

PANDDA  
29th Annual  
Conference  
2018

16 & 17 October 2018



People, Purpose  
& Passion  
*Be Extraordinary*



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& Passion  
*Be Extraordinary*

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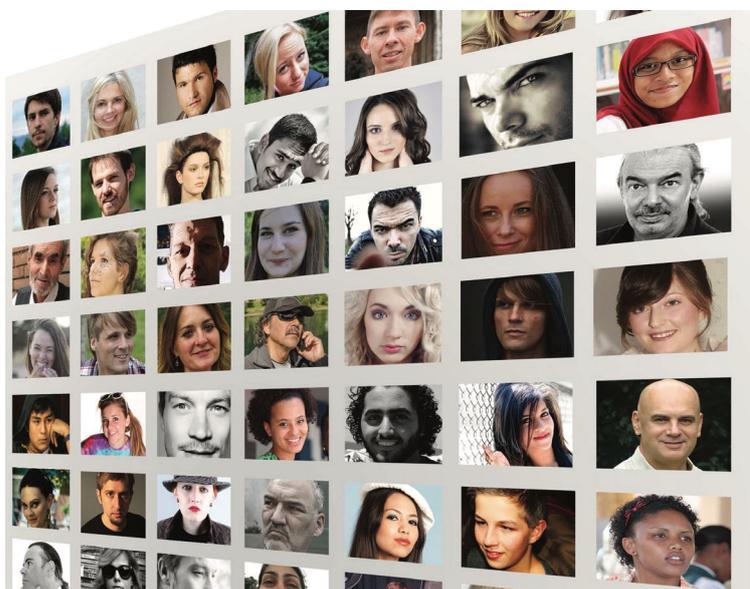
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## Become a Member

Join a nursing group that disseminates information and promotes communication between national and international organisations related to the field of developmental intellectual disability.

The Professional Association of Nurses in Developmental Disability Australia Inc. (PANDDA) represents the professional interests of nurses who support people who have an intellectual developmental disability.

Join and pay online or download the application form at [www.pandda.net](http://www.pandda.net)





## Convenor's Welcome

It is with great pleasure that the PANDDA Committee welcome you to Sydney and Parramatta for the 29th Annual PANDDA Conference. The theme for this year's Conference is "People, Purpose & Passion... Be Extraordinary".

Every day in your work life as nurses you do extraordinary things for the people we care for; you proudly wear on your sleeve your purpose and passion. The New World that is the NDIS provides nurses with the opportunities to showcase our passion and to be extraordinary.

You will discover that the work of the Keynote, Invited and Program Speakers is both inspiring and extraordinary. You will hear from people with a lived experience, families, therapist, medical specialist, nurses and Government who are leading with passion and purpose the opportunities to be extraordinary including advocating the abilities of people with intellectual developmental disabilities.

So come along, be passionate and experience what is new, interesting and uplifting as we learn and share together. We have assembled an inspired and passionate group of extraordinary presenters, who will present to a room of over 120 inspiring and passionate nurses.

As always, you will have the opportunity to debate, contribute and discuss the topics being presented and there will be ample opportunities to catch up with familiar faces and make new connections during the conference.

Thanks to you who have made your attendance at the PANDDA conference happen, and your employers who continue to value the Annual PANDDA Conference as the must attend disability nursing conference of the year. To the Conference & PANDDA Committees' who have been working toward this conference for the past 15 months my congratulations to you all in delivering what is an extraordinary conference program. Our sponsors have once again been generous and willing partners. The Committee looks forward to meeting with you all at this our 29th Annual National PANDDA Conference and AGM.

I trust you will leave the PANDDA Conference feeling Inspired, Passionate and Extraordinary and ready to book your place at our 30th Anniversary Conference next year

Warm Regards,  
Bob Weaver OAM, on behalf of the Conference Committee

## President's Welcome

### Welcome to the Professional Association of Nurses in Developmental Disability 29th Annual Conference.

The PANDDA committee have once again put in a huge amount of time and effort to deliver what we hope will be an interesting, thought provoking and exciting programme, we thank them for their efforts. We trust that you will participate in the discussions, sharing your own insights and achievements, thus making your attendance even more worthwhile. We would like to thank our sponsors for their continued support.

The program includes a diverse range of informative and respected speakers and presenters from different states of Australia who will share their wisdom, knowledge and experiences with us in line with the conference theme.

The work of the Kathryn McKenzie and her team at the Ombudsman's office is well known to many of us. It is pertinent that we hear more about the key findings from their work over the last 15 years as it informs current practice. It is appropriate to hear from Dr Chan at the NDIS Quality and Safeguards Commission and their work. Other speakers are known for their passion in this field and we look forward to hearing from all of them, regarding health, mental health, sexuality and sexual violence, carers, peer support etc. It sounds like a very interesting program.

There will be an update on the ongoing work related to the grant PANDDA received from the NSW Department of Family and Community Services to research and then redevelop the PANDDA practice standards. The partnership with the School of Nursing and Midwifery at Western Sydney University is evolving and will be expanded upon further at the conference.

We thank you all for participating in our conference and encourage you to network, share your passion and ideas, identify your current purpose in this changing world for people with intellectual disabilities. Let us move forward together toward similar goals where we make an extraordinary difference to the lives of people with intellectual disabilities and their families across our country.

Linda Goddard  
President

## Day 1. Tuesday 16 October 2018

09.00–09.15	<b>WELCOME TO COUNTRY &amp; CONFERENCE OPENING</b> Bob Weaver OAM, Conference Convenor and Sue Easton, Technical Program Convenor		
09.15–10.00	<b>KEYNOTE SPEAKER:</b> Jos & Deb Evans (Daughter and Mother) <b>Health literacy for people with intellectual disability: Parents with passion and purpose</b> Chair: Virginia Howie, PANDDA Committee		
10.00–10.40	<b>INVITED SPEAKER:</b> Nathan Wilson <b>Redeveloping the Speciality Practice Standards for IDD Nursing: The NDIS and Beyond</b> Chair: Dr Linda Goddard, PANDDA Committee		
10.45–11.30	<b>MORNING TEA AND TRADE DISPLAYS</b>		
11.30–12.10	<b>INVITED SPEAKER:</b> Gerard Stevens AM <b>People, Purpose and Passion: Wisdom – Reflection – Experience</b> Chair: Damian Heron, PANDDA Committee		
12.15–12.45	<b>CONCURRENT SESSION 1 (JARRAH ROOM)</b> Chair: Louise Hedges, PANDDA Committee	<b>CONCURRENT SESSION 2 (AVALON ROOM)</b> Chair: Catherine Hulst, PANDDA Committee	<b>CONCURRENT SESSION 3 (MADISON ROOM)</b> Chair: Denise Robinson, PANDDA Committee
	<b>"The child is no different": Acute care nurses experiences of caring for children with IDD</b> Dr Peter Lewis	<b>Your Purpose, Your Passion: The design of a descriptive nursing survey piloted among members of PANDDA</b> Hayden Jacques	<b>Using Carer Engagement and Motivational Interview/ Flipped Classroom/Process Mapping (MIFCPM) techniques to deliver staff CPD programs that will lead to service improvement and necessary adjustments for children with DD</b> Gail Tomsic
12.45–13.30	<b>LUNCH</b>		
13.30–14.15	<b>INVITED SPEAKER:</b> Kirsten Deane, Campaign Director of Every Australian Counts <b>The National Disability Insurance Scheme: It's Been A Long Journey. How Did We Get Here? And What's Next?</b> Chair: Dr Linda Goddard, PANDDA Committee		
14.15–15.00	<b>PROGRAM SPEAKER:</b> Professor Regina Lee, Professor of Nursing, School of Nursing and Midwifery, Newcastle University <b>The journey in building disability care</b> Chair: Dr Nathan Wilson, PANDDA Committee		
15.00–15.30	<b>AFTERNOON TEA AND TRADE DISPLAYS</b>		
15.30–16.15	<b>KEYNOTE SPEAKER:</b> Dr Jeffrey Chan, Senior Practitioner, Behaviour Support at the NDIS Quality and Safeguards Commission <b>People, Purpose and Passion for Disability Rights</b> Chair: John Ryan, PANDDA Committee		
16.15–18.00	<b>DAY 1 CLOSE AND WELCOME RECEPTION</b> Invitation to the Welcome Reception in the Hotel Atrium. Hosted by the PANDDA Committee		

## Day 2. Wednesday 17 October 2018

09.00–09.15	WELCOME TO COUNTRY & WELCOME TO DAY 2: Bob Weaver OAM and Damian Heron, Conference Convenors		
09.15–10.00	KEYNOTE SPEAKER: Dr Linda Godard People, Purpose and Passion... Be extraordinary. Models of disability nursing: The 6 Ps. Chair: John Ryan, PANDDA Committee		
10.00–10.45	KEYNOTE SPEAKER: Professor Julian Trollor, Chair, Intellectual Disability Mental Health, UNSW Closing the Gap for People with Intellectual Disability: Focus on Mental Health Chair: Dr Nathan Wilson, PANDDA Committee		
10.45–11.15	MORNING TEA AND TRADE DISPLAYS		
11.15–12.00	INVITED SPEAKERS: Tracy Wright has worked in Human Services for over 30 years, Tania Lewis is a Peer Mentor with CDAH and Dr Rebecca Pockney is an Occupational Therapist 'Keeping it Real' – Importance of peer support organisations in the development of nurse education in a large residential centre for adults with developmental disabilities. Chair: Virginia Howie PANDDA Committee		
12.00–12.30	CONCURRENT SESSION 1 (JARRAH ROOM) Chair: Louise Hedges, PANDDA Committee	CONCURRENT SESSION 2 (AVALON ROOM) Chair: Damian Heron, PANDDA Committee	CONCURRENT SESSION 3 (MADISON ROOM) Chair: Denise Robinson, PANDDA Committee
	Illumination: Practice up close and personal. The battle of the bowel. A review of nursing practice concerning optimal health outcomes for people who have intellectual disabilities, with specific reference to personal experience of bowel obstruction. Catharine Hulst	QUM what may – Use of analgesia in a teenager with developmental disability Georgina Hoddle, Nicholas Caires and Kara Cheung	Pathways to better care: successful approach to admission and discharge planning for patients with ID and challenging behaviours. A case study. Gail Tomsic
12.30–13.15	LUNCH		
13.15–14.00	INVITED SPEAKER: Marika Guggisberg Breaking a Taboo – Let us talk about People with Disabilities' Sexuality and the Increased Risk of Sexual Violence Chair: Dr Linda Goddard, PANDDA President		
14.00–14.45	PANDDA Annual General Meeting Convenor: Dr Nathan Wilson, PANDDA Vice President and Louise Hedges, PANDDA Public Officer Option 2 Workshop: Practical tips for the purpose of improving health literacy for people with intellectual developmental disability, Virginia Howie Chair: Damian Heron: PANDDA Committee		
14.45–15.00	AFTERNOON TEA AND TRADE DISPLAYS		
15.00–15.45	INVITED SPEAKER: Kathryn McKenzie: Director Disability, NSW Ombudsman Key findings from 15 years of reviewing the deaths of people with disability in residential care Chair: John Ryan PANDDA Committee		
15.45–16.00	PRESENTATION: Chris Atkins and Bob Weaver PANDDA Awards Catharine Hulst, Convenor PANDDA Awards & Dr Linda Goddard, PANDDA President		
16.00–16.15	CONFERENCE CLOSE AND INVITATION TO THE 30TH PANDDA CONFERENCE 2019 Sue Easton, Technical Program Convenor; Maree McCulloch, Conference Registrar; Bob Weaver OAM and Damian Heron, Conference Convenors FAREWELL DRINKS hosted by the PANDDA Committee		



## Keynote Speakers



### DR JEFFREY CHAN

Dr Jeffrey Chan is the Senior Practitioner, Behaviour Support at the NDIS Quality and Safeguards Commission. Jeff has worked in human services for nearly 30 years in government, non-government and statutory roles. He was the inaugural Victorian Senior Practitioner and Queensland's Chief Practitioner and Director of Forensic Disability. He believes that people with disabilities should be empowered to live a life of dignity free from restraints and seclusion. He was also a Finalist in the Australian Human Rights Award 2010 for Community (Individual) category for his work on protecting the rights of people with disabilities subjected to restrictive interventions.



### JOSELYN EVANS

Jos lives in her own home that Dad built on her parent's property after completing grade 12 when she was 17 years old. Joselyn does all her own housework and is a keen cook. Joselyn is always busy, working out with her mum, going to youth and Church functions and playing Basketball for Sunshine Coast Special Olympics. Jos has represented QLD and Australia in Aquatics and her State in Basketball. She has now retired from Aquatics. Jos loves talking to people and inspiring them to do their best and have a go.

### DEB EVANS

Deb and Justin have been married for nearly 38yrs and have 3 amazing adult children, Joselyn, Elias and Todd. Their eldest, Joselyn, is 32 years old and has Down syndrome. Deb was 23yrs old when she gave birth to Joselyn, and knew very little about the condition at the time of her birth. Deb was a Fitness Professional and a Learn to Swim Teacher, but she is now a stay at home mum who is kept very busy taking Jos to places she needs to go, maintaining the home and property and working as a partner in their building business from home and also onsite when she is needed.



### VIRGINIA HOWIE (INTERVIEWER)

Virginia is a Registered Nurse and parent of a child with intellectual disability. Virginia has extensive clinical experience, mostly as a specialist cardiac nurse in acute care. In her current position as a nurse lecturer, Virginia has become a strong advocate for people with disability in the academic setting, as well as the wider community through her teaching and doctoral studies.



**DR LINDA GODDARD**

Linda has worked in the area of intellectual disabilities for a few decades both in Australia and in England. Her experience includes working with people who have a range of physical and intellectual disabilities, complex health and mental health needs and behaviour challenges across the age range, in a number of settings. Her PhD focused on the physical and mental health needs of families who have sons and daughters with intellectual disabilities. Linda worked coordinated undergraduate and post graduate programs in nursing and in intellectual disabilities at Charles Sturt University Albury. Linda held the position of Senior Clinician in an organisation offering services to 700 people with intellectual disabilities. In 2014-2016 she returned to the UK, working as an Associate Professor in a Department of Learning Disabilities and Mental Health at London South Bank University. Currently Linda is the President of PANDDA and works as a Counsellor and Life Coach while considering her next role.



**PROFESSOR JULIAN TROLLOR**

Julian holds the inaugural Chair of Intellectual Disability Mental Health and is Head of the Department of Developmental Disability Neuropsychiatry (3DN), within the School of Psychiatry at UNSW Sydney. He leads a diverse, inclusive research program in intellectual and developmental neuropsychiatry. He works closely with people with intellectual disability, families and health advocates to promote services, government and policy responses to his department's research.



## Invited Speakers



### KIRSTEN DEANE

Kirsten Deane is the Campaign Director of Every Australian Counts, the campaign for the National Disability Insurance Scheme. She also serves Executive Director of the National Disability and Carer Alliance, the organisation which sits behind Every Australian Counts. Kirsten's previous roles include National Manager of Communications and Engagement at the Australian Federation of Disability Organisations, and she has served as both Co-Chair and Deputy Chair of the National People with Disability and Carer Council. She has also been a long term board member of both Down Syndrome Australia and Down Syndrome Victoria. A former journalist turned academic, Kirsten has three children and, as a result, has excellent conflict mediation skills.



### DR MARIKA GUGGISBERG

Dr Marika Guggisberg is a teaching and Research scholar at CQUniversity based in Perth. Her area of expertise includes violence in the family home. She completed her Post-Doctoral Fellowship undertaking research in the area of sexual violence and taught into the Postgraduate and Master program in Sexology for seven years at Curtin University. Dr Guggisberg received her PhD from the University of Western Australia for her investigation of the interrelationship between intimate partner violence with specific mental health impacts and health risk behaviours after earning a Master degree in Criminal Justice and an Honours in Psychology. She is known for her research on sensitive topics including sexual victimisation of women and children. She has presented at national and international conferences, is frequently invited as a guest presenter with many peer-reviewed publications, is an examiner of research dissertations, sits on the editorial board of several academic journals, and actively works towards prevention of violence together with her PhD students. Her passion to promote health and wellbeing including breaking taboo issues in relation to sexual violence. More recently her work has focused attention on people with disabilities and their disproportionate risk of sexual victimisation to work towards its prevention.



### KATHRYN MCKENZIE

Kathryn's responsibilities in the Ombudsman's office 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.



### GERARD STEVENS AM

Gerard Stevens AM is founder and Managing Director of Webstercare, a world leader in medication management innovation. From the introduction in 1980 of the first Controlled Dosage System to Australian RACFs, and the Webster-pak Multi-Dose System in 1985, Gerard's innovations now total about 600 and are used in RACFs and communities throughout Australia, supported by more than 3200 pharmacies. Gerard has received national and international recognition for his commitment to developing medication management solutions for improved patient care. This combined with the integrity with which he conducts his businesses, has seen him acknowledged as a driving force within the industry.



**DR NATHAN J WILSON**

Dr Nathan Wilson is a Senior Lecturer at Western Sydney University based in the School of Nursing and Midwifery. His research interests are in applied research that enhances the health, wellbeing and social participation of people with long-term disabilities. Dr Wilson presents regularly at national and international scientific meetings and has research collaborations with groups in Australia, New Zealand, Canada, the UK and South Africa. He is currently involved in funded research projects about: 1) identity and intellectual disability, 2) mentoring young unemployed adults with intellectual disability at Men's Sheds, 3) cross-modal community mobility of young adults with Autism Spectrum Disorder, 4) place of death and people with intellectual disability, 5) disability nursing standards of practice, and 6) toward the self-management of type 1 diabetes for people with intellectual disability.



**TRACEY WRIGHT**

Tracy has worked in Human Services for over 30 years, where she has held senior positions in non-government and government agencies, including police, child protection and disability and advocacy services. Over 19 years of her career was spent in NSW rural and remote communities where services are limited and access for people is often a challenge. Her consultancy work has included working with the NSW Ministry of Health, non-government services and providing advice to the National Disability Insurance Agency. Tracy is a citizen advocate and work towards the day when communities are truly inclusive. She is currently a Director of the Inclusion Australia Board, the peak body for people with Intellectual Disabilities.



**TANIA LEWIS**

Tania Lewis is a Peer Mentor with CDAH with a wealth of lived experience about residing in a large residential centre, having sustained a stroke at the age of 36 years. She recognises the frustrations of not being able to communicate verbally - having lost her own speech for a period of time and is a powerful advocate for the rights of those who may not use conventional communications methods.



**DR REBECCA POCKNEY**

Dr Rebecca Pockney is an Occupational Therapist, who has worked with people with developmental disabilities for over 25 years. She has been involved in assisting individuals transition from large residential centres to their own homes in the community in the UK and has undertaken research into the increasing peoples' community participation through the development of their meaningful relationships.

## Program Speakers

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### MR NICHOLAS CAIRES

Assistant Pharmacist, BMedSci

Nicholas is in his final year Master of Pharmacy student from the University of Sydney having completed an undergraduate degree in medical science with a major in pharmacology and physiology. He is currently working two casual jobs in separate community pharmacies. Nicholas has had previous experience working with a range of people as a private tutor and tennis coach.

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### MS KARA CHEUNG

Assistant Pharmacist, BSci, MPharm student

Kara is in her final year Master of Pharmacy student from the University of Sydney. She previously studied an undergraduate degree of Bachelor of Science and Business majoring in pharmacology at the University of New South Wales. Since then Kara has been interested in being able to provide the best possible health outcomes for patients.

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### GEORGINA HODDLE

CNE, RN, MAppLing (TESOL)

Georgina Hoddle is a Registered Nurse, currently working as clinical nurse educator in disability nursing. After studying General Nursing at St. Luke's Hospital she lived abroad for 30 years, re-training at Royal North Shore Hospital in 2005. Attaining a Masters in Applied Linguistics (TESOL) from Macquarie University in 2011 led to further teaching and conference presentations both nationally and internationally.

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### VIRGINIA HOWIE

Nurse Lecturer, RN, MCN-Cardiac, PHD candidate Central Queensland University (Noosa campus)

Virginia is a Registered Nurse and parent of a child with intellectual disability. Virginia has extensive clinical experience as a specialist cardiac nurse in acute care. In her current position as a nurse lecturer, Virginia has become a strong advocate for people with disability in the academic setting, as well as the wider community through her teaching and doctoral studies.

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### MS CATHARINE HULST

RN, BA(Hons), BN

Catharine has worked in disability nursing as a Registered Nurse for the last 34 years, holding the positions of Community Nurse, Program Officer, Lecturer (University of Western Sydney), and lastly Clinical Nurse Consultant (Health) at Metro Residences. Towards the end of the closure of Metro Residences she transferred to The Benevolent Society (TBS), with the Allied Health team. She left TBS in November 2017, and has been enjoying a gap year since then.

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#### MR HAYDEN JAQUES

Research Assistant completing Honours, Western Sydney University, BN, RN

Mr Hayden Jaques is a Registered Nurse, Hayden has experience working with people with mental health issues and acquired brain injury. He is in the process of finalising his Honours thesis and has a growing publication track record in the area of disability nursing. Hayden is the recipient of the 2017 PANDDA Nursing Research Scholarship for Honours Students and is in the process of finalizing his Honours thesis. Hayden has a growing publication track record in the area of disability nursing.

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#### REGINA LEE

Professor of Nursing, School of Nursing and Midwifery, Newcastle University, PhD

Regina Lee is currently a Professor in Nursing at the School of Nursing and Midwifery, The University of Newcastle, Australia. She has practiced nursing in Canada in the areas of NICU, paediatrics, school health and public health. Regina obtained her nursing registration in Edmonton, Alberta and Toronto, Ontario and in Hong Kong. She received her Bachelor Science degree in nursing from the University of Alberta in Canada and her Master of Science Degree in community health nursing in New York, United States. She obtained her doctoral degree in nursing at The Hong Kong Polytechnic University, Hong Kong. She had been working as a paediatric nurse in Edmonton and a public health nurse in Toronto, Canada. She had developed a Master of Child and Adolescent Stream Specialty and she teaches courses in child and adolescent health and development at the School of Nursing, The Hong Kong Polytechnic University. She is also the founder and President of Hong Kong School Nurses Association and Vice-President of the Hong Kong College of Paediatric Nursing. Regina is currently collaborating with a few World Health Organization Collaborating Centre to conduct research focusing on adolescent lifestyle behaviours, childhood obesity and simplified handwashing technique. She collaborates with school principals and allied health professional to implement school-based health projects that provide primary health care services including health promotion and disease prevention for the schoolchildren using a multidisciplinary and inter-sectoral approach in Hong Kong. Her research interest is of child and adolescent health in the areas of disabilities, special health needs, lifestyle behaviours and psychosocial wellbeing, childhood obesity-weight management programme, handwashing technique, mhealth interventions for adolescents and their parents, role of school nurses and health-promoting school framework.

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#### DR PETER LEWIS

Senior Lecturer, Director of Academic Workforce, University of Western Sydney, PhD, BA, RN, DipApSc (Nursing)

Dr Lewis has been working in the School of Nursing and Midwifery since 2015 after a nursing career spanning more than 15 years caring for children and young people with chronic illness in the acute care setting.

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#### GAIL TOMSIC

CNC Disability Services MCommNurs, BSc (Nursing), DipApSc (Nursing), Grad Dip Paed

Gail is Registered Nurse who has 30 years nursing experience with qualifications in the following speciality areas, community paediatric nursing, hospital in the home, child & family health, paediatrics, lactation and infant feeding, and nursing management. Gail has practiced in a wide variety of settings including hospital paediatric units, parentcraft residential unit, and in the community setting providing home nursing to both post acute, acute and chronic children discharged from hospital to home. Gail has worked in senior nursing positions for the past 13 years as a Clinical Nurse Consultant (CNC) in a Grade 2 and 3 levels and Nurse Unit Manager.

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#### DR NATHAN WILSON

Senior Lecturer, Western Sydney University, PhD

Dr Wilson is a disability nurse and researcher with an interest in research and programs that enhance the social and economic participation of people with a disability. He has published over 50 scientific papers and regularly presents at national and international conferences.

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### Non Presenting Co-Authors

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#### KATE O'REILLY

Associate Lecturer (non presenting co-author), Western Sydney University, BN, RN, Grad Cert Comm Nursing, Master Clin Rehab (Research)

Ms Kate O'Reilly is an Associate Lecturer in the undergraduate and post-graduate nursing program at Western Sydney University. Kate has completed a Bachelor of Nursing, a Master of Clinical Rehabilitation, and is now a PhD candidate exploring women's experience of traumatic brain injury. Kate worked in both inpatient and community settings supported by people following catastrophic brain injury and illness.

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#### DR MICHELE WIESE

Lecturer, Western Sydney University (non presenting co-author), PhD

Dr Michele Wiese is a psychologist and special educator with 30 years experience in the disability sector. Michele's research focus is on end-of-life care for people with intellectual disability.

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## Conference Abstracts

### DR JEFFREY CHAN

#### People, Purpose and Passion for Disability Rights

The presentation introduces the Behaviour Support function of the NDIS Quality and Safeguards Commission, in particular it will focus on the myths and assumptions the disability sector hold about restrictive practices. The role of the nursing professional is critical in protecting the rights of vulnerable Australians with developmental disability. The presentation will also provide an overview of the Convention on the Rights of Persons with Disabilities (2006) and how nurses play a role as rights bearers, particularly in safeguarding people with developmental disability who may be subject to restrictive practices.

### KIRSTEN DEAN

#### The National Disability Insurance Scheme: It's Been A Long Journey. How Did We Get Here? And What's Next?

The National Disability Insurance Scheme is a social and economic policy reform the size and scale Australia rarely sees these days. It's impact is as large and transformative as the introduction of Medicare or compulsory superannuation. Given it's size and complexity, the introduction of the NDIS was never going to be without its challenges. But for many people with disability and their families, the road to the NDIS has been rockier than anticipated - and definitely harder than it needed to be. Many believe the vision of the NDIS is being compromised by poor implementation. And they want that to change. This presentation will look at the long journey to the NDIS, where we are now and, most importantly, what needs to come next.

### JOS EVANS AND DEB EVANS

#### Health literacy for people with intellectual disability: Parents with passion and purpose

People with intellectual developmental disability have higher prevalence for obesity than the general population, which can lead to secondary conditions such as diabetes,

hypertension, cardiovascular disease and arthritis. Those at greater risk are women, people with Down syndrome and those living independently. Lack of physical activity and poor diet are contributing factors to the development of these chronic health conditions. Evidence suggests that barriers to adopting healthy lifestyle choices for people with ID are lack of enthusiasm, limited options and poor health literacy. Health literacy is the ability to obtain, process, and understand health information needed to make informed health decisions. Health education is central to health literacy. However, for individuals to realise the benefits of health education requires a high level of engagement, motivation, and cognitive ability, which is not so achievable for people with IDD. A number of strategies for engaging in exercise have been advanced, such as making the activity fun, adopting a one-to-one approach, and/or carer support. Motivation, preferences and routine are considerations for healthy eating.

Joselyn is a young woman who has Down syndrome. She is fit and healthy and has good health literacy. This presentation interviews Joselyn and Deb, Joselyn's mother, to explore how health literacy can be achieved for people with IDD.

### DR LINDA GODDARD

#### People, Purpose and Passion... Be extraordinary. Models of disability nursing: The 6 Ps.

Intellectual disability nursing is perceived to be the purist form of nursing, supporting people with disabilities and their families from the cradle to the grave (Gates, Fearn & Welch, 2015). It involves nurses working in *partnership* with people with intellectual disabilities and their significant others to ensure that their needs are met. *Planning* focuses on person centred approaches, working in partnership with other professionals, identifying individual strengths and the most appropriate strategies to achieve the best possible outcomes. It could be argued that to be *professional* in this area of work we need *passion*, we certainly need knowledge and we can often be extraordinary. This paper will look at our *purpose* as intellectual disability nurses and some of the nursing models used across the world.

**DR MARIKA GUGGISBERG**

**Breaking a Taboo – Let us talk about People with Disabilities' Sexuality and the Increased Risk of Sexual Violence**

The presentation will examine Australia's female population of about 2.5 million girls and women who live with some form of disability and implications in relation to expressing their sexuality. It is noted that the NDIS seems to omit this issue entirely. Are people with disabilities still believed to be non-sexual beings? Misconceptions will be discussed along with specific vulnerabilities for sexual victimisation and an overall lack of sexual knowledge. The recognised need for sexuality education and prevention training for females and males who live with disabilities, their families along with health care professionals will be highlighted along with presenting information on existing programs for patients and professional development possibilities for nurses working with families.

**GEORGINA HODDLE, NICHOLAS CAIRES  
AND KARA CHEUNG**

**QUM what may – Use of analgesia in a teenager with developmental disability**

The Objective of this work is to identify how various forms of analgesic medication are used with a young client who lives with a genetic disability and has different means of communication, and secondly whether the medications are used in a qualitative manner.

A Quality Use of Medication (QUM) review was conducted by two Masters of Pharmacy (MPharm) students, under the supervision of a Clinical Nurse Educator. The students were undertaking a 2-week placement in a disability centre and were granted access to the files of a young person with developmental but not intellectual disability. These files included medication charts, progress notes and the use of the Disability Distress Assessment Tool over the six previous weeks.

This information contributed to the assessment conducted by the Pain Management Team at a children's hospital who appreciated the data compiled by the MPharm students,

together with input from the Residential Unit Nurse Manager in charge of the support and care of this child. As a result of this assessment his/her opioid analgesia was increased and the modes of pain assessment, administration of other forms of analgesia and evaluation of effect were validated.

This young person now lives more comfortably because of the QUM review. QUM is one of the central objectives of Australia's Medicine Policy and means that management options are used wisely, are suitable and considered necessary, and are both safe and effective. This preliminary study may be considered a pilot for ongoing assessment of pain management for people with disability.

**MS VIRGINIA HOWIE**

**Practical tips for the purpose of improving health literacy for people with intellectual developmental disability**

People with intellectual developmental disability (IDD) have poorer health outcomes than people without IDD. This vulnerable group are more likely to have co-morbidities such as physical disability, epilepsy, heart disease, obesity, diabetes, hypertension, cancer and arthritis. Health education is essential for the prevention of these chronic conditions. However, evidence suggests that barriers to adopting healthy lifestyle choices for people with ID are lack of motivation, limited options and poor health literacy. Health literacy is the ability to obtain, process, and understand health information needed to make informed health decisions. Health education is central to health literacy. Health information for people with IDD is often offered in written form using Easy English style format. However, IDD is a diverse group and written information in simple format is not always effective to motivate change. Additionally, for individuals to realise the benefits of health education requires a high level of engagement, motivation, and cognitive ability, which is not so achievable for people with IDD.

The aim of this workshop is to offer some practical tips on novel ways to motivate a person with IDD to adopt healthy lifestyle choices that are long-lasting. The lead presenter

is a nurse lecturer who has a daughter with IDD. Using a lived experience approach combined with evidenced-based practice, the workshop seeks to engage participants by adopting an interactive and practical approach to promoting health literacy. Strategies are aimed at lifelong learning using a variety of novel and innovative techniques.

The session begins with a PPT presentation and brief overview of the importance of health literacy for people with IDD. Background information is offered concerning the consequences of poor health literacy, the challenges faced by health professionals in the delivery of health information, and engaging health consumers with IDD in planning for a healthy lifestyle. Topics covered are: barriers to health literacy such as literacy levels, physical and sensory disabilities; as well as facilitators such as motivational strategies and engaging others to promote health and wellbeing. The workshop includes an interactive style presentation where participants are asked to share a topic of interest, and then solutions are explored using a group problem-solving approach, guided by evidenced-based practice.

#### CATHARINE HULST

##### **Illumination: Practice up close and personal. The battle of the bowel.**

A review of nursing practice concerning optimal health outcomes for people who have intellectual disabilities, with specific reference to personal experience of bowel obstruction. People, purpose and passion in disability nursing has always been about supporting individuals to fulfil their potential and goals in order to lead full lives. Optimal health outcomes have necessarily been essential to this pursuit, and a major focus of the work. This paper reviews, in general terms, the nature of the giving and receiving of support, in a health context, for people who have intellectual disabilities, and the nurses who provide that support. A personal health experience is examined, as another useful body of evidence.

#### HAYDEN JACQUES

##### **Your Purpose, Your Passion: The design of a descriptive nursing survey piloted among members of PANDDA**

This research was developed as one part of a broader program of research funded by PANDDA. We aimed to develop and pilot a descriptive survey about the current range of skills and expertise of nurses and to identify and record the perspectives of members of this workforce regarding the development and implementation of clinical standards for nurses caring for people with intellectual and developmental disability (IDD).

#### METHOD

Survey content was validated using three sources:

1. A comprehensive literature review that focused on the role/s and skills that nurses perform when caring for people with IDD.
2. Qualitative data collected via semi-structured interviews of nurses who work with people with IDD.
3. Feedback from experts in the field.

The survey was designed to describe (i) demographic characteristics of the nurses, (ii) where nurses are working, (iii) what roles they perform, (iv) the nursing and habilitation skills they use, and (v) their views on the PANDDA Standards of nursing practice.

After examining test/retest reliability, the pilot survey was distributed using Survey Monkey.

#### RESULTS

Sixty-six members of PANDDA were emailed the survey link. 27% of those emailed fully completed the survey. Feedback from participants suggested that the survey was broad and comprehensive, but for most was very long and time consuming. Overall, participants expressed positive views about the depth of questions that specifically related to the practice of IDD nursing. All participants felt the survey was well structured. It flowed clearly and the questions were easily understood.

#### CONCLUSION

In the era of the NDIS, the piloting of this survey will contribute to the development of a national survey of nurses

working with people with IDD. This will in turn contribute to a strong evidence base that will support the design of a new set of practice standards for nurses caring for people with intellectual and developmental disability.

#### PROFESSOR REGINA LEE

##### **Promoting handwashing and sanitation behaviour change for children and adolescents with intellectual disability: A qualitative study**

#### AIMS

To explore the experiences of schoolchildren with mild intellectual disability (MID), school teachers, school principals and their parents who participated in a school-based simplified 5-step hand hygiene program extended to the home via mHealth in Hong Kong.

#### METHODS

Thirteen focus group discussions with 50 study participants were conducted among schoolchildren with MID, school teachers, school principals and parents participating in a school-based hand hygiene program in three special schools in Hong Kong. These discussions were then analyzed using Braun and Clarke's thematic analysis.

#### RESULTS

Five themes emerged from the data analysis: (1) Recognizing the importance of hand hygiene in the control of the spread of infectious diseases; (2) Acknowledging the simplified 5-step handwashing technique is practical and effective for students with MID; (3) Sharing the joint effort between the school and home in facilitating handwashing behavioral change among schoolchildren with MID; (4) Identifying the importance to provide a supportive environment to enhance the hand hygiene routine; and (5) Appreciating the benefits of extending the hand hygiene program to the home via mHealth tools by engaging the parents caring for their children with MID.

#### CONCLUSION

This qualitative study design addressed factors influencing implementation of the promotional approaches by examining the experiences of schoolchildren with MID, school personnel and parents. It includes being committed,

sharing responsibility, identifying and disseminating good practice, and appreciating the benefits of promoting hand hygiene care via a joint effort between school and family. This has significant implications for the potential for school nursing services to partner with key community stakeholders by adopting effective strategies for policy making and implementing health education and health promotion activities for children with intellectual disabilities in the school communities.

#### DR PETER LEWIS

##### **"The child is no different": Acute care nurses experiences of caring for children with IDD**

The aim of this presentation is to describe the findings from an interview-based qualitative study of nurses experiences of caring for children with IDD and their families in an acute care paediatric ward of a general hospital in Sydney, Australia.

#### METHOD

We conducted face-to-face interviews with seven registered nurses and one enrolled nurse working on a paediatric ward in a large general hospital. Interviews lasted between 20 and 40 minutes each and were transcribed verbatim. We conducted a thematic analysis.

#### RESULTS

Nurses who participated in this study compared their experiences of delivering care to children with IDD with their experiences of caring for children without IDD. Participants described how they cared for the medical needs of children with IDD in the same ways as they cared for those without IDD, but they identified differences between the two groups in the importance of adhering to familiar routines and of the time consuming nature of providing care for children with IDD compared to those without. Repeated opportunities to care for children with IDD contribute to the development of skills and confidence amongst nurses practicing in this setting. Finally, participants described how important it can be to integrate the parents of a child with IDD into the health care team because the parents possess knowledge and information about their child that is otherwise unavailable.

## CONCLUSION

Familiarity with nursing children with IDD is an important ingredient in the delivery of effective care to this patient population in the acute care paediatric setting. More could be offered at undergraduate and beginner practitioner levels to help engender confidence and foster competence to care for children with IDD.

## KATHRYN MCKENZIE

### Key findings from 15 years of reviewing the deaths of people with disability in residential care

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, such as community-based health programs.

## GAIL TOMSIC

### Using Carer Engagement and Motivational Interview/ Flipped Classroom/Process Mapping (MIFCPM) techniques to deliver staff CPD programs that will lead to service improvement and necessary adjustments for children with DD

This session demonstrates an innovative method of utilising the knowledge and experience of parents/carers of children with developmental disability (DD) and challenging behaviours of previous health care encounters to inform a staff education program that combines service redesign and quality improvement initiatives.

People with developmental disability (DD) face significant barriers in accessing health care. These include healthcare staff feeling not well equipped to manage a person with DD and challenging behaviour. This proposal outlines a innovative technique of combining methods used in education, change counselling and service improvement to encourage practice change of health staff working with patients with developmental disability and challenging behaviours using carer proxy patient experiences.

A facilitated CPD (continuing professional education) session using Motivational Interviewing and Flipped Classroom techniques is conducted with health staff to explore experiences and evoke "change talk". Process mapping is then used to identify "touch points" for improvements. Consumer engagement is elicited by conducting in depth interviews with parents of children with DD who have recently been through the patient journey. This information is then transferred to the process map which now contains both staff and parent/patient perspectives. This map is then returned to the clinical team and they are then encouraged to reflect on the parent feedback and review their goals. The final phase consists of an evaluation process and whether the goals have been met.

Nine health staff participated in the sessions. Almost all rated the sessions excellent. Useful learnings include process mapping exercises, discussions about reasonable adaptations and the importance of preparation. All participants had a positive shift in the ratings for confidence and knowledge working with carers and children with DD.

## GAIL TOMSIC

### Pathways to better care: successful approach to admission and discharge planning for patients with ID and challenging behaviours. A case study.

This presentation will provide an overview of a case study and how this led to building a pathway within the Children's Hospital at Westmead for children and young people with ID and challenging behaviour with complex health issues.

We describe a case of an adolescent boy with ID, autism and challenging behaviour with significant difficulties with health services access. He had put on significant amounts of weight and was suspected to have obstructive sleep apnoea. The ENT team recommended tonsillectomy and collaborated with the Specialist Disability Health Team (SDHT) in preparing for the admission. This required significant coordination between the family, SDHT staff and hospital staff. The result was a planned pathway describing the essential steps of the admission, the staff involved and tasks required. On the day of admission, the patient was given medications at home and transported to hospital. He was then escorted from the hospital entrance

into the operating theatre and given further premeds whilst registration occurred. He was then greeted by the anaesthetist who provided induction and subsequently underwent surgery. The surgery was successful and early discharge took place with discharge plans in place for analgesia, post op care and review by community nursing. This presentation will outline essential elements of admission planning and discharge for complex ID cases and the various steps undertaken to enable a successful procedure with positive results and experience.

#### GERARD STEVENS AM

##### People, Purpose & Passion: Wisdom – Reflection – Experience

The devil's in the detail when supporting your patient's medication needs – What 40 years of helping people manage their medication has taught me

Numerous innovations and technological developments have transformed medication management since the Websterpak® – the world's first multi-dose medication management system - was first introduced in 1985. But the formula for successfully helping people take their medication, as their doctor intended, remains the same. Understanding the specific needs of the individual, making full use of the systems and tools available, and always understanding that the devil's in the detail are just as important now as they were in the 1980s. In his address, Gerard Stevens offers insights gleaned from more than 40 years at the forefront of helping people make the most of their medication.

#### PROFESSOR JULIAN TROLLOR

##### Closing the Gap for People with Intellectual Disability: Focus on Mental Health

Despite the widely acknowledged over-representation of mental illness in people with intellectual disability, access to quality mental health care that meets the needs of this group is highly problematic. More than a decade since ratifying the United Nations Convention on the Rights of Persons with Disabilities, there is little evidence of closure of the large gap between the mental health needs of people with intellectual disability, and the capacity of services and professionals to deliver accessible, quality

mental health services. Government, sector and academic leads met recently in Sydney, Australia to develop national consensus on the appropriate response to the mental health needs of people with intellectual disability. The Communique represent the current thinking about how to improve this situation in Australia, by developing a series of practical recommendations for the sector. Implications for mental health professionals and their organisations will be discussed with a particular focus on psychologists and their respective training and regulatory bodies.

#### DR NATHAN J WILSON

##### Redeveloping the Speciality Practice Standards for IDD Nursing: The NDIS and Beyond

This presentation will first revisit the formation of the research partnership between PANDDA and WSU. That is, to conduct background research to inform the redevelopment of the 2002 PANDDA Standards. Second, the presentation will describe the year 1 objectives and provide an overview of outcomes. Third, the purpose and content of the final report to PANDDA will be discussed in some detail. Fourth, the goals of Year 2 of the partnership will be described with an insight into progress to date. Finally, some perspectives about future national and international research collaborations will be presented.

#### TRACEY WRIGHT, TANIA LEWIS AND DR REBECCA POCKNEY

##### 'Keeping it Real' – Importance of peer support organisations in the development of nurse education in a large residential centre for adults with developmental disabilities.

Development of person-centred home meeting training in  
Large Residential Centres

When service managers at a large residential centre for over 300 adults with developmental disabilities in NSW were tasked with establishing person-centred meetings for the residents living in each of the 19 'home units' they called upon a local peer support organisation to assist with developing and delivering training to assist nursing staff to engage those they support in such 'home meetings'.



## History of the PANDDA Conference Awards

In the 1990s PANDDA decided to acknowledge Nurses who presented papers at the Annual Conference with two awards. The awards recognise the best overall presentation and the presentation with the most promise by a novice presenter. The selection criteria stipulate that the winners of these two awards must be either a Registered or Enrolled Nurse and that the presentation must be of relevance to Developmental/Intellectual Disability Nursing. The winners of the two awards are determined by a select group of conference delegates.

In 2011, the PANDDA committee decided to name the awards in honour of two Nurses who have consistently demonstrated commitment, advocacy, leadership and compassion for people living with a disability, their families and to the Nurses who support them. These two Nurses are Dr Chris Atkins and Mr Bob Weaver.

In 1984, Chris and Bob were members of a small working party to determine what knowledge, skills and attributes Nurses required on graduation from Nursing studies at Colleges of Advanced Education. It was through this project that the idea of a professional organisation for Nurses working in disability was first conceived. After a suitable gestational period, PANDDA was born. Chris and Bob were, of course, founding members.

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### Chris Atkins Award

The CHRIS ATKINS AWARD is to be awarded to the presentation voted as the best at the conference.

Chris Atkins has a younger brother with an intellectual disability and has worked in the area of Developmental/Intellectual Disability Nursing since 1969. During her career Chris's focus has been on the education of Nurses about the complex health care needs of people with disabilities. Chris has consistently advocated for the role of Nurses in the provision of health care to people with disabilities through various committees, conference presentations and publications.

With the assistance and commitment of many Nurse clinicians, Chris was awarded her PhD in 1999 for her research on Nurses' perceptions of quality of life for people with severe multiple impairments. As a clinician, Chris has been pivotal to the success of one service's devolution from an institutional setting to the community by developing a model of Nursing and health care planning that supports clients with complex and chronic health care needs, their families and the work of the Nurses who support them. Chris' services to PANDDA include the roles of President, Secretary and Technical Program Convenor for the annual conference. Chris believes that people with disabilities and their families have a right to a professional service from the best educated and creative Nurses who practise from an evidence base.

### Bob Weaver Award

The BOB WEAVER AWARD is to be awarded to the presentation voted as the one with most promise by a novice presenter.

Bob Weaver has worked in the area of Developmental/Intellectual Disability Nursing since 1975 as a clinician, lecturer, leader and manager. He is known for his strong advocacy for people with disabilities through his work on the Guardianship Tribunal, the establishment of a disability recreation project in the Blue Mountains, the devolution of an accommodation services, membership of various committees, and action on behalf of individuals. Bob is a Member of the NSW Council for Intellectual Disability and is a Foundation Fellow and Life member of the Australian College of Mental Health Nurses an organisation in which he held positions at both state and national levels through the late 1980s and 1990s and early 2000.

Bob has served as PANDDA President, Vice President, Executive member and Conference Convenor for 25 of the 29 Annual Conferences. It is in this latter role that Bob is known for his encouragement of Nurses to present their knowledge and experiences to others. Bob also convened the working party that developed PANDDA's Standards for Professional Practice. Bob remains passionate about the right of people with intellectual disabilities to live their lives to their fullest potential.

People, Purpose  
& Passion  
*Be Extraordinary*