

NSW Health & DADHC
Development of a Service Framework to Improve
Health Care of People with Intellectual Disabilities

DISCUSSION PAPER RESPONSE

January 2008



Professional Association of Nurses in Developmental Disability Areas (Aust) Inc.

PANDDA

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RESPONSE TO THE DISCUSSION PAPER:

NSW Health & DADHC. Development Of A Service Framework To Improve Health Care Of People With Intellectual Disabilities. January 2007.

PANDDA (Aust) Inc commends NSW Health, DADHC and NSW CID for their recognition of deinstitutionalisation's failure to provide suitable health support for people with intellectual disabilities and applauds the considerable work evident in the discussion paper. In the absence of a national approach to the issues, PANDDA supports the development of a NSW service framework to improve understanding of health care needs and promotion of better health outcomes for people with intellectual disabilities.

PANDDA's greatest concern about the discussion paper is the apparent lack of a needs analysis. While it supports the five tier model in principle, it seems that the solutions have been proposed before there is a clear understanding of consumer and geographical health needs. Its second concern is the apparent lack of understanding of the role of Developmental/Intellectual Disability Nurses in health support for people with intellectual disabilities. PANDDA proposes that, within a needs analysis, there is a roundtable for discussion about Nursing's understandings of the health care needs of people with intellectual disabilities and the support Nursing provides.

PANDDA thanks NSW Health for the opportunity to comment and

- furnishes some introductory remarks
- presents some discussion of the options for Tiers 4 and 5
- offers for consideration a health care model developed by Developmental/Intellectual Disability Nursing, and
- provides additional comments on the discussion paper.

Introductory remarks

1. PANDDA believes that the lack of understanding of Nursing's role has come about as a result of the absence of Nursing leadership within DADHC. The position of Senior Practitioner (Nursing) has lapsed. PANDDA recommends that this position be reinstated to provide advice to DADHC re the health needs of its clients, health policy, staffing mixes and training related to health and to provide a means of communication between DADHC, NSW Health and the nurses employed in both Departments.
2. Developmental Disability Nurses replaced Mental Retardation Nurses in the 1980s. Developmental Disability Nurses are employed in work with children with developmental disabilities and with children and adults diagnosed with intellectual disabilities. There is no recognition of the term specialist

Intellectual Disability Nurse (as used in the discussion paper) by the NSW Nurses and Midwives Board or by the Australian Bureau of Statistics. Nevertheless, many nurses who work with people with intellectual disabilities exclusively prefer the title: Intellectual Disability Nurse. For that reason, this response uses Developmental/Intellectual Disability Nurse.

3. Education for Mental Retardation/Developmental/Intellectual Disability Nurses has always taken a biopsychosocial approach. The curriculum for Mental Retardation Nurses fitted well with the new undergraduate nursing courses in Colleges of Advanced Education and then Universities. In fact, Developmental Disability/Intellectual Disability Nurses had much to offer Nursing in the development of undergraduate programmes. Over the last ten years Developmental/Intellectual Disability Nursing has all but disappeared from undergraduate nursing programmes. Postgraduate programs for Developmental/Intellectual Disability Nursing flourished for a time but only exist now within generalist nursing or multidisciplinary post graduate programmes.
4. The role of Developmental/Intellectual Disability Nurses in the health of people with intellectual disabilities has been ignored for more than two decades¹. There are a number² of nurses who identify their specialty as Developmental/Intellectual Disability Nursing, most of whom are employed by DADHC operated or funded accommodation and community services. It is this resource which has enabled the continuing wellness of people with intellectual disabilities. They have promoted and monitored the physical health of people with intellectual disabilities and made clinical judgements which affect health outcomes for people with intellectual disabilities. Because of the high incidence of mental health problems/challenging behaviours among people with intellectual disabilities, there has also been an expectation that Developmental/Intellectual Disability Nurses promote mental health and manage mental illness and challenging behaviours. None of these activities would be possible without the Developmental/Intellectual Disability Nurse's ability to interpret the body language of people who are non-verbal and unable to use language in the usual ways. The lack of recognition of their work has resulted in an erosion of the workforce. Without attempts to offer education and a career path for the existing workforce and to educate and recruit replacement Developmental/Intellectual Disability Nurses, DADHC will lose this rich resource. The proposal regarding Clinical Nurse Consultants (CNCs) in the discussion paper, for example, actually appears to be an excellent opportunity to consider Nurse Practitioners in these roles. The roles described in the discussion paper lend themselves to this designation of nurse. The current workforce is more than adequately prepared to take on these roles.
5. People with intellectual disabilities come into contact with all nurses in a variety of health contexts. It is vital, therefore, that there is education for all

nurses about the health of people with intellectual disabilities and that there are specialist Developmental/Intellectual Disability Nurses who can act as a resource for nurses within other specialties.

6. Society has always expected Nursing to care for people who are vulnerable. The profession of Nursing is rapidly changing alongside changes in health care and in response to consumer expectations. Developmental/Intellectual Disability Nursing is meeting the challenges of modern health care by outlining its scope of practice³, as well as defining its professional expectations⁴ but continues with its historic values of caring for people who cannot care for themselves, supporting and empowering people with long term health problems to care for themselves, and helping people to promote their own health.⁵
7. The Health Care Plan (HCP) is an elusive term. A quick poll indicates that there are many and various interpretations of the term. Some standardisation would be valuable. Such standardisation needs to address the varying health care needs of people with intellectual disabilities.
8. Health assessment is vital to a HCP. There are a number of specific health assessment tools available, eg, CHAP, but they have two problems:
 - They do not address assessment of health in relation to functioning and social participation⁶
 - They do not contain enough prompts for people without health qualifications to assess people with complex health care needs.Nurses' education and practice is grounded in health assessment while doctors focus on illness assessment. Developmental/Intellectual Disability Nurses have developed a number of health assessment tools for people with complex health care needs for use by Registered Nurses (RNs). These attempt to address all aspects of health.
9. The discussion paper does not address the varying health care needs of people with intellectual disabilities in great enough detail. In South Australia⁷ for example, the varying needs are identified by three support levels, from clients who have no special health support needs, through those who have health support needs that require a GP plan, to those who have health support needs that require a comprehensive HCP developed by a RN. There are also guidelines for RNs in the assessment and development of the HCP. Whether these activities are identified formally or not, nurses do them every day in accommodation services and with people in their family homes (through various avenues such as practice nurses, discharge planning nurses, community nurses [DADHC or Health], and so on).
10. With deinstitutionalisation, most accommodation services are staffed by Support Workers with no qualifications related to health. It is an unreasonable expectation that they escort clients with complex health care needs to health

appointments. Even if a RN prepares information for the appointment, the questions asked and the information provided by doctors are poorly understood by the Support Worker. In many instances, this means that the doctor and RN have to communicate by phone at the time of the appointment or in other ways following the appointment. This can lead to delays in diagnosis and recommended treatment. It is also an unreasonable expectation that Support Workers assess the health of people with complex health care needs. There are too many instances of symptoms being interpreted as behaviour and managed as such. For people with pervasive complex health care needs, the support of a RN is required for constant monitoring of symptoms.

11. Support Workers' physical and mental health is also important. There is a need for reasonable working conditions, including a salary that matches the level of responsibility given to them, and for training which assists them to provide suitable health support for people with intellectual disabilities.
12. Families continue to support most people with intellectual disabilities in the family home. The single most requested support for their physical and mental health is suitable respite care. As in Aged Care Services, people with intellectual disabilities would benefit from a needs assessment and the provision of a service that reflects those needs, eg, if they have pervasive complex health care needs, nursing should be provided, in the family home or in home-like accommodation services.

Discussion of options for Tiers 4 and 5

Tier 4

PANDDA supports a combination of the three proposed options.

Health Clinic

The single most useful tool in the management of complex health care needs is the physician with experience with people with intellectual disabilities. (Such physicians may be available through various large residential centres or intellectual disability health clinics). In NSW, there is a longstanding professional relationship between these physicians and Developmental/Intellectual Disability Nurses. Health assessments and outcomes are more efficient and effective when this partnership exists. Developmental/Intellectual Disability Nurses bridge the DADHC/Health divide and assist people with intellectual disabilities and their families or paid carers to navigate the health care system. This partnership is best placed in a multidisciplinary context where clients can access the variety of services they need, without the confusion of having multiple points of contact. If the clinic (or at least, the physician) is affiliated with a training hospital, this facilitates access to specialist medical and allied health services, such as Dysphagia Clinics, Physical Disability Clinics, neurologists, gastroenterologists, dietitians, and so on.

Health Resource Team

While it is true that most people with intellectual disabilities live in the family home, the more severe the disability and the consequent health care needs, the more likely the person will be living in an accommodation service. Because of the concentrations of people with severe intellectual disabilities and complex health care needs, it would seem prudent to identify need in the Area Health Services before deciding on one specialist Health Resource Team (HRT) and/or CNC for each area, or the composition of the particular HRT. For example, there are DADHC operated and funded accommodation services whose resident population already benefits from the input of a full-time CNC (or related position). If those CNCs were asked to stretch their resources over a wider population, client services would falter. On the other hand, there are numerous group homes staffed by people with no health qualifications and no access to Developmental/Intellectual Disability Nurses. At meetings of the Health Planners Network, these staff identified the difficulties in meeting the requirements of a HCP without access to a health professional.

Clinical Nurse Consultants

The role of the CNC includes clinical leadership, education, research and administration. PANDDA supports the notion of a network of CNCs (but prefers that they were Nurse Practitioners) and notes that such a network should:

- Be placed where the need is
- Have a structural relationship with RNs who work with people with intellectual disabilities
- Have a structural relationship with a Senior Developmental/Intellectual Disability Nurse in DADHC

so that nurses can work together to meet the health care needs of people with intellectual disabilities, their families and carers in a collaborative way, instead of in the currently fragmented way.

PANDDA notes that the DADHC Health Care Review Team has begun to identify the number of Clinical Nurse Specialists that would be needed on the basis of clients' health support needs. This review has not considered the roles of education and research.

There has been insufficient time for PANDDA to discuss the issues surrounding the placement of such positions. While it seems timely to place the positions in NSW Health (so that people with intellectual disabilities have access to mainstream specialist health care), a Senior Practitioner (Nursing) would be responsible for ensuring that there is collaboration among Developmental/Intellectual Disability Nurses employed by both Departments. The multidisciplinary evidence base for practice with people with developmental disabilities is poor. This situation will continue in Nursing if attention is not paid to the Nurse Practitioner/CNC's role in research to develop an evidence base for Developmental/Intellectual Disability Nursing practice.

The relationship between the current DADHC positions and proposed CNC network

There are Developmental/Intellectual Disability Nurses working in a variety of positions in DADHC accommodation services and Community Support Teams who complete health assessments and develop HCPs, or assist others to do so. The positions include Nurse System Support Coordinator, Clinical Nurse Educator, Community Nurse, Residential Nurse Unit Manager and Registered Nurse. It is beyond the scope of PANDDA to comment at this time on the benefits and disadvantages of this variety of approaches. PANDDA strongly recommends that discussions are conducted with the Nurses who occupy the positions to come to an understanding of the roles they have in health support for people with intellectual disabilities, as a way to streamline these services and realize the "best fit" between the current and proposed services.

Tier 5

The various models proposed for specialist regional/state-wide support and clinical leadership each have their strengths. PANDDA suggests a discussion among the key players to identify the strengths of each model to create a comprehensive model. The model should be multidisciplinary, including nursing, in all aspects of its operation: research, expert clinical resource, clinical leadership, support, education, training and so on. The placement of the Tier 5 model requires a strong rationale related to best accessibility.

Health care models developed by Developmental/Intellectual Disability Nursing

There are accommodation services where people with intellectual disabilities and complex health care needs are concentrated. In response to need, and dependent on resources, Developmental/Intellectual Disability Nursing has initiated a number of health care models. For reasons of brevity, only one of these models is described.

In one DADHC funded accommodation service, 31 children and adults with severe intellectual disabilities and pervasive complex health care needs live in 7 community homes. Two homes with clients who are fragile and have unstable conditions are supported by a RN 24 hours, the remaining workforce being Support Workers. They are monitored by a Health Care Team (HCT) consisting of a CNC (Coordinator), Physiotherapist, Speech Pathologist and Endorsed Enrolled Nurse. The HCT assesses each client who then has an annual health review with a paediatrician or specialist Developmental Disability physician. The CNC then develops a HCP in collaboration with the other members of the HCT, client, family, house staff, school/day program, GP, allied health and specialists. The HCP becomes part of the annual ISP. One of the advantages of this model is the immediate availability of nursing, physiotherapy and speech pathology to

clients with significant epilepsy, orthopaedic deformities, respiratory disease, dysphagia, constipation and multiple medications.

Additional comments

1. While there has been a significant increase in the life expectancy of people with intellectual disabilities, and the accompanying problems associated with ageing, there is still a way to go before the gap between life expectancy for people with and without intellectual disabilities closes.
2. There is mention in the discussion paper of clinical research in developmental disability medicine. PANDDA suggests that clinical research should be in developmental disability health, in the sense of the WHO definition of health.
3. There is considerable rhetoric in the discussion paper about education/training, yet there are currently no suitable training programs for support workers who work with people with complex health care needs⁶ (and minimal training funding to organisations who employ these workers), education for Developmental/Intellectual Disability Nursing has been decimated (both at the undergraduate and postgraduate levels), and attendance by GPs at the education sessions offered has been poor. Without clear strategies for the resolution of these problems, the whole system will soon fail.
4. NSW Health have an excellent policy⁸ related to the needs of people with disabilities while in hospital. Compliance with this policy directive is mandatory but its translation into practice is patchy.
5. The high incidence of dental disease is identified and the discussion paper mentions options for special needs dentistry. PANDDA suggests that strategies to deal with the extended waiting times currently experienced, especially for those who require a GA for an examination, become a priority.
6. Appendix A which lists common health problems arises from Beange's⁹ groundbreaking work. It has overlooked, however, two of the problems that people with intellectual disabilities and complex health care needs most commonly experience: dysphagia and orthopaedic deformities. Dysphagia has implications for resources such as Dysphagia Clinics, Speech Pathologists and Dietitians. Orthopaedic deformity has implications for resources such as Physical Disability Clinics, Physiotherapists and Occupational Therapists. This appendix, while recognizing the special health problems for people with intellectual disabilities, cannot demonstrate the impact that such conditions, often in combination, have on their lives.

7. Finally, and most importantly, resources will be better managed if there is identification of the varying levels of health care needs, levels of support needed, desired outcomes and specific strategies to address each level.

NSW Developmental/Intellectual Disability Nurses are committed to continuing their 35 year history of supporting the health of people with intellectual disabilities, their families and carers. They have done so through a number of structural changes and are prepared to assist DADHC and NSW Health in any further discussions regarding a new structure. Contact with Developmental/Intellectual Disability Nurses can be made, in the first instance, through PANDDA.

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