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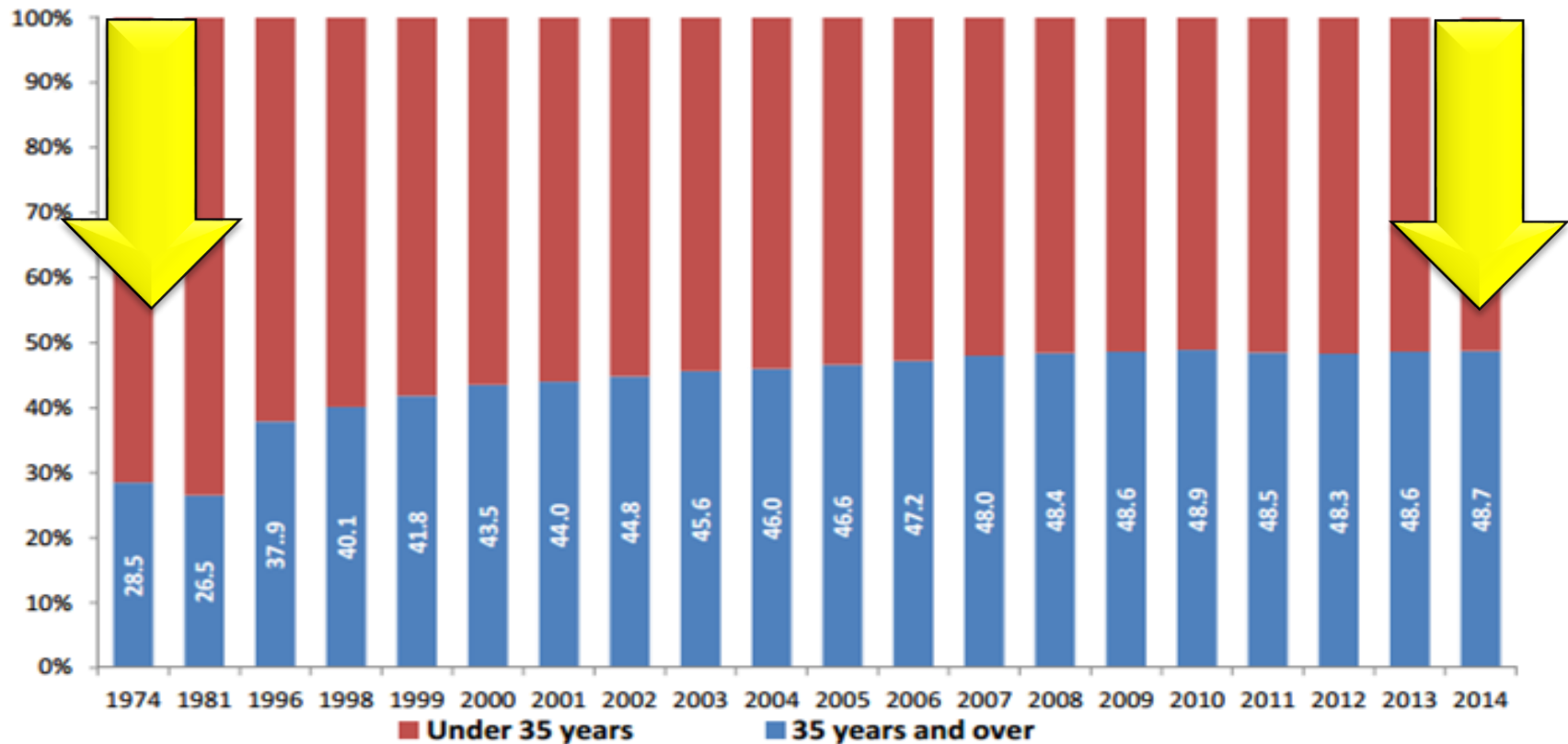
Meeting the challenges of health disparities for older people with ID:

Critical New Roles for the RNID

Professor Mary McCarron
Chair in Ageing and Intellectual Disability
Dean Faculty of Health Sciences TCD

Why Ageing and Intellectual Disability ?

Proportion of people with moderate, severe and profound ID: 1974 - 2014



Sources:

Mulcahy M (1976) Census of the mentally handicapped in the Republic of Ireland 1974: non-residential. Dublin: Medico-Social
National Intellectual Disability Database, Health Research Board, 2014

Celebration & Challenge of Ageing

- A success story
- Little known ageing
- A rapidly changing landscape





April 2014
The Path to
Universal Health
Care: White paper
on Universal
Health Insurance

**IDS-TILDA
WAVE 2
COMPLETE**

**Healthy Ireland –
A Framework for
Improved Health
and Wellbeing
2013-2025**



**The Assisted
Decision-making
(Capacity) Bill (2013)**

January 2013
National standards for
residential services for
children and adults with
Disabilities

**National Positive
Ageing Strategy**

2014

**JUNE 2008
IDS-TILDA
BEGINS**

2008

2013



June 2011
Time to move on from
congregated settings:
a strategy for
community inclusion

**IDS-TILDA
WAVE 1
COMPLETE**



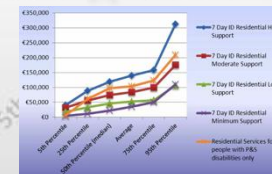
October 2011
National Housing
Strategy for People
with Disabilities 2011-
2016



2011

February 2012
New Directions –
Review of HSE day
services and
implementation
plan 2012-2016

**Value for Money and policy
review of disability services**





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Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Shaping the Future of Intellectual Disability Nursing in Ireland



The key challenges we must respond to for people with ID

- People with ID are more likely to have **higher levels of health need** and significant **health inequalities** than the general population (Cooper, Melville & Morrison, 2004, McCarron et al 2011, McCarron et al 2014))
- Health problems of persons with ID often go **unrecognised and unmet** (Lennox & Kerr, 1997; Emerson & Hatton, 2013)
- People with ID do **not access health promotion** and health screening services to the same extent as peers without disability. (Robertson et al 2000)

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.

and **almost 11 times higher in females** (SMR = 1077, 95% CI = 899,1278)



Mortality rates in the General Irish population compared to those with an Intellectual Disability from 2003 – 2012

McCarron, M.,
Carroll R., Kelly C.,
McCallion P.

**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 LANCET

Volume 383, Issue 9920, 8–14 March 2014, Pages 889–895

Deaths of people with intellectual disabilities in the UK



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Health Sciences, Trinity College, Dublin, Ireland (MM)
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The Confidential Inquiry into premature deaths of people with
intellectual disabilities in the UK: a population-based study

Pauline Heslop, Peter S Blair, Peter Fleming, Matthew Houghton, Anna Marriott, Lesley Russ



Nearly a quarter (22%, 54) of people with ID were younger than 50 years when they died. Median age at Death: 64 years

Avoidable deaths from causes amenable to change by good quality health care more common in people with ID (37%) than general population of England and Wales (13%).

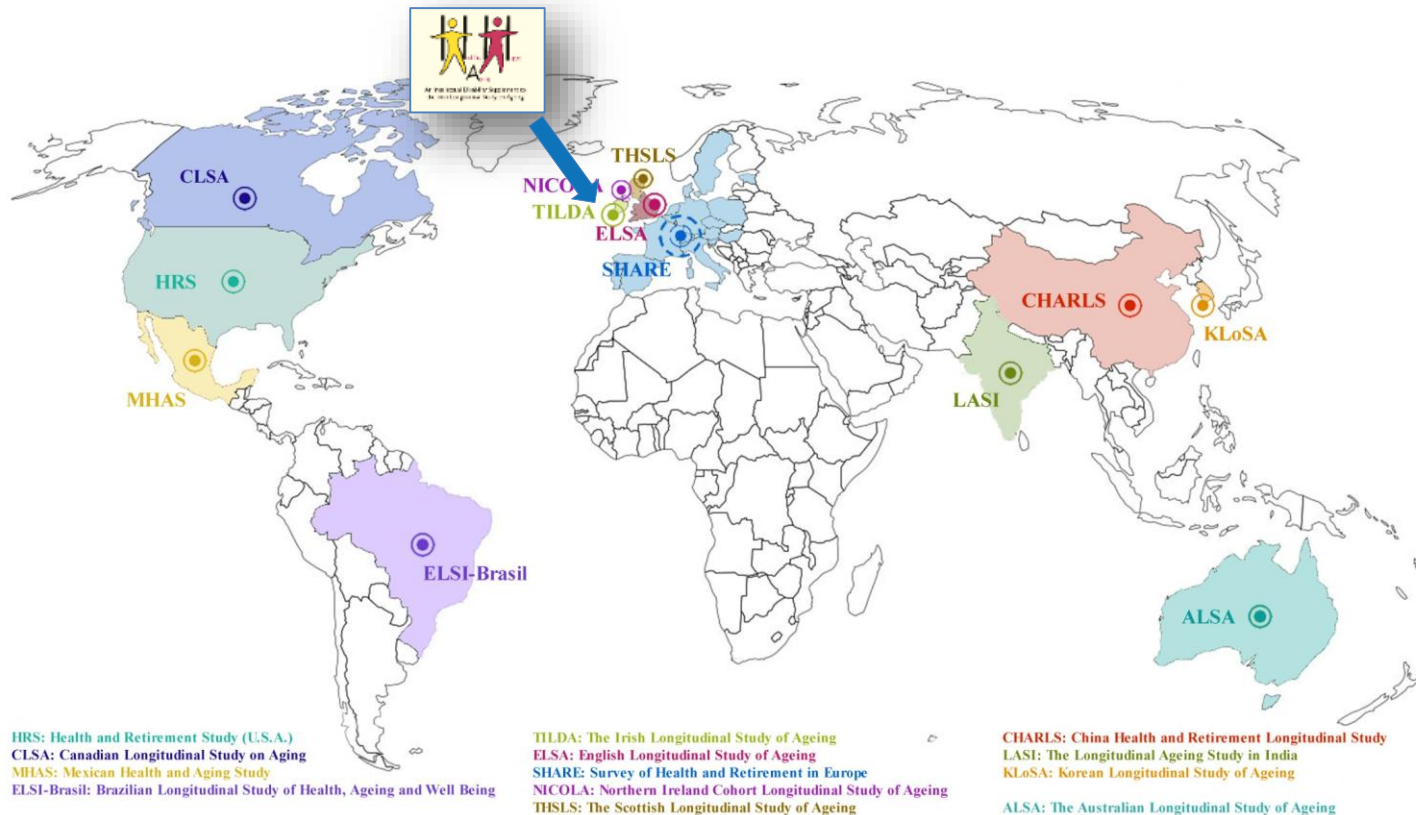
Heslop et al 2013

Key Role for the Registered Nurse Intellectual Disability (RNID)

- Promoting life long health
- Maintaining independence
- Postponing disability
- Reorienting ID services and implement service reform
- Integrating into mainstream health and social services -working across Primary Care, Acute Hospitals and Mental Health Services

The Global Family of Longitudinal Studies

Ireland leading the way in Ageing and ID

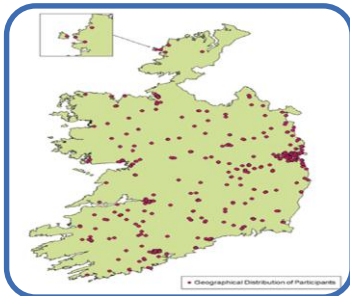


Intellectual Disability Supplement to TILDA



Intellectual Disability Supplement to TILDA (IDS-TILDA)

- Identifying the principal influences on ageing
- Comparable with the general population study - TILDA
- Random sampling – National ID Database



Wave 1: 2010

- 753 Participants
- 138 Services
- All levels of ID
- 55% Female; 45% Male
- Age 41 – 90 years
- All living circumstances



Wave 2: 2013

- Review SAC, Advocacy Groups & Additions influenced from W1
 - Similar Elements W1- W2 – additional objective measures

WAVE 3 has begun!



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An Intellectual Disability Supplement to
the Irish Longitudinal Study on Ageing

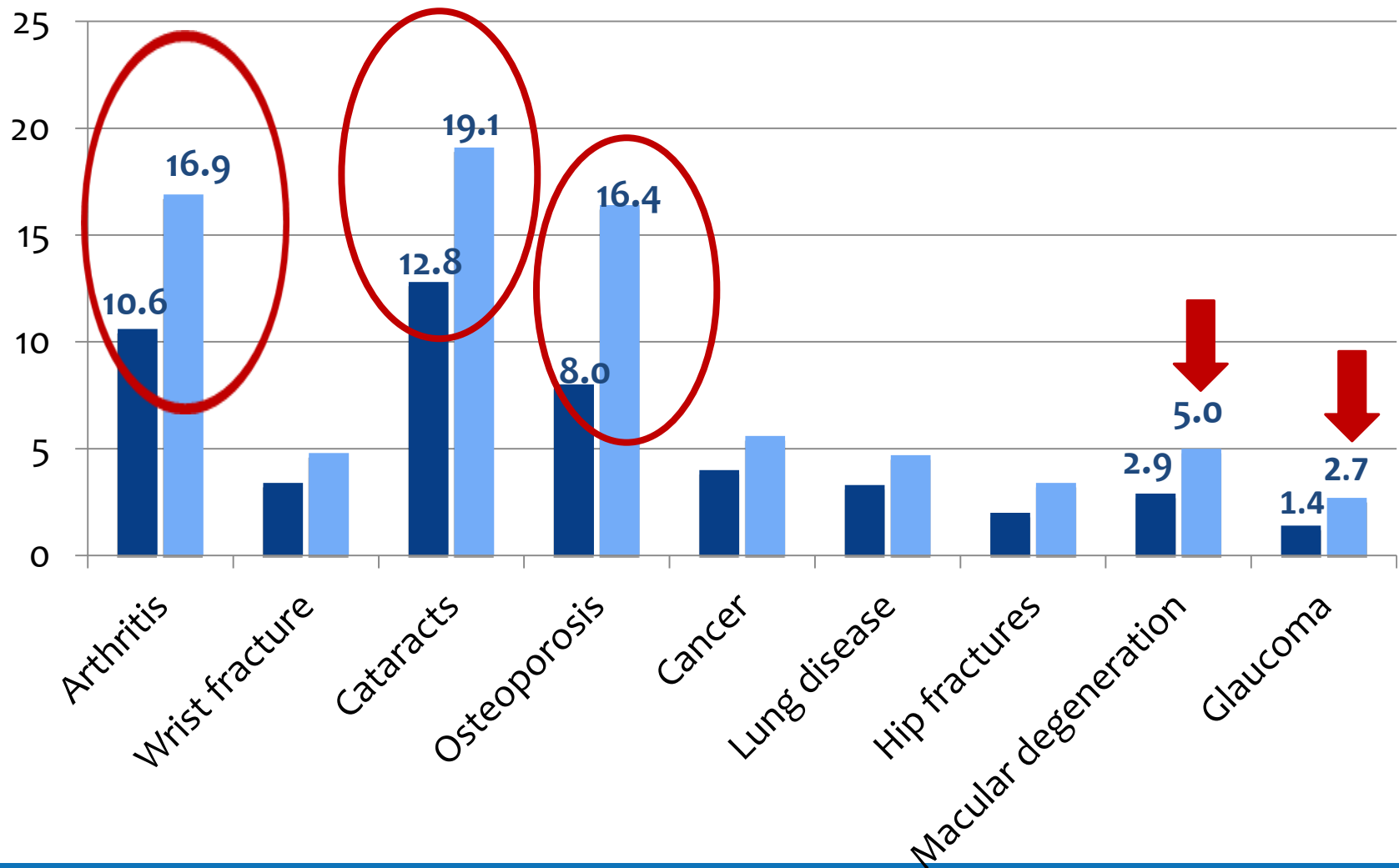
Summary of some key messages and implications for the Role of the RNID



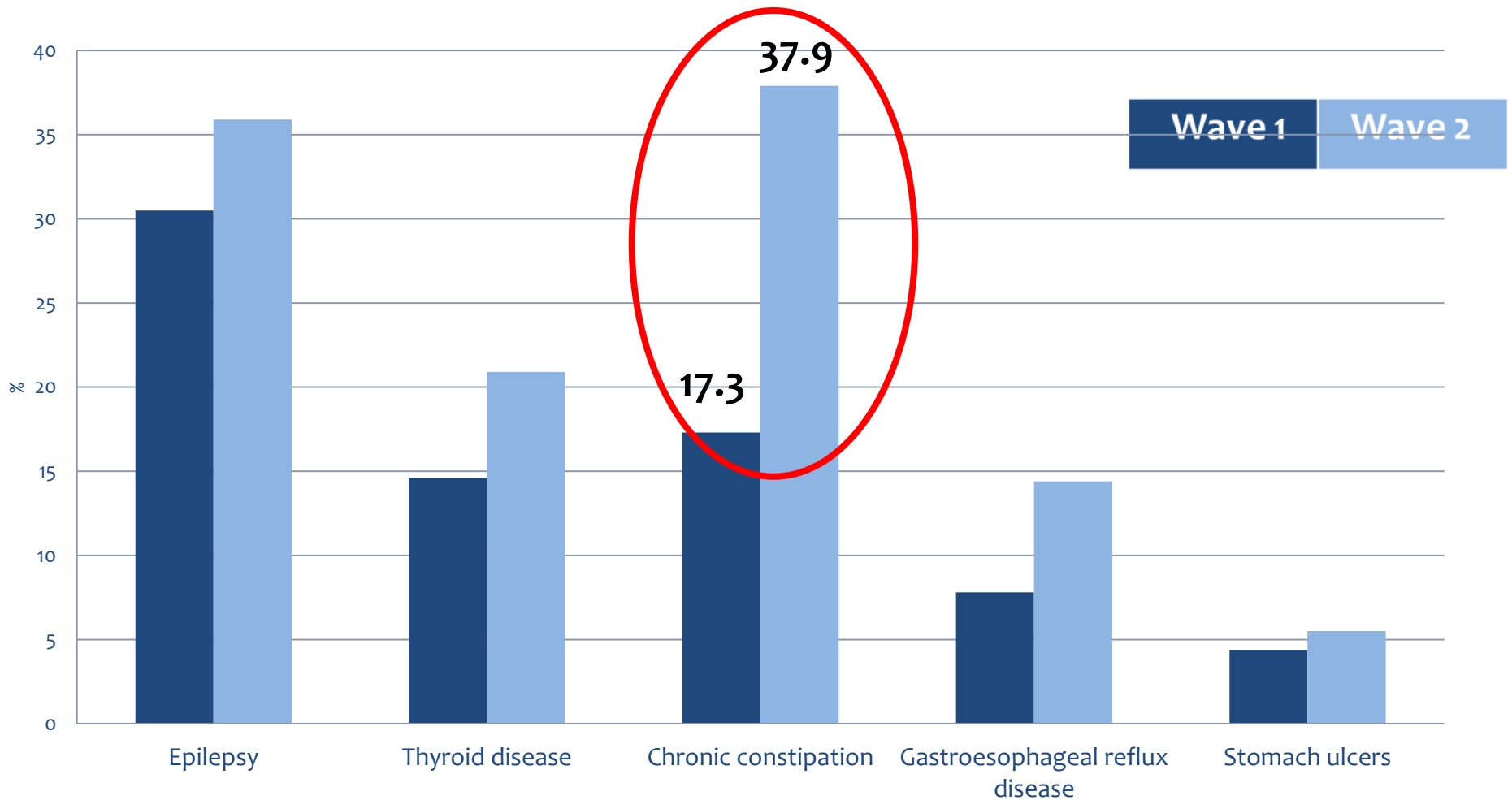
Changes in prevalence of chronic conditions

Wave 1

Wave 2



Changes in prevalence of chronic conditions





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)

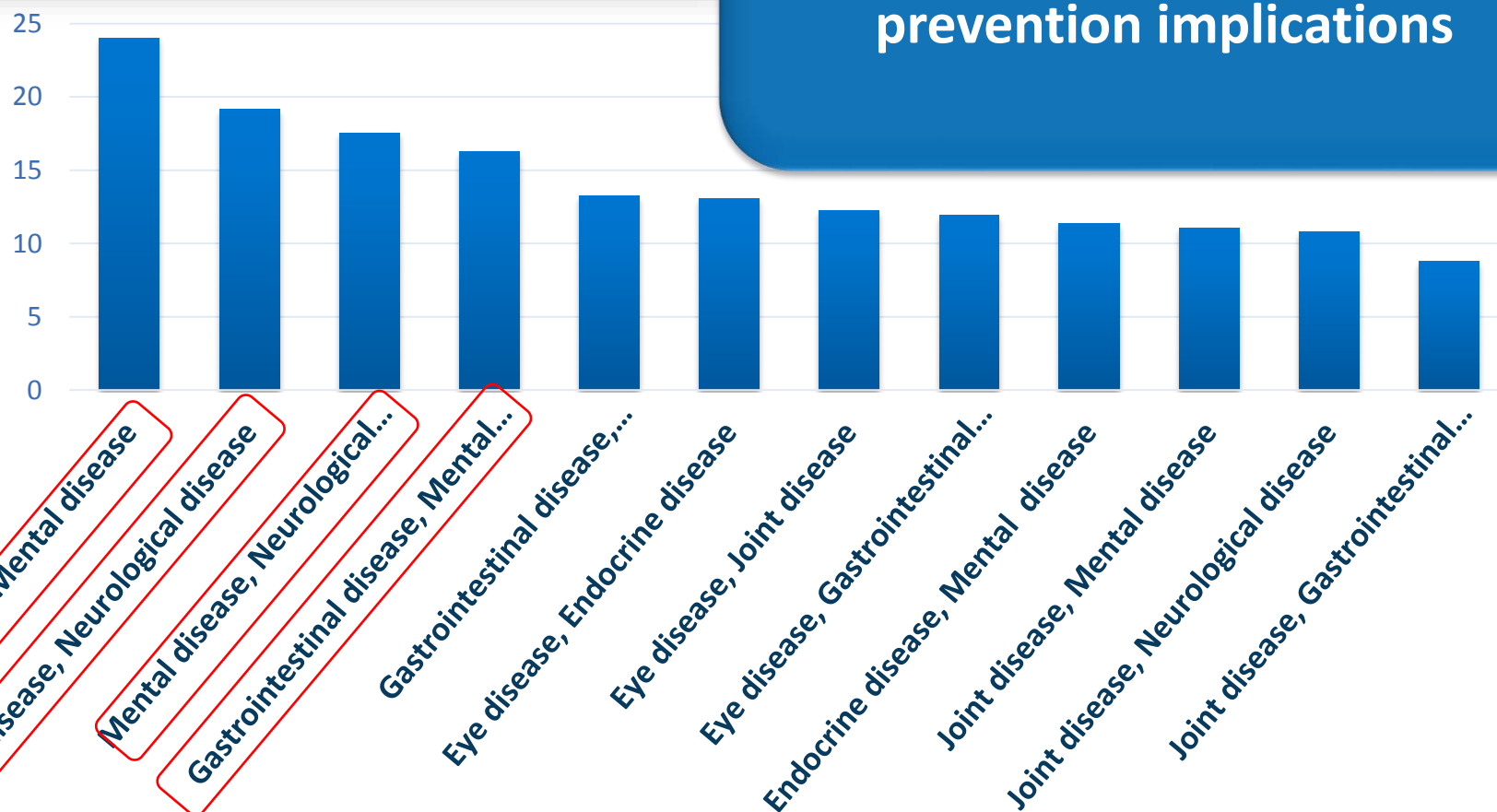
Mary McCarron^a, Janet Swinburne^a, Eilish Burke^a, Eimear McGlinchey^a, Rachael Carroll^a, Philip McCallion^{b,*}

^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

Disease patterns are different

Health promotion & disease prevention implications



Different Patterns than for the General Population

IDS-TILDA W2

Overweight/Obese – 66%

Diabetes – 7.5%

Myocardial Infarction - 1%

Hypertension – 17.5%

Osteoporosis – report doctors
diagnosis – **16.4%**

TILDA W2

Overweight/Obese – 79%

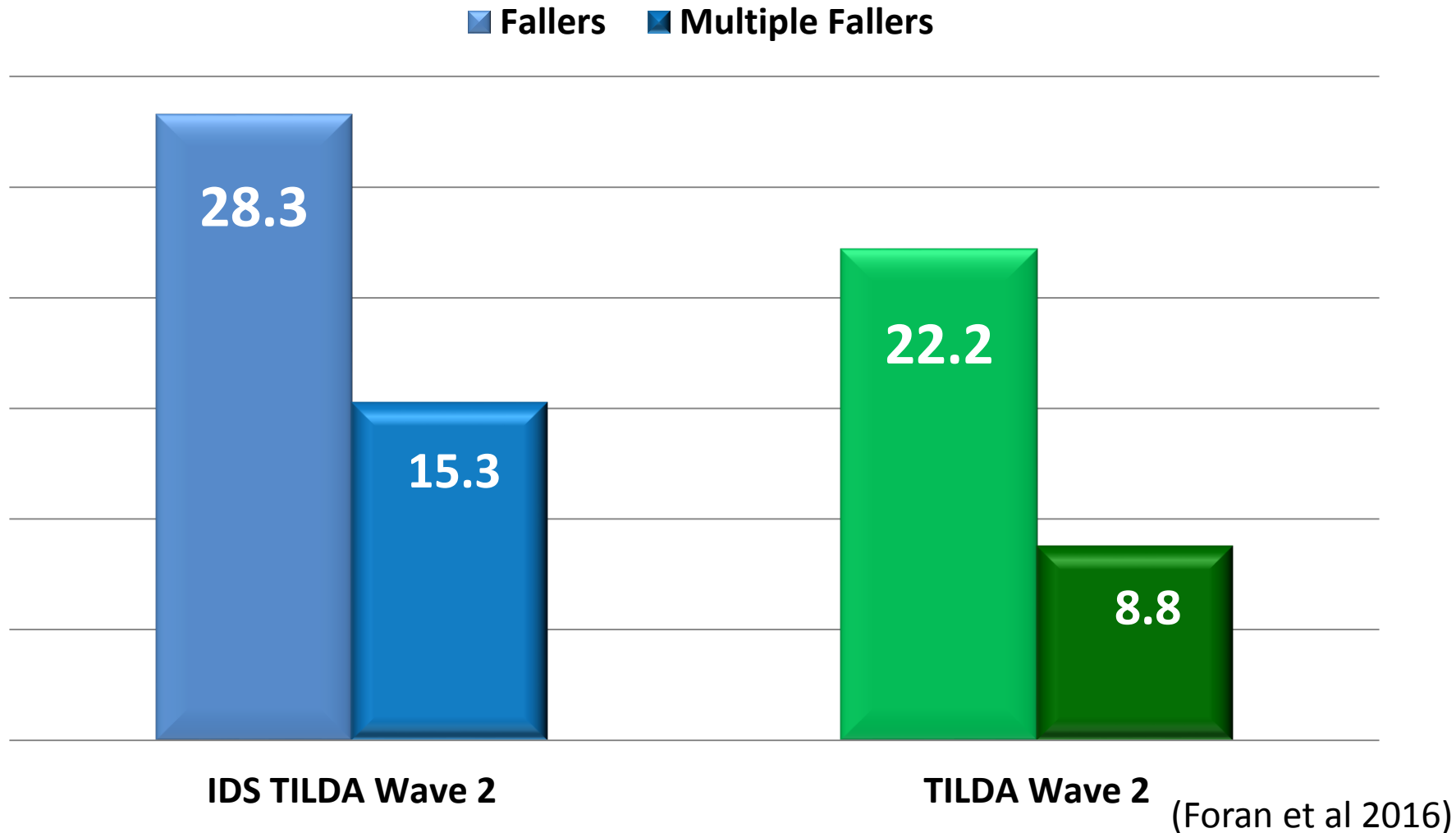
Diabetes – 9%

Myocardial Infarction – 5.5%

Hypertension – 37%

Osteoporosis – **14.3%**

Difference in Overall Falls Prevalence in People with an Intellectual Disability vs the General Population



Osteoporosis and Osteopenia

- Doctor diagnosed osteoporosis rose from **8%** in wave One to **14%** in Wave 2
- More dramatic and of concern is that at Wave 2 there were **measured** bone concerns of **33.1%** with osteopenia and **41%** with osteoporosis.

© 2016 (Darke et al 2016)

Of the men with objective evidence of
osteoporosis

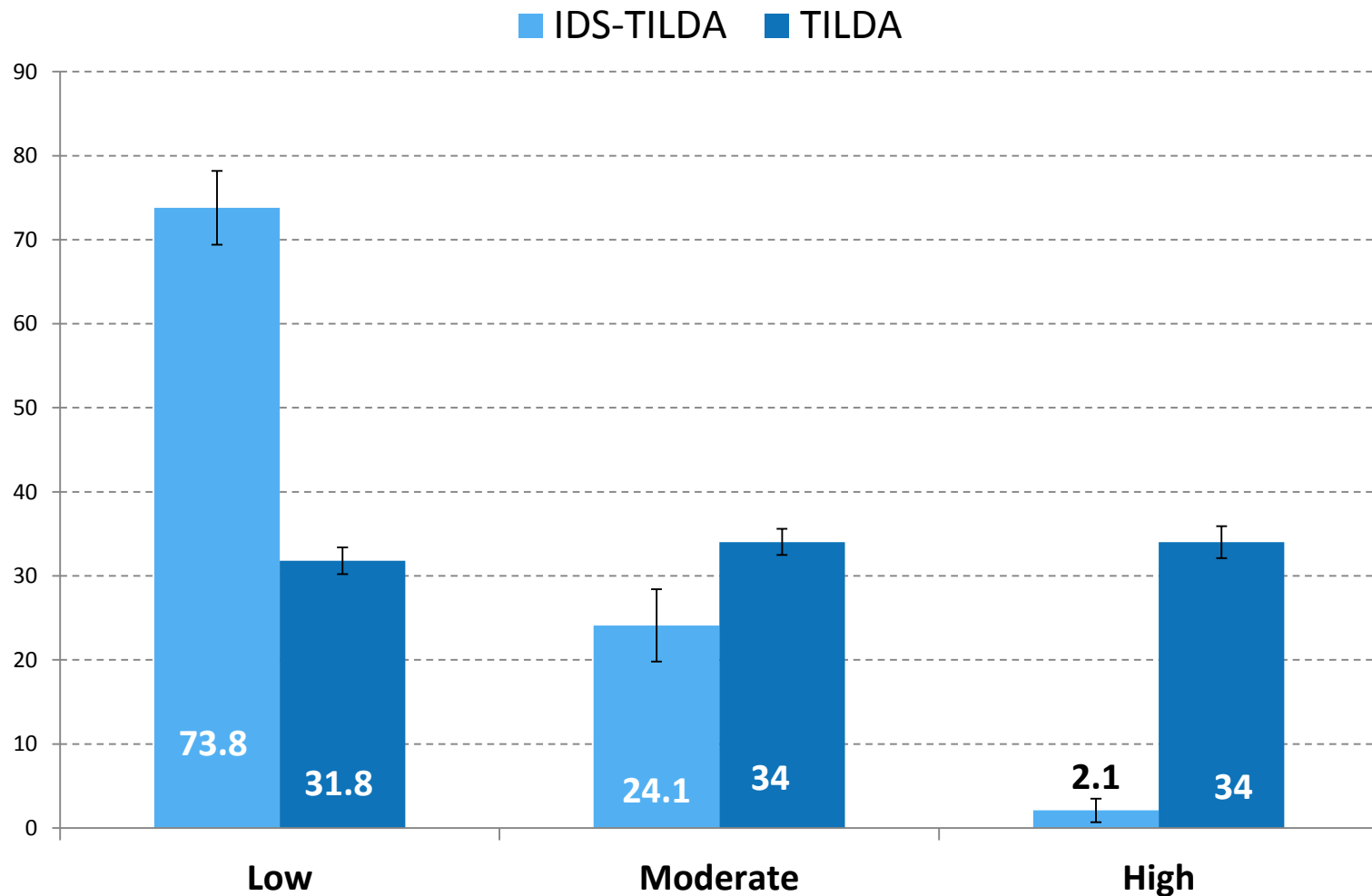
9 out of 10 did NOT have a doctor's
diagnosis

Of the women with objective evidence of
osteoporosis almost 7 out of 10 did NOT
have a doctor's
diagnosis of osteoporosis.

Implications for the RNID....

- Presenting **risks are very different** for people with intellectual disability- **poor assessment and screening needs to be addressed**
- **Health promotion and education** required to **target** these specific and different **risks**
- **Responses needed to potential for fractures**/complications especially **post-fall** due to undiagnosed osteopenia/osteoporosis
- Maintenance of health must encompass a **multidimensional and multidisciplinary approach**

LEVELS OF PHYSICAL ACTIVITY, WAVE 2



Point Prevalence of Dementia in Down syndrome over a 3 year period: IDS TILDA



**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**

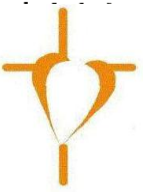


A 20 Year Longitudinal Perspective

- 77 Females with Down Syndrome
- Aged 35 years+
- First screened 1996
- Annual assessment for dementia (ICD-10 criteria) in Memory Clinic
- Comprehensive diagnostic work up and consensus diagnosis

(McCarron et al 2016)

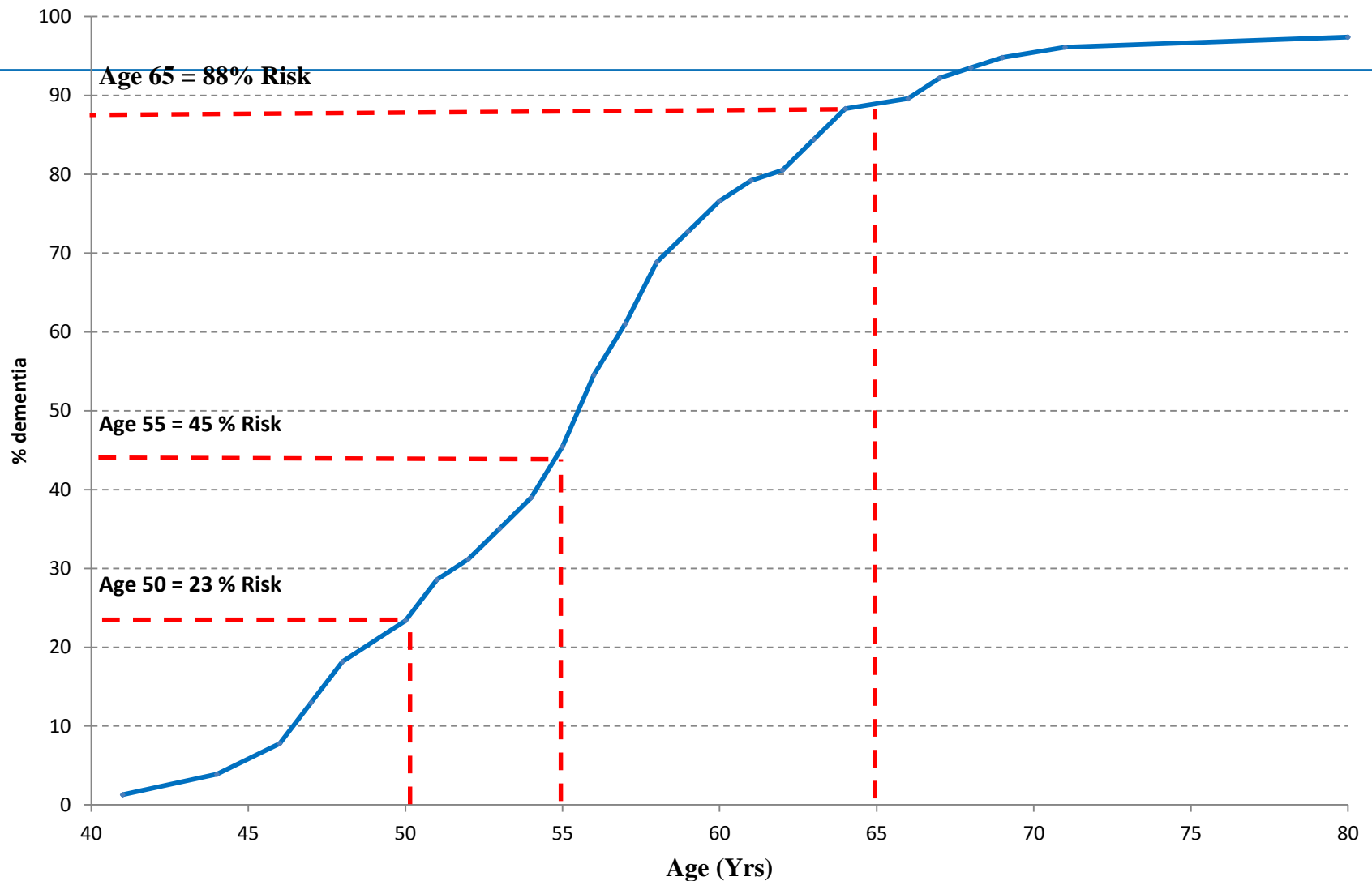
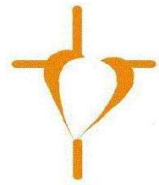
Summary of Key Findings



Over the 20 year follow-up period

- 97.4% - developed dementia
- Age of onset: 55 years (SD 7.07)
- 96.7% - persons with moderate ID developed dementia
- 100% - Persons with severe ID developed dementia
- None had dementia confirmed prior to age 40 years

Risk Trajectory According to Age

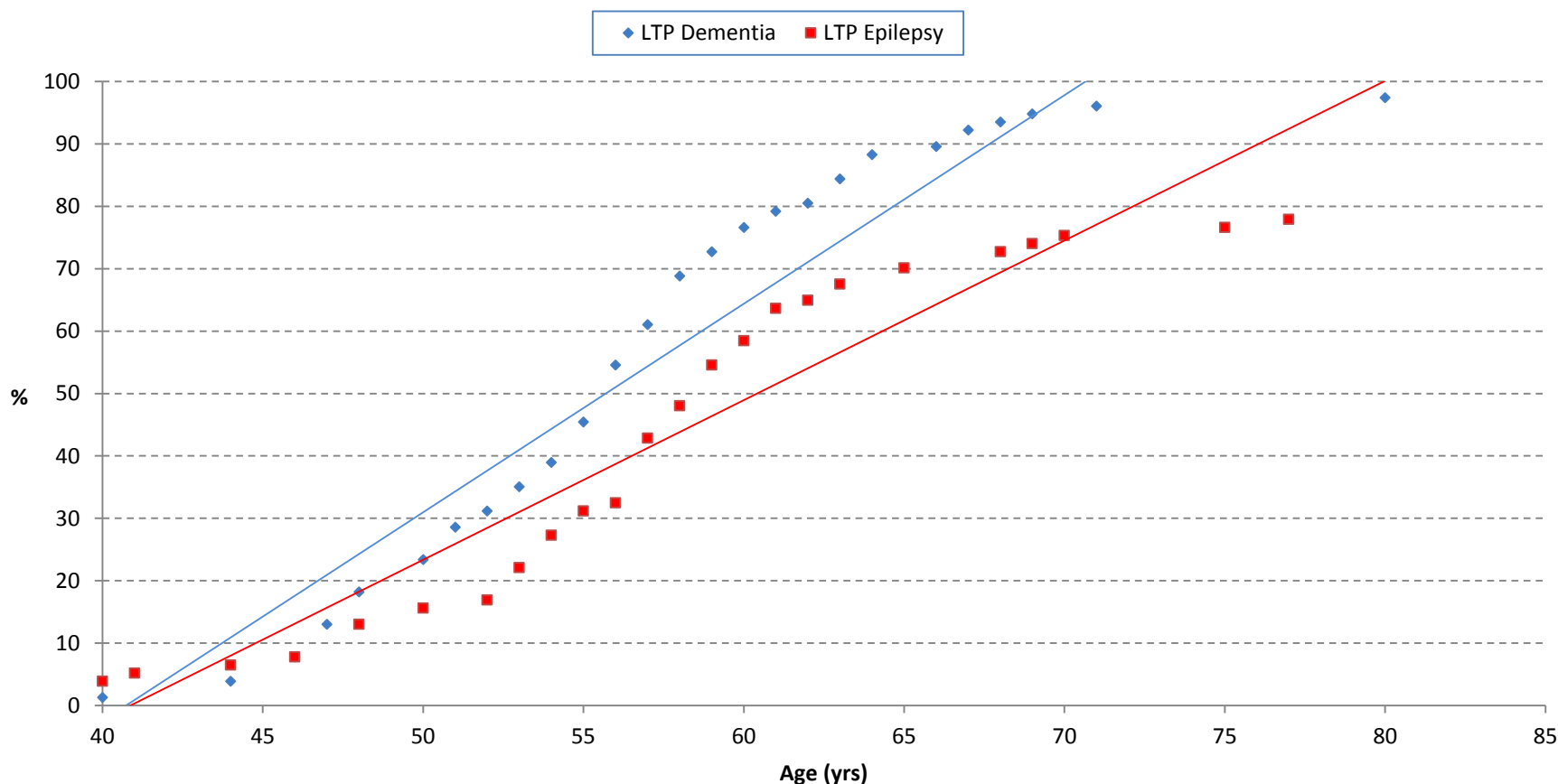


Dementia and Epilepsy

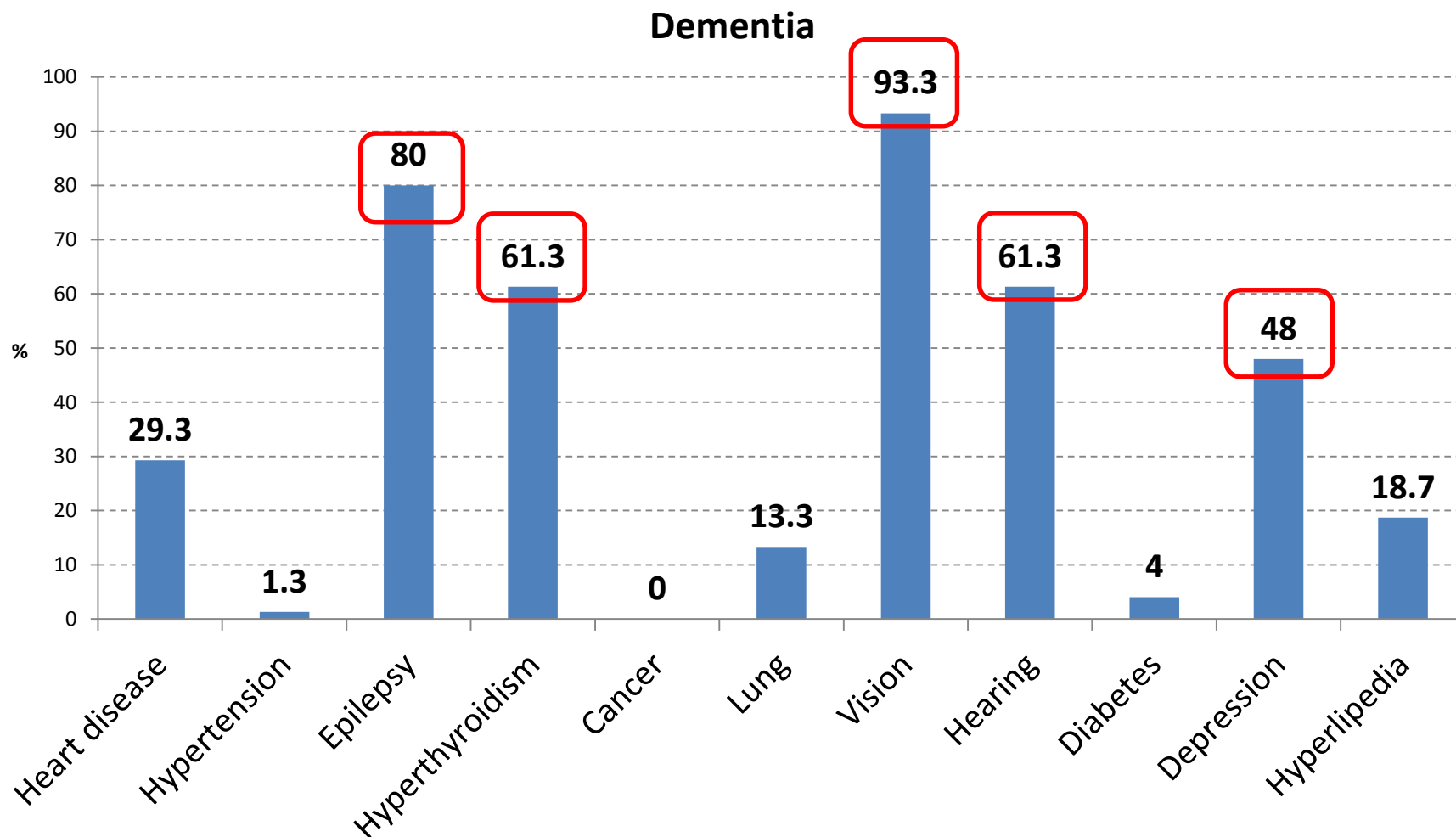


77.9% (60 of the 75 with dementia) had epilepsy

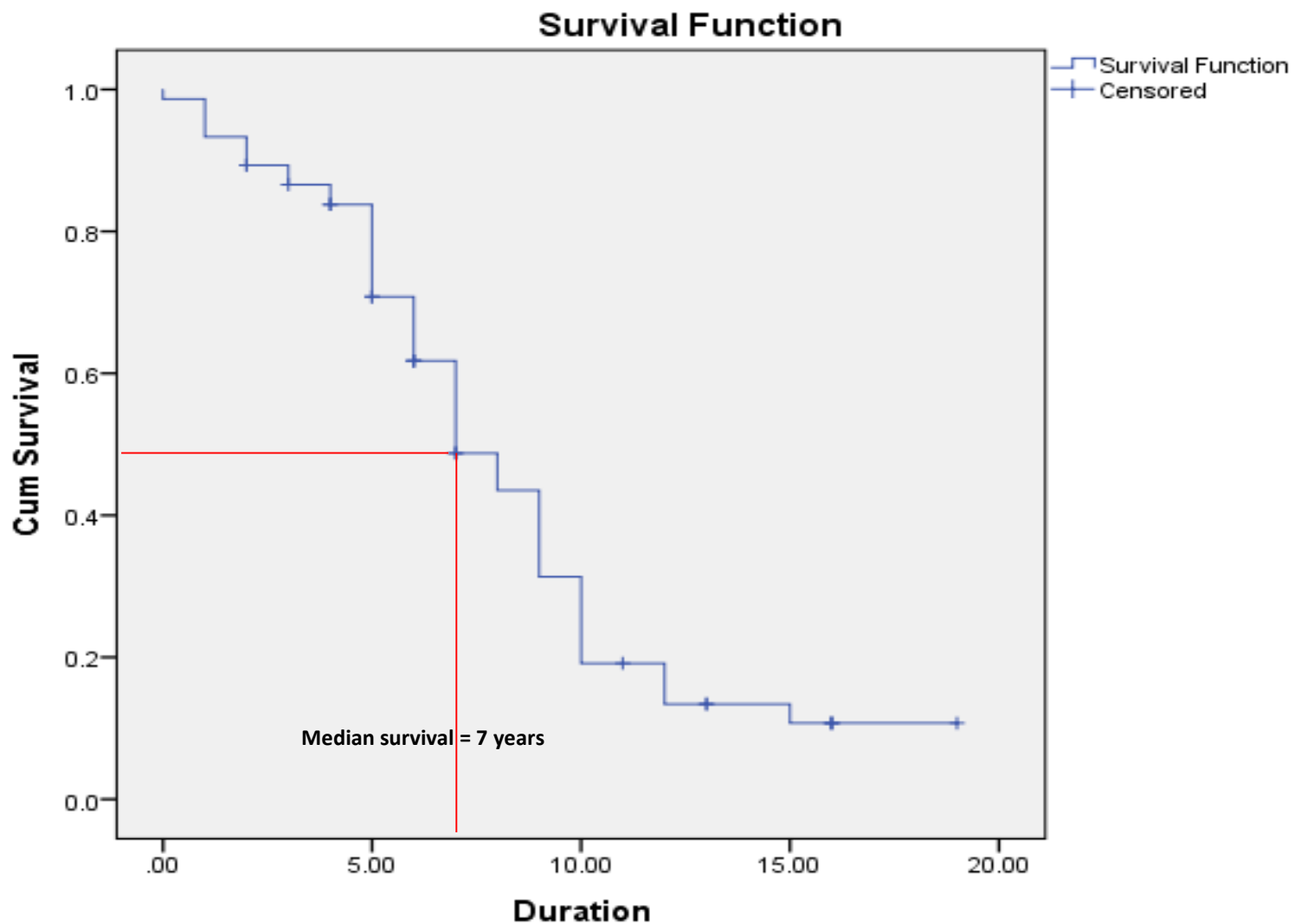
Life Time Prevalence



Co-Morbidities



Mortality



Implications for the RNID

SUBSTANTIAL INCREASED RISK OF DEMENTIA >50YEARS

- Rate of progression seems slightly increased, but, nonetheless:
 - 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**
 - **Association** between co-morbid **depression and dementia**
 - Little impact for **level of ID**
 - **Increased survival** at advanced dementia

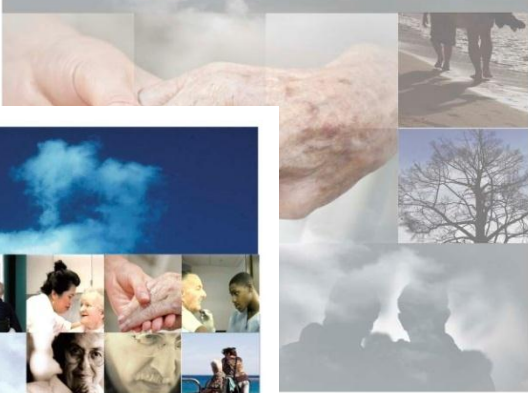
Improving Outcomes by Developing & Implementing Standards for Care

Standard 5:
Promoting Well-Being and Social Connectedness




Each person with dementia is supported to maintain and develop relationships with those who are important to them.


Standard 6:
Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs



Standard 1:
Appropriately Trained Staff and Service Development



Standard 2:
Memory Assessment Service




All people with intellectual disability have access to a memory assessment service specialising in baseline screening, dementia assessment and diagnosis in persons with intellectual disability.

Daughters of Charity Service

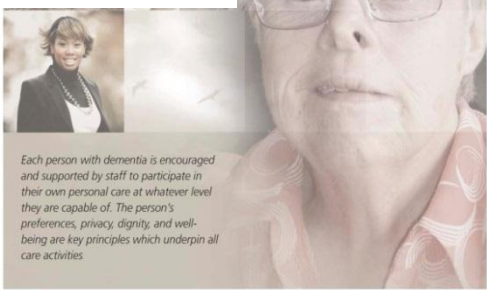
Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards

A Guide to Practise

McCarron, M & Reilly, E. 2010



Standard 3:
Person-Centred Care





Brain **E**xercises for **A**dults with **D**own **S**yndrome

Assessing the Feasibility of Cognitive Training to Increase Executive Functions in Adults with Down Syndrome **The BEADS study**

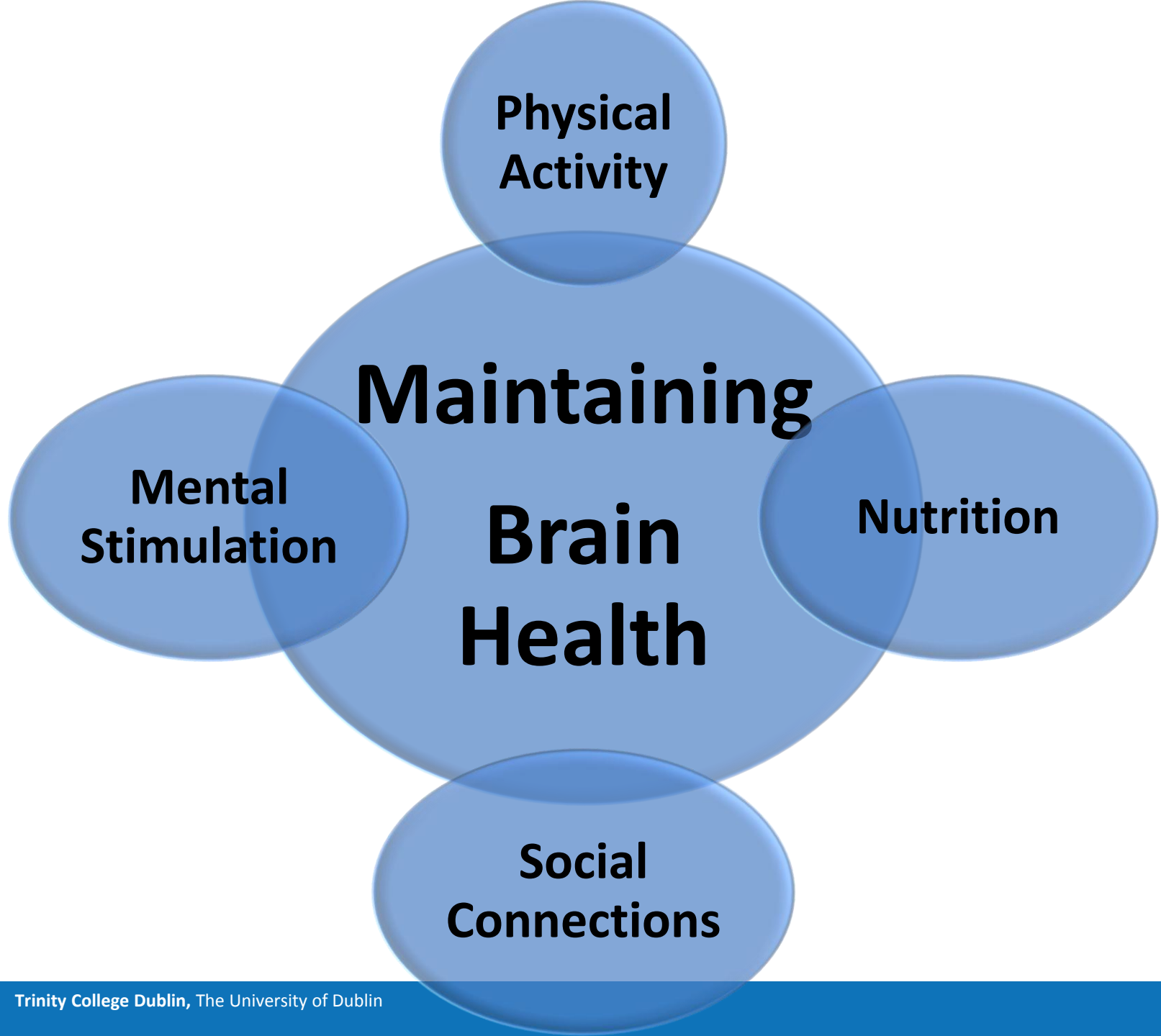
Source Eimear McGlinchey

Promoting Brain Health – Critical issues



Brain Exercises for Adults with Down Syndrome

- What **strategies** are currently in place to support healthy ageing and **to challenge the issue of AD in DS**?
- Are you aware of any **possible interventions** to deal with Dementia in people with DS and ID in general?
- Could such a **cognitive training program** be integrated into **daily care**?



Medicine Use

No
polypharmacy

0 – 4 medicines

Polypharmacy

5 – 9 medicines

Excessive
Polypharmacy

10+ medicines

Polypharmacy in IDS TILDA & TILDA

Polypharmacy	Wave 1	Wave 2	TILDA
Medicine Users	92%	95% ↑	69%
No Polypharmacy	46%	33% ↓	79%
Polypharmacy	32%	43% ↑	19%
Excessive Polypharmacy	22%	25% ↑	2%

(Dwyer et al 2016)

Anticholinergic Burden in Older adults with ID

Approximately **30% of the people studied were taking high levels of medicines with anti-cholinergic activity**, defined as having an anti-cholinergic burden (ACB) score of 5+.

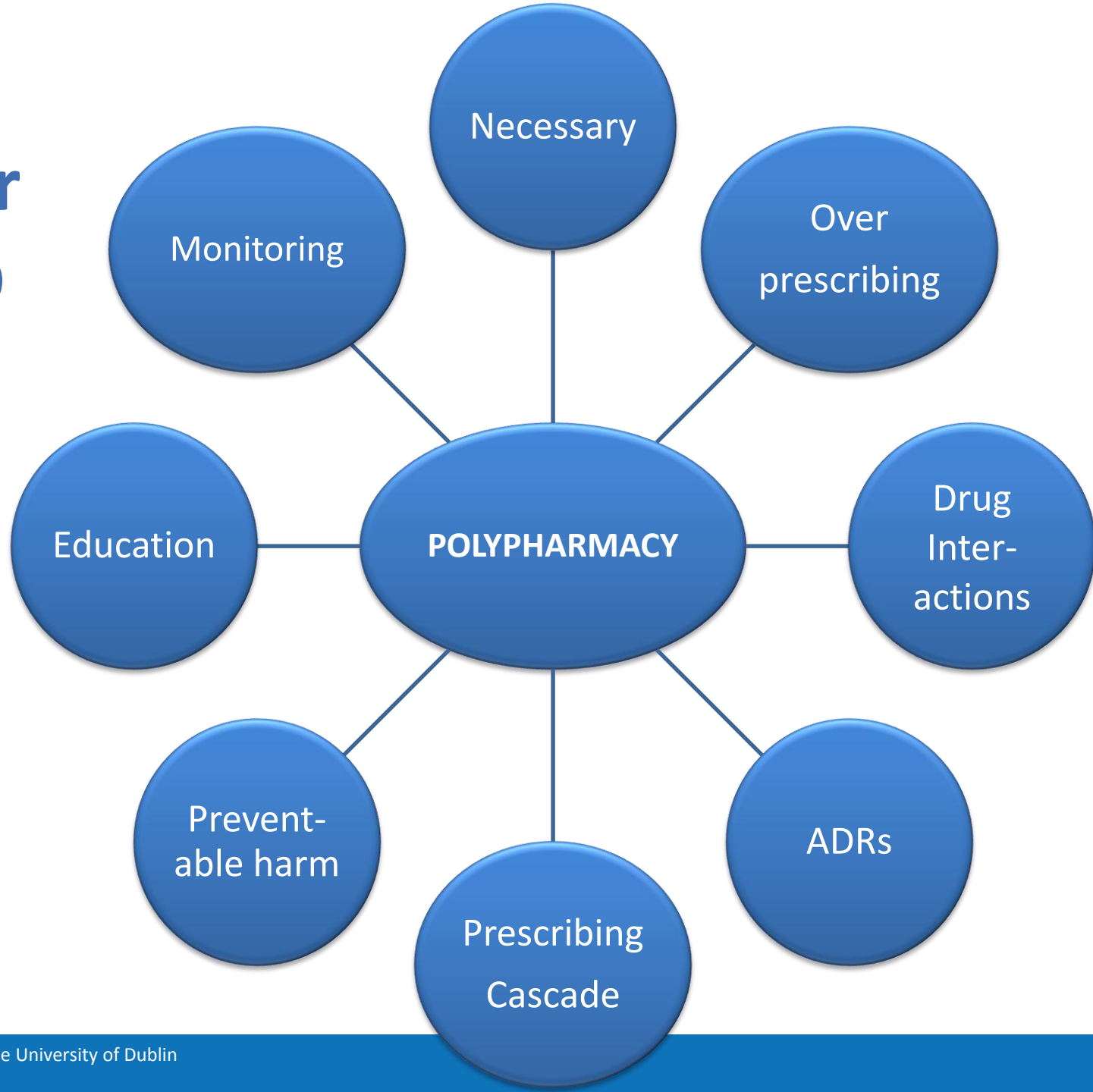
50% of people with intellectual disabilities in the study were taking medicines with definite anti-cholinergic activity compared to 4% of older adults in the general population.

Antipsychotics, accounted for **over one-third of the medicines with** a high anti-cholinergic score being taken by people with intellectual disabilities.

High levels of anti-cholinergic prescribing were associated with people in the study reporting **side effects of daytime drowsiness and chronic constipation**.

(Dwyer et al 2016)

Critical Issues for the RNID



Medication data is so important!

- Unique population
- Development of specific prescribing guidelines for doctors
- Better health and medicine services for people with ID
- Better health outcomes
- Identify at-risk groups



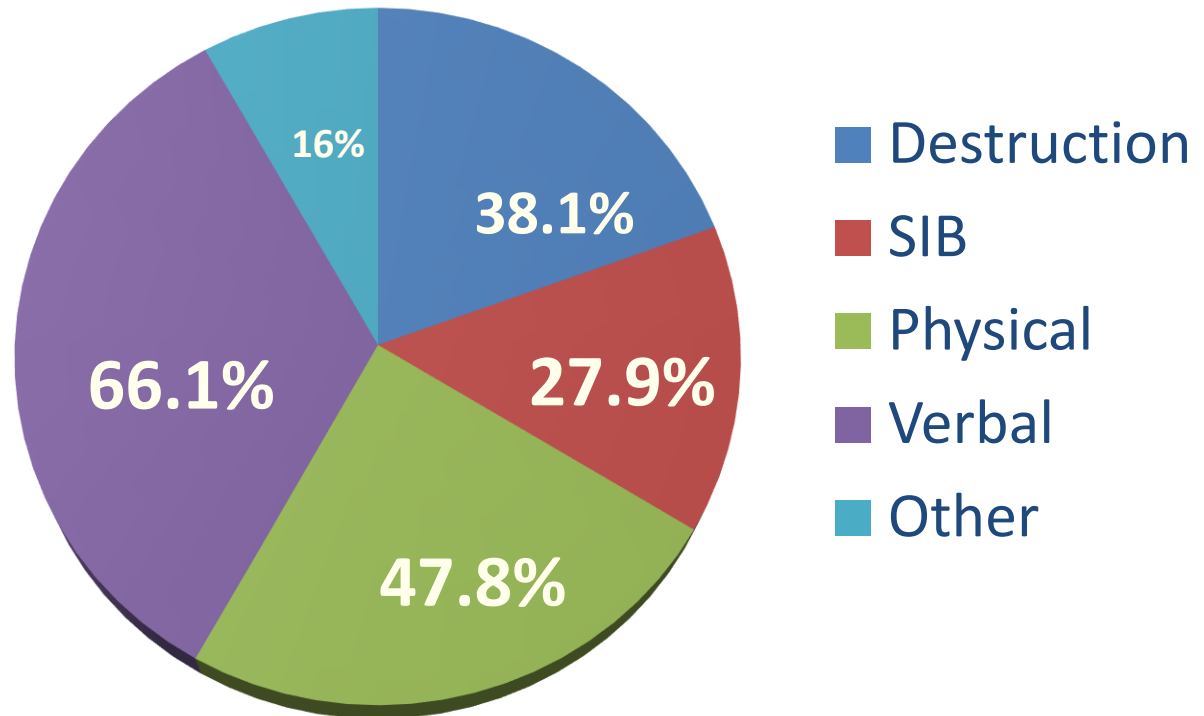
Role of RNID in Medication Use

- Safe and appropriate **provision of medicines**
- **Collaborating** with doctors, pharmacists and other health care professionals **on pharmaceutical care** plans for people with ID
- **Monitoring and reporting** adverse drug reactions and side effects of medicines
- **Educating and providing information** to people with ID about their medicines

Wave 2 Prevalence of Behaviour which challenges (BWC)

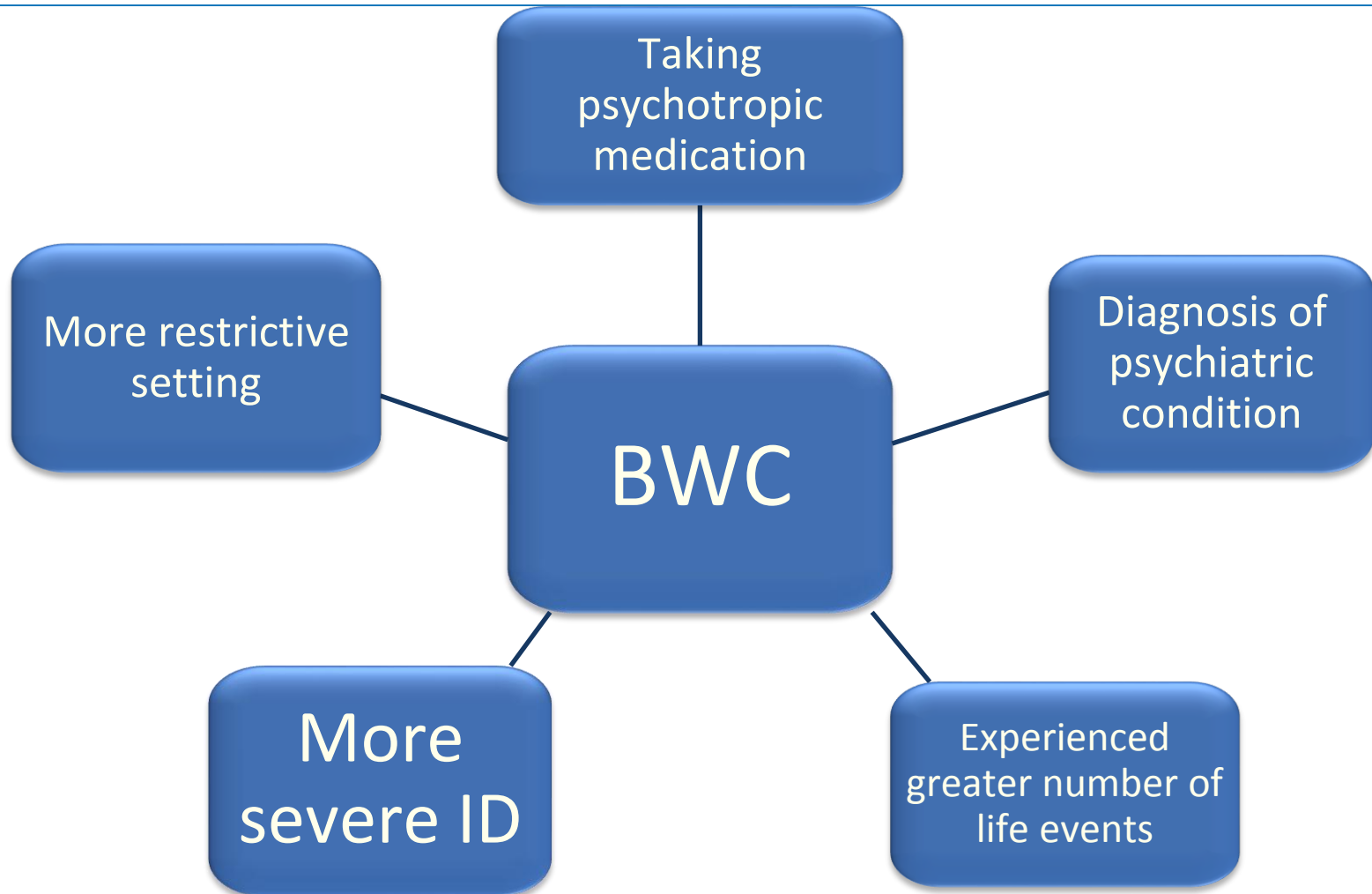
Types reported

- **53%** of participants displayed at least 1 type of BWC
- Majority (55%) those reporting BWC reported displaying >1 type



(Dwyer, C et al 2016)

Factors associated with Displaying BWC



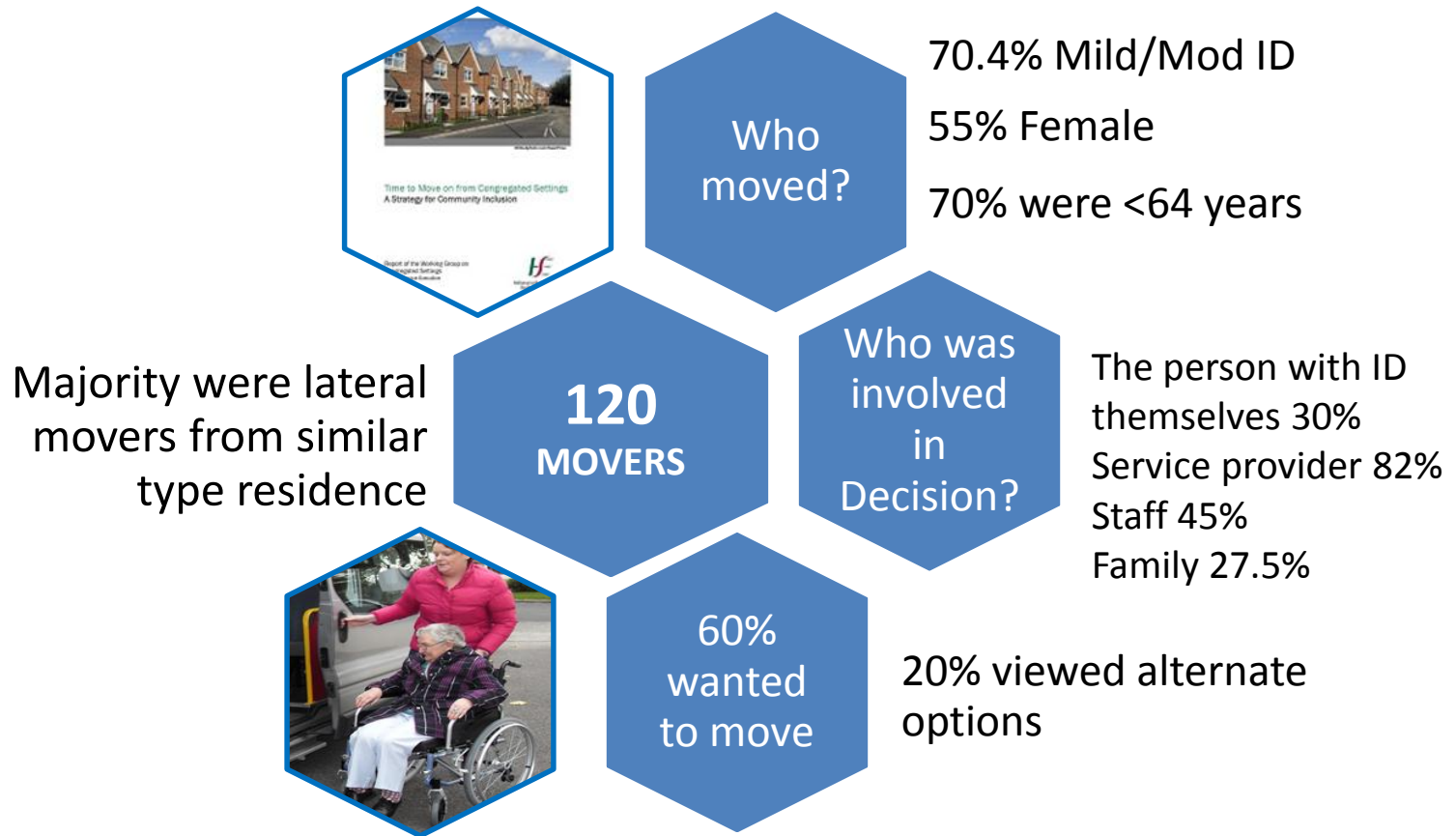
Factors independently associated with BWC in binary logistic regression models ($p < .05$)

Implications and Role of RNID

Need to build **specialist role** within the multidisciplinary team to guide, support and plan for the **complexity** in clinical practice to...

- **Guide the development of behavioural support plans** to aid older adults with ID to express frustration and anger in meaningful and more positive ways
- **Integrate risk management strategies** in care and care planning to recognise who may be at greater risk of displaying BWC, particularly those
 - with mental health problems
 - poorer communication skills
 - people who have experienced significant life events such as a change of keyworker or change of residence in last 12 months

Choice and Support – Moving Home



(O'Donovan et al 2015)

Transitions and personal choice

Some people with ID are changing where they live

- Not always by choice
- Not always involved in decision process
- Not always to the community



First indication of policy implementation on national level

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

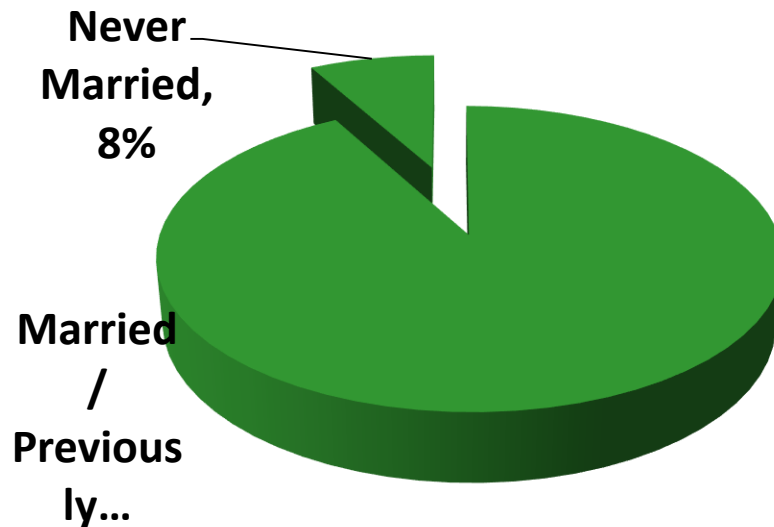
RNID has a Fundamental Role in Implementing Service Reform

As people with ID move from residential/institutions to community need to consider the changing role of the
RNID

- in facilitating '**real person centred choice**' for people with ID
- in **assisting decision-making**
- in **assisting PwID in transition process** and **planning**
- **to bring expertise** to delivery of health services in the community

Social Connectedness: Partners & Children

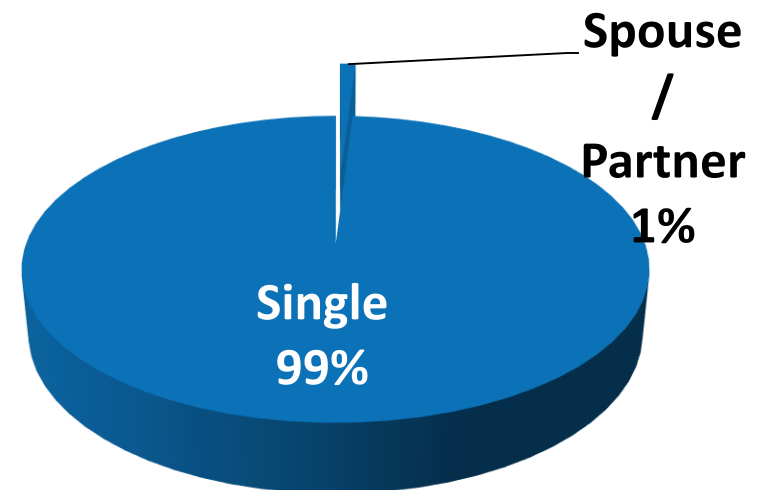
General Population (TILDA)



Mean No. of Children

2.8 – 3.3

IDS-TILDA Sample



Mean No. of Children

0.0

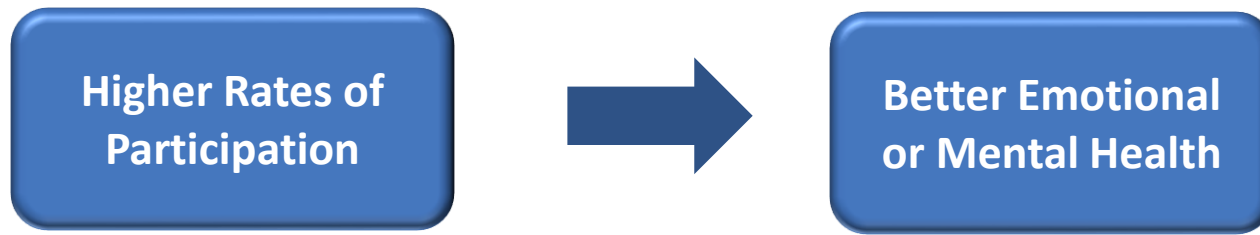
Interpersonal Relationships

- **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



Outcomes of Social Participation

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



- Across all 17 measures of participation **having friends outside your home** was the strongest predictor of better Emotional or Mental health

Role of the RNID in Social Participation

Staff

- Play an important social role
- RNID facilitators of social and community participation

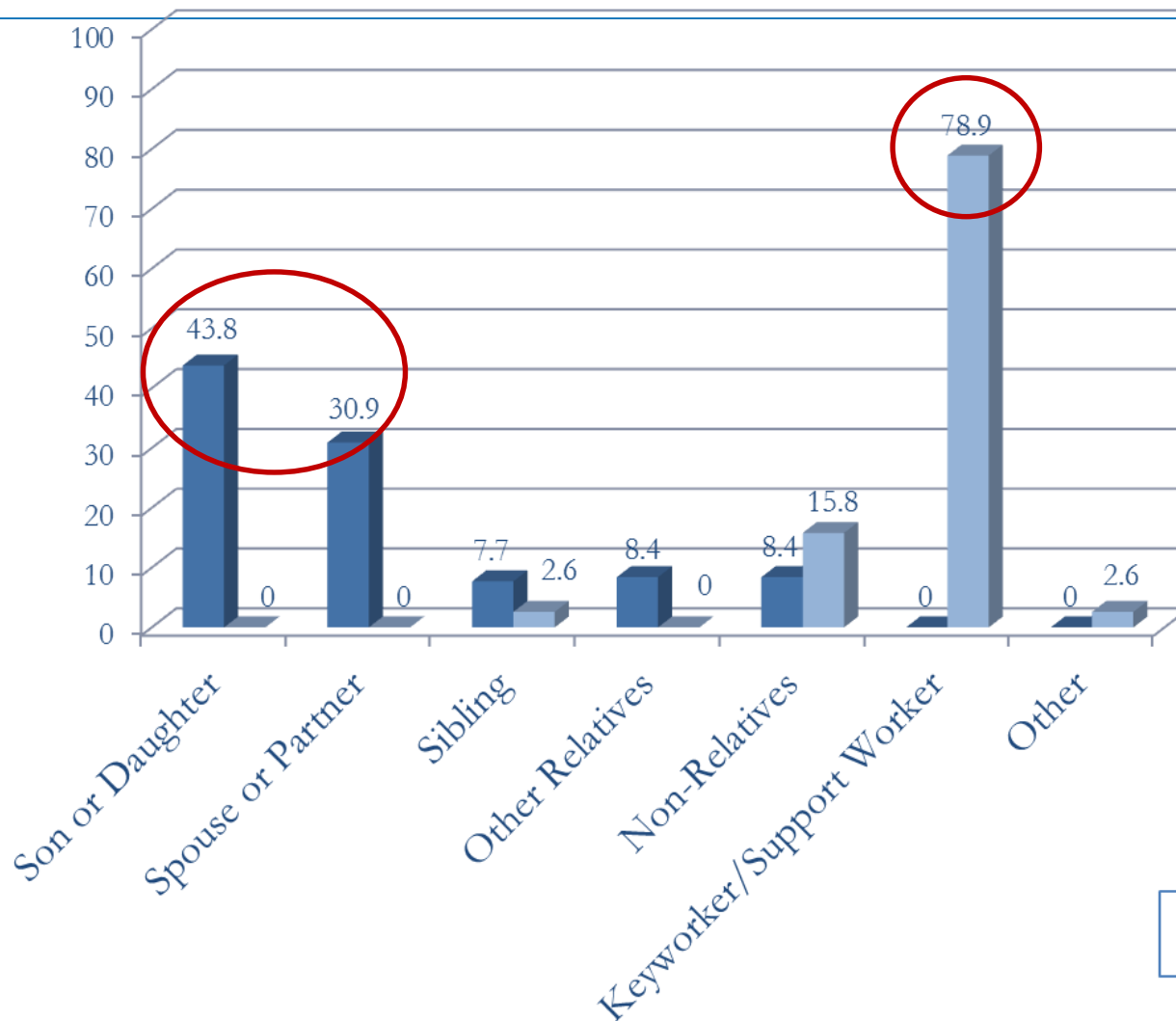
Policy

- High medical support needs across the lifespan
- Ageing population with high nursing support needs

Culture change

- RNID Leadership
- Move away from risk-averse
- Buy-in to individualised, person-centred *culture* (facilitating not paternalistic)

Supporting people at end of life



AIIHPC

All Ireland Institute of
Hospice and Palliative Care

■ TILDA at EOL interview

■ IDS-TILDA at Wave 1

Source: Janet O'Farrell (2015)

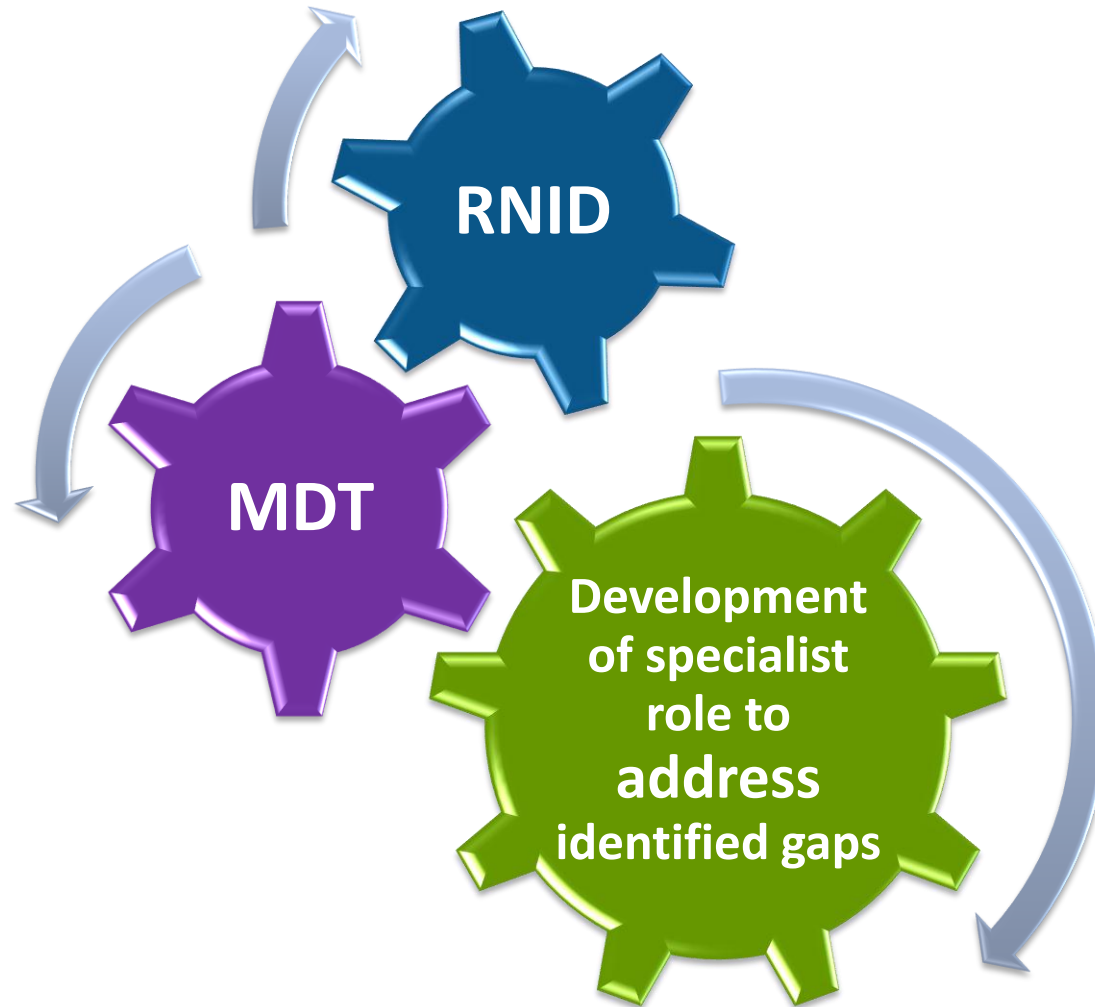
Issues for Family Carers; the 'triple decker sandwich'



Implications and role of the RNID

- Implementation of **Congregated Settings Report** must consider the **impact on families**
- **Support for sibling carers** of PWID
- **Community based liaison** role in supporting and planning with families
- Greater attention needed on **carer health** and self care

Key integration and development of the RNID





Brain Exercises for Adults with Down Syndrome

Developing Clinical Capacity



Influencing Policy Planning and Change Agent



Provision for the Changing and complex health need



Promoting Person Centeredness



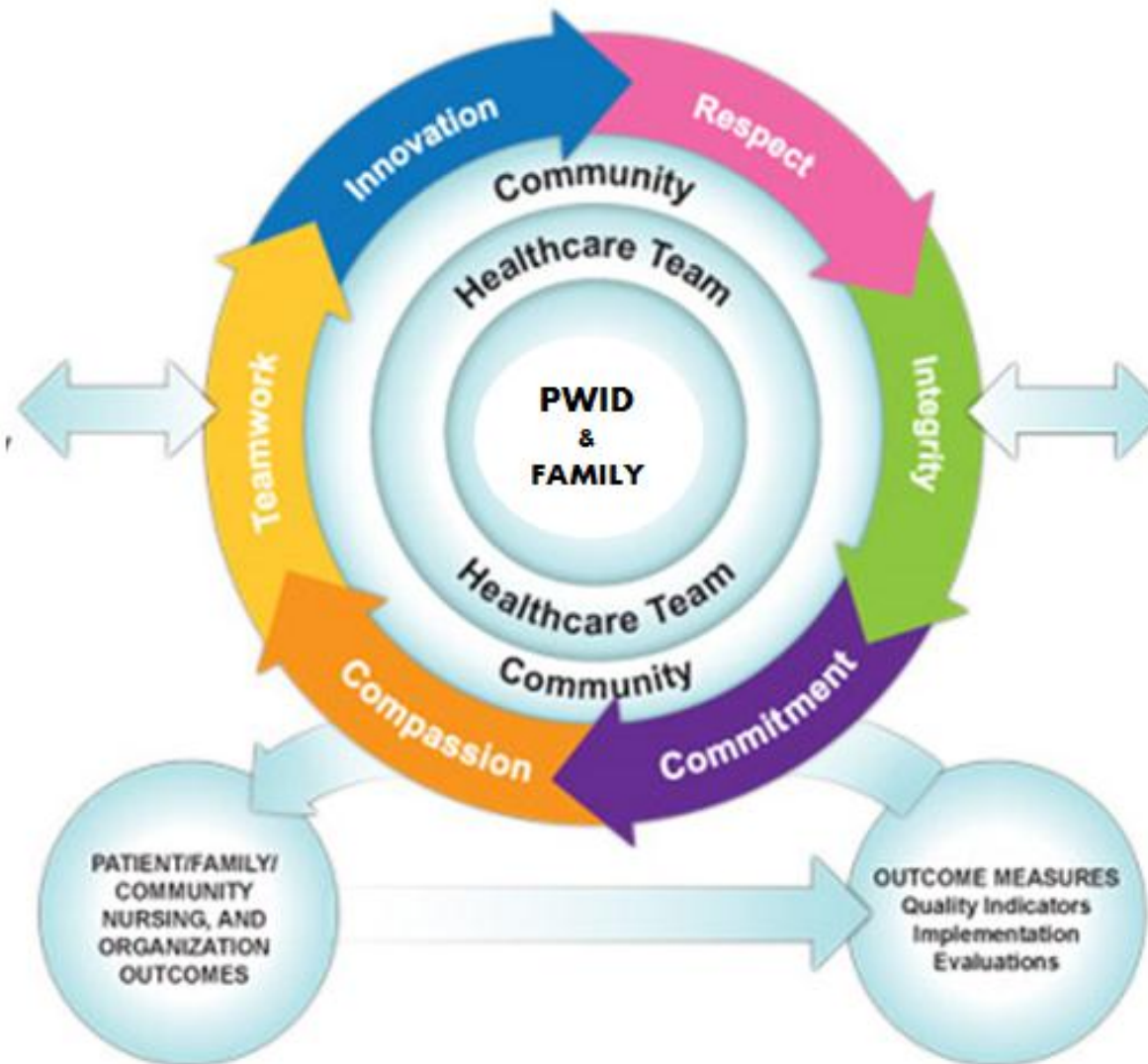
Enhancing Clinical Leadership



Supporting Family

Contribution of Specialist Role Development

- Developing, expanding role, Addressing gaps
- Developing strategy and meeting research need
- Enabling others
- Critical reflector and building knowledge



- Nursing Practice Expert
- Evidence Based Practice
- Professional Growth and Development
- Change agent

Making Changes



Houses of the
Oireachtas Commission
Coimisiún Thithe
an Oireachtais



Trinity College Investing in Ageing and Intellectual Disability



**Chair in Ageing and
Intellectual Disability**



**Ussher Assistant Professor in
Ageing and Intellectual
Disability**

Trinity College Investing in Ageing and Intellectual Disability

CPD and Post
graduate
Opportunities

Irish Observatory
of Ageing and
Intellectual
Disability



Acknowledgement



An Intellectual Disability Supplement to
the Irish Longitudinal Study on Ageing

**Grateful
appreciation to the
participants and
families**



**The funders and
supporters**



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