

Intellectual Disability Nursing: One world - many doors



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DISABILITY. MODELS FOR HEALTH A& SOCIAL
EQUITY 16-17 OCTOBER 2013**

Abstract



- Who are we?
- Where are we found?
- What do we do?
- What is important about the role of ID nurses?
- Where do we come from?
- How do we do what we do?
- What is our future? Short term and long term?
- Strategically managing PANDDA's Future.
- What is your future?

Who are we?



- **PANDDA:** Disability nursing has always differed from other specialised areas of nursing as it has not conformed to the ‘sickness model of care’;
 - focussed on habilitation and long-term care
 - historically played a major role in the provision of direct services in addition to the management and development of specialised needs-based services in a variety of contexts and settings including the family home.
 - continues to adapt to the changing demands of time through its foundation in reflexive and ethical practice (PANDDA 2012).

Where are we found?



- **Australia: Intellectual Disability Nurses – 2,510 (2001)**
 - 2011: **1811** nurses in this area – ADHC
 - 2012: 6636 nurses in the area of disability and rehabilitation
 - (AIHW 2012)
- **UK: Learning Disability Nurses – 24,309**
 - England 19,000 (Gates, 2011)
 - Ireland 5,309 (An Bord Altranais 2010)
- **Post graduate programs for RN's – DDNA 1000,s**
 - USA
 - Canada <https://ddna.org/>

Who are we?



- All of you ID nurses – Australia
- Dina Whatnell – New Zealand
- Ruth Northway – Wales
- Sue Read - UK
- Michael Brown – Scotland
- Roy McConkey - Ireland
- Wendy Nehring - USA
- Kathy Brown – USA DDNA

Scotland



- **The National Framework for Pre-registration Learning Disability Nursing Field Programmes**
 - It is an exciting time for learning disability nursing, an opportunity to progress a new era of practice and services that respond to contemporary agendas to meet the needs of people with learning disabilities, their families and carers now and in the future.
 - A well prepared, developed and supported workforce is essential to the delivery of quality health care for people with learning disabilities: the initial preparation of learning disability nurses is central to providing a high-quality educational foundation for practice (NHS, Education for Scotland 2013)

Developmental Disabilities Nurses Association

DDNA



- When you hire an RN or LPN/LVN who is certified in IDD nursing, you can be assured that the certified nurse has experience in working with persons with IDD, has demonstrated a high degree of expertise in the field of IDD nursing, and maintains that level of expertise by completing ongoing continuing education specific to the field of IDD nursing. Clients generally leave programs or facilities for one of four reasons: dissatisfaction with services, needs that exceed program capabilities, decline in health, or death. By having a certified nurse on staff, you can increase your clients' satisfaction with services, meet their complex nursing care needs, and help to ensure their health and quality of life. Having a CDDN or DDC makes the difference!
https://ddna.org/pages/about_us

What do we do?



- **Unique skills** (Clark 1998)
- **Managing chronicity and complexity**
 - Who else does this?
- **Teaching self care and healthy living**
- **Acting as advocate and guide through the healthcare system**
- **Providing the emotional or practical support**
- **Annual health checks** (Dixon 2010)
- And more.....

What do we do?



- **Daily**
 - Personal hygiene: Mouth care, bowels, TPR
 - Medication administration
 - Manual handling
 - Pain assessment, wound management
 - Violence assessment and prevention,
- **Other skills**
 - Peg and feeding techniques, pressure area care
 - Epilepsy, Physiotherapy
 - Mental health issues
 - Palliative care, Care of the elderly (McKeon 2009)

What do we do?



- **Fill in the missing pieces and the role is ever changing**
(Whatnell 2013)
 - People with disabilities go from ill to critically ill within a very short period of time (Ombudsman 2013)
 - Nurses recognise changes in the person's health, behaviour, or other indicators of illness (Alexanderson 2013)
 - Nurses need to coordinate approaches to health care with dream teams (Whatnell 2013)
- **Empower the health consumer with a disability**
 - Patient passport (person)
- **Educate the uneducated**
 - Conferences - PANDDA
 - Health professionals
 - ✦ Dancing anaesthetists (adverse events = behaviour issues)
 - Direct care staff

What is important about the role of ID nurses?



- They have a high degree of expertise in the field of IDD nursing, and maintain that level of expertise by completing ongoing continuing education specific to the field of IDD nursing (NNDA 2013).
- Nurses have so much knowledge
 - Past training – worked with 100's or 1000's of people with ID
 - Experience, knowledge, passion (invisible)
- Nurses ensure the person's voice is heard
 - Teach staff to listen to the person
 - Facilitate speech pathology workshops
 - Placements: ensure consistency of communication across all environments

Where do we come from?



- Early passion
 - Family members
 - Life experience
 - Previous experience – school
 - Placement experiences
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- What is it that motivates us to work in this area?

How do we do we do what we do?



- Versatile, adaptable
 - Take on the challenge (do we see that?)
- Current practice based on current knowledge
- Use our passions
- What else???

What is our future: Short Term?



- Education for all of those people who do not have the knowledge
 - Intellectual disabilities/Mental health (online course)
 - Health care needs – on line courses (epilepsy)
- Managing people with chronic and complex long term needs
 - Dream teams – with a person who has a disability
 - Annual health check: by nurses, client friendly (Whatnell 2013)
 - Hospital liaison nurses – the documents are there
 - ✦ The experiences of people with a disability in NSW public hospitals. Sydney. New South Wales Department of Health. (2012). Service framework to improve the health care of people with intellectual disability.
 - ✦ National Disability Services. (2013). NDS Submission: NSW State Health Plan 2013-2023

What is our future: Long term?



- When will expert nurses caring and advocating for people with intellectual disabilities demonstrate to the world that they have a place?
 - Respond to unmet need and tell the world (Tomsic & Tuckley 2013)
- How will we do it?
 - Find our fit!
 - Find our voices
 - Ensure we are visible
- Network: Nationally and Internationally
 - ✦ Succession plan: Students
 - ✦ Welcome nurses from other countries

Strategically managing PANDDA's Future



- **Strategic partnerships**
 - ADHC: Practice package: nursing and health care (Karen Alexanderson)
 - Agency for Clinical Innovation ID (Tracy Szantos)
 - CID: ID/MH round table (Jim Simpson)
 - UNSW: National Audit of ID content in the nursing curriculum (Julian Trollor)
 - ACMHN partnership (Kim Ryan & Ann Buck)
- **PANDDA initiatives**
 - Membership: committee members from around Australia (NSW, NT, Qld, SA, Tasmania)
 - PANDDA 25th Conference 15-16th November 2014 Sydney
 - IASSID Conference 2016: Nursing strand:
 - ✦ ID nurses from Australia, New Zealand, UK, Ireland, Canada and USA
 - Find our young nurses who will replace us
 - ✦ Comprehensive nurses work with people with disabilities, UK LD nurses

What is your future?



- We can do what ever we want to do
 - When will expert nurses caring and advocating for people with intellectual disabilities demonstrate to the world that they have a place?
 - Sit down, shut up and listen (Whatnell 2013)
 - How can we sell ourselves
 - Succession planning
 - ✦ New models
 - ✦ Funding avenues
 - ✦ On line resources
 - ✦ Think outside the door.
 - Find someone to replace you
 - ✦ Who are you a role model to?
 - ✦ What is your succession plan?
 - ✦ What partnerships are you promoting?

Intellectual disability nurses in Australia



- We have 110 people in the room with a an average of 30 years per person this equals:
 - 3,300 years of experience in the room.
- Each of us may have worked with up to 2,000 people over our working life
 - that is a total of 220,000 people
- How experienced and good are you?
- Now lets make it visible
- LETS CHANGE THE WORLD!!

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