Podcast Transcript: Suzan Temizer

- Hello and welcome to the first of the Next Sense Institute Podcast for 2022. My name is Trudy Smith and I am your host. I am the manager of Continuing Professional Education at the Next Sense Institute. Just so happy to have you back with us again in 2022 I'm hoping that it's a smoother year for everybody. We decided to start this year with a focus on hearing awareness week and our focus at the Next Sense and Next Sense Institute is very much around family centred early intervention and informed choice, which is one of the fundamental principles of family centred. early intervention informed choice of course, is ensuring that the people who are making these decisions, parents, families, and extended circle have all of the information they need to make the right decision for their child and of course, knowing that that can be flexible and fluid depending on changing needs as well but we wanted to tell you some stories and I'm so delighted to have Suzan with us today to talk about the first story. So Suzan welcome. Please tell us a little bit yourself and your family.

- Hi Trudy. Thank you for having me today. I'm thrilled to share my story. So I'm Suzan and we're a family of five. So I have my partner, my husband and my two boys Kivanc and Chatai and also my mother who lives with us. So that's our family unit. And Kivanc, he's 10 and he's a deaf child. And my youngest is a child who is of full hearing. He has normal hearing. So we're a mixed family, mixed bag. And you know , so I do have my mother who does live with us as I had mentioned, and she's a very active carer for my family, as well as for Kivanc.

- Oh, it's so great to have extended family involved. Isn't it? That's such a blessing. And we are here today to talk about the journey that you've been on with Kivanc. And did you ever have any family or personal history of people with hearing loss before he was born?

- Actually, we were unaware that there was anyone in the family that had congenital hearing loss. So, we had gone through the whole family planning process I'm that person who likes to plan and organise and be very informed of everything that I do. So, I was going through that process and of course as you know that process is based on your knowledge of your family history. So we asked family and they said, "No, there's nothing. , we know this person who doesn't speak very well. Who lives in a remote place overseas because all of our extended families overseas. So, we built this picture and after, Kivanc was born, we found out that there was congenital hearing loss in the family and so when we retraced it we realised the whole family hadn't any idea that this was actually something that existed. So we didn't know.

- Sure. So, coming to this then, I guess as people who didn't know anything about hearing loss, what advice and support did you receive when Kivanc was diagnosed with hearing loss?

- Yeah, so that whole journey is a bit of a blur, but then you have moments of this real focus. It's a very confusing experience at first because you never really expect when you get a diagnosis that you are going to hear, "Oh, your child has hearing loss or is a deaf baby." So, you first have this moment of it's sort of like a huge sense at that time of this loss or grief. And then you put on this what I call a conveyor belt of all negative. I see all these people and this is your community and your world has changed. And so we took some time to really understand who these people were and how they were going to help us and you just kind of go through this conveyor belt of support. So we were connected into the Deafness Centre at Westmead kids. We were part of a whole programme and connected into the ENT at Westmead and their registrars. We had a lot of counselling and support and we had to undergo a lot of baseline testing, counsellors, as I said, connecting to here in Australia and specialised paediatricians. So your journey begins into let's do some more checks. Let's get you all the supports you need. And so that was quite a initially an overwhelming experience because you're trying to navigate this whole new language all these new conversations and you are really just there with an eight week old baby trying to understand what this new world means.

- Yeah.

- So, we found that while we were trying to come to terms with what all this new world meant and what it looked like, , the people that we were connected to were very caring, very specialised incredibly experienced, very compassionate. And , everybody knew what you were going through and helping you navigate that experience. So, it was like you had everything that you really needed in the beginning to get that process started.

- Okay. And that's, that's great. That's good to hear. And you made the decision to choose listening and spoken language for Kivanc. Can you tell us a little bit about what that journey's been like?

- So in choosing the listening and spoken language programme how we ended up at Next Sense was that back with when we went into early intervention. We had no view on what we wanted except that he could be able to hear, listen and and speak like any other child and I think what was really difficult was that he had such a significant hearing loss that he was almost non-verbal and his input wasn't that great. So, , he wasn't responding as well to the therapy and it got to a point where he was relying on a lot of gestures, homemade gestures between he and I and the family and at one point through that early intervention process, I was hoping to see if I could introduce maybe Auslan at one point. And I felt like if he was leaning towards that maybe if he could have a little bit of that, that would get him to a point once he then connected over into being able to listen and speak. That would become the dominant language. And then I guess the goal from our therapist was to through that programme, the goal is to try and get to that end game, which is to be able to speak. and that would be the preferred language. And, , I was quite conflicted, our family we felt a bit conflicted about that because you really want to be able to give them what they need and that to say, "Can we use that as a stepping stone?" And, so I think at some point, I felt like well, we're not really getting there and he didn't have a reliable form of communication to be able to do that. So, there was a period of me asking, "Can we consider using a different form of language, auslan or sign language?" So, in reflection though, I think that if we had done that for Kivanc, I think that would've become the dominant form of communication and I don't think we would've gone down the route of ending up at the

Next Sense listening and spoken language programme and I don't think we would've ended up with a cochlear implant, which has now given him that full breadth of language where he can listen and speak and I think we got to that end game that is very hard to trust. It's very hard to know exactly how it's going to work out. So in the end, we got there but it wasn't the easiest process because you really had to trust that you were you were going to get there.

- Yeah. I'm curious. There's so much, I want to unpack in your story. So, he didn't get implants until later.

- Until he was eight.

- Wow. So people were doing listening and spoken language with him with not optimal access to all of the speech sounds

- Exactly. So he was severe to profound in one ear, which was the ear he eventually got an implant and his leftie was moderate to severe. So, it was quite significant. So in reflection, I would say, I felt as though he had a lot of years that he was without optimum input and not enough communication. And so, I guess he's in the mode of catching up but I also that if we potentially, I mean you can never know, but I also think that if we had, like I said, relied on sign language then we may have said, "You know what, he's happy with that." And never pushed it further than that. So I think that's ideally what, that was the goal for him is to it will take a bit longer, it was more of a I think even his doctors had said let's just see how he is going to respond and take our time because we want to be conservative about that in making that choice. And some children depends on what their loss is. It's very hard to make that call as a team with this care team, what's the best thing to do. And at the same time, I think a little was quite scared of the cochlear implant. As a family we thought this that's one thing that we're afraid of has to get to that because I think as a family, you somehow still hope that there's a chance that something can be done and I think a part of that is accepting and letting go that that is something that won't be a possibility and a part of that is the healing that you need, to make the best choices. And I think a part of that letting go was really important for our family to say, " You know what, he has a solution, there is treatment. And the best thing that could come out of that is that he's going to get more language and access to sound." And it's really changed his life and our life as a family. So then that way, he's is now he's speaking like any other child and he's cochlear is his dominant ear and, , his getting 95% full hearing and input from his cochlear. And, , he's really immersed into the hearing world now, which is what we wanted.

- Absolutely. That must have been tricky though at the beginning and I think all of your instincts are correct. You want a way to communicate with your child and to hear the good stuff as well as the bad stuff.

- Yes, exactly.

- That must have been really tricky. Do you feel like the advice you were given was unbiased and helpful and supported the choices that you were making as a family?

- You do feel that you sometimes, in that moment feel like the advice can be biassed and it doesn't mean that it is, or it isn't. But at that time I felt that it was maybe not the right decision for my child but the right decision for all children. And, , I, that's why there was a bit of that push in pull. And even when we were choosing should we go from a community school? , and that was something that I didn't talk to much but this was really, really important really key is that a part of Kivanc going to school, a big part of my value system and our value system as a family was that he needed to be in a community school and he had a right to go to school like any other child into a community school. And when we tried that for the first year with very little language, I mean, he was almost nonverbal, it was very, very stressful for him. And so when I was consulting I had advice and then I was connected into other organisations that was supporting children like Kivanc, the advice I was getting was he needs to be in the community school. That's his right. And so you are in consistently in the bias of other people of what you should be doing and that your child represents every other child. And that is true to a degree, but ultimately at the end of the day, when I was looking at that community school that was completely unprepared for a child like my son with all the needs that he needed and even just as far as how much compassion and understanding was available and how much time and specialised care that could be provided you just at the end of the day have to do what's right for your child. And when we were transitioning to Next Sense to that programme, I mean, it was just really clear. It was how much care into trying to understand his environment, how he was learning in that original school, what his needs were, what needs were not being met and understanding us as a family to help transition and speak to other parents and gain a lot of trust and understanding with the school to be a partner with the parent. And that was ultimately what was missing from the community school. So I realised that I was being told all these different opinions along the way but what really needed, what was really important was for me to get all that information and just try to take away the bias and just try to ultimately make the right decision for my own child. And I think that's the hard part as a parent because you are a parent, you are a carer, you can be sometimes the audiologist, you can be all the have these different hats, but you are really the advocate and you really have to trust yourself and believe that you have the right instincts. So at that point, it was like a leap of faith, and together as a family we just said that "Everyone's pushing their own agenda in a way." and you really have to take a step back and say, "Well , what's the right thing to do for him."

- Absolutely. And that's an incredibly brave decision, I'm, sure when you are surrounded by everyone who's got an opinion. And I think you've actually probably just targeted what I was really wanting to from you was the advice that you would give to other families that trust, , what's best for your family and take all the advice, but then find a fit. Do you, do you have other sort of advice that you would give families when they're thinking about how they're going to pre school, playgroups, school for their child? What advice have you got for families who have just coming into this world?

- So as a parent, I think that you always feel that you want to do the right thing but you don't know enough. You always feel that you are always playing catch up and that you to take the advice of everybody else to do the right thing by your child. but, I think you have to feel prepared to to challenge others. And if people aren't comfortable with you challenging them as a parent, it's not about how much you know versus what they know but it's about taking all the information and then just filtering and saying, well, I will take that and I won't take that, but also be prepared to be challenged. I think there are times when I was a little bit too fearful of making a choice that was going to have such a major impact and then taking those leap of faith that, , I described earlier with coming into Next Sense. That was where I felt really, really challenged to as a parent to say, what do I think, do I trust myself? And that's when you have to really wear your parent cap and say, "I've, I've taken all this information. I'm going to make a decision and I'm making the best decision that I can at this point in time." And to trust your instincts. And at the end of the day, you may make a decision now but there's no reason why that can't be adjusted or changed. So you just make the best decision that you can in that point of time and just be kind to yourself.

- I think that's such good advice. And I think that's what good family centred intervention is about. Here's the information we'll support you as you make the decision but ultimately you are the experts in your child. You are going to be with him on his entire life journey and so the decisions you make affect your family forever. And so I love that you have the strength to be able to make these decision and recognise that it can be fluid and flexible and all of those things but you'll do it as a family unit. I think Kivanc is incredibly lucky to have such a strong family around him supporting him with all of this as well. So thank you. I really appreciate you sharing. Did you have anything else about your story that you wanted to share with us, a sort of final message for families?

- Yeah, actually one thing that I think is really important that, , I am constantly seeking and I think that other parents I'm sure are in the same boat, , any kind of child needs that learning and hearing in that, immersing in that hearing world and really connecting and learning is not just about the school that your child attends but the connections they make in your community and I have a real passion for our children connecting into their community. And it's not that always that easy because children come from all over for the schools whether access is available for that specialised support. So, just early on, I would say think about: What does your child's community look like? Extracurricular activities are a real challenge for for children with hearing loss, children who have those other accommodations that are necessary and just think about how that's another piece of education that I think that now we are working on and just try to be prepared and look for that early on for those opportunities.

- Absolutely. Look, such great advice and look I'm so grateful for your time sis and thank you so much for being so honest and sharing this story. I'm really grateful.

- Thank you for having us. Thanks Trudy.

- It's a pleasure. Thank you everybody and we will have another episode coming soon. Thanks for being with us today. and we will see you all next time.