



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

- New projects and partners
- Research dissemination
- Research seminar series
- Disability practice courses
- PhD completions
- Farewells
- New publications

**Professor Christine Bigby**

Director - Living with Disability Research Centre

## New projects and partners in 2022

### Director Pathways study

**Research Team:** Dr Alan Hough, Professor Christine Bigby, Dr Ali Brookes

**Funding:** Purpose at Work (subcontract)

In conjunction with Purpose at Work, LiDs is undertaking a research project on board directors who have a disability. We will be interviewing 50 directors serving on for-profit, public sector or not-for-profit boards for a new study. Our aim is to learn about their pathways to boards and their experiences serving on boards.

### Families with adults with intellectual disability residing in group homes: Perspectives on family relations and quality of support

**Research Team:** Professor Christine Bigby, Dr Tal Araten-Bergman, Dr Carmit-Noa Shpigelman

**Funding:** La Trobe University, University of Haifa (Israel), The Victorian Endowment for Science Knowledge and Innovation (VESKI)

This cross-cultural research study aims to analyse the experiences of Australian and Israeli ageing families with a middle-aged member with intellectual disabilities. The qualitative framework designed for this study combines knowledge disability, ageing and family studies, and focuses on the family as the unit of analysis. The findings from this study will contribute understanding of the everyday realities and support needs of families at this life stage and in turn, assist to develop innovative approaches to supporting people with intellectual disabilities and their families across the life course.

### My Rights Matter evaluation

**Research Team:** Professor Christine Bigby, Dr Aaron Jackson, Dr Julia Duffy, Charity Sims Jenkins, Kathryn Bartlett

**Funding:** Philanthropic sources

CID is developing My Rights Matter, a program that promotes the right to decision-making and get the support a person needs. The program is designed to increase the decision-making skills of people with intellectual disabilities, build the understandings and capacities of supporters and service providers

around rights-based support and influence changes to related legislature and policy. LiDs has been contracted by the philanthropic funders to evaluate My Rights Matter, to measure the impacts of the program and add to the evidence base for supported decision-making.

---

### **Literature review on Best Practice for Supported Accommodation**

**Research Team:** Professor Christine Bigby

**Funding:** NDIS Quality & Safeguards Commission

LiDs have been tasked with undertaking a literature review on models of best practice and the drivers and inhibitors of best practice in supported accommodation setting, as set out in the terms of reference for the Own Motion Inquiry into Aspects of Supported Accommodation in the NDIS. This work aims to identify 'models of best practice for the delivery of supported accommodation that might be appropriate for consideration by the NDIS Commission in its capacity building work with providers and in the context of development of any future amendments to relevant practice standards and quality indicators'.

---

### **Practice framework development for Achieve Australia**

**Research Team:** Professor Christine Bigby, Dr Ali Brookes

**Funding:** Achieve Australia Disability Services

LiDs are undertaking a literature review as the first stage of developing a Practice Framework for Achieve Australia, an NSW-based disability services organisation that provides tailored support in the Greater Sydney and Northern Rivers areas. Achieve helps people find accommodation, access community and lifestyle programs, work, ways to develop new skills, support coordination and other NDIS support.

---

### **New Partners in the Embedding Active Support and Practice Leadership longitudinal study**

Life without Barriers and VMCH joined the study during 2021, and in 2022, Community Living Options from SA, and Melba Support Services from Melbourne had also joined. We are currently fast catching up on outstanding data collection delayed by COVID 19 restrictions and are nearing completion of data collection from Yooralla, Focus Vic, Jewish Care, Possability Victorian services, Unnisson, Golden City Support Services and Genu. In the last several months we have trained staff in Possability and Focus Vic in Active Support and Practice Leadership using our newly developed training materials.

## **Research Dissemination**

### **Increasing Hospital Access and Quality of Care for People with Cognitive Disabilities**

A team led by Professor Teresa Iacono is in the process of developing a new online training resource to support the systematic embedding of high-quality hospital care. This resource is based upon processes that emerged from previously funded research project on quality hospital care. Videos showing scenarios the key effective elements of the research form the focal points of the resource. The scripts for these videos were developed with input from relevant stakeholders. Some of these can be seen in the recording of a presentation at the August LIDS Seminar [\[link\]](#).

---

### **LiDs work on Support for Decision Making tabled in Queensland Legislative Assembly**

Professor Christine Bigby, Em. Professor Jacinta Douglas and Dr Elizabeth Smith prepared a report on the evaluation of the introduction of a Structured

Decision-Making (SDM) Framework based on the La Trobe Support for Decision Making Practice Framework for the Queensland Public Trustee (QPT). The results were subsequently tabled by the Legislative Assembly in March 2022. The implementation of SDM within the QPT followed 2019 amendments to Queensland's *Guardianship and Administration Act 2000* and the introduction of its *Human Rights Act 2019*, which placed new responsibilities on all QLD public sector entities. SDM formed part of a new *Customer First* agender for the QPT in line with these legislative changes and aimed to assist frontline staff in making better decisions through stronger engagement with Public Trustee customers and their support networks [\[link\]](#).

---

### **Forthcoming book about the historic Kew Cottages**

Honorary LiDs fellow Dr David Henderson has co-authored a new book documenting the history of the Kew Cottages, *Failed Ambitions: Kew Cottages and Changing Ideas of Intellectual Disability, 1887-2005*. The Kew Cottages, opened in 1887, were Australia's first purpose-built institution for people with intellectual disabilities. Two years after its establishment, some observers were already describing facilities at Kew as the most progressive of their kind in Australia. By the time the institution closed in 2008, however, it was considered a relic of a different, more regressive time, when people with intellectual disabilities were locked away, not seen or heard, and excluded from participating in society.

The book provides a keyhole through which to view a disability service system that, as Gillard put in her 2012 speech, has too often failed to respond individual human needs. To this end, the book interrogates understandings of marginality, gender and place in a specific institutional setting, and it explores the reality of the Kew Cottages as a repository for some of the least powerful and the most marginalised people in society. The history of the Kew Cottages encompasses myriad broad shifts in intellectual disability policy and practice in Australia. As such, it provides a key case study of the way in which the Australian disability service system has conceived of, accommodated and responded to people with intellectual disability over more than one hundred years.

*Failed Ambitions* will be published in April 2023 through Monash University Press. As part of this project the Kew History website is being reformatted making it accessible with contemporary technology and will be relaunched in the coming months.

---

### **New Active Support training resources**

COVID-19 restrictions had severely delayed filming for the new Active Support training resources, but this is now complete and the new website is under construction. Look out for the launch of these new updated instructional resources on Active Support in the next couple of months.

---

### **September is Fetal Alcohol Spectrum Disorder (FASD) Awareness Month**

LiDs researcher Dr Kerryn Bagley, who is based at the La Trobe Rural Health School, will be presenting at our next research seminar on 14 September about the awareness of this under-acknowledged yet significant condition. Dr Bagley's research looks at lived experiences of FASD and how professionals respond to it. This presentation forms part of FASD Awareness Month, organised by the Victorian FASD Special Interest Group (VIC FASD SIG). Dr Bagley is also co-chair of VIC FASD SIG in addition to her appointment at LiDs.

Our monthly research seminars resumed in March 2022, continuing in an online webinar format. This has allowed us to continue hosting guest speakers and audience members from interstate and overseas. Video recordings of past seminars and copies of the speakers' presentation slides are available on our website [\[link\]](#).

### Seminar topics

September	Dr Kerry Bagley, Living with Disability Research Centre, La Trobe University Ms Angelene Bruce, Birth Mum and FASD awareness advocate	<i>Fetal Alcohol Spectrum Disorder (FASD): Hidden in plain sight</i>
	Professor Anita Gibbs, University of Otago.	<i>Best practices for Justice: Practitioner views on understanding and helping youth living with Fetal Alcohol Spectrum Disorder (FASD)</i>
August	Professor Teresa Iacono, Living with Disability Research Centre, La Trobe University	<i>Increasing Hospital Access and Quality of Care for People with Cognitive Disabilities</i>
	Dr Jo Spong, Living with Disability Research Centre, La Trobe University	<i>Preparedness of a Regional Rural Mental Health Workforce to Support People with Intellectual Disabilities</i>
July	Emeritus Professor Jacinta Douglas, Living with Disability Research Centre, La Trobe University	<i>The Decision Support Questionnaire: Development, Reliability and Validity</i>
	Professor Christine Bigby, Director, Living with Disability Research Centre, La Trobe University	<i>Evaluation of a Structured Decision-making Framework used by the Public Trustee Queensland</i>
June	Associate Professor Ilan Wiesel, School of Geography, Earth and Atmospheric Sciences, The University of Melbourne	<i>Mainstreaming differentiation and individualisation as modes of inclusion in mainstream services</i> <a href="#">[link]</a>
	Dr Ellen Van Holstein, Vice Chancellor's Postdoctoral Fellow, RMIT University	<i>People with intellectual disability and the digitization of services</i> <a href="#">[link]</a>
May	Dr Nathan Wilson, School of Nursing and Midwifery, University of Western Sydney	<i>Beyond the dental chair: The role of caregivers in promoting oral health</i>
	Dr Matthew Lim, Research Fellow, Living with Disability Research Centre, La Trobe University	<i>'Filling in the gaps': Where the problems lie in addresssing the oral health of Australians with disability</i>

April	Dr Alan Hough, Director, Purpose at Work	<i>Governing for quality and safeguarding: A new arena for boards of directors of disability service providers? What can be learnt from other sectors?</i>
	Adjunct Professor Jennifer Clegg, Living with Disability Research Centre, La Trobe University	<i>Helping distressed people manage their chaotic emotions: The paradox <a href="#">[link]</a></i>
March	Associate Professor Ruth Walker, Disability and Community Inclusion/Caring Futures Institute, Flinders University	<i>Planning for the future among older parents of adults with intellectual disability.</i>
	Ms Jenna Macnab, PhD Candidate, Living with Disability Research Centre, La Trobe University	<i>Using a 'helicopter lens': An analysis of the substitute decision-making practice of New South Wales public guardians.</i>

## Disability Practice Courses



**LA TROBE**  
UNIVERSITY

## Disability Practice Courses - Online

The La Trobe Disability Practice courses continue to run. These are taught online and are offered as single subjects or a Graduate Certificate part time or full time.

The courses provide professionals working in diverse contexts with an opportunity to develop knowledge and skills to enhance their confidence and practice in working directly with people with disabilities and their families. It will also equip them to understand the current disability landscape at a time of significant reform and tackle disadvantage through system-level change.

In May 2022, course coordinator Dr Sian Anderson presented a webinar for prospective students about the course content, career outcomes and how to access Commonwealth Supported Places.

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: 0394795495

## PhD Completions

Dr Jade McEwan's PhD was conferred by Academic Boards in July 2022. Jade's thesis, titled *Regulatory Ritualism? Exploring Australian Governments' Approach to Monitoring Quality in Disability Services* has made a significant contribution to knowledge about quality in disability services, both in terms of how it is understood by staff and managers as well as measured by governments. Jade has also recently completed an internship with the Academy of Social Sciences, where she completed further work examining quality in disability services.

## Farewells and Welcomes

It was with great sadness that LiDS farewelled our historian Dr David Henderson in February. He is taking up a position as a researcher in the Office of the Senior Practitioner and will remain a honorary research fellow. We welcome Dr Aaron Jackson, as a research fellow whose background in anthropology and understanding experiences of fathers in caring for a child with severe disabilities. We also welcome new research assistants, Dr Alison Brookes, Dr Chris Cott, James Pilbrow, Samia Gupta and Karolina Aslimoska.

## New Publications

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

### Articles

Anderson, S. (2022). Threats to valuing diverse voices in public debates about disability. A case study from social media. *Research and Practice in Intellectual and Developmental Disabilities*. Advance online copy.

<https://doi.org/10.1080/23297018.2022.2051198>

Araten-Bergman, T., Bigby, C. (2022). Forming and supporting circles of support for people with intellectual disabilities – a comparative case analysis. *Journal of Intellectual & Developmental Disability*, 47(2), 177-189.

<https://doi.org/10.3109/13668250.2021.1961049>

Bigby, C., Douglas, J., Smith, E., Carney, T., Then, S., Wiesel, I. (2022). Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences. *Journal of Intellectual & Developmental Disability*, 47(2), 165-176.

<https://doi.org/10.3109/13668250.2021.1954481>

Brown, M., Condi, A., Davis, E., Goodwin, I., Winkler, D., Douglas, J. (2022). Young people in residential aged care: Is Australia on track to meet its targets? *Australian Journal of Social Issues*, 57(2), 329-343.

<https://doi.org/10.1002/ajs4.184>

Choate, P., Badry, D., Bagley, K. (2022). The Alcohol Industry and Social Responsibility: Links to FASD. *International Journal of Environmental and Public Health Research*, 19(13), 1-16. <https://doi.org/10.3390/ijerph19137744>

D'Cruz, K., Douglas, J., Serry, T. (2022). Humanising brain injury rehabilitation: A qualitative study examining humanising approaches to engagement in the context of a storytelling advocacy program. *Brain Impairment*. 91-103.

<https://doi.org/10.1017/Brlmp.2021.16>

Douglas, J., Winkler, D., Oliver, S., Liddicoat, S., D'Cruz, K. (2022). Moving into new housing designed for people with disability: preliminary evaluation of outcomes. *Disability and Rehabilitation*. Advance online publication.

<https://doi.org/10.1080/09638288.2022.2060343>

Ellis-Hill, C., Kayes, N., Douglas, J. (2022). We are human – an invisible and fundamental aspect of rehabilitation in acquired brain injury. *Brain Impairment*, 23(1), 1-3. <https://doi.org/10.1017/Brlmp.2022.1>

Garcia-Melgar, A., Hyett, N., Bagley, K., McKinstry, C., Spong, J., Iacono, T. (2022). Collaborative team approaches to supporting inclusion of children with disability in mainstream schools: A co-design study. *Research in Developmental Disabilities*, 120. <https://doi.org/10.1016/j.ridd.2021.104141>

Goodwin, I., Davis, E., Winkler, D., Douglas, J., Wellecke, C., D'Cruz, K., Mulherin, P., Liddicoat, S. (2022). Making homes more accessible for people with mobility impairment: A lived experience perspective. *Australian Journal of Social Issues*. Advance online publication. <https://doi.org/10.1002/ajs4.214>

Hayes, N., Akison, L., Goldsbury, S., Hewlett, Elliott, E., Finlay-Jones, A., Shanley, C., Bagley, K., Crawford, K., Crawford, A., Till, H., Crichton, A., Friend, R., Moritz, K., Mutch, R., Harrington, S., Webster, A., Reid, N. (2022). Key Stakeholder Priorities for the Review and Update of the Australian Guide to Diagnosis of Fetal Alcohol Spectrum Disorder: A Qualitative Descriptive Study. *International Journal of Environmental Research and Public Health*, 19(20), 1-20. <https://doi.org/10.3390/ijerph19105823>

Iacono, T., Douglas, S. N., Garcia-Melgar, A., Goldbart, J. (2022). A scoping review of AAC research conducted segregated school settings. *Research in Developmental Disabilities*, 120, Article 104141. <https://doi.org/10.1016/j.ridd.2021.104141>

Iacono, T., Goldbart, J., Douglas, S. N., Garcia-Melgar, A. (2022). A Scoping Review and Appraisal of AAC Research in Inclusive School Settings. *Journal of Developmental and Physical Disabilities*. Advance online publication. <https://doi.org/10.1007/s10882-022-09835-y>

Linehan, C., Birkbeck, G., Araten-Bergman, T., Baumbusch, J., Beadle-Brown, J., Bigby, C., Bradley, V., Brown, M., Bredewold, F., Chirwa, M., Cui, J., Gimenes, M., Gomiero, T., Kanova, Š., Kroll, T., Li, H., MacLachlan, M., Narayan, J., Nearchou, F., Nolan, A., O'Donovan, M., Sntos, F., Šiška, J., Stainton, T., Tideman, M., Tossebro, J. (2022). COVID-19 IDD: Findings from a global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities (IDD) and their caregivers. *HRB Open Research*, 5(27). <https://doi.org/10.12688/hrbopenres.13497.1>

Logan, K., Iacono, T., & Trembath, D. (2022). A systematic search and appraisal of intervention characteristics used to develop varied communication functions in children with autism who use aided AAC. *Research in Autism Spectrum Disorders*, 90. <https://doi.org/10.1016/j.rasd.2021.101896>

Moorhouse, B., Mainprize, E., Douglas, J., & Fisher, C. (2022). Comparing participation in sports discussion and art therapy groups in ABI. *Brain Impairment*, 23(1), 1-15. <https://doi.org/10.1017/Brlmp.2021.32>

Šarkić, B., Douglas, J., Simpson, A. (2022). 'I had nothing. It's just life experience that helped me through that situation': Australian audiologists' perspectives on audiological clinical practice for traumatic brain injury and rehabilitation. *Brain Injury*. Advance online publication. <https://doi.org/10.1080/02699052.2022.2092651>

Smith, E., Zirnsak, T.-M., Power, J., Lyons, A., & Bigby, C. (2022). 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*, 35(1), 46-59. <https://doi.org/10.1111/jar.12925>

Then, S-N., Carney, T., Bigby, C., Wiesel, I., Smith, E., & Douglas, J. (2022). Moving from support for decision-making to substitute decision-making: Legal frameworks and perspectives of supporters of adults with intellectual disabilities. *Law in Context*. Advance online publication. <https://journals.latrobe.edu.au/index.php/law-in-context/article/view/174>

Topping, M., Douglas, J., Winkler, D. (2022). "They treat you like a person, they ask you what you want": a grounded theory study of quality paid disability support for adults with acquired neurological disability. *Disability and Rehabilitation*. Advance online publication. <https://doi.org/10.1080/09638288.2022.2086636>

Trembath, D., Stainer, M., Caithness, T., Dissanayake, C., Eapen, V., Fordyce, K., Frewer, V., Frost, G., Hudry, K., Iacono, T., Mahler, N., Masi, A., Paynter, J., Pye, K., Quan, S., Shellshear, L., Sutherland, R., Sievers, S., Thirumanickam, A., Westerveld, M., Tucker, M. (2022). Spoken Language Change in Children on the Autism Spectrum Receiving Community-Based Interventions. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-022-05511-4>

Wellecke, C., D'Cruz, K., Winkler, D., Douglas, J., Goodwin, C., Davis, E., Mulherin, P. Accessible design features and home modifications to improve physical housing accessibility: A mixed-methods survey of occupational therapists. *Disability and Health Journal*. Advance online publication. <https://doi.org/10.1016/j.dhjo.2022.101281>

Wiesel, I., Bigby, C., van Holstein, E., Gleeson, B. (2022). Three modes of inclusion of people with intellectual disability in mainstream services: mainstreaming, differentiation and individualisation. *Disability and Society*. Advance online publication. <https://doi.org/10.1080/09687599.2022.2060803>

### Conference Papers and invited presentations

**Bigby, C.** (2022). Shared and supported decision making across the life course. Invited speaker NBPSA conference, Sydney, August.

**Bigby, C.** (2022). The tasks of Frontline Practice Leadership: evidence and tools for training  
British Institute of Learning Disabilities, International Journal of Positive Behaviour Support Conference, UK, June,

**Bigby, C.** (2022). Principles and practicalities the La Trobe Support for Decision Making Practice Framework. Invited speaker, Supported Decision Making in Practice, Disability Services Consulting and Baptcare. March 2022.

**Bigby, C.** (2022). Implementing active support in your organisation. Invited speaker, Improving Quality and Safety in the NDIS, March 2022.

**Bigby, C.** (2022) Ethics is everybody's business. 2022. Invited speaker. IASSID International Conference Series IASSID.

**Winkler, D., Douglas, J., D'Cruz, K., Goodwin, I., Wellecke, C., Davis, E., Mulherin, P.** (2021). Making Housing More Accessible: Perspectives of People with Physical Impairment, Occupational Therapists and Architects.  
International Brain Injury Association 2021 Virtual World Congress on Brain Injury, July 2021.

### Reports

Bigby, C., Douglas, J., Smith, E. (2021). *Considering human rights in decision making: Evaluation of the introduction of structured-decision making framework in the Public Trustee Queensland*. Living with Disability Research Centre, La Trobe University. <https://documents.parliament.qld.gov.au/tp/2022/5722T272-39B6.pdf>



This email was sent to [\\*|EMAIL|\\*](#)

[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)

\*|LIST:ADDRESSLINE|\*

\*|REWARDS|\*