

UNSW Disability Innovation Institute

Annual Review 2022



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UNSW
Disability Innovation
Institute

Our Team

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Cover image: *Eiffel Towers* by [Damian Showyin](#).



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Letter from the Director

It's always a pleasure when it's time to write my introduction to the UNSW Disability Innovation Institute's Annual Review. Sometimes, it's also a surprise to be reminded of the activities we've undertaken. Caught up in the flow and busy-ness of the year we tend not to notice how much we're doing, and often there isn't time to celebrate our achievements.

The Institute had an active year, with a major international webinar series A Past Still Present, and an overseas visitor, Professor Simon Woods. As you'll read, we also continued to progress in our various research work and collaborations to support accessible teaching and learning. We are starting to build relationships with disabled people's organisations and disability researchers beyond Australia through the Asia-Pacific region. Many of our research projects have a focus on genetic/genomic science and its implications for people with disability, but we are also developing a line of work in disability and disaster mitigation and response. Increasingly, we are benefiting from our growing network of Associates, and our links with other UNSW units such as the Australian Institute of Human Rights and the Allens Hub.

I hope you enjoy reading about life at the Institute's activities in 2022. If you're interested in our work, in collaborating with us, or becoming an Associate, please get in touch! We look forward to meeting you in 2023.

Jackie Leach Scully
Director
UNSW Disability Innovation Institute

'Throughout my time acting as Deputy Vice-Chancellor Equity Diversity & Inclusion (EDI), I've thoroughly enjoyed working with Jackie and the team at the UNSW Disability Innovation Institute. Their commitment to working with-alongside, not for-people with disability reflects the goals of EDI to create a more inclusive University, with space for everyone. Jackie's leadership is inspiring and integral to encouraging this work and I look forward to seeing what the Institute achieves this year.'

Professor Bruce Watson
Deputy Vice-Chancellor, Equity
Diversity & Inclusion (acting)

The UNSW Disability Innovation Institute works to produce sustainable change in the lives of people with disability, creating and sharing knowledge through research and education that is interdisciplinary, innovative and inclusive.

With our three goals, we aim to support the expansion of high quality, interdisciplinary disability research and education. We want to:

1. Support high quality research and education that facilitates the inclusion of people with disability as experts, teachers and researchers
2. Build a community of disability interest across UNSW and beyond
3. Be a thought leader and source of evidence-based expertise and advice.



Goal 1

Support high-quality research and education that facilitates the inclusion of people with disability as experts, teachers and researchers



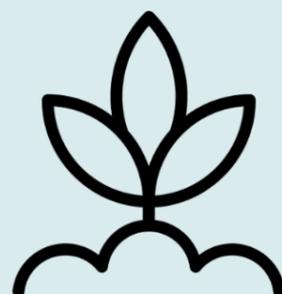
Seed Funding

2022 saw the return of our seed funding initiative, which allows us to support innovative research ideas that are likely to improve the lives of people with disability.

Our 2022 project, *Organisational systems to facilitate increased accessibility of public spaces*, was led by A/Prof. Carlo Caponecchia of the School of Aviation and included investigators Dr Vanessa Huron, also of the School of Aviation, and Dr Beth Mayland from Western Sydney University.

The project examined the systems businesses use to coordinate, manage, and improve accessibility for all users, and how these processes can be integrated into regular business practice and tailored to the nature of the business, its needs, objectives and communities.

Carlo, Vanessa and Beth explored the feasibility of applying Management Systems Standards (MSS) to accessibility management, using a mixed methods approach and establishing an advisory group. To further ensure an inclusive approach they used their connections with disability advocates and hired a research assistant with disability.



Inclusive Education

Professor Terry Cumming continued her involvement with [Diversified](#), a student-led project that aims to elevate the student voice in course design to increase accessibility for neurodivergent people.

In 2022, Diversified produced a report exploring neurodiversity and accessibility, *Diversified: Promoting co-production in course design and delivery between neurodivergent students and instructors*. The report was launched accompanied by a video featuring some of the students involved.

Terry also produced and hosted UNSW's 3rd Annual Inclusive Education Showcase as part of the Division of Equity Diversity & Inclusion's Diversity Fest, where educators across UNSW who teach inclusively shared their work. The showcase provided a unique opportunity for the learning and teaching community to find out about a variety of inclusive educational practices and how to incorporate them into their own teaching and learning, increasing the role of co-production and making courses and the university experience more accessible.



Big Ideas

Iva and Benjamin led the Institute's collaboration with UK and German colleagues in the implementation and evaluation of the Big Ideas initiative, in which theories that are usually inaccessible to people with intellectual disability are explained in an accessible way. This empowers people with intellectual disability to use these big ideas in research and advocacy.

The first workshop, on Spivak's big idea, was run virtually in December and was attended by five colleagues with intellectual disability. We have planned for further workshops in 2023.

Inclusive Research



Photo by Aditya Romansa on Unsplash.

Reproductive autonomy in the genomic age

Jackie Leach Scully is an investigator on this ARC-funded Discovery Project led by Professor Ainsley Newson from the University of Sydney. Advances in DNA sequencing mean pregnant women are now offered information on a rapidly expanding array of potential disabilities and disabling conditions. The genomic information may be complex and uninterpretable, and therefore of little use to clinicians or prospective parents. 'Reproductive autonomy', the ability to reflect critically on values, desires and preferences and to draw on this ability when making choices before and during pregnancy, is frequently given as the key underlying rationale for prenatal testing. Yet the dominant interpretation of reproductive autonomy remains seriously deficient, especially in terms of making decisions about disability.

Last year, Jackie worked with Dr Kerryn Drysdale of the UNSW Centre for Social Research in Health to interview healthcare professionals involved in reproductive medicine, exploring their understandings and views of reproductive autonomy, and how it is supported or challenged in practice. The interviews helped to design a series of disability-inclusive deliberative events, planned for 2023, to examine how these new tests can be offered and used in ethically responsible ways.

Epigenetics and pregnancy care in Australia for socially marginalised women

Epigenetics refers to the relatively transient chemical changes in the genome that can influence how genes are expressed and, it is currently thought, have significant effects on human health. While there is growing clinical evidence for some limited epigenetic effects during pregnancy on the development of the future baby, the language of epigenetics has been popularly adopted to explain a much wider range of phenomena. In this project, Jackie and Professor Kylie Valentine from UNSW are collaborating with ANU and Monash University to examine the impact of the science of epigenetics on antenatal care in practice, and on women's thinking about their own and their child's health before, during and after pregnancy. Jackie's particular research considers how epigenetic ideas affect the meaning of disability, particularly concepts of stigma and blame.

Like many other empirical projects, the study was severely delayed by various effects of COVID and of pandemic measures. During the second half of 2022, however, the research gained momentum. Initial findings are likely to be reported in 2023.

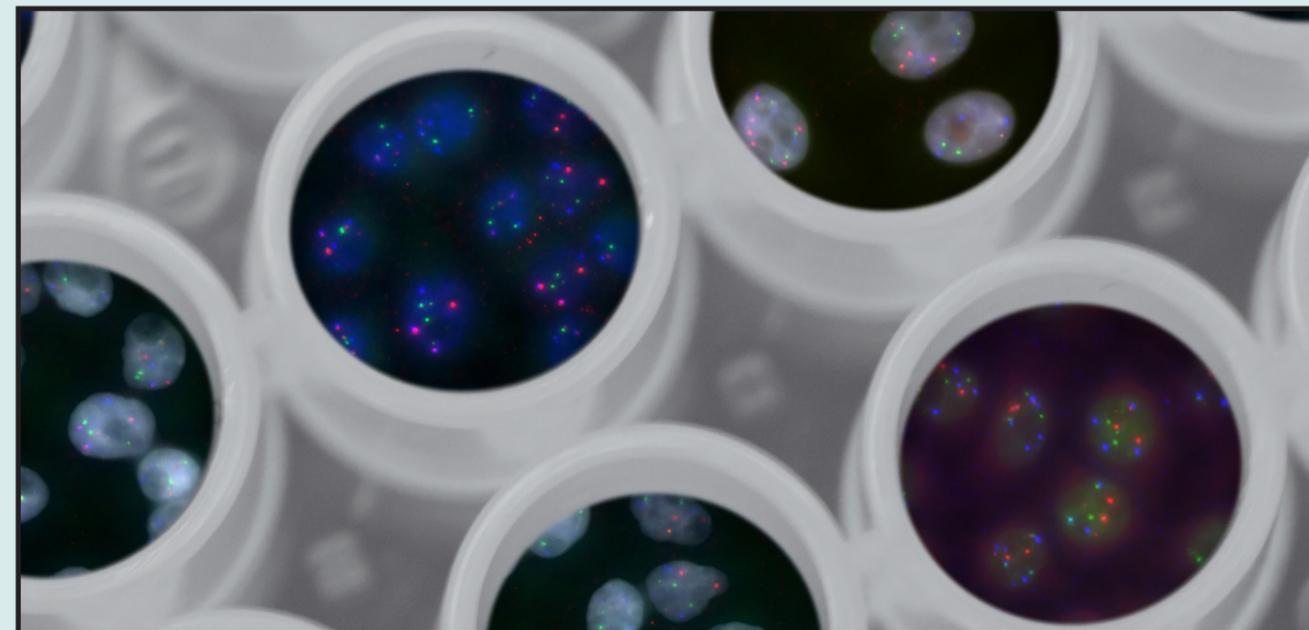


Photo by National Cancer Institute on Unsplash.

GeneEQUAL

Iva Strnadová and Jackie Leach Scully continued their involvement in GeneEQUAL. GeneEQUAL is an interdisciplinary research program co-led by Institute Associate Dr Elizabeth Emma Palmer alongside Iva and Jackie. The aim of the program is to create a more inclusive, person-centred and respectful genetic health care approach for people with intellectual disability. The team also includes co-researchers Julie Loblinzk OAM, Adjunct Lecturer at UNSW Sydney and Board Member of Self-Advocacy Sydney, and Skie Sarfaraz, Team Leader for the Leadership Peer Support program at Self-Advocacy Sydney.

The GeneEQUAL team continued to build on their past success in 2022, with multiple presentations at international conferences and to the Parliament of NSW, appearances on podcasts, publication of journal articles, and finally the award of \$1.6 million in funding over five years from the National Health and Medical Research Council (NHMRC) to continue their work.

Organ Quality Assessment (OrQA)

OrQA is a new technology, developed within the National Health Service of the UK, that uses artificial intelligence and image analysis to evaluate the quality of a donated organ ready for transplant. In the UK as in Australia, thousands of patients with disabling conditions are on waiting lists for the few donated organs that become available. Uncertainty about the health of a donated organ is a major reason why transplant operations fail to go ahead. This technology is being developed to provide transplant surgeons with more information and support their assessment of organ suitability for the patient.

Jackie is involved with the UK project team in initial consultations with surgeons and patients for the feasibility evaluation of this new technology.

Goal 2

Build a community of disability interest across UNSW and beyond

UNESCAP Meeting Side Event on Disability-Inclusive Disaster Risk Management and Reduction

In October, the Institute hosted a side event at the UN Economic and Social Commission for Asia and the Pacific (ESCAP) High-level Intergovernmental Meeting on the Final Review of the Asian and Pacific Decade of Persons with Disabilities, 2013–2022. Facilitated by the UNSW Institute for Global Development, the event, *Disability inclusion in disaster risk reduction and management: key to social and economic resilience in the Asia-Pacific region*, was held virtually with experts from the region in a panel chaired by Jackie Leach Scully and our own Rosemary Kayess, together with A/Prof. Michelle Villeneuve from the University of Sydney and Risnawati Utami, disability rights advisor and founder of OHANA Indonesia. The panel discussed the importance of including people with disability not just in response to disaster and emergencies, but in disaster preparedness and risk reduction, resilience and recovery.



Photo by Joanne Francis on Unsplash.

Associates Program

Our Associates Program continued to grow in 2022, increasing to 20 Associates across 6 faculties and beyond (with one Honorary Associate and one from the portfolio of the Pro Vice-Chancellor Education & Student Experience).

The Program works to build networks of disability researchers and other staff and fosters interdisciplinary collaboration within UNSW. Associates are regularly featured in our newsletter and on our website and are entitled to advice from our Academic Leads about best-practice disability inclusive research.

In December, to mark International Day of People with Disability, we held an event for our Associates where they were each invited to give a short presentation about their recent disability inclusive research activities. We were treated to a wide range of presentations, including topics such as making public spaces more accessible and an analysis of why NDIS participants might choose unregistered support providers.



UN Committee on the Rights of Persons with Disabilities (CRPD)

Our Academic Lead Engagement Rosemary Kayess was re-elected to the UN CRPD, to serve from 2023 to 2026, continuing her long association with the Committee. Rosemary held the position of Chair in this Committee until recently; she is now Vice-Chair.

Through her work with the CRPD and elsewhere, Rosemary provides the Institute with key connections to the Australian and international disability landscape.



Trophy Dreams Visual Communication Symposium

In July and August, we teamed up with the UNSW Library & Art Collection in a three-way collaboration with Studio A, Trophy Dreams. Studio A is a supported art studio that provides a working space, professional pathways and guidance to artists with intellectual disability, and is a longstanding partner of the Institute—you can see a painting by one of their artists on the cover of this review, and others on our website. The exhibition was a multi-artform interactive experience that included decorated graduation gowns and mortar boards created by three artists in response to their views on the meaning of universities.

In association with the exhibition, we co-hosted a half-day symposium on Visual Communication and Inclusive Practice. CEO Gabrielle Mordy gave a background on Studio A's history, ethos and practices, artist Greg Sindel described his approach to his work, and a panel discussion hosted by Jackie Leach Scully featured Scientia PhD scholar Chloe Watfern, who is carrying out research with Studio A, and Institute Associate Dr Scott Brown of the School of Art & Design.

Webinar: Starting the Conversation on Including Genes Associated with Non-Syndromic Hearing Loss in Reproductive Genetic Carrier Screening

One of our Director Jackie's PhD students, Lucinda Freeman, presented her research on the acceptability of prenatal screening for deafness. Lucinda is Head of Discipline, Genetic Counselling at UTS and brings many years of professional experience to her PhD work.

Lucinda explained that reproductive genetic carrier screening (RGCS) is a new type of genetic testing available to prospective parents, to identify their chances of having a child with a serious childhood onset genetic condition. We heard that there is no consensus on whether deafness should be included in this type of screening, with people holding very different, often polarised views. Her presentation reported on her empirical work with deaf people, and families of deaf children, that demonstrated how these views are often very different from the medical or health policy perspective. Lucinda explained that this is particularly problematic at a time when governments are considering implementation of population-wide reproductive genetic carrier screening.

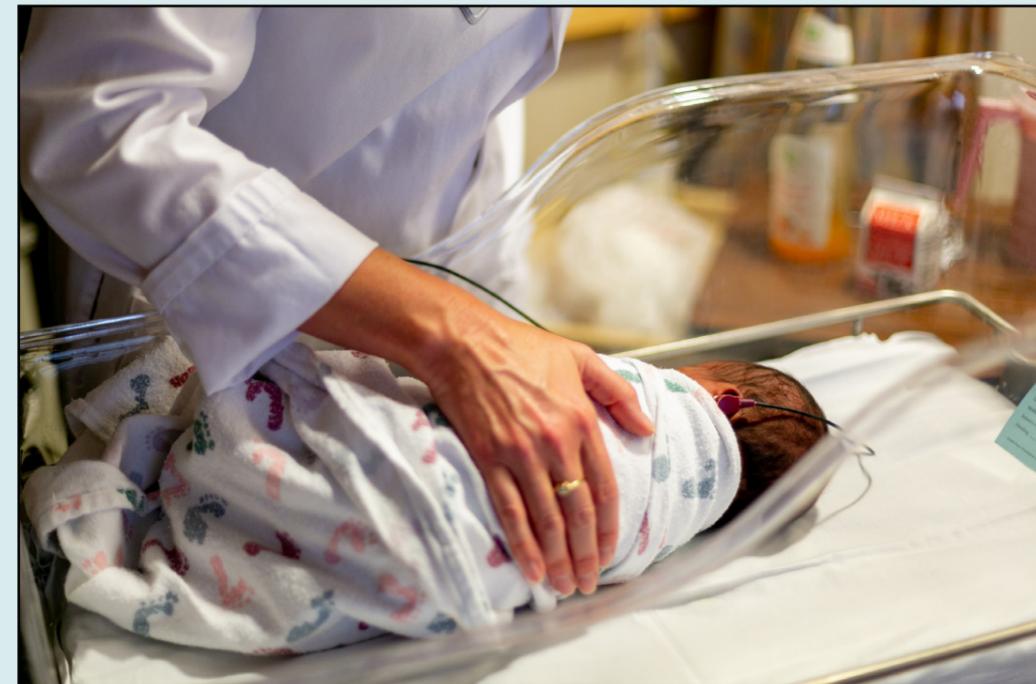


Photo by Solen Feyissa on Unsplash.

Goal 3

Be a thought leader and source of evidence-based expertise and advice

Inclusive Research Guidelines

In May we launched our second set of inclusive research guidelines, [Doing Research Inclusively: Co-Production in Action](#). The new guidelines build on our previous guidelines, *Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability*, and provide practical strategies for every step of the co-design process in research.

The guidelines, available in PDF, Word and Easy Read formats, provide a key resource for academic researchers, people with lived experience of disability, disability organisations, and any other people or organisations who understand and appreciate the importance of inclusive research.

The Institute produced an online launch event chaired by Professor Karen Fisher of the UNSW Social Policy Research Centre (and an Associate of the Institute), an expert in disability inclusive research. Two of the guidelines' authors, our own Professors Iva Strnadová and Leanne Dowse, also spoke about the importance of inclusive research and their experiences in developing the guidelines.

DOING RESEARCH INCLUSIVELY:

Co-Production in Action

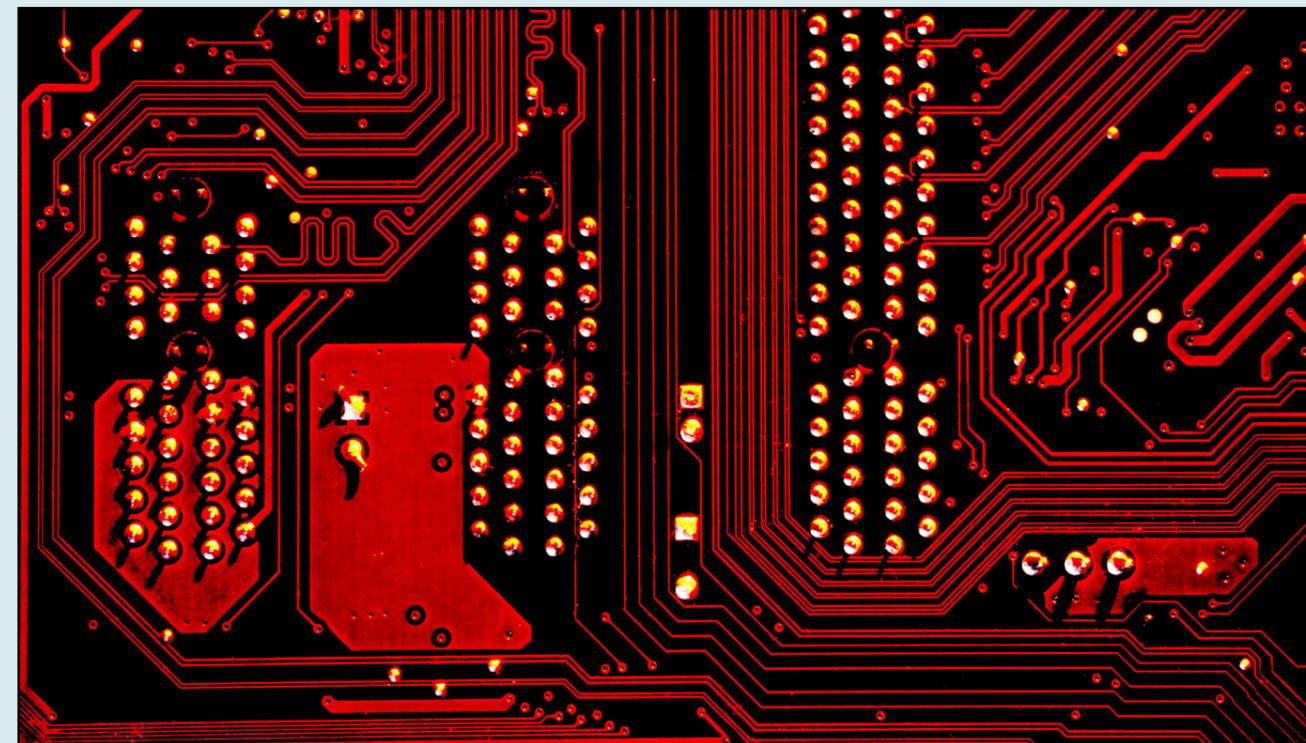


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ARC Centre of Excellence in Automated Decision-Making and Society

The ARC-funded Centre of Excellence in Automated Decision Making and Society is a national network bringing together universities, communities, government and industry. UNSW hosts one node of the network. Automated decision-making (ADM) includes intelligent technologies in which computers make decisions, with varying levels of human oversight. These technologies have the potential to drive profound change across many areas of our lives, including health and social care, transport, housing and communications, in ways that have obvious implications for people with disability. Dr Georgia van Toorn has been taking the lead in a theoretical and empirical examination of the impacts of ADM—positive and negative—taking the use of automation in the National Disability Insurance Scheme (NDIS) as a case study.

The effects of AI and ADM on the lives of people with disability are currently largely unknown, and the research undertaken within the Institute will play a pivotal part in understanding the long-term consequences of ADM for disability.

Disability Royal Commission

Eugenics Symposium

October saw the first event in our symposium *A Past Still Present: disability discrimination and eugenics from the Nazi Third Reich to COVID-19*. The symposium invited leading disability academics from Australia and beyond to discuss the question, 'Does the Nazi persecution and murder of people with disability in the mid-twentieth century continue to echo in the present day?'

Dr Darren O'Brien of the University of Queensland and A/Prof. Michael Robertson of the University of Sydney introduced the symposium in their first talk on scientific racism and the history of the *Krankenmorde* (the murder of the sick). The symposium webinar series continued throughout October and November with the following:

- » **Hans Asperger and neurodiversity** presented by Amanda Tink, Western Sydney University
- » **Memorialisation and commemoration** presented by Darren and Michael (mentioned above) and Christoph Hanzig, Hannah Arendt Institute for Totalitarian Studies in Dresden, Germany
- » **Eugenics in Australian immigration policy** presented by Prof. Karen Soldatic, Western Sydney University
- » **Making perfect people? Prenatal genetic screening and the legacy of eugenics** presented by Prof. Jackie Leach Scully, Institute Director
- » **Eugenics in COVID-19 pandemic responses** presented by Prof. Helen Dickinson, UNSW Canberra.

[Recordings of these events are all available on our website.](#)



Academic Lead Engagement Rosemary Kayess made significant contributions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in 2022, including a statement made to the First Nations People Strategic Advisory Group. As the Commission reported:

'Ms Kayess told the group that, despite Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities and endorsement of the United Nations Declaration on the Rights of Indigenous Peoples, the reality for most First Nations people, especially those with disability, was inequality and discrimination.

'Understanding segregation, whether it be implicit or explicit, subtle or overt, is critically important, along with its implications,' she said.

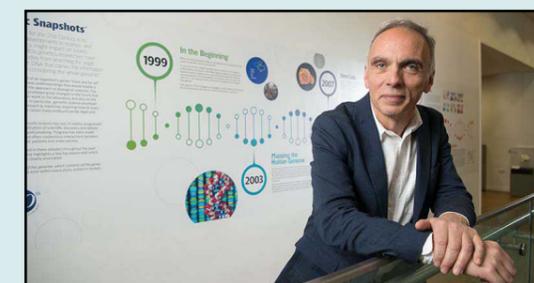
'People with disability are defined by the service system and not human rights.

'We know there is a high rate of disability within Indigenous groups, and there is a lack of community run and culturally responsive services so many First Peoples with disability don't access disability services.

'COVID-19 has been really interesting, in terms of the way it was obvious that policy makers don't conceive of people with disability outside the NDIS.'

Ms Kayess also said that autonomy rights are fundamental to maintaining and protecting the rights of people with disability, particularly in the criminal justice system.'

Visit from Simon Woods



In October the Institute welcomed its first overseas guest since the start of the COVID pandemic in 2020. Professor Simon Woods, Executive Director of the Policy, Ethics and Life Sciences Research Centre (PEALS) at Newcastle University, UK, visited the Institute for two weeks. During that time he gave a talk at a Macquarie University symposium on public values, and met with members of the UNSW Department of Developmental Disability and Neuropsychiatry (3DN).

Simon's research expertise includes end of life issues, and he engaged in important conversations about the implications for people with disability of the upcoming introduction of voluntary assisted dying (VAD) in NSW.

Manager's Update

In 2022 the Institute was operationalised into EDI, which gives us continuing operational support (including financial and other resources) from UNSW beyond our initial forecasted funding up to 2025.

Last year also saw the development of two new staff positions: our Inclusive Research Development Officer, a role filled by Benjamin Garcia-Lee, who works to build UNSW's disability-inclusive research capacity and support our projects; and our Project Administrator, a role filled by Isabella (Yssy) Burton-Clark, who was previously our Communications & Engagement Assistant.



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