

Advancing Years Different Challenges Wave 2 IDS – TILDA

Findings on the ageing of people with an intellectual disability

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THE
UNIVERSITY
OF DUBLIN



An Intellectual Disability Supplement to
the Irish Longitudinal Study on Ageing

IDS-TILDA: KEY MILESTONES



TILDA Sampling-
Geodirectory

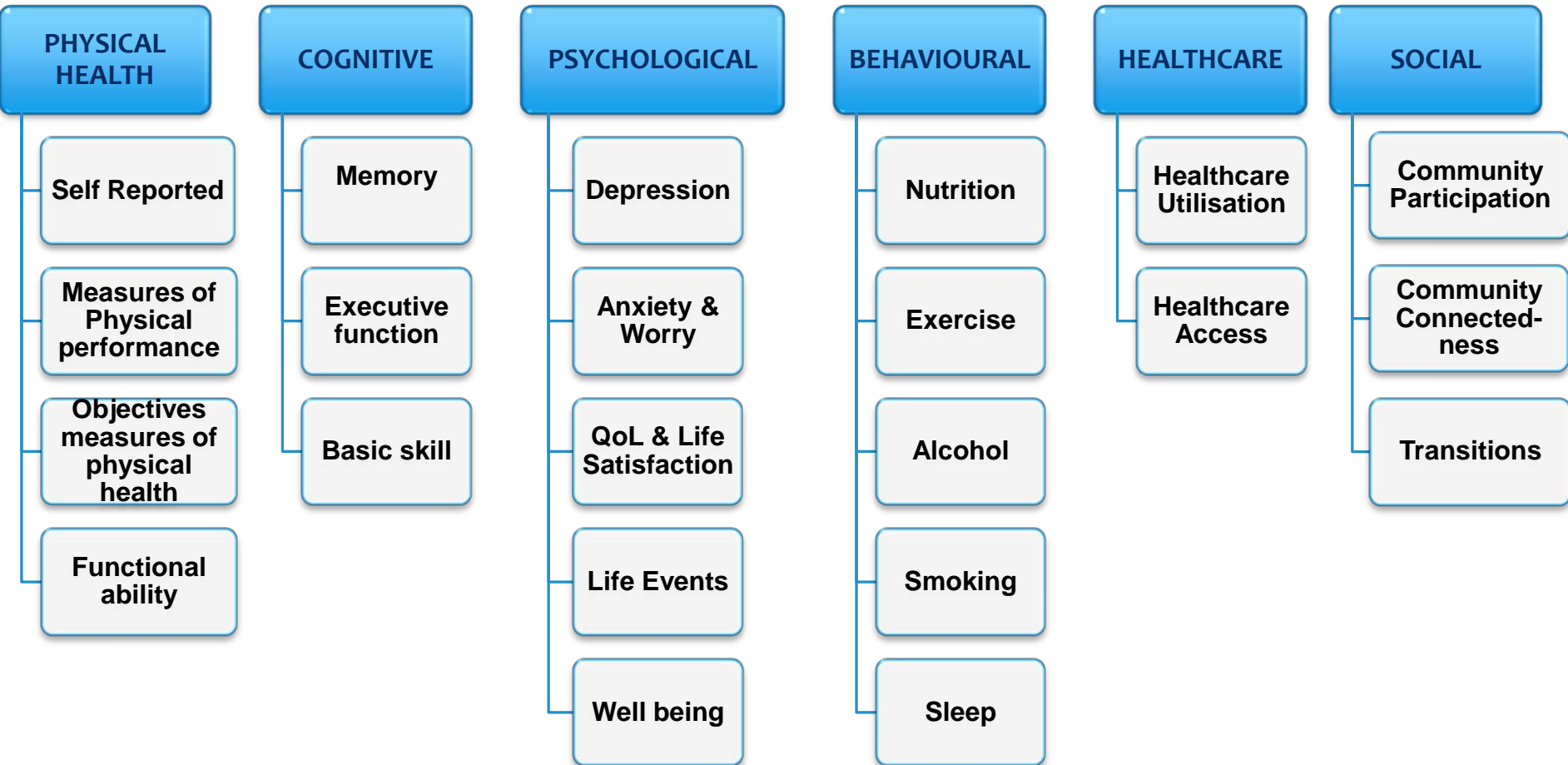


Important Opportunity

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



Underpinning Values Frame



IDS-TILDA Patrons



Photographic exhibition and logo competition



Consent form

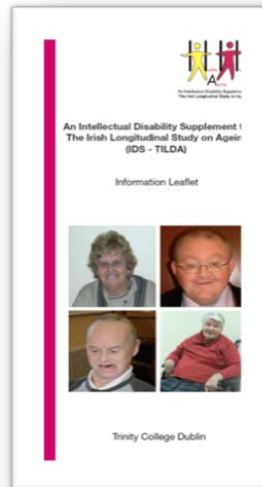
Please read this consent form.
If you wish to take part in this study please sign this consent form.

I agree with the following statements:

	I have gone through the information about this study.	<input checked="" type="checkbox"/>
	I know who to contact if I have any questions.	<input type="checkbox"/>
	My questions were all answered.	<input type="checkbox"/>
	I know that it is my choice to take part in this study.	<input type="checkbox"/>
	I understand this is a ten year study. I will be visited three times by a researcher from Trinity College Dublin.	<input type="checkbox"/>

Trinity College Dublin

Accessible information



Accessible dissemination

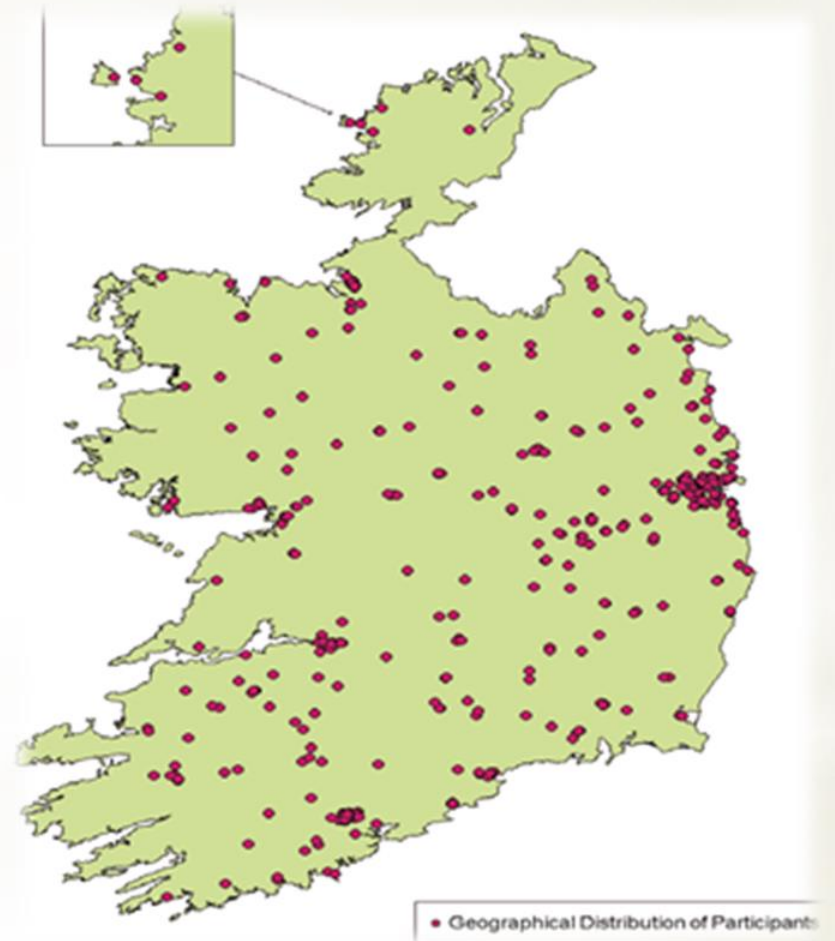
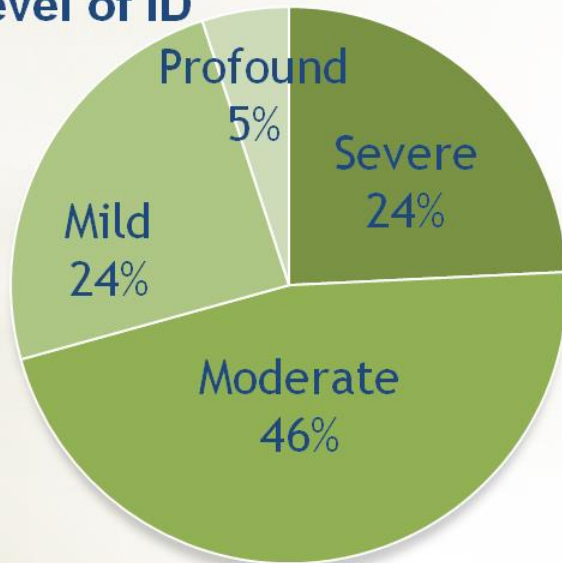
Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing

753 participants aged 41-90 years

* 45% Male, 55% Female

* 138 services nation-wide

Level of ID



WAVE 2

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.

The Health Fair - Suite of Non-invasive Objective Measures

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

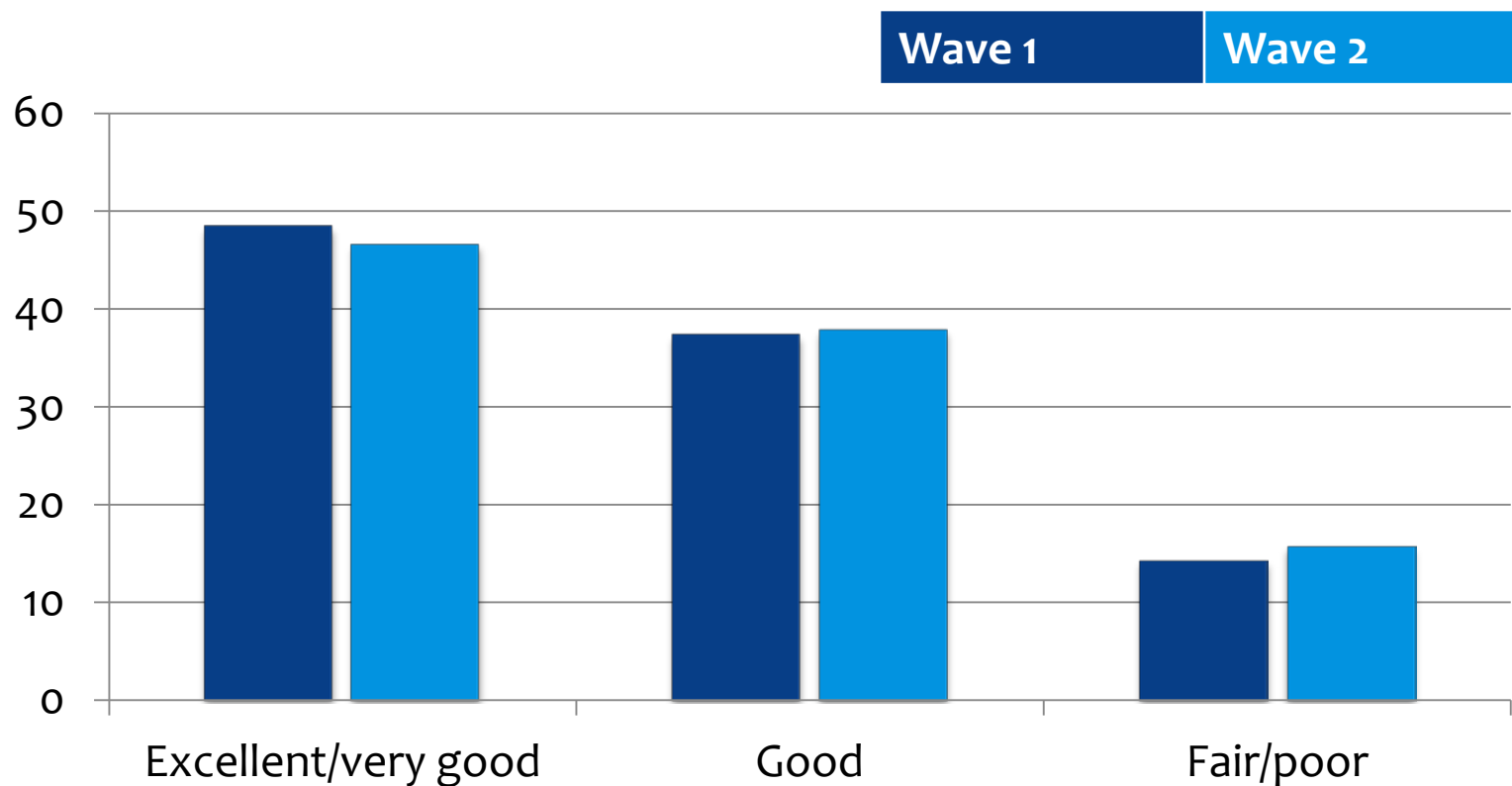


Face to face interview with carer or family member

A CHANGING HEALTH PROFILE



Self rated health from Wave 1 to Wave 2



Hypertension

- * 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.

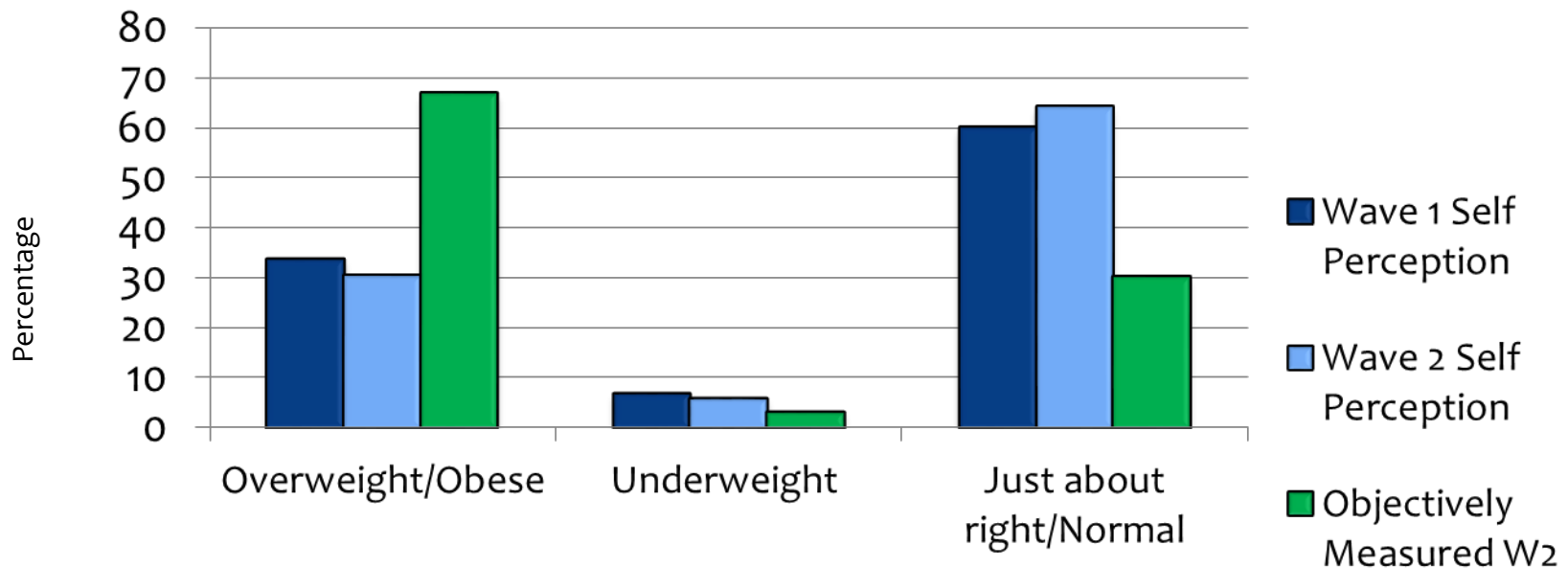
IN TILDA, 58% OF MEN AND 49% OF WOMEN WITH OBJECTIVE EVIDENCE OF HYPERTENSION UNDIAGNOSED.

Heart Attack

- * 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

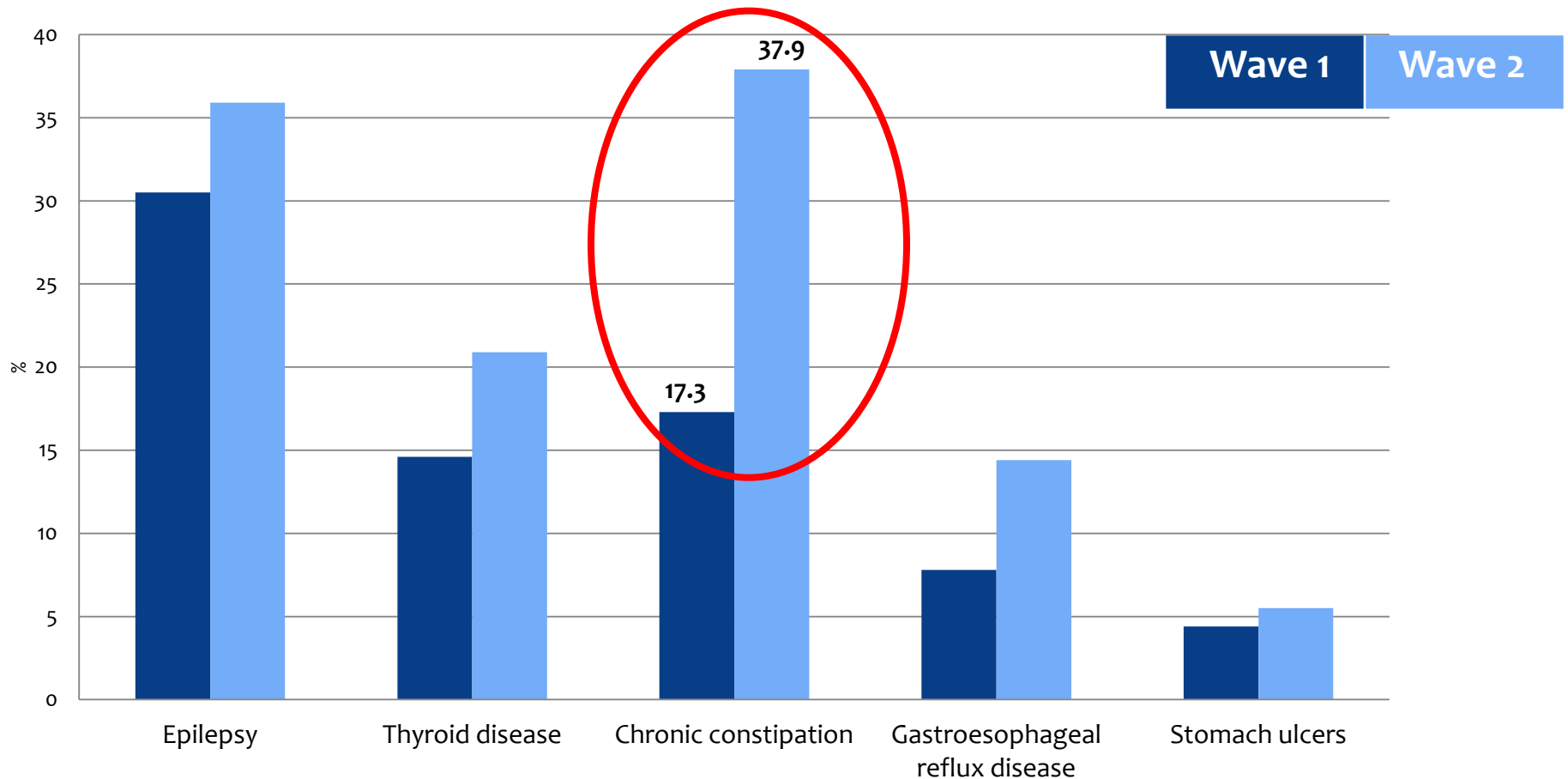
Prevalence of dementia among people with Down syndrome

WAVE 1: 15.8%

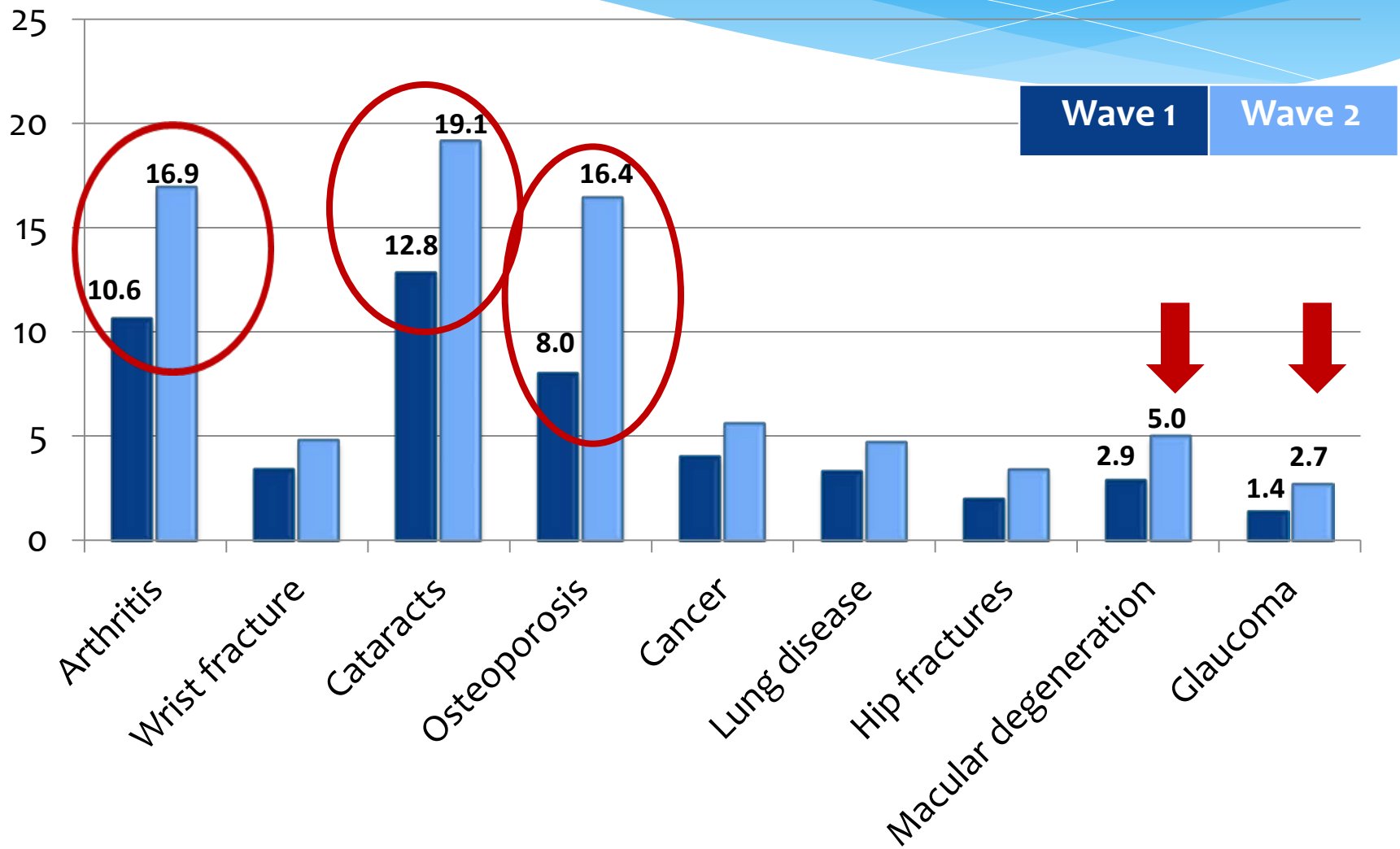
WAVE 2: 29.9%

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

Changes in prevalence of chronic conditions



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 Wave2 – 16.4%
Three year Incidence – 8.4%

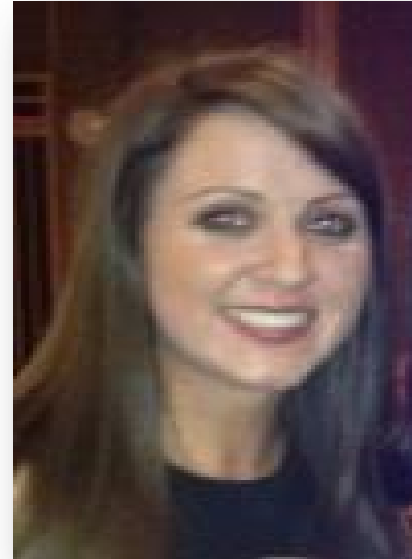
Objective measured evidence of poor bone health	QUS tScore %
Rt foot Osteopenia	33.5 (n=187)
Rt foot Osteoporosis	33.2 (n=185)
Lt foot Osteopenia	33.3 (n=187)
Lt foot Osteoporosis	35.1 (n=197)

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

Medications



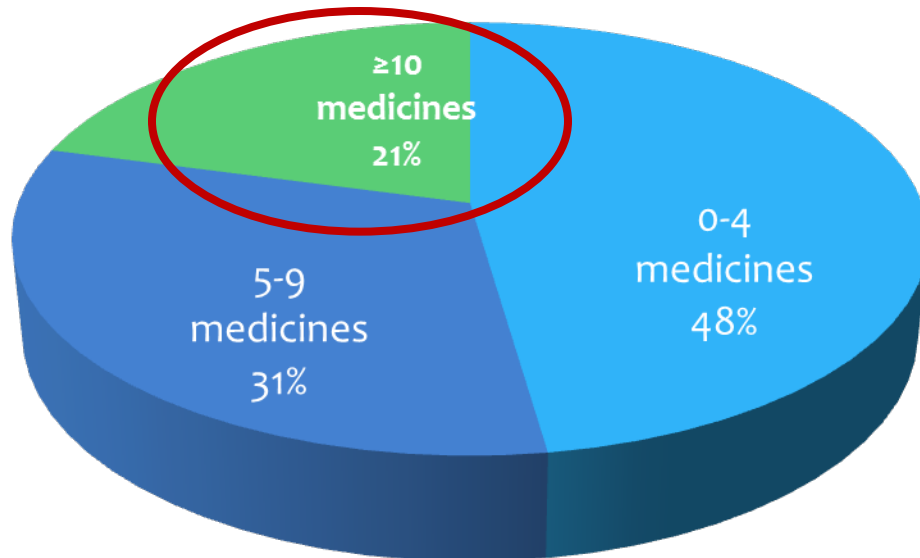
Anne Belton
PhD Student



Maire O'Dwyer
PhD Student

Polypharmacy compared to general population Wave 1

- * 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)

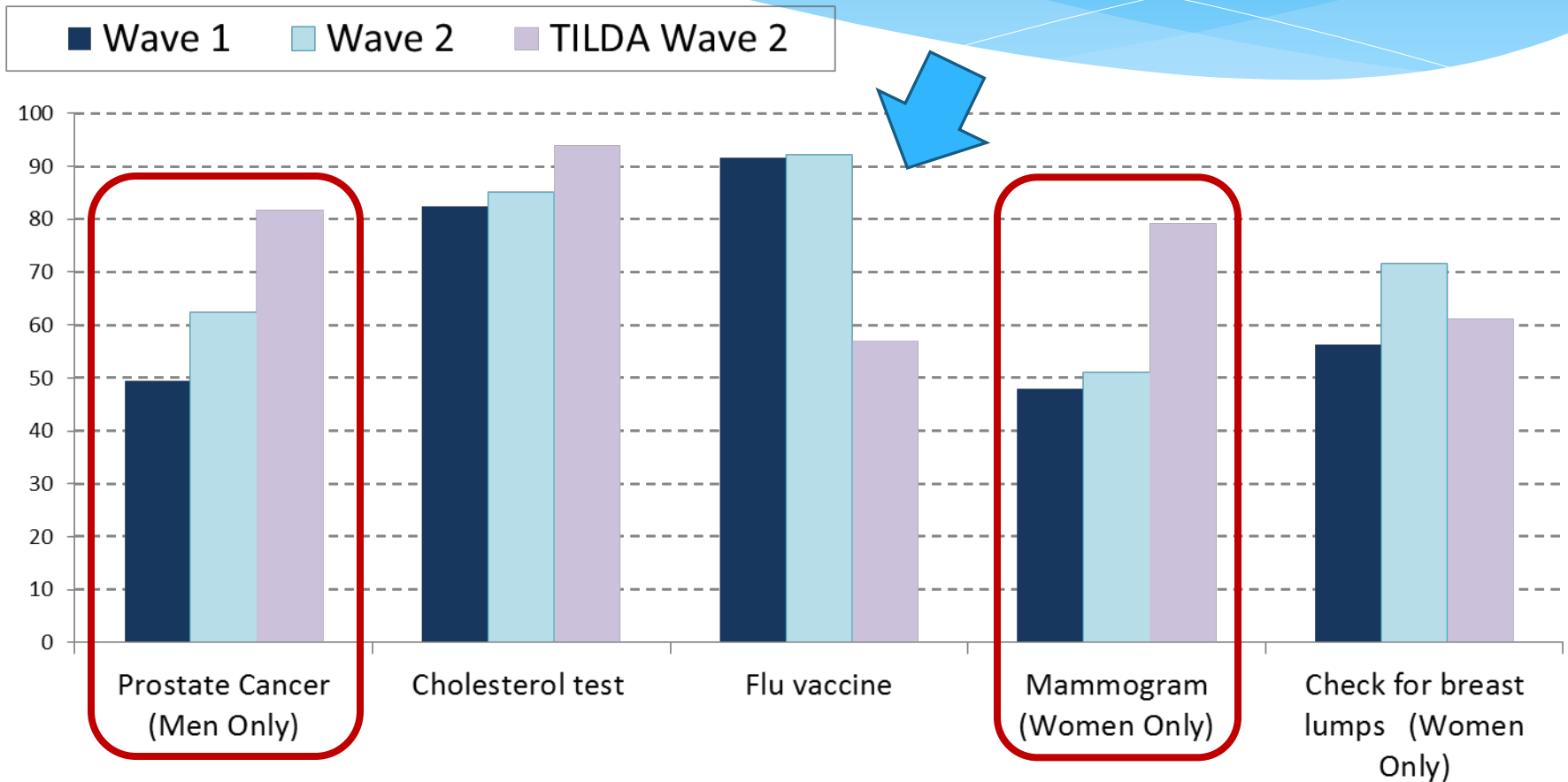
5-9 medicines 19%

≥10 medicines 2%

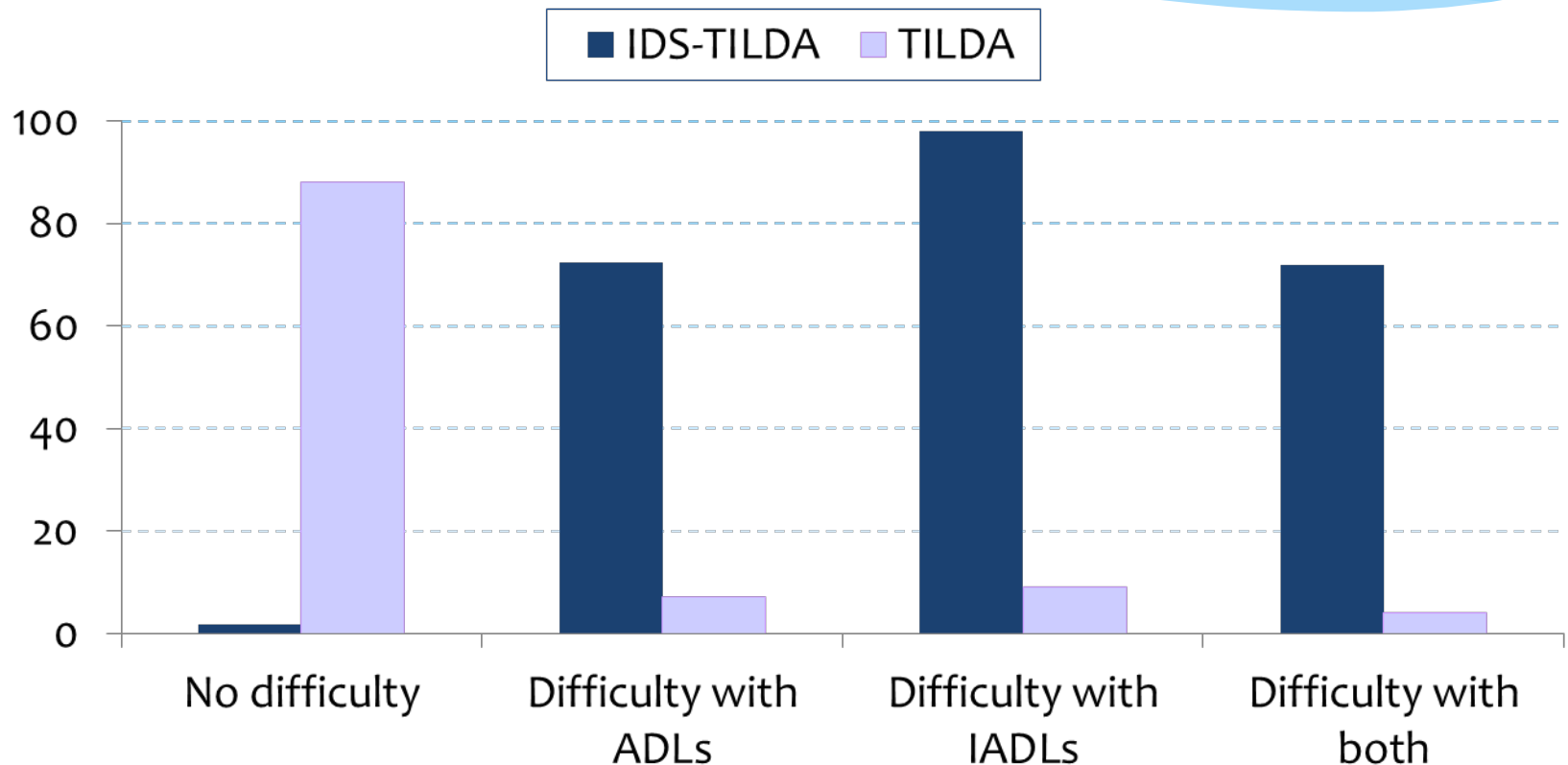
Health Care Utilisation



Screening changes between Wave 1 and Wave 2



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....

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

Social Engagement

Darren McCausland

PhD Student



Family Networks

- * 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.

Family Networks

- * They were far more reliant on siblings and extended family to provide family networks

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

- * 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

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.

Contact with friends

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.

Engagement in the Community

- 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.

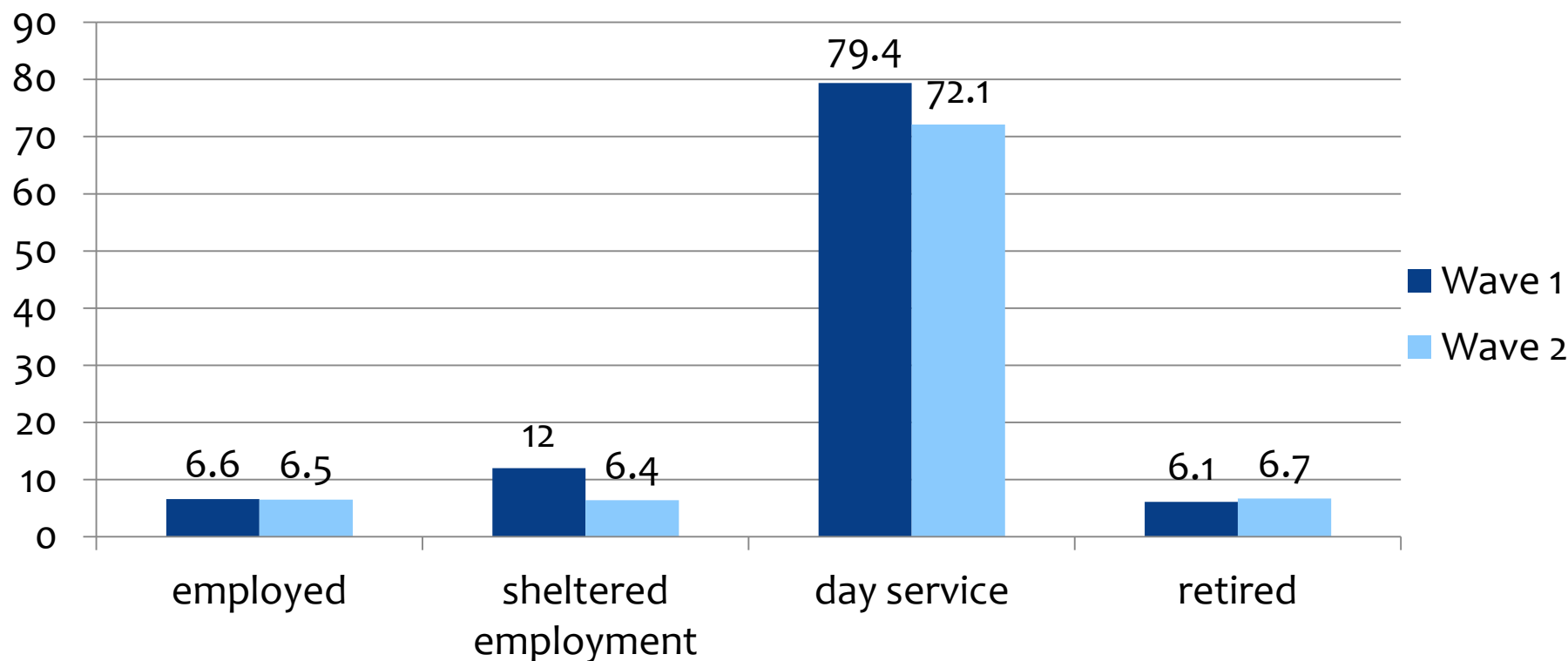


Participants spoke of the challenges they faced

“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”

Changes in Employment and Day Service Status - Wave 1 to Wave 2



The vast majority said they were very satisfied (59%) or satisfied (36.4%) with their day service.

What People said in wave 2 about their Day Service

“I’m very satisfied there, I enjoy meeting my friends and doing all the activities”

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

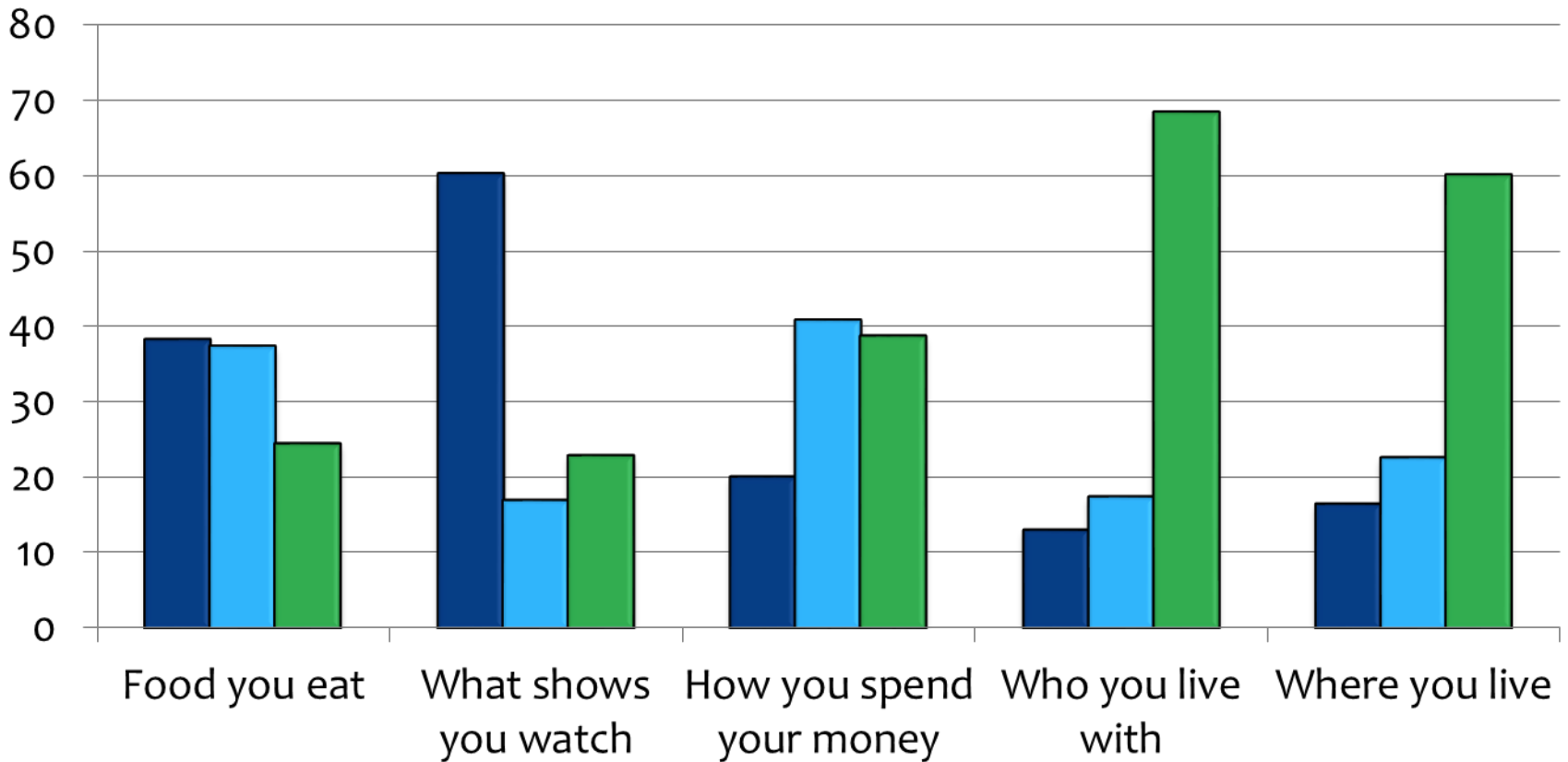
“If it closed I'd be lonely for it. I like the kitchen work. I have a lot of friends.”

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

Personal Choice

■ Wave2 Self ■ Wave2 Supported ■ Wave 2 Someone Else

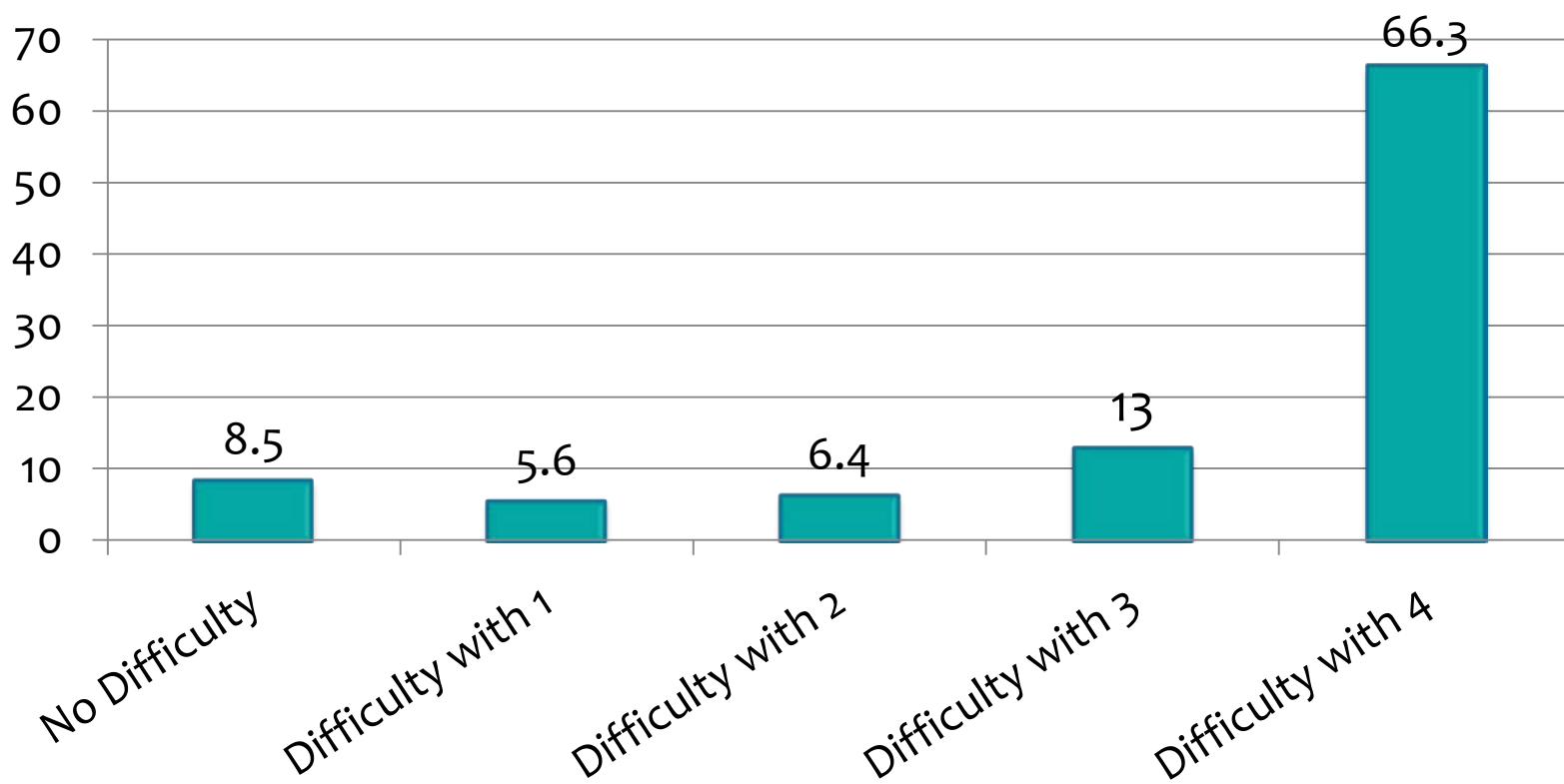


Life Long Learning

Dr. Carolyn Shivers



Total number of difficulties with reading, writing, numbers and/or handling money



Use of Technology

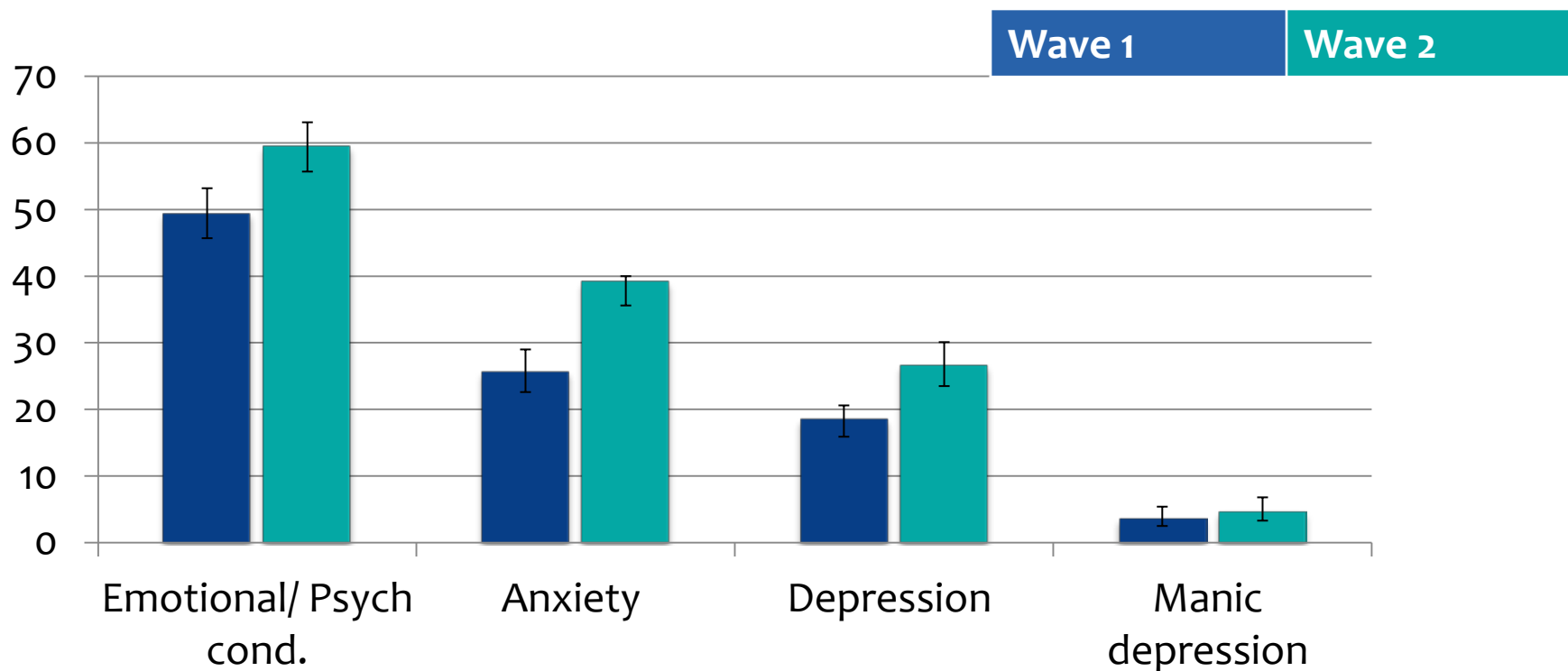
- Internet use grew very slightly from 7.3% to 10.5%, however, far below the 77% usage rates among the general population (CSO, 2012).
- Just 12.6% said that they were able to turn on a computer.
- Ownership of mobile phones at 23.8% continues to compare poorly with mobile phone ownership figures nationally.
- Less than **one in 20** could send a text message.

Mental Health

Dr. Niamh Mulryan

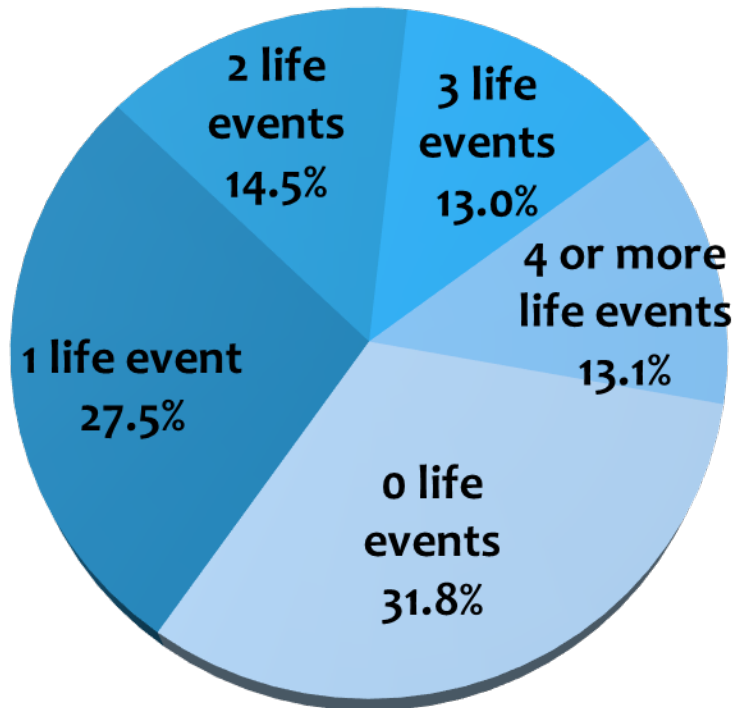


Reported Diagnosis of Emotional or psychiatric conditions Wave 1 & Wave 2



Life Events

Number of life events experienced



Note: n=692 Missing obs = 9

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

Implications and Emerging Issues

Summary of Key Findings: Dementia & Down syndrome

- * Prevalence of Dementia among people with Down syndrome almost doubled**
- * An associated increase in epilepsy with dementia**

Summary of Key Findings: Multimorbidity

- * 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

Summary of Key Messages: Cardiovascular

- * 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 anticolingerics
- * 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

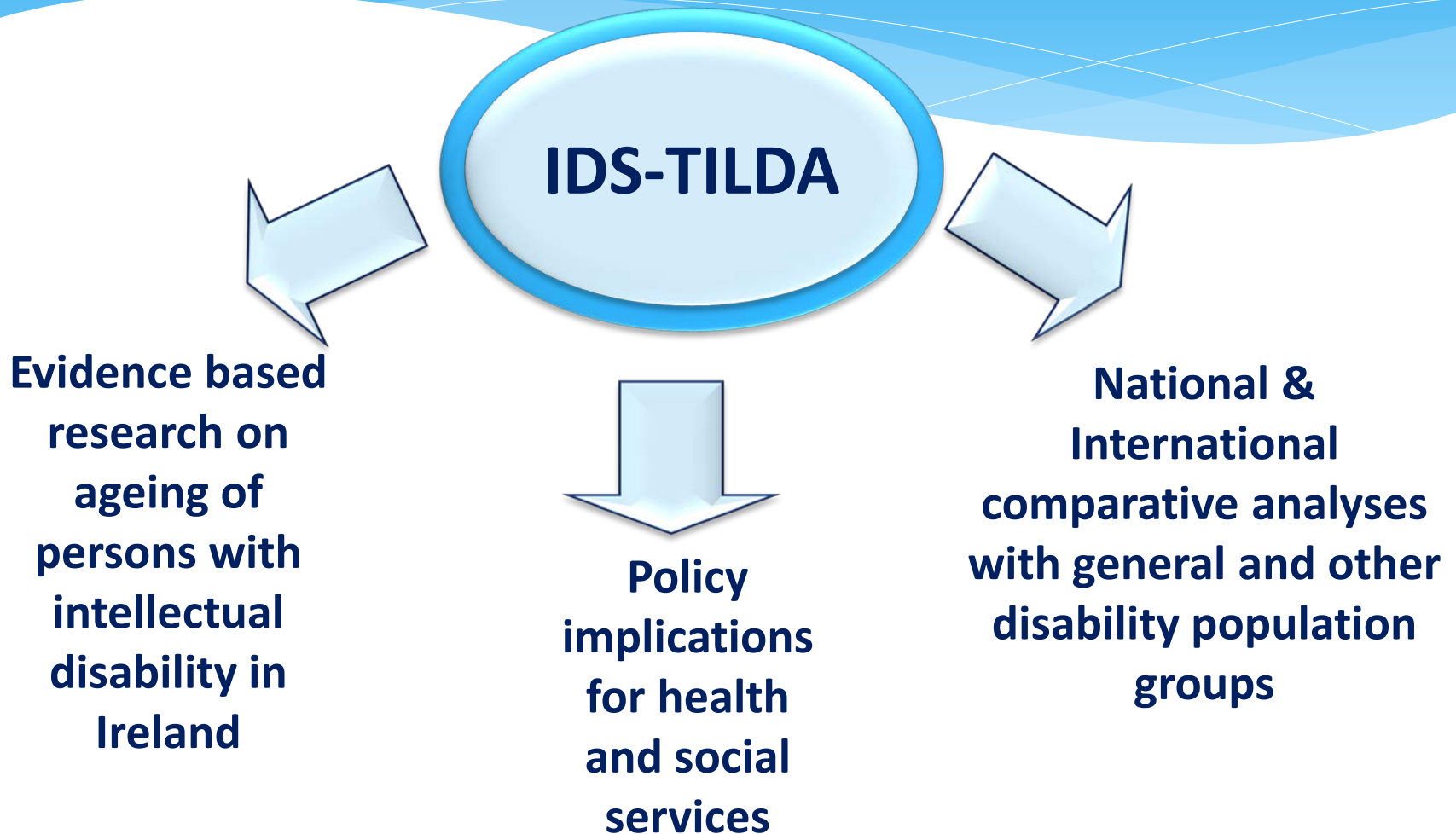
Summary of Key Messages: Osteoporosis and Osteopenia

- * 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





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)

Mary McCarron^a, Janet Swinburne^a, Eilish Burke^a, Eimear McGlinchey^a, Rachael Carroll^a, Philip McCallion^{b,c}

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^bCenter for Excellence in Aging and Community Medicine, University at Albany, Albany, NY 12222, USA

Exploring the Issue of Employment for Adults with an Intellectual Disability in Ireland

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

School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland

Accepted for publication 4 March 2013

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

Vol.5, No.4, 749-756 (2013)
doi:10.4236/health.2013.54099

Health

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 Carroll², Mary McCarron²

Mental health

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

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ATTENDANCE OF OLDER ADULTS WITH ID ARTICLE

ABSTRACT

Purpose: To investigate dental attendance patterns and reasons for nonattendance among older adults with intellectual disabilities (ID) in Ireland.
Methods: A cross-sectional survey of quantitative data and text analysis of qualitative data drawn from a nationally representative sample of 753 people with ID over 40 years of age in Ireland. Participants were considered as regular or irregular dental attenders for analysis of quantitative data. Text analysis grouped open-ended responses for analysis.
Results: There were slightly more females.

Dental attendance among older adults with intellectual disabilities in Ireland

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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

Sinead Foran,¹ Mary McCarron,² and Philip McCallion³

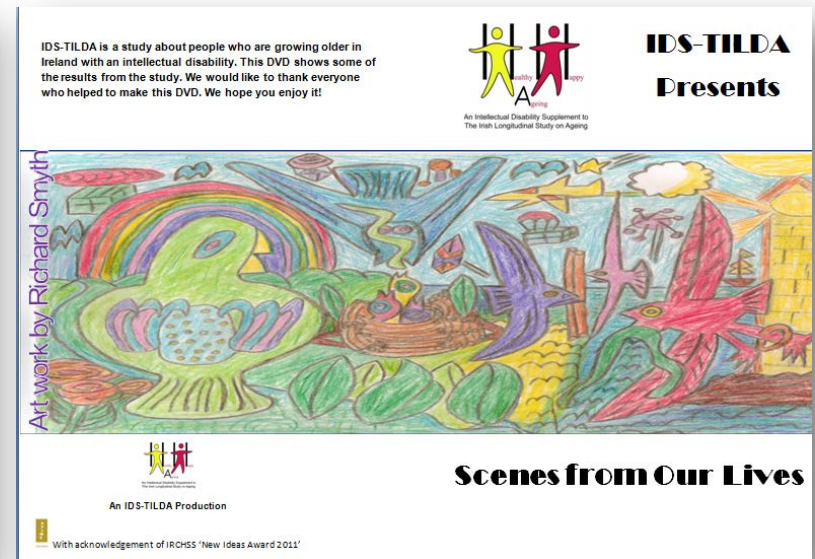
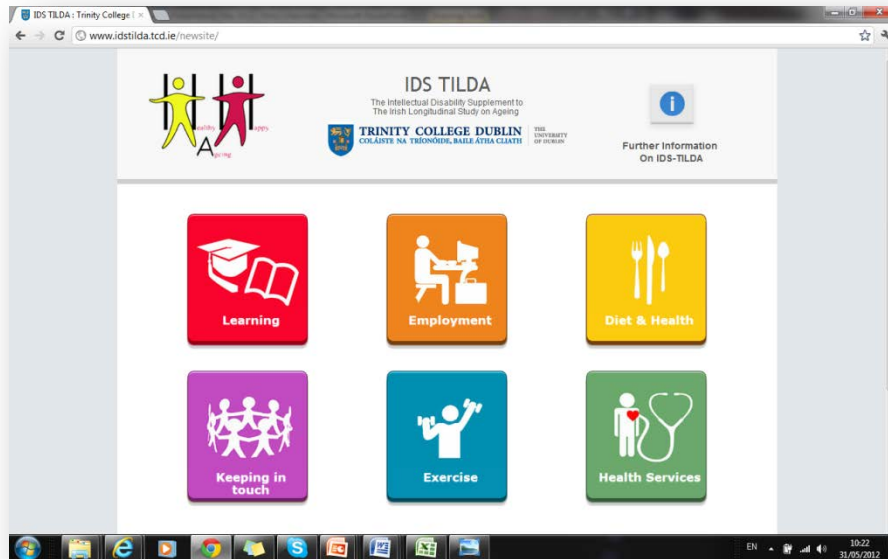
What It's Like to Grow Older: The Aging Perceptions of People With an Intellectual Disability in Ireland

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

INNOVATION IN DISSEMINATION

SCENES FROM OUR LIVES DVD

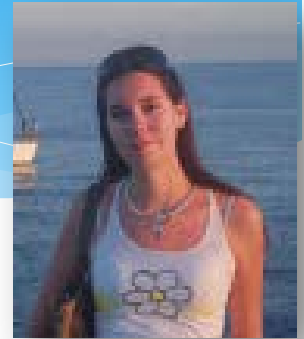
ACCESSIBLE WEBSITE



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 International Scientific Advisory Committee
- * The **service providers** involved in the study
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thank you



www.idstilda.tcd.ie