Submission
No 66

INQUIRY INTO DENTAL SERVICES IN NSW

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Date Received: 1/06/2005

Theme:

Summary

The New South Wales
Council for Intellectual Disability

SUBMISSION TO INQUIRY INTO DENTAL SERVICES IN NSW

Standing Committee on Social Issues
Legislative Council, NSW

May 2005

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The NSW Council for Intellectual Disability (CID) is a peak body representing the rights and interest of people with intellectual disability in NSW. Some of the roles that Council takes on as a peak body include providing policy advice, systemic advocacy, community education and information provision and dissemination. At least 1.5 - 2% of Australians have an intellectual disability (Wen 1997 and 2003).

In recent years, CID has focused heavily on problems with health care of people with intellectual disabilities. This submission is based on CID's experience, relevant research and consultation with dentists with expertise in intellectual disability.

Adequacy of health care generally for people with intellectual disabilities

Recent Australian research has shown very poor health outcomes for people with intellectual disabilities. For example, in Northern Sydney, 42% of medical conditions went undiagnosed in people with intellectual disabilities **and** half of the diagnosed conditions had been inadequately managed. (Beange and others 1995)

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 and others 2002)

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)

Adequacy of dental services for people with intellectual disabilities

A study of oral health in a sample of people with intellectual disabilities living on Sydney's lower North Shore found that dental disease was up to seven times more frequent than in the general population. (Scott and others 1998) Beange and others (1995) found that dental disease was the most common health problem faced by people with intellectual disabilities, occurring in 86% of all subjects.

In a review of people with intellectual disabilities who had died due to respiratory illness, the NSW Ombudsman looked at oral health issues. There is an association between poor oral hygiene and respiratory illness. Of 33 people who had died:

- Only 11 of 24 people with gastro-oesophageal reflux disease had had a dental review in the last year despite this disease being a major cause of erosion.
- Between 9 and 17 people had not had a dental review in the last year.

(NSW Ombudsman 2004)

It is often very difficult for a person with an intellectual disability to obtain appropriate treatment.

This problematic situation arises from a range of factors including:

- Communication issues between professional and patient – capacity to communicate, training of professionals in communication techniques
- The additional complexity of communication and cultural factors where a person is Indigenous or from a non English speaking background.
- A shortage of skills amongst dentists in working with people with intellectual disabilities. Dentists need particular training and skills due to:
    - The difficulty people with intellectual disabilities often have in recognising and explaining symptoms.
    - The fear and resistance of dental treatment often shown by people with intellectual disabilities due to limited understanding. This calls for extra time and reassurance by the dentist and sometimes requires sedation or a general anaesthetic.
    - The relationship between dental issues and particular health problems commonly experienced by people with intellectual disabilities.
- Health professionals need to spend more time with people with intellectual disabilities but the health system often does not allow for this.
- Poverty of people with intellectual disabilities and inadequate supply of free and subsidised dental services.
- Inadequate awareness of dental care issues amongst disability support workers and other carers; and lack of continuity of staffing in disability supported accommodation and therefore inadequate knowledge of an individual's history and needs. Dentists are often frustrated by the difficulty of getting a history from workers and by the difficulty of having their recommendations implemented in supported accommodation.

(Scott and others 1998; NSW Ombudsman 2004)

In the absence of regular, timely and high quality dental treatment, people with intellectual disabilities will often be in ongoing pain. For those with limited verbal communication, they may not be able to explain that pain. This can lead to the person being very distressed and exhibiting highly challenging behaviour.

A taxi driver was taking Peter to school. Peter became very agitated and the driver called the police. Doctors could find nothing wrong and gave Peter tranquillisers. Eventually a dentist, who understood people with disabilities, found a large dental abscess. When the tooth was removed, Peter's behaviour returned to normal.

Public dental services - Most people with intellectual disabilities are dependent on disability support pensions and so dependent on public dental services. Those services are provided by clinics at Westmead Hospital and the United Dental Hospital in Sydney for people with intellectual disabilities and similar "special needs", and by public clinics around the state. There are various problems with this system:

- Long waiting times at various services due to inadequate resources. At the biggest service, the Special Care Dentistry clinic at Westmead, there is a waiting time of 3-6 months for initial consultations, 6-9 months after that for treatment in the chair for most adults with intellectual disabilities (or up to 18 months for general anaesthetics). Whilst the clinic provides advice on interim treatment, patients may be in ongoing pain while they wait and they may not be able to verbalise that pain. At Westmead, the intention is to schedule checkups at least annually. This target is currently not being achieved and is well above the 3-6 monthly checkups and prophylaxis recommended by the International Association for the Scientific Study of Intellectual Disability (2002).
- Dentists working in generalist public clinics may have little knowledge of intellectual disability.
- An insufficiently uniform focus on preventative approaches, as opposed to just treatment of immediate problems. For example, much dental disease is related to brushing techniques, diet and inadequate consumption of fluoridated tap water.
- There can be a tendency for high level management to be focused on the number of patients seen rather than focussing on giving patients the time their disability might call for and time to ensure a preventive approach.
- There are particular problems in rural areas. Available resources vary considerably and tend to be less than in Sydney. There can be difficulty in accessing general anaesthetics at local hospitals. There is a lack of access to specialised clinics (though the Westmead clinic does some outreach work with children).
- The lack of a career path to encourage dentists to specialise in working with people with disabilities

Some people with intellectual disabilities use private dentists. However, it is very difficult to find a private dentist who is experienced with people with intellectual disabilities and willing to spend the time the patient needs for an affordable fee. There has been a limited advance in recent changes to Medicare. Patients can claim a Medicare rebate on three consultations with a dentist when dental problems may exacerbate major health problems.

Action required

1. Enhancement of the availability of public dental health services so that people with intellectual disabilities have access to timely and informed dental treatment.

2. As part of 1. above, isolating a specific and equitable budget for "special needs" dentistry in each NSW Health Area so as to address the current inequities in access to such dentistry across the state.

3. Ensuring that all dentists in the public system have appropriate training in working with people with intellectual and other disabilities.

4. Recognition of special needs dentistry as a specialty within dentistry. This would both appropriately acknowledge the high level of training and skills often required to work with patients with disabilities and encourage dentists to continue working in this field. At present, there is little incentive for dentists to continue for a long period working with people with disabilities. The Australian Dental Council has recommended the recognition of such a specialty. This recommendation has been implemented in Victoria. But the NSW Dental Board has not so far acted on it.

5. Ongoing education programs in oral health for people with intellectual disabilities, their families and disability support workers. (Limited education programs already operate such as the Smiles for Life program run by the special clinic at Westmead but these programs need to be expanded statewide and made ongoing.)

6. Within the disability services sector, there need to be measures to ensure these education programs are working and that dentists' recommendations are acted upon. One avenue to assist with this would be via the role of a network of clinical nurse specialists appointed to liaise between health services and disability services. This model is already acting successfully in the Illawarra area.

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

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

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

NSW Ombudsman 2004 *Reviewable Deaths Annual Report 2003-2004* www.ombo.nsw.gov.au

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

Wen X (1997) *The Definition and Prevalence of Intellectual Disability in Australia* Australian Institute of Health and Welfare www.aihw.gov.au

Wen, X.(2003) *Disability prevalence and trends* Australian Institute of Health and Welfare (AIHW) Canberra. www.aihw.gov.au