



Newsletter Summer 2022-2023

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

- Research report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of LGBTQA+ people with disability
- Fetal Alcohol Spectrum Disorder (FASD) Awareness Month
- 2022 Australasian Society for Intellectual Disability (ASID) conference
- 19th Conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (NR-SIG-WFNR)
- 2022 Summer Foundation Annual Public Forum
- New podcast about good support in group homes for CanadianThe Behaviour Speak Podcast series
- Research Seminar Series
- New Publications

Professor Christine Bigby

Director - Living with Disability Research Centre

Final LiDs Seminar on 14 December

Our final seminar will take place on Wednesday 14 December at 3pm AEDT via Zoom and will feature two presentations from our colleagues at the Summer Foundation. Email lids@latrobe.edu.au to register.

Research Dissemination

Research report for the Royal Commission into Violence, Abuse, Neglect and Exploitation of LGBTQA+ people with disability

LGBTQA+ people in Australia have consistently reported higher levels of violence, harassment and abuse and poorer physical and mental health than the general population. In turn, LGBTQA+ people with disability experience substantially greater challenges and poorer outcomes than LGBTQA+ people without disability, including experiences of violence, abuse and neglect.

LiDs Director Christine Bigby is one of the authors of a new research report that has been prepared in collaboration between the Australian Research Centre in Sex, Health and Society (ARCHS) and LiDs for the Royal Commission into Violence, Abuse, Neglect and Exploitation of LGBTQA+ people with disability. This work comprised a secondary analysis of data from two national surveys on the health and wellbeing of LGBTQA+ people in Australia, one which focused on young people aged 14-21 and the other on adults aged 18 and over. In many instances, large majorities of LGBTQA+ people with disability reported experiencing violence, abuse, neglect or exploitation. Experiences of abuse were also reported in relation to service systems, in intimate relationships and families. Adults categorised with more severe disabilities appear to be at even higher risk of abuse and a host of negative outcomes.

ARCHS Director Associate Professor Adam Bourne will conduct a seminar on

this work in early 2023. The full report and an easy-read version can be found on the Royal Commission website [\[link\]](#)

FASD Awareness Month

Every September is International Fetal Alcohol Spectrum (FASD) Awareness Month. FASD is a neurocognitive disability with a prevalence rate higher than well-recognised conditions such as Autism and Down Syndrome. However, professionals in health, social service, disability and education report that they know little about it. Australia has a National FASD Strategic Action Plan but at present does not have national FASD prevalence data, and there is general agreement among researchers and practitioners that rates are underestimated.

LiDs researcher Dr Kerryn Bagley is co-chair of the Victorian FASD Special Interest Group (VIC FASD SIG), which arranged a number of FASD awareness events and activities throughout the month. Our September LiDs Seminar was part of this programme, and featured presentations from Dr Bagley as well as FASD Parent Advocate Ms Angelene Bruce and Professor Anita Gibbs from the University of Otago, NZ.

A series of FASD video resources developed by LiDs and the La Trobe Rural Health School is available on our website [\[link\]](#)

2022 ASID Conference

A number of our researchers presented at the 2022 Australasian Society for Intellectual Disability (ASID) conference, which was held virtually across two days on 4 and 9 November. LiDs director Professor Christine Bigby is also the current president of ASID.

The theme of this year's conference was "Inclusion – being there, being involved and being valued", and featured keynotes and sessions delivered by researchers, service providers, policy and advocacy practitioners, self-advocates and family members of people with intellectual disabilities. LiDs researchers Prof. Christine Bigby, Prof. Teresa Iacono, Dr Jo Spong, Adjunct Prof. Jennifer Clegg, Dr Kerryn Bagley, Dr Sian Anderson, Dr Tal Araten-Bergman and Dr Carmit-Noa Shpigelman all contributed presentations.

Registered attendees are able to view recordings of the presentations on the conference site and will be available to the public in the near future [\[link\]](#)

2022 NR-SIG-WFNR Conference

Several LiDs researchers presented at the 19th Conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (NR-SIG-WFNR) in October. This was a hybrid conference held online and in-person in Maastricht, Netherlands. The NR-SIG is for clinicians and researchers in a multitude of disciplines interested in the rehabilitation of people across the lifespan with cognitive, emotional, psychosocial and behavioural deficits caused by acquired brain injury or neurological disease (both progressive and nonprogressive). LiDs researchers Em. Professor Jacinta Douglas, Dr Megan Topping, Dr Di Winkler and Ms Rebecca Leeson contributed presentations.

More information can be found on the conference website [\[link\]](#)

2022 Summer Foundation Annual Public Forum

Our shared researchers, adjuncts and close colleagues at the Summer Foundation held their 2022 Annual Public Forum on 25 November. This year's forum, held as a hybrid online/in-person event, focused on what housing and supports could potentially look like under a reimagined NDIS, after the scheme's 10-year review. Particular focus was given to Specialist Disability Accommodation (SDA).

ABC journalist Beverley O'Connor hosted a panel of experts: Rachel Thomas, an NDIS participant and SDA tenant; Paul Simmons, the CEO of NSW-based Ability SDA, and Kelly Chait, the Support Coordination Lead at the Housing Hub. More information can be found here [\[link\]](#)

Christine Bigby appearance on The Behaviour Speak Podcast

In October, our director Professor Christine Bigby was the featured guest on *The Behaviour Speak Podcast*, about LiDs research on identifying the key indicators of good practice and culture group homes (i.e., where residents live their best lives and staff, enjoy their work) and how to best reach those outcomes.

Behaviour Speak is a Canadian podcast that features conversations with behaviour analysts, researchers and consumers in Positive Behaviour Support, ABA, Acceptance Commitment Therapy and other areas of behaviour analysis. It is available via multiple streaming services including Spotify, Apple Music and Google Podcasts.

The episode and other Behaviour Speak content can be found on the podcast's website [\[link\]](#)

Research Seminar Series - 2022

Our monthly online Research Seminar Series continued with three final instalments in September, October and December. There was no seminar in November as the Australasian Society for Intellectual Disability (ASID) conference was running.

The online format has continued to be a success this year and has allowed us to host presenters and attendees from all around the world. Recordings of all our 2021 and 2022 seminars 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>
October	Dr Tal Araten-Bergman , Social Work and Social Policy, School of Allied Health, Human Services and Sport, and Living with Disability Research Centre, La Trobe University, Melbourne, Australia; Dr Carmit-Noa Shpigelman , Department	<i>"I kept telling him that we did not abandon him": family members' experiences supporting adults in supported accommodation during the COVID-19 pandemics</i>

	of Community Mental Health, University of Haifa, Israel	
	Associate Professor Christine Linehan, University College Dublin	<i>Caregivers' perceptions of the global impact of COVID-19</i>
	Megan Topping, Doctoral Researcher, Living with Disability Research Centre, La Trobe University/Summer Foundation	<i>"You're Supporting the Whole Person": Model of Quality Support Grounded in the Experience of Adults with Disability, Disability Support Workers and Close Others</i>
December	Dr Kate D'Cruz, Senior Research Fellow and Research Team Manager, Summer Foundation, Adjunct Research Fellow, Living with Disability Research Centre, La Trobe University	<i>Strengthening opportunities for people with disability to live independently: A co-design project.</i>

New Publications

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

Articles

Atkins, P., Bagley, K., Downey, H., Gardner, F., Sanders, R., Kanjere, A. (2022). Collaborative assessment as a learning tool for social work students. *Social Work Education*. Advance online publication. <https://doi.org/10.1080/02615479.2022.2118702>

Bagley, K., Six, K., Kenny, A., Hanson L. (2022). E-learning for fetal alcohol spectrum disorder: an environmental scan of the scope and content of free online training modules. *Research and Practice in Intellectual and Developmental Disabilities*. Advance online publication. <https://doi.org/10.1080/23297018.2022.2117074>

Banaszak-Holl, J., Morello, R., Soh, S., Cameron, P., Brown, M., Mitsch, V., Moubarak, R., Winkler, D. (2022). Do young people with neurological conditions in residential aged care use hospitals differently than those in the community? Evidence from Victorian hospital data, 2014–2017. *Health and Social Care in the Community*. Advance Online Publication. <https://doi.org/10.1111/hsc.14022>

Bigby, C., Douglas, J., Smith E., Carney, T., Then, S-N., Wiesel, I. (2022). "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*, 44(21), 6356-6364. <https://doi.org/10.1080/09638288.2021.1964623>

Booker, L., Spong, J., Deacon-Crouch, M., Skinner, T. (2022). Preliminary Exploration into the Impact of Mistimed Expressed Breast Milk Feeding on Infant Sleep Outcomes, Compared to Other Feeding Patterns. *Breastfeeding medicine: the official journal of the Academy of Breastfeeding Medicine*, 17(10), 853-858. <https://doi.org/10.1089/bfm.2022.0125>

Botchway, E., Knight, S., Muscara, F., Greenham, M., D'Cruz, K., Bonyhady, B., Anderson, V., Scheinberg, A. (2022). Rehabilitation models of care for children and youth living with traumatic brain and/or spinal cord injuries: a focus on family-centred care, psychosocial wellbeing, and transitions. *Neuropsychological Rehabilitation*, 32(4), 537-559. <https://doi.org/10.1080/09602011.2020.1833945>

Candish, L., Fady, J., D'Cruz, K. (2022). Storytelling as an intervention in traumatic brain injury rehabilitation: a scoping review. *Disability and Rehabilitation*. Advance online publication. <https://doi.org/10.1080/09638288.2022.2084778>

Clegg, J., Lansdall-Welfare, R. (2022). Helping distressed people with intellectual disability to manage their chaotic emotions. *Research and Practice in Intellectual and Developmental Disabilities*. Advance online publication. <https://doi.org/10.1080/23297018.2022.2106146>

- Currie, S., Douglas, J., Winkler, D. (2022). 'What's next?' The journey from hospital to community engagement from the perspectives of adults following severe acquired brain injury: a scoping review protocol. *BMJ Open*, 12(9). <https://doi.org/10.1136/bmjopen-2022-064226>
- Douglas, J., D'Cruz, K., Winkler, D., Topping, M., Bucolo, C., Finis, C. (2022). Development and preliminary evaluation of a novel participant-led video intervention to train disability support workers. *Health and Social Care in the Community*. Advance Online Publication. <https://doi.org/10.1111/hsc.13961>
- Goff, R., Sadowski, C., Bagley, K. (2022). Beyond survival: Strengthening community-based support for parents receiving a family service intervention. *Child and Family Social Work*. Advance online publication. <https://doi.org/10.1111/cfs.12979>
- Humphreys, L., Bigby, C., Iacono, T., Bould, E. (2022). Patterns of group home culture in organisations supporting people with intellectual disabilities: A cross-sectional study. *Journal of Intellectual and Developmental Disability*, 47(3), 252-264. <https://doi.org/10.3109/13668250.2021.1954482>
- Jamwal R., Jarman H., Roseingrave E., Douglas J., Winkler D. (2022). Smart home and communication technology for people with disability: a scoping review. *Disability and Rehabilitation Assistive Technology*, 17(6), 624-644. <https://doi.org/10.1080/17483107.2020.1818138>
- Jenkin, T., Anderson, V., D'Cruz, K., Collins, A., Muscara, F., Scheinberg, A., Knight, S. (2022). Engaging children and adolescents with acquired brain injury and their families in goal setting: The clinician perspective. *Neuropsychological Rehabilitation*, 32(2), 104-130. <https://doi.org/10.1080/09602011.2020.1801470>
- Jenkin, T., D'Cruz, K., Anderson, V., Scheinberg, A., Knight, 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>
- 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>
- Oliver, S., Douglas, J., Winkler, D., Pearce, C., Minter, E., Jarman, H., Topping, M. (2022). The healthcare needs and general practice utilization of people with acquired neurological disability and complex needs: A scoping review. *Health Expectations*. Advance online publication. <https://doi.org/10.1111/hex.13640>
- Oliver, S., Gosden-Kaye, E., Winkler, D., Douglas, J. (2022). The outcomes of individualized housing for people with disability and complex needs: a scoping review. *Disability and Rehabilitation*, 44(7) 1141-1155. <https://doi.org/10.1080/09638288.2020.1785023>
- O'Keefe, S., Radford, K., Farrin, A., Oakman, J., Alves-Stein, S., Cloud, G., Douglas, J., Stanley, M., Lannin, N. (2022). A Tailored Occupational Therapist-Led Vocational Intervention for People With Stroke: Protocol for a Pilot Randomized Controlled Trial. *JMIR Research*, 11(10). Advance Online Publication. <https://doi.org/10.2196/40548>
- Pollock, A., D'Cruz, K., Scheinberg, A., Botchway, E., Harms, L., Amor, D., Anderson, V., Bonyhady, B., Knight, S. (2022). Family-centred care for children with traumatic brain injury and/or spinal cord injury: a qualitative study of service provider perspectives during the COVID-19 pandemic. *BMJ Open*, 12(6), 1-10. <https://doi.org/10.1136/bmjopen-2021-059534>
- [Shorland, J., Douglas, J., O'Halloran, R. \(2022\). Age-Based Trends in Cognitive-Communication Management for Adults in Subacute Rehabilitation Following New Onset Traumatic Brain Injury. *American Journal of Speech-Language Pathology*. Advance online publication. https://doi.org/10.1044/2022_AJSLP-21-00357](https://doi.org/10.1044/2022_AJSLP-21-00357)
- Stagg, K., Douglas, J., Iacono, T. (2022). Living with stroke during the first year after onset: an instrumental case study exploring the processes that influence adjustment. *Disability and Rehabilitation*. Advance online publication. <https://doi.org/10.1080/09638288.2022.2131005> [JP1]
- Tilbury, C., Bigby, C., Hughes, M. (2022). The Production and Dissemination of Australian Social Work Scholarship: A Citation Analysis. *Australian Social Work*, 75(4), 407-419. <https://doi.org/10.1080/0312407X.2020.1798482>
- Topping M., Douglas, J., Winkler D. (2022). Factors that influence the quality of paid support for adults with acquired neurological disability: scoping review and thematic synthesis. *Disability and Rehabilitation*, 44(11), 2482-2499. <https://doi.org/10.1080/09638288.2020.1830190>
- Tse T., Lentin P., Douglas J., Carey L. (2022). Understanding activity participation 3-months after stroke: a mixed methodology study. *Disability and Rehabilitation*, 44(12):2868-2878. <https://doi.org/10.1080/09638288.2020.1849429>
- Wiesel, I., Smith, E., Bigby, C., Then, S-N., Douglas, J., Carney, T. (2022). The

temporalities of supported decision-making by people with cognitive disability. *Social & Cultural Geography*, 23(7), 934-952.
<https://doi.org/10.1080/14649365.2020.1829689>

A full list of LiDs-affiliated publications can be found here:
<https://www.latrobe.edu.au/lids/resources/articles-reports>

New Books

Topping, M., Douglas, J., Winkler, D. (2022). *Adapting to Remote Interviewing Methods to Investigate the Factors That Influence the Quality of Paid Disability Support*. Melbourne: SAGE Publications, Ltd.
<https://doi.org/10.4135/9781529601442>

Conference Papers and invited presentations

Anderson, S. (2022, November). **Digital inclusion? people with intellectual disability as users of social media: a review of the literature**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Bagley, K. (2022, November). **Building the capacity of educators to support students with intellectual disability in their most inclusive learning environment**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

[Bigby, C. \(2022, September\). Implementing the La Trobe Support for Decision Making Practice Framework in different settings. International Association for the Scientific Study of Intellectual and Developmental Disabilities \(IASSIDD\) Virtual Conference 2022 – September\[JP1\]](#)

Bigby, C. (2022, November). **Unsettling neoliberal imaginaries of 'mainstreaming' and 'choice and control'**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Bigby, C. (2022, November). **Evaluation of a structured decision-making framework in the Public Trustee Queensland**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Bigby, C. (2022, November). **Publishing in Research and Practice in Intellectual and Developmental Disabilities**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Clegg, J. (2022, November). **Helping distressed people with intellectual disabilities to manage their chaotic emotions**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Cubis, L., McDonald, S., Davis, E., Loy, C., Winkler, D., Douglas, J. (2022, October). **One Size Does Not Fit All: A qualitative investigation into the housing needs and preferences of people with Huntington's Disease**. 19th Conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (NR-SIG-WFNR).

Douglas, J., Leeson, R., Collins, M. (2022, October). **Outcomes of a Multi-component Community Connection program (M-ComConnect) for people with severe traumatic brain injury (TBI)**. 19th Conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (NR-SIG-WFNR).

Iacono, T. (2022, November). **Increasing quality hospital care for people with intellectual disabilities: a research translation project**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Shpigelman, C., Araten-Bergman, T. (2022, November). **"I kept telling him that we did not abandon him": the family caregivers' experiences during the first lockdown of COVID-19**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Spong, J., Iacono, T., Garcia-Melgar, A., Bagley, K., McKinsty, C., Hyett, N., Arthur-Kelly, M. (2022, November). **Supporting students with disabilities in mainstream schools: an expert panel consensus on elements of reasonable adjustments**. Annual conference of the Australasian Society for Intellectual Disability (ASID).

Topping, M., Douglas, J., Winkler, D. (2022, October). **Recommendations for allied health professionals helping disability support workers to deliver best practice from the perspective of adults with acquired neurological disability**. 19th Conference of the Neuropsychological Rehabilitation Special Interest Group of the World Federation for NeuroRehabilitation (NR-SIG-WFNR).

Reports

Hill, A. O., Amos, N., Bourne, A., Parsons, M., Bigby, C., Carman, M., & Lyons, A. (2022). *Violence, abuse, neglect and exploitation of LGBTQA+ people with disability: a secondary analysis of data from two national surveys*. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University.



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