EDUCATION AND HEALTH STANDING COMMITTEE

INQUIRY INTO GENERAL HEALTH SCREENING OF CHILDREN AT PRE-PRIMARY AND PRIMARY SCHOOL LEVEL

TRANSCRIPT OF EVIDENCE TAKEN
AT PERTH
WEDNESDAY, 6 AUGUST 2008

SESSION ONE

Members

Mr T.G. Stephens (Chairman)
Mr J.H.D. Day
Mr P. Papalia
Mr T.K. Waldron
Mr M.P. Whitely

Hearing commenced at 9.23 am

COATES, ASSOCIATE PROFESSOR HARVEY
Paediatric Otolaryngologist,
Princess Margaret Hospital for Children; University of Western Australia;
Universal Newborn Hearing Screening Committee,
examined:

The CHAIRMAN: Welcome, Professor Coates. Thank you very much for being available today. I am sorry for the delay. Thank you for your letters to the committee. At the moment we will not do anything more than just ask you these standard questions. The committee hearing is a proceeding of Parliament and warrants the same respects that proceedings in the house itself demand. Even though you are not required to give evidence on oath, any deliberate misleading of the committee may be regarded as contempt of Parliament. I am required to ask you the following three questions, to which I need an audible answer for Hansard. Have you completed the "Details of Witness" form?

Prof Coates: I have.

The CHAIRMAN: Do you understand the notes attached to it?

Prof Coates: I do.

The CHAIRMAN: Did you receive and read an information for witnesses briefing sheet regarding giving evidence before parliamentary committees?

Prof Coates: I did.

The CHAIRMAN: We will try to be as expeditious as we can with your time, and now we have other witnesses banked up. We have given you a set of questions to try to guide us through, but please feel free to take the committee to an opening statement and then deal with the questions as you wish. It is over to you.

Prof Coates: Thank you very much. I will not have a long opening statement. I just would like to state that I have a passion for newborn hearing screening and for screening of hearing issues in general in children. Another passion is Indigenous children's ear health. It has been said that if an Indigenous child is born with a hearing loss, they will undergo a spiral of despair—John Ah Kit from the Northern Territory stated this—whereby they are undernourished before birth and they are deaf in their school years, and then they go through the further spiral whereby they have educational and vocational impacts, and then may in fact end up in clashes with the judiciary and the law. Therefore, the importance of hearing in childhood is critical. Recently—about 10 days ago—the Medical Services Advisory Committee published a report on universal newborn hearing screening programs. This was an advisory group selected by the Medical Services Advisory Committee in 2003—so some five years ago—chaired by Professor Bryant Stokes, who is a prominent Western Australian neurosurgeon, and had educators and other interested scientists, including me, on that committee. It has come down strongly on the side of going ahead with a national universal newborn hearing screening program.

The CHAIRMAN: Do you want to tackle any of the questions now?

Prof Coates: I do. May I go through them?

The CHAIRMAN: Please do.

Prof Coates: The resources to raise Western Australian hearing screening, because of the size of our state, will involve initially obtaining the appropriate equipment and staff and people to teach

and arrange for dissemination of information about the program throughout the state. Therefore, initially, in the first year of the three-year business plan that was submitted to the health department, the other parts of the city would have screening. For example, Swan District Hospital, where there is no screening done, would have screening started at that hospital in the birthing unit, and then it would go to the major centres in the country, and at the end of three years every birthing unit that produces more than, say, 100 births a year, or perhaps fewer, would have the ability to do newborn hearing screening.

In other states, the current screening rate is close to between 95 and 100 per cent in Queensland, New South Wales and South Australia. Tasmania is going through this same process. Victoria is similar to Western Australia, where the testing is done in a selected number of metropolitan hospitals. The Northern Territory has the funding, and is progressing newborn hearing screening, as does the Australian Capital Territory.

The CHAIRMAN: Progressing universal screening?

Prof Coates: Yes. They have the funding and they are progressing the newborn hearing screening. Therefore, Western Australia and Victoria are the two states that need to get up to the 95 per cent so that we can then have true universal newborn hearing screening in Australia. We are the ideal country for it, because we have Australian Hearing, which can supply hearing aids to young children. We have the cochlear implant technology and we have the ability to get a national database through Australian Hearing whereby we can actually monitor the progress of children with hearing loss.

Mr J.H.D. DAY: I wonder whether I could just ask a question as we go along, if that is okay. Could I just ask why Swan District Hospital is excluded from the screening that does occur in the metropolitan area at the moment?

Prof Coates: I think there are others as well as Swan District. I think that is just the way it has been. Initially it started with those birthing centres that were the largest, and it has gone down in that way. We hope that Swan District will be the next cab off the rank.

Mr J.H.D. DAY: Unfortunately, I need to leave to go to a parliamentary party meeting. However, can I just make the observation that Professor Coates is very much the pioneer of neonatal hearing screening in Western Australia, and I think that may well be for Australia as well. Am I right in saying that? It is wonderful that he is able to give us evidence this morning. I just thought that should be acknowledged, and I look forward to reading the rest of the transcript. Thank you.

Mr T.K. WALDRON: Professor Coates, what does the newborn screening actually involve? Is it just a simple process?

Prof Coates: It is a relatively simple process, and people can be trained to do it. I think probably the best people to do the testing eventually in country Western Australia will be the maternity nurses, the midwives. If they are brought in on their regular job, instead of doing their midwifery work they will actually be handling the babies and putting the equipment into the ear. It is non-invasive. It takes less than 20 minutes usually, and it is not threatening at all to the child. It is a fairly straightforward procedure.

The next question you have here is about community savings. This was done for the Medical Services Advisory Committee by a group from, I think, Flinders University in Adelaide. Their pick-up was that the savings are about $1.2 million per child for the community over the lifetime in medical, educational and vocational issues. This is not dissimilar to the findings in the US, which are about $US1 million, and in Europe they are estimating about €800 000 for the saving. These savings are in the fact not only that the children can go to normal schools and do not need extra expensive training, but also they can go to university. They then will not be on pensions or disability pensions. There has been one statistic mentioned in the past, which is that 50 per cent of adults signing deaf in Australia are on pensions or are unemployed or have employment that is

probably directed towards their deaf society or groups like that. Therefore, it is important to do this program.

In our business plan, the annual cost of starting up the universal newborn hearing screening program, supplying equipment and running the program for three years is $9.2 million. As you will have seen in the figures, with the 80 or more children we have picked up we have probably saved $100 million so far, and we have been working on a $400 000-a-year budget, or thereabouts, until now. We were the first state to start limited screening, in 2000. The next step—the screening program for children older than newborns—is critical, because the facts are that the number of children who develop permanent hearing loss, either because they start with normal hearing and then progress to hearing loss as they get older, or they acquire hearing loss through meningitis, mumps or measles or head injury, doubles by age five and triples by age 10. In addition, there is what we call conductive hearing loss, which is due to a blockage in the middle ear. This is mainly manifested as the condition called otitis media with effusion, or glue ear, which is the popular term. This can lead, with infections, to a discharging ear, which is what is often seen in Aboriginal children, with a chronic suppurative otitis media, or discharging ear. These all lead to hearing loss.

I feel that any program that particularly looks at children at risk, such as the Telethon speech and hearing screening program, is an excellent one. The Variety Club of Western Australia has provided one bus to do this screening, and it is particularly done where the children would not otherwise have access to hearing testing, in various kindergartens and day care centres, particularly in the underprivileged suburbs of Perth. Another one will be based at Bunbury. In New Zealand there are 13 Variety Club ear buses. The buses are supplied by the Variety Club, but the staffing is done by the government health department. These go all over the state, testing the hearing of children at preschools, kindergartens and day care centres on a regular basis. They are able then to bring in ENT surgeons if the children need grommets, for example, in grommet blitz procedures. It is working well, and the Variety Club has stated that if we continue with this we could have one bus per year, which costs about $125 000, to each region in Western Australia. This is a wonderful opportunity in the west, because of our size.

The article about Indigenous children having 32 months of hearing loss due to glue ear, or discharging ears with hearing loss, comes from the Northern Territory and Queensland. There is not an economic cost for Indigenous hearing loss, to my knowledge. However, we are currently completing a paper requested by GlaxoSmithKline on behalf of Princess Margaret Hospital for Children from Access Economics, which shows the cost of ear infections, glue ear and chronic ear infections in Australia, using some excellent data.

I refer to question 5. A child could be born at Swan District Hospital, and because there is no newborn hearing screening, if the mother does not take the child to the nine-month check-up, where hearing testing is no longer done—no distraction testing is done because it has been discredited in the United Kingdom and here—the child could slip through and not have a hearing test until he or she attends school, where a regular hearing test is done. That, I feel, is not acceptable in the twenty-first century. The implications for the child are that the child may have hearing issues and learning issues, or speech and language delays, and have to attend speech therapists, and then would be behind in schooling and learning. This may impact the child the whole way through the education system, as the vocational outcome that might be expected is not achieved.

I believe that in Western Australia we have a very good program of testing. This is done by visits to the rural and remote communities. Also, Australian Hearing, on a national basis, also does testing. We are trying to coordinate it so that we do not end up in the same township at once, as happened to me in Balgo once, when I was there with our own audiologist, as well as a government audiologist. Firstly, there is no room and, secondly, we are over-servicing. We are trying to establish that coordination. We have visits to, for example, the east Kimberley at least twice a year, and to the west Kimberley at least twice a year. In between time the audiologists based in those areas are also

testing children. Obviously, because the community is fairly mobile, children will slip through the net, but on the whole Western Australia does a good job on hearing screening for these special groups of people.

Cochlear implants are supplied directly by the state government for people without health insurance through Princess Margaret Hospital for Children, and are also supplied indirectly by the commonwealth government. The numbers we are able to do are increasing since the newborn hearing screening program has revealed a large number of children with severe and profound hearing loss. The speech processors, which have a finite life, are supplied by Australian Hearing. The implants cost probably $25 000, and in addition to that there is the cost of the surgery and the more expensive cost of the assessment and rehabilitation, which can take six to 12 months following the cochlear implant.

The CHAIRMAN: I will just wrap a couple of things up. You have said that distraction testing has been discredited. Do you share the view that it has been discredited?

Prof Coates: Yes.

The CHAIRMAN: Is the data from the test of children kept anywhere once the assessment of the child is done? Who keeps the information about tests conducted on children and infants?

Prof Coates: In the newborn hearing screening program, it is kept in the health record, which every baby has. The subsequent testing can be placed within that childhood book as well. The age five or six testing at school will be kept, I expect, by the Department of Education and Training, in the school health nurse system, and they will act upon that if a child fails a screening test. They do a very good job.

The CHAIRMAN: I was under the impression that we might once have had in Western Australia something that approximated the universal screening for hearing loss. Am I mistaken?

Prof Coates: Western Australia was the first to start this in May 2000. It was not universal, in that universal implies that more than 95 per cent of the population of newborns are having the test. We were testing some 56 per cent of children born in Perth, and 46 per cent of Western Australia, because of the demographics.

[10.00 am]

The CHAIRMAN: So there was no specific policy change? It was not as if we were heading towards near universality and then that suddenly got canned?

Prof Coates: We have slowly continued to increase the number of hospitals that have been covered, with help from the health department. We are the only state that also has a private system running in parallel where the private patients in hospitals such as the St John of God system are offered hearing testing on their newborns, for which they pay.

Mr P. PAPALIA: Professor, I note that one of your key recommendations is that we identify at-risk children and they be tested at least six-monthly, yet you suggested in your statement a little while ago that at the moment our testing of some of these Aboriginal children up in the Kimberley was fairly good. How much beyond what has been done now do we need to go to achieve the objective that you suggested in your paper?

Prof Coates: I think we have to have more audiologists, more Aboriginal health workers who are trained in ear health so that we can have a pyramid system that is not like the system we tend to have, where the ENT surgeon is at the top and then the other doctors, nurses and health workers. We need a system where the health worker is at the top of the pyramid and they are the person on the ground who identifies Indigenous children with hearing loss, does the testing and then arranges for the nurse or doctor to manage them and send them to us. That is the way that it should work. Not all communities are being tested. As I mentioned, there is the mobility problem. In various

parts of Perth, particularly in the Midvale area, where we have just finished a five-year urban Aboriginal children's study, there are children who have slipped through the loop.

Mr P. PAPALIA: Is the cost of providing training for those health workers incorporated in your business plan for universal testing or is it a separate issue because you are targeting at-risk children?

Prof Coates: Yes, it is a separate issue.

Mr T.K. WALDRON: I am from the country. A local community health worker travels around conducting tests after children are born and then goes on to the next lot of testing. Would they have the ability to carry out that screening or would they need further training?

Prof Coates: They would need further training.

Mr T.K. WALDRON: At the moment, if they recognise that there may be a problem, they would refer them. Is that what happens?

Prof Coates: Yes. If the children were a bit older, they may do a test that they have been taught to do with audiological equipment, but not all of them have been trained that way. There are certainly questions to be asked when a two-year-old child says only five words. That should immediately spark the thought that that child has a hearing problem. The next step is to get a hearing test.

Mr T.K. WALDRON: Without universal screening at birth, someone could slip through.

Prof Coates: Absolutely.

The CHAIRMAN: Professor Coates, is there anything you would like to emphasise in your concluding remarks?

Prof Coates: No.

The CHAIRMAN: You made reference in your submission to auditory neuropathy and dyssynchrony. Are they totally unrelated to the auditory processing issues that are also described as being an area of learning difficulty?

Prof Coates: Yes, they are in some respects. The auditory processing disorder that children have in their older years often accompanies a long history of middle ear problems. They have not had the ability for the sound to process and for the brain to operate correctly and the wires are crossed, whereas children with the other auditory neuropathy dyssynchrony are born with a hearing loss. If they do the screening tests that are available, they actually pass. In most major centres throughout the world people are shifting towards an automated brain stem audiometry test rather than another test because up to 10 per cent of children have some form of auditory neuropathy or dyssynchrony at birth.

The CHAIRMAN: Are some auditory processing issues disconnected altogether from this type of auditory neuropathy?

Prof Coates: Yes.

The CHAIRMAN: Nonetheless, are the majority of the auditory processing issues the end point of years of undetected auditory neuropathy?

Prof Coates: No. One is at birth and the other is acquired after a number of years of having middle ear fluid and mixed signals going to the brain. That can be retrained to some degree. The other is managed with hearing aids or cochlear implants in children. It is very difficult to treat in adults.

The CHAIRMAN: Can auditory processing issues be other that simply mechanical issues with the ear?

Prof Coates: Yes, they can be central, within the brain.

Mr P. PAPALIA: Professor, you referred to studies that indicate a very high percentage of Indigenous children suffer from some form of auditory problem during childhood. Have there been

any studies on children in the juvenile justice system to determine what percentage has suffered from some sort of auditory loss?

Prof Coates: Not in the juvenile justice system. That is an excellent idea for a project if that were possible. Fiona Stanley mentioned this. I cannot remember the exact statistic, but the number of deaf Indigenous people in Darwin jail is eight, nine or 10 times what it should be. It is very large. It is to do with communication, socialisation and all the things that we have talked about.

Mr T.K. WALDRON: I think you mentioned before that sometimes the nutrition of the pregnant mother can cause problems.

Prof Coates: Yes. One of my colleagues in South Africa said that you can gauge a country's state of health by the state of the Indigenous children's ears. WA has a major problem in that four per cent of Indigenous children have chronic runny ears. It becomes a severe problem if it is 10 per cent. In some parts of Australia it is up to 70 per cent. What are the causes? They are the usual ones of poor nutrition, poor hygiene, lack of running water, lack of access to medical people, and overcrowding. These are public health issues. This is why we see such an improvement in urban Indigenous children. There are very few children with runny ears in the school age group, which is a delight to see.

The CHAIRMAN: Thank you very much for appearing today, Professor Coates. You will be sent a transcript of today's proceedings. You have 10 days to respond. If you have not responded to it within 10 days, the *Hansard* record will be taken to be correct. If you do need to say anything else, please send it back with the *Hansard*, making it clear that they are additional comments.

Hearing concluded at 10.09 am