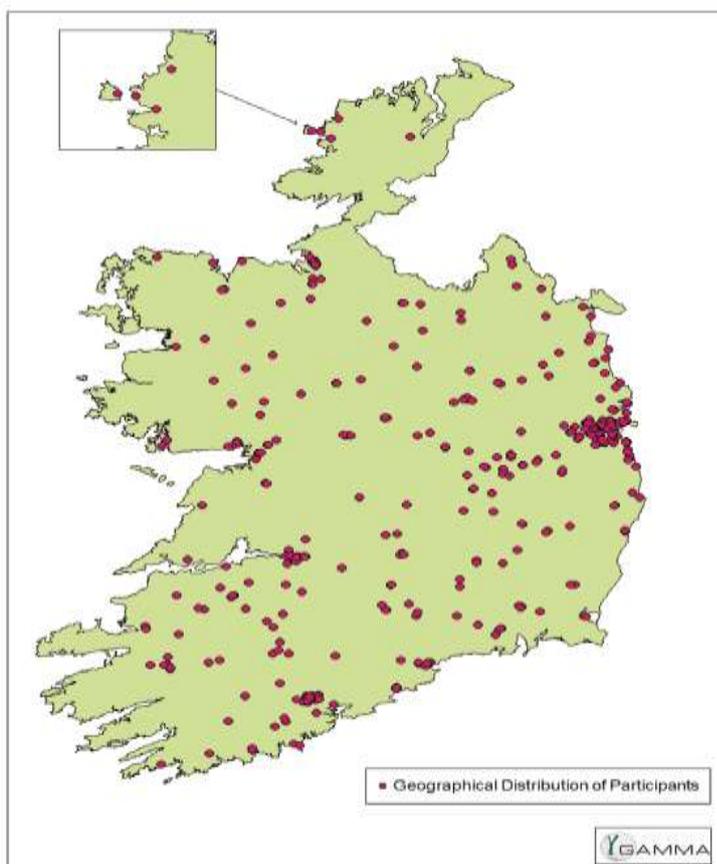
## The People Who Took Part

### Who took part

753 people took part in this study. They were from age 41 years to 90 years.

55% were women and 45% were men.

Most of the people were not married and only a few people had children.



People took part from all over Ireland. Each red dot on this map shows where people lived.

## What People's Education was Like

- 205 people never went to school.
- 346 people went to primary school.
- 13 people went to secondary school.
- 4 people had a diploma.
- 2 people had a degree.



## Where People Lived

More people who were older and had more difficulties lived in a residential centre. Over 560 people lived in their home for more than 6 years.

- 350 lived in a residential centre.
- 275 lived in the community.
- 38 people lived alone, with a small amount of help.
- 83 people lived with a family member.



Most people said they had their own bedroom but 150 people shared their room. Nearly half of those would like their own room.

## What Problems People had Getting around their Home

Climbing the stairs was hard for a lot of people. Some people were afraid of falling and others had poor eyesight.

Grab rails, ramps and widened doors and hallways made it easier to get about.



## Making Family Connections

A lot of people meet their family once or twice a month. Others meet their family twice a year or less. But there are a few people who never meet their family at all.



Very few people made telephone calls to their family. Nearly three quarters never wrote or text, emailed or used any sort of social media to contact their family.

## Making Connections with Friends

Nearly 300 people never meet up with friends.



People in a residential centre do not meet up with friends as much as people living at home. People see their friends less as they get older. People with a mild or moderate ID meet up with friends more often. 432 people do not phone their friends and 548

people did not write to their friends.

## Feeling Lonely

191 people said they felt lonely at some time. Women felt lonely more than men. People, who were younger, felt lonely some of the time. People who lived at home or in the community also said they felt lonely some of the time.



One person said *“I’d love to have a friend that I could go out for tea with or something like that.”*

Making friends was hard for some people. But 506 people said they had someone they could talk to about a private matter.

## What people do in their Community

We asked people if they voted. Only a small number of people said they voted in the general election. Most people told us they did not vote.



We asked about going on holidays. Over half went on holiday in Ireland in the last year. Not many people went on holiday in another country.

Going on day trips were popular. Most people went on a day trip no matter how old they were.



Being a neighbour is more than just living next door.



A neighbour is a friend who will help out if needed. 97 people told us they helped their neighbours. This was important and it made them feel good.

## Transport

People told us about the type of transport they used the most.



- 678 people used a minibus.
- 349 people used a taxi.
- 270 people were driven by their family.
- 155 people took the public bus.

People had problems using public transport. Some people said the signs were hard to read. People said it was hard to get on and off the bus. Other people said there were not enough buses. The bus stop was too far away for a lot of people.



## Social Activities.

In the survey the Special Olympics was the most popular activity. A lot of people were part of advocacy groups. Other people were in church groups.



Very few people used the internet. Only 172 people owned their own mobile phone. A lot of people had a hobby. Arts and crafts were the most popular hobby. Most people watched telly at least once a week.

Over 600 people liked going out for a meal, going for coffee and going shopping.



Other favourite things to do were going to the pub and visiting their family.

### **Difficulties Doing Social Activities.**

People sometimes found it hard to do their social activities. Because;

- They needed help.
- They had poor health.
- They found it hard to say what they wanted.
- They could not get a lift to their activity.
- They had no one to go with.

### **Difficulties Getting Around the Community.**

284 people had difficulty getting around their community. 147 people never travelled around their community.



Bumpy footpaths caused the most problems for people.

People also said signs were hard to read because the writing was too small.



Some people did not feel safe going out. Sometimes there were no road crossings. Some people found it hard to get into some buildings.



## Volunteering

Doing voluntary work is about helping others. 58 people did voluntary work because they enjoyed it. Others felt they were doing something good. And others did voluntary work because they liked to meet people.



# 2

## Health and Well being

### People's Health



639 people said they were healthy. More women than men said they felt very healthy. When people were older they felt their health was not as good.

### People's Medical Conditions

Most people with an ID get their health checked every year.

- 237 people had high cholesterol.
- A lot of people who had high cholesterol were overweight.



One in every six people had high blood pressure.

People had a lot of different medical problems. The chart below shows the top ten medical conditions people had and how many people had each condition out of the 753 people who took part.

	<b>Medical Conditions</b>	<b>The Number of People</b>
<b>1</b>	High cholesterol	237
<b>2</b>	Epilepsy	229
<b>3</b>	Constipation	130
<b>4</b>	High blood pressure	116
<b>5</b>	Thyroid disease	110
<b>6</b>	Cataracts	98
<b>7</b>	Arthritis	81
<b>8=</b>	Osteoporosis	61
<b>8=</b>	Diabetes	61
<b>10</b>	Gastroesophageal reflux disease	59

## Other health problems

As people get older they complain more of pain. Women overall complained of pain in more places than men. But men complained of a lot of pain in their feet.



Women got their bones checked for osteoporosis and arthritis more than men. Men broke their bones more often than women. This could mean that men need to have their bones checked regularly.



200 people had a fall in the last year. 14 people had 2 or more falls in the last year. Young people had a lot of falls.

People had problems with their bowels and bladder. Some people found it hard to go to the toilet. Others said they might have an accident before getting to the toilet.

A lot of people had problems with hearing and seeing. People had more problems as they got older. People had their check-ups often. But people who had a severe to



profound ID had a check-up less often. It can be very hard to find out if a person has a problem if they find it hard to talk. Staff will have to come up with more ways of doing these tests so everyone can have their regular check-ups.

## People's Emotional Health

People overall felt positive about their lives. But nearly half of the people in this study had an emotional problem. Nearly all of them were getting help from their doctor.



People who had Down's syndrome were less likely to have an emotional problem but more likely to have dementia in older age.

Women were more likely to feel sad than men. People who were lonely had sad feelings as well.

## The Health Services People Used

Overall people attended their health services the same as most of the people in Ireland.

The most used health service was the GP. Out of all the people taking part in IDS-TILDA 692 people went to their GP at least once in the last year.



People who



lived in a residential centre used health services more than those living at home or independently. We have to remember people who live in a residential centre tend to be older with more health problems. The next most visited health service was the dentist but people tended to go less as they got older. The chiropodist came next of the most used service and the optician was fourth on the list. Less used services were meals-on-wheels, palliative care services, geriatrician services and home help services, under 20 people reported they had used any of these services.

## Going to Hospital

People with an ID are less likely to have to stay in hospital than other people in Ireland but people with an ID are more likely to go to the out patients department or the accident and emergency room than other people in Ireland.



Overall people were satisfied with their healthcare services but some people told us they had to wait a long while to get an appointment. The biggest problem for people with an ID was not getting enough information that they could read or understand. Over half of the people taking part in this survey had never received easy to read information about keeping healthy and nearly three quarters had never received information about healthcare services.

## Taking Tablets

Nine out of ten people in this study were taking at least one tablet every day. The amount of tablets that people took was overall higher than the rest of people in Ireland. 445 people were taking five or more tablets every day and older people were more likely to be taking more tablets than younger people.



# 3

## People's Daily Life

### People's Lifestyle

People with an ID are likely to smoke or drink alcohol than in the rest of Ireland. as many men smoke women and people aged 50-64 are more likely to smoke than younger people aged 40-49 years. Very few people in this study drank alcohol.



less  
people  
Twice  
than  
who

Overall people said they eat a healthy diet but even so over half the people who answered the question on weight were overweight for their height. Women were more likely to be



overweight than men. Being overweight can lead to health problems and even though people eat a healthy diet they did not exercise as much as they should. Most people tended to exercise less often

and tended to do more gentle exercises especially people with a more severe ID or in the older age groups.



People had difficulty getting out and about, some because of their health some because they found it hard to walk too far

or could not walk at all, but a lot of people needed help to do any kind of exercise.



## Activities of Daily Living

People with an ID need assistance with their daily living activities to help them be the best they can be. In this study we asked a range of questions to see how much difficulty, if any, people had with three different areas of daily living.

1. If they had any difficulty doing some general physical activities.
2. If they had any difficulty doing some daily living skills
3. If they had any difficulty doing harder tasks and social skills.

### 1. Physical Activities

Most people could walk 100 yards without difficulty but people who were older found it harder. Most people could not or found it very hard to run a mile. The other daily physical activity people found the hardest was climbing a lot of stairs without stopping for a rest. Overall people had no problem or very little difficulty picking up a small coin, stooping, sitting for about 2 hours, stretching up their arms or pushing an object out of their way.



## 2. Daily Living Skills

People found bathing and showering the hardest activity of daily living to do on their own. To have a bath or shower 308 people needed some kind of help and 187 were completely dependent on help. Getting dressed which included putting on shoes and socks was the next hardest activity and cleaning your own teeth was another activity people found very hard to do on their own. Getting in and out of bed or walking across their room were the activities that were the easiest.



## 3. Living and Social Skills

Overall people in this study found doing these types of skills the most difficulty. 473 people were completely dependent on others to manage their own money, 462 people were completely dependent on



others to cook a hot meal, 380 were completely dependent on others to do grocery shopping and 338 were completely dependent on



others to make a telephone call.

## Personal Plans

Most people taking part and a key worker who supported them in setting goals and making choice.

People were less likely to have a personal plan and key worker if they were living at home or independently.



## Making Choice

Making decisions hard for people with need support and opportunity to make Overall people in a good level of

support in making their own decisions. Most people had their own choice in the television shows they watched, the food they ate and the clothes they wore.

Where the person lived had an effect on the amount of choice the person had, people living in a residential centre were more likely to have someone



else making the decisions in their lives. The areas where people with an ID had the least amount of choice was where

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else making the decisions in their lives. The areas where people with an ID had the least amount of choice was where



they kept their money, the support they needed, who they lived with, and where they lived.

## Where People went to Work

Only 50 people who answered the questions in this study had a job and nearly half of



them got paid less than the minimum wage. People worked in shops, cafés and doing contract work.

Some people considered their day service or sheltered work



shop as going to work, but a lot of these people said there was less and less work now as there were not many contracts coming in which could be as a direct result of the recession in Ireland.

## What Day Services People Used

Overall 597 people were attending a day service.

The most popular activity was arts and crafts, music,



multisensory therapy and other health therapies like massage. People also did cooking and baking in their day service, skill development such as social living skills and daily living

skills. Personal development was also offered and people did swimming, horticulture and computers in their day service.

There was a wide variety of choice for people attending a day service such as beauty therapy, bowling, drama and dance. But some people said their day service did not offer much for them, one person said “*we just sit around and do nothing*”, this makes it important to offer variety, support and choice for people.



People went to their day service on average four days a week and over a quarter of those going went by bus, and on average it took them 14 minutes. Two thirds of people going to a day service needed support. People needed to be linked because their eyesight was not too good, people needed help getting in and out of the bus because they were not too mobile and other needed to be accompanied to help them stay safe.

The majority of people taking part in this study were not doing any further learning or courses. Just 116 people were doing courses and the types of course they were doing included



personal development, computer skills, reading and writing. People had achieved certificates, diplomas and 2 people had achieved a degree.



When asked if they would like to do courses, 222 people were interested. The most popular courses people would like to do were computer courses or learn how to read and write.

## What Makes you Happy

The people who answered the questions about how they felt had to

be able to do so themselves without help from their support worker. Overall

people were happy with their lives, simple things made

people happy like birds singing, having their own

room or as one person said “

*when everyone is nice to me I'm happy*”. People

enjoyed being with their family and friends a great

deal. Others felt if they had a boyfriend or girlfriend it



would make them very happy. And others felt if they won the lotto it would be great

## What is Growing Old

People found it hard to describe what getting old was like. People described old as being grey haired and wrinkly others felt you might not be as healthy and may need glasses or a hearing aid. Others spoke about death when asked about getting old. Some felt very sad and remembered their parents who may have died and one person said “*some people go into hospital and don't come home*”.



Overall they were positive and felt old people could do everything young people could, such as work or play sport. Most people felt that things got better as they got older, but people did worry about getting older, men more than women. People were worried about getting really sick and not knowing what would happen to them, their family or who would take care of them.



## Retirement

When asked when they would like to retire 62 years was the average age people said they would retire. Most people in the study would prefer to keep working or going to their day service as long as they were healthy and able. But some people had to retire when they got to a certain age and others wanted to but there was nothing else for them to do. This shows us that people with and ID need guiding rules so everyone has an equal opportunity to do what they want to do.

## Conclusion

We have gathered a lot of information about what people thought growing old in Ireland with an ID is like. This report is only the beginning. We hope that the first findings will help all people begin to understand what it is like for people with an ID as they grow older. Over the next few months we will be examining what people said even further and will be writing about what we find in journals. We will be letting everyone know what we found out in this first wave of the study and we will also be making contact with people who took part and letting them know that we are preparing for the next step.

**Together lets work towards making Ireland the  
best place to grow older.**

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