



**Trinity College Dublin**  
Coláiste na Tríonóide, Baile Átha Cliath  
The University of Dublin

# Ageing with Down Syndrome: Latest Insights

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22 September 2018

@McCarrmMary

#ageingwithID

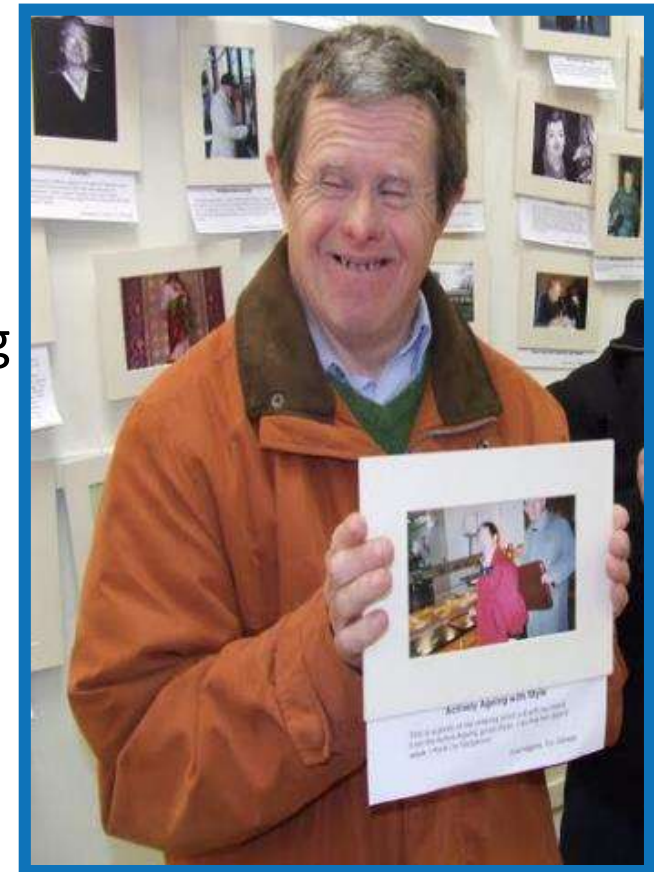


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# Ageing with Down Syndrome

## 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



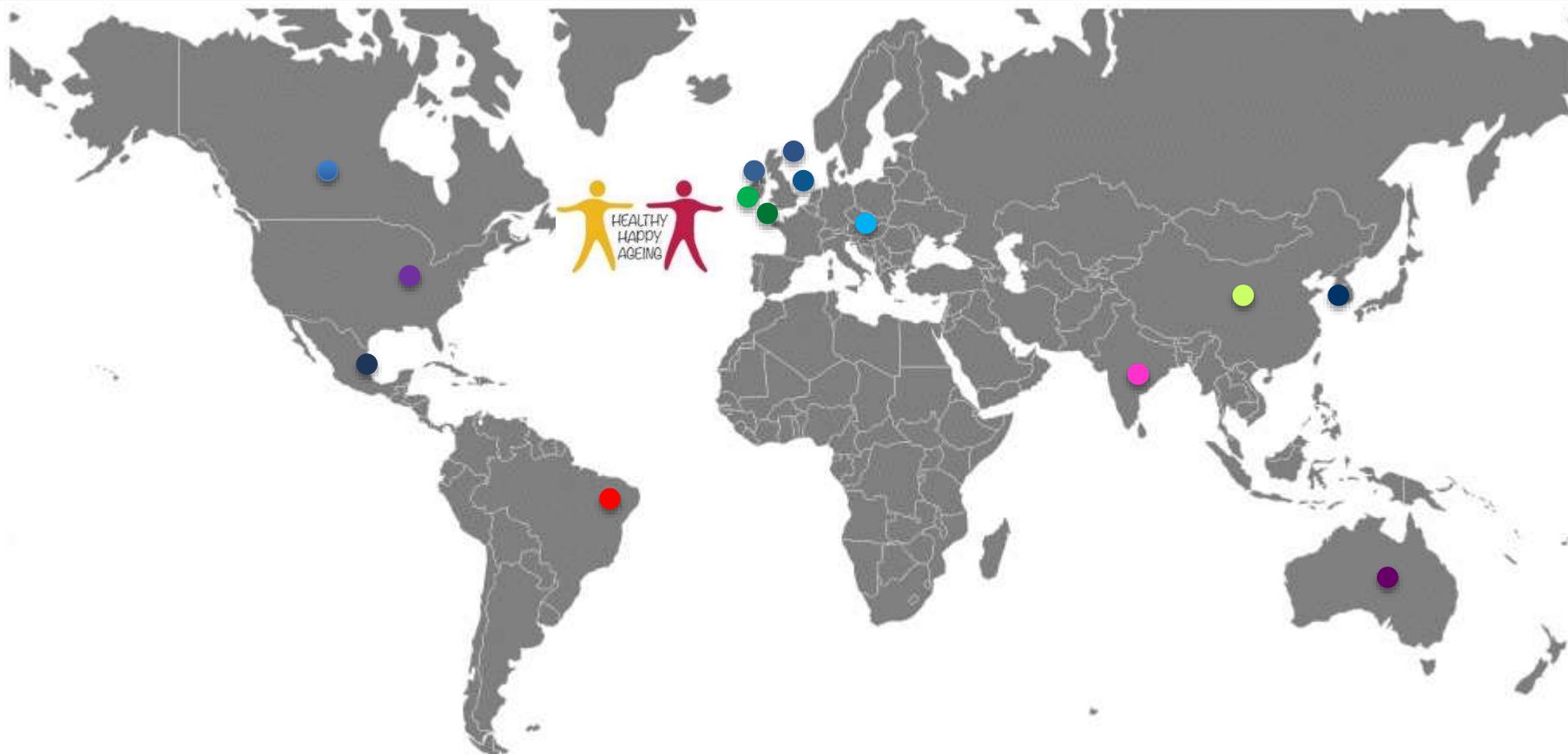


# IDS-TILDA

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

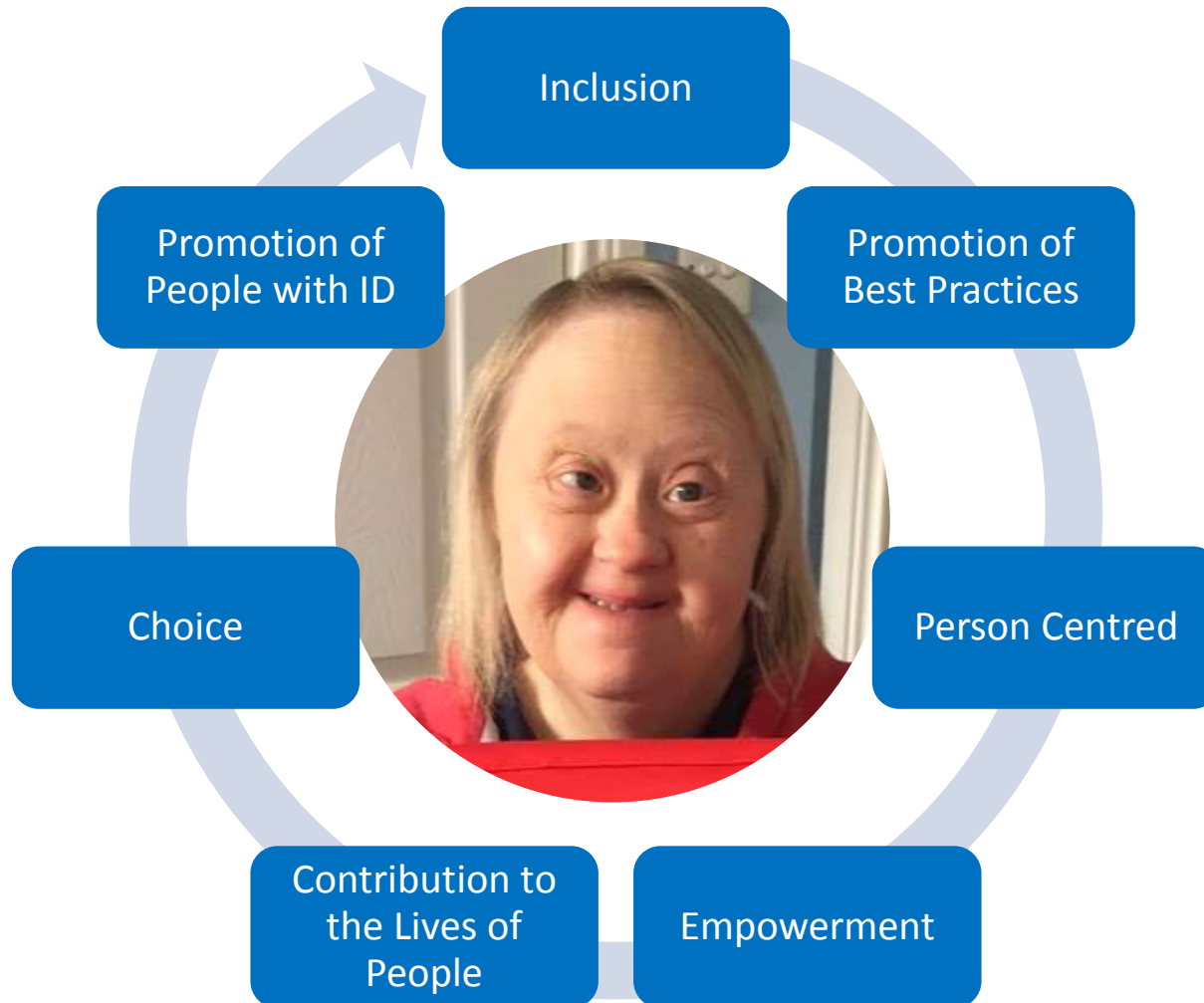
- **To understand the health characteristics** of people ageing with an intellectual disability;
- **To examine the service needs and health service utilization** of people ageing with an intellectual disability;
- **To identify disparities in the health status** of adults with an intellectual disability 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”

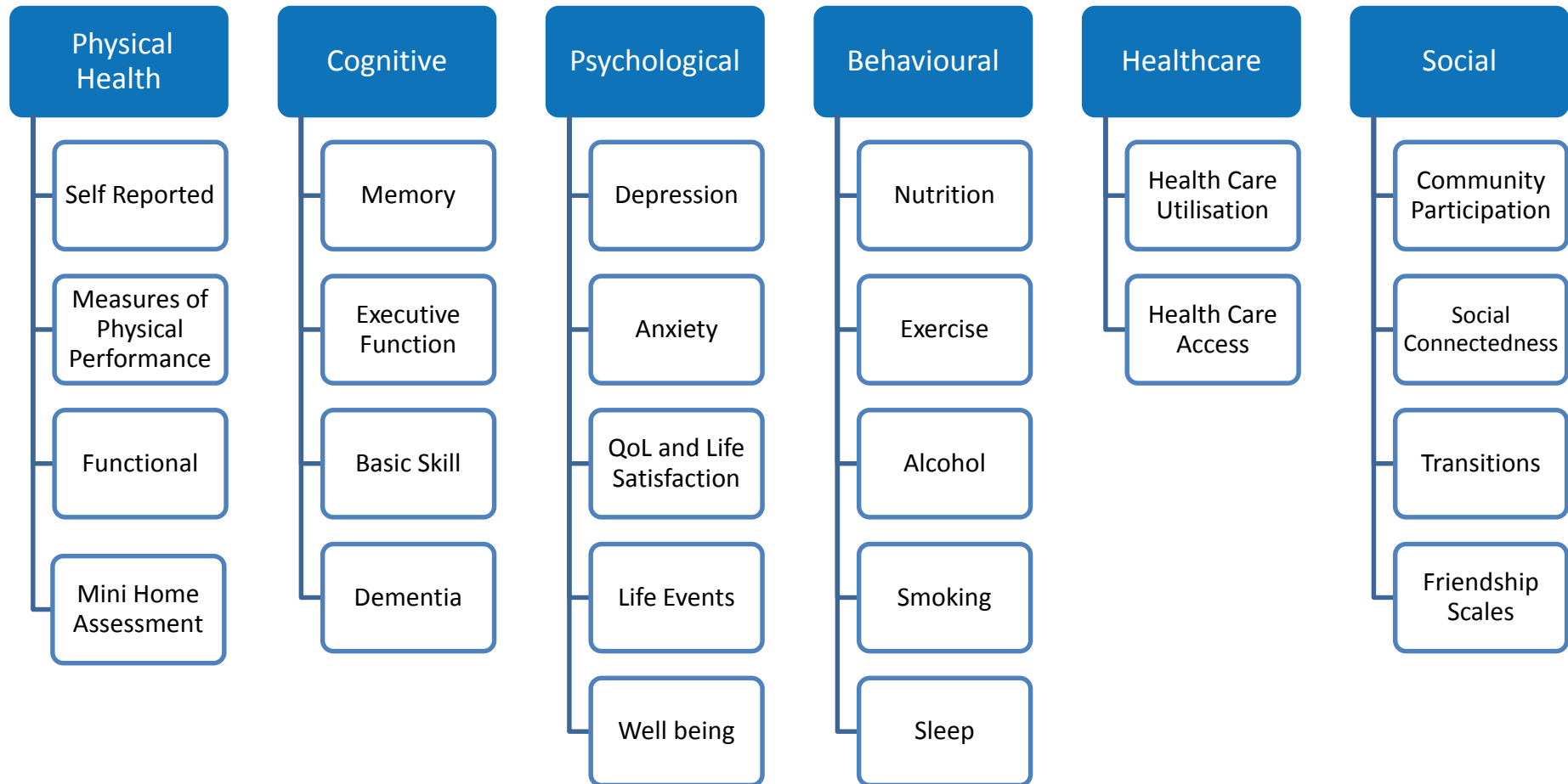




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# IDS-TILDA

## Underpinning Conceptual Framework

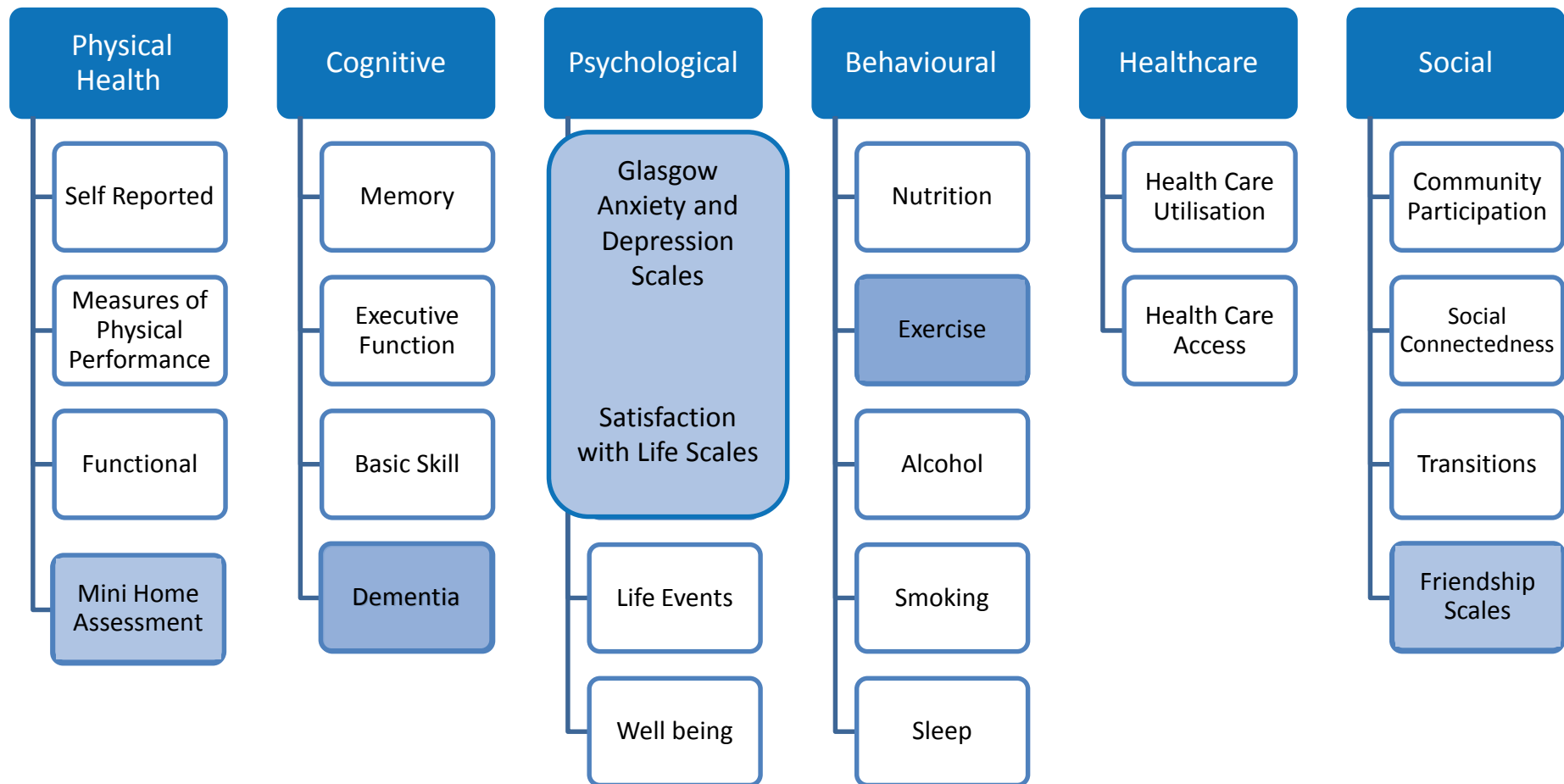




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# IDS-TILDA

## 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



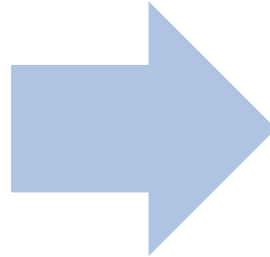
# Bone Health



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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



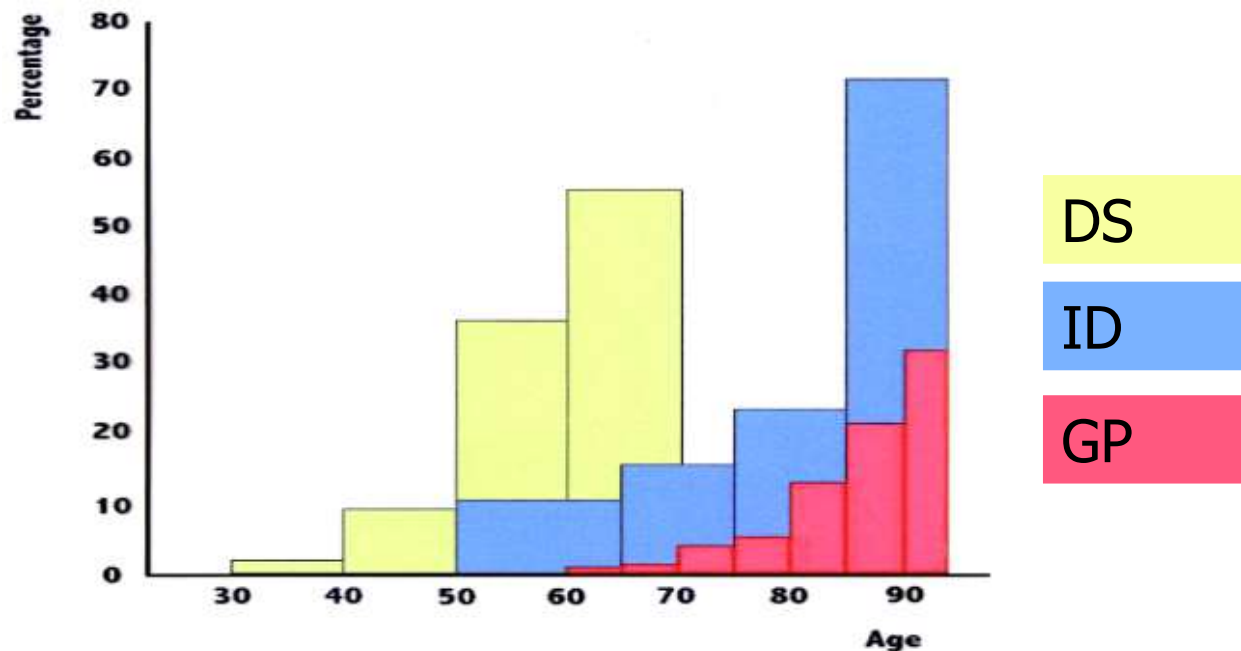
The Intellectual Disability Supplement to  
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## Opportunities:

- 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)



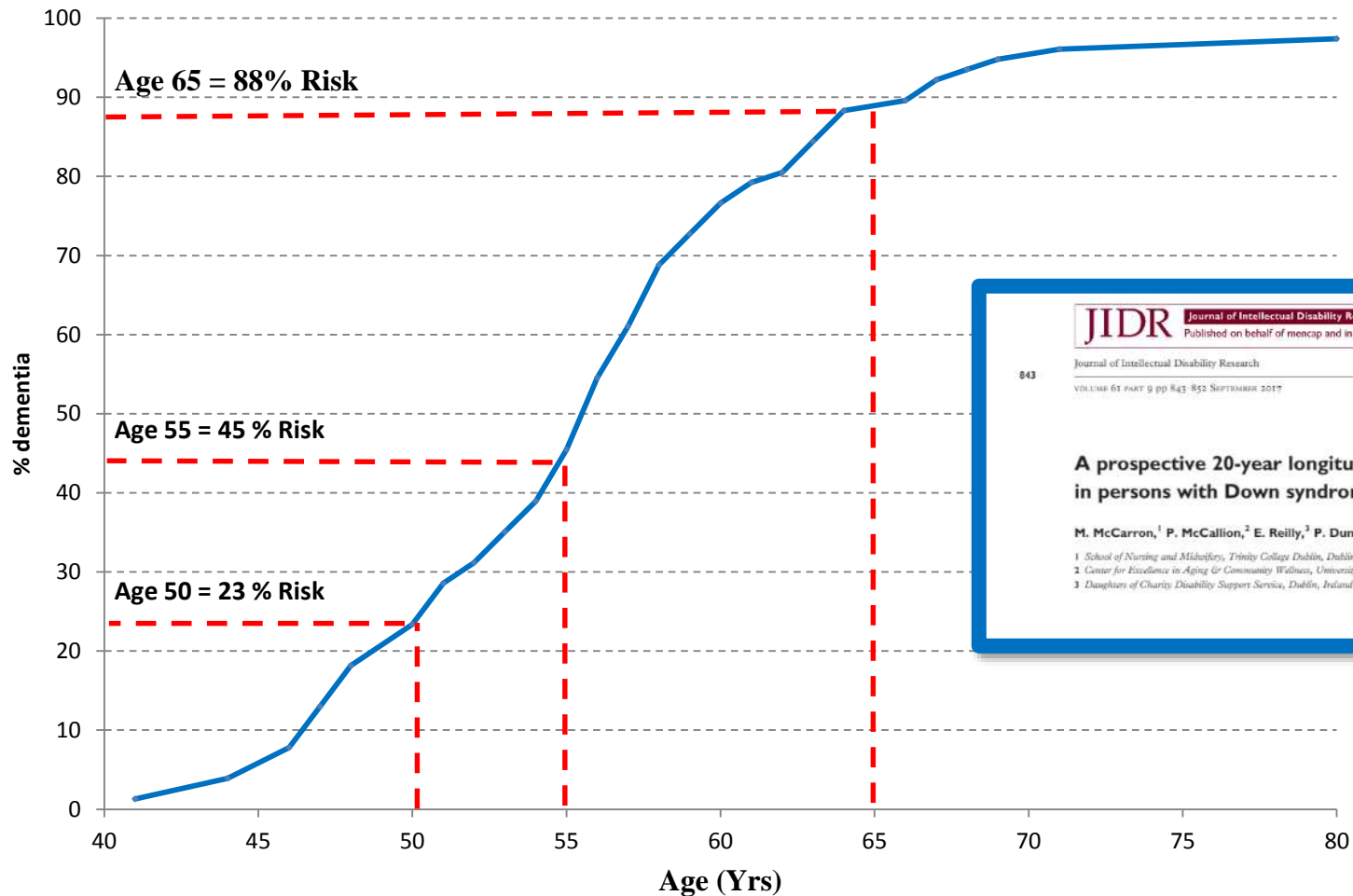
# Cognitive Ageing



- 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

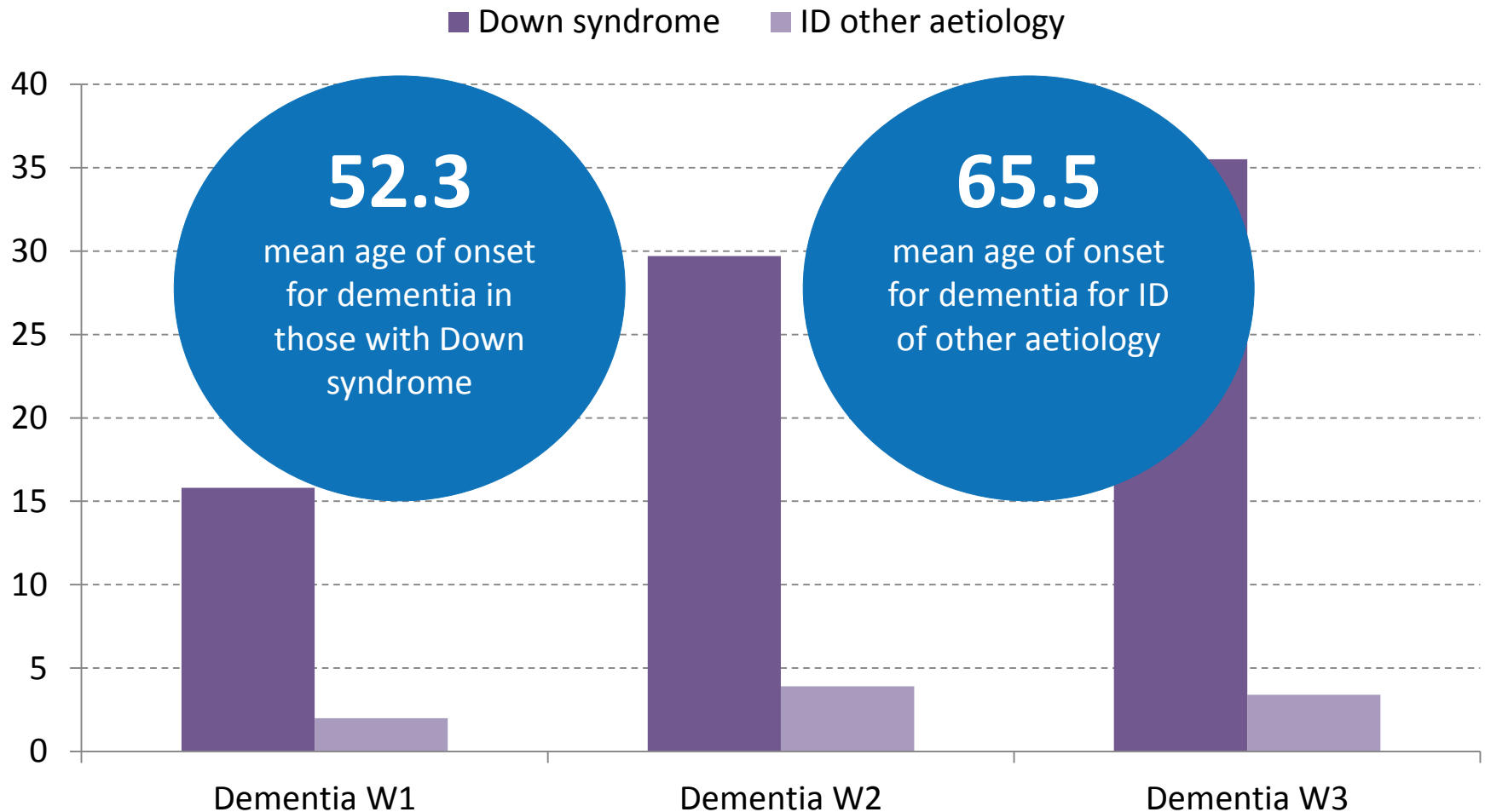




# Prevalence of Dementia



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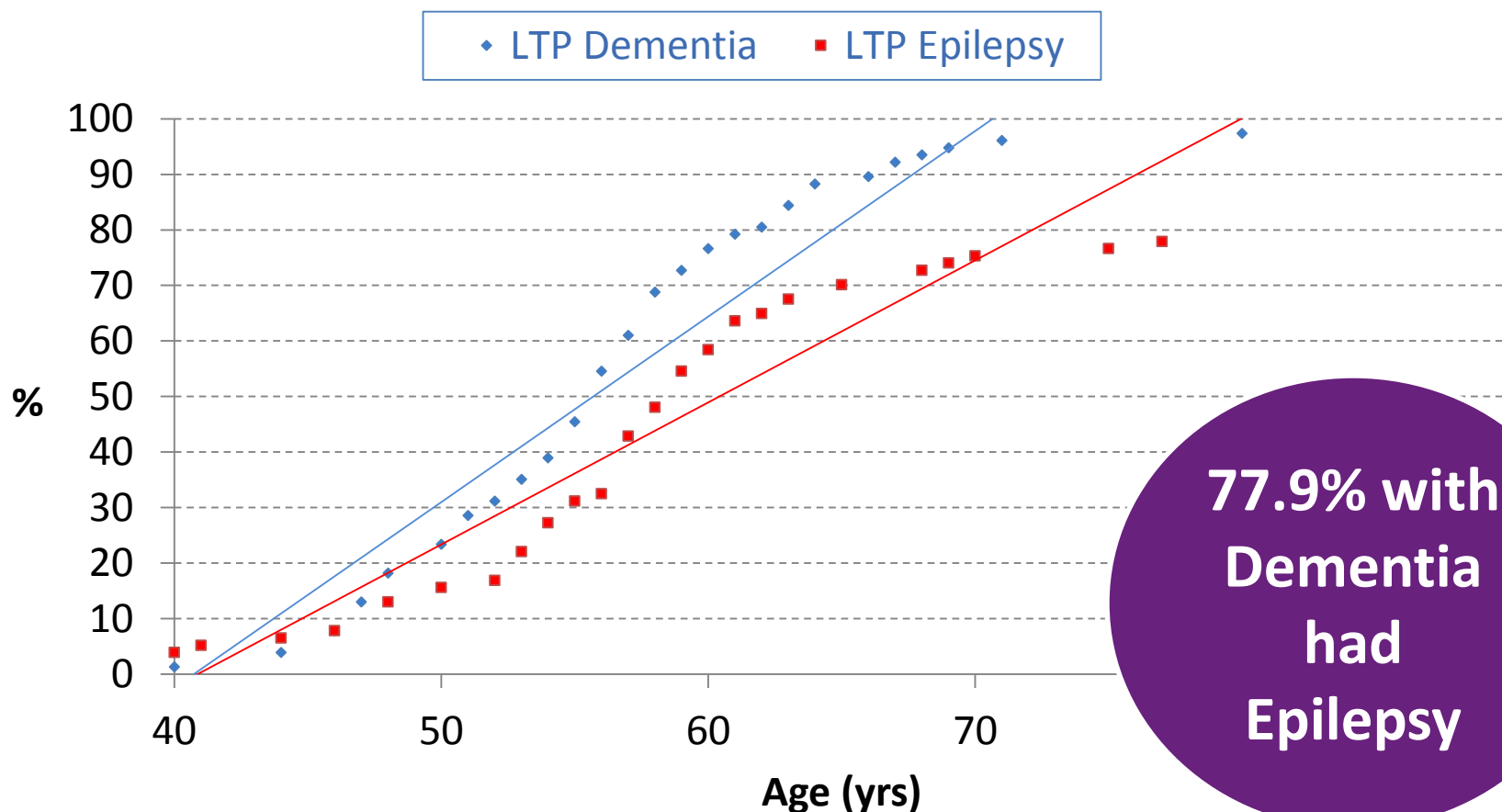


# Dementia & Epilepsy



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## Life Time Prevalence

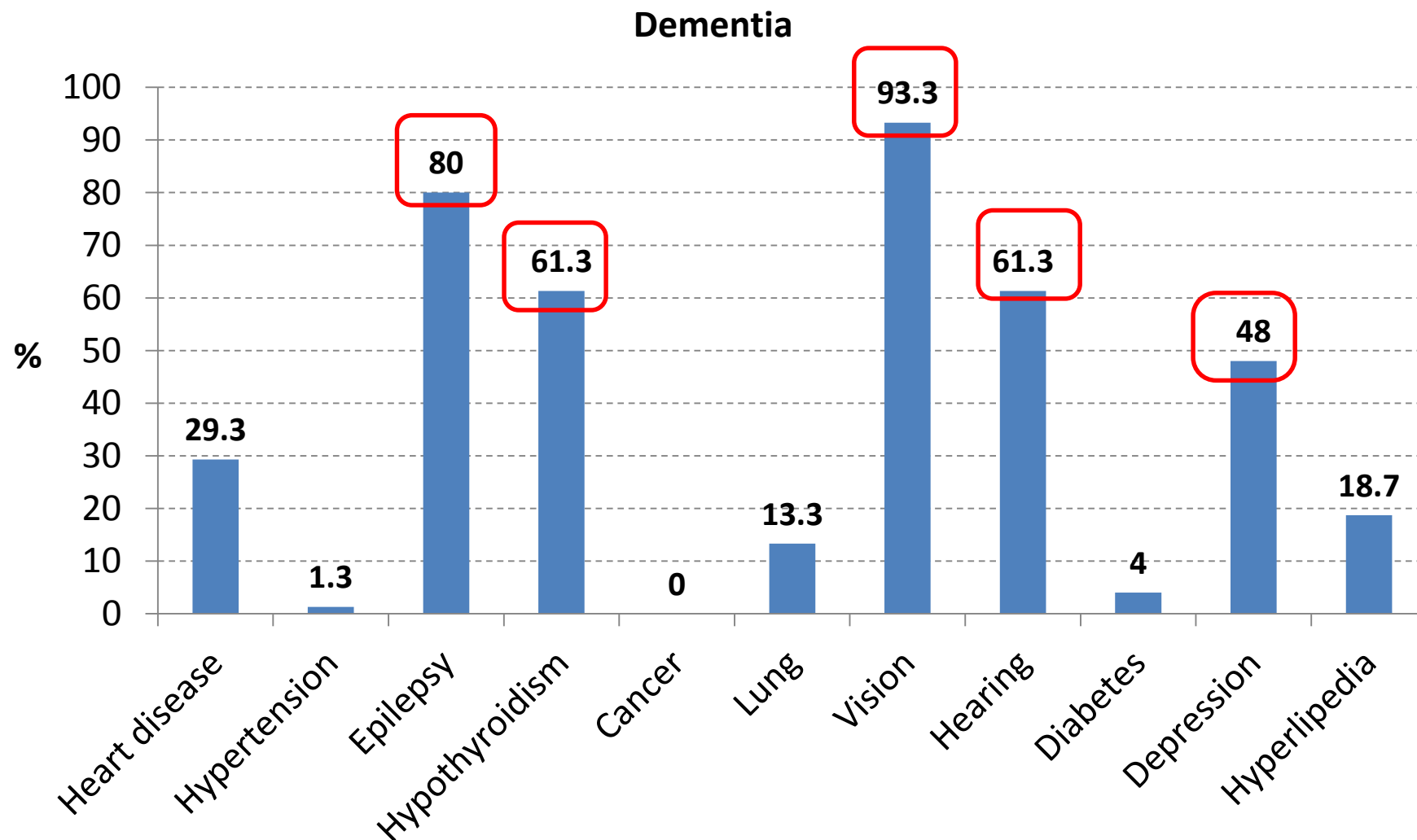




# Dementia Co-Morbidities



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# Cognitive Ageing



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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.



# Cognitive Ageing



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## Opportunity:

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



## 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.



# Cognitive Ageing



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## 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

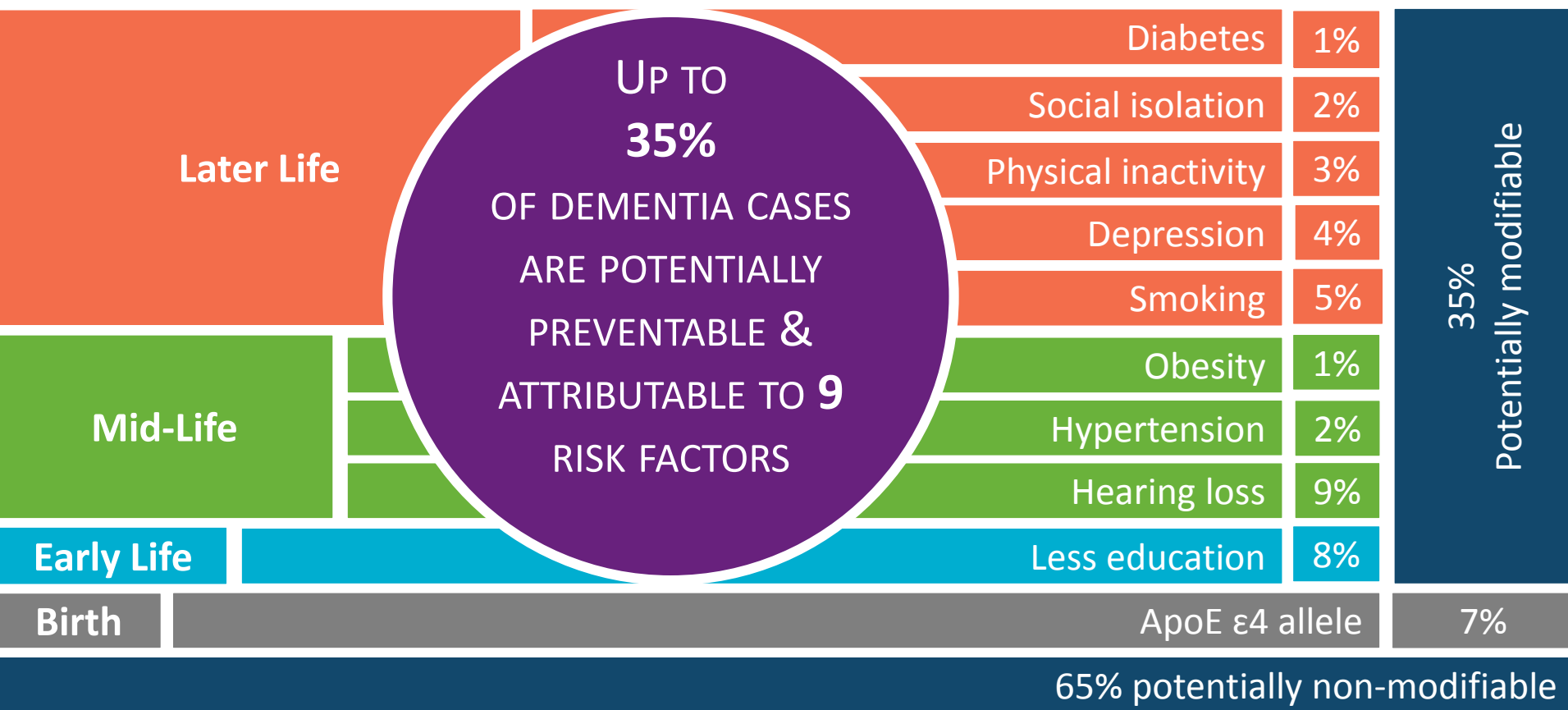
**Request A  
Full  
Diagnostic  
Workup**



# 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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## FierceBiotech

BIOTECH RESEARCH CRO MEDTECH

### Alzheimer's hopes dashed as Lilly gives up on amyloid drug solanezumab

by Phil Taylor | Nov 20, 2015 9:08am



## The Telegraph

### News | Science

#### Hunt for Alzheimer's cure suffers 'heavy blow' as Pfizer pulls out of research



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

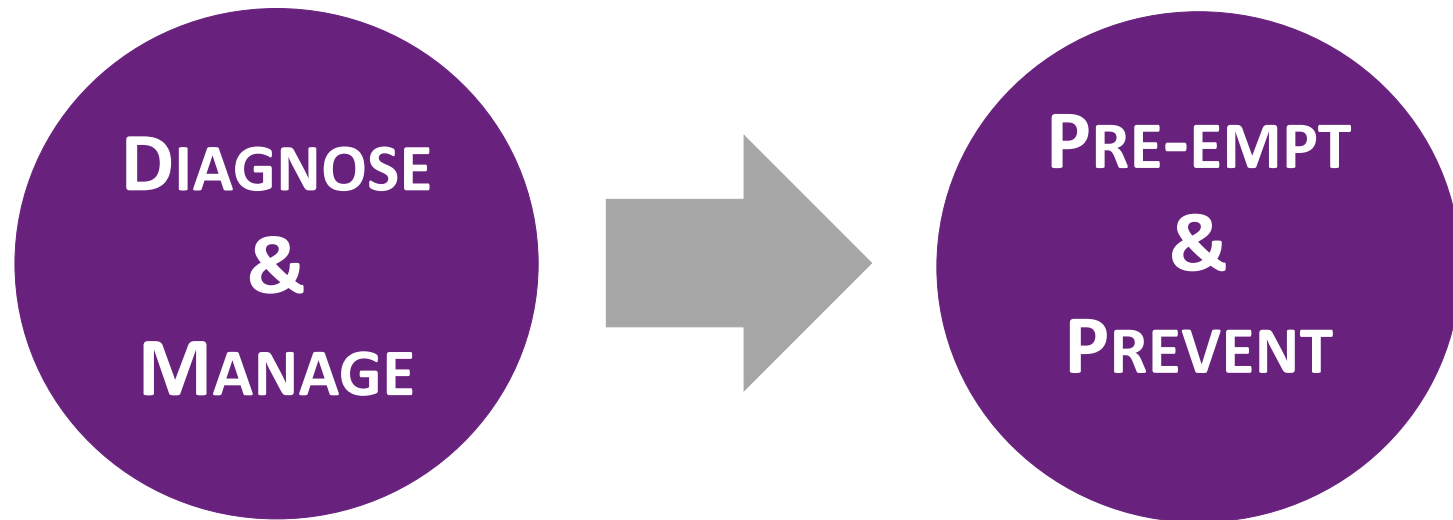


# Brain Health



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We need a **Paradigm Shift** in health care





## **B**rain **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](mailto: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



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# Thank You

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