

UNSW Disability Innovation Institute

Annual Review 2023



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UNSW
Disability Innovation
Institute

Our Team

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Letter from the Director

After a year as our Inclusive Research Development Officer Ben Garcia-Lee is now focusing on completing his PhD on the experiences of belonging and not-belonging in the lives of people with intellectual disability. We hope that Ben's experiences with us will continue to inform his work, and also hope to be able to collaborate with him as a researcher in the future. In his place, Michelle Tso has taken up the Inclusive Research Development Officer role. Michelle is well known to the DIIU, as a PhD student with interest in students on the autism spectrum and currently working as a Research Assistant on the GeneEQUAL project.

In mid-2023 Dr Georgia van Toorn accepted a teaching position in the School of Social Sciences at UNSW. However, she remains in contact with us as an Associate and as an Associate Investigator at the UNSW node of the ARC Centre of Excellence for Automated Decision-Making and Society (ADM+S); you can read about her ongoing work on the impact of ADM and artificial intelligence in general later in this Review.

A final goodbye was also a cause for celebration. At the end of 2023, the DIIU's longtime colleague Rosemary Kayess was appointed as the new Disability Discrimination Commissioner with the Australian Human Rights Commission. Taking up the position in 2024, Rosemary will champion human rights for people with disability. All of us at the DIIU want to thank Rosemary for her invaluable contributions to the establishment and ongoing success of the Institute. While Rosemary will no longer be a core member of the Institute, we very much hope we can continue our association and work together at some point in the future.

The past year has been a busy and active one for the Disability Innovation Institute, both at home and overseas. In the middle of 2023 I spent several weeks in the northern hemisphere, visiting Switzerland, Germany and the United Kingdom. While there I attended several conferences, did some teaching and some fieldwork for research projects, and most importantly was able to raise the profile of the Institute among disability researchers and activists. In the following months these contacts have led to a successful, multinational grant application, Disability Matters – more on that in our Newsletters in 2024 – and a collaboration with colleagues at Odense University Hospital, Denmark, steps towards the establishment of an international network focusing on the concept of hope in chronic illness and disability (you can read more about that later in this Annual Review).

During the year we also said goodbye to some of our valued colleagues. Isabella (Yssy) Burton-Clark, the DIIU's Project Officer since 2021, moved a very short physical distance to become Yuwaya Ngarra-li's Project Officer. We were sad to see Yssy go, but pleased to remain in contact and establish a bridge between the DIIU and the work of Yuwaya Ngarra-li. In October we welcomed Kate Vartuli as our new Institute Project Officer.

The DIIU would not exist without the continuing support of the UNSW community. In particular, we are part of the Division of Equity, Diversity and Inclusion and benefit practically from our collaboration, as well as working closely together to further the broader goals of the Division. I'd like to highlight our Steering Committee, chaired by Professor Bruce Watson, DVC Inclusion and Diversity during 2023, whose members not only provide ideas and advice but also act as ambassadors for the Institute within the University. We are also indebted to our external Advisory Council, all of whom are people with personal experience of disability, who offer an insight into the disability community beyond UNSW and who also act to raise our profile in the outside world.

In September of 2023 the final Report and Recommendations of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability were handed down. The repercussions and implications will extend many years into the future, but they underline the ongoing need for attention to the rights and needs of people with disability, and the importance of the work of the DIIU.

Professor Jackie Leach Scully
Director
Disability Innovation Institute UNSW

"The UNSW Disability Innovation Institute remains a global leader in inclusive research. In 2023, international collaboration led to new projects and partnerships expanding the Institute's impact. The breadth of the team's work reflects a commitment to inclusivity at UNSW and advocacy for disability rights. I'm inspired by the Institute's dedication to true inclusivity, reflecting our goal of equity and community support. Congratulations to Jackie for her exceptional leadership. UNSW is committed to the Institute's success and looks forward to its future achievements."

Professor Bruce Watson
Pro-Vice Chancellor Inclusion





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 mission 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, both domestically and internationally.

Our key aims are 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.



Our Research

The DIU continues to be a leader in interdisciplinary and inclusive research with a commitment to investigate topics of importance to the disability community.

Our current research areas focus on emerging issues in the use of artificial intelligence and the contested space of genetics and disability.



Photo: Members of the GeneEQUAL Team

GeneEQUAL

GeneEQUAL is an interdisciplinary research program co-led by Institute Associate Dr Elizabeth Emma Palmer, Academic Lead Professor Iva Strnadová, Julie Loblinzk OAM and DIU Director Professor Jackie Leach Scully. The aim of the project is to create more inclusive, person-centred, and respectful genetic health care approaches for people with intellectual disability. Originally seed funded by the DIU, the project has gone on to successfully acquire external funding and collaborate with a growing range of partners.

The team have co-produced a comprehensive educational toolkit for health care professionals, people with disability and their support workers to use when discussing genetics and genomic testing in clinical settings. In partnership with NSW Health, these resources were created to address the significant exclusion of people with disability from conversations and decisions made about their own healthcare.

This includes a series of short videos featuring the GeneEQUAL team that depict what it is like for people with intellectual disability going to see a healthcare professional for the first time. The scenarios were based on the real experiences of people with intellectual disability and the challenges they encountered.

In addition to the toolkit, the research team held co-production workshops with members of the intellectual disability community which led to the production of Easy Read documents.

With overwhelmingly positive feedback, the program has been extended for five years by the National Health and Medical Research Council (NHMRC) to support ongoing work with an additional \$1.6 million in funding.

Automated Decision-Making



Photo by Urupong on iStock

The Institute is excited to continue its partnership with the ARC Centre of Excellence in Automated Decision-Making and Society (ADM+S). The Centre brings together universities, government, and industry across Australia in the development of responsible, ethical and inclusive decision-making systems using artificial intelligence platforms. These technologies have the potential to drive profound change across many areas of our lives, including health and social care, transport, housing and communications.

Throughout 2023, Professor Jackie Leach Scully and Dr Georgia van Toorn have been investigating how disability support services and healthcare are impacted by automated decision making.

Epigenetics and Pregnancy Care in Australia for Socially Marginalised Women



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Funded by the Australian Research Council, Professor Jackie Leach Scully and Professor Kylie Valentine are working alongside colleagues from Monash University and ANU to investigate how knowledge about epigenetics is shaping antenatal care in Australia. Epigenetics is a relatively new field of study that looks at how diseases are transmitted across generations. During 2023 the research team undertook a scoping review of the academic literature, and have conducted interviews with scientists, clinicians, and allied health practitioners on their understanding of epigenetics and how to translate epigenetic knowledge into practical care.

The team has so far had one paper published and submitted a second at the end of the year. In 2024, the work will continue with further interviews and discussion groups with recent parents, to find out how they interpret epigenetics in terms of their own pregnancies and childcare.

TARGeT: Theories of Autonomy in Reproductive Genomics

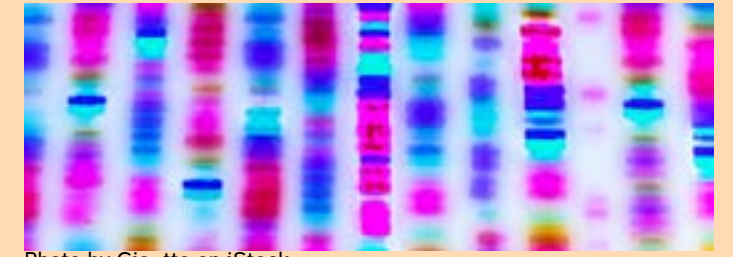


Photo by Gio_tto on iStock

Bringing together researchers from UNSW, University of Sydney, University of Melbourne and Memorial University located in Newfoundland, Canada, this project aims to provide new ways of thinking about genetic testing during pregnancy. Funded by the Australian Research Council, the team is re-examining the familiar concept of "reproductive autonomy" in the context of rapid technological advances that present new challenges to decision making in prenatal genetic testing for disability. During 2023 the project completed 25 interviews with a range of healthcare professionals who care for pregnant women: general obstetricians, foetal medicine specialists, general practitioners, clinical geneticists, genetic counsellors, and midwives, to find out what these specialists think about the expansion of prenatal testing and its impact on reproductive autonomy.

A paper based on these findings is now available: Drysdale, K., Scully, J. L., Kint, L., Laginha, K. J., Hodgson, J., Holmes, I., ... Newson, A. J. (2024). The salience of genomic information to reproductive autonomy: Australian healthcare professionals' views on a changing prenatal testing landscape. *New Genetics and Society*, 43(1). <https://doi.org/10.1080/14636778.2024.2332310>.

Organ Quality Assessment



Photo by sturti on iStock

Artificial intelligence is becoming an integrated part of the healthcare system in many parts of the world. This project is evaluating the use of a new tool that combines cutting-edge colour image analysis with an AI algorithm to assess the quality of donated organs prior to transplant.

Professor Jackie Leach Scully is working with researchers in the United Kingdom, undertaking initial consultations with medical professionals and patients about the feasibility and acceptability of this technology. During 2023 she interviewed a range of transplant specialists about their views, and while visiting the UK in July 2023 was able to hold focus groups both with transplant recipients and with members of the general public, to explore how they felt about the potential introduction of AI-supported organ quality assessment in transplant medicine.



Seed Funding

Five exciting new projects were launched this year with the assistance of seed funding provided by the Institute.

The goal in providing seed funding is to advance inclusive interdisciplinary research between UNSW academic researchers, people with disability, government, industry and community. These projects reflect the diversity of research questions being investigated across different faculties.

Each project works to strengthen the ever-growing network of disability focused researchers at UNSW.

Better Acknowledging and Resourcing the Information Accessibility Sector in Australia

Having quick and easy access to public health and safety information is vitally important to ensure communities are kept safe in times of natural disaster or emergency. This information, however, is not always accessible to people with disability, and this exclusion poses significant risk to their safety and ability to prepare for upcoming emergencies.

This project, led by Dr Ariella Meltzer, El Gibbs, Ayah Wehbe and Emma Barnes, aims to address this gap by identifying the experiences, facilitators, and barriers to accessing public safety information.

The team have conducted interviews with accessible information provider organisations. From the preliminary findings the team aim to make recommendations to improve co-ordinated support and resourcing of accessible information for people with disability.

People with Disability Influencing Disability Employment in Workplaces and Industries



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The joint project between UNSW, Flinders University and South Australian disability organisations, aims to address the influence of people with disability on the sustainability of improvements to inclusive employment and culture of workplaces and industry, with a particular focus on the aged care industry.

Using the process of co-production ensured that people with disability were involved at all stages of the data collection and as members of the research team, the community of practice and active members of their workplaces.

The project team includes Professor Karen Fisher, Dr June Alexander, Professor Sally Robinson, Jala Burton, Sandra Gendera and Dr Christiane Purcal.



Photo by serggn on iStock

Access to Justice and Technology

Jointly funded by the UNSW Allens Hub for Technology & Innovation, this project aims to develop a practical and transparent set of criteria for undertaking an accessibility audit of the existing Access to Justice initiatives (known as A2J). Working with Australian-based disability organisations, the team aims to create resources that enable service providers to start projects with accessibility at the forefront of their work.

The project team is led by Associate Professor Daniel Ghezlbash and Dr Matthew Keeley and includes Vasili Maroulis, Laura Elliott, Terri Mottershead, Sam Flynn, Noel Lim, Emily MacLoud, Catherine King and Adjunct Professor George Newhouse.

Education

Right to Repair



Photo by Juan Aunion on iStock

Also co-funded by the Allens Hub for Technology & Innovation, this project focuses on the reparability of medical and assistive technologies for people with disability. Bringing together researchers from faculties across the Social Sciences, Law and Engineering, the team is investigating issues of planned obsolescence, high costs of maintenance and device failure. Positioned at the interface of ethical, legal, technological and societal issues, this work aims to examine the complexity in which these devices exist.

The project team includes Professor Matthew Kearnes, Associate Professor Alexandra George, Dr Kayleen Manwaring, Professor Bronwen Morgan, Associate Professor Paul Munro, Dr Shanil Samarakoon, Dr Kevin Witzemberger and Wanda Kuai.

The Experiences of People with Intellectual Disability in Prison



Photo by MoreISO on iStock

People with intellectual disability are overrepresented in the Australian criminal justice system, with poorer incarceration experiences and lower rehabilitation outcomes than people without intellectual disability.

This project aims to identify the current needs, circumstances and outlook for people with intellectual disability, as well as investigating which specific factors affect the experiences and outcomes of this group.

Along with lived experience consultants the project team includes Dr Jane Hwang, Dr Julian Trofimovs, Dr Preeyaporn Srasuebku, Dr Samuel Arnold, Dr Rebecca Reeve, Frederikke Jensen, Victorian Advocacy League for Individuals with Disability (VALID), Dr Phillip Snoyman, Professor Julian Trollor and Professor Tony Butler.

Neurodiversity in Education

DIIU's Academic Lead Education Professor Terry Cumming delivered multiple talks this year focusing on neurodiversity. Attendees included members from various organisations such as UNSW Medicine and Health, UNSW Education Focused Community of Practice, Teaching for Equity & Diversity (TED), Medical Deans Australia and New Zealand Student Support Committee, UNSW Mental Health First Aid Network, UNSW Sydney Equitable Learning Services and the UNSW Climate Change Research Centre.

Professor Cumming also worked to secure \$26,000 in funding to create a suite of materials to support UNSW teaching staff to design and deliver their courses in a more accessible manner. The materials will be co-created by neurodivergent UNSW students and instructors.

Professor Iva Strnadová and Dr Joanne Danker hosted a short course for the UNSW School of Education. The course covered evidence-based practice for social and communication skills and sensory issues and school transitions, collaboration with families, and life-span perspective.



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Communications and Events

International Day of People with Disability

To celebrate International Day of People with Disability (IDPwD), on 4 December 2023 we brought together a panel of six extraordinary leaders in the disability space for a Q&A session followed by drinks and canapes. The event was also to mark fifteen years since Australia ratified the UN Convention on the Rights of Persons with Disabilities (CRPD).

We welcomed Dr Alastair McEwin AM, Commissioner with the Disability Royal Commission and former Disability Discrimination Commissioner, and June Riemer, deputy CEO of first People's Disability Network. Also joining the panel was Fiona McKenzie AM, Vice-Chairperson of the Council for Intellectual Disability, Professor Julian Trollor, neuropsychiatrist and head of the Department of Developmental Disability Neuropsychiatry (3DN) UNSW, and Rosemary Kayess, human rights lawyer and newly appointed Disability Discrimination Commissioner.

We were also very excited to have ABC disability affairs reporter Nas Campanella lead the discussion with questions put to the panel about the effectiveness of the United Nations Convention and if this has actually improved the lives of people with disability.

The panellists shared their experiences regarding what progress has been made since the ratification and what impact instruments such as the National Disability Strategy and the NDIS have on improving the lives of people with disability.

Our annual IDPwD is quickly becoming a highly anticipated tradition within the Institute, as it serves as a time to stop and reflect on the pertinent issues affecting our community. It is also a time to celebrate disability and the incredible work being achieved by our speakers, friends, and guests.



Photos: IDPwD event panel members



Photo: IDPwD event panel members and attendees

Right to Repair Workshop

The Right to Repair project, jointly funded by the DIIU and the Allens Hub for Technology, reached a milestone in 2023 by hosting a workshop that brought together academics from across the faculties at UNSW. DIIU Associate Professor Matthew Kearnes and Dr Kevin Witzemberger provided an overview of the complexity of the topic by situating it at the intersection between law, technology and society. The project focuses on the issues of living with assistive technologies, such as planned obsolescence of devices, technological dependency, equality of access to maintenance, human rights and agency.

Dr Kayleen Manwaring and Wanda Kuai from the UNSW Allens Hub for Technology, Law & Innovation explained the various legal and regulatory mechanisms at play that can help or hinder repair options for consumers. Associate Professor Lauren Kark shared her experiences of taking UNSW engineering students over to the Solomon Islands, a project that involves working with the existing hospital equipment and some ingenuity to come up with workable, low-cost solutions to the healthcare needs of patients.

The session concluded with an interdisciplinary discussion with representatives from NSW Health and the Assistive Technologies Suppliers Association.

The project team are now looking forward to opportunities to extend the research and share their findings.

Webinars

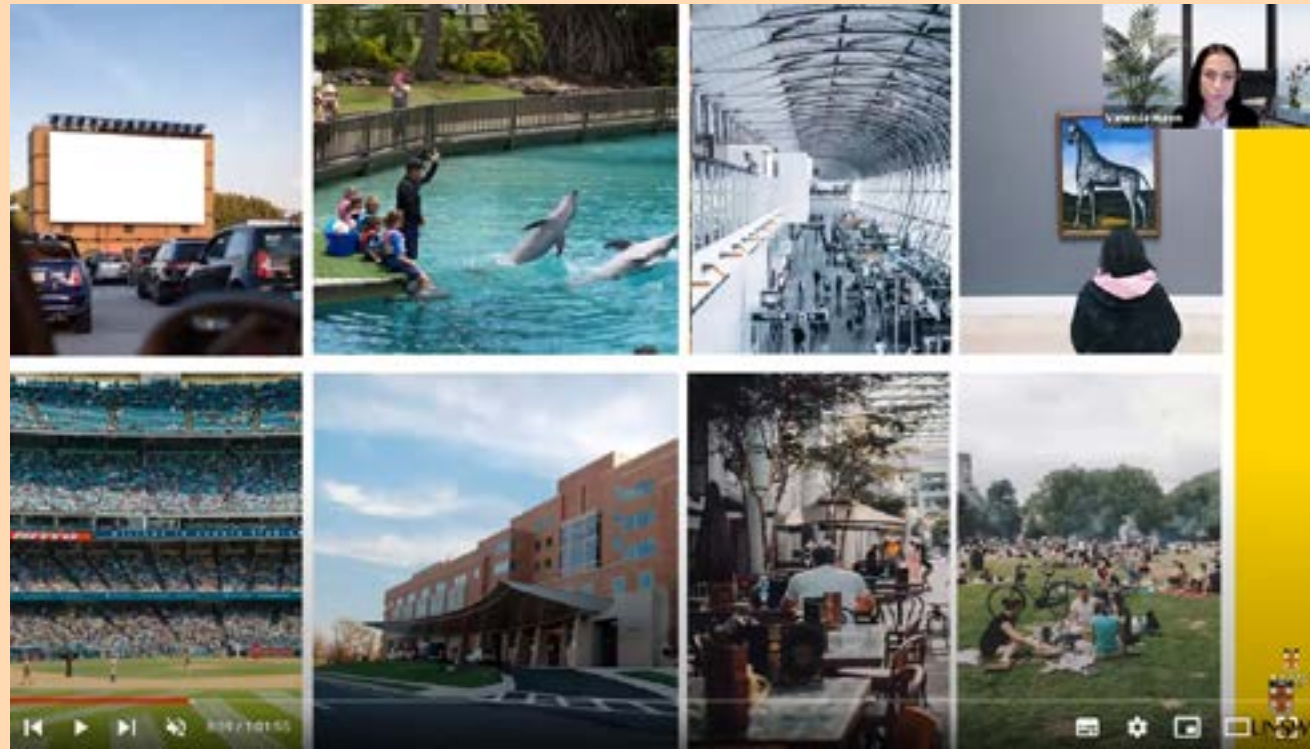


Photo: Dr Vanessa Huron presents in the webinar

Managing Accessibility of Public Spaces: Understanding how Public Space Operators Approach Accessibility

One of the Institute's Associates, Professor Carlo Caponecchia, along with Dr Beth Mayland and Dr Vanessa Huron, presented their research into managing accessibility of public places. This research was originally supported by seed funding from the DIU.

The team presented their initial findings from a systematic literature review and interviews with operators of public space venues. They identified that while accessibility in public spaces is important to those running the venue, the operators don't always know how to implement such changes.

The research also uncovered that most of the work put into public spaces is focused on the physical attributes of the location such as ramps, lifts and signage. Social and cultural aspects of place making for accessibility were not addressed and therefore need to be more widely considered among operators.

The research team have published an [industry summary report](#) that is available online, with further academic journal articles to be published in the coming year.

[You can also view the webinar recording here.](#)

Podcasts

Our podcast series continued this year with two new episodes uploaded. In the first episode Academic Lead Research Professor Iva Strnadová spoke with advocate Justen Thomas and DIU Inclusive Research Officer Benjamin Garcia-Lee about co-producing research and how they are using our new guidelines *Doing Research Inclusively: Co-Production in Action*.

The second episode featured 2023 Students with Disabilities Officer Michael Rahme in conversation with Jackie Leach Scully, discussing some of the barriers students with disabilities face. Michael also spoke about his aspirations for the year in office.

Stay tuned for more podcast episodes in 2024, kicking off with a discussion into automated decision-making and its impact on services for people with disability.

[Listen to the podcast series here.](#)



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Across UNSW and Beyond

Diversity Festival

Held throughout the week of 18-22 September 2023, the fifth annual Diversity Festival featured over 40+ free events for UNSW staff and students to foster a sense of belonging within our community.

The Disability Innovation Institute in collaboration with the Yuwaya Ngarra-li Partnership presented the keynote event titled *More than Diversity? How we can think differently about power and privilege*. Trans man and Olympic gold medallist Ellia Green OAM shared his touching personal experiences of diversity and acceptance, followed by a panel discussion chaired by Peta MacGillivray and including UNSW community members Quinton Vea Vea, Osca Monaghan, Professor Jackie Leach Scully and Melissa Golby. The panel tackled questions relating to the true meaning of diversity, equity and how institutions can work to dismantle structures of power and privilege.

[You can view the recording here.](#)



Photo: Diversity Festival event panel members

Within a global University, the Disability Innovation Institute strives to connect with international partner organisations to expand the reach and impact of disability inclusive practices.

Asia Pacific General Day of Discussion on United Nations CRPD Article 11



Photo: Rosemary Kayess leading the online workshop

In April, the DIU in collaboration with the UNSW Australian Human Rights Institute hosted the United Nations Committee on the Rights of Persons with Disabilities on their Asia Pacific General Day of Discussion. With representatives from across the Asia Pacific region, the working group shared experiences of living with disability with particular focus on emerging regional risks and humanitarian emergencies. The workshop produced a first draft of the general comment on Article 11, providing much needed context and insight into the lived experience of people with disability unique to the region.

Collaborations Overseas



Photo: Odense University Hospital main building

The DIU has begun a collaboration with Odense University Hospital, Denmark to establish an international network focusing on the concept of hope in chronic illness and disability. Bringing together a philosophical and ethical approach to disability, the partnership aims to extend the thinking around issues such as voluntary assisted dying, palliative care and reconstructions of the notion of wellbeing and "getting better" for people with disability and chronic illness. This collaboration is a direct result of the visit last year from Professor Simon Woods, now living in Denmark, and highlights the importance of maintaining the Institute's international connections.

Associates Program

Our Associates had another successful year, with significant progress being made with academic research programs and incorporating disability inclusive practices throughout UNSW. The growth of the network to include 31 members allows the Institute to draw on knowledge and expertise from various faculties and continue the expansion of disability focused research at UNSW.

2024 is already looking to be a busy year for the Institute, with plans underway to host events and produce online content to feature the work of Associates.

If you are interested in becoming an Associate, please reach out to the Disability Innovation Institute for more information.



Manager's Update

The Institute's operations continued under the Division of Equity, Diversity and Inclusion which enabled greater operational support and alignment with UNSW departmental structures.

The Institute is grateful to UNSW for its continuing support.



Photo: The Disability Innovation Institute Team

Governance

The work of the Institute is only possible through the assistance of the Steering Committee and the Advisory Council.

The Steering Committee provides internal oversight of the Institute and fosters collaboration between faculties. Members include academics from across the various UNSW Schools and is currently chaired by Professor Bruce Watson.

The Advisory Council is made up of members who are external to the University with lived experience of disability. Their contributions are vital to ensuring the work of the Institute is inclusive, and they help promote the vision and priorities of the Institute.

The DIU would like to thank members of both committees for their significant contribution to the ongoing success of the Institute. We look forward to working with them into 2024.



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