



Australian Association of Developmental Disability Medicine
Inc.

&

National and NSW Councils
for Intellectual Disability



**Submission to the
National Health and Hospitals Reform
Commission**

Summary of submission

Stark health inequalities

People with intellectual disabilities must be a central focus of the Commission. There are over 300,000 Australians who have intellectual disabilities. This is a similar proportion of the population as Indigenous people and “with health outcomes at least as bad”. (Royal Australian College of General Practitioners (2006)

The Australian research shows:

- Only 29% of health conditions being diagnosed and appropriately treated in people with intellectual disabilities.
- Very high rates of dental disease and both obesity and underweight.
- Life expectancy up to 20 years lower than the general population.

This stark inequality arises from a range of factors including challenges to communication between health professionals and patients, high rates and complex ranges of health problems, problems with skills and available time in the mainstream health workforce, a lack of specialised intellectual disability health services to back up the mainstream, health promotion and research tending to ignore people with intellectual disabilities, and lack of co-ordination within and between governments.

A developing recognition of the need for action

There is a growing international recognition of poor health outcomes for people with intellectual disabilities, the reasons for these and of the need for a complementary mix of strategies to address the problem. However, until very recently, there has been at best piecemeal acknowledgment of this issue by Australian governments.

Recent Commonwealth action

In 2007, the then Government put in place specific Medicare items for annual health checks for people with intellectual disabilities. This was a valuable first step which was followed by a Labor pre-election commitment:

“Labor does recognise that people with intellectual disabilities are disadvantaged in the health system. 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)

Multifaceted action is required to address this disadvantage, as has been squarely recognised by the NSW Government:

The NSW Government position

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), *Development of a service framework to improve health care of people with intellectual disabilities*)

Action required within the NHHRC Terms of Reference

Practical and cost-effective strategies are available to address the health inequalities facing people with intellectual disabilities. These strategies are based on a solid research base and/or precedents of successful local or international actions.

1) The framework for the next Australian Health Care Agreements

The *Beyond the Blame Game* report includes a benchmark on prompt diagnosis and intervention with children with a suspected disability. We are perplexed that the report does not follow this issue through the lifespan, including benchmarks in relation to key health issues for adults with intellectual disabilities.

2) A long-term health reform plan addressing the need to:

- a) reduce cost-shifting, blame-shifting and buck-passing** – There is a lack of clear responsibility for the health needs of people with intellectual disabilities and buck-passing on this issue between governmental disability services and health departments. There are various examples of largely piecemeal action around Australia that need to be built on to provide clearly stated cooperative arrangements between departments, including health departments taking primary responsibility for the health of people with intellectual disabilities.
- b) better integrate and coordinate care across all aspects of the health sector, particularly between primary care and hospital services** – There need to be enhanced communication between primary care services and hospitals, and access to day admissions for people with intellectual disabilities needing multiple tests/procedures or dental treatment under general anaesthetic.
- c) bring a greater focus on prevention to the health system; & e) improve frontline care to better promote healthy lifestyles and prevent and intervene early in chronic illness** - Health promotion campaigns need to include a focus on people with intellectual disabilities. The Medicare Benefits Schedule needs reform to remove the financial disincentive to health professionals spending extra time with patients with intellectual disabilities. GPs need more encouragement to use the Medicare annual health checks. The mainstream health system needs backup from specialised intellectual disability health services. Ongoing research is needed into health prevention and chronic disease management for people with intellectual disabilities.
- f) improve the provision of health services in rural areas & g) improve Indigenous health outcomes** – Strategies on these issues need to include the extra disadvantage of people with intellectual disabilities.
- h) provide a well qualified and sustainable health workforce into the future** – There needs to be enhanced training for undergraduates and practising health professionals, and training programs and career paths for specialised intellectual disability health professionals.

Proposed Principles

Unlike various other sources of disadvantage, there is no specific acknowledgment of intellectual disability in the proposed principles. The laudable thrust of the principles should squarely acknowledge the disadvantage faced by people with intellectual disabilities and factors that would make the principles more meaningful for this group.

The author organisations

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

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

Our collaboration seeks to improve the whole-of-life health and well-being of both adults and children with intellectual disabilities, and to enhance life decisions for their families.

Why people with intellectual disabilities must be a central focus of the Commission

There are over 300,000 Australians who have intellectual disabilities. This is a similar proportion of the population as Indigenous people and “with health outcomes at least as bad”. (Royal Australian College of General Practitioners (2006) *RACGP Budget Proposal, Medicare Benefits Schedule – Annual health assessment item for people with intellectual disability*)

The Australian research clearly shows that for people with intellectual disabilities:

- ✱ Only 29% of health conditions being diagnosed and appropriately treated. 42% of health conditions are undiagnosed **and** half of the diagnosed conditions are inadequately managed. (Beange H, McElduff A, Baker W (1995) “Medical disorders of adults with mental retardation: a population study” *AJMR* 99: 595-604)
- ✱ Obesity is up to three times the level in the general population. (Stewart L, Beange H, McKerras D (1994) “A survey of dietary problems of adults with learning disabilities in the community” *Mental Handicap Research* 7, 41-50)
- ✱ Dental disease is up to seven times more frequent than in the general population. (Scott A, Marsh L, Stokes ML (1989) “A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population” *ADJ* 43; 257-261)
- ✱ Psychiatric disorders are frequently not diagnosed and inappropriately treated. (Torr J. (1999) *The Psychiatry of Intellectual Disability: A Review of the Literature and Review of a Psychiatric Clinic for Intellectually Disabled Adults*. Department of Psychiatry, University of Melbourne)
- ✱ 42% of people who died in care were underweight and some died because of critical illnesses being untreated (Community Services Commission NSW (2001) *Disability, death and the responsibility of care* .A review of the characteristics and circumstances of 211 people with disabilities who died in care between 1991 and 1998 in NSW)
- ✱ Life expectancy is much lower than the general population, and approximately twenty years lower for people with severe disabilities. (Bittles

AH, Petterson BA, Sullivan SG, Hussain R, Glasson EJ, Montgomery PD (2002) "The influence of intellectual disability on life expectancy" *J Gerontol A Biol Sci Med Sci* 57:7; M470-M472)

The poor health status of people with intellectual disabilities arises from the interplay of various factors [1, 4-8, 25, 26]:

- Communication issues between professional and patient – capacity to communicate, training of professionals in communication techniques.
- High rates, and often complex ranges, of health problems.
- Increased risk for certain health conditions due to factors such as genetic syndromes.
- Health professionals need to spend more time with people with intellectual disabilities but the health system often does not allow for this.
- Diagnostic overlay – mistakenly assuming symptoms are related to the disabilities.
- Poverty and inadequate supply of free and subsidised health services.
- Inadequate multidisciplinary focus on health problems.
- Few health professionals having a special interest or specialised skills in intellectual disabilities.
- Many members of society attaching less value to people with disabilities.
- Health promotion, campaigns and research tending to ignore people with intellectual disabilities.
- Limited carer skills in recognising and acting on health problems.
- Inadequate cooperative action within and between governments.
- Limited or poor whole-of-life decision making and planning

The following case studies illustrate some of these factors:

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

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 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.

Christine (not her real name) is a determined middle aged woman with an intellectual disability and great sense of humour. She uses a little sign language but she 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.¹ 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 large major hospital is \$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.

The stark disadvantage in health experienced by people with intellectual disabilities calls for them to be an important focus of the National Health and Hospitals Reform Commission. Preferably, the Commission should be given a specific term of reference focused on the health of people with intellectual disabilities, as it already has on rural health and Indigenous health. In any case, people with intellectual disabilities should be a central focus of the Commission's work on its other terms of reference.

There is a growing international recognition of poor health outcomes for people with intellectual disabilities, the reasons for these and of the need for a complementary mix of strategies to address the problem. [37-42]

Solutions

Before addressing the Commission's individual terms of reference, we summarise the range of strategies that are needed to address the inequitable health and health care experienced by people with intellectual disabilities. The establishment in 2007 of Medicare items for annual health assessments of people with intellectual disabilities was an important acknowledgment of the specific health needs of this group. These Medicare items need to be complemented by [9-12, 34-42]:

1. Enhanced skills across the health workforce in the needs of people with intellectual disabilities.
2. Enhanced availability of free and multidisciplinary health care from professionals with the time required for adequate assessment and treatment.
3. Enhanced focus on people with intellectual disabilities in health promotion.
4. Specialist intellectual disability health professionals who can act as a consultancy, training and research resource to the mainstream health system. This needs to include specialist multidisciplinary centres around Australia.
5. Enhanced hospital care, including access to day admission for patients needing multiple tests/ procedures under anaesthetic.
6. Access to mental health services trained in diagnosis and management of psychiatric disorders in this population. Mandate that mental health services are to assess people with intellectual disabilities as part of meeting their funding commitments.
7. Ensure all federally funded research be required to include this population or demonstrate why they are excluded.
8. Enhanced research on the health of people with intellectual disabilities, in both mainstream and specialised research.

The Commonwealth Government commitment

“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 position

The NSW Government has recently acknowledged the need for multi tiered action on the health of people with intellectual disabilities. (NSW Health (2007), *Development of a service framework to improve health care of people with intellectual disabilities*) This paper sets out five tiers of necessary action:

Tier 1: Strategic health policy and population health

Strategies are required to improve promotion of the general health and well being of all people with an intellectual disability and their carers in all settings in the community. This includes working with communities, local councils and local health services to promote involvement of people with an intellectual disability and their carers, social inclusion and raise awareness of health issues.

Tier 2: Primary health and community health care

Strategies need to:

- improve primary intervention and early detection capacity and skills of the primary health and community care sector including the application of chronic disease prevention interventions to people with intellectual disability, and
- build capacity in the sector to provide integrated health care and support for people with an intellectual disability and their carers.

Tier 3: Acute health care services

This tier focuses on improving the capacity of the secondary health care system to care for and manage the additional health care needs of people with an intellectual disability who need to access hospital based in and outpatient services. This includes pre and post admission planning.

Tier 4: Specialist area/local health services

These services would work to support primary care services and others by providing specialist advice, assessment, interventions and treatments for complex intellectual disability health needs. Specialists would provide advice and practical support to people with an intellectual disability, their families, community health, GPs, other health and allied professionals, disability services and non-government service providers.

These services could comprise specialist Intellectual Disability Health Resource Teams and a network of Intellectual Disability Clinical Nurse Consultants.

Tier 5: Specialist state-wide clinical leadership, education, training and research

A recognised state-wide specialist centre would underpin and support the local specialist service infrastructure to provide specialist clinical advice and support to generalist primary and secondary health care services and to provide a focal point for teaching, evidence based research and advocacy initiatives. There is also a need to have better systems in place to monitor health outcomes.

The specialised tiers 4 and 5 services are needed in particular because of the complexity of properly diagnosing and treating many conditions in patients with intellectual disabilities. It is difficult for mainstream health professionals to acquire the skills needed to meet this challenge; people with intellectual disabilities are usually about 2% of their patients.

NHHRC Terms of Reference

1) The framework for the next Australian Health Care Agreements

We applaud the *Beyond the Blame Game* report except for its not acknowledging or addressing the health needs of adults with intellectual disabilities. This is a perplexing omission.

We do particularly support the identification of Ensuring a Healthy Start as one of the twelve health challenges and the proposed performance benchmarks associated with this challenge. We strongly endorse the proposed benchmark in relation to waiting times for diagnosis and intervention of children with suspected disability or developmental delay.

Solution - The clear health inequalities facing people with intellectual disabilities call for explicit acknowledgment across the lifespan, not just at early childhood. There is rightly a proposed benchmark in relation to comparative life expectancy for Indigenous people. There should be a similar benchmark for people with intellectual disabilities.

We could readily suggest a range of benchmarks for people with intellectual disabilities across the health challenges identified by the Commission or against the specific challenge of redressing the inadequate health care experienced by people with intellectual disabilities.

2) A long term health reform plan addressing the need to:

a) Reduce cost-shifting, blame shifting and buck-passing

Historically, intellectual disability was seen as a health condition and services for people with intellectual disabilities were provided by health departments, managed by doctors and largely staffed by nurses. In recent decades, it has become well accepted that intellectual disability is not an illness and services and staffing of them have

moved away from a medical model. A distinction has rightly been made between:

- Disability support services which assist people with intellectual disabilities with activities of daily living, to learn skills and to participate in the life of the community. These services are primarily the responsibility of government disability services departments.

AND

- The health services people with intellectual disabilities need to achieve standards of health similar to the general community. These are primarily the responsibility of health services in accordance with normal principles of non-discrimination on the basis of disability which are embedded in both the Disability Discrimination Act Commonwealth and local acts such as the Anti-Discrimination Act NSW.

Whilst the move away from the medical model of disability has overall been very positive for people with intellectual disabilities, it has led to buck-passing and a lack of clear responsibility in relation to health care. Health departments have been reluctant to take responsibility on the simplistic premise that there is now a separate disability department. Disability departments have tended to neglect health issues on the mistaken assumption that generic health services will adequately address the health issues of their clients. This buck passing is contributing to major health problems for people with intellectual disabilities [35].

There have been particular problems in relation to access to some general practice and specialised health services including mental health and drug and alcohol services.[36]

To seek to avoid or address these problems, there have been some positive actions by health or disability agencies, in some cases cooperative action, in others individual action, for example:

- Establishment of a small number of specialist academic and clinical centres to back up the mainstream health system, for example the Queensland Centre for Intellectual and Developmental Disability and the Centre for Developmental Disability Health in Melbourne.
- In NSW, provision of diagnostic and assessment services by specialised multidisciplinary teams, and, in some cases, provision of ongoing services to adolescents and adults with an intellectual disability
- A small number of other specialist clinics in public health establishments, for example at Royal Rehabilitation Centre, Westmead Hospital and Concord Repatriation General Hospital in Sydney.
- Disability departments developing health care policies and specific policies on issues such as nutrition – See for example, those of the Department of Ageing, Disability and Home Care NSW.

Solution - What is required nationally and in each state and territory is for health and disability departments to have clearly stated cooperative arrangements whereby the health department takes primary responsibility for appropriate health services to people with intellectual disabilities. In addition, the disability department should ensure that its systems and staff support health promotion, appropriate access to health services and ongoing health care management.

b) Better integrate care across the health sector particularly between primary care and hospital services

There is a range of problems here [13-17] including:

- Very long delays in accessing hospitals admissions for dental treatment under general anaesthetic. A significant number of people with intellectual disabilities need a general anaesthetic for dental treatment due to their resistance of treatment that they do not understand. The result can be long periods of pain whilst awaiting treatment.
- Similarly, an individual may need a day admission for multiple tests and procedures to be done under anaesthetic but these admissions tend to be very difficult to access.
- Hospitals not obtaining histories from primary health services for people who are unable to provide their own verbal history.
- Hospital being an unnecessarily distressing experience for a person with a disability, and discharge planning that does not take due account of the support needs of the person.

Solutions:

1. Enhanced access to day admission for patients needing multiple tests/ procedures or dental treatment under anaesthetic. People who cannot explain their symptoms and extent of pain should be recognised as a priority group for hospital admission.
2. Enhanced procedures for hospitals to access advice and support from, and coordinate discharge with, primary health professionals who know a patient.

c) bring a greater focus on prevention to the health system.

e) improve frontline care to promote healthy lifestyles and prevent and intervene early in chronic illness.

For people with intellectual disabilities, there is currently a very limited focus on prevention, health promotion, early intervention, and indeed, whole-of-life health planning. Persistent neglect of undiagnosed health conditions leads to overuse of emergency and hospital systems [18].

Due to the limited capacity of people with intellectual disabilities to explain symptoms and otherwise communicate with health professionals, they need longer consultations whereas the Medicare Benefits Schedule is weighted towards shorter consultations. There have been recent positive developments in the MBS including Items 718 and 719 for annual health assessments of people with intellectual disabilities by GPs, and item 132 for initial assessments of patients with complex developmental disorders by physicians. These developments should be extended into a more general acknowledgment across the MBS that health professionals need to spend more time with patients with intellectual disabilities.

It is very important that the existence and nature of an intellectual disability is diagnosed as early in childhood as possible and that the child's family then has access

to specialised advice on health care issues that may be associated with the disability. Integration across the sectors, including multidisciplinary diagnostic and assessment teams, is very important for timely diagnosis and access to support services for child and family.

Specialist children's health services, including paediatricians, are commonly accessed by children with intellectual disabilities and complex health needs. However, there is a major problem in transition to adult health care with there being very few adult doctors with specialised skills in working with people with intellectual disabilities and complex health needs. There needs to be a network of specialised intellectual disability health services to back up mainstream services across the lifespan.

Health promotion and health advocacy tools exist for people with intellectual disabilities which aim to improve and maintain wellness [19]. The Medicare items for annual health checks of people with intellectual disabilities by GPs [9] is one tool. The CHAP (comprehensive health assessment programme) tool for general practice [20] provide a process for significant increases in health promotion and screening, and increased early detection of health conditions. The CHAP can be used in the annual health check process.

People with intellectual disabilities are often excluded from health promotion and preventive strategies which require patients to present themselves and consent to services. Since the policy of deinstitutionalisation began, it is unclear who should bear the responsibility for arranging full participation in these programs for those with cognitive impairment. Every publicly funded health education and screening program should be required to include these citizens who cannot present themselves.

There is evidence of increased morbidity and mortality due to trauma in people with intellectual disabilities [3, 21-25]. To ensure safety for people with intellectual disabilities, research should encourage trials of prevention programmes. Safety and quality standards should include residents as well as staff of residential programs.

Solutions

1. Improved education for people with intellectual disabilities, their families and carers about preventative health.
2. Ensuring that all health promotion campaigns are required to include a focus on making the campaign relevant and accessible to people with intellectual disabilities.
3. Promoting the use of the Medicare assessment items and the evidence-based Comprehensive Health Assessment Program (CHAP) [20] with both providers and consumers. (In NSW, government policy requires accommodation services to use these strategies.)
4. Reforming the Medicare Benefits Schedule to recognise the longer time that doctors and other health professionals need to spend with patients with intellectual disabilities. There should not be a financial disincentive to health professionals spending appropriate time with a patient with an intellectual disability.

5. Ensuring that all GP Super Clinics include a specific focus on the health of people with intellectual disabilities through measures such as a regular clinic for people with intellectual disabilities and complex health needs.
6. Having a network of specialist multidisciplinary health teams and clinical nurse consultants who can focus on the specific health needs of people with intellectual disabilities.
7. Ensuring ready access to diagnosis and assessment services for children, including through specialist health teams, and the capacity to provide ongoing specialist services to older children and adolescents.
8. Establishing robust systems for transition of children with intellectual disabilities into adult health care.
9. Funding research into optimal prevention and chronic disease management for people with intellectual disabilities.

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.

f) improve health services in rural areas

People with intellectual disabilities in rural areas share the general disadvantage of all people in those areas. They also have particular disadvantages due to remoteness from the very limited specialised intellectual disability health services that currently exist and which are largely concentrated in metropolitan areas. There are exceptions that need to be enhanced, for example:

- In Goulbourn NSW, a GP who used to work in a specialised service has recently opened a weekly clinic to see patients with intellectual disabilities and complex health needs.
- In the New England area in north west NSW, some local GPs have developed a particular interest in people with intellectual disabilities.

Solutions

1. All strategies to improve health in rural areas need to take account of the needs of people with intellectual disabilities.
2. Enhanced access to specialised advice in relation to health problems of people with intellectual disabilities including by:
 - developing a network of specialised intellectual disability health services.
 - use of telemedicine to access advice from specialists in metropolitan areas.

g) improve Indigenous health outcomes

Indigenous people face a further disadvantage if they have an intellectual disability. Given that both Indigenous status and intellectual disability are related to very poor health outcomes, Indigenous people with intellectual disabilities are very vulnerable indeed to poor health. There is currently very limited linkage between the small number of specialised intellectual disability health services and Indigenous health services.

Solutions

1. All strategies to improve Indigenous health need to take account of the needs of people with intellectual disabilities.
2. Development of linkages between Indigenous health services and specialised intellectual disability health services.

h) provide a well qualified and sustainable health workforce

The mainstream health workforce is under skilled in communicating and working with people with intellectual disabilities. There is widespread non diagnosis, misdiagnosis and mistreatment of health conditions in this population ([26,27]). This situation could be improved by better undergraduate and continuing training of health professionals. Existing undergraduate training varies around Australia; the most extensive for medical students is at Melbourne and Monash Universities where training is coordinated by the Centre for Developmental Disability Health. In recent years, the Centre for Developmental Disability Studies in Sydney and the Royal Australian College of General Practitioners have also developed extensive continuing training materials for existing practitioners.

However, improved training for the mainstream workforce is only part of the answer; for most health professionals, people with intellectual disabilities will only be approximately 2% of their patients and so their specific needs will not be a training priority.

Mainstream health professionals need access to consultancy and training from colleagues with specialised skills in working with people with intellectual disabilities [34]. At present, there is very limited number of these specialised professionals and no clear career path or training program for them. The existing specialised professionals include some general practitioners, paediatricians, rehabilitation

specialists, psychiatrists, occupational therapists, dieticians, psychologists, physiotherapists and speech pathologists.

A current development that is an example of a way forward is the funding by the NSW Government of a Chair in Disability Mental Health – an initiative that aims to enhance workforce capacity in the provision of mental health services to people with an intellectual disability. To complement this Chair, the Government has funded the NSW Institute of Psychiatry to provide nine Advanced Psychiatric Fellowships in Disability Mental Health over three years.

The NSW Government has also acknowledged the need for a statewide network of specialised intellectual disability health services [34].

There is an ageing workforce of mental retardation nurses, most of whom work as residential care workers in large residential centres for people with intellectual disabilities. Whilst nursing qualifications are rightly no longer seen as the core requirement to be a residential care worker, nurses do have an important role in disability services to focus on the health care of clients, especially those with complex health care needs.

Solutions

1. Enhanced values based training for undergraduate and practising health professionals in the health care needs of people with intellectual disabilities.
2. Development of training programs and career paths for health professionals who specialise in the health care of people with intellectual disabilities.
3. Developing a clear role for nurses as health care professionals in disability services and ensuring an adequate workforce for this role by establishing a training program including refresher training of existing mental retardation nurses.

Proposed Principles

We applaud the thrust of the proposed principles. However, we are perplexed that, whereas various other bases for disadvantage in the health system are specifically acknowledged in the draft principles, there is not a single reference to people with intellectual disabilities whose disadvantage is so stark.

Principle 1: People and Family Centred

For this principle to be meaningful to people with intellectual disabilities, it needs to acknowledge that they need access to advocacy and other support to make choices that meet their needs. Some people will have families who can assist with this, others will not. Families also are often struggling with the day to day demands of being carers and need support if they are to be able to make meaningful health choices for a person with an intellectual disability.

Principle 2: Equity

We see it as centrally important that this principle squarely acknowledges intellectual disability as a source of disadvantage that needs to be remedied. As we have documented early in this submission, people with intellectual disabilities currently have starkly inequitable access to appropriate health care.

Principle 3: Shared Responsibility

This principle will be meaningless for many people with intellectual disabilities unless they are provided with the education and support they need to be understand and perform their responsibilities. The principle should state the health sector's responsibility to ensure this education and support.

Principle 6: Value for money

The current failure of the health system to meet the needs of people with intellectual disabilities is very expensive. 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.

Spending on health promotion, early detection and basic primary care intervention will reduce long-term dependency on the costly tertiary sector of hospital and emergency care, and this is especially the case for people with intellectual disabilities [10, 20, 28-30].

If people with intellectual disabilities undergo regular health checks and health promotion, then the health costs in terms of emergency and hospital interventions are significantly lessened. As currently stands, people with disabilities use more expensive health technologies if their basic health needs are not met by primary care intervention [31]. Whilst people with intellectual disabilities may require more time with a medical or paramedical practitioner [32], the outcome may in effect be better for long-term health and cause a concomitant decrease in health care dependency.

The following case study (and that of Christine earlier in this submission) illustrate the financial costs to government that flow from not addressing the health care needs of people with intellectual disabilities.

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 the Government:

- *Eight weeks in major hospitals – At least \$53,000, probably much more.²*
- *Air ambulance cost.*
- *Disability services staff 1:1 24 hours for three weeks in hospital, well over \$10,000.³*
- *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.

Principle 8: Broader Environmental Influences

For people with intellectual disabilities, poverty, extensive experiences of institutional life, long experiences of abuse and lack of access to adequate education have impinged on their capacity to access mainstream health services [33]. Many of the chronic diseases of people with intellectual disabilities are the result of nutritional and other environmental influences which they are unable to control. Examples include obesity and heart disease associated with junk food and lack of exercise. The principle should acknowledge these kinds of environmental influence.

² The average cost per patient day in a teaching hospital where Greg spent five weeks, is \$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.

³ The cost would be \$10,080 plus penalty rates based on pay scales for a residential support worker.

Principle 9: Taking the long term view

The prevalence of people with intellectual disabilities is increasing with the increased survival rates of premature babies. In addition, life expectancy of people generally means that they live longer than in the past and will require increasing levels of health services. The community of people with intellectual disabilities and their support networks are skilled in planning for the future and would be more than capable of assisting a visioning of health services for the future.

Principle 12: Public Voice

For people with intellectual disabilities, meaningful participation requires support and advocacy or their voices are unlikely to be heard. The principle should acknowledge this need which can be met partly by ensuring that the voice of individuals with intellectual disabilities and their families are heard, and partly by the health system listening to peak advocacy groups for people with disabilities.

Principle 13: A Respectful, Ethical System

There continues to be substantial discrimination by some health services based on the view that people with intellectual disabilities are of less value than other people. Principle 13 should acknowledge the equal value of all people and state that discrimination on the basis of disability, race etc is unethical.

Principle 15: A culture of reflective improvement and innovation

The scientific evidence behind formulas for health care for people with intellectual disabilities is growing and should be enhanced by specific research funding to develop and examine ways to improve health outcomes for people with intellectual disabilities.

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