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Ageing with an Intellectual Disability in Ireland

Prof Mary McCarron

Dean Faculty of Health Sciences Trinity College Dublin
Professor of Ageing and Intellectual Disability
PI of IDS-TILDA

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Celebration & challenge of ageing

- A success story
- Little known ageing
- Promoting life long health
- Maintaining independence
- Postponing disability
- Reorienting ID services
- Mainstreaming agenda
- Integrating health and social services

Mortality rates in the General Irish population compared to those with ID from 2003 – 2012

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HRB
Health Research Board

Summary of mortality findings

Mortality almost four times higher in ID population than in general population (SMR = 385; 95% CI = 370,400) and rates varied with age.

In

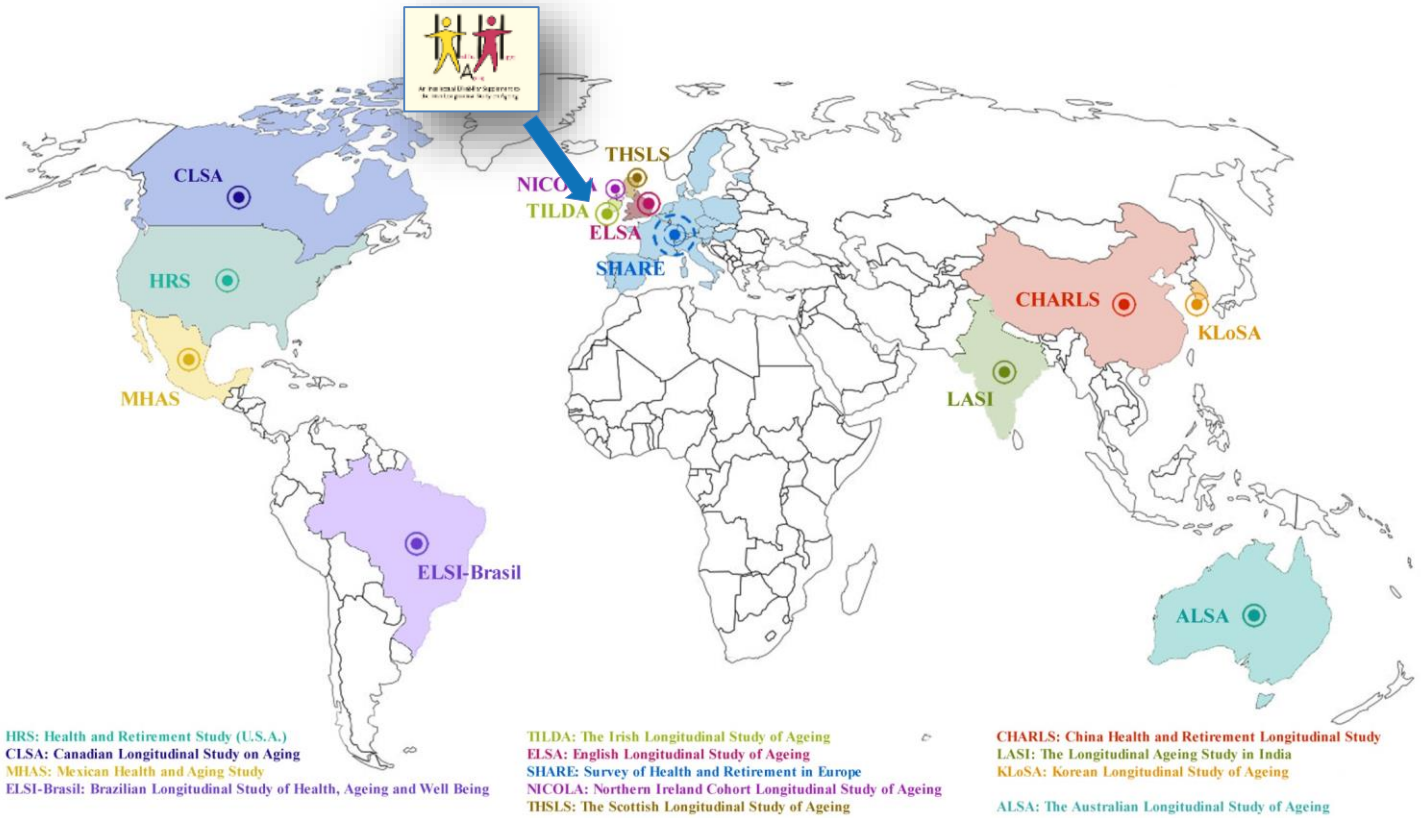
Mortality higher in women across age groups

Average age of death 19.07 years earlier than for the general population

54.73 years compared with 73.80 years

The Irish Longitudinal Study on Ageing

The global family of longitudinal studies



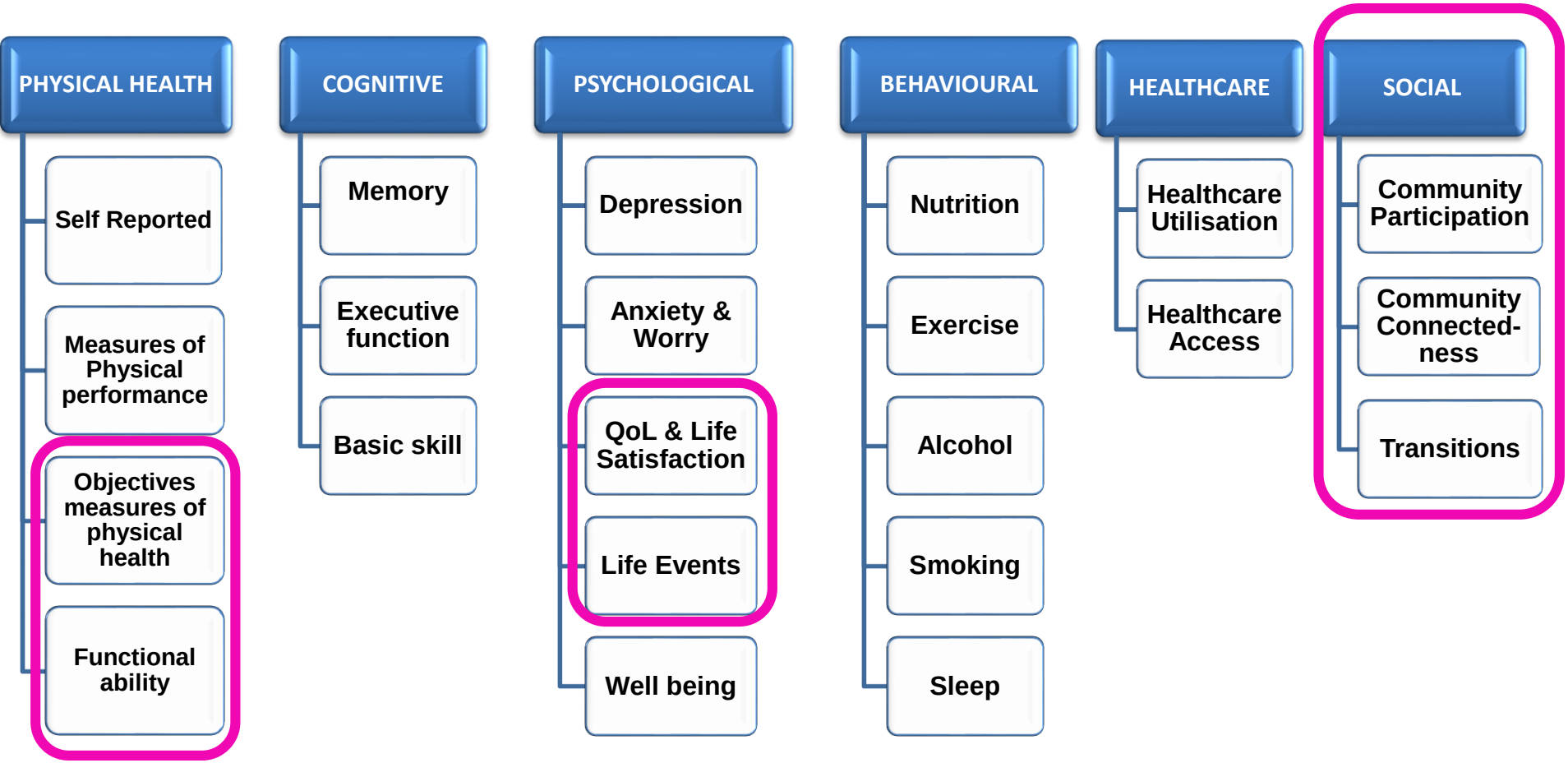
The Intellectual Disability Supplement to The Irish Longitudinal Supplement on Ageing

- Identifying the principal influences on ageing
- Understanding the contributors to successful ageing, health & quality of life in older persons with ID
- Building on the baseline to contribute to changes in policy and practice

"truly included people with intellectual disability in an evidence based academic process speaking for themselves which is hugely important"

(Minister K Lynch TD)

Refined and developed the conceptual framework IDS-TILDA

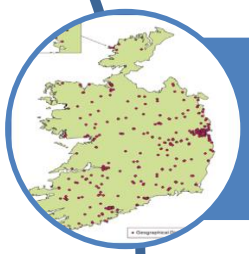


Celebrating ageing, increasing visibility of people with ID and promoting inclusion

IDS-TILDA VALUES FRAMEWORK UNDERPINNING ALL ASPECTS OF THE RESEARCH LIFECYCLE

IDS-TILDA participation

10% randomly selected from NIDD ≥40 years



Wave 1: 2011 8.9% (N=753); 55% Female 45% Male; 138 Services; All levels of ID

Wave 2: 2014 94% retention (N=708/753)

Wave 3: 2017 86% retention (N=609/708)

Undertaking the study

- **Questionnaires -** Pre-Interview Questionnaire, Face-to-Face Interviews using CAPI and Carers Questionnaire
- **Interview style** – Independent, supported or proxy

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Older adults with an intellectual disability – their understanding of the concept of ageing?

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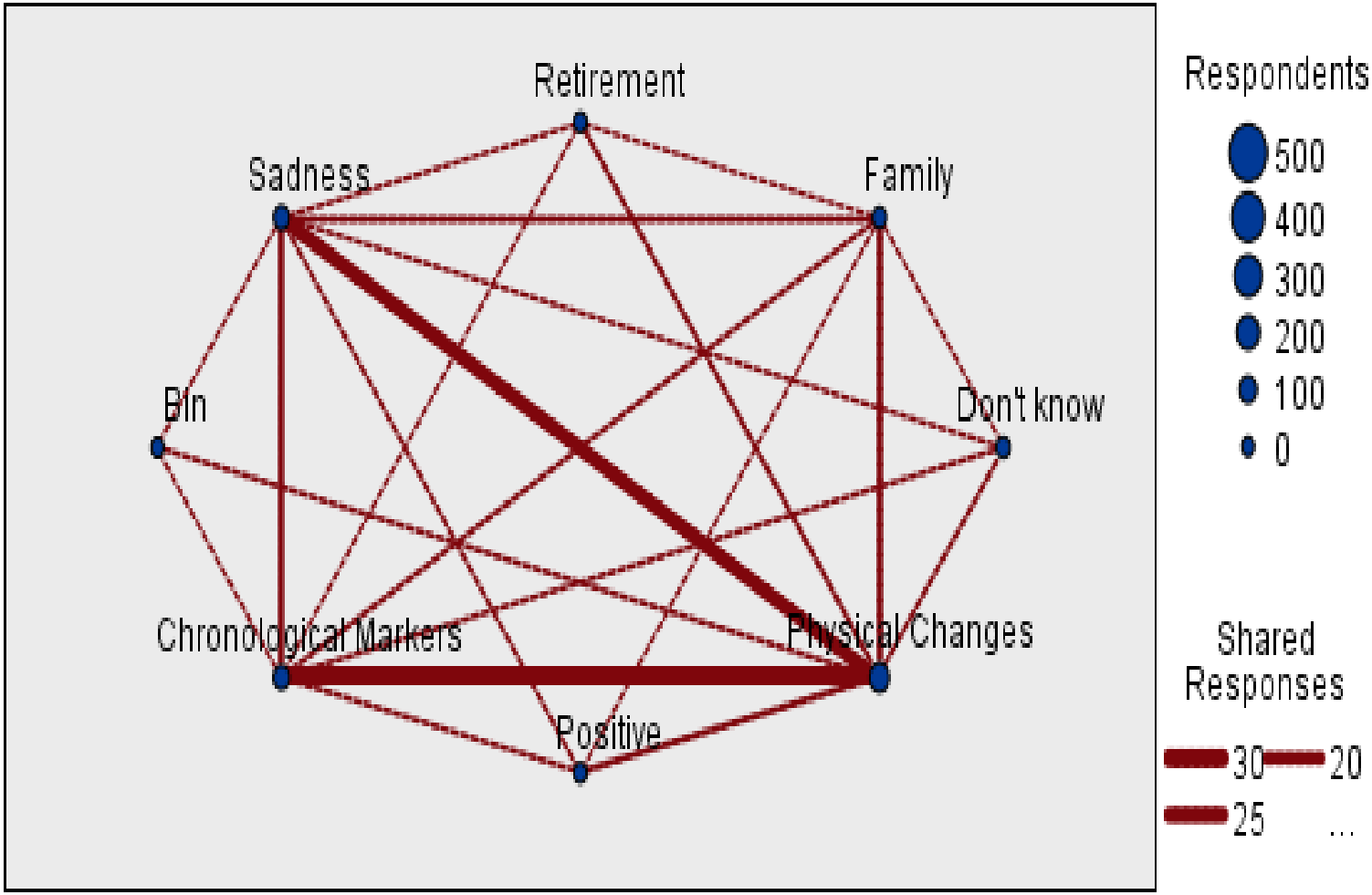
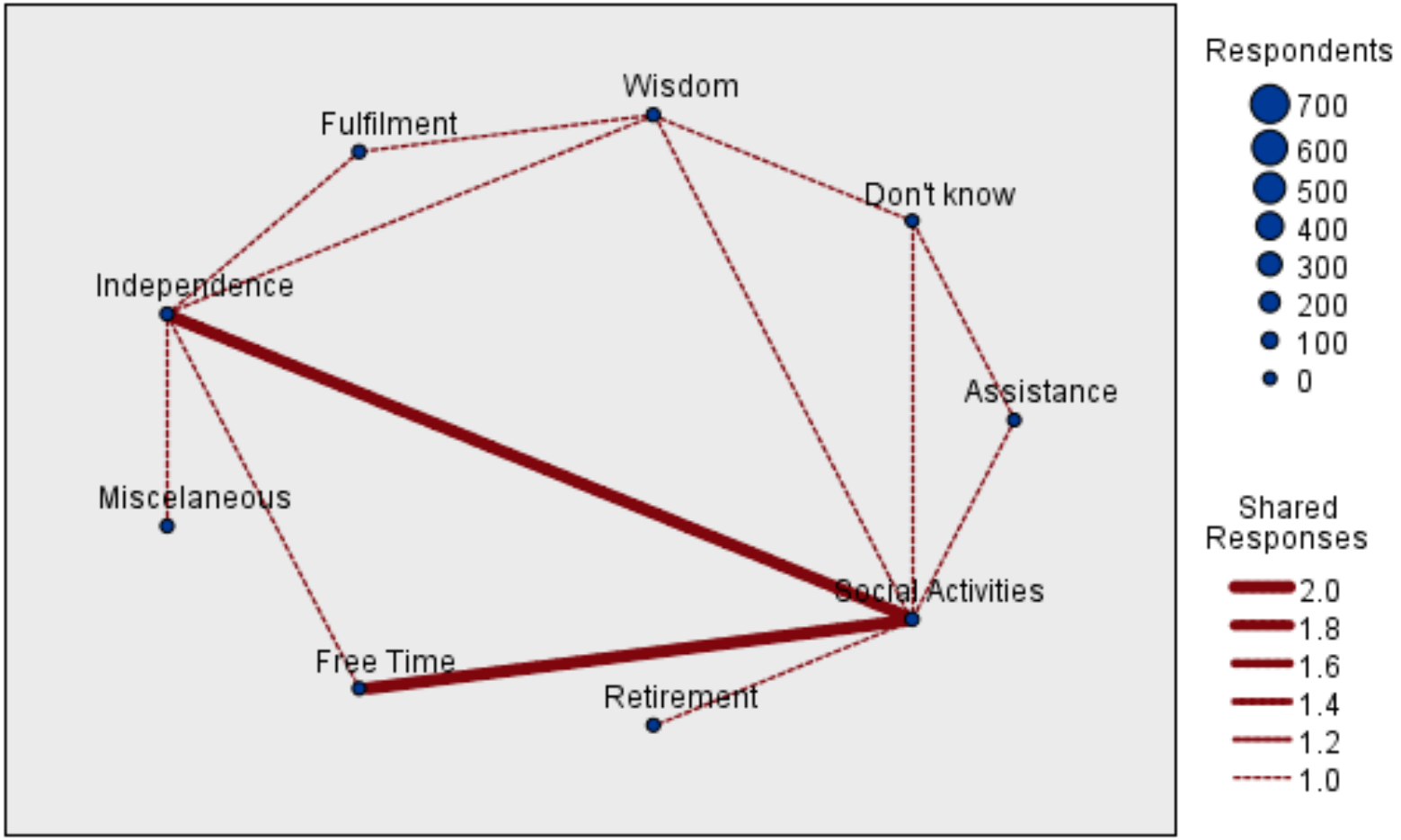
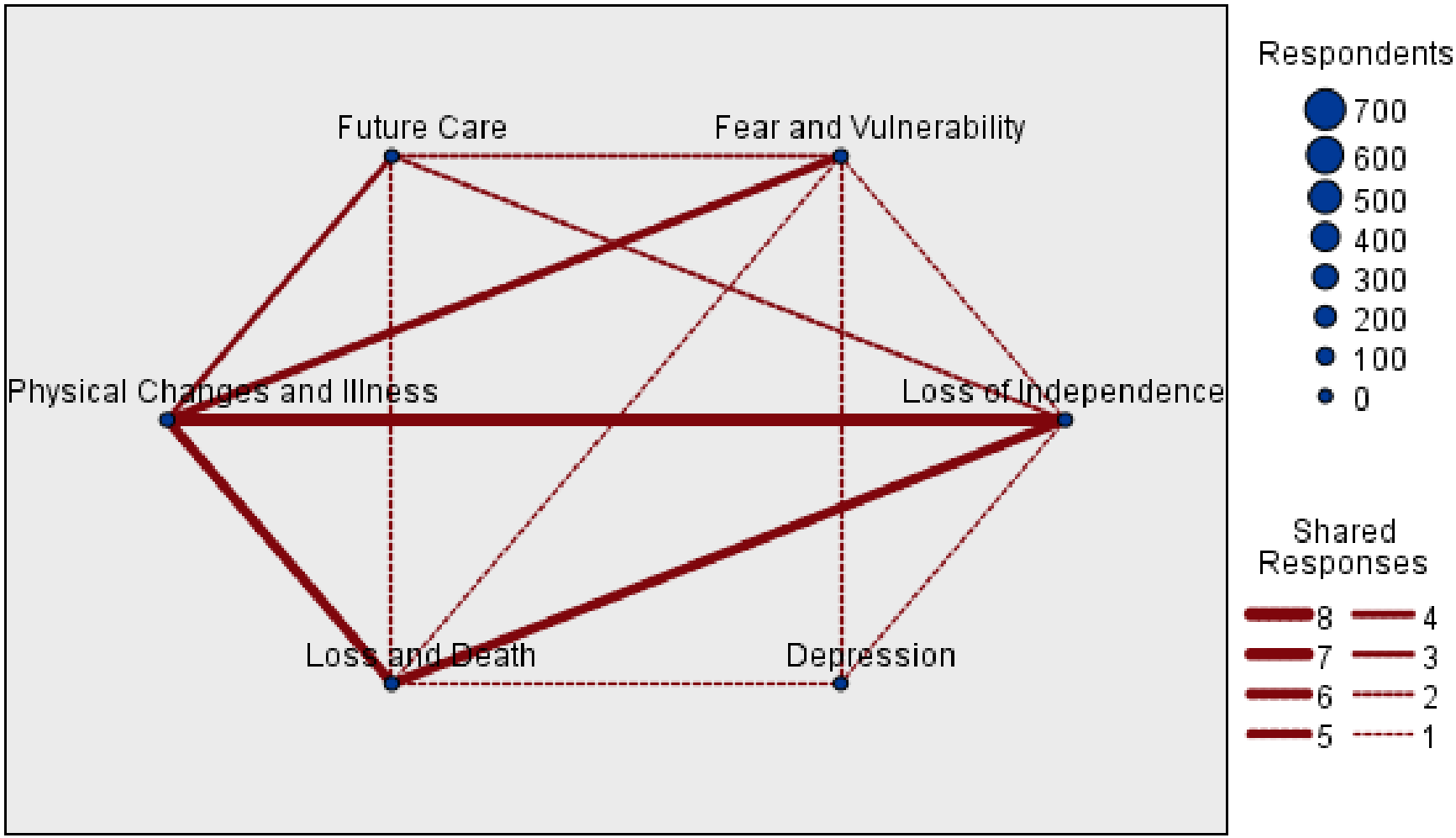
Getting old


Retirement
Sadness
Family
Bin
Don't know
Chronological Markers
Physical Changes
Positive
Respondents
500
400
300
200
100
0
Shared Responses
30
20
25
...

Good things about getting old



Concerns about growing old



“ I think old people are wise and have more experience and can do some of the activities that all other people can do of course in my case running is out cause I get too tired, I prefer to walk at a nice pace”

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Chronic conditions and complex needs

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Multi-morbidity

	IDS-TILDA W1	TILDA W1
Multimorbidity Prevalence	• 71.2%	• 58.6%
Age	• 63% aged 40 – 49 years	• Older age cohort
Gender	• Females twice as likely to be multi-morbid than males	• Equal gender distribution
Pairs of Chronic Conditions	• Eye Diseases • Mental Health Concerns • Joint Disease • Neurological Disease • Gastrointestinal	• Hypertension • Heart Disease • Stroke • Diabetes

Research in Developmental Disabilities 34 (2013) 521–527

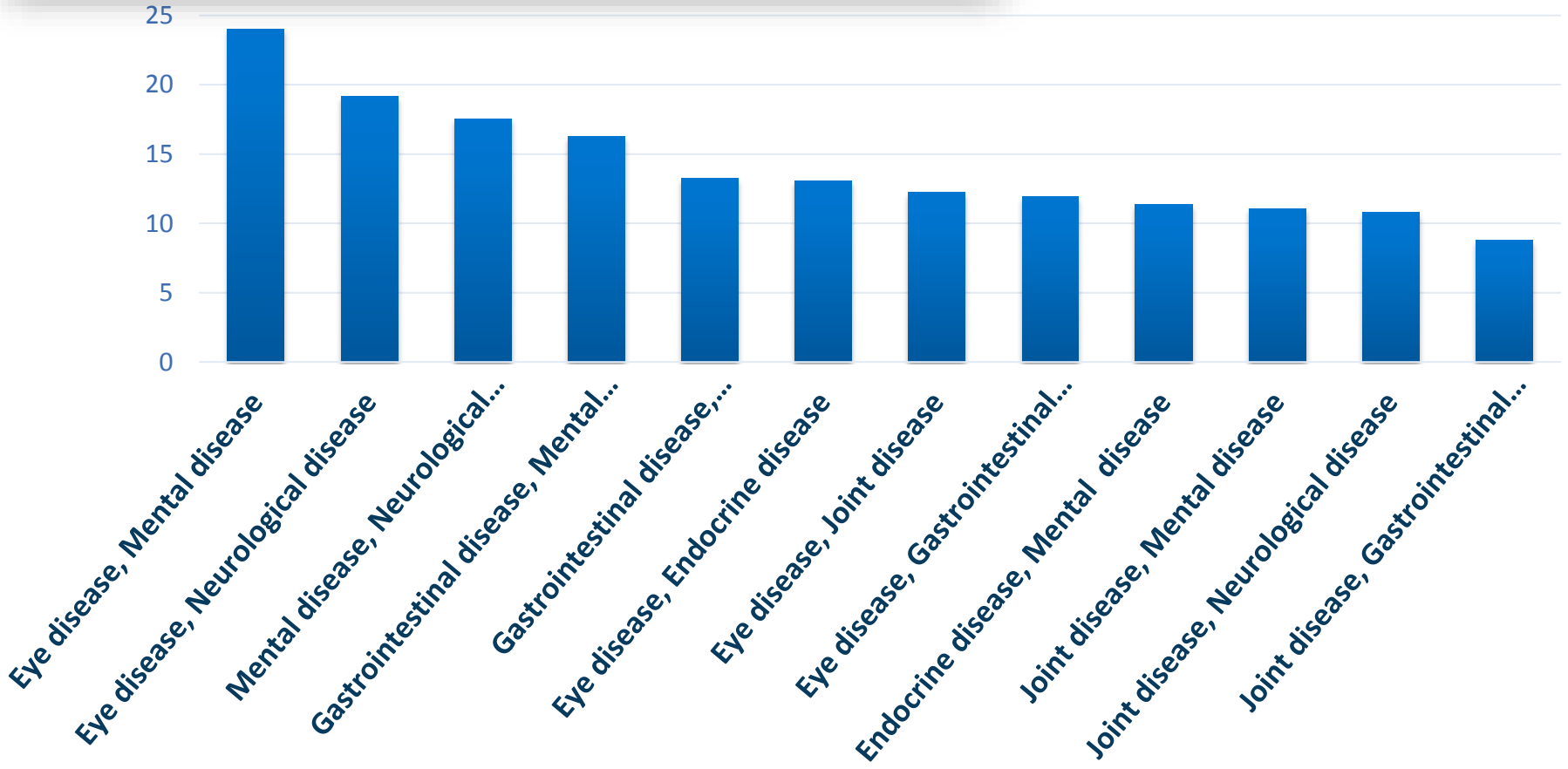
Contents lists available at SciVerse ScienceDirect

Research in Developmental Disabilities

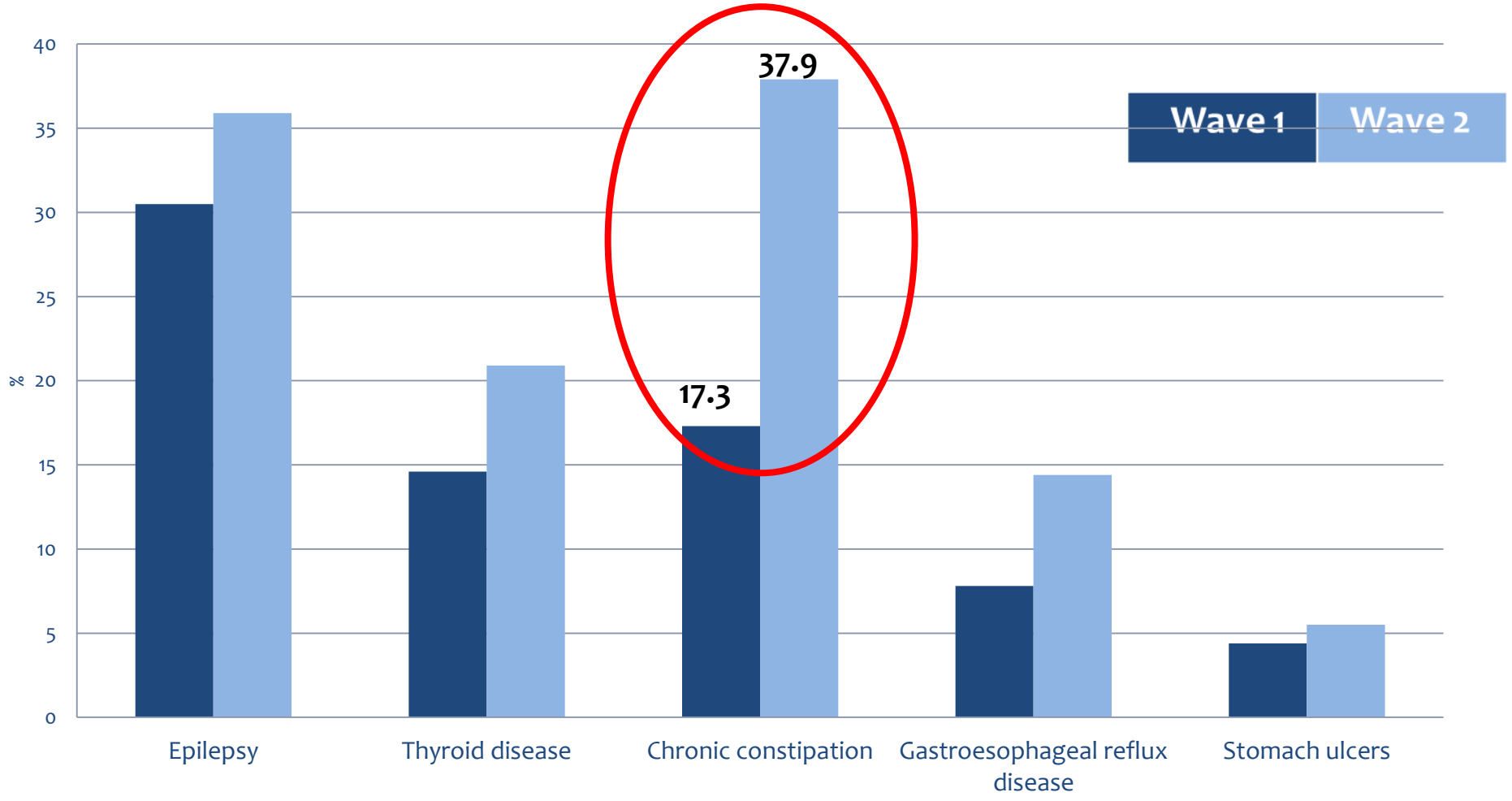
Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA)

Mary McCarron [a], Janet Swinburne [a], Eilish Burke [a], Eimear McGlinchey [a], Rachael Carroll [a], Philip McCallion [b,*]

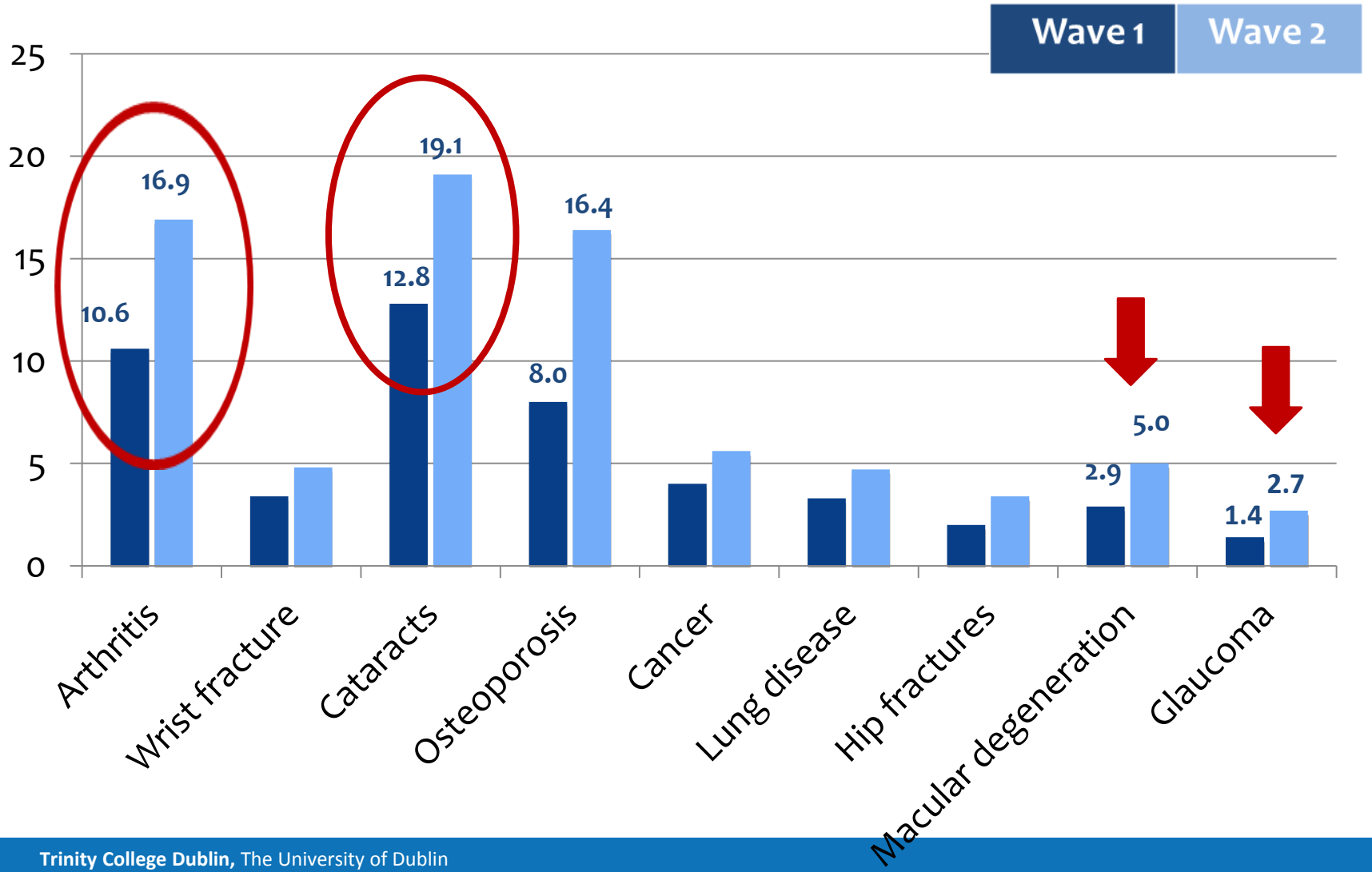
[a] School of Nursing and Midwifery, Trinity College Dublin, Ireland
[b] Center for Excellence in Aging and Community Wellness, University at Albany, Albany, NY 12222, USA



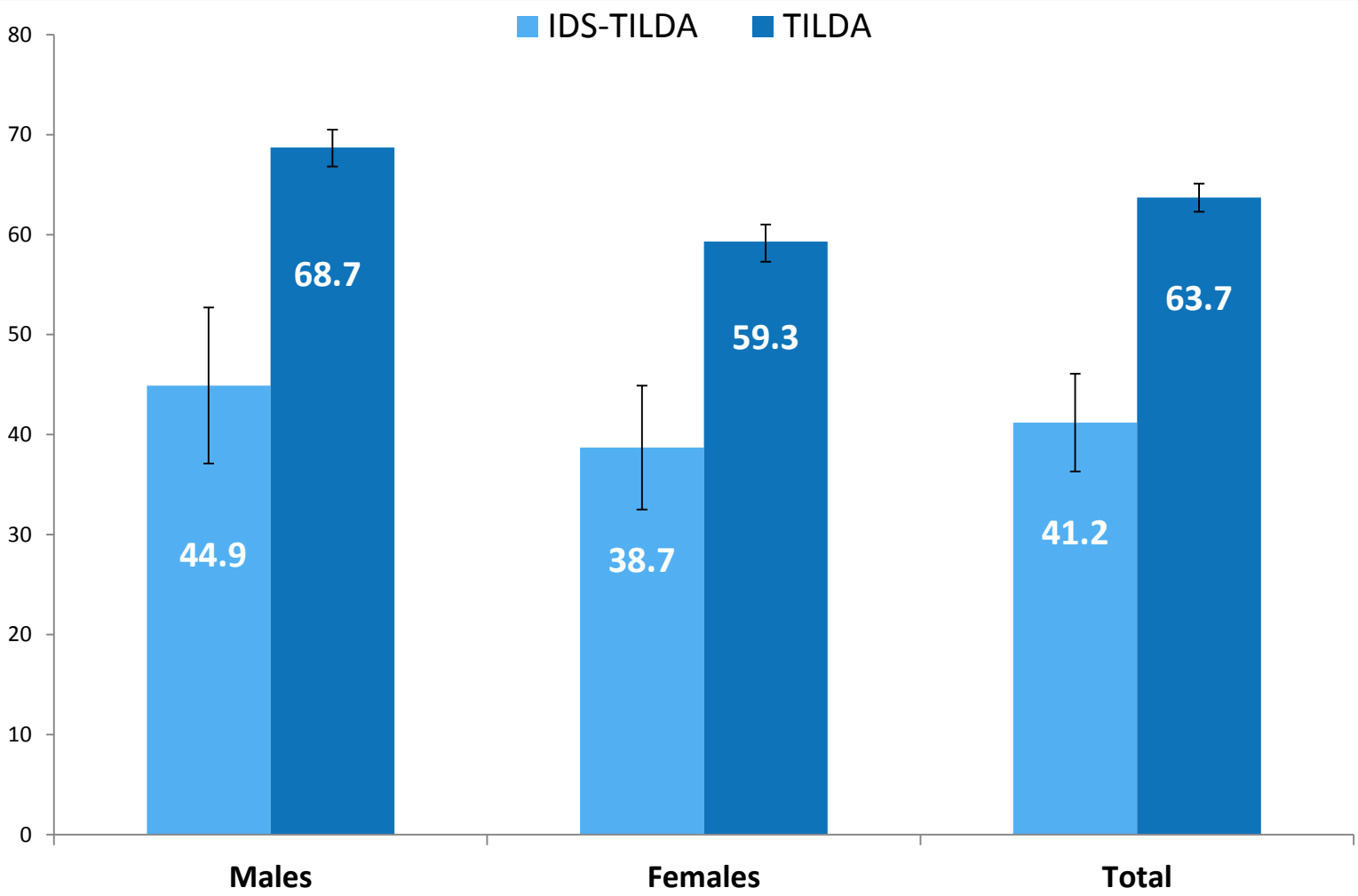
Changes in prevalence of chronic conditions



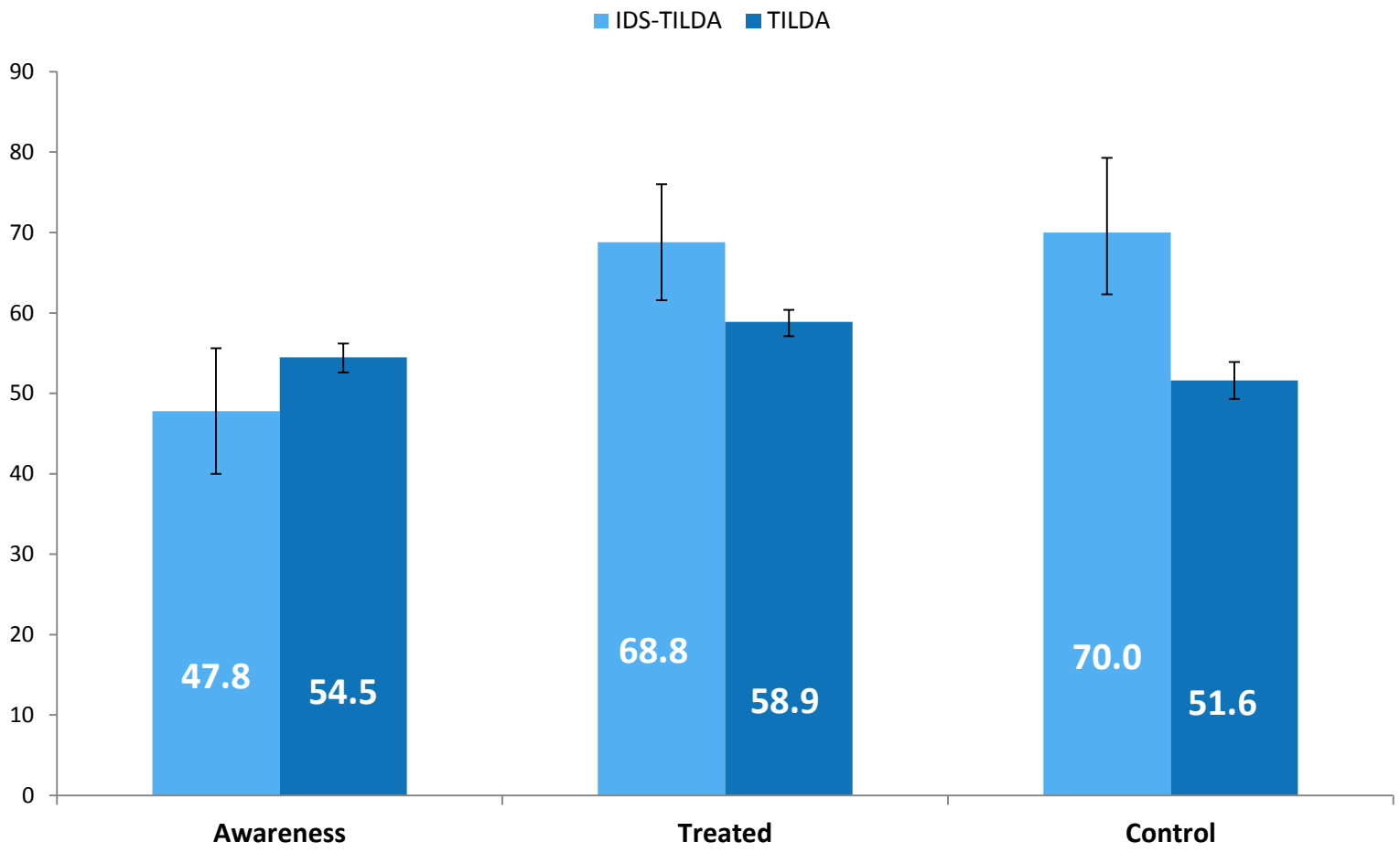
Changes in prevalence of chronic conditions



Hypertension prevalence, gender



Awareness, treatment and control



Questions remain?

- If risk levels are similar but prevalence is lower are there **other contributing risks** in the lives of the general population such as greater exposure to psychological stresses *which while present in the* lives of people with ID are likely to be somewhat different?

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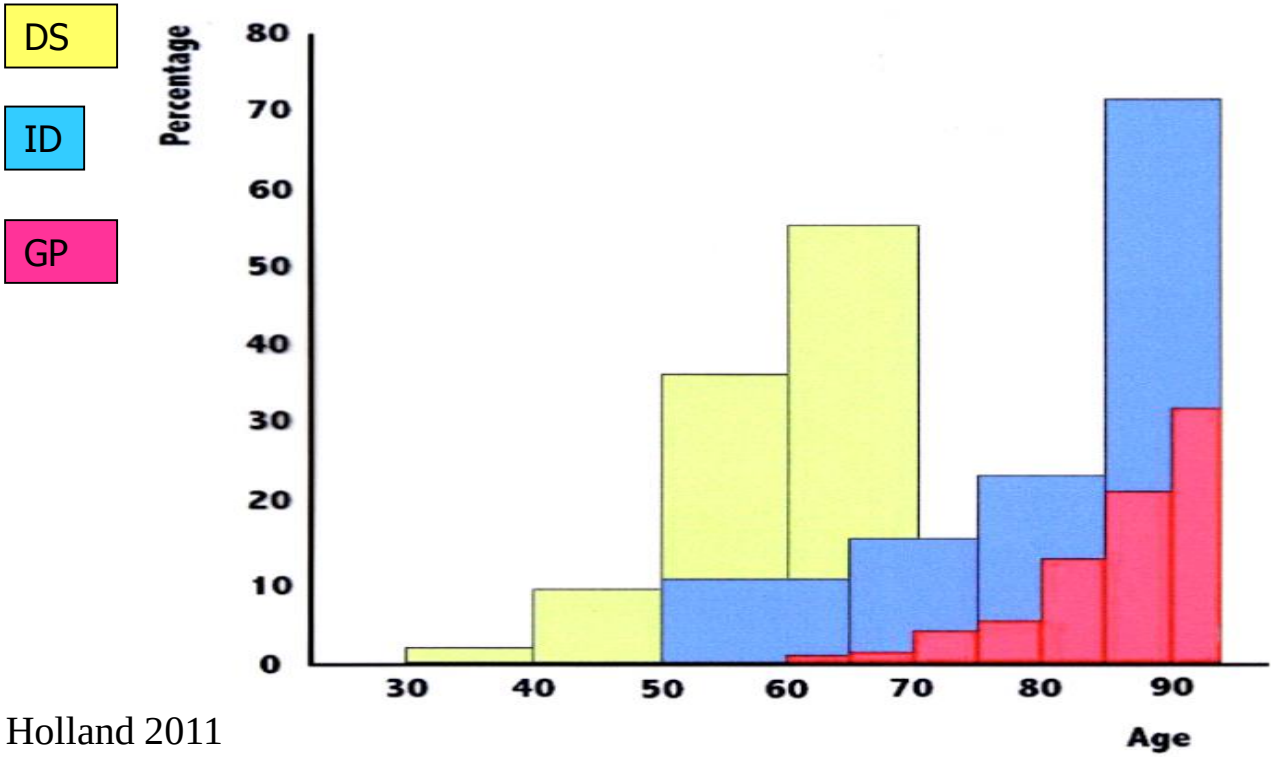
Dementia

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Comparative rates of dementia
Down's syndrome, I.D., general population



Holland 2011

Point prevalence of dementia in Down Syndrome over 3 year period

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

JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

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VOLUME 61 PART 9 pp 843–852 SEPTEMBER 2017

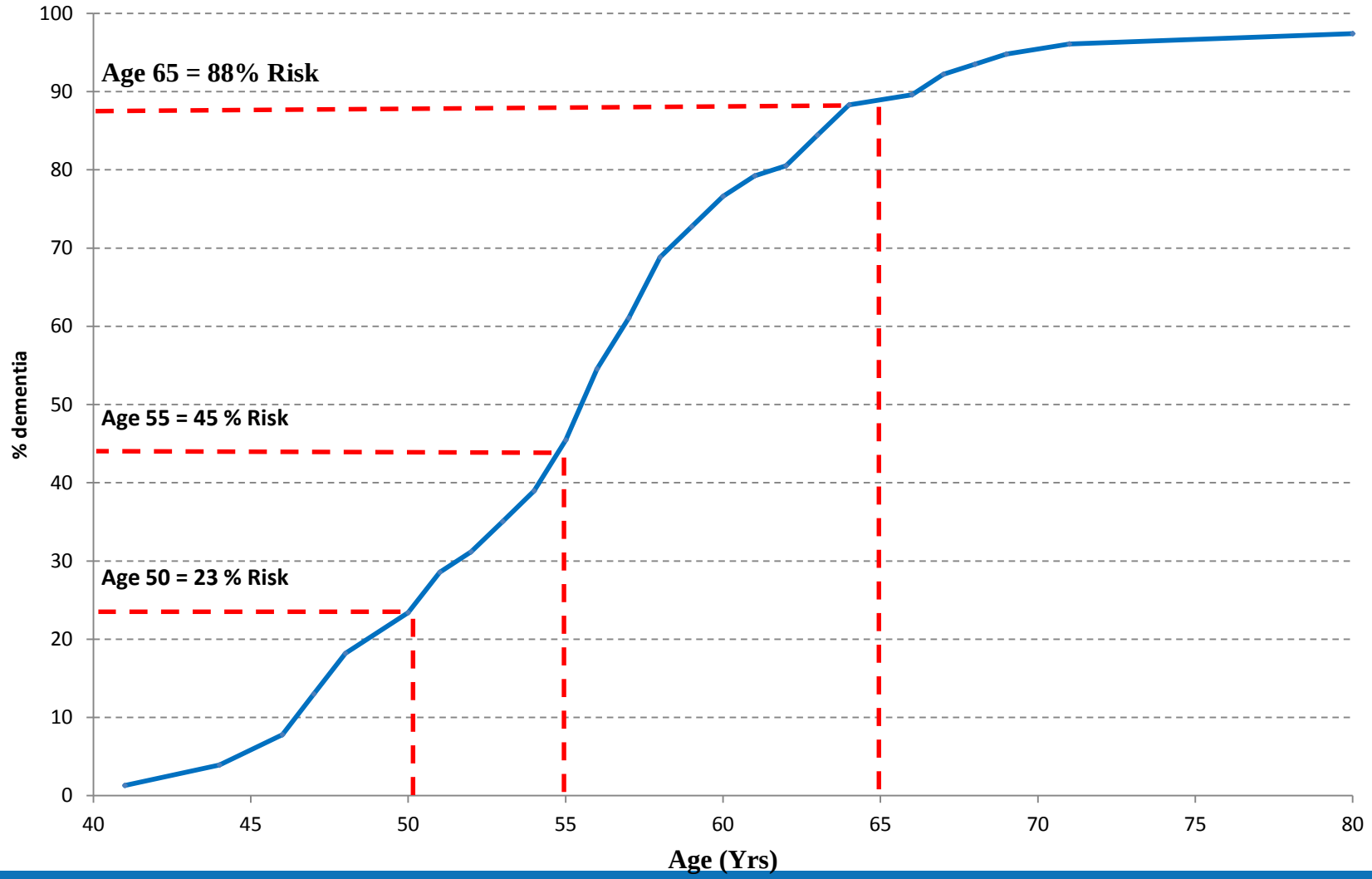
A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome

M. McCarron,[1] P. McCallion,[2] E. Reilly,[3] P. Dunne,[3] R. Carroll[1] & N. Mulryan[3]

1 *School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland*
2 *Center for Excellence in Aging & Community Wellness, University at Albany, Albany, NY USA*
3 *Daughters of Charity Disability Support Service, Dublin, Ireland*

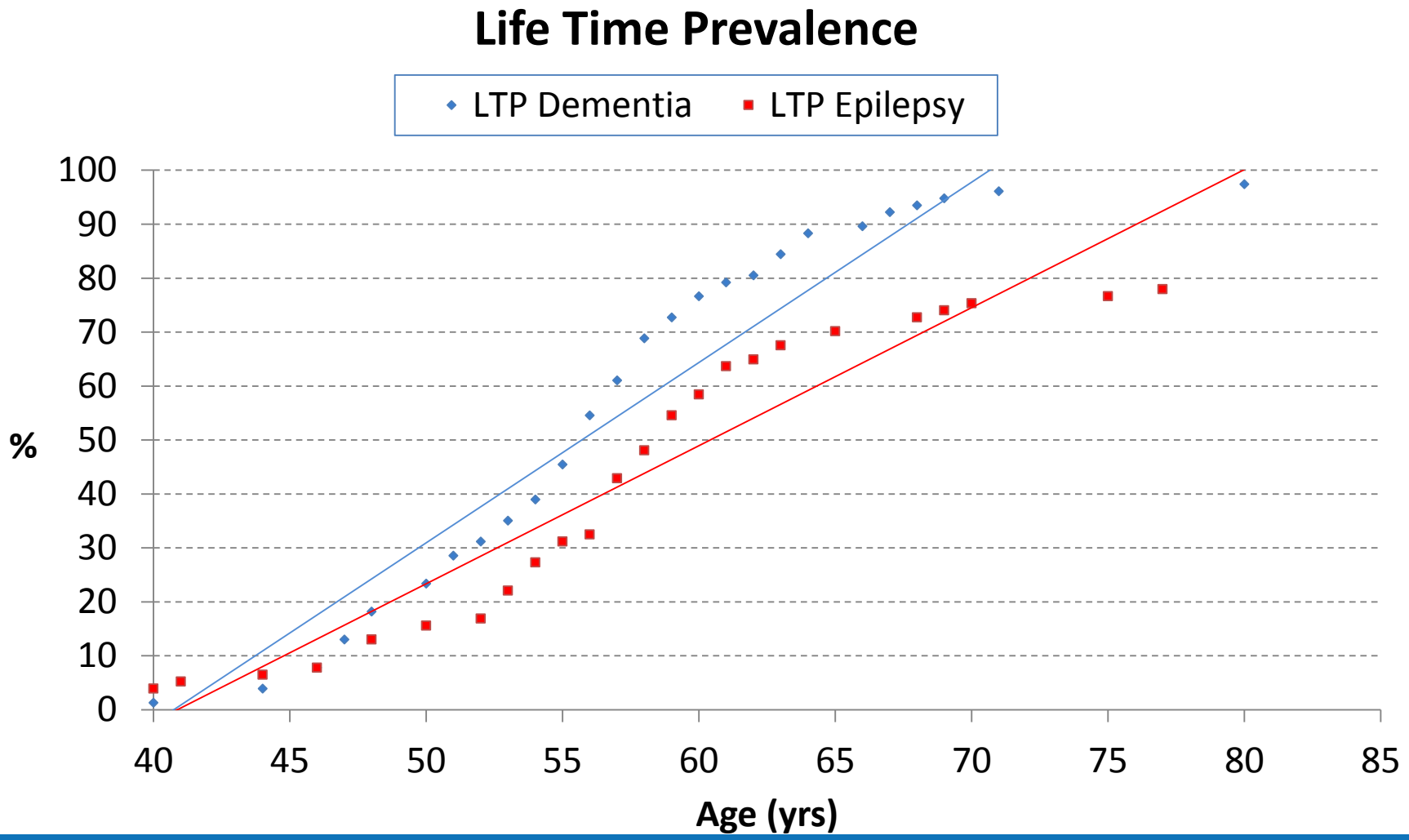
A Prospective 20 Year longitudinal follow-up of dementia in persons with Down Syndrome

Risk trajectory according to age



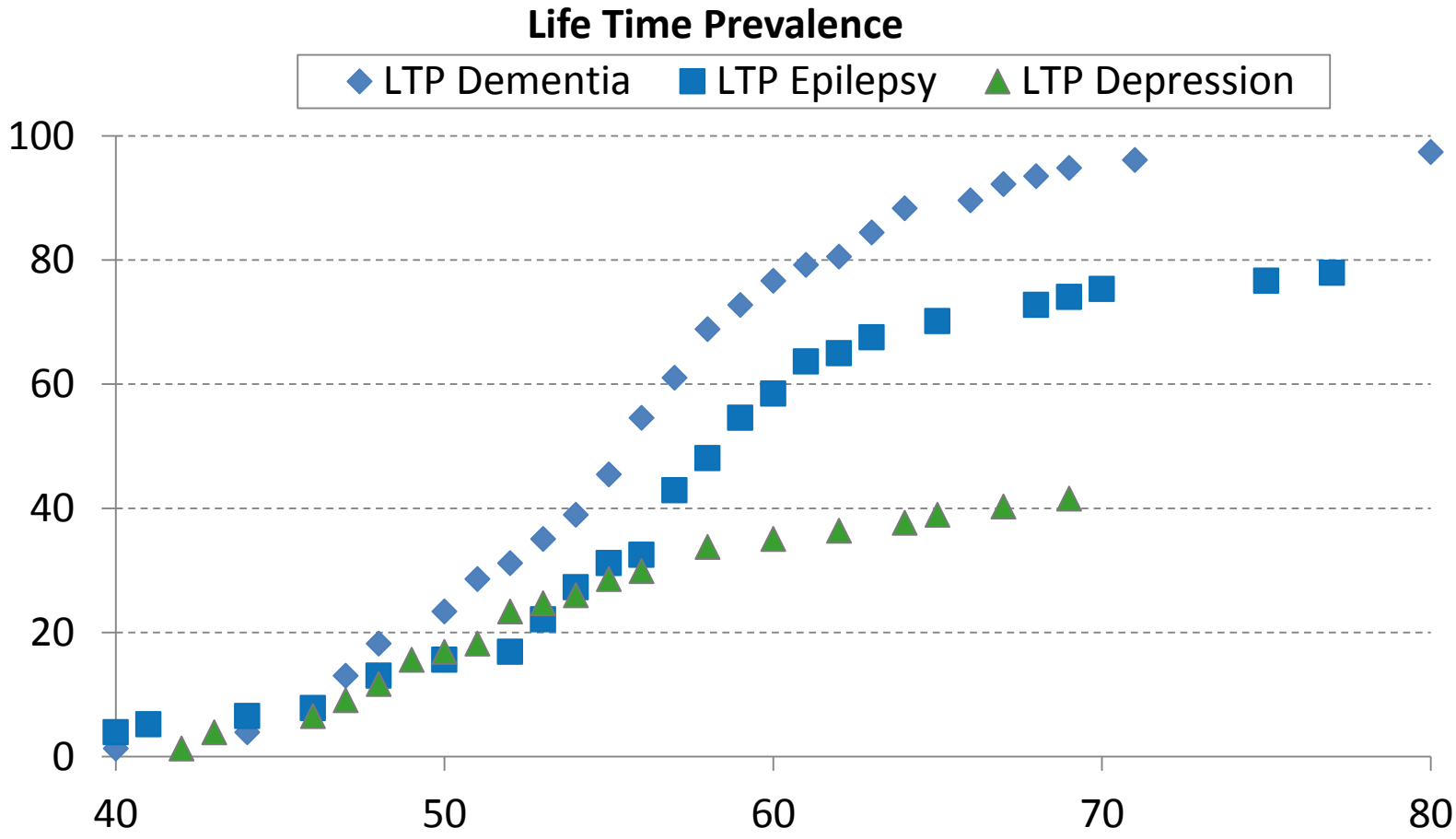
Dementia and epilepsy

77.9% (60 of the 75 with dementia) had epilepsy

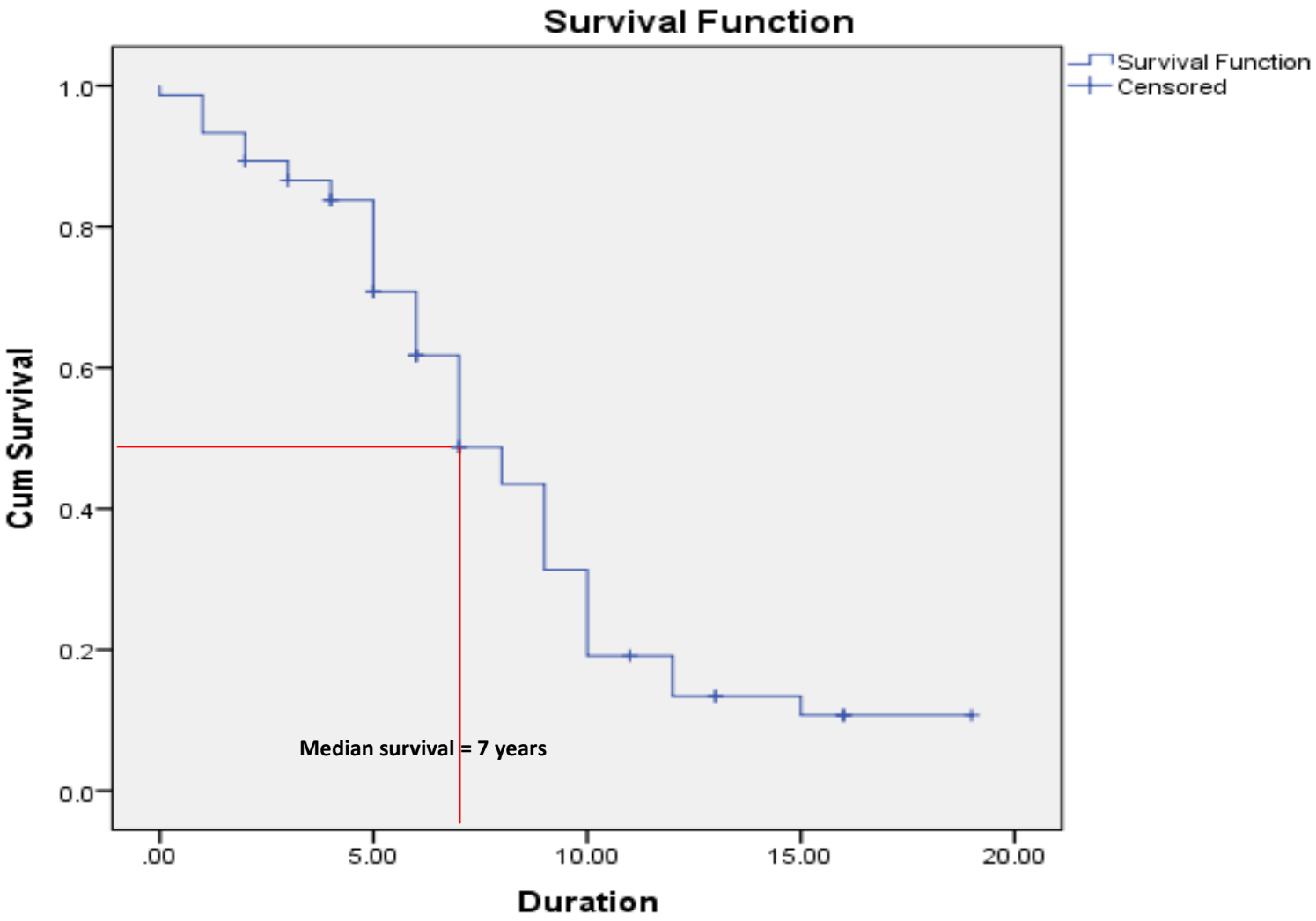


Dementia, epilepsy & depression

48% of those with dementia were also reported to have depression.



Mortality


Survival Function
Survival Function
Censored
Cum Survival
1.0
0.8
0.6
0.4
0.2
0.0
.00
5.00
10.00
15.00
20.00
Duration
Median survival = 7 years

Some key conclusions

Substantial increased risk of dementia >50years BUT……..

- Survival less precipitous than previously reported
- Rate of progression varies among individuals.
- Anecdotal reports of adults with Down syndrome "falling off a cliff" reflect unusual cases.
- High risk of new onset epilepsy
- Little Impact for level of LD
- Increased survival at advanced dementia

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Cognitive Training with Adults with Down syndrome

Dr Eimear McGlinchey
Research Fellow, IDS-TILDA

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The BEADS Study

Brain Exercises for Adults with Down Syndrome

Reasons for conducting study

Adults with DS at greater risk of executive dysfunction

Little research on computerised cognitive training with this population

Promising evidence in the general population on effects of cognitive training

Brain Exercises for Adults with Down Syndrome

Results
Overview Feasibility

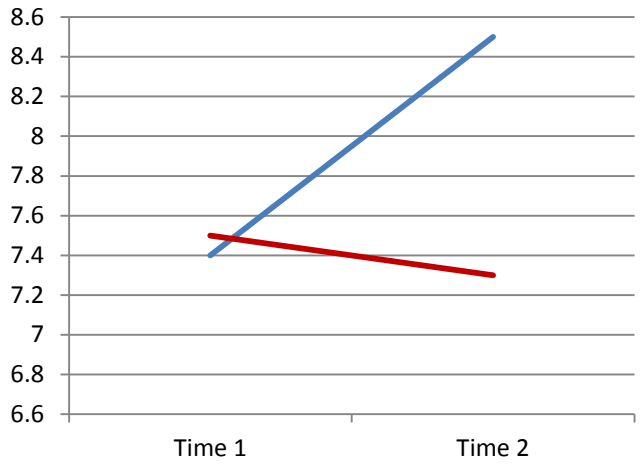
Participant	
Can participants play and progress the games?	✓
Do participants adhere to the training program?	✓
Do participants enjoy the cognitive training program	✓
Support Person	
How much support is needed to complete the training pr	60% completed independently by end of program
How much training is involved for those supporting participants?	1 training session
Environment	
Can the program be implemented in different environments? (e.g. at home and in day service)	Environment did not appear to have an effect on performance

Executive Function Scores: Pre and Post Intervention

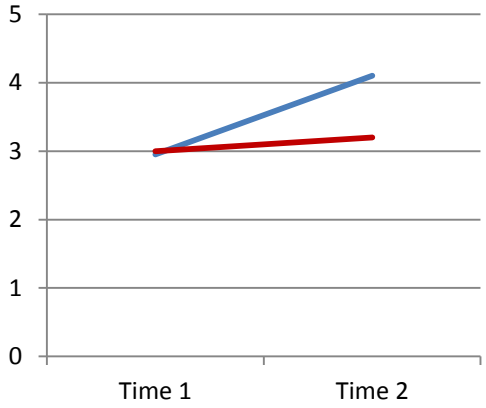
Behaviours of Executive Function			
	Mean	Mean	p-value
Inhibit	49.4	47.2	.067
Shift	62.8	59.7	.225
Emotional Control	52.6	48.2	**.001**
SelfMonitor	55.4	53.5	.385
Behavioural Regulation Index	54.7	51.8	.033
Initiate	61.5	55.1	**.006**
Working Memory	63.2	57.5	.015
Plan/Organise	56.5	53.4	.065
Task Monitor	60.0	58.6	.576
Organise materials	45.0	43.0	.148
Meta Cognitive Index	57.3	53.2	**.004**
Global Executive Composite	56.6	52.9	**<.001**

Behaviours of Executive Function*			
	Mean	Mean	p-value
Inhibit	49.6	47.7	.556
Shift	61.0	61.1	.981
Emotional Control	**49.1**	**45.8**	**.002**
Self-Monitor	60.8	59.4	.412
Behavioural Regulation Index	**54.5**	**52.4**	**.005**
Initiate	56.1	54.0	.165
Working Memory	59.5	57.3	.104
Plan/Organise	50.6	49.7	.431
Task Monitor	61.6	62.1	.740
Organise materials	**44.9**	**42.9**	**.030**
Meta Cognitive Index	54.3	52.7	.130
Global Executive Composite	53.1	52.8	.862

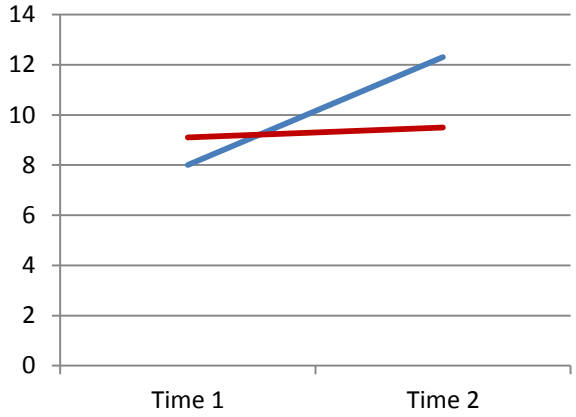
Scrambled Boxes



Spatial Reversal



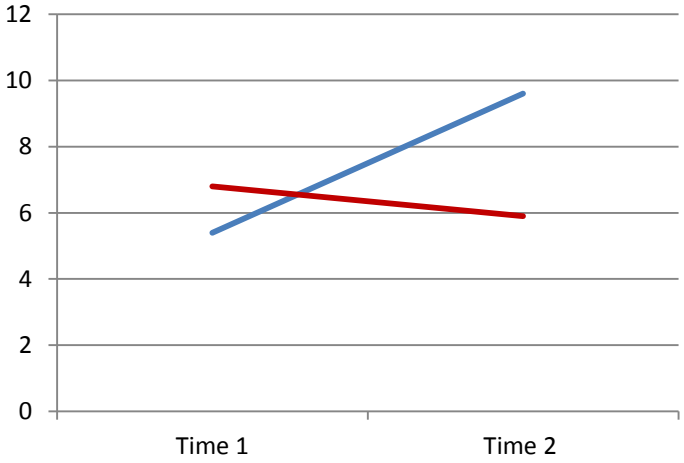
Tower of London



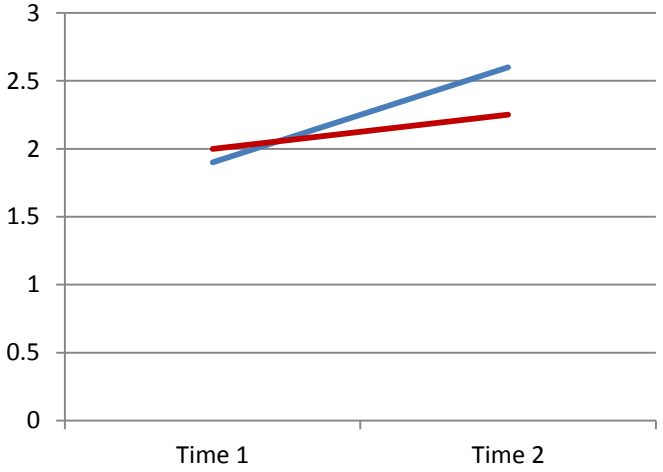
Active Group

Delayed Control Group

Dogs and Cats Stroop



Weigl Card Sorting



Results
What this tells us

Feasibility: Conducting a computerised cognitive training program with adults with Down syndrome is feasible

Effect of Neuropsychological Assessments: These results suggest that cognitive training does show promise for improvements in EF as measured by neuropsychological assessments.

Effect on everyday behaviours: The changes in scores on the BRIEF-A within participants were not as marked for behaviours of executive function as was seen for the neuropsychological assessments. Could be due to transfer effects.

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An exploration of the bone health of older adults with an intellectual disability

Dr. Eilish Burke

Ussher Assistant Professor in Ageing and Intellectual Disability

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Why explore bone health

Est. 300,000 people in Ireland have osteoporosis.

1 in 5 men and 1 in 3 women will develop a fracture due to osteoporosis

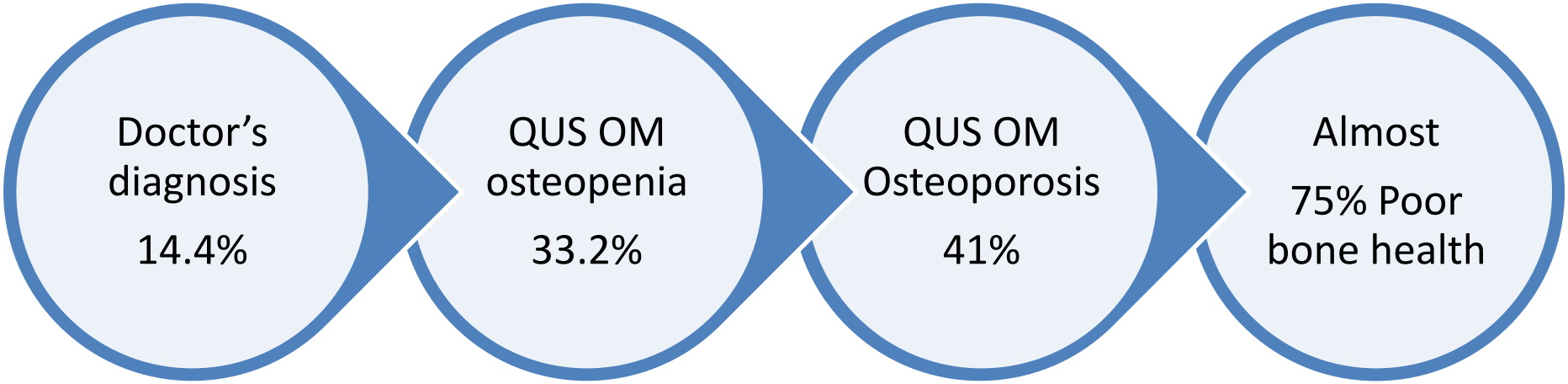
In the over-60s age group in Ireland, the mortality as a direct consequence of hip fracture is 20% within 6 to 12 months

Health Fair

The [illegible]nge of m[illegible]
[illegible]uality in p[illegible]

OS CALCIS –
calcaneus bone

PREVALENCE VERSUS DOCTOR'S DIAGNOSIS
Wave 2 (Health Fair N=575)



Key findings

Overall 2/3 of participants were taking medicines that contributed to poor bone health

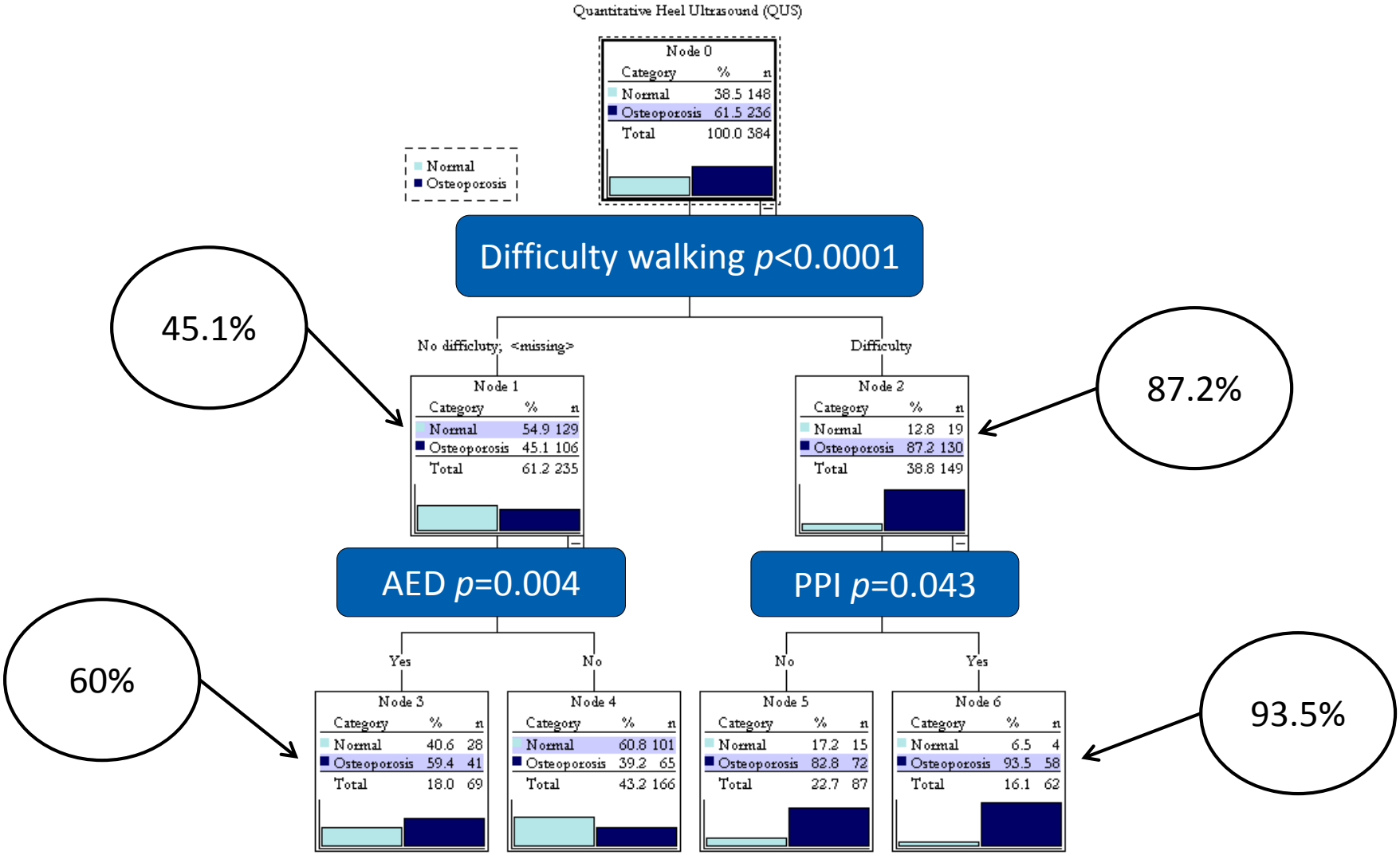
Over 1/5 of participants reported a history of fracture

Over 50% of the participants with Down syndrome had evidence of poor bone health

Men with ID were 12 times more likely to present with objective evidence of osteoporosis than their peers in the general population TILDA

Predictors of Osteoporosis

Chi-squared Automatic Interaction Detector Analysis (CHAID) Osteoporosis



Clinical practice & research implications

- Are the general population risk factors the most critical for people with intellectual disability?
- Education requirements for all healthcare professionals is imperative especially those in primary health care who are unfamiliar with the field of intellectual disability
- There is a need to establish assessment criteria specific to people with intellectual disability
- We need to consider how diagnosis is established to ensure standardised approach

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Medication use and polypharmacy in older adults with intellectual disabilities

Dr Máire O'Dwyer
Assistant Professor in Practice of Pharmacy

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Polypharmacy and excessive polypharmacy IDS-TILDA

Open Access Research

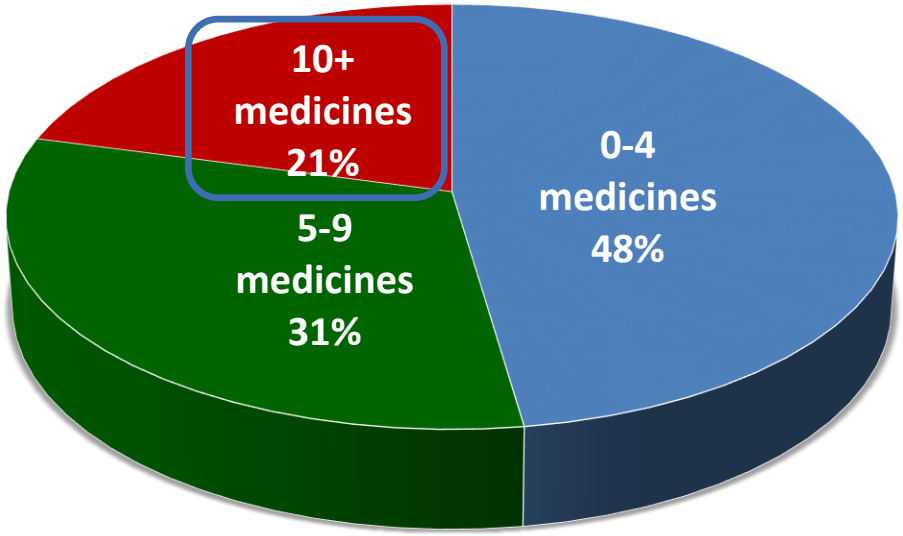
BMJ Open

Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study

Máire O'Dwyer,[1,2] Jure Peklar,[3] Philip McCallion,[4] Mary McCarron,[5] Martin C Henman[1]

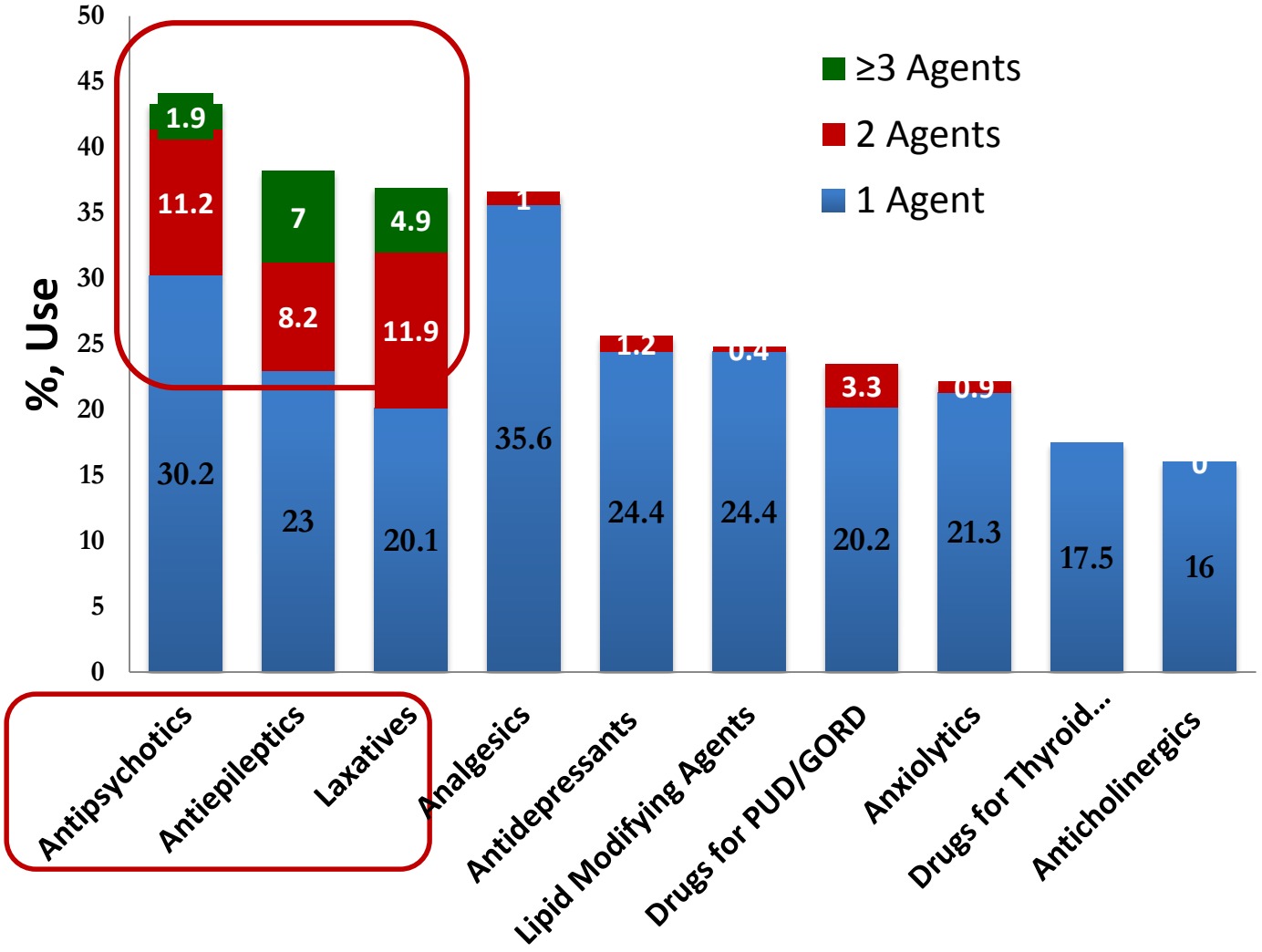
IDS – TILDA (n=736) (40+ years)

- ✓**Classification**
- ❑**No -polypharmacy : 0-4 medicines**
- ❑**Polypharmacy : 5-9 medicines**
- ❑**Excessive polypharmacy :10+ medicines**



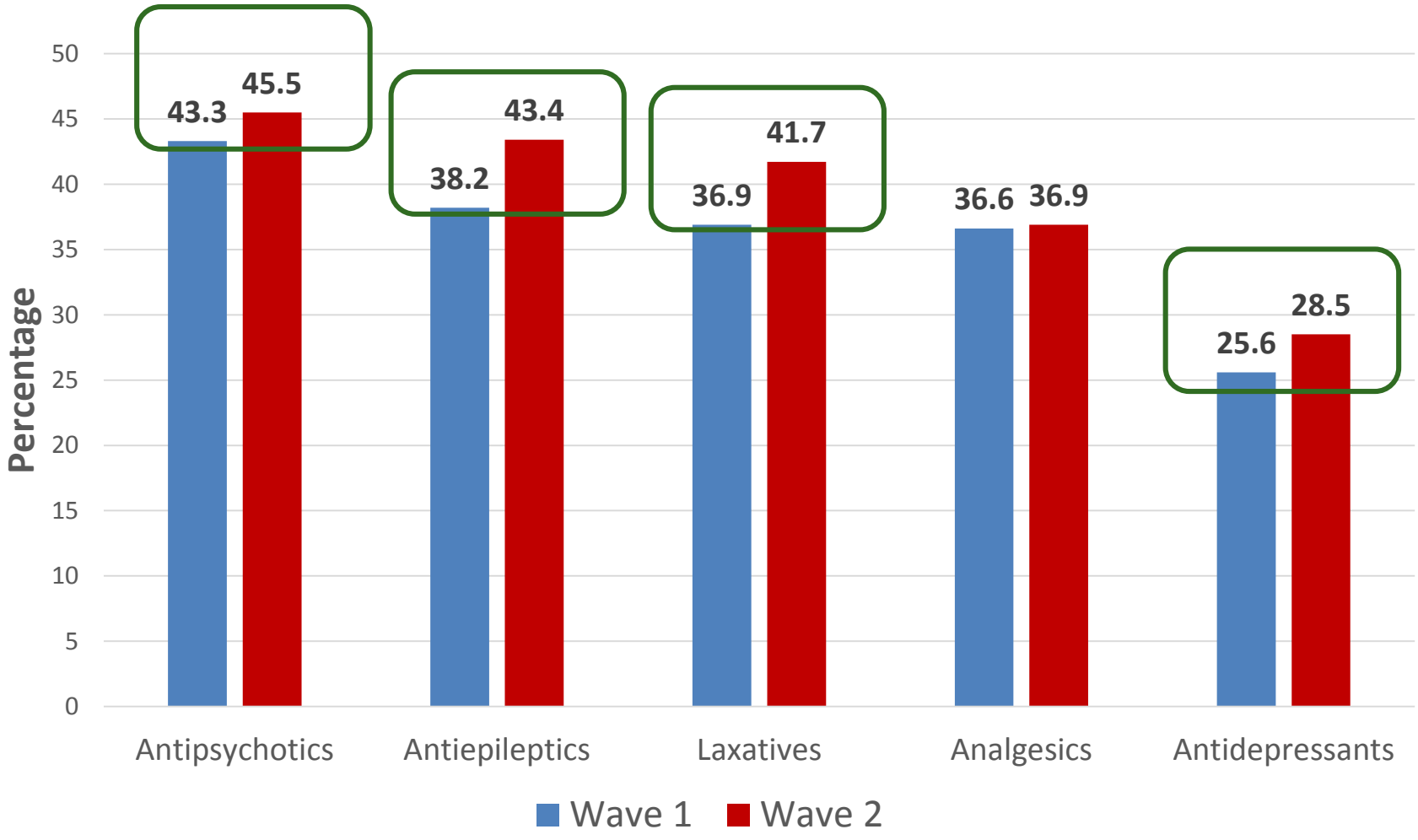
TILDA (Irish General Population 50+ years, n=8038) (Richardson et al 2012)	
5-9 medicines	19%
10+ medicines	2%

Frequently reported therapeutic classes: IDS-TILDA Wave 1

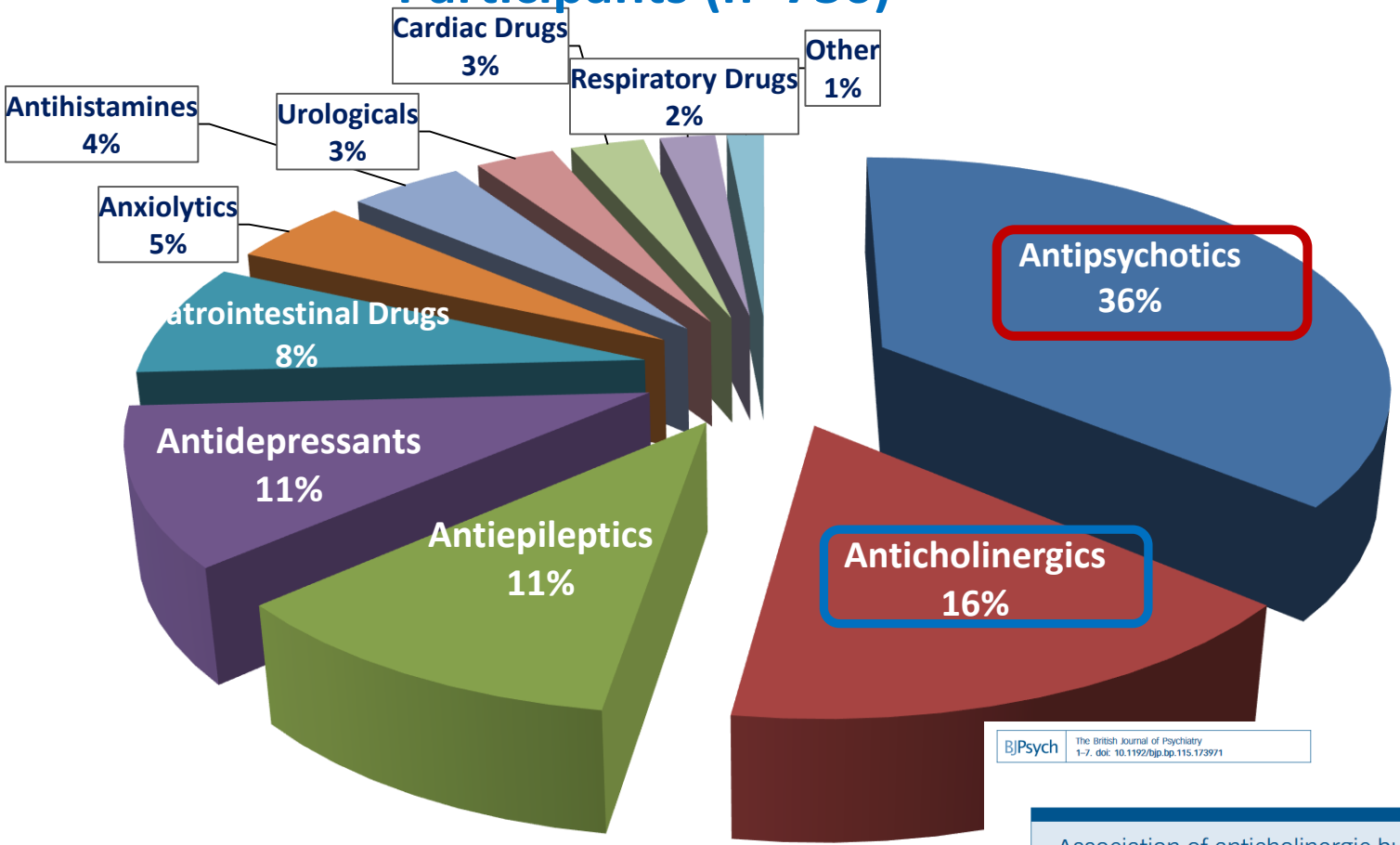


Three most Frequently Reported Therapeutic Drug Classes TILDA (Richardson et al., 2012)	
Drug Class	Frequency (%)
Lipid Modifying Agents	33
Agents acting on the renin-angiotensin system	26
Anti-thrombotic Agents	25

Change in prevalence in medication use



Contribution of Drug Classes to Total ACB Score in Participants (n=736)



BJPsych The British Journal of Psychiatry
1–7. doi: 10.1192/bjp.bp.115.173971

Association of anticholinergic burden with adverse effects in older people with intellectual disabilities: an observational cross-sectional study

Máire O'Dwyer, Ian D. Maidment, Kathleen Bennett, Jure Peklar, Niamh Mulryan, Philip McCallion, Mary McCarron and Martin C. Henman

New questions to be addressed

Is inappropriate polypharmacy associated with adverse health outcomes in older adults with ID?

Is high burden of sedative and anticholinergic effects associated with negative outcomes such as cognitive decline, frailty and mortality?

How can we reduce the burden to improve appropriate use of these medicines and improve patient outcomes and quality of life?

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Transitions and choice for older people with ID

Dr Mary-Ann O'Donovan

Assistant Professor in Intellectual Disability and Inclusion

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Transitions and choice

Aim

- To track the housing mobility and living transitions of older people with ID
- To examine the extent of personal choice in housing transitions
- To explore the impact of moving on health and health service utilisation

Research approach within IDS-TILDA

- Participants who changed place of residence between data collection waves

Key findings

Some people with ID are changing where they live

- Not always by choice
- Not always involved in decision process
- Not always to the community
- Some return to service provider for health care

Who moved?

70.4% Mild/Mod ID

55% Female

70% were <64 years

Majority were lateral movers from similar type residence

120 MOVERS

Who was involved in Decision?

60% wanted to move

20% viewed alternate options

Why is this research important?

First indication of policy implementation on national level to track …

- Impact of moves on people with ID
- Input of people with ID in decisions to move

Highlights the continuing need to …

- Address human rights of people with ID in making choices
- Reconfigure community to sustain and support community living by people with ID
- Explore relevancy and appropriateness of ‘Ageing in Place’ for people with ID

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Social and community participation of older people with intellectual disabilities

Dr Darren McCausland

Research Fellow, IDS-TILDA

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Findings: Networks and Relationships

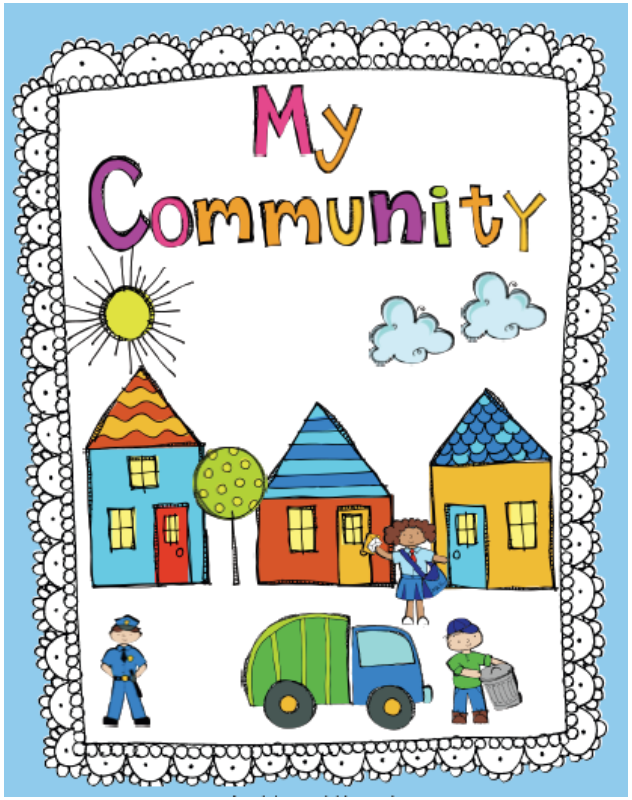
- Very different social networks
  - Many (43%) have no friends outside their home
  - Hardly any marry or have children
  - Paid staff replace intimate family networks
    - Important roles in supporting social activities
    - BUT also as close friends/confidants

- Type residence strongest factor in having friends (Ind/Family x 17)
  - Other factors: literacy, mental health, FL (IADLs)
- Only 40% had weekly family contact
  - Proximity to family strongest factor
  - Other factors: FL (IADLs), age, communication

Findings: Social Activity

- Vast majority OPWID are socially active (3% inactive)
- Most common activities:
  - Eating out (85%); Coffee (82%); Shopping (76%); Hairdresser (71%); Church (62%); Visit family/friends (60%); Cinema, theatre or concert (59%); Pub (57%)
- Choice? Group activities?
  - Less than ½ choose who they spend free time with
  - Only 1 in 3 choose where they go in their free time
- Family contact the strongest predictor of social activity
  - Other factors: mental health; FL (I/ADLs); physical health; having friends

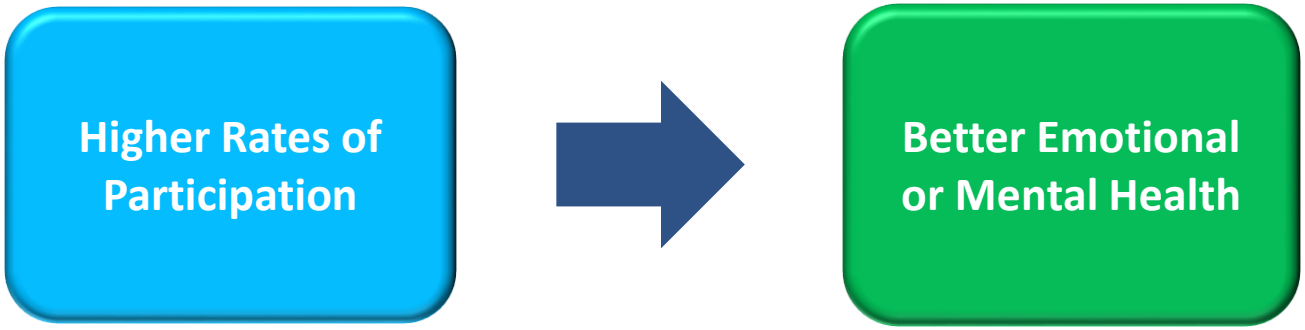
Local Community (LC) Participation



- 1 in 4 member of a group in their LC
  - IADL functioning strongest predictor of membership
  - Other factors: Residence; Literacy; Friends
- Family contact strongest predictor of social activity in LC
  - Other factors: Mental health; Residence; Literacy
- 3 in 4 had difficulty participating in LC
  - Residence the strongest predictor of having difficulty
  - Other factors: Physical health; Level of ID; ADL functioning

Findings: Outcomes of SP

Subjective outcome: Self/proxy-rated Emotional or Mental Health



- Across all 17 measures of participation (12 statistically significant)
- Of these measures, **having friends outside your home** was the strongest predictor of better EMH

Some Conclusions

- SP is complex – multiple factors influence experiences
  - Personal characteristics; demographic; social
  - Must not focus narrowly on one factor
  - Support needs don't disappear with move to community
- OPWID have greater challenges to participation, and
- Lower rates of participation than GOP
- Paid staff an important social support where natural supports are limited
- Participation related to better subjective outcomes for OPWID
- OPWID at risk of worse QOL and other outcomes
- Individualised approach required in policy and support services

Future questions

- What is community? What is community for older people with ID?
- What is the qualitative experience of older people with ID living in their local communities?
- What relationships are important to older people with ID?
- How inclusive and welcoming are local communities to older people with ID?

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Loneliness in older people with an Intellectual Disability

Andrew D. Wormald

PhD Student, IDS-TILDA

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

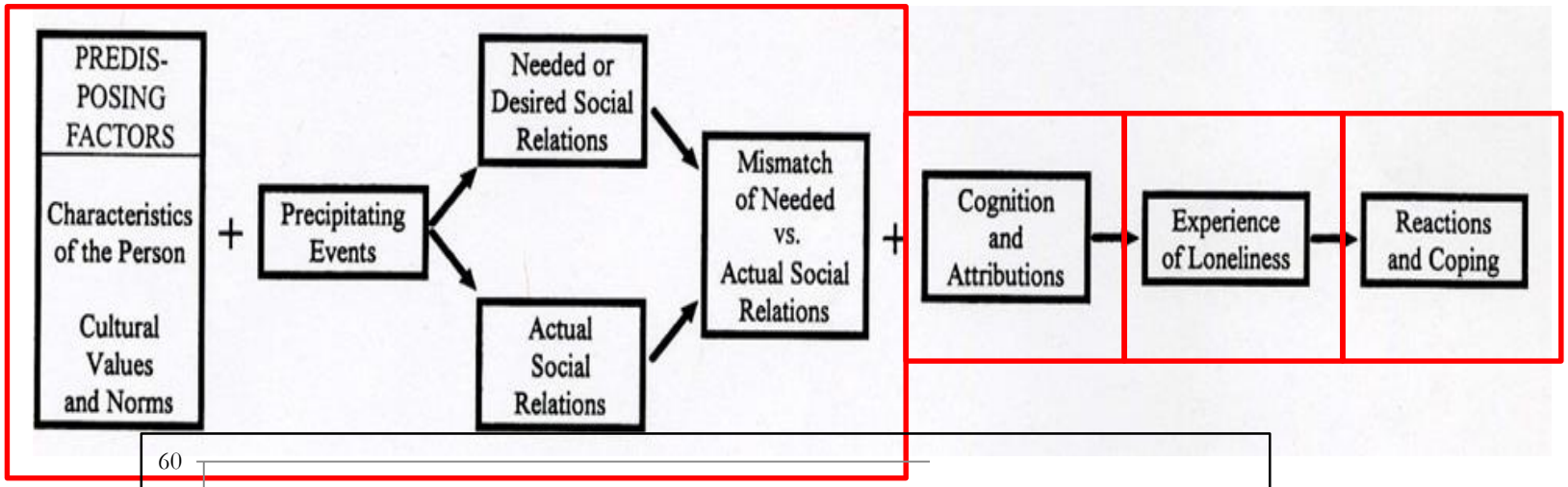
How is loneliness experienced by older people with an ID

Section	Question	Wording	Response set
Social Connectedness	SC8	Do you ever feel lonely?	Yes/No
	SC9	How often do you feel lonely?	Most of the time/ Some of the time/ Hardly ever or Never
	SC10	Do you ever feel left out?	Yes/No
	SC11	How often do you feel left out?	Most of the time/ Some of the time/ Hardly ever or Never
	SC12	Do you find it difficult to make friends?	Yes/No
	SC13	How often do you feel you lack friendship	Most of the time/ Some of the time/ Hardly ever or Never
	SC14	Do you ever feel isolated?	Most of the time/ Some of the time/ Hardly ever or Never

Self Report Only

N=317

How is loneliness experienced?



Cognitive Discrepancy Approach to Loneliness

Loneliness Activates Hypervigilance

A heightened state of alert

Disrupting Sleeping Problems

Raising Systolic Blood Pressure

Creates a distrust of others

Remembering more Negative events

Coping with Loneliness

Active Engagement

Lonely People do more moderate exercise

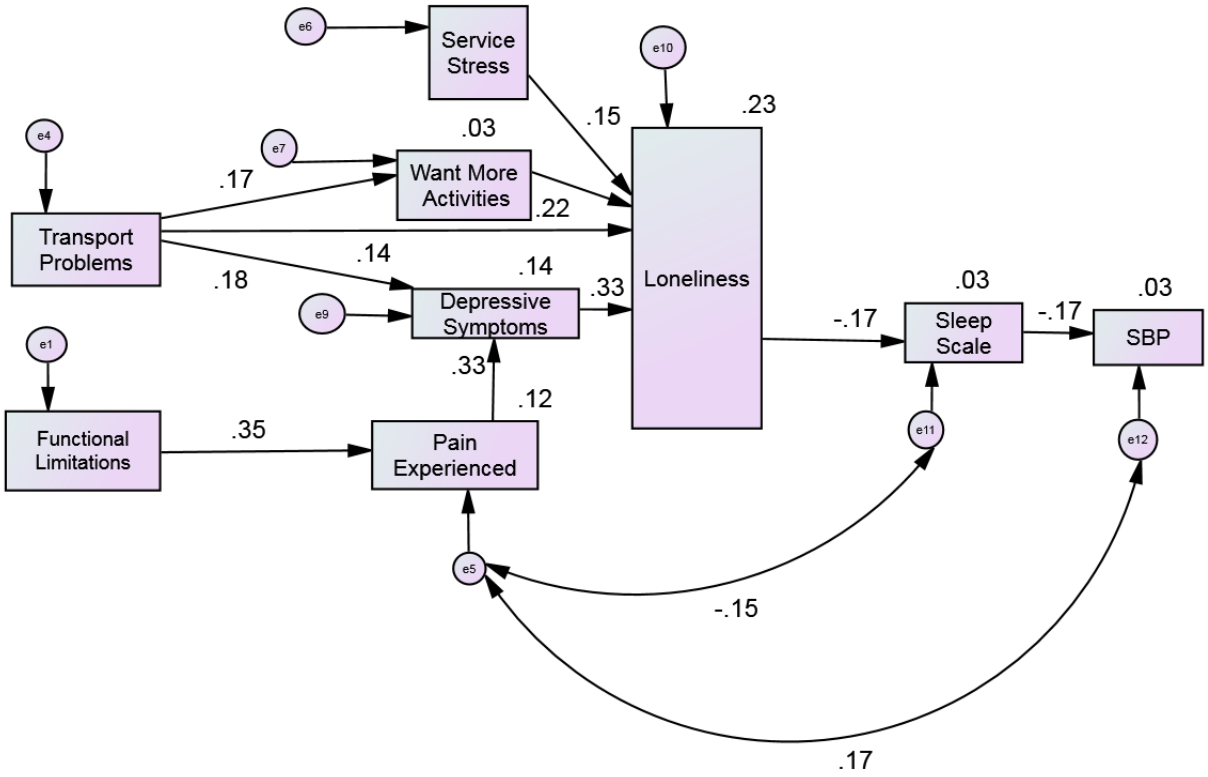
Report Diet as Good or Very Good

Attend Church Services

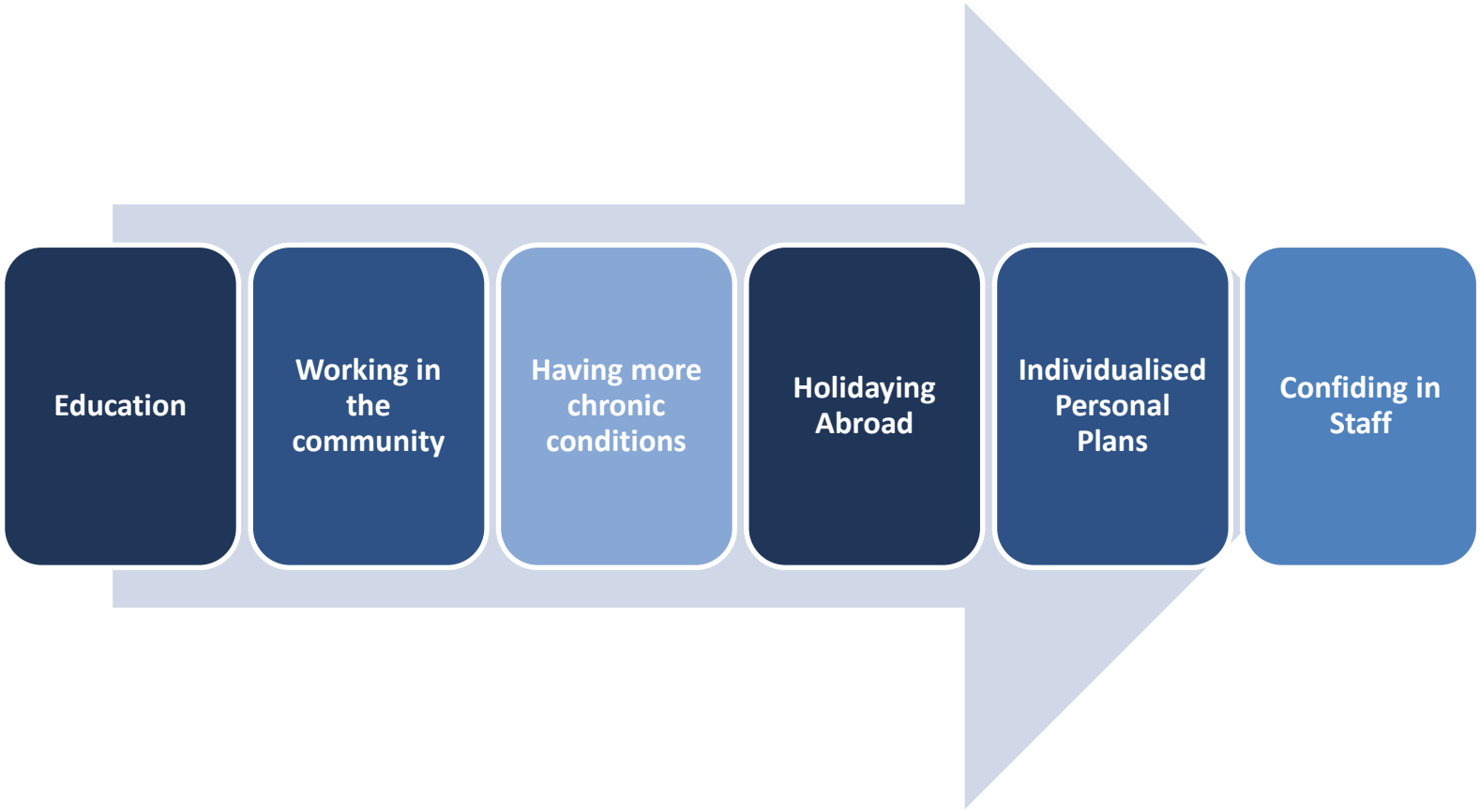
Vote in Elections

Ratios
Series
Binary
Logistic
Regressions

Final model


e6
Service Stress
e10
.23
.15
.03
e4
e7
.17
Want More Activities
.22
Transport Problems
.14
.14
.18
Depressive Symptoms
.33
Loneliness
.03
.03
-.17
Sleep Scale
-.17
SBP
e9
e1
.33
.12
Functional Limitations
.35
Pain Experienced
e11
e12
e5
-.15
.17

Protective against loneliness



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Family Care Giving

Dr Damien Brennan

Assistant Professor, School of Nursing and Midwifery,

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An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

Some points of context

- After prolonged and intensive use of institutions, Ireland is entering a ‘post-institutional’ era
- People with ID are living longer
- People with ID rarely form their own ‘traditional’ family structure
- People with ID will need support as they age
- Caring capacity within the family setting is diminishing in contemporary Ireland
- This raises questions and challenges regarding the future supports needed for older people with ID

Family Care Giving for Older People with Intellectual Disability

Key research questions

- What are the experiences of family care givers
- What family strategies best enable family care giving
- How can long-term care needs be anticipated and planned for

I absolutely adore her, I love her and she is the grandparent that they didn't have, that the kids didn't have (Participant, Urban Focus Group)

- Love, devotion, [illegible] commitment underpins caregiving
- How[illegible]

What's going to happen when we're gone? Now the girls idolise him but it…it no way I think that they should have to have him

- [illegible] family caregivi[illegible]
- Future [illegible]

I assumed that once I made their decision to look after [sister's name] that would be the end of the line. I never thought that there, that you know there might be another handover situation

Soci[illegible]es Care

Why is this research important?

- The family is identified as the main context of care provision in the 'post-institutional' era
- Socio demographic factors are diminishing caring capacity within the family
- Policy planning is required so as to avoided a resurgent demand for residential (institutional) care for older people with ID

New questions to be addressed

- How can family care giving be measured and costed
- How can political choices and social policy maximise the care giving within families
- How can the findings be applied to other fields. (child care, life limiting / chronic conditions, mental illness, palliative care)

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thank you

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National Association for People with an Intellectual Disability

AIIHPC
All Ireland Institute of Hospice and Palliative Care

NDA
National Disabilty Authority

HRB
Health Research Board

Department of Health & Children
AN ROINN SLÁINTE AGUS LEANAÍ

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Staidéar Fadaimseartha na hÉireann um Dhul in Aois
The Irish Longitudinal Study on Ageing