

Submission  
No 93

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY  
THE DEPARTMENT OF AGEING, DISABILITY AND  
HOME CARE**

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Janne Bidenko

## SUBMISSION – DISABILITY AND CARE SUPPORT

I am writing this as a concerned citizen, but have also been involved in the disability area for over 30 years and have been involved in a voluntary capacity with people who are deafblind for over 20 years. While working in the Intellectual Disability field I realised that Deafblind people did not get any funding unless deemed intellectually disabled. This was usually not the case, people who were congenitally deafblind were very quick to learn and very capable people, who had just not had the opportunity to reach anywhere near their capacity. What they had was a Developmental Disability due to lack of adequate input. Deafblindness is the combination of vision and hearing impairment to the degree that it affects learning, access to information, mobility and socialisation, it is known throughout the world as the most isolating of all disabilities. Unless there is one to one contact and tactile input a Deafblind person can be in a room full of people and be completely isolated. Each person is different depending whether they have low vision and poor hearing, low vision and Deaf, blind and vision impaired or have a profound loss of both senses, but it is still deafblindness and each person needs support to function adequately. It is not just a combination of deafness + blindness, as each of these impairments rely so heavily on the other sense to give meaning to their world. A person who is deafblind, living in a group home for people with an intellectual disability, is invariably left to sit in a corner with very little attempt at communication and interaction, usually leading to challenging behaviour, which is then addressed medically and not addressed as the function of lack of communication when staff cannot communicate.

Besides the needs of Congenitally Deafblind people not being addressed, people with Acquired Deafblindness, once they lose their second sensory ability, are condemned to isolation within their homes. Many people who have been supported by Deafness organisations for deafness, lose their sight from puberty onwards due to a recessive gene which they are usually unaware that they carry. The emotional impact of this at that age is enormous, leading to severe depression and isolation. There is no funding for Deafblind specific services to address these needs, people need to learn communication/reading skills such as Braille and mobility skills, through Blindness organisations, who are unable to communicate with Auslan signers. People are unable to leave their homes alone, if they cannot see or hear traffic they are at great risk and people have been hit by cars when they have believed they are still capable.. In countries like USA, Canada, Scandinavian countries, Netherlands and others, where specific funding is available for Deafblindness, Interpreter/Guides are trained and employed to work with people who are deafblind. This is urgently needed in Australia and must be part of any new national disability and support scheme.

In 1989 a small group of us formed a Social Group for people who are deafblind to try to relieve some of the isolation, which of course is only a band-aid, DeafBlind Association (NSW) Inc became incorporated in 1997 and over these years there have been ongoing attempts to gain funding to support Deafblind adults. A single Sensory Disability Service is unable to address the needs of a person with dual sensory impairment. This is recognised throughout the world, and most Western countries, and some emerging countries, now fund Specialised Deafblind Services. In Australia, only Victoria receives specific State funding.

A new National Disability Care and Support Scheme, including a no-fault social insurance would address the decline in funding I have seen over the past 30 years in intellectual disability. It would address areas of small incidence disabilities, such as deafblindness and others, presently neglected, which need little funding to make an enormous difference in their lives. If designed in such a way that all people with a disability were covered so that each person only received the assistance needed (get rid of waste), the present cost would be more evenly distributed. Areas that need to be addressed are: Most are very relevant to deafblindness as well as other disabilities.

- Funding directed to individual people to address individual needs e.g.
- People who are deafblind in group homes need to be in specific houses for only Deafblind, with staff who can communicate, which will not cost more than their current accommodation. Communication is our most basic Human Right.
- Deafblind people who currently receive no funding, outside their pension, funded to receive support of interpreter/guides to allow access to community, and aids and equipment. to increase access to information.
- Screening and training of authorised organisations and staff to supply support.
- Provision of long-term and essential care and support
- Training of specialised staff in all areas to achieve and improve desired and potential outcomes.
- Provide for people to participate in education, training and employment (this is seriously lacking for people who are deafblind)
- Provision of aids and equipment to give access to information, communication and education for people who are deafblind.

Only with a Nationally funded scheme will there be any chance of any equality within our society.

*Janet Bodenke*