

Welcome to the CDRP Newsletter

October 2021

Welcome to this edition of the CDRP Newsletter.

Welcome to our two new Lived Experience Postdoctoral Research Fellows: Dr Damian Mellifont and Dr Annmaree Watharow. These new career development positions are funded by the Faculty of Medicine and Health to bring the wealth of lived experience to our research programs in CDRP and beyond. We will introduce Damian and Annmaree in future newsletters as they settle in.

The last few months have seen CDRP collaborate on significant new projects which have, or will have, significant impact on disability policy and practice in Australia. For the first year the Sydney Disability team from CDRP and the Centre for Disability Studies have collaborated with National Disability Services to run the Annual Market Survey. Data collection and analysis is finished and results will be released by NDS soon. Another significant CDRP and CDS collaboration was the external validation of the NDIS Independent Assessments trial. The report on this research was an important part of the decision making by the NDIS Minister Linda Reynolds in her decision to scrap Independent Assessments. This [Croakey piece](#) provides commentary on working with the NDIS on this process.

Do you want to join the CDRP team? We are currently advertising for a Full-time manager. Please check out the job here: https://usyd.wd3.myworkdayjobs.com/USYD_EXTERNAL_CAREER_SITE/job/Camperdown-Campus/Centre-Manager--Centre-for-Disability-Research-and-Policy_0085584-2

Disability - Inclusive Community Development

Influence on Policy

- The Australian Institute for Disaster Resilience (AIDR)¹ develops, maintains and shares knowledge and learning to support disaster resilience in Australia. Associate Prof Villeneuve worked with AIDR to review and renew the [AIDR Community Engagement for Disaster Resilience Handbook](#) which now includes updated direction to the emergency management sector on disability inclusive community engagement. Case examples from our work in on disability inclusive community engagement in Australia are included in the new handbook that was launched in August 2020 (Commonwealth of Australia, 2020).
- Australia's National Disability Strategy is the mechanism to ensure that the rights, protections and meaningful participation of people with disability are incorporated into emergency management. The Department of Social Services is working across the Commonwealth, and with states, territories and the Australian Local Government Associate to develop a new National Disability Strategy that will incorporate, for the first time, disability inclusive emergency planning². Findings from our work on the Disability Inclusive and Disaster Resilient Queensland project informed the development of this new target indicator. Associate Prof Villeneuve advised Emergency Management Australia on the development of the targeted outcomes on disability inclusive emergency planning and worked with a multistakeholder committee to refine the action plan which was then sent to the Department of Social Services for carriage. The addition of disability inclusive emergency planning in the new National Disability Strategy is an important development for the progressive realisation of the rights of people with disability in emergency management that will require oversight and regular review and refinement throughout its early development, implementation, and evaluation.

¹ <https://www.aidr.org.au/about-aidr/>

² https://www.dss.gov.au/sites/default/files/documents/04_2021/australian-government-response-disability-royal-commission-public-hearing_5-covid-19-report.pdf

- The Disability Royal Commission Hearing 5 on COVID-19 Report. In collaboration with the University Centre for Rural Health and the Centre for Research Excellence in Disability and Health, A/Prof Villeneuve contributed submissions on the needs of people with disability in regard to emergency planning and response in disasters. A/Prof Villeneuve was also witness at DRC Hearing 5. In the DRC Hearing 5 [report](#), Villeneuve's recommendations (in her witness statement) concerning the role of the NDIS Quality and Safeguarding Commission were referenced in relation to Recommendations 15. In the [Australian Government response](#), Recommendation 15 was supported.
- On 27 August 2020, the Disability Advocacy Resource Unit (DARU), under the auspices of the Victorian Council of Social Service (VCOSS) and Disability Advocacy Victoria (DAV), held a forum on Disability and Disaster Resilience. The aim of the forum was to explore priority issues in emergency management for people with disability and look at why responses are failing to be consistently inclusive, despite the rights-based frameworks and policies that are in place. DARU committed to developing a paper that: (a) outlines the issues; (b) puts forward a suite of practical actions that institutions with responsibility for emergency management can undertake; and (c) can be used by disability advocates and peak organisations to advocate for change toward disability inclusion in emergency management. Supported by Ivy Yen, Senior Research Assistant, A/Prof led the issues paper which was completed on 1 August 2021. This issues paper will be used by disability advocates to lobby for change.
 - The paper includes an infographic of the 6 issues and 5 recommendations for action; an Easy Read version of the issues paper, a PDF full paper and word version
 - On 3 June, [A/Prof Villeneuve provided an overview of the Issues paper](#) at the DARU Advocacy Sector Conversations forums series
 - Citation: **Villeneuve (2021)**. Issues Paper: Clearing a path to full inclusion of people with disability in emergency management practice and policy in Australia. Centre for Disability Research and Policy, The University of Sydney, NSW, 2006.

Research & Research Education

Follow the links to learn more about our current research projects:

1. [Disability Inclusive and Disaster Resilient Queensland \(2019 – 21\)](#)

We have had a productive three years, co-producing tools that people with disability, the services that support them and emergency personnel can use to increase the inclusion of people with disability in disaster risk reduction.

We co-produced a number of open-access resources including:

- [A webinar series](#)
- [A video series](#)
- [A case study series](#)

A ministerial launch is currently being planned for 16 September 2021 in Brisbane Parliament House.

2. [Leave Nobody Behind \(2020 – 2022\)](#)

Visit the project website to learn more about the Leave Nobody Behind project from the. There you will find an infographic and webinar (Auslan Interpreted). Links to our surveys are also available at that link.

Three PhD students are contributing to this project

- **Michael Morris** is examining the joined up work between fire and emergency services and community services.
- **Louise Mitchell** is examining collaboration in bushfire recovery work in Bega following the black summer bushfires.
- **Sonny Patel's** thesis aims to build resilience to disaster in partnership with people with disability.

Jade Chang, Research Manager led the team in a poster that was accepted for presentation at **AFAC21** (Australia's largest emergency management conference). The poster profiles findings from the survey of people with disability in emergencies. It will be presented at AFAC21 in October 2021.

The research team including members of the **CDRP, the Natural Hazards Research Group and the School of Nursing** (all at The University of Sydney) are currently preparing two manuscripts from survey research on people with disability and carers in emergencies. Stay tuned for the findings.

3. [Disability Inclusive Emergency Planning in Victoria \(2020 – 21\)](#)

We are working in partnership with [VALID](#) and [Gippsland Disability Advocacy Inc](#) to develop capability in people with disability and disability advocates in Person-Centred Emergency Preparedness. This work is supported by the Victorian Department of Families, Fairness and Housing. We are working with three Gippsland Councils and emergency personnel to develop principles for inclusive municipal emergency planning. COVID-19 lockdowns in Melbourne and now Sydney have hampered our progress and so we are continuing to work together online.

4. [Emergency Planning Advice Service \(EPAS\) Program Evaluation \(2020 – 2021\)](#)

Our team is leading an evaluation of the EPAS Program in Victoria.

- **Aaina Walia**, honours student is examining the Emergency Planning Advice Service (EPAS) Program in Victoria. **Aaina is the 2021 recipient of the Douglas and Lola Douglas Scholarship in Health Sciences.** This undergraduate scholarship supports an occupational therapy honours student that has exhibited outstanding academic performance in their honours study.

New Research Projects Awarded

1. Person-Centred Capability Approach to Disaster Management with Homeless People (2021 – 2023)

This project is an extension of the current research in Queensland, led by A/Prof Villeneuve in partnership with the Queensland Government Department of Communities, Housing and Digital Economy. This new project will develop a Person-Centred Emergency Preparedness (P-CEP) Framework and Toolkit to build capacity in the homelessness/housing sector and develop a video-based interactive self-paced educational module to support emergency managers in their community engagement, risk assessment and disaster planning processes to support people with disability or people who are homeless or at risk of homelessness.

Further information can be found at this link <https://www.qra.qld.gov.au/qrrrf> and by accessing this media statement [More than \\$19 million in Disaster Resilience And Risk Reduction Funding For Queensland Communities - Ministerial Media Statements](#)

2. Person-Centred Emergency Preparedness Peer Support (2021-2022)

This is an ILC funded project led by the [Queenslanders with Disability Network](#) and A/Prof Villeneuve's research team. This project will scale the work we co-led to develop and implement the [P-CEP Peer Leadership Program in Queensland](#). The work will expand for delivery to South Australia, ACT, and NSW. Peer Leaders that co-developed the P-CEP Peer Leadership Program in 2020-21 will work in partnership with disability advocacy and Disabled People's Organisations to co-lead this work.



Listening and Learning in Ipswich. For more information visit https://collaborating4inclusion.org/wp-content/uploads/2021/08/CaseStudy_7_FINAL.pdf

News from our CDRP Honorary Affiliates

Dr Damian Mellifont

Damian is a neurodivergent researcher in CDRP, a member of the CDRP leadership team and head of the CDRP lived experience research lab.

Damian's most recent manuscript entitled, "***Ableist ivory towers: A narrative review informing about the lived experiences of neurodivergent staff in contemporary higher education***" has been accepted for publication in *Disability & Society*. Revealing positive experiences among neurodivergent staff, this study also cautions of persisting mental stigma and neuro-discrimination.

This study is helpful as it highlights that more needs to be done to advance a greater inclusion of neurodivergent staff in higher education. University leaders who genuinely value diversity and inclusion should be interested in this review and its suggestions for future research directions.

Dr Genevieve Johnsson

Authors: Dr Genevieve Johnsson, Autism Spectrum Australia, Centre for Disability Research and Policy & Dr Kim Bulkeley, Centre for Disability Research and Policy

Access to behaviour support services for individuals with a disability, particularly in rural and remote regions of Australia is significantly impacted by workforce shortages. Telepractice is emerging as a potential solution to expand access to a larger pool of qualified behaviour support practitioners, providing timely, quality, low-cost behaviour support services for people in rural and remote areas.

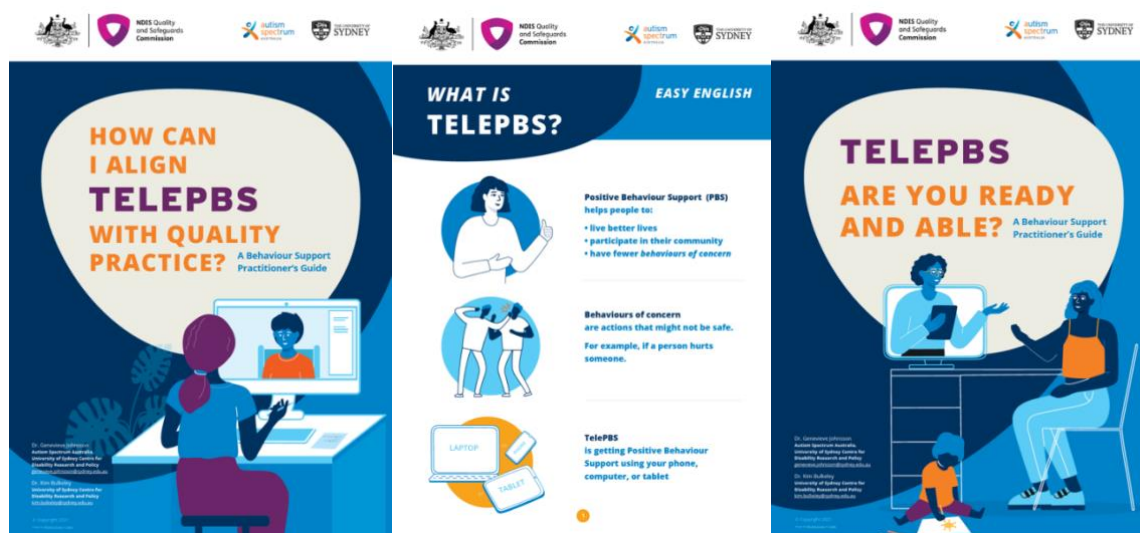
The emergence of COVID 19 also established the need for alternative service design solutions in the delivery of behaviour support where individuals were effectively isolated due to public health measures that reduced in person services, an unprecedented circumstance for people with disability and service providers.

In 2021, the NDIS Quality and Safeguards Commission funded Aspect to develop a range of resource materials to support Behaviour Support Practitioners to conduct TelePBS in a safe, competent and effective manner that also meets the NDIS Quality and Safeguards Commission's PBS Capability Framework and practice standards. Aspect collaborated with the Centre for Disability Research and Policy at the University of Sydney to develop these resources in three phases 1) literature and policy review, 2) stakeholder consultation, and 3) development of resources.

Resources for participants include TelePBS – Is it right for me (and my child)? and What is TelePBS? An easy read participant guide. Resources for practitioners include TelePBS – Are you ready and able? and How can I align TelePBS with quality practice?

These participants and practitioners' guides, along with findings from the Phase 1 literature and policy review and Phase 2 stakeholder consultation, as well as a range of videos and podcasts are available as a full suite of resources on the NDIS Quality and Safeguards Commission website at <https://www.ndiscommission.gov.au/resources/telepbs>

For more information contact Dr Genevieve Johnsson genevieve.johnsson@sydney.edu.au or Dr Kim Bulkeley kim.bulkeley@sydney.edu.au



Dr Susan Collings

Susan received a grant from NSW Department of Communities and Justice "to develop a fairer assessment model for parents with a cognitive disability involved in care proceedings before the Children's Court"

Further information can be found via the media release:

<https://www.dcj.nsw.gov.au/news-and-media/media-releases/innovative-solutions-for-fairer-justice>

Disability and Inequity

Commissioned research

- Llewellyn, G., Fortune., Baillie, J., Gordon, J., & Madden, R. *Capturing patient disability information in a Voluntary Patient Enrolment Scheme*, Australian Department of Health, 2021.

Publications

- Su, H., Llewellyn, G., Yi, Y., Cao, Y., & Liu, J. (2021). The feasibility of family-centred early intervention for children with disabilities in mainland China: Practitioners' perceptions. *Child: Care, Health and Development*, published on line 15th July, <https://doi.org/10.1111/cch.12898>

- Kavanagh, A., Hatton, C., Stancliffe, R. J., Aitken, Z., King, T., Hastings, R., Totsika, V., Llewellyn, G., & Emerson, E. (2021). Health and healthcare for people with disabilities in the UK during the COVID-19 pandemic, *Disability and Health Journal*, published online 17th July 2021, DOI: [10.1016/j.dhjo.2021.101171](https://doi.org/10.1016/j.dhjo.2021.101171)
- Emerson, E., & Llewellyn, G. (2021). The circumstances of children with and without disabilities or significant cognitive delay living in ordinary households in 30 middle- and low-income countries, *Disabilities*, 1(3), 174-186. <https://doi.org/10.3390/disabilities1030014>
- Emerson, E., Aitken, Z., King, T., Arciuli, J., Llewellyn, G., Kavanagh, A.M. (2021). The association between disability and risk of exposure to peer cyber victimisation is moderated by gender: Cross-sectional survey, *Disability and Health Journal*, published online 7th July 2021, <https://doi.org/10.1016/j.dhjo.2021.101170>

For more information about the CDRP or to get involved please check out our website:

<https://sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html>

Or follow us on Twitter: <https://twitter.com/USydCDRP>