



Centre for Disability Research and Policy

Welcome to our September 2023 Newsletter

Contents

DIRECTOR'S WELCOME:.....	1
CDRP AMATEUR ART COMPETITION	1
CENTRE MANAGER'S REPORT.....	2
CDRP'S NEW RESEARCH STRUCTURE.....	3
INTRODUCING our new visiting fellow: Victor Zhuang	5
CDRP'S CONTRIBUTIONS TO CONSULTATIONS.....	5
UPDATE FROM OUR LIVED-EXPERIENCE RESEARCH FELLOWS	7
NEWS FROM OUR CDRP AFFILIATES	10
NEWS FROM THE DISABILITY-INCLUSIVE WORKFORCE AND SERVICES PROGRAM.....	12
Launch of the Heart-led Website	12
NEWS FROM THE DISABILITY ACROSS THE LIFESPAN PROGRAM	13
NEWS FROM THE MENTAL HEALTH AND WELLBEING PROGRAM.....	14
Let's talk about VOICES: evaluating the impact on voice hearers of interacting with e-resources	15
NEWS FROM THE DISABILITY INCLUSIVE DISASTER RISK REDUCTION PROGRAM.....	16
National Forum on Disability Inclusive Disaster Risk Reduction	16
NEWS FROM the Indigeneity and Disability Research Stream.....	17
Translating Research into Artwork	17
International outreach	18
Sydney Southeast Asia Centre Timor Leste Field School.....	18
Successful EVENTS.....	19
Upcoming Events.....	25
Ageing and Dual Sensory Impairment Symposium.....	26
International Indigenous Disability Research Conference	26

DIRECTOR'S WELCOME:

Jen Smith-Merry

This month, we welcome Professor Shane Clifton to the CDRP leadership team, who began a new role of Associate Professor of Practice at the University of Sydney on the 25th of September, after finishing as Director, Respect and Inclusion Policy at the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation against People with Disability. We will introduce Shane more fully in an upcoming newsletter, but we are very excited to have him with us. Here is [a little more about Shane](#) to pique your interest.

In the newsletter this month we are highlighting the launch of the [Heart-Led Planning website](#) by Professor John Gilroy, Dr Kim Bulkeley and Dr Genevieve Johnsson. This research is another outcome from the ARC grants led by John, which have focused on the experiences of the NDIS by Aboriginal people in New South Wales. The newsletter also focuses on the exhibition of John's traditional wood burn art through which he illustrates experiences of the NDIS which emerged from his ARC projects.

We have also just launched our art competition, so please spread the invitation for participants far and wide. The competition will culminate in an exhibition to be held at the University of Sydney in November. Get arty and [make a submission](#)!

Jen

CDRP AMATEUR ART COMPETITION



Share your dreams of the future through lived-experience!

The Centre for Disability Research and Policy (CDRP), in collaboration with the Disability At Work Network (DAWN) is proud to launch its very first Amateur art competition for artists with lived experience of disability themed: **"Dreams and Debuts"**

The "Dreams and Debuts" amateur art competition is a Celebration of journeys and aspirations, aspiring to unveil dreams of the future – personal or universal, challenging or inspiring – as envisioned by artists whose perspectives have been shaped by their lived experiences of disability.

We invite all amateur artists with lived experience of disability to show through their art, their dreams, hopes, and achievements through the medium of their choice

Please submit your artwork online to enter the competition before Monday 30th October at midnight [through this online form](#) (accessible forms in word format available upon request)

For more details and terms and conditions of the competition please follow this link: [centre-for-disability-research-and-policy/dreams-and-debuts--lived-experience-art-competition.html](#)

A selected number of finalist artists will be invited to present their artwork during an exhibition at the Susan Wakil Health Building, from the 4th to the 14th of December. The winner of the competition will be awarded a prize of \$1000, and two runners-up \$400. A people's choice award will be awarded to the most voted artwork by the audience of the exhibition and receive a prize of \$200.

We look forward to being inspired by your amazing artwork!

CENTRE MANAGER'S REPORT

Virginie Lecomte Maloney

After several months of consultations with the CDRP leadership group, with all CDRP members and affiliates, with members of our wider community and with our research partners, we are excited to announce our new CDRP research structure. This structure will guide our research strategy for the next few years, recognising foundation research programs of the center as well as emerging areas of influence, and offering a research home for all our amazing researchers. Check out our new structure below!

Our CDRP leadership is evolving, as we thank two of our members for their participation in the group over the last year: Susan Collings who accepted a position at Western Sydney University, and Gordon Duff, who will focus on finalising his PhD over the next few months. Susan and Gordon will stay involved in CDRP's research, as affiliates of the centre.

We welcome two new members to the leadership group: A/Prof. Roxanna Pebdani, Director of Participation Sciences in the Sydney School of Health Sciences and Prof. Shane Clifton, Professor of Practice at the School of Health Sciences. Here is a little bit about our new leadership group members:



Associate Professor Roxanna Nasser Pebdani, (PhD, CRC, SFHEA) is Director of Participation Sciences and Rehabilitation Counselling Program Director in the School of Health Sciences at The University of Sydney. She has been a Certified Rehabilitation Counselor since 2008 and a Senior Fellow of the Higher Education Academy since 2021. Her research, teaching, and leadership activities have a common thread of equity and inclusion. Dr. Pebdani's research interests are in access to sex, sexuality, pregnancy and fertility for individuals with

disability. Her other streams of research include cultural competency and pedagogy in rehabilitation counselling.

Image description: Roxanna appears in the picture smiling, against a leafy and sunny background. She has lightly tanned skin, dark long curly hair and she is wearing a teal dress with flowers.



Shane Clifton commenced this week as Associate Professor of Practice in the School of Health Sciences, Faculty of Medicine. With a background in theology and ethics, Shane had a spinal cord injury in 2010, and has been an honorary associate with the CDRP since 2013. He spent the last four years working with the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Shane's research focus is on the well-being of people with spinal cord injury and other disabilities, as well as ableism and the development of an inclusive society. Shane will be teaching in the occupational therapy programs and joins

as part of the leadership group of the CDRP. He very much looks forward to collaborating with the CDRP team.

Image description: a photograph of Shane with a large smile. Shane a fair skin and very light brown short hair. He wears orange framed glasses and black headphones. Behind him we can see the headrest of his motorised wheelchair- Shane appears to be in a laneways decorated with colorful fairy lights.

As announced above, we are very excited to announce our first Amateur Art competition for artists with lived-experience of disability to showcase through their art their dreams and aspirations for the future. The finalist artworks will be shown in an exhibition at the University of Sydney from the 4th to the 14th December. Keep an eye out for the invitation to the exhibition launch on the 4th December. We are delighted to count among the jury members, our very own resident artist [Prof. John Gilroy](#), and [M. Sunflower](#), a culturally diverse Australian artist who identifies as living with disabilities, whose artwork had been chosen this year to illustrate the University Disability Inclusion Week.

CDRP actively participated in this year's Disability Inclusion Week, at the University of Sydney, with the organisation of two successful events to bring awareness of how to bring down access barriers in the everyday life of people with disability. More details in our Event section below.

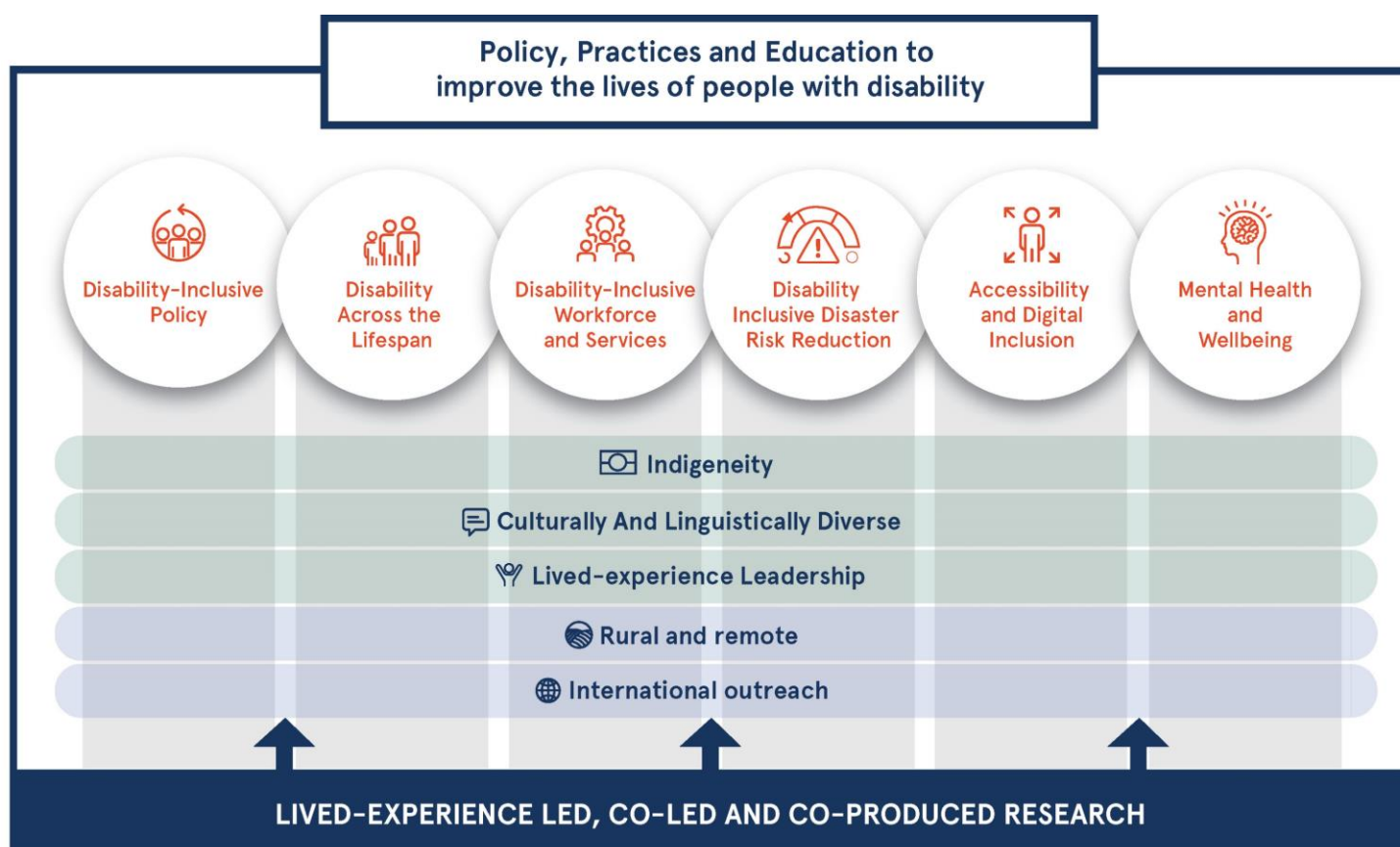
CDRP'S NEW RESEARCH STRUCTURE

We are proud to present to you our new research structure, after extended consultation with all of our members. The infographic below details the research programs (in orange writing) and translational themes (in blue writing, spanning across all research programs) around which our research is organised.

CDRP Research Programs regroup all current research projects led by our centre's stream leaders and cover a wide range of research from Policy design and evaluation

to research in accessibility, through to workforce and services, including all ages from early childhood intervention to disability in ageing population. Translational themes represent important component of CDRP research present throughout all our research projects.

These all supports our mission to develop “Policy, Practices and Education to improve the life of people with disabilities” in Australia, metro, regional, rural and remote, as well as around the world through our international outreach programs. All our research and teaching is lived-experience-led or co-led or co-produced with people living with disability, supporting the moto “Nothing about us, without us”.



THE UNIVERSITY OF
SYDNEY

Centre for Disability
Research and Policy

Image description: A document showing The University of Sydney Impact Centre for Disability Research and Policy (CDRP) research program in a visual format. Six research programs across the top are: Disability inclusive policy; Disability across the lifespan; Disability inclusive workforce and services; Disability Inclusive Disaster Risk Reduction; Accessibility and Digital Inclusion; Mental Health and Wellbeing. Translational themes, shown underneath the research programs in arrows spanning the whole length of the infographic are Indigeneity, CALD, Lived-experience leadership, Rural and remote, International outreach. A box on top of the infographic state our mission: policy, practices, and education that improves the lives of people with disability. A box at the bottom of the infographic, representing the foundation of CDRP’s work: Lived experience led, Co-led, and Co-produced research.

INTRODUCING our new visiting fellow: Victor Zhuang

Introducing Victor Zhuang who will be a visiting fellow with CDRP and the Faculty of Art and Social Sciences at the University of Sydney until August 2024.

Kuansong Victor, Zhuang is a faculty member at the Wee Kim Wee School of Communication and Information, Nanyang Technological University. Victor was a UK Chevening scholar in 2013/14, and a 2022/23 Princeton University Fung Global Fellow.



Victor's research lies at the intersections of communications, media, and cultural studies, and disability studies, especially as it pertains to inclusion and the workings of technology. He hopes to use his research to contribute to current debates about how inclusion happens both in Singapore and around the world. Find out more about his work at www.ksvictorzhuang.com

At the University of Sydney, Victor will be working on two book projects. The first examines the workings of inclusion in Singapore and analyses a diverse range of cultural phenomenon, specifically, policy texts and documents; public education campaigns and media representation of disability; carnivals celebrating disability inclusion; and accessible spaces and the built environment. This project examines how inclusion as an ideology is created, circulated, communicated, and consumed in Singapore, and undertakes an interdisciplinary approach towards understanding the logics of inclusion and the lived realities of disabled people in Singapore as well as the demands it places on the body politic.

The second book project is a joint project with Gerard Goggin. We explore the intersections of disability and emerging technologies such as IOT; 5G; automation and AI; driverless cars; and robotics. In particular, we are interested in understanding the socio-technical imaginaries of disability as encapsulated and envisioned in articulations of emerging technologies.

CDRP'S CONTRIBUTIONS TO CONSULTATIONS

Submission to the Review to Inform a Better and Fairer Education System by Dr Damian Mellifont (CDRP Lived-experience Research Fellow)

The submission offers an evidence-based response in relation to question 8: What does it look like when a school is supporting student mental health and wellbeing effectively?

The following key points were discussed:

1. Acknowledging a pressing policy issue involving the ongoing bullying and abuse of neurodivergent students in Australian schools
2. Evidence-based questioning about the effectiveness of school mental health programs
3. The risk of school-based mental health programs promoting an 'othering' of neurodivergent students

4. Supporting a policy shift towards neuro-inclusive programs across Australian schools.

Response to the NDIS Review 30 June 2023 Interim Report



Emeritus Prof. Richard Madden and Lived-experience research fellow Dr Annmaree Watharow submitted a response to the [NDIS review Interim report: “What we have heard”](#) released on the 30th June 2023. The report detail 10 areas for improvement, with five key challenges identified:

- Why is the NDIS the only lifeboat in the ocean?
- What does reasonable and necessary mean?
- Why are so many children entering the scheme?
- Why aren’t NDIS markets working?
- How do we ensure that the NDIS is sustainable?

Prof. Madden’s submission focused on Key Challenges 5 (sustainability), 3 (children) and 2 (reasonable and necessary). It also raises an important issue regarding the NDIS eligibility criteria, proposing to specifically focus on access to the scheme of people above 65 years old and participants of early childhood intervention, to manage financial sustainability of the scheme.

Dr Watharow’s submission answered to all 10 questions raised by the submission paper in linked to the 10 priority areas identified by the report:

- Applying and getting a plan
- A complete and joined up ecosystem of support
- Defining reasonable and necessary
- Early childhood supports
- The support and service marketplace

- Measuring outcomes and performance
- Achieving long term outcomes
- Help accessing supports
- Supported living and housing
- Participant safeguards

Annmaree submission draws on her lived experience as an NDIS participant as well as her research expertise. Her recommendations particularly insisted on the need to raise expectation of what a full participation to the society meant for people living with disability and that services included in the NDIS, and especially access to support workers should be revised to include a larger range of professional and social activities, as well as more flexibility in support services provision.

UPDATE FROM OUR LIVED-EXPERIENCE RESEARCH FELLOWS

Dr Annmaree Watharow

External Research Collaboration Seed Funding

Congratulations to our Lived-experience research fellow Dr Annmaree Watharow for being awarded a University of Sydney Seed Funding for development of external research collaboration and securing \$30,000, to support a collaboration with [Vision Australia](#) on the Dual Sensory Impairment project. The dual sensory impairment project (DSI project) combines research excellence and potential, and aims to promote a happier, healthier and safer life for older people living with combined vision and hearing impairment, known as dual sensory impairment (DSI). It will achieve this by creating and evaluating resources to support not just individuals and their families/carers, but also to raise awareness of DSI and skills for professionals and practitioners.

18th Deafblind International World Conference



Image description: Annmaree giving her keynote lecture at the conference- At the front of the picture, several audience members sitting around tables are facing the stage- on second

plan, Annmaree, a fair-skinned women with dark hair in a pony tail, wearing dark sunglasses and black top and pants, is sitting on stage in front of a microphone, next to her support worker. At the top of the picture, is a large screen streaming Annmaree's presenting.

Annmaree attended this World Conference which was held on the 22nd-28th of July, 2023, in Ottawa, Canada. The conference is held every four years, and this year's theme was 'Global Connections: The Future in Our Hands'.

Annmaree presented a keynote address on Wednesday 26th July, for Plenary Session 5: 'Bringing Experience, to Life, Research and Education'. In this address, she presented on her journey with deafblindness, how this has impacted her personal life and career in research and as a 'scholar-activist'. Annmaree advocated for the importance of involving people with lived experience in research.

During this conference, she also co-chaired a breakout session on 'Elevating Conference Accessibility and Inclusion for Individuals with Deafblindness: merging best practices from Vision, Hearing and Dual Sensory Impairment'. This panel highlighted the importance of using a universal design lens to address conference accessibility and inclusion.

Ageing and Dual Sensory Impairment Conference HAPPIER, HEALTHIER AND SAFER



Ageing and Dual Sensory Impairment
9th of November 2023
9am - 4:30pm AEST
Level 3 Susan Wakil Building
Rooms 308 + 309

Speakers:
Melissa Levi
Dr Annmaree Watharow
Dr Moira Dunsmore
Dr Julie Schneider
Dr Isabelle Boisvert

Accessibility contact:
annmaree.watharow@sydney.edu.au

SYDNEY Vision Australia

A multi-disciplinary conference on dual sensory impairment in older Australians convened by the co-leads of the Dual Sensory Impairment Project at the University of Sydney: Drs Moira Dunsmore, Julie Schneider and Annmaree Watharow

When: November 2023

Where: University of Sydney, Susan Wakil building

Who: practitioners, professionals in older care, health and social care, consumers, carers

The dual sensory impairment project (DSI project) combines research excellence and potential, and aims to promote a happier, healthier and safer life for older people living with dual sensory impairment (DSI). This will be a hybrid event.

Image description: against a dark blue background, a picture showing two hands touch signing on a third hand. At the bottom right, the logo of University of Sydney in Orange and the logo of Vision Australia in yellow. The title and text in white letters: Ageing and Dual Sensory Impairment, 9th November 2023, 9am-4:30pm AEST, Level 3 Susan Wakil health Building, Rooms 308+309. Speakers: Mellissa Levi, Dr Annmaree Watharow, Dr Moira Dunsmore, Dr Julie Schneider, Dr Isabelle Boisvert. Accessibility contact: annamree.watharow@sydney.edu.au.

Sensory loss is common. It increases rapidly in prevalence as the population ages. Australia does not recognise dual sensory impairment as a unique and distinct disability so there are no specific protections, policies and practices for this group of older Australians. There is little research knowledge about what supports work and there is very little directed to those living with, and caring for, people with dual sensory impairment. The dual sensory impairment project aims to translate the research we have done into beneficial outcomes for the community. As part of this brief, we are bringing together practitioners, professionals and consumers/carers for an multistranded, educational event that is informed by lived experience.

Dr Damian Mellifont

Sanist wonderland: Poem in the Research Handbook of Disability Policy on Disability Policy



The newly published "[Research Handbook on Disability Policy](#)" includes a poem by one of our lived-experience research fellows, Damian Mellifont.

"Sanist Wonderland" is a poem that challenges employers to reflect on the responses that neurodivergent people receive in the workplace when they disclose disability to employers and workplaces. It encourages pride in neurodivergent people, support from colleagues, and closes by asking a question to public service managers: 'How many disclose neurodivergence in the departments that you lead? If the numbers are few, as I suspect many will land, Are you nothing but a leader of a sanist wonderland?'

Mellifont, D. (2023). "Chapter 62: Narrative 18: Sanist wonderland". In *Research Handbook on Disability Policy*. Cheltenham, UK: Edward Elgar Publishing. Retrieved Sep 22, 2023, from <https://doi.org/10.4337/9781800373655.00072>

Assessment tool for inclusion of lived experience researchers

Dr Damian Mellifont's latest manuscript entitled, 'A rapid review informing an assessment tool to support the inclusion of lived experience researchers in disability research' has recently been accepted for publication in the Canadian Journal of Disability Studies. This is timely research that supports an inclusive and powerful message of 'No disability research about us without us!'

This rapid review aims to inform researchers with disability and their genuine allies about:

- a) scholarly discussions concerning the inclusion of researchers with lived experience of disability in lived experience led or co-produced disability research; and
 - b) a practical disability research assessment tool to support this greater inclusion.
- The themes identified each inform about ways of including people with lived experience of disability in research about disability across respective areas of designing disability research, conducting disability research, and disseminating and evaluating disability research findings. This exploratory paper offers a preliminary,

evidence-based assessment tool to help to include more researchers with lived experience of disability as leaders and co-producers of disability research.

NEWS FROM OUR CDRP AFFILIATES

Brain Injury: Developing Guidelines for Physical Activities Project - Draft Guideline – Lauren Hassett

In 2021 we received funding from the Medical Research Future Fund as part of the TBI Mission (Stream 2-Incubator) to “conduct a small-scale development project to identify best-practice evidence-based care for moderate to severe TBI and facilitate consistent implementation by developing clinical guidelines and protocols.”

We formed the BRIDGES (BRain Injury: Developing GuidELineS for physical activities) team and undertook a series of research studies and processes to develop an Australian physical activity clinical practice guideline. The guideline includes 10 recommendations to support the clinical decision-making of health professionals and increase uptake of safe and beneficial physical activity by children, adolescents, adults and older adults living with moderate to severe TBI.

We are pleased to announce that a draft version of the guideline is now available for public consultation. We invite anyone with an interest in this guideline to view the guideline document and provide feedback using an online form, both found at the following link:

<https://www.connectivity.org.au/connecting-to-current-research-projects/brain-injury-developing-guidelines-for-physical-activities/>

The guideline is being hosted on Connectivity TBI website for public feedback.

WHO 3rd Global Rehabilitation 2030 Meeting and Launch of World Rehabilitation Alliance

Geneva, July 2023

The University of Sydney, WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems is part of the Centre for Disability Research and Policy. The co-heads of the centre, Professor Emerita Gwynnyth Llewellyn and Dr Kim Bulkeley attended the 3rd Global Rehabilitation 2030 Meeting and Launch of the World Rehabilitation Alliance in July in Geneva at the headquarters of the WHO.



Gwynnyth was invited to provide an address to the meeting on financing in health systems for rehabilitation (pictured above) as part of a very full agenda. The tone of the meeting was set by the recent resolution at the World Health Assembly in May 2023 to prioritise

rehabilitation, expanding and integrating rehabilitation in health systems as part of Universal Health Coverage (UHC), emphasizing the importance of rehabilitation in primary care and as part of emergency preparedness and response. The resolution highlights the value of rehabilitation and positions ongoing supports for people with rehabilitation needs at the heart of health systems planning in both universal and primary health care.

The World Rehabilitation Alliance (WRA) was also launched in the days following the Global Rehabilitation Meeting, with a ceremony to welcome all 80+ members of the alliance. Emilia Clarke of Game of Thrones fame launched the alliance in [a short video](#), sharing her experiences of the value of rehabilitation following brain surgery. Emilia has a set up a charitable organization, [Same You](#) to promote awareness of brain injury and is a member of the World Rehabilitation Alliance.

The University of Sydney WHOCC has representation on four of the WRA working groups. Dr Rebecca Barton is on the workforce group; Jo Lewis is on the primary care working group; Assoc Prof Margaret McGrath is on the research working group; and Assoc Professor Michelle Villeneuve is on the emergencies working group.

We were also able to connect with our WHOCC rehabilitation colleagues in the Western Pacific from China, Korea, Singapore, Japan and Hong Kong and will continue to maximise our opportunities for collaboration. Dr Bulkeley was invited to address the Asia Pacific Rehabilitation Forum hosted by the WHOCC in Guangzhou in July 2023, providing some Australian insights into telerehabilitation.

For any further information about the WHOCC for Strengthening Rehabilitation Capacity in Health Systems, please contact Dr Kim Bulkeley kim.bulkeley@sydney.edu.au or go to our web site <https://www.sydney.edu.au/medicine-health/our-research/research-centres/who-collaborating-centre-for-strengthening-rehabilitation-capacity-in-health-systems.html>

NEWS FROM THE DISABILITY-INCLUSIVE WORKFORCE AND SERVICES PROGRAM

Launch of the Heart-led Website



Image description: On top of the picture is the sentence on black letters: "Planning with a heart, Head and Hand framework" Below this title is three pictures side by side: the first picture is a clear green heart on a khaki green background with underneath the word "Feeling", in the middle is the picture of the silhouette of a head in red against a pink background with the word "Thinking" and the last picture is a yellow handprint against a clear green background with the word "Doing" underneath.

Professor John Gilroy, Dr Kim Bulkeley and Dr Genevieve Johnsson have launched a website to educate the disability workforce about a more relational process to inform planning. The training focuses on how to work with people with disability.

<https://heart-led.org.au/>

Professor John Gilroy, Decolonisation and Disability theme leader for CDRP, lead a large four-year study exploring ways to improve the NDIS planning process for people with disability living in regional, rural, and remote regions of West NSW and Central Australia. Nearly 90 people were interviewed, including people with disability on the NDIS and workers involved in the planning process. Nearly half of the participants were from local Aboriginal communities.

The main finding of the study is that the NDIS is improving the lives and wellbeing of thousands of people with disability living in regional and remote regions of Australia. However the NDIS planning process of traumatic and scary for these people. Professor Gilroy said "the fear of losing your NDIS, or even a fraction of the current budget and items, is equivalent to workforce insecurity. The fear and trauma are justified as any negative changes impacts on their lives and independence".

The team concluded that the existing workforce training materials for the workers who are involved in the planning process, do not adequately cover the “heart-felt” experiences of the NDIS and the NDIS planning process.

CDRP co-designed a series of training modules with people with disability, local Aboriginal community-controlled organisations, allied health workers, the NDIA, and disability service providers. The training modules incorporate the Head, Heart, Hand holistic principles that captures the importance of THINKING, HEART, and DOING. This approach recognises that disability support planning requires consideration of thoughts and feelings, as well as practical application of these. By focusing on all three areas, the Heart Head Hand approach aims to create a well-rounded and comprehensive planning experience that prepares people for success in their personal and professional lives.

The website, heart-led.org.au, as well as including leading research papers and resources on the NDIS, also introduce materials to help build on the cultural safety of the disability workforce for Aboriginal and Torres Strait Islander people with disability. Professor Gilroy said that “these materials were designed and developed by Aboriginal people with disability and carers”.

CDRP will work with industry partners to grow this website with more exciting modules of workers in the disability services sector.

NEWS FROM THE DISABILITY ACROSS THE LIFESPAN PROGRAM

A Call to Action for Disability and Rehabilitation Research - Roxanna Pebdani

“Disability identity and ableism must be viewed intersectionally, and disability related research must attend to the many facets of a person’s identity.” (Saia et al., 2023)

Congratulations to our Leadership group member, Roxanna Pebdani and her team for this publication. They recently wrote ‘**A call to action for disability and rehabilitation research using a DisCrit and Disability Justice framework**’ with colleagues from San Diego State University, Portland State University, and UW Madison. The paper advocates for the use of Intersectionality, Dis/ability Critical Race Studies (DisCrit), and Disability Justice frameworks to adapt our research practices for maximum inclusivity and representation. The paper presents seven considerations to guide the development of intersectional and inclusive disability research.

This publication can be accessed here:

<https://www.tandfonline.com/doi/full/10.1080/09638288.2023.2242780#metrics-content>

NEWS FROM THE MENTAL HEALTH AND WELLBEING PROGRAM

The mental health stream has a fantastic range of research underway, but here we will summarise just two major funded projects that will be keeping us busy over the next 2+ years!

Co-designing the DRIV-R App: supporting people to drive their own mental health recovery



In partnership with Flourish Australia and Helen Glover from enLIGHT'ened Consultants, Nicola Hancock (CIA), Justin Scanlan (CIB) and Anne Honey (CIC) submitted a successful MRFF 2021 – Consumer-Led research grant. This project involves the digitalisation of the RAS-DS (www.ras-ds.net.au). In the first year (this year) we mid-way through developing, using an iterative co-design and testing process, a digitalised resource (Driv-R) to support collaborative use of the RAS-DS, a self-report mental health recovery measure. In 2024-25 we will be testing the feasibility and usefulness of the final Driv-R from both consumer and staff member perspectives as well as testing the impact of Driv-R on (a) consumers' mental health self-efficacy, and (b) consumers' overall mental health recovery.

Let's talk about VOICES: evaluating the impact on voice hearers of interacting with e-resources

<https://www.nslhd.health.nsw.gov.au/hearingvoices/Pages/default.aspx>



This project, funded by the Elizabeth Moyira Vine Research Fund and the Northern Sydney Local Health District, involves evaluating the usefulness and impact of online resources designed to encourage and enable holistic, evidence-based support for voice-hearers. Voice-hearing is an experience that affects many people and can be distressing and debilitating. However, the ways people approach, engage with and cope with their voices are a critical determinant of distress and functioning and evidence suggests that understanding one's voices can facilitate recovery. We have just commenced engaging with the lived experience advisory team to co-design the data collection components of the project.

The research team: Dr Anne Honey (lead), A/Prof Nicola Hancock, Karen Wells (PhD Candidate) A/Prof Justin Scanlan, Hayley Zink, Lyndal Sherwin.

NEWS FROM THE DISABILITY INCLUSIVE DISASTER RISK REDUCTION PROGRAM

National Forum on Disability Inclusive Disaster Risk Reduction



Australia's first **National Forum on Disability Inclusive Disaster Risk Reduction (DIDRR)** took place on the 2nd of June, hosted by the **Centre for Disability Research and Policy** at the **University of Sydney**. In partnership with the NSW Government and the Australian Institute for Disaster Resilience (AIDR), this groundbreaking event brought together a diverse group of key stakeholders to shape the future of DIDRR in Australia.

The Forum aimed to:

- Share the Leave Nobody Behind (LNB) 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.

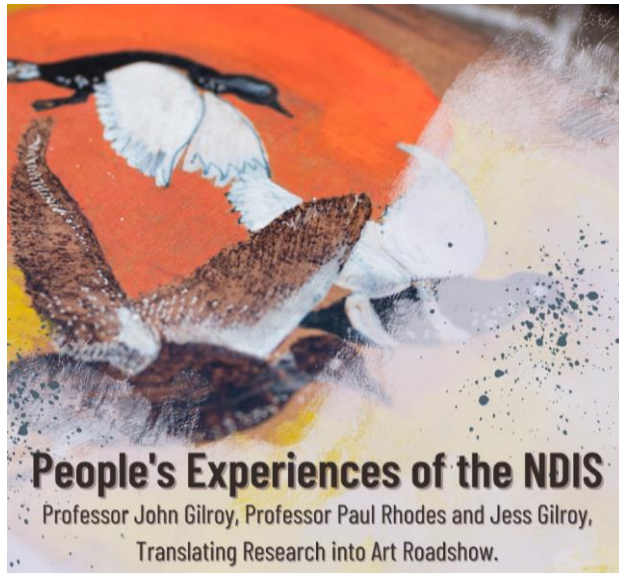
The Forum drew a diverse range of participants, including people with disability, carers, service providers, emergency services representatives, and expert in policy development. Together, they actively engaged in discussions, workshoping the framework using action orientated DIDRR knowledge and practices, as well as the latest insights from the LNB project.

View the event highlights video here: **National Disability Inclusive Disaster Risk Reduction Forum 2023**.

NEWS FROM the Indigeneity and Disability Research Stream

Translating Research into Artwork

As COVID lockdown and illness stopped his travel to country to meet rural and remote communities to talk about their needs regarding NDIS scheme, John Gilroy took on traditional woodburning art, and decided to start representing his research findings in his artwork.



John is a Yuin man from the NSW South Coast and is a professor of Indigenous health and disability, specialising primarily in disability studies. John has worked in disability and ageing research and community development with Aboriginal communities, government, and non-government stakeholders for most of his life. He is the first person to create Indigenous research methodologies in disability research.

His artworks translate the main

learnings and stories collected during Prof. Gilroy's research career and more specifically findings from his ARC-funded project: "A Better Life Under NDIS".

Image description: Three ducks flying, against an orange and yellow background, The two ducks at the back are black with white wings, the duck at the front is brown and white. Underneath the flight of ducks and in black letters is the title: "People's Experiences of the NDIS, Professor John Gilroy Professor Paul Rhodes and Jess Gilroy, Translating Research into Art Roadshow."

Produced in collaboration with two other artists, Prof. Gilroy's sister-in-law, Jess Gilroy, a Wiradjuri woman and a junior artist, and Professor Paul Rhodes, this collection of artworks tells the stories of hundreds of people with disability experience of the disability service system.

In July, he launched his artwork roadshow with a first exhibit in Orange, supported by partner organisation the Orange Local Aboriginal Land Council, followed by Brisbane. The exhibit provoked many local discussions on the diverse experiences of people with disability and the NDIS. These experiences are vastly different for Aboriginal and non-Aboriginal families, influenced by culture, history, lifestyles, and services.



Image Description: Picture showing a large group of people from diverse cultural background in a room surrounded by wood artworks displayed on tables- They are all facing the camera and smiling. Artist John Gilroy is standing in the front row, wearing a black polo shirt with aboriginal art print and a pair of jeans.

An exhibition of John's artworks will take place in Susan Wakil Health Building Faculty of Medicine and Health at the University of Sydney from the 21st November 2023. Registrations for the exhibit launch will open soon. Watch this space!

International outreach

Sydney Southeast Asia Centre Timor Leste Field School

July 2023

Dr Margaret Spencer and Dr Kim Bulkeley from the CDRP co-led a field school with 16 students from the University of Sydney under the auspice of the Sydney Southeast Asia Centre (SSEAC) and leadership of Dr Natali Pearson with funding from the Department of Foreign Affairs and Trade (DFAT) through the New Colombo Plan from July 16th to July 30th. Students were from Occupational Therapy, Social Work and Psychology and we also had an occupational therapy honours student join us. We linked in with five local students from the University Nationale Timor Leste (UNTL) and focused on employment of people with disability in Dili, the capital of Timor Leste. We were very fortunate to connect with government officials, including his excellency the President of Timor Leste, Jose Ramos Horta pictured below.

We had an opportunity to speak with his excellency in an informal meeting which gave the students time to ask questions and take in the many anecdotes he so generously shared with us.

We also had the opportunity to visit services and agencies that support people with disability and were overwhelmed with the generosity and welcome we received. The

students undertook a full unit of study in an intensive mode and were able to understand a great deal about the culture of Dili, learnt a bit of Tetum as part of the experience and connected with a wide range of stakeholders in the disability sector. SSEAC's Professor Michele Ford is leading an ongoing project on attitudes to employment of people with disability with CDRP's Dr Margaret Spencer and Dr Kim Bulkeley on the team.

We also have Dijin Wee, an honours student working on this project for the next 18 months with a focus on attitudes to people with intellectual disability. A large survey of 1000 people has been undertaken in Dili, which we worked on while we were on the Field School. The data has been collected now and we will commence analysis to gain insights into the attitudes of people in the community towards the employment of people with disability which can then inform policy responses.

For further information about the Timor Leste project or Field School please contact Dr Kim Bulkeley kim.bulkeley@sydney.edu.au

Successful EVENTS

NDIS Costs Webinar



In the context of [the independent review of the NDIS](#) initiated by the federal government, we held a webinar that brought together a **panel of experts, including service providers, policy researchers and researchers with lived experience of disability and NDIS participants**, to discuss what drives the current costs and sustainability of the NDIS. This panel provided perspectives on delivering an equitable and enduring scheme for all Australians living with a disability. The event recorded over 300 online attendees and we had over 60 questions in Q&A session. We apologise to those of you who asked a question that we did not have the opportunity to answer live.

Thank you to our panel members who participated and shared their insights on the NDIS promises and delivery:

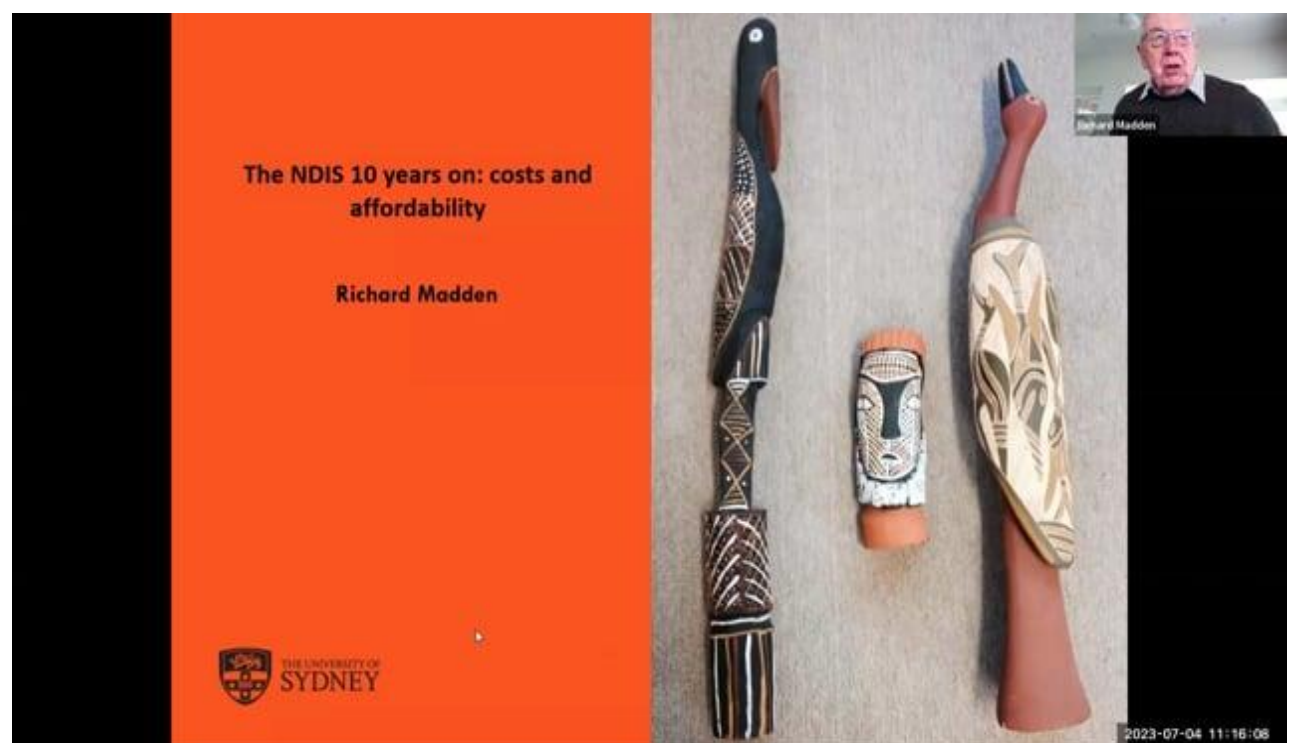
- [Em. Prof. Richard Madden](#) – Professor Emeritus, Faculty of Medicine and Health, Centre for Disability Research and Policy, University of Sydney
- [Martin Laverty](#) – CEO of Aruma Disability Services – Former Inaugural director of the board of NDIA.
- [Dr Kim Bulkeley](#) -Co-lead of the WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems – Centre for Disability Research and Policy, University of Sydney
- [Shane Clifton](#) - Director, Respect and Inclusion Policy, the Australian Royal Commission into Violence, Abuse, Neglect and Exploitation against People with Disability – Lived-experience researcher, Centre for Disability Research and Policy, University of Sydney

Thank you to our session moderator: [A/Prof. Justin Scanlan](#), Centre for Disability Research and Policy, Sydney School of Health Sciences in the Faculty of Medicine and Health, The University of Sydney.

The key points of this seminar are that the NDIS must be kept sustainable, which involves needing better measures to track the success of the scheme. The panel members emphasised that there needs to be measures to monitor the contribution of the NDIS on social outcomes, particularly non-financial considerations. Furthermore, the panel also highlighted that “Disability needs to be everyone’s business”. This means that support must be given to other organisations involved in the care of people with disability, such as charitable organisations and informal supports.


You can watch the recording of the webinar here:


[NDIS Cost and Sustainability Webinar](#)





Aboriginal Sign Language Forum – August 9th


The University of Sydney Diversity and Inclusion Team, the Yura Network and Disability At Work Network, DAWN, with the support of CDRP, organised and co-hosted the **Aboriginal Sign Language Forum** event on Wednesday, 9 August 2023. The day was filled with incredible discussions and connections that left a lasting impact.


 **Honoring Our Roots:** We started with Daniel McDonald's Welcome to Country, reminding us of the deep connection between language, culture, and history.


 **Finding Inspiration:** Melanie McKay-Cody's international keynote speech fired up our passion for preserving Indigenous languages. Her words made it clear that our efforts hold the key to preserving our cultural heritage.

 **Guiding the Day:** Professor **David Evans** led the way as our Master of Ceremonies, guiding us through discussions and making sure every voice was heard.

 **Mapping Our Languages:** Lauren Reed's exploration of Indigenous Sign Languages around Australia showed us the rich tapestry of languages that deserve recognition and celebration.

 **Language and Well-being:** Rodney Adams reminded us of the connection between sign languages and mental health. He sparked important conversations about the healing power of language.

 **Time Travel Through Words:** Dr. Bentley James took us on a journey through time, emphasising that our languages hold the wisdom of generations, and it's our responsibility to protect them.

 **Inclusivity Matters:** Dr. Scott Avery's call for inclusivity resonated deeply. He reminded us that our event aimed to create a space where every voice is valued, especially those with disabilities.


 **Part of the Solution:** Professor **Lisa Jackson Pulver**, Professor **Jakelin Troy**, and **Leilani Craig** gave us hope for the future. Embedding equity and inclusivity into the curriculum is the only way forward. This is something that the University MUST embrace if we are to come together to make sure that we see all different perspectives and are not limited to a majority viewpoint: *"We are facing the sorts of issues that has never been faced before. Yet we're being looked at as being part of the solution because there is something to be said about a mob of people who have the oldest continuing culture, continuous, in the whole wide world. 60,000 years through Ice Ages, through comet strikes, through everything, and it's time."* Thank you to **Charles Humblet** for facilitating this very rich conversation.



Image description: a group of people from diverse cultural backgrounds doing the Auslan applauds.

The impact that was created provided an opportunity for change and decision-makers to come together for the first time to discuss, plan, identify, and collaborate towards the awareness and elevation of First Nations voices that may have never been heard before – that will now push for the integration and implementation of Indigenous Sign Languages within the University’s curriculum. As we look back on the Aboriginal Sign Language Forum event, let's carry forward the insights and connections we gained. Together, let's continue preserving and celebrating Indigenous languages.

A special shout out to: Melanie McKay Cody, Rodney Adams, Lauren Reed, Scott Avery, Bentley James, Daniel McDonald, Ferran Thornycroft, Neil Fenelon, James Ashcroft, Lluwannee George, Craig Seinor-Davies, Kade Fenwick, Leilani Craig, David Evans, Lisa Jackson Pulver, Jakelin Troy, Charles Humble, Vicki-Anh Winfield, Virginie Lecomte Maloney, Andy Netherington, Sue-Ellen Simic and John Gilroy. Thank you all for the hard work and contributions you made to your field of work, for your colleagues, your families, peers, for the University, the community, and for the progression of our species.

Disability Inclusion Week – September 4th

Harm's Way Play Reading



*Written by Moira
Dunsmore*

*Image description: Nine
actors seated at a long
table for a play reading.
An AUSLAN interpreter
stands behind them.*

To mark the start of Disability Inclusion week on the 4th September 2023, we held a play reading of 'Harm's Way' in the Susan Wakil Health Building which was open to the public, staff and students of the University of Sydney. Harm's Way is a one-hour play that follows six people living with various degrees of combined hearing and vision loss, commonly known by a number of terms such as deafblindness and dual sensory impairment (DSI). The play was read by a combination of actors, with and without disability, communication support professionals and academic staff, as a way of translating complex health and disability challenges to a public audience to raise awareness of DSI.

This play was written by Dr Annmaree Watharow and directed by Izabella Louk. Annmaree is a research scholar at the Centre of Disability Research and policy; she is also a GP and a Masters graduate of Creative Writing. Annmaree lives with deafblindness, (the co-occurrence of hearing and sight loss, such that neither sense can compensate for the other) and now lives with the complexities of a profound hearing loss, and minimal vision. Annmaree created and wrote this play to communicate and translate the lived experience of deafblindness or dual sensory impairment to as many people as possible.

In this play, Annmaree uses therapeutic emplotment to structure the play to mirror a hospital admission, from the injury/illness/misadventure, through to post-discharge. Wherever possible conscious casting of people living with disability and or caring for people with disability was employed. The play was well attended and to date has had positive feedback. The next step is to promote this play publicly to ensure the lived experience of DSI is recognised and acknowledged in health care and more broadly.

You can watch the recording of the play reading here:

[" Harm's Way" : Exploring hospital experiences of people with sensory loss\(es\) - Play reading](#)



Assistive Technology Expo

The University of Sydney community turned out in large numbers to experience our Assistive Technology Expo on Wednesday the 6th September as part of the activities in our [Disability and Participation Major](#) unit of study [OCCP2090 Disability and Assistive Products](#) led by Bronwyn Simpson.

We had over 10 suppliers of assistive products ranging from bedding and adapted beds to thermomixers, communication devices, mobility equipment, low vision adaptations and eye gaze switches. It was a great opportunity for members of the university community to explore the potential of assistive technology as an enabler of greater participation for people who experience disability.

Students from the assistive products unit were encouraged to engage with the suppliers and develop a product critique as part of their studies. The suppliers generously provided a series of fifteen minute “Lightning Talks” at regular intervals to highlight particular products or approaches to applying technological solutions.



Image description: different views showing people attending exhibition stands- The banner of the Centre for Disability Research and Policy can be seen on the first photo in top left corner- In top right corner a picture of people using wheelchairs attending the stand of the company Permobil. In the bottom left corner, people attending the stand of the company Control Bionics, and on the bottom right corner people attending the stand of the company Liberator.

Upcoming Events

Disability Research HDR Symposium – October 27th 2023

After the very enthusiastic feedback we got from students attending last year, we are organising the second edition of our annual Disability Research HDR Symposium

Date: Friday 27th of October

Time: 9:30am-4:00pm

Location: Room 308, Susan Wakil Health Building

The **Disability Research HDR Symposium** is organised by the **Centre for Disability Research and Policy** in the Faculty of Medicine and Health and is offered to all HDR students with an interest in disability and rehabilitation research, from all university faculties. This event is also open to external students.

This year's symposium theme is "**Pathway from Research to Policy**". The event aims to provide an understanding of how disability research informs policy and an informed outlook towards disability careers outside academia. Our keynote speakers will be Janice Biggs, Manager Research and Evaluation Branch, Policy, Advice and Research Division at the [National Disability Insurance Agency NDIA](#) and Emily Forrest, Director of Policy and Advocacy at [National Disability Services NDS](#). The event will also provide opportunity to hear from former PhD students and learn about their career path.

This event will also provide opportunities for students to:

- Identify the transferable skills gained through the research degrees, and workshop their academic and industry CVs.
- Understand the range of academic, government and other industry career opportunities available.
- Talk to former HDR graduates in both academia and industry careers.
- Meet and connect with HDR students with similar research interests.

Spots are limited, so if you're a HDR student with an interest in disability and policy, please register here:

<https://CDRPDisabilityResearchHDRSymposium.eventbrite.com.au>

Ageing and Dual Sensory Impairment Symposium



Date: 9th November 2023

Time: 9 am to 4:30pm AEST

Location: Susan Wakil Health Building

A multi-disciplinary conference on dual sensory impairment in older Australians convened by the co-leads of the Dual Sensory Impairment Project at the University of Sydney: Drs Moira Dunsmore, Julie Schneider and Annmaree Watharow.

Secure your spot here:

<https://AgeingDualSensoryImpairmentInternationalSymposium.eventbrite.com.au>

International Indigenous Disability Research Conference

CDRP is organising the **first International Indigenous Research Disability Conference** hosted by Indigenous scholars and staff from CDRP and University of Sydney, led by Professor John Gilroy.



Date: 22nd and 23rd November

Location: Susan Wakil Health Building

This event is the first of its kind at the University of Sydney, aiming to explore and bring to light what the international platform of Indigenous disability research looks like under the United Nations (UN) Declaration on the Rights of Indigenous Peoples (DRIP) and Convention on the Rights of Persons with Disabilities (CRPD). The objective from this event is to develop a strategy for the University's research centres in how they engage in the Indigenous research space on a global scale under the UN's DRIP and CRPD. There are three questions we want to address:

What does the international disability research archive look like on a global scale?

How can scholars respect and empower Indigenous people with disability in research and research translation that is culturally respectful for Indigenous people?

What does decolonisation/Indigenisation mean in disability research?

Indigenous people are invited to do presentations on their research space, including their own research, and produce ideas on what the Strategy should look like. Presentations will be on what the research archive looks like in each presenter's nation and discipline area. Furthermore, there will be discussions on research ethics and Indigenous traditional research knowledge translation within a decolonisation/Indigenisation lens.

Everyone is welcome to attend and engage in the event. Seats are limited, secure your spot by registering here:

<https://InternationalIndigenousDisabilityResearchSymposium.eventbrite.com.au>

CDS/CDRP Monthly Seminars 2023

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

The next seminar will be held on the 5th of October. This seminar will present CDRP's work with [National Disability Services](#) of the [2022 State of the Disability Sector Report](#), by Roxanna Pebdani, Damian Mellifont, Gordon Duff and Justin Scanlan.

Register to attend online:

[CDS/CDRP disability study seminar – Thursday 5th October-1pm](#)

Upcoming seminars:

- Thursday 9th November : Luis Salvador-Carulla- “How to assess the support ecosystem for persons with disabilities? The case of psychosocial services in ACT and Western Sydney”
- Thursday 14th December : Tania Rose – “Differability and The Arts”

Keep up to date with our upcoming events: [Follow us on EventBrite](#)

Thank you for following and supporting CDRP's Research

Follow us on X (formally Twitter): [@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>