

**LA TROBE**
UNIVERSITYLIVING WITH DISABILITY
RESEARCH CENTRE

Newsletter - Autumn 2019

Dear <<First Name>>,

The first Living with Disability Research Centre Newsletter of the year takes a look back at the work of our Centre in 2018, and a look forward to upcoming events and projects in 2019.

In this issue:

- The Living with Disability Research Centre 2018 Annual Report
- Our first PhD completion for 2019
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Professor Christine Bigby

Director - Living with Disability Research Centre

Annual Report - 2018

The Living with Disability Research Centre 2018 Annual Report [PDF 2.3mb] offers a detailed summary of our work over the past year. The report contains a wealth of information about our Research Centre, our staff and governance. It also provides an overview of our ongoing and completed research projects including details of research outputs, training resources and academic publications. [Download your copy now.](#)



First successful 2019 PhD completion



We offer our congratulations to Dr Claire Quilliam, who will graduate on 23 May 2019, at the Shepparton Campus, La Trobe University. Her thesis “Group home bureaucrats? Understanding how staff use paperwork in group homes for people with intellectual disability” explored how staff in group homes for people with intellectual disabilities juggled their duties of supporting residents and other administrative tasks, in particular paperwork. She found that paperwork poses complex tensions for staff, who exercise discretion and manage paperwork to prioritise supporting residents. The findings suggest disability service organisations should explore ways of better using staff knowledge in designing paperwork. Four papers were published as part of Dr Quilliam’s thesis.

Quilliam, C., Bigby, C., & Douglas, J. (2015). Paperwork in group homes for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 40(3), 286-296.
<https://doi.org/10.3109/13668250.2015.1034255>

Quilliam, C., Bigby, C., & Douglas, J. (2018). Being a valuable contributor on the frontline: the self-perception of staff in group homes for people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 395-404.
<https://doi.org/10.1111/jar.12418>

Quilliam, C., Bigby, C., & Douglas, J. (2018). Staff perspectives on paperwork in group homes for people with intellectual disability. *Journal of Intellectual & Developmental Disability*, 43(3), 264-273.
<https://doi.org/10.3109/13668250.2017.1378315>

Quilliam, C., Bigby, C., & Douglas, J. (2018). How frontline staff manage paperwork in group homes for people with intellectual disability: Implications for practice. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 905-914.
<https://doi.org/10.1111/jar.12450>

New projects in 2019

We are pleased to announce that the Living with Disability Research Centre has embarked on eight new projects this year. The extraordinary scope and variety of these projects highlights the way our Research Centre works across an exceptional array of disciplines and research areas.

Building capability to support client decision making

Professor Jacinta Douglas and Professor Christine Bigby

Funding: TAC

Decision Making Practice Framework (Douglas & Bigby, 2018) to support practice within the Transport Accident Commission (TAC). The project will involve training a cohort of the TAC's independence claims employees to apply the strategy to their client planning interactions and deliver services consistent with contemporary disability practice. Following training, we will assess the training specific impact on the capability of independence claims employees to be effective supporters of decision making.

Contemporary disability practice: Ongoing horizon scanning program

Professor Jacinta Douglas and Professor Christine Bigby

Funding: TAC

The Horizon Scanning Program is designed to identify emerging and innovative advances in contemporary disability practice across the national and international disability sector. Our findings will assist the TAC to remain aware of developments in the definition, principles, and characteristics of contemporary disability practice and support their aim to be a world leading social insurer.

Improving muscle strength in young people with Prader-Willi syndrome

Professor Nora Shields, Professor Kim Bennell, Professor Nicholas Taylor, Dr Lauren Rice, Assoc. Professor Tania Markovic, Professor Christine Bigby, Assoc. Professor Jennifer Watts and Assoc. Professor Luke Prendergast

Funding: Medical Research Future Fund

This project, led by Professor Nora Shields, is a collaborative project with a number of investigators from La Trobe University, including Professor Christine Bigby, other Universities, and also involves partners in health services in various states. It will investigate the potential benefits of community-based exercise for young people with Prader-Willi syndrome (PWS). PWS is a rare, serious, and costly lifelong health condition. The research team will recruit 60 young people with PWS and randomly allocate them to two different types of exercise groups. Participants will be assessed at various points during the trial and the results compared. The aim of the project is to improve health outcomes for people with PWS and to provide high-quality evidence to underpin National Disability Insurance Scheme funding for people with PWS.

Early vocational intervention for people who have experienced stroke: A randomised pilot trial

Associate Professor Natasha Lanin, Professor Jacinta Douglas, et. al.

Funding: Stroke Foundation.

This clinical trial directly addresses a well-recognised unmet need for stroke survivors and a key public policy issue – loss of vocation (i.e., employment and education). Stroke is the leading cause of adult disability, and is strongly associated with high unemployment and receipt of disability support.

disability in social and support services

Dr Elizabeth Smith, Professor Christine Bigby, Assoc. Professor Anthony Lyons and Dr Jennifer Power

Funding: Building Healthy Communities Research Focus Area, La Trobe University

Rainbow Mel is a project that explores how LGBTIQ and gender diverse adults with intellectual disability experience inclusion and exclusion within disability and LGBTIQ services. The project includes LGBTIQ adults with intellectual disability and key informants with expertise in the inclusion of LGBTIQ people and/or people with intellectual disability. The aim of this project is to gain insight into the state of service provision and to explore potential methods to enhance the inclusion for this population. The project is a collaboration between the Living with Disability Research Centre and the Australian Research Centre in Sex, Health and Society.

Aging with intellectual disability: Exploring the impact of the NDIS on service provision

Dr Tal Araten-Bergman and Professor Christine Bigby

Funding: School of Allied Health, Human Services and Sport, La Trobe University

In Australia, the NDIS has generated a new context to explore the way disability services are funded and delivered for ageing people with disability and their families. Entry to the NDIS is restricted to persons aged 65 and under, but the legislation provides for existing NDIS participants who reach 65 to choose either to remain in the scheme or transfer into the aged care system. The aim of this project is to explore the perceptions of disability service providers about the needs and life circumstances of people ageing with intellectual disability.

Increasing inclusion and engagement for people with cognitive disabilities: Piloting a risk enablement training package for disability support workers in Victoria

Professor Christine Bigby, Professor Jacinta Douglas and Dr Suzane Vassallo

Funding: Building Health Communities Research Focus Area, La Trobe University

This project aims to determine whether training support workers in positive risk taking is effective in changing their attitudes towards enabling the people they support to engage in activities involving risk. Positive risk taking is one element of good service provision. This pilot research will enhance our understanding of positive risk taking in the disability sector.

Promoting equal rights under the Victorian Medical Treatment Planning and Decisions Act 2016: Supporting the rights of Victorians with cognitive disability.

Professor Christine Bigby, Dr Margo Sheahan and Professor Jacinta Douglas

Funding: La Trobe University

The project builds on the Centre's Supported Decision Making Project. It aims to enable Victorians with cognitive disabilities to make directives under the Act by identifying

institutions resource and enable these processes.

Monthly Seminar Series 2019



We have seen some fascinating presentations at our monthly seminars this year. In February, Dr David Henderson gave us an insight into the multi layered nature of historical reconstruction by focusing on one episode in the history of the Kew Cottages (Australia's oldest institution for people with intellectual disability), and Gail Ritchie tackled some difficult issues around abuse in services for people with intellectual disabilities. In March, we hosted our first international guest for the year: Dr Nicola Grove, Honorary Senior Lecturer, Tizard Centre, University of Kent. Dr Grove presented a wonderful seminar on how important 'small stories' are to building a sense of personal identity and how the exchange of such stories can help break down barriers and stigma in the lives of people with severe and profound intellectual disabilities. Meanwhile, just last month, Emeritus Professor Pavla Millar sought to untangle some of the historical and conceptual issues that underpinned the rollout of the NDIS in Australia, and Dr Sian Anderson spoke about how supporters act, exercise power and are regarded by self-advocates in independent self-advocacy groups.

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

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 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 link before each seminar.

Upcoming Seminars

Date	Speaker	Subject
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Tessa-May
Zirnsack

Understanding systemic and cultural violence against the cognitive disability community: A new theoretical model.

June 12

Dr Tal Araten-
Bergman

Models for forming and supporting circles of support for people with intellectual disability.

Dr Robyn
O'Halloran

Why hospitals don't measure the patient experience of people with communication disability?

July 10

Dr Ilan Wiesel

Finding the mainstream city: the ambiguities of 'mainstream participation' by people with intellectual disability

Assoc/Prof.
Karen Soldatic

Sorting myself out of the system: Social sorting and the disability income support system for Indigenous Australians living with disability

August 14

Dr Nastaran
Doroud

Recovering through everyday life activities: Findings from a participatory photovoice study with people experiencing mental health issues

Dr Kellie
Stagg

Communication impairment and the working alliance in stroke rehabilitation

September 11

Dr Elizabeth
Smith

The La Trobe Support for Decision Making Practice Framework

Prof. Christine
Bigby &
Prof. Jacinta
Douglas

The La Trobe Support for Decision Making Practice Framework

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Mid-year enrolments Disability Practice

Our new [online degrees in Disability Practice](#) are available for enrolment at mid-year. The options are as follows: [Graduate Certificate in Disability Practice](#), [Graduate Diploma in Disability Practice](#) and [Master of Disability Practice](#). Click on the hyperlinks to get your

If you would rather complete one subject in an area of your interest, you can enrol in a single subject via Open Universities Australia. Subjects available for mid-year enrolment are:

- [The Contemporary Disability Landscape](#)
- [Advocacy in Contemporary Disability Practice](#)
- [Ethical Issues in Disability Practice](#)
- [Understanding Complex and Challenging Needs](#)
- [Disability and the Law](#)

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. Our courses and subjects are suitable for those entering the sector or professionals already in the field.

Please contact our course coordinator, Dr Sian Anderson, with any queries

Email: Sian.Anderson@latrobe.edu.au

Telephone: 94795495



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A Master-class with Prof. Jennifer Clegg



Making claims that matter: A master-class
1 November 2019 (date to be confirmed)

This master-class sows new seeds as it elaborates on non-behavioural approaches to people with intellectual disability who have complex and challenging needs. There will be opportunities to see videos that show how interactions reveal attachment; to examine instruments that assess emotional development and levels of distress, and to discover new research and practice into attachment and Trauma-Informed Care. The master-class explores three issues that impede conceptual creativity: neoliberalism, unconscious prototypes, and bright-siding (“always look on the bright side of life”) – a key problem for policy development on climate change. Finally, participants will be invited to play with 6 heuristic devices that can boost the theoretical and social impact of qualitative research.

New Research

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

Anderson, S., & Bigby, C. (2019) Writing the script: the overt and hidden contradictions of supporters' work in independent self-advocacy groups. *Journal of Intellectual & Developmental Disability*, <https://doi.org/10.3109/13668250.2019.1592127>

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>

Barry, S., Knox, L., & Douglas, J. (2019). 'Time's up': the experience of entering residential aged care for young people with acquired neurological disorders and their families. *Brain Impairment*, 20(1), 37-48. <https://doi.org/10.1017/BrImp.2018.13>

Bigby, C., Bould, E., & Beadle-Brown, J. (2019). Implementation of active support over time in Australia. *Journal of Intellectual and Developmental Disability*, 44(2), 161-173. <https://doi.org/10.3109/13668250.2017.1353681>

Bigby, C., Johnson, H., O'Halloran, R., Douglas, J., West D., & Bould, E. (2019). Communication access on trains: a qualitative exploration of the perspectives of passengers with communication disabilities. *Disability and Rehabilitation*, 41(2), 125-132. <http://www.tandfonline.com/doi/full/10.1080/09638288.2017.1380721>

Boyd, M. J., Iacono, T., & McDonald, R. (2019). The perceptions of fathers about parenting a child with developmental disability: a scoping review. *Journal of Policy and Practice in Intellectual Disabilities*. <https://doi.org/10.1111/jppi.12287>

D'Cruz, K., Douglas, J., & Serry, T. (2019). Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. *Neuropsychological Rehabilitation*, 1-21. <https://doi.org/10.1080/09602011.2019.1586733>

Douglas, J. (2019). Loss of friendship following traumatic brain injury: a model grounded in the experience of adults with severe injury. *Neuropsychological Rehabilitation*. OPEN ACCESS <https://doi.org/10.1080/09602011.2019.1574589>

Douglas, J., Knox, L., De Maio, C., Bridge, H., Drummond, M., & Whiteoak, J. (2019). Effectiveness of Communication-specific Coping Intervention for adults with traumatic brain injury: preliminary results. *Neuropsychological Rehabilitation*, 29(1), 73-91. OPEN ACCESS <https://doi.org/10.1080/09602011.2016.1259114>

Iacono, T., Bould, E., Beadle-Brown, J., & Bigby, C. (2019). An exploration of communication within active support for adults with high and low support needs. *Journal of Applied Research in Intellectual Disabilities*, 32(1), 61-70. OPEN ACCESS <https://doi.org/10.1111/jar.12502>

OPEN ACCESS

<https://doi.org/10.1111/jppi.12290>

Mealings, M., Douglas, J., & Olver, J. (2019). Is it me or the injury: Students' perspectives on adjusting to life after traumatic brain injury through participation in study. *Neuropsychological Rehabilitation*, 1-22.

<https://doi.org/10.1080/09602011.2019.1574231>

O'Halloran, R., Douglas, J., Cruice, M., Davidson, B., McKinley, K., & Bigby, C. (2019). Representation and reporting of communicatively vulnerable patients in patient experience research. *International Journal of Speech-Language Pathology*.

<https://doi.org/10.1080/17549507.2019.1567815>

Šarkić, B., Douglas, J. M., & Simpson, A. (2019). Peripheral auditory dysfunction secondary to traumatic brain injury: a systematic review of literature. *Brain Injury*, 33(2), 111-128.

<https://doi.org/10.1080/02699052.2018.1539868>

Stagg, K., Douglas, J., & Iacono, T. (2019). A scoping review of the working alliance in acquired brain injury rehabilitation. *Disability and Rehabilitation*, 41(4), 489-497.

<https://doi.org/10.1080/09638288.2017.1396366>

Tilbury, C., Bigby, C., Hughes, M. (2019). Analysis of Australian Research Council grants awarded 2008-2017. *Australian Social Work*.

<https://doi.org/10.1080/0312407X.2018.1543437>



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