



## NMHCCF Advocacy Brief

### Issue: Intellectual/Developmental Disability (ID) and Mental Health

#### **Background**

Psychiatric disorders in people with intellectual disability (ID) are 3-5 times more common than in the general population. These disorders are frequently not recognised or are misdiagnosed and therefore not treated appropriately.

People with ID have particular risk factors that make them more vulnerable to developing mental health problems, including: biological factors (e.g., family history of mental illness, genetic disorders, medications), psychological factors (e.g., poor social skills, limited control over life), and social factors (e.g., family functioning, lack of social support, adverse life events). Other factors can include brain damage, epilepsy, repeated loss or separation, communication difficulties, poor coping mechanisms, family difficulties, deficits in social skills leading to impaired relationships, low self-esteem, and other psychosocial factors.

Often the most obvious symptom of mental illness in a person with ID will be behaviour that is unusual for that individual. This may include withdrawal, frequent emotional distress, mood swings that cannot otherwise be explained, altered perceptions, confusion, irrational fears and anxieties, or obsessions or psychosomatic symptoms that may be misinterpreted as being "attention seeking." Other behaviours may be those with a potential for self-harm.

#### **Key Points**

There has been a tendency to overmedicate people with ID particularly those who exhibit challenging behaviour. There is a place for medication, as well as specifically tailored psychological approaches.

There are many barriers to people with ID accessing mental health services or receiving informed and appropriate mental health care in Australia, including Australian psychiatrists reporting that they do not have the training or confidence to assess and manage people with ID. There are limited opportunities for Australian mental health clinicians to train in the assessment and care of people with ID and mental illness.

Mental illness in people with ID has been unrecognised, undiagnosed and untreated. Clinicians often believe that the problem is 'behavioural', caused solely by the ID rather than mental illness. As a consequence people with an ID will often not receive appropriate treatment for coexisting mental illness<sup>1</sup>.

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<sup>1</sup> Conversely, if behavioural changes in people with ID are incorrectly diagnosed as mental illness there is a danger that psychotropic medications will be used instead of well established behavioral interventions.

## Communication difficulties

Most psychiatric diagnoses are made on the basis of self-reporting, but some people with ID have limited ability to describe their symptoms. Some people with ID have a tendency just to agree with or give the answers that they think the questioner wants to hear. It is vital that, as well as talking to the person with ID in private, health practitioners (if possible with agreement) obtain a family history from the person or a carer with knowledge of the family's history. Some tools for interviewing someone with ID can be found at the following websites:

*NSW Council on Intellectual Disability CHAP tool*  
[www.som.uq.edu.au/research/qcidd/files/chap.pdf](http://www.som.uq.edu.au/research/qcidd/files/chap.pdf)

*Working with people with intellectual disabilities in healthcare settings*, fact sheet for health professionals, Centre for Developmental Disability Health Victoria  
[www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf](http://www.cddh.monash.org/assets/documents/working-with-people-with-intellectual-disabilities-in-health-care.pdf)

## Key Issues for Action

- People with intellectual disability and a mental disorder need holistic support from mental health, disability and other relevant human services<sup>2</sup>.
- The need to increase the proficiency of disability, specialist mental health services, justice, general practice, aged care and other primary health services in the early identification diagnosis, treatment and care of people with ID and a co-existing mental illness including a proven mental illness diagnostic tool in Australia.
- Mandated shared case coordination between disability and mental health services and family, carers or guardians where mental health and intellectual disability co – exist<sup>3</sup>.
- The concerns of parents of such children about the ongoing and future care of their children when they are no longer able to look after them.
- Difficulty experienced by consumers, their carers and families in accessing services and navigating multiple service disability and mental health services ensuring the involvement of carers, family members or guardian in the decision making<sup>4</sup>.
- The need for access to key social supports and particularly affordable and appropriate housing linked to support.

All health professionals play a significant role in supporting caregivers in recognising and meeting the needs of this client group and in ensuring that mental health services offer appropriate and timely services.

## **Name of Nominated NMHCCF contact on this issue**

**Eileen McDonald and Tony Fowke**

**Please contact NMHCCF Secretariat (details below)**

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<sup>2</sup> National & NSW CID & AADDM May 2011

<sup>3</sup> National & NSW CID & AADDM May 2011

<sup>4</sup> <http://www.adhc.nsw.gov.au>