



UNSW
SYDNEY



UNSW
Disability Innovation
Institute

2024 ANNUAL REVIEW

UNSW Disability Innovation Institute



What's Inside

| | |
|--------------------------|----|
| Meet our team | 3 |
| Letter from the Director | 4 |
| About the Institute | 6 |
| Sustainable Change | 7 |
| Our Research | 8 |
| Seed Funding | 14 |
| Education | 19 |
| New Resource | 22 |
| Associate Program | 23 |
| International Engagement | 24 |
| Events | 27 |
| Governance | 29 |
| Get Involved | 30 |
| Contact Us | 31 |

Acknowledgement of Country

UNSW acknowledges the Bidjigal people who are the Traditional Custodians of, and whose communities remain connected to, the unceded territories upon which the University's main campus is located.

Cover artwork:

Spunky Bush Trees by Emily Crockford, provided by **studio A**



UNSW
SYDNEY



UNSW
Disability Innovation
Institute

High Street, Kensington
disabilityinnovation@unsw.edu.au
diu@unsw.edu.au

CRICOS Provider Code 00098G

Our Team



Professor Jackie Leach Scully
Director



Professor Terry Cumming
Academic Lead
Education



Professor Iva Strnadová
Academic Lead
Research



Professor Leanne Dowse
Emeritus Professor



Professor Alastair McEwin AM
Professor of
Practice



Rosemary Kayess
Special Advisor



Lucy Sun
Manager



Dr Michelle Tso
Inclusive Research
Development
Officer



Kate Vartuli
Project Officer

Letter from the Director



Professor Jackie Leach Scully

Welcome to the 2024 Annual Review of the Disability Innovation Institute at UNSW.

More than ever, this year's Review makes any introduction from me almost superfluous: the work displayed here speaks for itself. I only want to emphasise that we haven't been able to include everything, and some of our ongoing work will appear in our next review of 2025.

It will be clear from the Review that the Institute is thriving, with ongoing projects producing important findings, new projects and collaborations underway, and new people being drawn into the work of the DIIU from across the university and beyond. We have hosted or participated in a number of events that have introduced us to fresh audiences, while our online webinars and podcasts have enabled us to raise awareness of our work across Australia and internationally.

All our activities, whether in research, education or engagement, are done in the spirit of collaboration, aiming to work with people with disability to increase inclusion and empowerment and reduce inequities.

These goals align with UNSW's longstanding strategy, and with the new Societal Impact Framework developed by the Division of Societal Impact, Equity and Engagement in 2024.

I am privileged to work with a team of dedicated and gifted people – especially Institute Manager Lucy Sun and Project Officer Kate Vartuli -- and with an expanding circle of committed colleagues across the university. It is thanks to their support that the DIU has achieved so much in 2024, and will continue to do so in the future.

"Throughout this year, the Disability Innovation Institute has excelled in producing high quality research that has contributed to the success of many global projects and partnerships. Their guidance on inclusive methods and interdisciplinary practices has changed the way we work across UNSW, exemplifying inclusion at all levels.

The expanding network of Associates from all faculties across the University showcases the ability of the DIU to bring people together in pursuit of a common goal.

I congratulate Jackie for her exceptional leadership and thank the team for their ongoing commitment to the success of the Institute."

Professor Bruce Watson
Pro Vice-Chancellor Societal
Transformation & Equity



About the Institute

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

Our goal is to embed inclusive ways of thinking and working into the core of UNSW's research, practices and engagement. We work in partnership with people with lived experience of disability to support various disability focused projects locally, nationally and globally.



Sustainable Change

The Institute is committed to the development of sustainable change in the lives of people with disability, exemplified by our contribution to the United Nations Sustainable Development Goals (SDGs).

The primary focus of the DIU is the reduction in inequality through high quality inclusive research produced by and with people with disability. We believe that all research is enhanced through the inclusion of people with lived experience. This is particularly important in settings where historical abuses of power and neglect of care have taken place.

Good health and wellbeing starts with knowing your rights about treatment options and having access to information.

Education for all is another core goal of the Institute, with inclusive education pedagogy and practices at the core of what we do.

Peace, justice and strong institutions, whether at home or overseas, are underpinned by recognition of human rights and inclusion for all.



Our Research

The DIU continues to lead the way in interdisciplinary and inclusive research with a commitment to investigating topics of importance to people with disability.

We are excited to share with you, in the following pages, a snapshot of the diverse range of project work and achievements of this year.

More information about our projects can be accessed on our [website](#).



Key focus areas

- Disability Inclusive Research and Co-Production
- Health, Wellbeing and Resilience
- Humanising Technologies for Disability
- Disability Resilience in Crises and Emergencies
- Advocacy and Policy

GeneEQUAL

2024 has been a big year for GeneEQUAL, an inclusive research team of co-researchers with lived experience of intellectual disability, clinicians, and cross-sectoral researchers delivering a research program of health and education projects.

GeneEQUAL has led several workshops over the year. Co-production workshops were held with people with intellectual disability at Self Advocacy Sydney and with healthcare professionals for the development of a point-of-care genetic health decision aid tool as part of the GeneEQUAL Choice project funded by NSW Health.

The team also led an interactive workshop for healthcare professionals exploring the GeneEQUAL Toolkit funded by the genomics team in the Queensland Health Office of Research and Innovation. The Toolkit with advice for health professionals has continued to have sustained reach, with almost 12,000 visits from 70 countries to the website. The co-produced Easy Read booklets cover genetic healthcare topics and have been directly downloaded over 1,000 times, while the videos contrasting poor practice with respectful, accessible and inclusive practice have been viewed by over 400 unique users.



Image: Dr Emma Palmer (left) and Prof. Iva Strnadová (right) presenting at a Genetic Alliance Australia event.

The team has disseminated their research in a variety of ways through the year. They have shared their findings at several conferences including meetings of the Human Genetics Society of Australasia, European Society of Human Genetics, UNSW Sydney Future Health Expo, Professional Association of Nurses in Developmental Disability Australia, and the Australasian Society for Intellectual Disability. Additionally, they have taken part in events for genetic organisations including the Genetic Alliance Australia at NSW Parliament, World Down Syndrome Congress, 22q11 Educational Symposium and 6th Asia Pacific Prader Willi Syndrome Conference.

Their research has been published in BMJ Quality & Safety, Frontiers in Psychiatry and Inspire magazine.



Image: Julie Loblinzk OAM (left) and Prof. Iva Strnadová (right) speaking at the Australasian Society for Intellectual Disability.

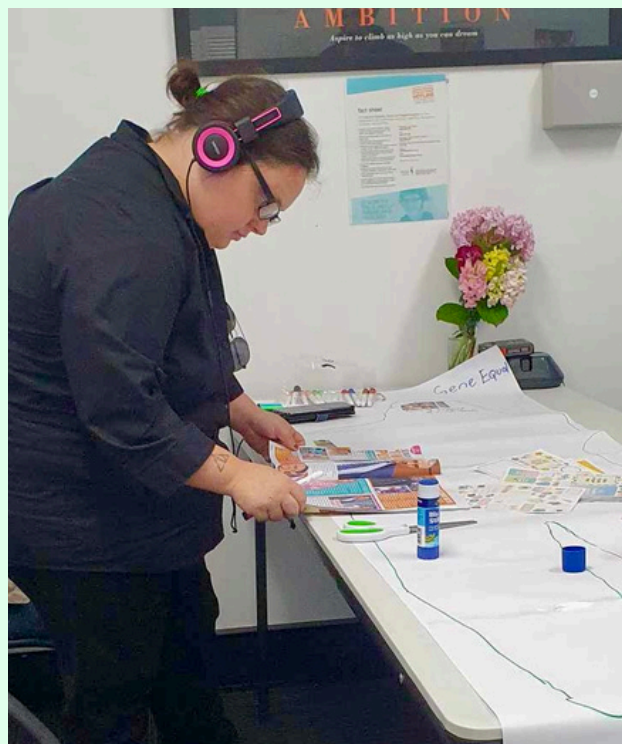


Image: A workshop participant undertaking a body mapping exercise.

Want more information about GeneEQUAL?

You can subscribe to the GeneEQUAL newsletter, to stay up to date with all the inclusive research programs. You can find further details on the website geneequal.com/geneequal/connect



Disability Matters

UNSW Sydney is proud to be a part of a new global collaboration: the Disability Matters project funded by the UK Wellcome Trust.

The six-year project aims to develop anti-ableist and anti-disablist approaches to disability research. The key aim is to make disability the driving subject of research. The project started last year and has already made significant contributions to the field of study.

Research is shared across the countries through a series of online symposia hosted by each Institution.

In August, the DIU hosted the Australian leg of the Disability Matters Online Symposia series. The online session featured presentations by:

- Dr Ellen Fraser-Barbour about lived experience knowledge honoured in inclusive research
- Dr Michelle Tso sharing her experiences with inclusive research methodology as an early career researcher
- Prof. Sally Robinson discussing steps to prevent everyday harm with a focus on young people with intellectual disability and their support workers

The transcript, recording and presentation materials are available on our website.

This project involves five Universities:

- University of Sheffield, UK
- Dr B. R. Ambedkar University Delhi
- University of Toronto
- Nanyang Technological University Singapore
- UNSW Sydney

Read more about Disability Matters project here:

<https://www.sheffield.ac.uk/ihuman/disability-matters>



Partnering with the CSIRO

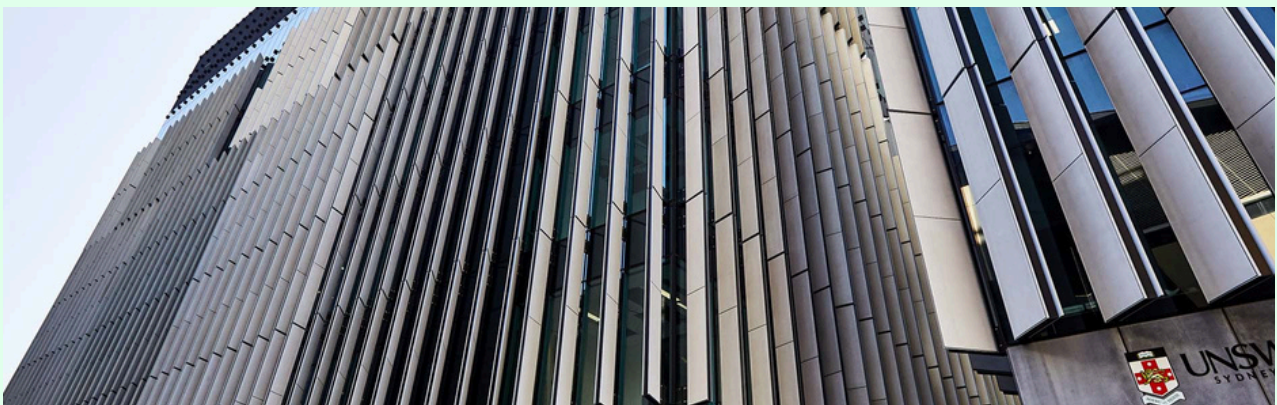
Ensuring Equity and Accessibility in the Integration of Artificial Intelligence and Automated Decision-Making in Engineering Biology.

This three-year project is jointly funded by the Critical Capabilities for Inclusive AI subproject within the Centre for Excellence in Automated Decision Making and Society, and the CSIRO's Advanced Engineering Biology Future Science Platform. Both artificial intelligence (AI) and automated decision-making (ADM) offer significant opportunities in medicine and the life sciences, including within the field of engineering biology. AI and ADM can be used to interpret complex data, undertake predictive modelling and create personalised treatment plans.

While AI and ADM represent a significant step forward in these areas, it is critical that these technologies are developed equitably, in order to avoid excluding or discriminating against certain groups and perpetuating global health disparities.

The aim of this joint project is to explore the barriers to achieving equitable use and access that may be associated with the use of AI and ADM within engineering biology.

The project will focus in part on people with disability and how they may be impacted by potential technological developments, both in Australia and internationally.



TARGeT: Genetic Testing Workshops

Work continued on the Theories of Autonomy in Reproductive Genomic Technologies project, known as TARGeT.

Over the month of March, four workshops were held in which participants shared their views on genetic testing in pregnancy. All of the participants had experienced pregnancy within the last two years, and they shared a range of experiences of and views about decision making within prenatal testing.

Prenatal screening and testing aims to identify foetal differences that could lead to a health condition or disability, information that can help women and couples decide on the future of the pregnancy. Our key interest in this project is how the process of prenatal testing can best enable people to make choices that are autonomous, i.e, that are informed, freely chosen, and reflect their own situations, values and beliefs.



Seed Funding

After a competitive application process, two projects were chosen this year to participate in the seed funding program, as both demonstrated quality inclusive and interdisciplinary approaches to disability research.

The DIU Seed Funding program was established to advance interdisciplinary research and support the ever-growing network of disability scholarship across UNSW.

Open to all current Institute Associates, the program works to foster collaboration between people with disability and researchers across a wide range of academic disciplines.



Fast facts

> Since the program began, 20 new projects have been funded

> 6 Faculties represented

> Over 100 academic staff involved

Using Virtual Reality to Prepare People with Intellectual Disability for Healthcare Interactions

Dr Stefan Michalski from the National Centre of Excellence in Intellectual Disability Health at UNSW, leads a project into the use of virtual reality technology to simulate the real world scenarios of going to the doctor and interacting with healthcare settings.



Image: A still of a scene from the virtual reality program where the participant walks up to the reception desk and checks in before their appointment. Participants can ask what they need to bring, for example their identification or Medicare card.

There are significant barriers in accessing healthcare in terms of the fear, anxiety and communication challenges for people with intellectual disability.

Using a virtual reality headset, study participants experienced three distinct scenarios: speaking with the receptionist, sitting in the waiting area, and speaking with the doctor. Users can also explore the space and look at objects that are commonly found in these areas. The design mimics a typical medical check-up to help people with intellectual disability prepare for these experiences.

Guided exposure to these unique and often challenging medical settings can help reduce feelings of stress, anxiety and discomfort for people with intellectual disability.

The virtual reality application uses artificial intelligence (AI). People can speak while in the VR environment and they can have a conversation with the receptionist and doctor, who will respond as if they were in real life.

The virtual program enables participants to ask questions about the time a procedure may take, what instruments are in the room and what the doctor will do. This helps participants to be adequately prepared for the appointment and know about their healthcare rights.

Another benefit of the digital environment is that participants can repeat the process as many times as necessary to feel comfortable.

"The DIIU... have really enabled us to do all of the co-design work and develop applications collectively with people with lived experience and identify needs that they have and we've been able to integrate that into the application. So without that funding these things are not really possible".

Dr Michalski in conversation with Nesh Nikolic on the Better Thinking Podcast, December 2024.
[Full episode available here.](#)



Image: A screenshot of a scene from the virtual reality program. A patient is speaking with the doctor about equipment.

Dr Michalski and the research team designed the program with users from the beginning, ensuring the feedback from testing sessions guided its development. The next step in the project is to collect more feedback to further enhance the user experience.

Integrating Lived Experience into Economic Evaluations of Disability Support Services



This seed funded project is examining economic evaluations of disability support services. It has already made significant progress in its mission to enhance how we assess the value of services for young people with developmental disabilities.

The project, led by **Dr Cate McHugh** from the School of Clinical Medicine, Discipline of Psychiatry aims to ensure that economic evaluations better reflect what matters most to the people these services support.

Key Milestones Achieved:

The team have completed a comprehensive scoping review into current practices in economic evaluation of services and interventions for children and young people with neurodevelopmental disabilities (NDD). The findings were presented at the 2024 International Neuropsychiatry Association Congress in Melbourne. The review has provided valuable insights which will guide the next stage of the project.

The analysis of 38 studies spanning 2007-2024 identified several critical gaps:

- Current evaluations predominantly use deficit-based approaches focused on costs rather than adopting asset-based frameworks that consider broader benefits
- Only 6% of evaluated costs relate directly to health outcomes, highlighting the need to consider wider social, functional and quality-of-life impacts
- Limited incorporation of perspectives from young people with disabilities and their families

- Few studies (only 6 out of 38) employed utility-based evaluations that would enable meaningful comparisons with programs outside healthcare
- Most studies focused on relatively short timeframes, potentially missing important long-term impacts

The research team have successfully established two advisory groups that are providing essential guidance throughout the research process:

- A Lived Experience Advisory Group comprising 3-4 paid co-researchers on the autism spectrum and/or with intellectual disability
- A Family/Support Worker Advisory Group consisting of 3-4 paid co-researchers who are family members or support workers

Current Activities:

With guidance from the advisory groups, accessible interview guides and materials have been developed for the next phase of the research.

- Beginning recruitment for interviews and focus groups with young people with developmental disabilities and their families/supports (target n=40)

- Developing and launching our Delphi consensus study with policy and decision-makers (target n=20)

Next Steps:

The coming months will focus on:

- Conducting individual interviews and focus groups
- Implementing the Delphi study with policy and decision-makers
- Integrating findings to develop recommendations for more inclusive economic evaluation frameworks

"This research has significant implications for how we assess the value of disability support services and allocate resources in the future. By better integrating lived experience perspectives into economic evaluations, we aim to ensure that service delivery aligns more closely with the actual needs and priorities of young people with developmental disabilities and their families."

Dr Cate McHugh

Education

4 QUALITY
EDUCATION



Inclusive education remains at the core of the work of the DIU. Professor Terry Cumming leads an exemplary program of work spanning the University and beyond, with a particular focus on building capacity of educators to understand better how to support neurodivergent students.

This year at a glance

> 12 presentations delivered
> 7 peer-reviewed journal articles published

Prof. Cumming represented UNSW at the First Global Heads Forum in Education and the inauguration conference of the Global Alliance of Educational Leaders and Department Heads (GAELDH), pictured below.

The conference was held in Hong Kong, and brought international representatives together to discuss how digital technologies and the expanding use of artificial intelligence impacts the field of education. Terry was also a guest speaker at the Australian Disability Clearinghouse on Education and Training (ADCET) webinar, along with the Diversified Team.



Images from left, Prof. Terry Cumming presenting at UNSW, representatives at the GAELDH 2024 summit.



Diversified

The collective of neurodivergent UNSW students, staff and academics known as Diversified, had an outstanding year.

The team presented at the Student Voice Australasia Symposium dedicated to exploring the transformative power of student voice in higher education. The event hosted by the University of Sydney brought together a series of case study sessions, keynotes and panel discussions exploring inclusive education.

The Diversified team have concluded the first phase of a project creating checklists and videos for education focused staff. The Inclusive Education Toolkit will launch officially next year, but testing is underway to ensure it reflects the needs of both students and staff.

[Learn more about Diversified online.](#)



Diversified team members from left: Karen Kriss, Prof. Terry Cumming, Aaron Saint-James, Chantel Le Cross and Associate Prof. Ian McArthur.

New Resource

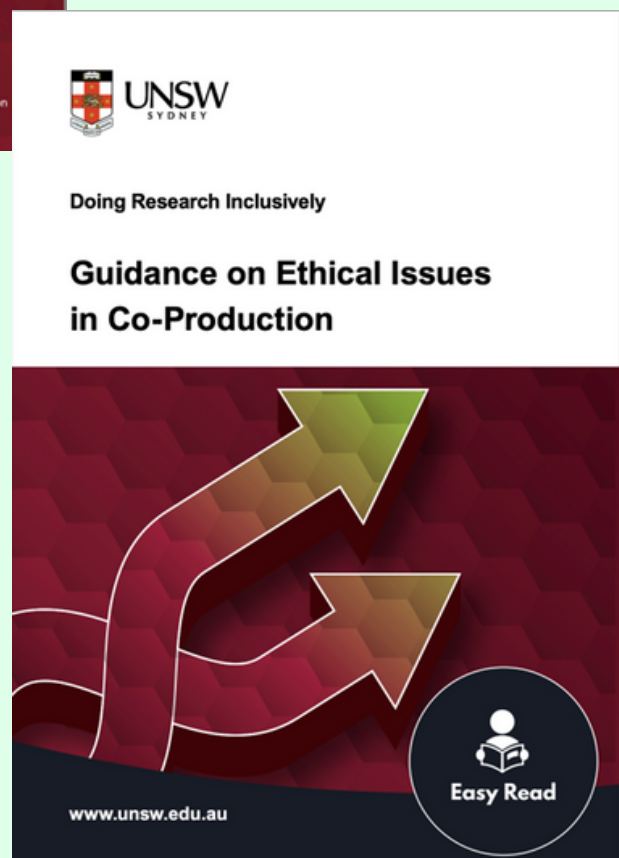


Fast fact

This resource has already been accessed in 40 countries outside Australia.

In October, we launched the latest addition to our inclusive research library of guidance.

Doing Research Inclusively: Guidance on Ethical Issues in Co-production is designed specifically for academic researchers and ethics committee members who review and approve applications, helping them understand and navigate ethical issues.



Associates Program

This year we welcomed more UNSW staff members into the Associates program.

The program was established to provide the opportunity for researchers to learn more about the methods of co-production and engage with colleagues from different Faculties and Departments.

The network also provides the opportunity for early career researchers to develop skills in translating their work into short presentations for a broad audience.

Our Associate Showcase events are held throughout the year, and bring together members of the community to share their latest work and crosspollinate ideas.

If you are interested in becoming an Associate, application details and [more information are available here.](#)



Images: Associate events and gatherings throughout the year.

International Engagement



As part of a global University we are excited to connect and collaborate with new international partners.

Institute Director Prof. Jackie Leach Scully was invited as an external expert to meet with a delegation of experts from India who are working to identify barriers to the inclusive design of Artificial Intelligence and Machine Learning tools in healthcare in India and Australia. The project is a collaboration between the Centre for Artificial Intelligence and Digital Ethics (CAIDE) and the University of Melbourne, in partnership with NALSAR University of Law and Ikigai Law in India.

The project aims to produce policy recommendations which can be proposed to both the Australian and Indian governments, on building inclusive approaches through the design of AI-enabled healthcare. It has the potential to create future collaboration between our two nations and help guide the conversation in the Asia-Pacific region around AI and healthcare.

The project is funded by the Department of Foreign Affairs and Trade (DFAT) under the Australia-India Cyber and Critical Technology Partnership. The DIIU will remain in contact with the project as it progresses to give expert external advice.

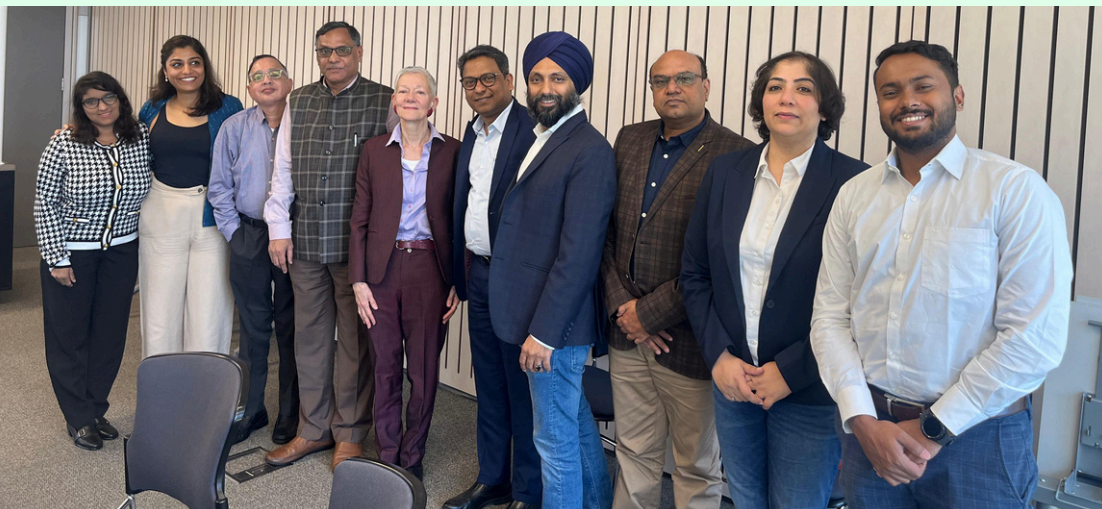


Image: Prof. Jackie Leach Scully (centre) and the delegation from India

The DIIU is a partner in a UNSW project that has been awarded seed funding from the Global Research and Impact Program. Other international partners are the Universitas Negeri Padang (UNP) and the Indonesian Association of People with Disabilities (PPDI). The lead investigator at UNP, Dr Antoni Tsaputra, received his PhD from UNSW. The project aims to examine attitudes and practices that promote the inclusion of students with disability in primary and junior high schools in Padang, which was the first city in West Sumatra to provide support for students with disability and promote inclusive education. This project extends disability inclusion research between UNSW Sydney, UNP and the PPDI.

In August, Prof. Jackie Leach Scully joined UNSW colleagues Dr Joyce Wu, Dr Shanil Samarakoon and A/Prof Paul Munro on a trip to Vanuatu as part of a DFAT-funded project focusing on providing off-grid energy to households in the islands.

A two-day workshop was held in Port Vila with Vanuatu energy providers, retailers, students from the Institute of Technology, and representatives of local women's groups and disabled people's organisations – the Vanuatu Society for People with Disability and the Vanuatu Disability Promotion and Advocacy Association. The goal of the workshop was to co-design the fundamental questions that need to be answered and problems that need to be solved for the project to be successful.

The workshop discussions revealed that chronic lack of resources and discriminatory attitudes towards people with disability remain serious barriers.



Images: Workshop participants.

With the aim of understanding the complex challenges of disability in Papua New Guinea (PNG), the UNSW Institute for Global Development (IGD) and the UNSW Social Policy Research Centre (SPRC) have been working closely with the United Nations Resident Coordinator's Office.

Meetings were held throughout the year, bringing together community leaders and staff of the United Nations with UNSW staff to explore and map inclusion activities. Key issues identified during this mapping were the relationship between intergenerational trauma and community healing, the role of disability in other social issues such as children and gender-based violence.



Image: Workshop participants in Vanuatu.



Image: DIIU Associate Meg Walker meeting with community leaders in PNG.

Further work is expected to be conducted within the region in the coming years, as the DIIU looks to expand existing partnerships with international organisations and connect with other research institutes.

Events

Diversity Festival

The week-long festival takes place across the UNSW campus and provokes discussion into every aspect of what it means to be inclusive.

This year, the DIU gathered a range of experts to spark discussion of people with disability in situations of natural disasters - a topic that is rarely discussed in open forums.

Tackling issues of inclusion, representation and empowerment, our speakers shared their experiences and insights on disaster preparedness, management and recovery.

Hosted by Professor Jackie Leach Scully, our panel included:

- Dr Antoni Tsaputra
- Cheryl Durrant
- Dr Ariella Meltzer
- Danielle Santos
- Professor David Sanderson

This event was organised in collaboration with the Australian Human Rights Institute.



Image: Dr Ariella Meltzer and Prof. Jackie Leach Scully with Leyla Craig and Inspector Andrew Walker from Fire & Rescue NSW. Image below: flood waters in Northern NSW.



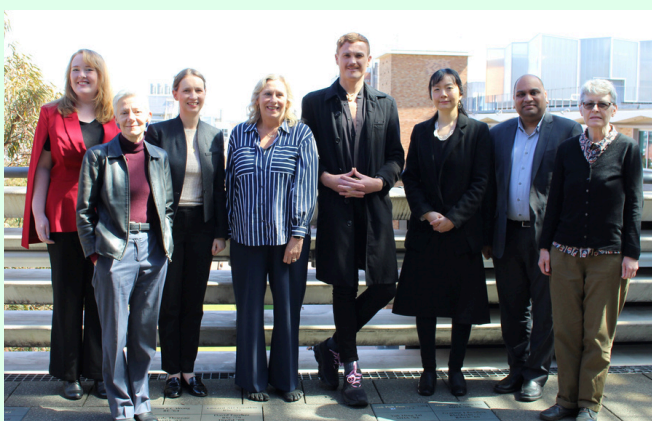
Inclusive Education

The 5th Annual Inclusive Education Showcase was also held during the Festival. The showcase brought together UNSW educators who teach inclusively to share their work about different inclusive technologies and practices.

Inclusive Education comprises practices that make teaching and learning more accessible to all students. It is framed by the principles of Universal Design for Learning (UDL) to increase the accessibility of tertiary education to a wider population of students.

Hosted by Professor Terry Cumming, the speakers included (pictured below):

- Lucy Jellema
- Associate Professor Melanie White
- Aaron Saint-James
- Dr Veronica Jiang
- Associate Professor Michele Madigan
- Dr Ramesh Walpola



SDG Showcase

A new event for the University brought together the best and brightest, in order to address the United Nations Sustainable Development Goals.

The Sustainable Development Goals (SDG) Showcase was held on 23 September 2024 and featured stalls from across the University showcasing the work in addressing global challenges.

The whole of university event was designed to shine a light on the progress towards the United Nations Sustainable Development Goals. Featuring panel discussions, workshops and exhibition stalls, from various Faculties and Centres, it spanned the range from world renowned research and game changing global initiatives, to everyday policy and practice.



Image: from left Institute Manager Lucy Sun, Prof. Jackie Leach Scully and Dr Michelle Tso at the DIU stall.

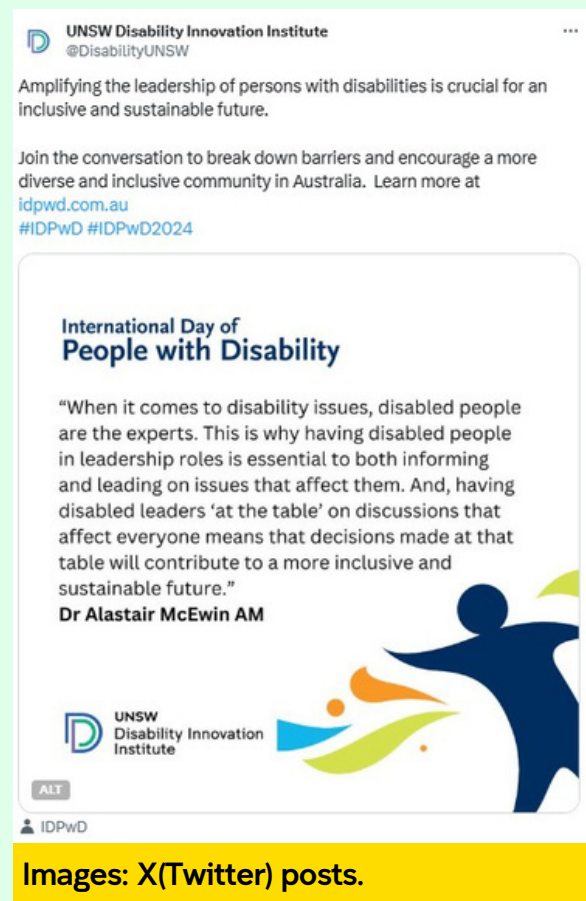
Celebrating IDPwP

We celebrated the International Day of People with Disability on 3 December 2024 by sharing with our online community what the day means to each of us. We collected stories and images from our community about what the day represents.

In the lead up to the Day, further events were held on campus and online. Institute Director Prof. Jackie Leach Scully was invited to take part in one of the National Health and Medical Research Council's (NHMRC) prestigious Speaking of Science webinars.

The series brings together scientific experts within their chosen fields to discuss topics at the core of health and medical research. The thought-provoking webinar tackled topics such as assumed vulnerability, ethical issues in research in disability, and the use of technology in aiding inclusion. The webinar was hosted by Dr Julie Glover and included Adam Johnston and Yvonne Parnell on the panel. A full recording and transcript of the event is [available here](#).

The Institute marked the day of significance online with our community.



Images: X(Twitter) posts.

Governance

Letter from the Chair of the Advisory Council

The work of the Institute is assisted by an Advisory Council made up of people with disability who are external to the University.

Council members have a commitment to inclusive research that is interdisciplinary and innovative and to embedding inclusive ways of thinking and working into the core of UNSW's research, practices and engagement. We have a broad range of expertise and networks that enables views, insights and connections beyond UNSW to be shared with the Institute. We also act to raise the profile of the Institute to external stakeholders and the community by promoting its vision, priorities and activities.

This year Council members participated in discussions that assisted the Institute in relation to fundraising, projects, resource development, key events and activities and the broader inclusive research agenda in Australia.



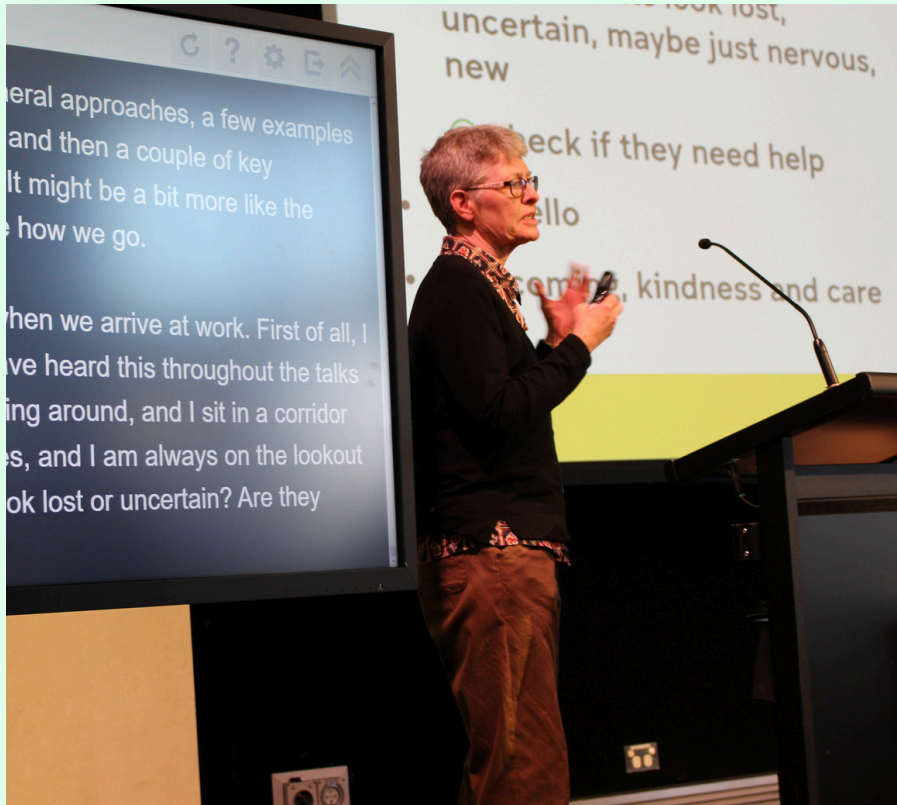
Therese Sands
Chair, Advisory
Council
Disability Innovation
Institute UNSW

If you are a person with disability interested in becoming a member of the Advisory Council, please contact diu@unsw.edu.au.

The internal Steering Committee also had a successful year, navigating significant workplace changes within the University. They helped promote the various activities of the Institute and provided critical strategic advice on a range of topics.

The DIU would like to thank both the Advisory Council and the Steering Committee for their ongoing dedication and support. Their guidance ensures the long term success of the Institute.

Get Involved



Want to attend future events?

To stay up to date with the DIU, sign up to our mailing list to receive a copy of our newsletter and upcoming event invitations:

www.disabilityinnovation.unsw.edu.au/contact-us.

[Visit the Events page on our website for upcoming announcements.](#)

Contact Us

Email

diiu@unsw.edu.au

Website

disabilityinnovation.unsw.edu.au

Follow us on Bluesky

[@disabilityunsw.bsky.social](https://bsky.app/profile/disabilityunsw.bsky.social)

