

Centre for Disability Research and Policy

Welcome to our May 2023 Newsletter

DIRECTOR'S WELCOME

In this edition, we highlight the collective and personal successes experienced by our CDRP members, including graduations (see Dr Stephanie Mantilla below), major new fellowships, grants and awards. CDRP has also had success in impacting policy and practice change, including the [recently announced](#) change to the funding of vocational education and training in NSW which will acknowledge and fund intersectional disadvantage for the first time. We are also hosting this week the [National Forum on Disability Inclusive Disaster Risk Reduction](#) which brings together senior government and NGO sector leaders around this significant ongoing work led by A/Prof Michelle Villeneuve.

Jen Smith-Merry



Image: Newest CDRP PhD Graduate, Dr Stephanie Mantilla, with her supervisors Prof. Jen Smith-Merry and Prof. Gerard Goggin. The three of them are in their graduation robes and hat and picture in front of a sandstones building of the University.

GRANTS AND AWARDS RECEIVED BY THE CDRP TEAM

Congratulations to the following individuals and teams for receiving these grants!

[Professor Jennifer Smith-Merry](#), director of CDRP, was awarded a prestigious [Industry Laureate Fellowship from the Australian Research Council](#). Securing more than \$2.5 million this project will, in partnership with the National Disability Insurance Agency, NDIA — address deficits in the National Disability Insurance Scheme for people with psychosocial disability, to make the scheme more effective and efficient for this group, with community benefits for all Australians.

The research will map the experience of clients within the NDIS as it currently operates and use new data to model improvements to the Scheme. To ensure the improvements will enable the NDIS to deliver better outcomes, they will be tested from client, economic and policy perspectives and take into account how the NDIS interacts with state and territory health and social care systems. Project deliverables will be directly transferable into NDIS

design through the partner, the National Disability Insurance Agency, and into federal and state policy. By making the NDIS more effective and efficient, this project will directly benefit participants in the scheme and at the same time deliver strong social and community benefits to all Australians.

Dr Sanet Du Toit is a Chief investigator with a successful team awarded \$1.5M from the **MRFF Dementia Ageing and Aged Care Mission for the project 'BEFRIENDING with GENIE'**: An intervention to reduce loneliness and increase social support and service access for Culturally and Linguistically Diverse (CaLD) people living with dementia and their caregivers'.



Image: MRFF Befriending with GENIE Project Management Group photo - left to right front row: Dr Manonita Ghosh, Professor Loretta Baldassar, Dr Sanetta du Toit, Professor Colleen Doyle, Dr Anita Goh. Left to right back row: Dr Catriona Stevens, Ms Bronte Jones, Ms Cristina Thompson, Dr Simone Marino

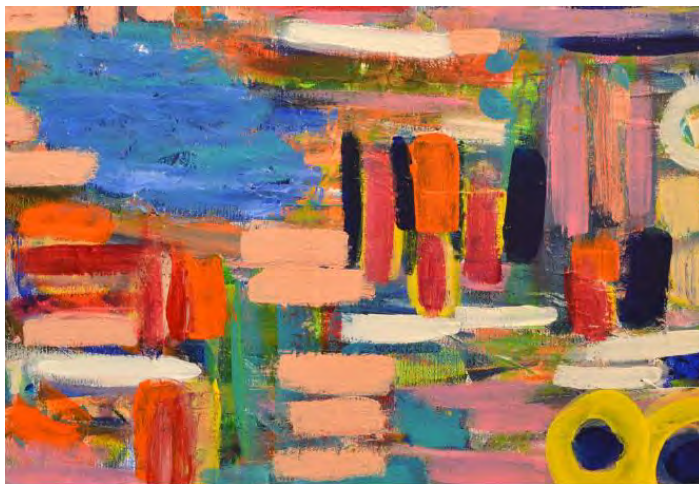
Strong social networks and connections are essential to support older people to maintain their health and quality of life as they age, live

independently for longer and access services when they need to. However, people with dementia and their caregivers from Culturally and Linguistically Diverse (CaLD) communities have unequal knowledge about, access to, and uptake of meaningful engagement that support their social connections. As a result, they are at increased risk of significant social isolation and increased risk of morbidity and mortality. Funded by the Medical Research Future Fund (\$1,480,064.60) – Dementia, Ageing and Aged Care Mission, Sanetta du Toit is a Chief Investigator on the BEFRIENDING with GENIE project that addresses improved outcomes for older people in the community who are living with dementia and their caregivers, from four language groups: Italian, Chinese, Vietnamese and South Asian. This project combines two evidence-based interventions, 'BEFRIENDING' which consists of informal conversations with a trained facilitator, and 'GENIE', which is an online database of support services and activities tailored to participants' interests and needs and a network mapping tool to measures their social supports over time. The project aims to improve the lives of the participants through a decrease in loneliness and increase in social and occupational engagement. Collaborators on this project are from Edith Cohan University, the National Ageing Research Institute, University of Tasmania, Swinburne University of Technology, University of Wollongong, University of Melbourne, Curtin, UWA, University of Southampton UK, City University of Hong Kong and Association for Culturally Appropriate Services.

Dr Sophie Lewis was awarded a Sydney Research Accelerator (SOAR prize). This prize will support her research on the experience of loneliness for people living with long-term conditions. Dr Sophie Lewis is a Senior Lecturer in Participation Sciences at the Sydney School of Health Sciences and member of the Sydney Centre for Healthy Societies. She is qualitative researcher and health sociologist and her research focuses on the experiences of people living with long-term conditions.

[A/Prof Nicola Hancock](#) (CIA), [A/Prof Justin Scanlan](#), [Dr Anne Honey](#) and collaborators were awarded \$557K from the MRFF Consumer-Led Research Scheme for the project '**DRIV-R: A co-designed personalised App to navigate and accelerate my mental health recovery**'. Associate Professor Nicola Hancock and team will use the findings from preliminary research and employ a rigorous co-design process, to develop and test the usefulness and impact of the DRIVing my own mental health Recovery (Driv-R) App. Driv-R will transform a widely used and well-tested self-assessment (RAS-DS: Recovery Assessment Scale – Domains and Stages), from an outcome measure into a self-directed process to support mental health consumers to navigate and drive their own recovery assessment, goal setting and action planning. Read more about this in the 'News from the Mental Health Stream' section.

Highly Commended – Accessibility in Action Awards



Ensuring Occupations are Responsive to People with Disability

Change is always difficult, but there is a pathway. Through this project, we have identified what is needed to help sectors and occupations realise a responsive approach towards people with disability.

Plain English, Easy Read and Auslan Translation are available at www.acola.org

Funded by the Australian Government Department of Social Services. Go to www.dss.gov.au for more information.



Creating an inclusive community together



outcomes will help create a more inclusive and equitable society that recognises and values the contributions of people with disability.

For more information visit [ACOLA Report: Ensuring Occupations are Responsive to People with Disability](#)

[Professor Gerard Goggin](#) & [Dr Damian Mellifont](#), as part of the '*Ensuring Occupations are Responsive to People with Disability, The Australian Council of Learned Academics (ACOLA)*' Project. The project aimed to address the exclusion, discrimination, and marginalisation that many people with disability face when accessing services. The project focused on the role of various stakeholders, from educators and training providers to professional bodies and governments, in developing inclusive and responsive courses to create a more equitable society. By implementing all aspects of the project's *Action Plan*, people with disability in education settings, as well as employers, service providers, and the wider community, stand to benefit significantly. The project's

INTRODUCING NEW CDRP MEMBERS

Jodie bailie



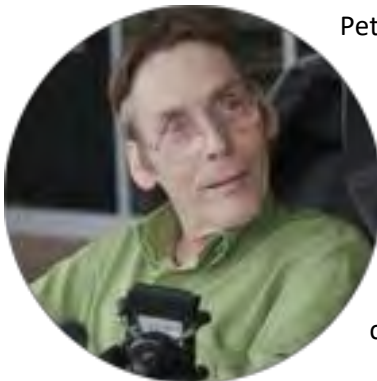
I am a Senior Research Fellow at the University Centre for Rural Health (UCRH) in Lismore, NSW. My research and evaluation efforts are focused on improving the way our healthcare system delivers care to priority populations. At the heart of my research is a strong health equity agenda, which originally aimed to enhance the quality of care provided to Aboriginal and Torres Strait Islander communities. More recently, my focus has shifted towards improving the care for people with disabilities. Starting in January 2023, I took on a part-time role with the CDRP to work on a NHMRC-funded Synergy grant with Professor Gwynnyth Llewellyn and colleagues. In partnership with young people with disability, our goal is to develop interventions that promote better lifetime mental health outcomes for young Australians aged 15 to 24 years who have disabilities. My profile contains a list of publications: [Dr Jodie Bailie \(sydney.edu.au\)](https://www.scribd.com/profile/Dr-Jodie-Bailie)

Jodie will be presenting at the next CDS/CDRP Seminar held on the 8th of June, 2023.

<https://www.eventbrite.com.au/e/643471349127>

Peter Tully

Queenslanders with Disability Network, CDRP Lived-Experience research officer.



Peter is a new member of the Disability Inclusive Disaster Risk Reduction (DiDRR) research team. From an IT business in an inner suburb of Brisbane to campaigning with Every Australian Counts, Peter maintains his dream to see people with disability flourish. Peter, with his wife Linda, joined Queenslanders with a Disability Network (QDN) which led to Peter's work in community advocacy. Together, Linda and Peter shine a focus on people with disability within their community.

Peter plays a prominent role in the development of disability awareness, advocating at every point of community connections and at all levels of government. In working with people either one-on-one or in workshop format, Peter likes to create a 'safe zone', that is, an environment where people are free to speak and so begin their journey to a more inclusive lifestyle. In his work towards building inclusive communities, Peter represents on the QDN Board, QDeNgage, numerous committees, government and industry roundtables and enquiries. Peter is a member of the Queensland Disability Advisory Council (QDAC) and the NDIS Industry Advisory Council (IAC).

CDRP's contributions to national Consultations

Disability Services Act 1986 Review



The Disability Services Act 1986 is currently being reviewed by the Department of Social Services, recognising the need to update this Act in the context of current Australian policy settings as well as our obligations as a signatory to the United Nations Convention on the Rights of Disabled Persons. This act was developed at a time when deinstitutionalisation was a key driver of disability services and

supports and is no longer fit for purpose alongside the major sector reforms brought about by the shift to a quasi-market model under the National Disability Insurance scheme. The review of this act has the potential to **explore service and support standards for the millions of Australians who experience disability**, not just the 500,000 NDIS participants.

The Centre for Disability Research and Policy developed a submission to the Disability Services Act 1986 Review: [a-new-act-to-replace-the-disability-services-act-1986](#) . We conducted two online consultations led by Dr Kim Bulkeley, Dr Genevieve Johnson and Mr Gordon Duff, which were attended by 30 participants. An online survey was also designed and distributed to members of our community to participate their thoughts and insights.

We would like to thank all the members of our community who participated in this consultation which helped shape the recommendations we submitted to DSS.

In this submission, further to answering questions presented in the consultation paper, CDRP made two major recommendations:

- Possibilities for the new Act to support **an increased representation of disability services staff with lived experience of disability needs** to be examined. Lived experience expertise in shaping and providing disability services is increasingly respected in many countries.¹ However, with 24 percent of Australian disability services having reported that they employ no people with disability, strong policy measures (i.e., quotas and legislative reform) are needed to address this pressing policy issue.²
- Any plans for **the new Act must be led by or co-produced with people with lived experience of disability**. To what extent will policymakers with lived experience of disability be included in the development of the new Act? **'Nothing about us without us'** applies to policymaking.

¹ Davies, K., & Butler, K. (2022). (Under) valuing lived experience in the disability workforce: A snapshot of Australian job recruitment. *Australian Journal of Social Issues*.

² Mellifont, D., Smith-Merry, J., & Bulkeley, K. (2023). The employment of people with lived experience of disability in Australian disability services. *Social Policy & Administration*.

National Disability Insurance Scheme

Breaking down Barriers: Co-designed recommendations to reduce stakeholder-identified NDIS access barriers for people with psychosocial disability



The project aims were to work with stakeholders to:

1. Understand the barriers to applying to the NDIS for people living with psychosocial disability, and
2. Identify solutions to remove or reduce these barriers and to synthesise these into a practical set of stakeholder-informed recommendations.

The project was conducted over three phases:

1. A scoping review of literature to identify previously reported barriers to applying to the NDIS
2. A national survey to identify current, stakeholder informed and prioritised barriers.
3. Co-design of practical, lived experience-informed recommendations to address NDIS access barriers with stakeholders.

Almost 400 stakeholders partnered with us to identify current barriers to applying for NDIS support.

They then engaged with us to develop seven key, lived experience informed, recommendations to address those barriers. These seven practical action-oriented recommendations need urgent implementation to enable the people living with psychosocial disability who are most

disadvantaged and most in need of NDIS support to be able to apply for that support. The feasibility and value of each of these recommendations is evidenced by them being raised across numerous previous national NDIS-focused reports including for example, the Tune Review and the 'Mind the Gap' report. Today, stakeholders are asking for more than policymakers' awareness of the barriers that deny much needed NDIS access – although these too are re-iterated and further detailed within this report. Stakeholders call for immediate investment in these practical actions to 'break down barriers' to accessing NDIS support and by doing so, improve the lives of many Australians living with psychosocial disability.

Submission to the NDIS Review – Richard Madden

This submission considers in more detail the impact on the NDIS of participants over the age of 65 and the provisions relating to early intervention participants and makes some proposals for change.

The submission draws substantially on Richard Madden's associated paper ('NDIS Financial projections: Comments on the 2021-22 Annual Financial Sustainability Report'). That paper comments on the 2021-22 NDIS Annual Financial Sustainability Report (2021-22 AFSR) and some of its assumptions (notably new entrants and additional inflation) and includes real terms cost projections for the NDIS. Issues discussed in the submission include:

1. the disproportionate impact on NDIS costs of inclusion of participants after they reach the age of 65, and the consequent transfer of significant costs from the aged care system
2. the large number of early intervention participants (over 25% of all participants) and their very low rate of exit from the NDIS.
3. the continuing lack of discussion in the AFSRs of the impact of early interventions and capacity building supports on future costs of the NDIS
4. the continuing lack of discussion of the relationship between the NDIS and mainstream services (which is an explicit requirement of the NDIS Act)
5. interstate differences in NDIS participation and cost.
6. the ongoing lack of key statistical information on NDIS participants, their support needs, content of support packages and supports provided
7. the existing absence of published NDIS statistics on participants' support needs (and associated functioning limitations), the supports included in NDIS packages and the supports delivered
8. differences across States and Territories in NDIS participation and average benefits

Centre of Research Excellence in Disability and Health: Submission to the National Disability Scheme Review: Enhancing and monitoring equity within the context of the NDIS

In our research, we use the term equity to refer to fairness. Persistent structural inequities are experienced by many Australians with disability across numerous life domains (e.g., employment, education) contributing to inequitable outcomes (e.g., life expectancy, mental health) when compared to Australians without disability (Fortune et al., 2021). The National Disability Insurance Scheme is an important policy reform for reducing inequities and therefore unfairness between Australians with and without disability, yet it also has the potential to exacerbate inequities between different groups of people with disability including between individuals receiving NDIS plans and those who do not. Understanding where inequities are exacerbated or reduced by the NDIS is critical to understanding how outcomes can be improved for the diversity of NDIS participants and Australians with disability more broadly.

This submission drew on evidence from research conducted by the Centre of Research Excellence in Disability and Health (CRE-DH) researchers and affiliates and highlighted two key areas of concern to the NDIS Review:

- equity within the NDIS in relation to access, plan budgets and spending, and experiences;
- approaches to enhance the monitoring and reporting on the effectiveness and equity of the NDIS.

The submission made 12 recommendations to tackle inequities found within the NDIS, critical to ensure NDIA public accountability for best efforts at reducing inequities within the context of the NDIS. The complete report can be accessed [here](#).

Submission to The Senate Select Committee on Australia's Disaster Resilience

Bailie J, Longman J, Villeneuve M. (2023) Submission to The Senate Select Committee on Australia's Disaster Resilience. Submission Number 103. University Centre for Rural Health, Lismore NSW.

This submission to the Select Committee on Australia's Disaster Resilience was led by Dr Jodie

Bailie and Associate Professor Michelle Villeneuve, in collaboration with Dr Jo Longman, researchers at The University of Sydney's, University Centre for Rural Health (UCRH) (JB, JL) and Centre for Disability Research and Policy (CDRP) (JB, MV).

This submission specifically addresses the terms of reference related to:

- a) current preparedness, response and recovery models, point iv) the role of Australian civil and
- b) volunteer groups, not-for-profit organisations and state-based services in preparing for and responding to and recovery from natural disasters.'

Research conducted by the UCRH six months after the 2017 floods in the Northern Rivers region of NSW revealed the profound impacts and systemic neglect experienced by people with disability and their carers during and after the flooding. Our study found that people with disability and carers were disproportionately impacted by the floods. Our study identified several barriers to evacuations, including inaccessible, conflicting, and confusing information, and poorly timed or incorrect warnings regarding flood-water levels and the possible need for evacuation, and communication barriers affecting access to emergency information and ability to seek assistance.

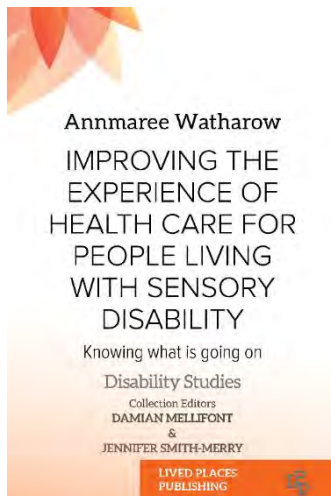
You can access the complete submission and recommendations here:

<https://www.aph.gov.au/DocumentStore.ashx?id=5d95593e-c134-48c0-8481-f2b79f24eb41&subId=741064>

UPDATE FROM OUR LIVED-EXPERIENCE RESEARCH FELLOWS

Book release - Improving Health Care Communication for people with sensory loss: Knowing what is going on

We congratulate [Dr Annmaree Watharow](#) on the publication of her book 'Improving the Experience of Health Care for people living with sensory disability'. This book was published on the 22nd of February, 2023, by Lived Places Publishing.



How does a patient with sensory disability – such as a hearing or vision impairment, or both – get effective communication from a health care provider?

Too often, the answer is that they don't. Communication is crucial for any professional–patient relationship, not least when disability is in the mix. For people living with sensory disability, however, the challenge of knowing what is going on with their healthcare, participating in shared decision making, and retaining an appropriate level of agency, is even greater. Using verbatim testimony from people with first-hand experience of sensory disability, this book explores issues such

as accessibility barriers in consent forms, patient information sheets and other paperwork; situational vulnerability to abuse and neglect; and dehumanisation, infantilisation, and disempowerment in care.

Written by **Dr Annmaree Watharow MD PhD**, a doctor and author with personal experience of sensory disability, the stories in this book are told using people's own words, to allow readers to hear directly from the people who most need their own agency. Vital reading for doctors, nurses, health care providers, and social support workers in practice and training, this book will change the way you view sensory disability. A link to this book can be found [here](#).

Employment of people with disability in Australian disability services

Dr Damian Mellifont has recently completed a study with **Professor Jen Smith-Merry** and **Dr Kim Bulkeley** that has investigated the employment of people with disability in Australian disability services. Informed by 2021 National Disability Services Workforce Census data, our research revealed that almost a quarter of survey respondents do not employ any people with disability in their disability service. Furthermore, only 19% of organisations employ people with lived experience of disability in management positions. You can learn more about our study findings and policy recommendations by accessing our recently published paper at <https://onlinelibrary.wiley.com/doi/full/10.1111/spol.12898>



[How Australia can get more people with disability into the workplace](#)

Australia is lagging when it comes to employing people with disability – quotas for disability services could be a start.

www.smh.com.au

This lived experience-led research has delivered practical policy implications. For example, in addition to receiving strong media attention about the need to employ and promote more people with disability in Australian disability services (see for example, <https://www.smh.com.au/business/workplace/how-australia-can-get-more-people-with->

[disability-into-the-workplace-20230215-p5cklc.html](#)), the research team and study findings were named in the Royal Commission into the Violence, Abuse, Neglect and Exploitation of people with disability public hearing 32 that was held in Brisbane from 13-17 February 2023.

NEWS FROM CDRP AFFILIATES

WHOCC Strengthening Rehabilitation Capacity in Health Systems



Dr Kim Bulkeley, Co-Head with Professor Emerita Gwynnyth Llewellyn of the WHOCC, attended a regional forum in Cambodia hosted by the Western Pacific Regional Office of the WHO with all the collaborating centres across the region.

The focus of the forum was implementation of the *For the future : towards the healthiest and safest Region - A vision for the WHO work with Member States and partners in the*

Western Pacific <https://www.who.int/publications/i/item/WPR-2020-RDO-001>

The engagement with other collaborating centres within Australia and more broadly was very productive and we are exploring options for ways to work together going forward. The World Rehabilitation Alliance <https://www.who.int/initiatives/world-rehabilitation-alliance> has accepted our WHOCC as a member and we are looking forward to working within this group to support the implementation of Rehab 2030 , <https://www.who.int/initiatives/rehabilitation-2030> the WHO's call to action for the development of rehabilitation.

We are represented on four of the working groups;
Research – Assoc Prof Margaret McGrath
Workforce – Dr Rebecca Barton
Emergencies – Assoc Prof Michelle Villeneuve
Primary Care – Ms Jo Lewis

If you have any questions about the work of our WHOCC, check out our web site www.sydney.edu.au/who-cc-rehab-health-systems or please reach out to kim.bulkeley@sydney.edu.au

National Taskforce on updating the National Guidelines on Best Practice in Early Childhood Intervention.

Dr Genevieve Johnsson is an affiliate of CDRP and work closely with several researchers of our centre. She is employed by Re-Imagine Australia, the leading Australian body for early childhood outcomes for young children with a developmental delay or a disability and their families.



The National Guidelines for Best Practice in Early Childhood Intervention (the Guidelines) were developed by Reimagine Australia (formerly operating as Early Childhood Intervention Australia) in 2015 based on consultations with practitioners, service providers, and peak bodies across the Australian early childhood sector. The Guidelines were commissioned by the National Disability Insurance Agency and have been a cornerstone for the early childhood intervention sector. Since the Guidelines were developed in 2015, our understanding of developmental delay, difference and disability, particularly through the emerging

lens of neurodiverse-affirming practice, inclusion, ableism and intersectionality, has rapidly matured.

Launched in 2019, the Australian government's Early Years Strategy is a national plan to support children's health, wellbeing, and early learning during the first five years of their life. The Early Years Strategy aims to provide a framework for improving outcomes for young children and their families. Reimagine Australia has been invited to work with the Government to provide vision and insight on the issues that will be important to consider in reviewing and updating guidance for Best Practice in Early Childhood Intervention.

A National Taskforce has been established by Reimagine Australia and has begun work on identifying the resources, strategies, and actions needed to update the Guidelines and their necessary translatable tools. Dr Genevieve Johnsson, affiliate of the Centre for Disability Research and Policy will Chair the National Taskforce and undertake an independent program of research based on this topic. This work will include desktop analysis of all existing data, policy and discussion papers, a series of best practice review forums with the early childhood sector, taskforce meetings including a government round table, and open forums at the Reimagine 2023 National Conference. A white paper will be delivered at the end of 2023 for the early childhood sector, including government and policy makers.

News from the DISABILITY-INCLUSIVE COMMUNITY DEVELOPMENT STREAM

Led by Associate Professor Michelle Villeneuve

Leave Nobody Behind Webinar Series



As an extension of the work of **Michelle Villeneuve's** research team, a webinar series called the '[Leave Nobody Behind](#)' Project was produced. This webinar series was organised in partnership with the [Australian Institute of Disaster Resilience](#) and hosted by Margaret Moreton, Executive Director of the Australian Institute of Disaster Resilience.

The [Leave Nobody Behind webinar series](#) showcases action-oriented good practice in Disability Inclusive Disaster Risk Reduction (DIDRR). Expert speakers from each DIDRR stakeholder group (government and emergency services, people with disability, and disability support services) share case studies of current progress, specific actions, implementation challenges and how they are being tackled, as well as what needs to happen next. Together the series demonstrates that key to success is multi-stakeholder collaborative action.

[Webinar 1: Actions government and emergency services can take on DIDRR](#)

This [webinar](#) focused on the role and contributions of Australian government and emergency services to developing DIDRR at the local community level. Through case studies, the speakers explored approaches that government and emergency personnel are using to put people with disability and their support needs at the centre of inclusive emergency management policy, planning and practice.

[Webinar 2: Actions that people with disability and their representatives can take on DIDRR](#)

Organisations of people with disability (OPDs), carer organisations and advocacy organisations can play a significant role in disaster policy, planning and interventions. Through their lived experience, leadership and roles as disability advocates, these groups represent the voice and perspective of their members. With in-depth understanding of the factors that increase risk for people with disability in emergencies, they also have access to informal networks of support and communication. This information is not readily available within mainstream emergency management.

This [webinar](#), focused on listening and learning from people with disability, OPDs, carer representatives and advocates, to learn about how they are taking action on DIDRR. This webinar shared case studies that showcased how to keep people with disability and their support needs at the centre of disability inclusive disaster risk reduction (DIDRR). The session considered peer-led approaches, implementation challenges and how they are being tackled, and what needs to happen next.

[Webinar 3: Actions that service providers can take on DIDRR](#)

This [webinar](#) shared how Australian service providers are taking action on Disability Inclusive Disaster Risk Reduction (DIDRR) in diverse service delivery contexts with different service delivery models, funding arrangements, and workforce capacity. This webinar also shared effective practices for linking personal emergency preparedness of people with disability (and other high-risk groups) to organisational preparedness and service continuity of the services that support them. Case studies that showcased current progress, specific actions, implementation challenges and how they are being tackled, and what needs to happen next were discussed.

You can access recording and transcript of these webinars on the Australian Institute of Disaster Resilience Knowledge hub [here](#)

Webinar 4: Learnings from DIDRR Framework for Action

A final webinar will be held in September 2023, where the team will share a multi-sector DIDRR Framework for Action.

For more details and registration, please access this [link](#).

National Forum on Disability Inclusive Disaster Risk Reduction



Australia's first [National Forum on Disability Inclusive Disaster Risk Reduction \(DIDRR\)](#) will be hosted by the [Centre for Disability Research and Policy](#) at the [University of Sydney](#). The University of Sydney is proudly partnering with the NSW Government Authority for reconstruction and the Australian Institute for Disaster Resilience (AIDR) to deliver this event.

The Forum is a free, by invitation event to gather information from key stakeholders about how to operationalise a multi sector, collaborative framework for DIDRR.

At this Forum, we will:

- Share the Leave Nobody Behind project research findings.
- Facilitate discussions about how to translate these research findings into inclusive policy, inclusive information, and inclusive practice.
- Gather input towards the development and operationalisation of a framework for cross-sector collaborative action on DIDRR that will be delivered later in 2023.

During the Forum participants including people with disability, carers, service providers, emergency services representatives, and those working in policy development will workshop the framework using action orientated DIDRR knowledge and practices, as well as emerging research from the LNB project.

News from the INDIGENEITY AND DISABILITY RESEARCH STREAM

Planning for a better life under the NDIS



Image: Four images in a square disposition representing from top left to bottom right: A light green heart on dark green background- a bright red head on a dark red background, a pink hand on a bright red background, a yellow house on a grey background, a dark green panel on the left of the images reads: “ HEART-LED PLANNING” in bright yellow capitals, underneath is the University of Sydney Logo in bright yellow; at the bottom is the written: “Planning for a better life with a disability in regional and remote Australia”

The *Planning for a better life under the NDIS* Research Team interviewed people with disability, carers and workers to find out about their experience of the planning process. The team heard from Aboriginal and non-Aboriginal people living in regional, remote, and very remote communities in Central Australia and Western NSW.

The research is based on interviews and focus groups based on the experiences of 87 people, including 55 people with disability, of which 25 had a support person beside them speaking with or on their behalf, 10 guardians and advocates, and 22 workers. Over half (56%) of people with disability in our sample identified as Aboriginal and Torres Strait Islander.

In late 2022, Dr Genevieve Johnsson (CDRP Affiliate) led the project into the knowledge translation phase and is using the data the research team collected to develop a training package to help workers support people with disability throughout the planning process. The

data revealed ten unique perspectives and needs which will be incorporated into a Heart, Head and Hand approach to planning. Genevieve presented these unique needs and perspectives and the training approach at the inaugural NDIS Quality and Safeguards Commission research roundtable held at the University of Sydney on 30th November 2022. Genevieve also presented this at the Pacific Rim Disability and Diversity conference in Hawai'i in March 2023, as well as at the NDIA Information Gathering for Access and Planning (IGAP) stream meeting in April 2023.

The training package is currently under development and is scheduled for availability via the Centre for Disability Research and Policy webpage by mid-2023.

Research team:

- Associate Professor John Gilroy (Chief Investigator), Dr Kim Bulkeley, and Dr Genevieve Johnsson, Centre for Disability Research and Policy, University of Sydney,
- Heather Jensen and Penny Watson, Flinders University
- Dr Angela Dew, Deakin University
- Professor Michelle Lincoln, University of Canberra
- Wayne Wright, Orange Local Aboriginal Lands Council

News from the MENTAL HEALTH RESEARCH STREAM

Health Consumer-led Research: App to Navigate and Accelerate Mental Health Recovery

Associate Professor Nicola Hancock

Consumer advocates, growing evidence, national guidelines and practice frameworks all emphasise the need for mental health consumers to participate more and have greater control over their mental health recovery planning. However, research indicates that services struggle to translate these empowerment principles into practice. Goal setting and action planning continue to be staff rather than consumer driven.

Image: MRFF Planning Day for co-design labs



We have recently been awarded an Australian Government's Medical Research Future Fund (MRFF) grant to address this issue!

Our project will support consumers to attain greater control over their recovery assessment, goal setting and action planning. Our project will co-design and test the impact of the DRIVING my own mental health Recovery App (Driv-R). This App will build upon a widely adopted, well-validated, recovery-focused mental health self-assessment (RAS-DS –

Recovery Assessment Scale – Domains and Stages). Extensive previous work and the co-design process will ensure consumer- and staff-prioritised features are embedded. In Phase

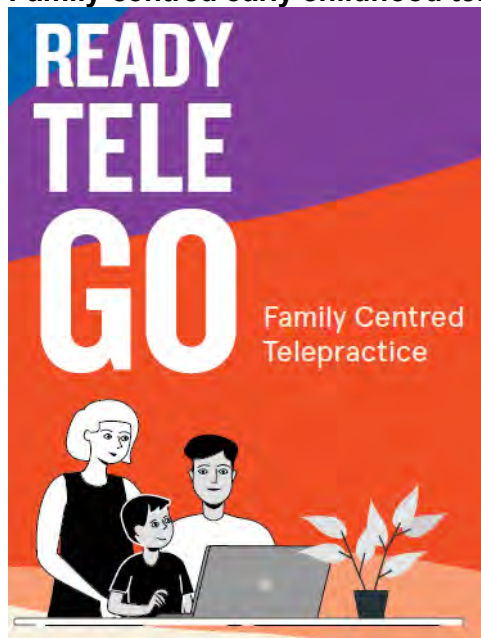
One we will co-develop and co-produce the App. We will use Human Centred Design to deeply engage consumer expertise within and beyond the research team. Iterative cycles will include deep-dive design labs, co-development, user-exploration and feedback processes. In Phase Two, we will evaluate the App using a multi-methods approach. First, a pragmatic trial will be conducted with consumer-staff dyads implementing Driv-R compared to practice as usual during a “waitlist” period. The primary outcome measured is mental health self-efficacy. Secondary outcomes include self-rated mental health recovery and “mastery of illness”. Second, feasibility analyses will examine consumers’ and workers’ perspectives on App usefulness, relevance and helpfulness. Third, data analytics from Driv-R will be examined for uptake, use and accessibility of the platform. Fourth, qualitative interviews will facilitate nuanced interpretation of findings. The outcome will be a freely available App that promotes consumers’ control over their mental health recovery journey.

Our investigator team includes: University of Sydney colleagues Nicola Hancock, Justin Scanlan and Anne Honey from CDRP; Lorraine Smith from Pharmacy; Naseem Ahmadpour from Architecture and Design; Helen Glover from Enlightened Consultants, and Flourish Australia colleagues Mark Orr, Sumathi Govindasamy and Grenville Rose. Research officers Andrew Povolny and Yidan Cao have recently joined the team. (PHOTO ADDED – first team planning day!)

News from the **WORKFORCE RESEARCH STREAM**

Telepractice in early childhood intervention in Australia

Family-centred early childhood telepractice



Researchers from the University of Sydney Centre for Disability Research and Policy, in collaboration with researchers from Monash University and Western Sydney University, partnered with Reimagine Australia to conduct a national survey to explore the experience of using telepractice to provide early childhood intervention and support. The survey captured the experiences of 259 early childhood practitioners who were using telepractice as part of their service delivery. The information gathered from the survey forms part of a broader initiative which aims to strengthen public policy and enable workforce development by promoting the use telepractice to the government. The first journal article titled Early childhood practitioners experience of telepractice and its alignment with a family-centred approach

is currently under review at the Journal of Child and Family Studies. As part of the knowledge translation, the team has also created a practice companion on family centred telepractice titled Ready, Tele, Go! Family-centred Telepractice. The companion is available on the Centre for Disability Research and Policy website here:

<https://www.sydney.edu.au/content/dam/corporate/documents/faculty-of-medicine-and-health/research/centres-institutes-groups/cdrp/ready-tele-go---family-centred-telepractice.pdf>

Research team: Dr Kim Bulkeley and Dr Genevieve Johnsson, Centre for Disability Research and Policy, University of Sydney, Jenna Bongioletti and Dr Joanne Hinit, University of Sydney, Dr Anoo Bhohti, Monash University, and Associate Professor Christine Johnston, Western Sydney University

Pacific Rim Disability conference – Hawaii, March 2023



Dr Genevieve Johnsson and Dr Kim Bulkeley attended the Pacific Rim Disability Conference in Honolulu, Hawaii presenting two papers on their research work in the disability space:

- Planning for a good life in regional and remote areas
- Supporting people with disability in rural and remote communities:
Local therapy community workers

Image: Dr Kim Bulkeley and Dr Genevieve Johnson presenting their research at the conference

We presented this work on behalf of our research teams and the presentations were very well received.

We were all saddened by the sudden passing of Judith Heumann, <https://judithheumann.com/> a fierce disability advocate who was scheduled to provide a keynote at this conference. It was such a privilege to hear her pre-recorded version of the keynote just days after she had passed, that was a passionate and wise call to action for all of us in the disability space.

It was a great opportunity to connect with colleagues with common interests and to rekindle our relationship with the University of Hawaii, Manoa Centre on Disability Studies

<https://cds.coe.hawaii.edu/> We have had one session with the team from CDS and are exploring options for a collaborative seminar later in the year. Please reach out if you have an interest in joining this collaboration.

EVENTS

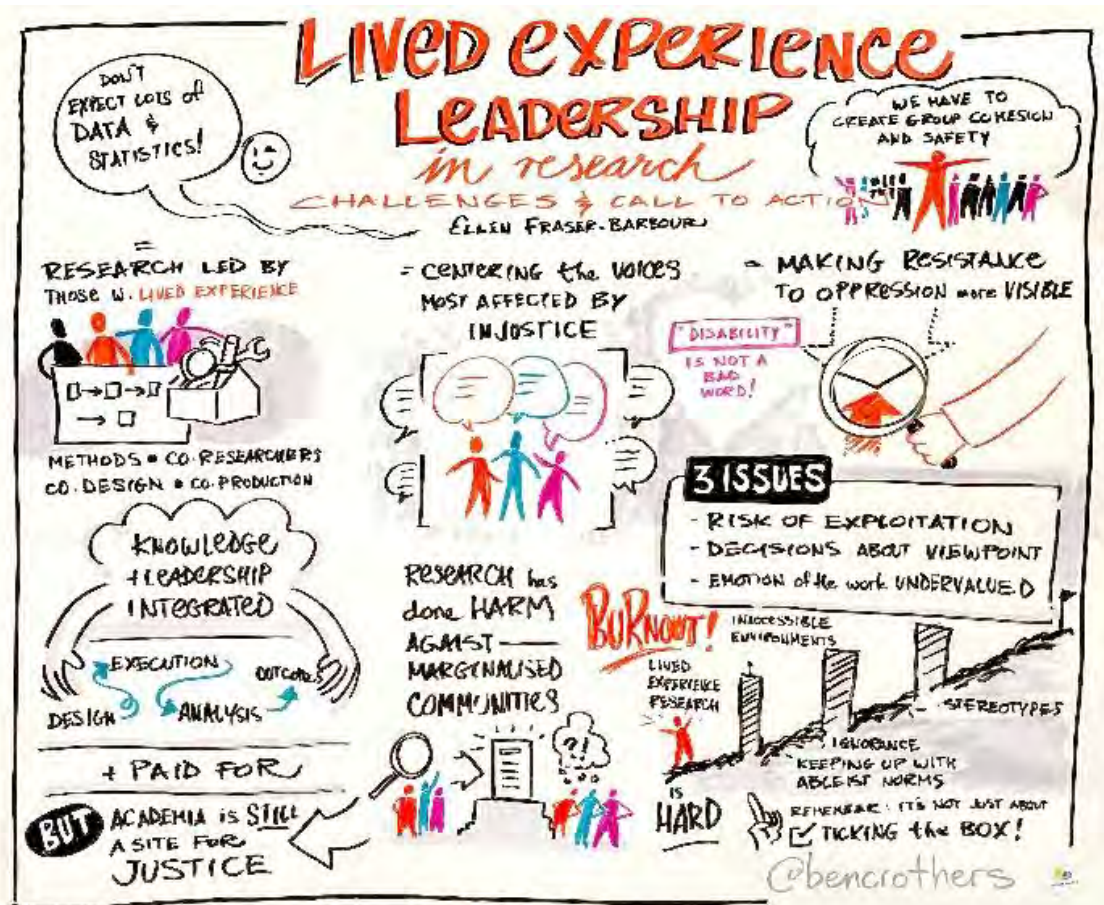
Call-to-Action Forum: Lived- Experience Led Research

On Thursday 27th April 2023 the Centre for Disability Research and Policy (CDRP) in collaboration with the DIAP for the **Call to Action: Lived Experience Led Research Forum**. There were 108 registrants and a large number of participants attended from across the university.

Professor John Gilroy delivered an acknowledgement to country sharing his recent artwork on the findings of his two ARC funded research projects. He showed this artwork to help frame the event as a research and research translation gathering.



Our keynote speaker **Ellen Fraser Barbour** from Flinders University in South Australia spoke about the importance of lived experience research for people with disability and the academy. This powerful presentation really set the scene for research led by people with disability.



Several researchers from across the University presented their “success stories” of lived experience led research.



Dr Damian Mellifont's presentation discussed the need for work environments to be shaped by people with disability and their allies. He also highlighted two lived experience-led studies: one about disability in the academy and another about the employment and promotion of people with disability in Australian Disability Services.

Dr Susan Collings' presentation brought to light the challenges of doing OOHC research. The voices of people with disability who live in OOHC are rather diluted by the politics of child removal. The voices of people with disability in OOHC research need to be empowered through governance models in the management and development of disability research in OOHC.

Paul Newman from the Matilda Centre spoke about the success of the Youth Advisory Board. He emphasised that having a diversity of people from different backgrounds ensure that questions and answers in the Mental health space.

Associate Professor Amanda Tattersall presented about the work of the Sydney Policy Lab in relational research. The presentation emphasised the importance of methods in community-led research. The presentation also discussed five principles of lived-experience research.

The **Centre for Disability Studies** presented on the success of their network of people with disability to help the Centre's research program. The speakers consisted of members of the network (**Melanie Nolan, Suzie Jessep, Sarah Butler and Erin**) and how it has empowered them as people and young scholars.

Dr Annmaree Watharow spoke about her experience conducting research, the need to be flexible and match methods to needs. She emphasised the need to be a good ally, as disabilities affect everyone, everywhere, and that people with disabilities were seen as 'invisible'. The presentation also highlighted the importance of building bridges between able-bodied and 'invisible' people.

Professor John Gilroy then led a yarning session on Aboriginal lived experience research. He spoke about disability research and how it is important to mentor young scholars. **Rodney Adams** spoke about culture with people who living with hearing disabilities, Aboriginal people have been communicating for thousands of years through song, dance and art. Scholars **Alix Beckett** and **Jemma Chao** spoke about doing research and the challenges they have with lived experience of disabilities.



This Call to Action was a great way to understand what the University of Sydney is doing well and what still needs to improve. Lack of opportunities for academics, staff, and students with disability in educational and research institutions were common theme for the day, how more funding mentoring and support is pivotal to grow, however there were many positives on what the university does well, having important events and conversations to collaborate and move forward.

Throughout the day, illustrator **Ben Crothers** captured essential messages delivered by our speakers. Highlights video of the day will be released shortly.

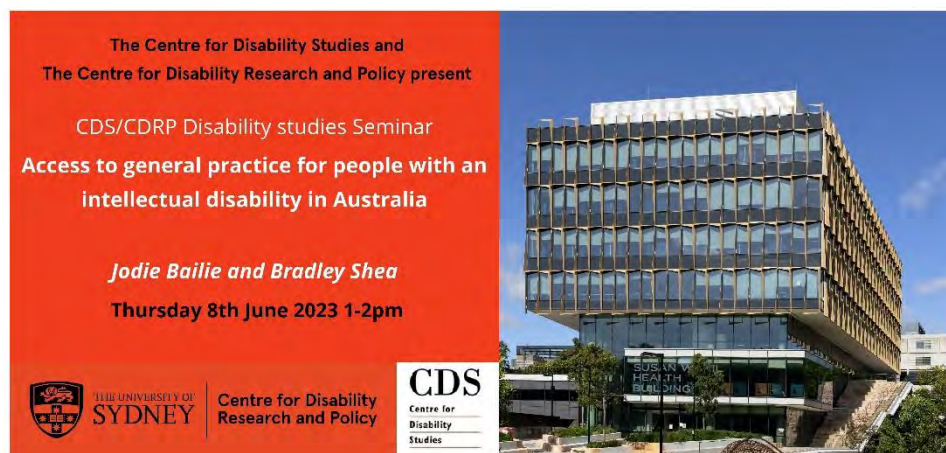
We have employed **Gemma Smart** to write up the day and its

outcomes as a formal 'Call to Action' for the University of Sydney. The "Call to Action to further lived experience led research at the University" will be submitted to the University Executive team through the Disability Inclusion Action Plan Implementation group.

CDS/CDRP Monthly Seminars 2023

We invite you to attend our monthly seminars, which are co-hosted with the Centre for Disability Studies. These seminars are an opportunity for the CDRP members and affiliates to present about current research in the disability field.

The next seminar will be held on the 8th of June, from 1:00pm-2:00pm. Jodie Bailie and Bradley Shea will present on "Access to general practice for people with an intellectual disability in Australia".



People with intellectual disability make up about 1–3% of the Australian population and, compared with the general population, experience poorer health outcomes, shorter life expectancy and higher mortality rates. Difficulties in accessing general practice care is thought to contribute to these inequitable health outcomes. Using a wholistic conceptualisation of access we undertook a scoping review of existing Australian peer-reviewed literature to identify factors impacting access to general practice for people with intellectual disability. This review is timely, as in 2021 the Australian Government released the National Roadmap for Improving the Health of People with Intellectual Disability, a policy initiative aimed at addressing health inequity experienced by people with intellectual disability.

Dr Jodie Bailie is a senior research fellow based at the University Centre for Rural Health (UCRH) in Lismore, with a long-standing commitment to improving the way our health system delivers care to people with intellectual disability. Jodie has a joint appointment with the UCRH and the Centre for Disability Research and Policy. Bradley Shea is a medical student who completed this scoping review under the supervision of Dr Jodie Bailie as a course requirement for the Doctor of Medicine at The University of Sydney's Faculty of Medicine and Health.

Register here to attend the seminar online:

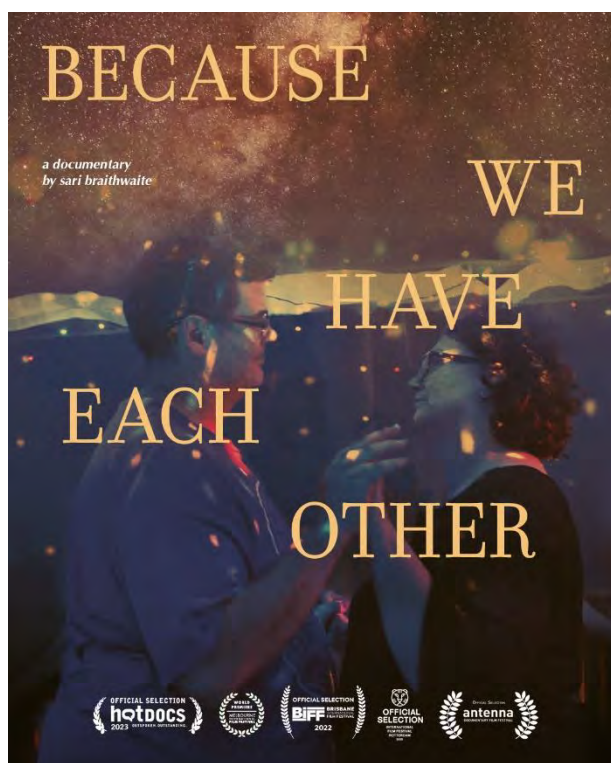
<https://www.eventbrite.com.au/e/643471349127>

Stay tuned for upcoming seminars for the rest of the year:

13th July 2023 – Glenda Jessup- The PIEL Survey app: Sampling lived experience

10th August 2023 - Alix Beckett- Jemma Chao- Representation of Indigeneity in disability research.

Go and See "Because we have each other" at the movie!



CDRP is supporting "[Because we have each other](#)", a documentary following the life of a neurodiverse family. Made over five years, Because We Have Each Other is a delightfully hyper-intimate feature from award-winning Australian Director Sari Braithwaite. This new feature invites us to share the mundane & the magnificent of the everyday life of a neurodiverse family in the forgotten working-class suburb of Logan

Don't miss out screenings in Melbourne this week, in Brisbane (QLD) on the 10th June and in Leederville (WA) on the 20th June

Find all screening information here: <https://becausewehaveeachother.com/#screenings>

ACT	Friday 12 May	The Arc, Canberra (Q&A with Sari Braithwaite and Munro Melano)	18:00
NSW	Wednesday 3 May	CHEC Theatre, Coffs Harbour (ScreenWave Festival)	16:15
	Thursday 25 May	The Ritz, Randwick (Q&A with Sari Braithwaite)	18:30
VIC	Sunday 28 May	Cinema Nova, Melbourne (Q&A with Sari Braithwaite and Chloé Brugalé)	14:30
	Sunday 4 June	The Classic, Melbourne (Q&A with Sari Braithwaite and Chloé Brugalé)	16:30
	Saturday 10 June	ACMI, Melbourne	11:00
	Sunday 11 June	ACMI, Melbourne	11:00
	Monday 12 June	ACMI, Melbourne	13:30
	Saturday 17 June	ACMI, Melbourne	11:00
	Sunday 18 June	ACMI, Melbourne	11:00
	Sunday 19 June	ACMI, Melbourne	13:30
QLD	Saturday 13 May	Logan City Council (Q&A with Sari Braithwaite and Family)	13:00
WA	Tuesday 20 June	Luna, Leederville (Q&A with Sari Braithwaite)	18:30

Selected screenings includes a Q&A session. For information on screenings in other states visit [Becausewehaveeachother.com](https://becausewehaveeachother.com)

BECAUSE WE HAVE EACH OTHER [Becausewehaveeachother.com](https://becausewehaveeachother.com)

Thank you for following and supporting CDRP's Research

Follow us on Twitter: [@USydCDRP](https://twitter.com/USydCDRP)

Contact us: disabilitypolicy.centre@sydney.edu.au

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