COMMONWEALTH OF AUSTRALIA

Official Committee Hansard

SENATE

COMMUNITY AFFAIRS REFERENCES COMMITTEE

Reference: Hearing health in Australia

TUESDAY, 13 OCTOBER 2009

SYDNEY

BY AUTHORITY OF THE SENATE

SENATE COMMUNITY AFFAIRS

REFERENCES COMMITTEE

Tuesday, 13 October 2009

Members: Senator Siewert *(Chair)*, Senator Moore *(Deputy Chair)*, Senators Adams, Boyce, Carol Brown and Williams

Participating members: Senators Abetz, Back, Barnett, Bernardi, Bilyk, Birmingham, Mark Bishop, Boswell, Brandis, Bob Brown, Bushby, Cameron, Cash, Colbeck, Jacinta Collins, Coonan, Cormann, Crossin, Eggleston, Farrell, Feeney, Ferguson, Fielding, Fierravanti-Wells, Fifield, Fisher, Forshaw, Furner, Hanson-Young, Heffernan, Humphries, Hurley, Hutchins, Johnston, Joyce, Kroger, Ludlam, Lundy, Ian Macdonald, McEwen, McGauran, McLucas, Marshall, Mason, Milne, Minchin, Nash, O'Brien, Parry, Payne, Polley, Pratt, Ronaldson, Ryan, Scullion, Sterle, Troeth, Trood, Wortley and Xenophon

Terms of reference for the inquiry:

To inquire into and report on:

Hearing health in Australia with particular reference to:

a. the extent, causes and costs of hearing impairment in Australia;

b. the implications of hearing impairment for individuals and the community;

c. the adequacy of access to hearing services, including assessment and support services, and hearing technologies;

d. the adequacy of current hearing health and research programs, including education and awareness programs; and

e. specific issues affecting Indigenous communities.

WITNESSES

Committee met at 9.04 am

CHAIR (Senator Moore)—Good morning. The Senate Community Affairs References Committee is continuing its inquiry into hearing. We have Auslan interpreters with us and they will be available should people need them. The two interpreters we have here today are Kylie Scott and Tanya Miller. Thank you very much.

I am aware that there was some questioning about captioning last week, but with the short time frame we were unable to arrange that for today’s hearing. Once again, as probably everyone in this room knows, it sometimes takes a bit of time to get all of those things in place. This room is looped, and I would like to thank the New South Wales government for doing the right thing as this room has been looped for many years.

[9.05 am]

REHN, Mr Christopher John, General Manager, Sydney Cochlear Implant Centre

CHAIR—Welcome, Mr Rehn. You have information on parliamentary privilege and the protection of witnesses. Thank you for your submission. You may wish to make some opening comments and then we will go into questions. As we said yesterday, we are trying, as much as possible, to turn this into a discussion rather than a formal question and answer process. If you would like to start then the senators will definitely have questions for you.

Mr Rehn—Thank you for the opportunity to present here this morning. I should also acknowledge and thank Cochlear Limited who stepped aside in order for a client oriented organisation, SCIC, to come and present.

Sydney Cochlear Implant Centre, or SCIC, is the biggest cochlear implant provider of its kind in Australia and, indeed, one of the largest of its type in the world. That is because we have been around a long time. We came on board with the cochlear implant technology, as developed in Australia, just over 25 years ago. We now have 2,500 existing clients and we are probably seeing about 350 new clients each year. We are an all-of-life service provider, which means that we do not specialise in children, adults or adolescents, we do the lot and we make sure we look after the client for a lifetime of care because a cochlear implant does require ongoing support forever.

We also have the government contracts for New South Wales and ACT so where public patients are concerned we provide those devices, where they have private health we provide those devices and where the charity is required—because we run as a non-profit—we support clients to access. Our focus is to make sure that there is timely access to the cochlear implant.

In looking at this report I would like to make a couple of observations. There is an inconsistency in Australia between what is the provision of hearing aids under the Commonwealth Hearing Services program and that of cochlear implants. It can be looked at under many tiers, but the point would be that getting access to bilateral hearing aids is relatively accessible with high quality devices fitted through Australian Hearing under the CSO provisions, whereas cochlear implants fall into the state domain and vary enormously. We believe that we look after the significant hearing loss group well in New South Wales and ACT, but that is really just looking at the current state of the technology and single-sided cochlear implantation. If you consider that bilateral cochlear implantation is becoming the norm, that hybrid devices are being developed, and other implantable technologies, such as bone anchored hearing aids, we are really going to be under enormous pressure to meet the growing needs. The question would be: why should the Commonwealth system provide the opportunity for hearing aids up to a certain degree of hearing loss and after that it becomes very haphazard around the country as to whether one can access a cochlear implant or not? We have a view that a consistent model that underpins the intention of the Commonwealth Hearing Services program developed for implantable technologies would be ideal. We also believe—and this is a very big part of SCIC—that we are geographically dispersed to make sure that we align the services to where the demand is, and that includes rural Australia, Northern Territory, New South Wales and ACT.

We also want to point out that upgrade devices, such as when new technologies become available that enable benefit to the client who is presently using technology, be accessible not unlike it is with hearing aids. Whilst provision is presently made under the Commonwealth Hearing Services program for upgrades to speech processes for children under the age of 21, we would like to see an extension to that system to enable adults who meet the appropriate criteria to also receive that benefit. Again, it is an inconsistency at the moment that I think is readily addressable.

I also think that whilst we all pat ourselves on the back in New South Wales and potentially the ACT for new born screening, which is terrific, really it is inconsistent across the country and it is only capturing one potential group of implantable technology recipients. Other screening needs to be extended, such as at the preschool age and indeed beyond. There may be some that argue that adults should be screened for hearing loss as well because it is obviously very prevalent in adults.

I would like to comment on service orientation. The cochlear implant is not for all. Whilst we would advocate universal access to keep consistent with, if you like, how it is for hearing aids, it really requires informed consent on behalf of the recipient or the parents if it is a child. That is managed in a very careful way through the services of SCIC and we also partner up with Australian Hearing, the Royal Institute for Deaf and Blind Children and other service organisations to make sure that a client who is determining a cochlear implant for their child's needs really understands what the road ahead looks like.

Lastly, I would just like to point out that a cochlear implant does cost across the life in terms of not just upgrades, but spare parts, maintenance services, batteries and so on to keep these devices going and provisions should be made to look at that for people where income may be low and their degree of disability. It is terribly important to make the ongoing costs accessible to the client.

My final comment would be that we are looking at the group who are probably the worst of the worst in terms of the disability of hearing loss. The implant technology kicks in where the other conventional technologies no longer provide the potential benefit to help that person communicate and function in a hearing-speaking world and indeed where sign language is required. This is the group that we cannot turn our back on. This is the group that really requires federal intervention to provide accessible services because they are so heavily reliant on this form of technology. Thank you.

CHAIR—Senator Boyce.

Senator BOYCE—I would like to firstly get an idea about your centre. Are you a not for profit?

Mr Rehn—We are.

Senator BOYCE—You say you are the largest in Australia. What percentage of the market—for want of a better word—would you see yourself having?

Mr Rehn—About a third.

Senator BOYCE—Is there a group of implant centres? Do you have a way of conversing with each other?

Mr Rehn—Yes. Obviously we network nationally. I do a lot of consulting work for other programs around the country. SCIC looks after New South Wales, ACT and parts of the Northern Territory. In terms of the network approach, we geographically spread our services with our surgeons, clinicians and so on to be where the demand is and that network feeds back into the central hub, which is basically in New South Wales, so professional development, difficult clients, complex cases and so on are all managed as part of a team, irrespective of geography.

Senator BOYCE—You were talking earlier about the worst of the worst. I am trying to get a sense of what proportion of people who have severe or profound hearing loss would use implants. Are there some nice dividing lines?

Mr Rehn—I will defer to my colleague, Professor Harvey Dillon, who is here today for the specific statistics. What I can tell you is that in children these days it is the expected intervention and preferred intervention. We are capturing something in the order of 90-plus per cent of children born with a significant hearing loss going forward to cochlear implantation. Again, my statistics can be corrected through Professor Harvey Dillon’s discussion. In adults it is nothing like that. We are probably scratching the surface with around the 10 per cent mark or less because the adult incidence is so great and yet the availability of the technology, particularly to the uninsured, is so poor. Going back into the non-profit side, that is why we have a non-profit, so that we can try to bridge the gap. In the case of children we can do that to some extent, but with adults it is an impossibly large number.

Senator BOYCE—You mentioned private providers potentially being reluctant to hand over clients. Could you flesh out for us what you mean there and what the market looks like for someone who has just been diagnosed so to speak?

Mr Rehn—For many existing private audiological providers their bread and butter comes from hearing aid fitting; they do not work in the field of cochlear implants. For a client who gets to a level where a cochlear implant might be indicated, they would actually—

Senator BOYCE—Is that when hearing aids do not help anymore?

Mr Rehn—Correct. It is when the benefit is very marginal on the hearing aids and they really need to take it to the next level, which would be the implantable technology route. At that level that audiologist, that private practitioner, would have to release the client from their care and see them taken over, if you like, through an implant centre such as SCIC. It is a potential loss of revenue so that reluctance can actually stop referrals. It is not a concern with the likes of say Australian Hearing, the largest provider of hearing services in the country. We have a very good collegial relationship where they, in a very timely way, pass the clients across where hearing aid technology is not enough, but in the small based private practitioner that risk is there.

Senator BOYCE—It is the profit motive that is causing this, but would it also be something of an ethics issue?

Mr Rehn—Yes. It is a challenge. You are right. It is the loss of a customer.

Senator BOYCE—I imagine the AMA might have some views on your view.

Mr Rehn—Potentially. I guess the grey area in that comment is that where implants kick in and where hearing aids kick out is a moving feast, so the professional development to keep private practitioners up to date with where the referral criteria should exist for a cochlear implant is a challenge for all of us. We do it through professional seminars and so on where we try to educate the audiological base out there in terms of what current fitting criteria suit the cochlear implant, but it is a difficult task.

Senator BOYCE—Should we take from that if cochlear implants cost $10 that would be the ideal solution for everyone?

Mr Rehn—No, I do not think so.

Senator BOYCE—Are there cases where hearing aids are a preferred solution?

Mr Rehn—Absolutely. I think it would be very important for me to state that you would not go down the implant line unless you had to. Conventional hearing aid technology can be removed and replaced very quickly, but cochlear implants require surgery. Whilst the speech processor can be upgraded, putting someone through surgery unnecessarily would be very concerning.

CHAIR—We heard yesterday that the movement going towards cochlear implants was moving down the scale.

Mr Rehn—It is.

CHAIR—I will not try to remember the terms because I will get them wrong, but people at a lower level of need are now moving towards your technology. Is that accurate?

Mr Rehn—Yes, it is accurate. Again, Professor Dillon can talk specifically to it. What we have seen is a phenomenon that says the children who have had say a serious hearing loss with conventional hearing aids have performed less than a profound hearing loss with a cochlear implant. We have seen some creepage down, so the severe category of hearing loss now is certainly the domain of implantation as well.

I should also point out that some of the emerging technologies like hybrid devices are designed to deliberately do both with the intention that says that where a person is on a trajectory down, down, down in terms of hearing loss, you can intervene at an earlier point, complement them with an acoustic, as in a hearing aid type signal initially, and then move the cochlear implant signal to them as their hearing loss deteriorates further.

Senator BOYCE—I was going to ask you what hybrid devices were. Does a hybrid device involve surgery?

Mr Rehn—Yes, it does. It is akin to having a cochlear implant and a hearing aid in the one external device and the internal device is very much a cochlear implant so you can manage that client depending on the specific hearing loss, but it is expected to capture people with a lot lesser hearing loss.

Senator BOYCE—Again, but for cost, is that the ideal solution for everyone?

Mr Rehn—Not for everyone, no. I think conventional hearing aids still have a very significant role to play in the lesser hearing losses, but when you get to the significant hearing loss category, the severe to profound and beyond, that is very much the domain of cochlear implants.

Senator BOYCE—I wanted to ask you about waiting lists for what you have referred to as known referred clients. Can you talk firstly about the size of the waiting lists and then what I could refer to as unknown clients? Can you talk about both of those please?

Mr Rehn—I put the statistics in the report, but to differentiate, we have a priority system here that focuses on children, so single-sided cochlear implantation for children is relatively accessible in New South Wales and the ACT. It would stand that a child picked up through newborn screening, where the parents have elected to look at the implantable technology, would get one in a timely manner which would be about three months post diagnosis. That is really the assessment process in itself and working through with the families on the issues associated with cochlear implantation.

Senator BOYCE—So there is no waiting list?

Mr Rehn—There is no waiting list in New South Wales and ACT for single-sided cochlear implantation. That does not give the bilateral access at all. For older children it varies dependent upon at what point you capture the child’s hearing loss. There can be anything from three months to about 12 months waiting depending on the circumstances of that child and it trickles down to the extreme end, which is adults, where SCIC do not market the services, so to speak. We are very interested in looking after the need as it is identified, but if we market for services all you do is literally move tens of thousands of clients from the unknown into the known, but still no mechanism of helping them because the financial underpinnings are just too great. The provision under New South Wales Health and ACT Health does not make allowance for what is the retrospective pool of adult clients that could benefit from cochlear implants.

Senator BOYCE—Can you quantify that pool at all?

Mr Rehn—Sure. I put it in the report. When we did the statistics on the incidence we came up with a view that if there were about 6,000 children and adults presently using a cochlear implant then there are probably something in the vicinity of 84,000 people who could potentially benefit from a cochlear implant, and yet we have only captured about 6,000. That is on the existing pool of people out there, it is not capturing what is the diagnosed rate as it stands today.

Senator BOYCE—Which is increasing.

Mr Rehn—It is increasing. Obviously with better hearing testing procedures and so on we are getting a better understanding of where the hearing loss numbers sit, but from an SCIC perspective, we would certainly see the potential for 400 or 500-plus adult clients per year coming through our door if there was no impediment for them accessing the device. We only see a couple of hundred of those clients because most of them fall into the domain of private health and can get the help they need.

Senator BOYCE—Are those people getting help?

Mr Rehn—Those with private health can access a cochlear implant in a timely way through services like ours. We also fund the SCIC charity fund with about 20 to 30 devices a year for uninsured adults to help reduce the public waiting list as well, but that is nothing like the incidence.

Senator BOYCE—I suppose one way to try to get at the figure is to say if you had a billion dollars in that particular fund how many adults would you anticipate that you would need to fund?

Mr Rehn—If we ignored the pool of clients out there who would be sitting at home with a loss that could be treated with a cochlear implant and just captured those who had actually been diagnosed today as needing one and also falling over the line towards implantation, it would probably be something in the vicinity of about 2,000 to 3,000 per year nationally.

Senator BOYCE—Who are missing out now?

Mr Rehn—Who are missing out now. If you go back into the pool we are talking potentially about 100,000 people. That is the issue. The retrospective pool is a very large one, let alone the actual diagnosis rate to capture those who are presently being tripped over into cochlear implant candidacy.

Senator BOYCE—Thank you.

CHAIR—Senator Adams.

Senator ADAMS—I would like to ask you some questions regarding the Northern Territory program and specifically on Indigenous communities. Were you involved at all with the Northern Territory intervention medical team?

CHAIR—No. Our involvement was stimulated as a result of clients either travelling from the Northern Territory to Sydney to receive access to the implant and then us backfilling the need. We are presently working with Northern Territory Health on better access, but at the moment we have a travelling team that goes into the Northern Territory to provide that service. There is a need for increased ENT work there. SCIC has a large pool of ENT surgeons who are very willing to be part of that, but it is pretty embryonic stuff at the moment.

To answer the question on the Indigenous, I think that is an area that definitely has to improve across Australia. Certainly the statistics are very poor in terms of how the Indigenous population can access cochlear implant intervention.

Senator ADAMS—Would the implant be a better way to go with some of these children? I am just thinking about their living conditions.

Mr Rehn—With many of them, yes. I think there is a whole heap of otitis media and other ear conditions that have to be properly treated and managed concurrently when you are looking at cochlear implant candidacy. The statistics would say that you are dealing with a lot more middle ear issues associated with the Indigenous populations, so other interventions are probably more appropriate, but where the cochlear implant is indicated we certainly need to do a better job of making it accessible and the service flexible to meet the specific needs of that population.

Senator ADAMS—Several of us are on another committee that travels around looking at Indigenous communities and that has probably been one of the biggest issues that we have found when visiting schools. The teachers have their microphones and a number of the schools have got special hearing rooms for the children to go to. It is quite incredible the number of children that are affected.

Mr Rehn—Absolutely. There is overlap because obviously the ear, nose and throat surgeons that we work with have a social responsibility, if you like, in providing support there and some of our ENTs presently do, but there is such a big job to do there. All of us are probably trying to do it better, but we are not nailing it yet.

Senator ADAMS—As far as the Northern Territory program goes are you looking at the newborns and trying to track them from there?

Mr Rehn—Yes. It works across both. There is a good audiological network in the Northern Territory that we feed into, so upon identification of children where implant technology might be indicated, working closely with our colleagues at Australian Hearing, when the implant work is indicated and our team is travelling to the area we screen those children for appropriate referral into the implant program.

Senator ADAMS—You were saying that your services are in New South Wales, ACT and the Northern Territory. Do the other states have a comparable program?

Mr Rehn—It varies. This is probably to my initial point that says there is great inconsistency across the country. My job here is not to take shots at other states.

Senator ADAMS—No, but we would really like to know what is happening in the other states.

Mr Rehn—New South Wales and the ACT probably lead the country in terms of the accessibility of the technology. Victoria is very good and then it drops way down from there. Queensland is on the improve and Western Australia, South Australia and the Northern Territory I would put in the poor category. Access to an implant in a timely way is very difficult in those other states. Again, that is single-sided cochlear implantation.

The way that cochlear implants are funded is under discretionary state funding, so there is no universal system at play anywhere in Australia for cochlear implants. It is up to the state and the lobbying process to work out. South Australia has a provision of less than 10 for the whole of the state for adults and children. Again, it varies greatly across the country and varies between adults and children.

Senator ADAMS—Do you consider that there should be a national approach?

Mr Rehn—Absolutely. Without a doubt it needs to follow the Commonwealth Hearing Services program in terms of hearing aid provision in that where a cochlear implant is indicated, which requires some degree of definition, it should be in an equitable manner.

Senator ADAMS—In looking at a child, how long does the operation take and what is the after care for that child?

Mr Rehn—If you used a child who had been picked up through newborn screening—and New South Wales has got a very good newborn screening program—we may well see the child within the first couple of weeks of life. We would do some objective and subjective testing with that child, in addition to what has been done elsewhere, like with Australian Hearing. We would work with the family to understand what the road ahead looks like because you could write a book on informed consent. In our view it is not just about understanding the risks of surgery, infection and things like that, but really understanding what the long-term implications are of having a cochlear implant in and managing that device to the outcome appropriate for that child and that child’s circumstances. That would normally take three months.

The youngest in our program history with an implant is about three months of age. After three months we would expect that we would be working acutely with them for probably 12 months or perhaps a little bit longer. They would also be partnered up with Australian Hearing. They may have a hearing aid in the opposite ear that they use for some degree of binaural benefit and an early intervention program, such as the Royal Institute for Deaf and Blind Children, which are presenting later on today. The marriage, if you like, between family, technology, early intervention provider, hearing aid provider and hearing services provider forms a union to totally support that family in the development of that child. Our job as an acute service provider would probably be about 12 to 18 months, but in the longer term we would manage that device audiologically forever, so 100 years plus. Acute services would be about 18 months.

Senator ADAMS—Once again I am concentrating mainly on the Indigenous children.

Mr Rehn—To answer your question specifically, the surgery itself would take about three hours. SCIC has about 12 hospitals that it works within to provide that, most of which are in the state system.

Senator ADAMS—I am just thinking about the transient nature of some of these families and the after care. Are there complications? A number of those families really would not understand the intricacies of what is being done. The child can hear and that is great, but there again there is the after care. What happens if they do not get back for any checks or anything like that? What danger is there in that respect?

Mr Rehn—The danger is that they do not reach their optimum level of functioning with the device. We have had to modify our program, like we do with children who have multiple impairments, to say that the standard approach to cochlear implantation does not work with these particular groups. We have to take a much more flexible approach. We may not see them as regularly, but we may be more intensive at the point where we see them. For instance, if it was a Northern Territory family, instead of seeing them once per week for 12 weeks, we might see them 12 times within two weeks. We have to modify the program to meet the very specific nature of their family and the dynamic in which they live. What we have found with our Indigenous populations is that it requires a lot of modification to bend and flex to keep working with the family to understand what the benefits are and how to achieve those. To be fair, a lot of that work is done pre-operatively so that the family understand what the road map ahead looks like. Again, we have to back it up with quality services that are specifically tailored to that client and that client's needs.

Senator ADAMS—Thank you.

CHAIR—Senator Williams.

Senator WILLIAMS—It is interesting that you said earlier on that around 90 per cent of babies with severe hearing loss are having implants. We had a witness yesterday, and the chair will correct me if I am wrong, who was basically saying that the situation now is that it is up to the parent to decide whether the child has an implant or not and she would like to see it turned around where it is automatic that the child has the implant unless the parents actually want to stop it. On your figures it is obviously very successful in the current system.

Mr Rehn—It is. I would very much hold short of mandating cochlear implantation. The suggestion that you would opt in a child to—

CHAIR—Opt out rather than opt in.

Mr Rehn—Having said that, if the sentiment there was that the funding should be provided to be universal so that any client can access it in a timely manner, I agree entirely. I think the decision to put a child through surgery for cochlear implants, the associated need for rehabilitation afterwards and the particular types of rehabilitation required needs a family to be fully versed on it. I would be very concerned about something that says that it is almost assumed that they must. That would be very concerning to me. I am in the business of cochlear implants, but it would be most concerning. We really do believe that in partnering up with the family that the family make an informed decision and that informed decision is about the choices for the child's life, irrespective of what that looks like.

We have children who use signing and a cochlear implant for, if you like, receptive information. We have children who are profoundly deaf, born to profoundly deaf parents, where it is about the enhancement to their current world; it may not be about the development of speech. Again, I would hold short of mandating cochlear implant surgery because it is surgery and it is a child, so that decision can only be made by a fully informed family.

Senator WILLIAMS—Any surgery with anaesthetics carries an element of risk.

Mr Rehn—Absolutely. I am digressing a little bit, but one of the greatest challenges we have is that everybody believes that newborn screening is a great thing, and it is, but a family holding their baby only a couple of days old in their arms with someone coming in and doing a very simple test to work out whether there might be a hearing loss and communicating that the child has the potential for hearing loss, is a devastating set of circumstances as they hold their perfectly looking child in their arms. To talk to them about surgery quickly after that, be it a couple of months and say, ‘We can fix this. We’ll just offer surgery’, would be most concerning. It is a journey that requires time, appropriate information to be provided and the ability of looking at other options that might be suitable. Again, it is the preferred intervention today. We accept that and we anticipate that most children would go through to receive a cochlear implant for a range of different outcomes, but again, I would hold short of mandating it.

Senator WILLIAMS—It is very interesting. We have certainly come a long way. I go back to my days in primary school where if someone was born deaf, they were deaf and dumb. They did not know how to speak. They could not put two words together. We have certainly come a long way since those days.

Mr Rehn—In the ideal environment, which is very typical these days, a child that has received hearing aids early or cochlear implants early with the appropriate intervention and care, nurtured completely by the family, can develop very good age appropriate speech and language and fully function, unlike the children that we would have seen back when we were going through school. Again, to make all the decisions that get to that type of outcome the family have to be across what that means. Many families come to us with, ‘Yes, just get on with it. Let’s just race for the surgery.’ Really, we need to take the time to get them to understand what the road map looks like and to be able to put the decisions in place. In some cases it may be moving closer to where the early intervention centres exist. There are huge life decisions that may need to be made, so I would hate to be in a situation where we told them, ‘Don’t worry, we’ll just fix this with surgery and then you can work out the loose ends later.’

Senator WILLIAMS—You obviously think that between the Commonwealth and states they are not covering the costs with appropriate funding and so on. How do you see that can be fixed?

Mr Rehn—At the moment the initial implantation is done at a state level through state health, so federal funding could be provided to enhance the picture under state health. The alternate model says that you try to provide a federal vehicle, if you like, to administer the cochlear implant access. The Office of Hearing Services and Australian Hearing have not been backwards in trying to accommodate cochlear implantation in its world through the provision of upgrades, but again the application of that is at this point just a bandaid because getting the initial implant seems to be the hard bit. Upgrades are accessible for children under the age of 21, but initial devices vary across the country.

A federal mechanism of overseeing a consistent approach, one that underpins the intentions of the Commonwealth Hearing Services program for hearing aid provision through funding made available to the states would, in my view, be a perfect model. As it is under state health and state hospitals it does require an intervention between federal and state governments. I do not think it can be federal only.

Senator WILLIAMS—I am pleased to see New South Wales is doing very well in this field. From the infant testing their record seems very good. Is there anything else that you would like to add, especially on the finance issue? It is always a big thing when you talk to any level of parliament—state, federal or even local government—the lack of funding for certain programs—

Senator BOYCE—We have had some figures yesterday, but they seem to vary, regarding the ongoing lifetime costs. Can you give us a sense of what that cost is?

Mr Rehn—Yes. If you take a view that says a child under the age of 21 will receive support under the Office of Hearing Service program for upgrades, spare parts, maintenance to the device and so on, which is very good, but from 21 years onwards they are going to live to an age of say 81 years of age, so it would be 60 years unfunded. We would anticipate that there would be about $100,000, or $1,600 per year, of maintenance costs associated with that device. When you looked at the upgrades and replacement of devices based on its useful life being concluded, it is probably another $150,000 as every four years new technology would become available or a replacement for the external part of that speech process would be required. You are looking at something in the vicinity of $250,000 over a 60-year period for a recipient with a single-sided cochlear implant. Obviously the number doubles if they are bilaterally implanted.

If you look at the issue of the internal device and its replacement, whilst it is designed to last a lifetime, we see reason to reimplant a small proportion of those people. The costs would increase, but we would anticipate for a single-sided implantation it would be something in the vicinity of $250,000 plus over the 60-year period.

What would we like to see? I think we have done a good job to this point in trying to make access possible in New South Wales and the ACT, but it varies after that point. The emerging technology is the advent of bilateral cochlear implants, the broadening criteria where an implant is offered, will only say it will be grossly inadequate moving forward. I do not think using retrospective data to predict how we are going to go from this point on is going to be appropriate. I think it really needs an appropriate look at the funding model that allows for all types of implantable technology to be offered in a timely manner and that is why a new funding model really is required.

Senator WILLIAMS—On those figures that you have supplied to us that is basically $80 or $90 a week for 60 years.

Mr Rehn—Yes.

Senator WILLIAMS—That is a quarter of a million dollars over 60 years, or $4,000 a year.

Mr Rehn—Correct.

Senator WILLIAMS—It is a lot of money.

Mr Rehn—It is a lot of money. As I said, that is based on single-sided cochlear implantation. Bilateral cochlear implantation is now almost the expected in the private domain. The only reason why we do not do it in the public, except in exceptional cases, is because we would rather give twice the amount of people one implant than half the amount of people two implants. You can see the imbalance in that picture between public and private. Again, hybrid devices, bone anchored hearing aids and emerging technologies will only make that limited state government funding even more stretched and more inequitable compared to the Commonwealth system for hearing aids.

Senator WILLIAMS—Is it accurate to say that private health insurance does not contribute much towards it either?

Mr Rehn—Private health covers the in-hospital component, so it is the surgeon cost, the anaesthetist’s cost, the hospital cost and the device cost. SCIC has no gap surgeons. Outside of that the rehabilitation costs, assessment costs and all of those things are not covered through private health. We do not use the user-pay system. We can bill appropriately for certain services and use charity funding for others.

Senator WILLIAMS—Thank you.

Senator ADAMS—What does Medicare pick up?

Mr Rehn—When I say appropriately, we appropriately bill Medicare under the provider number of the ENT surgeons for audiological procedures where electrophysiological testing is done. The reimbursement varies from that. In the most generous of cases it is $150 per session of reimbursement, which will certainly cover the cost, but much of the work that we are doing is not billable so the assessment procedures, processes and so on are all not billable, as is habilitation, speech therapy and those things. No doubt our colleagues later on today in the early intervention programs will talk about this, but a better funding model for rehabilitation services and early intervention services is certainly a worthwhile goal as well.

CHAIR—I have two lots of questions. One is regarding money and the other is regarding research, in terms of where we are going with improvement. My understanding is that the invention of the cochlear implant was an amazing step and changed lives, but there needs to be ongoing research to make sure we have new hybrids and new forms of technology, so I am interested in how that operates. I am still struggling to find out how you survive in terms of funding.

In your submission you talk about the fact that you are a public provider. You have a bank of ENT surgeons. Anyone that tells me in this situation that you have lots of doctors catches my attention, so what is the funding model that you have to make sure that you continue to exist?

Mr Rehn—The good news is that we do not employ the doctors. The doctors come under the state health system.

CHAIR—Do they work for you?

Mr Rehn—Yes. As part of their working for us they have to do a public and private load. They cannot be private-only surgeons. That is the biggest staffing cost for argument sake. For SCIC employees, biomedical engineers, audiological staff, speech therapists, teachers of the deaf, social workers and psychosocial support and administration staff, they will come under what we can appropriately bill for under Medicare and what revenues we might receive through fundraising and our charitable work. We receive some state government assistance for certain amounts of infrastructure for staffing. That generally is in the teaching and administration component of the organisation.

CHAIR—Under education?

Mr Rehn—No, under health. Historically, we have been lucky that it has been put under health rather than education and there has been a very limited amount in terms of business revenue with international clients where they might be fully fee paying. They are a useful mechanism of providing—like universities do with students—funding back into the model that allows for accessibility for the clients who are local.

CHAIR—And that is on a New South Wales and ACT base. Is that where those funding streams come from?

Mr Rehn—That is right. It is a very diverse organisation. There are two charities, one university and a foundation within the university and the state health systems in Canberra, so I have many bosses.

CHAIR—Which university?

Mr Rehn—The University of Sydney.

CHAIR—That is where the focus is on issues around hearing.

Mr Rehn—In addition to that there is the emerging hearing hub at Macquarie University which SCIC are certainly intending to be part of as well. That will be a centre of excellence, if you like, across multiple service providers, research bodies and manufacturers for further development of the implant and associated treatments.

CHAIR—Is that at Macquarie?

Mr Rehn—That will be at Macquarie University.

CHAIR—That is interesting. Is that Macquarie Medical?

Mr Rehn—It is Macquarie Medical and Audiological. Macquarie will have postgraduate medical training facilities which are certainly part of that hearing hub concept in the hospital that they have just built, but it is also the school of linguistics, audiology, speech therapy and so on.

CHAIR—Is the centre of your organisation at Gladesville?

Mr Rehn—Our main head office is at Gladesville. We have permanent sites at Newcastle and the ACT and we visit about 20 different rural and remote settings on a quarterly basis each year.

CHAIR—Does that cover the New South Wales process?

Mr Rehn—Yes, it covers New South Wales and ACT.

CHAIR—And then you have the travelling team to the NT?

Mr Rehn—Correct.

CHAIR—Does the NT government pick up some funding for that?

Mr Rehn—Not at this point, but we are working towards it. They have been quite receptive to the discussions.

Senator ADAMS—I think they should be.

CHAIR—I am going to make Mr Humphreys shudder by actually putting on record that we might have some discussion about visiting some of those places. We will be in contact with you about where we would get the most value from our visit.

Mr Rehn—Yes, we would be delighted.

CHAIR—Sydney is close. The worst thing about a Senate committee is gathering senators together at the same time so it may just be a couple of people. It will be very useful to see some of the places so we will talk with you later about that.

Mr Rehn—It would be a pleasure.

CHAIR—You have got a heading in your submission about the issue of research in terms of developing the technology and improving the knowledge, but I would think that your organisation would have particular interest there. Would you like to put something on record regarding where we go next?

Mr Rehn—Yes. A lot of our research focus is two-tiered. The first is better diagnostic processes to understand issues that might compromise or improve outcomes with the cochlear implant. A cochlear implant works well in cases where the damage is at cochlear level, but where auditory neuropathy or auditory desynchrony between the ear and the brain may be compromised, or at the point where the brain might be compromised, we need to better understand how to manage those clients. That is a particular area of focus because the more information we can gather prior to surgery, the more we are able to tailor rehabilitation to the specific needs of that child and keep families, particularly, in a position of understanding what possibilities are there for their child and counsel them appropriately. A lot of people take the view that says bang it in, promise them the dream and if it does not work, then you win some, you lose some. That is not the SCIC approach. A lot of the research is focused on the electrophysiological testing, the objective testing, towards understanding the degree of hearing loss, the site of lesion and all those sorts of things.

The second part is actually about the rehabilitation processes and how to optimise the fitting of a device to make it more efficient and more accessible. We are using video conferencing to deliver services and we have now done some pilot work in actually tuning the device across the internet. A client can be in Darwin and linked into the professionals in Sydney where we can actually manage that device. It is all research work at the moment and is certainly not commercial, but we think that those things will deliver huge improvements to how people access the service moving forward into the future, particularly with the shortage of skilled professionals out there in the field.

SCIC is linked in with the hearing CRC and the Macquarie hearing hub. We have PhD students and so on, and a lot of that work is about developing better technologies. That might be that we are a trial site for Cochlear Limited or it may well be that we are involved in a particular new program associated with the School of Linguistics to improve the teaching associated with professionals who come through the program.

CHAIR—Does that link internationally in terms of what advances are being made overseas as well?

Mr Rehn—Yes. We have dedicated research staff that not just attend, but bring back the world experience. Australia is certainly at the forefront of this technology, but we do not know it all. There are some very exciting places around the world where they have excellent models of service and research that are teaching us how to improve, how to make it more efficient, how to make it more accessible and how the technology is getting better and better.

CHAIR—There is an international link so there is a sharing of knowledge automatically. It is not just—

Mr Rehn—There is. I would have to say that it varies. I think that the conference circuit is a profit making vehicle in its own right. We have to be very discerning with where we use charitable funds to send our professionals to gain understanding, but I think we have that reasonably under control. We also set up professional links directly with clinics and in some cases in the past we have actually had staff sharing arrangements so that our staff can go over and work in a centre in the UK and then come back. We get that cross-pollenisation. Our leading surgeon also has a fellowship for ENT surgeons.

CHAIR—Is that Professor Gordon?

Mr Rehn—It is Professor Bill Gibson. Professor Gibson has fellows that come and train with him specifically in the diagnostic and surgical techniques associated with cochlear implants and have to contribute, if you like, research to that process while they are here.

CHAIR—Have you found the charitable stream drying up because of the global economic crisis?

Mr Rehn—It has been enormously challenging. We would say that we are operating on the charity side at about a third of what it is in an optimal period. The economic climate is a huge phenomenon to our fundraising success at the moment. We will not whinge and complain, but we can say that we have certainly seen times better than they are at the moment.

CHAIR—Is there anything that you wanted to tell us that we have not asked you about yet?

Mr Rehn—I would go back to that first issue of informed consent. I think that is a terribly important thing to achieve. I think that good collegial relationships as they exist—and an example would be where SCIC works in with the Royal Institute for Deaf and Blind Children and Australian Hearing—can achieve that informed decision making for a parent. I do not think that is something that can be rushed. I think good partnership and collegial relationship is what actually gets us across the line to a family success. I do think that it is time to bring the services to adults in line with the obligations under the Office of Hearing Services Act that exist for children. I think that is an area of immediate priority for those people who are on a disability;

those people covered under the act should be able to access upgrades in addition to their spare parts and maintenance services, as do children.

CHAIR—Yesterday we heard from a parent group and we are also hearing from some today. They talked about parent advisers where a network would exist so that when parents do face that information which they are given at a very vulnerable time that there are processes with people who have been through the same experience that can actually talk with them. That is a model used in a number of organisations. I know Senator Boyce was asking questions about that yesterday, but in terms of process is that network part of the work that SCIC does or does it have linkages with that?

Mr Rehn—Yes. We have linkages to many of the organisations that provide useful information to families or indeed adults who are looking at the issue. I would be very careful of mandating the requirement that they must go off to this or that group.

CHAIR—I do not think that you could.

Mr Rehn—That is right. I think there is certainly a role and a place for that sort of information to be provided when requested and where the need arises for clients. We have psychosocial support. Our social worker family counsellor is there to make sure that a family is not bolting the decision and that they have actually taken the time to consider alternatives. We do not do that as a policing strategy, we do that as good practice.

CHAIR—Supportive?

Mr Rehn—Yes.

CHAIR—Do you have that service with all your clinics?

Mr Rehn—Yes.

CHAIR—So the psychosocial provision is there?

Mr Rehn—Absolutely.

CHAIR—Would those people have special training in hearing aspects?

Mr Rehn—Absolutely. Our whole field requires very detailed understanding. I think we have the added responsibility of having to achieve informed consent. It is not just a case of, ‘Give this a try. If it doesn’t work it doesn’t matter.’ It is really a case of a family who agree to put their child under a surgical procedure really need to understand not just the risks associated with that surgical procedure, but what it is going to take to achieve success for that child, whatever that success looks like.

CHAIR—Is there anything else?

Senator ADAMS—No.

CHAIR—Thank you very much. We will be in contact because it would be useful to at least visit some of those places to have a look at what is going on. We will talk with you and also any other witnesses that had that suggestion.

Mr Rehn—Thank you for the opportunity to present.

[9.54 am]

RUNDELL, Mr David Thomas, President, Hearing Aid Manufacturers and Distributors Association of Australia

WILSON, Mr Ashley John, Vice President, Hearing Aid Manufacturers and Distributors Association of Australia

CHAIR—Welcome. You have information on parliamentary privilege and the protection of witnesses. Would you like to make an opening statement and then we can go to questions?

Mr Rundell—Yes, I will. I would like to thank the Senate committee for giving HAMADAA the chance to appear before you and offer our submission. I hope we have attempted succinctly within our submission that we have a very mature hearing aid market in Australia and one of the highest penetrations of aided hearing loss from within the developed countries. The Office of Hearing Services scheme has been a major contributor to this situation and from our perspective there is no doubt it works. As manufacturers, it has become a large part of our day-to-day business. We also believe it works because it allows sales of higher priced hearing devices under the scheme and it has allowed, to some extent, manufacturers to subsidise the devices sold in what we call the free-to-client market at a price that the government has accepted as fair value.

We also believe the OHS scheme can be further finetuned by allowing manufacturers freedom under the watchful eye of OHS to self-regulate the devices under the scheme. It is a bit like the European association which has self-regulation in terms of hearing devices offered under their schemes in Europe. Advancement of the technology is ensured and with the ever-shortening life cycle of devices at the moment, so we believe the goals of OHS will continue to be delivered without the need for constant formal negotiation and will result in a more efficient system for both parties.

CHAIR—Thank you. Mr Wilson, do you have anything to say?

Mr Wilson—No.

CHAIR—Senator Boyce.

Senator BOYCE—Perhaps you could explain to us the current situation in terms of the deed. How often do you renegotiate with OHS? Is it OHS that you negotiate with?

Mr Rundell—That is right. It is usually OHS. I believe the last meeting was March this year. It was agreed that we would have a two-year moratorium on device specification. That seems to be a varying time frame depending on what we agree on at the time.

Senator BOYCE—Is it a two-year moratorium on the device specification?

Mr Rundell—Yes.

Senator BOYCE—Does that mean that you will not introduce any new products in the next two years?

Mr Rundell—The way it works is that OHS will not demand new specifications on our devices at the free-to-client level.

Senator BOYCE—There is a round of negotiations every two years.

Mr Rundell—It could be one or two years. It depends on what we agree on at the time.

Senator BOYCE—Has it varied previously?

Mr Rundell—It has.

Senator BOYCE—Is that about what you will charge?

Mr Rundell—No. It is more about the specification of the device and what features are in the device.

Senator BOYCE—Is that regarding the cost to the government?

Mr Rundell—It is more about what value is attached to the price that the government is willing to pay, so if they want more specifications for the price that is there at the time, that is set by government so we get a better device.

Senator BOYCE—You do negotiate. There must be money negotiated.

Mr Rundell—That was negotiated upfront when the scheme was first started and it has been ongoing. There is never really a price negotiation.

Mr Wilson—No. It is more or less just CPI.

Mr Rundell—CPI increases.

Senator BOYCE—It is about what they get for their CPI indexed amount.

Mr Rundell—Exactly.

Senator ADAMS—When does the moratorium close?

Mr Rundell—The next time we will do something will be March 2011.

Senator ADAMS—Thank you.

Senator BOYCE—I am still not entirely clear on what that moratorium does.

Mr Rundell—The main issue is that the deed is a standing offer. That is the term for the contract we have as manufacturers with the government. It is the minimum standard or minimum set of features in a hearing aid that is allowed through the OHS scheme and hearing aids must be at least achieving that level. That becomes almost a point where the free-to-client devices, which are the majority of devices, must be of that standard. It ensures that substandard hearing aids are not available through the OHS scheme.

Senator BOYCE—Who decides on the level of the device? Is that a medical decision?

Mr Wilson—At the moment it is a decision made by the OHS looking at the technical landscape.

Senator BOYCE—That is at the basic level. Who makes the decision for a particular client who may need something more?

Mr Rundell—That is at the clinical level.

Senator BOYCE—Would that decision sometimes be affected by the client’s ability to pay for a top-up?

Mr Rundell—Yes. That is the way it works on the retail side.

Senator BOYCE—How long has your association existed?

Mr Rundell—Mr Wilson might know that answer. I have only had four years in this field.

Senator BOYCE—Is it more than four years?

Mr Wilson—Definitely. It is somewhere around 15 years.

Senator BOYCE—Can you give me a quick picture of the Hearing Aid Manufacturers and Distributors Association of Australia?

Mr Rundell—Most of the major brands in the world are in that group. There is one which supplies Australian hearing and medical hearing instruments that decided not to be part of HAMADAA, but the rest of the main manufacturers are part of that group. We meet reasonably regularly. It is mostly about the deed and that part of the business.

Senator BOYCE—Would you see yourself as representative of all of the technology available in the area worldwide?

Mr Rundell—Very much so.

Senator BOYCE—Is there manufacturing taking place in Australia or is it primarily distribution?

Mr Rundell—There is. It is manufacturing and distribution.

Mr Wilson—Because of the custom nature of a lot of the devices which are made from an impression taken of the ear, it is similar to a denture being made from an impression of the mouth. A lot of hearing aids are custom made so you have to have that local facility to provide that and of course after the fitting of the hearing aid you need the ongoing service and maintenance over the life of the hearing aid.

Mr Rundell—Just to give you an idea of the statistics, I know in our organisation that about 82 per cent are the behind the ear type of instruments and about 18 per cent are those custom type products.

Senator BOYCE—Is that 18 per cent?

Mr Rundell—Eighteen per cent are custom type products and 82 per cent are the behind the ear type products.

Senator BOYCE—I hesitate to use the word cheaper, but the 82 per cent would be cheaper.

Mr Rundell—No, they are about the same price. It just depends on what particular needs the client has.

Senator BOYCE—Is that about client choice, not about efficiency or price of the item?

Mr Wilson—It is not about price. It is about the consumer’s combined needs in terms of what they need from an acoustic standpoint and also getting the balance with the cosmetic aspects and so on which also comes into play.

Senator ADAMS—I would like to continue on with the moratorium. You said that 2011 is the next negotiation. Looking at the way technology is moving so quickly, is the two-year moratorium satisfactory? If something comes onto the market that you consider to be very necessary at the moment rather than waiting, then what would happen?

Mr Rundell—That is what is happening. That is why we believe that we do not need to have this regulation, the deed of negotiation. Some of our products have a product life cycle of 18 months at the moment so we will have new products onto the market within 18 months and the old ones will be discontinued.

Mr Wilson—Our global parent companies have their own R&D and engineering which create new products for global markets and the products that they create are the products that we distribute in Australia. Also, outside of the Office of Hearing Services scheme you have people who are private hearing impaired people that purchase hearing aids. Obviously manufacturers have to be competitive and bring new products to market on a regular basis, so what we are saying is by default, because we are being supplied by our parent companies who are competing in a global market, we continually get new technologies added to Australia and therefore the Office of Hearing Services scheme. The list of devices is continually growing.

Senator BOYCE—When you think about what has happened in five years with hearing it is incredible.

Mr Rundell—Yes.

Senator BOYCE—You probably heard me ask the questions about the Indigenous communities. What process do you use for supplying those areas, say for the Kimberley or the Northern Territory?

Mr Rundell—It is mostly for customers who want aids for those particular areas. We do not deliver any services ourselves.

Senator BOYCE—Your customer is OHS.

Mr Rundell—Yes, if there is a contract from a provider with OHS.

Senator BOYCE—Are your manufacturers’ customers OHS and audiologists?

Mr Rundell—That is right, yes.

Senator BOYCE—Is that it?

Mr Rundell—Yes. It is Australian Hearing too. Some of us have smaller contracts with Australian Hearing for products and things like that, so we do supply some specialised products to them as well.

Senator BOYCE—Are you involved with the expertise that goes with the fitting and then with the continual ongoing care, or is that subcontracted out?

Mr Rundell—The clinics have their own audiologists who fit the devices, but we have in-house trainers that are audiologists themselves who would assist with fitting. If there is a fitting problem with the client they will go and assist that particular client.

Mr Wilson—It is a very similar model to optometry where you have got the retail outlets, which are the people who are actually looking after the hearing impaired and they are typically staffed by audiologists. They are our customers and they do the diagnostic work, test the hearing, make decisions about what recommendations for what technology is going to work best for that particular patient and then at some point they may place an order with a manufacturer from our association.

Senator BOYCE—Thank you.

CHAIR—Senator Williams.

Senator WILLIAMS—Your organisation is responsible for about 350,000 devices. What is the average lifespan of the hearing aid?

Mr Rundell—The average seems to be about five years.

Senator WILLIAMS—I will refer to the elderly. Do you get the situation where they get hearing aids but rarely ever use them?

Mr Rundell—Anecdotally I hear that a lot.

Senator WILLIAMS—My mother and my mother-in-law basically refuse to use them. There is always the excuse that the batteries are flat or something.

Mr Rundell—I think we have all got older relatives like that.

Senator WILLIAMS—Do you have any statistics on that?

Mr Rundell—No. We do not have statistics like that.

Senator WILLIAMS—The reason I ask the question is that it is obviously a big cost to the government.

Mr Rundell—For sure.

Senator WILLIAMS—If they are putting a lot of money into hearing aids and then people are simply not using them then perhaps that money could be spent more wisely.

Mr Rundell—We believe in our technology so we want them to use them.

Senator BOYCE—A suggestion that was put to us was perhaps a co-payment of some sort that could be made for hearing aids to give them a value.

Mr Rundell—That is probably the point. If people get it for free then they do not attach a value to it. We have the same situation in our business. We do not like to give things away free to our clients either because they do not attach a value to it. We always try to attach a small value, whatever it is, because then at least there is something attached. They value it a lot more if there is a value to it.

Senator BOYCE—I would like you to outline for us the new technologies that are coming along so quickly. What is changing and what is new? Can you tell us a bit about the research and product development side of the industry?

Mr Rundell—Obviously it changes from brand to brand. Mr Wilson represents one brand from America. I represent a couple.

Senator BOYCE—Does everyone use a similar technology or are there different technologies?

Mr Rundell—The technology is very similar.

CHAIR—I would imagine that it would be difficult for the gentlemen to add to that.

Senator BOYCE—They are the association.

Mr Rundell—I can talk from my perspective. Phonak is my parent company in Switzerland. They have done a lot of work on computer algorithms for the hearing impaired and there is also the development of wireless products that are coming through. That is probably the biggest change that has happened in the last 12 months; products are now wireless. They can be connected to myriad electronic devices so you are not stuck with your hearing aids and nothing else connected to it. You can have your mobile phone, your TV, your GPS, the whole gamut of electronic devices, connected.

Senator BOYCE—You basically just sync them?

Mr Rundell—Exactly, through the Bluetooth interface. That has changed a lot.

Mr Wilson—In recent years in our industry the big move was switching from analogue technology into digital, which is the same as other fields of electronics. Again, just to give you another example, our company evolved from US submarine navy research.

Senator BOYCE—What is your company?

Mr Wilson—Sonic Innovations. We are a US NASDAC listed company. It was work done on algorithms relating to sound in an aqueous environment, being the ocean. Those particular scientists went back to academia and were interested in sound. They realised that with the human auditory system the cochlear was an aqueous environment and there was opportunity to apply that thinking to the human auditory system. Eventually that was commercialised and a new type of approach to hearing aid technology and amplification came about, so there are pretty advanced and exciting technologies coming into the global market on a regular basis.

Mr Rundell—The chips that go into these devices are just getting smaller and more powerful as the electronics develop over time. To run the electronic wireless type stuff with a tiny battery for eight hours a day for two weeks is incredible technology.

Senator BOYCE—The device, itself, can get smaller and smaller.

Mr Rundell—Exactly. That is happening.

Mr Wilson—Generally out there in the community—it is reducing significantly—there is still somewhat of a stigma attached to the idea of wearing a hearing aid versus spectacles, which have become a fashion item versus a medical device. There is this general requirement to make hearing aids as invisible and user friendly as possible because that helps people take the first step. Research shows that people, on average, wait about seven years before they take that first step when they have had an audible loss, and often it is not the person with the hearing loss that takes the step, but the influences around that person who say, ‘We’ve had enough. You’re getting a hearing test.’ Mr Rundell would agree that it takes seven years for people to get a hearing aid, but once properly fitted if they are without it for seven minutes they are very unhappy. If a hearing aid breaks down because they left it on the coffee table and the dog came in and chewed it then they want it repaired very quickly and returned to them so that is the service that we have to provide.

Senator BOYCE—You say that it takes an average of seven years, so what is the average age of those people? We are talking about people aging.

Mr Rundell—The average age for a hearing aid wearer is about 68 or 69 years. It has come down very significantly in the last few years.

Senator WILLIAMS—Is the age coming down?

Mr Rundell—The average age of wearing hearing aids is coming down.

Senator WILLIAMS—That is a clear indication that younger people have a hearing problem.

Senator ADAMS—You know why.

Senator WILLIAMS—It is too much boom, boom, boom.

Senator ADAMS—That is right.

CHAIR—I was going to ask you about teenagers or young adults who have severe or profound hearing loss and have been using hearing aids potentially since childhood. We had some evidence yesterday suggesting that it becomes very difficult for them when they are trying to be cool and teenage.

Mr Rundell—That is right.

CHAIR—I wondered if there was any research in the area of trying to assist them? We have been talking about smaller aids, but is there anything that looks like a funky aid?

Mr Rundell—The wireless stuff is really attractive to them because they can now be connected to their iPod through their hearing aids and they just look like a normal child because they have all the bits that other kids have now. That is important to them certainly at the teenage level. They do not want to wear hearing aids. They do not want to stand out as being someone different. They want something that they look normal with and these new aids give them that.

Mr Wilson—Additionally, with mobile phones and Bluetooth devices where you see people walking around airports or whatever now there is a lot more accelerated acceptance as far as the idea of wearing a hearing aid goes and people find it less threatening and confronting.

CHAIR—Senator Adams.

Senator ADAMS—You were saying that the batteries were becoming smaller, but for the elderly that is a real problem. Is there any way that can be overcome?

Mr Rundell—Possibly not. That is always going to be an inherent part of it. Some of the manufacturers have rechargeable hearing aids these days so they can just put it in a machine and it recharges the battery.

Mr Wilson—That is part of the clinician’s role to assess, for example, dexterity issues of a patient. You do not necessarily prescribe the smallest hearing aid for every person because if someone cannot manage their hearing aid due to arthritic fingers a large volume control might be something they need to access or an automatic volume control that does not require use of the fingers. There are a lot of decisions other than just small is better that are made at clinician level.

Mr Rundell—The battery is all about the power that is required to run this quite sophisticated device.

Senator ADAMS—That is right. I have a 96-year old mother and she uses tweezers. I am thinking is there something easier than this, but she is brilliant as far as her hearing goes. It has made a huge difference to her.

Senator WILLIAMS—Imagine I am 70-years old and I am a pensioner. The main cost of maintaining hearing aids is the batteries. Are there any other costs?

Mr Rundell—They might do a maintenance check every six months. It depends on wax build-up in ears. That can cause problems with the hearing aids. There is a regular maintenance of the hearing aid depending on the person and whether they are diligent with that or they want the manufacturers to do it for them. Everyone is different.

Senator WILLIAMS—What would an average cost be for a week for the batteries for someone who is relying on one hearing aid?

Mr Wilson—With the Office of Hearing Services program, which is the vast majority, it offers a battery and maintenance program. That is where some co-payment comes into play where the person has to contribute on an annual basis around $36 which then makes them eligible to have batteries provided free and maintenance of the hearing aid carried out for free.

Mr Rundell—That will depend on the use of the hearing aid. If they are a very good user then the battery might last 10 days or two weeks. It depends on the amount of usage per day that they have the aids in for.

Senator WILLIAMS—Thank you.

CHAIR—People have told me that there are thousands of hearing aids sitting in drawers around this country as we speak. Is there any recycling program? Can you take old hearing aids that are past their time to somewhere where they can be taken away and do something with them?

Mr Rundell—Yes. We have many charitable organisations where we give those recycled hearing aids.

CHAIR—People can give them back and then you can recycle?

Mr Rundell—Yes, absolutely. Unfortunately they usually need the more powerful aids. Some of the third world countries need the help. We have programs in Fiji, Samoa and Vietnam, so we are always looking for aids that we can give to those people to use.

CHAIR—Is that through HAMADAA or through your own company?

Mr Rundell—Through our own company.

CHAIR—Is that well known?

Mr Rundell—Yes.

CHAIR—It worries me. I used to visit lots of homes in a previous job and you could usually guarantee that there would be a drawer full of hearing aids.

Mr Rundell—That is true.

CHAIR—That really concerned me. Do most of the large companies have a process like that?

Mr Rundell—Yes, absolutely.

Senator WILLIAMS—You are saying that if someone returns a hearing aid you can then send them overseas to a more disadvantaged country where they can be used again.

Mr Rundell—Yes, absolutely.

Senator WILLIAMS—Can you give us an idea of where we can have those returned to? Is it the local GP? Where do people send them so that they can be used again?

Mr Rundell—I know Australian Hearing have a lot of returns. They can probably speak for themselves.

Senator WILLIAMS—I would like to publicise that fact.

Mr Rundell—Any of the manufacturers would gladly take old aids back and redistribute them. We can give you those details.

Mr Wilson—There are a number of clinicians in Australia who take their annual leave to go to South America or Africa. They do the sort of Fred Hollows of hearing thing. They have relationships with the manufacturers and know who has products that they can give to them. They also get donations of diagnostic equipment to use from a lot of the large retailers and so on as well.

Senator WILLIAMS—I would like to go back to the point about the average age of people using hearing aids getting lower. This is obviously brought about by excessive noise in their younger years.

Mr Rundell—That is probably one of the reasons. That is a known fact.

Senator WILLIAMS—Music.

Mr Rundell—You have got to look after your hearing. You only get one go at it.

Senator WILLIAMS—The reason I find it concerning is that I spent most of my life on the land and I have noticed that machinery, tractors and trucks are a lot quieter and yet we are seeing a situation where the average age of people relying on hearing aids is getting lower. I think we could probably say, in general, that most types of machinery—with better cabins, insulations, design and so on—have got a lot better over the last 20, 30 or 40 years. It is much better, in fact, yet we have this problem arising. Therefore, we have obviously got to look at some awareness campaign to warn people if they are going to have iPods blaring in their ears. I was walking down the street the other day behind a bloke and I could hear it a metre behind him. He had these things in his ears listening to this junk music, as I call it. I am sorry; I am old-fashioned. It is obviously a big concern. This is damaging people’s hearing; whether they are going to discos or nightclubs or whatever. Frankly, I cannot stand them myself, but this is obviously a big problem facing the nation as the cost of all of this gets higher and higher. We have heard so much evidence about people when they have hearing problems regarding the lack of communication and productivity, so what can we do about it?

Mr Rundell—I think an awareness campaign is probably an excellent idea.

Senator WILLIAMS—It is probably good for your business.

Mr Rundell—Yes, but I think it needs a concentrated effort from every party to bring this to the public’s attention. I agree with you. We have thought about it many times, but the cost of that sort of program is such a big thing that it gets beyond our financial resources as a group to do that.

CHAIR—And the effectiveness.

Mr Rundell—Yes.

CHAIR—Amongst all the other messages out there, how do you get this one heard?

Mr Rundell—That costs money to get it on the prime time and have a funky ad that people will take notice of.

Mr Wilson—For many years we have advocated that a slip, slop, slap campaign for hearing is well overdue.

Senator WILLIAMS—Good point.

Mr Wilson—Hearing and hearing loss is one of those invisible ailments. If someone has a white cane then you know instantly. I think another factor with the age coming down is people had high frequency hearing losses and learnt to live with it, so it was not so much a question of volume but clarity. The technology today is focusing a lot more on being able to give you better quality hearing in complex environments. You are seeing people who are younger accessing that technology and having a better quality of life, where previously, because the technology was not there to do it, they just had to put up with it until they got to quite a severe hearing loss level and then they had no choice.

Senator WILLIAMS—Some people find it embarrassing to wear hearing aids. They have a complex issue. They see it in the public eye that they have got a hearing aid and do not want people to see that because they will then know that they have a hearing problem. Is that the case?

Mr Rundell—That is still a stigma.

Mr Wilson—In terms of human psychology one of the worst, dare I say, negative campaigns for hearing was the Uncle Arthur in the comedy show that was on TV and that association between a silly, dithering person wearing a hearing aid and therefore having a hearing loss. Unfortunately, that is something that is associated with this stigma and we need to get people to realise that hearing loss is no different to vision loss or any other thing.

Mr Rundell—It is associated with age and getting older.

Senator WILLIAMS—People did not want to be seen as Uncle Arthur.

Mr Rundell—Yes, or being old because they needed a hearing aid.

Senator ADAMS—I can just make a comment. Having been involved with farming for many years, it is just the change of practice now in comparison to years ago where we would use the chainsaw or the lawn mower; the ear protection is there. There are a number of the farming newspapers around and very rarely do you see one without an ad for somebody with their correct protective gear on when they are using an implement. I think that message has come through and possibly with the older generation and moving on we are getting into that next bracket of those people who have suffered from hearing loss somewhere along the line. We just put up with the open tractors and all the other things; you did not take any precaution whatsoever.

Mr Rundell—I think the open industry was the same. They did not have hearing protection in the sixties and seventies. People were working in horribly noisy environments with no hearing protection at all for many years.

Senator ADAMS—Mining is another one where they are very strict.

Mr Rundell—It is interesting. The younger musicians that are coming through now are very careful about their hearing. They all have musician earplugs that they wear when they are performing. The musicians are very cognisant of the fact that they need to protect their hearing as they get older. It is not the people out there in the audience but the musicians themselves that are cognisant.

CHAIR—Thank you for your evidence and your submission. If there is anything you think we should know that we have not covered, please contact the committee.

Mr Rundell—There is one thing that I noticed when I came into the industry. Australian Hearing children get to 21 and then basically they are thrown out into the community to some extent. I am not sure that is a good thing for the community that they lose that lifeline of Australian Hearing at that point. They have got a hearing loss for the rest of their lives so I am not sure if there is a struggling community out there that has hearing loss which is not being helped to some extent.

CHAIR—I think the next witnesses will have a lot to say about that point. Thank you very much. That is a point that has been made consistently.

Senator BOYCE—I have a feeling there may be some collusion amongst witnesses.

Mr Rundell—Not at all.

Senator BOYCE—Thank you very much. The committee will now break until 10.45 when we will hear from Let Us Hear.

Mr Rundell—Thank you.

Proceedings suspended from 10.24 am to 10.48 am

COLEBROOK, Mrs Margaret Dorothy, Chairperson, Let Us Hear

FISHER, Ms Barbara, Committee Member, Let Us Hear

HIRON, Mrs Noelene, Committee Member, Let Us Hear

CHAIR—Welcome. You have information on parliamentary privilege and the protection of witnesses. We have your submission; thank you very much. It is one of the early ones. I have the feeling you wanted to talk to us. I would now invite any or all of you to make some opening comments and then we will go to questions.

Mrs Colebrook—Oral deaf people are the hidden disadvantaged who have not been identified or understood by the government. This is a statement made by one of our members. I hope to show you that this is true.

When the Australian government took the giant step to set up the Commonwealth Acoustics Laboratories in 1948 it became a big player in the history of auditory, oral, deaf education in Australia. CAL later became NAL, then Australian Hearing and now possibly Hearing Australia, as I saw it referred to by Minister Chris Bowen during Hearing Awareness Week. This organisation has become famous for its research and for its excellent service to those eligible for its community service obligations.

Children under 21 years have always been the recipients of this service, and parents and their deaf children have been extremely grateful for it. The expert audiologists, the same day repairs and the upgrading of technologies are part of the way they are always working towards improvements for their clients and are the envy of the world.

As a New South Wales teacher of preschool deaf children working in an Australian hearing centre for 28 years, I know the depth of professionalism and expertise amongst the staff towards the testing and fitting of congenitally deaf children, some of these having syndromes and other complex needs. Many now are premature babies kept alive in humidicribs who may be multihandicapped.

The nature of auditory oral education meant diagnosis as early as possible and the early fitting of at first one body aid, then two later behind-the-ear aids and then, in the 1980s, cochlear implants for the profoundly deaf. More recently under the SWISH program, that is the State-Wide Infant Screening Hearing program, in some states there is the testing of hearing at birth.

Auditory oral education means more than that. It also means training the children to use their residual hearing in as sophisticated a way possible with their hearing devices. This is done by consistent practice in listening skills which, added to lip-reading, gives the child two senses to work with. I have found as a teacher that even the most profoundly deaf child could learn to talk intelligibly.

Now some programs teach the auditory verbal method which cuts out lip-reading and depends solely on listening. This method is used with those children who have been fitted with cochlear implants. For many deaf children it is not surprising that their hearing devices become their most cherished possessions; first on after waking and last off when getting into bed. They are able to become part of family life, then the outside world, including school, friends, church, sport—you name it; they persevered in all the ways that children do. Some mothers told me their small deaf children would not let them remove their hearing aids until they were asleep because of this desire to keep on hearing the household sounds.

With the loop system, those with enough hearing can turn on the T-switch on the aid and hear the words on TV. Now with the Senate having passed into law in 2001 they have captions from 6 pm to 10.30 pm every night. Of course we would appreciate more programs captioned.

As vice president of a parent organisation a number of years ago I lead a small group of parents to a meeting with Australian Hearing. We were talking about various problems. We asked if Australian Hearing could help with the expenses of cochlear implants fitted to children. The Australian Hearing people became very enthusiastic and thus started Australian Hearing's great support for implanted children, a notably helpful gesture which was again gratefully received by the parents. It is of course important to say that the research revenue was greatly needed by the committee working on the cochlear implant, and the Australian government was to the forefront in supplying some of this.

As age 21 approaches it gives deaf young adults a terrible shock to realise they are going to be cut off forever from this reliable familiar service. Their anxiety becomes very apparent as to where to go to receive a comparable service to Australian Hearing. So you can see how much Australian Hearing has been an important and dependable part of a deaf child's life and why we feel the Australian government should continue to allow this gallant group of oral deaf people to access their services after the age of 21 years. We are talking about approximately 700 21-year-olds leaving Australian Hearing annually, hardly a huge number to cope with. Stopping these services does not make sense economically or productively as it risks unemployment, mental anguish and isolation. Not only that, but the longer the deaf person is without hearing devices the less stimulated the auditory mechanism is and the less effective it becomes if fitted again later. They cannot monitor their own voices so intelligibility drops and of course they cannot understand what is said to them.

Tragically, some deaf adults cannot keep up with the expenses required to go to private providers and end up stopping using their hearing devices. As you see in our submission, the cheapest digital hearing aid we have known recently fitted was $2,000. Australian Hearing buys them in bulk for $350. I am not sure if that is quite accurate, but that is the price I knew it to be about two years ago.

What we are asking for is that the government recognises their continued responsibilities to this group of oral deaf people who are forever trying to keep in the hearing world but are totally dependent on their hearing devices to do so. They are constantly hoping that these devices will not need repair or replacement.

Let Us Hear has always drawn to the attention of various ministers and others the huge level of deafness in Indigenous communities. With suppurating ears, or no eardrums at all, they do not fit the picture of the usual hearing aid fittings. We are extremely concerned that they too have the services of Australian Hearing stopped at 21 years of age.

We bring to you this plea on behalf of our group of oral deaf people forever trying to keep in the hearing world where they feel they belong, and forever hoping against hope their hearing aids or cochlear implants do not let them down. Let Us Hear wants to acknowledge with gratitude those ministers, parliamentary secretaries and advisers who have listened and supported us over the last 12 years: Senator Rachel Siewert and her advisers, the Howard government and its advisers, Kevin Andrews, Julie Bishop, Brendan Nelson, Tony Abbott, Christopher Pyne, Joe Hockey, Margaret May and John Perrin. In 2004 we saw Wayne Swan and Anthony Albanese, who were from the then opposition. We acknowledge the Rudd government and its advisers, Bill Shorten, Chris Bowen, Joe Ludwig—

CHAIR—Keep going.

Mrs Colebrook—I am determined to mention them because they have all given us their time. Ursula Stephens and adviser Louise Godwin; Maxine McKew and her adviser, Trish Hurley; Tallis Richmond, adviser to Brendan O’Connor; Kimberly O’Brien, adviser to Kate Ellis; Julia Sibraa, adviser to Mark Arbib; and managers of the Office of Hearing Services and managers of Australian Hearing.

CHAIR—Thank you. Do you have any comments to add at this stage?

Mrs Hiron—Not at this stage.

Senator BOYCE—The term ‘oral deaf people’ is not one that we have found in other submissions. Could you explain the terminology?

Mrs Colebrook—Oral means the deaf who have learnt lip-reading and speaking and, as I say, now listening.

Senator WILLIAMS—Could you just repeat that? I missed a bit of that.

Mrs Colebrook—Oral means talking deaf people as distinct from signing deaf people. We make that distinction because there are these differences in the deaf population, as we put in our submission. We use the term to separate this group whose parents have decided on the oral method of education as distinct from the people who use signing.

Ms Fisher—There seem to be three groups. There are the oral deaf, the signing deaf and then the acquired deaf. There do seem to be three different groups.

Senator BOYCE—The majority of people who would acquire deafness would be because of ageing?

Mrs Colebrook—Yes.

Senator BOYCE—We did have the view put to us yesterday that having surgery or treatment for deafness in infancy or early childhood should be based more on an opt-out system rather than the current opt-in system. The witness who put this view admitted that it was controversial but that all children ideally should have treatment with cochlear implant irrespective of whether their parents have oral deafness or are signing deaf. I am just interested in whether you—

Mrs Colebrook—Philosophically, I could not go along with that. I believe that parents have the right to choose. I can see that that might solve a lot of problems but I do believe that parents have the right to choose.

Mrs Hiron—I would like to comment on that. If it were mandatory that every child was fitted against the parents' wishes, the fitting of a hearing aid or cochlear implant is very, very much the beginning. Any family who does not have the ability or does not have the interest to teach that child almost every word it learns in those first few years, to give it listening exercises and everything else is a very big job. It would be useless to put a cochlear implant or hearing aid on a baby when the family were not prepared to support it through those training years.

Senator BOYCE—Thank you for that view.

CHAIR—I think that what the witness was suggesting was that with the information provided the parents could decide to say yes or no but it would be their choice to say no rather than the other way around. She was very clear on that. It was providing the same information base but then the parent making a conscious decision to say no rather than as it is now with the parent having to make a conscious decision to say yes.

Senator BOYCE—It was, as she phrased it, more of an opt-out system than an opt-in system, which is what we have at the present time.

Mrs Colebrook—Do you feel from that there is not enough information given to parents when they find their child is deaf?

Senator BOYCE—I do not know how much information is given. She was talking more about the circumstance where there was almost the philosophical divide, perhaps, between some parents who may themselves be signing deaf and for that reason may choose not to follow through on hearing aids or cochlear implants.

Mrs Colebrook—I feel that parents have that right to choose.

Senator BOYCE—You touched on something that I wanted to ask your organisation about, which is can you provide a snapshot of the sort of work that a parent or carer has to do when they have a child with a hearing loss?

Mrs Hiron—When you have a newborn baby—and my baby is 40 years old, so I am going back a long time now and techniques have probably changed a lot—but the first thing was just to get this little baby to look at you and realise from a very young age how important lips are. You cannot use your hands. You cannot point to anything. That is just the very basic beginning and it goes on from there. My son was taught by Margaret Colebrook. We went to Margaret every week from eight months old. We had the exercises that we had to do for that week; that is, teaching to listen, to speak and to just use his hearing and learn to lip-read. To give them all the experiences of going out on the weekend and taking your Polaroid camera and taking photos and coming home and talking about it. It is just a full-on commitment to get these children to the position that they are in at 21.

Senator BOYCE—You would encapsulate that as having the sorts of time constraints that a parent of any child with a disability would have? You would, perhaps, be unable to work full time et cetera?

Mrs Hiron—Definitely. That would be very difficult.

Senator BOYCE—I think we are fairly clear that you think we should be continuing on to support adults at 21 who have previously been clients of Australian Hearing. You have spoken a little bit about the difficulties it causes with potential unemployment. Can you talk to us about any particular individuals, obviously without naming them? Can you just give us some sense of how it affects individual lives?

Mrs Colebrook—Do you mean without the hearing aid?

Senator BOYCE—The fact that they do not have ongoing funding once they turn 21.

Mrs Colebrook—They have very high levels of anxiety about whether the hearing device is going to keep going and whether they are going to be able to afford the high price of a new hearing aid or cochlear implant upgrade. Those are heavy prices. They have the ongoing costs with batteries and moulds. In some cases they have to keep on having a new mould fitted until it really does become usable—

Senator BOYCE—That is right.

Mrs Colebrook—They might have to pay for each of the poor moulds before they get a good mould fitted, and that is pretty pricey. Then there are repairs. One of my old pupils who contacted me said he has a hearing aid that is disintegrating and the company has quoted something like $200 to $1,000 for repairs. He does not know until they get in there what it is going to cost. He might not have that money. He is unemployed at the moment. He might not have that money in the bank to pay for it so that he can go to have an interview with an employer.

Senator BOYCE—A lot of the statistics that we have had quoted to us have come from a report done by Access Economics, I think in 2006. Have you done any research, or are you aware of anyone else who has done research, around the employment prospects of people with hearing loss?

Mrs Colebrook—No. We are not in a position to do a lot of research with the three of us. We get information fed into us quite often. Unfortunately a lot of my stuff was wiped off my computer when my hotmail was eliminated by someone, so I do not have all those letters that I received. But a lot of it is, ‘I am waiting for something to go wrong because my hearing aid is malfunctioning and I do not know how I am going to pay for it.’

There is no help from Medicare for tests. The only thing that you can get money for is if you are past the $1,500 tax amount of money. For a hearing test you go to a consultant and you might have to pay $100 for the test before you go any further. People from our groups have to find somewhere to go to. They do not know who they are going to as to whether they are going to be a suitable audiologist or audiometrist who understands about people who are born deaf.

It is a very different situation for people who have learnt language whose speech might not be very clear from acquired deaf people who can feed back to you information about what they are hearing. These people have been used to hearing aids and cochlear implants. Then when they get older and turn 21 if they get a new one they have to get used to the new sound. They do not always know whether it is going to be suitable or not because they have to adjust sometimes for four months—you were saying with Bradley—before they know whether it is really going to suit them or not. That is quite a long time for a trial and nobody will give you a trial for that long. I am probably not saying this very well but there is the uncertainty. There is the position of when it does break down how much you are going to have to pay. All those sorts of things are constantly—

Senator BOYCE—You have raised a point there that I do not think anyone has mentioned before in that perhaps there is specific training needed for audiologists who are dealing with people who were born deaf; is that correct?

Mrs Colebrook—Yes. There are some private provider clinics now. The audiologists at Australian Hearing are specifically trained paediatric audiologists. There has been a lot of that sort of training done and it has been done wonderfully well because the earliest baby that I ever taught was Emma, probably. She was not even three months. They are well versed in testing babies and all the techniques. They keep on updating all the time. This quality of service and understanding and expertise from Australian Hearing is naturally not going to be there because Australian Hearing do the children. This is what we are saying. It is there and suddenly it is not there. Wherever they happen to be they might be lucky, or unlucky, to get someone who at least can understand what they are saying.

Senator BOYCE—I do not think that aspect of specialisation had been raised before now.

Mrs Colebrook—It is the Australian Hearing expertise. I think their ears might be burning but we cannot say that enough. You would not expect a person with any other disability to suddenly at 21 say about their specialists, ‘Well, no more of them. Also, they do not really know what to look for. They do not necessarily know where to go. They do not know what to look for.

Ms Fisher—Often their speech is poor and they would have very little confidence and they are unable to be assertive. Sometimes I think private providers perhaps—

Senator BOYCE—So they will settle for a lesser solution perhaps?

Ms Fisher—Yes. Private providers could get over-enthusiastic and perhaps suggest hearing aids that are not really suitable for them.

Senator ADAMS—You have said that there could be 700 people affected. Has any costing been done? If those people continued on after 21 has the department given you any idea as to what the cost would be?

Mrs Colebrook—We are always asked that question. We wanted to find out how much it cost to fit audiological children from nought to 21 just to get some sort of figure of those services so that we knew what might be ongoing—

Senator ADAMS—Yes, that is the ongoing—

Mrs Colebrook—but we were told that it was commercial in-confidence so we could not get that figure. I know that Rachel Siewert asked in Senate estimates—was it last year?

Mrs Hiron—Late last year.

Mrs Colebrook—She was given a figure of $39 million for the first year if Australian Hearing decided to allow this group to continue because that meant there would be more people coming back to be fitted and they would be more likely to come for the first year; therefore it would be a bulk group to start with but then it would even off after that. But I have talked to several other people. I talked to Anthea Green who used to be national manager of Australian Hearing and she said she thought that figure was too high. But for the first year it would be more.

Senator ADAMS—We will follow that up in estimates and see if we can get a result from that. As to the Indigenous issues, obviously you have an association there. Could you just give us—

Mrs Hiron—Mrs Colebrook has really got more knowledge of the Indigenous people. Aside from even the hearing of the Indigenous people, Mrs Colebrook has a great concern for the lives of Indigenous people, so I think it would be better if she answered.

Mrs Colebrook—I have several things I can say. One of the people I knew who was an audiologist was sent to an Aboriginal community south of Alice Springs. They used to do stints of a week at a community. He told me that the community had 72 people and when he looked in the ears of that number, 70 of them had suppurating ears and two had healthy ears. They are the sort of large numbers people are looking at. Then there was research into a school in the Northern Territory and there was one class where 90 per cent of the children had no eardrums.

These sorts of situations show you the huge, huge amount of deafness from otitis media problems that exist and with medication—they do not necessarily keep medication going to get rid of the infection. I think there are not the personnel on the ground covering the numbers of children and adults who need support medically and educationally simply to make a dent on the situation as it is now—of neglect really—where more money and more personnel have not been put into it over the years. I have told every minister for years that there is this terrible situation. I do not think people understood the extent of the problem.

Senator ADAMS—I do not know whether that community was Hermannsburg but our Indigenous committee did visit the school there. They have their own special hearing room. Eighty per cent of the children in that school of six hundred and something—

CHAIR—It is getting bigger all the time.

Senator ADAMS—Eighty per cent do have a hearing impediment of some description mainly caused through the ears not being looked after, of course. This is a huge, ongoing problem but work is being done to help alleviate it. But it is a problem that the Indigenous people over 21 would probably have even more difficulty in obtaining services, if they were able to.

Mrs Colebrook—Yes, and then it rubs off on unemployment. Antisocial behaviour is very much part of that sort of problem.

Senator ADAMS—I would just like to congratulate your organisation on the interaction you have obviously had with parliamentarians over many years. It is very good to read through your presentation just how many different groups of people you have been to see in parliament, and that is the latest spread the message.

Senator WILLIAMS—You have lived the real experience with your son—Bradley, is it?

Mrs Hiron—Yes.

Senator WILLIAMS—He is 40 years old now and no longer a baby, of course. Looking back on what you went through with Bradley what were the good things that occurred and what were the areas that need improvement in your opinion as you look at Bradley's education growing up, et cetera?

Mrs Hiron—Just thinking back to the preschool years the good things that occurred were just the improvement because before I met Bradley I did not know anyone who was congenitally deaf. I only knew old people who had gone deaf so it was a great learning curve to me. I do not think I really believed that he would ever speak, that he would ever play football or that he would ever get a job. It is a very depressing sort of scene. Mrs Colebrook was his preschool teacher and she said, 'He will learn. He will learn to lip-read.' As for his progress through school, when he left school he did a course on civil engineering drafting. He came out of that in 1983. He lost his job there because of the downturn at that stage. He has done various things over the years. Now he is a head gardener at a retirement village. He has an apprentice working under him. He earns $50,000 a year, $16,000 of which is paid in tax, and then there is rent and everything else, so at the end of the day there is not much left over to support his hearing needs. But the thing that has surprised me is just that if Bradley were here now he would be able to speak and understand.

Senator WILLIAMS—Is there anything you can think of that the government or departmental experts could do better in relation to your experience with Bradley?

Mrs Hiron—I think probably coming through the ages with education I think all of that has probably improved a heck of a lot anyhow, and I am not aware of that. But I do know and have seen the absolute tragedy of kids who just cannot get their aids. They have not got the money. Not every parent is in a position to support that, either. As parents get older they are earning less money themselves. That cutting off of their hearing is just diabolical.

Senator WILLIAMS—Do you mean at the age of 21?

Mrs Hiron—Over the age of 21, because a lot cannot get jobs. A lot of them cannot get jobs. There was a figure—I do not know—quite a few years ago that 68 per cent of profoundly deaf people were unemployed.

Senator WILLIAMS—As a result of that they simply cannot afford the batteries and maintenance whether they have cochlear implants—

Mrs Hiron—It is a spiral downhill. It is just a constant spiral downhill.

Mrs Colebrook—We had some young people who used to share a hearing aid to go to lectures. Obviously they are individually fitted hearing aids so this one was—

Senator BOYCE—This is at university, is it?

Mrs Colebrook—It was to go to TAFE lectures. One would wear one hearing aid in and then when the other one had lectures they would wear them. This was a group living together in a house. That is terrible.

Senator WILLIAMS—You mentioned in your opening address how you think more captioned programs should be around on television. With the introduction of digital television, do they actually have captions on all of the programs? Can you turn to that for all programs, or is it just that 6.30 till 10.30?

Mrs Colebrook—That is legislated for, and the ABC does put on a lot more. I mean for example I think question time has got captions.

Senator WILLIAMS—That is bad!

Senator BOYCE—We could save that money.

Mrs Colebrook—There are quite a number of programs that are captioned because that channel has opted to do it, but cable television does not have very much captioning at all. They are reluctant to go to that expense. For example—this is a different subject—if I had an oral deaf person here we have a signing interpreter but we do not have what is called real time captioning. That is the screen up and somebody typing what is being said onto the screen for the oral deaf who cannot hear what I am saying or you are saying. This is what this member said today about them being the forgotten group.

The people who are oral and who use devices cannot necessarily hear from a distance away what you are saying and if you put your hand up like that they cannot lip-read you either. I just wanted to use that example as a way of showing that they do some lip-reading and it is hard sometimes. If someone has a moustache it is hard sometimes. But if you have the real time captioning for occasions like this they are able to read what we are all saying, but people do not think of having it available for the oral deaf. They have this idea that everybody signs.

As to the government’s policy or strategy on employment they have mentioned providing interpreters, they have mentioned providing braille, but they have not mentioned anything about providing hearing devices or captioned videos or things like that for the oral deaf. So we make a point of saying this, but it is very hard to get it through, that the oral deaf are not catered for.

Senator WILLIAMS—Would you think that the biggest downfall in the Australian system at the moment is the lack of public support once people turn 21 years of age?

Mrs Colebrook—That is certainly one. That is our big thing. Why put all of this into them up until they are 21 and then suddenly drop them as though their deafness has gone away?

Senator BOYCE—It is an economic issue as well.

Mrs Colebrook—They really try so hard. We are here because they do not always stand up and say what their problems are.

Senator BOYCE—I have often wondered why Hearing Services alone is in the Department of Health and Ageing whereas most disability is covered within the Department of Families, Housing, Community Services and Indigenous Affairs. I have noted that you sort of pointed out that some types of deafness are being completely ignored by the National Health and Disability Employment Strategy. I note your recommendation that it be moved from under ageing but it is still within the Department of Health and Ageing. I wondered if perhaps there might be more notice taken of the needs of this particular disability if it went and lived with all the other disabilities.

Mrs Colebrook—We have seen Bill Shorten in particular from the very beginning and he is very concerned about this group. I know he has talked to Justine Elliot who is the Minister for Ageing, and hearing services are not mentioned in her title even. It is just ‘and responsible for hearing services’, but it is not up on her title. We feel with the one out of six quoted as having a hearing loss that there should be a minister for hearing services simply because there is this terrible problem with iPods and deafness for farmers, for example, coming from noisy situations, industrial situations and so on as well as aged people. We feel that there is such a large group we are talking about here who need some consistent sort of policy that we need one person to be looking at that. I do not think you can walk away from the idea that deafness now is a very, very large problem in our community.

Senator BOYCE—Your concern with it in relation to ageing is that naturally means a focus on acquired hearing loss rather than—

Mrs Colebrook—Yes.

Senator BOYCE—hearing across the board?

Mrs Colebrook—Yes. We look at it from the point of view that everybody has put so much into education of this group to get them here that they really need to continue on in all the ways that might help them keep in the job—do retraining, or whatever it might be these days that they need to do. It is a very complex world and it is a very complex disability.

CHAIR—I know that your organisation and individuals have met with everybody from what I can see and I hope that all those letters that you got back have not been totally lost because it would be interesting to trace through the series of responses that you have. You have given us a snapshot of that in your submission about various commitments that have been made over the years. I am sure people come down to the issue of budget. That is what they always come back to. That would be the point—

Mrs Colebrook—Yes and do not forget we have put the co-payment in. We have always put that in from the very beginning because we do think that people do appreciate something better if it is not necessarily just handed out.

CHAIR—Have you considered means testing?

Mrs Colebrook—We have, yes.

CHAIR—In terms of some information we had yesterday, one of the witnesses talked about a means testing arrangement. In terms of moving forward in any program that seems to be something that is favoured by governments. You have not mentioned that in your submission and I was wondering whether that is because you have rejected it or it had not been favoured?

Mrs Colebrook—When we talk about a co-payment for those we mean most except for the people who have a very low income or are unemployed whereby there would be some sort of help for them, perhaps a free aid. Most of the people who are desperate would be very happy for a basic hearing aid, because they are very good hearing aids. The basic hearing aids that are well fitted and kept in good service, they would be very happy to have that to continue on in the way they have been from the time they started.

CHAIR—And the support there –you have certainly listed the costings but one of the things that comes through your submission is the need for that intelligent, professional support that is also lost.

Mrs Colebrook—Yes.

CHAIR—It is certainly the financial impact but it is also the sense of security and the process that—

Mrs Colebrook—And there is a high mental problem—

CHAIR—Yes, and I notice that you have talked to Minister Arbib’s office about the recent mental health and disabilities program.

Mrs Colebrook—Yes.

CHAIR—It is certainly my understanding that in terms of the medical support for people with health issues that comes under health but the other programs are certainly part of the wider disability strategy, which is FaCHSIA, and that is the bane of government services, that they cross over a number of areas. But the area of hearing—and having spoken with Bill Shorten and his office—you would see that he personally believes that the issues of the hearing come under his area—

Mrs Colebrook—Yes, from the very beginning, yes.

CHAIR—There is no doubt. We cannot offer you any commitments but your contribution is now part of our inquiry. We are happy to keep on discussing these issues with you so that if you think of things as you see coming up on the website all our hearings and our submissions are there publicly and if you have comment on anything that has come up and wish to give us further information, please do so.

Mrs Colebrook—Thank very much and thank you for seeing us today.

CHAIR—Of course.

[11.30 am]

DEWBERRY, Ms Margaret, Executive Manager, Indigenous and Multicultural Services, Australian Hearing

DILLON, Professor Harvey, Director, National Acoustic Laboratory, Australian Hearing

KING, Ms Alison May, Principal Audiologist, Paediatric Services, Australian Hearing

CHAIR—Welcome. We have your submission, and we appreciate that. We know that no discussion of hearing in Australia could not but have heard from you. You know about parliamentary privilege and the protection of witnesses and I would ask that you identify yourself for Hansard when you speak, but could you very early tell me whether you are Hearing Australia or Australian Hearing because the two terms have been interchangeably used in submissions and also processes. I just wanted to clear that up for myself. We will go into questions but I would expect that you may have opening comments before we go.

Ms Dewberry—As to your question as to our correct name, officially our name is Australian Hearing Services but we trade as Australian Hearing just to make that distinction from the office of Hearing Services. There was a bit of confusion when the voucher system commenced so we shortened our name to Australian Hearing.

CHAIR—I hope you are going to clarify that because my mind still gets confused between the two; it is just so we know we can refer you to appropriately. Australian Hearing Services is your formal title but you trade in the community under Australian Hearing?

Ms Dewberry—That is correct. Australian Hearing welcomes this Senate inquiry into hearing health and we thank you for the opportunity to appear here with you today. Australian Hearing is the government provider of services under the Australian government hearing services program. The National Acoustic Laboratory is part of our organisation. The National Acoustic Laboratory, or NAL to use its acronym, is the world leader in applied research on hearing loss. Australian Hearing is a statutory authority within the Human Services portfolio.

We are the largest provider under the hearing services program. We employ over 1,100 staff. Eighty per cent of our staff are female; 26 per cent are part time. Of those 1,100 staff—this is at 30 September; obviously it changes—421 are clinical staff, audiologists and audiometrists. We have a large network of hearing centres across Australia. We have over 100 permanent offices and almost 300 visiting locations, that being a site where we take our service out to the community one day a week, one week a month or whatever the demand requires. We also have a special program for Indigenous Australians, a culturally appropriate program, where we deliver services within the community. Last financial year we visited 238 sites.

If you would like a bit of a break up in terms of urban, rural and remote?

CHAIR—It would be useful to get everything out on the table.

Ms Dewberry—Using the Department of Health and Ageing’s Accessibility Remoteness Index of Australia, the ARIA code, of our permanent and visiting sites which are our mainstream offices where we would provide voucher services and services to community service obligation, approximately 70 per cent would be in urban areas, 24 per cent in rural areas and six per cent in remote areas. Then if we look at our Indigenous outreach program you will find a slightly different trend, with 23 per cent in urban areas, 29 per cent in rural areas and 48 per cent in remote areas.

We can only provide services to people who are eligible under the hearing services program; we do not see private clients. You are aware the hearing services program has two components, the voucher scheme and the community service obligation. We are one of over 200 providers who compete to provide services under the voucher scheme but we do have a unique position in being the sole provider of services to community service obligation clients. We receive capped funding from the Office of Hearing Services, the Department of Health and Ageing to deliver services to community service obligations. This financial year that amount is $46.119 million.

I am happy to go through a bit more detail on our services to children, our adults with complex needs, our Indigenous programs, particularly on research relating to the effects of noise and hearing loss prevention programs if that is helpful for me to keep going.

CHAIR—That would be very helpful. It reflects the kind of questioning we had yesterday, so that is fine and senators will jump in if there is something they need to clarify or question.

Ms Dewberry—Certainly. With our paediatric program which you have heard a lot about already, this financial year we will receive $18.677 million to deliver services. We have approximately 14,500 children fitted with hearing aids, cochlear implants, that we care for and we would see a similar number of children who do not have hearing aids but come to us for a service because they are at risk of having hearing loss or they have a hearing loss which does not require hearings aids but requires ongoing monitoring and advice and information counselling for families.

The committee has heard a lot about the prevalence of hearing loss in terms of one in six Australians but I thought I would just talk about prevalence in terms of children firstly—

CHAIR—Could I just ask the question I asked yesterday? The statistic has been thrown around—it permeates all of our submissions—and most people trace it back to the Access Economics report. Does Australian Hearing agree with that?

Ms Dewberry—I will let Professor Dillon answer that because I think he was a bit involved in the calculations.

Prof. Dillon—I think I helped give them those numbers but they did it independently. It is an inevitable outcome. All you have to do, if you believe the Australian Bureau of Statistics as to how the profile of age is going to change in the future, then that tells you one fact. We already know from very good survey data from South Australia how the incidence of hearing loss changes with age. If you just simply take the distribution of ages that you expect at any year in the future and you team that up with what we know even if there is not more hearing loss from leisure noise—even if that does not happen—if we team up the incidence of hearing loss due to current noise and ageing with the age profile you end up with one in six now, heading towards one in four by 2050, so it could get worse than that if the impact of noise gets worse or it could—

CHAIR—And the only way is up?

Prof. Dillon—I think so. I think it is more likely to go up than down, let us put it that way.

CHAIR—Down in terms of the volume but in terms of process. It just interested me when that statistic is used so consistently, I just wanted to get something on record about your views about it.

Ms Dewberry—Between nine and 12 infants per 10,000 live births will be born with a moderate or greater degree of hearing loss. By school entry this will have doubled to approximately 20 children in every 10,000 born will have hearing aids or cochlear implants—

Senator BOYCE—I am sorry, was that first figure based on nine per 1,000?

Ms Dewberry—Between nine and 12 per 10,000.

Senator BOYCE—Per 10,000, okay.

Ms Dewberry—And then the figure trebles to approximately 32 per 10,000 by 10 years of age. We are fortunate to have newborn hearing screening programs rolling out around the country to identify that first cohort of between nine and 12 per 10,000 live births. So when a child is screened within the hospital, if they do not pass that test they are referred to a diagnostic centre, usually a hospital, to have the hearing loss confirmed. Then if that hearing loss is confirmed the child is referred to Australian Hearing where we commence those discussions about hearing aid options, cochlear implant options, early intervention options, educational options. We offer unbiased advice. We do not favour any particular program.

We have developed a resource as a result of feedback from families called *Choices* which gives an overview of hearing loss, the degrees of hearing loss and the sorts of hearing aids you can get. There are stories from families in there from hearing impaired children themselves. Then as a supplement to that book we list all of the intervention agencies and educational facilities in each state. I am happy to make a copy of the publication available if it would be useful.

CHAIR—It would be very helpful.

Senator BOYCE—One of our witnesses yesterday noted that *Choices* was not currently available.

Ms Dewberry—It is certainly still available. We refresh the supplement periodically, once every one to two years, to make sure it is still current. It is an important resource for our paediatric specialists. I am happy to make one available for you.

Senator BOYCE—Is it also available to families?

Ms Dewberry—Absolutely, yes. At the time of diagnosis when we are talking about the options of hearing aid, cochlear implant, early intervention, that is the time we go through that *Choices* booklet and point out what is relevant for that particular family because it covers the whole range of hearing. The families asked us to incorporate all of that into one booklet. So we then go through and work with the family as to what is relevant for their child at that particular time. We are talking about newborns at the moment.

Senator BOYCE—Would there be any newborns or under 12-month-olds who would not come to Australian Hearing? Is there another path?

Ms Dewberry—It is an interesting question. I might let Professor Dillon just talk about a child outcome study and some data he looked at—

Senator BOYCE—Perhaps if you wanted to just leave that if you were intending to talk about that.

Prof. Dillon—I am actually just going to try to fill in the gaps here so I will jump in here if I can. We are doing what is actually the world’s most comprehensive study of what happens to children when they have hearing loss. We have recruited 475 children at the time they first get their hearing aids, or some of them a little while after, but all before the age of three. We actually intend to follow them through until they are aged 20 or 21—

Senator BOYCE—When did you start this?

Prof. Dillon—We started in 2005. The oldest children are now seven and the youngest ones are three years of age. We have major data measurement points to look at what is happening to them at six months after they first get fitted, 12 months after they are fitted, age three, age five and then we will go on to age eight, 11 and 20 if we all hang around long enough.

Senator BOYCE—Some of the witnesses would like to think that you would also be able to do it at age 30 and 40.

Prof. Dillon—Personally, I would love that.

Senator BOYCE—Is this a specially funded program within NAL funding?

Prof. Dillon—We have cobbled together funds from wherever we could. In 2005 because at that stage New South Wales had universal screening, Victoria did not and Queensland was just about to begin so we thought: here is a natural experiment that basically could never happen anywhere else in the world where half the children would get screened at birth and the other half would not and then no matter which group they were in they would all get treated in the same way by Australian Hearing. So it was like the perfect experiment. We did not actually have funding. We got a little bit from here and there. We eventually got quite a bit of funds from the American government because they recognised the uniqueness of it and we have afforded it in whatever way we can.

CHAIR—Is there no Australian government money going in?

Prof. Dillon—Yes, there definitely is. Australian Hearing made a contribution. The biggest source of funds came straight from the Australian government as part of our regular, now base funding. We just diverted it from other projects to make sure we could do this one. A gap that we just discovered actually only in the last month or two, by matching together the database that Australian Hearing has on which children come to it with a database, or a sort of a database that the New South Wales government has on which children they have diagnosed, we have discovered there is a significant gap; 25 per cent of the children diagnosed have not ended up with rehabilitation, so they have fallen through the cracks somewhere along the way. We have only just discovered this and we are actively trying to look at the reasons why for every individual child. We are talking about 115 children roughly over a five-year period.

CHAIR—In New South Wales?

Prof. Dillon—In New South Wales, and we suspect the same thing is happening in other—

CHAIR—Will happen, of course, yes.

Prof. Dillon—But we do not have the database to do it.

Senator BOYCE—You have no idea whether the family has just then said, ‘Oh well, hearing loss, never mind, let us go home’, or whether there is some other pathway that they have found to treat—

Prof. Dillon—I am sure there would be a huge range of reasons, like the diagnosis might have been wrong, or the hearing loss might have recovered. That can occasionally happen. There might have been cultural issues to do with, ‘We do not want to deal with hearing loss.’ I do not know. I know nothing about the numbers. In six months’ time we will probably know. We will probably have found most of them and we will have an answer to that. But that brings me to one of the points I wanted to make. There is a real need for a national database associated with newborn screening so that we do not have to catch this up on a special-occasion basis, but it just becomes part of the system.

CHAIR—You are just telling us that that data is not being kept in a significant, appropriate and accessible way with all these programs across the state.

Prof. Dillon—They are just not coming together, that is right. Individual states have got their own records. They are all different. Australian Hearing has a database—

CHAIR—And I bet they are different methods.

Prof. Dillon—I bet they are.

CHAIR—Okay, so I will write that down straightaway as a recommendation. It is just that this committee is bedevilled across a whole range of issues—and has been I think forever—for the want of a nationally consistent database and it almost becomes black humour—

Prof. Dillon—That it does not exist.

CHAIR—We will have the database recommendation but that is something that you have been talking about and that really reinforces it. We had a map provided yesterday by the department which showed us the current status of newborn hearing across all the states and so that data is being kept, but trying to keep it in a way that can be easily accessed—I am sorry, this is just frustration coming out.

Ms Dewberry—We do believe that most hearing impaired children requiring hearing aids will come to Australian Hearing, particularly the infants, because there is not expertise in the broader industry to manage that type of hearing loss requiring hearing aid fittings. Certainly in the cochlear implant area there is. So we do believe that the majority of children do come to us.

Looking at our own data—we do put data on our website every year. Because we are the sole provider of services to children we feel an obligation to publish the information that we have on our database. So looking at our data for 2008 where we fitted just over 1,850 children for the first time—that is across all age ranges—the largest number of children fitted for the first time were born in 2008, which is showing us the effectiveness of newborn hearing screening. Previously our biggest cohort was closer to school entry; now it is closer to birth. However the next largest group fitted for the first time was at six years. That is showing that school entry is still an important time to detect hearing loss. We are aware that there are very few school hearing screening programs now in operation so we do have some concern that it may delay the identification and rehabilitation of children.

Senator BOYCE—Do you know which states do have them and which states do not?

Ms Dewberry—I do not have current information with me on that. Children would then come to us because of parental concern, teachers perhaps saying there is poor behaviour at school or poor school performance, so the parents go down that journey of the global paediatric assessment to determine—

Senator BOYCE—Crossing out the non, yes.

Ms Dewberry—Exactly.

Prof. Dillon—There is good potential there, too, because exactly the same technology that is used in many places in the world to screen newborn hearing is a very quick in the ear objective test could actually be used at school age to do the same thing, so it is literally a couple of minutes per child: device in the ear, look for the indication of the echo coming back from the inner ear which indicates the health of it, so it could be a much faster process now than when I was a child and there was limited screening at early ages at school.

Ms Dewberry—Once the children are in our care, for children requiring hearing aid fitting we provide ongoing services from that time until they turn 21. Those ongoing services include regular monitoring of their hearing levels so that we are responsive to any change in hearing levels either through medical intervention and/or adjustment of their devices. We replace lost and damaged devices, which you heard a little bit about yesterday. The hearing aids will eventually wear out. They do—with children they probably get replaced every three or four years—just through use. We provide the ear moulds when they are fitted with behind-the-ear hearing aids, information counselling for families and advice and reports to educational facilities. So we have a very close relationship with the educational facilities, with cochlear implant clinics if they have an implant and a hearing aid, the medical profession and so on.

As I mentioned, that is 14,500 hearing impaired children we care for. Based on self-identification of whether a person identifies as being Aboriginal and Torres Strait Islander, nine per cent of those children with hearing aids are Indigenous. I will move on to our services for adults with complex rehabilitation needs.

CHAIR—Are there any questions on that aspect of children’s services?

Senator ADAMS—I will have lots of them when we get to ‘Indigenous’.

Ms Dewberry—I will cover the Indigenous program separately but later.

Senator ADAMS—Thank you.

CHAIR—Are there any general questions? That is not to say that you cannot come back later; I just thought we could do it in sections. We will move on to the next one.

Ms Dewberry—Australian Hearing has a unique program for adults with severe to profound hearing loss or hearing loss and a severe communication impairment or for people who have other disabilities, such vision impairment, intellectual impairment and so on. This is quite a vulnerable group. We received $13.431 million this financial year to provide services. There are approximately 19,000 people whom we care for. These clients have to be eligible for the program for voucher services before they qualify to come to us under the Community Service Obligations program. These clients often are unable to communicate well, even with hearing aids, so they require extra support. We provide communication training programs to help them to maximise their residual hearing and work with their significant others to assist with communication strategies.

We have programs for frail elderly clients, particularly those in residential aged care facilities. There we look at options other than individual hearing aid fitting, which often is not the best device to use in that circumstance. Again, we assess clients’ needs; if they require an individual device we would certainly provide one. But there are other assistive listening devices that you can use with television, if that is their particular need. One is a personal listening system for only when the family visits, because often people do not want amplification when their family is not there with them. So it is just looking at different options that are available, which might mean better use of their hearing aids. We also provided information sessions for staff of residential aged care facilities on managing devices and on managing the environment. So we give them information on what they might do to improve listening conditions if it is particularly noisy. Not everybody within that residential aged care facility would be eligible to receive direct services from us, but they would benefit from the flow-on effect of the staff knowing about those things, which is a good outcome. I mention that group because it does not have a high profile, but it is a very important part of what we do as a safety net program. Are there any questions on that?

CHAIR—We were given evidence yesterday of there being some concern that hearing in aged care is not given the priority that the rhetoric says it has. In the list of things that should be done under the accreditation system that area is mentioned, but some witnesses put on record yesterday that they felt that perhaps it is not stringently examined. As Australian Hearing is the group that does that work the most, do you have any comment on that?

Ms Dewberry—Yes. That is really why we developed that special program for people who are frail elderly, particularly for those in residential aged care facilities, because the voucher program of 'provide an individual assessment, provide an individual device and follow-up services' does not necessarily work well in that environment. That is why we try to look at it a bit more holistically. We involve the family early on, if they are part of the program with the client. Often they have approached us to say, 'Can you come and see my parent?' We like them to be part of the program with the client so that they can help guide us as to the needs of that particular client. Looking at other devices and the environment as a whole is really an important element of this program and it fits so well under the community service obligation because we have that freedom to devise programs such as this as opposed to trying to work within the limits of the voucher program of the claim, both at the assessment and after the hearing aid has been fitted.

Senator BOYCE—When you say 'a hearing aid is sometimes the best solution', is that for technical reasons or for ongoing maintenance reasons?

Ms Dewberry—It can be for management reasons. It can also be the client's preference for how they want to receive the amplified sound. It can be quite difficult if the staff are not available to come and put hearing aids in for clients, if the clients cannot manage it themselves; whereas, if you can provide a personal listening system, which is just putting some ear buds in a person's ear or their putting some headphones on, they are more likely to be able to manage that independently. It is about giving the person the dignity to be able to manage the device themselves, so it is looking for what works for the individual. I might allow Harvey to talk about the National Acoustic Laboratories.

CHAIR—I have just made a unilateral decision, as we are going to run out of time and I want to move on to Professor Dillon. I suggest that we call you back to have a particular discussion around Aboriginal and rural and remote issues because I think there will be a large number of questions about them. Given the time we have, perhaps we could concentrate on other things and have a dedicated session at a later time on that area.

Ms Dewberry—Absolutely. We do have dedicated funding for programs and I would like to do that area justice.

CHAIR—Yes. I think that will be a major point, so we will defer that area. We will go on to other areas that we can cover today and come back to that area at another time. Professor Dillon, would you like to tell us of where we are going with NAL research and all that stuff?

Prof. Dillon—We do research into three major areas. The first is research into better ways of assessing hearing loss, because it is not just about putting on headphones and finding the softest sound that people can hear. The second is research into better ways of rehabilitating people, once their hearing loss has been diagnosed and assessed. That is ways of making the hearing aids work better or ways that clinicians can use to better match up what the hearing aid should do for the particular type of hearing loss that a person may have. The third area of research is prevention. We are fairly world famous in the second of those areas. In fact, any little place or shop around the world that sells hearing aids will know about NAL because they use our methods on a daily basis. In addition, we have an increasing number of successes in the other two areas: the prevention area and the device area, making hearing aids better.

Senator BOYCE—Can you tell us more about the prevention area? What research work are you doing there? I know that Senator Williams has a particular dislike of—

CHAIR—Boom, boom, boom.

Senator BOYCE—booms, booms.

Senator WILLIAMS—I find it annoying when driving.

Prof. Dillon—Yes. We know that the opportunities for leisure-induced hearing loss are growing. For the last five years on three occasions, we have stopped people in the streets and asked to borrow their MP3 player. Then we have measured on a dummy head the amount of sound coming out with their volume setting and asked them how many hours a day they wear it for. When you combine those two statistics, the amount of time and the amount of level, about 25 per cent of people—that has slowly been decreasing to where it is now about 20 per cent—are getting a daily noise dose just from their MP3 player alone that exceeds the allowable standard for industrial hearing. Of course, many of them may also be going to other noisy leisure activities—pubs, dance parties or concerts—or they may be working in a noisy industry as well. The ear does not care; it all just adds together.

Senator ADAMS—What is their reaction when you do that?

Prof. Dillon—It varies from, ‘Gee, I didn’t know that and I’ll do something about it,’ to, ‘I haven’t noticed anything.’ The younger that people are, the more bullet proof they appear to be. From one survey that we did, we found that people believe that—

Senator BOYCE—It is just not their ears, of course.

Prof. Dillon—No, that is right. There is an ‘it will happen to others, but it won’t happen to me’ type of belief. We are not funded directly to do a prevention program, but we take every opportunity that we can. We get on TV and radio as often as we can, when we have some research finding or even when there is a research finding from overseas, and the press does seem to lap it up. So, basically, we have tried to make use of free publicity to constantly get the message out about MP3 player use in particular.

Senator BOYCE—But you have no funding for public awareness campaigns.

Prof. Dillon—No. We have block funding from the federal government of $3.9 million a year to fund NAL in total. We apportion all of that across those three areas that I have mentioned, so prevention gets some of those funds. But that is not funding to do a public education program; that is funding to do the research to work out what an education campaign should be like.

We have done some. We produced a video a while ago and the Office of Hearing Services provided some additional funds that enabled us to get it to every primary school in Australia. We have received some extra funds from OHS to prepare an education program and we have employed a teacher to work out some educational materials that we can get into and accepted as part of the curriculum for primary schools across Australia. With the national curriculum review that is occurring at present, one thing we would like to see is our getting just a single statement accepted about children leaving primary school with a knowledge of the effect of noise or sound on the ears. That would fit in well with us providing an education program that then could be used across Australia.

Senator BOYCE—For the sake of the *Hansard*, you might like to tell us the title of the DVD that you have just held up.

Prof. Dillon—It is called *Damage Your Hearing and It Won't Come Back*.

Senator BOYCE—Just in terms of workplace controls on noise levels, am I right in assuming that the number or percentage of workers who are experiencing hearing loss is potentially falling—most of those people now would be retiring or would have retired recently—but the level of hearing loss by 'choice', for want of a better word, is increasing?

Prof. Dillon—Both of those are my belief. We have a study going at the moment that is trying to compile a profile of who is getting noise exposure, for how long and for what part of their life in Australia. When that study is finished, I could answer the question. But I am fairly certain that the answer to both is yes.

CHAIR—When is the study due to be finished?

Prof. Dillon—In about 2½ years time.

CHAIR—So that study is being undertaken over an extended period of time.

Prof. Dillon—Yes.

CHAIR—Is there anything else on that area? Professor, with the technology research, I am interested in changing and improving technologies. Does NAL have any role in looking at the aids and devices?

Prof. Dillon—Yes. We help invent some of the new technologies. In addition, because of our expertise, OHS consults with us regularly about what features are beneficial in hearing aids.

CHAIR—In the other process, I think a few of us have been confronted by the expense. One part of your brain knows that these things are expensive, but then you are given evidence that a cochlear implant is but one step and the device that accompanies it to maintain it has a limited life span and is extortionately expensive in terms of replacement. Is any work being done looking at whether there can be better technologies that will not require such short time frames or expensive processes?

Prof. Dillon—Yes. Around the world there is interest in lower cost methods of hearing care. That is being driven particularly by the need to get hearing care into developing countries, where there just is not that budget.

CHAIR—Absolutely; there is nothing.

Prof. Dillon—Just a few weeks ago, I was at a conference in America that was run by the American government and there we heard about the range: from $20 hearing aids that you buy from a coupon in the back of a magazine up to the $5,000 individual hearing aids. It is a very confusing and topsy-turvy situation. As a place for lower cost hearing aids emerges, I think there will be many changes in the industry over the next few years; with what success, no-one can quite predict at this stage.

Senator BOYCE—Does Australian Hearing, itself, purchase hearing aids? We heard previously from hearing aid manufacturers about having a deed of contract, so to speak, with OHS. Do you then get aids from OHS? Basically, how does it work?

Prof. Dillon—In the whole scheme, OHS does not handle or even purchase the hearing aids at any stage. OHS says—

Senator BOYCE—They undertake the negotiations for you.

Prof. Dillon—They say, ‘This will be the price; this is the minimum standard of specification,’ which, as we heard earlier, will not change for the next couple of years. Then manufacturers say, ‘All right, I’ll put these models of mine on the panel.’ Any individual provider can then purchase one of those directly from the manufacturer and, when they do, OHS gives the provider whatever the fee is—$350 or whatever the amount is—to purchase any one of those hearing aids. In that being done, Australian Hearing acts just like every other provider.

Senator BOYCE—When you say ‘$350’, is that a reasonably current sort of figure?

Prof. Dillon—That is my memory of the ballpark, but do not quote me on that.

CHAIR—But Australian Hearing has a contract with one particular provider.

Prof. Dillon—It does. But, again, Australian Hearing is no different from the other providers there. Many of the providers now are part of a chain that is owned by an overseas manufacturer. Just as Australian hearing currently has a contract with Siemens and therefore buys the majority of its hearing aids from Siemens, so the individual chains will buy the majority of their hearing aids from the overseas owner that manufactures those hearing aids. It is no secret in the industry that, I think in all cases, the actual price that the provider pays may not be the same as the amount reimbursed by OHS. It could be more or it could be less; often it is less.

Senator WILLIAMS—We have heard—and I know this through personal experience—that some people who have hearing aids use them very rarely, if ever. Do you have any statistics on how much money or how many hearing aids are put out in the community at huge expense and never used?

Prof. Dillon—Yes, we have surveyed that. I will give you the good news first: Australia has a higher take-up rate of people with hearing loss who have gone to get hearing aids, and that is good. Most countries are worried about the low take-up rate. In Australia it is low also, with about a third of the people with hearing loss obtaining hearing aids; that is good, as in many countries it is only about a quarter. But my best estimate is that somewhere in the range of 20 to 30 per cent of those who have hearing aids do not use them, and that is a lot of waste.

Senator WILLIAMS—Why don’t they use them? Do they find them inconvenient or annoying? Perhaps when they put a telephone to their ear, they hear buzzing. Is it the changing of the batteries? What are the reasons?

Prof. Dillon—All of those things contribute to it, but our research shows that the bottom-line message is that most of those who do not use them did not necessarily want them very much in the first place. They were encouraged to get them by family members. The Australian system for getting hearing aids, as I have said, has been very effective in getting a lot of people to get hearing aids and the associated care that goes with it, and the process is very well specified. But the whole change does specify a process. Providers are paid for diagnosing and assessing the hearing loss, fitting the hearing aid and providing the follow-up; they are paid for doing that process and not actually achieving an outcome. So what you pay for is what you get. We have quite a big volume of process—quite a lot of people being fitted with hearing aids—but we are not necessarily getting high outcomes. Many do use them. Hearing aids are fantastic and are getting a little bit better every year. For many people, they are the difference between participating and not participating in society, but they still fall a long way short of bringing hearing back to normal. So, if you really do not want a hearing aid for whatever reason, there are plenty of opportunities to find an excuse or a reason for not wearing one.

Senator BOYCE—Does this research refer to your client base, or is this research broader than that?

Prof. Dillon—It is across the OHS system. OHS asked NAL to do some research for it a few years ago to try to quantify usage and look at eligibility criteria.

Senator WILLIAMS—My mother would not wear a hearing aid and would have the television up so loudly that, when I would try to ring her, she would not hear the phone ring; that meant that I would have to drive around to see whether she was okay. When people have hearing problems, their hearing is obviously deteriorating. By having their televisions extremely loud so that they can hear them, is that doing more damage to their hearing?

Prof. Dillon—It is not likely, no. However, that is a good example: your mother does not have a problem; you have the problem.

Senator WILLIAMS—That is right. She would not answer the phone, so I would wonder whether she had collapsed or hurt herself—broken her leg or slipped over in the shower? So I would have to drive around to see her. Then, when I got near her house, I knew from the blaring television why she could not hear the phone ringing.

Senator ADAMS—I would like to ask Ms King a few questions. Firstly, could you comment on travel schemes not covering the cost of travel for families with children?

Ms King—Yes. Most states have a travel scheme to fund travel for people to attend medical appointments, but audiology is not considered a medical appointment.

Senator ADAMS—What has been done in that respect? Have you made any push to have that covered? It is a problem. They have to go to specialists, so why should that be excluded?

Ms King—It is something that we have been concerned about. It is something that is covered through state funding.

Ms Dewberry—We do try to schedule appointments so that they have a medical appointment when they have an Australian Hearing appointment. In that way we can leverage off the funding they might get to assist them to travel to the medical appointment.

Senator ADAMS—This committee has done an inquiry into patient assisted travel schemes. That is why I was wondering whether you have had any sort of input into having this included.

Ms Dewberry—We have tried to raise, with the various people who are responsible for travel programs, the fact that there is an issue in this area.

Senator ADAMS—I will be following that up rather seriously. I note here that universal newborn hearing screening—which currently is provided in New South Wales, Queensland, Tasmania, South Australia and the Australian Capital Territory—is going to be implemented by 1 January 2011 to the other states, including mine, which is Western Australia. Why hasn't this happened earlier?

Ms King—Some of the other states have been in the process of rolling out newborn screening. Victoria, for example, has been rolling it out over a staged program for the last three years and it will have been completed by the end of next year. Western Australia has had some screening and I understand that they have also committed themselves to rolling it out. Once again it is very much dependent on the local state situation. I believe that Professor Leigh this afternoon will be able to give you more information on the situation in Tasmania, but I believe that it is pretty well rolled out in that state as well.

Senator ADAMS—I am thinking back to years ago, when we used to have something like that in Western Australia; but it has just disappeared.

Prof. Dillon—Western Australia was the first and had a scheme going at least within the Perth area. The number of children being caught or being detected at birth was not as high as the one per thousand or 10 per 10,000 that one expects and they decided to cease the scheme. So it had a good start, but it was not kept up.

Senator ADAMS—I am not allowed to get into my Indigenous questions and I have been following that line.

CHAIR—You will get a chance.

Senator ADAMS—I will let someone else have a go.

CHAIR—We are running out of time, but I have one particular question about the difference between working with hearing aids and working with cochlear implants. Anything to do with cochlear implants seems to be a state responsibility. Do you know the history of that division?

Ms Dewberry—For us, it is partly because of legislation: our legislation does not cover us to provide that service. Do you have comment on the history of the development there?

Prof. Dillon—No. When our legislation was formed and reformed, cochlear implants were not around.

CHAIR—That is right. There would be legislative ability to change that. Ms Dewberry, you were watching yesterday when the department gave evidence; they will be returning. We will also put the question to the ministers at COAG because many of these things go across that area. It just seems that there is a clear division and yet consistently the evidence and submissions that we have had so far seem to reflect an increasing movement towards the cochlear implant method. It just seems strange that you work with young children and young people into their twenty-ones, a lot of whom have cochlear implants because of the way it happens, and you provide all the personal support and so on but you still do not determine whether they get an implant and you do not fund it; that goes back to the states.

Ms Dewberry—No. We do work closely with implant clinics. Obviously, where we feel that a child may benefit from an implant, we would refer them to the implant clinic and provide all the necessary documentation to help with the assessment of candidacy for an implant. It is a collaborative effort after that.

CHAIR—Are there cases where there is no money for such children to have cochlear implants? I know that the money we saw in the little diagram yesterday is capped at the state level. Have there been cases where the assessment indicates that that should be the appropriate procedure and, because of capped funding, it is not available?

Ms Dewberry—I am not aware of that happening with children.

Ms King—Neither am I.

CHAIR—Under the funding, children would be the priority.

Ms Dewberry—I believe so.

CHAIR—That is another question we will be asking all the state governments. From reading the evidence, that just seems to be an anomaly. With the provision that we will not get into the Aboriginal and Islander area, is there anything that you particularly want to put on record that we have not asked you about as yet?

Ms Dewberry—I do not think so. However, I would like to extend an invitation to the committee. I know that you will be visiting some places and you are very welcome to visit any of the Australian Hearing offices. We have one in Canberra, if that is more convenient, or you could visit our head office at Chatswood, where the National Acoustic Laboratory is located.

CHAIR—That is at Chatswood?

Ms Dewberry—Yes.

Senator ADAMS—I have a general question. The program does not follow on for people who are over 21 and have hearing difficulties. Have you been able to assess what the cost would be for that program to be continued? Another witness has told us that possibly approximately 700 people in that area are having problems. Can any of you help me with that?

Ms Dewberry—It was a question on notice from Senate Estimates a couple of sessions ago. The question went to the Office of Hearing Services, as the regulator of the program, and we did assist them by providing some information to help them with that calculation. I believe that the answer provided was $39 million for people aged from 21 to 64; that was our calculation. I believe that is the information we provided.

Prof. Dillon—That would assume that they all became eligible rather than just the means tested ones.

Ms Dewberry—Yes, that is right.

Senator ADAMS—That was my next question, which went to the copayment.

Ms Dewberry—The question was about everybody. Obviously, if it were a means tested arrangement, the figure would be different.

CHAIR—Professor, do you want to add anything at this stage?

Prof. Dillon—I could give you an answer to one question you asked before. You asked whether anybody has done the same thing as Access Economics. Their figure came to about 1.4 per cent of GDP in direct health costs and about another 1.3 per cent, I think, in indirect costs. An American academic made the point that these days, in terms of impact on jobs, a communication impairment is more of a disability than a physical disability. He had an estimate of 2½ per cent of GDP for America which is in the same ballpark as that done by Access Economics.

Senator BOYCE—Whose study was that?

Prof. Dillon—His name is Ruben. I can give you the details.

Senator BOYCE—It would be great, if you could; thank you.

CHAIR—Ms King, do you want to put anything on record that we have not asked about?

Ms King—No; it has been covered.

CHAIR—Thank you very much again for your time. We will contact you about having a particular session on Aboriginal and Islander services. Also, Professor, we will certainly try to make the time to come and look at NAL.

Prof. Dillon—That would be good.

CHAIR—It is extraordinarily well regarded and a centrepiece of the whole program that we do. We will have to do that this calendar year, which is rapidly running out. So we will go through the process of doing that. Thank you very much for your evidence.

[12.16 pm]

JONES, Mr Alexander, Private capacity, through Ms Tanya Miller and Ms Kylie Scott

JACKSON, Ms Leonie Mary, Private capacity, through Ms Tanya Miller and Ms Kylie Scott

CHAIR—Welcome. Thank you for your submission. We are really pleased that you could attend here and give evidence. Most of us have not worked very closely with interpreters before, so just let us know if we are doing the wrong thing. We ask that the interpreter do the same: just tell us if we are doing the wrong thing.

Ms Jackson—Before we go any further, I would like to clarify the interpreting situation. With our signing, Tanya will announce whether it is Alex or me and then interpret it into spoken English. We hope that will make it a bit clearer for the *Hansard*.

CHAIR—That is wonderful and it will make the system work.

Mr Jones—I may as well start. I am a deaf man and the father of a deaf child. I am involved in the Deafness Forum and work with captioning; therefore, I have a very large interest in this particular area, which is why I am attending today. Thank you very much for this opportunity.

CHAIR—Thank, Mr Jones. Ms Jackson?

Ms Jackson—Like Alex, I am a deaf person. I grew up within the Australian hearing system and had hearing aids. I am the parent of a deaf child also. In addition, I am and for the last 18 years have been a deaf educator. Again, thank you for this opportunity today.

CHAIR—We have your submission. For the record, you may like to make some comments, and we will be very happy to hear from you. We will then go to questions.

Ms Jackson—Yes, I would like to share my story. Many deaf and hearing impaired individuals have told me that they feel they do not fit into the hearing world or the deaf world; they are somewhere in between and just do not fit in either of those worlds. I feel that is a real shame. I can also relate to those comments. When I was growing up—as many hearing parents of deaf children can tell you—I was forced to hide my deafness because the professionals, the doctors and those in the medical field, said to my parents, ‘It is in your child’s best interests to become as much as possible like everybody else in the community so that they can fit into the wider community.’ But that omitted the fact that I am actually deaf. So, until the age of 18, I was forced to hide my deafness. I pretended to be like everybody else. I pretended that I could hear. I spoke, used my hearing aids and went to mainstream schools. However, at night, when I went to bed and took my hearing aids off, I was still a deaf person.

I think for a very long time we have used the same language; we have used language that says deafness is an issue. I think we need to think about the language we use from this point on going forward and perhaps think about ‘deafness’ as ‘difference’. I am deaf, which means that I am different from most of the people in this room—people like you—in how I live my everyday life. I use different technologies to assist me. Sometimes I use Auslan interpreters and I watch captioning; that is how, in my everyday life, I access things out in the community. In thinking about deaf children and their lives, it is important to think about how they will grow up and how we want them to grow up as individuals, rather than try to hide our or their difference—their deafness. What Mr Jones and I would like to talk about today has four different strands. As we have said, we are interested in a number of different things in the deaf area. Perhaps I might hand over to Mr Jones for his recommendations.

CHAIR—Thank you.

Mr Jones—I think this is a real opportunity to talk about health expenditure. You talked about this earlier and you know about the costs and expenses that come up. However, if deaf people were funded for these costs and expenses, there actually would not be any result on the GDP. Employment would result from any costs in education. By ‘costs’, I am talking about things such as those spoken of by Dr Rhonda Galbally last week in Canberra. She talked about *Shut Out*. I am not sure whether any of you have read *Shut Out*, but that report talks about people in Australia who live with disabilities and feel that they are shut out. Previously they were shut in, but now they have been shut out. We feel that in some ways we also have been shut out. The ‘shut out’ experience is very common for deaf and hearing impaired people and a lot of it is due to cost. We cannot afford to buy devices. We have had to pay $800 for a Baby Cry Alarm to make sure that I’m able to hear or understand that my son is crying. Recently, a new hearing aid cost me $7,500. My son’s college fund will have to be reduced. There is no Christmas fund and no Christmas holidays. So the costs really affect people’s everyday lives.

In terms of the costs, people raised the fact earlier that, when people reach the age of 21, they have financial costs that they did not have earlier; they may even have copayments. There are so many different ideas about how we can work around this. One thing I would like the committee to consider is that there are national disability carer organisations, which Rhonda Galbally talked about; they looked into what is called the National Disability Insurance Scheme. That we can collaborate and work with these sorts of schemes is a very powerful and worthwhile thought and it is something to look into. This so-called insurance scheme is fantastic. The reason for it being so great is that there are so many parents out there who find that their child is deaf and they do not know what to do and whether they are able to afford the necessary equipment and this insurance scheme can cover a lot of those costs. It is important that parents have the appropriate support, such as early intervention and the devices they need to make sure that their child feels included and a part of society. Leonie, do you want to talk about early intervention?

Ms Jackson—I will speak from my experience. When it was discovered that our child was deaf, which occurred through the SWISH program, we were referred through to early intervention. I was in a very fortunate position because I work for the Royal Institute for Deaf and Blind Children, so I am very familiar with whom to contact; I know who the best teachers of the deaf are and I know what I want for my son. But there are other parents, both hearing or deaf, who do not have the same level of information that I have, which enabled me to make an informed decision. I think it is a real shame that that is the situation within the Australian system. A lot of parents out there did not and do not realise that there are or may be services out there to assist them. I find that quite upsetting. I work in the area of deaf education and I am now the parent of a deaf child. So, in a sense, I find that there is a bit of a conflict in that these things are still happening.

I also think it is very important that, with early intervention, we provide all of the options and choices, because there is no one size its al for hearing impaired children. It is my very strong belief that there is not one approach that will suit everyone. As a country, we need to stop promoting that one approach is better than another. We need to promote the fact that cochlear implants are not necessarily better than hearing aids; nor is it the other way around, in fact. All deaf children are individuals, so we need to think about what the best fit for that child is. It may be that neither a cochlear implant nor hearing aids are the best fit for that child; it may be better for them to learn signing so that they are able to communicate. Perhaps the best for them is that they have speech and also use sign language. My son is going to have the benefit of both languages. Potentially he may be bilingual and in a mainstream school, perhaps with interpreters and captioning support. At the moment that is not available. That is something that I am going to lobby for and I really advocate for that here.

Mr Jones—This goes back again to access to resources. I want my deaf son to go to a local primary school that is situated around the corner from our house, but I am not sure whether they will have the appropriate support there. If he can go there, will the school be able to provide interpreters and captioning? Will all the equipment there be set up appropriately so that there is captioned television? Will the DVDs in the room be captioned? Providing access to resources is critical for us and my son, just as it is for any child in school and out in the community, so that they can feel fully included in our society. Things like captioning to access what is going on out there, as with going to the movies, is very important. All those lifestyle things are also very important so that they do not feel shut out—and that ‘shut out’ feeling does happen a lot.

Another thing that I think is quite important is that it is really nice to see how different countries overseas have been quite successful with different modes. An example of that might be in the United States in Colorado, where they have a system that I think is called Care. Leonie, is that correct?

Ms Jackson—Yes.

Mr Jones—They have a Care coordinator. With the system that is in place there, a baby or child, after being diagnosed with hearing loss of some description, is referred to what is basically an independent organisation where there is a person who has experience in dealing with parents who have recently undergone that same experience. So that person has that experience and has an understanding and knowledge of the variety of options and resources that may be out there what of the appropriate paths are; they provide the appropriate support for the parents. At the moment, the current system here does not have that—we just do not. We do not have good parental support. We need someone with that knowledge and that ability to connect because quite often people go through to the medical professionals. Of course, those medical professionals are very professional and very good, but there is not someone who can give those parents a variety of choices about access so that they are able to make informed choices.

I am actually lucky because I am deaf and that helps me and my son; I understand what my son’s situation is and what he might need. My son was diagnosed initially with a profound hearing loss and the professionals discussed with us that perhaps we should consider providing him with a cochlear implant. I thought, ‘Okay, I’ll consider that; I am open-minded with that.’ I decided not to go with that option and, instead, to go with the option of hearing aids. Six months later, after testing, we found that the initial diagnosis of profound loss was not correct. He actually has a severe to moderate loss, which is less than a profound loss. So he has a moderate to severe loss; okay. But, with a little thing like that, if my son had been born into a completely different situation, perhaps into a family who could hear and did not know anything about deafness, he may have gone straight into being given a cochlear implant, which would have actually removed any residual hearing that he did have.

So it is about the approach and fitting best with each individual. You cannot have one size fitting all. You cannot just close your eyes and hope for the best; you absolutely cannot. You need to look at each individual child and what their needs are, where they are living, how their parents can support them and what kind of appropriate support can be put in place.

CHAIR—Thank you. Are there any questions?

Senator BOYCE—Ms Jackson, parents yesterday suggested to us that it is a maze and it is very hard to find out where you can get resources from; and, if you do not know, how could others? But Australian Hearing has commented previously they have a resource called *Choices*. Are you aware of that resource and is there more or better that can be done with that resource?

Ms Jackson—For myself, the information in the *Choices* booklet is stuff that I knew previously. It was not really for deaf parents of deaf children, so it is not really written in a way that deaf parents usually would be able to work well with. For parents who are deaf, there are no Auslan translations and no DVD with captions available to be watched. For me, it was fine. However, other parents who are deaf have spoke to me and said that they could not understand all of it, because it was presented in English in a manner that they found to be inaccessible. So they have put it on a shelf and it has stayed there. However, as a deaf professional, I was quite impressed with that booklet.

Senator BOYCE—So it has its place, but there is a need for more.

Ms Jackson—Yes. I think it would be great to give various scenarios so that parents have an understanding of what might occur in real life situations; a DVD might be the most appropriate way of giving parents some sort of picture of what might happen. Parents whose child has been diagnosed as being deaf look at the hearing world. They look at the audiologists, the doctors and the nurses who can hear and, if they themselves can hear, they have no knowledge of what their child’s world might be like. They have no picture; they have nothing to relate to. There is nothing where they can see anyone being represented as deaf adults. I think parents find it very hard to picture what words on a page might mean for their child’s life in the future. Many parents who can hear go through a lot of grief; they are very shocked about the fact that their child is deaf, so they may not be able to absorb information very well. They may need to be given something that they can watch and then understand later, when they are feeling more prepared.

Mr Jones—Perhaps I can submit something also. As I raised earlier, the Care coordinator in the Colorado situation in the United States is a really good guide. The *Choices* booklet is fantastic to have, but missing from that booklet is the link, I guess, to an actual person who is able to meet up with those parents. Professionals do not have experience in counselling and support, as that is not their area of expertise; their area is to provide professional advice. In some sense, that does leave the parents in the dark. So I think the Care coordinator notion would benefit a lot of people and a lot of families.

Senator BOYCE—I know that some state governments have made efforts within the disability sector to do something like that Care coordinator role, with varying degrees of success. Mr Jones, you mentioned previously just one extra cost associated with having a child with a hearing loss, which was the baby alarm. Would the two of you like to comment on the things that are not covered by government subsidy or government help? We have heard already from OHS and Australian Hearing, but can you tell us of the things in ordinary life that you have to pay extra for? Are they lists like that?

Mr Jones—Perhaps I can give you a few examples. I am at home with my son for two days a week. I drive my son to North Rocks. It is my choice that he go to that particular area to have that service because I think it is very important for him to have access to both languages; that is Auslan and also English. So I head over to North Rocks. That is an institute that I feel New South Wales, and in particular Sydney, is very lucky to have because, in a sense, it is a centre of excellence. My child is provided with the opportunity to have auditory-verbal classes, which are really about developing his ability to have the necessary skills to listen to what comes in through his hearing aids and to adapt his speech to what comes through them. I, myself, went to speech classes but had no early intervention program; whereas my son has a fantastic opportunity to participate in an early intervention program. I have to take those two days off work so that I am able to do that for my son, and that is a cost. That is fine and I am not complaining about it, as it is very important for my son's future and that is why I do that; but I do not get any extra funds. Some additional money does come from the government; because my son is deaf, there is some financial support available, but it does not really cover an awful lot.

Senator BOYCE—Do you receive a carer payment or allowance?

Mr Jones—Yes, that is what I mean: the family carer allowance. It is a fairly small amount, but that is fine. I think it is $100 a week or something like that.

Ms Jackson—It is actually a fortnight.

Mr Jones—Yes, it is a fortnight, and that is fine. I do not know whether I can speak for many parents out there, but I can speak for myself. I have a pretty good job and I am okay, but many parents in Australia do not necessarily have that same situation.

Ms Jackson—I am just trying to think of other costs.

Mr Jones—When buying DVDs for my child, I always make sure that I look at the back to see whether they are captioned and there are a lot of them out there that are not. That is just a particular issue that I am thinking of.

Senator BOYCE—Never in the specials bucket or bin, anyway.

Mr Jones—Yes, exactly. In addition, children’s TV programs are not often captioned, so I tend to just look for something else. I think it is about my son’s future and his friends. With some of the programs his friends are watching not being captioned, will he be happy talking about the things they talk about which he has not been able to access? He may not feel fully included in the conversation because, with those programs not having been captioned, he will not have been able to watch them. Other people will be talking about them because they have been able to hear them.

These are the sorts of things that happened to me. I had lots of friends who could hear and who loved going to the movies. They would sit around at dinner and talk about the films they saw; I would sit there not saying a word, because I did not know what they were talking about. I had never seen those films. I was not able to access them and see them properly. There are captioned movies and now they are on every week in the city. That is not all of them; it is one film a week and it is usually a B-grade movie.

Senator BOYCE—Or SBS.

Ms Jackson—Exactly.

Senator ADAMS—Mr Jones, how did you get on with not being able to access services when you turned 21? Was that program in when you were 21?

Mr Jones—I might pass that question over to Leonie to answer because I moved to Australia from the United States about 13 years ago. I am a permanent resident. I am an Australian and I am very proud to be an Australian, but I cannot comment on that particular issue.

Ms Jackson—Just before I turned 21, I received some new hearing aids from Australian Hearing. I held on to those hearing aids for five or six years and looked after them very well. I knew that they were very expensive to replace, so I had to make sure that they were maintained in good condition. So, at about age 26, I was working but I was also at university part time, which meant that I hadn’t paid off my HECS debt and had other financial commitments. That meant that unfortunately I was not able to afford two new hearing aids, so I saved up my money and bought one new hearing aid. Eventually I wanted to buy two new hearing aids, so I went to the audiologist. They said, ‘That’s fine, but we have to do a hearing test first.’ So we did a hearing test and they said, ‘Unfortunately, you are not able to have two hearing aids.’ Because I had only had the one hearing aid for such a long time, my brain no longer received signals properly from the ear that had not been aided and would not benefit from having that other hearing aid. So I just have the one hearing aid. That is a fairly common story told to me by other deaf and hearing impaired individuals within Australia whom I have met; they have told me that they only had the one hearing aid, because they were not able to afford two.

Senator WILLIAMS—Mr Jones, how old is your son?

Mr Jones—He is 22 months old.

Senator WILLIAMS—When he was diagnosed with a hearing problem, the good news was that it was not as bad as they first thought. The diagnosis process must be very difficult. Has that process improved? Are they getting more accurate with the diagnosis of the very young, such as babies, or are there still areas there where they simply cannot determine the amount of hearing loss? Do you know the answer to that question?

Mr Jones—I definitely have to agree with you in that, when I was asked to consider his possibly having a cochlear implant, I said no. If I had said yes, I would have made sure that more accurate testing was done to make sure that diagnosis was 100 per cent accurate. So, from my situation and with my approach and my experience, that is just one situation. If I had said yes, we probably would have found out that he had better hearing than diagnosed initially. But I am not sure that that approach happens Australia-wide, because states have their own particular processes and ways of doing things. So appropriate protocols are needed in terms of implants being implanted or not because you need to make sure that that is the right decision. My son is incredibly precious about his hearing aids; he loves them. In the morning, the first thing I see is, ‘Where are my hearing aids?’ I say, ‘I left them in the kitchen,’ or whatever, and he will be gesturing at his ears because he wants his hearing aids. He really values them. He knows that they are of benefit to him. I am trying to say that these protocols need to be consistent Australia-wide. I am not sure whether I have answered your question.

Senator WILLIAMS—Yes, you have, very well. You gave the example of people with children who have deafness and hearing problems having personal contact, help and assistance through that program in America. Surely that would be of greater benefit than perhaps the way it is here in Australia; or, with what you have learned and seen in Australia, is the personal help, attention, support and advice et cetera given in Australia adequate?

Mr Jones—I do not want to steal the thunder of anyone who is to appear later, particularly Ann Porter; I know that she will probably be discussing something along these lines. Australian New Zealand Parents of Deaf Children has a small group of parents Australia-wide who recently heard from Dr. Christine Yoshinaga-Itano, who is actually in Australia at the moment. Dr Christine Yoshinaga-Itano is talking about that particular model they have in Colorado. To answer your question: definitely, we do not have enough parental support here. It is unfortunate that we also do not have a sufficient number of role models out there for parents so that they can actually see that there is someone who has done it and ‘my baby will be okay’. They do not know what people who are deaf or hearing impaired look like: ‘What are they, who are they and what do they do?’ That is because it is much more hidden and that, for so many years, there have been failures in the system. Also, there are not many deaf professionals out there—deaf or hearing impaired lawyers, doctors and audiologists. There is nothing out there for them to see, because the system has been failing for many years. There are no appropriate early intervention programs. There are no deaf or hearing impaired people working at a government level. Where are they? They need to be out there, and we have been shut out.

Senator BOYCE—During evidence yesterday, one witness suggested that the intervention that should be made when a newborn is diagnosed with a hearing loss should change from being opt in, where you choose to have treatment of some sort, to opt out. I would like your opinion on that. What I mean is that you would have to explain why you did not want treatment.

Ms Jackson—I will be polite in this setting and say that I disagree with the concept. Our experience is with having a child born deaf and then finding that their hearing loss is actually a bit different to how it was first diagnosed. I am scared to think that, if a decision were made to implant a particular baby at three or four months of age, its parents would still be going through the grieving process and there would be no way of making sure that the parents were making an informed decision in that short period of time.

Mr Jones—It is a disaster waiting to happen. I think it is interesting because that particular approach indicates to me that they are trying to ‘fix’ the problem—

Senator BOYCE—The medical model.

Mr Jones—exactly—and it does not necessarily need to be fixed. Some amazing things are happening in the medical professional field in terms of hearing aids and cochlear implants—some wonderful opportunities—and I definitely applaud that. At the same time, however, it is not a cure; it will not be fixed. These are tools and how we use these tools is what needs to be looked at. Parents and families and individual children need to have appropriate information; they need to be empowered with that. They need to be able to make an informed choice. They need to be able to know what they are deciding upon, when they go down a particular path. They also need to have appropriate backup. If the path that they have chosen to go along is not successful, they need to have another to go along. In addition, they need to know that is okay. They need to know that they do not have to keep going down the path they chose in the first place, having no ability to change.

Too often at schools in Australia I see deaf children who have come from programs, such as cochlear implant programs or oral programs, who use only speech and lip reading and who at 12 years of age do not have any language. They do not use their hearing aids. They do not have the language they had when they came at year 1. At 12 years of age, they do not have the literacy level they had at year 1. I cannot speak for myself, but I know that Leonie, as a teacher, has seen many students come through without that language. I do not want to see that happening in the future. This committee hearing is a wonderful opportunity because you are hearing now from two deaf people. It does not mean that we can speak for every deaf person, but we do know that there are too many deaf people of my age who are not working; they are on the disability support pension—and, basically, that is due to their lack of education and support at a younger age.

CHAIR—Thank you, Ms Jackson and Mr Jones. Is there anything that we have not asked you about that you particularly want to tell us of?

Ms Jackson—Yes. I would like to talk about all the decision-making steps I have seen over my life while I was growing up. For the last 30 to 40 years, I have seen decisions being made by committees, government ministers and service providers and those decisions have been made about what is best for a deaf or hearing impaired child but, unfortunately, at that level, there have been no parents of deaf children or deaf people themselves within those decision-making institutions. Those decisions are quite scary because they do affect some people and, unfortunately, the people making those decisions do not have that experience; they do not know how those decisions will affect the lives of people who are deaf or hearing impaired. Unfortunately, that has been sending a very clear message that deaf people and the parents of a deaf child are not good enough to participate at that particular level, even though they live with these conditions every day. So I would like to submit that the committee needs to think about perhaps setting up more-representative committees or decision making bodies that include the particular sorts of individuals that I have spoken of.

Mr Jones—All I have to say is that I agree with Leonie. I think it is very important to have a good balance of people because the decisions being made and the strategies being planned need the involvement of deaf and hearing impaired people. Perhaps that applies also to the National Disability Strategy now; we need to make sure that, with what occurs, we can work with certain people and connect up and liaise with others. As that experience is very similar to the experience we have had, we would like to work together with them. Thank you very much for this opportunity.

Ms Jackson—Thank you for the opportunity.

CHAIR—Thank you. The committee will now suspend until 1.45, when we will talk to Mrs Rayner on behalf of Aussie Deaf Kids and Mrs Porter on behalf of Australian New Zealand Parents of Deaf Children.

Proceedings suspended from 12.52 pm to 1.46 pm

RAYNER, Mrs Susan Elizabeth, Committee Member, Australian New Zealand Parents of Deaf Children

PORTER, Mrs Ann Kathleen, Chief Executive Officer, Aussie Deaf Kids

CHAIR—We will reconvene with Aussie Deaf Kids, Parents of Deaf Children with Unilateral Hearing Loss and Australian New Zealand Parents of Deaf Children.

Mrs Porter—I am the CEO of a parent group called Aussie Deaf Kids. We provide online support to families who are raising a deaf child in Australia. We also have a website which provides a lot of online information to families. The parents run two support groups. There is one for parents with children with bilateral loss and the other with unilateral loss. The families from the unilateral loss asked me if I would help them do a submission to this inquiry.

CHAIR—Parents with children with a unilateral loss?

Mrs Porter—Yes.

CHAIR—Ms Rayner.

Mrs Rayner—I am a member of ANZPOD, which is a loose coalition of parents who aim to have the parents’ voices heard, particularly in the formation of standards for newborn hearing screening. I am also a member of a few other parent organisations, one of which is the North Shore Deaf Children’s Association and they have also sent a submission in to this committee.

CHAIR—We have submissions from a number of the organisations that you are representing, so thank you very much. I would invite either or both of you to make some opening comments and then we will go into questions.

Mrs Porter—We have prepared an opening statement.

CHAIR—That is fine.

Mrs Porter—We represent parent groups from around Australia. We all want to improve hearing services for the children and families who are following in our footsteps. Our submissions are informed by our own experiences and also by the express needs of the families that we represent.

Being told that your child has a hearing loss is a devastating experience. Ninety per cent of deaf children are born to hearing parents who have little or no experience of childhood deafness, but all parents, whether they are hearing or deaf, are suddenly faced with the challenge of bringing up a deaf child. Deafness impacts on all aspects of our daily life. It changes our family forever. The family, as a whole, needs to be supported throughout their journey.

The newborn hearing screening initiative is wholeheartedly supported by parents. However, we believe that the current early diagnosis and referral services do not acknowledge the parent as expert and do not fully reflect families' needs. Irrespective of what you may hear from professionals, families want choices. Newborn hearing screening programs around the world have adopted the notion of informed choice. Each of the two words in 'informed choice' highlights an essential aspect of the decision making process for families. To be informed families need unbiased, reliable and accessible information, and they also need choices, choices about communication, technology, education and so on.

Early identification provides families with sufficient time to digest complex information, talk to professionals, other parents and deaf adults, before they are required to make a decision which may have a lifelong implication for their child.

We want our children to have equal access to hearing services, regardless of their level or type of hearing loss, where they live, their socioeconomic status or their ethnicity. These services include newborn hearing screening, early learning services, audiological services and the provision of hearing devices. Newborn hearing screening aims to identify babies who have a bilateral, moderate to profound hearing loss, but in the process babies with a mild and unilateral loss are also identified and parents of these babies hear the same thing, 'Your baby is deaf.' They go through the same range of emotional responses. These babies and families need support targeted to their particular needs. We all want our children to have the same access to communication and education as their hearing peers. We have outlined our vision for newborn hearing screening programs in a document entitled *Quality Standards for Newborn Hearing Screening Services Supporting Families* and a copy of this is attached in our submission.

The present system which comprises newborn hearing screening, early intervention and educational support sets out to provide our children with opportunities to become fully functioning and contributing members of society, only to trip them up at the final hurdle. The financial costs of living with lifelong deafness are enormous. At the age of 21 there are not many of them who can afford the expenses of this magnitude. Some are still students. Some have only limited years in the workforce. We also feel that the government should continue to fund hearing services for young adults after they turn 21, and we have suggested three options in our submission.

Parents and deaf adults are underrepresented in decision making processes which have direct implication on their lives. ANZPOD aims to ensure that parents of deaf children have a voice in the development of policy initiatives in hearing health and we ask that this wish be taken into consideration in any recommendations that may arise as a result of this inquiry.

CHAIR—Thank you. Mrs Rayner, do you have any comments that you would like to make at this stage?

Mrs Rayner—There has been a lot of talk today about the incidence of hearing loss affecting one in six people. We would like to submit that it is much higher than that if you take into consideration the impact on the other members of the family. It does not just impact on the person with the hearing loss, it impacts on all the people around them.

I would also like to say that the attitude of the community towards deafness is still something, in our opinion, that leaves a lot to be desired. Deafness is hidden. Mr Jones commented today that people are encouraged to hide their deafness. For example, we have a former Prime Minister who we all knew wore hearing aids, but there was never any public acknowledgement of some of the disability that he may have felt whilst he was sitting in a room like this because he could not hear properly. We are sending a message to our children that we do not value them the same as other people are valued in the community because they have to keep their disability behind closed doors and not talk about it. It is not visible. It may be visible for people who use sign language because they are using their hands to talk, but for oral kids it may not be as clear.

CHAIR—We will go to questions and I would like to ask a question for clarification. Ms Porter, in your submission and in your identification you have made very clear the different needs for people with unilateral hearing loss and those with other forms of hearing loss. It would be useful to have that spelt out. On one level you know that it is one as opposed to two, but what are the special aspects of that?

Mrs Porter—I am not an expert on that so I guess you should speak to an audiologist. The thing is that two ears are always better than one. Some of the data that comes out from studies in the states is quite old, but it suggests that a high percentage of those children need to repeat school. Usually children with a more severe hearing loss in their deaf ear need to repeat a grade at school. There are a lot of behavioural problems. There are safety issues because you need two ears to be able to locate sound. My daughter had a unilateral loss and she went on to have a bilateral hearing loss so she would say, ‘Where are you mum?’, and I would have to say, ‘I’m in the lounge’, or, ‘I’m in the kitchen’, because if I said, ‘I’m here’, even if I was standing right behind her she would not know where that was. There are a number of safety issues for kids like crossing the road or in the car park.

Traditionally we thought that if the kids sat in the right place in the classrooms so that they had access to the teacher’s voice that they could be okay, but we know that the amount of background noise is difficult for anybody with any level of hearing loss. For kids, the deafer they are in one ear the more of a problem that is. Those are the two things regarding the hearing in noisy environments. A kid with a unilateral hearing loss, one-on-one or in a quiet environment is fine, but as soon as they join a play group, preschool or classroom they start to experience problems, particularly if they are in the profound end of the spectrum.

CHAIR—If it is only in one ear people may not give them the same acknowledgement.

Mrs Porter—They think that they can hear with one ear so everything must be okay.

CHAIR—They are perhaps undervalued.

Mrs Porter—Yes. I know from my experience with my daughter. She was diagnosed at 4½. She had ongoing speech and language problems. Her language was quite delayed and things like that. I had started at 18 months to try to find out what was the matter with her. At 4½ she was diagnosed and when she went to school she was the failure. She really had a difficult time. She just could not learn to read. She used to come home and say, ‘Mum, I have to wear sandals to school tomorrow’, instead of sandshoes. It was issues like that. In fact, unfortunately when she actually lost the hearing in the other ear she did better because then she got a hearing aid and services at school. I guess that is a concern.

You have heard today that we have seen Dr Christine Yoshinaga. As parents we have spent all weekend with her. She calls it a failure model and she is very concerned about the kids with mild and unilateral hearing loss because we tend to intervene more when problems emerge. What she is saying is that we expect hearing babies to progress in their speech and language by one year in one calendar year, but when a child with a hearing loss falls behind we are expecting them to catch up more than a hearing child can. Some children do and, in fact, her data shows that. I think about 40 per cent of those children do, but they usually have good cognitive levels; they do not have other issues and things like that.

Particularly with respect to the unilaterals that asked me to put in this submission, we do not want our kids to fall behind before things start to kick in. We want to ensure that they stay on track all the way along.

I was just speaking to Margaret Dewberry and I have made one error in my submission. I said that if families chose to wait and see and chose not to have a hearing aid then they were ineligible for service from Australian Hearing. That is not correct. They are not ineligible. Can I ask Ms Dewberry?

CHAIR—She is not here but she will come back.

Mrs Porter—They are not ineligible, but they will be followed up at key areas or they will be directed to other hearing providers. The message that the families are getting, and I get this through my online group, is that Australian Hearing has abandoned them. The will at the top of Australia Hearing is that there is an acknowledgement that these children need the support and everything like that, but somehow that is not filtering down.

CHAIR—There is a communication issue occurring.

Mrs Rayner—Yes. Both of us would also like to acknowledge that the service that Australian Hearing offers our children is fabulous. It is world’s best practice. Wherever we go in the world every family envies us.

CHAIR—You would just like it longer.

Mrs Porter—That is right.

CHAIR—Senator Adams.

Senator ADAMS—Once your children reach 21 how are they going to cope or how are you going to cope? How old are they now?

Mrs Rayner—My son is 21 now.

CHAIR—Are you just going through it now?

Mrs Rayner—We are just in between. Just before his 21st birthday we had an appointment with Australian Hearing. The hearing aids that he is fitted with now are two years old so it was too soon to replace them. Australian Hearing does not completely cut out at 21; they will still provide services for very minor repairs and I think they can have access for moulds for another couple of years. Moulds are a big issue for my son because of the shape of his ears. It can often take two or three goes to take an impression to get a mould that fits properly. He is going to have to pay for that at $75 to $100 per mould per time, which is a pretty expensive exercise. If they do not fit properly then they give you feedback which is the high pitched whistle that everybody hears when you have got an old person next to you who is whistling. Not only is it annoying for everybody that is around them, but it is annoying for the person who has got the hearing aid in and they cannot hear properly.

He is in the process of completing a TAFE course so he is not actually out in the workforce yet. There is certainly no way that he could afford hearing aids on his 12 hours a week at Franklins and it may be some time before he is in a position to be able to afford to replace hearing devices.

We are in the position, as parents, that we can afford to keep funding him for a bit longer and that is one of the decisions that parents have to make. If you have that financial ability you are lucky, but many families do not have that. Maybe we should not be expected to do that either. He is becoming an adult and independent and we feel that he ought to be able to pursue that independence. Without his hearing aids he could not function. They are part of his being. He has worn them his whole life. He lip reads a little bit, but he is totally dependent on hearing devices for knowing what is going on around him. Whether your child wears hearing aids or an implant, when you take those devices off they are still deaf. It is not something that you cure by whacking a bit of technology behind their ear. There are many circumstances where different modes of communication are useful, but that is another argument.

CHAIR—What information did you get, as a family, as he got closer to 21? In the system people know the services are there until 21, but you do not think about it because you are going on with your life. I am interested to know, because it is still fresh in your mind, what information you had as a family that Senator Adams was talking about leading up to 21. What did Australian Hearing tell you?

Mrs Rayner—They provide the child with a package which is a little folder with different pieces of information about the types of things that you are looking for and explaining his level of hearing loss. They provide you with an audiogram so that you can find yourself another audiologist. My son has a file about this thick from Australian Hearing because when he was small he had fluctuating hearing loss and had to be tested about once a month. That information stays with Australian Hearing; it does not get passed on to future providers.

They are very happy to provide a summary of where he is at at the time, but it would seem to me that it would be better if that information went with the child to wherever they go.

CHAIR—To the best of your knowledge is that standard practice?

Mrs Rayner—To the best of my knowledge.

CHAIR—We will ask Australian Hearing about that because records are a very sensitive issue and Senator Adams would know that. If you are going to a new service provider then they need to know your whole history.

Mrs Porter—Especially for these kids, because they are complex.

Mrs Rayner—Finding a service provider that knows anything about congenital deafness is pretty difficult. In the main, audiologists in the private sector are well experienced with people with acquired loss because those people are their main clientele. They are certainly not paediatric trained in the main. There may be one or two, but we do not know where they are. A lot of private providers have to prescribe hearing aids from their parent company, which may or may not be the best aid for our children.

If you go to a private provider for the first time they will want to test you, so you pay for that, then they may offer you advice about a hearing aid which you may or may not be able to trial and it might not be suitable anyway. Some of the private providers are audiometrists rather than audiologists who certainly do not have any experience in working with congenital deafness. They do not understand the complex issues. Our kids go through habilitation, not rehabilitation. If you lose your hearing as an older person you are trying to get back what you had before. Our kids have never had it. We are moving forward into new places for them all the time and so they may not have that experience.

If you are fitted with a hearing aid that is not truly suitable for your hearing loss then it can do more damage than good. You have then lost that time and the money and then have to go off and find somebody else.

Mrs Porter—My daughter is 20 so we are just going into this journey. I think from about the time she was 18 it started to really worry her. It is a little thing that niggles in her head about how she is going to manage without parental support and things like that. She will quite often say to me, ‘Will you and dad help me?’ She only wears one hearing aid because she has no hearing in the other ear and without that hearing aid she basically cannot function. She wears it and she has an FM. There is just this underlying stress for them. There is anxiety about how they are going to cope. They are anxious anyway because they are leaving school where they got so many support services. She went to university, which is a whole different kettle of fish, but she has this constant underlying level of anxiety.

Australian Hearing does a really good run-up to 21 so she got her information. She is lucky that she has got new hearing aids. They really try to support these kids and I understand that it is not easy.

CHAIR—What is she hoping to do?

Mrs Porter—That is a moot point, and I am not sure that I want this on *Hansard*. She has actually dropped out of uni. She found it just too stressful. She felt that she had to work too hard. She worked harder than everybody else for less results and it really was affecting her mental health. Fortunately, she had the insight to phone me and say, ‘I don’t think I can do this.’ She was down at Canberra so she also had the issue of staying in a college. Fortunately she had the insight to say to me, ‘I’m not managing here. I think I need to come home and regroup.’ We have spent this year regrouping. I guess this is a problem. Mental health issues for these kids are big.

Mrs Rayner—In looking at the financial costs for them—not just looking at hearing aids—the other types of things that they will have to buy as they become independent of their parents are specialised smoke alarms and doorbells. We have a home loop system in part of our house whereby the person who wears the hearing aids can use the telecoil switch in the hearing aid in order to be able to hear the sound from the television. That is what he uses all the time and he has been used to using it all of his life. To go out and have to start purchasing these things is expensive. Loop systems, for example, vary in cost from about $400 to $900 per room, whether you install them yourself or have somebody install them for you. An FM system, which would be suitable for someone to use in the workplace, for example in sitting around a boardroom table with a teleconference type mic in the middle of it, is in the region of over $1,000. A smoke alarm-door bell system might cost about $500. There are specialised telephones that are available for people with hearing loss with specialised volume controls on them. I am not quite sure where the latest Telstra agreements are up to. There was a time that you could apply for a phone with a volume control on it which would be provided free from Telstra for people with disabilities. There are things like that which are in addition to their hearing aids, which are devices that he uses everyday. I know they do not buy them every week, but when you are first starting out in the workforce it is a cumulative cost. To leave home and set up those sorts of things would be expensive.

Mrs Porter—We hear people saying, ‘My friends are going on holiday’, and those kinds of things. As a parent it is really hard to deal with.

CHAIR—Senator Adams.

Senator ADAMS—Do you have rural members?

Mrs Porter—Yes.

Senator ADAMS—How are they getting on with access to audiologists? I am really looking at the patient assisted travel, which they are not eligible for?

Mrs Porter—No. It is a huge issue for families in rural areas. I can remember one parent that wrote to us to say that she had travelled to see the audiologist. She had travelled six hours and when they arrived the child had wax in their ear so they could not do the hearing test. She then drove home and had to have an ENT appointment to clear the wax. We have lots of families that travel vast distances to go and see an audiologist. You can appreciate that a lot of these are young families, so it is getting other people to look after their kids. They often have to stay over for long trips. For the country families it is a really big issue.

With cochlear implantation they do get some funding for their travel, but it is much more time consuming for rural families. It is an impost on their time and it is incredible. Sometimes I just cannot believe that they are that resilient and they just constantly come up and continue to do it. Some of these families with cochlear implants, by the time the kids have finished habilitation and everything, they have been to Sydney from the Northern Rivers of New South Wales something like 12 times in a very short space of time. It is incredibly disruptive on family lives and it is expensive. Even with rural travel it still does not pay for all those extra things when the family does not have a lot of money. It is costly, so families make decisions not to do it because they cannot afford to do it.

Mrs Rayner—There is a travel allowance available in New South Wales through the SWISH program, which is the newborn hearing screening program, for families to come to Sydney for diagnostic testing, but it is quite limited. The families have to pay for it upfront and then have it reimbursed, so they have that initial outlay. Also, I am not exactly sure, but I think that they will pay for one parent to come. If you are bringing down a baby from the country, you come by yourself with a four-week-old baby and then get a diagnosis of hearing loss; it is a very emotionally devastating position to be in without a support person being with you.

Senator ADAMS—As far as accommodation goes in Sydney, is there any accommodation specifically for country people coming down for appointments or anything like that?

Mrs Rayner—I do not know.

Mrs Porter—There may be at RIDBC because they do have some accommodation there.

Senator ADAMS—That is another huge factor in coming to Sydney.

Mrs Porter—Absolutely, but there is also childcare for the other kids staying at home. For the initial diagnosis an area of concern for us is that the mother will come on her own, and that really must not happen. Every time we hear a mother come on her own and she is told that her child has a hearing loss, it is just awful. For that diagnosis appointment you must have a support person with you; if only one parent is being financed then it is difficult.

Mrs Rayner—You ask any parent of a deaf child to tell you about the day their child was diagnosed with a hearing loss; we can tell you minute by minute what happened and who said what. I can remember that far more than many of the other milestones that they went through. It has such an impact on you. When you do it by yourself it is pretty ordinary.

Mrs Porter—Mr Jones only talked a bit about the care coordinator. The one thing that we often hear families say is that the babies are screened, they go to diagnostic audiology and then there is some time before they go to Australian Hearing where they start all their work with hearing aids and so on. There have been efforts to try to make that gap less ordinary. The thing we constantly hear parents say is that it is like this black hole. Somebody has told you that your child has a hearing loss and then you have got three weeks before you go to Australian Hearing. They do not know who to go to, who to turn to or anything like that.

I talk to families all over the world through other groups that I belong to about this care coordinator model. We keep on talking about the model in Colorado, but for families the Colorado and the UK are brilliant support models. When a child is diagnosed with a hearing loss the audiologist makes two phone calls. One is to the family doctor and the other is to the care coordinator. The care coordinator picks this family up. They are experienced in childhood deafness, they are teachers of the deaf and offer early intervention services and things like that. They pick this family up, look after them and guide them through this whole process. They are the point of contact, but they also have the knowledge to make the family feel that they are actually moving on with their child; they are not in this limbo where they are just waiting. These people have an understanding of childhood deafness. They can say, ‘Hold your baby like this. Talk to them like this. You can keep singing.’ It is all those sorts of things that families want to know. They say, ‘How do I talk to my baby?’ They are things that people have the knowledge of when working with young babies. This is why we really love this care coordinator model because it gives families a breathing space between diagnosis and choosing all these other options that they want to make.

The model that we have now is that parents are given this message that with newborn hearing screening you have to do things fast because that is how you are going to have the best outcomes for your child. The reality is that newborn hearing screening has given us some breathing space. It has given time for families to look at their options, to find out the information they need and to talk to professionals, other parents and deaf adults. We are not giving them that breathing space. It is a gift that newborn hearing screening has given families and we are not taking advantage of that, we are giving the sense of incredible urgency.

Mrs Rayner—Also, in Australia, we force families to choose one method over another. There is not a continuum of options where people can go up and down sliders as they need to at any given time. We want the babies to be able to communicate from day one. If they have to wait for hearing aids, however long it is, if the parents are not assisted through that period, then they think that they cannot communicate with their baby at all.

Mrs Porter—Often I have new mums come on to my group where the baby has just been diagnosed. The baby could be four or six weeks old. They will say, ‘I can’t talk to them. Before this I was talking and singing to them as I was changing their nappy.’ Suddenly they are given this diagnosis and they stop communicating with their baby. We need somebody who can nurture them along that process. They can still communicate with their baby. They have been, but they do not know that. That is why, as families, we really want the model that walks these families through and does not push them into one route or the other; it gives them time and space to make informed choices about where they are going.

Hearing parents want their children to talk. If their child is eligible for a cochlear implant they will go down that route, but for me it is tragic. I have babies who are three months old and the family have had MRIs and CT scans. They have been to numerous appointments and their babies are being implanted. These mothers have hardly held these babies. They do not know these babies. They know them only as trying to fit the technology.

Mrs Rayner—The bonding process is being interfered with because you spend so much time concentrating on doing all the hearing stuff that you are not actually looking at the baby itself.

Mrs Porter—We had a mum talk at a meeting we held last night. Her son has had four cochlear implants. He has had one on either side and both of them have failed. She has also started to sign. It does not make a really consistent care model for our kids throughout the process. They have just approved funding for one care coordinator in Victoria with funding from health and education.

Mrs Rayner—Actually I think it is three. There is one from health, one from the Education Department and one from the independent school system.

CHAIR—We will get information on the Colorado model. That will be printed out somewhere so we will find that. Is the care coordinator only for that early time or do they stay with the child throughout their life?

Mrs Rayner—It is until they start school.

Mrs Porter—It is always with somebody that the family can go back to. Each milestone along your child’s life you have to make new decisions and at each stage, as parents, we do not know what those are because as hearing parents of hearing children we kind of know the route we have gone, but this is a completely different kettle of fish. At each stage of the way we need guidance and support. It is not only in the beginning, it is when they start school, start high school and leave school. It is the whole time really.

CHAIR—Senator Adams, do you have any more questions?

Senator ADAMS—Not at the moment.

CHAIR—Senator Williams.

Senator WILLIAMS—Ms Porter, you said in your opening statement that two ears are better than one. I often have inner ear infections with one ear and when it is blocked off with cotton wool and chemicals it is amazing the reduction in hearing. The technology solutions for children with unilateral hearing loss—you are saying that hearing aids are only suitable for children with mild to severe hearing loss. You also say that a bone conduction hearing aid is not successful when applied with children and that the bone anchored hearing aid option is, however, not available to children through Australian Hearing. You then referred to the next one as the soft bone version and stated that there is no private health rebate and that at over $6,000 it is out of the reach of most families. You also say that the TransEar bone conduction hearing aid is not approved in Australia. It seems as though there are many things there but very few things are suitable. The last one was the TransEar bone conduction hearing aid, which is not approved in Australia. Is there any research? How successful is it? Will it be approved in Australia?

Mrs Porter—I do not know that. In my unilateral group I have families from overseas. I think about three of the kids are using TransEars now. They are quite new hearing aids.

They are very successful and they look cosmetically acceptable. My daughter actually wore a bone anchored hearing aid when she first lost her hearing in her other ear. It is quite painful. It has to push quite hard onto the scalp.

Senator WILLIAMS—It is irritating?

Mrs Porter—It is really irritating. The kids hate it. The parents have tried to make soft band things for the baby’s heads which are not incredibly successful. The children are not eligible for the bone anchored hearing aids or actual implantable devices because their skull is too thin. It is different to your cochlear implant; you need a thicker skull and what cochlear offer, for anybody who is going for a bone anchored hearing aid, is the soft band BAHA option where the processor is applied to a headband and kids can use that. We have a number of children in our unilateral group who are using the soft band BAHA. This is anecdotal and I have absolutely no idea, but the families think that it is making a big difference to these children. These are children with a profound unilateral hearing loss.

Senator WILLIAMS—They are expensive.

Mrs Porter—They are $6,000, which is not covered by private health insurance. For the few families who are using it, they really are pleased with the results. As I said, that is completely anecdotal. I have nothing to support that, but that is something that we need to evaluate.

Senator WILLIAMS—To get some public sector support for it?

Mrs Porter—Yes, or even some proper data for it to say: is this really a viable option at that cost?

Senator WILLIAMS—You are talking about the soft ear?

Mrs Porter—Yes, the soft band.

Senator WILLIAMS—The soft band version?

Mrs Porter—Yes. With unilateral hearing loss most of these children are going to be okay, but what we want to make sure is that they do not fall behind so that we have got to then try to pick up the pieces later on.

Senator WILLIAMS—Or support them through their whole lives.

Mrs Porter—Yes. With brain plasticity and everything we know how critical it is to start the auditory pathways early to develop all their auditory pathways. If we do this in the early years we might be improving them down the track. We do not know. We still do not have fabulous data for the best way to manage children with unilateral hearing loss around the world. I do not think that we ever realised the numbers involved. With newborn hearing screening suddenly we had so many kids with unilateral hearing loss and we had no idea that there were that many. We really do not know how to manage them well. Australian Hearing would probably be able to talk to you much more about that.

CHAIR—Have you raised the issues in your submission with Australian Hearing?

Mrs Porter—I have spoken to them about it.

CHAIR—Were they able to talk with you about some of the issues regarding the devices that are there, the evaluation of them and accessibility?

Mrs Porter—Yes. They do not have the funding. For the kids with mild to severe hearing loss they can use the hearing aids that all our kids get or they can have a bone conduction hearing aid and then once they hit school they can get an FM.

CHAIR—The other option was what Senator Williams read out?

Mrs Porter—Yes. I did not put that in the submission. Probably the better option for these kids is an FM when they hit school. There is not a wonderful take-up of hearing aids by kids in school with a unilateral hearing loss so I think that is why families really feel that they want to do it early to try to avoid problems in the early years. They want to try to get these kids up to speed.

Senator WILLIAMS—If they can do that with some government assistance surely that leads them down the pathway to what we call a normal life, normal job, earning income and paying tax, instead of being unemployed and a burden on the government or taxpayer's purse. An investment in the younger life is surely a good investment as far as government funding goes.

Mrs Porter—We know that early intervention is crucial for any child, even a hearing cognitively competent child. We know that the early years are crucial and that what we do in the early years will have an impact on the child throughout their life.

The thing with unilateral hearing loss that is fabulous is that the families now know. I read to my daughter for four years on the wrong side. She probably never heard a story that I read to her.

Senator WILLIAMS—You can read them again.

Mrs Porter—Those are the things that unilateral loss has given our kids. We know that if we put the kid in the right place in the car so that they can actually hear what is happening in the car and if we read to the good ear, all those things are really positive for unilateral hearing loss, but we do not know whether that is going to be enough to stop that percentage of kids who are going to have to repeat a year at school.

CHAIR—Is there anything that we have not asked you about that you really wanted to tell us?

Mrs Rayner—Not really. We would just like to emphasise the point that we would like parents and deaf adults to be at the table when policies are developed around decisions that are made on our and their behalf. Our deaf kids are going to grow into deaf adults.

Mrs Porter—We might have deaf grandchildren.

Mrs Rayner—That is right. That is possible.

CHAIR—No-one can tell.

Senator ADAMS—Is there any funding for installing the sound field amplification systems in classrooms? I note here that you feel that it should be funded.

Mrs Porter—The Lions Club do have some funding. There is funding within the school system for that, but it is dependent on the parent the whole time. The parent has to go to the principal. The principal has to be willing to use his funding to support this child. Sound fields benefit all children. If you were interested in Aboriginal and Torres Strait Islander children—

Senator ADAMS—I am not game to start on that, but that is the reason that I asked the question.

Mrs Porter—It benefits all children and it benefits the teacher. They call it the café effect. You are going into a reverberating room and everybody has to start shouting and then it just gets louder and louder. If you go to an environment where you can hear what people are saying, everybody else does not have to raise their voices for things to be heard.

Senator ADAMS—Do you know if there is any government funding going into that anywhere?

Mrs Porter—No. The parents that I know of who have managed to get sound fields for their children in the classroom have either funded it themselves or through the P&C. A few have got it through the Lions.

Senator ADAMS—I am specifically looking at the government, state or federal.

Mrs Rayner—They do fund sound field systems for some Aboriginal centres, but I do not know enough about that to be able to talk to you.

Something that has just suddenly occurred to me is the issue of following up the children who actually pass newborn hearing screening but then subsequently go on to develop hearing loss in those early years, so doing that follow-up screening. In New South Wales that argument has been put forward that the preschool screening is reliant on parents to use the blue book, or whatever the equivalent is in other states, which is a list of questions which parents are supposed to tick off on the child’s third and fourth birthday to see whether they are fitting into a certain category and whether or not they may or may not have a hearing loss. I do not think that is a terribly satisfactory way of finding out whether you think your child has a hearing loss or not. I think it needs to be a bit more scientific than that.

I agree with the fact that parents certainly are the best people to suspect that there might be a problem, but if you are just doing a normal tick-box screen it is not going to pick these kids up.

Mrs Porter—They just put out a paper in the US on this subject. It was published last week and it looks at kids with ongoing follow-up of children who pass screenings before they get to school. They have got a position statement over in the United States now about that.

CHAIR—We had some information yesterday about the difference between the way things can change and that after the newborn screening you can either pass or not. Even with people who pass there is a certain percentage who will develop hearing issues in the next few years. The only hope is in the states that are actually doing effective school testing.

Mrs Porter—Yes, that is right.

CHAIR—There were some concerns raised about the effectiveness of that. It all goes back to what services are available and also the role of the parent. That responsibility is consistently on the parent to be the ones stimulating the actions. It is a huge responsibility.

Mrs Rayner—As parents we want to say is, ‘Empower us. Give us all this knowledge. Do not make us dependent on everything. Empower us so that we know what to do.’

CHAIR—And where to go?

Mrs Rayner—Yes.

CHAIR—We will follow up. We will follow through with the states. We are already writing to the states to find out what they are doing. That will be another question to ask them. We have already made a note to ask them about what school testing they do. We hope to get a response back from them and we will follow up with Senator Adam's question about funding for specialised services at schools. My own experience in Queensland has always come down to whether there was a parent who was strong enough to fight the system and continue to fight. Thank you very much for your submissions and also your evidence. If there is something that you feel we need to know that you think about later, which often happens, then please contact us.

Mrs Porter—Thank you for your time; we really appreciate it.

Mrs Rayner—Thank you for the opportunity.

[2.38 pm]

WALTERS, Ms Sheena, Senior Manager, Services, Deaf Society of New South Wales

NELSON, Ms Kate Cecilia, Program Officer, Deaf Society of New South Wales, through Ms Tanya Miller and Ms Kylie Scott

CHAIR—Our next witnesses are from the Deaf Society of New South Wales. We are wanting to take a photograph for our records of us actually working effectively with interpreters. We would like to get your approval. We guarantee we will not identify you because it will be from behind, but of course the interpreters will be identified as they will be in the photo. This is just part of the ongoing process of our committee to show how we operate.

Thank you to the representatives from the Deaf Society of New South Wales.

Ms Nelson—I am a coordinator for the Auslan sign language courses and I am also involved in advocacy mostly for and on behalf of adult deaf people.

Ms Walters—I am from the Deaf Society of New South Wales; I am replacing Sharon Nann today. My role is senior manager of services.

CHAIR—Thank you. We have your submission and I would suspect that either or both of you would like to make some opening comments and then we will go into questions.

Ms Walters—I will give you a brief overview of the Deaf Society and our role. We provide services predominantly for the signing deaf community in New South Wales and we are a member of the Australian Federation of Deaf Societies, which has six state deaf societies. We are a service provider providing services from Auslan interpreting to employment services courses for deaf and hearing people and client and community services as well.

As you have probably noticed, our submission mostly focuses on access issues for deaf people and what we have found to be barriers for those people that access our services. We have set out the recommendations within our submission.

CHAIR—Ms Walters, could you tell us anything about the funding of your organisation? As it is ongoing, I would like to get it on record about how you are funded.

Ms Walters—A lot of our money comes from investments. We get some money from bequests. We have some money received from the state government, which is predominantly DADHC, and some money from the Department of Community Services as well.

CHAIR—Both at the state level?

Ms Walters—Yes.

CHAIR—Is the Deaf Society part of Deafness Forum, the national organisation?

Ms Walters—No. We are a separate organisation.

CHAIR—Ms Nelson, was there anything that you wanted to say just to start off? Are there any opening comments that you want us to be aware of?

Ms Nelson—I guess they are all related to access as Ms Walters was talking about. I will focus on education for deaf people because there are many deaf children who have difficulty accessing the curriculum, and that is usually related to a delay in language acquisition, either English or Australialn sign language. As I said, my work is mostly at the state level with the Department of Education. I would like to see clearer policy on how to actually work with those children well, because we see many deaf children who have fallen through the cracks. They are not able to access education via lip-reading and speaking oral education and they have not been able to acquire any language whatsoever—none at all. They are falling through cracks and we need someone to catch them. At this point there appears to be no service, system or clear statement on how we can make sure we can actually educate those children.

I think that there has been research that has been done that unfortunately says that generally deaf children have an education level behind that of their hearing peers.

CHAIR—Would Ms Jackson like to come and sit up here so that she can see?

Ms Jackson—That is fine.

CHAIR—It is just a bit difficult because the whole interpreting is based on us hearing what is going on. I was just a bit sensitive that you were unaware of what was going on. You can read the *Hansard*, Ms Jackson; it will all be there.

Ms Jackson—Thank you. I can also see if I can lip-read the interpreter, too, to see Ms Nelson.

CHAIR—Ms Nelson, it is clear from your background that you are focusing on the education. I will just check whether Senator Adams or Senator Williams have particular questions in the education area.

Senator ADAMS—As a child comes to a mainstream school what accommodation is given to them as to the help that they are provided with and what funding is there for a teacher’s assistant or someone like that who can support the child right from the start of their schooling?

Ms Nelson—I am not particularly familiar with the process of how the parents approach the schools and how they deal with them, but from my knowledge I believe the school actually assesses the child, makes recommendations and then from there they apply for funding. It may actually be related to the district that the school is located in and particular staff including perhaps a teacher of the deaf and as you said, a teacher’s aide, which I think are now referred to as a learning support officer. There may be a speech therapist or an auditory verbal therapist as well.

In our opinion the teacher of the deaf may be itinerant, which basically means that they are travelling between different places and they may only be available for 10 hours during the week or something, so the problem is that if the child is actually accessing school using Australian sign language and that teacher’s aide in New South Wales is not actually required to be fluent in Auslan, there is nothing that says that you have to be either at interpreter level or a particular level of fluency within the language. There is no measurement of what particular language ability that assistant should have. As I am sure has been said, 90 per cent of deaf children are born to hearing parents who do not have Auslan as a language at all and their only language model is a teacher or the specialist staff in the school. If the specialist staff they are using as a language model is not actually fluent, then that child is not going to be fluent in the language.

When teachers of the deaf study to become qualified as a teacher of the deaf they can either focus on the auditory verbal stream or the signing side of things; it is not a compulsory part. Usually my experience of teachers of the deaf who are actually fluent in Auslan is because they have a personal interest themselves and that personal experience and interest may be why they went on to become a teacher of the deaf. Learning Auslan is not necessarily a vital part of their education.

Ms Walters—I think we should use the international benchmark because I think that is quite inconsistent across Australia; other states have different models in place. That teacher training aspect is a real concern for us.

Senator ADAMS—For children out in rural and remote areas, how accessible is someone with expertise to visit those schools in the program?

Ms Nelson—Again, I think it is going to depend on the funding that is available and the hours that actually pays for. I know there are teachers of the deaf who can go out and may only visit someone out in the country in a rural area for five hours a week once a week, which is not really a lot of access.

Ms Walters—I think the service models that would be required in urban areas or where there are large populations compared to regional areas would be completely different. I think that realistically to expect that the services or the skills will be available in those areas is difficult in Australia, but certainly using technology is something that is becoming more and more prevalent and advantageous for kids out in those areas.

Senator ADAMS—Could you give us some examples of how that is being used?

Ms Walters—I think the next person that is coming to present will have more experience or knowledge around that. Professor Leigh is here. I am aware that, for example, RIDBC have started up a teleschool so services can be provided through video conferencing equipment.

Senator ADAMS—Thank you.

CHAIR—Senator Williams, do you have anything on education?

Senator WILLIAMS—No, I am fine. I am listening in. I am the one learning the most here today.

CHAIR—I have had experience with some people who have studied the Auslan language. Is that something that the society offers and are there other options for—from my understanding—

what is quite a complex study process that needs to be done? Also the assessment requires a lot of scrutiny in determining the examination? Correct me if I am wrong; there is a very high pass mark to actually get qualification with Auslan. I found it quite confronting when I heard how good you had to be to pass.

Ms Nelson—First of all I think you would probably have to separate out learning Auslan as a language and learning to become an interpreter.

CHAIR—Certainly there is a different level. I agree with that. And that is the case also for teachers. I am interested in your comment about knowledge and skills of teachers in our schools, the qualification requirement for them that you would like to see, because you have got some recommendations there, and how easily that would be achieved.

Ms Nelson—From what I know and, again, Professor Leigh will be able to clarify further if necessary—

CHAIR—We have been waiting for Professor Leigh. He has been mentioned many times.

Ms Nelson—The expectation is that they are already fluent in Auslan before they enrol in special education classes to the level of NAATI paraprofessional, which is the basic interpreter level. To become an interpreter at that level you do not have to go through an Auslan course. It may be perhaps that you come from a family who is deaf and your first language is Auslan so you have that fluency already or you have just been involved in the deaf community and learnt it along the way. There is no actual prerequisite to enrol in an Auslan course or to go through that particular Auslan course, but in general people do go through certificates II, III and IV, which is a national curriculum that is in place at this point in time, so there is assessment involved. There are subjects also.

CHAIR—Where do people do that?

Ms Nelson—Usually through the TAFE system. One of the only private providers in New South Wales is the Deaf Society of New South Wales. Usually in most states it is through TAFE providers. Other states are mostly provided up to certificate III and possibly IV level, whereas the Deaf Society is the only registered training authority that provides it up to diploma level.

CHAIR—As you would have seen in the terms of reference the teacher training courses is one of the key issues that we are considering with education. Do you know whether there is a standard expectation for the level of training of a teacher who chooses to work with people who are deaf and whether there is a certain level that they have to achieve before they can be a teacher in that area?

Ms Nelson—No, and that is why we are lobbying the Department of Education and Training for that. They might say that it would be good to have perhaps up to a certificate level III, which I suspect is not good enough because that is not fluent enough in the language and because they are teaching deaf children it is about using two languages—English or Auslan. It is not enough to be fluent in one language; you need to know how to move between the two languages because these are the two languages that the children will be accessing. I would suggest the equivalent to a level II paraprofessional interpreter qualification or fluency would probably be best.

CHAIR—We heard yesterday that people can have variations in Auslan. In my ignorance, I thought Auslan was Auslan and it did not matter where you were, but a gentleman gave evidence yesterday that said that there were quite significant differences from place to place; he used the term different accents in Auslan, which came as a huge surprise to our committee because we did not know that. He was actually talking about the need to have some consistency.

Ms Nelson—I would not say that there is a big difference. Of course there are variations. There are variations in Auslan. North and south tend to have a bit of their own dialect. I would not say that is a huge issue because deaf people from different areas can have a conversation and understand each other, so it is not a major impediment. Standardising a language is not particularly realistic because languages are dynamic and always change. You cannot legislate how people are going to use their language. There are different words in English that have different meanings and have changed meaning over time.

CHAIR—The French have tried. Are there any other areas? There are quite a few recommendations from the society in their process.

Senator ADAMS—Am I allowed to start on the Indigenous?

CHAIR—You certainly can. It was only to do with Australian Hearing that I limited your questions.

Senator ADAMS—I see that one of your recommendations is specific issues affecting the Indigenous communities and your primary area of concern is the lack of data available for deaf people who use signing in their Indigenous communities. Can you give me an idea of how much signing is used or just how these children advance or improve their education?

Ms Walters—To be honest, this is the area that we had the least amount to contribute to because we do not see a lot of Indigenous Australians accessing the Deaf Society services and I think that is common throughout Australia.

Ms Nelson—There is nothing really that I can add on that point.

CHAIR—Your second last recommendation is to investigate programs to encourage partnerships between service providers in the deafness sector and service providers in vision impairment and mental health. We have had a little bit of evidence about the mental health aspects, but you have put it in as a recommendation. Were there any particular things that led to that recommendation? It would be best practice to have that, but were there particular factors that led you to say that this needed to happen?

Ms Nelson—Again, it is related to delayed language acquisition and the social problems that occur from that particular event. It is the isolation, loneliness and the fact that there is no real bond with their family sometimes. We are generally talking about the high rates of mental illness in deaf children and deaf adults because of the problems that have gone on previously which are often related to communication access. In addition, service providers are not deaf aware so if there is a particular person who needs to access counselling or psychiatric services via an interpreter then you do need to be very careful, particularly in the process of interpreting. We need to make sure that the mental health professional is also aware of the fact that there may be issues because of their delayed language, how to also adjust to the fact that the culture that deaf people operate within is not necessarily the same as the wider community and language acquisition delays have a problem as well. I would like to have some understanding out there within the mental health providers about deaf community, culture and language.

CHAIR—Is there a willingness for that on the part of the mental health providers? Is that something they seem open to?

Ms Nelson—I think if it was offered, yes. If they were made aware that it was an issue then yes. In New South Wales, we can only think of two counsellors who are familiar with deaf culture and deaf language, and there was previously one psychiatrist. There are few choices for deaf people if they need that particular type of service or assistance.

CHAIR—The other thing in your recommendation was to do with private legal practitioners. We have heard across the board regarding concerns about access to effective legal representation and the isolation in the court processes in just getting personal support for people who have hearing issues. You mentioned particularly in New South Wales. Is there an effective system in New South Wales to ensure that there is translation and interpretation, and are people confident enough to ask for it?

Ms Walters—The area of interpreters for private legal appointments has always been unfunded and the Deaf Society has always funded that. The cost to us is about $10,000 to $20,000 per year and nationally it is about $60,000 to $80,000 per year. Deaf people ask us if they can have interpreters, but private legal practitioners are not often willing to pay for the cost of interpreting because it is $190 for one appointment and it is often a large proportion of the fee that they might be expecting from the deaf client themselves. It is a big disincentive for them to take on a deaf client. If it is not funded, essentially, then the legal practitioners will not pay for it and the deaf clients are disadvantaged, so this is why the deaf societies have been providing it over the years, and that is something that we hope that the federal Attorney-General’s Department will consider funding.

CHAIR—Have you asked them ?

Ms Walters—Yes.

CHAIR—Is it no response yet or have you received a response that is not good?

Ms Walters—No. We applied for a grant and were unsuccessful. We approached the state Attorney-General’s Department as well, but we have not had any luck there, nor with the Law Society.

CHAIR—Is it over a long period of time that you have been seeking this funding?

Ms Walters—Yes. We have been lobbying for several years.

CHAIR—We will follow up with the Attorney-General. It surprises me to an extent with legal practitioners because they have such itemised billing processes that you would think they could just whack another item in that says ‘access to interpreters’. They seem to be able to whack lots of other items in their billing.

Ms Walters—Yes, but our point is that we do not think that deaf people should have to pay for that.

CHAIR—We will follow up with the Attorney-General. I see the point. It is just with legal practitioners there is so much that is put out in their billing process, but you think that it should be a subsided service with that access provided rather than having to pay for it.

Ms Walters—Yes. It is just like access to justice for any other citizen in Australia. They can access the services without having to pay that additional cost.

CHAIR—What about in the courts themselves? This has been an issue. If someone is going through the legal process and is actually into a court appearance, is there standard access to interpreters in that process?

Ms Walters—Yes.

CHAIR—In the criminal court?

Ms Walters—Yes, but in the civil arena that is not the case. Again, that is charged.

CHAIR—With family law and all those things it would be an added expense?

Ms Walters—Interpreters are provided, but there are still improvements that can be made to ensure that appropriately qualified interpreters are put into those settings and that cases are not postponed because of availability of interpreters. That is also an issue.

CHAIR—If I was wanting to have an interpreter in New South Wales would it be done through your organisation? Would I call the society?

Ms Walters—There are several organisations that provide Auslan interpreters.

CHAIR—How many?

Ms Walters—About five, I guess. The Community Relations Commissions provide for the police and the court system. There are health care interpreter services that are funded by New South Wales Health. There is then the Deaf Society and there is also a national body that provides interpreters for private medical appointments called the National Auslan Booking and Payment Service. There are a few other private providers as well.

CHAIR—That is a challenge. Are there other questions?

Senator ADAMS—I have one more. You made a comment regarding the adoption of Auslan and where New South Wales lags behind other states in the adoption of Auslan as a language for instruction for deaf children who can benefit from it. Could you tell us what states are doing it well?

Ms Nelson—Victoria and Queensland are probably the two who are leading. Their policies and information are very clear on using Auslan, whereas New South Wales will say something about sign language but they will not use the term Auslan. It is actually very difficult to find information on whether Auslan is actually being used, whereas in Victoria and Queensland they have very clear listings of schools that use Auslan, where this is going on and how you can contact them. Queensland are now funding a block of $30 million to teach Auslan to teachers and staff that work in the school system, which is a fairly recent occurrence. There is generally more recognition of Auslan and it is actually valuable as an educational method, but in New South Wales you do not see that very much. It does not appear to be seen in that way.

Victoria also talks about interpreters. They talk about staff as people within their educational system, what their role is and what their remuneration is, whereas within New South Wales interpreters are just tucked under the realm of educational with a teacher’s aide, but that does not really recognise the skill level that they are using. There is a place for interpreters to be used in schools and if that is actually happening then there needs to be a clear job description. They do not need to just be called teacher’s aides. They need to be paid appropriately for the work that they are doing. That is the difference between New South Wales and Queensland and Victoria.

Senator ADAMS—Do the schools advertise that they provide that service so that the parents can have a choice of where their child could go to school? In WA children go to school within the area where they live, but if there was a service provided somewhere else would that child be able to then go and access the service at that other school?

Ms Nelson—I would have to say that I am not familiar with WA. In New South Wales the options are mostly that government schools will use oral programs, that is speaking and lip-reading. The only deaf school is basically the Royal Institute for Deaf and Blind Children so obviously you can tell that they are a bilingual program so they do use Auslan. As far as I am aware, there are no other government schools that will actually use that program. They might use a mix of auditory, verbal and total communication, so some signing with their speech. That is about it.

In reality, they may in fact use Auslan in the school, but they just do not label it. They do not let people know that it is actually happening, but they may have a teacher of the deaf who is using Auslan as well as the other methods that are going on in the school. It is not very clear. Nothing is really recognised as such and promoted.

Ms Walters—As Ms Nelson said, the information in New South Wales from the Department of Education themselves on which schools and what programs for deaf children is pretty hard to find. What we have found in working with the Parent Council for Deaf Education is that parents feel that when they are seeking information around options for their children, a lot of the hearing unit options are not really options because the service that is being provided is not really of a great standard. There is a big push for mainstreaming so kids are going to their local school on their own with itinerant support which is not always full time.

CHAIR—What happens if someone speaks another language altogether? You could be French or Italian and you also use Auslan. Is there a series of interpretations that needs to occur then?

Ms Nelson—We do not have any French sign language interpreters in Australia. If there was a child who was actually using another language other than Auslan or the language of Australia then they would have to learn Auslan. Deaf people are very good at learning other sign languages because they are very visual at their basis, but of course they would have to learn very quickly if they landed in Australia with Auslan signing people.

CHAIR—I am just thinking about some of the refugee situations. Some of the things that we have found are quite serious in terms of people with a whole range of issues, including the mental health stuff, and then the further isolation of having some hearing issues.

Ms Walters—For deaf adults in that situation that have come from overseas that we are servicing, we often put in place additional support called a deaf relay interpreter. Not only do you have an Auslan interpreter there but you also have an additional communication support that can assist to ensure that the communication is happening.

CHAIR—It is the layers of disadvantage that you have to work through. That is all the questions we have. If there is something that you think that we have not touched on and that you feel should actually be put into our area please contact the secretariat because often you go away and you think of something that you really should have mentioned.

Ms Walters—If I can just make one final point, one of the points in the submission also was to lift the cap from Auslan—

CHAIR—Yes, I saw that.

Ms Walters—That is one area that I believe is being reviewed at the moment by the federal government and we are hoping that that does get lifted because it certainly has a large impact on deaf people and the employment of deaf people in Australia. Access to interpreters work on an ongoing basis rather than just for the initial period from when they start work—

CHAIR—That is part of a general review of employment in disabilities that Mark Arbib and Bill Shorten are undertaking. You have put some information through about the importance of that review?

Ms Nelson—Yes.

CHAIR—So do these interpreters stop as soon as you settle in the job?

Ms Walters—Within the current funding structure there is $5,000 made available for deaf people to start work and after that point it is up to the employer, but that is not always very realistic.

CHAIR—We have had a lot of information about the Australian Hearing services ceasing when someone turns 21. Would the royal society like to make some comment on that?

Ms Walters—Just that that is a concern that people who are aged 21 to 65 do not have access to free services or subsidised services and we have a lot of clients that have problems with affordability of hearing aids—

CHAIR—I felt sure that you would have that view but I just thought I would give you the chance to put that on record as well. Thank you very much.

[3.09 pm]

LEIGH, Professor Gregory Ross, Chair, Royal Institute for Deaf and Blind Children; and Chair, Australasian Newborn Hearing Screening Committee

CHAIR—Welcome. We have your submission and also the attached statement from the Australian Newborn Hearing Screening Committee that you have sent to us as well. We are very keen to hear your opening comments. The comment earlier that we have heard your name mentioned is quite true. When you have a look at the *Hansard* you will see that a number of the witnesses have referred to your work so it is important that we hear from you directly and then we will go to questions. They will range over the whole area as well.

Prof. Leigh—I will endeavour to make brief introductory comments so that we leave time for that. But given that I am here reflecting two submissions I would like to make comments in regard to both, if I may.

CHAIR—We have plenty of time, so that is good.

Prof. Leigh—I will begin then with the Newborn Hearing Screening Committee and that submission. I think it is important to note that the Australasian Newborn Hearing Screening Committee is effectively a lobby group that has been advocating for the introduction of newborn hearing screening since 2000. From where I sit that seems like a very long time on this singular issue. Represented in that committee are key professionals in all of the areas that newborn hearing screening brings together and importantly parents and parent groups and, through them, consumer groups that are represented.

If we go back to March 2001, the Australasian Newborn Hearing Screening Committee was responsible for having generated the first consensus statement on newborn hearing screening in this country which was used as an instrument of lobbying over a long period of time to persuade governments of the benefits and value of implementing newborn hearing screening and I would like to believe that that process has been a pivotal component in the introduction of newborn hearing screening around Australia.

If we look at 2001 as a sort of dropping the flag, get-go on that whole issue, in 2001 there were no population based newborn hearing screening programs in Australia. There certainly were some targeted programs—and I could go into that later—but there were no population based programs. There were no programs that offered screening to every child born in any of the Commonwealth jurisdictions or any of the states jurisdictions.

The desideratum that was explicit in that consensus statement in 2001 was that we should have a national situation where every child born in Australia has access to having their hearing screened at birth and we have not relented in that view or in that ambition. Reflected in the submission that we made is that that desideratum will really only be fully met when we have two things. One is that we have full population coverage with newborn hearing screening across the country but, secondly, that we also have systems in place to ensure that the programs that are operating around the country can be judged to be of uniformly high quality and can in fact be judged to be actually doing what we believe that they are doing. To that end I will make a comment briefly in a moment about the need for data to support that process.

I would very much like to have on the record that the Australasian Newborn Hearing Screening Committee acknowledges the marvellous work that many state government jurisdictions have done in the implementation of newborn hearing screening. There is no question about that. Great strides have been made but—and there is always a ‘but’—we do not have full population coverage and we do not have the types of measures in place that we need to be able to judge the effectiveness and the outcomes associated with what we are doing in that regard. So we have not arrived at a point where we can claim success on all of those fronts.

Acknowledged in the submission is the fact that there are some processes underway. Certainly the development of national standards is something that our committee has been committed to. But I would like to point out if I may that in the submission senators will note that there were two maps at the back where I provided evidence on our understanding of coverage in this country. I would just like to point out that those figures are not derived from any official records because quite simply there are not any. So those figures are derived from the committee’s rather assiduous efforts in tracking and monitoring what is going on around the country and the contributions of our members of the committee who are in key roles around the country.

I stand by them as a reasonably accurate reflection of the state of play but the fact is that we could not produce an official report like that because we do not have a national data collection system that allows something as simple as that to happen, much less the more important process of tracking children to make sure that there is no falling between the cracks. Perhaps later I will have the opportunity to elaborate on what we might call the handshaking process between different levels of government and different service providers to make sure that what is well begun is not just half done but what is well begun really carries through to the outcomes that we are all looking for. If nothing else in what I say this afternoon or in what I submit gains traction I would hope that it is the issue of the plea to ensure that we have a better system for national data collection and management in regard to the important process of newborn hearing screening.

If I move very briefly to opening comments about our RIDBC’s submission, I think it would be fair to say that these two things are not unrelated. The fact that I happen to chair a research centre and professional education centre that is located within and operates through the aegis of RIDBC and the University of Newcastle I will put to one side; RIDBC and newborn hearing screening are two parts of the same process. The Royal Institute for Deaf and Blind Children is the country’s largest—indeed it is the oldest—provider of services to deaf and hearing impaired children. I am sorry, it is the country’s largest independent provider of those services and oldest provider full stop.

I could elaborate on many parts of the submission that I have made in regard to RIDBC but I think one of the things I would like to point out before we start is that the organisation brings to this topic a great depth and breadth of perspective reflecting the situation that exists currently which I am sure senators will have heard about over the last two days is that we are at a point in history where deaf and hearing impaired children have greater opportunities to achieve spoken language outcomes and associated outcomes than at any other point in our history. Reflecting that, the Royal Institute for Deaf and Blind Children’s primary client base is now children who are pursuing auditory oral options. But—and this is a significant ‘but’ that I would like to make one brief comment about before we go to questions—there is no question that we have this wonderful opportunity because of the advent of things like newborn hearing screening, cochlear implantation and associated techniques for habilitation and intervention. Without doubt the expectation should be that that will be the outcome for the vast majority of children. But there is also no doubt that although the intervention techniques are in place for the vast majority of those children, we also need alternatives for some children.

I would argue that it is critical that we recognise that deaf and hearing impaired children have never been, ever, a homogenous group and I would like to stress that the need to have a variety of different inputs to achieve outcomes for different children is not something that should be looked on as a matter of somehow catering to whim on the part of people. It is a consequence of the characteristics of the population that we are talking about that there can be no 'one-size-fits-all' approach to the intervention and ultimate education of children who are deaf and hearing impaired.

You only need to look at the studies on outcomes for children, even with the very best of interventions, to know that variability of outcome is something that is a characteristic and will continue to be so, ergo variation in input and diversity in opportunities and strategies for working with this population really do need to reflect that. It is against that backdrop that I would argue—perhaps I will leave it there—that we cannot and should not be looking at something that argues for a one-size-fits-all approach and you only do something different if that does not work. That is not a strategy that I could endorse or would in any way seek to perpetuate. I could go on at length about that but I think I will leave it there and acknowledge from RIDBC's perspective some credibility in talking on that particular issue.

CHAIR—Do you think that there is any hint that that is a government position?

Prof. Leigh—A one size fits all? No, I do not but I do believe because of this wonderful situation we find ourselves in that there is a tendency for some who are in bureaucratic management situations to think that an issue has been solved and that the need for some of the alternatives has diminished entirely rather than just being smaller in number. I think the evidence given earlier goes to this point: in a way, the extent to which we assiduously direct our efforts to any particular need should not be lessened by the fact that the numbers of children who require that alternative approach are suddenly smaller numerically. If that were the case we would not be where we are in the field of hearing impairment because relative to so many other fields it is a low incidence condition. We need to maintain a perspective over this that gives credence to and acknowledges the importance to maintain a diversity of responses. And, for someone working in the university you would expect me to say this of course, with high levels or preparation for each of those different types of approaches to make sure that the outcomes are good regardless of what the input needs are for particular children.

Senator ADAMS—Would you like to enlighten us a little bit more on the teleschool program that you have got? I have just got a paragraph on it but, coming from a rural and remote background, I am very interested just to see how it works.

Prof. Leigh—I will stress again that the RIDBC is a large and multifaceted organisation so it is another part of the organisation that is not directly under my responsibility but of which the organisation is certainly very proud. Teleschool operates on the premise that children need good access, particularly at the early intervention level, to quality intervention regardless of where they happen to be. The model is one that pairs high quality therapeutic and educational intervention based in Sydney with families wherever they may happen to be geographically located through one of a number of different technologies. The organisation has now pioneered the use of ISDN based point to point technologies, internet based protocols, that has a large number of families now with video conferencing equipment installed in their homes, cellular network based video conferencing technology and satellite technology that has over 150 children now in various rural, typically remote areas of Australia receiving regular typically weekly or fortnightly early intervention that is analogous to the early intervention they would receive were they in Sydney through that mechanism. It has been very, very successful. Matched with the fact that the organisation provides for those families to visit Sydney at least once a year, that means that the quality of intervention that those families are receiving has really been brought up to a level much, much more similar, if not arguably in some cases better than their city based counterparts.

Senator ADAMS—You did say all across Australia, but is that mainly New South Wales?

Prof. Leigh—It is predominantly in New South Wales but that is historical because the program started in New South Wales. My colleagues in teleschool would admonish me for not knowing exactly what the split is, but if we were to have a map here the next most densely indicated area of the country is Queensland, but there are children on the teleschool program in every state and indeed internationally in a couple of cases because of an arrangement with the Sydney Cochlear Implant Centre to assist.

Senator ADAMS—Another area was of course access for these children or their families to come in to see specialists for their early intervention and the fact that the patient assisted travel scheme does not cover audiology. Could you comment on that?

Prof. Leigh—Only to reinforce what you have just said. In this state the isolated patients transport assistance scheme, TAS—I think I have the acronym correct—is something that we know to exist and so we try to work synergistically with it. So if a family is coming for another purpose we will make that the time that the family makes their annual or biannual visit, whatever the case may be, to RIDBC. We have accommodation on site expressly for parents to be able to come and stay. We try to join all those dots up but there is no other assistance; you are quite right. It really has to be medically related and we get to piggyback on that rather than use it directly.

Senator ADAMS—Have you made any approach to the government seeing that it is a state based funded service to have audiology issues included within that scheme?

Prof. Leigh—I have certainly drawn it to the attention of successive ministers over time but I am not aware—again it is a different part of the organisation—of express submissions on that front. But I am happy to follow that up and make that known.

Senator ADAMS—It would be good if you could do that. I come from Western Australia so I am a bit horrified looking at the map at the back—

CHAIR—There is a big increase for 2008.

Senator WILLIAMS—There are big wins in New South Wales.

CHAIR—We will expect a speech on it then.

Senator ADAMS—Are you able to comment on just why Western Australia is so far behind in that? Usually we are fairly up with most of our health associated issues but this one is a bit disastrous.

Prof. Leigh—There is a particular irony in the fact that Western Australia is somewhat dragging the chain on this because the first one I mentioned in 2001 that there were no population-based newborn hearing screening programs, there was in fact a trial project. The first trial project of universal screening of all children in one hospital, or in one area, was indeed in Western Australia.

Senator ADAMS—I was just looking at the people on the committee with Associate Professor Harvey Coates and I am thinking how is this happening when he was so passionate.

Prof. Leigh—And he remains passionate. The only thing I can point to—and I believe this to be the case—is that the early outcomes from that project reflected a rate of identification that was below the international expectation for identification and the people that needed to be convinced that therefore it was a worthwhile strategy for identifying children at a very early age were not convinced that the investment was better than what is called targeted screening where you identify children with risk factors and only screen those children. What we now know is that the numbers during that screening for that trial period were anomalous, as can occur whenever you have small numbers. The state of New South Wales is a great example. We have had screening in place now since December 2002 and if you look at any six month or 12 month period and say, ‘What is the rate of identification of children with a hearing impairment?’, you will get a figure that looks below or above what you would expect to have.

If you look at the nine years we are sitting right on 1.15 per 1,000, which is exactly where you would expect to be. So the notion in the Western Australian program where you can look at a very small window of time and say, ‘Clearly this is not doing the job’, in my view was an incorrect conclusion, one which is now recognised as such and the state is moving towards a system. There is not enough time this afternoon to go into this but one of the issues I think in all of this is that what we now have are some very different looking systems in each of the states. That is not to say that is not a good thing in some cases because states have different issues. Remoteness in Western Australia is a significant issue, as it is in Queensland and New South Wales. But the funding mechanisms in the different states really do mean considerable differences exist.

I noticed before you were talking about asking questions of the states; the actual expenditure on these issue from our understanding is quite dramatically different on a per capita basis between the different states. As a consequence the programs take on quite different looks. The Queensland program for example has funding which extends well beyond the screening period to provide for family support and counselling. In other states that is not provided. The way in which the screening happens is funded differently in different states so that it ends up being in some cases tagged onto the end of midwives expectations as opposed to having dedicated screeners in some states. These are issues that we are really hoping to get to a little bit with the development of national standards, but standards only go so far because ultimately whatever is decided has to be funded. So the objective of newborn hearing screening by 1 January 2011 for every child is one that we are absolutely committed to and share but there do need to be some other issues ironed out around that.

Senator ADAMS—I have just been doing some work on the foetal alcohol syndrome and nowadays with a lot of women unfortunately consuming alcohol and having problems with drugs as well, is there any impairment as far as the hearing goes with the foetus? Is there any correlation to that in the research that is being done?

Prof. Leigh—I would indicate quite clearly that I am not a medical professional, but there is some association with foetal alcohol syndrome and hearing impairment but I could not speak to nature or incidence—certainly not incidence—of that. But, yes, the range of possibilities is broad and it does potentially include hearing and vision and cognitive impairments.

Senator WILLIAMS—Could I take you back to the newborn screening. I am ignorant on it, I am sorry, but where is it currently carried out in New South Wales? Is it at the hospitals, by the midwife or the community health centres? It is carried out at the hospitals; is that correct?

Prof. Leigh—It is indeed. This is where the devolution of the system comes into yet another level, it differs by area of health servicing in New South Wales. So some area health services will have an entirely dedicated team of screeners and in some cases it will become part of other professional category’s responsibilities. The good news in New South Wales—and I think New South Wales can be reasonably proud of this—I am not aware of a constituency anywhere else in the world that has gotten up to speed on population coverage quite as quickly as New South Wales. The problem is that we still do not have in New South Wales a really good collection of data around that. So, yes, we all believe that is exactly what is happening and I am absolutely confident that we are getting internationally very, very strong rates of follow-up. Kids are not being lost to follow-up, at least as far as having their hearing loss diagnosed through diagnostic audiology, but what is happening after that both in this jurisdiction and others around the country we really do not know because we do not track children beyond that.

Senator WILLIAMS—Is a screening test expensive? Do you use electronic machinery? Do you send noises to the baby to gauge a reaction? How does it actually work? I can tell you how to shear a sheep but I cannot tell you about a hearing test, I am sorry.

Prof. Leigh—There are two strategies that are used within Australia at the moment. We are down now to only one state using the second, so I will speak about the first because it is far and away the majority situation. It involves a test called automated auditory brainstem response. So the auditory brainstem will respond to the presence of sound with a characteristic—

Senator WILLIAMS—A two or three day-old baby?

Prof. Leigh—Absolutely.

Senator WILLIAMS—Continue.

Prof. Leigh—characteristic mineral pattern, a pattern like you would know from having seen an electroencephalograph type reading. There is a characteristic wave associated with reception of an auditory signal. The test is very simple. The child must be restful—sleeping—and will have an electrode typically put in two points, just adhered to their skin, and the sound will be fed to the child through a small coupler over their ear, right and left, and the process is entirely automated so it does not require high levels of skill on the part of the practitioner. The cost is entirely in the staff time associated with that and a small cost associated with the expenditure—

Senator WILLIAMS—Is the machine expensive?

Prof. Leigh—It depends on the type but, at a guess, tens of thousands of dollars.

Senator WILLIAMS—Ten thousand dollars, $12,000, $15,000?

Prof. Leigh—Closer to $50,000.

Senator WILLIAMS—The point I make with these questions is that in this day and age you would question why every baby born is not being tested in Australia, wouldn’t you?

Prof. Leigh—I would question that, yes.

Senator WILLIAMS—If it is that simple and the resident nurse can carry this out during a brief stay in hospital these days, of course. When ladies have babies these days they do not stay in hospital very long. When you and I were born they probably stayed there for 10 days but they are different circumstances now. I am just sort of asking myself why is this not being done to all babies. The clear message the committee has been given yesterday and today is that where there are problems, as soon as they are diagnosed, early intervention is essential and here in many areas you have the rough figures for Western Australia and Victoria especially, where the test is simply not being carried out, I find that quite amazing.

Prof. Leigh—It is amazing. I will come back to the Western Australian situation. We are yet to see officially what the response is to the target deadline of 1 January 2011. In the case of Victoria, to be fair, although over what seems like an eternity, they do have a strategy for rolling out the program in place so we do have targets known for Victoria. But the fact that for some years now we have had a difference where kids in metropolitan hospitals in Melbourne have been screened for a long time but kids in rural Victoria have not been I find frankly absolutely amazing, if not indefensible.

CHAIR—Which state is doing it differently?

Prof. Leigh—South Australia. South Australia uses a different technique which again is an automated technique using something called otoacoustic emissions. The hair cells in the inner ear actually produce an emission in response to being stimulated by sound and that technique measures that emission. It is a different test technique. The United Kingdom uses that entirely. We predominantly use auditory brainstem response and I would endorse that as being the preferred technique.

Senator WILLIAMS—Things have changed remarkably in the last 10 years for example. We used to have little country hospitals that would have obstetrics units. Of course births are not carried out in those little hospitals now; they are mainly done in a bigger town with the large population, which is all the more reason why they require fewer machines because you are actually having the babies born in a central area instead of scattered around smaller communities as it used to be for decades and decades.

Prof. Leigh—Indeed. I would be happy to advise the committee officially of the cost of this equipment but there are portable versions of this equipment, so in rural areas it is a very simple thing for someone who needs to be seen outside of the hospital system to have the machine taken to the child. So there are strategies. The difficult part of getting a system right is not the actual screening at the hospital, although that must be done correctly. The difficult part are all the things we are now talking about: making sure that follow-up is pursued and that all of the handshakes with all the correct agencies are really happening and kids are really getting to where they need to be.

Senator WILLIAMS—And, as with home births, to see that the baby is tested shortly after, of course.

Prof. Leigh—Indeed. Again, some states have higher demands in that regard. Home births in general are a very, very low incidence phenomenon in Australia, but states like Queensland and Western Australia where there are remote birthing hospitals they do have their own issues which are being dealt with very well in Queensland, I would have to say. That is where the difficulties in setting up a good system start to come in, to make sure that all of those i’s are dotted and t’s are crossed.

CHAIR—How much progress is your committee making on trying to get conformity and effective data collection?

Prof. Leigh—I will put the data collection to one side. The issue of conformity is being addressed, and we are delighted by this, through the AHMAC through a subcommittee called the Australian Population Health Development Principal Committee, which I think is one of the four principle committees under the health minister’s advisory council. It has through its screening subcommittee convened a working party to address the task of producing standards for newborn hearing screening. I am delighted to say that I think either by ex-officio or by invitation there are two members of that working party by invitation from the Australasian Newborn Hearing Screening Committee, but there are three other of our members ex-officioed from other roles on that committee. We are working on it. We are at the point where a set of draft standards is just about to be produced, but those standards very much relate to the screening process. How far they will go in terms of dictating all of these other things, including data management, is yet to be seen. The issue of data management is yet to be addressed. The committee’s recommendation that there be strong endorsement of that to be pursued as an issue is something that I very much hope might come from this process.

CHAIR—I think at just about every AHMAC there is a recommendation about data collection. It is about moving it forward so it gets there. It is so eminently obvious that is how it should work.

Prof. Leigh—On that, every child whom we are talking about will present to Australian Hearing. We are unique in the world. We have this organisation that provides a service to all children. Those kids once presented to Australian Hearing will find their way onto their database. The notion that we should find it difficult to create databases that can join those dots up seems to me to be totally illogical.

CHAIR—Is the Newborn Hearing Screening Committee funded by the federal government or do you just come together as a matter of passion?

Prof. Leigh—Since 2001 we have been a group of volunteers. We meet typically on a Thursday night by teleconference—though not every Thursday night—and have done for all of that period of time.

CHAIR—You have actually over a period of time that may seem glacial but is actually quite fast in government terms to achieve what you have now. That is admirable, so we will just have to make sure we support it and move it forward as much as we can. I would like to go back to the RIDBC. Professor, how is your institute funded? I am asking that of all organisations because of the convoluted methods of funding in this country and because of the reliance on donation, which is becoming more and more difficult to obtain. This is a longstanding institute, since1860, I think.

Prof. Leigh—This month next year it will be 150 years.

CHAIR—There are some splendid photo opportunities in that I would imagine. It is such a longstanding institute of such high repute, how do you continue to fund the work that you do?

Prof. Leigh—Predominantly through the generosity of supporters, far and away. I should have researched this. My colleague the chief executive—

CHAIR—If you want to take that on notice and get your chief executive who would have all of that stuff at his or her fingertips—

Prof. Leigh—I will be happy to provide a copy of the annual report but very briefly, roughly speaking, almost half of everything that we have as an operating budget comes from the support of donors and supporters. About another close to a quarter comes from investment income and what is left, around a quarter, is from government subsidy.

CHAIR—State and federal?

Prof. Leigh—Yes.

CHAIR—Do you have a board?

Prof. Leigh—We do indeed.

CHAIR—My understanding is that board has been diligent in promoting the organisation and is very high profile in many ways.

Prof. Leigh—It is indeed. We have been very fortunate over the years to have again an entirely volunteer board who do great work.

CHAIR—As we have heard from a number of organisations the task is getting tougher with the financial situation. I think one of the organisations told us it was 30 per cent down. I do not want to verbal—but I think it was about 30 per cent down on their standard donor base.

Prof. Leigh—When I provide the accurate figures you will see just by that breakdown I just spoke about having a reliance on a proportion of investment incomes as we do—

CHAIR—That has been affected as well.

Prof. Leigh—the last two years have been very, very difficult, yes.

CHAIR—The bulk of your submission has been focused quite rightly on education because that is the work of the organisation. I am interested in your recommendations about training for people who are working in the field. I take it that the statements you have made on pages 10 and 11 of your submission are not what is occurring, they are what you would believe should occur.

Prof. Leigh—Indeed. If I might, there are two things I would like to draw out of that. I was not sure about the extent to which it was proper and appropriate to take this committee’s work into the school education level of dealing with hearing impairment and deafness. But you asked a question earlier about the perceptions of bureaucracies as to how things are going. One of the things that we do struggle with—and the two presenters before me alluded to this as well—is that when some aspects are going really well and there are new technologies which really do arrive at wonderful new outcomes it is fairly easy to conclude that everything else is going well and therefore the need for specialist input and preparation for those people who are providing that specialist input is somehow lessened. Nothing could be further from the truth.

There certainly will be kids for whom the amount of specialised input will diminish over time. But achieving the status of not needing that specialist input—if that is not a too tortured way to say that—really does rely on highly skilled professional input and really good support for families in assisting them to achieve those outcomes. Against that backdrop we have seen a diminution in commitment, particularly at state government level, to the training and deployment, more importantly, of specialised staff in the area of deafness and hearing impairment. I have put some figures in the submission about the differences between expectations for preparation at a university level between this country and two other key constituencies; that is a problem. It is not because we do not want to provide that training but if you do not have the people to populate those programs and they do not have support to be able to undertake those sorts of levels of training, you are in a cleft stick. So the issue does need to be addressed.

We are enormously proud of the fact that through the collaboration with the University of Newcastle we have produced the number of graduates we have in recent years. If it were not for that there would be one university program in the country still working in this area—

CHAIR—Which is?

Prof. Leigh—The University of Melbourne.

CHAIR—Melbourne have been doing it for a long time, so now the two institutions of which you are aware that have specialist training programs are Newcastle and Melbourne.

Prof. Leigh—That is correct. Griffith University in Brisbane until quite recently had a program, but there is a question mark around that at the moment.

CHAIR—Yes, that question mark is very large. I have been questioning that question mark. In terms of encouraging people into the field, is there a difficulty in getting people who want to come and work in this specialised field of education?

Prof. Leigh—Yes and no. There is certainly no difficulty in attracting people's interest to it but sustaining that interest by identifying for them what the career pathway is, what the remuneration for that will be—and I do not mean that they are seeking additional remuneration—for them to stand aside from the workforce long enough to get the qualification, et cetera—

CHAIR—Which is extensive, yes.

Prof. Leigh—Those issues are problematic. If I had to point to one issue that I think is really problematic it is that everything that we have been talking about, the advent of newborn screening, the sort of learning curve that Senator Williams was talking about, adds a dimension of complexity to the role of working in this field that did not exist 10 years ago. We are suddenly asking people to know more about more things than we ever have before but at the same time we have got some government assistance saying, 'We do not need as many of these people and what we do need is only a little bit of support here or there', whereas those people providing that support really could be called upon to know a lot of issues across a very broad range.

We really do need to be providing for specialist intervention, so it is not less training, it is more dedicated and specialised training that means that teachers that the two representatives from the deaf society were talking about to work with kids who have those needs need to be specialised and provided with those skills. The teachers that we are going to have working with kids who are newly implanted need skills in auditory verbal, auditory oral intervention to make sure that we capitalise on all of those outcomes. We have started a graduate certificate program in that area to build on that but again you have to make it attractive to people. They want the knowledge but we need to make the system attractive. At the moment it is a full-fee-paying post-graduate degree program. Even if we had some system where we could offer a HECS exemption or that sort of thing to attract people into it would lighten the load on the people who we really want to see being more effectively trained.

CHAIR—One of the issues that has come up in some evidence and also in a couple of the submissions has been the heavy load on students who actually have hearing issues and the need for very serious specialist support for them as they are working through what for anyone is a difficult road to get through the expectations of any higher education location. But when you actually have further difficulties with the ability to just interact in the system and to hear, from what I have seen at the universities that I have worked with they have special support areas for all kinds of students with needs but I am not aware of any that have a specialist support program for students who have hearing issues. Are you aware of any that have that?

Prof. Leigh—Some universities are very, very good across the board and because they are good across the board that means that they will enlist the specialist services that any student with a disability needs. Griffith University in Brisbane has had a very proud history of providing dedicated services for deaf and hearing impaired students—

CHAIR—There is a question there.

Prof. Leigh—I am aware of that as well. At their zenith certainly that program was one that extended across all of the metropolitan universities in Brisbane with the services based—

CHAIR—Which started with Griffith, yes.

Prof. Leigh—And that is to be applauded. But you are quite right, a student first footing it to any institution in the country really does have a hard row to hoe to assemble the necessary support.

CHAIR—And to work through all the different issues. I do not think there is anything else because your submission is quite detailed.

Senator ADAMS—I want to deal with the adequacy of support services for Indigenous children with hearing impairment. You are saying here that despite considerable effort you are having real problems with that but there have been a few successes. Could you just expand on that?

Prof. Leigh—Yes, indeed. I think if there is a point to that whole area of the submission it is that we should be capitalising on where the successes are and seeking to replicate those. It is really a plea to say: can we as a basis for funding new initiatives look at where the successes are and analyse what those outcomes are? We talk particularly about a program that again speaks to the diversity of RIDBC, a program that RIDBC has had going with the greater metropolitan health service and the DET in the Southern Highlands area which has been a particularly successful intervention. There are elements of that that could be replicated elsewhere. I am not saying that is the only way to do it; but there are pockets of success, as you point out, that really need to be built upon rather than—

Senator ADAMS—This is always frustrating, especially with funded programs, that you will have a program in a rural or remote area that goes for three years that is highly successful but, because there is no recurrent funding available for it, or under the guidelines it cannot be re-funded, you lose the expertise of the people running the program and the enthusiasm of the students who are coming with it. These are the things that somehow we have got to be able to look at, especially in this particular area with things that have been successful. Once again, I am just noticing here with the sound and the interaction of sound systems that they are really working and something like that just should be funded and more and more of it. Our other committee has actually seen it in action and it is certainly is very, very good.

Prof. Leigh—Joined up with the sorts of things that I mentioned there, put in concert with each other you really can kick some goals on this issue. It is obvious, I think.

CHAIR—Are you aware what the policies are about those special enhancements in school rooms? We had a discussion with one of the previous witnesses about that and we just were not sure whether it is stimulated by the school or by a parent going to the school and whether it is a standard expectation that when you have students who have hearing issues that the schools provide that or whether it is more detailed. In the work that you do are you aware what the policies are across the states?

Prof. Leigh—I am certainly not aware of it being a standard response anywhere. I am aware of the fact that in South Australia there is some good advocacy and implementation work being done for kids in Indigenous communities.

CHAIR—The APY Lands is where we saw it. It was just the difference in six months of it being there, they could trace it. It was phenomenal actually, the difference in six months.

Prof. Leigh—And again, there are some good local initiatives in Queensland, but at a state level I am not aware of policy—

CHAIR—We will be asking the states about that. I was just wondering the kind of work that you do in education because even in your submission it just point to the immediacy of the response. It is not something that takes a long review process; it just works.

Prof. Leigh—If you had to pick a winner that is one that you would—

CHAIR—Is it very expensive?

Prof. Leigh—In the grand scheme of things, no.

CHAIR—That is true.

Prof. Leigh—I do not know whether it is appropriate or not but one of the nice aspects about an organisation like RIDBC is that it does cover so many of the different forms of intervention and so many of the—

CHAIR—Sure, yes.

Prof. Leigh—You mentioned visiting a school to look at that, so if the opportunity were to present itself to come and see a range of programs in action which offered the opportunity to see a lot of things cheek by jowl in a one-stop look—

CHAIR—We are actually looking at the opportunity to do some of those visits because it is one thing to sit in a room like this and talk theoretically and another thing to see it. We have committed to doing some. Senator Siewert is the chair of this committee and we will definitely be talking with her about that when we can. But it just seems to be such an important aspect of seeing what is actually occurring in the process.

One of the other things that came up in evidence was that the introduction of the newborn screening does show in early intervention that children need to be monitored consistently after that because it is not a one-off test. You really have to keep close monitoring on each individual child. There was discussion yesterday a little bit around the issue of school testing and some concern that perhaps the priority of school testing was not being maintained in some states and also keeping the data effective. The issue of the testing at preschool so as you enter the school years you know where you stand and through that. Is that something that the RIDBC looks at?

Prof. Leigh—Absolutely. I mentioned a figure before of we would expect to identify through newborn hearing screening about 1.1, 1.2 children per 1,000 children born with a significant hearing impairment. If you look at the data on children in this country who are receiving intervention from Australian Hearing, meaning that they have been fitted with a hearing aid, with newborn hearing screening we are talking only about having identified about one-third of the children who ultimately will be in receipt of those sorts of services. When you look at that data graphically the next spike in identification is around the time of school entry. That does not mean that all of a sudden kids become hearing impaired at the time of school entry. What it means is that that is the next logical time that this tends to be identified and it means we have left it too late for a number of kids who have acquired hearing loss between the time that they were screened at birth and that period of time. So something more systematic that seeks to identify those children is something that we have not made a specific recommendation about because I think there are different perspectives.

Western Australia still has a preschool hearing screen, a very good one. There would be different state views about that, but knowledge is the base of wisdom. If we can get information from all of the states about that and encourage the view that there should be a systematic approach, if not state based then federally, it is certainly something we would endorse and encourage to happen.

CHAIR—The view was raised yesterday, as I think your earlier comments were around the hope by many governments that they had found the silver bullet—I am verballing you, but that kind of thing. There was a view expressed that with the introduction of the newborn screening perhaps some people had thought that then there is not quite so much need for any other aspects of screening and there was a concern raised that everything would be put into the first one; it was your one chance and then funding would be withdrawn from other elements and it was a deep concern of the witness that did not occur on exactly the same basis as you have pointed out.

Prof. Leigh—That is a very reasonable concern.

CHAIR—I think in terms of questions for this afternoon you may have worn us out. There could well be other things and certainly you may think of other things that we need to ask. Actually, there was one thing. It came from this afternoon. Witnesses had said that one of the things they had personally experienced was the first round test produced a result and then down the track it was seen that the result was different, that there had been maybe not an error, but in fact the loss of hearing was not as great as indicated in the early test. Are you aware of any indication of the accuracy rate of the rounds of testing? It is an indication only in terms of parents having to make decisions about what they and their family will do in the raising of their child. There are different offers made for the future for people depending on the rating that they do originally get. Is there any indication about how accurate the first round of testing is and whether there is a standard time for when people should have a re-test when they are making decisions about hearing aids, implantation or whatever?

Prof. Leigh—Sure. The accuracy of the test is very high. I certainly could quote some statistics around that. The issue however, or an issue, is what is actually being tested. There was evidence given earlier about unilateral hearing loss. One of the reasons that we are very keen to see that included as a protocol for assessment is that there is evidence of some of those children progressing from a unilateral loss to a bilateral loss. Equally there is evidence of children's hearing losses of other descriptions that may have been identified through newborn hearing screening progressing to change the nature in nature which may include some changes in severity in either direction.

Once identified through newborn hearing screening and once established in an intervention system, particularly if the child is a candidate for a cochlear implant or whatever, there will be routine re-evaluation of their hearing status. But if the point that was being made is one that: is it possible to make judgements too soon about those things, in a very small proportion of children it is a possibility. There can be some resolution associated with some particular conditions. It is not common but it is possible, so routine monitoring is important. There is no question about that.

CHAIR—Already there has been some variation of opinion about how quickly people should act. We had evidence yesterday which was that there was a desire that people take action as quickly as possible to have the child able to experience ranges of experience that they would not have had if they had not taken action. You may have been in the room today when we heard evidence from some parents about the need to have a window of opportunity in which they can settle and think about things and actually look at options before they take any actual action. It is unsurprising in any area that you would have such a range of opinion. But even in the two days there have been quite different approaches to a joint concern for what is best for the child, so it comes back to the need to have appropriate advice I would think.

Prof. Leigh—I was just about to say I think ultimately what is key there is information. That really does mean assembling all of the people who have the right input at the family's discretion to make sure that all of that is there. If families decide to act more quickly on particular types of intervention then it is in the consequence of an informed consent to that. It goes back to my initial comment about one size not fitting everybody. There really does need to be an approach that hastens slowly on the basis of good information so everybody gets the opportunity to breathe in that process, to take the information in and act in accordance with it.

The reality is that the vast majority of people will choose to move quickly and will choose to move with particular types of intervention, but that is not everybody. There really does need to be some diversity in that response.

CHAIR—We had evidence today about a care coordinator position that is working in Colorado—and maybe other places but we heard about the Colorado experience—and a desire that something of a similar nature would be able to be implemented in Australia. Do you have any knowledge of that and whether that program of having this care coordinator, which I believe operates from the time of the test and the diagnosis to when the child starts school, that there is a person people can turn to? Is that a model that you have considered?

Prof. Leigh—Yes, indeed. In the Australian context the closest is not exactly the same. The closest we have to that is the system in Queensland that does appoint a family support worker to work with the families. I think the evidence is reasonably straightforward around that. The need for support for families through that information processing stage and dealing with decision making is very important. It does tend to get reduced in some people's perspectives to making decisions about whether I am going to use sign communication, or use something else. It really is not about things as raw as that sort of level of decision. It is about having the support that is necessary to come to terms with the situation, to process the information, to have somebody who is there for the family to assist them in where they need to go for that information with even something as simple as getting to the next appointment and all of those things that really do need care and support that we do not do as well and we certainly do not do consistently across the state programs in Australia. There is everything from the Queensland model through to: there is a social worker available if you think you might need to talk to them.

CHAIR—Take a number.

Prof. Leigh—Yes.

CHAIR—We can all get some information from the internet or somewhere about the Colorado model. Given the way that is presented have you given any thought to where that would best operate because the system as I understand it now is that the testing process is done in a hospital setting; that information is provided to the family that they may need to follow up; they go to an audiologist and then Australian Hearing steps in but it would seem to me that Australian Hearing is absolutely wonderful for the work they do—everyone talks about that—but it may not be the best location for this kind of care coordinator position because it would be too linked to the treatment. If our recommendation was to have a look at a care coordinator, how do you think that would work?

Prof. Leigh—I think even the people of Australian Hearing would say that that is too far down the process for that position to have clipped in. There are two different possibilities. One is to join families up with such and such a support person at the time of what is called referral. The other possibility is to join them up at the time of diagnosis. My inclination would be earlier rather than later, which is the way the Colorado model works. The principal promoter, or the person who has certainly written the most about the Colorado model, is Professor Christine Yoshinaga-Itano.

CHAIR—She is the woman who was here yesterday. We will have to chase her up.

Prof. Leigh—She spent the first six months of this year on sabbatical with us at the Renwick Centre and is currently on sabbatical for the second half of this year at the University of Auckland, so I am happy to provide the contacts and information for her.

CHAIR—That would be very useful. That model has been now mentioned by about four different witnesses, so it is obviously one that is fresh in people's minds.

Prof. Leigh—Colorado was a pioneer in newborn hearing screening and the model is one that we can look at because relative to some other US states it is of a similar size to Australian states so it does have some relevance in terms of population.

CHAIR—Is there anything that you wanted to get on record that we have not given you the opportunity to do so?

Prof. Leigh—I do not think so. There is a lot more I could say. I would be very happy to respond to any other questions to me or my colleagues. Thank you for your time.

Committee adjourned at 4.08 pm