



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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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

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Primate of the Anglican Church of Australia

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Robert Strike
President, Self Advocacy Sydney &
Chair, NSW Council for Intellectual Disability,
Lifelong Achievement Award, National Disability
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Richard Bruggemann
Professorial Fellow in Disability Studies & former
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Paul Bauert,
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Ron Mulock AO
Former Health Minister & Deputy Premier, NSW

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

Peter Baume AC
Emeritus Professor of Community Medicine &
former Federal Health Minister

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

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

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)

Chris Sidoti
Former Australian Human Rights Commissioner

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

Leon Piterman AM
Professor of General Practice
& Deputy Dean of Medicine, Nursing and
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Guy Hamilton AM
Former head of intellectual disability services,
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Reverend Jim Colville AM
Parent Advocate

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Philip Montgomery
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former Director of Medical & Health Services,
Disability Services Commission, WA

Helen Beange AM
Clinical Professor of Medicine

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

Malcolm Schyvens
Past President, Law Society of Tasmania

Jeremy Ward
Parent advocate & former Director,
Queensland Advocacy Inc

Adrian Sleight
Professor, National Centre for Epidemiology &
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Margaret Colville AM
Deputy Public Guardian of Tasmania

John O'Donnell
CEO, Mater Health Services, Brisbane

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

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

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

Adrian Keller
Chair, NSW Branch, Royal Australian & New
Zealand College of Psychiatrists

Stewart Einfeld
Professor of Mental Health
University of Sydney

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

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

Jan May OAM
Parent advocate

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 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

National organisations

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

Cancer Council Australia

Dietitians Association of Australia

Disability Advocacy Network Australia

Doctors Reform Society

Health Consumers of Rural & Remote Australia

National Disability Services

National Ethnic Disability Alliance

National Rural Health Alliance

People with Disability Australia

Professional Association of Nurses in Developmental Disability Australia

Public Health Association of Australia

Royal Australian College of General Practitioners

Rural Doctors Association of Australia

Sexual Health & Family Planning Australia

St Vincent de Paul Society National Council

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
Australian Human Rights Medallist

State and local organisations

Ability Options, Western Sydney

Advocacy for Inclusion ACT

Association of Doctors in Developmental Disability

Centre for Developmental Disability Health Victoria

Central Sydney GP Network

Centre for Disability Studies, Sydney

Checkpoint parent group, Eastern Sydney

Council of Social Service of NSW

Developmental Disability Council of WA

Disability Enterprises, Leura NSW

Down Syndrome Association NT

Family Advocacy, NSW

Family Planning NSW

Flintwood Disability Services, Western Sydney

Global Disability and Health Care Services

Health Consumers Network Queensland

Intellectual Disability Rights Service, NSW

McCall Gardens Community, Western Sydney

Multicultural Disability Advocacy Assn NSW

Nexus Inc, Hobart

Nulsen Haven Association, WA

Parent to Parent Association of Queensland

Parents without Partners NSW

Public Interest Advocacy Centre, NSW

Queensland Centre for Intellectual & Developmental Disability

Queensland Nurses Union

Queensland Parents for People with a Disability

Sherwood House Medical Practice, Innisfail

South Australia Council on Intellectual Disability

Speak Out Advocacy of Tasmania

Town & Country Community Options,
Maryborough

Victorian Advocacy League for Individuals
with Disability

Victorian Medicare Action Group

Waverley Community Living Program, NSW

Western Sydney Intellectual Disability Support
Group

Endorsements as at 23 November 2009