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.

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

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
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)

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”.

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

Helen Beange AM  
Clinical Professor of Medicine

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

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

Michelle Howard  
Public Advocate - Queensland

Malcolm Schyvens  
Past President, Law Society of Tasmania

Jeremy Ward  
Parent advocate & former Director, Queensland Advocacy Inc

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

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

Margaret Colville AM  
Deputy Public Guardian of Tasmania

John O’Donnell  
CEO, Mater Health Services, Brisbane

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

Mark Ierace SC  
Senior Public Defender, NSW
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

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

- Ability First Australia
- 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
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
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 24 March 2010