Wednesday 21 September 2016

DeafKidz International Leave No Deaf Child Behind Annual Conference.

JOHN COSTER: Good morning everybody, welcome to the Leave No Deaf Child Behind conference. Just some housekeeping before we start. Coffee at coffee break time will be next door, so don't go back downstairs, it's a long way. It will be next door. The toilets are just outside the door you came in, near the lifts, if there's a fire nothing is planned at the moment, the college staff will actually take care of us. Lunch is downstairs where you had your coffee this morning, and just my name is John Coster, I will be doing some tweeting today, if you are on Twitter I won't think you're rude if your head is in your phone, please feel very to tweet us a we have decided of a hashtag, so just over your shoulder here, Leave No Deaf Child Behind, I know it's quite long but we thought that way it would be quite unique for today. So hope you have a fantastic conference I will hand you over to lord Bruce.

LORD BRUCE: Thank you first of all good morning and welcome to Royal college of paediatrics and child health, wonderful venue. I used to live in a flat just a couple of blocks from here it's a part of the world I know it's a very nice part of the world. I have to say that I feel a little bit overwhelmed in the sense that this a very distinguished and well qualified audience and I am really just a lay person here trying to facilitate events. I am not going to, you have got the details of the CVs of speakers and things I don't need to repeat them all, I just had a couple of things about myself. I have known Steve four couple of years bat my engagement with the deaf community if you like is selfish or self-served in the sense that is because my now nearly 40-year-old daughter was born profoundly deaf, and since then I have always done everything I could to try to support the interests of deaf people and deaf children. Steve has asked me to help with this, which I am very happy to do.

Two things that are not on my CV which are mildly relevant, one is I happen to have been appointed or invited be the President of the Caribbean council which promotes all kinds of engagement really between the UK and the Caribbean which I think is relevant

given the work that DeafKidz is doing. Also, in my capacity as Chair of the international Development Committee, we did a report, that I think was quite useful and quite important on disability and support for disabled people in developing countries, and I hope you will appreciate that I certainly made sure that there was a very specific recognition of the needs of deaf people, and deaf children and indeed I am in the process of asking questions indeed after this conference may do more, to see to what extent the British Government is following that through. I hope that this conference and the people who are taking part and the follow up from it will help to focus on more ideas about that.

So, said that let's move on to the programme for today. I on behalf of the board of DeafKidz International, welcome to this one day conference, Leave No Deaf Child Behind, once you put it in once it will not have to be put in again. (laughter) it's about looking at the needs of deaf children and young people, especially in countries where resources are in adequate for everybody, very often therefore, people like deaf children are even more behind than everybody else. I think we're also talking about countries where the humanitarian space is extremely difficult. The ambition as I understand it is this not a one off, but the first of what will hope to be a recurring event. The next meeting is to be scheduled in Jamaica next year in partnership with the British council. That's looking at building a Caribbean wide integrated safeguarding health paediatrics ear and hearing care capability through DeafKidz America in association with the American academy of paediatrics. That's looks like a free ambitious follow up to this, but having seen and heard Steve in action, I am sure it will happen. But today we have an opportunity to learn and exchange knowledge of the challenge facing deaf children, how we collectively, community of deaf, hearing, agencies working in deafness, health development, humanitarian practioners child protection specialist, aid donor's academic, everybody, broadcasters can all work together, that the slogan becomes something meaningful to leave no deaf child behind.

We have got, for me an intimidating array of really excellent speakers with real commitments and qualification, people from Zimbabwe, South Africa the Palestinian

Red Crescent the UK police, you will see a whole variety moor I hope at the end of this process we'll emerge with some key points that come out many of you that have now or in the course of the day feel there are things you really need us to take a way please make sure you don't leave without ensuring that we're aware of them. In conjunction with Steve afterwards, we will be looking at ways of taking these specifically also to the UK, development department and ensuring that they do more because I think they have a capacity to do a lot more than they do.

So, that is the programme for the day I will be introducing the speakers as we go along. But in the meantime I think we should hear from Steve, who is the chief executive, director of DeafKidz International who has I know worked really hard to put this together so Steve.

STEVE CRUMP: Thank you very much a very good morning to you all. Very simply as far as I am concerned, sat in this room are the people that can make a difference I. We have got people working in health, development, humanitarian agencies and broadcasters It's you that can ensure that deaf young person can exercise their rights to health and avoid the agony of abortion, it's you that can newborn screening, or your vaccination programme you at the back there to ensure the earlier detection of deafness. It's you, that can work to respond to the needs of children, deaf children experiencing violent abuse they are safeguarded and get the support they need. Through your programme design, planning work, we can ensure inclusion. I know it's not easy and donors shy away from deafness, because it's expensive it's complicated, we don't understand it. It involves resources like waggers, it's difficult it something we have to overcome. Some progress has been made I am delighted to say this week at safe the children UK have achieved to fund an indepth assessment of the deaf children in the migrant crisis in Europe looking at the point of entry to Europe, Greece, point of transit, Hungary, their final destination, the experience of deaf children and y young people in the Netherlands that piece of work has been undertaken by and with really good friends Royal Dutch Kentalis in the Netherlands and the European union of the deaf. That's something we're really pleased we're making some progress. The outcome

ofted work is like to mean really change to the way that save the children and other agencies undertake their refugee migrant response work it's truly inclusive.

Other progress that been made Child Helpline International, they are working with other DeafKidz International to build a video relay capability into all their child helplines so that children everywhere can access counselling support in the communication mode of choice, and indeed just this week, communication in the US announced they would work with us to trial video relay platforms in South Africa in partnership with ChildLine South Africa and the learning that occurs there we will be able to create a platform a way of working that will be cascaded globally to the 173 child help lines. Lastly we're working with global end violence partnership to ensure the needs of deaf children are include. In the drive to realise strategic development goal 162 to end the abuse, exploitation and trafficking and violence and torture against children abuse against deaf children is endemic if you don't have the skills to communicate how can you say no. We're not having that; you're not having that. On this note, I would like to introduce a message to you all from Susan, Bissell the director of End Violence against Children programme with whom we're working.

(Video playing).

NEW SPEAKER: Hello everyone I am Susan Bissell, I'm speaking to you from the office in New York the global partnership of end violence against children, thank you so much for giving me the opportunity to speak with all of you. The global partnership to end violence against children called End Violence is committed to ensuring that all children grow up in a world free from violence and abuse, exploitation neglect, torture, trafficking, child labour, child marriage and female genital mutilation and cutting. A number of sectors or issues that are referred to in the single development goal agenda, the partnership is committed to ensuring that all children live safely, and without fear. This includes deaf children and young people. Adds we know they are especially vulnerable and at risk.

I warmly welcome today's conference, and I am delighted that the safeguarding of deaf children in low resource and complex settings is I only wish I could be there with you in person. End violence, this has 3 main goals, building political will, accelerating action and strengthening collaboration. Your meeting our joining hands here today is such a good example of that collaboration. Thank you so much for inviting us and I wish you well in your deliberations.

LORD BRUCE: So good you will hear it twice. (laughter).

STEVE CRUMP: You're not expecting this to be perfect are you? (laughter).

So we inch forward, we are making some progress but more needs to be done. Let's all of us today in this room, the decision makers you are the influencer that you are, let's get started to ensure together that no deaf child is left behind.

LORD BRUCE: Thank you very much. Our first speaker is Barbra Nyangairi. We all know that Zimbabwe is a challenging environment. Equally, it's full of some incredibly good people who look for the space to do things in a difficult environment, which I guess is what has to happen in a lot of developing countries. You will see from the notes that Barbra has a long and distinguished record of really supporting children, particularly children who are vulnerable and being abused, appeared very specifically deaf children, as the founder and director of the Deaf Zimbabwe Trust. Barbra, please come forward to us. (Applause)

BARBRA NYANGAIRI: Thank you. Good morning everyone. Thank you. It's a pleasure to be here and I am very excited to be in this conference today to talk about Deaf children in Zimbabwe and Africa, and I hope I can also give a global overview of what is happening with Deaf children in the continent.

So Deaf Zimbabwe Trust is a parents' movement, started by parents of Deaf children in 2012 and we started our operations in 2013, mainly because of the frustration that we saw with the education system in our country and that there was no movement. The educational outcomes of our children were very poor. There were no opportunities for

higher education. There was really no life except begging on the streets and petty selling and vending that was for them, so we began to work in Deaf education, access to health, sign language development and promotion, economic empowerment, research, media and communication, because there was very little research that had been done on the Deaf community in Zimbabwe before we started work.

So we have had a few successes to date, and I must say that it has not been an easy road and Lord Bruce did say it is a very difficult environment to bring any change because of the nature of the leaders that we have. But we have managed to increase visibility of Deaf issues in Zimbabwe. Sign language is now on the main news, which was not there. We have young people that are training as teachers so that we build resources for Deaf education in our country. We did three research projects and we looked at sign language variations, access to information for the Deaf community, and the educational experiences of Deaf adults, in order for us to be able to influence policy and speak from an empirical point of view to the policy makers.

We also have developed a model sign language bill because we have none in our country and we hope that this begins the discussion of harmonisation, in creating an inclusive community. We are also working at a sign language syllabi because sign language is not even taught in our curriculum, it's not used as a model of instruction for Deaf children in any way, so it is something that we continue to work on.

We have influenced examinations accommodations for children who are deaf and hard of hearing in the examinations, in order to ensure equality in assessment as well.

So we are working on that, because of the difficulty of the working environment we also are moving towards the litigation route, because dialogue sometimes does not work, and because it does not work we are providing platforms for young people with disabilities, with deafness, to litigate and raise their case through the courts to bring more accountability, so we are mobilising young people to litigate for increased access to information, which we have deemed becoming citizens, because we believe that becoming citizens is something that we need to do, but it is done through access to information. We are also mobilising parents to litigate for access to quality education for deaf children and we have started a back to school programme where we are looking at how do you then access higher education when you don't have the requisite

qualifications to do that, so we are, we have created a back to school programme for young people.

I will give a global overview of deafness, and these are statistics from the World Health Organisation, which reports that 60% of hearing loss is preventable and, where it has not been prevented, appropriate measures need to be provided. It's very unfortunate that, in low resource settings like ours, even what is preventable is not possible because of late detection. So 360 million people, about 5% of the global population has hearing loss, and nearly 32 million are children, and the majority of this I am sure are located in developing countries, and Zimbabwe is not an exception.

The most significant impact of hearing loss in children in our settings is poor language acquisition, which then does not provide them learning opportunities equal to the hearing counterparts, and so these have been the factors that we have noticed that affect the impact of hearing loss on children. The age of onset of hearing loss, the degree of hearing loss, the age of identification and the intervention, and in many cases in our settings, this happens very, very late, because we don't have the early detection mechanisms that Steve was talking about, and the environment in which we find ourselves also impacts greatly on the children.

The causes of hearing loss, genetic, conditions at birth, infections, diseases of the ear, noise, medicines, and I would say, in all these, the knowledge of these causes of hearing loss are not widely known in our settings, and because they are not widely known, we then go back and fall back on other things, such as witchcraft, which I will talk about later on, the genetic causes are ignored. The conditions of birth are not focused on. We don't treat infections quickly, and as effectively as we should. Diseases of the ear go undetected, or without effective treatment, and this exacerbates hearing loss in children.

And so the story of the African story and the Zimbabwe story of deafness is almost similar. If you have been working in Africa, you would find that there are similarities in the way deafness is viewed, in the way it is treated, and what happens to children who are deaf. So late detection of deafness, very, very peculiar to most African countries, and Zimbabwe has one government audiologist and the rest are in private

practice, not accessible to the poor communities, not accessible to those that are in outlying and far and remote areas.

Hearing is not one of the vital tests that we do as a country in our clinics. We do all other tests except the hearing test, so hearing loss is usually detected at times when the child is four or five, and by then the child has already started school and they are facing difficulties.

The location of deafness in the social fabric of Africa, and Zimbabwe in particular, is in the discourse of witchcraft, and occurs, and because it is located in that, there is shame for the family that has a child who is deaf, because you are stigmatised, there are bad attitudes, there is discrimination, and as a result many families end up hiding their children, so their children don't attend school and do not have the same opportunities as the other siblings in the family because of that. And so, when you come to the community in Africa, mostly you find the deaf amongst the most uneducated, they are illiterate, and don't have opportunities for further education or employment, and that results in a vicious cycle of poverty, because of where we have located deafness in our social fabric.

Lack of language choices. Because of the lack of any language started in the home, you will find that there are very few support services for parents, so when you then discover that your child is deaf, what then do you do? In our situation, very little support for the parents on alternative communications and interventions that are available, and because of that there is not much choice that is given to the parents in order to support the children. So poor language development then affects their educational and learning experience moving forward, and in our country, it is because of the lack of choice, there is a lot of extreme leaning on oralism vis a vis bilingualism where you are giving poor choices and alternatives for parents.

Access to education. Our means to secondary education, over 90% of children with disabilities are not in school and our research that we did, we found that 90% of children with deafness do not attend school, and the educational facilities do not support their education. There are few specialist teachers, but the brain drain has also resulted in many of them leaving the country for greener pastures.

All languages in our country have a syllabi, they use a framework for teaching them, but there is no sign language syllabus that we have created, and the reason for that has been that, "Find us the money and then we will provide the syllabus". "We have provided what you did with the syllabus for Shona, you asked the parents to give you the money to develop the syllabus", so it's a conversation of a lot of attitudes and willingness to provide education. As Steve said, it's either too expensive, or they just cannot be bothered.

Deaf education outcome is poor, and there is exclusion, so while Zimbabwe has an inclusive education system, you will find that, in our practice, it is more like you simply take a group of deaf children and you put them in a classroom far away from everybody else, do not see them, do not know that they are there, and that's it, you forget that they are there. We call that inclusion, when we have to report we report that we do have deaf children in our schools, but no learning is taking place because one teacher is teaching grade 1, 2, 3, 4, 5, 6 and 7, in one class, and so literally we call it babysitting our children and nothing really happens.

Access to health. Poor communication because of the lack of accommodations and provisions within our health system. Poor mental health services for children. Under diagnosis and under treatment of other chronic children or deaf children and the adult population at large, and so you find that we then have a lot of needs that are unmet within our health system because of the lack of understanding and we have begun to look at deaf awareness training, to begin to understand that some measures do not require money for you to be able to implement and to create a deaf-friendly health facility.

Wellbeing in the family and community. This is a function of where deafness is located in our social fabric, and as I have indicated earlier, deafness is located in the discourse of shame, and because of that the wellbeing of a deaf child within the family is also predetermined by how the parents perceive deafness in the family. So you find that many times it's neglect, in the family and in the home. Inability to participate fully in family life and community, and as a result the children grow up with poor social skills and have no opportunity to learn at home due to the communication barriers, and so

we are working on how do you work on improving the self-esteem, the self-worth; you are important, you are worth, so that they have a positive view of themselves for them to move on and be what they were created to be.

And so you find that, many times, because of the lack of support within the family, the deaf child is isolated, even from the family members. There is a lot of fear. We have a parents support group that we run, and many times it is about, "I don't know what tomorrow will hold for my child but I don't know how to support them to be more independent, and there is no facilities for them to be able to learn and to become independent adults in the future". So you will find the difficulties in communication then results in parents not being able to support their children through this journey, and that creates so many other problems as a result.

I think that it we have opportunity to change the situation. We have started we believe that a journey of a thousand miles begins with one step. We have taken that step, and together with DeafKidz International we hope to make more strides and not just steps but leaps, in the right direction, and we believe that this can be done through any detection of hearing loss, something that's needs to be integrated in our health systems so deafness is detected early. Psychosocial support for parents, in order to enhance positive parenting and to move away from the discourse of shame, to a more accepting and more tolerant and more open way of viewing deafness. Changing societal attitudes, to deafness is an issue that we continue to work on and I am glad that because of the visibility we have seen more people coming through, wanting to learn more, wanting to learn sign language and that has really helped. Building resources for deaf education, through training teachers who are deaf as well as increasing sign language support, for those teachers that are training to teach deaf children. Development of an inclusive education policy to guide practice, because many a times we do not have a policy in place that informs what we are doing, and that then results in fragmented and at times contradictory practice which does not provide support for the development of deaf education. Further research, I think that's an issue that is really lacking in our environment, where we do things, we implement things without research on visibility, where is it worked, what works, that then results in at times good intentions but bad results. So it's important that we also do research on many

issues in order for us to be able to inform the policy making process. The creation of deaf friendly facilities in education, health and all spheres of life, and inclusive society. Developing professional interpreter training, certification and registration. I must say that in many of our settings, our interpreters have not been trained either we continue to use a family member, a child or a deaf adult, we continue to use somebody who teaches at a deaf school, but there is not much professionalism that has resulted in a lot of challenges. Deaf awareness and disability management training, policy makers, Government departments, members of Parliament, and development partners for them to understand because together we can create an inclusive society. Thank you. (applause).

LORD BRUCE: Thank you very much Barbra, please take a seat because we're going to have another speaker, then comments and questions. A familiar story in many ways, indeed some of those issues are still very alive in the UK, never mind in Zimbabwe. But I have to say with a champion like you Barbra I think deaf children and their parents in Zimbabwe have some reason for hope. I think you covered pretty well every area you could think of that needs to be addressed, and indeed it's quite consistent what we found when we were doing our report on disability that shutting away people, deaf people and people with disability and treating them as somehow cursed or bewitched or all kinds, just isolated, huge challenge. Thank you for that. Before we come to comments and questions, another speaker Mariska Layton who you will see from the notes is a consultant with Cochlear Europe marketing consultant, and particularly engaged with the problems and the risks associated with CSOM, inner ear discharge and so forth. Mariska is going to talk to us about that and implication in developing countries and will also stay for questions and comments afterwards. Barbra just wants to get her notebook ...

MARISKA LEIGHTON: Good morning everyone thank you very much Steve for this opportunity, and I am looking forward to sharing some information that we are looking at, specifically in the UK, and in South Africa and hopefully some of the findings that we have found through this health promotion campaign with healthy ears, is

advantageous to all of you in the room.

So, we are passionate this promotion, you need to hear regardless of having discharge in ears. The prevalence I will go into that in a minute, is quite high in children, to Barbra's presentation earlier it's one thing to make sure that we look after those children, that have discharge in ears because hearing loss features very highly in that condition. Not alone on the other condition under lining.

I am going to go through also management of discharge in ears, and then as well the proven solution.

So if we look at the WHO data the data we can see that hearing loss features highly in this set group of children and you can see that on the slide the darkened area is where the concentration and prevalence lays. But not only is it hearing loss, it's also associated with mortality. So when we start this health promotion campaign in the UK, we noticed that even in the western world in the UK we have gaps that we're facing, let alone in countries like Zimbabwe and everyone that you are representing today.

So in the UK, it has been in the media in 2010 and 2014, that you can see that with the infrastructure supporting hearing loss, in the UK with very active charities, that unfortunately these patients are not being treated correctly.

So where hearing loss occurs with discharge in ears is a conductive hearing loss, and it forms in the middle ear where there is fluid build-up and blockage, and if you have not experienced conductive hearing loss you know if you put your fingers in your ears it will sound muffled, so with treating discharge in ears, hopefully it opens up that canal which will then give auditory stimulation and for those children to hear whether where it is seen as a temporary fix, until to make sure that they have got auditory stimulation.

So the research we have done through this health promotion is we're working with

key opinion leaders in the UK and Netherlands and in Scandinavian countries, is that we can see that hearing loss is featured very lightly in the WHO document, on CSOM. So we're working with Professor Schilder who's a Dutch ENT surgeon on this to update this document, where we will have a strong line of clinical path way to ensure children with discharge in ears to have a hearing assessment. The hearing assessment is caused between 15 to 30dB so it's quite a significant amount of hearing loss in these children.

Then also to understand the gaps in the professional environment, where we can see in the UK, audiologists there was working with hearing-aids are not looking at patient with discharge in ears as a risk factor.

Then to the last point of the research is we also have a proven device which can be surgically or surgically, to ensure that children have that stimulation to help them with their speech and communication which is vital as part of this project.

So the management of hearing loss which I mentioned it affects their language and their development and also their auditory stimulation but using air conduction hearing it is a temporary solution with this condition, because as a am sure you are aware if you take a bacterial infection, you close it up, it creates a bit of warmth it will just manifest itself. It important to keep that ear canal open and with that is where the bone conduction hearing device comes in it's used at the back of the bone, and it can be worn with a head band to help that ear canal to be breathing, to help the discharge to alleviate to have auditory stimulation.

The management of discharge in ears, it can also be temporary looked after by making sure that it's clear not using ear buds, if ear buds are available, and when suffering with discharge in ears it's very important to ensure that you have some specialist or educated audiologist to help with the condition, as we can see in the earlier data mortality is also a big part of discharge in ears. So it's not to be taken lightly.

Meticulous follow up and this is what we have fortunately in the UK we hour ear care clinics but less so probably in the countries you are working in. It's good to educate those nurses and audiologists to ensure that it's meticulously followed up to ensure that the discharge in ears are clearing up.

To have always have hearing loss at the forefront when noting that a child has discharge in ears.

So we do have some information available on a website called I want to hear, it talks about prevalence, it talks about what I have just mentioned which is hopefully helpful. Thank you very much. (applause).

LORD BRUCE: Thank you Mariska. I think again, not a condition that I would particularly familiar with, and I think actually what you have got across to us is it's preventable if it's treatable, and if it's not treatable, there are serious consequences. So in affect the presentation about a specific condition, and presentation about the general condition of being deaf, being a deaf child. I guess what we're looking at is how you prevent it, how you can treat it, how you can support people who have deafness in whatever degree. We now have a few minutes for comments and questions, so perhaps if I can first of all ask my lovely assistant John will come round with a microphone if necessary, if you have first of all any particular follow up questions you want to put to either of our panellist if you could say who you are the microphone coming on John at the front if you could say who you are that would be helpful.

FROM THE FLOOR: Thank you very much that was excellent, really, I was frozen watching you two present your presentation. My name is Professor Gatrad, I am a paediatrician, born in Malawi, educated in Zimbabwe, but now working in Pakistan with the deaf children and other projects that we'll come to a bit later on. One question really that is you mentioned about Shona as being a language, just saying am not sure it's education, when you teach someone sign language, is it universal or do you have to

teach them in two different languages? I am not sure, I have never really come across that so the question is for example, people who have learnt sign language here, if they go to say Malawi or Zimbabwe, would they be able to, is it English or is it I don't know, or is it just universal so can you please tell us about that.

LORD BRUCE: Just press the button ...

BARBRA NYANGAIRI: Thank you very much, very good question. Sign language is different everywhere just like any other language, different dialects, in my country sign language is different from sign language in Harare when we teach in sign language we're using what we're saying is the native language of the deaf person in that particular space, but there is signed-English, and so that then makes it possible for us to teach in English because in Zimbabwe English is the medium of instruction in most of our learning and so it's different everywhere.

FROM THE FLOOR: The problem is as a paediatrician I come across people who are bilingual and sometimes there is delay in speech, even in a normal situation, my question basically because I am involved with deaf children a broad, I am not very clear from your answer, whether we should be just teaching the children in English i.e., is there the English format or do we do it in Urdu for example, and just follow Urdu sign language, how long does it take to make, Shona sign language for example, how long would it take to become a sign language specialist or a teacher for Zimbabwe for example. I know it's a difficult question.

BARBRA NYANGAIRI: Right, thank you very, very difficult but I think for us as parents, the experience has been that you would have a deaf child and you probably do not know how to communicate with your child because there not much support that is provided in sign language training, for you as a parent, and countries where there are so many other centres you can go to. We have used what we call home signs in the home, to just get by, they are not comprehensive, that language is not very deep and so you find that that is created lots of limitations for our children in terms of vocab,

and expressing themselves and also it's limited to I am hungry, I want water, do that don't do that. Things like that. We as an organisation are actually working at developing sign language, and creating signs that are more comprehensive that are more abstract, and that would allow for better learning opportunities. I think it takes a real while for you to then become a fluent sign language user in role of the deaf adult is very important in teaching us the correct sign and sign language that we should use. But every country has a different situation and so it has to be contextualised in that way. I hope that answers a bit.

LORD BRUCE: Just to comment, I think there is a professor at the University of Copenhagen who has studied sign languages, and there are as many sign languages as spoken languages, some with common routes and some signs which are absolutely obvious and the deaf people know what they mean, but it is quite complicated to deliver on that. It takes three years to qualify in British Sign Language, the same as it would take you to qualify as an interpreter in French, so it's important to understand that it's a fully developed language, it's complicated.

But I think, from your point of view, the issue is, is there some basic communication skills that you can acquire, and the answer has to be yes. I am exactly in that situation. I have only done a basic sign language course. I feel very guilty; I am thinking about trying to see if I can do a refresher course. It is important to understand, you can get some basics, and that's helpful, but if you want a fully qualified interpreter, you are talking fully qualified and that takes time. Barbra has also pointed out the practicalities of building it up.

FLOOR: May I add a couple of points to what Barbra so ably responded. I am Joy Rosenberg. I am a teacher of the deaf and an educational audiologist. Two brief points. One is on your first question about how many different sign languages are there, appeared just as Barbra answered, as many as hearing languages, and I have worked in Asia for a very long time and travelled - a long time ago, I meant to say - I travelled where different sign language was used. Sign language users, whether

hearing or deaf, can communicate with one another much more readily when they land in a new country than can people with spoken languages, I think because they are practised and experienced in overcome kg communication barriers and also keen and eager. That's one thing.

The other thing is, your question is how long would it take for a child who has just come to you, and learning sign language, so this has a lot to do with development of language initially, and children of course are beginning to learn language even before they are born, we know now, and up to zero to two years of age, the learning curve is vast and it tapers off after that. If a child comes at eight or nine years old and has had no basis of language learning, either auditorially with hearing aids or cochlear implants, or visually by sign language, that's going to take very much longer than a child who has had at least some access and you are building upon it. There's lots more to talk about, but I shall leave it there for now.

LORD BRUCE: Thank you.

FLOOR: Good morning. I am Paul from Uganda. I have an experience to share and then a question. Our experience in Uganda about sign language, we agree it is varied and we have over 52 languages in the country, but we have taken a stand. The deaf community and the partners, we have lobbied for the sign language to be constitutional. It's in our constitution and it's an independent autonomous language. When we are teaching a child, the instruction on everything is in sign language, not signed English, not Ugandan, not any other language; it is sign language. So I think, for children, Sign UK supported us to start a pre-school programme. I think I have broken the microphone, sorry! I might be more amplified than the microphone!

Sign language, with support from Sign Health UK, we started a pre-school programme. Say the parents you are working with - if a deaf child is starting education at the age of 10, 11 and more, because they never had an induction, as the family is struggling, they have no access to the system in the country, so the situation is almost the same as in Zimbabwe.

So, what we have done, by starting the pre-school child development programme, we are encouraging children to come to school at the age of three, four, maybe below five, so for those children they are able to learn and sign almost more fluently than

any other adult, even in one or two years, because they are beginning on the principles of sign language communication and socialisation.

Sorry, my question was how much, from the Zimbabwe perspective, because therefore it takes so long, how long have you engaged and involved the deaf community and other players, because parents alone cannot make any headway without the deaf community.

BARBRA NYANGAIRI: Thank you very much. Definitely parents alone cannot make much progress without the deaf community. We work very closely with the deaf community, and particularly as the owners of the language, they are better able to help us in harmonisation, in developing the language, and one challenge that we have is that even though they do not have subject-specific sign language for the different subjects that are taught in school, and so we have been working at how do we begin to create the different signs for the different things that we are learning, and some words are more abstract, and therefore require us to think through, and so we do work together with the National Association of the Deaf and other groups that are working with the deaf community. Thank you.

LORD BRUCE: Another question here?

FLOOR: I am Suheir al Badernah from the Palestinian Red Crescent Society. My question to Barbra, she says that you detect the hearing loss very late. What is the average age of detecting the hearing loss?

BARBRA NYANGAIRI: I think the average age would be around seven, six or seven, when they start school. It's at the point when they are in the classroom that the teacher says, "I don't think this child is hearing me", and many times, because of the denial in the home, there are either excuses that the child started talking late, they cut out the bottom part of their tongue, they put things in their ears, and so there is recourse to so many other things that are not medical, and as a result of the delays, it's about six-seven years, that's when there is like confirmation, and so the ministry of education has got an audiological centre, but there is one in the country, and so every other parent has to come there, so you find that it is not visible, because of the status and the logistics, and when you come you may not find the audiologist there, and so we find that, because of that, there is very little detection of deafness at an early age.

FLOOR: (Suheir.) Could I continue? The other question is, do you find the families accepting teaching their children sign language, or they believe that it will affect their ability to communicate orally? And I have another, not regarding the sign language. According to our experience, yes, you say that we have different sign languages, but according to our experience, when deaf adults meet, even if they are from different countries, they could communicate to a certain degree together, because sign language is the body language, things from their environment, facial expression accompanying sign language, so it's easy for the deaf adults to communicate, even if they have two different languages, to a certain degree, to a level of communication. Thank you.

BARBRA NYANGAIRI: I think the family, we have a lot of work to do with the families, and there's one thing that we have been working on and copying from Steve's work on positive parenting, and so we have been able to come up with psychosocial support sessions for parents in order for them to be more accepting and to move away from the shame, because it's not shameful at all. You know, to move away from the discourse of witchcraft, because that's not really true. So it's issues of genetics, issues of diseases, that have caused hearing loss, as she has explained. We have heard so many situations of children that have discharge coming out from their ears, and they have not been provided support, which has been given paracetamol instead, so we are looking at how to make families more supportive and more accepting because of the community that's around them and the discourse of the way you find hearing loss is located does not provide for a lot of support for the family. And the variations, yes, they are there, and you will find that adults from, deaf adults from one town can communicate very well with deaf adults in another, and there is a different dialect but they are still able to understand. In this region, they use one sign, in another region they use another sign, and they are able to compare the various signs that are used.

LORD BRUCE: Can I ask Mariska a question. You indicated how serious the condition was, some of what you said was fairly technical. But in a developing country, are there a number of things that you could do that would be simple and achievable to diagnose the condition and treat it, because clearly that's what you are looking for, is solutions that are not going to frighten people off?

Mariska: I think what we have found is the education of the working professionals in the hearing community, I think it is connected with hearing loss, and many professionals that don't deal with hearing loss don't think of testing for hearing loss, so they just treat it with, as Barbra said, with paracetamol. So a takeaway maybe is to look at educating professionals in the hearing loss community to look out for the signs, and then if there is an outreach clinic, that they can make sure those children are being seen, to see the severity, and if that discharge can be dried up, and hopefully with auditory stimulation to open the ear canal.

LORD BRUCE: Another question?

FLOOR: I am Anu, a consultant physician based in the NHS and a qualified paediatrician. Thank you, Barbra and Mariska. They were brilliant presentations.

One remark really, about children and sign language. We all know that up to the age of five the brain plasticity of children is remarkable, and their ability to learn language or languages is very, very vast.

So I think trying to embed the use of sign language is really, really helpful, particularly in the deaf communities, and I think particularly breaking the barriers between parent and child to increase bonding, that is helpful. So I think that's really important, because under the age of five, children really learn very quickly, and having that ability, when children have that innate ability, I think it is everybody's responsibility and duty to make sure that children learn to be responsible adults and they are the future of the model.

LORD BRUCE: I am just checking if there is anybody that hasn't asked a question. This lady here, and then back.

FLOOR: I am Fred Marinus from Royal Dutch Kentalis Netherlands. I have a question for Mariska. I can see that nowadays quite some children in Africa can get a cochlear implant from India. The amount is still very low, but you also mentioned that we know it that there are a lot of children with middle ear problems. We hardly see any children with BAHAs, with bone anchored hearing aids in Africa. Do you know what the reason is for that, because they are cheaper than cochlear implants, they are less invasive, but still you don't see them. I only saw a few, and I saw already quite many

children with cochlear implants. I don't get the reason for this. Do you have an answer for that?

Mariska: Cochlear is present in South Africa, which is increasing the awareness. And to your question, it's the lack of awareness that implants are the solution, that has the benefit of both non-surgical and surgical. So I think it's about increasing that awareness, and we are working with our distributors in Africa and working with local communities.

LORD BRUCE: I think there's a couple of questions in front we're running out of time.

FROM THE FLOOR: Just a very quick question, you were referring to deaf link, deafness with regards to which witchcraft I am wondering whether there are any reports of deafness, whether it's prevalent that people believe deafness can be cured via witchcraft as well as inflicted by witchcraft.

BARBRA NYANGAIRI: Yes, and so that results in late help seeking behaviour, with regards so we believe that our child is deaf because of witchcraft so we will resort to witch doctor to try and cure it, and so in trying to cure it they have u various ways like cutting down, they believe that if we cut something underneath the tongue that the child will talk, or if we pour milk and chicken's blood in the ears the child will talk or we cut up certain places so as a solution, and of course definitely. It then results in delays and probably worsens the hearing loss if we would quickly go to the hospital and get assessment or treatment if theirs discharge that would be preventable. Many of the cases we have experienced as a parent talking together with other parents it has been result of the discharge that has caused that has not been treated correctly and earlier, that has caused severe hearing loss, and at times medication, TB, meningitis, childhood meningitis has also caused hearing loss. These diseases have not been treated quickly as a result that has affected so yes we look at witchcraft as a cause and we also go back to the witch doctor for a solution.

LORD BRUCE: Right I think sir you want to come back.

FROM THE FLOOR: Just to make a comment on one thing which I think is even in England we find people who perhaps in those children there is sometimes a delayed language and speech development, they want the tongue tie sorted out. Just a comment. The other thing is in developing countries we're talking about chronic otitis media, a lot of people probably sorry to be pedantic here in the medical sense the infection will properly be gram negative infections, some of the bacteria that are killed off tend to be with antibiotics that are perhaps more expensive, so I think it's probably better route to have more expensive antibiotics clearing otitis media, which even if you give penicillin they are cheap, you may not clear this infection so that's what my question is, rather than you King cochlear implants and BAHA and all the complicated stuff if there was access to more expensive antibiotics there would be much less expensive than the invasive or perhaps part invasive stuff.

MARISKA LEIGHTON: Through the research we have looked at antibiotics currently in the pathway in the UK are used up to 6 times before being referred. With CSOM it's recurring if it's recurring it should have a long-term permanent solution. Sometimes it's a mild bacterial infection that can be treated through the antibiotic, however if it's recurring it's a more severe condition which then reoccur unless that ear canal is left open all the time. So that's the current research we're looking at, is we know in the UK it's recurring through antibiotic use, and the canal is occlusion through the discharge it's making sure the canal is open. There's a few pathways so it's the mild one then the more severe, and we're looking at the more severe because it's unfortunately (inaudible) we have patients that we know off that have recurring ear infections for 10 years in the UK with infrastructure that have not been treated. So we're trying to create that awareness it's a solution, be it surgical or nonsurgical.

LORD BRUCE: There are more people with questions but we're due to have a coffee break I am told the coffee is here. We're also first of all the coffee break is also your opportunity to network, so you scan can ask your questions, secondly thereafter other panel discussions afterwards, so the questions and comments can still come in. So

what I am going to suggest is we adjourn for a coffee break now, by all means network ask your questions, but remember there are other opportunities afterwards. So let's go and have a coffee.

(Coffee break).

JOHN COSTER: Ok everybody shall we make a start again please. Thank you. Just before we start, a couple more housekeeping just to help it was noted by a few people that this light here is affecting the presentation at the front so we had it changed on to this screen as well, hopefully that will help some people at the back, also increase some of the volume. A final reminder that this evening there is a social gathering at the front line club from 6 pm to which you are more than welcome. Steve has asked me to point out we do have all your telephone numbers we will be ringing you to make sure. (laughter).

LORD BRUCE: Too busy networking to catch up with the programme, that's my problem. From what I can see and what I heard during the break, a lot of networking was going on which is good, and I'm sure it will continue. Steve of course is the arch networker he does it globally, but I think this is what the conference is all about. So this session between now and lunch, is a speaker then a panel, and when I call the panel up after proffer Smith has spoken, and in order to get on to the questions I will just ask them to introduce themselves very briefly so we can take questions and comments, but I am in little doubt that the conversation is lively and will continue to be so.

So, Professor Smith from the international centre for evidence disability, is what I understand, he's really going to address A) prevention, and just how you deal with these issues. If you see from his CV he has a huge hinterland of understanding of both the medical, social and the impact in developing countries of these issues but I think he can tell you much better than I can, what the issues are. I am going to ask him to

speak to us now and then if the panellists can be ready after he has spoken to come up

so Professor Smith.

PROF ANDREW SMITH: Thank you. Lord Bruce and Steve, thank you very much for your

kind introduction. I am delighted to be here today, it's a great pleasure to have the

opportunity to address you all. Also to talk about some of my favourite interests which

particularly are public health. So let's start.

Does anybody know who these two ladies are? Anyone?

FROM THE FLOOR: Helen Keller.

PROF ANDREW SMITH: Yes which is Helen Keller.

FROM THE FLOOR: On the right.

PROF ANDREW SMITH: No.

FROM THE FLOOR: On the right.

FROM THE FLOOR: On her right! (laughter).

PROF ANDREW SMITH: Helen Keller is on the right, a lady called Anne Sullivan is on the right, as most of you probably know Helen Keller was born both blind and deaf, but her companion Anne Sullivan enabled her to communicate with the world. She was a very good communicator, she said some very perceptive things. For example, many of you probably know this quotation. "Blindness separates people from things, but deafness separates people from people." Which I think is encapsulates it very clearly, but she also spoke about deafness, she said "I am as deaf as I am blind, but deafness is a much worse affliction." Not so many people know that but she obviously felt that being able

to communicate and listen to sounds was more important than vision. It's interesting

actually that the Helen Keller Society, only deals with blindness, they don't seem to deal with deafness as far as I know but way that was just by way of introduction.

What I would like to do today, is to kind of set the scene from a global perspective in terms of, first of all the WHO definition of hearing impairment, that's already been mentioned this morning by the lady from Zimbabwe, and I would like to explore that little more. Then to look at the size of the problem, both globally and regionally. Particularly focusing on developing countries, or as we like to say now, low and middle income countries. I would also like to look at the causes of hearing loss, and the consequences for people in society, for individuals in society, but relate that to the need to raise awareness and the difficulties of that. We probably all realise and know that is very difficult to raise awareness in this field. Then I want to go on to look at public health strategies, and interventions, because I believe that these are one of the key ways to address this huge problem of hearing loss in the world. I will give you a brief overview of what we do from the London School, running short courses on public health planet and then finally if there's time after this great long list, I will give you three case studies from my experience on the courses in different parts of the world.

So first of all, not all of you may know what we mean by hearing loss, or hearing impairment, some of you perhaps don't agree even with that terminology but I often use this on our courses. It's taken from a magazine for Australian teenagers it shows the different sounds according to their frequencies and according to their intensity. So across the top you have got frequency, and on the vertical axis have a got intensity, getting more intense so low intensity sounds and low frequency might be an ocean higher frequency but low intensity will be rustling leaves, as you get more intense, higher decibel levels you get tomb confidential, this is this so called speaker speech banana where you have different frequencies according to different pronunciation of different letters in the alphabet or different phrases, conversation increase in frequency and intensity, increasing intensity until you get extremely intense down here, rock bands, jet aircraft taking off and so on we can relate this table to the WHO levels of hearing loss. So this is what I am trying to do. These levels of hearing loss,

the WHO puts mild hearing loss at 25 decibels if you have got a mild hearing loss you can't hear any sound that's less than 25 decibels. You can see where that is, it's the sort of sounds you get in a library. Then if you have got a moderate hearing loss, the WHO says for adults that is set at 40 decibels so it cuts right across the speech banana, for children they have set it 10 decibels lower, so it's even more of an issue for children. Some people disagree with that demarcation, but it's still what is used by the WHO at the moment. Then severe loss is at 60, and profound loss at 80. So you can see that if the telephone is ringing loudly, you may just hear it if you have a profound loss, but generally you may not hear it. Lord knows other thing are louder than 80 decibels then hearing damage occurs when any of these sounds, when you hear these sounds the very loud sounds, over a long period of time, so chainsaw, rock band, listening to loud music for example, that's a key issue nowadays. That's usually at higher than the recommended intensity. 85, any sound higher than 85 decibels which is this line here, would be considered as a risk for noise induced hearing loss.

So those levels are the same as these levels here, the WHO grades, but all I want you to look at here is this group - moderate hearing loss, children and adults, severe hearing loss, profound hearing loss. These are all grouped together by the WHO which calls it "disabling hearing impairment". Again some people are not happy with that terminology. Perhaps "disabling" can sounds a bit pejorative, but it's an average hearing loss.

If we look at the size of the problem, taking in mind that definition, it was actually mentioned this morning that there are 360 million people in the world with this so-called "disabling hearing loss", moderate or worse hearing loss. It is excluding all the people with mild hearing loss, but these are the people with moderate or worse hearing loss. That's been increasing. I will show you a slide in a minute showing how it's been increasing quite dramatically over the last few decades. 328 million of those are adults, and 32 million are children. So 32 million children in the world, in 2012, so it's probably higher now, they had or have moderate or worse hearing loss, as defined by the WHO. But if you include mild loss as well, then the figure is more than 1 billion. So about 15% of the world population have mild loss.

If you add that to the 5% who have moderate or worse, you get a total number of over a billion people with any level of hearing loss. This is obviously a massive, massive number, but 80% live in low and middle-income countries. Today, we are focusing on children, this 32 million, but 80% of those live in the developing world. That's why we are focusing on the developing world from the London School and why I think this conference is focusing on that group. From a public health point of view, which is where I come from, this is where we have to, from a global public health point of view, this is where we have to focus our activities. This graph shows the increase in these global figures since 1985, WHO said there were 42 million, it trebled by 1995, by 2005 it doubled again and it's 60 million in 2012. So there has been a dramatic increase over the years in the figures.

You might say why is this number increasing, and also why are there more people with hearing loss in developing countries. It's partly due to the fact that there are more people in developing countries, but you might like to think about that and we can discuss that later during the discussion time.

So, just looking in terms of the severity at this pie chart, it just puts into a pie the different levels of severity, but you can see the blue slice of the pie is by far the largest, which is the mild hearing loss. But we know now that mild hearing loss in children is important, particularly in schooling. So the WHO has sort of ignored that a little bit in the past, and there has been a move to change these levels to take into account more about mild hearing loss.

And then, as the severity increases, the actual numbers decrease, so the people with profound hearing loss, 20 million in the world, are the smallest group.

And then this graph from WHO again, and we saw this this morning also, shows where the severity is worst. It's rather lumping together some of the figures, but in South Asia you have the highest figure, together with Russia and Central Asia. Then you have sub-Saharan Africa and Latin America, and then you have North Africa and the Middle East, Australasia and the developed world in North America. So those three different groupings.

But if you look at these figures by region - and these are the World Bank regions - it shows these are the millions of people, it shows that by far and away the largest

numbers of people with hearing loss are in South Asia, and that's India, Pakistan, Bangladesh, Afghanistan, and one or two other countries in that region. Some people might be surprised at that, but that is certainly where the largest numbers are, and they also have the highest prevalence. This is overall prevalence. It includes children, but 6.4%.

And then the next highest is East Asia, which includes China, and again a huge population number. Then lesser numbers. In the high income group, the developed countries, these are here. The ones with the lowest numbers are actually in the Middle East and North Africa. That's probably because they have the lowest numbers anyway, in that region.

It's not a consequence so much of the severity of the hearing loss, although in fact it does seem as if their prevalence figures, that's the percentage in the population, sorry, have lower prevalences than in other groups. We don't quite know the reason for that, whether that is true or not.

Looking at the childhood figures, going back, there are some green columns here. If we redo the graph to show these green columns just for children, again, we have the highest numbers of children with hearing loss in South Asia, India, Pakistan and Afghanistan, 2.4%. The next highest is in sub-Saharan Africa - so all the African countries, huge numbers there are. Lesser numbers in East Asia, Latin America and Asia-Pacific. So, again, if we are talking global public health, or at least regional public health, we should be focusing on South Asia and sub-Saharan Africa. Those are the countries or the regions, particularly sub-Saharan Africa, the needs are greatest, but the resources are the lowest, as all of you are aware.

Another way of looking at hearing loss is the burden. We were looking at the prevalence, the numbers of people with hearing loss, but we also ought to be able to use the severity of hearing loss - somehow measure the combined severity of all the people with hearing loss, and incorporate the severity of the hearing loss or the severity of the disability, if you like. This has been done by the WHO and other groups looking at the level of disability in all different health conditions, and there was a big initiative funded by the Gates foundation, the \$10 million programme, to look at the global burden of disease.

It sounds rather dramatic, but every condition which causes ill-health was measured for the burden of disability that it causes, and then all those conditions were ranked, from 1 down to 120. There were 120 different conditions. When you look at the top 12, you can see that hearing loss ranks at number 5, out of all these conditions. The top ranking was low back pain, followed by major depression - this is in 2013 - followed by iron deficiency, anaemia, followed by neck pains, and fifth was hearing loss. So hearing loss, as a cause of global disability, is a very large contributor. I think governments and NGOs have ignored this for decades, but this is strong ammunition to show, to encourage, to stimulate governments to pay attention to this burden of hearing loss, and the economic consequences that it causes. I will come on to that in a minute.

But I think we shouldn't ever forget that deafness affects individuals. Sir John Wilson was talking about this when he was asked about the numbers with deaf, how people go deaf. He said we should never think of statistics, the whole numbers. People go deaf one by one, or people go blind one by one, so always remember the effects on individuals. I collected some of these slides from around the world.

We know that hearing loss can damage speech and language and cognitive skills in young children. We know it can slow school progress. This is a photograph I took at a school in Kenya. The teacher had asked the children a question and everyone put their hand up except the little girl at the front who had a puzzled expression on her face. Maybe the teachers thought she was a bit backward or stupid, but the likelihood is she had a hearing loss.

Then of course it affects people obtaining a job. It causes job problems, when you've got a job, and it causes stigmatisation and isolation. We heard that described very well in Zimbabwe, so I think that happens in many countries. This picture was taken from Nepal. This man had brought his teenage daughter. She had never been to an ear clinic in her life but she had been deaf since birth. I think it just shows she was very shy, very reserved, and she was probably kept at home and not allowed to mix because it is such a stigma to the family to have a hearing loss and she probably wouldn't be able to find a husband in that community. Luckily she was able to get some form of treatment, and for her hearing loss.

Hearing loss is related to poverty, and in fact this is just some graphs that demonstrate that. Hearing impairment prevalence in children increases as the income in a country decreases so if, the lower your national income in a country is the higher the prevalence of hearing loss. This has been shown by this graph from WHO. So that's one thing. Another thing is the relationship between the parents' literacy and the prevalence of disabling hearing loss. As the parents' literacy rate increases, the prevalence of childhood hearing loss decreases. So there seems to be some relation to literacy this is all linked up with poverty. Hearing disability and the poverty trap, this applies actually to all disabilities, but it's particularly marked for hearing loss. Hearing loss leads to poverty, but poverty also leads to hearing loss. So you have a circular, or vicious circle the disability poverty cycle. It's particularly marked of all disabilities in hearing loss.

This slide just draws attention to the economic costs of communication disorders. Most of the work has been done in the developed world, in the USA they showed that hearing loss led to, it affected the total amount was 3% of the gross domestic product. In Australia it was over 1% of the gross domestic product. Huge economic affect. We need to find data on this from the developing world. This sort of data will convince governments and big NGOs where should they put their resources because there is a huge economic cost from hearing loss.

As you all know it's very difficult to mobilise resources against hearing loss. Why is this so? Well, we have talked about the negative perceptions, blindness evokes sympathy in somebody, but usually deafness evokes irritation. If somebody has a hearing loss, they can't hear what you are saying or could you repeat that, or you know, people feel irritated even somebody who knows, is a good friend would feel irritated so deafness causes irritation. There's also a huge amount of ignorance about what is hearing loss like. We play an exercise in our course, right at the beginning we have audiologists, ENT specialists people well used to dealing with people who have a hearing loss but we get them to put ear plugs in their ears and then they go for coffee break, we have some crunchy biscuits or something to eat, then come back after the

break and describe their experiences. Many people have said that this is a revelation, they have never really understood what it's like to have a hearing loss. They say I felt embarrassed or I felt I didn't want to speak, or I felt I was disconnected or somehow felt disempowered. So just that small experience of 15 minutes wearing ear plugs and trying to communicate with people, really revealed to professionals who dealt with it for years what it was actually like. That something we need to do. We also need to demonstrate the costs of hearing loss to society, and also the need for prevention and rehabilitation. We also need to know what the true size of the problem is, because these figs I presented from WHO are actually based on very soft data. It's not very good data. We need more surveys, I was involved in doing surveys at the WHO but it's quite time-consuming, they are very costly, and there are only a few being done in the developing world. So for example we only had 2 countries Africa where they had surveys. There's more needed. These problems lead too lack of political will and a lack of programmes and a lack of resources, so these are all some of the difficulties. Human resources, WHO has shown there's a huge lack of specialists in countries particularly sub-Saharan Africa but also in south Asia, audiologists and speech therapists. And there's to some extent in Latin America. Hearing loss is a huge problem in the world, most of the burden and need is in low and middle-income family countries. How do we deal with hearing loss in a situation like this? This picture was taken on the road from airport of Cape Town to city of Cape Town and it's actually you are smiling I think you must recognise it. It's an area of slum dwellings it's a township, in Cape Town so we always think of Cape Town as a beautiful city but it has some very poor areas. How do we deal with urban poverty like that, or rural poverty like this? This is an ENT clinic in Malawi, I it has to be held under a tree because there was nowhere else to have it. So how do we address that? Well I think personally, the answer is to reorientate our thinking towards the public health approach. This is especially for the clinicians who deal with ENT and audiology and paediatrics and so on. So what do we mean by the public health approach? Well we all know clinical medicine, we go to the doctor for a problem, the doctor makes a diagnosis, prescribes a course of treatment, then may ask for a follow up. That's clinical medicine, that's a one-to-one situation where everybody does that. That shows that consultation,

treatment and follow up. Health of individuals. Public health is the health of populations. So instead of doing a consultation, you do a survey. You have to make a diagnosis in the population, what is wrong with the population so you do a survey to do the size of the problem, and the causes of the issue in the population. Then you have population interventions, for example you may have prevention, different types of prevention, you may have other interventions. Like treatment of chronic otitis media we heard about this morning. If you do that on a large-scale, which in a planned way and in a planned programme, targeting where the need is greatest, then that is a public health intervention. The follow up is you do another survey. Maybe 5 years later, you resurvey the people to see whether you have been effective in your interventions.

Public health as well as the medical model, it also looks at the social model. So as well as thinking of problems as personal problems, also think of them as a social problem, and you need instead of medical care you might need social integration or social action, instead of personal adjustment it might be environmental manipulation. All these things, human rights social change, are all part of the public health approach.

The route to prevention I think, first of all you need to develop this public health orientation. Then you need to find ways of making a difference in a population. The way to do that is to target conditions which have two characteristics, first of all they should have a high prevalence because if you are going to make a difference there no point in dealing with rare conditions, so high prevalence, but you also for that same condition, need to have an effective means of controlling it. Or treating it. So if those two things go together you can start setting up public health intervention. So what you might do, is these are all the causes of hearing loss, but they have been divided into three groups, high frequency, moderate free consequence signed low frequency. We see chronic otitis media presbyacusis and ageing, you have the moderate frequencies like noise, ototoxic drugs infection and so on, foreign bodies, wax, they are quite common. So we should deal in public health we would address these the red circle and the blue circle but we would probably be less involved with the green circle. It's not to

say you don't deal with those, but the low frequency causes can be dealt with by clinical medicine.

The other criteria, the other key criterion for an intervention it should be cost effective, it's something that government and also NGOs pay attention to, that get the biggest bang for the buck. Make sure that the intervention you use is both effective, and you can afford it and you can measure it cost effectiveness, WHO does a lot of that.

Some programmes that I think should be cost effective in this field, although they have not actually been measured, so are these. Primary ear and hearing care, is a key intervention, I think, and that could be a cost-effective measure, providing affordable hearing it is on a massive scale. Training for programme planning, which we do in our short course, I think that could cost effective intervention, and setting up national and global programmes to reduce the burden of hearing loss. Although we don't have the evidence yet we need to get, it all those should be cost-effective. These are the WHO training manuals on prime ear and hearing care this is the when we set up the WHO guidelines on hearing-aids, we recommend that the price of a hearing-aid should come down to 20 dollars, it's still not enough supply of hearing-aids in developing world, we need about - if we need to cover everybody we need 30 million hearing-aids yearly in the developing world. WW hearing has been set up to deal with that, our course that we hold we hold it in 7 different locations in mainly in (name). I have just been to course in Hyderabad in India I am going to Lima. We also held it in Cape Town and Nairobi, we have so far taught over 600 health workers in public health planning because we need, we think people need to learn about public health planning in order to make a difference, in order to plan programmes to make a difference. this is what we do. We hope to develop a cadre of persons in the developing world who can set up these public health interventions against hearing loss. This would contribute to burden of hearing loss to reducing the burden all though we still need to find funding for this it's difficult to find the funds to do this.

So, WHO, quick just a few minutes on the role of WHO. It's becoming increasingly active under the leadership of doctor Shelly Chada who is now responsible for the deafness programme at WHO, producing a lot of information, multi-country assessment of national capacity. Situation analysis tool, planning and monitoring of national strategies, manual, it has world hearing day every third of March, this year it was particularly relevant because it was on childhood hearing loss, act now here is how. And there's been a report on newborn and infant hearing screening, another report on childhood hearing loss out this year. A report on the world hearing day.

The last thing that's happening at WHO which I want to draw your attention to is that, next year, there will be a new World Health Assembly resolution on prevention of hearing loss. The last one in WHO was in 1995, so 20 years later we are revisiting deafness, or WHO is revisiting deafness. Blindness has had far more resolutions than deafness, but at least there will be one next year, hopefully, ratified by all countries of the world on prevention of hearing loss. This will stimulate and encourage countries and governments and NGOs to address the issue even more so, so I think that's going to be very important.

Just now, briefly, in the last few minutes - can I have another five minutes? - we are just going to talk about planning. I am not sure if you can see the slide. This is the planning cycle. There are four components of that.

The first step is the situation analysis, where you assess the needs in the community, and you assess available resources.

Then, when you have done that, that will help you to determine your priorities. You then set those priorities and convert the options into a plan of action.

Then, once you have produced your plan, you implement your plan, and that's the third section, put it in motion and monitor the progress.

Then, in the last component, you evaluate whether or not your project, or whether your programme has made a difference. That, in essence, is the planning cycle. This is what we teach on our course. You need to set an aim. The aim is to initiate action for prevention of hearing loss and deafness through capacity building and planning. That's the why.

Then you set the objectives, how do you do the project. So you put in more detail, to develop and deliver an annual short course on planning. To train 15 paediatric nurses for eight neo-natal clinics, and so op. These are the objectives.

Then you set a timetable. Each objective has a set of activities, a timetable and a budget. At the same time, we incorporate the help systems approach. This is very much promoted by WHO. We need to hook at systems within the health system when we are setting up these projects.

So I will quickly show you these case studies. This is one from Khayelitsha. These studies are taken from the courses we run. We divide the course into groups and give them the task to devise a project at the end of the week on somewhere that they know. There was a group from South Africa in Cape Town who devised this project for their town.

First of all, they did a situation analysis. They found out the population of the town is about 400,000. The number of children is about 60,000. They looked at the number of people with hearing loss. They found some data, but the key point was that the number of children with hearing loss in the town was not known. There was no data, so what were they to do?

They did at least have an idea of what the causes were. There were high rates of otitis media, usually in poor communities you find very high rates of acute and chronic otitis media. HIV Aids and TB, moderate. Genetic, inherited causes were high. There were also perinatal problems. This is part of their situational analysis.

Then they planned it according to the geography. They look at the affected population. 40% of the population were unemployed, so there's huge poverty there. They looked at the healthcare institutions and what was the health workforce. Very poor, only two audiologists and two speech therapists for that huge community.

Then they looked at other resources available, and then service delivery. There was no dedicated funding for ear and hearing care, so they had to then set up their aim, to reduce the burden of hearing loss in children living in the town by 25% in five years. Having assessed the situation, then they decided what they wanted to do. They set out a list of objectives - I am not sure if you can read those - but there was a list of the

objectives. Each of those had activities and each had a timetable and a cost. So that just shows what can be done.

Some of the points I think you can get from this case study, the squalor and poverty may co-exist side by side with affluence. This township, this slum area, was just right near the airport. There is a huge need in such places, but very poor capacity and the lack of political will from the politicians to address it. Nobody has done anything about this problem for years. Yet there are very enthusiastic and committed people there. There was a school for the deaf there and it was actually marvellous. It was very inspiring to go there, to see what people were actually doing with incredibly limited resources. They need training, they need more resources, and of course external assistance is needed, but it must be provided in a sustainable way, because that's the vital thing. That was one of the most, one of the best studies that we had. The project that they proposed hasn't been put into action because the money hasn't been made available, but if such similar projects like that could be made in different countries, on a larger scale, and addressing other causes of hearing loss, with adequate resources, you could make a difference. So I have probably run out of time.

John Coster: Perfect!

PROFESSOR SMITH: I have two more case studies, but I will leave it there. I was talking about the Kenyan National Plan and also a study from India, but I think I will save those for later, in case we want to discuss those.

My conclusions. Hearing impairment is an urgent public health challenge. I strongly believe that, and I think the World Health Organisation, which is the largest public health organisation on earth, also now is beginning to believe that.

There is insufficient global data on the size of the problem, and on the key causes such as otitis media, noise, drugs, presbyacusis, and so on. Over 50% of hearing loss can be prevented through activities integrated into the health system. There is a critical shortage of human resources trained in this field. That is one of the key needs. But there's also a huge shortage of programmes targeting childhood hearing loss in these countries, so that's why we are here today. The final point is that funding and advocacy needs to be strengthened, I think, for public health communities for hearing health.

I give the last word to Helen Keller. "Alone we can do so little; together we can do so much." Thank you very much. (applause)

LORD BRUCE: Thank you very much. That was a very thorough overview, and so many of the challenges that we I think are familiar with, but encouraging to see it going up the international scale. Particularly at WHO. In my lifetime, the battle has been to get deafness addressed as a serious issue. It's the hidden disability. Every time people talk about it, it's the one that doesn't get noticed. However, Professor Smith is now going to take responsibility for the Panel, so those who are on the Panel should perhaps come up. I am going to vacate the Chair, because otherwise it's going to get too crowded up here. So can our panellists, Dr Williams, Joanna Clark, Fred Marinus and Stuart Harrison come up, please.

## Panel discussion

PROFESSOR SMITH: Can people hear what I am saying? I will probably use the microphone. So, I think we are now going to look at some of these issues that have been raised, both I think earlier this morning and in my presentation now. Who would like to start? The lady here?

FLOOR: Hello. I am Philippa from Deaf Child Worldwide. I was very interested in your presentation, thank you. I want to talk about double tab poverty. In the world we always talk about women finding themselves in poverty because of the lack of education, early pregnancy, et cetera. If women are educated, then that can alleviate the effects of poverty. So I wonder if deafness is similar. Poverty, you have said, is created by hearing loss, but I wonder if poverty is in fact, rather than being created by hearing loss per se, is created by the effects of lack of education that come about because of hearing loss.

So, when you look at more wealthy people, they have funds available to send their deaf child to a deaf school in India, for example, and therefore the effects of poverty do not have an effect on that particular deaf child.

So I wonder if there are just simply not enough specialist resources being distributed around the schools where deaf people are educated, and can I have your views on that.

PROFESSOR SMITH: Would somebody on the panel like to start?

FRED MARINUS: I am Fred Marinus, I am the project manager for international projects for Kentalis, which is a Dutch organisation which deals with care and education for deaf people. We work in many also African countries, and one of the things we see, indeed the education of girls stays behind that of boys, but there is also a stigma from parents thinking of "Why should I invest in this child, who will not be able to learn something?" Even though a lot of countries now have the free education policy, and children don't need to pay for the tuition fees at school, still they need to pay for transport or pay for uniforms, and a lot of parents, I know in Africa, especially, if they have a deaf child, they will keep it at home to work on the land because they don't see any future for that child. Therefore, we have, at Kentalis, together with deaf education in Kenya, has produced a documentary or some video clips about deaf role models, to make parents aware of the possibilities of their child, and to take away the stigma that deaf people are stupid and are not able to learn. Even though they don't have the possibilities to have all the academic skills or get a very high education, even in lower professions, they can earn a good living, have a family and be meaningful for society. So it is very important to raise some awareness with parents. We do that in different ways. We also heard this already this morning, to let people know that deaf people are able to do something, and still I think we have a long way to go, especially about girls. That remains a problem, I think, in society, but specifically also for deaf children.

JOANNA CLARK: Hello, I am Joanna Clark. I am the director of Deaf Child Worldwide, which is the international arm of the National Deaf Children's Society here in the UK. Philippa and I work for the same organisation.

Just to add really to what Fred was saying, because I think we agree with everything he said, and we work in similar areas. Our focus is perhaps more on education than on health per se, but we work very closely with parents' groups, and we do think that educating or imparting knowledge to parents is crucial. I think it works both in terms of being able to support the child very early on at home, to develop the sort of communication skills they need to then succeed in school is one of the things we would do.

Equally we talk to lots of parents' groups and we work with partners in 3 regions of the world we talk to a lot of parents and parents know if their child is deaf or if their deaf has hearing impairment.

Usually parents will know this long before there's any sort of formal diagnosis, so it's really important that parents and the families understand that actually there are things that can be done, even without massive resources to help children start to develop communication skills early on. because very often, and perhaps the link to health here is that we hear parents who have gone, taken their child to the doctor, the doctor may have diagnosed correctly, but quite often doesn't necessarily give the advice we would like to hear. Often the advice is quite honestly quite often it's wrong. Wait a couple of years it will all be all right, or there's nothing we can do until the child is at school because children don't get hearing-aids in a lot of countries until, they are not eligible for hearing-aids through any sort of public health system until they are at school. Which is when they are 5 or 6 or 7, and the lady from Zimbabwe was saying exactly this. You could say that it's too late, because nobody parents don't understand what they can do at home to help the child. So I think education across the board is a massive I issue.

DR BHANU WILLIAMS: I am Bhanu Williams a consultant paediatrician specialising in infectious disease, also global officer here at the college, thank you for that comment. One of the things I found in clinical practice is again that earlier intervention makes such a difference. Just give a short case history of a young boy we have been dealing with to illustrate some of problems, the intersection between health, education, deafness and immigrant culture we have come across a lot in the case we deal with. I am looking after a 12-year-old boy with HIV who we think become deaf following tuberculosis meningitis, which has got quite a high rate if it not managed swiftly at the beginning he was unwell in Angola initially he was managed correct for his TB meningitis, although the initial diagnosis was delayed and hits deafness diagnosis was delayed, they didn't had facility where they were which would have made a big

difference to this particular child.

He's now come to England he had multiple bereavement, his mother and father have died he is now in foster care. We're trying to manage this very bright 12 year old boy who is only interested in football and girls and try to whirl out how we disclose to him his HIV diagnosis, he doesn't speak English either, his native language is Portuguese, and trying to get an appropriate sign language interpreter whom he understand and trust's to try to gradually build up this relationship with him, to try and get him to understood his HIV, diagnosis to understand the need for him to take his medication, to try to understand the sexual health implications of some of the activities he would be liking to get up to with some of the girls at his specialist boarding school that he's at. I think he is now getting the input he needs, and this is a very bright boy who linking into Phillippa's question about poverty, I think that were he not getting all that input, it would be Vic that he would have a life entrenched in poverty even within this country, but actually with the correct input he now beginning to get this extremely bright boy will be able to make a really, really positive contribution to society and will be able to be economically better off, than he would have been but without these intensive interventions he would be completely alienated and would fail educationally. That's just clinician's overview from a child I have been involved with.

STUART HARRISON: Hi, I am Stuart Harrison. Adviser to DeafKidz International, in response to your question Philippa regarding education, I think the problem of education is it seems to be over shadowed by health. Health is often the first point for the family, so first contact, the doctor. The doctor often portrays a negative attitude regarding deafness, and what we need is health services that have an adoptive approach to the social model of deafness. That encourage sign language as a use of language communication. It doesn't matter on the level of hearing loss, what is important is that the child can communicate effectively. That's it doesn't matter if they are profoundly deaf or partially hearing, what is important is that. We need that encouragement within the medical system, to have awareness of sign language, to

encourage the use of sign language, yes there are technical ways such a hearing-aids but we need sign language as part of that interaction with the medical profession. A combined approach. I went to visit Zimbabwe at a school there, the school which Barbra runs. It inspired me it started me to think about what are we doing here in the west, started me to analyse that. What mistakes have we made. So in her school, they encourage deaf people to work in the school, to work as classroom assistants. So they can identify the skills of deaf people, and therefore they can offer them additional training, and to become educators. In a number of African countries, the schools for the deaf the so called schools for the deaf, offer an oral method of education. Oral method education is fine as long as you have the technology and hearing-aids to back it up but there's a lack of resources there. So for me, the important thing is that the medical system needs to work a long side the deaf community. It needs to have a stronger relationship, there needs to be an acceptance of that. Deaf people may not have the medical degrees, but they are the experts on deafness and the language needs of deaf children. So their needs to be collaborative approach we need to encourage that. We have seen that deaf people work in schools and we need that approach, we need deaf people as well as working in the education sector, deaf people working in the health sector too.

PROF ANDREW SMITH: Thank you very much everybody. Would the else like, does anybody have a question on that topic? You do? Steve. Sorry.

STEVE CRUMP: Thank you. I just wanted to ask Bhanu as a job paediatrician with a background in infectious diseases with the work you do in screening and such like, how could newborn screening be built into the protocols, the work you do. I mean what sort of steps would we as a community working in hearing care have to overcome to create that way of working which then becomes normalised right down to community health workers who might be doing the screening work round TB or HIV or whatever.

DR BHANU WILLIAMS: Thanks Steve. So two aspects to question there. First I think it's to do with newborn screening if I am correct which does take place in this country, it

should be universal. I don't think there are very few children actually who fall through the net. Then if there were problems in the first screening they get appropriate follow up. Where I see delays in diagnosis does tend to be in follow up after problems like meningitis, TB and otherwise, and sometimes side effects of drugs that are used to treat particularly things like multi-resistant TB. I see a skewed population because I am a specialist in infectious disease. The interesting perspective from looking at the UK experience is looking at the needs of deaf children in lower resources setting is what can be learned from some of the thing going realistically well in the UK the initial screening programmes and see what infrastructure and changes in process would be needed in order to screen babies in lower resourced settings for them to have the appropriate educational and where possible technological, but mostly educational interventions for them to be able to communicate as well as possible, accepting that early childhood development and early childhood acquisition of language, is so very important. That for me is almost more interesting question about how we can scale up what does work here, accepting what my colleagues have been saying about the need for an educational and social model. I think absolutely right, being more important really we're just there diagnose to then try to support but we need to work with people within education and deaf community to best facilitate these children to communicate, that has not happened with early diagnosis.

PROF ANDREW SMITH: Anybody else on the panel?

FRED MARINUS: I do want to comment on that. It's, I think it's not only about diagnosing early, it's important to know that you need to opt for holistic approach because if you diagnose early and you don't have any follow up, it's of no use. So, this I think why it's also important you have specialist, I know there are several programmes going on already on doing screening with questionnaires or with equipment, also in Africa or other developing countries, but we also have to work on the follow up and also what Susan was telling, already parents know very early that there's something wrong with their child, doesn't speak, so also those things have to be taken seriously, so also professionals and to know how to deal with this. Often you hear that when a

parent goes to a physician and says my child is not able to speak, and he says oh just wait until he's going to school, because by that time, he will know how to do it. He's just a bit delayed. You're missing out the critical period of language development, so that's why it's so important to start very early, like for instance what sign health are doing in Uganda they set up some centres where children can go to school before the age of 5, and I think that is a way where we all have to co-operate, see what is possible to work together in diagnostics in education, in everything.

PROF ANDREW SMITH: Maybe I could just like to make a quick comment to Steve's question in terms of how do you go about setting up a neo-natal hearing screening programme. I agree, absolutely with what you both said. It's very important to have these but you do need not only have screening but able to deal with the children who have been found to have a hearing loss, you shouldn't start a screening programme unless you do have that capability. Otherwise you are going to get a lot of disillusioned and parents and children. Just looking at the broader picture, now looking at I a little bit from the WHO perspective, there are so any problems with hearing loss in children, and neo-natal screening is obviously a very important part but universal screening is very expensive, we only have limited resources, how are we going to actually utilise and distribute those resources effectively in the most effective ways. I think WHO is trying to promote the fact that there should be national programmes developed, countries should try to develop national programmes for prevention of hearing loss, by prevention I am talking broadly primary, secondary, tertiary prevention which includes rehabilitation.

You might say, "Well, that's a pipe dream, it's never going to happen", but there are 40 countries out of the total number who already have national programmes - it's far too few and there needs to be more - and I was going to show you the example of Kenya, who has just adopted their new national programme for prevention of deafness. That includes things like universal and neo-natal hearing screening. It includes how do you deal with chronic otitis media. How it links with education, these sort of things. Malawi has just developed a national programme. It's important to bear in mind that it

is part of a larger picture. Nevertheless, we still have to do something now. We can't wait for countries to do that, but I think we have to think of the two things in parallel.

FLOOR: Thank you. I am Anita Williams and I work for Warchild UK. My interest is in what are the resources available for children who have been disabled because of armed conflict. I think this panel has the means to develop a response also as a humanitarian response. The numbers were impressive but I didn't see how many of those children actually were affected or were disabled because of conflict.

We work in refugee settings, so I have visited refugee camps in Jordan, Iraq, and we are in Lebanon. I was just wondering, what is the correlation between WHO and UNHCR. You talked about advocacy, and it's absolutely right, you need those figures. But if we are really going to make a call, we need to actually understand what are the resources available in those sort of settings, because those are very low-resource settings.

I was also wondering, are we just leaving it up to NGOs to pick up these sort of issues, because I can tell you, having visited those camps, I have not seen a WHO sign anywhere. We have seen UNICEF and UNHCR, but certainly not WHO, so I think there is a lacuna there.

I was also wondering what the panellists thought about what are the available resources at the moment for children who have been disabled or become refugees because of armed conflict. Thank you.

PROFESSOR SMITH: Thank you very much for that question. Maybe I will just respond to your specific question to me, and then I will hand over to the other members of the panel. I think it's a very good point about gathering data from children in conflict and in refugee situations.

When we have done surveys, we didn't specifically look at that, and I think WHO hasn't in the past done that, but obviously it's an increasing problem, a huge problem in the world now, and it's getting worse and worse by the day, so we should take account of that.

One opportunity to do that perhaps is that WHO is relooking at the way they gather the data on hearing loss, and there was a protocol that was set up in 1995, and it's obviously long in the tooth now, so they have just set up a working group to address

what sort of data WHO needs to gather for hearing loss. In the light of the upcoming resolution, this is going to be very relevant. I know some of the members on the panel, so I will put that point to them, that they should bear in mind the need to gather that data.

You asked another question?

FLOOR: To the panellists, what their experience was.

PROFESSOR SMITH: Right. Who would like to start?

STUART HARRISON: We have done some research on what happens in refugee camps, and it's quite interesting. An American group of volunteers went out to Haiti to provide support. Because of the earthquake a refugee camp was established, and deaf people were together, as a group, within that camp. As a group, they could therefore ensure they had access to information from the wider camp, and access to medical interventions, to food and to education, so the deaf people acted in support of each other.

In other camps, we find deaf people isolated. Therefore, refugee advocates can create these things in situ in the camps. If people can be identified, they can create their access to the support that they require.

STEPHEN CRUMP: I absolutely agree, we need to get a handle on the number of deaf children affected by conflict. The reality is we don't know, which is one of the reasons why we are undertaking the piece of work with Kentalis and other charities to resolve the issue of those deaf children who have been affected by conflict. The picture of the boy with the fox, we found that boy, who fled Northern Iraq, where the whole system had collapsed, living in a camp in Dunkirk. He had a cochlear implant, no processor working, and our good friends in Cochlear got him back to where he needed to be.

We take the view at DeafKidz International that the situation is such that we need to - Islamic Relief, Warchild and others, we are working with them to address this issue, and we will do that over time. We were talking to our good friends in the Palestinian Red Crescent about the children in the refugee camps in Jordan and how we might play a role there. Indeed, we were discussing possibilities in terms of particular children

affected by conflict, so there is a new area for us where we know that we're going to be working on it.

FRED MARINUS: I want to comment on that. Two years ago, we also tried to set up a project with Warchild in Uganda to address this group, but indeed there is a problem to find funding for such initiatives, so I think really we should have a look at that to involve the larger organisations in that part.

I know another organisation, Deaf Link in Uganda, a very small local NGO, is working with refugees in northern Uganda, and they have set up some very successful programmes in getting them into jobs.

I can also remember - and that's some time ago - in Ghana, there was a Liberian refugee camp. It was quite a large camp, but the positive thing in there is that some of the volunteers in that camp, they established a school for the deaf and, finally now, it's a bit more quiet again in Liberia, some of those volunteers moved and also the deaf people from that school moved back to Liberia and started their own school for the deaf, so sometimes you can also turn it into something very positive.

BHANU WILLIAMS: Thank you for the question. I don't have as much experience as others in the room about personally going and working in refugee camps. My experience is more with refugees who have come to this country. I would comment, having recently written a paediatric paper about refugees. both in camps and in the high resource settings they eventually end up in, that deafness as an issue is overlooked.

I have read quite a lot of papers whilst writing my own paper and things of importance were infectious diseases, mental health, eye problems, a lot about dental health, but very little about deafness coming up at all. In fact, I can't quote a statistic saying what portion of refugee children in camps may be deaf, either as a result of conflict or pre-existing the conflict.

I think that, in order to try and move deafness as an issue up the agenda, we need to have appropriate interventions for children, particularly educational, for their language and communication skills, but we firstly need to know how big the problem is. I think it's very overlooked, and one of the things that would be good, if it's possible - a lot of people have said, "We have gone and seen these deaf children isolated within

the camps" - is if that data can make its way into the published literature, I think it would be helpful in terms of awareness raising.

JOANNA CLARK: We don't have much experience of this, but I would say that there is very little knowledge about that. I am sure that, despite all the good work of WHO - and these are the figures that we all use, and they are quite high; they are the only figures, and the best figures there are - I am sure the figures are much bigger, and I am sure that actually the fact that we don't know how many deaf children there are in refugee camps is reflected by the fact that we don't know how many deaf and hearing impaired children there are more generally.

We still work in a lot of communities where we're finding deaf children every day, and we know that a lot of them don't go to school and aren't recognised. I know it is a big issue for the sustainability development goal, the provision of more data in some of these areas, which is very much lacking.

FLOOR: Could I add something to that?

PROFESSOR SMITH: Could I make a quick comment on that and then I will come to you. Just to say, you did make a comment about the need for WHO and UNICEF and UNHCR to start communicating together and working together. I agree with you.

I worked for UNHCR before I went to WHO, so maybe I can link them together or try to encourage that, because I think that would be very important. It's also this idea of getting into the published literature the information about the size of the problem in the refugees and war situations, because they are becoming so important. I think we need to do more of that. Sir, over to you, please?

FLOOR: I am Rob Clark, I am with Sign Health and with Signal. I would like to include Justin Smith, who is international director at Sign Health in this point, because I think it's a hugely important topic. I think a fair amount of work has been done. It's just never been pulled together.

I think a good starting point might be Cambodia, because there is no history of deaf services there at all, and I will ask Justin to add to it, because he was ten years working in Cambodia. A French organisation called Krousar Thmey began their campaign working in the camps, and because of the numbers of deaf children they found, they began setting up deaf schools in the camps, but now right across the whole

country they are the chief - indeed, probably the only - provider of deaf education in Cambodia.

I am sure that they have a huge amount of information they could contribute. It just needs somebody to start pulling it together on a sort of global basis, I think. Do you want to add anything, Justin?

FLOOR: Justin. Yes. I am Justin Smith. No relation to Professor Smith!

PROFESSOR SMITH: You never know! (laughter)

FLOOR: Justin Smith. Just to add to Rob, in Cambodia, there is a lot of information that you can gather there around the refugee camps by the Thai border. The situation there is that there were a group of deaf children who were together, and from that the deaf schools in Cambodia were established. now there are five deaf schools in the country led by Krousar Thmey, but that's only five out of 24 provinces, so there are huge gaps that need to be filled. That's all I wanted to say. So, yes, definitely there's information there that can be collected.

PROFESSOR SMITH: A question from Zimbabwe?

FLOOR: Thank you, ladies and gentlemen. I am Dumi Nala, I am from ChildLine South Africa. I just really wanted to make a comment particularly with the situation in South Africa, and thank you for the work that you have done.

We are facing major challenges in terms of resources, but also the mental health and the psychological wellbeing of deaf children is a huge problem, and I think there is really nothing in place for them, and those were providing resources in terms of psychosocial wellbeing and mental health.

They themselves are limited in terms of understanding the needs of deaf children, so in our country we look at the educational aspect, the medical aspect, but their mental wellbeing is also neglected a great deal. Of course, we are in a situation where HIV and AIDS takes priority in South Africa. That's all we talk about, so when you look at issues of disability, they are right in the bottom, and issues of children, they are the last ones. Children with disability are even more neglected.

So the issue of political will, and politicians understanding the needs is crucial so I was really grateful for the information you shared, thank you.

PROF ANDREW SMITH: The lady from Zimbabwe, maybe just time four quick comment from you.

BARBRA NYANGAIRI: Thank you very much I would like to speak to issue that was raised by Doctor Bhanu regarding HIV and aids communicating HIV infection to children who are deaf, that has been a huge challenge, particularly if the deafness is caused by meningitis, HIV treatment is also something that has been a cause I think I am not sure if much research has been done. But communicating that we have got a number of children, adolescents now, who are HIV positive, on treatment who we have not even been, we have not understood the diagnosis the treatment, if they ask a colleague are you taking treatment every day and the person says no so they stop. That has so much implications, so counselling, providing services, treatment, becomes a real issue so even when you do a for they don't understand why it's important for them to take their medication every day. That's been a real challenge as well.

PROF ANDREW SMITH: That it? Thank you very much everybody for a good discussion, we can continue over lunch. (applause).

(Lunch followed by workshops - no captioning required)

JOHN COSTER: Right. The last part of the day. If you have a belt, feel free to tighten it. We are nearly it there! I took pictures in each of the workshops. Hopefully they were interesting. I know a lot of questions have arisen and I think all of the notes from the workshops have been collected together, so they will be collated and distributed in a pack as well following the conference.

If you suddenly think to yourself we don't have your contact details, make sure you give us those, and obviously, getting ready for the Frontline Club, feel free to join us. We are in to the last part with the remaining two speakers now for the conference. I would like to introduce you to Mark Waddington, the CEO of Hope and Homes for

Children. Obviously Mark has a lot of experience in the humanitarian field and has been involved as the CEO of War Child. I know Mark has been a great advocate, as myself and many others in the room have been, so I look forward to what he has to say. Mark. (Applause)

MARK WADDINGTON: Good afternoon, ladies and gentlemen.

I run a charity called Hope and Homes for Children and what we do is reform child protection and childcare systems. We work in East and Southern Africa, certain countries which are outliers to us, Sudan, West Africa, also Central Europe and Eastern Europe and in Latin America. We close down orphanages and replace them with alternative family-based care.

I want to quote Cecil Chesterton: "There is nothing so inhuman as inhumane humanitarian."

Now, many of us will have supported orphanages at one time or another in our lives, and in fact Hope and Homes for Children started out by rebuilding the main orphanage in Sarajevo just after it was bombed during the war back in 1994, so we do understand the motivation in helping children in this way. But, in spite of the nobility behind that, there is a dark side to orphanages, and especially to all forms of institutional care. Here is why.

There is an industrial complex associated with orphanages. Orphanages are largely budgeted on a per capita basis, so for every child in an orphanage, the more money you get. The more children, the bigger the budget. When you are in a low resource setting, a humanitarian setting, or a low resource economy, then there are perverse incentives to hoover children into those institutions to swell the budget, because the directors of these places are largely politically appointed in the state orphanage system, and in building those budgets can then appoint members of their own family, community or ethnic group as workers within the orphanage system.

Equally, we have seen, in certain countries in Africa, how orphanages are established as private enterprises. The children in them are kept in a state of chronic malnutrition in order to attract donations and the directors or "owners" of those orphanages then top-slice the money and keep a significant proportion of it for themselves.

This industrial complex around orphanages preys on vulnerability.

I have recently met a young girl called Annie. She was born to two profoundly deaf (mum and dad) parents, and she went into the orphanage system. This is in Eastern Europe. She was literally extracted from the family. It's a medicalised system. They didn't believe her parents could look after her properly. The parents complained about that, and then the authorities moved her to a different orphanage and they were prevented from having access to her.

Now, we were working with local authorities to develop the services in place to support family based care of children who were vulnerable to going into orphanages. We managed to negotiate her back into her family, but that should never have happened in the first place, because deafness is not a condition that requires institutionalisation. With the right support, it can be cared for at home.

Before I crack on with the rest of the presentation, I want to posit the point that, if we are serious about inclusion, then we need to include hearing children of deaf parents, because Annie was fully able to hear - she wasn't deaf at all - so I am just asking us to spread that umbrella of inclusion as we move forward.

Here are some statistics around institutional care. 37% of all children in forms of orphanage care suffer extreme violence. Now, we have seen cases of children being doused in petrol and set on fire as a means of disciplining them by orphanage staff. Deaf children are more vulnerable to extreme forms of violence in institutional settings because they are less likely to be able to report it. Also, because they get very frustrated because they are unable to communicate, they are not supported to communicate, and that obviously influences their behaviour, and subsequent ways of disciplining them.

The culture associated with institutional care doesn't lend itself to open reporting, so violence persists and endures. For children under three, every three months they spend in an orphanage they lose one month of growth; that is stunting. It doesn't matter whether you are in institutional care in the US or institutional care in Romania or institutional care in South Africa; that stunting occurs in almost every orphanage setting, in terms of institutional care. Deaf children are obviously more vulnerable to stunting because they are less able and less supported to be able to communicate their needs, and often in these institutional settings there are no specialist staff.

Mortality. Here is the alarming statistic. 70% mortality has been reached in a number of the institutions that we work in. In fact, we have seen it in Khartoum reach 80%. These are not orphanages, they are mortuaries. This is why orphanage care is damaging. This is why it's unfavourable.

Underneath all of this is the issue of neglect. There has been a lot of research done by the likes of Harvard University, and one of the things they have developed is this concept of serve and return, and the understanding around it. There is a considerable evidence base to support this now. This is all common sense stuff.

Essentially, what that means is that, when you pick up a baby or a toddler, it will reach out, it will serve to you. Very often you will grab its hand, you will coo back at the baby. That's you returning to the baby. Within a stable relationship, consistently within a stable relationship, that authorises the genetic development of brain architecture and it leads to a very healthy brain architecture.

The problem is, when it's denied, children will learn, for example, not to cry. Very often, me and my colleagues will walk into a baby unit in an orphanage, where there will be 30 to 50, sometimes 100 babies in a room, in worst cases, and it will be silent; none of the children will be crying.

Harvard have done an iconic still-face experiment. I have just got a screen grab of it here. Essentially, what happens is, you have a normal relationship between a mother and her baby, and the baby reaches out and the mother reaches back, and they are making noises at each other. Then the mother just does a dead-pan face and holds it for about 60 seconds to a minute-and-a-half. The baby gets more and more distressed because her service is not being returned.

In that environment, that's absolutely fine. A little bit of stress does no harm to anybody. In fact, there is evidence to suggest it's quite healthy. But, if it endures and persists, you get a build-up of toxic stress in the brain of the baby, and that inhibits the neurological development at such an early age. This is the kind of consequence that you can see from that kind of neglect.

This is important, and it matters, and it matters because deaf children are very often excluded and marginalised from the kind of support that enables them to develop these kind of relationships consistently in stable settings in an orphanage. It just

doesn't happen. It creates a huge barrier to healthy brain architecture and its development, and especially to cognitive development.

You don't need me to tell you, deafness is not a learning disability. The problem is the lack of support around deaf children to enable them to catch up and achieve the same educational outcomes as their hearing peers. That is not provided in orphanage situations.

Here, these graphs are from the research at Harvard in fact, and they show the damaging effect that neglect actually does have.

It's from an experiment where they took children who had lived with different forms of neglect and children who had lived with no form of neglect or maltreatment. They put them in a room and they set them the same task of trying to open a locked box that had toys in it, and then using consistent criteria measured the extent to which they demonstrated creativity, confidence and assertiveness. In each case, it was children who had lived with neglect that showed less creativity, less confidence and less assertiveness.

The problem with institutionalised care system is that deaf children are marginalised within them, they live with more neglect than children with hearing.

So institutional care is a real barrier to education. It's a real barrier to physical development, we had a case in an orphanage that we have thankfully managed to close down where you small boy aged 6 came into the orphanage at the age of just over 2, and he was fully able to hear, he was left in the cot and he was confined to that cot day on day, year on year. He lost the ability to walk. And as a consequence he would lay down in the cot all day and they would leave his water bottle at the side of the cot and his milk bottle, very often with just mashed food in it, it would drip on to mattress that drip would migrate all the way across to where his head was eventually he got an ear infection and become profoundly deaf from one side to the other. Institutional care causes deafness, it causes physical impairment.

Of course it's a barrier to emotional and social development. Possible lit worst of it is the economic argument, it increases dependency on the state. Children who come

output of orphanages because they have not had the support to achieve the educational outcomes that other children will have done, or the physical development of other children would have done, are far more dependent on the state I they are less like to get a job more likely to require welfare and housing support. More like to fall into crime. We know that they are 100, sorry 10 times more likely to commit suicide.

The scale of the challenge globally is huge. There are more than 8 million children confined to in institutional care, we know from our own survey work which is just a wet finger in the air that a considerable proportion of them are deaf children. Deaf children are over represented in orphanages and institutional care situations. We know for example, that just under 20% of all children in the Rwanda state orphanage system are deaf, which is massively open representing the deaf community.

So family based care with the right support, promotes better language development. I mean this is self-evident. It promotes better health and educational outcomes. It creates a stronger, protective environment. That not to say there are not some families that don't look after their children properly and in particular find it difficult to look after deaf children, not least because of stigma and cultural issues but with the right support those families are more like to be able to succeed with that.

Where that cannot happen it doesn't mean to say we need orphanage's there are alternative forms of family based care. Kinship care in the wider extended family, foster care, family type homes and so on.

So Vasille is a boy I met quite recently in Moldova I will be there on Saturday I hope to see him over the weekend, so he was born deaf, and again he was taken into what is a medicalised system in Moldova, and lost access to his parents. Once again, working with local authorities we were able to get him back with his parents, and through those local authorities were able to development new services that prevented this from happening again tooth children. He's now happily back with his parents, he's got a hearing-aid, going through school, he started school last year for the first time, it was

a huge day for him. Plays football, there is no reason why he cannot be socialised in a largely normal way in a has regular children round him. This important in developing an inclusive de-institutionalisation model, a DI model. Firstly, we need the evidence base, that evidence base must include deaf children. We must disaggregate that data wherever possible so we can understand what the causes are of deafness, and what the needs are of deaf children.

Secondly, prevention is absolutely critical. What we know is that the prevention pathways that we work on, to actually prevent the abandonment or separation of children from their families in the first place, are also great entry points to work in a joined up way between social services, and medical and public health communities to actually get things in place like immunisation against childhood disease such as measles and meningitis, Rubella and mumps. Screening and treating syphilis and other infections in pregnant women. All these things that contribute to deafness.

The third is reintegration and placements. The vast majority of the 8 million children confined to orphanages are not or fans. We know from research done by Professor Kevin brown that across Europe 37 countries, more than 1 million children confined to orphanage's 96% of them, have one or both birth parents still alive. Nearly all of them have extended family. Across many African countries we're looking at 85% or more. The Mort of these children still have family. If we can work to support the families, not only do we benefit the child by enabling them to be back in the love care and protection of the family, but the family itself will benefit whether that is from improved housing or proved employment or action access to employment.

The fourth is closure. We have had a number of cases where we have been involved in supporting local authorities to close orphanages, state orphanages, and they have then relocated deaf children into other orphanages. So the orphanage is closed, but actually the ranks of other orphanages round it are swelling with deaf children. When actually what we need to be doing is developing the family support services to ensure the children go back to their own families or into foster care or other alternative

family arrangements.

Finally, legislation and policy. Must recognise the duty of care to deaf children and the rights of deaf children, which I will come to in a minute.

What we don't want to be doing is for instance, where Vasile was born, he ended up in an institution called Balti, the Balti orphanage we were able to close that down. What we don't want to do is pick off one orphanage at a time it simply won't work it's not doable we won't get anywhere. We systematic change. Thereafter 4 ingredients we tried to bring together we bake this cake slight differently we might have more than one ingredient in one country we adapt it to that context. The first is political will. It's not are job as a self-mandated international NGO to go about as a busy body go about closing down orphanages in country of the world. That is the responsibility of the state in those countries. We have to bring the state kicking and screaming to that mandate.

Otherwise it's not sustainable. We cannot sustain alternative family based care arrangements in every country around the world as a charity. The second is know how, we need to understand better the situation facing deaf children at their needs in the community and in the family, and we don't. Organisations like hope for homes for children, do not understand this well enough as yet. Civil society is the next big thing. This is what is really interesting and challenging at the same time. As an international NGO, we exist in a dysfunctional market place. Where there are 4 elements to that dysfunctional market place that certainly I recognise. Firstly, is very people who consume our services don't actually pay us for them, the children. That transaction is not how it would normally be as it would in other service arrangements.

Secondly the weight of our organisational and administrative accountability is to those who fund us who have no legitimacy and very little contact with the people we exist to serve. Third is that the funding architecture around NGOs and charities cultivates competition. That impedes collaboration.

Finally, the value for money metrics that funders often impose upon us, make working with deaf children appear to be expensive. Those metrics exclude deaf children from many funding arrangements it's relegates programming for deaf children to a specialist or niche discipline. That gives many funders a get out of jail free card. In fact, I won't name him we have a funder who has been very generous, that's why I won't name him, (laughter) he felt that we should write off disabled children because there was nothing we could do in our lifetime to actually deliver systematic change. Personally I refuse to do that, I am sure everybody in this room would agree.

We have also sat in front of ministers of State in variety of countries, whether it's Africa or Europe Latin America, who view the deaf community as a minority community, they view disability as a minority issue. Therefore, were not helping many children. So they are not getting a big bang for their buck. So it's very difficult to persuade them.

Which leads us to fourth ingredient in fact all roads lead back to Caesar, it's always got to be money in fact. We always end up in front of the Ministry of Finance somewhere wherever we work. The first thing I would say is the money is already there, it always is. Orphanages are being funded now so high can't we just shift the funding of orphanages from that over to various alternative family based arrangements.

It's helping people to see the light in that, and funders to see the light, so they stop that funding and move it over the additional funding is needed in the reform and transition.

So we have been doing some research in fact Steve was convened Hope and Homes for children in the Royal College to look into the perceptions of the medical and healthcare community in a number of countries of children who were confined to institutions, including disabled children and not least deaf children. So we interviewed more than 300 medical professionals in Moldova, 190 in Bulgaria and 100 in Romania.

The Romanians we have worked very closely with them now for 15 years, they had 105000 children, we have brought that down to less than 8000 children. When you talk to medical professionals in Romania though I don't think they have got a problem anymore, it's a bugger to engage them in a survey. We were unable to talk to fewer of them in Romania. We got a pretty good sampling total of 900 across the 3 countries. What you can see here is a word cloud of the words used to describe children in institution, you can see they are all positive, active, healthy, curious, developed, sorry not typical children in institution, just typical children. Curious, educated, joyful, so forth.

Then we looked at children in different things. But I think the one that really is illuminating is children with disability in institutionalised environment what I really alarming for me about these words, it comes through quite strongly in this word cloud is firstly it casts these children passive victims. If we cast deaf children and other children living with disability, as passive victims, then the policy response will see them as subjects of policy, and will simply impose services on them, impose solutions on them, and their families, rather than supporting them and their families to deal with their challenges. That's important, because what it does it ascribes deafness as a characteristic, it's not a characteristic it's a situational condition. The second thing it does is frame these children as problematic in the same way that very often adolescent adolescents are seen as problematic. That again gives politician us a get out of jail free card.

We don't have to look very far today in politics, certainly not least over the Atlantic, to politicians who would quite happily blame people for their circumstances. We cannot allow that to happen. These are medical professionals. They should understand this situation better.

All is not lost. We have some assets. The UN Convention on the Rights of the Child, which every country in the world except for the US has now signed up to. I want to quickly read you a section from the preamble because it's really important.

"Recalling that in the universal declaration of humans rights, the United Nations has proclaimed that childhood is entitled to special care and assistance, convinced that the family as the fundamental group of society and the natural environment for the growth and wellbeing of all its members, and particularly children, should be afforded the necessary protection and assistance so that it can fully assume its responsibilities within the community, recognising that the child for the full and harmonious development of his or her personality should grow up in a family environment, in an atmosphere of happiness, love and understanding."

This is a legal obligation. Institutions contravene that right. Article 2 of the convention on the rights of the child demands complete non-discrimination in the application of that convention, including obviously children with disabilities and deaf children. We need to employ the UN convention on the rights of the child. It's the primary document from which we derive our legitimacy to include deaf children in programming for development and humanitarian projects.

We then have the UN guidelines on alternative care. Institutionalisation of deaf children contravenes those guidelines.

We also have now the sustainable development goals. Steve mentioned earlier on, 16.2. Institutional care contravenes that and it is preventing us fulfilling that objective.

Finally, we have the UK Aid Strategy, the Department for International Development, addressing deafness and its consequence among children aligns closely with objective 4 of that strategy, which is tackling extreme poverty and helping the world's most vulnerable, which includes deaf children.

In DFID's response to the International select committee - I don't know if Malcolm is with us - the enquiry on disability and development committed DFID to ensuring that excluded groups are systematically and consistently included in policy programming and international work.

Institutionalisation is a mechanism of severe exclusion for deaf children and it increases the risk of the development of a disability, not least deafness.

In responding to Steve's challenge, what can we do, what can I do as a chief exec of an NGO? We've got a conference coming up in East Africa where we are bringing many of

our East and Southern African partners together. What I want to do is introduce the conversation around deaf children, and how we integrate them into our programming, at that conference. So I am going to commit to doing that and I will report back.

The second thing that I want to do is to begin to map out how my organisation actually deals with the integration of deaf children into our programming. I don't think we've got it right yet. I have learned a lot this morning, and I think there are gaps. And in fact I am not sure we even have a mapping tool, so we might need to come back to you for some advice. Regardless, I will report back on what we learn.

But I would like to send a challenge back, Steve. You have shown great leadership in bringing us all together here today. Don't let this be a one-off. Convene us again. Let's build momentum.

So a final thought. It seems to me that we separate deafness out as a specific theme requiring specialist support, and consequently in a policy environment it's framed as an additional issue, begging additional funds. It's a bolt-on.

Without wishing to diminish deafness, as a condition or situation, throughout the world in which we are increasingly valuing diversity, can we not begin to view deafness as a different form of "normal". Viewing deafness in that way compels inclusion and the integration of deaf children's needs in the planning and delivery across all existing services, and ultimately, if we do that, it's no longer a health challenge; it's a PR challenge. It's a perception and cultural challenge. It's an educational challenge, but one that would deliver an approach that might be more likely to ensure that deaf children are just as much a part of humanitarian development programming as anyone else. Thank you. (Applause)

JOHN COSTER: Questions.

FLOOR: I am Andre, I run the Meaka Bear Deaf Support, and I want to pick up on your last point about not viewing deafness so much as something that needs help, but something that is the new normal, especially for deaf kids or deaf people in general. We need to have that as our ethos, so my own daughter is deaf, her name is Meaka and she is now eleven. One of her biggest ambitions is to be, one, a fashion designer, and two, a foreman of some sort. And I went to visit her potential new school, it's a performing arts centre. When she was one, there was no specific diagnosis but she

just went deaf and we had to work on it. From that, I created Meaka Bears, and through that we are looking at different ways we can rely funding from funders, but look for ourselves, and we have come up with a cafe where we provide apprenticeships for young people, with a specific focus on disabilities, namely deafness, and where we are just trying to drive it forward that, if you are deaf, it's cool, and that's our slogan, and we are just trying to bring to the forefront of the wider community that being deaf is cool, it's okay and it's fine, and there is a lot of cool deaf people around, and if we can just make the rest of the world see that in a more or less stressful kind of life, as in we don't need you just to give us money, but we can get to where we want to be in the end.

MARK WADDINGTON: That's a really inspiring story and this is where the battle is. It's about culture and perception. Just going back to what I said earlier, deafness is not a learning disability. If the services are in place to enable deaf children, firstly, to be diagnosed properly as early as possible, and secondly, given the support that he they need to develop linguistic abilities and be included in mainstream education, they will have the same educational outcomes as hearing children will do.

Therefore, the issue is not deafness but society's view or value of deaf children. I think that's what we have to overcome.

FLOOR: Barbra. Thank you very much. I already had the microphone here! Thank you for the presentation, and there are two things I would like to raise that came for me key from your presentation. Parenting of children of the deaf. Many a time in my country, when deaf couple have children, they are taken away from them to be taken care of by a relative. Institutional care may not be available in such settings, but it's often that the parents don't want to give up their child, but often the children are taken away and looked after by grandparents or other relatives and that can create an atmosphere of abuse within the family, but there is no consultation regarding the supportive care of those children. Secondly, in Zimbabwe, removing, we have adopted on paper the practice of removing children from institutional care and they have come up with a family for every child, but the implementation has been a problem because of the bureaucratic nature of how do you even get access to the children that need the family settings and the support and adoptive care. The bureaucracy and the

hindrances are so huge that what are you working on policy in order to make this easier for parent or for families to be involved in foster parenting or adoption, for policy to be more allowing whilst looking at the interests of the child. For me, that's been a major area. My friend adopted a child, and it was not easy. The process is long, and it's such a battle, so you are given temporary care for a period, and you extend it to a year, but you still don't have a guarantee that you are going to have this child with you. So it's those processes, particularly within our context, I am not sure whether it applies to all African countries, but in Zimbabwe it's a headache to even have a child come into a family setting and move away from the institutional support. Thank you.

MARK WADDINGTON: That, for me, is the symptom of an inhumane humanitarian social service system, and you are absolutely correct, it's a real battle to try and change things. What I will say, though, is as difficult and challenging reform of such systems is, it can be done.

We work quite successfully in Sudan to do that, for example, where we have worked with babies that have been abandoned on the streets because they have been born outside of wedlock. Hugely stigmatised, and in fact sex outside marriage is a crime under sharia law, but we have worked with imams, police, social services, and we have been able to set up a family based foster care system right across the city that is picking up roundabout 700 children per year. When we started it, those foster parents themselves were suffering with stigma because they were taking these babies in, who were seen or perceived to be evidence of a crime.

Again, it was a PR campaign. We used TV and other forms of mass media. We also worked with the imams on their sermons in the mosque on Friday, and so forth, and that began to slowly change perceptions.

What happened was it reduced abandonment, because the stigma began to go down, so we were beginning to get to the root cause. Abandonment didn't fully come down but we got it down by roundabout 40%, which was quite a contribution to that problem, and at the same time the communities were more accepting of these foster families and were actually supporting them, with towels, soap, and all the things these families needed to look after the children properly. So, yes, it is challenging, but if

you can get the political will in place, it begins to give you traction for developing and pioneering services.

FLOOR: Rob Clark again. I just want to ask if your policy here is a political stance, or whether there is something that's more practical behind it? I say that because I am totally in agreement with all that you have said, but I am of an age when, of the people who was involved in closing the large institutions in this country, the rural hospitals for people with mental illness and learning disabilities, and that was absolutely right, and we went for a community approach. However, no system is perfect, and what we lost with those hospitals were two things. First of all, the ability for a consultant psychiatrist to say to our families, "There is a bed here whenever you are in trouble," which was wonderful. Even though that institution wasn't something that we liked, it was something that was there. So the possibility for respite, in emergency, was fantastic.

The other was sanctuary. You know, if nothing else, there were many situations in which those good institutions provided something which absolutely met the needs of certain individuals at certain stages in their lives, and we never found a way of - we never found a system to provide that, and we had lots of horror stories about people who returned to the community, and they returned to the community by being on the streets, taking drugs, et cetera, et cetera.

In your view and in your policies, do you see any place for institutions to help families with children in a difficult time?

Mark. It's a really point important, it's derived from actual experience a what I can say the institutions we close we close them as institutions but the building might remain, and itself is converted into, so we have done this in Ukraine, during the course of the conflict and we're now doing it elsewhere, we use the buildings to develop a complex, a platform for a complex of services. So for example Bulgaria one of our first closures 14, 15 years ago in a place called Plevan it's still being run as a community support centre that specialises in vulnerable families, there might be a case of severe domestic abuse where a young mother has two children and needs to find sanctuary, well she can come there and she can spend time there in safety with support, until the

other social services are able to kick in, and either resolve that issue or find alternative arrangements for her. Similarly, with older children, in supported living arrangements. For young children we tend to move them towards emergency foster care services. I think the key point is having the child at the centre of service delivery and the development of those services around them, so having a diversity of services is absolutely critical so you mould them around the particular child's needs. So the institution is closed as an institution, but we use it, the physical space to offer a complex of other services. We bring in local authorities to run those. I am not saying it's perfect either, you know this, you were on the business end of the stick of social services here, and it's not easy but it's a lot better than the system that depends on in institutionalised care.

FROM THE FLOOR: I wouldn't argue with that.

JOHN COSTER: Thanks Mark, we to move on now (applause).

STEVE CRUMP: I just want to say Mark flagged up some points about collaboration and momentum, I will refer to these when I wrap up in about 30 minutes' time.

JOHN COSTER: There you are! You are supposed to have been waving your arms by that point. I think we're going to show a film first is that right? A 5 minute film, we'll do that then I will introduce you.

(Video playing).

NEW SPEAKER: As part of its commitment to diversity and inclusivity the British council has been working in partnership with the Palestinian Red Crescent Society total communication school since May 2012, training a group of 18 students in art and craft of traditional stop motion animation.

NEW SPEAKER: They start with think in a new way, they think about stories and they

think about ideas in a very new and different way as the confidence it inspires it changes the child in the way they couldn't.

NEW SPEAKER: Like that, like this.

NEW SPEAKER: Under the guidance of experienced tutors, students are equipped with practical skills which they can then use to express themselves.

NEW SPEAKER: The animation process involves a lot of steps but all of them very common, they are very practical.

NEW SPEAKER: The most important thing is they work in groups very in sensitively it's like an intensive collective process.

NEW SPEAKER: As the students learn how to build basic models from plasticine and cardboard how to move the models by hand how to capture it with the help of cameras and computers, they begin to imagine a world of their own and quickly acquire confidence in communicating in this work in their animation.

NEW SPEAKER: The animation training aims to develop creative confidence as well as social competence. During open days and summer schemes, the students conduct their own animation workshops, sharing their newly acquired skills with their disabled and non-disabled peers.

NEW SPEAKER: Working on the animation project as helped to raise issues related to the status of the disabled, the deaf in particular, and of disability arts. In addition to the barriers faced by the sector creatively or professionally.

NEW SPEAKER: We're very, very keen in working with different communities and different groups who have different issues about access sing art and education. This project is both about art and education.

NEW SPEAKER: The British Council is committed to supporting similar initiatives in Palestine result of our conviction of the role of the arts in challenging perceptions and liberating talent.

NEW SPEAKER: One of the guys gave me a beautiful animated rose. It doesn't smell, but it's really beautiful.

JOHN COSTER: While Steve works his magic, as a journalist I get really caught up on words, do you know what I mean, John walk into the room and the room reacted what did John say, John said hi, everyone said hello back. Is it youth, we're very much on how we're caught on words. One of the things listening to your work earlier was how we talk round communication is that total communication, I just noticed that through Suheir's biog which hopefully you have all got one of these biogs, if you are missing anything we have got one here, a biog of all the workshop leaders all the people here today, when she started working it was with the total communication centre for the deaf. Which is quite interesting, the way we're looking at the total communication, it comes back to that holistic approach. I am trying to fill the time now while they are getting the PowerPoint, (laughter) I am not doing too well am I. There we go I would like to introduce you now, our final speaker is Suheir Al Badarneh who is the director at the Palestinian Red Crescent society.

SUHEIR: Thank you everyone my pleasure to be here in the context, thank you for Steve to invite us to be here. It was a long journey to be here and, but it will be I think of great benefit for all of us.

In my presentation I will speak just about the deaf education in Palestine, because in the other session we speak about early detection, late detection, interventions and others but in this presentation it just deaf education.

I want to just to give some numbers about the percentage of disability in Palestine,

it's according to disability survey done by the office of statistics, 2011. As you see here, you see that the percentage of disability ranges between 2.7, to 7% of the population. This is the range is because we either we use the narrow definition or wide definition. The narrow definition means we speak about all levels of disability, starting from mild to profound. We will speak about narrow definition, we speak about severe and profound cases.

This means that we have about 114,000 to 300,000 people in Palestine who have a kind of disability. Whether multiple or one kind, mild or moderate. Some numbers show the situation of persons with disability in Palestine like 37.6% of people with disabilities never go to school. 33.8% of persons with disabilities they go to school and then withdrew and here the question why they withdrew? Because of the situation in the schools, because they are instead of being include they were excluded in the schools. 53% of the persons with disabilities are I literate. This is also a lot of question marks on this. 87% of people with disabilities are unemployed. Of course, 3 is related to two things, first to situation in Palestine in general, high percentage of unemployment between all the population and the second thing that the people with disabilities opportunities in education, and in work is very limited.

Now we come to the statistics relating to hearing disability. Going back to the same survey in 2011, the number of people with hearing disabilities it ranges between 17000 to 42000 of the population. This is also 17000 is severe and profound, and then we go to the mild it ranges from 42000. According, in the scholastic: 2016 to 17, the children with severe profound hearing loss, deaf just 77 are in the schools, all the schools, public schools. About 741 with mild hearing loss are in the schools. This a lot of question marks on the public education for the deaf and for the hard of hearing. The number of deaf children now speaking about the special education, the number of deaf children attending the special education schools for the deaf is about 1800. Students and the age of 3 to say 18 years old. Which means the total number of deaf and hard of hearing in education whether it's public or special education, is about 2618.

Public education just some numbers and the deaf children have the right to education based on equal opportunities. In Palestine we have a law for the disabled since 1999, it's called law number 4. The law speaks very clearly about the role of the ministry of education, the ministry of health and all the ministries, all the governmental organisations, what they shall provide for the deaf and for the people with disabilities, but unfortunately it's not implemented it's not a priority for the Government.

The minister of education has adopted a policy of inclusivity. We have a policy, we are lucky, but all the people who are included is less than 800, or 850. We speak about inclusive education and we speak about the inclusion of 800-850 students with hearing problems in the school. However, the number of deaf children attending the mainstream schools are limited to 77.

Challenges for full inclusion. We know that the basic challenge is the mentality of authorities. We know in Palestine we have a political situation, affecting the money, the budget, but until now, people with disabilities, including the deaf children, are included in the bureaucracy or ministry of education or other ministries.

So the challenges for inclusion are limited financial resources of the ministry of education, which limits its ability to provide the number of teachers in the schools, so they could provide teacher assistants, the number of students in the class is about 40 or 30. In a public school, this means that if the deaf child goes there, even with a mild hearing loss, they will be excluded. Of course, this limits the ability of the schools to provide sign language teachers, equipment and tools, audio visual aids, FM system and any other things for inclusion.

Lack of awareness amongst teacher, headmasters, families and students. It's not just lack of awareness. It's lack of awareness and negative attitudes of mainly the professionals in the schools. The teachers, the headmasters, and the awareness in the families of the right of their children to be included in the schools.

The other challenges are the teachers' qualifications. The teachers of the schools, the public school, they are not qualified to teach deaf students, and in Palestine we don't

have any college or university that graduates teachers who are qualified to work with deaf children or to support them.

Going back to the limited resources, also, the teachers don't have enough training to be able to deal with deaf children and other disabilities. Difficulties in the curriculum. Some deaf children also and their families are reluctant to go to the mainstream schools. Sometimes we try to include deaf children and we go into the process of facilitating their inclusion in the schools. The number of kids in classes is limited, so it could be good opportunity for deaf to be included, but the deaf children and their families refuse the idea of being included in the mainstream school, because many of them had a bad experience in these schools, and they went and they withdrew, and many of the families have more than one child, so they have been having this experience for a long time.

Special education for the deaf. The special education for the deaf in Palestine, it's newly started, started before the 80s, by charitable societies working for charity. It's a kind of charity, we want to support them, but not as a right to provide the children with education, as their right, as people who must have the same opportunities like others. Especially, the special education developed in terms of opening new schools, at the beginning of the 90s, it developed towards the right based approach. A right for the deaf to have the equal education as the others, and since that time, in terms of opening new schools, and opening new programmes like total communication, exchange of experience and teachers training. Nowadays there are 17 schools for the deaf in Palestine all of them using all communication options, total communication, except one school which uses only the oral communication, and this supports the deaf of all levels of hearing loss.

Challenges for the schools for the deaf. We know it that, till now, limited financial resources to special schools for the deaf because the mainstream school is not a welcome environment for the deaf, but there are limited resources to provide education for all the deaf children who go to these schools. There is limited resources because most of these schools are either run by Islamic societies or sometimes clubs, and some of the schools are run by PRCS. We have just one college which has speech therapy and newly two universities started to provide diploma education. Teachers

get on the job training which is time-consuming and sometimes it's resources consuming to build the teachers and then retrain them when they are on the job.

Because all the schools are operating the national curriculum of the country, this means that we teach the same subjects. We use the same books, like the hearing schools, and we recruit the teachers according to their subject, and we recruit English teachers, Arabic teachers, and so on, and they are trained to use sign language while teaching the deaf, using the oral ways and the sign language.

The other challenges, the high transportation costs for the children. We have schools for the deaf and all of them are in the cities, and the children living in villages and in rural areas have to travel, some of them travel 40 or 45 minutes, and there will be high costs of transportation. And in the difficult situation politically, when there are checkpoints or closures, they need more time and it's more expensive. And no-one pays for this. The family carry this burden. And this limits also sometimes many of the children coming to the schools because of that. They are out of the schools. Not because we don't have the ability to have them in the school, but because they don't have access to come to the school. They don't have the money to pay for the transportation. We try to support the most children through some support which I will tell you about later.

Limitation of movement in regards to the political situation, checkpoints, separation is wall, affects negatively the regular access of the deaf students to their schools. Many of the children were not able to reach their schools in 2001 and 2002, during the invasion.

Now I will speak about deaf education in PRCS. In PRCS, we have an ambition where we serve or we provide services for different kinds of disabilities and centres in schools, and units for speech and hearing, and physiotherapy and so on, but we have schools for the deaf. These are built around the education programme in PRCS to contribute to inclusion by providing them with educational opportunities, raising their families and communities' awareness towards their rights and needs.

Specific objectives of the programme. Improve the communication skills, educational and academic level of the deaf children at the age of three to 18 years old. Enhance the early detection and intervention. Develop the creative skills for the deaf students.

Increase family and community awareness. Develop the sign language and disseminate it in the Palestinian community. Because the sign language in Palestine is relatively new, it started in the 1990s, so there is a big need to develop the sign language by establishing the new dictionaries, and to disseminate the sign language in the community, if we empower the deaf children, we provide them with the services, with the education, and the community is not able to communicate with them, so it's useless. So we work on the child, with their family, with the community, to facilitate the inclusion of deaf in higher education, university education.

The first experience in Palestine for the deaf schools to graduate deaf students from secondary education was in 2008-2009, where in our schools for education there was the first group of deaf adults, deaf students, who attend the public exam in Palestine. The exam, which is given for all the students, whether they are hearing or deaf, they attend the exam with full co-ordination with the ministry of education, with some modifications, for example providing sign language interpreter for part of the exam, deleting some questions, but it's not touching the quality of the exam.

From that time, we have a group of students graduating each year, and they went to the university. The first time in 2008-2009. When they went to the university, we think it's not the environment for them there, but we came in contact with them. After just one week, they come crying saying that we want someone to support us there. We sent them to a university, Al Quds university. It's a place of education where they go to exams, they go to some sessions, and they ask for sign language interpreting. We went to the university with it.

We had many meetings, in participation with the children, their families and with us, the heads of the university in Ramallah, and they would not provide an interpreter and they ask us to send an interpreter and we sent one. After a month, we couldn't do that. We said you must provide the sign language interpreter. So we added this to our responsibility, because we will not leave the children, after 15 years of working with them, to be lost in the university without any support, so we started to support them with a sign language interpreter.

Then, new graduates each year, so they also went to university. We provided a sign language interpreter and we opened negotiations with the administration. Finally,

they provided a sign language interpreter, and they are now trained with the other university. So this was also provided this for them, and we have now 60 graduates from the universities. They are graduates from our school and now they are graduates from the university, and some of them come to volunteer or to work at our school. Now the main activities for the PRCS, the schools for the deaf. We have our schools. You don't know the cities, but I will name them. We have school in Ramallah, in Nablus, in Bani Naim and Khanyounis.

We closely work with the families in the programmes family training, and I will talk about that later. The Ministry of Education and other organisation in the field of deaf education. This is basic things about the schools. The other activity is the speech and hearing units. We have 5 speech and hearing units in West Bank and Gaza, where we provide speech and therapy training for deaf children in our schools and we also provide hearing-aids here and we provide the hearing test. For the children from all schools and all ages, or people who need hearing-aids or need hearing test or speech training. Organised screening days in villages and rural areas y to contribution to earlier detection. 2 units provide early intervention, since 2011 we started this programme in Ramallah that we start with a child as soon as we discover the disability, sometimes that's 1 months old. But the total number of children coming each year is not more than 40 because we have just one speech therapist here. Provide family counselling, co-ordinate with the clinics, delivery hospitals and mothers and child centres. Train rehabilitation and CBR workers to be able to observe and detect the children with hearing problems. The third creative and extracurricular activities. We have a very nice folklore dancing group, groups, one in Ramallah, 4 folklore groups. The one in Ramallah now is known in all the community, all people ask them to come and do their performance, and to tell the truth the first time they performed in 2005 all of us were crying. Because we don't think, we who we believe in the rights to do everything and who believe in their abilities we don't think that they are able to do dancing also. Without hearing. They are so perfect, I will show you some of the pictures later. Animation, you see the film, so we have now a group of deaf adults about 15, who are able to train all children in how to do animation, they go to summer camps go to fun days with the hearing kids and they train them. The deaf training the

hearing. It's part of changing attitudes of deaf people it's very important to show the people that the deaf kids are many times more creative than us when they are provided with the opportunities, and with the, when we provide them with what they need what we understood their needs, when we understand how to communicate with them.

Drawing, face-drawing, balloon shaping we work on this with an organisation. Sports we have very fundamental football teams and tennis and volley ball. Embroidery, very nice scarves and so Owen finally we have a deaf club for the graduates, who graduate from the school we have 50 members in, it all the deaf graduates they come for activities in the school.

Family programme, like all other programmes we provide family training in sign language in other subjects, family participation in the schools and activities, they are all the time in contact with the school. Regular meetings between families and staff. Family member attend some classes and sessions with their children.

Sign language programme, sorry, it's long, boring? (laughter) organise sign language training for member of the local community, here we do 15 sign language training in the community for one semester not for the year. About 3, 400 participated in this sign language. We have volunteers, students from universities, we have policemen, we have bank men, many people and many organisations who provide services for they come for training and sign language. Of course we don't claim that we the sign language in all Palestine but we are contributing to that, but the aim is to make the sign language an own language in Palestine. Provide sign language interpreting in conference's meetings and workshops. Here the challenge we have a lot of interpreters, they are background is are teachers but they are training to be interpreters but they are not certified. Even that they don't, they have someone in the court or in the police station, they ask us to send interpreter even they know they are teachers. We are working on that in the coming year. Provide sign language interpreting for deaf children at two universities. Publish sign language dictionaries.

Of course in sign language dictionaries we don't publish in our own, we co-ordinate with the ministry of education and the deaf union and the deaf adults who participate in these. Awareness programme, contribute to the positive change in attitudes towards the deaf and the deaf schools. The deaf schools do the following to contribute to the awareness. Organise awareness and integration and integration activities in the mainstream schools for deaf children and their hearing peers, organise activities in the local community, organise visits to local institutions.

Some successes and achievements. A group of deaf graduates from secondary education every year since 2008. 90% of the graduates attend universities and colleges and followed by PRCS staff. In 2001, PRCS published the first educational sign language dictionary, hard work by the way, and later 3 other dictionaries. participants attended the sign language training is TCC school is considered a resource centre in deaf education we train other schools, and we provide training for different groups for the families, for community, and for the workers in other schools. We PRCS is the first provider for sign language interpreting in Palestine. PRCS is the main provider for hearing-aids, 300 to 500 beneficiaries yearly, this is a big challenge because we provide hearing-aids depending on external support and partners and we do work with banks and with the people from the private sector to try to gain money for the hearing-aids, because we don't have enough money to provide hearing-aids for the people, we have a waiting list of 1000 people who need hearing-aids. By the way the hearing-aids are relatively, high cost for the families, not to provide by the Government so the families have to pay. Many of the private sector they gain a lot of money from selling the hearing-aids, so it's a challenge and we after the only organisation that is providing this for free, or sometimes very small fees. PRCS has a big network with national and international organisation working on it field of deaf education, or related fields like ministry of education Minister of social a fairs British council, heart to heart, features, creative centre, DPOs. The deaf adults enrolled in the deaf graduates' club are well-known by other organisations are invited to do folklore dance's train other children in animation and other creative activities and they are very confident to do so.

Challenges. We face the same challenges that all the schools for deaf face, or let's say, all the organisations that work with the disabled face, but we have better opportunity than others because we are members in the international movement of the red cross and the Red Crescent, so we have commitments from our partners liked Swedish red cross, like the Spanish red cross. Thank you. But I will show you some pictures or photographs of the children in the activities. Thank you. This is a maths class. Technology class. The girls are matching words and pictures or I think a memory game in the toy library. Letters and a snake in the toy library. This it's the grub. One of the other groups. This is an experience for students' elections. It was coordinated with the community for elections in Palestine.

JOHN COSTER: Can you use the microphone.

SUHEIR AL BADARNEH: A sorry, because it's written. This is an experience of elections for students' council, and it was followed by the centre for community in Palestine they come and train the children and the teachers they want to do the whole process over election, three of the students win. Two girls and one boy. Here are the sport activity between the deaf children and the hearing, it's integration and sports. Our football team but there were young it's 3 years old this picture. This, we support also vocational training for the deaf, but with the local community, we don't have vocational training programme but we include them in workshops, in centres for ministry of labour or the Ministry of Education. We follow them, we provide them with Sign Language Interpreters and we also work in job placement for them, we succeeded to employ many of them in the local community and the private sector.

The first grade with a volunteer from the graduates, the deaf adults. And integration activity and one of the kindergartens, preparing this kindergarten for in inclusion of the child. Awareness activity in school for mainstream school. Peer education, a deaf child is teaching the other deaf child matching words and pictures. Deaf adults teaching the young. They are doing busy doing their wall picture. This is

the activity of shaping balloons with heart to heart organisation, they are saying "love you."

The graduates of 2016 with the President of PRCS. This is the class, 2016 class the secondary class. A deaf volunteer she is teaching them music. Celebrating the day, language of Palestine, 30th of March. All the school's students with the President in front. Children going to protest, to ask for their rights for education in front of the Ministry of Education. Activity on the child day. Children celebrating international workers' day, they are wearing the uniforms of the workers. A marathon in the international day of the persons with disabilities. A visit to Yasser Arafat tomb in the day of his death. Fitting a hearing-aid for a girl, she is happy. Here it's sign language training for the participants from the community. Sign language training. Children celebrating Mother's Day with their mothers. And this is a leadership training for the deaf adults with the youth department in PRCS, the training is done for the youth, hearing and the deaf. This is a meeting. Thank you. I hope it was interesting. (applause).

JOHN COSTER: Does anybody have a question they would like to ask?

FLOOR: I have a question. I wasn't sure whether to put my hand up, because I am not really involved with deaf education, but I understand the political situation between Palestine and Israel.

I understand the situations that similarly occurred between, for example, Northern Ireland and the Republic. You often find that deaf people from opposing communities don't share the similar oppositions between their communities because they are bonded by being deaf. Do you find the same? It might be a bit of a sensitive question, but I just thought I would pose it.

SUHEIR AL BADERNEH: Is this microphone working? I think that the deaf population have the same challenges all over the world, but building on the situation in each country, the challenges are different. By the way, before 2001, we had good relations between our school in Ramallah and school in Israel, and we had meetings face to face with them and there were meetings through Skype, but after the political situation

became worse in 2001, and they invaded the West Bank, we cut this relationship, and refused to have any communication with them. We know they would like to be with each other, but political reasons - it's not political, just humanitarian. If you want to go to visit them in their schools, we are not free to go any time, or to go to any activity. But I want to say that the deaf in that experience, they were very close to each other, even when there is a political problem. I don't know, does that answer the question?

FLOOR: Thank you.

SUHEIR AL BADERNEH: Thank you. I am very happy that I met you all in this conference. Goodbye. (applause)

STEVE CRUMP: Thank you, Suheir. I am just going to sum up and table a few look-forward points. But before I do that, I just want to say a few thank yous for today, and just to say this was the warm-up. So we start again properly in an hour! Just testing! I would like to thank Lord Bruce for his support today. I would like to thank the hard-working team of DeafKidz International, the advisers and staff, Jaz, Duma, Barbra, John Coster today, our hard working interpreters and palantypists. It is much appreciated.

And, of course, our warm friends, Cochlear Europe. Many thanks for today.

This is the beginning of a journey, I think, and certainly we will be continuing to work on DFID objective 4. We will be continuing to work on 16.2, the strategic development goal and environment of the children. Some of the points that have arisen, to me today, are that we need to better evidence, as a community, the incidence of deafness in low resource settings. So we need to be working with those working in health to ensure that we get the data with which we then better articulate the need and the case for support to decision makers, such as ministries of health, donors and so on. To invest into certainly the safeguarding of deaf children and young people and also ear and hearing care, and any ear and hearing care provision needs to be integrated. That's what we are trying to ensure in Pakistan, which is new born screening, onward referral to audiology, speech and language and sign language development, positive parenting. The clinical work of ear and hearing care cannot be separate from the deaf

community and the experience and language of the deaf community. We need to integrate the two.

I certainly see what we have here as a public health challenge, in the sense that the incidence of deafness is a greater challenge to public health than that of infectious diseases.

So there is much to do, and I think Mark mentioned earlier competition. I just want to make a point that DeafKidz is about collaboration, and so I am delighted today that so many of you have come together to collaborate. And also, that we will continue to move this discussion and this debate forward, and so, certainly, we look forward to meeting you again at the House of Lords in March next year, World Hearing Day, where Lord Bruce will be hosting us, and also we look to do this meeting again in Jamaica next year, where we will continue our discussions and our debate, but in the theatre of the Caribbean.

All the notes from the workshops, all the presentations will be sent on to you. They will be assembled and sent on to you, and then there will be communication coming from here on what's next. So what sort of forum do we gather in order to continue this debate and discussions, and to ensure that the decision makers I referred to earlier are aware of what we are trying to do.

So it remains for me to thank you for coming here today, to thank you for being part of this interesting gathering, and to look forward with you to a time perhaps when no child will ever be left behind. So thank you.

Outside in just a moment, grab a cab. We will see you at the Frontline club from six o'clock onwards. We have all earned it. Well done. (applause)