

UNSW Disability Innovation Institute

Annual Review 2021



UNSW
SYDNEY



UNSW
Disability Innovation
Institute

Our Team

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Cover image: *Untitled 3* by [Katrina Brennan](#).



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Letter from the Director

Welcome to the UNSW Disability Innovation Institute's first Annual Review. We hope that it will inform colleagues old and new about the Institute's activities in 2021, as well as show how the past year's work grounds all our efforts in the months to come.

As Director it has been both enjoyable and salutary to have the opportunity to look back over the past 12 months. In the rush of the everyday, it is very easy to lose sight of just how much we have achieved – and of the hard work that has gone into making it all happen. The core team of the Institute is relatively small; alongside the challenges being small sometimes presents, it ensures that we are a close-knit unit, motivated to generate a healthy network of collaborators and supporters across the university who help us carry out our mission. Chief among these is of course the Division of Equity Diversity & Inclusion (EDI), which provides us with an organisational home, a pan-university reach beyond the individual Faculties, and opportunities for cross-fertilisation with the Division's core goals.

Here, I just want to pick out a few highlights of 2021. In mid-year we took our first steps into

the world of podcasts, first with a contribution to the Institute of Global Development's podcast [Thinking on Development](#): Disability and Disasters, led by Professor David Sanderson and featuring the Institute's Rosemary Kayess and myself, with Michelle Villeneuve from the University of Sydney's Faculty of Medicine and Health. We then moved on to launch our own [series of podcasts](#), first taking a deeper look at the meaning of disability inclusion. In 2022 our podcasts will include a more in-depth feature on inclusive research, together with an episode marking the 15th anniversary of Australia's signing in 2007 of the UN Convention on the Rights of Persons with Disability.

Another highlight was our [new website](#) being launched in September. As well as aligning more closely with the UNSW style, the new website is more informative, more user-friendly and, crucially, has better accessibility. At around the same time we were able to launch our [Institute Associates Program](#), through which we seek to invigorate disability research and further nourish interdisciplinary collaboration at UNSW. We look forward to building the relationship with the Associates through events in 2022.

'I am delighted that the UNSW Disability Innovation Institute continued to be a leader in interdisciplinary and inclusive research in the disability field in 2021. The Institute's commitment to working with people with disability ensures that endeavours in research, policy and industry are accessible and collaborative. The Institute is working towards a more inclusive world for all, and I see it as a vital part of the UNSW Division of Equity Diversity & Inclusion.'

Professor Eileen Baldry AO
Deputy Vice-Chancellor, Equity Diversity & Inclusion

Research of course forms a central part of our work. As well as supporting disability-inclusive research across the university, we lead or are involved in a range of externally funded projects. You can read more about these starting on page 7. A particularly notable achievement in 2021 was our successful application for funding from the NSW Ministry of Health to support GeneEQUAL, a project that – for the first time – asks people with intellectual disability about their experiences of genetic testing and counselling. Led by Dr Emma Palmer from Sydney Children's Hospital Network and the Institute's Professor Iva Strnadová, this research aims ultimately to provide resources that will enable people with intellectual disability to make genuinely informed decisions about their genetic testing.

The year has also seen some arrivals and departures. Sadly, we had to say goodbye to Hannah Sheridan, Institute Manager, leaving us to go on parental leave; Kayla Lochner, Program Support Officer, who went on to the new challenge of a PhD in climate change injustice; and finally to Marie Delaney, Project Officer, who moved into a new phase of her life at the end of 2021. Marie will be particularly missed, as she has been

part of the Institute since its very beginning. In turn, however, we have welcomed Lucy Sun as our Institute Manager and Isabella Burton-Clark to take charge of communications and engagement.

Like all of us in the university and beyond, the Institute has been confronted with many unprecedented and unanticipated challenges over the past two years. In our research and engagement, we have tried to highlight how the COVID pandemic and pandemic measures have disproportionately affected people with disability. In the year ahead we will strive to raise awareness of disability, innovative and inclusive through research and education.

Jackie Leach Scully
Director
UNSW Disability Innovation Institute

The UNSW Disability Innovation Institute is active across research, education and engagement. In some cases we are directly funded to enable our members to focus on particular research projects, and some of these are described below.



Another aspect of the Institute's research life is the seed funding of small-scale projects across UNSW that will go on to attract further funding and become self-supporting. We also support high-level efforts towards inclusive teaching and learning.



Our Research

Research by Institute members aims always to be inclusive and interdisciplinary. We strive to pursue cutting edge knowledge in important and emerging fields, and where we see gaps in understanding and practice that have major impacts on the lives of people with disabilities. Reflecting ongoing research interests and collaborations, our current projects have a focus on the contested area of genetics and disability.



Epigenetics and Pregnancy Care in Australia for Socially Marginalised Women

Sponsor/Scheme: ARC Discovery Project Shared Grant

Start/End Dates: March 2021 - February 2024

Award: \$88,080.00

This three-year project funded by the Australian Research Council, involving DIIU Director Jackie Leach Scully along with Professor Kylie Valentine (UNSW Sydney) and colleagues at Monash University and ANU, aims to investigate how knowledge about epigenetics – a relatively new field studying how health and disease are transmitted across generations – is shaping antenatal care in Australia. Epigenetics has potential social, economic and health benefits, but these need to be balanced against some less obvious risks: for example, risks of discrimination against and stigmatisation of some women, and increases in social inequality.

The project will analyse current uses of epigenetic expertise in policy and clinical practice, and in materials that prospective parents and health professionals may use, to

see how such knowledge may be changing the experience of pregnancy for women. Ultimately, we aim to provide advice to practitioners and policy makers to ensure that epigenetics is used in ways that support autonomy and social inclusion. Jackie's particular interest is in how our growing knowledge of epigenetics shapes contemporary discussions of disability, disease, foetal harm and maternal responsibility, and the consequences for the lives of people with disability.

Due to start in mid-2021 the project has been delayed by COVID lockdowns in Melbourne and Sydney, but will be fully underway in 2022.

Photo by Aditya Romansa on Unsplash.



TARGeT: Theories of Autonomy in Reproductive Genomic Technologies

Sponsor/Scheme: ARC Discovery Project Shared Grant

Start/End Dates: June 2021 - June 2023

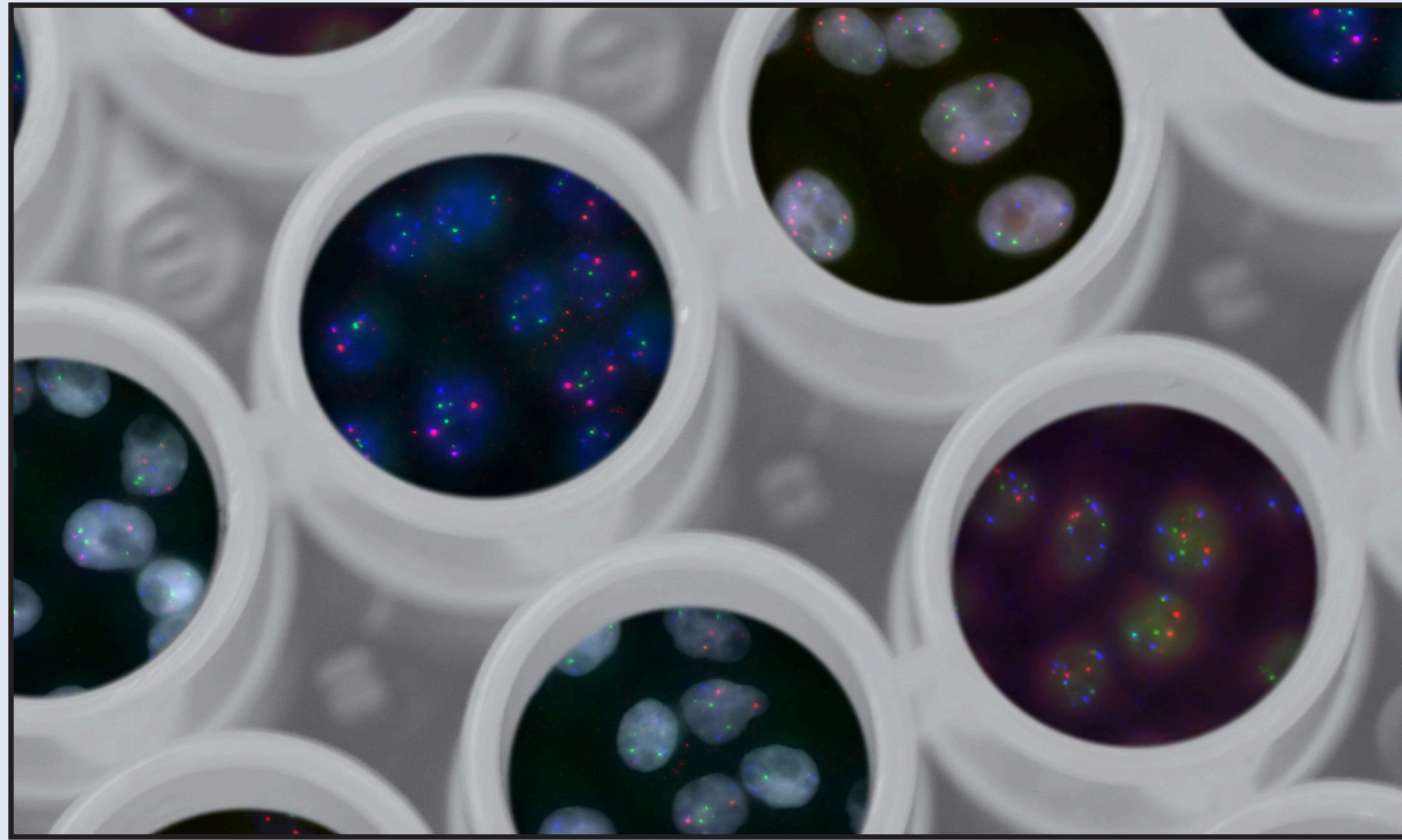
Award: \$175,170.00

Institute Director Jackie Leach Scully is co-investigator in an ARC-funded project, [Theories of Autonomy in Reproductive Genomic Technologies](#).

Recent developments in DNA sequencing mean that pregnant women are now offered genetic testing of their foetus that can give information on a rapidly expanding list of potentially disabling conditions. The rationale for offering genetic testing in pregnancy is usually that it will “maximise reproductive choice” or “autonomy”: that providing prospective parents with knowledge about their future child’s likely genetic makeup will help them make better, more informed choices. Yet today’s genomic information is often complex and hard even for clinicians to interpret unambiguously. There are questions to be asked about whether such information really helps parents make difficult decisions about their future, and the future of their child.

The project’s team of researchers (from UNSW, University of Sydney, University of Melbourne, and Memorial University, Newfoundland, Canada) are examining whether current understandings of what reproductive autonomy is, and how it can be exercised, are adequate in this new clinical landscape. In a series of in-depth interviews with healthcare professionals and with parents, we are exploring attitudes towards, experiences of and ethical concerns about contemporary genomic testing in pregnancy, focusing on the relationship between testing and reproductive autonomy. Jackie will be directing a large part of this empirical work, and will be examining how new genomic knowledge is influencing people’s thinking about disability in general and in particular the acceptability of prenatal selection around anomaly.

Photo by Toro Tseleng on Unsplash.



Genomics Education Inclusive of People with Intellectual Disability

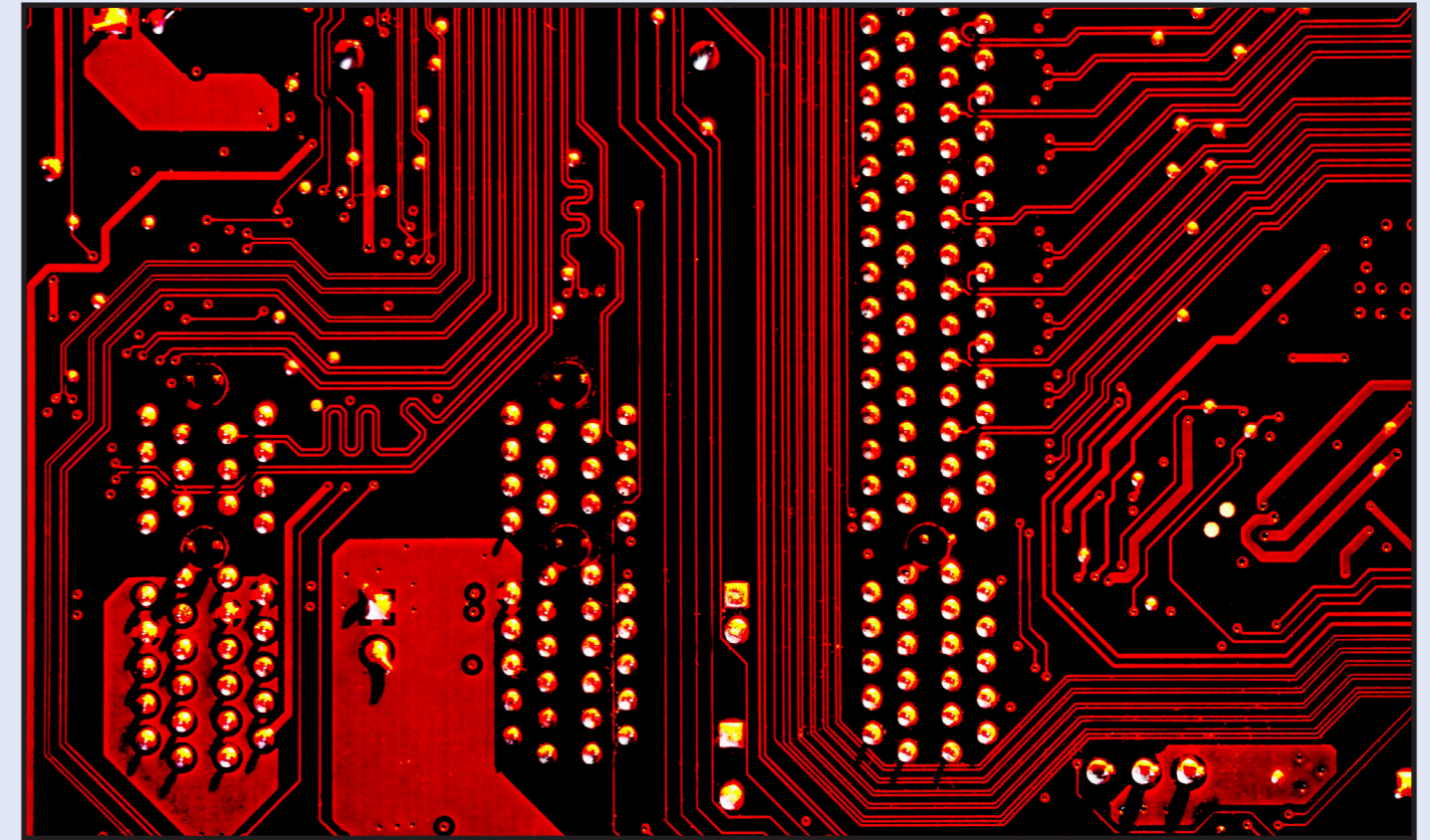
Sponsor/Scheme: NSW Health/State Government Contract
Award: \$121,235.27 (\$12,683.38 to Institute)

Genetics has revolutionised our understanding of the causes of intellectual disability and holds significant promise to improve health outcomes. The NSW Health Genomics Strategy aims to improve access to patient care that is value-based and integrated with all parts of the health system. It highlights the need to work with people with intellectual disability as equal partners to develop services that reflect their needs and preferences in line with ethical, legal and professional standards.

However, almost nothing is currently known about how people with intellectual disability as consumers experience genetic healthcare services. Strnadová et al.'s (2022) extensive scoping review screened over 1,000 relevant studies and found that only seven even attempted to directly engage people with intellectual disability about their experiences and opinions of genetics and/or genetic testing and/or genetic counselling. None of these studies had been conducted in Australia.

The aim of the GeneEQUAL project, supported by NSW Health, is to work with people with intellectual disability who have accessed genetic services to explore their knowledge, perspectives, experiences, education needs and preferences. This inclusive research study addresses a significant gap in NSW genetic healthcare delivery that is a potential source of inequity and discrimination. It provides an essential bridge to a better understanding of how testing and other genetic medicine could be made more inclusive and accessible for people with intellectual disability. GeneEQUAL will provide the crucial evidence base to guide subsequent co-development of accessible genetic resources to improve the wellbeing of people with intellectual disability through better inclusion in their own genetic healthcare.

Photo by National Cancer Institute on Unsplash.



Centre for Excellence in Automated Decision Making and Society

Sponsor/Scheme: ARC Centre of Excellence
Start/End Dates: 2019 - 2026

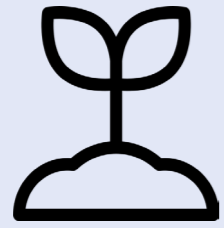
UNSW is home to one 'node' of the multi-university Centre of Excellence in Automated Decision Making and Society (ADM+S). Funded by the Australian Research Council, the ADM+S brings together researchers to examine how our world is responding to the growth of technologies that use artificial intelligence (AI) to make autonomous (or what appear to be autonomous) choices. These technologies range from the futuristic (like self-driving cars) to the very mundane -- "Robodebt" is of course a now notorious example of where automated decision making can go wrong in public services.

Disability is an area of interest that cuts across several of the themes and focus areas of the Centre. Dr Georgia van Toorn and DIU Director Jackie Leach Scully are developing empirical and theoretical analyses of significant case studies of ADM in disability support and healthcare. For example, previous commentators have noted that automated systems are best applied to standardised categories and norms, yet

by definition many people with disability fall outside the 'norms' of human form and function. This raises the risk (or even likelihood) that automated services will be too inflexible to identify and suit their needs.

In the course of 2021 Georgia began a series of interviews with key stakeholders involved in the debate over automating disability service assessments. Meanwhile, Jackie presented the developing conceptual work at meetings of the Australasian Association of Bioethics and Health Law and the American Society for Bioethics and the Humanities.

Photo by Michael Dziedzic on Unsplash.



Seed Funded Projects

Providing seed funding for inclusive disability projects allows the Institute to support innovative ideas at an early stage of development. Although we did not run the seed funding program in 2021, projects we had previously funded continued to flourish, publishing their findings and acquiring further research grants. We are pleased to have been able to recommence the program in 2022 and we hope to expand even further in the future.

A number of the projects published articles in 2021 in the following high-impact journals:

- » *Journal of Paediatrics and Child Health*
- » *Journal of Refugee Studies*
- » *Journal of Applied Research in Intellectual Disabilities*
- » *Social Policy & Administration*
- » *BMJ Open*
- » *Health and Social Care in the Community*
- » *International Journal for Equity in Health*
- » *Australian Journal of Public Administration*.

‘One benefit of our experience conducting inclusive research for this project has been a greater understanding of what is required for future research projects in this area, which assisted with our application for NDRP [National Disability Research Partnership] funding. Secondly, the project allowed us to demonstrate a track record of inclusive research. The networks and trust we developed through the pilot project have also been useful in preparing that application, although the politics of inclusive and collaborative work in the disability sector can be challenging.’

– **Dr Sophie Yates, Lead Researcher, ‘Gendered barriers to accessing personalised disability funding schemes’**



Researchers from the project ‘Data governance and the National Disability Insurance Scheme’ also published the results from their project in a new book, *The Handbook of Performance Management in the Public Sector* (Edward Elgar Publishing) and the lead researcher, Dr Sue Olney, contributed to *The National Disability Insurance Scheme: An Australian Public Policy Experiment* (Palgrave Macmillan). The team also contributed a response to the National Disability Employment Strategy consultation and the Disability Workforce Data Project.

Several activities that resulted from the seed funding for ‘Pathways to preventive care for people with severe mental illness’ have continued throughout 2021, including:

- » A Scientia PhD scholarship with the UNSW Centre for Primary Health Care and Equity
- » A project funded by Mindgardens Neuroscience Network
- » A project funded by the NSW Health Translational Research Grants Scheme
- » A project funded by the Mental Health Commission of NSW.

For a detailed list of Institute-related publications, see page 20.

‘Our experience of inclusive research has influenced how we apply for new funding. We now have greater capacity to argue for and include lived experience researchers. We used the experience of our DII-funded project in meetings with other disciplines/organisations about grant applications to argue for the value of inclusive methods and how to do it’ – **Dr Catherine Spooner, Lead Researcher, ‘Pathways to preventive care for people with severe mental illness’**

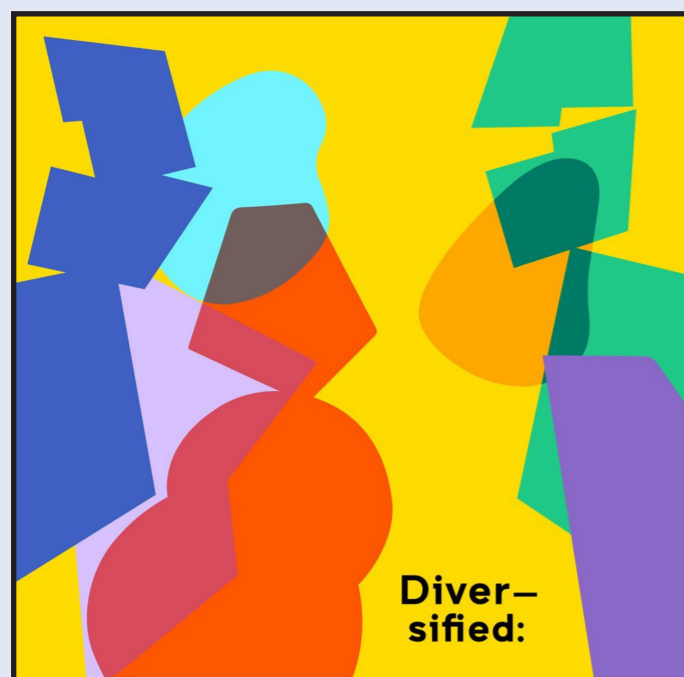


Education

Although the Institute is not centrally involved in teaching, members contribute to teaching in their own courses, to pedagogic research, and to UNSW's inclusive teaching and learning practices.

The Institute's Academic Lead—Education, Professor Terry Cumming, co-established an inclusive education group on campus, Diversified, using funding provided by the Division of Equity Diversity & Inclusion. This student-led group held three workshops that focused on co-production partnerships between neurodiverse students and lecturers in UNSW courses. The group is collating the information from the workshops and plans to present the highlights at an Inclusive Education Showcase during UNSW Diversity Week in 2022. The group has received more funding via the Faculty of Arts, Design & Architecture's Disability Champions, Karen Kriss and Alex Smith, and is currently working on the production of a video that will detail how lecturers and the wider university can support neurodiversity.

Terry also successfully applied for a grant through the School of Education Rapid-Fire Research Grant Scheme for the project 'University researchers as partners in implementing school-wide UDL [Universal Design for Learning]: An action research project'.



Engagement & Advocacy

A third important area of the Institute's work is engagement and advocacy with and on behalf of people with disability.

A major focus through 2021 has been the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC). The DRC commenced in 2019 and is due to report its findings and recommendations in 2024. Rosemary Kayess, the Institute's Academic Lead Engagement, was appointed to the Strategic Engagement Advisory Committee, a high-level advisory body for the DRC that provides the Commissioners and the policy team with advice based on a legal and policy analysis of Australia's obligations at international law with regards to the Convention on the Rights of Persons with Disabilities.

A submission to the DRC in June in response to the Rights and Attitudes Issues Paper was co-produced by the Institute and Women with Disability Australia. The Issues Paper focused on the role of community attitudes and the rights of people with disability. The submission examined the devaluing of people with disability, commonly referred to as 'ableism', that underpins inequality and discrimination, provided a legal analysis of Australia's obligations under the CRPD and the policy implications, and made recommendations for improvement.

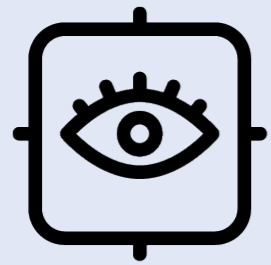
A 2020 piece of research, 'The Convention on the Rights of Persons with Disabilities: Shining a Light on Social Transformation', co-produced by

Rosemary Kayess and Therese Sands, a member of the Institute's Advisory Council, was the basis for expert evidence at the DRC's public hearing on the CRPD. The report describes the experience of inequality, discrimination and segregation that catalysed the disability rights movement and the development of a human rights convention on disability.

The Institute's Emeritus Professor Leanne Dowse, alongside other UNSW colleagues, completed a report for the DRC entitled 'Policy Responses to People with Disability'. The report indicates that justice systems across Australia in many cases enable, rather than prevent, violence, abuse, neglect and exploitation of people with disability. It also includes examples of good practice and alternatives to the current policing models that advocates say should be more widely practiced.

Meanwhile, Institute Director Jackie Leach Scully led on compiling a submission to the UN Special Rapporteur on the rights of persons with disability, Gerard Quinn, which informed his report on Artificial Intelligence and the Rights of Persons with Disabilities. The report was presented at the 49th session of the UN Human Rights Council in December 2021 and is available here:

On behalf of the Institute, Jackie also worked with the Allens Hub for Technology, Law & Innovation, Australian Society for Computers and Law, the Data Science Hub, the Centre for Social Impact, and the Centre for Cyber Security Research and Innovation at Deakin University, on a submission providing feedback to government on the Australian Data Strategy.



Communications & Events

The Institute continued to host accessible webinars and online events throughout 2021. Three webinars focused on research while a special event with disability advocate Nicole Lee marked International Day of People with Disability in December.

Culture, Disability & the Violence of Exclusion with Prof. Leslie Swartz

Over 150 people registered to attend our first webinar for 2021 which was presented by Professor Leslie Swartz from Stellenbosch University. Leslie spoke about the Esidimeni tragedy, when at least 144 people with intellectual disability and/or mental disorders died after being transferred to unregistered care centres in Gauteng province, South Africa. Leslie argued that awareness of the political use of concepts of culture remains a key imperative for people concerned with disability rights, especially in the context of global neoliberalism.

Improving Access to Primary Care for People with Severe Mental Illness

The Institute's June 2021 webinar highlighted the work of one of our seed funded projects. Dr Catherine Spooner and Dr Peri O'Shea spoke about their research on access to primary care for people with severe mental illness. The webinar took us through their research methodology as they explained that a consumer-inclusive and partnered approach is needed to provide the best care for people with severe mental illness accessing services. The research also supports the need for training and resources to help general practices become more responsive to the needs of people with mental health issues.

Disability Bioethics with Prof. Jackie Leach Scully

As part of UNSW's Diversity Fest in October, our own Jackie Leach Scully, Director of the Institute and a Professor of Bioethics, drew on the experience of her wide-ranging career to give an introduction to the ways in which feminist bioethics informs, and is informed by, critical disability studies.

International Day of People with Disability

In December, the Institute collaborated with UNSW's Division of Equity Diversity & Inclusion for an online event to mark the International Day of People with Disability. Nicole Lee is a prominent disability and domestic violence prevention advocate. She spoke passionately about the role that each person can play in preventing violence and disability discrimination, followed by a Q&A session with Jackie Leach Scully.

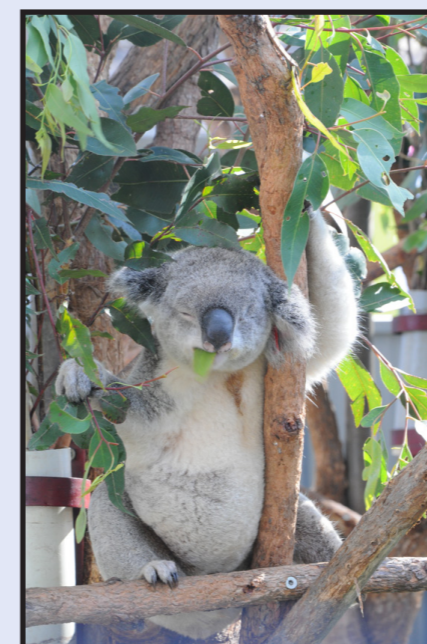


Newsletters

We continued our monthly newsletters throughout 2021. These are vital ways of updating our subscribers about our activities and providing resources such as articles, webinar recordings and podcasts.

Newsletters often included interviews with people associated with the Institute, such as Emeritus Professor Leanne Dowse, PhD student Lucinda Freeman, former Advisory Council chair Graeme Innes AM, and the UNSW Disability Champions Roshana Sultan, Isabelle Vertucci and Bani Aadam.

And, of course, our November Newsletter announced the Institute's new mascot: Evans Head CW (below), an injured koala who, because of his disabilities, lives permanently at Port Macquarie Koala Hospital. Jackie Leach Scully has adopted CW on behalf of the Institute.



Podcasts

We launched our podcast series in 2021, beginning with Graeme Innes AM and Rosemary Kayess in a discussion of the importance of inclusion and human rights to both academia and policy.

Our second episode featured Iva Strnadová (below), who spoke about the principles of inclusive research and why it matters. Iva shared her experiences of working with and learning from people with intellectual disability, as well as her own lived experience.

Keep an eye out for 2022's episodes, which explore the Institute's research, education and engagement in more depth.



Across UNSW & Beyond



2021 saw the development and introduction of the Institute’s Associates Program, one of the ways through which we build a network of disability researchers and foster interdisciplinary collaboration within UNSW.

Associates are current UNSW staff members or PhD students, and the program comprises representatives from six Faculties across UNSW.

The Institute currently has 18 Associates across 6 UNSW Faculties.

Medicine & Health



Arts, Design & Architecture



Business



Other



Associates Program

The Institute supports its Associates by profiling their research on our website or through DIIU-hosted webinars and podcasts, and by providing advice and guidance on conducting high quality inclusive disability research. Associates are also automatically eligible to apply for seed funding or bursary grants from the Institute.

Due to COVID restrictions our planned in-person launch of the Associates program was replaced by a video featuring the Institute’s Director, Academic Leads and three Associates—Prof. Valsamma Eapen, Dr Sophie Yates and Ms Michelle Tso—to welcome our new Associates and inform others of the Program.

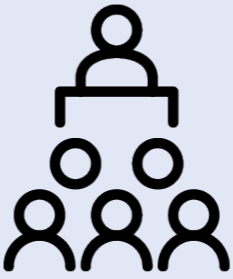
UNSW Canberra



Engineering



Science



As well as the Institute's work in research, education, engagement and outreach, we work constantly to raise awareness of disability issues across UNSW and in wider society.

We have provided advice to UNSW on the accessibility of online meetings and webinars.

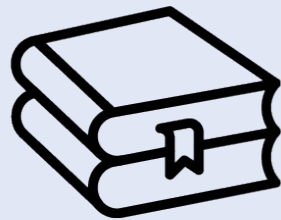
We have participated in UNSW’s Disability Inclusion Action Plan (DIAP). In 2021, the DIAP team was tasked with auditing the University’s current disability progress against the Australian Network on Disability’s Access and Inclusion Index according to 10 key focus areas. The results of the audit will inform the next three-year DIAP. Professor Terry Cumming, the Institute’s Academic Lead Education, contributed subject-level expertise through her examination of the key focus area of ‘Teaching & Learning’ (including UDL/assistive technology) and ‘Student Support’.

In September, the Institute’s Director Jackie Leach Scully participated in a panel discussion organised by Accessible Arts and the Sydney Arts Management Advisory Group, ‘Innovating Art Through Disability’. Jackie discussed the way in which the Institute pursues its interdisciplinary goals through connections with the arts, such as through using artwork by artists with disability

from Studio A on our website and in this Annual Review. Jackie took part alongside Eugenie Lee, a Korean-Australian conceptual artist who develops work expressing her lived experience with chronic pain, and Dan Graham, a neurodiverse writer and director from Sydney.

Jackie also took part in a discussion of Deaf culture for the Sydney Opera House’s Antidote Festival. The panel included Fiona Murphy, poet and author of the memoir the Shape of Sound, and Alex Jones, entrepreneur and Deaf activist now working with the Disability Royal Commission.





Publications

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