



We are pleased to be able to present you with the interim programme and speaker details for the AADDMM18 conference, further developments will be added as they come to hand. Note that details of the programme may change. We are grateful to NSW Health for providing funding for Dr Seth Keller's travel.

Please register online at aaddm.com.au/2018-aaddm-conference

DAY 1 - THURSDAY, SEPTEMBER 6, 2018

Time	
1:00 pm	Registration and coffee/tea
1:30-1:45 pm	Welcome
1:45-3:15 pm	<p>Changing health outcomes: The Big Picture Panel and presentations to include:</p> <ul style="list-style-type: none"> ▪ Dr Seth Keller, Past President of the American Academy of Developmental Medicine and Dentistry ▪ Prof Timothy Geraghty, President Australasian Faculty Rehabilitation Medicine ▪ Dr Kym Jenkins, President Royal Australasian College Psychiatry ▪ Ms Louise Farrell, Social Policy, NSW Health
3:15-3:40 pm	Afternoon tea
3:40-5:00 pm	<p>Clinical Genomics: Providing answers for families</p> <ul style="list-style-type: none"> ▪ Clinical Genomics: A cost effective way to provide answers for families who have a child with Intellectual Disability – A/Prof Tony Roscioli ▪ Genomics at the coal face: a clinical geneticist's perspective of the genomic revolution in neurodevelopmental disorders - Dr Emma Palmer ▪ New prospects in Down Syndrome - Prof Stewart Einfeld
5:00-5:20 pm	<p>Medicinal cannabis in children with complex epilepsy</p> <ul style="list-style-type: none"> ▪ Dr John Lawson
5:20-5:30 pm	Bob Davis Award
5:30-7:30 pm	Cocktail function

DAY 2 - FRIDAY, SEPTEMBER 7, 2018

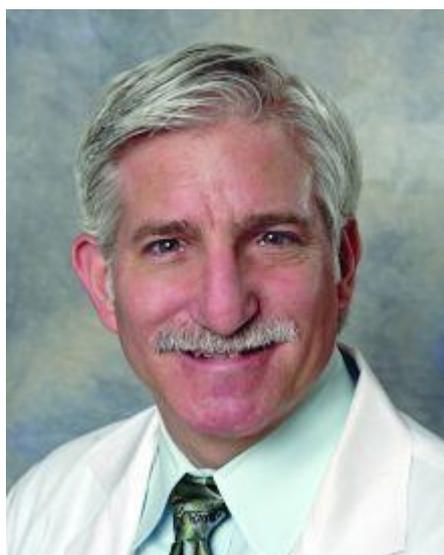
Time	Stream A	Stream B
8:30-9:00 am	Registration and coffee/tea	
9:00-10:20 am	End of Life Care <ul style="list-style-type: none"> Practices in Americans with Intellectual and Developmental Disabilities - Dr Seth Keller Hospital service use in the last year of life by Western Australians with intellectual disability (ID) - Dr Helen Leonard End of life Care Decisions for people represented by the Public Guardian - Ms Anna Gauci Talking about end of life - Prof Roger Stancliffe 	Health services innovation <ul style="list-style-type: none"> Management of nocturnal enuresis in children and adolescents with intellectual disability - A/Prof Patrina Caldwell Does Environment Impact On Learning and Wellbeing? - Ms Lesley Bruce My Signs – an app to facilitate mental health assessment of people with intellectual disability - Ms Thea Kremser Healthy Mind – an online Easy Read tool for building good mental health - Mr Chris Rule
10:20-10:50 am	Morning tea	
10:50 am-12:10 pm	Clinical hot topics <ul style="list-style-type: none"> Interoception in Clinical Practice. A new perspective on using interoception in clinical practice to deescalate behaviour - Ms Nicole Kyrkou & Dr Christel Burton Be a Diamond not a Kangaroo - Ms Maree MacDermid The Functional Side of Disability - Ms Kate McNamara 	Health services innovation <ul style="list-style-type: none"> Improving transition of young people for botulinum toxin A spasticity management - Dr Simon Paget Admission2Discharge Together – Improving hospital journeys and health outcomes for people with intellectual disability - Ms Lif O'Connor Building capability in NSW Health services for people with ID: The Essentials - Ms Tracey Szanto Functional assessments in clinical practice - Dr Amelia Lewis
12:10-1:10 pm	Lunch	
1:10-2:40 pm	From premature death to inclusion in health promotion and prevention <ul style="list-style-type: none"> Using big data to understand premature mortality and its drivers in people with intellectual and developmental disabilities - Prof Julian Trollor Mortality of people with intellectual disability – a population based study - Dr Seeta Durvasula Key findings from 15 years of reviewing the deaths of people with disability in residential care - Ms Kathryn McKenzie 	
2:40-3:00 pm	Afternoon tea	
3:00-4:30 pm	Can't we do better? Improving outcomes for young people at risk of contact with juvenile justice <ul style="list-style-type: none"> Using big data to understand the representation and profile of people with intellectual disability in NSW prisons - Prof Julian Trollor Juvenile Justice NSW: Supporting Young People with an Intellectual Disability or Cognitive Impairment - Ms Ruth Marshall 	
4:30-4:45 pm	Closing remarks <ul style="list-style-type: none"> Dr Jacqueline Small 	

KEYNOTE SPEAKER

Dr Seth M. Keller, MD, is a board certified neurologist in private practice with Advocare Neurology of South Jersey. He specializes in the evaluation and care of adults with Intellectual and Developmental Disabilities (I/DD) with neurologic complications. He cares for individuals with I/DD both in the community as well in New Jersey's ICF/DD centers. Dr Keller is on the Executive Board of the Arc of Burlington County as well as on the board for The Arc of New Jersey Mainstreaming Medical Care Board.

Dr Keller is the Past President of the American Academy of Developmental Medicine and Dentistry (AADMD) and is the co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). Dr Keller is also the director of the Adults with I/DD Special Interest Group in the American Academy of Neurology (AAN). He is actively involved in national and international I/DD health education as a speaker and webinar and workshop participant.

Raised in Philadelphia, PA, Keller received his bachelor's degree from Temple University, earned his medical degree from The George Washington University School of Medicine in 1989, and completed his neurology internship and residency at Bethesda Naval Hospital. He also served as a Navy neurologist at the U.S. Naval Hospital in Okinawa, Japan.



Thursday, 1:45-3:15pm

Changing health outcomes: The Big Picture

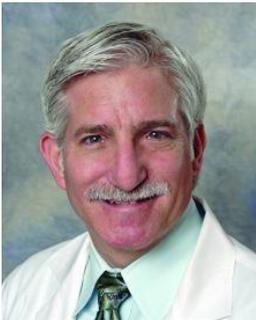
Chair: Prof Julian Trollor

Chair of Intellectual Disability Mental Health and Head, Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Sydney.

HOW TO DELIVER QUALITY HEALTH SERVICES TO THOSE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Dr Seth Keller

Past President of the American Academy of Developmental Medicine and Dentistry (AADMD). Co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG).



Individuals with Intellectual and Developmental Disabilities (IDD) often have complex and challenging health difficulties. Due to a lack of consistent and available expertise in this area of healthcare to this population, patient and family satisfaction is often reduced as well as health outcomes. This presentation will provide an overview on the progress and plans within the US health system to help tackle this universal dilemma.

About the speaker

Seth Keller is Co-Chair, National Task Group on Intellectual Disabilities and Dementia Practices. Chair, Special Interest Group Adult IDD, American Academy of Neurology. Past President, American Academy of Developmental Medicine and Dentistry

EDUCATION AND ADVOCACY ON DISABILITY ISSUES – CURRENT ACTIVITY IN THE ROYAL AUSTRALASIAN COLLEGE OF PHYSICIANS

Prof Tim Geraghty

President Australasian Faculty Rehabilitation Medicine, Royal Australasian College of Physicians; Division of Rehabilitation, Princess Alexandra Hospital, Metro South Health.

The introduction and progressive rollout of the National Disability Insurance Scheme (NDIS) since July 2013 has been one of the factors that has increased the level of awareness and understanding in general community regarding the issues facing people with disability (including developmental disability) in Australia. Over this period, there has also been an increase in disability-related and focussed activity in the Royal Australasian College of Physicians (RACP), in both the areas of education and policy and advocacy. Encouragingly, this disability-awareness (for want of a better term) seems to be slowly extending beyond the predictable sections of the College, such as Paediatrics and Child Health or Rehabilitation Medicine, and into its broader psyche.



About the speaker

Tim Geraghty is a Rehabilitation Medicine Physician and Medical Chair: Division of Rehabilitation, Princess Alexandra Hospital, Brisbane. He has been a Staff Specialist in the Queensland Spinal Cord Injuries Service for almost 20 years. He has a keen interest in strategic planning in rehabilitation services with the ultimate aim of improving services for people with a disability. He is the current President, Australasian Faculty of Rehabilitation Medicine (RACP).

RANZCP ACTIONS TO IMPROVE THE MENTAL HEALTH OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

Dr Kym Jenkins

President, Royal Australian and New Zealand College of Psychiatry.

The RANZCP is committed to understanding the psychiatry of intellectual and developmental disorders and recognises the special needs of this population, and in 2010 the RANZCP established the Section of Psychiatry of Intellectual and Developmental Disorders. This presentation will outline how the RANZCP is addressing implications for training, professional development and healthcare of this population across the lifespan, given the poor mental health and high rates of comorbidities experienced by this group.

About the speaker

Dr Kym Jenkins, President, RANZCP, has worked as a Psychiatrist across both public and private sectors. She has clinical and academic interests in physician health, professionalism and education. Dr Jenkins is keen to encourage interest in and foster educational opportunities in developmental disability.



MEETING THE NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITY IN THE NSW HEALTH SYSTEM

Ms Louise Farrell

Director Priority Populations, Health and Social Policy Branch, NSW Health.

The NSW Health system has a universal obligation to provide safe and high quality care to the NSW population, including people who have a disability. The Ministry of Health will outline the policy context for providing universal health care for people intellectual disability in the NSW health system as well as additional supports for people with an intellectual disability who have more complex needs.

About the speaker

Louise Farrell is the Director of the Priority Programs Team in Health and Social Policy Branch in the NSW Ministry of Health. Louise has worked in population health for more than 15 years across a range of areas including diabetes prevention, promoting a healthy weight, engagement with general practice and more recently palliative care, disability and carers.

Thursday, 3:40-5:00pm

Clinical Genomics: Providing answers for families

Chair: Prof W Ted Brown

Visiting Professor, Brain and Mind Research Institute, University of Sydney and Immediate Past Director Institute of Basic Research in Developmental Disabilities, Staten Island, New York.

CLINICAL GENOMICS: A COST EFFECTIVE WAY TO PROVIDE ANSWERS FOR FAMILIES WHO HAVE A CHILD WITH INTELLECTUAL DISABILITY

A/Prof Tony Roscioli

PhD FRACP FRCPath(UK). Staff Specialist in Clinical Genetics, Sydney Children's Hospital. Team Leader Neurogenomics, Neuroscience Research Australia (NeuRA) and Prince of Wales Clinical School UNSW.



Whole exome sequencing (WES) has become the standard of care for genetic services particularly for Intellectual Disability (ID). The results of the first 500 clinical exomes performed at the Randwick Genetic Laboratories are presented. This demonstrates that WES is characterized by high levels of patient safety, cost-effectiveness and clinical utility.

About the speaker

A/Prof Roscioli's clinical training has been in the fields of paediatric internal medicine and human genetics with an emphasis on intellectual disability and craniofacial malformations. He was recently awarded a fellowship of the UK College of Pathologists and leads a CRE and AGHA flagship in neurocognitive disorders.

GENOMICS AT THE COAL FACE: A CLINICAL GENETICIST'S PERSPECTIVE OF THE GENOMIC REVOLUTION IN NEURODEVELOPMENTAL DISORDERS

Dr Elizabeth Emma Palmer

Genetics of Learning Disability Service, Hunter Genetics, Waratah, School of Women's and Children's Health, University of New South Wales, The Garvan Institute for Medical Research, and Department of Medical Genetics, Sydney Children's Hospital.

Recent advances in next generation DNA sequencing (NGS) combined with databases that allow sharing of clinical and genotypic information between clinicians and researchers have led to an exponential increase in clinical diagnoses for children and adults with neurodevelopmental disorders. A major challenge is how we can best integrate this new genetic technology into the clinic. I will highlight our recent research evaluating the cost-effectiveness and clinical utility of NGS. The complexities of the consent process, and our recent collaborative research developing Easy Read resources for individuals with neurodevelopmental disorders, will be discussed. I will also present collaborative work delineating new neurodevelopmental disorders and information and support resources for newly diagnosed families and their clinicians.



About the speaker

Emma Palmer is a Clinical Geneticist working for the Genetics of Learning Disability service, a NSW state wide organisation that sees families with inherited genetic causes of intellectual disability and autism. She is also a clinical researcher with an interest in the genetics of epilepsy and intellectual disability, and member of the research group CoGenes based at Sydney Children's Hospital. She is a visiting scientist at the Garvan Institute in Sydney in the translational genomics unit.

NEW PROSPECTS IN DOWN SYNDROME

Prof Stewart Einfeld

Child Psychiatrist, Brain and Mind Research Institute.



Recent research has given new insights into the basic biology of Down syndrome revealing the mechanisms by which Trisomy 21 causes the phenotype. This has allowed investigation of potential therapeutic interventions with the prospect of major reduction of disability for the first time. We will describe our current research program in this area.

About the speaker

Stewart Einfeld is a child and adolescent psychiatrist at the Brain and Mind Centre, University of Sydney. His research clinical interests are in developmental disabilities including psychopathology and genetic syndromes.

Thursday 5:00-5:20pm

Medicinal cannabis in children with complex epilepsy

CANNABINOIDS FOR CHILDREN WITH COMPLEX EPILEPSY

Dr John Lawson

B.Med FRACP PhD. Paediatric Neurologist, Sydney Children's Hospital, Randwick.

Cutting edge research into the impact of cannabinoids for children with complex epilepsy and implications for clinical practice.

About the speaker

John Lawson is a Paediatric neurologist at Sydney Children's Hospital, Randwick and Associate Senior Lecturer, University of NSW. Major clinical and research focus is childhood epilepsy; including neuroimaging, social and psychological effects. Principal investigator in studies of medicinal cannabis in epilepsy, tuberous sclerosis including novel therapeutic agents.



Thursday 5:20-5:30pm

Bob Davis Award

Chair Dr Jacqueline Small

President AADDM and Developmental Paediatrician, Disability Specialist Unit, SLHD

To be announced. Established in 2015 and bestowed annually, this award recognises medical, other health professionals or individuals who have made substantial contributions to the healthcare of people with intellectual or developmental disability in Australia. The contributions may be in the areas of advocacy, clinical practice, research or education.

Friday 9:00-10:20am

End of Life Care

Chair: Ms Maria Heaton

Carer, CoChair Agency for Clinical Innovation, Intellectual Disability Network, NSW Health and Paediatric Palliative Care Nurse, Sydney Children's Hospital Randwick.

END OF LIFE CARE PRACTICES IN AMERICANS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (IDD)

Dr Seth Keller

Past President of the American Academy of Developmental Medicine and Dentistry (AADMD). Co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG).

Individuals with Intellectual and Developmental Disabilities (IDD) are living longer than ever before because of the greater appreciation for their quality of life and value as people with who deserve respect and dignity. Despite this, health complications all too often arise and the need to make important end of life decisions eventually needs to be made. There are a number of particular personal, social, legal, cultural and health issues that are all taken into consideration when end of life discussions are made. An American perspective on how this issue is handled will be reviewed.

HOSPITAL SERVICE USE IN THE LAST YEAR OF LIFE BY WESTERN AUSTRALIANS WITH INTELLECTUAL DISABILITY

Dr Helen Leonard

NHMRC Research Fellow, Telethon Kids Institute.



In this retrospective matched cohort study, of 591 people with ID dying between 2009 to 2013, it was found that they attended emergency departments more frequently but were hospitalized less frequently than the general population prior to their deaths. There is a need for improvements in access and coordination of healthcare for adults with ID.

About the speaker

Dr Leonard is a medically trained epidemiologist and NHMRC Senior Research Fellow. Committed to improving the health and quality of life of those affected and their families, she has established a multidisciplinary research group in childhood disability and co-authored over 250 publications.

END OF LIFE CARE DECISIONS FOR PEOPLE REPRESENTED BY THE PUBLIC GUARDIAN

Anna Gauci

Acting Assistant Public Guardian, Advocacy and Policy

The Public Guardian represents people with impaired decision making ability by making health and lifestyle decisions. This includes end of life care decisions. People with disability have the right to die with dignity and the right to access the same medical services and treatment available to the rest of the community, irrespective of age, disability, place of residence, socio economic status, cultural background or legal status. This session discusses the Public Guardian's approach to decision making about a persons end of life care, planning and treatment in line with the Guardianship Act 1987.

About the speaker

Anna is currently acting in the position of Assistant Public Guardian - Advocacy and Policy. She has worked at the Office of the Public Guardian for over 10 years as a guardian, managing and investigating complaints and providing information to stakeholders about guardianship and planning ahead. Her background in Occupational Therapy sparked her interest in working with and representing the rights of people with disability.



TALKING ABOUT END OF LIFE

Professor Roger Stancliffe

Professor of Intellectual Disability, Centre for Disability Research and Policy (Leader, Disability Services workstream), Course Director, Master of Health Science (Developmental Disability). Faculty of Health Sciences, University of Sydney.



People with intellectual disability have the right to know about dying and death, but carers fear that the person will be upset, so they avoid these topics. We found that talking about dying and death did not make people more fearful, anxious, or depressed. I will introduce our free online resource TEL *Talking end of life* <https://www.caresearch.com.au/TEL/> designed to help disability staff teach people with intellectual disability about end of life.

About the speaker

Roger is based at the University of Sydney's *Centre for Disability Research and Policy*. His research focuses on making a difference in the everyday lives of people with intellectual and developmental disability, including research on ageing and end of life.

Friday 9:00-10:30am

Health Services Innovation

Chair: Dr Linda Mann

General Practitioner at Your Doctors and VMO at RPAH in the Young Parents clinic

MANAGEMENT OF NOCTURNAL ENURESIS IN CHILDREN AND ADOLESCENTS WITH INTELLECTUAL DISABILITY

A/Prof Patrina Caldwell

Senior Staff Specialist Centre for Kidney Research & Discipline of Child and Adolescent Health, University of Sydney.

Achieving urinary continence is a milestone which can be more difficult to children and young people with developmental disabilities to achieve. Attainment of this milestone is possible for many, improving young people's independence and quality of life. This short, practical talk will focus on how to assess whether a young person with a developmental disability is ready to address their enuresis and strategies for treating the enuresis.



About the speaker

Patrina is a Senior Staff Specialist at the Children's Hospital at Westmead and an Associate Professor in the Discipline of Child and Adolescent Health, University of Sydney. She heads the multidisciplinary urinary continence service at CHW, caring for children across NSW.

DOES ENVIRONMENT IMPACT ON LEARNING AND WELLBEING?

Ms Lesley Bruce

Principal Cairnsfoot School for Specific Purposes.



An insight into how a custom designed school can both impact and support students, staff and families to connect thrive and succeed. The relocation of Cairnsfoot School has presented opportunities to challenge and expand our notion of a learning environment that enhances student outcomes.

About the speaker

Lesley is Principal of Cairnsfoot School. Her knowledge and expertise was used to facilitate certain design aspects of the new school and she subsequently led the school community through a successful relocation process. Her experience spans the fields of Early Childhood, Primary and Special Education.

MY SIGNS – AN APP TO FACILITATE MENTAL HEALTH ASSESSMENT OF PEOPLE WITH INTELLECTUAL DISABILITY

Ms Thea Kremser

Project Officer, Department Developmental Disability Neuropsychiatry. University of NSW.

People with intellectual disability have increased risk of mental disorders. Communication is a key aspect of mental health care, and communication difficulties are a frequent barrier to delivering high quality mental health care to people with intellectual disability. 3DN is developing an app which aims to meet the need for enhanced communication between clinician and patients with intellectual disability in the mental health context.



About the speaker

Thea is a project officer at 3DN with a background in psychology, intellectual disability, education design, and app design.

HEALTHY MIND – AN ONLINE EASY READ TOOL FOR BUILDING GOOD MENTAL HEALTH

Mr Chris Rule

Program Manager - eHealth.



Black Dog Institute has developed a new online, self-help program to support adults with mild to borderline intellectual disability experiencing depression, anxiety and stress. Built on the strengths of Black Dog's myCompass program, Healthy Mind is currently being piloted as part of an accessibility and feasibility trial.

About the speaker

Chris has almost 15 years experience in program management and business development across the health sector, with nearly 10 of those years working across a range of Black Dog Institute's education and treatment programs for workplaces, health professionals and communities. Chris's current role is responsible for managing Black Dog's publicly available eMental Health programs, their ongoing development, quality assurance and dissemination.

Friday 10:50am-12:10pm

Health Services Innovation

Chair TBA

IMPROVING TRANSITION OF YOUNG PEOPLE FOR BOTULINUM TOXIN A SPASTICITY MANAGEMENT

Dr Simon Paget

Paediatric Rehabilitation Specialist, Staff Specialist at the Children's Hospital at Westmead.

Many young people with physical disabilities from conditions like cerebral palsy require ongoing treatment for their spasticity once they become adults, including botulinum toxin A (BoNT-A) injections. This project aims to improve our understanding of how the health system and the experience and opinions of healthcare professionals, young people and their carers with the intention of identifying readily-implementable interventions to improve outcomes for young people and their experience of healthcare utilisation.



About the speaker

Dr Paget is a paediatric rehabilitation specialist and the Head of the Cerebral Palsy and Movement Disorders Service, the Children's Hospital at Westmead. He has particular interests in rehabilitation treatments and pain experience of young people with cerebral palsy.

ADMISSION2DISCHARGE TOGETHER – IMPROVING HOSPITAL JOURNEYS AND HEALTH OUTCOMES FOR PEOPLE WITH INTELLECTUAL DISABILITY

Ms Lif O'Connor

Clinical Nurse Consultant, Metro-Regional-Intellectual-Disability Network.

People with intellectual disability experience poorer health outcomes and negative hospital experiences. The A2D Together Project was developed using co-design principles, patient stories, local analysis and consultation with clients, carers, disability service providers and health staff. Issues impacting on quality of care were identified and addressed through the A2D Together Folder and a training program raising awareness of the rights of people with disability and person centred care.



About the speaker

Lif is the Clinical Nurse Consultant for the Metro-Regional-Intellectual-Disability Network (MRID) in South Eastern Sydney Local Health District.

BUILDING CAPABILITY IN NSW HEALTH SERVICES FOR PEOPLE WITH ID: THE ESSENTIALS

Ms Tracey Szanto

Manager Intellectual Disability Network, Agency for Clinical Innovation, NSW Health.



The Network, through the involvement of health clinicians and managers, consumers and carers as well as representatives from other agencies, seeks to build the capability of local health districts to meet the needs of people with intellectual disability of all ages.

About the speaker

Tracey manages the Intellectual Disability Health Network at the NSW Agency for Clinical Innovation. Tracey has a background in education, nursing and social work .

FUNCTIONAL ASSESSMENTS IN CLINICAL PRACTICE

Dr Amelia Lewis

Clinical Neuropsychologist, Disability Specialist Unit, SLHD.

Functional assessment tools assist clinicians in clarifying a person's support needs and have relevance for diagnostic decision making and intervention planning. They are essential components of a comprehensive diagnostic assessment which must consider the presence or absence of disability with reference to how a person functions in his or her environment. This presentation will explore the strengths and limitations of some common functional assessment tools and implications for clinical practice.



About the speaker

Amelia Lewis is a Clinical Neuropsychologist at the Disability Specialist Unit, a diagnostic and assessment team for children with neurodevelopmental delays or disabilities. She holds a Doctorate in Clinical Neuropsychology and a Master of Philosophy (Psychology) from Macquarie University.

Friday 10:50am-12:10pm

Clinical Hot Topics

Chair: TBD

INTEROCEPTION IN CLINICAL PRACTICE. A NEW PERSPECTIVE ON USING INTEROCEPTION IN CLINICAL PRACTICE TO DEESCALATE BEHAVIOUR

Dr Christel Burton

Medical consultant Disability Services, Women's and Children's Health Network, SA.

Ms Nicole Kyrkou

Developmental Educator.

This presentation talks to the specific context of interoception and behaviour in care settings. It will be informative and practical: how having an awareness of interoception can de-escalate difficult behaviour in care settings, Humanise the doctor patient interaction, Increase respect for both the patient and physician and Inform clinical examination techniques to the benefit of all. The presentation will use case examples of adults and children with developmental disability to highlight issues where asking key questions may make the consult safer and more effective.



About the speakers

Nicole Kyrkou is a Developmental Educator, a multi-disciplinary disability specialist with an interest in the interface between disability, health and behaviour. She has worked across disability services in accommodation, respite, case management, complex health and most recently education. She is currently in graduate medicine at Flinders University.

Dr Christel Burton is a medical consultant for Disability Services, Women's and Children's Health Network, Adelaide South Australia and a GP in private practice.

BE A DIAMOND, NOT A KANGAROO

Ms Maree MacDermid

Mother



How navigating the health care system should be like an Olympic standard netball team at their best, but is sometimes more like a rugby match after a big night out.... And how health professionals are a critical partner in the "whole of life" approach to disability care. The failure of connected care pathways and how that plays out in key performance indicators like life expectancy, family breakups, relinquishment rates and harder to measure factors affecting quality of life. And why we need to do better.

About the speakers

Maree worked for seventeen years as a nurse in acute care, midwifery and in Sth Sudan, Ethiopia and Eritrea. She now studies and works in aged care and has two sons, Joey and Finn. Joey has a severe developmental disability after an aggressive brain cancer as a toddler.

THE FUNCTIONAL SIDE OF DISABILITY

Ms Kate McNamara

My Time Coordinator for Tresillian Family Care Centres.

What is the impact of a diagnosis of disability on a person & their family. What are the needs that result from that diagnosis and how this translates to a good life by way of an NDIS plan.

About the speaker

Kate McNamara is NSW MyTime Coordinator for Tresillian Family Care Centres. MyTime is a national program providing facilitated peer support groups for parents and carers of children with a disability or chronic medical condition. With a background in policy and planning in the community services sector, Kate's focus turned to the disability sector when her daughter was born with Down syndrome. For the past 20 years Kate has focussed on parent and carer support in a variety of areas including MyTime and Triple P Stepping Stones Positive Parenting Program.



Friday 1:10pm-2:40pm

From premature death to inclusion in health promotion and prevention

Chair: Dr Elizabeth Thompson

Rehabilitation Physician, Prince of Wales Hospital and Greenwich Hospital

USING BIG DATA TO UNDERSTAND PREMATURE MORTALITY AND ITS DRIVERS IN PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Prof Julian Trollor

Chair of Intellectual Disability Mental Health and Head, Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Sydney.



People with intellectual disability experience a shorter life expectancy, and a higher proportion of potentially avoidable deaths than the general population. In order to attempt a deeper understanding of this observation, this presentation will attempt to triangulate findings from recent studies of mortality, health and well-being and health service use in people with intellectual disability. Proposed priorities for action will be proposed and discussed

About the speaker

Julian is a neuropsychiatrist who leads a diverse, inclusive research program in intellectual and developmental neuropsychiatry at 3DN. He works closely with people with intellectual disability, families and health advocates to promote services, government and policy responses to his department's research.

MORTALITY OF PEOPLE WITH INTELLECTUAL DISABILITY – A POPULATION BASED STUDY

Dr Seeta Durvasula

Senior Lecturer, Faculty of Medicine and Health, University of Sydney; Clinic Director, Centre for Disability Studies.

A population-based study of mortality in people with intellectual disability was conducted in northern Sydney. It showed age and gender adjusted mortality rates to be higher than those seen in the local general population. The main causes of death were respiratory illness and external causes. A follow up study showed that more than a quarter of these deaths were potentially preventable. Prevention strategies will be discussed.



About the speaker

Seeta is medical practitioner and clinic director of multidisciplinary clinics for people with intellectual disability. She teaches medical, dental and pharmacy students at the University of Sydney. Her research includes mortality, falls, frailty and health outcomes in people with intellectual disability.

KEY FINDINGS FROM 15 YEARS OF REVIEWING THE DEATHS OF PEOPLE WITH DISABILITY IN RESIDENTIAL CARE

Ms Kathryn McKenzie

Director Disability, NSW Ombudsman.



The Ombudsman's office has reviewed and reported on the deaths of people with disability in residential care since December 2002. Significant and consistent issues have been identified in relation to the preventable deaths of people with disability and their access to health services and necessary supports, including population health and community-based health programs.

About the speaker

Kathryn's responsibilities include reviews of deaths, projects and inquiries, and the Official Community Visitor scheme. Her background is in disability service provision and oversight, including roles at the Community Services Commission, the Public Guardian, and in NGOs.

Friday 3:00pm-4:30pm

Can't we do better? Improving outcomes for young people at risk of contact with juvenile justice

Chair: Mr Jim Simpson

Chair, Advocate NSW Council for Intellectual Disability.

USING BIG DATA TO UNDERSTAND THE REPRESENTATION AND PROFILE OF PEOPLE WITH INTELLECTUAL DISABILITY IN NSW PRISONS

Presented by Prof Julian Trollor, co-authors Julian Trofimovs, Professor Leanne Dowse

Chair of Intellectual Disability Mental Health and Head, Department of Developmental Disability Neuropsychiatry (3DN), School of Psychiatry, UNSW Sydney.

Available data suggest that people with intellectual disability (ID) are over-represented as both offenders and victims of crime. However, representative, population-based data examining representation of people with ID in custodial settings is a rarity. This presentation will use a large linked dataset in NSW to identify people with ID in NSW, examine their representation in custody, and determine demographic and sentencing differences between people with and without ID.

JUVENILE JUSTICE NSW: SUPPORTING YOUNG PEOPLE WITH AN INTELLECTUAL DISABILITY OR COGNITIVE IMPAIRMENT

Ms Ruth Marshall

Principal Psychologist Juvenile Justice.

The role of all Juvenile Justice staff is to identify any impairment as soon as possible, and then support and advocate on behalf of those young people and their families. Identifying intellectual disability or cognitive impairment can have significant implications for the young person including possible diversion. Supervision goals and treatment targets are met by adapting programs to meet individual needs both in custody and in the community. A multi-systemic, trauma-informed and strengths-based approach is required and we are working with other organisations and stakeholders, including individuals with a disability, in order to improve practice and outcomes.



About the speaker

A Forensic Psychologist registered in the UK and Australia, Ruth has worked in maximum security prisons, juvenile detention centres, and other forensic settings since 1980. Moving from Corrective Services NSW to Juvenile Justice as their Chief Psychologist in May 2011, Ruth is now JJ's Principal Psychologist with responsibility for the provision of psychological services to all JJ clients.