

Submission to the  
Community Affairs Committee  
Department of the Senate

**Inquiry into the Funding and Operation of the Commonwealth  
State/Territory Disability Agreement (CSTDA)**

by the  
Executive Committee Members  
of  
**The Australian DeafBlind Council**

August 2006

The Australian DeafBlind Council (ADBC) is a national council representing people who are deafblind, their support networks and organisations working in the field. Membership is open to people or organisations who meet this criteria.. ADBC is financed by subscriptions from members and government subsidy (if possible). Its Executive Committee is composed of three deafblind members, one family/support person member and three organisational or professional members. The President must be a person who is deafblind..

ADBC **objectives** are:

- to encourage self-organisation and self-determination by people who are deafblind
- to serve as a national assembly for meetings, communication and interchange
- to provide a forum for collective expression and discussion
- to work for improvement throughout Australia in education, health, welfare, rehabilitation, employment and recreation for deafblind people
- to cooperate with kindred organisations such as the NFBCA and the Deafness Forum
- to disseminate information
- to solicit support from government at various levels for people with deafblindness.

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## About Deafblindness

Deafblindness, the complex condition first made known world-wide by Helen Keller, is an unique and isolating sensory disability resulting from the combination of both a hearing and vision loss that significantly affects communication, socialization, mobility and daily living. The term dual-sensory loss is often used interchangeably with deafblindness, denoting that combined losses of hearing and sight are significant for an individual even where he or she is neither profoundly deaf, nor legally blind. It is the way in which one sensory disability impacts upon, or compounds the second impairment that causes the difficulties, even if taken separately, each single sensory impairment appears relatively mild. The impact of dual sensory impairment on an individual will vary according to the learning opportunities they have been afforded. Some Australians born deafblind will have little or no formal language and limited understanding of the world since they have never been able to watch and listen to others and the things going on around them. However, Australians who acquire their deafblindness may have the advantage of remembering sight and/or hearing and are more likely to have had access to language learning. Whatever the origins of their deafblindness, all people who are deafblind experience some level of isolation, frustration and exhaustion from confronting a world they perceive in a fragmented fashion.

Traditionally in Australia, service provision to those of its citizens who are deafblind has been provided by the large charities that specialise either in service provision to those who are blind or to those who are deaf. The exceptions have been Victoria, which has a deafblindness service provider agency, Western Australia Senses and the Foresight Foundation in New South Wales. The same split in service provision is evident in government sponsored education and medical programs. Because the unique needs of people who are deafblind do not neatly articulate with either well-established means of deafness or blindness service provision, a great many Australians who are deafblind have missed services aimed at addressing either their hearing or their vision impairment. In addition, there has long been, in many parts of Australia, a distinct absence of the specialised types of service required by children and adults who are deafblind , their families and caregivers. As a result, many people who are deafblind have received either no, or highly inappropriate services since they attained adulthood.

Further,

***The absence of national involvement in discrete policy development for this small but important area has resulted in Australians who are deafblind becoming another of our forgotten minorities.***

## Deafblindness in Australia

There are currently:

***no reliable data on the number of Australians who are deafblind.***

This is primarily because:

***deafblindness has not been perceived as a discrete area of disability in policy negotiations between federal, state, and territory governments.***

A rough estimate derived from a number of sources, however, is that there are at present, approximately 4000 Australian deafblind people of all ages. It is important to note that Australia has an ageing population, and that both vision and hearing loss are extremely common in people over the age of sixty five. It is not unreasonable to expect an increase in age-related acquired deafblindness in the coming years.

Our national disability policy is comprised of Commonwealth laws that apply throughout the country as well as separate disability services acts in some states and territories. Because policies have been established at different levels of government, there are often tensions, generally creative, on such issues as resource provision and service boundaries between federal, state, and territory governments. The system is loosely coordinated. However, because of these factors:

***comprehensive service provision to Australians who are deafblind has traditionally been in the “too hard” basket or the “fall between the cracks” category, with predictable results.***

As a first step in providing a much-needed solution to what many have for years perceived as an abysmal situation, the ADBC has campaigned in recent years for greater political awareness of the problems faced by Australians who are deafblind.

As part of this campaign, a National Deaf-Blind Forum was held at the Royal Blind Society in Sydney in July 2001. Some 30 to 35 representatives of Australian deafblindness agencies and special interest groups, as well as Commonwealth and state public officials attended the event. The Department of the Commonwealth Minister for Family and Community Services provided \$5,000 towards the cost of organizing the forum. The purpose of the event was to prepare recommendations to present to the National Disability Advisory Committee (NDAC) that would then bring those recommendations to the impending CSTDA negotiations. The CSTDA at that time focused on eight discrete areas of human services provision: accommodation support services, advocacy services, community support services, community access services, employment services, information services, print disability services, and respite services.

It was clear from the results of the National Forum that :

***None of the Australian states or territories came close to meeting the service provision needs of the Australian deafblind citizens who fell within their purview.***

Representatives from all states and territories reported the following:

- ***No coherent national or state policies or planning regarding services for people who are deafblind.***
- ***No policy level recognition that deafblindness is more than “the sum of its parts” requiring additional focus and support.***
- ***No funded individual, group, or systemic advocacy services in any state or territory focusing on the needs of people who are deafblind.***
- ***Lack of appropriate training in the area of deafblindness to ensure quality staff and services.***
- ***Lack of consistency between states in the ways they provide services.***
- ***No recognition of the communication needs of people who are deafblind or their right to participate in their communities.***
- ***No recognition of the increasing incidence of deafblindness and its associated issues as the population ages.***
- ***No research into specific areas of deafblindness including research into the need for service provision, interpreters and the needs of families and advocates***

A comprehensive report of the National Forum was sent to the Department of family and Community Services and a copy to the National Disability Advisory Council (NDAC). Time passed and after much further enquiry it transpired that ***NDAC claimed either (a) not to have received the report, or (b) to have mislaid it.*** Whatever the case, enquiries to NDAC members confirmed that

**the report’s recommendations had never been placed on the Committee’s agenda and had consequently not been considered in CSTDA negotiations.**

The Department of Family and Community Services (FACS) then allocated \$15,000 to ADBC in order to conduct research that would:

- Review information in the 1994 *Mary Ward Report* on deafblindness in Australia.

- Review the incidence of deafblindness nationally.
- Identify trends in deafblindness nationally.
- Produce an Action Plan so that “approaches can be made to Governments, Trusts and other funding bodies asking for funding, or so that issues can be brought to the attention of specific bodies on action needing to be taken for further research funding”.

A comprehensive report produced by consultant Meredith Prain was submitted to FACS in July 2005 and resubmitted in November 2005 with some modifications suggested by FACS. While the Minister has thanked the ADBC, our organisation is disappointed that no action has since been proposed by the Department and

***The ADBC requests that the Senate Inquiry recommends some concrete proposals based on the Prain Report***

A summary of the Prain Report’s major recommendations that affect deafblindness and the CSTDA follows:

RECOMMENDATION 1

***There is need to have the ADBC definition of deafblindness adopted by Federal, State, Territory and Local governments so that it appears on their websites and in their policy documents.***

RECOMMENDATION 2

***2.1 There is need to improve the accuracy of CSTDA data collection with relation to deafblindness through ADBC working with National Disability Administrators.***

***2.2 There is need to increase the number of people with deafblindness recorded by the ABS Disability, Ageing and Carers survey, through ADBC working with ABS to devise questions that will better capture this population.***

***2.3 If Rec 2.2 (above) is not successful, there is need to establish a voluntary register of people with deafblindness in Australia in order to determine with greater accuracy the number of people with this disability and to better monitor trends and changes in this population.***

RECOMMENDATION 3

***There is need to investigate the numbers of, services for and needs of aboriginal and Torres Strait Islanders who are deafblind, in order to develop guidelines for service provision to this group.***

#### RECOMMENDATION 4

***There is need for FACS and State and Territory government departments responsible for providing services to people with disabilities to make available funding to maintain The Link (Short Term Training Program for Adults).***

#### RECOMMENDATION 5.

***There is need for FACS through the CSTDA to provide funding to the States and Territories specifically for 3 hours per week community support for adults with deafblindness and 40 hours of interpreting per year per person over and above the National Auslan Booking Service, only used for medical appointments.***

#### RECOMMENDATION 6

***There is need for funding through the Department of Employment, Science and Training (DEST) and other government departments to Registered Training Organisations currently providing training on working with people with deafblindness, to develop and operate accredited short courses and certificate courses for staff working with people with deafblindness.***

(RECOMMENDATION 7 does not affect the Inquiry)

#### RECOMMENDATION 8

***There is need for funding through DEST and other government departments for services working with people with deafblindness to send staff to the nearest relevant training on deafblindness which in some cases will be interstate.***

#### RECOMMENDATION 9

***There is need for recurrent funding from FACS for an Information and Referral Service to develop and provide information on deafblindness-related services including interpreting, mailing lists, advocacy groups, networks and training to people with deafblindness, their families, carers, service providers, government agencies and the wider community.***

#### RECOMMENDATION 10

***There is need for funding from FACS to send 14 (two from each State and one from each Territory) Australians with deafblindness to the DeafBlind International Conference in Perth in 2007 and to pay for the cost of interpreters and support staff for these delegates***

RECOMMENDATION 11

***There is need for funding from FACS for an advocacy and policy officer for ADBC.***

(RECOMMENDATION 12 does not affect the Inquiry)

RECOMMENDATION 13

***There is need for additional funding for travel and accommodation from State and Territory government departments to ensure that people with deafblindness, including those living in rural areas, receive appropriate and adequate services from skilled and experienced service providers.***

RECOMMENDATION 14

***There is need for funding from DFCS and other government departments to deafblind specific services and organisations, to provide services to people with deafblindness over the age of 65 in the areas of case management, respite, community support, communication training and recreation. This funding should cover services to all States and Territories.***

RECOMMENDATION 15

***There is need for FACS and all State and Territory government departments responsible for providing services to people with disabilities to make funding available to tender for services specifically for people with deafblindness currently not being provided by the States and Territories in the following areas - accommodation, case management, respite, recreation, employment, counseling, and communication training.***