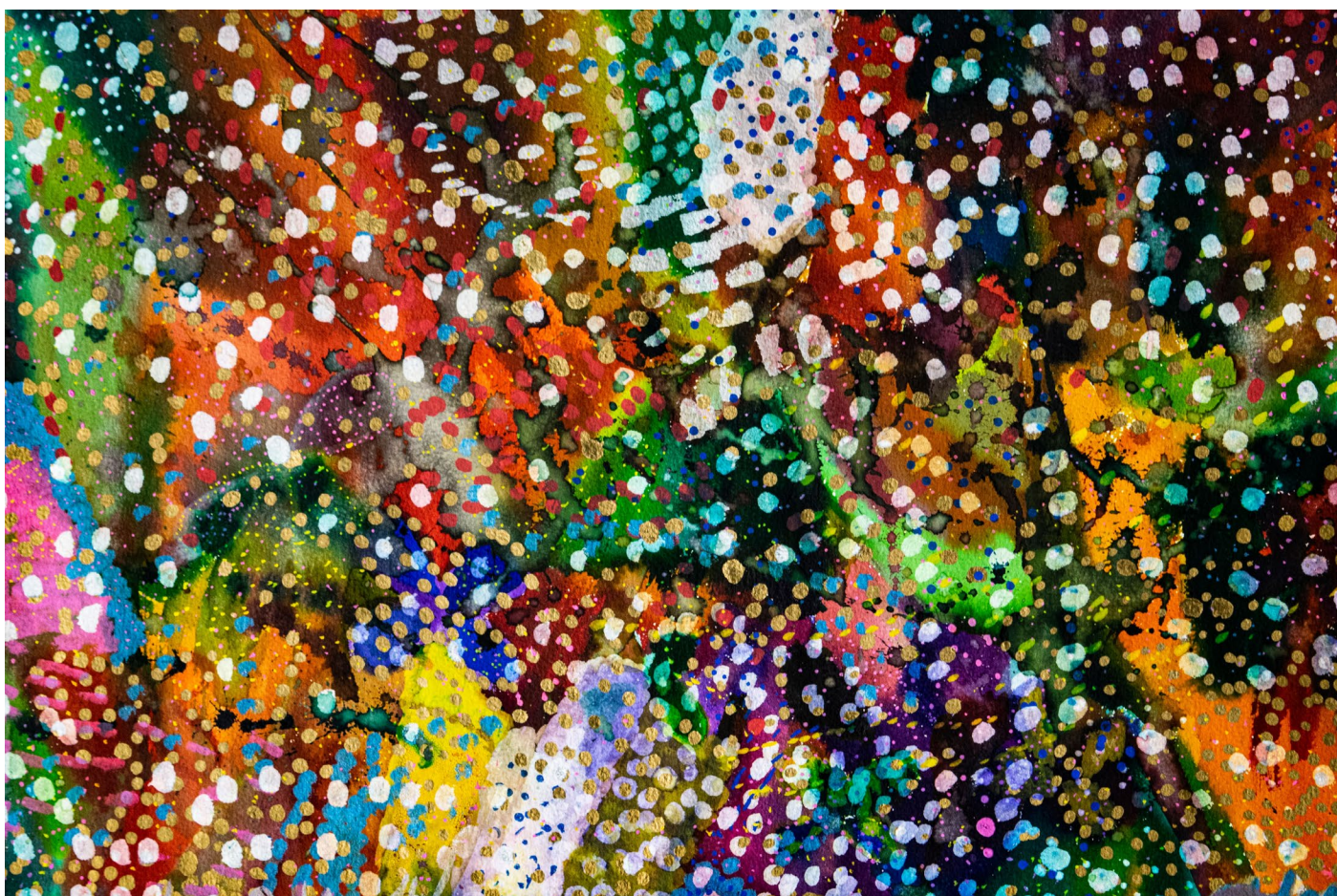




The Department of Developmental Disability Neuropsychiatry (3DN) 2020 Annual Report





2020 The Department of Developmental Disability Neuropsychiatry Annual Report

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

34 Botany St

UNSW Sydney

UNSW Sydney NSW 2052 Australia

Telephone +61 2 9065 8076

Facsimile +61 2 9931 9154

Email dddn@unsw.edu.au

Website 3dn.unsw.edu.au

Cover Image Colour Field by Melanie Newman, Studio Artes

Editors Rachel Roth & Julian Trollor

Design Rachel Roth

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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

In a year full of global and local challenges, it has been a privilege to oversee a body of work at 3DN which has had real impact. As with any organisation, 3DN staff had to rapidly adapt to the COVID-19 situation. We were fortunate that most of our projects were adaptable to this new way of working and all of our staff and students showed exemplary spirit as we adjusted to the 'new normal'.

The year commenced with a flurry of activity. 3DN provided significant leadership in mobilising the national response to COVID-19 for people with disability. We continue to be actively engaged in this endeavour through a formal appointment to a National Advisory committee. The start of the year was also remarkable because of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. 3DN's work featured in three of the public hearings that occurred throughout 2020 and was important to the Commission in understanding the gaps in health and wellbeing for people with intellectual or developmental disability.

The year has been wonderfully productive across multiple domains. The Australian Longitudinal Study of Autism in Adulthood and related studies about autistic burnout and other aspects of autism have been incredibly productive. The support we have had from the autistic community has been remarkable and the findings from the study continue to inform the current situation for autistic adults and the future tasks ahead as we seek to improve health and wellbeing for those on the autism spectrum. Our other longitudinal study the SAGE ID, or Successful Ageing in Intellectual Disability study wrapped up at the end of 2020. I am very grateful to Dr Liz Evans who has led this study for her dedication and development of the translational resource that will improve the ability of health professionals to respond to ageing and dementia in people with intellectual disability.

This year has seen the launch of significant resources. In a first, our Web App MySigns was released. This app helps facilitate mental health assessments of people with intellectual disability by allowing the collaborative use of a catalogue pictures and videos relating to the person's mental health and wellbeing. This is a truly unique project which will be of value in the clinical setting for people with disability and those who support them as they liaise with the health care providers. We launched another highly innovative resource in the second half of the year- the ID Health Data Portal. This project has created a web-based user interface which is used by all local health districts in NSW to understand the profile of people with intellectual disability living locally, when and why they use acute health services, and the associated pattern and costs of this health service use. This assists local health districts to plan their response to this population's needs. Such a project illustrates the transformative power of administrative data when it can be returned for use by the service systems which initially collected it.

We have continued to lead in the field of education about the health and wellbeing of people with intellectual and developmental disabilities. We have created new modules in our IDMH e-learning portal as well as planned for the future of our portal in a new platform. We partnered with the Northern Sydney Local Health District to provide a training and equipping programme for capacity building. We have presented at numerous public and professional forums online.

Our data linkage work has continued to be incredibly productive, delivering important findings in areas as diverse as intellectual disability, motor neuron disease, schizophrenia, younger people in residential aged care, and dementia. The importance of our work with large, linked data infrastructure has been recognised with a formal appointment to a formal role on the Advisory Committee for the development of the new National Disability Data Asset.

Several large projects commenced in the second half of 2020. These include ILC IDMH Service Pathway Web-tool, my project funded by the NDIS. This will enable us to develop resources to assist mainstream mental health services in their task of delivering better mental health support and improved clinical pathways through their services. The second large project which commenced was Improving Palliative Care Services for People with an Intellectual Disability, funded by the Department of Health. This project utilises a mixed methods approach to examine access to palliative care for people with intellectual disability and will develop a new model of palliative care service provision for his group.

Mid-year, we were delighted that New South Wales Health provided their contribution to the funding of the continuation of the UNSW Chair for the next five years. We are very grateful for this endorsement of the significance of our work. We also thank all those organisations and individuals who have funded the work undertaken in 2020. Funding is a critical issue. All our work is undertaken with external funding provided through project funding, grants and donations. Your ongoing support will enable us to address the substantial health inequality experienced by people with intellectual or developmental disability.



Research Activities

The Year in Review

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).

Milestones achieved

- Development and submit manuscript/s – Further papers submitted including on Employment and Community Mobility.

Milestones to be achieved: next 3-6 months

- Develop key knowledge translation outputs (e.g., resources/information packages for autistic people, carers/ support people and health professionals)

- Areas for discussion (milestones, budget, scope) Continuation of ALSAA beyond current funding.

2020 Annual Report

ALSAA has progressed well in gathering a large sample of Time 2 data and progressing related outputs. We are on track to deliver a comprehensive dataset relating to autistic adults in Australia. Scholarly outputs related to the majority of project aims have been published or are in final stages of manuscript development and submission. Particular outputs of note in this year have included topic areas of adulthood diagnosis of autism, longitudinal predictors of quality of life, the impact of sleep on mental health for autistic adults, and relationships between anxiety and intolerance of uncertainty.

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



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.

Overarching Project Milestones

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

Milestones achieved

- Phase 1 GDM study completed
- Phase 2 survey study recruitment has exceeded expectations.

Milestones to be achieved: next 3-6 months

- One journal article submitted
- Second journal article to be developed.

2020 Annual Report

Good progress with results of phase 1 research well received at the ASfAR conference. A manuscript regarding phase 1 outcomes is currently under review. Phase 2 study recruitment has exceeded expectations and related outputs will be produced early next year.

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- total budget \$401,255 ex GST

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.

Milestones achieved

- Finalised a Toolkit to support the use of the Easy Read resources
- Incorporated feedback from people with intellectual disability on the accessibility, content and design of the resources.
- Forwarded resources to NSW Health for final approval

- Developed a promotional video for people with intellectual disability and family and support persons.
- Designed a webpage to house the resources
- Milestones to be achieved: next 3-6 months
- Receive final approval from NSW Health
- Finalise Easy Read resources and Toolkit for publication
- Finalise webpage for resources
- Release and promote resources to i) NSW public health mental health staff and ii) people with intellectual disabilities and their supporters
- Areas for discussion (milestones, budget, scope)
- Final revisions after NSW Health review
- Recorded introduction video for mental health staff
- Stakeholder promotion list
- Further funding required for
- The development of further health and mental health Easy Read resources
- Evaluation of the effectiveness of Easy Read material.

2020 Annual Report

A suite of Easy Read resources summarising the Mental Health Act, rights and responsibilities of people receiving mental health care, the mental health service sector, and orientation to inpatient services was developed in 2020 using a co-design approach. The draft resources were reviewed by people with intellectual disability and their suggestions incorporated into the final versions. A short animation introducing the resources has been developed. Introductory videos for health professionals and the project webpage are also in development. The resources will be launched before the end of the year.

Weblink:

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

Extra Dataset projects

Years: Ongoing; Sponsor: None; Amount; Unfunded

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

Project Overview

3DN has been working on several other projects related to ID health. They are documented here.

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).

Milestones achieved

- Data analysis completed for project
- Manuscript drafted and awaiting review for submission.
- Initial analysis completed
- New analysis plan completed and awaiting new analysis.

Milestones to be achieved: next 3-6 months

- Submit manuscript for publication to an academic journal
- Complete new data analysis.

Annual Report

- Analysis has been conducted and a paper drafted for the comparison of underlying causes of death project. The paper is under internal review for journal submission.
- Analysis plan has been finalised for impact of ID labelling on health service trajectory, and data analysis has begun. Analysis will continue and a paper written in 2021.

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.

Milestones achieved

- Launched the web tool
- Evaluation of the web tool underway
- Preparation of peer review publication(s)
- Preparation of final report.

Milestones to be achieved: next 3-6 months

- Continue to work with the five sites that have not registered users for the tool
- Analyse evaluation data
- Submit final report
- Prepare draft of peer review publications.

Further funding required for: To keep the tool up to date further funding would be required to refresh the data. The tool could be expanded to host other related data e.g., data on potentially preventable hospitalisations.

2020 Annual Report

- The ID health data portal was finalised and launched in October 2020.

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>



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

Years: 2017-2021; 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

Publications and resources relating to the following aims:

- 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.

Milestones achieved

- Received data from CHeReL and AIHW.

Milestones to be achieved: next 3-6 months

- Data cleaning and commencement of data analysis

- Areas for discussion (milestones, budget, scope)
- Discussion with investigators to extend the project
- Discussion with investigators on priority areas.

2020 Annual Report

We are currently receiving the linked data from the CHeReL and AIHW. Once the data cleaning process has been completed at the end of 2020, the main deliverables for 2021 are a cohort profile paper, and two outputs on health service access and medication use in people with intellectual disability.

ID Health Education BY 3DN

2010 – Current, No current funding Sponsor: Nil, 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.

Milestones achieved

- Reviewed previous e-learning contracts and engaged NSW Health in contract negotiations to commercialise our material
- Assisted Sage-ID project with creating dementia modules to launch on our e-learning site
- Worked with new platform, Go1, to create a personalized portal for our users
- Developed pricing and engaged Go1 customer success team in discussion about subscription packages (to be launched in Phase 2).

Milestones to be achieved: next 3-6 months

- Finalise Offending module draft
- Provide notice to existing e-learning users about the transition
- Refresh already created promotional materials with updated information and new logo
- Contact Kademi to close down existing platform
- Update 3DN website pages and other resources with new e-learning information
- Launch new e-learning platform.

Areas for discussion (milestones, budget, scope): New e-learning platform hopefully to launch before end of 2020

Further funding required for: Personnel costs to develop and maintain modules.

2020 Annual Report

- Launched one disability module on Identifying and Responding to Abuse
- Drafted disability module on Offending Behaviours

- Worked with Go1 to discuss our business plan and customize our Portal
- Engaged NSW Health in contract negotiations to ensure IP ownership and right to commercialise
- Hope to launch new platform before end of 2020.

Weblink: www.idhealtheducation.edu.au



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, & 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.

Milestones achieved: last 3 – 6 months

- Knowledge Translation and Risk Assessment plans developed
- Initial meetings with Consortium Partners
- Formation of Project Advisory Group
- Recruiting for Consumer Advisory Group
- Recruitment process initiated for researcher with lived experience
- Literature review completed
- UNSW Ethics for consultations drafted
- NSW Health Ethics application for staff survey in development
- In principle support from SESLHD to pilot Tool.

Milestones to be achieved: next 3-6 months

- Hold first Project advisory Group and Consumer advisory group meetings
- Recruit researcher with lived experience
- Obtain ethics approval for consultations
- Complete consultations with people with ID, support networks, and mental health professionals
- Analyse consultation data
- Engage further LHD/SHN pilot sites
- Engage with potential web developers
- Areas for discussion (milestones, budget, scope)
- Recruitment of researcher with lived experience
- Mind map of Tool
- Consultation plan
- Ethics applications.



Using big data to understand the health status, service use, and service pathways of people with less common types of dementia

2018-2020, Dementia Australia Research Foundation, \$49,338

Project Team: Rachael Cvejic, Julian Trollor, Simone Reppermund, Brian Draper, Preeyaporn Srasuebkul, Janelle Weise, and Jess Walsh.

Project Overview

This study uses linked data from a large sample of people with less common types of dementia in NSW to describe patterns of mental and physical health problems and how they use health services. Findings will be compared to the NSW general population and to other more common dementia syndromes. This will inform the development of specific strategies that will allow health services to better meet the needs of people with less common types of dementia.

Overarching Project Milestones

- Data analysis
- Three rounds of consultation with dementia advocate
- Develop three resources to communicate findings to people living with dementia, their care partners, and health professionals
- Peer review publication
- Final report.

Milestones achieved

- Final report completed and submitted
- Resources with dementia Australia for approval to disseminate.

Milestones to be achieved: next 3-6 months

- Disseminate findings
- Prepare manuscripts for publication.

Further funding required for: Further funding to establish a larger program of work, which will inform health service needs of people with less common forms of dementia and will assist in guidance of health policy and services development for affected individuals.

2020 Annual Report

- Data analysis completed
- Consultation with Dementia Advocates completed
- Finalised resources to communicate findings to people living with dementia, their care partners, and health professionals
- Final report submitted and approved by funder
- Manuscripts in preparation.

Weblink: <https://3dn.unsw.edu.au/project/using-big-data-understand-health-status-service-use-and-service-pathways-people-less-common>



Using big data to understand the health status and service use of people with motor neurone disease

2019-2020 MND Research Institute of Australia \$95,476

Project Team: Rachael Cvejic, Carol Birks, Matthew Kiernan, Preeyaporn Srasuebkul, Janelle Weise, Claire Eagleson & Julian Trollor

Project Overview

People with motor neurone disease (MND) have complex care needs and require multidisciplinary support. Few studies have investigated health service use of people with MND and none had a specific focus on mental health use. This was a significant gap as people with MND have higher rates of some mental health disorders. This study aimed to describe and understand the mental health needs of people with MND and how they use mental health services through analysis of linked data from a large sample of people with MND in NSW. To understand the specific needs of people with MND, we compared findings for people with MND with those of people with other progressive neurological disorders and the NSW general population. This will help to inform the development of specific strategies that will allow mental health services to better meet the needs of people with MND.

Overarching Project Milestones

- Creation of project reference group
- Approval to use existing linked datasets by the NSW Centre for Health Record Linkage (CHeReLL): NSW Admitted Patients Data Collection, NSW Mental Health Ambulatory Data Collection, NSW Registry of BDM
- Using linked dataset, describe the characteristics of a population-based data linkage cohort of people with MND in NSW, including mental health profiles and common patterns of comorbidity.
- Quantify mental health service use of people with MND and compare findings to an appropriate neurological cohort and published statistics from the NSW general population.
- Quantify the impact of mental health concerns in people with MND on health service use.
- Consumer consultation interviews around i) interpretation of statistical analysis results and ii) plans for knowledge translation resources summarising the study results for people with MND, carers, and health professionals.
- Development of results resources for people with MND (including plain English version), carers, health professionals, and postcard for GPs/neurologists.
- Dissemination of results resources through website and MND Australia networks.
- Final report.

Milestones achieved

- Completed consultation with consumers
- Developed results resources

- Received feedback on results resources from MND Australia and project reference group
- Finalised resources and disseminated via 3DN/MND websites, MND Australia networks, and social media
- Submission of final report.

Milestones to be achieved: next 3-6 months

- Write publications for peer-reviewed journals
- Areas for discussion (milestones, budget, scope)
- Future funding opportunities.

Further funding required for: Linkage to other State and Commonwealth datasets including i) the MND Registry, ii) the NSW Cancer Registry, iii) NSW Notifiable Conditions, iv) Medicare Benefits Schedule, and v) Pharmaceutical Benefits Scheme. This would facilitate the discovery of determinants of health and health resource utilisation and costs, and the development of specific strategies and health policy to allow health services to better meet the needs of people with MND. Analysis of other sources of information on health service usage, such as GP records.

2020 Annual Report

- Data analyses complete
- Consultation with advisory group completed
- Launched resources for people with MND (including plain English version), carers, health professionals.
- Final report submitted to funder
- Manuscript in preparation.

Weblink: <https://www.3dn.unsw.edu.au/projects/using-big-data-understand-health-status-and-service-use-people-motor-neurone-disease>

MySigns: An app to facilitate mental health assessment of people with intellectual disability

2018 – 2020 NSW Health Innovation Grant \$184,260

Project Team Jenna Zhao, Janelle Weise & Julian Trollor

Project Overview

This project involves the development of a web application that can be used to support mental health assessment of people with intellectual disability and significant communication difficulties. The tool is to be used collaboratively between the person with intellectual disability, their carers and their mental health clinician. The app catalogues the unique objective mental state indicators for a person with intellectual disability who has difficulties with communication. Carers will use the resource to compile the person's unique catalogue, adding objective indicators and tagging their subjective correlate (e.g. recording the person's distinctive moaning that correlates with their feeling of anxiety). MySigns entries can be shared with the person's mental health clinician to assist in the person's clinical management.

Overarching Project Milestones

- Development of and user testing with a wireframe prototype
- Development of web application (build and test)
- Launch of web application
- Evaluation of web application using user survey data and website analytics
- Produce a final report.

Milestones achieved

- Final report written and delivered to NSW Health and GMO.

Milestones to be achieved: next 3-6 months

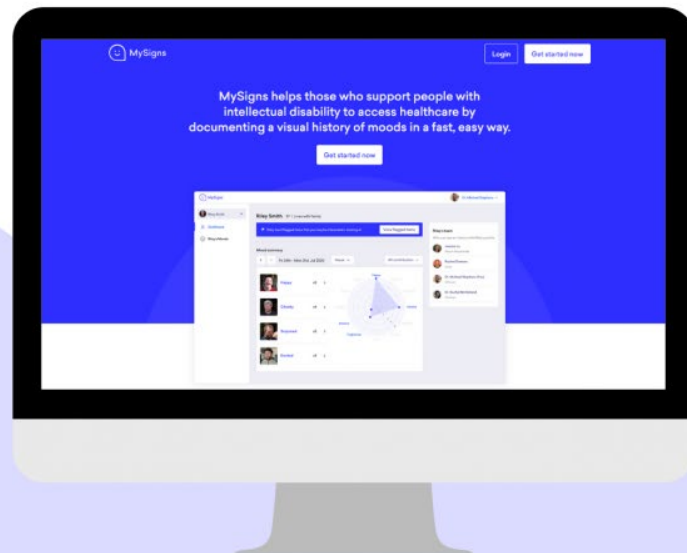
- Evaluation is underway and data to be looked at in July 2021.
- Areas for discussion (milestones, budget, scope)
- Project ended except for ongoing evaluation.

Further funding required for: Additional functionality and nice-to-have features and continued running costs (e.g. monthly payments to Amazon)

2020 Annual Report

- MySigns prototype tested on potential end users
- MySigns user interface and branding designed and implemented
- MySigns app built
- MySigns launched and promoted
- Ongoing evaluation of MySigns in place
- Final report delivered

Weblink: www.mysigns.health



3DN AT UNSW SYDNEY HAVE DEVELOPED

MySigns

an app to facilitate mental health assessment for people with intellectual disability.

MySigns is free to access on phone and computer.

Find out more and sign up at

www.mysigns.health



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DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



UNSW
SYDNEY

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.

Milestones achieved

- Reviewed and compared the online and existing draft face-to-face resources
- Worked closely with NSLHD to develop and refine face-to-face training materials for Level 3 workshop
- Created a virtual library of resources to accompany training workshop
- Contributed to the development of a framework for evaluation of training materials
- Co-facilitated the Level 3 face-to-face workshop in October 2020.

Milestones to be achieved: next 3-6 months

- Work closely with NSLHD to develop and refine face-to-face training materials for Levels 1 and 2
- Design and develop materials for the Train-the-Trainer workshop
- Deliver the Train-the-Trainer workshop
- Areas for discussion (milestones, budget, scope)

- The Level 3 workshop has been developed and delivered
- Train-the-Trainer is due to be run in January with the Level 1 and 2 workshops to be run in February-June.

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- Designed and drafted workshop materials for Levels 1, 2 and 3
- Contributed to the online implementation of training by participating as experts in Expert Reference Group meetings
- Produced one podcast to be used in the program
- Reviewed and compared the online and face-to-face resources
- Contributed to the development of an evaluation framework for the program
- Refined and finalized Level 3 workshop materials
- Co-facilitated the Level 3 workshop in October 2020.



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 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
- Ethics approval for 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.
- Final report.

Milestones achieved

- Project commenced October 2020.

Milestones to be achieved: next 3-6 months

- Establish project reference group
- Apply for ethics approval for data linkage work
- Prepare ethics application for stakeholder consultations
- Commence systematic review
- Areas for discussion (milestones, budget, scope)
- Scope for data linkage studies.

Further funding required for: No items identified at this stage.

2020 Annual Report

- Work for this project commenced in October 2020. We are currently preparing to seek ethics approval for the various aspects of this work.

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

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

- Submission of manuscript to MJA – currently under review.

Milestones to be achieved: next 3-6 months

- Respond to reviewers feedback
- 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)
- Our analysis show that people with ID are up to 4.5 times more likely to have a PPH compared to the general population in NSW. Action is required to reduce rates of PPH for people with ID.

SAge-ID Study (Successful Ageing in Intellectual Disability)

Years 2016 – 2020 NHMRC & ARC Dementia Research Fellowship \$468,151.20

Project Team: Liz Evans & Julian Trollor

Project Overview

Compared with the general population, people with intellectual disability may be more likely to experience age-related illnesses such as dementia. We currently lack a 'gold standard' approach to the diagnosis of dementia in people with intellectual disability. The Successful Ageing in Intellectual Disability Study (SAge-ID) is investigating the correlates of physical and mental health problems, including dementia, in older adults with intellectual disability, aged 40 plus. It also examines the well-being and care-giving experience of carers of older people with intellectual disability and evaluates the usefulness of selected instruments to assess dementia in people with intellectual disability. The project received additional funding in 2016 from the Australian Research Council and National Health and Medical Research Council, allowing us to include more participants in the study, and to examine models of care for people with intellectual disability who develop dementia. A further aim is to create translational resources regarding dementia in people with intellectual disability.

Overarching Project Milestones

- To contribute to knowledge regarding the correlates of dementia and dementia-related syndromes and other mental health problems in ageing adults with intellectual disabilities
- To investigate existing mental health, healthcare and support services accessed by people with intellectual disability who have or are at risk of dementia and other age-related health problems; and suggest potential improvements to pathways to care.
- To investigate mental health needs and service-use of family carers of adults with intellectual disabilities and how this relates to measures of carer stress.
- To evaluate selected instruments for screening for, and assessing cognitive decline in people with ID.
- To create Australian resources for people with ID, carers, and health professionals regarding dementia in people with ID.

Milestones achieved

- Case consensus results have all been finalized
- Data cleaning progressed
- Consultation for feedback on easy read booklet completed
- Carer resource progressed – outline finalised and most sections drafted
- Modules for health professionals refined and shortened considerably.

Milestones to be achieved: next 3-6 months

- Upload and expert review of modules, then launch
- Upload and dissemination of easy read and carer resources
- Finalise datafiles and dictionary

- Delphi paper submitted.

Areas for discussion (milestones, budget, scope): Scope and timing: This 5-year fellowship project has suffered some setbacks throughout the funding period, relating to participant recruitment, staff health and staff turnover. The project funding finishes in December 2020 and the final report is due to the NHMRC in June 2021. Resource-development work will be completed by end of 2020 and the datafile will be complete, with key data analysed. It is likely that some analysis and publications from the data will continue beyond this date. The key staff member involved in the project (Liz) intends to continue to work towards completion of these tasks as needed, beyond her contract with UNSW.

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Achievements in 2020:

- A fourth round of Delphi data was collected in the early part of the year and all Delphi data was then analysed – this resulted in a series of agreed-upon statements regarding service provision for people with ID who are at risk of, or who develop, dementia.
- Creation of content for 2 modules for health professionals on Dementia (now being refined)
- Creation of an easy read booklet on dementia for people with ID, and an accompanying booklet for carers (in draft form)
- Face-to-face training was given to a group of health professionals (March).
- Where the project is at: The project will end in December 2020.
- Future deliverables include the launch of modules and booklets, in early 2021, and future publications arising from the data.

Weblink: <https://www.3dn.unsw.edu.au/projects/successful-ageing-intellectual-disability-sage-id-study>

Addressing preventable disease burden to improve health outcomes for people with schizophrenia and related psychoses

Years: 2018-2020; Sponsor: UNSW Medicine Neuroscience, Mental Health, and Addictions, and SPHERE Clinical Academic Group Funding; Amount: \$39,500

Project Team: Rachael Cvejic, Phil Ward, Preeyaporn Srasuebkul, Simone Reppermund, Jackie Curtis, Katherine Samaras, Julia Lappin, Kimberlie Dean, Adrian Walker, & Julian Trollor

Project Overview

People with schizophrenia and related psychotic disorders are more likely to experience additional health problems and are more likely to die at a younger age than people without mental health problems. Most of the causes of early death in people with psychotic disorders are preventable, including cardiovascular disease, respiratory disease, and diabetes. This study uses linked data from a large sample of people with schizophrenia and related psychotic disorders in NSW to understand what physical health problems people with these mental illnesses have, how they access health services for these conditions, other complicating factors (e.g., contact with the criminal justice system) and how these may relate to negative outcomes including avoidable deaths. We are comparing our findings to the NSW general population and to people with other types of mental illness in NSW to discover the specific health vulnerabilities and treatment gaps. This will inform the development of specific strategies that will allow health services to better meet the needs of people with psychotic disorders.

Overarching Project Milestones

- Establish and characterise a population-based cohort of individuals with psychotic disorders in NSW, including physical and mental health comorbidities, and related service use.
- Determine the predictors of death in people with psychotic disorders, with a specific focus on predictors of potentially avoidable deaths.
- Acquire funding to build a large, linked dataset of people with schizophrenia and related psychosis for future study.

Milestones achieved

- Data analysis finished for Aim 2.
- 2 Papers drafted for Aim 1
- 1 Paper underway for Aim 2
- Drafted Plain-English for all aims, engaged a person with lived-experience of psychotic disorders to help development of resources.

Milestones to be achieved: next 3-6 months

- Publication of papers for Aim 1 and 2
- Publication of paper for Aim 3
- Disseminate Plain-English summaries for all aims
- Final report to be submitted in November.
- Areas for discussion (milestones, budget, scope)

- Aim 3 has been subsumed into a larger linkage project funded by the Research Infrastructure Scheme.
- Final report will be submitted with all papers drafted but not all submitted for publication.

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In 2020 we finalised the analysis for all three aims and are preparing for submission three papers based of this analysis (with at least one to be submitted by the end of the year). We have engaged a person with lived experience of psychotic disorders to help us develop relevant resources for GPs and other people with lived experience and their carers. These resources will likely be disseminated to GPs and advocate organisations by the end of 2020/early 2021.



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

Publications and resources relating to the following aims:

1. Determine the pathways for younger people with disabilities to RAC. We will examine clinical and sociodemographic predictors of discharge from hospital to RAC
2. Describe the health profile of younger people with disabilities discharged to RAC and compare this to a matched community-dwelling cohort
3. 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)
4. 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.

Milestones achieved

- Data analysis complete for aims 1 and 2.
- Funding secured for further two years of project from project sponsor.

Milestones to be achieved: next 3-6 months

- Complete data analysis for aim 3.

- Engage Summer Foundation regarding Aim 4.
- Submit paper for Aim 1.

Areas for discussion (milestones, budget, scope): Discussion with Summer Foundation on potential partnership grant. Develop relevant visualisations of the data for funder.

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This project saw significant progress in 2020. Data analysis was completed for aims 1 and 2, and a paper was drafted and sent out for review by the steering committee. A further two years of funding was secured from the sponsor (previously contingent on performance during the first year). A lived experience group with 9 individuals was established and 2 meetings have been conducted (with a third scheduled for December 2020/January 2021). Preliminary work has been done on Aim 3, in preparation for analysis in 2021.



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: Ongoing

Future deliverables: Manuscripts for publication, thesis submission, lay summary of results for consumers.

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: Complete the manuscript for the systematic review and prepare for the manuscript for a data project.

Oral presentation at 2020 IPDLN conference about the updates of readmissions and ED presentations after one epilepsy admission for people with Intellectual Disability

Current state of the project: Ongoing

Future deliverables: Publications and thesis. There will be two more manuscripts which will be integrated into the thesis. They are: 1) the manuscript for the socioeconomic and disability-related factors for epilepsy hospitalisation and readmission in people with intellectual disability; 2) the manuscript for the

characteristics of prescription and primary health care use in people with intellectual disability and hospitalised for epilepsy.

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

PhD Student: Julian Trofimovs

Supervisors: Julian Trollor, 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.

Achievements to date: First journal article under peer review.

Current state of the project: Ongoing

Future deliverables: Second and third journal articles are to be submitted in February 2021.

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: A scoping review of the literature has been published and data collection was completed. The first manuscript based on data has been submitted for publication. Further data analysis underway.

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: The final draft of the thesis is in preparation for submission in March 2021.

Current state of the project: Ongoing

Future deliverables: Outputs will include manuscripts for publication in academic journals, lay summary for participants and participating organisations/service providers, doctoral thesis and other translational outputs.



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.

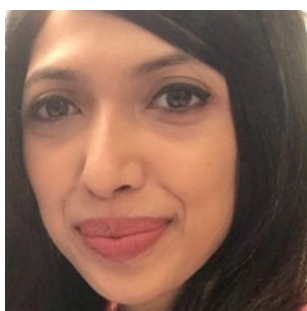


Dr Samuel Arnold

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 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.



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.



Dr Liz Evans

Research Fellow

Liz is a registered psychologist with a special interest in the mental health needs of people with intellectual disability. She is currently a recipient of an NHMRC-ARC Dementia Research Training Fellowship, which enables her to investigate age-related health and mental health in adults with ID. Liz holds a Bachelor of Psychology with First Class Honours and a PhD, both from the University of Sydney. Her PhD, awarded in 2010, was the first study worldwide investigating the behavioural phenotype of Mowat-Wilson syndrome. Liz's research interests include the mental health needs of older people with ID, and the study of behavioural phenotypes.

Qualifications:

B. Psych (Hons), Usyd; Ph.D., Usyd; Grad. Cert. OPMH, NSW Institute of Psychiatry.

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.

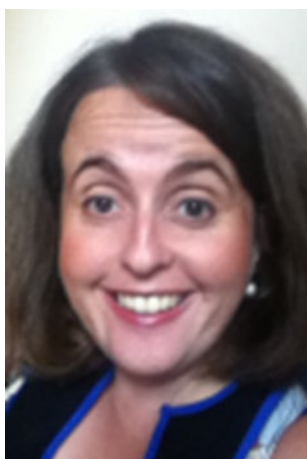


Dr Simone Reppermund

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

Research Assistant

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.

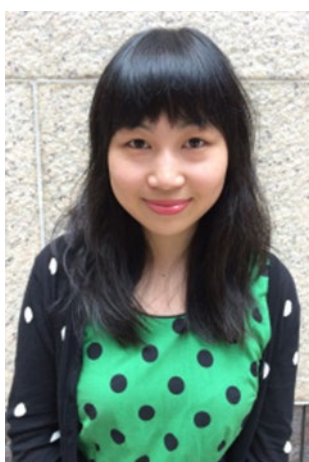
PhD Thesis Understanding uncertainty and bias to improve causal inference in health intervention research.



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 on the Intellectual Disability Mental Health (IDMH) e-learning project and the MySigns project. Jenna has a background in Psychology and educational development. She holds a Bachelor of Psychology (Hons, Class I) and a PhD in Psychology, 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 UNSW Psychology. 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

Research Funding

1. Australian Government NDIA; Development, implementation and evaluation of an interactive mental health service pathway web-tool for people with intellectual disability; 2020 – 2022; \$1,243,523 (Trollor, Weise)
2. Australian Government National Disability Insurance Agency; Building the capacity of nurses to deliver mainstream hospital and community based health services to people with Intellectual Disability and Autism Spectrum Disorder; 2020 – 2022; (\$1,188,796.91) (Cashin, Wilson, Griffin, Howie, Bryce, Buckley, Morphet & Trollor)
3. Australian Government, Public Health and Chronic Disease Grant Program National Palliative Care Projects; 2020 -2023; \$1,140,914.38; Improving palliative care services for people with an intellectual disability; (Trollor, Agar, Cvejic, Currow, Strutt, Vajdic, Chye, Srasuebkul, Weise, Reppermund, Szanto, Harlum, Tuffrey-Wijne, Greenland, Phillips)

Project Funding

1. Autism CRC; Investigating Autistic Burnout (#AutBurnout); 2020; \$37,880; (Trollor, Arnold, Weise Higgins)
2. Autism CRC; Strengths, Functioning and Support Needs: Understanding Autism Across the Lifespan; 2020-2021; \$258,000; (Trollor, Arnold, Higgins, Evans)
3. Northern Sydney Local Health District/State Government Contract; Design and delivery of the Intellectual Disability and mental Health: Specialist team and training program; 2020-2021; \$120,260; (Trollor, Weise, Zhao)

Other Funding

1. NSW Health; 2020 – 2025; \$2,500,000; Chair Funding; (Trollor)
2. UNSW Sydney, Research Infrastructure Scheme (RIS); 2020 – 2021; \$150,763; An interdisciplinary data platform to make neuropsychiatric and disability population-based research accessible and efficient; (Trollor, Reppermund, Sachdev, Brodaty, Christensen, Vajdic, Srasuebkul, Watkins, Katz, Baldry, Dean, Dobbins, Butler, Harris, Sowmya, Mohammadi)



Publications

Papers in Refereed Journals

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Reviews

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Submissions

- Public consultation on the Medical Research Future Fund Dementia, Ageing and Aged Care Mission Roadmap Dementia, Aged Care and Ageing Mission, Evans, E. 17/02/2020 Survey response <https://consultations.health.gov.au/ageing-and-aged-care/dementia-ageing-and-aged-care-mission-public-consu/>
- To include people with ID and DD in the National Mental Health and Wellbeing Pandemic Response Plan, National Mental Health Commission, Trollor, J.N. May-20 Written submission <https://www.mentalhealthcommission.gov.au/Mental-Health-and-Wellbeing-Pandemic-Response-Plan>
- Submission to the Select Committee on Autism, Arnold., S. R. C., Salomon, C., Higgins, J., Desai, A., & Trollor, J., 17/07/2020 Written submission <https://www.aph.gov.au/DocumentStore.ashx?id=d1e312a3-7be1-446d-9f96-6743a9e9d3e8&subId=686595> https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Autism/autism/Submissions
- Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Royal Australian and New Zealand College of Psychiatrists submission Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability" Trollor, J. 17/09/2020 Written submission www.ranzcp.org

- "Response to the Development of the National Preventive Health Strategy Consultation Paper"
National Preventive Health Taskforce, Trollor, J. Weise. J 30/09/2020 Written submission
- Medical Research Future Fund consultation to inform the third Australian Medical Research and Innovation Priorities 2020-2022 Aust Govt Health Trollor, J. 6/10/2020 Written submission
- Response to the National Disability Strategy position paper The Department of Social Services
Trollor Weise Oct-20 Written submission
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- Full National Palliative Care and End-of-Life Care Information Priorities consultation draft Australian Institute of Health and Welfare Cvejic, R. C., & Trollor, J. N. 6th October 2020 Survey response

Conference Presentations & Lectures

"National Audience

Keynote

- *Equality of access to healthcare for people with developmental disability; SCOPE Uni Melbourne Annual Conference; Trollor, J. Online; 12 November 2020*

Invited

- *National Disability Data Asset Inaugural Webinar with DSS Minister Hon Anne Ruston and Australian Disability Discrimination Commissioner Dr Ben Gauntlett; Trollor, J. Online Webinar; 24 November 2020*
- *Addressing health inequalities in people with intellectual disability: role of curriculum and training initiatives; Trollor, J. Australian Psychological Society: Psychology of Intellectual Disability and Autism Special Interest Group; Online; 19 November 2020*
- *Curriculum development & healthcare for people with intellectual disability; Trollor, J. Department of Health; Online; 19 November 2020*
- *Addressing health inequalities in people with intellectual disability; Trollor, J. National Round Table on Intellectual Disability Health, convened by Commonwealth Department of Health; Online; 2 November 2020*
- *Intellectual Disability Mental Health Drug & Alcohol: District Champions; Trollor, J., Zhao, J.;*

Intellectual Disability Mental Health Drug & Alcohol: District Champions Workshop Level 3 Northern Sydney LHD Education Centre, Macquarie Hospital, Ryde; 30 October 2020

- *Adult ADHD: an approach to diagnosis and treatment; Trollor, J., South East Sydney Local Health District SESLHD, Registrar Training Session; Online; 26 October 2020*
- *Addressing health inequalities in people with intellectual disability: time for action; Trollor, J., South East Sydney Local Health District SESLHD, Mental Health Grand Rounds; Online; 26 October 2020*
- *Autism spectrum disorders in adulthood: new research which informs clinical practice; Trollor, J. RANZCP Faculty of Adult Psychiatry's Inaugural Conference; Online; 24 October 2020*
- *Management of Mental Illness in People with Intellectual Disability: business as usual and COVID-19 considerations; Trollor, J. LHD and PHN professionals in Central Coast Local Health District; Online; 19 October 2020*
- *Autism in adulthood: what psychiatrists should know about assessment and management; Neuropsychiatry Registrar training, Royal Melbourne Hospital; Trollor, J. 13 October 2020*
- *Addressing health inequalities in people with intellectual disability: time for action; Intellectual Disability Mental Health Community of Practice; Trollor, J. Weise, J. Zhao, J. Eagleson, C. 6 October 2020*
- *Addressing health inequalities in people with intellectual disability: time for action; Trollor; J. INA Webinar; 23 July 2020*
- *Intellectual Disability Mental Health, Understanding Intellectual Disability and Mental Health; Trollor; J. Health Education and Training Institute (HETI); 30 April 2020*
- *Intellectual Disability Mental Health, Assessment & Management of Mental Ill Health in People with ID; Trollor; J. Health Education and Training Institute (HETI); 30 April 2020*
- *Intellectual Disability Mental Health Assessing and Managing Challenging Behaviour; Trollor; J. Health Education and Training Institute (HETI); 30 April 2020*
- *Trollor; J. COVID-19 pandemic: Prioritising the mental and physical health and well-being of people with disability; Trollor; J. NDS National Webinar; 23 April 2020*
- *Development of the Impact of Diagnosis Scale –Revised (IODS-R). Presentation at the Australian Society for Autism Research (ASfAR) Conference, Wellington, New Zealand (online). December 2020, Arnold, S. R. C., Lawson, L., Huang, Y., Hwang, Y. I., Higgins, J., Richdale, A., & Trollor, J. N*
- *Research (ASfAR) Conference, Wellington, New Zealand (online). December 2020, Higgins, J., Weise, J., Trollor, J., N., Pellicano, E., & Arnold, S. R. C.*

Other

- Choose your own adventure: Pathways to adult autism diagnosis in Australia” Poster Presentation, ASFAR 2020, Huang, Arnold, Foley, Trollor.
- Podcast; *The intersectionality between health and disability, building a Healthy Mind*; October, <https://www.teamdsc.com.au/podcast> October 2020; Trollor, J., Baldwin, P.

Regular Teaching Contributions

- *Intellectual Disability in Medical Practice*; Trollor, J., Zhao, J., On-line Lecture for Phase 1 Medical Students; UNSW Sydney; 12 May 2020
- *Intellectual Disability Mental Health*, Arnold, S., Cvejic, R., Re-occurring Lecture for Phase 3 UNSW Medicine





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