



**Submission to Productivity Commission
Inquiry into Disability Care and Support**

August 2010

Submission prepared by Rachel Miers and Karen Lloyd

Community consultations and preparation of this report were funded by the
Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)

Deaf Australia is pleased to have the opportunity to make this submission to the Productivity Commission's inquiry into a long term disability care and support system.

Acknowledgement

Deaf Australia would like to acknowledge the support of the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) for funding for community consultations on this issue and the preparation of this submission.

About Deaf Australia

Deaf Australia is the only Australian peak body, managed by deaf people, representing deaf people and their communities. We work with Australian Governments and collaborate with key stakeholders to ensure that Australia complies with the United Nations Conventions on the Rights of Persons with Disabilities.

Our Vision:

Deaf people are respected and fully included in the Australian Community and the right to use Auslan is legally recognised.

Our Submission

Deaf Australia has developed a 'Vision 2020' statement that covers issues of community and language, education, technology, access and interpreting, families, and self-determination and empowerment. www.deafau.org.au/profile/vision2020

Our submission reflects our Vision with scoping of 'Universal Design' as outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Article 2 and 4, f) to achieve inherent dignity and full and equal enjoyment of all human rights and fundamental freedoms (Article 1). It is important to ensure that the UNCRPD is part of the holistic design of a disability care and support system.

Further, our submission reflects 'Language' entitlements as outlined in article 2 of the UNCRPD. Sign Language is mentioned eight (8) times in five (5) different articles. These are:

- Article 2: Definition;
- Article 9: Accessibility;
- Article 21: Freedom of expression and opinion, and access to information;
- Article 24: Education; and
- Article 30: Participation in cultural life, recreation, leisure and sport.

Deaf Australia believes that a national disability care and support system should comprise of 'Universal Design' with scoping to the articles abovementioned.

Deafness can happen to anyone and can range from mild to profound hearing loss in one or both ears. Some deafness may be temporary (such as otitis media) but the majority of deafness is long term. 1 in 6 Australians has some form of hearing loss and by 2050, 1 in 4 will have a hearing loss (Access Economics, 2006).

In preparation for this submission Deaf Australia organised community consultations with Deaf people in each State and Territory and an online survey, with a total of 371 responding to the questions outlined in the Productivity Commission's issues paper. Community consultations were held in Auslan so that Deaf people could have full access to information and could readily communicate their views.

Deaf people talked of their frustrations in communicating and their experiences with barriers in accessing information and services. Hopefully a new system will remove the barriers and discrimination of all for deaf people.

Basic principles of a disability care and support system

Deaf Australia has participated in discussions with other peak disabled people's organisations, which has led to the development of a number of principles that we all agree must underpin a disability care and support system. These basic principles are:

1. People with disabilities and Disabled People's Organisations (DPOs) to be involved in all levels of governance in a new funding model.
2. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is the framework for the design of a new system requiring a significant cultural paradigm shift based on a human rights and social model of disability.
3. Proposed scheme is a national scheme which is:
 - a. based on entitlement for all who are eligible;
 - b. properly funded to address additional costs related to disability so that a person is able to have full enjoyment of their human rights;
 - c. based on equity for all who are eligible;
 - d. takes into account the impact of gender, indigenous background, cultural diversity and specific needs of children;
 - e. based on self determination;
 - f. committed to the empowerment of people with disabilities;
 - g. portable (a national scheme); and
 - h. responsive to changing circumstances of an individual over their lifespan.
4. That all existing obligations and commitments to non discrimination and inclusion of people with disabilities are maintained outside this scheme – i.e. costs not to be shifted to individuals, and preventative mechanisms must be put in place to prevent this happening.
5. This scheme will form a major initiative under the National Disability Strategy.
6. A strong independent advocacy support program is separately funded under the scheme to support and protect the rights and interest of people with disabilities eligible for funding.
7. That there is transparency in funding arrangements and appropriate consumer rights protection mechanisms.

Who should be eligible?

- ***Who should be in the new scheme and how could they be practically and reliably identified?***

It is Deaf Australia's position that any person with a disability (including any person who is Deaf or has a hearing loss, regardless of the degree of hearing loss, or who is deaf/blind) should be eligible for the new scheme. Deaf Australia believes the new scheme should be for everyone who needs it regardless of who they are or when or how they got the disability, with support from the community they are involved in. This is outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) Article 4 (c), *To take into account the protection and promotion of the human rights of persons with disabilities in all*

policies and programmes. This includes all people from birth to seniors over age 65 and is extended to include groups such as migrants and persons in the correctional services system and other institutional settings.

There are different forms of deafness. Some are temporary. Others are permanent and lifelong. Deafness can be present from birth, or it can be acquired through accident, illness or over-exposure to noise, or as part of the ageing process.

Deaf people have complex communication needs and are significantly disadvantaged due to lack of resources, early intervention and education systems that meet their communication needs, and appropriate services. Medical or aural rehabilitation 'solutions' with varying and unpredictable degrees of 'success' have been a dominant factor in deaf people's lives with little regard to the emotional and social wellbeing of the person, especially when deafness is present from birth or an early age.

Many deaf people are on low incomes, due largely to the failure of the education system to meet their needs and entrenched discrimination in employment. The 2008 Victorian deaf education review indicated that approximately 35% of deaf people are at or below the poverty line, compared with 10% of the general population. This raises the question of affordability of the equipment and services they need, e.g, digital communication technology which can provide effective communication avenues for deaf people can be cost prohibitive. Income and achievement often has little to do with the degree of deafness, which means that a scheme that is only for people with severe or profound disability (in the case of deaf people, based on the degree of hearing loss) would leave out many people who are worse off than some people who are eligible.

There are mechanisms in place for identification of babies and young children with a hearing loss, through universal newborn hearing screening programs operating in all States and Territories (although not all States and Territories are currently screening 100% of newborn infants). Identification of older people with hearing loss is also through a process of audiological testing. Systems for the initial identification of hearing loss are therefore quite well established in Australia, although they are less effective in Aboriginal communities, where hearing health problems are widespread and often go untreated.

After the initial identification of hearing loss, a system is needed to assess eligibility for disability support based on needs and shaped by the impact of a person's impairment on their capacity to undertake normal activities of daily living. It is critical that such a scheme maintains its capacity to respond to the complexity, diversity of need and context, allow for flexibility and resist the tendency of eligibility based schemes towards rigidity of policy and application of funding principles.

The system needs to recognise the need to include groups from the start that might fall through the gaps:

- Refugees and new migrants waiting for residency and citizenship papers;
- People with disabilities in the correctional services system;
- People with disabilities in segregated settings, such as institutions and boarding or rooming houses;
- Indigenous groups;
- CALD groups.

It also needs to include people with psychosocial disabilities and people with ageing related disabilities. It should be noted that deaf people can, and some do, also have other disabilities such as psychosocial disabilities and ageing related disabilities as well as deafness. We understand that traditionally ageing and disability services are funded by separate government departments. However, when a person has a lifelong disability, the disability and support needs do not change when age 65 is reached. If funding for support needs is to be separately managed according to some arbitrary age limit, there needs to be a seamless

transition from one funding source to another, with no impact on service delivery and support.

The system needs to develop an assessment process for individuals that:

- assess individual's needs separately from the needs of their family;
- is based on a social model of disability;
- is nationally consistent with uniform standards and conducted by well trained and prepared assessors; and
- provides an assessment at a location or setting where the individual is most comfortable.

The need to address the inter-face and inter-relationship between systemic and structural barriers to inclusion for people with disabilities in Australia and their individual and personal support arrangements must be taken into account by the Productivity Commission inquiry.

Who gets the power?

- ***How could people with disabilities or their carers have more power to make their own decisions (and how could they appeal against decisions by others that they think are wrong)***

The level of funding should be determined through a self assessment approach. Deaf people should make decisions and be entitled to services according to their own assessment of need. This is in line with UNCRPD Article 3a *respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons*.

It should be noted that one of the consequences of an entrenched medical/welfare model is a community of people used to having little or no power and little or no involvement in decision making. For a self assessment model to be effective, there would need to be an extensive and long term program of promotion and awareness raising of services available and the individual's right to choose, to enable deaf people to learn to make their own decisions. The need for this is particularly acute in regional, rural and remote areas. Services would also need to be nationally standardised, and not vary state by state.

More training would be needed for carers to assist deaf people who have been poorly educated and those with intellectual or learning disabilities or other additional disabilities in making decisions. This includes case managers who work with families of deaf children, job seekers, and those in tertiary education programs.

Consideration also needs to be given to how groups such as people living in rural and remote regions and those of low socio-economic background can best be enabled to self assess.

Advocacy and support will be a key requirement for self assessment to be effective. Deaf people and their families will need access to a strong independent advocacy system that provides individual and systemic advocacy approaches. This is to ensure that there is effective capacity to protect and promote rights and well being. To support this, there needs to be proper training and accreditation pathways for advocates. Advocates should ideally be Deaf/hard of hearing persons as these people bring to the advocacy process an understanding of the lived experience of deafness, and deaf people tend to relate better to other deaf people; this is true also of Indigenous deaf people, who relate better to Indigenous deaf people.

If a deaf person happens to disagree with a decision, they should be armed with information on how decisions are made i.e. a pathway plan, before appealing to an independently

managed authority which comprises of people with different disabilities to assess the merits of the disagreement. The panel should be fully supported with minimum guidelines and the person appealing the decision should present reasons why he/she should receive specific support under the scheme.

- ***How should the financial support and service entitlements of people be decided and by whom?***

Financial support could be offered in several streams depending on the person's communication needs. Deaf Australia realises that not all people with a hearing loss use Auslan as a preferred language and financial support should accommodate the person's needs and preferences.

Assessment of need and entitlement could be done through qualified assessors in collaboration with deaf organisations throughout Australia.

Existing services such as the National Auslan Interpreter Booking and Payment Service (NABS), funded by FaCHSIA, and the Employment Assistance Fund (EAF), funded by DEEWR, should remain unchanged. If these services were to be incorporated into the scheme, additional consideration is needed to ensure that interpreting for health appointments and employment interpreting do not either use up all of the person's allowance or miss out due to restricted allowances.

Generally, the services needed by Deaf and hard of hearing people include:

Early intervention and education

Deaf and hard of hearing people need early intervention from the time of diagnosis. The type of early intervention will depend on the age of onset of deafness and the type and degree of deafness. Children deaf from birth or an early age need very specific early intervention programs that enable them to acquire language fluency and to function competently in both the deaf community and the wider hearing community. Deaf children should have access to bilingual early intervention programs and their choices should not be limited only to speech based programs.

People who become deaf post lingually (as older children or adults) need different early intervention programs that train them to use what hearing they have remaining and/or to develop specialised life skills.

Education programs need to take account of deaf people's differing needs, at all levels and stages of the education system. Education support needs include bilingual (Auslan/English) education programs, speech and listening therapy, interpreting, notetaking, real-time captioning, tutoring.

In addition, because the education system has failed large numbers of deaf people, adult education programs are required. The TAFE system is not always the most appropriate pathway for deaf people; many need programs specifically tailored for their needs.

Interpreting

Provision of interpreting for deaf people who use Auslan. Most Deaf people require interpreting for some of their activities and interactions but not all. For example, in the workplace, the level of support needed can depend on the type of job, with some jobs requiring a lot of interpreting and some only a little. Interpreting support is currently available for some situations but not all; examples of situations where it is not currently available include purchasing a car (negotiation with a car dealer), enrolling in a community course (e.g. jewellery course) discussing tax matters with a tax agent, planning retirement with a financial

planner, attending local community events and so on. Not all people need an interpreter for all situations; some people need interpreting support more than others. Interpreting support needs to be available for all types of situations according to the person's need.

Employment

Deaf people are capable of working in a very wide range of jobs and employment situations. They do however, need some workplace modifications such as specific communication systems, adaptations to some established practices, and their employers and colleagues need some training in effective communication strategies. Deaf people also benefit from training in self-advocacy skills so that they can advocate for themselves in the workplace.

Because employers tend to have many misconceptions about deaf people, many deaf people also need assistance from specialised employment services to obtain suitable employment.

Hearing Aids

Provision of hearing aid, cochlear implants, batteries and so on. Batteries for cochlear implants can run at about \$1,000 per annum.

Technology for Communication

Provision of technology for communication purposes e.g. Internet and equipment to enable a deaf person to communicate anywhere in Australia. This includes use of video communication over the Internet and relay services. The need for this type of technology and service can be illustrated by the case of a man travelling 2 hours to visit a doctor, only to find the interpreter booking had been moved to 2 weeks later. This situation would have been avoided if this man had access to equipment to enable him to access visual interpreting relay to communicate with his doctor about the appointment change. As noted earlier, many deaf people are on low incomes and effective communication technology can be cost prohibitive.

Hard of hearing people who do not use Auslan often need to use captioning technology such as CART (Communication Access Real Time Translation) in situations where deaf people who use Auslan would use interpreters.

Home Safety and Communication Equipment

Provision of fire alarm systems (required by law) suitable for deaf people's households and workplaces; door, phone, baby cry alerts. Special visual equipment can be purchased from a specialist shop and is expensive, e.g. fire alarm costs approximately \$650 while a 'regular' one can be bought from a generic store like K-Mart for as low as \$25.

Family Services

Provision of sign language/communication education to enable hearing families with a deaf child to learn sign language and enable the child to participate in the family and in community/recreation activities with their family. Provision of speech therapy and family support for hearing children in deaf families.

Recreation / Leisure / Sport

Access to interpreters for recreation/leisure and sporting activities, e.g, museum tours and sports training. Provision of captioning on television, in cinemas, on DVDs and Internet downloads etc.

Youth Services

Deaf and hard of hearing youth need access to information, including information oriented to youth, and to Deaf adults who can act as mentors and assist in the development of coping skills and resilience.

Community Services

Because the education system has largely failed deaf people, many have a reading age of around age 9 years and they do not have ready access to information and ongoing learning, many deaf people need assistance with a range of activities such as understanding how the banking system works, how the Centrelink system works, how to access information about their rights and responsibilities in a range of daily living areas e.g. tenancy, help to understand letters and information sent to them in English, health education, parenting skills, marriage and relationship counselling and so on across a very wide range of need.

Aged Care

Deaf people who have been deaf all their life, or for a large part of it, do not stop being deaf when, at age 65, they officially become “aged” and move to an aged care service model. Their service needs as deaf people remain the same.

How much does each person need?

Support needs vary from person to person and family to family and can include but are not limited to the examples below.

Hearing family with one deaf child may require support in the following:

- Early intervention and education
- Hearing aids
- Technology for Communication
- Home safety and Communication Equipment
- Family Services
- Recreation/Leisure/Sport
- Youth services

Deaf adult who uses Auslan as preferred language:

- Employment Support
- Interpreting Support
- Technology for Communication
- Home Safety and Communication Equipment
- Recreation/Leisure/Sport
- Community and youth services
- Aged care

Deaf adult who prefers to use speech-based communication:

- Employment
- Technology for Communication
- Home Safety and Communication Equipment
- Hearing Aids
- Recreation/Leisure/Sport
- Community and Youth services
- Aged care

Not all people within these categories will need all of these services all of the time. Needs vary across the life span and any one person’s needs and preferences can change at any time.

How should ‘how much’ be determined

The level of funding for individual disability support should be determined through a self-assessment approach.

A number of suggestions have been put forward about how the global budget required to resource a new scheme is established. These include

- National disability social insurance scheme funded by an insurance levy to fund all legitimate claims for disability support.
- New dedicated or specific purpose tax to be introduced to promote universal access to disability support funding
- Further research needed to develop a better understanding of market place economics and different models of insurance that could be considered to support

The Productivity Commission should investigate the costs of NOT implementing a fully funded national disability support scheme based on self-determined, individualised budgets.

There is a strong need for the establishment of an independent national body responsible for the governance of a new disability support scheme. Article 33.3 of the UNCRPD states that *“persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process”*.

Key features of this body would be:

- Board made up of a majority of people with disabilities and DPO’s who are representative of key constituencies across Australia;
- It would make higher policy level funding distribution decisions;
- Support resourcing of local / regional disability resource centres that would play a key role in providing independent advice and support, development of initiatives at the local level that would enhance effectiveness of individualised funding allocation;
- Costs of operating the board to be funded;
- To have a research and development role in promoting significant cultural paradigm change around disability support;
- This body would be underpinned by specific legislation and report against UNCRPD based performance measures;
- Body to be reviewed regularly by relevant administrative review body.

A panel to determine supports and entitlement could be set up, with a structure including, for the deaf sector:

- Government Representative
- Consumer Representative
- Service Representative
- Representatives of different hearing loss experience (Deaf, Hard of Hearing, Deaf/Blind)
- Representatives of different demographic groups (CALD, Indigenous, Youth, Seniors)

It is important that panels or expertise groups are established as there are many aspects of deafness and few people have expertise across all areas.

The final amount of assistance provided could be agreed on the basis of a support plan, submitted by the individual and/or their family/advocate if required, which identifies the resources required, a costing of how those resources are to be provided (regional variations would need to be agreed upon, as the cost of support delivery in remote regions often greatly surpasses that delivered in metropolitan regions), and how the money will be spent. However such a support plan would need to be flexible and allow for changes – people should not be expected to plan every detail of their lives in advance, the plan needs to allow for ad hoc decisions and changes.

What services are needed and how should they be delivered?

• What kinds of services particularly need to be increased or created?

The UNCRPD states: *recognising the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication, in enabling persons with disabilities to fully enjoy all human rights and fundamental freedoms (preamble v).*

Inclusion

Funding for individualised disability support needs to support full participation in all areas of life – political, civil, social, cultural and economic – as set out in the various articles of the UNCRPD. A definition of disability support needs to:

- be broad to take into account the diversity of support needs according to the individual context – cultural diversity, geographic remoteness;
- allow for changing needs due to changing circumstances across the lifespan;
- have a capacity to respond to a crisis situation.

A new scheme should provide support based on self-determination of need. This approach needs to make allowance for supported decision making for people who require assistance and also needs to recognise the specific circumstances of those who are impacted by restrictive practices or who are in custodial settings such as prisons, detention centres and institutions.

Auslan and deafness awareness programs

Here's a radical thought: if Auslan classes were funded and provided free to everyone, including as a LOTE in schools, there would be much less need for costly interpreting services, deaf people would be much more easily included everywhere, and there would be much less need for a wide range of services. However, even if this were to happen, the provision of qualified interpreters would still be important for particular situations, e.g. employment, medical/health and education settings.

It may also be helpful for inclusion if deafness awareness programs were widely available at no cost in schools, workplaces, nursing homes, community organisations, shopping centres and so on.

Advocacy

Deaf Australia supports the position that people with disabilities and their families will need access to a strong independent advocacy program that provides a range of advocacy approaches, both individual and systemic to ensure that there is an effective capacity to protect and promote rights and well being in a new disability support scheme. This program should be funded such that both administration and delivery of advocacy support are independent of disability support program funding.

Community capacity

A new scheme will need to invest in initiatives that build community capacity, provide good information, encourage empowerment and choice and promote innovative development of disability support strategies that are life enhancing and value adding for people using individual budgets. In areas where "the market" has failed, specific development of supports may be necessary. The development of regional/local disability resource centres managed and operated by people with disability and their organisations is suggested as a possible structure for doing this work. These disability resource centres might also play a role in stimulating and supporting informal supports of families, friends and neighbours within local communities.

However, Deaf Australia has reservations about the current trend towards cross-disability service provision – including advocacy. This model does not work well for deaf people because the need for Auslan is not well understood or easily accommodated in cross-disability services. Deaf people are better served by deaf-specific services in combination with supported access to generic services.

Early intervention for deaf babies and children

Currently in Australia there are no effective and meaningful services that are being delivered to promote inclusion and whole of life approach in early intervention programs.

Universal newborn hearing screening is being progressively rolled out nationally and this is a good thing. However, without effective early intervention programs to follow on from diagnosis, universal screening it is next to pointless.

Unfortunately most current early intervention programs only promote the development of speech and listening skills and reflect a medical approach to deafness. These programs do not address the future life of the deaf or hard of hearing child, and their "deaf" self as well as their "hearing" self over the long term.

There is a need for the development and availability of bilingual (Auslan/English) early intervention programs that will ensure the child's right to their identity and to be part of a deaf community is preserved and developed, alongside the development of a spoken language that benefits them in the hearing community. A good bilingual program also has as its primary aim to enhance social and emotional wellbeing of the child and his/her family.

Existing AVT/Auditory-Oral early intervention programs could form part of a bilingual education program but by themselves are not enough to meet the child's needs.

Access to bilingual early intervention programs should be available without delay from diagnosis.

Early intervention for older children and adults

Early intervention for people who become deaf or hard of hearing post-lingually also is limited and focuses mainly on the provision of hearing aids and cochlear implants as a medical treatment. This approach is too limited. People who lose their hearing also need to learn to adjust to a new approach to life as a hard of hearing person, which involves new communication skills, life skills and adaptive behaviours.

Education

School education for deaf children has largely failed to meet their needs and this can be largely attributed to the exclusion of Auslan from the education system and deaf people from the education profession. This failure in education of deaf children worldwide, and the need to include sign language and deaf educators was acknowledged in a statement made at the International Congress on the Education of the Deaf (ICED) in Vancouver on 19th July 2010 (see attachment 1).

This situation is changing slowly in Australia, but the change is too slow, too piecemeal. Australia needs to legally recognise deaf people's right to use Auslan, and embrace Auslan and bilingual (Auslan/English) education for deaf people as a national policy.

Post school education needs to be more accessible, especially that provided by private educational institutions.

Adult education programs tailored for Deaf people need to be more widely available.

Auslan needs to be offered as a LOTE in Australian schools. It is currently offered only on a very limited basis, mainly in Victoria. In Victoria, Auslan as a LOTE accounts for the biggest increase in students studying it compared with other languages.

Many deaf adults also consider that educational programs for them should be free to compensate for the failure of education in the past as there is a high level of unemployment among the deaf. In the 2008 Victorian Deaf Education Review, 35% of survey respondents earned less than \$25,000 per annum, which would be identified as poverty line wages.

Interpreting

Currently, Auslan/English interpreting for private health appointments is funded by the Australian Government (NABS). Some interpreting for employment situations is also funded by the Australian Government (EAF). Interpreting for access to information and services is covered by the *Disability Discrimination Act*, and in practice means that:

- a. government services such as public hospitals, Centrelink, police etc should provide interpreters when needed. However, in practice, getting an interpreter can be difficult – at Centrelink people regularly wait at least 2 weeks for an appointment because it is hard to book interpreters at short notice; in hospitals, the staff are frequently not aware of the requirement to provide interpreters or the procedures for booking them, or they are too busy and consider it too unimportant; the police do not always accept that an interpreter should be provided;
- b. large businesses will sometimes provide interpreters – e.g., Westpac does this for staff and customers – but generally the deaf person needs to go through a lengthy self-advocacy process each time they need an interpreter;
- c. small business and professional services such as solicitors generally will not provide interpreters, on the grounds of “unjustifiable hardship”;
- d. large educational providers such as universities and TAFE will provide interpreters, but not always for all courses, e.g., often TAFE requires that a course be for employment related purposes before it will provide interpreters;
- e. adult education and private educational providers generally will not provide interpreters, on the grounds of “unjustifiable hardship”
- f. some churches and religious groups provide interpreters but most mainstream churches do not;
- g. private family-related activities such as weddings, funerals, special occasion celebrations, community activities must be funded by the individual; in some cases some specialist service providers (Deaf Societies) will provide interpreters free for some activities, most notably funerals.

Other issues related to interpreting include:

- Event organisers should include interpreting in their budgets so that deaf people do not have to continually demand and advocate for the provision of interpreting;
- Interpreter travel and accommodation costs e.g., to Katherine or Tennant Creek in the NT, can be exorbitant and eat up a lot of funding;
- Video Remote Interpreting stations and portable units can be a workable solution for many situations where interpreters are not available and distances are great;

- There are insufficient qualified interpreters to meet demand and this problem is even more severe in regional, rural and remote areas;
- Interpreters need ongoing training and incentives to engage in ongoing training; the industry needs to develop new models of service provision and career paths;
- There is a great need for good interpreters with good background in regional areas and an understanding of rural and Aboriginal culture;
- There continues to be a lack of awareness about the availability of funded interpreting in some health areas, e.g. for deaf parents at maternal health centres;
- There is a need for interpreters willing to travel to rural and remote areas

All of this means that the provision of interpreting services is piecemeal, confusing, inconsistent, costly and, with the exception of the NABS service, the deaf person usually has little or no say in who interprets for them. A new system is needed to provide funded streamlined high quality interpreting services for all situations where interpreting is needed, and based on consumer choice. Consumer choice should include interpreting for any purpose – for health, work, professional development, pleasure, community events, family occasions and so on.

Employment

Presently, Job Access offers the Employment Assistance Fund (EAF) that allows Deaf people (and anyone who has a disability) to be more included in the work environment. This scheme covers the provision of some kinds of equipment, some interpreting, and awareness training that enables hearing colleagues to better understand deaf people and effective communication strategies, and reassure employers about such issues as occupational health and safety. There are restrictions as to what deaf people can receive through this scheme and it needs to be broader and more flexible.

Deaf people are unable to readily access community and educational programs that will enhance their professional skills. This is due to a lack of funding to cover interpreting costs which can mean deaf people have to either miss out or resort to enrolling in TAFE where interpreters can be provided. This can lead to a high drop out rate as the deaf person gets a taste of the course and realises it is not what they want, while community programs offering 6-8 week courses may better suit their needs but are not accessible because of the lack of interpreting support.

Employment services specifically for Deaf people can be helpful in dispelling some of the misconceptions employers tend to have about deaf people, and educate them on issues such as effective communication strategies, safety, workplace modifications.

However, the current employment system does not always meet deaf people's needs, sometimes through insufficient funding, but also because the system encourages services to push people as quickly as possible into jobs that they may not be suited for so that the service provider can earn the placement fees, rather than providing career services that help deaf people into jobs that suit them and that become long term careers.

Some Deaf people also find it embarrassing to use employment services to approach employers on their behalf. They would prefer to be trained in self advocacy.

Deaf people may also need training and/or support in the workplace to ensure that they are not victimised, bullied or harassed and made to fear that they will lose their jobs if they ask employers for equipment, interpreting or other services.

In comparison with the general community, a high percentage of deaf people are unemployed or underemployed. Low income leads to stress in other areas of life, e.g, in recent years due to a sudden increase in prices following on from the mining boom, deaf people have been struggling with rent prices in areas such as Darwin and Perth.

Hearing aids

Currently a person can obtain free hearing aids and batteries from Australian Hearing if the person is under 21 years of age, on a Disability Support Pension or an Age pension. Hearing aids and cochlear implants are expensive, as are the batteries to operate them.

An example of how people can be disadvantaged is the family that paid \$79,000 for a cochlear implant for their child 18 years ago; the person is now not eligible for a free processor upgrade and cannot afford the upgrade; at the same time the spare parts to fix the processor she currently has are obsolete, so she is unable to either repair or replace her cochlear implant.

The Employment Assistance Fund can be used by some people to help them acquire or replace hearing aids, but there are restrictions and the scheme is not accessible by everyone who needs hearing aids.

Support for the costs of hearing aids and cochlear implants need to be available to all people of all ages. The cost of upgrades and maintenance and repairs also needs to be included.

Technology for Communication

For deaf people, communication is the key to inclusion and success. There is now a variety of communication technology available that deaf people can use effectively for their communication needs. Video chat over the Internet is being increasingly used by deaf people, as is captioned telephony by hard of hearing people. However, because visual communication such as video over the Internet requires high bandwidth speed and data transfer for clarity, it comes at a high cost to the individual.

The National Relay Service, which provides a telephony relay service between deaf people/hard of hearing people/people with a speech impairment and others in the community, is now quite out of date and needs to be urgently upgraded to include video relay, captioned telephony and SMS emergency services.

Hard of hearing people who do not use Auslan often need to use technology such as captioning or CART (Communication Access Aided Real Time Translation) in situations where deaf people who use Auslan would use interpreters. Like interpreters, this type of service is not widely funded, in fact is funded even less than interpreting services are.

Home Safety and Communication Equipment

Laws now require people to have working smoke/fire alarm systems in their homes and in the workplace. Ordinary smoke alarms do not work effectively for deaf people. An effective system costs \$650 – \$900 around 10-20 times more than an ordinary smoke alarm. Some states have limited smoke alarm subsidies but eligibility varies – e.g. in Victoria only Deaf people are eligible; in Queensland only Deaf and hard of hearing people on a pension are eligible.

Deaf people also need visual alert systems for such things as phones, doorbells and baby cry. Currently they must pay full price for these items themselves, and they can be expensive – e.g. \$800 for an effective baby cry alert.

All of these things need to be included in a disability support scheme for everyone who needs them.

Family Services

95% of deaf children are born to hearing parents, most of whom have no previous experience of deafness. Currently, early intervention services focus on the development of speech and listening skills and families are led to believe that this is the “solution”. This approach excludes the use of Auslan and puts the onus on the child to “fit in” with a hearing family.

Using this approach, very few families are able to communicate effectively with their deaf child. Families need to have the option of being able to learn Auslan so that they are able to communicate effectively with their child from the beginning, as well as the child learning speech (which takes much longer than does the acquisition of sign language fluency).

In addition, deaf children are not able to participate in local community programs e.g. Scouts and Girl Guides or local sports as those activities do not have the funding to provide Auslan interpreting or other communication access services for deaf children.

Deaf Children Australia offers some families a ‘respite’ program where parents can leave their child at a recreation program supported by a deaf person or a person with sign language skills to enable the child to participate in the program. However, this is an extremely limited program available only in one State.

Programs to enable families to learn Auslan and provide communication access services for their children need to be introduced.

Recreation / Leisure / Sports

Deaf people have the same needs to enjoy recreation, leisure and sports activities as any other person. The question is how they access it. Universal design needs to be incorporated into this area wherever possible – e.g. all activities and products incorporating visual communication should automatically include captioning.

Access to interpreters for recreation/leisure and sporting activities, e.g. museum tours and sports training needs to be widely available.

The transport and tourist industry needs to be encouraged/required to make travel accessible, e.g. visual information, access interpreters or captioned information readily available at tourist attractions, tours/attractions to include captioned information or notes, hotels to have accessible facilities.

Many Deaf people also have expressed wishing wish to travel to areas where deaf events / Auslan interpreted theatre performances are available but cannot not travel due to costs and low income.

Youth

Some States have youth programs, usually through the Deaf Society or Deaf Children Australia, however, they are intermittent and not consistently available across States or even within States.

National cohesive and locally responsive youth programs need to be introduced.

Suggestions for youth programs include:

- Community Hub for Youth
- Recreation Programs / Holiday Programmes
- Summer camps (1 week – 6 weeks)

Community Services

Many deaf people need community or “welfare” services that have traditionally been provided by charities known as Deaf Societies. Each state has a well established Deaf Society (but

the Territories do not). However, as demand has increased, fundraising has become more competitive, service quality, legal and regulatory requirements have become more strictly enforced, and the cost of providing services has risen, the provision of these traditional services has declined. Deaf Societies have also increasingly moved from a “welfare” approach to a “business” approach and increasingly will not provide services unless they are funded, usually by government.

Many services now take the form of “advocating” for the deaf person to have access to mainstream services such as counselling, with the Deaf Societies providing interpreters for a fee paid by the mainstream service. Deaf Australia believe that this is not the most effective way of meeting the unique needs of deaf people.

The provision of community services directly to Deaf people, in Auslan, which is considered to be the most effective method, is not generally funded and is not widely available. It needs to be.

Mental Health Services

In an unfortunate indictment of the current poor state of family support, early intervention and education for deaf people, mental health problems are relatively high among deaf people.

Currently, Queensland has a limited mental health service for deaf people, as part of the Princess Alexandra Hospital services in Brisbane, but its reach is limited and it is the only such service in Australia. This service needs to be expanded within Queensland and also made available nationally.

Aged Care

Currently aged care services do not usually take account of the specific needs people who have been deaf all their life or for a large part of it; and aged care services also do not generally do a good job of looking after the deafness-related needs of people with ageing-related hearing loss.

The provision of hearing aids is not enough. Aged care services need to incorporate additional strategies for looking after deaf and hard of hearing people in aged care facilities, strategies that can often be quite simple and for little or no additional cost, for example the provision of television and other entertainment with captions, information provided visually as well as aurally and so on.

For Deaf people who use Auslan, there is a need for aged care facilities with staff who are fluent in Auslan. It is not acceptable for aged Deaf people to be effectively abandoned in mainstream nursing homes staffed by people with whom they cannot communicate, with occasional visits from Auslan-fluent support staff or family; and superficial communication with staff or peers who can sign a little is also not acceptable. Our current system consigns most deaf people to a very lonely and undignified way of living out one’s last days.

Aged care services for deaf people need to be improved, including universal design wherever possible.

Specific additional needs of Indigenous deaf people

Indigenous deaf people have some additional issues and service needs that need to be addressed:

Access to GP’s and health centres: It is difficult for Indigenous deaf people in remote regions to travel to visit a GP or health clinic. Solutions to this might be the use of video conferencing or the service to visit remote areas, accompanied by an interpreter.

Interpreting: There is a need for Indigenous deaf people to be trained as Deaf Relay Interpreters to work as a relay between Auslan interpreters and Indigenous deaf people.

Technology for communication: Many regional and remote areas do not have Internet access or SMS coverage, and this further disadvantages deaf people who need it.

Family services: There are Indigenous deaf children whose parents have substance abuse problems and these deaf children need someone to take responsibility for them and care for them. It is suggested that Indigenous Deaf elders could take on this role.

Community services: Many Indigenous deaf people need specifically tailored counselling for domestic violence.

As a final general comment on service provision Deaf Australia believes that services need to account for their activities by registering with a national registry so that there are clear pathways and options available for all people needing services. This would also help with data collection which we clearly lack, and which could assist governments and service providers to better understand the overall provision of services and the gaps.

How could the ways in which services are delivered – including their coordination, costs, timeliness and innovation – be improved?

- ***How could a new scheme encourage the full participation by people with disability and their carers in the community and work?***

For deaf people, the long term key is effective family services, early intervention and education from the beginning of identification of deafness.

Family services, early intervention services and education for deaf people all need to be overhauled and radically improved. The current system of treating deafness as a medical problem to be fixed with medical/audiological solutions is too limited; it needs to be expanded and Auslan needs to be embraced. Many families of deaf children are not informed of other options, which largely leads to the current situation that deaf people are in. There is a need for a nationally available Early Intervention Program that is independently coordinated and managed/monitored to ensure that parents have access to a range of services that focus on the development of the whole child, including language and social development, e.g, Auslan supported programs.

Deaf people's right to use Auslan needs to be legally recognised; early intervention and education needs to be bilingual (Auslan and English) and families need to be enabled to learn Auslan and have a better understanding, early on, of deafness as a lived and lifelong experience.

Deaf people who are well educated and have a strong sense of wellbeing and confidence in themselves, their abilities, and their place in the world need few if any specialised community services further down the track (although of course there will always be some people both now and in the future who do need community services, mental health services and so on). They will need ongoing communication services and communication technology to enable their participation but with these services they are able to participate on a more level playing field as equals to their hearing peers.

They are also better equipped for the employment market and more able to advocate for themselves and their own needs.

Employment services need to be encouraged to place people in suitable employment rather than focussing on placing them in often unsuitable jobs as quickly as possible to bring in money to the employment service. Programs are needed to raise awareness among employers of the benefits of employing deaf people. Westpac has an excellent diversity program and employs a number of deaf people, with several initiatives in place, providing

Auslan interpreters for employees and customers and captioned videos in the workplace. This is a model that could be promoted to other employers.

The availability and supply of interpreting also needs to be addressed. The standards and status of interpreting as a profession need to be raised and the industry needs to develop service delivery models and career pathways that will encourage more people to take up interpreting as a profession.

The National Relay Service needs to be upgraded to incorporate a video relay service, captioned telephony and SMS emergency service.

Video remote interpreting services need to be more widely available. The Victorian Government has committed to a Video Remote Interpreting Service (VRI) that saw a pilot program of seven sites with high definition, high quality video conferencing facilities with interpreting service to link to families or clients in the remote regions of Victoria. Deaf Australia believes this will create greater opportunities and encourage/promote more participation by people who are deaf in the community where they live when utilising a portable high definition communication network scheme (see National Broadband Network below).

A new scheme needs to enable greater interaction for families of deaf children and youths with adults who are deaf and can share with them effective strategies and skills for success. Family relationships are often fractured as a result of poor family support, early intervention and education. When families learn to communicate effectively with their deaf members, they are able to communicate for life, maintain healthy family relationships and enable the family to participate in the deaf community, which is a vibrant and supportive community, as well as participating individually and as a family in the wider hearing community.

A combination of deafness awareness programs, diversity programs and initiatives for community organisations e.g. Lifesaving clubs, Scouts and sporting activities could highlight the benefits of and strategies for including deaf people in the community.

A new scheme needs to incorporate individual choice and decision making. To support this, particularly in the short to medium term, there needs to be resources and opportunities for enable deaf people to develop the knowledge, skills and confidence required to exercise their right to choose and decide for themselves. Ongoing opportunities for training and professional development also need to be incorporated in the scheme.

- ***What should be done in rural and remote areas where it is harder to get services?***

As discussed earlier, deaf people rely on visual communication. Modern technology provides some useful solutions for communication and service provision for deaf people in rural and remote areas.

The National Broadband Network (NBN) with high speed connectivity will hopefully help ensure that deaf people living in the rural and remote areas can use video over the Internet effectively and receive services through use of high speed broadband.

Video Remote Interpreting services would be particularly applicable for rural and remote areas.

Some early intervention and educational services could also be delivered via the Internet. The Royal Institute for Deaf and Blind Children currently provides a form of early intervention service called "Teleschool" which could be further developed and expanded nationally.

A great deal of information can now be made accessible over the Internet. Video clips of information in Auslan are increasingly appearing on the Internet, and this should be embraced as a way to provide accessible information about a very wide range of things, e.g., information about government services and programs, mainstream services, specialist services, health information and so on.

Auslan classes for families and others can also be provided via the Internet and/or video conferencing.

In areas where the Internet is not accessible, information could be provided on DVD and distributed through service providers and DPOs.

Appropriate and adequate resources would need to be available and specialist staff trained to provide these services.

Deaf people in rural and remote areas tend to not be aware of the services that are available to them or their options for requesting services. Community awareness programs need to be developed and delivered.

- ***How could a new system get rid of wasteful paper burdens, overlapping assessments (the 'run around') and duplication in the system?***

Deafness is usually a lifetime experience and once diagnosed most deaf people's deafness does not change. From a deaf person's point of view it is therefore absurd to be continually requested to provide evidence of their deafness for program eligibility purposes. Such "evidence" usually involves a visit to a GP to obtain a paper stating that the person is deaf. This involves needless expense for the Deaf person, a waste of the doctor's time and usually involves the deaf person informing the doctor of their condition rather than any actual medical examination.

Perhaps a system could be developed where on diagnosis a person is entered into a central registry similar to births deaths and marriages that does not require the person to notify such things as changes of address, and is issued with a card that identifies their deafness and its permanent nature. This card is then all that is required for "proof" or eligibility requirements for any program.

Throughout a person's life needs will change, e.g. a child's needs are different to those of an adult; when a person moves house they may have some associated one off needs for that location, and so on. Such changes should not be subject to external reassessment.

Needs self assessment into one central registry should eliminate a great deal of duplication and reassessment and paper burden.

In addition, better, more accurate statistics and data collection processes need to be developed and applied to the need for and development of services.

Funding

- ***How should a new scheme be financed?***

Deaf Australia supports the concept of a nationally funded and administered disability support system through a national levy.

Some services are already funded by a type of levy – e.g., the National Relay Service is currently funded by a levy on telecommunications carriers. This type of levy could be expanded to cover other types of service provision – e.g:

- the telco levy could be expanded to a levy on all telephone/communication bills to fund communication services for all, so that all citizens (including people with disabilities themselves) contribute to the fund;
 - a levy on all enrolments at all levels of education could be used to fund access across the board to these programs.
- ***How can it be ensured that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future***

Deaf Australia does not have a set idea of how much money should be available and how availability can be ensured to deliver the services that are needed.,

Organising and implementing a new disability policy

- ***Ideas of a scheme that will work***

The UNCRPD requires much more than access to services and is based on supporting “full and equal enjoyment of all human rights by all people with disabilities”

The UNCRPD provides for progressive realisation of social, cultural and economic rights. Deaf Australia agrees with the collective view expressed by people with disabilities and their organisations that Australia has the economic capacity to address these responsibilities immediately.

Deaf Australia will advocate strongly for implementation that is not compromised by rationing of funding or threatened by resistance to systemic reforms of disability support.

Suggested moves/approaches. A new scheme could employ a number of approaches in combination:

- Identify all existing disability support funding and associated administration funding by all levels of government (including National Disability Agreement, HACC and Mental Health) and restructure to address current demands, so that the maximum funds are spent on actual service delivery rather than on administration and rationing;
- Identify capacity of existing funding to address current demands for support;
- Introduction of a new hypothecated tax to address any shortfall in addressing current demands for disability support for all who meet eligibility requirements;
- Develop individualised budgets for eligible target group;
- Investigate the feasibility models such as NABS for other services;
- Build in flexibility and openness to change and incorporate CPI increase;
- Needs to be a holistic approach that considers whole of life issues;

- Guarantee funding regardless of age – separation of disability and ageing, and the transition from disability funding to aged care funding at age 65 is not necessarily the most effective approach;
 - Consult with consumer advocacy groups in aged care sector about whether people with ageing related disability should be part of this reform and at what stage should this happen;
 - Adopt learning from current initiatives that have already been commenced in various jurisdictions (especially Victoria, Western Australia, and Business Services reforms) and utilise experience from working models in other countries;
 - Significant investment required in workforce development and training to support a significant cultural paradigm shift in disability support. There is a need to better understand how far market needs will drive this reform and how much intervention from a more managed approach is needed;
 - Incorporate long range planning of the scheme taking into consideration environmental changes and technological advancements.
- ***While it may be a while to get the idea up and running, what should the government do now?***
- Funding for services to encourage their workforce to increase their skills in accredited or relevant courses.
 - Update resources.
 - Provide information FAQ's (including in Auslan) for people wishing to learn more about this and understand the scheme.
 - Public Relations showing the benefits of this scheme.
 - Funding for service providers to start programs (e.g., bilingual early intervention programs and recreation programs).
 - Strengthen the *Disability Discrimination Act* to require government, industry and service providers to make their businesses, services, information etc accessible and to make them accountable, rather than relying on a complaints based system.
 - Update relevant legislation (e.g. the Broadcasting Services Act) to mandate 100% captioning on television and other broadcast and electronic media, and in public places, restaurants and cafés, accommodation, public transport, workplaces, health centres and so on.
 - Provide visual and SMS access to emergency services and information broadcasts including use of Auslan in these broadcasts.

Name

Names discussed and suggested by the Deaf Community

- National Disability Insurance Scheme (not preferred)
- Disability Equity Scheme
- Enable Australia
- Inclusive Australia

- One link
- Sign link
- Access link

References:

- United Nations Convention on the Rights of Person with Disabilities
- Access Economics, 2006. *Listen Hear! The Economic Impact and Cost of Hearing Loss in Australia*. CRC Hear and the Victorian Deaf Society.,
- M. Therese Pierce and Rachel Miers, 2008. Deaf Education Review.