To Productivity Commission Input into Disability Care and Support

From Dr Damien Howard
Phoenix Consulting
damien@phoenixconsulting.com.au
And
Jody Saxton-Barney
Deaf Indigenous Community Consultancy
saxyio@smartchat.net.au

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, 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 unforseen 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 by a focus solely on linguistic and cultural differences
- 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 a 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.