RECOMMENDATION: NDIS FUNDING FOR PEOPLE WHO ARE DEAFBLIND

Deafblindness is described as ‘a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss which significantly affects communication, socialization, mobility and daily living’. Deafblindness is not just deafness plus blindness, as each of these disabilities rely so much on the other sense. Deafblindness is exponentially greater, according to the degree of each loss, but is profound without there being a profound loss in either or both.

As such deafblindness is definitely a ‘severe and profound’ disability’ (3.5) and should be considered of the greatest need when being considered for NDIS funding. Under the ‘Profound core activity limitations’, the criteria of **communication, mobility and self-care** all apply to the person who is deafblind. A person who is deafblind lacks **communication** with the general community, where the person uses tactile Auslan or tactile fingerspelling to communicate with others, this is usually not understood by others within the community. A person who is deafblind has a **mobility** problem, he/she is rarely able to leave the home unless accompanied by others, leading to isolation and depression. Without an **interpreter/guide** a deafblind person is unable to use public transport, as they cannot hear or see announcements and signs, they cannot hear or see traffic and even with a guide dog are at great risk. The cost of taxis is prohibitive for all but urgent travel. While a Deafblind person is usually capable of **self-care** within the home, he/she is unable to shop or attend to other needs outside the home, for which he/she needs an interpreter/guide which is not available to people in Australia.

To date the Australian Government has not given funding for adults who are adventitiously deafblind, yet it is believed that about 40% of the Deafblind community come within this group, from Ushers Syndrome, having been deaf from birth and usually losing their sight from puberty onwards. Many other countries provide interpreter/guides for these Deafblind people, giving access to a number of hours per week to attend to whatever needs that person has. In Canada these support people are called ‘Intervenors’, in the USA ‘SPCs’ (Special Support Person), in the UK ‘Independent Living Support Person’, but whatever the name throughout the world, this is an essential service for all Deafblind people.

The funding of technology would also increase the independence of Deafblind people, e.g. the Deafblind Communicator, although other technology is improved and developed all the time. Currently the cost of such technology is out of the reach of people who are deafblind, especially as at least 99% of these people are unemployed, due to the inability of the community to address their communication and mobility needs. With the use of technology, employment would be a greater possibility, as this is an intelligent sector of the population. With the help of technology, we have recent University graduates, but will there be employment available for them without assistance?

When looking at the needs of the Congenitally Deafblind, people with CDB, many are currently housed within intellectual disability housing, and as such are funded through

State funding. This is completely inappropriate housing, as the Deafblind person, who has a developmental disability because of lack of interaction, rather than an intellectual disability, is further disadvantaged and isolated by living with 4 other people who are hearing and sighted and who can interact with each other as well as with staff. The person is invariably left seated in a corner while other activities take place, which also invariably leads to ‘Challenging Behaviour’ because of the frustration incurred.

Individual funding would give the choice of the person with CDB, or family/advocate, to choose where to live. Living in a house, just for people who are deafblind would lead to better interaction and supports appropriate to their needs. Many of this group had communication when they were at school (in NSW, mostly The Royal Institute for Deaf & Blind Children), but lost this when sent to other accommodation at the age of 18. With staff that sign this communication would return, and for those who did not have this communication it would soon be learned in everyday/all day communication. I have been lucky enough to work with people in this group and have seen the immediate benefit of this re-introduction of sign language.

Chapter 4 discusses “What individualized supports will NDIS fund?” and the introduction states “Support and assistance aim to increase opportunities for people with disability by tackling such things as inadequate housing and the need for personal care and assistance in getting about and participating in the community….”. Both these are very relevant for the Deafblind community. As above, the **inadequate housing** relates to people with CDB and **the need for personal care and assistance in getting about and participating in the community** applies so greatly to all Deafblind people.

Chapter 5 goes on to discuss assessment, which include the “needs, wants and aspirations” of the person, and have cited “The International Classification of Functioning, Disability and Health” which lists nine domains of relevance, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, learning and applying knowledge, community social and civic life, general tasks and demands and major life areas.

Of course **communication** is the most important domain, but all nine domains are relevant to deafblindness and must be addressed to bring deafblindness out of the darkness. Looking at Activity and Participation Domains (they show details behind just one heading **“mobility”**), this clearly shows that deafblindness is covered within the 4 boxes shown just in this one domain – 1.Mobility, 2. Both moving around and using transportation, 3. Moving around in different locations and, 4. Moving around other unspecified, which include other issues faced by the person who is deafblind. This can only happen with individualized funding to just fund what is necessary for each person, this can be very cost affective. So looking at the following issues that need to be addressed in the provision of this most important funding for people who are deafblind:

- Assessment is problematic, if current ‘psychometric’ tools are used, these do not work for people who are deafblind.

- All assessments **must** take into account the CRPD, Australia cannot move forward with a radically different disability support system unless we address the ways in which we do not conform to this important document.
- DeafBlind Association (NSW) Inc does not accept the employment of ‘independent assessors’. The process should be transparent, with the individual who is seeking support able to be explicit about what his/her needs are and how supports will assist their access to the community and communication with others.
- We do not see anything in this draft about Advocacy, DeafBlind Association continues to be a completely unfunded Advocacy service, as well as supplying voluntary social interaction for people who are deafblind to relieve isolation. How will Advocacy be funded in the future?