Welcome to the CDRP Newsletter

April 2020

Welcome to our April 2020 CDRP Newsletter.

We are all concerned about the impact of Covid 19 on people with disability, their carers and families. There have been a number of statements which have been released over the past week which draw attention to their needs including this from the Centre for Research Excellence on Disability and Health and this Position Statement on Access to COVID-19 Prevention, Screening and Treatment of People with Intellectual or Developmental Disability from UNSW and colleagues working across intellectual and developmental disability organisations.

Within our centre Associate Professor Michelle Villeneuve has worked quickly with colleagues from the Queeslanders with Disability Network to develop a Person-Centred Emergency Preparedness (PCEP) Planning toolkit for COVID-19. There are more details about the plan and links for accessing it below.

In March we launched the Sydney Disability Network, which is a new mailing list for sharing disability-related news and events. It is open to anyone to join and post to. Please visit this link to subscribe.

We were sorry to farewell our Children and Young People stream lead Professor Joanne Arciuli last month. Jo has moved to Flinders University where she has taken up the position of Dean of Research in the College of Nursing and Health Sciences at Flinders University. This is tremendously exciting news and we really wish Jo all the best in the new role. Jo is planning to stay associated with CDRP as an affiliate and we hope that this provides an opportunity for strengthening our partnerships with Flinders.

Stay safe everyone, Jen.
Jen Smith-Merry, Director, Centre for Disability Research and Policy

Early Career Researcher news

CDRP is establishing its first Early Career and mid-career research networking group. Disability research is an ever-evolving space and the transition post PhD can be better supported by sharing stories, collaboration and expertise. For anyone who feels they could benefit from a community of researchers, post PhD and beyond, please share your details via the link. The meetings will be monthly on zoom starting in April 2020, no geographical boundaries are too far http://bit.ly/2WiYqOR If you have any specific questions, please email the CDRP ECR lead at sarah.wayland@sydney.edu.au

Disability - Inclusive Community Development

Click below to go to either the PDF or Word version of the PCEP COVID-19 Planning Tool.
We have also taken a few of the pages from the PCEP COVID-19 Planning Tool and made two extra separate printable planning tools. These are both really useful as they guide you to think about and then write down things that you will want to have in your COVID-19 plan.

Click below to go to the My COVID-19 Plan

Click below to go to the printable STOP sign. This is a sign that you can put on your front door to let people know you are at higher risk.

Printable Stop Sign

Disability Inclusive Disaster Risk Reduction (DIDRR) Queensland:

Winners of the Inspector-General Emergency Management Champion of Change Award

At the International Women’s Day Award Ceremony in Brisbane 2020, A/Prof Michelle Villeneuve and her team including the Queenslanders with Disability Network (QDN), the Community Services Industry Alliance (CSIA) and the Queensland Government Department of Communities, Disability Services and Seniors won the Champions of Change Award for their project: Disability-Inclusive & Disaster Resilient Queensland


We’d like to acknowledge our CDRP team who also worked on this project but not named on the above links including: Pradytia (Dytia) Pertiwi, RA and Cresta Markovic, RA

The DIDRR project was informed by inclusive stakeholder sessions held in Townsville, Rockhampton, Brisbane and Ipswich in 2019 with community members from the disability, community, health, emergency management and government sectors.

The outcome of this collaboration was the development of a DIDRR framework and toolkit and companion Resource Library which provides a roadmap and resources for people with disability, community and disability support services and local disaster management to work together to co-design DIDRR innovations, implement and evaluate their impact on decreasing risk and increase the resilience of people with disability to disaster.

The success of this project was centred on direct inclusion of people with disabilities and their support networks. We would like to acknowledge the outstanding work of the following individuals for their dedication to this project: Diana Young (DCDSS), Carrol Helander (DCDSS), Pradytia Pertiwi (Research Assistant), Cresta Markovic (Research Assistant) Ivy Yen (Research Assistant), Michelle Moss (QDN), Louise Abson (QDN), Matthew Gillett (CSIA) and Melissa Dower (CSIA) and Associate Professor Michelle Villeneuve (Project Lead),

The relevance of this project and its value to the sector is reflected in current work to review the Australian Institute for Disaster Resilience Community Engagement Handbook, a key piece of doctrine under the National Strategy for Disaster Resilience.

The UN Agency for Disaster Risk Reduction @UNDRR has shared the Queensland DIDRR Framework and Toolkit, indexing this resource on PreventionWeb and making it available worldwide. To access the range of project resource, please follow the links below:

- Website: https://collaborating4inclusion.org
Phase 1 of the Project was funded by the Queensland Government through the Department of Communities Disability Services and Seniors. Phase 1 focused on development of the DIDRR framework and toolkit. A/Prof Villeneuve and her team have been awarded funding to continue with Phase 2 (2019 – 2021). Phase 2 is proudly funded by the Queensland Government through the Queensland Disaster Resilience Fund (QDRF) and the Department of Communities Disability Services and Seniors. In Phase 2 we are taking the DIDRR framework and toolkit for a road test – implementing, evaluating and showcasing DIDRR in action!

**DIDRR NSW:**
A/Prof Villeneuve, Prof Dominey-Howes, Prof Llewellyn, and Dr Calgaro have partnered with 12 organisations in the emergency management, community and disability sectors to lead DIDRR research in NSW. Announced in 2019, the project is up and running from 2020 – 2022. The project titled Disaster Risk Management Practices that Leave Nobody Behind is funded through the Australian Research Council and the NSW Office of Emergency Management. Announcement: [https://www.arc.gov.au/news-publications/media/research-highlights/new-research-support-people-disabilities-disasters](https://www.arc.gov.au/news-publications/media/research-highlights/new-research-support-people-disabilities-disasters)

A/Prof Villeneuve and her team including Dr Crawford (Nursing), Dr Hinitt (Occupational Therapy), Dr Millington (Rehab Counselling) and Ivy Yen (Research Assistant, CDRP) partnered with Settlement Services International and Return Studios on a project to bring Person-Centred Emergency Preparedness (PCEP) to culturally and linguistically diverse communities in Western Sydney. This project is funded by Infrastructure NSW as part of the Hawkesbury-Nepean Flood Valley Directorate. We are producing videos about this project that will be available on the [www.collaborating4inclusion.org](http://www.collaborating4inclusion.org) website in the coming weeks.

In 2018, the A/Prof Villeneuve and her team won a Resilient Australia Award for their work in co-designing a toolkit to enable people with disability and chronic health conditions to self-assess their capabilities and support needs in emergencies and begin tailoring preparedness planning together with their service providers and support networks. Since that time, many health, disability, and community service providers have been introducing the PCEP into their practices. We are excited by the interest and uptake of this resource that was co-designed with service providers and people with disability and is proving useful to individuals and service providers in diverse contexts and settings. We will be using our learnings from this early implementation to revise and update the PCEP Toolkit in the coming year.

Two PhD scholarships are available as part of the grant to incoming students who meet the eligibility criteria. These three-year scholarships will be for study in the field of disaster risk reduction with high risk groups and will be advertised shortly. Expressions of interest or any questions should be directed to Dr Michelle Villeneuve at: [michelle.villeneuve@sydney.edu.au](mailto:michelle.villeneuve@sydney.edu.au)

**Disability and Inequity**

In collaboration with the Centre for Research Excellence in Disability and Health we are building a body of work on violence and people with disability. Components of this work are being conducted with the *Royal Commission into Violence, Abuse, Exploitation and Neglect against people with disability*. This month the *Australian Disability and Violence Data Compendium* will be released at [www.cre-dh.org](http://www.cre-dh.org). This *Compendium* comprehensively describes and compares over 25 datasets in Australia at the National and State/Territory levels that include both disability and
A series of Fact Sheets will be progressively released on the same website highlighting findings from the most robust sources of data on violence and disability in Australia.

Our most recent publication on health inequalities for people with disabilities in high income countries addresses the wellbeing of working-age adults with and without disability in the UK and associations with a range of variables. It can be found at https://www.sciencedirect.com/science/article/abs/pii/S1936657420300042?via%3Dihub

Indigeneity and Disability

Retention of the Aboriginal Health, Ageing and Disability Workforce Project

Despite a plethora of research into Aboriginal employment and recruitment, the extent and nature of the retention of frontline Aboriginal people in the health, ageing, and disability workforces are currently unknown. Frontline service delivery is defined in this project as Aboriginal people who are paid employees in the health, ageing, and disability services sector in roles that involve direct client, participant or patient contact. There is a need to identify the factors that inhibit (push) and promote (pull) staff retention or departure of this workforce from the sectors. This study will provide this much needed information.

The objective of this project is to uncover the factors that influence the retention of frontline Aboriginal workers in the health, ageing, and disability workforce in NSW who do not have university qualifications.

The proposed project aims to:

- Discover the “push” and “pull” factors for the retention of the frontline Aboriginal workforce in the health, ageing, and disability sector in NSW in relation to their role, employment and community
- Design evidence-based strategies for retaining the Aboriginal frontline workforce in the health, ageing, and disability sector in NSW

Project Governance

This research is funded by the Australian Research Council for three years and has been approved by AH&MRC ethics committee.

Advice will be provided to the project from our project partners, Indigenous Allied Health Australia, National Disability Services and the Aboriginal Health and Medical Research Council. We will also be guided by a project Advisory Group.

If you are interested in knowing more about the project please contact Chief Investigator Associate Professor John Gilroy: John.Gilroy@sydney.edu.au 0427 238 776 or Project Manager Folau.Talbot@Sydney.edu.au 0401 090 960

Planning for a better life under the NDIS:
A research project based in Central Western NSW and Central Australia

Project aims

The National Disability Insurance Scheme (NDIS) aims to support people with disability to obtain the supports they require to live an independent life.

This project wants to understand how Aboriginal and non-Aboriginal people with a disability living in rural and remote communities experience working with Local Area Coordinators (LACs), Community Connectors (Connectors) and National Disability Insurance Agency (NDIA) Planners to get NDIS plans that suit people with disability and their families.
The findings will help inform better ways to support peoples with disabilities to engage with the NDIS planning process in rural and remote communities.

The Research Team will interview people with disability, LACs, NDIS Planners, and Community Connectors who are based Central Australia and Central Western NSW.

This study is the first NDIS focused project to explore how people engage with LACs, NDIS planners, and Community Connectors during the planning phase situated in remote and rural regions. The project will also identify the workforce needs of LACs, Community Connectors, and Planners.

Guiding the project

The project has an Implementation Group, consisting of professionals in the disability workforce, and an Advisory Group, consisting of people with disability and carers of people with disability. These two groups guide the Research Team to ensure the project reflects local community ways of doing research.

If you are interested in sharing your experience about project please contact us on:

- Sarah-Jane Greenaway, Research Assistant Orange Local Aboriginal Land Council, Sarahjane.Greenaway@olalc.com.au or 02 6361 4742
- Nettie Flaherty, Research Assistant Centre for Remote Health Alice Springs, nettie.flaherty@flinders.edu.au or 08-89514778
- John Gilroy, Chief Investigator The University of Sydney, john.gilroy@Sydney.edu.au or 0427238776

Funded by the Australian Research Council (ARC).

A spotlight on our Honorary Associates

Dr Damian Mellifont is an Honorary Postdoctoral Fellow in the CDRP.

As a independent researcher with lived experience, Damian enjoys conducting studies that inform ways to help to redress ableism/sanism and advance the social and economic inclusion of people with disabilities.

Damian is currently working with Associate Professor Jennifer Smith-Merry on a research project that aims to explore the possible influences of contrasting emotions on the risk-reward decision making of persons who are neurotypical.

Some of Damian’s recently accepted and published papers include:

- Mellifont, D. (Accepted). Writers of Reform (apologies to The Doors): A study exploring how stigma is promoted and challenged within national newspaper reporting on neurodiversity. *Communicator*.

**Mental Health and Disability**

**New Research Grants**

1. **NSW Ministry of Health Grant – Evaluation of Peer Supported Transfer of Care (PeerSTOC)**

   In partnership with Australian National University’s ACACIA team, we have successfully tendered to conduct an 18 month, co-designed and co-delivered, mixed methods approach will be used to ensure that relevant qualitative and quantitative impacts and dimensions of the PeerSTOC initiative are captured in the evaluation. This project will involve three components:

   • an implementation evaluation to identify enablers and barriers to sustainable program delivery and potential future expansion.
   • an outcome evaluation - exploring outcomes for clients or users of the initiative and outcomes and experiences of peer workers delivering the initiative; and
   • an economic or value for money evaluation.

   Lead investigators include: Associate Professor Nicola Hancock, Dr Justin Scanlan, Dr Michelle Banfield and Associate Professor Sarah Norris

2. **Australian Department of Health - evaluation of national psychosocial support programs**

   In partnership, Nous Group (Nous) and the University of Sydney were recently successful in a tender to evaluate the National Psychosocial Support Measure (NPS-M) and Continuity of Support (CoS) programs. The evaluation will assess the implementation, impact and cost effectiveness of the programs, including the degree to which the services are meeting the needs of people with lived experience, their families and carers, and the impact of the programs on other services. The findings of the evaluation will inform decisions on the future of the programs, and advice to the COAG Health Council on future directions for psychosocial services. University and CDRP leads include Associate Professor Nicola Hancock, Dr Anne Honey, Lived Experience Researcher Deb Hamilton and Associate Professor Jennifer Smith-Merry

**Disability Services Stream**

**Forthcoming book**

Professor Emeritus Roger Stancliffe is lead editor of the following book to be published in April, 2020.


The book features 18 chapters by authors from 12 different countries around the world. In addition to two chapters with Roger as lead author, there are 4 other chapters co-written by CDRP staff and affiliates (these authors are shown in bold):

- *Choices and Transition from School to Adult Life: Experiences in China*. Tianxi Xu, Juan Tang, Yuan Zhou, and Wenwei Ouyang
- *The Choice of Becoming a Parent*. Marjorie Aunos, Marja W. Hodes, Gwynyth Llewellyn, Margaret Spencer, Laura Pacheco, Gunnel Janeslätt, Beth Tarleton, Lydia Springer, and Berit Höglund
- Adults with Intellectual Disability: Choice and Control in the Context of Family. Bernadette Curryer, Angela Dew, Roger J. Stancliffe, and Michele Y. Wiese
- *End-of-Life Choices*. Michele Y. Wiese and Irene Tuffrey-Wijne
A book launch symposium was held as part of the 35th Annual Pacific Rim International Conference on Disability and Diversity, March 2 & 3, 2020, in Honolulu, Hawaii. The symposium consisted of 7 short papers presented by 7 lead chapter authors, based on aspects of the book chapter he or she led.

Publications


