Welcome to the CDRP Newsletter



May 2021

Much of our attention over the past few months at a Centre for Disability Research and Policy (CDRP) has been turned towards the NDIS and ongoing issues with implementation and resourcing, including the PM and Ministerial announcements about so-called cost blowouts and independent assessments. While clear analysis and commentary on these changes and their impact on people with disability, supporters and allies is core to what we do, we also need to continue to recognise the real revolution of the NDIS as a policy in Australia and what it has offered to thousands of people with disability. The very act of the NDIS being conceived by passionate people in the disability and policy community and pushed into creation and implementation is significant in a way that we sometimes forget.

It reminds us to turn our heads to the next steps that need to be taken in moving forward inclusion for people with disability in Australia and the revolutionary policy changes that might be needed to make these changes happen. What are the other important areas in disability support that require this type of creative experimentation? And what would it take to get there?

Much of my own work focuses on the need for integrated responses to care and support for people with very complex support needs. This is an area where there have been significant programs put in place, but with little ongoing impact on the system that sits around them. Efforts we have evaluated through CDRP are the Partners in Recovery program and the NSW Government Integrated Service Response. Both were innovative and successful programs in their own right. Both are no longer operating and we move forward with a system that still contains the fractures and discoordination that led to their naissance.

The International Foundation for Integrated Care (IFIC) is currently hosting its international conference (virtually) over the month of May and I'm co-presenting a paper with Community Options Australia on some collaborative agenda setting we have done with them. Many of the problems, and indeed the solutions, to problems of integrated care have been well rehearsed but remain, because we are unable to implement the type of radical systemic change needed to reboot the health and social care systems to act in a more integrated way.

The NDIS rebooted disability support and systems and policies are still settling around it. How can we take this revolution in disability support and learn from its conception and implementation (both the good and the bad bits) to push for integrated health and social care?

If you have an idea and want to continue this conversation, then get in touch. CDRP works because of its connections with people with disability, government and non-government partners. It is through the different expertise within our team and within each of these groups that we are able to come up with creative solutions to these ongoing systemic problems.

Important update: CDRP announced as a Faculty of Medicine and Health Impact Centre. In April 2021 CDRP was named as one of the Faculty of Medicine and Health's new Impact Centres. This is a great step for CDRP as we join a group of highly respected Centres in FMH https://www.sydney.edu.au/medicine-health/our-research/research-centres.html Throughout this newsletter you will see a small amount of the depth of work we are undertaking in our renewed and expanded Centre, including amongst our honorary affiliates and students.

Jen Smith-Merry, CDRP Director

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Mental Health and Disability

The Centre's mental health stream continues to grow from strength to strength. In the last 12 months, despite all that COVID has thrown, we have built on our grants and research projects as well as capitalising on opportunities to have a real and meaningful impact on mental health practice! Here are just a few highlights:

Recovery Assessment Scale – Domains and Stages (RAS-DS). A self-report measure of mental health recovery. Our tool is continuing to have world-wide impact. In just the first four months of 2021, more than 2,400 people across 75 countries have engaged with the website and downloaded the tool! (www.ras-ds.net.au). Already translated into 16 languages, colleagues at Perdana University, Malaysia are now collaborating in the development of a Malay translation. We have also partnered with colleagues from RMIT in the development of a short form for people living with and recovering from anxiety.



Top 15 RAS-DS users (country)

1.	Australia Australia	840 34.74%
2.	United States	476 19.69%
3.	China	102 4.22%
4.	[+] Canada	91 3.76%
5.	United Kingdom	81 3.35%
6.	■ Netherlands	62 2.56%
7.	United Arab Emirates	47 1.94%
8.	India	42 1.74%
9.	■ Italy	39 1.61%
10.	(not set)	35 1.45%
11.	- Indonesia	30 1.24%
12.	Spain	27 1.12%
13.	.● Japan	26 1.08%
14.	Brazil	23 0.95%
15.	Thailand	23 0.95%

Evaluation of innovative national and state-wide mental health initiatives

Our team have successfully bid to conduct a number of independent evaluations of innovative pilot programs. Importantly, all our work is conducted by diverse teams that include researchers with and without lived experience.

Two current evaluations include:

- <u>HeadtoHelp.</u> In partnership with NOUS, our team, led by Dr Anne Honey are conducting an independent evaluation of this national program commissioned by the Australian Government Department of Health.
- NSW Peer Supported Transfer of Care (Peer-STOC). This program is the single greatest NSW investment in the mental health peer workforce. In partnership with lived experience academic colleagues from Australian National University, we are conducting an outcome, implementation, and economic evaluation of this initiative with the final report due to the Ministry in July.

Here is a taste of the very recent impacts that some of our lived experience HDR students are having on policy and practice:

- Karen Wells (PhD candidate and lived experience researcher) invited keynote at Royal Australian New Zealand college of Psychiatrists, ECT and Neurostimulation conference (2021) and lead author on the consumer chapter in the NSW Clinical Guidelines for ECT.
- Deb Hamilton (PhD candidate and lived experience researcher) invited keynote speaker NDIS and Psychosocial Disability Quality and Safety Forum (Mental Health Coordinating Council)

Disability - Inclusive Community Development

In collaboration with The University Centre for Rural Health and Centre for Research Excellence in Disability and Health Associate Professor Michelle Villeneuve contributed to submissions to the Royal Commission on the needs of people with disability in regard to emergency planning and response in disasters.

Information and statements can be found

https://disability.royalcommission.gov.au/publications/transcript-day-2-public-hearing-5-sydney

Associate Prof. Villeneuve wrote three Conversation articles were published on disability and disaster, including one co-authored with the University Centre for Rural Health and two featuring findings of a paper published in the International Journal of Disaster Risk Reduction in January 2021.

- 1. Bailie, J., Longman, J., **Villeneuve, M.**, Bailie, R., & Matthews, V. (2021). Floods can worsen inequality. Here are 4 ways we can ensure people with disabilities aren't left behind. *The Conversation*, https://theconversation.com/floods-can-worsen-inequality-here-are-4-ways-we-can-ensure-people-with-disabilities-arent-left-behind-157959
- 2. **Villeneuve, M.** & Styles, H. (2021). 3 things we can do now to help people with disability prepare for disaster. *The Conversation*, https://theconversation.com/3-things-we-can-do-now-to-help-people-with-disability-prepare-for-disaster-151843
- 3. **Villeneuve, M.** & Moss, M. (2020). 'Nobody checked on us': What people with disability told us about their experiences of disasters and emergencies. *The Conversation*, https://theconversation.com/nobody-checked-on-us-what-people-with-disability-told-us-about-their-experiences-of-disasters-and-emergencies-151198

Current research projects are:

Disaster Management Practices that Leave Nobody Behind (2020 – 2022) – an ARC Linkage grant involving no less than 12 community partners that receives funding support from Resilience NSW.

- Three PhD students started on 1 October 2020, each awarded a scholarship and working on the Leave Nobody Behind Project
 - Michael Morris his research is focused on joined up working between fire and emergency services and community/health services
 - Louise Mitchell her research is focused on bushfire recovery with a focus on Bega Valley
 - Sonny Patel his research is focused on co-producing disaster risk reduction with people with disability

Disability Inclusive Emergency Planning in Victoria (2020 – 2021) funded by the Department of Families Fairness and Housing and co-led with two disability organisations in Victoria – VALID and Gippsland Disability Advocacy Inc.

Disability Inclusive and Disaster Resilient Queensland (2019 – 2021) funded by the Queensland Government through the Queensland Disaster Resilience Fund and the Department of Communities, Housing and the Digital Economy. Led by A/Prof. Villeneuve, this project is conducted in partnership with Queenslanders with Disability Network and the Community Services Industry Alliance.

Additional collaborations are taking place with:

- CFA Victoria who have adopted the Person-Centred Emergency Preparedness toolkit for a new program called Emergency Planning and Advice Service.
- Disability Advocacy Resource Unit/VCOSS on an issues paper to support disability advocacy for inclusive emergency management
- Queenslanders with Disability Network on an ILC funded research project to scale our Person-Centred Emergency Preparedness (P-CEP) Peer Support Model to ACT, NSW, S. Australia and other parts of QLD where it was first co-produced and tested. Over the past two years, 35 Peer Facilitators with disability/disability advocates have been trained in and deliver P-CEP through peer support and mentoring (20 in QLD and 15 in Victoria)

A/Prof Villeneuve and her team on the Queensland project won two **awards** and received honourable mention at the national Resilient Australia Awards held in Canberra this year.

- 2020 **Resilient Australia Award.** Winner Community Award Category Queensland Division for Person-Centred Emergency Preparedness (PCEP) for COVID-19 for People with Disability and Highly Commended at the National Resilient Australia Awards. https://www.qra.qld.gov.au/news/queensland-resilience-recognised-awards
- 2020 Champion of Change Award (Inspector General Emergency Management Queensland) for Disability Inclusive Disaster Risk Reduction Framework and Toolkit. https://www.igem.qld.gov.au/about-us/awards/igem-champion-of-change-award/queensland-disability-inclusive-disaster-risk-reduction-framework
- A/Prof Villeneuve also received the honour of 2020 being recognised by the **Canadian Women in Global Health.**Recognised for contributions to global health including thought leadership, implementation, field practice, diplomacy, mentoring, and advocacy. Recognised at the 26th Canadian Conference on Global Health and my research profile published in the 2020 Canadian Women in Global Health List launched 20 October 2020 https://www.csih.org/en/michelle-villeneuve

Recent Tools Published – open access

Villeneuve, M., Abson, L., Yen, I., & Moss, M. (2020). *Person-Centred Emergency Preparedness (P-CEP) Workbook*. Centre for Disability Research and Policy, The University of Sydney, NSW 2006, ISSN: 2652-2241, Issue 2, No 1. https://collaborating4inclusion.org/wp-content/uploads/2020/08/2020-08-19-Person-Centred-Emergency-Preparedness-P-CEP-WORKBOOK FINAL.pdf

Villeneuve, M., Moss, M., Abson, L., & Buchanan, R. (2020). *Person-Centred Emergency Preparedness Planning for COVID-19 – for people with disability*. Centre for Disability Research and Policy, The University of Sydney, 2006. Multiple versions: https://collaborating4inclusion.org/covid-19-person-centred-emergency-preparedness/

- a. Australian National version
- b. Australian National Easy Read version
- c. ACT version
- d. Queensland version

Villeneuve, M., Dwine, B., Moss, M., Abson, L., <u>Pertiwi, P.</u> (2019). *Queensland Disability Inclusive Disaster Risk Reduction Framework and Toolkit*. A report produced as part of the Disability Inclusive and Disaster Resilient Project Series. Centre for Disability Research and Policy, The University of Sydney, NSW 2006, ISSN: 2652-2241, Issue 1/No 7 (Online) https://collaborating4inclusion.org/wp-content/uploads/2019/11/DIDRR Framework document FINAL.pdf

Recent publications include:

- 1. Ebrahimnejad, S., Villeneuve, M. & Tavakkoli-Moghaddam, R. (2021). An optimization model for evacuating people with disability in extreme disaster conditions: A case study. *Scientia Iranica* DOI 10.24200/SCI.2021.57431.5237 http://scientiairanica.sharif.edu/article 22296.html
- 2. Villeneuve, M. (2021). Building a Roadmap for Inclusive Disaster Risk Reduction in Australian Communities. *Progress in Disaster Science*. Accepted 24 March 2021. https://doi.org/10.1016/j.pdisas.2021.100166
- 3. Grady-Dominguez, P., <u>Ragen, J., Sterman, J.</u>, Spencer, G., Tranter, P., Villeneuve, M., & Bundy, A. (2021). Expectations and Assumptions: Examining the influence of staff culture of a novel school-based intervention to enable risky play for children with disabilities. International Journal of Environmental Research and Public Health. https://doi.org/10.3390/ijerph18031008 Role: co-senior author
- 4. Villeneuve, M., Abson, L., <u>Pertiwi, P.</u>, Moss, M. (2021). Applying a person-centred capability framework to inform targeted action on disability inclusive disaster risk reduction. *International Journal of Disaster Risk Reduction*. https://doi.org/10.1016/j.ijdrr.2020.101979
- 5. <u>Stillianesis, S.</u>, Spencer, G., Villeneuve, M., Sterman, J., Bundy, A., Wyver, S., Tranter, P., Naughton, G., Ragen, J., Beetham, K.S.(2021). Parent's perspectives on managing risk in play for children with disabilities. Disability and Society. Role: Evaluation lead designing evaluation of this and related study of educator experiences, Honours thesis supervisor. https://www.tandfonline.com/doi/full/10.1080/09687599.2021.1874298
- 6. <u>Bronwyn, S.</u>, Villeneuve, M., Clifton, S. (2020). The experience and perspective of people with spinal cord injury about well-being interventions A systematic review of qualitative studies. *Disability and Rehabilitation*. https://doi.org/10.1080/09638288.2020.1864668
- Pertiwi, P.P., Llewellyn, G.L., Villeneuve, M. (2020). Disability representation in Indonesian Disaster Risk Reduction Frameworks. *International Journal of Disaster Risk Reduction*. https://doi.org/10.1016/j.ijdrr.2019.101454 Role: PhD Supervisor
- 8. Calgaro, E., Villeneuve, M., Roberts, G. (2020). Inclusion: Moving beyond resilience in pursuit of transformative and just DRR practices for persons with disabilities. In A., Lukasiewicz & C. Baldwin, Editors. *Disaster Justice: How Australia rises to the challenge of disaster-laden future*. CSIRO Publishing, Clayton, Victoria. https://link.springer.com/chapter/10.1007/978-981-15-0466-2 17

Additional research outputs are all available at www.collaborating4inclusion.org

Disability and Inequity

Our work in collaboration with the Centre for Research Excellence in Disability and Health: CRE-DH continues apace. This work is building a body of evidence on violence and people with disability. The Australian Disability and Violence Data Compendium is available online at https://credh.org.au/publications/reports/. The final report on Nature and extent of violence, abuse, neglect and exploitation against people with disability in Australia is now available on the Commission's website at https://disability.royalcommission.gov.au/publications/research-report-nature-and-extent-violence-abuse-neglect-and-exploitation-against-people-disability-australia

At the same time we are working with Respect Victoria on primary prevention action research with women with disabilities; the first phase of this project involved a now completed evidence synthesis of primary prevention of violence against women with disability. The CRE-DH team on violence was successful in winning an ANROWS research grant for 2021-2022 titled Building a framework to prevent respond to young people with disability who use violence at home. More information is available on the ANROWS website at

https://www.anrows.org.au/project/building-a-framework-to-prevent-and-respond-to-young-people-with-disability-who-use-violence-at-home/ It is rewarding to be working together on this work on all aspects of violence impacting people with disability which is long overdue.

Together with the CRE-DH we presented a joint submission to the Royal Commission in response to their Issues Paper on Emergency Preparedness and Response. This paper covered concerns in relation to people with disabilities and natural hazard disasters as well as in the current COVID-19 pandemic. Our submission is publicly available on the Commission's website and the CRE-DH publications page at www.cre-dh.org We are also very pleased to see that emergency preparedness for people with disability will be included in the next National Disability Strategy (NDS) and the NDS Outcomes Framework.

We continue to research and publish about the factors influencing inequities experienced by people with disability compare to their non-disabled peers. The latest publications in this series are about the under-researched area of loneliness:

- Emerson, E., Fortune, N., Llewellyn, G., & Stancliffe, R. (2020). Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross sectional study, Disability and Health Journal, https://doi.org/10.1016/j.dhjo.2020.100965;
- Emerson, E., Fortune, N., Llewellyn, G., & Stancliffe, R. (2021). Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross sectional study, Disability and Health Journal, 14 (1), 100965. https://doi.org/10.1016/j.dhjo.2020.100965

We continue to publish research on the impact of COVID-19 on people with disability. For example, Emerson, E., Stancliffe, R., Hatton, C., Llewellyn, G., King, T., Totsika, V., Aitken, Z., & Kavanagh, A. (2021). The impact of disability on employment and financial security following the outbreak of the 2020 COVID-19 pandemic in the UK. Journal of Public Health, (advance online, 12th January, 2021) https://academic.oup.com/jpubhealth/advance-article/doi/10.1093/pubmed/fdaa270/6082833

Kavanagh, A., Dickinson, H., Carey, G., Llewellyn, G., Emerson, E., Disney, G., and Hatton, C. Improving health care for disabled people in COVID-19 and beyond: Lessons from Australia and England, Disability and Health Journal (advance online, 05 December 2020). https://doi.org/10.1016/j.dhjo.2020.101050

We are also continuing to explore issues in relation to identifying people with disability in population surveys and administrative datasets. There are publications on our concerns about identifying children at risk of cognitive impairments/ intellectual disability in international datasets for example, Emerson, E. and Llewellyn, G, in press, Identifying Children at Risk of Intellectual Disability in UNICEF's Multiple Indicator Cluster Surveys: Cross-sectional survey, Disability and Health Journal https://www.sciencedirect.com/science/article/abs/pii/S1936657420301187 and others in particular aspects of children and young people's everyday lives such as: Emerson, E., and Llewellyn, G. (2021c). The exposure of children with and without disabilities to violent parental discipline: Cross-sectional surveys in 17 middle- and low-income countries. Child Abuse and Neglect, 111, 104773.

http://dx.doi.org/10.1016/j.chiabu.2020.104773 Emerson, E., and Llewellyn, G. (2021b). Youth with disabilities are more likely than their peers to engage in hazardous child labour. Child: Care, Health and Development, 47, 119-127. http://dx.doi.org/10.1111/cch.12820

Disability and Workforce

The Disability Workforce Stream has had a busy few months managing a number of projects, engaging in some lobbying and industry support and doing my first community radio interview on The Wire, 2SER http://thewire.org.au/story/graduates-with-disabilities-find-it-harder-to-get-a-job/.



Research projects: Ass Prof John Gilroy, has updated the website with content on ARC project "The Retention of the Aboriginal Health, Ageing and Disability Workforce Project. The frontline workforce will be launched soon, and the employer survey will follow shortly. Left is the artwork commissioned for this project, and the description of "Resilience" painted in acrylic by Tan Martin. The inspiration for the artwork comes from many years as an Aboriginal woman working in rural and remote communities promoting health and well-being. The artwork depicts the visual narrative of many rural and remote Aboriginal family's vision of creating a positive and brighter future for family members with disabilities by building on community strengths and resilience.

Artwork: The hands in the centre of the artwork depicts the enhancement of Aboriginal and Torres Strait workforce within our communities. The larger centric

orange dots represent our children actively participating with health services providers to include their perception of health and well-being. The U-shaped symbols in the middle of the artwork depict Elders. Upholding traditional ways, customs, knowledge, and skills to heal and foster working relationships, within the community to achieve positive health outcomes. The green leaf bush medicine image incorporates physical spiritual and emotional healing of being drawn closer to ancestors for quidance. The outer U- shaped symbols depicts family members emotions of isolation

and financial burden. Extended separation from family and psychological stress factors arise due to the centralisation of health services. The half centric circles depict many Aboriginal communities. The red line represents Aboriginal families leaving communities to access regional centres for treatment. The white and coral dots depict the harsh drought conditions. Situating the whole image in the context of country.

The Jobs and Market Fund collaboration with ASPECT (\$800K over two years) is exploring service design for allied health supports including therapy assistants and telepractice as innovative components to increase access for rural NDIS participants. The research will develop a governance framework for this service model and evaluate the impact of therapy assistant and telepractice service delivery. The project roll out has been impacted by the COVID restrictions, but has now recruited therapy assistants in four rural communities, Broken Hill, Norfolk Island, Deniliquin and North West Tasmania. We have welcomed an occupational therapy honours student, Amanda Ha onto this project. Amanda will explore the experience of NDIS participants who work with the therapy assistants using a photo elicitation method, completing her project at the end of 2021. We have partnered with Services for Australian Rural and Remote Allied Health (SARRAH) to complete a scoping review of support workforce in allied health roles in rural and remote disability contexts. Dr Anna Moran from SARRAH, Dr Genevieve Johnsson (ASPECT and CDRP affiliate) and Dr Kim Bulkeley have formed the team completing this review which will be finalised by October 2020.

Industry collaboration:

Dr Kim Bulkely (Disability Workforce Stream Leader) was invited to contribute to a consultation process on the NDIS Quality and Safeguarding Commissions "Workforce Capability Framework" being facilitated by Bendelta Consulting. The framework is a comprehensive articulation of the attributes, skills and knowledge of workers to enable delivery of high-quality disability services.

Reimagine Australia (formerly ECIA) has relaunched and restructured their organisation to expand their focus and align with a contemporary view supporting families and young children with disability. Dr Kim Bulkely has been partnering with them over recent months to develop telepractice resources to support the sector in the pivot to online service delivery. Based on our telepractice research guidelines, and in collaboration with us Reimagine have developed an industry specific guideline and training package, translating our research to a wider audience.

The NDIA revised price guide was released in July, indicating a significant change to the definition of telepractice and the rules around claiming based on location of telepractitioners. Telepractice was now to be regarded as an indirect service and the location of the telepractitioner would determine the rate allowable for charging clients. Colleagues at TherapyConnect, Simone Dudley (Occupational Therapist and CDRP affiliate) engaged with us to develop a position and lobby for reconsideration of these changes that had significant unintended impacts on participants and providers. Reimagine Australia, SARRAH, Therapy Connect and CDRP all contributed to the process which resulted in a successful revision of these decisions.

Dr Kim Bulkeley was nominated for WHO Rehabilitation 2030 Intellectual Disability Package of Rehabilitation Interventions Development Group by the World Federation of Occupational Therapists. There have been online surveys and group meetings to finalise the interventions that will be recommended by the WHO. An interesting process with colleagues from across the globe discussing supports for people with intellectual disability. This part of the process will be finalised by the middle of 2021.

Dr Genevieve Johnsson, a CDRP honorary who is with Autism Spectrum Australia (Aspect) has been taking the lead with a collaboration on three projects:

- Tele Positive Behaviour Support research and resource development to explore and expand the use of telepractice in the provision of behaviour supports. A narrative review linked with this work has been published this month
 - Johnsson, G., & Bulkeley, K. (2021). Delivering behaviour support to children and adolescents with autism via telepractice: a narrative review. Research and Practice in Intellectual and Developmental Disabilities, 1-18. doi:10.1080/23297018.2021.1896975
 - In January 2021 the NDIS Quality and Safeguarding Commission engaged the TelePBS team to review the literature and consult stakeholders to develop a set of resources including practice guides, podcasts and videos. These resources will be publicly available and are due for completion by the end of June 2021.

- 2. A Jobs and Market Fund Project with DSS to implement and evaluate an allied health assistant model of service in rural and remote communities. This project has been impacted by the COVID restrictions but is now rolling out more broadly. The ethics protocol has been approved and an Occupational Therapy Honours student, Amanda Ha is completing a project using Photo Voice with NDIS participants to understand their experience of the allied health assistant supports. The evaluation will also include a cost benefit analysis and qualitative insights from the Aspect staff involved with the allied health service model.
- 3. Aspect conducted a survey with allied health staff and service users on their experience of telepractice in the rapid shift to online service delivery in response to the COVID 19 pandemic. Genevieve has gained retrospective ethics approval to analyse this data set, providing insights of relevance to the disability sector more broadly.

<u>Vancouver Foundation Grant Success:</u> Kim is a member of a large consortium of ten child development stakeholders, led by Dr Alison Gerlach from the University of Victoria and Jason Gordon from the BC Association of Child Development & Intervention, that have received a Vancouver Foundation grant for \$200,000. This grant will fund a project to explore the role of technology in promoting and expanding service quality and access for children with developmental and/or health concerns and their families in rural and northern British Columbia.

Services for Australian Rural and Remote Allied Health (SARRAH) have invited Dr Kim Bulkeley to participate in a consultation on the National Disability Research Agenda to include the voices of rural and remote allied health practitioners. Service providers for people with disability in rural and remote communities bring a unique perspective to this conversation and will have the opportunity to contribute on the 27th May in an online forum.

National Disability Research Agenda

The combined Sydney Disability Centres: CDRP and the Centre for Disability Studies are currently leading a consortium of 31 partners developing a research agenda for disability research in Australia for the next 10 years. The project is funded by the National Disability Research Partnership https://www.ndrp.org.au/ The project comprises of three phases:

- 1. Research mapping of existing disability research (completed). This phase identified 1241 individual research papers and 225 research reports over the 2018-2020 which focused on disability in Australia.
- 2. Consultation with the disability community broadly understood (underway). The survey (900+ participants) is now closed, but the NGO-led consultation and targeted consultation by the consortium is still underway.
- 3. Research prioritisation exercise (begins in June).

Get in touch with Jen (project lead) <u>jennifer.smith-merry@sydney.edu.au</u> or lvy (project manager) <u>ivy.yen@sydney.edu.au</u> for more information.

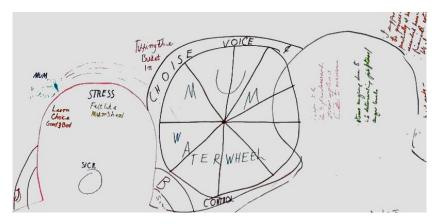
Disability Services

Postgraduate Research Students

In mid-August 2020, **Mr Hasrul Hosshan** was formally notified that he has satisfied the requirements for the award of the degree of Doctor of Philosophy (Health Sciences) at the University of Sydney.

Ms. Bernadette Curryer submitted her PhD thesis in mid-July 2020 "Self-determination of adults with intellectual disability within the context of family relationships" and it is currently under examination. Bernadette completed her thesis under the supervision of Prof. Emeritus Roger Stancliffe, Ass. Prof. Angela Dew (Deakin University), and Dr Michele Wiese (Western Sydney University). Using an Interpretative Phenomenological Analysis approach, individual interviews, dyadic interviews and dyadic body mapping were employed to gain an understanding of the lived experience of either receiving or providing support for choice and control.

The use of body mapping, an arts-based data collection method, provided an insight not always gained through interviews alone. One clear demonstration of this was the following image, drawn by a participant with intellectual disability, where the mother is depicted as a waterwheel keeping choice, voice, and control 'flowing'



The importance, complexity, and impact of family support on the attainment of self-determination emerged as a key theme. The experience of self-determination was impacted by family values, perceptions and beliefs, and the support strategies implemented. The tripartite-ecological theory of self-determination provided a framework to understand family influence, the support relationship, and the subsequent level of choice and control experienced. The results suggested that self-determination of adults with intellectual disability should be viewed as a relational concept and a whole-of-family approach to the development of self-determination is required.

Curryer, B. (2020), *Self-determination of adults with intellectual disability within the context of family relationships.* Unpublished thesis. The University of Sydney, Sydney, Australia

News from our CDRP Honorary Affiliates

Dr Geneveive Johnsson, CDRP leadership team and Aspect

It is widely recognised that people with a disability are among some of the most disadvantaged groups in our society, with comparatively poorer health status and a health system that often fails to meet their needs. Recent inputs and public consultation have confirmed that health and wellbeing continue to be a priority area for reform for people with a disability in the next decade of the National Disability Strategy. Project ECHO (Extension for Community Healthcare Outcomes), developed by the University of New Mexico USA uses live online case-based learning and mentorship to help remote medical and allied health professionals gain the expertise required to better support people with a disability. Genevieve Johnsson is currently exploring opportunities for CDRP to drive the first disability-sector led ECHO in Australia using a co-designed, partnership approach. For more information or to get involved please contact Genevieve on genevieve.johnsson@sydney.edu.au

Dr Damian Mellifont, CDRP leadership team

Damian is a neurodivergent researcher in CDRP and a member of the CDRP leadership team. He has been a very active member of CDRP for over 5 years.

Damian's most recent manuscript entitled, 'A Qualitative Study Exploring Neurodiversity Conference Themes, Representations and Evidence-Based Justifications for the Explicit Inclusion and Valuing of OCD', has recently been accepted for publication in The International Journal of Information, Diversity and Inclusion. This study reveals that neurodiversity conferences cover diverse topics which are fundamental to improving the lives of neurodivergent persons. Topics of education, employment, social inclusion, advocacy, health and policy are each receiving attention in conference flyers. The study cautions, however, that this attention is far from being evenly distributed. Furthermore, greater attention is needed on practical policy measures that can help to redress ableism.

The research also highlights that neurotypes are not evenly represented in conference materials. While not suggesting that Obsessive-Compulsive Disorder (OCD) or any other type of neurodivergence must be accounted for in all conferences that are promoted under the neurodiversity banner, it is proposed that these conferences need to reflect diversity to their greatest possible extent.

Access to Disability Services by Culturally Diverse Women

Access to the NDIS by culturally diverse women with disability: project by CDRP PhD student Gianina Raymundo. Please pass on this invitation to anyone you know who might be interested:

Are you a woman aged 18-64 years old, from a non-English speaking background who currently accesses disability services? Or are you a carer or guardian for a woman who fits this description? We would love to hear from you!

You are invited to participate in a 1-hour interview about your experiences of disability, accessing disability services and how you think access could be improved.

Our research aims to explore the experiences of culturally diverse women to identify factors that prevent or enable them to access disability services and the National Disability Insurance Scheme. For more information and to register, please click on this link: http://bit.ly/3c3BYB2 For any further questions, please contact Gianina Raymundo at gianina.raymundo@uni.sydney.edu.au



DISABILITY **SERVICES BY CULTURALLY DIVERSE WOMEN**



You are invited to participate in a research study exploring:

- Experiences of culturally diverse women with disability
- Factors that affect access to disability services and the National Disability Insurance Scheme (NDIS)

Who are we looking for?

You are a woman, OR a carer/guardian of a woman:

- Between 18 and 64 years old
- Born overseas/from a non-English speaking background OR has at least one parent born overseas/from a non-English speaking background
- Currently accessing disability services in NSW

What is involved?

- Short survey
- 1-hour interview about your experiences of disability and accessing disability services

For further information, please contact Gianina Raymundo (PhD Student) Email: gianina.raymundo@sydney.edu.au

How do I register?

Register using the following link or QR code: http://bit.ly/3c3BYB2



SCAN ME