8 May 2011

Productivity Commission
Australian Government
RE: Disability Care and Support Public inquiry

The Australian Association of Developmental Disability Medicine (AADDM) is a national organisation of medical practitioners who are committed to improving health outcomes for people with intellectual disability. The members of the association provide clinical medical services directly to people (children, adolescents and adults) with intellectual disability, as well as research, education and policy advice to government. We would like to provide the following submission to the productivity commission. Please also find as attachment a recent AADDM proposition of the Place of People with Intellectual Disability in Mental Health Reform and an AADDM position statement on the Health of People with Intellectual Disabilities.

AADDM strongly supports a review of the long term disability care and support scheme. We agree that the current system is fragmented, underfunded and unpredictable. Parents and carers often feel frustrated and extremely concerned about the future welfare of their child. We commend the Australian Government on rising to the challenge of improving this system to better support people with intellectual disabilities.

We would like to emphasise the following issues and concerns;

1. The quality of life of people with intellectual disability is dependent on an acceptable level of general physical and mental health. Current evidence highlights major inequities in access to health services and health outcomes.

2. Improving health services is a cornerstone of improving health outcomes, and this system must involve an effectively integrated primary and specialist health care network for both physical and mental health.

3. People with disability and their carers must have confidence that the service systems will meet their needs throughout their lifespan, with capacity to respond to increased needs at major periods of transition, eg going to school, leaving school.

4. Carers must remain an important component of the “patient/client unit”.

5. Intervention, support and care services must be delivered to provide adequate ongoing support for severe lifelong disabilities, as well as to people who are likely to make significant gains and “normalise” with intervention.

6. Determination of eligibility for services must not be based on diagnosis alone, but coupled with a standardised measure of function, and careful consideration of the accumulation of risks, eg psychosocial adversity, mental health problems.

7. The principles that underpin distribution of funds to people with disability must be similar across the range of impairments, eg client centred.

8. The limitations in current research evidence should be a challenge to government to better fund research into this high risk population, with demonstrated poor health outcomes. This is a priority as funding of services must increasingly be based on evidence.
9. People with intellectual disability need the services of specialist medical practitioners to ensure the
generic healthcare system has the ability and expertise to provide high quality healthcare.

Yours sincerely

Professor Nicholas Lennox
President

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Brisbane, Q. 4101 Phone: (07) 3163 2412 Facsimile: (07) 3163 2445
President: Professor Nick Lennox Secretary: Dr Jacqueline Small
POSITION STATEMENT ON THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITIES

We call for concerted action to redress the poor health status experienced by people with intellectual disabilities. We make this call to the Australian, and State and Territory, Governments.

There are over 300,000 people with intellectual disabilities in Australia. They have very high rates of health problems and these problems are often not diagnosed or appropriately treated. Life expectancy is reduced by up to 20 years.

There are many causes of this situation, ranging across communication barriers between patients and health professionals, complexity of diagnosis, lack of general and specialised skills in the health workforce, and health promotion campaigns and research not focusing on people with intellectual disabilities.

As well as the human and financial cost of poor health for people with intellectual disabilities and their families, there is considerable financial cost to the health, social security and disability service systems.

Governments need to take action to provide equity in health care for people with intellectual disabilities. All health care planning should include specific consideration of how it will meet the needs of people with intellectual disabilities.

There also needs to be a national network of health services specialising in the health care of people with intellectual disabilities. These services would be a consultancy and training resource to the mainstream health system so as to enhance its capacity to meet the needs of people with intellectual disabilities. The specialised services would facilitate collaboration between local health and disability services and undertake research.

We call on the Australian, and State and Territory, Governments to each and together work to redress the inequity in health care experienced by people with intellectual disabilities. In particular, we call on the Governments to establish a national network of intellectual disability health services.

February 2009

Contacts:
Jim Simpson, NSW CID
Ass Prof Nick Lennox, AADDM

Endorsements

Michael Kidd
President, Royal Australian College of General Practitioners 2002-2006
Dean of Health Sciences, Flinders University

Stephen Leeder AO
Director, Australian Health Policy Institute
Professor of Public Health and Community Medicine

Julian Gardner
Former Public Advocate, Victoria

Jeanette Moss AM
Parent advocate

Peter Brooks
Executive Dean of Health Sciences, University of Queensland
Professor of Medicine

Bruce Robinson
People with intellectual disabilities “face stark health inequalities”. (p 55)

Primary health care centres need “robust links to specialist multidisciplinary health teams who are skilled in the management of people with intellectual disabilities.”. (p 96)

“Labor does recognise that people with intellectual disabilities are disadvantaged in the health system. ….In many situations, GPs and other health professionals require access to specialist advice to provide the health services people with intellectual disabilities require. ….The health of people with disabilities needs to be part of [our] reform plans.” (Shadow Ministers Roxon and McLucas, November 2007)

The NSW Government has recently spelt out the need for a multi-tiered framework of action on the health of people with intellectual disabilities including the establishment of a statewide network of specialised intellectual disability health services to back up mainstream services. (NSW Health (2007), Development of a service framework to improve health care of people with intellectual disabilities)

The NSW Ombudsman, who review deaths of people with disabilities, has said that the proposed NSW framework “is critical to improve the health outcomes for this vulnerable community”. (NSW Ombudsman, Report of Reviewable Deaths in 2007, Vol. 1, p.ix)
POSITION STATEMENT ON THE HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY

We call for concerted action to redress the poor health status experienced by people with intellectual disability. We make this call to the Australian, and State and Territory, Governments.

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There are many causes of this situation, ranging across communication barriers between patients and health professionals, complexity of diagnosis, lack of general and specialised skills in the health workforce, and health promotion campaigns and research not focusing on people with intellectual disability.

As well as the human and financial cost of poor health for people with intellectual disability and their families, there is considerable financial cost to the health, social security and disability service systems.

Governments need to take action to provide equity in health care for people with intellectual disability. All health care planning should include specific consideration of how it will meet the needs of people with intellectual disability.

There also needs to be 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 so as to enhance its capacity to meet the needs of people with intellectual disability. The specialised services would facilitate collaboration between local health and disability services and undertake research.

We call on the Australian, and State and Territory, Governments to each and together work to redress the inequity in health care experienced by people with intellectual disability. In particular, we call on the Governments to establish a national network of intellectual disability health services.

Contacts:
Jim Simpson, NSW CID
Professor Nick Lennox, AADDM

Endorsements - individuals
Richard Larkins AO
Former Vice-Chancellor, Monash University & President, Royal Australasian College of Physicians

Michael Kidd AM
Dean of Health Sciences, Flinders University
Former President, Royal Australian College of General Practitioners & President-elect, World Organisation of Family Doctors

Kevin Cocks AM
Director, Queensland Advocacy Inc
Human Rights Medallist

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

Stephen Leeder AO
Director, Menzies Centre for Health Policy

Jeanette Moss AM
Parent advocate

Ron McCallum AO
Chair 2010, UN Committee on the Rights of Persons with Disabilities & former Dean of Law, University of Sydney
People with intellectual disability “face stark health inequalities”.

“Access to specialist medical services is a major gap to be addressed for people living with an intellectual disability.” (p 82)

“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.”

“People with disability [will] attain the highest possible health outcomes throughout their lives.”

“System changes flowing from [mainstream] health reforms and initiatives across Australia provide important opportunities to improve responses to the health needs of people with disability.”
Specialised resource services would greatly assist in addressing many of the health inequality concerns identified in research and help Australia meet its commitment to equal health outcomes arising from the UN Convention on the Rights of Persons with Disabilities.

Graeme Innes
Human Rights & Disability Discrimination Commissioner

The need for Government, both Federal and State, to recognise and address the poor health status of people with intellectual disability is of prime importance, and I am writing to confirm, on behalf of the College’s Executive Committee, endorsement of the Position Statement.

Maria Tomasic, President, Royal Australian and New Zealand College of Psychiatrists

NSW organisations
The NSW Government has spelt out the need for a multi-tiered framework of action on the health of people with intellectual disability including the establishment of a statewide network of specialised intellectual disability health services to back up mainstream services. (NSW Health (2007), Development of a service framework to improve health care of people with intellectual disabilities)

The NSW Ombudsman, who review deaths of people with disability, has said that the proposed NSW framework “is critical to improve the health outcomes for this vulnerable community”. (NSW Ombudsman, Report of Reviewable Deaths in 2007)

The NSW Opposition has supported a current pilot of a new intellectual disability health service and states, “much more needs to be done in terms of meeting the health needs of people with disabilities”. (Deputy Opposition Leader Jillian Skinner 2010)

<table>
<thead>
<tr>
<th>Organisation</th>
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<td>Ability Incorporated Advocacy Service, Alstonville</td>
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<td>Ability Options, Western Sydney</td>
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<td>ACES Inc, Port Macquarie</td>
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<td>Achieve Australia, NW Sydney</td>
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<td>Action for People with Disability, Northern Sydney</td>
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<td>Aftercare</td>
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<td>ADSSI (Aged &amp; Disability Support Services), Central Coast</td>
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<td>ANGLICARE Sydney</td>
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<td>Association of Doctors in Developmental Disability</td>
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<td>AFFORD (Australian Foundation for Disability)</td>
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<td>Biala Support Services, Ballina</td>
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<td>Blue Mountains Disability Services</td>
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<td>Carers NSW</td>
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<td>CareWest, Central &amp; Far West NSW</td>
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<td>Caringa Enterprises, Grafton</td>
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<td>Catholic Care, SW and Inner West Sydney</td>
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<td>CASS Care, Campsie</td>
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<td>Central Coast Disability Network</td>
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<td>Central Coast Living Options</td>
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<td>Central Sydney GP Network</td>
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<td>Centre for Disability Studies</td>
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<td>Challenge Disability Services, Tamworth &amp; north west NSW</td>
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<td>Checkpoint parent group, Eastern Sydney</td>
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<td>Citizen Advocacy Western Sydney</td>
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<td>Coffs Harbour Support Services</td>
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<td>Community Links Wollondilly</td>
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<td>Community Options Illawarra</td>
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<td>Council on the Ageing NSW</td>
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<td>Council of Social Service of NSW</td>
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<td>Cram Foundation, Illawarra</td>
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<td>Currajong Disability Services, Parkes</td>
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<td>Dare to Aspire, clinicians for community services</td>
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<tr>
<td>Disability Advocacy NSW</td>
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<td>Disability &amp; Aged Information Service, Lismore</td>
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<td>Disability Assistance for Shoalhaven Inc</td>
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<td>Disability Enterprises, Leura</td>
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<td>Disability Information Advocacy Service, Bathurst</td>
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<td>Down Syndrome NSW</td>
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<td>Essential Personnel, South East and South West Slopes, NSW</td>
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<td>Family Advocacy, NSW</td>
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<td>Family Planning NSW</td>
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<td>Flintwood Disability Services, Western Sydney</td>
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<td>Global Disability and Health Care Services</td>
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Almost on a daily basis we experience how deficient the existing health care system is when it comes to people with an intellectual disability. I find it heartbreaking to find clients being turned away as ‘having a behaviour’ rather than being treated for an abscess, clients being treated for abdominal pain with Gaviscon only to find out later that they are having appendicitis, clients being dismissed as being difficult while suffering from moving kidney stones.

Vahida Berberovic, CEO, Windgap Foundation

Queensland organisations
AEIOU Foundation for Children with Autism
ClinedQ (Clinical Education & Training Queensland)
Endeavour Foundation
Guyrow
Health and Community Services Workforce Council
Health Consumers Network Queensland
Integrated Family & Youth Service, Sunshine Coast & Rockhampton
Mamre Association
Multicap
National Disability Services, Queensland
Parent to Parent Association of Queensland
Queensland Advocacy
Queensland Centre for Intellectual & Developmental Disability
Queensland Nurses Union
Queensland Parents for People with a Disability
Queensland Support Services & Solutions
Sherwood House Medical Practice, Innisfail
The Umbrella Group, Townsville
Town & Country Community Options, Maryborough
UnitingCare Queensland
Vulnerable Clients Program Initiative, Queensland Ambulance Service
Warrina Services, Toowoomba

SA organisations
Barkuma
Bedford Group
Health Consumers Alliance
Interwork, Adelaide

SA organisations
Orana
SHine (Sexual Health information networking & education)
SA Council on Intellectual Disability

Tasmanian organisations
Advocacy Tasmania
Nexus, Hobart
Self Help Workplace, Launceston
Speak Out Advocacy Tasmania
Tascare Society for Children
The Parkside Foundation

Victorian organisations
Annecto – the people network
Carers Victoria
Central Access, northern Victoria
Centre for Developmental Disability Health Victoria
Disability Advocacy & Information Service, Wodonga
EW Tipping Foundation
Health Issues Centre
Karingal, Geelong
Mambourin Enterprises, Western Melbourne
McCallum Disability Services, Ballarat
Vatmi Industries
Victorian Advocacy League for Individuals with Disability
Victorian Medicare Action Group
Villamanta Disability Rights Legal Service
WA organisations
Activ
Carers WA
Developmental Disability Council of WA
Down Syndrome WA
Health Consumers Council WA
Identitywa
Midway Community Care
Nulsen Association
People With Disabilities WA
SECCA (Sexuality Education Counselling and Consultancy Agency)
Valued Independent People
Western Australia Health Consumers’ Council

ACT organisations
ACT Council of Social Service
Advocacy for Inclusion ACT
Community Connections
Community Living Association
L’Arche Genesaret
Sharing Places

NT organisations
Carers NT
Down Syndrome Association NT
Integrated Disability Action
Endorsements – individuals
(continued)

Allan Fels AO
Dean, Australian and New Zealand School of Government

Paul Stein AM
Chairman, Law & Justice Foundation NSW
Former Justice, NSW Court of Appeal NSW

Bill Carter QC
Retired Supreme Court Judge & Royal Commissioner

Justice Sally Thomas AM
Supreme Court of the Northern Territory

Michael Spence
Vice Chancellor, University of Sydney

Paul Greenfield AO
Vice Chancellor, University of Queensland

Ian O’Connor
Vice Chancellor, Griffith University

Janice Reid AM
Vice Chancellor, University of Western Sydney

Ross Milbourne
Vice Chancellor, University of Technology, Sydney

Sandra Harding
Vice Chancellor, James Cook University

Justin Beilby
Dean of Health Sciences, University of Adelaide

Nicholas Glasgow
Dean of Medicine and Health Sciences, ANU

Ian Puddey
Dean of Medicine, Dentistry & Health Sciences, University of WA

Bruce Robinson
Dean of Medicine, University of Sydney

Gwynnnyth Llewellyn
Dean of Health Sciences, University of Sydney

Allan Cripps
Pro Vice Chancellor (Health) & Simon Broadley
Dean of Medicine, Griffith University

Peter Smith
Dean of Medicine, University of NSW

Ian Wronski
Pro-Vice Chancellor, Medicine, Health and Molecular Sciences, James Cook University

John Catford
Dean of Health, Medicine, Nursing and Behavioural Sciences, Deakin University

Peter Dunkley
Pro Vice Chancellor Health, University of Newcastle

Alison Jones
Dean of Medicine, University of Western Sydney

Elizabeth Farmer
Former Dean of Medicine, University of Wollongong

Christopher Peck
Dean of Dentistry, University of Sydney

Janet Greeley
Dean of Human Sciences, Macquarie University

Jill Downie
Pro Vice-Chancellor, Health Sciences, Curtin University of Technology

Margot Kearns
Pro Vice Chancellor & Dean of Nursing, University of Notre Dame Australia

People with intellectual disability suffer untreated pain and disease due to a fundamental communication barrier with doctors. It is time for the health system to break down this barrier.

Kevin Cocks, Human Rights Medallist

Philip Montgomery
Former President Royal Australasian College of Medical Administrators & Director of Medical & Health Services, Disability Services Commission, WA

Sister Angela Mary Doyle AO
Former Administrator, Mater Hospitals & Queenslander of the Year

Michael Stanford
CEO St John of God Health Care & WA Citizen of the Year 2010

Chris Sidoti
Former Australian Human Rights Commissioner

Michael McDaniel
Adjunct Professor & former Dean of Indigenous Education, University of Western Sydney
The health status of people with intellectual disabilities is appallingly low. Their health needs must take priority – by supporting training for all health providers and implementing specialist health services across Australia.

Gwynnyth Llewellyn
Dean of Health Sciences
University of Sydney
Peter Brooks AM
Director, Australian Health Workforce Institute, University of Melbourne

Leon Piterman AM
Professor of General Practice & Deputy Dean of Medicine, Nursing and Health Sciences, Monash University

Alison Kitson
Head of Nursing, University of Adelaide

Helen McCutcheon
Head of Nursing & Midwifery, University of South Australia

Gerald Farrell
Head of Nursing, La Trobe University

Denise Fassett
Head of Nursing and Midwifery, University of Tasmania

Maxine Duke
Head of Nursing and Midwifery, Deakin University

Elaine Duffy
Head of Nursing, Midwifery & Indigenous Health, Charles Sturt University

Iain Graham
Head of School of Health and Human Sciences, Southern Cross University

Andrew Cashin
Professor of Nursing, Southern Cross University

Chris Mitchell
Former President, Royal Australian College of General Practitioners

Susan Hayes AO
Professor of Behavioural Sciences in Medicine, University of Sydney

Patricia O'Brien
Professor of Disability Studies, University of Sydney & former Director, National Institute for Intellectual Disability, Trinity College, Dublin

Tammy Jennings & Mark Parnell
Greens MLCs, South Australia

Michelle Stagg and Dell Stagg, Parent advocate and President, SA Council on Intellectual Disability

Jan May OAM
Parent advocate

Jackie Softly
Parent advocate and former Chair, Ministerial Advisory Committee on Disability, WA

John Entwistle
Parent advocate, GP and former member, National Disability Advisory Council

Grant Lindsay, Donna Rousham and Esther Tan, Parent advocates, Northern Territory

John Homan,
Parent advocate and inaugural Member, Disability Council of Queensland

Maria Circuit
Parent advocate and former Chair, NSW Council for Intellectual Disability

Pam Morris
Parent advocate

Antonia Scott
Former President, Down Syndrome NSW & Lecturer in Dentistry

Chris Cunneen
Professor of Criminology, Cairns Institute & School of Law

Neil Preston OAM
CEO, Greenacres Disability Services, NSW

Robert Yeoh AM
Former President, Alzheimer's Australia

Adrian Sleigh
Professor, National Centre for Epidemiology & Population Health, ANU

Kim Oates AM
Professor of Paediatrics & former CEO, Children's Hospital at Westmead

John O'Donnell
CEO, Mater Health Services, Brisbane

Helen Beange AM
Clinical Professor of Medicine

Brendan Crotty
Head of School of Medicine, Deakin University

Haydn Walters
Professor of Medicine, Universities of Tasmania & Notre Dame Australia

Geoff Mitchell
Professor of General Practice & Head, MBBS Program Ipswich, University of Queensland
Michael Field  
Associate Dean, Sydney Medical School

Bronwyn Hemsley  
Postdoctoral Fellow (Public Health), University of Queensland

Kathy Ellem  
Parent Advocate and Postdoctoral Research Fellow, University of Queensland

James Morton  
Haematologist & Oncologist, Founder, AEIOU Foundation

Elona Lang OAM  
Disability service manager

Ian Dempsey  
Associate Professor of Education & Editor, Journal of Intellectual & Developmental Disability

Lita Mathews  
Disability service manager, Western NSW

Keith McVilly  
Associate Professor in psychology, Deakin University

Sharon Friel  
Associate Professor in epidemiology, ANU & Former Director, Global Health Equity Group, University College London

*Endorsements as at 7 March 2011*