



The Department of Developmental Disability Neuropsychiatry (3DN) 2021 Annual Report



2021 The Department of Developmental Disability Neuropsychiatry Annual Report

**Our Vision: The highest attainable standard of
mental health and wellbeing for people**

UNSW Sydney

Rm 241 Biolink Building E25

UNSW Sydney NSW 2052 Australia

Telephone +61 2 9065 8076

Email dddn@unsw.edu.au

Website 3dn.unsw.edu.au

Cover Image Rock My World by Marie Tesoriero

Editors Rachel Roth, Julian Trollor & Daren Sirbough

Design Rachel Roth & Daren Sirbough

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About the Department

Introduction

The Department of Developmental Disability Neuropsychiatry (3DN) was established by the Chair of Intellectual Disability Mental Health in 2009. Core funding for The Chair is provided by the NSW Government, with contributions from both the Mental Health Branch, NSW Health, and Family and Community Services, Communities and Justice.

3DN sits within the School of Psychiatry and is part of UNSW Medicine. We champion the right of people with intellectual or developmental disability to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education and policy in the field of intellectual and developmental disability mental health.

Our Vision

The highest attainable standard of mental health and wellbeing for people with intellectual or developmental disability.

Our Mission

To improve mental health policy and practice for people with intellectual or developmental disability.

Our Guiding Principles

Human rights - People with intellectual or developmental disability have the right to the highest attainable standard of health and mental health care.

Equity in mental health care - People with intellectual or developmental disability have the right to equitable access to mental health services, delivered by an appropriately skilled workforce.

Excellence and academic leadership - As a centre of expertise, we provide high quality advice and promote excellence in clinical practice, research, education and policy

Innovation in health services - We translate research into practical benefit at the level of health systems and workforce capacity. We encourage the use of sound evidence in the implementation of new ideas.

Collaboration - We value the multidisciplinary context of our work. We actively engage stakeholders to share expertise and promote integrated systems in health and disability. We actively seek the participation of people with intellectual or developmental disability. We value our collaborations with carers and family members.

Ethical conduct - We act in accordance with professional and industry codes of conduct and practice, the human rights of people with intellectual or developmental disability, and the Guiding Principles in our Strategic Plan.

Chair's Report

Professor Julian Trollor

It is a privilege to be able to bring to you the 3DN annual report, for this, our thirteenth year. Once again, the challenges we have faced with lockdowns due to COVID-19, have been enormous. However, our dedicated staff and students have worked hard to ensure that disruptions to our projects and activities have been minimal. I am grateful for the dedication of 3DN staff and students, who are passionate about ensuring their work builds toward improvement in health policy and practice for people with intellectual or developmental disability.

Despite COVID-19, the year has been a very productive one in every respect. The sheer volume of work and activities conducted is testimony to staff and student efforts. In house, we have 14 active projects at 3DN itself and participate actively in multiple other external ones. The total value of our 3DN currently active projects is \$14.5 million AUD; with \$7.3 million AUD in new project and research funding awarded to 3DN in 2021 alone. The outputs have been many, including 39 journal articles, 8 policy submissions, and 23+ presentations of various types. One of my most cherished of the many things to happen at 3DN in 2021, is the employment of our first staff member with lived experience of intellectual disability, Tahli Hind. Tahli has used her skills and expertise to the benefit of so many projects. Whilst we have had many people with intellectual disability work in partnership with us, this is the first time we have had someone formally appointed to a 3DN university position. It represents the natural evolution of our emphasis on co-design, and we do hope we can continue to evolve this aspect of our work.

Once again we are very grateful to the Mental Health Branch of the NSW Ministry of Health for the core funding we receive from them. The continuity in core funding has been critical, enabling us to focus on the development of major components of our work, and allowing us to attract external funding to achieve the array of projects and deliverables we have today. We offer our sincere thanks also to the individuals and organisations who have partnered with us in projects and research, both in practical ways and through provision of funding. All of our work depends on external funding provided through project funding, grants and donations. Your ongoing support will enable us to play a critical role in addressing the substantial health inequality experienced by people with intellectual or developmental disability.

Professor Julian Trollor

Research Activities

The Year in Review

Project Name: Autism CRC Australian Longitudinal Study of Autism in Adulthood (ALSAA)

2014 – 2021 CRC Autism \$181,969

Project Team: Samuel Arnold, Sara Walker, Aishani Desai, Yunhe Huang, Julianne Higgins & Julian Trollor

Project Overview

The ALSAA is a longitudinal study of autistic and non-autistic adults, and their carers, aged 25+ years. The overall objective of the ALSAA is to identify and comprehensively describe the profiles of Australian adults on the autism spectrum and compare to a matched control group. Current longitudinal aims include

- Describe interval changes, and identify predictors, of mental health of adults on the spectrum and compare these with a control group
- Describe interval changes, and identify predictors, of quality of life for adults on the spectrum and compare these with a control group
- Examine the stability of autism symptomology overtime for autistic adults with and without intellectual disability
- Describe interval changes, and identify predictors, of carer/support person coping strategies, mental health and wellbeing
- Specifically, for adults with autism and intellectual disability, describe interval changes, and identify predictors, of mental and physical health
- Explore factors associated with healthy ageing for adults on the spectrum living in Australia compared to controls.

Overarching Project Milestones

- Comprehensive and unique profile of Australian adults with ASD through two longitudinal studies
- Use of longitudinal study data
- Utilisation of resources from ASD Connect Hub
- The output will train 12 PhD students, employ 6 postdoctoral fellows and generate 60 scholarly and additional lay publications (across multiple Autism CRC projects).

Weblink <https://www.3dn.unsw.edu.au/projects/australian-longitudinal-study-autism-adulthood>

Annual Report

Project was completed in 2021. The Annual Report at time of publishing was under embargo. The report can be found here <https://www.3dn.unsw.edu.au/projects/australian-longitudinal-study-autism-adulthood>

Project Name: Autism CRC Autistic Burnout

2020 - 2021 Autism CRC \$37,880

Project Team: Samuel Arnold, Julianne Higgins, Aishani Desai, Janelle Weise, Liz Pellicano & Julian Trollor

Project Overview

Autistic burnout is commonly described by autistic people – in everyday conversations, on social media (e.g., #AutBurnout) – but thus far neglected as a topic of academic research. An autistic self-advocate writes, “Burnout is an integral part of the life of an Autistic person ... Yet nobody, apart from Autistic people, seem to know about it” (Rose, 2018). Online accounts link autistic burnout to autistic ‘camouflaging’, or ‘putting on my best normal’. It is linked anecdotally to the high rates of associated health conditions. Yet lack of research on this topic means we know virtually nothing about its causes, correlates or consequences. This project seeks to put this right. Autistic and non-autistic researchers will co-produce an initial study using a Grounded Delphi Method (GDM) to understand autistic experiences of burnout and develop a working definition. We will use this definition to follow-up using ALSAA Wave 3 to explore risk factors.

Late in 2021 the project was a winner of the Autism CRC 2021 Achievement in Autism Spectrum Research Award – Inclusive Research Category.

Overarching Project Milestones

- Complete Phase 1 GDM Study
- Complete Phase 2 Survey
- Two journal articles
- Translational materials.

Annual Report Project was completed in 2021. The Annual Report at time of publishing was under embargo. You can find the report here

<https://www.3dn.unsw.edu.au/projects/australian-longitudinal-study-autism-adulthood>

Project Name: DET Mental Health Supports in Specialist Schools

2021, Victorian Government Department of Education, \$99,804.47

Project Team: Jenna Zhao & Julian Trollor

Project Overview

This project involves the design and development of e-learning modules for Mental Health Practitioners employed by the Victorian Government Department of Education and Training (DET) to specialist schools. This includes the development of five online learning modules, suitable for delivery in DET's Learning Management System, around the topic of mental health in children and young people with developmental disabilities. The work within this project forms part of the Mental Health Supports in Specialist Schools Initiative.

Overarching Project Milestones

- Content development for five e-learning modules on mental health in children and young people with developmental disabilities
- Design of interactive learning modules using e-learning authoring tools
- Provide resources to support the delivery of the professional learning content.

Annual Report

- Project is complete
- Created full text versions of all five modules
- Created Storyline files for all five modules
- User tested all five Storyline modules in DET's Canvas platform
- Added text-to-speech functionality to all five Storyline modules
- Collated resources to support the delivery of the professional learning content
- Launched all modules – including attending a PASS meeting to launch the modules
- 3DN is now considering how we can promote this work to other DET department.



Project Name: Extra Dataset projects

Years: Ongoing; Sponsor: None, unfunded

Project Team: Preeyaporn Srasuebkul, Adrian Walker, & Julian Trollor

Project Overview

3DN has been working on several other projects related to ID health.

Overarching Project Milestones

- Comparison of underlying causes of death for individuals with intellectual disability in disability in NSW, Australia, between NSW Ombudsman and Australian Bureau of Statistics (2020-ongoing)
- Examining the impact of ID labelling on health service trajectory (2019-ongoing).

Annual Report

- Manuscript for "Comparison of underlying causes of death for individuals with intellectual disability in disability in NSW, Australia, between NSW Ombudsman and Australian Bureau of Statistics" published in Journal of Intellectual Disability Research
- Manuscript for "Examining the impact of ID labelling on health service trajectory (2019-ongoing)" submitted and currently under revision for publication in PLOS One.

Project Name: Health profiles, health services use and transition to dementia in individuals with self-harm

Years: 2021-2023; Sponsor: Dementia Australia; Amount: \$75,000

Project Team: Simone Reppermund, Adrian Walker, Rachael Cvejic, Preeyaporn Srasuebkul, Brian Draper, Julian Trollor.

Project Overview Dementia and deliberate self-harm represent substantial public health burdens in the older population. However, the health outcomes, referral pathways and predictors of death are not well understood. Late-life depression has been linked to dementia and deliberate self-harm. The growing aging population, along with the high prevalence of depression in older adults has significant implications for the planning and equipping of health services to meet the needs of affected individuals. Depression is ranked as the single largest contributor to global disability and is a major contributor to mortality including suicide. In 2017, the highest age-specific suicide rate in NSW was among males aged ≥ 85 calling for urgent action to address the public health issue of suicide in older men. This research will reveal important targets for future detection, prevention, treatment and management, and it will further show avenues how to prepare the service system for the needs of this growing population.

Overarching Project Milestones

- Establish and characterise a population-based cohort of individuals with dementia and self-harm in NSW, including sociodemographics, physical and mental health comorbidities and related service use before and after self-harm. We will also explore the reverse relationship of self-harm being a predictor of dementia diagnosis by looking at people who self-harmed and subsequently developed dementia
- Determine predictors of death in people with dementia who self-harmed. Predictors of death include physical and mental health comorbidities, sociodemographics, and their interaction. We will also focus on factors indicating increased complexity including number of involuntary admissions to a psychiatric unit and severity of mental illness (indicated by frequency of admissions and treatment intensity)
- Build a large, linked dataset of people with dementia who self-harmed for future study, enabling investigation into 1. Costings of emergency department and inpatient stays and their predictors 2. Whole of health care and transitions, with linkage to other Commonwealth. Datasets.

Weblink <https://www.3dn.unsw.edu.au/projects/health-profiles-health-services-use-and-transition-dementia-individuals-self-harm>

Annual Report

- Project commenced mid 2021
- Directed Acrylic Graphs created
- Preparatory work for advocate group done
- Meet with steering committee and decide on cohort and analysis.
- Organise advocate group meetings
- Finished advocate group meetings (round 1)
- Analysis plan finalised
- Analysis for Aim 1 underway
- Advocate group meetings (round 2) finished.

Project Name: ID health Data Portal

2018-2021, NSW Health, NSW Mental Health Capacity Project

Project Team: Janelle Weise, Preeyaporn & Julian Trollor

Project Overview This project will create a web-based user interface (ID health data portal) to assist Local Health Districts and Specialist Health Networks in New South Wales to understand and respond to the mental health and health needs of people with intellectual disability in their area.

This interactive web-based tool will use the results of the linkage of multiple service systems data ('big data') to develop a regional profile of the demographics, health, acute care health service use and associated costs of people with intellectual disability. Whilst the linkage is retrospective, it identifies, at a population level, people with intellectual disability across New South Wales, and allows the development of a clear picture of the health and service needs of this group.

Overarching Project Milestones

- Preparation of the data for the web tool
- Consultation with key stakeholders on the key elements of the web tool
- Appointment of a web developer
- Work with web developer to design the web tool
- Complete user testing of the web tool
- Complete security testing of the web tool
- Collation of resources to assist in meeting the mental health needs of people with ID
- Launch web tool
- Evaluate web tool
- Peer review publications
- Final report.

Weblink

<https://www.3dn.unsw.edu.au/projects/using-big-data-develop-interactive-web-based-platform-inform-local-services-about-health-needs-people-intellectual-disability>

Annual Report

The ID Health Data Portal continues to be used by staff across NSW Health. Our evaluation of the Portal is ongoing.

Project Name: Intellectual Disability Mental Health (IDMH) e-Learning

2010 – Current, No current funding or Sponsor: Prior NSW Health, ADHC, FACS

Project Team: Jenna Zhao, Janelle Weise & Julian Trollor

Project Overview

This project is focused on delivering an online learning resource on intellectual disability mental health to those who provide support to people with intellectual disability. The e-learning site has separate portals for health professionals, disability professionals and carers. Each portal contains a comprehensive suite of online modules tailored to the different roles and learning needs of the group.

The project is currently focused on ensuring sustainability of the resource by transitioning the content to a new platform, Go1.

Overarching Project Milestones

- Develop new and maintain existing e-learning modules
- Refresh older e-learning modules
- Transition all e-learning modules to new platform
- Offer subscription packages and other bespoke training
- Milestones achieved: last 3 – 6 months
- Launched module for disability professionals on Supporting People with Intellectual Disability Who Come into Contact with the Criminal Justice System
- Provided our first subscription package to SANE Australia
- Explored the possibility of working with UNSW Short Courses to develop an IDMH Short Course
- Milestones to be achieved: next 3-6 months
- Launch dementia modules
- Explore opportunities for advertising modules
- Revise e-learning publication draft
- Areas for discussion (milestones, budget, scope)
- Exploring strategies to promote subscription packages and push bespoke training
- Continue to come up with strategies for e-learning in relation to a potential Centre of Excellence.

Weblink: www.idhealtheducation.edu.au

Annual Report

- Transitioned all e-learning modules to our new platform on Go1
- Designed and created a new informational website for ID Health Education
- Developed a subscription model for organisations interested in training their staff
- Offered bespoke training options and developed proposals for interested organisations, including Central and Eastern Sydney Primary Health Network, Cerebral Palsy Alliance and Unisson Disability
- Developed and delivered two webinars to GPs, doctors and other health staff in collaboration with NSLHD's Intellectual Disability Health Team
- Launched a module for disability professionals on Supporting People with Intellectual Disability Who Come into Contact with the Criminal Justice System
- Provided our first subscription package to SANE Australia.

Project Name: ILC IDMH Service Pathway Web-tool

September 2020 - September 2023 Department of Social Services ILC Mainstream Capacity Building
\$1,243,523 (GST excl.)

Project Team: Janelle Weise, Claire Eagleson, Jenna Zhao, Tahli Hind, and Dominique Abagi, & Julian Trollor

Project Overview People with ID are up to 4.5 times more likely to experience mental illness, and experience multiple barriers to timely and appropriately equipped mainstream mental health services. Our research shows that the mental health workforce is ill-equipped to meet this need, that staff have received little education about the needs of people with ID, and that at a systems level, there is poor delineation of responsibilities and interagency pathways between different government agencies. The siloing of health and disability services can result in blocked access and no clear referral pathway or collaboration between services. People with ID and their support networks also lack information about supports available, and when to access services.

A service pathway web-tool will be designed to i) target mainstream mental health services in NSW to promote collaborative approaches to service delivery for people with ID by guiding the development of localised, interconnected, and responsive services throughout a person's mental health journey and ii) provide tools for consumers to navigate the mental health sector.

Overarching Project Milestones

- Recruitment of staff and advisory groups
- Literature review: consultation with people with ID, support networks and NSW Mainstream mental health services to inform web-tool development
- Work with web developer to create web-tool
- Pilot the Tool (recruitment of three sites, training, implement evaluation)
- Evaluation of pilot data (engage stakeholders who have participated in the pilot, analyse data, use results to inform final design of the Tool)
- Implementation of the Tool (engage service directors, training, implement evaluation)
- Evaluation of the Tool and recommendations for national implementation of the Tool.

Weblink

<https://www.3dn.unsw.edu.au/projects/intellectual-disability-mental-health-service-pathway-tool>

Annual Report Stage 1 of the consultations with people with intellectual disability, their support networks, and mainstream mental health staff was completed and used to inform the web-tool content.

The web-tool has gone through multiple stages of development and is now nearing completion to start entering content.

- People with intellectual disability, support networks, and professionals have taken part in user testing at various stages of web-tool development
- The Project advisory groups have continued to provide advice around all aspects of the project.
- We are finalising methodology for the pilot which will begin in two Local Health Districts in early 2022.

Project Name: Improving palliative care services for people with an intellectual disability

2020-2023 Department of Health, \$1,140,914.38

Project Team: Julian Trollor, Meera Agar, Rachael Cvejic, David Currow, Rebecca Strutt, Claire Vajdic, Richard Chye, Preeyaporn Srasuebkul, Janelle Weise, Simone Reppermund, Tracey Szanto, Janeane Harlum, Irene Tuffrey-Wijne

Project Overview

Despite increasing rates of life-limiting conditions, people with an intellectual disability (ID) are under-referred to palliative care and there is currently no model of palliative care in Australia for services to meet their unique needs. Efforts to progress palliative care research in this area have begun internationally, but robust epidemiological data and a co-designed model of care to suit the Australian health care environment are needed. In this project, we will utilise a mixed-methods approach incorporating large linked administrative datasets and qualitative data to examine access to and the impact of palliative care for people with ID. We will consult nationally with people with ID, carers, and professionals, and will translate our findings into the co-design, trial and preliminary evaluation of a tailored model of palliative care for people with ID, to be integrated with existing primary and specialist palliative care services. We will also develop and launch a Toolkit to improve the accessibility and quality of palliative care services for people with ID nation-wide. Finally, we will establish a mechanism for improving the national data collection about people with ID receiving palliative care services, enabling benchmarking of service provision to this vulnerable group.

Overarching Project Milestones

- Creation of project reference group
- Ethics approval for linked data studies and consultation
- Linked data studies
- Consultation with people with ID, carers, service providers, and experts
- Co-design of new model of palliative care to meet the needs of people with ID
- Trial of co-designed model of care in South Western Sydney Local Health District
- Preliminary evaluation of model of care
- Production of Toolkit for model of care to be disseminated nation-wide
- Production of summaries of research findings for people with ID, carers, clinicians and health services
- Contribute to policy and legislative reviews as they arise over the course of the project.

Weblink <https://www.3dn.unsw.edu.au/projects/improving-palliative-care-services-people-intellectual-disability>

Annual Report

- Project Reference Group has been established and the first meeting held
- Ethics approved received for stakeholder consultations
- Commenced stakeholder consultations (both interviews, focus groups and surveys)
- Commenced systematic review and policy review
- Developing analysis plans for linked data.

Project Name: Making mental health information accessible for people with intellectual disability

July 2018 - Jan 2021, Mental Health Branch, NSW Ministry of Health. Part of Building Capacity in NSW Mental Health Services for People with ID project \$401,255

Project Team: Janelle Weise, Karen Fisher, Bronwyn Newman, Claire Eagleson & Julian Trollor

Project Overview

People with intellectual disability can experience communication difficulties, and these difficulties have been identified as a barrier to accessing and participating in health care. Accessible health-related information is important for supporting the best health outcomes for people with intellectual disability. The provision of Easy Read information, which adapts standard information into a briefer copy of the main points, is advocated as an important form of accessibility. There is a lack of research around the design and effectiveness of Easy Read material, and a lack of accessible information about mental health services. This project aimed to i) consult with people with intellectual disability and their support networks around the accessibility of health-related information and what Easy Read resources about mental health services are required and ii) develop and disseminate key Easy read resources for use in public mental health services within NSW.

Overarching Project Milestones

- Consultation with NSW public mental health services on the accessibility of their resources for people with intellectual disability including audits of i) resources provided and ii) priorities for Easy Read resources.
- Consultation with people with intellectual disability around accessibility of mental health information, resources required, and design
- Consultation with family and support persons around accessible information needs of people they support and how they help them to comprehend information
- Determine priorities for the development of Easy Read resources
- Inclusive consultation with CID members around how to best develop the resources for each priority area
- Draft Easy Read resources
- Consult with people with intellectual disability to evaluate and provide feedback on the resources
- Develop Easy Read Toolkit that will assist people i) to use the resources and ii) develop additional Easy Read material
- Launch and promote Easy Read resources
- Final report.

Annual Report

This Project was completed in 2021. Deliverables were met. 3DN remains in contact with Legal Aid regarding linking to their forensic easy read resources when completed.

Weblink <https://www.3dn.unsw.edu.au/projects/making-health-information-accessible-people-intellectual-disability>

Project Name: Measuring Outcomes That Matter: Conceptualising Contribution

2021 – 2023 Endeavour Disability Research 2021 Research Award \$ 79,981.35

Project Team: Samuel Arnold, Keith McVilly, Gigi Foster, Karen Fisher, John Walsh, Suzy Green & Julian Trollor

Project Overview

With initial funding from the Endeavour Foundation Disability Research Fund 2021 Research Award, we aim to achieve preliminary conceptualisation and development of contribution outcome measures. This work will challenge deficit-based paradigms and be pivotal in debates regarding NDIS assessments and funding.

Across three phases, contribution outcome measures will be produced including accessible versions. The first phase will use photovoice to gather the perspective of people with intellectual disability. The second phase will use Grounded-Delphi Method to gain stakeholder consensus on an operational definition of contribution. Phase three will use survey methodology to develop an assessment tool.

Overarching Project Milestones

- Ethics approval photovoice
- Photovoice workshop
- Photovoice gallery and data analysis
- Grounded Delphi Study
- Survey design and ethics
- Tool development
- Dissemination

Milestones achieved: last 3 – 6 months

- Ethics for photovoice component submitted

Milestones to be achieved: next 3-6 months

- Photovoice workshop
- Photovoice gallery.

Weblink <https://www.3dn.unsw.edu.au/projects/measuring-outcomes-matter-conceptualising-contribution>

Annual Report - Project recently commenced.

Project Name: NSLHD Intellectual Disability Mental Health: Specialist Team and Training Program

2020-2021, Northern Sydney LHD, \$119,660.24

Project Team: Jenna Zhao, Janelle Weise & Julian Trollor

Project Overview

The project involves the design and creation of education/training materials that builds capacity of general and mental health staff within NSLHD, as well as community managed organisations, working with people with intellectual disability. This includes the development of three one-day training sessions and the development and delivery of a one-day Train-the-Trainer workshop. Delivery and evaluation of the training materials is also part of this project. The work within this project forms part of the Intellectual Disability Mental Health (IDMH) Specialist Team and Training Program (STP).

Due to COVID-19, the project has expanded to include an online implementation of the program. The project team is involved only as consultants for the online implementation.

Overarching Project Milestones

- Design of three one-day training sessions
- Delivery of one, one-day Train-the-Trainer workshop
- Review and comparison of online and face-to-face resources
- Participation as consultants/experts in six Expert Reference Group meetings for the online implementation
- Participation in the development of a comprehensive evaluation
- Production of two podcasts
- Co-facilitation of three face-to-face workshops
- Evaluation of a sample of training deliveries involving different facilitators at different settings
- Provision of a final report that includes recommendations for continuous improvement.

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Project completed in 2021. All workshops were attended and evaluated. Final report was delivered.



Project Name: Predictors of breast screening in women with ID

Years 2021 -2022 Sponsor \$14,000 (WHRTN EMCR Research Fund)

Project Team: Janelle Weise

Project Overview Women with intellectual disability face systemic neglect in the Australian healthcare system and are less likely than the general population to undertake breast screening. Very little is known about how to make breast screening accessible for women with intellectual disability.

This project aims to: identify predictors of breast screening for women with intellectual disability, reach consensus on strategies for accessible breast screening for women with intellectual disability.

Overarching Project Milestones

- Data linkage – predictors of breast screening (July 2021 – January 2022)
- Delphi – consensus on strategies to enhance participation in breast screening for women with ID (February-May 2022)
- Final report – (July 2022)
- Milestones achieved: last 3 – 6 months
- Ethics approval
- Contact with Breast Screen NSW
- Literature review complete and written up
- Data analysis plan prepared
- Data analysis commenced.

Annual Report This new project funded by the WHRTN EMCR Research Fund aims to explore predictors of breast screening for women with intellectual disability, and reach consensus on strategies for accessible breast screening for women with intellectual disability. In 2021 key stakeholders have been engaged and preliminary data work has been completed.

Project Name: Provision of Easy Read information on public mental health services in New South Wales to CALD communities

July 2021 - June 2022, Mental Health Branch, NSW Ministry of Health. Total budget \$50,504 ex GST

Project Team: Janelle Weise, Claire Eagleson & Julian Trollor (3DN) and Lisa Woodland (MHCS)

Project Overview

People with intellectual disability can experience communication difficulties, and these difficulties have been identified as a barrier to accessing and participating in health care. Accessible health-related information is important for supporting the best health outcomes for people with intellectual disability. The provision of Easy Read information, which adapts standard information into a briefer copy of the main points, is advocated as an important form of accessibility. Individuals with intellectual disability from CALD communities face additional barriers to accessing information about mental health services and supports. Relying on family or friends as informal translators can be challenging or inappropriate in many situations, and can lead to inaccurate information being conveyed, conflicts of interest, and issues regarding confidentiality. This project aims translate the previously developed Easy Read information on public mental health services in NSW resources into languages most used in NSW (Simplified Chinese, Arabic and Vietnamese), utilising a consultation process to ensure cultural appropriateness and relatability.

Overarching Project Milestones

- Engagement with key stakeholders including Transcultural Mental Health Centre, NSW Refugee Health Service throughout the life of the project.
- Determine consultation and promotion plan
- Translation of the Easy Read resources and promotional materials
- Inclusion of culturally appropriate images
- Consultations with community members to review the comprehensibility, cultural appropriateness, and relatability of the resources with NSW public mental health services on the accessibility of their resources for people with intellectual disability including audits of i) resources provided and ii) priorities for Easy Read resources.
- Refinement of the resources based on feedback, final translation, and proofreading
- Inclusion of the resources on the 3DN Easy Read website and NSW Health website
- Promotion of the translated resources.

Annual Report

- The consultation and scoping stage of this project has been completed. We have consulted with a range of stakeholders who work with various CALD communities. They have advised on the most appropriate approaches for engaging community members to provide feedback on the resources during the consultation phase
- The resources are ready for translation and promotional materials are being finalised
- Despite delays in consulting with stakeholders due to Covid-19, we are now able to move forward with the next stages of translating the resources and facilitating community consultation.

Project Name: Reducing rates of potentially preventable hospitalisations for people with intellectual disability

Currently unfunded

Project Team: Janelle Weise, Preeyaporn Srasuebkul & Julian Trollor

Project Overview

This project aims to understand the rates and predictors of potentially preventable hospitalisations (PPH) for people with intellectual disability.

Overarching Project Milestones

- Compare the rates of PPH for people with intellectual disability compared to the general population.
- Identify predictors of PPH for people with intellectual disability.
- Articulate strategies for reducing rates of PPH for people with intellectual disability.
- Enhance ID health data portal to include data on PPH.
- Milestones achieved: last 3 – 6 months
- Preparing funding submission to NHMRC TCR on improving health of people with intellectual disability.
- Milestones to be achieved: next 3-6 months
- Continue to seek opportunities to fund this work. In particular how to fund work on predictors of PPH for people with ID.
- Areas for discussion (milestones, budget, scope).

Annual Report

3DN's Australian first research published in the Medical Journal of Australia found that people with intellectual disability are up to 4.5 times more likely to be hospitalised for conditions that could have been adequately managed in primary care or through prevention.

Potentially preventable hospitalisations are a marker of poor access to primary and community-based health care and are symptom of the systemic neglect faced by people with intellectual disability in the Australian health care system.

This study found that epilepsy accounted for the highest rates of preventable hospitalisations for people with intellectual disability. At a rate up to 25.7 times more than for the general population.

People with intellectual disability were also found to be up to three times more likely than the NSW population to be hospitalised for a vaccine-preventable condition.

Our research calls for systemic action to reduce the rates of preventable hospitalisation for people with intellectual disability. Including a national population health strategy for people with intellectual disability.

Project Name: Understanding the health and support needs of younger people with disabilities discharged from hospital to RAC.

Years: 2019-2022; Sponsor: Summer Foundation; Amount: \$402,190

Project Team: Rachael Cvejic, Simone Reppermund, Preeyaporn Srasuebkul, Brian Draper, Adrienne Withall, Tim Watkins, Adrian Walker, & Julian Trollor

Project Overview

Younger people living in residential aged care (RAC) typically have high clinical needs and experience activity limitations as a result of disability. It is well acknowledged that inappropriate placement in RAC (often due to a lack of other options) contributes to a number of significant issues for younger people in RACs, including social isolation, lack of appropriate recreational activities, and a lack of support to actively participate in everyday and community-based activities. The project utilises existing linked datasets (currently held by our team at 3DN) from which we are identifying the health, support needs and pathways of younger people with disabilities discharged from NSW hospitals to RAC from 2001-2015. We are using these findings to identify avenues to improve health outcomes for young people discharged to RAC from hospital, in line with recommendations made in the Royal Commission into Aged Care Interim Report. The project involves consumers and community members to ensure the work is relevant to the needs and wishes of younger people with disabilities.

Overarching Project Milestones

- Determine the pathways for younger people with disabilities to RAC. We will examine clinical and sociodemographic predictors of discharge from hospital to RAC
- Describe the health profile of younger people with disabilities discharged to RAC and compare this to a matched community-dwelling cohort
- Compare short-, medium-, and long-term outcomes following hospitalisation for younger people with disabilities discharged to RAC to those of a matched community-dwelling cohort (e.g., time to and rates of representation to the emergency department (ED) and/or readmission and risk of death)
- To build capacity through an ongoing partnership with the Summer Foundation. As part of a broader, ongoing program with the Summer Foundation we propose to establish a new linked cohort of all younger people living in RAC from the National Aged Care Data Clearinghouse, linking to other relevant datasets, including future potential to link to the NDIS.

Weblink <https://www.3dn.unsw.edu.au/projects/understanding-health-and-support-needs-younger-people-disabilities-discharged-hospitals-residential-aged-care>

Annual Report

- Analysis for Aims 1 and 2 finalised. Analysis for Aim 3 commenced
- Three advocate meetings conducted for feedback on work
- Substantial edits were requested by co-authors for first manuscript, these have now been incorporated
- Considering alternative funding options to Partnership application
- Begun planning new resources for health professionals and people with lived experience.
- First manuscript submitted.

Project Name: Understanding health service system needs for people with intellectual disability - ID Health Links

Years: 2017-2022; Sponsor: NHMRC \$ 1,216,388

Project Team: Simone Reppermund, Preeyaporn Srasuebkul, Elizabeth Nguyen, Peiwen Liao, Claire Vajdic, Sallie Pearson, Louisa Jorm, Rachael Moorin, Rebecca Reeve, Timothy Dobbins, Nick Lennox, David Harley & Julian Trollor

Project Overview

We are conducting the first whole-of-population, whole-of-health service study of service users with intellectual disability. Our multi-disciplinary team has conceived an innovative matched cohort design that will generate robust estimates of disease prevalence, health service use and costs. This cohort study will create the most comprehensive linked data set relating to the health profile of people with intellectual disability internationally and will develop a unique resource to examine their health and wellbeing and drivers of service use and costs. Further, it will inform sector and services development, particularly in the area of demands on sector components, prescribing practices, and preventative health access. The impact of the NDIS roll out will be evaluated, and the data used to inform policies and practices to improve the coordination between the health and disability sectors and to improve efficiency of services for people with intellectual disability. This unique contribution to public health knowledge will shape an approach to addressing the health inequalities experienced by people with intellectual disability and will therefore assist the Australian Government to meet its obligations to this population under the UNCRPD.

Overarching Project Milestones

- Profile the rates of health resource utilisation and associated costs for emergency presentations, hospitalisations, general practice (GP) consultations, non-hospital specialist and allied health visits, cardiovascular disease surveillance, and participation in cancer screening programs, and their predictors, for people with ID and compare these with a cohort of matched controls without ID from the NSW population
- Characterise the prescribed medicines use profile and their predictors in people with ID and compare these to the control group
- Evaluate the impact of the transition to the NDIS on health resource utilisation and determinants for people with ID
- Use a knowledge translation framework to identify interagency policy, services and professional implications of the findings, and engage our rich links with people with ID, advocates, service providers and government to mobilise responses to the health needs of people with ID.

Annual Report

We are currently working on a cohort profile paper and awaiting a data refresher.

PhD Projects

Cancer prevention, risk, care pathways, and outcomes in people with intellectual disability

PhD Student: Elizabeth Nguyen

PhD Supervisors: Claire Vajdic, Simone Reppermund & Julian Trollor

Short project description: The project aims to use linked data to assess cancer-related outcomes and service use in people with intellectual disability at a population-level, to bring to light factors that may contribute to the poorer outcomes experienced by the intellectual disability community due to cancer. Analyses will include comparisons of adults with and without ID to reveal differences in the pathway to cancer diagnosis, such as cancer screening utilization and type of diagnostic technique used. Treatment patterns will also be analysed, including time to treatment after cancer diagnosis, concordance with clinical guidelines, and prescribing practices. Continuity of care between oncology, general practice and specialist health services will also be explored.

Current state of the project:

- Preparing manuscript for publication
- Preparing dataset for future analysis

Future deliverables:

- Publication addressing end-of-life in people with intellectual disability
- Publication about cancer incidence in people with intellectual disability

Physical Health Profiles and Service use in Intellectual Disability - A Data Linkage Study

PhD student: Peiwen Liao

Supervisors: Simone Reppermund, Claire Vajdic, Julian Trollor, Rachael Cvejic

Short project description: The aim of this project is to explore epilepsy-related health service use and outcomes in people with intellectual disability in NSW. To achieve this aim, this project uses systematic review to assess the epidemiology of epilepsy in people with ID and how significant this condition is among other health conditions, then utilises a data linkage approach to examine the characteristics of, contributing factors for, and outcomes of health service use in people with ID and compare to a matched group of people without intellectual disability.

Current state of project and achievements to date: Oral presentations at 2019 ASID conference about the ongoing systematic review on prevalence/incidence of physical disorders in people with Intellectual Disability, 2019 ADR conference (4th International Conference on Administrative Data Research) about readmissions and ED presentations after one epilepsy admission for people with Intellectual Disability and 2020 IPDLN conference about the updates of readmissions and ED presentations after one epilepsy admission for people with Intellectual Disability.

Publication: Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability—a systematic review. PloS one. 2021 Aug 24;16(8): e0256294.

Two manuscripts submitted: Readmission and emergency department presentation after hospitalisation for epilepsy in people with intellectual disability: a data linkage study; Factors associated with acute care service use after epilepsy hospitalisation in people with intellectual disability & one manuscript in preparation: Mortality rate, risk factors and causes of death in people with intellectual disability and epilepsy.

Thesis draft.

Achievements in 2021: One publication: Liao P, Vajdic C, Trollor J, Reppermund S. Prevalence and incidence of physical health conditions in people with intellectual disability—a systematic review. PloS one. 2021 Aug 24;16(8): e0256294. Two manuscripts submitted, One manuscript in preparation. Thesis draft.

Current state of the project: Ongoing.

Future deliverables: 3 publications and thesis submission, February 2022.



Intellectual Disability, Mental Health and the interaction with the Criminal Justice System and Support Services

PhD Student: Julian Trofimovs

PhD Supervisors: Professor Julian Trollor, Professor Leanne Dowse

Short project description:

The aim of this project is to determine the health and service usage profile of a cohort identified as having an Intellectual Disability (ID) to have been in the Criminal Justice System (CJS) in New South Wales (NSW). This project will utilise a unique longitudinal data linkage dataset with a near population sized sample of people with an ID in NSW. This project will both profile who this cohort is, in terms of their ID diagnostic profile, CJS contacts and support service use, and how their pathways through the CJS interact with service and support agencies. In this way this project will explore the complex nature of life-course pathways through the CJS for people with an ID.

Current state of project and achievements to date:

After shifting my candidature to part-time one year ago, my fourth year has now been completed and the set milestones for the past year have been achieved. With the analysis for my thesis completed I am now in the process of writing up my dissertation and submitting manuscripts for publication. I have one article published in a peer-reviewed journal with a second currently under review and the third in the process of being finalised for submission for publication in the coming weeks.

Where the project is at & Future deliverables:

As of the beginning of 2022, my project is currently at the point where my analysis is completed, and I am submitting manuscripts for publication. These submissions include:

1. *'Using linked administrative data to determine the prevalence of intellectual disability in adult prison in New South Wales, Australia'* published in the Journal of Intellectual Disability Research Volume 65 issue 6 June 2021. <https://onlinelibrary.wiley.com/doi/abs/10.1111/jir.12836>
2. *'Disability support and reincarceration after a first adult prison custody episode for people with Intellectual Disability in New South Wales, Australia'* currently under review after resubmission following first round of reviewer's comments in the Journal of Criminology
3. *'Post-release community mental health support for prisoners with intellectual disability and serious mental illness and reincarceration in NSW, Australia'* manuscript drafted and being finalised with view to submission for publication in the coming weeks.

Further, I am in the process of writing up my discussion chapter, revising my background chapter to incorporate the more recent research published in the previous two years and writing sections connecting my three analysis chapters coherently together. The aim for 2022 is for the submission of my thesis in the second half of this year.

Pathways, predictors and impact of receiving an autism spectrum diagnosis for adults in Australia

PhD student: Yunhe Huang

Supervisors: Julian Trollor, Samuel Arnold, Kitty-Rose Foley

Short project description: This project aims to understand the pathways, experiences and psychological impact of receiving an autism spectrum disorder (ASD) diagnosis in adulthood for people living in Australia. This project will utilise a combination of Australian Longitudinal Study of Autism in Adulthood (ALSAA) and additional survey data to examine the process from first concern to receiving a diagnosis from the perspectives of autistic adults and carers, factors influencing age of diagnosis in adulthood, and compare the perceived psychological impact of ASD diagnosis between people diagnosed in childhood versus adulthood. This project will also involve a series of interviews to explore adults and carers' experiences of support during and after diagnosis from a variety of source including professional services, family, social relationships and online.

Achievements to date: Two manuscripts have been published based on data from this project. All data analyses have been completed.

Current state of the project: Ongoing.

Future deliverables: Manuscripts for publication in academic journals, lay summary for participants and participating organisations/service providers, doctoral thesis.

Access to Mental Health Services for Women with Intellectual Disability

PhD student: Erin Whittle

Supervisors: Karen Fisher, Julian Trollor

Short project description: This project is a mixed method study, which aims to investigate the experience of women with intellectual disability who have sought mental health support. It uses case study methodology to investigate the lived experience of women with intellectual disability and their networks who have sought to access services. It also uses large scale data linkage to interrogate the demographic profile of women with intellectual disability and mental health service use, as well as broader patterns of service usage among the group.

Achievements to date: Data collection complete; data analyses complete; final draft of thesis in preparation

Current state of the project: Ongoing

Future deliverables: Thesis; peer reviewed papers



Pine For Me
Marie Tesoriero 2022

Our People

Professor Julian Trollor



Professor

Professor Julian Trollor is a neuropsychiatrist and holds the inaugural Chair of Intellectual Disability Mental Health at the University of New South Wales (UNSW). He also heads the Department of Developmental Disability Neuropsychiatry within the School of Psychiatry at UNSW.

Julian is involved in diverse research programs including ageing and cognitive decline in intellectual disability, intellectual disability in the criminal justice system, human rights and healthcare in intellectual disability, and ageing studies in the general population.

Julian is also developing and delivering courses in mental health and intellectual disability and works with Government Departments at both State and Federal level to improve capacity to deliver psychiatric services to people with intellectual disability.

Dr Rachael Cvejic (née Birch)

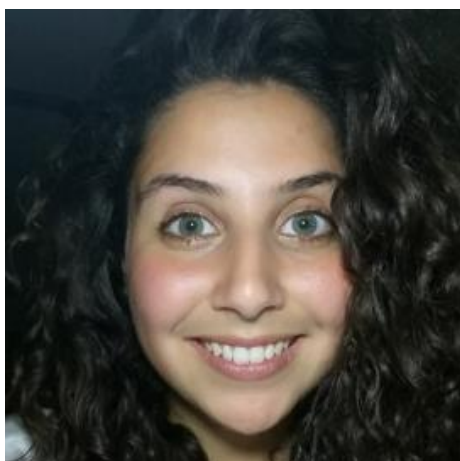


Lecturer

Rachael is a registered psychologist and early career researcher with broad research interests including neuropsychology and neuropsychiatry. Her clinical and research experience includes working with people with mild and major neurocognitive disorders, intellectual and developmental disabilities, and inherited neurodegenerative disorders including fragile X-associated tremor ataxia syndrome and Huntington's disease. Rachael is currently involved in a number of educational and research activities at 3DN, with a focus on health service use of people with less common types of dementia; hospital presentations for self-harm in people with mental health and drug and alcohol comorbidity; preventable disease burden in people with psychotic disorders; intellectual disability mental health; mental health workforce capacity.

Qualifications:

Bachelor of Psychology (Honours); Master of Brain and Mind Sciences; Ph.D.



Dominique Abagi

Project Officer

Dominique is a Project Officer contributing to the development of a mental health web tool with and for, persons with intellectual disabilities, their support networks, mental health professionals and other health and disability professionals. She is a graduate of a Bachelor of Arts, Psychology and is currently studying a Master of Public Health while completing accreditation as an ABA therapist.

She has worked and volunteered widely in the disability sector. In particular, as a support worker, as an aide in a Special Education School and has assisted in developing an Indonesian NGO's vocational training program for persons with disabilities.

Rooted in these experiences, Dominique has a passion for improving health opportunities and community accessibility for persons with disabilities. And hence, hopes to address health inequities experienced by people with disabilities through the intersection of practice, policy, and research.



Dr Samuel Arnold

Postdoctoral Research Fellow

Sam is a Postdoctoral Research Fellow in Program 3 of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), the world's first national, cooperative research effort focused on Autism. He is a registered psychologist with a background in supporting adults with intellectual disability, acquired brain injury or dual diagnosis in community settings. He formerly worked as a Research Fellow at the Centre for Disability Studies (CDS), University of Sydney. He completed his PhD in 2016 on the "Measurement and Conceptualisation of Support Needs".

In 2008 Sam won the Branko Cesnik Scientific Award for best scientific paper at the Health Informatics Society of Australia (HISA) Conference and in 2011 won the Inaugural Bob Weaver Award for presentation with most passion and promise at the Professional Association of Nurses in Developmental Disability Australia (PANDDA) Conference. His research interests include autism, intellectual disability, disability, mental health, assessment and models of service delivery.



Ms Claire Eagleson

Project Officer

Claire has a background in psychology and is currently working as a Project Officer managing various 3DN projects. Current projects include consultation with people with motor neurone disease and their care-partners around linked mental health data, and the development of Easy Read materials for people with intellectual disability utilising the mental health system. Her projects have included the development and implementation of the Intellectual Disability Mental Health Core Competencies Framework manual and toolkit; a national curriculum audit of intellectual disability content taught in Australian medical and nursing schools; and a project with the Royal Australian and New Zealand College of Psychiatrists examining workforce and future training capacity in the area of intellectual and developmental disability mental health.

Qualifications: BPsych (Hons); MPsych (Clinical), The University of NSW.



Tahli Hind

Project Administrator

Tahli Hind is a Project Administrator at 3DN. She has a lived experience of intellectual disability (ID) and mild cerebral palsy. Tahli took part in the 2-year uni 2 beyond program at The University of Sydney, run by the Centre of Disability Studies, in which she participated in health and music subjects. Tahli has also accomplished multiple TAFE courses in business administration. After completing her HSC in 2010, Tahli undertook the Arrowsmith program, a brain development course, over four years.

Tahli has completed advocacy work for the Centre for Disability Studies around uni 2 beyond as well as the 3Bridges Arrowsmith program.

Currently Tahli is working on the Intellectual Disability Mental Health Service Pathway Tool project, assisting the team to develop Easy Read information and documents to ensure the website is accessible for people with ID. Tahli feels that people with ID have the right to access quality health services and information that they need no matter what their challenges may be. She feels she can bring her own experiences to this role and likes seeing people benefit from the work that she does.

In her spare time, Tahli is passionate about sport and a keen para-rower.



Julianne Higgins

Peer Researcher

Julianne Higgins is an experienced autistic advocate and peer-researcher. Julianne was late diagnosed at the age of 62. She brings diverse rich experiences to her research, having lived in various cultures, worked as an artist, as well as various professional and unskilled endeavours, she also spent twenty + years studying at university at both undergraduate and post graduate levels across academic disciplines/faculties. The focus of her Masters' Degree, incomplete due to onset of ME/CFS, was on Anxiety Disorders, Counselling and Stress Management. A background in philosophy, psychology and meditation

complemented her academic work and her voluntary work with Griefline and Beyond Blue. She is an Alumna of Autism CRC Research Academy 2015, to which she was an Autistic Advisor for the Inaugural Workshop. She has been an advisor to the ALSAA study for several years. Since 2016 Julianne has presented at several autism conferences, covering areas of Diagnosis, Co-Existing Conditions, Health Care, and most recently at APAC2019 on Participatory Inclusive Peer Research and Co-Production.



Mr Daniel Pua

Administrative Assistant

Dan provides admin support to the Department of Developmental Disability Neuropsychiatry. He also takes care of administrative duties relating to the Clinic for the Assessment of Neuropsychiatric Disorders in Intellectual Disability (CANDID) as well as the Successful Ageing in Intellectual Disability (SAGE-ID Study). Dan has a key role in the department's multimedia portfolio, maintains the 3DN website, assists in a number of projects and provides limited tech support to the department.



Dr Simone Reppermund

Senior Research Fellow

Dr Simone Reppermund is a UNSW Scientia Fellow within the School of Psychiatry. Her area of research is cognitive disorders with a focus on mental health and ageing. Simone has a PhD in Psychology and worked previously in the field of depression and cognitive function at the Max Planck Institute of Psychiatry in Munich until 2008 before she moved to Australia. From 2008-2014 she worked as a research fellow at the Centre for Healthy Brain Ageing, UNSW Australia, where she managed a large longitudinal study (Sydney Memory and Ageing Study) combining neuropsychological, medical, environmental and genetic components to identify risk factors for cognitive decline. Her research interests include depression, cognitive impairment, everyday activities in old age, successful ageing and mental health in intellectual disability.

Qualifications: Dipl.-Psych., PhD



Ms Rachel Roth

Administrative Officer

Rachel Roth provides administrative & finance support to the Department of Developmental Disability Neuropsychiatry.



Dr Carmela Salomon

Project Officer

Carmela Salomon is a 3DN Project Officer working on a range of initiatives to support responsible psychotropic prescribing and cardiometabolic health in people with intellectual disability. Her PhD research (completed in 2014) explored mental health consumer experiences of antipsychotic discontinuation. Antipsychotic discontinuation is associated with a number of potential side effects including sleep disruption and other physical, cognitive, emotional and psychotic withdrawal syndromes. As well as collecting novel first person characterisations of these syndromes, her research focused on identifying coping strategies and suggestions for mental health service change from people with lived experience of medication discontinuation. In addition to a PhD in Health Sciences, she holds a Post-Graduate Diploma in Advanced Mental Health Nursing and a Bachelor of Nursing Science. Carmela has clinical experience in community and inpatient mental health settings and is passionate about increasing consumer input in mental health research and system management.

Qualifications: PhD (UoM); PGrad Dip Advanced Clinical Nursing- Mental Health (UoM); Bachelor of Nursing Science (JCU)



Dr Preeyaporn Srasuebkul

Senior Data Analyst

Preeyaporn's training and research is based on biostatistics and pharmacoepidemiology. As a Senior Data Analyst at 3DN, she is mainly involved in the Intellectual Disability Mental Health Data Linkage Project of the department. Preeyaporn is providing consultation on data collection, data management and statistical analysis for the project.



Dr Adrian Walker

Research Assistant

Adrian is a research assistant studying the experience of young people with disability in residential aged care and addressing preventable disease burden in populations experiencing psychosis. Adrian completed his Bachelors in Psychological Science (Hons, Class I) in 2015, and is currently awaiting the award of his PhD in Cognitive Science (both from UNSW Sydney). Adrian has also worked coordinating the School of Psychology Peer Mentoring Programs, and as a data analyst in the School of Psychology. Adrian is passionate about improving the experience of people with disability in the healthcare sector and equipping medical professionals with the tools to make better decisions regarding disability.



Ms Sara Elsie Walker

Project Officer

Sara Elsie Walker is a 4th Year Psychology graduate with a keen interest in Autism research. She has worked as an in-school aide for students with High Special Needs, including Autism Spectrum Disorder, Intellectual Disability, Obsessive Compulsive Disorder and Anxiety. From this role, she developed an interest in the mental health of autistic people and a passion for understanding and accommodating their differences. She would like to contribute to making the world a kinder and more hospitable place for everyone who feels different.

Ultimately, she is interested in pursuing Clinical Psychology and would like to use her research experience as a platform for informing her work as a clinical practitioner in the future.



Dr Tim Watkins

Data Management Officer

Tim recently completed his PhD in biostatistics (graduating in December) at the University of Sydney and the George Institute for Global Health. He sought potential new ideas to improve the quality of health intervention research, focusing on the concepts of causal inference, research bias, decision making and uncertainty. A deeper understanding of the cognitive factors underlying analysis decisions, research conclusions, and the reporting of results suggested strategies that may reduce the proportion of research with false or overconfident findings. Tim is now applying these insights and his experience as a biostatistician to a number of data linkage projects at 3DN. Prior to the PhD, Tim completed a Master of Biostatistics through the University of Sydney and delivered by the Biostatistics Collaboration of Australia. During this time, he also worked as a database manager, programmer and website developer at the Royal Prince Alfred Hospital Allergy Unit.

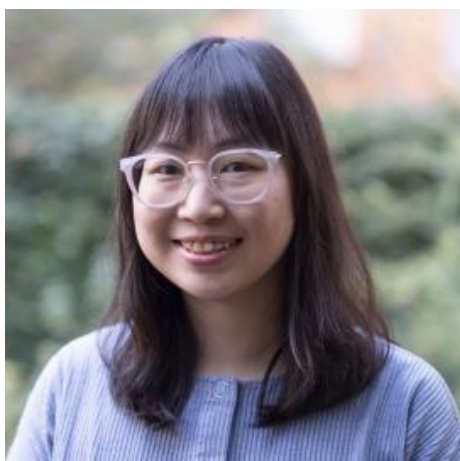
PhD Thesis Understanding uncertainty and bias to improve causal inference in health intervention research.



Dr Janelle Weise (née Govett)

Lecturer

Janelle Weise is a Lecturer working on a range of initiatives to enhance the capacity of the health and mental health workforce to deliver accessible, effective and efficient healthcare to people with intellectual disability. She has a Bachelor of Applied Science (Occupational Therapy) (Hons) and a Masters of Public Health and has worked across clinical, service delivery and managerial roles within the disability and health sectors. Janelle is passionate about addressing the inequitable access to healthcare and poor health outcomes experienced by people with Intellectual Disability.



Dr Jenna Zhao

Project Officer

Jenna is currently a Project Officer managing various projects that aim to build capacity in the mental health workforce. Her current projects involve managing 3DN's e-learning portfolio and developing intellectual disability mental health training programs. Jenna has a background in Psychology and educational development. She holds a PhD in Psychology and a Bachelor of Psychology (Hons, Class I), both from UNSW Sydney. She has research experience working with infants and children, and individuals with mood disorders. She has also previously managed the UNSW School of Psychology Peer Mentoring

Programs and worked as an educational developer for core Psychology courses at UNSW. Jenna is passionate about learning and teaching at the university level, and education and training of adults in general.

Students



Miss Yunhe Huang

PhD Student

Yunhe Huang is a PhD candidate in Program 3: Adulthood of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). Her project seeks to understand the pathways and experiences of people who received their ASD diagnosis in adulthood. As a bilingual speaker of Mandarin Chinese and English, she also has a strong interest in how culture and language influence our understandings of health and disability. Her research interests include cross-cultural psychology, mental health, and developmental disabilities.

Yunhe graduated with a Bachelor of Psychology (Honours) from University of Adelaide in 2017. She has also had experience working with people with intellectual disabilities during her placement with Citizen Advocacy SA in 2016.



Ms Peiwen Liao

PhD Student

Peiwen's PhD project will be exploring health profiles and health services use in people with intellectual disability by using big data linkage, to comprehensively detect the complex needs of health services among this vulnerable population. She holds a Bachelor of Traditional Chinese Pharmacy in China and completed her master programme of Public Health majoring epidemiology at Karolinska Institute. Her passion for pursuing her doctorate degree in this area is driven from her master thesis, which was a register-based and population-based study in the field of developmental disabilities.



Ms Elizabeth Nguyen

PhD Candidate

Elizabeth is PhD candidate investigating cancer service utilisation and outcomes in people with intellectual disability. Her research involves working with the Intellectual Disability Mental Health Linkage team at 3DN and the Translational Cancer Research Network.

Elizabeth holds a Bachelor of Science with Honours in Psychology from the University of Sydney. Her research interests include intellectual disability, mental health and translational research. She is particularly interested in using big data to inform policy



Ms Erin Whittle

PhD Candidate

Erin is a PhD Candidate

Other PhD Students within 3DN

Mr Julian Trofimovs PhD Student

Research Grants and Funding

Tier 1 Funding

- NHMRC Investigator Grant APP2009771; 2022 – 2026; Total Funding \$2,372,570.00; Addressing Health Inequality Experienced by People with Intellectual Disability (Trollor)
- NHMRC Project Grant APP2006240; 2021- 2025; Total Funding \$2,479,755.50 ; Developing a model of Preventative Healthcare for People with Intellectual Disability (Trollor, Harris, Kavanagh, Fisher, Long, Reppermund, Harris-Roxas, Spooner, Sharma)
- NHMRC Project Grant APP2007541; 2021 – 2025; Total Funding \$1,252,778.00. Development, validation and implementation of a computerised tool to assess instrumental activities of daily living. (Reppermund, Brodaty, Numbers, Clemson, Kochan, Draper, Delbaere, Trollor, Anupama Ginige, Wesson)

Project Funding

- Dementia Australia Research Foundation, Self-harm in people with dementia - using big data to improve outcomes and inform strategies to prevent self-harm and suicide; 2021 -2023; \$75,000; (Reppermund, Trollor, Draper, Cvejic)
- Endeavour Foundation Disability Research Fund; Research Award; 2021-2023; \$79,981.35; (Arnold, McVilly, Trollor, Walsh & Foster)
- NSW Health; Translation of 3DN Easy read resources on mental health services; 2021 – 2022; \$50,504 (Trollor, Eagleson, Weise)
- Department of Education and Training (DET); Mental Health Supports in Specialist Schools Initiative; 2021; \$109,784.92 (Trollor, Zhao).

Other Funding

- Australian Government; 2021-2023; \$1,000,000 Chair Funding (Trollor)
- Women's Health Research Translation Network Grant 2021 - 2022 \$14,352.26 (Weise).

Publications

Papers in Refereed Journals

- Weise, J., Mohan, A., Walsh, J., Trollor, J.N. Salutory Lessons from the Delivery of Mental Health Services to People with Intellectual Disability–A Historical Perspective from Intellectual Disability Mental Health Experts in New South Wales, Australia. *Journal of Mental Health Research in Intellectual Disabilities*, 2021; 14(1), 70-88.
- Ahluwalia, T.S., Prins, B.P., Abdollahi, M., Armstrong, N.J., Aslibekyan, S., Bain, L., Jefferis, B., Baumert, J., Beekman, M., Ben-Shlomo, Y., Bis, J.C., Mitchell, B.D., de Geus, E., Delgado, G.E., Marek, D., Eriksson, J., Kajantie, E., Kanoni, S., Kemp, J.P., Lu, C., Marioni, R.E., McLachlan, S., Milanese, Y., Nolte, I.M., Petrelis, A.M., Porcu, E., Sabater-Lleal, M., Naderi, E., Seppälä, I., Shah, T., Singhal, G., Standl, M., Teumer, A., Thalamuthu, A., Thiering, E., Trompet, S., Ballantyne, C.M., Benjamin, E.J., Casas, J.P., Toben, C., Dedoussis, G., Deelen, J., Durda, P., Engmann, J., Feitosa, M.F., Grallert, H., Hammarstedt, A., Harris, S.E., Homuth, G., Hottenga, J.J., Jalkanen, S., Jamshidi, Y., Jawahar, M.C., Jess, T., Kivimäki, M., Kleber, M.E., Lahti, J., Liu, Y., Marques-Vidal, P., Mellström, D., Mooijaart, S.P., Müller-Nurasyid, M., Penninx, B., Revez, J.A., Rossing, P., Räikkönen, K., Sattar, N., Scharnagl, H., Sennblad, B., Silveira, A., Pourcain, B.S., Timpson, N.J., Trollor, J., van Dongen, J., Van Heemst, D., Visvikis-Siest, S., Vollenweider, P., Völker, U., Waldenberger, M., Willemsen, G., Zabaneh, D., Morris, R.W., Arnett, D.K., Baune, B.T., Boomsma, D.I., Chang, Y.P.C., Deary, I.J., Deloukas, P., Eriksson, J.G., Evans, D.M., Ferreira, M.A., Gaunt, T., Gudnason, V., Hamsten, A., Heinrich, J., Hingorani, A., Humphries, S.E., Jukema, J.W., Koenig, W., Kumari, M. Genome-wide association study of circulating interleukin 6 levels identifies novel loci. *Human Molecular Genetics*, 2021; 30(5), 393-409.
- Baldwin, P.A., Rasmussen, V., Trollor, J.N., Zhao, J.L., Anderson, J., Christensen, H., Boydell, K. Idtwo: A protocol for a randomised controlled trial of a web-based mental health intervention for australians with intellectual disability. *International Journal of Environmental Research and Public Health*, 2021; 18(5), 1-13.
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Submissions

- Cvejic, R. C., Weise, J., Arnold, S., Eagleson, C., Zhao, J., & Hind, T. Intellectual disability fact sheet consultation, The Australian Commission on Safety and Quality in Health Care, Written submission, November 2021.
- Performance audit of Australia's COVID-19 vaccine rollout. Auditing is the Australian Department of Health, The Australian National Audit Office (ANAO), Written Submission Trollor, J., September 2021
- National Medicines Policy (NMP). , Australian Government, Written Submission Trollor, J., September 2021
- Managing ASBD during COVID-19, NSW Health, Written Submission Trollor, J., September 2021
- Acceleration of vaccination of NDIS participants and workers, Aust Govt Advisory Committee for the Development of the Australian Health Sector Emergency Response Plan for Novel Coronavirus Management and Operational Plan for People With Disability. Written Submission Trollor, J., September 2021
- Opioid Analgesic Stewardship in Acute Pain Clinical Care Standard – Consultation, Australian Commission on Safety and Quality in Health Care, Trollor, J., Survey Response, September 2021
- Response to the Draft National Preventive Health Strategy, National Preventive Health Strategy, Written Submission, Trollor, J., Weise, J., March 2021
- National Children's Mental Health & Wellbeing Strategy, The National Mental Health Commission (Australia), Written submission, Trollor, J., February 2021

Conference Presentations & Lectures

National Audience

Keynote

- Systemic neglect of the health care needs of people with intellectual disability: evidence, implications and actions; ASID Annual Conference; Online; Trollor. J, 17 November 2021
- Accessible Mental Health Services for People with Intellectual Disability: Progress and Challenges, Launch of NSW Statewide Intellectual Disability Mental Health Hubs, Trollor, J. Sydney, 24 February 2021.

Invited

- Leadership and advocacy for better health outcomes for people with Intellectual Disability; CESPHN Program Launch; Online; Trollor. J, 2 December 2021
- Understanding the mental health needs of people with cerebral palsy and intellectual disability; Trollor, J., Salomon, C., Walker, A. CP Achieve Symposium 2021; Online; 17 June 2021
- Improving Behaviour Support: a medical perspective; Trollor, J. NDS Virtual Conference; 9 June 2021

- Using Linked Data to Understand the Health Needs of People with Neuropsychiatric Disorders; Trollor, J. Population Health Research Network Linkage Luminaries Webinar Series; 13 May 2021
- Working to Improve the Mental Health of People with Intellectual Disability: the doctor as advocate; Trollor, J. Online, Health Education and Training Institute (HETI); 29 April 2021
- Working to Improve the Mental Health of People with Intellectual Disability: Working with the individual; Trollor, J. Online, Health Education and Training Institute (HETI); 29 April 2021
- Reppermund S (2021). Late-life depression and dementia –health profiles, health services use and transition to dementia. Invited talk at the Dementia Collaborative Research Centre Anxiety and Depression in Dementia Research Network International Symposium, Sydney Australia (virtual symposium)
- Reppermund S (2021). To tweet or not to tweet? Using Twitter to promote research. Invited webinar presentation for the Australasian Society for Intellectual Disability.

Other

- Discussion on Comprehensive Health, Lifestyle Risk Factors and Oral Health Practice Alerts; NDIS Provider Webinar; Online; Trollor, J., Taylor, S., Chan, J. 19 November 2021
- Exposing inequalities through experiences of COVID and disability, Australian Social Policy Conference (ASPC), UNSW Sydney; Online; Scully, J., Gibbs, E., Dickinson, H., Carey, G., Green, C., Trollor, J., Robinson, S. 26 October 2021
- Launch of new online modules for mental health practitioners working specialist schools, Mental Health & Wellbeing Practice, Inclusive Education Professional Practice, Schools and Regional Services; Victoria Department of Education and Training (DET), Trollor J., Zhao J. Online; 27 August 2021
- Senate Select Committee on Autism inquiry into the services, support and life outcomes for autistic people in Australia; Trollor J., Arnold S. The Grace Hotel, Sydney; 15 April 2021
- Reppermund S, Jang S, Numbers K (2021). Prediction of dementia: Differences between performance-based versus informant-reported measures of functional impairment. Talk at the Australian Association of Gerontology, virtual conference
- Reppermund S, Heintze T, Srasuebkul P, Trollor J (2021). Transition to dementia in people with late-life depression compared to older people with other mental illnesses. Alzheimer's Association International Conference 2021, virtual conference
- Reppermund S, Heintze T, Srasuebkul P, Trollor J (2021). Late-life depression and dementia –health profiles, health services use and transition to dementia. Talk given at the Australian Dementia Forum 2021, virtual conference
- Reppermund S, Heintze T, Srasuebkul P, Trollor J (2021). Late-life depression and dementia – Comparing health profiles, health service use and transition to dementia in inpatients with late-life depression and other mental illness. Poster presented at the WPA World Congress of Psychiatry 2021, virtual congress.

Regular Teaching Contributions

- Intellectual Disability Mental Health: Webinar for Health Staff; Trollor, J., Zhao, J., Northern Sydney Local Health District; Online Webinar; 24 June 2021
- Intellectual Disability Mental Health: Webinar for GPs and Other Doctors; Trollor, J., Zhao, J., Sydney Local Health District; Online Webinar; 24 June 2021
- Intellectual Disability in Medical Practice; Trollor, J., Zhao, J., Lecture for Phase 1 Medical Students; UNSW Sydney; 11 May 2021
- Intellectual Disability Mental Health & Communication, UNSW Sydney Phase 2 Medical Students, Society and Health component, Weise, J., Quarterly 2021
- Intellectual disability mental health, UNSW Sydney, School of Psychiatry, UNSW Sydney Phase 3 Medicine students, Cvejic, R., 5 times 2021.

Media

- Mental illness in adults with intellectual disability; Psych Matters, Royal Australian and New Zealand College of Psychiatrists RANZCP; Podcast; February 2022; (O'Connor, Trollor, Frankiln, Bennett, Bathgate, Hind, Eagleson) <https://psychmatters.ranzcp.org/1072258/9407341-mental-illness-in-adults-with-intellectual-disability-assessment>
- Reaction to the recommendation of the Disability Royal Commission; ABC PM Radio; 27 September 2021; (Trollor)
- Interview for ABC, 7:30 Report; Royal Commission's report into the vaccine rollout and the "path" ahead for people with disability as restrictions ease; Television, 1 September 2021 (Trollor)
- Podcast ABC; August 2021 (Pellicano, Wenn, Hall, Lilley, Mahony, Arnold, Trollor, Yudell); <https://www.abc.net.au/radionational/programs/allinthemind/>
- Appointment/Achievements; Campus Morning Mail; Reimagining lives of lecturers; 12 November 2021; (Arnold, Higgins); <https://campusmorningmail.com.au/reimagining-lives-of-lecturers>
- News article; UNSW Newsroom; UNSW researchers receive 2021 Autism CRC Award; 5 November 2021; (Arnold, Higgins); <https://newsroom.unsw.edu.au/news/health/unsw-researchers-receive-2021-autism-crc-award>
- News article; Senior Australian news and research; Western Diet Linked to Increased Depression in Over 45s; 7 September 2021; (Reppermund); <https://www.seniorau.com.au/9842-western-diet-linked-to-increased-depression-in-over-45s>
- News article; Retail Pharmacy Magazine; Western Diet linked to depression for those 45+; 2 August 2021; (Reppermund); <https://retailpharmacymagazine.com.au/western-diet-linked-to-depression-for-those-45/>

- News article; National Tribune; Western Diet Linked to Increased Depression in Over 45s; 29 July 2021; (Reppermund); <https://www.nationaltribune.com.au/western-diet-linked-to-increased-depression-in-over-45s/>
- News article; Mirage News; Western Diet Linked to Increased Depression in Over 45s; 29 July 2021; (Reppermund); <https://www.miragenews.com/western-diet-linked-to-increased-depression-in-604277/>
- News article; Media Net; Western Diet Linked to Increased Depression in Over 45s; 29 July 2021; (Reppermund); <https://www.medianet.com.au/news-hub-post?id=204842>
- News article; National Tribune; More than \$11m awarded to UNSW medical research projects; 1 July 2021; (Reppermund); <https://www.nationaltribune.com.au/more-than-11m-awarded-to-unsw-medical-research-projects/>
- News article; Mirage News; More than \$11m awarded to UNSW medical research projects; 1 July 2021, (Reppermund); <https://www.miragenews.com/more-than-11m-awarded-to-unsw-medical-research-588510/>
- News article; UNSW Newsroom, More than \$11m awarded to UNSW medical research projects; 1 July 2021, (Reppermund); <https://newsroom.unsw.edu.au/news/health/more-11m-awarded-unsw-medical-research-projects>
- News article; Mirage News; Funding Success to Identify Early Stages of Dementia; 1 July 2021, (Reppermund); <https://www.miragenews.com/funding-success-to-identify-early-stages-of-588378/>
- News article; Media Net; Funding Success to Identify Early Stages of Dementia; 1 July 2021, (Reppermund); <https://www.medianet.com.au/news-hub-post?id=203511>



Acknowledgements

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If you would like to donate to support research in intellectual or developmental disability health and wellbeing at 3DN, please contact Julian Trollor or Rachel Roth on (02) 93481072 Or via ddd@unsw.edu.au.