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Developmental Disability Neuropsychiatry 3DN

2017 Annual Report



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DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY

Department of Developmental Disability Neuropsychiatry (3DN)

2017 Annual Report

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2017

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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About the Department

Introduction

The Department of Developmental Disability Neuropsychiatry (3DN) was established by the Chair of Intellectual Disability Mental Health in 2009. Core funding for The Chair is provided by the NSW Government, with contributions from both the Mental Health Branch, NSW Health, and Family and Community Services.

3DN sits within the School of Psychiatry within UNSW Medicine. We champion the right of people with intellectual or developmental disability to the same level of health and mental health care as the rest of the population. We promote a standard of excellence in clinical practice, research, workforce development, education and policy in the field of intellectual and developmental disability mental health.

Our Vision

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

Our Mission

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

Our Guiding Principles

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

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

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

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

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

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

Chair's Report from

Professor Julian Trollor

It has been a great privilege to continue to oversee the Department of Developmental Disability Neuropsychiatry throughout **2017**, and to celebrate our progress towards achieving improved mental health for people with intellectual and developmental disability. As a department, we continue to learn a great deal across clinical, research, workforce development and policy platforms, both about existing challenges, as well as innovative solutions.

Since its inception in 2009, 3DN has been firmly committed to strengthening workforce capacity and provision of high quality education. This year our e-learning platform has been substantially enhanced by the launch of three new modules for disability professionals and eight new modules specifically for carers. The expansion of our on-line training platform to include resources for carers recognises the central role carers play in promoting positive health outcomes for people with intellectual disability.

A number of other exciting workforce capacity building initiatives got underway this year. Stakeholder consultations to scope the development of a state-wide tertiary intellectual disability mental health service have begun. As part of our ongoing Successful Ageing in Intellectual Disability Study, an evidence-based guideline to support general practitioners to better diagnose and manage dementia has been developed.

Policy focused work conducted by 3DN in 2017 has highlighted the ongoing underrepresentation of people with intellectual disability in Australian mental health policy, particularly outside of the forensic context. In response to an advocacy partnership with key national leads including 3DN, it was positive to see the needs of people with intellectual disability recognized in The Fifth 5th National Mental Health and Suicide Prevention Plan. Moving forward, we will continue to advocate for greater explicit inclusion of people with disabilities within new and existing policy documents.

Our research agenda has continued to mature. Increasingly, we recognise the interconnectedness of physical and mental health outcomes for the wellbeing of the individual. Recent analysis from our data-linkage work, for example, highlights how, in addition to problematic psychiatric service availability and utilization, people with intellectual disability experience lower life expectancy, and higher death rates from potentially avoidable causes including cardiometabolic diseases. To progress responses to this issue we began recruiting people with intellectual disability and carers into a pilot

physical activity and healthy eating program. I would like to invite you to read through the detailed project descriptions within this report to learn more about other exciting research work currently underway in our department.

Of course, none of the work undertaken at 3DN would be possible without the generous support of our funding partners and other collaborators. It is with great gratitude that I acknowledge our funding partners, as well as the people with intellectual disability, carers, health professionals and academic and clinical experts who contributed invaluable expertise to our projects throughout the year.

Looking forward to 2018, I am excited to continue work with our partners and dedicated department staff. At 3DN we are committed to ensuring meaningful improvements in the mental health and wellbeing of people with intellectual and developmental disability.

A handwritten signature in blue ink, reading "Adrian Rollo". The signature is fluid and cursive, with the first name "Adrian" and the last name "Rollo" clearly distinguishable.

Research Areas, The Year in Review

3DN has a diverse, interdisciplinary and inclusive 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 studies on adults with Autism Spectrum Disorders with the Autism Cooperative Research Centre, intellectual disability and dementia work undertaken in collaboration with the Dementia Collaborative Research Centres (DCRC), and have a number of collaborations with the Centre for Health Brain Ageing (CHeBA).

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

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

Short description This project represents multi-disciplinary collaboration between the UNSW, the NSW Ministry of Health – Mental Health Branch, the NSW Government Department of Family and Community Services and Aging, Disability and Home Care Services, Council for Intellectual Disability, Inclusion Australia, NSW Government Agency for Clinical Innovation– Intellectual Disability Network, NSW Ombudsman, NSW Office of the Public Guardian, NSW Government Department of Education 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 ID 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 ID and mental health issues at both the national and state levels, with an emphasis on translational outcomes. The project supports a number of PhD candidates who are completing projects relating to complex needs, easy read resources, people with intellectual disability in contact with the criminal justice system and other aspects of data linkage.

Achievements Analyses of mortality, mental health inpatient and emergency department presentations and costings are in progress. Results from linked data showed that compared to the general population, people with ID who used mental health services

had a skewed diagnostic profile, higher rates of uncertain diagnoses, higher service use including more frequent and longer admission and visits to the community mental health service. Moreover, they also had higher death rates/premature mortality including from preventable causes when compared with the general population (Trollor et al, 2017). We also found that ID status increased the likelihood of readmission to a psychiatric facility and emergency department presentations after the first psychiatric admissions (Xue et al, 2018).

A recently published in-depth analysis and review of current Australian mental health policy to assess the representation of people with ID by our group (Dew et al., in press) found limited inclusion of this population. We identified 37 relevant mental health policy documents and less than half of these documents mentioned people with ID. In addition, nine pieces of mental health legislation for all states and territories were analysed and people with ID were only mentioned in relation to forensic parts of the Acts addressing fitness to plead and the need for additional support in this context. Importantly, none of the mental health policies consulted people with ID or their supporters as stakeholders to inform policy development. A debate paper on clinical implications of the underrepresentation of people with ID in Australian mental health policy is currently in progress.

Qualitative data collection was completed, and the primary analysis was finalised. Results indicated that there were key barriers and enablers identified across four domains of access: utilisation of services; service availability; relevance, effectiveness and access; and equity and access. 23 interviews and focus groups were completed. Participants included 7 people with lived experience of mental health and intellectual disability, 10 carers and support people and 23 service providers across both disability and mental health services, from rural and metropolitan NSW and SA.

A systematic literature review on key barriers and enablers to accessing mental health services for people with ID was published in the Journal of Mental Health Research in Intellectual Disabilities in December 2017. The primary qualitative analysis has been submitted to the Journal of Applied Research in Intellectual Disabilities and is currently under review. Secondary analyses of the qualitative data, in particular patterns of emergency department usage and the lived experience of key gaps in mental health policy are currently being prepared for submission. Easy read and plain English versions of all papers produced from the project have also been developed with substantial input from the consumer reference group.



Chief Investigators Julian Trollor, Eric Emerson, Roshel Lenroot, Leanne Dowse, Karen Fisher, Kimberlie Dean

Associate Investigators 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 Angela Koelink; 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 and Melinda Smith; Mental Health Commission of NSW, represented by Julie Zieth; NSW Ministry of Health – Mental Health Branch, represented by Judith Burgess; Mental Health Review Tribunal, represented by Anina Johnson; Council for Intellectual Disability and Inclusion Australia, represented by Jim Simpson; National Disability Services, represented by Gordon Duff; NSW Office of the Public Guardian, represented by Justine O'Neill, NSW Ombudsman, represented by Kathryn McKenzie

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

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

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

Short project description We aim to improve the quality of physical activity and nutrition related care available to adults with intellectual disability. To do this we are undertaking a project to identify and analyse the impact of previous healthy lifestyle interventions for people with intellectual disability; identify barriers and enablers of healthy lifestyle change for adults with intellectual disability by analysing relevant literature and conducting focus groups with people with ID, carers and services managers; develop on-line learning modules for allied health professionals to better equip them to tailor physical activity and nutrition relation interventions to the needs of this population; develop an evidence based physical activity and nutrition program for adults with intellectual disability; conduct a feasibility trial of the program with adults with mild to moderate intellectual disability; refine the program content and delivery based on results of the feasibility trial. Longer term, we hope to conduct a sufficiently powered clinical efficacy trial of the refined program.

Current state of project and achievements to date We have secured partial funding for the project under the Department of Family and Community Services Liveable Communities grants scheme. We have conducted the literature reviews, stakeholder consultations and designed the evidence-based physical activity and nutrition intervention. Ethics approval for the feasibility trial has been granted and we have recruited an initial cohort of participants. The trial will commence in early 2018. The online learning modules have been drafted and are currently under review with external topic experts.

Future deliverables Our future plans include finalising and launching the on-line learning modules for allied health workers, conducting the feasibility trial of the 'Get Healthy!' program and using results to refine the program and trial methodology for future use in a sufficiently powered efficacy trial.

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



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

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

Short project description 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. Our specific objectives are to consult with NSW Health Mental Health services to determine and quantify the need for a tertiary intellectual disability mental health service; consult with people with intellectual disability, carers and support networks as to how this service can meet their needs and provide a timely and quality service; consult with experts in intellectual disability mental health to identify and reach consensus on key clinical priorities of the service; determine how this service can best enhance the capacity of the mainstream mental health workforce to meet the needs of people with intellectual disability and mental ill health; and identify the resources required to run such a service. This project is phase one of a larger project that aims to pilot and evaluate the effectiveness of a tertiary mental health service for people with intellectual disability in NSW.

Current state of project and achievements to date Mental health service representatives from 14 NSW Local Health Districts have completed an online survey identifying what support their services require from a tertiary service, and their views on how the service could be structured. A Delphi survey consultation was conducted with 25 intellectual disability mental health experts in NSW to reach consensus on how a tertiary service should operate.

Where the project is at An online survey is underway with family members and support networks of people with intellectual disability to identify the key clinical priorities of a tertiary service and how it should operate. We also plan to hold focus groups and interviews with people with intellectual disability to discuss their needs and views on how a tertiary service should work.

Future deliverables Publications will detail results from the consultation surveys, focus groups and interviews. A final report will summarise the views of all stakeholders on the clinical priorities of a tertiary intellectual disability mental health service, and how it could best operate.

Intellectual Disability Mental Health Core Competencies Framework Project

Project Team Claire Eagleson, Janelle Weise, Jessica Walsh & Julian Trollor

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

Current state of project and achievements to date We have now launched the Framework Manual that identifies core competencies in 11 key areas and an accompanying Toolkit that provides practical advice as to how mental health professionals can make adaptations to their practice. Two launch forums were held that included presentations by speakers with expertise in adult, and child and adolescent intellectual disability mental health, along with disability support professionals and carers. Multiple publications are reporting on results from the consultation stage of this project.

Where the project is at An evaluation of the Framework and Toolkit's effectiveness in supporting practice and attitudinal change is ongoing.

Future deliverables Publication reporting on the uptake of the Framework and Toolkit, a profile of individuals who downloaded it, and the evaluation of its effectiveness.

INTELLECTUAL DISABILITY MENTAL HEALTH CORE COMPETENCY FRAMEWORK:

A PRACTICAL TOOLKIT FOR MENTAL HEALTH PROFESSIONALS



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The Australian Longitudinal Study of Adults with Autism (ALSAA)

Project Team Samuel Arnold, Ye In (Jane) Hwang & Julian Trollor

Short Description 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 adults with autism. This study, funded by the Cooperative Research Centre for Living with Autism (Autism CRC), is following a cohort of adults with autism aged 25+, their carers/family member and a control group of community members without autism. We hope the information from this study will help guide the formation of better policies, improved service provision and generally a better understanding of life in adulthood for people with autism. 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.



Current state of project and achievements to date Almost 300 adults with autism have participated in time 1 data gathering, with on-going recruitment in time 2. Time 2 questionnaires have been revised through a comprehensive, inclusive consultation process. Publications using ALSAA data on leisure activities, aging, depression and suicide, and emotion regulation have been submitted or accepted.

Where the project is at Time 2 data gathering has commenced.

Future deliverables Publications in the near future include

An overview of the ALSAA inclusive research protocol and baseline participants characteristics

An examination of loneliness in adults with autism

An examination of medication prescribing patterns and mental health profiles

An exploration of carer's mental health

An exploration of employment in adults with autism

Undergraduate Medicine and Nursing Curriculum Development (Phase 1)

Project Team Claire Eagleson, Beth Turner & Julian Trollor

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.

Current state of project and achievements to date 14 medical and 31 nursing schools participated in the study. Results suggest that intellectual disability content taught within medical and nursing schools is highly variable and limited. Two publications outlining what intellectual disability content is taught have been published.

Where the project is at This phase of the project has been completed. With further funding we would like to develop, evaluate and implement a national education framework and implementation toolkit for nursing and medical schools. This would provide up-to-date, evidence-based teaching materials and resources to be incorporated into existing curricula.

Future deliverables We are preparing two further publications outlining how the intellectual disability content is taught and a further publication comparing the results from the current audit of medical school curricula with one completed in 1995 by Lennox and Diggins (1999).

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

Project Team Claire Eagleson, Rachael Cvejic, Janelle Weise, Jessica Walsh, Kimberley Smith & Julian Trollor,

Short Description Psychiatrists have a key role to deliver quality mental health care to people with intellectual and developmental disability (IDD). However, Australian psychiatrists have reported that they have received insufficient education in this area, and lack confidence to provide quality care for this population. To address these concerns there have been consistent calls for advanced, subspecialty training in IDD for psychiatrists. In collaboration with the Royal Australian and New Zealand College of Psychiatrists (RANZCP), this project aims to determine the current psychiatric workforce capacity and future training capacity in IDD psychiatry.

Current state of project and achievements to date Data from the RANZCP 2014 Workforce survey was analysed to estimate the size of the IDD psychiatry workforce in Australia and New Zealand. An online survey of RANZCP psychiatrists with expertise or an interest in IDD psychiatry was conducted to examine the characteristics of this workforce, gauge support for subspecialty training, and estimate future training capacity.

Where the project is at Findings suggest that there is a reasonable coverage of psychiatrists working with people with IDD in major metropolitan areas, but the majority are working only limited practice hours in this area. There is support, and appears to be training capacity available, for subspecialty training in IDD psychiatry.

Future deliverables Three publications reporting on the results from both surveys. A final report will be provided to the RANZCP which will include suggested IDD mental health core curriculum items for i) generalist and ii) specialist training.

Thinking-and-motor-skills-premutation-carriers-fragile-x

Project team Rachael Cvejic (nee Birch) & Julian Trollor,

Short description This project examined 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 included study sites based in NSW (UNSW Sydney) and Victoria (Monash University). Our research team based at 3DN lead the UNSW Sydney site, with a focus on neurocognitive and neuromotor function among adult males who carry the FMR1 premutation. Our findings have been disseminated in various formats (e.g. scientific publications; presentations to consumers, academics and health practitioners).

Where the project is at This project has been completed. We will continue to publish findings from the study.



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

Project team Liz Evans, Tanya Duckworth & Julian Trollor,

Short description The life expectancy of people with intellectual disability (ID) is increasing dramatically. Compared with the general population, people with ID 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 ID. Moreover, we currently lack a 'gold standard' approach to the diagnosis of dementia in people with ID. 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 ID, aged 40 plus. It also examines the well-being and care-giving experience of carers of older people with ID and evaluates the usefulness of selected screening questionnaires and assessment instruments for assessing dementia in people with ID. 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 includes a focus on the current pathways to care for people with ID who develop dementia, as well as a focus on producing resources to improve the recognition of dementia in people with ID.



Achievements We have written a comprehensive guideline for GPs regarding the diagnosis and management of dementia in people with ID. This guideline is designed to supplement the new NHMRC dementia guidelines and will be housed both on the 3DN website and within a larger set of guidelines surrounding dementia in special population groups.

Where the project is at We have just commenced wave 3 of data collection to existing participants in the study and begun to recruit new participants in an expanded sample.

- We have held a consumer consultation with people with ID regarding what they would like to see in resources about ageing and dementia in people with ID. The input from the consultation group was very informative for shaping the direction of the resource, which we are now working on.
- We are mid-way through compiling the relevant information from which to create an online training module for health professionals working with people with ID who may have dementia.

Future deliverables

- A Delphi process examining improving service delivery for people with ID and dementia is planned.
- Paper-based resources for people with ID and carers will be housed on the 3DN website.

Other investigators Teresa Iacono, Jennifer Torr, Perminder Sachdev, Henry Brodaty

Project ambassador Michael Sullivan.

Intellectual Disability Mental Health (IDMH) e-Learning

Project Team Kimberley Davies, Thea Kremser & Julian Trollor

Short Description This project focuses on providing an online learning resource on intellectual disability mental health for those who provide support to people with intellectual disability.

There are three portals within the website for different audiences; health professionals, disability professionals and carers. The modules in each portal have been designed specifically for each audience and their role in providing support.

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



Achievements

E-Learning for Disability Professionals

Three new modules were launched for professionals working in the disability sector.

E-Learning for Carers

Eight new modules were launched specifically for carers. The modules are arranged over three courses

Foundations

Mental health and Illness

Specific Mental Illnesses

An accompanying 'Wellbeing Record' was also launched to assist carers to identify changes in a person's wellbeing.

E-Learning for Health Professionals

There are currently 15 modules for health professionals.

Where the project is at Funding was received to develop a further 10 specialist modules for disability professionals. Building on the existing modules, these will include topics such as specific mental illnesses,

providing mental health support throughout the life course and providing psychological support through difficult situations. The modules will be released throughout 2018.

Further funding is being sought to expand the e-Learning resource for health professionals and carers.

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.



Dr Rachael Cvejic - Lecturer

Rachael is a registered psychologist and early career researcher with broad research interests including neuropsychology and neuropsychiatry. Her clinical and research experience includes working with people with mild and major neurocognitive disorders, intellectual and developmental disabilities, and inherited neurodegenerative disorders including including fragile X-associated tremor ataxia syndrome and Huntington's disease. Rachael is currently involved in a number of educational and research activities at 3DN, with a focus on: health service use of people with less common types of dementia; intellectual disability mental health; mental health workforce capacity. Qualifications: Bachelor of Psychology (Honours); Master of Brain and Mind Sciences; Ph.D.



Dr Sam Arnold - Postdoctoral Research Fellow

Sam is a Postdoctoral Research Fellow in Program 3 of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), the world's first national, cooperative research effort focused on Autism. He is a registered psychologist with a background in supporting adults with intellectual disability, acquired brain injury or dual diagnosis in community settings. His position is based at the Department of Developmental Disability Neuropsychiatry (3DN), University of New South Wales. He formerly worked as a Research Fellow at the Centre for Disability Studies (CDS), University of Sydney. He completed his PhD in 2016 on the "Measurement and Conceptualisation of Support Needs". He also works as a casual academic with the Western Sydney University. Sam previously provided counselling and clinical services at the NSW Developmental Disability Health Unit (DDHU) and the Northern Sydney Intellectual Disability Health Team (NIDH). He previously held an additional role of part time Project Officer Evaluation at NIDH, and previously provided crisis telephone counselling with LifeLine Penrith and Parramatta. Sam conducts education about research principles, psychology and disability studies, sexuality, behaviour of concern, person-centredness and actively supporting people to live in the community. In 2008 Sam won the Branko Cesnik Scientific Award for best scientific paper at the Health Informatics Society of Australia (HISA) Conference and in 2011 won the Inaugural Bob Weaver Award for presentation with most passion and promise at the Professional Association of Nurses in Developmental Disability Australia (PANDDA) Conference. Qualifications: BA(Psych) Macq, PGDip(Psych) MA(Analytical Psych) WSU, PhD USyd, MAPS



Ms Tanya Duckworth - Research Assistant

Tanya is currently the Research Assistant on the Sage-ID Study. She is also part of the Older Australian Twins Study (OATS) Collaborative Research Team and the Amyloid Imaging Study for the UNSW School of Psychiatry, Faculty of Medicine, where she has worked as the Research Administrative Assistant (2010-2012) and is also currently employed as the NSW Research Assistant. Tanya completed her Bachelor of Arts (Honours) in Psychology in 2012, through Central Queensland University. Her honours thesis was in the area of neuroinflammation and genetics, titled Heritability of Excessive Daytime Sleepiness and Associated Inflammation in Older Australian Twins. This research project investigated the genetic and environmental contribution of pro-inflammatory cytokine interleukin-6 (IL-6) to a common symptom of neurodegenerative disease, excessive daytime sleepiness (EDS). The research was undertaken as part of the Older Australian Twins Study under the supervision of Professor Julian Trollor, Head of 3DN, Chair of Intellectual Disability Mental Health and Chief Investigator on OATS (UNSW), and Professor Greg Roach of the Appleton Institute, Adelaide (CQU). Qualifications: Bachelor of Fine Arts; Bachelor of Arts in Psychology (Honours); Master of Brain Mind Sciences.



Ms Claire Eagleson - Project Officer

Claire is currently working as a Project Officer managing three 3DN projects. The first involves the development and implementation of 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. The latest project involves working with the Royal Australian and New Zealand College of Psychiatrists looking at current workforce capacity in the area of intellectual and developmental disability mental health, and the potential for the development of subspecialty training in this area for future psychiatrists. Previously Claire has worked at the Institute of Psychiatry, Psychology and Neuroscience, London managing a program of research aimed at examining cognitive maintaining factors of worry in emotional disorders, and at the Brain & Mind Research Institute assessing the efficacy of an e-Health program for generalised anxiety versus pharmacological treatment. Qualifications: Bachelor of Psychology (Hons) and Master of Psychology (Clinical) from the University of NSW.



Dr Liz Evans - Research Fellow

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

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.

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.



Miss Jane Yein Hwang – Research Assistant and PhD Student

Jane is a PhD student & Research Assistant 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 Thea Kremser - Project Officer

B Psych (Hons), Cert IV TAA Thea has a background in public health research and project management (physical activity and cancer control), and also has clinical experience in community mental health and counselling. She has been responsible for counselling and triage in a community setting, where her clients included adults with intellectual disability. Thea has a strong interest in adult education and professional development, and has developed and provided training in cancer control, mental health triage, and counselling.



Mr Daniel Pua - Administrative Assistant

Dan 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). Dan has a key role in the department's multimedia portfolio, maintains the 3DN website, assists in a number of projects and provides limited tech support to the department.



Dr Simone Reppermund - Senior Research Fellow

Dr Simone Reppermund is a UNSW Scientia Fellow within the School of Psychiatry. Her area of research is cognitive disorders with a focus on mental health and ageing. Simone has a PhD in Psychology and worked previously in the field of depression and cognitive function at the Max Planck Institute of Psychiatry in Munich until 2008 before she moved to Australia. From 2008-2014 she worked as a research fellow at the Centre for Healthy Brain Ageing, UNSW Australia, where she managed a large longitudinal study (Sydney Memory and Ageing Study) combining neuropsychological, medical, environmental and genetic components to identify risk factors for cognitive decline. Her research interests include depression, cognitive impairment, everyday activities in old age, successful ageing and mental health in intellectual disability. Qualifications: Dipl.-Psych., PhD



Ms Rachel Roth – Administrative Officer

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



Dr Carmela Salomon - Project Officer

Carmela Salomon is a 3DN Project Officer working on a range of initiatives to support responsible psychotropic prescribing and cardiometabolic health in people with intellectual disability. Her PhD research (completed in 2014) explored mental health consumer experiences of antipsychotic discontinuation. Antipsychotic discontinuation is associated with a number of potential side effects including sleep disruption and other physical, cognitive, emotional and psychotic withdrawal syndromes. As well as collecting novel first person characterisations of these syndromes, her research focused on identifying coping strategies and suggestions for mental health service change from people with lived experience of medication discontinuation. In addition to a PhD in Health Sciences, she holds a Post-Graduate Diploma in Advanced Mental Health Nursing and a Bachelor of Nursing Science. Carmela has clinical experience in community and inpatient mental health settings and is passionate about increasing consumer input in mental health research and system management. Qualifications: PhD (UoM); PGrad Dip Advanced Clinical Nursing- Mental Health (UoM); Bachelor of Nursing Science (JCU)

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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) e-learning project. The aim of this project is to improve mental health outcomes for people with intellectual disability by improving knowledge of mental disorders in health and disability professionals. Previously, Kimberley completed an honours degree in Psychology at the University of Sheffield (UK), and a Master's Degree in Psychological Research Methods at The University of Liverpool (UK), where her thesis examined maternal interactions and PTSD.

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: 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.



Ms Janelle Weise (née Govett) - Project Officer & PhD Candidate

Janelle Weise is a Project Officer working on a range of initiatives to enhance the capacity of the health and mental health workforce to deliver accessible, effective and efficient healthcare to people with intellectual disability. She has a Bachelor of Applied Science (Occupational Therapy) (Hons) and a Masters of Public Health and has worked across clinical, service delivery and managerial roles within the disability and health sectors. Janelle is passionate about addressing the inequitable access to healthcare and poor health outcomes experienced by people with Intellectual Disability.



Ms Erin Whittle - Research Officer & PhD Candidate

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.

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.

Students



Ms Snow Li - PhD Candidate

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.



Ms Bronwyn Newman - PhD Candidate

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

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



Dawn Ee - Medical student

Dawn is a 4th year medical student at UNSW undertaking her Independent Learning Project at 3DN in 2017. She is involved in the Australian Longitudinal Study of Adults with Autism (ALSAA) in Program 3 by the Cooperative Research Centre for Living with Autism (Autism CRC). Her interest in autism and developmental disability grew through her involvement as a Special Olympics volunteer in her school days. This is also her motivation for pursuing medicine. Dawn is interested in the experience of friendship and her project will explore the determinants of loneliness in adults with

autism.

Other PhD Candidates within our Department

Julian Trofimovs - PhD

Janelle Weise – PhD and Project Officer (Bio above)

Erin Whittle – PhD and Research Officer (Bio above)

Jane Hwang – PhD and Research Assistant (Bio above)

Research Grants and Funding

Tier 1 Funding

- NHMRC Project Grant APP1123033; 2017 – 2021; Total Funding \$1,216,388.80. Understanding health service system needs for people with intellectual disability. (Trollor, Vajdic, Lennox, Moorin, Reppermund)

Research Funding

- CRC Autism; 2017 – 2021; \$786,309. Base Resources Funding Program 3 (Trollor, Foley)

Project Funding

- NSW Health, South Eastern Sydney Local Health District, 2017 -2018 \$202,686 MySigns (Trollor)
- NSW Health, South Eastern Sydney Local Health District 2017 – 2018 \$158,171 Building on MyCompass to develop an on-line treatment for Anxiety and Depression for those with borderline to mild intellectual disability (Christensen, Trollor)
- Ageing, Disability and Home Care ADHC; 2017-2018; \$258,066.50 Intellectual Disability Mental Health e-Learning for Disability Professionals (Trollor)

Other Funding

- Agency for Clinical Innovation; 2017; \$7,462.25; Sponsorship 2018 National Roundtable (Trollor)
- NSW Health; 2017; \$5,000; Sponsorship 2017 Research to Action Day; (Trollor)
- Ageing, Disability and Home Care ADHC; \$5,000; Sponsorship 2017 Research to Action Day; (Trollor)

Publications

- Aerts, L., Heffernan, M., Kochan, N.A., Crawford, J.D., Draper, B., Trollor, J.N., Sachdev, P.S., Brodaty, H. Effects of MCI subtype and reversion on progression to dementia in a community sample. *NEUROLOGY*, 2017; 88(23), 2225-2232.
- Armstrong, N.J., Mather, K.A., Thalamuthu, A., Wright, M.J., Trollor, J.N., Ames, D., Brodaty, H., Schofield, P.R., Sachdev, P.S., Kwok, J.B. Aging, exceptional longevity and comparisons of the Hannum and Horvath epigenetic clocks. *Epigenomics*, 2017; 9(5).
- Birch, R.C., Cohen, J., Trollor, J.N. Fragile X-associated disorders: Don't miss them. *Australian family physician*, 2017; 46(7), 487-491.
- Birch, R.C., Trollor, J.N. Action Tremor, Impaired Balance, and Executive Dysfunction in Midlife. *JAMA Neurol*, 2017.
- Birch, R.C., Hocking, D.R., Cornish, K.M., Menant, J.C., Lord, S.R., Georgiou-Karistianis, N., Godler, D.E., Wen, W., Rogers, C., Trollor, J.N. Selective subcortical contributions to gait impairments in males with the FMR1 premutation. *Journal of Neurology, Neurosurgery and Psychiatry*, 2017.
- Foley, K.R., Pollack, A.J., Britt, H.C., Lennox, N.G., Trollor, J.N. General practice encounters for young patients with autism spectrum disorder in Australia. *Autism*, 2017, 1362361317702560.
- Hocking, D.R., Birch, R.C., Bui, Q.M., Menant, J.C., Lord, S.R., Georgiou-Karistianis, N., Godler, D.E., Wen, W., Hackett, A., Rogers, C., Trollor, J.N. Cerebellar volume mediates the relationship between FMR1 mRNA levels and voluntary step initiation in males with the premutation. *Neurobiol Aging*, 2017; 50, 5-12.
- Hwang, Y.I.J., Foley, K.R., Trollor, J.N. Aging well on the autism spectrum: the perspectives of autistic adults and carers. *Int Psychogeriatr*, 2017, 1-14.
- Koncz, R., Mohan, A., Dawes, L., Thalamuthu, A., Wright, M., Ames, D., Lee, T., Wen, W., Sachdev, P.S. Incidental findings on cerebral MRI in twins: the Older Australian Twins Study. *Brain Imaging and Behavior: an international journal*, 2017, 1-10.

- Salomon, S., Evans, E. & Trollor, J. (2017). 'Barriers and enablers of healthy lifestyles for adults with an intellectual disability: a systematic review'. *Journal of Intellectual Disability Research* (Under Review)
- Salomon, S., Bellamy, J., Evans, E., Teasdale, S., Samaras, K., Ward, P.B., Hsu, M., Trollor, J. (2017). 'it just slips away': a qualitative exploration of barriers and enablers of healthy lifestyle engagement for older Australians with intellectual disability. *Research and Practice in Intellectual and Developmental Disabilities* (Under Review)
- Trollor, J., Srasuebkul, P., Xu, H., Howlett, S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open*, 2017; 7(2), e013489.
- Trollor, J.N., Eagleson, C., Weise, J., McKay, R. Development and dissemination of a core competency framework. *Journal of Mental Health Training, Education and Practice*, 2017; 12(4), 237-248.
- Weise, J., Fisher, K.R., Trollor, J. Establishing Core Mental Health Workforce Attributes for the Effective Mental Health Care of People with an Intellectual Disability and Co-occurring Mental Ill Health. *Journal of Applied Research in Intellectual Disabilities*, 2017.
- Weise, J., Pollack, A., Britt, H., Trollor, J.N. Primary health care for people with an intellectual disability: an exploration of consultations, problems identified, and their management in Australia. *Journal of Intellectual Disability Research*, 2017.
- Weise, J., Trollor, J.N. Preparedness and training needs of an Australian public mental health workforce in intellectual disability mental health. *Journal of Intellectual and Developmental Disability*, 2017, 1-10.

Published Abstracts

- Cations, M., Withall, A., White, F., Trollor, J., Loy, C., Gonski, P., Brodaty, H., Draper, B. WHY AREN'T PEOPLE WITH YOUNG ONSET DEMENTIA AND THEIR CAREGIVERS USING FORMAL SERVICES? *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 2017; 1(suppl_1), 1403-1403.
- Ciobanu, L., Sachdev, P.S., Trollor, J.N., Reppermund, S., Thalamuthu, A., Mather, K.A., Cohen-Woods, S., Stacey, D., Toben, C., Baune, B. Genome-Wide Gene Expression Signature Of Depression. *European Neuropsychopharmacology*, 2017; 27, S484.
- Ciobanu, L., Sachdev, P.S., Trollor, J.N., Reppermund, S., Thalamuthu, A., Mather, K.A., Cohen-Woods, S., Toben, C., Stacey, D., Baune, B. Transcriptome Signature of Depression. *European Neuropsychopharmacology*, 2017; 27, S513.
- Eagleson, C., Weise, J., Birch, R., Trollor, J. EQUIPPING PSYCHIATRISTS TO MEET THE MENTAL HEALTH NEEDS OF PEOPLE WITH AN INTELLECTUAL DISABILITY. Paper presented at the Australian and New Zealand Journal of Psychiatry, 2017. 51, 47-47.
- Harrison, F., Aerts, L., Seeher, K.M., Lloyd, A., Trollor, J.N., Guastella, A., Brodaty, H. SYSTEMATIC REVIEW OF ASSOCIATIONS BETWEEN BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA AND CYTOKINES. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 2017; 13(7), P1024.
- Trollor, J., Livingstone, A., Salomon, C., Weise, J., Eagleson, C., Walsh, J., Birch, R. INITIATIVES TO BUILD WORKFORCE CAPACITY IN INTELLECTUAL DISABILITY *MENTAL HEALTH*. Paper presented at the Australian and New Zealand Journal of Psychiatry, 2017. 51, 46-46.
- Trollor, J., Srasuebkul, P., Heintze, T., Reeve, R., Reppermund, S. HIGHER MENTAL HEALTH SERVICES USE IN PEOPLE WITH INTELLECTUAL DISABILITY INDICATES A NEED TO BETTER EQUIP SERVICES. Paper presented at the Australian and New Zealand Journal of Psychiatry, 2017. 51, 33-33.

Other Publications

- [Policy analysis: Summary for Policy Makers](#)
- [Policy analysis: Summary for Service Providers](#)
- [Policy analysis: Plain English Summary](#)
- [Making Mental Health Policy Inclusive of People with Intellectual Disability](#)
- NSW Institute of Psychiatry / HETI Podcasts
- Evans, E., Duckworth, T., (2017). Dementia in people with Down syndrome: What does the research tell us? Voice 5(3): 5-8. This translational article, written primarily for family members, carers and service providers, was the feature article in the Voice special issue on Ageing and Future Planning

Conference Presentations & Lectures

National Audience

Keynote

- Improving Mental Health and Wellbeing for People with Intellectual Disability: From Research to Practice, Trollor, J. Psych DD Conference, Sydney, 24th November 2017

Invited

- Improving Mental Health Outcomes For People with Intellectual Disability Trollor, J., Grand Rounds, Royal North Shore Hospital, Sydney 7 December 2017
- Assessment and Management of Epileptic Encephalopathies: A Neuropsychiatrist's Perspective, Trollor, J., Epilepsy Society of Australia ASM, 1 November 2017

- Mental Health in People with Intellectual Disability, Priorities and Progress, Trollor,J., RANZCP Western Australia Psychiatry Special Interest Group, 30 October 2017
- Improving Co-ordination Between Services to Support People with Intellectual Disability and Mental Illness. Trollor,J., Psychiatry Ground Rounds, Prince of Wales Hospital, 9 October 2017
- What Can 'Big Data' tell us about Health Inequalities for people with Intellectual Disability, Trollor,J., Brain Sciences Colloquium, Sydney, 4 September 2017
- Collaborative mental health care to support adults on the autism spectrum, Trollor,J., MHPN Collaborative Mental Health Care, Webinar, 5 June 2017
- Assessing and Managing Challenging Behaviour, Trollor,J., HETI Health Education Training Institute, On-line, 25 May 2017
- Understanding Intellectual Disability and Mental Health, Trollor,J., HETI Health Education Training Institute, On-line, 18 May 2017
- Assessment & Management of Mental Ill Health in People with ID, Trollor,J., HETI Health Education Training Institute, On-line, 18 May 2017
- Exposing the Health Gap for People with Intellectual Disability, Trollor,J., AADDM Conference 2017, Adelaide, 4th May 2017
- Initiatives to Build Workforce Capacity in Intellectual Disability Mental Health, Trollor,J., Salomon,C., Weise,J., Eagleson,C., Walsh,J., Birch,R., RANZCP Congress 2017, Adelaide, 2 May 2017
- Responding to Health Inequalities in People with Intellectual Disability, Trollor,J., NSW Ombudsman, 2 May 2017
- Higher Mental Health Services Utilization with Intellectual Disability Indicates a Need to Better Equip Services, Trollor,J., Srasuebku,P., Heintze,T., Reeve,R., Reppermund,S., RANZCP Congress 2017, Adelaide, 1 May 2017
- Integrating Data on Mental Health Service Provision to Improve Mental Health Services for People with Intellectual Disability, Trollor,J., RANZCP Congress 2017, Adelaide, 1 May 2017

- Using Big Data to Understand Health and Wellbeing in People with Developmental Disabilities, Trollor,J., QLD Health, Queensland, 7 March 2017
- Exposing the health gap for people with intellectual disability, Trollor,J., Parliamentary Fourum, Parliament House, Sydney, NSW, 21 February 2017
- Addressing health inequalities experienced by people with intellectual disability, Trollor.J., 21 Disability Council NSW Parliament House, Sydney, 21 February 2017

Other

- Poster presented to the Australian Dementia Forum Evans, E., Black, C. and Trollor, J. Dementia Screeners for people with Intellectual Disability. Melbourne, October 2017.

Regular Teaching Contributions

- Intellectual Disability in Medical Practice, Trollor, J., Kremser, T., Lecture for Phase 1 Medical Students, UNSW Australia, 16 May 2017

Acknowledgements

Thank you to all 3DN Staff and Partners.



Bequest Page

Support Our Research

We appreciate your interest in our projects and research.

Donations to our department will assist in research for people with Intellectual Disabilities, to ensure the highest attainable standard of mental health and wellbeing for people with intellectual or developmental disability.

Donations to 3DN

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

Or via dddn@unsw.edu.au.

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