Growing Older with an Intellectual Disability in Ireland 2011

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

An Accessible Report
Growing Older with an Intellectual Disability in Ireland 2011

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People we would like to thank

- I am delighted to publish this report on growing older with an intellectual disability in Ireland.

- This study would not have happened without the help of a number of people.

- I would like to thank everyone with an intellectual disability who took part in the study, their families and their support workers.

I would like to thank the TILDA (The Irish Longitudinal Study on Aging) team for their support.
I would like to thank the people who helped us with the study.

- The scientific committee
- The people in the National Intellectual Disability Database
- The Walkinstown Advocacy Group
- The Clare Inclusive Research Group
- The Showcard review Group from Aras Attracta
- The National Federation of Voluntary Bodies
- Inclusion Ireland
- The Health Research Board
- The Department of Health and Children
- Everyone who was involved in the logo design, photographic exhibition and the DVD project.
- All those people who helped us to create this book.

Yours Sincerely

[Signature]

Professor Mary McCarron
Principal Investigator
Intellectual Disability Supplement to TILDA
Introduction

This study is about people who are growing older with an intellectual disability in Ireland. We felt it was important to understand the health and well-being of people with intellectual disability as they got older.

Aim of the Study

This study will help us learn about people with an intellectual disability who are growing older.

How people were selected for the study

- People who were registered on the National Intellectual Disability Database
- People who were over 40 years old

The questions we asked

We asked questions about

- Home
- Health
- Jobs
- Family and friends
- The future

With this information we can understand what is important to people with intellectual disability as they grow older.
Who took part?

- 753 people took part in this study. They were age 41 years to 90 years.
- Just over half were women. Just under half 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 were people are living.
People’s education

- 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

- 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.
Problems people had getting around their home

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

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

Meeting family

- A lot of people meet their family once or twice a month.

- Others meet their family twice a year or less. A few people never meet their family at all.
• Very few people made telephone calls to their family. Most people never sent a text or email.
• Very few people use the internet.

Meeting friends

• A lot of people never meet up with friends.
• People in a residential centre did not meet up with friends as much as people living at home or in the community.

• More than half of the people did not talk to their friends on the phone
Most people only meet their friends at their day service or work.

Most people’s friends were the people they lived with.

Feeling lonely

Some people answered the questions on loneliness and half of them said they felt lonely at some time.

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

People said that they found it hard to make friends.

506 people said they had someone they could talk to about a private matter.
What people do in their community

- Only a small number of people said they voted in the general election.

- Over half of the people went on holiday in Ireland in the last year. Some 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.

- A neighbour is a friend who will help out if needed. 97 people told us they liked helping out their neighbours and it made them feel good.
Transport

- Most people did not use the public bus or train.
- Most people used their service minibus, a taxi or were driven by their family.
- People had problems using public transport.
- The signs were too hard to read.
- It was too hard to get on and off the bus.
- There were not enough buses. The bus stop or train station was too far away.
Social Activities

• The Special Olympics was the most popular activity. A lot of people were part of advocacy groups.

• A lot of people had hobbies. Arts and crafts were the most popular hobbies.

• Most people watched TV at least once a week.

• Over 600 people liked going for out for a meal or going for coffee
Difficulties doing social activities

• People sometimes found it hard to do their social activities.
• People needed a lot of help.

Difficulties getting around the community

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

• Bumpy footpaths caused the most difficulty 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 said they enjoyed doing voluntary work.

It made them feel good to help people.

They also met people when they did voluntary work.
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 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.

• High Cholesterol and high blood pressure is bad for your health

People had a lot of different medical conditions. This chart shows some medical conditions people had:

<table>
<thead>
<tr>
<th>Medical conditions</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 High cholesterol</td>
<td>237</td>
</tr>
<tr>
<td>2 Epilepsy</td>
<td>229</td>
</tr>
<tr>
<td>3 Constipation</td>
<td>130</td>
</tr>
<tr>
<td>4 High blood pressure</td>
<td>116</td>
</tr>
<tr>
<td>5 Thyroid disease</td>
<td>110</td>
</tr>
<tr>
<td>6 Cataracts</td>
<td>98</td>
</tr>
<tr>
<td>7 Arthritis</td>
<td>81</td>
</tr>
<tr>
<td>8= Osteoporosis</td>
<td>61</td>
</tr>
<tr>
<td>8= Diabetes</td>
<td>61</td>
</tr>
<tr>
<td>10 Gastroesophageal reflux disease (like heartburn)</td>
<td>59</td>
</tr>
</tbody>
</table>
Other health problems

- A lot of people complained of pain.

- Women got their bones checked for osteoporosis and arthritis more than men.

- Men broke their bones more often than women.

- 200 people had a fall in the last year.

- Younger people had a lot of falls.

- A lot of people had problems with hearing and seeing.
• People had regular check-ups.

• People with more severe intellectual disability did not have regular check-ups.

• Eyesight and hearing got worse as people got older.

People’s emotional health

• Nearly half of the people in this study had an emotional problem like depression or anxiety.

• Nearly all of them were getting help from their doctor.

• People who were depressed said they often felt lonely.
The health services people used

People used a lot of different health services.

- 692 people went to their doctor at least once in the last year.

- 475 people went to the dentist. But people who were older did not go as often

- 469 people went to have their feet checked.

- 310 people went to the optician to have their eyes checked.
Using health services

- People in the study did not stay in a general hospital very often.

- Some people had to wait a long time to get appointments.

- A lot of people did not get information about their health that they could read and understand.

Taking tablets

- Most people took at least one tablet every day.
- Older people were likely to take more tablets than younger people.
People’s lifestyle

- Not many people in this study smoked.
- Not many people drank alcohol.
- Overall people said they eat a healthy diet **BUT** half the people were overweight.
• People did not do enough physical exercise like running or dancing.

• Older people did less exercise than younger people.

Activities of daily living

People said they needed help with their day to day activities.

1. Physical Activities

• Most people could walk 100 yards without difficulty.

• Most people could not run a mile.

• Most people found it hard to climb a lot stairs.

• People found it easy to stretch their arms or push an object out of their way.
2. Daily Living Skills

• 495 people needed help having a bath or a shower.

• 312 needed help getting dressed.

• 318 people need help cleaning their teeth.

• Getting in and out of bed and walking across their room were the easiest activities.
3. Living and Social Skills

People said that these skills were the hardest.

- 473 people needed other people to take care of their money.
- 462 people needed others to cook their meals.
- 380 people needed someone else to do their grocery shopping.
- 338 people needed others to make a telephone call for them.
Personal Plans

- Most people had a personal plan.
- They also had a key worker.
- The key worker helped them set goals and make choices.

Making choice

- Making decisions can be very hard for people with an ID. People got a lot of help to make their own choices.
- Most people chose what TV shows they watched.
- Most people chose what food they ate.
• Most people chose what clothes they wore.

• Most people did not choose where they kept their money.

• Most people did not choose where they lived. Most people did not choose who they lived with.

**Where people went to work**

• 50 people in this study had a job.

• 22 people got paid less than the minimum wage.
• People worked in shops and cafés.

• Some people did gardening.

• A lot of people said there was less and less work now as there were not many contracts.

Some people said going to their day service or sheltered work shop was their work.
What day services people used

- 597 people were attending a day service

- The most popular activities were arts and crafts, and music.

- People also did cooking and baking in their day service.

- Some people learned about computers
Some people said there was not much to do in their day service.

One person said “we just sit around and do nothing”.

Most people went to their day service for four days a week.

Most people went to their day service on the bus.

Some people had poor eyesight and some people needed help to get in and out of the bus.
Lifelong learning

• Only 116 people were doing a course.

• Computer skills were the most popular.

• Reading and writing was also popular.

• 222 people would like to do a course in the future.

What makes people happy

• Overall people were happy with their lives.

• Simple things made people happy.

• Family and friends made people happy.
One person said “when everyone is nice to me I’m happy”.

- Others felt if they had a boyfriend or girlfriend it would make them very happy.

- Some people felt if they won the lotto it would be great.

What is growing old?

- Some people felt they were young.

- Others thought they were old.

- People felt getting old was having grey hair and wrinkles.
- Others thought getting old meant you could get sick.
- Some people felt getting old meant you could die.

One person said “some people go into hospital and don’t come home”.

- Most people felt old people could do everything young people could do like go to work.

- Most people felt that things got better as they got older.
Some people did worry about getting older, men worried more than women.

- People were worried about getting really sick.
- People worried about not knowing what would happen to them.
- People worried about their family.
- People worried about who would take care of them.

**Retirement**

- Most people said they would like to retire at 62 years of age.
- A lot of people would like to keep going to their day service as long as they were healthy.
People are worried that they will have nothing to do when they retire.

What will happen next

We are going to give this report to the government to let them know what is important to people.

We will be contacting everyone again soon.
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