

Health and People with Developmental/Intellectual Disabilities

POSITION STATEMENT

EXECUTIVE SUMMARY

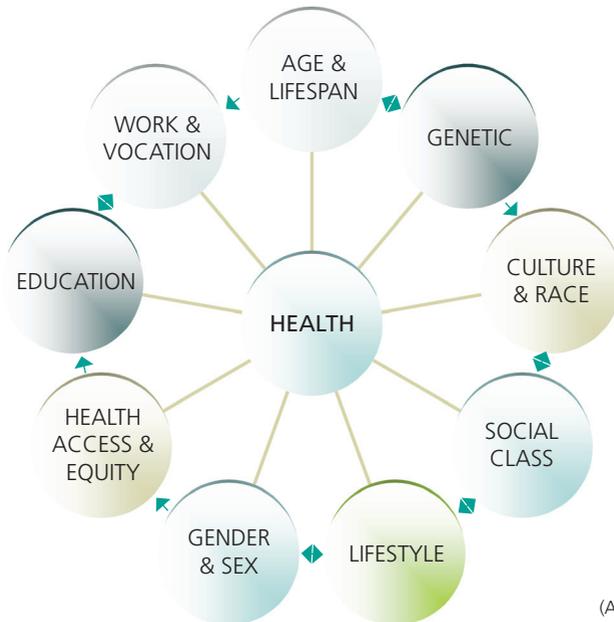
This position paper has been developed by the Professional Association of Nurses in Developmental Disability Areas (PANDDA) (Australia) Inc. and contains 10 statements about the health needs of people with a developmental/intellectual disability from a nursing perspective. These statements are presented under a Nursing framework that requires promoting principles of rights, choice, inclusion and independence to all people with a developmental/intellectual disability. PANDDA acknowledges the tripartite biopsychosocial definition of health espoused by the World Health Organisation (WHO): 'health is a state of physical, mental and social well being, not just the absence of disease or infirmity' (WHO, 2001). However, PANDDA also recognises the *absence of disease or infirmity* is an almost impossible state for anyone to achieve, irrespective of disability, throughout the entire lifespan. Therefore, the promotion of health as an achievable aim lies in ensuring that variations in health (physical, psychological and Social) do not become a barrier to having the opportunity to experience the type of quality life individually strived for (Saunders, 2003).

BACKGROUND

The recent surge of interest in the Health of people with developmental/intellectual disabilities has come about in part due to deinstitutionalisation highlighting the inadequacy of mainstream community services (health and social) to respond to the health needs of a population with unique health needs. Higher rates of health problems than the rest of society are the reality for people with developmental/intellectual disabilities with a healthcare system insufficiently educated and experienced to provide a specialist service (van Schroyenstien Lantman-de Valk, 2005; Cooper et.al. 2006). Healthcare and social care needs are not mutually exclusive concepts; without good health one cannot enjoy a socially enriching life and vice versa.

PANDDA believes much of the recent focus has been on purely physical health outcomes with morbidity and mortality gaining the most attention. Health, as a biopsychosocial construct, aims to identify and address the wider influences on health that are inherent within a population health approach: identifying then deconstructing the factors that contributed to the health concern in the first place.

INFLUENCES ON HEALTH



(Arevalo, 2003)

This approach mandates for the recognition that we all have our own perceptions or belief systems about health which will contribute to future illnesses; in practice this means seeking the views of people with developmental/intellectual disabilities. For example; what one person considers sexually healthy behaviour another may consider sexually unhealthy, what one person considers nutritionally healthy another considers unhealthy. These individual beliefs impact upon our health into the future, not just today.

This Position Statement intends to take what we know about the health and the health deficiencies of people with a developmental/intellectual disability to provide a summary of action required to enhance the health and well being of people with a developmental/intellectual disability.

1 A POPULATION HEALTH APPROACH

The constructing and defining of developmental/intellectual disability as a population with specific health requirements requiring a unique and individualised approach to healthcare provision. A population health approach exists for women's health, indigenous health, the health of gay and lesbian people, mental health, health and ageing, and recently men's health. Why not Developmental/intellectual Disability Health? Such an approach would require the recognition of the diversity of support needs for people with a developmental/intellectual disability including, but not limited to; early intervention, chronic and complex health /mental health problems, sexual health, forensic issues, behavioural issues, transition during the lifespan, aged care issues and palliative care.

2 THE SPECIALIST PRACTITIONER

Recognition and consolidation of the specialist role of the Developmental Disability Nurse within a population health approach. PANDDA has always maintained that the role of a Disability Specialist Nurse was both essential and beneficial to people with a developmental/intellectual disability. It remains imperative that specialist disability Nurse Practitioners (NP) and Clinical Nurse Consultants (CNC) are developed and utilised by health and social services.

3 SPECIALIST DISABILITY MULTIDISCIPLINARY TEAMS

Further development of specialist multidisciplinary teams across the healthcare and social care fields aimed at providing age-specific (paediatric and adult) primary care services to people with a developmental/intellectual disability. In the United Kingdom, age specific community based disability teams serve each geographical area and are Department of Health Funded; such a model is recommended. Expansion of the current developmental/intellectual disability clinics would provide the starting point for localised multidisciplinary teams.

4 UNIVERSAL HEALTH SCREENING AND HEALTH ASSESSMENT ACROSS THE LIFESPAN

The development of a universal Australia-wide model to provide health screening, assessment and service outcomes for all people with a developmental/intellectual disability across the lifespan together with staff educated in its implementation. Guidelines such as those published by the International Association for the Scientific Study of Intellectual Disability (IASSID, 2002) make a good starting point.

5 EMPOWERMENT

Improvement in the skills of healthcare and social care staff in the areas of communication and consent; the views and beliefs of people with a developmental/intellectual disability can be better understood and acted upon. Decision making competence should be explored further (van Schroyenstein Lantman-de Valk, 2005) with clear national guidelines for health services similar to those in the United Kingdom (Department of Health, 2001).

6 GENDER AND HEALTH

Mainstream population health work recognises gender as a specific determinant across the lifespan for different health outcomes, developmental/intellectual disability research and practice is yet to follow this lead. Recent research still shows people with a developmental/intellectual disability are treated as gender neutral or asexual (Umb-Carlsson & Sonnander, 2006).

7 RESEARCH

The encouragement, development and funding of a national research agenda aimed at determining evidence based practice within a framework of empowerment of people with developmental/intellectual disabilities. Joint scholarships and/or partnerships between peak bodies and research centres may engender a more collaborative approach. Federal and State Government departments responsible for health and social care should also work more collaboratively towards a national approach to research.

8 ACCESS AND EQUITY TO HEALTH

The development of initiatives to enhance the capacity and ability of people with a developmental/intellectual disability to access health and social care. Such initiatives might include exclusive community based developmental/intellectual disability health centres based on the successful formula of Women's health centres. Another initiative might include the removal of some socio-economic barriers and geographical barriers to accessing adequate and timely healthcare.

9 EDUCATION

A National and strategic approach to the minimum education required for all staff working with people with a developmental/intellectual disability; agreement needs to be made about which personnel are able to do which tasks (Mott, Chau & Chan, 2007). This would need to include care workers, social workers, Nurses, Doctors as well as therapeutic specialists. Such workforce planning would need to be refined at the national level with involvement from academic, vocational together with peak industry and professional bodies.

10 THE NEED FOR THE DEVELOPMENTAL/ INTELLECTUAL DISABILITY NURSE

Whilst the philosophy of the last thirty years has changed the direction of health care for people with developmental/intellectual disabilities towards community based independence, a recent shift is beginning to recognise the role of the developmental/intellectual disability nurse. PANDDA has always promoted and continues to promote the role of the Developmental Disability Nurse as one based on an holistic and rights led approach whose aim is to promote wellbeing in the individual, their family, their community and culture. Federal and State Governments need to produce and publish their position on the role and need for nurses who support people with a developmental/intellectual disability.

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