The New South Wales
Council for Intellectual Disability

SUBMISSION TO SENATE SELECT COMMITTEE ON MENTAL HEALTH

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The NSW Council for Intellectual Disability (NSWCID) is a peak body representing the rights and interest of people with intellectual disability in NSW.

We also make this submission on behalf of our national counterpart, the National Council on Intellectual Disability, whom we represent on health issues.

Prevalence of psychiatric disorder amongst people with intellectual disabilities

At least 1.5 - 2% of Australians have an intellectual disability (Wen 1997 and 2003). An intellectual disability is distinct from a psychiatric disorder and this is reflected in different service systems for people with intellectual disabilities on the one hand and people with psychiatric disorders on the other hand.

However, the one individual may have both conditions. And there is consistent research showing that people with intellectual disabilities have at least two to three times the prevalence of psychiatric disorders as compared with the general population. Given that the recent National Survey of Mental Health and Wellbeing identified 18% of adult Australians as having a psychiatric disorder, then we can estimate that a minimum of 36% of Australian adults with intellectual disabilities can be expected to have major mental health problems. Research in New South Wales and Victoria (Einfeld & Tonge, 1996 a & b) found that over 40% of children and adolescents with intellectual disabilities had psychiatric disorders using carefully validated measures.

It flows from the above that at least 0.6% or 6 per thousand persons in the population will have intellectual disability and a psychiatric disorder. To put this in perspective, one can compare the prevalence of schizophrenia in the community. According to recent research, that prevalence is between 1.5 and 8 per thousand. It is thus apparent that the prevalence of intellectual disability with major psychiatric difficulties is approximately as common as schizophrenia. (Einfeld 2002)

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)
- "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)

Adequacy of psychiatric services for people with intellectual disabilities

It is commonly very difficult for a person with an intellectual disability to obtain appropriate psychiatric diagnosis and treatment. Psychiatric disorders in people with intellectual disability are frequently not recognised or are misdiagnosed, and therefore not treated or inappropriately treated. (Reiss 1990; Torr 1999) 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)

This problem 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 in intellectual disability amongst mental health professionals.
- A lack of accepted diagnostic criteria for assessing psychiatric disorder in people with intellectual disabilities.
- Minimal research into the presentation and treatment of psychiatric disorders in people with intellectual disabilities.
- Diagnostic overlay – The mistaken assumption that symptoms are related to the disability and challenging behaviour that may flow from factors such as difficulties in communication.
- Health professionals need to spend more time with people with intellectual disabilities but the health system often does not allow for this.
- Poverty and inadequate supply of free and subsidised health services.

- Inadequate cooperative action within and between governments, including between mental health and disability services agencies. Since the separation of mental health and disability services which occurred around 1980 in various states and territories, it has often been very difficult for people with intellectual disabilities to access mental health services. Mental health services tend to say that people with intellectual disabilities are not their priority or responsibility.

(Torr and Chiu 2002; Select Committee on Mental Health 2002; Simpson, Martin and Green 2001; RACGP 2005; Einfeld 2002, Simpson and Sotiri 2004)

There are particular problems for people with intellectual disabilities and psychiatric disorders when they become involved with the criminal justice system. Diversion and other support services are often not available because of demarcation issues over responsibility between health and disability services. (NSW Law Reform Commission 1996; Simpson, Martin and Green 2001)

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)

Alarmingly, the Third National Mental Health Plan does not include a focus on people with intellectual disabilities.

Action required

1. Improved training:
    a. In intellectual disability for mental health professionals.
    b. In mental health for intellectual disability professionals.
    c. For general practitioners in the needs of people with dual diagnosis.
    d. All such training to include the particular needs of Indigenous people and those from culturally and linguistically diverse backgrounds.
2. Ensuring that people with intellectual disabilities have equitable access to public mental health services.
3. Enhanced cooperation between mental health services and intellectual disability services.
4. The Medicare Benefits Schedule to better reflect the extra time a doctor needs to spend with a person with an intellectual disability.
5. Enhanced availability of psychiatrists and other mental health professionals with particular expertise in intellectual disability.

Strategies 1-3 are commonly seen as answers to this problem. However, there are major challenges to achieving systemic change through them. Great thought and high level commitment is needed for them to achieve major change. (See for example the

discussion and recommendations in Select Committee on Mental Health 2002 Chapter 11 and Simpson, Martin and Green 2001 chapter 4.4 and 4.21)

Strategy 2 calls for both specific action to ensure that public mental health services are inclusive of people with intellectual disabilities and a considerable enhancement of the size of those services so that they can meet their responsibilities generally.

Strategy 4 has been advocated in recent years by various intellectual disability advocacy and medical groups and has recently been endorsed by the Royal Australian College of General Practitioners.

Strategy 5 is key. Appropriate diagnosis and treatment of psychiatric disorders in people with intellectual disabilities poses particular challenges. And yet, at present, there are only 5 to 6 full time equivalents of psychiatrist time specialising in this group in Australia (Einfeld 2002).

For mental health services to provide adequate care to this group, they need to be backed up in the public system by a considerably expanded number and organised system of psychiatrists and other mental health professionals with a particular expertise in diagnosis and treatment of psychiatric disorders in people with intellectual disabilities. These specialists could act as consultants to other mental health professionals (and perhaps general practitioners), both in relation to individual cases and be a source of training and research. Such a specialist resource exists in the United Kingdom.

It would seem to us that without such a specialist resource, it will be very difficult for other strategies to improve the mental health treatment currently being received by people with intellectual disabilities.

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