This submission from Parents of the Hearing Impaired of South Australia focuses on issues around deaf and hearing impaired children and their families, and issue for these children as they become adults. The focus on this disability is not to infer that there are in anyway lesser needs across other areas of disability but rather the limiting of this submission to the area of our knowledge and expertise.

Eligibility

Who should be in the new scheme and how could they be practically and reliably identified? Which groups are most in need of additional support and help?
What could be done about reducing unfairness, so that people with similar levels of need get similar levels of support?

The recent Senate Committee Report Hear Us: Inquiry into Hearing Health in Australia (May 2010) is a comprehensive document that covers many aspects of the sorts of information required as consideration of hearing loss and its coverage as part of a disability and care support scheme.

Based on the costs identified due to lost productivity due to hearing loss $6, 667m in 2005 (Access Economic, Listen Hear! 2006 p 8) there is likely to be a range of need across a wide spectrum of both age and level of hearing loss.

For example current research is showing that children with mild hearing loss or hearing loss in one ear (Unilateral hearing loss, UHL) are at risk of delays in language development and in many cases the repeating of some years of schooling. So clearly there is a need for these children to access quality early intervention programs appropriate to their needs. So in the case of early intervention, the level of loss should not be a way of determining eligibility, especially since there is such a strong body of research demonstrating the level to which the effects of hearing loss can be mitigated with early diagnosis and quality early intervention.

With newborn hearing screening the majority of these children identified with a hearing loss will be captured by the screening data. The development of a national data base to collate this data will ensure that the children are identified and records maintained regardless of movement around the country.

The provision of hearing aids and cochlear implants for these children up to the age of 21 is currently covered by the Office of Hearing Services (OHS) through Australian Hearing. Assistive devices such as FM units are also provided to the under 21 years group.

In the "Hear Us" report a major area of need identified by the inquiry were those who became ineligible for support from Australian Hearing after turning 21. For these young people many were still trying to establish themselves in their careers, either completing university studies, studying within a trade or simply at the very beginning years of their career pathway. At this time they can ill afford the costs associated with repair and replacement of hearing aids or cochlear implant speech processors. In the event of not being able to afford such repairs and as such not being able to hear, these young people's employment and career prospects are seriously undermined, preventing them from reaching their potential and in turn resulting in lost productivity for the country.

Australian Hearing also provides support to a range of older Australians if they have pension cards or other criteria as defined by Australian Hearing eligibility requirements. This leaves a considerable percentage of the population without support for the cost of maintenance, repair and replacement of hearing aids and speech processors. If people are unable to hear properly due to their hearing needs not being met, then their employment capacity is seriously reduced, with many opting out of the workforce because they can not hear enough to stay there. There is considerable information in the Hear Us report on this issue, so it is not further discussed here.

There is a real issue of unfairness for families who live in non-metropolitan areas are at great need with respect to children with hearing loss. Ease of access to paediatric audiologists, Ear, Nose and Throat surgeons and of course quality intervention programs is a huge issue for families. Similarly ease of access to newborn hearing screening is an issue for non-metropolitan families. The coverage of screening in non-metro areas across different status varies widely and in some instances parents are required to travel considerable distances with their newborns in a bid to have their hearing tested. This is due to the lack of availability of appropriate equipment and qualified staff. In addition, even if there is access to newborn screening in some non-metropolitan regions, the there is often a lack of capacity in the infrastructure of the area to cope with additional diagnoses and early intervention support for children with a hearing loss. There is a serious need to look at how we deliver services to non-metropolitan families of children with a hearing loss to ensure that these children are not further disadvantaged by their remote location, in addition to their hearing loss.

Power

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

How should the amount of financial support and service entitlements of people be decided (and by whom)?

In the area of support services accessed by children with a hearing loss, it is the parents and caregivers who are making these choices. Historically parents are rarely treated as equals in any decision making process, when in fact, it is the parents who best know both the individual child and the logistics and family dynamics that are such a critical factor in these types of decisions. Parents need access to unbiased information and transparency from service providers. As the child's life time case worker, the parent/care giver must be provided with all information that relates to the child and his/her disability. It is completely unacceptable to have service providers deciding that they themselves will act as gate keepers of information and that they will determine what information a parent can or can not have. Parents have the right of access to all information pertaining to their child.

All service provider organisations should have a requirement to demonstrate how they obtain measures of service quality from the individuals they provide services to. There should be mechanisms to allow individual service users to provide feedback and to see how that feedback is tracked through the various levels of the organisation's management to improve service provision.

Where decisions are made by others that the person with a disability (or their carer) disagrees with, there needs to be an appeal process. An ombudsman type position established specifically for this sector would be the ideal scenario for assessing these situations and making an independent referees decision.

A model that provides the funding to the individual rather than the organisation certainly empowers individuals with disability or their carers, to choose the service that best meets their needs. The capacity to choose and to take "their money with them" is also a highly motivating scenario for service providers to ensure that they are meeting the needs of the people accessing their service. However where the current system is likely to be block grant government funding to the organisations, a shift to the funding of the individual would make financial planning and future strategic planning vastly more difficult due to the lack of certainty of incoming funding. Many service providers within disability are not for profit organisations that operate on very tight budgets and this type of financial uncertainty may well be the difference between solvency and insolvency for some and that is certainly not what we would want to see in this sector. Perhaps it may be that there is a "known level" of infrastructure based funding provided to the organisation but salary costs related to provision of a direct service is funded by the monies given to the individual upon choosing the service from that organisation? If the monies go directly to the individual as opposed to the organisation of the individual's choice, there would be significant issues around accountability of acquitting this funding. The notion of ensuring that individuals or their carers can be empowered by choosing where and how their support funding is spent is meant to make things easier for the person accessing services. If monies were provided directly to the individual or their carer, but in doing so it came with an onerous burden of accountability in relation to acquittal of funds, it would defeat the purpose. Perhaps it is preferable for there to be some model where by the individual accessing the service, nominates that service as being the recipient of all or part of their support funding and funding goes direct to the organisation. However there would still need to be some degree of flexibility in the event that the person decides on a change of service provider over the course of the financial year and as such their funding would go with them.

What services are needed and how should they be delivered?

An area of huge lost productivity is where people are not working at their capacity due to not being able to hear properly because of hearing aids/speech processors that need to be repaired or upgraded. Currently those under 21 years of age and those over 65 or in receipt of other government support pensions are eligible for support via the Office of Hearing Services through Australian Hearing. As stated earlier the lack of support for those over 21 and those under 65, especially those on low incomes means that many are unable to maximise their hearing and for those over 21 their ability to reach their potential is seriously undermined and those under

65 similarly are denied the opportunity for full participation in the workforce if their capacity to hear is significantly reduced.

The recommendation by the committee (p95 Hear Us) is that former child clients of Australian Hearing remain eligible for services until the age of 25 with this eligibility being subject to a means test. If the former child clients do not meet the means test requirements, they are to have an option to access Australian Hearing support on a fee for service basis until the age of 25. PHISA would strongly suggest that this recommendation be implemented as part of the disability and care support package.

The Senate Committee made a further recommendation in this regard (p95 Hear Us) that the eligibility for the Australian Government Hearing Services Voucher Program be extended to include all Australians, subject to eligibility and means test. It is interesting to note that (Hear Us p 91 point 5.167) "The committee believes that the costs to the Australian Government of expanding Australian Government Hearing Services Program eligibility to provide assistance to more Australians, especially those on low-incomes, would be off-set by the improved productivity and contribution those people would be able to make if their hearing needs were better met." Where means tests are utilised, PHISA's preferred option would be a sliding scale of eligibility with those not meeting the means test, provided with some level of co-pay or subsidy type of payment towards the cost of hearing aids and speech processors.

In many cases families not residing in metropolitan areas need to travel long distances, at times needing overnight accommodation before returning home, in order to attend appointments. The Patient Assisted Travel Scheme (PATS) currently only covers travel for medical appointments. Where possible medical appointments are arranged together with audiology appointments in order for families to access., however there are still many occasions where families need an audiology appointment only and as such can not access PATS. The Hear Us report (p95) has a recommendation that the PATS scheme eligibility be expanded to include support for people accessing audiological services. Again the advantages gained by individuals being fully productive as a result of optimised hearing, feeds back into the economies of the system.

The Federal Government has recently announced initiatives in relation to Universal Newborn Hearing Screening at a national level. As part of this initiative there is a working party looking at National Standards associated with this screening. A fundamental aspect of these standards is the need to ensure that babies identified with a hearing loss have access to quality intervention programs provided by professionals with the appropriate levels of training in this area. Simply identifying the loss is just the first step. Hearing loss is one area in which the impact of the loss can be significantly mitigated with the provision of amplification and quality early intervention before 6 months of age. There are again issues of access in this respect. The provision of a range of methods of intervention in the area in which the family live can sometimes limit their choices and this is of course even more the case for families not living close to major city or suburban centres. So there is the issue of access to specific programs and also the level of qualification of those providing these services. Again Hear Us report p 51, the Senate committee makes a recommendation 4.72 with regard to "the Department of Education, Employment and Workplace relations engage with state and territory education systems, higher education providers of training for teachers of children with hearing impairment, and major stakeholders (including the Royal Institute of Deaf and Blind Children and parent representative bodies), to develop and implement an agreed national qualification standard for teachers of children with hearing impairment. This standard is to be benchmarked against international best practice."

Whilst this addresses the issue of quality of intervention programs in the longer term, it does not help address the issue of families living in remote locations and their capacity to access quality early intervention. With the roll out of the National Broadband Network, this technology can be used to provide better access to early intervention programs for those families unable to access a local service. The use of teleconference style technology allows the family to access intervention programs based in the major cities without the need to travel long distances with their young child. However this model of intervention relies on access to quality equipment and broadband technologies to ensure that both teacher/therapist and the parent/child have clear access to both what is being shown and said. This equipment comes at a cost but could be used for other similar access to other services required by other members of the community. The provision of this type of technology should be further explored by the commission to determine how much improvement in overall productivity may be achieved across the board by being able to bring specialist services to individuals and families living outside of major cities and suburbs.

One of the biggest issues for individuals under the current system is that of the "blame game". When parents try to access certain things for their child, they are told "oh that is not a disability issue, that is a health department responsibility"…and of course health tells them it is disability and so parents get caught in the middle with no support and don't know where to turn. This is probably even more so the case for adults with a hearing loss. Similarly support in early intervention and school settings changes between states in Australia. With the increasing transience of the population for work and other reasons, parents need some degree of certainty as to what to expect in moving between states. A child's hearing loss does not change just because their family moves from one state to another. A new system needs to have a national focus from newborn screening all the way through. When babies are diagnosed this becomes part of a national data set. Similarly levels of early intervention and education support should be equal such that parents do not find out at a later date that they may have disadvantaged their child by moving states for differing job opportunities. A national data set documenting the child from diagnosis onwards should avoid the need to complete additional sets of paper work if the family moves. The childs' needs remain the same, just the location of delivery changes and as such it is an unnecessary burden for families to "re-apply" for everything due to changes in residential location.

Funding

As previously noted, the Senate Inquiry Committee believes that costs associated with the changes to access to services provided by Australian Hearing would be off-set by the improved productivity and contribution those people would be able to make if their hearing needs were better met.

With respect to funding other aspects of the scheme, in terms of children and hearing loss receiving a diagnosis, early intervention and ongoing support into adulthood, clearly there are many departments involved. Health, disability and education are a few of those and as such there maybe the capacity to cost shift across different departments, especially if funding for a National Care and Support package brings a more national based funding model. Similarly efficiencies of scale and reduced duplication of paperwork and organisational bureaucracy, if a more national approach is adopted, would hopefully lead to cost savings that can be better utilised in direct support to those that need it.

Currently there is a clearly recognised deficit in the provision of services to those with a disability and their carers in our society. There will need to be an injection of additional funds even if other cost savings and productivity increases are made. Any funding model needs to be one that provides on going certainty that it will generate adequate care models into the future and perhaps as suggested in the briefing notes, a medicare style of levy may be a way to achieve this. However PHISA is not really in a position to compare or contrast current funding models against future options. We are sure there are better qualified people to do those costings and comparisons.

For too long, many members of the community have been outwardly sympathetic to those within the community with a disability but equally prepared to do nothing about it. The move to National Care and Support Package that may result in additional levy or perhaps increases in taxes in order to fund the package, will actually highlight that this is not just a disability issue. This is a community issue and it is incumbent on all members of an enlightened society to accept that everyone has a part to play in the ongoing support of disability within the community. The issues discussed in this submission are in essence the things that those without disability readily take for granted. It is not about "getting something more" but rather "getting access to what everyone else already has access to".