

# Centre for Disability Research and Policy

## Welcome to our December 2022 Newsletter

### DIRECTOR'S WELCOME:

2022 has been another significant year for a Centre whose work focuses on the changing world of disability policy and practice. We have much to be relieved about with the significant amount of attention now being paid to disability as a core part of national social and health discourses. Disability is prominent as part of our national agendas in a way that we could only dream about when the NDIS was first announced more than 10 years ago.

Next year the NDIS turns 10 and we have a review of the scheme underway, we also have a new disability strategy being implemented, the launch of the next phase of the National Disability Research Partnership and, we hope, the cementing of the National Disability Data Asset as a core research and knowledge too. We therefore end the year with excitement about next year – there remains much to do and contribute to and we are well placed in CDRP to continue to shape policy and practice to make lives better for people with disability in Australia and our region.

We also end the year with huge congratulations to the following CDRP members who have been promoted this year. Promoted to Senior Lecturer: Rebecca Barton and Jodie Baillie. Promoted to Associate Professor: Roxy Pebdani and Margaret McGrath. Promoted to Professor: John Gilroy. Career development, including promotion, for CDRP members is a core goal for the centre so these promotions are a significant outcome for all of us.

Wishing you all a safe and happy break.

*Jen Smith-Merry*

*Image: A wooden Christmas tree lit-up with small fairy lights on a beach, at sunset*



### A MESSAGE FROM CDRP MANAGER:

As the year draws to a close, we all reflect on how 2022 treated us all. For me, 2022 was a year of discovery (a new field, a new University, a new team...a whole new world), and renewed purpose, as I could reconcile my personal and professional goals by supporting people with disability and their families through meaningful research, and sense of belonging, thanks to the very warmly welcoming community I found within CDRP. I am feeling extremely grateful to be part of this purpose-driven team all working toward “improving the lives of people with disability in Australia and the Asia-Pacific”. I would like to extend my thanks to all of you, for being a very engaged community that has, many times this year, answered our call for participation, from attending events in person or online to contributing your voice to our policy consultations in the form of workshops or online surveys. Please read on to get some updates on what we have been up to over the last few months

We value the insights and lived-experience our community can contribute to our research and policy work and we are looking forward to hearing and relaying your voice next year. With the first opportunity coming very soon in the new year, with CDRP preparing a submission to the [Department of Social Services consultation on a new version of the Disability Service Act](#). We will be seeking your feedback on this new proposal for this very central piece of policy through a series of workshops organised in January and an online survey that will be open from next week throughout January, to give plenty of time for people to have a chance to share their thoughts with our consultation teams. Stay tuned and check your emails for our next call to participation!

You can also follow us on Twitter [@USydCDRP](#) for regular updates on our research and our collaborators'.

*Virginie Lecomte Maloney*

## **INTRODUCING OUR NEW CDRP LEADERSHIP GROUP**

As announced in our last newsletter edition, following up on the decision from our July Strategy Day to appoint a CDRP leadership group, 5 CDRP academic members got selected after a competitive EOI process to be part of CDRP first leadership group. They will be joining the rest of the leadership team, our director Prof. Jen Smith-Merry, our deputy-director A/Prof. Michelle Villeneuve and our centre manager, Dr Virginie Lecomte Maloney, to stir CDRP research strategy during the next 12 months.

Please welcome to **CDRP 2023 leadership group**:

### **Gordon Duff**



Gordon is a PhD candidate investigating the dynamics of value cocreation and service innovation in the NDIS, linked to an ARC Linkage Grant on the quality of life of adults with an intellectual disability. Prior to joining Sydney, Gordon held senior management positions in the health and human services sectors in the UK and Australia, most recently as General Manager for National Disability Services, the provider peak body, where he had oversight of national functions for research, policy, workforce, and sector development. He is a former Fulbright scholar in Non-Profit Leadership for his work supporting applied research and innovation in the context of Australian disability reform. He is a Visiting Fellow at UNSW Canberra Public Services Research Group, an Associate of the Disability Innovation Institute at UNSW Sydney, and an independent

advisor to the University of Melbourne Disability Institute, supporting the establishment of the National Disability Research Partnership as a world class disability research and policy hub. Gordon is a member of ASID, IASSIDD, the Australasian Research Management Society (ARMS), the Australasian Evaluation Society (AES), the International Research Society for Public Management, and the International Initiative for Disability Leadership (IIDL).

*Image: Mr Gordon Duff*

### [Dr. Susan Collings](#)



*Image: Dr Susan Colling*

Dr Susan Collings is a Senior Research Fellow and Program Lead in Disability and Child Protection at the Research Centre for Children and Families at the University of Sydney, Faculty of Art and Social Sciences. She is a research affiliate with the Centre for Disability Research and Policy and sits on a number of committees concerned with overcoming the inequalities faced by parents with intellectual disability and their children. Her research focuses on building evidence on the lived experiences of disability and the social inequalities for children and families impacted by child protection and out-of-home care. Susan leads co-design and arts-based research to privilege knowledge based in lived experience and is internationally recognised for her research on parents with intellectual disability and their children. Her research has appeared in over 50 publications and reports.

### [Dr. Damian Mellifont](#)



*Image: Dr. Damian Mellifont*

As a neurodivergent researcher, Damian Mellifont (PhD) leads and contributes to studies that advance the economic and social inclusion of people with disability. Damian is proud to be a member of the Centre for Disability Research and Policy (CDRP) Leadership Group at The University of Sydney. Damian strongly advocates for the disability inclusion mantra of, 'Nothing About Us Without Us' to be consistently applied to research about disability.

### [Dr. Genevieve Johnsson](#)



*Image: Dr. Genevieve Johnsson*

Genevieve is a psychologist with 15 years of experience working in the disability sector and an Honorary Senior Research Fellow with the Centre for Disability Research and Policy at the University of Sydney. Genevieve is passionate about community-based participatory research and developing programs and services that improve access for children with disability and their families. Genevieve's research areas include early childhood developmental support, community participation and inclusion, rural and remote service access, and the role of telepractice in providing quality support.

### A/Prof. Justin Scanlan



Image: A/Prof. Justin Scanlan

Associate Professor Justin Scanlan is an occupational therapist with a clinical background in mental health. His research is focused on the experiences of individuals living with psychosocial disability interacting with the NDIS as well as evaluation of innovative services for individuals with mental distress and the experiences of the mental health workforce. He is committed to promoting inclusion of individuals with lived experience in both research and teaching. Alongside his role at CDRP, Justin teaches mental health units of study in the undergraduate and graduate entry master occupational therapy programs and is the NSW Practitioner Member on the Occupational Therapy Board of Australia

## CDRP'S CONTRIBUTIONS TO NATIONAL CONSULTATIONS

### Australia's Disability Strategy 2021-2031: Consultation to inform the Strategy Guides



Creating an inclusive  
community together

In October 2022, the governments launch a national [consultation on two new guides under the Strategy](#) to help improve its implementation:

- A guide to assist governments, businesses and the community to **apply the Strategy's Guiding Principles**.
- A guide on how governments, businesses and the community can **Involve People with Disability in Evaluations**.

Both guides aim to drive improvements to policies, programs, and services so they are accessible and inclusive for people with disability.

To prepare a submission on behalf of CDRP, our center put together a team of experts in co-design and lived experience research:

- Dr Genevieve Johnsson
- Dr Kim Bulkeley
- Dr Damian Mellifont
- Dr Annmaree Watharow
- Dr Virginie Lecomte Maloney

You can access and read CDRP's submission on our webpage: [CDRP- Consultation on the Strategy Guides](#)

To build a strong and diverse response, we reached out to CDRP's community and asked you to provide your feedback to inform CDRP's contribution with your specific lived experience. Our team facilitated a workshop attended by over 20 participants, where we debated the principles guiding both the "guide to apply the Strategy principles" and "the guide for involving people with disability in evaluation".

For the first time, we also sent around an online survey to offer different modes of participation to cater for all communication preferences. We always endeavour to make our contents as accessible as possible and will aim at offering more ways for our community members to participate in our future consultations. We also welcome your feedback on accessibility features we could add to our centre's communications.

CDRP's submission advocated for a stronger emphasis on the efforts that must be made in all contexts to allow people with disability to take a central place in all decision-making affecting their lives. The team pointed out the use of ableist language in some of the principles of both guides.

Our submission defended Communication as a human right and the necessity for accessibility to be built-in in all systems.

As a group, we support normalisation of disability in the society and encourage to stop talking about disability and start talking about different abilities and a range of varying abilities. The language used in the guide should be modified to acknowledge people's abilities rather than acknowledging their disability and working with people to maximize that ability, shifting from a negative appraisal to a valuing perspective of the contribution of people with disability.

Specific recommendations were made about the guide for evaluation proposing to add as founding principle "Leadership" of people with disability in evaluation, supported by expert allies, rather than co-design.

The team defended another additional principle to be considered: "Investments" with the need to invest in accessibility, adjustments, employment, and resourcing to support high-standard co-design and lived-experience-led evaluation protocols. The need for better recognition of the expertise of people with lived experience through appropriate remuneration and inclusion in the research team.

We value the particular perspective our CDRP community contributed to this discourse. We would like to thank all who shared their insights with us and provided their feedback!

## Employment White Paper Consultation



Building on the outcomes of the Jobs + Skills Summit, in October the governments sought contributions for the Employment White Paper, to provide a roadmap for Australia to build a bigger, better-trained and more productive workforce – to boost incomes and living standards and create more opportunities for more Australians.

A submission, that was prepared on behalf of CDRP by a team of our academic members:

- Dr Kim Bulkeley
- Dr Caroline Alcorso
- Prof. Richard Madden
- Prof. Jennifer Smith-Merry
- Dr Damian Mellifont

Their submission focused on the shortage of workforce in the care economy, in parallel with the dire employment rates of people with disability. The juxtaposition of the lack of a disability workforce with the low rates of disability employment points to an obvious conclusion that this group of underemployed and unemployed people would be a significant asset to the disability sector.

You can access and read this submission our webpage: [CDRP submission to The Employment White Paper](#)

They propose the development of a policy framework that recognises and promotes the employment of people with lived experience of disability as a desirable and valuable potential workforce to address the shortages in the disability sector. They argued policy levers within the NDIS and public service can be mobilised to encourage targets for employment of people with disability as part of engagement as an NDIS provider or as a government agency. They suggested trials of programs that train and support organisations to shift their thinking around employment of people with disability and development of training qualifications in advocacy and mentoring.

They also highlighted a need for the revision of the employment support payment, judging the policy fundamentally ableist in the assumption that you no longer have a disability if you have been able to work for two years. Solutions proposed to reform DSP so this policy supports employment people with disability rather than being a barrier:

- recognition of their disability as a life-long condition as part of the initial application for the DSP, placing them in a designated category that maintains eligibility for the DSP
- not to be over-penalised for earning additional income. Limits on income before tapering applies, and lower tapering rates
- A more informed and enlightened approach to DSP eligibility is required to not disadvantage people with disability who are more at risk to experience longer periods of unemployment.

Employment of people with disability targeting areas of workforce shortage is a key shift in employment policy that has the potential to transform the employment rates of people with disability.

## NATIONAL DISABILITY RESEARCH PARTNERSHIP (NDRP) DISABILITY RESEARCH AGENDA



For the last 12 months, CDRP in collaboration with Centre for Disability Studies (CDS), affiliated centre to the University of Sydney, has led a consortium of academic and non-government partners to develop a [National Disability Research Agenda](#), as part of the [National Disability Research Partnership](#) (NDRP).

Recommendations for the National Disability Research Partnership's establishment and *Preliminary Research Agenda* have been released on the 14<sup>th</sup> December 2022, indicating the areas of key focus for disability research. Initial consultations held during the agenda setting research project identified four areas where research is needed:

- Research about making services better;
- Research about different experiences of people with disability in Australia;
- Research about how systems can support people better; and
- Research about improving mental health and wellbeing.

Access the preliminary research agenda [here](#)

The NDRP research agenda is being developed to guide the allocation of research funding by the NDRP over a ten-year time period. It will provide the foundation for the NDRP to deliver on its vision to facilitate a collaborative and inclusive disability research program that builds evidence for successful policy and practice.

The Australian Government has announced funding of \$15 million to fully establish a National Disability Research Partnership over 2022-23 to 2024-25.

Minister for Social Services, The Hon Amanda Rishworth, and Minister for the NDIS, the Hon Bill Shorten have confirmed the Australian Government's support for the NDRP.

"Using research to help design evidence-based policy solutions will help us move towards achieving that vision," Minister Rishworth said. "The NDRP is an Australian-first entity that will build knowledge through partnerships it will also recognise and value the lived experiences of people with disability and prioritise co-design and collaboration."

Read the full media release here: [Improving the lives of Australians living with disability through research](#)

Next steps: consultation in early 2023...

NDRP is now working on expanding the research agenda and developing a framework which will guide the allocation of NDRP funding. In early 2023, they will invite feedback through an online survey and a series of workshops with the disability community.



## NEWS FROM OUR CDRP's AFFILIATES

### Professor Luis Salvador-Carulla receives Tom Trauer Award

*Image: Honorary Professor Luis Salvador-Carulla on a stage receiving the Tom Trauer Award from the presenter, with his name and award projected on a screen behind him. Behind him is a member from a panel sitting at a table. To the right are upright banners for the Mental Health Service Conference and Mental Health Service Awards.*



[Luis Salvador-Carulla](#), Honorary Professor of the School of Public Health, and member of the CDRP, University of Sydney, has received the 2022 Tom Trauer Award for his contribution to mental health service research in Australia and internationally. His multidisciplinary team at the Mental Health Policy Unit (originated at University of Sydney and now at University of Canberra) has developed a series of innovative tools to help decision making in mental health policy and planning. These tools include service classification systems, atlases of mental health care and computer-driven decision systems that

have been adopted and used in 35 countries around the world.

DESDE ("Description and Evaluation of Services and DirectorIEs) is a tool to describe code services across sectors and for different target groups that has been used for developing local atlases of care in mental health, disabilities, social care, aged care, chronic care and other areas. It has been core to the development of a new approach to the analysis of the context of care to improve the implementation of interventions at local level. It allows international comparisons that have allowed, for example, the evaluation of services for mental health in remote areas of the world including Lapland (Finland), Nunavik (Canada) and the Kimberley (Western Australia). The approach combining local information and global comparisons has provided a new framework for understanding complexity in health care under the GLOCAL project (<https://nceph.anu.edu.au/research/projects/glocal-global-and-local-observation-and-mapping-care-levels>)

This international work has improved our understanding and evaluation of care in Australia.



## WHO Collaborating Centre for Strengthening Rehabilitation Capacity in Health Systems



*Image: Dr Kim Bulkeley and colleagues standing in front of a forum banner, at the WHO Collaborating Centre regional forum in Siem Reap, Cambodia.*

The [WHOCC for Strengthening Rehabilitation Capacity in Health Systems](#) has been redesignated by the WHO as part of the Western Pacific Regional Office (WPRO) from July 2022-2026. The centre will be led by Professor Gwynnyth Llewellyn and Dr Kim Bulkeley. Kim recently attended the WHOCC regional forum in Siem Reap (Cambodia) and met with colleagues from across the region to identify areas of shared interest and potential collaboration to support the [For the Future](#) plan.

The activity plan for the WHOCC includes four activities:

- Mapping rehabilitation in UHC and PHC in targeted WPRO member states;
- Developing resources to facilitate task sharing in PHC;
- Supporting national rehabilitation frameworks, strategic plans and monitoring;
- Development of data sets in health, functioning and disability.
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The WHOCC has also recently been approved as a member of the [World Rehabilitation Alliance](#) which is a mechanism for implementing [Rehabilitation 2030](#). We will contribute to four workstreams within this context:

1. Workforce
2. Primary care
3. Research
4. Emergencies

Please reach out to [kim.bulkeley@sydney.edu.au](mailto:kim.bulkeley@sydney.edu.au) if you have an interest in being part of the work of the WHOCC.

## UPDATE FROM OUR LIVED-EXPERIENCE RESEARCH FELLOWS

### Breaking the Barriers to people living with psychosocial disability applying for NDIS support



Research Team: Debbie Hamilton, Damian Mellifont, Jennifer Smith-Merry and Justin Scanlan

Almost 400 people/organisations participated in our National Mental Health Commission funded project. In this project we explored with you the current barriers to people with psychosocial disability applying to the NDIS and then with you we developed key stakeholder recommendations to address those barriers.

We are thrilled to announce that the project is now complete, and the report is available.

*Image: NDIS logo (white letter of NDIS on purple background) on a blue sky background piercing through a wall of white bricks.*

Link to Full Report can be found here: [Breaking the Barriers to people living with psychosocial disability applying for NDIS support](#)

### Release of the ACOLA Report on “Ensuring Occupations are Responsive to People with Disability”

As a neurodivergent researcher, Dr Damian Mellifont leads and contributes to studies that advance the economic and social inclusion of people with disability. Damian is a proud member of the CDRP Leadership Group.

Damian has actively contributed to the latest Australian Council of Learned Academies (ACOLA) report entitled, 'Ensuring Occupations are Responsive to People with Disability' by conducting a scoping review and actively participating in review processes.

This timely and informative report can be accessed at <https://www.disabilitygateway.gov.au/document/3141>.

Damian is enjoying working with team leader [Associate Professor Nicola Hancock](#), Associate Professor Justin Scanlan and Deb Hamilton on the National Mental Health Commission funded study examining NDIS access barriers for people with psychosocial disability. The Australian Journal of Social Issues has recently accepted our manuscript on this important topic for publication. You can access this article here: [Barriers to applying to the NDIS for Australians with psychosocial disability: A scoping review](#). A second manuscript that looks at stakeholder-proposed solutions to redressing these barriers is now under development.

Damian is currently working on an exciting project with [Dr Annmaree Watharow](#) that is comparing and contrasting our experiences as researchers with disability. This study aims to reveal evidence-based ways in which to advance an academy that better supports employment and career development opportunities for lived experience researchers.

## A second successful meeting for DualSIG – Dual Sensory Impairment special interest group.

In 2018, [Moira Dunsmore](#), [Julie Schneider](#) and [Annmaree Watharow](#) set up a dual sensory impairment special interest group with the goal of sharing research and experiences, with the goal of building better understandings in the nascent field of deaf-blind/dual sensory impairment (DSI) studies. This was then, a small mutual support group but after completing PhDs was resurrected this year to become International and with the additional goal of translating research into benefits for individuals, families and communities.

The first renewed DualSIG meeting took place in July 2022, with attendees not just from the CDRP, but Canada and the UK and was more a getting to know what everyone-is- doing-in-the-field session.

Following up on this meeting, highlighting the need to raise awareness of dual sensory impairment and communication needs of people with deafblindness with the practitioner community, Annmaree and Moira set up to organise workshops at the University of Sydney. The workshops were developed in collaboration with Roslyn Barnes, an accredited teacher in Auslan, Deafblind Tactile, Hand over Hand/English, as small hands-on groups focusing the different communication modes for people with deafblindness, including Haptics signing (tactile signing on people's arms or hands), and tactile AUSLAN. A series of four workshops was held between September and November and were very positively received.



*Image: two pictures of a hand touching an arm, in contrasting colors; text: DUALSIG- Dual Sensory Impairment Special Interest Group- Touch Messaging A small hands-on group workshop.*

The second meeting in December was bigger with greater global reach to Brazil, Netherlands, Norway and even Perth and Melbourne. We had a mix of practical and research presentations around the topic of Social Participation: [Dr Peter Simcock](#) spoke on the deafblind studies course he convenes in Birmingham, because professionals have poor literacy around the concerns and support needs of people who live with co-occurring hearing and sight loss. Two multi-sensory impairment interventionist teachers from the UK, Claire Mahood and Carolyn Grieg spoke about their work with schools and young people. [Professor Colette Browning](#) from Melbourne distilled her thoughts on a few decades work in the field of social participation and reminded us that people living with DSI want better social interactions where they choose, not more social interactions to choose from. And finally [Karen Wickham Grey](#) from Perth gave us a glimpse of the hub that she runs that provides social engagement, educational sessions, creative opportunities, covid vaccinations and support and more.

It is clear that this group fills a gap where researchers, practitioners and those with lived experience can learn from each other to translate good ideas into reality.

## NEWS FROM THE INDIGENEITY AND DISABILITY RESEARCH STREAM

### Planning for a better life under the NDIS

*Image: A painting representing three brightly colored houses- the ground is red; there are rocky hills in the background. Two people in wheelchair are represented in the driveway of the first house; a little kid in blue running towards them; a dog is near the house; a third person in wheelchair is pushed by a woman near the second house.*



Artist: Billy Kenda, Bindi Mwerre Anthurre Artists, Alice Springs, Northern Territory

In 2020-2021, 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 project is now moving into the knowledge translation phase and will be using the information they received to produce 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.

On behalf of the project team, Dr Genevieve Johnsson recently 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 30<sup>th</sup> November 2022.

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

#### Research team:

- [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 WORKFORCE RESEARCH STREAM

### Telepractice

*Image: A mother and her daughter are sitting at home on their lounge. The daughter is sitting on her mum's lap; they are both looking at a laptop the mum is holding; the mother is waving at someone on the laptop; they are both smiling.*



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-centered 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-centered telepractice titled Ready, Tele, Go! The companion will be available on the Centre for Disability Research and Policy website in January 2023.

#### Research team:

- [Dr Kim Bulkeley](#) and [Dr Genevieve Johnsson](#), Centre for Disability Research and Policy, University of Sydney,
- [Dr Anoo Bhopti](#), Monash University
- [Jenna Bongioletti](#) and [Dr Joanne Hinitt](#), University of Sydney
- Associate Professor [Christine Johnston](#), Western Sydney University



## EVENTS

### Leader in Disability Keynote Lecture – Prof. Gerard Goggin

*Image: Headshot of Prof Gerard Goggin*



For its inaugural Keynote Lecture, [the Centre for Disability Research and Policy \(CDRP\)](#) at the University of Sydney partnered with the [Sydney Southeast Asia Centre](#) to host a special event on the 14<sup>th</sup> November, welcoming back to Australia [Gerard Goggin, Professor of Media and Communications](#), returning from three years at Nanyang Technological University, Singapore. This event was hosted in Hybrid mode in CDRP's HQ, the Susan Wakil Health Building, and welcomed more than 100 people both in person and online, from Australia and Singapore.

In a lecture entitled "[Disability in Digital Societies in Australia & Southeast Asia](#)", Prof. Goggin presented his work on emerging technologies, disability, rights, and equalities in Australia and Singapore, and gave a broad overview on the different approach to accessibility in both countries. We endeavored to make this lecture as fully accessible as possible for all who attended, providing high-quality live captioning and AUSLAN interpreters throughout the event. Prof Goggin took special care to deliver a very accessible lecture, through the language and visual tools he used.

The lecture was followed by a vivid discussion with a panel of experts in the field, who joined us both in person and online:

- [Professor Alistair McEwan](#), Ainsworth Chair of Technology and Innovation, The University of Sydney
- [Dr Leyla Craig](#), Disability Inclusion and Engagement Officer, Fire and Rescue NSW, specialist in disaster risk reduction in Southeast Asia
- [Dr Genevieve Johnsson](#), Psychologist and researcher, specialist in technology-based training and support for rural and remote professionals, including Southeast Asia.
- [Dr Kuansong Victor Zhuang](#), Fung Global Fellow at the Institute of International and Regional Studies, Princeton University, and International Postdoctoral Scholar at the Wee Kim Wee School of Communication and Information, Nanyang Technological University

After the lecture, the attendees in person enjoyed some delicious food and drinks and took advantage of the opportunity to meet with other key stakeholder in the disability research in Australia and South-East Asia, in successful networking evening.

Thank you to all who contributed to make this event an enjoyable evening!

## Disability and Rehabilitation Higher Degree Research (HDR) Symposium

The Disability and Rehabilitation HDR Symposium was held on Thursday, 20<sup>th</sup> of October at the Julie Wu Lecture Theatre 321, Susan Wakil Health building. The Symposium was attended by around 50 HDR students, either in-person or online. These students were primarily from the Faculty of Medicine and Health, and Faculty of Arts and Social Sciences.

The Symposium involved a day-long program, which intended to give HDR students more opportunities to hear from lived-experience researchers, understand the transferable skills they have attained during their MPhil/PhD journey, hear about potential careers from people within academia and in the industry, and meet other research students.

The program included:

- Keynote Lecture by [Professor Shane Clifton](#)
- Lived-experience research panel: Dr Damian Mellifont, Dr Scott Denton, Prof Shane Clifton, Dr Annmaree Watharow, Dr Martin Raffaele; moderated by Dr Rebecca Barton
- Transferable skills workshop: Prof. Jennifer Smith-Merry
- Disability Sector Landscape and Opportunities session: Gordon Duff
- Industry career panel: Dr Cherry Baylosis (Disability Advocacy NSW), Dr Jade Chang (CDRP), Dr Genevieve Johnsson (Re-Imagine Australia), Dr Nicola Fortune (Department of Social Services, Australian Government); moderated by Dr Virginie Lecomte Maloney

Thank you to all our speakers and moderators for contributing to this event. The event received unanimously positive feedback from attending students, who particularly enjoyed the exposure to lived-experience-led research, as well as exploring a wide array career paths that may be available to them after their PhD, including roles in governmental agencies and non-for-profit organisations.

Given such a positive reception from the students, we will be organizing a new Disability research HDR symposium next year.



1. *Prof. Shane Clifton, in a motorised wheelchair, presenting his lecture to HDR students at the Julie Wu Theatre, with his presentation projected onto three screens behind him.*





1. Dr Damian Mellifont's video presentation projected on screen at the Julie Wu Lecture Theatre.



2. Panelists - from left to right: Dr Annmaree Watharow and her haptic signs interpreter Suzanne Look; Dr Martin Raffaele; Prof. Shane Clifton; Dr Rebecca Barton in Julie Wu Lecture Theatre. Panelists Dr Scott Denton and Dr Damian Mellifont attending the presentation online and projected on screens.



3. Dr Scott Denton joining the panel online, projected on screens in the Julie Wu Theatre. We can see the other panelists in front of the screen. Panelists: Dr Annmaree Watharow and her haptic signs interpreter Suzanne Look; Dr Martin Raffaele; and Prof. Shane Clifton seated at the stage of the theatre, with Dr Rebecca Barton moderating the panel from the lectern.

## International Research Seminar – Mark Deuze

CDRP and The Discipline of Media and Communications, Faculty of Art and Social Sciences at the University of Sydney co-hosted on the 29<sup>th</sup> November an hybrid international seminar presented by [Professor Mark Deuze from the University of Amsterdam](#), while he was in visit in Sydney. Prof. Deuze is Professor of Media Studies at the University of Amsterdam's (UvA) Faculty of Humanities and presented a talk entitled:

“What Makes You Happy (Can) Also Makes You Sick: On the Mental Health and Well-Being of Media Professionals” in which he explores ways we can map, explain, and tackle the mental health crisis among media professionals.

Those who attended in person got the opportunity meet Prof. Deuze and discuss their common interest over a lunch offered by CDRP.

## Kim Santow law and social justice panel: The promise and pitfalls of a marketised NDIS

Supported by the Kim Santow Law and Social Justice Fund, Sydney Law School's annual panel discussion closely examines a legal issue in its socio-cultural context, with social justice and human rights considerations central to the discussion.

The National Disability Insurance Scheme (NDIS) holds great promise for improving the lives of people living with disability, but due to its marketised structure it also has a number of pitfalls. The panel discussion was facilitated by Australia's Disability Discrimination Commissioner, Dr Ben Gauntlett. To discuss this difficult policy issue, this year's panel brought together a range of perspectives:

Professor Emeritus Ron McCallum AO – former Dean of Sydney Law School and an expert in disability and labour law.

Dr Angela Jackson - Lead economist at Impact Economics and Policy, with expertise in distributional analysis, labour markets, disability, health, gender, housing and fiscal policy.

Deborah Connors – Deborah has been a NDIS client since late 2016. She has experienced and employed a variety of support services in that time – including carers, cleaners, nurses and physiotherapists. The experience has run the gamut from superb and life changing, to terrible and despairing. As a result of the good support services, she eventually found Deborah has been able to continue to work fulltime and participate fully in life, and is living evidence of the NDIS goals.

Giancarlo de Vera –Senior Manager of Policy at People with Disability Australia. Passionate advocate for disability, multiculturalism, racial justice, LGBTIQ+ affairs and cultural diversity. Named one of the 40 Under 40 Most Influential Asian-Australians of 2021.

## Spotlight on CDRP HDR students

### Bronwyn Simpson, PhD Student



*Image: Headshot of Bronwyn Simpson*

**Tell us a bit about you?** I am a PhD student and Associate Lecturer at the University of Sydney. I worked as an occupational therapist for 16 years, specialising in rehabilitation and assistive technology. I realised a love for teaching OT students after dabbling in some casual teaching work, and gradually increased this part of my work: I'm now working 4 days/week at the university as well as completing my PhD. I am from a family of OTs (my other and husband) and have a 6-year-old daughter.

**What led you to do a research degree?** While working in rehabilitation, I embarked on what I planned to be a quality improvement project, improving our handwriting training resources for adult stroke survivors. A grant from the National Stroke Foundation turned it into a Masters research project, which I finished in 2015. I returned to research once I realised I wanted to pursue an academic career, and commenced my PhD in 2019. I'm studying a novel program (a resort for people with spinal cord injury (SCI)) as a case study. I am interested in how the program combines disability and hospitality services, and also what we can learn about addressing well-being from a program that has this as its central focus. I'm very lucky to have two supportive and expert supervisors: Michelle Villeneuve and Shane Clifton.

**How is your research progressing?** I'm just over halfway through now, enrolled part-time. Covid disrupted my planned timeline, and I focused on background reading and writing early on. I have published two studies: a systematic review about well-being outcomes from the perspective of people with SCI, and a scoping review of qualitative studies about well-being interventions. These two papers have helped me understand the well-being outcomes that people report and value, how programs address well-being, and the gaps in these services. It's been useful to have a strong grounding in this research from the start, as this background work has helped to frame my thesis.

This year I have focused on data collection, and have completed 21 interviews (people with SCI and program staff), and a document analysis. I've also been conducting observations at the site, and will spend a lot more time doing this over summer as Covid restrictions have eased (and the beach activities begin!). I've presented early findings at three conferences: how the program addresses well-being at a national OT conference, analysing critical program elements in relation to occupational well-being theory (at an international OT conference) and how the program contributes to assistive technology service provision (at a national assistive technology conference). Preparing these presentations has been an opportunity to analyse and interpret the data in relation to specific questions. This process will help as I come to write up my findings.

**Do you have any advice for someone considering signing up for a research degree?** Choose a topic you are passionate about: I've remained interested in my topic because it's fascinating and worthwhile. Be strategic about choosing a project where you'll have good networks and support. And good supervisors are worth more than gold! To clinicians I'd say, don't see research as very separate to your clinical work. You bring your clinical skills to research, and research can relate to your very real and relevant questions you've identified as a clinician.

## Spotlight on CDRP HDR students

### Stephanie Mantilla, PhD Student

Image: Headshot of Stephanie Mantilla



#### Tell us a bit about you?

I have a BA (Media and Communications) with First Class Honours from the University of Sydney. Throughout my PhD, I have worked as a tutor in a few health sociology units and enjoy digital content creation on the side. I submitted my PhD thesis in late September of this year and have since taken up a position as a Postdoctoral Researcher in the Sydney School of Public Health.

#### What led you to do a research degree?

My mum developed an invisible disability in 2016, and I wanted to better understand people with invisible disabilities' experiences and what causes the discrimination they face, including how the media contributes to the discrimination. So, I decided to do Honours in 2018 where I got the opportunity to

research the representation given to people with invisible disabilities in an Australian drama with Professor Gerard Goggin as my supervisor. I found that I had really enjoyed the research experience and still had so much more I wanted to learn about invisible disabilities and the media – especially in the area of health communications. So, in 2019, I started a PhD with a focus on people with invisible disability with a health communications orientation with Professor Jen Smith-Merry and Professor Gerard Goggin as my supervisors. The thesis is titled *Invisible Disability, Public Health, and Visual Social Media Communications*.

#### How is your research progressing?

I submitted my PhD thesis in late September. I have been fortunate to have had such a positive PhD experience despite the rather tumultuous period brought about by the pandemic. I have had the opportunity to present my research at various conferences and even leverage my passion for making digital content when making conference videos and participating in competitions, like 3MT and Visualise Your Thesis. I owe my positive experience largely to my two wonderful supervisors Professor Jennifer Smith-Merry and Professor Gerard Goggin, who were both supportive and also challenged my thinking in a way that made my research even stronger.

I have recently taken up a position as Postdoctoral Researcher in the Sydney School of Public Health, where I will be able to continue developing my interest in health communications research. As part of my new role, I will be helping research COVID-19 news and social media representations to help better understand their role in helping manage controversy and promote trust. I'm excited to have the opportunity to expand my research interests into this new and important area.

### **Do you have any advice for someone considering signing up for a research degree?**

Embarking on a PhD is a great way to explore and learn more about a topic (or topics) you're really passionate about. The PhD experience is challenging in the best possible way. It encourages you to step out of your comfort zone and push your thinking beyond its usual boundaries – I think that's what makes it such an illuminative experience. It also presents you with a range of opportunities that help develop both your research and professional skills, like presenting your research at conferences.

One piece of advice that really resonated with me throughout my PhD experience – as a self-admitted perfectionist – is to focus on *progress over perfection*. Ideally, there would be time for both, however, I think because the PhD a relatively long stretch of time it's easy to get too caught up in aiming for perfection at the expense of progress. So, I think going into the PhD with a mindset where you continually prioritise making progress helps ensure you're on the right track.