Hearing health and wellbeing in Australia

THURSDAY, 6 APRIL 2017

SYDNEY

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Members in attendance: Dr Freelander, Mr Georganas, Mr Zappia, Mr Zimmerman.

Terms of Reference for the Inquiry:

To inquire into and report on:

The significant percentage of Australians experiencing hearing loss and the related social and economic impact of hearing impairment to the long term health and wellbeing of Australia, with particular reference to:

1. The current causes and costs of hearing loss, and ear or balance disorder to the Australian health care system should existing arrangements remain in place;
2. Community awareness, information, education and promotion about hearing loss and health care;
3. Access to, and cost of services, which include hearing assessments, treatment and support, Auslan language services, and new hearing aid technology;
4. Current access, support and cost of hearing health care for vulnerable populations, including: culturally and linguistically diverse people, the elderly, Aboriginal and Torres Strait Islanders and people living in rural and regional areas;
5. Current demand and future need for hearing checks and screening, especially for children (12 years and younger) and older Australians at key life stages;
6. Access, availability and cost of required drugs, treatments and support for chronic ear and balance disorders sufferers;
7. Best practice and proposed innovative models of hearing health care to improve access, quality and affordability;
8. Developments in research into hearing loss, including: prevention, causes, treatment regimes, and potential new technologies;
9. Whether hearing health and wellbeing should be considered as the next National Health Priority for Australia; and
10. Any other relevant matter.
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Committee met at 08:40

CHAIR (Mr Zimmerman): Welcome. I declare open the public hearing and thank you for your attendance today. To assist members of the public, this room is fitted with a hearing loop, and the proceedings will also be translated into Auslan. In addition, the proceedings of the hearing are captioned and are available via a live, remote captioning stream. Before we begin can I ask a member of the committee to move that the media be allowed to film the proceedings today in accordance with the rules set down for committees, which include not interfering with committee proceedings and not taking footage or still images of members', committee staff members' and witnesses' papers or laptop screens.

Mr ZAPPIA: I so move.

CHAIR: It is moved, so that is carried. Dr Brown, before we begin, do you have any objection to being recorded by the media during your participation in this hearing?

Dr Brown: No, I do not.

CHAIR: These hearings are formal proceedings of the parliament. Giving false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence you give today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make a short opening statement that goes to your submission?

Dr Brown: First off I just wanted to thank very much the committee for giving me the opportunity to be a witness today. By way of introduction, I am a cochlear and vestibular physiologist, which means I am a laboratory researcher. There are essentially two issues I want to discuss today, the first of which relates to what I can see is a need or opportunity for Australia to make great inroads through improving the diagnosis of dizzy patients in firstline healthcare centres, particularly the emergency department. It is here where I think that significant financial and social burden can be alleviated through the use of newly developed vestibular testing that has been developed in Australia.

The second issue I want to discuss relates to drawing attention to the fact that we have seen a steady decline in the number of people performing basic hearing research in Australia. By basic I mean essentially researchers that are exploring the fundamentals of hearing, the cause of hearing loss and are trying to develop new therapeutic or medical devices to improve hearing. As an endpoint to both of these issues I would strongly support making hearing health and wellbeing a national research priority. I also suggest that balance health be incorporated within that umbrella research priority as well, given the large overlap between hearing and balance disorders.

Dr FREELANDER: Thanks very much for coming and giving us the benefit of your research. Certainly it is an important area. Is there evidence that this is an increasing problem as our population is ageing?

Dr Brown: Certainly as our population is ageing both hearing and balance disorders and the social and financial costs of those disorders is increasing. Particularly with balance disorders, the incidence increases quite significantly with age.

For patients who are admitted to the emergency department, one of the key things to do is to try to understand whether their dizziness is caused by a peripheral or a central disorder. The key issue there is that, if it is a central disorder, there is a risk that it could be due to a cerebrovascular issue like a stroke, which can potentially have life-threatening consequences.

The elderly patients admitted to the emergency department with dizziness are often sent off for imaging, and it is often the case that the imaging could have been supplanted by bedside tests, by studying the vestibular system through monitoring eye movements. That would have prevented the patient from going off to imaging, it would have given a more accurate diagnosis and it would have alleviated some of the financial burden of the imaging.

Dr FREELANDER: Have you thought about the pathways to vestibular assessment that we could do on a population basis?

Dr Brown: Certainly. There have been several publications by top-level researchers who have accurately assessed the steps and processes that we should be taking when diagnosing dizzy patients. There are now guidelines in emergency departments for assessing patients. There is a particular guideline for dizzy patients which has been given the acronym 'HINDS', which essentially involves a head impulse test, which is a test of the vestibular system; nystagmus, which means rapid movements of the eyes, either spontaneously or upon gazing in a particular direction; and then deviation of skew. Those three simple diagnostic tests or measurements can give the first-line practitioner an indication of where the dizziness may be originating from.
Dr FREELANDER: Would you think that there is any role for the National Acoustic Laboratories, for example, in these sorts of assessments?

Dr Brown: One of the issues that I want to raise today is the fact that there is an increasing movement, at least for hearing research, towards clinical research. That has been improving the hearing services in Australia for the last 15 years. It is an extremely important thing to do. Hearing problems are obviously a significant burden to the Australian public. Hearing research now is primarily done on people, and by that I mean human subjects, so we are performing research on people and we are using that data to better inform hearing practice.

The same is not necessarily true of vestibular research yet, but that is why I advocate that there should be the same level of commitment towards improving clinical research for vestibular disorders as there currently is for hearing disorders. That is where I think institutions like the National Acoustic Laboratories could come into play, because we are talking about the development of vestibular devices. NAL have unique experience in developing such medical devices.

Mr ZAPPIA: I want to pursue the issue of the researchers themselves. In your submission you talk about the dwindling number of researchers. Firstly, what do you attribute the dwindling numbers to? Secondly, you talked about the figure of 13 that came together the last time you had a conference. I take it that was from across Australia?

Dr Brown: Yes. In terms of the reason for the decline, I think that is primarily driven by a push for students to be taken up into the clinical research side of things. What I am talking about here is that basic laboratory researchers in Australia are decreasing. Australia did have, 30 years ago, some of the world's best auditory physiologists and auditory neuroscientists, and that led to things like the invention of the cochlear implant and an improved understanding of how the cochlea works. The professors that were at the forefront of cochlear research and basic science back then have now reached retirement age and they simply have not been supplanted by mid-career researchers, primarily because there has been a push—not specific to hearing but an overall push—from basic laboratory research through towards translational clinical research, or research which then gets translated into clinical practice. So that is where I think the bulk of students wanting to get into research have been taken up to.

Students who are interested in frontline laboratory research for hearing are now driven towards going overseas once they have finished their PhDs, and we have seen a lot of that in the last five years. We are now producing a lot of PhD candidates who are no longer staying in Australia and developing their careers. They are actually moving overseas. Part of that is actually the nature of research. Most students are encouraged to go overseas for the postdoctoral part of their career once they have first finished their PhDs—and certainly that is what I did—but fewer and fewer of them are returning to Australia because the opportunities for laboratory hearing research overseas is much, much higher.

Mr ZAPPIA: Who is responsible for those opportunities? Is that a government thing? Is it the universities themselves? I am just trying to get my head around it.

Dr Brown: I think that it is the universities, but it also comes from the resources and the institutions that the universities are aligned with. Over the last 15 or 20 years we have obviously had the development of audiology courses through Australia, and that has improved the diagnosis of hearing problems. It has also meant that there is an increasing trend towards audiological research in Australia, so students coming through now see the wealth of research that has been performed in the clinical field and—this is my own subjective opinion—they get this impression that that is where their careers lie, so that is where their attention is taken towards. They also see the dwindling numbers of professors who are around studying basic auditory science in Australia. They see that as a potentially futile career, so that is why they are starting to trend towards more clinical-based research.

Mr ZAPPIA: Lastly, I want to talk about the issue of the cost to society for people who suffer from an imbalance problem. You talk about it. Has anyone ever done any research to try to quantify what that cost is?

Dr Brown: Certainly in the United States they have. We now know that, at least for the emergency departments in America, the cost of diagnosing dizzy patients in emergency departments is close to $10 billion. That cost is largely due to the increased numbers of patients being sent off for imaging, so most of that $10 billion cost associated with diagnosing dizzy patients in the United States, at least, is associated with imaging. They have estimated that that cost can be brought down by at least $1 billion with the use of bedside vestibular testing.

We do not have the same numbers in Australia, but we can rely on the fact that we have a similar incidence of vertigo or dizziness in emergency departments. About four per cent of all emergency department attendees or admissions have dizziness. Drawing from the costs of our emergency departments in Australia, I have essentially rationalised that, in Australia, our emergency departments cost for dizzy patients is around about $143 million per
year and that we could potentially save between $14 million to $22 million per year by developing or instituting these bedside vestibular tests into emergency departments. I think that is probably why most neurologists and neurotologists have advocated that this is a potential area that we should be addressing.

**Mr ZAPPIA:** Thank you.

**CHAIR:** Can I just follow-up that question and some of your earlier answers. Can you just explain, for the non-medical amongst us, what bedside vestibular testing involves and why there appears to be some reluctance within the system to adopt what you are recommending?

**Dr Brown:** In the last 10 years Professor Michael Halmagyi and Professor Ian Curthoys developed the head impulse test. The head impulse test is a fantastic vestibular test. It involves monitoring the position of the eyes relative to the head whilst performing a very rapid or rotatory acceleration of the head—so a little head turn. On the basis of that you can determine whether or not a patient's dizziness is peripheral or central in many cases. Neurologists have been doing this technique for many decades, except they used to just rely on standing in front of a patient and looking at it with their own eyes.

**Dr FREELANDER:** Can you just explain what you mean by central or peripheral?

**Dr Brown:** Dizziness can either be caused by a brain stem pathology like a lesion, a stroke or a vascular ischemia, or it can be related to a peripheral pathology like a viral infection of the inner ear, vestibular neuritis, viral labyrinthitis, or many other diseases like Meniere's disease and benign paroxysmal positional vertigo. These are all acute syndromes that cause a sudden onset of rotational severe vertigo in patients. As far as the patient is concerned, the vertigo is very similar whether it is a central cause or a peripheral cause. They will come to the emergency department just being flat out dizzy, and it is up to the neurologist, when the patient is eventually routed to the neurologist, to assess the cause of that vertigo so that the patient can begin the correct treatment. A neurologist will have developed all of these techniques through their research of looking at the eye movements relative to the head and using the vestibulo-ocular reflex as a measure of determining whether the cause of the balance dysfunction or disturbance is in the brain or in the ear.

Over the last 10 years Australia has developed video head impulse goggles or video goggles that can be attached to the head. They are very cheap at one level to produce and they provide a very effective and much more accurate measure of the vestibulo-ocular reflex that anybody can perform. Now, these bedside vestibular tests that used to be performed by a specialised neurologist can be performed by nurses and much less specialised practitioners essentially because there are now devices. In many cases, there are research laboratories around the world that are using iPhones to capture at least nystagmus in many sufferers. We are starting to see technology being developed now to the stage where it can surpass what neurologists used to be used for, and that technology can certainly be used in emergency departments. There have been studies demonstrating that that technology can be used in emergency departments. There is actually a phase 2 trial underway at the moment in America, where they are using these video head impulse goggles in emergency departments and they are assessing the benefits of using those devices in their emergency departments.

**CHAIR:** But they are not using those anywhere in Australia at the moment?

**Dr Brown:** Not in Australia, even though they were developed in Australia. Royal Prince Alfred Hospital might be using them for some research aspects, but they are yet to be rolled out across Australia. That is partly because of the natural slow uptake of new technologies. It is also partly because there is an ongoing feeling that if you do not send patients off for CT or MRI imaging there is a risk that you might miss a stroke patient. That has now been demonstrated not to be the case; it has been demonstrated that video goggles actually provide a much more accurate diagnosis of central lesions than MRI or CT scanning can provide.

**CHAIR:** Your comments in relation to the research effort in Australia—is that a trend that is happening internationally as well, or are there countries where there has actually been an increase in research that you would regard as exemplar models?

**Dr Brown:** I cannot speak to that. My subjective opinion is that overseas they still have a fairly good basis for an uptake of students going into basic frontline hearing research.

**CHAIR:** In relation to balance disorders and the different causes, how often are they related to hearing loss?

**Dr Brown:** That is a somewhat difficult question to answer. We know that of people with chronic balance disorders about one-third of them will have an associated hearing symptom. I cannot give you an answer about the number of patients with a chronic hearing disorder that have a similar balance disorder. There is a reason for that: essentially, the vestibular system is fantastic at adapting over time. Many people will have a vestibular deficit and not actually be aware of it because centrally we adapt. The vestibular brain stem is fantastic at adapting to any peripheral loss. So people with hearing loss that might have an underlying vestibular deficit will
often not be aware of that vestibular deficit. It is only when we see chronic balance patients where they have acute episodes of vestibular loss that we can demonstrate that they are people who have certain vestibular problems, and we can then assess in those people the number that have hearing problems. It is about one-third.

CHAIR: I suppose the issue for us as a committee is that obviously our terms of reference are very specifically in relation to hearing loss. Your submission, to some degree, is a plea for balance disorders not to be forgotten in the mix.

Dr Brown: Yes.

CHAIR: In terms of our terms of reference and the recommendations, where do you see the interaction and linkages?

Dr Brown: If you were to ask most hearing practitioners how many of their patients they see that have balance problems, they would say that the number is quite high. I cannot give you an exact number, but very clearly all of the balance patients that are seen through various emergency departments, neurologists and ENTs—those practitioners work very strongly with hearing practitioners. Most balance patients will be seen by both hearing specialists and balance specialists. I have been involved in training audiologists through masters courses in Australia, and we spend a large portion of time educating them about vestibular disorders, specifically because we are aware that they certainly will see a high percentage of patients with balance disorders. Obviously, it is not just the fact that they will be looking at patients with dizziness; they will also have to understand the anatomy of the inner ear. The inner ear houses both the cochlear and the vestibular organ, and pathologies that affect the inner ear tend to affect both hearing and balance.

Dr FREELANDER: Have you had any direction with the ENT surgeons regarding research into Meniere's and other balance disorders?

Dr Brown: Yes, absolutely. I work very closely with a couple of ENT surgeons. It has been a real struggle to get ENT surgeons to adopt basic research. There are a couple out there that are certainly willing to work with basic researchers. I happen to work with them, so I am very lucky in that regard. There is a philanthropic body called the Garnett Passe and Rodney Williams Memorial Foundation Australia, which is essentially a foundation that funds otolaryngology research, and they have been doing this in Australia for many years. They have, in recent times, come to the conclusion that they need to be supporting particularly clinicians to have uptake research in Australia, not just supporting basic researchers. So there is a push for the surgeons and ENT practitioners to take up basic research and work very closely with basic researchers as well.

Dr FREELANDER: Are there any specific centres of excellence for ENT research into these areas that you are aware of?

Dr Brown: No, there is not—not like there is for hearing research.

Dr FREELANDER: Are there better treatments for Meniere's these days?

Dr Brown: For Meniere's, there are many treatment options. One of the problems with Meniere's disease, like other balance disorders, is that the symptoms wax and wane. So any treatments or clinical trial often has a large difficulty in assessing whether or not the treatment was effective or the symptoms would have naturally abated anyway. So clinical trials for either pharmaceuticals or medical therapy interventions have to assess diseases like Meniere's over a long period of time and against an appropriate placebo. Most clinical trials of treatment of Meniere's disease that have incorporated a placebo have found similar rates of improvement. That highlights two things: Meniere's disease is just a really difficult disease to assess treatments in, but it also demonstrates that stress and self-perception of the disease are large triggers for the disease itself. That is simply because, if a patient believes that they are getting help, their stress levels reduce and the symptoms of the disease often reduce as well.

CHAIR: Thank you for your time today, Dr Brown. It has been very useful. Today's proceedings have been recorded by Hansard, so a transcript of your evidence will be available. If there are any errors in that transcript, notify the secretariat staff as quickly as possible. We thank you for appearing before the committee this morning.

Dr Brown: Thank you.
LEIGH, Professor Gregory, Chair, Australasian Newborn Hearing Screening Committee
POULAKIS, Dr Zeffie, Secretary, Australasian Newborn Hearing Screening Committee

[09:05]

CHAIR: Do you have any objection to being recorded by the media during your evidence this morning?

Prof. Leigh: No.

CHAIR: These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make an opening statement that goes to your submission?

Prof. Leigh: Put quite simply, we believe that Australia enjoys a position as a world leader in delivery of services for children with hearing loss, particularly children with congenital hearing loss. That is evident across a wide range of services, but, from our perspective, that is particularly evident in regard to the early identification of hearing loss; the provision of really high quality and routinely and freely available hearing services—including, importantly, technologies, whether they be hearing aids or cochlear implants; and the quality and availability of early intervention services. Across all of these areas, we believe that Australia has achieved standards that are, without doubt, at the forefront of international best practice, and we are very proud of that, as we believe we should be as a country.

Currently, in the area that we represent, certainly more than 95 per cent of all children born in Australia are now screened for hearing loss at birth. We wish we could put our hands on our hearts and say that we know exactly what that percentage is, but, as our submission has indicated, we are currently very poor at maintaining that data and overseeing that data on a national basis. My colleague, Dr Poulakis, is the co-director of the Victorian Infant Hearing Screening Program, where we can say, with confidence, that more than 99 per cent of all children receive a screening for hearing at birth. We just cannot make those judgements nationally because of the lack of available data.

One of the points that we want to make this morning is that children identified through these types of programs will typically go on to engage with technologies and then with early intervention services in time frames that are minimised by the quality and the connectedness of the services that we have in place in Australia. From international evidence, and, indeed, from the quality evidence from the long-term outcomes for children with hearing impairments study here in Australia, we know that timeliness matters. Even small delays, measured in months—weeks even—can be represented in long-term delays to language and communication development that go on into childhood and potentially into adulthood. Time matters in this context. That is the important message that we want to deliver to this inquiry this morning: that, when it comes to the provision of hearing services to children who are born with hearing loss, the availability of services, the accessibility and quality of those services and, most importantly, the timeliness of those services are absolutely paramount. In regard to all three of those aspects, the Australasian Newborn Hearing Screening Committee holds, I would say, grave concerns for the future of hearing services in Australia in regard to our capability of maintaining that timeliness as we move into a new framework of contestability and changed frameworks for referral pathways for children with hearing loss.

As an aside, and I will be very brief, Dr Poulakis and I are part of the planning program for what will be the ninth Australasian Newborn Hearing Screening Conference, in Melbourne, in May. At the last biennial conference, in Sydney, we hosted Professor Christie Yoshinaga-Itano as our keynote speaker. Professor Yoshinaga-Itano is one of the world-recognised pioneers of newborn hearing screening and a world recognised leader in the field of early intervention. And at the time, she, in her speech in fact to our conference, was openly in awe at the quality of services we have in Australia, particularly in regard to the connectedness and the timeliness with which we are able to deliver on those outcomes. Quite simply, when she was told about the then quite nascent plans for the transition of the Hearing Services Program out of Australian Hearing and into full contestability, privately, and publicly to a certain extent, she told us:

Why would you want to mess with a system that is the envy of the world and trade it is something that has proved to fail elsewhere?

I would be happy to come back to that point.

We are not here this morning to argue that the system does not need improvement. Indeed, our submission goes to very definite areas where we feel there are urgent needs to improve systems for data collection, data management and oversight of programs. But we are here this morning to say that we very definitely feel we are at a point where, after 70 years of unmitigated improvement in the quality of hearing services, unless we do
everything we can now to put a floor under things and make sure we only continue to improve, we are at risk of going backwards on some fronts; and the front we are most concerned about is the timeliness of service engagement for children who come out of the programs that we represent. I know that was a long preamble.

CHAIR: It was not too long at all.

Prof. Leigh: I will be delighted to take questions on our submission and indeed to canvass some of those other broader issues that we think are so important.

CHAIR: Are the statistics that you refer to about 95 per cent screening effectively a 'best guess' in the absence of the comprehensive data sets that you recommend should be maintained?

Prof. Leigh: It is really a matter of privileged information because on our committee we have the coordinators of all the state programs who report to us the data that is not publicly reported.

CHAIR: So can you typify the approximately five per cent that you believe are not being tested? What cohorts of the community are escaping the system—if I can put it that way?

Dr Poulakis: It is likely to be children or infants who are born in hospitals that are more remote or further geographically away from where screening services are based; that would be one group of children that would be disadvantaged. Infants where their families might be choosing to not have any form of health intervention may also decline the hearing screen as part of their not wanting to have any intervention at all. It will be infants that are born in hospitals that are more remote or infants that are born at home, who are less easy to capture when they are not actually in a hospital setting. It will be families where English is not their first language so accessing services is already difficult for them. There are a number of sociodemographic issues that explain why that five per cent may not access a hearing screen.

CHAIR: In summary, it is people in remote locations, infants born outside the hospital system and infants whose parents decline to get testing. Is that a reasonable summary?

Dr Poulakis: Yes.

CHAIR: In your submission you obviously refer to the need for ongoing testing. You make the comment that in some states children are receiving a hearing screening in pre-primary school years. Which states are currently undertaking that testing?

Dr Poulakis: I know it is not happening in Victoria where I am from. I believe it is happening in New South Wales.

Prof. Leigh: It is happening to a limited extent but no longer in New South Wales. I believe it is in Queensland but, again, we are not privy to those issues. In some states, the programs were wound back following newborn hearing screening, which we think was a regressive step.

CHAIR: My third question goes to the heart of the issue that you raise in relation to contestability. I assume your default or starting position is that you believe that the current system should be maintained. But if the move to contestability continues to proceed, what would be your recommendation as to how you create a contestable environment that does not reduce the quality of services being provided to infants and young people?

Prof. Leigh: There are several aspects to answering that, and you are right—we come from the position of saying that the system is not broken and we do not think it particularly needs fixing. I will go to what, perhaps, would otherwise have been my last point: we cannot see how the contestable system works in a country as demographically diverse as Australia without some requirement of obligation on at least some, if not a central service provider.

The international experience that we have in this context is, for example, when the National Health Service in the UK made hearing services for children contestable, we saw a very rapid move to large-scale hearing service providers—in that case, Boots pharmacies and Specsavers—coming into that market and, in the relatively short term, one of those providers stepping back from that provision, leaving market failure in a number of areas. In the absence of an obligation on a service provider, it left a market failure and a gap in the system. We are assured by the National Disability Insurance Agency that those sorts of gaps under a contestable service will be rectified, because it is their job to rectify that. But if you go back to the issue of timeliness, any absence of service availability in the framework that we currently have represents a lack of timeliness, which represents a long-term outcome for a child with hearing loss. It is the equivalent, we would say, of having an ambulance at the bottom of a hill rather than a fence at the top.

Under the NDIA's requirements for the transition of hearing services out of the Hearing Services Program and into the NDIA, we were told, for example, that by the first half of 2016, we would have a new paediatric referral pathway and data collection mechanism in place. It is now almost the middle of 2017, and were still do not have
the results of those outcomes. We are moving to changing a system without having all of those things assured. I honestly believe that, in the absence of that obligation on a service provider, we will see failure, and that failure will be in rural and remote locations. It will be in areas where it is less possible to provide a service in a commercially and economically viable way for someone who is in the market for what are, essentially, commercial reasons. At the moment, that concerns us in regard to the centrality of Australian Hearing as a referral link in the chain. Children come out of diagnostic audiology and are referred to Australian Hearing, where we have uniform standards of capability and uniform capabilities in terms of resources and, importantly, a geographic spread of those capabilities. What we need to see is evidence that those things—service standards and ability on the ground to deliver—can be replicated in a contestable market, which, at the moment, we are not terribly reassured by in the transition process.

**CHAIR:** I suppose the follow-up question to that is: are there other conditions that are identified at birth or in the early years of a child's life where there is not a central referral point like Australian Hearing, where contestability is, effectively, already in place and where there are either gaps or where you believe it works? The second question is: if we are looking at environments where contestability has been introduced, would you say the UK is the most relevant for us to look at?

**Prof. Leigh:** I will answer the first question first, and perhaps we can both comment on the second. We are in a situation in Australia with hearing loss where we have had the gold standard in managing a particular condition. I work for an organisation that has a similar interest in vision impairment, and we are now into our fifth or sixth year of trying to establish a national register for childhood vision impairment to give us anything like the quality of data and awareness of the condition that we have in regard to infant hearing loss. We currently have less than 25 per cent accountability for children with significant vision impairment in Australia. We have, sitting on the table right now, with the available database and the available system for intervention in newborn hearing issues, a world-leading quality of data availability, which, again, we see as being at great risk as we move into a contestable service where there is no obligation on providers to provide data into a central repository. Right now, Australian Hearing holds data on pretty much every child with hearing loss identified in Australia. It has given us the capability of planning services; it has given us the capability of research. I cannot think of another childhood disability where we have that quality of data. As to whether the UK is the right place to look to, it probably is not the best, but it is one of the ones where we can look to see what happens with a move from a publicly required service to a fully contestable service.

If I may be permitted one other digression, in the United States they have never had public funding overall at a federal level for the sorts of services we are talking about, and without even making public funding contestable. We talk in Australia about having a rate of loss to follow-up from screening through to diagnostic audiology—in Victoria less than two per cent of children get lost in that system. The best evidence we can find in the United States is that the state that claims country leadership in the United States has 11 per cent of children lost to follow-up. In states like Louisiana, 32 per cent of children on average are lost to follow-up. Massachusetts claims that roughly one-quarter of all children get lost between screening and intervention through early intervention. We have the data capability in Australia to track all of that at the moment. We need better data capability, but maintaining that data in a contested service system and being sure that we can put our hands on our hearts and know that we are achieving the outcomes that we want to achieve through public funding of programs like newborn hearing screening is going to be a very difficult process. It is another of the targets for the transition for the NDIA hearing services program that was set for the first half of 2016, and we have yet to see any evidence on how that data management process is going to happen.

**CHAIR:** You might like to take this on notice. If you have any of that comparative international data about the loss to follow-up in more detail, that is very germane to this issue. So, if you are able to provide that to the committee in due course, that would be very useful.

**Prof. Leigh:** Certainly.

**Mr GEORGANAS:** Going back to the five per cent that are missed, some of the reasons were rural and regional areas, parents not wanting any intervention, non-English-speaking backgrounds et cetera. What could we put in place to ensure that we capture a big proportion of that five per cent? Is there anything that we are doing incorrectly? Parents not wanting intervention is pretty black and white, but, for example, non-English speaking backgrounds is something that you would think we would be dealing with in this day and age.

**Dr Poulakis:** I can certainly speak to the experience in Victoria. The background is that all the newborn hearing screening programs are state funded, so there is state government funding that underpins each of the programs. They do run entirely independently of each other and have different funding models and different service delivery models. In Victoria, we have the advantage of not having a large geographical space to cover, so
we do acknowledge that advantage, but one of the things that you can do is ensure that you have people on the ground who are responsible for delivering a service in a particular geographic area. When you have people who have an obligation—once again coming back to that term—to provide a service and account for the service that is being provided in a geographic area, then you have an impetus and a responsibility to provide that service. So we have done things like provide information in languages other than English, engage with interpreter services at local hospitals or via telephone where local interpreters are not available, and ensure that there are outpatient clinics that are operating at geographically accessible locations for families when returning to the hospital where the baby was delivered is not really an option for them. So there are a number of practical steps that can be taken. Links with the maternal and child health services that operate in each state and territory are also really integral, as are very good links with the audiologic services so that we do not let families fall through gaps purely because no one is following up. But that really is about having obligations and staff who have that as a responsibility and ensuring that you are resourcing your programs to do exactly that.

Mr GEORGANAS: So the most important thing would be to have people on the ground?

Dr Poulakis: Absolutely.

Mr GEORGANAS: More people on the ground would cover a big proportion of that five per cent.

Dr Poulakis: And people on the ground geographically who know what is going on in that region or that population or that community. If we Indigenous populations, there must be links with community workers and health workers who work with those populations directly so that there is actually a whole network of people making sure that a child's hearing health is being looked after as well as the rest of their health.

Mr ZAPPIA: Professor Leigh, I want to ask if you could elaborate a little more with respect to your concerns about the contested services. Is that because of the transition to the NDIS or is it also because of the possibility of the privatisation of Australian Hearing?

Prof. Leigh: It is both, and the things have become conflated. If we were moving to a fully contestable service and Australian Hearing stayed privatised, many of the issues we are talking about would remain. I will come back to the experience in the UK. It is one thing to say that services are funded and that there is adequate funding for services to be available, but it is another thing to say that someone will pick up that funding and provide the service in all locations. Again, the experience in the UK is that some of the big providers decided that it was not economically viable or appropriate for them to be in those locations. Under a contested service arrangement, even with Australian Hearing still in the system, nobody in that system is obligated to provide those services in every location. We are not confident that they will be in every location.

But if Australian Hearing stays as a government funded provider and is made accountable for then there is an issue for the commercial viability of alternative service providers. We are in a cleft stick. We have looked variously at models that divide the country up on regions and make service providers obligated for certain areas et cetera, none of which—at least in my understanding or our perception—meet the sorts of service levels that we currently have in that space, but if that is where we are moving then we need to be looking seriously at that issue first and foremost: who is going to be obligated to provide those services? Having a system that says, 'We'll fix it when it breaks,' given what we know about the radical implications of delay in the service pathway that we currently have, is unacceptable. It is an unsustainable position to say, 'We'll fix it when it goes wrong.' We need to have it sorted before we move to that arrangement.

Dr FREELANDER: Thank you very much for coming today and for your terrific submission. I have had some of the service providers complain already about the NDIS funding model and delays between commencement of early intervention and funding. Has any thought been given to making severe congenital hearing loss an automatically fundable condition, where funding starts from day 1?

Prof. Leigh: Absolutely. I am talking outside the brief of the Australasian Newborn Hearing Screening Committee now, but the notion that there be what the NDIS refers to as reference packages seems to me to be an absolute given—that children who meet certain criteria with regard to the severity of their hearing loss, coming straight off the end of diagnostic audiology, should have access to a known package for immediate engagement with early intervention. That is one part of it.

The other part is that, as we move into a contestable arrangement for all of these services, the notion of timeliness at the moment is covered by the fact that there is a single obligated provider in and out in very quick time. If we are looking at what will necessarily be a period of shopping around and trying to understand what the service profile is, we are adding time into the process—time we quite literally do not have. So I am a strong personal advocate—it is not necessarily a position of the committee—for the notion that there be a guided referral pathway, that the NDIS be responsible for a system of putting a guide by the side of families in that circumstance.
to get them quickly through that process and that not be this, 'Go away and find who you might like to get your services from,' because, as desirable as that may be in terms of the principles of the NDIS, it adds time and slippage into the system.

**Dr FREELANDER:** And those parents are in a state of shock on day 1 anyway.

**Prof. Leigh:** Absolutely.

**Dr FREELANDER:** Secondly, do you see any defects in the function of the National Acoustic Laboratories now in the newborn assessment?

**Prof. Leigh:** NAL has been the overseer—and I should disclose here I am co-investigator on the long-term outcomes for children with hearing impairment study. That study has been a major contributor to our understanding of the efficacy of newborn hearing screening. The National Acoustics Laboratories has had a central role in that; notwithstanding, of course, that that is with funding from the cooperative research centre and the National Institutes of Health and co-investigators from other places. So I do not see any in our field, no. It has been a part of the rising tide that has lifted all of our boats in that area.

Your question does provide us with the opportunity to comment on another area in our submission, and that is: if we move to a fully contested service, if Australian Hearing is privatised, what becomes of that capability? Importantly, where does the national data management locus of control that we currently have end up? As I said, as someone who has been struggling for six years to try and assemble anything like the quality of data we have in hearing loss for a childhood condition like vision impairment I can tell you how hard it would be to get that back if it is lost. So, who is going to be the keeper of the data? Who is going to be the national centre?

We have advocated in our submission—the ANHSC submission—to the inquiry into hearing services under the NDIS for the development of a national demographic and research component. Whether that is now, in the future or somewhere else, we honestly believe it needs to be a government funded entity that is the keeper of the flame, if you like, for the quality of data and oversight that we have. It would be an international travesty to lose that. There is probably only one other country in the world that has anything like the quality of demographic data around hearing loss that we have, and that is Denmark. That is because they have this national approach to what they do.

**Dr FREELANDER:** Thirdly, has any thought been given to routine follow-up testing of otherwise normal children?

**Dr Poulakis:** Infants who passed their newborn hearing screen?

**Dr FREELANDER:** Yes.

**Dr Poulakis:** Yes, there are programs and protocols and procedures in every state and territory. They do differ somewhat between different jurisdictions. But, yes, the answer is that, depending on what sort of risk factors you might present with at birth or in the early years of life, you will be referred on to an audiologist for further testing because you are at a higher risk of having a hearing loss develop later in childhood.

**Dr FREELANDER:** What about those who are not high risk? Is there any recommendation or thoughts of a repeat?

**Dr Poulakis:** That is where there are conversations happening at the moment for those children who passed their hearing screen, do not have a risk factor for hearing loss and who may have a hearing loss that is as yet undetected—that there might be room in our system to provide for preschool or upon-school-entry hearing screening at that time.

**Mr GEORGANAS:** Could I just follow on from that question. Entry at school and—what was the other one?

**Dr Poulakis:** Or preschool—four years old.

**Mr GEORGANAS:** Is that because it is a good place to capture them all, or is it a particular age that you are looking at?

**Dr Poulakis:** There are a number of reasons. Some of them are really epidemiological, meaning that by that age a number of children will have developed a permanent hearing loss, so that is a good time to try and catch them. So, it is a clinical reason. The other one is really because of being able to catch a large group of children in fewer places rather than having to visit them in many places. That is why we do newborn hearing screening in hospitals; we can capture a lot of infants at that one spot. So, it is for convenience and efficacy.

**Prof. Leigh:** It is worth pointing out that data that we have available through Australian Hearing show that there are currently two paediatric peaks for identification of hearing loss: not surprisingly one of them is in the first year of life, and we have been magnificently successful in achieving that, and the other one occurs just
around school-entry or preschool-entry age. We think that is, in all likelihood, as Zeffie has just said, representative of the fact that hearing losses that have been acquired or have developed during that period of time become evident then because that is when kids are coming in to interface with demands on their communication systems that mean that their hearing loss becomes more evident. But it does present as a logical point to be assessing that as well. We have a panel devoted to the question of preschool screening at our forthcoming conference in May to canvas that issue in much more detail.

**Dr FREELANDER:** I just have one last question. How long has your dataset been running now?

**Dr Poulakis:** The one in Victoria, specifically?

**Dr FREELANDER:** Overall.

**Dr Poulakis:** I can only speak for the Victorian one, because that is the one I am responsible for. We have been collecting data since the onset of universal newborn hearing screening in Victoria, which occurred in 2005. We have been collecting data and have a dataset that has been going for 12 years now.

**Prof. Leigh:** Nationally, Australian Hearing every year publishes their demographic data on children and youth. Certainly, I am aware of that being made available for at least the last 30 years and I suspect it goes right back to the development of the original National Acoustic Laboratories system. I absolutely applaud the data collection processes that are in Victoria, and the program that Zeffie oversees. Each state has a very different approach to data collection. The quality of the data that is collected around newborn hearing screening differs markedly state by state. For example, in the state we are sitting in right now there is no electronic database collection of newborn hearing screening data; it is reported ad hoc on other bases.

We would direct the members' attention back to our submission and the chronic need for us to be able to apply the standards that the Australian Institute of Health and Welfare have already documented and to require states to not only respond to those seven indicators but also to be in a position where each state can respond to that by having effective data management systems. Frankly, some of them at the moment—while not impugning the quality of the programs, the quality of reporting on outcomes from the programs differs markedly. If we are taking some aspects of the floor out—we hope not, but if we are—with taking out the data management system that Australian Hearing currently has, then we are going to have to look to other systems of data collection, and we want to make sure all of those are absolutely effective.

**Dr FREELANDER:** We will be getting submissions later on about Indigenous hearing health, but do you have any special recommendations for follow-up of the Indigenous population?

**Prof. Leigh:** Only to the extent that they fall into that category that Zeffie was talking about—that is, being hard to capture in some of these areas. The incidence of congenital hearing loss in the Indigenous population is not particularly different to the rest of the population. The incidence of acquired hearing loss through middle-ear disease is. But, getting children into the system is often the difficulty, and we applaud the Queensland newborn hearing screening program, which works in collaboration with a program in that state called Deadly Ears. It is an Indigenous based system, and collaboratively they work very hard to make sure that Indigenous populations are captured into their newborn hearing screening programs. But it is an issue.

**Dr FREELANDER:** Australia wide?

**Prof. Leigh:** It is an issue in Western Australia, it is an issue in this state. Frankly, without really good data we do not know how significant an issue it is to be able to comment on whether or not the rate of coverage is the same in Indigenous areas as in others.

**CHAIR:** The issues you have raised in relation to the NDIS in referring to contestability are obviously significant ones. Just so that we do not potentially end up throwing the baby out with the bathwater with our recommendations, do you see any strengths of the NDIS model as it will relate to people with deafness and hearing loss and any improvements that will arise from the NDIS overall?

**Prof. Leigh:** Potentially, yes. The difficulty that we have with our field is that it was such a well developed, mature service system that lots of the ills that the National Disability Insurance Scheme was seeking to rectify did not exist in our system. In fact, through a combination of state-based—as in government based—services and charitably supportive services, the coverage was really quite exemplary. The benefits may well accrue to areas where there were not services as readily available before, but it is hard to identify where that might be. If it is delivered, the benefits will be with regard to the definition of standards for everything that we do that will govern that contestability. At the moment, those standards well and truly exist. They are built into Australian Hearing etcetera, but they are not promulgated as national standards in any sense. So if we end up coming out of this with promulgated standards and accountabilities that are driven somewhere nationally, and we have talked about the
lack of that, then that would be a great outcome of the NDIS. But, (a) it is a big issue and (b) we do not see the evidence of that having been delivered at this point.

CHAIR: Thank you, Professor Leigh and Dr Poulakis for your time today. It has been a very informative and helpful session for us. Any additional information that you are able to provide the committee, particularly in relation to some of that comparative international data, would be gratefully received. If you are able to do it by 20 April, through the committee secretariat, that would be fantastic. If the committee has any further questions, we will send these in writing through the secretariat. A transcript of the proceedings today will also be forwarded to you. Thank you again for making your time available.
MEE, Ms Carolyn, Director, Sound Scouts (cmee4 Productions)

[09:41]

CHAIR: Before we get under way, can I just check that you have no objection to being recorded by the media today?

Ms Mee: No.

CHAIR: I just would remind committee members that there was a confidential submission submitted by Sound Scouts as well. As we are in a public hearing, people need to be careful about referring to that in the public hearing. These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Do you want to make a short opening statement before we go to questions?

Ms Mee: I will, although it might not be that short. I am the founder of Sound Scouts. Just to explain, Sound Scouts is a hearing screening solution that integrates the science of a hearing test in a mobile game. It has been developed in collaboration with the National Acoustic Laboratories, the research arm of Australian Hearing. Over the past six years, in the course of developing Sound Scouts, I have become aware of the challenges facing children and adults with hearing issues. In meeting children from remote communities in north-western Australia to children from the northern suburbs of Sydney, one thing is clear: a child with undetected, untreated hearing issues will struggle. They will struggle to learn, they will struggle to socialise and, ultimately, they will struggle to be happy. Undetected hearing issues have the potential to destroy lives. For that reason, we strongly believe that Australia should adopt the World Health Organization's guidelines and implement school entry hearing screening for all children starting school, with a follow-up test in year 5, in line with NAPLAN, or upon high school entry.

Young children rarely know they have a hearing issue. While they may manage at home in a relatively quiet environment, surviving at school, where they have the added challenge of learning and socialising, is a very different scenario. Anyone who has spent time in the classroom or playground will appreciate how noisy these environments can be. For a child with an undetected hearing issue, these conditions will quickly become overwhelming and the child will suffer. Data from Australian Hearing does show that many children are fitted with their first hearing aids after the first few years of school. Typically, that is after the child begins to fall behind and someone looks to find out why. Sadly, by this time, not only may the child have fallen behind academically but their self-esteem will be in tatters.

To better understand the need for an accessible school screening program, I would like to share an email sent to us from Nadia Murphy:

'I am a speech pathologist working in rural Tasmania, working with a very diverse case load of students in a geographically wide area. Until recently I was based in Queenstown on the west coast of Tassie, a place 2½ hours from the nearest audiology clinic. During my time in Queenstown there were many children on my case load whose hearing was queried. I often recommended hearing assessment for these children, but it was rarely followed through. The local health nurse could screen with a pure-tone assessment, but her resources were stretched thinly. Families often had unreliable cars, had to take the whole family for appointments as it was a full day to get there and back, or simply could not afford the petrol. Schools were very frustrated as there were students in their classrooms who they felt could not hear, but they had no evidence to back this up and thus no support.

'When I discovered Sound Scouts I was blown away—hearing screening in the palm of my hand that can be used by teachers and parents. Although I am working with students in a less remote area now, many of the same issues apply. Recently I assessed a little boy who had been diagnosed with low language and who had difficult behaviour in the classroom. Hearing had been mentioned as a potential problem for many reasons including behaviour and distance. It had not been screened. I downloaded Sound Scouts and screened his hearing. He was thoroughly engaged by the iPad, thought it was a game and attended the whole way through. His result came out as a fail. This one screening has the potential to significantly change this little boy's life for the better.'

This is a common scenario we hear from both teachers and clinicians around Australia who are faced with the challenge of identifying without the necessary resources why a child is struggling. Sound Scouts was developed in direct response to recommendation 8 of the 2010 Senate inquiry into hearing, which says that all children, on commencement of their first year of compulsory schooling, should have their hearing screened. To date no action has been taken on that recommendation, perhaps due to the associated costs and accessibility of traditional testing. But today this is where technology can make a difference by revolutionising the delivery of healthcare services,

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providing low-cost, accessible solutions, and Sound Scouts is an evidence-based hearing screening app that can meet this recommendation.

As adults and as a nation it is our responsibility to ensure our children are well placed to prosper in the school environment where they are expected to learn and grow and establish the foundations on which their futures are based, appreciating that our children's futures form the basis of our nation's future. Hearing must become a national health priority. The nation needs to be reminded of the importance of hearing and also that a single test at birth is only the first step in ensuring a lifetime of good hearing. Thank you.

**CHAIR:** Thank you, Ms Mee.

**Dr FREELANDER:** I have just a couple of questions. You mentioned that you can test for sensorineural and conductive hearing loss. Does it distinguish between the two?

**Ms Mee:** It does. It has been designed to detect sensorineural and conductive hearing loss and also auditory processing disorders, which, if you are not familiar with that, is a brain-based hearing issue that is particularly impactful in school environments where you are trying to differentiate target sounds.

**Dr FREELANDER:** It will distinguish between the three?

**Ms Mee:** When the game is played well and played under the recommended conditions, then around 80 per cent of the time we can differentiate between the conditions.

**Dr FREELANDER:** You mentioned also that you have National Acoustic Laboratories approval.

**Ms Mee:** All the science behind Sound Scouts has been developed by Dr Harvey Dillon. We have worked very collaboratively with Dr Dillon in his capacity as director of the National Acoustic Laboratories, so it is an app 100 per cent founded on science, and if anyone knows Dr Dillon they will know he is very particular. We tested thousands of children in conjunction with a paediatric audiologist to ensure that the test results from Sound Scouts aligned with the test results from that paediatric audiologist.

**Dr FREELANDER:** Are you recommending universal screening at school entry age?

**Ms Mee:** Yes. What we would like to see, and what we believe Sound Scouts will enable, is universal screening at school entry. The access to Sound Scouts makes the cost affordable and it does not require the services of a trained professional; any responsible adult can supervise testing. It could be done within the school environment or it could be done at home. All that is required, at the moment, is a tablet device and a decent set of headphones.

**Dr FREELANDER:** Why did you get into this field? I just ask for my own interest. Are you an audiologist?

**Ms Mee:** No, for full disclosure, I do not have a background in audiology. I have a background in media and I was introduced to digital media and the concept of serious games. We heard a lot from Professor Leigh about the importance of data and I think the beauty of what we have developed is that it is a data collection tool. Going back to why I got into it, I have three children and my two boys both had difficulty learning to read and their self-esteem was severely impacted by that. As a mother, I had firsthand experience of seeing the impact of a condition that is undiagnosed and how long it takes to come back from even one or two years of having an undiagnosed problem.

**Dr FREELANDER:** Thank you very much.

**Mr GEORGANAS:** I would like to know more about the actual screening application. How does it work and what is it? Is it an app on a mobile, an iPad or a computer? What does it show and what is the game?

**Ms Mee:** It is an app that takes the form of a narrative-driven game and it is delivered on both iOS and Android tablets at the moment. We are looking to potentially deliver on mobile phones in the future, although we have not tested that delivery method yet. The children effectively play the game with a set of headphones and their interactions with the game collect data points that are then processed through an advanced algorithm, which delivers a report back to the device and also via email if the parents, teacher or caregiver have submitted their email address. The report advises if the child has normal hearing or if they have a hearing issue. If they have a hearing issue then we suggest, based on the results, whether they are best to see a GP, Australian Hearing, a speech pathologist or an audiologist. The advantage of the game is that the children actually love playing it and they do not realise that they are being tested, so they are surreptitiously tested. As a means of collecting hearing data, it is very effective. When we look at the tracks from the data, the end result is that, we can very clearly see if the child has attended well and there are many measures built into the metrics of the algorithm that detect all these variabilities. I would like to say that no stone has been left unturned, but we are always assessing and improving. We have the ability to collect the data and we know where tests are being taken geographically and we are
certainly seeing an uptake in remote communities and communities where there is a lack of services. From early testing and early use we are receiving very positive feedback.

Mr GEORGNAS: My follow-on question from that is: will this particular screening ideally be delivered in schools or homes? That then takes me to another question. It is two in one, sorry! What sort of knowledge does an adult need to supervise the app and the test the child is taking, and how do you know it is being done correctly?

Ms Mee: Those are great questions. What we have endeavoured to do in the user interface is have the steps the adult has to walk through to set the app up be very clear. Through our development cycle—as mentioned, I have been working on this for six years—we trialled it with a lot of parents. We have seen the stumbling blocks and we have corrected them. So we have endeavoured to make it very, very clear what they have to do. They need to conduct the test in a quiet environment. They need to ensure the headphones are working, and there is a built-in check to see if the headphones are working. Really, in terms of supervision, they just need to discourage the children from tapping repetitively when there is no noise present. The app collects all that data, and if the child does tap repetitively the results become invalid and the parents can test again with that information. So the only thing the parent has to do is discourage the child from tapping and supervise them when listening and engaging with the game.

That said, we review all the data and all the results. Our team reviews all the fail results as a measure, and we can see from the data if the results come from some reason other than a hearing issue, including inconsistent play and things that like. There are measurements within the algorithm to detect those issues.

CHAIR: In relation to the thoroughness of the testing—if I can put it that way—effectively you are flagging a potential problem, but have there been any issues of people who have used the app who do have a hearing issue that was not caught by the app?

Ms Mee: I do not have that information—if they have had hearing loss and it has not been detected. We do include in the app that it is just one form of hearing testing and, if someone feels there is a problem, they should seek other advice.

CHAIR: I suppose my question is whether, if an app based solution is being used as part of some universal testing regime, it is thorough enough for that purpose.

Ms Mee: When we set out to develop Sound Scouts one of the key issues that we were looking at was: did the child have a hearing loss that would impact on their ability to manage at school and do well at school? That has been a key metric. Sound Scouts is certainly capable of detecting a broad range of hearing loss, but even audiometry nurses can miss it in children. It is a screening tool. There is no screening tool that will detect 100 per cent of cases. I think, based on our efficacy and sensitivity, which is up around 89 per cent to 90 per cent, and what you get for the cost, it is highly efficient.

I might also take the opportunity to raise the point that a lot of the discussions are around sensorineural hearing loss, which is obviously very important to address and attend to, but the numbers are small. The number of children suffering from conductive hearing loss as a result of otitis media and also auditory processing disorder is far more significant and the hearing impairment these children experience is equally debilitating. You have children with moderate hearing loss as a result of ongoing glue ear or otitis media that no-one knows about because it has just become the norm.

The mother of one of the first children we picked up heard me talking about the indicators of hearing problems—that the child is loud and may be distracted. This mother was a school teacher. She went home after that conversation, rang me the next morning and said: 'Oh my goodness! I think my daughter has hearing loss. Can we trial Sound Scouts?' When she did, the child failed. She had a hearing condition, or an ear condition, that required surgery. She had grommets implanted, and, very fortunately, she was able to start school with good hearing.

Mr GEORGNAS: How old was this child?

Ms Mee: She was around four years and nine months old, so she was just preparing for school the following year, and it is not uncommon. I think that in all the schools I have been to—anecdotally, of course—I have seen five per cent to 10 per cent of children with hearing problems and many need attention.

CHAIR: Final question: is the current app suitable for children up to the age of 12?

Ms Mee: Yes.

CHAIR: Have you considered products for older students and, for that matter, adults?

Ms Mee: Yes, we absolutely have. At the moment we are only bound by our financial resources. The app, as it stands, will detect hearing loss in adults. It is just that the interface is specifically designed for children. So, yes,
there is nothing to stop us from taking the now advanced algorithms that we have developed and making it applicable for adults.

**CHAIR:** But if an adult played it today—

**Ms Mee:** It would pick up the hearing loss, yes.

**Mr ZAPPIA:** I just want to get it clear in my mind. The service is already out there—it can be provided. Is the service made available primarily to community organisations like schools or is it available to anyone? And, if so, how do people know about it?

**Ms Mee:** It is available. It is on the App Store and it is on Google Play, so it is available. Individuals are utilising it at the recommendation of Australian Hearing. You may or may not know that Australian Hearing had to introduce a fee for their hearing screening, and that fee is $120. If the child is found to have sensorineural loss the family does not have to pay that fee—it is absorbed—but if they do not have sensorineural loss the family has to pay $120, which is obviously very expensive. Families ringing Australian Hearing with concerns are told about Sound Scouts as a triage tool, so that is one method of finding out about it. Also, we have been trying to communicate with schools. Our biggest problem at the moment is lack of resources to make people aware of the app. We had excellent funding from NSW Health, but that funding cannot be used for advertising, so, in effect, we have built this highly sophisticated tool that is world-class and not enough people know about it.

**Mr ZAPPIA:** But if a school takes it on board, do they have to provide some funding?

**Ms Mee:** They have to pay for it, yes. At the moment it is charged at a fee per test session per child. If an individual buys it for home, it is around $15. If schools buy it, then the price is reduced through bulk purchasing.

**CHAIR:** Fantastic. Thank you for your time this morning. I do not think there were any questions that we asked you to take on notice, but if we do have any further questions we will send them to you in writing through the secretariat. The Hansard transcript of proceedings will also be forwarded to you for minor corrections in due course. Thank you for your time today.

**Ms Mee:** Thank you for having me.
HENDERSON, Ms Fleur, Executive Officer, Parents of Deaf Children
PORTER, Mrs Ann, Chief Executive Officer, Aussie Deaf Kids

[10:06]

CHAIR: Good morning. I now call representatives from Aussie Deaf Kids and Parents of Deaf Children. I will go through the formalities, which you have heard a couple of times already this morning. Do you as witnesses appearing before the committee have any objections to being recorded by media during participation in this hearing?

Ms Henderson: No.

Mrs Porter: No.

CHAIR: For the record, these hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Thank you both for joining us today. Would you like to make any opening statements before we move onto questions?

Ms Henderson: Yes, thank you, we would.

CHAIR: Are you both doing one?

Mrs Porter: We are going to do it together. I am going to add a little snippet.

Ms Henderson: I will start. Thank you, Chair, for this opportunity. We appear today as two separate organisations who share a common goal—that is, to ensure families and carers of deaf children in Australia are fully supported and provided with appropriate, evidence-based information to ensure they are equipped to make good choices for their children during these crucial early years of development and decision-making, and in the future. Parents of Deaf Children and Aussie Deaf Kids have borne witness to the various changes that have occurred in Australia with respect to supporting these families. However, at no time has the pressure for parents being greater than it is now.

Currently, these support systems are in a state of flux. Whilst we welcome the introduction of the NDIS, there is still confusion around the lack of clarity with regards to current eligibility requirements, consistency of support and an understanding of just what is going to be included in the plans for our families. Furthermore, the future of Australian Hearing has not been discussed with us, and the proposed change of ownership from the consortium is providing us with some considerable concern, as you can appreciate. Now, more than ever, our families need support to assist them in navigating the complexities of both our current and future hearing services and what this support may look like. Thank you.

Mrs Porter: I want to add a few other points. We have heard today that we have had a mature and effective system for providing children with hearing loss, and their families, with the services and support that they need. But we are moving into uncharted waters, and the changes to the system must be transparently assessed, the risks identified and mitigated, and the results must improve on the current system. The potential sale of Australian Hearing, and the transition of hearing services to the NDIS and the contestable marketplace, has been quite an opaque process to us, where the views of the people who will be most affected by any of these changes—the people with hearing loss, and their families—appear to have received scant attention.

We would urge this committee to remember that changes made today will affect the lives of children and their families for decades to come. We want children who are diagnosed with hearing loss, and their families, to have access to high-quality services, technology and support wherever they live and whatever their socioeconomic status. Every child deserves the opportunities that our system can deliver, irrespective of the capacity of their family to navigate the system and advocate for their needs. Thank you.

CHAIR: Thank you very much. It was very succinct. Why are there two organisations?

Ms Henderson: What are they, did you say?

CHAIR: No, why are they. Do you do different things?

Ms Henderson: We do. Parents of Deaf Children has been state funded since the 1960s. We look after families in New South Wales predominantly; that is our gambit. We provide face-to-face support as well as online support.

Mrs Porter: I actually started Aussie Deaf Kids after my daughter lost her hearing. We largely provide online parent-to-parent support. Parent groups in Australia and around the world really struggle for funding so they come and go. It is a very under resourced area, but we know the support the parents get from other parents is actually
critical in their whole journey with their own deaf child. We are largely funded by private donations. We have not received any government funding to date.

**CHAIR:** Thank you for coming together for your submission.

**Ms Henderson:** We work together all the time.

**CHAIR:** It is not always the case in some other areas of the health sector.

**Mr GEORGANAS:** In your submission you say how important the family surroundings are for a child that has been diagnosed with hearing loss, and the pressure that puts on a family. Can you tell us some of those pressures that are on that family and the lack of support?

**Mrs Porter:** You can well imagine what it is like to have a baby and to be told within a couple of days where there is no apparent reason for hearing loss that this child has a hearing loss. Most families have no concept of what it is like to have a deaf child. The first deaf child that they ever met is their very own child. We do not have experience in parenting deaf children. A lot of our parenting is around how we were parented but we do not know how to parent a deaf child; there are different things that need to be done. So besides the stress of it and going through the grieving process and everything, you do not have a clue what you are supposed to be doing. That is why, as you have heard from the Newborn Hearing Screening Committee, there is this clear pathway where you do not actually have to think. You know where you are going and you do not have to worry about: is the service going to do the right thing by child, by my family? And how much is this going to cost? All of those issues do not come into play. The fact that that is changing is causing families a lot of stress.

We did a survey of our families when they were first looking at Australian Hearing being sold. Parents said to us they just did not know how they would navigate the system if it had not been like it is. I work with a lot of parents who have children that have hearing aids and onto early intervention causes enormous stress throughout that period. They guide them and the wellbeing within the family. As Ann pointed out, our statistics are that 90 per cent of our deaf children, as I am sure you have heard before, are born to non-deaf parents and so it is their first experience with it and they honestly do not have a clue. Do they need a cochlear implant? Do they need a hearing aid? Do they need to look at Auslan? If it is unilateral loss, do they bother doing anything? What choices should they make? As a parent, when you have new child you already have a whole lot of issues going on and this means even more choices. There are still choices that they have to make, but I think that pathway going back to Australian Hearing saves a lot of that angst. It can cause a lot of instability in the family home. The discussions put a lot of stress on a marriage. If it is a single parent raising a child, again, it is just more stress. If they have other children, they have to drag all those children off to various appointments.

There are simple things, as Ann touched on, such as if they are going down the pathway of hearing aids a baby constantly pulls the hearing aids out. If it is cochlear implantation, they may have to go through putting their child under anaesthetic and having a major operation. These are incredibly stressful things. If they are going down the Auslan pathway, how are they going to get support? How will that child go to school? These are the sorts of things that are constantly going through the minds of the families. It causes a lot of stress for the family and their extended family as well.

**Mrs Porter:** As you have heard, the newborn hearing screening program is different in each state. In Queensland they have really great system where they have family support facilitators. Once the child is screened, the family support facilitator comes in and they are there for the family until the child turns six. They are largely psychologists and social workers and they can walk with the family throughout that period. They guide them and explain information they have not understood and all those sorts of things. We do not have that in every state. In fact, parents often say there is a black hole they go into where there just seems to be no support around them.
CHAIR: So you would say Queensland does it best?

Ms Henderson: I think so in Australia, yes.

Dr FREELANDER: Let me reassure you, unless anyone on this committee knows anything different, that no decision has been made yet about what is going to happen with hearing services. I agree with you that it has been rather opaque so far, but that is the purpose of this committee. Thank you for coming along today. We are consistently told that the present system is world’s best practice. It is very hard to know how that could be improved. But did you see any signs now that things are worse than they were, for example, when your children were diagnosed?

Mrs Porter: Clearly my daughter is a lot older than Fleur’s. I think we can see cost pressures on Australian Hearing. Certainly it can be quite hard for families to get appointments or timely appointments, particularly after the newborn hearing screening period is over. Once the kids are a bit older, it is much harder for them to get appointments. They still get world-class devices and everything, but we used to be able to get loaner aids, FMs and things like that when technology broke down and that is not always possible now. We seem to see longer lag times in repairs of devices that were not apparent a few years ago. I would say that for parents who see advantages in a contested environment those are the things that they would cite as being helpful—to be able to get more timely appointments and to have repairs done in a more timely fashion.

What I do not think most parents understand are the complexities of the service and also the capacity and expertise of the people providing services to children. Parents think that they will just be able to go to the local Westfield, but that person, possibly, will not be able to provide the best service for their child. While it looks attractive, in the long term we do not believe that the outcomes will be. But that is the main reason why parents say they cannot wait to be able to choose their service provider.

Dr FREELANDER: From what you are saying, you are suggesting that a more guided pathway that is—

Mrs Porter: Yes. If we are going to a contested environment, parents are going to need significant help in understanding the process, and who the right people are to see them—that not every person who says that they sell hearing aids is the right person. They are going to really need to understand that a lot of the providers get commissions and they upsell, and that those devices may not be the best devices for their child. We are going to have to have significant support around parents to provide them with the information that they need. The parents that we are always concerned about, of course, are those of low socioeconomic status, migrant families, and regional and remote families. All those people that we constantly worry about are going to be the people that are most disadvantaged by this. People in metropolitan areas—well-educated families—will manage. But we want every child to have the same opportunities. It should not be dependent on the capacity of your parents to understand the system.

Dr FREELANDER: Can I ask both of you how you felt about the medical interventions from day one—whether the information and investigations et cetera were provided appropriately to you.

Ms Henderson: Are you referring to cochlear implantation or the diagnosis—

Dr FREELANDER: From the diagnosis. Was it explained to you appropriately, and were you directed in the right way to the interventions?

Ms Henderson: I am not sure how to answer this. From our organisational perspective, I think the feedback is that, currently, it works well. The majority of children are referred to Australian Hearing, and that, as I think we have addressed, has worked really well. I think that the social support is the thing. When they first have the hospital introduction to the social worker, they are in shock, so anything that is said to them—as I said, they go away to think about these things. They are kind of left a little bit alone. Then they have follow-up appointments. Often the diagnosis is not completely identified at that time. For instance, it could be that, if you had a caesarean section, they might say to you, ‘We are not sure if they have failed this hearing test, because it could be fluid from the caesarean section that is causing a false positive on the testing.’ A lot of the time, they are still in denial; they think that maybe it is not hearing loss. It is not until a few weeks later, when they get the actual audiology appointment, usually through the hospital again or Australian Hearing, that it sort of sinks in and they get the diagnosis. Sometimes, they are waiting for genetic testing. It almost seems like there is not a specific cut-off. There is a pathway that can be very varied.

Dr FREELANDER: And you would say that that audiology appointment is the focus?

Ms Henderson: It is, yes.

Mrs Porter: I would like to add that all the guidelines that we have around the hearing pathway and early intervention are around parents having an informed choice. I have to say that, quite often, the family will go to an
ENT, and the ENT just sends the family on a route. We know that the first information that you are provided with really does bias your way of thinking and does not always make for an informed choice. We quite consistently hear from parents, and when we survey parents, that they wish that they had been provided with all the information at the time of diagnosis. They did not know what they did not know, so they often do not know what information to ask for. If the ENT says to you, 'This is what you do,' you just do it, basically, and that is not always the best.

In general, as to the care—my daughter had a unilateral loss, and she lost her hearing in the other ear when she was seven, and we had fantastic service from the Deafness Centre at Westmead. They spent hours and hours with us.

**Dr FREELANDER:** The audiologists say that, often, that first appointment takes a long period of time because the parents require a lot of information.

**Ms Henderson:** They may need a follow-up, because the grief can be so overwhelming for some families, and it is a big culture shock in some CALD families. There is a lot of grief and shame in those families. They do not understand. The audiologists are fantastic. We have some fantastic professionals working in the health environment for hearing and they just have to spend a lot of time with them getting them through that process, wearing two hats, if you like, as a bit like a social worker.

**Mr ZAPPIA:** Mrs Porter, could you just clarify for me: you made a comment earlier that it is more difficult to get appointments. Were you referring to Australian Hearing appointments?

**Mrs Porter:** Yes.

**Mr ZAPPIA:** Can you expand on that and clarify for me: is it more difficult because there are more families wanting to see the people who work at Australian Hearing, or have you been able to detect other reasons why it is more difficult?

**Mrs Porter:** We are not sure what that is or where the pressure is coming from. We consistently hear in our online groups of families having to wait significant times to get another appointment, which is hugely stressful for families. If a kid cannot hear at school—my daughter used to just melt down if something went wrong with her equipment at school. So it is within Australian Hearing. To me, it seems that it may be cost pressure; I do not know. There is improvement that we can have within the system, but I think that Australian Hearing is where we should work on improving the system rather than diversifying it.

**Mr ZAPPIA:** Thank you.

**CHAIR:** I have some follow-up questions to some of those themes that you raised in your submission. How would you rate the perception of Australian Hearing amongst parents? Is it very highly rated or somewhere in the middle, to the scale of zero to 10?

**Mrs Porter:** I would say maybe eight. When we did the survey when they were going to sell Australian Hearing, most people said that they would prefer to stay with Australian Hearing. I cannot remember the numbers exactly, but there were two parents who actually supported being able to choose a hearing service provider. If a kid cannot hear at school—my daughter used to just melt down if something went wrong with her equipment at school. So it is within Australian Hearing. To me, it seems that it may be cost pressure; I do not know. There is improvement that we can have within the system, but I think that Australian Hearing is where we should work on improving the system rather than diversifying it.

**Mr ZAPPIA:** Thank you.

**CHAIR:** Would you agree with that, Ms Henderson?

**Ms Henderson:** I would, and I would also like to add—and I think you have heard this before—that they do really well to juggle newborn appointments. I have had my own daughter's appointments cancelled numerous times because they have said to me, 'We've got a baby just diagnosed. Can we change you?' And absolutely every family is like, 'Of course,' because we have all been in that boat. So they do juggle that. If a device breaks, they absolutely do what they can. They bend over backwards to try and fix it because they are aware that that child is going without the hearing at school and so forth. They do a lot of things very well, and I would agree with Mrs Porter that it is very well thought of by families. They understand. A lot of our families travel overseas and for work and so forth and come back saying, 'We came back. We wanted to live in Australia. This is just such a leading service.' But, as for any organisation, it is not without things that could be addressed and hopefully helped. That would be a question, I think, for Australian Hearing.

**CHAIR:** Just to be clear, the points where there are occasional concerns about service levels that relate to appointment times and repairs, are there any other areas of concern in relation to—

**Mrs Porter:** Those are the two principal issues that we hear from families in our online groups.
CHAIR: You mentioned that you do have some parents and members who support a contestability model. Is it primarily born out of that concern about more immediate access to services or are there other reasons why people support it?

Mrs Porter: It appears to be that they think they will get more timely appointments. As I say, I do not think they fully understand.

CHAIR: You wrote in your submission on obvious issue about Australian Hearing providing services up to people aged 26. What is your understanding of what the NDIS model will mean for people over 26? Is it likely to enhance that by providing greater universality up to 65?

Mrs Porter: You may know more than we do, but to us it still remains unclear. It is unclear to us what is going to happen with the NDIS to children past early intervention. We do not know. We campaigned very hard as parents of deaf children for the NDIS, because we saw an opportunity for our kids to have lifelong support, particularly around the issue of devices. Our kids cannot do all the things that we allow them to do by providing this amazing service at a young age without devices. I know many young adults who wear one device because they cannot afford to wear two.

CHAIR: But it is not clear to you yet as to whether the NDIS will cover people aged over 26.

Mrs Porter: We do not know.

CHAIR: But if it did, you would consider that to be an enhancement on the current system?

Mrs Porter: Absolutely. I think if they do not pick up those people, we definitely need to have a look at another way of providing assistance to people over 26. People do not go on holiday, they cannot put a deposit on the house and things like that because of hearing aids. We really need a tax break or something. Our kids cannot work without the devices.

CHAIR: I will just ask a final question: have you had much interaction with the NDIA? What has been your perceptions of that interaction?

Mrs Porter: There has been an early intervention working group that we were invited to as parent groups a little bit down the track. We were grateful to be invited to that. I think that they really do understand the complexities of the situation. I think they really do understand that we need a really clear pathway from newborn hearing screening and that we need every child who is diagnosed with a hearing loss to get some package so that there is not delays. I think they really understand that.

CHAIR: So they have been quite receptive?

Mrs Porter: Absolutely.

CHAIR: Was your perception that they are just drowning under the weight of the task before them at the moment—

Mrs Porter: I think so.

CHAIR: rather than there being a barrier in their mindset.

Mrs Porter: I think they really understand what the needs are and that is hard to do it. I think what the actuaries are saying they can do is an issue. I would just say one more thing around the NDIS: a lot of services that used to be provided by the state governments are dropping away because of the NDIS. One of those is early intervention for deaf children. The state governments have traditionally provided a lot of early intervention for deaf kids around the country. We have seen with the rollout of the NDIS in the ACT that the ACT government pulled out of early intervention services. We are seeing the same thing in Queensland. Those services are often for families who want bilingual intervention for their kids. Not every child is able to learn to speak. It is leaving a lot of families high and dry.

We have discussed that with the NDIA and they have said that is not something that they can deal with. The state governments do not seem to be interested. Maybe the federal government can address it. I think we are hearing it in other services as well, but it certainly is a concern. We need to be able to provide bilingual intervention for children. Who is going to fill this? There is only one early intervention service provider, which is RIDBC, where the possibility is there. All the others only provide services for families who want their children to talk. I think it is something that somebody at some level of government needs to address.

CHAIR: If there are no further questions, I thank you for making your time available this morning. It has been very helpful and we are very grateful for your contribution to the inquiry. If we have any further questions, we will provide them in writing through the committee secretariat. A transcript of your evidence will be made
available to you as well. If you can find anything that you would like to correct or add to, please let us know as soon as possible. Thank you.

Proceedings suspended from 10:35 to 10:55
CHAIR: I welcome Hearing Aid Audiometrist Society of Australia. Can I check whether you have any problems in being recorded by the media, if they choose to present during your presentation today?

Mr Khairy: No, not at all.

CHAIR: These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Thank you for your submission to the committee. Would you like to make an opening statement before we move onto questions? And, when you start you might explain, for those of us who are uninformed, the difference between an audiometrist and an audiologist. Wikipedia did not make it all that clear for me.

Mr Khairy: Actually, that is part of my statement, so I will explain that briefly. A registered HAASA— which is an acronym for the Hearing Aid Audiometrist Society of Australia—audiometrist with full membership status would have completed either School of Biological Science at the Sydney Institute TAFE NSW, or Open Training Education Network, OTEN, to study the Diploma of Audiometry, which was until recently called Hearing Device Prescription and Evaluation. It is a two-year course with more than 900 hours of clinical practice before requesting admission to the full membership of HAASA.

Many audiometrists have elected to provide services to eligible Commonwealth hearing service recipients under the Commonwealth government Department of Health and Ageing program. To be accredited with the Commonwealth hearing services and a full member of the society, an audiometrist must undergo a competency examination of both their practical and theoretical skills and knowledge. HAASA audiometrists undertake to abide by the rigorous standards of practice, rules, code of conduct and ethical standards set down by the association with the scope of practice well within their sight. A program of continuing professional education and development, CPED, must be undertaken and achieved by a set period of time in order to meet the requirements of members for the Hearing Aid Audiometrists Society.

HAASA members are dedicated to uphold the highest possible standards of practice to ensure quality hearing health care into the future. Members of HAASA are hearing aid audiometrists who have met the requirements and standards established by the society and the Commonwealth of Australia to provide hearing assessments, fitting and rehabilitation when hearing aids are needed. Thank you; open for questions.

CHAIR: What can an audiologist do that an audiometrist cannot, and vice versa?

Mr Khairy: I would like to think that anything an audiologist can do an audiometrist can do. However, to be fair, audiologists are trained more in the clinical discipline of neurophysiology, so assessments of vestibular function disorder—balance disorder—the brain stem itself and other issues. Audiometrists are not totally focused on that. It is part of our studies and our qualification, but we do not focus on that. We mostly focus on the hearing health and rehab for mostly the adult population. Hearing aids of different sorts is our main discipline. Again, if an audiometrist would like to take further studies and expand their scope of practice, there is no limitation to that.

CHAIR: I might just start with one question. Are you familiar with the ACCC’s report in relation to issues surrounding the issuing of hearing aids?

Mr Khairy: Yes, I am aware of that.

CHAIR: I am just wondering whether you have any response to the concerns that were raised in the ACCC’s report—specifically whether your association has a view on the use of commissions and incentives in the hearing aid industry.

Mr Khairy: The ACCC report did not bring anything we did not know. As a matter of fact, on a number of occasions we raised the issue of the ethics and practice within our industry. The distinction has to be made, though, that there is a difference between clinical standards and standards of practice for providers of hearing aids. Most clinicians do not run their own practice—they are an employee of a much larger operation. In those larger operations, or a business as such where things like this would occur, a clinician can sometimes find themselves between a rock and a hard place. There is an ethical issue that has to be addressed. Historically, our industry prides itself on giving, for example, free hearing assessments. Free hearing assessments, in a sense, bring clients to the door and so on. There is something at the end of the line of those free assessments. It may be something that needs to be revisited.

I do not personally want to be dismissive of the finding of the ACCC. I think it needs to be expanded. We need to go into the details of how big this issue is and then we need to have a recommendation, with the help of the association and the professionals within the industry. This industry remains self-regulated and it has worked. It
Mr Khairy: I do not think there would be an argument from any of us.

CHAIR: What would be the arguments against the governments seeking to prohibit commissions or incentives?

Mr Khairy: Absolutely—100 per cent. The thing that we also have to be careful about is that, under commercial law, there are issues that have to be addressed as well. Can we do that in a free enterprise market? There is a component of our industry that is a commodity, which is hearing aids. Now there are people who sell them online. There is another component of our industry, which is the clinical practice and the ethical part of fitting a hearing aid and discussing why clients need the hearing aids, why these ones and not the other ones and so on. That is the part that needs to be regulated.

We are moving into an unbundling system in Australia. In the past, our hearing aid fittings were part of the service. You walk into a clinician's office, you discuss the issue with them and they will give you an option that would fit your hearing loss. And that option would include the cost of the hearing aid, the hearing fitting, the rehab. In many cases, for the life of the hearing aid you do not put your hand in your pocket to pay for this hearing aid again, unless there is a major issue with repairs and so on. But all the clinical follow-ups and the reprogramming and assessment are absorbed in the initial cost of the hearing aid. If you are going to unbundle this now and say, 'The hearing costs that much and your service costs that much,' then we are really walking into a system that says, 'The hearing aid is a commodity. It's something that has a value. Let's value what this is and see what the clinical backing of it is worth.' This is new to us in Australia. It is pioneered in the US. Evidently, that is where it was started. But now is more and more in this industry that is coming into this. There is a mixed feeling about it within the industry. Do we really want to go that way? Or do we want to stick with the way that we have done things based on Australia? We have prided ourselves on having probably one of the best hearing systems in the world. And it has worked because we have taken a holistic approach on it. Once you start to dissect and have this separate from that, that is where problems occur.

Mr ZAPPIA: Mr Khairy, thank you for appearing before the committee. Can I ask you whether the society has any views in respect to hearing services coming into the broader National Disability Insurance Scheme area. If you do have any views, or in particular, do you have any concerns about that?

Mr Khairy: Yes, I do have some concerns. As a hearing health practitioner myself in the state of New South Wales, which is a fully rolled out NDIS area at the moment, I can tell you, on behalf of myself on my colleagues, that we have no idea how the system works. There has not been any formal engagement with the NDIS officials to come and tell us, basically, from the hearing health side of things, how exactly the system works. Are we waiting for the patient to walk into our office and we initiate that? Does the patient walk, initiate and give us some mandate from the NDIS—some documents to fill? The picture we are getting from NDIS—they were quite dismissive when we questioned them. They were saying, basically, 'Your percentage of the entire program as hearing care providers is minimum in the scheme of the NDIS itself. So just don't fuss about it too much.' That was delivered to us in one of our CPED programs when we invited some official to come.

It might not be the major part of NDIS, but we still need to know if it is means tested; if it is level tested. At least with the Office of Hearing Services, the current program tells us that there is a threshold which we can actually accept new people under. What constitutes a disability as far as hearing loss? We do not know. So there are all these areas that we need to actually clarify before we can be physically engaged in the NDIS scheme.

Mr ZAPPIA: Can I just clarify: the society has not been formally consulted by anybody and nor do you have a place on any of the advisory committees?

Mr Khairy: No. We have been on many meetings with the Office of Hearing Services through different programs. As a matter of fact, there has been more than one time that the officials, or whoever was supposed to be representing NDIS, were not even present in our meetings. I am trying to reach out to them, but, for me, the national president, I do not even know who to contact at the NDIS to speak about hearing services. The Office of Hearing Services, OHS, acts at the moment as an 'inbetweener'. When we go to the Office of Hearing Services and ask them, 'How does the NDIS work?' they say, 'We'll get back to you because we don't know ourselves.'
Mr ZAPPIA: Just an unrelated question: with respect to practising as an audiometrist, does a person have to be a member of your society, or can they practice without being a member?

Mr Khairy: No; there are two societies in Australia—HASA is one of them and it accredits audiometrists. Audiometry is a profession for which you can get the academic qualifications but then, as part of my opening statement, you need to qualify under a particular competency examination to actually prove that you have these clinical standards. At the moment, that is done through ourselves and another accreditation association. To practice as an audiometrist, that is the pathway that we would recommend.

Mr ZAPPIA: Thank you.

Dr FREELANDER: My concern is that we have an ageing population. The number of people with significant hearing loss is going to gradually increase. Yet, it seems to me that regulation of provision of hearing aids, No. 1, is very poorly organised and No. 2, there is very little involved in training people how to use hearing aids and in following up people once they have been given hearing aids. Do you think that there are any ways that we could regulate better and that we could also teach people more about how to maintain and use their hearing aids?

Mr Khairy: I think, like everything else, the educational program must start very early in the piece. We have advocated and, many times, our members have voluntarily gone to schools to start at the very grassroots of actually educating high school students about dealing with sound and the damaging effect of sound. At this very grassroots area, a person might start to learn that, 'Potentially, I could be wearing a hearing aid if I don't protect my ears properly.' Down the track, a person would have an idea of what a hearing aid is.

The experience can be the other way, though. A person realises, 'I have some funding available for me to go and obtain a hearing aid. I am being pressurised by my family and friends. I don't recognise that there is a problem, but I must use these funds to get a hearing aid. Well, I will just going get a hearing aid to keep everyone happy.' There is no convincing the person that they require a hearing aid, simply because the hearing loss is a silent thing. Many people would walk into our practice complaining about their partners having a problem hearing them, rather than them finding out that they have a problem. Then we have to counsel this person about how they actually have acquired hearing loss. We might find that they have worked in an industry of some sort. There is an educational program that must come in at some point to let people know about the benefit of this system.

What happens in our clinic, as far as training and retraining if we use the current model that is present, works well. In a private practice, purely away from the government-funded program, people have a vested interest in keeping a client coming back and that is why they do the best that they can to be able to keep that client. It is self-serving at the same time—why don't we do the same thing for the government-funded program? It is the same standard. If you are trained properly as a clinician, there should not be something that distinguishes between one or the other.

Dr FREELANDER: You have said that you agree with the ACCC findings. Do you think you can identify those practices that are over-upgrading hearing aids?

Mr Khairy: Hence my recommendation that this needs to be expanded a bit more. The investigation must go into finding who was actually responsible for this. It is also important for us, as an association of professionals, to be able to identify who exactly—it may be a certain sector, and we are all tarred with the same brush. It may be a particular sector of the professionals that does that. That may well be the case, but from memory, I think what came out of the investigation was that there were something like 85 reports to the ACCC—do not quote me on the numbers, but it was something within that—29 of which were actually reported by the professionals themselves and 50-something of which were reported by the public. In the scheme of things, when you consider that in Australia there is an average of 420,000 to 450,000 hearing aids that are dispensed all over the place, we need to put this into perspective. Yes, there are some issues out there, but the vast majority of people who practise this in this industry are professionals at the highest level.

Mr GEORGANAS: I might just follow on from one of the questions that Dr Freelander asked. You made a statement saying that private practice is working much better in terms of services providing what is required for particular patients to ensure that hearing aids are working correctly and they are using them correctly. Then you said: why can't we have that in the government system? Obviously, you are saying that there is a vast difference between the two and the way the services are provided. How could you fix that; and can you tell me some of the differences that take place in the two sectors?

Mr Khairy: Let me start with something slightly controversial. Let's take Australian Hearing, for example, who predominantly see children and pensioners—this is what we have always known Australian Hearing to do. When a clinician refers a child to Australian Hearing, they quite often refuse to see that child. Why? Because they do not know, if this child has hearing loss or not. They need to make sure that the child has a hearing loss before
Australian Hearing accepts them. You asked the ladies who were speaking before a question about why they are refusing them. I can tell you: because we have been told by Australian Hearing officers that they need to know that the child actually has a hearing loss in order to see them. Because they are not in the business of screening, maybe that is how they perceive themselves. But to us—professionals, doctors, GPs and paediatricians—if there is an issue with child, I want to be able to refer them. This is a government department entrusted with this, but they are refusing to see children. They will only see a child once the hearing test is done or at least they have got some evidence that there is a hearing loss and they will carry on from that. That is No. 1.

Number 2: there is an issue between running a private office, where the onus of standards lies with the person or the professional who runs the office, and running a government funded system with all the different tangles and crosschecks, which I can understand. The government needs to make sure that, when they deliver a particular service, it is done appropriately. However, there are so many rules, regulations and hoops that a person has to jump through—for example, to get an approval for a hearing aid, you need to get a GP to sign a letter to say: 'Yes, I agree.' However, GPs, much of the time, are unaware that a person actually has a hearing loss. This test should be done so everyone who requires a hearing test can go and get a hearing test, come back with the result of that test and show it to the doctor, so the doctor can approve it. An approval is needed from a doctor who sometimes, with all due respect, is not that well trained in identifying hearing loss and so on, and that takes away from the professional status of an audiometrist—or an audiologist for that matter. So the system needs to be tweaked and then it would work a bit better.

Mr ZAPPIA: Can I just follow up with a clarification: under what circumstances would you, for example, refer someone to Australian Hearing services? What kind of patient?

Mr Khairy: Predominantly children, because paediatric assessments and paediatric work require clinicians with particular training in this field. If a person does not have accreditation—and a clinician would identify this—a professional would look at a patient and, if that patient is a child up to a certain age, then they would refer them on to people who specialise in this, and that is the pathway we take.

Dr FREELANDER: Thank you.

Mr GEORGANAS: Regarding regional and rural areas, is there a shortage of audiometrists in those areas? If so, why do you think that is the case?

Mr Khairy: Quite a number of members of our association do rural service. Hence why audiometrists are still providing this service to this day—because the vast number of audiometrists are found in rural Australia. There is an emphasis on supporting those members in what they do, because there are a lot of people who do not want to do the work around this area. Those communities are the ones who need the support from the government. Perhaps there could be a program which can foster particular assistance to those people who wanted to do this type of job.

I will say this again—and I might sound as if I am anti-Australian Hearing, but this is happening—Australian Hearing are funded under the community service obligation to assist children with certain needs. They have vans and vehicles that are equipped to test people particularly in those remote areas. Yet the evidence that many of my members have been feeding to us is that those vans are found mostly around Castle Hill and the main cities around Sydney to test the general public. You have to ask the question: why? With all the Australian Hearing offices in metropolitan cities, why are vans travelling and screening people in those areas? What is the purpose of this, when those vans should be out in the remote areas testing children? I might put it to you that I want you to look into it. The fact is that an Australian Hearing branch would set up at a Centrelink office to test people at Centrelink, who predominantly could be pensioners. It is a good market for them. So they set up shop at a Centrelink office and screen people who walk in, and a professional who does not belong to Australian Hearing goes. The reports that I am receiving from my members say that there has been presence of Australian Hearing in Centrelink offices. I want to question that. What is the purpose? If that is the case, why is that so?

Dr FREELANDER: And they are not fulfilling their obligation in rural and remote areas?
Mr Khairy: I am not going to make a call on whether they are fulfilling their obligations or not. I am putting the question to the committee: why are they at Centrelink offices? Whether they are fulfilling their obligations or not, that is a different question. This requires an answer—why is an establishment like Australian Hearing screening pensioners at a place where pensioners are available, day in, day out?

Dr FREELANDER: They should be given the opportunity to respond to this. If you have any evidence for this, you should provide it to us.

Mr Khairy: I will endeavour to do so.

Mr GEORGANAS: This committee heard from the ACCC during a hearing a couple of weeks ago. They looked into the area of hearing, products for hearing et cetera. They basically came up with their report. They told us—I suppose I can be corrected by the other members if I have not got it quite right—they have written to all the different organisations telling them to basically look into their procedures and ensure that they are doing everything possible to ensure that there is no ill practice taking place. My question to the HAASA is: have you instigated or put anything in place that the ACCC has requested or asked of the organisations to ensure that they are doing everything possible to ensure that—there is an obligation on everyone, I suppose—they are doing the right thing?

Mr Khairy: There is an obligation on our part that we engage with the ACCC on an ongoing basis, and we have written to the ACCC acknowledging their findings. We are formulating a formal response to the ACCC with our recommendations and how, as an association of professionals, we would like to see things developing down the track. One thing I would like to add is the percentage of who is actually rendering the service out there. When you consider there is an average of about 300 or 350 or so of hearing care providers who are contracted to the government to provide services, a distinction must be made between how many of those are the mum and dad clinics or the private practitioners clinics out there and how many of them are vertical integrators who are owned by multicorporates, and then the data will start to make sense. Again, I am not pointing the finger at anything. I think we need to find out a little bit more information from the ACCC about exactly where those shortcomings are coming from. Then we will be able to have a much broader picture about how we can deal with it down the track.

CHAIR: I thank you for appearing before the committee today. It has been very helpful. If the committee has any more questions, it will provide them to you in writing through the committee secretariat. You will be provided with a Hansard transcript of today's proceedings. If there are any further matters that arise from the transcript, please contact the committee secretariat. Thank you again for joining us for the hearing.
HOGAN, Professor Anthony, Member, Australian Society of Rehabilitation Counsellors

SCHWENKE, Ms Cristina, Chief Executive Officer, Australian Society of Rehabilitation Counsellors

[11:28]

CHAIR: Thank you for joining us at this public hearing today and also for your submission to the committee. Do you have, as witnesses appearing before a committee, any objection to media recording of any of your evidence?

Ms Schwenke: No.

CHAIR: These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Did either of you want to make an opening statement?

Ms Schwenke: On behalf of the Australian Society of Rehabilitation Counsellors, I take this opportunity to thank the committee for inviting us today. ASORC—that is the acronym; you must now be sick of acronyms or confused by them—is the peak professional body representing just over 1,000 rehab counsellors throughout Australia. Its mission is to promote the profession of rehab counselling and to foster the professional capabilities of its members. As you know, I am accompanied by Dr/Professor Hogan, who has been a member of ASORC for over 20 years, and during the course of this hearing I will defer to him, as he is the expert on this issue.

The existing model of hearing conducted in Australia has been in place since the Second World War, and we feel it is in urgent need of revision. From the late seventies, researchers and clinicians at the National Acoustic Laboratory, as well as community based advocates, were recommending that the Australian model be adapted to world's best practice, which at that time was a Scandinavian model. Despite substantive developments in approaches to rehab hearing services globally, Australia continues to lag behind world's best practice. Today, best practice is evidenced in the work of institutions such as the Danish Ida Institute, and the research literature demonstrates that best practice is evidenced in client education, effective communication training, psychological support for individuals and their families, and the provision of hearing devices—so it is not just about devices.

Because best practice service models are not offered to the Australian community, our submission to this committee has drawn attention to the hundreds of millions of taxpayer dollars that we feel are being wasted each year through the ineffective provision of hearing aids and devices. Our submission is based on robust and independently conducted research which demonstrates that up to one out of three people who receive a hearing aid rarely, if ever, use their device and up to two out of three people who use their device still regularly experience communication breakdown in everyday settings. So, the many social and health aspects of hearing loss cannot be rectified simply by the provision of a device. If there are health effects associated with impaired hearing, the research suggests that such effects are related to either the underlying medical condition that causes the impairment or the psychological impacts of stigma or communication stress. The former is unavoidable; the latter is preventable through the provision of an effective program of rehab.

To the extent that an economic cost is associated with impaired hearing, the majority of this cost is attributed to lost productivity, a loss that can be properly addressed through vocational counselling and support. As mentioned in our submission, this loss can be remedied and at the same time register an estimated saving to the government—and, more importantly, the taxpayer—of between $240 million and $550 million.

Submissions to this committee inquiry have overwhelmingly called for the provision of a holistic, client centred approach to hearing services. Such an approach requires the provision of rehabilitative counselling by appropriately trained professionals, supported by community education programs led by national consumer groups. Most audiologists and audiometrists do not, in our view, have the appropriate training in rehabilitative counselling or community education. The committee's attention is drawn in particular to submissions from Better Hearing Australia, SHHH—that is, Self Help for Hard of Hearing People (Australia)—and the Whirled Foundation, all of which call for a substantive role for the community sector in the provision of hearing services.

We similarly note that, despite the provision of funding for rehab services by the Office of Hearing Services, barely five per cent of clients were offered this service by existing eligible service providers. We have consulted our members and documented our members' expertise, experience and capacity to provide hearing rehab services in Australia. Our members have extensive experience—mental health assessments, adjustment to disability, motivational counselling et cetera—in working with deaf and hearing-impaired people, and this expertise includes addressing the more complex needs of those whose hearing impairment is severe or worse. Our research shows that the support needs of hearing-impaired clients vary by severity of hearing impairment. On average, people with mild losses require eight hours of intervention; moderate, 13 hours; and severe, 21 hours.
In our submission we have proposed an alternative approach to the delivery of hearing services in Australia, and in our recent submission to the parliament's NDIS inquiry we also proposed significant changes. Our strong recommendation to this committee is that the Office of Hearing Services program and the NDIS services for deaf and hearing-impaired people be amended and sufficiently funded so that patient education, psychosocial and vocational rehabilitation needs of hearing impaired people can be properly addressed.

**Mr GEORGANAS:** In the view of ASORC, how effective is the current system in supporting Australians who have experienced hearing impairment as a result of workplace noise, and how can this support be improved?

**Ms Schwenke:** I am going to hand over to Anthony for that.

**Mr GEORGANAS:** And more and more of it is being identified, I suppose?

**Prof. Hogan:** It has been since 1990, when the then Worksafe Australia initiated the noise management in the workplace program. That is the last time we had a prevention campaign. Over that time we have seen behaviour change. My thermometer is the staff member on the tarmac at the airport. We have seen cultural change with people taking up hearing protection and noise control, and that has been terrific. But, basically, when you look at the workers compensation process, workers compensation has traditionally been seen as part of the person's retirement package. They are not offered rehab. They are given a lump sum under the table of maims and routinely not provided with hearing aids or rehabilitation. This is particular concerning, as we know that companies routinely screen and check the hearing of their staff and monitor them going deaf. They do not intervene. They do not offer them hearing services. They might give them a quick talk on hearing protection and so forth—address their legal requirements. They may do a noise survey.

When you look at the Safe Work Australia data, the majority of rehab costs associated with hearing claims are legal and the lump sum payment—predominantly legal. So, people under, for example, WorkCover New South Wales would not get a hearing rehabilitation service. As we draw to your attention in some of our submissions, we also note that addressing people's lifelong needs has been recognised in legislation in this parliament, and we concluded that the cost is shifted to the Commonwealth when they retire and they go into this Office of Hearing Services program. I have put this question to the Office of Hearing Services a number of times, and it is an issue they do not want to know about. So, basically, we are getting a cost-shift going on as well.

**Mr GEORGANAS:** I suppose this is more of a statement than a question. As reflected in some of the advertisements you see on TV, where they say, 'It does not matter how long ago you had you hearing', you can see they are actually targeting older people as part of that.

**Prof. Hogan:** Yes. The workers compensation law is that the liable employer is your employer of today and the last five years. In terms of targeting the worker, we saw in the recent weekend papers offers of Coles discount vouchers if you go along to a certain provider of hearing services. I question whether it is legal to offer an incentive in conjunction with the provision of an Australian government funded program, but that is what they do.

**Mr GEORGANAS:** So you would say that currently there is no intervention when monitoring has been done, or predominantly there is no intervention at a workplace whilst monitoring is taking place and you can see a decline in hearing, which could be or may not be from that particular workplace. How would you implement something like that? How would that be implemented, because to me it seems like a good thing to do, instead of just saying, 'Take more care. Put on your earmuffs,' or whatever other hearing safety things—

**Prof. Hogan:** All the materials were prepared by Worksafe Australia in 1990—introduction of a noise management at work program, how to control the noise, how to educate the staff, how the staff would be involved in noise control design and management and also the referral to rehabilitation services for workers with what they would call 'noise injury'.

**Mr GEORGANAS:** In other words, a lot of that has not been implemented.

**Prof. Hogan:** Exactly. The Canadian research would suggest that a key barrier to prevention is the fact that we are not intervening and saying that this person had their hearing injured at work and their needs are being addressed. Basically, noise injuries are an administrative process. You fill out a form when you retire and you get a compensation claim. It is not an injury management process.

**Mr GEORGANAS:** I know you have mentioned some figures of what it costs us in productivity and a whole range of other things; could you put a dollar value on what not having those interventions is costing us?

**Prof. Hogan:** There is a dollar value in our submission with regard to the Safe Work Australia compensation payments.

**Mr GEORGANAS:** I saw that.
**Prof. Hogan:** One of the things that I am concerned about is that, to date, research to link the impacts with the outcomes has not been funded, and it is a huge gap in the research. We know that there are a bunch of health effects which are associated with hearing impairment, but we do not know if they are a causal or just happenstance—I happen to have high blood pressure and I happen to have bad hearing, for example. The causal work started to be done in the States, but we are a long way from those causal models. The Access Economics report of 2006 talked about the $11 billion. Further research suggests that that figure is too high, because hearing impairment itself adds two per cent to the unemployment number; the remainder of the unemployment of people with hearing impairment is often related to a second disability or illness. The economic cost is in the lower end of the billions, not the higher end of them.

But the real effects are on social inclusion and social participation: the older person being able to talk to their grandchildren, to participate at the club, to go to a movie. It is the social inclusion aspect. This goes back to when Alexander Graham Bell first designed hearing services. His whole aim was that people would take their place in society. We have a system in Australia that gives people devices and that is not focused, rather, on ensuring that they can take their place in everyday life.

**Ms Schwenke:** That is one of the jobs of a rehab counsellor. I am not sure whether people know the difference. I have heard the term 'social worker' mentioned, but this is a particular profession that has a specific role to play in getting people rehabilitated to participate in society, be educated or get back into employment.

**CHAIR:** In relation to that, is there specific training that goes towards being a rehab counsellor for someone who is hearing impaired?

**Ms Schwenke:** Absolutely. Typically it is a postgrad degree.

**CHAIR:** Focusing just on hearing?

**Ms Schwenke:** No. This is to be a rehab counsellor generally.

**Mr GEORGANAS:** So it is a rehab counsellor broadly.

**Ms Schwenke:** It is. It covers a range of things, including hearing, because they deal with people with a range of disabilities, but there is no particular module that I am aware of, even in these courses, that is specifically related to hearing.

**Prof. Hogan:** When I was at Sydney Uni, I offered to the rehab counsellors a semester program specifically on hearing.

**Ms Schwenke:** We do know our counsellors work in this area, because they responded extremely well to a survey we ran. You have, if you like, a body of professionals waiting to be used well. They are already doing it.

**Prof. Hogan:** We have that evidence here to table: a survey of our membership which shows the extent to which they are involved and the kinds of services that they operate. The amount of technical knowledge with regard to hearing can be covered quite quickly; the rehab counsellor learns the skills in counselling and behavioural change, particularly in the context of recovering from an acquired disability. That is what we have expertise in and that is the work we do. Our concern, as evidenced by our data, is that the rehab services are not being provided for people with hearing impairment. Their psychological needs are not being addressed. Their needs to make changes in communication at home and with the family or in the workplace are not addressed, because they are not trained how to do it or their workplace is not trained how to do it. They are the skills that we bring to the table and that people in other parts of the world think should be part of hearing services.

**CHAIR:** What is the difference between what a rehab counsellor would provide and what a psychologist would provide?

**Prof. Hogan:** The rehab counsellor, in my view, is the specialist in adaption-to-disability counselling. As we can show by our evidence, we do routine mental health assessments and we provide mental health counselling. The clinical psychologist, who technically is a person who has a registration as a psychologist, may do in-depth forensic and clinical reports, such as are provided for a court, but there are many people who have various qualifications in different types of counselling—welfare work, social work—and provide generalist services. Even with the psychologists and the rehab counsellors, we have specialists who work in pain and trauma. Psychologists specialise, for example, in psychological trauma and providing counselling. So there are similarities, but we have the particular expertise in coping with disability.

**Ms Schwenke:** Just to add to that, we increasingly find people with psychology degrees doing the postgrad work in rehab counselling to work specifically in that area, and in a way that tells you that there is something that they are not getting there, that it is an add-on they require.

**Dr FREELANDER:** Can your members access mental health care plans for funding at all?
Ms Schwenke: I cannot answer that question immediately. I would have to check that, but I would not think so.

Prof. Hogan: My understanding is that at this stage we cannot. We are not registered to at this stage. We would very much like to be at the table.

Dr FREELANDER: I was thinking that or allied health care plans might be an option.

Prof. Hogan: We would love to be admitted to that table.

Dr FREELANDER: Have you spoken to the NDIS about funding models for it?

Ms Schwenke: The nearest we have come is putting in this submission to their inquiry, but it is a bit of a closed shop. We have not been invited to sit at any table to discuss these issues as yet.

Dr FREELANDER: The NDIS is not a finished article.

Ms Schwenke: Correct.

Dr FREELANDER: I know they are receiving submissions from a whole range of occupations about service provision and inclusion in service models. Have you had any feedback from them at all?

Prof. Hogan: No. We have prepared a submission to the current Senate inquiry on the NDIS. In the context of this inquiry, we are quite concerned, because we believe the NDIS will set a very high fence. By 'high fence', we mean you must have quite severe to profound hearing loss in order to be included. We are hearing anecdotally, as other speakers have pointed out, that the states are shifting their services to NDIS in terms of disability.

Dr FREELANDER: Very much so.

Prof. Hogan: It is going to create a huge chasm. Either you are going to be very severe and get a service or you are going to get zip. The analogy I draw members' attention to is the Richmond report in the 1980s. The people who were in the schedule 5 hospitals at the time and were deinstitutionalised got a gold card, and everyone else ended up in boarding houses in the back of Balmain. Do you remember that?

Dr FREELANDER: Unfortunately, I am old enough to well remember the experience.

Prof. Hogan: As am I. Sorry; I got distracted.

Dr FREELANDER: What are your funding models?

Prof. Hogan: There is a second issue, and I refer to some of the earlier speakers today. The first thing we have in a population when a person acquires a severe profound hearing loss is an uneducated customer, and we are asking them to come to the table to articulate what they want as their rehab or disability support plan. We have a very uneducated market, and market education is seriously required for people to be able to say what they need and want. We have a process, as we heard earlier, of technology capture: someone can provide you with a device or whatever. Part of the response we have heard from NDIA is, 'Isn't a cochlear implant enough?' or, 'Aren't hearing aids enough?' We are saying, 'Far from it.' From the vocational data itself it is evident that basic support needs about taking your place in society are not going to be met. I will come back to my previous point, though. The majority of people are not sufficiently impaired with their hearing to make NDIS.

Dr FREELANDER: Yes, that is true.

Prof. Hogan: And that then goes back to 26- to 64-year-olds.

Dr FREELANDER: I have a couple of other questions. Have you had any problems dealing with Australian Hearing, and do you get referrals from Australian Hearing?

Prof. Hogan: No.

CHAIR: No to the second question or no to the first question?

Ms Schwenke: I cannot speak for every individual member, but not generally, not as a society and not from an organisational perspective.

Prof. Hogan: My concern with the Australian Hearing model—and they are the biggest provider, in my understanding—is that it is hearing aids and more hearing aids. And this goes back to the 1970s. A chap in the States, Mark Ross, pointed out that when they were marketing hearing aids in the seventies and the late sixties the message was very clear to the providers: if you cannot provide a hearing aid to the person and fix them, you are the failure, because the devices are really good. This has created a culture for the last 50 years where people are not looking at the person holistically. They are just saying: 'If this device is not the one that is going to fix you, the next generation will. You are just going to have to wait for it.' There has been this ongoing promise that technology will deliver.
Mr GEORGANAS: You said 'holistically'. I know each individual is different and the requirements of individuals are very different. Can you give us an example of a holistic approach, which would include—

Prof. Hogan: We would say: 'First of all, before we do anything to you, we're going to enable you to get across the page in terms of what you need to know about your hearing, what your options are and, specifically, what problems you are trying to solve. It is not about: we're going to come in, measure your hearing and tell you that you have an impairment and we have a device that can fix that. It is about: what is your problem; what can't you do?'

Mr GEORGANAS: I suppose they could be someone who cannot hear properly in a crowded room or cannot do their job anymore.

Prof. Hogan: Our data would say that even with a hearing aid two-thirds of the people are going to have problems hearing in a noisy room. Maybe part of their package would be that we would teach them some communication skills about how they can say in a comfortable way to people, 'Hey, we need to turn down that background noise because I can't actually hear what is being said.' The common problems are with the phone, the doorbell and the TV, which are all remediable by low-cost devices, including mobile phones today.

There is information about alternative and low-cost technologies and support in asserting oneself. I had one guy once who had profound hearing loss overnight. That person needed grief counselling, support and then basic communication training before he was able to begin to make decisions about his rehab program. They are the kinds of things we are talking about: education about what their needs are and what their options are, coping skills and management skills, and also support for the family. If I came home tonight with diabetes and the doctor had said, 'Change your lifestyle,' that is a household discussion. It is not just an individual discussion. We need to bring the family with the person.

Mr GEORGANAS: So it is much more than a hearing aid?

Prof. Hogan: Much more.

Ms Schwenke: Absolutely. We do not want to not recognise the brilliant work done in devices and, yes, best practice on that level, but let's not be smug about it and assume it is best practice on what you have asked about the holistic level. We are about, sure, outcomes and about the best use of taxpayers' money.

Prof. Hogan: When I was evaluating the cochlear implant program, we could basically say, 'With this device we are going to double your quality of life and halve your problems, but we only brought you to 70 per cent.' It is this mind the gap—it is the 30 per cent or 40 per cent, depending on what your needs are and if you are in the workplace. People would report how they basically have to manage their own disability in the workplace because, basically, if you do not fit in you do not stay. It is not about appropriate workplace adaptation. People often need support in how they can cope with the communication in the workplace when it is all by overhearing the gossip and so forth that they cannot hear. They are the kinds of supports that people have. These are largely ignored, or basically ignored, in the existing system. People are sent away to cope.

Mr GEORGANAS: And other devices, apart from hearing devices, that exist.

Prof. Hogan: Yes.

Ms Schwenke: Correct.

Prof. Hogan: Just on your previous question, I have not done workplace work for some time now. My opinions are based on when I was doing noise management control in those workplaces. Hopefully they have changed, but I have not seen the evidence.

Mr ZAPPIA: Are any of the counselling services covered under the MBS schedule?

Ms Schwenke: No.

Prof. Hogan: No, but, again, this—and I know it is very close to our president's agenda—would be really good if it could be admitted to the table.

Mr ZAPPIA: If, under the new home care trial that is underway, a GP needed the services of a range of other allied health professionals, including a counsellor, then that would not be covered under that package?

Ms Schwenke: No.

Prof. Hogan: Our funding would not be, no.

Ms Schwenke: As someone else earlier said, there is a range of education that has to be done with GPs as well because they do not necessarily always understand that if someone comes to them with hearing loss it is more than just a device.
CHAIR: Just to be quite clear, who would manage a patient's support in the model that you are proposing? Obviously you are saying that the deficiency of the current system that you have is, effectively, that services and audiologists are providing the assessment and the hearing aids, but then they are not giving the complete care that the person needs to cope with the other emotional and psychological factors et cetera. Who would actually be managing the care program for an individual?

Prof. Hogan: I would like to avoid a turf war here.

CHAIR: I am not asking you to participate in one! But, for example, for people with chronic illnesses, we now obviously have a new model where there is greater focus on who is going to manage the care. I am assuming that you have something in mind for—

Prof. Hogan: There is a variety of models. With an uninformed community, as we have at the moment, it is difficult for the client to be their own case manager. We would like to see dialogue with the audiologists and the audiometrists as to how we could make this work. I think that is an important thing that needs to occur. In the flowchart in our submission, you could come into the system either through us or through that provider. The other alternative model is by nurse audiometrists or nurses who are working in GP practices. Lots of nurses out in the community do audiometry, and there is a professional body of those mainly women providers. It could easily be managed as an allied service from within the GPs as well, and that that person case managed and referred to either program.

Part of our training, and I defer to Cristina, is that rehab counsellors are trained as case managers; that is what we do. Often, with an injured worker, they will come to us and we will organise a series of services for them: GP, audiologist, psychologist—whatever it is they need. What we do not have in the current system—and Australian Hearing is a good example, for example, with complex clients: a person comes as a complex client, and there is no case management. My understanding is that they are not referred to anybody else; you get your device or your more advanced device. In the old days, there were people like Sharan Westcott, who was the chief audiologist of Australian Hearing. She ran some great programs for people with complex clients, but those people are gone, and the business now has a focus on devices, not on the management of complex needs. It needs to be recovered in some form, and we think we should be a part of that dialogue and be helping them do it.

CHAIR: You mentioned in your opening remarks that you believe the Danes had a model that was better suited to current needs. What, essentially, is the difference between the Danish model and what we have at the moment in Australia?

Ms Schwenke: If I could just refer back to that, because there were three specific things that they did. We are talking about client education, which Anthony has mentioned; effective communication training; and psychological support for individuals and their families—besides the hearing device. What we are hearing is that it is a lot about the hearing device and not enough about those other aspects.

Prof. Hogan: Leaders with Australian Hearing from decades ago—Geoff Plant, Marg Anderson—were sponsored by various processes, including Australian Hearing and National Acoustics Laboratories, to go overseas and investigate these programs. Their reports that these things should be adopted are a matter of record, but they have never been adopted, because we have a very device-centric model. That is partly an historical accident. The initial model set up in Australia was the kind of model that we are talking about. That was after the war. Then we had the rubella epidemic, German measles, and all of the resources got shifted to kids. That is good—what you have been hearing is that we have excellent children's services; don't break it. But, in the meantime, we forgot about the adults and we never went back. What our submission is saying is that the initial design was good. In the early days, the audiologists were also trained in psychology, but, currently, you could be an engineer and become an audiologist. They are not getting those other skills. We are talking about generational change there. With the epidemic—if I can use that word—the wave of older people, coming through in the next 15 years, we do not have time for generational change in the hearing service providers. We need to diversify the model.

CHAIR: You would not last long as a politician, if you called it an epidemic of older people! Thank you very much for your time today. If we have any further questions, we will provide them on notice.

Prof. Hogan: Am I allowed to respond to an earlier question, Chair?

CHAIR: We will keep moving. If you want to provide a written response, feel free.

Ms Schwenke: We have a couple more papers, which we understood we could just table with you. Can we do that?
CHAIR: That is fine; you can provide them to the committee secretariat. You will be given a Hansard transcript of your evidence today. If there are any matters arising from that, please contact the secretariat staff. Thank you, again; it is very much appreciated.

Ms Schwenke: Thank you very much.
CAVALLETTO, Mr Bart, Director, Services, Royal Institute for Deaf and Blind Children

REHN, Mr Chris, Chief Executive Officer, Royal Institute for Deaf and Blind Children

[11:59]

CHAIR: Welcome. Thank you for joining us at midday. Do you have any objection if any media want to record any of your evidence today?

Mr Rehn: Not at all.

CHAIR: I will just remind you that these hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make a short opening statement?

Mr Rehn: Yes, please.

CHAIR: Fantastic. Thank you for your submission, as well.

Mr Rehn: It is a pleasure. The Royal Institute for Deaf and Blind Children is Australia's largest non-government provider of hearing and vision services. We are a complex organisation that cover the education, health and disability sector. We are focused on getting the right outcomes for people with hearing and vision loss.

About 6,000 Australians access our service on an annual basis. We run the largest cochlear implant program of its kind in Australia and one of the top five in the world at the Sydney Cochlear Implant Centre.

Our primary concern is really the wellbeing of people with hearing and vision loss and making sure that they are well supported. If you are looking specifically at the hearing context, RIDBC has led a consortium that has been in discussions with government in regard to the future of Australian Hearing, not because we have wanted to entice government to privatise Australian Hearing but because, more importantly, we were concerned with the types of ownership that could happen should it go through a normal commercial sale process from the government into private ownership.

That focus really looked at three specific issues. The first was preserving what is great about Australian Hearing as a very important service provider, particularly to vulnerable Australians—those Australians covered under the community service obligations. The second was to ensure, if you like, that there was protection, particularly for those vulnerable clients. And the third was an extension of services to cover all aspects of hearing loss, inclusive of cochlear implants and areas that Australian Hearing does not provide for.

Our services are nationwide. We use both physical sites—that is, visiting sites—and telepractice. One of the areas that we particularly focused on is how you actually deliver services to clients in remote and rural areas. Those clients typically have been well served under the Australian Hearing model but we have some concern about how NDIS may impact on them with regard to the specifics of how services are delivered. Particularly, we would say that we are very strong on the idea that there should be a single obligated provider of services to vulnerable clients—those clients covered under the community service obligation.

We really strongly advocate for improved awareness of hearing loss. We believe hearing loss is a highly treatable condition. It requires a comprehensive response, but it is actually well within Australia's ability to respond to the hearing health needs of Australians. We think that there are critical elements that require transdisciplinary understanding that the NDIS has not yet captured and we are very keen to make sure it is not, as Anthony said before me, a product process but actually a more comprehensive, multidisciplinary approach to how we actually help Australians navigate their journey from hearing loss to success.

We strongly recommend that the national hearing health database be confirmed. When you have one provider, such as Australian Hearing, it captures a lot of information, but as the state-by-state rollout of newborn screening has occurred we have been very keen to make sure that we harness and capture the data that probably sets Australia apart from the rest of the world. We capture and understand a lot about our newborn hearing loss. We would like to see that extended, obviously, to adult clients as well.

We think that screening is very important and, whilst we have done a great job, I think, from an Australian perspective in introducing newborn screening, other age categories should be captured in that screening process. Hearing loss is a very significant factor for the elderly, and our view would be that there needs to be introductions of screening processes to assist elderly people understand that they have a hearing loss and what treatment options are best for them. We also support the fact that the Commonwealth government should see hearing health as a national health priority as well.
We are proud to be part of this space. We have been in it for 156 years. We think we are pretty good at it. We like the fact that great outcomes are now possible for those people of all ages with hearing loss. The technology helps, but it is really only one part of the journey. I might just flick across to Bart to see if there are any other comments you would like to make.

Mr Cavalletto: I might just add two comments, if I could. One of them is around Australia being a leader in early intervention for children with hearing impairment, based on early access to that. One of the things that we would like to see maintained as part of Australia's hearing environment going forward is that early access. We are starting to see some switch there. I know that I can speak for a number of other providers—early access to early intervention for children with hearing impairment is absolutely critical. We are seeing that change through the NDIS and that is a significant concern for us.

The other comment I would make is that we have talked about hearing loss in adults. We are probably capturing, and are able to provide high-end services to, eight per cent of the people that we think could benefit from things like cochlear implantation in adults. The risk and the link between hearing loss and cognitive decline, such as dementia in the elderly, is becoming very clear as time progresses. Having people who are not able to access high-end hearing services will leave us exposed going forward. They would be my additional comments.

CHAIR: Thank you; you were enthusiastic there. I might kick off some questions. Can I just check before we do, though: are you under any constraints in relation to discussing your involvement in the bid for Australian Hearing?

Mr Rehn: Yes.

CHAIR: What are the parameters in which we can ask you questions about that?

Mr Rehn: You can ask me any questions that you like. The response that you get might actually be conditional on the constraints that are in place.

CHAIR: Okay, that is understood. Can I ask you a question about the bid for Australian Hearing? Can I be clear from your introductory statement—because there was a slight contradiction, if I can be so bold—you almost indicated that part of the rationale for the bid for Australian Hearing was almost a blocking mechanism to stop it being eventually sold to a commercial provider. Or have I misread your comments in that regard?

Mr Rehn: From our perspective, this is a very important service provider to vulnerable Australians, and we believe the government should retain ownership of it. However—

CHAIR: So your preference is for the government to retain ownership of Australian Hearing?

Mr Rehn: Correct; that is right. Under a National Disability Insurance Scheme, we see some challenges associated with full contestability of the space that Australian Hearing occupies. We have been in discussion with governments about what we think are the risks associated with a fully contestable area and community service obligation clients. But, with a Commission of Audit recommendation for the sale of Australian Hearing for the potential of it being moved into commercial ownership, as a consortium and as a very interested party to the hearing health space in Australia, RIDBC assembled a group of leading organisations—Cochlear Ltd and Macquarie University—to consider whether there was another model, should government move it into non-government ownership.

CHAIR: Can I clarify that the model you propose is a not-for-profit model?

Mr Rehn: It is.

CHAIR: My third question in relation to this is that you mentioned that you thought there were opportunities to expand service provision under the model that you are proposing; without inviting you to criticise Australian Hearing—although you can if you want to, of course—do you believe that there are deficiencies in the current model, and where do you see the greatest opportunities for expansion?

Mr Rehn: Maybe I will answer the second question first. I think the biggest phenomenon that has impacted on outcomes in the last 30 or 40 years is the advent of the cochlear implant. Australian Hearing funds very limited repair and upgrade services for cochlear implants, but is not actively involved in the cochlear implant space. Our view is what we consider to be a total service model. We are already providing this under RIDBC, where you can transition people from the different technologies as they see fit. Australian Hearing deals, largely, in the hearing aid technology and the bone-anchored hearing aid technology; it does not deal with the cochlear implant from a clinical service delivery perspective.

CHAIR: Is your concern, then, that people who need a cochlear implant are not being referred at the appropriate time, because of the narrow focus of Australian Hearing?
Mr Rehn: Yes, if we made it a little broader than Australian Hearing, one of the challenge that we believe is real is that it is quite difficult to see the transition between hearing aids to cochlear implants. Commercial interests get in the middle of it, and I think that, quite often, it is left to the client to discover when they need to look at the next step of cochlear implantation, because it does not fall within the remit of the private audiologists that they see. We deal with over 4,000 Australians with cochlear implants, and most of those people would have self-referred into a cochlear implant program rather than go through an audiological channel to receive that cochlear implant.

So from our perspective, creating an environment where you can seamlessly transition between the technologies is highly desirable, as is, importantly, providing access to those services. Cochlear implants have largely been a city-centric service in Australia. The model we have used with the Sydney Cochlear Implant Centre in New South Wales and in Canberra, Darwin and parts of Victoria is to actually improve that access to those high-quality services so they are not requiring patients to travel. Today, the two biggest issues we face are access and awareness—making sure people understand their hearing loss and what the treatment options are and access to quality services for it. One of the things that I think was a phenomenon well before the NDIS is convenience trumps all. Making sure that those services are conveniently embedded within communities where large cohorts of people with hearing loss exist is really important.

CHAIR: What is your understanding of what the NDIS will mean for people over the age of 26 and under 65?

Mr Rehn: It is a grey area. We would like to believe that some future process will actually capture those, but we do not have a very clear view of what the NDIS is going to mean for those people.

Mr Cavalletto: I think that is right. The aspiration or the expectation of all of us is that for that cohort between 26 and 65 it will potentially open up services for them based on their level of hearing loss. We just need to be clear on what the entry criteria for those people will be.

Dr FREELANDER: Thank you for coming along today, we really appreciate it. I worked with the RIDBC in the past and it is a fantastic organisation you should be very proud of, and I am sure you are. Am I right in saying you feel that for Australian Hearing the best option is for it to stay in government hands?

Mr Rehn: Going right back to some of the original scoping work the federal government did on the future of Australian Hearing, we made three observations. The first was that if you are going to retain it, it needs to be invested in because it is not everything it needs to be. It is a great, world-leading organisation—I am not here to criticise Australian Hearing—but it has, if you like, opportunities for improvement and expansion of services. The challenge that we see specifically in that investing is that it is slightly at odds with the philosophical approach with NDIS. Having full contestability of a space and the government seeking to be and remain to be a big player in it is an oddity to us. That is not to say that the government will or will not do what it wants to do, but it seems unusual to make a space contestable and then invest in and grow it to be, if you like, the dominant player within it. They are challenges we foresee, but we are not clear on which way the government are going to go. The government have been absolutely consistent and they have made no decisions on the future of Australian Hearing. Our view and our reason for stepping forward was that we wanted to be pre-emptive. We would hate to read in The Sydney Morning Herald that it had been sold to an overseas hearing aid provider and all of a sudden the world changed for vulnerable clients.

Dr FREELANDER: If we start from that base, to me the problem primarily seems to be with the NDIS and how it approaches—I can only speak for children, really—that group of kids with severe congenital hearing loss. There seems to be not a proper way of them getting early intervention as soon as possible.

Mr Rehn: It is a complex network of service providers, with Australian Hearing absolutely in the centre. Even if you took Australian Hearing out, we very firmly believe that in an NDIS landscape you should have an obligated service provider. We run services in Darwin like early intervention services, telepractice services and cochlear implants services. In usual form we base ourselves right next door to Australian Hearing so that we can better coordinate services and not complicate the journey for a client. But we do it in a not-for-profit guise. From our perspective, you cannot make money in Darwin by delivering these services, but that does not make it an unimportant service; it is a highly important service to the people of the Northern Territory. If you put a commercial lens on it and said, 'It's full contestability from tomorrow and nobody is going to be obligated to be in Darwin,' how many providers are all of a sudden going to say, 'We're up for that; we'll cross-subsidise from our Mosman-based hearing service provider to make sure Darwin continues'?

So we actually believe that the best way that contestability can happen is that government may actually tender for this work. If it is not Australian Hearing, then perhaps put it out to a tender process where you will obligate a service provider to provide those services to ensure you do not actually see market failure.
Mr Cavalletto: In terms of the early intervention space, we have had very clear flows for newly diagnosed children with hearing impairment. They will have their newborn screening, they will go to diagnostic audiology services inclusive of RIDBC, they will go to Australian Hearing and, at that same time, they will be advised of the benefits of early intervention and the providers. So that has been a very close-knit and a very tight community. Parents have flowed to where they need to be. Services have provided the early intervention as soon as the kids hit the door, so to speak. I think what we are seeing, though, is that through the NDIS families getting access to a package in order to pay for early intervention services really has been delayed significantly.

What you are seeing is organisations like RIDBC, in essence, wearing the cost of providing those services. The other thing we are seeing is really patchy plans. Parents who can and cannot advocate for themselves are getting very different outcomes. And you are getting very different outcomes within families no matter how well they can advocate for themselves. So it is not the best situation that we are in currently. We get that it is teething, we get that it is growing, but we are not sure that we can see light at the end of that tunnel just yet.

Dr FREELANDER: Other service providers have put exactly the same thing. They are expected to take up the slack while they wait to get a package which is, sometimes, taking months. So it would be better to have a tick of the box if you have a child with severe hearing loss, and they all get a set funding that will start from day 1.

Mr Rehn: If I could just add to Bart's point, as well, in the slightly different way. We understand in NDIS there will be a lot of shiny new shingles and great websites out there that purport to do a lot of great things for people with hearing loss. As a long-standing quality provider of those services, we see the impact where people have been in the wrong hands. And, importantly—and I will use the child example—child development time is burnt as a result of not getting the right support at the right time. You cannot strictly put a commercial lens. We are fortunate that we have a philanthropic component to our service delivery that allows us to be the difference between an adequate level of service and a great level of service in achieving outcomes. But we are concerned that the journey is complicated for a new family where diagnosis has just hit them as they try and navigate who will be the provider that can provide the outcomes that their child is capable of.

Mr Cavalletto: You really do have to understand they are highly vulnerable patients and families who are in incredible levels of grief on the diagnosis of hearing loss. They are looking for a light, and any light will do. There is very significant difference and evidence around outcomes for multidisciplinary teams and transdisciplinary teams as opposed to sole providers. So we do also need to look at the quality outcomes and the quality of providers.

Mr Rehn: I think a specialisation is really important, too. Not everybody can work with a paediatric caseload. Not everyone can deal with the complex adult. Where we are a highly specialised organisation is we provide services directly and specifically for that. Small-based providers are somewhat challenged to be experts across all fronts. They are issues that are potentially at risk as those new shingles go up and those new websites—

Dr FREELANDER: And we are already seeing that.

Mr Cavalletto: I would say the same thing about audiology—not just early intervention providers. Getting specialist paediatric providers of audiological services is very tough. It is a very small pool.

Dr FREELANDER: And a very time-consuming one, as well.

Mr Cavalletto: Yes, quite right.

Mr ZAPPIA: Since the July election of last year, have there been further discussions between the society, Macquarie University and Cochlear with the government about the privatisation of Australian Hearing?

Mr Rehn: I will not say about the privatisation of Australian Hearing, but it is a matter of public record that we provided a submission to the federal government in September last year that looked at what we thought was an appropriate model should government decide to privatise Australian Hearing.

Mr ZAPPIA: Yes, but my question was: has there been further negotiations with the government and the other two parties?

Mr Rehn: We under confidentiality deed in regard to that.

Mr ZAPPIA: With respect to the contested services, is it your understanding that the NDIS, in terms of the use of the words 'contested services', will end up as a system whereby the individual will be able to choose the service provider, or is it your understanding that a service provider will be providing the service to the government and then the individual will have to go to that provider?

Mr Rehn: The former.

Mr ZAPPIA: The former—where the individual will choose which service provider they go to?
Mr Rehn: That is right.

Mr GEORGANAS: You mentioned earlier, in your opening remarks, about the Commonwealth retaining the services. You gave some examples where services could be eroded and you gave the example of Darwin. In a contestable market, could you give us any other examples of where there could be some erosion, specifically where it is black and white that there would be a big difference.

Mr Rehn: I guess the remote and rural is the easy one to say: unless there is enough money to be in a place, why would a commercial operator choose to be—

Mr GEORGANAS: You could tie it by saying, 'You get this particular service, but part of that agreement is to service this area as well.' So there are ways around it.

Mr Rehn: There are possibilities and ways—and I should say not all private providers would take a view that they are not interested in helping vulnerable Australians. The second is probably in terms of the quality issue.

Mr GEORGANAS: That is what I am more interested in.

Mr Rehn: The depth of services in providing paediatric services, the depth of services for complex clients, the types of networking to achieve good outcomes with Indigenous Australians—those types of areas I think are really quite at risk in an NDIS landscape. Again, that is why we believe having an obligated provider to look after those cohorts, as has been in the past with Australian Hearing, is so important.

Mr ZAPPIA: I have two questions about the submission you referred to earlier, which you lodged with the government in September last year: is that a publicly available document, and has the government responded to you?

Mr Rehn: To the first question I would say, no, it is not a publicly available document. The second is: whilst we have had conversations with government, we are under a confidentiality deed for that issue.

CHAIR: I have a final question to try to encapsulate everything. If you could determine the outcome for the arrangements in relation to the sector, is it a fair summation that you would say that effectively the current system should remain in place—that is, Australian Hearing remains government owned and is the obligated service provider for effectively the cohorts that it works with at the moment, particularly young people, but you would like to see Australian Hearing expand its range of services to include things like the provision of cochlear implants? Is that a fair summation?

Mr Rehn: Probably starting with having an obligated single provider is really important to making sure that the community service obligations continue to receive a high-quality standard of care. At the moment that high-quality standard of care comes via Australian Hearing. We see some risk associated with the NDIS and full contestability for Australian Hearing, so government would need to recognise the need to invest in Australian Hearing if it is to be able to continue to develop services to meet the needs of those vulnerable Australians.

CHAIR: So, effectively, at the moment, we have a contestable market for adults and a single provider, effectively, for children. Is that a fair summation?

Mr Rehn: Yes, that is right.

CHAIR: The model that you are proposing is effectively for the government to say that there is an obligated service provider that may or may not be Australian Hearing. Is that your proposition?

Mr Rehn: Our position as an organisation is that government should obligate a single service provider in an NDIS landscape. If it is Australian Hearing, all well and good, because we know they have a great track record in that space. If it is not, the contestability could be that it is open to tender and may the right organisation that can meet the needs succeed in delivering services for a period of time under contract to the government.

CHAIR: If there are no further questions, thank you very much for appearing today. It has been very useful. If we have any further questions, we will provide them to you in writing through the committee secretariat. You will be provided with a Hansard transcript of today's proceedings. If there is anything arising from that, could you come back to the committee secretariat as soon as possible. Thank you very much for your time. Can I ask a member to move that the document presented by the Australian Society of Rehabilitation Counsellors be incorporated in the committee's records. Is it moved that way?

Mr GEORGANAS: I so move.

CHAIR: I declare that carried. Thank you.

Proceedings suspended from 12:25 to 13:13
CUNNINGHAM, Mrs Julia, Treasurer, Audiometry Nurses Association of Australia Inc

HAWES, Mrs Tracy, President, Audiometry Nurses Association of Australia Inc

CHAIR: We will resume proceedings. I now call representatives of the Audiometry Nurses Association of Australia. I firstly ask whether you have any objection to being recorded by the media if they are present today?

Mrs Hawes: No, that is fine.

CHAIR: Thank you for the submission that you made to the inquiry, which was very helpful. These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence you give today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make an opening statement?

Mrs Hawes: Yes. Our organisation is a not-for-profit organisation which represents the professional interests of audiometry nurses, facilitates their ongoing education and provides a forum for their professional support and development. An audiometry nurse completes study for three years as a registered nurse and then undergoes the audiometry certificate at the Australian College of Nursing, which involves extensive practical and theoretical training.

Our audiometry association has clinical practice standards which recommend three-yearly peer reviews. As nurses, we adhere to the national competency standards for registered nurses set by the Australian Nursing and Midwifery Accreditation Council. Most of our audiometry nurses work for New South Wales Health in community health centres throughout the city and rural areas, offering free diagnostic hearing testing.

Unfortunately, there are limited jobs in audiometry as there is no succession plan for this specialty service. The course costs $5,610 to complete two audiometry subjects—audiometry nursing 241 and clinical issues in audiometry nursing 242. Subject 242 requires a minimum of 60 hours of clinical placement or until deemed competent by a clinical adviser in audiometry. These clinical advisers have a minimum of three years working in audiometry and have completed a workshop designed for clinical advisers of audiometry nursing students. Both units are worth 150 hours of study. There is no incentive to do this course as there is not usually a job at the end of it.

Due to a lack of audiometry nursing positions across the local health district, with often only one per district, the audiometry nurse may have to travel several hours to provide a hearing service in a hearing clinic. Currently there are long waiting lists for hearing services in community health, from six weeks to several months, maybe even five or six months. Families and clients are then faced with long-distance travel for hearing services in their local health district.

Besides community health audiometry hearing clinics, there are limited options for clients to have their hearing tested for free, especially in rural and remote areas where there may not even be a private audiology service. Costs of private hearing testing are often out of the reach of the disadvantaged, vulnerable families in Aboriginal communities. The average hearing test in the private sector costs about $140. We are seeing more vulnerable clients—children in out-of-home care, Aboriginal clients and refugee clients—with complex health needs.

New programs have been initiated by the government without the workforce to sustain them. Referrals from these programs are usually internal through the multidisciplinary team in community health, which saves costs. Paediatricians, ear, nose and throat specialists and other allied health services, school psychologists and families refer children to community health for free diagnostic hearing testing.

Rural and related areas have a short supply of audiometry nurses and hearing screeners to participate in screening programs for Aboriginal populations and rural health programs. Public hospitals and other government audiology centres such as Australian Hearing have strict criteria for services and are often overloaded or unable to see the clients, who end up being referred through community health hearing clinics run by audiometry nurses. It is not unusual for the audiometry nurse to cover the whole LHD—local health district—and run several clinics at different sites to provide hearing services.

All babies have newborn hearing screening at birth which rules out all but mild hearing loss. Children can develop conductive hearing issues such as glue ear and chronic otitis media due to poor living conditions, social status and reduced access to health care. Some congenital disorders and other factors can cause progressive permanent sensorineural hearing loss which develops after birth. Children born overseas—for example, refugees—may not have had a hearing test or could have been exposed to noise damage and low-socioeconomic living conditions which have contributed to their hearing loss. It is therefore important to have ongoing hearing services available to pick up these vulnerable populations before it impacts on their lives in our community.
Our main focus is on primary health care, working in partnership with allied health and other hearing health stakeholders. An audiometry nurse performs a comprehensive history and hearing assessment, providing a holistic health approach which may take up to an hour for each client. Often there are other referral pathways necessary after diagnosis. Many children have speech, learning and behavioural issues as a result of hearing loss which can impact on their overall potential in society. Often this is not picked up until the child goes to school. Early intervention with hearing testing will identify issues which can be addressed before they impact on the child's health, wellbeing and development.

Aboriginal and other vulnerable populations are the most disadvantaged, with reduced access to hearing services and testing, often residing in low-socioeconomic rural and remote areas. Ongoing referral costs to see an ear, nose and throat specialist are also a problem. Once the diagnosis is made, children are often sitting on a public health waiting list for over 12 months just for grommets whilst their hearing loss may become worse and their learning potential is on hold. The impact related to the hearing loss in the community is immense. As audiometry nurses we would like to have better access to and affordability of hearing services for all clients; a succession plan for audiometry nurses, with structured training and support by having a hierarchy of consultants and specialist nurses in this area; affordable training, with scholarships to undertake study in audiometry; and hearing screening offered to all children prior to school entry.

CHAIR: What is the difference between an audiometry nurse and an audiometrist?

Mrs Hawes: As audiometry nurses we are registered nurses, and then we do further study in audiometry through courses at the College of Nursing. An audiometrist can do a TAFE course. They could just be a layperson that does not have a diploma or graduate certificate in anything.

CHAIR: In relation to audiometry as a discipline, is there anything that an audiometrist can do that an audiometry nurse cannot do, or vice versa?

Mrs Hawes: We do not fit hearing aids. An audiometrist might work in a private enterprise and fit and sell hearing aids, but we are nurses. We are more vocational, I suppose. We do nursing and then do the audiometry course. It is non-profit and it is usually in the government sector.

CHAIR: How many audiometry nurses would there be practising in Australia at the moment?

Mrs Hawes: In our organisation we have about 100. We have had a lot more, but because there is no succession plan it has often been a dual role—you may be an early childhood nurse and an audiometrist. Because we do not have any KPIs they have taken these nurses out and put them into early childhood just to meet the criteria and the KPIs they need. Therefore audiometry has declined and we do not have as many clinics and audiometry nurses. I work for Western Sydney, so I have clinics from Auburn all the way through to Mount Druitt.

CHAIR: Who runs those clinics?

Mrs Hawes: Me.

CHAIR: You are a community health nurse, yes?

Mrs Hawes: Yes. When I started 15 years ago as an audiometry nurse, we had 12 audiometry nurses. It has not been a priority, but we have more programs coming in. We have New Directions, which is an Aboriginal program; programs for vulnerable families to help kids before they go into out-of-home care; and we have the out-of-home care kids. Community Services requests that they have a hearing test at least every year, and we have to do that; we have to test these children.

Mrs Cunningham: It is not mandatory to be a member of our association, so, to answer your question, there could be more audiometry nurses that we do not know about.

Mrs Hawes: Yes. And working in private practice too.

Mr GEORGANAS: Thank you for your submission. In your written submission, and you touched on it in your oral submission, you spoke about waiting times. In the written submission it was several months.

Mrs Hawes: Yes. It varies.

Mr GEORGANAS: What are the causes of this? Could you tell us what the causes are and how those waiting times can be rectified.

Mrs Hawes: We could rectify them by having more audiometry nurses. We are getting more and more children who seem to have hearing loss who also have behavioural, speech and language issues. We get a lot of referrals from ear, nose and throat specialists—children in, I guess, low socio-economic areas requiring grommets.
Mrs Cunningham: With a lot of audiometrists, audiology is not their core position. I am an example. My core position within health is as a community nurse, so audiology is something I do as well.

Mr GEORGANAS: As a community nurse, yes.

Mrs Cunningham: I work in Maitland. We were doing only 1½ days a week. I had to put in a submission to try and increase that because we have—

Mr GEORGANAS: This was for audiology?

Mrs Cunningham: For audiology, yes. We have got a five-month waiting list, so to have some extra clinics or some extra time would take away from whatever other role the nurses are in. There are very few audiology nurses that are employed as an audiology nurse. They are generally employed as an early childhood or community nurse and do audiology as a specialty.

Mr GEORGANAS: For the layperson, like me and maybe some others on the committee here, can you explain the actual role. Obviously it combines with nursing, but could you just give us a bit of an example of what you actually do.

Mrs Hawes: What we do when we see a client?

Mr GEORGANAS: Yes.

Mrs Hawes: They are usually referred to us, with an issue, through a central referral service. We do not see anybody just for a routine test, unless they have come through community services—

Mr GEORGANAS: Are they usually referred by a GP, or by—

Mrs Hawes: It can be a GP, ENT, school, speech pathologist or family— anybody can refer, as long as there is an issue. We pick up that there is an issue, and it could be a multitude of things. We then do a full assessment. The suite can take up to an hour, because we fill out the hearing health history, we do a holistic approach, we look at all the factors from birth, we see if they passed their hearing screening at birth and we look at their health history, and we have a report form that includes all the questions and how they are doing at school, what their speech is like and if they have seen any other parts of the allied health team. We look at all of that and then we do the otoscopy, so we check their ears; then we do tympanometry, so we can tell if they do have glue ear—fluid in their ears—it tells us the compliance; and then we do the audiology hearing testing with headphones.

After that, if they do have a problem, we have a referral process where we either refer back to the GP for treatment if it is otitis or any other condition that the GP can fix. Sometimes, they go on to see their ear, nose and throat specialist, because it is a little bit greater than expected. We will see them back in our clinic in six to eight weeks if the GP decides, ‘Well, just blow your nose and have some antibiotics or nasal spray, whatever.’ We see them again, so we often see one child, maybe, two or three times. We do not keep seeing them for the sake of seeing them, but we do need to see them to see if the treatment has worked. If not, that is when they might be seen by a specialist.

A lot of the population that I see cannot afford to go and see the ear, nose and throat specialist, so they have to wait on the waiting list at the major hospitals. Then they see them and they have to wait on and other waiting list if they need grommets or removal of tonsils and adenoids. So it is a long process, and you could be waiting up to two years.

Mr GEORGANAS: How detrimental is that time factor for the kids?

Mrs Hawes: It is huge. I have had children who have come into my clinic after a few months and they have said, ‘Oh yes, we are on all the waiting lists,’ and their tonsils are meeting, they have sleep apnoea, they are not learning and they are irritable. Finally, you see a child at the other end of it who has had all of this removed and treated and they are different children. They can behave, they can sit down in the class, they can learn and their speech has improved. It is amazing.

Mr GEORGANAS: Because we are inquiring into hearing, obviously, what detrimental effects are there on hearing through lack of other procedures, for example, tonsils and adenoids?

Mrs Hawes: These kids are held back in school, obviously. They do not go on to do well, at all. They cannot learn and their speech is affected, so then they are bullied at school, they are ostracised from their peers and they become unwell.

Mr GEORGANAS: Thank you.

Dr FREELANDER: How difficult is it to get a child into see an ENT surgeon?

Mrs Hawes: Very—if you have some money, they get straight in.

Dr FREELANDER: So you are saying there is a degree of difficulty according to your family income?
Mrs Hawes: Absolutely; in a lot of the area that I work in, in Western Sydney, the families cannot afford whatever it would be to see the ear, nose and throat specialist.

Dr FREELANDER: How much does it cost?

Mrs Hawes: I think it can be several hundred dollars. If they cannot afford the hearing test, which could be $140 in the first place, they are certainly not going to be able to afford double or triple that. And then, to get grommets put in, I think it can be several thousand dollars. These families might be on social security. They do not have any chance of affording that.

Dr FREELANDER: So they cannot get into see an ENT surgeon privately—

Mrs Hawes: They go onto the public waiting list.

Dr FREELANDER: At which hospitals?

Mrs Hawes: It is very hard to get into Westmead—very hard—you have to know a paediatrician that attends that hospital. They have to be quite serious—severe—to get in. My kids have got a better chance of getting in at Nepean at this stage, but that could mean that they are still waiting 12 months.

Mrs Cunningham: Some rural areas do not have access to ear-nose-throat specialists at all, so they have to travel. Tamworth is a classic example. At the present time there is no local ENT, so people have to travel distances, and once again that has an impact on the waiting list in whatever area they are travelling to, whether they go east or south.

Dr FREELANDER: Many quite large public hospitals do not have public ENT clinics.

Mrs Hawes: No, that is right, so that is limited.

Dr FREELANDER: What tends to be the waiting time between when you detect a hearing problem and treatment of that problem for those patients?

Mrs Hawes: With an ENT?

Dr FREELANDER: Yes.

Mrs Hawes: As I said, it could be months before they can get into a clinic, if they do have an audiology or ENT clinic, depending on which hospital and which direction they go.

Mrs Cunningham: Newcastle currently has an 18-month to two-year waiting list.

Dr FREELANDER: So it is years.

Mrs Hawes: It can be years, yes. I have had clients that say it is two years to get into this particular hospital.

Dr FREELANDER: What is your relationship with Australian Hearing?

Mrs Hawes: Good. We used to be able to refer our difficult or autistic children to them, if we could not test them in our clinic, because we just do play audiometry with headphones; they do VROA, which is free-field screening. We loved it when they would take our kids and say, 'Yep, we can test them; we'll get a result,' but, because of their capacity and funding, it has been very difficult to pass those kids on. They have sort of said, 'Can you just try again?' We have often had to say: 'Come back in three months, and maybe their development might've improved. Practice at home with the headphones, come back to us and we'll have another go at it.' If we have a child that we test that might have a sudden hearing loss and it is sensory-neural, they have been fantastic. I can refer them straight across, send the information and the reports to them, and they will get them in straightaway, which is great. These kids are fixed up with hearing aids and devices quite quickly.

Mrs Cunningham: If it is not a sensory-neural loss, it is fee for service now, which is difficult.

Dr FREELANDER: It can be an impediment. There is consensus that even kids who have passed their newborn hearing test should be retested on a population basis prior to starting school.

Mrs Hawes: That is what we recommend.

Dr FREELANDER: How effective do you think you will be in providing those services?

Mrs Hawes: We used to do school screening in our area until maybe 10 to 12 years ago. We used to test all five-year-olds’ hearing, vision and speech. We did find quite a lot of sensory-neural losses and a lot of issues that we followed up. Now, we are getting a lot of teachers who would like to refer the whole class to us, because they know that they have got to school and they have problems. It would be very hard to test them in the preschool environment. You may have to set up clinics in the community health centres to provide screening for four-year-olds, a little bit like with the StEPS Vision Screening. Hearing is a little bit harder to do in a noisy environment, obviously, so it would potentially be better to have community health centres run screening clinics.

Dr FREELANDER: Do you have enough staff to do that?
Mrs Hawes: Me? No, that is the problem. It is not prioritised. No KPIs cover that.

Mr ZAPPIA: You have answered pretty much all the issues that I wanted addressed. I take it from your answers that most of your work is with children from low-income families. Would that be a fair summary?

Mrs Hawes: That is why they are coming through community health for a free service—or for complex needs: they might have so many different issues that they cannot afford to spend the money on every single service that they need, so if they can tick one off by coming through community health, it might be hearing.

CHAIR: We heard evidence this morning from Sound Scouts, who have an app to assess children's hearing. Have you looked at utilising that in any of your practices?

Mrs Hawes: We have not. We know Australian Hearing recommend that to many of the families. The local health districts have not taken that on board, because it is fairly new.

CHAIR: I suppose when they are coming to you, they have already been identified as having a problem, haven't they?

Mrs Hawes: Yes, they have.

CHAIR: So Sound Scouts is almost like a prescreening.

Mrs Hawes: Someone else has already identified the big issue. But we do not just do screening; we do the full testing.

CHAIR: Thank you for coming today. I would not say it has been cheerful, but it obviously points to some of the issues we need to look at. Thank you for providing your perspective on that; it is very much appreciated. You will be provided with a copy of the transcript of the hearing today. If there are any issues arising from that, please let the committee secretariat know. Thank you for the work you are doing in such difficult circumstances.
O'LEARY, Professor Stephen, Member, Australian Society of Otolaryngology Head and Neck Surgery

[13:35]

CHAIR: Welcome and thank you for appearing today. Can I just check that you have no objection to the media recording?

Prof. O'Leary: That is fine.

CHAIR: Thank you. These hearings are formal proceedings of parliament and the giving of false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. The evidence you give today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make an opening statement that goes to your submission?

Prof. O'Leary: I am presenting for the Australian Society of Otolaryngology Head and Neck Surgery in the capacity of a member who has been asked by the society to prepare the submission because of a particular interest in hearing and balance. I would like to emphasise a few points.

The first point is that hearing loss is, to a large extent, treatable if people can gain access to treatment. It is treatable in the sense that we can oftentimes get people's hearing up to a level where they can communicate and participate in society. That is not to say that the hearing device is the whole of the treatment—far from it—but when we do provide people with appropriate measures for hearing, the experience of ENT surgeons is that their engagement in society, their contribution and their mental wellbeing improves a great deal. We also recognise that there are other people that need extra assistance. We have heard today the value, for example, of psychological help. I believe, frankly, that audiologists, audiometrists and most people in the profession, including doctors that have an interest in this field, recognise that importance.

The next thing to say is that it is also our experience that a lot of people are not gaining the appropriate treatments. It has been said here today that only about 10 per cent of people that would benefit from a cochlear implant are actually accessing that. We also know that a lot of people who would benefit from hearing aids either do not have them or are not using them. This is a complex matter to understand. It does seem to have a certain place of community awareness because it seems that whenever any particular emphasis on cochlear implants is placed in the media we certainly get a lot more referrals for people who need help. So if there is a greater awareness there seems to be more of a tendency for people to gain help. There may be issues in terms of referral, particularly from people that have hearing aids, at an appropriate time. There is also probably a lot of work that needs to be done in the community around expectations of what good hearing rehabilitation looks like with a device. In other words, if hearing aids do not provide absolutely everything or do not provide you with perfectly normal hearing it is not actually well enough understood.

The third thing I wanted to emphasise was that we agree that Australian Hearing is a gem in the crown of hearing for children in Australia and that there is serious risk of it being privatised or of it being in the current environment we are moving into for disability. Not only does Australian Hearing provide a quality service to all Australians but also it has provided the research that is really required to properly assess people. It has done it because it has been a government organisation that has actually been mandated with that role. A lot of the Australian Hearing Services methods are used internationally. Australian Hearing Services are thinking carefully about service to remote communities, for example, and how to use technology for that. So not only is there a risk to the service provision but also there is a risk to the integrity of world-leading research that would lead to better outcomes for the rest of the Australian people.

In terms of access to services, one point we wish to emphasise is that we note that the access to cochlear implants in the public system varies considerably from state to state. In some states you can wait on the waiting list for a very long period of time, and this is an issue, particularly for young children. Also, for public patients particularly, when their processor wears out there is not a way of getting a new processor through the public system. This is a very big issue.

ENT surgeons also give a lot of service to the Indigenous population, and many of us have a particular interest in Indigenous Australians, among whom it must be said that hearing loss is a very considerable issue. Hearing loss often is established by the age of one or before and may persist throughout childhood in Indigenous children. This means that it exceeds, by a considerable degree, the rates for an emergency in Australian hearing, according to the World Health Organization. We also know that a lot of the children have hearing loss that continues on into adulthood. This of course affects their education and employment opportunities and increases the risk of interaction with the criminal justice system. There has been work done to identify children, particularly in the Northern Territory, and to provide an assessment of their hearing, but what seems to be lacking is access to more definitive treatment. We know that a lot of kids are coming off programs at the end of the Northern Territory
service for children and they still have the same hearing loss, because they have not been able to access surgical treatment.

That brings me to another major issue that we see—that was really dealt with in the last presentation—and that is that there seems not to be a recognition in the health system that hearing loss in children is, in a sense, a form of emergency. It is not given the priority, by state categorisation systems, on waiting lists that it probably deserves. What you find in hospitals is that an ENT department will have to give service to either head and neck surgery or a cancer and it will always be the child with a hearing loss that comes off second best. That is because the system itself, across the country, does not prioritise surgical or medical treatments for hearing loss. In other words, the importance is not recognised.

Another point relating specifically to Indigenous people in this country is that it is very clear for those of us that work with Indigenous people that the short-term nature of any program that is designed to provide assistance means that there is a lack of coordination. There is a lack of coordination between the states and the Commonwealth, and there is a very short view to therapy, which means that treatment and ongoing treatment, which you need for at least the time that a young person is a child, seem to vary according to where the money has come from at a particular time. So we believe strongly that there should be a nationally coordinated approach to the treatment of Indigenous children.

There are just a couple of other things. We believe that telemedicine provides considerable opportunity for servicing people in remote areas. We think that there needs to be considerable innovation in how screening would occur, because we also support the idea of screening children before school, and also older people, but, with the current methods, it probably is not going to happen. It could readily happen, I believe, if new technologies were embraced and taken care of.

In terms of research, which is part of your remit, we are moving into a time of pharmacological and regenerative medicine in hearing loss. The first trials of such a medication will occur in Melbourne in a couple of months from an American company. Australian scientists have always been at the forefront of hearing and I think, in terms of the national profiling in this area, investment in that field would be well worthwhile. Do you want me to speak on balance as well, briefly?

CHAIR: Yes.

Prof. O'Leary: Okay, because we had two parts of our submission. I will be brief about balance. I will say firstly that it is a very complicated matter in terms of both the physiology and the treatment. It means that a lot of people are having great difficulty finding practitioners or groups of practitioners who can actually provide them with meaningful answers that actually lead to their therapy. This is because, really, it needs to be dealt with from a multidisciplinary approach. To treat balance problems requires a team of otolaryngologists, neurologists, audiologists, physiotherapists and often psychologists.

Those kinds of structures do not really exist. They exist to some extent for falls, but they do not exist for people with more general balance problems. There really could be a lot of work done to improve the plight of people with balance problems if this were initiated. Secondly, people with balance problems often also have hearing problems. All the social isolation and the lack of confidence that goes with hearing is exacerbated by balance problems as well. We do support the idea that community-based organisations are in a very good position for providing support to people with balance issues.

Mr GEORGANAS: Thanks for the submissions today and appearing before the committee. There are a couple of things that you raised in your submission and in your oral submission as well. One was the surgical treatment of middle ear infections for kids, the waiting list and the prioritisation within the medical health system that we have. How can this be accelerated? What is a way of accelerating this list, getting shorter time frames and getting people in there?

Prof. O'Leary: All health systems have a list of categories of urgency of treatment. Those categories tend to be based pretty much on a sense of life-and-death types of considerations. One way around it would be to mandate that anything that treats hearing loss in a child was automatically given a greater priority. There are special schemes for Indigenous children and for people living in remote areas to access treatment—surgical treatment, particularly—but the problem about that is that it does not change the fact that once you put a child on a waiting list, they still have to compete for other priorities. I think that the best solution would be to change the priority of these conditions in the formal structure in which cases are categorised and prioritised in health systems.

Mr GEORGANAS: That leads me to the next question: when someone is suffering from hearing loss or is losing their hearing, is there an optimal time for intervention through surgery? When we say surgery—and you
use the term 'surgery' in your submission—are we talking about cochlear surgery or other types of surgery? What is the optimal time for that period?

**Prof. O'Leary:** Are we talking children here in particular?

**Mr GEORGANAS:** Children and adults.

**Prof. O'Leary:** I think that surgery is part of the general treatment. For ENTs, surgery is one of the tools in our armamentarium. We do a lot of medical treatment. We are often the first people to see people who have had a sudden hearing loss, for example. For children, there is clearly a need for young children who cannot hear to hear before the age of three so that they can learn to speak, otherwise they will not. For young children—particularly Indigenous children who go for months and years with glue ear, for example—there is a benefit in getting that treatment as early as possible so that their speech and language can develop and their social interactions can be normalised and the social interactions of their families as well.

So I think there is a particular issue with treating conditions like glue ear or middle ear effusions in young children. These tend to be the people that languish on waiting lists, when there is probably a critical time they should be treated.

**Mr GEORGANAS:** And in adults?

**Prof. O'Leary:** In adults, the problems relate more to access to surgery for conditions where a hearing aid will not suffice in the meantime. That is particularly with respect to cochlear implantation. We try hard in cochlear implant clinics to prioritise someone who is still in work, for example, who is losing their hearing, so that they can keep contributing to the economy of the society. But, of course, that depends on resource allocation. So the real problem for people on public waiting lists for cochlear implants is that they are often falling out of engagement and production in society, and becoming socially isolated.

**Mr GEORGANAS:** So you would say time is of the essence?

**Prof. O'Leary:** By the time someone recommends a cochlear implant to you, time has probably elapsed, unfortunately, in many cases—yes.

**Mr GEORGANAS:** Thank you.

**Dr FREELANDER:** Thanks very much, Professor O'Leary, for your submission. It is very interesting. My concern is about disadvantaged people. In my electorate, which is Macarthur, in south-west Sydney, we have a lot of single-parent families and parents on low incomes, who find it virtually impossible to access ear, nose and throat surgeons. There is no public ENT clinic at our local hospital. As far as children are concerned, the waiting list at the Children's Hospital at Westmead runs for years. I do not think Sydney Children's Hospital has a functioning public ENT clinic. So, whilst it is interesting to hear your submission on the importance of early intervention, it seems to me that ENT surgeons have done very little to remedy the problem. Do you have any answers to that?

**Prof. O'Leary:** That sounds like a particular New South Wales quandary to me. I do not think it is the same issue in Victoria, where I am from. There are ENT departments in all hospitals. I can only reiterate that the system itself does not prioritise the treatments for these children. I again draw the analogy with head and neck cancer. If someone with a head or neck cancer case comes into a hospital, they will get treated straightaway. If a child comes in with glue ear—which of course will affect their hearing—they will languish on a waiting list because the system itself does not provide them with priority.

I believe that, if that were redressed at more of a hospital level, or by a state or Commonwealth directive or something like that, perhaps the hospitals would be happy to put the resources in to getting those children treated, and the ENT surgeons, from what I see, would be very happy to provide that service.

**Dr FREELANDER:** It seems to me that it would be good for the ear, nose and throat surgeons to advocate that publicly.

**Prof. O'Leary:** Yes. The argument is seen most strongly, probably, by those of us who work with Indigenous communities. Not everyone works in an area where there is social disadvantage; that is true. But I think this argument about the importance of raising the priority of medical and surgical treatment of children with these conditions is getting stronger, and I welcome the opportunity to be able to put this opinion today.

**Dr FREELANDER:** Good. Thank you very much.

**Mr ZAPPIA:** Professor O'Leary, I would be interested in your views on this. You have said that Australia is a world leader when it comes to hearing services. You also said that we as a nation do not prioritise hearing conditions. How did we become a world leader—and what were the contributing factors to getting us to that point—if we do not give priority to the very conditions that we are a world leader in?
Prof. O'Leary: That is a very good question. I think that there are two things that have been outstanding. One is the National Acoustic Laboratories. They have provided unbelievable leadership for the world, and continue to do so. That is at considerable risk right now, I think, with thoughts of potentially privatising AHS.

The cochlear implant is the other field where we are still held in extremely high regard. That has been technology driven, admittedly, but of course it has filled a particular gap where people could not be helped. Where there seems to be less of a concern by the health system is in the people with a lesser degree of hearing loss and in children, particularly. It is because the hearing has not been as bad, I think, and because it is not a new problem, in a sense—glue ear has been around for years, and children have had hearing loss for years. But the consequences for their development have come into sharper focus over recent years, and that is how I think this apparent dilemma could occur. I would advocate strongly that more work be done in models for service delivery for Australians to rectify that type of problem.

Mr ZAPPIA: I have one other question—and you touched on it very briefly—and it is about the National Disability Insurance Scheme. Do you have any views about the transition of hearing services to that scheme?

Prof. O'Leary: I think Victoria is performing pretty well. Tasmania sends its cochlear implants to Victoria. South Australia has been more of an issue. I do not know about the west. Queensland has not been as good, and New South Wales has been better, I understand.

CHAIR: You mentioned some trials that are underway in Melbourne. Could you elaborate on what those trials are looking at?

Prof. O'Leary: For the first time, there is a drug that it is hoped will regenerate hearing. Fortunately for Australia, in many ways, the first human trials will occur in Melbourne in a couple of months time. I must declare that I am actually the principal investigator on this. Being a professor, it is my job. But it is just a reflection that we have moved from where treatment of hearing has been entirely about devices to now there are about four start-up companies in the US who are looking at medical treatment for hearing. We would be lucky if it works with the best solution. That is at considerable risk right now, I think, with thoughts of potentially privatising AHS.

Dr FREELANDER: Are these hair cell regenerators?

Prof. O'Leary: Yes.
Mr GEORGANAS: Can I ask what the name of the drug is?

Prof. O'Leary: The name of the company is Frequency.

Mr GEORGANAS: If you have hearing loss and it is declining, is there any particular drug that works at the moment to prevent that or to slow it down? I know there are a couple around that work on the—

Prof. O'Leary: The simple answer is that intensive medical therapy can stop that progression or slow it down in some people. But there are no drugs that can just arrest hearing loss, as I think you are suggesting, right now.

CHAIR: Thank you very much for your time today. It has been very instructive. We will forward you a copy of the transcript. If you have any changes you wish to make or issues arising from that, please contact the committee secretariat. Thank you so much for your time.
COLLINGRIDGE, Dr Louise, Executive Officer, Independent Audiologists Australia

COLLINS, Mr Grant, Vice-President, Independent Audiologists Australia

[14:02]

CHAIR: Thank you for joining us. Before we get underway, can I just check that you have no problems if there are any media that want to record any part of your testimony.

Dr Collingridge: Not at all.

CHAIR: To get the formal bit out of the way, these hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Thank you for your submission. Would you like to make an opening statement in support of your submission?

Dr Collingridge: Yes. Thank you for inviting Independent Audiologists Australia to participate at this public hearing. We are a not-for-profit incorporated association that was established in 1987 with members across Australia. We promote and support clinical practices owned by university qualified audiologists. We are closely affiliated to Independent Audiologists New Zealand and the Academy of Doctors of Audiology in the US. Our members operate more than 200 clinics where they prevent, assess and rehabilitate hearing and balance disorders for Australians of all ages according to our stringent code of ethics. We welcome this opportunity to raise key issues and answer your questions.

The recent ACCC report revealed a culture of failed targets, commissions or clinical bonuses and preferred manufacturer arrangements in the distribution of hearing devices in Australia. Commissions or bonuses contribute to high hearing device costs, create conflicts of interest for clinicians and are often not transparent to patients or their referring doctors. IAA—that is us—take a strong position that failed targets, commissions and kickbacks are unacceptable in any healthcare setting. Corrupt practices reported by the ACCC have been taking place under the watch of self-regulation by professional bodies, regulation of unregistered healthcare practitioners according to a code of conduct in several states and rules set by funding bodies, including the Office of Hearing Services.

This inquiry, your inquiry, asked representatives of the ACCC last month whether further regulatory measures should be taken by Commonwealth or state governments, and whether further regulatory measures might preclude behaviours reported by the ACCC. IAA strongly believe that mandatory registration for audiologists and audiometrists, each with their own and separately defined scope of practice, and with a professional board under the Australian Health Practitioner Regulation Agency—AHPRA—that regulates influences from industry as well as clinical practices, is essential to enforcing professional standards acceptable in health care within the audiology field. Our largest self-regulating body, Audiology Australia, to which most of our members belong, asks the public to report incidents of conflict of interest, but states that it is unable to take any action on this because it cannot regulate the businesses that employ audiologists. Audiology Australia has said that it would support regulation and AHPRA, if government were to offer this option.

Regulation of health care is a contemporary issue, in particular where a healthcare profession and an industry are closely related, as is the case for audiology. Self-regulation has proved itself inadequate in the case of our profession. The Australian public should be protected in every clinical setting, regardless of which health profession is attending to their needs. Healthcare providers—such as the nurses we have just heard from, the doctors we have just heard from—and psychologists attending to those with hearing and balance disorders are required to register with AHPRA. Optometrists, who offer vision services comparable to the hearing services offered by audiologists, are required to register with AHPRA. It is difficult to see that those professionals pose a higher risk to the public than that posed by audiologists, who are involved in the diagnostic assessment and treatment of those with complex conditions for many people who are vulnerable, from newborns to the elderly.

Audiology is regulated in most countries in the world: in the US, Canada, UK, South Africa, Brazil, Israel and many countries in Europe. It is important to realise that audiology would already be a registered profession in Australia under AHPRA, along with the 14 other registered healthcare professions—or 15 if you include the recently included paramedics—if it had been registered in all states prior to 2010. So, it is an accident of history that we are not a registered profession.

In promoting mandatory registration and strict regulations for the audiology field, we have the support of audiologists and also of consumer groups, like Self Help for Hard of Hearing, Better Hearing Australia and Parents with Deaf Children. For audiology to become a registered profession under AHPRA now, we need a COAG decision to instruct AHPRA to form a professional board for audiology. Individual state governments need to be aware that audiology is a profession that requires mandatory registration and national regulation. Then
the topic needs to be placed on the COAG agenda so that a decision to regulate audiology nationally via AHPRA can be made, and the rules and regulations drawn up. So we ask this committee to use its influence to recommend that audiology and audiometry be included as registered healthcare professions, regulated by a professional board overseen by AHPRA. We ask that you inform state health ministers and premiers of your recommendation, and advise that the question of audiology regulation be placed on the COAG agenda. We also ask you to recommend that resources are made available for stakeholders to work together to ensure that the code of conduct that will be enforced by the new professional board serves to prevent the practices reported by the ACCC.

There have been some great ideas presented today, as well as in submissions, to potentially improve and retain hearing health and wellbeing of Australians. But unless we ensure protection through regulation of one of the major means of intervention—that is, hearing aid prescription and rehabilitation—then these gains are going to be potentially lost. Thank you.

CHAIR: Thank you very much. Before I throw to Dr Freelander, can I ask: what other associations exist for audioligists?

Mr Collins: There is Audiology Australia and there is ACAud—Australian College of Audiology.

CHAIR: So there are three organisations?

Mr Collins: Two. We are not a regulatory body of any description.

Dr FREELANDER: I should just declare that I do rent premises to an audiologist in private practice. I do not see that as a conflict of interest, but I will declare it. What relationship does your profession have with the national hearing service?

Dr Collingridge: I can certainly say that many of our members are former audiologists who have worked in Australian Hearing, so many of us have firsthand experience of having worked there. We would like to see Australian Hearing as a resource, as a government-owned agency that we can refer particular patients to. But we need to make it very clear: when Australian Hearing are talked about now, there is a blurring between the services for children and how they are operating in what is the Office of Hearing Services' voucher scheme for adults, for pensioners. There has been a change in that over the last number of years. So since Australian Hearing became a for-profit government agency, we have found ourselves, as Australian citizens and small- to medium-size business owners, having to compete with a for-profit government-owned agency, which we understand to be unprecedented.

Dr FREELANDER: And do you see that it has competitive advantages to your services?

Mr Collins: Yes.

Dr Collingridge: Yes. We are very sure that there is a competitive advantage to Australian Hearing in the voucher scheme. In an ideal world, we would not be competing with our own government, so we would prefer to see a decision made around Australian Hearing; however, that does not mean we necessarily consider that its services for children ought to be automatically privatised. It is a complicated issue. Every discussion around Australian Hearing needs to be forefronted with whether we are talking about the services for adults, for which the audiologists are paid clinical bonuses—which is the Australian term for a commission—for hearing aid sales, or the services for children, which have more of the philanthropic feel that we have been hearing about today.

Dr FREELANDER: Is there a suggestion that Australian Hearing has been changing its delivery model in the last few years?

Dr Collingridge: We have evidence that they have changed, they are changing. There is online, publicly available evidence of contracts they are offering GPs for direct pathway, which is contrary to the Office of Hearing Services's rules. They have an online advisory service, which directs people towards them. We have heard about their fee-for-service for children. We can see through that a thread of seeking to become profitable, which is what they have been tasked to do.

CHAIR: Would you mind providing some of that online documentation you referred to to the committee?

Dr Collingridge: Yes.

Dr FREELANDER: Going back to the ACCC's recent findings, did you agree with them? Do you believe there is—

Dr Collingridge: One hundred per cent.

Dr FREELANDER: How can that be regulated?

Dr Collingridge: It is interesting, because we have to look at the parallel between the medical profession and the pharmaceutical industry to see how that relationship has been regulated. It may not be perfect, but if you look
at the code of conduct for medical practitioners under AHPRA, there are very clear statements around conflict of interest and avoiding conflicts of interest. We see that that is a necessary step. Because audiology is very interrelated with technology and technology is sold in industry and the hearing aid industry being what it is, we do believe there need to be very clear guidelines around that, as well as the banning of commissions, which has not been taken up by any of the self-regulating bodies. We understand from the Office of Hearing Services contribution to this inquiry that they say that they may consider it, but that is only going to protect one portion of Australians. We are looking at protecting the whole of the Australian population.

Dr FREELANDER: Do you see the audiometric societies and the audiological societies as merging together to be registered under AHPRA?

Mr Collins: Yes, both. You cannot regulate one without the other, because we are dealing with similar populations and issues. There would have to be separate terms of regulation and scope to practise, because they are very different professions, skill sets and education requirements.

Dr Collingridge: We do also believe that the public has not been well informed about what the difference is between an audiologist and an audiometrist.

Mr Collins: Wikipedia too, by the looks of it!

Dr Collingridge: Currently, the self-regulating bodies have again left that up to a self-assessment type of tool. Clearly, we see that there is a very big difference in the expectations of someone operating with a TAFE diploma versus a postgraduate master's degree. That is simply an educational standard and difference in ability to apply new knowledge and innovate. We understand that the training for audiometrists is intended to be a hearing assessment for the purpose of fitting a hearing aid to adults. There is a defined scope of practice around that.

Dr FREELANDER: There has been consensus that children, as well as having their newborn screening test, should be retested prior to school entry. Do you see yourselves as having a role in that and do you agree with the premise?

Mr Collins: Yes. We already do have a role in that. A lot of our members do regional and remote work and, as part of our work, we do those school-age screenings, definitely—or preschool age.

Dr FREELANDER: What is the cost of that?

Mr Collins: There is some funding there—it depends. Some are fully funded under some Indigenous health programs. A screening assessment can vary. We work off billable hours in my clinic, so it just depends on how long a screening is. It might be anywhere from $40 to $75 for a screening. If there is a history of chronic disease, it could be fully Medicare claimable.

Mr ZAPPIA: To become an audiologist, how many years of study are required? How long is the course?

Dr Collingridge: It is a minimum of five years of university study, because you have to have an undergraduate degree, which is a minimum of three years, and then it is a two-year full-time master's degree.

Mr Collins: Then there is a 12-month internship period under a registered audiologist.

Dr Collingridge: Under Audiology Australia.

CHAIR: I suspect I have had experience with this, but are there are many snake oil salesmen in the hearing sector that cause you concern? I raise that because I remember a speaker coming to my Rotary Club selling his cassette tapes that played 'unhearable' music that would solve your hearing loss. Is that a frequent occurrence?

Dr Collingridge: It is an occurrence. Another related concern is the number of online businesses that are starting up. For example, last week I had a phone call from a company that had set up a company called Hearing Aid Comparisons Online. Their previous experience had been selling mortgages and private health insurance, which are products. They wanted to set up a referral system whereby we would pay them for each referral and we would pay them a percentage of every referral that turned into a hearing aid fitting. He had arrangements with some companies already, and I asked how they were getting around the ethics of that, given that it is unethical to pay for a referral, and that any additional payment on a hearing aid is going to push the price up even further for the public. He admitted that he did not know much about audiology before he set up this business. That is just one recent example. There are many people who are doing very similar things and are trying to cash in on what is perceived, unfortunately, as starting with the Access Economics report that created a supposed market. Whilst we may agree that there are many people fitted with hearing aids who do not use them, it is also a misunderstanding to think that everyone with a hearing loss needs a hearing aid or benefits from a hearing aid. We have heard this morning a lot about some of the supplementary rehabilitation that is part of what audiologists are able to offer and are trained to offer. It ought to be equally recognised. The service provision needs to be equally recognised as the device provision. We have heard already mentioned today that whilst Australia's system may be considered
'enviable' by some people—that is the much quoted term—it is sometimes hard to see when the services are not funded and are not valued, and everything is focused on a device.

**Mr Collins:** That is getting back to the earlier discussions about bundled versus unbundled—including the price of the service in the hearing aid. There, really, is no such thing as a free hearing test, for example. It is just bundled into the price of the hearing aid which then is elevating the price of the hearing aid. If you do not purchase a hearing aid when you go into your free test, your time is then made up for the next person who buys their hearing aid.

We believe in—and we advocate to our members; we do not enforce it—unbundling and transparency. We clearly designate where the charge is for our time and our expertise. Whether that is rehabilitation—in terms of not prescribe a hearing aid—we talk about strategies and assist with communication skills and retraining, and we do not fit a device. Or we supply that rehabilitation in addition to the device and we charge for our time for those services.

**Dr Collingridge:** In an ideal world, it should not matter to the audiologist if there was adequate funding from government and health funding. It should not matter to the audiologist whether their time was spent fitting a hearing aid, assessing somebody, counselling somebody, providing a follow-up, visiting a school or visiting a nursing home. All of those kinds of functions ought to be equally funded in the same way that any other allied healthcare's time is funded. But we have had this model where all of the funding is attached to a device. That has been exploited by a number of companies that are closely linked. They will say they are not vertically integrated but they may have a parent company that owns both, et cetera. It is where there are close associations between the device industry and the professionals that they employ.

**Mr GEORGANAS:** What proportion of hearing aid clinics are owned or partially owned by hearing aid manufacturers? Are you aware of any parent companies?

**Dr Collingridge:** The Hearing Care Industry Association represent those companies. Recently, one of their responses to the ACCC report has been that they claim 60 per cent of the overall market of the adults' hearing aid fitting.

**Mr GEORGANAS:** That is an audiologist that is owned by a manufacturing company?

**Dr Collingridge:** No. Those are chains of hearing clinics. Many of them have close ties to the hearing aid manufacturers.

**Mr GEORGANAS:** What sort of ties? What would the ties be?

**Dr Collingridge:** They may have a parent company that owns both the clinic chain and the hearing device chain and then the clinic chain has a requirement or preferred provider agreement.

**Mr GEORGANAS:** Basically, a parent company that owns those other companies.

**Dr Collingridge:** They own a number of companies.

**Mr GEORGANAS:** How difficult does that make it for an individual owner-operated or small company?

**Dr Collingridge:** Which is what we represent.

**Mr GEORGANAS:** In terms of competition, how does that affect the smaller people?

**Mr Collins:** It does not really have too much of an effect. The only effect it has is: if you are choosing to unbundle and be transparent with your pricing and charge for your time, not offering—a lot of these companies offer the free hearing tests because they have bundled models, and that is what their marketing is based upon, whereas we—

**Mr GEORGANAS:** So there are no difficulties in competing with them?

**Mr Collins:** Pricewise, obviously they own the company; so they have a link with the hearing aid manufacturers. Obviously, we cannot compete in terms of purchase price of hearing aids.

**Dr Collingridge:** But their prices are designed to be very profitable for them. One of the biggest competitors for the small businesses at the moment, ironically—and we hope it is going to change very soon with your influence—is Australian Hearing. It is ironic because Australian Hearing ought to be a resource that we can all tap into rather than it being competitive with us. But they do. They do have that competitive advantage. The chains, because they are privately owned, are subject to the same kinds of trading laws and so on as we are.

**CHAIR:** You started to segue to the issue that I was going to raise. We heard from, obviously, the rehabilitation counsellors this morning. I think that their concern was that, on occasion, audiologists would not have the training to provide a broader support to someone with hearing loss—be it psychological or broader
counselling. Do you see much scope to increase collaboration and so on for people who need that broader range of services?

Mr Collins: Potentially. First and foremost, knowledge is empowerment. Being able to accurately describe and communicate why they are having their problems is the first thing in key rehabilitation, whether hearing aids or not. Really, those in the hearing industry are best to deliver that knowledge to them. We do provide rehabilitation and counselling and strategies with or without devices. But there is definitely scope there where we, potentially, have done as much as we can, and a referral on to a suitable counsellor or psychologist may well help to assist.

In using it as a broad method of channelling the majority of participants to, the demographics that you are working with may have short-term memory issues. If you sent them to a counselling session there is a chance that that not much may be retained. At least with a device there is some sort of tangible thing that they can get assistance with—someone can put it in and take it out in the morning. Whereas if you did not have that, in terms of if you are funding only counselling, you may have a bit of an issue there.

CHAIR: A final question from me. Dr Collingridge, at one stage during the hearings today you were shaking your head in vehement disagreement with something that one of the witnesses was saying. Can you recall what that was?

Dr Collingridge: I think that has happened several times!

CHAIR: I suppose the broader question is—just for our benefit because we, obviously, hear a perspective from those in the chair—is there anything that you, as someone who has sat through most of the day, that you have heard from other witnesses that you think has led the committee down the wrong path?

Dr Collingridge: I think, certainly, a good understanding of audiometrists and audiologists is important. This is not in any way a criticism of audiometrists. They train to do what they do. There is an overlap between what audiometrists do and what audiologists do. That overlap happens to coincide with the funding from the Office of Hearing Services, which is the primary funder in our field because we have been quite left out of much of Medicare and other types of funding. So there is a misconception that audiologists and audiometrists are interchangeable. They may be interchangeable when it comes to doing a basic hearing test and fitting a hearing aid to an adult. That is, unfortunately, where the funding is. So that is why there is a perception. Hopefully, that is cleared up.

I think one of the other areas—again, I have already mentioned this—is to clearly separate the practices of Australian Hearing related to the voucher scheme, which are competitors for profit and are aggressive at the moment, from their work with children. We have been tracking this inquiry and the inquiry into the NDIS. Consistently, when they are asked questions, or when questions are asked around this, we hear about their work with children—which is admirable and which we all see benefits from and completely support. But that tends to be the halo.

In the process of being tasked with becoming a profitable for-profit agency in order to be sold, which is a well understood, transparent issue, they have become a major competitor and very aggressive with that competitive advantage. We do not necessarily want to see them disappear. We would like to see them as a friendly resource, rather than having to compete with our own government, which seems completely bizarre. We understand, from the small business ombudsman, who we have had dealings with, that there is no other profession or industry that has to do that in Australia.

Dr FREELANDER: Do you have any difficulty getting your clients access to ENT surgery?

Mr Collins: In the private capacity, no, but publicly, yes. The more regional you get, the harder it is. I am Queensland based, and, in Queensland it takes about 18 months to two years for public access. I live up in Townsville. We have got 30 sites from Townsville down to Brisbane, and then outreach into Mount Isa, Quilpie, Charleville and all of those regional and remote areas.

Mr ZAPPIA: Could you give me a summary or an overview as to what funding is available for hearing services for a member of the public who comes to see you? What is covered under the Medicare Benefits Scheme and what is covered by Australian Hearing? I am trying to get my head around what a client or a patient is confronted with.

Mr Collins: I will start at a paediatric level. With Medicare, if the doctor recognises a chronic disease then they could possibly get access to a Medicare Chronic Disease Management referral, which covers audiology, which is $52. Yes, community health nurses, but they are inundated. There is some funding there through Indigenous health for some remote communities, which fully funds some of the paediatric services there. You can also go privately, which is anywhere from $90 to $190, depending on where you go; there is private health

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insurance, but there are usually gaps there as well; and there is Australian Hearing. If hearing loss is detected, you want to know about funding for hearing aids and rehabilitation et cetera. If you are a child, then Australian Hearing—all of your funds are automatically covered. With adults, once you turn 26, if you are talking about hearing aids then that stops. NDIS is meant to kick in then, but that depends on the degree of your hearing loss.

Mr ZAPPIA: Do any of the private health insurance companies pay for any of that—say, for a hearing aid?

Mr Collins: For adults?

Mr ZAPPIA: Yes.

Mr Collins: Yes, but there is generally a gap. The problem, again, is that they just charge for a device, not for any rehabilitation or services like that. They do contribute, and the amount that they contribute varies between $400 and probably $2,000. If you are between 26 and 65 and you meet the criteria for NDIS, what is meant to happen is that you are meant to then be able to gain access to the Hearing Services Program via NDIS, as well as other support agencies and networks. If you do not meet the criteria then you are fully self-funded—your private health insurance covers whatever. Again, if it is a chronic disease, you might get a CDM referral. If you are over 65 and you are not eligible for a pension: nothing—private health insurance and that is it. In terms of cochlear implants—we work in that field—private health insurance and Medicare pretty much covers most of that—it depends on different models. Because we are unbundled, we do not give any, but Medicare covers everything.

Dr Collingridge: I would like to point one thing out, which is something that we have raised before. In 2012, Medicare introduced some item numbers for audiology, which require a request from an ENT surgeon. Now there is a disparity in the funding for the same procedure whether an ENT claims it or an audiologist claims it. We see that as unfair and we hope that Medicare will review that and introduce some equity.

CHAIR: And if you are over 65 and on a pension then you are entitled to the voucher from Australian Hearing?

Mr Collins: Yes.

Dr Collingridge: Or if you are on a disability pension.

Mr Collins: There are a couple of other funding options there, but they are not normal funding pathways. But hopefully NDIS will clear up some of that.

CHAIR: Thank you for your evidence this afternoon. It has been very useful. We really appreciate your time and also appreciate your travelling so far as well. If you have come down from Townsville just for this we are very grateful. You will be sent a copy of the transcript of your evidence today, and if there are any issues arising from that please contact the secretariat. If there is any further information that you think the committee could usefully have—and I think we specifically asked for some more details about the competition with Australian Hearing—could you provide that to the committee secretariat, preferably by 20 April if you can. That would be much appreciated. Thank you again for both the submission and appearing today.

Proceedings suspended from 14:36 to 14:55
SPRING, Mr Stephen, Private capacity

CHAIR: We might get back underway. I will just check whether you are happy for media recording of part of your testimony?

Mr Spring: Not a problem.

CHAIR: These hearing are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. I would like to start by inviting you to make a short statement.

Mr Spring: Thank you. What I would like to do today is present some of my story and then I am quite happy to answer some questions at the end. Some of it is a little bit technical, but what it will hopefully help the committee do is understand some of the difficulties and problems in inner ear research. I was diagnosed with Meniere's disease by Professor Bill Gibson in 2004, when I was 38. I was told by Professor Halmagyi that I should be expecting retirement. I was quite devastated. I went on to become the vice president of the Meniere's Research Fund at Sydney University. I believe Daniel Brown, who is a fellow at Sydney University at the Meniere's Research Fund, gave evidence this morning.

CHAIR: He was our first witness, yes.

Mr Spring: I essentially became very frustrated with the glacial level of inner ear research. I found it extremely frustrating partly because I had a personal interest in getting it better as fast as I could but also because of the way that the whole structure of inner ear research in Australia takes place. I was very lucky that I found a friend and an advocate, Bill Gibson. Bill Gibson, who you may have heard of, was one of the pioneers of the cochlear implant and set up the majority of the cochlear implants centres here in Sydney. This is his autobiography, which explains some difficulties he had right at the very beginning trying to convince the community that the Sydney Cochlear Implant Centre was going to be successful. We look upon the cochlear implant program now as being a great Australian initiative, whereas it was not back then. I am quite happy to presented his autobiography as an exhibit if you want to take it.

I was stuck in this dilemma where I had Meniere's disease, nobody could help me and there was no cure. I entered up having a situation where I had to do a lot of private research myself. I run a legal practice. Essentially, what I did is a set up a war room and accumulated well over 3,000 research articles. I employed some people to privately help me understand what was going wrong with me.

Bill Gibson taught me that Meniere's disease is a disease of the endolymphatic sac. The endolymphatic sac is this organ that hangs off the end of the vestibular apparatus. That is actually the immune node of the ear. It is the immune defence organ of the inner ear. When that goes wrong in Meniere's disease, it has implications on the vestibular system, as well as the cochlear. You do not just have balance problems; you have hearing loss, tinnitus and all those other problems that you may have been alerted to by the Whirled Foundation, who may have also given evidence. The trouble is, though, that the endolymphatic is a tiny little organ that is buried right down in the middle of the skull and there is very little you can actually do with it, although various different surgeries have been tried over the years. The long and short of it is that it is known to be an incurable and degenerative condition.

The research that I did—and there was over seven years of it—led me to believe that I had some genetic defects in my immune system. Privately I undertook a whole series of genetic tests and immune tests, and I discovered that a lot of research had been done in the 1970s and 1980s by pioneers who had discovered a lot of these problems, but the actual research itself was not translated into medicine and it languished in the books and journals of the day. I essentially travelled around the world to various different things, and Bill Gibson introduced me to a number of these professors who had run major research organisations back in the seventies and eighties and who had retired. I embarked on a program with another guy, called Lindsay Wing, who was looking at inner ear problems as an immunological problem. Whereas traditionally when people have problems with their inner ear it becomes a surgical issue, and if it becomes really bad you will get cochlear implants, the research path that I took was to look at the immunology of the inner ear.

For various different reasons—I will not go into some of the technicalities—a lot of people who do have Meniere's disease, and we are up to nearly 75 per cent, have genetic defects which at the moment are detectable but unrecognised. I went on to develop a vaccine and I have been working with a number of Meniere's disease patients, through their doctors, to develop a program where their immune system is changed to be able to rehabilitate the endolymphatic sac. People with Meniere's disease have much higher rates of autoimmune disease, much higher rates of diabetes and much higher rates of heart disease, so it is a systemic disease. The committee
may think that the hearing loss and the tinnitus is bad and the vertigo is much worse, but left untreated it has enormous systemic effects later on down the track.

The way that inner ear research is structured in Australia is extremely disparate. From my time at the Meniere's Research Fund—and I am quite sure Daniel would have told you this—I know the funding model for inner ear research is one where essentially you compete for funds and the rest of it is all private. The work that I did cost me an absolute fortune, but I really had no choice; I was stuck in a situation where I was the afflicted one. The Meniere's Research Fund, which was set up by Bill Gibson and Bruce Kirkpatrick—and Celene, who is up the end there, has also been a member for many years—is essentially volunteer work, and the money originally came from philanthropy. I think this is very short-sighted, because solving the problem before we even get to cochlear implants seems to me to be a much better solution. I have now been able to develop a series of genetic tests and a genetic algorithm, and hopefully I will be putting those into good use over the next few years.

What I really want to talk about today is the disconnect between ENT, audiologists and immunology, and that has particular Australian relevance because genetic defects similar to those found in people with Meniere's are also rampant in the Australian Aboriginal population, and that is probably one of the contributory reasons they suffer much higher rates of hearing loss, especially when they are young. It goes on to have an enormous impact upon not just the general community but their learning and behaviour.

There was a day when Australia used to be a world leader, at the cutting edge, but what we tend not to be able to do is translate that into adequate treatments. Part of the problem, and my experience through the Meniere's Research Fund, is that it takes a group of people who are passionate about a particular disease, certainly in this case, to get private funds together, and then the NHMRC funding will then supplement the various different projects that they have. The problem is, though, that none of that is integrated. We have a situation where you have people doing inner ear research in a bit of Europe and a little bit in America and a little bit here. Daniel Brown's laboratory, in the Brain and Mind Centre, is the only Meniere's research specific laboratory in the whole of the world. They can punch above their weight, but unless all the little ends are all being stuck together you do not get the full picture.

Daniel Brown does not have a clinical arm. Anything that is new and innovative is going to be tested on animals, and then he is going to hit a barrier. He is not going to be able to translate that into clinical trials because the money is not going to be there. Daniel Brown has developed a very innovative diagnostic tool for detecting Meniere's disease early. We cannot get it into market. I have developed this immunological treatment. It is almost impossible to get it into market. What I am suggesting is that what we need to do is look at a funding model where much of this stuff is integrated.

Probably the best model to look at would be the one that Chris O'Brien set up at the Lifehouse over in Camperdown. He was a cancer patient himself and he was able to look at the research, the treating doctors, the support groups and integrate all that into one single model where the research became translational medicine. Out of that came a much greater understanding that cancer is numerous different diseases. I think that is the kind of model that needs to take place. We do not have in this country a centre of excellence for ear and balance health. We just do not have it. Stephen O'Leary runs the Bill Gibson professorship down in Melbourne—there are a little bits like that—but there is nothing that pulls them all together and says: why aren't we looking at prevention?

It is the way that the industry has developed over a period of time. It is not something that is anybody's fault. But I think, taking things forward, if we are going to take hearing and balance as a serious health implication for our ageing population, integrating all of those disciplines together—as Stephen O'Leary said: sometimes you have to be able to have a multidisciplinary approach, especially when you have children. That to me seems to be the best way. So from an inner ear research point of view it should not really be up to private individuals to scratch around, when the benefit for the community, if there is successful translational medicine, is going to far outweigh the initial investment.

We only have to look at the cochlear implant program. Right at the very beginning it was one or two individuals. They needed state money to be able to kick that thing off. The Chris O'Brien centre—the Lifehouse—needed state money and federal money to kick that off. It is beyond the capacity of individuals, even if they are quite rich philanthropists. We are talking tens of millions of dollars. But the benefit to the community by prevention far outweighs the $10 million.

I would simply summarise by saying that we do have the ability to be world leaders if we are able to integrate the infrastructure so that Daniel Brown's work, my work, work from Stephen O'Leary—all of these things—can come together. At the moment you have little pockets of it that do not seem to be able to talk to each other. That, to me, is a very inefficient way of running something which is so fundamentally important to people's health.
Mr ZAPPIA: Mr Spring, thank you for appearing before the committee, and I commend you for the extraordinary effort that you have made towards finding solutions. It would seem to me that your pitch is that there ought to be a coordinated effort made and that that should come from the government, in terms of either providing funding or in fact by pulling it together. Has there been any attempt, to your knowledge, by the various pockets which are currently working in silos, to come together? Has anyone suggested it, from amongst whatever there is out there, to at least come together and share your work? Or would it be your perception that they all prefer to work in silos because they each want to have their own small domain?

Mr Spring: You have hit the nail right on the head. Part of the problem with the general research community is they like to be able to work in silos because each one is chasing their own particular field of interest. Once they build up this bank of NHMRC funding, they continue on with that and become self-funding. There is nothing wrong with that, but if the way that you are getting information is competitive, and the way that you are getting information is via the medical journals—there are gaps between them. The great brainstormed ideas of the medical profession that have led to the cochlear implant, for instance, have only come about when people have collaborated. Again, let’s go back to the cochlear implant. It took electronics; it took audiologists; it took ENT surgeons; and it took a whole series of normally disparate professions to talk to each other to say, ‘How can we do this?’ I think that is where we need to go. Unfortunately, immunology, and the massive impact that it has on hearing health, is not really taken as far as it could be. I think this is the gap that needs to be filled. It would probably take a coordinated effort—if the funding is available—by government to bring those people together.

CHAIR: For those of us who have not had direct experience of Meniere's disease, could you give us a snapshot of how the disease manifests itself, what life was like for you after the diagnosis and how it deteriorated.

Mr Spring: With the program that I have done, I have a very slight hearing loss, and I have a miniscule bit of tinnitus. I am one of the lucky ones because I have been able to help myself, with other people around. However, what normally happens is the first sign is a violent vertigo attack, when the room simply starts to spin, and this is because the fluid that is inside the endolymphatic sac is actually stimulating the vestibular organs. You therefore have no control over it. It is often accompanied by vomiting because your brain becomes disorientated. Most people tend to fall to the floor because they cannot stand up. You end up with a roaring tinnitus, which is probably like standing next to a jet engine. At the beginning it will subside, but eventually those symptoms can often merge into one, so you have constant tinnitus, and then eventually, over a period of time, you will start to lose your hearing. That is because, as the inner ear starts to break down, the delicate hair cells that are in the cochlear start to become damaged. It becomes fibrotic, and when it becomes fibrotic the ear has no method of cleaning itself out, and therefore the disease sets in; it becomes degenerative.

Not only do you lose all your sense of who you are because you cannot communicate with the world; you lose your orientation because you cannot stand up. Having chronic imbalance means that you cannot walk on sand or drive a car. It means that you are too frightened to go down the street to pick up your groceries because, if you have a Meniere's attack whilst you are there, you are going to be on the ground, prostrate and throwing up. That is the kind of thing that people end up living with. There are varying degrees of severity. For some people it is a minor nuisance, but for some people is completely devastating. I am lucky that I did not end up with a really devastating form.

CHAIR: The research that you have done—and you have talked about the treatment that you have helped develop—is that now being more widely used?

Mr Spring: It is one of those things where I can help people via their doctors. There is a small program that I have been running privately via doctors, and there is some interest with the Healthy Hearing & Balance Care centre in Bondi Junction, because those people understand what Meniere's disease is. The trouble with a lot of ENT surgeons is that they do not get the immunology connection. So, because it is not a standard kind of treatment, they tend to do the conventional treatments that have been proven not to work. Then, when it gets really bad, they say, 'Don't worry; you can have a cochlear implant.' The treatment that I have been working on is all about preventing the disease getting worse. It does not mean that, if there is a little bit of damage, your hearing might come back 100 per cent. But, if it comes back 75 per cent or 80 per cent and you have your balance back again that is preventing the disease from becoming more degenerative.

Mr GEORGANAS: I hear you loud and clear about the importance of coordination with the different groups working in silos. Is there a way that you can get them together? Are they willing to work with one another? It might be easier said than done when it comes to actually getting them together. Do you have a view on that process?

Mr Spring: My view is that everybody who works in medical research does so for the right reasons. There are going to be some people who want to get rich and famous, but there will also be a whole bunch of people who
simply want to plod away and contribute to society—and, if their name gets on some papers, that is fantastic. There are various models. Over at the New South Wales university, the Lowy Foundation have donated a large amount of money for genetic research. They provided the money for the hardware, and that enabled the New South Wales government and a couple of other government organisations to say, ‘If we’ve got some money, we’ll contribute an equal amount, and we’ll put you in a box that is specifically designed for this kind of thing and we can run patients through here and the amount of information that we get can then be used for translational research.’ The Chris O’Brien situation, when they set up Lifehouse, was based on a similar model. It is beyond the capacity of any one philanthropist and it is beyond the capacity of any one organisation to stick all that together. I think it requires a concerted effort from state governments and the federal government and the people who have the expertise and the skills on the ground to be able to say, ‘That's the vision that we need to share.’

Dr FREELANDER: Thanks for coming today. Meniere's disease is a terrible disease. My father had it and was very disabled by it towards the end of his life.

Mr Spring: I am sorry to hear that.

Dr FREELANDER: I have not actually read much about it, and I was interested to hear some of the things that you said, such as that there are genetic defects identified in Meniere's disease.

Mr Spring: What happens is the body has an inability to recognise and process viral and bacterial antigens. Therefore, you have a gene dose effect, where some people have these low copy numbers of these genes and some people have normal copy numbers in these genes. Meniere's disease is a disease of Caucasians mainly, and most of it is Northern European. Australia has a population where we have a vast number of people who have genes from the Northern European gene pool. Some of those gene defects are prevalent in the northern Australian Aboriginal population. It is partly because of the way the human population has become fairly isolated in certain parts. But, when we have immigrants who come from Northern Europe and we are looking for solutions, we have to take their genetic background into account.

Dr FREELANDER: Have they identified these genes?

Mr Spring: The cost of gene sequencing used to be $15,000 or $20,000 a go; nowadays it is relatively cheap, at a couple of thousand dollars. It is not that difficult to identify if you know what you are looking for. There is no point going ahead and trying to do gene studies when you are trying to find a needle in a haystack.

Dr FREELANDER: But are there any published papers that have identified the gene?

Mr Spring: There are numerous papers that have been published. I basically brought all these little parts together and, now that the gene sequencing has become cheaper, I want to incorporate it into my treatment as a first screen. Hopefully in the next couple of years we will be able to publish some papers about that, but as I said before—

Dr FREELANDER: But as yet there is nothing published?

Mr Spring: No. The majority of this stuff was done in the seventies and eighties, but it tended not to be recognised. What they knew at the time was much more limited than what they know now.

Dr FREELANDER: Did you say you have developed a vaccine for this disease?

Mr Spring: Yes. There is a particular way you can get antigens into the body. It is not an injectable, but a sublingual.

CHAIR: Could you just explain that?

Mr Spring: Sublingual mean it goes under your tongue. The antigens are then recognised by the immune system. It is typical immunotherapy, but done in a slightly different way, and this was pioneered by a guy called Lindsay Wing. He was nearly 90 when I met him, 10 years ago. He was kind of laughed at by the ENT community because he was doing immunotherapy to help his Meniere's patients. Unfortunately, I think he had a heart attack and then stopped practising. But immunotherapy has now become the way of treating cancers. In other words, you are using your body's own immune system to be able to stimulate it in the right way to be able to help solve some of the diseases which are impossible to solve any other way. The vaccine I have developed is essentially a series of antigens that stimulate the immune system in a particular way that goes to overcoming the gene defect that is inherent in those people.

Dr FREELANDER: One would have to say, from my reading, that there is no proof.

Mr Spring: That is exactly right.

Dr FREELANDER: Bill Gibson has retired now. Have you been able to interest any particular ENT research group into picking up on your theories?
Mr Spring: Yes. I have travelled to a number of different conferences. I know Stephen O'Leary. We put in various different government grants for the NHMHC. But you are competing with everybody else. I understand there is a limited amount of funds, and sometimes you are on the bottom of the pile. The other thing about immunology and the ENT profession is that never the twain shall meet, so a lot of the stuff—

Dr FREELANDER: You had better be careful, I think there are a couple of ENT surgeons behind you, and they might have their knives out!

Mr Spring: I think they would properly concede that that is the case.

Dr FREELANDER: This morning, Dr Brown made a similar point to you, that there is more of a need for research into Meniere's disease and balance disorders. He was lamenting the fact that some of the ENT surgeons in the past that had an interest were retiring, and there was a need to set up a specific Meniere's research group. It would seem to me that that is what you are asking for.

Mr Spring: I suppose what I say is that Daniel Brown is essentially little much more than a one-man band, and I am little much more than a one-man band. And I believe bringing all these things together with proper government funding to do things preventively is going to have much greater impact long-term. The other thing that is very important to realise—and you just touched upon it with the point about Bill Gibson and retiring. Bill Gibson, as a pioneer, developed a lot of techniques to detect endolymphatic hydrops, which is the medical name for Meniere's disease. It requires a doctor to be able to insert a needle through the eardrum to touch essentially a little membrane that is inside the inner ear. There are very few people in Australia that do that, so if you have Meniere's disease but do not know and are undiagnosed and you go to a doctor with symptoms, they say, 'We can only go on symptoms because there is no real test.' But the truth of the matter is that Bill Gibson has been teaching people around the world how to do this test and it is the gold standard. But it is not properly taught in the universities and very few people pick up on that. Whilst he has written books, it is not something that is structured, and things tend to get lost in the system.

CHAIR: Thank you very much for coming along today and giving evidence. It has been quite a fascinating insight.
CHAIR: Welcome and thank you for participating in today's hearing and for making your time available. These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament—which sounds far more serious than hopefully it will be! The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Would one of you like to make an opening statement?

Mrs Andersen: Good afternoon. Thank you, on behalf of Hear for You, for having us here today to speak about our organisation. With me are our CEO, David Brady, Chairperson Kim Jones and New South Wales Coordinator John Lui and one of our mentees, Year 10 student Olivia Barnes. Thank you for providing the captions of those who, upon these captions, can feel included.

I wear one Cochlear implant and one hearing aid. I have been deaf all my life. I am the founder of Hear for You which I established in 2008 using a Churchill Fellowship Award to study global business and programs for deaf teenagers, combined with my own life changes. Our aim is for all young people with a hearing loss to realise their full potential in life. We now provide mentoring programs to students throughout Australia. Since June 2008, over 700 deaf teenagers have been involved with the program. We have their positive feedback. Our model is based on trained, deaf, successful adult mentors providing inspiration, motivation, confidence and support to deaf students at such a vital stage of their lives.

An estimated 21,000 children and teenagers in Australia have some form of hearing loss. Many use hearing aids and Cochlear implants. They can experience isolation in mainstream schools. They are shut up in social isolation. They face consistent stigmatism about their hearing loss. Research has shown that teenagers who have those social isolation problems associated with making themselves understood are four times more likely to have a mental health disorder. I would like to highlight some of our key recommendations from the submission to this inquiry:

- To investigate and work with organisations such as Hear for You;
- To initiate a national investigation into the lives of deaf teenagers in the Australian education system;
- To commission an academic study in schools regarding the levels of communication, proficiency and psychosocial outcomes and find the best cost-saving solutions;
- To then use the results to provide the basis for best practical education for deaf students and, where needed, educate schoolteachers on deafness, hearing loss prevention and how to help tackle the bloody stigma of living with hearing loss;
- To implement hearing screening programs for all schoolchildren and, when those children are identified with hearing loss, to provide them, along with their parents, with unbiased information about deaf support services available to them;
- To prioritise and support youth mentoring at state and federal level for deaf students, we recommend you go one step further and trial an at-risk program aimed at deaf teenagers in mainstream schools.

We have made other recommendations in our written submission for you to consider, especially to make hearing health and wellbeing a national health priority. As evidence, I am pleased to present Olivia Barnes to explain how Hear for You transformed her life. After Olivia, John Lui will provide a brief overview of deaf teenagers' experiences with Hear for You and how the program works, and share with you directly the voice of young deaf Australians.

CHAIR: Welcome, Olivia. Did you get the afternoon off school?

Olivia Barnes: Yes. Good afternoon. My name is Olivia Barnes, and I am 16 years old. I am in year 10. I was diagnosed with severe hearing loss when I was just six weeks old, and had my first hearing aids fitted a few weeks later. I wear hearing aids in both ears. I refer to myself as deaf. Being deaf is at times isolating. Being a deaf teenager is very isolating and, for me, very lonely, especially at school. Starting high school at Queenwood...
School for Girls in 2014 was a very challenging experience for me. Suddenly there were twice as many girls in my year. That meant 50 per cent of my year 7 class did not know me or know anything about my deafness. I struggled with the pace, rushing from class to class, and trying to hear was exhausting. Trying to keep up with conversations at recess and lunchtime was almost impossible. I fell behind socially. I was not being included. I was not getting any invitations to social events. It was very hard.

By chance my mum saw an article about Hear For You in a magazine, and she immediately thought it could be something that could help me. In April 2014, I attended Hear For You for the first time and can honestly say I felt like I found gold, because I met other deaf people just like me. It may seem strange, but before Hear For You, I did not know many other deaf people. My family does not have any history of deafness, and I had not had all that much to do with deaf people. There are many other deaf teenagers and the deaf mentors at Hear For You. I do not feel so alone. Hearing about their experiences and seeing young deaf adults with jobs, family and personal achievements is inspirational for me. At Hear For You, I made really good friends. I am part of a strong social group. I feel included. I feel right in there, not hanging on the edge. I feel like my friendship is valued. The best part is I do not have to tell my story, because my story is their story.

Through Hear For You, I have become more confident. I have the skills to be my own advocate. I found the strength in year 8 to ask my school if I could do a presentation to my year on what it is like to be deaf. My school was very supportive. Why did I speak to my year? Because deafness was not understood because there is nothing there. In my presentation, to further demonstrate what it is like to be deaf, I brought in earplugs for the girls to put into their ears. I would then do my presentation to the whole school. It was worthwhile. Everyone now knew my story. Not everyone suddenly became my friend, but a lot of girls became more considerate. It was a small change but it made a big difference to me.

Educating my school on what it is like to be deaf has been very important to me. It let them know that just because I wear hearing aids I cannot hear like they do. I cannot hear well at all in noisy places and I cannot hear soft voices. It let them know that covering their mouth or turning away from me when speaking makes it almost impossible for me to be part of a conversation.

Being deaf, I am often misunderstood. I was able to get the help I needed from my mentors at Hear For You. Hear For You has been there for me. I learned so many skills to help prepare me for my next phase as a young deaf person. I have learned social skills, I learned how technology can help deaf people and I have learned about career choices. I learned how to use my voice to stand up for myself. I learned that I can and should make valuable contributions to the community. I would love to become a Hear For You mentor when I am older.

I urge you to please seriously consider making hearing health and wellbeing a national priority as soon as possible. I am one of the lucky ones to have found Hear For You, which has made me realise my potential. I wish every deaf and hard of hearing teenager like me can access Hear For You and, more importantly, live in an Australia where there is no stigma on hearing loss. It is my future Australia too. You have the power to change it for millions of people like me. Please help us, because there is nothing there. Thank you for listening to me. I would like to hand over to John, one of my mentors.

**CHAIR:** Thank you, Olivia. That was a fantastic presentation.

**Mr Lui:** Thank you, Olivia. Good afternoon, honourable members. My name is John Lui and I am the New South Wales programs coordinator. I was born profoundly deaf and I have one cochlear implant. I am here to talk about the experiences our mentors have had with deaf teenagers from all levels of the hearing spectrum, different backgrounds and schooling systems.

The vast majority of our teenagers are from a hearing world. Their family may have no history of hearing loss, they go to a mainstream school full of hearing students and they have little to no connection with the signing and deaf community. They all want to be, and are, otherwise normal. You would not know they or our mentors were deaf unless they told you. Deafness is invisible.

Every day they encounter barriers and ignorant misconceptions such as: 'Oh, you'll be fine, my grandfather went deaf too, and he only needed hearing aids to be better,' or, 'If you can hear me, how can you be deaf?' or, 'If I speak louder can you hear me? Can you understand me now?' When it comes to unavoidable interactions such as at the shop counter or public transport, if the teenager does not understand what was said they may not want to ask the person to repeat themselves for fear of holding up the line or for fear of embarrassment. Sometimes the person they are talking to can become angry if they think that the deaf teenager is being rude and ignoring them. This can lead to psychosocial issues as they feel ashamed and embarrassed at having to repeatedly explain their situation of hearing wherever they go.
At school, they struggle not because they do not understand the subject but because they do not understand the teacher. They get questions from teachers like, 'Why are you copying from friends next to you?' A teacher may be facing the blackboard or whiteboard with their back to the room, saying, 'Can you hear me now? Good, you're okay,' or 'It's time for dictation; I want you to write down what I'm saying on a piece of paper without looking at me.' It is sometimes assumed that because we can hear and speak we can understand in the same pace and manner as our hearing peers. If we do not understand, people may think we are intellectually disabled, which creates an unfair perception.

These barriers, misconceptions and stigma are the results of decades of misinformation about what deafness really is. The parents of deaf children can become concerned about these societal stigmas and focus on fixing their child by teaching them to hear and speak from a young age and integrate them into mainstream schools. But there is another problem which is not seen until they enter the minefield of their early teenage years, when it comes to social situations which are heavily based on auditory skills, on tone of voice and on being able to read between the lines. It is already tough enough for a hearing teenager, never mind a deaf one. Their hearing has to be turned on by conscious choice; for hearing teenagers it is always on. Hearing teenagers can access information at random by listening osmosis; deaf teenagers cannot, so they can miss out on small social cues and educational building blocks, none of which are significant in isolation but incredibly debilitating when compounded over time.

In a well supported academic environment they can still do brilliantly but, as we all know too well, playground rules are a different beast altogether. Our teenagers are trying the best they can to engage in what can be extremely unforgiving peer interactions, such as informal group discussions or social gatherings. To quote the poet John Donne: 'No man is an island entire of itself; every man is a piece of the continent, a part of the main.' Deaf teenagers today sometimes feel like they are an island. Hear for You gives them the chance to be part of the whole again. Olivia Barnes is a perfect example of this. When she first came to Hear for You she was so timid and so quiet. Over time, as she made some friends and got to know the mentors, she slowly came out of her shell.

Later on her mother emailed me with some great news. She said that Olivia had had enough of the bullying from her classmates and decided to use her own initiative and talk to her entire year and the whole school about what it is like to be deaf. We were all amazed. She was only in year 8. This is the first time we have seen this happen out of all the teenagers in schools we have worked with across the country. The confident, happy Olivia you see today is so different from who she was before. She is one of our many teenagers who are on their way to fulfilling their life potential.

Parents are telling us that their teenagers are more proactive in their self-advocacy and less embarrassed about wearing the hearing devices. It has improved dramatically. They are smiling more and with confidence and never stop talking. The parents feel like they have their old son or daughter back. I hope these experiences shared with you today will compel you to seriously consider the recommendations highlighted in our submission, not just for my future or for Olivia's but for all Australians. Thank you for listening.

CHAIR: How are you funding Hear for You at the moment?

Mr Brady: We rely very much on donations and applications to trusts. We compete with many other different charities for the very small pool. We get very little funding from government. As for NDIS, we estimate about 30 per cent might get funding but we still have to find 70 per cent to fund all the programs that we do.

CHAIR: Sorry if I am asking you to repeat yourself, but how many teenagers would you be able to support during a year?

Mr Brady: We have 9,000 teenagers through schools. Right now, if we had the current level of funding, about 500. If we had more funding, we would be able to do a lot more.

Mrs Jones: It is really based on being able to scale. At the moment we are restricted by our funding.

Dr FREELANDER: Thank you very much for allowing us to hear your very inspiring stories. It was really a great privilege. Thank you for coming along today. Olivia, what things do you think are the most important in supporting you in your career at school?

Olivia Barnes: Having Hear for You there has been really helpful because I do not have many hearing friends obviously because of the stigma and people not liking to repeat themselves. I have more deaf friends and because of that I am more happy and confident. I think that is really great, because a lot of people in mainstream schools—90 per cent of deaf people come from hearing parents—do not have any sort of awareness about deaf people. I would say, 'I can't hear you,' and they go, 'It's fine, it doesn't matter.' But with my deaf friends we always repeat; we are always saying what we need to say.

Dr FREELANDER: Has Hear for You helped your school help you?

STANDING COMMITTEE ON HEALTH, AGED CARE AND SPORT
Olivia Barnes: Yes, it helped me a lot. Obviously, it helped with having deaf friends. In some ways it helps my school, because they gave me the confidence to be able to speak to my school. Without Hear for You, I think I would be hanging in the background. I do not think I would be the person I am today.

Mr Lui: I will just add on a little bit: we also help schools, as in we can contact schools and say, ‘We’re happy to come along, mentor and present to deaf students in that school.’ But often some schools can be reluctant to allow us in, because either they do not know what we do or they would rather not have these students get outside support for whatever reason, which is quite confusing. But wherever possible, we do help schools that request our assistance in helping their students and their year group understand what it is like to be deaf.

Dr FREELANDER: It seems to me that it might help all schools if you were able to provide some input about how to deal with hearing impaired kids.

Mrs Jones: I think there are two sections to that. The first section is that in Olivia’s case, she came to Hear for You. One of the challenges that we have is actually be able to find those deaf teenagers. At the moment, there is no formal pathway for identifying those children, often teenagers, who need that support. That is the conundrum that we are in. It is going out and cold calling to schools to say, ‘Do you have any deaf teenagers?’ This is one of the things we would like the committee to be looking at, in terms of what the processes are and how we can all work together to actually identify those children and teenagers. We can then respond either within the school infrastructure or outside. That, again, is another part of this.

Dr FREELANDER: I know in my electorate there are a number of children with cochlear implants, with hearing loss and with hearing aids in the high schools. I had not heard of Hear for You until I was on this committee. I am just thinking that one way that you could perhaps increase your community awareness would be to go to the education department and try to get some input into the school curriculum.

Mr Brady: I would like add onto that. One of the challenges we have overall in Australia, especially with schools, is what Olivia was mentioning: there is nothing there, there is no education program for hearing health and there is no education about deafness. When we are at school, having hearing loss, we try to be mainstream. We try to be normal. That is because we have a stigma. We have our friends and peers, and they do not understand. So instead of always repeating and saying, ‘I have an issue; I have hearing loss,’ we tend to say, ‘Okay, we’ll just continue down a path.’ I was just having a chat with Olivia earlier. It was about how there are a lot of health programs for children in schools, but there is nothing on hearing. I wonder if one of the other challenges we have is that there is no understanding at all.

Dr FREELANDER: Or very little. There is no formal program that teaches all of us about hearing difficulties.

Mr Brady: There are no official hearing health programs for teenagers at school at all—even at primary school. There is no understanding in classes. John, is that what you found?

Mr Lui: Yes, that is correct. Firstly, we are trying to find the teenagers. Secondly, if we do find them, they are sort of like, ‘No, no, I’m not deaf.’ There is often mild hearing loss. Or they say, ‘Why do I need to come to Hear for You and meet these other deaf teenagers? I’ve got hearing friends. I do well at school. I’m doing brilliantly.’ That is all fine, fair enough. But when they leave high school and they leave that structured environment of academic school and start going to university or the workplace, starting to advocate for themselves, that is when they are sort of at a loss.

Dr FREELANDER: The teenage years are difficult enough. Thank you very much.

Mr ZAPPIA: Can I commend all of you for appearing before the committee. I think your presentation and appearance has certainly informed me quite a bit about what it must be like for young people trying to get through life, let alone education. In your submission, you talk about 9,000-plus students—I think it is—who would probably have a hearing impairment of some sort. We do those figures come from?

Mr Brady: The actual figures come from Australian Hearing. They have set out a report on the demographics—of people under 26, there are 21,000 in that report. Then they gave it a breakdown of different age groups that are being treated at Australian Hearing. We got that figure from the Australian Hearing report in 2015.

Mrs Jones: Just remember, these are the children and teenagers who are actually getting to the audiologist. So let’s assume that is the tip of the iceberg, and there are lots of families who do not recognise disruptive behaviour as being linked to a hearing loss.

Mr ZAPPIA: I ask that for this reason: my understanding is that there are about 10,000 schools across Australia, or thereabouts—maybe a bit more with the primary schools. Therefore, if you were to average it out at
one or two per school—I am not saying that the figures are necessarily like that in every school—that, in itself, would create some challenge to governments trying to implement a program. My other question—and it is probably more pertinent to your recommendations—is that you have a range of recommendations in your submission, and if I was to say to you, what would be the two or three most important things that you would like to see changed that would help you, what would they be? It follows on from Mike’s question earlier on.

**Mr Brady:** I believe that we have three main ones out of there. One is to prioritise the youth mentoring program that includes deaf and hard of hearing teenagers. We want to use the best practice from Batyr, which is for mental health. I think Samuel Refshauge was part of that. We actually work with him. And the other one is through AIME—Australian Indigenous Mentoring Experience. We find that those two program models are really good and we would like to see the prioritisation of them. The other is more research to actually find out what is happening with deaf and hard of hearing teenagers at high schools across Australia. There are no facts—there is no research. We did this amazing study in 2008 to find out what was out there. There was nothing. There is no real concrete research. There are many others, but the other one is, basically, need to educate the whole classroom. We want to get to all of those schools, because we have fantastic intervention programs. We work hard with Auslan, speaking and all of that, but when they get to high school or when they get later in primary school, we keep forgetting the environment that they are in. There is no understanding for a hearing person who has no idea about deafness and they are with a deaf person in their school for the first time—teachers as well. We believe there needs to be an education program about their hearing health, but also about their own hearing prevention as well, because, without that, that environment is not going to be very nice for the deaf teenager. We are seeing that all of the time.

**Mrs Jones:** If I could to add to that: our issue is always about the database of those teenagers, and it would be a request to actually be formally connected or be part of a formal referral pathway, so that we can make that connection. Mr Chair, I understand that we do not have much time, so if I may just put in a final statement to help summarise our case today?

**CHAIR:** Sure; I will just check whether there are any more questions first. I just have one question before we conclude: are you able, with your resources, to provide specific services to people from different cultural backgrounds, and also young people living in rural Australia and Indigenous communities?

**Mrs Jones:** I will start off. The answer is yes. Part of that multicultural positioning is that we embrace—if they are in rural and regional areas, we actually ran a rural and regional program. Over to you.

**Mr Brady:** We do rural and regional—we have been trialling through a thing called Life Goals and Skills program, which is a two-day weekend. We are trying to target specific areas, respond to demand and requests from parents, teachers and audiologists from rural and regional areas. This year we start at Rockhampton and Newcastle. Again, the funding is from the community. We try to go out there, and also, hopefully, with some teenagers with NDIS. If we had more resources, we could reach out to a lot more rural students. The difference between a rural teenager—I am from Armidale, New South Wales—

**CHAIR:** Never mind.

**Mr Brady:** and it is so different from the city. That is one of my passions. I will hand back to Kim.

**Mrs Jones:** We do have Georgie Sameer, who is Muslim. We do cover quite a range of different communities. One of the ones we have not really talked about is the different communities within the deaf community itself, which is Auslan and oral deaf. When Olivia started Hear for You, it was really to focus on the oral deaf, but part of that embracing of different cultures is to include Auslan as well. That is what we have done since then.

**Mrs Andersen:** I would like to add to that. About 86 per cent of babies who are born deaf are born to families with no history of deafness. They have hearing parents with a hearing background. That is why I started Hear for You, because I think the most important thing is to try to educate the ones who need help.

**CHAIR:** Would you like to give your closing statement?

**Mrs Jones:** Thank you. As chair of Hear for You, I am at the other end of the life cycle with tinnitus. I thank the committee for your interest in hearing health and wellbeing. Unlike other challenges in our community, hearing loss is invisible and can affect you at any stage of your life. The committee may be aware of identifying hearing loss in small children, and, as you have just heard, we are focused on older children and teenagers and how we can support them to become confident, educated individuals who will reach their potential in life.

We focus on hearing health issues for deaf teenagers in schools so that they can navigate their daily challenges. They are on the verge of getting jobs, going to university and going out and engaging with the community. So what happens when these deaf teenagers leave school? The issues they face continue. Our concern is that no-one...
is paying attention to these isolated young people, and we should be educating all young people about hearing health.

Our challenge is that there is no direct pathway to find these kids. We offer knowledge, skills in connections for deaf teenagers. Our deaf mentors have lived the deaf experience and are giving back to the next generation of teenagers. So how does a teenager find us? Let me remind the committee: around 21,000 people under 21 are deaf, 90 per cent of whom have hearing parents. Around 9,000 of those are teenagers scattered, as you said, throughout nearly—there are 3,000 secondary schools in Australia, and we have seen 700 so far. As you heard from Olivia Barnes and from John, being different at high school can be very difficult for young adults as they learn to manage themselves as well as others around them in terms of learning activities and socialisation. They do not want to be seen as different, will resist what they see as stigma, of being singled out for assistance by itinerant teachers. Teachers report that some with cochlear implants and hearing aids are even reluctant to use FM systems and other supports in school.

Stigmatism about hearing loss in the community is preventing young Australians from achieving their life potential. We need more support to identify these young people so as to deliver our evidence-based programs in a formal referral pathway of a deaf child's journey to adulthood, arming them with the knowledge, skills and connections to help them manage the psychosocial impacts of their hearing loss. We have 26 recommendations and we are here to work with you and others to make hearing health and wellbeing the next national health priority. We are Hear for You.

CHAIR: Thank you all very much for joining us this afternoon. We have heard from a lot of experts today, but I think it has been extraordinarily valuable hearing about your own personal experiences, because it puts the importance of this inquiry into context. Thank you all for presenting so well. You are great ambassadors for Hear for You, and you should be very proud. Thank you for coming.
KONG, Associate Professor Kelvin, Indigenous Health Committee, Royal Australasian College of Surgeons

TRUSKETT, Dr Philip Gregory, President, Royal Australasian College of Surgeons

[16:02]

CHAIR: Thank you for joining us this afternoon, and thank you also for your submission to the inquiry. Do you, as witnesses, have any difficulties about being recorded by the media this afternoon?

Dr Truskett: No.

CHAIR: Do you have any comment to make on the capacity in which you appear?

Prof. Kong: I am an ear, nose and throat surgeon.

CHAIR: Thank you. These hearings are formal proceedings of the parliament. The giving of false or misleading evidence is a serious matter and may be regarded as a contempt of the parliament. The evidence given today will be recorded by Hansard and attracts parliamentary privilege. Would you like to make an introductory statement?

Dr Truskett: I appear before you as a general surgeon; I am not an ear, nose and throat surgeon. The reason I have come today is to underscore, from the point of the view of the Royal Australasian College of Surgeons, how important we believe Indigenous ear health is. I was devastated to hear that, at the age of one, almost 90 per cent of Indigenous children actually have middle ear disease which impedes their hearing. This has an incredible impact on their ability to learn, their ability to learn language, and some of it is absolutely irreparable if not picked up early. It flows on, of course, to school, and they are difficult to be educated. If they are difficult to be educated, it is difficult for them to get employment. At the other end, the telling statistic is that something like 60 per cent of incarcerated Indigenous Australians have hearing impairment. So it is clearly something needs be rectified and be put high on the agenda, because it has such an incredible impact on Indigenous wellbeing.

I have come to introduce my colleague Kelvin Kong, whom I have known for many years. He is a proud Worimi man and he is an ENT surgeon, so he will be able to give you information that relates to the process of what he has experienced, both as an Indigenous person and as an ear, nose and throat specialist.

Prof. Kong: Thank you very much for that introduction. I am quite excited to be here and I really want to thank you for your time, particularly at the end of the day, so hopefully I will not be too dull in my presentation!

Rather than go through the submission that we have made, I thought I would digress a little bit and reflect on a story I have from last year. There was a kid, a seven-year-old Aboriginal kid, who presented to the rooms with hearing and also some discharge in the ear.

CHAIR: Where do you practise?

Prof. Kong: In Newcastle. I practise in Newcastle. This kid presented to me and, after doing a history and an examination, what I found was—which I have footage of, which I am very happy to forward to you—a maggot in the ear of this child. Here was a seven-year-old kid in the middle of urban Australia with a problem that, from the literature, is in Third- and Fourth-World countries in terms of health status. The dichotomy that exists in ear disease in this country is appalling in terms of access to health care.

But that really highlights the kinds of issues that I think this Senate inquiry has been hearing—that is, this kid had lack of access to ear care at a very early age, the problem has been missed by screening processes or other school processes, they are behind in their schooling and education, their speech and language are delayed, and they are seven years old. And we are talking about a very early [inaudible] here. Even without going into what is happening to them from a social perspective, we know that the outcomes for this kid in employment and lifelong opportunities are just devastating. It breaks my heart to see these kinds of kids in a population where I think we have the ability to reverse this, and it is something that I am extremely passionate about trying to change.

CHAIR: Thank you very much.

Dr FREELANDER: Thanks very much for coming along today. I have a lot of similar concerns, including concerns about access to care not just for kids of Indigenous origin but for kids who are poor. I think that we could do a lot better and I think the ENT surgeons could do a lot better, if I can be brutally honest. Many of the children that I have seen cannot get in to see an ENT surgeon. In my electorate, which is in south-western Sydney, we have no public ENT clinic, and none of the local private ENT surgeons will bulk-bill patients. So, many children of school age who have hearing loss cannot be treated, or have waiting times for treatment that are measured not in weeks or months but in years. We could be doing a lot better. I think part of that is much better access to ENT surgical treatments, and I am interested in your views on how we can do that.
**Prof. Kong:** Yes, absolutely. I think one of the features underpinning this is the ability of the public health sector to deal with the ear problems that we are dealing with. If any of you called any public hospital, I think you would have that issue in terms of access to ear, nose and throat services. There is a paucity of ENT services available, and, rather than it being mainly attributed to the ability of ENT surgeons, I think it is a real management matter, where we need to provide the services in conjunction with the hospital. We have been screaming at them to provide more clinics and more services. A lot of the ENT surgeons who want to provide these services are actually told to pull back on services because they create a wait list, and if you create a wait list then there is no operating time to do this. So I think there are a couple of elements that need to be teased out in how to rectify this. Of course, none of this is on the public record because there is no way that anyone would admit that that is what is being said. But, certainly, from an indirect measure, this is what a lot of ENT surgeons have been told.

**Dr FREELANDER:** I think that, if an ENT surgeon is using our day surgery unit and our public hospital to operate, they should be compelled to have a public ENT clinic.

**Prof. Kong:** Without question, absolutely. I think, more so, that every ENT surgeon has an obligation to provide some public services to that. It is getting that access to public services which is quite hard for an ENT surgeon to engage in with a hospital in terms of a wait list. I think one of the big problems—I can speak for New South Wales; I cannot speak for outside of my state—is that a lot of the KPIs around hospitals and operating are purely based on operating wait lists.

**Dr FREELANDER:** Yes, I know.

**Prof. Kong:** Now, the problem with operating wait lists is that they do not actually address the problem. You see from only the few presentations today that we are talking about a problem, which is ear disease and hearing, and yet the solution is the operating wait list. That is not the solution to ear problems. The solution to ear problems is a strategy which is on a national level, looking at all the factors so that, if this is your kid at 12 months of age with hearing loss, we can rectify every problem along the way, from hearing services, hearing support and teaching, to access to medical services and also surgical services. There is a really big combination associated with that. The other part is that we talk about intersectorial support in this area. The education department needs to be involved and correctional services need to be involved. It is the whole-of-government and also the whole of the medical workforce that needs to be addressed. This is not just a one-off waitlist. Some of the frustrations that I have are that, particularly as a surgeon, I am always asked to address the waitlist. But, before we even start a clinic, certainly in Newcastle, we will not even go to a community until we have ear health services, hearing services, operating lists, clinic nurses and teachers on board. That is a minimum requirement to make sure that we get the right service done, because an operation is not always the answer.

**Dr FREELANDER:** We need a proper pathway. The other thing that seems to be an issue is that when a child is identified as having a hearing problem it seems to be seen as a one-off treatment program and follow-up services seem to be particularly poor, especially with Indigenous kids.

**Prof. Kong:** Again, one of the frustrations that I have had with the access to services—particularly with the money that is forwarded to remote services—is itinerant surgery and the one-off nature associated with that. One of the big problems is, I think, that a lot of people who are ringing or emailing me to try and get me involved in this process are looking for the exotics, in terms of going to remote Australia, when in fact they drive past three communities and fly over another 20 to get to a remote community. One of the things I try and encourage is for people to get back to their local health district and work with their local health district to try and enact a program which is multilayered and involves several jurisdictions to make sure that—going back to the same principle, which is in our submission—a kid with hearing loss gets the appropriate treatment that is required, which is not necessarily a surgical outcome.

**Dr FREELANDER:** Thank you.

**Mr ZAPPIA:** It is a recurring theme, but the incidence of hearing problems amongst Indigenous people seems to be very high. Why is that?

**Prof. Kong:** How long have you got?

**Dr Truskett:** It is multifactorial.

**Mr ZAPPIA:** I am aware that there are a whole range of other health issues that have a much higher occurrence amongst Indigenous communities. But hearing seems to be quite commonly referred to.

**Prof. Kong:** Yes, absolutely. It is probably a little bit of a simple picture, but it purely comes down to access. One of the common themes in multiple submissions to this inquiry is that the low-socioeconomic Aboriginal—and more generally in non-Indigenous Australia—access to ear care is very poor. We need to improve on that.
I think what is happening with our Aboriginal and Torres Strait Islander population is that, by the time they are getting access to ear care, they have already missed the boat. If we pick it up at high school then that one- to three-year-old age group, which is a crucial time of learning and developing, is already lost. When you get to that stage the access at that age is not necessarily important because if you go to emergency there are heart attacks, there is trauma and there are all these other things that are going on. When we talk about silent ear disease no-one really minds so much; a kid is quietly sitting there and not worrying about it. But, in fact, over the next 10 years of their life their learning falls behind, their education falls behind, the perforations get larger and the complications associated with ongoing discharge get worse. So you get this scenario where—I am talking about some communities that I visited—over 90 per cent of eardrums are perforated. I think I was smiling during the last presentation when stigma was mentioned. I have been to the community in Bidyadanga, where the kid that was stigmatised was the kid that did not have cottonwool in its ear from discharge because that kid was the teacher's kid. Every other kid walking into the classroom had discharge pouring out of their ears. It just astounded me that they are walking into the classroom with discharges and perforations and they are blocking their ears and so their hearing is even worse. It is a travesty that we are seeing this kind of thing. What is alarming is that there is this dichotomy where people picture it as an exotic, remote kind of condition, but we are talking about Newcastle. I think Newcastle is exotic, but it is not that remote, certainly in its presentation with what we are seeing.

Mr ZAPPIA: I understand that they have not had the care in their early years, but I get the impression, and I might be wrong, that even putting aside the fact that they have not been treated there is a higher level of hearing or ear problems with young Indigenous children than there is across the broader community. Am I wrong in that perception?

Prof. Kong: No, you are not wrong. Most of those issues start from 12 months of age. In our general population the peak incidence of otitis media would be in kids around three or four years old, but in the Aboriginal population that peak goes right down to under 12 months. So before you even get to one or two years of age you are already developing complications from otitis media. So the lifelong trajectory that that kid is going to endure is going to be one of hearing loss, and mainly conductive hearing loss. Interestingly, sensorineural hearing loss is actually pretty much on a par with the non-Indigenous community. So our SWISH program, our newborn hearing program, which is one of the most magnificent things that have come from this country, is wonderful. The percentages of hearing loss that we are seeing in our Aboriginal population are very similar. The sensorineural component is very similar, but it is that conductive component associated with otitis media, chronic suppurative otitis media, perforations and lack of care from there.

CHAIR: What are the preconditions for otitis media? Is it poor hygiene?

Prof. Kong: Again, there are multiple things associated with that. Certainly, in some of the early research that I have done, there has been overcrowding and a lot of social determinants of health—nutrition, access to health care and also the childcare environment. Because of the overcrowding in the social environment, there are a lot of kids together, and they are all sharing the bugs and getting that. I think that is where we are seeing the under-12—

CHAIR: So, it is a contagious condition?

Prof. Kong: Otitis media is not contagious, but upper respiratory tract infections are contagious, and they block the Eustachian tube.

Dr FREELANDER: The more kids you have got together, the more viral infections—

Prof. Kong: The 'day-care effect' is probably a nicer way to discuss that.

Dr FREELANDER: They also tend to have a lot of iron deficiency, which predisposes you to superficial infections as well—and a lot of smoking in the environment.

Prof. Kong: Passive smoking is a big issue in that, and that is starting to come down. You can see that some of the quit programs that have been targeted towards Aboriginal communities have actually improved the take-up rate of quitting or stopping smoking. Hopefully, we can start seeing the tail end of some of those attributing factors.

CHAIR: Have you had any exposure to Queensland's Deadly Ears Program?

Prof. Kong: Yes.

CHAIR: It has been put to us that that is probably the most effective of any of the states. Would you agree with that?

Prof. Kong: I am a proud New South Wales man! If I critically reflect on it, I think it is a really good program in the sense that it is a holistic care model. I think that there are pluses and minuses. I do not think that it is the be-
all and end-all in terms of model; otherwise, we would have no ear disease in Queensland, but Queensland has one of the highest ear-disease rates and perforation rates. I think what it really illustrates is that there is a real, pertinent need for a national strategy, and KPIs that we can benchmark off each other. Hearing loss is one thing, but what does that mean for immunisations, antibiotics, access to primary care, awareness and teachers being aware? In some of the communities I have been to, particularly around Tamworth and Inverell, they have great programs because the teachers are aware that the kids are not hearing well. There is no access, because it is quite hard, so they make sure that there are speakers in the classroom. With things like that, it is not necessarily thinking about the be-all and end-all in terms of medical and surgical treatment; it is about making sure—going back to the same point—that every kid can hear, learn and develop so that they become a contributing member of society and, more importantly, reach their potential.

**CHAIR:** I am told that you already covered this, but what percentage of otitis media cases do not respond to antibiotics?

**Prof. Kong:** Otitis media is not necessarily infection. Eustachian tube dysfunction or blockage of the Eustachian tube leads to fluid in the middle ear, which is the deafness that we talk about—

**CHAIR:** So otitis media is—

**Prof. Kong:** Complicating that can be an infection, which is otitis media. A lot of people might treat otitis media as just fluid in the ears, which is not actually infection. Sometimes they say that they are not responding to antibiotics, when, in actual fact, it is not the infection that is causing the hearing loss. It is definitional from that perspective.

**Dr Freeland:** One of the issues that have been brought up is that kids get their newborn screening tests, which is great, but there are a group of kids, often with conductive hearing loss, that do not get picked up, and that we should have a national screening program prior to starting school. Do you agree with that?

**Prof. Kong:** Absolutely. Newborn hearing is one form of picking up sensorineural hearing loss, no doubt about it. What that alluded to in history is that what we then started doing was stopping screening programs because we were picking up the hearing loss early on from there. The misnomer with that is that people were confusing sensorineural with conductive hearing loss, and so then a lot of the screening programs were scrapped. There were some screening programs brought into schools to try and combat that—before you start school, you actually get a hearing test to do that. Why I would argue against that is that, by the time they get to five years of age, we have missed the boat. We need to be tackling this at a very, very early age, as in 12 months and onwards, to pick up the hearing loss and the conductive loss at that period.

**Dr Freeland:** What time do you think is the ideal time to test?

**Prof. Kong:** Testing from 12 months and onwards is ideal, from my perspective, in picking up that hearing loss. The one-to three-year-old age group is crucial in picking up conductive hearing loss.

**Dr Freeland:** Do you think that we should be retesting between one and three?

**Prof. Kong:** Absolutely, yes. The detail of that is harder, because I think that screening programs, in themselves, are quite expensive and time consuming. Again, if we had benchmarks on a national level, we could tailor a child-screening check or the maternal programs or the Mums and Bubs program. At the moment, they are not actually mandated—they tick boxes and the hearing test is varied across Australia. If we actually had some kind of benchmark to say, 'They need this type of hearing test at this age,' tick the blue box, then we can make sure that we do not miss those conductive hearing losses.

**Dr Freeland:** If I can reiterate, what you are saying to us is that we need a proper pathway for managing kids, once they have been identified as having hearing loss, that involves not only surgical treatment but also medical interventions, speech and language, school et cetera? We need to develop a proper pathway.

**Prof. Kong:** Absolutely. It is not necessarily mandating what is actually involved in that; it is saying, 'Right, if we're going to have a really serious hearing program here—no matter what kind of deficit you're enduring—what are the things we need to make sure that this kid gets through?' And it is all of those factors that we talked about.

**CHAIR:** Thank you very much for coming in this afternoon. That has been very helpful, and it is a good way to end the day. We will send you a copy of the Hansard transcript of your evidence. If there are any issues arising from that, please contact the secretariat. Thank you for all that you are doing with the surgeons.

**Prof. Kong:** Thank you very much.

**Dr Truskett:** Thank you.

**CHAIR:** Thank you all for attending, particularly those of you who have been here for a large part of the day—our loyal customers! I particularly want to thank our Auslan interpreters; it has been a long day for us, but
probably a longer day for both of you. You have had to pay attention to everything that we have said! I will stop talking so that you can stop translating. Thank you.

Committee adjourned at 16:21