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, present and emerging.

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Sara Donaldson

Report Images:
In 2019 we launched a Diversity in Disability Image Competition to support photographers and images that depict the full spectrum of disability. After careful consideration, one grand prize winner and 13 finalists were selected from over 100 submissions by photographers across Australia. With so many well-crafted, impactful and diverse images to choose from; our job was not easy. We are pleased to showcase these images throughout this report.
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Letter from the Director

Throughout 2020 concern about the potential significant adverse effects of COVID-19 on people with disability added new urgency to the Melbourne Disability Institute’s continued mission and drive to facilitate high impact disability research to improve the lives of people with disability, their families and carers.

In the context of COVID-19, our key strategic themes – opportunity and equity, inclusive communities, health and well-being, markets and sustainability and policy and practice – were all very relevant, demonstrating the importance of a well-structured and adaptable Strategic Plan. We also continued to prioritise data and data access; interdisciplinarity; experience-based co-production with people with lived experience of disability; and active partnerships.

A highlight of the year was our COVID-19 seed funding round, which supported 17 projects responding to the pandemic by providing rapid evidence to inform policy or practice decisions. Funded projects focused on a wide range of COVID-19 impacts, from tracking and improving remote learning and service delivery for people with disability, to maximising social connectedness through online music gatherings and a new digital platform connecting carers, and looking at ways to build resilience and continue care for Aboriginal communities.

Another highlight was collaborating with the Summer Foundation to establish the Building Better Homes Campaign (www.buildingbetterhomes.org.au) to advocate for mandatory accessible housing standards and initiating key research to demonstrate that the benefits of accessible housing would exceed the costs.

We also commenced some ground-breaking research for the Commonwealth and Victorian Governments to analyse the utilisation of NDIS Plans for the Commonwealth and Victorian Governments. This research utilises both quantitative and qualitative methods and is expected to shed new light on why NDIS Plans are being used less than was expected.

Within the National Disability Research Partnership (www.ndrp.org.au), a national disability research and policy initiative led by MDI, we have achieved two major milestones: released a tender to develop
a national disability research agenda, and formed a working party, bringing together people with disability, academics and experience from government and industry, that will help steer the initial two-year establishment phase. This is a critical first step in ensuring a sustainable funding stream for disability research and innovation in Australia.

At the University of Melbourne there is a very broad and deep spectrum of endeavour, and MDI’s ongoing challenge is to enable and coordinate the bringing to scale of research that is inclusive, insightful and impactful. In 2020 we focused on supporting early-career researchers through our community of practice and PhD students through our scholarship program to build research capacity and support collaboration with the sector. By bringing together leading academics and stakeholders, we are working towards building a systematic and comprehensive knowledge base about the research and policy and practice interventions that offer the best benefits for people. MDI is also working to build capability through the establishment of ‘Disability Hubs’ in key Faculties, Schools and Departments, which are also designed to foster inter-disciplinarity.

In October we invited five community organisations that recently completed our Community Based Research program to present their projects, key findings and talk about the research partnership with the University. Spanning the impact of sport, building social connections, setting up micro-enterprises through to improving workplace skills, we heard about initiatives that are making a difference and the research that is delivering evidence of the positive impact on peoples’ lives.

Finally, we were pleased to celebrate the International Day of People with Disability with a free public webinar featuring a panel discussion around opportunities to reshape the landscape for disability research, policy and practice.

One of the adverse effects of COVID-19 was that the international work of MDI, became much more challenging.

As always, we pay tribute to the hard work of the executive team and the MDI core staff who support the vibrant disability research community at the University of Melbourne.

As we enter 2021, we look forward to working with our diverse partner and stakeholder community to identify new, collaborative and innovative ways to support the research and evidence needed to guide policy and practice reforms which will significantly benefit people with disability.

Professor Bruce Bonyhady AM
Executive Chair and Director
About Us

As one of the University of Melbourne’s five Interdisciplinary Research Institutes, the Melbourne Disability Institute’s mission is twofold – to build vision and greater activity across the University’s faculties and disciplines in disability-focused research, and to be a portal to the outside world for translating and disseminating disability knowledge that builds a platform for addressing the critical issues of our time.

MDI builds research capacity through fostering connections and collaborations, raising ambition, and supporting research activity and partnerships. MDI’s strong relationships with industry and government stakeholders and communities beyond academia seek to ensure research is accessible and imparts societal benefits.

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
Director, Melbourne Disability Institute

Professor Anne Kavanagh
Chair, Disability and Health
Academic Director, Melbourne Disability Institute

Dr Anna Arstein-Kerslake
Associate Professor, Melbourne Law School

Professor Brendan Gleeson
Director, Melbourne Sustainable Society Institute

Professor Lorraine Graham
Professor of Learning Intervention, Melbourne Graduate School of Education
Our team

As MDI entered our third year in 2020, our core strength remained our dedicated team of academic and professional staff, and the diverse and multidisciplinary community of scholars and external stakeholders who also call the Institute home.

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 sustained commitment to MDI’s purpose.

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

Dr Simon Wilkins
Director and Co-founder of Translating Research at Melbourne (TRaM)

Our team

As MDI entered our third year in 2020, our core strength remained our dedicated team of academic and professional staff, and the diverse and multidisciplinary community of scholars and external stakeholders who also call the Institute home.

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Professor Bruce Bonyhady, AM
Executive Chair and Director

Ms. Kirsten Deane
General Manager

Dr Sue Olney
Research Fellow, Policy

Ms Sara Donaldson
Engagement Manager

Mr Campbell Message
Program Manager
Team movements

In December 2020 Professor Anne Kavanagh stepped down from her role as Academic Director of the Melbourne Disability Institute to invest her time in building the size and impact of her own research program. We would like to thank Anne for her many significant contributions to the establishment of MDI. Anne has brought to her role as Academic Director her lived experiences of disability and a deep commitment to improving the lives of all people with disability, their families and carers. We also offer sincere thanks to Tessa de Vries for her tireless dedication and commitment to MDI’s mission. Tessa has stepped back from her role as Institute Manager to focus on the establishment of the National Disability Research Partnership, an MDI led initiative which will help drive a national disability research agenda and significant long-term investment in disability research.

At the end of last year our team farewelled Lishia Singh upon completion of her secondment with MDI. We would like to thank Lishia for her work on the NDIS Utilisation project, the NDRP as well as her help with shaping the most recent round of seed funding grants.
Research

MDI leads and facilitates highly impactful research initiatives that extend across the University, the Melbourne precinct, Australia and internationally. MDI’s research initiatives demonstrate a strong commitment to fostering enduring interdisciplinary connections with researchers from the University of Melbourne and other institutions, as well as with all tiers of government, industry, and partners from the community.

This year the Melbourne Disability Institute, like so many others at the University, had to pivot and quickly adapt to remote work. During this change we wanted to keep up our commitment to supporting research that bring positive impact for people with disability, their families and the disability service sector. We reached out across the university to see what COVID-10 related research was happening and what people thought were the pressing questions, and then opened a designated COVID-19 funding stream.

We were pleased to fund 17 outstanding projects which responded to the pandemic by providing rapid evidence to inform policy or practice decisions. Visit our website to see details of the COVID-19 projects here.
Seed Funding

The MDI Seed Funding scheme is intended to support small-medium projects at the discovery or pilot end of research and that are likely to have practical outcomes, involve strong partnerships and have a clear pathway to sustainable funding.

In 2020 we adapted the seed funding scheme to address an identified need, gap or deficiency in responses to COVID-19 which affects people with disability, their families and carers as well as rich collaborations with the disability and health sectors including advocacy groups, services and government. We were able to direct nearly $300,000 to fund 15 new projects designed to help support people with disabilities and their families and carers in the COVID-19 pandemic and beyond. Further, we supported 2 existing projects which have been amended to incorporate new information on the Coronavirus.

Funded projects focused on a wide range of COVID-19 impacts, from tracking and improving remote learning and service delivery for people with disability, to maximising social connectedness through online music gatherings and a new digital platform connecting carers, and looking at ways to build resilience and continue care for Aboriginal communities.

Seed Funded Projects

The impact of transitions to remote learning due to the COVID-19 pandemic response on Victorian school students with disability

**Lead researcher:** Manjula Marella  
Nossal Institute for Global Health, Melbourne School of Population and Global Health

**Team members:** Lisa Gibbs, Alexandra Devine, Matthew Harrison, Catherine Smith, Fleur Smith, Lana Logam

This project aims to investigate the impact of transitions to remote learning due to the COVID-19 pandemic response on Victorian school students with disability and their families.

**Objectives:**

- To explore the experiences of students with disability and their families as a result of the transitions to remote learning due to the COVID-19 pandemic response.

Disaster Recovery for people with a disability across the lifespan: a scoping review

**Lead researcher:** Lisa Gibbs  
Child & Community Wellbeing Unit, Centre for Health Equity, Melbourne School of Population and Global Health

**Team members:** Dana Young, Anne Kavanagh, Mary Sayers

**Partner organisation:** Children and Young People with Disability Australia

This project aims to conduct a rapid review of the literature regarding the
disaster recovery experience and needs of people with a disability, looking at the specific needs across age groups and life stages. In previous epidemics, disasters and major hazard events existing health, social and economic inequalities have worsened. The evidence also tells us that a significant number of affected people will have extended mental health, emotional and social difficulties, and this will be disproportionately felt by people with disabilities. A recent survey found due to COVID-19 families of a child with a disability are already experiencing negative impacts on child education, access to support workers and NDIS funding with reported mental health & wellbeing worsening overtime (CYDA, April 2020). The proposed scoping review will contribute to supporting this at-risk group by generating evidence-informed best practice recommendations.

Online Music Gatherings: Applying existing knowledge about music and connection to online groups

Lead researcher: Kat McFerran
Faculty of Fine Arts and Music

Team members: Grace Thompson, Anthea Skinner, Teresa Hall, Melissa Murphy

This project aims to examine the ways in which online music gatherings can respond to the additional levels of isolation and restriction experienced by members of the disability community during the COVID-19 pandemic. Since many disabled children, adolescents and adults engage in music making, listening, and singing in their everyday life, this project will offer a structure to scaffold social interactions with a new online community. The project team will partner with participants to evaluate how, when and why different types of online music gatherings might be of value.

Impact of COVID-19 on Disability Support Workers (DSWs) in Australia

Lead researcher: Ashley McAllister
Disability & Health Unit, Melbourne School of Global and Population Health

Team members: Anne Kavanagh, Helen Dickinson, Stefanie Dimov, Melissa Kavenagh

Partner organisation: University of New South Wales, Canberra

This study aims to describe and monitor the working conditions, and the health and well-being, of DSWs in Australia during COVID-19 to inform interventions to promote their health and well-being. This study is critical because COVID-19 created unprecedented conditions making DSWs at high risk of exposure and transmission of COVID-19 through their work (e.g. assisting with teeth brushing). Many DSWs also see other changes to their working conditions (e.g. reduced hours, less control, higher demands), which previous research (including articles from the research team) shows significant effects on mental health. We need evidence to ascertain the potential consequences for people with disabilities that DSWs support. We will rapidly translate survey findings into proposed key lessons that can inform how best to support DSWs during the COVID-19 crisis and other future crises to minimise the impact on DSWs and people with disabilities.

Risk of transmission of COVID-19 among people with disability and their support staff

Lead researcher: Anne Kavanagh
Melbourne School of Population and Global Health

Team members: This project was rolled into Ashley McAllister’s project above
People with disability often have underlying health conditions that make them more susceptible to serious illness or death if they contract COVID-19. They are at risk of contracting the virus if they have disability workers entering their living, working and recreational spaces, and they are less able to physically distance and limit exposure to others in close contact. Some live in congregate settings, further increasing the risk of exposure and spread. This project will collect data from people with disability and support workers to map networks of care. The findings could help governments and organisations plan to prevent and respond to outbreaks among people with disabilities and their workers and plan for risk of disruption to essential care and support if disability workers are infected.

Implementing early detection and intervention for infants with developmental disabilities via telehealth – educational resources for families and health professionals

**Lead researcher:** Alicia Spittle
Department of Physiotherapy

**Team members:** Abbey Eeles, Jeanie Cheong, Rod Hunt, Iona Novak, Catherine Morgan

**Partner organisations:** Royal Women’s Hospital, Royal Children’s Hospital, University of Sydney, Cerebral Palsy Alliance

Guidelines recommend infants at high risk of cerebral palsy and other developmental disabilities, such as infants born preterm or with brain injury, are monitored closely following birth with developmental assessments and referred to early intervention as needed. With face-to-face assessments restricted due to COVID-19, there are many infants and their families who may miss out on timely assessment and support. Our aim is to create an online education module for health professionals (health and disability sectors) on how to use telehealth to facilitate early detection for infants at risk of developmental disabilities, along with resources for families.

**The impact of the COVID-19 pandemic on early childhood intervention services in Australia**

**Lead researcher:** Tim Moore
Department of Paediatrics & Murdoch Children’s Research Institute

**Team members:** Susana Gavidia-Payne, John Forster, Kerry Bull, Janene Swalwell

**Partner organisations:** Royal Melbourne Institute of Technology, Noah’s Ark Inc., Monash University

With the onset of the COVID-19 epidemic, the Australian early childhood intervention (ECI) sector is facing an unprecedented challenge. Most ECI services have had to switch their mode of service delivery from home-based or clinic-based visits to various forms of telepractice, which has presented many challenges for families and providers alike. The aim of the proposed study is to examine the impact that the COVID-19 pandemic is having on ECI service provision and to provide guidance to families and providers on how to ensure effective support and maintain best practice, with a particular focus on their experience of telepractice delivery.
Continuing to care in the time of COVID-19: Evaluation of a communication and service delivery program for Aboriginal Australians living with disability from remote Northern Territory Communities

**Lead researcher:** Margaret Kelaher  
Melbourne School of Population and Global Health  
**Team members:** Dr Damien Howard, Libby Massey, Melinda Fajerman, Desireé LaGrappe, Jacob McCue, Elizabeth Willis, Rebecca McCue, Gayangwa Lalara, Joyce Lalara, Gwen Lalara, Julie Wunungmurra, Bronwyn Daniels, Olga Daniels, Vickerina Nganjimirra, Philippa Dalach  
**Partner organisation:** Machado-Joseph Disease Foundation

This project aims to address the needs of Aboriginal Australians living disabilities from remote NT. Travel to these communities has been banned due to COVID-19. Aboriginal Australians with disabilities are literally cut off from service providers. The overall aims of the project are to improve access to timely, accurate and culturally informed information and services to:

- Minimise deterioration in physical and mental health related to changed service delivery models;  
- Maximise service delivery and research capacity that is accessible, prevention focussed and addresses Aboriginal workforce needs;  
- Inform future health care policy and service provision.

The impact of the COVID-19 pandemic on the National Disability Insurance Scheme allied healthcare services and consumer experiences transitioning to telehealth

**Lead researchers:** Belinda Lawford  
Department of Physiotherapy  
**Partner organisations:** Griffith University, Murdoch Children’s Research Institute, Australian Catholic University, Deakin University

The aim of this project is to investigate how the COVID-19 pandemic has impacted National Disability Insurance Scheme (NDIS) allied healthcare services and consumer experiences transitioning to telehealth. We will conduct a survey to examine the experiences of adults and children with a disability receiving such care via NDIS during the pandemic, including the perceived safety, effectiveness, acceptability, benefits and limitations of telehealth delivery. This information will inform decision making around future funding of telehealth services by NDIS allied healthcare providers once the pandemic has ended.

Remote but Connected: a co-created digital platform to enable caregivers to support independent living for people with disability in the face of Covid-19.

**Lead researcher:** Lynette Joubert,  
Department of Social Work  
**Team members:** Nathan Grills, Greg Wadley, Wendy Chapman, Rod Carracher, Manjula Marella, Victoria Palmer, Penelope Pane  
**Partner organisations:** Yooralla
The COVID-19 pandemic is impacting people with disability highlighting a need to create alternative (remote) avenues for service delivery. Caregivers provide an important link to disability services. Our pilot intervention digitally links caregivers to resources and networks, as well as exploring pathways for linking people with disability to these resources.

This project aims to:

- To clarify the resource pathways caregivers access in supporting people with disability in independent living.
- To co-create a digital platform to improve caregiver access to these resources by carers
- To evaluate acceptability/feasibility of the digital platform for caregivers and people with disability.

Crisis resilience in people with multiple sclerosis (C-RIMS); immediate concerns during the acute and adjustment phase of the COVID-19 pandemic

**Lead researcher:** Claudia Marck  
Disability and Health Unit, Centre for Health Equity, Melbourne School of Population and Global Health  
**Team members:** Yvonne Learmonth, Brody Heritage, Lisa Gibbs, Assunta Hunter, Diana Walker, Petra Skeffington, Allan Kermode, Ingrid van der Mei, Lydia Frampton  
**Partner organisations:** University of Western Australia, Murdoch University, MS Australia

Following strong responses from the disability sector in relation to the potential impact of the COVID-19 pandemic the Australian Government endorsed the development of a management and operational plan. To address this pressing concern, our project aims to identify the impact of the COVID-19 pandemic on people with disabilities, using a case population of people with Multiple Sclerosis (MS). We will identify issues raised and experienced by people with MS and their carers during the COVID-19 pandemic and identify policy-relevant templates for healthcare implementation to address urgent needs through the adjustment and recovery phases of this pandemic.

**NIV @ Home**

**Lead researcher:** David Berlowitz  
Department of Physiotherapy  
**Team members:** Mark Howard, Liam Hannan, Nicole Sheers  
**Partner organisations:** Victorian Respiratory Support Service, Austin Health

People with COVID-19 are not the only ones who need a ventilator. Over 800 Victorians live well at home with non-invasive ventilation (NIV), most of whom have ventilatory failure secondary to their disability (motor neurone disease (MND), muscular dystrophies, spinal cord injury, etc). People with disabilities are understandably reluctant to attend the Austin Hospital to start NIV (usual practice) during the COVID-19 pandemic. NIV@Home will pilot whether using home NIV implementation and remote patient monitoring to substitute for day admissions and clinic attendance in people with disabilities is a feasible model for testing in a future, adequately powered, multi-centre study.
The impact of COVID-19 on service provision for children and young people following major traumatic injury: A longitudinal, qualitative study

Lead researcher: Sarah Knight
Developmental Disability & Rehabilitation Research, Murdoch Children’s Research Institute

Team members: Adam Scheinberg, David Amor, Vicki Anderson, Edith Botchway, Louise Harms, David Bowen, Nick Rushworth, Dianne Lucas, Beth Costa, Bruce Bonyhady, Jessica Pellow, Kajol Aegle, Rebekka Nies, Joanne Liparota

Partner organisations: Disability Care Australia, Brain Injury Australia, Spinal Cord Injury Australia, Transport Accident Commission

COVID-19 has led to rapid changes in service provision for young people with disability. In 2019, we conducted an environmental scan of leading national and international organisations from health, education, insurance and disability sectors to understand rehabilitation models for young people with disability due to major traumatic injuries. We are now presented with a unique opportunity to build on this work to examine the organisations’ responses during the acute, adjustment and recovery stages of the COVID-19 pandemic. Specifically, we aim to identify enablers, barriers, and best-practice innovative approaches to meeting the ongoing needs of young people with traumatic injuries.

Without targeted service provision, children with developmental disabilities and their families may be disproportionately adversely affected by direct and indirect effects of the COVID-19 pandemic (1,2). This project aims to mitigate the adverse effects of the pandemic on high-risk children with complex developmental disabilities at Royal Children’s Hospital (RCH) Department of Neurodevelopment & Disability (NDD) and embed longer-term implementation where benefits are demonstrated. We will use participatory implementation research methods to develop, implement and evaluate a system of telehealth and remote support, adapting service provision to the changing needs of children and families throughout the pandemic.

Developing a telehealth physical rehabilitation program for people with moderate to severe stroke using an integrated knowledge translation approach

Lead researcher: Cathy Said
Department of Physiotherapy

Team members: Coralie English, Emily Ramage, Elizabeth Lynch, Erin Bicknell, Dani Hitch, Natalie Fini, Kelly Bower

Partner organisations: University of Newcastle, University of Adelaide, Western Health
The aim is to develop a telehealth physical rehabilitation program for people with moderate/severe stroke. There is strong evidence that rehabilitation reduces disability in stroke. COVID-19 has led to restricted outpatient services and reduced access to rehabilitation for stroke survivors. There are challenges providing telehealth rehabilitation to stroke survivors with moderate/severe disability. Traditional rehabilitation for this population relies on physical assistance from therapists and specialised equipment. There are also safety considerations for stroke survivors and carers. There is an urgent need for an evidenced-based guide to providing safe physical rehabilitation via telehealth to people with moderate/severe physical disability following stroke.

Pathways for responding to conflict and high-risk behaviours in families: A feasibility study based on families living with a child/young person with autism

**Lead researcher:** Cathy Humphreys
Department of Social Work

**Team members:** Keith McVilly, Gemma Dodevska

**Partner organisations:** Amaze, Women with Disabilities Victoria, Siblings Australia, Centre for Excellence in Child and Family Welfare, Domestic Violence Victoria, Brotherhood of St Laurence.

This research aims to investigate the difficulties of familial conflict, high risk behaviours, and sources of support for families living with a child/young person with Autism Spectrum Disorder (ASD). This research will include the lived experiences communicated by family members as well as input from practitioners and managers within disability, family violence and autism services about their perspectives on responding to needs of families with ASD. It also seeks to better understand when support may be most important, across prediagnoses, diagnosis and beyond. The outcomes of this small-scale study may identify pathways for service development in this area, and further inform sensitive and appropriate service provision and interventions for families where there is a child/young person with ASD. The project has been amended to also investigate the impact of COVID-19 on family support and conflict.
**MDI Research**

The Melbourne Disability Institute leads and facilitates highly impactful research initiatives that extend across the University, the Melbourne precinct, Australia and internationally. MDI’s research initiatives demonstrate a strong commitment to fostering enduring interdisciplinary connections with researchers from the University of Melbourne and other institutions, as well as with all tiers of government, industry, and partners from the community.
MDI Research Projects

Housing Pathways Project

Author: Alicia Yon

For many Australians, access to suitable, secure, and affordable housing is a challenge. For people with disability, this is amplified. The National Disability Insurance Scheme (NDIS) is helping to change this as it provides tailored supports so that NDIS participants can access funding for activities of daily living, such as cooking, cleaning, and personal care. Being able to choose where to live and with whom to live are also an essential foundation for a normal life.

NDIS participants whose housing needs can only be satisfied through highly specialised housing have access to Specialist Disability Accommodation (SDA) funding. However, only about 28,000 NDIS participants out of an expected total of 500,000 participants (or six per cent) will be eligible for SDA. Since there are no detailed guides available on meeting the housing needs of the ‘other 94 per cent’, this group and its diverse housing needs is the primary focus of the MDI NDIS Housing Pathways project.

This guide is designed to help to start filling the current knowledge and information gaps on non-SDA housing options. We start with a four-step plan to help NDIS participants find a home that is right for them and then identify key questions, answers, and information sources to guide decision-making. The guides are written in a way which we hope will be accessible and easy to understand and enable NDIS participants to navigate the often-challenging pathway to finding a home that is right for them.

This project has been made possible through a collaboration with the Brotherhood of St Laurence and with the input of people with lived experience of disability.

NDIS Plan Utilisation

Lead researchers: Ashley McAllister and George Disney
Melbourne School of Population and Global Health
Team members: Anne Kavanagh, Bruce Bonyhady, Sean Byars, Alex Devine, Mediya Rangi, Adyya Gupta, Lishia Singh, Helen Dickinson
Partner organisations: Department of Health and Human Services, Department of Social Services, University of New South Wales

This project aims to provide a detailed description of the predictors of plan utilisation through sophisticated quantitative analysis of longitudinal NDIS data across Australia, investigate the reasons for the patterns of low utilisation through qualitative participant interviews in Victoria, investigate utilisation rates from comparable programs with individualised funding models in Australia and internationally, and develop recommendations for improving utilisation in Victoria and how policy interventions could be evaluated. This project has been amended to investigate the impact of COVID-19 on plan utilisation.
NDIS Plan Utilisation (Victoria)

Lead researchers:
Dr Alexandra Devine, Research Fellow, Melbourne School of Population and Global Health
Dr Mediya Rangi, Research fellow, Melbourne Disability Institute & Melbourne School of Population and Global Health
Ms Marie Huska, Research Assistant, Melbourne Disability Institute & Melbourne School of Population and Global Health
Ms Jody Barney, Indigenous Research Consultant
Dr Ashley McAllister, Research Fellow, Melbourne School of Population and Global Health

The National Disability Insurance Scheme (NDIS) Utilisation Project – Victoria aims to better understand how and why NDIS plan utilisation may vary between participants, with a specific focus on psychosocial disability, First Peoples and Culturally and Linguistically Diverse participants. The project utilised a mixed methods approach drawing on quantitative and qualitative data.

Acknowledging proposed changes to the NDIS, perspectives shared provide timely insights into the lived experiences of participants, demonstrating that whilst utilisation is influenced by individual level factors, it is equally impacted by factors occurring across the NDIS system, and, broader societal level concerns. The research found, that while overwhelmingly there are very significant benefits from the NDIS, utilisation was more effective for those with previous experience navigating disability systems as they were more readily able to access the Scheme; advocate needs and aspirations; and immediately utilise plans with existing services. Others required more time to learn how to navigate a complex system; identify and access required and available services; and build trusting relationships with workers that enabled further utilisations. These processes can be lengthy and are easily disrupted, especially for participants reliant on thin markets.

For all participants, effective utilisation was undermined by the limited availability of services and supports that meet diverse disability and cultural needs and aspirations. Whilst this is influenced by geographical distance, it speaks more broadly to the significantly short supply of skilled workers, therapists and professionals in the context of increasingly stretched and difficult to integrate mental health, aged care and disability systems. Finally, participants continue to experience systemic barriers to inclusion across multiple life domains (e.g. education) and systems (e.g. health). These factors intertwine to compound disabling environments, undermining capabilities and contributing to poorer health and well-being. All of which can make it very difficult to effectively utilise NDIS funding in a way that enables individuals to meet their needs and aspirations to fully participate in and contribute to their communities and for the NDIS to achieve its vision.

Governance and policy research

Lead Researcher: Dr Sue Olney, Research Fellow Melbourne Disability Institute

MDI’s research into commissioning examines how governments design, fund, oversee, evaluate and deliver services and support for people with disability and who is involved in that process, with the overarching aim of increasing choice and control for people with disability in that environment. This research threads
though the business of government in multiple jurisdictions and across multiple service systems, touching on direct and delegated decision-making about the use of public resources at national and regional levels, and at strategic, operational, and individual levels.

In 2020, conscious of long-term risks to people with disability posed by the COVID-19 pandemic, MDI worked with a range of research partners within and outside universities and in governments in Australia and internationally to contribute to policy and academic discourse in two key areas: employment for people with disability and individualisation and marketisation of disability support. This work included:

- research into the risk and potential public and private costs of labour market exclusion of people with disability post-pandemic, and possible policy solutions;
- contracted research and reports for the Victorian Government related to employment of people with disability in the public sector and more broadly;
- research into the governance, collection and use of data in complex service systems and its implications for access and equity; and
- research into public sector reform, outsourced service delivery, service interface and navigation, and implications for access and equity.

**Victorian Government Disability Workforce Data Project**

**Researchers:** 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. To monitor progress towards this target, it wants to accurately measure the percentage of the public sector workforce with disability. However, employees are not obliged to share disability-related information about themselves at work, and the percentage of Victorian public sector employees voluntarily disclosing disability is low.

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 project is being conducted in two stages, between October 2020 and April 2021. Our findings, drawing on literature and practice in Australia and overseas, will underpin development of targeted recommendations for action in the Victorian public sector and future research.
Community Based Research

There is an increasing need for organisations to ensure that their programs and practices are informed by and, ideally, grounded in, well-conducted, relevant, scientific research. The Melbourne Disability Institute’s Community-Based Research Scheme 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.

The Community-Based Research Scheme builds on the expertise of the Centre for Program Evaluation in the Melbourne Graduate School of Graduate Education and links a university researcher with the community organisation to help guide and undertake the research project.

Research support provided through the Scheme 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.

In 2020 we were pleased to support researchers to begin nine projects through our Community-based research scheme partnership, to a total value of $72 000.

Community Based Research Projects

UsherKids Australia Ltd | Understanding the needs of families of young children with Usher syndrome in Australia

By understanding the needs of young children with Usher syndrome and their families in Australia, service providers, educators and clinicians can be better informed to provide improved interventions, care and support. This has potential to make a impact on the long-term health and wellbeing outcomes of this under researched demographic. This project will include a series of in-depth case studies of Victorian families to determine what are the experiences of these children and their families and what are barriers and facilitators to best meeting the needs of these children and families.

Murray Human Services Inc. (trading as We Are Vivid) | Better Autism Services for Rural and Regional Victoria

We are Vivid’s focus on Day Services and Supported Employment (both of which have a strong capacity building emphasis) and seeks to better support the people it serves by not just maintaining, but significantly improving, those services. This project will involve a literature review of world’s best practice in the context of day care and supported employment services for people with autism and placing that knowledge in practical examples of what practice looks like at the point of service delivery.

Horses For Hope Limited

Horses For Hope uses equine assisted narrative therapy to improve the capacity of people significantly impacted by mental
health, abuse, trauma. Services are useful for a broad range of people including people with Autism. Through therapeutic interaction with various horses, people interact (not ride) with horses at different times in the progression of their therapy. This project will collect evidence to support the proposition that the Horses for Hope method can be taught to other mental health professionals and be easily implemented elsewhere. A significant increase in professional implementation of Horses For Hope methods supported by a growing evidence base could provide evidence of new methods whereby young people with mental health issues can be supported.

**Accessible Beaches Australia**

Beach-going is a way of life in Australia, but at the moment a significant segment of the community face barriers to accessing them. 1 in 5 people in Australian have some form of disability and, without support, many of those people will be prevented from fully enjoying the pleasures of the beach. But this is slowly changing. Accessible Beaches’ central mission is to make all patrolled beaches in Australia accessible for people with a disability. This project will measure the health and wellbeing impacts and barriers and facilitators that access the beach has for people with a disability. This will provide an evidence base to support Accessible Beaches' advocacy in support of beach accessibility and provide information to other organisations about the positive impacts of beach recreation on health and wellbeing outcomes for people with disability.

**Mansfield Autism Statewide Service**

Evaluating behaviour support services provided in-home for Victorian children with autism and their families under NDIS

Mansfield Autism Statewide Service (MASS) have been providing an in-home service to clients with Autism and their families since 1970. This project will undertake literature reviews of autism services and evaluation tools, then contrast with to an evaluation of the service. Tools will be developed to capture the colour and richness of the service with the aim of providing a cost benefit analysis of their service to be shared with funders and people with a disability and their families.

**Inclusion Melbourne | Electoral Inclusion and People with Cognitive Impairment**

In 2018, Inclusion Melbourne examined a range of worlds’ best practice strategies for boosting electoral inclusion. The 2018 ICanVote Campaign represents the combining of the best elements of this work, culminating in the icanvote.org.au portal, developed in easy English for people with cognitive impairment, and launched for the 2018 Victorian State election. This project will research and consolidate the past outcomes of policy work; develop a case for a scaled-up model for ICanVote; and develop a research report based on the review and a forum.
Ethnic Communities’ Council of Victoria | Raise Our Voices – Disability self-advocacy for CALD communities

Raise Our Voices plans to improve understanding of the disability service system for people with disability from culturally and linguistically diverse (CALD) communities. It aims to build voice, awareness of support pathways and ensure that disability services and the NDIS continue to respond and include the needs of CALD participants with disability, their families, carers and communities. This project will evaluate the effectiveness and impact of Raise Our Voices and its key undertakings:
- Building the skills of people with disability from CALD backgrounds through self-advocacy training workshops
- Establishing peer-led groups led by people with disability from CALD backgrounds.
- Improving awareness of quality service provision by developing an online CALD Disability Resource Hub which will manage and distribute an existing ECCV monthly NDIS e-newsletter.

Down Syndrome Victoria | Building Knowledge Project

Down Syndrome Victoria is partnering with Royal Children’s Hospital Department of General Medicine to demonstrate an approach for achieving positive health outcomes for children with Down syndrome and their families across Victoria by piloting the delivery of a specific Down syndrome clinic and family healthcare tool, co-designed with paediatricians, families and people with Down syndrome. This project will evaluate the experience of children with Down syndrome and their families. The overall pilot, which is funded through an Information, Linkages and Capacity Building grant will then be upscaled across Victoria.

A2K Media. The Disability Justice Lens

A2K Media hope to increase the economic participation of disabled creatives in the Australian Screen Industry, through researching the experience of disabled people and current attitudes in the sector. This will include the specific barriers, discrimination and inequity, as well as the solutions to these issues and suggestions for inclusive screen practice. This is part of a larger program to develop training modules to the broader sector of disability from a human rights perspective.
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 2020 we were delighted to welcome three new PhD researchers to our cohort.

Ludmila Fleitas Alfonzo

**Project:** Young Carers  
**Supervisors:** Dr Tania King  
**Project description:** This project aims to identify the causal pathways that contribute to poorer life outcomes among young carers. It will inform the implementation of programs and policies to support young carers, and in doing so, will reduce disparities and improve the economic, social, health and educational outcomes of this vulnerable group.

John Carey

**Project:** CycLink: Linking children and young people with disability to community participation in cycling  
**Supervisors:** Professor Alicia Spittle, Dr Rachel Toovey, Professor Christine Imms and Professor Nora Shields.  
**Project description:** This research will aim to develop and support inclusive cycling opportunities for children and young people with disability in the community.
Fellowships

In 2020 we were pleased to support two fellowships offered through the Melbourne Sustainable Society Institute’s Community Fellows Program. The program aims to support research that will lead to positive 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.

Brenna McIntyre
Kevin Heinze Grow

Academic Mentor: Jennifer Davidson
Exploring the use of non-verbal movement-based therapies for adults who experience a speech disability

James Houghton and Gabriele Rukas
Ethnic Communities’ Council of Victoria

Academic Mentors: Dr Mediya Rangi and Alexandra Devine
Health literacy of people with disability from culturally and linguistically diverse backgrounds: Impact of the pandemic

Disability Research Community of Practice

As part of the Melbourne Disability Institute’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 (e.g., 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 into 2020, holding monthly meetings which provided a forum for university researchers to present on their projects, answer questions from peers and colleagues and find out more about opportunities and disability research taking place across campus.

In 2020, the Disability Research Community of Practice became a home for researchers to discuss the impact of COVID-19 and the fact that there is a real danger that the needs of people with disability will be missed, mistaken or ignored. We were able to mobilise the community to address the need for a new
evidence base, as public policy scrambled to keep abreast of the pandemic.

Through regular meetings and discussions, we were able to help accelerate priority research and research translation and support a coordinated effort and response from the University.

Building on the success of the Community of Practice, we will continue to drive the Community of Practice into 2021, creating a platform for University of Melbourne researchers to become informally bound together by shared expertise and passion to improve the wellbeing of people living with disability through research, by gathering insights, building understanding and sharing knowledge.

**Research Translation**

The Melbourne Disability Institute offers support and research translation tools to help researchers think beyond traditional ways of producing and disseminating research to increase research integrity, uptake, and applicability.

**Policy and Practice Advice**

MDI facilitates the interaction between research and implementation to help identify the aims, stakeholders, main messages and strategies to best deliver policy and practice innovation and improvements for people with disability, their families and carers.

**Design and Data Visualisation**

There is an increasing demand for research to be presented in a visually engaging way, in order to make information accessible and have a high impact. MDI offers researchers assistance with report formatting and creating accessible, visual summaries of their projects. In 2020 we formatted 14 reports, designed 3 infographics and provided 2 one-page project briefs. We also created an accessible communications guide which was presented at the University’s professional staff conference.

**Disability Advisory Touchpoint**

Research agendas and results should be led by and communicated in partnership with people with disability. In order to maximise timely research during the initial COVID waves, MDI offered an advisory touchpoint made up of a small group of people with disability with extensive lived experience who could offer quick and constructive advice to researchers looking to fast track their research. The touchpoint is a tool for researchers (and any involved in the process) to keep research integrity through close and multiple contacts with people lived experience, as needed.

**Human Centred Mechanical Design**

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 attachable sporting hardware to everyday wheelchairs, unique and cheap design for getting clothes from inaccessible cupboards, solutions for accessing public transport and more.

**Academic Visit**

In 2020 MDI hosted Catalina Santa Cruz Leyton, Education Psychologist specialising in early childhood development and psychometry from the Centre of Educational Justice of the Catholic University of Chile. Catalina’s research weighed the outcomes of a longitudinal study that involves Chilean children with different levels of hearing or visual impairment who attend mainstream or specialised educational institutions. She connected with a broad range of stakeholders during her time with MDI.
Advocacy and Engagement

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.

COVID-19

Australians with disability are a vulnerable population in the COVID-19 pandemic because they are at elevated risk of morbidity and death due to underlying health conditions. This is frightening because:

- The health sector is under-prepared to meet the urgent health care needs of people with disability.
- The disability service sector will not be able to meet the care needs of people with disability.
- Information on what to do is not easily accessible. For example, some people may not understand why there is disruption to their usual daily care routines.

We joined with the Centre for Research Excellence in Disability and Health to produce policy recommendations to protect people with disability in Australia.

An important message about COVID-19 and people with disability
https://drive.google.com/open?id=10yY5g2vpm-BsX3QQoZnRoLaqp0AKcke7

Policy action to protect people with disability in Australia
https://drive.google.com/file/d/1zZD6DLk8ONPenvzjoQs8dvKkCFvalos_/view?usp=sharing

As part of our advice to governments, Professor Anne Kavanagh was appointed to the Commonwealth Department of Health Disability Advisory Group and Professor Bruce Bonyhady was appointed to the Victorian COVID-19 Disability Taskforce.
**Accessible Housing**

In 2020 the Australian Building Codes Board (ABCB) issued a Consultation Regulatory Impact Assessment (RIA) addressing a proposal to include minimum accessibility standards for housing in the National Construction Code (NCC). We joined with the Summer Foundation to initiate three important pieces of research in response to the Consultation RIS and to drive an advocacy campaign to deliver strong support for the inclusion of minimum accessibility standards. Ultimately our efforts culminated in the development of the Building Better Homes Campaign, a national campaign to ensure an accessible building code for all Australians. Our advocacy efforts are outlined below:

1. **Review of the Centre for International Economics (CIE) report**

   We engaged Mr Andrew Dalton, Director AdHealth Consulting (former Associate Professor, Deakin Health Economics, Deakin University) and Emeritus Professor Rob Carter, Deakin University (former Alfred Deakin Professor and Foundation Director, Deakin Health Economics) to advise on the economic credentials of a possible regulation to include minimum accessibility standards in the National Building Code.


2. **Survey of people with disability**

   We commissioned Dr Ilan Wiesel, Senior Lecturer in Geography at the University of Melbourne, and Dr Andrew Martel, Lecturer in Architecture, Building and Planning at the University of Melbourne, to survey people with disability to support Dalton and Carter’s economic analysis. Their survey received more than 1000 responses within 10 days. This survey report also includes the results from 40 interviews and adds valuable information about people’s experiences. This extra data aligns with the advice from the Office of Best Practice Regulation to include qualitative analysis in all Regulatory Impact Statements, particularly when important elements cannot be quantified or monetised.

   Read the survey results here: [https://disability.unimelb.edu.au/__data/assets/pdf_file/0019/3522007/Accessible-Housing-FINAL-REPORT.pdf](https://disability.unimelb.edu.au/__data/assets/pdf_file/0019/3522007/Accessible-Housing-FINAL-REPORT.pdf)

3. **Audit of accessible features**

   Dr Andrew Martel from The University of Melbourne Faculty of Architecture, Building and Planning contributed to an Audit of Accessible Features authored by the Summer Foundation and Latrobe University researchers.


MDI and the Summer Foundation prepared two submissions in response to the ABCB Consultation RIA which included key recommendations in favour of sensible minimum regulations which will, at long last, make housing accessible and Australia fairer and more inclusive.

**First submission: 31 August 2020**

**Second Submission: 8 October 2020**
Response to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Issues Paper

Employment

We worked with the Centre of Research Excellence Disability and Health on a response to the issues paper released in May 2020 by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. The paper invited information and discussion on the experiences of people with disability in employment.

Contributors to the response, published in August 2020, included Dr Alex Devine, University of Melbourne, Associate Professor Jennifer Smith-Merry, University of Sydney, Professor Anne Kavanagh, University of Melbourne, Professor Gwynnyth Llewellyn, University of Sydney, Professor Helen Dickinson, UNSW Canberra, Dr Nicola Fortune, University of Sydney and Ms Celia Green, UNSW Canberra, all from the Centre of Research Excellence in Disability and Health; Ms Stefanie Dimov and Ms Marie Huska from the Disability and Health Unit, Centre for Health Equity, University of Melbourne; and Dr Sue Olney, Melbourne Disability Institute, University of Melbourne. The report is available at https://credh.org.au/submissions-to-the-disability-royal-commission/


National Disability Data Asset

The National Disability Data Asset (www.ndda.gov.au) is bringing together administrative data sets with the aim of providing new insights through the data and research to improve the lives of people with disability. This is a very important initiative which is very complementary to NDRP and Professors Bruce Bonyhady and Anne Kavanagh are both members of the National Disability Data Asset Disability Advisory Council.
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Events

Remarkable Insights Panel
We were pleased to contribute to this panel, held by Remarkable through their Remarkable Insights Conversation forum, to talk about how schemes such as NDIS will be central for governments, businesses and communities as we focus on economic recovery. The NDIS, launched by the Australian government in 2013, provided the long-awaited change in the services and supports delivered for people with disability, enabling them to have greater choice and control. Professor Bruce Bonyhady spoke about this transformation, ‘The Greatest Nation Building Project on Earth’, and the enormous opportunities - providing significant job creation both for people with disabilities and the disability support workforce; stimulating digital innovation, creating new markets and the potential for new investment.

Community Based Research Showcase
In October we invited five community organisations that have recently completed the program to present their projects, key findings and talk about the research partnership with the University. Spanning the impact of sport, building social connections, setting up micro-enterprises through to improving workplace skills, we heard about initiatives that are making a difference and the research that is delivering evidence of the positive impact on peoples’ lives.

Imagining a New Way Forward: a panel discussion about the future of disability research, policy and practice
This free public webinar, held on the International Day of People with Disability, featured a panel discussion around opportunities to reshape the landscape for disability research, policy and practice and what the roadmap could look like to achieve a more inclusive society and economy which might make for a healthier, happier and more resilient Australia by 2030.

Professional Staff Conference
We presented on inclusive communication and provided practical tips to help make sure everyone can understand your messages and stay connected.
We need to invest in the careers of researchers and policy makers with disability

Ellen Fraser-Barbour & Professor Sally Robinson

It doesn't seem too much of an ambit claim to say we...

76 views 0 comments

Why the disability community can wake up in 2021 more optimistic

Dr. Scott Avery

Why the disability community can wake up in 2021 more optimistic that research and policy will serve...

55 views 2 comments

Harnessing partnerships to improve outcomes for people with disability

Professor Anne Kavanagh

Harnessing academic, advocacy, policy and industry partnerships to improve outcomes for people with...

87 views 4 comments
National Disability Research Partnership (NDRP)

We are pleased to be coordinating and leading the establishment of a new National Disability Research Partnership (NDRP). The National Disability Research Partnership vision is to facilitate a collaborative and inclusive disability research program that builds the evidence for successful innovation in policy and practice.

The Commonwealth government has provided seed funding to establish the NDRP. A two-year establishment phase is being guided by a working party and has five core deliverables:

- A national disability research agenda
- A governance model to support the long term NDRP
- Mapping and developing disability research capacity
- A practical guide to NDRP research
- Pilot projects designed to deliver new evidence and test the NDRP process and ability to deliver on its vision.

NDRP Principles


- High quality, collaborative research
- Recognise the knowledge of people with disability in research
- Value all forms of knowledge
- Build research capability

In 2020 we achieved three major milestones: formed a working party made up of people with disability, academics and independent advisors; released a tender to develop a national disability research agenda; and established a Disability Research Collection together with the Analysis & Policy Observatory.

We are pleased to have made the first steps in ensuring a sustainable funding stream for disability research and innovation in Australia and are now working on the governance consultation and the pilot projects.
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