The New South Wales
Council for Intellectual Disability

# SUBMISSION TO THE PRODUCTIVITY COMMISSION ON THE HEALTH WORKFORCE

*July 2005*

## Who this submission in from

The NSW Council for Intellectual Disability (NSWCID) is a peak body representing the rights and interest of people with intellectual disability in NSW. Roles that Council takes on as a peak body include providing policy advice, systemic advocacy, community education, and information provision and dissemination.

This submission is also made on behalf of the National Council on Intellectual Disability which NSWCID represents on health issues.

## A crisis quiet for too long

Recent Australian research has shown:

- The life expectancy of a person with an intellectual disability is much lower than the general population, approximately twenty years lower for people with severe disabilities. (Bittles &others 2002)
- In Northern Sydney, 42% of medical conditions went undiagnosed in people with intellectual disabilities **and** half of the diagnosed conditions were inadequately managed. (Beange & others 1995)
- Obesity for people with intellectual disabilities is up to three times the level in the general population. (Stewart & others 1994)
- 42% of 211 people with disabilities who died in care were underweight and some died because of critical illnesses being untreated (Community Services Commission 2001)
- Dental disease was up to seven times more frequent than in the general population. (Scott & others 1998)
- Psychiatric disorders in people with intellectual disability are frequently not diagnosed and inappropriately treated. Only 20% of people with depression or bipolar disorder were receiving anti-depressants or mood stabilisers while 80% were receiving antipsychotic medication. (Torr 1999)

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## Why is it like this?

The poor health experienced by people with intellectual disabilities arises from a wide range of factors:

- Communication issues between professional and patient.
- High rates, and often complex ranges, of health problems.
- Diagnostic overlay – The mistaken assumption that symptoms are related to the disability.
- Inadequate multidisciplinary focus on health problems.
- Few health professionals having a special interest or expertise in intellectual disability.
- Disability services have moved away from a "medical model" but without systems being established to ensure appropriate health care.
- Many members of society attaching less value to people with disabilities.
- Health promotion, campaigns and research tending not to focus on people with intellectual disabilities.
- Inadequate training of health and disability professionals.
- Poverty.
- Health professionals need to spend more time with people with intellectual disabilities but the health system often does not allow for this.
- Inadequate supply of free and subsidised health services.
- Limited capacity of carers to ensure a person's access to health services.
- Inadequate cooperative action within and between governments to define and respond to the health needs of people with intellectual disabilities.

In short:

- People with disabilities "carry a huge burden of undiagnosed or poorly managed health problems" (Royal Australian College of General Practitioners 2005)
- "There is a lack of appropriate strategies" to address the "poor health outcomes" of people with intellectual disabilities. (Australian Health Care Summit Communiqué 2003)
- "I have acknowledged the importance of addressing the specific health needs of people with intellectual disability and would be happy to examine possible avenues of addressing this issue." (Hon Tony Abbott, Minister for Health, letter to NSW Council for Intellectual Disability 8 October 2004)

## International commonality

There is a growing international recognition of poor health outcomes for people with intellectual disabilities, the reasons for these and of the need for a complementary mix of strategies to address the problem. (NHS Health Scotland 2004, Meijer, Carpenter & Scholte 2004, US Department of Health and Human Services 2002, International Association for the Scientific Study of Intellectual Disability 2002, Department of Health UK 2001, Disability Rights Commission 2004.)

## Problems in the health workforce

Many of the causes of inadequate health care set out above relate to the health workforce. We now elaborate on these problems and potential solutions:

### *Tertiary education*

All health professionals need education on intellectual disability, covering:

- Communication with a person with an intellectual disability, including meeting the additional challenges where the person is Indigenous or from a non English speaking background.
- Diagnostic approaches where communication is limited.
- The equal rights of people with intellectual disabilities to non-discriminatory health care.
- Addressing symptoms for what they are rather than mistakenly seeing them as part of the disability.
- Health conditions often suffered by persons with intellectual disabilities and assessment, treatment and prevention approaches.

There are good resource materials on these issues, for example Management Guidelines Developmental Disability Version 2 2005.

However, there is currently very limited education at a tertiary level on the health needs of people with intellectual disabilities. For example, in undergraduate medical training across Australia, a study found only 2 to 15 hours of training in intellectual disability (Lennox and Diggens 1999a). 76% of general practitioner saw themselves as inadequately trained to treat patients with intellectual disabilities (Lennox and others 2000).

In nursing training in NSW, there used to be separate courses in general nursing, psychiatric nursing and mental retardation nursing. These courses were merged on the basis that there would be a comprehensive course covering all these aspects of nursing. However, now the University of Wollongong is the only university campus of 19 in NSW that has a discrete and compulsory subject on intellectual disability. In other universities, there is some but very limited coverage in generic subjects. (Communication with Isla Bowen, Lecturer in Developmental Disabilities, University of Wollongong)

### *Ongoing training*

There are some good training materials for ongoing training but there tends to be poor uptake on these by the health workforce. For example, NSW Health commissioned the Centre for Developmental Disability Studies to develop and implement a training package for staff in NSW hospitals. Most of the training has not occurred due to staff not taking up on advertised sessions. It would appear that training is unlikely to be attended unless it is mandatory and/or there is provision for relief staffing.

### *Specialists in intellectual disability health*

There needs to be a multidisciplinary resource available around the country that can:

- Undertake diagnostic assessments of the health care needs of some people with intellectual disabilities who have complex medical conditions. This would be on referral from a general practitioner.
- Provide advice and training to doctors and other health and disability professionals

- Foster the development of better local networks of GPs, other primary health workers, health specialists and disability service workers.
- Lead research and development of enhanced knowledge about the health of people with intellectual disabilities.

This specialist resource is needed because:
- There is a wide body of specialised knowledge about health and intellectual disability, for example susceptibility to particular health conditions, diagnostic methods, what "symptoms" are or are not associated with the disability rather than being signs of disease. This specialised knowledge base also needs further development.
- Appropriate diagnosis and treatment of health conditions in people with intellectual disabilities is often very challenging due to factors including communication difficulties between doctor and patient.
- Health workers do not tend to see training to assist them in meeting that challenge as a priority.
- A multi-disciplinary approach is often required to diagnosis and treatment of more complex conditions, and this approach is often not available for people with intellectual disabilities, or at least not available from professionals with the requisite understanding of intellectual disability.

We favour this specialist resource taking the form of an intellectual disability health resource team in each health area. This would be a multidisciplinary team that includes a doctor who specialises in intellectual disability and professionals in other disciplines such as nursing, dietetics, speech pathology, neurology, psychiatry and alcohol and other drugs. Each team would focus on the varying needs and available resources in its local area.

At present, there is a very small number of bodies providing some of the above roles in Australia – the Centre for Developmental Disability Health at Monash University, the Queensland Centre for Intellectual and Developmental Disability and the Centre for Developmental Disability Studies in Sydney. There is also some useful local leadership work occurring, for example by collaboration between general practitioners and disability service providers in the New England area of NSW.

There is no established specialty or career path in intellectual disability medicine.

Another useful specialist resource would be in intellectual disability liaison nurse in major hospitals. There is a liaison nurse between disability services and health services in Wollongong.

## *Mental health*

Approximately 40% of people with intellectual disabilities also have mental health conditions (Einfeld & Tonge, 1996 a & b) (Einfeld 2002) Assessment of these conditions is often very difficult due to factors including communication difficulties and a lack of accepted diagnostic criteria. And yet, at present, there are only 5 to 6 full time equivalents of psychiatrist time specialising in this group in Australia (Einfeld 2002).

In a 1996 study, over 70% of psychiatrists saw themselves as inadequately trained in intellectual disability. 85% felt that patients with intellectual disabilities and

psychiatric conditions received a poor standard of psychiatric care. (Lennox and Chaplin 1996)

In short,

> "There is an urgent need for academic research, increased clinical expertise and substantial increased resources in the much neglected area of dual disability"(Burdekin 1993).

People with intellectual disabilities and psychiatric disorders were acknowledged as a high level needs group in the Second National Mental Health Plan 1998. However, in 2003,

> "The development and implementation of effective service models for other groups with complex needs, such as people with mental disorder and intellectual disability, are yet to be realised and need to be afforded higher priority."

(Steering Committee for the Evaluation of the Second National Mental Health Plan 1998-2003 2003)

There needs to be an enhanced availability of psychiatrists and other mental health professionals with particular expertise in intellectual disability.

## Nexus with the National Health Workforce Strategic Framework

Action on the issues we have raised in this submission would be consistent with the principles in the Strategic Framework, in particular:

- Principle 2 – Distribution of the workforce should optimise equitable access to health care for all Australians, and recognize the specific requirements of people and communities with greatest need.

- 5 – A realignment of existing workforce roles or the creation of new roles may be required to address health needs and provide sustainable quality health care.

- 6 – Health workforce planning should be population and consumer focused.

## People with other disabilities

This paper focuses on people with intellectual disabilities who comprise approximately 2% of the population. There are also approximately 7% with borderline intellectual disabilities.

Much of what is said here would apply similarly for people with other disabilities.

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## References


Australian Health Care Summit Communiqué (2003) *The Old Parliament House Blueprint for Health Reform.*

Beange H, McElduff A, Baker W (1995) "Medical disorders of adults with mental retardation: a population study" *AJMR* 99: 595-604

Beange H, Durvasula S, Baker W (2002) "Mortality of people with intellectual disability in northern Sydney" *JIDD* 27; 255-264

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

Burdekin, B. (1993). Report of the National Inquiry into the Human Rights of People with Mental Illness. Australian Government Publishing Service, Canberra., Human Rights and Equal Opportunity Commission**:** Chapter 21: People with Dual and Multiple Disabilities.

Community Services Commission (2001) *Disability, death and the responsibility of care* (A review of the characteristics and circumstances of 211 people with disabilities who died in care between 1991 and 1998 in NSW)

Department of Health UK (2001) *Valuing people: a new strategy for learning disability for the 21st century* Chapter 6, "Improving health for people with learning disabilities"

Disability Rights Commission UK (2004) *Equal treatment: closing the gap*, investigation into health inequalities facing people with learning disabilities and mental illnesses. http://www.drc.org.uk/newsroom/healthinvestigation.asp

Einfeld S (2002) Submission to the Select Committee on Mental Health, Legislative Council of NSW, submission on behalf of the Special Interest Group in Intellectual Disability of the Royal Australian and New Zealand College of Psychiatrists.

Einfeld S.L., Tonge, B.J. (1996a) "Population Prevalence of Behavioural and Emotional Disturbance in Children and Adolescents with Mental Retardation. 1. Rationale and methods". *Journal of Intellectual Disability Research*, Vol 40, part 2, 91-98

Einfeld S.L., Tonge B.J. (1996b) "Population Prevalence of Behavioural and Emotional Disturbance in Children and Adolescents with Mental Retardation. 2. Epidemiological findings". *Journal of Intellectual Disability Research*, Vol 40, part 2, 99-109

International Association for the Scientific Study of Intellectual Disability (2002) *Health Guidelines for Adults with an Intellectual Disability.* www.iassid.org/pdf/healthguidelines-2002.pdf

Lennox N (2002) *Issues Paper – National Health Priority Targets for Adults with Developmental Disability* Developmental Disability Unit, Faculty of Health Sciences, University of Queensland

Lennox NG, Chaplin R. (1996) The Psychiatric Care of People with Intellectual Disabilities: The Perceptions of Consultant Psychiatrists. Australian & New Zealand Journal of Psychiatry. 1996; 30(6):774-780

Lennox NG, Diggens J and Ugoni A. (2000) "Primary health care for people with an intellectual disability: General practitioners attitudes and provision of care", *Journal of Intellectual and Developmental Disability*, Vol. 25 No.2, pp127-133, June 2000

Lennox NG, Diggens J. (1999a) " Medical Education and intellectual disability: A survey of Australian Medical Schools", *Journal of Intellectual & Developmental Disability*, Vol. 24, No. 4, pp. 333–340.

Lennox NG, Diggens J. (1999b) "Knowledge, skills and attitudes: medical schools' coverage of an ideal curriculum on intellectual disability", *Journal of Intellectual & Developmental Disability*, Vol. 24, No. 4, pp.341–347.

Lennox NG, Diggens J, Ugoni A.(1997) “Barriers and Solution to the General Practice Care of People with an Intellectual Disability”. *Special Issue IASSID Congress: Primary Health Care, Journal of Intellectual Disability Research*, Oct 1997, vol. 4; part 5: 380-390.

Lennox N, Rey-Conde T, Bain C, Purdie D, & Bush R. (2004). *The evidence for better health from health assessments: A large clustered randomised controlled trial.* Paper presented at the IASSID World Congress, Montpellier.

*Management Guidelines Developmental Disability Version 2* (2005) Therapeutic Guidelines Ltd North Melbourne

Meijer M, Carpenter S, Scholte F (2004), “European manifesto on basic standards of health care for people with intellectual disabilities” *Journal of Policy and Practice in Intellectual Disabilities 1:1 10-15*

NHS Health Scotland (2004), *Health needs assessment report – people with learning disabilities in Scotland.*

Royal Australian College of General Practitioners, “RACGP Calls for Increased Support for Medicare Services for People with Disability”, Media Release, 4 March 2005

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

Steering Committee for the Evaluation of the Second National Mental Health Plan 1998-2003 (2003). *Evaluation of the Second National Mental Health Plan*. Canberra, Commonwealth of Australia**:** 37.

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.

US Department of Health and Human Services (2002) *Closing the gap: a national blueprint to improve the health of persons with mental retardation* www.surgeongeneral.gov/library