



**NSW Council for
Intellectual Disability**

**NATIONAL ROUNDTABLE ON
THE MENTAL HEALTH OF
PEOPLE WITH INTELLECTUAL DISABILITY**

BACKGROUND PAPER

Prepared by

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Note: the case studies in this paper have been written or edited in a way that avoids identifying particular individuals

PURPOSE AND SCOPE OF THIS PAPER

This background paper sets the scene for the National Roundtable by:

- Promoting a common understanding of the mental health needs and poor access to appropriate mental health care of people with intellectual disability.
- Summarising the relevant policy framework
- Proposing elements of an ultimate objective - a mental health system that meets the needs of people with intellectual disability
- Summarising actions to date toward achieving each element of the objective
- Listing some possible options for incremental action over the next five years

This paper complements the draft of *Mental Health Services for People with Intellectual Disability – A Guide for Providers* (the Guide) which will also be distributed to roundtable participants. The guide will be an important tool to assist health services provide equitable access and appropriate treatment to people with intellectual disability and a mental disorder. Many roundtable participants have chosen to also attend a focus group on the draft Guide the day before the roundtable.

WHAT WILL HAPPEN AT THE ROUNDTABLE?

The Roundtable will include:

- A welcome address by Rosemary Huxtable, Deputy Secretary of the Australian Department of Health and Ageing.
- An opening address by Allan Fels, Chair of the National Mental Health Commission
- A scene setting session where participants will hear from consumer representatives and professionals with experience and expertise in the mental health needs of people with intellectual disability, including information on *Mental Health Services for People with Intellectual Disability – A Guide for Providers* (the Guide)
- Table discussions focused on:
 - Practical, incremental actions that could be taken individually and collaboratively by roundtable participants over the next five years;
 - Seeking a consensus on the elements of the ultimate objective - a mental health system that meets the needs of people with intellectual disability; and
 - A specific discussion on the draft of the Guide.
- A plenary session aimed at bringing together the outcomes from table discussions and seeking consensus on the elements an effective service system, incremental action and a process for ongoing collaboration.

EXECUTIVE SUMMARY

People with intellectual disability (page 7)

Between 1% and 3% of the population has an intellectual disability. The impact of an intellectual disability on a person's functioning varies greatly from person to person and will be increased if the person also has a mental disorder. An intellectual disability impedes a person's ability to access health care.

How we see an intellectual disability is significant for determining the respective roles of disability and mental health services. In contemporary conceptions, mental health services need to accommodate mental health needs and disability services focus on disability support needs.

The mental health of people with intellectual disability (page 11)

Established risk factors for mental disorders commonly exist for people with intellectual disability including social exclusion and isolation, poverty, contact with the criminal justice system, misuse of drugs and alcohol, poor physical health, physical disability and intellectual disability itself.

The research indicates that, at any one time, between 20% and 40% of people with intellectual disability have mental disorders, including schizophrenia being 2-4 times more prevalent than in the general population.

It is often very difficult to diagnose a mental disorder of a person with intellectual disability. Challenging behaviour of people with intellectual disability can have various contributors including unmet communication and environmental needs and mental disorders. It is often very difficult to determine the exact contributors. Disability and health professionals have complementary and interconnected roles in assessing and responding to challenging behaviour. A multidisciplinary approach is often vital to addressing complex challenging behaviour.

The research evidence on the mental health of people with intellectual disability shows:

- poor access to mental health care,
- frequent errors in diagnosis,
- psychiatrists and GPs perceiving themselves to be inadequately trained and
- psychiatrists perceiving people with intellectual disability as receiving a poor standard of mental health care.

In Australia, there is a relative lack of available data related to the mental health of people with intellectual disability.

Poor mental health for people with intellectual disability has considerable cost to individuals and to governments. This includes considerable cost to the health and disability budgets, notably including the entitlement based National Disability Insurance Scheme.

National policy framework (page 22)

A range of key national policy initiative support national action on the mental health of people with intellectual disability - in particular the National Roadmap for Mental Health Reform, the National Disability Insurance Scheme (NDIS), the National Disability Strategy and its underpinning UN Convention on the Rights of Persons with Disabilities. These initiatives make it timely to act on the mental health inequities experienced by people with intellectual disability. In the case of the NDIS, there is clear scope for collaborative action with mental health services to lead to improved mental health and reduced costs to government.

The ultimate objective (page 27)

It is important to have a vision for the kind of system that would effectively meet the mental health needs of people with intellectual disability. This vision provides an ultimate goal and a benchmark for incremental action towards that goal.

We propose the following elements of an effective system:

1. The needs of people with an intellectual disability and a mental disorder are specifically considered and accommodated in all mental health initiatives.
2. People with intellectual disability and their families receive education and support to prevent mental disorders and to obtain early and timely assistance for mental disorders.
3. All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.
4. A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services - by provision of consultancy and training, and through research.
5. Ongoing joint planning by disability services, schools and mental health and other relevant services including:
 - a. Identification of referral and treatment pathways.
 - b. A framework and capacity for collaborative responses where intellectual disability and mental disorder co-exist.
6. Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.
7. Collection and analysis of data which measures mental health needs, access to services and outcomes of people with intellectual disability.

8. All of these elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

The roundtable will seek to achieve a consensus on the elements of an effective system. However, most time at the roundtable will be focused on practical, incremental actions that can occur over the next five years. The roundtable needs to take account of the current tight fiscal environment.

Actions to date and options for action 2013 – 2017 (page 30)

To promote consideration of practical action, the paper summarises initiatives to date in relation to each of the above elements and non-exhaustive and wide-ranging options for initiatives that might be taken over the next five years.

Practical initiatives may relate to existing policy commitments such as the finalisation of the National Recovery-Orientated Mental Health Practice Framework and the roll out of the National Disability Insurance Scheme.

Initiatives may also focus on enhancing current systems of service delivery.

INTELLECTUAL DISABILITY - AN OVERVIEW

WHAT IS INTELLECTUAL DISABILITY?

Intellectual disability is the contemporary Australian term for what used to be called sub-normality, mental retardation or intellectually handicapped. In the United Kingdom, the preferred term is learning disability.

Historically, the most widely accepted definition of intellectual disability was the 1983 definition of the American Association on Mental Retardation (AAMR):

'Significantly sub average general intellectual functioning resulting in, or associated with, concurrent impairment in adaptive behaviour and manifested during the developmental period.'

In essence, this definition required an IQ below 70 to 75, significant deficits in adaptive functioning and the disability to have arisen by the age of 18. Adaptive functioning covers the conceptual, social and practical skills needed in everyday life.

This definition has been used for eligibility for intellectual disability services provided by State and Territory Governments.

In recent decades, it has become increasingly accepted that the most important issue in terms of whether a person needs ongoing disability support is whether they have significant deficits in adaptive functioning. There should be substantial flexibility in relation to IQ levels. (Australian Government 2012; American Association on Intellectual Disability 2010, chapter 12; Moran 2013)

Intellectual disability can arise from a wide range of conditions, for example Down syndrome and fragile X syndrome. Autism often, but not necessarily, involves intellectual disability.

Disability services are not intended or designed to address the clinical mental health needs of their clients. Just like other members of society, people who have an intellectual disability and a mental disorder need access to mental health services appropriate to their needs. However, disability services will commonly have a very important part to play in the holistic meeting of the needs of a person with an intellectual disability and a mental condition.

PREVALENCE OF INTELLECTUAL DISABILITY

Between 1% and 3% of the population has an intellectual disability.

Historically, the 'theoretical prevalence' was put at 2-3% based on extrapolation from statistical models of IQ scores.

A Western Australian study found a prevalence of intellectual disability of 1.4% based on linkage of data from disability services and schools (Leonard and others 2003). This would indicate approximately 300,000 people with intellectual disability in Australia. A current similar study indicates a prevalence of 1.8% (Bourke, Leonard and others 2012).

In costing the proposed National Disability Insurance Scheme, the Productivity Commission used as its main data source the 2009 ABS Survey of Disability, Ageing and Carers (SDAC). This survey indicated that 206,720 people were identified as having an intellectual disability by self-report or report of a carer. By way of comparison, the Commission looked at the 2003 Australian Burden of Disease (BoD) data which is based on a range of sources and indicated that 249,100 people had an intellectual disability (Productivity Commission 2011, chapter 16).

It is likely that the SDAC figures do not include many adults who prefer not to identify as having an intellectual disability. Identification of intellectual disability in population surveys tends to peak in early adolescence and then fall away in early adulthood. In the 2003 SDAC, the reported rate of intellectual disability in the age group 5-14 was over twice that for the overall age group 0-64. (Australian Institute of Health and Welfare 2008). People who choose not to identify as having an intellectual disability may not seek out disability services but their intellectual disability will still be relevant to how mental health services need to accommodate their needs.

SUPPORT NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITY

The impact of an intellectual disability on a person's functioning varies greatly from person to person. The impact on functioning will be increased if the person also has a mental disorder. An intellectual disability impedes a person's ability to access health care.

The majority of people with intellectual disability are able to lead largely independent lives but may need support with some activities, in particular what the Productivity Commission described as 'self-management' - insight, memory, decision-making and ability to control one's behaviour. These factors would be expected to impede a person's ability to seek out appropriate health care, communicate with the health professional and act on health advice.

Other people with intellectual disability face 'core activity limitations' (limitations in self-care, mobility and communication). Many of this group have extremely limited verbal communication.

In the 2009 SDAC, about half of the people who specified intellectual disability as their main condition had daily support needs with self-care, mobility and/or communication. The other half were in the self-management category.

In the current Western Australian prevalence study, 91% of those with intellectual disability are in the mild to moderate range of intellectual disability and 9% in the severe range. (Burke, Leonard and others 2012) People with severe intellectual disability could be expected to need 24 hour support. The support needs of people in the mild to moderate range may range from just needing ad hoc support with self-management through to 24 hour support.

A coexisting mental condition will tend to increase the support needs of a person with intellectual disability.

CHANGING CONCEPTIONS OF INTELLECTUAL DISABILITY

How we see an intellectual disability is significant for determining the respective roles of disability and mental health services in addressing the needs of a person with intellectual disability and a mental condition. In contemporary conceptions, mental health services need to accommodate mental health needs and disability services focus on disability support needs.

Historically, an intellectual disability was seen within a clinical paradigm where it was viewed as a condition within the individual similar to an illness or disease. Doctors and nurses were the main deliverers of services and services were delivered in hospital like settings (Cocks 1998).

In recent decades, the social model of disability has moved to centre stage. This model emphasises not only the condition of the individual but the social context in which they live and the way in which this context frames the disability - for example, through attitudes of exclusion or inclusion or through accommodations (or lack of them) to disability. There is a distinction between the intellectual impairment of a person and the disabling effect of the social environment that does not cater for the impairment. A variant on the social model is the interactional model which accepts that there is a biological basis to disability, but this interacts with social and economic factors to produce disability (NSW Law Reform Commission 2012).

The UN Convention on the Rights of People with Disabilities 2006 says:
'disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.' (Preamble (e))

Implications of this evolution in conception of intellectual disability are that, in general:

- Health and other mainstream services have a responsibility to provide accessible and appropriate services to people with intellectual disability.
- Disability services have the complementary role of providing the supports people with disability need to live and participate in the community, for example support with self-care, mobility and decision making.

Good disability support will reduce the likelihood of a person developing a mental disorder.

THE OVERALL HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY

One of the barriers that hinders participation in society by people with intellectual disability is inadequate health care.

The National Health and Hospitals Reform Commission (2009) reported that people with intellectual disability face *'stark health inequalities'*.

Also, in 2009, the Australian Government paper *Primary Health Care Reform in Australia* said *'People with intellectual disability die prematurely and often have a number of unrecognised or poorly managed medical conditions as well as inadequate health promotion and disease prevention.'*

For example, Australian research has shown:

- The life expectancy of a person with an intellectual disability is 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 disability and half of the diagnosed conditions were inadequately managed (Beange & others 1995)
- Obesity for people with intellectual disability is up to three times the level in the general population (Stewart & others 1994; De & others 2008)
- Inadequate receipt of health promotion and screening activities (Lennox 2007 & 2010)
- Poor access to mental health care – see below.

THE MENTAL HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY

RISK FACTORS

Established risk factors for mental disorders commonly exist for people with intellectual disability.

There is very limited research evidence in relation to risk factors that predispose a person with intellectual disability to a mental disorder. However, risk factors associated with mental illness listed in *The roadmap for national mental health reform 2012-2022* commonly exist for people with intellectual disability:

- Social exclusion and isolation
- Poverty
- Neglect, abuse and trauma
- Contact with the criminal justice system
- Misuse of drugs and alcohol
- Poor physical health
- Physical disability
- And intellectual disability itself.

Children and adults with intellectual disability have an increased risk of exposure to low socioeconomic position (Emerson, 2007). Indeed, recent research has suggested very similar patterns of association between socioeconomic position and mental disorder in children with and without intellectual disability (Emerson & Hatton, 2007).

People with disability are more than twice as likely as other people in Australia to live in poverty, with 27.4% living below the poverty line (ACOSS 2013).

People with intellectual disability are overrepresented in the criminal justice system (NSW Law Reform Commission 2012, chapter 4). The overrepresentation is particularly clear amongst young offenders - up to 14% of young offenders in juvenile detention in NSW have an intellectual disability with IQ below 70 and a further 32% has an IQ between 70 and 80. Forty two percent of detainees were overweight, 50% had hearing loss, 78% were risky drinkers, 65% used illicit drugs at least weekly, 87% had at least one psychological disorder. 27% had been removed from their families. Only 38% were attending school prior to going into custody. 45% had had a parent in prison (Indig and others 2011).

A recent data linkage study of 680 NSW adult prisoners with intellectual disability found that 60% had a diagnosed mental disorder and that 70% had a substance use disorder. Forty five percent had both of these conditions (Baldry and others 2012 and communication with Professor Baldry).

People with intellectual disability have very high rates of sensory and physical disabilities (AIHW 2008).

See above in relation to the poor physical health experienced by people with intellectual disability.

PREVALENCE OF MENTAL DISORDERS

The research indicates that, at any one time, between 20% and 40% of people with intellectual disability have mental disorders. Schizophrenia is 2-4 times more prevalent than in the general population.

There is variation in prevalence across studies. This is related to a number of factors including differences in study populations, the challenge of diagnosing mental disorders in people with impaired communication and the conceptual issue of whether 'problem behaviours' are included in the definition of mental disorders.

A Western Australian study linked the population based registers of mental health services and intellectual disability services. Dual diagnosis cases were those with an intellectual disability on the disability register and a psychiatric illness on the mental health register. Problem behaviour was only counted if it also had an ICD-9 diagnosis of mental illness. Overall, 31.7% of people with intellectual disability had a psychiatric disorder. This included 3.7-5.2% schizophrenia, whereas the prevalence in the general population was 1.26% (Morgan & others 2008).

In adults with intellectual disability in the Glasgow area of Scotland, the rate of mental ill health was 40.9% on clinical diagnoses, 35.2% (DC-LD), 16.6% (ICD-10-DCR) and 15.7% (DSM-IV-TR)¹. The main variation between these rates was that over half of the 40.9% was 'problem behaviour' which was not included in the lower percentage findings. The rate of psychotic disorders was between 2.6 – 4.4% (Cooper & others 2007).

In a large NSW study, Einfeld & Tonge assessed a broad range of behavioural and emotional disturbances in children and adolescents with intellectual disability. They found that 41% could be classified as having severe emotional and behaviour disorder or being psychiatrically disordered (Einfeld & Tonge 1996a and 1996b).

As well as people with intellectual disability having high rates of mental illness, rates are higher again amongst offenders with intellectual disability (Smith and O'Brien 2004). As noted above, Baldry and others (2012) found 60% of prisoners with intellectual disability had a diagnosed mental disorder.

¹ The DC-LD is the Diagnostic Criteria for Psychiatric Disorders for use with adults with learning disabilities. The ICD-10-DCR is the International Classification of Disease, 10th revision, Diagnostic Criteria for Research. The DSM-IV-TR is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, published by the American Psychiatric Association.

CHALLENGING BEHAVIOUR AND MENTAL CONDITIONS

Challenging behaviour can have various contributors including unmet communication and environmental needs and mental disorders. It is often very difficult to determine the exact contributors. Disability and health professionals have complementary and interconnected roles in assessing and responding to challenging behaviour. A multidisciplinary approach is often vital to addressing complex challenging behaviour.

Challenging behaviour is

- culturally abnormal behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or
- behaviour which is likely to limit use of, or result in the person being denied access to, ordinary community facilities (Emerson 2001).

Challenging behaviour can have various contributing and inter-related factors including biological, psychological, social and developmental. For example, challenging behaviour can be apparent when the person:

1. Wants something but cannot explain and/or
2. Is bored and/or
3. Is unsettled by an environmental change, eg moving home or the departure of a favoured staff member and/or
4. Is in pain but cannot verbalise this and/or
5. Has a mental disorder.

Psychologists and other behaviour practitioners in disability services approach challenging behaviour by assessing the function of the behaviour and devising strategies to address the function. The strategies focus particularly on addressing environmental and skills development factors. For example, if the person cannot explain what they want, strategies may focus on developing the person's communication skills and the skills of family and support workers in communicating with the person. If the person is bored, strategies focus on providing a more stimulating and interesting environment. The Australian Psychological Society (2011) has developed minimum standards for a behaviour support plan. See Appendix 1.

The roles of health professionals include identifying if behaviour arises in whole or in part from physical or mental conditions and to propose appropriate treatments including medication, counselling and cognitive behaviour therapy. Relevant health professionals include GPs and other primary health practitioners, paediatricians, psychiatrists, mental health nurses and a range of other mental health professionals.

Diagnosis of mental disorders in people with intellectual disability is very challenging. Many people with intellectual disability have limited verbal communication and experience an atypical profile and presentation of mental disorders. These diagnostic challenges may lead to considerable under diagnosis of mental conditions in people with intellectual disability. Diagnosis can be all the more challenging where a person with intellectual disability is

Indigenous or comes from a CALD background. Also, for children with or without an intellectual disability, diagnosis of mental conditions has particular challenges.

At times, it can be very difficult to draw a clear dividing line between behaviour that arises from a mental disorder and behaviour that results from environmental and skills factors. This arises from:

- The challenges to diagnosis of mental disorders in people with intellectual disability
- A person's challenging behaviour can arise from the interplay of a range of contributing factors, rather than a single factor alone
- People with different training and different skill sets (e.g. behaviour practitioners and psychiatrists) can bring different perceptions to the same situation.

The following case study illustrates some of the complexities of diagnosis of mental disorders in a person with intellectual disability and how a thorough assessment can lead to a diagnosis.

CRAIG is a 35 year old man with intellectual disability and autism. He does not speak. He lives in a group home. From childhood, Craig has had complex challenging behaviour and he has seen many psychologists and psychiatrists. Over the years, he has had many behaviour support plans and has been prescribed a range of antipsychotic and other psychotropic medication but with limited impact on the behaviour. Craig's behaviour is affected by factors such as disruptions to his environment - changes in staff or routine, very hot weather and periods when a co-resident was intrusive towards Craig.

Craig then saw a psychiatrist with expertise in intellectual disability. The psychiatrist took a thorough history including talking with Craig's mother, a residential worker and the current behaviour practitioner. In addition to a baseline of behavioural disturbance, there was a cyclical pattern to Craig's behaviour with periods lasting a week or more where he was irritable and aggressive, with loud and constant vocalisations. During these episodes, Craig was also hyperactive and was not able to concentrate on his daily activities. He had a decreased need for sleep and often would not sleep at all. Careful history from his mother indicated that this cyclical pattern became apparent in adolescence.

The psychiatrist made a provisional diagnosis of bipolar disorder and prescribed a mood stabiliser. Craig's mental state and behaviour became much more stable.

Another significant factor is that there are situations where psychotropic medication is necessary to address behaviour, at least in the short term, despite there being no specific diagnosis of a mental disorder. The medication may be needed, initially, to provide a window of opportunity for other strategies to be implemented and the situation to be regularly reviewed with a view to refining the analysis of the contributors to the behaviour.

A multidisciplinary approach is often vital to addressing complex challenging behaviour. Often psychologists, other behaviour practitioners, psychiatrists and other relevant professionals should work together bringing their complementary/overlapping skills. This multidisciplinary approach should lead to the development of initial strategies to address behaviour. There should then be periodic review of the contributing factors to behaviour and the strategies needed to address them.

As the Australian psychological Society (2011) says,
'Challenging behaviours can be complex, and consequently working in an interdisciplinary team with professionals such as speech pathologists, occupational therapists, psychiatrists and general practitioners is most effective. Interdisciplinary assessment can provide a richer understanding of the unmet needs that underlie challenging behaviours.'

The importance of multidisciplinary collaborations is a key theme of Dossetor and others (2011), *Mental health of children and adolescents with intellectual and developmental disabilities*. For children and adolescents, teachers and paediatricians are other key players in any interdisciplinary team.

Finally, it must be a given that all professionals will act in active and inclusive collaboration with the person with intellectual disability and their family and other advocates.

The case study on the next page illustrates the need for and value of a multidisciplinary approach. The challenge at present is to make this approach much more available.

LANA is 12 and lives in Sydney with her parents Gemma and Paul and older brother. She has intellectual disability, autism and associated emotional and behavioural disturbance. Until Lana was nine her family and school were able to meet her needs through their skilled and thoughtful joint work.

However, in late 2010 Lana's behaviour at school deteriorated dramatically resulting in injury to others and repeated suspensions for Lana. She presented as highly anxious and agitated. In early 2011 the family and Principal decided that she was no longer safe to attend school. The family, school and local disability service collaborated closely, but several slow and systematic attempts to re-introduce Lana to school failed.

Since early 2011, Lana has been at home with her family. Family members are regularly assaulted. On particularly difficult days, Gemma has had to physically restrain her on an hourly basis, leading to Gemma being bruised, scratched and bitten. Gemma and Paul have both reduced their work hours. Lana became increasingly inflexible and reluctant to be separated from Gemma. She escalated quickly if respite workers attempted to take her out to give the family a break.

Lana now has a paediatrician and a psychiatrist who review her case regularly and consult with another psychiatrist who has expertise in autism and intellectual disability. She has a disability services case manager, who has helped arrange some flexible, in-home respite, a behaviour support practitioner, occupational and speech therapists.

This clinical group is being supported by the Statewide Behaviour Intervention Service, the tertiary clinical service in NSW disability services. All clinicians are collaborating closely with the family to design and implement an agreed clinical plan.

Lana remains at home. Her anxiety is beginning to dissipate and her coping skills have improved as a result of the collective intervention. Treatment has included environmental management, adaptive skills building, sensory processing / arousal regulation programs, augmented communication strategies, pharmacology, graduated access to the community, and training of support staff. A transition plan is currently being developed in collaboration with the school, which has remained in contact.

ADEQUACY OF MENTAL HEALTH CARE

The research evidence on the mental health of people with intellectual disability shows:

- **poor access to mental health care,**
- **frequent errors in diagnosis,**
- **psychiatrists and GPs perceiving themselves to be inadequately trained and**
- **psychiatrists perceiving people with intellectual disability as receiving a poor standard of mental health care.**

The Einfeld and Tonge (1996a and b) study found 41% of children with intellectual disability having severe emotional and behaviour disorder or being psychiatrically disordered. Only 9% of primary carers of this 41% had ever sought assistance from professionals with expertise in both mental health and intellectual disability. A further 31% had had contact with professionals working in one but not both fields. Thirteen percent had sought help from a level one professional and 47% had not sought any help. Clinical experience suggested that people had not sought help since they felt it would be unhelpful or was unavailable (Einfeld & Tonge 1996a and 1996b).

Psychiatric disorders in people with intellectual disability are frequently not recognised or are misdiagnosed and inappropriately treated (Reiss 1990; Torr 1999). Specifically, in a Melbourne study, only 20% of people with depression or bipolar disorder were receiving anti-depressants or mood stabilisers while 80% of this group were receiving antipsychotic medication (Torr 1999).

Psychiatrists and GPs see themselves as inadequately trained to treat mental disorders in people with intellectual disability and express interest in further training. Psychiatrists see people with intellectual disability as receiving a poor standard of care (Cook and Lennox 2000; Lennox and Chaplin 1995; Lennox and Chaplin 1996; Lennox, Diggins and Ugoni 1997; Phillips, Morrison & Davis 2004; Edwards, Lennox & White 2007; Jess & others 2008).

In Australia, there are a very limited number of psychiatrists and other mental health professionals with expertise in intellectual disability, and no system for such specialists to be available when needed.

NSW Council for Intellectual Disability has recently surveyed public advocates/guardians and key community advocacy groups around Australia in relation to access to a range of appropriate services for people with intellectual disability who are in contact with the criminal justice system. In relation to access to mental health services, the mode and mean responses were that individuals were 'sometimes' able to access mental health services when they needed them and that these services were 'sometimes' appropriate to the person's disability related needs. Participants chose between the following options in answering these questions: always, usually, sometimes, rarely, never. This may suggest an approximately 25% chance of being able to access appropriate mental health services.

CASEY is a young Aboriginal woman, who has been multiply diagnosed with a range of mental and cognitive conditions, including behavioural and emotional conditions emerging in childhood and adolescence. These include ADHD, Conduct Disorders, Adjustment Disorders, Personality Disorder and Bipolar Affective Disorder. Casey has also been identified as having a developmental delay and intellectual disability (IQ 64). She has a long history of self-harm, physical abuse and trauma. She has used alcohol and other drugs from a young age and after the age of 13 she barely attended school.

She began to be noted by the Police as disturbed, suicidal and homeless in her early teens. She was admitted to hospital under the Mental Health Act on numerous occasions where she was usually sedated and restrained and released the following morning. In one year alone Casey was the subject of 87 Police events. On numerous occasions services such as Community Services and the local hospital said they could not support Casey. In one six month period, she was held in juvenile detention from one to 39 days, with a total of 128 days spent in custody. Police noted that Casey needed medical and mental treatment but instead was being bounced around between Police and the Hospital. The only time Casey was not being picked up police or held in detention was during a respite placement for 6 months during which time Casey did not come into contact with Police, DJJ or hospitals.

After this Casey was again imprisoned in DJJ detention and was repeatedly admitted to psychiatric facilities under the Mental Health Act where she was restrained and sedated. Recently Casey was transferred into a residential setting with a disability focus and there has been a significant reduction in police contact (Baldry & others 2012).

MARIA was middle aged and living in a disability services group home. She had previously lived an isolated existence with her mother.

Over six months, Maria had increasingly agitated and disturbed behaviour, delusional thoughts and weight loss of 20 kg. Residential workers took her to the local emergency department on a number of occasions but no mental disorder was diagnosed. Finally, she saw a community psychiatrist with expertise in intellectual disability mental health, who diagnosed psychotic depression.

Maria was then an inpatient of a mental health unit for three months. However, the community psychiatrist did not have control over treatment there. A registrar decided Maria's diagnosis was autism spectrum disorder and she was treated with high dose benzodiazepines and a low dose atypical antipsychotic. Outpatient follow up was promised, but did not occur.

A month after discharge, group home staff took Maria to the local emergency department. She was dehydrated and no longer passing urine. She received intravenous rehydration and the plan was for discharge back to the group home. Her carers refused to take her home. She was then readmitted to the psychiatric inpatient unit, finally properly treated for her psychotic depression and recovered.

PETER has a mild intellectual disability and lives independently with drop in support. He was referred to the local mental health service by his outreach worker after he stopped attending work and was found in a self-neglected state, refusing to get out of bed.

The diagnosis given by the mental health service was 'behavioural'. Peter was deeply depressed.

CLAUDIA is in her mid 50s. She has a mild intellectual disability. Her past history is not well documented and no informants are available. She was admitted to a psychiatric hospital from her own home, after she became hyperactive, loud, intrusive, aggressive and increasing disorganized and erratic in her behaviour. She was diagnosed with dementia and admitted to a locked psychogeriatric nursing home.

Claudia was subsequently carefully reviewed by a psychiatrist who diagnosed her with bipolar disorder. She was successfully treated and efforts are now being made to return her home.

There has been a long-standing concern about overuse of psychoactive medication to address the challenging behaviour of people with intellectual disability.

A 1991 study of people with intellectual disability in a NSW institution found that 60% of residents were receiving one or more neuroleptic drugs at relatively large doses. The use of these drugs was not associated with a psychiatric illness but more closely related with the severity of problem behaviour. Thirty four percent of those receiving neuroleptics had dyskinetic movements suggestive of tardive dyskinesia and a further 30% had a mild tremor. Drug dosages had not been reviewed for prolonged periods of time and often it was impossible to obtain the exact reasons why drugs have been started (Sachdev 1991). There is reason to think that the situation has improved significantly in NSW since the Sachdev study with improved behaviour support, access to consultant psychiatrists in intellectual disability institutions and the implementation of guardianship legislation.

In Victoria, disability services are required to report use of 'restrictive interventions' to the Office of the Senior Practitioner (OSP). These include chemical and mechanical restraint and seclusion. Chemical restraint is defined as the use of medications where the primary purpose is to control a person's behaviour as opposed to treating an identified/diagnosed medical illness or condition. In 2010/11, 1911 people were reported to be subject to restrictive interventions, with 1836 of these being subject to chemical restraint. One thousand six hundred and sixty four of those received medication on a routine basis and the others only on a PRN basis. Disability services are required to provide behaviour support plans to the OSP for each person subject to restrictive interventions. The quality of behaviour support plans had improved over time but the quality of most plans continued to be low. The plans that resulted in decreases in restrictive interventions were significantly better quality than other plans (Office of the Senior Practitioner 2011).

Eighty eight percent of people with intellectual disability subject to restrictive interventions in Victoria were in need of independent psychiatric review according to the consensus views of a psychiatrist and a pharmacist (Thomas and others 2010).

A 2004 survey of Australian psychiatrists found the vast majority agreed that '*inadequacy of community social supports often makes the inappropriate prescription of antipsychotic drugs necessary.*' (Torr and others 2008).

Both the Australian Psychological Society (2011) and the Australasian Society for Intellectual Disability (2011) have taken strong positions against the misuse of restrictive practices and pressed for action to reduce their use.

Guidelines for doctors seek to ensure cautious and evidence based use of psychotropic medication to address challenging behaviours (Therapeutic Guidelines 2012).

A Melbourne roundtable auspiced by the Royal Australian and New Zealand College of Psychiatrists in 2011 agreed that it was important for medical colleges to endorse an appropriate guideline in relation to the prescription of psychotropic medication to people with an intellectual disability. This guideline should include provision for comprehensive assessment and management including non-pharmacological treatment whenever possible (RANZCP 2011).

Disability ministers from around Australia have initiated action to develop a national strategy to reduce the use of restrictive practices in disability services (Standing Council on Community and Disability Services 2012).

LACK OF DATA

In Australia, there is a relative lack of available data on the mental health profile of people with intellectual disability across the lifespan, the correlates of mental disorders, the predictors of mental health outcomes, the associated costs and the service pathways engaged.

The potential of linked data has been demonstrated by the existing Western Australian database, Intellectual Disability Exploring Answers (idEA) (Leonard and others 2004) and recently in NSW by a joint disability services/NSW Health project, which have had physical health as its main focus (PWC 2012).

Data linkage can cross-link administrative datasets from a range of service systems which address the support needs of people with intellectual disability. For people with intellectual disability and mental disorders, data linkage has the potential to reveal diagnostic profiles, service use, service costs, predictors of outcomes and relationship of these factors to non-health supports. The capacity to link administrative datasets from a range of services and supports therefore has substantial potential to impact on mental health outcomes for people with intellectual disability, and would be likely to accelerate the development of appropriate services and policy.

Uniform data collection and interrogation on the mental health profile and outcomes of people with intellectual disability would provide a clear measure of whether mental health services are accessible to people with intellectual disability and whether mental health outcomes area equitable for this group.

THE COST OF POOR MENTAL HEALTH

Poor mental health for people with intellectual disability has considerable cost to individuals and governments. This includes considerable cost to the health and disability budgets, notably including the entitlement based National Disability Insurance Scheme.

Costs for people with intellectual disability and families

- Human cost to the individual in terms of suffering and participation in the life of the community
- Financial cost to the individual in terms of reduced capacity for employment
- Human cost for families who support a person with an intellectual disability and mental disorder
- Financial cost for families through reduction in employment capacity so as to meet the support needs of their family member.

Cost to government

- Financial cost for the disability services sector due to increased support needs of a person with a mental disorder and psychosocial disability. This cost will be particularly clear in the entitlement based National Disability Insurance Scheme
- Financial cost to the health sector due to inadequate mental health prevention, early intervention and treatment so that a condition becomes chronic and/or acute
- Financial cost to the justice system related to offending behaviour
- Financial cost to the economy and taxation revenue due to reduced employment for people with intellectual disability and family members.

NIKOLAS is aged 14 and has a severe intellectual disability, autism and cyclic mood disorder. He needs 1:1 care which is provided by his family. He easily becomes distressed and then is aggressive and self-injurious. His father often has to sleep with him and gets minimal sleep. The family is under enormous ongoing stress and the father has depression. However, the family remains determined to provide the support their son needs

Nikolas and his family have considerable support from their GP and disability services. They also live in one of the few areas in Australia that has a multidisciplinary intellectual disability health team which works collaboratively with the family, GP and disability services. Involved professionals include a clinical psychologist, psychiatrist, paediatrician, cross cultural consultant and family therapist.

Without this combination of support, it is likely the family would not be able to cope with Nikolas's very high and complex needs and he would need 24 hour supported accommodation.

KPMG estimated that the involvement of the intellectual disability health team was leading to a net saving to government of \$167,900 a year.

For a more detailed version of this case see KPMG 2010

NATIONAL POLICY FRAMEWORK

A range of key documents support national action on the mental health of people with intellectual disability. These are summarised with web links at Appendix 2.

Key points include:

UN Convention on the Rights of Persons with Disabilities 2006 (CRPD)

People with disabilities have a right to *'the highest attainable standard of health'*, including equal access to mainstream health services and provision of specialised disability health services where needed (Article 25).

National Disability Strategy 2010-2020 (COAG 2011)

The COAG strategy is intended to guide policy and program development by all levels of government and actions by the whole community. The strategy commits all government to six key outcomes, including that people with disability attain highest possible health and wellbeing outcomes throughout their lives.

To achieve this outcome, the strategy specifies policy directions including:

- All health services being able to meet the needs of people with disabilities.
- Universal health reforms and initiatives, including in mental health, addressing the needs of people with disability, their families and carers

National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme Act 2013 creates a framework for national access by people with disability to the assistance that they need to lead well supported and participating lives in the community. In the first instance five launch sites will commence operation in July 2013, led by the NDIS Launch Transition Agency.

The NDIS has eligibility provisions based on reduced functional capacity resulting from a broad range of disabilities, including combinations of disabilities (NDIS Act 2013, Section 24).

The Act and draft Rules provide a framework for the complementary responsibilities of the NDIS and health services. The NDIS will not be responsible for clinical mental health services or early intervention to reduce the progression of a mental health condition. However, the NDIS will be responsible for non-clinical support including allied health and other therapy directly related to managing or reducing the functional impact of a psychiatric condition.

There is a strong nexus between the complementary responsibilities of the NDIS and mental health services. If people with intellectual disability have adequate disability supports, they may be less likely to develop mental disorders and disorders may be much easier to treat. If people do not receive appropriate mental health services, their

disability support needs may be much greater and more expensive to meet.

The National Mental Health Strategy

The Strategy has guided mental health reform in Australia since 1992, when Australian health ministers agreed to the original National Mental Health Policy and the first five-year National Mental Health Plan, representing the first attempt to coordinate mental health care reform in Australia through national activities. The Fourth National Mental Health Plan (2009 – 2014) was the first plan that explicitly adopted a whole of government approach. Key documents under the Strategy include:

National Mental Health Statement of Rights and Responsibilities 2013

Mental health consumers have the right to access assessment, support, care, treatment, rehabilitation and services that facilitate or support recovery and wellbeing on an equal basis with others. They are entitled to high-quality services and appropriate treatment.

Fourth National Mental Health Plan: An Agenda for Collaborative Government Action in Mental Health 2009-2014

The Plan's five priority areas also include 'Social inclusion and recovery', and 'Prevention and early intervention'.

A key action relevant to people with co-occurring mental illness and intellectual disability concerns '*adoption of a recovery oriented culture within mental health services, underpinned by appropriate values and service models*' (Action 4, Fourth Plan: page 23).

As part of this action's implementation, a National Recovery Forum was held in Melbourne in June 2012, and supported the drafting of a national recovery-oriented mental health practice framework. Through this forum and related consultations, discussions included recognition that rates of mental illness are high among people with co-occurring conditions and complex needs, including people with intellectual disability; and that, for many people with high and complex needs, their mental illness may remain undiagnosed and ineffectively connected to mental health services. Discussions covered how recovery-oriented approaches can better address the needs of people with co-occurring conditions, including the importance of multi-disciplinary and collaborative approaches.

The outcomes of consultations are reflected in the draft framework, which is currently being finalised by the Safety and Quality Partnership Standing Committee of the Australian Health Ministers' Advisory Council. It is expected to be endorsed by the Standing Committee on Health later in 2013.

National Standards for Mental Health Services 2010

The Standards include two specific references to people with intellectual disability.

Standard 4 - Diversity responsiveness -requires mental health services to identify the diverse groups that access their service, including people with physical and intellectual disability. The standard goes on to specify that services planning and service implementation should ensure non-discriminatory practices and equitable access to services.

Standard 7 - Carers- Specifies that services should consider the needs of carers, specifically including carers of people with intellectual disability.

The Standards require mental health services to ensure non-discriminatory practices and access for diverse groups including people with intellectual disability.

The Roadmap for National Mental Health Reform 2012-2022 (COAG 2012)

The roadmap sets six priorities:

1. Promote person-centred approaches
2. Improve the mental health and social and emotional wellbeing of all Australians
3. Prevent mental illness, with a focus on at risk groups including people with intellectual disability.
4. Focus on early detection and intervention
5. Improve access to high quality services and
6. Improve the social and economic participation of people with mental illness.

In relation to priority 5, the Roadmap states:

Some people who experience mental health issues have good access to a range of services and supports; others do not. In particular.... people with disabilities.... [who can] experience multiple barriers that discourage them from accessing mental health services and support. Governments need to reduce the significance of these barriers by providing targeted and innovative supports, and by expanding the presence and availability of services to at risk and isolated communities....This is best achieved through partnerships between government, private, non-government and community organisations that ensure effective, well integrated services and responses (page 24).

Strategy 31 states:

Support innovative service delivery models for marginalised and disadvantaged groups.

SOME KEY AGENCIES

There is a wide range of agencies with roles relevant to the mental health of people with intellectual disability. Coordination of those roles is important to maximising results and achieving a system that provides clear and accessible pathways for consumers.

Here we list some of the key agencies:

- Commonwealth and State/Territory agencies responsible for health, disability support, education, employment, justice and human rights.
- Professional colleges and associations.
- Peak health and disability advocacy and service provider groups.
- Mental health and disability service providers.
- Universities and TAFE.

This list is not exhaustive. It is included for the benefit of roundtable participants who are less familiar with the mental health agency landscape.

SOME KEY AGENCIES

Australian Government

Australian General Practice Training - Administers Australian Government funded prevocational and continuing training for general practitioners.

Australian Human Rights Commission - Leading the promotion of human rights in Australia, including by education, policy development and dealing with complaints.

Department of Education, Employment and Workplace Relations - National policy leadership and funding of a range of education and employment programs.

Department of Health and Ageing, Australian Government - National policy leadership and funding of a range of mental health programs. Principal responsibility for primary care.

FAHCSIA - Funds disability services, including employment and advocacy services, the Better Start initiative for children and the Helping Children with Autism package. Leading the development of the National Disability Insurance Scheme.

Medicare - Paying for medical and some allied health treatment by the private health sector.

National Mental Health Commission - Leadership of national improvement in mental health through an annual report card, and advising and collaborating across sectors.

State and Territory governments

Disability agencies of the States/Territories - Leadership of policy, and providers and funders of a wide range of disability services.

Education agencies of the State/Territory governments - Lead policy and provision of school education.

Health agencies of the States/Territories - Planning and policy leadership, providing and funding health services including public mental health and forensic health services.

SOME KEY AGENCIES (cont.)

Peak health and disability groups

Australian Medicare Locals Alliance (AMLA) - Acts as a lead change agent for the Medicare Locals network and supports their performance.

Disability Services Australia - The peak body for non-government disability services.

Health and disability professional colleges and associations - Education and training of professionals and policy advocacy.

Mental Health Council of Australia - the peak non-government organisation representing and promoting the interests of the Australian mental health sector.

Mental Health in Multicultural Australia - Provides a national focus for advice and support to providers and governments on mental health and suicide prevention for people from culturally and linguistically diverse (CALD) backgrounds.

NACCHO - The national peak body representing Aboriginal Community Controlled Health Services (ACCHSs).

Disability and mental health advocacy and peak groups - Individual and systemic advocacy and resource production.

Other

Mental health NGO service providers - Provide a wide range of clinical and support services.

Intellectual disability health centres/teams - Specialised assessment and treatment on a consultancy basis, advice and education to other professionals, research leadership. There is a small number of these, mainly in large capital cities.

Universities and TAFE - Tertiary education of health and disability professionals

THE ULTIMATE OBJECTIVE - A MENTAL HEALTH SYSTEM THAT MEETS THE NEEDS OF PEOPLE WITH INTELLECTUAL DISABILITY

It is important to have a vision for the kind of system that would effectively meet the mental health needs of people with intellectual disability. This vision provides an ultimate goal and a benchmark for incremental action towards that goal.

We propose the following elements of an effective system:

1. The needs of people with an intellectual disability and a mental disorder are specifically considered and accommodated in all mental health initiatives.
2. People with intellectual disability and their families receive education and support to prevent mental disorders and to obtain early and timely assistance for mental disorders.
3. All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.
4. A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services by provision of consultancy and training and through research.
5. Ongoing joint planning by disability services, schools and mental health and other relevant services including:
 - a. Identification of referral and treatment pathways.
 - b. A framework and capacity for collaborative responses where intellectual disability and mental disorder co-exist.
6. Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.
7. Collection and analysis of data which measures mental health needs, access to services and outcomes of people with intellectual disability.
8. All of these elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

GETTING TO THE OBJECTIVE - A LONG AND WINDING ROAD

The roundtable provides an invaluable opportunity to bring together a wide range of participants, including consumer representatives, families, service providers, professionals and representatives from government agencies, to share their perspectives on key issues and to chart a meaningful and achievable way forward.

The roundtable will seek to achieve a consensus on the elements of an effective system to meet the mental health needs of people with intellectual disability – an ultimate goal and objective.

However, the roundtable needs to focus on practical, incremental actions that can occur over the next five years:

- To inform action under existing policy settings such as the next COAG National Mental Health Plan, the roll out of the National Disability Insurance Scheme and implementation of national education reform, and
- Ways to improve the mental health of people with intellectual disability by enhancing current systems and without relying on significant new funding allocations from treasuries.

It would be a waste of the opportunity created by the roundtable if it focused on an expensive wish list rather than practical action that participants can go away and do now.

The Roadmap for National Mental Health Reform 2012-2022 states:

'This Roadmap outlines the direction governments will take over the next 10 years. Over recent years many governments have significantly increased their expenditure on mental health. Implementation of this Roadmap by jurisdictions will ensure this money is well spent and delivers better models of care and support for people with mental illness, thereby creating more cost-effective and sustainable interventions. It is about better targeting the existing funds where they are needed and to the right models of care.'

At the same time, action on improved mental health for people with intellectual disability is not only a role of governmental health agencies. A range of other government and non-government agencies have major roles, including disability agencies. In particular, the current national focus on disability reform, in particular the National Disability Insurance Scheme, creates opportunities to consider the role of disability support services in enhancing the provision of quality lifestyles and behaviour support services, with a flow on effect of reduced mental ill-health for people with intellectual disability.

Also, there may be scope for better or more equitable use of existing budgets within health agencies so as to improve the mental health of people with intellectual disability.

THE GUIDE PROJECT

In parallel with the roundtable, DoHA has funded the Department of Developmental Disability Neuropsychiatry at UNSW to produce *Accessible Mental Health Services for People with Intellectual Disability: A Guide for Providers*.

The Guide aims to develop a framework of understanding and action with respect to people with intellectual disability, for all frontline mental health service providers. It will provide an overview of intellectual disability mental health, why accessible services are important, the principles that should guide service delivery, practical strategies for inclusive and accessible services and the implications for the service system.

The Guide will be an important tool for action by health services so that they can provide equitable access and appropriate mental health treatment to people with intellectual disability.

UNSW is seeking to make the Guide useful for all mental health services including not only those funded by the Commonwealth but equally those provided or funded by the States/Territories.

ACTIONS TO DATE AND OPTIONS FOR ACTION 2013-2017

Forty-one roundtable participants from around Australia responded to our survey asking them to identify initiatives to date towards better mental health for people with intellectual disability and proposed future initiatives. A collation of the survey results is being sent to roundtable participants.

In this section, we summarise actions to date and some possible actions that might be taken over the next five years so that incremental progress can occur. The actions noted are drawn from the survey results and from our other research and consideration of the issues. They are not an exhaustive list.

The possible actions are not intended as a prescriptive or definite list. They are meant to provide a basis for discussion at the roundtable.

Both the proposed elements of an effective system and incremental action towards them rely considerably on the complementary roles of different agencies and service sectors. In considering priority incremental actions, roundtable participants can valuably consider how existing standards, practices, resources and infrastructure can be adapted to improve things like coordination and referral pathways and person centred and recovery oriented approaches. It will also be valuable to consider workforce supply, planning and distribution across sectors.

The development of *Accessible Mental Health Services for People with Intellectual Disability: A Guide for Providers* (the Guide) will be able to underpin or contribute to a range of options for action

Finally, it is valuable to be conscious of what drivers of change are available. One driver of change is national and State/Territory policies and existing mechanisms to support their implementation. Others can be much more local and individual. The survey asked roundtable participants to specify what had led to current initiatives on intellectual disability mental health. Responses indicated that a high proportion of advances have flowed from advocacy by professional groups and champions in the health system.

INCLUSION IN ALL MENTAL HEALTH INITIATIVES

Element 1 - The needs of people with an intellectual disability and a mental disorder are specifically considered and accommodated in all mental health initiatives.

Links to national policy framework

CRPD, NDS Policy direction 3, 4th NMHP Standard 4, RNMHR especially Strategies 17 and 31 and pages 10, 20, 24.

CRPD	United Nations Convention on the Rights of Persons with Disabilities
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
4 th NMHP	Fourth National Mental Health Plan 2009 - 2014
NSMHS	National Standards for Mental Health Services
NMHSRR	National Mental Health Statement of Rights and Responsibilities
RNMHR	Roadmap for National Mental Health Reform 2012 - 2022

Actions to date

- Acknowledgment of people with intellectual disability in the 4th NMHP.
- Focus on co-occurring conditions at National Recovery Forum 2012.
- DoHA funding of roundtable and Guide project.

Some options for incremental action

1. Include a specific focus on intellectual disability mental health in the proposed national recovery-oriented mental health policy framework.
2. Promote take up of personally controlled electronic health records by people with intellectual disability.
3. Each government health agency to develop a definitive pathway for inclusion of people with intellectual disability in all workup of mental health policy documents and funding initiatives.
4. Federal government to consider the mental health needs of people with intellectual disability in development of primary healthcare policy and programs.

PREVENTION AND TIMELY INTERVENTION

Element 2 - People with intellectual disability and their families receive education and support to prevent mental disorders and to obtain early and timely assistance for mental disorders.

Links to national policy framework

CRPD, NMHSRR, NDS Policy directions 2, & 4, NDIS, NSMHS Standards 4 & 7, RNMHR especially Priorities 2-4, Strategies 17,19 & 31, and pages 10, 20, 24.

Actions to date

- DoHA funding of *Accessible Mental Health Services for People with Intellectual Disability: A Guide for Providers (the Guide)*.
- Development of education resources and training by specialist intellectual disability health services and advocacy groups, including Stepping Stones parent training.
- Medicare items for annual health assessments of people with intellectual disability.

Some options for incremental action

1. Including in the launch sites of the National Disability Insurance Scheme particular focuses on:
 - Development of communication and coping skills to help prevent or minimise mental illness.
 - Ensuring planners developing participant plans have skills in intellectual disability mental health.
2. In implementation of current national schools reforms, include specific consideration of how to incorporate action on the mental health of students with intellectual disability.
3. Development of self-advocacy skills and groups for people with intellectual disability and a mental disorder.
4. Development of further plain English and easy read information for people with intellectual disability and their families. Funding a partnership between consumer, disability and mental health sectors for this purpose.
5. Action to improve the take up rates on annual health assessments of people with intellectual disability.

EQUITABLE ACCESS AND SKILLED TREATMENT

Element 3 - All mental health services provide equitable access and appropriately skilled treatment to people with intellectual disability.

Links to national policy framework

CRPD, NMHSRR, NDS Policy directions 1 & 3, RNMHR especially Priority 5, Strategy 31, and page 24.

Actions to date

- DoHA funding of the Guide project.
- Research and recommendations on use of psychoactive medication – Victoria.

Some options for incremental action

1. The Guide to act as a resource to assist government and non-government mental health services to provide equitable access and skilled treatment for people with intellectual disability.
2. Medicare Locals to consider what action they can take on intellectual disability mental health.
3. Resolution of national guidelines on the appropriate prescription of psychoactive medication to people with intellectual disability.

SPECIALISTS IN INTELLECTUAL DISABILITY MENTAL HEALTH

Element 4 - A national network of specialist intellectual disability mental health professionals is available to support mainstream mental health services – by provision of consultancy and training, and through research.

Links to national policy framework

CRPD Article 25, NDS Policy directions 1 & 3, NDIS, 4th NMHP Standard 4, RNMHR especially Priority 5, Strategy 31 and page 24.

Such a network exists in the United Kingdom (Dossetor and others 2011, chapter 25). It is in keeping with the views of the National Health and Hospitals Reform Commission (2008 at 2.4.5 and 2009 at 3.2) and NSW Health that there needs to be a network of specialised intellectual disability health teams. The cost effectiveness of such an approach is supported by an economic analysis prepared for NSW Health by KPMG (2009).

There is very broad support across the mental health and disability spheres for the need for specialist intellectual disability mental health professionals to backup mainstream mental health services (National and NSW Councils for Intellectual Disability and Australian Association of Developmental Disability Medicine 2011).

Actions to date

- Local or ad hoc development of specialist psychiatry and team approaches including:
 - Dual Disability Service in Department of Health Vic.
 - Two specialist health facilitators in mental health services Qld.
 - Specialist clinics in intellectual disability physical and mental health services, mainly in some capital cities.
 - Chairs at UNSW and University of Sydney.
 - Inclusion of psychiatry component in three pilot intellectual disability physical and mental health teams – NSW.
 - A very small number of private psychiatrists with expertise in intellectual disability mental health.
 - Funding of advanced trainee positions in intellectual disability mental health – NSW.

- Various research studies including:
 - Australian Child to Adult Development Study (Tonge survey).
 - Program to improve mental health of people with intellectual disability and carers by education and training of parents and workforce (Tonge survey).
 - Building an evidence base in psychopharmacology (Dossetor survey).
 - Improving mental health outcomes of people with intellectual disability – multifaceted project lead by A/Prof Trollor, UNSW.

- RANZCP Special Interest Group in the mental health of people with intellectual disability.

Some options for incremental action

1. Action by the RANZCP to develop the training and recognition of intellectual disability psychiatry as a subspecialty.
2. Ongoing monitoring and pursuit of funding opportunities including under the Specialist Training Program managed by DoHA.
3. Development of a chapter in disability medicine in the RACGP (Marles survey.)
4. Policy driven research on issues such as protective factors against mental ill health, adapted psychological treatment strategies and valid mental health screening and assessment tools.
5. Create clinical coordinator positions in public mental health districts focused on intellectual disability mental health.

COLLABORATION BETWEEN AGENCIES

Element 5 - Ongoing joint planning by disability services, schools and mental health and other relevant services including:

- **Identification of referral and treatment pathways**
- **A framework and capacity for collaborative responses where intellectual disability and mental disorder co-exist.**

Links to national policy framework

CRPD, NDS generally, NDIS, RNMHR especially Strategy 29 and page 24.

Actions to date

- Focus on co-occurring conditions at National Recovery Forum 2012.
- Dual Disability Working Group – WA.
- Initiatives in some States/Territories to meet the needs of small numbers of people with exceptionally complex needs including the People with Exceptionally Complex Needs initiative in WA and the Integrated Services Program in NSW.
- MOU and Guidelines between disability and mental health services NSW including implementation strategies.
www.adhc.nsw.gov.au/_data/assets/file/0010/237277/MOU_ADHC_and_NSW_Health_2010.pdf
- Co-location in disability services of Mental Health Service for People with Intellectual Disability – ACT.
- Collaborative use of individualised funding and local area coordination – WA.
- School Link program between Children’s Hospital at Westmead and schools – NSW.
www.schoollink.chw.edu.au
- Developmental psychiatry clinic – an interagency multidisciplinary approach for children and adolescents with complex needs (Dossetor survey).

Some options for incremental action

1. Focus on the importance of multidisciplinary and collaborative approaches in the proposed national recovery-oriented mental health policy framework.
2. Development of a national strategy for collaboration between mental health, disability, schools and other relevant agencies based on clearly defined and accountable roles and collaborative practices.
3. As for 2. But with a specific focus on the launch sites for the NDIS.
4. Collocation of some mental health and disability services.
5. Training in intellectual disability mental health including a focus on shared language and understanding of issues and collaborating skills.
6. Mental health agencies negotiating with the National Disability Insurance Scheme to ensure movement out of psychiatric hospitals of people with intellectual disability housed there for want of another option.
7. As part of the proposed national strategy to reduce the use of restrictive practices in disability services, seek to ensure that decisions about use of psychoactive medication are based on the shared skills of appropriate health and disability professionals.

EDUCATION AND TRAINING

Element 6 - Training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services, schools and health services, particularly including primary health and mental health services.

Links to national policy framework

CRPD, NDS Policy direction 1, NDIS, 4th NMHP Standard 4, RNMHR especially Strategy 29 and page 24.

Actions to date

- DoHA funding of the Guide project.
- Audit of intellectual disability health content in medical and nursing faculties around Australia (Trollor survey).
- Inclusion of content on intellectual disability health in some medical and nursing faculties.
- Inclusion of intellectual disability mental health issues in curriculum and training modules of RACGP (Marles survey).
- Development of competencies in intellectual disability mental health for NSW Mental Health staff (Trollor survey).
- Development of training curricula and resources and conduct of training programs by specialist intellectual disability health services in a number of States.
- Development of practice resource for psychologists by APS.
- Development of Beyond Speech Alone resources for counsellors. www.bridgingproject.org.au/std-resources.htm
- The Australian Government, along with all jurisdictions, contributes funds to Mental Health Professional Online Development (MHPOD). MHPOD includes a module on intellectual disability mental health.

Some options for incremental action

1. Development of minimum intellectual disability health content in medical and nursing faculties.
2. Program to build the skills base of practice nurses.
3. Examination of the ongoing training needs of GPs.
4. Development of online training material for disability and mental health professionals.

DATA

Element 7 - Collection and analysis of data which measures mental health needs, access to services and outcomes of people with intellectual disability.

Links to national policy framework

CRPD, RNMHR especially major task 1 of working group on mental health reform.

Actions to date

- Building of resource to link data of disability, mental health and other NSW agencies (Trollor survey).

Some options for incremental action

1. Specific inclusion of people with intellectual disability and their families in any independent surveys of people's experiences of, and access to, mental health services. (The National Mental Health Commission has recommended that such surveys occur on a regular basis.)
2. Exploring opportunities for data linkage between mental health services, Medicare and the National Disability Insurance Scheme.

MULTIPLE DISADVANTAGE

Element 8 - All of these elements include specific focus on contributors to multiple disadvantage including poverty, isolated lives, alcohol and other drugs misuse, Indigenous status, CALD backgrounds and contact with the criminal justice system.

Links to national policy framework

CRPD, NDS, NDIS, 4th NMHP Standard 4, RNMHR especially Priority 2 & 5, Strategies 17 & 31, and page 10, 20, 24

Actions to date

- DoHA funding of the Guide project.
- Certificate in forensic disability course at Monash University.
- Education on intellectual disability for Indigenous people – NT.
- Forensic disability mental health professionals in, or consulting to, some disability agencies.

Some options for incremental action

1. All training resources and programs should include focuses on cultural competence and other sources of multiple disadvantage.
2. Further development of legislative pathways and accommodation options for people found unfit to be tried or not guilty on the grounds of mental impairment.
3. Further development of legislative and service pathways to allow diversion from the criminal justice system.
4. Develop forensic disability certificate to a degree course.

APPENDICES

APPENDIX 1

The Australian Psychological Society (2011) has developed minimum standards for a behaviour support plan:

Minimum standards for a behaviour support plan

- Plans should be formulated in plain language and any technical terms should be explained in lay terms.
- The identified behaviour(s) should be operationally defined and the topography should be detailed (form, intensity, frequency and duration).
- The hypothesised function(s) of each behaviour, based on a documented functional assessment, should be outlined.
- Predictors and setting events should be described in detail (e.g., places, activities, people and personal circumstances such as health status or social incidents), together with strategies to minimise their occurrence or diffuse their impact.
- The person's preferred circumstances and needs should be outlined; i.e., details of the circumstances under which the behaviour is known not to occur because the person's needs are met and they are happy.
- Environmental (social, physical, organisational and procedural) strategies should be detailed. These should include strategies to explicitly enhance the person's quality of life and wellbeing.
- Educational strategies should be described, together with details of associated reward and reinforcement programs designed to enhance the development of alternative, more adaptive behaviours.
- The goals of the BSP should be outlined, as should the review/evaluation timeline and procedures (including data collection processes and time lines). Details of the circumstances under which the review process might be brought forward should also be included.
- Communication strategies should be detailed, providing a clear explanation of the person's receptive and expressive communication skills and the strategies (including any augmentative or alternative communication techniques, aids or devices) that those who provide support should be using.
- Crisis management procedures (Carr et al., 1994) should be specified.
- The educational and other support needs of those expected to implement the plan should be outlined.
- Team coordination, communication and responsibility protocols should be detailed and include contact options for short-term consultations and clarification of the plan.
- Any legal requirements, such as details of the consent process and the necessity for guardianship, or others' approvals for particular procedures etc., should be documented.

APPENDIX 2

UN Convention on the Rights of Persons with Disabilities 2006 (CRPD)

www.un.org/disabilities/convention/conventionfull.shtml

Australia took a major role in the development of the CRPD which was adopted by the United Nations in 2006. Australia ratified the Convention in 2008.

The Convention says that *'disability is an evolving concept and results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others'* (Preamble (e)).

The general principles of the convention include respect for inherent dignity and autonomy, non-discrimination, and full and effective participation and inclusion in society (Article 3.)

Article 25 of the Convention states that people with disabilities have a right to *'the highest attainable standard of health'*, including equal access to mainstream health services and provision of specialised disability health services where needed.

Other articles emphasise rights to:

- liberty on an equal basis with other people (article 14)
- freedom from exploitation and abuse open (article 16)
- protection of the integrity of the person (article 17)
- access to community support and other habilitation services (articles 19, 26)
- education (article 24)
- work and employment (article 27)
- governments to collect information including statistical and research data to enable them to implement policies to give effect to the convention (article 31).

UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care 1991

www.un-documents.net/pppmi.htm

These principles were endorsed in the National Mental Health Policy in 1992. The principals specify that they are to be applied without discrimination of any kind such as on grounds of disability. They emphasise the civil rights of people with mental illness. They also state the right to the best available health care according to a person's needs.

National Disability Strategy 2010-2020

www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy

COAG adopted the National Disability Strategy in February 2011. The strategy is intended to guide policy and program development by all levels of government and actions by the whole community. It looks *'beyond the specialist disability sector'* and aims to *'focus our efforts towards achieving a society that is inclusive and enabling, providing equality and the opportunity for each person to fulfil their potential'* (page 5).

The Strategy commits all government to six key outcomes, one of which is:
People with disability attain highest possible health and wellbeing outcomes throughout their lives.

To achieve this outcome, the strategy specifies policy directions including:

Policy direction 1 - All health service providers (including... mental health) have the capabilities to meet the needs of people with disability.

Policy direction 2 - Timely, comprehensive and effective prevention and early intervention health services for people with disability.

Policy direction 3 - Universal health reforms and initiatives address the needs of people with disability, their families and carers.

System changes flowing from health reforms and initiatives across Australia provide important opportunities to improve responses to the health needs of people with disability. Key health reforms with implications for people with disability include increased focus on support for mental health. These reforms need to ensure that people with disability are not left behind (pages 55-56).

Area for future action 6.6 states:

Address issues specific to people with disability as part of the national expansion of key public health strategies such as mental health so that they explicitly meet the needs of people with disabilities.

Policy direction 4 - Factors fundamental to well-being and health status such as choice and control, social participation and relationships, to be supported in government policy and program design.

National Disability Insurance Scheme (NDIS)

www.ndis.gov.au

The NDIS is being developed in response to the Productivity Commission report, *Disability Care and Support* (2011). That report concluded:

Current disability support arrangements are inequitable, underfunded, fragmented and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed (Overview booklet, pg 5).

The National Disability Insurance Scheme Act 2013 creates a framework for national access by people with disability to the supports that they need. In the first instance, five launch sites will commence operation in July 2013, led by the NDIS Launch Transition Agency.

The agency will be able to provide general supports to people with disability including assisting them to obtain supports that they need. More specific assistance will be available

to 'participants' in the scheme. Basically, a person with disability is eligible to become a participant if the person:

- has a disability that is likely to be permanent and which results in substantially reduced functioning in key life activities or
- early intervention supports are likely to reduce the persons future disability support needs. (NDIS Act, sections 24 and 25)

Importantly, the disability that underpins eligibility to be a participant can arise from '*one of more intellectual, cognitive, neurological, sensory or physical impairments*' or impairments from a 'psychiatric condition' (Section 24).

Once a person is a participant the agency will work with the person to prepare a participant's plan based on the person's goals and aspirations. This plan can include both general supports that will be provided, and reasonable and necessary supports that will be funded under the NDIS.

The agency must be satisfied that any support that it provides or funds is most appropriately funded or provided through the NDIS and is not more appropriately funded or provided through other general systems of service delivery:

- I. as part of a universal service obligation; or
- II. in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability. (Section 34 (f))

NDIS draft Rules set out how the agency intends to apply this provision. In relation to mental health, the draft rule says that the NDIS will not be responsible for clinical mental health services or early intervention to reduce the progression of a mental health condition or any residential care whose primary purpose is mental health treatment or rehabilitation or whose service model primarily employs clinical staff.

However, the NDIS will be responsible for non-clinical support that focuses on a person's functional ability including support to undertake activities of daily living and participate in the community and social and economic life. This would ordinarily include allied health and other therapy directly related to managing or reducing the functional impact of a psychiatric condition including social and communication skills development and behavioural and cognitive interventions.

(National Disability Insurance Scheme Rules-Supports for Participants, Schedule 1, Considerations relating to whether supports most appropriately funded through the NDIS.)

The National Mental Health Strategy (the Strategy)

The Strategy has guided mental health reform in Australia since 1992, when Australian health ministers agreed to the original National Mental Health Policy and the first five-year National Mental Health Plan, representing the first attempt to coordinate mental health care reform in Australia through national activities. The Fourth National Mental Health Plan (2009 – 2014) was the first plan that explicitly adopted a whole of government approach. Key documents under the Strategy include:

National Mental Health Statement of Rights and Responsibilities 2013

www.health.gov.au/mentalhealth

Mental health consumers have the right to access assessment, support, care, treatment, rehabilitation and services that facilitate or support recovery and wellbeing on an equal basis with others. They are entitled to high-quality services and appropriate treatment. They are entitled to participate in all decisions that affect them, to receive high-quality services, to receive appropriate treatment, including appropriate treatment for physical or general health needs, and to benefit from special safeguards if involuntary assessment, treatment or rehabilitation is imposed.

Fourth National Mental Health Plan

www.health.gov.au/mentalhealth

The *Fourth National Mental Health Plan: An Agenda for Collaborative Government Action in Mental Health* (2009-2014) operationalises the National Mental Health Policy 2008 and sets out specific actions to improve the lives of people with mental illness and their families.

The Plan includes five priority areas including 'Social inclusion and recovery', and 'Prevention and early intervention'.

A key action relevant to people with co-occurring mental illness and intellectual disability concerns 'adoption of a recovery oriented culture within mental health services, underpinned by appropriate values and service models' (Action 4, Fourth Plan: page 23).

National Standards for Mental Health Services 2010

www.health.gov.au/mentalhealth

The Standards includes two specific references to people with intellectual disability.

Standard 4 - Diversity responsiveness - requires mental health services to identify the diverse groups that access their service, including people with physical and intellectual disability. The standard goes on to specify that services planning and service implementation should ensure non-discriminatory practices and equitable access to services.

Standard 7-Carers - Specifies that services should consider the needs of carers, specifically including carers of people with intellectual disability.

The Standards Implementation Guidelines state that mental health services should have:

- Documented policies, procedures and work practices that recognise and respond to the needs of the community, including recognising physical and intellectual disabilities. (Criterion 10.2.1)
- A documented entry policy and procedures including on how to ensure that the needs of diverse groups, including people with intellectual disability, are addressed in the entry process. (Criterion 10.3.1)
- Treatment options needed to address diverse groups including people with intellectual disability. (Criterion 10.5.2)
- Processes to identify and support carers (criterion 7.5).

The Standards include a standard for services that supports recovery and covers: uniqueness of the individual; real choices; attitudes and rights; dignity and respect, partnership and communication; evaluating recovering (Standards: pages 42 to 44).

The Roadmap for National Mental Health Reform 2012-2022

www.health.gov.au/mentalhealth

This COAG initiative outlines the direction Australian governments will take over the next 10 years. The Roadmap includes whole of government and cross-portfolio directions for mental health reform that governments will take, building on current efforts to improve the lives of people with mental illness, their carers and families.

New governance and accountability arrangements outlined in the Roadmap have been established. A new Working Group on Mental Health Reform co-chaired by the Commonwealth Minister for Mental Health and the Victorian Minister for Mental Health will oversee detailed work on mental health reform, and ensure that all levels of government are engaged in reform.

The Working Group will be assisted by an Expert Reference Group chaired by the National Mental Health Commission.

The Working Group will have responsibility for four major tasks over the next 18 months. The Working Group will:

- Prepare a response to the National Report Card on Mental Health and Suicide Prevention for consideration by COAG by mid-2013.
- Improve access to data to support reporting on mental health reform.
- Develop indicators and targets for national mental health reform by the end of 2013.
- Review the Fourth National Mental Health Plan and develop a successor for consideration by COAG in mid-2014.

The Roadmap sets six priorities:

1. Promote person-centred approaches
2. Improve the mental health and social and emotional wellbeing of all Australians
3. Prevent mental illness
4. Focus on early detection and intervention
5. Improve access to high quality services and
6. Improve the social and economic participation of people with mental illness

The Roadmap identifies Strategies to address these priorities. In relation to people with intellectual disability, the Roadmap states:

The risk of developing a mental illness is higher when a person is socially excluded and isolated or experiences poverty, neglect, abuse or trauma; misuses drugs or alcohol; is in poor physical health or has a physical or intellectual disability (page 10).

The roadmap notes that good mental health can be achieved by tackling risk factors. Preventive activity should be directed towards those people who are perceived to be at

increased risk, for example people at risk of contact with the criminal justice system (page 20).

In relation to priority 5 - improve access to high-quality services and supports - the Roadmap states *'Some people who experience mental health issues have good access to a range of services and supports; others do not. In particular.... people with disabilities.... [who can] experience multiple barriers that discourage them from accessing mental health services and support. Governments need to reduce the significance of these barriers by providing targeted and innovative supports, and by expanding the presence and availability of services to at risk and isolated communities....This is best achieved through partnerships between government, private, non-government and community organisations that ensure effective, well integrated services and responses.'* (page 24).

Strategies relevant to people with intellectual disability include:

Strategy 17 - Identify populations at risk of experiencing mental health issues and provide targeted programs.

Strategy 19 - Increase programs targeted at reducing exposure to risk factors for mental illness .

Strategy 29 includes - Improve integration of clinical and nonclinical mental health services and strengthen coordination with broader community services.

Strategy 31 -Support innovative service delivery models for marginalised and disadvantaged groups.

A Contributing Life: The 2012 National Report Card on Mental Health and Suicide Prevention

www.mentalhealthcommission.gov.au

In its report card, the National Mental Health Commission identifies four priority areas for action:

1. Mental health must be a national priority for all governments and the community.
2. We need to provide a complete picture of what is happening and closely monitor and evaluate change.
3. We need to agree on the best ways to encourage improvement and get better results.
4. We need to analyse where the gaps and barriers are to achieving a contributing life and agree on Australia's direction.

Based on these priority areas, the Commission made 10 recommendations focused on:

1. A regular independent survey of people's experiences of, and access to, mental health services.
2. Increased access to timely and appropriate mental health services.
3. Reducing involuntary practices including seclusion and restraint.
4. Action to reduce early death and improve physical health.

5. Including the mental health of Aboriginal and Torres Strait Islander peoples in 'Closing the Gap' targets.
6. Achieving the same national commitment to safety and quality in mental health services as in general health services.
7. Investing in healthy families and communities.
8. Increasing participation in employment.
9. No one being discharged from mental health services into homelessness.
10. Reducing suicides.

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