PANDDA 30th Annual Conference 2019



IS YET TO COME

dream - believe - act - achieve







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## Conference Committee

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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





## Convenor's Welcome

It is with the greatest pleasure that the PANDDA Committee welcome you to Sydney and Parramatta for the 30th Anniversary PANDDA Conference and Annual General Meeting. The theme for this year's Conference is "the BEST is yet to come. dream – believe – act – achieve". Thirty wonderful years and the Best is yet to come!

We have assembled an inspired and passionate group of presenters, you will discover the work of the Keynote, Invited and Program Speakers is both inspiring and extraordinary. You will hear from people with a lived experience, families, medical specialists, nurses and Government who are leading with passion and purpose the opportunities to be the Best, including advocating the abilities of people with intellectual developmental disabilities.

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, you may even recognise someone from thirty years ago. In PANDDA's 30th Anniversary year we will acknowledges our past and looks forward to our future; indeed the Best is yet to come.

So come Celebrate bring your stories your passion and your commitment to people, their families and PANDDA; much has changed in thirty years and there are many stories to be told.

Thank you for your attendance at the PANDDA Conference and thanks to your employers who have continued to value the Annual PANDDA Conference. To the PANDDA Committee who have been working toward this conference for the past 15 months my congratulations to you all in delivering what is truly an extraordinary conference program. Our sponsors have once again been generous and willing partners. I look forward to meeting with you all.

I trust you will you leave the 30th PANDDA Conference feeling Inspirited, and you will be able to dream, believe, act and achieve in your roles as nurses.

Warm Regards,

Bob Weaver OAM, on behalf of the Conference Committee

## President's Welcome

Welcome everyone to the Professional Association of Nurses in Developmental Disability 30th Annual Conference.

This year's conference is particularly special as the 30th conference marks a major milestone for PANDDA. The PANDDA conference committee, once again led by Bob Weaver, have put together an exciting program that is fitting for such a celebration.

The 30th annual conference combines presentations from esteemed national leaders in the field, loyal friends of PANDDA, and some novice nurse presenters all mixed with the usual activities and fun. No doubt you will all contribute in your own way to the discussions as we all celebrate this wonderful milestone together.

As always, the conference is not possible without the support of sponsors and we thank our sponsors for their support this year. In addition to some promising presentations, there will be an update to the research program that PANDDA partners with Western Sydney University. As always, the PANDDA annual general meeting will be held during the conference and I urge all members to not only attend the meeting, but also consider becoming a part of the PANDDA committee as new ideas and fresh energy is always welcome.

We hope that you all enjoy this conference and take away many new ideas and fresh perspectives into the amazing work that you all do working with people with intellectual and developmental disabilities, their families and their key supporters.

Associate Professor Nathan Wilson PANDDA President







# Day 1. Tuesday 22 October 2019

08.45-09.00					
	WELCOME TO COUNTRY				
	Uncle Bruce Gale				
	CONFERENCE OPENING  Nathan Wilson Provident PANDDA and Pah Weaver OAM. Conference Convener.				
	Nathan Wilson, President PANDDA and Bob Weaver OAM, Conference Convenor Chair: Sue Easton, Technical Program Convenor				
	-				
	KEYNOTE SPEAKER: Adjunct Professor Sue Hawes  What was + what is = what can be. The role of nurses in developmental disabilities				
	Chair: Bob Weaver, PANDDA Committee				
09.45–10.20	INVITED SPEAKER Kim and Jae Creevey				
	Conscious bias towards disability. A family experience				
	Chair: Sue Easton, PANDDA Committee				
10.30-11.15	MORNING TEA AND TRADE DISPLAYS				
	KEYNOTE SPEAKER Jack Kelly and Jim Simpson, NSW Council of Intellectual Disability				
	Challenging health – the latest intellectual disability health advocacy and action in the health system and NDIS  Chair: Virginia Howie PANDDA				
	•				
	KEYNOTE SPEAKER Professor Julian Trollor  Health and Wellbeing of Autistic Adults and their Carers				
	Chair: Associate Professor Nathan Wilson, PANDDA				
12.45–13.45	LUNCH				
13.45-14.25	CONCURRENT SESSION 1	CONCURRENT SESSION 2	CONCURRENT SESSION 3		
	(JARRAH ROOM)	(AVALON ROOM)	(MADISON ROOM)		
	Chair: Maree McCulloch, PANDDA	Chair: Julie Gibson, PANDDA	Chair: Denise Robinson, PANDDA		
_		A New Zealand First:	Intentional Community Housing:		
_	CPR and Basic Life Support for				
	all of us, more than just a dream	A National Survey of IDD Nurses	A Case Study		
	all of us, more than just a dream Speaker: Elisha Deegan	Speaker: Henrietta Trip			
14.30–15.15	all of us, more than just a dream Speaker: Elisha Deegan OPTION 1 PANDDA Annual General Mo	Speaker: Henrietta Trip	A Case Study Speaker: Jennifer Rollo OAM		
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14.30–15.15	all of us, more than just a dream Speaker: Elisha Deegan  OPTION 1 PANDDA Annual General Mo Convenor: Associate Professor Nathan V  OPTION 2 WORKSHOP (MADISON ROC Speaker: Sharon Paley	Speaker: Henrietta Trip eeting Wilson, PANDDA President and Louise Hedges	A Case Study Speaker: Jennifer Rollo OAM  5, PANDDA Public Officer		
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14.30–15.15 15.15–15.45 15.45–16.30	all of us, more than just a dream Speaker: Elisha Deegan  OPTION 1 PANDDA Annual General Mc Convenor: Associate Professor Nathan V  OPTION 2 WORKSHOP (MADISON ROC Speaker: Sharon Paley Chair: Belinda Munyard, PANDDA  AFTERNOON TEA AND TRADE DISPLAY KEYNOTE SPEAKER Dr Seeta Durvasula	Speaker: Henrietta Trip  eeting  Wilson, PANDDA President and Louise Hedges  DM): Restraint Reduction: procedure, policy	A Case Study Speaker: Jennifer Rollo OAM  5, PANDDA Public Officer		
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14.30–15.15 15.15–15.45 15.45–16.30 16.30–19.30	all of us, more than just a dream Speaker: Elisha Deegan  OPTION 1 PANDDA Annual General Mc Convenor: Associate Professor Nathan V  OPTION 2 WORKSHOP (MADISON ROC Speaker: Sharon Paley Chair: Belinda Munyard, PANDDA  AFTERNOON TEA AND TRADE DISPLAY KEYNOTE SPEAKER Dr Seeta Durvasula Frailty and Ageing in People with Intel	Speaker: Henrietta Trip  eeting  Wilson, PANDDA President and Louise Hedges  DM): Restraint Reduction: procedure, policy  S  lectual Disability — Emerging Challenges	A Case Study Speaker: Jennifer Rollo OAM  5, PANDDA Public Officer		





# Day 2. Wednesday 23 October 2019

09.00-09.15	WELCOME TO COUNTRY AND WELCOME TO DAY 2 Bob Weaver OAM and Sue Easton, PANDDA				
09.15–10.00	KEYNOTE SPEAKER Adjunct Professor Kim Ryan Recognition of nurses and the important role they play in people lives Chair: Sue Easton, PANDDA				
10.00-10.15	PANDDA CELEBRATES 30 YEARS Chair: Bob Weaver, PANDDA				
10.15-10.45	MORNING TEA AND TRADE DISPLAYS				
10.45-11.30	KEYNOTE SPEAKER Clinical Professor Robyn Wallace Closing the Gap for People with Intellectual Disability: Focus on Mental Health Chair: Maree McCulloch, PANDDA				
11.30-13.00	INVITED PROFORMACE PLAYBACK THEATRE				
13.00-14.00	LUNCH				
14.00–14.40	CONCURRENT SESSION 1 (JARRAH ROOM) Chair: John Ryan, PANDDA	CONCURRENT SESSION 2 (AVALON ROOM) Chair: Julie Gibson, PANDDA	CONCURRENT SESSION 3 (MAIN ROOM) Chair: Denise Robinson, PANDDA		
	QUM Again? Revisiting analgesia administration in a young person with developmental disability Speakers: Georgina Hoddle, Olivia Morcos and Johannah Flynn	Toward nurse-led oral health interventions for people with IDD Speaker: Zhen Lin	Experience Sampling Method and the everyday experiences of adults with intellectual disability: A feasibility study toward supported selfmanagement of chronic illnesses Speaker: Nathan Wilson		
14.45–15.10	PANDDA RESEARCH PROJECTS UPDATES Dr Peter Lewis and Associate Professor Nathan Wilson Redeveloping the Speciality Practice Standards for IDD Nursing Chair: Bob Weaver PANDDA				
15.10-15.30	AFTERNOON TEA AND TRADE DISPLAYS				
15.30–15.45	PRESENTATION Chris Atkins and Bob Weaver PANDDA Awards Virginia Howie, Convenor PANDDA Awards and Nathan Wilson, PANDDA President				
15.45–16.30	KEYNOTE SPEAKER: Tish Bruce, Executive Director Health Ministry NSW  NSW Health – Enhancing and Integrating health care for people with Intellectual Disability  Chair: Associate Professor Nathan Wilson, PANDDA				
16.30–16.40	CONFERENCE CLOSE AND INVITATION TO THE 31st PANDDA CONFERENCE 2020  Nathan Wilson, President PANDDA; Sue Easton, Technical Program Convenor; Maree McCulloch, Conference Registrar;  Bob Weaver, Conference Convenor				
16.40-17.40	FAREWELL DRINKS Hosted by the PANDDA Committee				







# Keynote and Invited Speakers



#### DR HELEN BEANGE AM

Helen has been a friend and supporter of PANDDA for the past 30 years, we at PANDDA are honoured to have Helen attend and address the 30th PANDDA Conference. Helen was a pioneer in the healthcare of people with intellectual and developmental disability (ID) and continues to highlight significant health disparities. She demonstrated that the health of people with ID was poorer than the general community by undertaking population surveys that showed high rates of undiagnosed health conditions. Helen cofounded AADDM and Health SIRG, IASSID, two organisations dedicated to improving the health of people with ID. Dr Helen Beange AM has been awarded the inaugural Honorary Life Membership AADDM in 2016.



### **TISH BRUCE**

Tish is the Executive Director, Health and Social Policy Branch and currently acting as the Executive Director Mental Health Branch at the Ministry of Health. She is responsible for the development, implementation and governance of health policy and strategy in relation to the areas that span from early years to end of life, from acute to community and primary care and from universal to targeted care. Tish worked in the NSW public health sector as a clinician and manager across a diverse range of service settings and geographic areas. She has managed significant health system implementation and reforms over this time and has had a continuing interest in working to improve the health and wellbeing of people experiencing vulnerability.



DR SEETA DURVASULA (MBBS, DCH, M Paed., MPH, PhD)

Seeta Durvasula is a medical practitioner and Clinic Director of two multidisciplinary health clinics for people with intellectual disability, including one of the six specialised multidisciplinary health teams established by NSW Health. She has over 30 years of clinical experience in the health of people with intellectual disability. Seeta is a Senior Lecturer in Developmental Disabilities with the Faculty of Medicine and Health, University of Sydney. She teaches medical, dental and pharmacy students, and a Unit in the postgraduate course, Master of Health Science, (Developmental Disability) at the University of Sydney. Seeta's research areas are in mortality, falls, vitamin D deficiency, frailty and health outcomes in people with intellectual disability. She is an editorial consultant for the Journal of Intellectual and Developmental Disability and is a peer reviewer for a number of other journals. Seeta is a member of the Committee of the Australian Association of Developmental Disability Medicine (AADDM).





# Keynote and Invited Speakers



### ADJUNCT PROFESSOR SUE HAWES

Sue is the Chief Nursing and Midwifery Officer of the Northern Territory. She started her nursing career by completing a Mental Retardation Certificate and remained working in disability services for nearly 15 years. Sue was a founding member of PANDDA and has held Ministerial appointment under the Disability Services Act 1985 for over 10 years. Sue's career spans including work in academia, consulting and large scale, national transformational change programs. She is now a senior executive able to mobilising high level strategic plans. Sue has an Executive Master of Business Administration, is a Board Director and Fellow of the Australian College of Nursing and an Adjunct Professor at Charles Darwin University and Queensland University of Technology.



#### JACK KELLY

Jack has worked in the disability research and advocacy sector for the past four years. He started his research journey with the Centre for Disability Studies Inclusive Research Network in 2015, moving into a one day a week position as Research and Administration Assistant. Jack currently holds a position at the Council for Intellectual Disability as a Project Worker where he has worked on various projects, such as Mainstream and Me and My Health Matters. Jack is a co-facilitator of information sessions and a developer and tester of easy read documents. Jack also works at the University of Technology Sydney as a Research Assistant working on My Home My Community. Jack is passionate about advocating for the rights of people with intellectual disability, with a strong focus on good health care due to his own experience within the health care system.



#### PLAYBACK THEATRE

At Playback Theatre Sydney, we invite stories from the audience and engage in with you to encourage empathy, create connections and build bridges of understanding. We use reflection, laughter, movement, sound, silence and stories to bring people together. Our experiential performances are designed to turn your stories into moving, funny and beautiful improvised theatre that illuminates the human condition.







# Keynote and Invited Speakers



#### ADJUNCT ASSOCIATE PROFESSOR KIM RYAN

Adjunct Associate Professor Ryan is the former Chief Executive Officer of the Australian College of Mental Health Nurses (ACMHN). The ACMHN is the peak professional mental health nursing organisation and the recognised Credentialing body for mental health nurses in Australia. Kim is passionate about mental health and mental health nursing holding a more prominent position on health agendas at local, state, national and international levels and believes this can only be achieved with a strong, united, professional voice. Kim believes that through mental health nursing and nursing we can improve the lives of people with mental health problems. She was awarded the position of Adjunct Associate Professor by Sydney University in 2009 in recognition of her contribution to the nursing profession. In December 2016 Kim was awarded the inaugural Australian Mental Health Prize by Prime Minister Malcolm Turnbull.



#### JIM SIMPSON

Jim has had a leading role in many areas of service system and legislative reform including well supported alternatives to gaol for offenders with intellectual disability and legislation covering guardianship, disability services and independent complaints and monitoring bodies. In recent years, Jim's work has particularly focused on improved health care for people with intellectual disability and the development and implementation of the NDIS.



### 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. Further details and resources are available at https://3dn.unsw.edu.au. Follow 3DN on twitter @3DN\_UNSW.



### **ROBYN WALLACE**

Clinical Associate Professor Robyn Wallace is a consultant physician in internal medicine in Hobart, Tasmania. She runs a perioperative medical service, and specialised physical healthcare services for adults with intellectual disability and adults with mental illness. Robyn teaches medical students, participates in some smallish but interesting research, and is a student herself most of the time. She is a board member of a disability service provider and of the Internal Medicine Society of Australia and New Zealand.





# Program Speakers

#### ASSOCIATE PROFESSOR NATHAN WILSON

Academic, Senior Lecturer Western Sydney University (PhD)

Nathan Wilson has a background as a nurse specialising the in the care of people with intellectual and developmental disability.

As a researcher, he is interested in applied studies that enhance the health, wellbeing and participation of people with disabilities.

#### **ELISHA DEEGAN**

Registered Nurse, Graduate Certificate in Pediatrics and Continence Assessment, Current Nursing Honours in research student. Clinical Care Manager at St Giles; Member of Tasmania Brach of Australian Resuscitation Council

Elisha is a nurse with nearly 20 years' experience who has been working at one of Tasmania's largest disability organisations, St Giles, for the last 4 years. Elisha is currently completing an honours project at the University of Tasmania with high hopes of continuing on to complete a PhD to see her research project through to implementation.

#### **GEORGINA HODDLE**

CNE, RN, MAppLing (TESOL) Sydney University, Faculty of Pharmacy, Achieve Australia Inc., and Alliance Health Services Group

Georgina Hoddle is a Registered Nurse (RN) with experience as a clinical nurse educator in disability nursing, and as an RN in Aged Care. Georgina has supervised both Bachelor and Masters students of Pharmacy, as well as undergraduate nursing students on clinical placements which led her to understand the need for the correct assessment of pain in people with disability, particularly those who are non-verbal.

### **OLIVIA MORCOS**

BPharm student, Assistant Pharmacist

Olivia Morcos is a 4th year Bachelor of Pharmacy student, University of Sydney. She is currently employed at Ramsay Pharmacy, St George Private Hospital. Olivia undertook a 2-week placement at a disability centre in Sydney (2019) focusing on the follow-up of quality use of medicines in young people with developmental disability.

### JOHANNAH FLYNN

Residential Unit Nurse Manager, Registered Nurse

Johannah Flynn is a Specialist Disability Registered Nurse (RN) from Ireland who has extensive experience supporting adults and young people with intellectual disability/complex health needs. Johannah has facilitated Sydney University placements for both Masters and undergraduate students of Pharmacy and Nursing during her time as both an RN and in her current position as Residential Unit Nurse Manager.





# Program Speakers

#### HENRIETTA TRIP

Registered Nurse, PhD (Otago) Senior Lecturer, Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand

Henrietta's research interests are populations considered vulnerable, long-term conditions, service access, equity and nursing education. She is the Chair of the Canterbury Disability Provider's Network and Chair of the National Disability Nurses Branch in Te Ao M ramatanga – New Zealand College of Mental Health Nurses.

#### JENNIFER ROLLO OAM

Projects Manager at Genetic Alliance Australia. Past President of RASAID, President of CdLS Australasia Inc.

Jenny Rollo is the mother of a 36 year old man who has a significant intellectual disability. Facing a future void of any real, humane options for supported living for her son, Jenny and a group of other local parents with the same concerns pooled their knowledge and talents to advocate for purpose-built homes for their sons and daughters. What developed over the 11 years of lobbying became a person-centered cluster development of homes that were designed and built for the 15 original residents.

### JAE CREEVEY

Flight Paramedic and brother of Harrison

Jae Creevey is currently a flight paramedic and came from a background working in disability support services and is brother to a young man who lived with a disability. Since his brothers passing, Jae and his family have been sharing Harrison's story and working to effect change for the betterment of people living with disability. The primary focus is on promoting holistic, patient centred care and striving for systemic policy change within the health care system to ensure better outcomes for people living with a disability.

#### KIM CREEVEY

Primary School Teacher, Queensland Education and mother of Harrison

Kim is currently a primary school teacher working for Queensland Education. Kim studied primary and early childhood education at university and has worked in the industry for over 25 years. A shift in the education policies in Queensland has seen an era of inclusion and exposed Kim to numerous individuals with a variety of disabilities. Kim is married and the mother of three wonderful boys, one of which suffered an ABI at three years of age and was diagnosed a quadriplegic. Along with her husband they became the primary carers for Harrison for 15 years. Following Harrison's avoidable death in 2015, Kim has been actively working to advocate for change in legislation to the health and disability sectors in the areas of law, education and disability support.





# Program Speakers

#### **SHARON PALEY**

RN, Florence Nightingale Scholar, Principal Advisor Restrictive Practice Standards

Sharon is a registered nurse, who has worked with children and adults who have intellectual disability over the past 36 years. Sharon has a professional interest in behaviour support and reducing and eliminating restrictive practices. Specialising in behaviour support and reducing aversive practices for 20 years she has authored papers, books and presented on both topics internationally. She has led the development of interdepartmental government guidance on the use of restrictive interventions, developed frameworks of best practice, implemented organisational change, reviewed the use of restrictive practices and acted as an expert witness in civil, criminal cases and the court of protection in the UK in cases related to the restriction of liberty and human rights of people.

#### MS ZHEN LIN

Bachelor of Nursing, Research Assistant, School of Nursing and Midwifery, Western Sydney University

Ms Zhen Lin is a Registered Nurse with over three years' experience working as a research assistant in different research projects within the nursing discipline. Her research training has developed comprehensive skills in literature reviews, quantitative and qualitative methods, including data collection for randomised controlled trial (RCT) studies and data analysis for qualitative studies.







#### ASSOCIATE PROFESSOR NATHAN WILSON

Experience Sampling Method and the everyday experiences of adults with intellectual disability:

A feasibility study toward supported self-management of chronic illnesses

### Research Aims

To explore, using Experience Sampling Method, if people with mild-moderate ID can respond to a survey about their experiences and feelings using a mobile device. If this is feasible, it can potentially be used for people with ID who have a chronic illness, such as diabetes, as a way to increase self-management and provide optimal care.

#### Methods

We developed an online survey and tested this with 19 adults with ID who used a mobile device to answer the survey over a period of 7 days.

#### Results

The method was both reliable and valid although improvements need to be made with the survey layout, stability of the app across different mobile devices, and to make the language more accessible.

### Conclusion

Experience sampling Method using a mobile device holds great promise in helping people with mild-moderate ID who also have a chronic illness to better self-manage their symptoms and, in partnership with nurses and other supports, provide better care.

### **ELISHA DEEGAN**

CPR and Basic Life Support for all of us, more than just a dream

#### Research Aims

Identification of guidelines, protocols, practice principles for delivery of cardio pulmonary resuscitation (CPR) and basic life support (BLS) to people in wheelchairs or those with atypical chest shape.

#### Methods

Extensive literature review.

#### Results

Four published articles were discovered; two discussed the importance of CPR techniques being taught to carers of medically fragile children. The other two papers identified the lack of guidelines for delivery of BLS and CPR to people with atypical chest shapes and those in wheelchairs. This included some discussion regarding techniques being taught to Learning Disability Nursing Students in the United Kingdom. The authors of the second two papers discovered acknowledged the need for further research.

One guideline was located that mentioned removal of a patient from a chair to the floor for the purpose of CPR.

#### Conclusion

There is a recognized requirement to remove disparities in the provision of healthcare to people with a disability, the introduction of expanded guidelines including BLS for people with atypical chest shapes and those in a seated position would likely lead to reduced mortality rates for this cohort during emergency situations

### GEORGINA HODDLE, OLIVIA MORCOS AND JOHANNAH FLYNN

QUM Again? Revisiting analgesia administration in a young person with developmental disability

A Bachelor of Pharmacy student (4th year, BPharm) followed-up the Quality Use of Medicines (QUM) review conducted in 2018 by two Masters of Pharmacy students, supervised by a Clinical Nurse Educator. These 2-week placements in a disability centre allowed access to the files of a young person with developmental (but not intellectual disability); medication charts, progress notes and the Disability Distress Assessment Tool (DisDat) compiled over a 3-month period were examined.

Prescribed analgesia includes MS Contin (BD), paracetamol and ibuprofen (PRN doses). Data analysis illustrates gaps in





administration although DisDat and Registered Nurses' (RNs) pain assessment indicated the teenager's pain was severe. As this young person has various and different means of communication (using their eyes, and is learning to use an augmentative communication device), questions concerning site and severity of pain should be standardised and specific. All staff should receive education to correctly assess the location and pain score, administer PRN analgesia and proceed with an evaluation of its effectiveness.

Understanding pharmacokinetics is essential for RNs to optimise and ensure QUM. MS Contin reaches peak morphine concentrations 4-5hrs after administration with levels persisting for 12hrs. It would be appropriate to ask this young person if they are experiencing pain 4hrs after the MS Contin morning dose and use clinical judgement and RN assessment skills to decide whether PRN paracetamol or ibuprofen (or both) are required.

Data compiled by the B.Pharm student was of use for this teenager's recent Hospital Pain Management Review, and they do live more comfortably because of this and the previous QUM review, which is recommended annually.

#### HENRIETTA TRIP

A New Zealand First: National Survey of IDD Nurses

#### Research Aims

To identify and explore the role of registered and enrolled nurses working alongside people with intellectual and developmental disability (IDD) in New Zealand

### Objectives

- Identify the role of nurses in relation to the wider health sector in terms of community, primary, secondary and tertiary care.
- Illustrate the specific skills nurses use to improve the health outcomes for people with intellectual disability.
- Identify education priorities for nurses working with people with intellectual disability.

#### Methods

A descriptive survey design approach was used and the link disseminated via Survey Monkey to prospective participants using purposive and snowball sampling. Due to the sample size, analysis was undertaken using descriptive statistics. The survey tool was adapted with permission from that devised and implemented by Dr Nathan Wilson and colleagues, Western Sydney University and PANDDA (Professional Association of Nurses in Developmental Disability Australia Inc.). Ethical approval was through the University of Otago, reference code 19/040.

#### Results

At the time of submitting this abstract, the survey was currently underway at which point 41 responses had been received out of a possible 254 (16%).

#### Conclusion

This research will contribute to the Australasian body of knowledge about the specific role of intellectual and developmental disability nursing. The results will inform priorities in New Zealand nursing education and workforce, as well as the development of IDD nursing practice standards.

#### JENNIFER ROLLO OAM

Intentional Community Housing. A Case Study

#### Research Aims

To build an intentional community for a group of friends who have intellectual disability.

### Methods

Case study of Ryde Area Supported Accommodation for Intellectually Disabled (RASAID)

#### Results

The RASAID project has been a tremendous success for the residents who have each shown positive developments in their lives. They settled quickly into their new homes and are now able to live their lives on their terms. Parents and siblings can support their loved ones with more vigour now they are not providing the hands-on physical care.







#### Conclusion

This concept can be copied by other families – picking and choosing aspects of the design and build to suit their own people's needs. The model is also an example to housing providers of the innovative nature of families. Disability housing is not a "one size fits all" affair.

#### KIM AND JAE CREEVEY

### Conscious bias towards disability. A family experience

Harrison Creevey was a boy who lived with a disability. He lost his life when hospital staff repeatedly failed to act in accordance with best practice and neglected to treat him appropriately, seeing him for his disability and not as a person.

This presentation will consist of a detailed account of a boy who lost his life after receiving sub-standard care. It will be a personal walkthrough of his journey and it will highlight the many shortfalls and failures present in the care of this boy. It will be conducted by his family who were present and have been campaigning for change and justice in the years following his passing.

#### **SHARON PALEY**

Restraint Reduction; procedure, policy, improving practice and current issues.

The use of restrictive practices with people who have intellectual disability is controversial (Allen 2011, Paterson 2009, Paley- Wakefield 2013). Concerns about restrictive practices are often raised by the media, advocates and people who have been exposed to their use. Frameworks for practice internationally often provide standards by which restrictive practice can be used, outline codes of practice for training or legislate for their use with protections; it has been asserted (Allen 2011), that this is potentially creating an authorising environment. There is a lack of focus on building the necessary knowledge and skills for reducing the use of restrictive practices and improving practice (CBF 2019, CYDA

2017). The author questions whether legislative or procedural approaches alone are sufficient for achieving a reduction is the use of restrictive practices across settings. This presentation will refer to international research and evidence on the topic, discuss approaches for reducing the use of restrictive practices (Deveau & Leitch 2018, Huckshorn 2006, Paley- Wakefield 2013)), highlight ethical decision making (Paley 2014) and provide an opportunity for discussion.

#### **SHARON PALEY**

Is the message 'restrain better' when it should be 'restrain less'?

The presentation will discuss relevant research and evidence.

The presenter and author will question whether relevant legislation and policy internationally is creating an authorising environment that does not necessarily lead to a decrease in the use of restrictive practices. Is the current message 'restrain better' not 'restrain less'?

The author will highlight common barriers to reducing and eliminating restrictive practices and discuss how organisations and individuals might overcome some of these.

The author will explore evidence-based models for reducing and eliminating restrictive practices and consider how organisations can adopt reduction strategies/approaches and incorporate them into systemic cultural change that leads to a real reduction in reliance on restrictive practices.

The author will encourage discussion and seek to explore opinion about this controversial topic and what delegates believe might address some of their practice concerns with a focus to reduce reliance on restrictive practices.





#### MS ZHEN LIN

Toward nurse-led oral health interventions for people with IDD

#### Research Aims

To summarise existing evidence regarding the oral health status and problems in people with Intellectual Developmental Disability (IDD), and to identify strategies in intervention research associated with improving oral health outcomes in this population.

#### Methods

One structured literature search was applied to screen oral health research studies in people with IDD. Two independent scoping literature reviews were conducted in line with the study aims.

#### Results

- Prevalence of dental problems is significantly higher in people with IDD when compared to general population; poorer access to services and anxiety during dental procedures were also key issues for this vulnerable group;
- people with IDD with their oral health, strategies including different aspects from daily oral hygiene support to optimizing dental clinic settings, as well as assessing efficacy of outreach oral health services.

#### Conclusion

A uniform approach to supporting oral health for people with IDD is unlikely to succeed. Further quality interventional study is needed to support the diverse needs of this population. Presented will be a summary of a program of nurse-led research that is starting in this area.







# A Brief History of PANDDA

In 1983 with a move towards nurse education in Colleges of Advance Education and later Universities, a group of nurses came together to ensure the professional interest and standards of nurses supporting people with intellectual disability would be maintained. They formed a Working Party at the suggestion of Meryl Caldwell-Smith AM, Chief Nursing Officer for the New South Wales Department of Health. Their task was to produce 'exit competencies' showcasing the skills, knowledge and expertise that nurses graduating from colleges and universities would need in order to support people with an intellectual disability. The Working Party was made up of Dr Chris Atkins PhD, Diana Dalley, Ross Fear, Elisabeth van Leeuwen, Bob Weaver OAM and Carol Welsh.

'Meryl was looking out for us, when she suggested we needed to do something about nurse education. It took a year of work to produce the core elements/'exit competencies' document to ensure that the clinical skills of nurses would be maintained. (Bob Weaver OAM, 2014. Dawn to Dusk: Celebrating 200 Years of Service at Rydalmere).

From this undertaking, the Working Party saw a need for a professional organisation in order to have a greater advocacy voice, to represent and maintain the professional interest skills

and knowledge of nurses caring for and supporting people with intellectual disability.

In 1989 the Professional Association of Nurses in Developmental Disability Australia (PANDDA) was established, led by nurses originally from Rydalmere, Marsden Centre, Grosvenor and Riverside along with staff from other residential centres and university academics. Many nurses originally from Rydalmere and Marsden were foundation members; some like Norma Cloonan, Catharine Hulst, Penny Kearney, Russell Jones, Chris Atkins and Bob Weaver remain active committee members today. One of the early committee members Chris Laurie came up with the original name for PANDDA, The Professional Association for Nurses working in Developmental Disability Areas. Later changed to The Professional Association of Nurses supporting people with Developmental Disability Australia (PANDDA Inc).

Through PANDDA, Nurses supporting people with a developmental disability were able to liaise with universities and government departments to ensure professional standards in developmental disability nursing were maintained, and the rights and self-determination of people with an intellectual disability were upheld and protected.

# PANDDA Timeline

President: Diana Dalley
Vice President: Glenn Ball
Secretary: Chris Atkins
Treasurer: Catharine Hulst
Committee: Rosemarie Kyle, Roslyn Rowlands, Barbara
Anderson, Kathryn Harris, Marie Cummins, William Ferrett,
Lyn Ramsay, Jan Lang, Russell Jones, Denise Heap, Isla Bowen,
Johanne Dawson, Lynette Booth, Margaret Gerry, Jeffrey
Green, Penny Kearney, Shanny Ooi, Stephanie McMahon, Rae
Samuel, Bob Weaver and Lisa White

1989





1990

President: Diana Dalley Vice President: Glenn Ball Secretary: Chris Atkins Treasurer: Catharine Hulst

1st Conference: Change & Diversity – Developmental Disability

Nursing:

Convenor: Glenn Ball (Gladesville Hospital)

President: Susan Gallagher
Vice President: Glenn Ball
Secretary: Chris Atkins
Treasurer: Catharine Hulst
2nd Conference: Empowerment: Marketing the
Professionalism of Nurses in Developmental Disability.
Convenor: Glenn Ball (Western Suburbs Leagues
Club, Unanderra)

• 1991

1992

President: Susan Gallagher Vice President: Bob Weaver Secretary: Chris Atkins Treasurer: Catharine Hulst

Membership Secretary: Penny Kearney

3rd Conference: Developmental Disability Nursing:

Moving On

Convenor: Bob Weaver (University of Western Sydney,

Westmead Campus)

President: Margaret Gerry
Vice President: Helen Wright
Secretary: Chris Atkins
Treasurer: Catharine Hulst
Membership Secretary: Penny Kearney
4th Conference: Clients with Challenging Behaviours: Aspects
of management
Convenor: Bob Weaver (University of Western Sydney,
Westmead Campus)

1993

1994

President: Margaret Gerry
Vice President: Bob Weaver
Secretary: Helen Wright
Treasurer: Catharine Hulst
Membership Secretary: Penny Kearney
5th Conference: People with Developmental Disability
and Their Families. 1994 The year of the Family.
Convenor: Bob Weaver (University of Western Sydney,

Westmead Campus)







President: Margaret Gerry Vice President: Bob Weaver Secretary: Norma Cloonan Treasurer: Vivienne Gan Membership Secretary: Penny Kearney

6th Conference: Transition & Nurses Convenor: Bob Weaver (Rydalmere Centre, Rydalmere) • 1995

1996

President: Chris Atkins Vice President: Bob Weaver Secretary: Lorraine Bettison Treasurer: Vivienne Gan

Membership Secretary: Penny Kearney 7th Conference: Best Practice

Convenor: Bob Weaver (Lachlan Centre, North Ryde)

President: Chris Atkins
Vice President: Bob Weaver
Secretary: Lorraine Bettison
Treasurer: Russell Jones
Membership Secretary: Paula Firmstone
8th Conference: Professional Issues
Convenor: Rae Samuel (Blaxland Centre, Ryde)

1997

1998

President: Bob Weaver Vice President: Sandra Hoot Secretary: Cecily Spradbrow Treasurer: Russell Jones

Membership Secretary: Paula Firmstone

9th Conference: Health Issues for People with Developmental

Disabilities

Convenor: Rae Samuel (Blaxland Centre, Ryde)

President: Bob Weaver Vice President: Sandra Hoot Secretary: Cecily Spradbrow Treasurer: Russell Jones

Membership Secretary: Mary MacPherson 10th Conference: Visions for the Future 2000 & Beyond Convenor: Rae Samuel (Blaxland Centre, Ryde) 1999





President: Sandra Hoot Vice President: Paul Hawes Secretary: Norma Cloonan Treasurer: Russell Jones

Membership Secretary: Mary MacPherson

11th Conference: Nurses in Developmental Disability:

Who Needs Them!

Convenor: Lorraine Bettison (Epping RSL Club, Epping)

President: Paul Hawes Vice President: Bob Weaver Secretary: Cecily Spradbrow Treasurer: Russell Jones Membership Secretary: Lorraine Coughlin 12th Conference: Diversity in Practice Convenor: Cheryl Jones/Paul Hawes (Epping RSL Club, Epping)

President: Paul Hawes Vice President: Bob Weaver Secretary: Norma Cloonan Treasurer: Russell Jones

Membership Secretary: Lorraine Coughlin
13th Conference: Developmental Disability Nurses: Promoting

Healthy Lifestyles.

Convenor: Bob Weaver (Epping RSL Club, Epping)

President: Paul Hawes Vice President: Norma Cloonan Secretary: Paul Leckie Treasurer: Russell Jones Membership Secretary: Lorraine Coughlin 14th Conference: Developmental Disability Nursing: Where to

from Here Convenor: Cheryl Jones (Epping RSL Club, Epping)

President: Norma Cloonan Vice President: Paul Hawes Secretary: Lindy Isaksen Treasurer: Russell Jones

Membership Secretary: Lorraine Coughlin

15th Conference: Person Centred Support: The Challenges for

Nurses working in Developmental Disability Convenor: Bob Weaver (Epping RSL Club, Epping)







President: Norma Cloonan Vice President: Margaret Mason

Secretary: Lindy Isaksen Treasurer: Russell Jones

Membership Secretary: Lorraine Coughlin 16th Conference: Developmental Disability Nurses: Lost or just

harder to find!

Convenor: Bob Weaver (Epping RSL Club, Epping)

2005

2006

President: Norma Cloonan Vice President: Margaret Mason Secretary: Mary MacPherson Treasurer: Russell Jones

Membership Secretary: Lorraine Coughlin

17th Conference: Access & Equity: Health Care for People with

Developmental Disabilities

Convenor: Bob Weaver (Epping RSL Club, Epping)

President: Norma Cloonan
Vice President: Margaret Mason
Secretary: Mary MacPherson
Treasurer: Russell Jones
Membership Secretary: Lorraine Coughlin
18th Conference: PASSION: Imagine the possibilities...awaken
your dreams and rediscover your passion for developmental

disability nursing Convenor: Bob Weaver (Epping RSL Club, Epping) 2007

2008

President: Norma Cloonan Vice President: John Ryan Secretary: Cecily Spradbrow Treasurer: Russell Jones

Membership Secretary: Lorraine Coughlin 19th Conference: Building & Connecting Bridges Convenor: Bob Weaver (Epping RSL Club, Epping)

President: Norma Cloonan
Vice President: John Ryan
Secretary: Cecily Spradbrow
Treasurer: Russell Jones
Membership Secretary: Lorraine Coughlin
20th Conference: Changing Times: Words,
Experiences and Dreams
Convenor: Bob Weaver (Epping RSL Club, Epping)

2009





2010

President: John Ryan
Vice President: Norma Cloonan
Secretary: Cecily Spradbrow
Treasurer: Russell Jones
Membership Secretary: Lorraine Coughlin
21st Conference: Coming of Age: A Celebration of
developmental Disability Nursing. 2010 The International
Year of the Nurse. Convenor: Bob Weaver; Technical Program

Convenor Chris Atkins (Mercure Hotel, Parramatta)

President: Linda Goddard
Vice President: Norma Cloonan
Secretary: Cecily Spradbrow
Treasurer: Russell Jones
Membership Secretary: Lorraine Coughlin
22nd Conference: Owing Our Practice: Learn
from yesterday, Live for today, Hope for
tomorrow (Albert Einstein)
Convenor: Damain Heron/Bob Weaver; Technical Program
Convenor: Chris Atkins (Sebel Hotel, Parramatta)

• 2011

2012

President: Linda Goddard Vice President: Norma Cloonan Secretary: Sue Easton Treasurer: Russell Jones Membership Secretary: Lorraine Coughlin

23rd Conference: Great Expectations: Take nothing on its look; take everything on Evidence. There is no

better rule (Charles Dickens)

Convenor: Damian Heron/Bob Weaver; Technical Program Convenor: Chris Atkins (Novotel Hotel, Parramatta)

President: Linda Goddard
Vice President: John Ryan
Secretary: Sue Easton, Treasurer: Russell Jones
Membership Secretary: Lorraine Coughlin/Norma Cloonan
24th Conference: Partnership & Possibilities — Nursing
Practice in Disability. Models for health care and social equity.
If opportunity doesn't knock, build a door (Milton Berle)
Convenor: Damian Heron/Bob Weaver; Technical Program
Convenor: Sue Easton Conference Registrar: Alicia Rogers
(Novotel Hotel, Parramatta)

2013

2014

President: Linda Goddard Vice President: Bob Weaver Secretary: Sue Easton Treasurer: Russell Jones

Membership Secretary: Norma Cloonan

25th Conference: Through the looking glass – Wisdom,

reflection, experience.

Convenor: Damian Heron/Bob Weaver; Technical Program Convenor: Sue Easton; Conference Registrar: Maree McCulloch

(Novotel Hotel, Parramatta)







President: Sue Easton
Vice President: Louise Hedges
Secretary: Sue Easton
Treasurer: Russell Jones/John Ryan
Membership Secretary: Norma Cloonan
Public Officer: Louise Hedges

26th Conference: Enable the Future: Change-Choice-Rights-Wellbeing-Practice. Convenor: Damian Heron/Bob Weaver; Technical Program Convenor: Sue Easton; Conference Registrar: Maree McCulloch (Novotel Hotel, Parramatta)

2016

President: Linda Goddard
Vice President: Nathan Wilson
Secretary: Sue Easton
Treasurer: Russell Jones/John Ryan
Membership Secretary: Norma Cloonan
Public Officer: Louise Hedges
28th Conference: Waves of Change...Oceans of
Opportunity...Starts With Us. Convenor: Damian Heron/Bob
Weaver; Technical Program Convenor: Sue Easton; Conference
Registrar: Maree McCulloch, PANDDA Awards Convenor:
Catharine Hulst (Novotel Hotel, Parramatta)

2018

President: Nathan Wilson
Vice President: Louise Hedges
Secretary: Sue Easton
Treasurer: Russell Jones/John Ryan
Membership Secretary: Norma Cloonan
Public Officer: Louise Hedges
30th Conference: The Best is yet to come -dream – believeact-achieve Convenor: Bob Weaver; Technical Program
Convenor: Sue Easton; Conference Registrar: Maree
McCulloch; PANDDA Awards Convenor: Virginia Howie
(Novotel Hotel, Parramatta)

2015

President: Sue Easton Vice President: Louise Hedges Secretary: Lisa Craig

Treasurer: Russell Jones/John Ryan Membership Secretary: Norma Cloonan Public Officer: Louise Hedges

27th Conference: A New World: Inspiring Abilities. Convenor: Damian Heron/Bob Weaver; Technical Program Convenor: Sue Easton; Conference Registrar: Maree McCulloch; PANDDA

Awards Convenor: Catharine Hulst (Novotel Hotel, Parramatta)

2017

President: Linda Goddard Vice President: Nathan Wilson Secretary: Sue Easton

Treasurer: Russell Jones/John Ryan Membership Secretary: Norma Cloonan

Public Officer: Louise Hedges

29th Conference: People, Purpose & Passion: Be Extraordinary. Convenor: Bob Weaver; Technical Program Convenor: Sue Easton; Conference Registrar: Maree McCulloch; PANDDA

Awards Convenor: Catharine Hulst (Novotel Hotel, Parramatta)

• 2019





### 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.

### 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' 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 26 of the 30 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.



