Advancing Years Different Challenges Wave 2 IDS – TILDA

Findings on the ageing of people with an intellectual disability

Prof Mary McCarron
First national study to include a representative sample of people with an intellectual disability – Sampling frame NIDD – Random sample.

First time people with an ID are represented in a concurrent longitudinal study on ageing in Europe and to the best of our knowledge, internationally.
Underpinning Conceptual Frame

**PHYSICAL HEALTH**
- Self Reported
- Measures of Physical performance
- Objectives measures of physical health
  - Functional ability

**COGNITIVE**
- Memory
- Executive function
  - Basic skill

**PSYCHOLOGICAL**
- Depression
- Anxiety & Worry
- QoL & Life Satisfaction
  - Life Events
  - Well being

**BEHAVIOURAL**
- Nutrition
- Exercise
- Alcohol
- Smoking
- Sleep

**HEALTHCARE**
- Healthcare Utilisation
- Healthcare Access

**SOCIAL**
- Community Participation
  - Community Connectedness
  - Transitions
Underpinning Values Frame

IDS-TILDA Patrons

Photographic exhibition and logo competition

Accessible information

Accessible dissemination
Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing

753 participants aged 41-90 years

* 45% Male, 55% Female
* 138 services nation-wide

Level of ID

- Profound: 5%
- Severe: 24%
- Mild: 24%
- Moderate: 46%

Geographical Distribution of Participants
Wave 2 commenced 2013

All Wave 1 participants invited

Retention

- The overall response rate to wave 2 was 94% (708/753)

- Keeping in touch strategy

Additional Elements

- Two new data collection elements were added to wave 2:
  1. Health assessment
  2. End of life (EoL) interview.
Grip Strength

Timed Up and Go

Blood Pressure

Waist and Hip Circumference

Height and Weight Measurements

Quantitative Ultrasound (QUS)
End of Life Interview

Voices questionnaire (modified)

IDS-TILDA Wave 1 data

Face to face interview with carer or family member
A CHANGING HEALTH PROFILE
Self rated health from Wave 1 to Wave 2

Wave 1 vs Wave 2

- Excellent/very good
- Good
- Fair/poor
Prevalence of hypertension in IDS-TILDA participants increased between Wave 1 and Wave 2 from 15.9% to 18.1%.

This was 50% lower than rates in the general population of 37% (TILDA).

There was little difference in diagnosed and measured hypertension except among those with severe and profound ID.

IN TILDA, 58% OF MEN AND 49% OF WOMEN WITH OBJECTIVE EVIDENCE OF HYPERTENSION UNDIAGNOSED.
The prevalence of heart attack was 1.6% in IDS-TILDA Wave 2 compared with 5.5% among the TILDA population Wave 2.
Self perception of weight status versus objectively measured

IDS-TILDA Wave 2 MEASURED overweight/obesity: 67%
TILDA Wave 1 MEASURED overweight/obesity: 79%
Point Prevalence of dementia among Down syndrome

Prevalence of dementia among people with Down syndrome

WAVE 1: 15.8%
WAVE 2: 29.9%

The prevalence of epilepsy increased from 19.2% to 27.9% for those with Down syndrome.
Changes in prevalence of chronic conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Wave 1</th>
<th>Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>35.8</td>
<td>35.6</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>15.0</td>
<td>15.6</td>
</tr>
<tr>
<td>Chronic constipation</td>
<td>17.3</td>
<td>37.9</td>
</tr>
<tr>
<td>Gastroesophageal reflux disease</td>
<td>15.0</td>
<td>15.6</td>
</tr>
<tr>
<td>Stomach ulcers</td>
<td>15.0</td>
<td>15.6</td>
</tr>
</tbody>
</table>
Changes in prevalence of chronic conditions

I always need to link someone due to my sight difficulties and severe epilepsy which means I am never on my own.
Bone Health

Eilish Burke
PhD Student
Osteoporosis

Doctors reported diagnosis
Wave 1 – 8.1% to Wave 2 – 16.4%
Three year Incidence – 8.4%

<table>
<thead>
<tr>
<th>Objective measured evidence of poor bone health</th>
<th>QUS tScore</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rt foot Osteopenia</td>
<td>33.5 (n=187)</td>
</tr>
<tr>
<td>Rt foot Osteoporosis</td>
<td>33.2 (n=185)</td>
</tr>
<tr>
<td>Lt foot Osteopenia</td>
<td>33.3 (n=187)</td>
</tr>
<tr>
<td>Lt foot Osteoporosis</td>
<td>35.1 (n=197)</td>
</tr>
</tbody>
</table>

TILDA: Doctors reported diagnosis Wave 2 – 14.3%
Two year incidence – 5.6%
Medications

Anne Belton
PhD Student

Maire O’Dwyer
PhD Student
91% Reported use of medicines (Max. 19 meds)

- Non-polypharmacy: 0-4 medicines
- Polypharmacy: 5-9 medicines
- Excessive polypharmacy: ≥10 medicines

TILDA (Richardson et al., 2012)

<table>
<thead>
<tr>
<th>Medicines</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>5-9</td>
<td>19%</td>
</tr>
<tr>
<td>≥10</td>
<td>2%</td>
</tr>
</tbody>
</table>

0-4 medicines: 48%

5-9 medicines: 31%
Health Care Utilisation
Screening changes between Wave 1 and Wave 2

- Prostate Cancer (Men Only)
- Cholesterol test
- Flu vaccine
- Mammogram (Women Only)
- Check for breast lumps (Women Only)
Difference in ADL and IADL between TILDA and IDS-TILDA
Social Issues – Living Transitions

Mary Ann O’Donovan
PhD Student HRB Scholar
Transitions between Waves

120 people (17% sample)

- 55% female
- 70.4% mild/moderate level of ID
- 70% 64 years or younger
- 60% wanted to move
- 20% viewed alternative options
- High reported happiness post move
## From here to there….

<table>
<thead>
<tr>
<th>PREVIOUS RESIDENCE</th>
<th>WITH FAMILY/ INDEPENDENT</th>
<th>COMMUNITY GROUP HOME</th>
<th>RESIDENTIAL</th>
<th>OTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>With family/ independent</td>
<td>66.7% (n=6)</td>
<td>6.5% (n=4)</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Community group home</td>
<td>22.2% (n=2)</td>
<td>45.2% (n=28)</td>
<td>23.9% (n=11)</td>
<td>66.7% (n=2)</td>
</tr>
<tr>
<td>Residential institution</td>
<td>0.0%</td>
<td>46.8% (n=29)</td>
<td>60.9% (n=28)</td>
<td>0.0%</td>
</tr>
<tr>
<td>Moved within same campus</td>
<td>0.0%</td>
<td>0.0%</td>
<td>8.7% (n=4)</td>
<td>33.3% (n=1)</td>
</tr>
<tr>
<td>Other</td>
<td>11.1% (n=1)</td>
<td>1.6% (n=1)</td>
<td>6.5% (n=3)</td>
<td>0.0%</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>62</td>
<td>46</td>
<td>3</td>
</tr>
</tbody>
</table>
Social Engagement

Darren McCausland
PhD Student
Family networks of older people with ID in Ireland looked very different to that of the general population

- older people with ID are generally
  - single/unmarried
  - without any children or grandchildren.
They were far more reliant on siblings and extended family to provide family networks.

Most family members of older people with ID lived in different neighbourhoods than their relative with ID; this is very different than that reported by TILDA for the general population.

I only go out in the community with my sister or staff.
Contact with family

There was a slight downward trend in rates of regular contact with family and friends between Wave 1 and Wave 2.

For respondents with severe-profound ID the rate was even lower with less than one third having contact with family.
Just over half of respondents (56.6%, n=392) said that they had friends outside their own home.

I would like to go more places if I had someone to come with me

Levels of contacts with friends in community group homes were closer to those in institutional settings than those living in independent/family residences.
Almost two-thirds (64.2%) of participants either experienced difficulty or else did not travel around their community at all.

Community Group Homes had levels of community engagement similar to that of institutions.

These findings raise concerns for the planned movement from congregated settings of often older adults with severe and profound ID and higher levels of ill-health.
Participants spoke of the challenges they faced

“I’m not very steady on my feet and need help walking around the town”

“I was taught to go on the bus by my mother but the bus stop was moved; now my parents have to pick me up”
The vast majority said they were very satisfied (59%) or satisfied (36.4%) with their day service.
“I’m very satisfied there, I enjoy meeting my friends and doing all the activities”

“I love coming in and meeting friends and having a chat, having someone to go for a walk with. Great to have my dinner with my friends. I like doing different things.”

“I am there 11 years this year and I am very happy there”

“If it closed I’d be lonely for it. I like the kitchen work. I have a lot of friends.”

“I have friends there. Its something to do. It gets me out during the day”.
Life Long Learning

Dr. Carolyn Shivers
Total number of difficulties with reading, writing, numbers and/or handling money

- No Difficulty: 8.5
- Difficulty with 1: 5.6
- Difficulty with 2: 6.4
- Difficulty with 3: 13
- Difficulty with 4: 66.3
Use of Technology

- Internet use grew very slightly from 7.3% to 10.5%, however, far below the 77% usage rates among the general population (CSO, 2012).

- Just 12.6% said that they were able to turn on a computer.

- Ownership of mobile phones at 23.8% continues to compare poorly with mobile phone ownership figures nationally.

- Less than one in 20 could send a text message.
Mental Health

Dr. Niamh Mulryan
Reported Diagnosis of Emotional or psychiatric conditions Wave I & Wave 2

- Emotional/Psych cond.: Wave 1 > Wave 2
- Anxiety: Wave 1 = Wave 2
- Depression: Wave 1 > Wave 2
- Manic depression: Wave 1 < Wave 2
Most Common Life Events:

- Change of staff in home or day service (30.2%)
- Change of key worker (20.8%)
- Moving within service organisation (19.1%)

Life Events Most Often Reported as Stressful: Change of staff; major illness or injury; change or routine; moving within the service; death of a parent or sibling; death of a friend; new person moved; change of key worker

Number of life events experienced:
- 1 life event 27.5%
- 2 life events 14.5%
- 3 life events 13.0%
- 4 or more life events 13.1%
- 0 life events 31.8%

Note: n=692 Missing obs = 9
Implications and Emerging Issues
Prevalence of Dementia among people with Down syndrome almost doubled

An associated increase in epilepsy with dementia
Patterns of multimorbidity for people with ID are different from those of people of similar age in general community. This goes beyond earlier onset of dementia.

Marked increase in incidence between Waves of arthritis, cataracts, and osteoporosis.

Need for education for health care professionals to understand and appropriately respond to these differing patterns.
Self-reported hypertension in people with ID at 17.5% was more than 50% lower than TILDA self-report findings of 37%.

In addition there was no significant difference between measured and self report hypertension in people with ID (17.5% versus 18.2%). In TILDA at Wave 1 reported was 37% and measured was 63%.
Summary of Key Messages: Obesity & Overweight

* Lower rates (66%) in people with ID than in general population (79% TILDA sample)

* 66% is still unacceptably high

* Lifestyles of people with ID with poor food choices and little activity suggest this will be both increasing concern and a difficult problem to resolve.
Summary of Key Messages: Medications

- Extremely high level of excessive polypharmacy (21% versus 2% in TILDA)
- Interclass polypharmacy also high
- High use of anticolinergics
- 37% on laxatives with 12% >2 and 5% >3 agents

Considerable concern that this medication use and the resulting high levels of constipation are impairing quality of life
Summary of Key Messages: Osteoporosis and Osteopenia

* Doctor diagnosed osteoporosis doubled from 8.1% in Wave 1 to 16.4% in Wave 2

* More dramatic and of concern is that at Wave 2 there were measured bone concerns of 33.3% with osteopenia and 35.1% with osteoporosis.
Summary of Key Messages: Transitions and Daily Lives

- 17% had moved by Wave 2; many moves did not appear to result in changed type of locations but most reported being happier as a result.

- There appears to be some decline in contact with family and with friends outside the home.

- There were no increase in employment

- The finding of low literacy and numeracy skills requires a different response from services if older adults with ID are to be successfully supported in living more independent lives
Ensuring Data from IDS-TILDA Supports Positive Ageing

IDS-TILDA

Evidence based research on ageing of persons with intellectual disability in Ireland

National & International comparative analyses with general and other disability population groups

Policy implications for health and social services

Ensuring Data from IDS-TILDA Supports Positive Ageing
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)

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2Center for Excellence in Aging and Community Wellness, University at Albany, Albany, NY 12222, USA

Epidemiology of Epilepsy in Older Adults With an Intellectual Disability in Ireland: Associations and Service Implications

Mary McCarron, Marie O’Dwyer, Eilish Burke, Eimear McGlinchey, and Philip McCallion

The influence of environment, predisposing, enabling and need variables on personal health choices of adults with intellectual disability

Philip McCallion1, Eilish Burke2, Janet Swinburne2, Eimear McGlinchey2, Rachael Carroll3, Mary McCarron2

Mental health

A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome

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Research Article

Expanding Assessment of Fear of Falling among Older Adults with an Intellectual Disability: A Pilot Study to Assess the Value of Proxy Responses

Sinéad Foran1, Mary McCarron2, and Philip McCallion3

What It’s Like to Grow Older: The Aging Perceptions of People With an Intellectual Disability in Ireland

Eilish Burke, Mary McCarron, Rachael Carroll, Eimear McGlinchey, and Philip McCallion
INNOVATION IN DISSEMINATION

SCENES FROM OUR LIVES
DVD

ACCESSIBLE WEBSITE
IDS-TILDA Team and PhD students

Co-PI, Prof. Philip McCallion
Dr. Rachael Carroll, Statistician
Sinead Foran
Eimear McGlinchey
Janet O’Farrell
Marianne Griffiths
Andrew Wormwald
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* The **IDS-TILDA Research Team** and **Field Researchers**

* The **International Scientific Advisory Committee**

* The **service providers** involved in the study

* **People with an intellectual disability, their carers and families,** who are participating in the study

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thank you