

RESEARCH PROFILES

Andy Smidt

I qualified as a speech pathologist in the UK in the 1980s and worked in a multidisciplinary team for what was then called adults with learning difficulties. This opened my eyes to the way that training was provided. We ran some great workshops for direct care staff and the feedback was always good but I saw minimal changes in the group homes and day services I worked in. I became fascinated in measuring change as a result of training – not just smiley faces on a piece of paper but real, measurable changes. I was interested in challenging behaviour and came across the work of Richard Hastings. He was using a tool called CHABA to look at staff attributions about the causes of behaviour. I liked the tool but wanted to look more closely at the attributions related to communication. This formed the basis of my PhD where we looked at training as being about changing attitudes rather than about learning skills (Smidt, Balandin, Sigafoos, & Reed, 2009).

I remember working with staff who supported adults with autism and having a conversation with them about their role. They saw their role as keeping everything as constant as possible so that nothing ever went wrong – if the person who needed the same coloured pants every day for work never had to experience not having those pants available then they were doing their job. If the person who only ate spaghetti on Mondays, had spaghetti on Mondays, then they were doing their job. This unfortunately did not always work and while I was working with them, a tree fell on a powerline near the house and the things that always needed to happen could not happen. The world was about to fall apart. I wanted them to understand that their role was to teach the person how to cope with the unexpected. Could they set up a situation where something small went wrong every day and

they could gradually expose the person to coping strategies? This moment was really important in my understanding about attitudes. These staff had developed a strategy and for a long time it worked for them. If I did not understand their reasoning, my training was not likely to be effective. I need them to trust me enough to tell me their beliefs about behaviour so that we could discuss options. I could only hope to change what they were doing if I understood why they were doing it and if they trusted me enough to listen to my ideas.

I am also interested in understanding how to build engagement with people with severe to profound intellectual disability. I have developed an intervention based on using highly motivating stimuli within a behaviour chain interruption strategy. Combining these two ideas resulted in an intervention called SensEngage (Yuile, Smidt, & Quinlan, 2020). We have so far carried out two studies about SensEngage which have good results. Adolescents who were hard to reach, disengaged or self-engaged, were able to request more of a specific stimulus using a recognisable behaviour which could be recognised by communication partners as a potential communicative act. I am keen to do more research in this area particularly with adults with severe intellectual disability.



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REFERENCES

- Smidt, A., Balandin, S., Sigafoos, J., & Reed, V. A. (2009). The Kirkpatrick model: A useful tool for evaluating training outcomes. *Journal of Intellectual & Developmental Disability*, 34(3), 266-274. doi:10.1080/13668250903093125
- Yuile, L. E., Smidt, A., & Quinlan, S. (2020). Valuing relationships: The impact of a sensory program on the interactions of adolescents with severe-to-profound intellectual disabilities. *Journal of Intellectual Disabilities*, 1-27. doi:10.1177/1744629520921730

Bronwyn Newman

I completed my PhD in 2020 at UNSW Sydney. My supervisors were Professor Karen Fisher (Social Policy Research Centre) and Professor Julian Trollor (Department of Developmental Disability and Neuropsychiatry - 3DN).

MY PHD RESEARCH:

Thesis title: Using easy read information about mental health for people with intellectual disability

Thesis link: https://www.unsworks.unsw.edu.au/primo-explore/fulldisplay?docid=unsworks_71950&context=L&vid=UNSWORKS&lang=en_US&search_scope=unsworks_search_scope&adaptor=Local%20Search%20Engine&tab=default_tab&query=any,contains,newman&offset=0

My PhD grew from the realisation that people with intellectual disability often miss out on getting the mental health information and mental health services they need.

The research had three parts:

- i) An analysis of all Australian and NSW government policy about mental health
- ii) Interviews to find out how mental health staff, people with intellectual disability, their carers, families and advocates about used easy read. 49 people from 4 agencies were interviewed. One agency was an advocacy service and the other three were mental health services.
- iii) An audit of the easy read or accessible information that staff used at their agencies.

THE RESEARCH FOUND FIVE MAIN THINGS:

- Mental health policy stated that all people have a right to information but most policy did not have instructions about how to communicate clearly with people with intellectual disability.
- The mental health agencies did not have much accessible information. Most mental health staff had not used easy read.
- Only the agencies specialised in working with people with intellectual disability often used accessible information and easy read. The people with intellectual disability and the staff who used easy read said it was very useful.
- Most mental health staff did not think people with intellectual disability were given enough information or time to make decisions about mental health information.
- Whether or not easy read was available was only one part of making information accessible. The relationships between people with intellectual disability, their families or carers and service providers also affected how people made decisions about their mental health information.

PUBLICATIONS:

Newman, B. (2019) Easy read: using it well, webinar presented for the Australasian Society of Intellectual Disability (ASID), 25 September 2019, available at: <https://www.asid.asn.au/publications/webinars>.

Newman, B. (2019), 'The responsibility of making information accessible', Intellectual Disability Australasia (IDA) magazine, vol 40, no. 2, 2019 pp. 6-9, available at <https://www.asid.asn.au/files/2680_ida_volume_40_issue_2_june_2019.pdf> .

I plan to publish 2 papers from my thesis. One about the representation of the right information in Australian mental health policy and another about using easy read.

REFLECTIONS

My interest in information access stemmed from working as a social worker and seeing the struggle many people with intellectual disability and their families faced when seeking health information and services. After a work-life full of people, doing a PhD was a solitary activity in many ways. It was important to develop relationships with other students and colleagues at UNSW to share the progress and ask the many questions about how to do all sorts of things- both research and university admin challenges. I appreciated the honest and ongoing support of my supervisors and colleagues. And was surprised by the willingness of interview participants to share their struggles to meet the communication needs of people with intellectual disability. It was a wonderful privilege to study full time for four years.

INTERESTS - WHAT I AM DOING NOW.

Since completing my PhD I have continued to work at UNSW. I am involved in a couple of different projects that reflect my interest in promoting the right to health information, and seeking to include people with intellectual disability in broader conversations about health, health services and health literacy.



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Nic McKenzie

PhD Research in progress

INTRODUCTION ABOUT SELF AND EXPERIENCES/INTERESTS

Tena koutou katoa (greetings everyone). I'm Nic McKenzie, from Christchurch, New Zealand.

I am the daughter of a special education teacher mum and a big-hearted dad. It is probably no surprise that I followed a similar path to my mum, training as a speech-language therapist/pathologist after leaving school. After a few years I took a more generalist role in the learning disability sector, where I found my passion, and where I have continued to work for more than twenty years. I constantly find new things that drive my interest in this work (successes, changing attitudes, injustices, unmet rights, service quality issues), but it is ultimately the people that keep me motivated and engaged.

For the last eight years I have worked as a contractor, usually on projects that have a learning and development, policy, or quality focus. I am particularly interested in issues related to rights, ageing, death and dying, and communication. Despite some of the gains that have been made by people with learning disabilities, there are many areas of life where people's rights remain unmet. One such area is decision-making at the end of life, and is a topic in which I have previously researched. The findings from that study demonstrated that the participants with learning disabilities were able to successfully take part in Advance Care Planning. However, it also highlighted issues related to access and quality of planning. The need for more research, and solutions, prompted me to embark on PhD study, which I am carrying out at the University of Otago's Centre for Postgraduate Nursing Studies.

PHD TOPIC

My PhD study utilises a Participatory Action Research methodology, with the objective of developing an approach to planning that really works for people with learning disabilities, and that addresses the issues of access and quality.

In this research work I am directed and supported by a co-research group that includes seven older adults with learning disabilities and a small group of disability service managers. To date we have completed two of the study's three action research cycles. In cycle one we explored the current process of Advance Care Planning (interviewing health professionals and others, reviewing documents

and literature, examining tools/resources and processes), analysed data, and identified potential improvements. In cycle two we developed a new process and the resources required for that process. We are currently working on cycle three, trialling and evaluating the new process and resources. It is exciting and challenging work.

REFERENCES FROM PUBLISHED WORK

The paper referenced below relates to my previous research on Advance Care Planning. It provides insight into the factors that contribute to successful Advance Care Planning, from the perspective of people of learning disabilities, and discusses the access and quality issues in detail.

McKenzie, N., Brandford, S., Mirfin-Veitch, B., & Conder, J. (2017). "I'm Still Here": Exploring what matters to people with intellectual disability during advance care planning." *Journal of Applied Research in Intellectual Disability* 30(6): 1089-1098.



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Bernadette Curryer

PHD THESIS TITLE: SELF-DETERMINATION OF ADULTS WITH INTELLECTUAL DISABILITY WITHIN THE CONTEXT OF FAMILY RELATIONSHIPS

Intellectual disability has been a focus of many aspects of my life; personally as a mother of an adult daughter living with intellectual disability, as well as professionally and academically. The promotion of the NDIS as the vehicle to enable choice and control for people with disability and their family was the catalyst for my PhD, the exploration of self-determination of adults with intellectual disability within the context of family relationships. This study was conducted under the supervision of Prof Roger Stancliffe, A/Prof Angela Dew and Dr Michele Wiese through the University of Sydney.

Using an Interpretative Phenomenological Analysis approach, the experience of adults with intellectual disability and their key family support person, in exerting or supporting choice and control, was explored. This study was undertaken in 3 phases.

So far, three papers have been published sequentially as part of this thesis.

1) An opinion and perspective article discussed the existing literature concerning self-determination of adults with intellectual disability, the family context and impact of current Australian disability policy based on individualised funding.

Curryer, B., Stancliffe, R. J., & Dew A. (2015). Self-determination: Adults with intellectual disability and their family. *Journal of Intellectual & Developmental Disability*. 40(4), 394-399. doi:10.3109/13668250.2015.1029883

2) Phase 1 of the study explored the lived experience of adults with intellectual disability as they attempted to exert choice and control with support from family. Key findings included the centrality of family in the lives of participants, and the acceptance of limitations to choice and control when instigated by family. Such limitations were generally viewed as a sign of love and care.

Curryer, B., Stancliffe, R. J., Dew, A., & Wiese, M. Y. (2018). Choice and control within family relationships: the lived experience of adults with intellectual disability. *Intellectual and Developmental Disabilities*, 56(3), 188-201. doi:10.1352/1934-9556-56.3.188

3) Phase 2 of the study looked at the experience of key family support people, all mothers, as they supported the choice and control of their adult son or daughter with intellectual disability. Key findings included the complexity of the support relationship, with a tension between the recognition of the right to choice and concern for consequences. The mothers felt an ongoing sense of responsibility for the decision-making of their son or daughter. Support roles undertaken by the mothers, depending on the complexity and type of choice being considered, were on a continuum from facilitator, guide, influencer through to final decision-maker.

Curryer, B., Stancliffe, R. J., Wiese, M. Y. & Dew, A. (2020). The experience of mothers supporting self-determination of adult sons and daughters with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 33(3), 373-385. doi.org/10.1111/jar.12680

The final phase of the study looked at the dyadic relationship between adults with intellectual disability and their mothers. The key findings included a perception of their lives being entwined, and recognition that the relationship, although a source of stress, also enhanced both lives. The support provided by the

mothers was influenced by their personal values and based on an in-depth knowledge of the son or daughter. The use of body mapping as a data collection method was an interesting aspect of this study. This method provided additional insight into the dyadic relationship. Figure 1 is an example of a small section of one body map, depicting the daughter's view of her mother as a waterwheel; keeping choice, voice and control flowing for the daughter.



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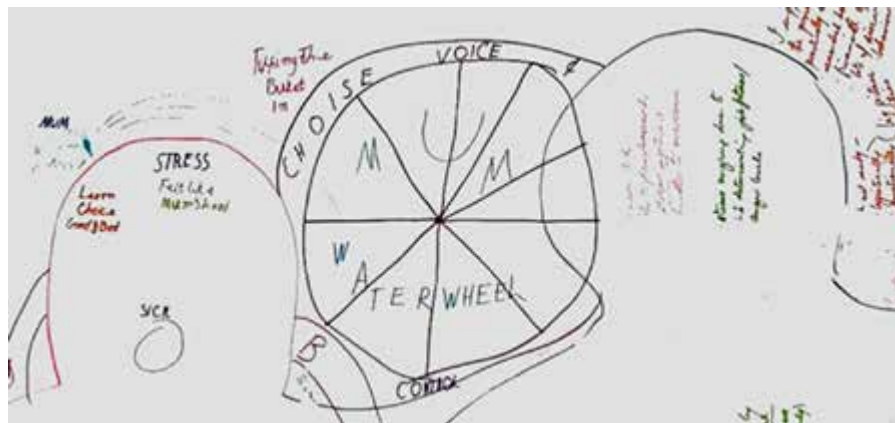


Figure 1 An example of a body map image from thesis

The implications of this research centre on the need to consider self-determination as a relational concept. Key family members both support and influence choice and control and therefore we need a 'whole-of-family' rather than individual approach to the development of self-determination.

This thesis has been submitted for examination. If anyone is interested in this topic and would like to discuss further, please contact Bernadette at bernadette.curryer@sydney.edu.au