



National and NSW Councils
for Intellectual Disability
&
Australian Association of
Developmental Disability Medicine

**Proposal for specialised services to enhance the
capacity of the mainstream health system to provide
equitable and cost effective health care to people with
intellectual disabilities**

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Summary

There are over 300,000 people with intellectual disabilities in Australia. Their health status is well researched and poor. They have very high rates of health problems and only 29% of health conditions were diagnosed and appropriately treated. Life expectancy is reduced by up to 20 years.

There is a range of 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 people with intellectual disabilities being excluded from health promotion campaigns.

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.

Government needs to take action to provide equity in health care for people with intellectual disabilities.

This proposal advocates the funding of a network of specialised services focused on the health care of people with intellectual disabilities. These services would comprise multidisciplinary teams and a network of clinical nurse consultants.

This would not be a parallel health system for people with intellectual disabilities. The proposed services would rather be a consultancy and training resource to the mainstream health system, facilitate the development of local networks and undertake research.

Development of these services would be a staged process building on the very limited specialised services that already exist. Initial steps that should be taken by 2010 are the funding of 5 health resource teams and 30 clinical nurse consultants in priority locations around Australia.

Detailed proposal

What we seek from the Commonwealth Government

This paper seeks a grant to the States and Territories:

- **aimed at** redressing the fundamental health inequity experienced by people with intellectual disabilities
- **by** the establishment of a national network of health resource teams and clinical nurse consultants who can provide specialised backup to the mainstream health system.

The author organisations

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

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

Poor health outcomes

There are **over 300,000 people** with intellectual disabilities in Australia. This is a similar proportion of the population as Aboriginal people and with similarly poor health. (Royal Australian College of General Practitioners 2006)

Recent Australian research has shown:

- In Northern Sydney, 42% of medical conditions went undiagnosed in people with intellectual disabilities and half of the diagnosed conditions were inadequately managed. That is, **only 29% of conditions were diagnosed and properly treated.** (Beange & others 1995)
- **Hypertension was twice the level in the general population** but had only been diagnosed in 32% of cases. (Beange & others 1995)
- **Obesity in 25% of women**, three times the level in the general population. (Stewart & others 1994) This would suggest that, across Australia, there are at least 45,000 women with intellectual disabilities who are obese, and therefore at greatly increased risk of diabetes and hypertension, and increased risk of heart disease, cancers and osteoarthritis.
- **Dental disease up to seven times more frequent** than in the general population. (Scott & others 1998) For example, 15.5% - indicating 46,500 across Australia- had severe periodontal disease, which often leads to loss of teeth and the need for dentures.
- Psychiatric disorders in people with intellectual disability are frequently undiagnosed and inappropriately treated. Specifically, **only 20% of people with depression or bipolar disorder were receiving anti-depressants or mood stabilisers while 80% were receiving antipsychotic medication.** (Torr 1999. See also Senate Select Committee on Mental Health 2006)
- **Lower life expectancy** of a person with an intellectual disability than the general population, twenty years lower for people with severe disabilities. (Bittles & others 2002)

This situation arises from a range of factors:

- **Difficulties in communication** between patient and health professional. An intellectual disability often involves major limitations in verbal communication.
- **Complex ranges of health problems.** In her 21 years, Vivian has had a range of conditions that many specialists found very hard to diagnose – a potentially fatal spinal dislocation; a baby sized build-up of blood in her uterus due to her having no vagina; and dementia that was ultimately found to be reversible and perhaps associated with undiagnosed lupus and her anti-epileptic medication. (See case study below.)
- **Diagnostic overlay** - the mistaken assumption that symptoms flow from the disability. For example, specialists saw declines in Vivian's mobility and continence as caused by her Down syndrome. Greg's restlessness in intensive care was seen as a product of his disability and he was heavily sedated with a massive negative reaction, whereas he turned out to have a visible sinus on his buttock. (See case studies below.)
- **The health system often does not allow for the time** a professional needs to spend with a person with an intellectual disability.
- **Health promotion, campaigns and research** tending to ignore people with intellectual disabilities.
- **Inadequate skills and multidisciplinary focus in the health and disability services systems.** With Vivian, a particular doctor with unusual expertise in intellectual disability has played a key role in seeking out correct diagnoses and treatment. With Danielle, it was only an intellectual disability health clinic that suspected that Danielle had osteoporosis after she had two fractures to her pelvis in two months – she was only 37, had no history of significant trauma and was on an anti-epileptic which increases the risk of osteoporosis. Her osteoporosis is now being treated.
- **Values** – many members of society, including some health professionals, do not attach the same value to people with intellectual disabilities as to other people.

Vivian (not her real name) is a fun loving 21 year old woman who has Down syndrome. Through her childhood, she had a succession of unusual health conditions which specialist doctors found it very difficult to diagnose and properly treat:

At age 5, following a throat infection, Vivian developed pain and stiffness in her neck. Her condition gradually deteriorated over a few weeks and she saw various specialist doctors. Finally, an orthopaedic surgeon recognised a 12 mm dislocation at the top of her spine. A jolt could have killed her. She was in hospital for four weeks and in traction for one week before her spine had repositioned enough to do the necessary spinal fusion operation. The spinal dislocation had been misdiagnosed as unproblematic Atlanto-Axial instability which can accompany Down syndrome. Specialists had also mistakenly seen her reduction in mobility and loss of continence as caused by her Down syndrome.

When Vivian was 12, she complained of stomach and back pain. She put on weight and her condition deteriorated. She saw 13 specialist doctors over two years and had many investigations. Her deterioration led to her moving from a mainstream school to a special school which she hated. Finally, a specialist ordered an ultrasound of her uterus which showed a body of blood the size of a baby. Vivian was found to have no cervix or vagina (a rare condition called Rokitanski Syndrome) . She had urgent surgery and a hysterectomy at the age of 14.

Vivian was depressed after this experience. Her mother (herself a health professional) suspected she also had lupus which may be more common in a person with Down syndrome. Over the next few years, she was diagnosed as having a psychosis, epilepsy and then dementia. The stigma of a mental illness had a major effect on Vivian's self esteem and social life. She was given various psychotropic and anti-epileptic medications. She lost her speech and many skills. Finally a rheumatologist did diagnose Vivian with lupus and said that it may have caused depression and seizures. Also, the Epilim that Vivian was taking can occasionally cause reversible dementia, and depression can create the impression of dementia. With the treatment of her lupus and big reductions in medications, Vivian has recovered from her "dementia". She is talking and joking again and relearning lots of skills.

In each case, a particular doctor with unusual expertise in intellectual disability played a vital role in helping Vivian's parents to weigh up all the specialist advice they were getting and locate specialists who were ultimately able to correctly diagnose Vivian's health problems.

Vivian's health problems have had an enormous emotional and financial impact on her family, including a major negative effect on their capacity to work.

Cost of the status quo

As well as the **human and financial costs** of poor health for people with intellectual disabilities and their families, there is considerable financial cost to the health and disability services systems and the economy generally:

- **Cost of treatment** of avoidable conditions and conditions that are diagnosed late, including hospitalisation, intensive care, medications.
- Cost of mistaken and inadequate diagnosis and treatment.
- Cost to the disability services system from **increased support needs** flowing from avoidable conditions.
- **Cost to the economy and the social security systems** of parents needing to leave the workforce or reduce their work to care for their son or daughter.

For example, the late diagnosis of Greg's pneumonia cost government well over \$60,000 in hospital costs and special 1:1 disability services care. Christine's pneumonia and chronic lung disease resulted from a hospital not acting to meet the risk of her pulling out her nasogastric tube with an immediate cost to the hospital system of over \$40,000.

Greg (not his real name) is a strong and healthy young man with a full and active life. He has an intellectual disability and no speech. He was ill and saw a GP three times in a week. He was diagnosed as having a cold and then, when he could not walk, vertigo. That day, his mother insisted on taking him to hospital where he was X-rayed and found to have such severe pneumonia that he went into respiratory collapse the next day. Greg was fully ventilated in intensive care for five weeks and remained in hospital for a further three weeks.

Cost to Government:

- *Eight weeks in major hospitals – At least \$53,000, probably much more.¹*
- *Air ambulance cost.*
- *Disability services staff 1:1 24 hours for three weeks in hospital, well over \$10,000.²*
- *Extra staff member in group home for nine days recuperation period.*

While in hospital, Greg was very restless. Doctors mistakenly assumed that this was because of his disability – an example of “diagnostic overlay”. Seven different psychoactive medications were tried to address Greg’s restlessness, two with massive negative reactions. His mother then correctly suggested that he had a pilonidal sinus on his buttock causing great pain and the restlessness. With Greg unable to explain his restlessness, he should have had a very thorough physical examination which would have shown the sinus.

Christine (not her real name) is a determined middle aged woman with an intellectual disability and great sense of humour. She uses a few signs but has no speech. She has a history of chest infections, bowel obstructions and anxiety. Chris was admitted to a regional hospital on a Monday with diarrhoea and vomiting, including vomiting whole food that she had eaten three days before. She continued to persistently vomit and was very upset.

On the Wednesday morning, a bowel obstruction was diagnosed and a nasogastric tube was inserted to drain Chris’s stomach. Her guardian and group home staff warned the hospital that she would not understand or tolerate the tube and suggested sedation. No action was taken. Chris pulled out the tube, aspirated much of the contents and contracted severe aspiration pneumonia. She was moved to intensive care in a major hospital and spent four weeks in intensive care, nearly all of the time on a ventilator. She was then moved to a high dependency ward where she spent a further three weeks recovering from the pneumonia.

Early in the period in intensive care, Chris also had surgery for the bowel obstruction and recovered quickly from that. Her stay in hospital was extended by about six weeks by the pneumonia. Also, the pneumonia has left her with chronic lung disease.

Cost to the government from Chris’s pneumonia – conservatively \$40,000 for six extra weeks in hospital.³ There will also be the ongoing cost of treatment of Chris’s chronic lung disease and the illnesses this makes her vulnerable to.

¹ The average cost per patient day in a teaching hospital where Greg spent five weeks, was \$1,020. Greg was then in another large Sydney hospital for three weeks, average cost per patient day \$832. (Australian Institute of Health and Welfare 2005, Table 4.2). This indicates a total cost of \$53,172. However, the cost of Greg’s hospitalisation was presumably much higher because he was ventilated in intensive care for five weeks.

² The cost was \$10,080 plus penalty rates based on pay scales for a residential support worker.

³ The average cost per patient day in a large major hospital was \$832. (Australian Institute of Health and Welfare 2005, Table 4.2). This indicates a base total cost of \$34,944. However, the cost of Chris’s hospitalisation would have been much higher because she was in intensive care for four weeks and then had a special assistant in nursing with her all the three weeks she was in the high dependency unit.

Human rights context

The poor health care experienced by people with intellectual disabilities sits in **stark contrast** to the UN Convention on the Rights of Persons with Disabilities which Australia ratified in July 2008. Article 25 of the Convention states:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Action required

There is growing and authoritative national and **international recognition of the need for a complementary mix of strategies** to address the poor health status of people with intellectual disabilities. (NHS Health Scotland 2004, Meijer, Carpenter & Scholte 2004, US Department of Health and Human Services 2002, International Association for the Scientific Study of Intellectual Disability 2002, Department of Health UK 2001, Disability Rights Commission 2004, Special Olympics 2005.)

Strategies needed in Australia include:

- Specify that all health reform initiatives need to take account of and respond to the health care needs of people with intellectual disabilities.
- Benchmarks in the Australian Health Care Agreements.
- Enhanced focus on people with intellectual disabilities in health promotion.
- Enhanced skills across the health workforce.
- Enhanced availability of free and multidisciplinary health care from professionals with the time required for adequate assessment and treatment.
- Specialised intellectual disability health professionals who can act as a consultancy, training and research resource to the mainstream health system
- Enhanced hospital care, including access to day admission for patients needing multiple tests/ procedures under anaesthetic.
- Clear allocations of responsibility between disability and health departments.
- Access to mental health services trained in diagnosis and management of psychiatric disorders in this population.
- Enhanced research on the health of people with intellectual disabilities, in both mainstream and specialised research.
- Yearly measurement/publication of health status of this population

The establishment in 2007 of Medicare items for annual health assessments of people with intellectual disabilities was an important national acknowledgment of the specific health needs of this group. There has also been a range of limited initiatives in States and Territories.

Priority action

The top priority should be development of **specialised resource services** in the health care of people with intellectual disabilities.

Specialised services are needed because:

- Appropriate diagnosis and treatment of health conditions in people with intellectual disabilities is often very challenging and requires access to specialised knowledge and skills.
- Health workers do not tend to see training to assist them in meeting that challenge as a priority. For most, only about 2% of their patients will have an intellectual disability. Local networks and skills will not be developed unless someone is driving that process on an ongoing basis.
- There is an established body of expert knowledge about health care of people with intellectual disabilities (IASSID 2002; Lennox and others 2005) but there are currently extremely limited systems for patients and mainstream health professionals to access professionals who have this expertise.

These specialised services would **not be a parallel health system** for people with intellectual disabilities. They would rather be a resource to the mainstream health system.

The specialised services should comprise:

1. **Intellectual disability health resource teams** – A multidisciplinary team in each health area that can:
 - **Undertake diagnostic assessments** of the health care needs of some individuals with complex medical conditions. This would be **on referral**

from the patient's general practitioner who would retain responsibility for the patient's ongoing treatment.

- **Provide advice and training** to mainstream doctors and other health and disability professionals on health promotion and health care of people with intellectual disabilities.
- **Foster the development of better local networks** of GPs, other primary health workers, health specialists and disability service workers.
- **Facilitate referrals to mainstream** specialist doctors and other health professionals.
- **Undertake research and academic teaching** on health needs and optimal treatment approaches.

A multidisciplinary focus is very important because of the range of skills that are often required to assess complex health needs. Also, a multidisciplinary approach is much more calculated to produce a holistic health management plan for an individual, an active health promotion approach, and development of skilled local networks.

Each team would include at least one doctor (such as a general practitioner with expertise in the area). Each team should also include professionals in nursing, dietetics, speech pathology, physiotherapy, occupational therapy, psychology, alcohol and other drugs, dentistry, neurology and psychiatry. Other specialists should be available as needed also. Professionals should either be on the staff of the team or be available to it as needed.

There should be a central team in each State/ Territory with a research, academic and leadership role with the other teams. There is a range of options as to where teams should be placed in the health and tertiary education structures, including scope to build on existing structures.

The structure of the teams would vary from region to region. For example, in some rural areas, the team might comprise a clinical nurse consultant, a part-time local doctor and access to local allied health staff and medical specialists, with ongoing training and consultancy from the State's central team. In major population centres, there would be a clearer need for full-time and dedicated staff positions.

2. **A network of clinical nurse consultants** - There should be a national network of clinical nurse consultants focused on the health needs of people with intellectual disabilities. Their role should include both **facilitating high quality health promotion and care for individuals with complex needs and development of local skills and networks** in the health and disability service systems. The balance of these roles could vary with local needs, in particular whether there is an intellectual disability health resource team driving local change. The NSW Department of Ageing, Disability and Aged Care has successfully trialled a model focused primarily on health care planning for individuals.

These services would have a **full lifespan focus but would initially give highest priority to adults** who are particularly poorly served by the existing health system. The problems are not as great for children who have access to paediatricians, some of whom specialise in developmental paediatrics.

The resource services would **not be a step back to the medical model of intellectual disability**. The role of health services is to maximise the health of

people with intellectual disabilities, not to move back towards a system where an intellectual disability was seen as a health condition and where health professionals were seen as the leaders in provision of disability support services. A key ingredient of the services would be that they be staffed by health professionals with a positive values base focused on people with intellectual disabilities as equal and fully participating members of society – so that staff are able to act as role models and educators on these issues for other health professionals.

Danielle (not her real name) lived at home with her ageing parents. She is a central part of her family and enjoys housework and outdoor activities. She has an intellectual disability, severe epilepsy and bipolar disorder.

When Danielle was 37, she complained of pain in her pelvis and said that she could not walk. Her father took her to her to hospital. The doctor in casualty said she was just playing up as part of her disability. When she did not improve, her father took her to her GP and then back to hospital and insisted on an x-ray. She had a fractured pelvis. Two months later, she was again in pain and an x-ray revealed another fracture in the pelvis. Danielle had two months of bed rest with the fractures, needing full care from her elderly father.

Danielle's father took her to an intellectual disability clinic. The doctor there knew that her anti-epileptic medication increased her risk of osteoporosis. The doctor obtained a bone density scan which confirmed that she had severe osteoporosis which caused the fractures. Danielle now receives regular drug infusions to treat the osteoporosis.

In view of Danielle's young age, anti-epileptic medication and no history of significant trauma, a bone density scan should have been done after her first fracture. The second fracture might then have been avoided.

Note – The cases used to illustrate this proposal are stark. There are also many significant but less dramatic examples occurring around Australia from day to day and week to week.

Initial proposed steps

Development of the specialised resource services would be a **staged process building on existing specialised services**. A small number of these has developed in some States and in a piecemeal and often ad hoc manner. Existing services would provide a foundation of expertise to train and support staff of new services.

Initial proposed **steps that could be taken by 2010** are:

- Establishment of five new health resource teams in a range of priority locations.
- Establishment of thirty clinical nurse consultant positions, again in a range of priority locations around Australia.
- These new services could be supported by existing specialised services (and financial provision should be made for this). Telemedicine could assist to provide some consistency of national coverage.

These initial steps would be evaluated to guide the roll-out of further services.

Cost of the proposed services depends on a range of factors, including the capacity to claim on Medicare for some services, and the extent to which the time of existing State and Territory health and disability services staff can be devoted to the proposed teams.

Some indicative figures:

- Core funding of Centre for Developmental Disability Health in Melbourne, \$900,000.
- Core funding of Queensland Centre for Intellectual and Developmental Disability, \$800,000.
- Remuneration package for clinical nurse consultant \$83,304-\$93,516. Plus 5-10% on costs.

The **cost of these proposals should be readily offset** by the savings to the health and disability service systems of better health and avoidance of major illness. There is also a striking potential for savings in human and financial costs to people with intellectual disabilities and their families.

Existing government and community support for this proposal

“Labor does recognise that people with intellectual disabilities are disadvantaged in the health system. Many people require consultations well beyond the usual time of GP visits.In many situations, GPs and other **health professionals require access to specialist advice** to provide the health services people with intellectual disabilities require. Labor is committed to reform in both the health and disability sectors.The health of people with disabilities needs to be part of both reform plans.” (Shadow Ministers Nicola Roxon and Jan McLucas, letter to NCID and AADDM 23 November 2007)

The **NSW Government** has recently spelt out the need for multi tiered action on the health of people with intellectual disabilities, ranging from improved primary care through to the establishment of a statewide network of specialised intellectual disability health services to back up mainstream services. (NSW Health 2007). The NSW Minister for Health has approved this framework in principle and a business case to advance it is currently being prepared. However, this business case will need to compete with many other priorities for NSW Government funding.

The NSW framework was the subject of a **consultation process** in 2006. This process showed **almost universal support** for the need for specialised intellectual disability health resource services, from:

- The disability community, for example the Down Syndrome Association NSW, the Spastic Centre, the Multicultural Disability Advocacy Association, Disability Council of NSW.
- Professional associations, for example the Royal Australian College of General Practitioners, the Royal Australian College of Physicians, Dietitians Association of Australia and the Dean of Medicine, University of Sydney.
- Other leading community groups, for example NCOSS, the Family Planning Association of NSW
- Government agencies such as the Departments of Ageing, Disability and Home Care, Community Services, Housing , Education and Training.

The **Victorian, Queensland and South Australian Governments** have also acknowledged the need for specialised services by funding one specialised centre each.

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