



# COVID-19 RESEARCH FUND

People with disabilities are among those most at risk of contracting COVID-19 and experiencing the negative social, economic and health consequences.

The Melbourne Disability Institute, an interdisciplinary research institute at the University of Melbourne, has directed nearly \$300,000 to fund 14 new projects designed to help support people with disabilities and their families and carers in the COVID-19 pandemic and beyond. Further, we've been able to support 2 existing projects which have been amended to incorporate new information on the Coronavirus.

Funded projects focus 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.

The new way of delivering services virtually will be investigated through a range of projects looking at tele-health for family well-being, the impacts on early childhood intervention services, and providing resources for families and health professionals on early detection of infants with developmental disabilities.

**Academic Director of the MDI, Professor Anne Kavanagh said "the projects represent MDI's commitment to making a difference to the lives of people with disabilities through rigorous and relevant research during this unprecedented time."**

Other projects are tracking the impact of COVID-19 on disability support workers, collecting evidence for the use of non-invasive ventilators in the home, and mapping networks of care to help prevent and respond to outbreaks among people with disability and their support networks.

All projects that have been selected specifically 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.

Through this initiative, the MDI is hoping to encourage and support interdisciplinary projects with active partnerships with the disability sector to deliver evidence to support informed policy recommendations.

**"The COVID-19 pandemic has shown the virus to be pervasive and deadly to our most vulnerable" said Bruce Bonyhady, Executive Director of the Melbourne Disability Institute.**

**"We are hopeful this effort will help fast track research impact on policy to help people with disability, their families and carers."**

MDI will continue to take a research leadership role in this pandemic and beyond and looks forward to working with the community to see this happen.

For more information, please contact Tessa de Vries, Institute Manager at [tessa.devries@unimelb.edu.au](mailto:tessa.devries@unimelb.edu.au)

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## COVID-19 PROJECTS

- The impact of transitions to remote learning due to the COVID-19 pandemic response on Victorian school students with disability
- Disaster Recovery for people with a disability across the lifespan: a scoping review
- Online Music Gatherings: Applying existing knowledge about music and connection to online groups
- Impact of COVID-19 on Disability Support Workers in Australia
- Risk of transmission of COVID-19 among people with disability and their support staff
- Implementing early detection and intervention for infants with developmental disabilities via tele-health – educational resources for families and health professionals
- The impact of the COVID-19 pandemic on early childhood intervention services in Australia
- 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
- Crisis resilience in people with multiple sclerosis (C-RIMS); immediate concerns during the acute and adjustment phase of the COVID-19 pandemic
- NIV @ Home
- The impact of COVID-19 on service provision for children and young people following major traumatic injury: A longitudinal, qualitative study
- Extending tele-health and remote family well-being support for children with Neurodevelopmental Disability
- Developing a tele-health physical rehabilitation program for people with moderate to severe stroke using an integrated knowledge translation approach
- NDIS Plan utilisation (amended existing project)
- The impact of the COVID-19 pandemic on the National Disability Insurance Scheme allied healthcare services and consumer experiences transitioning to telehealth
- 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 (amended existing project)
- 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

# COVID-19 PROJECTS

## EDUCATION

### **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

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 include:

- 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.
- To investigate coping and adaptive strategies utilised by students with disability and their families with swift transitions and changes in pedagogical practice.
- To document learning and teaching methods and supports that students with disability and their families find useful for remote learning.

## WELL-BEING AND CONNECTEDNESS

### **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

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

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, and to whom.

## WORKFORCE

### **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

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

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.

## EARLY INTERVENTION

### **Implementing early detection and intervention for infants with developmental disabilities via tele-health – educational resources for families and health professionals**

Lead researcher: Alicia Spittle

Department of Physiotherapy

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 tele-health 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

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 tele-practice, 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 tele-practice delivery.

## **INDIGENOUS FOCUS**

### **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

Partner organisation: Machado-Joseph Disease Foundation

This project aims to address the needs of Aboriginal Australians living with 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.

## TARGETED RESEARCH

### **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

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

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

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.



## **Extending tele-health and remote family well-being support for children with Neurodevelopmental Disability**

Lead researchers: Kate Milner and David Amor  
Department of Paediatrics & Royal Children's Hospital

Partner organisations: Royal Children's Hospital, CanChild Centre for Childhood Disability Research in Canada, Australian Catholic University

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 tele-health and remote support, adapting service provision to the changing needs of children and families throughout the pandemic.

## **Developing a tele-health physical rehabilitation program for people with moderate to severe stroke using an integrated knowledge translation approach**

Lead researcher: Cathy Said  
Department of Physiotherapy

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.

## **NDIS AND NDIS MARKETPLACE**

### **NDIS Plan Utilisation**

Lead researchers: Ashley McAllister and George Disney  
Melbourne School of Population and Global Health

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.

## **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.

## **FAMILIES AND CARERS**

### **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 (existing project that has been amended)**

Lead researcher: Cathy Humphreys  
Department of Social Work

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 pre-diagnoses, 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.

### **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

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.