National & NSW Councils for Intellectual Disability

Australian Association of Developmental Disability Medicine

SUBMISSION TO SENATE COMMUNITY AFFAIRS REFERENCE COMMITTEE

THE GOVERNMENT'S FUNDING AND ADMINISTRATION OF MENTAL HEALTH SERVICES

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SUMMARY

The problem

People with intellectual disability have very high rates of mental disorders. However, diagnosis is very challenging. Many people with intellectual disability have limited verbal communication and experience an atypical presentation of mental disorders.

Research shows very poor access to mental health services for people with intellectual disability and a mental illness. Psychiatrists and GPs see themselves as inadequately trained to treat this group. Mental disorders are frequently not recognised or are misdiagnosed and inappropriately treated.

In Australia, there are only isolated pockets of expertise in intellectual disability mental health. In England, there is a well developed specialty in intellectual disability mental health.

What we seek from government in mental health reform

1. The needs of people with an intellectual disability and a mental disorder should be specifically considered and accommodated in all mental health reform. In Part B of this submission, we set out how this should be done in relation to current Commonwealth reforms.

2. All funding of mental health services should include a specific requirement that the services will provide equitable access and appropriately skilled treatment to people with intellectual disability.

3. The government should fund a network of specialist intellectual disability mental health psychiatrists, nurses, psychologists and other professionals. These professionals would act as a consultancy, training and research adjunct to mainstream mental health services.

4. Enhanced joint planning by disability services and mental health services including development of a mandated shared case coordination capacity where intellectual disability and mental disorder co-exist.

5. Mandated training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services and mental health services.

The core aspects of our views are summarised in our proposition below, which has been circulated since late February, 2011, and has been endorsed by key stakeholders in mental health and intellectual disability.

PROPOSITION

People who have both an intellectual disability and a mental illness need to be included from the start in mental health reform. They currently have very poor access to appropriate mental health services.

Government needs to address this problem, in particular by funding specialised intellectual disability mental health psychiatrists and nurses who can act as a consultancy, training and research adjunct to mainstream mental health services.

THE AUTHOR ORGANISATIONS

The Australian Association of Developmental Disability Medicine (AADDM) is a national organisation representing medical practitioners who are committed to improving health outcomes for people with intellectual disability.

The National and NSW Councils for Intellectual Disability are peak associations representing people with intellectual disability, their families and disability services agencies.

For the last ten years, we have been working together to raise awareness of the health inequalities facing people with intellectual disability and to advocate practical actions to redress these inequalities.

PART A - THE ADEQUACY OF MENTAL HEALTH FUNDING AND SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITY (Term of Reference (f) (iii))

The need

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

Little has changed since the Burdekin report.

There are over 300,000 people with intellectual disability in Australia. While an intellectual disability is not itself a mental disorder, people with intellectual disability have very high rates of mental disorders. (Einfeld, Ellis and Emerson 2011; Einfeld & Tonge 1996a and 1996b; Cooper & others 2007; Morgan & others 2008)

Diagnosis is very challenging. Many people with intellectual disability have limited verbal communication and experience an atypical profile and presentation of mental disorders. It can be very difficult to distinguish to what degree a person's challenging behaviour relates to a mental disorder as opposed to factors such as communication impairments and problems in the person's environment.

The mental health needs of people with intellectual disability are poorly met. Australian research shows:

- Very poor access to mental health services for people with intellectual disability and a mental illness. In a ten year period, only 10% of adults with intellectual disability and a mental disorder had received mental health intervention (Einfeld & Tonge 1996b; Einfeld & others 2006). By contrast, Slade & others (2009) found that 34.9% of the overall community with mental disorders had received treatment in a twelve month period.

- Psychiatrists and GPs see themselves as inadequately trained to treat mental disorders in people with intellectual disability. 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, Diggens and Ugoni 1997;Phillips, Morrison & Davis 2004; Edwards, Lennox & White 2007; Jess & others 2008)

Mental 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)

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.

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 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. A registrar decided her 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 and recovered.

In Australia, there are only isolated pockets of expertise in intellectual disability mental health. There is not one staff specialist position devoted to this need. There is one recently established chair at the University of NSW. A number of advanced traineeships are available through the NSW Institute of Psychiatry, but, with the lack of a career path, it has proved difficult to recruit trainees.

By contrast, in England, there is a well developed specialty in intellectual disability mental health.

The current situation results in great human and financial cost to people with intellectual disability and their families, as well as considerable financial cost to the health, social security and disability service systems.

What people with intellectual disability need

- People with intellectual disability and a mental disorder need holistic support from mental health, disability and other relevant human services.

- Where there are grounds to think that a person with intellectual disability needs psychiatric treatment, the person needs access to health professionals with the skills required for accurate diagnosis and optimal treatment.

What we seek from government in mental health reform

1. The needs of people with an intellectual disability and a mental disorder should be specifically considered and accommodated in all mental health reform. In Part B, we consider how this should be done in relation to current Commonwealth reforms.

2. All funding of mental health services should include a specific requirement that the services will provide equitable access and appropriately skilled treatment to people with intellectual disability.

3. Government should provide specific funding for a network of specialist intellectual disability mental health psychiatrists, nurses, psychologists and other professionals. These professionals would act as a consultancy, training and research adjunct to mainstream mental health services. This would include clinical services in local areas and education centres of excellence linked to universities. The services are needed across the lifespan, for children, young people, adults and older people.

4. Enhanced joint planning by disability services and mental health services including development of a mandated shared case coordination capacity where intellectual disability and mental disorder co-exist. The psychologists, social workers and other professionals in disability services have a key role in working with mental health professionals to ensure a holistic response to mental disorders.

5. Mandated training in intellectual disability mental health to minimum standards for front-line and other professional staff in disability services and mental health services.

Funding of specialist intellectual disability mental health professionals is vital to the success of the joint planning and training of mental health and disability staff.

Action on the above steps would result in:

- Improved access to mental health care for people with intellectual disability,

- Improved mental health treatment and holistic support of people with intellectual disability and a mental disorder,

- Improved health and quality of life for people with intellectual disability and a mental disorder, and

- More appropriate use of psychotropic medication with people with intellectual disability.

The focus of this submission is on mental health reform, rather than disability support needs such as supported accommodation and support with community participation and skills development. Disability support needs are the responsibility of the disability service system. People with intellectual disability and mental disorders also need to be squarely included in the movement towards ongoing expansion and reform of that system.

Our highest priority

We seek national action to fund specialist intellectual disability mental health psychiatrists and nurses. This is the standout current gap in the health and disability professionals needed for intellectual disability mental health.

Broad support for our stance

The core aspects of our views are summarised in our proposition below, which has been circulated since late February, 2011, and has received the endorsements of key stakeholders. As leading individuals and organisations in both mental health and disability sectors, the endorsers of our proposition give their full weight to our call for systemic change in policy, funding and service delivery for this group of marginalised Australians. .

PROPOSITION

People who have both an intellectual disability and a mental illness need to be included from the start in mental health reform. They currently have very poor access to appropriate mental health services.

Government needs to address this problem, in particular by funding specialised intellectual disability mental health psychiatrists and nurses who can act as a consultancy, training and research adjunct to mainstream mental health services.

See Appendix 1 for the list of endorsers of the proposition.

Nick 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 ongoing stress but determined to provide the support their son needs. Nick and his family have considerable support from disability services and an intellectual disability health team including a psychiatrist who regularly reviews Nick's mental health and medication. Without this support, it is likely the family would not be able to cope with Nick's very high and complex needs.

The context of "stark health inequalities"

The National Health and Hospitals Reform Commission reported in 2009 that people with intellectual disability face "stark health inequalities". This is the case for both physical and mental health. In 2009, we wrote our *Position Statement on the Health of People with Intellectual Disability*.

That position statement calls for

1. All health care planning to include specific consideration of how it will meet the needs of people with intellectual disability.

2. The funding of a national network of health services specialising in the health care of people with intellectual disability. These services would be a consultancy and training resource to the mainstream health system.

That position statement has been endorsed by:

- 36 national organisations including numerous leading groups across the disability and health sectors.

- 165 state and local organisations

- 130 eminent individuals.

The position statement and list of endorsers is at
www.nswcid.org.au/standard-english/se-pages/health.html

In February 2011, we moved to seeking endorsements of our specific proposition on the mental health needs of people with intellectual disability. This proposition is in line with the National Disability Strategy:

The National Disability Strategy

Australia took a major role in the development of the UN Convention on the Rights of Persons with Disabilities which was finalised in 2006. 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.

On 14 February 2011, the Council of Australian Governments adopted the National Disability Strategy which 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 give effect to this outcome, **COAG has specified policy directions and action areas including that expansion of national action on mental health should "explicitly meet the needs of people with disability".**

PART B - RESPONSE TO OTHER TERMS OF REFERENCE

We now respond to the other terms of reference of the inquiry. We focus on the needs of people who have both an intellectual disability and a mental disorder.

(a) The Government's 2011-12 Budget changes relating to mental health

There are major positive aspects of the budget changes. However, they do not mention people with intellectual disability. For the changes to improve the mental health care available to people with intellectual disability, the implementation of the budget changes will need to specifically respond to the needs of this group:

1. **Headspace centres and early psychosis prevention and intervention centres (EPPIC)** should be required to ensure that their services can provide equitable access to people with intellectual disability. Also, specific funding should be allocated to one or more Headspace and EPPIC centres to specialise in intellectual disability mental health and act as a consultancy and training resource to other Headspace and EPPIC centres. Headspace and EPPIC centres also need to work in collaboration with paediatricians who have a leading role in prevention, early action and treatment in relation to mental disorders in children and young people with intellectual disability.

2. **Family mental health support services** should be required to be established and operated in a manner that ensures equitable access to people with intellectual disability.

3. The small expansion of mental health **employment services** and the *Building Australia's future workforce* package need to include a specific focus on people with intellectual disability and a mental illness.

4. The **competitive funding pool for co-investments from states and territories** should include a priority of development of specialist intellectual disability mental health services.

See below for comments on how other budget initiatives need to accommodate people with intellectual disability and a mental disorder.

(b) changes to the Better Access Initiative, including:
(i) the rationalisation of GP mental health services,
(ii) the rationalisation of allied health treatment sessions,
(iii) the impact of changes to the Medicare rebates and the two-tiered rebate structure for clinical assessment and preparation of a care plan by GPs, and
(iv) the impact of changes to the number of allied mental health treatment services for patients with mild or moderate mental illness under the Medicare Benefits Schedule

An intellectual disability inherently leads to the need for longer consultations with general practitioners and longer and more consultations with psychologists. Therefore, we see a significant detriment to people with intellectual disability from the reduction in the Medicare rebate for GP mental health care plans and the capping of allied psychological consultations at 10 rather than 12.

(c) the impact and adequacy of services provided to people with mental illness through the Access to Allied Psychological Services program

We note the expansion of the ATAPS program with new funding to be provided to Medicare locals to enable them to target "hard to reach areas and groups that are currently under serviced". While we do not have data on this, the overall poor access to mental health services experienced by people with intellectual disability strongly implies poor access to psychological services for those people with intellectual disability who do not have access to appropriately skilled psychological services through disability services. <u>This group should be specifically considered in the rollout of the ATAPS expansion.</u>

There is evidence that where people with intellectual disability and a mental disorder access appropriate psychological treatment through ATAPS, successful outcomes flow. (Riches, V.C. & Dickson, R 2010).

(d) services available for people with severe mental illness and the coordination of those services

Care coordination by Medicare Locals or large NGOs in Medicare Local regions.
We understand that these organisations will be funded to provide coordination services and flexible funding to purchase services for people with severe mental illness where there are service gaps and unmet needs.

<u>For the care coordination initiative to work for people with intellectual disability and a mental illness:</u>

- <u>people with intellectual disability and a severe mental illness need to be recognised as one of the current areas of unmet need.</u>
- <u>each Medicare Local / NGO needs to establish collaborative arrangements with local disability services.</u>
- <u>for people not eligible for case management by local disability services, typically including people with borderline intellectual disability and a mental illness, the Medicare Local /NGO needs to provide case coordination.</u> This need arises similarly for those people with mild intellectual disability who do not identify themselves as having an intellectual disability and so reject intellectual disability services.

NSW CID has been funded by the Department of Health and Ageing to develop web-based resources to encourage collaboration between Medicare Locals and local disability groups. This project will seek to raise awareness of the mental health needs of people with intellectual disability and the need for collaboration between mental health services and intellectual disability services.

Expansion of the *Support for day to day living in the community* and the *Personal helpers and mentors* programs
<u>Funding of these programs needs to include a requirement that programs provide a proactive strategy which will ensure equitable access to people with intellectual disability and a mental illness</u>, in particular people with borderline intellectual disability who are usually not eligible for local disability services.

(e) mental health workforce issues, including:

(i) the two-tiered Medicare rebate system for psychologists,
(ii) workforce qualifications and training of psychologists, and
(iii) workforce shortages

See Part A of our submission where we have explained the fundamental shortage of mental health professionals with the skills and availability to meet the often complex mental health needs of people who have both an intellectual disability and a mental disorder.

(f) the adequacy of mental health funding and services for disadvantaged groups, including:
(i) culturally and linguistically diverse communities,
(ii) Indigenous communities, and
(iii) people with disabilities

Additional disadvantage in mental health care arises where a person has an intellectual disability, a mental disorder and an additional disadvantage related to their cultural or linguistic background, Indigenous status or an additional disability such as impaired sight or an acquired brain injury.

These additional needs must be specifically accommodated both in reforms to mainstream mental health services and in the establishment of specialised intellectual disability mental health services.

(g) the delivery of a national mental health commission

Intellectual disability mental health needs to be a specific focus of the National Mental Health Commission and 10 year roadmap for reform of mental health

(h) the impact of online services for people with a mental illness, with particular regard to those living in rural and remote locations and other hard to reach groups

The potential efficacy for people with intellectual disability of a **portal for online mental health therapy** needs to be carefully considered. It will certainly not be effective unless the design of the portal includes specific steps to ensure that it is accessible to people with limited literacy and intelligence. To the degree that the portal cannot be made effective for people with intellectual disability, steps are required to ensure that their needs are accommodated in other ways.

APPENDIX 1 - ENDORSERS OF OUR PROPOSITION

PROPOSITION

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Government needs to address this problem, in particular by funding specialised intellectual disability mental health psychiatrists and nurses who can act as a consultancy, training and research adjunct to mainstream mental health services.

Individuals

Patrick McGorry AO
Australian of the Year 2010 & Director, Orygen Youth Health

Maria Tomasic
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Consultant Psychiatrist, Centre for Disability Health, Adelaide

Meg Smith OAM
President, Mental Health Association NSW &
Associate Professor, Adjunct, Social Justice & Social Change Centre
University of Western Sydney

Tony Fowke AM
President, World Federation for Mental Health & Mental Health Carers Arafmi Australia

Monsignor David Cappo
Commissioner for Social Inclusion, SA

Gordon Parker AO
Executive Director, Black Dog Institute

Terry Carney
Professor of Law, University of Sydney &
President 2005-2007, International Academy of Law and Mental Health

Anne Deveson AO
Advocate & co-founder SANE Australia & Schizophrenia Fellowship NSW

Ian Hickie AM
Executive Director, Brain and Mind Research Institute, University of Sydney

Bruce Tonge
Professor & former Head of Psychology, Psychiatry and Psychological Medicine, Monash University

Ian Everall
Professor & Head of Psychiatry, University of Melbourne

Philip Mitchell AM
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Helen Christensen,
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Allan Fels AO

John Mendoza
Director, Connetica & Adjunct Professor, Health Science

Jill Gordon
President, Australian College of Psychological Medicine

Toby Hall
Chief Executive Officer, Mission Australia

Sally Sinclair
CEO, National Employment Services Association

Andrew Fuller
Clinical Psychologist & Fellow, Departments of Psychiatry and Learning and Educational Development, University of Melbourne

Alan Robinson
Parent advocate, WA

Eileen Baldry
Professor of Criminology, University of New South Wales

Duncan Chappell
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Colleen Pearce
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Graeme Smith
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Lisa Warner
Public Guardian Tasmania

Dianne Pendergast
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Ros Montague
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Stan Alchin OAM
Former Director of Nursing, Rozelle and Gladesville Hospitals &
Former President, Aftercare

Stewart Einfeld
Professor of Mental Health, University of Sydney

Greg O'Brien
Emeritus Professor of Developmental Psychiatry, Northumbria University, former Associate Dean, Royal College of Psychiatrists

Jenny Torr
Chair of the RANZCP Special Interest Group in Intellectual Disability & Director of Mental Health, Centre for Developmental Disability Health Victoria

Jenny Curran
Senior Consultant Psychiatrist in Child & Youth Intellectual Disability Psychiatry, Disability Services, South Australia

Bill Glaser
Consultant Psychiatrist to the Statewide Forensic Services, Disability Services, Victoria

Julian Trollor
Chair in Intellectual Disability Mental Health, UNSW

David Dossetor
Director for Mental Health, Sydney Children's Hospital Network & Child Psychiatrist with a special interest in intellectual disability and Autism

National organisations

Australasian Society for Intellectual Disability (formerly Australasian Society for the Study of Intellectual Disability)

Australasian Society for Psychiatric Research executive committee

Australian Association of Social Workers

Australian College of Mental Health Nurses

Australian Council of Social Service

Australian Infant, Child, Adolescent and Family Mental Health Association

Australian Medical Association

Carers Australia

Community Collaboration Committee, Royal Australian & New Zealand College of Psychiatrists

Mental Health Carers Arafmi Australia

Mental Health Foundation Australia

Mission Australia

Multicultural Mental Health Australia

National Disability Services

National Rural Health Alliance

Neami

Professional Association of Nurses in Developmental Disability Australia

Royal Australian & New Zealand College of Psychiatrists

SANE Australia

Other organisations

ACT Mental Health Consumer Network

Aftercare NSW

Arafmi Mental Health Carers and Friends Association (WA)

Council of Social Service of NSW NCOSS

Mental Health Association NSW

Mental Health Council of Tasmania

NSW Consumer Advisory Group – Mental Health

Western Australian Association for Mental Health

APPENDIX 2 - REFERENCES

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