Dr Capi Wever -The idea of "Saving deaf children" The role of Family Centered Counseling & Informed Choice

Greg Leigh: Well, welcome back everyone. Welcome to the third of our keynote plenary presentations. Again, this morning, we'll be hearing from Dr Capi Wever. I introduced Capi at length yesterday, before he challenged us, quite considerably, on numbers of fronts and I'm quite sure that in presenting his second address, today, that he will do a little more of the same.

As Capi explained yesterday, he's chosen to present his two papers in the reverse order of what appears in the programme so, today, we'll be hearing from Capi on the topic of the idea of saving deaf children; the role of family centred counselling and informed choice. Please welcome Dr Capi Wever.

Capi: Well, thank you very much. I will try to embroider a little bit of what I talked about yesterday and, first of all, I would like to thank the organisers for inviting me here, again, and really impressed, as I just mentioned, by the meeting and by the environment. This is this morning from the Tower in the city. It was a sunny day so we went out there and had to take a look. It was just gorgeous. Talked to a lot of people and people are really emphatically involved in what they're doing and it's, I think, the most beautiful thing that can happen to you in your profession.

Yesterday, I tried to explain to you that I believe that it's really critical, whatever you do in your profession, that you develop a self-awareness and a critical awareness of your whereabouts in space and time and that reverse engineering, looking at where we came from, can really help in clarifying that and it can be beneficial to what we do. And I also explained to you that, at the end of my talk, that I believe that the way that we think about deafness and the moral space that we move in, really has direct repercussions for the way that we perceive parents and I'm going to try to make that step to the way that we perceive parents and the way that we counsel them as well.

So I've labelled my talk "Saving" Deaf Children and I've put the word 'saving' between quotes and my initial thoughts about this, what develops during the phases that I was working on my PhD thesis in the late 1990s. As I explained to you, I was hired by Professor [unintelligible 00:02:53] in [unintelligible 00:02:54] to analyse the wild debate that was going on in that period. And he wanted it to be analysed by, I guess, somebody from the outside but, at the same time, he gave me a Resident spot so he knew that he had a little bit of control over what I was going to say and nonetheless, I never experienced that. But, what I did during my PhD Thesis is interviewing, really that was the groundwork of what I did, was interviewing parents, interviewing teachers, interviewing adult deaf people, just to get a feel for what kind of area, what kind of room that was, that I was in. Really essential, I think, for me at least, to understand and try to write up a story that really has some bearing on reality. And one of the things that struck me straight off when I was for me, this was a new field. Deafness was completely new. I'd worked on disabilities previously so I had some sense of what I was looking at but I'd never had anything to do with deafness so it was completely new for me. And what struck me was the enormous and almost emphatical involvement of everybody in the field. It was overwhelming. I had never seen it anywhere else. Parents were enormously involved and teachers were involved and linguists were involved and researchers were involved and people who were heading schools were involved and

everybody seemed to be so emphatically involved with what they were doing. But, there's a down side or a potential down side to that as well. When I first came upon this impression, I visited a Professor in Utrecht who was …his core business was children with autism. And I was telling him this. I said, "Hey, you know, I'm doing this PhD study and I'm interviewing these people and they're so involved with what they're doing that…." And he was like, "Yeah. I recognise this. We have this too and in the field of autism". So there's …it seems to be that there's something about children and something about disabled children, at least that was my first …I didn't have children at the time. Actually, my daughter was born on the day, one hour before I had to defend my thesis. It was really terrible. Actually, they speeded up the delivery a little bit so I was on time. And .. so I had no…I could not fall back to intuition. I didn't have children so for me, it was all new, and I correlated it with children and I correlated it the children with a disability in general. So, this is a little bit what my impression of the field was. People were almost like superheroes, really putting all their efforts into what they were doing. And parents, these weren't normal parents. These were superhero parents. They were so involved and went out of their way, moved from one side of the country to the other to get the best school. I mean, you don't typically see that in regular parenting. It was just amazing.

So let's look at little bit closer at the model of superheroes and what is…if you read a story or look at a movie about superheroes, what does that mean? Well, generally if you look at a superhero story, you will see that these people live in a morally dualistic world. It's a very transparent world where the differences between heroes and villains is very clear. There's hardly a grey in between. And remember what I talked about yesterday, and you will start to see similarities. The superhero, typically, has no doubt. Doubt is not a part of his language arsenal. The world is transparent and the superhero is very convinced about what he does. And thirdly, even though they blow up half city blocks in trying to get to the villains, it doesn't seem to matter. They never focus on the damage that they do. So it seems to be that the message is, whatever they do it's collateral damage. Whatever happens along the way, it's justified by the end goal. And, indeed, the end of the story usually is very good. It's and good augured. The hero always wins. There's always a victorious moment at the end of the story. So if you compare this to what we were talking about yesterday, it seems, indeed, that this is a portrayal of the world as dealing with tame problems. A two dimensional world in which there is no doubt and there is great transparency between the moral values that we live in. And I think that's very appropriate because it's a comic and a comic or a book or a movie is an idealisation of the world that we live in or perhaps it's an idea of the world that we would like to live in. But, typically, it's not the world that we actually do live in. So let's move to the world that we do live in and talk about the Cheiron Larsen case.

I'm not sure if you are aware of this case. This is a case that took place in the early 1990s in the United States and it's actually back to home, it really is about what we're all together here for. Cheiron Larsen was a deaf child, a profoundly deaf child, congenitally deaf child, born into an ASL family with at least one other deaf sibling. He didn't have any cochlear implants. I believe, at the time, that this was becoming actual. He was six or seven years old, I'm not certain about that, but he was older. He wasn't three or four. And for some reason or another, Cheiron ended up in a foster home. I believe the reason was that his mother left the children alone with somebody to take care of them and stayed away for a couple of days

so there were more issues in that family. It wasn't just deafness. There were more issues involved. So Cheiron and his brother were placed in a foster family and that's when the ball started to move cause these foster parents were hearing. The school that they attended was a hearing school and this whole ball started to move about, why didn't these two children have cochlear implants. And it went so far that they took it to Court. The foster parents took the biological parents to Court. And the claim of the lawyer was that the denying Cheiron and his brother cochlear implants was to be perceived as neglect and, moreover, it was to be perceived as a medical emergency meaning it wasn't just neglect but something that we needed to do something about now, right now. So this is from an author that wrote about this in the ethics Journal for Medical Ethics. [unintelligible 00:09:35] And she writes that these are the arguments that they used. They were claiming that cochlear implants were in the best interests of these children. Now that might sound very familiar to you. We use that term a lot and I will come back to it, just in a moment. To realise their potential – we've heard that in the past days as well. And this is the medical emergency part – it was to be performed between the age of 0 to 4 because that was the window of opportunity to act. So, it seems that from an argumentative structure, these are the two arguments that were central in claiming that these two children really needed to get a cochlear implant immediately. Immediately was formulated by a biomedical emergency which really puts it outside of an issue of values or opinion. It's just something that needs to be done. And the best interests argument that I will argue does, pretty much, the same thing. The best interests argument does not invite dialogue, does not invite debate. It pretty much forces you into a certain direction of choice.

So the characteristics are that the problem is perceived as a tame problem. It is depicted as a medical emergency. What's going on is depicted as something of in the best interests of the child. And it goes so far that it completely isolates the child from his environment. I mean, whatever happens to these parents, obviously, doesn't seem to matter. It's all about the child. And any collateral damage that might be happening, in the meantime, seems to be put aside as collateral damage, as something that we need to accept because we're going for that greater goal. And that is the way that the best interests argument works so we should be careful when you see that flying by. I mean, it's the same kind of rhetoric as the life and death rhetoric. Who is to stand up and say, "Well, we're offering every child the best start in life." It is almost impossible to say, "Well, not me. I don't think that that's the case." So, that really reveals its rhetorical nature and means that you should think, when you see this, rather than go along with it, but it's difficult to do. Who could be against it?

And remember what I said yesterday about Michel Foucault and he would say that these arguments are trying to avoid dialogue, are trying to reframe the whole debate into a two dimensional problem, into a tame problem and not really inviting you, not really engaging you to think about the details or the nuances of the story. So, it more or less functions as a linear absolute, just as the life and death argument does. It forces you into a certain direction. It overrules everything else just as, pretty much, what we said about hearing yesterday. And hearing is also, or functions as, a linear absolute. Every bit of hearing is to be considered good. And this…it's very hard to bring in other arguments when this takes place. So, as I said at the beginning, the way that we think about deafness and the way that we think about children and the way that we think about parents are strongly interrelated. So if

you understand how we think about deafness, how we think about hearing loss and how we think about children in general and deaf children in general, you will start to see and realise how we are likely to relate to parents in our counselling. There is a strong and direct relation between how we view what we do, the implicit moral space that we move in, the rhetoric that we have internalised. I don't think it is explicit. I don't think we do this purposely. I think we live in that world in how we approach and counsel parents. And I think that the Cheiron Larsen case shows this beautifully. I don't think they went after these parents purposely. I think they went after these parents because they came out of a specific moral space; a specific way of thinking about hearing loss as being a linear absolute, as being an emergency, as being something that had to deal with a child's best interests. And that really drove the way that they dealt with parents, sending them to a foster home, taking parents to Court, and contesting the position of parents in that relationship. So there is a strong relation between the two and let's try to, again, back engineer a little bit, again, to get it a little bit more detailed of where are we coming from which is, a little bit, what we talked about yesterday and where are we heading.

So what is the original purpose of newborn hearing screening. I'm still struggling with that, even after yesterday. So let's look at it again because there has to be a benefit model. I mean, it cannot be the case that we're just doing this with no reason at all. initially, when we started this, there must have been a very clear benefit model. And what do mean with a benefit model? And this goes for any treatment that we do. I've made it specific to a developmental problem because there is something specific about the child and developmental issues in childhood. So, okay, so we have this intervention that we're doing, be it newborn hearing screening or screening for breast cancer, and the reason that we do this must have something to do with assumptions in the future. I mean, why change a winning team. If everything is okay, why are we setting up this enormous thing called new born hearing screening. There must have been assumptions about something that we did not like, downstream, that was driving us to do this. Moreover, we must assume that by intervening we may cause downstream liabilities but these downstream liabilities do not weigh up to the assumed benefits. So the balance of benefits and liabilities are in favour of the benefits. But, we're not going to wait for 20 years. I mean, that's the problem for ..in developmental issues. We're not going to sit there and intervene with whatever we're going to do and wait for 20 years and measure and see if we actually materialised what we wanted to realise. So, we need this intermediate measures, these intermediate definitions of benefits and liabilities and we're assuming that there is a very strong correlation also something that is difficult, sometimes, to actually materialise. So we're coming up with these intermediate benefits and measures. We're assuming that there is a strong correlation with why we're really doing it and we're really doing it because of these assumptions that we have about something that is really wrong with deaf people in their young adolescence and adulthood. Okay. So there's assumptions, right there, downstream. And there's also intermediate arguments, somewhere in the middle, childhood, a little bit later maybe, and these intermediate benefits and intermediate liabilities and benefits model really tell you how we think in an etiological sense. How do we assume that these downstream benefits correlate with our interventions so both are very interesting. So let's look a little at them a

little bit closer. So, in reality, it is the downstream problems that must have driven why we are doing what we're doing today. So what are these downstream problems?

Well, even though some of you may not know this person, and it's not specifically about William Stokoe, a brilliant linguist that really wrote up a lot about deaf adolescence and deaf adults in the 50s and 60s but his generation, I'm showing his photo here for what he stands for. I think that first, I mean if we're talking about what was wrong with deaf adolescence and deaf adults downstream, the generation of scientists that did their work in the 50s and 60s really were pivotal. They really gave us a sense about where these people were at. And I think it's, even though you may not have read what they did, it still structures the basic emotion that we have when we think about deaf people. Basically what they did is, what Stokoe and the others did is they showed us the failure of the profoundly deaf in the downstream. So these are, so to say, the empirical facts. But, there is an etiological causation that is immediate to what they did as well because they were evaluating how these people were doing after 75 years of oralism. So, there was an immediate correlate to an etiological way of thinking. So it wasn't just an empirical, factual summary of what was wrong but also immediately, not even purposely, but just by doing it after 75 years of oralism, it was also an etiological claim about why this happened to these people. And, of course, we saw a pretty awful piece of movie yesterday and this is pretty much the same situation. So I'm not sure if this is the case and I try to…I mean, it would be for me. I had the feeling, when I interview teachers, that there was a sense of shame about that historical past that we have behind us and that it led, for some people, to a feeling of urgency, that we needed to repair something. And where did this feeling of shame come from? Well, these are logical questions. How did we embark on such a totalitarian project and did not see the limits for 75 years? How did it last for so long? And how could we have been driven by such a one-sided aim, in spite of our best intentions because I'm very convinced that everybody in the field is extremely motivated to do the best that they can. So, in spite of our best intentions, this is what happened. So the moral space is, these factors really play an important factor. Of course, the empirical facts – and I've put them between quotes and I'll come back to that in a minute because it actually is critical because they are less factual than we think that they are – the etiological thinking, because that really leads us to the why do we need that or this or that intervention to fix this problem, and the emotions that surround it, feelings of shame, feelings of urgency. So let's look at little bit at the downstream facts.

Well, if you look at the literature that was published in that period, I mean these are just some of the things that we know and that they focus on. We know that, in spite of our best intentions, about 90% of deaf people, depending on who you quote, at the end of the day, after 18 years or 16 years or 12 years of education, were pretty much unable to pragmatically use spoken language. And we're still very strongly sign language dependent. There were extreme literacy delays, a low educational performance. As an adult, they were under-employed. There were serious mental health risks involved and, in terms of social belonging, many of the deaf, really, lived and functioned in the deaf world, with a capital 'D'. So, we know they were doing badly but how and why? What is the etiological rationale behind it? So let's look a little bit closer at what literature has to say about that. And these are more recent quotes. Well these are the empirical facts. I've mentioned them already.

This is Ching in her introduction of one of her articles, “Many children with profound hearing loss have difficulties acquiring speech, language, and literacy.” Okay. So these are the facts. So let’s look a little bit closer at the etiological reasoning behind it. This is from [unintelligible 00:21:27] and says, “Okay. So we know that there’s problems with speech and language acquisition, but if detected late and thereby compromising optimal childhood and compromising lifelong vocational prospects”. And so, now we start seeing a sort of sequence in our reasoning. We know what the problem is and we know how we perceive the logic behind the problem; how we perceive the aetiology. So we start getting a little bit more detailed benefit model. So we know that downstream, there is issues. There’s lower vocational prospects and, now, we believe that this is caused by an impaired cognitive development. And we believe that that is caused by an impaired language development. And we believe that that is caused because we detected hearing loss late. And if we do so earlier, and we intervene in that sequence, we assume, doing the intervention and now you may argue with me if this is correct but it could be sign language as well, but doing the intervention will better the vocational outcomes of this chain of events.

But, let’s go back to the better vocational prospects that I just talked about. I put them between quotes. That’s, I said just now that I think they are less factual than we think they are. And I think …I’ll try to explain that to you. I think it is pretty hard to talk about prospects without defining a moral space. It is difficult to talk about best interests without some basic assumptions. Better prospects? Which better prospects? Which better prospects are we talking about? Is it common sensical? No it’s not. There is a large number of values and benefits involved. And it only becomes common sensical if you make choices; if you take a position in that cluster of best interests or values that are involved. Because how are we going to benchmark them? Are we going to benchmark them based on the hearing world? Are we going to benchmark them to the deaf world? Are we going to be talking about what is pragmatically possible? Are we going to use cognition and language as something overrides everything else? Are we going to believe that social emotional issues are to override everything else? Are we considering family and the natural parents as sacred, as something that can’t be touched? Or do we think that we need to do social justice? Are we focusing on the individual? Are we focusing on the group? Or are we focusing on society? Are we focusing pragmatically? Or are we reasoning through values? Are we believing that what we can do is …we can do ..we can optimise the outcome or are we fundamentally believing that what we need to do is a trade-off? As you can see, there’s a lot of values that fit perfectly in that best interests argument and there are a mixed bag. And you need to make choices before they start to make sense.

So the moral space only becomes transparent by deciding on which value hierarchy is important to you; which value overrides which and how do we view liabilities? Are we going to weigh them or are we going to perceive them as collateral damage that we accept? So, is it about something, what we can achieve theoretically or is it about what we can achieve pragmatically? So we need to have a better understanding of where we’re coming from in terms of our moral space. As I’ve already mentioned, there are some theoretical backbones to that. I mean are we talking about a tame problem? Are we perceiving the problems as complex wicked problems? Are we assuming that we can reason through values, theoretically, or are we pragmatists in how we reason? Are we going to focus on the

individual or are we going to focus on the individual as part of a larger whole, as part of an ethnic group, as part of family? Where are we going to stand? And are we going to focus on performance outcome – cognition, language – or are we going to focus on emotional outcome in terms of best interest?

Now having said that best interests really is a mixed bag doesn't say that it is completely relativist. I mean, there are definite, popular moral spaces, especially in the western world. And I think that two of them are very important and they deviate the way we think. I mean, that's why I'm showing it to you. I think that there is a cognitive linguistic moral space that is very popular and especially in Anglo-Saxon countries, I think, and probably the most in the United States of America, you can see this. You can see this. And what is the cognitive linguistic moral space contain of? It means that you're orienting yourself on performance mostly. You're focusing on the individual, on language, on cognitive development. That is really paramount. What's also logical that countries such as the USA does that because it doesn't have any safety ropes. I mean, if you're not doing well educationally, if you're not doing well in cognitive terms, if you're not doing well in language terms, you'll fall through the holes. And you'll end up on the street. There is no safety rope. So it doesn't make any sense to talk about happiness. Happiness is direct correlate of how somebody does in cognitive terms. If you look at welfare states, such Sweden, The Netherlands, Denmark, Norway, you'll see that they tend to focus more on emotional wellbeing. And they can afford to do that because we do have a safety net. So we can afford the arrogance of saying, "Well, you know, it's not really quite essential that you perform the best that you can be in school because we have something to catch you if you fall, so to say. So, feeling good and being happy is something that come to the forth more often in those countries and, of course, whatever we do, we want it to be equally available to everybody.

But the problem with both of them is that they tend to be monolithical and aimed at the optimising. They're really believe that the ideal world exists and that's where things start going wrong, I believe. If you look at the consequences for hearing loss, the cognitive linguistic model, I think, would lean more towards cochlear implantation, towards early cochlear implantation. And I think that the emotional or kind of approach that we would see in the welfare states might lean more to sign language, might lean more towards deaf culture support. And as I said, both of them would want to put that into legislation.

Let's take it one level higher. We talked about that yesterday as well. If we talk about the problems that we're perceiving, I think that we are perceiving that cluster, that mixed bag of values that we're talking about in terms of best interests as something that can be solved, that can be unravelled, that we can make transparent, for somehow and some reason. I think that is very questionable and the problem with that is that we tend to start simplifying when we do that. It's hearing loss, stupid, I mean it's …why are you…why am I standing here and talking to you for an hour. It's the hearing loss. Just fit them a hearing aid and cochlear implants and they'll be fine. And we actually do hear that now and then. And this is from Parry in 2008 who says that, "cochlear implant children actually do better than normal hearing children". So that's fascinating. And opposed to that view, as I said yesterday, is the idea that problems are wicked, that developmental problems are wicked problems and I'm going to stand still a little bit more than we did yesterday. It means that problems are multi-causal, they're interdependent, and solutions can lead to unforeseen consequences. Now

that might sound familiar. That there are no clear solutions. That it involves changing behaviour and that it all takes place at the organisational boundaries. I mean this sounds a lot more reasonable to me than depicting these problems as tame problems.

So the next thing that is common, I think, is that we look at these children and we look at these problems from a performance orientation and we can go either way in this. And the most popular performance oriented perspective, I think, is the liberal cognitive perspective. It is a performance model – we really want these kids to do the best that they can do in terms of language and cognitive development; first as a more communitarian model, meaning focusing on family, focusing on ethnic group, belonging, etc. etc. This is probably the dominant model that we have right now. And the third issue is that we believe, and this, I think, is critical, that the optimal really exists; that in spite of all the negative stuff that we see, that we can fix them if we just get it just right, if we get the perfect intervention in place, if we can just get these parents on board, we can fix it all and we can make them into normal children. So it's assuming that the clinical, almost optimal situation actually exists and that there's something that we can attain. There's a little parallel to cochlear implantations because I think it plays a major role in that discourse as well. In general, whenever you see a depiction of a dystopia, meaning a negative and grossly exaggerated negative portrayal of a problem, be aware, because they always come in a couple. When you see dystopia, you know that utopia is around the corner. It's trying to point a direction to utopia. So what have we seen from cochlear implants. We know that there's been a lot of studies that have shown that children who were implanted at 7 or 8 or 9 or 10 were really doing a lot worse than those that were implanted under 3. And there's also some evidence that children who are implanted between 1 and 3 are doing better than those who were implanted between 3 and 6 but, and I'm not a cochlear implant expert but to my knowledge, there's not a lot of evidence that children who were implanted under 3, let alone under 1, do greatly better than those who are implanted between 1 and 3. Nonetheless, subliminal message seems to be that by sketching this dystopia, these children are doing abysmal if you implant them at 7, it seems to be that there's a linear line to be perceived here and that if we get it all right, if we get them as early as possible and implant them at one week, or maybe even in utero, they'll be fine.

Now the same happens for utilitarian utopia. It's all round as well, people who focus on happiness and believe that, if you do it right, if you get it just right, you can fix every problem that there is. And this is from a PhD thesis that will be defended next month in the Netherlands by one of our Residents actually, and she claims that cochlear implants, the children are happier than normal hearing children. Well, that's interesting. Certainly, knowing that happiness is affected very soon if you look at the literature from a broader perspective. I mean, just name the chronic disease and look at happiness studies and people do worse. Look at physical stigma and people do worse. Look at bullying and people do worse. Actually, look at higher education, look at doctors, and they do worse, in terms of happiness. So how can they be happier than normal children?

So let's go back to parents or superhero parents and how we deal with these people. So I said, the way of thinking that I try to illustrate to you really is related to that and the Cheiron Larson case illustrates that; how we think about deafness and how we think about interests and how we think about children really leads to a specific way of dealing with parents.

Hence, the idea of 'saving' deaf children, even though it might be beautiful, in a way it does tend to be rather ideological and emotional. It tends to strongly believe in the right thing. It tends to be encompassing and not about nuance. It tends to dismiss negative outcome as collateral damage. It tends not to be so open to self-critique and it tends to view problems as tame problems. So really looking at it from a focused in, locked in kind of perspective.

Well, let's broaden it up a little bit and see where is this coming from. Why is the bar raised so much when we deal with children because it seems to be a generic kind of thing? We see it in deafness but we also see it in other children's studies of children with other disabilities. What is the origin of our heightened emotions when we deal with children? And especially when they're sick.

Well, generally, we perceive children through a best interests discourse in western society. This is the common way of looking at children and we can see that in the United Nations as well. But, best interest is a right discourse and a right discourse is all about the individual. It separates the individual from its environment and also, it tends to be absolute in its claims. It is not satisfied with mediocre outcome. It wants the perfect outcome. And in the western world, it's commonly come to define or redefine the relation between parents and the state and I'll come back to that later. And the way that it's being argued, just like I showed you yesterday, is to flee to the extremes. We've seen that in the life and death rhetoric and this guy was amputated, both of his legs and his arms and the argument that at least he's still alive. And so it, by saying that, you are really fleeing to an extreme and locking people in your rhetoric and best interest works in pretty much the same way. Who could argue against best interest? I mean who could say, "No, I'm not for best interest." And is that the way that it's oftentimes being argued is through extremes. You flee to extremes. For example, Jehovah Witnesses and blood transfusions, by showing this and cases of parents who are denying their children blood transfusions. It makes a lot of sense is separate the child from his or her family and the best interest argument sounds very convincing. And the same is, of course, true in child battery. But the question is what happens in between? We're selling the best interest argument based on extremes but does it make a sense to do that?

So, in general, the way we look at children is – and we've done that for over 100 years – is that we believe that we need to protect children; that means, keep them away from the dangerous and morally rejectable adult world. But at the same time, and that's where it becomes interesting, we believe that children should be subjected to the adult rationality. Our rationality is an interesting term, here. They have to be supervised by a rational adults. And then the question comes, are parents the right rational agents in that relationship? Are they rational enough? And we hear this argument everywhere. We hear it when we talk about voting rights. It's a dangerous thing when you see it. So educational and constitutional implications have been the result of this and it's also given rise to child psychology, to education, as a new holder of this knowledge of childhood. And as I said before, it's let to a, how shall I call it, a potentially tension between the state and other agents of rationality and biological parents. And as we know, that does have a long history. And most of it is good. Somebody came up to me yesterday and said, "So how about vaccinations?" I mean vaccinations are great, as far as I am concerned. So there is a lot of good stuff about it but the frame behind it is the same. We are deciding for parents and so we give ourselves the right to stand in their shoes and we have legislation to enforce that. Children have to go to

school. In many countries, vaccinations have to be done. Yet that seems to be on the rise. And it seems to be conjoined by an army of scientists who are supporting this. Remember what I said about Foucault. It helps – science helps to steer away from the feeling of paternalism and feeling it has nothing to do with opinion. It's about science. So just like medicine, as I just showed you, it often argues based on extremes. The case is argued based on extremes – just some examples, I don't want to show too many of them but you are familiar with them.

So parents really started to revolt against this idea in the 1950s. They started to stand up and reclaim their position and really reclaim their authority in that relationship. So if you look at today, what is the situation like today? Of course, overt moralism has retreated. Nobody would dare to step on parents that way anymore. And we've learned from history and most people distance themselves from interventions like those that I just showed you, based on this idea of paternalism. But, between the lines, we ought to be careful. Modern versions are more subtle but can be just as paternalistic as what we've just seen, just more subtle. And psychosocial interests and best interests are really the new paradigm. Science really helps us to stay away from paternalism. And science, as Foucault would probably say, is now being the butcher. So no, we don't step on parents anymore. We don't do that. We find that unacceptable. We counsel them. But counselling has an intrinsic risk and the risk is that we're going in when opinion has not formed yet. So it allows us to be non-paternalistic but to be extremely paternalistic at the same time because we're really encountering a blank sheet of paper. And something changed, I think, when newborn hearing screening was introduced, that allows that to happen.

One thing that I've found when interviewing parents of deaf people is that there was a distinct change. I can't say if it was two years or three years of age, but there was a point in the narrative of parents that really was a tipping of the way that they were perceiving their child and the way that they encountered the world, and it had to do – this is how I really verbalised it – with the encounter of a concrete child and a concrete child means that the child, his or herself, started giving feedback. You can actually monitor and go by the child. When a child is three or four months old, it doesn't give a lot of feedback yet. The six year old, though, it tells you exactly what they want to be done and parents really changed because of that and became much more empowered. Also, as time went along, initially the first year, first two years, parents were struggling. They didn't have knowledge. They were looking on the internet, reading books but they weren't there yet. If you talk to parents when children are three or four years old, they often were para-professionalised. They were very much into the literature. They know more than I did about the problem. So the position of parents really does change in time. Thirdly, I would argue, that most hearing people, 90% of deaf children are born to hearing people, that hearing people intrinsically are audists in their perception. I mean, there's nothing negative about it; that's just the way we are programmed to be. So we believe in the linear absolute of hearing. So if you intervene in the first year of life, you're likely to encounter a blank sheet of paper that is pretty much audist in its basic composition. So they're much more likely to follow your counsel, so to say, but it doesn't lower the burden on us, as care providers.

Before I came here, I walked up to our main implant surgeon just to sort of see if there was some validity to what I'm saying here. So he's a senior cochlear implant surgeon and does a

lot of research. I said to him, “Johann,” I said, “how is counselling these days? With these parents? Compared to ten years ago, before we had newborn hearing screening?” And if it isn’t the content of his expression that is interesting, it is the speed and the emotion that was involved in answering. He was answering within .2 seconds. So it was immediate. He didn’t have to think about it. It was, “Oh it’s so easy these days. It’s great. It’s easy.” And so I said, “Why?” “Well, because they don’t have an opinion,” he answered. So it’s a lot easier to convert, so to say, parents to a cochlear implant kind of view. So that means that, as counsellors, we really should be aware of this because are we counselling…what is our counselling ideology? How do we perceive counselling? Are we counselling in terms of vineyards as I would be advocating, meaning that you – of course, you take into consideration what the characteristics are of the child but are you sketching, seeing, and trying to be as neutral as you can or are you really trying to push into a specific direction with what you do? Because you can and we know you can, if you look at the definition of counselling in the dictionary, it goes all the way from an exchange of opinions and ideas, which is very sort of neutral, to a private opinion or purpose. So where are we at? Are we perceiving it as a tame problem? Are we tap tapping people into a specific direction? Is that what we’re doing? Or is that what we don’t want to do?

So the pressure on parents is, I think, extremely high, especially in the western world. I mean this is from an article by Time Magazine – Are you Mom enough? Actually, I cut off the top. She’s breastfeeding a 7 year old. I didn’t want to do that. But it sort of defines the picture. It’s Time Magazine, so its’ a serious magazine. It’s about how high we’ve put the thresholds for parents to perform, especially if they’re highly educated, if they’re from a western country, parents and especially mothers feel that the pressure is on. So what is our basic view on parenting, then?

Well, in the literature, you can see there are two basic ways of which you can approach parenting and they relate to what I was saying before. You can look at parenting through a radiant kind of view which they call optimising parentalism which implies that parents need to provide the ideal opportunity, not an opportunity; no, the best opportunity. And then there’s this softer version which is called satisfising parentalism which says that parents only need to provide a reasonable or basic opportunity and that makes a huge difference, in which position you take in these two and how you counsel parents. Optimising parentalism is often times value or best interest driven. It tends to be monolithical. It tends to depart from a very narrow hierarchical view on values and interests and so it discounts competing values and it’s only satisfied with what I said before, with the optimal outcome; not with an intermediate outcome. And the critique, of course, is that it’s unreasonably demanding. It’s unrespectful to parents. It’s badly defined and it doesn’t realise that, and it lacks empirical founding. It ignores heterogeneous character of interests that I’ve tried to show to you and the interwoven nature of interests that I’ve also tried to show them to you. And actually, this view on parenting has been tested. It’s been tested in 1972 by a Court case in the United States; very famous, [unintelligible 00:45:48] versus Wisconsin and the case was of the State versus an Amish family in the USA. And as many of your probably know, the Amish are very communitarian in their lifestyle. They live in their own community and that means that they’re providing education for their children up to the 8th grade. After the 8th grade, they cannot deliver that and the choice is the child leaving the community to go to higher

education or are we accepting this and viewing them through a communitarian set of spectacles. It went all the way to the High Court and, actually, the Amish won the case meaning that the State – I think it was the State of Minnesota – in their ruling, said that parents had the right not to provide the optimal but to provide a reasonable outcome in their children that was congruent to their ethnic or religious background.

So there are strong limitations to the absolute way of viewing parenting. It hijacks parents in a very one-sided way, fixed to a single interest. While the reality of all of you know, who have children, is really balancing. There's more interests involved and it's really difficult, as a parent, to do that, I think. It doesn't account for the limitations that parents may have to deal with such as poverty, financial, job issues. And it assumes that interests represent a transparent and non-judgemental frame which it doesn't and it assumes that best is a non-ambiguous concept. And, in general, it assumes that parenting is like engineering and actually allows a very tight way of dealing with your children. And just look at that assumption of the best. How far are we going to go? Where are we going to put the threshold? What do we feel is the best that parents should really achieve? Now, personally, I believe that what we'd like to do in life and what we do here, as well, sort of putting the threshold just behind us. So we're safe, if you recognise that. But it does mean that it's completely subjective. If your personal situation is determining where you lay the threshold of defining what is normal and what is not normal, you start entering a slippery slope. I mean, are we all supposed to send our children to Prep Schools? Is that the …in their best interests and if you can't do that, should we intervene? I mean, how far are we going to go with that, based on which values? Is it measured by the chances of getting into a top school or by the final measure of a career or is it the socialising experience, the network that you develop there? Is it measured by wellbeing? Is it measured by your experience of different ethnicities? How are we going to benchmark that? So how reasonable is it? It is not a uniform frame. Now, in general, and this is from the Hippocrates, of course. It's in medicine very common. If you cannot provide clarity, if you cannot operationalize a term, you have to be careful about what you do and first of all, not harm. If you cannot operationalize a concept, if you cannot measure it, if you cannot prove benefit reliably, and if you do incur damage on parental autonomy, really, I think there's only one thing left. Be careful, be modest and be pragmatic about what you do and don't start push/pulling with parents over what is in the best interests of their children.

So, obviously, this view has my sympathy, it satisfies in parentalism. It is a different form of looking at parenting. Parents have the obligation to do what is good enough, not what is best so how do they operationalize good enough? Parents may know that something is, perhaps, not in the best interests of their child. They may know that. But they may…are still under no obligation, as Blumstein has said, to actually provide that. So, the standard that we use is not the optimal standard but, now, this is the interesting part I think, it's the minimum standard for functioning independently in their society and not whatever society as O'Neill has mentioned. And that implies that we may apply different standards to people who come from and agrarian background versus people who live in a big city. So at least a level which will minimally fit the child for independent adult life in its society. So it really means that all we can do, I think, reasonably, is be pragmatic and use life itself as a leading point and realise the truth and facts when you serve rather than dictate. They don't dictate any

direction. They serve us. They help us. Or as the French say, 'penser avec les mains' or the Americans, who are an English speaking country say, 'think on your feet'. Solutions must be friendly and must be useful at the same time. Or, from hands and voices, whatever works for a child is what makes the choice right.

Now, shortly, back to the Cheiron Larsen case and how did that end? Well, it ended with a win of his deaf parents. And the argument was, the judge ruled that he felt that cochlear implants were not …the argument for cochlear implants wasn't strong enough to overrule all the arguments involved. Hence, the ruling was in favour of the parents. The children were not implanted. They were …went back to their biological family.

So to wrap it up, as I started, I said, superheroes live in a moral, transparent, dualistic world where heroes and villains are readily available and recognisable. Is that the world that we live in? I think we should think about that. I don't think we do. I think the problems we deal with are wicked problems and are much more complex. And that is not something that we should cry about. It's something that is an enormous enrichment of what we do. It makes…me…we need to talk with each other which is, I think, what defines us as human beings. No ambivalence or doubt? Definitely, there are ambivalences or doubt and I think that we need to self-reflect. We need to look at ourselves in a mirror – not every day, perhaps, but regularly and be self-critical about what we do. Is the damage that we may incur on the way to be considered a means to an end – collateral damage? I don't think so. I think we are responsible for the damage that we incur, and we stay responsible for it and we should be aware of that. And is the story always a happy ending? Is it end good, all good. Well, of course, hope is not sufficient. It doesn't necessarily have to lead to that and we are responsible for the outcome as well. So, in general, I think that…I hope I've convinced you that we should be historically aware, we should be aware of our place in time and space and I think that really leads to a position of modesty to realise that the problems that we are dealing with are really, are intrinsically wicked, that we need to be self-critical and evaluate it at all times and be pragmatic rather than principle driven. Be resilient to utopic stories. Be critical of them. And people who claim that they're aiming for the optimal outcome and be willing to change. Learn from history. This is a picture that I really like. It's sort of as when I said you really need to have everything in place to be able to do that so that's interesting to talk about when we talk about our session on counselling; be able to really change your position based on the balance that is required. So being able to move from one [unintelligible 00:53:54] to the next, just based on what nature of what the environment around you predicts.

Thank you very much. It was great to be here and I hope that you've enjoyed the talks.

(Applause)

Greg Leigh: Again, wow. Thank you so much, Capi. I found myself, as I was – and I'm sure other people in the room would agree with me – as I listened to you at various times nodding in furious agreement and then thinking, gee, there's something I would like to share with you about an aspect of our field and realise that what you were doing was, at the same time, putting our field under a magnifying glass and looking at it. And somewhere through the presentation, I think I realised that you magnifying glass became a mirror and had the opportunity to look at some of the things that I have held to rather strongly during my career and it's ..nice to have

somebody hold a mirror up as well as a magnifying glass every now and again and I think you did that brilliantly. Would you join me again in thanking Capi.

[End of recorded material]