



THE UNIVERSITY OF  
MELBOURNE

# Melbourne Disability Institute Annual Report



2022

## Acknowledgement of Country

The University of Melbourne acknowledges the Traditional Owners of the unceded land on which we work, learn and live: the Wurundjeri Woi Wurrung and Bunurong peoples (Burnley, Fishermans Bend, Parkville, Southbank and Werribee campuses), the Yorta Yorta Nation (Dookie and Shepparton campuses), and the Dja Dja Wurrung people (Creswick campus). The University also acknowledges and is grateful to the Traditional Owners, Elders and Knowledge Holders of all Indigenous nations and clans who have been instrumental in our reconciliation journey.

We recognise the unique place held by Aboriginal and Torres Strait Islander peoples as the original owners and custodians of the lands and waterways across the Australian continent, with histories of continuous connection dating back more than 60,000 years. We also acknowledge their enduring cultural practices of caring for Country. We pay respect to Elders past, present and future, and acknowledge the importance of Indigenous knowledge in the Academy. As a community of researchers, teachers, professional staff and students we are privileged to work and learn every day with Indigenous colleagues and partners.

## Report Images

In 2019 we launched a Diversity in Disability Image Competition to support photographers and images that capture the full spectrum of disability.

We received more than 100 submissions from all around Australia. With so many well-crafted, diverse and eye-catching images to choose from, our job was not easy. After careful consideration and much deliberation, 13 finalists were selected.

We are pleased to showcase some of these images throughout this report, including the image on our cover, titled *Carl on the Beach*, submitted by Carl F. Thompson.

## Publication

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This Annual Report is available online: [www.disability.unimelb.edu.au](http://www.disability.unimelb.edu.au)

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## Message from the MDI Director

This year we celebrated the five-year anniversary of the Melbourne Disability Institute (MDI). It has given us the opportunity to reflect and consider what we have been able to achieve in the years since the Institute was established – but also think about the work that remains. Despite all the progress that has been made in disability policy and practice over the last few years, in our view our mission remains as important as ever - strengthen the evidence base needed to drive much needed reform to get the best outcomes for people with disability and their families in this country.

While there is still a long way to go, the creation of the Australian Disability Strategy and the National Disability Insurance Scheme (NDIS) speaks to our aspiration as a country to embed the ideals of respect, inclusion and equality across the Australian community.

And while for many years disability policy in this country was thwarted by a lack of data and evidence, the creation and funding of the National Disability Research Partnership and the National Disability Data Asset speak to a commitment to ensure the change we want to see is underpinned by good data and evidence.

The creation of MDI five years ago was a response to all of these enormous changes in the disability sector. The foundational work we have done over the last few years means the University of Melbourne is well positioned to be at the forefront of disability research over the next five years. We would therefore like to take this opportunity to thank the leadership of the University for their vision and foresight in investing in the

creation of the Institute and for their ongoing commitment to our work.

Most importantly, we would like to thank all of the researchers, people with disability, organisations, partners and collaborators we have worked with over the past five years for their passion, commitment and dedication to doing whatever they can to dismantle the systemic barriers facing people with disability and creating real and lasting change. We look forward to continuing to work with you over the next five years.

This year we were once again involved in a wide range of collaborations and partnerships.

We continued to support the considerable endeavours of our faculty colleagues to set up collaborative interdisciplinary research hubs across the University. These hubs bring together the knowledge, expertise and experience of a wide range of researchers with people with disability, their representative organisations and other community partners to tackle the challenges facing people with disability. Four hubs are now up and running with a further two in the pipeline.

We were also proud to host and help facilitate the National Disability Research Partnership (NDRP) again in 2022. This year the Australian Government further demonstrated its commitment to disability research by dedicating \$15 million to support the partnership for the next two years. Later in this report you can read about the work that is being done to establish the NDRP as an independent entity and how the NDRP working party is further refining the National

Disability Research Agenda and Framework – and how you can get involved in their important work.

The Australian Government has also committed further funding for an enduring National Disability Data Asset. This year the NDDA commissioned researchers to work on five test cases to demonstrate the benefits of large-scale data mapping and linkage. MDI's Senior Research Fellow, Dr George Disney, was selected to lead the NDDA test case on mental illness and psychological distress. Dr Disney was also part of another University of Melbourne team lead by Dr Zoe Aitkin that delivered the test case on the Identification of people with disability in linked administrative data.

With our partners at the Brotherhood of St Laurence and Bapcare, we also launched new, ground-breaking research into Tier 2 of the NDIS in a report called Access to support for working-age Australians with disability without individual NDIS funding.

Conducted by MDI's Dr Sue Olney along with Amber Mills and Liam Fallon from the Brotherhood of St Laurence, the research shed light on how working age Australians with disability who do not receive funding from the NDIS are faring. The findings demonstrated that there is a significant gap between the promoted availability and accessibility of support and services to people with disability who are not NDIS participants, and people's experiences of attempting to find and use them. The report garnered national attention and we are pleased to be able to support ongoing research into this important area.

Finally at the end of the year, I was honoured to be appointed to Co-Chair the Independent Review of the NDIS, along with highly respected former Commonwealth public servant Lisa Paul AO PSM.

The work of the Independent Review is being supported by a panel of five experts, including leading disability advocates Dougie Herd, Kevin Cocks AM and MDI's own Kirsten Deane.

Work on the Review commenced in October, with a final report due in late 2023.

The Review will mean that my time at MDI will be more limited next year. But Kirsten and the rest of the dedicated team will make sure all of MDI's vital research and engagement activities will continue.

Finally, I would like to take this opportunity to thank the MDI team and all our partners. It is your hard work, values, dedication and commitment to collaboration and co-design that is the heart and soul of all we do at MDI. We look forward to continuing to work with you.

**Professor Bruce Bonyhady**  
Executive Chair and Director



**About MDI**

Established in 2018, the Melbourne Disability Institute (MDI) is focused on building the evidence base to address the complex problems and systemic barriers facing people with disability in this country.

MDI works to bring together people with disability, families, and representative organisations with researchers to co-produce research that improves social and economic outcomes, inclusion and well-being of people with disability.

Our focus is on research that has real world impact, transforming disability policy, programs and practice.

**Vision**

To improve health, social and economic outcomes for people with disability through high quality research, translation and teaching.

**Mission**

We facilitate and support interdisciplinary research that makes a difference. We bring people with disability, families, representative organisations and researchers together to co-produce research that addresses the complex and systemic barriers facing people with disability. We then focus on how that knowledge can be translated into policy and practice to have real-world impact.

At MDI, we believe our strength lies in collaboration. Together our dedicated team of academic and professional staff, the diverse and multidisciplinary community of scholars we are fortunate to work with, and the broad range of passionate community organisations who partner with us, all come together in the interests of improving outcomes for people with disability and their families in this country.

This year we were sad to say goodbye to Campbell Message, who has lead the Community Based Research Program (CBRP) for a number of years.

The CBRP has enabled more than 36 community organisations to have a research project completed to inform their advocacy, improve their practice, innovate or capture their impact – all with the aim of making a difference in the lives of people with disability and/or their families. It has led to some fabulous outcomes. Campbell has been an invaluable member of the MDI team –not only with his stewardship of CBRP but also with his wizardry at trivial pursuit! We wish him well with all his new adventures.

**Melbourne Disability Institute**



**Professor Bruce Bonyhady**

Executive Director

**Professor Rob Carter**

Foundation Chair in Disability Economics

**Associate Professor Sue Olney**

Research Fellow - Policy

**Dr George Disney**

Senior Research Fellow - NDIS

**Dr Yi Yang**

Research Fellow

**Dr Raelene West**

Research Fellow

**Dr Paul Jacobs**

Research Fellow

**Kirsten Deane**

General Manager

**Sara Donaldson**

Communications and Engagement Manager

**Campbell Message**

Programs Manager

**An Nguyen**

Operations Manager - Finance

**Tessa De Vries**

NDRP Project Coordinator

## Executive Committee



**Professor Bruce Bonyhady**  
Director  
Melbourne Disability Institute



**Professor Rob Carter**  
Foundation Chair in  
Disability Economics  
Melbourne Disability  
Institute



**Professor Mark Considine**  
Redmund Barry  
Distinguished Professor  
Faculty of Arts



**Dr George Disney**  
Senior Research Fellow  
MDI and Disability and  
Health Unit, Melbourne  
School of Population and  
Global Health



**Dr Piers Gooding**  
Senior Research Fellow  
Melbourne Law School

## Our New Executive Committee

Throughout the last two years MDI has been working with Departments, Schools and Faculties across the University of Melbourne to set up collaborative interdisciplinary hubs focused on disability research. Four hubs are already up and running, with a further two expected to launch next year.

At the end of the year we brought representatives from these hubs, as well as individual researchers from across the University, together to form a new Executive Committee for MDI. The aim of the Committee is to deepen connections between the hubs and other researchers, and to create new opportunities for collaborative work across Schools and Faculties. This is a very important part of our work as an interdisciplinary institute. Complementing MDI's existing research projects and research partnerships within and outside the University, the Committee will also provide strategic advice on MDI's broader program of work and activities.

The Committee will also kick start work on MDI's new strategic plan, which we expect to complete next year.

We would like to thank everyone who served on our previous Executive Committee for their generosity in sharing their time, expertise and wisdom with us. They helped steer MDI through its creation and early years and we are most grateful for all of their input. We are also grateful to those who will be staying on in the new committee, continuing to share their expertise and learnings since MDI was founded. For those who are finishing up we extend our deep gratitude – thank you to Professor Anne Kavanagh, Associate Professor Anna Arstein-Kerslake, Professor Brendan Gleeson, Professor Lorraine Graham, Professor Mark Hargreaves, the Hon Jenny Macklin, Professor Barbara McPake, and Professor Abigail Payne.



**Professor Nathan Grills**  
Nossal Institute for Global  
Health



**Professor Lou Harms**  
Chair and Head of School  
of Social Work



**Professor Christine Imms**  
Apex Australia Chair  
of Neurodevelopment  
Department of Paediatrics



**Dr Paul Jacobs**  
Research Fellow  
Melbourne Disability  
Institute



**Professor Shelley Mallett**  
Professorial Fellow in  
Social Policy  
School of Social and  
Political Sciences



**Associate Professor Lisa McKay Brown**  
Assistant Dean, Diversity  
and Inclusion  
Melbourne Graduate  
School of Education



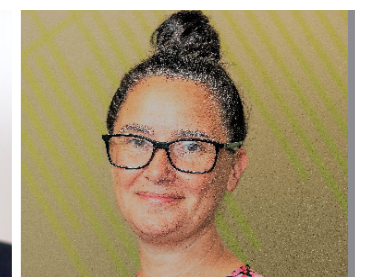
**Professor Keith McVilly**  
Professorial Fellow in  
Disability and Inclusion  
School of Social and  
Political Sciences



**Associate Professor Sue Olney**  
Brotherhood of St Laurence  
Principal Research Fellow,  
School of Social and  
Political sciences



**Associate Professor Peter Raisebeck**  
Architectural Practice,  
Faculty of Architecture  
Building and Planning



**Associate Professor Georgina Sutherland**  
Deputy Director  
Disability and Health  
Unit, Melbourne School of  
Population & Global Health



**Associate Professor Jason Thompson**  
Principal Research fellow  
Faculty of Architecture  
Building and Planning



**Dr Raelene West**  
Research Fellow  
Melbourne Disability  
Institute



**Associate Professor Illan Wiesel**  
Associate Professor  
Urban Geography,  
Geography, Earth and  
Atmospheric Sciences



**Kirsten Deane**  
General Manager  
Melbourne Disability  
Institute

This year MDI was delighted to be able to partner with the Brotherhood of St Laurence to establish a Chair in Disability Economics. We were fortunate to have Professor Rob Carter join the team.

Rob has extensive experience in economic evaluation and health services research across a wide range of settings. He retired as an 'Alfred Deakin Professor' in late 2019 from Deakin University but continued his research interests, particularly in the economics of disability.

Rob has held a number of senior research positions in his career, including being Foundation Head of Deakin Health Economics (2006-2019); Director of the University of Melbourne Health Economics Group (2000-2006); Deputy Director of the Monash University Health Economics Unit (1993-1999); and Head of the economics team within the Technology Assessment Branch at the Australian Institute of Health and Welfare (1990-1993).



**Professor Rob Carter**  
Foundation Chair in Disability Economics  
Melbourne Disability Institute

## PhD Scholarships

Supporting students to undertake a PhD is an important part of MDI's mission to facilitate and support collaborative and interdisciplinary research at the University.

Each year we are delighted to be able to allocate Australian Government Research Training Program scholarships to students whose interest in disability research aligns to the work of our disability research hubs.

From a competitive field, we were fortunate to have Joanna Butchart join the MDI team. Supervised by Dr George Disney at MDI and the Disability and Health Unit in the Melbourne School of Population and Global Health, Joanna's PhD project will use linked health and administrative data to look at

adult health outcomes for people with childhood disability.

Joanna has worked with children and adolescents with disability since 2005, across Australia and as an Australian volunteer for international development in Fiji.

For the past 12 years Joanna has worked as a physiotherapist in the Victorian Paediatric Rehabilitation Service at Royal Children's Hospital Melbourne. Joanna has been involved in previous clinical research developing a socially assistive robot, the NAO robot, for paediatric rehabilitation.

This year we were pleased to be able to offer two new research fellowships. Each fellowship is focused on looking at impact and outcomes from the introduction and implementation of the National Disability Insurance Scheme.

From a competitive field of talented candidates, we were delighted to welcome Dr Raelene West and Dr Yi Yang to the MDI team. Over the next three years, Rae and Yi will develop a multi year, multi project program of work across both the NDIS and the Australian Disability Strategy.

Rae and Yi will join a community of academics and experts working together at the University of Melbourne to strengthen the evidence base and inform future research, policy and practice in this dynamic area.

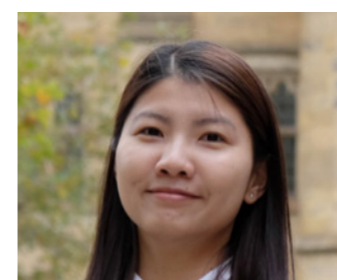
As you will see below, Rae and Yi bring to MDI a wide range of experiences and expertise and an outstanding set of research skills. We consider ourselves very fortunate to have them join the MDI team.



**Dr Raelene West**  
Research Fellow  
Melbourne Disability Institute

**Dr West** is passionate about creating positive social change. Her research field is critical disability studies, with a focus on delivery of support services. She has been involved in disability advocacy, has lived experience of disability and has been on numerous disability committees.

She has a PhD in Sociology - Disability from the University of Melbourne and has worked for the last few years on a range of projects in disability and aged care. She has publications in areas of ableism, individualised funding models, marketisation of service delivery, use of technology in service delivery and human rights.



**Dr Yi Yang**  
Research Fellow  
Melbourne Disability Institute

**Dr Yang** is a quantitative research fellow with a PhD in Epidemiology from the University of Melbourne. Her research interest is on NDIS impact and outcomes.

Her areas of focus include identifying and explaining inequalities in disability service utilisation, estimating health inequalities for people with disability, and modelling potential policy changes or interventions that could address these inequalities. Yi uses causal inference concepts and techniques in her work, and has prior experience in the field of cancer epidemiology.

## NDIS Review

This year the Albanese Government announced a year long independent review of the National Disability Insurance Scheme (NDIS). Our Executive Director Bruce Bonyhady was honoured to be nominated to Co-Chair the review, along with Lisa Paul AM.

The work of the review is being supported by a panel of five experts, including leading disability advocates Dougie Herd, Kevin Cocks AM and MDI's own Kirsten Deane.

Work on the review commenced in October, with a final report due in late 2023.

The review will mean that Bruce's time at MDI will be more limited next year. But Kirsten and the rest of the dedicated team will make sure all of MDI's vital research and engagement activities will continue.

You can read more about the NDIS review here: <https://www.ndisreview.gov.au/>



MDI's research initiatives demonstrate our strong commitment to fostering enduring interdisciplinary connections with researchers from across the University of Melbourne, with other academic institutions, as well as with all tiers of government, industry, and disability representative organisations. We look to support research that is driven by the priorities of people with disability and involves people with disability and their organisations in every aspect of the research process.

### Disability Research Hubs

Over the past year we have continued to work with our colleagues across the University to establish disability research hubs. We believe the creation of the interdisciplinary hubs strengthens our ability to draw together different experiences and expertise to address complex problems. The hubs also allow individual researchers to continue to have an academic and disciplinary home, while creating the capacity, time and space to build new partnerships and try new approaches.

This year saw the continued operation of three hubs and the introduction of a fourth network. Planning and scoping continued for a further two hubs.

As the naming conventions indicate, the hubs are not all identical and do not operate in the same way. They reflect the theoretical frameworks, philosophies, practices, characteristics and histories of their academic homes. What they do have in common is their desire to see the dismantling of systemic and attitudinal barriers that prevent the full inclusion of people with disability in all aspects of society, and a deep commitment to co-design and co-production.

MDI is delighted to be a partner to these initiatives and we look forward to continuing to support research that will make a real difference in the lives of people with disability and their families in this country and overseas.

### The Healthy Trajectories Child and Youth Disability Research Hub

Healthy Trajectories brings together researchers focused on consumer partnered, interdisciplinary and inter-sectoral research to address the needs of those with child-onset disability and their families. This hub is based on the Children's Campus and brings together researchers from the Department of Paediatrics, the Royal Children's Hospital and the Murdoch Children's Research Institute. The hub has also partnered with the Young People's Consumer Council to ensure the voice of young people is heard loud and clear.

This hub was fortunate to receive a grant of more than \$1million from the Royal Children's Hospital Foundation to support its important work.

The hub's core streams of work are:

1. Early childhood initiatives – research that addresses issues that arise early in a child's life.
2. Child and family wellbeing – research that looks at what is needed to support wellbeing for all family members through different life stages.
3. Optimising health in disability – research focused on health service access and use, as well as interventions that minimise the impact of multiple health issues on quality of life.

4. Inclusive education – research that helps build schools and create learning environments that support students with disability.
5. Participation – research focused on understanding how best to support children and youth with disability and their families to be involved in all aspects of home, school and community life

In October, the Hub awarded four seed funding grants to support research conducted in partnership with young people with disability and/or their parents/caregivers.

#### Loneliness, social isolation and mental health for young people with disability

Lead investigator: Zoe Aitkin, Disability and Health Unit, Melbourne School of Global and Population Health, University of Melbourne

#### Feasibility of goal sharing digital interface to empower children with disability and their families and improve collaboration: A qualitative, pre-implementation study

Lead investigator: Sarah Knight, Murdoch Children's Research Institute

#### Consumer preferences and early life predictors of physical activity for children born very preterm: A mixed methods study

Lead investigator: Tara Fitzgerald, Department of Physiotherapy, University of Melbourne

#### Music technologies for people with disabilities: Creating a framework to assess suitability for individual students

Lead investigator: Anthea Skinner, Victorian College of the Arts, University of Melbourne

The Healthy Trajectories team has also partnered with the team from CanChild – Center for Child Disability Research at McMaster University in Canada, to deliver a Melbourne Campus offering of their Family Engagement in Research program.

### Social Work Disability Research Hub

This hub is focused on co-creating with people with disability, their families and carers, futures and communities that are inclusive and equitable. The hub already has a number of projects underway:

#### Towards Inclusion Project

Project Team: Dr Lyndal Hickey, Dr Jennifer Davidson, Professor Lou Harms

The Towards Inclusion Project aims to understand how inclusive communities can be achieved by focusing on the experiences and expertise of people with disability and their families and the solutions they can offer.

This project is a collaboration between the Melbourne Social Work Disability Research Hub, the Melbourne Disability Institute and Bapcare, a key provider of NDIS Local Area Coordination in Tasmania and South Australia.

#### Hobsons's Bay Sport for Youth of All Abilities program

Project Team: Dr Jenny Conrick

The Hobsons's Bay Sport for Youth of All Abilities program brings together social work researchers, Hobsons Bay Community Fund, Compton Green Real Estate, Hobsons Bay City Council and the Hobsons Bay community in an innovative partnership to develop, implement and evaluate a 6-week sport inclusion program with three local sports clubs for children living with autism spectrum disorder (ASD).

#### Transition to Independent Living project

Project Team: Dr Lyndal Hickey and Professor Lou Harms

The Transition to Independent Living project explores the perspectives of adolescents and young adults (AYA) with cerebral palsy and their family members transitioning to independent living. It focuses on the barriers and enablers within families, communities



and services systems that impact on AYA transition.

The project is a collaboration between the Social Work Disability Research Hub, CP-Achieve at Murdoch Children's Research Institute, The Royal Children's Hospital and St Vincent's Hospital Melbourne.

The Hub is also working with the Funds in Court team from the Supreme Court of Victoria on two disability justice projects, evaluating the introduction of communication facilitators at VCAT for people with complex communication disabilities, and a wraparound program with Colac Otway Regional Advocacy Service for young people with disability.

### **Melbourne Graduate School of Education Disability Research Collaboration**

The first act of the MGSE collaboration was to establish a working group, bringing together academics from a range of disciplines across the Faculty. The group then focused on developing a terms of reference, guiding principles, vision and rationale for the operation of the collaborative. The group has also put together protocols to be used when co-designing with people with disability and community partners.

Two research projects are already underway:

The first is a collaborative project with community partner Aspect, and examines physical spaces for neurodiverse staff and students at the University of Melbourne. This project has been funded through a MGSE seed grant. Co-designed and co-produced, all research assistants working on this project identify as neurodiverse. The team began by interviewing staff and students about their experiences of working and studying at MGSE. They hope the results will lead to change in policy and practice within the Faculty.

The second project is in partnership with Down Syndrome Victoria (DSV). This project is funded through the MDI Community Based Research Program. It focuses on the factors that influence parent decision-making when deciding whether to transition their child to a mainstream or specialist secondary school after attending a mainstream primary school. The project will interview young people with Down syndrome and their family members.

### **Disability Law Network**

The Disability Law Network brings together a group of legal scholars from across the Melbourne Law School with an interest in disability. Commencing at the end of 2022, the first act of the group was to partner with the Centre for Employment and Labour Law to organise a special lecture by Professor Lisa Waddington titled *When Staff with Disability and University Meet: Some Reflections from an International and Comparative Perspective*. Professor Waddington is a Professor in European Disability Law, and International and European Law at Maastricht University. Scoping work for two more research hubs in the School of Social and Political Sciences and the Faculty of Architecture Building and Planning is almost complete. We hope these hubs will be up and running next year.

## **Seed Funding**

Each year MDI runs a small seed funding scheme to support new disability research across the University. The grants are intended to support small to medium sized projects at the discovery or pilot end of research. Our focus is on funding and facilitating projects that are driven by, and with people with disability and/or their families. To be successful, projects must address a topic of importance to people with disability and must involve people with disability and their organisations in all aspects of the research process. We also look for projects that are likely to have practical outcomes as well as a pathway to further research and funding.

This year we were pleased to be able to direct almost \$235,000 to fund eight new projects. The successful projects focused on a diverse and wide range of topics, from examining vaccination rates amongst people with disability through the COVID19 pandemic to the development of a computer game focused on accessible city design.

### **Characterising the hidden population of people with disability in Australia, who are not NDIS participants, using the Multi-Agency Data Integration Project (MADIP)**

Of the 2.2 million people in Australia with a disability under 65 years old, only 534,655 are National Disability Insurance Scheme (NDIS) participants. While there is data that describes the characteristics of the NDIS population, there is no single data source to identify people with disability who are not NDIS participants. Through data linkages of the 2018 Survey of Disability, Ageing and Carers, the 2016 Census of Population and Housing, and NDIS participant data in MADIP, this project aims to:

- Identify the population of people with disability who are not NDIS participants within SDAC and the Census
- Describe the characteristics of people with disability who are not NDIS participants in terms of disability characteristics, support needs, and demographic, geographic and socio-economic characteristics
- Examine how their characteristics differ from NDIS participants

#### **Project Team**

Leads: Dr Zoe Aitken, Senior Research Fellow, Disability and Health Unit, Centre for Health Equity, Melbourne School of Population and Global Health

Dr Glenda Bishop, Research Assistant, Disability and Health Unit, Centre for Health Equity, Melbourne School of Population and Global Health

Team: Dr Sue Olney, Professor Anne Kavanagh, Dr George Disney

### **Early Childhood Intervention and the National Disability Insurance Scheme: examining inequality in access, plan allocation and use in the early childhood period**

Timely access and use of effective early intervention services for children with developmental concerns and disabilities is crucial to reduce inequities in social and health outcomes. This project will look at data for all children (under 6 years) who use the NDIS funded Early Childhood (EC) program and examine whether there are social inequities in who is eligible for support, the type of support they receive and whether there are inequities in timely access to supports and spending of NDIS funding. Findings from the research will be used to inform future research on policy, process and funding changes to optimise early childhood intervention.

#### **Project Team**

Leads: Dr George Disney, Senior Research Fellow, Disability and Health Unit, Centre for Health Equity, Melbourne School of Population and Global Health

Dr Bridget O'Connor, Post Doctoral Fellow, Healthy Trajectories Child and Youth Disability Research Hub

Team: Professor Christine Imms, Karen Dimmock, Dr Joanne Griggs, Dr Anita D'Aprano, Dr Alys Mendus, Professor Lisa McKay-Brown, Catherine Bain, Dr Charmaine Bernie, Dr Yi Yang

### **Creative Development for Accessible City Computer Game**

This project will develop a proof of concept city-building computer game focused on accessible city design. Informed by lived experience of disability, the experience in a virtual environment will drive new understandings of how built environments and urban spaces create accessibility and inaccessibility and will aim to influence the future design of a wide range of computer games.

#### **Project Team**

Lead: Associate Professor Eddie Paterson

Team: Dr Radha O'Meara, Timothy Williams, Qambar Ali Akhteyari, Madeleine Little, Hugh Crosthwaite

### **Community Visitor Schemes within the NDIS and OPCAT landscapes: Inspection powers and reporting to safeguard the rights of people with disabilities**

Community Visitor schemes are a key mechanism in ensuring the safeguarding and achievement of human rights. The unique powers of the Community Visitors to undertake unannounced, onsite visits to closed sites such as group houses, clinical facilities and supported residential services (SRSs) provide crucial 'eyes on the ground' monitoring and assessment of resident wellbeing, living conditions and service quality. This study will examine the ongoing role of Community Visitor schemes in safeguarding people with disability following changes brought by the National Disability Insurance Scheme (NDIS).

#### **Project Team**

Leads: Dr Piers Gooding, Melbourne Law School, Dr Raelene West, Melbourne Disability Institute

Team: Dr John Chesterman, Public Advocate for Queensland, Sarah Forbes, Manager of Safeguarding, Inclusion and Volunteers Program with the Victorian Office of the Public Advocate

### **Am I speaking to a human?: Voice, choice and the role of technology companies in designing accessible virtual assistants**

This project investigates how people with disabilities use virtual voice assistants, and related technologies (such as Amazon Alexa, Apple Siri, Google Duplex) in their daily lives. The research team will consider the ways in which people with disabilities do, or do not, find these technologies useful and what they use the technologies for. The project will also consider the ways in which people with disabilities think about and respond to privacy and cyber security considerations in their use of digital technologies.

#### **Project Team**

Lead: Professor Jeannie Paterson, Professor of Law, Co-Director of the Centre for AI and Digital Ethics

Team: Gabby Bush, Dr Yvette Maker

### **COVID-19 Vaccine Strategy Project**

This project will extend and complement analyses currently being conducted by Commonwealth Government on COVID-19 vaccination and outcomes for people with disability. Using ABS survey data and administrative disability data, the project team will investigate the uptake of COVID-19 vaccinations, access to treatment, and serious outcomes and deaths from COVID-19 among people with disability compared to the general population.

#### **Project Team**

Professor Anne Kavanagh, Disability and Health Unit, Centre for Health Equity, Melbourne School of Population and Global Health

## A National Summit and Research agenda supporting voting by people with cognitive disability

Approximately 500,000 Australians with cognitive disability experience barriers to participating in democratic processes and, in particular, in casting their votes in local, state and national elections. This project seeks to build on and scale up the ICanVote project nationally to address the democratic deficit experienced by people with cognitive disability across Australia.

### Project Team

Leads: Professor Keith McVilly, Disability & Inclusion, The University of Melbourne School of Social & Political Sciences

Associate. Prof. Paul Ramcharan, The University of Melbourne School of Social & Political Sciences

Team: Nathan Despott, Ms Jenna Hepburn Inclusion Melbourne

## Towards developing innovative evaluation approaches to measure the public health impact of social enterprises

Over the past decade evidence has emerged that identifies the potential role of social enterprise in addressing health inequalities. This project seeks to understand whether and how current approaches in the evaluation of social enterprises conceptualise and measure their public health impact, with a specific focus on people with disability.

### Project Team:

Lead: Associate Professor Lucio Naccarella, Principal Research Fellow-Health Workforce Evaluation & Implementation Science Unit, Centre for Health Policy, Melbourne School of Population and Global Health

Team: Jessica Rowlings, Marie Huska, Heidi Butler-Moore, Chris Riseley, Sue Lee Seng, Dr Alexandra Devine, Dr Sue Olney, Dr Matthew Harrison, Dr Jemimah Ride

## Collaborative Projects

The Melbourne Disability Institute both leads and supports a wide range of high impact national and international research initiatives. These initiatives demonstrate MDI's strong commitment to interdisciplinary collaborations with researchers from across the University of Melbourne and other institutions, as well as with people with disability, their families, their representative organisations, all tiers of government and industry.

### The Tier 2 Tipping Point: Access to Support for Working-Age Australians with Disability without Individual NDIS Funding

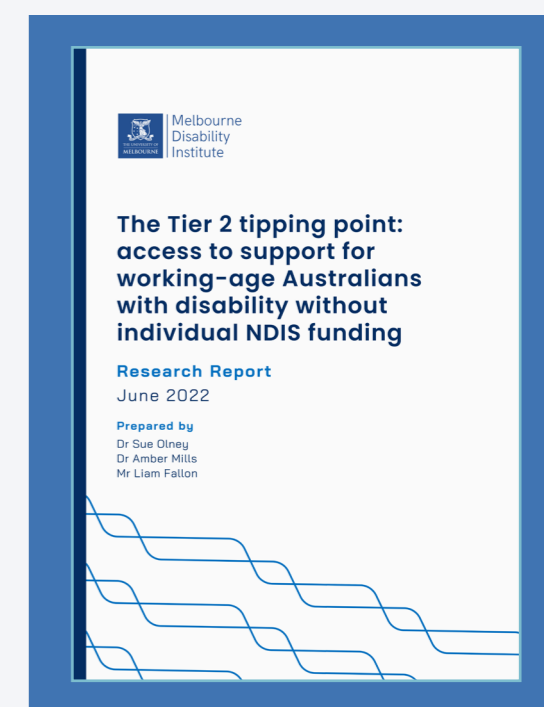
This year we were delighted to release the ground-breaking report *The Tier 2 Tipping Point: Access to Support for Working-Age Australians with Disability without Individual NDIS Funding*.

More than 500,000 Australians receive individual funding through the National Disability Insurance Scheme (NDIS) to purchase support and services to meet their disability-related needs. But inclusion of people with disability in mainstream society is a critical component of the NDIS insurance model. For that reason, the NDIS was also intended to help all Australians with disability - including 2.4 million people aged under 65 years - connect with a larger ecosystem of services and supports, and to help communities become more welcoming and inclusive.

This element of the original three-tiered structure of the NDIS - Tier 2, implemented as Information, Linkages and Capacity Building - is not achieving its stated aims. Tier 2 of the NDIS is an underexamined, high-risk and complex policy environment that is shaping the life course of some of Australia's most

marginalised citizens, with far-reaching social and economic costs.

This research sheds direct light, for the first time, on the experiences of people with disability who are not NDIS participants navigating universal service systems. Conducted by Dr Sue Olney from MDI in partnership with the Brotherhood of St Laurence, the research offers important insights into financial, logistical, and personal challenges faced by Australians with disability in their day-to-day lives.



## Investing in Disability in India

**Project Lead:** Professor Nathan Grills

MDI is proud to partner with the Nossal Institute to continue vital research on the costs and benefits to investment in disability support in India. Despite the curve balls thrown up by the COVID19 pandemic, the partnership has gone from strength to strength and has led to a full program of work between the University and the Indian government. This ground breaking partnership is focused on practical, targeted and mainstream solutions to improve outcomes for people with disability and their families in India.

Work underway has already identified, for example, that families experience additional significant costs when there is a family member with a disability and lower incomes. This finding has strengthened the case for investment.

The partnership has also enabled practical outcomes, such as 500 people enrolling in a co-designed disability training program. The impact of the program is now being evaluated by the University.

We are proud to partner with Nossal, the Department of Foreign Affairs and Trade (DFAT), and the Indian Department of Empowerment of Persons with Disability on this important work.

## Virtucare

**Project Lead:** Professor Nathan Grills

VirtuCare is a research initiative that will develop a virtual model of care to address health and rehabilitation needs of people with disability in India.

Supported by the Australian Government through the Australia-India Council of the Department of Foreign Affairs and Trade,

VirtuCare was formally launched at the Australian High Commission in New Delhi during the University's delegation to India in September.

The initiative has received in-kind support from partners including the Public Health Foundation of India, the George Institute India, University of Adelaide, Infosys, the Emmanuel Hospital Association, and eSanjeevani through the Government of India's Centre for Development of Advanced Computing based in Mohali.

## National Disability Data Asset - Test case

**Project Team:** Dr George Disney, Dr Yi Yang, Peter Summers, Professor Anne Kavanagh, Professor Bruce Bonyhady, Kirsten Deane

In 2021 the Australian Government committed to an enduring National Disability Data Asset. The NDDA is a government initiative designed to test how linked administrative and health data can be used to better understand the life-outcomes for people with disability in Australia.

This year the focus of the NDDA was to explore and identify the best ways to share, link and access data and information. One of the ways the NDDA did so was by funding five test cases. Each test case explored various aspects of data linkage and analysis and demonstrated the benefits of large scale data mapping and linkage.

Two teams from the University of Melbourne were selected to lead two of test cases. Researchers from MDI and the Disability and Health Unit in the School of Population and Global Health joined

with researchers from La Trobe University to look at the mental health service use, needs and health outcomes of people with disability and mental illness. The project used data from the Victorian Government and the Commonwealth Government.

## NDIS Utilisation – Project for the Department of Queensland Government

**Project Team:** Dr George Disney, Dr Yi Yang

Since the NDIS began in 2013, there has been ongoing concern that participants in the scheme rarely use all their NDIS funds. "Utilisation rates" as they are known, have been persistently low for many participants since the scheme began. While high utilisation is clearly not a goal in itself, low rates can suggest people with disability might not be getting the support they need.

In 2022, the Queensland Government commissioned researchers from MDI and the Disability and Health Unit in the School of Population and Global Health to look at NDIS utilisation rates amongst different groups of participants in the scheme and in different areas in Queensland.

The aim of this project is to better understand what helps or makes it hard for Queensland participants to use their funds to meet their needs and aspirations.

## Inclusive Design for Employment Access

**Project Team:** Professor Bruce Bonyhady and Dr Sue Olney, Melbourne Disability Institute, and Dr Alexandra Devine, Disability and Health Unit, MSPGH

The Melbourne Disability Institute is part of an international consortium, led by McMaster

University, exploring demand-driven solutions to persistent marginalisation of people with disability in the labour market.

The aim of this work is to find, share, or develop effective policy interventions and tools to equip and encourage employers to recruit, retain and promote people with disability in a range of industries, contexts and places, and to build disability- confident workplaces.

Australia's unique contribution to the research is examining the impact of the NDIS funding model on pathways to work and employment.

## Community-Based Research Grants

There are many creative and innovative programs and services being run by and for people with a disability in the Australian community. Many are developed and run by small organisations who often lack the time and resources to capture their impact, evaluate outcomes achieved or identify ways to further extend and strengthen their practice.

At the same time there is an increasing need for organisations to provide evidence of outcomes and impact, particularly to funders. Robust independent academic research can be helpful in capturing impact. It can also be useful to provide evidence to strengthen advocacy for change.

MDI's Community-Based Research Program aims to meet the research needs of community organisations by providing research support and evaluation of innovative programs that are making a difference in the lives of people with disability, their families and carers.

Research support provided through the program may include a scoping report, literature review, data analysis and a small research project. Research can lead to outcomes such as improved service delivery, the development of new services, improved ability to advocate effectively or the improved capacity to undertake future research projects.

MDI matches the community organisation with a University of Melbourne researcher to undertake each project.

In 2021 we were pleased to support researchers to begin six projects to a total value of \$90,000. We also provided a small amount of additional funding to some of the successful organisations to cover additional expenditure.

### **Ngaanyatjarra Pitjantatjara Yankunytjatjara Women's Council (NPY Women's Council)**

Project: Best practice model for Accessing Allied Health Services for children with a disability living in remote communities of central Australia

<https://www.npywc.org.au/>

This project will look at developing an evidence base for the delivery of best practice early childhood early intervention models that meets the cultural needs of First Nations children with a disability, their families and communities. The project will also assist in the larger task of providing evidence to inform guidelines around the funding of therapy.

### **Villamanta Disability Rights Legal Service Inc.**

Project: Supporting wills as tangible decisions

<https://villamanta.org.au/>

This project will evaluate an initiative by Villamanta Disability Rights Legal Services to develop tools and resources to support people with intellectual disability to prepare a will.

### **Youth Disability Advocacy Service (YDAS)**

Project: Analysis of individual advocacy data to identify the prevalence and type of advocacy issues experienced by disabled young people.

<https://www.yacvic.org.au/ydas>

This project will analyse individual advocacy data to identify common issues experienced by young people with a disability. The results will be used to provide recommendations on successful advocacy interventions and inform systemic advocacy for change.

### **Down Syndrome Association of Victoria (DSV)**

Project: Closing the gap – authentic inclusion in education for people with down syndrome

<https://www.downsyndrome.org.au/vic/>

This project will look at the experience of young people with Down syndrome transitioning from primary school to high school and will help develop resources to help young people and their families successfully transition to mainstream secondary education.

### **Brain Injury Matters Inc**

Project: The impact of peer support groups on people with acquired brain injury (ABI)

<https://www.braininjurymatters.org/>

This project will look at best practice tools and methods for peer support groups supporting people with an Acquired Brain Injury.

### **Scope Australia (& Funds in Court)**

Project: Communication facilitators pilot program - Civil Matters

<https://www.scopeaust.org.au/>

This project will evaluate Scope Australia's pilot program to provide targeted support to people who use alternative communication systems during civil court matters.

## National Disability Research Partnership



2022 marked the end of the National Disability Research Partnership's (NDRP) two-year establishment phase. In June 2022 the NDRP Working Party, led by MDI, published a series of recommendations for setting up and running a National Disability Research Partnership.

The reports are based on feedback from the disability community and a range of other stakeholders who contributed during the establishment phase. The reports make recommendations to the Australian Government about how the NDRP could work when it is launched in 2023.

The report includes information on:

- The NDRP Guiding Principles
- Governance: who should run the NDRP and how?
- Commitment to research done by and with people with disability
- A preliminary NDRP research agenda
- How the NDRP will fund research
- How the NDRP will help build research capacity
- How the NDRP will share new knowledge
- Community of practice: how the NDRP will bring people together

- Communication: how we will tell people about the NDRP and listen and learn from others.

The NDRP was provided with an additional \$2.5 million of funding in the October 2022 budget. This brings the total Commonwealth funding for the first three years of the NDRP to \$15 million.

Access the reports here: [Learnings and Recommendations](#).

### What happens now?

From August 2022 to mid-2023, the NDRP Working Party and the Australian Government are working on establishing the NDRP as an independent entity. This involves setting up a new entity, opening to members, and running a nomination and election process for directors of the first full board. The Working Party will also refine its preliminary research agenda to reach a fit-for-purpose NDRP Research Agenda & Framework, and work with University of New South Wales to develop guidelines for ethical co-production of disability research.

Keep an eye out for the official launch of the NDRP in mid 2023.



## About the NDRP

As part of MDI's ongoing effort to support University of Melbourne researchers working in the field of disability, we introduced a community of practice to:

- Provide a forum to showcase research, share information (for example research findings, experiences, lessons learned, best practice) and problem-solve
- Spark dialogue about translation of research into policy and practice
- Encourage collaboration within and outside of University
- Develop, facilitate and mobilise resources for research
- Cultivate champions and facilitate connections between researchers who might not otherwise be aware of each other's work

We continued this initiative in 2022 holding monthly meetings which provided a forum

for university researchers to present their research, answer questions from peers and colleagues and find out more about opportunities and disability research taking place across campus.

This year our sessions covered a wide diversity of topics from the experience of disadvantaged groups in the National Disability Insurance Scheme to the importance of co-design in designing and implementing research with people with disability.

The community of practice continued to be a great place where researchers can share and test ideas and build new collaborations.

Conducted completely online during 2022, this coming year we hope to be able to hold some face-to-face sessions to open up new opportunities for networking and collaboration.

For the third year in a row MDI collaborated with Professor Graham Schaffer from the Melbourne School of Engineering to continue to run the Human Centred Mechanical Design course.

The subject invites people with lived experience of disability to collaborate with small groups of engineering students and provide their expertise on potential innovations and opportunities for design solutions.

Students gain practical and theoretical understanding of employing creative human centred design thinking principles. MDI helped structure the course so students could learn about disability over a number of lectures.

At the conclusion of the course the students came up with some really innovative designs driven by lived experience.



### Let Us In Podcast

In 2022 we were delighted to partner with ABC to create a ground-breaking podcast series to uncover what's really going on for people with disability in Australia today.

Over the course of seven episodes, Kurt Fearnley and Sarah Shands travel across Australia to speak to people with disability, their families and researchers about the big issues impacting Australians with disability. Issues like transport, living with COVID, education and employment.

We are pleased to share that the podcast has now been shortlisted an international podcast award.

You can find the podcast on the ABC listen app, Apple Podcasts and Spotify.



### Ableist Cities Symposium

In December we were proud to partner with the Melbourne School of Design to host the inaugural Ableist Cities Symposium.

*Disrupting the Ableist City: Reimagining Spatial Justice to Access in Australian Cities* was a full day event looking at accessibility in Australian cities thirty years on from the introduction of the Disability Discrimination Act.

The event brought together everyone from experienced academics who have worked for many years to improve accessibility to early career researchers just beginning their PhD's.

Topics ranged from the development of new applications and technologies to map accessible venues, through to the need to push forward in getting a fully accessible tram network in Melbourne.

The symposium also looked at the impact of the current building standards on accessibility, how people with vision impairment navigate the built environment.

Overall, it was a fantastic day of discussion reminding us of just how far we have come – and just how far we still have to go. MDI looks forward to being a part of the next Ableist Cities symposium to be held in late 2023.



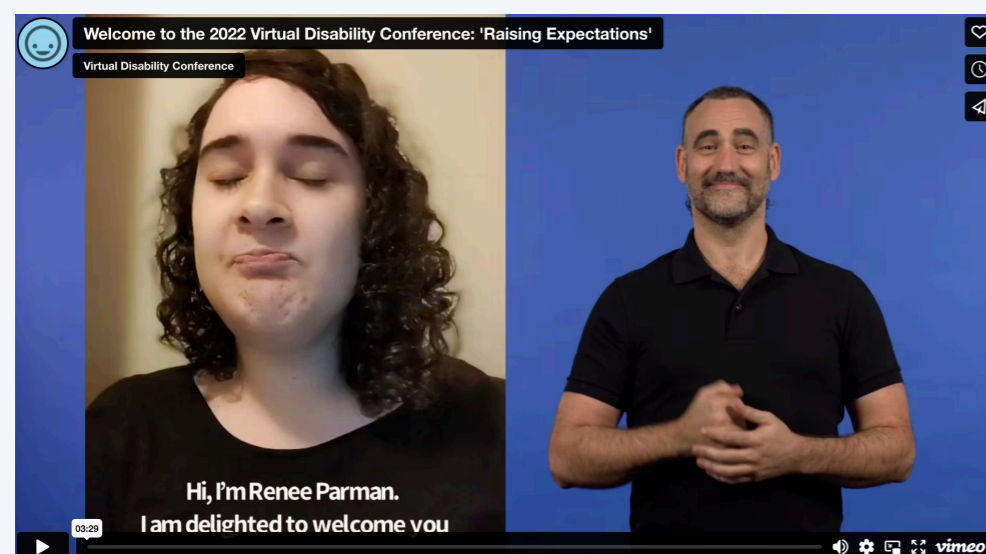
## Virtual Disability Conference

In 2022, MDI was pleased to partner with our colleagues at the University of Melbourne, Scope, National Disability Services and The Australian Federation of Disability Organisations for the third biennial National Virtual Disability Conference.

The theme of this year's conference was "Raising Expectations". Many people are aware of the commentary by former Disability Discrimination Commission Graeme Innes AM about the "soft bigotry of low expectations". Presentations at the conference looked at what needs to be done to break down the systemic barriers to greater participation by people with disability ways to raise expectations for a better future.

MDI was proud to sponsor the closing symposium "Inequality, Inequity and Inclusion: What Exactly Do We Expect the National Disability Insurance Scheme to Deliver?" Researchers from MDI and the Disability and Health Unit were joined by members of Our Voice from Inclusion Australia and disability advocate Dougie Herd to talk about what the research tells us about the experience of inequality and inequity amongst particular groups of NDIS participants and what else we need to look at to start to address persistent disadvantage.

The session also looked at what else needs to be done outside of the NDIS to make sure all people with disability have their needs met and are included in the life of the community. We look forward to continuing to be a part of this important event in 2023.



Income	
Melbourne Disability Institute core funding	\$970,000
Strategic funding	\$300,000
Other	\$232,324
External grants	\$861,312
<b>Total:</b>	<b>\$2,363,636</b>
Expenditure	
<i>Directorate</i>	
Core salaries	\$347,332
Events and communications	\$99,849
General administration	\$5,659
<i>Research Enabling Expenditure</i>	
Salaries	\$740,953
Seed funding	\$572,048
PhD scholarships	\$2,001
Other (including external grants)	\$1,471,138
<b>Total:</b>	<b>\$3,238,980</b>



- achieved **more than 920 media impressions** across online, print, television and radio
- developed a **new partnership with ABC** to deliver *Let Us In*, a ground-breaking new podcast on disability with hosts, Sarah Shands and Kurt Fearnley
- dedicated **more than \$500,000 to disability research** across, seed funding and community-based research grants, disability research hubs and collaborative research projects



**\$572,048**

Allocated to disability Research Seed Funding



**2**

NDIS Research Fellowships



**10**

Community of practice meetings



**4**

New faculty-based disability research hubs

## Media

**85**  
Television

**220**  
Radio

**583**  
Online news

**34**  
Print news

**+284**  
new Twitter followers

**Melbourne Disability Institute  
University of Melbourne**

Building 161, Parkville Campus  
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