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Department of Developmental Disability Neuropsychiatry Annual Report 2015

Never Stand Still

Medicine

Department of Developmental Disability Neuropsychiatry

Department of Developmental
Disability Neuropsychiatry (3DN)
Annual Report 2015

Postal Address

34 Botany St
UNSW Australia
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

Editor	Rachel Roth & Julian Trollor
Design	Rachel Roth & Daniel Pua

Cover image	Gary Radler
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2015

Department of Developmental
Disability Neuropsychiatry

Annual Report

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

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About the Department

Introduction

The Department of Developmental Disability Neuropsychiatry (3DN) was established by the Chair of Intellectual Disability Mental Health in 2009. The Chair is funded by Ageing, Disability and Home Care, Department of Family and Community Services NSW.

3DN is part of the School of Psychiatry within UNSW Medicine. We champion the right of people with an 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 an intellectual or developmental disability.

Our Mission

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

Our Guiding Principles

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

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

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

Collaboration - We value the multidisciplinary context of our work. We actively engage stakeholders to share expertise and promote integrated systems in health and disability. We actively seek the participation of people with an 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 an intellectual or developmental disability, and the Guiding Principles in our Strategic Plan.



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Chair's Report

Professor Julian Trollor

I have had the privilege of leading the Department of Developmental Disability Neuropsychiatry (3DN) as it makes real progress in supporting people with intellectual or developmental disabilities to reach the highest attainable standard of mental health and wellbeing. The past year has been an active and exciting one for our department. I would like to express gratitude to our staff for their hard work and to our partners and funders for their support. I would particularly like to thank the many people with intellectual or developmental disability and their families, supporters and carers who have so willingly shared their expertise and experience with us. Without this generous support the work that we do would not be possible.

Over the past year we have sharpened our focus on capacity building in the mental health work force. We continue to lead the development of the NSW Institute of Psychiatry Fellowship program which provides trainee psychiatrists with an in-depth 1-year immersion in intellectual disability psychiatry. We have developed a core competency framework in intellectual disability mental health (IDMH) for public sector mental health staff. We will launch the competency framework and a clinician toolkit in the coming year. These products will make a significant contribution towards improving workforce confidence, knowledge and skill in working with people with an intellectual disability.

Tertiary intellectual disability medical and nursing curriculum will also play a key role in shaping future workforce preparedness. Our recent audit of Australian medical and nursing school intellectual disability content has given us some clear directions for curriculum improvements. In particular, the audit highlights a lack of intellectual disability content in many tertiary medical and nursing degrees, and that key areas of relevance to people with intellectual disability are often not taught. Lack of consumer and carer involvement in tertiary intellectual disability health content has also been identified. These findings will guide a future push for a national intellectual disability tertiary education framework.



In recognition of the ongoing concerns of many mental health staff about lack of preparedness to work with people with intellectual disability, we have expanded our IDMH e-learning website. Our free and interactive website now contains nine modules that health professionals can undertake to advance their skills and confidence in working with people with an intellectual disability. It gives me great pleasure to announce that more than nine new modules will be launched by the team in the coming year.

3DN's clinical and policy research agenda has also expanded greatly in this past year. In response to the growing recognition of the links between physical and mental health, and the known problem of psychotropic overprescribing in this population, we have commenced a positive cardiometabolic health project for people with intellectual disability. Major resources related to this work will be launched in the coming year.

Our NHMRC Partnerships for Better Health Project Improving the Mental Health Outcomes of People with Intellectual Disability is a flagship research project which brings together big data to examine the mental health and service use for people with intellectual disability, investigates the inclusion of people with intellectual disability in mental health policy, and examines the barriers and enablers to access to quality mental health supports for people with an intellectual disability. This work is now maturing to bring translational benefit to people with intellectual disability and their carers. A key to the success of this work



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has been the strong commitment from the Partnership Team and the deep engagement of the consumer reference group for this work.

Longitudinal data collection and analysis from our Successful Ageing in Intellectual Disability (Sage-ID) study has continued throughout 2015 and the team have been busy with their knowledge translation work. My heartfelt congratulations to the project lead for this work, Dr. Liz Evans, who was recently awarded an NHMRC-ARC Dementia Research Development Fellowship that will allow her to continue and expand this important study. Along similar lines, it has been encouraging to see the further development of the Australian Longitudinal Study of Adults with Autism as part of our work with the Cooperative Research Centre for Living with Autism (Autism CRC). This will be an important study which will bring many insights into the health and wellbeing of adults with Autism.

Our department is a hive of activity and there are too many individual projects to mention. However, it is important to acknowledge the success of Dr Rachael Birch, who graduated in the past year with her PhD. Rachael's ground breaking research into premutation carriers of the Fragile X gene has helped to identify associations between a number of specific

genetic, radiological and clinical characteristics of carriers of this gene. This research project represents collaboration between UNSW Australia, Monash University, Murdoch Children's Research Institute, Genetics of Learning Disability service and Neuroscience Research Australia. We look forward to developing evidence-based resources for distribution to Fragile X families and health practitioners based on the work that Rachel has undertaken.

As we move forward into 2016 and beyond, I am proud of what 3DN and its partners have accomplished and excited about the future. An emerging challenge is our role in informing cross-sector service and policy development as the National Disability Insurance Scheme gathers momentum. Our staff is committed and enthusiastic, and together with our partners, funders and people with intellectual disability, we look forward to continuing our efforts to achieve the highest attainable standard of mental health and wellbeing for people with an intellectual or developmental disability.



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Key Research Areas

3DN has a diverse research program which spans clinical neurosciences, data linkage, policy analysis, service evaluation, ageing and dementia in intellectual disability, and the criminal justice system. We also lead the intellectual disability and dementia work undertaken in collaboration with the Dementia Collaborative Research Centres (DCRC), and the inflammation, cardiovascular and metabolic risk factor work undertaken within the Centre for Health Brain Ageing (CHeBA).

3DN Research & Projects

National Health & Medical Research Council Partnerships for Better Health Project, Improving Mental Health Outcomes for People with an Intellectual Disability



Our Partnership Team has developed a research plan which will improve access to, and quality of mental health services for people with an intellectual disability. Using a linked NSW Ministry of Health and Ageing, Disability & Home Care dataset, we will integrate the data from our Partners to develop a comprehensive profile of mental ill health and service use in people with an intellectual disability. Interrogation of these data will identify the linkages and gaps between service sectors (mental health, disability, justice, and education) and the benefit of cross-sector work including the impact of various initiatives in NSW in the area of intellectual disability and co-occurring mental ill health. We will complement our data driven approach with comprehensive analysis of policy relevant to intellectual disability mental health, to address key gaps in policy and policy development in this area. In addition, qualitative research with focus groups will identify ways to improve the recognition of mental disorders among clinical, disability and education service staff, and will work with people with an intellectual disability to identify and deliver means of improving access to mental health services and supports for people with an intellectual disability. The findings will develop an evidence base to guide the development of clinical services and policy for people with an intellectual disability to meet their fundamental right to quality mental health support.

Background

Australians with an intellectual disability represent a significant minority group who have very poor mental health status compared to the general population, and who experience exceedingly poor access to mental health services and supports. The failure of current systems and services to address the specific mental health needs of people with an intellectual disability is apparent to governments, policy makers, clinicians, researchers, consumers and their support persons, and has provided a unifying platform for this Partnerships Project. The current situation is at odds with Australia's obligations under the United Nations Convention of the Rights of Persons with a Disability (CRPD, ratified by Australia in 2008).

This National Health and Medical Research Council (NHMRC) Partnerships for Better Health Project grant to the value of \$2.4M was awarded to Professor Trollor and his Team of Co-Investigators and Partner Organisations in 2013 and commenced in September 2014. It consists of cash and in-kind support provided by Partners and a co-contribution from the NHMRC which is based on the strength of the Partnership and integrity of the research strategy. The Project will run for four years to 2018 and promises some exciting developments in our understanding of mental illness in this marginalised population. It will significantly enhance the body of evidence on the access to, and uptake of, mental health services for people with an intellectual disability who experience significant disadvantage in our current service system. The project also provides exciting career and PhD opportunities for those interested in this area.

Aims

In collaborating with key mental health, disability, education, justice and consumer agencies, our Project seeks to fulfil four main aims:

- To create an annualised linkage of administrative minimum datasets of our Partners to enable a detailed examination of mental health profiles and service utilisation, patterns of cross-sector service provision including specific gaps, the impact of recent service initiatives for people with an intellectual disability, and to enable comprehensive development of intellectual disability mental health services in NSW.
- To analyse Commonwealth and State mental health policy to determine the current representation of people with an intellectual disability and to establish strategies which will enhance intellectual disability mental health policy.
- To engage with stakeholders including consumers and support persons (including family and non-family carers), to inform improved recognition of mental ill health, accessibility of mental health services and mental health policy for people with an intellectual disability across the lifespan and;
- Progressing to maturity a partnership which develops and applies an evidence based approach to intellectual disability mental health service development, policy and reform across the lifespan for people with an intellectual disability.



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Positive Cardiometabolic Health For People With Intellectual Disabilities: An Early Intervention Framework



People with an intellectual disability experience reduced life expectancy and an excessive morbidity burden compared to other Australians. Poor cardiometabolic health is one key area of inequality, including high rates of obesity, diabetes, and hypertension. Factors that may make some people with an intellectual disability more vulnerable to cardiometabolic ill-health than the general population include: excessive psychotropic prescription and psychotropic polypharmacy; lower physical activity levels; unequal access to quality healthcare; pre-disposing genetic syndromes; and social exclusion and economic disadvantage. Positive and preventative interventions are needed to address excessive cardiometabolic morbidity and mortality in this population.

In collaboration with the authors of a previously published generalist cardiometabolic monitoring algorithm, “Positive cardiometabolic health: an early intervention framework for patients on psychotropic medication” (Curtis, Newall et al. 2011) we will develop a guideline to meet the specific needs and risk profiles of people with intellectual disability.

This project is phase one of a larger study investigating responsible psychotropic prescription in people with intellectual disability.

Aims

- To review the literature relating to cardiometabolic morbidity and mortality in children, youth and adults with an intellectual disability
- To adapt a generalist early intervention guideline to proactively manage the cardiometabolic health of people with an intellectual disability
- To develop an accompanying website of positive cardiometabolic resources suitable for clinicians, formal and informal carers and people with an intellectual disability
- To broadly distribute this toolkit of cardiometabolic resources via conferences, forums and publications

Intellectual Disability Mental Health e-Learning

Purpose:

The e-Learning site www.idhealtheducation.edu.au was launched on 22 July 2013. The site is an interactive education resource for everyone with an interest in intellectual disability mental health.

Registration is free and easy. Under the 'Professionals' section there are modules for health and disability practitioners. The site is also useful for students and other professionals who want to learn more about intellectual disability and mental health.

Users have access to the first nine modules for health practitioners, covering these topics:

- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Mental Disorders in Intellectual Disability
- Communication: the basics
- Improving your communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability
- Legal and Ethical Practice



Modules specifically designed for disability workers are currently being developed. The first three will be released in January 2016. The modules will cover these topics:

- Why is it Important to know about Mental Health in Intellectual Disability?
- Introduction to Mental Health
- Mental Health in Intellectual Disabilities
- A Person-Centred Approach to Supporting Mental Health and Well-being
- Recognising Common Mental Illness
- How to Support a Person with a Possible Mental Illness
- Behaviours of Concern
- Inter-agency Working with Health Professionals
- Interventions, Medications and Support in Treatment
- Acute Mental Health Conditions
- Supporting Carers, Colleagues and Self-care

How the site was developed:

This site is the result of a collaboration between 3DN, the NSW Department of Family and Community Services (Ageing, Disability and Home Care), and the NSW Ministry of Health. As the idea for the site developed, many others became involved too.

The idea for this resource grew out of a series of local workshops run by 3DN. Many mental health staff attended the workshops, and many more were unable to attend. The resources required to run these workshops meant that a more sustainable format was called for. So the idea was born to create an online version of the workshops, making the material accessible across Australia, to anyone at any time.

The content of the site was developed by a team of medical, mental and allied health professionals. The team has clinical, administrative and research experience and represents the health, welfare and disability sectors. People with an intellectual disability also had a role in developing content for the site, as you will see when you progress through the modules.

Intellectual Disability Mental Health (IDMH) Fellowships

3DN has assisted several trainee psychiatrists in obtaining an in depth one year training experience in intellectual disability and mental health. These Fellowships are awarded on a competitive basis by the NSW Institute of Psychiatry, and the majority have been funded by Aging Disability and Home Care, NSW Government Department of Family and Community Services.

Specialist skills and knowledge acquired include:

- Detailed knowledge regarding the epidemiology and manifestations of mental illness in people with an intellectual disability.
- Detailed knowledge about the impact on carers of supporting a person with an intellectual or developmental disability and co-occurring mental ill health.
- Clinical skills in the assessment, formulation and management of mental ill health in people with an intellectual or developmental disability.
- Ability to competently communicate with people with an intellectual or developmental disability with complex communication needs to a high level, and to appropriately engage both the person with an intellectual or developmental disability and their support networks and family in the care planning process.
- Ability to perform high level interagency and intra-agency working recognising and developing optimal intersection points between services, in particular mental health services and disability services.
- Comprehensive understanding of different models of service delivery in intellectual disability mental health.
- Ability to work effectively in a variety of settings to improve access to timely specialist mental health care for people with an intellectual or developmental disability .
- Awareness and exposure to research and academic programs in intellectual or developmental disability and mental ill health.

Thinking and Motor Skills in Premutation Carriers of Fragile X



Background:

Fragile X-associated tremor ataxia syndrome (FXTAS) is a recently identified neurodegenerative disorder affecting a proportion of older adults who carry a moderate expansion (also known as a 'premutation') of the fragile X gene. Symptoms of FXTAS include problems with balance, coordination, memory and thinking skills. At present, the understanding of this syndrome, including why some people develop cognitive and motor symptoms and others do not, is in its infancy. We are performing detailed memory and balance tests on adults (aged 18+) who carry the Fragile X premutation to determine the effect of the gene expansion on their health.

Aims:

The overarching aim of this project is to determine the prevalence and correlates of neuropsychiatric symptoms associated with the fragile X premutation and FXTAS.

Intellectual Disability Mental Health Core Competencies: A Child and Adolescent Mental Health (CAMHS) Workforce Perspective

Background:

Compared to the general population, health surveys have revealed that people with an intellectual disability experience very poor health status, characterised by higher mortality, and elevated rates of common mental disorders at 2-3 times that of the general population. However, despite both the frequency and complexity of their mental health care needs, people with an intellectual disability experience significantly lower rates of participation in preventative health initiatives, illness and disease detection, and treatment of mental health problems.

Ensuring an adequately skilled and confident mental health workforce is a critical component of improving mental health outcomes for people with an intellectual disability. In particular, building the awareness and skill level of Children and Adolescent Mental Health and Youth Mental Health services through education and training in intellectual disability mental health is in-keeping with the early intervention ethos of mental health care modelled by the Early Psychosis Prevention and Intervention Centre (EPPIC). Improvements in early phases of care are also likely to have the greatest benefit on outcomes for young people with an intellectual disability and mental illness.

Developing core competencies and establishing a standard level of education in intellectual disability mental health is pivotal in achieving this aim.

Aims:

- Assess CAMHS staff attitudes and training needs in relation to children and young people with an intellectual disability and mental illness, and
- Develop core competencies for staff in the provision of services to these children and young people.

Renewal of Nursing School Intellectual Disability Curriculum: Building capacity to better prepare registered nursing graduates to meet the complex health care needs of people with an intellectual disability

Background:

Australia's higher education sector plays a key role in preparing registered nursing graduates to enter into the health workforce and meet the diverse healthcare needs of our population. However, most registered nursing students will graduate with little or no understanding of the specific health care needs of people with intellectual disability, a population which experiences a disproportionately high burden of disease and illness and poorer health outcomes when compared to the general population.

Aims:

This project is the phase one of a five phase project which that aims to develop and implement a national tertiary educational framework in the area of intellectual disability health and intellectual disability mental health.



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Renewal of Medical School Intellectual Disability Curriculum: Building capacity to better prepare medical graduates to meet the complex health care needs of people with an intellectual disability

Background:

Australia's higher education sector plays a key role in preparing medical graduates to enter into the health workforce and meet the diverse healthcare needs of our population. However, most medical students will graduate with little or no understanding of the specific health care needs of people with an intellectual disability, a population which experiences a disproportionately high burden of disease and illness and poorer health outcomes when compared to the general population.

Aims:

This project is the phase one of a five phase project which that aims to develop and implement a national tertiary educational framework in the area of intellectual disability health and intellectual disability mental health. Specific aims of the project are to:

- determine and quantify how medical schools are currently preparing medical graduates to meet the health care needs of people with an intellectual disability,
- describe both the barriers and facilitators for inclusion of intellectual disability health and intellectual disability mental health curriculum content faced by medical schools,
- compile intellectual disability health and intellectual disability mental health curriculum resources, and
- identify and engage intellectual disability leaders (champions) from medical schools across Australia.



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Australian Longitudinal Study of Adults with Autism Spectrum Conditions (ALSAA)



Background:

Currently, understanding of life in adulthood for people with autism is very limited. This has significant implications for the day to day life of individuals on the spectrum with services and the general public lacking in awareness and understanding of the specific needs of people with autism.

Researchers at 3DN and the Autism Cooperative Research Centre CRC are undertaking a questionnaire study to learn about life in adulthood for people with autism/Asperger's syndrome. Participants in the study are adults who are 25 years or older, who have a diagnosis of Autism spectrum disorder/Asperger's syndrome and/or their main carers

Recruitment for this project is ongoing. Taking part in the study involves:

- Completing a questionnaire either online or via a paper copy. The questions will be about many aspects of life including mental and physical health, employment and other day occupations, behaviour, emotions, coping, memory, friendships and health service utilisation. Time taken to complete the questionnaires may vary greatly, but the majority may take between 2 to 3 hours. Questionnaires do not have to be completed all at once.
- Completion of a second questionnaire about two years later.

Aims:

The aim of this study is to describe the physical and mental health, productivity and overall wellbeing of adults living on the autism spectrum in Australia. This longitudinal resource will provide insight into the correlates and predictors of health and wellbeing of adults with autism in Australia as they age.

Results from this study will be shared with individuals with autism, relevant organizations, clinicians, policy-makers and other researchers. 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. Additionally, the results of this study will be used by other researchers within the Autism CRC to develop interventions and tools which will aim to improve many facets of life for this population.

Using big data to answer important questions on health and wellbeing for people with autism spectrum disorders

Background:

This project will utilise big data sets to answer important questions about the health, wellbeing and health service use of people with an autism spectrum disorder (ASD).

Aims:

- Using data from the national Bettering the Evaluation and Care of Health (BEACH) program, we will explore GP consultations with their younger patients (aged up to 25 years) with ASD. This will help us understand what happens at the primary care level in terms of issues being managed, medications being prescribed, and referrals being made, in comparison to people without ASD.
- Using our existing NSW state-based linked administrative data infrastructure, we will explore the potential of an existing Autism flag or identifier to examine mortality, cause of death, and health outcomes in Australians with an ASD and compare these to the general population.

The Successful Ageing in Intellectual Disability (SAge-ID) Study

Background:

People with intellectual disability are living longer, with many living active productive lives. As they age, people with intellectual disability face the same health and mental health issues as the rest of the community, but some will experience these at much younger ages. The SAge-ID Study is looking at the rates of physical and mental health problems in older people with Intellectual Disability. We also hope to learn what things help a person with ID to stay healthy as they age.

The SAge-ID Study is a new collaboration between researchers from the University of New South Wales, La Trobe University, and Monash University. The project has received funding from Ageing, Disability and Home Care, the Dementia Collaborative Research Centres – Assessment and Better Care, and from La Trobe Rural Health School.



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The Year In Review

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

This project represents multi-disciplinary collaboration between UNSW Australia, the NSW Ministry of Health – Mental Health & Drug & Alcohol Office, NSW Government Department of Family and Community Services and Aging, Disability and Home Care Services, National and NSW Council for Intellectual Disability, NSW Government Agency for Clinical Innovation– Intellectual Disability Network, NSW Ombudsman, NSW Office of the Public Guardian, NSW Government Department of Education and Communities, NSW Department of Justice, Justice Health network, Mental Health Commission of NSW, Mental Health Review Tribunal, and the National Disability Service.

It is widely recognised that people with an intellectual disability experience substantially poorer mental health outcomes than the general population, and face increased barriers to accessing appropriate mental health care.

The project aims to improve access to and quality of mental health services for people with an 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 to guide the development of targeted, appropriate services. The overarching aim of the project is to improve access to services for people with an intellectual disability and mental health issues at both the national and state levels, with an emphasis on translational outcomes.

Analyses of mortality, mental health inpatient and emergency department presentations are in progress, and a health economist is being introduced to the project to undertake a health care cost analysis. Results from linked data showed that compared to the general population, people with an intellectual disability who used mental health services had a skewed diagnostic profile, higher rates of uncertain diagnoses, and 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.

A NSW-wide review and analysis of policy to determine the current representation of people with an intellectual disability in mental health policy showed limited representation of people with intellectual disability across the documents with only 19 of the 60 making any mention of this group. Based on this analysis, work is continuing to develop a comprehensive policy framework underpinned by the inclusion of people with intellectual disability, in line with Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities.

A systematic literature review on key barriers and enablers to accessing mental health services for people with an intellectual disability revealed substantial gaps in the evidence base around barriers to access, particularly around lived experience. A number of key areas were identified, including the availability and quality of services, knowledge deficits among service providers, and organisational barriers. Enablers that were identified included inter-agency collaboration and education.

Recruitment of participants for interviews investigating the experiences of people with intellectual disability, carers and service providers in both mental health and intellectual disability has commenced. There has been a strong response from participants and data collection is currently underway.

A consumer advisory group has been established in order to ensure accountability and adherence to the principles of inclusive research and to provide expert advice on research design and content.



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Project team: Julian Trollor, Erin Whittle, Preeyaporn Srasuebkul, Snow Li, Tess Heintze, Rebecca Reeve, Angela Dew, Ulrika Athanassiou & Simone Reppermund

Investigators: Julian Trollor, Eric Emerson, Rhoshel Lenroot, Leanne Dowse, Karen Fisher, Kimberlie Dean, Eileen Baldry, Tony Florio, Grant Sara, Phillip Snoyman, Les White

Partner Organisations: Agency for Clinical Innovation – Intellectual Disability Network, represented by Tracey Szanto; NSW Department of Family & Community Services - Ageing, Disability and Home Care, represented by David Coyne and Carol Hannaford; NSW Department of Education & Communities, represented by Melissa Clements; NSW Department of Justice - Corrective Services NSW, represented by Phillip Snoyman; NSW Ministry of Health – Justice Health & Forensic Mental Health Network, represented by Kimberlie Dean; Mental Health Commission of NSW, represented by Sarah Hanson; NSW Ministry of Health – Mental Health & Drug & Alcohol Office, represented by Christine Flynn; Mental Health Review Tribunal, represented by Anina Johnson; National and NSW Council for Intellectual Disability, represented by Jim Simpson; National Disability Services, represented by Philippa Angley; NSW Office of the Public Guardian, represented by Justine O'Neill, NSW Ombudsman, represented by Kathryn McKenzie



Responsible Psychotropic Prescribing Project

To date we have secured funding for the project from Mental Health Kids NSW, conducted an extensive literature review exploring cardiometabolic risk in this population, and developed adult and youth intellectual disability specific cardiometabolic monitoring algorithms. We have also compared prescribing patterns in people with and without an intellectual disability in Australian primary care settings using data from the BEACH study and produced a range of publications and presentations addressing psychotropic prescribing in this population.

Our future plans include: launching the cardiometabolic monitoring algorithm and toolkit in a workshop setting; producing and launching consumer and carer postcards promoting the cardiometabolic monitoring algorithm; launching an on-line training module for health professionals addressing cardiometabolic risk in this population; and producing podcasts addressing responsible psychotropic prescribing in adult and child and youth populations with an intellectual disability.

Project team: Carmela Salomon, Jessica Walsh, Julian Trollor

Cardiometabolic Health Project Steering Committee Members: Jackie Curtis, Andrew Watkins, Simon Rosenbaum, Katherine Samaras, Philip B. Ward.

Intellectual Disability Mental Health (IDMH)

E-learning – Disability Modules

As part of the wider intellectual disability mental health online portal this project aims to expand the existing resource to include e-learning modules on intellectual disability mental health specifically tailored to disability workers. The purpose of this is to improve mental health outcomes for people with an intellectual disability by educating particular target audiences. Disability workers have a valuable role in improving the mental health and well-being of people with an intellectual disability and in many cases play a pivotal role in assisting a person with intellectual disability to access mental health supports.

To date, consultation with disability professionals has been undertaken to identify learning needs and the first modules are being drafted; with the first three modules planned to be launched in early 2016. By the end of 2016 it is expected that all eleven modules will be available on the site and an evaluation of their effectiveness will follow.

Project Team Members: Julian Trollor, Kimberley Smith & Thea Kremser.



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Thinking and motor skills in premutation carriers of fragile X

This project examines the interrelationships between clinical, radiological and genetic markers among adults who carry premutation expansions of the fragile X mental retardation 1 (*FMR1*) gene. Carriers of the *FMR1* premutation are at risk of developing fragile X-associated tremor ataxia syndrome (FXTAS); a neurodegenerative disorder characterised by the progressive development of intention tremor, gait ataxia, parkinsonism and cognitive decline. The broader research program includes study sites based in NSW (UNSW Australia) and Victoria (Monash University). Our research team based at 3DN lead the UNSW Australia site, with a focus on neurocognitive and neuromotor function among adult males who carry the *FMR1* premutation. Baseline assessments of cognitive, motor, and psychiatric function, together with neuroimaging and *FMR1* molecular measures for this study were completed between 2011 and 2013. Our findings, which have been disseminated in various formats (e.g. scientific publications; presentations to consumers, academics and health practitioners), provide strong evidence for associations between a number of specific genetic, radiological and clinical characteristics. We are currently seeking further funding to expand the cohort, undertake follow-up assessments with those who completed baseline assessments, and to develop evidence-based resources for distribution to fragile X families and health practitioners.

Project team: Julian Trollor, Rachael Birch

Investigators: Wei Wen, Kim Cornish, Nellie Georgiou-Karistianis, Sylvia Metcalfe, Anna Hackett, Carolyn Rogers, Darren Hocking, Ali Archibald, David Godler, Stephen Lord, Jasmine Menant.

State Intellectual Disability Mental Health Core Competencies Framework Project

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 for this workforce 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.

The Core Competency Framework has now been completed and plans for its launch and implementation across NSW are underway.

Achievements:

- The project has identified core competencies in 11 key areas. The Framework also details varied resources the workforce can access to develop these competencies through professional development.
- Reports have been provided to the NSW Ministry of Health on the attitudes and confidence of the NSW mental health workforce to deliver services to people with intellectual disability, and on workforce training needs.
- We have been successful in securing further funding from Mental Health Kids, NSW Ministry of Health to implement the Framework and associated resources across NSW.



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Future aims:

- A varied implementation project has been planned. This includes an accompanying toolkit which describes practical ways the workforce can achieve the core attributes described, forums in local health districts, and an evaluation of the Framework's effectiveness in supporting practice and attitudinal change.
- We aim to introduce the Framework to as wide a network of NSW mental health workers as possible to encourage professional development, with the long term goal of enabling greater access to mental health services for people with intellectual disability across the state.

Project team: Julian Trollor, Claire Eagleson, Janelle Weise, Jessica Walsh



STudio ARTeS

Glen Turnbull, Waratah 2014, Acrylic on paper. WINDOWS OF OPPORTUNITY is an independent, not for profit organization that provides creative programs to adults with disability. Each artist retains copyright for the Images.

Undergraduate Medicine and Nursing Curriculum Development (Phase 1)

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, and identify locations within the curriculum where this content could be included. The first phase of the project, the national medical and nursing curriculum audit, has now been completed.

Achievements:

- 14 medical schools and 31 nursing schools participated in the study. Results suggest that intellectual disability content taught within the medical and nursing curricula is highly variable and remains limited.
- A number of publications outlining what and how intellectual disability content is taught are underway.

Future aims:

- The audit is the first component of a multi-phase strategy to build workforce capacity in Australia by renewing medical and nursing intellectual disability curriculum.
- We plan to develop, evaluate and implement a national education framework and implementation toolkit for nursing and medical schools, which will provide up-to-date, evidence-based teaching materials and resources to be incorporated into existing curricula.

Project team: Julian Trollor, Claire Eagleson, Beth Turner

The Australian Longitudinal Study of Adults with Autism (ALSAA)

Currently, understanding of life in adulthood for people with autism is very limited. This has significant implications for the day to day life of individuals on the spectrum with services and the general public lacking in awareness and understanding of the specific needs of people with autism. The aim of this study is to describe the physical and mental health, productivity and overall wellbeing of adults living on the autism spectrum in Australia.

Where we are at:

ALSAA was launched in July 2015 and data collection is underway. Participants with autism to date are aged between 25 and 79 years with an average age of 40 years. Of the 59 people who have completed the questionnaire gender was reported as male for 23 adults (39%), female for 28 adults (47%) and other for 8 adults (14%) (including genderqueer, non-binary, transgender and gender fluid).



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Achievements:

- Publication of manuscript in the Australian Family Physician titled 'Management of mental ill health in adults with autism spectrum disorders'
- Development of a one page snapshot summary of the above manuscript for adults on the spectrum, service providers, clinicians and families.
- Publication of the first newsletter from the Australian Longitudinal Study of Adults with Autism (ALSAA) October 2015
- Conference presentation at the Asia-Pacific Autism Conferences (APAC) in Brisbane September 2015 titled "Prescription of medications by Australian general practitioners in young people with autism spectrum disorders"
- Poster presentation at the Asia-Pacific Autism Conferences (APAC) in Brisbane September 2015 titled "The Australian Longitudinal Study of Adults with Autism (ALSAA)"

Project team: Julian Trollor, Kitty-Rose Foley, Jane Hwang

Investigators: Torbjorn Falkner, Nick Lennox, Amanda Richdale, Julian Trollor

PhD project– Ageing Well as an Autistic Adult in Australia

This PhD project aims to explore and define the theoretical concept of 'ageing well' as an autistic adult in Australia. It consists of 3 studies: the ALSAA, qualitative interviews and an exploration of state-based administrative linked datasets. The aim of the interviews will be to develop an in-depth understanding of the meaning and experience of 'ageing well' as an autistic adult in Australia. Interviews will be conducted with autistic adults (aged 25 and over), carers of autistic adults, disability support workers and healthcare professionals with experience working with autistic adults in Australia. Please refer to the relevant sections for further information about the ALSAA and data linkage projects.

Where we are at:

This study has been approved by the UNSW Human Research Ethics Committee. At present, we are in the process of piloting and finalising the interview materials. Recruitment will begin in mid-November. We hope to begin data collection in December 2015 and continue through to March 2016.

What we hope to achieve:

We hope to develop an in-depth, qualitative understanding of the salient aspects of ageing well for autistic adults in Australia. This will complement the quantitative data from the ALSAA and linked datasets to present a comprehensive picture of the health, wellbeing and lives of autistic adults in Australia for whom there is a paucity of information. This will create a useful information base from which to frame future, more concentrated research efforts regarding autistic adults. It will improve understanding of factors which positively and negatively influence ageing for autistic adults, highlighting important areas to target for service development. Also, this research has the potential to assist in the development of effective and relevant policy and tools to improve the health and wellbeing of autistic adults and their carers.

Project team: Jane Hwang, Kitty-Rose Foley, Julian Trollor



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Using big data to answer important questions on health and wellbeing for people with autism spectrum disorders

Where we are at:

We have developed one manuscript which describes 'Encounters with young patients with autism spectrum disorders in Australian general practise.' This paper explores data from the BEACH program and is to be submitted for publication in 2016.

What we hope to achieve:

Through this project we hope to provide a large set of studies investigating mental health profiles, general health profiles, and mortality and health costs for individuals with autism. This will have a positive impact on addressing current knowledge gaps, and will lead to improved care and health outcomes for individuals with autism.

Project team: Julian Trollor, Kitty-Rose Foley, Preeyaporn Srasuebkul, Nick Lennox, Kate van Dooren, Tony Florio.

SAGE-ID Project The Successful Ageing in Intellectual Disability (SAGE-ID) Study

Wave 1 data was collected between 2011 and 2013. In total, 117 adults with ID participated, and for 78 of those participants, a family carer also participated. A subset of the sample with ID also participated in face-to-face assessments, and Focus groups were held with both family carers and with professionals working with people with ID. Wave 1 results are currently being drafted into five manuscripts. The first publication, about Central Nervous System medication use, was published in 2015.

Wave 2 is currently underway, as we collect data from the same people to determine any changes that may have occurred since Wave 1 and to understand lifestyle habits that may help some people remain healthier than others. In addition, we are currently focusing on translating the findings from Wave 1, along with other evidence from the literature, into useful resources for people with ID and carers. These resources will focus on how to promote healthy ageing in people with ID. Part of that project will involve consultations with people with ID and carers regarding how we can match the resources to their needs.

Dr. Liz Evans has received a NHMRC-ARC Dementia Research Development Fellowship which allows us to continue this important study. We plan to collect Wave 3 data from the existing sample, as well as expanding the sample to include more people.

So far, the project has involved one student, Emily O'Brien. Emily completed her Medicine Honours project with 3DN, and for this project she analysed the carer questionnaire data. Emily's report was well-received and she passed with First Class Honours. We hope that the expansion of the project will also ensure further opportunities for research students.

We would like to thank everyone who has participated in the study and the carers who have completed questionnaires to facilitate participation. We would also like to thank the organisations that assisted with recruitment for the project.



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We will be expanding the SAGE-ID study in 2016, 2017 and 2018. If you or someone you know would like to participate, please call the study team on 9385 1344. People are eligible to participate if they:

- *Are aged over 40*
- *Have an ID*
- *Can complete a survey themselves (with help from a friend if needed) or if they have a relative, carer or friend who is happy to complete one about the person with ID.*

Prominent findings so far:

Analysis of Wave 1 data this year has revealed elevated rates of cardiovascular disease and diabetes, compared with the general Australian population of the same age. The rate of dementia, particularly younger onset dementia, in the sample was also high, but much of this was accounted for by people with Down syndrome. There was a high rate of central nervous system polypharmacy in the sample, which is consistent with other studies of polypharmacy in younger people with ID. Polypharmacy was associated with higher levels of behavioural disturbance. Overall, results suggested there was adequate rationale for prescribing amongst the sample, but that continued review of medications is still important in older adults with ID.

Approximately 30% of the family carers in the study experienced high rates of psychological distress, and this is higher than that in the general population. However, the rates of symptoms of depression in the family carer sample did not differ from the general population. The experience of family carers was explored in series of focus groups, in which carers revealed that caring for an ageing adult with ID involves both positive and negative experiences across the lifespan. For some full-time carers, the transition towards involving other informal and formal support networks can be stressful. Carer supports and improvements in services for ageing individuals with an ID could minimise the negative impacts of this transition.

The study has found that although most of the people with ID did go to their GP during the prior 12 months, access to specialist health care services, particularly in mental health, is poor. This is especially so for those living outside of the metropolitan region.

Project team: Julian Trollor, Liz Evans, Adrian Davis

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



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Professor Julian Trollor



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 an intellectual disability.

Dr Rachael Birch

Lecturer



Rachael is a registered psychologist with broad research interests including neuropsychology, neuropsychiatry, and neurodegenerative diseases. Her PhD research (completed at 3DN in 2015) included the establishment and comprehensive characterisation of a cohort of adult males who carry premutation expansions of the fragile X mental retardation 1 (FMR1) gene. Carriers of the FMR1 premutation are at risk of developing fragile X-associated tremor ataxia syndrome (FXTAS); a neurodegenerative disorder characterised by the progressive development of intention tremor, gait ataxia, parkinsonism and cognitive decline. Her research integrates data obtained from neuropsychological, neuromotor, and psychiatric assessments, together with structural neuroimaging and FMR1 measures to determine the interrelationships between clinical, radiological and genetic markers among this cohort.

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

Dr Simone Reppermund

Research Fellow



Simone currently manages an NHMRC funded Partnership for Better Health Project Grant entitled: Improving the Mental Health Outcomes for People with Intellectual Disability (ID).

The objective of the project is to improve access to, and quality of mental health services for people with ID. Using a linked NSW Ministry of Health and Ageing, Disability & Home Care dataset, we will integrate the data from our Partners to develop a comprehensive profile of mental ill health and service use in people with ID. Interrogation of these data will identify the linkages and gaps between service sectors (mental health, disability, justice and education) and the benefit of cross-sector work including the impact of various initiatives in NSW in the area of ID and co-occurring mental ill health. We will complement our data driven approach with comprehensive analysis of policy relevant to ID mental health, to address key gaps in policy and policy development in this area. In addition, qualitative research with focus groups will identify ways to improve the recognition of mental disorders among clinical, disability and

education service staff, and will work with people with ID to identify and deliver means of improving access to mental health services and supports for people with ID. The findings will develop an evidence base to guide the development of clinical services and policy for people with ID to meet their fundamental right to quality mental health support.

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.

Dr Adrian Davis

Research Assistant



Initially completing a Bachelor of Science (BSc) with Honours in Psychology, Adrian then completed a Masters of Applied Science in Environmental Management, followed by a PhD in Ecology. His PhD involved undertaking extensive research investigating the ecology of Sydney's parrot population- why they are doing so well and how they use the urban environment.

Adrian has worked on a variety of research projects, including visual perception, student learning and feedback and cockatoo tracking studies. He has now returned to Psychology, and is assisting with the SAge-ID Study (Successful Ageing in Intellectual Disability) at 3DN. The study is looking at the physical and mental health needs of older people with Intellectual Disability, and aims to identify how to help this population stay healthy as they age.

Ms Claire Eagleson

Project Officer

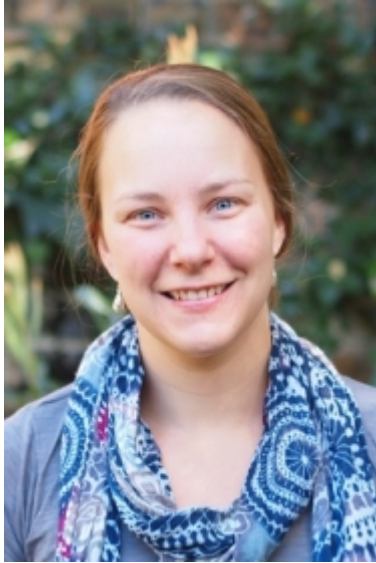


Claire is currently working as a Project Officer managing two 3DN projects. The first involves the development and implementation of an Intellectual Disability Mental Health Core Competencies Framework manual which aims to improve workplace capacity in this area. The second is a national curriculum audit of intellectual disability content taught in Australian medical and nursing schools.

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.

Ms Janelle Weise (nee 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 an 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 an Intellectual Disability.

Dr Liz Evans

Lecturer / Research Officer



Liz is a registered psychologist with a special interest in the mental health needs of people with intellectual disability. As a lecturer at 3DN, she is involved in both the educational and research activities of the department. Liz holds a Bachelor of Psychology with First Class Honours and a PhD, both from the University of Sydney. Her PhD, awarded in 2010, was the first study worldwide investigating the behavioural phenotype of Mowat-Wilson syndrome. Liz's research interests include the mental health needs of older people with ID, and the study of behavioural phenotypes.

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

Dr Kitty-Rose Foley

Postdoctoral Research Fellow



Kitty is a Research Fellow in Program 3 of the Autism CRC research program, the world's first national, cooperative research effort focussed on Autism. Kitty has a Bachelor of Science (Bsc) in Occupational Therapy graduating with honours and a Doctorate of Philosophy (PhD). Her PhD involved examining the transition from school to adulthood and exploring post-school adult life for young people with Down syndrome. She completed her PhD at the Telethon Kids Institute through Edith Cowan University in Western Australia.

While in Perth, Kitty worked as a paediatric Occupational Therapist with children with disabilities. She has a strong passion for working in the field of disability and believes in taking a holistic approach to both understanding domains of life and finding ways to improve life outcomes for people with disabilities.

Kitty's current research interests are surrounding mental and physical health, wellbeing and participation for adults with Autism Spectrum Disorder.

Kitty is currently working as part of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). She is playing a key role in developing questionnaires for the Australian Longitudinal Study of Adults with Autism Spectrum Disorders (ALSAA). Please see this website for further information about the Autism CRC. <http://www.autismcrc.com.au/>

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 Thea Kremser

Project Officer



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 an 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.

Qualifications: B Psych (Hons), Cert IV TAA.

Mr Daniel Pua

Administrative Assistant



Daniel Pua provides administrative 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). Daniel assists in a number of projects within the department, maintains the 3DN website and provides limited tech support to the department.

Ms Rachel Roth

Administrative Officer



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

Dr Carmela Salomon

Project Officer



Carmela Salomon is a 3DN Project Officer working on a range of initiatives to support responsible psychotropic prescribing and cardiometabolic health in people with an 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.

Miss Kimberley Smith

Project Officer



Kimberley joined 3DN in February 2015 and is currently working as a Project Officer on the Intellectual Disability Mental Health (IDMH) e-learning project. The aim of this project is to improve mental health outcomes for people with an 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 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 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.

Ms Jessica Walsh

Project Officer

Jess joined 3DN as a Project Officer in October 2015. Her role focuses on knowledge translation, ensuring 3DN's resources and research findings are effectively utilised to improve the health and wellbeing of people with an intellectual or developmental disability. She works across three main projects: the Intellectual Disability Mental Health Core Competencies Framework, the Positive Cardiometabolic Health for People with Intellectual Disabilities project, and the Successful Ageing in Intellectual Disability study.

Jess completed a Bachelor of Arts – Psychology (Honours) degree at Macquarie University in 2011. She subsequently worked on the implementation of new community health services and the development of consumer resources in both the mental health and dementia care sectors. Jess has broad clinical interests including neuropsychology, dementia, genetics, and the improvement of services for people with diverse and complex needs.

Postgraduate Students

Miss Jane Yein Hwang

PhD Student



Jane is a PhD student in Program 3 of the Autism Collaborative Research Centre program. Her research focuses on developing a comprehensive profile of older adults with Autism Spectrum Disorders.

Jane's research interests lie within developmental and community psychology with a particular focus on ageing and social inclusion.

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.

Ms Snow Li

PhD Student



Snow is a PhD candidate 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.

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.

Dr Rebecca Reeve

Health Economist

Dr Rebecca Reeve joined 3DN as a Health Economist in May 2015. She is also a Senior Research Fellow at the Centre for Social Impact. She is passionate about using her skills as an economist and econometrician to improve social outcomes.

Rebecca's research focusses on vulnerable populations including Indigenous Australians, people at the end of life, people with dementia, people with drug and alcohol problems and vulnerable children. Her work has been published in peer reviewed journals, reports, The Conversation and the mainstream media.

Rebecca was previously employed at the Centre for Health Economics Research and Evaluation (CHERE), UTS, where she was Program Manager of the centre's policy evaluation program of research and taught in the postgraduate unit "Introductory Health Economics". Rebecca has a PhD in Economics from Macquarie University, awarded in 2010. During her PhD studies she was employed as a casual academic at Macquarie University where she taught microeconomics and econometrics

Clinical Fellows

Dr SUNNY WADE

MB BS, BSc (Hons); Fellowship year 2014-2015



Training Setting and Experience

Dr Wade completed the fellowship as part of Advanced Training in Forensic Psychiatry. Clinics were held at Long Bay Correctional Complex, the Community Justice Program, the Department of Developmental Disability and Kogarah Diagnostic and Assessment Service. Dr Wade assessed, managed and consulted on patients with intellectual disability, mental health and complex needs. She contributed to policy development through the Justice Health and Forensic Mental Health Network ID Steering Committee, and carried out research with the University of NSW.

Value to the sector and individual

Dr Wade's fellowship provided an excellent opportunity for longitudinal forensic assessments including fitness to stand trial. She had the opportunity to meet with international colleagues to discuss perspectives on fitness to stand trial restoration. Further advantages of the fellowship included gaining expertise in ID mental health, an area not traditionally included in forensic psychiatry training, but highly relevant to the criminal justice setting. Familiarity with coexisting mild intellectual disability and challenging behaviours was particularly beneficial given the overrepresentation in the forensic population.

Comments from Dr Wade

"The Fellowship allowed me to develop skills of providing informed mental health care to a group of vulnerable people within the criminal justice setting. With more psychiatrists gaining confidence and expertise in this area, through the fellowship, there is a greater chance that patients' mental health and functioning will be optimised. Alongside appropriate community supports, this provides an improved greater opportunity for people with ID to stay out of prison and lead meaningful lives".

Dr ROWAN KEIGHRAN

BSc (Med) MB BS (Hons); Conjoint Associate Lecturer (UNSW); Fellowship Year 2014-2015



Training Setting and Experience

Whilst undertaking an Intellectual Disability Neuropsychiatry Fellowship, Dr Keighran has had the opportunity to network with similarly minded professionals from a diverse range of backgrounds and has been able to move between hospitals and service networks in order to obtain the unique experiences required.

Value to the sector and individual

Dr Keighran believes patients with Intellectual Disability Mental Health concerns are often complex in biological, psychological and sociocultural spheres. The Fellowship training has been invaluable in providing him with an approach to such patients and exposure to management strategies which would otherwise not have been adequately addressed during his psychiatric training. For Dr Keighran, the Fellowship has enhanced his clinical knowledge base and he feels he will undoubtedly be a better Neuropsychiatrist (and Psychiatrist) because of it. Dr Keighran aims to utilise these skills in his future practice which will be of value to a sector which evidently continues to struggle in having even its most basic of psychiatric needs met.

Comments from Dr Keighran

"I was fortunate in obtaining a 12-month Fellowship which has enabled me to continue my Advanced Training in Neuropsychiatry and Intellectual Disability. Intellectual Disability is a core component of the Neuropsychiatry program and the Fellowship year has permitted an excellent grounding in this area. Without a solid understanding of Intellectual Disability Mental Health, most Advanced Trainees in Psychiatry would be quite ill prepared for the demands inherent in the field. This is a serious concern given the uncertainties ahead in the Intellectual Disability service industry. The Fellowship provides a flexible apprenticeship model which equips trainees for their own future psychiatric practices but also promotes education and the teaching of these skills to others."

Dr CLINT PISTILLI

BPsyc (Hons) MBBS; Fellowship Year 2015



Training Setting and Experience

Dr Pistilli is completing his final year of advanced training as a generalist in Psychiatry. He chose to use a special training fellowship offered through the NSW Institute of Psychiatry to pursue his interest in the Psychiatry of developmental and intellectual disabilities. He is involved in the running of specialist ID clinics across a variety of local health districts (LHD) in Sydney including the Prince of Wales Hospital, Concord Hospital, the Children's Hospital Westmead and the Brain Mind Research Institute (BMRI). He regularly participates in the joint NSW Health and ADHC meetings for the South West Sydney area established under the Memorandum of Understanding (MOU).

Value to the sector and individual

The fellowship fills an important gap in the current training curriculum for psychiatrists and a deficit in the availability of funded training positions in specialist mental health ID services. The fellowship allows

Dr Pistilli to understand and learn how ID services are delivered across a variety of service models and to work closely under the supervision of key experts in the field. Dr Pistilli hopes to use his training to build capacity in both the public and private health sectors to improve the accessibility of adequate mental health care for people with an intellectual disability.

Comments from Dr Pistilli

"Through the fellowship program I am immensely grateful that I have the opportunity to acquire expertise and formalise my training in this area of psychiatry, where currently no formal program through the college exists. The psychiatrist working with developmental and intellectual disabilities requires a special expertise in the needs of this diverse patient group, which enables them to perform management and leadership roles whilst working closely with other health and disability services. Exposure to these types of experiences in mainstream psychiatry is scarce".

Research Grants and Funding

Tier 1 Funding

1. NHMRC Project Grant APP1103746; 2016-2019; Total Funding \$645,101. Does gastrostomy improve the lives of children with severe disability and their families? (Downs, Leonard, Trollor, Geelhoed, Nagarajan, Wilson, Forbes, Ravikumara, Jacoby, Wong)

Research Funding

1. NSW Government; 2015; \$292,000. Enabling mainstream systems to be more inclusive and responsive to people with disabilities (Bigby, C., Iacono, T., Douglas, J., Tipping, S., Cheng, C., Tracy, J., Shields, N., Trollor, J., Taylor, N.)
2. NSW Ministry of Health; 2015; \$180,000. Safe and responsible psychotropic prescribing for persons with comorbid IDMH issues (Trollor)

Project Funding

1. NSW Ministry of Health; 2015; \$70,000. Implementation of Mental Health workforce competencies (Trollor)

Other Funding

1. Ageing, Disability and Home Care ADHC; 2015; \$1,250,000, Additional funding for the Chair in Intellectual Disability and Mental Health (Trollor)
2. Ageing, Disability and Home Care ADHC; 2015; \$150,000, Additional funding for the Chair in Intellectual Disability and Mental Health (Trollor)
3. Ageing, Disability and Home Care ADHC & NSW Ministry of Health; 2015; \$500,000, Additional funding for the Chair in Intellectual Disability and Mental Health (Trollor)
4. Ageing, Disability and Home Care ADHC & NSW Ministry of Health; 2015; \$64,000, Additional funding for the Chair in Intellectual Disability and Mental Health (Trollor)
5. UNSW; 2015; \$207,236. 2015 UNSW Major Research Equipment & Infrastructure Scheme (Thom, Anderson, Barry, Brodaty, Broderick, Curtis, Eapen, Hardeman, Lloyd, Maloney, Morris, Nelson, Parmenter, Rosenbaum, Sachdev, Simar, Smith, Steel, Trollor, Turner, Vollmer-Conna, Ward, Shannon Weickert, Yang)



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Research Output

Publications

1. Arcot, J., Kim, J., Trollor, J., Brodaty, H., Crawford, J., Sachdev, P. Anthropometric indices in a community-dwelling Australian population aged 70-90 years: The Sydney Memory and Ageing Study. *Nutrition & Dietetics*, 2015; 72(1), 8-15.
2. Birch, R.C., Hocking, D.R., Cornish, K.M., Menant, J.C., Georgiou-Karistianis, N., Godler, D.E., Wen, W., Hackett, A., Rogers, C., Trollor, J.N. Preliminary evidence of an effect of cerebellar volume on postural sway in FMR1 premutation males. *Genes, Brain and Behavior*, 2015; 14(3), 251-259.
3. Birch, R. C., Cornish, K. M., Hocking, D. R., Trollor, J. N. (2014). Understanding the neuropsychiatric phenotype of fragile X-associated tremor ataxia syndrome: a systematic review. *Neuropsychology Review*, 24(4): 491-513. doi: 10.1007/s11065-014-9262-9
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Commissioned Articles

Trollor, J., Franklin, C., Salomon, C. (2015). "Prescribing psychotropics to adults with an intellectual disability." *Australian Prescriber* (under review)

Trollor, J., and Salomon, C. (2015). "Assessing and treating mental illness in adults with intellectual disability." *Medical Observer* (under review)



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Invited Commentary

Trollor, J., and Salomon, C. (2015). "Longitudinal cohort study of people with intellectual disability shows high rates of mental disorders and challenging behaviour, and reveals unnecessary psychotropic drug prescription in primary care." *Evidence Based Mental Health* (under review).

Book Chapters

Evans LJ; Trollor JN, 2015, 'Attention Deficit Hyperactivity Disorder (ADHD)', in Hemmings C; Bouras N (ed.), *Psychiatric and Behavioural Disorders in Intellectual and Developmental Disabilities*, edn. 3rd, Academic

Reports

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- 3DN Letter regarding Proposed Closure of the Centre for Disability Health, Modbury, S.A.
- 3DN Consultation on NSW Health Policy Directive - People with a Disability: Responding to Needs During Hospitalisation
- 3DN Submission to The Commonwealth Department of Health: Electronic Health Records and Healthcare Identifiers
- 3DN Submission for the NDIS Quality and Safeguards Framework

Reviewer of policy documents for;

- NSW Health
- NSW Agency for Clinical Innovation



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Conference Presentations & Lectures

1. An introduction to Mental Ill Health in People with an Intellectual Disability, Trollor, J., NSW IOP Lectures, RANZCP Office Sydney, 25 March 2015
2. Mortality and Cause of Death in People with an Intellectual Disability in New South Wales, Australia, Trollor, J., Srasuebkul, P., Florio, T., Howlett, S., Xu, H., BGBD ID Lecture, IASSID. Honolulu, USA, 14 May 2015
3. Positive Cardiometabolic Health for adults with intellectual disability: an early intervention framework, Trollor, J., Salomon, C., Curtis, J., Watkins, A., Rosenbaum, S., Samaras, K., Ward, P., BGBD ID Lecture, IASSID. Honolulu, USA, 14 May 2015
4. Comparing behaviour changes of adults with intellectual disability with and without Down syndrome, Foley, KR., IASSIDD Americas Regional Congress, Hawaii, May 2015
5. Primary health care and problems managed for young people with Autism spectrum disorder, Foley, KR., IASSIDD Americas Regional Congress, Hawaii May 2015
6. Building Accessible Services for People with an Intellectual Disability, Trollor, J., Illawarra IDMH Forum, Wollongong Hospital, 29 May 2015
7. Successful Ageing For People with Autism Spectrum Disorders, Trollor, J., Foley, KR., Hwang, J., ASPECT Practice Research Forum, Mercure Hotel George St Sydney, 6 August 2015
8. Davis, A; The Prevalence of Dementia and Mental Illness in Older Adults with Intellectual Disability: Results of the SAGE-ID Study.; 16th International Mental Health Conference, 12 -14 August 2015
9. Targets and Tools for Positive Cardiometabolic Health in People with ID, Trollor, J., Salomon, C., Curtis, J., Watkins, A., Rosenbaum, S., Samaras, K., Ward, P., 2015 AADDM Workshop, Prince of Wales Hospital & UNSW Australia, 14 August 2015
10. Psychotropic Drugs and Cardiometabolic Health: Changing Practice, Trollor, J., Salomon, C., 2015 AADDM Workshop, Prince of Wales Hospital & UNSW Australia, 14 August 2015
11. FX Update: Findings from Australian Projects, Birch, R. C., Kraan, C., & Trollor, J. N. Fragile X Update, Y Hotel Hyde Park, Sydney NSW, 31st August 2015
12. Australian Longitudinal Study of Adults with Autism (ALSAA), Trollor, J., Foley, KR., Hwang, J., Asia Pacific Autism Conference, Brisbane, 10 September 2015
13. The Australian Longitudinal Study of Adults with Autism (ALSAA) Foley, KR., Hwang, J., Poster presentation at the Asia-Pacific Autism Conferences (APAC) Brisbane September 2015
14. Prescription of medications by Australian general practitioners in young people with autism spectrum disorders, Foley, KR., Asia-Pacific Autism Conferences (APAC) in Brisbane September 2015
15. A Collaborative Approach to Improve Mental Health Outcomes of People with an Intellectual Disability, Reppermund, S, Trollor, JN and the NHMRC Partnerships for Better Health Project Team of the Project 'Improving the Mental Health Outcomes of People with Intellectual Disability, 4th Annual NHMRC Symposium on Research Translation jointly with CIPHER – Policy and Research: Working together to improve the health of Australians. Sydney, 27-28 Oct 2015



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16. Rethinking psychotropic prescribing practices in people with ID, Trollor, J., Salomon, C., ASID, Melbourne Australia, 12 November 2015
17. Ageing and Dementia in People with Intellectual Disability, Trollor, J., Forum: 21st Annual Conference APS College of Clinical Neuropsychologists, Port Stephens, 20 November 2015
18. Improving the mental health and wellbeing of people with intellectual and developmental disabilities, Trollor, J., Inaugural Professorial Lecture, UNSW Australia, 3 December 2015



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