

Welcome to the CDRP Newsletter

August 2022

Director's welcome

We are very pleased to announce the appointment of Associate Professor Michelle Villeneuve as Deputy Director of the Centre for Disability Research and Policy. Michelle has been a long standing member of CDRP and is well known for her national and international work on disability-inclusive disaster risk reduction. You can read more about her current research later in this newsletter. Michelle's appointment is part of the development of the centre's management structure and strategic plan, made possible by our recognition as a Faculty of Medicine and Health Impact Centre.

This month we also welcomed a new lived experience research assistant to our team – Jemma Chao. Jemma has been seconded to us from the Poche Centre. Jemma Chao is a Wiradjuri woman from Western New South Wales who also has family heritage from Europe. Jemma is an experienced Strategic Planner, Event Manager, and Academic Research Assistant. Jemma is highly skilled in collaborating with Aboriginal communities in health, disability, and community events initiatives. Jemma will be working 2 days per week on developing capacity for lived experience research at the University of Sydney. This work has been funded by the University of Sydney Disability Inclusion Action Plan through the culture strategy. She will also work 2 days per week to assist Associate Professor John Gilroy on the work of his SOAR Fellowship.

Jemma's appointment contributes to the broader work of CDRP in developing University-wide researcher capacity in working with lived experience researchers. Understanding of the value of lived experience research is the first step in developing capacity, but what we have found is that while many researchers then get to the step of understanding why we need lived experience researchers, and include them in research, there is less thought about the need to support lived experience researchers through employment and further career development. It is essential that we also fight for recognition of lived experience in career opportunities and development.



Jemma Chao



A/P Michelle Villeneuve

Professor Jen Smith-Merry

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A message from CDRP Centre Manager

We value community engagement in our research and we are developing new ways to engage more meaningfully with our CDRP community. A few weeks ago, we reached out to ask how you were envisaging the research we do as a centre, in the form of a survey sent to the whole CDRP community. This was also an opportunity for us to get to know you better and consider how we could communicate and engage more efficiently with you.

I would like to shout out a big thank you to the 170 members of our community who answered the survey in the two weeks it was open. Your input has been extremely valuable to us and will be incorporated into CDRP's new strategic plan, which will be finalised by the beginning of 2023. Among the many suggestions we received, there was a convergence of interest for CDRP research to focus more on :

- Support for children with disability and their families; disability support in the school
- Neurodiversity and translation of neurodiverse literature into policy
- Quality of disability services and NDIS
- Culturally and Linguistic diverse communities

We are grateful that our community recognised how highly CDRP values Lived Experience, and we will be working towards improving standards of co-designed research in the field, as well as promoting lived experience-led research in disability.

Results from the survey have contributed to the research teams' discussion on CDRP 2022-23 Strategy Day, held in July. Our researchers discussed how to best structure research at CDRP to highlight areas of impact and areas of expertise and increase internal and external visibility; which research programs should we support and prioritise and which new programs we would like to develop and how. In the few pictures below, you can see our researchers hard at work, intensely brainstorming.



With our centre growing, a need for a new governance structure has arisen, and the appointment of a leadership group was decided. Presentation of the new CDRP leadership group in the next edition of the newsletter.

Finally, a majority of the participants to our survey expressed their enthusiasm to participate in an annual event bringing the whole CDRP community together. We are looking at organising this for early next year and will make sure we send an invitation to everyone.

CDRP supports the Re-Imagine Statement “Every Child Every Possibility”

CDRP co-signed the Re-Imagine Statement “Every Child- Every Possibility” which recognises the importance of supporting young children and their families, and campaign to prioritise a national reform program that will enable families to have access to services and supports for their child through a well-resourced, easy to navigate, inclusive and culturally responsive service system.

Reimagine Australia is calling upon families, professionals, organisations and political representatives to universally support a program of investment in national service system reform, in order to establish one easy to navigate system that best enables young children to reach their full potential. A system that maximises the opportunity of their early childhood years, and that is harmonised at Federal, State and Territory levels.

You can download full statement here:

<https://reimagine.org.au/wp-content/uploads/2022/03/TheReimagineStatement.pdf>

For more information on how to support the Re-Imagine statement:

<https://reimagine.org.au/every-child-every-possibility/>



Consultation on the Draft National Guideline for supporting autistic children and their families

The Autism CRC has released last month the draft version of Australia’s first National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families.

<https://www.autismcrc.com.au/supporting-children>



National Guideline for supporting autistic children and their families

The draft version of this new guideline for supporting autistic children and their families was made available for public consultation, and invited individuals and organisations to share their feedback on the guideline before the 29th of August.

CDRP has put together a team of disability-inclusive policy development researchers to prepare a feedback submission. The team included:

- Dr Rebecca Sutherland, Lecturer and Speech Pathologist, Researcher, Centre for Disability Research and Policy, University of Sydney <https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/rebecca-sutherland.html>

- Dr Damian Mellifont, Lived Experience Research Fellow, Centre for Disability Research and Policy, University of Sydney <https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/damian-mellifont.html>
- Dr Genevieve Johnson, Honorary research associate, Centre for Disability Research and Policy, University of Sydney - Practice Leader (Innovation) at Autism Spectrum Australia <https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/genevieve-johnsson.html>
- Dr Kim Bulkeley, Lecturer, Leader of the Disability Workforce Research Stream, Centre for Disability Research and Policy, University of Sydney <https://www.sydney.edu.au/medicine-health/about/our-people/academic-staff/kim-bulkeley.html>

In an effort to capture the voice of our wider community and provide informed feedback on the guideline, the team held a workshop, designed to offer our community members with lived experience of neurodiversity, or with an interest in supporting the neurodiverse community, the opportunity to participate their feedback to CDRP's submission.

Thank you to all who attended the workshop and contributed their deeply insightful comments on the guideline. The team has incorporated into their submission the essence of the discussions that took place during the workshop (within the strict word limit imposed by the feedback form).

In line with CDRP's values, a specific emphasis was included on the value of lived experience to inform practice, as well as the need to consider all culturally and linguistically diverse communities when making recommendations. CDRP submission also highlighted the importance to develop a treatment approach for each child in partnership with the child and their families.

Disability-Inclusive Community Development

Homelessness - Inclusive Disaster Risk Reduction

How can people experiencing homelessness stay safe in disaster?

That's the question being addressed through the Homelessness-Inclusive Disaster Risk Reduction Project in Queensland. The project builds on the success of our disability-inclusive disaster risk reduction work in Queensland communities over the last few years. This time we are focusing on people experiencing homelessness, in recognition of the high rates of disability among that population and their increased disaster risk. We are investigating how to adapt the Person-Centred Emergency Preparedness framework and toolkit to assist people who are homeless to plan for their safety and support, and how service providers and emergency managers can work together to provide inclusive emergency responses.

The team is surveying, consulting, and working closely with people with lived experience of homelessness and disability, housing and homelessness service providers, and emergency managers working in councils, state government and emergency services across the state. 165 people from among these stakeholder groups attended a webinar hosted by the project team on 2 August to learn about the project and its early research findings, and how they can be involved. The webinar recording can be viewed at <https://collaborating4inclusion.org/homelessness-and-disaster/> Stakeholders are now invited to participate in one of the nine Knowledge to Action Workshops which will be held in communities along the Queensland coast, as well as a virtual workshop for people in more remote locations.

This project is funded by Queensland Government and conducted in partnership with Queenslanders with Disability Network and Community Services Industry Alliance.

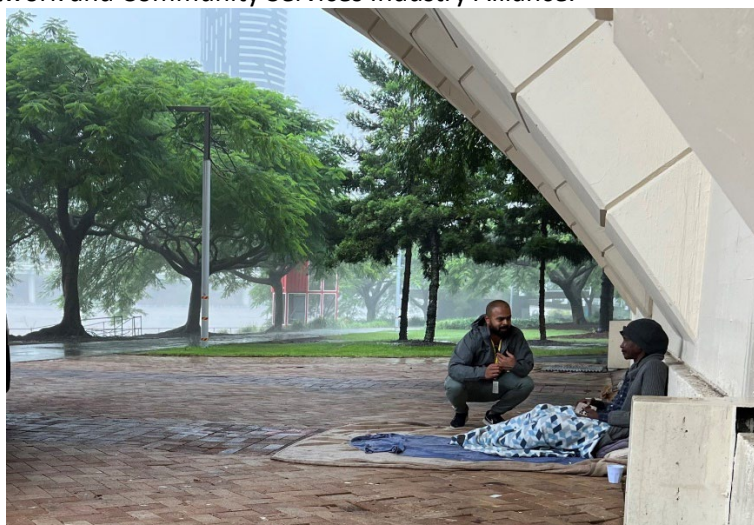


Image caption: The homelessness outreach worker (left) was able to transport this man (right) to a safe location just hours before this Brisbane Park was flooded in February 2022 (Photo credit: Micah Projects)

Michelle was interviewed by the Canberra Disability Review winter edition, more details can be found

» [Canberra Disability Review \(advocacyforinclusion.org\)](https://advocacyforinclusion.org/)

For more information visit: <https://collaborating4inclusion.org/didrr-australia/>

Disability Workforce

Dr Kim Bulkeley (workforce stream leader) recently presented a paper with Dr Genevieve Johnsson at the National Rural Health conference in Brisbane, on Disability Therapy (Allied Health) Assistants in partnership with ASPECT. The full report on this project is available here

<https://www.autismspectrum.org.au/uploads/documents/Therapy/Therapy-Assistant-Evaluation-Report.pdf>

The Community Services Industry Alliance and Allied Health Assistants Network Australia invited me



In this Forum, presentations will be given by keynote speakers:

Dr Kim Bulkeley, Senior Lecturer for the Faculty of Health and Medicine at University of Sydney and Workforce Stream Leader for the Centre for Disability Research and Policy

Chantelle Robards Allied Health subject matter specialist for Boosting the Local Care Workforce

Event details

ONLINE

Date: Wednesday 17 August 2022

Time: 10:00am to 12:00pm (Brisbane - AEST)

Tickets: FREE - Register via Eventbrite

to address a national online forum about allied health assistants in the NDIS context. We had a lively discussion with an engaged group of participants where we were able to translate the research from the ASPECT Therapy Assistant project about the framing of therapy assistants in the disability space.

The therapy assistant workforce is a priority in the NDIS Workforce Plan and there is a need to grow the conversation about how this role can be developed in a considered and helpful way in the disability sector. Kim

has been suggesting the need to reconceptualise the role in a more collaborative, person-centred

way, by positioning the therapy assistant as a central part of the team rather than a direct alignment with the therapist primarily. She proposes linking in with the ICF framework to reinforce the focus on participation and function as the key principle driving the design of therapy assistant models of service delivery.

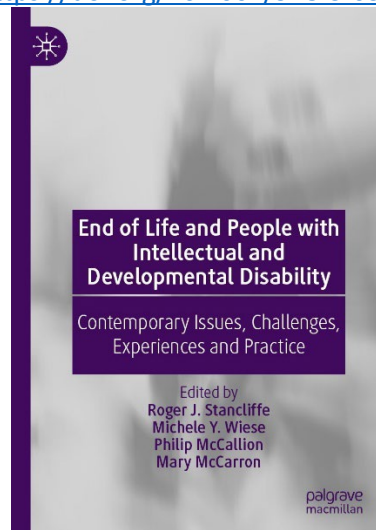
Dr Kim Bulkeley is a chief investigator on the **Tapping Into Tech project**, <https://onlineacademiccommunity.uvic.ca/tappingintotech/> funded by the Vancouver Foundation, which is a collaboration led by Dr Alison Gerlach from Victoria University on Vancouver Island. The project takes a Participatory Action Research approach. Survey data collection from parents and service providers in the early childhood sector in rural and northern communities of British Columbia is nearing completion. A scoping review has been submitted, outlining the current evidence base for technology enabled services to children and families with developmental concerns. The next phase of the project involves community visits to discuss the survey and scoping review findings to three target communities on Vancouver Island and in the northern region of British Columbia.

News from our CDRP Honorary Affiliates

Emeritus Professor Roger Stancliffe

Professor Emeritus Roger Stancliffe is a researcher in the intellectual and developmental disability field with a special interest in community living. Roger's recent co-edited book was published in June 2022.

Stancliffe, R. J., Wiese, M. Y., McCallion, P., & McCarron, M. (Eds.) (2022). *End of life and people with intellectual and developmental disability: Contemporary issues, challenges, experiences and practice*. Palgrave MacMillan. <https://doi.org/10.1007/978-3-030-98697-1>



This book brings together two challenging topics, end of life and intellectual and developmental disability. It guides the reader about how to respectfully and sensitively involve people with intellectual and developmental disability and their caregivers (family and staff) in all aspects of mortality, dying and death. There is a particular focus on challenging and new topics, including suicide, do not resuscitate orders, children, people with profound and multiple disabilities, death doulas, accessible funerals and the COVID-19 pandemic.

The book identifies barriers and care challenges and offers practical responses. Chapters include real-world personal stories to ground the issues in lived experience and realistic scenarios with reflection questions to support translation into practice. Lists of resources, many designed

specifically for people with intellectual and developmental disability, are provided to support practical implementation.

In July, Roger was interviewed about his end-of-life research on Minnesota Public Radio (USA). <https://www.mprnews.org/episode/2022/07/21/roger-standcliffe-on-end-of-life-research-for-people-with-disabilities>

Roger Standcliffe, recent publications.

1. Fortune, N., Curryer, B., Badland, H., Smith-Merry, J., Devine, A., **Standcliffe, R. J.**, Emerson, E., & Llewellyn, G. (2022). Do area-level environmental factors influence employment for people with disability? A scoping review. *International Journal of Environmental Research and Public Health*, 19(15), 9082. <https://doi.org/10.3390/ijerph19159082>
2. Emerson, E., Aitken, Z., Totsika, V., King, T., **Standcliffe, R. J.**, Hatton, C., Llewellyn, G., Hastings, R. P., & Kavanagh, A. (2022). The impact of the COVID pandemic on working age adults with disability: Meta-analysis of evidence from four national surveys. Advance online publication. *Health & Social Care in the Community*. <http://doi.org/10.1111/hsc.13882> Published open access.
3. Cameron, L. A., Tonge, B. J., Howlin, P., Einfeld, S. L., **Standcliffe, R. J.**, & Gray, K. M. (2022). Social and community inclusion outcomes for adults with autism with and without intellectual disability in Australia. *Journal of Intellectual Disability Research*, 66, 655-666. <http://doi.org/10.1111/jir.12953> Published open access.

Dr Genevieve Johnsson

Genevieve is an Honorary Senior Research Fellow with CDRP and partners with several organisations in her work.

She has been working with an incredible group of individuals, caregivers and professionals to co-design a Community Inclusion survey with Plumtree Children's Services. The family survey is now live! https://lnkd.in/dBnDi6_3

The survey is for families who have a child with disability aged 0-14 years who want to have theirs and their child's voices heard on their experience of community participation and inclusion.

This survey is part of Plumtree's Peer-led, Co-designed Community Inclusion project funded by the Department of Social Services. The Centre for Disability Research and Policy at the [University of Sydney](https://lnkd.in/d-qT4MfB) is conducting the research. You can read about the research here. <https://lnkd.in/d-qT4MfB>



Image is of a boy sitting on the ground with his mum and dad. They are all looking at a survey on an iPad together.

https://www.linkedin.com/posts/genjohnsson_inclusion-community-activity-6949864209820061696-a1F6?utm_source=linkedin_share&utm_medium=member_desktop_web
The website is here <https://plumtree.org.au/for-families-by-families/community-and-me/>

Dr Damian Mellifont

Damian is a member of the Centre for Disability Research and Policy (CDRP) leadership team and lead of the lived experience-led research work stream.

Damian's most recent manuscript entitled, "A critical analysis of the neurodiversity paradigm involving individual expressions" has been accepted for publication in the Journal of Humanity and Social Justice (JHSJ). This paper offers evidence indicating that the neurodiversity paradigm is indeed facing an ethical crisis. This crisis is proposed to originate from an ideological preference as predominantly held by neurodiversity paradigm proponents. These persons tend to embrace the social model that sees disability as originating from unequal social structures, while typically rejecting a medical model that recognises disorder. This paper reveals the prospect of a shift towards an inclusive neurodiversity paradigm, whose qualified acceptance of medical and social models, in turn supports greater individual expressions.

Dr Jodie Baille

Vulnerable populations more severely affected by flood events

Inclusion of people with disability and carers in both flood preparedness and recovery efforts is urgently needed in Australia, say University of Sydney researchers. People with disability and their carers experienced profound impact and systemic neglect during and after the 2017 Northern Rivers floods, with many still unable to access stable housing, and at relatively high risk of post-traumatic stress disorder (PTSD) six months later, finds a University of Sydney study.

Published in BMJ Open, researchers surveyed and documented the experiences of over 250 people either with disability or carers affected by the 2017 Northern Rivers flood event. The study is one of the few Australian studies reporting on how people living with disability and carers are affected by disasters. The findings could help inform recovery efforts for the 2022 Eastern Australia floods.

Analysis found the flood event compounded existing physical and mental health issues and people with disability and carers were more severely affected by the flood event. People with disability and their carers were twice as likely to have their homes flooded, as housing in flood prone areas is generally more affordable. They were also four times more likely to be displaced, with a lack of access to safe long or short-term housing for more than six months. Six months after the flood, many people with disability or carers were either highly distressed or twice or three times the odds of probable PTSD.

"The severity and frequency of floods are likely to increase – attention to the public health consequences of extreme weather events is urgently needed, especially for people with disability and carers," said lead author Dr Jodie Baille from the University of Sydney Centre for Rural Health, Faculty of Medicine and Health.

The study identified multiple accessibility and public health issues which still persist - preventing vulnerable people from receiving the support they need.

“Carers play a vital role in providing support for people with disability and yet their experiences during disasters and its impact have received very limited attention.”

The Disability Royal Commission has heard concerns that people with disability are being overlooked or left behind in emergencies and are at much greater risk of neglect during emergencies. Submissions called for the need for people with disability to be included across all levels of emergency planning and response. The Commission is ongoing.

The researchers say there is a risk of history repeating itself among flood affected communities from the 2022 Eastern Australia floods.

“Floods expose and exacerbate existing social inequalities for people with disability and carers. We must ensure people with disability are included at all stages, including preparedness, response and recovery,” said Dr Bailie.

Widespread barriers to accessing support

The study also revealed people with disability and carers often felt they were left to fend for themselves during and after the flood event. This included access to financial disaster relief, healthcare or social services. Long-term isolation and disruption to usual support networks also contributed to long-term mental health impacts and distress.

One of the greatest challenges was how evacuation information was issued, often failing to take into account the needs of people with disability.

One participant said deaf people were given oral directions that were not accompanied by sign language, and some reported not being able to hear warning sirens. These communication barriers affected how quickly people responded to the need to evacuate.

A lack of affordable accommodation for displaced people with disability and carers, which resulted in them living in unsafe accommodation which often had mould or structural damage.

“Nobody should be left behind during emergencies and disasters,” said co-author Associate Professor Michelle Villeneuve.

“This study shows more than ever, people with disability and carers need to be equal partners when designing impactful policy and resources that truly benefit them. Only then can real development and change occur.”

Associate Professor Villeneuve leads ‘Collaborating 4 Inclusion’, a research team dedicated to disability inclusive disaster risk reduction in Australia. The research brings emergency personnel together with people with disability, carers and support services to design inclusive tools that are helping to shape emergency responses.

The team also monitors the update of these tools in practice and measures the impact on the health and wellbeing of people with disability and carers during disasters.

Carers NSW CEO, Elena Katrakis, supports Professor Villeneuve’s advocacy for more inclusive disaster responses: “The recent severe flooding in northern NSW has again highlighted the particular challenges experienced by people with disability and their carers,”

‘This research provides important evidence of the need for additional and ongoing support for people with disability and their carers affected by severe weather events. Carers NSW is pleased to be a part of this critical work.’

Jodie Bailie, recent publications.

1. Fortune, N., **Bailie, J.** and Llewellyn, G. (2022), The need for improved Australian data on social determinants of health inequities. *Med J Aust.* <https://doi.org/10.5694/mja2.51698>

Spotlight on CDRP HDR students

Rene Fraser, PhD Student



Tell us a bit about you? I am an Occupational Therapist working with Child First Therapy, Caswell Health Care. I work with children with disability and their families. I have been working in the disability sector for 19 years.

What led you to do a research degree? I developed an interest in supporting children who have restricted eating that interferes with family mealtimes and routines and found that there was limited research to guide my practice. So I signed up to do a masters by research with the University of Sydney in 2020. Dr Kim Bulkeley and Dr Rebecca Barton are my supervisors and my topic is *Parent interventions for children with disabilities who are restricted eaters*.

How is your research progressing? I am really enjoying the research experience and find that it compliments my clinical work. Completing research has enabled me to learn about my topic in detail complimenting my clinical skills. I have also learnt a range of new skills completing research which I'm enjoying.

I have completed a scoping review on restricted eating interventions that is close to being ready for submission for publication and really helped me to be clear on what evidence is out there and the current approaches that are being used. I am taking a qualitative approach to answering my research questions to understand in a rich and deep way the experiences of children and families who experience the impact of restricted eating as well as hearing from professionals about their practice. I have completed 5 interviews with parents and 11 interviews with professionals and will analyse this data thematically in the coming months. I recently successfully applied to upgrade my degree to a PhD and will now add in an additional component to the research, including a study with children who experience restricted eating and translating the findings into resources that can be used by families and practitioners.

Do you have any advice for someone considering signing up for a research degree? If you are keen, take the leap! If you are passionate about your topic you won't regret it. Completing my research has provided me with so many opportunities that I didn't even think of before. There is a lot of flexibility however organisation is key and taking the time at the beginning to set up your systems will help you.

