



Our Spring newsletter takes a look at the latest news from the Living with Disability Research Centre.

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### **Professor Christine Bigby**

Director - Living with Disability Research Centre

## Interested in Supported Decision Making?

### **We are looking for people to participate.**

We are conducting a new study 'Frameworks for Supported Decision Making'. The project has two aims. First, to identify the significance of supported decision-making and the essential elements of supported decision-making frameworks. And second, to understand the key issues that are fundamental to successfully implementing supported decision-making in Australia.

The study has been commissioned by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, and it will help to inform the Royal Commission's final recommendations. The project is being led by Professor Christine Bigby with colleagues from the Living with Disability Research Centre, the University of Sydney, UNSW, the University of Melbourne and QUT.

At present we are seeking participants to take part in online focus groups to discuss the issues that need to be addressed in thinking about the design and implementation of frameworks for supported decision making. We are looking for family members of people with cognitive disabilities, disability service providers and advocates to participate. With any luck, we will be holding face-to-face focus groups for people with cognitive disabilities early in the new year.

If you are interested in participating, please contact either Christine Bigby, [c.bigby@latrobe.edu.au](mailto:c.bigby@latrobe.edu.au) or Lauren De Losa, [l.delosa@latrobe.edu.au](mailto:l.delosa@latrobe.edu.au) or phone us 03 9479 1016

## New Projects and Partners in 2021

### **Active Support, Practice Leadership and Organisational Culture: A longitudinal study of the determinants of the quality of supported accommodation services for people with intellectual disabilities**

**Research Team:** Professor Christine Bigby, Dr Lincoln Humphreys, Jane Bowden Dodd

**Funding:** Industry Partners

Our longitudinal Active Support study aims improve the quality of front-line staff practices and practice leadership in services and thus the quality of life of people with intellectual disabilities using services. This project, the longest of its kind in Australia, builds on an ARC Linkage study that identified the factors that predicted good Active Support in supported accommodation services. The project has now broadened its focus to include the impact of culture, teamwork and other organisational features that have an impact on the quality of support. The project is funded by industry partners, who also gain access to an annual independent report on the quality of support in their services.

Despite onerous restrictions on interstate travel in 2021, we were pleased to visit Tasmania for data collection at Oak and Dundaloo disability services. Meanwhile, we were also able to collect data at Genu and annecto in Victoria. Reports have been prepared and shared with senior management at each of those organisations. In early 2022, we look forward to resuming the data collection with all our industry partners that we were forced to put on hold due to Covid related restrictions in 2021.

Finally, we extend a warm welcome to Focus ACT, VMCH and Life Without Barriers, who have recently joined this project. They will join our existing partners on the project. Current partners: annecto, Dundaloo Services, Focus Individualised Support Services, GenU, Golden City Support Services, Help Enterprises, Identitywa, Jewish Care, Oak Possability, Rocky Bay, Unisson Disability Services, Yooralla.

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### **An evaluation of the RecruitAble**

**Research Team:** Professor Christine Bigby, Dr Tal Araten-Bergman, Dr William Crisp, Dr Sian Anderson

**Funding:** RecruitAble

Get Skilled Access, in partnership with Randstad Australia, is designing and delivering an inclusive employment recruitment program for people with disabilities named RecruitAble. The program aims to develop and test new inclusive recruitment pathways for people with disabilities to be used by mainstream recruitment agencies and employers. The Living with Disability Research Centre has been contracted to conduct an external evaluation of the

RecruitAble pilot. The evaluation will employ a theory-driven approach that will consider the effectiveness of the RecruitAble pilot, as well as provide insight into what works, for whom and why. The project will also map the mechanisms through which changes occur. It is anticipated that findings could provide insight into the impact of specific strategies developed to increase the participation of people with disabilities in the workforce. Moreover the knowledge developed from this evaluation could also provide evidence to inform future design of programs to assist in building supports and organisational responses that are tailored to the needs of mainstream recruiters and employers, and thus assist in creating more effective, equitable and inclusive workplaces for all.

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### **Scripts of family dynamics in ageing families with developmental disabilities: A cross-cultural exploration**

**Research Team:** Professor Christine Bigby, Dr Tal Araten-Bergman, Dr Carmit-Noa Shpigelman (University of Haifa, Israel)

**Funding:** Veski Study Melbourne Research Partnerships

The aim of this multi-national project is to describe and analyse the experiences of ageing families that include a middle-aged adult with intellectual disabilities residing in a group home. The research seeks to explore the dynamics and meaning of interpersonal and intergenerational relationships in Australian and Israeli families living and ageing with intellectual disabilities. The research uses

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and the adult with intellectual disabilities. This methodological approach provides a broad view of the dynamic interplay shaping the lived experience of each family member, as individuals as well as the family as an entity in and of itself. Findings will contribute to our understanding of the everyday realities and support needs of families in this life stage and will assist in developing innovative approaches to supporting people with intellectual disabilities and their families across the life course.

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### **Violence, abuse, neglect and exploitation of LGBTQ+ people with disability.**

**Research Team:** ARCSHS and Living with Disability Research Centre

**Funding:** Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

This project is lead by our colleagues at the Australian Research Centre in Sex, Health and Society and includes researchers from the Living with Disability Research Centre as collaborators. The aim of the project is to conduct and report on comprehensive secondary analyses of two significant national surveys of LGBTQ+ adults and young people with disability in Australia. These analyses are expected to provide data on experiences related to violence, abuse and harassment with further attention given to patterns according to key intersections such as sexual orientation and gender identity.

We recently published a literature review on the experiences of social inclusion/exclusion of this cohort of people in the context of disability services

(see below). Meanwhile, a second article on the perspectives of LGBTQ+ adults with disability on disability services is in the works and we hope to see it published soon.

Smith, E., Zirnsak, T., Power, J. et al. Social inclusion of LGBTQ and gender diverse adults with intellectual disability in disability services: A systematic review of the literature. *Journal of Applied Research in Intellectual Disabilities*. DOI: [10.1111/jar.12925](https://doi.org/10.1111/jar.12925)

## Support for Decision Making

The La Trobe Support for Decision Making Practice Framework learning resource, launched in 2019, is now being widely used by supporters of people with disability across Australia and in some other countries around the world. The Framework is the first evidence-based guide to supporting people with cognitive disabilities to make decisions. Already, the Framework has been adapted and used by the Queensland Public Trustee and the Transport Accident Commission to support and improve practice.

The latest findings from our Support for Decision Making project show the positive impact of training in the framework on parents of adults with intellectual disabilities, as highlighted in our articles below. Moreover, our current work in progress demonstrates a statistically significant change in decision making support after training in the Framework has been completed.



### Latest publications from this project:

Bigby, C., et al. (2021). Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences. DOI: [10.3109/13668250.2021.1954481](https://doi.org/10.3109/13668250.2021.1954481)

Bigby, C., et al. (2021). "I used to call him a non-decision-maker, I never do that anymore": Parental reflections about training to support decision-making of their adult offspring with intellectual disabilities. DOI: [10.1080/09638288.2021.1964623](https://doi.org/10.1080/09638288.2021.1964623)

Carney, T., et al. (2021). Paternalism to empowerment: All in the eye of the beholder? DOI: [10.1080/09687599.2021.1941781](https://doi.org/10.1080/09687599.2021.1941781)

## Impact and Dissemination

Our Research Centre is grounded in the real-world challenges of turning policy visions into changed experiences for people with cognitive disabilities. To this

end, our researchers are often engaged in disseminating research findings in a variety of contexts and settings. For example, in October, Professor Christine Bigby provided a submission to the public hearing of the Joint National Disability Insurance Scheme Committee into the NDIS workforce. The following month, Professor Bigby was invited to speak at a UK Health and Learning Disabilities Network webinar on “The most important dimensions of group homes that promote feelings of being at home for residents. The event was organised as part of a new SSCR/NIHR Research project on 'homeliness' in group homes for people with learning disabilities. Meanwhile, in September, Professor Bigby and Dr Lincoln Humphreys were both invited by Per Arvidsson, PhD Candidate, Malmo University, Sweden, to present recent research on Practice Leadership in Australia and discuss the launch of our Frontline Practice Leadership training resource [practiceleadershipresource.com.au](https://practiceleadershipresource.com.au). Arvidsson is examining whether Practice Leadership can be adopted in Swedish services. To do so, he will be drawing on the Frontline Practice Leadership training resource to train staff in Sweden about how to do Practice Leadership.

## Research Seminar Series - 2021



The Living with Disability Research Centre's 2021 Research Seminar Series will finish with our final seminar for the year on 8 December with two presentations that will review two recently published books exploring the National Disability Insurance Scheme (NDIS). The presentations will look at the successes and failures of the NDIS and the ongoing issues around achieving the social inclusion of people with intellectual disabilities. If you miss a seminar, you can always access slides from the completed presentations here:

[Research Seminar Series](#)

## Understanding FASD

## **Understanding Fetal Alcohol Spectrum Disorder (FASD): A free online seminar for the health and community sector**

Fetal Alcohol Spectrum Disorder (FASD) has gained increased recognition as a major health concern in Australia in recent years. The condition is characterised by learning, behavioural, memory, functional and physical impairments that are lifelong. FASD affects more Australians than Downs Syndrome, Spina Bifida and Cerebral Palsy combined, yet most professionals do not feel equipped with the information they need to recognise or respond to it effectively. This free webinar, sponsored by the La Trobe University Rural Health School and the Living with Disability Research Centre, aimed to help health and community service professionals by providing a wide range of information on FASD. The webinar was held on 9 September, 2021. To watch a recording of the seminar, click on the button below.

[View Recording](#)

## **Disability Practice Courses**



As 2021 draws to a close, we would like to extend our congratulations to all our Disability Practice staff and students who have shown such resilience throughout a difficult year. The challenge of navigating a Covid-19 interrupted year should not be underestimated. We would like to thank everyone who has worked so hard to make our Disability Practice courses such a success. We look forward to welcoming our next cohort of students in 2022.

Our flexible, online courses equip students to undertake a range of challenging and exiting roles in the rapidly growing disability sector and can lead to a satisfying career in improving the lives of people with disabilities and their communities. If you would like more information about any of the courses we offer, please contact our course coordinator, Dr Sian Anderson, with any queries.

Email: [Sian.Anderson@latrobe.edu.au](mailto:Sian.Anderson@latrobe.edu.au)

Telephone: 94795495

## Farewell Lizzie Smith

Finally, we would like to wish Dr Elizabeth Smith farewell as she leaves the Living with Disability Research Centre to embark on the next phase of her career at the Research Division within the NDIS.



Lizzie Smith joined our Research Centre more than five years ago. She was an instrumental member of the Support for Decision Making research team and worked on a variety of other projects here over the years. We would like to thank Lizzie for everything she brought to our research team and our culture.

## New Research

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

### Articles

Araten-Bergman, T., & Bigby, C. (2021). Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis. *Journal of Intellectual and Developmental Disability*. DOI: [10.3109/13668250.2021.1961049](https://doi.org/10.3109/13668250.2021.1961049)

Bigby, C., & Anderson, S. (2021) Creating opportunities for convivial encounters for people with intellectual disabilities: “It looks like an accident”. *Journal of Intellectual and Developmental Disability*, 46(1), 45-57. DOI: [10.3109/13668250.2020.1812178](https://doi.org/10.3109/13668250.2020.1812178)

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S., & Wiesel, I. (2021) “I used to call him a non-decision-maker, I never do that anymore”: Parental reflections about training to support decision-making of their adult offspring with intellectual disabilities. *Disability and Rehabilitation*. DOI: [10.1080/09638288.2021.1964623](https://doi.org/10.1080/09638288.2021.1964623)

Brown, M., Condi, A., Davis, E., Goodwin, I., Winkler, D., & Douglas, J. (2021). Young people in residential aged care: Is Australia on track to meet its targets? *Australian Journal of Social Issues*.

DOI: [10.1002/ajs4.184](https://doi.org/10.1002/ajs4.184)

Ford, A., Douglas, J., & O'Halloran, R. (2021). The experience of close personal relationships after stroke: scoping review and thematic analysis of qualitative literature. *Brain Impairment*. DOI: [10.1017/BrImp.2021.12](https://doi.org/10.1017/BrImp.2021.12)

Humphreys, L., Bigby, C., Iacono, T., & Bould, E. (2021). Patterns of group home culture in organisations supporting people with intellectual disabilities: A cross-sectional study. *Journal of Intellectual and Developmental Disability*. DOI: [10.3109/13668250.2021.1954482](https://doi.org/10.3109/13668250.2021.1954482)

Kappelides, P., Bould, E., & Bigby, C. (2021). Barriers to physical activity and sport participation for people with intellectual disabilities from culturally and linguistically diverse backgrounds. *Research and Practice in Intellectual and Developmental Disabilities*. DOI: [10.1080/23297018.2021.1939114](https://doi.org/10.1080/23297018.2021.1939114)

Licari, M., et al. (2021). Th course and prognostic capability of motor difficulties

in infants showing early signs of autism. *Autism Research*, 14(8), 1759-1768.  
DOI: [10.1002/aur.2545](https://doi.org/10.1002/aur.2545)

McEwen, J., Bigby, C., & Douglas, J. (2021). How leaders in day service organisations understand service quality. *Research and Practice in Intellectual and Developmental Disabilities*.  
DOI: [10.1080/23297018.2021.1951619](https://doi.org/10.1080/23297018.2021.1951619)

Šarkić, B., Douglas, J., Simpson, A., Vasconcelos, A., Scott, B., Melitsis L., & Spehar, S. (2021). Frequency of peripheral vestibular pathology following traumatic brain injury: a systematic review of literature. *International Journal of Audiology*, 60(7), 479-494,  
DOI: [10.1080/14992027.2020.1811905](https://doi.org/10.1080/14992027.2020.1811905)

Tilbury, C., Hughes, M., Bigby, C., & Fisher, M. Research end-user perspectives about using social work research in policy and practice. *The British Journal of Social Work*, 51(4), 1186–1202.  
DOI: [10.1093/bjsw/bcab022](https://doi.org/10.1093/bjsw/bcab022)

### Book Chapters

Bigby, C. (2021). 'The scheme was designed with a very different idea in mind of who a disabled person is': The National Disability Insurance Scheme and people with intellectual disability. In Cowden, M., & McCullagh, C. (eds.) *The National Disability Insurance Scheme: An Australian policy experiment*, Palgrave MacMillan: Melbourne.

Bigby, C. (2021). Programs and Practices to Support Community Participation of People with Intellectual Disabilities. In P. Liamputtong, *Social Inclusion*. Springer

Bigby, C., & Douglas, J. (in press). Examining the complexities of support for decision making practice. In Khemka, I., & Hickson, L. *Decision making by individuals with intellectual and developmental disabilities: research and practice*

Henderson, D., & Bigby, C. (2021). Stories from the wild west frontier: The National Disability Insurance Scheme experiences of people with severe and profound intellectual disability. In Cowden, M., & McCullagh, C. (eds.) *The National Disability Insurance Scheme: An Australian policy experiment*, Palgrave MacMillan: Melbourne.

Iacono, T., & Bigby, C. (2021). The health inequalities of people with intellectual and developmental disabilities. In P. Liamputtong, *Public Health: local and global perspectives*, 3<sup>rd</sup> edition. Melbourne: University of Cambridge Press.



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