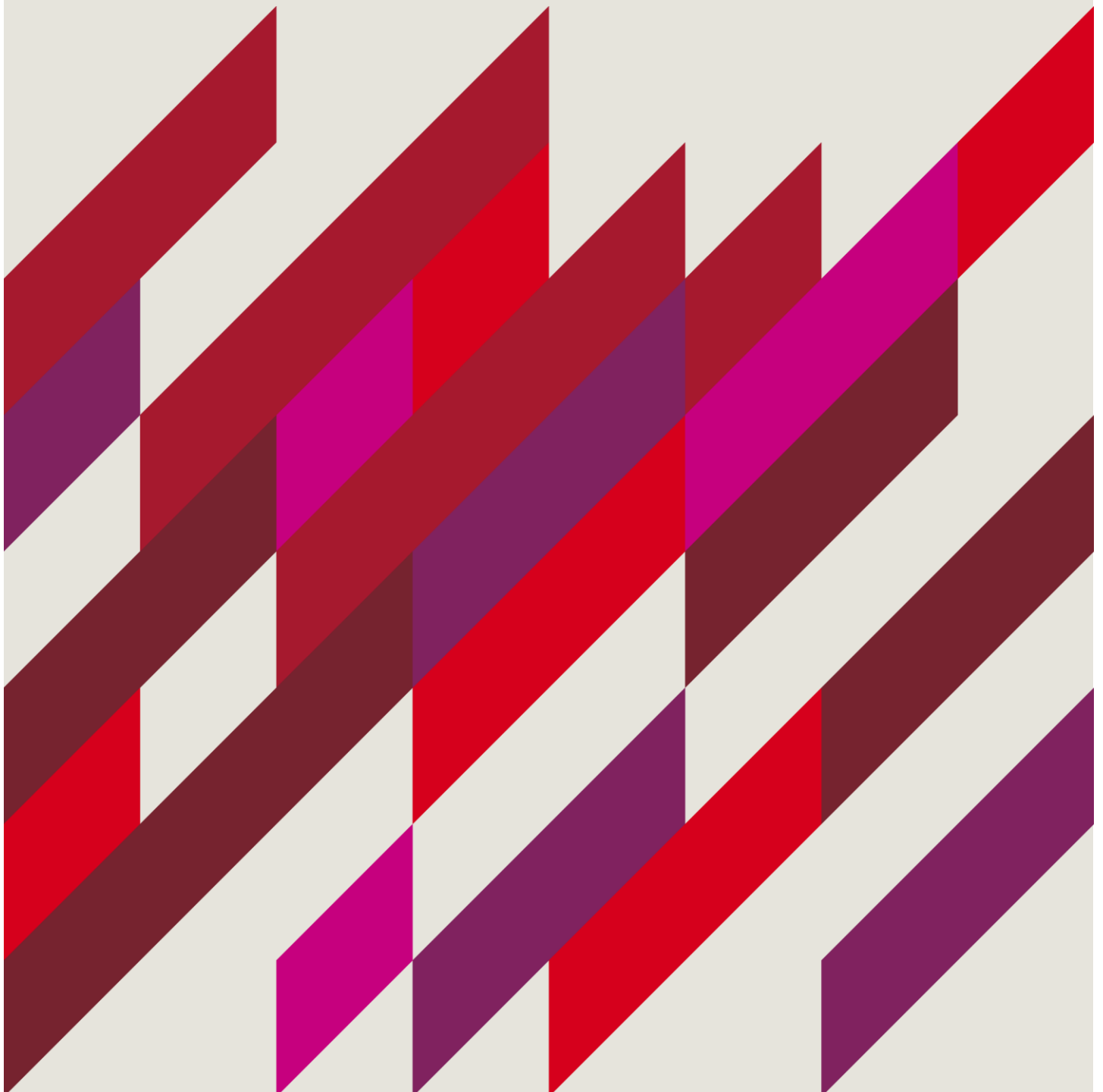




Hearing Health in Aboriginal & Torres Strait Islander peoples

Proceedings of the Indigenous Hearing Health symposium held on March 5th 2019 at Macquarie University



**“Quai bidja,
jumna paialla janwai
– Come here we speak
together.”**

“On behalf of the Darug people, I welcome you to this Country of the Wattamattagal clan of the Darug Aboriginal nation. I pay my respects to the local Aboriginal Elders past and present and to the ancestors of the Land, the knowledge and culture. We welcome people of all nations and faiths.

We further honour and pay our respects to the ancestors and spirits of this land and humbly ask that all members of the Macquarie community are granted the capacity to wingara – to think, to learn and to walk safely upon this pemul (this land). We celebrate with you our ongoing attachment to and custodianship of this Country. Help us to respect the Aboriginal history and to protect the fragile environment.”

Aunty Julie Janson of the Burruberongal clan of the Darug nation
HAWKS BURY RIVER PEOPLE

Foreword

Macquarie University has an increasingly global reach in hearing health, through its collaboration with the World Health Organisation, and its representation on the ‘Lancet Commission on Global Hearing Health’, which provides a broad perspective on the design of sustainable solutions for hearing health problems. Macquarie’s Australian Hearing Hub brings together a collaborative partnership of stakeholders in hearing health which can address multiple facets of complex problems in hearing health, and deliver solutions through a uniform implementation framework. These include; internationally renowned researchers across a broad range of disciplines relevant to hearing health; educational programs in audiology, speech pathology, early intervention and deaf education, and sign language

interpreting; the Federal Government’s hearing services program that delivers ear and hearing care to Aboriginal and Torres Strait Islander peoples through its community-service obligation program; national early intervention services and organisations, a globally-leading manufacturer, and community advocacy and support organisations. In March 2019, Macquarie University launched its ambitious “Hearing Strategy 2030” which seeks to harness the connective capacity across the University to transform hearing health at national and global levels.

Aboriginal and Torres Strait Islander populations have some of the highest rates of middle ear disease globally. Our commitment and dedication to a global public-health approach compels us to

act to address this stark inequity in hearing health.

Professor Catherine McMahon, Chair of Indigenous Hearing Health Symposium & Chair of Libby Harricks Memorial Oration is the Director of the Macquarie University Research Centre H:EAR [Hearing, Education, Application, Research] and Director of Audiology at Macquarie University. She is a member of the Hearing Health Sector Committee, which developed the Roadmap of Hearing Health, an expert advisor for the World Health Organisation, and an invited Commissioner for the Lancet Commission on Global Hearing Health.



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Executive Summary

“Deep Listening. It's very embedded in our culture, not just as a Yaegl/Bundjalung person, but right across our nation. It is called *Dadirri* from East Arnhem Land – listening to one another. If there is a problem with hearing, kids are not learning this process of deep listening and connecting to the land and feeling the country...How we communicate is very much how we yarn with each other. In *Bundjalung/Yaegl*, the term is *gan'na* and it's about hearing, listening, feeling, thinking and understanding. Young kids are learning this right up until they are old because this is how you transfer your listening and learning.”

[Dr Liesa Clague, PhD and Yaegl/Bundjalung/ Gumbaynggirr woman]

Problem: Australia has the 2nd best healthcare system in the world, but some of the highest rates of chronic middle ear disease in Aboriginal and Torres Strait Islander children. The resultant hearing loss affects educational outcomes, social and behavioural outcomes, connection to land, culture and community, and the over-representation of Aboriginal people in the criminal justice system.

The World Health Organisation considers middle-ear disease in Aboriginal and Torres Strait Islander peoples to be a ‘massive public health problem’. In remote communities in Northern and Central Australia, the prevalence of middle-ear disease or, otitis media (OM) is as high as 1 in 2 children between 0-3 years, with 1 in 4 having bilateral OM with ear discharge (effusion). The hearing loss that results is associated with poorer educational outcomes, social and behavioural problems, and contributes to the over-representation of Aboriginal people within the criminal justice system. Cultural effects of hearing loss within this population disrupts the development of connections to the land, their sense of belonging, and connection to the community.

Despite a 2017 study ranking Australia the second best healthcare system to the UK National Health Service - prevalence data for OM in Aboriginal Australians

living remotely are similar to Nigeria and the Solomon Islands, which have considerably less-developed healthcare systems. Compared with the non-Indigenous population in Australia, OM occurs earlier in life, more frequently, and is more severe in its manifestation. Despite this acknowledged problem, however, Australia lacks any national data on the prevalence of OM in Aboriginal and Torres Strait Islander peoples. Medical interventions, such as ongoing and liberal antibiotic prescription, vaccination programs, and health check programs continue to have limited efficacy due to low rates of uptake and compliance, and clearly need to be rethought if we are to make any significant move towards ‘closing the gap’.

Rethinking our approach is critical - we need to accelerate our efforts to scale up improvements towards closing the gap in hearing health, and direct them towards solutions that are effective for the needs of these communities.



Whilst significant financial investment and human resources have been put to addressing this major health inequity in Australia, both its prevalence and its negative impact on the individual and society have not substantially changed since the 1970's, and existing solutions are clearly not meeting the unique needs of Aboriginal and Torres Strait Islander communities. Taking a public-health approach will facilitate the development and implementation of sustainable initiatives for solving the problem of OM in Australia's indigenous population, particularly where the social determinants of health are major contributing factors to the wide and sustained disparities in hearing health. Core components of a public-health approach require an understanding of the community for which solutions are being designed, including their priorities and conceptualisations of health. For example, whilst ear and hearing care may not be considered a priority at a community level, designing solutions

from a community perspective helps ensure that a care pathway can be embedded into existing systems and processes, and prioritised accordingly. A community-based approach factors in the cultural appropriateness of solutions, and whether they are implementable and sustainable — for example, will antibiotics be refrigerated, and how accessible are nutritional foods such as fruit and vegetables for the community in question?

A public health approach prioritises the development of a national ear and hearing care strategy and approach to addressing hearing loss — specified as the first of 8 key priorities in the National Roadmap for Hearing Health, endorsed by the Council of Australian Governments (COAG) on 8th March 2019. A national ear and hearing care strategy must span government at federal and state levels, local communities and businesses, and social and community organisations that can advocate for, and support the widespread implementation of, hearing-health policies and programs. To this end, policies and programs must extend their reach beyond the health sector, to encompass housing, education and social services. Their effectiveness must be measured by significant changes to the prevalence, incidence, and impacts of OM in Aboriginal and Torres Strait Islander peoples. Importantly, any solutions must be co-designed with the communities it seeks to reach, and these communities must be empowered to manage their own health, at all levels of engagement, from individuals, to their families and beyond. This connects Australia to the global agenda. Currently, the World Health Organisation is developing the World Report on Hearing (expected to be released on March 3rd, 2020), to highlight the burden of hearing loss, and identify ways in which to address this at all levels of government and within systems of care. The Lancet Commission on Global Hearing Health (to be released on March 3rd, 2021) aims to develop and integrate the evidence-base to provide recommendations to prevent hearing loss and promote hearing health, and initiate a global movement to facilitate this.

Recognising the impact of colonisation, and the need for self-determination by Aboriginal people, as well as the core values of respect and cultural integrity are all important to the design of implementable and sustainable solutions. At the level of individuals, high prevalence of smoking, of poor hygiene, and inadequate nutrition must be addressed. Ensuring access to good-quality housing, clean water and sanitation is critical to outcomes — and are basic human rights. Co- and multi-morbidity of OM with other chronic diseases is not uncommon in Aboriginal and Torres Strait Islander communities, and similarities exist in the approach required to reduce the incidence and severity of hearing, vision, and cardiovascular problems. Aligning approaches to addressing Indigenous health to a single framework will lead to solutions that can be effectively embedded and governed by individual communities. Health in such communities is a complex issue, which requires the need for complex approaches to solutions.

Solution: A public health approach prioritises the development of a national ear and hearing care strategy, takes an evidence-based approach to care for the population, and implements effective and cost-effective solutions across a wide range of settings and with cross-sectorial support.

Libby Harricks Memorial Oration

Macquarie University Research Centre H:EAR, Australian Hearing Hub, Deafness Forum of Australia and Audiology Australia presented the 2019 Libby Harricks Memorial Oration, which was given as part of the Indigenous Hearing Health Symposium. The Oration series raises awareness of issues of hearing health, deafness and ear and balance disorders. <https://www.deafnessforum.org.au/events/libby-harricks-memorial-oration/>



Professor Andrew Smith



Professor Andrew Smith is a world renowned public health expert at the International Centre for Evidence in Disability at the London School of Hygiene and Tropical Medicine. Previously, he worked for the World Health Organization, being responsible for the deafness and hearing loss prevention program between 1986 and 2008. Prior to that he worked for the UN in The Gambia and Pakistan.

GLOBAL HEARING HEALTH: CHALLENGES & OPPORTUNITIES

I am very honoured to be asked to give the Libby Harricks Memorial Oration to open the symposium on Indigenous Hearing Health at Macquarie University.

Libby Harricks who experienced a profound hearing loss as a young adult overcame many obstacles to become a champion for Deaf people in Australia. I feel very inspired by her achievements for the Deaf Community.

My oration will focus on the challenges and the opportunities for Global Hearing Health. I will relate this to programs I have been involved with in low and middle incomes (LMI) countries. The challenges faced by the world are the numbers and location of hearing loss, the lack of information, and the lack of awareness. Opportunities do exist in the form of the public health approach to develop sustainable initiatives in low and middle income countries. I will address the important role of the

World Health Organisation (WHO). I would like to relate the public health approach I use in LMI countries to address Indigenous Hearing Health in Australia.

GLOBAL PREVALENCE OF HEARING LOSS

On World Hearing Day (3rd March), 2018 the World Health Organization released some shocking figures. The main message was that by the year 2050, if nothing was done, the global number of people with disabling hearing loss would reach 900 million - double what it is today. The WHO regional picture (see Figure 1, over page) shows that the high income group which includes Australia, and other regions of the world, are showing an increase in the figures. The World Bank defined region with the highest figures is South Asia, comprising Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal Pakistan, and Sri Lanka. The historical look at the problem shows the figures have been increasing for more than the last 30 years. Figure 2 shows the WHO estimates of the increases in the numbers of people with disabling hearing loss, (bilateral 'moderate or worse' hearing loss) since 1985.

The global numbers have increased progressively with most of the burden of hearing loss consistently in low and middle income countries. In 2018 WHO stated that 90% of the burden of hearing loss is in LMI countries and this percentage is continuing to increase.

What is driving this increase in hearing loss?

Surveyors are using improved measuring techniques for hearing loss and are therefore finding more people with hearing loss when they do surveys.

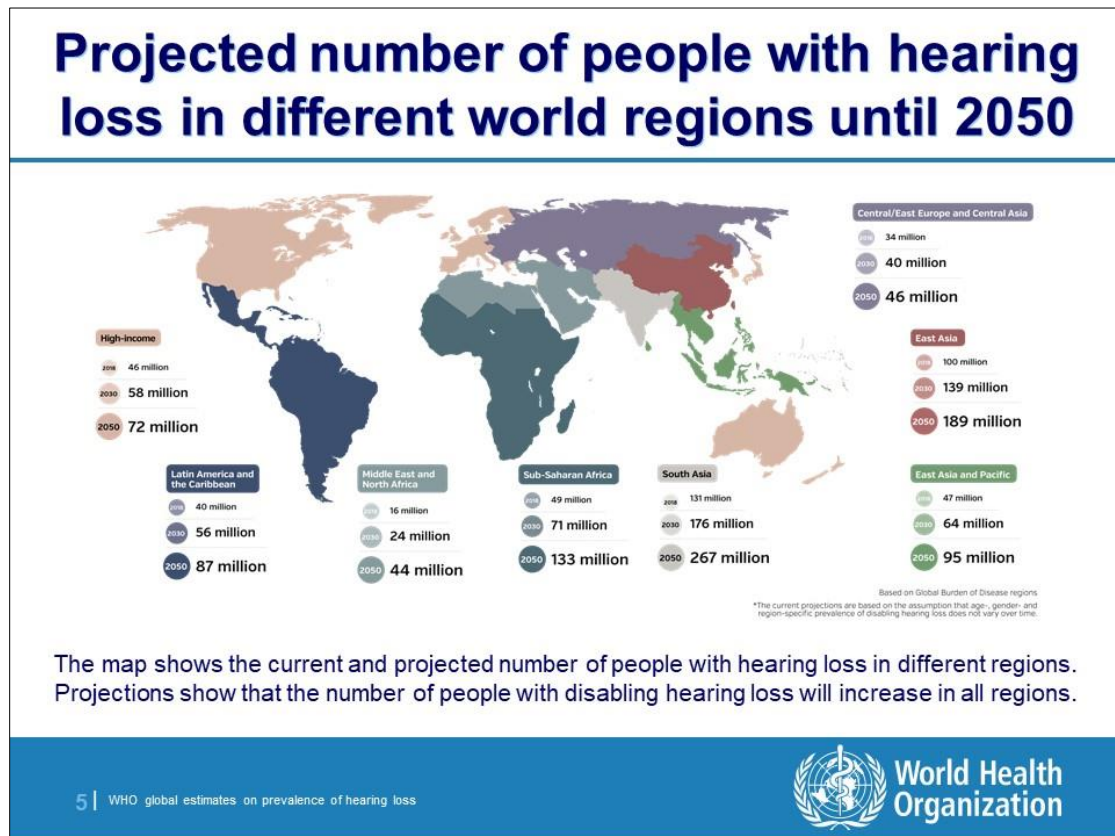


Figure 2: WHO estimates of regional numbers with disabling hearing impairment 2018 – 2050. Slide Courtesy of World Health Organisation.

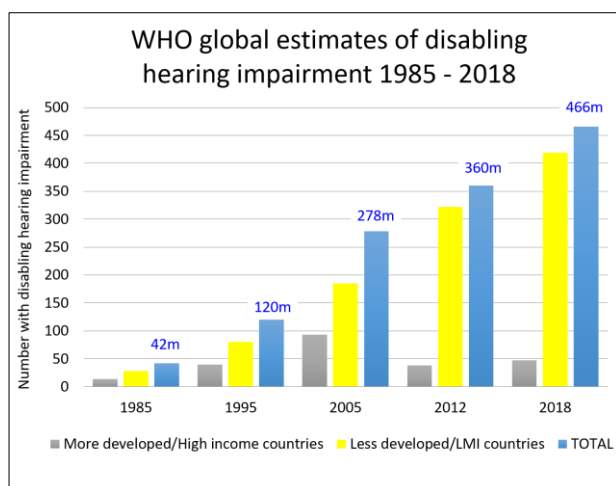


Figure 1: WHO estimates of global numbers with disabling hearing impairment 1985 – 2018.

The amount of noise induced hearing loss in the world is increasing everywhere. Occupational noise-induced hearing loss occurs globally, with higher rates in LMI countries where the controls and regulations on exposure are not available or not enforced.

There was a survey conducted in 2004 amongst remote Inuit Indigenous communities in northern Canada which showed very high levels of occupational noise-induced hearing loss. The surveyors commented that the rates of noise-

induced hearing loss were similar to those found in LMI countries (Ayukawa & Rochette 2004). The noise induced hearing loss is often potentiated by chronic otitis media in childhood.

It was found that the Inuit people often do not wear hearing protection when they go hunting and sustain hearing damage from rifle fire. They use very noisy ice drills when they go fishing in the winter to break through thick ice. Some of the Inuit people use snowmobiles with the silencers removed. This technique enables them to travel faster for long distances over the ice to go hunting and visit neighboring communities.

Inuit artists do a lot of carving of soapstone and the grinders are used for long periods at very high noise levels, at 95 dBA, which is well above the maximum safe level of 85 dBA.

The population of the world is increasing and the numbers of people with disabling hearing loss will also increase. People are living longer in all parts of the world including in LMI countries. The prevalence of hearing loss is much higher in the elderly group and this will massively increase the burden of hearing loss. Recent estimates published by WHO (2018) show that the total global population is set to increase by about 11% between 2010 and 2020. The global population in the over

65 years age group is set to increase by about 37% during the same period.

There is an epidemic of noise-induced hearing loss caused by people world-wide wearing earphones and earbuds at high volume for long periods of time.

SEVERITY OF THE GLOBAL BURDEN OF HEARING LOSS

The previous section looked at *prevalence*, which is concerned with measuring the numbers of people in the population with disabling hearing impairment.

A better measure of the burden of hearing loss would also take account of the *severity* of the condition. A study called the Global Burden of Disease (GBD 2017), is doing this for all health conditions including hearing loss. It measures the burden of disability that a particular disease causes to an individual, and then calculates the burden in the whole population. The measure used is called the disability-adjusted life year (DALY). It has two components; the first is *years of life lost (YLL)* due to premature death, the gap between when you die from a disease and the average age of death in a population. However, deafness causes very little YLL.

The other component is *years lived with disability (YLD)*. This is the component measured for hearing loss; years lived with the disability are multiplied by a factor less than 1, the level of which is set in proportion to the severity of the hearing loss. YLD are calculated for hearing loss in populations, and then summed for all countries and communities, in order to obtain a global figure which can be ranked in comparison with other health conditions. A recent Lancet paper (Wilson et al. 2017) which used global burden of disease data showed that hearing loss was the 11th leading cause of years lived with disability in 2010, but by 2013 and 2015 it had risen to the fourth leading cause, suggesting that hearing loss has increased in burden. Vision loss, which most people thought was more important, is still ranked between 9th and 11th mainly because the programs against blindness, such as Vision 2020, have been very successful. Global Blindness has peaked because, as we have seen, deafness is continuing to increase. The latest figure for 2016 in the global burden of disease study shows hearing loss is now ranking at number three (GBD 2017).

LACK OF INFORMATION & AWARENESS

Another key challenge is the lack of information and lack of awareness about hearing loss. I was involved with 15 different prevalence surveys around the world using a WHO Survey Protocol. The most recent survey we did was in Ecuador, where adults were found to have a prevalence of 6.4% with disabling hearing loss, similar to the current global figure.

What is striking is the small number of prevalence surveys that have been done. This was noted in a meta-analysis by Stevens from the WHO (Stevens et al. 2011). They assessed over 3000 studies, but only 42 were judged rigorous enough to be included. Their main conclusions were that the estimates of hearing impairment were uncertain because so few population-based surveys have been done. Therefore, we urgently need repeated cross-sectional population-based surveys in regions with the highest prevalences.

Another problem is the high cost of hearing loss - \$750 billion - highlighted by the WHO in 2017 (WHO 2017). Several credible prestigious economic foundations have put together this figure. Hearing loss and poverty are linked. Hearing loss leads to poverty and poverty leads to hearing loss in a vicious cycle.

Why is it so difficult to mobilise resources against hearing loss? There are negative perceptions - blindness tends to evoke sympathy but deafness evokes irritation. And there is a stigma associated with deafness. The idea of “deaf and dumb” is still pervasive - people don't like to show that they are wearing hearing aids or they don't want to wear them. There is a lot of ignorance around hearing loss in the general population.

What is hearing loss like?

That is one of the issues. We cannot clearly show the general public what it is like to have a hearing loss. There are attempts to do this with using videos published on websites to demonstrate what it's like listening to music with different levels of hearing loss.

Young people are unaware that loud noise and listening to loud music will damage their hearing. Many people who go to rock concerts are totally unaware that it may cause a serious problem later in life.

This lack of awareness leads to a lack of political will generally and that leads to an inability to prioritize and a lack of programs and resources.

It is very important to raise awareness. Surveys themselves are a very good way of raising awareness. A survey generates a lot of publicity, and that gets people more interested and increases general understanding of some of the problems of hearing loss.

OPPORTUNITIES

In order to address effectively the huge problem of hearing loss in the world, I believe it is essential to have a population-based public health approach as well as a one-to-one clinical approach.

Let us consider the example of a slum in Nairobi, Kenya, a lower-middle income country. Kibera is

reputed to be the one of the largest slums in Africa. It lacks proper sewage facilities and the rivers and streams are highly polluted. The question is – how do we deal with hearing loss in situations like this?

Figure shows the monthly ear care clinic in a remote part of Malawi, a low-income country in southern Africa. Local people have no other access to ear and hearing care. How do we deal with public health in situations like this?



Figure 3: ENT outreach clinic, rural Malawi. Slide courtesy of Dr Piet Van Hasselt

The answer is we need to re-orientate our thinking towards the public health approach, particularly amongst clinicians in ENT and audiology, but also in health planners.

The epidemiologist and WHO Director, Dr Robert Beaglehole (2009) said. "Public health is the art and science of preventing disease, promoting population health and extending life through organised local and global efforts."

This definition gives you an understanding of the breadth and reach of public health. It is useful to compare it with clinical medicine which centers on the health of individuals. In clinical medicine there is a consultation with the patient, the diagnosis is made, treatment is prescribed and usually follow up occurs. Public health is quite similar, but instead of dealing with the health of individuals, public health deals with the health of populations. Instead of having a consultation, you would do a survey in order to diagnose the health of the population, and then you would carry out a population intervention.

The intervention might be a prevention program; a very important aspect of the public health approach. It may be a clinical intervention such as providing hearing aids but doing it on a massive scale at a price that the majority of people can afford. It then becomes a public health intervention.

In order to follow up what you are doing, you do another survey. There are similarities between public health and clinical medicine and they overlap.

When we look at which conditions should be targeted, Figure shows the frequency of causes of hearing loss, according to WHO. In red, are the most frequent causes. In the blue area the moderate frequency causes. The causes in red and blue should be targeted by the Public Health approach because they are relatively common. The low-frequency causes in green can be dealt with on a one to one basis by clinicians.

The route to a public health intervention is to target causes of hearing loss that have a *high prevalence*

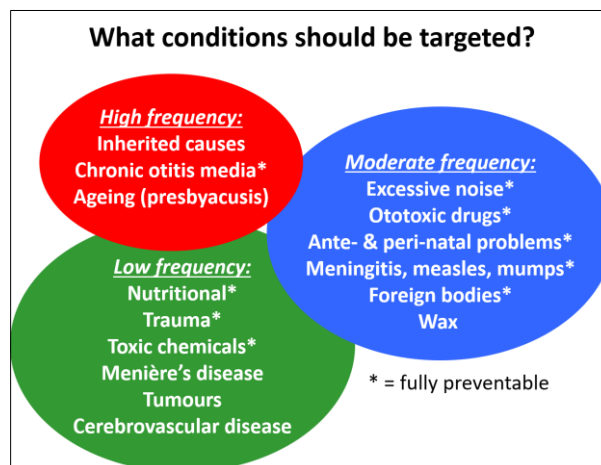


Figure 4: Causes of hearing loss by frequency. and at the same time have an *effective means of prevention or control*. The intervention used must also be *cost-effective*. A Government will be unlikely to implement an otherwise effective intervention if it costs too much.

It is important to do cost effectiveness studies of key interventions, since such studies are greatly lacking in this field. Cost-effectiveness studies require good epidemiological data. This means that more prevalence surveys of hearing loss will need to be conducted in order to provide such data.

In 2017, WHO stated that a number of interventions in hearing healthcare were cost-effective (WHO 2017).

The box lists public hearing health programs that are likely to be cost-effective, but for which cost-effectiveness data is currently lacking.

Public Health Programs which are likely to be cost-effective:

- *primary ear and hearing care, providing affordable hearing aids on a massive scale,*
- *setting up national programs*
- *training for program planning,*
- *health education and advocacy*

All these need to be assessed for their cost effectiveness in comparison with other health programmes.

I would like to present examples of two LMI countries that recently developed a national strategy or plan for ear and hearing care, looking at some of the challenges they faced, and how they overcame them.

KENYA: EXAMPLE OF A LOWER-MIDDLE INCOME COUNTRY

The Republic of Kenya

Capital Nairobi

Population 48.5 million

Area 582,646 sq km (224,961 sq miles)

Major languages Swahili, English

Major religion Christianity

Life expectancy 63 years (men), 69 years (women)

GNI per capita (2017) between US\$996 and \$3,895

Kenya is in the lower middle income group (Gross National Income, GNI per capita between US\$996 and \$3,895). They have recently developed and started implementing their national strategy for ear and hearing care.

The key challenges to the provision of ear and hearing care in the country were lack of a national program, uncoordinated service provision, inadequately trained human resources, inadequate financial resources, lack of infrastructure and supplies, and lack of data on burden of disease. They have fairly good numbers of personnel compared with most African countries: ENT surgeons (85), audiologists (7), clinical officers (200), audiology

officers/technicians (12) and speech language therapists (16). Almost all are in major urban areas except for Clinical Officers of which only 50% are in rural areas. There is a mismatch between the need and the location of staff.

Professor Isaac Macharia and colleagues first attempted in 2008 to set up a national strategy. A middle level officer in the Ministry of Health

Major causes of preventable hearing loss (as seen in most low income countries)

- *Chronic ear disease*
- *Infectious diseases of childhood, including meningitis*
- *Noise-induced hearing loss*
- *Ototoxic drugs*
- *Deafness and hearing impairment related to consanguinity*

represented what they were doing within government and was tasked with taking the draft plan to the Minister. It didn't work – the Minister wasn't really interested and the stakeholders lost interest and the committee died.

Fast forward to 2013, there was more interest, this time starting from the top with a Minister of Health who showed possible interest in ear and hearing health. They needed a push because of other competing priorities. Professor Macharia invited Dr Shelly Chadha, the WHO Technical Officer in charge of the global program for prevention of hearing loss to meet the Minister of Health and give a convincing exposition of what needed to be done.

This transformed the situation. The Minister convened a National Committee which he chaired. WHO planning tools, available on the WHO website [1] were used for developing the national strategy. The committee carried out a situation analysis, and SWOT analysis, devised the vision, mission and guiding principles. They set up goals and SMART objectives – Specific, Measurable, Achievable, Reliable, and Time-bound. The plan was done rigorously and clearly set out roles and responsibilities.

The National strategy provides a framework for the coordination and mobilisation of resources. It addresses advocacy at all levels, human resource capacity building, access to services and assistive devices and data collection. The strategy is an

¹ https://apps.who.int/iris/bitstream/handle/10665/206138/9789241549479_eng.pdf;jsessionid=BoDEoDAAC896F1E6AF557E84B7D92E4C?sequence=1

https://apps.who.int/iris/bitstream/handle/10665/206141/9789241509954_eng.pdf?sequence=1

excellent plan with a clear goal and good strategic objectives.

The plan was published by the Government and because the Minister of Health was involved, he took ownership of the plan. The Minister launched it at a national workshop, awareness was raised and the plan was implemented.

The plan had a rocky start but a successful outcome. What next though? There must be *sustainability in setting up a national plan*. The Kenyan Ministry of Health want to cascade the plan out to county level, identify resources, and plan regional meetings. Resource allocation has been devolved to county level. The counties will be expected to allocate money in their own budgets to implement this plan.

Professor Macharia stated that what was most needed to succeed was *leadership, determination, patience and endurance*. I believe this is the route to sustainability.

MALAWI: EXAMPLE OF A LOW INCOME COUNTRY

The Republic of Malawi

Capital Lilongwe

Population 18 million

Area 118,484 sq km (45,747 sq miles)

Major languages English, Chichewa (both official)

Major religions Christianity, Islam

Life expectancy 60 years (men), 65 years (women)

GNI per capita in 2017 US\$995

Malawi is a small country in southern Africa, along the shores of Lake Malawi. 80% of people are rural, 23% have no education and 55% live below the poverty line. Until recently they had only one ENT surgeon for 18 million people, now there are two. There is a low investment in health. They have one clinical officer in ENT and are training 15 more ENT clinical officers. There are challenges on all fronts. There is no focal person for ear and hearing health at the Ministry of Health, although they do have a national committee on Ear and Hearing Health.

Dr Wakisa Mulwafu is the first ENT surgeon; he is very dynamic and active and has achieved a lot. A national plan has been developed in 2016 instigated by Dr Mulwafu. It is more theoretical than the Kenyan plan because there hasn't yet been an opportunity to implement it. The key outputs cover training, infrastructure & equipment, procurement of supplies, reduction/prevention of ENT diseases, research, monitoring & evaluation, management and supervision. These outputs are fine and resources are needed to implement them.

External bodies are helping with facilities and training. An audiology clinic has been set up by an Australian charity and local audiologists are being trained. A UK charity has provided a converted vehicle to do outreach otology and audiology clinics. Hearing aids are being provided by a US Hearing Aids company foundation.

Capacity building is an essential component of the plan. Figure 3 shows the first group of 15 clinical officers who are being trained by Dr Mulwafu. There are plans to train more ENT surgeons and set up centres of excellence. A lot is being achieved on the basis of very limited resources.

These are two examples from a lower middle income country and a low income country in the developing world. There are some lessons from Kenya and Malawi in terms of developing programmes for the hearing health of Indigenous People in Australia.



Figure 3: Clinical Officer trainees for ENT. Photo courtesy of Dr Wakisa Mulwafu.

ROLE OF THE WORLD HEALTH ORGANISATION

The World Health Assembly Resolution on Prevention of Deafness and Hearing Loss passed in 2017 has really set the scene for moving forward. The resolution sets out the key actions that Member States and also WHO need to do in developing a

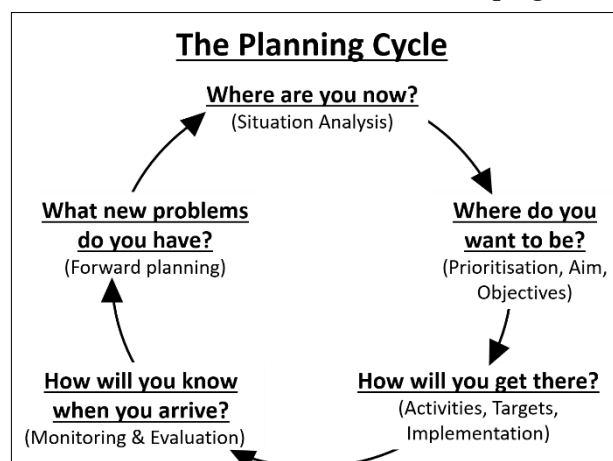


Figure 4: The Planning Cycle.

program of ear and hearing health. Since it was ratified unanimously, all countries have an obligation to start to address these actions.

Current activities at WHO to address hearing loss, under the capable leadership of Dr Shelly Chadha are increasing. The new World Hearing Forum is bringing stakeholders together, the first World Hearing Report is being developed, the Primary Ear and Hearing Care Training Resource and the WHO Survey Protocol are being re-vamped. A survey method is being developed for Rapid Assessment of Hearing Loss (RAHL), which will make it a lot easier and faster to carry out prevalence surveys once this has been validated.

For World Hearing Day 2019 the theme was “Check your Hearing”. WHO has just released an app *HearWHO* and anyone is able to check their hearing on their own.
(<https://www.who.int/deafness/hearWHO/en/>).

What can you do?

"Think globally, act locally."

This slogan, from Dr Lee, a former WHO Director general, emphasizes the need to think at the global level but implement most activities in a local setting.

Acting Locally:

The first thing is to develop a coherent and rigorous plan using the planning cycle (Figure 4).

- Determine the size, location and causes of the problem.
- Use the public health approach together with the clinical approach.
- Self-empowerment is important.
- Focus on primary health care, with training at all levels starting with the primary level.
- Use the WHO materials and guides.
- Set up links with Indigenous groups in other countries for research and development.

Figure 4 shows a simplified version of the planning cycle. Decide where you are now, where you want to be, how you will get there and how you will know when you arrive. This is set out in detail in the WHO planning manuals mentioned previously.

Monitoring and evaluation is important to track progress and know whether you have achieved what you set out to achieve.

HEALTH BY THE PEOPLE: A WAY FORWARD

This section is further to the hearing health survey carried out in 2004 amongst Inuit People in Nunavik, in northern Canada, that I mentioned previously. The communities are very isolated and scattered around the edge of the Ungava Peninsula bordering Hudson's Bay. Since there are no roads the survey team had to go by ship, (a Canadian icebreaker, in which they installed a sound-proof

booth). They found high levels of middle ear infection and hearing loss and disability, comparable to levels found in LMI countries.

Inuit men were found to suffer from three times more hearing loss than women due to noise induced hearing loss from the causes that I mentioned earlier. The team wanted to do more to prevent hearing loss. They obtained a selection of ear protectors for the hunters but allowed them to test and make the choice themselves as to which sound protectors they wanted. The hunters were concerned that the sound protectors would make it difficult for them hear the animals when they were hunting. This is not done for sport but to feed the community they live in.

They were able to select a protector which did not reduce their ability to hear the animals. The model chosen was then stocked in the local shops at an affordable price.

Self-empowerment is very important. Kenneth Newell, formerly Director of the WHO Division of Strengthening of Health Services brought out a revolutionary WHO report in 1975 called 'Health by the People' (Newell 1975). He collected many examples of how different local communities through self-empowerment made their own choices of the type of health care and health workers they wanted. Village health workers were selected from the villages themselves. These ideas led to the development of *primary health care (PHC)*, one of the biggest achievements of the WHO since its foundation. Last year was the 40th anniversary of the Alma Ata Declaration which launched PHC, which is still relevant today. WHO developed the Primary Ear and Hearing Care Training Resource based on and linking with PHC.

Community-based rehabilitation (CBR) is also important, and CBR workers also come from the community. We should also remember that the people with hearing disability are part of the wider disability movement, which includes the rights of people with disabilities enshrined in the UN Convention on the Rights of Persons with Disabilities (CRPD).

A PLAN FOR FUTURE ACTION

My idea is to link up researchers and program developers in Indigenous groups from different parts of the world. This has already been done in the polar regions with the Circumpolar Health Research Network and the Circumpolar Health Observatory which gathers data and records information.

The research network brings together researchers including Indigenous People from around the Arctic Circle including Alaska, northern Canada, Greenland, Scandinavia, Finland and Russia. There

is an International Journal of Circum-Polar Health [2].

It would be an excellent idea for Indigenous People and others who research and work in these fields in Australia to come together with others in different parts of the world to share knowledge, ideas and experience.

ADVOCACY FOR PUBLIC HEARING HEALTH: THE WAY FORWARD

I would like to mention that a biography I read about Libby Harricks said that as the first president of the Deafness Forum she actively lobbied on behalf of Deaf and hearing-impaired people at the highest levels. She was the archetype of a successful Deaf achiever despite her profound hearing loss.

Libby Harricks' actions reminded me of Helen Keller, a famous Deaf achiever born in the 19th century. Helen Keller was blind and deaf.

She said, "I am just as deaf as I am blind. The problems of deafness are deeper and more complex, if not more important than those of blindness. Deafness is a much worse misfortune, for it means the loss of the most vital stimulus, the sound of the voice that brings language, sets thoughts astir, and keeps us in the intellectual company of man. Blindness separates us from things but deafness separates us from people." [3]

I was recently at a conference in Bali and the organisers invited young Deaf Achievers from Indonesia to the conference dinner.

These young deaf achievers are working in fashion, computing, management, and many other areas. They were awarded prizes at the conference to recognize their achievements.

There should be *advocacy for public hearing health* at every level of society. I think it would be a good idea to involve Indigenous Deaf Achievers in the planning and implementation of a program for sustainable Indigenous Public Hearing Health.

Leadership, determination, patience and endurance are the keys to success.

² <https://www.tandfonline.com/toc/zich20/current>

³ From a letter by Helen Keller to Dr John Kerr Love in 1910

Dr Liesa Clague & Dr John Kelly



Dr Liesa Clague is an Aboriginal woman of the Yaegl people from the North Coast of NSW on her mother's side, and Manx heritage from the Isle of Man on her father's side. She is a lecturer at Macquarie University in Indigenous

Health Education, and has a Masters in Audiology. Previously, she has worked with the Aboriginal Health and Medical Research Council of NSW and Aboriginal Medical Services in NSW. She has also worked in the non-government sector with organisations including Family Planning NSW and Family Planning NT.



Dr John Kelly is originally from Sydney, NSW, and works as a GP in the Yirrkala region of north east Arnhem Land in the NT.

PERSONAL EXPERIENCES & REFLECTIONS

[Liesa] There is a large difference in the way Aboriginal people see the country. I grew up in the heart of Australia after my parents got married and moved to Alice Springs. My dad was one of the first social workers in that part of the country. He worked from Katherine all the way down to Alice Springs, and there was my uncle John, who worked all the way from Katherine to Darwin. So, I grew up with lots of Aboriginal people around us. We moved for a brief time to Darwin before moving back to my mother's country on the north coast of New South Wales, Yaegl country. Later I came to Sydney where I went to high school. Obviously, I'd spent a lot more time out bush.

My parents sent me to boarding school and said, "We need you to hone your skills and education. It's really important for your future." So I was sent to Sydney. But I just wanted to say that all those experiences have led me to follow a similar path to my mother. My mother came to Sydney to study as a nurse and I am a nurse by trade. I started my first training in Redfern AMS. That is where I first started to see the impact on ear health with Dr Peter Carter at the time, working very closely with Aboriginal health workers, who were being trained

in audiology and to understand ear health. I then moved to Darwin for a short period. However before moving, I came to Macquarie University and did Audiology. I worked as a community nurse for the Daruk AMS and Western Sydney Area Health. It was while I was working in this position that I learnt more, and the amount of screening that we did in the schools with the young kids, which no longer happens now. I was seeing a broad spectrum of kids with ear and hearing problems, but the majority of those kids were Aboriginal kids. There were maybe two non-Aboriginal kids, but the other six to eight were Aboriginal kids who were going to Australian Hearing to be looked at for gluey ear and so on.

And that program was wonderful. But now no longer occurs.

And then moving to Darwin for a short period and seeing similar problems in Darwin and what was happening there. I actually grew up with hearing problems as well. So, I can understand and relate to lots of the people I work with, on these conditions, because we grow up experiencing hearing problems in our families. So, it's no wonder we become passionate about wanting to help our people.

[John] My family background is more Irish than English. I think there was some Norwegian sailor that got lost and found his way. I grew up in Sydney and I ended up doing general practice in north east Arnhem Land. I have worked in developing countries, not in settings where I could do much about ear problems, because there wasn't the set up. And in terms of Australia, my main Aboriginal experience is in working on Palm Island in Queensland and in the traditional ancestral lands of north east Arnhem in the Northern Territory. I don't know if anyone here knows where their ancestors were living, tens of thousands of years ago. For the Yolngu people, who are the main inhabitants of north east Arnhem Land, tens of thousands of years ago, the land was divided by natural borders such as rivers and hills, into regions that are nowadays called homelands. Today we call those little settlements in these homelands the outstations.

And so when someone says his family is here, he means for tens of thousands of years. And these places still have the traditional, often sacred places that have been handed over for hundreds of generations.

Most Aboriginal people in Australia aren't allowed access to the land of their ancestors as it has become owned by others, and some of the history and knowledge of the land of their ancestors is lost to them.

But in this pocket of the world, that connection and access is fully intact, and it is interesting what effect

it appears to have had on the mental health of the people.

As an example, we haven't had a suicide in recorded memory in these outstations that we service. They will occur in east Arnhem Land but only in people living in the towns, where suicide is not uncommon. This, I think, says a lot about our history. In these outstations, we haven't got any alcohol, no sniffing. In fact, the court of law recognises the outstations as one of the main therapies. And I think that says a lot about what we have lost but what is still there in these parts of the world. Which makes outstations and their homelands very special.

Health delivery here is not exactly cheap. It's an \$800 charter to get to that place. Small communities are often 10 to 100 people and we serve about 12. A beautiful part of the world. Some of them have schools, some have shops and some don't. Lots of beautiful places. There is a lot of bush tucker. I have gone hunting with an adopted family and caught 12 fish in half an hour with a spear. And then they threw one to the crocodile they were watching all along. Mind blowing sort of place. And yes I am giving them a plug. It's really special. English is a second language. Very traditional. Quite an amazing culture.

HOW DO HEARING PROBLEMS IMPACT ON CULTURAL NORMS?

[Liesa] Deep Listening. It's very embedded in our culture, not just as a *Yaegl/Bundjalung* person, but right across our nation. It is called *Dadirri* from east Arnhem Land, the Bundjalung people call it *Gan'na* in our language – listening to one another. And if we could translate into English, it is about deep listening. And so if there is a problem with hearing, they are not learning this process of deep listening and connecting to the land and feeling the country. It's really important that it is part of what you think of when you are developing projects in regards to hearing, because it's really embedded in our culture about listening.

We did, and still do, heavily rely on oral communication. Our stories are all oral. How we communicate is very much how we yarn with each other. So you just need to be aware that the same process is happening right across Australia. The terms are different in each place. In Bundjalung/Yaegl, the term is *Gan'na* and it's about hearing, listening, feeling, thinking and understanding. And I wanted to make you aware that is more than listening with your ears. It is a complex and lifelong learning. Young kids are learning this right up until they are old because this is how you transfer your listening and learning.

[John] I imagine if you lose your sense of hearing, that has a pretty profound effect. When you cannot hear, with English as a second or third language in

some of those communities, how on earth are you going to learn English? It is a huge disadvantage. On top of that, that's going to have a profound impact on work opportunities and, quite predictably, self-esteem.

There is no coincidence of overrepresentation in jails of people with hearing issues; it is completely predictable. That doesn't take into account all the social implications... losing that sense of connectedness with your own society. It is a devastating condition.

From a doctor's point of view, when people come in, health literacy often relies on concepts which are only in the English language. If you don't have the English language - some of those concepts are hard enough to transport to another language as it is – I find there is an overrepresentation of people with hearing issues in those who have the high burden of disease and in those who are not taking their medications. Most health providers don't address their hearing when doing their consent. It's just a pervasive thing.

[Liesa] One of the key things is a lot of the Aboriginal communities have their own sign language and it has been part of their communities a long time before Auslan. I have seen my mother in an interview on national TV, and my cousin was with her, she did the sign - she knew straight away, it was 'not to answer'. It's very clever, and very good for us. The people in the general world wouldn't pick up those signs.

Little gestures mean messages. A lot of people don't realise that is happening. There are other forms of communication happening on top of just listening. We take for granted, because we are not asking the right questions when we interact with Aboriginal and Torres Strait Islander people - we are not asking them what forms of communication are you using in your household, other than spoken language. We don't do that.

[John] Absolutely. There is a price to it too, isn't there? I see the same thing - this amazing sign language. It takes a lot of energy. Often it is certain people given the role of doing the communicating. If you think of it, if you have a significant percentage of the population with the same problem, it can take a bit of a toll on the community. Sometimes people come into the clinic and I don't have anybody who can do sign language.

[Liesa] But another thing is that it is about humour. In those circumstances, John, you have got to have a good sense of humour to get through some of these debilitating illnesses you go through. That's what gets some of our mob through some of the hard times, in regards to grief and loss. Because when you lose your hearing, you are going through loss; you are grieving for the loss of being able to

communicate with your mum, individuals etc. Being part of that interaction is very important.

HOW DO YOU PROBLEM-SOLVE BARRIERS AND DEVELOP SOLUTIONS?

[Liesa] Individuals, families and communities are all connected, and I think it is important, when you're starting off with individuals, that you realise you need to get the right people involved.

[John] There is the saying, 'it takes a village to raise a child'. It's really true up there. A very beautiful part of the culture is that there is community decision-making. A practical tip in the clinic is that the person you're talking to may not be the decision-maker for that child. Particularly if it is the person doing the communicating, they are often not the decision-makers.

[Liesa] That is one of the key tips - you really do need to clarify, when you are doing the consultation with the child, that you have the right person in the room. When I worked for NSW Health, we had Housing for Health (<https://www.health.nsw.gov.au/environment/aboriginal/pages/housing-for-health.aspx>). I found, when I worked on that program, it was really about going into homes – where there was a lot of crowding - but if the children and family were having one shower a day, it reduced infections. That was a simple thing, but it is very difficult to implement when you don't have running water in your homes, the shower recess is broken, and multiple things are happening; 80% of the homes that were assessed didn't have hot water which meant that only 20% in the communities were getting hot water. Being involved in that program, actually working in communities – where there was a drop in infection rates, in scabies - was really working. But now that program is not occurring.

Also, I worked for StreetWise Magazine, and they brought out cartoon magazine literacy, to get out to communities about making sure you look after your ears, and getting young people monitored in regard to their hearing, because of the high rates of hearing problems.

[John] If I get somebody with ear pain, and they have acute otitis media, I scratch my head in wonder. They have acute otitis media, but what is causing the ear pain? It is usually a tooth. In some of the studies, they have shown that less than 5% have pain. The same with fever.

This is a problem. In Sydney, people come in with pain, I look in their ear and diagnose acute otitis media. I give them this talk. "Here is a script for an antibiotic, if the pain doesn't settle in 48 hours then fill it out. If you have any problems with your hearing at three months, then come back." You can't do that there - it is asymptomatic. You have to get them back. Following the standard protocols you

have to go in and check for resolution of the bulge of the ear drum every week, with intent of changing the antibiotic dose if you are not winning. It is a different mindset.

This is not the only barrier though. Another problem is diagnosis. When you learn about ears there are the classic signs that everyone gets good at. A bulge appearance like a doughnut is acute otitis media. If there is a hole with pus in the centre – acute otitis media with perforation or chronic suppurative otitis media... they are easy. But unfortunately, when you go and look at people's ears, in reality, they don't often fit those things. You look in the ear and there is some scarring in part, some granulation tissue there, you can't make out the anatomy, maybe a retraction....mmm is that some pus? It can be messy. And that's when you actually manage to see the ear drum. If you think about it, doctors and nurses have come from Sydney, where they don't see anything about ears except for acute otitis media. They are starting from close to scratch. We have Aboriginal health workers that may have more time to get used to seeing the pathology up there in the ears. But before we had video otoscopy, teaching people how to learn what they are seeing in an ear drum was not easy. You can't exactly go in and say, this structure is this.

One of the most challenging conditions to diagnose with otoscopy alone is the glue ear or otitis media with effusion as it is known. A normal-looking ear and a full-on glue ear can look very similar. It is like a full glass of water and an empty glass of water from the distance. It is not that straightforward. You have to rely on measuring the mobility of the eardrum, but using tympanometers in the past were not widespread in these places.

The protocol for glue ear is based on seeing if it persists for at least three months - but how do you do that when we are struggling to diagnose it in the first place. Especially if they don't have tympanograms or pneumatic otoscopy.

Now let's go a step further. Let's say you have made a diagnosis of a middle ear disease - let's say a long standing perforation with pus. First you have to explain it to the patient who, quite frankly, doesn't trust you a lot of the time - why should they? If you have staff turnovers every four months, you don't have those relationships. You are telling them about the treatment for a thing they can't see. They can't see it, and on top of that, the medications don't work that well in getting rid of their problem. And even if the drops or medication settle the infection, you still have holes in ear drums. The pus might disappear with ear drops but the big hole won't - that's important.

On top of that, there are the problems with the hearing test. It might take 30 minutes. At an outstation, a nurse or doctor will have many patients

to see, all with these different conditions of the body like rheumatic heart disease. I tell you what, no-one has time to do a hearing test, even if they knew how to do it. We wind up relying on someone external to that system to do that unless a health service is very well resourced. You could say let's refer it, but it is \$1,800 to get a hearing test. You could be waiting a long time to get a hearing test.

On top of that, even if we do have an audiometer and we use it on a patient, no-one trusts your opinion anyway. And no-one will base a hearing aid or surgery on it.

Next step, once hearing loss is documented and thought likely to persist, is to help people hear. This often means *hearing hats* (bone conductor hearing aids) or hearing devices, or they might go to schools with sound-field amplification systems or have surgery.

You go to half the schools, and they don't have the amplification systems, they don't have the systems and the speakers, and a lot of the times, if they do, the teachers don't use them.

There's no key performance indicators or accreditation requirements around these things. You will get people who are passionate about this sometimes, who will do these things, but it is very patchy. And these sound amplification systems often don't fully help the very hearing impaired.

There is this reliance on ENT surgeons, but the average hearing improvement we are told is about 12 decibels. There is usually a one-year waiting period for the surgery; you have to have \$1,800 to do the test before they will proceed - it's hard.

To me the most exciting option is *hearing hats*. They are fantastic. They get a lightbulb moment when it is on them ... it is fantastic, one of our best interventions. But it can take a long time to get these. Traditionally, it is face-to-face access, and that is a delay. And then there is the shame involved for these kids to wear it. There was a fantastic initiative I heard, where everybody had to wear a hat band at school - it was great. And then, of course, what happens is they go missing. We looked into why they go missing, and we found the most common reason was the batteries ran out, and they didn't know it was the batteries. And often there are these visits with Australian Hearing, but of course they are limited with their resources. Primary health care often leave it all to Australian Hearing health care, whereas in reality we need to be knowledgeable and proactive about hearing hats, we need to check the batteries, we need to know these things. So, we found that was the most common cause of loss of these \$300-\$500 hearing hats was batteries needing changing.

In terms of primary intervention, breastfeeding is a risk factor. We have one of the highest breastfeeding rates in the world. Vaccine doesn't work for our population, unfortunately. Passive smoking. Most people do smoke, but they share a pack, a whole community, and they smoke outside. So that isn't a big factor in our community, at least. It might be in some. We still get that message to them, because we can do that.

And then the big elephant in the room - housing. There is no coincidence that middle ear disease and rheumatic heart disease are common in developing countries and Aboriginal homes. They are diseases that thrive in overcrowding. There was a high rate of rheumatic heart disease in Melbourne, in the 1930s, when housing improved so did that condition. We shouldn't have to prove that fire is hot, and we shouldn't have to prove that this is important. Yet this fact is ignored by all but the health sector.

My problem is that I can't do anything about the housing. Funnily enough, we actually used Medicare money once to build a dwelling. And nutrition - this is potentially another risk factor we might be able to do something about. Try going to the shop and buying some fresh fruit and vegetables - eight dollars for half a soggy rockmelon.

[Liesa] On top of that, you might get two or three of your kids with the same problem. Can you imagine the economic burden for the family, and community, to have a number of kids going through the same thing? We were talking about that; it puts a huge burden on the community that isn't getting a lot of money anyway. This also applies to Western Sydney, which has the highest population of Aboriginal and Torres Strait Islander peoples in the whole of Australia. We should be looking at our own backyard and dealing with the issues. When I was first working, the Public Health Unit worked with another organization - that was probably part of Flemington markets. They used to get boxes made up for lower-income families. They pay \$10, it is taken to the household and they would share it among family groups.

We did a study in the Public Health Unit in Western Sydney, and we found that the closest things to the residential housing - and it still is today - was McDonald's and Kentucky Fried Chicken. Where was the fruit and vegetable market? It was 30 minutes away by car or by bus. So, we need to start being proactive and advocate, and have these sorts of things being closer to the population that we need to service. We were doing that, and it got shut down.

We need to go backwards now and start putting those programs that have worked back in place. We didn't need research to see the improvements in the Aboriginal community. We saw much happier environments, much happier people, less occurrence

of diseases - because they were having fruit and vegetables.

I went to a lecture last night when I should have been working on our PowerPoint about public health, and they were talking about all of those things. We are teaching people these things, but are we doing it? The cost in doing it is minimal. If we talk about how much we are spending on research, we should be focusing on putting those programs that have worked back into place.

Another program: school gardens in primary schools - bush tucker, kitchen gardens. One of the programs I saw in my own community was the Aboriginal medical service found that this small school, that had a high proportion of Aboriginal kids, had scabies and other problems. So they decided that they would supply them with vitamins. The kids wouldn't take them. But the kids were then given fruit and vegetables, and they loved it. So, kids were given fruit and vegetables each day at school, and with the money that they saved, they introduced a school garden into the premises, where they were growing their own fruit and vegetables.

It's an easy way to resolve certain things, but we are not being creative enough to take on board these activities that have numerous learning and health impacts and outcomes and run with it. We want to put more money into research. I know it is valid, and you are going to be talking about it, but I sort of think 'put your money where your mouth is'. Put those programs back in place that are low-cost and are part of health promotion.

These are cost-effective programs. Housing for Health took \$7000 per house to improve housing conditions for the Aboriginal population. We know that. We shut down a program that was having a great effect. We were training up Aboriginal Environmental Health Officers here in New South Wales. I don't know if that program is still going. It was introducing Aboriginal people back into their communities, to teach their communities the relevance and rationale of why we do these things.

[John] The other thing that I would say, with hearing aids - there is actually a wonderful subsidy system for Aboriginal people to access them. There is one group that misses out, and they are people between 27 and 49 years old. The problem is that when these people do get a job, they're often low-income jobs, and they don't get the subsidy for the hearing aid. There is a wonderful culture of things being shared when you have them, which means that you share the things that you have. So, nobody in this age range with a job is selfish enough to get a hearing aid. It is not considered the done thing. It would be selfish, in their culture - at least in north east Arnhem Land. It is a problem, because people choose not to get the hearing aids, and instead give their money to someone else.

[Liesa] The other thing related to that is when people in a community have jobs, they share that money with people. If a person needs to be flown out to Darwin, the person with the job will give them the money to do that. It puts a lot of pressure on the family, who now does not have the \$800. There are so many dynamics that we are not aware of, unless you have that conversation about what is actually going on in the community. There is a lot of shaming, too, that is underlying, that Aboriginal people won't talk about in our communities, because they don't want other people knowing how hard it is.

[John] With regard to solutions - we should continue to advocate for housing, even as a human rights issue, independent of health. In terms of nutrition, there are a few ideas around local fruit and vegetable production and subsidies for these in these remote communities. In terms of screening and diagnosis, one of the biggest developments we have had is the video otoscopy. That is the most exciting thing to me in the last couple of years because you can see it.

That means several things.

1. From a training point of view, it is easier to train. We run a quick video and we can teach people how to look at an ear. We talk about an 'angel' which is what the ear drum looks like - the head and body of the angel is the malleus, and above the wings is the attic. Then we talk about position, colour, clarity and mobility. And we can show them a few common ear conditions. Teaching them how to use tele-otoscopy and a tympanogram, these last two are the most important things.
2. From the patient's point of view, the patient is now seeing their pathology, and that changes from an education point of view. You realise it isn't just some concept - you can see it.
3. You can obtain an expert opinion - sometimes immediately. Sometimes you get something, "I would like an ENT surgeon to see that." Email it, and instantly they give advice and make a recommendation. It transforms our problems. You can get more access, recalls, get the people back more easily.
4. If you're having surgery, oral consent doesn't work for us - it has to be visual. We have had people who have had two years of trying to convince them to have surgery. And then you show them pictures, and pictures of what will happen if they don't do anything, pictures of going into the theatre... and suddenly they want the operation today.

We have decided to become proactive about hearing aids and making sure hearing support is on the

radar with our local schools. Australian Hearing have taught us how to do troubleshooting, and we have people coming in for the batteries now. Fantastic. There is communication with the schools. But of course there are things we can't do – and too many problems out there. There are less and less Aboriginal health workers with the time. All the staff have competing responsibilities.

[Liesa] The establishment of the Redfern AMS in 1971 actually is about that. But the Australian Government has not endorsed it, to really support the needs of communities in owning their own health. They still want their own control.

The money goes to all the administrators - hospitals, whether they have Aboriginal people attending or not, get a cut of that money. From my understanding, the end bits actually go to the Aboriginal medical services. When they say they are going to give a huge amount of money, it has to cater for a wide-reaching audience - administrators, lots of people - before it gets to where it needs to go. Sometimes it is the communities who put these programs together and get funding who work through the problems. Purple House and others have had actual artists sell their paintings, to then give that to the community to fund. So they are doing the work themselves. This is the communities. Not politicians or government, but communities - because they see the need. They can see the ears, see the perforation. There are other good stories that we don't hear about. It's the tragic stories that we do hear about.

WHAT RESOURCES ARE AVAILABLE?

[Liesa] I worked for Streetwise, the magazine, before it closed down. We found that in our communities we love playing cards, so we decided that putting messages on playing cards about health was a way of introducing, subtly, good health promotion. Flipcharts - developed when I worked at Family Planning, about yarning about your body.

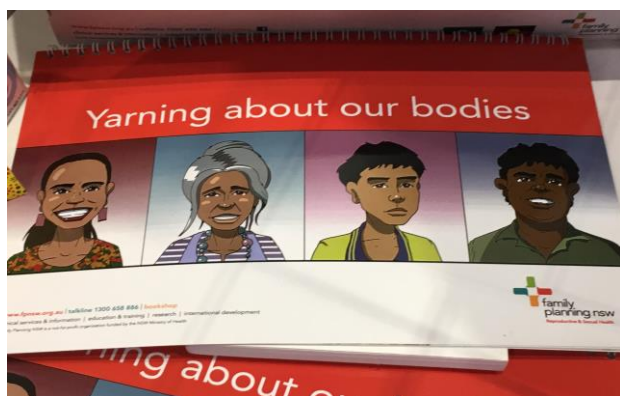


Figure 5: Health card that uses cartoons and stories to educate people about health issues.

This (Figure 5) is my beautiful daughter, and my auntie, my nephew and uncle. I got a person to

sketch them in a good story together. This is a little card that you can put in your pocket. You could do the same for hearing. Then you open it up, and it tells you all the story. You tell the story through using cartoons and storytelling to get information out to people.

But low literacy. It was low literacy - lots of pictures and DVDs. When I worked at AHMRC, we came up with a video of the Aboriginal services who are doing amazing nutritional programs. And also exercise programs for the older generation, like me. And, obviously, cartoons. But we also developed a brochure that had no words.

We need to start being creative in how to get the message out there. There are lots of ways to do this. We talked about apps. We talked about a number of things; technology - we can also get them to do a video game. The world is our oyster, I believe.

One of the benefits is making sure you talk to local Aboriginal and Torres Strait Islander peoples, when you go out to the communities, and find out what their needs are. Their priority might not be hearing - it might be cardiovascular, or diabetes, housing. Once you get that priority, then they might look at what you're going to suggest as hearing health.

Working maybe in partnership with other organisations, like the Heart Foundation or Diabetes Australia, but there will be communities that have been brought together because of the Stolen Generation, that do not get on. That's another level of complexity in our communities. How you address that? I am still working on it. But having a conversation is part of that journey.

My mum grew up on Ulgundahi Island (Figure 6), which means, 'shape of an ear', which I thought was very poignant. That is the mission where she grew up, on the Clarence River.



Figure 6: Slide used during Dr Clague and Dr Kelly's talk, showing a picture of Ulgundahi Island.

Samantha Harkus



Principal Audiologist for the Aboriginal and Torres Strait Islander Service at Australian Hearing, Sam has 25 years' experience working in paediatric services, as well as working with Aboriginal and Torres Strait

Islander communities. She is responsible for managing a program aiming to overcome the barriers that prevent equity and access to hearing services for Aboriginal and Torres Strait Islander peoples - distance, culture, language and history. Recently, she has completed her Masters of Public Health, specialising in Aboriginal and Torres Strait Islander public health, at the University of NSW.

CLOSING THE GAP IN HEARING REHABILITATION OUTCOMES

Closing the gap in hearing rehabilitation outcomes for Aboriginal and Torres Strait Islander children requires four key components; (1) supporting primary health to continue to lower the age of referring for diagnostic hearing assessment, (2) reduce the interval between diagnostic hearing assessment and referral to Australian Hearing, (3) reducing the interval from first appointment with Australian Hearing to first hearing aid fitting; and (4) reducing the interval between the first fitting and the first follow-up. We also need to continue improving the quality of follow-up support, who we support, and improving outcomes.

Australian Hearing is a national organisation, funded by the Australian government, with a main aim to reduce the impact of hearing loss in children and adults. In 2018, Australian Hearing saw approximately 5000 Aboriginal and Torres Strait Islander adults through both our Hearing Centres and our Outreach program; half were seen in Hearing Centres (Figure 7, top). That is an interesting trend: every year, about 2% more Aboriginal adults are actually coming to be seen in our Hearing Centres, not at Outreach locations, which I think is fantastic. A bit less than 5000 Aboriginal and Torres Strait Islander kids were seen, 30% of those have hearing aids and 70%, are not aided at the time that we see them (Figure 7, bottom). However, they may go on to be aided. And 65% were seen through the Outreach program in communities, so we see more kids in Outreach.

In Australian Hearing, about 110 audiologists are involved in Outreach - urban, regional or remote. About 8 years ago, we were going to 100 Aboriginal Community Controlled services, so it is more than

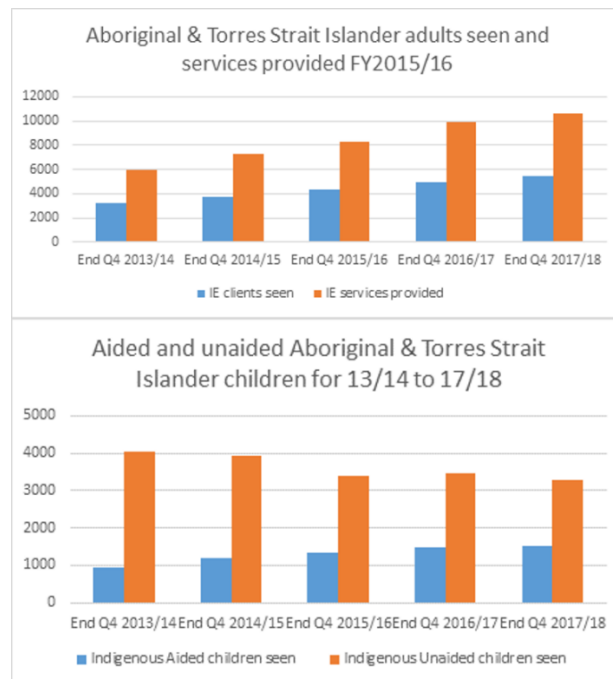


Figure 7: Services provided to Aboriginal and Torres Strait Islanders, adults (top) and children (bottom), by Australian Hearing.

this now. We work in more than 240 locations, and 60% are in remote Australia, including the Laynhapuy Homelands. We average about four visits per community per year, but that varies widely from fortnightly for a full day at the Aboriginal service at Redfern, to three, four or five visits in remote communities. Part of our Outreach is about building relationships. That's really, really important, and providing awareness-raising and training.

What I learnt in my Master of Public Health course about 'closing gaps': if you continue to do the same as you have been, that won't work, and the gap will continue to widen, because outcomes are continuing to improve all the time for non-Indigenous Australians. Doing what you are doing for the other population, in this case non-Indigenous Australians, won't work either, because the gap will remain the same. We want to close the gap. So what you have to do for that population is to do better than you are doing for the other population. That might be doing more, or something different, or doing something together. That is what is required if you want to close gaps. You have to take bigger steps to make exponential improvements, to achieve equity in outcomes, which is what you want.

Australian Hearing publishes a demographics report every year about Australian children who wear hearing aids, including the age of first fitting. Before 2008, the report was for all Australian children. After 2008, we separated out the data for Aboriginal and Torres Strait Islander children from the rest of that population (Figure 8).



Figure 8: Age of first fitting of hearing aid in all children (blue), and Aboriginal and Torres Strait Islander children (red).

For the non-Indigenous population, in 2008, since the introduction of newborn hearing screening, there is now a big peak in age of first fitting for <1 year-olds with a secondary peak after starting school. But when you considered Aboriginal children separately, there was no peak before 1 year of age, but a huge peak after they start school.

We can partly account for this because the main driver of hearing loss in this population is ear disease, which starts very, very early, a few months after birth, but is not present at the time of newborn hearing screening. So the world class newborn hearing screening system in Australia doesn't help with this because it is not present at birth.

Once we identified this late age of first hearing aid fitting, we knew there were some things we had to start doing. We had to develop and share this narrative to ensure that we could influence those who played a part in this pathway, including our own audiologists, to try to reach families of younger children better, and also trying to reach out to families to help them understand the importance of early action.

Eight years later, this was the year before last, what is happening now? 403 Aboriginal kids were fitted for the first time that year, as opposed to just over 300 kids 8 years ago. When we compare the proportion of children fitted by age group, it is clear that the age of first hearing aid fitting is actually starting to move down from an average age of eight years to six years. And the proportion of Aboriginal kids fitted within the first five years of life has doubled. So we have improved, from one in 10 Aboriginal kids receiving their first hearing aid by

the age of five, to one in four. It's fantastic, but we have a long way to go.




If you think about the pathway from primary health to diagnostic test to Australian Hearing, it looks like this: identification of first infection by primary health, then identification of chronic infection by primary health. Then you have the identification of potential hearing loss, and the referral for a diagnostic hearing assessment, still by primary health. Following that there is the first referral to Australian Hearing, then a wait to see Australian Hearing, and then onto the first fitting.

Our aim is to make the gaps between those steps smaller. We would like to reduce the intervals between identification of chronic infection and referral for hearing assessment, then between hearing assessment and first appointment with Australian Hearing, and then between first fitting and first follow up, so that everything happens within that first critical three years for speech and language development, not after.

EARLY RECOGNITION OF HEARING LOSS

Ear infections can start early in the first few years of life, easily by three months of age, can become chronic by six months, and you can have moderate hearing impairment in the first year of life. Certainly, we know that there is a lot of moderate hearing loss in the one-two year age group in the Northern Territory. But early recognition of otitis media-related hearing loss is strongly reliant on primary health staff. Anecdotally, a lot of those primary health staff rely on parents and carers to recognise the behaviours associated with hearing loss. Here is an interview with a Child and Family Health Nurse who says, 'So most of it is now parental concern,' where you rely on the parent to tell you if they think their child has hearing loss. But when we asked the Child and Family Health Nurse, 'Do you think all parents would notice?' she said 'Definitely not. I think only the most interactive parents, mainly.'

We are relying on parents to notice hearing loss, but we recognise that parents are not necessarily good at that. Social research carried out by Australian Hearing and also by the Department of Health shows that hearing loss and ear trouble is normalised by a lot of Aboriginal families because they have had it for generations - since colonisation. Many rely on teachers to pick up hearing loss, but that is well past the best age for intervention.

Australian Hearing   **WESTERN SYDNEY UNIVERSITY**  **INAL**
National Acoustic Laboratories

PLUM listening behaviour scale
A child's behaviour is a good indicator of how well they are hearing.

The PLUM (Parent-evaluated Listening and Understanding Measure) helps Primary Health practitioners to find out from parents/carers about the child's everyday listening behaviour, and whether the child may need help to hear better.

How to do it? Talk through each question with the parent/carer. For each question, the family indicates how often the child has shown this behaviour in the past few weeks. Explain and give examples as required. What you know about the child, family and the community will help. Working with an interpreter when needed will give you better information.

At the end, score using the guide provided. The PLUM can be repeated when needed to check the child's progress.

Child's name _____ DOB (DD/MM/YYYY) _____

Name of respondent: _____ Name of interpreter (if applicable): _____

Has your child been well/healthy? YES NO *If yes, proceed to the PLUM questions below*

Do they have a hearing device? ☐ Unaided ☐ Aided – YES

If yes, how often? ☐ Never ☐ A little ☐ Sometimes ☐ A lot ☒ Always

Date:		Listening behaviour How often does your child do this?				
Questions Ask parent/carer to think about the <i>past few weeks</i> .		Never	A little	Sometimes	A lot	Always
1	When it's quiet, and you call your child and they can't see you, do they hear you? <i>Eg. Child turns towards your voice, or answers from another room</i>	0	1	2	3	4
2	When it's noisy, and you call your child and they can't see you, do they hear you? <i>Eg. Family gathering, TV on. Child turns towards your voice or answers.</i>	0	1	2	3	4
3	When it's quiet, if you ask your child to do something easy, can they do it? <i>Eg. Sit down; Come here; Give me the cup; Put your rubbish in the bin.</i>	0	1	2	3	4
4	When it's noisy if you ask your child to do something easy, can they do it? <i>Eg. Family gathering, TV on, music playing.</i>	0	1	2	3	4
5	When it's quiet, does your child join in a conversation with you, or with someone they know? <i>Eg. Answering or asking questions, making or responding to a comment</i>	0	1	2	3	4
6	When it's noisy, does your child join in a conversation with you, or with someone they know? <i>Eg. Family gathering, TV on, music playing.</i>	0	1	2	3	4
7	When it's quiet, and you're talking, singing or telling a story, does your child join in & follow? <i>Eg. Listen along, copy what you're doing, ask questions about a story.</i>	0	1	2	3	4
8	When it's noisy, does your child understand you when they can't see you? <i>Eg. In the pram facing away; child in back seat of car and parent in front.</i>	0	1	2	3	4
9	Without seeing them, does your child know people by their voices? <i>Eg. Someone on the phone; someone calling out from another room.</i>	0	1	2	3	4
10	Does your child notice other sounds around them? <i>Eg. Dogs, birds, cars, TV sounds, phone, rain and thunder, sirens.</i>	0	1	2	3	4

PLUM Scoring:		% Score
Score in quiet	A (Add scores for Q.1+3+5+7+9)/20 X 100	
Score in noise	B (Add scores for Q.2+4+6+8+10)/20 X 100	
Overall score	C (A + B)/2	

Figure 9: The Parent-evaluated Listening and Understanding Measure (PLUM).

AGE OF FIRST FITTING

So there appears to be a lack of reliable, valid, objective tools that can help primary health to explore this area well. If you ask, 'What is in your toolbox to help?' this particular nurse said, 'Probably not much. Since newborn hearing screening, it's probably not checked that much by child and family health nurses.'

When a parent responds 'no' to the very common question of 'Are you concerned about your child's hearing', primary health staff are not sure whether the parent knows what the signs of hearing loss look like, whether they know what to look for. So primary health staff need a range of valid tools that they can use with confidence to identify very young children with hearing loss and refer them for hearing evaluation as early as possible within the first five years of life.

ASSESSING FUNCTIONAL LISTENING

The Parental Evaluation of Aural performance of Children, or PEACH, (Ching & Hill, 2007) is a validated scale used by paediatric rehabilitative audiologists. This positions parents as experts in their child's hearing, and gives them the right questions to obtain the right answer, instead of

asking an open question of whether they are concerned about their child's hearing.

The PEACH explores everyday functional listening behaviour, because age-appropriate listening behaviour is a good indicator of a child's hearing ability. The PEACH is validated from age 3 months and upwards, with mild loss or greater. The score obtained is then plotted against a normal curve for age to identify whether a problem exists. In Australian Hearing, PEACH results inform or reinforce our decisions about whether or not to fit, and the functional impact of hearing aids.

We wanted to explore whether we could use a modified version of the PEACH to provide primary health workers with a better way of identifying hearing problems in children. Australian Hearing, the National Acoustic Laboratories and Western Sydney University are collaborating with a number of communities in urban and remote Australia to adapt the PEACH and evaluate this with 40 remote and 40 urban/regional children, funded with an Indigenous Advancement Strategy grant. The revised scale is called the Parent-evaluated Listening and Understanding Measure (PLUM, Figure 9). Data collection is easy: families are invited to participate, there are demographic questions,

looking in ears, doing tympanometry, questions about overall health, age of onset of chronic disease.... However, involvement of the local community is key to its success, so the involvement of Aboriginal Health Workers is very important.

Here is an example of how the PEACH has been modified: The PEACH asks 'Does he understand what you say in the car?' Audiologists know what this question is asking. It's a question that explores hearing without visual cues, in a situation with some background noise. In remote communities, you quickly realise that you have to adapt that, because families may not travel in a car very often, and when they do they may be in the back seat with the child on their lap, or the front seat with a child on their lap. Or they may be on a bus, a community transport bus, for instance. However, when we were trying to simplify the wording of this question more with people in Katherine, in the Northern Territory, they said, 'Look, isn't this question asking about listening in a confined space?' We said, 'No, it's about hearing when there are no visual cues, and some background noise.' This was a lightbulb moment where we understood the level of assumed knowledge that underlies the question.

After we all got over that, they said 'Well, is that like when you're pushing a stroller outside and the child's facing away?' So we changed the question to what it's really asking 'When it is noisy, does your child understand you when they can't see you?' And then gave examples, including being in a stroller and the child is facing forward, or in the car, specifically 'child in the backseat, parent in the front'. In this way, we improve the tool so that it doesn't matter whether it's an audiologist or a primary health worker using it.

We are pairing the PLUM with the HAT Scale: Hearing and Talking. It asks five questions, depends on the child's age group, and we are going through the same iterative process so that it can be picked up and used by a non-speechie. And the parent is the expert.

That is one of our strategies for closing that gap.

REDUCING THE INTERVAL BETWEEN FIRST APPOINTMENT & FIRST FITTING

The second is the interval between first appointment with Australian Hearing and the first fitting. Once a diagnostic service, such as Deadly Ears (an Aboriginal Hearing Health organization in Queensland) which also works in an outreach capacity, refers to us, the wait time to see us when we are next in the community could be three months or so, depending on when our next visit is scheduled. That is a real risk for losing momentum. Something that's important to the family at the time of referral is then two months away, and as they wait there's that risk that they begin to wonder whether a

hearing aid is so important. So, could we see them, and aid earlier if appropriate, if we used a partnership tele-audiology approach, particularly looking at 0 – 5 year olds?

We proposed this to Deadly Ears and they said yes, let's give it a go. This program is called TeleFIT. The model is: Deadly Ears are in a community for a week with a large team. They identify 0 - 5-year-old children and refer them to us in the usual way. Kids who are too young to be behaviourally tested in the outreach setting, but they have ear health history and listening behaviours consistent with significant hearing loss, they refer to us as well.

The family is given the choice if they want to see us next day, with the Deadly Ears audiologist using tele-audiology, or if they would like to wait - most families said next day. We pre-prepare a kit of bone-conduction devices for Deadly Ears and because they have quite a few ex-Australian Hearing audiologists, we often don't have to train them very much. They go through a training process, according to what is needed. On the day, the Australian Hearing audiologist and the Deadly Ears audiologist catch up before the clinic and talk through each of the children who are being referred. Then the family arrives for the video appointment (Figure 10).



Figure 10: Using a telehealth approach to reduce the interval between referral, first appointment and first fitting (picture courtesy of Australian Hearing).

The Australian Hearing audiologist leads the appointment, but the Deadly Ears audiologist is an active participant. There are also vital hands at the other end, for putting on the hearing aid, trying it out... That lightbulb moment you get - you know you're onto something when you get that, when you put a bone conduction aid on and there is a change in the child's listening behaviour.

Only one family has declined a fitting through this process. Now that we have introduced a new video follow-up program, we will do that a couple of weeks later.

In 2016, we completed a one-year trial of TeleFIT with three Queensland Gulf communities, which then became 'business as usual' in 2017. The person doing the clinic last week emailed this morning to say they had nine referrals, which is enormous and we couldn't fit them in. Now we are working out how to maintain momentum for those families.

Looking at our three communities and our pattern for fittings for 0 - 5-year-olds between 2010-2013, there was an average of less than one child aged five or under in each of those years. In 2014 to 2015, when got better at finding ways of reaching children earlier and aiding earlier, we saw an average of six children 0 - 5 year olds fitted per annum and most were five-year-olds.

When we introduced TeleFIT we went up to 13 children fitted in 2016; eight were fitted through the TeleFIT process, and five were fitted through the face-to-face program, and four of these were aged ≤ 3 years. And in 2017, four were fitted via TeleFIT and nine were fitted face-to-face, and of these, seven were aged ≤ 3 years.

In summary, after the implementation of TeleFIT, we have seen a reduction in the age of first hearing aid fittings in those communities. Importantly, there is no observable difference in outcomes whether you have been getting face-to-face or tele-outreach.

REDUCING THE INTERVAL BETWEEN FITTING & FIRST FOLLOW-UP

In 2017, of 219 Aboriginal children fitted for the first time in remote communities, the average interval between the first fitting and the first follow-up was five months. Our internal quality benchmark, to follow-up children first fitted with a hearing aid, is two weeks. So in Outreach we are well outside this, and even longer than the average inter-trip intervals. So we are missing follow ups for quite a few kids on our return visit to the community.

Early intervention for speech/language isn't funded for young kids with otitis media-related conductive hearing loss, so you lose the opportunity to reinforce hearing aid use. And 25% of those children were lost to follow-up at the time I obtained the data, which was September the following year. So outcomes for many of those kids could already be expected to be poor, without even beginning to consider any other factors that might relate to the child or family or community. But we can't significantly increase our face-to-face Outreach services: it would be an enormous cost, and our audiologists would burn out. Outreach audiologists love their work, but we have seen what happens when they have just done too much, and they have left the program.

So we decided to consider whether we can do it via TeleOutreach. We service 160 remote communities with multiple service points within each community: the clinic, the school, the early childhood centre. We

cannot easily tap into the in-house videoconferencing infrastructure that primary health and schools have. There are technological firewalls in place, there's limited bandwidth, and you need an intermediary at the other end. Families don't usually have the technology at home - computers, internet, phone... It is unusual for a family in a remote community to have all these things. So we had to think about solutions.

There is an American health conferencing application used with the International Space Station, but it cannot get through a Northern Territory health service firewall. We found Zoom gets through firewalls. If reception gets bad at one end; the whole thing goes down if you use Skype. But with Zoom, that is only a problem on one end, not both.

So we developed a model where, during the fitting in the community, the audiologist talks to the family about nominating a Hearing Helper. It's a temporary thing, firstly to help with logistical support - equipment, transport - but also to be in that space of providing practical and psychosocial support in the early days of aid use. The parent nominates the Hearing Helper who is usually somebody based in the early childhood centre or the health clinic or the school. Those people, apart from everything else, are well positioned to support that child as they start to wear the aid, to watch for changes in listening behaviour, and inform the family of progress - providing we help them do that.

The concept of building supportive environments comes from the World Health Organisation and public health approaches, the Ottawa Charter for Health Promotion. When we first contact the Hearing Helper, we give them the fact sheet that clearly says, 'What sort of things can you do to help?' You can provide support to the child, and you can do this by doing any of the following. Number two is watching for changes in these listening behaviours, and give them some clear ideas of what that looks like. And then, of course, practical stuff around participating, helping to set up the tele follow-up. Ideally it is the child, family, and the Hearing Helper at the appointment. We actually find that in most cases, it is all of those people, which is fantastic. But even if it is only the Hearing Helper who attends they can still build that supportive environment and indirectly support the family.

We are really surprised to find that the quality of the interactions is actually often better than in person. That is because in the video setting they are away from the busy-ness of the school or clinic. Plus, we have cued them in to what to look for in terms of changes in listening behaviours, so they often come to the video appointment prepared, saying they have been watching, and telling you what has been happening.

From April to December 2018, following the introduction of the TeleFUP, the tele follow-up program, 186 children were fitted. Not everybody was referred, and of the people that we were referred, not all were followed up with. But of the 40 children who attended the Tele Follow-Up program, the average wait time was 29 days for the kids who attended the follow-up, and 85 days if they were seen face-to-face.

IMAGINING THE FUTURE

So we imagine a future with blended service delivery. So you have a strong face-to-face outreach program, which we need in order to build the tele-outreach program on top of, where clients become used to moving between the two streams. For the first time, we begin to imagine that there is a way of meeting some of our own internal quality benchmarks that in the past we have not been able to understand how to do. In closing gaps, we need to do more, do different, and do together. Services working collaboratively, and I imagine that we have these loose shoelaces that bind us together, and we are just pulling tight on those shoelaces and pulling ourselves closer together. So that families can walk that pathway in a more timely way. And the key ways to do it, are through collaboration and tele-practice.

Professor Amanda Leach



Professor Amanda Leach is the leader of the Ear Health Research Program, Child Health Division at the Menzies School of Health Research. She leads a Centre of Research Excellence in ear and hearing health for Aboriginal and Torres Strait

Islander children, and is leading the update of the 2010 Otitis Media Guidelines, which will include an app for use in the field. Recently, Amanda has become the joint chair with Associate Professor Kelvin Kong for the Hearing for Learning Initiative, which is a funding partnership between the Balnaves Foundation, the Northern Territory Government and the Australian Government. She is the 2019 NT winner of the Telstra Business Women's Award.

OTITIS MEDIA AMONG ABORIGINAL AND TORRES STRAIT ISLANDER CHILDREN IN THE NORTHERN TERRITORY

SOCIAL DETERMINANTS OF HEALTH AND OTITIS MEDIA

The Trachoma Eye Health program was one of the first to do the prevalence of ear disease in the 70's (Moran et al. 1979). They identified that about 18% of young children under four years of age had chronic suppurative otitis media. The WHO has a

standard of 4% for being an emergency public-health situation, so otitis media has been identified as a pretty serious problem.

Deborah Lehmann and colleagues developed this conceptual framework on the causal pathways to otitis media, hearing loss, educational and social disadvantage (Lehmann et al. 2008a). Certainly, colonisation of Australia, the fixed settlements, and marginalisation, overwhelmingly impact on this condition, which works down through the housing, and creating the poor hygiene. There are many things to be considered on the individual level as well, including smoking and poor nutrition. It is a very complex issue, with the need for very complex approaches to solutions.

Remote housing is a challenge, although in the Northern Territory there has been great improvements in housing. But at the same time, these old houses are being pulled down while these new houses are being brought up. So we are not seeing all that much change. The capacity of those houses might be improved and be sustained for a while. However, Jacoby (2011) showed the association between the number of rooms in the house and infection rates. Their study demonstrated that a baby in a house that has fewer rooms is more likely to be colonised by pneumococcus, and this applies equally to Aboriginal and non-Aboriginal families. The risk of having pneumococcus with another child in the house, if that crowding exists, is about threefold. So if you can build a house with eight rooms if this is what is needed in housing design, you are massively reducing risk. If you live in

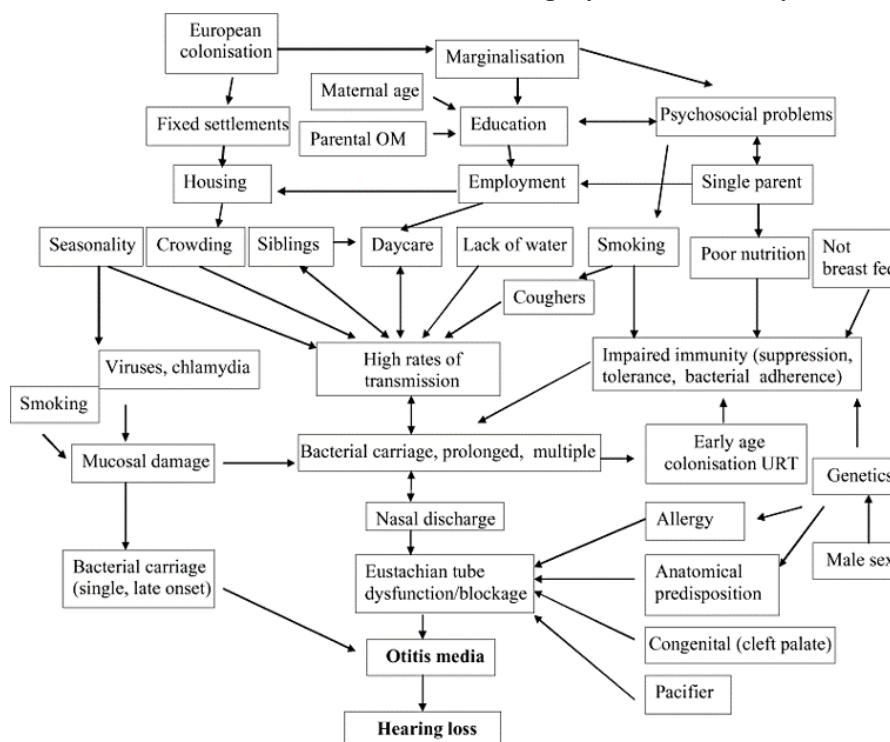


Figure 11: A causal network for otitis media (OM). URT, upper respiratory tract.
Source: Lehmann 2008a.

a crowded house in the Northern Territory, you are significantly more likely to develop chronic suppurative OM - in fact, 20% more likely.

The *No Germs on Me* - a hand-washing program relating to washing hands after going to the toilet, changing nappies or preparing food (Figure 12), was extended to include respiratory transmission. We swabbed the hands of children in day care and in remote communities. We know children are always getting infection after infection, and adults are having to take time off work. If you compare that to what was happening in remote communities... You could grow a bug on 4% of children in childcare, and 40% in the remote community. A massive surprise that we were able to culture these bugs. It meant hand washing is critically important, and needs to be done frequently. With respiratory infection, it is much more complicated.



Figure 12: Image from the 'No germs on me!' campaign. Source: Northern Territory Government of Australia

In 2016, I was interviewed by The Conversation about reducing otitis media and hearing loss (Leach 2016), and what needs to be done. At the same time, Professor Jonathan Carapetis (Paediatrics, Telethon Kids Institute) and Professor Hugh Taylor (Melbourne Laureate Professor, Harold Mitchell Chair of Indigenous Eye Health, Melbourne School of Population and Global Health, University of Melbourne) were interviewed about reducing the impact of rheumatic heart disease (Carapetis 2016) and eliminating trachoma (Taylor et al. 2016), respectively. Quite independently, we came up with the same types of things. The Health Department needs to invest in equipment, clinical training, and make appropriate decisions about the prognosis. These infections are largely bacterial, not viral. You will be told by your GP that the child has a viral infection and they don't need antibiotics, but it is different in remote areas.

The Education Department has a role in making sure that they are aware of the children's hearing issues, and the communication problems of those children need to be understood by teachers. Ensuring housing department houses provide taps that work, drain, soap and mirrors are not dropped

on the floor and lost, and the journalist considered this to be the Housing Department's responsibility, they need refrigeration for safe storage of medication. Most families we worked with in the Top End don't have fridges. Local councils and retail outlets need to make sure there are affordable products for families to purchase to stay clean and keep their children germ free.

THE GAP BETWEEN ABORIGINAL AND NON-ABORIGINAL EAR HEALTH

A/Prof Kelvin Kong is lobbying for a national approach to monitoring ear health to understand the burden of ear disease. The gap in ear health outcomes is not well-known – the studies include the Kalgoorlie longitudinal study (1999-2005, Jacoby 2011), the GP consultation data (1998-2006) and the data from our group in the Territory (2001 to 2013 population level data from 15 remote communities) that shows us what is happening in Aboriginal children, but not the non-Aboriginal population. More recent data comes from our randomised control trials in five of the largest Top End communities, including one in Western Australia (2011-2017 RCT in 5 remote communities in the NT and WA). Further, work will come out on urban Aboriginal and Torres Strait Islander children with the WATCH Trial extension, which aims to understand whether you use watchful waiting or use antibiotics for children with bulging eardrums. The INFLATE trial is for children with otitis media with effusion, to see if blowing up the balloon with the nose can open up the Eustachian tube and improve hearing. And the Perth suburban study of OM perspectives is setting up a Birth cohort, so we should learn some more about what is happening in urban Aboriginal children.

The Kalgoorlie study from Lehmann (2008b) investigates the age-specific prevalence of otitis media in Aboriginal and non-Aboriginal children on routine examination by ENT specialists (Figure 13, over page). This shows that the gap, which indicates a significantly higher prevalence of ear disease, starts at one month and continues until nearly 2 years of age. Hasantha Gunasekera et al.'s (2007) study looked at GP presentations across Australia, and 2% of those problems identified by GPs were of Indigenous patients. Ear problems were the 4th most common, and Indigenous children had significantly more chronic suppurative otitis media. They were not getting more oral antibiotics or ENT or audiology referral, which identified a discordance between the problem and the way it was being managed. Obviously, identifying across the country a need for evidence-based practice.

Data on the prevalence of middle ear perforations was published in 2005, using data from 2001 when we went to 29 communities across the Northern Territory. The baseline data for this study was published by Morris et al. (2005) which showed that

77% of eligible children in the communities were examined. Twenty-six communities had prevalence rates of middle ear perforation above 10%, 16 communities above 20% and the mean was 24%, significantly higher than the 4% which the World Health Organisation identifies as a massive public health problem. There is a lot of variation and it is almost impossible to pick any trends - whether it is regional, or the size of community. In the 1970s, the Trachoma survey identified 18%, and here we have 24% in 2001. So it has got worse, not better.

When we had funding to do extra surveillance across the Northern Territory, we tracked whether any change has occurred – the data showed 24% in 2001, when 709 children were seen. In 2003, it was slightly down and in 2011, quite a dip. However, more recently, no further improvement. For suppurative otitis media, bulging or perforated eardrums, this is observed in around 40% of these children, at an average age of about 18 months. Otitis media with effusion is similar, perhaps a little bit higher, and persistent across that time period. Sadly, less than 10% are “normal”.

We have longitudinal data from four large Top End communities, funded by a vaccine trial. The data suggests that at one month of age and two months of age, there is a very high proportion of kids with OME. By four months (when we use otoscopy and

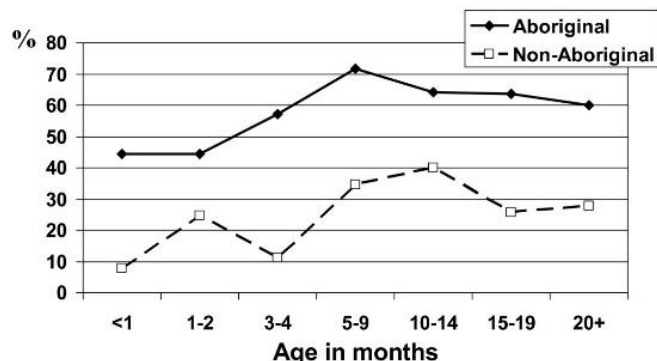


Figure 13: Age-specific prevalence of OM in Aboriginal and non-Aboriginal children on routine examination by ENT specialist. Source: Lehmann et al. (2008b).

tympanometry), you start to get the first perforations, and then six months of age, ongoing. So not one child goes through this period of early childhood with normal ears. What about the hearing impairment associated with these clinical diagnoses? We have research audiologists funded because the normal referral pathways were not meeting the frequency of assessment that we needed for an RCT. Here we have the children with clinically normal hearing (with 15 dB chosen as the threshold). So even with normal ears, quite a lot of children with possibly mild hearing loss, and some moderate. There is a massive problem in these one to three-year-olds.

The portfolio of work of the NHMRC CRE in Ear and Hearing Health of Aboriginal and Torres Strait Islander children on the transition through the clinical diagnosis of otitis media, starting with normal. We are looking at the risk factors, and the health promotion to keep kids' ears normal, to use vaccines in the best way possible, and using Big Data. Indigenous capacity-building has been a big part of our program and we have been pretty successful and seen great highlight around that. The Soap Tree is a story about using medicinal plants for hygiene purposes to get that conversation going. The CRE has funded an update of the OME guideline. The OME guideline addresses 250 PICOT questions - population, intervention, comparison, outcome and timeline. There are eight OM diagnoses to be addressed. The population might include healthy children and prevention, or children with a particular diagnosis, or high or low risk. The interventions might be prevention in primary, secondary or tertiary - all the different treatment options that we have, and looking at all the comparisons. And the outcomes, we are most interested in hearing outcomes, quality of life, resolution of signs, adverse effects, and improvement, over short, medium, and long-term timelines. You can rapidly see how this matrix comes out to 250 questions. And this is now all in the app!

Most people will use the app to assist in diagnosis and education. But a lot of us are keen to dig right down into the size of the effect, the strength of the recommendation. The guidelines do have influence - the 2010 Guideline rolled out extensive training nationally and had a substantial impact on government strategies, frameworks and enquiries. For example, the Care for Kids Ears campaign, Deadly Ears Deadly Futures program, the West Australian Ear Health Strategy, South Australian Ear Framework, Parliamentary enquiries, AMA report card, Catching Dragonflies, and other reports and guidelines. Many of these refer back to what the guideline says we must be doing. It has been a very important document, and updating it is also very important. The evaluation of that particular guideline in 2013 showed that really it was struggling at that time. It was successful where the service had ear health as a particular focus. It required ongoing training and campaigns, due to high staff turnover. Leadership was what influenced the use of the guidelines. Families need support navigating the referral pathway and guidelines, and collaborative care models to deliver the best quality care.

The recommendations that came out of that report - there should be locally-based trainers in the service, and two levels of training. I think this is really important. GPs and others medically managing OM need help with training, and other staff to opportunistically screen and refer to the GP for

treatment, to relieve the pressure on primary health care, to make accurate diagnoses. In 2017, the Siggins Miller report suggested what the elements of a good training model for Indigenous ear health outreach services should be. While this is not really an evidence-based document, it was what the sector was suggesting was important. A series of short sessions, use new technologies, and be delivered face-to-face and web-based. It should be regularly supported by supervision in the workplace, including by visiting health professionals, contribution to that supervision and training, or supervision at a distance, which is what we have seen more of today. And, eventually, this should lead to recognition and certification and articulation within the VET sector, and possibly to university. Great ambitions and goals.

Where is the EVIDENCE: It's not just about ears

HEALTH: Ongoing high prevalence of OM among young children in remote communities.

EDUCATION: Poor NAPLAN results for NT Indigenous children

SCHOOL READINESS: High vulnerability (AEDC) at school entry for children with chronic OM

JUSTICE: Very high proportion of Indigenous prisoners have hearing loss

WORKFORCE: Rapid staff turnover. OM is complex and difficult to detect, diagnose, and manage.

Our response within the CRE was to fund the update of the guideline, using the GRADE approach, and now step 2, transition to an App. It has a lot more than a book could have in it, including a clinical section, a communicate section and a diagnosis section. It has language translations of things a general practitioner might need to talk to the family about, such as speech and language problems, hearing problems, cleaning, infection, it is all there. And we are currently developing this in five languages. Then, we need to evaluate that, with a survey that will go out to GPs.

HEARING FOR LEARNING INITIATIVE

Our next stage is around the Hearing for Learning Initiative, which will apply all of the Guideline material and the app, to help support local community members to be employed, trained and integrated, and to receive ongoing and continuing education. The Hearing for Learning Initiative is a stepped-wedge randomised trial. Community mentors and health professional champions will support the role of local employees - respecting their roles in the communities in which they work. Local community members are uniquely positioned with

positive health change potential. They have cultural knowledge, language, and they have confidence of the families, they have networks, they know who the child's carer is or carers are. They can network very well. So by supporting their professional development on country, we think we can do a lot more for ears.

We also have new technology, such as HearScreen, which could be used for school children in remote communities and is currently being evaluated by an Aboriginal research officer. HearScreen or HearTest is hearing screening or testing with a smart phone. Health facilitators can be very effective in health services. Video-otoscopy specifically performed by a healthcare facilitator and assessed asynchronously by a general practitioner had similar or better accuracy compared to face-to-face otoscopy. This is what we want to see, people in remote communities conducting video-otoscopy and tympanometry, possibly also HearScreen on a daily basis and to save precious time.

The Hearing for Learning Initiative is an innovative community-based service enhancement model to address the crisis in ear and hearing health, in Aboriginal children in the Northern Territory specifically. It is a phase 3 stepped-wedge cluster randomised trial.

Our funding partners are the Balnaves Foundation, NT Government and Federal Government. Neil Balnaves was the Chancellor for Charles Darwin University. He was a philanthropist with an interest in medicine, the arts and particularly for disadvantaged populations and Indigenous populations. So he was really keen to support this initiative.

We talk about addressing the crisis in ear and hearing health, but what crisis are we talking about? It is not just about ears. It is about health, education, poor NAPLAN results, high vulnerability on entering school, even before entering school children are struggling. We have heard about data from prisoners, with a very high proportion of those men having hearing loss. And the workforce crisis - rapid health staff turnover, and dealing with the complexity of diagnosis, the time needed, and getting correct management. So it's not easy, it's complex, but we think we can do it. The NAPLAN reading results for Indigenous children in the Northern Territory is pretty poor.

In a study from Western Australia (Bell et al. 2016) of 22,000 children, developmental vulnerability on school entry, or the AEDC index, was found to be about 30% higher for children with chronic otitis media or respiratory disease. They found that of all of the chronic diseases that led to vulnerability, otitis media was 70% of that risk. This is in an Aboriginal and non-Aboriginal population, showing that chronic OM definitely has an impact on their

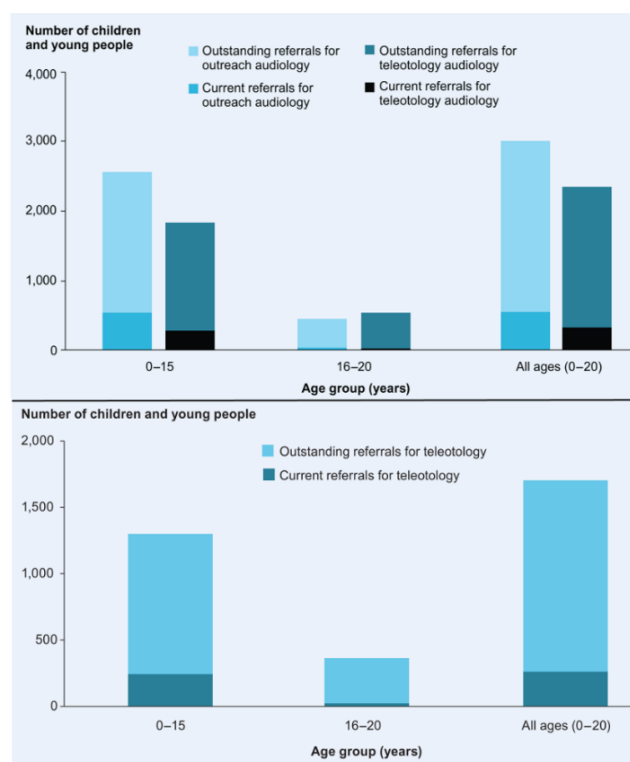


Figure 14: Outstanding and Current referrals for audiology (top) and teleotology (bottom), as at December 2017. Source: Australian Institute of Health and Welfare, 2018.

trajectory. Children with chronic OM are entering school already behind.

A paper from Canada (Brownlie et al. 2004) describes the link between language impairment in young males and aggressive behaviour. It is not about otitis media, but we can make some links between otitis media and language impairment, which is then linked to delinquent behaviour and increased rates of arrests and convictions.

In **primary health care**, where our research nurses have made a diagnosis of AOM or a CSOM in infants enrolled in a vaccine trial over five years. Nurses made notes in medical records of nearly 2000 cases of AOM or CSOM, flagging the need for follow-up ear assessments by the primary health services. We found that only 13% of these cases were followed up within 7 to 10 days. Of those who had an OM at follow-up, only 50% received appropriate antibiotics. It is just showing again that primary healthcare is just not delivering for these kids.

Figure 14 shows data from the *Australian Institute of Health and Welfare*. Outstanding referrals from audiology and related services in Northern Territory, December of 2017, it has just been published. You can see there are over 2000 children on audiology waitlists, and also for ENT consultations.

What are the **workforce issues** we are trying to deal with in the Northern Territory? There is some

very interesting data on resident health workforce, related to turnover and retention (Russell et al. 2017). Using payroll data for 53 remote primary health care clinics, the results are clear that the stability is very low, with half the staff leaving within four months. The consequences of that was that it is costly to have these people flying in and out, sub-optimal continuity of care and compromised health outcomes broadly, and particularly with otitis media and ear care. So their recommendation was imperative to address adequate resourcing and evaluating staff models, which stabilise remote health care. There is so much that needs to be done. We need evidence to look at the ears, and the children, the families, and community. I would love to see every child being seen at every opportunity.

In August last year, the **Hearing for Learning Initiative** was launched in the Northern Territory by Chief Minister Michael Gunner, the Health Minister, Natasha Fyles, and Neil Balnaves, AO. The goal of the Hearing for Learning Initiative is to work with communities to establish reliable, sustainable, culturally appropriate services that ensure that every ear of every child is healthy and hearing every day. Over the 4-year HfLI evaluation period we aim to recruit 20 remote, rural or urban communities, 40 Ear and Hearing Clinical and Education Support Officers and 5000 children 0 to 16 year of age. The Hearing for Learning Initiative will fund employment, certificate II training in ear and hearing clinical and education skills, mentoring and

integration of community-based Ear and Hearing Clinical and Education Support Officers. It will also support communities and services to integrate the Ear and Hearing Clinical and Education Support Officers into current services to create reliable, sustainable, integrated, culturally appropriate clinical and education services for Aboriginal and Torres Strait Islander children who have ear and hearing problems.

The benefits for families are that the Ear and Hearing Clinical and Education Support Officer will provide safe, culturally appropriate, reliable and expert clinical and education services for children who have ear and hearing problems; explain how ear and hearing problems can affect their child's behaviour, listening, talking, playing and learning; explain how to detect, treat and manage ear and hearing problems; and link the family with services to get the best help from the clinic, specialists and school. Importantly, it will complement the current ear health care model. It is not funded to replace primary health care services, FIFO visiting specialists, or any other services currently in place.



Figure 15: A/Prof Kelvin Kong and Prof Amanda Leach, Joint-Chairs of the Hearing for Learning Initiative.

Our purpose: we serve and engage the world through discovery, dissemination of knowledge and ideas, innovation and deep partnerships.

THE CHALLENGE

Otitis media is the main contributing factor to hearing loss among Australian Indigenous children. It is treatable and preventable.

Indigenous children experience otitis media and resultant hearing loss earlier, more persistently and more severely than non-Indigenous children. This has life-long impacts on education and employment opportunities, increasing the risk of incarceration within the criminal justice system. Aboriginal self-determination and the principal of justice should be the foundation for designing & implementing culturally-appropriate services to **close the gap** between Aboriginal and non-Aboriginal people.

CSOM: a “massive public health problem”



Otitis media - characterised by a **younger age** at first episode, **higher frequency** of infection, **greater severity** and **greater persistence** than in non-Indigenous children.

Equipment provision & training programs need greater visibility



These programs upskill primary health & Aboriginal health workers to use screening equipment in order to detect ear problems and refer where appropriate.

High rates of incarceration & hearing loss



Indigenous people make up 27% of the Australian prison population, costing about \$3.9 billion / year. An NT study showed that about 94% have significant hearing loss.

Surgical support reduces waiting times but barriers exist in training & access to experts



However, mixed success in coordinating access to tertiary care (i.e. surgery), due to systemic barriers consistently identified in some States.

Lack of a cross-sectorial approach



A public health approach is needed to reduce CSOM and its consequences. In particular, to improve housing and infrastructure (reducing overcrowding), improve nutrition, hygiene and reduce passive smoking.

Higher burden of disease (AIHW)



Rates of HL burden in children aged 0–14 in 2011 was **12 times higher** than for non-Indigenous children. Burden of disease from otitis media in Indigenous children was **8.6 times higher**.

No national data



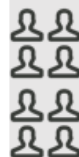
National data are lacking on the management and treatment of OM & other ear problems in primary health. We need to understand the **size and key determinants** associated with the hearing problem.

No national governance framework



Federal, state-based and community-based initiatives exist to address this public health problem. However, no governance structure nor cross-sectorial committee exists to align programs & oversee outcomes.

Insufficient reach for a national approach



The Healthy Ears - Better Hearing, Better Listening outreach program provides increased access to coordinated primary & secondary care. 106,087 patients have accessed an ear health service in 406 locations between 2014-17-greater reach is needed.

Telehealth not effectively used



To reach remote Indigenous communities, the systems and processes to facilitate telehealth from diagnosis to rehabilitative services need to be developed, implemented and evaluated to maximize uptake.

The solution is through a public health approach which includes:

1. **Defining the problem** through a systematic collection of information about the magnitude, extent, characteristics and impacts. Currently, we have no national data about otitis media, which will be an important step to understanding the scope of the problem and ways to address this;
2. **Identifying risk and protective factors** will enable the development of implementable and cost-effective solutions;
3. **Developing and testing prevention and intervention strategies and programs** that are cost-effective and culturally appropriate; and
4. **Ensuring widespread adoption** through a strong engagement, dissemination, and training approach that is embedded in the community.

The effects of these interventions need to be monitored, and the impacts and cost-effectiveness evaluated.

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