



NATIONAL COUNCIL ON
Intellectual
DISABILITY

National and NSW
Councils for
Intellectual Disability



Australian Association of
Developmental Disability Medicine

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.**

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Endorsements - individuals

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Michael Kidd AM
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Former President, Royal Australian College of
General Practitioners

Kevin Cocks
Director, Queensland Advocacy Inc
Human Rights Medallist

Fiona Stanley AC
Director, Telethon Institute for Child Health
Research
Australian of the Year 2003

Stephen Leeder AO
Director, Australian Health Policy Institute

Jeanette Moss AM
Parent advocate

Bill Carter QC
Retired Supreme Court Judge & Royal
Commissioner

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Emeritus Professor of Community Medicine &
former Federal Health Minister

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Primate of the Anglican Church of Australia

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Vice Chancellor, University of Newcastle & former
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Robert Strike
President, Self Advocacy Sydney,
Lifelong Achievement Award, National Disability
Awards 2009

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Ron McCallum AO
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with Disabilities &
former Dean of Law, University of Sydney

Tony Fitzgerald AC QC
Former Royal Commissioner,
President Queensland Court of Appeal &
Justice NSW Court of Appeal

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

Justice Sally Thomas AM
Supreme Court of the Northern Territory

National Health and Hospitals Reform Commission final report 2009

People with intellectual disabilities “face stark health inequalities”. “Many of our reform recommendations ... will assist”.

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

Pre-election promise

“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.i)

David Richmond AO
Former chief executive of agencies including
NSW Health & the Olympic Coordination
Authority

Ron Mulock AO
Former Health Minister & Deputy Premier,
NSW

John Hannaford
Former Health & Community Services
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Paul Bauert,
Director Paediatric Services Royal Darwin
Hospital & President AMA NT

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

Kevin Stone
Parent advocate & Executive Officer, Victorian
Advocacy League for Individuals with Disability

Margaret Ward
Parent advocate & former Deputy Chair,
Disability Advisory Council of Australia

Bruce Tonge
Professor of Psychological Medicine & Head
of the School of Psychology, Psychiatry and
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Philip Mitchell AM
Professor and Head, School of Psychiatry,
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Stewart Einfeld
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Parent Advocate

Peter Brooks
Director, Australian Health Workforce Institute,
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Richard Bruggemann
Professorial Fellow in Disability Studies & former
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Errol Cocks
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Trevor Parmenter AM
Professor of Developmental Disability Studies &
past President, International Association for the
Scientific Study of Intellectual Disabilities

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

Guy Hamilton AM
Former head of intellectual disability services,
Western Australia

John Taplin
Professor of Psychology, University of Adelaide

Eileen Baldry
Justice Medallist & Associate Dean, School of
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Helen Beange AM
Clinical Professor of Medicine

Roger West
Former President, Guardianship Tribunal, &
Community Services Commissioner NSW

Adrian Sleight
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Michelle Howard
Public Advocate - Queensland

Malcolm Schyvens
Past President, Law Society of Tasmania

Jeremy Ward
Parent advocate & former Director,
Queensland Advocacy Inc

Kim Oates AM
Professor of Paediatrics & former chief
executive, the Children's Hospital at
Westmead

Margaret Colville AM
Deputy Public Guardian of Tasmania

Philip Montgomery
Executive Director, Royal Perth Hospital &
former Director of Medical & Health Services,
Disability Services Commission, WA

John O'Donnell
CEO, Mater Health Services, Brisbane

Mark Ierace SC
Senior Public Defender, NSW

Faye Druett
Former Deputy Chair of People with Disability
Australia & Disability Council of NSW

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

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

Leon Piterman AM
Professor of General Practice
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Susan Hayes AO
Professor of Behavioural Sciences in
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Jan May OAM
Parent advocate

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

Patricia O'Brien
Professor of Disability Studies, University of
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Maria Circuit
Parent advocate and past Chair, NSW Council
for Intellectual Disability

Chris Cunneen
Professor of Criminology & member, Crime &
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Pam Morris
Parent advocate

Neil Preston OAM
CEO, Greenacres Disability Services, NSW

Michael Field
Associate Dean, Sydney Medical School

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

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

National organisations

Ability First Australia

Association of Genetic Support of Australasia

Australian Council of Social Service

Australian Federation of Disability Organisations

Australian Healthcare & Hospitals Association

Australian Society for Special Care in Dentistry

Australasian Society for the Study of Intellectual Disability

Baptist Union of Australia

Best Buddies Australia

Cancer Council Australia

Dietitians Association of Australia

Disability Advocacy Network Australia

Doctors Reform Society

Health Consumers of Rural & Remote Australia

Life Without Barriers

Lifestyle Solutions Australia

National Disability Services

National Ethnic Disability Alliance

National Rural Health Alliance

People with Disability Australia

Prader-Willi Syndrome Association of Australia

Professional Association of Nurses in Developmental Disability Australia

Public Health Association of Australia

Royal Australasian College of Physicians

Royal Australian College of General Practitioners

Rural Doctors Association of Australia

Sexual Health & Family Planning Australia

St Vincent de Paul Society National Council

The Smith Family

Williams Syndrome Association

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

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

NSW organisations

Ability Options, Western Sydney

Achieve Australia, NW Sydney

Action for People with Disability, Northern Sydney

Aftercare

ANGLICARE Sydney

Association of Doctors in Developmental Disability

Blue Mountains Disability Services

Carers NSW

CASS Care, Campsie

Central Coast Disability Network

Central Coast Living Options

Central Sydney GP Network

Centre for Disability Studies

Checkpoint parent group, Eastern Sydney

Community Links Wollondilly

Council on the Ageing NSW

Council of Social Service of NSW

Cram Foundation, Illawarra

Disability Advocacy NSW

Disability Enterprises, Leura

Disability Information Advocacy Service, Bathurst

Down Syndrome NSW

Family Advocacy, NSW

Family Planning NSW

Flintwood Disability Services, Western Sydney

Global Disability and Health Care Services

Greenacres Disability Services, Wollongong

Hunter Carers for Intellectual Disability

IDEAS, Tumut

Interaction Disability Services, Western Sydney

Intellectual Disability Rights Service

Jewish Care Sydney

Macarthur District Temporary Family Care

McCall Gardens Community, Western Sydney

Mai-Wel Group, Hunter Region

Martin and Associates, Disability Clinicians

Mater Dei, Camden

Multicultural Disability Advocacy Association

New Horizons Enterprises

Northcott Disability Services

Northside Enterprises

NSW Bar Association

NSW Nurses Association

Parents without Partners NSW

PATH (Penrith Association for People with Disabilities)

Public Interest Advocacy Centre

SEE Foundation, Western Sydney

St George & Sutherland Community College – Disability Options NSW

Shopfront Youth Legal Centre

Sunnyfield Association

Sylvanvale Foundation
The Disability Trust, Illawarra

The Housing Connection, Northern Sydney

UnitingCare Disability, NSW

UnitingCare NSW ACT

Valmar Support Services, South Western Slopes

Waverley Community Living Program

Wesley Disability Services

Western Sydney Intellectual Disability Support Group

Windgap Foundation, Eastern Sydney

Youth Justice Coalition

Other state and local organisations

Advocacy for Inclusion ACT

Centre for Developmental Disability Health
Victoria

Developmental Disability Council of WA

Down Syndrome Association NT

Down Syndrome WA

Health Consumers Network Queensland

Identitywa, WA

Nexus Inc, Hobart

Nulsen Haven Association, WA

Mambourin Enterprises, Western Melbourne

Parent to Parent Association of Queensland

People With Disabilities WA

Queensland Centre for Intellectual &
Developmental Disability

Queensland Nurses Union

Queensland Parents for People with a
Disability

Sherwood House Medical Practice, Innisfail

Self Help Workplace, Launceston

South Australia Council on Intellectual
Disability

Speak Out Advocacy of Tasmania

Tascare Society for Children, Hobart

Town & Country Community Options,
Maryborough

Victorian Advocacy League for Individuals
with Disability

Victorian Medicare Action Group

Endorsements as at 10 May 2010