S. 2

**The Parkside Foundation**

# Submission to Inquiry into the principles and objectives that should form the basis of the new Disability Services Act

**April 2009**

## Who this submission is from

The Parkside Foundation is a not-for-profit company which provides services to people with disabilities, older people and their carers across Southern Tasmania. Parkside provides a range of community access, tenancy support and respite services to people with intellectual disabilities and their families.

The CEO, Brian Treanor, is a Registered Nurse who trained in Ireland, specialising in the care of people with an intellectual disability. He holds a Bachelor of Adult and Vocational Education and is currently studying Medicine (Bachelor of Medicine - Bachelor of Surgery) at the University of Tasmania.

## Submission summary

People with intellectual and developmental disabilities have poor health outcomes and reduced life expectancy compared to the general population. We believe that the new Disability Services Act should reflect the UN Convention's statement on health for people with disabilities and by incorporating it into the proposed legislation.

## Poor Health Outcomes

It is estimated that there are over 300,000 people with intellectual disabilities living in Australia. This is a similar proportion of the population as Aboriginal people and both groups share poor health outcomes (Royal Australian College of General Practitioners 2006).

Unfortunately there is little Tasmanian research on the health needs of people with intellectual disabilities but the literature from elsewhere in Australia has shown that:

- In Northern Sydney, 42% of medical conditions went undiagnosed in people with intellectual disabilities and half of the diagnosed conditions were inadequately managed. That is, only 29% of conditions were diagnosed and properly treated. (Beange & others 1995);
- Hypertension was twice the level of that in the general population but had only been diagnosed in 32% of cases. (Beange & others 1995);
- Obesity in 25% of women with disabilities, three times the level in the general population. (Stewart & others 1994) This would suggest that, across Australia, there are at least 45,000 women with intellectual disabilities who are obese, and therefore at greatly increased risk of diabetes and hypertension, and increased risk of heart disease, cancers and osteoarthritis;
- Dental disease up to seven times more frequent than in the general population. (Scott & others 1998) For example, 15.5% - indicating 46,500 across Australia – had severe periodontal disease, which often leads to loss of teeth and the need for dentures;
- Psychiatric disorders in people with intellectual disability are frequently undiagnosed and inappropriately treated. Specifically, only 20% of people with depression or bipolar disorder were receiving anti-depressants or mood stabilisers while 80% were receiving antipsychotic medication. (Torr 1999. See also Senate Select Committee on Mental Health 2006); and
- A person with an intellectual disability has a lower life expectancy than the general population, twenty years lower for people with severe disabilities. (Bittles & others 2002).

## UN Convention

The UN Convention on the Rights of Persons with Disabilities Article 25 of the Convention states that:
"*Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. ... Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, ... Parties shall:*

*a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
*b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and service designed to minimise and prevent further disabilities, including among children and older persons;*
*c. Provide these health services as close as possible to people's own communities, including in rural areas;*
*d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*
*e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*
*f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability."*

## Tasmanian Context

In Tasmania, the Community Integration Plan started in 1991 with the aim of closing the state institution, Willow Court. In 2001, Tasmania became the first State to no longer have a state-run institution for people with disabilities.

The philosophy underpinning the deinstitutionalisation is enshrined in the Disability Services Act (Tas) 1992. The move was not only a physical transfer of service provision facilities but the initiation of a 'non-medical model' or community based approach to service delivery.

This approach was reflected in the development of the new service structures. Firstly, the (then) Department of Community Services tendered services to the non-government sector and encouraged the development of new community based non-government organisations (NGO's). Secondly, medical and nursing positions were not included in the support matrix developed by these emerging services.

The outcome of this process has been:

- People with intellectual disabilities in Government funded NGOs are supported by workers who have no formal training in health care and are not health care providers;
- People with disabilities access generic healthcare professionals on the same basis as the rest of the community (i.e. make an appointment to see their General Practitioner if they have any health issues); and
- There are currently no specialist disability health services in Tasmania to support these healthcare professionals.

There is little doubt that the closure of Willow Court has resulted in a significant increase in the quality of life for the former residents. Institutional care is not an appropriate model of service delivery and we do not wish to see a return to those days. However, the philosophical underpinning that led the move away from the 'medical model' does not recognise the additional health needs of this target group. Whilst people with disabilities are not "sick" (and do not require full-time care of doctors and nurses) they do have additional healthcare needs. Unfortunately, as demonstrated in the above research, these needs often go unnoticed. The current Disability Services Act, the service delivery framework and the healthcare system fail to acknowledge, identify or address these needs.

For example, the Standards for Service Delivery, against which funded organisations are assessed (as part of the current Disability Services Act), make no reference to health issues or outcomes for people with disabilities. There is no requirement for people with disabilities to have regular medical or dental appointments and there is no means to assess that medication has been correctly administered within the support agency.

## Other States

### Specialist Services

At present there are a small number of bodies providing intellectual disability health resource teams in Australia - the Centre for Developmental Health at Monash University, the Queensland Centre for Intellectual and Developmental Disability, and the Centre for Developmental Disability Studies in Sydney.

### Review of deaths in care:

Queensland and New South Wales have formal processes to review the deaths of people with disabilities living in supported accommodation. The aim is to identify any factors which may contribute directly or indirectly to deaths that are preventable or may affect the safety and wellbeing of people with disabilities in care. Consideration is given to facts such as health care planning, responses to staff to critical incidents and service policies or procedures. The objective is to reduce or remove risk factors associated with preventable deaths.

### Systemic approaches:

The NSW Government has recently spelt out the need for multi-tiered action on the health of people with intellectual disabilities, ranging from improved primary care through to the establishment of a statewide network of specialised intellectual disability health services to back up mainstream services (NSW Health 2007). The NSW Minister for Health has approved this framework in principle and a business case to advance it is currently being prepared. However, this business case will need to compete with many other priorities for NSW Government funding.

### Annual Health Checks:

In 2007 the Australian Government recognised the need for comprehensive health assessments for people with disabilities through the introduction of Medicare Items 718 and 719. In New South Wales it is a requirement that funded service providers ensure all people with intellectual disability in their care undergo comprehensive health assessment on a two yearly basis. There is no such requirement in Tasmania.

## Changes to the new Act

It is important that the new Disability Services Act makes reference to health outcomes for people with disabilities. Tasmania needs a legislative framework upon which we can develop policies and initiatives to address this neglected issue. We hope the revised Act will become the cornerstone upon which new systems can be developed that enhance access for people with disabilities to health care services and support generic health care professionals to meet the needs of this group. The new Act has potential to raise the profile of this issue and could be a stimulus for local research (perhaps through the Menzies Centre or the University of Tasmania). This legislation should also provide a mandate for the establishment of a process to review the deaths of all people with disabilities living in supported accommodation.

## Contact

Brian Treanor
CEO, The Parkside Foundation
Level 3, Quay Building
31 Cambridge Road
BELLERIVE, TAS 7018
btreanor@parkside.org.au
Phone 03 6244 4133.

## Acknowlegements

This document draws upon information contained in:

> Simpson J & Lennox N, 2008, *Proposal for specialised services to enhance the capacity of the mainstream health system to provide equitable and cost effective health care to people with intellectual disabilities*, National and NSW Councils for Intellectual Disability & Australian Association of Developmental Disability Medicine.

## References:

Beange H, McElduff A & Baker W, 1995, "Medical disorders of adults with mental retardation: a population study" *AJMR* 99: 595-60.

Bittles AH Petterson BA, Sullivan SG, Hussain R, Glasson EJ & Montgomery PD, 2002, "The influence of intellectual disability on life expectancy" *J Gerontol A Biol Sci Med Sci* 57:7; M470-M472.

NSW Health, 2007, *Development of a service framework to improve health care of people with intellectual disabilities.*

Royal Australian College of General Practitioners, 2006, *RACGP Budget Proposal, Medicare Benefits Schedule – Annual health assessment item for people with intellectual disability.*

Scott A, Marsh L & Stokes ML, 1989, "A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population" *ADJ* 43; 257-261.

Stewart L, Beange H & McKerras D,1994, "A Survey of dietary problems of adults with learning disabilities in the community" *Mental Handicap Research* 7, 41-50.

Torr J, 1999, The *Psychiatry of Intellectual Disability: A Review of the Literature and Review of a Psychiatric Clinic for Intellectually Disabled Adults,* Department of Psychiatry, University of Melbourne.