SUPPLEMENT AND ADDITIONS TO A PRESENTATION TO THE

PRODUCTIVITY COMMISSION HEARING

- **WEDNESDAY 6TH APRIL 2011**

Presenters:

Carla Anderson, Manager of Able Australia Deafblind Services.
Phil Harper, Research Consultant, ACCAN project.
Heather Lawson, Deafblind person

BACKGROUND

Australian deafblind population

The Australian DeafBlind Council define deafblindness as

> "a unique and isolating sensory disability resulting from a combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living" (Australian DeafBlind Council brochure)).

The major causes of deafblindness include Congenital Rubella Syndrome, premature birth, CHARGE Syndrome, Usher Syndrome, Cytomegalovirus and other viruses and diseases such as Meningitis. Usher Syndrome is a genetic form of deafblindness where a person has a hearing loss at birth and loses sight, as they get older. A significant number of the survey participants have Ushers Syndrome and comprise two very distinct groups. Ushers 1 are born deaf whereas Ushers 2 are born with hearing. Both groups have late onset blindness as adults.

According to a report by Access Economics (2006), the current breakdown of numbers of people with deafblindness in Australia indicate that there are some 7000 to 9000 people who are deafblind under 65 and 281,000 people that are deafblind over 65 years of age and over if people with a mild hearing loss are included.

People with deafblindness have a double disability. About 90% of the information we receive about the world comes through vision and hearing. A person living with deafblindness uses residual vision and/or hearing, touch, smell and taste to make sense of the world. The impact of dual sensory loss varies and can include difficulties with:

- Communicating with others
- Orientation and mobility
- Access to communication technology
- Access to information and everyday experiences
- Independence and daily living skills
- Education and training
- Relationships
- Financial access to aids and equipment
- Employment

An ability to communicate is essential for anyone to participate and feel a sense of belonging in the world. For deafblind people, unless there is appropriate support to meet their communication needs both human and through the electronic and social media channels, they are at risk.

According to Tellefson (2009), in Australia, there are two distinct cultural groups within the deafblind community. This is also the case globally. The first group are born blind and lose their hearing as adults. They tend to continue to use speech as their main communication and have a variety of hearing devices to enable them to communicate.

The second group are born deaf and lose their sight as adults. This group are culturally deaf and use Australian Sign Language (Auslan) to communicate. A significant community of deafblind people has a genetic condition called Usher Syndrome (Type 1 or 2). They are born deaf and develop Retinitis Pigmentosa, (tunnel vision) when they are adults. In late adulthood, some continue to lose their sight completely.

A person with deafblindness may strongly identify with the blind culture or the deaf culture (in some cases, neither) as well as the culture of their

family of origin. An understanding of the complexity of their culture is important for communication, language and learning. There is a deafblind culture and it has been nurtured through the development of social and recreation groups supported by organisations like Able Australia.

Where Auslan is the first language, a person may have difficulty reading and writing English and therefore require support mechanisms such as interpreters or trainers who can use Auslan directly with them. If Auslan is not the first language the deafblind person may communicate by spelling the alphabet into the palm of a person's hand and this is called deafblind finger spelling. Some people with deafblindness have sufficient hearing to enable them to speak and they usually have hearing aids. If they are blind and don't know Braille, all their information is gathered audibly and this can result in poor spelling. Conversely, if they know Braille or have had good hearing or good sight, their literacy may be of a very high standard (Tellefson, 2009).

According to the Australian DeafBlind Council (ADBC), many deafblind people suffer from or are at risk of depression and anxiety:

> "Many deafblind people have had a life (or large segments of life) of isolation, loneliness, boredom, frustration, communication difficulties and breakdowns, unemployment, and the frustration of relying on support workers for simple tasks and chores. They also had to make the continual adjustments that are necessary as sight or hearing (or both) deteriorate over time. The loss and grief is ongoing, not only because of the deafblindness itself, but the changes and deterioration of the senses that often take place. As changes occur, deafblind people experience fear and worrying about the future. They worry about accommodation, support, safety, and more years of loneliness and isolation. Distractions in the deafblind person's life are limited and often difficult to sustain. The high percentage of depression and anxiety in the current

sample is understandable, given the issues and challenges that arise" (2010).

In terms of services for deafblind people, Victoria, New South Wales and Western Australia have organisations that directly support them with a range of services. Victoria, through Able Australia, deafblind people has been very well supported through the establishment of a computer and online skills training and drop-in centre, AbleLink, in central Melbourne. Deafblind people are able to attend Ablelink in their own time to use computer equipment that has all the necessary accessible software and hardware to suit their needs. Other States have fewer or no services at all and deafblind people have to rely on support from either deaf or blind agencies.

In Victoria, the deafblind community group, who have predominantly been involved with the Deaf community when they were younger, have strong language skills through using Auslan. As their sight worsened, many have adapted to understanding Auslan through tactile interpreters. Fortunately, through regular training and more recently an accredited TAFE course on deafblindness sponsored by Able Australia and Kangan Institute, interpreters and deaf people are learning about deafblind interpreting.

In New South Wales, the deafblind services are located in Vision Australia and the deafblind group consists of people with Ushers Syndrome, Type 2 (still have some sight and speech) and blind people with hearing impairments. Their communication needs are very different as are their telecommunications needs.

There are a considerable numbers of deafblind people, who have other disabilities who may live in group homes. Due to their deafness, often their communication needs are not met because staff is not sufficiently skilled in using Auslan or other required communication modes. There is not a clear picture around their capability in accessing telecommunications. Just getting any services is a huge battle for them.

Due to the diversity of people with deafblindness, this group has a unique combination of requirements when it comes to accessing everyday support and using communication devices as well as online services. One common factor is that people who are deafblind are becoming more isolated due to insufficient support to assist them getting out and about. They have to rely heavily on human support options (eg; interpreters, communication support people, guides and carers), communication devices and social networking online services to interact with the 'outside' world. Many deafblind people do not have access to these devices nor are trained to use social networking options.

While many deafblind people are able to enjoy participation in daily life it is subject to the impact of their dual sensory loss on their ability to communicate, access information, form relationships with people and be independent. More often than not, support systems such as accessible technology or support workers are required to assist their participation, and a balance between the two is important.

Attached to this submission is a matrix which illustrates examples of ten deafblind people's life situations including their vision and hearing loss, what services and support systems they have, funding, assistive device access, need requirements and current problems. Some of these examples have been elaborated on as case studies to further show the difficulties a deafblind individual faces.

This matrix was developed as members of the Productivity Council present at our presentation on the 6th April, requested more information and examples of solutions to a diverse range of life experiences of deafblind people in Australia.

We are more than happy to provide further information regarding this matrix and / or discuss with you where the role of the NDIS can effectively benefit deafblind people.

ACCESS TO COMMUNICATION, TELECOMMUNICATION EQUIPMENT AND SOCIAL NETWORKING SERVICES

Accessing appropriate equipment and software programs that suit the individual needs of deafblind people is very challenging. Often they are very expensive because the equipment and programs are built for a very small market and there is no money to be made from them. Accessing any training in the community is extremely difficult due to the complex communication needs, cost of interpreters and inaccessible formats. Even specialist training provided for vision loss, e.g. Braille training, mobility training is often inaccessible. Though there are excellent training materials for Braille and for accessing technology and much of it is in audio format or in a format that is not accessible.

While technological advances are proving to be beneficial to those experiencing single sensory loss (i.e.; deafness or blindness), it is becoming evident that such advances are not taking place for people who are deafblind, particularly the high cost to purchase the technology. The Helen Keller Centre (USA) reinforces this point in their submission to the US Federal Communications Commission (FCC) inquiry on the formation of a National Deaf-Blind Equipment Distribution Program (Federal Communication Commission, 2011):

> "… the ongoing efforts by these individuals to mitigate daily isolation, and the barriers they face to civic and social involvement when they cannot afford the cost of equipment or the training on how to use it. Not being able to afford expensive specialized communications technology, HKNC says, prevents people who are deaf-blind from obtaining the information and

> tools they need to compete in the job market" (Federal Communication Commission, 2011).

This is further expanded by the US Federal Communications Commission in their preamble to establishing the "Twenty-First Century Communications and Video Accessibility Act of 2010, Section 105, Relay Services for Deaf-Blind Individuals" (4th April 2011)

> "Every American should have the ability to use our nation's communications services. The ability to communicate enables people to be independent, productive, safe and secure. In recent years, technological innovation has dramatically changed the ways that we communicate and acquire information. Most Americans can now choose among a wide selection of digital and Internet-based voice, text, and video communication methods to meet their individual and daily needs. The proliferation of these technologies has provided new ways to secure employment, shop, learn, acquire health care, and participate in civic affairs. Until now, however, accessibility barriers confronting people who are deaf-blind have largely prevented this community from enjoying these benefits."
> (http://www.fcc.gov/Daily_Releases/Daily_Business/2011/db0406/FCC-11-56A1.pdf).

Telecommunication Trends for the Deaf Community

In determining the best telecommunications solutions for the deafblind, it is important to identify the emerging trends within both the deaf community and the blind community. It is interesting to note that many "inventions" for people with disabilities have later become mainstream devices. For example the Kurzweil Scanner was invented for blind people and now is a household item. Audio books and podcasts were the sole domain for blind people until quite recently. Phones with a vibrating ring tone were originally the only used by deaf people.

In looking at some trends within the Deaf community in their uptake of telecommunications, they have been able to adopt telecommunication technologies successfully and these improved communication tools have enabled them to define themselves as a group and strengthen their relationship with family, friends and the wider community:

- The Fax machine allowed deaf people to communicate with the wider community;
- The TTY enabled deaf people to talk to each other without the use of an Interpreter;
- The National Relay service have closed the communication gap between deaf people and the hearing world;
- SMS, by accident, has become the perfect mobile phone service for deaf people and has become the preferred communication tool of the world. It is cheap, has been adopted by governments and work places, is mobile and does not discriminate on who is using the service;
- Video, via the Internet has enabled deaf people to talk to each other in their first language;
- Video Relay has enabled many Deaf people to communicate in their first language (sign) with anyone.

Telecommunications for Deaf people have strengthened their culture and improved communication with the wider community. New technologies have become more accessible, affordable and easier for the deaf community and more importantly, the deaf community have been able to adapt mainstream technology for their benefit (eg; ACE Video Relay Service uses Skype). The Federal government has funded services to support the Deaf community in their uptake of technology, eg the National Relay service and the planned SMS emergency service.

Telecommunication Trends for the Blind Community

Blind people have embraced technology and in many cases their technologies have become mainstream. Inventions specifically for blind people, have now become mainstream. Eg Scanner, Audio books,

- Audiotapes of books enabled blind people to read independently.
- Podcasts provide access to information
- Screen readers on computers and mobile phones.
- Scanning software to translate hard copy text into electronic
- Voice Phones.

The emerging technologies that have liberated and empowered these two disability groups have not been as evident within the Deafblind Community. In fact, the deafblind community has become even more marginalised from their deaf and their blind communities.

> **Telecommunication Trends for the Deafblind Community**
> Imagine for a minute that the telephone is a barrier to communication. Then imagine the printed word is another barrier. Now picture a visually and hearing impaired grandmother using assistive technology on a computer to communicate with her grandchildren by e-mail. I have personally experienced amazing transformations on the part of people with multiple disabilities. I have seen through the use of this type of technology and specialized training, people rediscover their lives and even find new purposes to get behind. This technology and training is much more than connecting people to information. It's about improving our collective state by including everybody (Federal Communications Commission, 4th April 2011).

The Able Australia Survey findings recently completed indicate a huge lag in the uptake of technology for the deafblind community in comparison of the deaf and the blind communities separately. This can, in part be explained by the fact that many deafblind people identify as either deaf OR blind and seek services accordingly. They would not identify themselves as deafblind.

Many adults with deafblindness have some vision or some residual hearing and many can use the same technologies as the deaf or the blind, but, due to their individual complex needs, they often need support and assistance in sourcing and configuring these solutions. The Deafblind community need individual customized solutions. For the small number of adults with limited functional vision or hearing, the world of SMS, Video, screen readers and podcasts is largely, not available to them. However, they still demand access to these tools, as they like to have “hands on” experience with how communication is happening around them. This may involve a support worker facilitating part or all of this process. A clear example is that SMS has gained considerable popularity within the Blind community, even though they can just as easily talk on the phone. People who are blind, recognise it is an important communication tools and they want to participate.

Satoshi Fukushima, an associate professor in the Research Center for Advanced Science and Technology at the University of Tokyo and deafblind, best sums up the need for human support workers to assist his access to information:

> "Most products are not designed with deafblind people in mind from the beginning, so often they are not really easy to use. As voice recognition technology continues to be improved, I think a refreshable Braille display, which can automatically display the voice of your conversation partner won't be just a dream. However," he says, "in the end, machines will not solve everything, so, I think it is important that a combination of human support and technology be combined for the complete solution" (Microsoft, n.d.1).

How can services be improved for adults with deafblindness?

Many deafblind people currently access services at blindness agencies. These people are usually low hearing and can speak. They are relying of

speech access and audio devices to improve communication or on low vision devices. Where problems arise is when the deafblind person needs to communicate using Auslan. There is simply no provision of interpreters. This is a huge problem in the service delivery of mobility training, computer training and Braille training.

Ablelink has been a successful model in providing access to technology but is only available in Melbourne. Given the low numbers of deafblind people, and the expertise required in providing this technology it doesn't seem feasible to duplicate this centre around Australia.

It is more feasible to rely on the groups that currently exist and provide them with support to extend their resources and services so that the deafblind community can access their services. Basic computer literacy in terms of the ability to type on a keyboard and learn basic commands has been shown to improve the ability for a person to uptake new technology, because of both confidence and transfer of skills.

Accessible and affordable technology and supported training has the potential to open the door enabling this community to participate more fully in the wider community.

2009 RESEARCH AND SURVEY FINDINGS

71 Deafblind people from across Australia participated in the survey.

Below is a snapshot of the findings:

- 69% of deafblind respondents state that they have a landline service (also called fixed line) at home only 45% use the service.

- 85% of Australians have a mobile phone (ACMA, 2010), only 46% of deafblind people have a mobile phone. (The real figure is likely to be

smaller given that we have only been able to access known deafblind people who have access to deafblind services.)

- 77% of people had a computer in their home with also having an Internet connection, only 43% of deafblind people have the same access (ACMA 2010-1).

- Lack of access to essential communication and telecommunication devices are caused by:

    - Insufficient funds or funding support to purchase required specialised equipment or software to enable telecommunication devices and online services to be accessed in the same way as others can;

    - Insufficient training options to learn how to use telecommunication equipment, computers and the Internet. Due to their complex communication needs, finding skilled trainers is difficult;

    - Insufficient funding for support staff or Interpreters to assist deafblind people with learning how use telecommunication equipment, computers and the Internet;

    - Support staff and Interpreters also need training to work with deafblind people because of their complex communication requirements;

    - Lack of braille training (Braille Training is almost non-existent for the deafblind community. The training is requires an interpreter and the training materials need to cater for students with English as a Second language);

- Braille Devices currently available are expensive and are not designed for deafblind people. They are built for blind people who are relying predominantly on speech output with the braille as an additional output.

- Social Networking - only 8 of 71 are using Facebook – most cannot access Facebook, Twitter, Skype, etc;

- Only 11 out of 71 participants are using online services such as banking

- To access a mobile phone, a deafblind person needs combinations of the following:

    1. Screen magnification software
    2. Speech output software
    3. Wireless keyboard
    4. Mobile handset
    5. Braille display with braille keyboard

In conclusion, it is abundantly clear that the NDIS will potentially provide the much needed human and communication technology support required by deafblind Australians to enable them to participate in and enjoy community life as close to the same way as other Australians.