



"Through the Looking Glass... Wisdom, Reflection, Experience... 10 years on

PANDDA 35th Annual Conference
Monday 14 and Tuesday 15 October 2024
Novotel Parramatta

35
YEARS
pandda



2024 PANDDA Conference
Monday 14 & Tuesday 15 October 2024
Novotel Parramatta



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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.

Other benefits include collegial support, networking and contribution to your profession; a voice in many state and national bodies; discounts for the annual PANDDA conference and educational programs; free webinars and a quarterly newsletter; and a professional identity, recognition and autonomy.

Join and pay online at www.pandda.net

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Convenor's Welcome

Dear Colleagues and Friends,

On behalf of the PANDDA Committee, it is my pleasure to welcome you to Dharug Country in Parramatta, Sydney. Thank you all for joining us for the 35th PANDDA Conference and Annual General Meeting over the next two days.

We are thrilled to welcome nurses, individuals with lived experience, care workers, and health professionals. Our conference theme, **"Through the Looking Glass – Wisdom, Reflection, Experience... 10 Years On,"** invites us to explore the progress and challenges we have faced over the past decade.

Inspired by Lewis Carroll's timeless tale, *Through the Looking-Glass*, we embark on a journey that blurs the lines between reality and imagination. Like Alice, who navigates a whimsical world and confronts her own identity, we, too, are called to reflect on our past experiences. These reflections can teach us invaluable lessons as we move forward.

I encourage you to draw inspiration not only from Alice's journey but also from our distinguished keynote speakers: Chris Stirling, RN Senior Vice President of the Crisis Prevention Institute in the UK, and Dr. Natalie Ong, Developmental Behavioural Paediatrician at Children's Hospital Westmead, Sydney. Additionally, we are fortunate to have speakers with lived experience, experts from the Council for Intellectual Disability, the Centre of Excellence in Intellectual Disability Health, our talented program speakers, and a performance from Playback Theatre to Celebrate PANDDA's 35th year.

Let us embrace the spirit of self-reflection, awareness, and acceptance as we navigate the complexities and joys of our profession. Through our collective dedication, may we illuminate the path for those we care for, guiding them toward a brighter and more inclusive future.

As Lewis Carroll said to Alice, "The secret, Alice, is to surround yourself with people who make your heart smile. It's then, only then, that you'll find wonderland."

I hope you find your own wonderland over the next two days. I encourage you to:

- Discover the latest advancements in intellectual disability healthcare.
- Engage in our concurrent sessions.
- Visit our Sponsors and their trade displays.
- Enjoy the captivating performance by Playback Theatre.
- Listen to PANDDA President Gail Tomsic as she shares the extensive work undertaken by PANDDA this year.
- Outreach, network and forge new connections that inspire collaboration and joy.
- Ponder taking on a position within the PANDDA Committee.

As we commemorate 35 years of PANDDA as a formal organisation, let us reflect on our journey and achievements while looking ahead to the future of nursing and support for individuals with intellectual and developmental disabilities in Australia. We will also present two awards at the end of the conference: the My Story Award, recognising an individual or group with lived experience, and the Chris Atkins & Bob Weaver Award for the best presentation. You can find the award criteria in your conference booklet, and I would like to extend my gratitude to Virginia and Tessa Howie for bringing the concept of the My Story Award to the PANDDA Committee.

Your presence and participation over the next two days will contribute significantly to the success of this landmark conference, promising a memorable and rewarding experience for all.

Warm regards,
Bob Weaver OAM, Conference Co-Convenor
on behalf of the PANDDA Conference Committee



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President's Welcome

Welcome everyone to the Professional Association of Nurses in Developmental Disability 35th Annual Conference.

Once again, the PANDDA Conference Committee has created a great and inspiring program for everyone to enjoy and learn from. As always, a highlight of every PANDDA conference is the opportunity to meet, interact, laugh and talk about nursing together under the one roof. It will be great to hear from Dr Natalie Ong, Developmental Paediatrician, about the journey to improve health staff capability with the development of an innovative program and Chris Stirling from the Crisis Prevention Institute from the UK. We also have some new nurse presenters this year and it will be wonderful to hear about the diverse work that nurses do to help people with intellectual and developmental disability lead the best life possible and see how far we have come.

A big thank you to Bob Weaver and the PANDDA Conference Committee for all of the hard work that goes on behind the scenes. As always, the conference is not possible without the support of our sponsors, and we thank our sponsors for their support this year.

The PANDDA annual general meeting will be held during the conference. This is an important meeting where a new committee will be elected and I urge all PANDDA members to consider becoming a part of the PANDDA committee. New ideas and diverse impetus are always needed and welcomed.

On behalf of the PANDDA executive, we hope that you will not only enjoy this conference and the time to connect with like-minded peers, but also to embrace the continuing professional development opportunities our wonderful speakers offer.

Once again, a sincere acknowledgement to you all for the work that you do supporting and caring for people with intellectual and developmental disabilities, their families and their key supporters.

Gail Tomsic
 PANDDA President

Major Sponsors



Other Sponsors





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Day 1. Monday 14 October 2024

8.15am	ARRIVAL DAY 1 Registration, Coffee and Tea in the PANDDA Club Lounge Photographers will be present throughout the Conference. If you do not wish to have your photo taken, please inform the photographers.	
9.00am	ACKNOWLEDGEMENT TO COUNTRY Denise Robinson, PANDDA Committee	
9.10am	WELCOME DAY 1 PANDDA 25th ANNIVERSARY YEAR Bob Weaver OAM and Sharon Paley, PANDDA Conference Co-Convenors	
9.20am	KEYNOTE SPEAKER Chris Stirling RN, Senior Vice President, Crisis Prevention Institute, United Kingdom Chair: Sharon Paley, Vice President PANDDA	
10.10am	SPONSORSHIP ACKNOWLEDGEMENT PANDDA Conference Committee	
10.15am	MORNING TEA Visit Trade Displays and Network in the PANDDA Club Lounge	
11.00am	INVITED SPEAKER: SYMPOSIUM Looking Back, Looking Forward – Inspiring the next Generation of Nurses in Intellectual Disability Health Care Dr Seeta Durvasula; Tahli Hind; Katrina Sneath; Janelle Weise; Claire Eagleson; and Michaela Kobor Chair: Gail Tomsic, President PANDDA	
12.00pm	CONCURRENT 1 & 3: LENNOX ROOM Chair: Julie Gibson, PANDDA Committee	CONCURRENT 2 & 4: MADISON ROOM Chair: Denise Robinson, PANDDA Committee
12.05pm	1. Jackie Boyle RN Working with the experts: Co-production of resources for genetic healthcare for people with intellectual disability	2. Macey Barratt RN, PhD candidate Parental experiences of quality of life when caring for their children with intellectual disability
12.35pm	3. Dr Virginia Howie RN, PhD and Tessa Howie, Self-advocate Novel strategies in pain control for people with intellectual developmental disability	4. Dr Natasha Jojo RN, PhD Enhancing Disability Nursing Practice in Australia: Addressing Educational Preparedness
1.05pm	LUNCH Visit Trade Displays and Network in the PANDDA Club Lounge	



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Day 1. Monday 14 October 2024

1.55pm	INVITED SPEAKER "Just Include Me" – inclusive health practices for people with intellectual disability David Pech and Pamela Darling, Council for Intellectual Disability (CID) Inclusion Project Health Chair: Bob Weaver OAM, PANDDA Conference Convenor	
2.40pm	CONCURRENT 5: LENNOX ROOM Chair: Gail Tomsic, President PANDDA	CONCURRENT 6: MADISON ROOM Chair: Macey Barratt, PANDDA Committee
2.45pm	5. Dr Nema Hayba PhD The MyED Project: Qualitative interviews with adults living with disability to improve Emergency Department experience	6. Dr Sarah Burton RN, PhD Exploring the effectiveness of a clinical governance model
3.15pm	AFTERNOON TEA Visit Trade Displays and Network in the PANDDA Club Lounge	
3.40pm	INVITED SPEAKER Helen Lavery MBE, RN, Facilitator, Positive Choices Network, United Kingdom Chair: Sharon Paley, Vice President PANDDA	
4.20pm	DAY 1 CLOSE Bob Weaver and Sharon Paley Conference Co-Convenors	
4.30pm	WELCOME RECEPTION Invitation to Welcome Reception in the PANDDA Club Lounge	



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Day 2. Tuesday 15 October 2024

8.00am	ARRIVAL DAY 2 Registration, Coffee and Tea in the PANDDA Club Lounge	
8.30am	PANDDA ANNUAL GENERAL MEETING Chair: Sharon Paley, Vice President PANDDA	
9.00am	ACKNOWLEDGEMENT TO COUNTRY Denise Robinson, PANDDA Committee	
9.10am	WELCOME DAY 2 AND SPONSORSHIP ACKNOWLEDGEMENT Bob Weaver OAM and Sharon Paley, PANDDA Conference Co-Convenors	
9.20am	KEYNOTE SPEAKER Improving healthcare for children and young people with intellectual and developmental disability in hospital. Reflections into the past, present and envisioning the future Dr Natalie Ong Chair: Gail Tomsic, President PANDDA	
10.05am	MORNING TEA Visit Trade Displays and Network in the PANDDA Club Lounge	
10.40am	INVITED SPEAKER National Centre of Excellence in Intellectual Disability Health (Council for Intellectual Disability) Driving Change Team, Sophie Howlett and Raylene Griffiths Chair: Sharon Paley, Vice President PANDDA	
11.20am	CONCURRENT 7, 9 & 11: LENNOX Chair: Sharon Paley, Vice President PANDDA	CONCURRENT 8, 10 & 12: MADISON Chair: Maree McCulloch, PANDDA Committee
11.25am	7. Professor Nick Lennox An AHA! Moment: A CHAP in time is just sublime. The What, Why, and How of Annual Health Assessments for People with Intellectual Disability	8. Heather Miller RN Cradle to Grave – The Role of Nurses Supporting and Advocating the Health Needs of People with Intellectual Disability Across the Lifespan
12.00pm	9. Julie Gibson RN The Impact of Disability on the Family	10. Eduardo Fraga da Silva, PhD Candidate Through the Technological Looking Glass: A Decade of Progress and Future Horizons in Nursing
12.35pm	11. Brent Hayward RN, PhD and Dr Anita Moyes RN, PhD The future of nursing in Australian schools for students with disabilities: A proposed research agenda	12. Gina Wilks RN High Intensity Management Plans for people with ID: Then and Now, Wowsers what a Difference



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Day 2. Tuesday 15 October 2024

-
- 1.15pm **LUNCH**
Visit Trade Displays and Network in the PANDDA Club Lounge
-
- 2.00pm **INVITED SPEAKER: PERFORMANCE PRESENTATION**
Playback Theatre: PANDDA 35 years Celebration
Chair: Michael Pooley Playback Theatre: Presentation and interactive discussion
-
- 3.30pm **AFTERNOON TEA**
Afternoon Tea and Farewell Reception in the PANDDA Club Lounge
PANDDA AWARDS
Awards are announced and presented
INVITATION
Invitation to the 2025 PANDDA Conference
-
- 4.20pm **CONFERENCE CLOSE**
-



PLAYBACK THEATRE SYDNEY

Playback Theatre Sydney has been creating story based improvised theatre performances since 1980. They have performed for audiences at conferences, in training rooms, with NGOs and community groups, at schools and in the theatre. In their performances, the actors and musician turn stories from the audience into compelling theatre, on the spot. In the sharing of stories from the audience, they facilitate an alternate style of communication through storytelling. Their practitioners come from diverse fields such as acting, law, drama therapy, academia, and leadership training, and they share their joy in applied improvisation and their deep appreciation of the power of stories to build bridges of understanding between people.



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Keynote Speakers



CHRIS STIRLING

Senior Vice President, Crisis Prevention Institute

A Registered Nurse, Chris has post graduate qualifications in restraint reduction, education, and behaviour therapy. He has extensive experience working in inpatient and community-based services for children, young people, adults, and older adults with complex needs ranging from intellectual disabilities, mental impairment, mental ill-health, brain injury, and dementia. Co-creator and author of the MAPA training model he has also worked as an associate University Lecturer. He is responsible for research of the CPI workplace training program and manages the worldwide training team for CPI International. Chris also founded the UK based Restraint Reduction Network, which is now part of the British Institute of learning Disabilities Group.



DR NATALIE ONG

MBBS (Melb), MRCPCH (UK), FAMS (Sing), FRACP (Aust), MClined (Flinders), PhD (Sydney)

Natalie is a developmental paediatrician of over 20 years' experience in developmental behavioural paediatrics with special interests in intellectual disability health and patient Safety, clinical education, child development service development, autism and learning disorders. She is currently Senior Staff Specialist for the Child Development Unit, Children's Hospital Westmead. She has led the development of multidisciplinary assessment services at Wollongong, Illawarra and Shoalhaven LHD (2010-2012) and Sydney LHD (2012-2017).

Natalie was also the team lead for the Fairfield Specialist Disability Health service (2012-2017), providing clinical care and leading capacity building projects in development of clinical pathways, training and education of the health workforce to improve care for children with developmental disability. She has led the development of an eLearning program designed to upskill GPs and Practice Nurses on conducting health and developmental surveillance using the child Personal Health Record. She also co-facilitates the Masters of Paediatrics program (University of Sydney) and teaches Child Development with the Sydney Child Health Program and Royal Australasian College of Paediatrics Community Child Health Program. In her advocacy role for children and young persons with developmental disabilities, she is a member of the Neurodevelopmental Paediatric Society of Australia. She is the medical co-chair for the ACI Intellectual Disability network committees and has been on the RACP Community Child Health/ Adolescent and Young Adult Medicine committees advocating for the needs of children with disability. She completed her PhD with the Faculty of Medicine and Health on "Improving care for children and young people with intellectual disability in hospital" through the development of an Adapted Patient Safety Education Framework for staff caring for children with intellectual disability. Natalie has developed a training program (Motivated for Change) that utilises strategies from Adult Learning, Behaviour Change and Quality Improvement. This program has been shown to enable the health workforce to embed reasonable adjustments into practice, demonstrating changes to quality of care and the patient experience.



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Invited Speakers



SEETA DURVASULA (SYMPOSIUM)

Seeta is a medical practitioner with clinical experience in the health of people with intellectual disability and complex health conditions. She is a Senior Research Fellow at the National Centre of Excellence in Intellectual Disability Health, University of NSW Sydney. Seeta is working on the Australian Department of Health and Ageing project, developing the Intellectual Disability Health Capability Framework and supporting educational resources for tertiary students in nursing, medical and allied health fields. She is also engaged in other Centre projects of establishing a National Clinician Network, and undertaking a scoping review of health system reforms that can improve the health of people with intellectual disability.



TAHLI HIND (SYMPOSIUM)

Tahli is a lived experience researcher at the National Centre of Excellence in Intellectual Disability Health. Tahli feels that people with intellectual disability have the right to access quality health services and information that they need, no matter what their challenges may be.



KATRINA SNEATH (SYMPOSIUM)

Katrina is a lived experience researcher at the National Centre of Excellence in Intellectual Disability Health. Katrina is very passionate about advocacy for people with disability. She has had different advocacy roles in New Zealand and Sydney.



JANELLE WEISE (SYMPOSIUM)

Janelle is a researcher at the National Centre of Excellence in Intellectual Disability Health. She has worked on a range of initiatives to enhance the capacity of the health care sector to deliver accessible, effective and efficient healthcare to people with an intellectual disability.



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CLAIRE EAGLESON (SYMPOSIUM)

Claire is a Project Manager at the National Centre of Excellence in Intellectual Disability Health at UNSW Sydney. She has a background in psychology, and over the last decade has worked on projects that aim to enhance the capacity of the health workforce and students studying to be future health professionals to successfully work with people with intellectual disability and their support networks. She has a keen interest in using co-design to produce accessible resources that support people with intellectual disability and their carers and families to learn about and access physical and mental health services. Recent projects have included the development of the Intellectual Disability Mental Health Connect website and working with the Department of Health and Aged Care to produce the Intellectual Disability Health Capability Framework to enhance intellectual disability content in pre-registration health program curricula. Now she is developing resources and guidance to support the implementation of the Framework.



MICHAELA KOBOR (SYMPOSIUM)

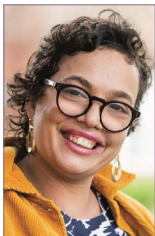
Michaela is a Workplace Support Officer at the National Centre of Excellence in Intellectual Disability Health. She supports the lived experience team at the Centre with their research projects and advocacy work.



DAVID PECH

I have had the privilege of working with and for people with disability for more than 11 years. Over that time, I have been part of advocacy organisations and education institutions across the country. I am most proud of the work that I have done in collaboration with people with intellectual disability. At the Council for Intellectual Disability, I was part of an innovative project about supported decision making, and I am now working on inclusion in health and palliative care.

I completed a Master of Psychotherapy and Counselling at Western Sydney University, and a Master of Philosophy at the University of Sydney, where I wrote a thesis about the work of feminist author, Virginia Woolf. My studies have enriched my commitment to the values of diversity, connection and person-centred practice.



PAMELA DARLING

I am passionate about sticking up for the rights of people with disability. I think everyone deserves a fair go. I am very proud of speaking on The Drum, on ABC Radio, at the Royal Commission and to the NSW Government about the rights of people with intellectual disability.

My dream is to become a motivational speaker that travels and speaks up for people's rights. I want people to listen and for them to make changes in the world.

I work at the Council for Intellectual Disability. I am a hard worker. I have worked on the right to employment and I have worked on accessible communication, especially by making Easy Read documents. Now I am working on women's health and palliative care. I wanted to do health work because it is the most important thing for everyone. We need to change how doctors and hospitals treat people with intellectual disability and people with disability in general.



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Invited Speakers



SOPHIE HOWLETT

Sophie Howlett is the Team Lead, Driving Change at the National Centre of Excellence Intellectual Disability Health (NCOEIDH). She represents the Council for Intellectual Disability (CID) at the Centre, one of nine organisations in the NCOEIDH Consortium. She received a Masters of Policy & Applied Social Research (MPASR) and a Bachelor of Social Science (B.Sc.) from Macquarie University, Sydney. When not working, Sophie is a busy mother of twins, who loves writing, being creative, gardening and being in nature.

Sophie has over 15 years' experience in public policy, strategy, program direction, and academic research spanning Australia, the UK and the US. She is firmly committed to using her education and experience to further the principles of social justice and health equity and serving as an agent for positive social change. Much of her career has been dedicated to systemic advocacy in health for people with intellectual disability, mental health issues and older adults. She has led legislative and policy reform for Australians and published in peer-reviewed papers in this area. In her recent tenure in US healthcare administration, she advocated on improved equity in healthcare and services for people with a disability, older adults, and those experiencing mental illness or substance use disorders. She is a passionate advocate keen to drive positive change in public policy towards improvements in health outcomes for all Australians.



RAYLENE GRIFFITHS

My name is Raylene and I am a Driving Change Project Worker at CID NSW Council for Intellectual Disability with the National Centre for Excellence in Intellectual Disability Health. I have a talent for inclusion work. I also do excellent work in easy read testings, reflection documents and meetings as to improve the quality of life as equal human rights and systems of health. My talents are admin, good service and ethical framework, with logical thinking.

I work well with management, work colleagues, those of CID or external organisations. I love cooking and sharing recipes to be friendly to people in my personal life. I facilitate The Voices Hearing Group at New Outlook Centre. I love religion and the Anglican faith. I love giving compliments and spreading love that way.



HELEN LAVERTY

I have been a registered nurse in learning disabilities for 42 years, and it remains a passion! My career has taken me from training in a long stay facility right up to today to the giddy tidal wave of inclusion! Nursing people who have a learning disability is a real POSITIVE CHOICE and one if given the chance of being 18 again I would choose again! I have experience in care situations across the age spectrum, and in both health and social care. I made the shift to nurse education in 1987 as I wanted to take the inclusion message to a wider audience. I am very fortunate in that my career has given me opportunity to have my life and career touched by such a rich and diverse group of people.



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Program Speaker Biographies

1. JACKIE BOYLE

Jackie Boyle is a Clinical Nurse Consultant and Genetic Counsellor with the NSW Genetics of Learning Disability (GOLD) Service, providing genetic services to families with inherited intellectual disability. She is a member of the GeneEQUAL inclusive research team which aims to make healthcare and education inclusive, person centred and respectful.

2. MS MACEY BARRATT

Macey Barratt is a nursing research academic. Her nursing background included paediatric nursing and seeing them through their palliative care journey. She is currently finalising her PhD where she has explored the partnership between children, family members and healthcare professionals when the child has a life-long condition.

3. DR VIRGINIA HOWIE

Virginia is a nurse academic, and parent of Tessa who was born with mild intellectual disability (ID). Virginia's research interests are in improving quality of life and health outcomes for people with ID. As a PANDDA committee member, Virginia is involved in several PANDDA projects that aim to promote nurse involvement to improve quality healthcare for people with ID.

3. MS TESSA HOWIE

Tessa is a keen sportswoman who enjoys swimming training with Special Olympics, representing Queensland in 5 national games. Tessa attends regular karate training, attaining her brown and white striped belt in August. Tessa lives independently with assistance through the NDIS and support workers who assist with travel, shopping and community participation.

4. DR NATASHA JOJO

Dr. Natasha Jojo is an Assistant Professor and an early career researcher under the Faculty of Health at the University of Canberra. She has an academic background

in mental health. Her specific research focus on children with Intellectual Disability and their parents, training them in sexuality and sexual abuse prevention. She has completed her PhD from National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore, India in 2018. Her PhD work assessed the "Effectiveness of Behavioral Skills Training (BST) on Knowledge of Sexual Abuse and Resistance Ability among children with Intellectual Disability.

5. DR. NEMA HAYBA

Dr. Nema Hayba specializes in consumer-driven qualitative research, focusing on health equity for vulnerable populations. As the lead for engagement on the MyED project, she explores the care experiences of individuals living with disabilities to enhance Emergency Department services. She has also worked with cancer survivors, adolescents, refugees, and asylum seekers to improve their healthcare access and well-being.

6. DR SARAH BURTON

As a Registered Nurse I have worked across community, sub-acute and acute settings. Roles focused on advanced practice, education, research and quality have led to a focus on clinical governance further enhanced through research studies. Currently I support safety and quality priorities for people with disability as General Manager Safety and Quality at Multicap Limited.

7. PROFESSOR NICK LENNOX

Nick trained as a general practitioner, who has a PhD and was Director of two Centre of Excellence, and currently is a Medical Advisory to the Australian Government Department of Health and Aged Care. He has developed several innovative strategies including the Annual Health Assessment (AHA) process call the Comprehensive Health Assessment Program (CHAP).



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8. MS HEATHER MILLER

Heather Miller is a registered nurse specialising in intellectual disability nursing, with over 25 years' experience. Her diverse background spans community learning disability nursing, medical teaching, post-graduate nurse education, and disability case management. She currently works as a disability practice nurse, facilitating health professional education in disability and health, and supporting breastfeeding for babies with Down syndrome.

9. JULIE GIBSON

Julie Gibson – is a Registered Nurse. She trained at Royal Perth Hospital Western Australia. She then worked in the Gynaecology ward in Queen Elizabeth Hospital, South Australia followed by Princess Alexandra Hospital, Brisbane Qld in the Burns Unit. She had a break from nursing raising 5 children. She returned to nursing after refresher education and worked at Youngcare in 2007/2009 then QCIDD/ MIDAS at Mater for 10 years as a Clinical coordinator.

10. EDUARDO FRAGA DA SILVA

Ed is a data scientist and a PhD candidate in Robotis: and AI Consultant working in Emerging Technologies – Designing and implementing Machine learning and Data analytics solutions.

11. DR BRENT HAYWARD

Brent is a registered nurse and Credentialed Mental Health Nurse who has worked in a variety of nursing roles over the last 22 years, mostly in clinical, regulatory, and policy roles which support people with intellectual and developmental disability. Brent is presently a Senior Lecturer in the School of Nursing and Midwifery at Monash University.

11. DR ANITA MOYES

Dr Anita Moyes was a school nurse for almost 20 years and completed her PhD in school nursing in Western Australia in 2020. Her main interests are in lifespan development from the prenatal period to young adulthood; the mental and psychosocial health of children and young people, and community nursing.

12. GINA WILKS

Gina Wilks has been involved with NDIS participants since the NDIS was rolled out in the Hunter Valley. Gina is a Clinical Nurse Consultant and runs a Nursing and Training Organisation that supports people with high intensity support needs to be as independent as possible. She is a specialist high intensity care, as well as training teams in all high intensity skill descriptors. She develops management plans and training packages to meet the needs of the people living with disabilities.



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Abstracts

| Parental experiences of quality of life when caring for their children with intellectual disability

Presented by Macey Barratt, RN, PhD Candidate

Aims

Parents of children with moderate to profound intellectual disabilities play a crucial role in providing direct care, but often demonstrate heightened parental stress and reduced quality of life. This review explored perceived quality of life from experiences of parents when caring for young and adult children.

Methods

A qualitative systematic review following Joanna Briggs Institute meta-aggregation approach has been completed and reported according to PRISMA guidelines.

Results

17 qualitative studies were included. Three synthesised findings were identified: "Challenges and rewards of being a parent carer," "The real cost of caregiver burden," and "Surrendering self for duty – the mothers role."

Conclusion

Parents of children with moderate to profound intellectual disabilities reported diminished quality of life for themselves and their families, experiencing increased physical and mental health issues associated with caregiving burdens. Mothers, in particular, emerged as the primary caregivers and reported losing their identity due to caregiver burden. Future research is needed that determines what effective support systems and interventions are in place to alleviate parental caregiver burden, with a focus on enhancing quality of life and well-being for all family members.

| Working with the experts: Co-production of resources for genetic healthcare for people with intellectual disability

Presented by Jackie Boyle, Bachelor Health Science (Nursing), Graduate Diploma Genetic Counselling, Masters in Bioethics, Graduate Certificate Child and Family Health Nursing.

Overview

Genetics promises to inform better, more tailored health care, but many people with intellectual disability have never accessed genetic healthcare or have had poor experiences with it. Clinicians lack knowledge and skills in how to engage with people with intellectual disability and see genetics as too complex for them to understand.

The GeneEQUAL inclusive research team co-researched how to address this problem. Co-researchers with intellectual disability are expert members of our research team, bringing their lived experience and accessibility expertise.

Content of presentation

Following extensive consultation with people with intellectual disability, clinicians and educators, a toolkit of resources was co-produced. The Toolkit consists of Easy Read resources to help people with intellectual disability understand genetic healthcare and a series of videos to show clinicians how to use reasonable adjustments and provide person-centred and strengths-based genetic healthcare.

Mixed methods evaluation from the perspective of people with intellectual disability and clinicians found that the Toolkit met the expectations of both groups. Most importantly reflections of both groups on the co-production process were positive and showed that co-production not only produced a highly valued Toolkit, but also drove clinicians' motivation to change their clinical practice.

The toolkit is currently freely available online at the Centre for Genetics Education <https://www.genetics.edu.au> and the GeneEQUAL website <https://geneequal.com>. Global engagement has been extensive, with visits by over 5,000 people from over 53 countries.

Development and evaluation of this Toolkit demonstrates the value of the co-production model which should be applied more broadly to improve healthcare for people with intellectual disability.



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| Exploring the effectiveness of a clinical governance model

Presented by Sarah Burston BSc (Hons), MSc, PhD

Overview

At Multicap we specialise in the support of complex customers. Many present with significant co-morbid health and behavioural challenges. They are at risk of entering or re-entering hospital, aged care, or forensic disability services. To assist frontline teams to provide life-long support to customers, we have developed a clinical governance model that is supported by a structure of focused forums. We have been validating our approach through developing an evidence base of the impact of these forums for our customers.

Content of presentation

The focused forums bring together the right group of people to provide advice, assist in navigating health services and operational support. The Complex Behaviour Forum has demonstrated that behavioural outcomes of those receiving the enhanced support offered by the forum improved. This was evidenced by a reduced rate of incidents, oversight of restrictive practices and no instances of relinquishment due to behaviour (Carberry et al 2024).

Similarly the Complex Health Forum has evidenced a reduction in health related incidents for customers with health management plans who were discussed at the forum. Building the knowledge, capability and confidence in our teams to support the health needs of customers is also observed and an area of current research focus.

These forums are a significant investment in both time and the specialist skills of those involved which has to be accommodated as an indirect cost. However, this approach to clinical governance has demonstrated benefits to the individual customers, their support teams and the wider organisation.

| Through the Technological Looking Glass: A Decade of Progress and Future Horizons in Nursing

Presented by Eduardo Fraga Da Silva, Masters in Cloud computing and PHD candidate in AI and Robotics

Reflecting on the conference theme "Through the Looking Glass," this presentation examines technological progress in nursing over the recent years and projects future technological trends. We explore the roles of artificial intelligence (AI), robotics, and cybersecurity, discussing their impact on patient care and nursing practice.

Methods

For this presentation papers were surveyed using a "then and now" approach. This presentation will focus on three main sections: AI, robotics, and cybersecurity, each beginning with a snapshot on previous years, followed by current examples and future projections in nursing. During the presentation will be used an AI self-driven device (turtlebot). A 5-minute Q&A concludes the session.

Results

This analysis reveals significant technological advancements:

AI in Nursing: Early diagnostic tools have evolved into sophisticated care planning systems. Current AI applications show a 15% improvement in early intervention outcomes. Projections suggest AI could automate up to 40% of routine tasks by 2034.

Robotics in Care: Basic assistive devices have progressed to advanced prototypes, reducing physical strain on nurses by 10%. Future robotics may revolutionize patient mobility and monitoring.

Cybersecurity: Data security has transformed from basic privacy measures to complex, AI-driven systems. However, only 30% of surveyed papers report robust measures specific to emerging technologies.

Challenges include ethical considerations, specialized training needs, and potential job role transformations.

Conclusion

This decade-long journey "through the looking glass" reveals transformative potential in nursing. Embracing these technologies while addressing challenges will be crucial for advancing patient care and nursing practise in the coming decade.



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| The Impact of Disability on the Family

Presented by Julie Gibson, Registered Nurse

The story of a life lived in a big family and the impact this has on my family.

I will present a personal view of the impact of a child with a disability on our family and the personal experience relating to conference theme of Alice through the Looking Glass – looking back at Michael’s life.

The presentation will provide an insight into how someone’s words of advice can affect a person living with a child with a disability.

Timeline of journey of birth through 12 years of life. Lessons learnt navigating the health system and keeping a family functioning during that journey.

| The MyED Project: Qualitative interviews with adults living with disability to improve Emergency Department experience

Presented by Dr Nema Hayba, Bachelor of Exercise and Sport Science, Masters in Nutrition and Dietetics, PhD in Nutrition and Dietetics

Aims

This study explores the experiences of adults with disabilities regarding their care in the Emergency Departments (ED) at Westmead, Blacktown, and Mount Druitt Hospitals in Western Sydney Local Health District (WSLHD). The aim is to identify their needs and preferences for ED care to guide the design of future interventions that enhance the ED experience.

Methods

Semi-structured interviews were conducted with participants recruited through snowball and purposive sampling. Eligibility criteria included: i) adults aged 18+, ii) living with a disability, iii) having an NDIS plan, iv) able to provide informed consent, or able to participate in a supported model and v) visited one of the three EDs in the last 12 months. Researchers engaged disability organizations and NDIS service providers in WSLHD. Four engagement models were employed: (1) 1:1 interview with eligible individuals, (2) 1:2 interviews with individuals and a support person, (3) 1:1 interviews with supporters of individuals unable to consent, and (4) 1:1 interviews with epistemic experts (e.g., disability specialists, academic

clinicians). Interviews with epistemic experts were included to supplement data from cohort participants given the prior challenges in recruiting vulnerable participants for research.

Results

Twenty-eight interviews have been conducted: half with patients with disabilities and half with experts. Most patients lived with intellectual disability. Results will be presented based on thematic analysis.

Conclusion

This study is still underway and complete findings will be presented at the conference.

| The future of nursing in Australian schools for students with disabilities: A proposed research agenda

Presented by Dr Brent Hayward RN CMHN MEd PhD and Dr Anita Moyes RN MN PhD

Aims

Little is known about the work of nurses in Australian schools for students with disabilities. The aim of this presentation is to propose a research program addressing this gap and seek preliminary feedback from nurses.

Methods

We reviewed the literature about nurses working in schools for students with disabilities in Australia and internationally. We placed these results in the context of deinstitutionalisation and subsequent reforms of nursing education and registration, developments in inclusive education school policy and legislation, school nursing and health policy, recommendations of the Disability Royal Commission, and the review of the National Disability Insurance Scheme.

Results

Australian researchers have begun to explore school nursing in Australia, but nurses in schools for students with disability remain poorly represented. These nurses are performing a vital role in schools in an era where their work is overshadowed by school and disability policy reform debate. We have developed a program of research to explore nursing in schools for students with disabilities in Australia from the perspectives of the nurses themselves and other stakeholders.



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Conclusion

It is a crucial time for nurses in schools for students with disabilities as Australian authorities wrestle with responding to disability reforms and school systems aggressively pursue a health agenda. These nurses, as part of the broader school nursing workforce, should be leading this work. We are inviting conference delegates to contribute their feedback and ideas on this research proposal.

| Novel strategies in pain control for people with intellectual developmental disability

Presented by Dr Virginia Howie Virginia Howie, RN PhD GCTE and Ms Tessa Howie, self-advocate.

Overview

This case study presentation uses a lived experience approach to explore novel ways to help people with intellectual developmental disability control pain during potentially painful clinical procedures.

Content of presentation

First, the presenting history of the skin problem on the foot is detailed. Next, the medical and podiatric management of the skin problem is explained. Pain control measures using a type of cognitive development therapy are then examined. What works for the subject is explained in her own words. Other options for pain control are explored. Conclusion: individuals with intellectual developmental disability can be offered alternative methods of pain control to pain medications in specific clinical circumstances.

| Enhancing Disability Nursing Practice in Australia: Addressing Educational Preparedness

Presented by Dr Natasha Jojo, PhD in Nursing

Aims

This study examined the state of disability nursing practice in Australia following the implementation of the National Disability Insurance Support (NDIS) scheme.

Methods

An integrated literature review was conducted to know about nursing care of people with intellectual disability in Australia. Five electronic data bases were systematically searched: CINAHL, MEDLINE, PsycINFO, Scopus, and Cochrane Library using a set of selected search terms, and following PRISMA guidelines. Studies written in English and published in peer reviewed journals during 2010-2023, are included in the review. The final sample for this integrative review comprised of 28 studies.

Results

The data was then thematically analysed, and the following three themes emerged: Workforce development and professional standards, hospital experience and support needs of individuals with IDs, and nursing curriculum and ID. Study findings suggest that nurses lack preparation for effective health communication with individuals with IDs and their families. Evidence is insufficient to guide nursing practice and policies in ID care. Varying understandings of practice standards exist among nurses. Nursing curriculums in Australia fail to adequately prepare students to manage the unique needs of individuals with IDs, perpetuating the high mortality rates in this population. Specialised nursing practice areas are vital for meeting the complex needs of individuals with IDs.

Conclusion

Reintroducing a disability nursing specialty and integrating dedicated study units and clinical placements in undergraduate programmes are recommended steps to improve care outcomes and support the overall well-being of this population.

| An AHA! Moment: A CHAP in time is just sublime. The What, Why, and How of Annual Health Assessments for People with Intellectual Disability

Presented by Professor Nick Lennox, MBBS, BMedSc, DipObst, PhD, FRACGP, FASID, FFIASSID

Overview

The importance of Annual Health Assessments (AHAs) for people with intellectual disability, and how to find and use the Comprehensive Health Assessment Program (CHAP) tool.

Content of presentation

Annual Health Assessments for people with intellectual disability are supported by the MBS. The CHAP is the only evidenced-based tool for conducting Annual Health Assessments for people with intellectual disability in Australia.

Professor Nick Lennox will explain:

- Why Annual Health Assessments are important for people with intellectual disability.
- What the CHAP is.
- Why the CHAP is important for people with intellectual disability.
- Where to find information about Annual Health Assessments and download the CHAP.



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Nick will also discuss the Department of Health and Aged Care's work to improve the uptake of Annual Health Assessments for people with intellectual disability, through making the CHAP freely available, integrating the CHAP with clinical software, and promoting Annual Health Assessments.

| Cradle to Grave – The Role of Nurses Supporting and Advocating the Health Needs of People with Intellectual Disability Across the Lifespan

Presented by Heather Miller, RN, Grad Dip in Intellectual Disability, Cert IV in Breastfeeding Education (Community), Cert IV in Training and Assessment

Overview

Drawing from the lived experience of parenting a 10-year-old with intellectual disability and two decades of working in disability health, this presentation offers a journey through the Looking Glass. It explores the wisdom gained, reflections shared, and experiences drawn from intellectual disability nursing 10 years on, spanning from birth to end of life.

Content of presentation

This presentation will explore the role of disability nurses in guiding and advocating for the health needs of individuals with intellectual disabilities across the lifespan. From prenatal genetic testing, nurses are well-placed to support families in navigating complex health decisions. In the early years, the session will examine the importance of advocating for breastfeeding and early intervention strategies to promote optimal development.

As adolescents with intellectual disabilities transition from paediatric to adult healthcare, nurses play an essential role in ensuring a smooth and supportive transfer between services. In adulthood, the focus will shift to proactive healthcare approaches, including access to primary care, comprehensive annual health checks, and empowering individuals to engage in managing their own health.

The presentation will also cover advanced care planning and palliative care, highlighting the nurse's role in supporting dignity and quality of life during the dying process. Attendees will gain a comprehensive overview of how disability nurses facilitate access to equitable, person-centred care throughout the lifespan.

Reflecting on lived experience this session will outline practical strategies, provide additional knowledge and demonstrate the impact of proactive, continuous healthcare support over the last 10 years. Concluding with recommendations for best practice, this presentation underscores the importance of disability nurses in ensuring equitable, high-quality healthcare from cradle to grave.

| High Intensity Management Plans for people with ID: Then and Now, Wowsers what a Difference

Presented by Gina Wilks, Masters Nursing (Advanced Practice) Grad Cert Paediatric Nursing Cert IV Training and Assessment

In this session we will reflect on past practice and look into how far Management Plans have come in the past 10 years. We will review Current Requirements, discuss current best practice for content in High Intensity Management Plans and the Implications for supporting people with Intellectual Disability.

We will use a Case study on use of a High Intensity Management plan with a client with an Intellectual Disability and Complex Care needs to enable them to be in control of their care needs.

Content of the Presentation

Evolution and Current Practices in Management Plans for people with Intellectual Disabilities and a brief introduction to the session's objectives and agenda.

Reflecting on Past Practices and an overview of management plans 10 years ago. Key differences and improvements over the past decade and examples of outdated practices and their limitations.

Current Best Practices in High Intensity Management Plans. Best practices and standards in today's high-intensity management plans and practical applications and benefits of these practices.

Supporting Individuals with Intellectual Disabilities Introduction to the case study. Overview of the client's intellectual disability and complex care needs, strategies used to involve the client in their gastrostomy care and benefits and outcomes of using a high-intensity management plan.



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Bob Weaver and Chris Atkins PANDDA Award

Bob Weaver (OAM) and Dr Chris Atkins are founding members of PANDDA. This award honours their contributions to PANDDA Inc in meeting the healthcare, support, and service delivery needs of people with intellectual developmental disability. The Award also recognises their enduring leadership in education, research, and professional guidance through the discipline of nursing.

BOB WEAVER AND CHRIS ATKINS

In 1989, a group of nurses that included Bob Weaver (OAM) and Dr Chris Atkins recognised the need for a professional organisation to represent nurses working in the area of intellectual developmental disability. Hence, PANDDA Inc was formed. Since its inception, Bob has served as president, vice-president, executive member, and conference convenor for almost 37 years. Bob was awarded the Order of Australia Medal in 2014 for his tireless work in advocating for people with disabilities throughout his 50-year career as a nurse. Dr Chris Atkins also served as president, vice-president, and executive member since the founding of PANDDA Inc. Chris was the first nurse to attain a PhD in intellectual developmental disability in Australia. Bob and Chris are both life members of PANDDA Inc.

The Chris Atkins and Bob Weaver PANDDA Award is presented at the annual PANDDA conference to an eligible presenter(s) who attains the highest score on the presentation criteria scoring sheet.

ELIGIBILITY CRITERIA

To be eligible for the award, a conference presenter(s), or one member of the presenters must be a Registered Nurse or Enrolled Nurse; present a paper of relevance to the nursing and support of people with intellectual developmental disability; and not be an invited speaker.

SCORING

- Each eligible presentation is judged by conference delegates who are randomly selected by the Award presenters and who voluntarily agree to act as referees. There are three referees for each eligible presentation.
- The PANDDA award is presented at the end of the conference. Criteria scoring sheets will be collected and collated by the Award presenters.
- If any scores are tied, the Conference Committee will have the final decision.

My Story PANDDA Award

My Story PANDDA Award will be presented to a person/s (or family member/s) with lived experience in intellectual developmental disability who is actively involved in a conference presentation of relevance to the nursing/healthcare and support of people with intellectual developmental disability.

This award recognises the valuable contribution that self-advocates make in improving nursing care. PANDDA, in harmony with the motto from the United Nations International Day of People with Disabilities, supports "Nothing about us without us". The United Nations believes that people with disabilities should be actively involved in the planning and strategies of policies that affect their lives.

This award is jointly presented by Dr Virginia Howie, her daughter, Tessa Howie, and PANDDA Inc. Tessa was born with mild intellectual disability, which was the starting point for Virginia's thesis on registered nurses caring for people with intellectual disability. Virginia is passionate about the education of nurses in intellectual disability care. Tessa is passionate about people with disabilities being treated the same as everybody else. PANDDA is passionate about the inclusion and support of people with lived experience expressing their voice.

This award is being presented for the first time at the 35th annual PANDDA conference 14 and 15 October 2024.



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A Brief History of PANDDA Inc

In 1983, as nurse education began evolving within Colleges of Advanced Education and later, Universities, a group of dedicated nurses came together to advocate for the professional standards and interests of nurses supporting individuals with intellectual disabilities. At the encouragement of Meryl Caldwell-Smith AM, then Chief Nursing Officer for the New South Wales Department of Health, they formed a Working Party. Their mission was to develop "exit competencies" that would outline the essential skills, knowledge, and expertise required for nurses graduating from these institutions to effectively care for individuals with intellectual disabilities.

The Working Party included notable members such as Dr. Chris Atkins PhD, Diana Dalley, Ross Fear, Elisabeth van Leeuwen, Bob Weaver OAM, and Carol Welsh. Reflecting on this initiative, Bob Weaver noted, "Meryl was looking out for us when she suggested we needed to enhance nurse education. It took a year of dedicated effort to produce the core elements of the 'exit competencies' document, ensuring that clinical skills for nurses were upheld." (Bob Weaver OAM, 2014, Dawn to Dusk: Celebrating 200 Years of Service at Rydalmere).

Recognising the need for a stronger advocacy platform, the Working Party established the Professional Association of Nurses in Developmental Disability Australia (PANDDA) in 1989. One of the founding committee members, Chris Laurie, initially proposed the name "The Professional Association for Nurses Working in Developmental Disability Areas," which was later refined to "The Professional Association of Nurses Supporting People with Developmental Disability Australia." This change allowed PANDDA to expand its reach across all Australian states and territories.

Through PANDDA, nurses dedicated to supporting individuals with intellectual developmental disabilities can connect with families, educational institutions, and government entities to uphold professional standards and advocate for the rights and self-determination of those they serve.

As we celebrate PANDDA's 35th anniversary in 2024, we remain committed to supporting both individuals with lived experiences and the nurses and care staff who assist them. This milestone year also brings the introduction of the annual "My Story Award," recognizing the voices of those with lived experience. The upcoming conference will feature a record number of presentations by individuals with lived experience. We take pride in our rich history and look forward to the future of PANDDA and the dedicated nurses who make a difference in the lives of people with intellectual developmental disabilities.

PANDDA Committee 2024

The Early Years





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PANDDA Annual Conferences 1990–2024

2024: 35th ANNUAL PANDDA CONFERENCE

THROUGH THE LOOKING GLASS... Wisdom, Reflection, Experience...
10 years on

2023: 34th ANNUAL PANDDA CONFERENCE

Embracing Partnerships in Health Care

2022: 33rd ANNUAL PANDDA CONFERENCE

NURSES: Engineering Health Pathways

2021: 32nd ANNUAL PANDDA CONFERENCE

Navigating The Future: Leadership you can Trust

2020: 31st ANNUAL PANDDA CONFERENCE

2020 Vision: Wellness and Health... character, ethics
and integrity in developmental/intellectual disability

2019: 30th ANNUAL PANDDA CONFERENCE

The Best is yet to come

2018: 29th ANNUAL PANDDA CONFERENCE

People, Purpose & Passion

2017: 28th ANNUAL PANDDA CONFERENCE

Waves of Change... Oceans of Opportunity... Start With Us

2016: 27th ANNUAL PANDDA CONFERENCE

A New World: Inspiring Abilities

2015: 26th ANNUAL PANDDA CONFERENCE

Enable the Future: Change – Choice – Rights – Wellbeing – Practice

2014: 25th ANNUAL PANDDA CONFERENCE

Through the Looking Glass... wisdom, reflection, experience

2013: 24th ANNUAL PANDDA CONFERENCE

Partnerships & Possibilities – Nursing Practice in Disability. Models
for Health & Social Equity

2012: 23rd ANNUAL PANDDA CONFERENCE

Great Expectations: Take nothing on its looks;
take everything on evidence. There's no better rule

2011: 22nd ANNUAL PANDDA CONFERENCE

Owning Our Practice – Learn from yesterday, live for today, hope
for tomorrow

2010: 21st ANNUAL PANDDA CONFERENCE

Coming of Age – A Celebration of Intellectual/Developmental
Disability Nursing

2009: 20th ANNUAL PANDDA CONFERENCE

Changing Times... Words, experiences and dreams

2008: 19th ANNUAL PANDDA CONFERENCE

Building and connecting bridges

2007: 18th ANNUAL PANDDA CONFERENCE

Passion! Imagine the possibilities

2006: 17th ANNUAL PANDDA CONFERENCE

Access and Equity: Health care for people with a developmental
disability

2005: 16th ANNUAL PANDDA CONFERENCE

Developmental Disability Nurses: Lost, or just harder
to find?

2004: 15th ANNUAL PANDDA CONFERENCE

Person Centred Support: The Challenges for Nurses working
in Developmental Disability

2003: 14th ANNUAL PANDDA CONFERENCE

Developmental Disability Nursing: Where to from Here

2002: 13th ANNUAL PANDDA CONFERENCE

Developmental Disability Nurses: Promoting Healthy Lifestyles

2001: 12th ANNUAL PANDDA CONFERENCE

Diversity in Practice

2000: 11th ANNUAL PANDDA CONFERENCE

Nurses in Developmental Disability: Who Needs Them!

1999: 10th ANNUAL PANDDA CONFERENCE

Visions for the Future 2000 & Beyond

1998: 9th ANNUAL PANDDA CONFERENCE 1998

Health Issues for People with Developmental Disabilities

1997: 8th ANNUAL PANDDA CONFERENCE

Professional Issues

1996: 7th ANNUAL PANDDA CONFERENCE

Best Practice

1995: 6th ANNUAL PANDDA CONFERENCE

Transition & Nurses

1994: 5th ANNUAL PANDDA CONFERENCE

People with Developmental Disability and their Families –
1994 The year of the Family

1993: 4th ANNUAL PANDDA CONFERENCE

Clients with Challenging Behaviours: Aspects of management

1992: 3rd ANNUAL PANDDA CONFERENCE

Developmental Disability Nursing: Moving On

1991: 2nd ANNUAL PANDDA CONFERENCE

Empowerment: Marketing the Professionalism of Nurses in
Developmental Disability

1990: 1st ANNUAL PANDDA CONFERENCE

Change and Diversity in Developmental Disability Nursing

FREE ONLINE
CPD PROGRAM



EVERY NURSES BUSINESS

PANDDA has remained as a leading strategic partner on this project up until July 2024 when funding ceased. Since the establishment of the National Centre for Excellence in Intellectual Disability Health under the guidance of the National Director Dr Julian Troller, we are pleased to announce that they will continue to host this website and promote access.

ABOUT THE FREE CPD PROGRAM

The learning site is separated into different learning levels and covers six domains (modules) of content including relevant to caring for people with ID and/or ASD: care imperatives; communication to individuals with ASD and/or ID; understanding communication from individuals with ASD and/or ID; environments of care; supporting positive behaviour; making things go well; and introduction to the NDIS.

Completion of the learning material at the foundational, intermediate, and advanced levels and satisfactory completion of the optional assessment will be deemed to be equivalent to one unit of AQF level 8 postgraduate study. This can be presented to universities to consider for advanced standing. More details will be available soon at: www.pandda.net



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35
YEARS
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PANDDA 35TH ANNUAL CONFERENCE
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