Ageing with Intellectual Disability in Australia:

Disability Funding, Retirement and End of Life

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Congratulations!

10 years of research on the *Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing* (IDS-TILDA)

- Longitudinal
- Comparison with the general community
- Nationally representative sample

Establishing *The Trinity Centre for Ageing and Intellectual Disability*
Overview

– Australia’s National Disability Insurance Scheme (NDIS)

– Transition to Retirement

– End of Life
Australia’s National Disability Insurance Scheme (NDIS)
NDIS: The Basics

- **National** scheme with staged roll out 2013-18. Transition arrangements for existing disability service users.

- Large increase in disability services and supports – **doubling** of the number of people served (and doubling of disability workforce).

- For NDIS participants ($N = 460,000$, predominantly people with ID and DD) portable, *individualised funding* is an **entitlement** (previously budget capped), to pay for supports that are “reasonable and necessary” based on the persons individual NDIS plan.
  - Choice of service providers, with the freedom to change providers if desired.

- **Health care** is funded and provided **separately** (e.g., under Medicare).
NDIS and Ageing

- NDIS participants must be *aged less than 65* when they first apply to enter the NDIS.

- Aged care services are funded and operated separately from the NDIS and are available to all Australians with or without disability.

- NDIS participants who are turning 65 or older can opt to:
  - remain with NDIS funding
  - or switch to receive supports through the Commonwealth aged care system.
Transition to Retirement
Retirement – A risky proposition (Bigby, Wilson, Stancliffe & Balandin, 2011)

– Aging of workforce in facility-based employment (sheltered workshops)

– For services - declining productivity

– For workers – stamina, health issues – right to retire

– Anxiety about retirement:
  “I’ve got my friends here (at work) you know I go home and I go to work, that’s enough for me …no-one thinks of retiring…”

  “…you sit at home and you don’t do anything”
Retirement – A risky proposition (Bigby, Wilson, Stancliffe & Balandin, 2011)

– Absence of alternatives
  – Default is segregated disability day programs

– No funded mechanisms to support the transition to retirement

– Some ad-hoc retirement programs; disability-specific options

– Limited conceptualisation of what might be possible

– Disconnection with prevailing ideas about social inclusion

– Mainstream community groups willing but hesitant about inclusion.
Overall Study Aims – to develop and test a service model

- Increase capacity of **mainstream community groups** to include older adults with intellectual disability

- Enable people with disabilities to “join in” their local communities

- Older people (45+) to cut down work **one day per week**

- Support to join a community or volunteer group based on their interests.
Transition to Retirement (not full retirement)

- **One day per week**, instead of working, the person attends a **mainstream community group** of their choice and receives support from group members who volunteer to be **mentors**.

- **Mentors** trained to provide effective support and ensure activities are available.
Why MAINSTREAM Community Groups?

Participants had spent many years in *sheltered employment and disability housing* (e.g., group homes).

**Mainstream Community Groups are:**
- Socially inclusive
- Serve other retirees without long-term disability
- Low cost
- Local
- Focus on a wide variety of **specific interests**
- An existing community resource.
**Type of Volunteering Opportunity or Community Group**

**MEN (n=17)**

**VOLUNTEERING**
- Community (soup) kitchen (n=1)
- Community garden (n=1)
- Community nursery (n=1)
- Aviation museum* (n=1)
- Lifeline charity shop* (n=1)

**COMMUNITY GROUP**
- Men’s shed* (n=8)
- Seniors group (n=1)
- Seniors choir (n=1)
- Bowls club (n=1)
- Seniors 10-pin bowling league (n=1)

**WOMEN (n=10)**

**VOLUNTEERING**
- Cat protection society* (n=1)
- Community nursery (n=1)
- Frail-aged social group (n=1)

**COMMUNITY GROUP**
- Exercise* and social group (n=1)
- Community (teaching) kitchen (n=1)
- Seniors group (n=4)
- Walking and knitting group (n=1)
eBook

Transition to retirement: A guide to inclusive practice

– 163 pages: sets out in detail how to implement the TTR program. Supported by 26 embedded video clips.

– now available on the iBook Store and Google Play.

– Online access to the full 63-minute DVD

– 13 chapters
  – includes the stories of six men and women in their 50s, 60s or 70s.
NDIS funding of *Transition to Retirement* (TTR)

– Our disability service provider research partner **AFFORD** is offering transition to retirement as a routine service option for people with disability.

– Individualised NDIS funding provides a means for service users to pay for TTR if the include TTR in their NDIS plan.

– However, NDIS funding can also be used for traditional community participation supported by a disability worker.
Policy and Practice Implications: From community presence to social inclusion

– Older adults with intellectual disability can be supported to successfully join mainstream community groups.
  – With support and recognition, mainstream community groups are willing to welcome members with intellectual disability.

– Participants worked in sheltered employment, had mild/moderate disability and little or no evident challenging behaviour (not formally assessed) and were capable of routine self-care.

– There are benefits for the person with intellectual disability and the community group members.

– The nature and timing of retirement is highly individual (e.g., age range was 45 to 72). Some people prefer to continue to work (at least part time).

– The “respite effect” for family caregivers is very important. Likewise, meaningful activity and social connections are important for people with intellectual disability.

– This approach is not retirement specific, and should be able to be used with people of any age.
IDS-TILDA: Monitoring employment and retirement

- IDS-TILDA enables representative data to be reported about employment, retirement, and activities in retirement. Such data are potentially useful in evaluating policy (e.g., changes to sheltered employment).

- Currently in Australia, there is no nationally representative, publicly-available outcome data for people with ID, some data about employment, and none about retirement.
End of Life
Excellence in Dementia Care for People with Intellectual Disability in Ireland

- **Daughters of Charity Service:**
  - Willow View and Meadow View homes

- Positive lifestyle with meaningful activity and skilled care

- Has provided the opportunity for a dignified death with the privacy, comfort and security of being cared for in one’s home by familiar caregivers, with fellow residents and support for close family involvement.
End of life: Some Australian findings

- Disability staff often uncomfortable/unwilling to talk about death with people with ID (Wiese et al., 2013).
  - Fear of upsetting people with ID – (over)protection.
  - Available research suggests fears are overstated (Stancliffe et al., 2016, 2017).

- Almost all people with mild/moderate ID can identify people who they know who have died (Stancliffe et al., 2016).

- Currently developing an online training curriculum to support disability staff to have everyday conversations with people with ID about end of life.

End of life: Some Australian findings

Compared to adults without ID (Stancliffe et al., 2016)

– **Understanding the concept of death**
  – Less complete understanding of death.
  – Wide range of levels of understanding. Some adults with (milder) ID have a sound understanding, others have far poorer understanding.

– **End of life planning**
  – Knew far less about end-of-life planning, and were less self-determined (wide range).

– **Fear of death**
  – Reported greater fear of death (very wide range).

– **Assessment instrument development** to assess these domains (Stancliffe et al., 2017).
Australian data linkage study of deaths of service users with intellectual disability

A recent data-linkage study from New South Wales, Australia (Trollor, Srasuebkul, Xu, & Howlett, 2017) showed:

- Median age of death **54 years**

- **Potentially avoidable deaths**
  - 38% of deaths in the ID cohort and
  - 17% in the general population cohort.

- **Incorrect cause of death**
  - In 16% of cases of people with ID, cause of death data in the state registry of deaths was incorrectly recorded
  - Intellectual disability or a related diagnosis (e.g., Down syndrome) was inappropriately listed as the cause of death.

- **Advocacy and political response**
  - Strong advocacy and significant media coverage of these continuing health inequalities resulted in political attention to the issue.
Safeguards about death: Balancing protection and dignity

– Striking an appropriate policy balance between safeguards and overly intrusive investigation.

– In New South Wales, all deaths of people with disability living in out-of-home care must be reported to the coroner.
  – If the person dies at the group home, this is done by calling the local police, who come to the group home.
  – Perverse incentives may result in people being transferred to an acute hospital or nursing home.

– In our research, these procedures can be quite disruptive and interfere with the dignity and privacy of the person’s death.

– Overwhelmingly, with expected death, these reporting procedures revealed no problems.
Example of useful Coronial Recommendations: Coronial inquest into the death of “AR”

– 29-year old man, with a diagnosis of autism and severe intellectual disability, and sudden and unexpected death, the cause uncertain.

– Investigative delays and the consequent lost opportunity to obtain current accounts of important matters resulted in an absence of evidence
  – did not assist in the task of determining the cause of death.

– Findings from this inquest resulted in the NSW disability department (ADHC) developing formal procedures for management - *Operational Guidelines for the Review of the Death of People with Disability*, including:
  – appointment of an internal independent person to undertake an immediate inquiry including obtaining witnesses' versions of the events in as much detail as possible
  – report being sent to the NSW Ombudsman's under the *Reportable Incident Scheme - Part 3C Ombudsman Act 1974* (NSW).
Future Australian Safeguards: NDIS quality and safeguarding framework


— “`serious incidents’ …. covers events, such as deaths in care, which are required to be reported regardless of cause.” (pp. 50-51).

— The operational implementation of this reporting requirement is currently unclear.
References

Ebook

Peer-Reviewed Journal Articles


References


