

2018 Annual Report

Department of Developmental Disability Neuropsychiatry (3DN)



Department of Developmental Disability Neuropsychiatry (3DN)

2018 Annual Report

34 Botany St
UNSW Sydney
UNSW Sydney NSW 2052 Australia

Telephone	+61 2 9931 9160
Facsimile	+61 2 9931 9154
Email	dddn@unsw.edu.au

Website	3dn.unsw.edu.au
Cover Image	Left; Yvonne Stocker, Untitled 2012, Colour pencil on paper, 290mm x 410 mm, Studio ARTES © Image copyright is owned by Yvonne Stocker. Centre; Shai de Vletter-Sont, Blue Poodle, Acrylic on canvas, 255mm x 255mm. © Image copyright is owned by Shai de Vletter-Sont. Right; Heather McCarthy, Untitled 2013, Miroma. © Image copyright is owned by Heather McCarthy and Miroma.
Editor	Rachel Roth & Julian Trollor
Design	Rachel Roth & Daniel Pua



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

2018

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



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Contents

05	About the Department
07	Chair's Report
10	Key Research Areas & The Year in Review
39	Our People
53	Research Grants and Funding
54	Research Output
63	Acknowledgements & Bequest Page



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.

3DN sits within the School of Psychiatry within 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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Chair's Report

Professor Julian Trollor

What an active and exciting year 2018 has been for us at the Department of Developmental Disability Neuropsychiatry! Across our research, education, clinical and policy platforms we have made progress towards our vision of achieving the highest attainable standard of mental health and wellbeing for people with intellectual or developmental disability. I would like to thank our collaborators, including people with intellectual or developmental disability, carers, family members and funding partners for their ongoing generosity. Without your support and belief in our vision, the milestones our department reached in 2018 would not have been possible.

The year has been marked by a rapid expansion of our data linkage work. The ability to link data from multiple service systems has provided our department with exciting opportunities to expand our understanding of health and service utilisation patterns among people with intellectual or development disability. Multiple data-linkage projects are currently underway in our department, including projects to: shed light on the health status and service use of people with less common types of dementia; identify physical health problems among people with schizophrenia and related psychosis; understand the predictors of repeated self-harm in people with mental health and drug and alcohol comorbidity; assess cancer-related outcomes and service use in people with intellectual disability; and determine the health and service usage profile of people with intellectual disability within the criminal justice system.

I am thrilled to announce that our work to construct the first whole-of-population, whole-of-health service study of service users with intellectual disability has commenced this year. This unique matched cohort study will create the most comprehensive linked data set related to the health profile of people with intellectual disability both nationally and internationally. Once established the data-set will provide insight to health and wellbeing and drivers of service use and costs in this population compared to the general population. It will be a platform on which we will build studies to understand how services can better support the health needs of people with intellectual disability.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

At 3DN we aim not only to understand health patterns and service usage, but also to translate research into programs and products with practical benefit for people with intellectual or developmental disability. Our department coordinated a major knowledge translation event, the National Roundtable on the Mental Health of People with Intellectual Disability, in March 2018. The roundtable brought together 130 clinicians, academics and sector representatives and provided an exciting space to workshop recommendations for improving mental health services and outcomes for this population. The subsequent Communique has set a range of agreed national priorities for action which we hope will encourage rapid development of capacity in intellectual disability mental health. This year, as part of our ongoing efforts to tackle the high rates of ill health and premature mortality from preventable causes among adults with intellectual disability we launched a prototype physical activity and healthy eating program, *Get Healthy!* Attendance and engagement levels in the trial program were high and exploratory clinical outcome data indicates the program positively impacted several measures of cardiometabolic health.

Fostering workforce capacity is another cornerstone of our mission here at 3DN. This year we were excited to add multiple new modules to our IDMH e-learning platform. These include modules to enhance the capacity of disability professionals to meet the needs of people with intellectual disability and autism spectrum disorder and modules addressing the support needs of people with intellectual disability at risk of self-harm and suicide. Additionally, we developed a comprehensive guideline for general practitioners to enhance their capacity to support diagnosis and management of dementia in people with intellectual disability. Our efforts towards understanding current and future psychiatric workforce and training capacity in intellectual and developmental disability psychiatry also continued throughout 2018, including the development of a prototype curriculum for subspecialty training in this field. I invite you to read through the remainder of our annual report to learn more about the many exciting projects we have underway.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

I would like to thank all the department staff and broader UNSW Sydney colleagues for their ongoing commitment to excellence and enthusiasm for our shared mission here at 3DN. There is still considerable work to be undertaken to overcome the multiple health inequalities faced by people with intellectual or developmental disability. Reflecting on progress to date, however, I feel optimistic about the future, and look forward to continuing our journey towards achieving the highest attainable level of mental health and wellbeing for people with intellectual or developmental disability into 2019.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Research Areas, The Year in Review

NHMRC Partnerships for Better Health Project – ‘Improving Mental Health Outcomes for People with Intellectual Disability’

Project Team: Simone Reppermund, Preeyaporn Srasuebkul, Tess Heintze, Erin Whittle, Snow Li, Bronwyn Newman, Julian Trollor

Partner Organisations: NSW Ministry of Health – Mental Health Branch, NSW Government Department of Family and Community Services and Aging, Disability and Home Care Services, Council for Intellectual Disability, Inclusion Australia, NSW Government Agency for Clinical Innovation– Intellectual Disability Network, NSW Ombudsman, NSW Office of the Public Guardian, NSW Government Department of Education, NSW Department of Justice, Justice Health network, Mental Health Commission of NSW, Mental Health Review Tribunal and the National Disability Service.

Short project description: The project aims to improve access to and quality of mental health services for people with intellectual disability using an innovative multi-pronged, mixed method approach. The project uses large scale data linkage, comprehensive policy analysis and inclusive qualitative methodologies to establish an evidence base from which to guide the development of targeted, appropriate services as well as improving access to services for people with intellectual disability and mental health issues at both the national and state levels, with an emphasis on translational outcomes.

Achievements to date: Analyses of mortality, mental health inpatient and emergency department presentations and costings have been completed. Results from linked data showed that compared to the general population, people with ID who used mental health services had a skewed diagnostic profile, higher rates of uncertain diagnoses, higher service use including more frequent and longer admission and visits to the community mental health service. Moreover, they also had higher death rates/premature mortality including from preventable causes when compared with the general population. Hospital admissions related to cancer, mental illness and heart disease increased the risk of death significantly. We also found that ID status increased the likelihood of readmission to a psychiatric facility and emergency department presentations after the first psychiatric admissions. Analysis of qualitative data on barriers and



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

enablers to accessing mental health services provided empirical evidence of anecdotal experiences and provided insight into the ways users, carers and service providers navigate an often hostile system.

As a major knowledge translation event for this project, the 2018 National Roundtable on the mental health of people with intellectual disability was held in March 2018 and brought together 130 clinicians, academics and sector representatives to workshop recommendations to improve mental health services and outcomes for this population.

Current state of the project: The project will be completed in December 2018.

Weblink: <https://3dn.unsw.edu.au/project/national-health-medical-research-council-partnerships-better-health-project-improving-mental>



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

Project Team: Claire Eagleson, Rachael Cvejic, Janelle Weise, Kimberley Davies, 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: A secondary analysis of data from the RANZCP 2014 Workforce survey suggested that psychiatrists who work with people with intellectual or developmental disability were more likely to undertake greater clinical hours (all practice areas) and outreach work compared with the wider psychiatry workforce. Most intellectual or developmental disability psychiatrists were based in major cities, with a similar distribution pattern to the broader workforce. One journal article reporting on these results has been published. Building on this analysis, an online survey of RANZCP psychiatrists with expertise/interest in intellectual or developmental disability psychiatry indicated that a small number of psychiatrists are responsible for the majority of clinical hours in IDD psychiatry, raising concerns around future capacity with the current lack of training pathways in this specialty area. Strong support was provided for subspecialty training in intellectual or developmental disability psychiatry, and preliminary evidence suggests there is potential training capacity. A further two manuscripts outlining these results have been submitted for publication. Consultation with the RANZCP took place around potential options for the enhancing intellectual or developmental disability generalist and specialist education. An example curriculum for subspecialty training in IDD psychiatry, and suggested enhancements to the Stage 2 training syllabus are in the final stages of development. These will be available for working groups to reference if subspecialty training is developed.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Current state of the project: This project is nearing completion. As this scoping study indicated a need, and support for, the development of subspecialty training, discussions with the RANZCP will continue around its future development.

Future deliverables: A final report will be provided to the RANZCP with suggested intellectual or developmental disability health core curriculum items for i) generalist and ii) specialist training.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

'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 B. Ward, Scott Teasdale, Chris Tzarimas

Short project description: People with intellectual disability experience disproportionately 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.

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 will be launched in January 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*.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Current state of the project: 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: On-line learning modules will launch in early 2019. Results from the feasibility trial and literature reviews are currently being refined for publication.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Intellectual Disability Mental Health Core Competencies Framework Project

Project Team: Janelle Weise, Claire Eagleson, Jessica Walsh, 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 that identifies core competencies in 11 key areas and an accompanying Toolkit that provides practical advice as to how mental health professionals can make adaptations to their practice have been launched and are available on the 3DN website. The documents were launched at forums that included presentations by speakers with expertise in adult, and child and adolescent intellectual disability mental health, along with disability support professionals and carers. Multiple journal articles reporting on results from the consultation stage of this project have been published.

Current state of the project: The evaluation of the Framework and Toolkit's effectiveness in supporting practice and attitudinal change ended in late 2018. The vast majority of users agreed or strongly agreed that the core competencies were applicable to their work, clear, improved their knowledge about intellectual disability mental health, and were achievable to work towards. All survey responders said that they would recommend the Toolkit to others.

Future deliverables: A publication is planned reporting on the uptake of the Framework and Toolkit, a profile of individuals who downloaded it, and the evaluation of its effectiveness.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Intellectual Disability Mental Health (IDMH) e-Learning

Project Team: Maria Ko, Kimberley Davies, Thea Kremser & 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 modules for disability professionals on mental health in people with intellectual disability and autism spectrum disorder and supporting people with intellectual disability at risk of self-harm and suicide. The site currently offers eight learning modules for carers, 13 modules for disability professionals, and 17 modules for health professionals.

Current state of the project: More learning modules are underway and expected to be launched in early 2019. We are also exploring more efficient and sustainable ways to deliver the e-Learning resource, as well as seeking further funding opportunities to expand the resource.

Future deliverables: Modules to be launched in early 2019 include a series of modules for allied health professionals on adapting healthy lifestyle interventions for people with intellectual disability, and modules for disability professionals on positive wellbeing and supporting people with intellectual disability to understand death and dying including end-of-life issues.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Making health information accessible for people with intellectual disability

Project Team: Julian Trollor, Janelle Weise, Bronwyn Newman

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: An ethics application has been submitted to UNSW HREC.

Current state of the project: Pending ethics approval consultation with people with intellectual disability and their family members and support networks will commence.

Future deliverables: Publications will detail results from the consultation focus groups and interviews. A final report will summarise the views of all stakeholders on the accessibility of health related information for people with intellectual disability across their health journey and the type of resources that are needed to promote access and participation in the Australian health care system.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

Project Team: Janelle Weise, Rachael Cvejic, Claire Eagleson, Jessica Walsh, Maria Ko, 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: Consultation has been carried out with four stakeholder groups:

- Mental health service representatives from 14 NSW Local Health Districts completed an online survey identifying what support their services require from a tertiary service, and their views on how the service could be structured.
- A Delphi survey consultation was conducted with 25 IDMH experts in NSW to reach consensus on the clinical priorities of a tertiary service and how it should operate.
- Interviews were undertaken with eight people with intellectual disability to consult around how the service could best serve the needs of people with intellectual disability and co-occurring mental ill health.
- Consultation via online surveys (available in four languages) was carried out with 42 family members and support persons of people with intellectual disability and co-occurring mental ill health to determine the priorities for a tertiary service, and how it could best operate to meet the needs of people they support.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Current state of the project: All data has been collected and a final report has been submitted summarising the views of all stakeholders. Overall, all groups supported the development of a tertiary IDMH service.

Future deliverables: Four publications detailing results 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>



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

Project Team: Samuel Arnold, Yunhe Huang, Ashley Stevens, & 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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Achievements to date: Almost 300 autistic adults participated in wave 1 data gathering, with increasing numbers likely to be achieved in wave 2. Wave 3 data gathering will commence late 2019. Surveys and outputs have been designed in consultation with autistic and carer advisors. Further publications relating loneliness, psychotropic medication prescribing, psychometric tool validation and inclusive research processes have been submitted or accepted.

Current state of the project: Wave 2 data gathering and rolling recruitment continue.

Future deliverables: Publications in the new future include:

An examination of employment and unemployment for Australian autistic adults

A literature review and subsequent model analysis of predictors of carer's mental health

A review of pathways to autism diagnosis in adulthood

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Undergraduate Medicine and Nursing Curriculum Development

Project Team: Claire Eagleson, Rachael Cvejic, Beth Turner, 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. Four publications outlining what intellectual disability content is taught and how it is taught have been published.

Current state of the project: This phase of the project has been completed. 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: A final publication is being prepared comparing the results from the current audit of medical school curricula with one completed in 1995 by Lennox and Diggins (1999).

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>



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

Project Team: Liz Evans, Julian Trollor, Rebecca Daly

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

Project ambassador: Michael Sullivan.

Short project description: The life expectancy of people with intellectual disability is increasing dramatically. Compared with the general population, people with intellectual disability may be more likely to experience age-related illnesses such as dementia. The increased risk of dementia in people with Down syndrome is now well-established, but less is known about dementia in other forms of intellectual disability. Moreover, 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 screening questionnaires and assessment instruments for assessing 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 expand the study to include more participants, and also to examine models of care for people with intellectual disability who develop dementia, and produce resources aimed at improving the recognition of dementia in people with intellectual disability.

Achievements to date: In 2018, we presented a poster at the Australian Dementia Forum regarding the wellbeing of family carers whose relative with intellectual disability has dementia.

We have written a comprehensive guideline for GPs regarding the diagnosis and management of dementia in people with intellectual disability. This guideline designed to supplement the new NHMRC dementia guidelines, within a larger set of guidelines surrounding dementia in special population groups.

Publications from SAge-ID to date include 3 papers and more than 6 presentations to national and international conferences.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Current state of the project: We are nearing completion of the third wave of surveys, interviews and assessments for the original cohort. 76% of those receiving surveys have completed them. Recruitment of a second sample from the community and from clinics focused on dementia in people with intellectual disability is ongoing. We have held a consumer consultation with people with intellectual disability regarding what they would like to see in resources about ageing and dementia in people with intellectual disability. The input from the consultation group was very informative for shaping the direction of the resource. We have compiled the content for an online training module for health professionals working with people with ID who may have dementia.

Future deliverables: A Delphi process examining improving service delivery for people with intellectual disability and dementia is planned in early 2019. Paper-based resources for people with intellectual disability and carers will be completed and made downloadable from the 3DN website. An online module for health professionals will be housed on the www.idhealtheducation.com.au website. Results from the surveys and online Delphi process will be reported in publications and a final report to funders.

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



Tuberous Sclerosis Complex (TSC)

Project Team: Sunita Misra & Julian Trollor

Short project description: Tuberous Sclerosis complex (TSC) is a rare, multisystem genetic disorder that causes benign tumours to grow in the brain and on other vital organs such as the brain, kidneys, heart, eyes, lungs, and skin. A combination of symptoms may include seizures, developmental delay, behavioural problems, skin abnormalities, lung and kidney diseases. Of all the possible manifestations of this complex disorder, the cognitive and behavioural problems represent the area of greatest concern to parents and caregivers. This project aims to: provide first-hand experience in setting up a multidisciplinary clinic for adults with a complex genetic disorder, TSC; assist acquisition of knowledge of standardised psychological assessment tools which would be suitable to evaluate on the Neuropsychiatric morbidity in adults with TSC; assist acquisition of knowledge of evidence based neuropsychiatric intervention program for the TSC psychopathologies; and allow development of expertise in provision of training and education to carers, parents and health practitioners in mental health and complex genetic disorders such as TSC.

Achievements to date: A literature review has been completed of the standardised psychological assessment tools which would be suitable to evaluate the Neuropsychiatric morbidity in adults and children with TSC.

Current state of the project: A systematic literature review of the evidence-based studies for the neuropsychiatric intervention is being conducted. This includes a review of the psychotropic medications found to be effective in the treatment of various psychopathologies in TSC.

Future deliverables: A literature review for the psychological interventions is planned. An information booklet is also being developed.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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: Available data suggest that people with intellectual disability experience higher rates of ill health, poor access to responsive health services including to preventative health initiatives, and ultimately, premature mortality. Specific healthcare services for this population are very limited, such that responsibility falls almost entirely on mainstream healthcare professionals and services that are ill equipped in this area. 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 largest and most comprehensive linked data set relating to the health profile of people with intellectual disability internationally and will develop a unique resource representative of Australian disability service users with intellectual disability to examine the health and wellbeing of people with ID 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 inequalities in health and wellbeing 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: Our study team has begun regular meetings to progress this important work. Ethics approval from various involved ethics committees has been granted.

Current state of the project: We are currently in the process of receiving data custodian approvals and linking the administrative datasets via the Centre for Health Record Linkage and the Australian Institute of Health and Welfare. Data analysis is anticipated to start in late 2019.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Future deliverables: Publications will detail results from the aims of this project:

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 intellectual disability and compare these with a cohort of matched controls without intellectual disability from the NSW population.
2. Characterise the prescribed medicines use profile and their predictors in people with intellectual disability 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 intellectual disability.
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 intellectual disability, advocates, service providers and government to mobilise responses to the health needs of people with intellectual disability.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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 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: A steering committee has been formed and Local Health Districts and Networks are being consulted on the types of information that they would like to access, and how they would like to be able to access this information within an interactive web-based tool.

Current state of the project: 3DN are currently working to prepare the data for our web-based. We are also working with information technology experts on the design and implementation of the web-based tool.

Future deliverables: An interactive web-based tool will be available to Local Health Districts and Specialist Health Networks in New South Walt to assisting them to understand and respond to the mental health and health needs of people with intellectual disability in their area. A final report will summarise the process of developing and evaluating the web tool.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

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.

Current state of the project: Data analyses for this project are underway

Future deliverables: Key findings of this project will be disseminated via peer reviewed publications and conference presentations for the scientific community; summaries for clinicians and services; plain English summaries for families and carers and dementia-friendly summaries for people with dementia.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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: Data analyses for this project are underway

Future deliverables: Specific outcomes of this pilot project will include pilot data to be included in funding applications to support project expansion; manuscripts targeting the scientific community; summaries for health professionals and services; plain English summaries for people with MH and DA comorbidity, family members and carers.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

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.

Current state of the project: This project has just commenced and will continue through 2019

Future deliverables: Specific outcomes of this pilot project will include pilot data to be included in funding applications to support project expansion; manuscripts targeting the scientific community; plain English summaries for people with psychotic disorders, their carers and families; summaries for health professionals and services.

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.

Achievements to date: A literature review has been drafted on the topic and a project timeline has been established. Research questions and the statistical analyses required to answer them have been discussed.

Current state of the project: Preparation of data-linkage is underway and access to the linked-dataset is expected this year. An analysis plan for the dataset is currently in preparation.

Future deliverables: A literature review of the topic will be published to synthesise the existing knowledge base. Original research publications will report findings from the data analyses and suggestions on how to improve service provision will also be explored within the publications.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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 at various local forums as well as the International Conference for Communication in Healthcare (Porto, Portugal 1-4 September 2018) and the Australasian Society for Intellectual Disability (Surfers Paradise 2018).

Current state of the project: All data collection is complete. The anticipated thesis completion date is during the first term of 2019.

Future deliverables: Insights about making information accessible using easy read suitable will be provided to service providers and policy makers. Findings will be submitted to relevant journals in the months ahead.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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 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

and 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 Overall, the milestones listed for the first year have been achieved on time. During the past 9 months, the confirmation has been achieved, including submitting a literature review and an oral presentation to the panel. This work set the foundation for the PhD research plan. Now a systematic review has been conducted to help further shape the research questions.

Current state of the project: A systematic review of the morbidity rate of physical health conditions in people with intellectual disability

Future deliverables: Systematic review findings will be submitted for publication. The research proposal for the first study will be designed based on the findings of the systematic review, and the findings of the first study will be detailed in the future manuscript.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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 Intellectual Disability to have been in the Criminal Justice System (CJS) in New South Wales (NSW). This project will utilise a unique longitudinal data linkage 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 intellectual disability diagnostic profile, CJS contacts and support service use, and how their pathways through the CJS interact with service and support agencies. In this way this project will explore the complex nature of life-course pathways through the CJS for people with an intellectual disability.

Achievements to date: The first year has been completed and the set milestones for that year have been achieved; first year confirmation successfully completed, literature review/first chapter completed.

Current state of the project: Data for the first three publications/chapters have been analysed and are currently being drafted for publication. Papers will focus on the following topics:

1. What proportion of the NSW adult custody population as recorded in the Australian Bureau of Statistics Prisoner census 2014 has an intellectual disability, who is this group as detailed in their diagnosis and agency contacts, what is the experience for this group in relation to this particular custody episode (e.g. self-harm, offences in custody, prior custody episodes, offence profile).
2. Hospital admitted patient and emergency presentations and for people with intellectual disability in contact with corrective services.
3. Examination of the effect receiving a disability service after index custody episode on the probability of reincarceration in people with intellectual disability.

An ethics amendment is currently being finalised with 3DN's data manager to include additional data-sets into the established data linkage (Bureau of Crime Statistics Research court records and Department of Juvenile Justice custody data).

Future deliverables: There will be several future publications and chapters.

1. A costings study on the provision of disability services post-release from prison for an intellectual disability cohort.
2. An analysis of the use of court diversions for an intellectual disability cohort, subject to data access.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Pathways to 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 Adults with Autism (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:

An outline of research questions and proposed component projects has been created. Currently working on a systematic scoping review of existing research on diagnosis of ASD in adulthood between 2008-2018 and a research proposal for PhD confirmation.

Current state of the project: The project team is currently producing an ethics application for all components of this project including linkage of ALSAA data. Self-report and informant-report versions of an online survey for individuals diagnosed in adulthood is under development in consultation with ALSAA autistic advisors. Format and structure of the interview component will be designed following release of survey.

Future deliverables: The systematic scoping review will be submitted for publication following completion in 2019. Findings from the survey (triangulated with ALSAA data) and interview will also be written and submitted for publication.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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 the rates of ambulatory mental health utilisation and emergency department presentation.

Achievements to date: Data linkage study 1 was published in the peer-reviewed journal BMJ Open and presented at the 28th European Psychiatry Congress. The qualitative study was presented at the Australian Social Policy conference. The literature review was selected as a knowledge translation project by the Disability Innovation Institute and the findings were presented in mural painting at UNSW. Snow was also the successful applicant for the HRD speed networking award 2018.

Current state of the project: Data linkage study 2 is currently under review with journal Health Service Research.

Future deliverables: Snow will complete her studies and submit her thesis in 2019.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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. His position is based at the Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales. 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". He also works as a casual academic with the Western Sydney University.

Sam previously provided counselling and clinical services at the [NSW Developmental Disability Health Unit \(DDHU\)](#) and the [Northern Sydney Intellectual Disability Health Team \(NIDH\)](#). He previously held an additional role of part time Project Officer Evaluation at NIDH, and previously provided crisis telephone counselling with LifeLine Penrith and Parramatta.

Sam conducts education about research principles, psychology and disability studies, sexuality, behaviour of concern, person-centredness and actively supporting people to live in the community. 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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.

learning project. The aim of this project is to improve mental health outcomes for people with intellectual disability by improving knowledge of mental disorders in health and disability professionals.

Previously, Kimberley completed an honours degree in Psychology at the University of Sheffield (UK), and a Master's Degree in Psychological Research Methods at The University of Liverpool (UK), where her thesis examined maternal interactions and PTSD.

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 Kimberley Davies



Research Officer

Kimberley joined 3DN in February 2015 and is currently working as a Project Officer on the Intellectual Disability Mental Health (IDMH) e-



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Ms Claire Eagleson



Project Officer

Claire is currently working as a Project Officer managing three 3DN projects. The first involves the development and implementation

of Intellectual Disability Mental Health Core Competencies Framework manual which aims to improve workplace capacity in this area. The second is a national curriculum audit of intellectual disability content taught in Australian medical and nursing schools. The latest project involves working with the Royal Australian and New Zealand College of Psychiatrists looking at current workforce capacity in the area of intellectual and developmental disability mental health, and the potential for the development of subspecialty training in this area for future psychiatrists.

Previously Claire has worked at the Institute of Psychiatry, Psychology and Neuroscience, London managing a program of research aimed at examining cognitive maintaining factors of worry in emotional disorders, and at the Brain & Mind Research Institute assessing the efficacy of an e-Health program for generalised anxiety versus pharmacological treatment. She

holds a Bachelor of Psychology (Hons) and Master of Psychology (Clinical) from the University of NSW.

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.

Miss Jane Yein Hwang



PhD Student & Research Assistant

Jane is a PhD candidate in the 'Adulthood' program of the Cooperative Research Centre for Living with Autism (Autism

CRC). Her PhD explores the experience of ageing for autistic adults in Australia and involves a longitudinal study, interviews and the investigation of linked data.

Jane's research interests lie in intellectual and developmental disabilities, ageing, mental health and health technology.

Jane is also a Research Assistant for the Australian Longitudinal Study of Adults with Autism (ALSAA), a national questionnaire study that aims to profile the health and wellbeing of autistic adults in Australia.

Jane completed her Bachelor of Psychology with Honours at Macquarie University. Her honours research involved examining the restorativeness of social environments following periods of attentional fatigue. She also has experience working as a Research Assistant at Macquarie University.

Jane submitted her PhD in July 2018.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Ms Maria Ko



Research Officer

Maria is a registered psychologist with professional experience in government, non-government organisations and private practice. Prior to

joining 3DN, she worked in behavioural research in a government setting to improve existing processes and design evidence-based interventions. Maria has a strong interest in human rights and mental health and has worked in international development and capacity building roles in Mongolia and India.

Maria is currently working on the Intellectual Disability Mental Health (IDMH) e-learning project. She holds a Bachelor of Psychology (Hons), Master of Psychology (Educational and Developmental) and Master of Human Rights.

Ms Thea Kremser



Project Officer

B Psych (Hons),
Cert IV TAA

Thea has a background in public health research and project management (physical activity and cancer

control), and also has clinical experience in community mental health and counselling. She has been responsible for counselling and triage in a community setting, where her clients included adults with intellectual disability. Thea has a strong interest in adult education and professional development, and has developed and provided training in cancer control, mental health triage, and counselling.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Ms Rachel Roth



Administrative
Officer

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

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 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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Dr Janelle Weise (née Govett)



Project Officer

Janelle Weise is a Project Officer 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.

Ms Erin Whittle



Research Officer

Erin is a Research Officer currently working on Aim 3 of the NHMRC Partnerships for Better Health Project - Improving the Mental Health

Outcomes for Persons with Intellectual Disability, which focuses on a qualitative exploration of the barriers that impede access to mental health services for people with intellectual disability.

Erin holds a Masters of Public Health from UNSW, and a Bachelor of Arts (Hons) in Sociology and Gender Studies from the University of Sydney. Her research interests are qualitative research methods, the social determinants of mental health and wellbeing and health inequities.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

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

Other PhD Students within 3DN

Ms Janelle Weise	PhD and Project Officer (Bio above) Graduated in 2018
Ms Erin Whittle	PhD and Research Officer (Bio above)
Ms Jane Hwang	PhD and Research Assistant (Bio above)
Mr Julian Trofimovs	PhD Student



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Ms Marisse Sonido

ILP Student

Marisse is a 4th year medical student at the University of New South Wales. She is currently undertaking an Independent Learning Project on the mental health of carers of adults with autism. 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.



Ms Madeleine Harsanyi

Honours Student



Madeleine is a 4th year occupational therapy student at the Australian Catholic University. She is currently undertaking an Honours Project

on employment and unemployment for autistic adults using data collected through the ALSAA study. Developmental disability and employment are two areas that Madeleine has a keen interest in, and she hopes to be able to implement the skills, knowledge and experience she gains at 3DN in 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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Research Grants and Funding

Research Funding

- 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

- NSW Health; 2018; \$401,255 IDMH Big Data, Easy Read and SCORM, (Trollor)
- University of Sydney Seed Funding Scheme: Mental Health, Drug and Alcohol Comorbidity; \$19,795, Using big data to understand the predictors of repeated self-harm in people with mental health and drug and alcohol comorbidity (Chitty, Cvejic, Morley, Srasuebkul, Dawson, Carter, Trollor)
- Dementia Australia Research Foundation; 2018; \$50,000 “Using big data to understand the health status, service use, and service pathways of people with less common types of dementia (Birch, Reppermund, Draper, Trollor)

Other Funding

- 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)
- UNSW Medicine Neuroscience, Mental Health and Addictions Theme and SPHERE Mindgardens Clinical Academic Group seed grant scheme; 2018; \$39,500; Addressing preventable disease burden to improve health outcomes for people with schizophrenia and related psychoses” (Trollor)
- Mental Health Commission of NSW; 2018; \$6,052.00; CALD consultation for tertiary IDMH service development; (Trollor, Weise)



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Publications

Papers in Refereed Journals

Cai, R.Y., Richdale, A.L., Dissanayake, C., Trollor, J., Uljarević, M. Emotion regulation in autism: Reappraisal and suppression interactions. *Autism*, 2018; 23(3), 737-749.

Cai, R.Y., Richdale, A.L., Foley, K.R., Trollor, J., Uljarević, M. Brief report: Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders*, 2018; 45, 1-8.

Cations, M., Draper, B., Low, L.F., Radford, K., Trollor, J., Brodaty, H., Sachdev, P.S., Gonski, P., Broe, G.A., Withall, A. Non-Genetic Risk Factors for Degenerative and Vascular Young Onset Dementia: Results from the INSPIRED and KGOW Studies. *Journal of Alzheimer's Disease*, 2018; 62(4), 1747-1758.

Ciobanu, L.G., Sachdev, P.S., Trollor, J.N., Reppermund, S., Thalamuthu, A., Mather, K.A., Cohen-Woods, S., Stacey, D., Toben, C., Schubert, K.O., Baune, B.T. Co-expression network analysis of peripheral blood transcriptome identifies dysregulated protein processing in endoplasmic reticulum and immune response in recurrent MDD in older adults. *Journal of Psychiatric Research*, 2018; 107, 19-27.

Cvejic, R.C., Arnold, S.R.C., Foley, K.R., Trollor, J.N. Neuropsychiatric profile and psychotropic medication use in adults with autism spectrum disorder: results from the Australian Longitudinal Study of Adults with Autism. *BJPsych Open*, 2018; 4(6), 461-466.

Cvejic, R.C., Eagleson, C., Weise, J., Davies, K., Hopwood, M., Jenkins, K., Trollor, J.N. Building workforce capacity in Australia and New Zealand: a profile of psychiatrists with an interest in intellectual and developmental disability mental health. *Australasian Psychiatry*, 2018; 26(6), 595-599.

Cvejic, R.C., Hocking, D.R., Wen, W., Georgiou-Karistianis, N., Cornish, K.M., Godler, D.E., Rogers, C., Trollor, J.N. Reduced caudate volume and cognitive slowing in men at risk of fragile X-associated tremor ataxia syndrome. *Brain Imaging and Behavior*, 2018.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Davies, G., Lam, M., Harris, S.E., Trampush, J.W., Luciano, M., Hill, W.D., Hagenaars, S.P., Ritchie, S.J., Marioni, R.E., Fawns-Ritchie, C., Liewald, D.C.M., Okely, J.A., Ahola-Olli, A.V., Barnes, C.L.K., Bertram, L., Bis, J.C., Burdick, K.E., Christoforou, A., Derosse, P., Djurovic, S., Espeseth, T., Giakoumaki, S., Giddaluru, S., Gustavson, D.E., Hayward, C., Hofer, E., Ikram, M.A., Karlsson, R., Knowles, E., Lahti, J., Leber, M., Li, S., Mather, K.A., Melle, I., Morris, D., Oldmeadow, C., Palviainen, T., Payton, A., Pazoki, R., Petrovic, K., Reynolds, C.A., Sargurupremraj, M., Scholz, M., Smith, J.A., Smith, A.V., Terzikhan, N., Thalamuthu, A., Trompet, S., Van Der Lee, S.J., Ware, E.B., Windham, B.G., Wright, M.J., Yang, J., Yu, J., Ames, D., Amin, N., Amouyel, P., Andreassen, O.A., Armstrong, N.J., Assareh, A.A., Attia, J.R., Attix, D., Avramopoulos, D., Bennett, D.A., Böhmer, A.C., Boyle, P.A., Brodaty, H. Study of 300,486 individuals identifies 148 independent genetic loci influencing general cognitive function. *Nature Communications*, 2018; 9(1), 2098.

Dew, A., Dowse, L., Athanassiou, U., Trollor, J. Current Representation of People with Intellectual Disability in Australian Mental Health Policy: The Need for Inclusive Policy Development. *Journal of Policy and Practice in Intellectual Disabilities*, 2018; 15(2), 136-144.

Glasson, E.J., Wong, K., Leonard, H., Forbes, D., Ravikumara, M., Mews, C., Jacoby, P., Bourke, J., Trollor, J., Srasuebkul, P., Wilson, A., Nagarajan, L., Downs, J. Evolving Trends of Gastrostomy Insertion Within a Pediatric Population. *Journal of Pediatric Gastroenterology and Nutrition*, 2018; 67(5), e89-e94.

Hedley, D., Uljarević, M., Foley, K.R., Richdale, A., Trollor, J. Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety*, 2018; 35(7), 648-657.

Hofer, E., Roshchupkin, G.V., Adams, H., Knol, M., Lin, H., Li, S., Zare, H., Ahmad, S., Armstrong, N., Satizabal, C., Bernard, M., Bis, J., Gillespie, N., Luciano, M., Mishra, A., Scholz, M., Teumer, A., Xia, R., Jian, X., Mosley, T., Saba, Y., Pirpamer, L., Seiler, S., Becker, J., Carmichael, O., Rotter, J., Psaty, B., Lopez, O., Amin, N., Lee, S., Yang, Q., Himali, J., Maillard, P., Beiser, A., DeCarli, C., Karama, S., Lewis, L., Bastin, M., Harris, M., Deary, I., Witte, V., Beyer, F., Loeffler, M., Mather, K., Schofield, P., Thalamuthu, A., Kwok, J., Wright, M., Ames, D., Trollor, J., Jiang, J., Brodaty, H., Wen, W., Vernooij, M., Hofman, A., Uitterlinden, A., Niessen, W., Wittfeld, K., Bulow, R., Volker, U., Pausova, Z., Pike, B., Maingault, S., Crivello, F., Tzourio, C., Amouyel, P., Mazoyer, B., Neale, M., Franz, C., Lyons, M., Panizzon, M., Andreassen, O., Dale, A., Logue, M., Grasby, K., Jahanshad, N., Painter, J., Colodro-Conde, L., Bralten, J., Hibar, D., Lind, P., Pizzagalli, F., Stein, J., Thompson, P., Medland, S., Sachdev, P., Kremen, W., Wardlaw, J., Villringer, A., Duijn, C., Grabe, H., Longstreth, W., Fornage, M., Paus, T., Debetto, S., Ikram, A., Schmidt, H., Schmidt, R., Seshadri, S. Genetic Determinants of Cortical Structure (Thickness, Surface Area and Volumes) among Disease Free Adults in the CHARGE Consortium. *bioRxiv*, 2018.

Hwang, Y.I., Foley, K.R., Trollor, J.N. Aging Well on the Autism Spectrum: An Examination of the Dominant Model of Successful Aging. *Journal of Autism and Developmental Disorders*, 2018.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Jiang, J., Thalamuthu, A., Ho, J.E., Mahajan, A., Ek, W.E., Brown, D.A., Breit, S.N., Wang, T.J., Gyllenstein, U., Chen, M.H., Enroth, S., Januzzi, J.L., Lind, L., Armstrong, N.J., Kwok, J.B., Schofield, P.R., Wen, W., Trollor, J.N., Johansson, Å., Morris, A.P., Vasan, R.S., Sachdev, P.S., Mather, K.A. A meta-analysis of genome-wide association studies of growth differentiation factor-15 concentration in blood. *Frontiers in Genetics*, 2018; 9, 97.

Lee, T., Thalamuthu, A., Henry, J.D., Trollor, J.N., Ames, D., Wright, M.J., Sachdev, P.S., Team, O.R. Genetic and Environmental Influences on Language Ability in Older Adults: Findings from the Older Australian Twins Study. *Behavior Genetics*, 2018; 48(3), 187–197.

Li, X., Srasuebkul, P., Reppermund, S., Trollor, J. Emergency department presentation and readmission after index psychiatric admission: A data linkage study. *BMJ Open*, 2018; 8(2), e018613.

Man, J., Kangas, M., Trollor, J., Sweller, N. Clinical Practices and Barriers to Best Practice Implementation of Psychologists Working with Adults with Intellectual Disability and Comorbid Mental Ill Health. *Journal of Policy and Practice in Intellectual Disabilities*, 2018; 15(3), 256-266.

Reppermund, S., Dowse, L., Dew, A., Trollor, J. Representation of people with intellectual disability in Australian mental health policy. *Australian and New Zealand Journal of Psychiatry*, 2018; 52(7), 618-619.

Salomon, C., Bellamy, J., Evans, L., Reid, R., Hsu, M., Teasdale, S., Trollor, J. 'Get Healthy!' A physical activity and nutrition program for older adults with intellectual disability: pilot study protocol. *Pilot and Feasibility Studies*, 2018; 4(1), 144.

Salomon, C., Britt, H., Pollack, A., Trollor, J. Primary care for people with an intellectual disability — what is prescribed? An analysis of medication recommendations from the BEACH dataset. *BJGP Open*, 2018; 2(2), bjgopen18X101541.

Salomon, C., Whittle, E., Bellamy, J., Evans, E., Teasdale, S., Samaras, K., Ward, P.W., Hsu, M., Trollor, J. A qualitative exploration of barriers and enablers of healthy lifestyle engagement for older Australians with intellectual disabilities. *Research and Practice in Intellectual and Developmental Disabilities*, 2018, 1-10.

Stacey, T.L., Froude, E.H., Trollor, J., Foley, K.R. Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*, 2018.

Trollor, J.N., Eagleson, C., Turner, B., Salomon, C., Cashin, A., Iacono, T., Goddard, L., Lennox, N. Intellectual disability content within pre-registration nursing curriculum: How is it taught? *Nurse Education Today*, 2018; 69, 48-52.

Trollor, J.N., Eagleson, C., Turner, B., Tracy, J., Torr, J.J., Durvasula, S., Iacono, T., Cvejic,



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

R.C., Lennox, N. Intellectual disability content within tertiary medical curriculum: How is it taught and by whom? *BMC Medical Education*, 2018; 18(182), 1-10.

Wang, L., Crawford, J.D., Reppermund, S., Trollor, J., Campbell, L., Baune, B.T., Sachdev, P., Brodaty, H., Samaras, K., Smith, E. Body mass index and waist circumference predict health-related quality of life, but not satisfaction with life, in the elderly. *Quality of Life Research*, 2018; 27(10), 2653-2665.

Weise, J., Fisher, K.R., Whittle, E., Trollor, J. What can the experiences of people with an intellectual disability tell us about the desirable attributes of a mental health professional? *Journal of Mental Health Research in Intellectual Disabilities*, 2018; 11(3), 183-202.

Whittle, E.L., Fisher, K.R., Reppermund, S., Trollor, J. Access to mental health services: The experiences of people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 2018; 32(2), 368-379.

Wong, K., Leonard, H., Pearson, G., Glasson, E.J., Forbes, D., Ravikumara, M., Jacoby, P., Bourke, J., Srasuebkul, P., Trollor, J., Wilson, A., Nagarajan, L., Downs, J. Epidemiology of gastrostomy insertion for children and adolescents with intellectual disability. *European Journal of Paediatrics*, 2018, 1-11.

Zhang, H., Sachdev, P.S., Thalamuthu, A., He, Y., Xia, M., Kochan, N.A., Crawford, J.D., Trollor, J.N., Brodaty, H., Wen, W. The relationship between voxel-based metrics of resting state functional connectivity and cognitive performance in cognitively healthy elderly adults. *Brain Imaging and Behavior*, 2018; 12(6), 1742-1758.

Book Chapters

Trollor, J., Hwang, J. 2018. Autism Spectrum Disorders in Later Life *Oxford Research Encyclopedia of Psychology*.

Reports

Fisher, K.R., Whittle, E., Trollor, J. How to improve the NDIS for people who have an intellectual disability as well as a mental illness, 2018.

Reviews

Cvejic, R.C., Trollor, J.N. Transition to adult mental health services for young people with an intellectual disability. *Journal of Paediatrics and Child Health*, 2018; 54(10), 1127-1130.

Salomon, C., Trollor, J. Young people with an intellectual disability experience poorer physical and mental health during transition to adulthood. *Evidence-Based Nursing*, 2018; 21(1), 20.

Trollor, J.N. Commentary on "Context and tension in psychiatric diagnoses in people



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

with intellectual disabilities: challenges and responses" (Britt, Davies, & Daffue, 2018). *Research and Practice in Intellectual and Developmental Disabilities*, 2018; 5(2), 114-117.

Whittle, E., Fisher, K.R., Reppermund, S., enroot, R., Trollor, J. Barriers and enablers to accessing mental health services for people with intellectual disability: a scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, 2018.

Editorial

Trollor, J. It's time to address the mental health needs of people with intellectual disability, 2018; 26, 575-576..

Published Abstracts

Cvejic, R.C., Srasuebkul, P., Trollor, J.N. Does administrative health data have a place in behavioural phenotype research? 2018; 62, 666-667.

Hwang, J., Trollor, J., Foley, K. *Successful ageing in adults with autism spectrum disorders*. 2018. *Australian and New Zealand journal of psychiatry*, 52, 21-22.

Trollor, J., Srasuebkul, P., Reeve, R., Heintze, T., Reppermund, S. Building capacity in intellectual disability mental health in local health districts: a cost-benefit analysis, 2018; 52, 75-76.

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
-



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Conference Presentations & Lectures

International Audience

Invited

Successful Ageing in Adults with Autism Spectrum Disorders, Hwang, Y I., Trollor, J., Foley, K., RANZCP Conference, Auckland 17th May

Building capacity in intellectual disability mental health in local health districts: a cost benefit analysis, Trollor, J., Srasuebkul, P., Reeve, R., Heintze, T., Reppermund and the NHMRC Partnership Team, RANZCP Conference, Auckland 14th May

National Audience

Keynote

What can big data tell us about the mental health of students with intellectual and developmental disabilities? Trollor, J., Srasuebkul, P., Flack, L., NSW Teachers Federation Centre for Professional Learning Mental Health of Students with Disability K-12 Conference, NSW Teachers Federation Sydney, 5th November 2018

Closing the gap for people with intellectual disability: focus on mental health, Trollor, J., PANDDA 29th Annual Conference: People, Purpose, & Passion, Novotel Hotel Paramatta, 16 October 2018

Using big data to understand premature mortality and its drivers in people with intellectual disability, Trollor, J., AADDM Conference UTS Sydney, 6 September 2018

Using big data to understand the representation and profile of people with intellectual disability in NSW prisons, Trollor, J., Trofimovs, J., Dowse, L., Srasuebkul, P., AADDM Conference UTS Sydney, 6 September 2018

2018 National Roundtable on the Mental Health of People with Intellectual Disability, Trollor, J., UNSW Sydney, 27th March 2018

Presentations

Adults' Disclosure of their Autism: A Mixed Methods Investigation, Australasian Society for Autism Research Conference, ASfAR, Gold Coast, Huang, Y., Hwang, Y. I., Trollor, J., Arnold, S., 6 December 2018



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

"The single most important thing that has happened to me in my life": Preliminary Investigation of the Impact of Diagnosis Scale –Revised (IODS-R), ASfAR Conference, Gold Coast, Arnold, S. R. C., Lawson, L., Hwang, Y. I., Richdale, A., & Trollor, J. , December 2018

Sleep quality and the autism spectrum from mid-adolescence to old age, ASfAR Conference, Gold Coast, Joveska, S., Richdale, A., Lawson, L., Arnold, S. R. C., & Trollor, J., December 2018

Identifying the online health information needs of adults on the autism spectrum with intellectual disability using an inclusive methodology. ASfAR Conference, Gold Coast, Brooker, K., Lennox, N., Harley, D., Baker, A. R., Darch, H., Szeto, H., Arnold, S. R. C., & Urbanowicz, A., December 2018

Adults' disclosure of their autism: a mixed methods investigation, E-Poster presentation at the ASfAR Conference, Gold Coast, Huang, Y., Hwang, Y. I., Trollor, J. & Arnold, S. R. C., December 2018

Mortality and cause of death of those on the autism spectrum: An investigation of linked data, Poster session presented at the ASfAR Conference, Gold Coast, Hwang, Y. I., Srasuebkul, P., Foley, K. -R., Arnold, S. R. C., & Trollor, J., December 2018

Preferred autism terminology in the Autistic community, , E-Poster presentation at the ASfAR Conference, Gold Coast, Foley, K. -R., den Houting, J., Lawson, L., Arnold, S. R. C., Richdale, A. & Trollor, J., December 2018

Building an International Consortium on Geriatric Depression, Society for Mental Health Research Conference, Noosa, Australia, Reppermund S, Cohen-Woods S, Brodaty H, Christensen H, Trollor J, Mather K, Sachdev P, 29 November 2018

Recommendations for an effective mental health system for people with intellectual disability – Results from a major knowledge translation event, Society for Mental Health Research Conference, Noosa, Australia, Reppermund S, Kremser T, Trollor JN and the NHMRC Partnerships for Better Health Project Team of the Project 'Improving the Mental Health Outcomes of People with Intellectual Disability', 28 November 2018

'How is the right to accessible information represented in Australian mental health policy?' Australasian Society for Intellectual Disability Conference, Gold Coast, Queensland, Newman, B. 14-16 November 2018

Mental health in autistic adults and their carers: Findings from the Australian Longitudinal Study of Adults with Autism (ALSAA), Psychologists working in the field of Developmental Disability (PSYCHDD) 27th Annual Conference, Parramatta, NSW, Arnold, S. R. C., & Stevens, A., November 2018

Cancer prevention, treatment, and outcomes in people with intellectual disability, Translational Cancer Research Network Symposium, TCRN, Sydney, Nguyen. E., 30 October 2018



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

What can Big Data tell us about people with intellectual disability? Trollor, J., Srasuebkul, P., Heintze, T., Trofimovs, J., CMO Symposium HETI, Higher Education Cumberland Hospital North Parramatta, 18 October 2018

Preferred terminology in the Autistic community: what's in a name? Occupational Therapy Australia NT/QLD Regional Conference, Gold Coast, Foley, K.-R., den Houting, J., Lawson, L., Arnold, S. R. C., Richdale, A. & Trollor, J., October 2018

'How can easy read documents be used to make mental health information more accessible?' (poster) International Conference of Communication in Healthcare, Porto, Portugal, Newman, B. 4-6 September 2018

Does administrative health data have a place in behavioural phenotype research? The 21st Society for the Study of Behavioural Phenotypes International Research Symposium, Melbourne, Cvejic, R., 29 Aug 2018

Understanding and responding to the mental health needs of people with intellectual and developmental disabilities, Trollor, J., Coffs Harbour, 17 August 2018

Using big data to improve service provision for people with intellectual disability, Mental Health Ground Rounds, Trollor, J., Prince of Wales, Sydney, 6 August 2018

'How is easy read Information about mental health used to enable access to information?' Mental Health Drug and Alcohol Research Conference, Macquarie Hospital, North Ryde, Newman, B. 2 August 2018

What can Big Data tell us about people with intellectual disability, Trollor, J., Justice Health Malabar, Sydney, 1 August 2018

'How is Easy Read Information about Mental health used to enable access to information?' UNSW Arts Post Graduate Conference ,UNSW, Sydney, Newman, B. 20 July 18

Meeting the Mental Health Needs of People with Intellectual Disability in Local Health Districts, Trollor, J., Premier & Cabinet, Sydney 10 July 2018

Meeting the Mental Health Needs of People with Intellectual Disability in Local Health Districts, Trollor, J., RANZCP ACT Travelling Scholar QT Hotel, Canberra, 21 June 2018

Mental health and wellbeing in people with intellectual disability: What every trainee psychiatrist needs to know, Trollor, J., RANZCP ACT Travelling Scholar, Canberra Hospital, 21 June 2018

Mental health in family carers of people with intellectual disability with and without dementia: the need for cooperation across service sectors. Poster presented to the Australian Dementia Forum, Sydney, Evans, E., O'Brien, E., & Trollor, J., 4-5 June 2018.

Understanding Intellectual Disability in a CL Psychiatry Context, NSW Advanced Training in Consultation-Liaison Psychiatry Program, NSW RANZCP, Sydney, Trollor, J., 30 May 2018

Understanding Intellectual Disability in a Primary Health Context, Trollor, J., Central and Eastern Sydney PHN 23 May 2018



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Meeting the Health Needs of People with Intellectual Disability in Local Health Districts, Trollor, J., Grand Rounds, Westmead Hospital, 3 May 2018

The Australian Longitudinal Study of Adults with Autism (ALSAA): Inclusive research protocol development and baseline sample characteristics, Poster session presented at the INSAR Annual Meeting, Rotterdam, Netherlands, Arnold, S. R. C., Foley, K.-R., Hwang, Y. I., Trollor, J., & The Autism CRC Program 3, May 2018

Loneliness in Adults on the Autism Spectrum: Testing a theoretical model of loneliness, Poster session presented at the INSAR Annual Meeting, Rotterdam, Netherlands, Ee, D., Hwang, Y. I., Reppermund, S., Foley, K.-R., Srasuebkul, P., Trollor, J., & Arnold, S. R. C., May 2018

Other

Dying for Change, Roundtable, The Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 6 November 2018

Dying for Change, Seminar and Panel Discussion, The Disability Innovation Institute, UNSW Sydney, 5 November 2018

Using big data to improve service provision for people with intellectual disability, Mental Health Ground Rounds, Trollor, J., Prince of Wales, Sydney, 6 August 2018

Expert Panel Member, Trollor, J., First National Virtual Disability Conference (Australia), Online, 21 March 2018

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



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Acknowledgements

Thank you to all 3DN Staff and Partners.

Bequest Page

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.



UNSW
SYDNEY



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY