Ageing with Down Syndrome: Latest Insights

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#ageingwithID
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
The IDS-TILDA Story

First nationally-representative longitudinal study on ageing with an intellectual disability comparable to the general population
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.**
IDS-TILDA: Values Framework

“Nothing about us, without us”

- Inclusion
- Promotion of People with ID
- Choice
- Promotion of Best Practices
- Person Centred
- Contribution to the Lives of People
- Empowerment
 IDS-TILDA
Underpinning Conceptual Framework

Physical Health
- Self Reported
- Measures of Physical Performance
- Functional
- Mini Home Assessment

Cognitive
- Memory
- Executive Function
- Basic Skill
- Dementia

Psychological
- Depression
- Anxiety
- QoL and Life Satisfaction
- Life Events
- Well being

Behavioural
- Nutrition
- Exercise
- Alcohol
- Smoking
- Sleep

Healthcare
- Health Care Utilisation
- Health Care Access

Social
- Community Participation
- Social Connectedness
- Transitions
- Friendship Scales
IDS-TILDA
Underpinning Conceptual Framework

- Physical Health
  - Self Reported
  - Measures of Physical Performance
  - Functional
  - Mini Home Assessment

- Cognitive
  - Memory
  - Executive Function
  - Basic Skill
  - Dementia

- Psychological
  - Glasgow Anxiety and Depression Scales
  - Executive Function
  - Basic Skill
  - Dementia
  - Life Events
  - Well being
  - Satisfaction with Life Scales

- Behavioural
  - Nutrition
  - Exercise
  - Alcohol
  - Smoking
  - Sleep

- Healthcare
  - Health Care Utilisation
  - Health Care Access

- Social
  - Community Participation
  - Social Connectedness
  - Transitions
  - Friendship Scales
IDS-TILDA Participant Involvement
“Nothing about us, without us”
Celebrating 10 Years of IDS-TILDA

“Nothing about us, without us”
Trinity Centre for Ageing and Intellectual Disability Launch

“Nothing about us, without us”
Optimising Wellbeing
For people ageing with Down syndrome

Productive Wellbeing
Material Wellbeing
Physical Wellbeing
Social & Emotional Wellbeing
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
Advocating for Productive Wellbeing
Providing Real & Meaningful Opportunities
Advocating for Productive Wellbeing
For Real & Meaningful Opportunities
Circles of Support

Opportunities:

• Greater preparedness for:
  • Employment
  • Changes in Residence
  • Personal Choice
  • Cognitive Training
  • Technology Use
  • Retirement Planning
  • Specialist Care Centres
Trinity graduates, Talita Holzer Saad and Robbie Fryers, winners of the 2017 James Dyson Award with Pat O’Shea and Patrick in Front Square.
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

Opportunities:

• Schedule annual hearing and vision testing
• Check for ear wax build-up
• Remove trip hazards
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.
Chronic constipation leads to pain, distended stomach, haemorrhoids, depression and disorientation.

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

Opportunities:

- Encourage daily physical activity
- Review diet and medications
- Screen for coeliac disease
People with Down syndrome have a higher rate of hypothyroidism than the general population.
Hypothyroidism

Opportunity:
• Look for mood changes, sleepiness or confusion
• Request an annual blood test
People with Down syndrome have a higher rate of sleep apnoea than the general population.
People with Down syndrome have a higher rate of sleep apnoea than the general population.

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**

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

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

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)
➢ 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

Age 65 = 88% Risk
Age 55 = 45% Risk
Age 50 = 23% Risk

% dementia

Age (Yrs)

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

M. McCarron, P. McCallion, E. Feil, P. Dunne, R. Carroll, & N. Mulryan
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. Department of Human Services, Support Service, Dublin, Ireland
Prevalence of Dementia

- **52.3** mean age of onset for dementia in those with Down syndrome
- **65.5** mean age of onset for dementia for ID of other aetiology
Dementia & Epilepsy

Life Time Prevalence

- LTP Dementia
- LTP Epilepsy

77.9% with Dementia had Epilepsy
Dementia Co-Morbidities

Dementia

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

### 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.**
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

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

- 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
Up to 35% of dementia cases are potentially preventable & attributable to 9 risk factors.

- Diabetes: 1%
- Social isolation: 2%
- Physical inactivity: 3%
- Depression: 4%
- Smoking: 5%
- Obesity: 1%
- Hypertension: 2%
- Hearing loss: 9%
- Less education: 8%

ApoE ε4 allele: 7%

65% potentially non-modifiable

Source: The Lancet Commission 2018
• **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.
99.7% of all RCTs for Alzheimer disease have failed in the past 15 years.
We need a Paradigm Shift in health care

**DIAGNOSE & MANAGE**

**PRE-EMPT & PREVENT**
Brain Exercises for Adults with Down Syndrome

Assessing the Feasibility of Cognitive Training to Increase Executive Functions in Adults with Down Syndrome

The BEADS study

Source: Dr Eimear McGlinchey
Translating Findings

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

www.tcd.ie/tcaid/  #ageingwithID
Thank You

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