



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Ageing with Down Syndrome: Latest Insights

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@MccarrmMary

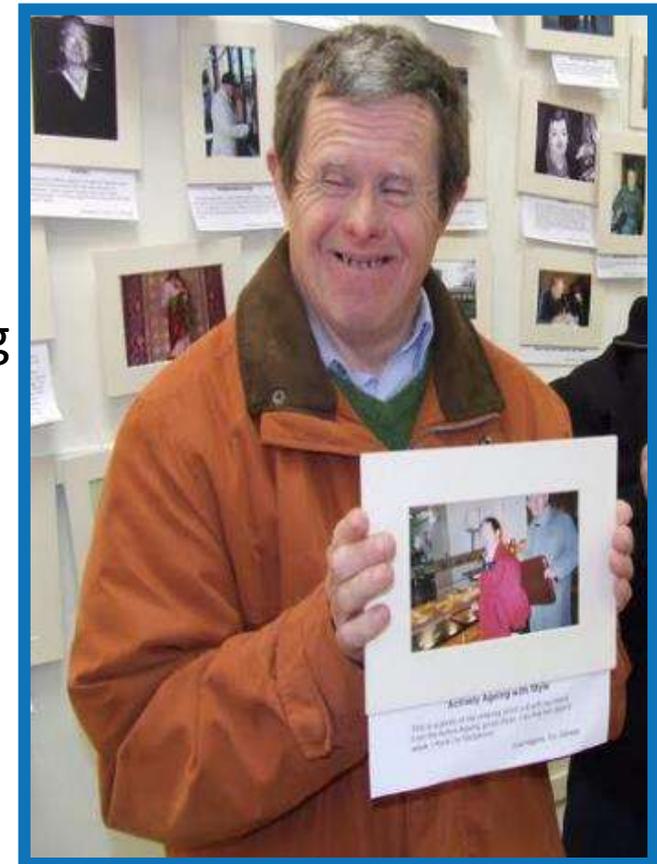
#ageingwithID



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

Ageing with Down Syndrome Opportunities

- This is a success story
- Little known about ageing with DS
- Opportunities to:
 - Promote lifelong health and wellbeing
 - Maintain independence
 - Postpone decline
 - Reorient services
 - Mainstream the ID agenda





IDS-TILDA

Joins the Global Family of Longitudinal Studies



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The IDS-TILDA Story



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First nationally-representative longitudinal study on ageing with an intellectual disability comparable to the general population





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IDS-TILDA

Objectives

- **To understand the health characteristics** of people ageing with an intellectual disability;
- **To examine the service needs and health service utilization** of people ageing with an intellectual disability;
- **To identify disparities in the health status** of adults with an intellectual disability as compared to TILDA findings for the general population; and
- **To support evidence-informed policies, practices and evaluation.**



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IDS-TILDA: Values Framework

“Nothing about us, without us”

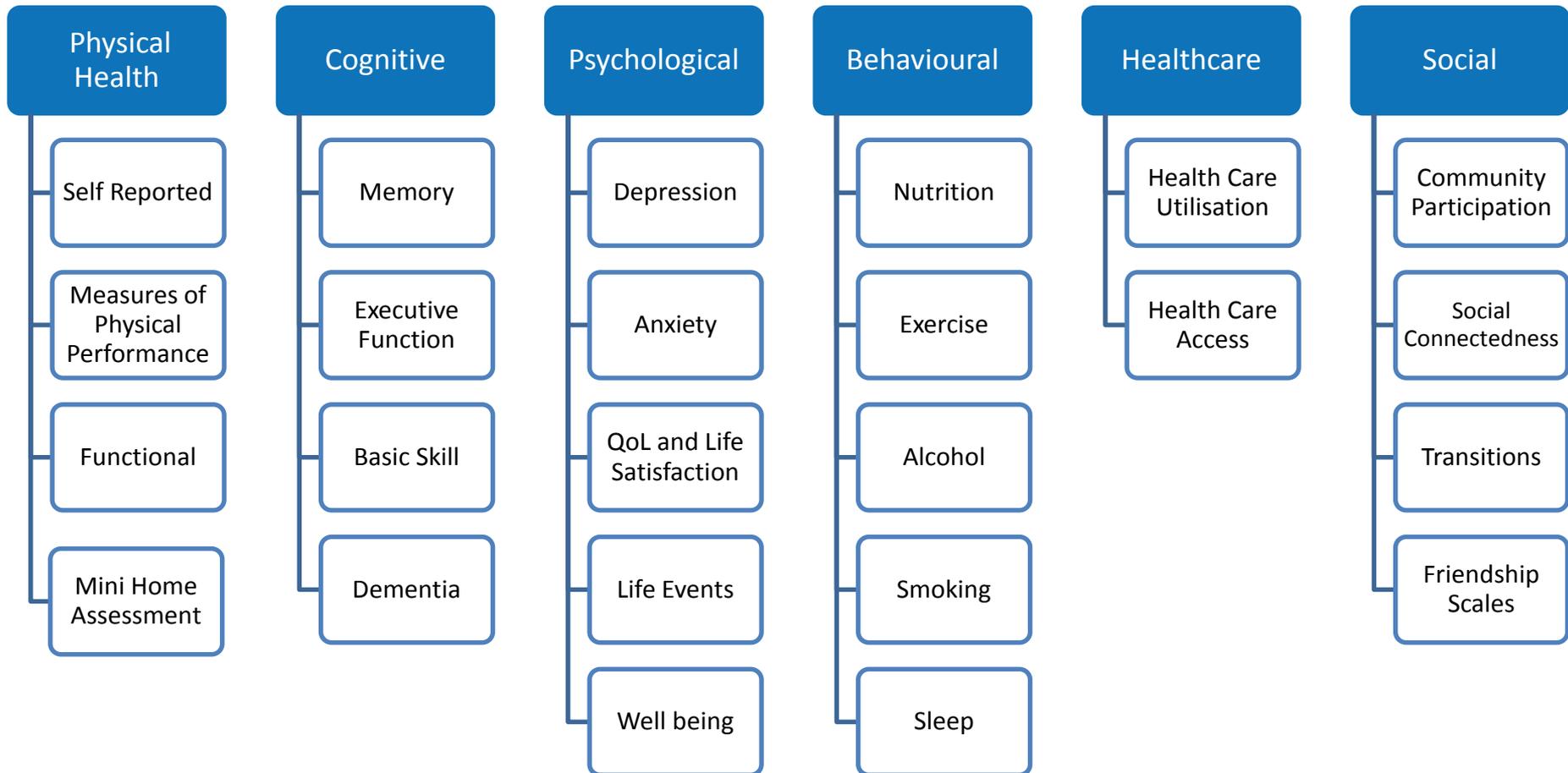




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IDS-TILDA

Underpinning Conceptual Framework

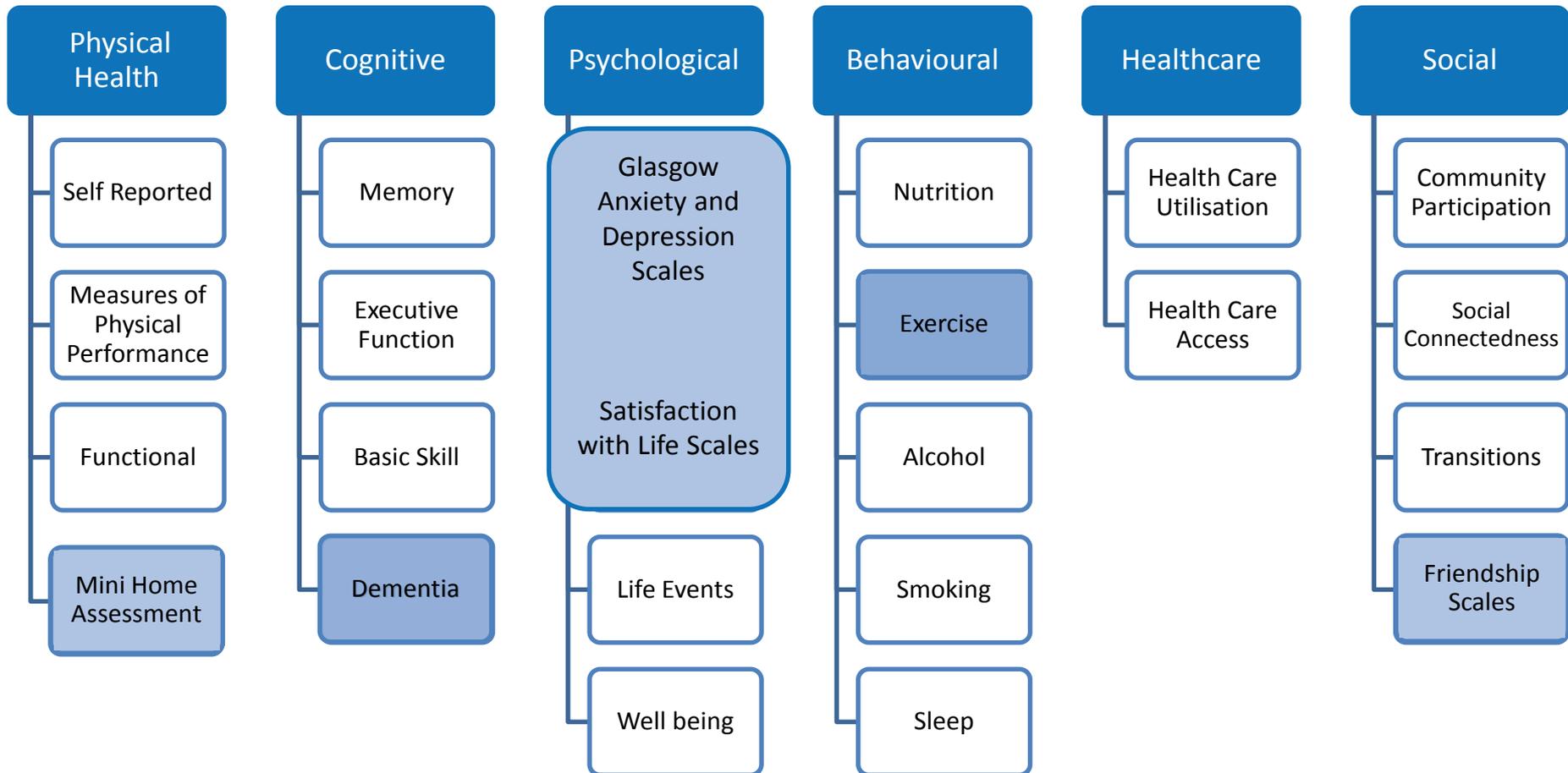




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IDS-TILDA

Underpinning Conceptual Framework





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IDS-TILDA Participant Involvement

“Nothing about us, without us”





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Celebrating 10 Years of IDS-TILDA

“Nothing about us, without us”



Trinity Centre for Ageing and Intellectual Disability Launch

“Nothing about us, without us”





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Optimising Wellbeing

For people ageing with Down syndrome





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What is Productive Wellbeing?

For people ageing with Down syndrome

**Productive
Wellbeing**

What a person
does in their life-
home, work,
leisure and
education.

**Physical
Wellbeing**

Individual's health-
diet, exercise and
health checks

**Social &
Emotional
Wellbeing**

Inclusion in community,
having friends, ensure a
sense of self worth

**Material
Wellbeing**

Planning ahead-
housing, retirement



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Advocating for Productive Wellbeing

Providing Real & Meaningful Opportunities





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Advocating for Productive Wellbeing For Real & Meaningful Opportunities





Circles of Support



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Circles of Support



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Opportunities:

- Greater preparedness for:
 - Employment
 - Changes in Residence
 - Personal Choice
 - Cognitive Training
 - Technology Use
 - Retirement Planning
 - Specialist Care Centres



Technology Use



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Trinity graduates, Talita Holzer Saad and Robbie Fryers, winners of the 2017 James Dyson Award with Pat O'Shea and Patrick in Front Square



Eyes & Ears



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More than **20% of older people with Down syndrome have cataracts.**

More than **20% of older people with Down syndrome report poor hearing.**



Eyes & Ears



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Opportunities:

- Schedule annual hearing and vision testing
- Check for ear wax build-up
- Remove trip hazards



Constipation



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Chronic constipation leads to **pain, distended stomach, haemorrhoids, depression and disorientation.**

Level of intellectual disability and mobility are significantly associated with constipation, while age is not.

For people with Down syndrome, there is also an **increased risk of Coeliac disease.**



Constipation



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Opportunities:

- Encourage daily physical activity
- Review diet and medications
- Screen for coeliac disease



Hypothyroidism



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People with Down syndrome have **a higher rate of hypothyroidism** than the general population.



Hypothyroidism



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Opportunity:

- Look for mood changes, sleepiness or confusion
- Request an annual blood test



Sleep Apnoea



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People with Down syndrome have **a higher rate of sleep apnoea** than the general population.



Sleep Apnoea



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Opportunities:

- Keep a sleep log to monitor the duration and quality of sleep
- Speak with your GP about snoring, gasping or interrupted sleeping



Bone Health



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50%

of IDS-TILDA
participants with
Down syndrome
have evidence of
poor bone health

60%

of people with ID
were taking
medications that
contribute to bone
loss

20%

of people with ID
have experienced
a fracture



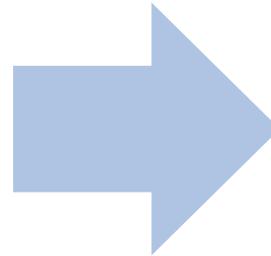
Bone Health



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6%

of men
had received a
doctor's diagnoses
for osteoporosis
Wave 2



90%

of men
had objective
evidence of poor
bone health
Wave 2

Men in IDS-TILDA were **12 times** more likely to present with osteoporosis than men in the TILDA study





Bone Health



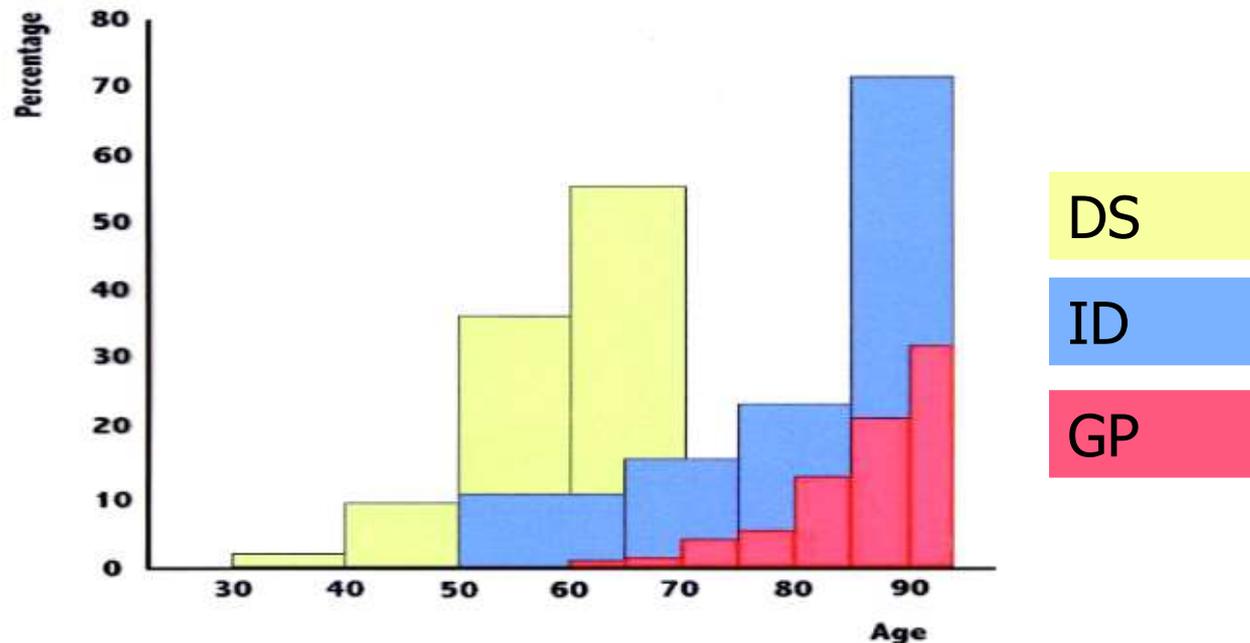
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Opportunities:

- Request a GE Lunar Achilles Quantitative Heel Ultrasound
- Consider a DEXA Scan (if possible)
- Download the *Better Bones! Better Health!* App by Dr Eilish Burke (forthcoming)



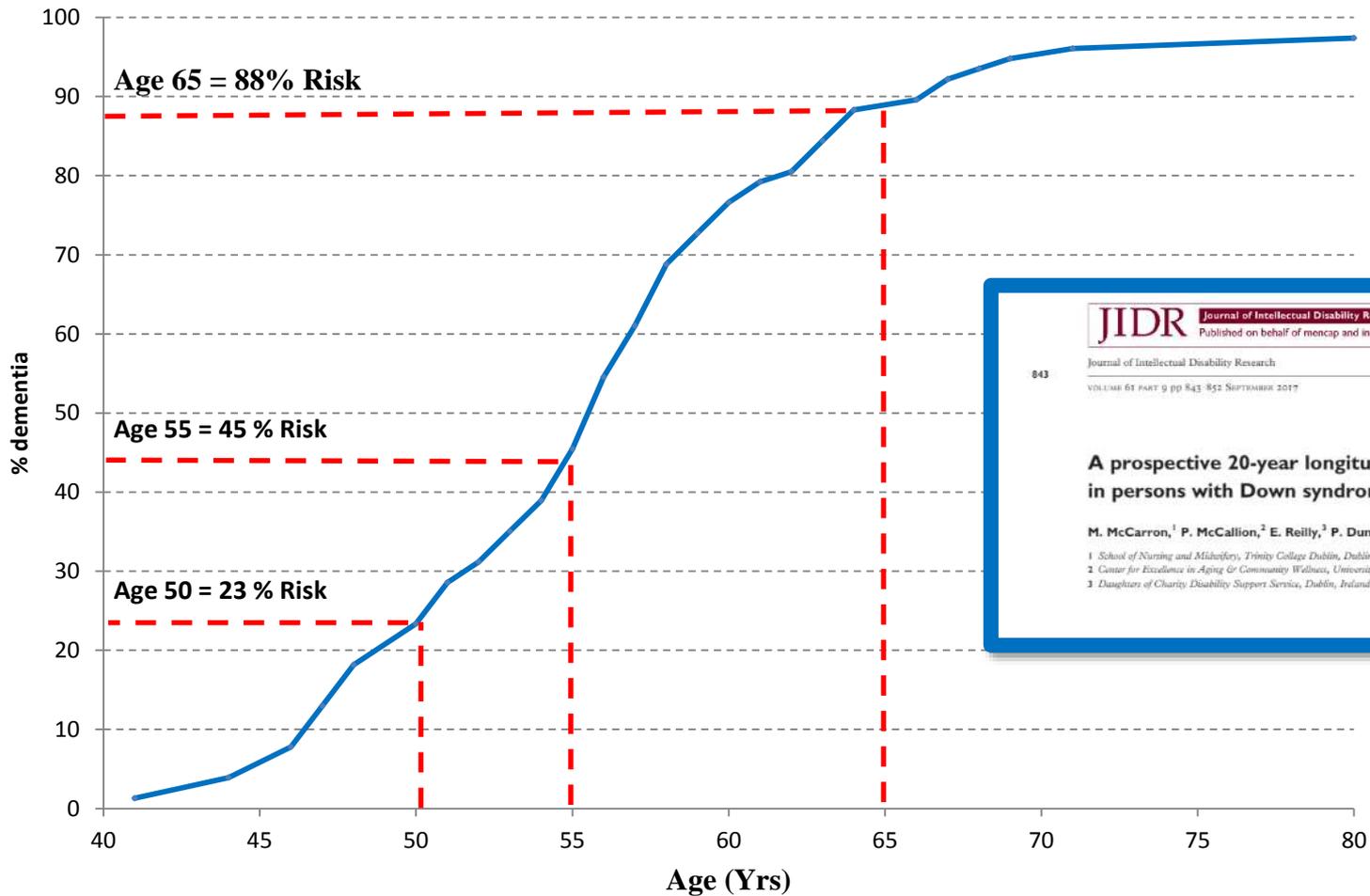
Cognitive Ageing

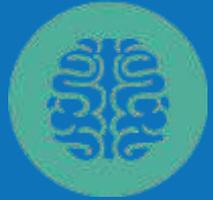


- The incidence of dementia could be up to **five times higher** than in people without ID (Strydom *et al*, 2013)
- **Much higher rates** in people with Down syndrome (McCarron *et al*, 2014, 2016; Strydom *et al*, 2010)



Risk Trajectory By Age

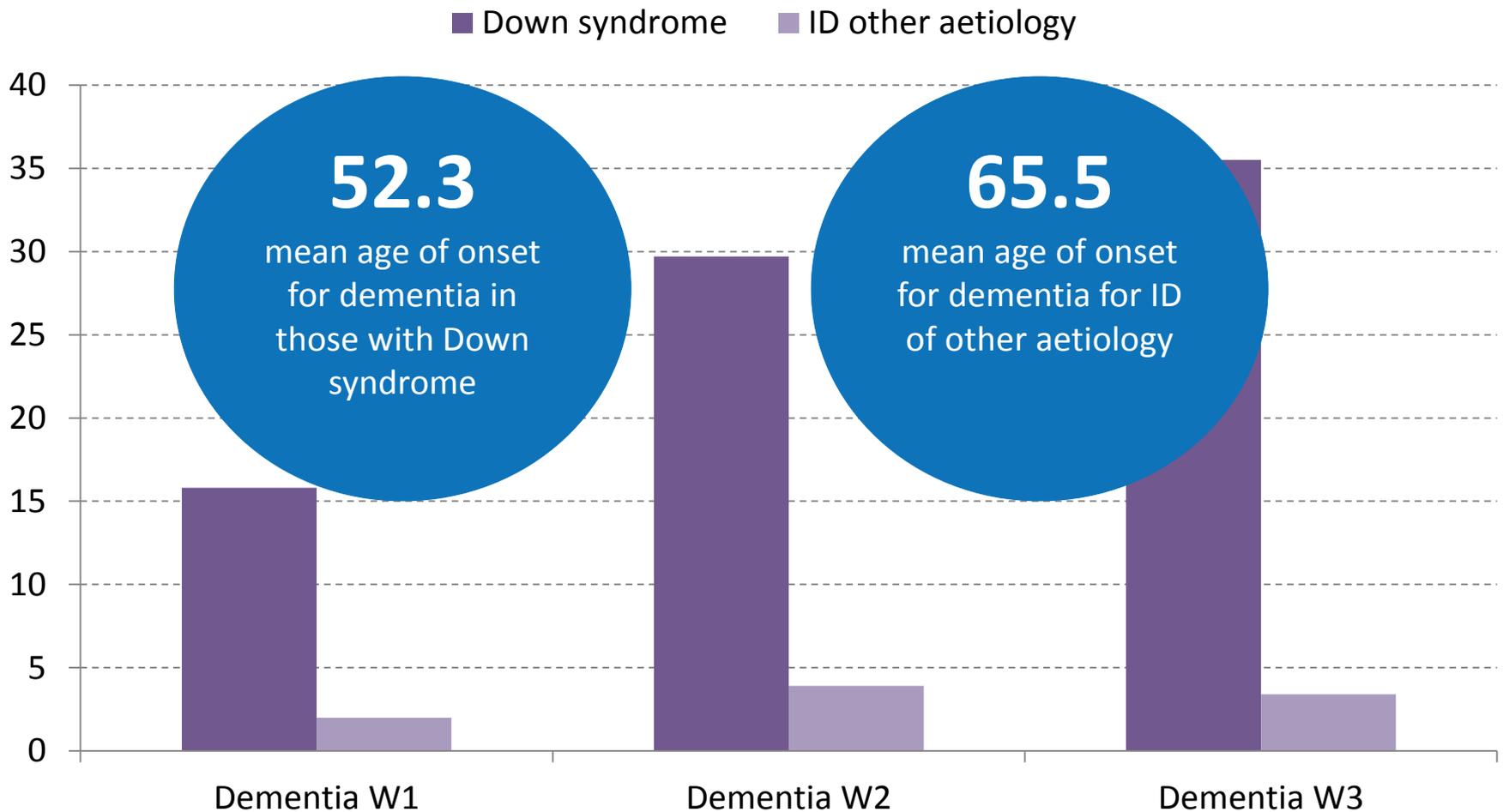




Prevalence of Dementia



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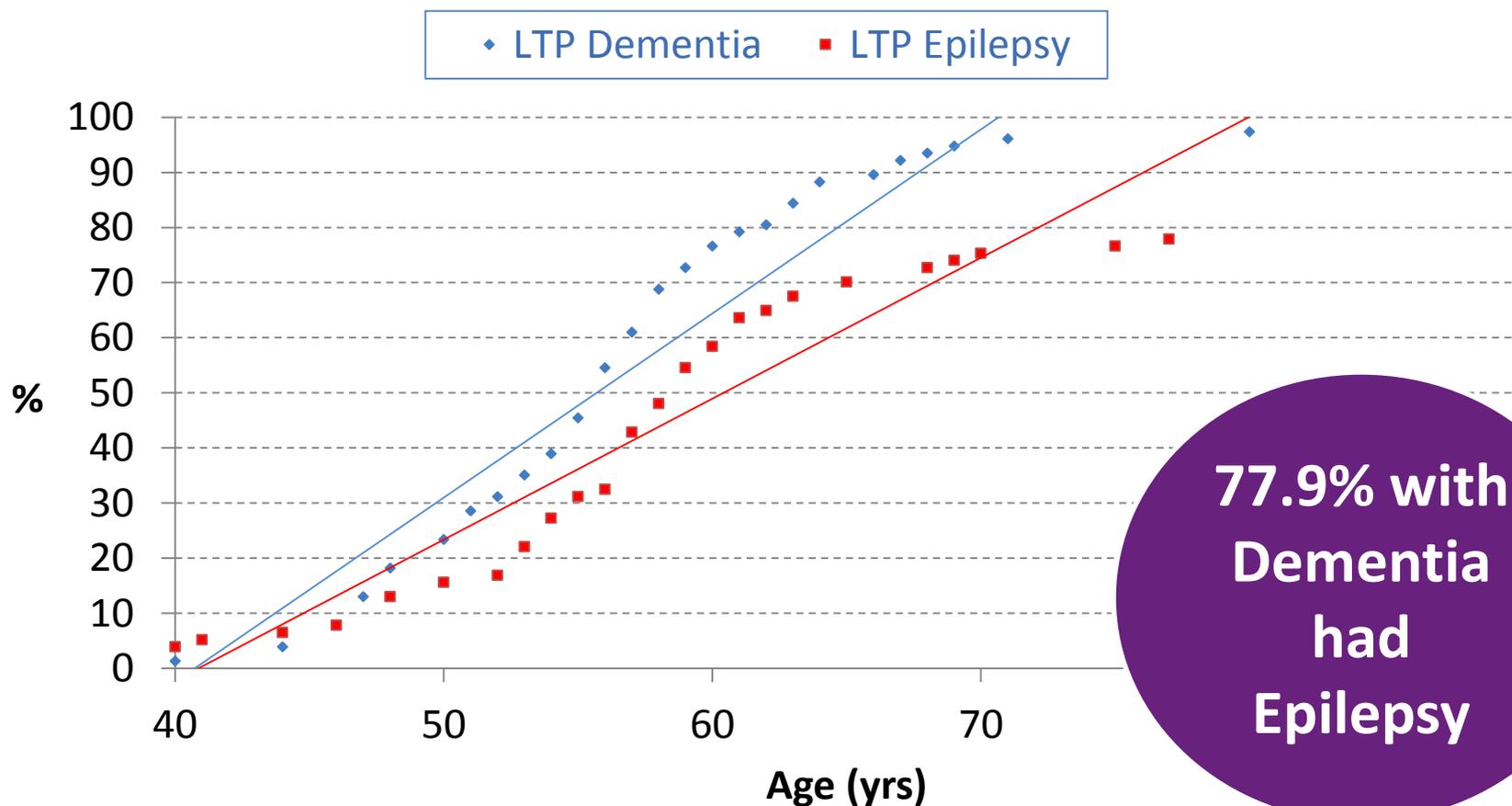


Dementia & Epilepsy



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Life Time Prevalence

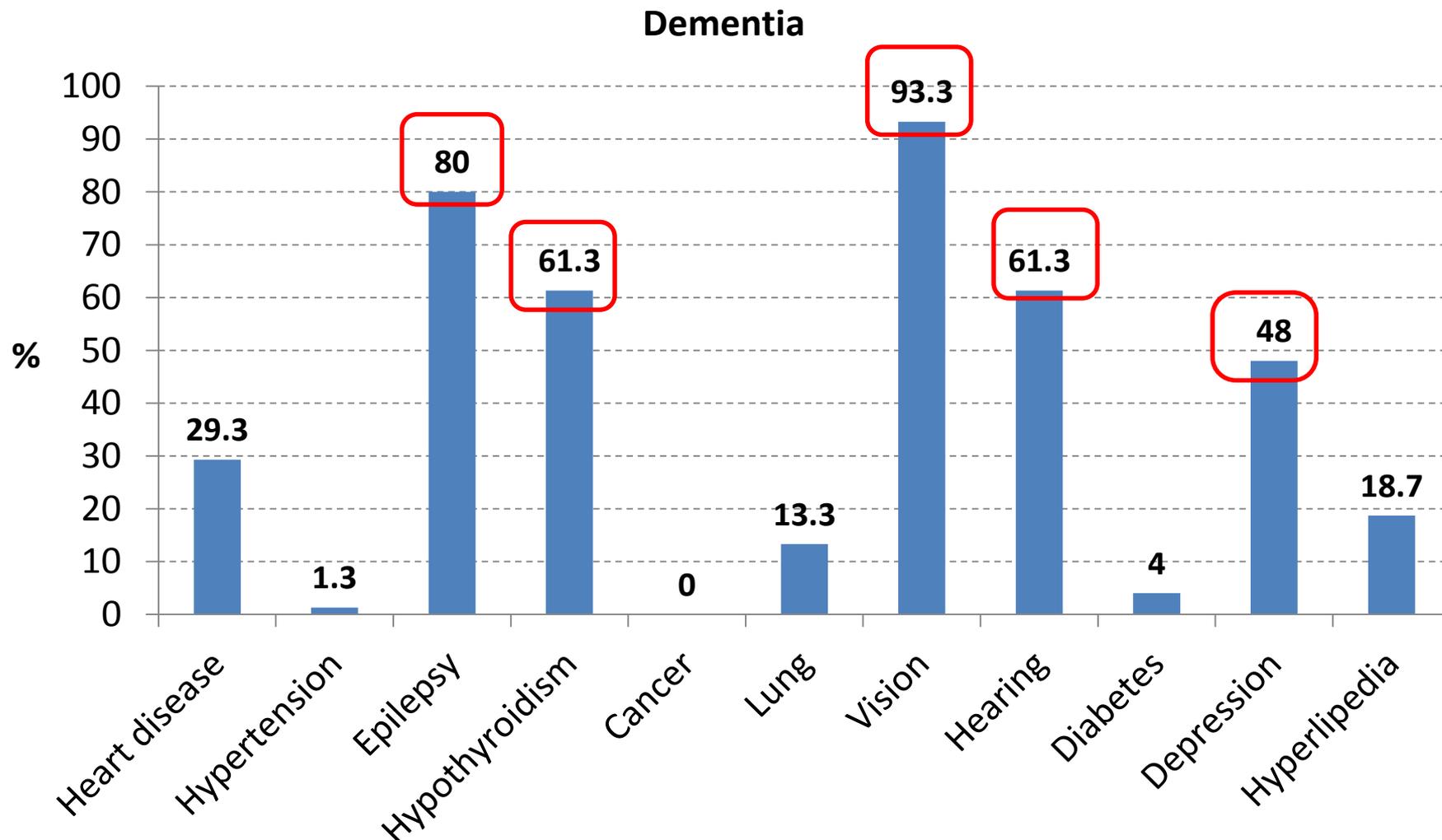




Dementia Co-Morbidities



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Opportunities:

- Consider other physical or mental health problems such as:
 - Depression or other mental illness
 - Sensory impairment (vision and hearing)
 - Thyroid impairment
 - B12 & folate deficiency
 - Medical problems (drug interaction, infection, pain, epilepsy)
 - Major life events (separation, bereavement, moving)
 - Catatonic Regression

Catatonic Regression in Down Syndrome

Unrecognized & Treatable Cause of Regression

1. Clear and Obvious Regression

2. Symptoms

- **Motor Activity:** Slowing; getting stuck; hyper outbursts
- **Speech:** Decreased; muted; slower
- **Withdrawal:** Less engagement (people/environment); less noticing
- **Mood:** Flat; less enjoyment; depression or aggression
- **Negativism:** Refusing to participate or follow instructions
- **Stereotypic Movements:** Tics; posturing; grimacing
- **Abilities:** Reduction in skills, self care and daily living skills
- **Eating:** Slower; refusal to eat; weight loss
- **Sleeping:** Interrupted

3. Bush-Francis Catatonia Rating Scale



Cognitive Ageing



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There is a substantial increased risk of dementia >50 years but

1

- Survival **less precipitous** than previously reported.

2

- The **rate of progression varies** among individuals.

3

- Anecdotal reports of adults with Down syndrome **'falling off a cliff'** reflect **unusual cases**.

4

- There is a high risk of **new onset epilepsy**.

5

- The level of learning disability has little impact.

6

- There is **increased survival** at advanced dementia.

Opportunity:

- Of those with Down syndrome and without a diagnosis of dementia, **47% had never had a dementia assessment.**



Cognitive Ageing



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Diagnosing Dementia with Down Syndrome is **Highly Complex**

- The clinical presentation of dementia in persons with ID can differ.
- Personality and behavioural changes seem to occur earlier.
- Standardized tests often prove difficult and inaccessible.
- There may be communication difficulties for all involved.
- Improvised care environments undermine patient-centred planning.
- There may be a lack of base line data (personally and historically).
- High staff turnover limits symptom recognition.

Diagnosing Dementia with Down Syndrome is **Highly Complex**

Opportunities:

- Baseline Memory Clinic assessment at 35
- Annual Assessment after 35
- Person Centred Plan Development
- Staff Training
- Service Redesign
- Mainstream Policy Inclusion

**Memory
Clinic for
People
with ID!**



Cognitive Ageing



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Physical

Vital Signs

Urinalysis

Full Physical Examination

Vision & Hearing Tests

Blood Work

Neuro-Imaging

CT Scan or MRI
(depending on feasibility)

Neuro-Psychological Testing

Informant & Objective Measures

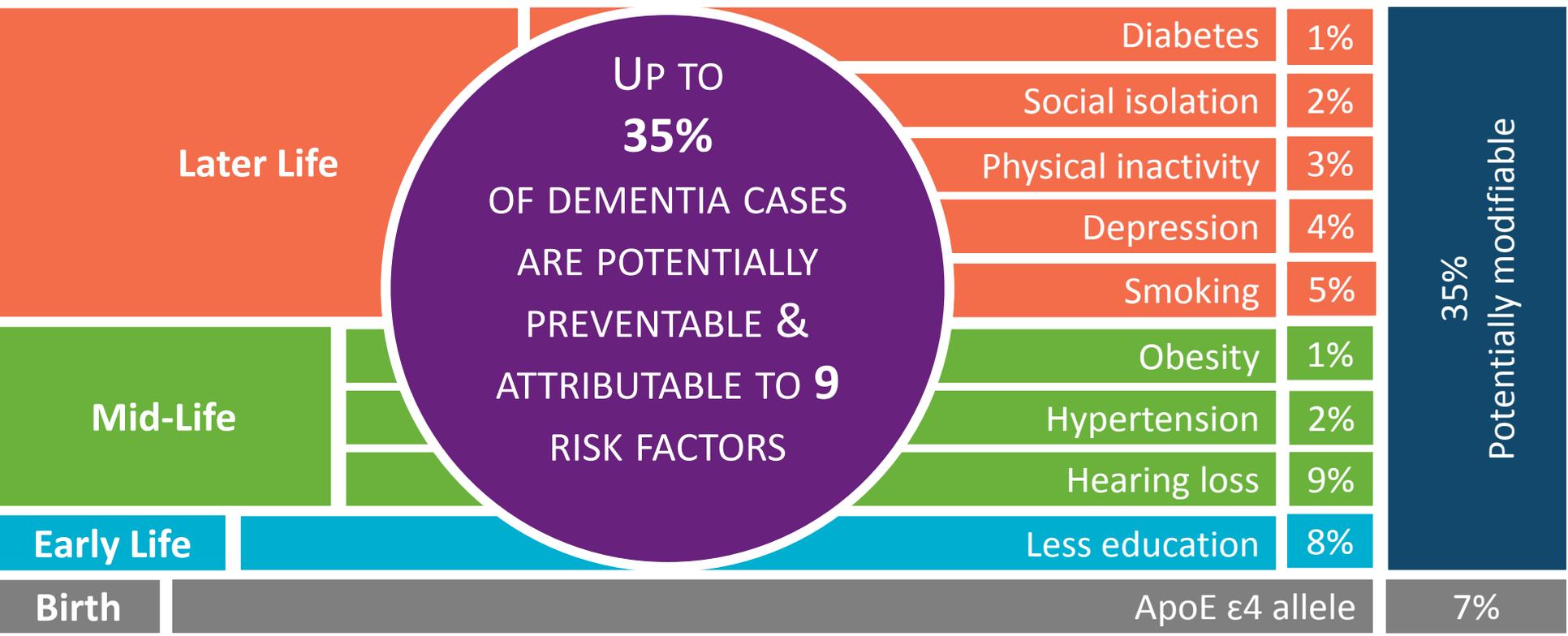
**Request A
Full
Diagnostic
Workup**



Brain Health



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SOURCE: THE LANCET COMMISSION 2018



Brain Health



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- **Brain health and prevention MUST be the targets**
- Dementia is too narrow a target
- Dementia is artificially defined by loss of function
- **What matters is the social, psychological and biological determinants of brain health**
- This is critical for people with an Intellectual Disability and in particular those with Down syndrome.

Brain Health



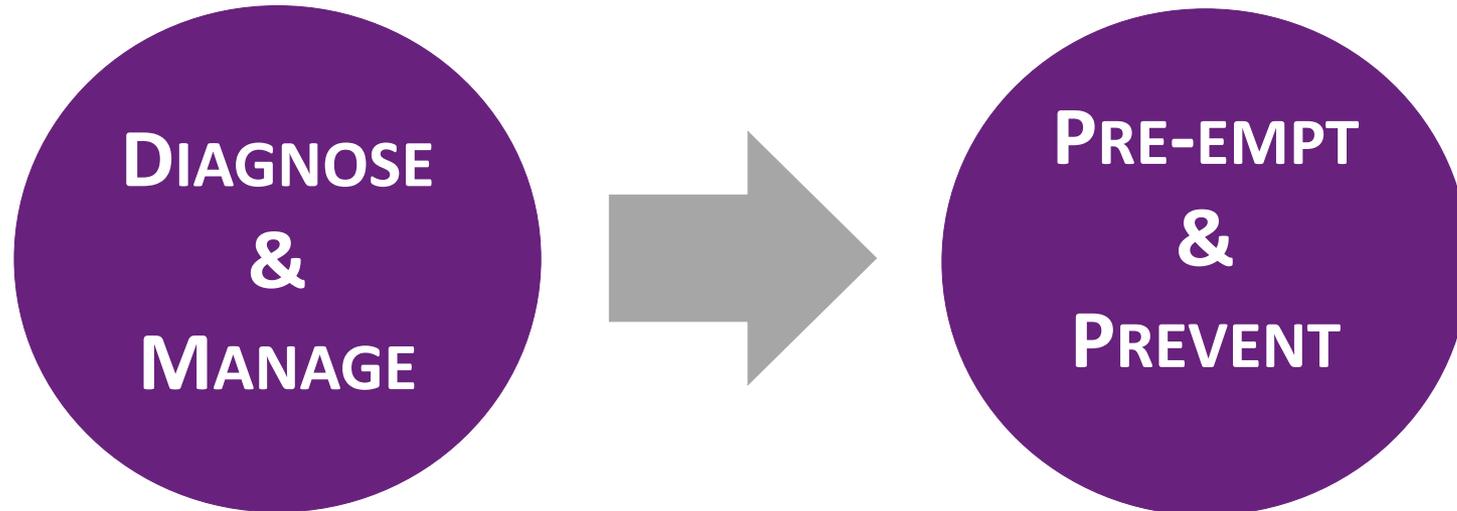
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**99.7% OF ALL
RCTs FOR
ALZHEIMER DISEASE
HAVE FAILED IN THE
PAST 15 YEARS**



We need a **Paradigm Shift** in health 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: Dr Eimear McGlinchey

Translating Findings



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Working with the
Federation of
Voluntary Bodies' 60
member services,
initially exploring
service responses to
dementia



Specialist Care

Specialist Care Centre of the Year: Daughters of Charity



Future Directions



We want to ensure that people with Down syndrome are given the opportunity to be involved in dementia research



Research in dementia needs to focus on **dementia prevention**

We need to focus research at a much younger age

Will you be an ambassador for dementia research?

We want to engage with people with Down syndrome and their family and carers

Encourage involvement on a national scale

Do you know someone with Down syndrome who would like to co facilitate information days on dementia research?

Contact : Eimear at mcgline@tcd.ie



Together, let's tackle dementia!



Stay Connected



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The Trinity Centre for Ageing and Intellectual Disability is an international and multi-disciplinary research centre examining key issues in ageing and the life course, informing policy and debate at the national and local level.

ABOUT

IDS-TILDA



Participant Involvement



Research Themes



Education and Knowledge Transfer



PPI Ignite@TCD



www.tcd.ie/tcaid/

[#ageingwithID](https://twitter.com/ageingwithID)



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Thank You

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