Retirement and End of Life for People with IDD

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Overview

Retirement

- Experiences of people with IDD (article)
- Transition to Retirement (book)

End of Life

- Talking End of Life (website)
- End of Life and People with IDD (book)

Retirement of People with IDD

- People with IDD are living longer.

- There is little research on retirement.

- Services are not always prepared to support older people with IDD.

Retirement Experiences of Adults with IDD

– The purpose of this study was to learn about the retirement experiences of older adults with IDD.

– Interviews with 9 adults with IDD

– Adults were 45+ and stopped or reduced paid work.

– Allies helped with technology and questions.

Participants

Name*	Age	Gender	Race	Ally	Years Known Ally	Work Type	FT/ PT	Living Arrange-ment	Partial/ Full Retirement	Years Retire
Community employment										
Jenny	66	Female	White	Mary	20+	Community with little/no support	PT	Apartment, alone	Partial	1
Bill	65	Male	White	Mary	20+	Community with little/no support	FT	Apartment, spouse	Full	5
Callie	63	Female	White	Mary	20+	Community with support	PT	Apartment, spouse	Partial	5
Carol	65	Female	White	Mary	20+	Community with support	PT	Foster home	Plans on partial	1
Peter	69	Male	White	Mary	20+	Community with support	FT	Apartment, roommates	Full	24
Barb	64	Female	Black	Debra	6	Community with support	PT	Group home	Full	1
Mateo	52	Male	Latino	Henry	21	Community with little/no support	FT	Family home	Full	9
Facility-based employment										
Jessica	62	Female	White	Lori	1	Facility-based	PT	Group home	Full	1
Didi	61	Female	Black	Lucy	7	Facility-based	PT	Group home	Full	2
Robert	70	Male	Black	Kate	13	Facility-based	PT	Group home	Partial	1

Preparation

Adults with IDD had a limited understanding of retirement.

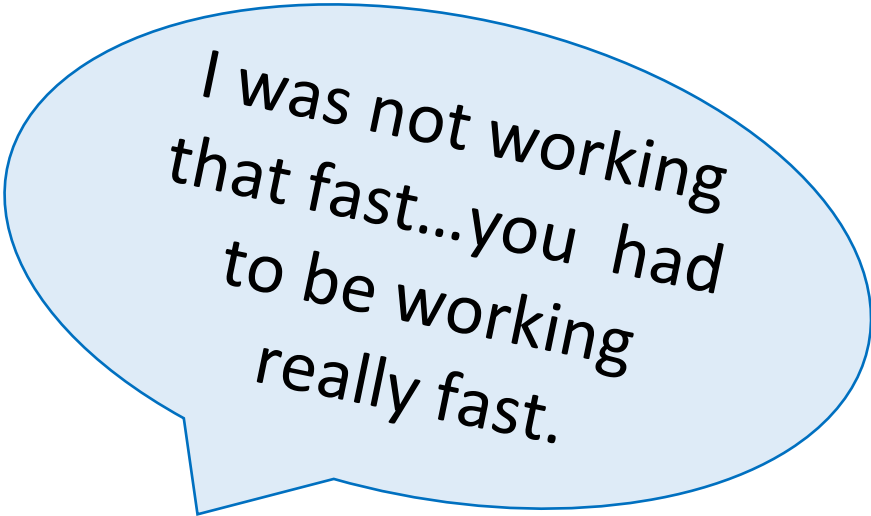I didn't know what retirement was.

Delaying Retirement

- Making money

- Health insurance/retirement

- Worried about being bored

- Pressure to keep working

I wanted to keep on working…to keep our health insurance.

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Push Factors

– Long hours

– Work expectations

– Coworker interactions

– Health and mobility

I was not working that fast...you had to be working really fast.

Pull Factors

– Health and sleep

– Milestone achievements

– Financially secure

– Freedom/choice

I put my years in

With my health. That was scary. I decided to stop because then after a while I would fall here, fall there.

Adjustment to Retirement

It makes me sad. Work. I love work.

Now we can do our own stuff.

More relaxed. Calmed down...I could sleep when I need it.
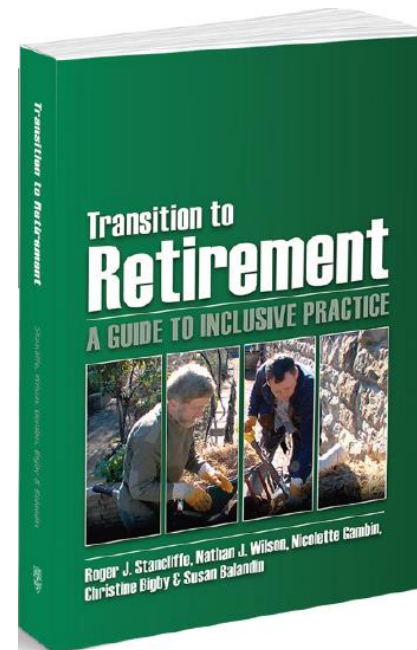
TTR Manual and DVD or eBook:
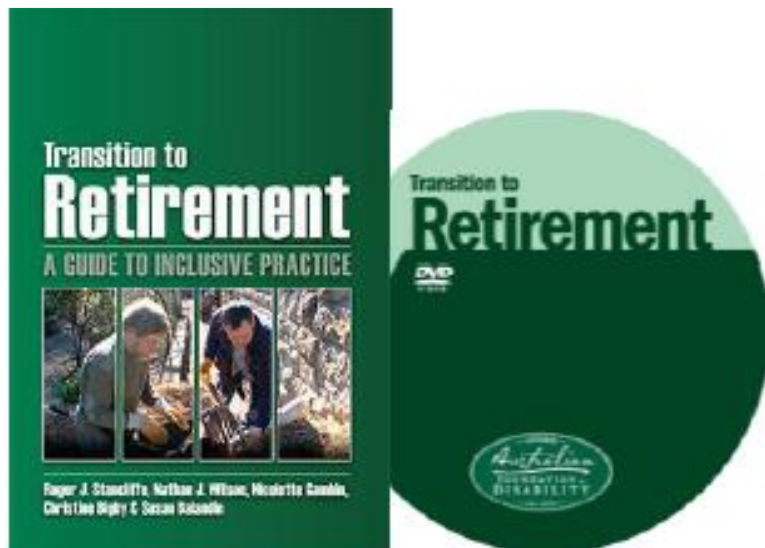# Sydney University Press

Manual contains real life vignettes, tips, travel training appendix, planning forms, and resources.
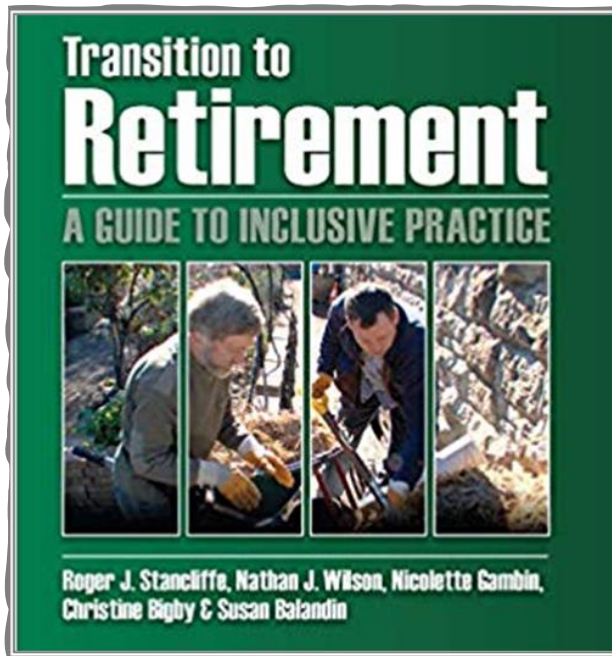
Print Manual + DVD
https://sydneyuniversitypress.com.au/products/78677

eBook
Google Play   iBookstore

Transition to Retirement

- Awareness of retirement

- Peer role models and positive messages

- Age or retirement indicators?

- Mainstream community groups

- One person at a time

(Stancliffe et al., 2013)

In Australia, older workers with ID joined mainstream community groups

- The person chose the community group.
- The person went to their group on a day off from work.
- The group was close to them or easy to get to.

How do you support adults?

- Promote retirement

- Facilitate a planning meeting

- Find a community group

- Set a new routine:

    - Focus on scheduling, travel training, activities for the group, and social support

- Find and teach mentors

- Monitor and give ongoing support

Community Groups

Joanne joined a knitting group.

Laurie joined the choir.

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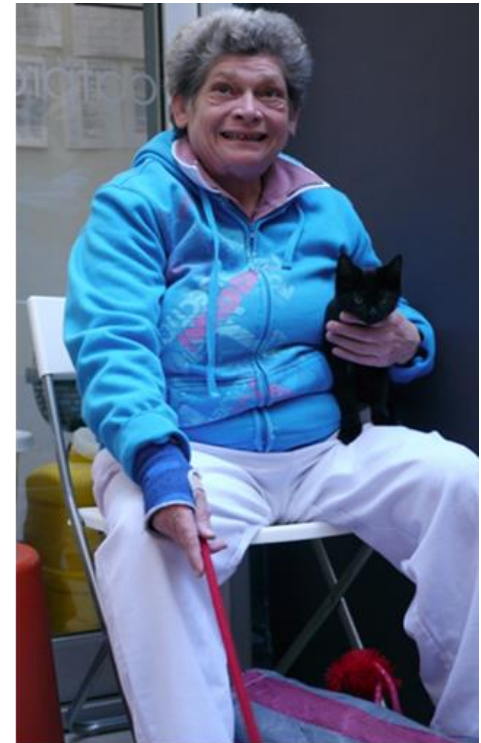Centre for Disability Research and Policy

Volunteering

Graeme volunteered at a plant nursery.

Shirley volunteered at an animal shelter.

What People Said About Their New Group

I'll keep on doing it for the rest of my life, bowling. (lawn bowls)

People are so nice...We talk about all sorts of things. (seniors social group)

I find it really good going there. (community garden)

They're my mates...they look after me, they talk to me…and sometimes I help them. (men's shed)

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End of Life

Resources to support older adults with IDD

End of Life Resources

Many end-of-life resources like the *Books Beyond Words*, **designed specifically for people with intellectual and developmental disabilities,** are available. You can find resource lists in:

– **2022 book: *End of life and people with intellectual and developmental disability***
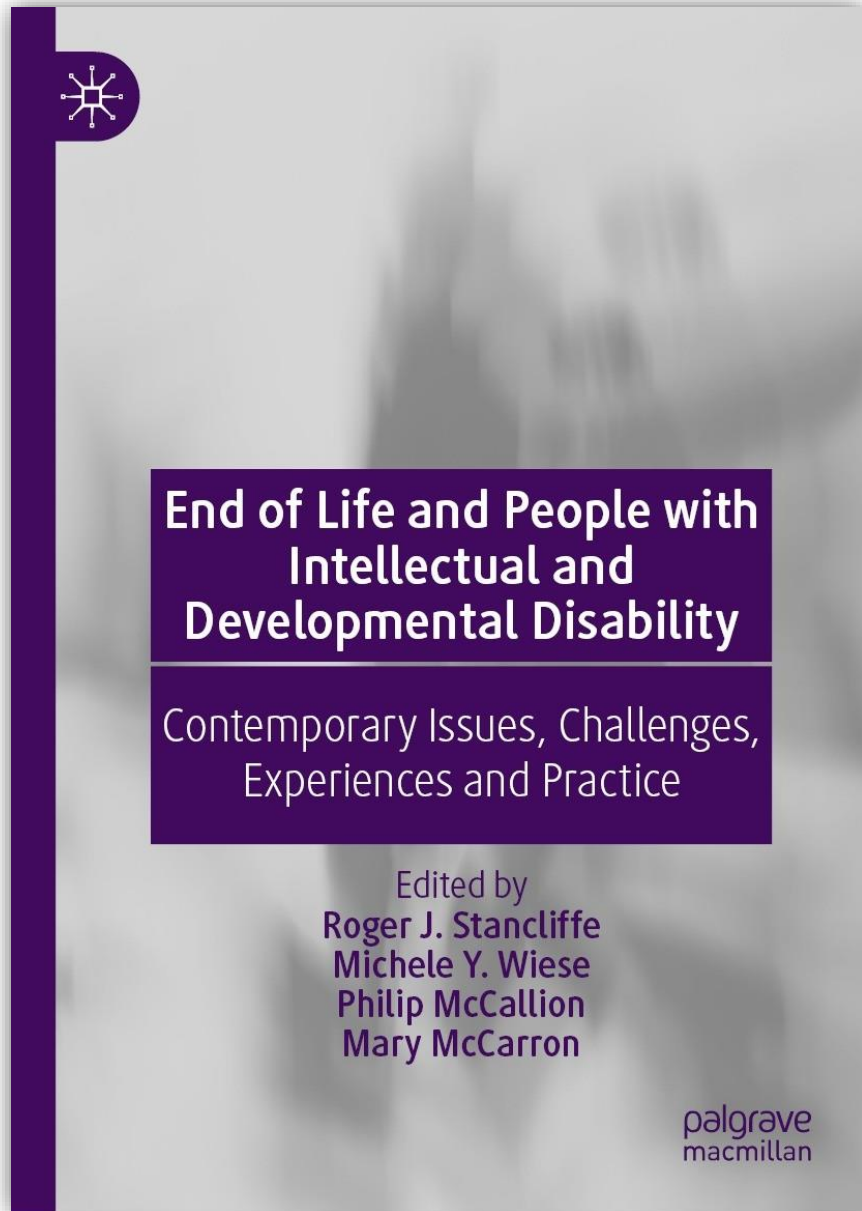
(at the end of most chapters & in Ch.17 *End of Life Resources*)
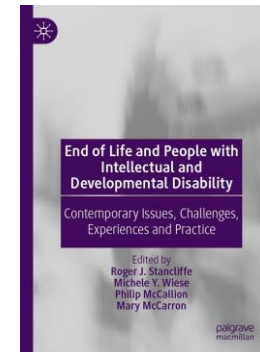
– ***Talking End of Life (TEL) website***
  www.caresearch.com.au/TEL
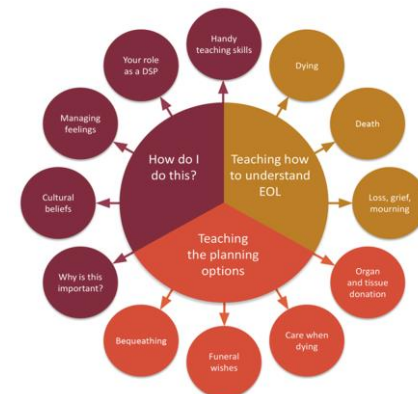
2022 publication...

For more information:

https://link.springer.com/book/10.1007/978-3-030-98697-1

Use your 20% discount code ☺

- 17 chapters; 37 authors from across the world
- Topics incl. suicide, DNR, children, profound disability, doula, accessible funerals, COVID
- Real-world stories to ground issues
- Resources
- Readership: researchers, practitioners, families

End of Life and People with Intellectual and Developmental Disability

Contemporary Issues, Challenges, Experiences and Practice

Edited by
Roger J. Stancliffe
Michele Y. Wiese
Philip McCallion
Mary McCarron

palgrave macmillan

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Background: Protection from End-of-Life Issues

People with intellectual disability (ID) have few opportunities to understand or plan for end of life, because carers and clinicians protect them (and also protect themselves) from issues of dying and death.

- End-of-life decisions are made by others and people with ID are routinely excluded from participation, including not being made aware of their own terminal diagnosis (Kirkendall et al., 2017)

- Seemingly widespread acceptance of the notion that "people with intellectual disabilities are unable to make decisions related to end of life **and need to be protected.**", (Kirkendall et al., 2017, p. 985).

- Not invited to funerals (Forrester-Jones, 2013).

- Disability support staff strongly support the right of people with ID to know about end of life but didn't know how to inform them.

Why protect people with ID from dying and death?

"Protection" and inaction partly motivated by fear of upsetting the person/doing harm.

Reasons

- Do no harm

- Concerns about the person not understanding

- Don't know what to say

- Discomfort in discussing death.

The impact of being excluded from a funeral

From **Talking End of Life (TEL)** Module "Funeral wishes".

– Kathie <u>can</u> talk about this difficult subject

– She *initiated* repeated opportunities to do so with her support staff

The impact of being excluded from a funeral
From **Talking End of Life (TEL)** Module "Funeral wishes".

Being excluded from a funeral

What you would do to help Kathie say goodbye to her mother, even though she was not able to go to her funeral?
From **TEL** Module "Funeral wishes"

Saying goodbye

Benefits of being included in a funeral

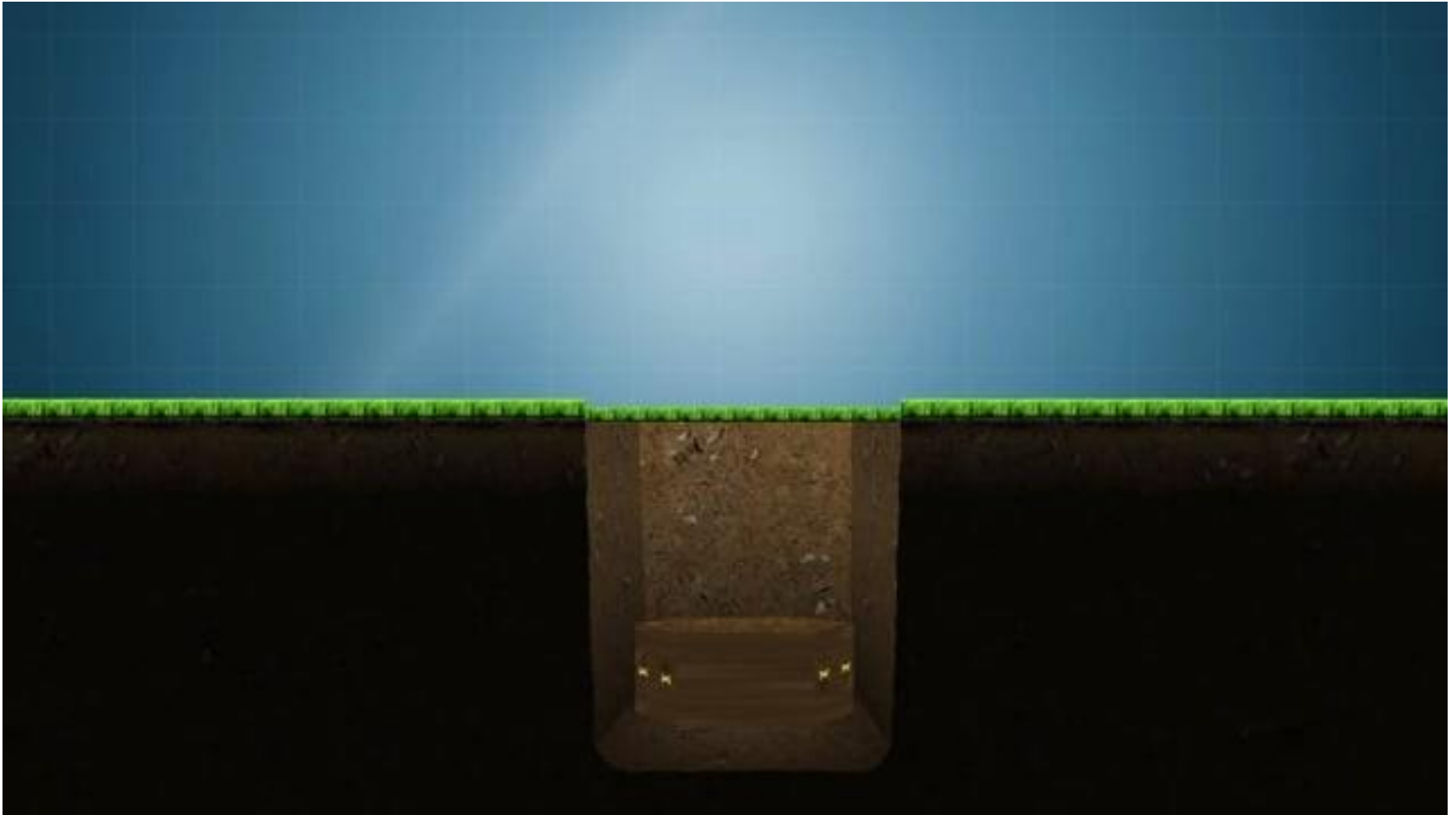From **TEL** Module "Funeral wishes"

Richard talks about going to his mother's funeral.

Being included in events
related to dying and death

Helping People Understand Funerals

From **TEL** Module "Funeral wishes"

Animation explaining burial.

Dying to Talk (Stancliffe et al., 2021)

– Our *Dying to Talk* project, provides the *first direct empirical evidence* on the long-term psychological effects of talking about end of life. We evaluated change over time in:

  – **Depression**

  – **Anxiety**

  – **Fear of death.**

– We also measured "*Encounters*" (conversations or activities related to end of life) during the pre-test and throughout the 6-month intervention.

Our Intervention: Everyday Conversations (and activities) about End of Life

Wiese et al. (2015) advocated

- Instead of avoidance and protection, **repeated opportunities to learn and talk about dying and death** need to be provided as part of everyday life

- These opportunities should be provided across the lifespan when the person is well

- Needs to be done sensitively, at the person's own pace, with emotional support as needed.

When Mum Died

Sheila Hollins and Lester Sireling
Illustrated by Beth Webb
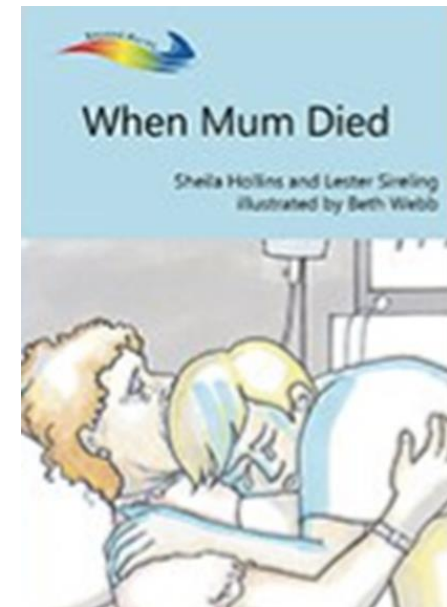
Examples of Encounters

TRAINED DISBILITY STAFF ENCOURAGED PARTICIPANTS TO TALK ABOUT END OF LIFE (usually for no more than a few minutes)

Prompted by:

– News item (e.g., bushfire, terrorism, death of a celebrity) involving death or risk of death

– TV program with some content related to end of life

– Seeing something in the community (cemetery, funeral director's, church)

– Specific issue related to a dead person (Looking at a photo of the dead person, attending funeral, picking up person's ashes) – **arose rarely.**

Client-initiated "Encounters" (Stancliffe et al., 2021)

– For each encounter we collected data from participating staff on:

   – **Who** initiated the encounter

   – How **comfortable** the client was during the encounter.

– Most encounters were initiated by the adult with intellectual disability.

– This finding strongly suggests that adults with intellectual disability

   – Want to know about dying and death

   – Feel comfortable enough with the topic to raise the issue themselves.

Percent of Encounters Initiated
(pre-test and intervention phases combined)
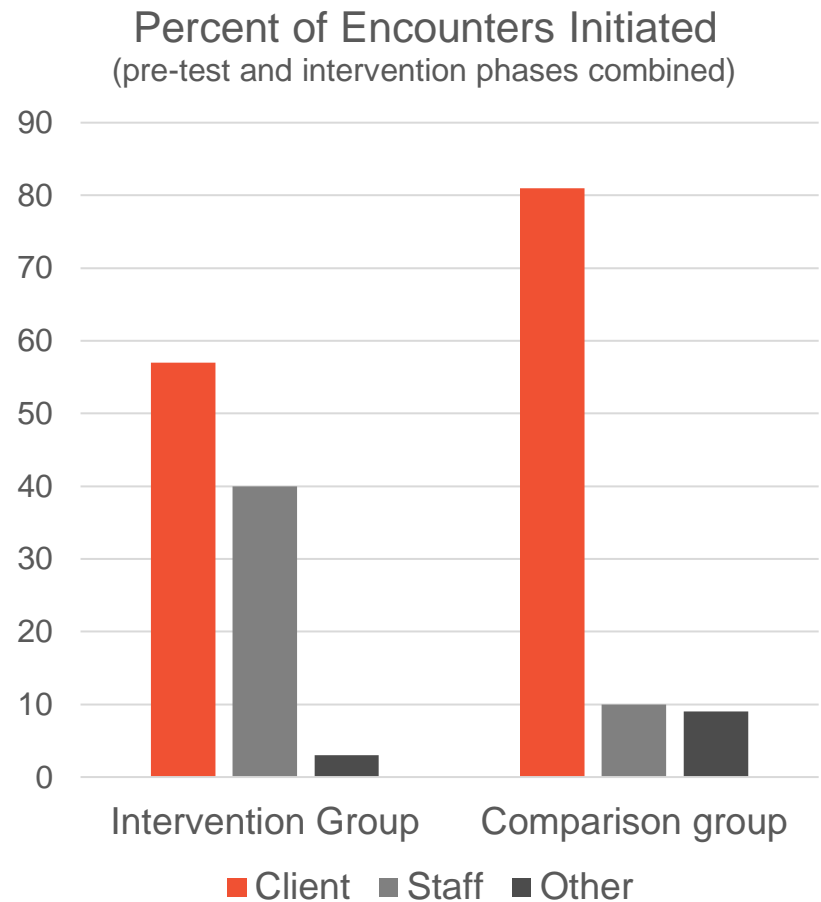
Staff-rated Client Comfort with Encounters

– Ratings could range from

– Very comfortable

– Somewhat comfortable

– A little uncomfortable

– Very uncomfortable.

– *Very/somewhat comfortable* were the most common ratings

– *Very uncomfortable* was the least common rating but still occurred occasionally.

Percent Comfort Ratings
(pre-test and intervention phases combined)

Legend: VC, SC, LU, VU
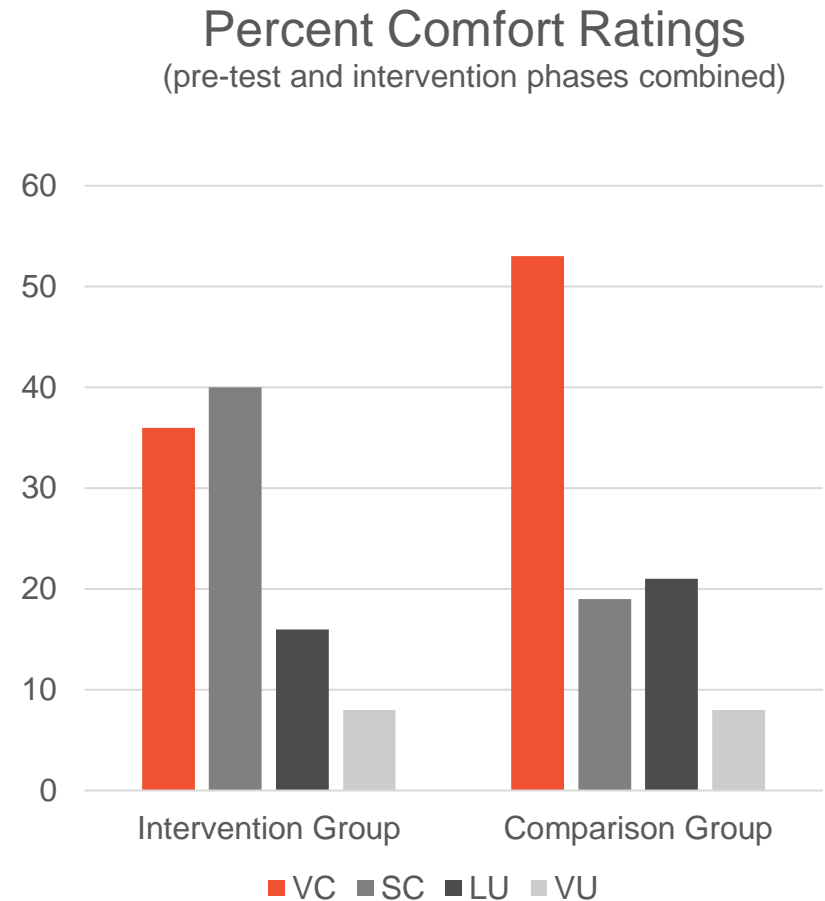
Following a 6-month intervention that involved talking/learning about end of life

- There was no significant pre–post change in assessed
  - Depression
  - Fear of death

- Anxiety improved significantly.

Results

Talking about dying and death does not make people more fearful, anxious, or depressed.

– At 6 months, intervention participants did NOT fare significantly worse than their pre-test scores on any psychological measure. The same was true for the comparison group. There were **no adverse events** (serious negative outcomes).

Conclusions

– Most people with ID could participate in end-of-life discussions and activities without obvious discomfort.

  – A few experienced *transient* **discomfort** at times when discussing end of life. Most managed their discomfort themselves. A small number asked to stop. Prompts about stopping were offered if the person appeared uncomfortable.

– **Concerns about doing long-term harm are unfounded.**

– Families, service providers and researchers can have end-of-life conversations and support people to engage with the topic, without fear of negative psychological consequences.

– Some individuals were quite fearful, so sensitive judgements are needed.

Accessible Funerals (Chapter 10)

– Many people with IDD are **not invited to the funerals of loved ones** (Forrester-Jones, 2013)

Goodbye Jim

– Little information available about **adaptations to the funeral proceedings** to accommodate the needs of people with IDD and, where desired, to enable *active participation* in the service itself.

– Resources available to **help people understand and prepare to go to a funeral**, but no research known about the effectiveness of these efforts.

Questions?

Thank you!

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