

**SENATE COMMUNITY AFFAIRS REFERENCES
COMMITTEE
INQUIRY INTO THE FUNDING AND OPERATION OF
THE
COMMONWEALTH STATE/TERRITORY DISABILITY
AGREEMENT**

Dr Jennifer Torr

Dip Aero Eng (Dist), MB BS, MMed(Psychiatry), FRANZCP, Member FPOA,
GCHE

Senior Lecturer and Director of Mental Health

Centre for Developmental Disability Health Victoria

School of Primary Health Care

Monash University

At the hearing of the Inquiry into funding and operation of the Commonwealth State/Territory Disability Agreement in Melbourne on 28 September 2006 Professor Bigby and I were invited to make further submissions to the committee on issues related to the training of health professionals into the health care needs of people with intellectual disabilities, the provision of health care to people with intellectual disabilities and research into the health and wellbeing of people with intellectual disabilities.

In the interests of completing this submission I refer members of the committee to a number of web based resources if more detailed information is required as well as attaching copies of:

1. submission to the Senate Inquiry into Mental Health.
2. submission to Victorian Government Dementia Framework Review
3. submission to National Framework for Action on Dementia
4. 2006 teaching in Victorian medical schools

Summary/Conclusion

Health outcomes for people with intellectual disability are poor. In Australia people with intellectual disability die on average 20 plus years earlier than the general population. People with intellectual disability generally cannot take responsibility for their own health and rely on others to recognise a health problem, arrange appointments and give a history.

I have not covered issues related to policy and practice in disability funded accommodation services. The focus of disability services has been on social care. Fair enough but for a population who cannot speak for themselves, who have high rates of morbidity, unrecognised health needs and early mortality there also needs to be a coordinated approach to health involving both the disability and health sector. It is not enough to expect untrained direct support workers to identify possible health problems and navigate an often less than welcoming and untrained health system. Community nursing for community residential units would be a step in the right direction.

Until recently there was minimal teaching on intellectual disability health at the undergraduate and postgraduate medical level. Teaching in the allied health professions remains generally neglected. The establishment of academic centres in intellectual disability health in 4 states has provided the foundation for the developing field of developmental disability medicine. The academic centres have been crucial in providing and supporting the development of expertise, education of health professionals, development of importance resources, provision of clinical services and advocating for improved health outcomes for people with intellectual disabilities. Much of the “critical mass” of doctors in developmental disability medicine operate from these centres. These centres need to be supported, to be viable and to be in all states and territories.

However more than academic centres are required. There are no career options for doctors interested in developmental disability health. By career I mean a vocational focus to develop personal expertise and communal expertise in developmental disability health.

Health Outcomes for People with Intellectual and Developmental Disabilities

Health outcomes for people with developmental disabilities remain poor and average life expectancy is only 50-60 years, at best 20 years less than the general population. In 2004, people with disabilities in the care of disability services died an average of 25 years earlier than the general population (NSW Ombudsman 2005). Standardised mortality ratio for people with intellectual disability in Sydney’s North Shore is 4.8 compared with the general population (Durvasula, Beange et al. 2002).

Comorbid medical, sensory and psychiatric disorders are common and are often undiagnosed (Center, Beange et al. 1998). The NSW Ombudsman reports

Most of the disability services group had an intellectual disability in addition to at least one other disability. Besides intellectual disability, the main recorded disabilities were physical disability (47.8%, mainly cerebral palsy), sensory disability (43.5%, mainly sight impairment), and psychiatric disability (23.2%, mainly schizophrenia). The majority of disability service residents had two to three disabilities.

Furthermore in populations of people with intellectual disability living in disability service accommodation the commonly reported health conditions included epilepsy (39%), mental illness (20%), respiratory disorders not including asthma (46%), gastrooesophageal reflux (30%), diabetes (16%), hypertension (13%) etc. Of note the commonest causes of death are respiratory and circulatory disorders. For a sobering read the committee is referred to the NSW Ombudsman report of Reviewable Deaths 2004.

Diagnosis of disorders may be missed for a range of reasons

1. Communication impairment
2. Challenging behaviour
3. Atypical presentations
4. Rare disorders
5. Reliance on informant history
6. Barriers due to “privacy”
7. Lack of training of health professionals
8. Lack of experience of health professionals
9. Lack of specialist services (especially adult specialist services)
10. Systemic issues limiting access to health services
11. More time is required for assessment
12. Discriminatory practices

Academic Centres in Intellectual Disability Health

Academic centres in intellectual disability health have been established in Victoria, New South Wales, Queensland and South Australia. There are no equivalent academic centres in Western Australia, Tasmania, ACT or Northern Territory. Deinstitutionalisation of care over the last 2-3 decades has seen social care split from health care. Social care is the province of disability services whilst health care is provided by community based general practices and mainstream health services. Mainstream health has not met the special health needs of people with intellectual/developmental disabilities. The neglect begins with the training of health care practitioners. Generally these centres have been established in response to the deinstitutionalisation of care of people with intellectual disabilities and the transfer of primary health care responsibility from the institutions to general practices and mainstream health services. These centres are generally involved in the provision of clinical consultation services, education of health professionals at the undergraduate and postgraduate levels, research regarding health and health care delivery and advocacy to improve policies affecting health and well being of people with intellectual disabilities. The focus is predominantly on adults with intellectual and developmental disabilities.

The funding arrangements for these centres vary from state to state. In Victoria the Centre for Developmental Disability Health Victoria, is located within the School of Primary Health Care, Faculty of Medicine, Nursing and Health Sciences, Monash University and receives core funding and oversight from Disability Services. The funding agreement is reviewed every 3 years. The Centre for Developmental Disability Studies University of Sydney has not received core funding for a number of years and relies on project funding to continue. Of note there is a lack of initiative of health departments to address the health needs of people with intellectual/developmental disabilities.

The dedicated professionals at these centres, often accidental academics, have developed into a growing force nationally and internationally. Without the bedrock of the academic centres in intellectual disability health there would not have been the impressive development of expertise in this field over the last decade. There would

not have been the direct clinical services and support for general practitioners. Educational programs for health professionals at the undergraduate and postgraduate levels would not have been developed or delivered. There would not have been the expertise to write the management guidelines book. The Australian Association for Developmental Disability Medicine would not exist. There would have been less advocacy for improving policies relating to the provision of health services to people with intellectual and developmental disabilities.

I recommend members of the committee visit the websites of these centres for an overview of activities and achievements.

Centre for Developmental Disability Health Victoria

<http://www.cddh.monash.org/>

Centre for Developmental Disability Studies

<http://www.cdds.med.usyd.edu.au/>

Queensland Centre for Intellectual

<http://www.uq.edu.au/qcidd/>

Centre for Intellectual Disability Health

Does not yet have a website

Teaching Program of the Centre for Developmental Disability Health Victoria

All academic centres are involved with education of medical practitioners and other health professionals. The teaching program at CDDHV is an example of the importance of the academic centres in intellectual disability health in educating current and future health professionals in the health care needs of people with intellectual and developmental disabilities. Prior to the establishment of these centres there was minimal teaching in developmental disabilities.

The Centre for Developmental Disability Health Victoria now contributes to years 1, 2, 4 and 5 of the undergraduate medical curriculum at Monash University and years 1,2,5 and 6 at the University of Melbourne. These contributions take a number of forms including lectures, tutorials, workshop, resource material and site visits. Teaching packages have been developed to enable tutors in the Regional Clinical Schools to deliver teaching sessions on Developmental Disability Medicine to students in regional Victoria. Learning objectives have been set both for individual sessions and the entire vertically integrated curriculum in Developmental Disability Medicine. All sessions are evaluated, and results have been very positive indeed.

Please see attachment “2006 Teaching in Victorian Medical Schools”.

The importance of training in Developmental Disability Medicine is being recognised and discussed in international forums. At the recent (August 2006) combined European conference of the International Association for the Scientific Study of Intellectual Disability (IASSID) and the European Association of Doctors in Disability Medicine (MAMH) in Maastricht, a roundtable on medical education in Developmental Disability Medicine was held. Models of undergraduate and postgraduate programs were discussed. The Dutch have the most highly developed postgraduate program for education of specialists in Developmental Disability Medicine. The Victorian model for undergraduate education in Developmental Disability Medicine received accolades for being the outstanding model of best practice.

Postgraduate Teaching

Selective in Psychiatry of Intellectual and Developmental Disabilities, 6 week subject in the postgraduate psychiatry program: Master of Psychiatry University of Melbourne and the Master of Psychological Medicine Monash University. This subject attracts 5-10 students annually

Introduction to Developmental Disabilities is an elective subject in the family medicine program. It is also offered as 5 10 hour CPD modules

- How GPs Manage Complex Problems in People with Intellectual Disability
- Causes of Developmental Disability
- Working with Services for People with Developmental Disability
- Communicating with People with Developmental Disability
- Problem Behaviours in People with Developmental Disability

Unfortunately there has been very limited uptake of these options.

Academic staff at CDDHV also guest lecture at other Universities including Latrobe University, RMIT University.

EDUCATIONAL PRODUCTS

Again the focus is on CDDHV. However all the academic centres have developed a range of educational products.

Health Scenarios in Developmental Disabilities

This interactive DVD introduces users to Jacqui, Colin, Sara and Geoff. Through video scenarios you will learn about their lives and how their developmental disability affects them. A medical consultation with each person highlights particular issues in the healthcare of people with developmental disabilities. An accompanying knowledge base, extensively illustrated with images and personal stories, provides an overview of developmental disabilities, explores general issues in healthcare, communication strategies, mental health and illness in people with intellectual disabilities and the experiences of families and carers.

Other Educational Products

In association with various mainstream organisations CDDHV has produced a number of booklets including:

- Menstrual Management and Women with an Intellectual Disability: A Guide for Victorian GPs
- Options for Menstrual Management: Resources and Information for Staff and Carers of Women with Intellectual Disabilities
- Epilepsy: The Plain Facts
- Pap Test: The Plain Facts
- Hospital Care for people with a Disability
- Assessment of Sexual Knowledge Tool
- Smoking Education program

Details on these publications can be found at

<http://www.cddh.monash.org/products-resources.html#health>

Management Guidelines in Developmental Disabilities Version 2

<http://tg.com.au/index.php?sectionid=93>

Australian medical practitioners and other health professionals who are acknowledged experts in intellectual and developmental disabilities have authored Management Guidelines in Developmental Disabilities Version 2. This book is housed within the stable of Therapeutic Guidelines. Many health services subscribe to the online series of these books. Many of the authors are staff at the academic centres for intellectual/developmental disability health throughout Australia.

Australian Association of Developmental Disability Medicine

<http://www.cddh.monash.org/aaddm.html>

The Australian Association of Developmental Disability Medicine (AADDM) was formed in September 2002 as a network of doctors with an interest in pursuing improvement in the disparity of the health status of people with intellectual and developmental disability (DD) compared with that of the general population of Australia. Its main focus is the professional development of its members and their clinical colleagues in their role to improve this disparity.

The major initiatives of AADDM over the last year include:

- Strong representation on the Royal Australian College of General Practitioners curriculum review committee resulting in training requirements regarding disability and developmental disability in particular.
- Lobbying for medicare item for annual health assessments of people with intellectual disabilities
- Annual AADDM conference.

AADDM members are also lobbying their respective specialist colleges regarding training requirements in disability. AADDM also plans to develop clinical guidelines. I direct members of the committee to a recent newsletter of AADDM for an overview of activities and initiatives.

<http://www.cddh.monash.org/assets/aaddm-newsletter.pdf>

Training and Workforce Issues

A survey was conducted by AADDM in 2004 amongst doctors known to have an interest in the health care of people with developmental disabilities in Australia. The survey identified 90 medical practitioners whose clinical practice comprised at least 10% of patients with intellectual disabilities. A variety of medical practitioners are interested in developmental disability medicine – general practitioners and specialists including paediatricians, general physicians, rehabilitation physicians, neurologists, public health practitioners, general psychiatrists and one old age psychiatrist.

AADDM concluded that a critical mass of doctors interested in developmental disability medicine existed in Australia. However 90 doctors nation wide, working part time in developmental disability, is barely a critical mass to meet the level of health care need of people with intellectual/developmental disabilities in Australia and this “critical mass” is vulnerable especially in certain subspecialties as well as in certain regions. The distribution of doctors across regions and discipline is also not uniform. Often only one or two medical practitioners of a specialty group are the champion/s within their respective fields in each state.

Clinical training in specialist areas requires the existence of specialist services. I will focus on mental health because that is most familiar to me and also there is serious unmet mental health needs in people with intellectual disabilities. There is high mental health needs in the population with intellectual disability. This is due to a range of psychosocial issues but also the underlying neurodevelopmental abnormalities/injury leading to the intellectual disability makes the person vulnerable to a range of psychiatric disorders. To my knowledge there is only 1 ½ recurrently funded psychiatry trainee posts in Australia. One post at the Victorian Dual Disability Service (VDDS) and 1/2 post in Queensland. I don't know if there is a post at the new CIDH in South Australia. There is an accredited post at the Centre for Developmental Disability Health Victoria but there is no dedicated funding. Consequently the CDDHV only sometimes has a psychiatry registrar. CDDHV also offers an elective subject “The Psychiatry of Intellectual and Developmental Disabilities” in the masters program at Monash University and University of Melbourne. As I mentioned at the hearing there is no associated clinical placement although the trainees are welcome to attend the clinics.

A repeat survey of Victorian psychiatrists and trainees in 2004 found no real differences from the survey completed in 1995 in terms of perception of quality of care provided to people with intellectual disability in the public mental health system, training and confidence in assessing and caring for people with intellectual disabilities. The free comments were overwhelmingly in favour of specialist services and training opportunities. Of note Victoria has the best provision of dual disability services through VDDS and CDDHV as well as sympathetic neuropsychiatric clinics in Australia yet this has barely touched the sides of meeting the training and service provision needs.

At the other end of the spectrum Western Australia there are no dual disability or general specialist health services for adults with intellectual disability. A private psychiatrist offers assessments on Saturday mornings.

My assessment is that the opportunity for specialist psychiatric assessment for people with intellectual disabilities in Victoria is the best in Australia, yet many people cannot access timely and informed care. The focus on mental health at the CDDHV is frequently questioned by Disability Services on the grounds that the focus should be on primary health care and support for general practitioners. There is also concern that there is a duplication of the work done by VDDS. CDDHV actually complements the work of VDDS. Access to assessment by VDDS is only available to people on Area Mental Health Service (AMHS) caseload. CDDHV provides clinical assessments to adults with intellectual disabilities referred by their general practitioners and occasionally psychiatrists, neurologists and even AMHSs. Around 70% of referrals are for challenging behaviour due either to impaired social cognition and frontal lobe functioning and a range of psychiatric disorders. The vast majority of people referred with these problems do not need, would not be accepted by area mental health services or have actually been refused services by area mental health services. This is usually because the presenting problems are not within the current remit of AMHSs – although sometimes it is discriminatory, and sometimes due to lack of training and expertise. There is also the issue of monitoring and review of chemical restraint – the use of psychotropic medications to control behaviour rather than specific treatment for a diagnosed psychiatric disorder. The Intellectual Disability Review Panel (IDRP) reports up to a quarter of people in disability services accommodation are on chemical restraint. There is nowhere within the public health system for the expert prescribing of psychotropics for behaviour disorders nor the monitoring, review or cessation of such treatments. CDDHV has limited capacity to offer such a service. We are aware of many people who are on extreme amounts and combinations of psychotropic medications without diagnosis and without expert review.

Research

The evidence base on which professionals practice in the field of intellectual disability health is underdeveloped. Hence continued research is essential to being able to provide evidence based care to people with intellectual and developmental disabilities. Not only will this require funding, but identification of intellectual disability health as a priority research area. In addition laws relating to consent and privacy need to find mechanisms to protect a vulnerable population but to also allow participation in ethically designed and approved research.

Privacy and Confusion

Years after the introduction of federal and state privacy laws confusion reigns as to what is and what isn't allowed with regard to sharing personal and health information. Staff at day programs have told me that they are not allowed to know about problems a person maybe having at the community residential units or the person's health problems (that may be relevant to their care at the program) because the day program is like work and employers don't have a right to know these things. I would argue that day programs also constitute a care environment and therefore a duty of care and a need to know if it is relevant to the person's care. Who has the capacity/authority to decide what is relevant?

In protecting the "privacy" of people with intellectual disabilities the result is often that the person is denied the right to be known and therefore understood. Some non government organisations have a standing policy of rotating care staff every 2 years. So who has longitudinal knowledge of a person on a day to day basis? How can a diagnosis of dementia be made if support staff have only known the person for a month?

My colleagues and I have often not been able to access pertinent information due to "privacy". Access to past files is most difficulty. Health information is locked away in files past and not easily accessible. IQ testing for eligibility for services is considered top secret. If a person cannot give their own history to a health professional who will and who can? If a person cannot consent for themselves about release of private information then who makes that decision? Who decides who should receive a copy of the assessment report? If there are no next of kin, who is the person responsible?

REFERENCES

Center, J., H. Beange, et al. (1998). "People with mental retardation have an increased prevalence of osteoporosis: a population study." American Journal of Mental Retardation **103**(1): 19-28.

Prevalence of and risk factors for osteoporosis in a community population of 94 young adults with mental retardation was examined. Results show lower bone mineral density in this group than in an age-matched reference population. Factors associated with low bone mineral density included small body size, hypogonadism, and Down syndrome in both genders and a high phosphate level in females. Low vitamin D levels were common in both genders, despite high levels of exposure to sunshine. A history of fracture was also common. Low bone mineral density and fracture were associated in females but not males. Because morbidity following fracture is likely to be more serious in this population, further investigation of osteoporosis and prevention strategies for both osteoporosis and fractures are important.

Durvasula, S., H. Beange, et al. (2002). "Mortality of people with intellectual disability in northern Sydney." Journal of Intellectual & Developmental Disability **27**(255-264).

NSW Ombudsman (2005). Report of Reviewable Deaths 2004 Sydney NSW Ombudsman