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DEAFBLIND CONGRESS, LILLE FRANCE

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VASUDEVI: Just signs, if somebody calls your name your brain lights up in a different way. And this happens to adults. It also happens to children slightly to the side. That shame and pride require two things. One is, you have to have an idea that you exist. You have to have a concept of self. You have to have an idea of yourself that other people can, that self can do good things and bad things, that you can be ashamed about and proud about. That you are you. How can you feel shame and pride? If you don't have good and bad standards how can you feel shame and pride. But I think, this is the logic of this view, OK. But I think there are problems with this. One is the problem that to understand somebody else to understand that you are good and bad arrives very, very late in the day. OK. And this problem with this traditional view is making the assumption that, let us say you are faced with me, I am your evaluator, OK. The traditional view makes a distinction between me attending to you, and you understand that I am attending to you, that is step number one of understanding. But it is not so important for shame and pride. What you need to understand is that not just me attending to you, but me, a few months later, like when you are about three years of age in infancy, me, evaluating you in some way. OK. Now, one of the questions that this raises is, can you ever have, can you ever understand, can you ever see somebody attending to you without understanding how they are attending to you. Without understanding the evaluative component of understanding. Can you ever understand attention without understanding what it is saying, what that attention is actually saying. OK. So traditional view separate out the simple emotions that come from understanding that somebody's attending to you, from these complicated emotions like shame and pride and embarrassment, complex embarrassment that can only come from understanding that you are being evaluated. As I said the problems with this view are the standards, understanding standards emerge because of perceptions in fact that something is approved of or disapproved of by people. You don't reach an understanding of standards and then understand that other people are adopting the standards. You first, I think, understand that people are approving or disapproving of you and from that you develop an understanding that there is something like a standard. So it is through people's

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emotional reactions to you that you can understand standards. So before the development of the self, of themselves, of a concept of self, infants can already, I'm going to argue understand themselves in relation to other people and can perceive emotional reactions of other people towards themselves. OK. So, my argument is, that in order to understand other people's evaluations of you, you do not need to have an idea, conceptual idea of yourselves. You don't need a complicated conceptual idea of standards, you need to be able to relate to people who are trying to engage with you and you need to be able to perceive their evaluations of you not separate from their attending to you, but embedded as part of their attending to you. OK. Now let me move on to something, a kind of emotion that we all think about very commonly as being a self—conscious emotion. All of these things, by the way, embarrassment, pride, shame, have often been known as self—conscious eye motions. These are clips from the internet and this is a positive embarrassment which you will all recognise if I pay too much nice attention to you, you will all show it. It is kind of unavoidable. If I look deeply into your eyes and say you have the most beautiful eyes in the world you might feel pleased and turn your gaze away for two seconds or half a second before you come back. And the interesting thing is, this is the kind of reaction which traditional views say babies should not feel until about 18 months, it is not an embarrassment, it's a simple embarrassment that comes from exposure to positive attention, to simple attention. Now, I would like to argue that in fact one of the studies that we have done has shown it is not the case you need a complicated idea of yourself to feel that kind of embarrassment, it is in forms of embarrassment as early as two or three months of age. I show you this video clip and what you will see is a baby of two—and—a—half months, a baby of two—and—a—half months being carried with a mirror. When the baby's eyes move down to the right side of the mirror image you can only see the mirror image. When the baby's eyes move to the right side of the mirror image she catches sight of herself. What you will see is catch a sight of herself, the start of a smile, the smile intensifies and at the peak of the smile, because the emotion is so overwhelming, there is a turning away, it is a very familiar thing. The mother is laughing and smiling and incredibly pleased because the baby has discovered a friend in the mirror. You will see those reactions. If a baby does that to you when it says hello, you think it is wonderful because you feel I matter, I made a difference to the baby, I aroused something in her which says you matter. So it is a strong

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powerful reaction. It is a simple thing. It is not a result of a concept of self. It is a result of a perception of positive attention from the other. OK, it is a recognisable reaction. And there are developments in that reaction. If you look at those pictures from the top left to the bottom right you will see a progress of the same sort of behavioural reaction, slight kind of turning away of the face. Sometimes the arm coming up to hide the face. Going on from two months to about three years. What is developing there, is the intensity, discreetness of the reaction. So that when you and I were going to hide our faces we would turn away perhaps more subtly, we might bring our hand up to cover our mouth, is a common one. If they're embarrassed and shocked but positive, their hands come up to cover their mouths like that. The babies are doing it in a crude and whole—body way. The resemblance in the reaction is the same. What is also changing is the context in which it is occurring. The babies are doing it simply to somebody looking at them, themselves or another person. As you get older you might do it because you are caught doing something funny, or you catch sight of yourself in the mirror with something strange on your face, as is happening with this boy here. My argument is these emotional reactions are continual, they start early, they become more complex. So what about shame? That was embarrassment. It was a very positive kind of shy embarrassment, shy coyness, what about shame? Shame is a funny thing. For embarrassment you can have a clear pattern of response. Gaze connection, attention connection, intense smiling, and turning away at the peak of smile, turning away or hiding at the peak of the smile. Shame, there is no clear pattern of expression, even in adults. Some kinds of typical signs of shame but you don't have to have all of these to feel ashamed, you don't have to have any of them to feel ashamed, is and the most clear signs is the collapse of the body. So you might find yourself unconsciously, when you have a negative thought about yourself or when you are caught doing something you can't correct is your body instead of being like that, goes like that, your shoulders slump. The corners of the mouth often go downward, your lower lip can be tucked between the teeth, your eyes are lowered, often downward or to the side, you want to hide and withdraw from the world. You want to withdraw from tasks situation and disappear, you don't want to be present in the situation in which you can't handle because there's nowhere for you to go. If you are a speaking person, then you have often negative verbal self—evaluations. These are some of the signs we recognise as I say, as typical of shame. What about in infancy? Well, if you

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follow the traditional model of thinking about when shame should develop, no way, until three years, you don't have a concept of self, you can't have shame. But there are some situations, we don't know enough about this, there are some situations which although we don't know enough about, seem to be good candidates for exploring some kind of shame reaction. And one of the candidates towards this, for this, is something called the still face. I'll show you a video clip. This is a very famous set of experiments done basically to show, hang on, one second, done basically to show babies, even two and three—month—old babies, really mind when the person they are talking to suddenly goes blank, it is a famous study.

SHOWS VIDEO

Now it is horrible. It was very useful at the time to show that two—month and three—month—old, typically developing babies are not just responding in some automatic fixed—action kind of way to people, but they really mind it when people to whom they're talking to stop talking to them. And it is, in this kind of situation that this is, you could actually see it as paradigmatic situations, typical situations as you and I may experience in our lives. With somebody whom he likes stops responding in the same way. When somebody we are in love with, stops writing to you or stops seeing you, something is cut, something goes blank or still. What happens when you have no voice? Nowhere to go or no way to respond to it? This is a very young baby I will show you a clip of and what you will see is the mother talking to the baby and this is in an experimental situation when there is a knock on the door the mother is told, please make your face blank. The mother makes her face blank and the baby, you will see will look puzzled, will look down a little bit for the first time, smile goes away, they look up, try to smile again to re—engage the mother, they don't succeed, they look away. What you might get in this situation is not these complex shame reactions but signs, simple things like the body the shoulders sloping and smile going away, gaze going away. Now I need to find something like this. Come and how much it connects them when the connection with the care—giver is broken. Six months old McKenzie, face—to—face, he asks mom to talk and play with her daughter the way she normally does.

NEW SPEAKER IN VIDEO: Hi sweetheart.

VASUDEVI: Obviously their connection is strong. The baby is engaged, responsive, clearly emotionally content. Then the doctor instructs the mother to disengage by making a still face. She

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stays there but doesn't respond to her baby. McKenzie is confused at first, she's not used to mum acting like that. Mum turns back but keeps the still face. McKenzie expects her to re—engage but when she doesn't, look how the baby reacts. Even at this young age she tries to entice mum to get back with her. She reaches out, she smiles, she flails her hands — all strategies for getting mum's attention. When that doesn't work she becomes fussy, emotionally agitated. And finally she just gives up. The meaning of the event is this emotion.

I kind of find these, it makes my skin crawl when I see the studies but you have to remember having done the studies in the past, developmental psychology has learnt a huge amount from the power of emotional reactions before and without words. What emotional engagement can do to you and expectations it gives you and disappointment and the loss it gives you when they go away, when the engagement goes away. OK. All in all, these are some kinds of emotions that we don't, we cannot say for certain that shame is there in infancy but the reason for saying there is no shame in infancy is problematic, conceptually circular, confusing the evidence or contradictory or all, what we are left with is that these emotional engagements are more powerful than we can understand as yet. And there's a strong need for clarity. One of the things I've been thinking about in relation to shame and pride is that they are sort of powerfully interpersonal emotions and what's happening there, when you relate to people is that you're in a constant, if you like, unconscious, unthinking process of managing how much you reveal yourself to another person or how much you hide yourself from another person. If you take shyness and showing off two extremes of either hiding from other person or revealing yourself to another person, you see both phenomenas. We've looked at both in infancy, we haven't yet looked at showing off, but both of these could be two ends of one dimension of how we relate to other people and how we manage the intimacy with other people, if I did not have a PowerPoint presentation, if I was not bound by my conventions to being here, probably I would come out to the front and show off more to you, right. Probably I would feed on your reactions to either shrink to myself some more or think "Oh my God they don't like it" or expand because you are giving me positive feedback. There is something in this relation, even a relation between a speaker and such a large audience. There is something in a relation where each of us mean more than you because I'm in the spotlight is managing our intimacy all the time. Babies are doing this as well. One of the things is let us look at showing off as early form

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of pride as a kind of pride. Not pride in the sense of somebody verbally saying "I'm great" but pride in the sense of feeling and expanding myself and allowing yourself to come closer to see me. Now, what does pride look like? Well there is no standard expression for pride. It is one of those positive emotions which can show itself in very many different ways. There isn't a fixed kind of pattern. I was trying to extract different situations all the way from two months down to three years of babies, sort of feeling really good when somebody responds to them positively and pondering with this kind of strong feeling of some, very strong smile and often a repetition of the thing that elicited that response from other people. That's a good way of showing off in infancy. It is to look at — let me show you this. I'll somehow show you the video because it is much clearer what I mean. This is an example of babies not just showing off but repeating something that other people have praised but actually provoking the other to an even slightly stronger reaction. Something called teasing which babies, even from nine months do. And here is a baby, what she's doing you can see, what you're going to see is she has just been able to, she has learned how to hand over things, to give things to the father or mother when they ask for them. She has a bunch of keys in her hand, the father asked and gives it, and then she changes her mind and says I'm going to trick you. She offers it back, the father puts his hand out and then she pulls it away. She's provoking positive reactions from the other and she has a wicked laugh which is wonderful.

NEW SPEAKER IN VIDEO: Thank you.

VASIDEVI: What this is showing amongst, apart from the fact it is fantastic, it is a revelation of initiative and provocativeness in infants how they lead interactions with others. If you want to be boring the infant knows the connection between her action and knows the other person's reaction, and repeating the action, it is a boring interpretation but that is also presented as what you can learn from this. I show you another example which is simpler. Of what you might call clowning, repeating something to make here people laugh. This is the first instance where you will see the mother ask the baby, "Are you dancing." The baby shakes her head like that, the mother says "Are you shaking your head?" and starts laughing because the baby shakes her head again and again, because the mother is laughing the shaking of the head is going on and on, sometimes two weeks, every time the baby remembers, until the mother has no desire to laugh and then the baby gives up. And so it goes.

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So if I come back to this that oval shape there, you see from very young babies with that smiling response, the shy response to the self from the self in the mirror, a response attending to the self, connecting with you, visually connecting with you, a strong emotional reaction. Then, somewhere in the middle from about seven to ten months, you see the baby's responding to the acts that they do, to other people's responses to those acts. As you get older you get babies repeating things like showing an object they have in their hand or pointing to something there, which is far away from them and playing with other people's attention to them. And so on it goes through verbal things and reported thoughts and events and actions all the time. OK. So I'm coming towards the end. I would just like to say that if you're talking about the formation of the self, or the perception of the other experience the proposal acceptance of yourselves and the perceptive experience of the other are often very mixed up. So, the simple point is this — I cannot perceive you or your reactions without at the same time experiencing the feeling of "oh they like me" inside me. That's my experience, that's my perceptual experience of you and you cannot do the same to me the other way. I cannot experience me without looking at you and knowing what you are doing that is linked to my experience of myself. So, my knowledge of myself is completely tied up to my knowledge of you. And my knowledge of you is completely tied up and constitutive of my knowledge of me. This is coming back to my point about engagement. If you engage with babies, make connections and then they can expand further on those connections, their understanding their being a self constitution of themselves is constant in them you. You talk to babies, you address them as you, you are becoming a part of themselves all the time. As we are not just babies but even as adults, in every moment of these connections your experience of you is tied up with what you perceive of me and vice versa. In development, engagement is crucial and I'm kind of going through a little fast now to wind up the talk, engagement is crucial, these moments of connection are, they build you and they build me. The starting point for this has got to be something like being the other person seeing you as a "you" rather than as an "it" and building on it. I'm going to jump to something which is for about a minute, which is a study that we recently did which is looking at very young babies motor responses to adults approaching them. It is a body response to another body but it isn't just a body, these are two people and the reason I'm going to talk about this, I want to show you these clips is because psychology understands extremely little

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about motor development and it is often called the Cinderella of Psychology. Motor behaviour because it is like, it is just the body who cares about the body? What psychologists are interested in is the mind, but actually if we accept that we don't accept a dualism between the mind and body, understanding the body and its responses to others very early on could be extremely important. OK. I'm just going to skip to a video clip of three—month—old babies, responding to mothers who are reaching down to pick them up. And I show you three clips in a row and then I show you a clip of two—month—old baby doing the same thing. What I want you to look at is as the mother's arms are approaching the baby to pick them up. What the baby is often doing is before the mother touches them, what the baby is doing is sometimes widening their arms out like to make space for the mother to pick them up or sticking their legs out and stiffening them to make their body rigid and more easily picked up. It is crazily early to be doing such anticipatory adjustments but two and three—month—old babies are doing this. If they're doing that much anticipation, one body to another body at that age what else are they doing? And where is it going? We don't know the answers. These are three—month—olds. Mother is going to approach another baby. Look at the legs out and head up, this is a little bit ridiculous, ha. I go to the conclusions and then I stop. In conclusion, all of these self—conscious feelings, shame, pride, embarrassment, often guilt, envy, jealousy, I think they precede a concept awareness of self in typical development. Embarrassment, shame and pride I think, could be understood better by thinking of them as ways of managing the self in relation to the other rather than thinking of them as conceptual clicks or conceptual advances which are almost independent of the child's experience. These are happening in little ways all the time in engagement. I've said engagement is developmentally crucial for awareness of others attending, others evaluations and learning from others, right. If others can find a point of connection, smiling at you, smiling at something you do, tickling your body, looking at something that you're looking at, going further, any of these points of connection could be a starting off point which is absolutely crucial for taking you down roads that neither person knows. Engagement by the way has got to be genuine, otherwise it doesn't work. You can't write a recipe book for engagement, you have to be there, open to the other. We need to take seriously, infants and people's ability to perceive other people's emotional reactions to them. These perceptions affect us in the present and very much carry us into the future and they

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constitute the selves, ourselves as we are now. OK, I stop now. APPLAUSE

COMMENTATOR: Thank you very much for a fascinating and interesting opening presentation. You've already given us many ideals that we will return to in the discussion later on this morning. And I have absolutely forgiven you for my examination, all those years ago. We are going to take a short break, a ten minute break. Just as you saw the baby on the video with the keys and taking it towards the adult and pulling them away this, is not quite a coffee break yet. So it is just a short ten—minute break so we can set up the stage and make some changes. In that time you can stretch your legs, or you could spend the ten minutes thinking up the questions that you've already formulated that you want to ask us later on. So we will be back in ten minutes.

NEW SPEAKER: My I take advantage of these ten minutes for a small practical announcement. People that have to present something this afternoon in the workshop session, you must go to the preview room to have your stuff checked, your PowerPoint, whatever. The preview room is, there are signs but if you are down where you have registered you go up the big stairs and it is to the right, OK. Hello, thank you. Great. Yes sound level is great. Great ten minutes it is. Lovely. Thank you.

COMMENTATOR. OK. Otherwise we'll run out of time. OK. If you would like to make your way back to your seats. We will be starting in one minute. OK. Are we all now ready? I will give you a few seconds to take your seats. The doors are closing the aircraft is about to depart. Business class only. OK. I think tomorrow when we have these breaks, as we talked in our presentation, standards whether we meet standards will determine whether we feel shame and pride, we will put ourselves on the clock so we get our coffee break on time. So, thank you and welcome back to the continuation of this morning's theme. I'm now going to invite Dr Andrea Hatheri who lectures at the University of Cluj—Napoca which in Romania. And among other topics that Andrea lectures on, she particularly specialises in deafblindness and multi—disabilities and has developed a range of courses in Romania from undergraduate to Masters level. She has also been involved in the development of resources and teaching approaches in Romania. It was in this capacity that I first met Andrea. And Professor Vasudevi Reddy mentioned earlier the last time we had met and the last time I met Andrea was to be given a lesson on Romanian food and I'm sure a few Romanian

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beers as well! So I'm now going to welcome and invite Andrea to respond to Professor Vasudevi Reddy's lecture from the perspective of congenital deafblindness.

ANDREA: Thank you for the invitation and presentation. I would like the presentation of mine to invite you to have a reflection of what pride and shame means in the context of congenital deafblindness. I must confess that I was, you know, challenged by the theme that I was given by the Scientific Committee, but also you know a theme that it is interesting and a theme that was not very well approached during the previous studies. So, of course I started with looking about what does the emotional development, social emotional development mean? And the most complex definition that I found was that emotions are multi—component and co—ordinated processes of psychological subsistence, including cognitive and peripheral, physiological processes. Rather a complex definition, but we will see in a few minutes. You know with the methodology that I use what is it all about within the context of deafblindness? So how can we define shame and pride in the context of congenital deafblindness and what should we relate to? This is the reflection I'm inviting you to have for the whole presentation that I'm going to proceed. The methodology that I use was of course starting with analysing the literature of speciality and existing studies about shame and pride within deafblindness. Then a focus group with researchers in the field of psychology questionnaires that I applied for — thank you very much who are working in the field and interviews narratives of deafblind people — and of course in the end the interpretation of results. Should I, OK, I imagine I would have to slow down.

So, in the end, should I say it again. The last two sentences, so the questionnaires that I applied for teachers working in the field and interviews and narratives of deafblind people concerning their own experiences related to shame and pride and interpretation of results and conclusions. Starting with the literature of speciality I have to limit my limitation, because I didn't find so many studies with these issues. The speciality follows the key social implications of deafblindness like isolation, deprivation, disconnection, confusion, helplessness, withdrawal, aggression, depression, self—abuse. So nothing on or as I said knowledge limitation because I didn't find anything of the developmental of self—conscious, moral, emotions, related to the development of self—awareness and you know the technology of standards. The concepts that there are also articles

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and papers on the concepts of shame and guilt that are mostly mentioned for adults with deafblindness in the context of experiences and awareness of being different. Then the focus group with the researchers in the field of psychology followed and this was quite an interesting and again challenging thing to me because as you had see the researchers in the field of psychology who do not have this experience of working or approaching the field of deafblindness or multiple impairment, they do not understand the implications of deafblindness in the development of language, self—concepts, self—evaluation, self—esteem and behaviour. And their focus was that we need to use batteries of tests or standardised tests and inventories and validated measurements in order to say there is, especially as you will see for those people who are non—verbal children. So their main argument that research must be evidence—based. Their main argument was if there is no verbal language and if there is severe delay in cognitive development then there is no understanding of these emotions and the implicitly behaviours. The difference they said should be considered within different complexity of impairment and use of communication system and linguistic abilities. That is pre—verbal, non—verbal, sign language and verbal or written. But, as I ask them this question the main issue is how can we be sure — slower — how can we be sure that we assess shame and pride and not other behaviour displays? And if we cannot measure it does mean it doesn't exist? Unfortunately the focus group has no tangible results and final conclusions but at this moment I would like to just say a few words about my perspective. When I started 13 years ago on intervention and teaching I had a different kind of knowledge and understanding and related to what I know now. It makes me wonder and it makes me think how will it look like in ten years' time about my knowledge and my understanding about what deafblindness is about? Maybe I will keep, you know as I said understanding and knowledge, but definitely for me it's changed and things that I was unfortunately right at that time or considered to be right at that time, it changed in these years. So we cannot say for sure that our priorities in research, in intervention, in teaching would not change in time and of course, this presentation will have also have some recommendations as well. About the questionnaires for practitioners, you will find it here interesting the questionnaire was applied to 27 teachers who are working in the field of deafblindness. They have between two and 17 years of practice. They are working with people, individuals between 5 and 17 years of age. And the

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question was about their knowledge and opinion about the concepts of shame and pride, name implications of deafblindness, ways in which people with deafblindness present shame and pride and their development of these moral emotions. I would just like to give some of the results. So the practitioners considered the main implication of deafblindness are communication difficulties, isolation, and limited experiences and that deaf blind people are not well understood and they usually labelled in their abilities. They have self—autonomy and adaptation, difficulties in social inclusion, people tend to have low expectancies regarding their performance and learning, "people" meaning who are in deaf community within the society and sometimes even professionals. So how do the practitioners define what pride and shame is and in just a few words. Pride, it means high self—esteem, self—appraisal without any justification, they refuse to accept help from the others, feeling happy and content, very high confidence and to feel superior. And shame? Self—esteem, embarrassment, fear to be judged by others, feeling bad about their behaviour or situations, lack of shyness, guilt in different context due to failure, being aware that she or she is different from others. Two practitioners think that people with deafblindness, children whom they are working with express pride and shame. And the answer is yes, or they don't know. Many of them at least half of them answered they don't know if they express shame and pride as their, as moral emotions and self evaluation, self—conscious emotions. And the response differs for what they think of the key factors that come into the display of the social emotions. Like level of impairment, social learning, development of language and ability of self—evaluation. And there are others who interprets emotions and they attribute significance. What could be the behavioural displays of pride and shame in the practitioners' view? They gave some as I said behavioural displays. How could they recognise if the child in the context of interaction, could they present this emotion? They said for pride, smile, laughter, big gesture, or posture, eye contact, applause, aggressiveness, or they said it is the same as for the people without disabilities. And for shame? Isolation, avoiding people, hiding the face, crying, aggressiveness, refusal to drop, or the same of people without disabilities, even though it was not mentioned in the questionnaire that has to be different or not. As a reflection of what the teachers' responded. Do practitioners realise the importance of emotions in learning even though it is not only about shame and pride. It feels to me they don't give so much importance to how this emotions are so involved in learning and

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achievement, especially within the educational context. Is just participation in activities and interactions in activities enough for learning? Because most of the time we say yes the child needs to participate and needs to be an active participant but is this participation enough for his learning? Then how can we organise the environment so that we allow behaviours to manifest and interpret them adequately, because even us, when we attribute significance, we don't know for sure that we are really right in that attribution, so we have to be aware of our own interpretation and consequences also. One thing that I think is important is are we aware of how the children interpret our own emotions and our own may have yours? I say this because I work for children for four years before going to the university and there was always one child who said, "Why are you so nervous today." But for me it is not something I would or should show to the children and not relate to them or the class, but it was one of those days. "Why are you so nervous today?" So at that time I have to confess, at a time I didn't put so much importance to this, but now, and lately, more and more becoming a priority. What kind of feedback do we offer? As I said, are we aware of our own behaviours and our own emotions? Because even though we are not so consciously aware of what we would like to transmit like the behaviours and emotions, children could interpret and people would interpret these and will react to that. Do practitioners and this is also something that I would consider, do practitioners feel shame and or pride related to their intervention? Here I mean shame that they acknowledge they have limitation in not knowing. So there's a need for training about emotions and their impact I think. Learning means engagement as Professor Vasudevi Reddy said, self—regulation and achievement. I would like now, because I have five minutes left, I would like now to go to the part of the interviews and narrative. I've chosen just one fragment of this part because the person who answered is a really special person to me. He was one of my former students and whenever I had him he asks me if I remember the fun times that we had together and the time that we shared and the laughter that we had. While he doesn't mention anything about my great teaching but . . . but he mentions all the nice emotions and the well being of our interactions, so this is what he, and he published so well, I have to say now he is one of my students at the special education department so I have to be really, really proud of him. And this is what he said when asked about his own experiences. "We're living in a society in which we have the tendency to compare and observe each other regarding our cognitive and emotional

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performances. I will confess one of my experiences related to pride. I used to have a classmate who likes to compare who is good and who makes mistakes. Making all kinds of remarks to everybody. I was annoyed by his attitude and I was thinking that this is not right. So I was avoiding having this feeling of pride and over self—confidence until one moment when I took my final exams in school. Looking at the grades I realised my colleague had low scores and I had the highest score, so I was embraced by enormous pride that I accepted. After that, I stopped this feeling thinking this does not help me in relationships with the others. I stopped comparing myself, I started to feel positive that I have my own values and qualities that I can enjoy and be pleased."

So going towards the conclusion, is it all about evidence—based or we can say that it is also about you know, a person—based research? That means we really need to know how that, how the people interact, what do they feel, what do they think of this environment that we like to think that we create and we offer and we manage so well. I think this is more important to find out about anything, the development of emotions, the development of ability, the interactions and communication, that it has to be more focused on the person and not just on what we manage to evaluate. In conclusion, approaches and discussions about shame and pride in the context of congenital deafblindness are ongoing and challenging. We acknowledge our limitations but we emphasise the importance of sensitive and responsive environment, development of special and emotional competencies, awareness regarding their involvement and effects. Thank you for your attention and invite.

COMMENTATOR: Thank you Andrea for giving us more ideas to throw into our melting point for discussion after your coffee break. I'm particularly struck you said of the pupil who doesn't necessarily remember all of your good teaching but does remember the interaction with another human being. I think that was echoed in much of what Vasudev said. If you bring yourself to situations all sorts of exciting things can happen. I'm now going to invite Emma Boswell on to the stage to give her presentation.

I'm going to first do the introduction of Emma. Emma Boswell is the national coordinator for SENSE, the national Usher coordinator for SENSE as part of the Usher specialist team. She has worked in this role since 2011 but overall she's worked for SENSE for seven years. I'll continue my

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theme of when the last time I met people. Because the last time I met Emma was when she graduated with a diploma in Deafblind Studies, accredited by the Open University. A moment of immense pride, I am sure. And now, I will invite Emma to respond to Professor Vasudevi Reddy's talk from the perspective of acquired deafblindness.

EMMA: Thank you Paul. Good morning everyone. As Paul has already said my name is Emma Boswell. The title of my presentation is Usher Experience, Shame and Pride. I will talk about my background, I had to get closer to the laptop. I'll talk about my background, experiences at different stages of life associated with shame and pride for Usher people and how this can be linked to mobility, communication and identity. Then I'll finally talk about the way forward, acceptance and adjustment for my conclusion, which will take us into the break. A little bit about myself. I have Usher Type 1, I also have additional eye cataracts, old cataracts and macular, I have cataracts but they're mild at the moment. I was a guide dog user but my guide dog has retired and I will be a guide dog user again because I'm on the waiting list. I use mobility equipment such as canes. As Paul said I work for the charity SENSE I am the national Usher coordinator which means I head up the Usher specialist team and we are based in the UK. So thinking about my presentation, Shame and Pride, I would say there is similarities with congenital deafblind people but I'm going to talk more about acquired deafblind people and Usher is one part of that. It is very unique in a way from Usher—acquired deafblindness. Like the general population people with Usher experience shame and pride at different stages of life, at different stages and it is usually in a response to a life experience, something that is happening to them. So, it is the same for the general population. Just checking with my interpreter that she's getting all that, which she is. For example, maybe somebody who is very young, a teenager with Usher and they're first diagnosed they may be reluctant to use sign language and as they get older as all of us do, we relax a bit more and they may be more accepting of sign language. Another person with Usher might be reluctant to use a communicator guide service. They may prefer to use a mobility aid but through life experience they may change this opinion and in the end accept an intervention to this service. So, shame and pride is also the same as everybody else link achievements and failures. People with Usher will achieve the same as everybody else, they may go to university like Paul has said that I managed to get my diploma, they may go into extreme sports. I know people

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with Usher that have done a bungee jump or used a tandem bike, but also failures. For example I know people that have been learning to drive and they may have failed their driving test and the same for the general population, they feel disheartened by this. But in the end, once they have passed their driving test it is a real sense of achievement of the different things for people with Usher is they may be short-lived because they may have to give up driving because their eyesight may deteriorate. The affects of somebody's vision does affect how people feel, people with Usher how they feel. They determine this at SENSE as a life crisis. This happens on average every five years from diagnosis, they may have to adapt and adjust to this diagnosis. Then somebody may go to university and this is a different environment from school days, that will be another life crisis for them. Maybe through their employment, raising a family, these are the things the stages in their life which will bring on a life crisis. We see people come back to our service at that stage. So, people with Usher, they can experience a sense of shame linked to things like mobility problems, they may have problems walking. You may notice with people with Usher don't walk in a straight line which causes them embarrassment or shame. They could have issues with communication. They may have difficulties lip-reading. They might have difficulties with their sign language. They might have difficulties accessing information. That can bring on a sense of shame. An example, I know a client with Usher, who was getting on the train, thought they were on the right platform, but actually got off at the wrong station, because they couldn't hear the announcements that the train wasn't stopping at their said station. Another thing that can happen with people with Usher is they can lose their identity. They may have been born with a very hearing mainstream identity. For example Usher Type 2 or type 3 and when they are diagnosed as a person with deafblindness, they are used to be being in the mainstream world and they're torn whether to become part of the new deafblind community. Another thing we have noticed is that people with Usher can be very self-conscious about how they fit into the world and society where people are looking at them, whether they've got mobility or communication issues, they begin to feel very self-conscious. Going to grab a water there, excuse me. So, yeah, linking to feelings of self-consciousness, it means that for example, one lady I know with Usher, she's an Usher Type 1 and over 80, but in her younger days, she was a prominent member of the deaf community. Her sight was very, very good for an Usher Type 1, but then as she got older her

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vision did deteriorate, her field of vision was narrower, which means she would miss what people are talking about in large groups. They would use visual frame line language and later as the vision changed again, she couldn't see people even in her line of vision because it got so narrow. So as the communication got difficult for her she actually withdrew from the deaf community leading to a real sense of shame. So linked to mobility problems, people do feel embarrassed and shameful about using mobility equipment for example a cane. And people with Usher have problems in dark, badly lit situations, so for example in a restaurant, if there's an environment without any colour contrast, one place for example might be like a conservatory full of glass, which means a person with Usher might not know where the door is, leading to further feelings of shame and embarrassment. They may feel the first step into a room, if there's no colour contrast, leading them to be clumsy and lead them to fall over. So, I've spoken a bit how people with Usher can feel a sense of shame. But there's lots of positive as well, they can feel a sense of pride. For example maybe getting a new guide dog or learning how to use a communicator guide service. We very much encourage people to become positive role models at SENSE. They may feel proud they've learnt new communication method, like hands—on sign language, learning Braille. Or communication, they may become advocates for those methods leading to a sense of pride, there may be pride about their new identity. This can lead to a life crisis to some but a sense of pride for others. And here I've just listed some issues on my PowerPoint about this, how different issues can lead to a sense of shame for some people but a sense of pride for others. So some clients that we come across, for example, a Type 3 client that I know may be very apt at using a mobility assistant like a cane, but another person, another client and in my experience this is the same for me, they may be reluctant to use a mobility cane. I myself, I pack in my backpack but rarely use it, unless I'm in a situation that I don't know. Other people feel comfortable to pack it away and put it in the backpack, it is different issues to the issue of mobility and it evokes a different feeling for different clients. Other people may be very proud of the fact they've a lovely cute guide dog that people want to come and stroke and have an attachment with, that's very much how I felt. But other people I know really don't want the responsibility of having an animal or pet in the home. So every client we come across has a different perspective to these issues. An Usher Type 1 client that I know that might have poor

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balance, so they might get dizzy as they're walking out in strange environments and I know lots of Usher clients will complain that they trip over people, children with buggies and children running around and bicycles and may be suitcases. And another client I know that was very fond of cycling when their sight was fine and stable, then they started to cycle in the middle of the road so now they use a tandem and they're very much proud of how they've overcome this barrier. For sign language users, which is mainly User Type 1 and some Type 2, they are very proud of the fact they use sign language. But for Usher Type 2 and Type 3 they don't know any sign language, so this can actually bring on a sense of shame of the fact they can't communicate to Usher Type 1 leading to communication breakdown. Usher Type 2 in a noisy situation with background noise they might miss what people are saying, so there's lots of communication breakdowns that we as Usher people will experience, especially meeting new people. For example if you meet somebody in a darkened room you might be able to grasp what they're saying by lip-reading, then that person will go off and say goodbye to you. A few weeks later they may come up and say "Hi Emma, so nice to meet you", because I met them in a darkened environment, I don't recognise them. Some people think you're rude but on the back of this, some people might be very proud of the communication skills that they have. We're seeing more and more clients with cochlear implants which means they can continue using spoken English and they're very, very proud of that fact. Communication skills again, like I've said are a sense of pride in Usher people that we know. Some people when they're first diagnosed with Usher, they will feel a sense of shame and they won't want to tell anyone. So for example their employers or boss, they'll keep it a secret from everybody. Clients learn to bring on acceptance though, then they're more of the proud of the fact they have Usher. They're very proud they know their communication access needs and they'll tell everybody what they know. So we see a very broad spectrum of clients and how they react to things that are happening to them and life experiences they are having.

And now I'll move on to acceptance and adjustment. I would say encourage people you meet with Usher to learn as much as possible about their own eye condition. The more information they have about their Usher Syndrome, the more they can control the situation that they're in and actually adapt to the situation. And remind the clients you know with Usher, that there may be times they'll be ignored, misunderstood — but it happens to everyone, it is part of life and not just or because

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of their Usher. So, in conclusion, I have talked about the sense of shame and pride that people with acquired deafblind Usher in particular feel. And as a professional myself, meeting many clients with Usher I would say it is important to remember they're all individual and react to things very, very differently. The emotions they feel will be very varied. Usher people can overcome their sense of shame to be proud of the things they're achieving. Thank you very much for your time and thank you for listening.

COMMENTATOR: I would like to say thank you. I would like to say thank you to Emma. I think if I join it to Andrea's presentation when she spoke about the difference between evidence—based and person—based it was very important to hear. And thank you for Emma for sharing your own personal stories and also the stories of other people with Usher Syndrome because again that's very important to keep that at the focus of our mind.

By bringing the theme of identity, you're already helping us to think about topics that will come later in the week as well. So thank you very much indeed. We are now at the coffee break. And we will take a break until 11.30am, so we have 25 minutes for coffee. So when you leave the doors, there will be members of the Scientific Committee at each door to take your questions, you can write them down and tell the Scientific Committee, we will make sense of those. And after coffee break we will have a discussion with Professor Vasudevi Reddy, Dr Andrea Hatheri and Emma, thank you very much.

COMMENTATOR: Hello and welcome. Panel back; Andrea Vasudevi and Emma. OK I think we are almost ready to start. We'll probably have about 20—25 minutes or something for this session with questions and answers. We've had many requests sent in from the audience and we won't have the chance probably to go through and ask every question, but the Scientific Committee will keep these questions for the moment because they may come back in the session on Wednesday. But I could perhaps make one or two other quick practical announcements that the setup of this room is not absolutely perfect with where interpreters are in relation to the main thoroughfare and the main door, so if anyone is coming in or out of the building it would be helpful to try and keep out of the line of sight of all the interpreters and either dip down or use one of the stairs at the side

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rather than coming right front of the interpreters. That would probably be helpful for us all. So, yes, we've had many, many questions and we've tried to find some themes that we can explore with Emma, with Vasudevi and with Andrea. And there were also a couple of comments, and I think we're working towards getting some of the presentations available to people — that was a very specific question that came up and then it will allow us to get more into the interesting topics that came out of this morning. I'm going straight in with some of the videos that appeared at the end and perhaps this was an example of Vasudevi teasing the field of deafblindness and communication with some potential future possibilities and looking at the motor aspects and particularly those videos at the end where the small infants were anticipating the actions of the adult. There was a series of questions but in summary one was about the fact that babies can show these bodily responses to approaches from adults at such a young age, what could this mean for our understanding of the way congenitally deafblind children develop and have an understanding of others on a bodily level, on a tactile level? I'm going to pass that to Vasudevi in the first instance.

VASUDEVI: OK, I don't know whether it was actually a tease to you, or whether it was a tease to me, but it is true that because we understand so little about motor development and the promise that there are motor. There is motor responsiveness which is so subtle so early it could be enormously important for whether our sensory problems, deafness, blindness or other things maybe. What does it mean? One of the things that we can draw from that is this idea, it was another question actually also there, is the idea that or the fact that anticipation is present. Anticipation of patterns. Now, for anticipation of patterns to occur, there have to be regularities in experiences. So these experiences are not occurring with magic knowledge that the mother is going to pick me up, they're occurring because I have had some experiences like that and I have learned in these contexts this is what mother is going to do. Right. The question I think for deafblindness is two things. One is A, you can see cognitive grasp if you like, of regulators in other people's actions. In other words you can see in deafblind people that they might be able to grasp what somebody's doing and what patterns are going to happen. That they have expectations for other people's behaviour and they understand that this approach or this whatever movement means they're going to do such and such. In other words it is the beginnings of understanding

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other people's intentional actions. So obviously, this opens a door to saying you can see in the body's responsiveness, the infant's understanding of intentionality to some extent, grasp of patterns expectations for behaviour and so on and so forth. The problem is as Alexis raised if you have a congenitally deafblind infant and that infant has not got the experience of perceiving the approach, OK, all the infant has got is repeated experiences of sudden pick up, sudden on set movement of the body, how does that infant then build—up regulators and develop expectations? The answer is from within the deafblind practitioner community is different ways of announcing patterns and so on. So similarities in promise, but different patterns.

COMMENTATOR: A different medium of making that connection. I'm going to pass that to Andrea, from your experience of working with congenitally deafblind children, does that make sense? Have you got ideas and advice of how do you build those anticipatory patterns the tactile modality? It is so much going on, as I said without us being aware of.

VASUDEVI This is why, especially when it is about tactile interaction and development of such abilities through other forms of communication that we really need to be very good observers and I think that this kind of you know, development of self—awareness and interaction and me and you and dialogues and giving the reinforcements and just being a very good observer. Also, you are not just the one who develops abilities or develops these emotions but it is also about your own. So even, and mostly in tactile communication the way you transmit the way that you interact, the way you invite is not just from your perspective to the child's perspective, it has to be so much vice versa as well. This is for me and probably other practitioners, invitation and would I interpret my interaction and the way that I'm doing things? I think it is possible but I don't think so many people think of that on the impact of own emotions, own behaviour, tactile responses, tactile feedback and I think it is possible to do the same thing. For so many years I can say from my experience we related so much on the verbal language, the formal language, but so many things happen without verbal language on a non—verbal level and initial level in the development. Sorry again, this is a quickism and I accept it. That I talk too fast! Should I sit?

COMMENTATOR: That's perfectly fine. I'm struck by one of the things that you said that relates to a question that came Andrea, in your presentation, about perhaps people seeing something. So the child or the person may be doing something that the other person isn't recognising that as an

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emotion or isn't recognising it as a communication or an interaction. Do you think, what do you think needs to be tackled there in terms of attitudes and approaches?

There should be much more engagement and also understanding as I said of what you are doing and what you are interpreting and what you are observing. And what you are expecting because unfortunately our expectations, you know sometimes within the activities and the interactions they are conducting our behaviours and our way of doing things. So, I think just a positive detachment and not seeing the whole person but interaction between the person and yourself, I think it will be more like encouragement or evidence or something that you are doing things for.

COMMENTATOR: Thank you very much. I'm going to go to a question, a specific question that was posed for Emma. It was about how do people with Usher overcome those feelings of shame that you spoke about? Can you give us some examples, ideals, how do people overcome those feelings?

EMMA: I would say that you can't force people to overcome these feelings. It's how they respond to what is happening to them and what their life experience is. In our experience at SENSE for some people it might take a few months for them to get rid of this feeling of shame. And for other clients they may never accept it. What we try do is get people to reflect on how Usher affects them as a person and try to remove the feelings of denial for example. We try and give them as much information as possible.

COMMENTATOR: I always remember from the diploma from the Deafblind Studies that Emma took part in and we had presentations from two men who were talking about the day they were given a diagnosis of Ushers Syndrome. One of the men said, "When I realised my vision would go, perhaps in ten years, or in 20 years, I decided to learn Braille and to begin adapting my communication for the day when I would no longer have vision". The other man said "As, soon as the doctor told me I bought myself a very expensive motorbike and I went on a tour of Europe to sample wine and women." This is how he put it!

COMMENTATOR: So can I just follow up a related question to Emma from the point that you answered before. How would we help people with Usher who don't want to be part of an Usher community?

EMMA: Well again, you can't force somebody. We find that all of our clients are very different and

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very unique. What is important is once they're part of a community it could be a mainstream community, a blind community, a deaf community and you can't force them it is very individual choice really. Some people when they get their Usher diagnosis, they want to meet other people that are like them. Again, we don't force that but that's what some people choose to do. Others do not and it is up to them at the end of the day.

COMMENTATOR: Thank you. I'm going to return to some of the points we were thinking about before, about the tactile adaptations that we might have to do for deafblind people. This is a two—part question. First of all thinking about the work that Vasudevi showed us first of all. Could you give us an idea of what are the main sources of shame and pride for people? How do infants know that that's the kind of emotion they should have in a particular situation?

VASUDEVI: It is not so much they know what emotion they should have. I think your question is what kinds of situations, what kinds of situations do give rise to shame and pride and what are the similarities if you like? How can we generalise across all types of disabilities and people and so on? I think what's in common amongst all of them is either the presence of or the absence of recognition and affirmation. So I look at you and I cannot recognise faces, I'm terrible so I look at you and pass you. In that moment I'm denying you, right. By not recognising you I'm denying you. So, in a sense the first—term in today's sessions, denial, shame and pride, which we did not touch upon is actually completely closely linked to shame and pride. The denial, the experience of denial of me or the experience of denial of something I'm doing or the experience of denial of something I have said, all of them have as a common thread some aspect of me is being denied. OK. And this denial can lead to if you like, experience of, so now what, I am nobody, where do I go, what do I do? This is the shrinking feeling of shame. Or, in terms of full recognition, right, if the absence of denial is positive and you say, this thing that you are is nice or this thing that you do is nice and so on, and so forth that's the pride situation. Now these situations are, it doesn't matter whether you do it through vision, you do it through words, you do it through vocal language or sign language or you do it through touch. All that matters is a person is being recognised in some aspect of him or her. Does that kind of get to you? I just wanted to add some authors say that these moral emotions are within, from words and some say that they are socially learned, so if we accept that they are from birth and innate and then just the environment has to do, has to reinforcement be

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the reinforcement. You did that like how you should be proud of this, or you shouldn't do this according to some standards or moral standards and you should feel ashamed about what you did. So, we do give these messages to the children in there. And also it is relate to their achievement, they can anticipate even before the verbal communication, they can anticipate failure or success, and this kind of achievement emotions are also related to being, feeling shamed or feeling proud of what is going on within that activity.

COMMENTATOR: I said there was a two—part thing because the second part and perhaps Andrea's hinted at part of it there, a question from someone was about many of the videos that we saw, both partners had vision and they may have been learning something about responses to each other's emotions through vision and the question was about how could we build that conceptual understanding of shame or pride in the tactile modality.

NEWSPEAKER: I have a two part answer to the two—part question. The first answer is that engagements on to the concepts of connection or engagement. Although vision in the typical developing case is absolutely extremely useful and enriching for advance warning of approach or intention or emotion. If you throw away the words, mutual gaze and keep to the words "mutual attention or engagement" you can translate that into touch. So yes it would be great if we could look at each other and I know we're looking at each other and we don't have that and I have my eyes in some sort of way and I can use it, you can make a connection with me through mutual touch. Me touching you while I am touching you, that's a point of connection that can be built on. I'm speaking, teaching grandmothers to suck eggs here, but all the translators are doing this all the time. If you hold on to engagement and connection and expanding of the engagement and connection, not just me to you, but to the things I do and so on, you have an expansion there. I was answering part one. The answer part two, is Paul did his PhD on the framework to congenital deafblindness and how you can develop and help a child with congenital deafblindness to make connections and talk about the future and talk about things out of reach with congenitally deafblind infants. On page 57, you wrote . .

COMMENTATOR: I said to Vasudevi, if she goes back to that the forgiveness will be withdrawn to that I gave her earlier on. If you're having sleepless nights I can give you the web link to read page 57 and the other ones. We're almost out of time and one of the ideals for this week was

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about commonalities and differences and what we can learn from each other. I'm going to pose a question to Emma and Andrea particularly, what we can learn from each other, but Vasudevi may also have a view about what you think we can learn about congenital and deaf blindness acquired. The ideal is you can learn from the field of congenital deafblindness and what have you learned from the field of acquired?

From the presentation specifically it is how the focus on the group of congenital deafblind people, it's how they're perceived by professionals. For acquired deafblind coming from the point of view the person the deafblind person themselves is the expert.

For me the commonalities is we all experience these emotions but as a difference for acquired deafblindness is more about identity and empowerment I think.

COMMENTATOR: This has set us up for the next two days of the conference. Vasudevi do you want to make any final comments on things that you see can link the fields of deafblindness?

VASUDEVI: So in terms of commonalities it is just the richness of the different mediums if you like of communication which mostly we ignore. The fact that there are different ways of — you know in the videos that you saw the babies are responding with their bodies and their eyes and their ears and noses and we mostly don't know enough how this happens. So the message is it's there in all of us these different mediums and it is a matter of shame for most sciences that we have ignored it, we don't know enough about it. So the commonalities are very promising.

COMMENTATOR: We have, unfortunately run out of time. But I would like to say one last thank you to Emma, to Vasudevi and to Andrea for the morning's presentations and for helping us understand more of the topic of shame and pride. Your job has only started because you now have to think about these topics for the rest of the week and generate some discussions amongst yourselves. Thank you to all of you and thank you to all of our presenters. Thank you.

NEWSPEAKER: I didn't speak this morning but we have the three main sessions not the last day. The last day you have the workshop, the networks meeting in the morning. In the afternoon you have a presentation by William Green about the history of deafblindness to acquired and congenital deafblindness. Then, you have another session about the commonalities between acquired and congenital deafblindness prepared by the whole communication network and Paul is in charge of running and chairing this session. He prepared a questionnaire, this questionnaire is

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in your bag. It is in your bag you have two questionnaires, one is the questionnaire of satisfactory sheet or something. I have to pronounce it well. It is a bit difficult for me sometimes! Next one you can fill it in or out, Paul told me he said you can fill it in or fill it out. Because you have questions about all the activities that you will go through. But you have another questionnaire about the commonalities and this one you must fill it in today, latest tomorrow. You put it in this box before tomorrow lunch time. I'm correct? This one is important because it will be one of the ways to feed the last session that will be chaired. The box will be on the stage so you can't miss it. Thank you.

French people, the workshop to be translated from English to French or some of them from French to English, is written down on the where you have been in describing yourself for the workshop, when you registered downstairs. It is written, there is four workshops translated and three translated, so from, French, English to French, to sign language. So be careful because some workshops are at the same time so that's difficult. You just go to one place, yeah. So everything is downstairs. Now for lunch because that's one of the very important times, you have some tickets, yeah. You will go up to Jean de Flanders, where you present the ticket to the volunteer at the door and you will be given a lunch box, I hope it is good, so that is easy. You just take a seat, organise yourself and ask one of the volunteers. If there's a problem you just ask. Good appetite. Enjoy your meal. We try to be back at 1.15pm for the workshop. It is going to be short. Can you hear me. So you don't want me to work this afternoon. OK, OK thank you. Talk to you later.

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DEAFBLIND CONGRESS, LILLE FRANCE

AUGUST 28, 2013

JACQUES SOURIAU: Hi everybody its time to resume the meeting. You're required last effort. I know you are tired. You are tired and I am re- retired. Okay. I wait a few seconds until everybody has managed to sit down.

So, this afternoon is dedicated to 2 main activities that are related to how congenital and acquired deafblindness are living together. The scientific committee thought it would be nice to start this with a new story of Dbl, because Dbl has been created mainly by professionals working with congenitally deafblind children but the mood of the beginning is probably still there its important for Dbl to move to total understanding of how acquired and congenital deafblindness are connected to each other.

In order to address the problem of the history of Dbl we asked William Green to address this question. William Green is an old man {laughter}

WILLIAM GREEN: He makes me feel so comfortable really!

JACQUES SOURIAU: I am older than he is really but we belong to the same category. William is the past Dbl president. And I am ante deluvian past President myself, it means something which happened before the big flood, before Noah's time. So we have had the same experience at the level of DBI. I have been working with him for many years, he was part of my team in the 80s for 7 years, and then before that he was in Norway, and after that he moved to Italy. So he has a long experience of deafblindness, both sides of it. He was part of an important survey that took place in the 70s in Norway, that everybody quotes when it comes to studies, about the number of people who are deafblind. And he has also worked with congenitally deafblind people so he has lot of experience. I am supposed to be the moderator of this session but I never found how to moderate William {laughter} so I am not sure I will succeed this afternoon! . But I think it will go well, so William I give you the floor.

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WILLIAM GREEN: Thanks Jacques. You know, like every speaker here they have had 2 responders, I thought that was very sweet, but absolutely not? I think I have 330 responders here. We're doing it in a rather slightly different format. I want you to challenge and dispute (loss of sound)

So just to give an idea, already talking about the word sculpture how does that fit into the history of deafblindness? Well it does actually because its the way of looking at a sculpture. One you analyse it according to your experience and what I think is interesting is that you cannot experience other people's experience according to Lang in the 50s and 60s. I think that is very, very true. Now, in teaching its also influenced, there are 2 ways to make a sculpture at least. The most common ones is you have a small start and you build up to something. You know where you are going, and each small bit you add on actually stimulates the next step. And we will talk about Vergovski later on with his concepts.

There is another way of looking at sculpture as Michaelangelo and Rodin in particular, they say within each piece of marble is a sculpture. My job is just to knock off the rough edges. So its changed from moulding in teaching and shaping, its a question of finding out the sculpture inside of a person. Does that make sense?

Those 2 agree with me that's very nice! . {Laughter} its starting well. 3 people, sorry.

Okay just the interpreter. So sculpture has also an influence. I am going to go through, I am going to ask you in a way if everything works correctly, what do you see in this sculpture and how does it relate to deafblindness? No I am not. That was just a trial. Okay. Make that bigger ... yeah.

Now its a question of perception once again based upon experience. So different people will see different things within this sculpture. I think. Is that correct? Yeah? So, if I am a psychologist which thank God I am not, I would say well this little child is in a safe - - sorry I am describing a tree with a baby in the middle of the branches. Another person might say if I was from the physiotherapy world I might say how on earth did he get up there, what muscles were

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involved. Might be thinking how can we help him get out of the tree. There are other ways of looking at it.

Does anyone see anything related to deafblindness in that statue? You're a very lively audience today {laughter} you're all thinking about what we're wearing tonight and if our shoes will be good enough to walk on. What can you see, come on guys! . Project something (voice from the floor) Debbie being my ex-boss I think that's a very good idea and its very true. Something else? Microphone? Yep are we okay with microphone? Do you want the question? Really you can't hear me at all? Please give a microphone to the person who just spoke. Please Debbie.

FROM THE FLOOR: I said, sorry Debbie speaking, I said perhaps its all the supports around the person, maybe that exemplifies DBI and all the service organisations and parents and everybody.

JACQUES SOURIAU: Anything else? No okay then I go on.

There is something there. Oh?

FROM THE FLOOR: Well actually as I see that child I think its very isolated and alone in the world and it has difficulties getting out into the world, and that's why its crawling into a safe cave or something inside the tree.

JACQUES SOURIAU: Thank you.

FROM THE FLOOR: Margaret from Poland. It remind me 2 hands and fingers around the child. The tree remind me of hands, those tree remind me it seems to me that they are 2 hands round the child like that yes, and fingers around the child.

JACQUES SOURIAU: I think I have I mean there are if you keep on with these questions I won't get on to the second sculpture so I am a bit worried. We will come back to these things later is that okay? If not won't be able to say.

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I see that tree has roots. And what I am going to do today is to try to have a look at what are those roots. All the things you have said are correct and slightly differently, they are correct for you. What is important is all those thoughts about what it means yeah, what does that mean? It means trans disciplinary, its a trans disciplinary affect in life. All those individual perceptions about the child and the tree become useful where they are shared with other people and all those perceptions are put together. The child is the hub, hub being like the airport, centre of satellites.

The next one. Firstly I would like to say that on this one I think its rather interesting because in the history of deafblindness we have been very much concentrating about children, and here we see children but in the left hand corner you see an added on bit of the sculpture which is a very, very worried teacher. About the oh my God how am I going to handle that?

I think that's quite nice because I think there were a time when the teachers of deafblind children were just as isolated as the deafblind child themselves and the family.

Yes, I rather like this one. Its sort of like disagreement its also brothers and sisters, siblings which I heard the other way are the most stable part of the family. They don't always agree as most brothers and sisters don't, but if you see anything else just please put up your hand. Okay then I will go on.

We have something to look forward to. We want something to look forward to. We know its there, we reach for it. We're constantly reaching outwards to find solutions, we're going in many, many different directions. Yeah. The first love. We all, well apart from you Jacques, we all had it. {Laughter} he had the first 20 loves I think it was. {Laughter} and they are not just to do with gender. I think this is a very, very touching start, its mind against mind. And I see in this a most beautiful sentence which I think should be thought about. Is in Africa and in many other countries they use the expression "I see you" . That's not a physiological thing, its really a, I see your existence. Its a wonderful way of saying to someone else I see you is a great form of respect and I love that.

The exchange, I see this as the exchange of meanings. Looking into, finding out what

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the other person is trying to say and going to say. Of course, become a family, Dbl in some context has been considered to be a bit like a family. I believe that. I think people working in the field of deafblindness do feel an emotional bonding with other people in the field.

Of course, there are people like Ula who doesn't always agree, and they can get rather angry sometimes, but its an anger of passion. There's so much passion in our world, isn't that true? Look around here. I can actually see you and I can see the passion within you. We might not always disagree, and we might actually have, Sven unfortunately is not here, we might have opinions. Oh. I think we have lots of thoughts, I think there's a difference between having opinions and sharing them, and being opinion yayed which stays with you forever.

Then don't forget Jacques. He doesn't know what I am going to say and I don't know what I am going to say either. But knowing he's a grandfather, this is the role of a grandfather in those roots. The way I perceive things has certainly being influenced by grandfathers and grandmothers. There can be turmoil within the family the father might be disagreeing with his son, in this case, and this very touching I think I am very much taken to this sculpture. Its I think the dilemma, I think it explains a dilemma of what's going to happen. You're looking away, you're separating from me, are you okay with that, are you worried about that, and the question is are you worried?

I have my worries my worry is what's going to happen when I am no longer there. That I think is the raw, the situation for many families. By the way there's one burning attitude that I have learnt over the time, there is no such thing as an impossible family but there are thousands of families in impossible situations. And that is the difference but the respect we should see them, we should try to alter in some way those difficult situations and support them.

Then this is rather interesting. I still believe that the collaboration across sizes, colours everything is beautiful and its always heading somewhere. This for me is collaboration. And then Anna remembered me that in this statue they are all actually dead I was not very happy with that.

Then there's an aspect of going back to the 50s and 60s, it started from there actually,

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that we all need a personal space and this had been demonstrated by people like Desmond Morris in a popular way with body positions and space it says here if you can't read it, "Gasp, an alien" . Not just any alien I am a personal space invader. It goes on. "Golly that sure is uncomfortable" . What does that mean to me, what do I think about? Yeah it was in probably from the psycho analytical way that if people are constantly within that space it can give a rather distress full situation psychologically, do you remember that Jacques or?

JACQUES SOURIAU: No.

WILLIAM GREEN: That comes with age. {Laughter} there are studies talking about what is the preferential difference between people, we have the intimate , the personal , the social. You shouldn't have that one. Oh you don't, good. That was one they said you can't show that one, so I am not going to.

Then I rather thought this was rather sweet and as Debbie finished off her pictures with cats I thought I am going to have cats here, and it states "Ollie was not only haunted by his last 2 live's but they had no clue about personal space" . I don't know, we do talk about it with deafblind people, what's it like to always being so dependent of people coming into that personal space for mobility, for communication, for information. They said its fine, what choice do I have. I don't know.

So, actually I feel Jacques rather alone with you. I really would like someone else to come up and help me a bit because I feel a bit unprepared, and everything else is so prepared. Anyone like to come up and hold my hand for a while? Anna that's very nice of you, that's completely not organised. {Laughter}

JACQUES SOURIAU: What a surprise. {Applause}

NEW SPEAKER: Sorry William I am not as nice as the person you asked to come on stage you

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felt lonely with me, Anna Nafstad works in Norway, she belongs to the organisation called Stabed (?), support system for people with special educational needs.

WILLIAM GREEN: Anna thanks for coming up. I have no idea what she's going to ask me, and people said we know with you we really don't know what to expect and putting you together with Anna, you really have no idea what we're going to talk about.
So, Anna

ANNA: Okay William thank you so much for letting me come up to interview you. That's been a dream for many, many years.

WILLIAM GREEN: Really?

ANNA: Yeah, because I have always being curious about how you, what you learn you know on all your travels through all those countries and all the deafblind people you met, all the professionals you met, the books that you read. I think you are in my view you are a pioneer of our time, a pioneer in our time. And I really like you to tell something about the journey that you made. In my country there are sculptures like you showed and you have also lived in Oslo, worked in Norway for several years so we share this influence by these sculptures and this park. But maybe we also share some fairy tales. And there is a fairy tale in Norway, about a guy called Askeladden he is very humble, I think you are also very humble. I think you are in my view you are humble. This Askeladden he travelled he noted he was very attentive to people that he met. I wonder if its not a way of telling exactly history but a story. Is it possible for you to tell something when you worked in Norway. I can start. And the first the thing I learnt about you was that you started the central team for deafblindness and Jacques said that you worked in the survey. Actually, what you did was that you were hired by the ministry of social affairs to interview all the deafblind in Norway. You were only the person who could do that because you were the only person that knew about who was able to communicate with all deafblind people.

The first thing I knew about you was that you are a communicator. E do you have

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something to say about that? , What's your relationship to communication?
WILLIAM GREEN: Yeah, wow, well I think we're sort of like social animals, and I think communication and sharing things together are highlights you know. Its a way we share, we actually think about it. You know I am a social person that makes me rather human in a way, according to the definition of humanity. We live to communicate. I think that have been very attracted to that in Norway. I came to Norway as, well I would say a hippy, I had curlier hair than yours I had an earring, I was amazed by the communication I want to communicate people and I think I still do.

I must refer to concept of pioneer, hi Frank I just thought about mentioning you soon. I don't know of any pioneer that actually when he was doing things thought of himself or herself A being a pioneer it was not to get the title of pioneering, it was the mounting was there I wanted to climb it. Usually when we talk about pioneers they are usually dead. Now I hope for some people's distress I am not quite dead yet, but its true these names were given afterwards and I don't believe, I think a pioneer is someone who works with a child for year after year and I think they pioneer maybe on different dimensions but I think there are pioneers in this audience who are not internationally well-known or visited thousands of countries but their every day work is pioneering.

Frank last night said something, is the day of pioneers finished? And I thought wow that's interesting, was that right frank that's what you asked. Ah that's great, a better if you could do it fine.

FRANK: William, Frank speaking. Are the days of the pioneers are over? Or are we entering a new phrase.

WILLIAM GREEN: We are definitely, we need pioneers today and they are out there I think Frank. Because the conditions have changed, we need pioneers to combat against politics, political attitudes. I really believe that. I have seen the change. We were allowed to be pioneers it was the right moment to be there. I am not a pioneer today, but I still have thoughts. But I know

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out there are future pioneers who don't want to call themselves that, but they are desperately needed. They are desperately needed. Because times have changed. So the type of pioneering will change but the goal of pioneering will still be there that's what I think. And you know I share thoughts, not knowledge. Is that right yeah I do that.

ANNA: I understand that you mean that you were not a pioneer because there was an occasion provided by society to do that kind of job which is different from pioneers which more have to fight is that what you mean?

WILLIAM GREEN: I think that's exactly what I mean. So what else did I get from Norway, which has remained with me. It was very much a, humanitarian approach I think it still is. One thing that I remember even one of the first conferences I went to I think in Norway, we were talking about quality of life indicators. That in itself is rather interesting because a Finnish guy defined the quality of life as not just having things, its also being and loving. That is what he considered as being the primary motivation for quality of life {inaudible}

Now going on from that in history, which I will refer back to, its been I think it was even mentioned in Gill's opening I am not sure it was mentioned the fact that or somewhere that disability was considered as being a strain on society many, many years ago.

Disability was how can we say, non productive, they didn't contribute to society. I disagree with 100% with that concept I am glad we have left that behind. I really do because, and I even had a chat outside with a medical guy we all know, and Jude Nicolas, and I mentioned the thought to him and he said that's true, so I would like to share it with you.

Now if its true that the quality of life is knowledge or access to knowledge, what have we learned from deafblindness? Okay can I make that slightly different - if everybody could see would we know as much about the eye. If everybody could hear perfectly, would everybody, sorry

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I got disturbed, does he want to say something? Oh sorry sorry. We have so much knowledge because of people who are not considered normal. But their contribution is being there, that's all.

And what we have learned about the brain has helped actually people understand more about the difference between mind and brain. So their contribution to my quality of life is just by being there. And they have contributed to my knowledge background. I think that's okay for the moment.

ANNA: Okay I think that's explains also even more about why you resist to be called a pioneer, that you tell about what this has taught you rather than vice versa. As I understand it.

WILLIAM GREEN: Yeah.

ANNA: When, after you went to Norway you went to France, it was a different country to work in, it must have been different things, different thoughts you had there, different things you learnt there.

WILLIAM GREEN: Yeah I think every country I have been has taught me, I mean its a privilege very much that I have seen differences. I would say, and I will come back to this later, that maybe the Nordic I was very much interested in the holistic approach, maybe in France I was more reflective in a way, it was more - - it was quite influenced in the beginning Jacques I feel by psycho an lists it was very analytic and reflective. In Italy I really felt it was very much methodology and empirical, and everything should be documented. So every country had its own really identity in some way. And I loved bringing those identities together to get a really more holistic. Now why do we use the word holistic, where did it come from? Well actually it didn't come from Norway. It came from a long time before that did come from Karl Rogers who were talking about a more global way of looking at the person.

It also fed on to IEPs, individual educational programmes. Its led on to people centred

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approach. It did not come suddenly. There is a history where it came from. This history I am telling you is my perception of history but it might not be everybody's. . Its what I feel

I think that sometimes its very interesting to look at history, I think it was also mentioned in a sense of it was, and in some countries still very medically dominated. The doctors, sorry Alexis you can agree with this or not its okay I've got the microphone. It was a medical model. We were looking very much at the physiology of the disability I feel. I hope I am going to get a contra argument, another type of argument about that. But something happened.

We went from that medical model to another model which suddenly was spreading around. Shall we call it the behavioural model? The behaviour, therapy model. The behaviourist movement.

Now is there any movement that you disagree with 100%? For me no, and there isn't. I am eclectic and pragmatic. And I take the best that's out there. So what did I get from the behaviourists which the doctors love because they wanted the research, they wanted the stories to be much more scientifically –

ANNA: Evidence based.

WILLIAM GREEN: It wasn't just a case of negative enforcement it was much more than that and Bandura took it on with cognitive thinking. We're still talking about informed consent. We went also into what I would call the Carl Roger's period that was also mentioned a few times yesterday and that has someone who was interested in teaching in some ways, even though Carl Rogers said you can only teach when you put yourself in the situation of learner.

I think that what he said which I like so very much, and its sort of like has dominated me and this is going through all the countries, is that a teacher is the gadfly of other people's development. Now what some people might immediately say, what is a gadfly? And I don't know the name of that in other languages, not even in French a do you know Jacques. Its an insect that

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bites the bottom of a horse. And the horse runs. And he said we are the gadfly of other people's development. I do not develop for you, I just create the stimulus to go on and develop. What have the linguists, ooh I love the linguists I really do. The first time I heard about (name) I heard why are they taking people from that part of the world who is this guy that everyone is talking about. He taught me about next step. , What's the next step. I thought about that yesterday, and we said shame and denial. No, shame and pride excuse me. Those are opposites of a pool. But there are stepping stones from shame to pride I want to know what the stepping stones are. Anne said and Loria confirmed it that if we do not present the child or the other person, the adult with the next step, he or she will remain at the stage they are. We talked about regularity. Yes that has been a huge thing in the past. I don't think you can go into a school today without a calendar of what's going to happen. That's preparing for what's going on. And incidentally, in language, and the Canadians I was talking to the other night said yes talk about that. Okay the regularity, we know what's coming is the basis of security. Could you imagine being just sitting there not knowing what's going to happen and someone comes and takes your hand and takes you and it could be an ice cream or the dentist. And you don't know. We can prepare for it.

If you ask a child and I have said this to a few people in many different context. If you ask a child about what they did yesterday which we have used very much as an approach, the language will be reduced to a certain level. Meaning, if I ask my son what did you do yesterday, he will say "I went to the cinema I saw a good film and a guy dined that's it" . If I say tell me about the party you are organizing next week, his language will come out to content, format, and everything else, his language will be richer. And I believe that could be true in the case of deafblind children too, so we should be able to find a way, which is not equal for everyone not the same way, a way of introducing the future but based upon the past experiences which is the same as why we're talking about history today, hoping that it will go forward.

I think I should give you sometime for some questions, I get carried away you know what I am like.

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ANNA: Okay if we go through all the things you put in your sack from all these encounters, and what you read, if you think about today, what do you think are the most important resources in the work with deafblind people?

WILLIAM GREEN: Like what is resources or

ANNA: Any kind of resources

WILLIAM GREEN: Resources are these guys, each individual is a resource for somebody, and many people in some cases is that what you meant?

ANNA: I didn't mean anything about the answer, I asked you the question.

WILLIAM GREEN: I am just wondering what the question means

ANNA: You want another question? Can you find any value perspectives across all the value perspectives that you found even.

WILLIAM GREEN: Yes I think one of the values that I have in a way or at least try to have is the value of tolerance. And I think a word which I have talked about in many contexts is empathy. I think if I asked just to give an example, for me empathy is the big one the really the most important. If I asked the people in the audience to all close their eyes, and say close your eyes and think when you were 15 about a teacher. In the majority of cases you might not be able to even repeat the subject that they taught you. But you will remember them because of the empathy that you felt, the pride, of being there. Does that make sense?

I reflect upon a guy who made me feel important, he shared with me and it was an empathic situation, so empathy is what we're trying for in communication. And that empathy leads

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to the ability, according to me, disagree its fine, to dialogue. And if we look at even going back in history from Holland, van new den's definition of what is a dialogue where emotions are involved, we use the languages acceptly for the other person, then we're still doing it actually today I think so. So yes I think apart from friendship, closeness, everything else with the people I have been privileged to be with over the years, I have learnt tolerance. I think accepting the differences, and actually enjoying those differences.

I have never really liked putting people into boats which sometimes I have a problem talking about "The deafblind" . I see them as human beings who are just a bit different from me and thank God we have people who are different in the world, and I can't see why we always have to put - - I can academically see why its useful but in my personal relationship and communication I just see them as a guy who's a bit different. I have lots of friends who are really very different from me and I accept them because they are friends. So I don't know if that is anywhere like what we should be talking about, but anyway, just go on.

ANNA: I think I like the way you speak, because its kind of you just you make it just kind of ordinary human.

WILLIAM GREEN: I think I even said to, I mean the commonalities is the humanity we share, I really believe that. And we're human and proud I am quite happy sometimes to be that.

ANNA: But you think there's a historical perspective in that or has it changed over the years or is it the same?

WILLIAM GREEN: , Wow I hope I have changed in certain ways in the sense that I hope I have developed because of those feelings and emotions. I think differently now of course then I did 10 years ago, and I am willing to change my point of view. And I think that is important that we don't go through life with one opinion, we share that opinion as I said before with other people and then we develop. I think we learn, and in fact that's why we went the way of concepts like parent

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training, staff training, we talked about staff development Jacques do you remember those discussions and even conferences we had about development replacing the word of training. Its, yeah, I don't really know, that's very personal in a way, yeah, wow. Yes I have definitely changed because my opinions or thoughts have changed. They go on and on changing with everything I have heard here, and with the Canadians the other evening sitting round the table sharing, you changed me with your way of looking at things, you changed me. And I cannot forget that that's why its so difficult for me to sit here and talk. Every individual discussion I have had during this week has affected me, and touched me and added on to my repertoire of emotions. So yeah, I have changed and I I think when I am really old like Jacques, it really comes to the stage where I will feel I am old when I can no longer change. And I think that is, could be one of the definitions of feeling old. I have no, nothing to say anymore. It can be a feeling, I still have things to say so I must be still alive.

Now its that, I think, - oh then a couple of other things. I have learnt a lot about empowerment. And advocacy, and I think that's great but there are us cliché which I love, I mean someone says oh William you use so many cliché's many people use it then there must be some sense in it.

ANNA: 10 minutes.

WILLIAM GREEN: I can't read that Jacques, I think it said something about 10 minutes.

Empowerment. We have a to be careful with the word empowerment and how we use it. I hate it, I really hate it and it annoys me when I say I am enabling you, I am enabling you.

ANNA: Sorry?

WILLIAM GREEN: I am enabling you to be empowered. I am empowering you to be empowered. Do you ever get that feeling sometimes, there's always the one up man ship which comes from J

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hayly I will give you the right to be empowered. That shouldn't be what its like. It should come from inside. I have 10 minutes.

Families, yes I thought about that, when I talk about families I cannot resist to talk about Virginia setter the Palo Alto group and what they think about families, how they treat it that's where structural and systemic family therapy came from that being used today but we don't no where it came from. Sometimes it not bad to find out. My tradition has been to do something and when I do it, try to find out why I am doing it. I rely on these guys to help me to find out why I am doing the things I do.

I didn't do it to get a job. I wanted to understand my job. Families yes, going back to stepping stones between shame and pride. Its a bit, comes also from the Palo Alto group comes also from crisis. I am sorry if you have heard this before but you know in Chinese all over you that there are not 2 different words, crisis and development is the same word. And that for me is rather important. I know that I have experienced very, very important crisis in my life, but I wouldn't be sitting here with you today, if that crisis had not happen. So there is a crisis, go through different steps to acceptance and there are 9 I think. 9 steps. You go through anger, you go through why me, you go through the different steps I won't name them now. And what's interesting for me is talking to families about how did they manage to go from one step to the other, what they will say or what many said at least in Italy, friendship and my social network that's what help me get through this stage of crisis. Unfortunately, not every family and every deafblind person has a social network. Or has access to a social network. So that could be a problem area.

Oh

yeah

ANNA: William I think you have said very many wonderful thing about value perspectives and you refuse to say much about the historical perspective, and I think every good interview is the one person being interviewed resisting the questions. So I think

WILLIAM GREEN: Can I just say is Paul Hart here, are you here Paul? Paul is actually

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wandering round the world and he's talking about happiness, happiness. I think that's lovely, then I just read a book Paul I think I might have mentioned it the other evening, a woman who's 50 she said its extremely so stressful always looking for happiness. So there is like this double bind action part about actually you can, if your definition of happiness it can be quite stressful looking for it. One man's happiness is another man's poison, so can't define happiness. We should be defining absolutely the concept of research. It should be empirical, it should be great, but I still love the 20 interviews you had with families and a report from it or knowledge from it. It doesn't have to always be so empirical I think. I am happy with anything that's done and I will take the best from it.

Any questions, do we still have - - okay then yeah, oh God I didn't talk about that at all. So history is in the making, unfortunately in the history many of the people involved in that history are no longer with us and they can be theoreticians or people like you, I am thinking about the Mikes the Marys that are no longer with us they are pioneers I believe. I really I think that in a few years time many of the people sitting in this room will actually be part of history and you are actually making history in what you do every day. Just tell us about it. Okay. Then I think that, any questions? Or comments, any disagreement, 100%. 50? 40? 30? Okay.

ANNA: Shakta has a question for us?

FROM THE FLOOR: I have a question. Could you tell us about the history of Dbl {laughter} when it started, how it developed, who were the first ones that some of them, I understood that if you want to be historical you have to be dead, so I think it would be essential for this conference to know where DBI comes from {laughter} {applause}

WILLIAM GREEN: Do you agree with him? {Applause} you want to know about DBI in 2 minutes. I tell you I have here the history of deafblind education from 1832. I have the information about population of deafblindness from 1905, could you ask me something about that.

Dbl wow I mean yeah I have been slightly involved in that in different roles, carrying

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banners and making cups of coffee in the beginning, to other possibly more important things. Dbl actually started, well I mean we all have, you are much better at this can't you just come up here and tell us? I see Dbl working mainly with blind children, they got together within that population, there were deafblind children. A group of people sat around a table and said we need something particularly a pertaining to deafblindness, Jill will quite obviously agree with me because she also started things, she says everything starts around a kitchen table. And then it became, it was mainly because of loneliness, teachers were just as isolated as the –

NEW SPEAKER: When was that?

WILLIAM GREEN: Oh yeah, we elderly its very good to get out of questions like that you can always say I am too old to remember dates, let's say 50, 60 years ago, gill nod? Right. 50, years ago it formed the IA DB which was the international association of the deafblind, started at the end of the 60s I think thank you Gill. We slowly changed our name because we realised we were not just interested in education we want to become something else, Dbl. Dbl is a network organisation, so networks were very important, and many of the networks here actually do not know where it started. It started actually with sub-committees on particular themes. Jacques Souriau, someone from North America, we sat the the Nordic centre, we decided that some of the sub-committees are so important as a knowledge source that we started to come up with a definition of networks which we proposed in Portugal. The definition of networks. So everyone of the networks I think, no, we have some new ones coming up now which were not part of that.

NEW SPEAKER: William I have a question do you remember when for the first time a person with acquired deafblindness or a person who is working in the field of acquired deafblindness, joined DBI conference? The first person with acquired deafblindness or the first person working with acquired deafblindness came to a Dbl conference

WILLIAM GREEN: I don't know about the conference overhaul, I can go back, Portugal yes, oh God, Portugal yes, Brazil absolutely, Sweden, there have been deafblind participants.

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FROM THE FLOOR: {Inaudible}

WILLIAM GREEN: I think only in the beginning couple possibly when it was still IA DB that there were no participants, but now its different.

NEW SPEAKER: I think its important of course it was a very educational orientated association from the beginning but its difficult to find a conference where there was no person with acquired deafblindness I think maybe not the very first one but there has always been somebody there.

WILLIAM GREEN: I would like to say Jacques just on to that for me its very much important that deafblind people are involved in this, even if they cannot I still believe one of the best things DBI has done is to have an agreement with the world federation of the deafblind and we do go there not to instruct we go there to learn. We do bring that learning back to Dbl, I would think Gill would you agree with that, we try to and we do. We have members of the world federation coming to this conference.

JACQUES SOURIAU: Okay thank you William, thank you an now, thank you Frank, I think your question was also prepared {laughter} and I think the next session will go further this first one and we will have an image of what is the state of the art in this conference context. So have a break for 15 minutes, and we will be back in 15 minutes. {Applause}

(Break)

NEW SPEAKER: Please can you sit down. Please, please. Are you ready? Are you ready interpreters? Interpreters? Interpreter users? {Laughter} its okay. 1 minute, okay we wait 1 minute.

Okay. I was not supposed to chair this meeting but its my pleasure to introduce Ole Mortensen, he's a member of this scientific community, he's if I remember your job its your information officer something like this, at the Danish association of the deaf. No? But you will

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correct me. He's been very active member of the scientific committee as all the other ones, but its something more than we did, he all over the week he prepared the this last session, he collected all kinds of of information about how congenital and acquired deafblindness are working or connected together, and he managed to describe what was the state of the art at the beginning of the conference and somehow how it has changed all over the conference. So Ole the floor is your OLE MORTENSEN: Thank you Jacques good afternoon. I have a dream. {Laughter} or rather we, the scientific committee, has a dream. Today on the date is 50 years ago that Martin Luther King had his "I have a dream" speech in Washington. We felt that it fit very well with our dream that I am going to tell you about now. Our dream of the future for the Dbl conferences.

We have just heard the history of William green, sorry the history of DBI {laughter} {applause} and now we'll turn our heads and our eyes to the future.

So in this talk I am going to talk about the forth part of the theme for this conference the part that has to do with commonalities across deafblindness and learning.

When we at the scientific committee started out working for the preparation of this conference, we quickly decided that we wanted to address the issue of the separation or distinction between the group of acquired deafblindness and the group of congenital deafblindness professionals working in those groups. We wanted to try to focus on that synergy that is there but has not previously been released.

We have heard criticism of previous conferences like this one, criticism mainly coming from professionals working N the field of acquired deafblindness and we wanted to make sure that we listen to that criticism.

Now these 2 sides of deafblindness, they have been developing side by side over the years, for a number of years now but not with much interaction.

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As William said historically DBI started out as an organisation for educators of deafblind children, later came the teachers and rehabilitation workers at first working with people with usher type 1. Now acquired deafblindness comes in many more forms, different shapes, we have usher type 2, usher type 3, we have old age deafblindness a very big group that is very much in focus some countries now.

Conferences like this one have always had to deal with this, H idea that there are 2 groups that may not feel that they have very much in common.

There's always been a sort of a sibling rivalry, we saw the picture one of the pictures that William showed us of the little girl looking very angrily at her brother. There has been that sibling rivalry between the 2 groups, a little like, well at the conference if they have 10 workshops then we must have 10 workshops as well.

So that was the starting point for us, and we wanted in the scientific committee to make this conference as appealing for professionals working with acquired deafblindness as possible. We did this several ways, we did this by actively encouraging more abstracts on acquired deafblindness, we did it by including the topic I am talking on today in the theme, because we genuinely feel that there is much to be learnt from each other at conferences like this, also in other professional settings and there are many more commonalities than we normally think there are.

We also did it by having a new type of plenary session that did not take their starting points in either one or the other side of deafblindness, but focused on topics that were relevant for both sides. And of course that would require each of every one of us to translate the information that we got from those plenarys into something that would fit into our own way of looking at things, and that's an important part of what I am going to talk about now.

But why is it so interesting? What's the negative impact if we don't find anyway of sort

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of solving this problem, if we don't find any commonalities but just keep on doing what we we have been doing so far. We could just continue to have conferences where we have 2 conferences in 1, the overall conference with some plenaries and a focus conference acquired deafblindness and one on congenital deafblindness, and in the evening you would be able to meet new colleagues, from the other side of deafblindness. Could be very nice, they have not heard your stories, they don't know your jokes its nice to meet people like that once in a while.

But we might also experience that people working in the field of acquired deafblindness might feel less and less involved, less and less having - having less sort of, wishing less and less to participate in the conferences and since Dbl is an organisation covering both sides we felt that that would be really bad.

We might also miss out on we think excellent opportunity to actually learn from someone working N slightly similar but also slightly different professional fields and thereby also missing out on the synergy that we might have.

Finally we might experience that the gap that have been starting to show between the 2 sides might grow deeper, might grow wider and from a political point of view from a campaign point of view that would be really bad. We need in the society we're living in today, we need to have this unity, we need to be able to stand together as one group a group as big as possible. We know how difficult it is to have disability on the agenda, disability services are under pressure in many, many countries in Europe, so we need that kind of solidarity, and we need to stick together in that fight as well.

Now many of you might not care about this political or campaign point of view because you think well, I am doing my job, I don't really I am not really interested in what happens at a European level or what happens at a political level, but I hope by the end of this talk you will agree with us in the scientific committee that there are things for you to gain as well.

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So I am going to present to you the thoughts of the scientific committee as I interpret them. What does that mean, as I interpret them? Well it means we have had discussions, we have had many discussions based on what we think, how we see things in the scientific committee. We have had discussions every day of this week when the members of the scientific committee met after a whole day of plenaries and workshops. We made a point of actually going to workshop on the other side of deafblindness that each of us are working in so we discussed that at the end of the day. I will include some of those impressions and experiences of the scientific committee and also I would like to share with you some of the results of the plenary, sorry the questionnaire that many of you have filled out. So altogether I hope this will form the basis for the points that we wish to make.

So its not an evaluation of this conference, this is mainly to spark interest and reflection and discussion among yourselves. We think you are the ones that actually hold the future of the field of deafblindness in your hands, and note that I said "The field" of deafblindness using the singular of the word because we think that is where the future lies

So what we're not trying to do is trying to eliminate the differences that are there, we're not trying to push to find similarities that are not there, but we feel that there are commonalities or at least some of us feel there are enough commonalities lying somewhere just waiting for us to find them if we start looking for them.

In one of the workshops earlier this week, someone said I think it was someone from Sense, that Sense is as I understand it involved in a diploma course on deafblindness at the open university and someone who had who is involved in that said that and I am quoting from my memory now, well actually am quoting from the paper where I quote it from my memory she said "We have not yet any idea of the common practices and similarities at the moment. We're still learning what to learn from each other's experiences" .

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We think it seems a pity if we don't at least make the effort to explore what we might gain if we try to work a little bit closer together.

So what are the commonalities in deafblindness? I will start by walking through some of those, our thoughts on the commonalities and I will also look at how can we learn from each other, so that's a kind of the 2 headlines for this presentation.

We know that its quite a broad generalisation to look at or to use the distinction between acquired and congenital deafblindness its one we use traditionally and one we have used traditionally within the Dbl and other places, but we realise that there are people who are congenitally deafblind who might benefit from services for acquired deafblindness and the other way round. But this its the way that we have seen or describe the world within the Dbl that is the way of looking at things that we have also used here so I will talk about acquired deafblindness and congenital deafblindness

These 2 groups have one thing in common, actually 2 things in common, they have difficulties hearing and difficulties seeing. But is that all? Do they have anything else in common?

Many I have talked to think that or seem to think that the commonalities that they are not many of them, and they are quite few to find, few to find? Hard to find. And we think there maybe some reasons for this. One of the reasons is that the field of deafblindness and profession of deafblindness is so specialised today, and we love to feel highly specialised. We specialists in communication, in old age deafblindness and so on its part of our professional identity, our professional tradition and its very much a part of how we see each other and how we see ourselves.

Now traditionally we have had to advocate for deafblindness as one unique and special disability, that was different from hearing impairment, different from vision impairment and that very special consequences. I think that is the specialised way of looking at ourselves or our

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perception of ourselves as very specialised people, that's where that comes from.

But it also means that when we are so specialised differences between the 2 groups they stand out and they may even seem bigger than they are. There's a Danish neuroscientist, because we have those in Denmark as well, there's a Danish neuroscientist who said that the more we know about a subject harder it is for us to see new things. I think that's part of the issue here, that we get too focused too much on what's different because we know so much about our own, well, profession.

Its not that we cannot gather knowledge from other groups, from other professions and in the questionnaire there was one question pertaining to that, asking where do you go for new knowledge outside your own field. Let's just first say before I show you that result that there were 137 of you that answered the questionnaire, 98 in the group of congenital deafblindness, 17 that works primarily in acquired deafblindness and 22 that work in both areas.

So and I should also add though we are, or are referred to as the scientific committee this is not a scientific survey. So for you, for all the PhDs and masters students in the house we know that, but maybe it gives us just a little bit of inspiration or it gives us at least a basis for some of the pace for discussing these things.

So, here we have a slide on the screen showing the distribution of the answers, and you will be seeing that the congenital people working in congenital deafblindness they will be red throughout these slides. People working in acquired deafblindness are orange, those who work in both fields are blue.

When you look at the screen, or the slide you will see that these are percentages of all the people in that group so when we see that there are about 35% of professionals working in congenital deafblindness who look to the field of autism for new knowledge, it means 35% of the 98 people professionals working in congenital deafblindness

So in this question you had the, you could tick off more than one answer. Some of you

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did that, some of you only ticked off one and that is why the sum of all the red columns will not be 100, just to let you know that.

But what it shows is that its very obvious that people working in congenital deafblindness they look to autism, they look to intellectual disability, they look a little bit to blindness, visual impairment, they to look psychology that's the field they are looking to the most when it comes to new knowledge. Not very much looking at deafness and hearing impairment, not very much looking at physical disability. A little more looking at neuro science, and about 30% looks to the other side of deafblindness.

That's more or less the case for both the ones working in congenital deafblindness, acquired deafblindness and both that they are looking at, they are about 1 third of the people are actually looking at the other side of deafblindness.

Another thing that sort of stands out is that the professionals coming from the field of acquired deafblindness, about 70% of them look to the field of deafness and hearing impairment for new knowledge. Maybe its not so strange considering older people with acquired deafblindness who have a type of syndrome with congenital deafness and some kind of progressive vision impairment.

So its not that we don't go to other areas for new knowledge, but it seems that as soon as it comes close enough to our own profession, so close that we start to see the similarities, we also start to focus on differences instead.

And what are those differences? Firstly the methods of intervention and support are of course very different in the 2 areas. There are central elements that are different for instance within acquired deafblindness there is an element of transition or loss, having had something and losing it, having had vision losing vision whereas in the congenital deafblindness maybe a central factor here is development. So developing from a situation, but not as much a transition type.

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There's a difference of culture. There's a difference of the number of professionals working in the field, many people working in congenital deafblindness, few people working in acquired deafblindness. Maybe you could say that in congenital deafblindness the professional is very often the expert, while in acquired deafblindness the person himself is often regarded or recognised as an expert on his own life.

Big difference in the tradition for and possibilities for learning and research. There is more than a hand full of PhDs at the time on congenital deafblindness, and we have some of them in the house today. There are next to none in acquired deafblindness. A couple of Sign Language yes, but no-one to my knowledge who have actually researched in rehabilitation programmes for people with acquired deafblindness.

There's the amount of support for each individual with deafblindness. And thereby how big a role the professional plays are you a parenthesis in the life of the deafblindness or are you maybe the most important person for the deafblindness as could be the case in congenital deafblindness.

Some would argue and have I heard that argument here at is conference that this also in the field of congenital deafblindness some attempt to see the deafblind person as an object, whereas in acquired deafblindness the person is is often seen as a subject.

So I am sure you have, you can think of many more differences yourselves. These were some of them. But despite these differences there are commonalities.

And you actually agree on that. No? Did you say no? That's good. You will get the chance later. Some of you agree on that because there was a question, how much can we learn from the other side and which kind of has the implication if you learn something its because there are commonalities, and the numbers are as I said this is not a scientific survey, but its reassuring that somewhere between 40 % and 60% of the people working in congenital and acquired

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deafblindness feel that there's very much to be learned and of course they are the ones who will have professional relations with both sides, they feel there is even more to be learned.

What is reassuring here is that there are, there seems to be an agreement that there is something to be learned, that there are commonalities. What is also shows is that this feeling is more prevalent in, within the ones of you who work in congenital deafblindness than acquired deafblindness. It just strikes me I am really going to say those words many times today, congenital deafblindness and acquired deafblindness. Wow.

So we have some ideas on commonalities, some of you have ideas on commonalities and some of you have ideas that there are not any commonalities. I will now suggest that you use 2 minutes among yourselves 2 and 2, 3 and 3, and discuss with the person or persons sitting next to you what is the biggest commonality. So for you yourself to have this discussion, to start affecting, there is no answer you don't need to report anything back, just 2 minutes among yourselves.

(Pair discussion)

OLE MORTENSEN: Right your 2 minutes are almost up.

So, now you have heard what the person sitting next to you is thinking about this, now you will hear what the scientific committee is thinking about this. There is a very long list that we have compiled on commonalities and I am not going to read them all-out to you now, I will take a few but please trust me when I say that we have many more to substantiate this argument the way that we see it.

So commonality number 1, very person with deafblindness have problems with communication, with access to information and with mobility. We had 3 themes at the plenaries over the past days, they are also common for everyone with deafblindness, denial, shame and

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pride. The identity issue, empowerment issue. Some feel that maybe one side maybe congenial deafblindness side could learn something from the acquired deafblindness side here, but its an important issue. A very practical but important thing, recognition of people with deafblindness, we know that there are very many people with congenial deafblindness living in services for people with multiple impairments, intellectual impairments. We know that they are there but they have not really been found.

We know that there are many elderly who have acquired deafblindness but have not been found because they are recarded as maybe having cognitive problems or so on. The same sort of problem. Andrea on the very first day mentioned a whole list of things: Isolation, deprivation, disconnection, aggression and so on. People don't really expect much of you, you're underestimated, you have a feeling of being different. From the workshop on siblings the other day, it became quite clear that the experiences of the sibling are very similar regardless of whether your brother or sister has acquired or congenial deafblindness.

From a service point of view we need to have a person-centred approach. We need high ethical standards across the field, doesn't matter which type of deafblind person you are working with. We need good staff training. We use at this moment we use many different types of assessments, ways of assessing functioning and so on. We saw also through this on this conference that there is a need for, and there's a wish, for pushing the limits. We saw the son of Olav who wanted to push his own limits or he was encouraged to push his own limits, and at one of the workshops we saw a young deafblind man who ran marathons.

Now some of these commonalities we share with other groups of disabilities, some of them we share with the whole of humanity. And what have made sense to us is to look at the ones or look at the commonalities in practice, because these conferences are places where we need to expand out and develop our practice. So that is what we will focus on and what we have focused on. Of course it's obvious that even though 2 persons may have the same problem, the approaches used to solve that problem will be very different. A 10 year old deafblind child born 2

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month prematurely who has severe neurological problems, she has problems with mobility, access to information, just as the 96 year old lady who has just lost the last remainder of vision. They have sort of problems in the same domain, but of course the approaches used to solve the problem must be completely different.

So what is unique to deafblindness - because we discussed that many times in the scientific committee, we found out there is a question that is unique to deafblindness, and that question is how can 2 minds connect in a world where most everything happens through vision and hearing? William had this wonderful picture of a statue of 2 persons connecting their minds, and to us that is sort of sums up that issue.

Now if it is the case that there are commonalities, how can we go about learning from each other? That's is the second part of what I am going to talk about.

We have been looking at the kind of learning that takes place at conferences like this. Of course learning also takes place in other context, at home and many other places but here we are focusing on learning at conferences because that is where we are. Traditionally learning at conferences has taken place in 2 ways, a very direct way where you can say this approach this intervention can also be used by me in my work. Or the indirect way, I am not able to use exactly that approach but it gives me an idea how to change a little bit and I can use that at home.

Information in workshops at conferences like this are often of the first kind, kind of the copy paste approach. Some one says this is what we have done, this is what we have found out, and the audience is able to more or less if they want to, take that home and use that same approach. It could be an art project for 2 congenitally deafblind young people living together in a home, we could use that in Denmark as well. It could be network groups for men with usher type 2, some of you might have heard that it was describe in a workshop couple of days ago. And if you work with that group, that could be something for you to take home and use on the spot.

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That is why, that's because we in these workshops we have a target audience. We have an intended audience in our heads and that is people like me so we go to a workshop as a presenter and we present information, for people like me who share my background, who share my type of work, who share my culture and so on.

So there's not much translation needed here. Copy paste you can take it back home if you want to.

What we don't too very often is to take that, to take our knowledge and maybe make it a bit more general so instead of looking what we have done, instead of explaining what we have done, also explaining how we have done it and why we have done it.

We think that if we sort of take, if we take the learning points and remove them a little bit from the context where they were generated, we think that they maybe more accessible and more usable for others as well, including others who do not share the same background that we have.

That was the idea of having presenters present on topics that were not directly related to one or the other area of deafblindness. We wanted to present something that was a bit more general, but still had relevance for both groups. And then it was up to us to make sense of it, and to use it as part of our knowledge base. We were helped by having to 2 responders putting this into a framework of deafblindness, but we had to do the work ourselves and it does require some brain work to do that. Its easier to have a project or intervention presented you put it in your pocket, you go home and you do it.

Workshops are as you know a big part of conferences like this , a lot of learning takes place there, a lot of learning takes place in the plenaries, but even more takes place in the workshops.

At this conference we have had 82 workshops. Many were good, some were not so

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good, that's the way it always is. Maybe the subject was not as strong as we in the scientific committee thought it would be when we read the abstract maybe it was the presenter, maybe it was the audience, maybe it was a mix.

Over the past 3 days we have all participated in 6 workshops, 2 each day. 340 people. That means that we together in total have spent 255 work days sitting at a conference, ah, at a workshop sorry. More than 2000 hours, 255 work days for those of us who work 8 hours, 5 days a week. That is really a lot of time spent on that, that's why we think its so important that we really make the workshops work and maybe this is why we think that instead of just imagining this has to make sense to someone like me, why not think about this has to make sense to someone like me but maybe also to someone who's not quite like me. Because he or she might need it too.

So when we talk about sharing knowledge across deafblindness, its not enough to say well of course we're willing to share knowledge, the door to our workshop is open please come in, you're free to listen to what I am going to say. Its not as simple as that. It takes 2 tango as someone said. Or I think it was said in one of the workshops the other day, there was a quote by Eleanor Roosevelt who said understanding is a 2 way street. I really I think that the needs to be a motivation for the person who's going to learn and a need to make your information accessible and understandable by the person who's presenting the information.

It has to be a conscious effort, you have to prepare it and of course its more work than if you just are telling your story to one of your colleagues.

We have been having conferences in this format since, well since I probably would say since the first Dbl conference, its not only the Dbl conferences, its only conference in the field that we're working in. It feels good, it feels comfortable, this is away that we're used to doing it, we can have our presentation from the last conference we can specific it up a bit and present it again, maybe some new slides, maybe not. New dress. But it feels good, it feels safe we know what do, we know what expect. Well what's fine, Olav told us on the first day he was really emphasising

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that we should try to get out of the comfort zone. I am not sure he was meaning exactly this but I think that his point also goes for this. If we try to get out of the comfort zone we can actually achieve some things we're not achieving at the moment.

Now there is a question of motivation here because you need to be motivated to be able to learn something, you need to be able to or you need to be motivated to take in information that is not exactly the information that comes from another place than where you normally get it.

I asked you in the questionnaire how many of you would like to attend a workshop from the other side. Let me just maybe say here that we had at this conference, 82 workshops, 46 of them on congenital deafblindness, 60, no, 14 on acquired deafblindness and 22 on both or neither. Maybe more general ones. In Senigallia at the Dbl conference, Senigallia in Italy, we had 93 workshops even more than we had this time.

So I asked you, do you think that you will want to attend a workshop from the other side of deafblindness, and both sides, congenital and acquired 75% said yes. 3 quarters. So did you do it?

I was thinking show of hands now but I think show of feet so I think you need to get the blood rolling, all of those who went to a workshop on the other side of deafblindness than the one you are working with in, please stand up in just a second because we need to have the French translator. Please stand up.

Okay I would say about half. Thank you very much. Scientific committee we don't really count because we agreed on oh yeah I told you ongoing to workshops on the other area than the one we're working with, but it seemed to me just unscientific as the questionnaire, I would say around 50%, half of you did actually go.

FROM THE FLOOR: {Inaudible}

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OLE MORTENSEN: Which I why you have not been added to this slide which is a question which does not make sense if you are working in both fields. Exactly.

So, yeah. We asked you if you feel that you gain more from a conference that covers both sides than you do if you go to a conference on your own, in your own field and well very many said yes, of course the ones working in both fields they were more than 80% have said yes of course because here they get the full buffet of things to choose from. 50% of congenial deafblindness said they actually gain something from going to a conference if there's something there from the other side. About 25% said not very much, but to some extent did they gain something, and 5 to 10% said not really so that's about where we are, that there is very reassuringly, there is a picture here that we both, in both groups feel that there is something to gain from this and I think that Dbl will probably be very happy to hear that as well.

But the we must also consider this, we are asking people who are already here if they think that they will gain to be here. I think that if DBI would want to look into this, it could be interesting to get also answers from the ones who did not attend this conference and who for some reason chose not to come.

Yeah. Need to keep track of my papers here ...

So, yeah, and I really am not very comfortable with having a man you script because I don't normally do that but since I am not just speaking on my own behalf I wanted to make sure I am on the page as the rest of my colleagues in the scientific committee, but this just means that I need to know where to go now. Yeah so. I am sorry.

Obstacles. Are there obstacles to learn from each other? I asked that question. And I have just shown you a slide that has no explanations its a slide of the 3 groups, the orange columns the red columns and blue columns, divided into 6 groups, and its very clear that in the middle there are 2 groups, there are 2 questions where the acquired are much different than the

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others.

If you just use half a second to think why, what can it be where can it be that people in professionals in acquired deafblindness feel there are so much more obstacles in learning from each other, what can be the obstacles that are so specific for them. Just reflect for 10 seconds. Could we have the English transcription removed for a second? I know you are dying of suspense, what they are actually saying is that about 25% of people working in acquired deafblindness says that there is a lack of mutual respect. Making an obstacle for learning from each other. Could be something for the other side to think about. Could something be done here?

The other question where the acquired deafblindness professionals feel that they are very different from the others is on the question there's no interest in learning from the other side, that has to do with themselves, ourselves, what it says we don't have the interest in our field to learn from the other field.

So there are things to work on here, we don't have the whole solution, but I wanted to share with you how you perceive this coming into the conference. Because this was, seems like many days ago but I think it was 4 days ago, you may have a different impression now.

So, do I think that this can be done, that we can learn from each other? Certainly. Do I think, do we think that something can be gained from it? Absolutely. We don't know how much until we try but we really think that there's something can be gained. Do we think it will happen? Nah, at least not by itself. It will take sometime and some effort to start doing workshops in another way. We as humans are generally not very comfortable in changing our ways and how should we do it, how would we go about it. This away we're used to doing it. Well, where's Gill because I am throwing the ball in your direction now. We think that DBI should help this process along, facilitate it by producing a how to manual. On how to increase knowledge sharing at conferences on deafblindness. A manual, guidelines, advice on how to share knowledge with people who are not like you. It could be a written manual did could be a video, of course it should

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be accessible for our colleagues who have problems seeing or hearing or both of course goes without saying.

It should be written by specialists in knowledge sharing, specialists in adult education, people from university, just to name something. I know we have a lot of competencies in the Dbl, and I think this is something that could be solved. But why not make it an e-learning programme. We have heard that discussed here as well. Why not make it a compulsory e-learning project. You don't get to present at a Dbl conference unless you take the e-learning programme. Just an idea.

Through this manual are colleagues would be able to make even more interesting work shops, but now with a special attention on sharing with each other, learning from each other, across the field of deafblindness. So the ball went to Gill and DBI, I think the ball should also go to the next scientific committee for the world conference in 2 years, for the European conference in 4 years. I think in modesty, maybe we have started made a little ripple in the water, a small people, or small snowball we have tried to push. We feel that ball may roll even bigger by way for instance of the Dbl focusing on this way of developing the Dbl and the collaboration within the Dbl across the fields. I think we could do it also on the next conferences if the scientific committee wants to take, to rise to the challenge and maybe continue some of the work that we have tried to set in motion here.

We have a number of ideas and recommendations for the next conferences, things we have actually just thought up after we planned this one which is why we have started, but we already now see there are thing that could be different in the next conferences. So we hopeless that the future scientific committees will take the ball and run with it, and if they want to take part of our experiences they are very welcome.

I think the time is right, we think the time is right for this now. The times they are a changing like Bob Dylan said, for those of you born after 1980 ask some of the other participants with grey hair who that is. And Anna who we just saw on stage recently said at a Nordic

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conference that in your opinion professionals are becoming more more individualistic, cultures are very strong they are breaking up a little bit being replaced by a new and maybe more independent approach, autonomous approach. Questioning both the way that we normally do things here, and also being more open to picking up methods and approaches from other fields. I think that actually this is a very good time that is is happening, maybe there's a reason why its happening now because the time is right for this.

I will wrap up now, and I started out with a quote from Martin Luther King. Professor Hermans yesterday he had a number of wonderful quotes from philosophers, poets and everyone that fit in very well with what he was saying. As I said I do believe that we can find learning, many places, we can find inspiration, many places also outside what we do ourselves. So when I turn to the arts, to find a good quote, strong quote to end this talk, this is what I got.

On the screen I have a picture of Meowth, the cartoon cat from the series Pokemon, Japanese cartoon. This particular character is a cat, a very friendly looking cat and her name is Meowth. I think she could actually be part of the scientific committee because what she said in Pokemon, the movie, those of you who have seen the movie you can go to coffee now. This is what she said "We do have a lot in common. Maybe if we started looking at what's the same instead of always looking at what's different, well, who knows?" She said. Well who knows. Thank you. {Applause}

And now there's coffee.

(Coffee break)

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NEW SPEAKER: Please can you take a seat for the last session, last moment together. . Its a pleasure for me to introduce Monsieur Fevre who is the father of a lady who is deafblind because of Rubella. He has been the first President of ANPSA, he is the boss of the centre of for the handicapped in France. He is very involved in trying to make politics develop in France. I will really leave him to let him explain to you what he is doing. Thank you for welcoming him.

MONSIEUR FEVRE: Many thanks. First of all, I would like to thank you all for being here as well as the scientific committee and the organisation committee for this event, for their remarkable work in putting together this gigantic organisation, this gigantic event so I am not going to give all the names of those involved, although I will quite a number of people in my presentation, more particularly yes the present is on its way.

So I would like to talk to you about 2 periods in my life. First of all, my daughter Anne-Claire is going to be turning 50 at the end of this year. When she was born we knew there was a risk, there was a likelihood of Rubella. And the diagnosis quickly identified congenital cataract and she had blue lips, she had a significant cardiomyopathy, and the physician was reassuring he told us well she's not going to make it, and if she does you will take her to the hospice to, what we used to refer in France as the special psychiatric unit in France. In those days. So we actually walked away, we ran away and what for? Well we met our friends in Boston, and they put us in touch with Sense and in those days Candova(?), and in they in turn put us in touch with the one who undertook the first assessment and the first projects very sharp projects for Anne Claire, the expert in those days.

Basically as people were enabled to nobody could really look after her in terms of formal assessment. And very quickly we met this expert who within a matter of 15 minutes identified a diagnosis and that's when we went forward and with this marriage with these bringing together the people of high intellectual calibre, researchers in the field of deafblindness and as we were the first ones to bring in a child with a Rubella and deafblindness as a result of Rubella. Then when the first section was established for mainly with Rubella and we then founded the national organisations for deafblind. There were so few of us. I mean basically you can't put

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together in that association or organisation with only 1 couple of parents. And basically that is what happen at the time.

This is what we did, and putting together parents with professionals and organisations that had an interest in this issue. So in French contacts it was not a parent organisation that was established but an organisation bringing together all these stake holders in the field of deafblindness so there was a mix and match of people then.

Then 50 years later, 50 years down the road what has happened since then. Well my responsibilities as follows, well a number of establishments a number of units for children for adults have been created, established in France from a variety of examples from the UK from the Netherlands without any co-ordination and quite scattered manner from this point in the years 2000 we created on requests of our Government a centre the CRESAM, which is a resource centre , a high level resource centre which was brought together with another centre covering all types of disabilities for blind people, impaired people and the second centre created on requests of the Government for all those who experienced severe sensory challenges or disability as a result of non stabilised epileptic conditions.

So the mission statement, the remit can be summarised as follows. It boils down to integrated as the deafblind people so one in every 5 deafblind people over the next few years in terms of rarer disabilities we need to properly identify these people and we need to properly fund these people and you need to include every one. Without creating or almost without creating any new space or new room with the specialised units and following the principle of institutionalisation and financial constraints. We accepted to take this job on at this time, at that time we decided ongoing ahead putting together an organisation bringing together high level experts, high level specialists, resource centres with teams decentralised teams across regions in France and of course local teams had to be connected with a national centres, the CRESAM.

Then we were requested to support the deafblind people as much as we could without

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creating any new organisation. But according to the principle of integration and copying what has been done in some of the countries in North America, i.e. regional antennas to leverage from as many local resources as possible for epileptic people, for people with blindness, for behavioural disorders, this a horizontal system while vertically going to the resource centre every time they experience a lack of competence from their part, or very specific and very rare cases and highly complex cases, as in the CHARGE syndrome and a few others.

This requires a real ground breaking cultural milestone it really requires a revolutionary step forward in thinking process in our countries because every disabled person is placed under the super vision of a team and a physician and then all of these experts are going to have to be taught that they will be working hand in hand together. Collaborating with each other without necessarily having a supervisor or team leader. I don't know whether this a challenge that has been put forward, whether we'll be able to rise up to the challenge but this is a fascinating endeavour. And we must not, and in this respect we do not want for this to end up over generalising the approach taking to deal with deafblind people with people putting under the care of experts that are only experts in blindness or in deafness.

Now, we are facing a major challenge and we are being asked to come up with solutions for highly complex issues because now our daughter was born 50 years ago, she was born in the context where we were told she will die before you. Will. However, we're going to die far later than expected and she will die maybe 30 years later. What is going to happen then, after we die? For the time being there's no answer to that issue.

Second challenge. We've been dealing with parents a great but not really with siblings. Brothers and of sisters of families of people with, where deafblind people live. We need to really get cracking and we need to unite and come together and bring together a strength. We need within a group as small as that of deafblind, deafblind people where a team that's competent in the field sits 400 kilometre away. We need to act and bring together and leverage from all skills and competencies in the field. And I would like to tell you about my personal opinion, very often in this

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forum we have heard about H experts and their clients and as far as we're concerned as parents, this reality is somewhat different.

We have the highest respect for those researchers and teachers at the highest possible level in terms of and we do not want to question their expertise, have a for people with deafblindness both children and a adults. There's a huge expertise that can be pooled in terms experts in contact with people with deafblindness because the poach has to be customised it has to be on a one-to-one basis every deafblind people presents a specific case scenario in itself. This is about day-to-day life experience there. They too have their expertise and can be used as a pool of resources. The only thing is that very often they are the has taken over they don't benefit from the continuity of this knowledge they don't necessarily have the general background knowledge as to conceptual ice and to forward, and to educate third parties so I would say quite honestly, where does expertise lie?

Well within parents. That's what I want to tell you. Parents have to deal with experts, specialist in remarkable organisations and units. However, people have been trained to welcome to accommodate needs for elderly ladies aged 80, they wake up a number of occasions at night and we need to coach them as parents to tell them no this is not a rare epileptic condition, this is not a severe trauma, or respiratory trauma, I don't know what because we do have a form of expertise that is deficient, lacking in terms of expertise, but our expertise is that of continuous care. Then the 4th floor of the expert is place for my daughter, really the expert is my daughter. She has far more experience in terms of dealing with day-to-day experiences and challenges and obstacles in day-to-day life than I have. She overcomes a number of obstacles in such a way for instance if I drive, if I take the wrong turn, if we make the slightest mistake she hits the dash board vehemently because she knows every single bump along the road, she knows exactly where we are and where we make a mistake.

So then all of this brings us to the conclusion that expertise is diverse, takes varied shapes, very often it can be concrete, tangible theoretical, and we need to bring together all the

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levels of intervention in terms of what we refer to as parents our proven expertise, its not a recognised expertise but informal expertise if we trust, really this is key we need to conjugate all our expertise we need the to bring together all our expertise, and adapt situation to every one of those levels so that we can exchange experience.

There we are, I believe that in the next 3 years giving the funding available we are going to be trying to reach out for every single case of deafblindness with benefiting from support, home support or in specialist units and Government, and in particular the national consignment office provides with the funding has decided this year there will be an overall assessment in document in a report as thick as that of all the sources available in terms of complex disability and disability involving great deal of dependency, and these resource will not only list establishments organisations and units for deafblind people they will include organisations where there is even only one deafblind individual. This will also bring together the work of practitioners of the private sectors who are absolutely resource themselves. This is an overall assessments of resources available, from this regional pilot will base their work on so as to decide whether they can mobilise the engage and local team low resource or whether they want to pool their resource of central centres such as CRESAM so, this a cultural revolution in itself. They didn't, they were not used to dealing with things on a case by case basis, they should not become themselves mere consultancy offices. But they will increasingly become and rely upon professionals out there, experts out there and support those. And really system for providing whole support has been engineered and put in place notably in Nordic countries for the people who come and visit our clients in their home, and their experience has to be enhanced, paid accordingly, remunerated and coached for instance in so far as county hospitals in some countries.

So this is what we're currently involved in these days. Yesterday and the day before yesterday, on reading the abstracts of this conference of all the workshops. I learned amazing stuff. There's mines of information, there's a wealth of information out there to make use of but we need to go forward and we need to dare contacting each other, those amongst us that are at the real sources of these, even if they are English speaking. Sometimes its a challenge. However I

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do believe that we'll get there gradually we'll need to, we'll get to a point where there's osmosis between 1 on 1 contact of patient or clients and what you all represent, i.e., expertise you as experts of the highest level of the highest calibre. Thank you. {Applause}
NEW SPEAKER: Well I will hand the microphone to another mother, who has also a specific statue please will you hand the microphone to gill.

GILL: Thank you Dominique. Monsieur Fevre, I think you have said everything we have been trying to say all week. I feel a bit like a historical relic now, we are book ends. We both have Rubella children, if you remember in my opening presentation our discipline of deafblindness I said came from the Rubella children of the 1960s. And here we are, both with Rubella children, and of course I am also the chief executive of Sense. So Monsieur Fevre is talking about Conover Hall I know it well.

I have some very important task to too, I know that you want to go and be prepared for the gala dinner. So I am very conscious of time. But its a President's prerogative, before I do the really important task, to make some observations about the conference. Am I permitted?

The first thing is referring back to some presentations I am not sure about my die logical self anymore. I am not sure what my meta position is, {laughter} and I am not sure where my promoters are {laughter}. Sonia, I was struck by your very difficult choice. Can I give you some advice? You could have taken the beer and stayed in the hotel for the preparation. {Laughter}

Also in my opening presentation I said that parents were as important, if not more important, than professionals. So I agree with Monsieur Fevre, that is exactly what I want to restate. I also want to restate and add that over the years people with acquired deafblindness have come more and more into our world. And from Dbl's point of view we are delighted with that. We have no problem with your presentation, Ole, we believe we have much to learn from each other.

I also had a dream. My dream was 30 whatever years ago, that I would be on a platform as a parent with deafblind people, from both congenital and acquired deafblindness, with families, and with professionals all of equal status. I said that in my opening presentation, and I

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restate it now. I would like to thank the scientific committee for having the wisdom and foresight to look across the commonalities when they were setting the programme. . I am reflecting on some of the presentations from people like Jean-Christian, like Svein Olav, like Caroline Potter, from all worlds of deafblindness. In those presentations, I am fairly sure they hardly mentioned deafblindness at all. Caroline's dialogical self was about her role as a volunteer, as a learner. And what courage, did we miss the fact that she told us she was in love? How wonderful , how courageous.

Jean-Christian I do not look at Jean-Christian as a deafblind person, I look at him as a colleague and hopefully a friend. The fact that he is a crazy man {laughter} flying planes, has nothing to do with my respect for him as a deafblind friend.

So my dream was about us all being people and working together. And I think the question really is, there is no choice. Our world is small. And to reach out to politicians and to change it, we have to work together. My only other point would be that indeed I would go further because I am not sure that we have almost by default, limited opportunities. Jean-Christian runs art groups that include deafblind people, they include blind people, they include deaf people, and they include people from the mainstream. Sense is more and more looking not to just the external agencies Ole that you showed in the presentation, but I would turn to the arts world. . I would turn to mainstream outdoor activities, we should be reaching at much, much more. Our horizons should be much much wider.

We do have a challenge - I am just about to finish, its okay Dominique you are looking at me, we do have a tension we need to address. We need some label so we can maintain our professionalism, our skills. And yet our parents and our deafblind people are not necessarily even calling them deafblind. You heard Sven Olav he goats much information from the autistic organisations. Families and deafblind people have the right to pick and mix to get the best from wherever they can. Our challenge must be that we must be the best. So we have a lot to think about.

Finally Ole, DbI has no problem accepting your challenge about the how to manual, I

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am not sure its exactly the right tool, but that needs discussion, but actually its your challenge, huh, I am happy to because Dbl is not this magical body up there. Actually Dbl is every single one of you. If Dbl didn't exist, there would have been a focus group over this conference trying to pull together a co-ordinating group. You are Dbl. So you meet the challenge of widening our deafblind people's horizons a long with deafblind people Lynda, along with deafblind people as equal partners. So that is something we will take forward for the next conference.

So turning to some important things. As Ole said, we have I have cot some ceremony to do. I make no apologies for this because actually there is sometimes isn't enough ceremony in life. This is a bit administrative but I do believe ceremony is important. If we believe that our conferences are important we should acknowledge the organisers of this conference and we need to look forward to future conferences.

There's 2 things I want to do now. The first one is you know where the next Dbl world conference will be, it will be in 2015 N Romania. And in a minute I am going to ask Cristiana and James Thornberry, Cristiana Sloan from Sense international Romania to come up and say a few words about the world conference. And the second is a proper announcement. Dbl as a process for choosing where the next European conference will be, and you actually don't know, its like the Nobel prize winner. {Laughter} so there's should be a drum up here when I announce it to do a roll of drums. {Applause} I am not announcing it yet {laughter}

I will let you know you can do that again

First of all I would like Cristiana and James to come and say something about the world conference to be held in Romania in 2015. They are coming down. Come forward Cristiana?
CRISTIANA: I think I am forward enough. Dear all, 2015 is drawing near. I am extremely pleased to invite you to Romania where the next Dbl world conference will take place. Although not completely finalised, the tentative dates are May 20 until 30th 2015.

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Bucharest the capital city of Romania and also its largest metropolis of 2 million people, has been selected as a host city for this event. In my parent's youth, Bucharest was known as the little Paris. In time the city has gone through lots of changes, the changes creating an interesting blend of old and new.

I am pretty sure that at least some of you are familiar with some names. One of sad memory I am not mentioning it here, because we manage to get rid of him. Eventually, but also some names that have made Romania famous. George Enescu the great composer, Brâncuși the famous sculpture, Eugène Ionesco the playwright, Angela Gheorghiu the wonderful opera singer. Ilie Năstase the nasty tennis player. Nadia Comăneci the fantastic gymnast. I can continue like this, mentioning names that made Romania famous

I shouldn't forget to say a few words about Romanian hospitality, and I am sure that people who have visited us on pleasure or with business will recognise this. Of course I have not forgotten Dracula, but I can assure you it is a false myth. {Laughter} as a passionate activist in the field of deafblindness I would like to add something extremely important.

If everything I have mentioned so far has not convinced you to register for the next world in Romania in 2015, for sure what I will share with you in a minute will definitely influence you.

2000 when we registered as a local NGO working with and for deafblind people in Romania, we had to start from scratch. We were told there was no person with deafblindness in Romania, but we knew that most of the people we are now working with were in long stay hospitals or in the best scenario, at home with their families with no educational support.

There was not even a word in the dictionary for deafblindness. In 13 years, without false modesty, I can tell you that we have achieved so much and we would be pleased to share with you our achievements if you come over to visit us. So be prepared for a great conference,

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put the dates in your diaries, as we are anticipating that the conference will be a huge success. At the same time, your participation is vital, in what we are sure will be a great celebration of all our work, and also a fantastic opportunity for people with deafblindness, their families, professionals in the field, to meet, share ideas, personal experiences, and last but not least, have fun. Looking forward to meeting you in Romania in 2015. {Applause} thank you.

JAMES: Thank you very much Cristiana. I don't really have much more to add, apart from adding that Mr Olav's challenges that were given to us a couple of days ago, and Ole challenges that were given us to a little earlier on, we have heard them and we will try to do our best.

GILL: Lovely thank you. There were 2 delegates here, Vula and Shirley from the last world conference in Brazil, sadly they had to leave, but they left a gift for Cristiana as the last world conference organisers to the NewWorld conference organisers and I am going to ask Stan Murow to come down and present a mosaic that was made by a people in Brazil.

STAN: Its a great pleasure to have this honour on behalf of the organizing committee of the last conference, Brazil. I had this honour as part of the Canadian delegation in 1999, when we received a plaque for the 13th world conference which was held in Mississauga in 2003. Its my honour now to hand this over to you on behalf of the Brazilians I will just have to put this down because its in a paper I am scared I might drop it, its very fragile. So on behalf of Shirley and the other organisers in Brazil, from the last conference, this is for you to cherish for the next 2 years, and to hand over to next conference people for their contribution for the year 2019 who ever that might be. No no –

CRISTIANA: Its a pleasure. If I am still alive! . {Applause}

GILL: Lovely thank you. Okay, and now I will need the drum roll because as I said, I am really delighted to allowance that the next European conference will be held in Denmark. {Applause} and I think Lars from the centre for deafblind is here, I think Lars is going to tell us about Denmark.

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NEW SPEAKER: Thank you very much I am not going to tell you so much about Denmark but I think I will I want to say thank you to Dbl, thank you to the organisers of this conference, and to the delegates for an interesting and exciting conference here in Lille. I think its has been very thoughtful to hear and experience the different speakers and workshops I leave this conference inspired and full of hope. Hopeful because I believe that our community in Dbl contributes to develop good and sustainable deafblind services in our countries, in spite of local or national challenges.

The standard of the workshops represented and the plenary sessions has been of such high quality. I know that me and my staff leave this conference with more knowledge, more new contacts and a feeling of being part of a unique specialised fields.

And then its with great pleasure and pride that I am able to announce that European Dbl conference is going to take place in Aalborg in Denmark. {Applause} in Aalborg the centre for deafblindness and hearing loss is situated. Its a national wide centre for children and adults with deafblindness and hearing loss. At the CDH we believe that everyone with or without deafblindness has the right to develop and engage in social relationships. Its our principle duty to ensure that children and adults related to CDH get the best possible conditions to master their own live with potentials and competencies they have. And to achieve this collaboration with others being or working in the deafblind field all over the world is necessary. Through Dbl, international and Nordic contacts we keep an eye on ongoing developing process. We always need to know more and we need to be able to define the uniqueness of being deafblind in the normal life settings. In corroboration with the Dbl, the CFD , the national board of social services in the Nordic welfare centre, CDH and I look forward to welcome you to the 9th conference. We will do our very best to follow up the brilliant work that are friends colleagues have done here in Lille. Our aim is to host a highly professional conference that meets all people with deafblindness. We want to host a conference where we together can explore, where we can learn more and we challenged. For us its very important that we as human beings are able to grow to grow a little each day and that we are broaden our perspectives on the world. For us its important that everyone gets the possibility to experience knowing a little bit more today than yesterday.

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As I told you I wasn't going to say so much about Aalborg or Denmark, I can do that about 2 years I perhaps, but I would very much like to welcome Aalborg in 2017. Thank you.

GILL: There is a tradition that a conference , the previous conference holder passes on a statue to new conference organisers. I think this is actually particularly important because this statue was made by Lex Grandia so I think its Lex Grandia we lost him for those of you who don't know he was a person, but he happened to have acquired deafblindness and he actually passed seamlessly from acquired deafblindness to congenital deafblindness. He cared about families, he cared about children, and he cared about his friends and colleagues who were deafblind. He used to call me Brave Scotland. I loved him deeply as I know all of you did. So Lex's statue is returning to Denmark, we hope that you will put it on display when you hold the conference. I am going to ask Dominique to give you the statue. Sorry I need to get out of the way.

DOMINIQUE: As heavy as the heavy work you are taking on. {Laughter} {applause}

NEW SPEAKER: Thank you for giving me a problem coming home on the airplane! .

GILL: Its a burden and its a joy.

Also Jacques, the Chair of the scientific committee has something very important to give you, from all the work that the scientific committee did in preparation for this committee, Jacques has a very important huge book in detailed form that is giving you the answers step-by-step. Jacques could you come up and present this tome to Lars for us please.

JACQUES SOURIAU: Here it is {laughter} {applause}

GILL: Its a tiny blue book.

LARS: Thank you very much. I have to convince you to join the conference in 2 years, but I could mention some names we have Ole Mortensen, we have a very young tennis player, I can't remember her name she's blonde, but I hope you join us thank you. {Laughter}

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DOMINIQUE: Here's a bag if you want it.

GILL: Thank you Lars, I think that's my duties done. There will be more opportunities for thank use. I am not going to do thank yous in any detail just now but it goes without saying that this conference has been brilliant, had it not? {Applause} so I am going to hand over to Dominique.

DOMINIQUE: Well like Gill said its time to say thank you to everyone who has been making this conference being quite a nice time that we spend together. And first of all I want to thank all the deafblind people who have participated in the exhibition. Through the photographs, the art pieces, through the art craft that you have seen made out of cardboard and these sorts of things. Through the {inaudible} on the first day. I really want to thank all deafblind people for your participation because this is very important to us. {Applause}

I also want to thank the scientific committee because you can have a nice building, you can think well we'll do a conference in there but if you have no content there is no use to come. And the scientific committee has done a really great job in putting up this conference. So please can you come very quickly just to see Valerie so she can thank you very you know, its a very simple gesture to remember all the work that you have done for this conference and so that it tells you that we are very happy to have been able to work with you. {Applause} thank you very much.

You have to remember all those faces because you know those people are able to help you really in putting a lot of very interesting thoughts and reflections to our work. Thank you very much for all of these. {Applause}

And we wish also to thank people who have been very, very present during the conference, they were dressed with white shirt, I think they have been very helpful. They started right from the station, if you needed help at the station well they were there, they help you at the lunch time, they help you in the corridor to find you way in this big building, so please all the

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volunteers that we have some come from an association called France Bénévolat Lille, some are friends of ANPSA, some are professional in different places, and some are friends of deafblind people so please would you come down all the ones with white shirt? Could you come down? {Applause} they have been, they really have been a great team because without them, we would have maybe lost some people in Lille or you know some people might not have arrived here. Once they have their little bag they will help you once again at the station for tonight to go to the gala place, you can meet them at Flanders station, and the meeting point is between McDonald and the information desk. And there they will be able to help you in finding the tram that will lead you to the gala dinner place. You will be able to go by small groups, and they will start to meet you at 6.20, and will be going up to 6.40. So you go to station, you find the white shirt, maybe they will have put it on their back because some might want to dress up, off to the gala dinner. Thank you very much all of you. {Applause} it was really a pleasure to be with you. A pleasure to know new. Thank you. {Applause} (thank you in French).

So well, maybe we start the conference with some delay, but we are concluding right on time. Gill you have the last word.

GILL: Thank you everybody, we need to go to the gala dinner, everything is been said. (Conference closed in French) {applause}

DOMINIQUE: There are many questions in the box but I suppose if you have not - - I forgot something very important. Really I am sorry. But I forgot some people that were very, very important, and they are the ones that because they are important we sort of forget them, they are the interpreters. {Applause} interpreters on the floor, interpreters up there, the one that have tried to transcribe, all these we need to thank those so the technicians, the one that have made this conference work also {applause} thank you. {Applause} thank you sorry. I am sorry!