

Ageing with Intellectual Disability in Australia:

Disability Funding, Retirement and End of Life

Presented by

Professor Roger Stancliffe

Centre for Disability Research and Policy



THE UNIVERSITY OF
SYDNEY

—
Centre for
Disability
Research
and Policy



*Image artwork copyright Helen Cooke, an artist supported by
Sunshine's Community Access Program Art Studio.*

University of Sydney



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)



THE UNIVERSITY OF
SYDNEY



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.
 - Option for self-management. Can hire own staff if self-managing.
- **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



THE UNIVERSITY OF
SYDNEY

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
 - Decision to retire not self-determined (McDermott & Edwards, 2012).
- 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.



Peter volunteering at the second-hand book store

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)

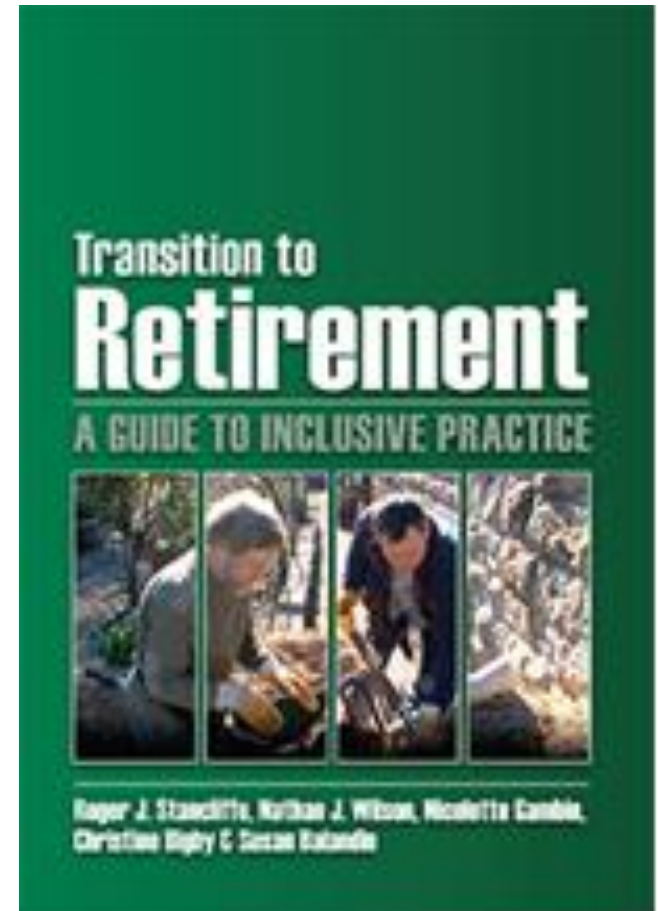
Seniors group (n=4)

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 they 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



THE UNIVERSITY OF
SYDNEY

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.
- Special issue of *Journal of Applied Research on Intellectual Disabilities* (JARID) on end of life (late October, 2017)

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, Srasuebku, 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



- Under the NDIS, a new *national* safeguards policy – the *NDIS quality and safeguarding framework* – will be implemented when the NDIS is fully rolled out. <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/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

Stancliffe, R. J., Wilson, N. J., Gambin, N., Bigby, C., & Balandin, S. (2013). *Transition to retirement: A guide to inclusive practice*. Sydney: Sydney University Press.

Peer-Reviewed Journal Articles

Bigby, C., Wilson, N. J., Balandin, S., & Stancliffe, R. J. (2011). Disconnected Expectations: Staff, family and supported employee perspectives about retirement. *Journal of Intellectual & Developmental Disability, 36*(3), 167-174. doi: 10.3109/13668250.2011.598852

Bigby, C., Wilson, N. J., Stancliffe, R. J., Balandin, S., Craig, D. & Gambin, N. (2014). An effective program design to support older workers with intellectual disability to participate individually in community groups. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 117-127.

McDermott S. & Edwards R. (2012). Enabling self-determination for older workers with intellectual disabilities in supported employment in Australia. *Journal of Applied Research in Intellectual Disabilities, 25*, 423–32. doi: 10.1111/j.1468-3148.2012.00683.x.

References

- Stancliffe, R. J., Bigby, C., Balandin, S., Wilson, N. J., & Craig, D. (2015). Transition to retirement and participation in mainstream community groups using active mentoring: A feasibility and outcomes evaluation with a matched comparison group. *Journal of Intellectual Disability Research, 59*(8), 703-718. doi: 10.1111/jir.12174
- Stancliffe, R. J., Wiese, M. Y., Read, S., Jeltres, G. & Clayton, J. M. (2016). Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ? *Research in Developmental Disabilities, 49-50*, 47-59. doi: 10.1016/j.ridd.2015.11.016
- Trollor, J., Srasuebkul, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open, 7*:e013489. doi: 10.1136/bmjopen-2016-013489
- Wiese, M., Dew, A., Stancliffe, R. J., Howarth, G., & Balandin, S. (2013). 'If and when?': The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. *Journal of Intellectual Disability Research, 57*, 980–992. doi:10.1111/j.1365-2788.2012.01593.x



Centre for Disability Research and Policy

www.sydney.edu.au/health_sciences/cdrp/

Email: roger.stancliffe@sydney.edu.au

