



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Destination Unknown: How IDS-TILDA had to make its own roadmap

Prof Mary McCarron

Principal Investigator, IDS-TILDA

14th November 2019

@ageingwithID

#ageingwithID

Prominent Alumni



Jonathan Swift
1682



Bram Stoker
1864



Oscar Wilde
1871



Ernest Walton
1922



Samuel Beckett
1926



Mary Robinson, 1963
President of Ireland 1990-1997



Mary McAleese, 1973
President of Ireland 1997-2011

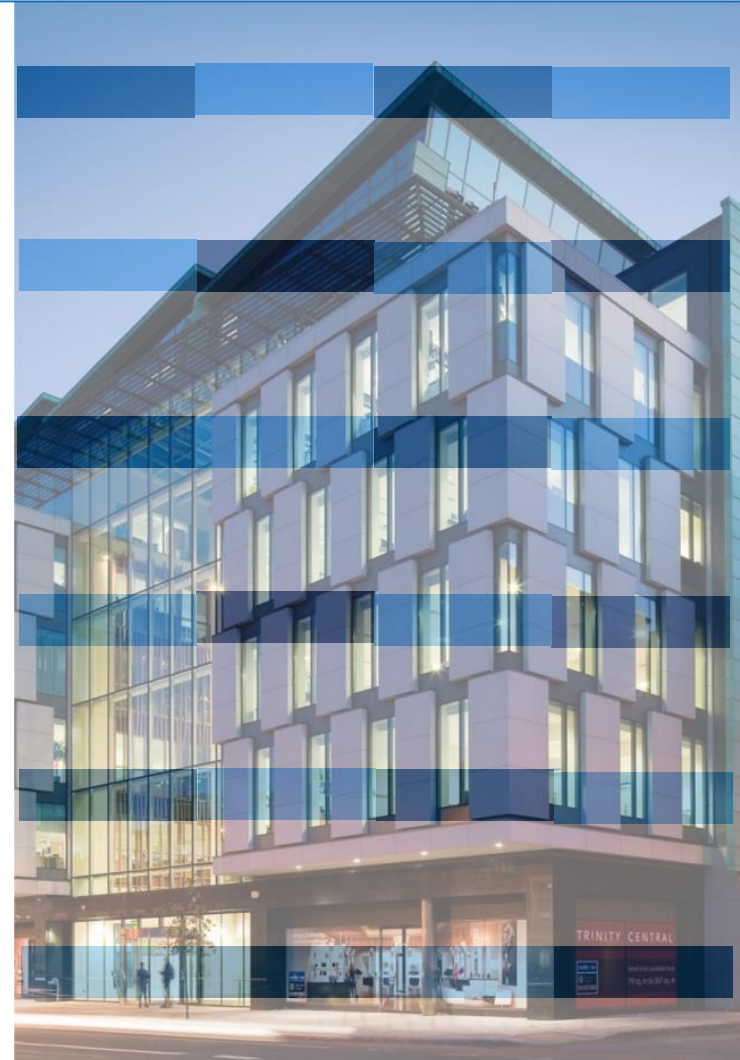
Scale

A research intensive University in the heart of Dublin City

17,000 **2,500**
STUDENTS **STAFF**
from **122** Countries **800** academic

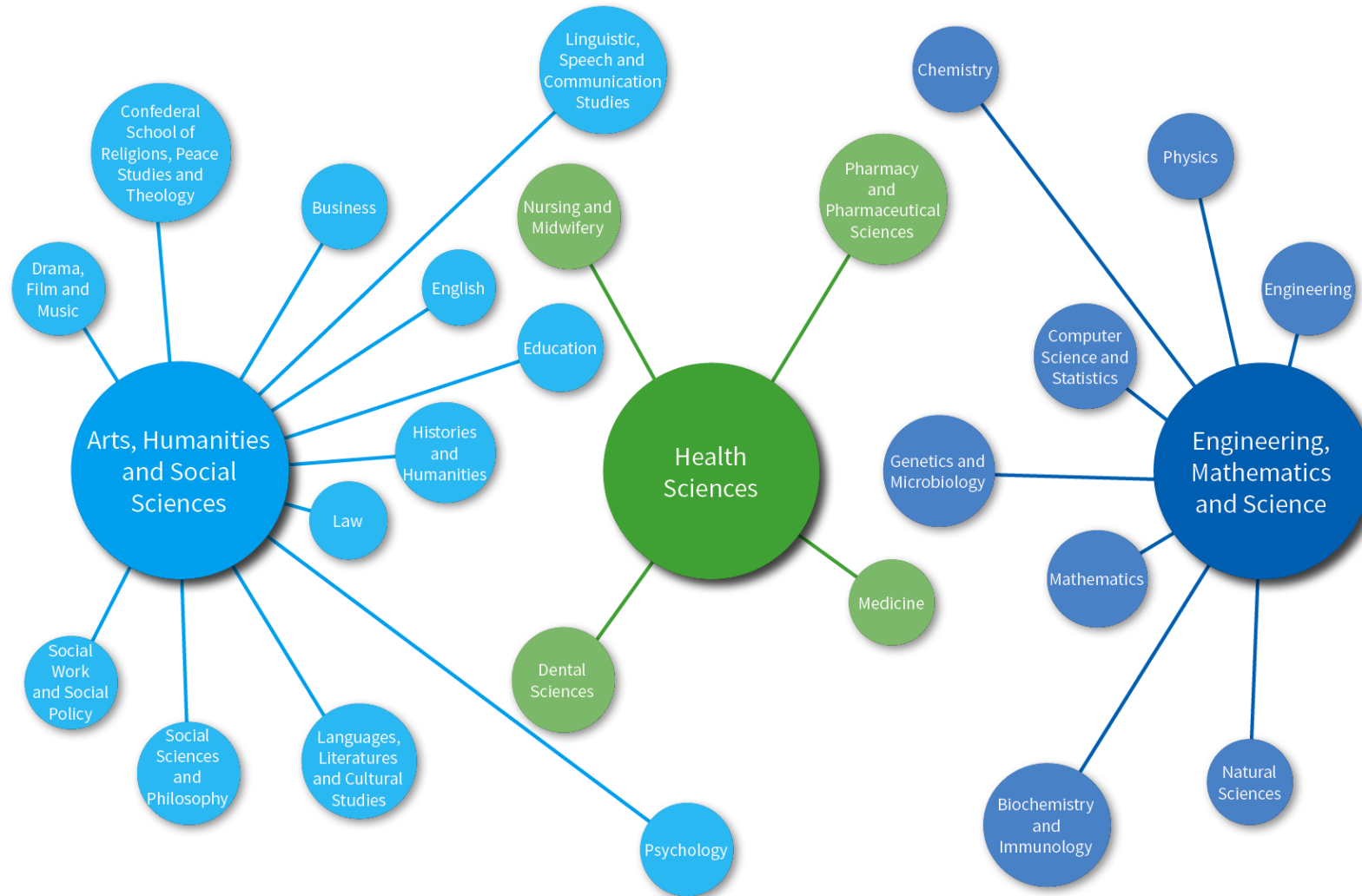
11% of **&** **40%** **ARE**
Students of Staff
INTERNATIONAL

6,000,000
ITEMS IN LIBRARY COLLECTION
access to **30,000+** journals



Faculties / Schools

The research eco-system





Gender Inequality

Large gender gaps in senior levels of Irish academia

Vast majority of top-paid posts held by men despite policies to promote equality

© Fri, Aug 3, 2018, 00:01

Gender equality in third level remains a distant hope

Latest figures show some improvement but discrimination deeply rooted

© Fri, Aug 3, 2018, 01:00

Why we need more women at the top of higher education

An intractable gender imbalance persists at the most senior levels

© Mon, Sep 17, 2018, 17:46



Gender Inequality

HEA | HIGHER EDUCATION AUTHORITY
AN BORD NAS um ARD-OIDEACHAS

REPORT OF THE EXPERT GROUP

HEA National Review of Gender Equality in Irish Higher Education Institutions

JUNE 2016



University Presidents



426 Years

SOURCE: HIGHER EDUCATION AUTHORITY



My Story

**Stewarts Care
RNID Training, 1981**



**Registered General
Nurse, 1990**





Daughters of Charity



**Ward Sister
St Joseph's Centre, Clonsilla**





Nurse of the Year: 1990

Nurse of the Year

Kildare nurse scoops award



● Mary McCarron, a ward sister in St. Joseph's Hospital, Clonsilla, Co. Dublin, was selected Nurse of the Year in Jury's Hotel, yesterday.
Picture by BRIAN FARRE

It's teamwork, says Mary

NURSES work as a team, said Mary McCarron, explaining why our interview with the Lucozade Nurse of the Year was being conducted by committee.

Mary, a ward sister in St. Joseph's hospital in Clonsilla, was telling us how she found her job very satisfying, and why she liked it so much. "In any respects, success in this job can be slow, but like Winston Churchill said: success is getting from failure to failure without loss of enthusiasm.

"Now, do you like that one, Sister Patricia," said Mary, turning to her.

"Oh, very apt indeed," said Sister Patricia. "I suppose you could say too that we are the voice of the voiceless," she added, to the obvious approval of Sister Maura sitting opposite at the presentation luncheon in Jury's Hotel yesterday.

Margaret Mann chimed in to say why she nominated her colleague Mary for the award in the first place. "I've worked with her for three years. She has very high standards of caring and a very good, holistic approach to care. And she's also a real extrovert — great fun entirely."

As winner of the 15th annual award, Mary, originally from Clonsilla, Kildare in Co. Cavan, is now living in Kildare, Co. Meath, with her husband Noel and 13-month-old daughter Louise. She was presented with her citation and crystal trophy by Alastair Finlayson, managing director of Beecham Ireland, who will also pay for her to attend a conference later this year in Chicago organised by the Association for People with Severe Mental Handicap.

St. Joseph's, run by the Sisters of

Charity, provides care for 260 patients, and also runs a community-based service with houses in Dublin and Limerick. Besides running a unit in the hospital, Mary McCarron also trains student nurses.

In her spare time, she is chairperson of Kildare Athletic Club, running marathons and cross-country races with PE teacher husband Noel, who has represented Ireland in the marathon. She also does canoeing, rock climbing and hill walking.

Yesterday, though, was purely for celebration, with flowers arriving at the luncheon from patients and colleagues. There would be further celebrations later in the day, with Sister Maura insisting she was in charge of booking the pub.

There were two other finalists in the competition, Margaret Burke, a staff nurse at Portlucula Hospital in Galway, and Maura Murphy, a public health nurse from New Ross in Wexford.



Mary McCarron, ward sister, St. Joseph's Hospital, Clonsilla, Dublin and a daughter of Mr and Mrs Connolly, Clonsilla, Kildare, Co. Cavan is one of the three finalists in this year's Lucozade Nurse of the Year award

Cavan nurse shortlisted for Nurse of the Year award

Three finalists have been selected for this year's Lucozade Nurse of the Year awards. The Lucozade awards, which are now in their 15th year, will be presented at a function in Dublin on Monday, Feb. 12th next.

The shortlist for the Nurse of the Year award is as follows:

Mary McCarron, Ward Sister, St. Joseph's Hospital, Clonsilla, Dublin 15.
Maura Murphy, Public Health Nurse, New Ross, Co. Wexford
Margaret Burke, Staff Nurse, Portlucula Hospital, Ballinacree, Co. Galway.

Since the Lucozade Nurse of the Year awards were established in 1974, some 7,000 nurses have been nominated for the Awards.

The Awards scheme was developed by Lucozade in association with the Irish Nurses Organisation. The prizes take the form of a bursary to attend an appropriate international nursing conference of the winner's choice.

The purpose of the Awards scheme is to give public recognition to the excellent work and high standards of the

Mary Takes Top Nursing Prize

KILCOCK

"A clear sense of direction and above all else to help people with severe mental handicap lead a happy and meaningful life"

- Ita O'Dwyer,
President of ABA



The Many Paths We Take





Trinity Centre for Health Sciences





HRB Clinical Nursing Research Fellow 1999-2002

‘Influence of Alzheimer’s Dementia on Time Spent Caregiving for Persons with Down syndrome and Alzheimer’s dementia’.

JOURNAL OF INTELLECTUAL DISABILITIES

**Time Spent Caregiving for Persons with
the Dual Disability of Down's Syndrome and
Alzheimer's Dementia
Preliminary Findings**

M. McCarron

ARTICLE
**Alzheimer's dementia in
persons with Down's
syndrome**
Predicting time spent on day-to-day caregiving
MARY MCCARRON Trinity College, Dublin, Ireland

**A Revised Stress and Coping Framework for Staff Carers of Persons with
Intellectual Disabilities and Dementia**
Mary McCarron^{1,*} and Philip McCallion²

Article first published online: 24 OCT 2005
DOI: 10.1111/j.1741-1130.2005.00024.x



Journal of Policy and Practice
in Intellectual Disabilities
Volume 2, Issue 2, pages
139-148, June 2005

JARID
Journal of Applied Research in Intellectual Disabilities 2011, 24, 189-198
bild
Published for the British Institute of Learning Disabilities

The Role and Timing of Palliative Care in Supporting Persons with Intellectual Disability and Advanced Dementia

Mary McCarron¹, Philip McCallion², Elizabeth Fahey-McCarthy³ and Kevin Connors⁴

¹School of Nursing and Midwifery, Trinity College Dublin, Dublin, Ireland; ²Center for Excellence in Aging Services, University at Albany, Albany, New York, NY, USA; ³School of Nursing and Midwifery, Trinity College Dublin, Ireland; ⁴St Francis Hospice, Raheny, Ireland



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

Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia

M. McCarron^{1,*}, M. Gill², P. McCallion³
and C. Begley¹

Article first published online: 20 JUN 2005
DOI: 10.1111/j.1365-2788.2005.00704.x



Journal of Intellectual
Disability Research
Volume 49, Issue 7, pages
560-566, July 2005



Lecturer, School of Nursing & Midwifery

Development of Higher Diploma in Dementia and Intellectual Disability 2002 - 2005





Head of School: 2008-2011 School of Nursing and Midwifery, TCD



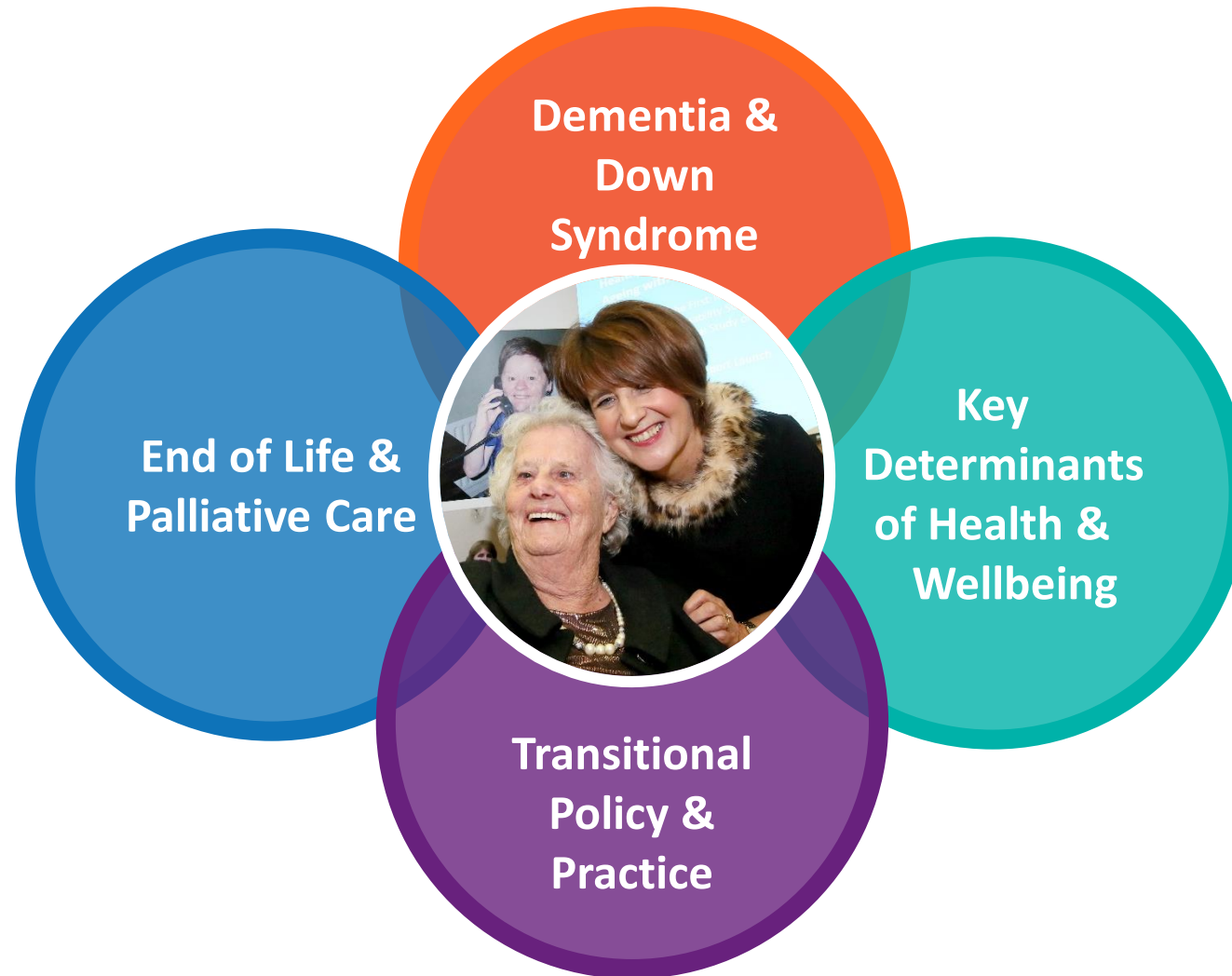


Dean, Faculty of Health Sciences: 2011 -2019





Thematic Interests





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

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

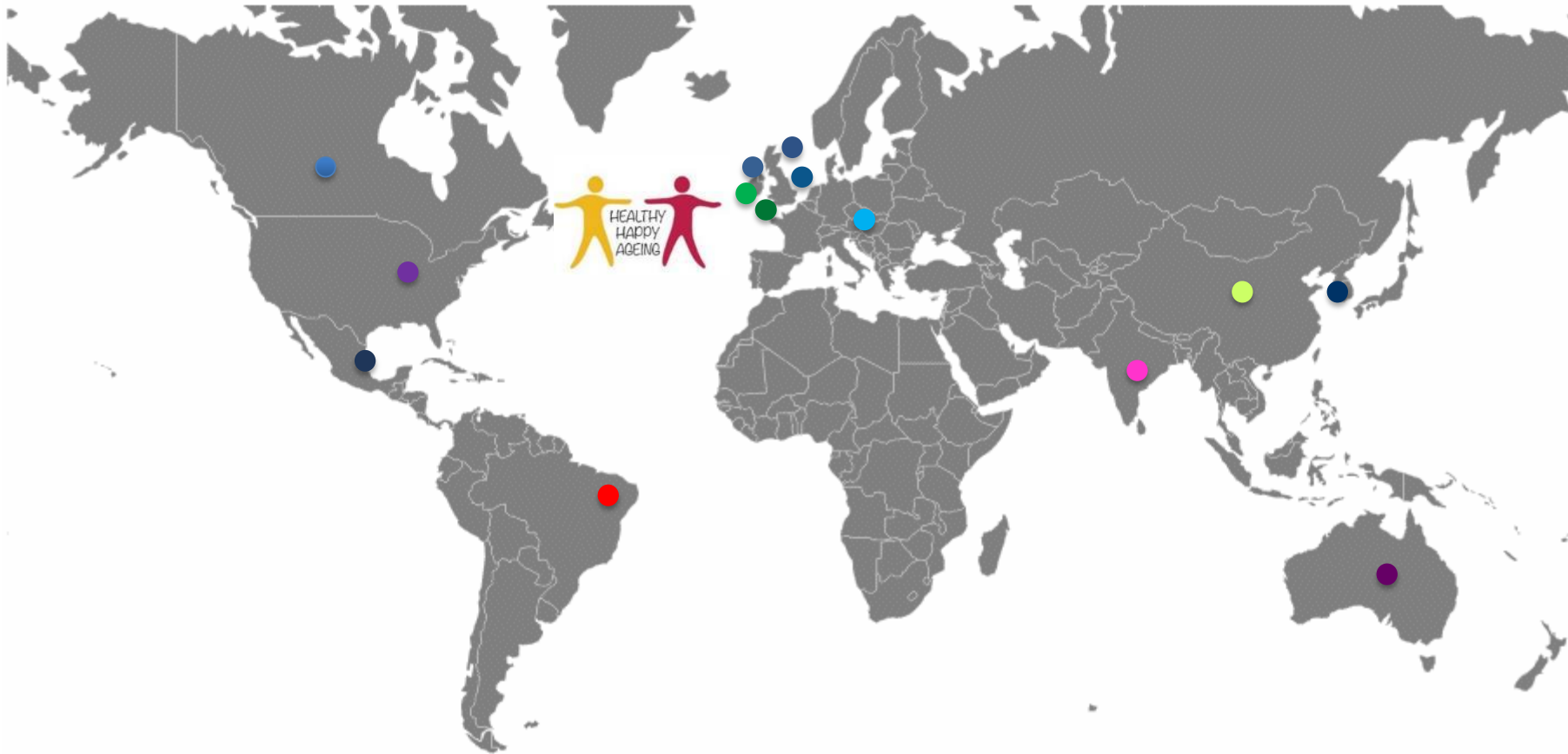


IDS-TILDA

Joins the Global Family of Longitudinal Studies



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



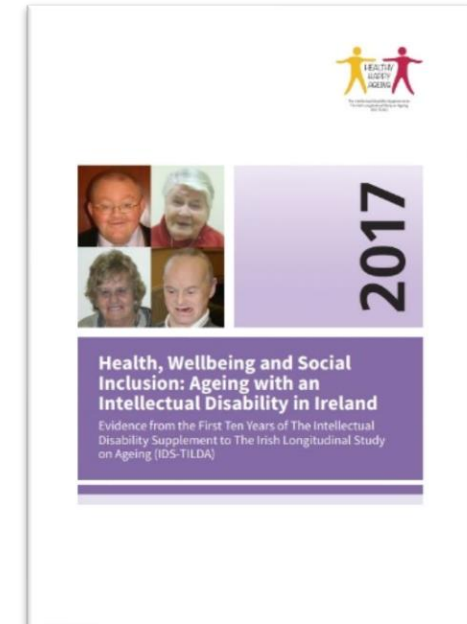
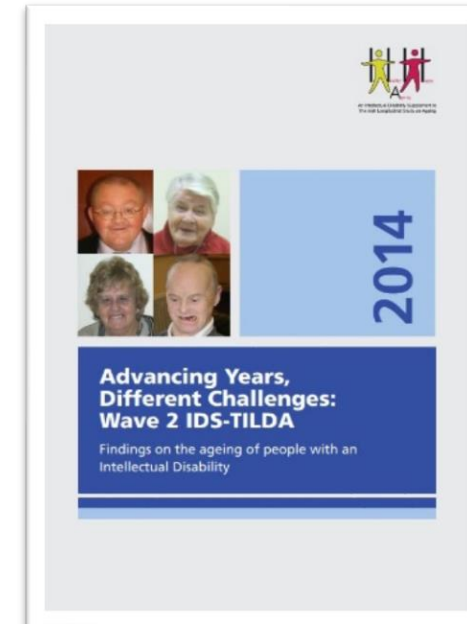
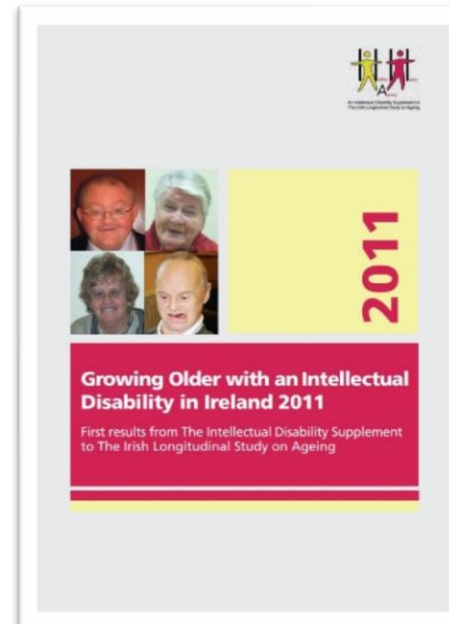


The IDS-TILDA Story: 2007 – Present



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

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



Celebrating 10 Years of IDS-TILDA

“Nothing about us, without us”



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



December 2018

IDS TILDA secures
another **€1.5 million** for
the next three years
from the
Health Research Board





Director, Trinity Centre for Ageing and Intellectual Disability: 2017 - Present





IDS-TILDA

Objectives



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

- **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.**



IDS-TILDA: Values Framework

“Nothing about us, without us”



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





IDS-TILDA Participant Involvement

“Nothing about us, without us”



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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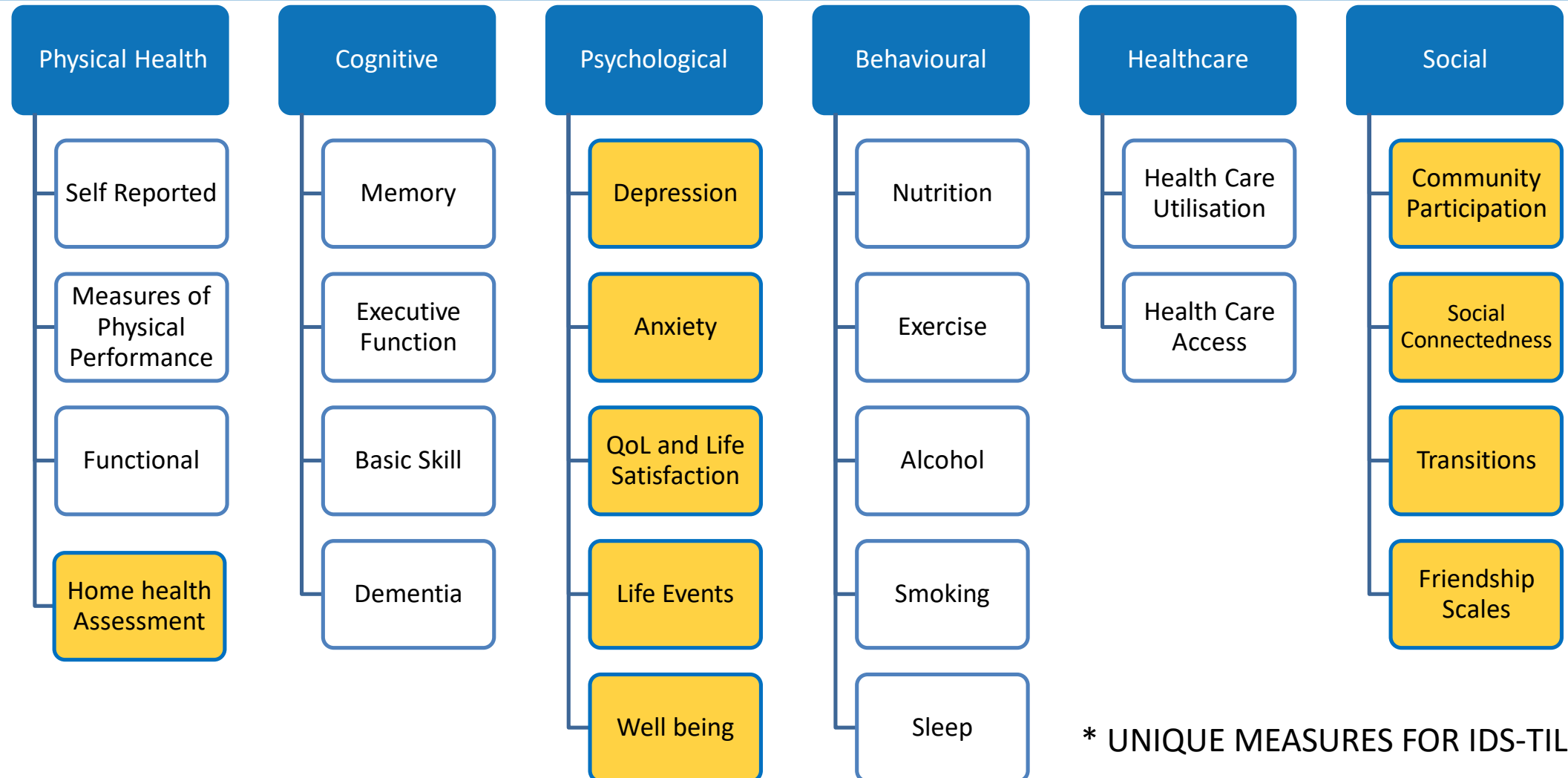


IDS-TILDA

Underpinning Conceptual Framework



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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IDS-TILDA Wave 4: Health Fair

Expanded Objective Health Measures



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Grip Strength

Timed Up and Go

Blood Pressure

Waist and Hip
Circumference



Height and Weight
Measurements

Quantitative
Ultrasound (QUS)

Blood Drop Sample

Oral Health
Assessment



Nutrition Intake

Hair Sample

Short Performance
Physical
Assessment
Battery

Calf Measurement
and Foot
Assessment

@McCarrmMary

#ageingwithID



What IDS-TILDA Teaches Us



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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CHRONIC CONDITIONS & THE AGEING ID POPULATION



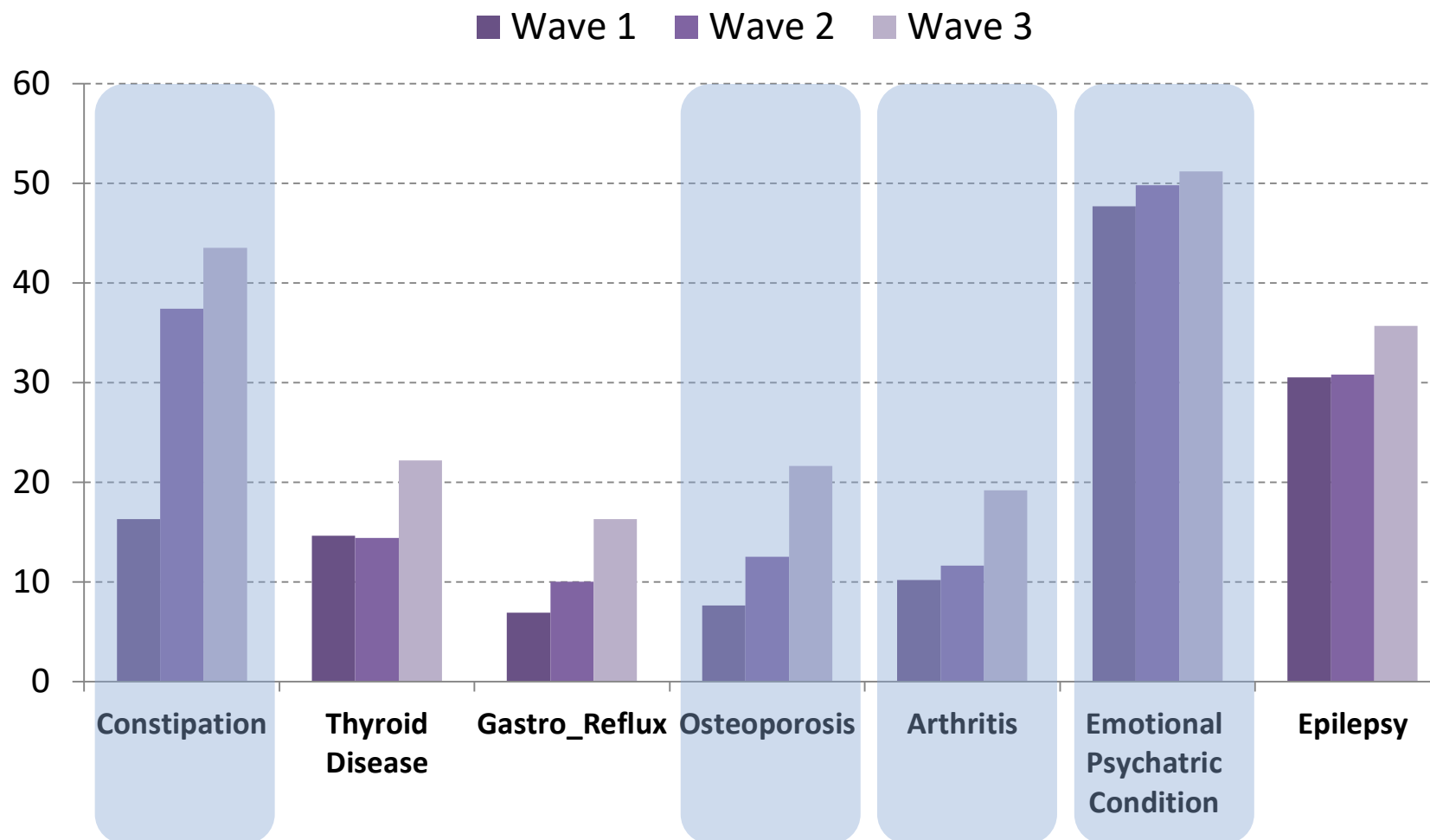
What IDS-TILDA Teaches Us

Prevalence of Chronic Conditions

**Opportunity:
Encourage
Non-Pharmacological
Interventions**



The Intellectual Disability Supplement to
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What IDS-TILDA Teaches Us Oral Health

Opportunity:
Oral Health Intervention
Programme



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

28%
IDS-TILDA
participants
reported that they
had no teeth at all



67.8%
IDS-TILDA
participants with
total tooth loss did
not receive
prosthetic
dentures



- **2x** more likely to have difficulty eating
- **3x** more likely to be on a softened / liquidised diet
- **2x** more likely to report chronic constipation



What IDS-TILDA Teaches Us

Translating our Findings on Oral Health



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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brushmyteeth.ie

A website showing people
how to brush their teeth



What IDS-TILDA Teaches Us





Bone Health



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My Measurements

Name: _____

	HEIGHT	_____ cms
	WEIGHT	_____ Kgs
	BLOOD PRESSURE	_____ mmHg
	HEEL ULTRASOUND - QUS	T Score _____

8%
Doctor-
diagnosed
osteoporosis
Wave 1

16%
Doctor-
diagnosed
osteoporosis
Wave 2

21.6%
Doctor-
diagnosed
osteoporosis
Wave 3

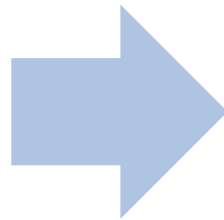
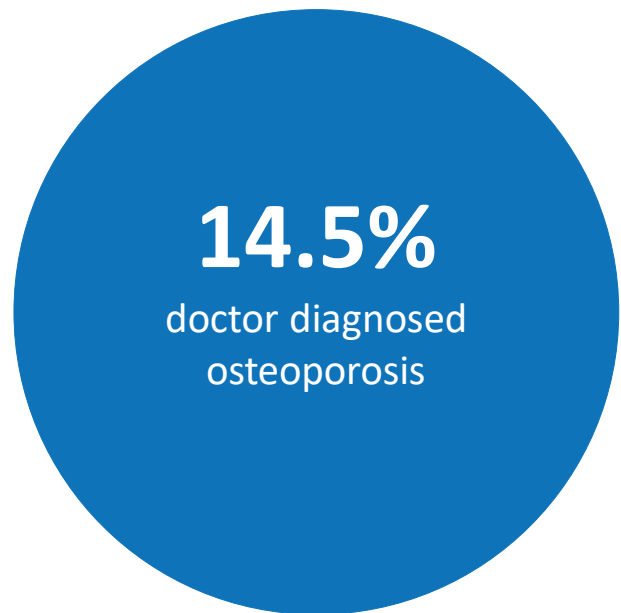


What IDS-TILDA Teaches Us

Bone Health during Wave 2



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Objectively measured bone health:

41% with osteoporosis

33.1% with osteopenia



These figures represent those who did the Quantitative Ultrasound in Wave 2 (n=575)



What IDS-TILDA Teaches Us

Translating Our Findings on Bone Health



The Intellectual Disability Supplement to
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Get Wise About Your Health – Bone Health

In 2020, Get Wise will produce an accessible
online health education programme around
bone health for people with ID

Funded by EIT Health in association with
Erasmus MC Rotterdam



What IDS-TILDA Teaches Us

Translating Our Findings on Chronic Conditions



The Intellectual Disability Supplement to
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A MOOC (Massive Open Online Course) to develop best practice when engaging people with an intellectual disability in health assessments.

This course is running now on FutureLearn.com and is available for the next few weeks.



What IDS-TILDA Teaches Us

Translating Our Findings on Physical Activity



The Intellectual Disability Supplement to
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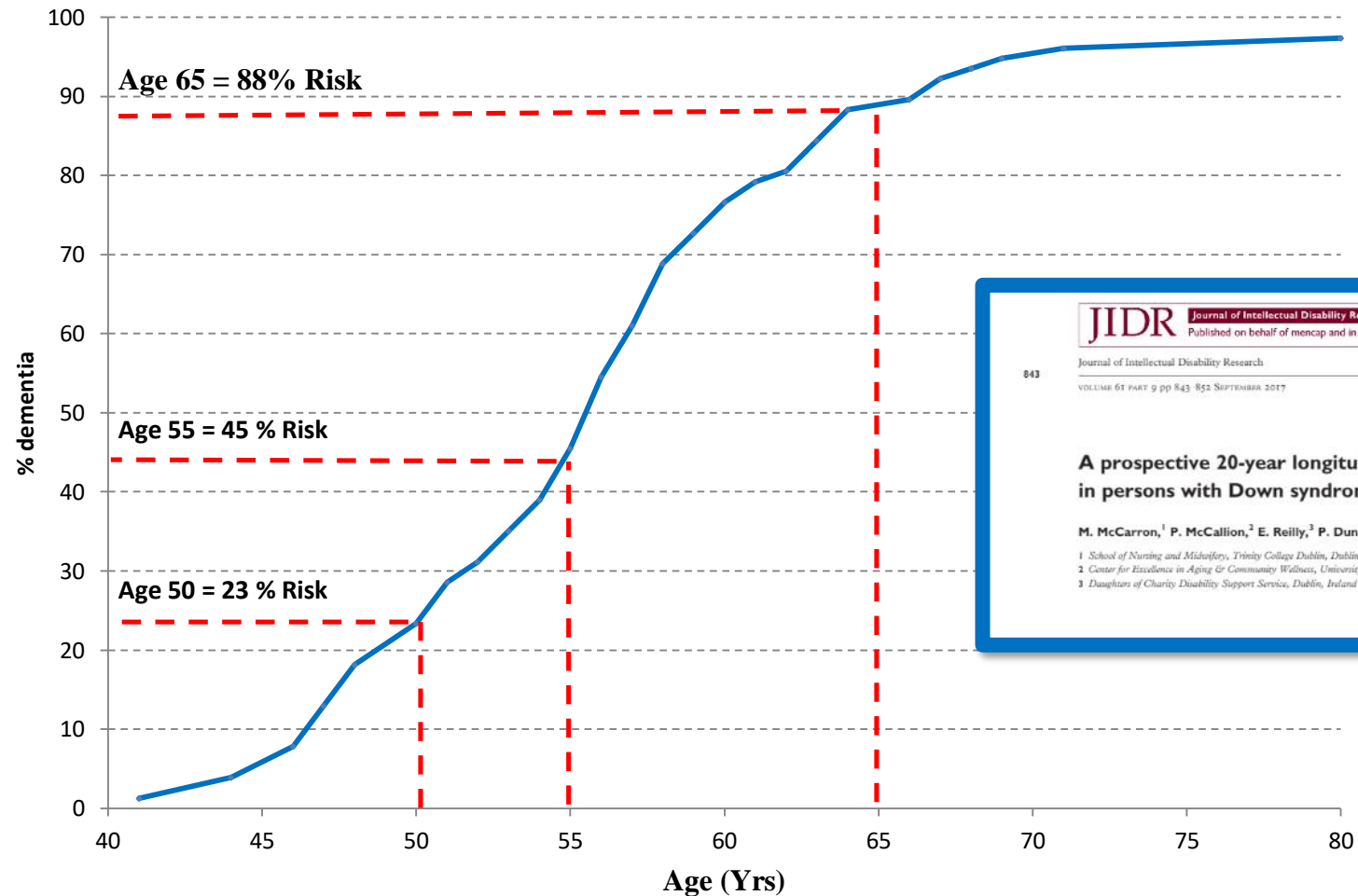


P-PALs is a pilot project supporting older people with ID to lead physical activity among their peers.
Phase 2 will run in 2020.

Funded by EIT Health in association with Age & Opportunity's Go for Life, University of Barcelona and the Technical University of Munich



Risk Trajectory By Age





Influencing Public Policy

THE IRISH TIMES

Sat, Nov 21, 2015

NEWS

SPORT

BUSINESS

OPINION

LIFE & STYLE

CULTURE

Health & Family > Parenting | The Health Centre | Get Swimming | Get Running

Ireland ill-prepared to address needs of those with Down syndrome and dementia

As a result, a vulnerable group is falling between the different care systems



It is impressive today to see young people with Down syndrome attending mainstream classes in local schools, and as adults holding jobs, attending university, living in their own flats and houses, supporting their families as well as being supported by them, and participating in sports. Photograph: Thinkstock



Outcomes Focused





What IDS-TILDA Teaches Us

Translating our Findings on Dementia



Trinity Centre
For Ageing and
Intellectual Disability



Tallaght
University
Hospital

Ospidéal
Ollscoile
Thamhlachta

An Academic Partner of Trinity College Dublin



Daughters of Charity
Disability Support Services



What IDS-TILDA Teaches Us

Translating our Findings on Dementia



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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We want to ensure that people with Down syndrome have 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.**



Include the voices of people with Down syndrome in the conversation on dementia



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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“Like everybody here, I have dreams for the future. There are things that I want to do and I know dementia might play a part of my life too.

So, when you start talking about dementia, I want to be included in that conversation. I want to be included in the conversation about my future.

I want to be empowered so that I can choose how to reduce the risk of dementia”

- Mei Lin Yap





What IDS-TILDA Teaches Us



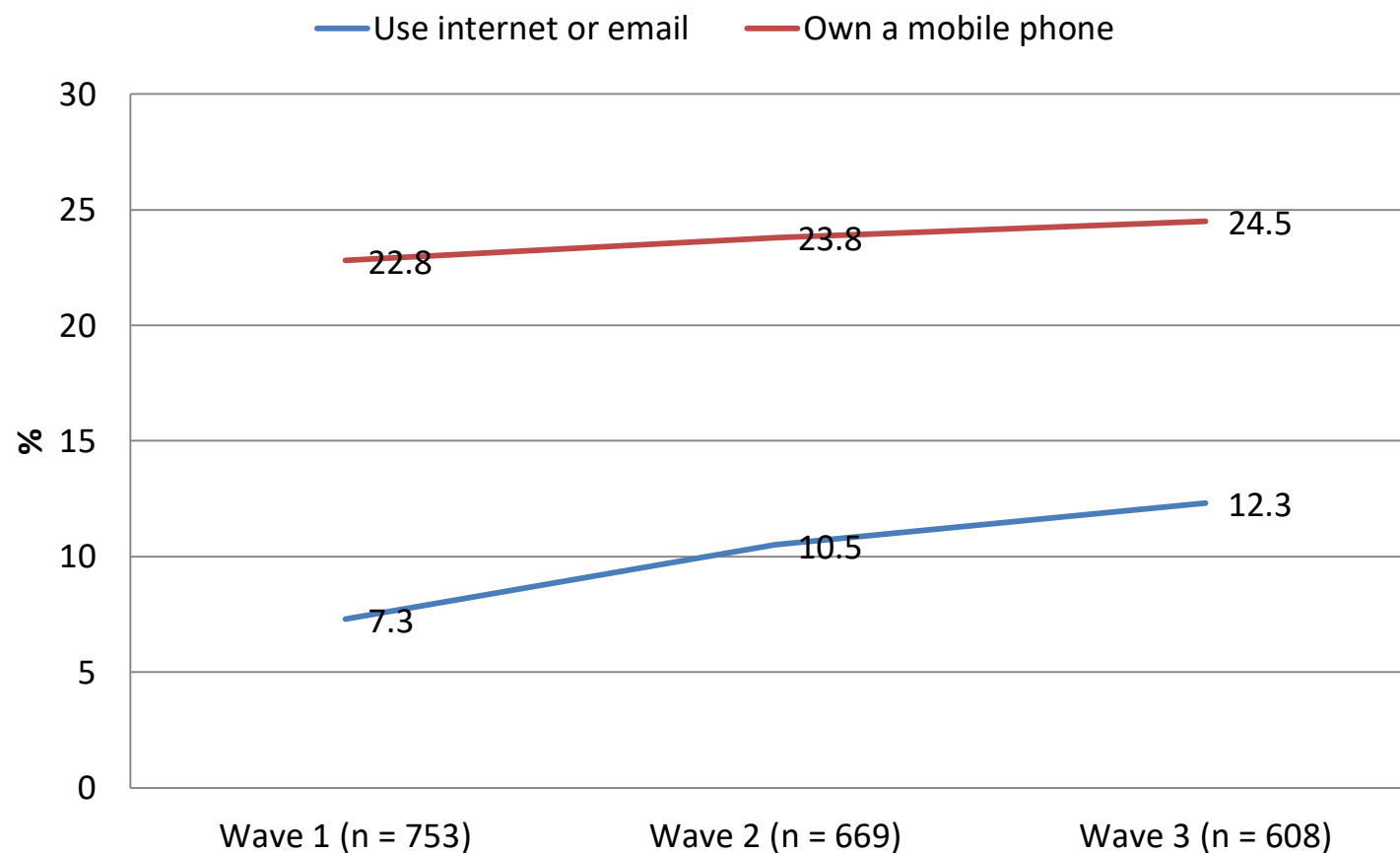
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eHEALTH & mHEALTH & THE AGEING ID POPULATION

What IDS-TILDA Teaches Us: Technology



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



35%
access to
computer

75%
difficulty using
a computer

99%
cannot use
social media
or search
engines
without
assistance

What IDS-TILDA Teaches Us: Translating our Findings on Technology



The Intellectual Disability Supplement to
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Stewarts Care will be trialling a roll-out of the **Way2Be** wayfinding app among their clients

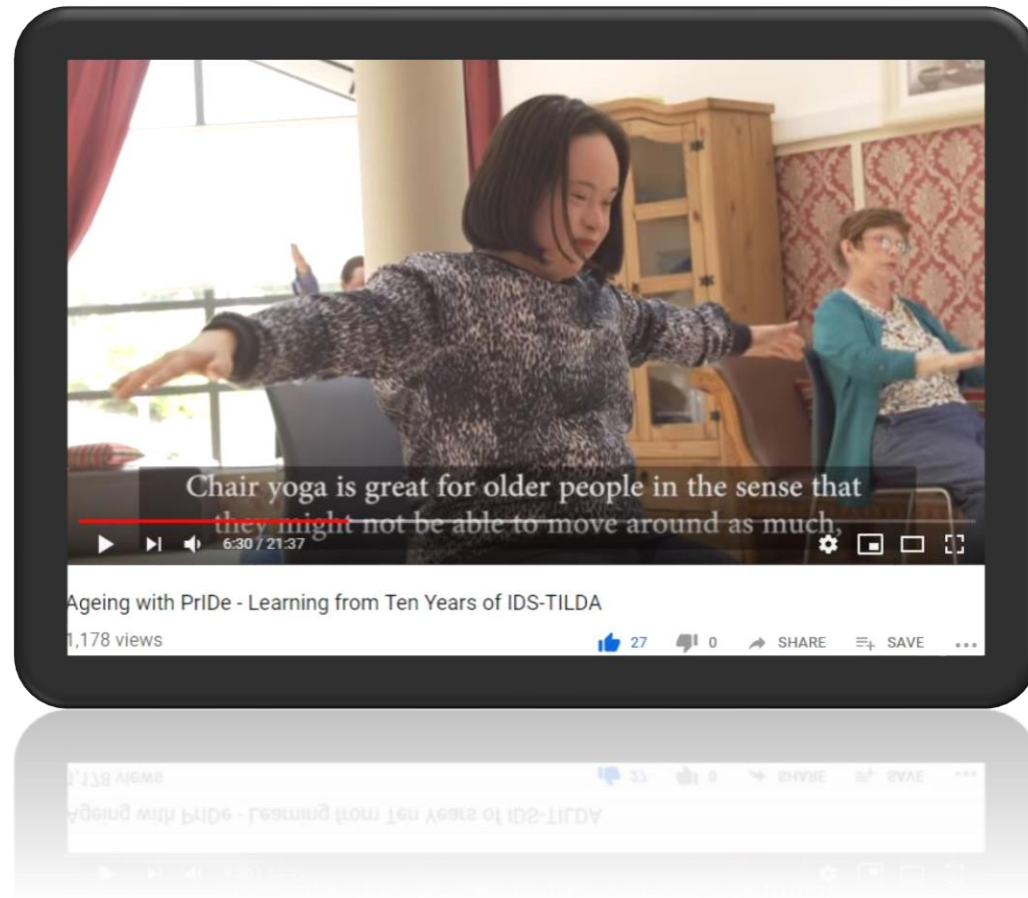


Stewarts
Per Tenebras Ad Lucem

What IDS-TILDA Teaches Us: Knowledge Translation



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



Ageing with PrIDe

A health promoting video based
on ten years of IDS-TILDA:
1,700 views this year



2019 HRB Impact Award



“Prof McCarron has an incredible track record of **translating her research into practice**. As a result she is now is delivering better health and care... and driving policy change that is transforming the lives of people with intellectual Disability as they age.”

Dr Darrin Morrissey
Chief Executive, Health Research Board



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

“Vision without action is merely a dream. Action without vision just passes the time. **Vision with action can change the world.**”

— Joel Barker



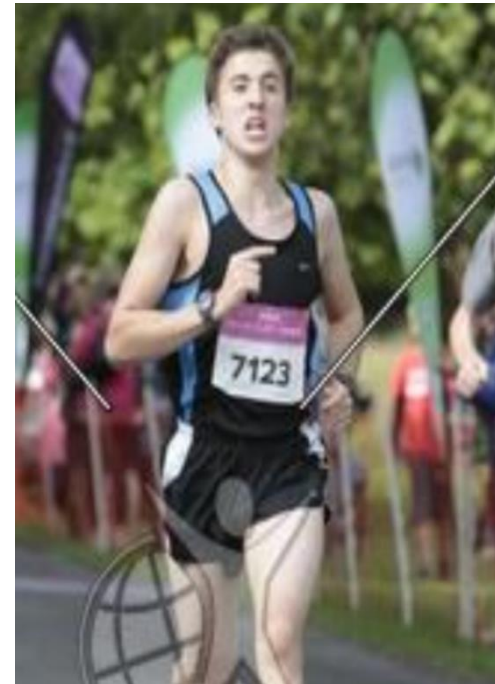
What I've Learned



1. Consistency of thematic interests over time
2. Perseverance of effort or 'stick-ability'



My Story

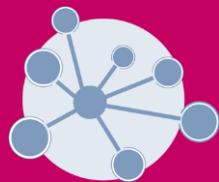




My Story

Don't be afraid to fail.
Be afraid of not trying.





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Gaeilge



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](#)



IDS-TILDA

Acknowledgements



The Intellectual Disability Supplement to
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The IDS-TILDA Team extends grateful appreciation to:

- Participants, Families and Carers
- The IDS-TILDA Steering Committee and International Scientific Advisory Board
- Advisors and Advisory Groups
- Our Funders



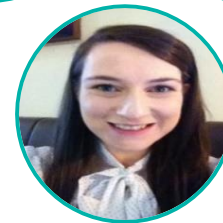


IDS-TILDA

The Team



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
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Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

Thank You

Mary McCarron

Professor of Ageing & Intellectual Disability

Principal Investigator, IDS-TILDA

Director, Trinity Centre for Ageing and Intellectual Disability

Director, National Intellectual Disability Memory Service

Policy and Service Advisor on Dementia Daughters of Charity Disability

Support Service

Email: mccarrm@tcd.ie

Website: www.tcd.ie/tcaid

@ageingwithID

#ageingwithID