

Melbourne Disability Institute

Annual Report

2021





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The Melbourne Disability Institute (MDI) is situated on the land of the Woiwurrung (Wurundjeri) people of the Kulin nation and conducts its activities on Aboriginal land.

This land has never been ceded and the impacts of colonisation are ongoing. MDI acknowledges Traditional Custodians' continual care for country, the importance of Indigenous sustainability practice and knowledge, and the Woiwurrung and Boon Wurrung's ongoing contributions to the life of this city and this region.

MDI pays respects to Elders past and present.

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t: +61 3 9035 6416

The information in this publication was correct at the time of printing. The University of Melbourne reserves the right to make changes as appropriate.

This Annual Report is available online at www.disability.unimelb.edu.au

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.

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Professor Bruce Bonyhady
Executive Chair and Director

Letter from the Director

A global pandemic, big changes to the National Disability Insurance Scheme, a Royal Commission – to say the last couple of years have been a challenge for people with disability would be something of an understatement.

At MDI we are committed to help build the evidence base to address these challenges - and many others - that confront people with disability and their families and carers in this country.

We are fortunate to be part of a wide network of colleagues, collaborators and supporters across the university and in the community who help us carry out our mission.

The challenges facing us this year have demonstrated why it is so important for everyone to work together if we are to achieve real lasting change. At MDI we are committed to working together at all levels to achieve that change – in research, policy and practice.

In collaboration with researchers across the university and our colleagues in the disability community, we have been deeply engaged in policy discussion and analysis at global, national, and regional levels this year. At the national level, MDI has been pleased to be able to contribute to major discussions regarding the future of the National Disability Insurance Scheme

(NDIS). MDI submissions to consultations and enquiries highlighted deep flaws in the proposal from the National Disability Insurance Agency to introduce so-called “independent assessments”. The lack of evidence for the proposed approach was clear and ultimately contributed to the defeat of the proposal. MDI also provided feedback on the most significant changes to the NDIS Act since the NDIS commenced. The suggested changes led to the rights of people with disability being protected and the maintenance of the national governance of the NDIS. We also made a submission to the Joint Standing Committee on the NDIS, which recommended the need for independent research to ensure the sustainability of the NDIS and that it works for everyone.

This year there have also been national discussions regarding the disproportionate impact of the COVID19 pandemic on people with disability, the pressing need for new national building standards to increase the availability of accessible housing and the need for reform of employment services.

At every turn we have argued for the importance of evidence-based reform and the need to ensure changes are always co-designed with people with disability, their families and the representative organisations.

But if our advocacy efforts are to be genuinely fruitful, we also need to make sure we continue to build the evidence base. This year we have tried to do that in a number of different ways.

Across the university, we are working with our colleagues to set up collaborative interdisciplinary research hubs, bringing together the knowledge, expertise and experience of a wide range of researchers to tackle the challenges facing people with disability.

This year saw two hubs get up and running. The Children and Youth 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 Families and Communities research hub is based in the Department of Social Work in the School of Health Sciences.

We are currently scoping out a further three hubs and have plans for at least two more.

Through our seed funding program, we committed more than \$220,000 to help shape and explore new disability research through collaborative partnerships with people with disability, their families and their representative organisations.

We have also built significant external partnerships through our Community-Based Research Program with \$100,000 allocated to meet the research and evaluation needs of community organisations.

As well as supporting disability-inclusive research across the university, we lead or are involved in a range of externally funded projects. This year for example we completed two large projects which looked at how participants in the National

Disability Insurance Scheme used the funding provided by the NDIS.

This world-leading research focused on the experience of participants known to experience disadvantage in the scheme, such as First Nations participants, and participants from Culturally and Linguistically Diverse backgrounds. This work has made a major contribution to our understanding of how the scheme works on the ground – and ways it can be improved to improve outcomes for all.

With our partners at the Brotherhood of St Laurence and Bapcare we have also begun what we hope will become a much larger body of work looking at the experiences and needs of people with disability who do not receive support from the NDIS.

We have also continued to host the National Disability Research Partnership (NDRP). At the end of the year, we were thrilled to hear the Federal government commit to funding the Partnership for the next two years. The government also committed further funding for an enduring National Disability Data Asset which will be a vital research platform for NDRP and disability research more broadly.

These two initiatives are critical to continuing to build the evidence base necessary to address the challenges facing people with disability in this country.

Finally, I would like to thank the MDI team and all our partners for your hard work, dedication and commitment to collaboration and co-design.



Professor Bruce Bonyhady AM
Executive Chair and Director

About Us

Welcome to the Melbourne Disability Institute (MDI) at the University of Melbourne. We facilitate collaborative, interdisciplinary research to build the evidence base necessary to inform disability policy, programs and practice and to advance opportunity and equity for people with disability, their families and carers.

We are committed to co-producing collaborative research, where people with disability are involved not just as participants, but as co-creators of knowledge. Throughout our work, we

strive to promote the inclusion and well-being of people with disability, explore issues that are, or are likely to become, important to people with disability and recognise, foster and communicate the contribution people with disability make to research.

The work of MDI is building on established programs and partnerships, including the Scope-University of Melbourne partnership, the [Hallmark Disability Research Initiative](#) and the [NHMRC Centre of Research Excellence in Disability and Health](#).



8

PROJECTS

funded through our seed funding program



10

EVALUATIONS

funded through our community based research program



922

NEWS STORIES

Online and in print



2,009

FOLLOWERS

on Twitter



41

EVENTS

Community of Practice, Conferences, Seminars



1,562

SUBSCRIBERS

Our newsletter reached more than 1500 monthly

Executive committee

The MDI Executive Committee provides advice to the Director and acts as a conduit for communication across the various Faculties of the University.

[Professor Bruce Bonyhady, AM](#)

Executive Chair and Director, Melbourne Disability Institute

[Professor Anne Kavanagh](#)

Chair, Disability and Health
Academic Director, Melbourne Disability Institute

[Professor Brendan Gleeson](#)

Director, Melbourne Sustainable Society Institute

[Professor Lorraine Graham](#)

Professor of Learning Intervention,
Melbourne Graduate School of Education

[Professor Mark Hargreaves](#)

Pro-Vice-Chancellor, Research
Collaboration and Partnerships

[Professor Lou Harms](#)

Chair and Head of Social Work,
Department of Medicine, Dentistry &
Health Sciences

[Professor Christine Imms](#)

Apex Australia Chair of
Neurodevelopment and Disability,
Department of Paediatrics

[The Hon. Jenny Macklin](#)

Vice-Chancellor's Fellow, Melbourne
School of Government, Melbourne Law
School

[Professor Barbara McPake](#)

Director of Nossal Institute and Chair of
Global Health, Melbourne School of
Population and Global Health

[Professor Shelley Mallett](#)

Professorial Fellow in Social Policy, Social
and Political Sciences

[Professor Keith McVilly](#)

Professorial Fellow in Disability and
Inclusion, Social and Political Sciences

[Professor Abigail Payne](#)

Director, Melbourne Institute, Melbourne
Institute of Applied Economic and Social
Research

Our team

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.

We extend our sincere thanks to all team members, including those engaged as casual Research Assistants and Research Fellows throughout the year to support MDI projects and activities, for their passionate commitment to disability research.

Professor Bruce Bonyhady, AM
Executive Chair and Director

Ms. Kirsten Deane
General Manager

Dr Sue Olney
Research Fellow, Policy

Dr Raelene West
Research Fellow

Dr Paul Jacobs
Research Fellow

Ms Sara Donaldson
Engagement Manager

Mr Campbell Message
Program Manager

Ms Tessa de Vries
NDRP Coordinator



Disability Research Hubs

Disability Hubs

Building disability expertise into the academy

Over the past year, MDI has been successful in attracting more than one million dollars in external research funding. With more opportunities on the horizon and the Federal government committing further funding to the National Disability Research Agenda, we want to make sure the University of Melbourne has the expertise and capacity to respond and contribute to building the much-needed evidence base in disability.

Over the past year we have been working with our colleagues across the university to establish disability research hubs. These hubs recognise that interdisciplinary collaborations allow researchers to draw on the strengths of a range of disciplines to address complex problems.

Interdisciplinary research also allows individuals to have an academic and disciplinary home while at the same time having the capacity, time and space to build new partnerships and try new approaches. Interdisciplinary collaborations

This year saw the creation of two hubs.

The first is a hub focused on Children and Youth bringing together researchers from the Department of Paediatrics, the Murdoch Children's Research Institute and the Royal Children's Hospital. This hub has already been successful in attracting funding from the Royal Children's Foundation and work has already commenced on a number of exciting projects.

The second hub is focused on Families and Community and is based in the Department of Social Work in the School of Health Sciences. Together with our community partners, Bapcare and the Brotherhood of St Laurence, work is already underway on a diverse range of projects.

Scoping work has commenced to establish a hub in the Graduate School of Education, the School of Social and Political Sciences and Architecture Building and Planning.

We hope to establish a further two hubs across the university in the coming year.

We look forward to further reporting on the collective impact and growth of the Disability Research Hubs initiative.

Impact and Advocacy

At MDI we are committed to high quality research that addresses key issues facing people with disability. We look to lead, facilitate and support research that has both reach and impact.

This year we joined with researchers across the university, people with disability, their families and representative organisations and non-government community organisations in advocating for evidence-based policy and program reform.

In areas as diverse as housing regulations, health and the National Disability Insurance Scheme, we worked to ensure robust research and data was part of the national policy debate.

We joined with advocates around the country to raise awareness of the ongoing impact of the COVID19 pandemic on people with disability and their families. The pandemic has continued to bring into sharp relief existing social inequalities and inequities, and how often people with disability and their families are forgotten in disaster planning and relief.

We joined with people with disability, their families and their representative organisations in speaking out against proposed changes to the National Disability Insurance Scheme including so called “independent assessments”. We also joined with people with disability and their advocates in expressing concern regarding proposed changes to the NDIS Act. Thanks to everyone’s concerted efforts, the legislation was amended at the final hour and provides a strong foundation for the operation of the scheme in the future.

We partnered with organisations across the country to advocate for the inclusion

of minimum accessibility standards for all new housing in the National Construction Code.

Predicting the very real risk that the benefits of mandatory standards had been underestimated and that the voices of people with disability would not be heard during deliberations about the new code, MDI engaged economists to advise on the impact of including minimum accessibility standards. We also commissioned a survey of people with disability and their families to capture their views.

Together with the Summer Foundation MDI also established the Building Better Homes campaign to advocate for the inclusion of minimum standards. This campaign built on decades of advocacy by the Australian Network for Universal Housing Design. As a result of this research and continued strong advocacy, in April 2021 Building Ministers from across Australia formally committed to the inclusion of mandatory minimum standards in the National Construction Code. This will lead to major improvements in the quality of life for Australians with disability and facilitate older Australians being supported to age in place.

Beyond our work on these issues, MDI also made more than seven submissions to government inquiries and consultations, appeared before two senate committees and spoke out strongly in the media about the need for evidence-based reform. Looking ahead to 2022 many challenges remain. We will therefore continue to speak out to ensure proposals for reform and change are based on high quality evidence and data.

Melbourne Disability Institute Director Bruce Bonyhady, who helped design the NDIS, this month warned that independent assessments would "blow up" the vision of the scheme by undermining the process of accessing support.

 The Australian

Cost blowout crushes National Disability Insurance Scheme

It is so wrong but they don't seem to care," Mr Bonyhady, now the director of the Melbourne Disability Institute, said.

29 Aug 2021



'You're either in or you're out': NDIS architects say scheme is inequitable



By [Jewel Topsfield](#)
July 22, 2021 – 4:06pm

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12

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NDIS changes could give agency chief powers to cut funding, former chairman says

Director of the Melbourne University's Melbourne Disability Institute, Professor Bruce Bonyhady, says the move to mandate accessibility in the future.

"What it means is that over time, more and more housing will be accessible, both people with disability but also for older Australians, most of them who want to age in place," says Professor Bonyhady.

The MDI previously undertook a study which found that 80 per cent of people with disability were adversely affected their

The Sydney Morning Herald

NDIS architect Bruce Bonyhady urges rethink of independent assessments

ABC Investigations / By [Pat McGrath](#) and [Alison McClymont](#)

Posted Thu 18 Mar 2021 at 6:09am, updated Thu 18 Mar 2021 at 10:38am

New guidelines to ensure all new housing accessible for people with disability





Research

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

Seed Funding

The MDI Seed Funding scheme is intended to support small to medium sized projects at the discovery or pilot end of research. We look to support projects that are focused on developing the much-needed evidence, data and research to address the complex problems facing people with disability in this country.

This year we focused on projects that could demonstrate they were driven by the priorities of people with disability, were likely to have practical outcomes, involved strong partnerships and had a clear path to sustainable funding.

In 2020 our seed funding round focused exclusively on the impact of COVID19 on people with disability and their families. Given the pandemic continues to have a

disproportionate impact on many people with disability, we also continued to support projects that addressed this critical need.

We also looked for projects that aligned with the **National Disability Strategy** and reflected the vision and principles of the **National Disability Research Partnership**.

We were pleased to be able to direct nearly \$220,000 to fund eight new projects which focused on a wide range of topics, from designing inclusive learning spaces to exploring the support needs of people with early-stage vision loss. We also funded an additional two projects out of round. Details on each are provided on the next few pages.

Seed Funded Projects

Finding better outcomes for children and caregivers through improved care pathways for those with complex medical needs

Summary: Cerebral palsy is complex and lifelong. Being involved with multiple professionals and services requires care coordination and good communication between families and caregivers, health professionals, specialists and service providers. This project aims to improve the tertiary care hospital experiences of children with medically complex cerebral palsy and their families and caregivers, as well as improve service delivery.

Project Team: Professor Christine Imms, Associate Professor Adrienne Harvey; Dr Susan Gibb; Ms Rose Babic; Ms Frances Hunter; Ms Gretta Jealous; Professor Dinah Reddihough; Dr Daisy Shepherd; Professor Rob Carter; Dr Gordon Baikie

Opening Eyes to the Experience of Vision Loss

Summary: While there is some research about the emotional and psychological impacts of vision loss, little has been done to evaluate how these factors influence people's behaviour. In particular, many people report not knowing how to navigate discussions about their condition when they are first diagnosed, or when their vision loss is still undetectable to others. This project aims to identify the support needs of people with early-stage vision loss.

Project Team: Dr Alexis Ceecee Britten-Jones, Associate Professor Lauren Ayton, Associate Professor Karyn Galvin, Mr Leighton Boyd, Mrs Rosemary Boyd, Ms Emma Bennison

Designing Learning Spaces for Diversity, Inclusion and Participation – Pilot Project

Summary: In Australia and internationally, evidence-based school facility design has not kept pace with inclusive education policies and agendas. Well-structured research and evaluation is needed to investigate how design can better respond to the complex needs of all primary and secondary students and support their effective participation in learning and in the life of their school. This project will explore a significant research gap regarding how best to accommodate students with disability in inclusive school settings. The ultimate objective of our planned multi-year research program is to ensure that students with disability—and indeed all students—are included and supported by educational facilities.

Project Team: Dr Benjamin Cleveland, Associate Professor Kate Tregloan, Associate Professor Christhina Candido, Dr Paul Loh, Professor Lorraine Graham, Professor Janet Clinton, Associate Professor Wes Imms, Professor Christine Imms, Professor Bruce Bonyhady

Experts of Experience: The Voice of the Client in Service Governance and Innovation in the NDIS. Step One: Participant Engagement Process

Summary: Our team is planning to apply for a large grant to examine the way choice and voice work for participants, their families and providers in the National Disability Insurance Scheme. As the first step in this process, we want to work with people with disability, their families and their representative organisations to codesign the larger project. We will focus on project design, how best to recruit participants, how to pay them for their time, how to balance the recruitment of different cohorts in the

sector, and how to recruit researchers with life experience of disability to work in the project once it is fully funded.

Project Team: Professor Mark Considine, Dr Carmel Laragy, Dr Raelene West

Health Justice Partnerships in inner city Melbourne: A lived experience evaluation by women experiencing psychosocial disability, domestic violence and legal problems during the COVID-19 pandemic

Summary: Although there is an increasing recognition of the need for integrated services for women experiencing domestic violence, there is no research exploring the lived experience of a Health Justice Partnership by women who are experiencing psychosocial disability, domestic violence, and legal problems. This project will address this research gap by focusing on Victorian women experiencing these issues during the COVID-19 pandemic.

Project Team: Dr Clare Glover-Wright BSc(Hons) PhD, Associate Professor Cathy Vaughan, Dr Jesse Young

Attitudes of Australian autistic communities to Applied Behaviour Analysis, Positive Behaviour Support and social skills interventions

Summary: The United Nation Convention on the Rights of Persons with Disabilities (CRPD) and Convention on the Rights of the Child (CRC) together declare that all children with diverse abilities, including neurodiverse children, have the right to dignity, autonomy and inclusion within their communities. In accordance with these international human right instruments, this project seeks to investigate the attitudes of children and young adults with lived experiences of autism towards three frameworks for autism intervention that are popular

within Australian schools: Applied Behaviour Analysis (ABA), Positive Behaviour Support (PBS) and social skills therapy.

Project Team: Dr. Matthew Harrison, Ms Jess Rowlings, Ms Stephanie Weir

Exploring approaches to build the self-advocacy capabilities of young job seekers with cognitive disabilities to engage in the labour market

Summary: Paid employment helps people meet a range of human needs including financial security, mental and physical health, belongingness, and a sense of meaning. However, many young people with intellectual and/or psychosocial disabilities experience complex barriers to gaining and maintaining employment. This project will build on the Youth Employment Study (YES) that aims to understand what helps young people find and maintain work.

Project Team: Dr Paul Jacobs, Dr Alexandra Devine, Associate Professor Cathy Vaughan, Ms. Stefanie Dimov, Ms Kristy De Rose, Ms Bella White, Ms Rhiannon Jones

Work-life in Wodonga: Co-design workshops for housing and work opportunities with people with disabilities in regional Victoria

Summary: This project will investigate relationships between inclusive and diverse medium-density housing and accessible neighbourhood infrastructure, highlighting what is necessary to enable, promote, and sustain work-life opportunities for people with disability in Wodonga.

Project Team: Dr Andrew Martel, Dr Kristen Day, Ms Mary Ann Jackson, Ms Saumya Kaushik

Additional Projects

Access to ABS's Multi-Agency Data Integration Project (MADIP)

MDI provided funding to ensure University of Melbourne researchers could access the MADIP data asset. First established in 2015, MADIP is a secure data asset combining information on health, education, government payments, income and taxation, employment, and population demographics (including the Census) over time. It provides whole-of-life insights about various population groups in Australia, including their use of services like healthcare and education, and outcomes such improved health and employment.

Cost benefit analysis on investing in disability in India

MDI partnered with the Nossal Institute to undertake a cost benefit analysis on investing in disability support in India. This work highlights the importance of practical, targeted and mainstreamed solutions for real world impact and ensures equitable participation in development for persons with disability and others at risk of exclusion.

This project also received support from the Department of Foreign Affairs and Trade (DFAT), the Indian Department of Empowerment of Persons with Disability (DEPWD) and the University.

Community-Based Research

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 eight projects to a total value of \$100,000.

Community Based Research Projects

Aspergers Victoria Incorporated - Teens Work Know How Program - for neuro-divergent students

The Aspergers Victoria Teens Work Know How program offers autistic teens in the mainstream school system with a positive and supportive pathway to work experience. This project will evaluate the impact of work experience, including the impacts on attitudes and understanding of host employers and their staff about autistic team members.

Amaze - One-to-one Peer Support Program for carers of Autistic Children with complex support needs

Amaze is the peak body for autistic people and their supporters in Victoria. This project will help determine the best models and frameworks for a new 1-to-1 peer support program targeted to the

primary carers of autistic children with complex support needs.

Barwon Disability Resource Centre - Community Diversion Pilot Program for Young People with a Disability

The Barwon Disability Resource Centre Community Diversion Pilot Program helps to divert young people with a disability away from the criminal justice system. This project will evaluate the effectiveness of the pilot to both improve practice and to share key learnings with the broader community.

BPD (Borderline Personality Disorder) Community - Meeting the Missing Middle with Relational Support

BPD Community is a grassroots, peer led, independent not for profit organisation dedicated to providing a voice for all members of the BPD community in

Victoria. This project will evaluate the model of relational support with a view to further developing peer support for people with BPD.

Disability Resources Centre - The Buddy Network

The Disability Resource Centre Buddy Network matches trained supporters who have lived experience of disability with others in the community waiting for individualised advocacy support. This project will evaluate the strengths of this innovative approach and the ways it could fill an important gap for many advocacy services.

Fragile X Association of Australia (FXAA) - Supporting the Fragile X community virtually: what works?

The Fragile X Association supports people who are impacted by Fragile X and works to raise awareness of Fragile X-associated disorders. This project will evaluate the effectiveness of their virtual support programs and activities and will help to inform the design, delivery and evaluation of future supports and activities.

Genetic Support Network of Victoria - Genetic Support Group Database

The Genetic Support Network of Victoria provides education, advocacy and support to people with genetic conditions and those who support them. This project will evaluate the usefulness of a database of support groups for those with rare and genetic conditions and explore ways to expand and improve support.

Keys of Life - Enabling all students with disabilities and their families to access and benefit from instrumental music lessons

Keys of Life trains instrumental music teachers to teach students with disability, connects families with trained teachers and creates a community where students, families and teachers can come together to share in and benefit from music. This project will examine the benefits of

learning an instrument for children with disability and explore the key features of a successful learning program.

Syndromes Without A Name (SWAN) Australia - Finding the Gaps

SWAN supports families with children who have a disability associated with undiagnosed or rare diseases. This project seeks to collect data to help to identify gaps and barriers in accessing services and supports.

VALID Inc. - Advocacy for Absolutely Everyone

The VALID advocacy program provides one-on-one assistance for a person with disability to help solve a problem. This project will look at key features and costs of successful advocacy programs that support people with complex needs and their families.

Collaborative Research

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.

Commonwealth Study into NDIS Plan Utilisation

Commissioned by: the Department of Social Services, Commonwealth Government

Project Team: Dr George Disney, Project Lead, Yi Yang, Research Fellow, Peter Summers, Research Assistant, Dr Adyya Gupta, Research Fellow, Dr Sean Byars, Research Fellow, Professor Bruce Bonyhady Co-Principal Investigator, Professor Anne Kavanagh, Co-Principal Investigator, Kirsten Deane (synthesis report)

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.

As a result, the Commonwealth Department of Social Services commissioned researchers from the University of Melbourne to conduct a project to look at utilisation rates in the NDIS.

The project looked at:

- How NDIS utilisation rates compared to other individualised funding schemes around the world
- How utilisation rates compared for different groups of participants in the scheme

- What factors influenced utilisation – what helped participants use their funding and what stood in the way?
- What interventions might help and what other evidence do we need to collect and consider?

This quantitative research carried out for this project focused on three groups - Culturally and Linguistically Diverse and First Nations participants as well as participants from low socioeconomic areas. The researchers looked to see if there were differences between participants, and to try and understand why some people may not use all their NDIS funds. Plan size, spending and utilisation for each group was analysed.

Instead of a simple descriptive comparison, the research method considered factors and variables that are important drivers of plan size and spending to ensure comparisons between participants were genuinely "like for like".

Findings:

Utilisation is not a particularly useful metric to measure the impact of the scheme. It is also important to consider drivers of NDIS plan size and spending individually, particularly if tracked over time. Future research needs to focus on outcomes people are able to achieve with their funding – particularly if the scheme is to address inequality for disadvantaged groups.

The NDIS Plan Utilisation Project (Victoria)

Commissioned by: the Victorian Government, Department of Health and Human Services (now Department of Families, Fairness and Housing)

Project Team (Qualitative): Dr Alexandra Devine, Dr Mediya Rangi, Ms Marie Huska, Ms Jody Barney, Indigenous Research Consultant, Professor Anne Kavanagh, Professor Bruce Bonyhady, Professor Helen Dickinson, UNSW, Dr Ashley McAllister

Project Team (Quantitative): Dr George Disney, Ms Yi Yang, Mr Peter Summers, Professor Anne Kavanagh, Professor Bruce Bonyhady

This mixed-methods project aimed to better understand how and why NDIS plan utilisation rates may vary amongst Victorian NDIS participants. It examined what helps or makes it hard for Victorian participants to use their funds to meet their needs and aspirations.

The **quantitative part** of this project looked at how and why utilisation rates varied amongst Victorian NDIS participants by examining:

- Inequities in plan size and spending amongst groups of participants already identified as experiencing disadvantage in the scheme. These groups included First Nations participants, participants from a Culturally or Linguistically Diverse background and participants with a psychosocial disability
- The impact of remoteness on plan size and spending
- The impact of prior experience of disability services on plan size and spending

The **qualitative part** of this project interviewed more than 100 NDIS participants and plan nominees between

April and December 2020 to understand their perspectives on what helps, and what makes it hard to use NDIS funds in a way that meets needs and aspirations.

The project focused on groups of participants that were reported to experience more difficulties navigating the complexity of the NDIS. This included participants with psychosocial disability, participants who identify as Culturally and Linguistically Diverse, and participants who identify as Aboriginal and Torres Strait Islander (First Nations).

The Tier 2 Tipping Point: Access to support for working age Australians with disability without individual NDIS funding

Commissioned and funded by: The Melbourne Disability Institute, the Brotherhood of St Laurence and Bapcare

Project Team: Dr Sue Olney, Research Fellow, Melbourne Disability Institute, Dr Amber Mills, Senior Research Fellow, Brotherhood of St. Laurence, Liam Fallon, Research Officer, Brotherhood of St. Laurence

The Melbourne Disability Institute, with the Brotherhood of St. Laurence and Bapcare, has been researching if and how working-age Australians with disability who are not NDIS participants are finding and using any support and services they need to participate in society and the economy. There are approximately 1.8 million Australians with disability in this group - 12 per cent of Australia's working-age population.

This research, conducted across three Australian states, combines data from multiple sources including surveys, focus groups and a desktop scan of the service landscape. It sheds direct light in the experiences of people with disability who are not NDIS participants, and their families and support networks, navigating

universal service systems. The project findings will be published in mid 2022.

Change starts with sport – the public and private benefits of inclusive community sport Disability Workforce Data Project

Commissioned by: The Melbourne Disability Institute

Project Team: Dr Sue Olney, Research Fellow, Melbourne Disability Institute, Alexander Oswald, Intern, MDI

Approximately 15 percent of people around the world have a disability and many experience isolation and marginalisation in their communities. In Australia, research reveals persistent gaps between people with and without disability in income, access to work, opportunities to participate in their community, safety, access to health and education, and participation in sport, recreation and leisure activities.

All of those gaps can compromise the physical and mental health of people with disability and limit their social and economic networks.

This project examines practical enablers and barriers to people with disability participating in local sport as players and in non-playing roles, and mutual benefits for people with disability, clubs and communities.

Victorian Government Disability Workforce Data Project

Project Team: Dr Sue Olney and Dr Paul Jacobs, Research Fellows, Melbourne Disability Institute

The Victorian Government has committed to increasing the number of people with disability employed in the public sector and set a disability employment target of 12 per cent of the public sector workforce by 2025. In 2020, the Victorian Public Sector Commission (VPSC) and the

Department of Health and Human Services (DHHS) commissioned the Melbourne Disability Institute to investigate evidence-based approaches to improve the Victorian Government's collection of disability-related data from current and prospective employees in recruitment and in ongoing collection of workforce data beyond 2021. The research was conducted in two stages, between October 2020 and April 2021.

Our findings were submitted to the VPSC in two detailed reports and presented at a range of meetings with key stakeholders across government. This research has underpinned changes to survey instruments and workplace culture across the Victorian public sector to encourage employees to feel safe in sharing disability-related information about themselves at work, and attracted interest from federal, state and territory governments around Australia.

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 research consortium, led by McMaster University, exploring demand-driven solutions to persistent marginalisation of people with disability in the labour market.

The aim of that 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.

National Disability Research Partnership (NDRP)

In 2021 the National Disability Research Partnership entered its second year. Hosted by MDI and funded by the Department of Social Services, the NDRP aims to facilitate a collaborative and inclusive disability research program that will build the evidence for successful innovation in policy and practice

The two-year establishment phase features six activities:

1. Establishing a research agenda to guide Australia's investment in disability research
2. Developing guiding principles to centre the lived experience of people with disability
3. Designing a governance model to best support the future NDRP
4. Establishing a guide for disability research
5. Developing a plan for rapidly improving
6. Supporting research done by and with people with disability

This year the major focus of NDRP was the delivery of a pilot research funding round, designed to fund vital disability research.

To be eligible for the pilot round, projects had to be carried out by and with people with disability, align with the NDRP Guiding Principles and address an area of demonstrated importance to people with disability.

The NDRP received over 120 applications and allocated more than \$1 million in funding.

The selected projects listed here involve academics, disability advocacy organisations, services and community organisations and cover a broad range of

areas that are important to people with disability:

- ['Bringing It Home': The exploration and co-design of consumer-led methodologies to understand lived experience of home and living within a National Disability Research Partnership.](#)
- [Co-designing Resources to Increase Access to Information and Services: Syrian and Iraqi people with disability from refugee backgrounds and service providers](#)
- [Designing a Continuum of Best Practices for the Inclusion of Students with Intellectual Disabilities in Higher Education](#)
- [Experiences of police apprehension for psychosocial disability: a co-designed investigation](#)
- [Giving voice to rural and remote First Nations NDIS participants who are Deaf or hard of hearing in the Northern Territory.](#)
- ["Saying who you are": Identifying best practice to support positive identities for LGBTQ people with intellectual disability.](#)
- [Stepping out in the world – the new adulthood for Gen Zs with Down syndrome](#)

- [Supporting the woman, supporting the mother: Examining the interface between the NDIS and family support services for mothers with intellectual disability in New South Wales](#)
- [The eternal child: When best interests are not in the best interests of young people with disability](#)

In December, the Australian Government confirmed the future of the NDRP, announcing funding of more than \$12.5 million for a National Disability Research Partnership (NDRP) over 2022-23 to 2024-2025.

This additional funding is a major milestone in achieving the vision of a world class disability research and policy hub. MDI is delighted to have played a part in its establishment.

Bringing It Home: The exploration and co-design of consumer-led methodologies to understand lived experience of home and living within a National Disability Research Partnership

Monash University, SDA Alliance, University of Melbourne, Social Ventures Australia, Griffith University

[Read more](#)

Co-designing Resources to Increase Access to Information and Services: Syrian and Iraqi people with disability from refugee backgrounds and service providers.

Deakin University, Settlement Services International, NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors, Victorian Foundation for Survivors of Torture (Foundation House)

[Read more](#)

Designing a Continuum of Best Practices for the Inclusion of Students with Intellectual Disabilities in Higher Education

The University of Sydney, Centre for Disability Studies, Flinders University

[Read more](#)

Saying No to Stigma: Identifying and supporting...

Experiences of police apprehension for psychosocial disability: a co-designed investigation.

RMIT, Victorian Mental Illness Awareness Council

Giving voice to rural and remote First Nations NDIS participants who are Deaf or hard of hearing: Northern Territory

NDRP



Research Support

Research Support

Scholarships

Supporting students to undertake a PhD is an important part of the work that the Melbourne Disability Institute does to foster collaborative, interdisciplinary research at the University of Melbourne.

Each year we allocate Australian Government Research Training Program scholarships to students whose interest in disability research aligns closely to our research agenda.

In 2021 we were delighted to welcome three new PhD researchers to our cohort.

[Marlies Wanasili](#)

Supervisor: Dr Cathy Said

[Kerry Britt](#)

Supervisor: Professor Christine Imms

[Heidi Peart](#)

Supervisor: Dr Piers Gooding

Education Support

Human Centred Mechanical Design

For the second year, MDI collaborated with Professor Graham Schaffer from the Melbourne School of Engineering to develop a new subject, Human Centred Mechanical Design. 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. The subject aims to give students 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, including a sliding adaptable mouse, a drinking glass holder, a portable and multifunctional chopping board and more.

Disability Research Community of Practice

As part of MDI's ongoing effort to support University of Melbourne researchers working in the field of disability, in 2019 we introduced a community of practice to:

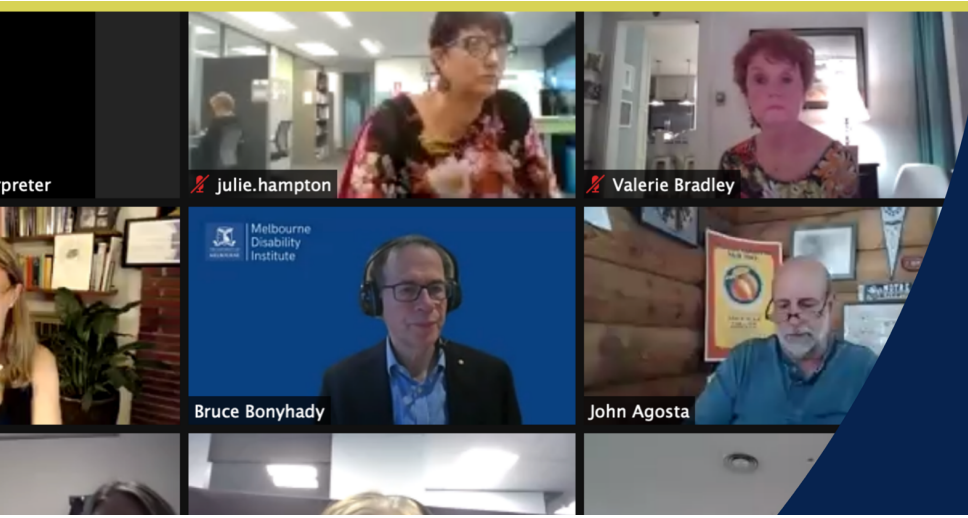
- Provide a forum to enable showcase research, share information (for example research findings, experiences, lessons learned, best practices) and problem-solve relevant to disability research
- Spark dialogue about disability, research and translation of research into practice
- Encourage collaboration within and outside of the University of Melbourne
- Develop, facilitate and mobilise resources for disability research
- Cultivate champions and facilitate connections between experts who might not otherwise interact

We continued this initiative in 2021 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 monthly sessions covered a wide diversity of topics from the experience of disadvantaged groups in the National Disability Insurance Scheme to the ongoing and disproportionate impact of the COVID19 pandemic on 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 2021, this coming year we hope to be able to hold some face-to-face sessions to open up new opportunities for networking and collaboration.



Community of Practice



Events and Activities

Events and Activities

MDI regards engagement on disability issues as central to our value in sharing knowledge. Extending our engagement with communities beyond the University is fundamental to increasing our impact and influence.

Communication

We use multiple communications channels and a variety of digital platforms to help carry out our mission to facilitate a collaborative, translational research program.



Conferences, Seminars and Events

Presentations and Conference Participation

At Risk: Older Women Experiencing Homelessness in Australia

Housing for the Aged Action Group
Presentation by Kirsten Deane,
Melbourne Disability Institute

Where to From Here (WTFH) Conference

A national conference for the disability sector
Presentation by Professor Bruce Bonyhady
and Kirsten Deane, Melbourne Disability
Institute

Reboot STEMM Conference

Presentation by Kirsten Deane,
Melbourne Disability Institute

**Australia and New Zealand Third Sector
Research Association and Social Policy
Lab****Webinar on the NDIS**

Presentation by Kirsten Deane,
Melbourne Disability Institute

Australian Social Policy Conference

The compounding burden of mutual
obligation

Panel session: Welfare policies as a
complex system disaster for women

Presentation by Dr Sue Olney, Melbourne
Disability Institute

**Community Mental Health Association
National NDIS and Mental Health**

Conference Examining the interface of the
NDIS and DES and its influence on the
right to work for people with psychosocial
disability

Presentation by Dr Sue Olney, Melbourne
Disability Institute, Dr Alexandra Devine,
Melbourne School of Population and
Global Health

**International Research Society for Public
Management (IRSPM) Conference**

Using data to promote equity in complex
networks

Presentation by Dr Sue Olney, Melbourne
Disability Institute

**International Centre for Classroom
Research (ICCR) research group**

The study of learning and teaching in
classrooms

Presentation by Matthew Harrison,
Graduate School of Education

**University of Melbourne Medical Student
Conference**

A discussion on the medical and social
models of disability

Presentation by Professor Bruce Bonyhady

and Kirsten Deane, Melbourne Disability
Institute

Occupational Therapy Australia

Presentation by Professor Bruce
Bonyhady, Melbourne Disability Institute

National Disability Services

Presentation by Professor Bruce
Bonyhady, Melbourne Disability Institute

**Joint Standing Committee Independent
Assessments**

Testimony by Professor Bruce Bonyhady,
Melbourne Disability Institute

**Senate inquiry on Independent
Assessments**

Testimony by Professor Bruce Bonyhady,
Melbourne Disability Institute

**Australian Disorders of the Corpus
Callosum**

Presentation by Kirsten Deane,
Melbourne Disability Institute

2021 Dinah Reddihough symposium

Grand Round: The Power of Expectation
Presentation by Kirsten Deane,
Melbourne Disability Institute

**Building a Local and Diverse Regional
Workforce - Activating Gippsland's
Renewable Energy Workforce Regional
Forum**

Presentation by Dr Sue Olney, Melbourne
Disability Institute

[Seed Funding Projects](#)**TRAM Research Showcase**

Presentation by Matthew Harrison and
Carmel Mesiti, Melbourne Graduate
School of Education

**MND Victoria and MND 10th Annual
National Conference**

NIV at Home

Presentation by Professor David Berlowitz,
Physiotherapy

**Musicological Society of Australia
Conference**

Using online music gatherings to support social inclusion for people with disabilities in Australia during the COVID-19 Crisis
Presentation by Associate Professor Grace Thompson, Melbourne Conservatorium of Music, Dr Anthea Skinner, College of the Arts

Australasian Society for Intellectual Disability Annual Conference

Reconnecting Online During Covid-19 Lockdown: Negotiating Creativity and Leadership in Online Music Gatherings
Presentation by Dr Anthea Skinner, College of the Arts, Professor Kat McFerran, Melbourne Conservatorium of Music

Australian & New Zealand Association for Health Professionals Conference

Embedding stigma reduction into the medical curriculum: a focus group study
Presentation by Dr Ashley McAllister, Melbourne School of Population and Global Health

2021 Housing Assembly Conference

Presentation by Erika Martino, Melbourne School of Population and Global Health

Allied Health Australia Virtual Conference 2021

Participant experiences with National Disability Insurance Scheme funded allied healthcare services during COVID-19

Presentation by Belinda Lawford, Physiotherapy, Professor Kim Bennell, Physiotherapy

[Hosted events](#)

Monthly Disability Research Community of Practice

10 sessions in 2021 with each session dedicated to project sharing or a featured guest speaker.

Two-Day International Initiative for Disability Leadership (IIDL) conference

A 2-part session dedicated to sharing innovations in disability policy, practice and research, networking and problem solving - across countries and agencies.

Two disability sector roundtables on proposed NDIS policy changes

A 2-part meeting to organise advocacy and a coordinated response on proposed policy changes to the NDIS

End of year panel discussion to mark the International Day for People with Disability

Kurt Fearnley, former Paralympian and host of ABCTV's One Plus One, moderated our end of year panel discussion with well-known disability advocates, El Gibbs, Dougie Herd, Damian Griffis and Professor Anne Kavanagh.

At a glance



\$6.3M

external
funding
2019-2022



30

research
publications



3

scholarships
allocated in
2021



\$220,000

allocated to
seed-fund
disability
projects



+3

new
research
fellows



31

new
external
partners



+609

new
followers
on Twitter



10

disability
research
community of
practice meetings



\$100,000

allocated to
community-based
research

Financial Statement

Income

Melbourne Disability Institute core funding	\$940,240
Strategic funding	\$330,000
Other	\$27,572
External income	\$1,105,824

Total: \$2,403,636

Expenditure

Directorate and core staff salaries	\$502,953
Admin, communications and general	\$55,205

Total: \$558,158

Research Enabling Expenditure

Salaries	\$834,686
Seed funding	\$422,437
Partnership development	\$39,742
Other	\$1,093,421

Total: \$2,948,444

Melbourne Disability Institute

disability.unimelb.edu.au

twitter.com/MDI_Uni

md-i@unimelb.edu.au