Telecommunications and Deafblind Australians

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ACRONYMS

ADBC	Australian DeafBlind Council
ACCAN	Australian Communications Consumer Action Network
ACMA	Australian Communications and Media Authority
DBCDE	Department of Broadband, Communications and the Digital Economy
DEP	Disability Equipment Program
TTY	Teletypewriter
USO	Universal Service Obligation
VA&EP	Victorian Aids and Equipment Program

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1. EXECUTIVE SUMMARY

This report details a consumer research and education project concerning the usage of telecommunications by people experiencing deafblindness in Australia. A survey was developed and distributed through Able Australia's national networks to deafblind people, case studies were collated, and a consumer information website was developed for deafblind consumers and their support networks.

The research findings and case studies presented provide a snapshot of current access to telecommunications including the limitations and barriers faced by deafblind Australians; The findings and recommendations will assist government and consumer organisations with communications policy development.

On a broad level, the research shows that people who are deafblind have significant difficulty accessing telecommunication devices. The reasons for this include:

- 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 ways 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 to 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.

It is important to note that the survey was not provided in Auslan: the same resource challenges faced by organisations providing services to people who are deafblind were faced by the researchers, and it was clear from the data that many participants required assistance to complete the survey. However many respondents contributed additional comments along with their survey responses, demonstrating their enthusiasm to participate and to have their experience represented.

It should also be noted that while the issues identified in the report are focused on supporting telecommunications access, similar issues arise in deafblind people's access to everyday life experiences such as shopping, banking, housing, travel, and participation in community.

The report also documents the development of a dedicated website focusing on deafblind telecommunications in Australia. The website continues to be an innovative resource for the deafblind community in that it was designed for and by its members. The website was created by communications consultant Peter Tarrant, who is deafblind himself, and involved collating relevant information on telecommunications and social networking with support from colleagues. Ultimately the website aims to empower members of the deafblind community to learn through online community, and to access and share information specifically related to their lived experience. The website development continues at www.dbt.org.au.

The report concludes with a series of recommendations aimed to make communications more available, accessible and affordable for consumers experiencing deafblindness.

2. BACKGROUND

2.1 About the project

The project was facilitated by Able Australia, through the Ablelink service, and received funding from the Australian Communications Consumer Action Network's (ACCAN) Grant Scheme, which funds projects that represent the interests of consumers in relation to communications issues.

A project steering committee was established, with Claire Tellefson, coordinator of Ablelink leading the project and providing on-going support to the research project workers. Consultant Phil Harper was employed to conduct a survey into the implications of current telecommunications technology use for deafblind consumers, and to publish the findings in this report. Peter Tarrant, a communications consultant who is deafblind himself, was employed to research and develop a web based resource, envisioned as a website where deafblind people and others could access information about telecommunication services, accessible equipment, and online communication options.

2.2 The 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 such as Meningitis. A significant number of the survey participants have Ushers Syndrome, a genetic form of deafblindness where a person has hearing loss from birth and loses sight as they get older. People with Ushers Syndrome comprise two very distinct groups: Ushers 1 are born deaf, whereas Ushers 2 are born with hearing. Both groups experience late onset blindness as adults.

According to a report by Access Economics, the current breakdown of numbers of people with deafblindness in Australia indicates 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 (when people with a mild hearing loss are included). It is predicted that the population with a dual sensory loss (hearing and vision) could increase with the aging of the population to 1,135,500 by 2050 (Access Economics, 2006).

Deafblindness is sometimes considered to be a double disability, however the challenges faced by people who are deafblind are often more complex. About 90% of the information we receive about the world comes through vision and hearing. A person who is deafblind uses residual vision and/or hearing, touch, smell and taste to make sense of the world, and their experience will vary depending on a range of factors.

The impact of dual sensory loss varies and can include difficulties with:
• Communicating with others
• Orientation, mobility and balance

- Access to information and everyday experiences
- Independence and daily living skills
- Education and training
- Relationships
- Financial access to aids and equipment
- Employment

This can result in feelings of:
- Grief and loss
- Isolation
- Frustration
- Fatigue
- Low confidence and self-esteem (Able Australia website)

According to Tellefson (2009), there are two distinct cultural groups within the deafblind community. The first group are born blind and lose their hearing as adults. People in this group tend to continue to use speech as their main means of communication, and make use of a variety of supportive hearing devices. The second group are born deaf and lose their sight as adults, often as a result of Usher Syndrome Type 1 or 2. People in this situation are culturally Deaf and use Auslan to communicate. Most people with Usher Syndrome develop Retinitis Pigmentosa (tunnel vision) when they are adults, and some continue to lose their sight completely.

It is also important to understand the range of literacy issues that arise from dual sensory disability. Many people who are Deaf as children will learn to communicate using Auslan. Where Auslan is a person's first language, they may have difficulty reading and writing in English, and therefore require support from interpreters or trainers who can communicate with them in Auslan. If Auslan is not their first language, and they don't use speech, a deafblind person may communicate by fingerspelling, or spelling the alphabet into the palm of a person's hand. Some people who are deafblind have sufficient hearing to enable them to communicate through speech, and will usually have hearing aids. If a person is blind and doesn't read Braille, all their information is gathered audibly and this present literacy challenges. Conversely, if they read Braille or have had good hearing or good sight earlier in life, their literacy may be of a very high standard (Tellefson, 2009).

There may also be a difference between the ways that a deafblind person communicates expressively and receptively. For example, people who were born with hearing and learned to speak early in life may continue to communicate this way, but as a result of their vision and hearing loss they may rely on Braille or tactile fingerspelling for receptive communication.

Depending on their experience, a person who is deafblind may identify with Deaf culture, or the blind and low vision community, or in some cases neither. There is a growing deafblind culture in Australia and it has been nurtured through the development of social and recreation groups supported by organisations like Able Australia. An understanding of the complexity of this culture is important for communication, language and learning.

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

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 literacy challenges that arise" (ABDC, 2010).

Victoria, New South Wales and Western Australia have organisations that provide direct support to deafblind people through a range of services. Able Australia have supported deafblind people in Victoria since 1967, through several programs including the establishment of Ablelink, a computer and online skills training drop-in centre 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, members of the deafblind community who were involved with the Deaf community when they were younger and still had some level of sight, have strong language skills in Auslan. As their sight worsened, many have adapted to understanding Auslan through tactile signing. Fortunately, through regular training and more recently an accredited TAFE course on deafblindness sponsored by Able Australia and Kangan Institute deafblind interpreting is becoming more common and skilled.

In New South Wales, Vision Australia provide the majority of services to the deafblind community. Vision Australia services are mostly tailored to blind people with hearing impairments, and people who are deafblind as a result of Ushers Syndrome Type 2. Their communication needs are very different as are their telecommunications needs.

There are 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 are not sufficiently skilled in using Auslan or other required communication modes. Accessing services can be a huge battle, and there is not a clear picture around their capability in accessing

telecommunications. Further research into these challenges may be beneficial.

Due to the diversity of people with deafblindness, this group has a unique combination of requirements when it comes to accessing and using communication devices and online services. One common factor is that people who are deafblind are becoming more reliant on communication devices and online social networking services to interact with the outside world.

2.3 Inclusive telecommunications and deafblind people

There is little conclusive evidence documenting the experiences of deafblind consumers in accessing and using communications technology in Australia – a gap that this project begins to fill.

Consumer and disability groups have advocated that "access to information and communication services are an essential tool for all people with disability to be able to participate to the fullest extent possible in Australian society" (Asher, 2010). Many deafblind people are able to enjoy participation in daily life, however their participation is subject to the impact of their dual sensory loss on their independence, in terms of their ability to communicate, access information, and form relationships. More often than not, unique support systems need to be developed, that often rely on support workers and telecommunications technologies.

A balance between human and technological support systems is important. Satoshi Fukushima, an associate professor in the Research Center for Advanced Science and Technology at the University of Tokyo and a deafblind person himself, 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).

Accessing appropriate equipment, software, and training that suit the individual needs of deafblind people is very challenging. Because assistive technology represents a comparatively small commercial market, equipment can be very expensive. Accessing any training in the community is also difficult due to the complexity of communication needs, the high cost of interpreters, and formats that are inaccessible to people with dual sensory loss. Much of the specialist training developed for people with vision impairment to learn Braille, for example, is in audio format that is inaccessible to many deafblind people.

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, with a particular barrier being the high cost of purchasing the equipment. The US based Helen Keller Center reinforce this point in their submission to the US Federal Communications Commission (FCC) inquiry on the formation of a National Deaf-Blind

Equipment Distribution Program:

> "… 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).

In determining the best telecommunications solutions for people who are 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. The scanner, audio books and podcasts, and the vibrating ring tone function on mobile phones are all examples of assistive technologies that have moved into the mainstream marketplace.

Telecommunication Trends for the Deaf Community

The Deaf community has been successful in adopting a range of telecommunication technologies as tools to reinforce relationships with family and friends, and to define their community. Some services have been government supported, such as the National Relay Service, and the planned emergency SMS service. Others have been mainstream commercial technologies like SMS on mobile phones, or various online video call programs.

• 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 who speak Auslan 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 (e.g. ACE Video Relay Service uses Skype). The Federal government has funded services to support the Deaf community in their uptake of technology, e.g. the National Relay service and the planned SMS emergency service.

Telecommunication Trends for the Blind Community

People who are blind or have low vision have generally embraced technology , often relying on audio technology:

- 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 text

Telecommunication Trends for the Deafblind Community

The empowering effect of emerging technologies in the deaf and vision impaired communities has not been as evident within the deafblind community. In fact, the deafblind community has been somewhat left behind, becoming further marginalised as a result of the strides made in technology for single, but not dual sensory impairment.

The Survey findings indicate a huge lag in the uptake of technology for the deafblind community, when compared the deaf or blind communities. This can be explained in part by the fact that many deafblind people identify as either deaf or blind, and seek services accordingly. Respondents were generally less likely to identify themselves as 'deafblind'; as a result they may have difficulties finding technological solutions and accessing support appropriate to their specific communications needs.

Many adults who are deafblind have some vision or some residual hearing and many can use the same technologies as people who are deaf or blind. However, due to their individual complex needs, deafblind people often need additional support and assistance in sourcing and configuring these solutions. People who are deafblind need individualised solutions, customised for unique needs. For the small number deafblind of adults with limited functional vision or hearing, the world of SMS, Video, screen readers and podcasts is largely inaccessible to them; however the "hands on" experience with the communications world going on around them is highly valued. Using these popular communications technologies may involve facilitation of all or part of the process by a support worker. A clear example is that SMS has gained considerable popularity with people who are blind, though it is traditionally a visual medium. These consumers recognize SMS as an important communications tool and they want to participate.

In many ways, all people in modern society are striving for the right to an individual customised solution. In fact, there is a trend for society to want "many solutions" to cater for a range of individual interests. Driving this technological boom is an appetite for new devices that present customisable communications solutions and deafblind people are no exception.

Customized Solutions

South Australian based organisation NovitaTech provide holistic solutions for people with complex communication needs, and often build the solution themselves:

"NovitaTech specialises in the prescription, manufacture and supply of custom solutions for clients with a need in the areas of orthotics, seating & mobility, communication, and environmental control. Ensuring a correct match of technology with the individual's needs can lead to the provision of a very complex solution. These solutions often require the integration of a number of disciplines to deliver the desired outcome." http://www.novitatech.org.au

It is hard to imagine being able to provide a similar service for the deafblind community. Not only are they an extremely small community but also they are spread all over Australia. They are not a united group due to their diverse communication styles and subsequent diverse needs.

The deafblind community are often "hidden" in society, relying on family members or on the services of the service providers for people with a single sensory impairment. Unfortunately the solutions that are assisting these communities are further isolating the deafblind community; the Deaf community has largely moved away from text, and people who are blind have tended to move further into the audio world. Both these trends are impacting heavily on the deafblind, who need individualised solutions.

How can services be improved for adults who are deafblind?

Many of the deafblind respondents who use speech and have some residual hearing currently access services aimed at people with a vision impairment, and use speech access, audio, or low vision devices to improve communication. Deafblind people whose first language is Auslan experience a much greater challenge in accessing services. Training that relates to their visual impairment –mobility training and Braille training for example – is not available in a format that considers their hearing impairment. Accessing Auslan interpreters to make training available in their first language is expensive, and often difficult to access under support funding schemes.

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 individualised technology solutions, it does not 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 –the ability to type on a keyboard and learn basic commands – has been shown to improve a person's ability and confidence in the uptake of new technology. Supported training, along with accessible and affordable technology has the potential to open the door enabling this community to participate more fully in the wider community.

There are three key principles that must be addressed in order to achieve 'access for all':
- Availability: having the necessary equipment or communications essential to deafblind people to participate equally in society .
- Accessibility: telecommunications equipment, customer premises equipment (e.g.; phones) and web-based online services should be accessible and usable by deafblind people
- Affordability: deafblind people and other people with a disability are currently burdened by the extra cost of accessible equipment to achieve a similar level of access or use to that of their non-disabled counterparts. The Federal government's Regional Telecommunications Review, found that 'People with special needs require access to new technologies and support mechanisms at an appropriate price to enhance their interaction with society'" (Eardley, Bruce & Goggin, 2009).

The terms 'Availability', 'Accessibility' and 'Affordability' are used as guidelines (benchmarks) by Governments, industry regulators and consumer bodies such as ACCAN, to ensure that the industry

meets universal requirements necessary to allow all people to enjoy their products and services. However, depending on how such issues are considered, measured and mandated by the policies of particular groups, some benchmarks may not meet the current needs of the consumer (Clark & Harper, 2002).

It is also important to take into consideration the wider divides that deafblind people face. The deafblind population has very limited access to services in general, let alone telecommunications. There is a chronic shortage of general support services for deafblind people throughout Australia. This impacts upon their communication skills, independence, mobility, mental health, and housing. Without these needs also being addressed, it is almost impossible to provide equity in telecommunications for deafblind people.

The National Disability Strategy (NDS) was one of the key recommendations from the 2007 Senate Inquiry into the Commonwealth, State and Territory Disability Agreement (CSTDA) later adopted by the Rudd government. The strategy includes the integration of the UN Convention on the Rights of Persons with Disabilities into the agreed policies and programs affecting people with disabilities. The Strategy aims to address the barriers that are faced by Australians with disability and promote social inclusion. ACCAN in response to the NDS discussion paper produced a document "Connecting Us All: The role of the national disability strategy" (ACCAN, 2010).

2.3.1 UN Convention on the Rights of Persons with Disabilities

In December 2006, the United Nations General Assembly adopted the Convention on the Rights of Persons with Disabilities (the Convention). The Convention came into force as part of international law in May 2008. In July 2008, Australia agreed to put the Convention on the Rights of Persons with Disabilities into practice.

The aim of the Convention (Article 1) is to make sure that people with disability enjoy human rights, freedoms and respect as others.

The following is a selection of key parts of the UN Convention that directly impact on people with deafblindness and their access to participation in society. A full copy of the Convention can be accessed at http://www.un.org/disabilities/convention/conventionfull.shtml:
- Article 2 addresses 'Communication', 'Language' and 'Universal Service where access to all is available in the appropriate format, language and design;
- Article 9 addresses 'Accessibility' in all aspects of society;
- Article 21 addresses the 'Freedom of expression and opinion, and access to information, where people with a disability have a right to participate, provide input and access information in their own language (eg; sign language) and accessible formats;
- Article 28 – addresses the right to have an equal standard of living, social equality and support as all others receive.

2.3.2 The National Disability Strategy and ACCAN's perspective.

ACCAN submitted a response to the National Disability Strategy (NDS) discussion paper made available by the Department of Family, Housing, Community Services and Indigenous Affairs in

2008 and the Shut Out report in 2009.

The Federal government asked the Productivity Commission and the Disability Investment Group to make recommendations in response to the reports and ongoing community engagement. ACCAN has asked that the Government "acknowledge that affordable access to communication services and information technologies enables economic participation and promotes inclusive communities as well as assisting people to live independently" (ACCAN, 2010).

Six key principles were written that ACCAN believe the NDS should endorse and adopt:
1. Improve access to preferred information and communication equipment that will enable people with disability to access voice, voice-equivalent or text-to-speech telephony services and the internet and National Broadband Network; People with disability need to have the right equipment to make a call or browse the Internet.
2. Improve available, affordable and accessible communications services for people who are Deaf, or have a speech or hearing impairment to reflect new digital technologies available via the internet and provide access to emergency services via these service channels;
3. Ensure all levels of government and contracted public service providers deliver best practice in the accessibility of electronic, print, web and audio-visual communications;
4. Promote universal design of information and communication equipment by incorporating accessibility criteria in all government procurement policies and publicly funded service provider contracts;
5. Ensure people with disability have affordable and accessible internet, voice and government services delivered via the National Broadband Network;
6. Implement a transition plan to provide for universal audio description and captioned DVDs, Cinema, Online and television broadcast services of high quality, enforced by the Australian Communications and Media Authority.

Telstra is currently responsible for providing 'Standard Telephone Services' to all Australians, under the Universal Service Obligation (USO). Standard Telephone services (STS) are defined as:
• a telephone service fit for the purpose of voice telephony, or
• if voice telephony is impractical for a person with a disability, a form of communication that is equivalent to voice telephony. (ACMA, 2010_4).

As part of the USO, Telstra maintains a Disability Equipment Program, which provides assistive telecommunications technology such as Teletypewriters (TTY) which connect through a Telstra phone line.

It is important to note that the definition of Standard Telephone Services –and therefore the Telstra DEP – does not currently include mobile or internet based services and technologies. ACCAN sees the National Disability Strategy as providing an opportunity to move forward in the expansion of the Universal Services Obligation: expanding its scope to encompass the current standards of digital telephony, providing Australians with disability access to the essential equipment and services they need to interact in the ever expanding information and communications technologies that are part of the Australian social economy (ACCAN, 2010).

The Federal government's establishment of USO Co to "take responsibility for the delivery of the Universal Service Obligation and other public interest obligations" (Department of Broadband, Communications and the Digital Economy, n.d.), will eventually replace Telstra as the USO provider. According to the Department, USO Co's functions will include the provision of funding for the delivery of:

• the USO for voice telephony services, voice equivalent services, and payphones;

• public interest services such as emergency call handling functions (000, 112, 106);

• special services such as the NRS;

• and the migration of voice-only customers to a fibre-based service after the copper exchange is decommissioned.

This new development has implications for what collaborative efforts are made to address the telecommunication needs of deafblind Australians.

The next section will explain the methodology used to obtain data. The analysis demonstrates the successes, failures and gaps in access to telecommunication services for Australian deafblind people.

3. SURVEY FINDINGS AND ANALYSIS

3.1 Methodology

A Project Steering committee was established and met regularly in the early stages of the project to provide information and advice. The initial tasks included establishing an ethics committee to oversee the survey development.

On a broad level, the survey aimed to investigate levels of access among people who are deafblind to mobile, and online telecommunication devices and services such as: TTY (Telephone typewriter), Braille TTY, Large Visual Display TTY, Fax, national relay service, video phone, SMS, email, MSN, Skype, Facebook, Twitter, National Relay Service, Video Relay, as well as online services such as banking, shopping, travel, online learning and social networking. In comparing results with data on the general population, themes related to the needs, barriers and limitations to communications use by deafblind consumers could be identified.

The survey was to be available nationally for any person who is deafblind, regardless of whether they became deafblind at birth or later on, and regardless of whether they use sign language or speech. This would require a range of accessibility considerations, discussed below. The purpose was to obtain data from a wide range of experiences, to understand the experiences of deafblind people using a range of communication technology.

The survey was sent to deafblind people across Australia either by post or email, through Able Australia and Australian DeafBlind Council networks. The digital version of the survey was produced in both Word and Pdf formats, ensuring accessibility for a range of assistive devices. A consent form and an information sheet were sent out with the survey. Members of the Australian Federation of Deaf Societies also forwarded the survey package to their clients, and promoted the study through their networks.

The research consultant was available to assist deafblind people who had trouble accessing the survey format and provided alternate options, including a phone interview.

The sample

There were some limitations to this sample, but the limitations themselves shed light on the nature of the challenges that deafblind consumers face in accessing communications. As such they are traditionally an under-researched part of the community.

- The survey returned 71 responses: this is a very positive result (a 35% response rate), considering only approximately 195 known addresses (home or email) were available from service providers. Many respondents also added comments, which demonstrated their enthusiasm for participating in the research.
- However, the number of responses was small when considering the total number of people who are deafblind in Australia. While we do not have exact figures, reports suggest that the number of people under 65 who have both a severe to profound hearing and vision loss, could be between 3,984 (Prain report 2005) and 6,000 (Access Economics 2007)
- Of the 71 respondents, 14 live in a group home and do not use any telecommunication devices or access any online services. It is understood that most of these 14 respondents have additional disabilities as well as deafblindness. All other respondents currently access least one

telecommunications option.

- Participation in the survey was dependant on the ability to deliver the survey directly to participants via the service providers they were already engaged with (other research suggests that there are large numbers of deafblind people not currently connected in some way to service providers), the accessibility of the information (an Auslan version was unfortunately not possible with limited resources for video production), and the availability of additional support that many participants required (71% of respondents required assistance to complete the survey)

- Responses came predominantly from Victoria (68%). This is likely a result of the strong services and support networks that exist for deafblind people in Victoria. The overwhelming response from one State raises the question of whether results are truly a national response. However, it is well known that Victoria has a large population of deafblind people who have migrated from other States due to the quality of services available to them. The researchers suggest that services available in Victoria such as Ablelink provide an excellent model for other States.

- As the project was based in Victoria, the research team had limited resources to follow up potential respondents in other States and relied more heavily on service providers who had contact with deafblind people;

- The data shows consistently low usage of telephone, fax and mobile phones on a weekly basis among respondents – (1 – 5 times a week) which does not correspond with wider community usage levels of the same communication devices ;

- Many respondents added comments, which demonstrated their enthusiasm to participate;

- Percentages shown are either of the total sample of 71, of total responses to a particular question, or based on responses to a preceding question. These distinctions are made in the text.

The following section provides details of the key findings, quantitative data, comparative data which enables an understanding of how people who are deafblind compare in their usage of telecommunication services with the wider community.

3.2 Findings and Analysis

This section of the report will summarise general observations and demographic data including gender, type of deafblindness, age, communication methods used, where they live, income source, support used to complete the survey and what telecommunication devices they use.

3.2.1 Demographic Information

Male	26	37%
Female	45	63%

Gender

A large proportion of respondents were female, which could lead to an indication that deafblind women use telecommunications and social networking more often than deafblind men. However the findings also show that 58% of deafblind men have a mobile phone, compared to 38% of deafblind women. Interestingly, 48% of deafblind women have a landline compared to 38% deafblind men. In relation to computer usage, 69% of deafblind men have a computer and Internet connection compared to 64% women. This could indicate that deafblind men have been more progressive in take-up of other telecommunication and online options. Support for this

observation is demonstrated further as the findings indicate that only 13% of deafblind women surveyed have used Facebook, compared to 31% of deafblind men.

Age

With 64% of respondents aged 45 years or older, many of them have missed the opportunity to utilise computer and online services skills for potential work opportunities. An ACMA report found that "the majority of older non-internet users see no real benefit in using the Internet, seeing it as not relevant to their lifestyle; while non-internet users aged between 18 and 49 years identified cost as the major barrier to connection" (2009).

Under 18	Number	% of respondents
18 – 24	3	4%
25 – 34	7	10%
35 – 44	15	22%
45 – 54	25	36%
55 – 64	11	16%
65 – 74	8	12%
75 or older	-	

Type of Deafblindness

This data is likely to be somewhat inaccurate, as the question was not sufficiently clear. The main reason for the confusion may be that people who have Ushers Syndrome experience various degrees of dual sensory loss, increasing as they get older, thus their experience may sit somewhere on the spectrum between "born deafblind" and "deafblind after birth". This likely accounts for the 18% of respondents who answered "other". It is also known that Auslan is the first language of many of those who have Ushers Syndrome, and these people may have found the survey inaccessible.

Born deafblind	24	34%
Deafblind after birth	33	47%
Other	13	19%

Living Arrangements

The most interesting statistic in relation to living arrangements of respondents was that 32% live in a supported home (23% of deafblind men live in a supported home compared to 35% of deafblind women). Further research is required to assess the circumstances of supported home living, and to what extent they restrict an independent lifestyle, as well as access to a variety of telecommunication options, particularly for deafblind women.

Live alone	19	27%
Live with partner	17	24%
Live with parents	8	11%
Live in supported home	23	32%
Live with other people (e.g.; friend)	6	8%
Other	4	6%

3.2.2 Availability and affordability of technology and services

WHAT IS YOUR SOURCE OF INCOME?

Work	13	18%
Pension	64	90%

DO YOU LIVE IN THE CITY OR COUNTRY AREA?

City (metropolitan)	58	84%
Country (rural)	11	16%

DO YOU HAVE MONEY / FUNDS TO BUY ACESSIBLE DEVICES?

Yes	19	38%
No	31	62%

WHICH STATE OR TERRITORY DO YOU LIVE IN?

ACT	1	1%
New South Wales	11	15%
Northern Territory	-	-
Queensland	3	4%
South Australia	2	3%
Tasmania	1	1%
Victoria	48	68%
Western Australia	5	7%

It is unknown how many people who are deafblind live in regional and rural areas and there is no doubt that we would have had difficulty reaching them to participate in this survey. 83% of respondents live in the city or a metropolitan area. Services for deafblind people in regional and rural areas are very limited and it is known anecdotally that many have relocated to metropolitan areas to access better support services.

Access to telecommunications services in regional and rural Australia is also limited, particularly in regards to mobile and broadband services. Service costs are higher, which restrict the ability to purchase affordable products and services that deafblind people, who are mostly on a pension income, require.

The response rate according the State or Territory is not surprising, with 68% of respondents residing in Victoria. Victoria has a strong service provider network for many years, including the only computer training centre for people who are deafblind in Australia.

90% of respondents were on a pension, and all respondents who said they work, also said that they receive a pension. Only one respondent has a full time job in the public service and is well supported for his communication and technology needs. The others who work have part time or casual work. 27% of deafblind men have some form of work compared to 13% of deafblind women.

Being on a pension reduces the ability to access expensive assistive hardware or software. Funding options for individuals needing assistive technologies fall into three categories: private purchase, public funding, or other sources such as philanthropic grants. Individuals living with disability have been demonstrated to have significant disability-related expenses and substantially lower incomes than the Australian population in general (Australian Senate Community Affairs Reference Committee, 2002). They therefore tend to have less disposable income with which to privately purchase needed technologies (Saunders & Wong, 2009). A further consideration is that being on a pension provides an avenue to access some equipment free of charge under some funding programs.

The survey asked "do you have money/funds to buy accessible devices?". 38% of respondents answered yes, and 62% answered no. It should be pointed out that many of the respondents who said 'Yes' do not use Braille. The technology that these respondents would have access to is screen reader software that magnifies the images and text on the computer monitors. The cost difference between a screen reader for magnification ($600 – 800) and a Braille device ($3,800 for a Brailliant and up to $10,000 for a BrailleNote) is significant.

Minority groups such as deafblind consumers tend to have little influence over market forces and the types of products and services that companies seek to mass market. In addition, because many deafblind people and people with disabilities are on a pension, or earn lower incomes than the general public, they have fewer funds to significantly impact any competitive trends.

In another interesting observation, "some people with disabilities have been reluctant to acquire mainstream communications products at all because the adaptive equipment needed to make these devices work for them has been too expensive" (National Council on Disability, 2006). Frequently, computers and mobile phones are essential elements to a communication solution, yet while add-on applications and adaptations are sometimes eligible under a state funding scheme, they are of limited or no use without these self-funded 'generic' items. For example, one study participant required a Nokia mobile phone and 'Connie' refreshable Braille device. With these items she is able to independently use public transport safely, to read barcodes in shops, move around using GPS and to text her friends and support workers. At $3,000 the 'Connie' is not eligible for State funding. The Nokia phone ($600) is not funded. Cheaper phones cannot be used with the Connie (Layton et al 2010).

Along with strong support service networks, deafblind people in Victoria have access to funding support programs provided by the Victorian Government that assist in arranging specialised equipment for people with disabilities. These programs include the Victorian Aids and Equipment Program and Individual Support Packages (ISPs), both provided by the Department of Human Services. These programs are not available in most other States and Territories.

The Victorian Aids and Equipment Program (VA&EP) is a subsidy program for the purchase of aids and equipment, and home and vehicle modifications for people with permanent or long term disability. While each State and Territory has their own equivalent government funding scheme, Victoria's programme compares favourably with other schemes and is seen as relatively generous in its equipment provision and lack of means testing. Therefore, the following commentary upon the Victorian funding situation can be expected to be experienced more severely in other Australian jurisdictions.

Recent critiques of the VA&EP identified extremely limited equipment coverage when compared with the variety of technology actually available on the market (Wilson, Wong & Goodridge, 2006; Pate & Horn 2006; Layton, Wilson, Colgan, Moodie & Carter, 2010). The International Standards Organisation (ISO 9999) publish a classification system for assistive products or devices for people with disability, which includes,

'any product (including devices, equipment, instruments, technology and software) especially produced or generally available, for preventing, compensating for, monitoring, relieving or neutralizing impairments, activity limitations and participation restrictions' (ISO 2007:2).

This internationally recognised publication lists a set of Electronic Communication Devices within 'Assistive Products for Communication and Information' (Chapter 22 p 44-50), including:

- 22 12 Assistive products for drawing and writing (incl. portable note taking devices for Braille; manual Braille writing equipment)
- 22 18 Assistive products for handling audio, visual and video information (incl. CCTV; decoders; induction loops)
- 22 21 Assistive products for face-to-face communication (incl. communication boards and symbols; dialogue units or synthetic speech output equipment)
- 22 24 Assistive products for telephoning (and telematic messaging)
- 22 30 Assistive products for reading
- 22 33 Computers
- 22 36 Input devices for computers (incl. specialist software; peripherals)
- 24 24 Assistive products for positioning (incl. desks; workstations)

Of the 89 categories of products listed under this chapter, only 3 are provided by the VA&EP (Layton et al, 2010 p 80). A comparison of the 9 devices offered by Telstra Disability Services with ISO 9999 identifies 2 device categories covered by this scheme. Despite the presence of these two funding schemes in Victoria, the vast majority of enabling technologies for communication and information are not eligible for any funding support.

While this exhaustive taxonomy does list some devices, such as hearing aids, that are available from other sources, Australia's funding support can be seen to be extremely limited overall. Many of the items ineligible for funding from these government sources are useful to a wide variety of people living with the effect of disability or aging, and are crucial to those living with dual sensory loss. A recent study of assistive technology use and unmet need by 100 Victorians with a wide range of disabilities, identified that communication devices 'represent around 32% of items currently in use but ineligible for VAEP funding' (Layton et al, 2010 p 85). Ineligible equipment included customised pens, magnifiers and glare resistant sunglasses; accessible desks, communication boards, computers, software and peripherals; and

mobility canes, proximity monitors, GPS devices and mobile phones. (Layton et al, 2010 p 84).

In 2009, the Department of Broadband, Communications and the Digital Economy (DBCDE), asked for public comment and submissions on the 'Feasibility Study into an Independent Disability Equipment Program'. Able Australia responded that deafblind people being "extremely marginalised because they have not been able to access mobile phones. This is as much an economic factor as not only can they afford access equipment but they also feel they cannot afford their land line, Internet and also a mobile phone" (Tellefson, 2009).

The Able Australia submission goes on to note that for a person who is deafblind to access and utilise a mobile phone, he or she 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

The submission further notes that:
"Access to telecommunication is an equity issue and until is it available, "off the shelf", there is a requirement to develop specialist equipment that provides access. The specialist equipment is an expensive add on and should be subsidised.

"Subsidised Access" does not only mean a subsidy for the individual to purchase the equipment, but it includes the research, testing, configuring and maintaining efficient equipment solutions to ensure access to telecommunication.

Subsidised Access should also include subsidies for monthly plans for all their telecommunications, as this is their sole means of communicating with the world and being able to live independently in their community" (Tellefson, 2009).

The survey asked participants how they paid for the accessible devices they do have. There is some confusion in the responses in relation to who paid for the TTY and Braille TTY. Some indicated that they had paid, but in fact apart from paying the telephone line rental, both equipment items are provided at no charge through the Telstra DEP . However, that a large number of respondents paid for their access to accessible devices or software programs, indicates the economic burden placed on them in order to gain access to telecommunications. Not surprisingly, the findings showed that those who were able to access government funding were pre-dominantly from Victoria which has a range of equipment and support funding programs for people with disabilities not available to the same extent in other States and Territories.

WHAT ACCESSIBLE DEVICES WOULD YOU LIKE TO HAVE?

Braille TTY	2	3%
Braille Note / Pacmate	8	11%

Braille Display	3	4%
CCTV	12	17%
Screen Reader (JAWS / speech)	7	10%
Braille easy-link (for mobiles)	6	8%
Deafblind Communicator	8	11%
Magnification software (e.g.; Zoomtext)	11	15%
Other: list	7	10%

The survey also asked what accessible devices respondents would like to have. The response to this question highlights a plea from deafblind people to have access to accessible equipment and software that would not burden them financially. The current Telstra DEP does not cover many of these 'wish list' items. This indicates that a revised program needs to be considered to be more inclusive of a wider range of accessibility needs, including those of deafblind people. The DEP only targets equipment that assists access to the telephone such as a TTY. It does not include equipment or software programs to access a mobile phone, nor a computer, which enables access to the NRS Internet Relay.

The Productivity Commission's draft report on Disability Care and Support (2011) spells out how a national disability insurance scheme could address the needs of people with a disability not only in relation to "the costs of support" but assisting better access to everyday life including social participation, access to information, referral and web services and funding support.

The report recommends that any support would need to be "reasonable and necessary" (p.20) and would include such areas as:
• Aids and appliances
• Community access support
• Respite
• Specialist accommodation support
• Other (p.21)

It is critical that the Productivity Commission is made specifically aware of the unique needs of deafblind people as highlighted in this report in relation to both communication technology support as well as community access requirements in order to successfully utilise the communication technology available.

3.2.3 Accessibility of Communications Technologies

HOW DO YOU COMMUNICATE?

Auslan	44	62%
Fingerspelling	13	18%
Speech	25	35%
Other	6	8%

SURVEY FINDINGS AND ANALYSIS

DID YOU HAVE SUPPORT TO HELP COMPLETE THIS SURVEY?

Yes	50	71%
No	20	29%

The data indicating how deafblind respondents communicate show that a higher proportion use Auslan and fingerspelling compared to those who use speech. It is important to note that many people will use a combination. In relation to gender and use of Auslan, 65% of deafblind men use Auslan compared to 60% of deafblind women. Interestingly, only 27% of deafblind men use speech only, compared to 40% of deafblind women.

71% of respondents answered that they required assistance to complete the survey. The results of this question indicate that most deafblind people require support to read documents whether in print form or on the computer. Support could be in the form of a person who reads or signs written text, or through accessible technology and/or software. Not all people who are deafblind have access to these support options, which impacts on their participation in community life.

WHAT TELECOMMUNICATIONS DEVICES DO YOU USE TO MAKE CONTACT WITH PEOPLE AND SERVICES?

Computer / Internet	43	61%
Mobile phone	33	46%
Landline telephone	32	45%
Fax	19	27%
TTY	16	23%
Large Visual Display TTY	8	11%
BrailleTTY	7	10%
Communication Board	5	7%
Other	4	6%
None	14	20%

DO YOU HAVE ACCESS TO A LANDLINE TELEPHONE, MOBILE AND INTERNET SERVICE?

Landline	Yes	49	69%
	No	8	11%
Mobile	Yes	32	45%
	No	19	27%
Internet	Yes	43	61%
	No	9	13%

As indicated earlier in this report, 14 of the 71 respondents (20%) do not have access to telecommunications in their home. It is understood that most of these 14 respondents also have other disabilities.

Further research is required to assess whether any form of telecommunications access could assist their independence or participation in the community.

According to two studies by the Australian Communications and Media Authority (ACMA), 88% of people have a home landline (2009, p.10) and 82 per cent of adult consumers with a fixed-line telephone used three or more communications services (ACMA, 2010_2). The survey findings indicate that 86% of deafblind respondents, not including those who live in group homes with no access to any telecommunication devices, have a landline service at home, and 56% have a mobile phone service. 75% have an Internet service (either dial-up or broadband). If we include all respondents, then the data indicates that 69% have a landline, 45% has a mobile phone and 61% have an Internet service.

Landline

While 69% of deafblind respondents state that they have a landline at home (also called fixed line), only 45% of respondents use the service regularly. For deafblind people, direct phone calls via a landline would require a TTY, Braille TTY, or Large Visual Display TTY, and/or the use of the National Relay Service (NRS).

TTY	16
Braille TTY	7
LVD TTY	6
Telephone handset	25
Other – cordless phone	3

HOW OFTEN DO YOU USE YOUR TELEPHONE/TTY?

None	9	18%
1 – 5 times a week	29	59%
6 – 10 times a week	5	10%
11 or more times a week	4	8%

ABOUT YOUR LANDLINE PHONE (% BASED ON 49 RESPONDENTS WHO HAVE A LANDLINE)

Can you hear on the telephone?	Yes	19	39%
	No	28	57%
Do you have volume control on the phone?	Yes	31	63%
	No	15	31%
Do you have a phone with large buttons?	Yes	14	29%
	No	29	59%
Can you answer the telephone when it rings?	Yes	23	47%
	No	23	47%

Do you have an accessible device that works with your telephone? For example, flashing light or vibrating pager.	Yes	26	53%
	No	20	41%

Phone use data indicates that deafblind people do not use the landline often. 77% of respondents who have a landline only use the phone up to 5 times a week or not at all. Only 8% make more than 11 calls per week.

This statistic is in stark contrast to the average number of phone calls made by other Australians. While we don't have evidentiary data, anecdotal information indicates that the phone is used for calling family, friends, making appointments, getting information, paying bills and countless other things. The ability to communicate through the telephone helps bind the community together and allows an avenue for social participation and enjoyment (Power & Power, 2004, 2007).

Of interest in the responses on landline phone services, many respondents did not have a phone with large buttons (59%), when Telstra provide a "Big Button / Multi Purpose phone" through the DEP, which has buttons twice the size of the normal phone as well as volume control. This phone is available through the DEP.

Further investigation is required on how deafblind people access the landline phone, to assess why of the 57% who cannot hear on the phone, 30% do not have volume control (it could be that many of the respondents use a Teletypewriter (TTY) or related equipment). It is also unclear why 47% cannot answer the phone when it rings despite the availability of accessible devices (vibrate alert systems, flashing lights, tactile devices, etc.) to support them. Is a "Big Button" phone with volume control and a vibrate alert connection a solution for those deafblind people who have some hearing?

PLEASE RATE YOUR PHONE SERVICE (% BASED ON 49 RESPONDENTS WHO HAVE A LANDLINE)

Very Good	Good	OK	Fair	Not Good
8	18	11	1	6
16%	37%	22%	2%	12%

IF YOU ARE UNHAPPY WITH YOUR PHONE SERVICE PLEASE TELL US WHY

Costs too much	11	22%
Poor service	6	12%
I don't need it	1	2%
Don't know	-	0%
Other	5	10%

According to an ACMA study, 81% of respondents, reported high levels of overall satisfaction with their fixed-line telephone (2010_3, P.9). While 75% of deafblind respondents who had a landline at

home reported satisfaction with their service, a sizeable number of respondents (22%) expressed that the service is too expensive.

While the Telstra DEP program is essential, there are limitations. Many who have TTY related products or other equipment provided by the DEP would be locked into a Telstra service, as a requirement to access the service is payment of a phone line rental. While they have the ability to make a choice from other providers supplying mobile phone and broadband services, they are unable to take advantage of bundling options because the phone is locked with Telstra.

The fixed line phone solution provided by the Telstra DEP for deafblind people with low vision, is a Large Visual Display unit with no features to adjust the size, colours or speed of the scrolling text. Using a TTY may not be comfortable for someone who uses speech, as there is no voice input. Further, people who are deafblind do not have access to ongoing training to ensure they are able to use the equipment to its full extent. When the equipment breaks, they therefore cannot use the telephone and they are reliant on support services or friends to help organise for repairs. There is some training available from the National Relay Service (NRS), in how to use a TTY to access the NRS. Other features of the device are not covered in training, and it is unclear to what extent the training officers have skills and knowledge of how TTYs are used by people who are deafblind.

Braille Devices

The solution for deafblind people with no functional vision is a Braille TTY. These devices were introduced about twenty years ago and provide deafblind people access to the phone either directly to another TTY or to any phone via the National Relay service.

Braille TTYs enable deafblind people who use Braille to access the telephone service. Like the TTY and Large Visual Display TTY, Braille TTYs have been provided to deafblind people through an application to the Disability Equipment Program (DEP) managed by Telstra Australia. The only cost is the monthly line rental charge. This unit is a standalone unit and was developed by Telstra, at considerable cost, to satisfy the Universal Service Obligation. The TTY is designed to display scrolling text typed at the speed a person is talking. The Braille keyboard connects to the TTY and displays this scrolling text. This device has extremely low usage within the deafblind community.

The problems are complex:
• Very few Braille readers can read scrolling text at the speed a person is talking
• The Braille is only in Grade 1, making reading it even slower.
• There is no way to navigate back through the conversation.
• The TTY Unit is not a standard model and learning its command structure is difficult.
• Ongoing maintenance issues.
• The "Braille TTY" has not evolved to embrace emerging technologies – it is still the same unit that was first introduced in 1990.

Further, some deafblind people are not fully proficient in reading or using Braille and require

training in literacy and Braille skills –those that use Auslan would require an Auslan interpreter to access Braille training and unfortunately there is no funding to support the interpreter access. These problems indicate why there are low usage levels with Braille TTYs.

Due to the prevalence of Usher Syndrome within the deafblind community and the fact that Retinitis Pigmentosa is a deteriorating eye condition, there is a dire need for deafblind people to learn Braille. Currently, this is the only way a person can access a computer or phone when they no longer have any functional vision or hearing. It is very difficult for a person who is deafblind to access Braille training in Australia, due to the cost of interpreters and the one to one support required to teach this skill.

The situation is exacerbated, as people who are blind are tending to move away from Braille, given the range of technological audio based solutions available. Many children who are blind no longer learn Braille at school and there are even fewer adults with late onset of blindness who learn Braille. For many people with dual sensory impairment however, Braille continues to be essential.

Braille Training is almost non-existent for the deafblind community. The training requires an interpreter and the training materials need to cater for students with English as a Second language. The training takes more time and most organisations that provide services for people with vision impairment do not have the resources or expertise to offer Braille training for the deafblind community.

Several factors affect access to Braille devices for people who are deafblind:
1. Braille Devices are expensive.
2. Braille devices are not designed for deaf people. They are built for people who are blind, and who rely predominantly on speech output with Braille as an additional output. The speech is overly verbose and often quite technical, making it unnecessarily difficult for a Braille user.
3. Australian Suppliers don't have the local markets to supply a wide range of Braille displays.
4. Configuring a Braille display to work with a mobile phone has is quite complex and is not really done by the suppliers as their objective is to find speech solutions and Braille is never tested as the sole output. Furthermore, suppliers are unable to "product test" a range of products other than their own.
5. Able Australia informally does product testing, but does not have the funds to buy the range of products as they become available, to adequately test them.
6. Many of the support workers for a deafblind person are deaf and can provide no assistance if the Braille device has speech output and no visual display.
7. Many deafblind would benefit from also having a screen with magnification as they can use some functional vision to assist with their learning, but Braille solutions don't usually include low vision solutions. This doesn't impact so greatly on a person who is blind or has low vision, as they can use speech as their alternative output. Solutions need to combine magnification and speech and Braille but mostly they only provide ONE option. The new iPhone doesn't provide magnification AND Braille at the same time.

A Braille device is an expensive way to access a computer or phone and general support for Braille devices is generally not strong among service providers. When attached to a phone or computer, Braille is a mechanical representation of the screen reader. Braille is tacked on as an afterthought and as such, is usually clunky, difficult, non-intuitive, and above all, expensive.

This comes back to Universal Design and the need to provide truly flexible options. If a solution works for a small community of deafblind people with complex sensory needs, it will be robust and flexible enough for large numbers of the community. If Access Economics figures are accurate, then the community will benefit from this valuable insight into the need for truly customizable solutions as the top priority in Universal Design.

In the computer world, it has largely been the success of customized accessibility options built into the operating system that have provided the best access to computers to the majority of people. This has been achieved largely due to American legalisation but the result is of great benefit to the whole community who have embraced "Personalised" settings in creative ways.

The National Relay Service

DO YOU USE THE NATIONAL RELAY SERVICE?

Yes	27	38%
No	30	42%

The National Relay Service (NRS) was established by the Federal Government in 1995 with the aim to provide a telephone connection between deaf, hearing impaired, deafblind and speech impaired people, with hearing people –and vice versa. Available 24 hours a day, 7 days a week, it enables users of text communications such as TTYs, Braille TTYs, Large Visual Display (LVD) TTYs and computers (via Internet Relay), to make telephone calls in the same way that everyone else can enjoy. The Australian NRS was the first relay centre in the world to provide a dedicated emergency service number (106).

Of the 57 respondents who have a telecommunications service, 47% have used the NRS, and 53% do not use it. Although the NRS is a valuable and appreciated service, there are difficulties with achieving a seamless connection and communication.

HOW DO YOU ACCESS THE NATIONAL RELAY SERVICE? (% BASED ON 27 RESPONDENTS WHO USE THE NATIONAL RELAY)

TTY	13
Braille TTY	5
LVD TTY	4
Internet Relay	10
'Speak and read'	-
Other	1

Survey results suggest that most calls to the NRS are from TTY callers; for a deafblind person to participate in a call conversation with a hearing person, a relay officer types back what the hearing person is saying then types 'Go Ahead' (GA) allowing the TTY caller to respond. For deafblind people to use this process effectively, it will depend on a number of things:

• English literacy skills that enable them to converse with the hearing person via text;
• Ability to see and read the text on the screen (TTY and LVD TTY);
• Ability to maintain the pace of conversation (relay officer typing speed);
• Braille reading and typing skills when using Braille TTYs;
• Ability to navigate an online Internet Relay service and see the text on the screen.
• Relay officer recognising that a deafblind user is part of the call and understanding their particular communication needs

Training is usually initially provided to the deafblind person to learn how to use the NRS, but ongoing support or training to improve their skills in using the service are not available. An ACMA report on the performance of the NRS in 2008-9 notes that "there appears to be a declining need for training sessions among potential NRS users in recent years" (ACMA, 2010). The report goes on to suggest that the advent of the Internet Relay, improvements in information provision of the NRS website and familiarity with the Internet are factors in why fewer training sessions are required (ACMA, 2010). As you will note further in this report, NRS usage levels by deafblind people are very low, suggesting that training for deafblind people to better access the NRS and in particular Internet Relay is critical and overdue.

HOW OFTEN DO YOU USE THE NATIONAL RELAY SERVICE? (% BASED ON 27 RESPONDENTS WHO USE THE NATIONAL RELAY SERVICE)

None	3	11%
1 – 5 times a week	17	63%
6 – 10 times a week	1	4%
11 or more times a week	4	15%

According to the 2008-9 NRS Performance report, over 8,000 deaf, deafblind, hearing and speech impaired people are accessing the NRS every month (ACMA, 2009). To give some indication of how small the usage level by deafblind people is, of the 27 who use the NRS, 20 (74%) respondents use the service up to 5 times a week or not at all. Only 19% of survey respondents use the NRS more than 11 times a week. This is an important statistic and indicates that despite the NRS providing a 24/7 access 'bridge' between deafblind and hearing people (as with others), it is being under used by deafblind people. The survey results suggest that there may be some additional barriers to the ones identified above. This needs to be investigated further by the NRS and the government.

PLEASE RATE THE NATIONAL RELAY SERVICE

Very Good	Good	OK	Fair	Not Good
6	10	7	1	2
22%	37%	26%	4%	7%

IF YOU ARE NOT HAPPY WITH THE NATIONAL RELAY SERVICE (NRS), PLEASE TELL US WHY:

Poor help desk service	2
Relay Operator types too fast	5
Relay Operator forgets I am deafblind	2
I can't use Internet Relay	1
I can't read the website for information	1
Don't know	-
Other	3

Of the 27 respondents who use the National Relay Service, despite an overall high satisfaction level (85%), a significant number (52%) have made comments about why they are not happy with their access to the service. These comments correlate with the anecdotal experiences deafblind people have raised previously and supports the need for better dialogue between deafblind people and the NRS, as well as consideration for targeted training to improve their access and usage levels. Currently, no deafblind person is a member of the National Relay Service Consultative Council (NRSCC).

Emergency Services

CAN YOU ACCESS EMERGENCY SERVICES (FIRE, POLICE AND AMBULANCE)?

Yes	34	48%
No	14	20%
Did not answer	23	32%

IF YES, WHICH NUMBER DO YOU RING TO CONTACT EMERGENCY SERVICES?

000	26	76%
106	10	29%
112	1	3%

Data shows that 25% (14) of deafblind people who have some form of telecommunication service cannot access emergency services. When emergency services are supposed to be accessible to all, this is very troubling. A 106 service was established for deaf, deafblind and speech impaired people to access emergency services via a TTY or related devices. The data shows that of 30 respondents who have, a TTY, Braille TTY or Large Visual Display TTY only 10 (33%) know how to access it.

Many people may not be aware of the challenge that Deaf and deafblind people face in accessing 000. Deaf people calling 000 directly without using a relay service may be seriously disadvantaged; 000 will request the caller to say 'police, fire, or ambulance' in order to assess whether the call is a legitimate request for assistance. If the operator receives no response, they will ask the caller to dial '55'. If the caller cannot hear this request they will be disconnected and will receive no assistance. Clearly, urgent action is required to ensure all deafblind people can access emergency services.

SURVEY FINDINGS AND ANALYSIS

Fax

DO YOU HAVE A FAX MACHINE?

Yes	26	37%
No	29	41%
Did not answer	16	23%

While fax machines are declining in popularity, people who cannot afford the high costs of alternate telecommunication options are still using them. This is particularly the case for those living in regional and rural areas, who cannot afford STD or mobile charges. It is well known that when fax machines became available, deaf people were quick to adopt them for social and business communications because of the visual nature of the technology and the relatively low cost (Power & Power, 2007). Deafblind people who have some vision would use them with large markers so that the written message was reasonably easy to understand. Fax machines are reasonably user friendly and not much training is required to use them compared to a mobile phone or computer / Internet service.

HOW OFTEN DO YOU USE A FAX MACHINE?

None	8	31%
1 – 5 times a week	13	50%
6 – 10 times a week	3	12%
11 or more times a week	2	8%

Of interest, is the number of times the fax machine is used on a weekly basis – 81% only uses the fax up to 5 times a week or none at all. This raises the question of cost vs. benefit of fax devices, however anecdotal evidence suggest that they are a useful backup device when other options fail. The problem that these consumers face however is that as fax is an increasingly outdated technology, there are fewer people and services can be communicated with by fax.

Mobile

In comparison with the general Australian population's use of telecommunication devices, 85% of Australians have a mobile phone (ACMA, 2010), whereas the findings from the survey indicate only 48% of deafblind people surveyed have a mobile phone. The real figure is likely to be smaller given that respondents were people who had already accessed deafblind services, and have received some degree of support in finding a communications solution appropriate for them. Those who have not accessed deafblind services are likely not to have the same level of telecommunication devices or services. This requires further investigation.

Do you have a mobile telephone at your home?	Yes	34	48%
	No	22	31%
Can you hear on the mobile?	Yes	14	20%
	No	20	28%

Do you have volume control on the mobile?	Yes	22	31%
	No	11	15%
Do you have a mobile with large buttons?	Yes	3	4%
	No	30	42%
Can you answer the mobile telephone when it rings?	Yes	21	30%
	No	13	18%

What type of mobile phone do you have?	
i. Nokia	20
ii. Samsung	3
iii. LG	4
iv. Sony Ericsson	-
v. iPhone	5
vi. Motorola	1
vii. Other	2
Do you have an accessible device that works with your mobile phone?	Yes	26	37%
	No	20	28%

IF YES, WHAT DEVICE DO YOU HAVE?

Braille Easy Link	1
'Voice over'	-
Other - magnification	8

**HOW OFTEN DO YOU USE A MOBILE PHONE?
(% BASED ON 34 RESPONDENTS WHO HAVE A
MOBILE PHONE AT HOME)**

None	2	6%
1 – 5 times a week	13	38%
6 – 10 times a week	3	9%
11 or more times a week	16	47%

Similarly to landline usage, mobile phone usage by people who are deafblind is considerably lower than the rest of the community. 44% of respondents who have a mobile phone only use the phone up to 5 times a week or none at all. Correspondingly, 47% use the mobile phone more than 11 times a week.

Mobile phone charges for many are prohibitive and the evidence indicates that almost half of the deafblind respondents who have a mobile phone are not getting value for their money due to low usage.

WHAT SORT OF PHONE BILL DO YOU HAVE?

Prepaid	12	35%
Monthly Plan	20	59%

The 2010 ACMA study on the take up and use of voice services by Australian consumers indicates that the "level of mobile phone take-up among household consumers in Australia stood at 85% at June 2010. (2010-2, p.12). 68% of consumers were on a contract with a monthly bill (capped or pay-as-you-go), while 32% were pre-paid customers. (2010_2, p.16). Of the deafblind respondents, Of the deafblind respondents who use a mobile service, 59% have a monthly plan, and 35% have a pre-paid arrangement.

PLEASE RATE YOUR MOBILE PHONE SERVICE

Very Good	Good	OK	Fair	Not Good
5	14	4	6	3
15%	41%	12%	18%	9%

IF YOU ARE NOT HAPPY WITH YOUR MOBILE PHONE SERVICE, PLEASE TELL US WHY:

Costs too much	6
Poor service	5
Poor mobile reception	3
I am on a contract	4
I don't need it	1
Other – keypad too small/poor LCD screen	5

The 2010 ACMA study included questions on satisfaction with various telecommunication services. In relation to mobile services, 80% of respondents who use a mobile service reported high levels of overall satisfaction (2010_3, p.9). A significant proportion of deafblind respondents reported satisfaction with mobile phones services. Of the 34 respondents who have a mobile phone, many also expressed dissatisfaction with the service due to services being too expensive, being provided a poor service or phone access problems.

With the mobile services market now providing more than just voice call options (for example SMS, email, Internet, videocommunication, games and so on (ACMA, 2010), deafblind people are struggling to access basic mobile services due to access requirements such as screen readers, Braille connectivity, text to speech software, etc. This equipment is not available or affordable because mobile services are not covered under the Universal Service Obligation which provides for the Telstra DEP funding. In reality, this represents a missed opportunity, and leaves deafblind consumers isolated from enjoying the range of communication options available to others.

Computers, Internet & Websites

I HAVE RECEIVED COMPUTER TRAINING

Yes	35	61%
No	12	21%

As more than the number of respondents who have an Internet service answered this question, the percentage calculation is based on the total number of respondents who have a telecommunications device or service (57).

IF YES, WHERE FROM?

School	4	7%
Home	8	14%
Friends	7	12%
AbleLink	19	33%
Training Course / Classes	11	19%
Work	7	12%
Other	6	10%

Some respondents provided multiple answers to this question.

A recent ACMA study indicated that 77% of Australians had a computer and internet connection in their home (2010-1). Only 61% of deafblind people had access to a computer and an Internet connection.

DO YOU HAVE AN INTERNET SERVICE?

Yes	43	61%
No	13	18%

A reasonably high number of respondents who have a telecommunication service have an Internet service (75%). This compares with 77% of the general population. While there is not much difference between the two groups in Internet connectivity statistics, there is a marked difference between the two groups in the level and variety of usage. This report indicates some examples of the disparity and why.

The 2010 ACMA report also shares the frequency of Internet use in Australia:
* 28 per cent of the total Australian population aged 14 years and over were estimated to be 'heavy' internet users (online more than 15 hours a week);
* 27 per cent were considered to be 'medium' internet users (online between 7 and 15 hours a week)
* 23 per cent 'light' Internet users (online up to 7 hours a week) (2010-1).

This survey erred in not asking how often the Internet is used and this should be followed up

in future research opportunities, but given theusage levels of other communication technology by people who are deafblind, and the difficulties they have with accessing computers and the Internet, anecdotal evidence indicates that current average usage levels of other communication would be low.

WHAT SORT OF SERVICE DO YOU HAVE? (% BASED ON 43 RESPONDENTS WHO HAVE AN INTERNET SERVICE)

Dial-up	5	12%
Broadband	33	77%

At June 2010, approximately 77 % of the population 14 years and over were connected to the Internet at home and 66% had a broadband connection (ACMA, 2010). According to our findings, 77% of deafblind respondents have a broadband connection and a few respondents did not know which service they have.

WHICH INTERNET SERVICE DO YOU USE? (% BASED ON 43 RESPONDENTS WHO HAVE AN INTERNET SERVICE)

Telstra Bigpond	20	46%
Netspace	4	9%
TPG	1	2%
TadAust	4	9%
iPrimus	1	2%
Other	13	30%

As earlier pointed out, many respondents are tied to a Telstra connection because they already have a Telstra service via their DEP equipment provision linking to a Telstra line rental service.

HOW DO YOU ACCESS YOUR INTERNET SERVICE? (% BASED ON 43 RESPONDENTS WHO HAVE AN INTERNET SERVICE)

Braille Note / Pacmate	3	7%
Braille Display	4	9%
Screen Reader (JAWS or speech)	8	18%
Magnification software (e.g.; Zoomtext / Window Eyes)	22	51%
Other (e.g.; fatbits, large screen, etc)	9	21%

A range of hardware and software programs allows access to the information provided on the Internet. Some respondents have a mix of access devices that support different purposes. Sometimes a magnification software program cannot satisfactorily access a graphic or picture and so a screen reader program might assist. Many of these items are expensive and time consuming to learn to use effectively. Many have had these devices or programs for years and still have not learned how

to use basic and popular services that others take for granted.

PLEASE RATE YOUR INTERNET SERVICE (% BASED ON 43 RESPONDENTS WHO HAVE AN INTERNET SERVICE)

Very Good	Good	OK	Fair	Not Good
11	15	8	3	2
26%	35%	19%	7%	5%

IF YOU ARE NOT HAPPY WITH YOUR INTERNET SERVICE, PLEASE TELL US WHY:

Costs too much	6
Poor service	4
I am confused by Internet plans	2
Poor Internet reception	4
I am on a contract	1
I don't need it	-
Other	4

The 2010 ACMA study included questions on satisfaction in relation to Internet services with 80% of respondents who use an Internet service, reporting high levels of overall satisfaction (2010_3, p.9). 75% of deafblind respondents reported satisfaction with their Internet services. Of the 43 respondents who have an Internet service, many also expressed dissatisfaction with the service due to services being too expensive, being provided a poor service, confused about their Internet plan or poor Internet reception problems, etc.

DO YOU FIND IT EASY TO READ WEBSITES?

Yes	19	33%
No	31	54%

As more than the number of respondents who have an Internet service answered this question, the percentage calculation is based on the total number of respondents who have a telecommunications device or service (57). Findings show that a significant proportion of the deafblind respondents (54%) indicated they have difficulties with accessing a website.

IF NO, WHY IS IT HARD TO READ WEBSITES?

Too much information	8
No text only option	7
I can't change screen colour to help me read	5
I can't use the mouse to navigate the website	3
Font size is too small	6

Not enough pictures and photos	3
Other – no access to magnification, need support assistance, don't understand the words	6

The reasons listed in the above table reinforce the difficulties deafblind people face when accessing websites. Many websites do not support web standards (e.g.; W3C). Vision Australia note increasing problems with website access as people who are blind or have low vision "face an uphill battle with the growing prevalence of touch screen technologies that are totally inaccessible, the persistence of online information being provided in only inaccessible PDF formats, and an increasing web based consumerism that is unregulated and often inaccessible, to name but a few areas of growing concern" (Ah Tong-Pereira, 2009). For deafblind people, the issues are the same, only more difficult as text – to - speech software will only work for those who have some hearing.

HAVE YOU HEARD OF THESE SOCIAL NETWORKING SITES?

Facebook	39	55%
My Space	17	24%
MSN / Yahoo	31	44%
Skype / ooVoo	24	34%
Blogging	12	17%
Twitter	15	21%
LinkedIn	7	10%
Wikipedia	18	25%
You Tube	21	30%

While there is comparatively high awareness level of Facebook among the deafblind respondents, only 8 out of 39 respondents are actually using it. Likewise 24 respondents are aware of Skype and ooVoo as videocommunication options but only 2 are using it or have tried it. One respondent has tried blogging compared to 35% usage levels in the wider community (ACMA, 2010_1).

WHAT ONLINE SERVICES DO YOU USE? (% BASED ON 43 RESPONDENTS WHO HAVE AN INTERNET SERVICE)

Banking	11	15%
Shopping	9	13%
EBay	4	6%
Online learning	8	11%
Government services	15	21%
Other (list)	3	4%
None	17	24%

According to a recent ACMA study, 64 per cent of persons using the Internet via a computer went online for banking and finance related activities and according to our survey only 11 out 57 deafblind respondents (19%) use such services (2010_1).

As already noted that deafblind people have many barriers in accessing the computer, the Internet and online services, their lack of confidence in doing financial transactions online where they cannot visually see what is going on (in comparison to going to a bank) is very real. This deserves further investigation to substantiate the reasons behind the very low usage levels towards online services.

It is clearly evident that deafblind people who live in Victoria benefit from the services Ablelink provide. The ability to organise structured or unstructured training and visit Ablelink as a drop-in centre to meet other deafblind people provides a positive training and social networking environment.

If yes, can you tell us what problems you have had?

HAVE YOU HAD PROBLEMS WITH INTERNET SCAMS OR OTHER ONLINE SECURITY ISSUES?

Yes	19	27%
No	12	17%
I don't know	4	6%

As deafblind people become more proficient at using telecommunications and online services, they are at risk of fraudulent behaviour by scammers and hackers. These type of fraud schemes occur in emails, web sites, chat rooms, message boards, etc. As many deafblind people are not able to fully access what is happening on the computer screen at one time, they could be easily tricked and not aware that information is false or that a computer virus is downloading. With the high number of problems and concerns expressed by deafblind respondents, a possible solution to reduce risk is awareness training.

People pretending to be a friend	17
Getting an email asking me to donate money	19
Getting an email asking for my credit card and bank details	9
Getting an email telling me I have won a prize	15
Computer viruses or other malicious software	13
Other (list)	5

The low response in following up problems supports the urgent need for awareness training for deafblind people.

WHEN YOU HAD A PROBLEM, WHO DID YOU TELL?

My family	13
Police	3
Able Australia staff	8
Others	8
No one	2

Of the 57 respondents who have some form of telecommunications access, 38 (66%) have either a PC or Apple computer.

WHAT SORT OF YOUR COMPUTER DO YOU HAVE AT HOME?

Desktop Computer (PC)	37	65
Desktop Computer (Apple)	1	2
Laptop Computer (PC)	17	30
Laptop Computer (Apple)	3	5
Other (netbook)	1	2

WHAT DO YOU USE THE COMPUTER FOR?

Getting information on the Internet	34	79
Photos	21	49
Email	39	91
MSN or Yahoo (Instant messaging)	16	37
Facebook (Social networking)	14	32
Games	8	19
Writing stories	12	28
Video communication (e.g. Skype)	13	30
Other- online learning / study, letters, volunteer work.	7	16

WHICH DO YOU SPEND MOST OF YOUR TIME DOING ON THE COMPUTER?

Only pick 3 please

Getting information on the Internet	27	63
Photos	6	14
Email	38	88
MSN or Yahoo	11	25
Facebook	8	19
Games	6	14
Writing stories	7	16

Video communication	2	5
Other (research, info storage, work)	6	14

A 2010 ACMA study on the "shift to an Online environment" indicated that Australians are using Facebook 81% of time while on social networking sites (2010_1). Survey results show that only 19% of deafblind respondents use Facebook regularly. It would be a useful exercise to further investigate why there is such a low figure, what barriers prevent greater usage levels and whether such social networking sites are accessible to deafblind people who use Braille devices.
Chat is an increasingly popular pastime for online social networking, yet only a small number use MSN or Yahoo, Facebook and videocommunication. Only one (1) deafblind respondent has experienced blogging. Deafblind women were under-represented in usage levels of chat programs with only 3 out of 43 respondents having used Facebook. According to the ACMA, 85% of Australians over the age of 14 years are accessing social networking sites such as Facebook (2010_1, p.20).

The gap between deafblind respondents and the rest of the community who use social networking sites is enormous and indicates that deafblind people, in particular deafblind women, are missing out on a free and popular communication and social participation option that many others enjoy.

The Australian Deaf community who use Auslan is beginning to embrace videocommunciation with the availability of free online services such as Skype and OoVoo and the Australian Communication Exchange providing a free Video Relay Service trial. Government funded Video Relay Services (VRS) have been available overseas for a number of years (Sweden since 1998, USA since 2002) and requires high speed broadband and access to a webcam to operate. While VRS presents some difficulties because it requires reasonable vision to see the other person on the monitor who is actually in a remote location, there are solutions to limit the barriers for those deafblind people who use Auslan, such as full screen projection of Auslan communication as well as a support person or interpreter being available to interpret for those who require tactile communication. This latter solution is available in the USA and Sweden.

For many Australians the Internet is also becoming an important source of news and information with over 6 million persons accessing the mainstream online news sites from home during June 2010 (Australian Communication & Media Authority, 11 November 2010). It would be interesting to investigate what percentage of the 27 respondents who accessed the Internet for information also sourced the news online.

4. WEBSITE AND CASE STUDIES:

An important feature of the project has been the development of a website with a focus on providing accessible information to deafblind people about telecommunication and online services and products.

Peter Tarrant, who is a deafblind person himself, has been undertaking this work with guidance and support from Claire Tellefson, the Ablelink Co-ordinator. Peter has been involved with Ablelink for more than 12 years and has assisted the collation of information on technology from Australia and overseas relevant to people with deafblindness and stored on the Ablelink website. The new website, found at www.dbt.org.au will include accessibility features to ensure it can be accessed by anyone.

The website will also attempt to help introduce popular online services such as text and video blogging to deafblind people in a safe website environment. It is a website that is 'owned' by the deafblind community, supported and guided by Ablelink and Able Australia staff.

During the project we were able to develop case studies that mirrored the experiences that deafblind people currently have with communication technology. Below are seven examples that show how adaptive technology can provide a bridge to communications access but also demonstrate where barriers occur with mainstream products. The case study names are pseudonyms.

CASE STUDY 1 FRANK

Frank is deafblind and has Ushers Syndrome (Type 1). Profoundly deaf since birth, he developed Retinitis Pigmentosa (or tunnel vision) as he got older. Frank has a tiny amount of remaining functional vision but relies on tactile communication in Auslan and uses a cane to assist him with mobility.

Frank learnt Braille when he was first losing his sight and prefers to type using a Braille keyboard. When he first went to Ablelink to learn how to use a computer, he was unable to touch type and his functional vision was not enough to see the keys. It was not practical to attach a Braille keyboard to a computer so he first had to learn to touch type. He did this using a set of Braille instructions.

Frank has a Braille TTY at home for making phone calls. He doesn't use the relay service via computer. Frank has had problems booking a taxi via the relay service using his Braille display as his request arrives on a special TTY and not through the regular booking. However, the taxi service has been good at following up on these issues.

Frank does not have a mobile phone and cannot use SMS. This makes him feel "out of the loop" with his deaf friends. He mainly uses email for communication and belongs to many email lists of deafblind groups around the world. Now he uses Facebook to connect with a wider circle of friends.

Frank started learning Windows, by using a Braille display to read the screen and using a Qwerty keyboard to input commands.   His progress was extremely slow because of the visual nature of

Windows and the complicated Braille representation. Frank started to make progress when he was able to change the display colours on the monitor (black background with yellow text) and change the size and colour of the mouse pointer. He was able to recognize menus and commands using a handheld magnifier. Once he is in his email or in the Internet he reads the text using a refreshable Braille display. The Braille display works by displaying the text that is spoken by JAWS screen reader, although Frank turns the speech off.

Frank also uses some free software (called Fatbits) to magnify the information on the screen that he is unable to magnify within Windows settings. It works in the same way as Microsoft's docked Magnifier.

Frank continues to visit Ablelink to improve his computer skills and knowledge. When he has problems at home, he comes to Ablelink to learn how to solve them and fix them himself.

Frank has a personal computer at home with a refreshable Braille display. He has also set up home networking, including a wireless connection for his Internet. It was quite a challenge to add broadband to his existing TTY and fax connection. Frank also has a Pacmate – a Braille notetaker without a screen. This has been very challenging to learn but he prefers to check Facebook on his Pacmate, using his wireless connection.

He uses email, the Internet, deafblind discussion groups and reads newsletters, using his Braille display via screenreader software. His most enjoyable pastime on the computer is making simple animations. Frank has MS Office 2000 on his computer and is able to use Word documents, calendar, email and the Internet. He finds Windows 98 and Windows Vista the easiest operating systems to access. He finds Windows 7 difficult and confusing.

His biggest problem with computers is when there are photos and videos on email attachments or the Internet – he is not able to access them because there is no text reference to explain what they are. Frank also has problems checking his beloved Carlton football scores on the AFL site as they keep changing it and adding advertising or banners that interfere with his Braille display.

Accessing information and being able to communicate with other people enables Frank to be more independent and feel more involved with his family, friends and other people.

CASE STUDY 2 JULIE

Julie is deafblind and has Ushers Syndrome. Deaf since birth, she lost her sight as a young adult. Julie uses Auslan to communicate and uses Braille (both grade 1 and 2). Julie cannot see well enough totally relies on Braille to link to any communication devices to access information. Julie uses a range of communication technology.

Nokia E75 mobile phone

Julie bought this recently after searching for a long time to find a Braille device that worked with mobile phones. Ablelink was able to help her trial two Braille devices that worked with Nokia mobile phones. After a few weeks she decided Easylink suited her best and Ablelink helped train her to

use it. The Easylink Braille device uses a Bluetooth connection to the Nokia E75 and works well. The Easylink device only works with mobile phones that have the Symbian operating system.

Julie is able to use SMS and vibrate alert. Vibrate alert is great for when SMS messages arrive and she also uses it for an alarm. One day she wants to learn how to use the calendar, email and the Internet. She is now learning how to read text in shorthand because often SMS calls do not use full spelling (for example, "LoL" means "Lots of Laughs", "Laugh out Loud", or "Lots of Love").

Julie uses the mobile phone to make appointments, contact friends and family and use it for emergencies. Mobile SMS calls can be made anywhere and anytime. Julie shared an experience where soon after getting the mobile phone she had a sudden back problem and was lying on the ground and not able to get up. She was able to access her mobile phone nearby and sent an SMS to a friend who quickly came to her home and helped her out. If she had not had the mobile, she could have been stuck for hours and at risk. Having a mobile phone makes her feel more safe and independent.

Julie has found that having a mobile phone allows her to feel the same as everyone else – being able to access a mobile and make SMS calls. Making contact with people is quicker than email.

Julie has a prepaid plan and is now finding she is saving money and time not having to use the TTY or emails as much to contact people.

Computer access

Julie has used a computer for a number of years, first learning basic computer skills at RVIB (now Vision Australia), then accessing more regular training at Ablelink. She has a PC with a Windows XP system. To access information, she used JAWS software and a Braille device "Brailliant 24".

She has a dial-up connection to an ISP to access emails and information. She will soon change to a broadband plan that she can afford, as she wants faster broadband speed because the dial-up service is too slow when downloading large document files and photos.

Julie regularly uses email to contact her friends and family in Australia and overseas, make appointments, send information about deafblindness, and look for information about travel and world events. She also writes stories and articles about activities she is involved with and shares them with others.

Julie still finds it hard to access the Internet because there are images and tables that are not accessible, or text is in colour formats that Braille devices cannot access. She cannot access PDF documents and is frustrated when documents are poorly formatted so that she cannot find where the text begins to easily navigate through them.

Having computer access is a very important part of Julie's life because it reduces isolation, allows her to do things such as contacting her friends and writing stories and helps her feel part of the

world.

BrailleNote device

A few years ago, Julie was able to get government funding to access a BrailleNote device. Because it is a very expensive device, funding support is critical for people who are on a pension. A BrailleNote is a small portable computer that has a Windows operating system and allows the user to write and read documents, access and send emails and store files.

Julie found the BrailleNote was an important breakthrough in improving her independence, particularly as she is a frequent and independent traveller. Before she got her BrailleNote, she could only communicate messages or read information from her computer at home or at Ablelink. The BrailleNote allows her to read information on the train, plane or in a car, prepare emails, check the weather and read books (downloaded from the Internet).

There are still a few problems with the BrailleNote – it has a short battery life, it is expensive and her version does not have a wireless connection. Like the computer, she has problems accessing documents poorly formatted or inaccessible to Braille devices.

Having a BrailleNote improves Julie's independence and privacy and she is less reliant on support people to access information.

CASE STUDY 3 RHONDA

Rhonda's hearing has changed over time and she now has a cochlear implant, which allows her to hear some speech. She can speak well but needs Auslan for communication support. Rhonda has a small amount of functional vision but prefers to read Braille.

Rhonda uses communication technology for everyday life as well as university study. She has a mobile phone, computer, BrailleNote and Braille TTY to assist her in making phone calls, communicating with others and reading or sending information.

Her mobile phone is a Nokia 6129 Classic and she is able to access it by using a screen reader program called "Talks5" and a Braille device via Bluetooth. She has a "Brailliant 24". She uses the mobile for SMS, calendar and email. She does not use the Internet because it is too expensive. Rhonda uses vibrate alert to know when calls come through.

She has found the mobile phone great for her independence. For example, she was able to use SMS to get directions to assist the taxi driver find her friends when travelling interstate.

Rhonda has two computers - a desktop and a Toshiba laptop computer which both use the Vista operating system. She uses a mix of Window Eyes screen reader and a Braille device (Brailliant 24) to access information on the computer. Window Eyes allows her to access PDF documents. Rhonda is able to use a computer through her years of experience but as her vision decreased, Ablelink was able to assist her with using access software such as Windows Eyes and hardware such as Braille devices and TTY's.

A broadband service allows her to access emails, the Internet and a wireless connection for her laptop. She is able to use the computers from word processing, calendar, email and the Internet. Rhonda is familiar with Windows XP, Vista and Windows 7 and found that Windows 7 is better for accessibility.

Rhonda shares what she enjoys about her communication devices:

"I prefer emails as I have a good record of my conversations and I am a fast touch typist. I also quickly get in and out of email using my Braille display. Next I love SMS on my mobile phone and love having this when I am travelling although often I just rely on Magnification or speech, as I can't carry the Braille display around with me everywhere. Thirdly, I like to make phone calls using the National Relay Service on MSN as I can look things up at the same time. Fourthly, my backup is my Braille TTY for when my computer is down and that is the only way to receive incoming calls. I loved having a BrailleNote when I was at university as I could read all my study notes on the train".

CASE STUDY 4 ALEX

Alex is deafblind and has Ushers Syndrome (type 1). Alex is profoundly deaf and has low vision. He can see people communicating with him but it depends on having good light and clear communication. Alex communicates using Auslan and writing notes. He can read large print notes when he communicates with people who don't sign.

Alex is employedand his employer has been very supportive in providing communication devices that assist his access. He has a CCTV for magnification of documents and computer with large widescreen monitor. Each time his vision has changed, his employer has made adjustments to assist him.

Computer access

Alex has an ACER PC at work using Microsoft XP. With a large widescreen monitor, the computer has been adapted to allow large font size for easier reading. Alex can access Word documents, calendar, email and the Internet. He learned how to use a computer through a training package at work with the assistance of an interpreter.

He enjoys access to the computer because it allows him to keep working, read and send emails, have contact with people and read stories or activities about what is going on in the deafblind and wider community.

Mobile phone access

Alex recently bought an Apple iPhone 4. He loves it because the iPhone has built in accessibility features such as "Zoom" which allows the screen information to increase; "White on Black" which provides better contrast for reading and "Large Text" which enables the text size to increase up to 56pt.

He mostly uses his iPhone for SMS calls but also for getting information on the Internet and making video calls to his friends and family who live in another State. Because he finds it easy to use, he is using his mobile phone more than his TTY to make calls.

CASE STUDY 5 ROSE

Rose is deafblind and has some residual hearing. She uses a variety of technology to access mobile phones and computers. She loves her Nokia 7120C mobile phone, which includes a screen reader program called Nuance Talks 5, which converts the display text of a mobile phone handset into speech. She uses a headset connected to the mobile by Bluetooth to make it easier to hear the text-to-voice program. The only major problem is that the mobile volume range is not loud enough in noisy areas.

Her prepaid phone has a built-in message alert service and she can access voice calls, SMS, calendar, email, keyboard and the Internet. The phone gives her independence and allows her to make contact with her friends and family.

CASE STUDY 6 STEVE

Steve is deafblind and has Ushers Syndrome (Type 1). Born deaf, his vision loss gradually worsened as he got older. He still has some vision and uses a cane to assist him with mobility. He communicates using Auslan.

Steve loves his time on computers and has a few different computers at home including a laptop and netbook. He remembers first learning how to use a computer from his brother with an Apple II many years ago. Through trial and error and advice from Ablelink he has learned how to create and maintain websites.

He uses Windows XP and Windows 7 but prefers Windows 7 because it is more accessible to his needs. He uses JAWS screen reader and magnification to assist him in reading information on the screen. He likes to check on news, sports, weather and other information as well as email communication to his friends and family in Australia and overseas. He also uses a computer program called MessageNet to send SMS messages to mobile phones, as he doesn't have a mobile.

As accessing information through his computer and the Internet is vital to Steve, he is continually frustrated at the daily barriers he finds with websites, software programs and social network sites.

CASE STUDY 7 BREE

Bree was born blind and as a teenager started to lose her hearing. She uses a combination of communication technologies, now enjoys blogging and keeps herself busy teaching Braille as well as working as a Braille proofreader.

She uses a MacBook Pro laptop and has a PC desktop computer and uses a variety of access methods to read information on the computers. This includes JAWS, Windows Eyes and VoiceOver (Mac) as well as Braillestar 40 for the computer. Bree also has a BrailleNote Apex for her University

studies.

She uses word processing, email and the Internet and has a cable broadband service with a wireless connection for her laptop. Bree learned to use the computer from training as well as self-directed learning. She enjoys using her MacBook Pro and will soon include "Windows for Mac" so she can use two systems on the one computer.

Bree "loves doing independent research with my computer for university. I can read comments of others in my class who are also studying by distance education and can find out what they are doing. It helps me prepare my presentations over the computer etc. Recently this led to my first High Distinction for my Research and Inquiry subject at uni."

5. CONCLUSION AND RECOMMENDATIONS

With the increasing switch from home phone (analogue services) to digital (VoIP phones, mobile and internet services) which offers a greater range of services, the benefits are only possible for Australian deafblind people if they are designed to be accessible. As noted by the report from the US National Council of Disability.

"As novel ways to exchange communication and information continue to radically change the way that Americans work, learn, shop, and participate in civic affairs, it is critical that Americans with disabilities, including individuals with functional limitations in their ability to see, hear, move around, or process information, have equal access to these technologies (2006)."

5.1 Recommendations:

1. That the Department of Broadband, Communications and the Digital Economy, when reviewing the National Relay Service, as announced by Senator Conroy in 2010, also include a review of current disability equipment programs, and consider funding– possibly through the newly formed body, USO Co - an expanded and independent telecommunication equipment program, which would cover adaptive – and customised where required - technology for landline, mobile and Internet communication products and services, as well as subsidies for access to mainstream products and services – such as internet plans – when required by people who are deafblind. Such an Independent Equipment Program would also include adaptive technologies which enable people with deafblindness to access mainstream telecommunications devices.

1a. That the Independent Equipment Program promotes guidelines on these accessibility standards and works with equipment and telecommunication providers to ensure these standards are met. These providers include Australian Communication Exchange, Vision Australia, Able Australia and Telstra.

1b. Provision of devices with full accessibility which would include customised solutions combining one or more of the following: speech output, screen magnification and Braille output, alternative keyboard input in qwerty and Braille.

1c. That, until such an independent scheme is in place, State-based Aids and Equipment Programs range of eligible devices be expanded to include adaptive technologies which enable people with deafblindness to access mainstream telecommunication devices.

1d. That, under an Independent Disability Equipment Scheme, centres in each State and Territory be established to showcase a range of accessible telecommunication devices and adaptive technology solutions including text, speech and Braille output, screen magnification and keyboard and speech input options

1e. That USO Co make funding available – possibly via such an Independent Disability Equipment Scheme - to provide training in the use of the devices and adaptive technology

1f. That, until such time as Universal Service Obligations pass to USO Co, that Telstra is required as part of its USO, to contribute funding for such training.

2. That, until such time as an Independent Disability Equipment Program is established:

2a. the Telstra Disability Equipment Program be expanded to include customised devices to access a range of telecommunication solutions to access issues.

2b. A clear procedure is established for ongoing maintenance of equipment supplied under the Telstra Disability Equipment Program.

2c. Telstra works with Vision Australia, Australian Communication Exchange and Ablelink to ensure configuration of new devices includes text, Braille and speech output, screen magnification and alternative keyboard inputs.

2d. Ongoing research and development is undertaken to ensure Australians with deafblindness can access current telecommunication technology.

2e. Telstra regularly produces clear guidelines on how devices can be customised for the specific needs of individuals with deafblindness. These guidelines could be made available on the Able Australia Telecommunications website.

2f. That when an IDEP takes over responsibility for disability equipment, it also takes over responsibility for each of the recommendations outlined above.

3. That the National Relay Service expand their procedures to include the following:

3a. The provision of start-up training to people with deafblindness when they first receive their TTY or Braille TTY and that ongoing training is made available. This may require the use of interpreters, note takers and support workers. This training should also include how to use emergency services to increase their access to and usage of these services.

3b. That training of NRS relay officers, and NRS equipment and procedures, be reviewed to ensure the best quality of service is available to deafblind users of the NRS

3c. That annual review meetings be held between the NRS's Relay and Outreach providers, deafblind service providers, and people with deafblindness to ensure all parties are kept informed of relevant information.

3d. That a person with deafblindness be included on the NRSCCC as a representative of the deafblind community.

4. That funding of the National Auslan Booking Service (NABS) include interpreter support for deafblind people to undertake Braille training, enabling them to better access important government and community information that relates to their health, wellbeing and participation in the community.

5. That all information about telecommunication services and training resources is available in all accessible formats, including text, Braille, Auslan, audio and electronically.

5a. That telecommunications retailers educate all staff on the accessibility features of their products on an ongoing basis.

5b. That telecommunication service providers provide clear and accessible information about their goods and services and develop a procedure for providing accessible phone help to customers with deafblindness.

5c. That the federal government legislate that all websites developed and provided in Australia conform to Web Content Accessibility Guidelines(WCAG 2.0) accessibility features for websites.

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