**Parent Perspective: Kari Harbath Part 2 Descriptive Transcript**

**[Visual Description]** A baby who is deafblind sits on a cushion and smiles. She has a tracheostomy tube.

**[On-Screen Text]** Parent Perspective: Kari Harbath
Sloan’s Mom
Early Days With Early Intervention

**Kari Harbath:** Yeah, you know I think the biggest thing, it all goes back to like many times, and I know this isn't always the case, but with deafblind, um, babies in general, there can be medical complexities associated with their diagnoses. And so, Sloan had a long list, so we were at the hospital every other day. I mean, there was a while where I had like a planner going and we were down at the hospital three times a week, and we had a routine of like the coffee shop we would hit, the appointments, the lunch spot we would hit, and then we would go home because we were there so often.

And so, during that time, what was hard is that we were continuing, I mean the diagnoses and the reports, and the, even just the medical opinions on Sloan don't end when you're in the NICU, like when you leave the NICU.

And so, we were continuing to receive um, you know thoughts on what Sloan's quality of life might look like, or what her future might look like, because it was all so dark and heavy, and it felt like we went from what we thought, we were going to be sweet new parents with a sweet baby.

We went from that to like full-time doctors and a child that we weren't sure was going to make it to the next day. And we were up all-night listening to the Stats monitor alarms go off, making sure her oxygen levels were okay. You know, we weren't doing the typical stuff at home that most parents are doing, like she wasn't crying because she was hungry. She was crying because she was in pain over the latest you know, like thing, we had to change, the latest tube or whatever.

And my husband and I, you know we, were giant children in a way, and so, like Disney adults, Harry Potter adults. And so, for us, you know, I mean, we were, I think, really good at all of the medical stuff. But there was a part of us that just wanted to relax, and just wanted to say, like, oh, wow! We love this is fun, like, and we can't wait for the day that we get to go to Disneyland and take her there. But we didn't know what that would look like for Sloan. Or we can't wait for the day that we get to go to the park, but we didn't know what a park looked like for Sloan.

And so, we were living so intensely in this just really exhausting mode, and then the future was so tenuous and like, unsure that we just, we were lost, and we weren't, there was no relaxing, and it was exhausting.

So yeah, it was a, it was a hard, stressful time.

And my husband and I, we’re kind of private people. We liked our space and our quiet, and suddenly our house is like a rotating door. I mean, it was like every day we had an appointment. Somebody came in, but the best part was quickly, we learned they loved us, and they loved Sloan. No matter the state of our house, no matter the state of Sloan, the state of us. I mean, I remember my mom giving me a hard time, because, like I was wearing mismatched socks almost every day, and she would bring me a pair of socks, and be like Kari just wear matched socks for one of these appointments.

I was like, I don't care about the socks, mom, like we've got to figure out Sloan and so that just speaks volumes so like these people were coming in the house, and quickly things became very comfortable.

And so, we had, so, physical therapy, occupational therapy, speech therapy. We had a deafblind specialist, which was Sundie. Um I can't ever think of the appropriate term, but like a visual specialist, vision specialist, Margaret. We had um like city physical therapist, Barbara. Then we had, we had homecare and like city support. So, we had both going at the same time, and then we had vision, and then we had a deaf specialist for a while, and then we decided to take that away because we were doing a lot.

And in terms of signs, Sundie could help us with it all because she was our deafblind specialist. And so yeah, so we had an appointment at least once a day for a long time, if not more.

And it was amazing. And when the like, the first moment that I can remember where we went from, just that tension and the tension sort of released was actually Margaret, our vision specialist, came over. And when Sloan was first born, we thought maybe she had some usable vision. She's had some additional diagnoses since then, and she's now like profoundly blind. But she did have, she showed some signs at first that she was seeing a few things, and so we were testing that with some red visuals, some bright Mylar paper, or different things. And so, Margaret was coming over, and we were practicing that, and she had noticed that my husband and I had pictures of us at Disneyland up in the house. She noticed we had, like Disney things around, Harry Potter things. And so, she stopped, and she said one day, like, you know, that Sloan will get to go to Disneyland, right? And she was talking to us about like how Sloan would get to go to Disneyland. She said something to the effect of like, we’ll get her a big Mickey, and she'll feel Mickey, and learn who Mickey is, and then we'll go to Disney, and she'll be able to feel the Mickey character and know she's at Disney that way.

And then she started talking about very, like realistic, ways that Sloan could enjoy Disney. And now, again, fast forwarding to today. I know how Sloan could enjoy Disney, it's so clear. But at the time it seemed so far-fetched.

And that was, that seems like such a small thing for most people like, oh, yeah, well, of course your daughter would enjoy Disney, but for my husband, Aaron, and I at the time it was so meaningful. Poor Margaret said this to us, and it became, it was less a therapy session for Sloan and more for us.

And immediately my husband and Aaron, my husband, Aaron, and I just started sobbing with Margaret, and we're like nobody has said the word Disney about, you know, around Sloan since she was born.

And Margaret started to use the word fun like, oh, my gosh! This is so fun! Look, this is so fun! Around Sloan like she was pointing like Sloan’s engaging with this, it’s so cool and fun.

And Aaron and I were just crying the whole time because we're like nobody has used the word fun. Like everything has been hard or scary or death, or like hard outlooks. And suddenly it was like the sun started to come out, and something was kind of fun and kind of bright and kind of okay. And slowly, as specialists started coming through, every specialist had something to offer like that.

Where they would come in and make a fun moment for us, and it was not just for Sloan. I mean, obviously, Sloan needs that and needs that growth and development. But it was also for us, because we're the ones day in and day out who are providing her those opportunities. And so we were, we had the support from the therapists and the interventionists and the experts saying, hey, look! This is fun. Do these things. And then we were like, okay, Sloan, we'll do these things while those people are gone.

And suddenly she was developing and growing and engaging, and it was transformative.

**[Visual Description]** A baby who is deafblind sits on a cushion and smiles. She has a tracheostomy tube.

**[On Screen text]**
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