Faculty of Medicine, The Department of Developmental Disability Neuropsychiatry 3DN

2019 Annual Report

Department of Developmental Disability Neuropsychiatry (3DN)

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2019

The Department of Developmental Disability Neuropsychiatry

Annual Report

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

UNSW SYDNEY

3DN | DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

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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

What a privilege it has been for me to oversee the body of work represented in our annual report for 2019. People with intellectual or developmental disability are a substantial minority of the Australian population who experience significant health disadvantage. Our work at 3DN has seen us address this issue by making rich contributions in our core domains of Research, Building Capacity and Consultancy. Our core competencies in the area of knowledge translation, research, ideological focus, collaboration and consultation, and internal culture and collegiality have been borne out repeatedly throughout 2019. In particular these have been evident as we have worked together as a team, with colleagues from other disciplines and universities, with representatives from the disability and health sectors, and with people with disability and their advocates. The 2019 annual report represents a brief overview of the activities conducted within the department, with a specific focus on our research and project work.

With so any positives it is hard to pick specific highlights! We have seen substantial expansion of our data linkage platform work. This has seen us discover and report major findings related to health and wellbeing of people with intellectual disability and those with autism spectrum disorders. Important work has been completed to understand how deaths and drivers of deaths for these groups, as well as health service system needs and gaps. Our data work in this area is expanding rapidly. We now have PhD scholars working on projects related to cancer prevention and risk; care pathways and health outcomes in people with intellectual disability; physical health profiles and service use in intellectual disability; intellectual disability, mental health and the interaction with the criminal justice system; mental health for individuals with complex support needs; and access to mental health services for women with intellectual disability. Our data work has also expanded to other areas of interest including people with schizophrenia ana related psychoses, people with less common types of dementia, younger people in residential aged care and people with motor neurone disease.

Our capacity building in the health and disability sectors has continued. We have substantially expanded our E-Learning platform with an array of new modules, conducted training and seminars, and busied ourselves by progressing the many initiatives that arose from our 2018 National Round Table and Communique. One of our PhD scholars has worked hard to understand the utility of easy read Information about mental health for people with intellectual disability, and we have been fortunate to receive funding for the development of easy read materials for use in the public mental health sector. We have 'flipped' our linkage work on is head to work on the development of an interactive web-portal for NSW

Health services, which enables an understanding of the population demographics of people with intellectual disability within local health district (LDH) catchments, and allows a comprehensive understanding of health needs, admission and emergency presentation metrics, and benchmarks these against like LHDs. Importantly we are building in tools to assist LHDs to respond to these health needs. In a series of substantial milestones for the sector, we completed our Intellectual Disability Mental Health Core Competencies Framework Project, and our scoping work for a State-Wide Tertiary Intellectual Disability Mental Health Service. As a result of our work, we are pleased to see NSW leading in service developments nationally, including by the establishment of a new formal tertiary mental health service and other mental health enhancements.

We have also focussed on work of national importance, including being engaged by the NDIS Quality and Safeguards Commission report on the Causes and contributors to deaths of people with disability in Australia, and make a series of recommendations for action to reduce deaths. Funded by the Autism CRC, our leadership of a national study of Autistic adults, the Australian Longitudinal Study of Adults with Autism (ALSAA), has been particularly strong. We have strengthened our inclusive research practices, continued discovery about the health and wellbeing of Autistic adults, and one of our PhD scholars has produced innovative work on pathways, predictors and impact of receiving an autism spectrum diagnosis for adults in Australia.

Our work on ageing and preventative health has continued. The Successful Ageing in Intellectual Disability (Sage-ID) has completed data collection. An online Delphi study examining care pathways for people with ID and dementia has been completed, and guidelines for Australian GPs on assessing and managing dementia in people with ID have been published.

We are most indebted to those organisations and individuals who have funded the work we have undertaken in 2019. The work we undertake, including all of our staff time, is funded by grants and donations. Your ongoing support will enable us to continue our leadership of work aims to ensure the highest attainable standard of mental health and wellbeing for people with intellectual or developmental disability.

Research Activities
The Year in Review

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

Project Team: Julian Trollor, Rachael Cvejic, Phil Ward, Preeyaporn Srasuebkul, Simone Reppermund, Jackie Curtis, Katherine Samaras (St Vincent's Hospital), Julia Lappin, Kimberlie Dean, Adrian Walker

Short project description: 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 will use 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 will compare 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.

Achievements to date: We have received ethics approval and data analysis has commenced. Currently, one manuscript has been drafted, with the second set to start at the beginning of 2020.

Current state of the project: Ongoing

Future deliverables: Specific outcomes include:
1. The development of two published manuscripts, one on addressing the establishment of a population-based cohort of individuals with psychotic disorder in NSW, and another on determining the predictors of avoidable deaths in individuals with psychotic disorders.
2. The building of plain-English summaries for people with schizophrenia and related disorders, and their carers and families.
3. Summaries of the research for health professionals and their families.
4. Expanding the project by using pilot data from the current project.

Weblink: https://3dn.unsw.edu.au/project/addressing-preventable-disease-burden-improve-health-outcomes-people-schizophrenia-and

Equipping Future Psychiatrists to Meet the Mental Health Needs of People with Intellectual and Developmental Disability

Project Team: Claire Eagleson, Rachael Cvejic, Janelle Weise and Julian Trollor

Partner Organisations: The Royal Australian and New Zealand College of Psychiatrists (RANZCP)

Short project description: Psychiatrists have a key role to deliver quality mental health care to people with intellectual and developmental disability. However, Australian psychiatrists have reported that they have received insufficient education in this area and lack confidence to provide quality care. To address these concerns there have been calls for advanced, subspecialty training in intellectual and developmental disability for psychiatrists. In collaboration with the RANZCP, this project aimed to determine the current psychiatric workforce capacity and future training capacity in intellectual and developmental disability psychiatry.

Achievements to date: An analysis of RANZCP workforce data and a survey of psychiatrists with expertise/an interest in intellectual and developmental disability psychiatry indicated that there may be a lack of workforce capacity in this practice area in future. Strong support was indicated for subspecialty training in this area, and preliminary evidence suggested that there is potential training capacity. Suggested enhancements to the Stage 1 and 2 training syllabi, and an example curriculum for subspecialty training were developed. These have been provided to the RANZCP and discussions are continuing around their potential implementation. Three publications have resulted from this project.

Current state of the project: This project is now complete, and the final report has been submitted. 3DN plans to administer a short survey on behalf of the RANZCP further investigating the capacity to offer Trainees rotations in this practice area.

Future deliverables: We will continue to work with the RANZCP to support the development of enhanced education for future psychiatrists around the mental health needs of people with intellectual and developmental disability.

Weblink: https://3dn.unsw.edu.au/project/equipping-future-psychiatrists-meet-mental-health-needs-people-intellectual-and

'Get Healthy!' Improving physical activity and nutritional outcomes for adults with intellectual disability

Project Team: Carmela Salomon, Jessica Bellamy, Renae Reid, Michelle Hsu, Liz Evans & Julian Trollor

Project Steering Committee Members: Jackie Curtis, Andrew Watkins, Simon Rosenbaum, Katherine Samaras, Philip Ward, Scott Teasdale, Chris Tzarimas

Short project description: People with intellectual disability experience disproportionally high rates of lifestyle related illnesses; yet remain poorly engaged in healthy lifestyle interventions. This project aims to improve the quality of healthy lifestyle resources and care available to adults with intellectual disability. To do this we will undertake a literature review of previously conducted physical activity and nutrition related interventions in this population. We will identify barriers and enablers to healthy lifestyle change by analysing topical literature and conducting focus groups with people with intellectual disability, carers and services managers. Based on research findings we will develop an evidence based physical activity and nutrition program, conduct a feasibility trial of the program and refine program content and delivery based on trial results. In order to enhance workforce capacity, we will develop online learning modules for allied health professionals to better equip them to tailor healthy lifestyle interventions to the needs of this population.

Current state of project and achievements to date:

Comprehensive topical literature reviews and stakeholder consultations with carers, managers and adults with intellectual disability were conducted. Findings from the stakeholder consultations have been published and highlight local barriers and enablers to healthy lifestyle uptake. Five online learning modules targeted at allied, health and disability workers who deliver interventions to people with intellectual disability were developed and were launched in early 2019. A prototype group physical activity and healthy eating program, *Get Healthy!* was developed with input from topical experts. Eight participants took part in a feasibility trial of the program. Pilot attendance and engagement levels were high and exploratory clinical outcome data indicates the program positively impacted several measures of cardiometabolic health including waist circumference, cardiovascular fitness and physical strength. The trial protocol has been published in the peer reviewed journal, *Pilot and feasibility Studies.*

Where the project is at: The project is nearing completion. Funding is being sought to extend this work by conducting a sufficiently powered efficacy trial of the *Get Healthy!* program.

Future deliverables: Results from the feasibility trial are currently being refined for publication.

Weblink: https://3dn.unsw.edu.au/project/get-healthy-improving-physical-activity-and-nutritional-outcomes-adults-intellectual

Intellectual Disability Mental Health Core Competencies Framework Project

Project Team: Janelle Weise, Claire Eagleson, and Julian Trollor

Partner Organisations: Mental Health Branch, NSW Ministry of Health

Project Steering Committee Members: Bernadette Dagg, David Dossetor, Tony Florio, Christine Flynn, Roderick McKay, and Tania Skippen

Short project description: The mental health workforce report feeling ill-equipped to meet the needs of people with intellectual disability and co-occurring mental ill health, contributing towards barriers to quality care. With the aim of increasing workforce capacity, this project developed core competencies in intellectual disability mental health for NSW mental health staff. The core competencies describe the attributes required to successfully work with people with intellectual disability and mental ill health. The Framework provides a tool to facilitate service and professional development, which in turn can enhance the quality of practice in this area.

Achievements to date: The Framework Manual and an accompanying practical Toolkit are available on the 3DN website. Through user data collected when individuals download the documents, we have found that these resources have been well utilised. The evaluation of the Framework and Toolkit's effectiveness in supporting practice and attitudinal change is now complete. Almost all users agreed that the core competencies were applicable to their work, clearly presented, improved their knowledge about intellectual disability mental health, and were achievable to work towards. All survey respondents said that they would recommend the Toolkit to others.

Current state of the project: This project is complete, with the final report on the implementation of the Framework Manual delivered to NSW Health.

Future deliverables: A publication reporting on the results from the evaluation of the Framework Manual and Toolkit is currently being drafted.

Weblink: https://3dn.unsw.edu.au/idmh-core-competency-framework

Intellectual Disability Mental Health (IDMH) e-Learning

Project Team: Jenna Zhao, Janelle Weise, Rachael Cvejic, Dan Pua & Julian Trollor

Short project description: 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.

Achievements to date: This year we launched five modules for disability professionals. The topics included supporting good mental health in people with intellectual disability, supporting people with intellectual disability to understand and cope with death and dying, engaging people with intellectual disability in end-of-life discussions and providing support at the end of life, providing mental health support to people with intellectual disability through transitions and life events, and personality disorders in intellectual disability. We also launched a series of five modules for allied health professionals on adapting healthy lifestyle interventions for people with intellectual disability. All of our modules for health professionals are now available for NSW Health staff to access through HETI Online.

Current state of the project: More learning modules are underway and expected to be launched in early 2020. We are also in the process of transitioning our e-Learning to a new platform, as well as seeking further funding opportunities to expand the resource.

Future deliverables: Modules to be launched in early 2020 include modules for disability professionals on identifying and responding to abuse and neglect of people with intellectual disability and supporting people with intellectual disability who come into contact with the justice system. Our e-Learning will launch on its new platform by mid-2020.

Weblink: The e-Learning can be accessed at www.idhealtheducation.edu.au

Making health information accessible for people with intellectual disability

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

Short project description: 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' or 'Easy English' information is advocated as an important form of accessibility. Easy Read materials adapt standard information into a briefer copy, which contains only the main points of information as well as pictures to assist with comprehension of the text. While there is a great deal of support from disability advocates, there is little consistent evidence about the design and effectiveness of Easy Read material. Easy Read health information is becoming more available, however, there is a lack of research that explores the impact of accessible information for people with intellectual disability across their health journey, particularly the impact of accessible resources on health literacy to facilitate access and participation.

As such this project aims to consult with people with and intellectual disability and their family members and support networks about:

1. The accessibility of health-related information for people with intellectual disability across their health journey, and
2. The type of resources that need to be developed and implemented to promote access and participation in the Australian health care system.

Achievements to date: We have conducted consultation with three groups:

1. Focus groups with 23 people with intellectual disability around how they currently find health information, how it is presented, what health information they think is important to be presented in Easy Read format, and what makes information easy to understand.
2. Interviews and focus groups with 11 family members and support people around what health information is currently available for people with intellectual disability, what is needed, and how to make this information accessible.
3. Local health districts and specialty networks regarding health information that is currently provided to people when they use mental health services and what information should be prioritised to make available in accessible formats.

Focus groups have also been run with people with intellectual disability around the content and presentation of planned Easy Read resources.

Current state of the project: Easy Read versions of documents conveying important information about mental health care and services are being developed. These will undergo user testing before being finalised and disseminated.

Future deliverables: Easy Read resources in development include information about the NSW Mental Health Act, rights and responsibilities of voluntary and involuntary mental health patients, information about available mental health services and how to access them, and an orientation guide to inpatient mental health services. A toolkit providing advice on how to support people with intellectual disability to use Easy Read documents will also be produced.

Weblink: https://3dn.unsw.edu.au/project/making-health-information-accessible-people-intellectual-disability

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

Project Team: Jenna Zhao, Janelle Weise & Julian Trollor

Short project description: 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). Carers also use the app to make a record of the person's mental state at a given time for review by a clinician in the context of the person's clinical management.

Achievements to date: This year, working closely with a chosen web development agency, we have designed a prototype of the web app and have undertaken user testing with a small group of carers and mental health clinicians.

Current state of the project: Following some revisions of the prototype, the app will be ready to be built by our web developers.

Future deliverables: MySigns will be launched to the public in 2020.

Weblink: On its way!

Preventing Avoidable Deaths of Australians with Disability

Project Team: Carmela Salomon, Preeyaporn Srasuebkul, Julian Trollor

Short project description: Compared to the general population, people with intellectual disabilities are more likely to experience multiple health disadvantages including an elevated mortality rate and lower age of death. They are also at increased risk of dying from potentially avoidable causes. In order to address these disparities, it is vital to develop a national insight into the prevalence of, and factors affecting the deaths of people with disabilities. This project was commissioned by the National Disability Insurance Scheme's (NDIS) Quality and Safety Commission **(The Commission)**, as they prepare to establish Australia's first nationally consistent arrangement for reporting deaths of people with disability receiving NDIS funding. We will support the work of the Commission by:

- Conducting an Australia wide scoping review of causes and contributors to deaths of people with disability. The aim of the review is to provide the Commission with a national baseline picture of trends, issues and current monitoring practices relating to deaths of people with disability across Australia based on findings from existing state and territory reports.
- Arising from the key themes and findings identified in the review, we will provide expert guidance to inform a statistical analysis that will be undertaken by the Australian Institute of Health and Welfare (AIHW), in the context of AIHW's development of new national disability dataset.
- Provide expert advice to the NDIS Commission on the development by AIHW, of key performance measures that the NDIS Commission could consider incorporating into its Analytics Framework for the purposes of assisting the NDIS Commission to respond to and mitigate systemic risks of harm to people with disability.

Current state of project and achievements to date: The scoping review has been completed and presented to the NDIS team. A full report of findings, along with summary documents outlining key findings and recommendations are available on the NDIS website: https://www.ndiscommission.gov.au/news-media/research-deaths-people-disability. Our team at 3DN has also conducted a series of consultations with AIHW to support their statistical analysis design.

Where the project is at: This project is nearing completion.

Future deliverables: Finalise and submit report of consultation services provided

Weblink: https://3dn.unsw.edu.au/project/preventing-avoidable-deaths-australians-disability

Scoping work for a State-Wide Tertiary Intellectual Disability Mental Health Service

Project Team: Janelle Weise, Rachael Cvejic, Claire Eagleson, Jessica Walsh and Julian Trollor

Project Steering Committee Members: Tara Carthy, David Dossetor, Alix Goodwin, Sarah Hanson, Keith Johnson, Leanne Johnson, Lucinda Mora, Henry Newton, Jim Simpson, Tania Skippen, and Tracey Szanto

Short project description: Two consecutive National Roundtables on the Mental Health of People with Intellectual Disability and the NSW Mental Health Commissions Strategic Plan have all recommended the need for a specialist intellectual disability mental health (IDMH) service that can i) provide both timely and appropriate access to mental health care for people with intellectual disability and complex needs, and ii) enhance the capacity of the mainstream mental health sector in this area. This project aimed to consult with multiple stakeholders to determine and reach consensus on i) the clinical priorities of a tertiary IDMH service, ii) identify the resources required to run such a service, and iii) ascertain how this service could educate the wider mental health workforce.

Achievements to date: Comprehensive consultation was carried out with four stakeholder groups: NSW mental health service representatives, IDMH experts, people with intellectual disability, and family members and support persons of people with intellectual disability. All groups supported the development of a tertiary IDMH service and provided valuable information on the clinical priorities of such a service and how it could operate.

Current state of the project: This project is complete, and the final report has been submitted.

Future deliverables: Four publications reporting on findings from the consultation surveys and interviews are in preparation.

Weblink: https://3dn.unsw.edu.au/project/scoping-work-state-wide-tertiary-intellectual-disability-mental-health-service

The Autism CRC's Australian Longitudinal Study of Adults with Autism (ALSAA)

Project Team: Samuel Arnold, Yunhe Huang, Ashley Stevens, Natalie Roberts & Julian Trollor

Partner Organisations: The Cooperative Research Centre for Living with Autism (Autism CRC)

Australian Longitudinal Study of Adults with Autism (ALSAA)

Short project description: Currently, understanding of life in adulthood for people with autism is limited. This has significant implications for the day to day living of individuals on the spectrum, with services and the general public lacking in awareness and understanding of their specific needs. This study, funded by the Cooperative Research Centre for Living with Autism (Autism CRC), is following a cohort of adults with autism aged 25+, their carers/family member and a control group of community members without autism. We hope the information from this study will help guide the formation of better policies, improved service provision and generally a better understanding of life in adulthood for people with autism. Results of this study will be used by other researchers within the Autism CRC to develop interventions and tools aiming to improve many facets of life for this population.

Achievements to date: We have recently published on our baseline cohort profile and our inclusive research process. Publications have also included a paper on loneliness in autistic adults and papers on the needs of caregivers of autistic adults.

Current state of the project: We are still recruiting more participants and hope to secure funding to conduct data gathering for a third and future timepoints.

Future deliverables: Deliverables in the near future include paper looking at the impact of diagnosis of autism in adulthood, cardio metabolic risk factors, physical activity and a paper of the state of employment for autistic adults in Australia.

Weblink: https://3dn.unsw.edu.au/project/australian-longitudinal-study-adults-autism-spectrum-conditions-alsaa

Undergraduate Medicine and Nursing Curriculum Development

Project Team: Claire Eagleson, Rachael Cvejic and Julian Trollor

Project Steering Committee Members: Andrew Cashin, Seeta Durvasula, Linda Goddard, Teresa Iacono, Nicholas Lennox, Carmela Salomon, Jane Tracy, and Jennifer Torr

Short project description: Research suggests that tertiary education is the best time to influence the knowledge, skills and attitudes of health professionals as students are more open to learning new concepts and ideas. The curriculum project aimed to audit all medical and nursing schools in Australia for intellectual disability physical and mental health content.

Achievements to date: Fourteen medical and 31 nursing schools participated in the study. Results suggest that intellectual disability content taught within medical and nursing schools is highly variable and limited. A majority of future doctors and nurses will either have little to no knowledge of necessary adaptations when working with people with intellectual disability. Four publications outlining what intellectual disability content is taught and how it is taught have been published.

Current state of the project: This audit phase of the project is complete. We are currently seeking further funding to develop a national education framework and implementation toolkit for nursing and medical schools. This would provide up-to-date, evidence-based core competencies, teaching materials, and resources to be incorporated into existing curricula. The toolkit would be piloted in exemplar universities, before a nationwide roll-out.

Future deliverables: One final publication comparing the results from the current audit of medical school curricula with an audit completed in 1995 by Lennox and Diggens (1999) is being drafted.

Weblink: https://3dn.unsw.edu.au/project/renewal-medical-school-id-curriculum-building-capacity-better-prepare-medical-graduates-meet

https://3dn.unsw.edu.au/project/renewal-nursing-school-id-curriculum-building-capacity-better-prepare-registered-nursing

The SAge-ID Study - Successful Ageing in Intellectual Disability.

Project Team: Liz Evans, Julian Trollor, Rebecca Daly and Janelle Weise.

Other Investigators: Teresa Iacono, Jennifer Torr, Perminder Sachdev, Henry Brodaty.

Project ambassador: Michael Sullivan.

Short project description: 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.

Achievements to date:
Survey, interview and assessment data collection is now complete.
Three rounds of an online Delphi study examining care pathways have been completed.
Guidelines for Australian GPs on assessing and managing dementia in people with ID have been published.

Current state of the project: Ongoing.

Future deliverables: Resources on dementia for people with intellectual disability and carers, along with two modules for health professionals, will be launched in 2020. Publications arising from data analysis and A report from the Delphi study will provide a useful advocacy tool.

Weblink: https://3dn.unsw.edu.au/project/successful-ageing-intellectual-disability-sage-id-study

Understanding the health and support needs of younger people with disabilities discharged from hospitals to residential aged care

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

Project Steering Committee Members: Di Winkler, Deidre Mackechnie, Ingrid Honan

Short project description: 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 will utilise existing linked datasets (currently held by our team at 3DN) from which we will identify the health, support needs and pathways of younger people with disabilities discharged from NSW hospitals to RAC from 2001-2015. We will use these findings to identify avenues to improve health outcomes for young people discharged to RAC. The project will involve consumers and community members to ensure the work is relevant to the needs and wishes of younger people with disabilities. This project is funded by the Summer Foundation.

Achievements to date: Ethics approval has been granted, with data analysis to commence at the beginning of 2020. Formation of an advocate advisory group is on track to begin in 2020.

Current state of the project: Ongoing

Future deliverables: Specific outcomes include:

1. Identifying predisposing factors upon which to focus for the prevention of new RAC admissions.
2. Developing a better understanding of the support needs of younger people with disabilities.
3. Identifying opportunities to improve health outcomes for those discharged to RAC.
4. Creating a joint funding submission with the Summer Foundation to undertake a broader program of work on younger people with disabilities in RAC.

Weblink: https://3dn.unsw.edu.au/project/understanding-health-and-support-needs-younger-people-disabilities-discharged-hospitals

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

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

Short project description: At a population level, there is little representative data on the health resource use and costs, including preventative health care, prescribing patterns, and their predictors for people with intellectual disability but the creation of such knowledge is critical to inform efforts to improve their health status. 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.

Achievements to date: We have received ethics approval and are currently awaiting data linkage by the AIHW. Analysis will start in late 2020.

Current state of the project: Ongoing

Future deliverables: Publications and resources relating to:
1. 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.
2. Characterise the prescribed medicines use profile and their predictors in people with ID and compare these to the control group.
3. Evaluate the impact of the transition to the NDIS on health resource utilisation and determinants for people with ID.
4. 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.

Using big data to develop an interactive web-based platform inform local services about the health needs of people with intellectual disability

Project Team: Julian Trollor, Janelle Weise, Preeyaporn Srasuebkul, Lloyd Flack, Tony Florio

Project Steering Committee Members: Nicole Marchisone, Matthew Covers, Clare Daley, Tracey Szanto, Anna Gauci, Phillip Snoyman, David Coyne, Andrea Taylor, Scott Clark, Vincent Ponzio, Leanne Johnson, Jim Simpson, Kathryn McKenzie

Short project description: This project will allow us to 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.

Achievements to date: We have consulted with Local Health Districts and Specialist Health Networks on the need for and characteristics of a web-based platform. We are working with web developers to build the platform which will be tested in February.

Current state of the project: Ongoing

Future deliverables: The ID health data portal will be available for use by NSW Health employees. Two peer reviewed publications are planned to include one on the development and utility of the ID health data portal and an evaluation of ID health data portal.

Weblink: https://3dn.unsw.edu.au/project/using-big-data-develop-interactive-web-based-platform-inform-local-services-about-health

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

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

Short project description: People with motor neurone disease (MND) have complex care needs and require multidisciplinary support from a range of generic and specialist health services. Few studies have investigated health service use of people with MND, and none to date have had a specific focus on mental health service use. This is a significant gap given that 15% of people with MND will develop frontotemporal dementia, 17% present with affective disorders, and that neuropsychiatric symptoms (e.g. apathy, disinhibition, and stereotypic behaviour) have been found to be present before the onset of motor symptoms. The aim of this study is to describe and understand the mental health needs of people with MND and how they use mental health services through the analysis of linked data from a large sample of people with MND in NSW. By comparing our findings in people with MND to those of people with other progressive neurological disorders (e.g. Alzheimer's disease) and the NSW general population, we will understand the specific needs of people with MND. 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.

Achievements to date: Data analysis using the linked data sets has been completed. We found that people with MND are frequently hospitalised for nervous system disorders, respiration disorders, and injury and poisoning. The most common mental health diagnoses people with MND are hospitalised for include organic mental health disorders (such as dementia), mood disorders, and disorders related to alcohol and drug use. While mental health service utilisation for people with MND is higher than the general population as expected, people with MND have lower service utilisation than people with other progressive neurological disorders. While it is not clear why this is the case, it is possible that people with MND may be more likely to receive care outside of hospital settings, or that physical health concerns may take precedence. For people with MND, those who utilised mental health services were found to stay in hospital for physical health reasons longer than people with MND who had not used mental health services. These results will help mental health services plan and provide care that meets the needs of people with MND. We have also conducted consultation around how we can best communicate these results to key stakeholder groups.

Current state of the project: Three fact sheets are currently being developed to communicate results of this project to:

1. People with MND and their family and carers
2. People with MND and frontotemporal dementia
3. MND clinics and health professionals

These resources will undergo further user testing before being finalised and disseminated.

Future deliverables: In addition to the above three fact sheets, publications reporting on findings are planned. A final report will be provided to the MND Research Institute of Australia.

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

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

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

Project Steering Committee Members: Annette Moxey, Tom Morris, Deidre Mackechnie, and Kaele Stokes

Short project description: People with dementia experience high rates of mental and physical health problems. It is important that the health system is prepared to meet their needs. Most research has focused on the health of people with Alzheimer's disease, the most common type of dementia. Less is known about the health status and health service use of people with less common types of dementia, including frontotemporal dementia and dementia due to other disorders or diseases. This study will use 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.

Achievements to date: Data analysis has been completed and we have undertaken two rounds of consultation with dementia advocates.
Three resources are being developed to communicate the results of this project to people living with dementia, their care partners, and health professionals. A fourth resource is being developed to support people living with dementia and their care partners to initiate a discussion with General Practitioners to promote their health and prevent avoidable hospitalisations.

Current state of the project: Ongoing

Future deliverables: In addition to the above four resources, three peer reviewed publications are planned. A final report will be provided to the funder Dementia Australia.

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 predictors of repeated self-harm in people with mental health and drug and alcohol comorbidity

Project Team: Rachael Cvejic, Kate Chitty (USyd), Julian Trollor, Nicholas Buckey (USyd), Kirsten Morley (USyd), Preeyaporn Srasuebkul, Andrew Dawson (Sydney LHD), Greg Carter (Hunter New England LHD), Tess Heintze

Short project description: Chronic use of alcohol and other drugs is one of the greatest risk factors for repeated self-harm and suicide. Very few studies have specifically focused on preventing repeated presentation to acute health services and admission for self-harm specifically for people with drug and alcohol comorbidity. To best design such interventions a better understanding of the specific predictors of repeated self-harm in this population is necessary but under-researched. We will use big data to directly address this gap. Our work will facilitate the identification of those at greatest risk of repeated self-harm in people with mental health and drug and alcohol comorbidity and enable the development of targeted interventions to reduce the risk of future self-harm and suicide.

Current state of the project: Ongoing

Future deliverables: Two manuscript are drafted for peer reviewed journals and there will be a final report to the funder.

Weblink: https://3dn.unsw.edu.au/project/using-big-data-understand-predictors-repeated-self-harm-people-mental-health-and-drug-and

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.

Easy read Information about mental health for people with intellectual disability.

PhD Student: Bronwyn Newman
Supervisors: Karen Fisher and Julian Trollor.

Short project description: This is a qualitative mixed methods study which includes policy review, resource mapping and interviews. The project aim is to understand more about how easy read can make information about mental health more accessible for people with intellectual disability.

Achievements to date: All data collection and analysis has been completed. Data collection included a policy review and qualitative interviews across four sites, three NSW public health services and an advocacy agency. All Commonwealth, NSW and participating local health district policy has been reviewed and 49 interviews have been conducted. Participants included people with intellectual disability, paid support staff, allied health, nursing and medical practitioners. The study found that easy read material was not widely used to communicate about mental health information at study sites. People with intellectual disability used easy read to communicate in many contexts, but not in health services. Mental health agency staff were committed to enabling access and had varying levels of skills and confidence to implement accessible communication. Participating staff suggested that flexible health agency processes and ready availability of accessible information supported them to enable information access. Preliminary findings have been presented in various forums.

Current state of the project: All data collection is complete. Thesis has been written and submitted. Bronwyn is awaiting examiner reviews and hopes to graduate in 2020.

Future deliverables: Findings will be provided in various formats, including easy read. Insights about making information accessible using easy read will be provided to service providers and policy makers. Findings will be submitted to relevant journals.

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

PhD student: Peiwen Liao
Supervisors: Simone Reppermund, Claire Vajdic, Julian Trollor

Short project description: The aim of this project is to identify the physical health needs of people with intellectual disability in NSW and explore to what extent the current health services respond to these health needs. To achieve this aim, this project will use a data linkage approach to explore the epidemiology of core physical conditions, i.e. epilepsy.
and related health service use, and determinants of comorbid conditions and health service
use compared to a matched group of people without intellectual disability.

Current state of project and achievements to date:
Currently waiting for the new data linkage to come meanwhile doing some analyses with the old data linkage. Ethics approval for the current project based on the old data linkage was received and some preliminary analyses have been conducted. Other achievements include two conference presentations:
1) Oral presentation at 2019 ASID conference about the ongoing systematic review on prevalence/incidence of physical disorders in people with Intellectual Disability.
2) Oral presentation at 2019 ADR conference (4th International Conference on Administrative Data Research) about readmissions and ED presentations after one epilepsy admission for people with Intellectual Disability.

Current state of the project: Ongoing

Future deliverables: Publications and thesis. In detail, health outcomes and healthcare outcomes of epilepsy hospitalisation in people with Intellectual Disability will be analysed and compared with that in the general population. These outcomes include, but are not restricted to, readmission and ED presentation risk.

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 data-set 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: Second year has been completed and the set milestones for that year have been achieved; ethics amendment was granted for the analysis for three chapters, with two chapters now drafted with the intention of submitting for publication imminently. The analysis for the third chapter is currently under way with that chapter being drafted with the aim of submitting for publication in the coming months. A fourth and final analysis/chapter is being outlined and an ethics amendment for this will be submitted in the next month.. I am halfway through my third year and am on track to complete the milestones set for this year which include finalising and submitting for publication 3 articles/chapter and finalising a fourth.

Current state of the project:

I have three chapters drafted, two of which will be submitted for publication in the coming weeks. This includes;

1. This study uses linked administrative data encompassing disability, health and corrections data for the year 2014 to estimate the prevalence of ID in adult custody, explore how ID representation within administrative data impacts prevalence estimates, and what patterns of identification reveal about support service access for this group.

2. This paper examines the role of disability support services post-release from adult custody for a sample of adults in NSW (n = 1,157) who have an identified intellectual disability. The likelihood of a further custodial sentence following release for those with and without disability support was examined using Kaplan–Meier survival methods. A multivariate Cox proportional-

hazard survival analysis examined the hazards of receiving a disability support services and returning to custody, after controlling relevant confounding variables.

3. Investigate inpatient use and health profiles for ex-prisoners with an intellectual disability across the life of the cohort with a specific focus on the first 12 months post-release from prison: specifically, the proportion of released prisoners who had hospitalisations and emergency department (ED) presentations; the amount of resources used (bed days, separations and cost); and the most common reasons for hospitalisation and for mortality.

Further, I am in the process of finalising the analysis for a fourth chapter that focuses on the use of case studies to bring greater detail to the pathways through health and service usage and the CJS for individuals with ID.

Future deliverables: Aiming to apply for funding to incorporate the linking of other data sources to generate further analysis and publications.

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 accepted for publication. The online survey and interviews are both underway following ethics approval. Preliminary quantitative and qualitative data analysis have begun.

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.

Building a better mental health system for individuals with complex support needs

PhD Student: Snow Li

Supervisors: Julian Trollor, Leanne Dowse, Simone Reppermund, Preeyaporn Srasuebkul

Short project description: There are three main studies in this project. The first is a qualitative study examining the barriers to accessing generic health and social care services. The second and third studies are data linkage studies examining emergency department presentation and readmission after index psychiatric admission: and the impact of an index psychiatric admission on rates of ambulatory mental health utilisation and emergency department presentation.

Achievements to date:

Publications:

- Journal article: Emergency department presentation and readmission after index psychiatric admission: a data linkage study. BMJ Open [First author]
- Book chapter: Community-Based Support for People with Disability: Theory and Practice. Chapter 10. Managing challenging behavior ISBN: 978-7-5080-9703-9

Peer-reviewed conferences:

- Australian Social Policy Conference:
  Presented paper: Barriers to accessing generic health and social care services: a qualitative study of staff supporting clients with complex support needs in Australia.
- 26th European Congress of Psychiatry:
  Presented paper: Emergency department presentation and readmission after index psychiatric admission: a data linkage study

Other publications and knowledge translation practice:

- Co-authored a disability article for Disability Issue of Inner Sydney Voice Magazine: people with intellectual disability and mental illness: a forgotten minority
- Anti-poverty week mural design and painting [October 2017]
- Speaker for UNSW Research to Impact workshop [August 2019]

Winner of 2018 UNSW Medicine HDR mentor program

Postgraduate research student representative for UNSW Medicine research committee

Winner of Global ConsenSys MBA Blockchain Venture Competition

Current state of the project: Final editing stage

Future deliverables: Thesis submission

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: Case studies have been collected and data analysis has been completed. Analysis of linked datasets has also been completed. A scoping review of the literature has been completed and a manuscript is in preparation for submission.
An oral presentation at the ASID 2018 conference summarising preliminary results and the ongoing project was delivered.

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.

Miss Rebecca Daly

Research Assistant

Rebecca is a research assistant for Successful Ageing in Intellectual Disability (SAge-ID Study). Rebecca holds a Masters of Applied Psychology from Trinity College Dublin and a Bachelor of Psychology (Hons) from Queens University Belfast. Rebecca is passionate about high standard service delivery for people with intellectual disabilities and mental health difficulties. Prior to joining 3DN, Rebecca worked in the area of neurofeedback therapy and has over six years' experience in clinical and service provision roles within the disability sector.

Dr Tess Heintze

Data Analyst

Tess joined 3DN in June 2015 as a Data Analyst mainly involved with the Intellectual Disability Mental Health Linkage Project. Her previous research concerned welfare and labour policy and its impacts on the American population. Tess has worked as a Data Manager and programmer for large datasets and, prior to obtaining her PhD, as a community social worker engaged with mental health clients.

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.

Dr Yvonne Ho

Data Analyst

Yvonne (Ying Wai) completed her BPsychSci (Hons) in the University of Queensland, before acquiring an APAI PhD scholarship to pursue research in Quantitative Genetics applied to forensics and the justice system. While writing her thesis she gained some experience in large linked datasets, twin and family analyses, and biostatistics. She is working as a data analyst with the Intellectual Disability Mental Health Data Linkage Project at 3DN, where she will be using linked datasets to investigate socio-medical factors affecting prognosis of rare neurodegenerative disorders, and access to medical services for people with intellectual disability. In addition to her research and analytical work she is also involved in community service as a telephone crisis supporter.

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

Dr Natalie Roberts

Research Assistant

Natalie is currently working as a research assistant within Program 3: Adulthood of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). She recently completed her PhD in psychology and holds a Master of Research and Bachelor of Arts (Psychology) from Macquarie University. Natalie has a particular interest in assessing and exploring altered states experiences. Her PhD and Master's research focused on the induction, personality, and consciousness correlates of Autonomous Sensory Meridian Response (ASMR).

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.

Ms Ashley Stevens

Research Assistant

Ashley is a research assistant for Program 3 of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). Ashley holds a Bachelor of Psychological Science from the University of New South Wales and will be completing her Bachelor of Social Science (Psychology) (Honours) from Charles Sturt University in 2018. Ashley is also a trained Applied Behaviour Analysis (ABA) therapist who is passionate about helping people with developmental and behavioural difficulties reach their fullest potential. Her research interests lie in relationship psychology, the translation of interventions into practice, and intellectual and developmental disabilities.

Mr 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.

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
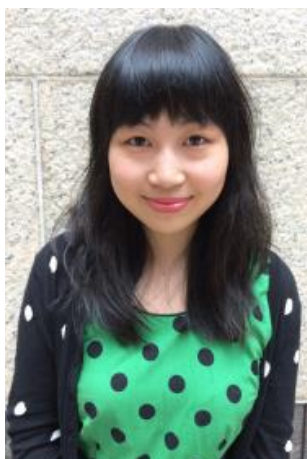
Dr Janelle Weise (née Govett)

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 Snow Li

PhD Scholar

Snow is a PhD scholar at 3DN researching complex support needs in individuals with intellectual disability and co-occurring mental illness. Her passion for this research topic is driven from her previous community work experience supporting mental health carers. Snow holds a Master Degree in Public Health, a Master Degree in Health Communication from the University of Sydney and a Bachelor Degree in Science majoring Psychology from the University of New South Wales. Her current research interests are public health strategies for mental health and support for individuals with complex support needs.

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 Bronwyn Newman

PhD Candidate

Bronwyn's PhD project will seek to examine what makes information about mental health accessible for people with intellectual disability and explore the impact of accessible information on equality. Bronwyn has had extensive experience in various roles within the disability sector in NSW. She is excited to be working on her PhD within the NHMRC Partnerships for Better Health Project - Improving the Mental Health Outcomes for Persons with Intellectual Disability as this brings great opportunity to inform practice and promote equality in disability and mental health spheres.

Bronwyn completed a Bachelor of Social Work at Sydney University and a Master of Policy and Social Research at Macquarie University.

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

Ms Marisse Sonido

Casual Research Assistant

Marisse is a 5th year medical student at the University of New South Wales. In 2019, Marisse has been working as a Casual Research Assistant on the ALSSA Project. Developmental disability and mental health are two areas that Marisse is particularly interested in, and she hopes to do one day apply what she learns with 3DN to her future career.

Affiliates

Dr Tony Florio

Externally appointed

Dr Tony Florio (PhD, MPsych(Clin), MAPS, MACS) is a Conjoint Senior Lecturer for the UNSW School of Psychiatry. He is also a Clinical Psychologist & Cognitive Computing Scientist. Part of his role at 3DN involves engaging in research with the Department of Developmental Neuropsychiatry at University of NSW, where he is involved in the Intellectual Disability Mental Health Data Linkage Project. Tony plays a consultative and facilitator role in this Project, providing invaluable consultation on data collection, data management, statistical analysis and the clinical aspects of Intellectual Disability and Mental Health.

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3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Research Grants and Funding

Research Funding

1. 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 intellectual disability; (Trollor, Agar, Cvejic, Currow, Strutt, Vajdic, Chye, Srasuebkul, Weise, Reppermund, Szanto, Harlum, Tuffrey-Wijne, Greenland, Phillips)
2. Summer Foundation, 2019 -2021, $402,188, Understanding the health needs of younger people with disabilities discharged from hospital to RAC (Trollor, Cvejic, Reppermund, Srasuebkul, Draper, Whithall)
3. Motor Neurone Disease Research Institute of Australia (MNDRIA)/MND Research Grants - Innovator Grants; 2019 – 2020; $95,476.04; Using big data to understand the health status and service use of people with motor neurone disease (Trollor, Cvejic, Kiernan)

Project Funding

1. Autism CRC; Investigating Autistic Burnout (#AutBurnout); 2020; $37,880; (Trollor, Arnold, Higgins)
2. Autism CRC; Strengths, Functioning and Support Needs: Understanding Autism Across the Lifespan; 2020-2021; $252,000; (Trollor, Arnold, Higgins, Evans)
3. NSW Health; Evaluation of the Intellectual Disability and Mental Health National Disability Insurance Scheme Residual Functions Program; 2019 – 2021; $274,875 (Fisher, Purcal, Zmudzki, O'Shea, Newton, Trollor, Weise, Srasuebkul,
4. Autism CRC; Development of an Autism specific Quality of Life Assessment for the use of Autistic Adults; $13,300; 2019; (Trollor, Arnold)
5. NDIS Quality and Safeguards Commission, 2019, $102,687.20 Preventing Avoidable Deaths in People with Disability, (Trollor, Salomon, Srasuebkul)

Other Funding

1. 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
2. UNSW Sydney, Research Infrastructure Scheme (RIS); 2019-2020 $175,945; Understanding the Health and Service System Needs of People with Mental Health, Developmental Disabilities, Cognitive, and Neurological Disorders - Establishment of an interdisciplinary Big Data Hub. Short title: Interdisciplinary MDCN Big Data Hub

(Trollor, Reppermund, Sachdev, Brodaty, Srasuebkul, Christensen, Vajdic, Mather, Dowse, Fisher, Baldry, Dean)

Publications

Papers in Refereed Journals

- Arnold, S., Foley, K.R., Hwang, Y.I.J., Richdale, A., Uljarevic, M., Lawson, L., Cai, R.Y., Falkmer, T., Falkmer, M., Lennox, N., Urbanowicz, A., Trollor, J.N. Cohort profile: The Australian Longitudinal Study of Adults with Autism (ALSAA). *BMJ Open*, 2019.

- Arnold, S.R.C., Uljarević, M., Hwang, Y.I., Richdale, A.L., Trollor, J.N., Lawson, L.P. Brief Report: Psychometric Properties of the Patient Health Questionaire-9 (PHQ-9) in Autistic Adults. *Journal of Autism and Developmental Disorders*, 2019, 1-9.

- Bentvelzen AC, Crawford JD, Theobald A, Maston K, Slavin MJ, Reppermund S, Kang K, Numbers K, Brodaty H, Sachdev P, Kochan NA (2019). Validation and normative data for the TICS-M telephone cognitive screen: The Sydney Memory & Ageing Study. Journal of the American Geriatrics Society 67(10):2108-2115.

- Cations, M., Withall, A., Low, L.F., Radford, K., Trollor, J., Brodaty, H., Sachdev, P., Gonski, P., Broe, G.A., Cumming, R.G., Draper, B. Clustering and Additive Effects of Nongenetic Risk Factors in Non-Autosomal-Dominant Degenerative and Vascular Young Onset Dementia. *Alzheimer Disease and Associated Disorders*, 2019.

- Davies, K., Eagleson, C., Weise, J., Cvejic, R.C., Trollor, J.N. Clinical capacity of Australian and New Zealand psychiatrists who work with people with intellectual and developmental disabilities. *Australasian Psychiatry*, 2019.

- Desrivières, S., Jia, T., Chu, C., Liu, Y., van Dongen, J., Papastergios, E., Armstrong, N., Bastin, M., Carrillo-Roa, T., den Braber, A., Harris, M., Jansen, R., Liu, J., Luciano, M., Ori, A., Roiz Santiañez, R., Ruggeri, B., Sarkisyan, D., Shin, J., Sungeun, K., Tordesillas Gutiérrez, D., van't Ent, D., Ames, D., Artiges, E., Bakalkin, G., Banaschewski, T., Bokde, A., Brodaty, H., Bromberg, U., Brouwer, R., Buechel, C., Quinlan, E., Cahn, W., De Zubicaray, G., Ehrlich, S., Ekström, T., Flor, H., Fröhner, J., Frouin, V., Garavan, H., Gowland, P., Heinz, A., Hoare, J., Ittermann, B., Jahanshad, N., Jiang, J., Kwok, J., Martin, N., Martinot, J., Mather, K., McMahon, K., McRae, A., Nees, F., Papadopoulos Orfanos, D., Paus, T., Poustka, L., Saemann, P., Schofield, P., Smolka, M., Strike, L., Teeuw, J., Thalamuthu, A., Trollor, J., Walter, H., Wardlaw, J., Wen, W., Whelan, R., Stein, D., Apostolova, L., Binder, E., Boomsma, D., Calhoun, V., Crespo-Facorro, B., Deary, I., Hulshoff Pol, H., Ophoff, R., Pausova, Z., Sachdev, P., Saykin, A., Wright, M., Thompson, P., Schumann, G. Epigenome-wide meta-analysis of blood DNA methylation and its association with subcortical volumes: findings from the ENIGMA Epigenetics Working Group *Molecular Psychiatry*, 2019.

- Eagleson, C., Cvejic, R.C., Weise, J., Davies, K., Trollor, J.N. Subspecialty training pathways in intellectual and developmental disability psychiatry in Australia and New Zealand: current status and future opportunities. *Australasian Psychiatry*, 2019.

- Ee, D., Hwang, Y.I.J., Reppermund, S., Srasuebkul, P., Trollor, J.N., Foley, K.R., Arnold, S.R.C. Loneliness in Adults on the Autism Spectrum. *Autism in Adulthood*, 2019; *1*(3), 182-193.

- Glasson, E., Downs, J., Jacoby, P., Wong, K., Leonard, H., Bourke, J., Nagarajan, L., Ravikumara, M., Forbes, D., Wilson, A., Srasuebkul, P., Trollor, J. Risk of Hospitalizations Following Gastrostomy in Children with Intellectual Disability. *The Journal of Paediatrics*, 2019.

- Hwang, Y.I., Arnold, S., Srasuebkul, P., Trollor, J. Understanding anxiety in adults on the autism spectrum: An investigation of its relationship with intolerance of uncertainty, sensory sensitivities and repetitive behaviours. *Autism*, 2019.

- Hwang, Y.I.J., Srasuebkul, P., Foley, K.R., Arnold, S., Trollor, J.N. Mortality and cause of death of Australians on the autism spectrum. *Autism Research*, 2019; *12*(5), 806-815.

- Jiang, J., Thalamuthu, A., Koch, F.C., Liu, T., Xu, Q., Trollor, J.N., Ames, D., Wright, M.J., Catts, V., Sachdev, P.S., Wen, W. Cerebral Blood Flow in Community-Based Older Twins Is Moderately Heritable: An Arterial Spin Labelling Perfusion Imaging Study. *Frontiers in Aging Neuroscience*, 2019; *11*(169), 1-8.

- Lipnicki, D.M., Makkar, S.R., Crawford, J.D., Thalamuthu, A., Kochan, N.A., Lima-Costa, M.F., Castro-Costa, E., Ferri, C.P., Brayne, C., Stephan, B., Llibre-Rodriguez, J.J., Llibre-Guerra, J.J., Valhuerdi-Cepero, A.J., Lipton, R.B., Katz, M.J., Derby, C.A., Ritchie, K., Ancelin, M.L., Carrière, I., Scarmeas, N., Yannakoulia, M., Hadjigeorgiou, G.M., Lam, L., Chan, W.C., Fung, A., Guaita, A., Vaccaro, R., Davin, A., Kim, K.W., Han, J.W., Suh, S.W., Riedel-Heller, S.G., Roehr, S., Pabst, A., van Boxtel, M., Köhler, S., Deckers, K., Ganguli, M., Jacobsen, E.P., Hughes, T.F., Anstey, K.J., Cherbuin, N., Haan, M.N., Aiello, A.E., Dang, K., Kumagai, S., Chen, T., Narazaki, K., Ng, T.P., Gao, Q., Nyunt, M.S.Z., Scazufca, M., Brodaty, H., Numbers, K., Trollor, J.N., Meguro, K., Yamaguchi, S., Ishii, H., Lobo, A., Lopez-Anton, R., Santabárbara, J., Leung, Y., Lo, J.W., Popovic, G., Sachdev, P.S. Determinants of cognitive performance and decline in 20 diverse ethno-regional groups: A COSMIC collaboration cohort study. *PLoS Medicine*, 2019; *16*(7), e1002853-e1002853.

- Mewton L, Reppermund S, Crawford J, Bunce D, Wen W, Sachdev P (2019). Cross-sectional and prospective inter-relationships between depressive symptoms, vascular disease and cognition in older adults. Psychological Medicine 49(13):2168-2176.

- Petrie, K., Trollor, J., Dean, K., Harvey, S. Medical students' preferences regarding Psychiatry teaching: a comparison of different lecture delivery methods. *MedEdPublish*, 2019; *8*(3).

- Reppermund, S., Heintze, T., Srasuebkul, P., Reeve, R., Dean, K., Smith, M., Emerson,

E., Snoyman, P., Baldry, E., Dowse, L., Szanto, T., Sara, G., Florio, T., Johnson, A., Clements, M., McKenzie, K., Trollor, J. Cohort Profile: Health and Wellbeing of People with Intellectual Disability in New South Wales, Australia – A data linkage cohort. *BMJ Open*, 2019.

- Reppermund, S., Heintze, T., Srasuebkul, P., Reeve, R., Dean, K., Smith, M., Emerson, E., Snoyman, P., Baldry, E., Dowse, L., Szanto, T., Sara, G., Florio, T., Johnson, A., Clements, M., McKenzie, K., Trollor, J. Health and wellbeing of people with intellectual disability in New South Wales, Australia: a data linkage cohort. *BMJ Open*, 2019; 9(9), e031624.

- Reppermund, S., Weise, J., Cvejic, R., Trollor, J. How can we provide better healthcare for people with an intellectual disability? . *Journal: Frontiers for Young Minds*, 2019.

- Samaras, K., Makkar, S.R., Crawford, J.D., Kochan, N.A., Slavin, M.J., Wen, W., Trollor, J.N., Brodaty, H., Sachdev, P.S. Effects of Statins on Memory, Cognition, and Brain Volume in the Elderly. *Journal of the American College of Cardiology*, 2019; *74*(21), 2554-2568.

- Satizabal CL, …, Reppermund S, et al. (2019). Genetic architecture of subcortical brain structures in 38,851 individuals. Nature Genetics 51(11):1624-1636.

- Sonido, M.T., Hwang, Y.I., Trollor, J.N., Arnold, S.R.C. The Mental Well-Being of Informal Carers of Adults on the Autism Spectrum: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, 2019.

- Srasuebkul, P., Reppermund, S., Dean, K., Trollor, J.N. Factors associated with death in people with intellectual disability *Journal of Applied Research in Intellectual Disabilities*, 2019.

- Trollor, J.N., Weise, J. Inclusive and collaborative practice: the key to accessible mental health services for people with an intellectual disability and co-occurring mental ill health. *The Australian Journal on Psychosocial Rehabilitation*, 2019; *Summer 2018-2019*.

- Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I., Cai, R.Y., Dissanayake, C., Richdale, A., Trollor, J. Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 2019.

- Weise, J., Fisher, K.R., Turner, B., Trollor, J.N. What is the capability of the Australian mental health workforce to meet the needs of people with an intellectual disability and co-occurring mental ill health? *Journal of Intellectual and Developmental Disability*, 2019.

Book Chapters

- Cvejic, R.C., Trollor, J.N., Hocking, D.R. 2019. Fragile X-associated tremor ataxia syndrome Degenerative Disorders of the Brain (pp. 143-162).

- Evans, E. & Trollor, J. Dementia in people with Intellectual Disability. In Pond, D., Phillips, J., Day, J., McNeill, K., Evans, E., Trollor, J., Anstey, KJ., Peters, R., (2019). People with Dementia: A Care Guide for General Practice. NHMRC Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People (CDPC), Australia.

Published Abstracts

- Eapen, V., Arnold, S., Harley, D., Trollor, J. Autism spectrum disorder over the life course: from diagnosis to management. 2019. Published in Australian and New Zealand Journal of Psychiatry, 53, 41-41.

- Reppermund, S., Cohen-Woods, S., Brodaty, H., Christensen, H., Trollor, J., Mather, K., Sachdev, P. AGEDEP: Building an International Consortium on Geriatric Depression. 2019. Published in International Psychogeriatrics, 31, 92-92.

- Srasuebkul, P., Reppermund, S., Dean, K., Trollor, J. Factors associated with death in people with intellectual disability, 2019; 63, 801-801.

- Trollor, J., Srasuebkul, P., Reppermund, S., Heintze, T. Translating findings from population health data, qualitative research and policy analysis into clinical benefit for people with intellectual disability, 2019; 63, 681-681.

Submissions

- 3DN's Response to NHMRC's Development of a Culturally and Linguistically Diverse Dementia Research Action Plan
- 3DN's Response to Department of Social Services, Australian Government, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Terms of Reference
- 3DN's Response to Australian Commission on Safety and Quality in Health Care Survey on the draft second edition of the Australian Charter of Healthcare Rights
- 3DN's Response to Australian Commission on Safety and Quality in Health Care Review of the Australian Charter of Healthcare Rights
- 3DN's Submission to Parliament of Australia, Senate Community Affairs References Committee Accessibility and quality of mental health services in rural and remote Australia
  https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MentalHealthServices/Submissions

- 3DN's Submission to National Institute of Health Future Directions in Research on Fragile X Syndrome and FMR1-Related Conditions
- 3DN's Submission to NSW Health, Briefing for NSW Health on autism self-harm and suicide (private)
- 3DN's Submission to Productivity Commission, Inquiry into the role of improving mental health to support economic participation and enhancing productivity and economic growth
- 3DN's Submission to Legislative Council, National Institute of Health NSW Government in Response to the Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales
- 3DN's Response to NSW Health, NSW Ministry of Health on the consultation draft of the NSW Strategic Framework and Workforce Plan for Mental Health 2018-2022
- 3DN's Response to NHMRC, Development of a Culturally and Linguistically Diverse Dementia Research Action Plan https://www.nnidr.gov.au/research-and-funding/development-culturally-and-linguistically-diverse-dementia-research-action-plan
- 3DN's Submission to CID, Mental Health Regulation 2019
- 3DN's Submission to RACGP, Standards for general practice residential aged care (Standards for GPRAC)

Other Publications Contributions

- The Senate, Community Affairs References Committee Accessibility and quality of mental health services in rural and remote Australia, December 2018 https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/MentalHealthServices

- NSW Strategic Framework for Mental Health 2018-2022 A Framework for NSW Health Services

Conference Presentations & Lectures

International Audience

Presentations

- Dying for Change Roundtable, Trollor. J IASSIDDD World Congress, Glasgow, UK, 8 August 2019
- Translating findings from population health data, qualitative research and policy analysis into clinical benefit for people with intellectual disability, Trollor. J, Srasuebkul P., Reppermund S., Heintze, T. IASSIDDD World Congress, Glasgow, UK, 6 August 2019
- Health profiles, hospiatlisations and emergency department visits in late-life depression and associations with dementia; Reppermund S, Heintze T, Srasuebkul P, Trollor J. International Psychogeriatric Association, Santiago de Compostela, Spain; 2019
- AGEDEP: Building an International Consortium on Geriatric Depression; Reppermund S, Cohen-Woods S, Brodaty H, Christensen H, Trollor J, Mather K, Sachdev P. International Psychogeriatric Association, Santiago de Compostela, Spain; 2019

National Audience

Keynote

- Health and Wellbeing of Autistic Adults and their Carers, Trollor, J., 30th Annual National PANDDA Conference 2019, The Novotel Hotel, Parramatta, Sydney, 22 October 2019
- Health needs of people with intellectual disability in NSW prisons, Trollor, J. Corrective Services NSW 2019 Psychology Conference, Ryde-Eastwood Leagues Club, 27 August 2019
- Improving the mental health and wellbeing of people with intellectual or developmental disability; Trollor, J. RANZCP Congress 2019; Cairns Convention Centre; 16 May 2019

Invited

- Advancing mental health services development for people with intellectual or developmental disability: academic contributions; Trollor; J. School link Anniversary Celebration Children's Hospital Westmead; 11 November 2019

- Mental health and wellbeing in people with intellectual disability; Central Coast Intellectual Disability; Mental Health- creating pathways; Trollor; J. Crowne Plaza Terrigal; NSW; 28 October 2019
- Emerging Findings in Autism in adulthood; Trollor; J. AADDM Conference; Telethon Kids Institute; Perth; 4 October 2019
- Dementia in Down syndrome; Trollor; J.; Evans; L.; Down Syndrome Conference; Novotel Central Hotel; Sydney CBD; 27 September 2019
- Autism in adulthood: what future psychiatrists should know about assessment and management; Trollor, J., Arnold, S., Stevens, A. St George Mental Health Unit; 13 September 2019
- Mental health and wellbeing of people with intellectual or developmental disability: challenges in the provision of integrated supports; Trollor, J. ACT Government Senior Practitioner Forum; Canberra; 31 May 2019
- Re-building capacity in the psychiatry of intellectual and developmental disability: NSW and National Developments; Trollor, J. RANZCP Congress 2019; Cairns Convention Centre; 14 May 2019
- Old Dog, New Tricks, an adult psychiatrist's view on using the new National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia" in clinical practice; Trollor, J. RANZCP Congress 2019; Cairns Convention Centre; 13 May 2019
- Intellectual Disability Mental Health; Understanding Intellectual Disability and Mental Health; Trollor, J. HETI Health Education Training Institute; On-line; 9 May 2019
- Intellectual Disability Mental Health, Assessment & Management of Mental Ill Health in People with ID; Trollor, J. HETI Health Education Training Institute; On-line; 9 May 2019
- Intellectual Disability Mental Health, Assessing and Managing Challenging Behaviour; Trollor, J. HETI Health Education Training Institute; On-line; 9 May 2019
- Responding to the Health Needs of People with Intellectual Disability: Role and Responsibility of PHNs; Trollor, J. Australian Government Primary Health Network Mental Health Stepped Care Workshop; AAMI Park Olympic Boulevard; Melbourne; 7 March 2019

Presentations

- The impact of mental health on acute health service provision in motor neurone disease: A big data study; Trollor, Cvejic, Ho, Srasuebkul, Kiernan, Birks. MND 30th Annual International Symposium, Perth, Australia, 5 December 2019
- Responding to the health needs of people with intellectual disability- from research to action in PHNs; Trollor, J. Roundtable on the Health of People with Intellectual Disability; Rydges Hotel Sydney Airport; 2 August 2019
- Out of sight, out of mind… the health and wellbeing of people on the autism spectrum; Trollor, J. School of Psychiatry, Academic Forum; UNSW Sydney; 26 June

2019
- Health and Wellbeing in Autistic Adults and their Carers; (Arnold, Stevens, Trollor) Sutherland Hospital Mental Health Grand Rounds;10 April 2019
- Using administrative data to understand the health profile of people with less common dementias; Cvejic, R. C., Ho, Y., Srasuebkul, P., Reppermund, S., Draper, B., & Trollor, J. N. NHMRC National Institute for Dementia Research Australian Dementia Forum; Hobart, Tas, Australia; 2019
- AGEDEP: Building an International Consortium on Geriatric Depression; Reppermund S, Cohen-Woods S, Brodaty H, Christensen H, Trollor J, Mather K, Sachdev P. International Society for Bipolar Disorders, Sydney, Australia; 2019
- Dementia in Down syndrome; Evans, E., Trollor, J. Presented to the NSW Down syndrome Association Health Conference; Sydney, Australia; 2019
- Can research guide integrated care for people with intellectual disability who develop dementia? Evans, E., Trollor, J., Daly, R. Poster presented to the Australian Dementia Forum; Hobart, Tas, Australia; 2019

Other

Regular Teaching Contributions

Julian Trollor convenes the Psychiatry teaching within the School of Psychiatry, for Phase 3 Medicine, UNSW Sydney

Intellectual Disability in Medical Practice, Trollor, J., Kremser, T., Lecture for Phase 1 Medical Students, UNSW Australia, 10 May 2018

Intellectual Disability Mental Health, Cvejic, R., Re-occurring Lecture for Phase 3 UNSW Medicine

Several 3DN staff contribute to student tutorials and examinations for Phase 3 Medicine, UNSW Sydney

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Acknowledgements

Thank you to all 3DN Staff and Partners.

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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 make a donation to support research in intellectual or developmental disability health and wellbeing at 3DN, please contact Julian Trollor or Rachel Roth on (02) 9931 9160

Or via dddn@unsw.edu.au.