

Service Provision to Australians who are Deafblind

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Deafblindness, the complex condition first made known world-wide by Helen Keller, is a 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. There are four basic groups of deafblind Australians:

- Those who are hearing and sight impaired from birth or early childhood,
- Those blind from birth or early childhood who subsequently acquire a hearing loss that has a significant functional impact,
- Those who are profoundly deaf from birth or early childhood who subsequently acquire a vision loss that has a significant functional impact; and
- Those who acquire a hearing and sight impairment later in life that has a significant functional impact.

The impact of dual sensory impairment on an individual will vary according to the learning opportunities they have been afforded. 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.

Traditionally in Australia, service provision to those of its citizens who are deafblind have been provided by the large charities that specialise either in providing support 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 absence of national involvement in policy development for this small but important area has resulted in Australians who are deafblind sailing, like the hero Ulysses in the Iliad, between the opposing perils of the many headed Scylla-like monster of traditional Blindness agencies and the huge Charybdis-like vortex of the traditional Deafness agencies, each with their own priorities and agendas.

Recent census data reveal that there are some 18% of Australians with disabilities, impairments and handicaps of various sorts but 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 the policy negotiations between federal, state and territory governments. Rough estimate, would, however, place the number at approximately 1500 people of all ages. Comprehensive service provision to Australians who are deafblind has traditionally been in the “too hard basket” or of the “fall between the cracks” category, with predictable results. As a first step in providing a much-needed remedy to what has become an abysmal situation, the Australian DeafBlind Council (ADBC), the national peak body, has in recent years campaigned for greater political awareness of the problems attending service provision.

Consequently, a National Deaf-Blind Forum was held at the Royal Blind Society (RBS) in Sydney in July 2001. This agency has since become part of the very large Vision Australia agency that provides specialized services in New South Wales and Victoria, The National Forum brought together some 40 representatives of Australian deafblindness agencies and special interest groups, as well as Commonwealth and State public servants. It resulted from letters written by ADBC to the Commonwealth Minister for Family and Community Services, who provided \$5,000 towards the costs of organising it. The purpose of the event was to prepare recommendations that would be brought to the attention of the National Disability Advisory Committee (NDAC), and through that Committee, brought to the table during periodic negotiations over the Commonwealth-States Disability Agreement (CSDA). All states and territories were represented at the event except Northern Territory and Tasmania

It is clear from results of the forum that no Australian state or territory was close at that time to meeting the needs of its citizens who are deafblind. This predicament is just as evident in areas covered by the CSDA as it is in such areas as education, transport, health, or housing.

Critical Nation Wide Issues:

Representatives from all states and territories reported the following:

- No coherent national or state policies regarding services to people who are deafblind.
- No coherent national or state planning around services for people who are deafblind.
- No real policy level recognition that deafblindness is more than “the sum of its parts” and requires real additional focus and support.
- Major gaps in service provision in ALL of the CSDA areas in each state and territory.
- No funded individual, group or systemic advocacy services in any state or territory focused on the needs of people who are deafblind.
- Lack of any appropriate levels of training in the area of deafblindness to ensure quality of staff and services.
- Lack of consistency between states in service responses.
- No recognition of the communication needs of deafblind people or their right to participate in the community.
- No recognition of the increasing incidence of deafblindness as the population ages or the associated issues.
- No research into specific areas of deafblindness including training of staff, interpreters, families and advocates.

The following is a summary of deafblindness Issues related to the CSDA by program target area:

1. Accommodation Support Services:

Critical issues including but not limited to:

- Lack of choice in housing, and limited information of what is available;
- Lack of assistive technology to support truly independent living;
- Lack of adequately trained staff, particularly in relation to communication;
- Lack of flexibility in service delivery in both in house and outreach service delivery;
- Limited focus on the needs of the individual;
- Lack of a national mechanism that guarantees a minimum level of support;
- Issues around safety in homes from
 - other residents

- staff;
- Lack of appropriate services for young people who are deafblind;
- Lack of awareness of the negative effects of the interaction of the person's condition and an unsympathetic environment;
- Lack of awareness about deafblindness and the needs of deafblind people by staff and accommodation settings;
- Limited available services result in the young being placed in nursing homes and psychiatric institutions or institutions for people with an intellectual disability. and
- An overall lack of funding to provide appropriate accommodation options.

2. Advocacy Services:

These are not funded in the area of deafblindness. Critical issues are:

- A poor awareness of the concept and use of advocacy for people who are deafblind;
- No independent deafblind advocacy service in all areas;
- No group and systemic advocacy structures, alongside training and support for people who are deafblind to manage advocacy;
- Lack of information about advocacy services to community;
- Confusion over where the responsibility for advocacy lies, i.e. Commonwealth or States;
- No structured mentor and peer programs for people who are deafblind: and
- No funding to support access to rights.

3. Community Support Services:

Community support services are integral to the ability of people who are deafblind to function in the community. Critical issues are:

- Lack of appropriately trained staff;
- Lack of individually focussed and gender and age appropriate programs;
- A lack of information, literature and correspondence in the format of individual choice;
- Inadequate availability of one on one support hours;
- Inequitable access to services that exist for other people including general community services;
- A lack of adaptive technology and maintenance;
- Inadequate transport assistance; and
- A lack of essential broad services, such as therapy, case management etc.

4. Community Access Services:

Most people who are deafblind face real isolation from the community, as a result of communication and mobility issues. Critical issues include:

- Severely limited staffing and interpreting hours;
- Lack of programs which meet the needs of people who are deafblind who require more one on one support;
- Lack of creative programming which addresses individual communication needs and continued development;
- A poor range of choices;
- Limited staff/workers/etc with appropriate knowledge and training;
- Poor transport access;
- Information not in accessible formats;
- Services inflexible and unable to adapt to consumer timetables and needs; and
- Lack of services or focus on meeting needs of age and ageing population.

5. Employment Services:

Employment services do not meet the needs of people who are deafblind. Critical issues included:

- Absence of pre-vocational experiences to assist in making choices;
- WAT tables that may not rate needs as high as they are;
- Lack of funded training options, especially with some experience of deafblindness;
- Lack of trained workers with appropriate communication skills to ensure safety and understanding of work;
- Lack of longer term support once placed on work;
- Lack of resources for adaptive technology and training for fellow workers;
- Lack of additional support for employers (e.g. extended post placement support etc);
- Lack of awareness programs for employers and managers;
- Lack of capacity to adapt and modify workplaces; and
- Lack of alternatives to employment.

6. Information Services:

Information is critical to people who are deafblind. Critical service provision issues include the following:

- Information needs are broad and diverse and information is rarely freely available in appropriate formats;

- Governments and others do not take responsibility for providing their information in accessible formats increasing the burden for information services;
- Need for all Governments to provide for all information inaccessible formats;
- Need for all agencies, instrumentalities, utilities, businesses, etc to provide for all information inaccessible formats; and
- Need for legal guidelines/standards to support these last two points.

7. *Print Disability Services:*

Access to printed information is a critical issue and it is an under-serviced area. Issues included the following:

- Inability of current services to provide information in appropriate formats;
- Information available to the general public should be available on request in appropriate formats for people who are deafblind;
- Need for availability of adaptive technology to provide access to information.
- Absence of one to one support to access information; and
- Lack of access to qualified interpreters.

8. *Respite Services:*

Respite is a critical need for people who are deafblind and their families.

There was in Australia in 2001 and is currently a:

- Lack of acceptance that respite need not be centred based;
- Lack of acceptance that the prime focus of respite is the deafblind person, even though both the person and the family benefit;
- Absence of choices, which should include other options, such as:
 - in-home respite
 - holiday programs
 - centre based setting
 - interstate;
- Need for respite to be located within a reasonable distance, even in regional areas.
- Need for respite care which is based on individual needs but also coordinated and consistent with other services;
- Lack of options with trained workers; and
- Respite and shared or substitute care need to be defined in terms of time and needs to be coordinated.

The following recommendations were made by those who attended the Forum:

1. That a coherent, combined National/States deafblindness policy be prepared and implemented. This should include the following:
 - a. recognition of the isolation of Australians with deafblindness and the associated deprivation (deafblindness is more than just “the sum of the parts)
 - b. An assertion that people with deafblindness have complex needs over and above those of the majority of people with a disability (there is specific legislation in the UK covering this issue)
 - c. That there is added isolation for those who are deafblind in rural populations and a lack of staff trained in communication methods,
 - d. There is lack of a cohesive structure in some States and Territories to provide required specialised services
2. There must be recognition by Australian governments of the grossly inadequate provision of services for people with deafblindness in most States and Territories. This is an imbalance that must be rectified.
3. That an independent advocacy service for people with deafblindness needs to be established as the uniqueness of deafblindness restricts access to generic advocacy.
4. A funded National Training Program needs to be established to provide training courses for staff employed in the deafblindness field at certificate diploma and tertiary levels and should include distance education (the embryo of such a concept already exists).
5. Services in Australia should be funded to provide Australia-wide information and advice on deafblindness.
6. Interpreter/communication services must be included in CSDA categories and an adequate level of funding be provided for this service.
7. A service should be funded in all States to enable people with deafblindness to better participate in community activities.
8. A policy should be established that people with common forms of communication, where desired, be grouped together and staff with appropriate communication skills be employed and funded

9. *There should be wide recognition that people with deafblindness need flexible respite and accommodation options that cater for their specific requirements.*

10. *That issues associated with aging and deafblindness (including acquired vision and hearing loss) be the subject of a major Government review.*

Après le deluge, quois?

At the conclusion of the event, its organisers forwarded the Forum Report to the National Advisory Council on Disability, from which there was no response and consequently no action. The vacuum was filled by ADBC with a number of follow-up letters and visits to Government in Canberra. Ultimately the Department of Family and Community Services made a \$15,000 grant to ADBC for more research on the number and needs of Australians who are Deafblind.

Beyond this outcome, there have been more recently, several policy triumphs for people with multiple disabilities, notably the following:

- A complaint via the Disability Discrimination Act (Scott v Telstra) succeeded in having access for TTY users included in standard telephone service in Australia.
- Mr. Bruce Maguire successfully complained via the DDA against the Sydney Organising Committee for the Olympic Games over the lack of accessibility of their web site for people using screen readers. The complaint is believed to have had a major impact on awareness among Australian web page designers about the need for accessible design
- Complaints from university students via the DDA about problems with access to course materials in accessible formats has led to a national forum on the topic, involving most Australia's universities

To the present, the DDA has not been used to redress specific Deafblindness-related issues.

The Bottom Line

If we in Australia can afford expensive overseas trips for politicians, or massive spending on elite sports, or other many indulgences of a prosperous society,

Surely

we can afford to provide Australians who are Deafblind with comprehensive, coordinated, community-based support