



# **Productivity Commission – long term care and support scheme**

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# **1. Introduction**

## **1.1. About the Deafness Forum**

Deafness Forum is the peak body for deafness in Australia. Established in early 1993 at the instigation of the Federal government, the Deafness Forum now represents all interests and viewpoints of the Deaf and hearing impaired communities of Australia (including those people who have a chronic disorder of the ear and those who are deafblind).

The Deafness Forum exists to improve the quality of life for Australians who are Deaf, deafblind, have a hearing impairment or a chronic disorder of the ear by:

- advocating for government policy change and development
- making input into policy and legislation
- generating public awareness
- providing a forum for information sharing and
- creating better understanding between all areas of deafness.

## **1.2. Our consultation process**

Deafness Forum has consulted with its members to gather feedback on this topic. A face to face consultation was held in Sydney with interpreters, hearing loop and real time captioning provided to ensure complete access and full participation by the members who attended. Following this day a number of draft submissions were sent out to our full membership for their comments and endorsement.

Members that have specifically endorsed this submission and contributed to it include:

- Ai-Media
- CICADA Qld
- Better Hearing Australia Sunshine Coast
- Self Help for Hard of Hearing Australia (SHHH)
- The Shepherd Centre
- SCIC
- Printacall
- Pat Fulton Hearing Coach
- Kaye Gooch

## **2. Prevalence, incidence and impact**

### **2.1. Definitions**

Deafness Forum uses the following definitions when discussing deafness.

Where Deaf is used with a capital D, it is referring to those members of the Deaf community who share a common language and culture. In Australia, that language is Auslan (Australian Sign Language).

Hearing impairment can be anything from mild to moderate to severe to profound. The impact differs for each person. This may be due to when their hearing loss occurred, their educational, employment and social experiences, or other factors. Hearing impairment, hearing loss, hard of hearing, deaf and deafness are used interchangeably and generally relate to people who use a spoken language and who may use a hearing aid or cochlear implant and/or other tools and technologies.

Chronic disorders of the ear refer to people with different disorders (such as Meniere's disease, tinnitus, etc) which may or may not be accompanied by a hearing loss.

Congenital deafness refers to hearing loss present at/detected at and/or soon after birth.

Throughout this document, we have used the term "long term care and support scheme" as we disagree with a medical model.

### **2.2. Prevalence and impact of hearing loss**

One in every six Australians is currently affected by hearing loss. Prevalence rates for hearing loss are associated with increasing age, rising from around 1 per cent for people aged younger than 15 years to three in every four people aged over 70 years.<sup>1</sup>

The net consequence of hearing loss is a reduced capacity to communicate. The ability to listen and respond to speaking is reduced, and for some, the ability to speak is lost or impaired. Reduced communication abilities impact on a person's life chances through the reduced opportunity to equitably participate in education, to gain competitive skills and employment and to participate in relationships. Adverse health effects are also associated with hearing loss.

Hearing, vision and touch enable us to interact with our environment at all levels. Of the three primary senses, hearing is the foundation sense used for communication between people. A loss of hearing acuity fundamentally changes the ability of the individual to communicate, and through this, limits their ability to interact with society. This has social and economic consequences both for the individual and for society.

Historically and still today hearing loss is the unseen and often unrecognized disability because the impairment doesn't affect a person's mobility or impact on their

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<sup>1</sup> Access Economics ibid page 5

ability to care for themselves. However they are affected by being excluded from participating in society due to the financial burden of the disability, the limitations placed on a person with hearing loss because of the lack of access and inclusion.

While interventions such as hearing aids and cochlear implants enhance a person's ability to communicate, they do not eliminate the disability. Furthermore, the majority of people with hearing loss (85 per cent) do not have such devices.<sup>2</sup>

In 2005 the real financial cost of hearing loss was \$11.75 billion or 1.4 per cent of GDP.<sup>3</sup> By comparison, only 0.034 per cent of GDP is expended on hearing loss or \$288 million.<sup>4</sup>

These costs do not include:

- the costs of otitis media which can be substantial in some sub-populations, such as Aboriginal children;
- the net cost of loss of wellbeing (disease burden) associated with hearing loss, which is a further \$11.3 billion.

The largest financial cost component is productivity loss, which accounts for well over half (57%) of all financial costs (\$6.7 billion). Nearly half the people with hearing loss are of working age (15-64 years), and there are an estimated 158,876 people not employed in 2005 due to hearing loss. The productivity cost arises due to lower employment rates, and higher rates of earlier retirement, for people with hearing loss over 45 years and subsequent losses in earnings.

Furthermore there are two aspects to the impact of hearing loss on taxation revenue for the government. Lower workforce participation, absenteeism and premature death mean that the people affected are contributing less income tax revenue. Lower income levels among the hearing impaired mean lower capacity to consume goods and services than people with normal hearing. Reduced consumption of goods and services means reduced consumption tax contributions.

Access Economics calculated that the cost of tax foregone in 2005, based on the premises set out above, was \$2 billion. Of this, \$1.33 billion (67 per cent) represents lost income tax revenue and \$0.67 billion (33 per cent) is lost consumption tax.<sup>5</sup>

Still the government spends only a fraction of this on its hearing loss programs.

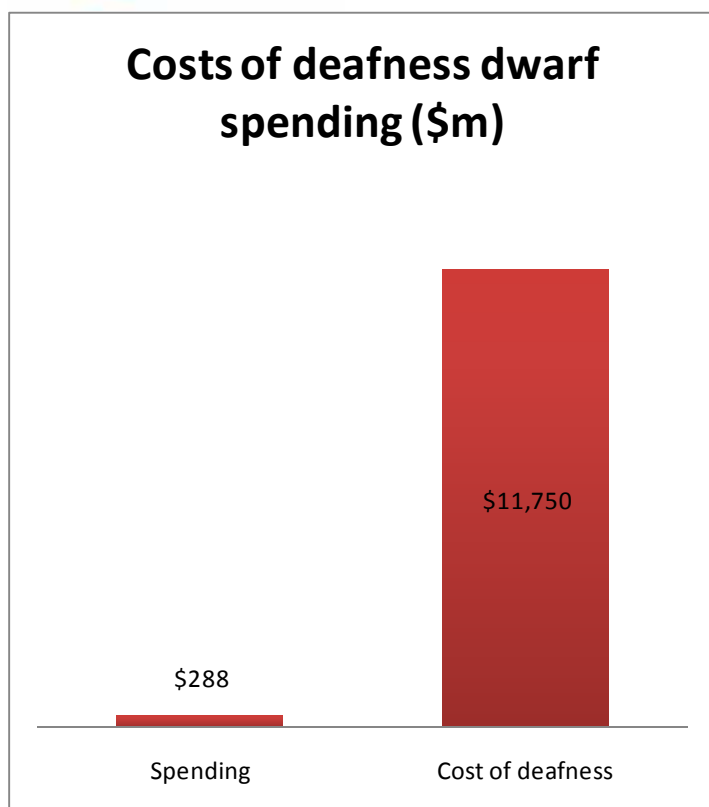
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<sup>2</sup> Access Economics ibid

<sup>3</sup> Access Economics ibid

<sup>4</sup> Access Economics ibid page 48

<sup>5</sup> Hear Us: Inquiry into Hearing Health in Australia 2010, chapter 3



### 3. Our comments

We are pleased to have the opportunity to provide this information to the Productivity Commission.

Deafness Forum welcomes the possibility of a long term care and support scheme to provide the access necessary for people with hearing loss to participate fully and productively in mainstream society.

Our submission responds to the Productivity Commission's request, in its Issues Paper, for comment on the design implications of the Convention on the Rights of Persons with Disabilities for a long term care and support scheme or similar scheme.

We urge the Productivity Commission to use the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as the core design of a long term care and support scheme.

Australia ratified the CRPD in July 2008. The CRPD sets out the human rights and fundamental freedoms of persons with disability. Australia's ratification of the CRPD represents a solemn undertaking to recognize, respect, protect and fulfill the rights it contains. The CRPD is binding upon all Australian governments and their agencies.

The CRPD does not create 'new' human rights, but instead applies existing human rights to the specific circumstances of persons with disability. It is comprised of civil and political and economic, social and cultural rights. Civil and political rights are immediately realizable, which means that they must be complied with at and from the point of ratification. Economic, social and cultural rights are progressively realizable, which means that immediate compliance is not required at the point of ratification. However, parties must work towards their full realization to the maximum extent of their available resources.

Human rights are normative values or standards that are accepted as being applicable to all persons, at all times, and in all circumstances. In an important sense they do not represent 'optimum' conditions. They are 'basic' or 'fundamental' requirements for human dignity. While economic, social and cultural rights are progressively realizable; this should not be understood as meaning that they are aspirational and not basic or fundamental.

It follows from this that we believe that the Productivity Commission must take care to ensure that in formulating recommendations for a national support scheme for persons with disability it does not conceptualise CRPD rights as expressing optimal conditions that are to be aspired to, but which may not be achievable, either immediately or at all. The CRPD expresses normative conditions that persons with disability are entitled to expect as of right. This is especially the case in relation to CRPD civil and political rights.

The Productivity Commission's recommendations, therefore, must be formulated so as to reflect Australia's international human rights obligations under the CRPD.

We believe that a long term care and support scheme and supporting institutional arrangements as recommended by the Disability Investment Group would make a major contribution to implementation of Australia's obligations under the CRPD

We believe that consideration by the Productivity Commission should commence from the perspective that scheme design, including the purposes for scheme funds and the roles of institutional arrangements, should

- encompass the full range of human rights and obligations recognised by the CRPD (thus for example addressing participation in and reasonable adjustments to mainstream activities rather than only specific disability services and supports)
- include measures to remove disabling barriers on societal and institutional as well as individual levels (noting the social model of disability adopted by the CRPD)
- enhance capacity for effective participation in decision making by people with disabilities, including through support for and recognition of the roles of advocacy and representative organisations.

### 3.1. Recommendations

A full list of recommendations made in this submission is provided as Appendix A.

### 3.2. Implications of the CRPD on the Rights of Persons with Disabilities for scheme design

Implications of provisions of the CRPD for scheme design are discussed below. For convenience relevant CRPD text is inserted followed by comments and recommendations.

### 3.3. Article 1 - Purpose

*The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*

The purpose of the CRPD as indicated in article 1 is to promote full and equal enjoyment of “all” human rights by persons with disabilities rather than a more restricted set of services and opportunities. In the context of a long term care and support scheme this implies that consideration should commence from as wide a set of choices for people with disability and their families as possible.

The Productivity Commission Issues Paper indicates that the proposed scheme under consideration is not intended to provide services to all people with a disability, many of whom need no or few supports... “mainly drawn from those with severe or profound disability, though an appropriate coverage may include some people with moderate disabilities and exclude some categorised by the ABS as severe or profound”.

We have long disagreed with the Australian Bureau of Statistics (ABS) classification, which uses “core activity limitation”. A hearing loss impacts on an individual’s ability to communicate, which in turn impacts on education, employment, relationships and health. Arbitrary medical definitions of “severe” and “profound” should not deny eligibility to those who nevertheless suffer effective exclusion because of their level of impairment. The cost-effectiveness of providing access for those with mild or moderate impairment can be as high (if not higher) than for those with severe or profound impairment. The general principle should be the effectiveness of delivering inclusion for each dollar invested in access.

**Recommendation 1:** A long term care and support scheme must commence from the basis that the scope of the scheme should facilitate full and equal enjoyment of the full range of human rights for people with disability, not based on the severity of their disability. A baseline quality of life index could be established and resources provided to lift up those people with a disability to achieve a quality of life within an acceptable range.

**Recommendation 2:** Such a scheme should use an ***inclusive definition*** as set out in the CRPD. *Article 4 (c) of the UN CRPD requires that States Parties need to take*

*into account the protection and promotion of the human rights of all persons with disabilities in all programs and policies.*

**Recommendation 3:** A scheme should support **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 (many people with hearing loss have multiple disabilities), 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. Eligibility for disability support needs to be proactive – for example contacting people on a disability or sickness benefit and assessing them for rehabilitation measures. The current approach is that nothing happens unless the person with a disability makes an application. People with disabilities suffering from depression or in a marginalized group don't know they can apply or don't apply because they don't think they will get anywhere.

**Recommendation 4:** A scheme should recognize the need to include **groups** from the start that might **fall through gaps**, such as:

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

**Recommendation 5:** A scheme should include people with psychosocial disabilities and **people with ageing related disabilities**.

- While ageing related disability has been excluded in the terms of reference for this inquiry, Deafness Forum feels that a new scheme needs to consider this group as the needs and support strategies are similar across the lifespan: the need for specialist equipment and supports for people with hearing impairment do not stop at age 65. Solutions that incorporate elements of universal design will have benefits to those over 65.

**Recommendation 6:** People with disabilities **under the age of 65** when a new scheme is introduced should continue to be eligible beyond this age and for the remainder of their lives. In relation to those people over the age of 65 acquiring ageing related disability prior to the introduction of a new scheme, Deafness Forum recommends that Productivity Commission Inquiry consider this in the context of links between this inquiry and the separate inquiry into aged care.

**Recommendation 7:** Deafness Forum recommends that as part of such a long term care and support scheme, an independent statutory body be established to develop an **assessment process** for individuals that:

- Assesses individual's needs separately from 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,
- Provides an assessment at a location or setting where the individual is most comfortable.
  - For example, Indigenous people need a more proactive and culturally appropriate response.

*Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

The definition of disability in article 1 is inclusive, not exhaustive. In particular the list of types of disability (physical, mental, intellectual or sensory) is not exhaustive; and reference to “long term” impairments is not exclusive – and does not exclude impairments which are long term but episodic (Ménière’s Disease or Tinnitus for example), or long term but not necessarily lifelong.

Hearing loss can be evaluated by degree of severity against other conditions. Moderate hearing loss is comparable to a moderate depressive episode and severe hearing loss is comparable with pneumonia as well as more advanced diabetes, resulting in complications.<sup>6</sup>

While we do not advocate a medical approach to inclusion in a long term care and support scheme, we include these comparisons to illustrate the importance of including people with hearing loss in such a scheme.

People with hearing loss who may not require significant “care or support” nonetheless do require significant measures of barrier removal to ensure their full and equal enjoyment of human rights and social and economic participation. These access services should be included within a long term care and support scheme.

Disabling barriers to equal participation in mainstream services, facilities and opportunities are a significant source of needs for services and support directed specifically to people with hearing loss.

A scheme which reduces disablement and the social and individual costs of disablement over time accordingly needs to have sufficient scope to address disabling barriers in society.

**Recommendation 8: *People with hearing loss must be included*** in any long term care and support scheme to enable them to participate in every day activities and overcome disabling barriers.

The CRPD definition clearly adopts a social/environmental model. As noted by the Preamble to the CRPD “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and

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<sup>6</sup> Access Economics ibid page 78

effective participation in society on an equal basis with others". In the context of a long term care and support scheme this implies that:

- while threshold eligibility criteria may include reference to medically based assessment of impairment, entitlements within the scheme will appropriately require reference to other factors determining the disabling effect associated with a person's impairment;
- while one purpose of a long term care and support scheme is to compensate for and meet the costs of disabling effects resulting from interaction between impairment and social and environmental barriers, another purpose is to reduce or eliminate those barriers (for individual scheme beneficiaries and more broadly).

A National Disability Commission and Australian National Disability Research Institute as recommended by the Disability Investment Group would have important roles in this respect.

**Recommendation 9:** The Productivity Commission should base its work on a **social model of disability**, taking into account the effect of disabling environments in considering appropriate eligibility criteria and levels of benefits or entitlements.

Indigenous Australians, especially children, are reported as having ear or hearing problems at twice the rate of non-indigenous children, primarily due to the high rates of otitis media.<sup>7</sup>

Additional comments on issues for Indigenous Australians can be found at Appendix B.

**Recommendation 10:** The Productivity Commission take into account the particular **impacts of disadvantage affecting Indigenous people** in Australia when determining eligibility criteria.

### 3.4. Article 2: Definitions

*For the purposes of the present Convention:*

- *"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;*
- *"Language" includes spoken and signed languages and other forms of non spoken languages;*
- *"Discrimination on the basis of disability" means any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural,*

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<sup>7</sup> FaHCSIA 2006:54

*civil or any other field. It includes all forms of discrimination, including denial of reasonable accommodation;*

- *"Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;*
- *"Universal design" means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. "Universal design" shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.*

The definitions in article 2 (including reference to universal design and reasonable accommodation and the breadth of the definition of discrimination) give an early indication of the breadth of disability related adjustments which a long term care and support scheme could appropriately seek to address, both on an individual and social basis.

### **3.5. Article 3 - General principles**

*The principles of the present Convention shall be:*

1. *Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;*
2. *Non-discrimination;*
3. *Full and effective participation and inclusion in society;*
4. *Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;*
5. *Equality of opportunity;*
6. *Accessibility;*
7. *Equality between men and women;*
8. *Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.*

The General Principles set out in article 3 of the CRPD may be appropriate to reflect the design of a long term care and support scheme.

**Recommendation 11:** The Productivity Commission ensure that at all stages its consideration of ***the implications of the CRPD on the Rights of Persons with Disabilities for scheme design*** include the implications of the substantive provisions of the CRPD in addition to its general principles and purpose.

### **3.6. Article 4 - General obligations**

*4.1. States Parties undertake to ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability. To this end, States Parties undertake:*

- 1. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;*
- 2. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;*
- 3. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;*
- 4. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;*
- 5. To take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise;*
- 6. To undertake or promote research and development of universally designed goods, services, equipment and facilities, as defined in article 2 of the present Convention, which should require the minimum possible adaptation and the least cost to meet the specific needs of a person with disabilities, to promote their availability and use, and to promote universal design in the development of standards and guidelines;*
- 7. To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost;*
- 8. To provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities;*
- 9. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.*

Institutions such as a National Disability Commission and/or an Australian National Disability Research Institute as proposed by the Disability Investment Group would complement and add value to existing Australian Human Rights Commission functions and activity (and equivalent statutory roles of State and Territory equal opportunity bodies) through:

- having a significantly greater resource base for disability rights activities;
- working in co-operation with Australian Human Rights Commission policy, educational and other activities; and

- potentially resourcing the use by individuals and organisations of complaint and other processes under the Disability Discrimination Act.

The Disability Investment Group recommended that its proposed Australian National Disability Research Institute be established and receive initial funding in advance of commencement of a long term care and support scheme (while also recommending that substantially expanded funding be provided through a long term care and support scheme once commenced).

The Australian Government bears international responsibility for implementation of obligations under the CRPD. If institutions as recommended by the Disability Investment Group are established as part of Australia's response to its obligations under the CRPD, the Government might consider providing these institutions with a similar combination of independence and responsiveness as applies to the Australian Human Rights Commission:

- Independence in being able to identify and pursue priority issues without direction or veto from government; but
- Responsiveness through a responsible Minister being able to issue references requesting work on particular issues (generally accompanied by specific purpose resourcing to conduct this work).

**Recommendation 12:** The Productivity Commission to consider institutional arrangements supporting a long term care and support scheme or similar scheme include **allocation and resourcing of roles addressing the obligations** specified in CRPD article 4.1.

*4.2. With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law.*

Clearly a long term care and support scheme provides a major mechanism for applying resources to the realisation of human rights consistently with article 4.2 of the CRPD. It is not clear that a distinction between economic social and cultural rights on the one hand, and civil and political rights on the other, would be highly relevant for a long term care and support scheme given that:

- as emphasised in the Preamble to the CRPD, human rights are indivisible; and
- all rights require the application of resources (for example civil and political rights in the justice system or in access to democratic processes).

In particular it does not appear:

- that actions under a long term care and support scheme to promote achievement of rights categorised as civil and political rights can or should be excluded; or

- that these actions should receive automatic priority over actions to promote achievement of rights categorised as economic, social and cultural.

The design of a long term care and support scheme should be undertaken with a view to the enjoyment of the full range of human rights. This question needs to be addressed at the individual level as well as giving consideration to the global budget requirements to make the scheme workable and sustainable.

The level of funding for individual disability support should be determined through a self assessment approach. Self assessment models have worked effectively in UK and much better than costly bureaucratic controls and assessment process. This requires an investment in trust – a complete reversal of the current obsession with bureaucratic micro-management and intervention based on distrust of individual and family capacity to make good decisions around purchasing supports. The research evidence, here and internationally, in programs that trust the individual demonstrate greater program effectiveness and efficiency. Self-determination should also extend to control in decisions about the process of how needs are met.

A system of audit and review by the independent statutory authority would mitigate against any fraud.

*4.3. In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.*

Clearly the obligation under article 4.3 to consult with and involve people with disability through their representative organisations is highly relevant to appropriate governance arrangements for, and operations of, institutions administering a long term care and support scheme.

The CRPD does not specify in any detail how consultation with and involvement of representative organisations should occur. One essential point however would appear to be the need for financial support from the scheme also to enable representative organisations to perform their roles effectively in relation to scheme operation (including not only minimum funding to enable participation in advisory structures and the like, but also provision of technical support and capacity building measures to ensure that participation can be effective.)

Consideration could also be given to the possible role of a long term care and support scheme in providing a sustainable and adequate funding base for representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation.

**Recommendation 13:** The Productivity Commission to consider mechanisms to include ***involvement of and consultation with disability representative organisations*** in scheme governance and operation, including:

- needs for funding, technical support and capacity building measures to enable disability representative organisations to participate effectively;
- the role of a long term care and support scheme or similar scheme in providing a sustainable and adequate funding base for disability representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation.

*4.4. Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent.*

No comment.

*4.5. The provisions of the present Convention shall extend to all parts of federal states without any limitations or exceptions.*

No comment.

### **3.7. Article 5 - Equality and non-discrimination**

*5.1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.*

*5.2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.*

*5.3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.*

A long term care and support scheme and roles for administering institutions would be expected to have major impacts on reasonable accommodation on individual and systemic levels both on issues covered by the DDA and more broadly.

The Productivity Commission has previously considered issues of reasonable adjustment in its review of the DDA. While the review concluded that overall the DDA had been reasonably effective in achieving benefits in excess of its costs, the PC also pointed to limited progress in a number of areas, notably employment, including in securing effective and efficient provision of reasonable adjustment.

It appears clear that current legislative and funding arrangements are insufficient to ensure provision of reasonable adjustment to a level consistent with human rights or to the level which would be economically efficient. Current arrangements feature:

- a very general and briefly (yet not clearly) stated requirement to make reasonable adjustments under the DDA;
- fragmented information on practical measures for making reasonable adjustment;
- a lack of systematic research on innovation in making reasonable adjustments; and
- limited funding and other support for making reasonable adjustments (outside of the coverage of existing compensation schemes).

The Productivity Commission review of the DDA provides some discussion of economic reasons why current arrangements would be expected to deliver less in achieving reasonable adjustment and other aspects of equality and inclusion than would be economically efficient. Issues include:

- *Information search costs:* An adjustment which might be low or no cost to make will nonetheless not be expected to occur (in particular but not only in small business environments) if practically useful information and authoritative information on regulatory requirements takes too much time or expertise to find;
- *Transaction costs in current compliance arrangements:* A compliance approach principally relying on individual complaints while inexpensive in any individual instance will not always provide the most efficient means of achieving widespread social change without additional accompanying and supporting measures;
- *Externalities:* Current costs of adjustment fall principally on employers and other enterprises expected to make them, and costs of failure to make adjustments fall most directly on people with disability, while a significant stream of benefits from adjustments would be anticipated to accrue to government in reduced welfare costs and increased tax revenue (through increased employment) and costs of specialised support (for example when a private bus operator provides an accessible service there will be reduced demand for government taxi subsidy schemes).

A long term care and support scheme featuring appropriate roles for institutions such as a National Disability Commission and Australian National Disability Research Institute as proposed by the Disability Investment Group should be considered as a means of addressing these issues. These roles could include:

- providing access to practical information;
- conducting, co-ordinating or funding research on technical and other innovations;
- roles in development of technical and/or regulatory standards;

- funding for making of adjustments – to people with disability and to people required to make adjustments.

On the issue of funding to assist people responsible for making reasonable adjustments (such as employers), a scheme design might either:

- Seek to specify from the outset what adjustments will and will not be funded; or
- Provide decision-making criteria but allow room for negotiation and flexibility (for example regarding whether adjustments should be fully funded by the scheme, or continue to be wholly the responsibility of an employer or educational institution for example, or be made by mixed sources of funding).

Given the range of adjustments and circumstances in which a need for adjustments may arise an approach which provides for flexibility and further specification case by case may be preferable.

A new scheme for funding disability support cannot be expected to address all the issues that impact on people with disabilities. Ongoing structural reform work to address systemic barriers and remove discrimination needs to be properly funded and is not the direct task of a national disability support scheme.

**Recommendation 14:** Deafness Forum recommends the establishment of an ***independent statutory authority*** responsible for the governance of a new disability support scheme.

Options for funding such a scheme include:

- A National Disability Social Insurance Scheme funded by an insurance levy (like Medicare) to fund all legitimate claims for disability support. While the capacity to provide an entitlement based scheme is attractive when compared with current situation, there are also concerns about how the insurance culture might continue to portray disability as something negative to be insured against. Other concerns are how an insurance driven scheme might use cost-driven thinking to impose support strategies that would undermine self-determination and choice for individuals. If this scheme is too closely linked with Medicare, there is a risk that it might reinforce a medical model of disability – as against supporting a social model approach set out under the CRPD.
- A new dedicated or specific purpose tax to be introduced to promote universal access to disability support funding. The purpose of such a tax would be to support an individual to fully participate in all areas of community life and to optimise their contribution to Australian society. It was suggested that funding allocated for this scheme could be benchmarked against the percentage of national Gross Domestic Product (GDP) committed to this program. This would create a basis for measuring government performance and assist us to track progressive or regressive trends in expenditure.

- Private contribution is also suggested by the Productivity Commission Inquiry paper. We do not support the idea of an asset test for full entitlement to the scheme.
- The working group felt that further research is needed to develop a better understanding about both the market place economics and different models of insurance that could be considered to support such a scheme.

Currently the total funding in disability support is administered by all levels of government with large levels of duplication in administration. A significant amount of the total disability support budget is spent before it reaches people with disabilities. There have also been many reports on service system failure and waste in various jurisdictions that highlight the broken nature of current approaches.

**Recommendation 15:** The Productivity Commission should investigate the **cost of NOT implementing a fully funded national disability support scheme** based on self-determined, individualised budgets.

Key features of a funded body could be:

- Board is made up of a majority of people with disabilities and DPOs who are representative of key constituencies across the nation. Representation would also need to take into account the need for gender equity and input from indigenous people and people from culturally diverse backgrounds.
- It would make higher policy level funding distribution decisions.
- It would support resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. Funding (in part) for such activities is already present in some jurisdictions such as Victoria and West Australia.
- Costs of operating the Board would be funded through this scheme by Government, taking into account the full participation costs for board members and payment of sitting fees.
- It would have a research and development role to drive significant cultural paradigm change around disability support.
- This body would be underpinned by specific enabling legislation and report against CRPD based performance measures. This would include funding for an independent complaints and appeals body.
- Body to be reviewed regularly by relevant administrative review body.

Deafness Forum believes a system based on individualized funding would allow for more choice.



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 CRPD.

A definition of disability support needs:

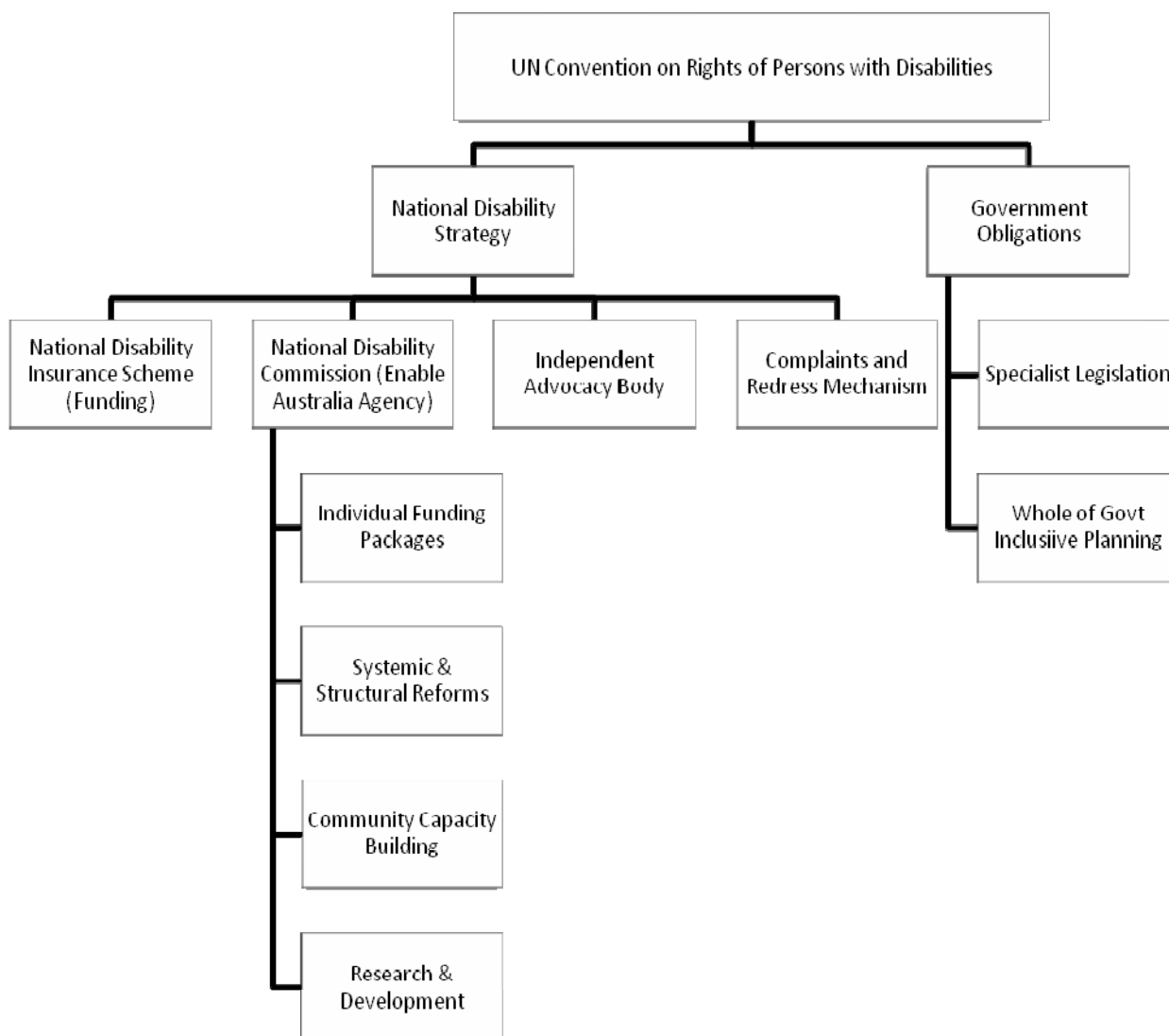
- To be broad to take into account the diversity of support needs according to the individual context – cultural diversity, geographic remoteness,
- To allow for changing needs due to changing circumstances across the lifespan, and
- To have a capacity to respond to a crisis situation.

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 and institutions.

Deafness Forum 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.<sup>8</sup>

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<sup>8</sup> See DANA's "A Proposal for a New Administrative & Leadership Framework for Disability Advocacy"  
[www.dana.org.au](http://www.dana.org.au)



**Recommendation 16:** The Productivity Commission consider how scheme funding might be applied, and institutional roles assigned, for achieving **reasonable adjustments**, in all of the areas of life covered by the CRPD, including:

- provision of access to practical information;
- conducting, co-ordinating or funding research on technical and other innovations;
- roles in development of technical and/or regulatory standards;

- funding for making of adjustments – to people with disability and to people required to make adjustments.

*5.4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.*

No comment.

### **3.8. Article 6 - Women with disabilities**

*6.1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.*

*6.2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.*

Deafness Forum understands that The Preamble to the CRPD recognises that “women and girls with disabilities are often at greater risk, both within and outside the home of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation”. Multiple disadvantages experienced by women with disability applies in Australia in a range of areas dealt with by the CRPD.

While Deafness Forum has no specific recommendation on this issue, we **support** recommendations made by the Australian Human Rights Commission and Women With Disabilities Australia in this area.

### **3.9. Article 7 - Children with disabilities**

*7.1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.*

*7.2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.*

*7.3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.*

Hearing loss has a very specific impact on children and, depending on when their hearing loss is identified, will determine the amount of significant support they will need in developing language and accessing education and eventually employment. The total estimated cost for early intervention services in 2005 was over \$20 million.<sup>9</sup>

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<sup>9</sup> Access Economics 2006: 57

**Recommendation 17:** A long term care and support scheme to provide financial assistance to ***enable deaf children to participate in society including early intervention*** services.

Research, clinical practice and experiences reinforce the tenet that children who enter early intervention before six months of age will have the greatest opportunity to achieve their fullest potential across all developmental domains. The most effective way of detecting infants with hearing loss early enough to promote the best possible outcomes is through universal neonatal hearing screening for all newborns.

The importance of early intervention is being recognised by the government in Recommendation 8 of the recent *Hear Us* report which recommends that the Council of Australian Governments extends its commitment for universal newborn hearing screening to include hearing screening of all children on commencement of their first year of compulsory schooling.<sup>10</sup>

Given the crisis in ear health among Indigenous Australians, urgent priority should be given to hearing screenings and follow-up for all Indigenous children from remote communities on commencement of school.

Most Indigenous children who experience regular fluctuating hearing loss through childhood are unable to access sound field amplification (which amplifies the voice of the teacher to the whole class), but are eligible for individual hearing aids that they are often reluctant to wear.

The fragmented and silo ridden mainstream institutions and professions are commonly unable to respond in the holistic, collaborative ways needed to address issues around Indigenous hearing loss.

**Recommendation 18:** A care and support scheme should take ***particular notice of the issues faced by indigenous children***. Refer to Appendix B

### **3.10. Article 8 - Awareness-raising**

*1. States Parties undertake to adopt immediate, effective and appropriate measures:*

- 1. To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;*
- 2. To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;*
- 3. To promote awareness of the capabilities and contributions of persons with disabilities.*

*Measures to this end include:*

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<sup>10</sup> Commonwealth of Australia, (2010). *Hear Us: Inquiry into Hearing Health in Australia*

1. *Initiating and maintaining effective public awareness campaigns designed:*
  1. *To nurture receptiveness to the rights of persons with disabilities;*
  2. *To promote positive perceptions and greater social awareness towards persons with disabilities;*
  3. *To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;*
2. *Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;*
3. *Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;*
4. *Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.*

There would clearly be roles for institutions administering a scheme in relation to awareness raising and attitude change pursuant to article 8 comparable to roles of other social insurance agencies such as OHS and motor accident authorities.

There is little awareness of hearing loss (including an awareness of the risk of noise injury – such as tinnitus and/or noise-induced hearing loss). Awareness campaigns regarding disability in Australia to date have not been conducted from a particularly rigorous evidence base or included:

- a strong impact evaluation framework;
- a close connection with other policy tools; or
- a sufficient resource base for large scale and sustained effort.

Institutions administering a long term care and support scheme would be better placed to act in the above areas (directly and through funding of and co-operation with activity by disability organisations and other relevant government and non-government organisations).

**Recommendation 19:** Institutions administering a long term care and support scheme be empowered to undertake and fund **awareness raising measures** in accordance with article 8 to address attitudinal barriers.

### 3.11. Article 9 - Accessibility

*9.1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include*

*the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:*

- 1. Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;*
- 2. Information, communications and other services, including electronic services and emergency services.*

*9.2. States Parties shall also take appropriate measures to:*

- 1. Develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;*
- 2. Ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;*
- 3. Provide training for stakeholders on accessibility issues facing persons with disabilities;*
- 4. Provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;*
- 5. Provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;*
- 6. Promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;*
- 7. Promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;*
- 8. Promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.*

While rights and obligations provided for by the CRPD and requiring attention under a long term care and support scheme are not restricted to accessibility issues, article 9 (considered in conjunction with article 4 in particular) provides a very substantial work program which Australia has accepted the obligation to address.

Each element of this article indicates roles that could be taken up by a National Disability Commission or Australian National Disability Research Institute or both. As in other areas these roles could involve both direct activity, and funding of and co-operation with activity by disability organisations and by other relevant government and non-government organisations.

**Recommendation 20:** Institutions administering a long term care and support scheme or similar scheme be **empowered to undertake and fund measures** in accordance with each element of article 9 of the CRPD.

### **3.12. Article 10 - Right to life**

The text of this provision is not reproduced here as we have no specific comments on article 10.

### **3.13. Article 11 - Situations of risk and humanitarian emergencies**

*States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*

Institutions administering a long term care and support scheme could have significant roles in improving responses to disability within responses to situations of risk pursuant to article 11.

This could include development and monitoring of application of appropriate standards for disability aspects of emergency responses and safety systems in relation to the built and natural environments and also in relation to human environments such as responses to domestic violence as noted above by reference to article 6.

It does not appear necessary to make more specific recommendations at this point regarding specific inclusion of article 11 within the scope of a long term care and support scheme, beyond the recommendations already made for breadth of scope regarding scheme funding and institutional competence.

### **3.14. Article 12 - Equal recognition before the law**

*12.1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.*

*12.2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.*

*12.3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.*

*12.4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a*

*competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.*

*12.5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.*

As indicated by article 12, equal recognition before the law for people with disability is not confined to issues of formal legal capacity but may include requirements for support and advocacy. These issues need to be included in design of a long term care and support scheme

### **3.15. Article 13 - Access to justice**

*13.1. States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.*

*13.2. In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.*

Access to justice, as well as being a human right in itself, is one of the means for securing implementation of human rights more generally. Measures to bring the operation of justice system institutions (such as courts and tribunals, policing and corrections system facilities) into compliance with the CRPD would be expected to be the financial responsibility of governments responsible rather than calling on the funding from a long term care and support scheme.

There could however be roles for institutions administering a long term care and support scheme in:

- Supporting development and implementation of standards and procedures to promote equal and effective access to justice;
- Funding use of the justice system by individuals and representative organisations including legal and other advocacy and support.

### **3.16. Article 14 - Liberty and security of the person**

*14.1. States Parties shall ensure that persons with disabilities, on an equal basis with others:*

- 1. Enjoy the right to liberty and security of person;*
- 2. Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.*

*14.2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.*

Issues of liberty and security of the person under article 14 may not appear directly within the scope of a long term care and support scheme. However, a reduction in disproportionate imprisonment rates for people with hearing loss may be expected from the provision of more effective supports through a long term care and support scheme – with consequent reductions in personal and social costs. This might be considered as one set of success indicators for such a scheme.

### **3.17. Article 15 - Freedom from torture or cruel, inhuman or degrading treatment or punishment**

The text of this provision is not reproduced here as we have no specific comments on article 15.

### **3.18. Article 16 - Freedom from exploitation, violence and abuse**

*1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.*

*2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.*

*3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.*

*4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.*

*5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.*

Funding for systemic and individual advocacy should be considered as an essential part of monitoring arrangements under a long term care and support scheme.

### **3.19. Article 17 - Protecting the integrity of the person**

The text of this provision is not reproduced here as we have no specific comments on article 17.

### **3.20. Article 18 - Liberty of movement and nationality**

The text of this provision is not reproduced here as we have no specific comments on article 18.

### **3.21. Article 19 - Living independently and being included in the community**

*States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

- 1. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- 2. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- 3. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

Implementation of the rights to independent living including access to necessary services and supports as required by article 19 are clearly key objectives for a long term care and support scheme. Institutions responsible for implementation of a long term care and support scheme should be expected to take a major role in monitoring success against the outcome statements provided in clauses (a) (b) and (c) of this article – on a national level and on a more fine-grained basis including in relation to particularly disadvantaged groups (for example by reference to multiple disabilities and the experience of Indigenous people and culturally and linguistically diverse people).

All people who are Deaf or have a hearing impairment have the same right to access facilities as do people who are hearing, to be included in the community.

To provide adequate communication access for people who are Deaf or hearing impaired a combination of the following list is usually what is required:

- Real Time Captioning – used in education, meetings, health care, and events in sports stadiums such as concerts.

- Audio Loops – installed at service counters, transport platforms or any place where a verbal announcement is likely to occur. Also should be in theatres, court rooms, cinemas or other auditoria.
- Auslan Interpreters – to be provided in the workplace, at meetings, conferences, theatres, court rooms.
- Captioning – facilities should be available on TVs in hotels/motels and other accommodation and wherever there is a verbal announcement being made such as places of transport.
- Volume control phones – should be available in the workplace, hotels/motels and other accommodation, public telephones, emergency phones in lifts.
- Fire/smoke alarms – the current audible alarms are not suitable for Deaf and hearing impaired. Those that are suitable for people with a hearing loss are considerably more expensive than audible alarms.

### **3.22. Article 20 - Personal mobility**

*States Parties shall take effective measures to ensure personal mobility with the greatest possible independence for persons with disabilities, including by:*

1. *Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;*
2. *Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;*
3. *Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;*
4. *Encouraging entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities.*

Agencies administering a long term care and support scheme or similar scheme should be expected to have major roles in implementing the obligations provided by article 20 on measures to ensure personal mobility.

### **3.23. Article 21 - Freedom of expression and opinion, and access to information**

*States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:*

1. *Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;*

2. *Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;*
3. *Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;*
4. *Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;*
5. *Recognizing and promoting the use of sign languages.*

All people who are Deaf or have a hearing impairment have the same right to access information so they are included in the community.

To provide adequate communication access for people who are Deaf or hearing impaired a combination of the following list is usually what is required:

- Captioning – used in education, meetings, health care, and events in sports stadiums such as concerts.
- Auslan Interpreted version to be provided for online videos posted.

Roles for institutions administering a long term care and support scheme in implementation of article 21 on freedom of expression and information could include:

- funding for provision of interpreting or captioning;
- funding for research on technologies to facilitate communication (including for people who are Deaf or have hearing or speech impairments);
- advocacy and/or support for advocacy by representative organisations.

### **3.24. Article 22 - Respect for privacy**

The text of this provision is not reproduced here as we have no specific comments on article 22, except to say that in some instance, people should be able to disclose their disability without concern for privacy strictures. Often our members are told they cannot put up a notice about their hearing loss because of privacy issues. Comments from members include:

- When I think about Privacy Policy for a person with hearing impairment, particularly in health, the key element is my choice to decide that I need people to know I have a disability and need my hearing aids [or cochlear implant processor] to communicate with them. For example, in hospital, my choice would be to have a notice at my bedside to raise awareness of my needs.
- My carers need to know I can't hear them if at that time I don't have my hearing aids in, for example I have just had a surgical procedure. It is possible therefore that there might be an inappropriate perception of my ability to

communicate as a consequence in the above situation which could severely compromise my response that may be important, if they are not aware.

- The balance of benefit is overwhelmingly in favour of people knowing that I have a hearing difficulty so people can communicate with me.

### **3.25. Article 23 - Respect for home and the family**

*23.1. States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that:*

- 1. The right of all persons with disabilities who are of marriageable age to marry and to found a family on the basis of free and full consent of the intending spouses is recognized;*
- 2. The rights of persons with disabilities to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education are recognized, and the means necessary to enable them to exercise these rights are provided;*
- 3. Persons with disabilities, including children, retain their fertility on an equal basis with others.*

*23.2. States Parties shall ensure the rights and responsibilities of persons with disabilities, with regard to guardianship, wardship, trusteeship, adoption of children or similar institutions, where these concepts exist in national legislation; in all cases the best interests of the child shall be paramount. States Parties shall render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.*

*23.3. States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families.*

*23.4. States Parties shall ensure that a child shall not be separated from his or her parents against their will, except when competent authorities subject to judicial review determine, in accordance with applicable law and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.*

*23.5. States Parties shall, where the immediate family is unable to care for a child with disabilities, undertake every effort to provide alternative care within the wider family, and failing that, within the community in a family setting.*

The Preamble to the CRPD notes that “persons with disabilities and their family members should receive the necessary protection and assistance to enable families

to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

A long term care and support scheme or similar scheme should be expected to have a major role in implementation of Australia’s obligations under clauses 3 to 5 of article 23 to provide support where required to people with disability in their role as parents and to families of children with disability.

This could include ensuring access to early intervention programs.

### **3.26. Article 24 - Education**

*24.1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and life long learning directed to:*

- 1. The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;*
- 2. The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;*
- 3. Enabling persons with disabilities to participate effectively in a free society.*

*24.2. In realizing this right, States Parties shall ensure that:*

- 1. Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;*
- 2. Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;*
- 3. Reasonable accommodation of the individual’s requirements is provided;*
- 4. Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;*
- 5. Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.*

*24.3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:*

- 1. Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;*

2. *Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;*
3. *Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.*

*24.4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.*

*24.5. States Parties shall ensure that persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others. To this end, States Parties shall ensure that reasonable accommodation is provided to persons with disabilities.*

Education is a real struggle for children with a hearing loss. Some studies report that people with hearing loss were 2.42 times less likely to have completed high school.<sup>11</sup>

People with hearing loss have poorer educational and employment outcomes than the rest of the population. The number of people with more severe degrees of hearing loss that report completing a trade course or higher is less than half that of the general population.<sup>12</sup>

Having had their chances of attaining adequate literacy compromised early on in the education system, higher or tertiary education is often not seen as a realistic option. This is compounded by a lack of access at universities and TAFE colleges. The flow on from this is obvious.

Research shows that it is quite common for children to have a disability in addition to hearing loss. This factor, referred to as dual diagnosis, is a particular issue for children with hearing loss as it has profound implications for their educational placement and subsequent life chances. Fortnum et al (2002:176) report that 27.4% of children with hearing loss have at least one other disability.<sup>13</sup> From a sample of 17,169 children with hearing loss, there were reports of 4,709 children having an additional disability, with 7,581 disabilities (or an average of 1.6 disabilities other than hearing loss per disabled child) reported. The most common additional disabilities were learning difficulties (11.1%) and visual impairment (5.7%) followed by a series of conditions with a prevalence of 2%-3% (developmental delays, cerebral palsy, speech and language, musculoskeletal, psychosocial and

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<sup>11</sup> Access Economics op cit page 56

<sup>12</sup> Ibid, page 56

<sup>13</sup> Fortnum et al (2002:176)

neuromotor). Additional educational and community services costs are incurred when children with hearing loss have more than one disability.<sup>14</sup>

**Recommendation 21:** a long term care and support scheme or similar scheme and institutions administering such a scheme could have major roles in ensuring **non-discriminatory access to education** including making of reasonable adjustments. These roles could include:

- conducting, co-ordinating or funding research on technical and other innovations;
- funding for making of adjustments (including human and technological supports) – to people with disability and possibly to educational institutions;
- funding or coordinating training;
- conducting or funding legal and other advocacy.

### 3.27. Article 25 - Health

*States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:*

1. *Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
2. *Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*
3. *Provide these health services as close as possible to people's own communities, including in rural areas;*
4. *Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*
5. *Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*

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<sup>14</sup> Ibid, page 24

6. *Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

Hearing loss can be evaluated by degree of severity against other conditions. Moderate hearing loss is comparable to a moderate depressive episode and severe hearing loss is comparable with pneumonia as well as more advanced diabetes, resulting in complications.<sup>15</sup>

The net consequence of hearing loss is a reduced capacity to communicate. The ability to listen and respond to speaking is reduced, and for some, the ability to speak is lost or impaired. Reduced communication abilities impact on a person's life chances through the reduced opportunity to equitably participate in education, to gain competitive skills and employment and to participate in relationships. Adverse health effects are also associated with hearing loss.

Adult hearing loss is associated with an increased risk for a variety of health conditions including:

- diabetes (Wilson et al, 1992; Mitchell, 2002);
- stroke (Mitchell, 2002);
- elevated blood pressure (Wilson et al, 1992);
- heart attack, particularly those rating their hearing as poor (Hogan et al., 2001);
- psychiatric disorder, particularly those rating their hearing as poor (Hogan et al., 2001);
- affective mood disorders (Ihara, 1993; Mulrow et al, 1990);
- poorer social relations (Mulrow et al, 1990);
- higher sickness impact profiles (physical and psycho-social (Bess et al, 1989);
- reduced health related quality of life, particularly those with more severe hearing loss (Wilson, 1997).<sup>16</sup>

**Recommendation 22:** institutions administering a long term care and support scheme could have significant roles in implementation of article 25 including:

- promoting and assisting in development of **standards** for effective access to health services;
- monitoring of **outcomes**;
- **support for individual and systemic advocacy** in relation to health and health care.

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<sup>15</sup> Access Economics 2006:78

<sup>16</sup> Access Economics op cit page 23

Hearing loss contributes to diminished cross cultural competencies among some Indigenous people through the use of avoidance as a way of coping with culturally unfamiliar social processes embedded in services such as childcare, education and health. This means that services to Indigenous communities where hearing loss is common need to focus on being culturally responsive as well as using effective communication strategies; such as using amplification.

### 3.28. Article 26 - Habilitation and rehabilitation

*26.1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:*

- 1. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;*
- 2. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*

*26.2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.*

*26.3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.*

**Recommendation 23:** A long term care and support scheme would be expected to assist in addressing:

- **gaps in access** to habilitation and rehabilitation services which clearly exist in hearing impairment;
- **limitations and inconsistencies in availability** of assistive technologies; and
- **breadth of scope of habilitation and rehabilitation** services and programs, and inclusiveness of these services and programs including in relation to people with multiple disabilities, culturally and linguistically diverse people and Indigenous people.

### 3.29. Article 27 - Work and employment

*1. States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the*

*right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:*

- 1. Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;*
- 2. Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;*
- 3. Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;*
- 4. Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;*
- 5. Promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;*
- 6. Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;*
- 7. Employ persons with disabilities in the public sector;*
- 8. Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;*
- 9. Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;*
- 10. Promote the acquisition by persons with disabilities of work experience in the open labour market;*
- 11. Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.*

*2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.*

**Recommendation 24:** A long term care and support scheme and institutions administering such a scheme could have major roles in ensuring **equal employment opportunity** including making of reasonable adjustments. These roles could include:

- providing access to practical information;

- conducting, co-ordinating or funding research on technical and other innovations;
- roles in development of technical and/or regulatory standards;
- funding for making of adjustments – to people with disability and possibly to employers;
- conducting or funding legal and other advocacy.

Without a solid educational background, finding employment is a real challenge for people with hearing impairment. Those who do manage to enter the workforce can be hampered by the need for special equipment, training and workplace adjustments. Given the difficulties in finding and keeping a job, it is no wonder that promotion and career advancement is out of reach for many people with a hearing impairment.

Providing adequate and timely intervention at the time of diagnosis (at any age) without delay will be an investment in the future. People with hearing loss are excluded from full participation in society and their productivity greatly reduced.

Of people with hearing loss aged 15-64 years, 55.6% reported being in paid work compared with 62.4% of people without hearing loss. If employment rates are lower for people with hearing loss, this loss in productivity represents a real cost to the economy.<sup>17</sup>

In 2005 an estimated 1.76 million Deaf and hearing impaired Australians were of workforce age. However, their overall participation rate and the proportion in full time employment are considerably lower than for hearing Australians.

Around 160,000 Australians leave the workforce each year because of their deafness.

Waiting until their jobs are in jeopardy is waiting too long.

Without financial assistance for hearing aids and cochlear implant processors, real time captioning in the workplace, ongoing access to interpreters in the workplace or other accessible technology (such as volume control phones and hearing loops for meeting rooms) Australians who are Deaf or have a hearing impairment may struggle to participate in the workforce.

Discrimination on the basis of disability is against the law. But without adequate support in the workforce, why would an employer hire someone with greater support needs, with greater costs to the employer? For example, to bring in interpreters for weekly section meetings is a considerable expense for a small business, one which Auslan for Employment does not go far enough to cover.

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<sup>17</sup> Access Economics Report 2006

And for Australians with a hearing impairment, who need real time captioning at weekly meetings, there is no assistance.

People with hearing/deafness disabilities have difficulty in seeking and gaining employment, and in gaining promotions. Often, due to their disability, they are underemployed and have low incomes, limiting their ability to purchase hearing aids or cochlear implant processor upgrades and other assistive devices. Also in this situation are the long term unemployed people in the catch 22 situation of being unable to gain employment because they do not have a hearing aid, and unable to afford an aid because they are not employed.

There are many workforce challenges, for example access to Auslan interpreters, real time captioning professionals, real issues for rural and remote areas, and alarming indigenous hearing health issues. Indigenous Australians experience ear disease and associated hearing loss at up to ten times the rate of non-Indigenous Australians.<sup>18</sup>

With cochlear implants, free upgrades of processors are given to children but not adults. This means that those on low incomes have to self-finance subsequent speech processors. At present, a complimentary processor is given at the time of surgery for fitting of the implant; after that, an adult implantee must finance replacement processors from their own funds. As many deaf adults have low incomes, replacement costs of "hearing devices" (hearing aids, speech processors etc) is prohibitive, and health insurance policies often only cover a small portion of the total cost.

### **3.30. Article 28 - Adequate standard of living and social protection**

*28.1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.*

*28.2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:*

- 1. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;*
- 2. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;*

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<sup>18</sup> Hear Us: Inquiry into Hearing Health in Australia 2010, chapter 8

3. *To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;*
4. *To ensure access by persons with disabilities to public housing programmes;*
5. *To ensure equal access by persons with disabilities to retirement benefits and programmes.*

The role of a long term care and support scheme would include preventing or reducing poverty and ensuring an adequate standard of living as required by article 28 (although it should also go beyond this specific minimum standard to include facilitation of enjoyment of the full range of human rights).

Article 28 itself also reinforces the point that an adequate standard of living is not envisaged as being able to be ensured simply by provision of financial benefits alone.

A National Disability Commission and/or Australian National Disability Research Institute as proposed by the Disability Investment Group could have important roles in ensuring that Australia addresses its obligations under article 28 regarding access to disability related services, devices and other assistance.

### **3.31. Article 29 - Participation in political and public life**

*States Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:*

1. *Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected, inter alia, by:*
  1. *Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use;*
  2. *Protecting the right of persons with disabilities to vote by secret ballot in elections and public referendums without intimidation, and to stand for elections, to effectively hold office and perform all public functions at all levels of government, facilitating the use of assistive and new technologies where appropriate;*
  3. *Guaranteeing the free expression of the will of persons with disabilities as electors and to this end, where necessary, at their request, allowing assistance in voting by a person of their own choice;*
2. *Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:*

1. *Participation in non-governmental organizations and associations concerned with the public and political life of the country, and in the activities and administration of political parties;*
2. *Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.*

It would not be expected to be an appropriate role for a long term care and support scheme to meet directly the costs to governments of ensuring access to and participation in electoral processes.

However there could be appropriate roles in:

- meeting participation costs for individuals (whether as electors or as candidates);
- research and technical development;
- addressing participation in non-government organisations.

### **3.32. Article 30 - Participation in cultural life, recreation, leisure and sport**

*30.1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:*

1. *Enjoy access to cultural materials in accessible formats;*
2. *Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;*
3. *Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.*

*30.2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.*

*30.3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.*

*30.4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.*

*30.5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:*

1. *To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;*
2. *To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;*
3. *To ensure that persons with disabilities have access to sporting, recreational and tourism venues;*
4. *To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;*
5. *To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.*

As emphasised by article 30, the aims and scope of a scheme for support for people with disability should not be confined to survival and subsistence, or even to issues of economic participation, but should include full and equal enjoyment of rights to social and cultural participation and contribution.

It costs more to live with a disability than it does without a disability. Whether the costs relate to pharmaceuticals, aids and equipment, or specialist devices to enable everyday living. The costs mount up.

The burden of disease from hearing impairment is 3.8%, which is greater than that of three of the National Health Priority Areas – asthma, diabetes and musculoskeletal conditions.<sup>19</sup>

Hearing aids and other devices (cochlear implant speech processors, BAHA processors) can be expensive for adults to purchase, and with no financial assistance from the government available. Hearing aids or cochlear implant speech processors may need to be upgraded on average every 3-5 years with the outlay being similar to the cost of a second-hand car. Along with hearing aids or speech processors, deaf people need to purchase batteries every week, as well as special equipment eg special smoke alarms, baby monitors, alarm clocks and much more.

In addition to all these costs, people with deafness may have additional disabilities. They also, like as other Australians, may have temporary or chronic illness, effects of aging, and everyday living expenses to deal with.

People with hearing loss are marginalised in many activities such as access to TV, the cinema, DVDs, theatre, in fact public events of just about every type. Going to the doctor, a funeral, buying a car and parent-teacher night are all fraught. Needing an interpreter is a real barrier to participation in such events. Other obvious issues include the person risking missing out on important information or misunderstanding.

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<sup>19</sup> Access Economics Report 2006:76

**Recommendation 25:** Deafblind people are especially challenged. The Australian Deafblind Council has submitted a paper to the Productivity Commission and Deafness Forum **supports** their recommendations.

### **3.33. Article 31 - Statistics and data collection**

*31.1. States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention. The process of collecting and maintaining this information shall:*

- 1. Comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities;*
- 2. Comply with internationally accepted norms to protect human rights and fundamental freedoms and ethical principles in the collection and use of statistics.*

*31.2. The information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.*

*31.3. States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others.*

As noted by the Disability Investment Group report, collection of data and statistics as is required by article 31 is fundamental to the operation of a scheme. This would assist in providing an evidence base for implementation actions and in monitoring progress achieved.

Consistent with the social model of disability adopted throughout the CRPD, data collection needs to go beyond data about impairment and about functioning of services and facilities specifically addressed to people with disability to also include data about social and environmental barriers and process in reducing these barriers and their impact.

**Recommendation 26:** Deafness Forum **supports** the Australian Human Rights Commission recommendation on this clause of the CRPD, relating to collection and making available of data on implementation of each element of the CRPD and including benchmarking and measurement of progress over time.

### **3.34. Article 32 - International cooperation**

The text of this provision is not reproduced here as we have no specific comments on article 32.

### **3.35. Article 33 - National implementation and monitoring**

*33.1. States Parties, in accordance with their system of organization, shall designate one or more focal points within government for matters relating to the implementation of the present Convention, and shall give due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors*

*and at different levels.*

*33.2. States Parties shall, in accordance with their legal and administrative systems, maintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.*

*33.3. Civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.*

A National Disability Commission and Australian National Disability Research Institute as proposed by the Disability Investment Group would provide an important part of Australia's framework for promoting and monitoring implementation of the CRPD as envisaged by article 33.

**Recommendation 27:** Deafness Forum **supports** the recommendation by the Australian Human Rights Commission that an Australian Disability Research Institute or similar institution should be considered for early implementation ahead of implementation, or even final determination, of other scheme elements.

### **3.36. Article 34 - Committee on the Rights of Persons with Disabilities**

The text of this provision is not reproduced here as we have no specific comments on article 34.

### **3.37. Article 35 - Reports by States Parties**

*35.1. Each State Party shall submit to the Committee, through the Secretary-General of the United Nations, a comprehensive report on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard, within two years after the entry into force of the present Convention for the State Party concerned.*

*35.2. Thereafter, States Parties shall submit subsequent reports at least every four years and further whenever the Committee so requests.*

*35.3. The Committee shall decide any guidelines applicable to the content of the reports.*

*35.4. A State Party which has submitted a comprehensive initial report to the Committee need not, in its subsequent reports, repeat information previously provided. When preparing reports to the Committee, States Parties are invited to consider doing so in an open and transparent process and to give due consideration to the provision set out in article 4.3 of the present Convention.*

*35.5. Reports may indicate factors and difficulties affecting the degree of fulfilment of obligations under the present Convention.*

Development of data and indicators through a long term care and support scheme would be expected to assist greatly in ensuring that reporting under article 35 is meaningful and assists in achieving effective implementation over time.

### **3.38. Article 36 - Consideration of reports**

The text of this provision is not reproduced here as no relevant implications have been identified at this point from article 36.

### **3.39. Article 37 - Cooperation between States Parties and the Committee**

The text of this provision is not reproduced here as no relevant implications have been identified at this point from article 37.

### **3.40. Article 38 - Relationship of the Committee with other bodies**

The text of this provision is not reproduced here as no relevant implications have been identified at this point from article 38.

### **3.41. Article 39 - Report of the Committee**

The text of this provision is not reproduced here as no relevant implications have been identified at this point from article 39.

### **3.42. Article 40 - Conference of States Parties**

The text of this provision is not reproduced here as no relevant implications have been identified at this point from article 40

### **3.43. Article 41 - Depositary**

The text of this provision is not reproduced here as no relevant implications are envisaged to arise from article 41.

### **3.44. Article 42 - Signature**

The text of this provision is not reproduced here. Australia having already signed the CRPD (on 30 March 2007), no further implications arise from article 42.

### **3.45. Article 43 - Consent to be bound**

The text of this provision is not reproduced here as no relevant implications have been identified.

### **3.46. Article 44 - Regional integration organizations**

The text of this provision is not reproduced here as no relevant implications have been identified.

### **3.47. Article 45 - Entry into force**

The CRPD having already entered into force (including for Australia) no further implications appear to arise from this provision.

### **3.48. Article 46 - Reservations**

*1. Reservations incompatible with the object and purpose of the present Convention shall not be permitted.*

*2. Reservations may be withdrawn at any time.*

Australia did not enter any reservations on ratification of the CRPD and it is thus unnecessary to consider pursuant to article 46 whether any reservations made are compatible with the object and purpose of the CRPD. Australia did make the following interpretive declarations:

#### ***Declaration***

*Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards;*

*Australia recognizes that every person with disability has a right to respect for his or her physical and mental integrity on an equal basis with others. Australia further declares its understanding that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards;*

*Australia recognizes the rights of persons with disability to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others. Australia further declares its understanding that the Convention does not create a right for a person to enter or remain in a country of which he or she is not a national, nor impact on Australia's health requirements for non-nationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and reasonable criteria.*

No comment.

### **3.49. Article 47 - Amendments**

No comment.

### **3.50. Article 48 - Denunciation**

No comment.

### **3.51. Article 49 - Accessible format**

No comment.

### **3.52. Article 50 - Authentic texts**

No comment.

## 4. Conclusion

In summary:

- There are potentially unprecedented opportunities for Australian society through a long term care and support scheme that delivers access and inclusion for people with disabilities.
- Any omission of people who are Deaf or have a hearing impairment would be a major flaw of any new scheme – this would be in opposition to any needs-based or human rights approach.
- Hearing loss is the unseen and often unrecognized disability because the impairment doesn't affect a person's mobility or impact on their ability to care for themselves. However they are affected by being excluded from participating in society due to the financial burden of the disability, the limitations placed on a person with hearing loss because of the lack of access and inclusion.
- Spending a small percentage of GDP on a long term care and support scheme makes economic sense in an affluent and progressive nation like Australia; and will avoid much larger economic costs into the future which will flow from inaction.
- A levy similar to a Medicare levy might be suitable however tying it to Medicare may reinforce a medical model of disability, which we would oppose. Similarly we not convinced that insurance terminology is appropriate.
- Such a scheme should not be means tested or asset tested as this would reinforce people with disability being penalized for having a disability and being worse off than their counterparts without disability. This would contravene the entire purpose and intent of the CRPD

At Deafness Forum, we believe that this is an unprecedented and even historic opportunity to initiate a new scheme rather than trying to fix old systems and programs that are clearly not meeting the needs of people with disabilities, their families and carers.

*"To accomplish great things, we must not only act, but also dream; not only plan, but also believe." Anatole France*

## 5. Contact

If you have any questions about the information contained in this submission, please contact

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## 7. Appendix A: Summary of Recommendations

**Recommendation 1:** A long term care and support scheme must commence from the basis that the scope of the scheme should facilitate full and equal enjoyment of the full range of human rights for people with disability not based on the severity of their disability.

**Recommendation 2:** People with hearing loss must be included in any long term care and support scheme to enable them to participate in every day activities and overcome disabling barriers.

**Recommendation 3:** The Productivity Commission should base its work on a social model of disability, taking into account the effect of disabling environments in considering appropriate eligibility criteria and levels of benefits or entitlements.

**Recommendation 4:** The Productivity Commission take into account the particular impacts in this respect of disadvantage affecting Indigenous people in Australia when determining eligibility criteria.

**Recommendation 5:** The Productivity Commission ensure that at all stages its consideration of the implications of the CRPD on the Rights of Persons with Disabilities for scheme design include the implications of the substantive provisions of the CRPD in addition to its general principles and purpose.

**Recommendation 6:** The Productivity Commission to consider institutional arrangements supporting a long term care and support scheme or similar scheme include allocation and resourcing of roles addressing the obligations specified in CRPD article 4.1.

**Recommendation 7:** The Productivity Commission considers mechanisms to include involvement of and consultation with disability representative organisations in scheme governance and operation,

- needs for funding, technical support and capacity building measures to enable disability representative organisations to participate effectively;
- the role of a long term care and support scheme or similar scheme in providing a sustainable and adequate funding base for disability representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation.

**Recommendation 8:** The Productivity Commission consider how scheme funding might be applied, and institutional roles assigned, for achieving reasonable adjustments, in all of the areas of life covered by the CRPD, including

- provision of access to practical information

- conducting, coordinating or funding research on technical and other innovations
- roles in development of technical and/or regulatory standards
- funding for making of adjustments – to people with disability and to people required to make adjustments.

**Recommendation 9:** The Productivity Commission should base its work on a social model of disability, taking into account the effect of disabling environments in considering appropriate eligibility criteria and levels of benefits or entitlements.

Indigenous Australians, especially children, are reported as having ear or hearing problems at twice the rate of non-indigenous children, primarily due to the high rates of otitis media.<sup>20</sup>

Additional comments on issues for Indigenous Australians can be found at Appendix B.

**Recommendation 10:** The Productivity Commission take into account the particular impacts of disadvantage affecting Indigenous people in Australia when determining eligibility criteria.

**Recommendation 11:** The Productivity Commission ensure that at all stages its consideration of the implications of the CRPD on the Rights of Persons with Disabilities for scheme design include the implications of the substantive provisions of the CRPD in addition to its general principles and purpose.

**Recommendation 12:** The Productivity Commission to consider institutional arrangements supporting a long term care and support scheme or similar scheme include allocation and resourcing of roles addressing the obligations specified in CRPD article 4.1.

**Recommendation 13:** The Productivity Commission to consider mechanisms to include involvement of and consultation with disability representative organisations in scheme governance and operation, including:

- needs for funding, technical support and capacity building measures to enable disability representative organisations to participate effectively;
- the role of a long term care and support scheme or similar scheme in providing a sustainable and adequate funding base for disability representative organisations to enable them to engage in systemic advocacy in support of identification and elimination of barriers in Australian society and to participate in and contribute to monitoring of progress in implementation.

**Recommendation 14:** Deafness Forum recommends the establishment of an independent statutory authority responsible for the governance of a new disability support scheme.

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<sup>20</sup> FaHCSIA 2006:54

Options for funding such a scheme include:

- A National Disability Social Insurance Scheme funded by an insurance levy (like Medicare) to fund all legitimate claims for disability support. While the capacity to provide an entitlement based scheme is attractive when compared with current situation, there are also concerns about how the insurance culture might continue to portray disability as something negative to be insured against. Other concerns are how an insurance driven scheme might use cost-driven thinking to impose support strategies that would undermine self-determination and choice for individuals. If this scheme is too closely linked with Medicare, there is a risk that it might reinforce a medical model of disability – as against supporting a social model approach set out under the CRPD.
- A new dedicated or specific purpose tax to be introduced to promote universal access to disability support funding. The purpose of such a tax would be to support an individual to fully participate in all areas of community life and to optimise their contribution to Australian society. It was suggested that funding allocated for this scheme could be benchmarked against the percentage of national Gross Domestic Product (GDP) committed to this program. This would create a basis for measuring government performance and assist us to track progressive or regressive trends in expenditure.
- Private contribution is also suggested by the Productivity Commission Inquiry paper. We do not support the idea of an asset test for full entitlement to the scheme.
- The working group felt that further research is needed to develop a better understanding about both the market place economics and different models of insurance that could be considered to support such a scheme.

Currently the total funding in disability support is administered by all levels of government with large levels of duplication in administration. A significant amount of the total disability support budget is spent before it reaches people with disabilities. There have also been many reports on service system failure and waste in various jurisdictions that highlight the broken nature of current approaches.

**Recommendation 15:** The Productivity Commission should investigate the cost of NOT implementing a fully funded national disability support scheme based on self-determined, individualised budgets.

Key features of a funded body could be:

- Board is made up of a majority of people with disabilities and DPOs who are representative of key constituencies across the nation. Representation would also need to take into account the need for gender equity and input from indigenous people and people from culturally diverse backgrounds.
- It would make higher policy level funding distribution decisions.

- It would support resourcing of local/regional disability resource centres that would play a key role in providing independent advice and could support development of initiatives at the local level that would enhance effectiveness of individualised funding allocation. Funding (in part) for such activities is already present in some jurisdictions such as Victoria and West Australia.
- Costs of operating the Board would be funded through this scheme by Government, taking into account the full participation costs for board members and payment of sitting fees.
- It would have a research and development role to drive significant cultural paradigm change around disability support.
- This body would be underpinned by specific enabling legislation and report against CRPD based performance measures. This would include funding for an independent complaints and appeals body.
- Body to be reviewed regularly by relevant administrative review body.

**Recommendation 16:** The Productivity Commission consider how scheme funding might be applied, and institutional roles assigned, for achieving reasonable adjustments, in all of the areas of life covered by the CRPD, including:

- provision of access to practical information;
- conducting, co-ordinating or funding research on technical and other innovations;
- roles in development of technical and/or regulatory standards;

funding for making of adjustments – to people with disability and to people required to make adjustments.

**Recommendation 17:** A long term care and support scheme to provide financial assistance to enable deaf children to participate in society including early intervention services.

**Recommendation 18:** A care and support scheme should take particular notice of the issues faced by indigenous children. Refer to Appendix B

**Recommendation 19:** Institutions administering a long term care and support scheme be empowered to undertake and fund awareness raising measures in accordance with article 8 to address attitudinal barriers.

**Recommendation 20:** Institutions administering a long term care and support scheme or similar scheme be empowered to undertake and fund measures in accordance with each element of article 9 of the CRPD.

**Recommendation 21:** a long term care and support scheme or similar scheme and institutions administering such a scheme could have major roles in ensuring non-

discriminatory access to education including making of reasonable adjustments. These roles could include:

- conducting, co-ordinating or funding research on technical and other innovations;
- funding for making of adjustments (including human and technological supports) – to people with disability and possibly to educational institutions;
- funding or coordinating training;
- conducting or funding legal and other advocacy.

**Recommendation 22:** institutions administering a long term care and support scheme could have significant roles in implementation of article 25 including:

- promoting and assisting in development of standards for effective access to health services;
- monitoring of outcomes;
- support for individual and systemic advocacy in relation to health and health care.

**Recommendation 23:** A long term care and support scheme would be expected to assist in addressing:

- gaps in access to habilitation and rehabilitation services which clearly exist in hearing impairment;
- limitations and inconsistencies in availability of assistive technologies; and
- breadth of scope of habilitation and rehabilitation services and programs, and inclusiveness of these services and programs including in relation to people with multiple disabilities, culturally and linguistically diverse people and Indigenous people.

**Recommendation 24:** A long term care and support scheme and institutions administering such a scheme could have major roles in ensuring equal employment opportunity including making of reasonable adjustments. These roles could include:

- providing access to practical information;
- conducting, co-ordinating or funding research on technical and other innovations;
- roles in development of technical and/or regulatory standards;
- funding for making of adjustments – to people with disability and possibly to employers;
- conducting or funding legal and other advocacy.



**Recommendation 25:** Deafblind people are especially challenged. The Australian Deafblind Council has submitted a paper to the Productivity Commission and Deafness Forum supports their recommendations.

**Recommendation 26:** Deafness Forum supports the Australian Human Rights Commission recommendation on this clause of the CRPD, relating to collection and making available of data on implementation of each element of the CRPD and including benchmarking and measurement of progress over time.

**Recommendation 27:** We support the recommendation by the Australian Human Rights Commission that an Australian Disability Research Institute or similar institution should be considered for early implementation ahead of implementation, or even final determination, of other scheme elements.

## 8. Appendix B: Indigenous Hearing loss

The profile of disability related to hearing loss is different among Indigenous Australians to that of other Australians. The widespread and early onset of Indigenous hearing loss means in many communities most people (70% in remote communities) have some degree of hearing loss. This contributes to group impacts on the whole community, as well as individual disability issues. There are family and community 'ripple effects', where the demands and needs of Indigenous children and adults with hearing loss impacts on the capacity of other family members to engage in work, education, access to health care and participation in normal activities. There is also an educational 'ripple effect' where the need for one-to-one assistance and for behavioural interventions of Indigenous children with hearing loss limits the educational opportunity of other students who share their classroom. As well as a greater proportion of the community being affected by hearing loss, the early onset of Indigenous hearing loss results in greater and longer term impacts than late onset, mostly noise induced hearing loss of other 'hard-of-hearing' Australians. These include impacts on psycho-social development, social functioning, educational outcomes, social and emotional wellbeing, and employment, involvement in family life and community and over representation in the criminal justice system.

Further, the interaction between hearing loss and cultural differences act to obscure awareness of, and compound the impact of Indigenous hearing loss. Features of this interaction include the following.

- Cultural and linguistic differences acting to obscure the awareness among non Indigenous people of the presence and effects of hearing loss among Indigenous people.
- Hearing loss contributing to diminished cross cultural competencies among some Indigenous people through the use of avoidance as a way of coping with culturally unfamiliar social processes embedded in services such as childcare, education and health. This means that services to Indigenous communities need to focus on being culturally responsive as well as using effective communication strategies; such as using amplification.
- Western communication processes being highly 'audistic', that is they heavily focused on communication through auditory means and less on visual communication strategies such as reading body language. This is especially so among the professions who have been through an education processes that strongly favours those with good auditory/verbal skills. The outcome of this is that educators and health professionals who are seen as 'suitably qualified' to work with Indigenous communities, where many if not most have some degree of hearing loss, are usually lacking in the communicative skills needed to do so successfully with their many clients with hearing loss.
- The available professionals with training and expertise in hearing loss are often prevented by policy from being able to utilise their skills effectively. For

example, the 'special education model' of service provision in education means the skills of teachers of the deaf are often unable to be effectively engaged with Indigenous children with hearing loss. The special education model assumes a few children have needs for intensive mainly individualised support, after a detailed and often lengthy assessment process. This model prevents most Indigenous children with hearing loss, commonly the majority of students in a classroom, from accessing needed support services. Access to beneficial equipment is also obstructed by policy in some areas. The policies and practice of the Australian Hearing Services means that most Indigenous children who experience regular fluctuating hearing loss through childhood are unable to access sound field amplification (which amplifies the voice of the teacher to the whole class), but are eligible for individual hearing aids that are difficult to obtain and which they are often reluctant to wear.

- Finally, the fragmented and silo ridden mainstream institutions and professions are commonly unable to respond in the holistic, collaborative ways needed to address issues around Indigenous hearing loss.

As well as hearing loss being a widespread disability in its own right when it is one of multiple disabilities it impacts on indigenous people's involvement in processes that enable access to disability support.

Hearing loss is a significant but usually invisible obstacle to navigating through disability support processes. Needed capabilities that are influenced by widespread, early onset hearing loss include skills in oral English, literacy, listening and understanding, cross cultural competencies, and phone communications skills. When even mild hearing loss is part of the mix of disabilities it plays an important part in obstructing needed support.

Hearing loss also impacts on the power to make decisions, especially informed decisions. The widespread and transgenerational influence of hearing loss impacts on the capacity of many Indigenous adults to become involved in mainstream communication processes needed to understand and decide on disability issues to do with them and/or their children. However, it is important not to locate this obstacle only with Indigenous people with hearing loss. The limited competencies of non Indigenous people (in awareness of Indigenous people having a hearing loss or having effective communication skills) is a major component in the barriers Indigenous people with hearing loss have engaging in mainstream processes.

### **Educated inadequacy**

In part non Indigenous people's limited communication skills are derived from the lesser importance of non verbal communications (such as use of body language) in Western cultures. However, this is then magnified significantly by the education system, as noted above. The listening/literacy focus of educational processes mean that those non indigenous people with listening problems (mild to moderate hearing loss and/or auditory processing problems) usually do not have sufficient success within the education system to qualify as 'professionals'. This means that there are few graduates in education, health or other professions (with the exception of a few

specialist areas such as teachers of the deaf) who have the personal experiences or training to have developed more extensive non-verbal communications skills.

Thus, the graduates of tertiary education generally tend to be 'audistic', meaning they are highly skilled in verbal/auditory communication and literacy, but are less skilled in visual communication strategies, such as using body language. Such 'visual' communication skills are more developed by Indigenous cultures and are often heavily relied upon by Indigenous people with hearing loss.

Thus the professionals who have 'qualified' in western education systems often are very limited in the skills that would enable them to communicate effectively with many of their Indigenous clients with hearing loss. The extent of this major obstacle is then 'masked' by a focus, especially among non Indigenous people; solely on cultural and linguistic differences as obstructing communications.

Currently training in 'cultural competencies' are seen as needed by professionals but training in awareness of hearing loss and communications strategies with people with hearing loss is not. Training to develop cross cultural competencies and the use of Indigenous cultural/communication brokers is certainly needed to overcome some of the communication barriers derived from combined linguistic/cultural/listening communication barriers. However, without focussed consideration of specific communications issues around hearing loss', this compensatory training is not sufficient.

The use of Indigenous cultural/communication brokers, overt post service training of Western professionals in hearing loss as well cross-cultural competencies, are critical elements in support services for Indigenous people with disabilities.

### **Eligibility matters**

The operations of the current systems of to confer eligibility to access services tell us how services unintentionally discriminate against Indigenous people with hearing loss.

Most support services require an individual needs assessments by qualified professionals. However, there is often a reluctance by Indigenous people to engage with Western professionals. The experience of past intrusion into their lives (for example, the stolen generation) by government agencies has left a legacy of fear of unforeseen and undesired outcomes arising from engagement with mainstream services and professionals.

A second obstacle relates to assessments to eligibility being undertaken by Western trained professionals who are not sufficiently culturally competent and who use frameworks that are not adequately culturally adapted. This makes the outcomes of engagement with 'assessment' unpredictable and uncomfortable, both of which inhibit willingness of to be engaged with these processes.

These factors result in Indigenous people being excluded from eligibility for support with the consequence that they become excessively reliant on the material and

human resources of family and community. Given the existing multiple forms of disadvantage experienced by the Indigenous community, the level of support available is often limited and the need to provide it can have a considerable impact on family and community. Thus, as noted above, the high levels of unsupported disability have a disruptive ripple effect on the whole indigenous community.

These 'facts' about eligibility are true for many disabilities, but especially true for hearing loss. Hearing loss is endemic in Indigenous communities because of childhood ear disease. This hearing loss is often unidentified because of

- early onset,
- poor access to screening and assessment services,
- cross cultural masking of hearing loss though a focus solely on linguistic and cultural differences and
- anxiety about participation in unfamiliar processes, which is commonly associated hearing loss, leading to avoidance of hearing testing.

In addressing Indigenous disability there needs to be an advocacy 'built in' to any support processes. This is because of the particular types and profiles of disadvantage experienced by Indigenous communities are different to those of other Australians and are often ignored. A good example of this is the needs around conductive hearing loss community that are largely ignored by mainstream institutions in policy.

Also, the existence of multiple disabilities, one of which is widespread hearing loss, impacts on involvement in processes that enable easy access to support. Hearing loss is a significant but usually invisible obstacle to navigating through disability support processes. Capabilities that are adversely affected by widespread, early onset hearing loss include oral english, literacy, listening skills, cross cultural competencies, and phone communications skills.

These issues suggest that a 'population' based approach to Indigenous disability and hearing loss in particular is needed. For example, Indigenous children with hearing loss may be eligible to receive a hearing aid but for varying reasons, do not obtain one or wear them if obtained. The provision of a sound field system would be an economical alternative to a number of children in a classroom with mild to moderate hearing loss each being fitted with an Individual hearing aid. This type of 'population approach' would cater to the identified needs of a group without the need for each person of that group needing to be 'assessed' by services which are often not availability nor culturally appropriate. A population approach would provide sound field systems because of known prevalence levels in the group rather than being available through individual assessments.

### **The Indigenous Deaf community**

The preceding refers mainly to Indigenous people who are hard of hearing (mild to moderate levels of hearing loss). More severe levels of hearing loss that are more obvious because of the reliance on signing and major difficulties with verbal communication concern fewer people, but the disadvantage experienced is among

the most extreme in the Indigenous community. In making the following comments I rely on a submission to the Senate hearing inquiry made by Jody Saxton Barney.

Most in the Indigenous deaf community do not use Auslan (the language used by most non Indigenous Deaf Australians). Rather they use local community and family signing system which links people into their local community when there is a widely used local signing system. However, when there is not a widely used community signing system individuals can become highly dependent on a few or even a single family member with whom they can communicate most easily. This isolation and dependence can lead to exploitation or even abuse, especially around money and sex. The linguistic isolation means that people have very limited access to the support services provided to non Indigenous Deaf Australians. Use of interpreters is difficult because local community sign language is not known by interpreters and communities may not want community outsiders to learn the signs which are often closely associated with secret cultural matters. Deaf Indigenous people may face community ostracism for teaching outsiders community signs, or using community signs away from 'country' which may not be culturally permitted.

Deaf Indigenous people are isolated and disadvantaged by the combination of cultural differences, multiple layers of linguistic differences and mainstream services unresponsive to their needs. Since use of Auslan acts as a passport to access disability support services, not using Auslan renders most Indigenous Deaf people excluded and 'stateless' even within the disability community. This includes involvement in education, where the development of literacy enables use of text based communication. It also includes access to health care, involvement in employment and engagement with the mainstream Deaf community. A constant complaint of the Indigenous Deaf community is that they are not consulted about their perspectives or needs by any of mainstream or Deaf specific inquiries and also that mainstream Deaf groups do not speak for them. The involvement of Deaf Indigenous people in a disability support system must start with a dialogue that takes the time to establish meaningful communication with Deaf Indigenous groups and individuals around Australia.

This information provided by Dr Damien Howard, Phoenix Consulting (NT)