

The Department of Developmental Disability Neuropsychiatry 3DN

2016 Annual Report







Department of Developmental Disability Neuropsychiatry (3DN)

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2016

Department of Developmental Disability Neuropsychiatry **Annual Report**

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





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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. 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 intellectual or developmental disability to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education and policy in the field of intellectual and developmental disability mental health.

Our Vision

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

Our Mission

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

Our Guiding Principles

Human rights - People with intellectual or developmental disability have the right to the highest attainable standard of health and mental health care.

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

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

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





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Collaboration - We value the multidisciplinary context of our work. We actively engage stakeholders to share expertise and promote integrated systems in health and disability. We actively seek the participation of people with intellectual or developmental disability. We value our collaborations with carers and family members.

Ethical conduct - We act in accordance with professional and industry codes of conduct and practice, the human rights of people with intellectual or developmental disability, and the Guiding Principles in our Strategic Plan.





Chair's Report Professor Julian Trollor



2016 has been an exciting and rewarding year characterized by a surge in our research, clinical, policy, and workforce capacity building agenda and outputs.

Our department understands that improving the quality of care available to people with intellectual disability will not be possible without a skilled and educated workforce. For this reason we have continued to focus strongly on workforce capacity building throughout 2016. I am delighted to announce that during this time we launched another five e-learning modules for health

professionals, and eight e-learning modules for disability workers. This year also marked the launch of the Intellectual Disability Mental Health Core Competencies Framework, which articulates competencies for NSW mental health staff. It is our hope that these targeted educational resources will strengthen workforce confidence and capacity to provide quality mental health care to people with intellectual disability into the future.

Hand in hand with our workforce capacity building efforts, we have focused on sharing our research findings widely through publications in reputable journals, conference presentations and workshops. Findings from our longitudinal research into successful aging in intellectual disability (SAGE-ID), for example, were published in *Research in Developmental Disabilities* and have helped to shed light on the experiences of family carers who support adults with intellectual disability as they age.





Knowledge translation efforts based on Dr Rachel Birch and colleagues research into thinking and motor skills in permutation fragile X carriers have also been ongoing, including publication of papers targeting clinical neuropsychologists, neurologists, and dementia care workers.

Our data linkage work is also continuing and has helped to build an increasingly comprehensive picture of the health and service system challenges facing Australians with intellectual disability. Our data analysis has highlighted high death rates and premature mortality in people with intellectual disability. We hope to use these statistics for positive change in health policy, health promotion and health services. We received funding in mid-2016, for example, to commence a pilot intervention program to improve physical activity and nutrition outcomes for adults with intellectual disability. We also launched the positive cardiometabolic framework and toolkit for adults with intellectual disability. The goal of this suite of resources is to educate and equip both general practitioners and other health care professionals to identify and support people with intellectual disability who are at increased cardiometabolic risk.

There are far too many exciting projects underway at 3DN for me to report in any depth here. However, I hope that you will take the time to read through the detailed project descriptions that follow to as an encouragement. We have been particularly excited by the development of a strong translational focus of our work which has allowed rich and meaningful engagement with people with intellectual disability.

My heartfelt thanks also to the health professionals, disability support workers, carers, advocates and people with intellectual disability that have been so generous in sharing their time and expertise with us throughout the year. To our funders and research partners I also owe a debt of gratitude. Without your contributions and belief in us, many of the milestones we reached this year would not have been possible.





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I would like to thank our dedicated staff, both past and present, for their contributions, and their enthusiastic embrace of the department's vision of achieving the highest attainable standard of mental health and wellbeing for all Australians with intellectual or developmental disability.

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Key Research Areas &

The Year in Review

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).







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Project title: Get Healthy! Promoting Healthy Lifestyle Change for Older Australians with Intellectual Disability

Project Team: Dr Carmela Salomon (project coordinator); Prof Julian Trollor; Dr Liz Evans; Jess Walsh; Chris Tzarimas; Dr Simon Rosenbaum; Dr Jackie Curtis; Dr Jackie Curtis; Dr Scott Teasdale; Prof Katherine Samaras; Andrew Watkins; A/Prof Philip Ward; Jessica Bellamy.

Short description: The aim of this project is to reduce lifestyle related diseases and deaths in older people with intellectual disability by developing accessible healthy lifestyle training tools and an intervention package.

Where the project is at: This project commenced in mid 2016. We are currently refining the intervention design protocol.

Achievements: A comprehensive literature review has been conducting to identify:

- Barriers and facilitators of healthy lifestyle engagement
- Design and impact of previous nutrition and physical activity interventions in this population
- Appropriate outcome measurement tools and scales to apply to this population

The literature reviews will inform the pilot intervention design.

Future deliverables:

- Consult with older people with intellectual disability, carers and service providers about barriers and enablers to engagement in healthy lifestyle programs.
- Develop a free on-line training module to equip allied health professionals to deliver effective lifestyle interventions to people with intellectual disability.
- Develop and evaluate the impact of a tailored healthy lifestyle intervention in a small number of people with intellectual disability and their carers.





Project title: Scoping work for a State-Wide Tertiary Intellectual Disability Mental Health Service.

Project Team: Prof Julian Trollor and Ms Janelle Weise

Short dscription: This project aims to determine and reach consensus on the key priorities and resource requirements of a state-wide tertiary intellectual disability mental health service.

Where the project is at: This project commenced in late 2016 and we are in the methodological design phase.

Achievements: Ethics approval has been granted for phase one of the project, consulting with NSW public mental health services.

Future deliverables: We aim to consult with people with intellectual disability, their family and support networks, intellectual disability mental health experts and NSW public mental health services about their views on the need for a tertiary service and how such a service, if one existed, could best operate in NSW.





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Project title: A Historical Perspective of Intellectual Disability Mental Health Services in NSW.

Project Team: Prof Julian Trollor, Ms Janelle Weise and Dr Adith Mohan

Short Description: This qualitative study interviews key health and disability professionals and intellectual disability advocates to explore i) their historical experience of delivery of, and access to, mental health services for people with intellectual disability in NSW; ii) what have been the strengths and weaknesses of service delivery; iii) what have been the facilitators and barriers to enhancing the quality of mental health services available to people with intellectual disability; and iv) what can be learnt from their historical perspective to enhance current services for people with intellectual disability

Where the project is at: We are currently in the process of writing up the findings of this research for dissemination.

Achievements: The findings from this study were presented at the RANZCP congress in 2014

Future deliverables: To publish our findings in a peer reviewed journal.





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Project title: Positive Cardiometabolic Health for People with intellectual Disability: an Early Intervention Framework

Project Team: Prof Julian Trollor, Dr Carmela Salomon, Ms Jessica Walsh and Dr Rachael Birch.

Short Description: People with intellectual disability experience poorer health and higher mortality rates than the general population. One of the major contributors to this health inequality is cardiometabolic ill health. Cardiometabolic risk factors for people with intellectual disability differ from the general population and include high rates of psychotropic prescription and certain genetic syndromes associated with intellectual disability. This project aims to improve psychotropic prescribing practices and cardiometabolic health outcomes in people with intellectual disability and co-occurring mental ill health.

Achievements: Positive Cardiometabolic Health for People with intellectual Disability: an early intervention framework and resources was launched at a forum in July 2016. We distributed copies of the adult and adolescent versions of the Early Intervention Framework, and promotional postcards for people with intellectual disability and carers to take to their doctors. All resources, including the cardiometabolic toolkit and presentations from the forum are now freely accessible online. We published two papers in peer reviewed journals on: the development of the Early Intervention Framework, and GP prescribing patterns to people with and without intellectual disability, respectively. We were also commissioned to publish an article on psychotropic prescribing to people with intellectual disability.





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Where the project is at: We are currently developing a series of podcasts titled *Responsible Psychotropic Prescribing to People with intellectual Disability* and creating an online learning module to teach health professionals about cardiometabolic health in people with intellectual disability and the Early Intervention Framework.

Future deliverables: To launch the podcasts and online learning module.





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Project title: General Practice and the Delivery of Primary Health Care to People with Intellectual Disability – Problems Managed and Treatment Provided.

Project Team: Prof Julian Trollor, Ms Janelle Weise, Prof Helena Britt, Dr Allan Pollack

Short Description: This project involves an analysis of the Bettering the Evaluation and Care of Health (BEACH) data set (January 2003-December 2012) to identify: the problems and disorders for which people with intellectual disability seek medical and mental health care in Australia, the way in which the problems and disorders are managed, the treatments offered, the characteristics of the general practitioners who provide care to people with intellectual disability, and the length and type of consultation.

Where the project is at: We have finalised the analysis of the BEACH data and are currently working on developing an accessible summary of our findings.

Achievements: Three papers have been published in peer review journals.

Future deliverables: To disseminate our findings to GPs and to look for future funding to continue work in this area.





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Project title: Ageing Well as an Adult on the Autism Spectrum in Australia.

Project team: Miss Ye In (Jane) Hwang, Dr Kitty-Rose Foley, Prof Julian Trollor

Short Description: This mixed-methods investigation aims to define and explore the theoretical concept of 'Ageing Well' for adults on the autism spectrum in Australia who are 25 years old or older; it involves three studies. The Australian Longitudinal Study of Adults with Autism (ALSAA) is a questionnaire that aims to understand the health and wellbeing of autistic adults and their carers. It covers many domains such as physical and mental health, day activities, and health service use. The second study involves interviews with 15 autistic adults and 9 carers with the aim of investigating what it means for autistic adults to 'age well'. The final study involves the examination of linked, NSW state-based administrative datasets to examine mortality and cause of death for autistic adults with and without intellectual disability compared to the general population.







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Achivements: Status: Data collection is complete for all three studies. Study findings are being disseminated via conference presentations and are being prepared for publication in peer-reviewed scientific journals.

Future deliverables: This project hopes to provide meaningful insight into the circumstances, ideals and needs of autistic adults in Australia as they age. It will contribute new and important information to our understanding of the health and wellbeing of autistic adults and encourage the development of more inclusive models of ageing.





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Project title: Intellectual Disability Mental Health Core Competencies Framework Project

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

Short Description: The mental health workforce reports 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 been launched across NSW, and an accompanying Toolkit has been produced and will be launched shortly.

Achievements:

- The launch of the Framework Manual which identifies core competencies in 11 key areas and details varied resources the workforce can access to develop these competencies through professional development.
- A forum and workshop which included presentations by speakers with expertise in adult and child and adolescent intellectual disability mental health, along with disability support professionals and carers.
- An accompanying Toolkit has been developed, which will provide more practical advice to mental health professionals across NSW as to how they can make adaptations to their practice when working with people with intellectual disability.

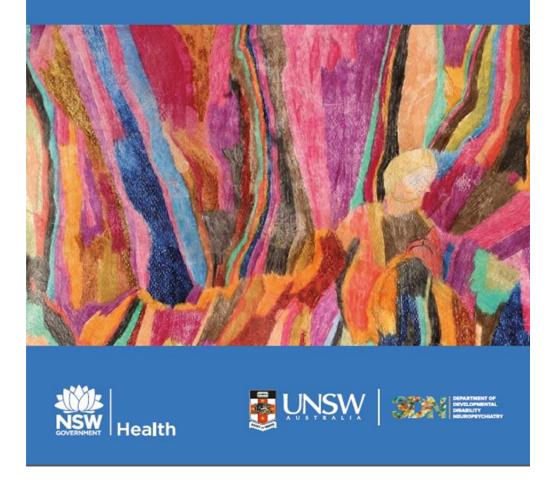
A project has begun to evaluate the Framework and its effectiveness in supporting practice and attitudinal change.





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INTELLECTUAL DISABILITY MENTAL HEALTH CORE COMPETENCY FRAMEWORK: A MANUAL FOR MENTAL HEALTH PROFESSIONALS



Future deliverables: We aim to introduce the Toolkit 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.





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Project title: Undergraduate Medicine and Nursing Curriculum Development (Phase 1)

Project team: Prof Julian Trollor, Ms Claire Eagleson, Ms Beth Turner

Short 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, 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.
- Two publications outlining *what* intellectual disability content is taught have been published.

Future deliverables:

- A further two publications outlining *how* the intellectual disability content is taught are in development.
- 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 title: NHMRC Partnerships for Better Health Project – 'Improving Mental Health Outcomes for People with intellectual Disability'

Project team: Project team: Prof Julian Trollor, Ms Erin Whittle, Dr Preeyaporn Srasuebkul, Ms Snow Li, Ms Bronwyn Newman, Dr Tess Heintze, Dr Rebecca Reeve, Dr Angela Dew, & Dr 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 Alix Goodwin; NSW Department of Education, 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 Gordon Duff; NSW Office of the Public Guardian, represented by Justine O'Neill, NSW





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Short description: This project represents multi-disciplinary collaboration between UNSW Sydney, the NSW Ministry of Health – Mental Health & Drug & Alcohol Office, the 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 intellectual disability (ID) 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 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.







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Achievements: Results from linked data showed that compared to the general population, people with an ID who used mental health services had a skewed diagnostic profile, higher rates of uncertain diagnoses, higher service use; including more frequent and longer admissions and more 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 ID 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 UNCRPD.

A systematic literature review on key barriers and enablers to accessing mental health services for people with 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.

A consumer advisory group ensures accountability and adherence to the principles of inclusive research and to provide expert advice on research design and content.





Project title: Thinking and Motor Skills in Premutation Carriers of fragile X

Project team: Prof Julian Trollor, Dr Rachael Birch

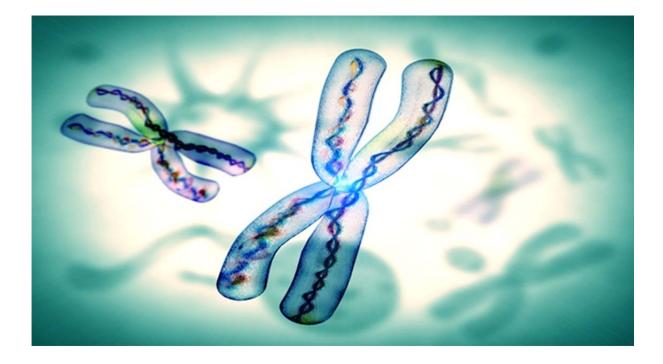
Other Investigators: A/Prof Wei Wen, Prof Kim Cornish, Prof Nellie Georgiou-Karistianis, Prof Sylvia Metcalfe, Dr Anna Hackett, Ms Carolyn Rogers, Dr Darren Hocking, Dr David Godler, Prof Stephen Lord, Dr Jasmine Menant.

Short Description: 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 Sydney) and Victoria (Monash University). Our research team based at 3DN leads the UNSW Sydney site, with a focus on cognitive and motor function among adult men who carry the *FMR1* premutation.





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Achievements: Baseline participant assessments for this study were completed between 2011 and 2013. We have continued to publish findings of this study throughout 2016, including papers targeting clinical neuropsychologists and dementia care workers.

Future deliverables: We are currently seeking further funding to follow-up this cohort and develop evidence-based resources for fragile X families and health practitioners.





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Intellectual Disability Mental Health (IDMH) E-learning – Disability Modules

Project team: Prof Julian Trollor, Miss Kimberley Smith & Ms Thea Kremser

Short Description: As part of the wider IDMH online portal this project is developing e-Learning modules specifically tailored to professionals in the disability sector. Disability professionals have a valuable role in improving the mental health and well-being of people with intellectual disability and in many cases play a pivotal role in assisting a person with intellectual disability to access mental health supports.



Achievements: Eight new e-Learning modules were launched this year. These cover topics such as "An Introduction to Mental Health", "How to Support a Person with a Possible Mental Illness" and "Supporting Behaviours of Concern".

Future deliverables: The e-Learning will continue to expand throughout 2017 as further modules are released.





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Intellectual Disability Mental Health (IDMH) E-learning – Health Professional Modules

Project team: Prof Julian Trollor, Miss Kimberley Smith & Ms Thea Kremser

Short Description: The 3DN e-learning site http://idhealtheducation.edu.au/ offers a comprehensive suite of e-learning modules about mental disorders and people with intellectual disability tailored to health professionals

Achievements: Five new modules about people with intellectual disability and mental disorders were published for health professionals in 2016 These were:

Module 9 Equality in mental health care - a guide for clinicians

Module 10 Consent, decision-making & privacy - a guide for clinicians

Module 11 Challenging Behaviour I – Introduction

Module 12 Challenging Behaviour II – Assessment

Module 13 Challenging Behaviour III - Management





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Intellectual Disability Mental Health (IDMH) E-learning – Carer Modules

Project team: Prof Julian Trollor, Miss Kimberley Smith & Ms Thea Kremser

Short Description: The 3DN e-learning site http://idhealtheducation.edu.au/ offers a comprehensive suite of e-learning modules about mental disorders and people with an intellectual disability tailored to health professionals and disability professionals.

Future Deliverables: In mid-2017 3DN will launch e-learning tailored to carers – those who provide unpaid care and support to people with an intellectual disability. Six modules will cover an introduction to mental health and mental disorders, detecting changes, and signs and symptoms of common mental disorders.





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

Project team: Dr Liz Evans, Prof Julian Trollor, Ms Clancy Black.

Other investigators: Prof Teresa Iacono, Dr Jennifer Torr, Prof Perminder Sachdev, Prof Henry Brodaty.

Project ambassador: Mr. Michael Sullivan.

Short 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 prevalence and 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. The new project includes a focus on the current pathways to care for people with intellectual disability who develop

dementia, as well as a focus on producing resources to improve the recognition of dementia in people with intellectual disability





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Achievements in 2016:

- Liz Evans presented at the NHMRC National Institute for Dementia Research conference.
- Our paper on dementia in people with intellectual disability, written for the *Australian Journal of Dementia Care,* was published as a feature article during dementia awareness month.
- Our findings regarding family carers' experiences of caring for an adult with intellectual disability was published in *Research in Developmental Disabilities*.
- Data from the study was used to inform a presentation regarding healthy ageing in people with intellectual disability, presented by Dr. Simone Reppermund, at the IASSID conference. In the same symposium, Liz Evans presented on the key challenges and potential strategies for achieving translational research
- With the assistance of staff at NSWCID, we held a consultation with consumers with intellectual disability regarding most useful content and layout for resources to increase awareness regarding dementia.

Future deliverables:

- Guidelines for GPs on how to assess and manage dementia in people with intellectual disability, which are currently under review.
- A paper reviewing current evidence regarding dementia care pathways for those with and without intellectual disability is in development.
- A paper on the usefulness of screening checklists is in development.
- We will produce a suite of resources about dementia for people with intellectual disability, carers, service providers and GPs.





Staff & Affiliates

Professor Julian Trollor – Chair & Department Head



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.





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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 Xassociated tremor ataxia syndrome (FXTAS); a neurodegenerative disorder characterised by the progressive development of intention tremor, gait

ataxia, parkinsonsism 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.





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Dr Simone Reppermund – Senior 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 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 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 intellectual disability to identify and deliver means of improving access to mental health services and supports for people with intellectual disability. The findings will develop an evidence base to guide the development of clinical services and policy for people with intellectual disability 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





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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.

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 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.





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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 intellectual disability. She has a Bachelor of Applied Science (Occupational Therapy) (Hons) and a Masters of Public Health and has worked across clinical, service delivery and managerial roles within the disability and health sectors. Janelle is passionate about addressing the inequitable access to healthcare and poor health outcomes experienced

by people with intellectual Disability.

Dr Liz Evans - Lecturer

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 intellectual disabiliy, and the study of behavioural phenotypes.

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





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Ms Clancy Black - Research Assistant

Clancy completed a Bachelor of Psychology with First Class Honours at the University of Sydney. Her honours thesis was in social psychology, and examined the negative impact of objectifying female politicians. She has worked on a variety of research projects, including intervention studies aimed

at reducing prejudice towards individuals who are Muslim or of a sexual minority, as well as studies considering the role of phone applications in improving user nutrition. Currently, Clancy is a research assistant working on the SAge-ID Study (Successful Aging in Intellectual Disability) with UNSW 3DN.



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.





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

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/





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

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 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 administrive 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.





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Ms Rachel Roth - Administrative Officer



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

Dr Carmela Salomon – Project Officer



Carmela Salomon is a 3DN Project Officer working on a range of initiatives to support responsible psychotropic prescribing and cardiometabolic health in people with intellectual disability. Her PhD research (completed in 2014) explored mental health consumer experiences of antipsychotic discontinuation. Antipsychotic discontinuation is associated with a number of potential side effects including sleep disruption and other physical, cognitive, emotional and psychotic withdrawal syndromes. As well as collecting novel first person characterisations of these syndromes, her research focused on identifying

coping strategies and suggestions for mental health service change from people with lived experience of medication discontinuation. In addition to a PhD in Health Sciences, she holds a Post-Graduate Diploma in Advanced Mental Health Nursing and a Bachelor of Nursing Science. Carmela has clinical experience in community and inpatient mental health settings and is passionate about increasing consumer input in mental health research and system management.





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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) elearning 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 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.







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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 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.





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

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.

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.





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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...

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.





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Clinical Fellows

Dr REBECCA KONCZ

MBBS (Hons), B. Liberal Studies International; Fellowship Year 2016

Training Setting and Experience

Dr Koncz is completing her final year of specialist training as an Advanced Trainee in Consultation-Liaison Psychiatry. Her interest in intellectual disability stems from her previous experience in neuropsychiatry as a clinical and research Fellow, owing to the inherent clinical and academic overlap between these fields. Her current Fellowship in Intellectual Disability and Neuropsychiatry capitalises on a broad range of training opportunities across a variety of settings. This includes experience with adult intellectual disability psychiatry clinics at Concord Hospital and Prince of Wales Hospital, a neurodevelopmental disorders clinic at Westmead Children's Hospital, and continued clinical work and research at the Neuropsychiatric Institute, Prince of Wales Hospital.

Value to the sector and individual

The Fellowship provides a unique training experience to develop skills in clinical assessment and management of people with intellectual disability and neuropsychiatric conditions. As an Advanced Trainee in Consultation-Liaison psychiatry, Dr Koncz is well placed to advocate for patients and their carers in the general hospital setting, and to navigate the systemic challenges that are characteristic of the fragmentation between mental health and disability services. She continues to be actively involved in research in this complex area, and opportunistically provides education regarding intellectual disability psychiatry to staff across disciplines. Dr Koncz aims to use the Fellowship as a platform to work across health and disability, government and non-government sectors, in order to raise the standard and improve the quality of access to mental health services for people with intellectual disability.





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Comments from Dr Koncz

"The Fellowship provides an invaluable opportunity to develop clinical, academic and advocacy skills across the complex realms of intellectual disability and neuropsychiatry. This is timely, particularly in view of the current paradigm shift towards the National Disability Insurance Scheme. The Fellowship places us in a unique position during this transition to provide continued clinical care and advocacy for people with intellectual disability and their carers, as well as provide education and training to the health workforce at large. Collaboration with other medical specialties, allied health services and non-government sectors is vital in developing more comprehensive, integrated disability and health care services."





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Dr HARSHA EDIRIWEERA

MBBS; Fellowship year 2016

Training Setting and Experience

Dr Ediriweera used his fellowship in his final advanced training year to gain extensive clinical experience in Intellectual Disability Mental Health (IDMH) and neuropsychiatry in a variety of settings in metropolitan and regional NSW. His training involved neuropsychiatric, adult, child and adolescent clinics in Department of Developmental Disability and Neuropsychiatry at UNSW, Diagnostic and Assessment Service Kogarah, Northern Intellectual Disability Health, SAL Consultancy and outreach clinics in Armidale and Inverell. In addition, he was actively involved in capacity building in IDMH in the Illawarra.

Value to the sector and individual

The IDMH fellowship provided Dr Ediriweera with a unique experience to develop a different skill set which will be invaluable in his career as a psychiatrist. In addition to the better knowledge in diagnosis and management of neurodevelopmental conditions impacting on mental illness,

this has provided the opportunity to understand health inequalities and strengthen advocacy across government and non-government sectors.

Comments from Dr Ediriweera

"Apart from the above, this fellowship has provided me access to work with experienced senior clinicians and different public and private organisations in the sector, which will be invaluable from a career and sector development. I think the fellowship has provided a tremendous and unique opportunity to its recipients to expand their career paths and the disability sector to build its own capacity with more skilled personnel











Research Grants and Funding

Tier 1 Funding

 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)

Project Funding

- 1. Ageing, Disability and Home Care ADHC; 2016-2017; \$140,000. Scoping work for a State-Wide Tertiary Intellectual Disability Mental Health Service (Trollor)
- 2. Ageing, Disability and Home Care ADHC; 2016-2017; \$100,000. Equipping Future Australian and New Zealand Psychiatrists to Meet the Mental Health Needs of People with intellectual Disability (Trollor)
- 3. NSW Health Family & Community Services; 2016-2017; \$90,861.91. The healthy lifestyle project for older Australians with intellectual disability, (Trollor)

Other Funding

 UNSW Australia; 2016; \$218,097; UNSW Major Research Equipment & Infrastructure Scheme; (Lord, Asper, Barry, Booth, Broderick, Close, Delbaere, Gandevia, Herbert, Kark, Krishnan, Menant, Parmenter, Redmond, Sturnieks, Thom, Trollor, Tzarimas, Van Doorn, Ward,

Schofield)





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Publications

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- 10. Evans, L.J., Black, C., Trollor, J. Dementia in people with intellectual disability. *Australian Journal of Dementia Care*, 2016.
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- 12. Foley, K.R., Taffe, J., Bourke, J., Einfeld, S.L., Tonge, B.J., Trollor, J., Leonard, H. Young people with intellectual disability transitioning to adulthood: Do behaviour trajectories differ in those with and without down syndrome? *PLoS ONE*, 2016; *11*(7), e0157667.
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Other Publications

Why Do People With Intellectual Disability Die? Plain English Summary. https://3dn.unsw.edu.au/sites/default/files/newsevents/events/Deaths%20in%20Intellectua l%20Disability%20Service%20Users%20in%20NSW%20Easy%20Read_final.pdf

Making Mental Health Policy Inclusive of People with Intellectual Disability. A summary for policy makers.

https://3dn.unsw.edu.au/sites/default/files/ddn/resources/Policy%20analysis_Summary%2 0for%20Policy%20Makers_final.pdf

Making Mental Health Policy Inclusive of People with Intellectual Disability. A summary for service providers.

https://3dn.unsw.edu.au/sites/default/files/ddn/resources/Policy%20analysis_Summary%2 0for%20Service%20Providers_final.pdf

Making Mental Health Policy Inclusive of People with Intellectual Disability. Plain English Summary.

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The Department of Disability Neuropsychiatry (3DN) 2016 -2021 Strategic Plan <u>https://3dn.unsw.edu.au/sites/default/files/ddn/page/3DN%20Strategic%20Plan%202016-2021.pdf</u>

The Department of Disability Neuropsychiatry (3DN) 2015 Annual Report <u>https://3dn.unsw.edu.au/sites/default/files/ddn/page/3DN%20Annual%20Report%202015.</u>pdf





DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Conference Presentations

& Lectures

National Audience

Keynote

1. Intellectual Disability Mental Health Core Competency Framework, Trollor, J., Core Competencies Forum Launch, Prince of Wales Hospital, Sydney, 30 March 2016

Invited

- Ageing well on the autism spectrum in Australia a qualitative study. Hwang, Y.I., Foley, K.R., & Trollor, J.N. Oral presentation at the 2016 Australian Society for Autism Research (ASfAR) Conference, Perth, WA, Australia, December 2016
- 3. Equipping LHDs to Meet the Mental Health Needs of People with Intellectual Disability: Why is it necessary and how can it be done?, Trollor, J., Clinical Advisory Council, North Sydney, NSW , 25 November 2016
- 4. Neurocognitive correlates of reduced thalamus volume in men who carry premutation expansions of the *FMR1* gene. Birch, R. C., Hocking, D. R., Wen, W., Cornish, K. M., Georgiou-Karistianis, N., Rogers, C., & Trollor, J. N. . Australasian Cognitive Neuroscience Conference, Shoal Bay, NSW, Australia, November 2016
- Ageing Well' as an autistic adult in Australia a mixed methods investigation. Hwang, Y.I., Foley, K.R., & Trollor, J.N. 49th Australian Association of Gerontology (AAG) Conference, Canberra, ACT, Australia, November 2016
- Ageing well as an adult on the autism spectrum in Australia Hwang, Y.I., Foley, K.R., & Trollor, J.N. 15th National Conference of Emerging Researchers in Ageing (ERA), Canberra, ACT, Australia, October 2016





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- 7. Intellectual Disability Mental Health Core Competency Framework Evaluation Survey, Trollor, J., Clinical Advisory Council, North Sydney, NSW, 13 October 2016
- Action on Intellectual Disability Mental Health, Trollor, J., NSW Council for Intellectual Disability Conference 2016, Doltone House, Sydney, 15 September 2016
- 9. Psychology and Restrictive Practices: Lessons from research and clinical practice, Trollor, J., 2016 APS Congress, Exibition Centre, Melbourne, 13 September 2016
- 10. Utilisation and costs of hospital services for patients with intellectual disability, Trollor, J., Srasuebkul, P., Reeve, R., IASSID Conference, Melbourne, August 2016
- 11. A scoping review of pathways to dementia diagnosis for people with and without intellectual disability Iacono, T., Pearce, N., Evans, E., Hodgkin, S.. Paper presented as part of an oral symposium at the IASSIDD World Congress, August 2016.
- 12. Developing a knowledge translation strategy to support effective and tailored services to promote healthy ageing in people with ID. Evans, E., Goodenough, B., Trollor, J. Paper presented as part of an oral symposium at the IASSIDD World Congress, August 2016.
- Symposium chair: Aging and Intellectual Disabilities. 2016 IASSIDD World Congress, Melbourne, Australia, Reppermund S, Evans E, Davis A, Trollor J (2016, August). How is Successful Ageing Defined for People with intellectual Disability? Journal of Intellectual Disability Research 60, p.727. Talk given at the 2016 IASSIDD World Congress, Melbourne, Australia.
- Using Big Data to Understand Health and Wellbeing in People with Developmental Disabilities, Trollor, J., Srasuebkul, P., Heintze, T., Reeve, R., Cumberland Hospital Academic Forum, 29 June 2016
- 15. Using Big Data to Understand Health and Wellbeing in People with Developmental Disabilities, Trollor, J., Srasuebkul, P., Heintze, T., Reeve, R., Sutherland Hospital Academic Forum, 1 June 2016
- 16. Intellectual Disability Mental Health Developments & Resources, Trollor, J., MH CYP Subcommittee, North Sydney, 20 May 2016





- 17. Down Syndrome and Mental Health: An Australian Perspective, Trollor, J., Salomon, C., SMC Conference and Function Centre, Sydney, 13 May 2016
- 18. Autism Research at 3DN, Trollor, J., Foley, KR., Hwang, J., Giant Steps, Sydney, 4 May 2016
- Dementia in people with Intellectual Disability: A longitudinal study with a knowledge translation focus. Evans, E., Trollor, J., Poster and brief oral presentation presented at the NHMRC National Institute for Dementia Research Forum, May 2016.
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- 1. Using Big Data to Understand Health and Wellbeing in People with Developmental Disabilities, Trollor, J., Srasuebkul, P., Heintze, T., Reeve, R., Child and Mental Health Services (CAMHS) Prince of Wales Hospital, Sydney NSW, 1 September 2016
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Regular Teaching Contributions

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Reports

The Department of Disability Neuropsychiatry (3DN) 2016 -2021 Strategic Plan <u>https://3dn.unsw.edu.au/sites/default/files/ddn/page/3DN%20Strategic%20Plan%202016-2021.pdf</u>

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

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