The success of neonatal hearing screening and potential for adult hearing screening
22nd March 2011

RT HON MALCOLM BRUCE MP: Move on to the screening. Stephen you have just been re-elected.
NEW SPEAKER: My apologies for being late.
RT HON MALCOLM BRUCE MP: Are we
NEW SPEAKER: Yes we are ready.
RT HON MALCOLM BRUCE MP: Okay. So, the - this is really is to have a briefing and discussion on the newborn screening program, which was campaigned for by NDCS quite a long time ago going back a long way and it obviously has been extremely important and successful early diagnosis is important but Brian, yes, you are going to give us a brief financing. Basically the floor is yours and then we can take questions.
NEW SPEAKER: Thank you very much for the invitation. When I joined the NDCS 3 and a half years ago our chief executive gave me a book the history of the NDCS to mark our sixth anniversary and I came to 19 seventh 7 and that is when NDCS launched its campaign for newborn hearing screening. There was a conference in Manchester they passed the resolution wanting early identification and support for young children and it was presented to Alf Morris minister for disability then. This campaign took 29 years to reach fruition when newborn screening was rolled out good things take time, yes we have campaigned long and we believe we have had really a system that is now the envy of the world there will be criticisms here but stands out by comparisons with other countries as a very, very good screening program.

Thanks to professor Adrian Davis and Gwen Carr for this information, I have stolen some of their slides from their presentations, I did not ask them if I could do that but I thank them in advance

The vision, this is basically what underpins all screening programs of children this is to improve the outcomes through high quality screening program which is safe effective in terms of assessing the child's needs and then family centred with early intervention, those are the key words of the screening program

. In terms of the benefits, there is a lot of research which shows quite clearly that if you identify children as being deaf before the age of 6 months and give them good quality support they can start school with age appropriate language if they have the levels of support, this is a quote from professor Marsha who was commissioned by the Irish government to produce a report on what works on deaf education, the Irish government were reviewing and that - there is no single aspect of raising and educating deaf children.... So that research, what works every thing this came out, top of the list.

. In terms of the data we have had to the end of March 2010, I am just over 3 and a half million babies screened and 5, well almost 5,000 800 have been identified as being deaf.

. In terms of I said we think we have got a very good screening system compared to many other countries in fact, most other countries was the scope of the program, there are obvious elements from providing parents with pre screening information, the screening itself assessment and diagnosis and early intervention and service provision around that its a holistic model the path way is not stopped at the screening at the point where we think the child may have a problem it goes right the way to support, that can be different from number of other screening programs that

are commissioned by health itself

That I think is you know has given us, that is one of the reasons why we are that. The other why we are one of the top, other is that we have a quality assurance program with standards and peer review going on, so that we can assess progress against those standards.

There are 26 standards. In fact, I have got an extract from publication that I put from one of the NHS publications which lists the standards. Also I forgot to hand out a copy of my presentation as well if people would like it

There is one that goes across the whole path way, one about the screening process, a set of indicators or standards against the assessment and diagnostics of deafness, 6 around early intervention and one around multi-disciplinary strategy around deaf children

There's a quality assurance program which assesses the quality of screening against those 26 standards

This is a graph which shows for England as a whole how services have performed against those standards, its difficult to, I could not get all 26 standards on that which I why you have got that, but the screens are the strengths and there is one consistently failed that is 25 that is the availability of social care. Family support is crucial to children and yet, we know from our own research that there is actually a widespread neglect of statutory duties under the children's act with regard to assessing deaf children, social care, that is a major weakness it was a weakness in the fur hound of quality assurance report this is Q A 2 which is a report that was produced in 2009

You can begin to see, you will not see them quite clearly but the sorts of number 2 is one, a weakness relative weakness against information, number 7 is the screens completed within 4 to 5 weeks is one of the standards, again quite weak there

Under 9 no clear responses, there tends to be patchiness in terms of the response rates at different screening programs are getting a bit of a post code lottery sometimes over referral and sometimes under referral

. One of the big weaknesses in number 15 which is audiology assessments within 4 weeks. If you are a parent and told at the screening point that your child may have a problem with their hearing you want to really know what is wrong as soon as possible you don't want to be left hanging around weeks and weeks which is why 4 weeks with an assessment with an audiology was put in as a standard and we know there are struggles to meet that standard, its slightly worrying for us with new performance framework with the Health Service which in some senses is a strength we will focus on owe comes and not processes. But these waiting times can be crucial for parents and we would not want in the performance management of the National Health Service to loose sight of some of these important process issues for families. Those are the things. This is a much, much better picture than round one the report we got in 2006.

This graph shows all screening sites PCTs are asked to evaluate themselves against the standard and then you get the peer review, the external people having a look at that, there is a difference between the self assessment score and the score of the quality assurance team and generally people are self assessing themselves at a higher level than the external evaluator would say which would suggest her is some value in having this external assessment and why despite the financial cut backs and every thing else NDCS would be keen to maintain some sort of quality audit, independent audit program across this program

The identified weakness those are the 3 key ones. Information for parents, waiting times for assessment and access to social care.

You can also see the analysis by PCTs. Some are much stronger, this illustrates the post code lottery, London, during the first quality assurance visit was weak. London again is weak there. L you have some very good sites in London and then sites 50% or 60% of the children are being screened whereas most other areas are getting the high 90%. {Bell ringing}

RT HON MALCOLM BRUCE MP: Carry on.

NEW SPEAKER: Obviously for NDCS point of view when we are trying to exercise influence in local areas London south-east, Humber are target areas for us.

. Within each of these there will be PCTs that do better than others so we have to be selective in those board bands but London is a worry.

Looking at the future, I think the good think about the future is that public health has been given a priority and the funding for screening has been ring-fenced or so we understand and we also, although public health is going to local authorities this program is going to be a nationally commissioned program. But its just the screening that is going to be that, the audiology the multi-agency follow up and that lot is still commissioned locally that is where you get

RT HON MALCOLM BRUCE MP: This is what Peter was concerned about

NEW SPEAKER: Yes the post code lotteries.

. So, what the future holds? I suppose some of our concerns are the levels of support following diagnosis.

The report so far has said the education is good and we know the Education Service through our own surveys are under threat and are being cut by local authorities and we have come across cases where local authorities are saying we are desperate we have to cut services we will cut services for the under 2s because its not a statutory responsibility, apart from that being the last place you want to cut, if you are going to cut that is the last place you want to cut and they are wrong there is a statutory response ability say we are trying to cover that

But the level of support following diagnosis is important

Quality of audiology support. One of the relative weaknesses was the quality of assessments. We do know that her are a lack of audiologists that are trend in paediatric audiology the modernising scientific careers program are trying to address that but we are still watching that program with interest. We understand there is still debate over the curriculum for the training of audiologist, I don't thing the association of audiologists are perfectly happy with the curriculum. We are not sure how the funding will come through with the abolition of the strategic health authorities. We want to see continuity of the quality assurance arrangements. They perhaps cannot be to the same level as they were when the program was first started but certainly where we are getting the management information through showing there can be weaknesses we hope that the quality assurance issue is coming through

Also school entry screening. For every baby identify another child develops a hearing loss. So, we fear there is some complacency growing into the system, our child could not possibly be deaf because it would be picked up at birth, it can't be picked up at birth so the idea of school entry screening, promotion program saying that each child should get screening before they start school, that is not the case. So one of NDCS campaigns is to look at that screening and getting to make sure that is done properly and possibly with the emphasis on health visitors and the at the health check at 2 and a half is a as well.

As we say complacency in the system. And that is me.

RT HON MALCOLM BRUCE MP: We are proposing to take all of the presentations together so it’s Sue.

DR SUE ARCHBOLD: Thank you very much, thank you I am Sue Archbold from the Ear Foundation work closely with the NDCS and RNID we introduced cochlear implants in the UK for children and work closely with all of the hearing technologies both for children right through teenagers and into adults and I will pass on to Crystal for the adults.

Since 2006 5,000 diagnosed and what I will do is illuminate that with 2 or 3 examples

So, newborn hearing screening being a success as Brian said overwhelmingly we can be very proud of newborn hearing screening both for the way in which its implemented the comprehensive ness of it and the quality assurance the set up

Here is a Christmas baby born on the 25th December. Failed the newborn hearing screening but implanted in Nottingham in 2006. So she was actually implanted before her parents would have known she was deaf before newborn hearing screening she had access of the spoken language of her home before they even had known she was deaf

Here she spoke her first word 3 months after implant. At 18 months told she was starting to speak. Went to mainstream with age appropriate speech at 2 and a half and also using sign language there is nothing about learning to hearing through an implant and use sign too. She has deaf and hearing friends

Mainstream school, in the top groups she is above average for reading and writing because she started school knowing the language and knowing the spoken language.

. Then of course, NICE came along recommending bilateral implants and fee be was one of those that had a second cochlear implant for 2 ears being better than one. But for fee be unlike for those of simultaneous bilateral implants there were 3 and a half years between her operations so she got used to one ear and its taken a long time and work by her, parents and teachers to use that hearing.

For Phoebe and her family newborn hearing screening has been a success and there are many like her, as her mother said it ties up with what Brian was saying, at the time its very hard, it did open up these opportunities and it was worth the heart ache putt parents and families need support at that time

. As her mother was saying she was implanted before they even knew she was deaf

However, the same story is not true for all. Adrian Davis one study he cave me and it twice up with what you were saying, a girl with severe loss in her right and profound in left. Identified early at one month old. Fit fitted with hearing aids at 2 and a half months but her aids were extremely poorly fitted.

So we have the technology. Newborn hearing screening but unless the aids are properly fitted then we are not as effective as we possibly can be and that is what he was saying about the importance of experienced paediatric audiologists at this time, its a very skilful job

Again not for all, you said about complacency, this Mum, from research we have done, at 8 to ten months I bee can to think are you sure she can hear but was fault-ly reassured. Ticking the box been through screening job done. So she did not query it, she did not query that, that child had progressive loss and went on to have a cochlear implant so was pretty deaf by the time she had a cochlear implant, but she waited a long time because the system was not in place to pick her up

Another one. She passed newborn screening but did not have an 8 month check, no checks in place, she turned her tests were conclusive. This child had neuropathy. There children that have later access not just to implants but services

because A} complacency we think the job is done we don't survey them and B} complex ones are again being missed.

. But newborn hearing screening is great but only as good at the services that follow. One Mum, the test is brilliant but it's just the start, because you don't know what you don't know.

. The support after, as we saw there was a great spread from the quality assurance outcomes that we were showing from Adrian

One Mum, there is a lack of support for those diagnosed with deaf babies. Some people were wonderful and encouraging. We need more equity of service to these services.

Lastly looking at one access for cochlear implants we know early intervention is effective. , early implantation is effective in the first year of life but the path way of early implantation is no way straight forward. The hospital did not tell us about the process or the centre and brushed us off and said weight until she is old enough because the audiologists were not up to speed with the path way or how to move forward. The path way for diagnosis to implantation is complex. Again the speed at which the process moves forward was dependant on the intervention of F parents. The process was quicker when diagnosis was made in an audiology centre along side a cochlear implant centre. So those that were at a distance were at risk of being missed or delayed because the more general audiology services were not up to speed with referral guidelines example

In fact, there is no clear consensus of when children should be referred to a implant centre and children with progressive losses or auditory neuropathy are at a loss.

A great job has been done with newborn screening and it has been so effective and we should be proud of it. I was there the day that Susan got the news that it would move forward and I remember that day! .

It has been hugely positive for many but we need to have continued surveillance particularly for those with more complex needs and those with progressive losses that may get missed and we need those joined up services that talk about social care and the clear path way not yet implemented. Particularly thinking about educational support which is changing and these days very challenging times we need to make sure as you said, that the standard and excellent standards are kept up and implemented.

We are working more and more with adults and RNID so I am happy to pass on to you crystal to talk about adults and the need for adult screening

. Thank you. And I have these. Thank you very much.

CRYSTAL ROLFE: Thank you Sue. My name is Crystal Rolfe. We are looking to rake action on hearing laws this June we will change our name to action on hearing loss so our name represents what we do.

It encompasses all of our work

I want to outline what the need is in terms of getting people to take action on their hearing loss we know that 9 million people have hearing loss in the UK. That 6 million of them can benefit from hearing aids. Only 2 million people in this country have hearing aids we know not all of them get the most benefit out of them but they should be, there are 4 million people with unaddressed hearing loss in the UK today

We also know that people delay taking action to adjust their hearing problems for about ten years.

One of the reasons for that is that GPs often fail to refer. Some of Adrian Davis's research show up to 45% of GPs don't actually refer on to audiology. We

know that GPs tell people things like oh you don't want to worry about getting one of those big old things a beige banana that sits behind your ear you will have to wait a couple of years before you get one of those.

We know GPs are a part of the problem, there is stigma around hearing loss still and a lot of people don't feel that they are ready to move on at that point

There we have done lots of research that as soon as you get hearing aids the sooner you adapt and therefore the more benefit you get, that is adapting the hearing aid in terms of the sound quality but also in terms of putting it in your ear, the simple thing like having the dexterity to reach up to your hear can be the thing that stops people getting one. If you get used to that process early on it's easier to get benefit.

We know unaddressed hearing loss leads to social isolation, lots of our research reports show the impact that hearing loss has on people's social life. But also the impact that it has on mental health, there are lots of research late lately, showing the impact that hearing loss can actually have on dementia. Often dementia can actually seem worse than it is, or more progressed than it is if somebody has a hearing problem. I think that is really very interesting area to be looked into further, more and more evidence is coming out in that area at the moment.

So what evidence is there already in favour of a national hearing screening program? . Adrian Davis has done a lot of the work around this and one some of the things is that he asked people to their hearing loss if they have one. He asks lot of questions and the 2 key questions coming out of that is very effective why people put up with hearing loss was obvious. Do you have difficulty with your hearing and do you have difficulties following a conversation where there is background noise. So obvious questions to ask but that helps us identify who has a hearing loss.

. The other things that helped were using some kind of hand held screen and particularly picking people up using checking at 3 kilohertz and 4 kilohertz there is a range of things you can screen adults with. All to acoustic emissions as the newborn hearing screening uses and there are hand held devices and speech and noise checks but these are the 2 that were T best in combination in that piece of research to actually pick up hearing problems

Now, in order to implement a national hearing screening program first of all we need a trial of one. We need to know actually how would a national hearing screen work in the real world how would it work in different areas of the UK, what are the work force issues do we have capacity at the moment what protocols and administrative requirements are best but also what would the take up be at each stage would people take up the offer of a screening if invited too GP surgery would people if referred to audiology go, if you offer somebody a hearing aid would they take it, would they then T continue to use that hearing aid and what would the outcomes be at each stage in terms of the health social and economic outcomes. So really we need to convince the national screening committee of what the benefit would be to individuals of a national hearing screening program and what the cost effectiveness would be as well

So, last year RNID have worked with well-known and economic company, to look at the cost benefits of hearing screening and what they found is that the benefits do clearly out way the cost. This information will be publicly available once published in summer 2011 although early indications are very positive. There are different ages we could decide to deliver it but 65 was the most cost effective age to deliver a national screening program.

Of course, we want people checking their hearing at all ages and specially as people got older but that is the best age that we found at this point in our research

There is not a national hearing screening program for adults at the moment. What the RNID do have are hearing checks. So we have a really quick and simple easy to use hearing check which you can do on line or on the telephone. It's a speech and noise check, so it does not identify all types of hearing loss. It's not possible at the moment with the technology that exists to do a pure tone check on the telephone or internet because people can pick up the noise. People can be filtered to the GP to be asked questions about their ears. It picks up people with age E related and noise induced hearing loss. It takes a couple of minutes to do; we will have some demonstrations later on.

It gives people that first initial step to check out what their hearing might be in the comfort of their own home so they can then go and talk to their GP and have that looked at their hearing loss. Its not a substitute for a diagnostic taste its a first step to encourage people to take action

Now we have an action on human loss campaign to try to encourage people at the moment to take action sooner to reduce that ten years it takes people at the moment to do something about their hearing problems.

Part of that campaign what we are doing is that we have developed a hearing check pre vile if you go on line and do our hearing check you can print something out it looks like a prescription but its your hearing test results so you can go to your GP and say I have done RNID hearing check and it shows a hearing loss. It will encourage the dialogue so the GP refers you on so you are not the 45% of people that do not get referred for a test

We have worked with a panel of GPs on a set of information centre for GPs to make sure we are using the right language for them and working with the royal college of GPs to disseminate that information. That is helping to educate GPs and promote the information we are using.

Also working with royal college of GPs to make surgeries accessible for hard of hearing people.

Now hearing check is one part of this, part of the problem is that we still really need to reduce the stigma of wearing hearing aids and other hearing devices.

. In the corner here I have a little picture; this is an ear mould with a little flower on probably more interesting to females that want to get hearing aids than males. But its demonstrating that at the moment hearing aids have come a long way they are smaller, more attractive but we still have a long way to go, people are trying to fit jewellery into hearing aids people try to make them look like Bluetooth devices we need to be careful around our messages because on one hand we are saying if you have a hearing loss take action do something about it don't be afraid to tell your friends and relative that you have a hearing problem so they can be more deaf aware and better with communication. On the other hand we are saying there are devices that you can hide and nobody needs to know you have a hearing problem. We have to be careful with that communication but we also need to recognise that people want something attractive and modern

. Hearing screening isn't the only answer to getting people to take action sooner, we have also be working with a market research company looking at people's attitudes and motivation to take action to address their hearing loss and that is where they are in different parts of the country how they differ from one area to the next. And really, trying to find out more about why people do and don't take action. Looking at things like you know, lots of older people we call them the "must not grumble", don't want to make a fuss and how we get to these people and encourage them. We don't want people to take action that are not going to actually use those

hearing aids. But we really need a trial of a national hearing screening program, in order to actually test out how effective the national hearing screening program could be and measure what the up take would be we have a consortium group looking at how a pilot of the national screening could work

So screening is only one part of getting people to take action. In order to reduce that by ten years as it currently exists. There R risks attached we don't want to put people off and we want to make sure they serve to capacity as well, current research needs to address how it will work in the real world and what the costs are.

. Okay. Thank you.

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RT HON MALCOLM BRUCE MP: Thank you all 3 of you for, excellent presentations. We have come a long way but still have places to be. Can I kick off with one question. To you Sue.

Cochlear implant, first of all are they suitable for all early diagnosed children and to what extent are there problems, I heard you know it does not cure it, it makes a difference.

Also where are we with cochlear implant specially people that are born deaf because I am interested, my daughter, I wonder whether we will get over that.

DR SUE ARCHBOLD: I will take the last bit first.

So one of the biggest growing group having cochlear implants are those that were born deaf and the groups the adult groups coming to the ear foundation they used to be all deafened adults and now they are more than half born deaf with implants. Obviously the outcomes are not going to be of the same order as if they had been implanted as young children or even as teenagers but finding benefit we have one of these adults who group up using BSL and now has an implant in her 30s coming to speak to a conference on Saturday

Funding is difficult to get for adults but its interesting that is a crow wing group. Some of the adults that have been against cochlear implants have now moved forward there is one man that is now wearing 2 and so, things are moving on, with different levels of expectation not expecting to use the telephone but expecting to be able to lip read more easily and expecting to have access to environmental sounds and enjoy music.

RT HON MALCOLM BRUCE MP: Improved speech.

DR SUE ARCHBOLD: Yes over time

With regard to children we are not about access, just cochlear implant its about access to whatever is appropriate for that deaf child, but for the majority of totally deaf children cochlear implant is the main means of access to technology for them, but bone anchored hearing aids we are doing a lot of work with those, where there is very little known and there are the same number of bone anchored hearing aids users in the country as implants. But it takes them a long time to get there because again, audiology services don't think about referring for bone anchored hearing aids and people don't realise that they can have a one on a soft band and not an operation and they make an incredible difference.

So children after diagnosis should have access to whatever they need whatever technology whatever communication support. Whatever family support and then you need the paediatric audiologists that is the key to decide what is appropriate.

NEW SPEAKER: I have a bit of a list.

. RNID, if I can start with cochlear a couple of precise one what percentage of children go on to receive a cochlear implant from the neonatal what is the actual percentage terms.

What percentage of those operations allow the children's to present themselves orally by the time they go to school, that is the key thing

There are a few others on there, I was involved many years ago so I have been out, I am getting up to speed and I am aware that cochlear implants have advanced tremendously in the last ten years

Thirdly on the cochlear implant side how different would that figure be without the implants? So the first one what percentage of those, the whole neonatal, which was a fantastic, I new Susan when she was pushing for this and it's fantastic to come back and see how its progresses.

What percentage actually goes to get a cochlear implant. What percentage allows the children to manage orally by the time they get to school and the last figure what would that figure be without implant, probably low. Really the first 2 questions.

D1: The

DR SUE ARCHBOLD: The over 5,000 diagnosed are a range of deafness but about 80% of those were diagnosed with profound and totally deaf. Its by far, its, I don't like the word "treatment" its the most common way to move forward and with differing communication needs that is not to say I think we have moved on considerably from those old arguments you have a cochlear implant or you sign, you know thank heavens for that

NEW SPEAKER: I remember that years ago

RT HON MALCOLM BRUCE MP: A cochlear implant has a different effect on different people, some will be more oral than others.

DR SUE ARCHBOLD: What cochlear implants can do is pretty well guarantee it can give you access to the sounds of speech, 20 db right across the range what the brain then does with it is a different matter because its not hearing and talking out, and what of course, we know is that many not many, but a significant numbers of these children may have an audio language processing problems. Interestingly what cochlear implants have done is enabled us to identified those children which we have difficulty before. So to answer your question about what% T would be come communicating orally by the time they go to school, we have a series of graphs that I can show you which shows you percentage and how the percentage changes at the age which the child has been implanted, if its implanted under the age of 2 that is

NEW SPEAKER: Which is the main thrust of the Neonatal Screening

NEW SPEAKER: 2 is quite old these days, but if we say if they are implanted under 2. Then we will say that if unless there are significant other difficulties because you know, then you know 80 to 90% of those will be using oral communication

They maybe using sign support but they will speak intelligibly and able to understand conversation

NEW SPEAKER: That is almost Mira clues.

NEW SPEAKER: The problem is that its not normal hearing one to one its fine but we know what schools are like, we know what the outside world are like and there are the same problems with noise.

NEW SPEAKER: At least they are growing up with it which means that children are very adaptable if they grow up with an impairment they are better to manage it than say age onset.

DR SUE ARCHBOLD: Yes and these children are, I am not - these children are acquiring accent a local accent you can't teach a local accent they have to acquire it by hearing and a major problem for education is what support do they need because its different but if they are not functioning the same A hearing children they are not functioning as profoundly deaf children but nor are they functioning as hearing

children and some need working out exactly what we ought to be doing.
NEW SPEAKER: Brian. I can answer your question in a way but not as directly as you want, what I can do is give you some figures from the early years foundation profile scores of deaf children and how they compare against all children and in the early years foundation they do number of assessments against 13 criteria covering language social behaviour, numeracy literacy and number of things. You reach a good level of development if you score 78 across those 13 areas.

Now what we have seen is an improvement in the number of percentage of deaf children getting that good level of attainment, so in 2007, it was 14.8%. In 2010 it was 22.1%. So it looks as though there is progress

If you take the 2010 figure that 20 - if you are deaf you are still 60% less likely than hearing children to have reached that developmental milestone, if you dig deeper where are the problems still, against those 13 assessments you will find that the biggest deficit is still in the area of language and communication, I don't have those figures I have to go back and look them up.

There is evidence of progress being made but the there is still a big grab and we know from all of the evidence that the child's language when they start school is a key determinate of what they do when they leave school. We have to work on this area and going back to what Sue was saying we have to look carefully of the support going to families in those early years so we can close that gap by
NEW SPEAKER: The reality is that cochlear implants because they are improving so fast that figure would be no wear need. 28%.
NEW SPEAKER: 22%. On the evidence you have you have to say
NEW SPEAKER:
DR SUE ARCHBOLD: There is evidence to show difference in reading ages and so on, but you ask about communication orally. They may have some sign support too but I did not say about the level of their oral language and the problem is in a noise they are miss hearing, so we have the language and communication
RT HON MALCOLM BRUCE MP: It's not a cure for deafness.
DR SUE ARCHBOLD: Not at all. It's easy to interpret it as that.
NEW SPEAKER: But it's more advanced a lot than ten years ago. I remember when it all came out; we all knew that was nonsense that it was quite a challenge to deal with. What is clear to me though is that in ten years cochlear implants have improved. Their capacity considerably
DR SUE ARCHBOLD: Yes some have digital aids and the acquisition of digital aid has been huge
RT HON MALCOLM BRUCE MP: Can I check if any body else wants to come in? If not.
NEW SPEAKER: I have some…
RT HON MALCOLM BRUCE MP: Its fine I wanted to check.
NEW SPEAKER: One of our main problems I think is that the services, the Social Care services the Education Service have not kept pace with the technology to make the most effective use of it, it goes back to the training of audiologist, training of teachers of the deaf and maintaining their numbers and the Social Care is crucial, I can think of a case where a baby had cochlear implant where D Education Service advised against it because the family have to support the baby they have not got the parenting skills to do that. And there is not any social work going into support the family, it's an expensive operation that will not work because the social care is not there to support the family.

It comes back to the support services.

DR SUE ARCHBOLD: Absolutely.
NEW SPEAKER: Thank you for that.
I have a bunch of audiology ones no. All right.
. I used to be a trustee of RNID. Sorry.
NEW SPEAKER: I comment on adult screening if you are dealing with children I will keep quite for a moment.
NEW SPEAKER: I will probably ask similar things
Screening years ago, I am glad its still on and I think its more likely now because not least because of the success of neonatal.
A couple of specific questions, where exactly before I get to the screening bit, where is audiology provision in the health White Paper, its not ring-fenced or anything, is it specifically in the White Paper for just under of the GP consortia.
NEW SPEAKER: Yes.
NEW SPEAKER: That is something I will have to keep my eye on because audiology is.
NEW SPEAKER: Can I come in there, I work with crystal at RNID, I am Roger, research and poll seeing we are concerned its not sighted as a condition as a service in the White Paper. So what we are doing, we are look accounting to see taking the White Paper at its word, we need to create more person centred. Localised services we are trying to do just that for audiology so we have a problem going on now that will be different models of audiology and all of the points that crystal made D the 45% of people are not referred by their GP, clearly there should be a better way of doing audiology, its more accessible, more localised so doing a bit of work on that this year, later in the year we can come back to you add talk about what we are doing in that area before we present it to the Department of Health.
NEW SPEAKER: That equally, I am more than likely to be very happy to lobby for that. So
NEW SPEAKER: Stephen sorry, also. Audiology was discussed as an amendment in the bill committee there was quite a around the issue of how GP consortia, how we ensure the GP consortia have the ability to commission audiology and use a wide example officers and the response was they will be support, that was it so we are, I can send you the link.
NEW SPEAKER: We will have to do drilling down on that, the framework commission, if we can get it into the very, very quickly in a shape or form I would advice that because audiology being audiology if its not actually written down somewhere it will go in certain areas that is something we need to pick up.
NEW SPEAKER: I can follow up on that for the Lords because we might get more success there.
NEW SPEAKER: Yes.
NEW SPEAKER: Another question now on to the screening. Let's say we get to that time in however, long it is hopefully a couple of years or so that we get a pilot.
Have you any decisions where the pilot is likely to be? For instance to tell you where I am coming from I would not have it in an area where there is heavily industrialised industry because that would ask you the outcome. I would probable have it. I mean there are not as many .... There are still 25,000 you know, my advice what I am trying to say to you is have it probably in an area where there is age onset and not supporting people with the industrial deafness but that would skew the data
. The second thing you will have real deliverable challenges of audiology if this ever happens because there is in sufficient capacity I would suggest, unless we get something in the framework commissioning in 2 years there will definitely be in

sufficient capacity, this is an important time and we need to have a about of a discussion around where we go and who we lobby you know, that is the objective we want to get to, which I agree will make a hell of a difference, getting people to have hearing aids before they have to and before they get too old, that is where we are now that is where we want to get to. There are key things that the RNID and who ever else Parliamentarians need to focus on quite smartly because you have a window of opportunity at the moment and it would be nice to do something on that

. Hearing aids stigma.

CRYSTAL ROLFE: Can I deal with those 2 first before I forget the questions

. We have a consortium group that is looking at how we can implement a trial, that includes Aberdeen university the MRC, and so we have got really good professors on board that are helping make sure that any research that we did design was a really good sample, that would be taken into account industrial deafness we would make sure its in an area that does not have a high proportion of industrial deafness and UK wide so it would not necessarily be in England. So

RT HON MALCOLM BRUCE MP: It would.

NEW SPEAKER: It wouldn't necessarily be in England we are looking across the UK. We are taking into account all of those factors and also making sure that we have got a good sample size and the right amount of elderly people in the population because we might find an area where a lot of GPs are interested in trialling out a trial but there are not enough elderly people in the area. We will take those things into account, we have Adrian Davis who has done a lot of research and professor David Stephens that has done a lot of research previously

Moving on to the second question, making sure there is a deliverable and challenges capacity across audiology. That's why we need a trial really what we think is that if we, if we think that the results would show that you would have a slow trickle of people extra capacity would be needed. And very much we need support to make sure that the resources are available for that but we don't think there is going to suddenly be 4 million people that stand up and go and take action tomorrow, what we do think it will help capacity in the long run because if people take action sooner it means that they will needless support when their hearing aids move on. They will need support but perhaps less support. But obviously with audiology because once you have cot somebody in the system you will have to continue to support them, so really that is why we need a trial to find out how many people would take up screening, what the capacity issues would be, how the work force would cope and you really need support to make sure there are resources.

NEW SPEAKER: I agree with that I think it’s obvious that the earlier you get people on age onset deaf process the easier to get used to their hearing aids and less grief for the husband and wife when the TV is on full blast as cherry is often with me

. I have to say that quite often when we receive presentations they have figures that you just pluck out of the air I am not sure how act those figure are but know the proportion of people who get fitted with a hearing aid once over 70 or 75 and can't progress with it is much higher than when its over 65.

NEW SPEAKER: Just on that point chairman, Alan job son chief executive of {inaudible} audiologist we have capacity, we have 1,000 shops around the country we have 15 hundred professionals registered with health professional council who are the professionals so far as hearing aids are concerned and they I think there is an opportunity if I might suggest.

NEW SPEAKER: I hear what you are saying this is something where the private sector can work effectively with the NHS.

RT HON MALCOLM BRUCE MP: Or opticians.
NEW SPEAKER: Maybe a point of information, if I may fur of all on the progress of the implementation of the legislation. I understand and maybe not, correctly informed with matters but I understand that the Department of Health intention is to progress choice for provider starting with community services
NEW SPEAKER: Based on quality not price.
NEW SPEAKER: Absolutely quality on price. That the first of the series of service which could be subject to any one provider would be adult services and I suggest could be an opportunity on that to look at commissioning not just additional as it were service but also bolt on screening into that.

Because of the fact that capacity, the 4 million that we are aware that access the service currently are possibly substantially made up of people that do not actually need to see their GP for a hearing problem and they probably wouldn't see themselves as ill, they would not see themselves in any shape or form as deaf. The - giving people an direct access to a service would in our view raise awareness enormously, very quickly reduce the issues of stigma, very quickly encourage early intervention because people would be self motivated to go and use the service on the high street in a way they used any other services.
NEW SPEAKER: The key you would have its an interesting column John that the private public, things have not moved on in the last ten years with a separate hat I was a member of the Hearing Aid Council years ago and the reputation generally is I know is in a different place than over ten years ago so there is an opportunity now. There would still be concerns and issues because of the constant rub of NHS verses private that has been going on for years but because underpinning spread of the willing provider of quality not cost I think there is an opportunity but I am keen to explore because I am fed up with private public hearing aid issue, one of the things I differ from what you are saying is that although the individuals of that age would rather walk over hot coals to admit they are deaf disabled or what have you. Their hearing loss is a lot worse than they give of. If they get a hearing aid early enough their improvement, their life style will be considerably all of us know that a hearing aid does not cure it but just amplifies knows so they are much better, they will never want to define themselves as disabled or whatever

That is what early screening will do, the plus side of that if its do-able, I am really interested I really am, is that there will be a trickle initially, there will be a flood because if I had 100 people in a room 65 years old, I guarantee you that if I put them all through a hearing aid audio test I would anticipate anywhere between 30 to 40% would have a hearing loss that could be improved with a hearing aid.
CRYSTAL ROLFE: Over 50% of people over 60 have a hearing loss, but the issue is at the moment lots of people even if you test those people a lot of them don't want to do take action that is why there is a lot to do around stigma. What the research needs to highlight is that by implementing a national screen you then make taking action on the hearing, if you invite every body
NEW SPEAKER: Once you get over the tipping point, there is a stigma and design hearing aids all jolly stuff but the key tipping point. We get to the tipping point where 2 thirds of the people down a particular street say blooming heck I need a hearing aid. You will transform it very, very quickly thank you chairman.
RT HON MALCOLM BRUCE MP: They are all very interesting stuff and my, I don't think the RNID has a problem the private sector are not a fully taped resource and you know capacity is there we have to find ways of pulling it out, which are affordable and there are a load of mechanisms that need to be thought about but after

all you know you give people free tests and vouchers or whatever there are a whole load of mechanisms you can deliver but I take the point that we have to use that capacity

I mean, its interesting when you look at the numbers of children, this is the problem isn't it when you campaign on anything on deafness, the proportion of people born or acquire deafness early on is relatively small and thinly spread almost every where, the same percentage across the population unlike the aisle where people manage to live in one space and get a whole load of resources put behind it, I can say that (Laughter). Actually have nothing against Gaelic speakers! (Laughter). Just looking at communication services for the deaf

So that is the first problem which is why actually campaigning on behalf of age related deafness has advantage of reaching a lot more people and pushes it up, we as campaigning politicians if you start to reverse the stigma and start to get 65 year olds to have their ears tested you are in a different ball game the politicians will have to buckle, hopefully that will, you can use that to say what about the people that are young and need support, they may need sign language interpreters or other communication support so, I mean I think its good that you presented it right across the spectrum. And I mean I don't know what the sort of level, I am assuming we flattened out at the percentage of children who will be born with the deafness, we eliminated the most known courses there are genetic courses, a member of our group he was going to come. Michael can I think was one of 6 in his family. He is the only hearing one of his siblings and he has brother who is married and had more deaf children.

Its genetic factor, I am assuming therefore having eliminated the known courses you have obviously meningitis measles.

NEW SPEAKER: The one area is the survival rate of premature babies often those babies have a range of additional needs as well, I think we are getting an increase in children with who are deaf and significant other difficulties.

RT HON MALCOLM BRUCE MP: Don't miss interpret me there, when the numbers are small its easy to say is it worth the investment and your campaigning has actually demonstrated it is. Right across the spectrum, after all whether it's cochlear implants or hearing aids technology and other communication support, you know, it benefits all kinds of deafness. But the big numbers make big politics in the way that small numbers can't, somehow that is the connection, my frustration all the time has been a lot of sympathetic hearing, you have to say the same storey over and over against. And oh yes we will do something about it, indeed the pilot scheme that I am interested to get the report about. I use it at prime ministers question what are you going to do to support, to be fair Gordon Brown gave a positive response, on the back of that you have Andrew {inaudible} with a couple of pilot schemes. If those pilot schemes were identified themselves the next step you know is to say when are you going to roll out, what will you do about it. My point is not entirely facetious, they get an awful lot of money I mean if you take Welsh and Gaelic, I can watch a Gaelic television in London, I can't have a channel for deaf, combination of signing and subtitles. And what deaf people tend to say they don't just want mainstream programs but sometimes programs for deaf people focus sin on issues on healthcare, employment opportunities all of those things. So, you know. I think anything that can kind of add to the weight and then start to sort of, you know you don't have difficulty getting sympathetic response but you get a lot of difficulty getting money and resources.

NEW SPEAKER: One of our sort of next steps in a sense I think we need to have

a bit of a discussion around the screening pilot.
RT HON MALCOLM BRUCE MP: Yes you sort of, who is working on that is that partnership with RNID and government again.
CRYSTAL ROLFE: RNID have a lead on it at the moment we are closely with MRC and talking to people in Scotland as well.
RT HON MALCOLM BRUCE MP: Department of Health involved.
CRYSTAL ROLFE: Not at the moment we are talking to the national screening committee.
NEW SPEAKER: F what are they saying indeed.
CRYSTAL ROLFE: They have given us a list of things they would like to see as part of the Trust. They would like to see a randomised controlled trial if we can answer questions as part of that then they are happy to.
RT HON MALCOLM BRUCE MP: The MRC are? .
NEW SPEAKER: The trial. We are looking at the moment how we can fund the trial but the national screening committee want to see certain things answered as part of the control first mainly to do with up take and GP referrals as well, we are looking how we can answer those questions as part of the trial as well.
NEW SPEAKER: I don't know if it would be in the remit of APPG or, I would be very, very keen to get to know more about that and would be like Malcolm you have said that you were doing P and Qs with Gordon Brown, now I can see that and put real focus on that and with Paul burden Stowe the minister of Department of Health I am sure he at least would give us a good listing.

In a sense, because it's so successful with neonatal all of those years ago, this is an opportunity for the age onset deafness screening to catch up its just obviously has a different impact in scale if we go down that road. Can I leave that to you lot. To contact me and set something up.
NEW SPEAKER: Stephen we can send you a detailed note who we are talking to contact DH and Scotland as well. And some of the funding streams we are pursuing so we will send you a note.
NEW SPEAKER: Good, good. All round it would be useful.
NEW SPEAKER: Yes
NEW SPEAKER: Is there a consortium working in relation to the bill the health bill or is it not focused or basically keeping in touch
NEW SPEAKER: There's a consortium but I will contact your office and I will have a brief with you
NEW SPEAKER: Presumably broadly par of this.
NEW SPEAKER: Broadly it's a resource issue. It's clearly RNID's lead.
NEW SPEAKER: Good.
RT HON MALCOLM BRUCE MP: Can I bring the meeting too close. I am supposed to be somewhere else

But to say thank you very much for your presentations that have been excellent and the work you have done behind them that is more important and for forward momentum, a lot of good news here but clearly lots that politicians have to come in and so again if you reflect afterwards on things that are helpful to ask questions or follow ups feel free to do so. Stephen's contact or me. We will do what we can. Thank you all very much.