Building upon the **strengths** of **yesterday**'s nurses to inspire **hope today** and lead to **improved health** care **tomorrow**.

PANDDA conference: Learn from yesterday, live for today, hope for tomorrow

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Yesterday, Today, Tomorrow

- Build upon the strengths of **yesterday's** nurses
  - What happened
  - What were the results
  - What did we learn

- Inspire hope for **today**: we do make that difference!
  - What is the situation today: People with ID, families, nurses?
  - What is it we do well?
  - Where are we all situated

- Improved health care **tomorrow**
  - Visibility of intellectual /developmental disability nurses
  - Broaden and make visible our scope of practice
  - Define what we do differently and tell the world

Yesterday: What happened?

An invisible population

- Prior to the 70's institutions
  - Registered intellectual disability nurses
  - Separate nursing registers in NSW, Victoria, SA and Tasmania (6 registers) (Russell, 2000).
  - Did we actually promote a 'medical model?'
- 1981 International Year of the Disabled
  - People moved to the community:
  - Comprehensive health care
  - Specialist intellectual disability nurses
  - Holistic assessment (Nehring 1991, Russell 2000, Atkins 2007)

Yesterday: What were the results?

- Worked with children and adults with intellectual/ developmental disabilities living in institutions in major cities, often away from their families.

- Undergraduate nursing curricula: international recognition

- The nurses were as invisible as the people they cared (Nehring 1991)

- Addressed the physical, psychosocial needs of a client group who often experienced complex and chronic health care needs.

Yesterday: What did we learn?

- To climb mountains
- Nothing was impossible
- Collegiality
- Holistic care
- To meet the chronic and complex needs of clients, often with limited support from allied health professionals

Who are the people?

- 166,700 people were specifically diagnosed as having an intellectual disability (AIHW 2006).

- Changes related to definition and description of disability:

  - Increase in number of boys 2.7 – 4.9% severe to profound restriction

  - Increase in number of young people 5-7% to 8-9% (AIHW 2007)

  - Increase in numbers of children with Autism, ADHD

  - Living longer: Long term functional limitations: (Davis, Shelley et al 2009)

  - One in four children under the age of 15 years required assistance with self-care, mobility and/or communication to allow them to participate within the community.

Today: Parents

- 99% of children are cared for in the family home (AIHW 2006)
  - Live to full potential
  - Impact of disability minimised

- Experiencing physical and mental health issues;
  - Chronic or complex possibly requiring acute health care (Mioche 1995; Brehaut, Kohen et al. 2004; Mackey and Goddard 2006; Narramore 2008)
  - Long term functional limitations: adverse consequences for carers (Davis, Shelley et al 2009)
  - May lead to burnout (Morris and Edwards 2006).
  - Often overlooked by health professionals resulting in adverse health outcomes (Barr 2007).

- Who cares for the Carers?

Today: Intellectual /Developmental Disability Nursing

- Invisible or disappearing
  - 2001:
    - **2510** nurses with the knowledge and experience required to offer a quality service (AIHW 2003)
  - 2011:
    - **1811** nurses in this area – ADHC
  - What about the nurses who are not counted but out there doing their work?
  - Where are they?

Today: Nursing

- 1984: Comprehensive nursing programs
  - Beginner level nurses: medical surgical; mental health and intellectual disability (Russell 2000).
  - Overtime ID/DD component eroded and replaced
  - Placement not compulsory
  - Lack of education for all health disciplines
- A lack of exposure results in a health workforce with minimal professional experience to care for people with intellectual disabilities and their families (Clark 2006).

Today's challenges

- The face of the consumer
  - Complex treatment regimens, life threatening conditions (Leiter, Krauss et al 2004)
  - Potential for chronic and complex illnesses related to disability (Rehm, Bradley 2005; Yantzi, Rosenberg 3t al 2007)
  - Limited assistance for families who manage the care (Tadema & Vlaskamp 2009)
  - Families face many health challenges across the lifespan (Goddard, 2010)
- Succession planning?
  - Where are our future nurses?

Good news from the conference

- It is an exciting and challenging time (Kalkman, 2011)
  - **Nurses are good at doing the holistic stuff the whole person, there is a role for nurses in this new world**
  - However we need experienced staff to tease out the issues: to tell the positive stories
- We have permission to use our licence (Wilson 2011)
- A thought:
  - Other health professionals come in to work individually with a person, write their notes and go to the next person.
- A Myth: Nurses use a medical model
  - In the area of disabilities we have always used a holistic model we had no allied health professionals, we did it!

Tomorrow

- We have to leave a legacy:
  - Our knowledge and skills related to the holistic needs of people with intellectual/developmental disabilities and their families across the life span and in a multitude of environments.
- We have to be fit for purpose (Wilson 2009)
  - To use our licence to do research and to publish
  - Avoid being passengers on the train of change

Tomorrow: How do we do it?

- Research and Publish: Build upon what has been done
  - Australia: Chris Atkins, Nathan Wilson, Penny Kearney – there are others!!
  - Overseas: Nehring USA, McKeon (Scotland), Griffith et al (UK)
- Be open to the possibilities
- Succession planning
  - It is critical that we identify novel approaches to the placement of nursing students' with people who have intellectual disability to further develop their clinical skills and increase the nurses awareness of the clients individual health care needs.

Tomorrow: how do we do it?

- Mentoring through:
  - PANDDA, Senior Nurses,
  - Those who have researched and published
- Join forces
  - Share ideas
  - Leave a legacy
  - What do we all think? How do we do it?
- Health and well being is a fundamental right for all people including people with intellectual disabilities and their families (World Health Organisation 2007).

References

Atkins, C. (2007). Response to the discussion paper: NSW Health & DADHC. Development of a service framework to improve health care of people with intellectual disabilities. Sydney, PANDDA Professional Association of Nurses in Developmental Disability Areas (Australia) Inc.

Australian Institute of Health and Welfare (2007b). Young Australians: their health and wellbeing 2007. Canberra, Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare (2006). Disability updates: children with disabilities Canberra, Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare. (2003). Nursing labour force 2002 *Health Labour Force Series no. 29. Canberra: Australian Institute of Health and Welfare.*

Barr, O. (2007). Working effectively with families of people with learning disabilities. In B. Gates (Ed.), *Learning disabilities: toward inclusion (5th ed.). Edinburgh: Churchill Livingstone/Elsevier.*

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., . . . Rosenbaum, P. (2004). The Health of Primary Caregivers of Children With Cerebral Palsy: How Does It Compare With That of Other Canadian Caregivers? *Pediatrics, 114(2), e182-e191.*

Clark, L. (2006). Intellectual impairment: a forgotten speciality. *International Journal of Nursing Studies, 43(5), 525-526.*

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2009). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child: Care, Health and Development, 36(1), 63-73.*

Goddard, L., P. Davidson, et al. (2008). "People with an intellectual disability in the discourse of chronic and complex conditions: an invisible group?" Australian Health Review **32**(3): 405-414.

Griffiths, P., Bennett, J., & Smith, E. (2008). The size, extent and nuture of the learning disability nurisng research base: A systematic scoping review. *International Journal of Nursing Studies, 46(2009), 490-507.*

References

Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (2004). The Consequences of Caring: Effects of Mothering a Child with Special Needs. *Journal of Family Issues, 25(3), 379-403. doi: 10.1177/0192513X03257415*

McKeon, M. (2009). A survey of clinical nursing skills in intellectual disability nursing. *Journal of Intellectual Disabilities, 13(1), 31-41. doi: 10.1177/1744629509103517*

Morris, T. L., & Edwards, L. D. (2006). Family caregivers. In I. M. Lubkin & P. D. Larsen (Eds.), *Chronic illness impact and interventions (6th ed.). Sudbury Massachusetts: Jones and Bartlett.*

Narramore, N. (2008). Meeting the emotional needs of parents who have a child with complex needs. *Journal of Children's and Young People's Nursing, 2(3), 103-107.*

Nehring, W. M. (1991). Historical look at nursing in the field of mental retardation in the United States. *Mental Retardation, 29(5), 259-267.*

Porter, L. and S. McKenzie (2000). Professional collaboration with parents of children with disabilities. London, Whurr Publishers.

Rehm, R. S., & Bradley, J. F. (2005). Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed. *Qualitative Health Research, 15(6), 807-820.*

Russell, L. (2000). Milestones in Australian nursing Contexts of nursing: an introduction. J. Daly, S. Speedy and D. Jackson. Sydney, MacLennan and Petty.

Tadema, A. C., & Vlaskamp, C. (2009). The time and effort in taking care for children with profound intellectual and multiple disabilities: a study on care load and support. *British Journal of Learning Disabilities, 38, 41-48.*

World Health Organisation. (2007). Health and human rights.   Retrieved 20 March 2007, from http://www.who.int/hhr/en/.

Yantzi, N. M., Rosenberg, M. W., & McKeever, P. (2007). Getting out of the house: the challenges mothers face when their children have long-term care needs. *Health & Social Care in the Community, 15(1 %R doi:10.1111/j.1365-2524.2006.00663.x), 45-55.*