**Parent Perspective: Kari Harbath Part 1 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
Learning the Diagnosis

**Kari Harbath:** So, she was born at thirty-seven weeks through an emergency Cesarean, and then she was life flighted from our local hospital to our statewide Children's Hospital, primary children’s, and while she was there, we knew when she was born that there were going to be some complications at her birth, but we didn't know the extent to which things were going to happen.

So, we weren't really adequately prepared for um like the diagnosis we were going to receive, and what we were going to, ah, what our future looked like. So, she was in the NICU for three months, and in those three months she, her biggest issues were like airway complexities. Lots of medical complexities were going on with Sloan at the time, and we really weren't even sure she was going to survive.

So when you picture like, you know, we just enter parenthood, brand new parents, in our mind we pictured like we'd have the matching robes and take the picture right, and then you end up on Instagram, and everything's cute, and then you go home and you lose some sleep, and five years later they're in school, and you're back at work, and life is typical, just like everybody else.

I think that's what we pictured, but we found ourselves at the NICU, and we were there all day long, every day, and Sloan was intubated for the first two weeks. We couldn't hold her. She was, I mean, just so high-risk.

She, if she just moved wrong, she would extubate herself. She was so hard to intubate, and they were really afraid of her passing in those early two weeks.

In those two weeks, you know, she was covered in bilirubin lights. Um! She had all kinds of medical hookups. I mean really to put it bluntly, she felt like a little alien, and we couldn't hold her. We couldn't touch her, and so it really felt like this person came out of me, and suddenly was just on this, this table, and like wasn't a human to us.

And then in those two weeks doctors started to come through and diagnose her with other lifelong disabilities, and she has a list of other disabilities. But in those diagnoses the audiologists came by, and did you know the audiology tests, and they came back and showed that she was profoundly deaf, and we received that diagnosis. I was like a week and a half into her after her birth.

And then, the day, the next day, and we expected she may have some hearing related issues, because she has a cleft palate and a cleft lip. And so, you know, sometimes like those go hand in hand. So, we were prepared for that, we're like, okay, we can handle that, we've thought about this.

Then the next day the ophthalmologist came through, and we weren’t expecting this at all, and he checked her eyes.

And the audiologist was very kind, had a great bedside manner, and this is like an experience that I think sometimes you know, parents don't talk often about, but the ophthalmologist was totally different. Um, probably just, this was a typical day for him at the NICU, came through checked Sloan’s eyes, and we were standing there and looked up at us, and just said she's blind, probably won't see more than shadows, if she sees shadows, will be blind for life, there's no treatment, and walked away.

And this was the first time my husband and I were hearing of that, so we knew she was profoundly deaf. And then suddenly we were hit with the fact that she was also completely blind.

And then the picture of like, you're standing there, and you're looking at what feels like this alien life force that was supposed to be this cute, squishy baby that you've seen in movies, right where you're holding them and feeding them. And they're making cute little sounds, and you know, and it was just a totally different experience than we expected in those early days, and it was really hard and traumatic, and um, and it held a lot of emotional weight for us, and when we were told about the blindness, you know, just to speak to the emotional experience of it like I was in shock, and I, I think I couldn't quite process what he had just said. And my husband basically just I mean to us like at the time we didn't know anything about deafblindness, right?

It's hard for me to talk about now, because I know who Sloan is now, and she's a wild human, and she's living her best life better than I am somedays.

And so it's hard for me to talk about now. But when I look back at myself at the time, my husband and I, all we could think of was sort of this dark, quiet, petulant world, because in a lot of ways I think society had created this image for us, and that's how we viewed being deafblind from our sort of ableist, you know non deafblind perspective. And so, my husband, you know, in a state of shock sort of collapsed to the ground, and just started sobbing, and we were sitting there by her bedside, and we decided to get up, and we left and because we didn't want to draw attention anywhere in a room with like six other babies who were all facing their own journeys, so we didn't want to draw attention to us, or cause the other parents to, you know, cause a scene, and so we left, and we went home and called my parents. My parents came over, and we all sat and cried for a while, and, and then basically, my mom said, which might make me tear up, but my mom said, we're gonna stick with Sloan, and we're gonna do this, no matter what. And she said, you can cry, but we're going back to the NICU and we're gonna hold her hand, and we're gonna stick by her side. Um, you know, and do what it takes.

So we did. We went back to the NICU that evening, after we received the diagnosis, we sat by her little alien baby side, still kind of like a little alien at the time, and it was, and it was, it was really really hard. I mean, it's an experience I look back on, and at the time like, you know, and I’m still recovering from a really traumatic delivery. I was in a wheelchair. I was super swollen. I had been to the ER twice on my own, and then Sloan was barely surviving. They didn't know she was going to make it, and if she did make it her life, we weren't sure what it looked like. She's deafblind, she also has other disabilities. We were told she would, you know, in a lot of ways, from a medical perspective, we haven’t met with early interventionists, yet we haven’t heard from physical therapists, yet we haven’t heard from that side of the world, yet. So from the medical lens, Sloan's life and medical capacity is very limited. There's really, she won't see, that's the medical fact. She won't hear, that’s the medical report. And that's what they're there to deliver, and they leave.

And so for us there was so much more that we didn't know, and we didn't have access to at the time that was so heavy and emotionally charged.

And so, then, as the weeks went on, my mom, this kind of leads into like a connection to early intervention. My mom actually knew um someone, Bess Denison, she's an early interventionist based out of Utah, and she's been involved in the deafblind community for years and years, and my mom called her like the day after we found out about Sloan's deafblind diagnosis, and asked if they could meet at a McDonald’s and talk about what we do.

Um! So Sloan’s still in the NICU she's receiving just endless treatment right, and people are poking and prodding her. She can't see. She can't hear. She's covered in things, IVs, I mean, just think about from, like a medical trauma perspective, being in Sloan’s shoes as a baby. I mean what a way to enter the world! Um, and then, as parents, we are exhausted, we're tired. We're emotionally overwhelmed. This is not, you know, I don't as new parents, often I think you're not prepared, fully prepared, for the contract you're signing before you go into the contract of parenthood. and we didn't. We just didn't know what was ahead for us. Um, and so it was a really hard time. Um, but my mom met with Bess who's an early interventionist and Bess at the time basically, said, all you need to do right now is just show up and love on Sloan as much as you can, give her positive touch, positive reinforcement, hold her, snuggle her, and then Bess had a few other ideas. One was before any cares or treatment Sloan was receiving because she was receiving so much medical care and treatment to, you know, touch her head, have doctors touch her head, nurses touch her head. Touch her before performing any painful procedures, to let her know they're there.

Um, and then we started practicing just small gestures or signs, while she’s at the NICU to let her know, hey, it's mom or hey, it’s dad, or it's grandma or grandpa because we were there all the time.

And so, as time went on, and this actually became a really amazing thing for us and for Sloan, and we think that it's been a big contributor to Sloan’s success.

But Sloan had a primary NICU nurse, Sam, who was right on board with this like instruction from Bess, the deafblind early interventionist, and she made, and I have pictures of it, but she made a list of instructions for doctors and nurses to follow whenever they interacted with Sloan. So they would walk up to Sloan’s bedside, and they would stroke her forehead or touch her forehead before they performed any cares, or, like, you know, checkups of any kind.

And then, when they performed cares which in the NICU were, like, you know, checking her heart rate, or changing a diaper. They performed them in the same order every time, so Sloan would learn what she could expect was going to happen, because she obviously can’t see or hear what's coming next.

And so these routines were established, while in the NICU and Sloan over time became a very fearless, trusting little human.

And even in the NICU I mean, it was amazing, you know, just the signs she showed already of being willing to let people touch her. She engaged with people, and it really, I think, all started with this like transition into early intervention just weeks after her birth.

**[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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The contents of this video program were developed under a grant from the U.S. Department of Education, #H326T230030. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Susan Weigert.
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