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:
Celebration & Challenge of Ageing

- A success story
- Little known ageing
- A rapidly changing landscape
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 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
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 (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!
Summary of some key messages and implications for the Role of the RNID
Changes in prevalence of chronic conditions

- Arthritis: Wave 1 = 10.6, Wave 2 = 16.9
- Wrist fracture: Wave 1 = 12.8, Wave 2 = 8.0
- Cataracts: Wave 1 = 19.1, Wave 2 = 16.4
- Osteoporosis: Wave 1 = 16.9, Wave 2 = 10.6
- Cancer: Wave 1 = 12.8, Wave 2 = 8.0
- Lung disease: Wave 1 = 5.0, Wave 2 = 2.9
- Hip fractures: Wave 1 = 2.9, Wave 2 = 1.4
- Macular degeneration: Wave 1 = 1.4, Wave 2 = 0.5
- Glaucoma: Wave 1 = 2.7, Wave 2 = 1.2

Note: The changes in prevalence are indicated by red arrows for the conditions: Wrist fracture, Arthritis, and Cataracts.
Changes in prevalence of chronic conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Wave 1</th>
<th>Wave 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td>37.9%</td>
<td>37.9%</td>
</tr>
<tr>
<td>Thyroid disease</td>
<td>17.3%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Chronic constipation</td>
<td>17.3%</td>
<td>17.3%</td>
</tr>
<tr>
<td>Gastroesophageal reflux</td>
<td></td>
<td></td>
</tr>
<tr>
<td>disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stomach ulcers</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Disease patterns are different

Health promotion & disease prevention implications
## Different Patterns than for the General Population

<table>
<thead>
<tr>
<th>IDS-TILDA W2</th>
<th>TILDA W2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overweight/Obese</strong> – 66%</td>
<td><strong>Overweight/Obese</strong> – 79%</td>
</tr>
<tr>
<td>Diabetes – 7.5%</td>
<td>Diabetes – 9%</td>
</tr>
<tr>
<td><strong>Myocardial Infarction</strong> – 1%</td>
<td><strong>Myocardial Infarction</strong> – 5.5%</td>
</tr>
<tr>
<td>Hypertension – 17.5%</td>
<td>Hypertension – 37%</td>
</tr>
<tr>
<td>Osteoporosis – report doctors diagnosis – <strong>16.4%</strong></td>
<td>Osteoporosis – <strong>14.3%</strong></td>
</tr>
</tbody>
</table>
Difference in Overall Falls Prevalence in People with an Intellectual Disability vs the General Population

<table>
<thead>
<tr>
<th>Fallers</th>
<th>Multiple Fallers</th>
</tr>
</thead>
<tbody>
<tr>
<td>28.3%</td>
<td>15.3%</td>
</tr>
<tr>
<td>22.2%</td>
<td>8.8%</td>
</tr>
</tbody>
</table>

IDS TILDA Wave 2

TILDA Wave 2

(Foran et al 2016)
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.
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

IDS-TILDA    TILDA

<table>
<thead>
<tr>
<th>Low</th>
<th>Moderate</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>73.8</td>
<td>24.1</td>
<td>31.8</td>
</tr>
<tr>
<td>34</td>
<td>34</td>
<td>34</td>
</tr>
</tbody>
</table>

Trinity College Dublin, The University of Dublin
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

Age 65 = 88% Risk
Age 55 = 45% Risk
Age 50 = 23% Risk
Dementia and Epilepsy

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

Life Time Prevalence

- LTP Dementia
- LTP Epilepsy

Trinity College Dublin, The University of Dublin
Co-Morbidities

% Dementia

- Heart disease: 29.3%
- Hypertension: 1.3%
- Epilepsy: 80%
- Hyperthyroidism: 61.3%
- Cancer: 0%
- Lung: 13.3%
- Vision: 93.3%
- Hearing: 61.3%
- Diabetes: 4%
- Depression: 48%
- Hyperlipida: 18.7%
Mortality

Median survival = 7 years
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
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 Eimear McGlinchey
Promoting Brain Health – Critical issues

- 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**?
Maintaining Brain Health

- Physical Activity
- Nutrition
- Mental Stimulation
- Social Connections
Medicine Use

- No polypharmacy
  - 0 – 4 medicines
- Polypharmacy
  - 5 – 9 medicines
- Excessive Polypharmacy
  - 10+ medicines
## Polypharmacy in IDS TILDA & TILDA

<table>
<thead>
<tr>
<th>Polypharmacy</th>
<th>Wave 1</th>
<th>Wave 2</th>
<th>TILDA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine Users</td>
<td>92%</td>
<td>95%</td>
<td>69%</td>
</tr>
<tr>
<td>No Polypharmacy</td>
<td>46%</td>
<td>33%</td>
<td>79%</td>
</tr>
<tr>
<td>Polypharmacy</td>
<td>32%</td>
<td>43%</td>
<td>19%</td>
</tr>
<tr>
<td>Excessive Polypharmacy</td>
<td>22%</td>
<td>25%</td>
<td>2%</td>
</tr>
</tbody>
</table>

(Dwyer et al 2016)
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

- Necessary
- Over-prescribing
- Drug Interactions
- Prescribing Cascade
- ADRs
- Preventable harm
- Education
- Monitoring
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)

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

Types reported:

- **66.1%** Destruction
- **38.1%** SIB
- **47.8%** Physical
- **27.9%** Verbal
- **16%** Other

(Dwyer, C et al 2016)
Factors associated with Displaying BWC

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

- Taking psychotropic medication
- Diagnosis of psychiatric condition
- Experienced greater number of life events
- More restrictive setting
- More severe ID
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

Who moved?
70.4% Mild/Mod ID
55% Female
70% were <64 years

Majority were lateral movers from similar type residence

120 MOVERS

Who was involved in Decision?
The person with ID themselves 30%
Service provider 82%
Staff 45%
Family 27.5%

60% wanted to move

20% viewed alternate options

(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)
- Never Married, 8%
- Married / Previously... 92%

Mean No. of Children
2.8 – 3.3

IDS-TILDA Sample
- Single 99%
- Spouse / Partner 1%

Mean No. of Children
0.0

Source: Darren McCausland
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

<table>
<thead>
<tr>
<th>Staff</th>
<th>Policy</th>
<th>Culture change</th>
</tr>
</thead>
</table>
| • Play an important social role  
• RNID facilitators of social and community participation | • High medical support needs across the lifespan  
• Ageing population with high nursing support needs | • RNID Leadership  
• Move away from risk-averse  
• Buy-in to individualised, person-centred *culture* (facilitating not paternalistic) |
Supporting people at end of life

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

Development of specialist role to address identified gaps
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

PATIENT/FAMILY/COMMUNITY NURSING, AND ORGANIZATION OUTCOMES

OUTCOME MEASURES
Quality Indicators Implementation Evaluations
Making Changes
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

Grateful appreciation to the participants and families

The funders and supporters

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