KEY THINKERS FORUM

Opinion Paper

Indigenous Ear Health

On 6 August 2019, the Poche Indigenous Health Network hosted its 11th Key Thinkers Forum, bringing together professionals, community members, academics, students and policy makers. This 'Poche Opinion' explores some of the key thematic issues raised during the forum.

Professor Tom Calma AO, Patron and Chair of the Poche Network, facilitated the forum, guiding the conversation between audience members and a panel of guest speakers.

Panel members included:

- Prof Kelvin Kong, Paediatric & Adult Otolaryngology, Head & Neck Surgeon, John Hunter Hospital
- Samantha Harkus, Rehabilitative Audiologist, Hearing Australia.
- Professor Dennis McDermott (Deceased April 2020) Pro Vice-Chancellor (Indigenous), La Trobe University
- Adjunct Associate Professor Carmen Parter, Wingara Mura PhD candidate

In order to stimulate the discussion, a Briefing Paper was made available prior to the event, and the Forum was accessible online via the University of Sydney IT team. The video-recording is available

- Opening
- Prof. Kelvin Kong
- Sam Harkus
- Prof. Dennis McDermott
- Carmen Parter
- Poche Opinion

You can download a copy of the event program here.

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The issue of ear disease and hearing loss in Indigenous communities- the facts

For Indigenous children, hearing loss is widespread and much more common than in the broader Australian population[1]. One in 10 (10%) Aboriginal and Torres Strait Islander children aged 4–14 years have ear or hearing problems compared to 3% of non-Indigenous Children.[2] Otitis Media is twice as common in Indigenous children compared to non-Indigenous children and hearing loss is 5 times more likely.[3] In fact some Indigenous communities have a prevalence of chronic suppurative otitis media up to 10 times higher than the 4% that the World Health Organization (WHO) identifies as being 'a massive public health problem' requiring 'urgent attention'.[4]

Hearing issues tend to start early for Aboriginal people, and there is often an overlying narrative of poor social determinants leading to a 'failure to thrive'.

The power of association

Unfortunately, the facts cannot capture the full picture. There are ongoing effects from hearing loss that can last a lifetime. From difficulty in education and learning to unemployment and incarceration, lots of aspects of the Indigenous experience can be affected throughout life. The are some common storylines amongst those who suffer hearing loss in the early years: starting with ear disease and hearing loss from childhood to leaving school early and the realization that entering the workforce is not a viable option. This might lead to behaviours which result in incarceration, and a courtroom process that might also be severely disadvantaging by the hearing loss and difficulty in communicating. There might be supports that exist like rehab groups in prison, but the inability to participate is restricted due to hearing loss. This can become a cycle and can last a lifetime if there is no

[1] Burns J, Thomson N (2013) Review of ear health and hearing among Indigenous Australians. Australian Indigenous HealthInfoNet.
[2] 2014/15 NATSISS: National Aboriginal and Torres Strait Islander Social Survey
[3] Australian Bureau of Statistics (2006) National Aboriginal and Torres Strait Islander Health Survey: Australia, 2004-05. (ABS Catalogue no. 4715.0) Canberra: Australian Bureau of Statistics
[4] WHO/CIBA (2000) Prevention of hearing impairment from chronic otitis media. (WHO/PDH/98.4) Geneva: WHO

intervention in a timely manner. Delayed diagnosis and remediation can be disempowering on many different levels, especially for children and adolescence.

The Indigenous perspective

"Unless you are hearing, you cannot do anything else." (Kelvin Kong, 2019)

The history of the Aboriginal people is mostly passed down orally; it is a language of storytelling, listening and learning. Language and culture are greatly valued. "Oral traditions substantiate Aboriginal perspectives and Torres Strait Islander perspectives about the past, the present and the future…. Speaking is the primary form of communication in Aboriginal and Torres Strait Islander cultures. Concepts and beliefs have been passed on from generation to generation through specific cultural practices, traditions, languages, laws and family relationships. The oral traditions of instruction include storytelling, song, dance, and art- and craft-making."[5] It is a cruel irony, therefore, that hearing and listening are so difficult for so many Aboriginal people.

How to look at it the issue through a new lens- new ways of forming policy

The picture is complex. There are social determinants and racism overlaying an already complex problem. Screening is too siloed for us to categorically say that there is a national prevalence. Hearing loss remains a controversial issue as the evidence says that it can be overcome if the support systems surrounding it are effective. The evidence says if the child is 'otherwise healthy', does not require amplification and is not delayed in getting it, and is socio-economically advantaged, then hearing loss can be overcome. Unfortunately, these conditions might not be realistic or accessible for many Aboriginal communities. Awareness and access to evaluation and testing might not be readily available to diagnose the issue in the first place. Otitis media continues to be viewed in many settings through a non-Indigenous lens, including at the policy level, and this leads to miss or poor diagnosis of the hearing condition.

[5] https://www.qcaa.qld.edu.au/about/k-12-policies/aboriginal-torres-strait-islander-perspectives/resources/storytelling

Opinion Paper

In order to properly deal with these issues we need to fight the 'distractors' that lead our attention elsewhere. It needs to be a national strategy and avoid siloes. We need to hold governments and fund holders accountable. And we need consultation to be properly carried out. Policy needs to be co-designed with the affected population if it is going to make a difference.

We know the pathways to care - we have evidence-based guidelines - and yet barriers remain in place that prevent them being put into effect. Currently, funding barriers have resulted in NSW Health not funding otitis media screening - we need to push the policy makers to change this and survey all states and territories to determine their screening policies and practices.

The complexity of the problem calls for a holistic approach. Cultural safety and more effective tools of communication need to be embedded in policy. It is time to challenge the western perspective as otherwise things will not change. Reporting on ear disease in Indigenous communities is "falling on deaf ears". Data collection happens but not in a systematic and comprehensive way. This is a national public health issue and should be dealt as one.

Resistance to tailoring approaches and the 'one size fits all' strategy negate all that we know about problems in Aboriginal health. It will take a whole new perspective to solve the issues and Indigenous ways of doing, knowing and being need to form the basis of this. This is not to say that the standard approach should be ignored, more that the two types of knowledge should be brought together for a new policy and practices to emerge. Reciprocity is an essential ingredient for effective communication and policy making. As Durham et al put it, we need to build the governance structures needed for paradigm shift to achieve a multi-sectoral approach, develop shared system level goals and develop system-wide feedback processes.[6]

If we wait until a child enters school to deal with the issues; we have "missed the boat". Finally, policy is emerging that attests to this theory. The NSW Health Policy Directive the

[6] Durham, J., Schubert, L., Vaughan, L., & Willis, C. D. (2018). Using systems thinking and the Intervention Level Framework to analyse public health planning for complex problems: Otitis media in Aboriginal and Torres Strait Islander children. PloS one, 13(3), e0194275. doi:10.1371/journal.pone.0194275

"First 2000 days framework"[7] is based on the idea that to leave such fundamental issues any later leaves the sufferer at a severe disadvantage. Hearing Australia, as a peak body, believe that hearing needs to be targeted before the age of three. Some would say this is too late, and that it needs to be before one year old.

Closing the gap

When it comes to 'closing gaps':

Doing the same as you have been won't work. The gap will continue to widen.

Doing what you are doing for the other population won't work. The gap will remain the same, and

Doing better than you are doing for the other population (doing more, doing different, doing together). This is what's required to close gaps and achieve equity in outcomes.

Success stories

We need to change the conversation from deficit to strengths based. There **are** some programs making a real difference. Telemedicine can bridge the gap of distance and access- for example, the tele-fitting of hearing aids is significantly shortening the time between referral and fit in the Ear Portal project. Screening combined with immunization visits have worked well in the Pina Karnbi project. Additionally, there is a growing push for Indigenous sign languages to be re-invigorated as they contain the fundamental lores and knowledges. Building the Indigenous workforce in this area will see a higher rate of uptake of services, and it is up to education providers to tailor the course design so that Indigenous students are more comfortable with it and the University or VET sector environment as possible.

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[7] Summary: The First 2000 Days Framework is a strategic Policy Document which outlines the importance of the first 2000 days in a child's life (from conception to age 5) and what action people within the NSW Health System need to take to ensure that all children have the best possible start in life.
Document type: Policy Directive
Document number: PD2019_008
Publication date: 08 February 2019
Author branch: Health and Social Policy

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Australia has introduced a much-needed mandatory newborn hearing check however, subsequent to this newborn check being introduced, we have seen a 'stepping back' in primary health care. Our chances of intervening in a more timely manner to ongoing issues should be mandatory for all checks required for a child between the ages of 3 months and 4 years. We need to support primary health practitioners and the wider workforce (Nurses, Aboriginal Health Workers etc) to be checking in ears as regularly as possible. *Practitioner incentive schemes* should be used to push the hearing loss agenda.

Research alongside practice

Screening and checking are important but are not the full picture. A proper data set on which to base a national strategy would be a good start. Research should not be done in isolation and research teams either need to include Indigenous members or a good understanding of Indigenous research methodologies if they are to fully grasp the complexity of the problem. Research with a co-design approach and proper community consultation is imperative if we are going to start dealing with this issue.

Summary of observations

- Hearing loss has many and long-lasting effects on the sufferer's life
- Aboriginal history was built on oral traditions so hearing has been paramount in connection to culture
- Policy needs to change to acknowledge the holistic picture of health and the role of hearing in that
- Hearing issues tend to start early for Aboriginal people, and there is often an overlying narrative of poor social determinants leading to a 'failure to thrive', and
- A whole of community approach is needed to deal with not just hearing loss but the social determinants that affect health generally.

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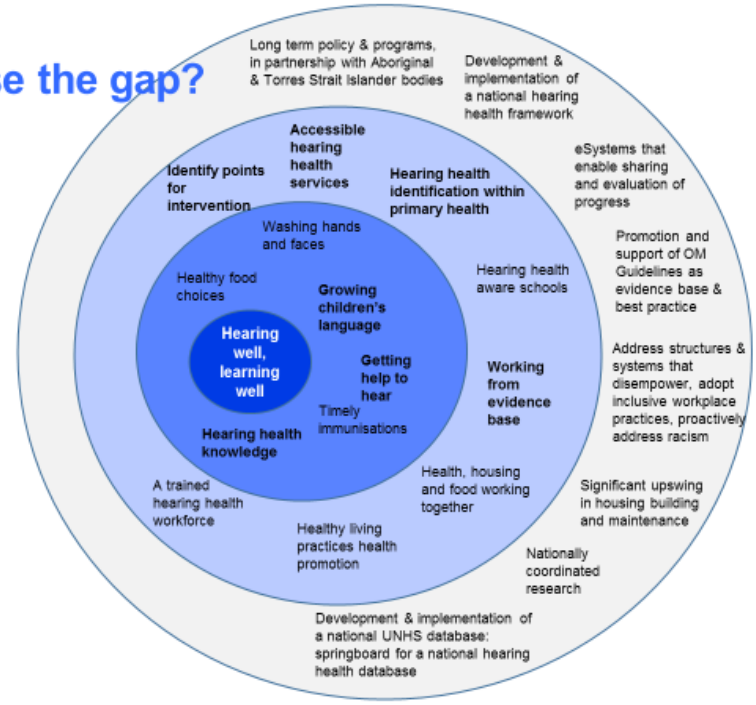
What's needed to close the gap?

- The central circle is the ultimate outcome: **good hearing & language for communication and learning.**
- The next circle: actions within the power of the **individual and family**
- The next circle: actions at the **community or organisation** level.
- The outermost circle: actions at the **societal or political level.**



Hearing Australia