

Gwen Carr - Keynote

Not everything that counts can be counted and not everything that can be counted counts: perceptions of quality in newborn hearing screening programmes

[Start of recorded material]

I'm standing here feeling a little daunted, at the end of the day, but grateful that you're all still in the room and not in the bar which is, I guess, a good sign. I'd like to just start by saying 'thank you', 'kia ora', 'thank you' for asking me. It's a real privilege and a pleasure to be here. I've been looked after very well this week and have learned a lot from some time with the colleagues in the Ministry of Health and in the Ministry of Education and we're about to move into a not dissimilar structural context at home so I'm collecting everything I can to take home and, hopefully, we will implement some learning that we take back from you, too.

It struck me earlier on, especially listening to the panel about the incident and we've had incidents too; not just one like that. We've had other types of incident as well and you always learn from them. But I think it's true to say, none of us sets out to be bad at what we do. We come into...whatever profession we come into, whether it's speech language therapy, education of the deaf, medicine – and we walk into this field committed to do a very good job. And equally, parents don't set out to be that family from hell. And yet, we have professionals from hell and families from hell and it's about a mismatch. It's about different perceptions of what we're really looking at and what we're experiencing. So, I'd like to look – I'm going to share with you some of the practice and learning that we've had in England over a long period of time, and we're still learning, and some exploration, I think, about maybe we ought to look at quality in a slightly different way. And it struck me this morning, listening to [unintelligible 00:02:02] who said, "We should go back and think about the motivation for where our programmes came from" and also listening to Brian and Greg and others, talking about 'we've come a long way'. I think Pat said that in his first presentation, "We've come a long way."

So, nurture, grow, and enrich. We have come a long way. And I'd like to start with – I just thought at the end of the day, you might want to watch a little bit of television; saves me talking for five minutes. This was a 19 minute film which I had edited down to just under five minutes and if we ever needed to understand why we do what we do and how far we've come, this might be it. It's a British Council film made in 1946, so I'm not in it, nobody here can take any blame, I don't think, for this. But I'm hoping my guys over there are now going to zoom into action and this film, 1946, British Council – listen to the accents as well – Oh, it's gone. It's called a triumph over deafness.

(Music) (Beginning of film)

Narrator: Deafness is a handicap that passes almost unnoticed by those of us who enjoy normal hearing. But in recent years, much research has gone into finding ways and means of lessening the handicap and a visit to the Deaf Clinic at Manchester University is one very good way of showing what's been done in this field.

Female: Good morning.

Female: Good morning.

Female: Will you put the telephone to your ear, like that? When you hear a sound in the telephone, put up your finger and put your finger down when the sound stops. I want to find the quietest sound you can hear.

Narrator: Mrs Wilson has been sent to the University Clinic by her doctor to find out how much hearing she has left and what use she can make of it. Hearing tests are made with an audiometer which produces a series of pure tones from very low to very high and they can be varied from very soft to very loud. The patient listens carefully and assists in the job of measuring accurately the amount of hearing which is still left in each ear. The audiometer test is already showing that Mrs Wilson has sufficient hearing left for her to make use of a hearing aid. A further test is made. Mrs Wilson listens through various hearing aids of different design to a recorded voice which is reproduced through a loudspeaker at normal conversational loudness. Help for the deaf child is more complex and difficult. For the very young deaf child usually grows up to be dumb. This is Maureen, aged four. She was born deaf and hasn't yet learned to speak.

Female: Watch Maureen. Go. Go. Go. Would you like to try? Now you try. That's right. Put it in there. Go. Go. Will you try her?

Male: Go. Go. Go. Go. Go. Go. Go. Go. Go. Go.

Narrator: The test proves that Maureen is very deaf; much deafer than Mrs Wilson. But Maureen's mother is reassured that her child need not grow up to be dumb if she will agree to send her to a special Junior School for the Deaf. The atmosphere of these special schools corresponds as near as possible to that of a school for normal children. The teacher speaks to the child at all times and there is no sign language or gesture. Soon the child adapts itself to the new circumstances and begins to look for and imitate speech. The first attempts of the born deaf child are often silent, as you see with Freda, aged three.

[unintelligible 00:07:08]

Female: Where's the cow? Yes. The cow? Cow. Cow. Where's the aeroplane? Yes, aeroplane. Aeroplane. Where's the bear? Yes, bear. Yes.

Narrator: One thing is now clear. Less than 50 years ago, very few of these children, whom you see here, would be talking. Still less would they be singing and dancing as they are today. We can all help in this work. A little sympathy and understanding for those whom we know to be deaf is, in itself, sufficient to spur them on to greater efforts and, thereby, help them further in their triumph over deafness.

(Noise) (End of film)

It really makes you glad that we work in the times we work in, doesn't it? And it is an amusing film from many perspectives. It does make you smile and it makes you anti-nostalgic, if you like, but it also almost moves me to tears when I see that and children who were four and don't even...haven't discovered a voice and the fact that there seems to be a pride in the fact that these children don't gesture or sign. Because what it says is that these children have no communication and, therefore, no real relationships with their families. So, we have come a long way because this is today's era that we're operating in. We've got children being screened. We've got snug fitted hearing aids, on babies, very early giving them that opportunity to reach audibility. We've got the acceptance and recognition of sign as a language and a true tool to

communication and to social wellbeing. We have cochlear implants and we have very family focused services and the sorts of partnerships that we've heard about earlier on.

But, we live in difficult times and when Greg emailed me to ask me about coming to the Conference and I saw it was called Nurture, Grow, and Enrich, times at home, for us, have been very hard. I've been looking at your budgets this week. It's all looking grand in New Zealand and Australia. It's not looking grand in England. And we have some very difficult and challenging times. We have budget cuts. We have teachers of the deaf and our speech language therapists who are of an age and who are retiring and we don't have the professions coming through to the same extent. We've had pressures in audiology, thankfully, probably now being addressed. But we have had some difficult times. And every year, there's something called the Richard Dimbleby Lecture which is broadcast on the BBC. And last year, it was by Sir Paul Nurse who's President of the Royal Society and Paul Nurse was a geneticist and a true scientist and the Royal Society serves to promote science in its translational form for the real benefit of the public's health. And last year's lecture was called The New Enlightenment. And this was something that just struck me in our difficult times. It's often in mixed up and chaotic circumstances that the most creative work is done. Remember Harry Lime in The Third Man who said, "In Italy, for 30 years under the Borgias, they had warfare, terror, murder, bloodshed, but they produced Michael Angelo, Leonardo da Vinci and the Renaissance. In Switzerland, on the other hand, they had brotherly love. They had 500 years of democracy and peace. And what did that produce? The cuckoo clock. So, in these straitened times, when we are challenged, I think we just have to remember that we can actually do magnificent things and when things go wrong, we have to actually think it's possible to get the very best learning out of them.

So I'll just give you a little bit of a context about England and several people have said to me in the last couple of days, "Oh course, we look to England because you have a really good programme." Well, we think we do have a good programme. But the more I go round, the more I see there are things that other folks have got that we don't have. So, I'll be going home making a bit of a fuss. I won't be that person from hell but I will be being quietly assertive. So, our programme was fully implemented in 2006 and that completed a five phase roll-out that started in 2001 in different areas of the country. We're the pink bit, by the way. Several ditches and ponds, some way over. We've got 53.1 million births and that was the last official statistic; sorry, population and about 675,000 births annually. We have 115 local screening programmes. And those programmes – the actual screening element of the programme – rather like your own, here, is funded by the National Screening Committee directly from the Department of Health and then our follow on programmes are separately funded but we network and work in partnership with them so that our programme has that longitudinal view 0 to 3 years and into early intervention. And we have 33 nationally defined quality standards which were brokered by a multidisciplinary team of stakeholders from all the different professions and voluntary sectors and parents organisations and we utilised those to really guide the quality framework for the programme.

And when we finished rolling out in 2006, we started a quality assurance programme and we've now done four cycles of quality assurance. And rather like people on the panel were saying this afternoon, every time there are recommendations made to the sites and when we go back for the next visit, we look to see how far they've gone in their recommendations and we grade them. And we publish them so that it does do a lot to get the data in because we publish on whatever data we've got from them, and if the data is not well completed, it doesn't represent them well, so. Just so you know, our contact hearing aids are readily available, high quality, free at the point of delivery. We have a network of Cochlear Implant Centres. We have a model of provision similar to that in Australia and New Zealand where we have health provision, education provision, social care in the mix. In our context, a teacher of the deaf is usually the main

intervention provider; in some areas, it may be speech and language therapy but it's a very similar methodology and we have the provision, at least theoretically, of a full range of communication options.

But, in April this year, we've transitioned out of the NHS so local services are still being delivered through the NHS framework but as a team, and as other screening teams, we've moved, as a unit, over into Public Health England. Now, sitting in the audience here, you'll think, "So what?" But for us, that's actually been quite a culture change, in one way, and we have not gone begrudgingly but we've gone with a level of anxiety about how it will affect our ways of operating. But it's been established to sort of separate it from the NHS and with a very strong remit – and I guess this is similar to yours – to actually reduce inequality and to really promote the nation's health and wellbeing. And the screening programmes have all transitioned into one of eight directorates. There are five directorates that are looking after, quite badly as far as I can see, so far. Things like HR and IT and payroll although we did get paid last month so I suppose that's something. And then there are three major delivery directorates: one specialising in evidence and knowledge and research; one specialising in children, young people, and families; and the one we've been put into which is health and wellbeing. Originally, it was called service improvement and population health. But a charismatic leader who we've stolen from the CDC (Centre for Disease Control) in the States, has come to rescue us and he's decided we will be called 'health and wellbeing'. And for me, that's a great thing to be called because it isn't ...for me, deafness, and I will use the term deafness to mean the full range of hearing loss and if I say 'deaf children', I mean children might maybe bilaterally, unilaterally, from mild through to profound. So that's just the terminology we use. But for me, it is about wellbeing; wellbeing for families and wellbeing for children and deafness is not, in itself, a health issue. So I'm pleased to be in this directorate and I think it gives us lots of opportunities.

And at the same time, we've reorganised our services. So, we have separately from the cancer programmes although the cancer programmes are also in our directorate; we've got two non-cancer adult programmes – abdominal/aortic aneurism and diabetic eye screening – and then the antenatal and newborn are in two clusters. So newborn hearing screening is now with newborn infant physical examination screening and I have inherited the foetal anomaly screening programme in my group; and then sickle cell and thalassemia, a blood spot programme and infectious diseases in pregnancy are sitting in another group. But in reality, we are working together, probably for the first time. So, it was interesting for me to visit the National Screening Unit here and see this as a regular operational way of working which is clearly successful. And we have smaller targeted programme teams and bigger support teams looking at things like comms and training and something else – oh, quality. I shouldn't forget that. And there are opportunities and challenges for us. So this is our vision. I think it will probably resonate, to a large extent again, with yours. It's about improving outcomes for every child through high quality screening, good assessments, and family centred early intervention. And I think that's a concept that isn't necessarily ...it's universally shared but not necessarily similarly understood, in many ways. So that's been something we've been trying to unpick. But it is about improving outcomes. And, in our context, I think it's when the Screening Committee put a lot of money into newborn hearing screening – it was a brave thing to do because the outcomes are not realised in the health domain. They're realised in the education and social care domains. So, the Department of Health won't necessarily save any money by their investment. But education and social care will, if all goes well.

And we have a number strategic aims. And, as you can see, they're fairly wide ranging. But I think, as strategic aims, they cover everything that we would really want to cover in a programme that seeks to, if you like, not necessarily save children's lives but certainly, massively transform children's lives. And we do want to promote and inform family friendly services and it is about enabling parents to make informed choices. So there are issues about the quality of information and knowledge and understanding to do that. And as a

programme centre, we also need to be effective ourselves. We want to ensure equality of access and yet I'm jealous of Pat's statistics because we can't do this. We have...we are so data rich but it's an area that we actually haven't analysed and it's something we need to do. But the bottom one is, we want to be recognised as a quality programme. We want to be evidence based and benchmarked. And that leads us to look at quality and we've heard a lot about quality today. So this is really how we envision our approach to quality. We're managing the population through the process, like a sieve and we're making a universal offer with effective systems, failsafes to ensure that we keep people within the system and we don't lose them because we don't know where they are, and with a culture of monitoring, evaluation, and improvement. And we publish very detailed care pathways – this is the Well Baby protocol, this is the Early Audiological Assessment, there's one for NICU, there's Neonatal Intensive Care Unit, there's one for follow up. So it's fairly prescriptive in terms of the recipe.

But we've talked a lot today about quality. And I'm going to just put a few numbers past you in a minute but it...I always resonate or it resonates with me that Plato said, "It's knowledge, not numbers, that really counts"; good decisions are made on knowledge not numbers. So how do we ensure that the numbers and the data we have actually translates into knowledge that affects the quality of the programme. So if you look at what quality is, cause we talk about things being quality but quality, actually, doesn't mean good. Quality just means how something is. You can have poor quality, high quality, great quality. So quality, in itself, is a movable feast. And it's the nature or the character of something and it can be affirmative and negative. And we have, in our systems, loads of what I would call neutral quality markers where we tick the boxes. We say, "Did this happen in the time it was supposed to be happening?" And then we celebrate the fact that our babies get screened in a timely way, get referred in a timely way, get assessed in a timely way, and come out the end in a timely way. Does that mean it was quality? No, it just actually means it was timely. So I think we really need to look, as well, at subjective measures and perceptions of quality because I might say to you, "You know, I saw the best film I've ever seen, last night" and recommend it to you and you'd go and see it and say, "Gwen, what were you talking about? I thought it was awful." Because we all have different ways of being and different aspirations. So, I think we need to think about what that will be like. And quality is also an issue of outputs and outcomes. And we all use the word 'outcomes' when we're talking about every aspect of our programme. Yet, are they really outcomes or are they things we do? And I think that affects how we might assess the quality. So an output is something that derives from a process. So we have loads of outputs in our pathways. So a step in a care pathway is actually an output or if you change the way you deliver a service; that's an output. It's not an outcome. An outcome is what happens as a result of that. So, from a child's perspective, is the increased developmental process; from a family perspective, perhaps does the parent feel more confident or at ease with the situation they're dealing with.

And when we're looking at our programmes, I think we need to actually separate what outcomes and outputs are because it's very easy to decide that your outputs are your outcomes. And I don't think that you necessarily, then, really measure the quality and I think we really need to be careful about how we do that. So I'm going to actually be a bit challenging to myself as well as, I hope, to others and actually saying in a data rich context, where we're counting everything that we can count, and we are counting some things in our programme that we haven't looked at in the last 12 years because we're not quite sure what we're supposed to do with it, but it's there. Or a lot of the numbers are there. And are we actually not counting some of the things that we ought to be counting because they're the things that matter? So if we look at our data system – we have a data system called Escreener Plus. As my colleague, Lindsay, mentioned in the Screener Workshop, this is Electronic Screener Plus but we do have humans as our screeners – we don't electronic screeners. But this is a routine screening management tool and this is what we know. I just

checked before we came away that...where we're up to as of December, we've got one hell of a lot of records on the system. We've done an awful lot of tests. We know how many babies we're referring. And we know how many we're screening – over 13,000 babies a week get screened. 338 are referred and 27 – over three babies a day – are actually positively identified or recognised as having permanent childhood hearing impairment. It tells us a baby's journey through the process and it tells us some good things about the difference between when we started, after full roll out, and where we are now. So, for example, screen refer to assessment has gone from 29 days down to 16 days in that five year period. Amplification provision has gone from just under six months to just over eight weeks. And for us, that means entry intervention happens at the same time because one of our quality standards is that audiology services at the point of identification, not audiological certainty, must refer within 24 hours to the early intervention service. And the early intervention service, then, must respond and contact the family within two days and offer a visit. Now the family can say, "Come next week" or they can say, "Can you come tonight?" But by and large, babies and families are entering into an early intervention service about nine or ten weeks of age. So, that's been good for us to be able to track. But our database, which is very extensive, stops at the point of referral into intervention. So whilst on the other side, in the education side they, too, are data rich, in terms of outcomes and tracking progress but the two don't fit together. And this is a real challenge for us to be able to knit this together and it's something we're only just beginning to think that we can achieve so that children's outcomes can actually be tracked right back and looked at in terms of their aetiology, their journey, and perhaps have a more holistic look. And then, obviously it tells us how services are responding and performing against quality standards and, interestingly, in our case from the incident which was similar to yours, it was picked up through routine data monitoring and then, actually, put the other way rather than coming up from the local context. What the data doesn't tell us, how good our practitioners are or how well we work together because we talk about how well we work together but we know from families that it doesn't always feel like that to them. It doesn't tell us about the child's developmental outcomes cause we've not got there yet. It tells us nothing at all about the family's experience and it doesn't tell us about outcomes for families.

But when we started our quality assurance, we decided we'd look at the audit data, so we looked at the routine data and meshed it into the quality assurance process in which we decided, as well, to have self-assessment by services. So services assess themselves against the quality standards and then we verify it. And we send the butchers in to look at other people's meat. Because we operate a peer review system. So screeners look at screeners; audiologists look at audiologists; teachers look at teachers. They are all trained so that they ..it's a moderated process and we think it's been a strength of the programme in terms of its acceptability to the field. But I absolutely agree with you, [unintelligible 00:29:48], I think to have somebody to stand back from that, as well, would add a richness that would enhance the programme. But I think it's been the fact that people are peers that have made it acceptable in the field because nobody gave us a mandate to actually do this, we just took the space cause it was there. And then in the last cycle, we introduced case study reviews. So we chose babies from their unique identifier on the database, of usually a baby with a moderate loss and, perhaps, another one with a profound, and we then said to every stakeholder involved in that baby's care, we want all your notes in relation to this case.

Well, it caused mayhem. People were ringing up saying, "Could you choose another baby?" Because, despite the fact that the audit data and the process looked really hunky dory, the case studies told us otherwise. And then, once we'd done all this process, we'd give them back a report. They have the opportunity to question and challenge the report before it goes public. It then goes to those responsible for funding the service and then we actually publish them so they're freely available online. And I think it's probably important to say,

when we did cycle 1, it looked like all the services were great. And it was only when we actually started thinking, well, they can't be that good, that we started delving down a little bit lower. So that was a question of, it we'd gone off the data and what they said they were doing, we'd have said everybody was fine. And yet we knew, from parent reports, that things weren't fine. So I think it's a question of we've refined what we've looked at, at every stage. And we look at how they're governed and their strategic partnerships. We look to see if the commission of services actually meet the needs of the children and families because how to specify the service rests at local level. We give them the specification that they need to perform against but we don't actually have the mandate to say, "You must do all that." They can turn round to us and say, "Well, we can't afford all that." We look to see how they have a quality improvement culture in place and whether they are engaging families in their development. And these are just our areas of quality standards and there's nothing unusual there. You would expect all of those to be measured appropriately. And then again, timeliness, whether they're – how good are they at actually putting their data in? And we look at how they coordinate and we look at how they fit their hearing aids. So, all of those things you would expect, I think, to look at in terms of the quality of a service.

And then we added the support for developing communication within a framework of informed choice. And in our context this was a very difficult standard for people because we're very, or have been, very politically driven by the philosophical belief of whoever headed up an intervention service. So if you live in one area of England, you may only be offered...you would, perhaps, be identified, whipped through very quickly for a cochlear implant, straight onto an ABT programme. You may never know of the existence of any other way forward. You may never meet a deaf adult. You will meet families, perhaps, who share that type of approach and support it. And in other areas of the country, you may actually, regardless of level of hearing loss, go straight into a sign/bilingual system. So the standard became you must be able to equitably provide access to a framework of informed choice. And in the early intervention workshop, tomorrow, we're going to be talking about that and [unintelligible 00:34:09] and his keynote tomorrow is going to be exploring it from a deeper perspective. You will soon realise that I'm not the philosopher. I'm Mrs Practical. I am a reflective practitioner, however. They have to identify and respond to complex needs because it was felt that children with complex needs were still getting a raw deal, even though 40% of them were being picked up early. And we also said, "We require you to have a functioning, what we call, a chswg – which is Children's Hearing Services Working Group – and on that working group, it's a strategic group. It must plan together and parents and service users must be equal members of that group, as must members of the deaf community. And then, a couple of years ago, we did a quality workshop based on these principles in Como. I don't know if, maybe, some people here were at that quality workshop. And we actually shared – it was a mixed group of people: parents, clinicians, and people from all different aspects – and we shared and discussed what the standards were and what visions and goals were. And there was a lot of agreement about these are the right quality markers. There was some variation in what people felt were desired outcomes. But there were huge differences in priorities in defining quality. So parents chose different indicators to be top of their list than planners and funders did. So, it showed immediately that we actually need to broker this in some way. And a lot of services have said to us, "Oh well, we know that parents like our service cause we do satisfaction surveys." But does satisfaction with a service actually mean it's a quality service. And I filled in a questionnaire. I was upgraded on the way in, which was lovely, although I was wakened up to do the questionnaire. First question – did we greet you by your name when you came on the plane? So I ticked 'yes'. Presumably they'll get some points for that. I couldn't care less. But there wasn't a question, "Did we disturb your much needed sleep by waking you up to do a questionnaire?" So, you know, does it mean that it is a quality thing? You get the behaviours that you choose to measure. And I think that's

a danger for us when we define outcomes and they're usually the ones that you can measure, that's the way people will perform. And I don't know if you have standardised tests of educational attainment for children in schools in New Zealand and Australia. We have them at home, SATS, standardised assessment tests. They're imposed on children at 7 and 11. They're tested in science, maths and English. So the teachers do science, maths and English in that year, they don't know where anything is, they've never heard of a king, no other culture, but they're knocking spots of each other in science, maths, and English. You get what you choose to measure. So a couple of years ago, with John Bamford at the helm, we actually tried to undertake a study and it set out to be about outcomes. It didn't evolve to be about outcomes. The most useful parts of it came in trying to look at what quality was from a parental perspective.

And it's interesting cause you'll see my boss, collaborator, Adrian Davis, who many of you, you will know his name in newborn hearing screening, he's a great thinker. He's an epidemiologist. And we evolved the joke in every research meeting. We said, "Have you heard the joke about the epidemiologist?" "No, I haven't heard the joke about the epidemiologist." And we said, "Well, there's a guy with a magnifying glass and there's a patch of light on the floor – a spotlight. And the guy who's an epidemiologist with a magnifying glass is really going through every area of the ground with his magnifying glass having a look for something. And somebody comes along and they say, "What are you looking for?" And the epidemiologist said, "I'm looking for my glasses. I've dropped them." And the guy said, "Well, where did you drop them?" And he said, "Well, over there." So he said, "Well, why are you looking here, then?" And he said, "Well, there's a light here." And you look, sometimes, for what you want to look at and not necessarily for where you should be looking.

So we were trying to see how we could do this. So we developed a questionnaire. This was very much Ayliss Young's leadership in this particular piece of work. We developed a questionnaire which was for parents to tell us about their views of services. But we didn't want to just have a satisfaction questionnaire although you might think this is a satisfaction questionnaire, it's just a slightly deeper one. But we actually asked them to describe the structure of what they got, in terms of its timeliness and its availability to them. And then we tried to ask them about the content of intervention. We never got to the point where we actually looked at the curriculum, if you like, of intervention. But they looked at...they measured it in terms of the quantity of what they got and the relevance as well as the satisfaction. And then the process of it, so we asked them, actually, do you think it's important, what you're getting because we did have some parents say, "Well, she comes every week and I'm not sure what she is." And I ...this is not a lie. One parent put, "She has never done the ironing." This was a teacher of the deaf going in. So, clearly the teacher of the deaf had failed to explain the relevance of her support. And then we asked them about the impact of the intervention, which may be positive or negative. And these are just a couple of screenshots from the actual questionnaire. So they ...the families themselves listed all the people they were having, down the left hand side. They nominated them. And then we asked, "Who have you had contact with?" And then, "If you have had contact with, how much do you get?" Tick if you were offered the service, as opposed to had to go and look for it. Tick if you were offered it but actually you didn't want it. You refused it at the time. Tick if you would have liked to have actually had it but were never offered it. And tick if you feel it was hard to get the service. So we tried to get a feel for the situation that they were in. And then we asked them about what sort of behaviours the professionals displayed: so did they get enough time to talk to them; do they include you in designing the support for you and your family; can you personalise it; how well do the professionals take into account your culture and lifestyle when they're working out support plans. So, I will be coming at half past three every week, whether you like it or not, and if you're out, tough. And we asked them to grade the extent and then asked them to say how important it was for them, "How important is this for you, now?" And then, "Has the support made a difference?" So overall, how much has this professional support made a

difference, not only for your child but for you and your family and yourself as a person? And both Mums and Dads or other carers filled this in. And then we asked them, "Has the difference been positive or has it been a negative impact on your family?" And at the same time, we were doing this, we were actually undertaking QA cycle 2; two completely different processes but they were going on at the same time. And then we were able to actually look at what we were getting on both things. And what was very interesting and dismaying was that parents who were expressing high levels of satisfaction with their services, were in services that were failing to meet the quality standards and the we felt were inadequate services. So they may have a had a hearing aid fit at nine weeks; unfortunately, they didn't have a service that knew how to fit a hearing aid well. So this was early on in our process, remember, I would...I don't want to run down any of our professionals cause I think we've all been on a steep learning curve, working with families and children early on and I think the response has been fantastic. But, one of the things we asked, of course, in the research study was how do you feel about what you're getting now. And the families had very young children because of the nature of the study. And you have to ask yourself that if they look back in years to come, if they said they were satisfied, would they still be satisfied in the knowledge of how their child and their family had progressed? We won't know that. But the areas of most dissatisfaction were in these two domains: professional communication and information sharing – which they perceived to be gatekeeping. We use the term 'gatekeeping' as the approach where you would say, "I'm not going to give you that yet. You're not ready for that yet. I'll give you this bit of information because I think you're still grieving or I don't think you'll cope or might get upset." So, parents were upset about gatekeeping and more or less said to us, "We want all the information. We'll decide whether we read it. We'll decide when we're ready but please don't tell me I can't have it. They were very upset about bias and they didn't like not being given informed choice. In other words, they didn't know what they didn't know and if you don't know, you can't ask. And they also felt that the language some professionals used really made it clear where value judgements were being made about different ways. The other thing they complained about was a lack of cohesion and coherence in the way support was offered. Now, look at the QA. QA felt, when the self-assessments that they were great teams. So we've all been congratulating ourselves, we have. Health and education working really well together. We've got different professionals all feeling they were a team but what families said was, "They think they're a team but it doesn't feel like a team." So, if you think of the information and communications, these are just a couple of screening leaflets. Well researched, well written, good feedback, and we've got masses of other, I think, quality information that we give out to families. And yet, here's a photograph I took. Mark Douglas is going to recognise this place because he actually was working in this place when this photograph, when this sign was up there. But as you take your baby to the Clinic, this is the sign you see. "Warning: Deaf people" And they actually thought it was to tell you that, as you drive your car in, there may be people on the campus, because a lot of deaf people are employed here, there may be deaf people on the campus who will be unaware and won't hear your car coming in. But, of course, I walked in and thought, "Oh my God, the deaf people just be coming out to attack you at any moment. I must keep my eyes open for one." And when I shared it with the Head of the service, that sign had been up for about four years and nobody had ever said. But when we asked the parents, they said, "Yes, I've always thought that was awful. I didn't know what it meant." So we need to be careful, don't we?

And the other thing that they said that they wanted, in both the 'my views on services' questionnaire and in our Quality Assurance programme was that the family experience was made much more positive when the professionals worked and delivered in a truly multidisciplinary way. So, some people having prominence when others, not everybody thinking they would be the key worker, and they expressed the need to have

seamless services. Now do you use the word 'seamless' in your vocabulary? You' talk about something was good if it as seamless. So what do we mean by 'seamless services'?

Now I hesitate to show the next picture because when I went shopping on Sunday, due to the fact that my luggage arrived 24 hours after me, I thought I 'll just go and get a few staples with my compensation money. And I have to say, this garment that I'm going to show you is in lots of the shops in Auckland. So please, nobody have one on. This is a seamless garment. As you can see, it's probably a wonderful manufactured thing because there are no seams in this garment. But it doesn't fit. It doesn't look good. It's probably quite uncomfortable to experience. So, I wonder whether 'seamless' actually mean ill-shaped and, in my mind, this is what we're aiming for. The model helps, of course, but this is a garment which is well-seamed. So there are lots of seams in this garment. It's probably been made by lots of people. But the seams are so well put together that you can't see them, nor feel them, and it fits well. And I think this is what we want our services to be: our screening services, our intervention services, our medical services, need to work so well together that they feel a good fit for families. And why do they fit families really well? Cause families are all different sizes, although I will be taking, I have to say, the Trim Milk – I've fallen in love with the Trim Milk. So what a public health intervention pack. You've got full fat, on one of the jugs, and Trim on the others, and in England, Trim means quite shapely and nice. So I'm really stocking up on the Trim Milk. But it is about fit for purpose and something that meets a family's needs. And this was just one of the quotes that came out of the research. This was a piece of research undertaken in 2011 and this was in a context where the service had rated its multidisciplinary working very highly; felt they were a good team. Clearly the parent, who said this, did not feel they were a good team. I'll just give you a moment to read to the bottom. Okay? So just whizzing on, I don't want to go too far over late but I did start late, Greg.

So we talked about outcomes. So let's just think about those outcomes for a minute. We all know that early identification isn't enough. That isn't the intervention. It's part of the intervention but it's not enough. We know from lots of research now, a great body of evidence, incontrovertible evidence really, that the gains and advantages are predicted on early identification plus early intervention. Is one without the other unethical? But it has changed how we think about the services we deliver and it's quality intervention that makes the difference. And I don't know, yet, whether we know what quality intervention looks like. So how are we going to define and develop and assess what quality is like? So if you look at the research and we could spend another hour doing that but we won't cause I know you'll be doing it anyway. Are early identified children doing better? Well, yes they are. But Cathy mentioned this morning about speech. And a couple of the studies do look at speech but they haven't actually found necessarily a link. But we're looking at language, vocabulary, quality of life indicators, if they're there, are usually related to audition rather than other aspects of life, and are we forgetting to look at children's learning because we do want to see educational outcomes. When Brian spoke this morning, he was talking about kids doing as well as non-deaf kids yet there's very little of the research looking at learning. Karen Kritzer in the US looking at mathematical learning and finding that deaf children, even very early identified deaf children, have not got foundational mathematical concepts to start school. And Theresa [unintelligible 00:52:03] is looking at the development of executive function; others, Brenda Schick, theory of mind. But we're actually measuring the language because we've decided that's the golden goal. And yet, recent work from Chris [unintelligible 00:52:15] has been looking at pragmatics. And they've been looking at their kids who, in the Colorado context, of course, they've got a nice tight natural group. They've got children who are identified early and have had what we would consider to be a quality intervention and they're looking at children who are doing great in their language. They're up there on the scores. They're got great vocabularies. Some of them achieving quite well educationally, within the typical range. And yet, when she's looked at their pragmatic skills, these children's

pragmatic skills, they're social use of language is right at the bottom. It's on the floor and completely out of kilter with their language and vocabulary scores. And if you look at the mainstream studies, low pragmatic ability is actually what puts you in a risk position for resilience and bullying and the lack of ability to actually socially interact with confidence. And are we then, actually meeting what a family would define they wanted as an outcome for their children? I don't think so. So I think we really need to think about that.

And we have great longitudinal studies going on. And I didn't get to [unintelligible 00:53:39] presentation this morning cause I was in the screener workshop – this afternoon rather. But I am going to listen to her next week and are we really learning enough from our longitudinal studies to inform the intervention. I don't think we are yet. We're watching children and tracking children but are we really saying hey, if that gap is opening there, what can we do to change the intervention to close that gap at every step because it isn't acceptable anymore for those gaps to still be there when children are eight. And I think...I'm sure you will know about [unintelligible 00:54:15] studies with that language technology. We know an awful lot now, about the quantity of conversational interaction in the home being a very important indicator for later successful outcomes. Are we really doing that ...are we supporting families in that as early interventionists or are we setting them on homework programmes to develop more vocabulary to follow a certain pathway. And there's plenty of evidence out there now that children do better when families are engaged with services. And yet what does engaged actually mean? Does it mean that they're just being compliant with what we want them to do? Or does it mean that they are actually moulding our intervention because they are taking the lead in what they want for their children. And I think we really need to question ...we often say, hard to reach families. And yet there are no hard to reach families. But there are hard to reach services. And I think we need to change that concept around.

And as we get towards the end, I just want to share this with you. You may have heard about this. Our outcomes framework in the NHS is very set and it's very output based I think. But just recently, we've had to have a new look at patient outcomes within NHS. We had, in mid-Staffordshire, we've had to have a public inquiry because there was the most monumental failure of care. In-patients were just so badly let down. There were some deaths. There were very uncomfortable, almost cruel patient interventions. Nurses and doctors forgot, really, what their purpose was and that it is all about patient care. And the reason they did was because the outcomes framework that judged the quality of hospitals, was target driven. And it was target driven for patients not to stay too long in A&E. It was target driven so you find yourself, if you get up to three hours and 59 minutes in A&E, you're on a trolley and in the corridor fast because you can't stay in A&E. But in a serious note, this was a monumental failure of care that was presided over by people who should have known better. And the people delivering the care, doctors and nurses who go into this profession to deliver care, felt that in order to meet their targets, they lost sight of the fact that compromising family centred care was the wrong thing to do, a wicked thing to do. And we had out of this, investigation the Frances Report. And it's really salutary reading. And at the same time as this was going on, unconnected and not a causal relationship but associated, we've had a Children and Young People's forum who have been looking at defining outcomes in families and young people's terms. They are not the same as those people who are planning service feels that the outcomes should be. And I think, in this way, in this context, for us, parents of deaf children have been ahead of the game because parents of deaf children have been telling us what our services should look like and I don't think we've always listened. And one of the things that I did in my career, between being a Head of Service and then coming into a more academic and health related strategic post, was I went to work for four years at the National Deaf Children's Society in London, as the Director of UK Services. And I can absolutely say I learned more in four years working for a parents' organisation than I learned in 25 years of being a service deliverer. And, you know, they have

written the book and they have got the T-shirt and they're walking the walk and why some of us still think we know better than parents, I'm not sure.

And in terms of the Staffordshire enquiry, they came up with two very strong messages. One was that people who use services become experts by experience. And that's a term that's now used. So you have your professional experts but it's vital to have experts by experience in the team. And the other thing that's been now adopted is what we call the family and friends test. So every health practitioner, every service provider, is asked to say, "Would you want this service delivered in this way for your family and your friends?" It does make you stop and think.

So, I'm sure you will have seen these before because leadership has come from this part of the world in really defining a parental concept of outcomes and Anne Porter and others have been real drivers for this to take forward. So there's the global Parents of Deaf Children position statement in 2009 that actually states, quite outright, what we would like as services; what we think outcomes should be. And then the – do you call it Anne's Pod? Or do you say ANZPod? Quality standards for newborn hearing screening services supporting families. We weren't permitted to do that in our context, so we use theses. Fantastic way of actually envisaging quality standards from a different perspective. And then also, this morning, Greg mentioned the family centred early intervention conference in Austria and I was a member of the organising committee. And I'm now a co-Chair of the next conference, so that's a little bit of an advert. But I've put that up there because one of the things that came out of that conference as an international consensus. It will be published by the end of this month. It was written by medics, teachers, therapists, audiologists, parents, deaf people – the whole constituency who has an interest in our field. And it isn't a wish list. For every single principle, there is research evidence and practice evidence to back it up.

So, I truly hope that we will move to a position where we understand what the really important outcomes are, defined by families as well as by services and programmes and we start to evaluate and measure those because we have come a long way but we haven't come far enough. And I do think we need to think about what it is our definition of outcomes the right definition or are we still thinking of outputs? Are our models of service delivery the right models of service delivery? Are our partnerships true partnerships or is it parent partnership if parents are compliant? Are we utilising experts through experience properly in both deaf communities, that's small 'd' and big 'd' deaf, and our cultural communities where we deliver services to? And I think we should celebrate our successes but never should be think that there isn't more to do. So not everything that counts can be counted, or can it? And certainly, not everything that can be counted counts. So maybe we should take a hard look and think are we counting some things that are taking our time and energy, when we're thinking about quality and should we be putting our magnifying glass where we've dropped our spectacles and not just where there's a light?

Thank you.

[End of recorded material]