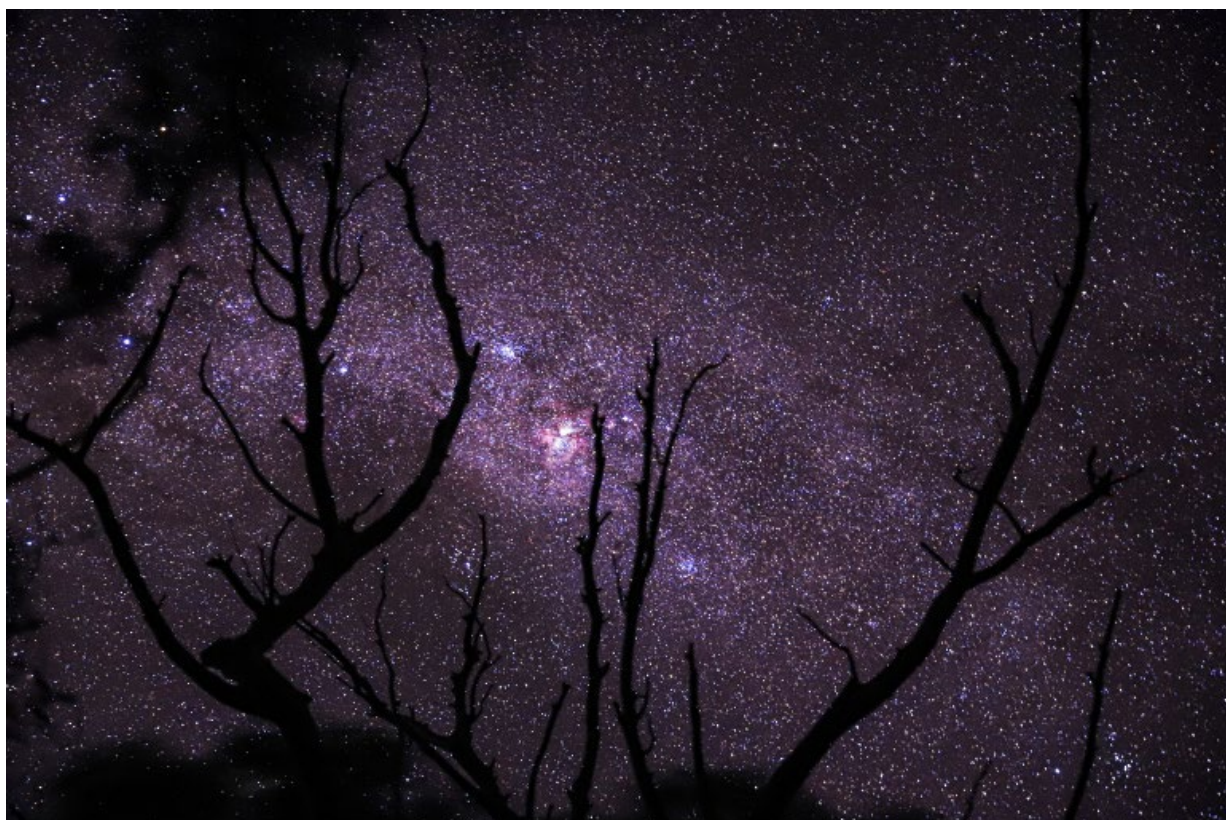


The Department of Developmental Disability Neuropsychiatry (3DN)

2022 Annual Report



Photography by Ben McLoughlin

"The Milky Way"

Measuring Outcomes That Matter: Conceptualising Contribution 2021 – 2023;
Endeavour Disability Research



UNSW
Department of
Developmental
Disability
Neuropsychiatry

The Department of Developmental Disability Neuropsychiatry 2022 Annual Report

**Our Vision: The highest standard of
health and wellbeing for people with
cognitive disability.**

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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 Discipline of Psychiatry and Mental Health and is part of UNSW Medicine and Health. 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 standard of health and wellbeing for people with cognitive disability.

Our Mission

To improve the health and wellbeing of people with cognitive disability through high-quality research, education and training, consultancy, and clinical work.

Our Guide

- We prioritise honesty, accuracy, and ethical conduct
- We value co-designed and inclusive approaches
- We identify and address critical health gaps in a timely manner
- We strive to apply innovative thinking and creativity to our work.

Chair's Report

Professor Julian Trollor

This year has been our most productive on record as we continue to work towards our mission. Our staff and students have embraced our growth and development as a department and delivered projects and research of major significance. Two major National Health and Medical Research Council grants commenced this year. One is a major partnership initiative with multiple co-funders, collaborating organisations and academics. This project focuses on the important area of preventative health care for people with intellectual disability. Another, an investigator grant, is a critical opportunity to expand the research program to address key gaps in understanding and response to mental health needs, physical health including preventative health, and premature deaths of people with ID.

The education and workforce teams have been busy with multiple important projects, including the delivery of face to face and online training to local health districts and large organisations such as SANE, delivering a masterclass on health checks and healthy lifestyle interventions for the NDIS Quality and Safeguards Commission and development and launch of new e-learning modules for health and disability professionals. A major development in the work has been the inclusion of lived experience experts in all workshops and training activities. The team has also been busy developing new electronic resources including our Intellectual Disability Mental Health Connect webtool, funded by the Department of Social Services. This webtool is unique in supporting the development of localised, interconnected, and responsive services throughout a person's mental health journey and providing tools for consumers, their supporters, disability, and health professionals to navigate the mental health sector. I am looking forward to the launch of this tool in early 2023. A major component of our work has been a lead role in the development of an Intellectual Disability Health Capability Framework for future doctors, nurses, allied health professionals and dentists. When adopted by our tertiary education sector, this will have a substantial impact on equipping these future professionals to be able to deliver better health care to people with intellectual disability.

It has been exciting to see the productivity of our data and research teams as they work on multiple projects, ranging from examining factors related to discharge to residential aged care, through to palliative care service use for people with intellectual disability. The use of data is a hot topic, and we have continued to play an advisory role in the development of the proposed National Disability Data Asset.

A big highlight in the year was the photovoice gallery event in June that saw over 150 attendees and featured in television news bulletins. This event was part of a project “Measuring Outcomes That Matter: Conceptualising Contribution”, funded by our research partner Endeavour Disability Research. The project is challenging prevailing deficit-based paradigms to build a tool measuring contribution to society by people with intellectual disability. Art from this wonderful project can be found though out this report.

When I said we had been busy, I meant it. We have 13 in house active projects and participate actively in multiple other external ones. The total value of our 3DN currently active projects is \$35 million AUD; with \$3.9 million AUD in new project and research funding awarded to 3DN in 2022. The outputs have been many, including 42 journal articles, 9 policy submissions, and 42 presentations of various types. We have had cause to celebrate with key staff promotions this year: Dr Simone Reppermund to Associate Professor and Dr Janelle Weise to Senior lecturer. Our PhD students Dr Peiwen Liao and Dr Yunhe Huang (with a Dean’s award) have graduated with outstanding success.

We are very grateful to the Mental Health Branch of the NSW Ministry of Health and the Australian Government Department of Health and Aged Care for the core funding we received from them this year. The core funding is critical, enabling us to complete essential pieces of work focussed on the mental health and wellbeing of people with intellectual disability. We also thank the many individuals and organisations who have sponsored and supported our projects and research. Our work continues to rely entirely on external project funding, grants and donations. The ongoing support from these many sources enables us to play a critical role in addressing the substantial health inequality experienced by people with intellectual or developmental disability.

Research Activities

The Year in Review

Project Name: Addressing Health Inequality Experienced by People with Intellectual Disability

2022 – 2027; NHMRC Investigator Grant; \$2.37M

Project Team Julian Trollor

Project Overview

This investigator grant is a critical opportunity to expand my research program to address key gaps in understanding and response to mental health needs, physical health including preventative health, and premature deaths of people with ID. The program will: address prevalence, determinants, costs and outcomes of mental illness in people with ID including the impacts of treatments; respond to the physical health gap by examining preventative health care of people with ID with multiple and complex needs, examining drivers of potentially preventable hospitalisations, and examining predictors and care pathways for those who are frail or at risk; and will address cause specific mortality, and drivers of potentially avoidable deaths.

Overarching Project Milestones

- Prevalence and Drivers Mental Illness
- Use and continuity of health services
- Impacts MI on physical health
- Psychotropic medication
- Preventative healthcare
- Drivers of PPH
- Frailty
- Qualitative care pathways
- Get healthy
- Mortality
- Predictors of potentially avoidable deaths.

Annual Report

Good progress has been made in planning and allocation of resources and personnel to each component of this large project. There has been significant work in the coding for identification of the cohorts for several components and the planning of data analysis. Additional related activities are being explored, such as

the operationalisation of a multiple and complex needs definition within an administrative linked data context. A key first output identifying the prevalence of mental illnesses for people with intellectual disability should be available in 2023.

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

2021-2023; Dementia Australia; \$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 (e.g. Pharmaceutical Benefits Scheme for medicines use, Medicare Benefits Schedule for primary care, allied health and specialist care data and National Aged Care Clearinghouse).

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

Annual Report

- Analysis for all three aims completed, including sensitivity analyses.
- Drafts for three papers completed and circulated to investigators.
- Three lived experience advocate meetings conducted.
- Research presented at two conferences in 2022, winning one presentation award.

Project Name: Intellectual Disability Health Data Portal

2018-2021; NSW Health, NSW Mental Health Capacity Project; currently unfunded

Project Team Janelle Weise, Preeyaporn Srasuebkul & Julian Trollor

Project Overview

This project will create a web-based user interface (intellectual disability 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.

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 Intellectual Disability Health Data Portal continues to be used by staff across NSW Health.

Project Name: Intellectual Disability Health Education

2010 Onwards; Department of Health and Aged Care, prior NSW Health, ADHC, FACS; currently unfunded

Project Team Jenna Zhao, Jessica Ward, Janelle Weise & Julian Trollor

Project Overview

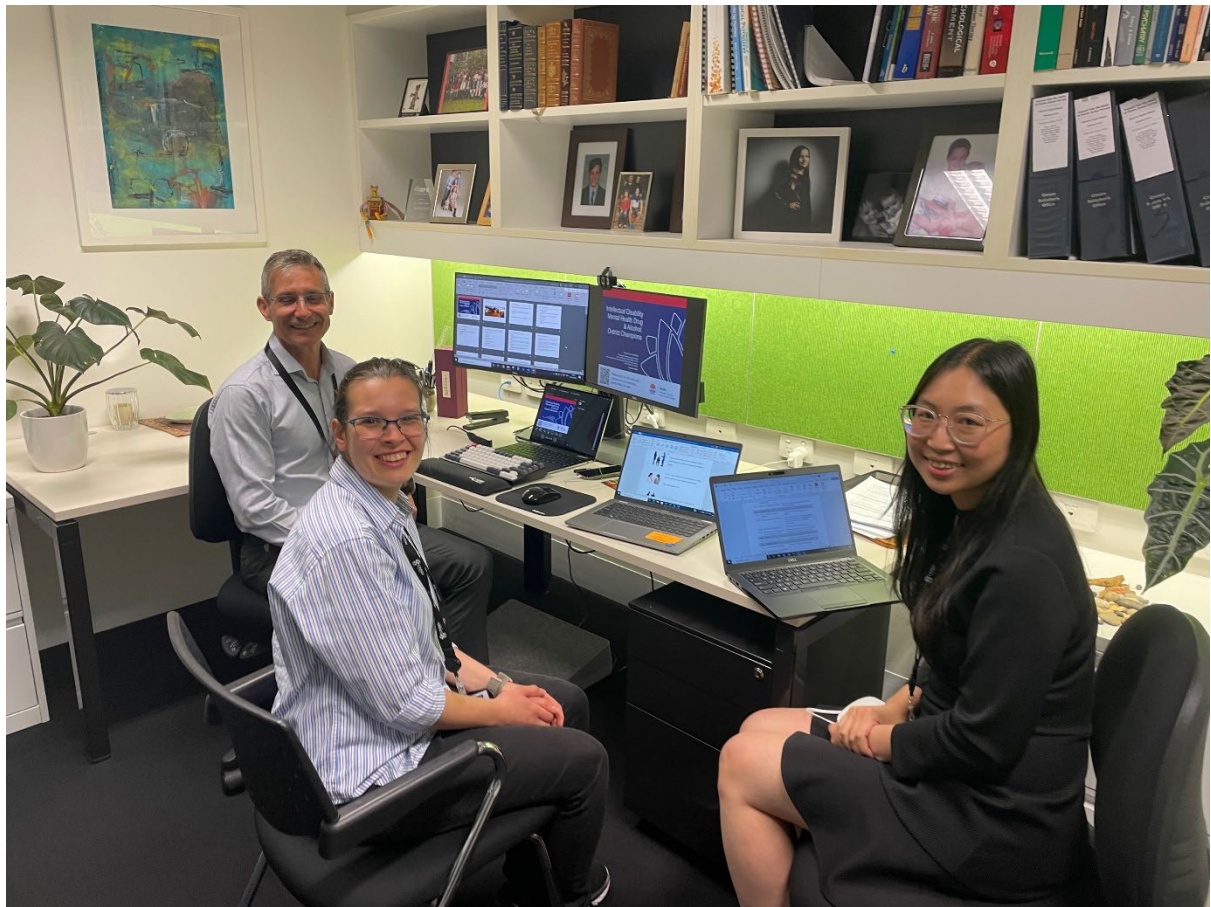
This project is focused on delivering an online learning resource on intellectual disability mental health to those who provide support to people with intellectual disability. The e-learning site has separate portals for health professionals, disability professionals and carers. Each portal contains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

The project also includes providing bespoke education and training solutions (e.g., webinars, workshops, online panels and masterclasses) to organisations.

Weblink: www.idhealtheducation.edu.au

Annual Report

- Delivered online training and panel discussion to SANE Australia staff working on their pilot service for people with intellectual disability and/or autism spectrum disorder.
- Developed and delivered an online masterclass on health checks and healthy lifestyle interventions for the NDIS Quality and Safeguards Commission
- Delivered two intellectual disability mental health workshops to Northern Sydney Local Health District staff.
- Included lived experience experts in all of our workshops and training activities.
- Launched a set of two modules for GPs and other health professionals on dementia care for people with intellectual disability.
- Launched a module for disability professionals on supporting people with intellectual disability and dementia.
- Provided more e-learning subscription packages to health and disability organisations.



**Presenting to Northern Sydney Local Health District “Train-the -Trainer Workshop”.
Julian Trollor, Tahli Hind & Jenna Zhao
November 2022**

Project Name: ILC Intellectual Disability Mental Health Service Pathway Web-tool
2020 – 2023; Department of Social Services ILC Mainstream Capacity Building;
\$1,243,523

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

Project Overview People with intellectual disability 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 intellectual disability, 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 intellectual disability 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 intellectual disability 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.

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

Annual Report 2022

- Version one of the Intellectual Disability Mental Health Connect webtool was finalised in early 2022. Final user-testing took place before the start of a pilot evaluation.
- The webtool was piloted in two NSW health districts over a 6-month period. Feedback was also sought from the Project Advisory Group and Lived Experience Reference Group. The pilot feedback was analysed and used to inform the post-pilot modifications plan.
- Modifications to the webtool are underway, with revisions to the content, the creation of new tools and infographics, and minor structural changes to the webtool.
- We are currently planning the launch webinar which will take place in early 2023.

- Ethics approval is being sought for the full evaluation which will take place over a 6-month period after the launch.
- The Project advisory groups have continued to provide advice around all aspects of the project.

Project Name: Intellectual Disability Health Capability Framework Development Project

2022-2023; Department of Health and Aged Care (DoHAC); \$257,743.79

Project Team: Claire Eagleson, Jenna Zhao, Janelle Weise & Julian Trollor

Project Overview Health outcomes for people with intellectual disability are significantly worse than for the general population. Many health professionals have minimal training in health care for people with intellectual disability. The DoHAC led the development of the National Roadmap for Improving the Health of People with Intellectual Disability in collaboration with people with intellectual disability, their support networks, health professionals, health and disability organisations, researchers, other experts and governments. As part of the Roadmap, the DoHAC is leading the Intellectual Disability Health Curriculum Project, which includes the development of an Intellectual Disability Health Capability Framework. The Framework will set out clear capabilities and learning outcomes for future health professionals regarding health care for people with intellectual disability. This work also follows the Disability Royal Commission's key recommendation that a capability framework be developed.

3DN project members are part of a larger Drafting Group involved in developing the Framework.

Annual Report

- Conducted workshops with people with intellectual disability, their carers, family and support persons, and academic, clinical and accreditation experts
- Implemented a consultation survey for academic clinical and accreditation experts.
- Conducted a desktop review of key documents and resources.
- Analysed and triangulated data from consultations to draft an initial list of core capabilities.

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

2020-2024; Department of Health and Aged Care (DoHAC), \$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 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 intellectual disability. We will consult nationally with people with intellectual disability, 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 intellectual disability, 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 intellectual disability nationwide. Finally, we will establish a mechanism for improving the national data collection about people with intellectual disability receiving palliative care services, enabling benchmarking of service provision to this vulnerable group.

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

Annual Report

- One additional non-NSW Health site for stakeholder consultation recruited.
- Various ethics amendments approved.
- Two Project Advisory Group meetings held.
- Additional stakeholder consultations conducted (interviews, focus groups and surveys).
- Linked data analysis plans developed.
- Data extraction of policy review progressed.
- Drafting of systematic review.
- Abstract presented at the Palliative Care NSW State Biennial Conference.

Project Name: Measuring Outcomes That Matter: Conceptualising Contribution
2021 – 2023; Endeavour Disability Research; \$ 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.

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

Annual Report 2022

It was a successful year for the Contribution project despite COVID-19 related delays. We held a highly successful photovoice gallery event in June that saw over 150 RSVP and coverage from Channel 9 news. We won additional funding to expand the gallery and conceptual foundation to include indigenous artists with intellectual disability. We have started the grounded Delphi phase though have been unable to make up delays incurred from COVID as yet.



**Photovoice gallery event,
Julian Trollor, Sam Arnold and AUSLAN Interpreter.
June 2022**

Project Name: NHMRC Preventative Healthcare Grant for People with Intellectual Disability

2022 – 2027; NHMRC Partnership Project; \$2,479,756.00

Project Team Janelle Weise, Julian Trollor, Bela Laginha, Dominique Abagi, Tahli Hind, Angus Liu, Simone Reppermund, Preeyaporn Srasuebkul (3DN) and Mark Harris, Anne Kavanagh, Karen Fisher, Janet Long, Ben Harris-Roxas, Catherine Spooner, Anurag Sharma, Chris Hatton, Paul Crosland, Jaithri Ananthapavan, Jane Tracy, Jenny Bowman (external), Nick Lennox

Project Overview

Preventative health care is a key pillar of Australia's long-term national health plan (6), yet equity in preventative health care remains elusive for many disadvantaged groups, especially those with intellectual disability. For this group, the endpoints have their genesis earlier in life with poor access to health care, including preventative health care. Our research shows that people with intellectual disability are less likely to access primary care to have their preventative health care needs met compared to the general population (8, 9). International research indicates that people with intellectual disability have poor engagement in preventative health care compared to the general population (10) including lower rates of vaccination, participation in health lifestyle interventions, and preventative health screening measures such as cancer, cholesterol, and oral health screening. Targeted translational research is required if preventative health care is to be inclusive of people with intellectual disability.

Our agreed vision is to improve health outcomes for people with intellectual disability by undertaking a program of work which: maps the specific gaps in preventative health care policy and practice; determines the impact of these gaps on the health and wellbeing of people with intellectual disability; drives targeted innovation in policy and service design; and, through maturation of our partnership and its influence, builds new capacity for preventative health care across the lifespan for people with intellectual disability. Contemporary health and disability research practice supports the adoption of disability inclusive research methods, valuing people with disability, and those who support them as experts in their own experience and needs. Our program is therefore co-designed, using a multi-phased mixed methods approach underpinned by a strong implementation science framework.

Annual Report

- The partnership project commenced in February 2022.

- We are co-designing our work with people with intellectual disability and have employed two lived experience researchers and formed a lived experience reference group.
- Early in 2022 we consulted with key stakeholders to confirm the priorities of this project.
- We have received ethics approval to consult with people with intellectual disability, their support networks and health professionals about the barriers and facilitators to accessing preventive health care.
- We have commenced an audit of the accessibility of health information and have designed a study to explore the conceptualization of health literacy for people with intellectual disability.
- We are currently reviewing Australian preventive health care policy to understand how people with intellectual disability are represented.
- Analysis of our administrative health data is underway. We are exploring cardiovascular disease, cancer screening, immunizations, and engagement in primary care.
- A realist review has been initiated to understand what makes general practice-led preventive care accessible for people with intellectual disability and why and in what context?

Project Name: Predictors of breast screening in women with Intellectual Disability
2022; Women's Health Research, Translation and Impact Network (WHRTN) EMCR
Research Fund; \$14,000

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 intellectual disability (February-May 2022)
- Final report – (July 2022).

Annual Report

This project was completed in 2022. The outcomes of this project were:

- The identification of predictors of breast screening for women with intellectual disability compared to women without intellectual disability.
- Consensus reached by national and international experts on strategies for accessible breast screening for women with intellectual disability.
- Manuscripts are currently being prepared for publication.

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

2021 - 2022; Mental Health Branch, NSW Ministry of Health; \$50,504

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.

Annual Report 2022

- After initial consultation with multicultural organisations, bilingual Cultural Support Program workers reviewed the English versions of the Easy Read resources and provided advice around language and images.
- The research team sourced culturally appropriate images for each language and finalised the resources ready for translation.
- After delays with project due to Covid-19, the Easy Read resources were translated into Arabic, Simplified Chinese, and Vietnamese by the Multicultural Health Communication Service.
- Promotional materials ready for the launch were also translated.
- We have consulted with community members who speak Arabic, Simplified Chinese, and Vietnamese to review the comprehensibility, cultural appropriateness, and relatability of the resources.
- The final stages of the project will involve implementing changes based on these consultations, finalising the resources, and promoting them to Arabic, Chinese and Vietnamese communities within NSW.

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.

Annual Report 2022

Our work on potentially preventable hospitalisations has been published in the Medical Journal of Australia.

Project Name: Understanding health service system needs for people with intellectual disability – Intellectual Disability Health Links

2017-2022; 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.

Annual Report

We received updated datasets and have finalised a draft of a cohort description manuscript. Intellectual Disability Health links data have been used in several projects, such as predictors of participation in breast cancer screening, palliative care work, preventive care, and prevalence of mental disorders in people with intellectual disability.

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

2019-2022; Summer Foundation; \$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.

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

Annual Report

- All analysis finalised for Aims 1 to 3.
- First paper of two drafted and accepted for publication.
- Resources for people with lived experience and health professionals conceived, produced, and had feedback received from multiple stakeholder groups, now approaching distribution.
- Two more advocate conducted.
- Second paper of two drafting commenced.
- Interim Report submitted to funder (The Summer Foundation).

PhD Projects

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

PhD Student Julian Trofimovs

Supervisors Professor Julian Trollor, Professor Leanne Dowse

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 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 intellectual disability in NSW. This project will both profile who this cohort is, in terms of their intellectual disability 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 intellectual disability.

Current state of project and achievements to date

I have two articles published in a peer-reviewed journal with a third currently under review. I am in the process of writing up my thesis with the intention of submitting next year.

Where the project is at

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

- '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>
- 'Disability support and reincarceration after a first adult prison custody episode for people with Intellectual Disability in New South Wales, Australia' published in the Journal of Criminology, Volume 55 issue 2 2022.
<https://doi.org/10.1177/26338076221087461>

- 'Post-release community mental health support for prisoners with intellectual disability and serious mental illness and reincarceration in NSW, Australia'
Under review with the British Journal of Psychiatry Open.

Lifestyle related diseases & preventative healthcare for people with intellectual disabilities

PhD student Jessica Bellamy

Supervisors Professor Julian Trollor, Dr Janelle Weise, Dr Preeyaporn Srasuebkul, Professor Jackie Curtis

Project description

The aim of this project is to examine the relationship between lifestyle related disease burden and access to preventative healthcare, such as Exercise Physiology, in people with intellectual disabilities. To achieve this, this project utilises a linked data approach to determine the prevalence of lifestyle related diseases in people with intellectual disability and identify their predictors (including the use of psychotropic medication and early intervention of modifiable risk factors such as diet and exercise through referral to allied health). Additionally, I will use systematic review to determine efficacy of lifestyle related exercise interventions for this population, before using qualitative approaches to explore barriers and enablers of access of such lifestyle interventions from the viewpoint of people with intellectual disability. And finally, I will examine attitudes, knowledge and skills of Exercise Physiologists in the provision of lifestyle relation interventions for people with intellectual disability.

Current state of project and achievements to date

I commenced my PhD part-time in June 2022. I have set and completed milestones in preparation for confirmation of candidature (including UNSW Research Integrity & Data Management Plan courses, HDR Essential course, faculty & school inductions). I have commenced my literature review and am concurrently drafting my methodology to be used for the linked data analysis. I have completed a 5-day intensive 'Introductory Analysis of Linked Data' course (USyd).

Where the project is at & future deliverables

This project is ongoing. Future deliverables (within the next 12 months) include:

- Ethics completion and commencement of linked data project
- Completion of narrative literature review
- Confirmation of candidature
- Contribution to 3DN projects (including the 'preventative healthcare' project, the 'Intellectual disability health links' project, and the 'Intellectual disability health capability framework' project).



Photograph by Daniel

Measuring Outcomes That Matter: Conceptualising Contribution 2021 – 2023;
Endeavour Disability Research

Our People

Julian Trollor - Chair of Intellectual Disability Mental Health, and Head, Department of Developmental Disability Neuropsychiatry - Professor



Julian is the inaugural Chair of Intellectual Disability Mental Health at UNSW Sydney. He also heads the Department of Developmental Disability Neuropsychiatry within the School of Psychiatry at UNSW. He is a clinician and academic with a background in neuropsychiatry.

Julian leads national initiatives in health care for people with intellectual and developmental disability. He works with Commonwealth and State Government Departments to improve health services for people with an intellectual or developmental disability. He sits on multiple

Commonwealth and State Government Committees and provides advice to regulatory bodies in his area of expertise. Julian also develops and delivers courses in mental health and intellectual disability.

Julian is involved in diverse research programs that examine the health inequalities experienced by people with intellectual or developmental disability and design solutions to the issues arising. He is passionate about inclusive research practices and enjoys rich interdisciplinary collaborations.

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.

Susan Adrian – Project Administrator



Sue has experience advocating for people with disability to get good health care. To advocate is when you or someone else do things so that your rights and needs are met. Sue did this through her work at the University of Sydney. Part of this work involved communicating with people with disability and the people who support them about NDIS and ways to get the supports they need. Sue wants all people to be treated equally.

Sue has also worked for many years. In this time, she has worked at Target and in an

office. Sue recently has started to advocate for more support to be given to people with disability who want to work after retirement age or later in life.

Sue will be supporting the preventive health care project. This project is also called Intellectual Disability Health My Way. Sue is excited to support people with intellectual disability to have good health.

Samuel Arnold - Lecturer



Sam is a lecturer with the Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales. He was recently focused on the Australian Longitudinal Study of Autism in Adulthood (ALSAA) and is now leading a study developing the construct of contribution for application to outcome measurement, funded by the Endeavour Foundation Disability Research Fund 2021 Research Award.

Sam is a registered psychologist with a background in supporting adults with disability in community settings. He formerly worked as a Research Fellow at the Centre for Disability Studies (CDS), University of Sydney and previously provided counselling and clinical services at the NSW Developmental Disability Health Unit (DDHU) and the Northern Sydney Intellectual Disability Health Team (NIDH). He completed his PhD in 2016 on the "Measurement and Conceptualisation of Support Needs".

Rachael Cvejic – Research Fellow



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 disability, mental health conditions, and inherited neurodegenerative disorders including fragile X-associated tremor ataxia syndrome and Huntington disease. Rachael is currently involved in a number of educational and research activities in the Department of Developmental Disability Neuropsychiatry (3DN) which aim to improve

health outcomes for people with intellectual and developmental disability, neurological conditions, and mental health conditions. Her current projects utilise a broad range of research methods including surveys, interviews, Delphi method, and data linkage.

Qualifications:

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

Aishani Desai – Research Assistant



Aishani Desai is currently working part-time as a Research Assistant in 3DN. She is also a PhD candidate, enrolled in the Combined PhD/Master of Clinical Neuropsychology Program at Macquarie University. Her project is focused on investigating the role of cognitive and psychological factors in predicting return to productivity following a traumatic brain injury. She is passionate about understanding brain-behaviour relationships and its translational applications to better help diagnostic and interventional efforts.

She holds a Bachelor of Science (Hons) in Psychology from the University of Warwick (UK) and a Master of Science in Developmental Neuroscience and Psychopathology from University College London (UK) and Yale University (USA). Previously, she has conducted graduate level autism research, which focused on parsing heterogeneity through the investigation of comorbid alexithymic traits and their relative contributions to the neural processing of social information. She has also worked as a psychologist in the areas of neurorehabilitation, epilepsy surgery, movement disorders and neurodegenerative disorders in her hometown of Mumbai, India.

Claire Eagleson – Project Officer



Claire has a background in psychology and is currently working as a Project Officer managing various 3DN projects. She has an interest in enhancing workforce capacity and inclusive research. Current projects include the development of a webtool, Intellectual Disability Mental Health Connect, for people with intellectual disability, their supporters and professionals, and the development of the Department of Health's Intellectual Disability Health Core Capability Framework to inform university curricula. Previous 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; 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; and development of Easy Read materials for people with intellectual disability utilising the mental health system.

Previously Claire has worked at the Institute of Psychiatry, Psychology and Neuroscience, London managing a program of research aimed at examining cognitive maintaining factors of worry in emotional disorders, and at the Brain & Mind Centre assessing the efficacy of an e-Health program for generalised anxiety versus pharmacological treatment. She holds a Bachelor of Psychology (Hons) and Master of Psychology (Clinical) from the University of NSW.

Amanuel Hagos – Project Officer



Amanuel works as a Project Officer with the Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales. He is currently managing the project on improving palliative care services for people with intellectual disability.

He holds undergraduate and postgraduate degrees in public health and is in the last stretch of his PhD at the School of Population Health. His PhD explores care pathways, best care options and barriers and enablers to health services for older adults who are in contact with the justice system.

Amanuel has worked extensively in health program management and health services research including designing and implementing palliative care services for vulnerable groups of population.

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.

Tahli Hind – Project Administrator



Tahli Hind is a Project Administrator at 3DN. She has a lived experience of intellectual disability 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 intellectual disability. Tahli feels that people with intellectual disability 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

Yunhe Huang - Research Officer

Yunhe Huang is a research officer working on several projects related to physical and mental health using linked data. She has recently submitted her PhD thesis on experiences of autism diagnosis in adulthood. She has previously completed a Bachelor of Psychology (Honours) from University of Adelaide in 2017.

Andrea Kargodorian - Research Manager

Andrea is the Research Manager at 3DN which provides strategic, administrative, management and technical support to the 3DN research portfolio. Andrea holds a Bachelor of Psychology (Hons.) and a PhD in Behavioural Neuroscience. She is a member of the Australasian Research Management Society with interests in research development and impact.

Bela Laginha – Research Officer

Bela is a Research Officer helping to develop a preventative health care model for people with intellectual disabilities.

After gaining University of Sydney degrees in Science and Arts, she went on to complete a Master of Medical Science, including a thesis in brain research. She then gained qualitative research experience working on various preventative health care projects.

Bela is keenly interested in improving health care for vulnerable populations and recognises the value and importance of directly consulting and engaging with them.

Peiwen Liao – Research Officer



Peiwen is a data analyst in 3DN. She works on projects that use large-scale linked data to examine health and health service use of people with intellectual disability. She has recently finished a PhD on examining epilepsy-related health issues in people with intellectual disability using big data. She has previously completed a Master of Public Health (MPH) majoring in epidemiology and biostatistics from Karolinska Institute in 2017. She also holds a Bachelor of Science in Traditional Chinese Pharmacy from Chinese Pharmaceutical University.

Angus Liu – Data Analyst



Angus is a Data Analyst at 3DN where he is mainly involved in the preventive health care project. He has a Bachelor of Science from the University of Sydney, and a Master of Public Health from UNSW.

Katya Numbers



Katya is a Postdoctoral Research and Lecture with a background in experimental memory research. Her current work focuses on modifiable lifestyle factors associated with increased dementia risk and identifying behavioural phenotypes of very early dementia. The majority of Katya's work is focused on the associations between dementia risk and older adults' subjective experiences of cognitive decline, attitudes towards ageing, and changes in ability to perform everyday activities. Katya also has a keen interest in uncoupling negative stereotypes around ageing and neurodegeneration, especially in field of

medicine, and is involved many groups and projects that aim to understand when and why age-based prejudice occurs and how it can best be challenged in research and clinical settings.

Simone Reppermund – Senior Research Fellow



Simone is a UNSW Scientia Senior Lecturer within the Discipline of Psychiatry and Mental Health. Her area of research is cognitive disorders with a focus on mental health and ageing. Simone has a PhD in Psychology (Ludwig Maximilian University Munich) 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, 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.

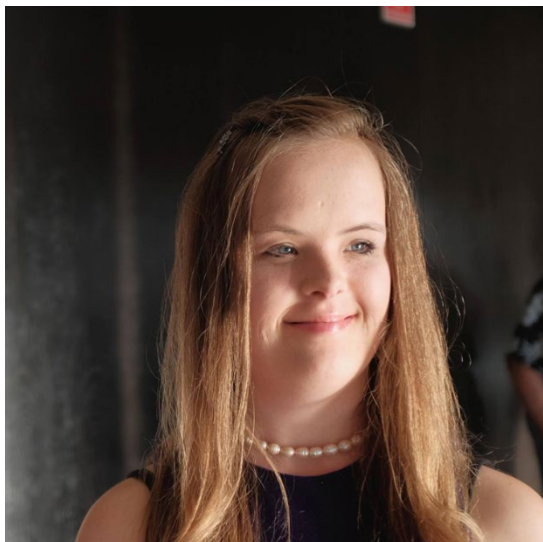
Simone's current research focuses mainly on late-life depression, cognitive impairment including dementia, everyday activities in old age and mental health in people with intellectual disability. Through her research, Simone aims to improve health and mental health outcomes for people with cognitive and mental disorders. She uses a range of methods, including interrogation of large linked datasets, development of diagnostic tools and analysis of factors associated with depression in late-life and cognitive decline. Simone has published over 100 peer-reviewed publications with a total of >6500 citations.

Rachel Roth – Administrative Officer



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

Katrina Sneath



Katrina Sneath is a Project Administrator at 3DN. She has had different advocacy roles in New Zealand (NZ) and Sydney. In NZ, Katrina was involved with Malatest International and was able to interview people with disabilities about how to make their lives more accessible and see what changes were needed in housing and care. She had a similar experience through Achieve Australia, in Sydney. In NZ, Katrina has delivered workshops at Idea Services to train new support workers. Similarly, Katrina supports trainees at Hotel Etico, Sydney as a mentor. Katrina is very passionate about advocacy for people with disability. Katrina was born

with a disability and has loved helping others with a disability since she was young. She lives independently in her own flat and is looking forward to increasing her experience in advocacy.

Katrina was involved in Uni2Beyond, where she audited Health and Science classes. In her spare time Katrina enjoys reading books, diamond painting, singing, dancing,

loves being creative, and expressing herself. She also enjoys going on adventurous walks and trying new things every day.

Preeyaporn Srasuebkul – Senior Research Fellow



Preeyaporn Srasuebkul is a Senior Research Fellow at the Department of Developmental Disability Neuropsychiatry, Discipline of Psychiatry.

Preeyaporn's research interests include statistical methods applied to epidemiology and population health studies. Past projects involved survival analysis, complementary log-log transformation used in discrete survival analysis, and Poisson regression used in HIV cohorts. Current projects involve using survival analysis and zero-inflated Poisson regression.

Julian Trofimovs – Data Analyst & PhD Candidate

Julian is a PhD scholar at 3DN researching health and service usage of individuals with intellectual disability and co-occurring mental illness to have been in the criminal justice system. His work has a particular focus on the opportunities of administrative data-linkage research and quantitative research methodology to inform policy. Jules holds a Master Degree in Research Methodology from Humboldt University Berlin, a Bachelor degree with Honours in Social Science from the University of New South Wales and worked as data manger on The Mental Health Disorders and Cognitive Disabilities (MHDCCD) in the Criminal Justice System (CJS) linked administrative data project at UNSW School of Social Sciences. Jules commenced as a Data Analyst at 3DN in 2022.

Adrian Walker – Research Officer

Adrian is a research officer studying how we can improve health outcomes for those with mental illness, as well as those with intellectual disability, using large-linked datasets. Adrian completed his Bachelors in Psychological Science (Hons, Class I) in 2015, his PhD in Cognitive Science in 2019 (both from UNSW Sydney). Adrian has also worked coordinating the UNSW School of Psychology Peer Mentoring Programs, and as a data analyst in 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.

Jessica Ward – Project Officer



Jessica is a Research Assistant that works on various research projects within 3DN. Her current projects involve helping to develop a preventative care model for people with intellectual disabilities and developing content for the 3DN's e-learning portfolio to build capacity for health and disability workforces.

Jessica has a background in Psychology. She holds a BSc (Hons) in Psychology from Lancaster University and an MSc in Clinical and Health Psychology from the University of Manchester, U.K. She subsequently gained experience supporting people with intellectual disabilities within a dementia

service for the National Health Service in England.

Jessica is passionate about improving healthcare and health outcomes for under-represented populations by supporting co-designed research to drive new models of care and policy action.

Tim Watkins – Data Management Officer



Tim Watkins works as a biostatistician in the Department of Developmental Disability Neuropsychiatry (3DN). He joined in 2019 after completing a Master of Biostatistics through the University of Sydney (delivered by the Biostatistics Collaboration of Australia), and a PhD in Biostatistics at The George Institute for Global Health and the University of Sydney focusing on the concepts of causal inference, research bias, and uncertainty in health intervention research.

At 3DN, Tim has used linked administrative health data to examine topics including the movement of people under 65 from hospital to residential aged care, emergency department readmissions for people with intellectual disability and epilepsy, and uncommon forms of dementia. He is also working towards creating a major neuropsychiatry linked data platform.

His methodological research interests focus on making it easier for researchers to conduct high quality research, with less chance of bias and improved causal inference leading to findings that are more trustworthy. Ongoing work includes an analysis plan template for observational studies; and the website causaldiagrams.org that aims to make it easier for researchers to create and use causal diagrams.

Qualifications

BSc (physics) (UNE), Grad Dip Biochem (UNSW), MBiostat (USyd), PhD (USyd)

Janelle Weise (née Govett) - Senior Research Fellow



Janelle Weise was awarded her PhD in 2018 and is a Senior Research Fellow at the Department of Developmental Disability Neuropsychiatry, an Occupational Therapist & Public Health professional.

As a researcher she has worked 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 an intellectual disability.

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 health and 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. She is currently completing a Master of Education (Educational Psychology).

Students

Lauren Bertolissio – Honours Student



Lauren Bertolissio is an honours student at Western Sydney University, currently studying occupational therapy. In collaboration with the 3DN team, she will be conducting a research project for her honours program. The project focuses on the experience of loneliness for autistic adults in Australia, specifically looking at the progression overtime.

Lauren is motivated to help autistic people live a fulfilled life. She aims for her research to increase the knowledge about autistic adult's experiences to improve their health outcomes and life satisfaction.

Jessica Bellamy – PhD Candidate



Jessica is a practicing clinical Exercise Physiologist and current PhD candidate with 3DN. She is passionate about providing access to effective preventative healthcare, particularly Exercise Physiology, to people with intellectual disabilities. She believes her significant clinical experience compliments her research, as she strives to undertake truly translational work.

Jessica holds a Bachelor of Exercise Physiology, and Masters (Research) of Science from the University of New South Wales.

Ping-Hsiu Lin – PhD Candidate



Ping is a PhD student at UNSW. Ping completed his Master of Brain and Mind Sciences and Master of Philosophy in Psychology at the University of Sydney. His PhD project focuses on the development and validation of a computerised IADL assessment designed for older people with cognitive decline. Ping is passionate about better understanding the daily functioning change occurring in the early stage of cognitive decline and improving the quality of life of older people with cognitive decline.

Sharon Nguyen – Honours Student



Sharon Nguyen is a third-year Occupational Therapy Honours student at Western Sydney University. In collaboration with the 3DN team, she will be conducting a research project as part of her Honours program. Her research will focus on the barriers to preventative healthcare screening for autistic adults.

Sharon is passionate about improving accessible healthcare for autistic adults. She hopes for her research to increase the knowledge of the barriers to preventative healthcare screening to reduce premature mortality and improve health outcomes for

autistic adults.

Erin Whittle - PhD Candidate

Erin is a PhD Candidate. Erin submitted in 2022

Erin Spike - PhD Student
Biostatistics and Databases Program





Art by Alessio

Measuring Outcomes That Matter: Conceptualising Contribution 2021 – 2023;
Endeavour Disability Research

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)

Project Funding

- Australian Government; Contribution to the co-design of the Intellectual Disability Health Capability Framework; 2022 – 2023; \$257,743.79 (Trollor, Eagleson, Weise, Zhao)
- NSW Health; Intellectual Disability Mental Health Training Framework for CAMHS and Safeguards Teams; 2022 – 2024; \$300,000 (Zhao, Trollor, Dossetor, Carunana, Bansal, Eapen)
- UNSW Institute of Human Rights; A starting point to addressing implicit bias in the healthcare of older people; 2022; \$10,000 (Ambrens, Andrews, Kenning, Delbaere, van Schooten, Lim, Trollor, Macniven, Ginnivan)

Other Funding

- Understanding the perinatal mental health of people with intellectual disability. Psychiatry and Mental Health Career Development Seed Grants; \$8,000. (Cvejic)
- Enhancing the Contribution Project. UNSW Psychiatry and Mental Health Career Development Seed Grant for EMCRs. 2022; \$8,000 (Arnold)
- UNSW Women's Wellbeing Academy's 2022 small grants; 2022; \$5,000 (Huang, Liao)
- Australian Government; 2021-2023; \$1,000,000 Chair Funding (Trollor)



SANE Workshop

Sam Arnold, Michael Bartels, Lived Experience Presenter and Julian Trollor

Publications

Papers in Refereed Journals

- Pracilio A, Wilson NJ, Kersten M, Trollor JN, Cashin A. A discourse analysis of the representation of nursing in the National Disability Insurance Scheme pricing guide and eligibility criteria. *Collegian*. 2022
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- Lilley R, Lawson W, Hall G, Mahony J, Clapham H, Heyworth M, et al. "Peas in a pod": Oral History Reflections on Autistic Identity in Family and Community by Late-Diagnosed Adults. *J Autism Dev Disord*. 2022
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Published Abstracts

- Matison A, Thalamuthu A, Reppermund S, Flood V, Trollor J, Wright M, et al. Nature Versus Nurture – Studying the Relationships Between Diet and Depression in Older Adults. Oxford University Press (OUP); 2022. p. 1118-.

Submissions

- Lessons learned during the COVID-19 pandemic, Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability; Written Submission; Trollor; November 2022
- The Role and Functions of an Australian Centre for Disease Control Prevention-Promotion-Protection; COVID-19 Disability Advisory Committee; Written Submission; Trollor; November 2022
- Response to the draft Framework for the development of a National Health Literacy Strategy to support the National Preventive Health Strategy 2021-2030; Written Submission; Trollor, Weise; 2022
- Response to AMC of the Review of the Accreditation Standards for Primary Medical Programs; Written Submission; Weise, Eagleson, Zhao, Trollor; October 2022
- Lessons learned during the COVID-19 pandemic. Advisory Committee on the Health Emergency Response to COVID-19 for People with Disability; Written submission to Commonwealth Department of Health; Trollor; 2022
- Pre-October 2022 Australian Federal Budget Submission; On behalf of Royal Australian and New Zealand College of Psychiatrists, RANZCP; Trollor; July 2022; Written Submission
- Draft Australian Evidence-Based Clinical Practice Guideline for ADHD-consultation; Discipline of Psychiatry and Mental Health, UNSW Medicine & Health, The Department of Developmental Disability; Trollor, Weise; March 2022; Written Submission

- Queensland Government, Parliamentary Inquiry into Mental Health Services in Queensland on behalf of RANZCP QLD Branch Submission to the Parliamentary Inquiry into Mental Health Services in Queensland 2022; Trollor, Franklin; February 2022; Written Submission
- Inquiry into the opportunities to improve mental health outcomes for Queenslanders; On behalf of Discipline of Psychiatry and Mental Health, UNSW Medicine & Health, The Department of Developmental Disability Neuropsychiatry 3DN; Trollor, Weise; February 2022; Written Submission.

Conference Presentations & Lectures

National Audience

Keynote

- Supporting the Health and wellbeing of people with intellectual disability in and beyond prisons; Health Care in Secure Settings conference 2022; run by Justice Health and Forensic Mental Health Network; NSW Health, ICC Sydney; Trollor, J., Dowse, L., Srasuebkul, P. 9 June 2022.

Invited

- Lawson, L., Richdale, A., Chalmers, A., Uljarevic, M., Morris, E., Arnold, S. R. C. & Trollor, J. (2022, November 28-29). Transdiagnostic pathways to understanding anxiety and depression in autistic adolescents and adults [Conference presentation abstract]. Australian Society for Autism Research (ASfAR) Conference, Geelong, Victoria. <http://asfar.org.au/>
- Arnold, S. R. C., Scott, K., Marie, T., Santina, T., Huynh, D., Mason, B., Desai, A., Foster, G., Green, S., Walsh, J. & Trollor, J. (2022, November 24-25). The Contribution Project [Invited conference presentation]. Professional Association of Nurses in Developmental Disability Australia (PANDDA) 33rd PANDDA Conference: Nurses Engineering Health Pathways, Sydney, NSW, Australia. <http://www.pandda.net>
- Using Mortality Data to Improve Health Care for People with Intellectual Disability; Trollor, J., NHMRC Research Translation Symposium; Online; 18th November 2022
- Using linked administrative data to understand the health and wellbeing of people with intellectual disability in custody; Trollor, J., Trofimovs, J., Corrective Services; Online; 16th November 2022
- Health Care for People with Intellectual and Developmental Disabilities, An Overview of the Australian Landscape; Trollor, J., American Association of Developmental Medicine and Dentistry; Online Webinar; 16th November 2022
- Arnold, S. R. C., Hind, T., McVilly, K., Mason, B., Desai, A., Foster, G., Green, S., Walsh, J. & Trollor, J. (2022, November 4 & 9). Contribution is at the heart of inclusion, being involved and being valued [Conference presentation abstract]. Australasian Society for Intellectual Disability (ASID) 2022 Annual Conference, Online. <https://asidconference.com.au/>
- Providing Better Health Care for People with Intellectual Disability; Trollor, J., PHN TAS; Online Webinar; 31st October 2022
- Building Capacity to Meet the Health Needs of People with Intellectual Disability; Trollor, J. NSW Health; Sydney; 28th October 2022

- Dementia in People with Down Syndrome; Trollor, J. Down Syndrome Queensland, Webinar; 17 October 2022
- Utility of Data Linkage in Disability and Mental Health Research; Trollor, J., Watkins, T., Srasuebkul, P., Cvejic, R., Reppermund, S., Weise, J. UNSW Psychiatry and Mental Health Academic Forum; 28th September 2022
- Utility of Analysis of Linked Data in Disability Health Care; Trollor, J., Department of Health Disability Data Working Group; 14 September 2022
- Considerations for the NDIS of the AAT in Relation to People with Intellectual and Developmental Disabilities: A Neuropsychiatrists Perspective; Trollor, J., Annual Conference of the National Disability Insurance Scheme Division (NDIS) of the Administrative Appeals Tribunal, Clarence St, Sydney; 14 September 2022
- Numbers, K (2022, September). Understanding the Brain: Where we've been and where we're going. Invited talk, Ku-ring-gai City Council.
- Lessons from the Future - Looking Back to Better Look Forward An adult psychiatrist's view; Trollor, J., Huang, Y., Neurodevelopmental and Behavioural Society of Australasia, 9th Annual Conference, Sheraton Hotel, Sydney; 27 August 2022
- Numbers, K (2022, August). The Brain: Past, present, and future. Invited talk, Malabar City Council
- Arnold, S. R. C., Higgins, J., Weise, J., Pellicano, E., & Trollor, J. N. (2022, May 15-19). Diagnosis of autistic burnout [Conference presentation abstract]. The Royal Australian & New Zealand College of Psychiatrists 2022 Congress, Sydney, NSW, Australia. <https://www.ranzcp2022.com.au/>
- Using Linked Data to Understand the Health Needs of People with Neuropsychiatric Disorders Focus on People with Intellectual Disability; ACI Population Health Research Network Linkage Luminaries Webinar Series; Online; Trollor, J., 11 May 2022
- Working to Improve the Mental Health of People with Intellectual Disability: the doctor as advocate; Trollor, J. Online, Health Education and Training Institute (HETI); 5 May 2022
- Working to Improve the Mental Health of People with Intellectual Disability: Working with the individual; Trollor, J. Online, Health Education and Training Institute (HETI); 5 May 2022
- People with disabilities: COVID-19 considerations; ATAGI; Online; Trollor, J., 27 April 2022
- (2022) Improving palliative care services for people with intellectual disability. Concord Hospital Palliative Care Education Session, Cvejic, R. C.,* & Hagos, A invited speaker (virtual)
- Reppermund S, Walker A, Cvejic R, Srasuebkul P, Wand A, Draper B, Trollor J (2022). Self-harm and dementia - using big data to improve outcomes and

inform strategies for self-harm and suicide prevention. Talk given at the Australian Dementia Research Forum, virtual conference. This talk won an award for best oral presentation in Public Health and Prevention

- Reppermund S, Walker A, Cvejic R, Srasuebkul P, Wand A, Draper B, Trollor J (2022). Self-harm and dementia. Protocol of an inclusive research project to inform strategies for self-harm and suicide prevention. Talk given at the Society for Mental Health Research Conference, Hobart, Australia
- Reppermund S (2022). Assessment of Activities of Daily Living to detect early cognitive impairment: Differences between performance-based versus informant-reported measures. Invited talk at Occupational Therapy Australia National Working with Older People Interest Group (virtual webinar)
- Numbers, K., Lam, B. C. P, Crawford, J. D., Kochan, N. A., Sachdev, P. S., & Brodaty. (2022). Dyadic patterns of subjective cognitive reports as predictors of incident dementia. Talk presented as part of a Featured Research Session (FRS) at the 2022 Alzheimer's Association International Conference (AAIC). Hybrid-San Diego, CA, USA/Virtual Conference.

Other – Community Engagement

- Systemic neglect in the health care of people with intellectual disability: evidence and implications for LHD services; Trollor, J., Grand Rounds, Wollongong Hospital; Wollongong; 1st December 2022
- Intellectual Disability and Severe Mental Illness: Implications for Assessments, Supports and Services; Trollor, J., Gunaratne, P., Westmead Ground Rounds, Westmead Hospital; 24th November 2022
- Intellectual Disability Mental Health Resources, Intellectual Disability Mental Health Connect Webtool pilot; Trollor, J. SESLHD Clinical Council; Online; 24th November 2022
- UNSW Sydney MEDSoc address; Trollor, J., Sydney, Australia; 23 September 2022
- Capacity Building in Intellectual Disability Health Care- A National Perspective; Trollor, J., AADDM 2022 Conference; Sydney, Australia; 29 August 2022
- Pharmacological Approaches to Behaviours of Concern; Trollor, J., AADDM 2022 Conference; Sydney, Australia; 29 August 2022
- Introduction to 3DN; Trollor, J., UNSW Sydney, HDR Seminar; 9 August 2022
- Intellectual Disability and Severe Mental Illness: Implications for Assessments, Supports and Services; RANZCP Congress 2022, ICC Sydney; Trollor, J., 18 May 2022
- UNSW Sydney, New College Postgraduate Village 2022 Easter Formal Dinner; Guest of Honour Trollor, J., 14 April 2022

- (2022) Digital health and disability inclusion. Talking HealthTech Summer Summit; Mason, G., Simmons, L., Perkins, J., & Cvejic, R. C. (online).
- (2022) Everyone has the right to high-quality palliative care. Talking HealthTech podcast 241; Cvejic, R. C. (online).
- (2022) Janelle Weise and Preeyaporn Srasuebkul. Using data to identify and respond to the health needs of people with intellectual disability. Given to CESPHE disability network
- (2022) Karen R Fisher, Peri O'Shea, Janelle Weise, Aimee Blackam. Evaluation of the Intellectual Disability Mental Health tertiary services – Intellectual Disability Mental Health peer expertise informing practice improvement. Given to ACI.

Regular Teaching Contributions

- Introduction to Intellectual Disability in Health Care; Trollor, J., Zhao, J., On-line Lecture for Phase 1 Medical Students; UNSW Sydney; 10 May 2022
- Intellectual Disability Mental Health: Webinar for Health Staff; Trollor, J., Zhao, J., Northern Sydney Local Health District; Online Webinar; 24 June 2021, 14th November 2022, 28th November 2022.

Engagement

- Mental illness in adults with intellectual disability; Psych Matters, Royal Australian and New Zealand College of Psychiatrists RANZCP; Podcast; February 2022; (O'Connor, Trollor, Franklin, Bennett, Bathgate, Hind, Eagleson) <https://psychmatters.ranzcp.org/1072258/9407341-mental-illness-in-adults-with-intellectual-disability-assessment>.

Media

Television interviews

- Arnold, S. R. C. & Trollor, J. (2022, June 17th). Feature segment on Channel 9 evening news Sydney on the Contribution gallery at UNSW Wallace Wurth atrium.

Television mentions

- PM with Linda Mottram 6:30pm to 7:00pm | ABC (Perth, Geraldton, Albany, Esperance, Broome, Bunbury, Kalgoorlie, Karratha, Newcastle, Muswellbrook, Gosford, Wagga Wagga, Lismore, Tamworth, Port Macquarie, Coffs Harbour, Orange, Horsham, Warrnambool, Shepparton, Ballarat, Wollongong, Bega,

Bendigo, Mildura, Launceston, Canberra, Dubbo, Sale, Albury-Wodonga, Hobart, Melbourne, Sydney) | 17 March 2022

- ABC News 7:00pm to 7:30pm | ABC (Adelaide, Hobart) | 17 March 2022, 7:49pm AEDT
- News Bulletin 8:00am to 6:05pm | Sky News Extra (Australia) | 6 June 2022, 5:16pm AEST.

News articles

- Linda never leaves her son Jacob alone in hospital – and she's certain it has saved his life ABC News | by Celina Edmonds 4 March 2022, 6:01am AEDT
<https://www.abc.net.au/news/2022-03-04/health-inequality-faced-by-people-with-intellectual-disability/100872226>
- Jamila's disability is debilitating but invisible, which can lead to anxiety ABC News | by Charles Brice 17 March 2022, 6:09am AEDT health treatments are tailored for those with a variety of disabilities. Neuropsychiatrist Julian Trollor, from the University of New South Wales, said specific groups seem to be experiencing even higher rates of anxiety.
<https://www.abc.net.au/news/2022-03-17/learning-to-live-with-disability-and-anxiety/100907442>
- Hospitals only note a person's intellectual disability 20% of the time – so they don't adjust their care The Conversation | by Adrian Raymond Walker, Julian N. Trollor 3 May 2022, 11:30am AEST However, our study suggests most of the time, when a person with intellectual disability goes to hospital, this does not happen because the hospital remains unaware of their needs. By Adrian Raymond Walker, Julian N. Trollor. <https://theconversation.com/hospitals-only-note-a-persons-intellectual-disability-20-of-the-time-so-they-dont-adjust-their-care-180590>
- Opinion Hospitals rarely adjust their care for a person living with an intellectual disability University of New South Wales | by Adrian Raymond Walker 4 May 2022, 12:01pm AEST Adrian Raymond Walker, Research Officer - School of Psychiatry, UNSW Sydney and Julian N. Trollor, Professor, Medicine and Health, UNSW Sydney
<https://newsroom.unsw.edu.au/news/health/hospitals-rarely-adjust-their-care-person-living-intellectual-disability>
- Hospitals only note a person's intellectual disability 20% of the time – so they don't adjust their care Croakey | by Alison Barrett 6 May 2022, 2:18pm

AEST...recognition of intellectual disability in health care and service records is “critical” to the care of people with intellectual disabilities, according to Adrian Raymond Walker and Professor Julian N. Trollor at the University of New South Wales. <https://www.croakey.org/hospitals-only-note-a-persons-intellectual-disability-20-of-the-time-so-they-dont-adjust-their-care/>

- Hospitals only note a person's intellectual disability 20% of the time Health Times | 17 May 2022, 11:20am AEST Adrian Raymond Walker, Research Officer - Psychiatry and Mental Health, UNSW Sydney and Julian N. Trollor, Professor, Medicine and Health, UNSW Sydney
<https://healthtimes.com.au/hub/disability/73/news/nc1/hospitals-only-note-a-persons-intellectual-disability-20-of-the-time/6966/>

Radio / Podcast Mentions

- 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>
- The Kenny Report 5:00pm to 6:00pm | Sky News (Australia) | 7 February 2022, 5:37pm AEDT
- NEWSRADIO MORNINGS 9:00am to 12:00pm | ABC NewsRadio (Australia) | 4 March 2022, 11:54am AEDT
- News Radio Breakfast 5:30am to 9:00am | ABC NewsRadio (Australia) | 6 March 2022, 6:18am AEDT

Awards

Katya Numbers - Arc PGC Research Supervisor Award – UNSW Sydney Faculty of Medicine & Health

Staff Picture



Acknowledgements

Thank you to all 3DN Staff and Partners.

Support Our Research

We appreciate your interest in our projects and research.

Donations to our department will assist our work to ensure the highest attainable standard of mental health and wellbeing for people with intellectual or developmental disability.

Donations to 3DN

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) 9065 8076 or via dddn@unsw.edu.au