



LIVING WITH DISABILITY
RESEARCH CENTRE



Newsletter - Winter 2019

Dear <<First Name>>,

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Professor Christine Bigby

Director - Living with Disability Research Centre

Conference Recap



Over the past few months, researchers from the Living with Disability Research Centre have been busy at conferences in Australia and around the world disseminating findings from our research projects. It has been a particularly busy couple of months for the Director of our Research Centre, Professor Christine Bigby. In March, Professor Bigby and Dr Elizabeth Smith were at the Australian Guardianship and Administration Council conference in Canberra to present the La Trobe Support for Decision Making Practice Framework and outline initial findings from the trial of resources for decision supporters. We are pleased to say that as a result of these presentations, the Queensland Public Trustee has decided to adapt the framework for use in their work supporting the financial decisions of their clients. In May, Bigby delivered a keynote address at the British Learning Disabilities Conference in the UK, on embedding Active Support in supported living services, and another, on convivial encounters, at the Social Inclusion Conference, at the Utrecht University of Humanities in the Netherlands. The following month, Bigby delivered a plenary on community participation at the Asia-Pacific Autism Conference in Singapore.

Professor Jacinta Douglas was also overseas in the middle of this year. She was invited to present at the Neuropsychological Rehabilitation Conference, in Granada, Spain. She presented on how participant led videos can enable people with cognitive and communication impairments to have choice and control. At the conference, Professor Douglas showed how these videos have the potential to improve the delivery of support for people with acquired brain injury.

Finally, in August, intellectual disability researchers from around the world

gathered in Glasgow, Scotland, for the triennial IASSIDD World Congress. The Living with Disability Research Centre was well represented at the Congress. Professor Teresa Iacono delivered three presentations, including one that outlined findings from a study of hospital encounters by people with intellectual and developmental disability. Lincoln Humphreys presented on the development and psychometric properties of the Group Home Culture Scale and Professor Bigby somehow found the time to collect a research prize (see below) and deliver six presentations across the four days of the conference. To view the slides from some of these presentations click on the button below.

CONFERENCE PRESENTATIONS

Administrative Appeals Tribunal - Digest

In case you missed it, the Living with Disability Research Centre and Brotherhood of St Laurence recently released the latest Administrative Appeals Tribunal (AAT) Quarterly Digest. The Winter 2019 Digest offers an overview of some important themes arising from recent AAT decisions about the NDIS. By exploring AAT decisions, the Digest aims to capture the way the Tribunal is dealing with some common issues raised in appeals against NDIS decisions. The Winter edition highlights five emerging themes that have featured in recent AAT decisions:

- The need for a proper and balanced use of operational guidelines
- The downsides of flexible use of funding
- The health system and the NDIS interface
- The importance of impairment
- Affordability and access do not affect ‘availability’ of treatment



DOWNLOAD AAT DIGEST

Voting Report

Our report on strategies to support people with intellectual disabilities to participate in voting was released shortly after the Victorian state election in May this year. This ground-breaking, Australia-first research was the result of a collaboration between the Living with Disability Research Centre, Australia's electoral commissions – led by the Victorian Electoral Commission – and Inclusion Melbourne. The research found that limited support from family members and carers was a major barrier to electoral participation and emphasised the importance of designing strategies to empower and enfranchise people with disabilities who have previously lacked support. Other recommendations included proposals that electoral commissions note the role law reform might play in removing families' and carers' doubts about who has the right to vote, and that peer education be further explored to build capacity of people with intellectual disabilities.



Strategies to Support People with Intellectual Disabilities to Participate in Voting

Professor Christine Bigby, Ms. Sophia Tipping,
Dr Emma Bould & Ms. Rebecca Thiele

New PhD Candidates - 2019

We would like to extend a warm welcome to three new PhD candidates who have recently joined our Research Centre. Charity Sims-Jenkins

joined the team earlier this year. She is working on a theory-informed approach for self-advocates with intellectual disability to share their experiences of self-determination with staff working in services for people with intellectual disability.



Charity Sims-Jenkins

Two more PhD candidates – Megan Topping and Joanna Shoreland – also joined the team in the middle of the year. We wish our newest team members all the best as they embark on what can be an extremely rewarding journey

New Partnerships and Projects

The Living with Disability Research Centre is pleased to announce that it has recently commenced new partnerships with some of Australia’s leading disability organisations and service providers. IdentityWA recently engaged us to update and digitize our suite of training resources on aging and intellectual disability. Meanwhile, HELP Enterprises in Queensland, Oak Possibility in Tasmania and Victoria, and Melba Disability Support Services in Victoria, will join our longitudinal study of Active Support and Practice Leadership, to which we are also adding a focus on service culture. Soon, we will also commence working with the Queensland Public Trustee to translate the La Trobe Support for Decision Making Practice Framework, so that it can be better used by the Queensland Public Trustee in its own evaluations of service effectiveness.

The Living with Disability Research Centre has also embarked on four new projects in the past few months. Each project touches on one of the core themes at heart of our mission, which is to conduct research that improves the social inclusion and participation of people with cognitive disability.

Identifying Quality

Professor Christine Bigby, Professor Teresa Iacono, Dr Lincoln Humphreys and Dr Tal Araten-Bergman

This project will develop resources to build NDIS service providers’ capacity to deliver high quality evidence-informed practice to people with intellectual disabilities in supported living services. Essentially, the project is concerned with embedding practices that support people with intellectual disabilities to exercise choice and control, and to be engaged and active participants in their own lives. Over the course of two years, this project will develop a suite of evidence-informed resources for front-line and managerial staff to assist them in understanding what, exactly, high quality practice looks like and how it is best achieved. A parallel suite of easy to understand resources will be developed for people with intellectual disabilities and their supporters to assist them in identifying quality practice in supported living services. The project draws on ten years of practice quality research in supported living services and aims to increase the capacity of NDIS providers to deliver high quality evidence-informed practice.

Regional Allied Health Disability Working Party

Professor Teresa Iacono

Teresa Iacono (Living with Disability Research Centre and La Trobe Rural Health School) is leading a working party comprising Bendigo disability and training organisations and representatives from the National Disability Services. The working party is seeking to build a local Rural Workforce initiative to develop and deliver a plan to strengthen rural allied health workforce capacity within the context of the NDIS. In early 2020, the Working Party will host a future forum to discuss the needs for, and strategies around, developing regional allied health workforce capability in disability and the NDIS. Further details about the this forum will be included in future newsletters.

V/Line and Passengers with Communication Difficulties

Professor Christine Bigby and Dr William Crisp

Funding: Scope

Dr William Crisp recently embarked on the third and final phase of a broader project that examines the experiences of passengers with communication difficulties on V/Line services. The first phase consisted of consulting with the passengers and V/Line staff and was completed in 2016. During the second phase, Scope Australia used evidence collected during phase one of barriers and facilitators to design and implement interventions to improve services for people with intellectual disabilities. The third phase now involves consulting with passengers with communication difficulties a second time to ascertain if their experiences of using V/Line services are noticeably different since the Scope interventions were implemented across V/Line services.

Stories from the ‘wild west frontier’: the NDIS experiences of people with severe and profound intellectual disabilities

Dr David Henderson and Professor Christine Bigby

Funding: La Trobe University

This project explores and recounts personal stories of people with severe and profound intellectual disabilities and the issues they have encountered in their dealings with NDIS. The aim of this project is to insert people with severe and profound intellectual disability into the public narratives about the NDIS. To do so, this project will draw on a series of interviews with family members and service providers who know well and have acted alongside people with severe and profound intellectual disabilities in their dealings with the NDIS. Most commonly, people with physical or sensory disabilities are the public voice of disability advocacy. And when advocacy is more nuanced, there is a tendency for people with mild intellectual disabilities to act as proxies for all people with intellectual disability. Unless others represent them in public areas of advocacy and in private transactions with the NDIS, the perspectives and experiences of people with severe and profound intellectual disabilities are liable go unnoticed and ignored. By addressing some of the issues around supporting people with more severe intellectual disabilities, this project seeks to draw out and juxtapose the NDIS experiences of individuals with, and without, strong advocates and also recount the sometimes relentless struggles of even the most resourceful parents and supporters.

Monthly Research Seminar Series



We have hosted an impressive mix of established and emerging scholars at our monthly research seminar series this year. Seminar presentations have covered a wide range of topics that suggest a growing interest in multidisciplinary scholarship around intellectual disability and acquired brain injury. Some highlights from our seminar series included a wonderful presentation by Dr Robyn O'Halloran (La Trobe University) on why hospitals don't measure the patient experience of people with communication disabilities. Another equally impressive presentation by Dr Karen Soldatic (Western Sydney University) delved into issues around the disability income support system for Indigenous Australians living with disability. Another highlight was the July presentation of Dr Ilan Wiesel (University of Melbourne), which gave us an insight into the theoretical debates, conceptual ambiguities and normative biases surrounding the terms 'mainstream', 'specialist', and 'participation', specifically when applied in the context of contemporary urban societies.

Our seminars are usually held on the second Wednesday of each month (3:00 pm - 5:00 pm), in the [Library seminar room 1.34, Level 1 of the Borchardt Library, La Trobe University, Bundoora Campus, Melbourne](#). The seminars are open to the general public and everyone is welcome to attend. If you cannot attend in person, our seminars can also be accessed remotely through the use of the Zoom teleconferencing system. You can dial in using the [free Zoom App \(Windows and Mac\)](#). Please [contact us](#) for the access to link before each seminar.

[Slides and papers from our monthly seminar series](#) are available on our website.

A Workshop with Prof. Jennifer Clegg

Making Claims that Matter: Non-behavioural Approaches to Supporting People with Intellectual Disabilities

The Living with Disability Research Centre and ASID are proud to present a one-day workshop with Professor Jennifer Clegg – Making Claims that Matter: Non-behavioural approaches to supporting people with intellectual disability.



Dr Clegg has a national and international reputation for her research on disability policy. She is the editor of the *Journal of Intellectual and Developmental Disability* and has published widely on a variety of topics, including conceptual and empirical analyses of a relational approach to practice in intellectual disability.

Professor Clegg has also designed and taught an online module in the La Trobe graduate certificate of disability practice. The module is specifically concerned with practice with people who have complex and challenging behaviour, and this workshop provides an introduction to some of the key ideas that inform the course.

The one-day workshop will explore new approaches and new ideas for practitioners who work with people with intellectual disability and complex and challenging needs. It will explore the latest research and practice into attachment and Trauma Informed care, through mediums such as videos, which show how interactions reveal attachment, and instruments that assess emotional development and levels of distress. As well as providing an alternative lens through which to view and understand challenging behaviour, the workshop will consider three issues that can impede conceptual creativity in supporting people with intellectual disability: neoliberalism, unconscious prototypes, and bright-siding.

For more information, please contact us at libs@latrobe.edu.au. To book a spot, click on the button below.

When & where?

Friday, 1 November 2019
10.00am - 3.30pm

Teaching Room 4,
La Trobe University, City Campus,
360 Collins Street Melbourne.

Cost: \$100.00

BOOK NOW

Disability Practice Courses - 2020

The inaugural year of our Disability Practice course will soon draw to a close. It has been an exciting year, particularly for Dr Sian Anderson, our course coordinator who received the Pro-Vice Chancellor's Teaching Award this year, as part of her work with the team teaching social policy.

The feedback from our 2019 cohort of Disability Practice students has been very encouraging:

- I enjoyed this subject and learned a lot about this area of disability”*
- “The best aspect of the subject was the great feedback and support from the teaching team and the library”*
- “The discussion forums, reading and*

videos were excellent resources for learning.”

In 2020, we will continue to offer our [online degrees in Disability Practice](#). We will be offering subjects such as the *Contemporary Disability Landscape*, *Enhancing Social Inclusion*, *Support Planning for People with Disabilities*, and *Translating Evidence into Disability Practice*. All subjects will be available as single subjects and can be taken by practitioners seeking to pursue professional development opportunities. Our postgraduate courses can lead to a satisfying career in improving the lives of people with disabilities and their communities. All courses and subjects have been designed by expert staff involved with the [Living with Disability Research Centre](#) at La Trobe University.



If you are interested in enrolling in one of our online degrees in Disability Practice in 2020, please contact our course coordinator, Dr Sian Anderson, with any queries.

Email: Sian.Anderson@latrobe.edu.au

Telephone: 9479 5495

Distinguished Achievement Award

Finally, we are delighted to announce that Professor Bigby's sustained and enduring contribution to research in the field of intellectual disability was acknowledged at the IASSIDD World Congress in Glasgow. Bigby was presented with the Distinguished Achievement Award for Research. The award recognises a significant contribution to the sciences related to intellectual and developmental disabilities through a sustained and important contribution over time. Professor Bigby said she was honoured and humbled to receive the award.

New research publications by our staff at the Living with Disability Research Centre.

Articles:

Ashley, D., Fossey, E., & Bigby, C. (2019) The home environments and occupational engagement of people with intellectual disabilities in supported living. *British Journal of Occupational Therapy*.
<https://doi.org/10.1177/0308022619843080>

Bigby, C. (2019) Accommodating cognitive differences: New ideas for social work with people with intellectual disabilities. In M. Payne and E Reith Hall (Eds.) *Routledge handbook of social work theory*. London: Routledge. 448-460.

Bigby, C., & Wiesel, I. (2019) Using the concept of encounter to further the social inclusion of people with intellectual disabilities: what has been learned? *Research and Practice in Intellectual and Developmental Disability*, 6(1), 39-51.
<https://doi.org/10.1080/23297018.2018.1528174>

Bould, E., Bigby, C., Iacono, T., & Beadle-Brown, J. (2019). Factors associated with increases over time in the quality of Active Support in supported accommodation services for people with intellectual disabilities: A multi-level model. *Research in Developmental Disabilities*, 94.
<https://doi.org/10.1016/j.ridd.2019.103477>

Carney, T., Then, S., Bigby, C., Wiesel, I., & Douglas, J. (2019) NDIS plan decision making: or when tailor-made case planning met Taylorism and the algorithms. *Melbourne University Law Review*, 42(3).

D'Cruz, K., Douglas, J., & Serry, T. (2019) Personal narrative approaches in rehabilitation following traumatic brain injury: a synthesis of qualitative research. *Neuropsychological Rehabilitation*, 29(7), 985-1004.
<https://doi.org/10.1080/09602011.2017.1361844>

Honan, C., McDonald, S., Tate, R., Ownsworth, T., Togher, L., Fleming, J., Anderson, V., Morgan, A., Catroppa, C., Douglas, J., Francis, H., Wearne, T., Sigmundsdottir, L., & Ponsford, J. (2019) Outcome instruments in moderate-to-severe adult traumatic brain injury: recommendations for use in psychological research. *Neuropsychological Rehabilitation*, 29(6), 869-916.
<https://doi.org/10.1080/09602011.2017.1339616>

McEwen, J., Bigby, C., & Douglas, J. (2019) Moving on from quality assurance: exploring systems that measure both process and personal outcomes in disability services. *Journal of Policy and Practice in Intellectual Disabilities*.
<https://doi.org/10.1111/jppi.12295>

Whitehouse, A., Varcin, K., Alvares, G., Barbaro, J., Bent, C., Iacono, T., et al. (2019) Pre-emptive intervention versus treatment as usual for infants showing early behavioral risk signs of autism spectrum disorder: a single-blind, randomized controlled trial. *Lancet Child and Adolescent Health*, 3(9), 605-615.
[https://doi.org/10.1016/S2352-4642\(19\)30184-1](https://doi.org/10.1016/S2352-4642(19)30184-1)

Wiesel, I., Whitzman, C., Gleeson, B., & Bigby, C. (2019). The National Disability Insurance Scheme in an

urban context: Opportunities and challenges for Australian cities. *Urban Policy and Research*, 37(1), 1-12.
<https://doi.org/10.1080/08111146.2018.1481026>

Reports:

Administrative Appeals Tribunal Quarterly Digest – Winter 2019 edition. Brotherhood of St Laurence and Living with Disability Research Centre.
http://bit.ly/Quarterly_Digest

Bigby, C., Tipping, S., Bould, E., & Thiele, R. (2019). Strategies to support people with intellectual disabilities to participate in voting.
<http://hdl.handle.net/1959.9/563636>

Podcasts:

Still, F., & Bigby, C. (2019). NDIS Sector Development Podcast, National Disability Services (NDS). How to design effective supports to facilitate community participation.
<https://player.whooshkaa.com/episode/381683>

Bigby, C. (2019) ASID Research to Practice. *What makes a good group home?*
<https://player.whooshkaa.com/episode?id=421289>



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