

Submission to the Senate Committee Inquiry into Hearing Health in Australia

Jody Saxton-Barney
Deaf Indigenous Community Consultancy
P.O.Box 955
Shepparton Victoria 3632

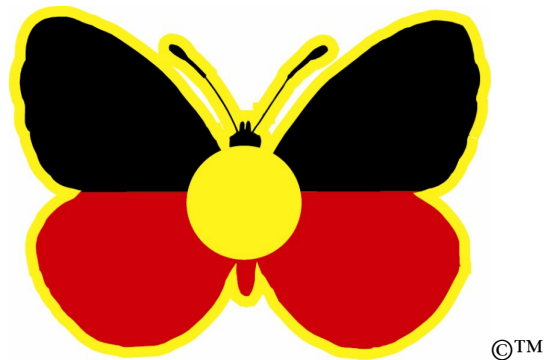


Table of Contents

Executive Summary	3
Background	4
Implications for Indigenous Deaf people	5
Conclusion and Recommendations	13

Executive Summary

The Deaf Indigenous Community Consultancy hopes to showcase and provide this committee with some of the true facts and issues faced by Indigenous Deaf people across Australia. It will look at the ways in which Indigenous Deaf people are disadvantaged by the barriers facing them on a daily basis.

The Deaf Indigenous Community Consultancy was established in 2007 after its sole proprietor Jody Saxton-Barney had been working in the field for over 20 years as well as having a lived experience as an Indigenous Deaf person. The information presented in this submission is not only hers personally, but is based on the shared experience of the 575 other profoundly Deaf Indigenous people consulted with by the Deaf Indigenous Community Consultancy. This information has been collected into a database that contains information on over 5,200 individuals with hearing loss across the country. This includes the Torres Strait Islands, remote, rural, regional, urban and metro areas in each state and territory.

The barriers faced by the Indigenous Deaf community are more complex than those of the mainstream Deaf and Indigenous hearing communities. It can be agreed that the complexities involving family, housing, education, welfare, justice and communication impacts us all regardless of our cultural background or disability. However, there is a greater disadvantage within our Indigenous communities where there is a high likelihood of hearing loss contributing to the experience of longer and more entrenched racism and oppression. Indigenous Deaf people are also more likely to have high risk behaviours and have a reluctance to obtain needed supports due to their experience of, or beliefs about, the barriers of accessible communication.

This submission is based on the stories heard by the consultancy and makes recommendations that may see a change in the way business is done for our mob.

Background

This submission is made by Jody Saxton-Barney who is a Deaf Aboriginal woman, living and working from the regional city of Shepparton in Victoria. Her work has involved areas across the country and consists of consultancy and training for organisations, departments, community co-operatives and service providers. The work done by the Deaf Indigenous Community Consultancy aims to share professional and cultural knowledge of her years of experience and connection to countries across the nations in the field of Deafness and community development. This work looks at the impacts of deafness in Indigenous communities on community capacity building, workplace training and assessing, effective workplace practices and strategic planning on improving access for deaf consumers in communities, benefits for communication tools such as sign language and cultural language bridging.

Currently there is no Indigenous Deaf voice on any of the Deaf representative boards, Australian Hearing Services, Government or Corporate bodies. This submission seeks to highlight that there are voices out in the community that need to be heard and with their permission this submission by Deaf Indigenous Community Consultancy seeks to do this on their behalf.

Currently Indigenous people with disabilities are working towards a national representative body that will include Deaf Indigenous people. But at the moment the national voice of Deaf Indigenous people is not yet available to be heard in states and territories and will be sometime before it can support such a minority, especially people living in and on country.

Difficulties faced by this minority group are often greater than others within the disadvantaged Indigenous community and the difficulties are greater than those impacting other Indigenous people. They are often suppressed and vulnerable. The compounding factors of being Indigenous and Deaf, without fluent or semi-fluent communication skills are difficult to describe in this submission. There is a complex matrix of needs and issues that are related to cultural groupings within Indigenous communities, communication difficulties as well as exploitation or neglect by others.

How we are different to mainstream Deaf Australians

To understand the position of Indigenous Deaf people it is important to understand how they are different to mainstream Deaf Australians. The use of Auslan (Australian Sign Language) provides a cultural link between mainstream Deaf Australians. In this culture people are identifiable through their signs in terms of age, their schooling, their community (state) in a similar way to the varieties of use of oral language among the hearing community. There are variations of signs that are used around a central core of common signs that link people together as a community of Deaf people.

This is not the case for Indigenous Deaf people. Only 45 of the 575 Indigenous Deaf people I have made contact with and for whom there is information on with my data base can use Auslan, only approximately 19-22 are fluent. They have generally learnt this method by being placed in schools for the Deaf, or parents who have sent them to other families in the cities to get educated.

Indigenous Deaf people

Indigenous Deaf people's use of local cultural signs, hand talk and gestures is linked to knowledge of country, history, family, storytelling and lore, ceremonies, customs and performances. Out of the 17 variations of communication sign languages and hand talk signs used in communities served by Deaf Indigenous Community Consultancy the use of these signs off country or in other parts of the country by the Indigenous Deaf person is offensive and dis-respectful and punishable by cultural law. Doing this can and has led to the individual Deaf person being banned or rejected by their communities. I describe this to explain the importance of local communication that cannot be used outside people's Country.

These locally used signs follow the linguistic structures of Aboriginal or Torres Strait languages not Auslan or English. This creates a barrier to having a unified sign language that establishes a single Indigenous Deaf cultural group of the type that exists for mainstream Deaf people. Further, since Indigenous Deaf people are more closely linked to the culture of their family and community, a separate Indigenous Deaf culture of the type that exists for mainstream Deaf Australians is not culturally appropriate. It also means the type of state and territory Deaf organisations and national peak bodies cannot truly represent the aspirations and needs of Indigenous Deaf people.

The connection that Indigenous Deaf people have is one based on their commonalities of being Indigenous and Deaf. They communicate with other Indigenous Deaf people in a vastly different mode of communication than those who use Auslan and are non-Indigenous. The mainstream Deaf community at large will often say to Indigenous Deaf people "just say your Deaf, that's enough, don't complicate your life by being Indigenous too". This response occurs more in urban and city areas and more for fair Indigenous Deaf people such as I am.

The Deaf Community as a whole are keen to support work with Indigenous Deaf people, however, they have not established appropriate cultural protocols or employ Indigenous Deaf people to do that work. One such program that was carried out in South Australia was a huge success. However, due to funding cuts and re-shuffling of offices, the program went from Deaf Services to Disability Services.

This was like a huge slap in the face to the Indigenous Deaf community who felt they were treated less fairly than other Deaf community members who stayed with the Deaf society and continue to do so. Consequently Indigenous Deaf people do not use the service and haven't been seen much since by the Deaf community at large. Indigenous Deaf people see these kinds of responses as a refusal of others to believe Indigenous Deaf people have capacity to do things themselves and that there is a disrespectful disinterest in providing culturally appropriate services to them.

Mainstream sign language services that are trained only in Auslan often have limited capacity to bridge the communication divide with Indigenous Deaf people. Many of the Indigenous Deaf community have had little exposure to Auslan. The non-verbal communication or hand talk used in community is different to Auslan and often takes into consideration a vast array of meaning in just facial expressions alone. This kind of communication is context bound to the community and the land on which the Indigenous person lives.

There is great interest for formally trained interpreters to learn such community communications skills. However, there are usually no funds to employ Indigenous Deaf people to teach them or these consultants are used for their knowledge at a low rate of pay. This has caused many concerns in community as knowledge is shared but not valued. Also Indigenous Deaf people often express the desire that their use of hand talk, gestures or cultural signs should be on an equal par with and have equal access to training and pay as Auslan interpreters.

Indigenous Deaf Relay Interpreters, now called Deaf Interpreters often support hearing Interpreters in working with Indigenous Deaf people at court or during medical appointments. This 'relay interpreting' is meeting needs but sometimes causes concern as many of the Indigenous Deaf interpreters are related or connected by kinship. The stress on these Indigenous Deaf interpreters is of concern and there are incidences of Indigenous Deaf interpreters being overworked and having limited training opportunities made available to them.

Interpreters that work within the communities around the country have reported some difficult issues and skill shortages. There have been issues in relation to how they support Indigenous Deaf to participate in the wider deaf community. There is strong cultural Lore and responsibilities that Indigenous Deaf Interpreters must adhere to that are as important as the ethical boundaries for formally trained Interpreters.

Those who wish to work effectively with Indigenous Deaf people need to ascertain their communication mode, then using appropriate interpreters and deaf interpreters that have a good knowledge base of that mode ensures effective communication. This process reduces the risks of complications around miscommunication within education, employment, legal settings and during medical

intervention. There is a need for standards that ensure Indigenous Deaf Interpreters are used when needed, that their role is respected and they are appropriately paid for their skills and knowledge.

In relation to Deaf Indigenous people acquiring Auslan, Auslan is important for some but the introduction of learning Auslan for education purposes must be given together with the maintenance of traditional oral language, as well as community signs, otherwise the person risks losing their connection with their family, culture and identity. Some Indigenous Deaf people resist or reject opportunities to learn Auslan because it can only happen at enormous cost to maintaining their culture and Indigenous identity. Support for Indigenous Deaf people must be through total communication if it is not to be at the cost of loss of identity or access to their home communication.

The Importance of Family

It is obvious from consultation with these communities the importance of the sense of belonging to family for most Indigenous Deaf people and their families. In the face of all the complex layers of living day to day as an Indigenous person in Australia, the families of Indigenous Deaf people create a family unity that includes Indigenous Deaf people.

With the majority of the 575 people consulted with, the main support available is from family. Indigenous Deaf people's prime responsibility and sense of duty is also to their family. Some experience violence, and even abuse from some family members but accept this as 'normal' as they have limited opportunities to see anything different. Mimicking behaviour is common in deaf cultures around the world as a way of learning from the context they are in as well as gaining acceptance.

In Indigenous communities this can mean being taught the way to dance, do ceremony, doing tasks required and being in the company of Elders. But when behaviour of those they are around is anti-social or negative Indigenous Deaf people often believe that this is normal. It is often only when they are enabled by their family to make decisions themselves and experience the consequences that they understand processes they are involved in.

However, often they are involved in family, community and societal processes with only a limited partial understanding of what is happening. Because of their intense focus on family and culture this is especially true when they are involved in mainstream processes, such as in health, education and criminal justice.

Teaching through family can give them greater ability to have their status in community acknowledged and not resentfully seen as an individual who is unfairly favoured due to their hearing loss. Service providers often obstruct Indigenous Deaf people exercising control of their own life by having the "welfare mentality" and acting on "behalf of the client" instead of advocating for the client and working with the family.

It is clear from what has been already said that Indigenous Deaf people's views of family are complex and at times heated due to oppression, racism, discrimination and intimidation. The imposition of other's authority on deaf family members is often overwhelming and individuals are forced to comply without understanding clearly what their rights are in being free from discrimination and harm. This reality is a constant reminder that early intervention into hearing health and communication support for families will help alleviate the communication burden on families.

Indigenous Deaf people report that they are more reliant on their families than deaf people in the wider community. As has been discussed their connection to family and country is more primary than any Deaf cultural identity of the type that is more important in non-Indigenous community. That acceptance of family and community as the primary focus in people's lives happens even if it comes with serious negative consequences. For example, being exploited and abused by some family members.

Indigenous Deaf people are often engaged with their communities and many work at supporting others within the community. Those who have talents and abilities are in paid work and living productive lives. However, there are also those who are not coping let alone able to be productive in their life. They are often at the extreme edge of family and society. They are subjected to family and community violence/abuse and have a high level of dis-engagement from education and other services. They often become targets of "scape-goating" or are exploited in their work for their families doing duties around the home or sent to work for others in a way that is exploitative. Indigenous Deaf people that are targeted as scapegoats are often subjected to being left with illegal goods, believing that they are "care taking". Often their limited communication skills make them easy targets for taking the blame for other's mistakes. They are used for free baby-sitting, or used for their resources such as cars, housing, and caring for Elders.

The impact of hearing health on Indigenous families is extreme, the cost factor for families and the knowledge of where to access affordable ear health care and communication support, is escalating out of control as families are provided with mis-information, unrealistic expectations, discrimination, oppression and failure of services to deliver programs. It is common that services manipulate or give only one or two options that the service prefers or are simply expected to accept whatever is arranged for them. Choice for Indigenous Deaf people is often denied or delayed or they are provided with inadequate services.

Mental Health, Children and Women

Many of the 575 Indigenous Deaf people consulted with have had some time struggling with their mental health. In discussions with them they raise issues relating to identity, belonging, the effects of drugs and alcohol, abuse and discrimination. These challenges are compounded because they have limited understanding and knowledge of western knowledge systems like health and how the criminal justice system works. Inadequate understanding of Indigenous Deaf people by others and without proper explanations being given by others have resulted in people being mis-

diagnosed or incarcerated without having knowledge of why they are locked up or treated in these ways.

A larger portion of Indigenous Deaf people who have been consulted with by the Deaf Indigenous Consultants are female. These women and young girls are aged between 18 months and 84 years of age. Their concerns of gender equality and access are compounded by tradition and lore, family and commitment. Their positions in their families and community are often determined by others long before they develop their own 'voice' and direction. They often have a unique strength and determination to know how to survive in their environments.

The issues raised by a large portion of these women are the fear of having their children removed or abused. They often speak about the barriers to accessing appropriate women's health services as well as their rights to other types of services. Many of these women have never heard of accessible services to health care such as NABS, NRS or interpreters. Their lack of knowledge and the disadvantage this puts them, can be seen due to the limited resources provided to these women, such as television, internet, telecommunications and transport.

The following comments are based on information of 370 Indigenous Deaf children who were consulted with. These children are aged from 18 months to 18 years of age. Many of these children are frightened by the way in which they cannot express themselves. They are innocent about the way their environment is formed and express desires such as returning home, going on country, developing a secure identity and learning to communicate to get an education and better their opportunities.

Existing youth initiative programs do not cater for these children, respite services cannot provide for these children and there is limited or no access to qualified interpreters in educational setting for these children. The generational trauma caused by the oppression of Indigenous people in general also impacts on these children so they carry a banner of anger and racism which they do not understand. They are often segregated, placed in specialist schools, or removed from schools altogether. Some are living on the streets, or have returned to grandparents on country.

Many that are living in community are viewed by authorities and members of their families and extended families as "too hard to handle". Some have talents that save them from being sent away. Children with talents such as art, performance, hunting, sport are more likely to be supported by their families and accepted by the community and institutions. It is important to state that these are the views given by the children consulted with.

Some children who are given support devices to help them in accessing sound and language only have limited use of them when they are told to leave their equipment at school or clubs, due to them being so expensive to replace by hearing services if they are lost or damaged at home. However, this limits these children's participation in family life which, as mentioned earlier, is so hugely important to them.

Education

Education happens at all stages of life, and is no different for Indigenous Deaf people. Indigenous Deaf people engage with the world visually which incorporates another layer of understanding. The educational level of the 575 Indigenous Deaf people consulted with varies. Whilst most attended schooling the educational level achieved was limited by barriers such as the access to alternative formats, such as highly visual materials and culturally appropriate supports. Often schools have provided support by a non-Indigenous person who cannot use local culturally based signs, so the child cannot understand them. For Indigenous Deaf students there must be protocols in place to ensure that there are culturally appropriate supports provided. Indigenous Deaf students need visual connection as well as other total communication modes that will provide students with the best possible foundations that will support their learning.

Sometimes equipment is provided that can assist children to communicate. Communities need to have full access to such equipment that will support their learning. These materials are costly and take years to obtain and funding applications are at times rejected, denied or delayed by government decisions and responsibility shifting between agencies. Children need access to this equipment out of school as well as at school.

Housing

Inappropriate housing causes huge concerns for Indigenous Deaf people. There are only a few that have support appliances such as alarms and door bells etc to help them with emergency procedures. They often live in overcrowded housing as they are easy targets for other members of the family and community to stay with, without contributing to the keep of the house or sharing the expenses of putting food on the table. While this kind of sharing is customary in Indigenous cultures, more often Indigenous Deaf people are not asked if others 'can stay' they are told others 'are going to stay'. The generous nature of many of the Indigenous Deaf is that they will bring people in for company, as they are often isolated or lonely and desire company. It is often hard for Indigenous Deaf people to access and remain in affordable housing, housing with good sanitation to reduce infections and also to support the large groups that congregate there over periods of time such as for "sorry business".

Services failure to support Indigenous Deaf People

Indigenous Deaf people are constantly sent to government funded programs and government agencies that are not equipped or simply fail to adequately support them. For example, many of those consulted with have stated that they have been sent to a program for job-searching and have had no access to interpreters and that they have been given a time frame to complete a set course without funds to have interpreters or note takers.

They report that workplaces will often only employ them under a wage assistance scheme and after 13 weeks they are then jobless even though they were assessed very favourably to continue in the position. Many have stated they have been interviewed for positions only to hear on the grapevine they didn't get the job because they are deaf and black. When asked why they don't access support such as advocacy or legal support due to discrimination they reply saying "oh the government don't want us to work, they want us to stay dumb blacks".

Those who attend sporting events or social events are often excluded from participation and become observers or runners - jobs given to them by others at the event. Recreational activities are few and far between and those who have established their own dance, art, sport or clubs are facing problems with management, funding and having "white" controllers. This is seen by Indigenous Deaf people participating as a "slap in the face" as they know they are capable. So they may withdraw and don't perform.

Interpreters

The barrier of limited access to interpreters, as stated earlier in this submission, is a major problem. There are only 19-22 fluent Auslan signers from this group of 575. They utilise Auslan interpreters only when necessary or enforced by courts. These interpreters are professional NAATI level and are working under extremely difficult conditions to try and cover the communication bridge. This is difficult when there is not adequate training for these interpreters to work with Indigenous Deaf people. Such training would help interpreters have a clear understanding of the inner world of Indigenous Deaf people if it's taught to them by an Indigenous Deaf person.

Representation

There is no way that Indigenous Deaf people currently represent themselves in telling government their needs. Establishing such a network of Indigenous people takes money and commitment to appropriate communication processes given the diversity that has been described earlier. Only with this ongoing commitment can representation at a national, state and local level occur.

This is complex because the disability sector isn't even at that point yet. As a minority within a disadvantaged group Indigenous Deaf people are usually in the hands of other people to speak for them and about them, most often without their knowledge. This is personally and culturally unacceptable and disrespectful. However, it must be said that most often that Indigenous Deaf people, their interests and needs are not spoken about at all. In looking at the submissions to the inquiry there is almost nothing about Indigenous Deaf people and certainly nothing else other than this submission from Indigenous Deaf people.

There is a common misconception that Deaf non-Indigenous or hearing Indigenous or professionals who have contact with them can provide a culturally appropriate

and accurate representation of the needs of Indigenous Deaf people. This is not the case, indeed it is often some members of these groups, who may feel they have a right to speak for Indigenous Deaf people, who sometimes oppress, abuse or neglect Indigenous Deaf people.

Accountability and Research

To consider why the perspective of Indigenous Deaf people is seldom presented you only have to look at the information that is presented. Agencies provide statistics about those who access a particular service or have had hearing tests as part of community funding. These statistics do not show the stories behind the numbers. They do not tell of the devastation that is experienced due to difficult to access services, delays in providing services, lack of understanding or responsiveness to cultural events and customs that conflict with testing. Information on the true needs and barriers faced by Indigenous Deaf people are not collected, nor are their views of the services asked for.

There is often an assumption that the needs of Indigenous people with disabilities will cover the needs of Indigenous Deaf people, but most Indigenous Deaf people do NOT see themselves as having a disability. The term Disability is not common in Indigenous cultures or languages, so the need to support community members who are Deaf is seen as one of *need* not disability. Neither mainstream nor Indigenous specific services are currently meeting the support needs, or providing the much needed access and support needs required by Indigenous Deaf people.

Despite the longstanding and urgent needs of Indigenous Deaf people no government or agency has ever allocated funding for formal research. There have sometimes been attempts at consultancy with the community as part of larger projects. These have generally failed to engage in a culturally appropriate, communicatively adequate process as well as to take the time to obtain the real perspectives from this group. It seems often that it is 'too hard', so it is simply not done.

I am sorry to say, and meaning no disrespect for the Senators involved, that the same is largely true for this inquiry.

Conclusion

It is necessary to say that this submission only scrapes the top of the iceberg for the Indigenous Deaf community. It is hoped this submission does, however, give you some insight of the concerns expressed by Indigenous Deaf people in Australia.

I wish to conclude that, their lives are not all depressing and full of conflict with abuse or violence. They have an extremely strong sense of self-respect and continuously stay patient and forgiving, waiting to showcase their skills and abilities as do other community people. This inquiry will not easily understand the needs of these people who are badly affected by the decisions of family, services, departments and government. These groups are deaf and blind to our needs as Indigenous Deaf people.

The over-representation of Indigenous Deaf people at the extreme edge of Indigenous disadvantage in all areas, health, education, criminal justice, mental health, housing, community services etc will continue to increase unless infrastructure is in place to ensure that the voice of the Indigenous Deaf community is heard and responded to.

Recommendations

1. Indigenous Deaf people are consulted when seeking knowledge on the impacts affecting their lives and not left as an after thought.
2. Indigenous Deaf children are protected from harm.
3. Indigenous Deaf children are given all forms of communication at an early age to ensure cultural appropriateness and cultural identity as well as access to mainstream services and opportunities.
4. The use of cultural language and signs are respected and used with English and Auslan to enhance communication choices.
5. Indigenous Deaf Adults who are incarcerated have access to qualified Indigenous Deaf advocates and Indigenous Deaf interpreters for all formal interviews and court matters.
6. Indigenous Deaf women are provided with support services that are culturally appropriate in supporting their families and reducing the risk of removal of their children.
7. Indigenous Deaf employees are protected and given appropriate pathways to secure long term employment.
8. Indigenous Deaf people have access to aids and equipment for all their needs not only in educational settings and that aids and equipment are permitted to go home with them.

9. Indigenous Deaf people have resources to ensure they can participate in recreational, sport and social and cultural activities in relation to communication modes (such as interpreters, relay interpreters and tutors).
10. Indigenous Deaf students are provided with essential educational tools to encourage their learning and participation in schools.
11. Indigenous Deaf people have appropriate access to all medical and health related appointments with Indigenous Deaf relay interpreters or interpreters.

I wish to thank you for the opportunity to put forward these views and expressions of concern faced by Indigenous Deaf people across the country. Please be assured that these views are those of the community that I am also a part of.