Welcome to the CDRP Newsletter

December 2019

Welcome to the end of year Newsletter for the Centre for Disability Research and Policy (CDRP) for 2019.

Thank you to all our supporters during the year. I’ve enjoyed meeting you at events, conferences and research meetings throughout the year.

This year has seen a large number of grant successes for the CDRP, including ARC Linkage grants led by Stream Leads Michelle Villeneuve and Jo Arciuli, and the consolidation of our existing projects, particularly those around a significant focus on the disability disaster risk reduction work led by Dr Michelle Villeneuve.

This year we welcomed new streams of work focusing on Disability Workforce, led by Dr Kim Bulkeley and another stream on Disability Policy led by Dr Scott Denton. And we will also shortly farewell Professor Roger Stancliffe who has led our Disability Services research stream since the Centre started. Within the CDRP Roger’s work has focused most recently on the important Talking End of Life project helping people with intellectual disabilities understand and plan for the end of life. Roger has been incredibly important to the work of the CDRP more broadly. He has been unwaveringly supportive of the Centre and its goals and this has been shown through his equal commitment to large and important projects such as the Centre for Research Excellence in Disability and Health to the micro but necessary tasks of daily Centre management. We will miss him but are very happy that he has been appointed Professor Emeritus so can continue his involvement with our work.

On 25th November 2019, in a ceremony at Camperdown in the Medical Foundation Building Auditorium, Professor Roger Stancliffe was the recipient of the Lifetime Achievement Award from our colleagues at the Centre for Disability Studies. The award is based on his 43-year contribution to the field of intellectual disability as a practitioner, teacher, writer and researcher.

A big ‘behind the scenes’ outcome for CDRP for 2019 was our five-year review which was received very positively by the Review Committee, Faculty and Provost. We have now been renewed for a further 5 years.

We are looking forward to working with you in 2020 and wish you a Merry Christmas and New Year.

Jen Smith-Merry, Director, Centre for Disability Research and Policy

Disability - Inclusive Community Development

The intensity of Australian bushfires that came extra early this year are certainly raising awareness about disaster preparedness. Research led by Dr Michelle Villeneuve addresses the inclusion of people with disability in reducing their disaster risk and enabling governments, community and emergency services personnel to take effective action to remove the barriers that increase risk for people with disability in emergency situations. Three projects currently underway include:

1. ARC Linkage – A team led by Dr Michelle Villeneuve has received $408,000 in funding through the ARC’s Linkage Projects scheme to answer critical questions about how to assist people with disabilities in disasters. The research will determine what their support needs are, and how they might help themselves to better prepare for disasters, to ensure that Australia meets its commitment to leave nobody behind in disaster events. With additional support and cooperation from no less than 12 partner organisations, including the NSW Department of Justice, the Local Community Services Association, and Australian Red Cross Australia, the research team will co-design effective mechanisms that State and Federal decision makers can use to scale-up disability-inclusive disaster risk reduction across Australia.

By developing emergency-preparedness tools and collecting data about the support needs of people with disabilities in emergencies, this project will improve their access to community level disaster risk reduction. The intended impact of this research will be lives saved and injury prevented for over four million Australians with disabilities who are at higher risk of injury and death than the general population when disasters strike.


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

2. Phase one of a partnership project on Disability-inclusive and Disaster-resilient Queensland was led by Dr Michelle Villeneuve in collaboration with the Queenslanders with Disability Network (QDN) and the Community Services Industry Alliance. Funded by the Queensland Department of Communities, Disability Services and Seniors, we produced A Disability Inclusive Disaster Risk Reduction Framework and Toolkit with a companion Resource Library. The first of its kind! These resources will be launched on 3 December – International Day of People with Disability. Hon Min Coralee O’Rourke, MP will officially launch the resources on behalf of the Department of Communities, Disability Services and Seniors. To find these resources, visit: https://collaborating4inclusion.org/disability-inclusive-disaster-risk-reduction-didrr/ . Details on Phase 2 of Disability-inclusive and Disaster-resilient Queensland project are forthcoming. Stay tuned on Facebook:
https://www.facebook.com/disabilitynaturaldisasterstudy/?ref=bookmarks

3. Settlement Services International – Ability Links has teamed up with CDRP and Return Studios to roll out person-centred emergency preparedness community capacity building in Culturally and Linguistically Diverse (CALD) communities in the Hawkesbury-Nepean. This participatory and action-oriented research is funded by Infrastructure NSW as part of the Hawkesbury-Nepean Flood Valley Directorate. Return Studios is capturing the process and working with our team of investigators from Allied Health and Nursing to tailor the Person-Centred Emergency Preparedness Toolkit https://collaborating4inclusion.org/prepare-nsw/ so that people from CALD and Non-English Speaking communities, including people with disability - can get prepared for natural hazard emergencies.
Disability and Inequity
National Disability Research Partnership. Gwynnyth has been a core part of the discussions for the $2.5 million National Disability Research Partnership led by Bruce Bonyhady which was announced by the NDIS minister last week. Here is a copy of his speech: https://ministers.dss.gov.au/speeches/5266?fbclid=IwAR3q_ecWBctznTXDPdOvvZjdbc3FxQg4OiHb-vZtHajiNbrdveQncAtdreY CDRP will be leading one of the strands of work related to this partnership.

Highlights in the Disability and Inequity Stream include contributing to the set-up of the National Disability Research Partnership over the past six months. CDRP is a foundation partner of the newly announced National Disability Research Partnership funded by the Department of Social Services. This partnership led by the Melbourne Disability Institute at the University of Melbourne with a number of universities and research institutes, government agencies, peak disability bodies and leading disability service organisations will capitalise on Australia’s leadership in innovative disability policy and service reform to build a world-first Hub in Disability Research and Policy. The NDRP has secured $2.5 million three-year funding. A major contribution of CDRP in the first years of the Partnership will be leading the development of a research agenda. The research agenda will identify key disability policy research priorities and questions that the Partnership will address, and coordinate and leverage existing research.

Stream members lead, with others, including Prof Roger Stancliffe, Dr Qingsheng Zhou, Dr Nicola Fortune, Professor Shane Clifton, Dr Jerome Rachele (University of Melbourne) and Associate Professor Hannah Badland (RMIT), Work Program 1 for the CRE-Disability and Health. The development of the Disability and Wellbeing Monitoring Framework is now complete with several papers submitted detailing the development process, including an External Panel of Advice comprising people with lived experience of disability and the gaps in disability data in Australia. Work is now underway on preparing a benchmark report utilising the available data on 93 of the 128 indicators in the framework which is based on social determinants of health and human rights perspectives. This work was presented to DSS policy personnel responsible for leading the development of the updated National Disability Strategy in early October.

Publishing highlights include the finalisation of a chapter on ‘Sexuality and the disregard of lived reality: the sexual abuse of children and young people with disabilities’ for the Routledge Handbook on Sexuality and Disability in press for publication in 2020. We continue the population-based work on health inequities for people with disabilities in high income countries including the impact of discrimination on the health of working age people with disabilities with an upcoming publication in the Journal of Public Health and one under review on the association of various variables with subjective wellbeing of people with and without disability. Using the UNICEF MICs, we continue our focus on children with developmental disability with a paper on ‘Prevalence of underweight, wasting and stunting among young children with a significant cognitive delay in 27 low and middle-income countries’.

Early Career Researcher news
Collaboration think tanks were held in November in Sydney and Warrnambool by Dr Sarah Wayland to explore resource development needs for carers of people who suicide attempt, funded by SANE Australia.
Mental Health and Disability


National research priorities for Psychosocial Disability and the NDIS. Dr Nicola Hancock and HDR student Deb Hamilton recently presented research findings at a successful, invitation only event hosted by La Trobe University in Melbourne. This event drew together Bruce Bonyhady one of the original architects of the NDIS, Gerry Naughton, Strategic Advisor for Mental Health for the NDIS, with researcher and lived experience expertise around the country to collectively identify future priority research areas for NDIS and Psychosocial Disability. Deb’s lived experience informed project examines NDIS participants experiences of decision making, choice and control. Nicola presented findings from the National Tracking Transitions project.

Disability Services Stream

Professor Roger Stancliffe will be retiring at the end of 2019 and has been granted Emeritus Professor status by the University of Sydney (effective January 2020). In November 2019, Roger Stancliffe was the recipient of the Centre for Disability Studies Lifetime Achievement Award.

At a sold-out event held on 21/11/19, Roger Stancliffe and CDRP Honorary Senior Research Fellow Dr Michele Wiese presented a half-day workshop on Talking end of life with people with intellectual disability (TEL): How-to workshop.

Children, Young People and Disability

Indigenous Australians with Autism: A Scoping Review Benjamin Bailey and Joanne Arciuli

Benjamin Bailey and Joanne Arciuli are affiliated with the Centre for Disability Research and Policy, University of Sydney, Australia. Corresponding author: Joanne Arciuli (joanne.arciuli@sydney.edu.au).

Aboriginal and Torres Strait Islanders with developmental disabilities such as autism are among the most marginalised people in Australian society. We reviewed research involving Indigenous Australians with autism based on a search of the peer-reviewed and grey literature. Our search identified 1,457 potentially relevant publications. Of these, 19 publications were in line with our main areas of inquiry: ASD diagnosis and prevalence, carer and service provider perspectives on autism, and autism support services. These included 12 journal publications, 3 conference presentations, 1 resource booklet, and 1 thesis dissertation. Findings suggest similar prevalence rates for autism among Indigenous and non-Indigenous Australians, although some Aboriginal and Torres Strait Islander people with autism may not receive a diagnosis or may be misdiagnosed. We also discuss research on the perspectives of Aboriginal and Torres Strait Islander carers and Indigenous and non-Indigenous service providers, as well as barriers and strategies for improving access to diagnosis and support services.
Disability Workforce

Allied Health Assistant workforce development project:

Dr Kim Bulkeley will partner with Dr Genevieve Johnsson (an Honorary with the CDRP) from ASPECT to conduct an evaluation of their allied health assistant project which was successful in securing funding in the recent Job and Market Fund program ($868,291). This two-year project will develop an Allied Health Assistant (AHA) workforce in remote locations to deliver professional, culturally competent therapy services to participants in their local community in thin market areas. The evaluation will focus on development of a governance framework and building our understanding of the impact of delegated practice models.

Telepractice: A real choice for quality therapy services in rural areas

Dr Kim Bulkeley presented at the recent Australasian Society of Intellectual Disability (ASID) conference, 6th-8th November in Adelaide on her work with colleagues from TherapyConnect, Dr Monique Hines and Professor Michelle Lincoln exploring the delivery of therapy services using online platforms. The presentation formed part of a rural symposium which focussed on a wide range of research including people with an intellectual disability. Resources related to this presentation, a video, practice guideline and policy brief is available on the CDRP web site https://sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy/disability-workforce.html

Inquiries into, NDIS Planning, Supported Independent Living, and General issues around the implementation and performance of the NDIS

Dr Kim Bulkeley appeared before the Joint Standing Committee on the National Disability Insurance Scheme on Thursday the 21st November. The focus was on issues for NDIS planners in rural and remote areas as part of her role as a board director with Services for Australian Rural and Remote Allied Health (SARRAH). Issues identified included awareness of rural and remote contexts in planning; rural and remote training; collaboration with local service providers; and the complexities experienced by rural and remote NDIS participants. The full transcript of the hearings will be available shortly on http://parlinfo.aph.gov.au
Disability and Policy development

Disability, Disadvantage and Vocational Education and Training

Throughout the year Associate Professor Jen Smith-Merry and Professor John Buchanan from the School of Business Analytics, along with research assistants Ivy Yen, Ally Drinkwater and Dr Bruce Smith from the CDRP have been leading a project to develop new policy options for disability, vocational education and training and employment in NSW. The research project was funded by the NSW Department of Industry (and since government reorganisation, now the Department of Education). The project has produced an extensive systematic narrative review of work in these areas and a draft set of policy options based on 71 interviews with stakeholders. The project findings were workshopped in a Hackathon hosted by Dr Geoff Lee, Minister for Skills and Tertiary Education in August and the final report will be delivered to the government in December.