Moving from "either/or" to "and" in EI: Families share

By Bettie T. Petersen Shared at the EHDI Conference on 3/6/23

Communication with their child and extended family

Jasmine shared that many deaf people expressed their frustrations growing up oral and then learning a signed language later in life. These people wished that ASL had been part of their lives all along. They also were sad that their families were no longer able to communicate with them. "That really impacted us that we didn't want to lose that connection with our kids." However, since they don't anticipate that their extended families will be able/willing to learn ASL, they wanted their kids to have hearing aids and CIs to be able to communicate with the hearing world as well.

Benefits of bilingualism

Danielle said, "As soon as we found out that he was deaf, immediately, [we were] trying to learn as much sign language as we could." Their goal was to sign with Len early so that if they did get CIs, they could use the signs as a "bridge to helping him understand the sounds and to hopefully start speaking."

Jasmine said that a bilingual approach provides "a good language foundation from ASL, but also English because that's what they need in this world, and the ability to read and write makes a huge difference in opportunities and potential."

Matthew: We had decided on pursuing a bi-bi educational course, to get CIs, but also to strongly pursue ASL and learn it as a family. ... I knew that ASL was going to be a part of what we were going to pursue, and the CIs were basically hedging our bets because we had no clue as to what deaf education was like in our area. ... So, we did both.

Identity

Jason said, "the ability to communicate ourselves and develop her own identity. ... Communication is just everything. You don't have the language and the vocabulary; you can't develop an identity."

Jason explains that it's related to developing Theory of Mind¹. "How we relate to other people and all these things. I mean, it's part and parcel to humanity."

As Len's personality began to develop, Danielle realized that "even if he couldn't be implanted, he was going to be happy. And that's, I mean, that's all that matters. ...I want Len to be seen as Len – who happens to be deaf. ... He's who he's meant to be."

Danielle: My mission is making sure that my son is a part of that [culture] because his deafness is who he is and he's always going to be. And that's a big reason why we sign, too.

¹ Jason explains that he was most impacted by an article by Kordus (n.d.) that he found on Reddit. Kordus explains Theory of Mind as an understanding that other peoples' thoughts are different from your own. The link to the article can be found in the references.

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Choices

She (Phil's wife) knew they would probably do the CIs but also "wanted him to learn sign as well because we were making a decision for him that he wasn't able to make, and I struggled with that personally."

Phil: there was no reason for that. ... You can be both. ... I'd rather him be bilingual. ... We want to put him into the position where he has the background and the know how to ...have that kind of flexibility in life. ... It's just another language.

Jasmine: If something is not working, it gives us permission to change or if one of them wants to do it one way and the other wants to do a different way. That's totally fine. ... As long as they get what they need and they're happy.

Jasmine: ... there's two different ways. Go straight ASL and that's all – just visual. Or you're cochlear implant oral. That's your life. Since then, we've been able to meet a lot of deaf people with a variety of experiences. ... So, now we see a greater variety of different options and different lifestyles. We've just been able to reach out to the Deaf community and see a lot of different ways of doing it. ... When we had all our discussions about – should we do ASL or English? We thought, we need both for everything that we wanted.

Jasmine emphasizes that she "would love for them to be bilingual bicultural in both ASL and English. ...After that...be able to get a job. Go to college if they want or trade school if they want and find their own path."

Belonging

Danielle: "I just want to make sure [that] I'm always sensitive to the culture and just kind of making sure that we expose Len to that and make sure that he feels included in that community."

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Barriers in EI – a few examples

Jason: you kind of get wrapped up in developing verbal language and devoting your time to that. And getting to know speech therapy and the early intervention. They're all giving you these concrete things to do and you're not getting any concrete things to do with ASL. You're getting all this energy from everybody around focused on verbal language.

Matthew: "We heard from the research to learn sign language. We heard from the Deaf community to learn sign language. And then we went to the hearing educators, and they wanted to do literally anything but ASL."

Matthew expressed appreciation for their audiologist who supported the family by suggesting resources for ASL support as well as any listening supports, they might be interested in. Matthew felt like he got more support and options than other parents he had talked to in his area.

The early intervention program they were participating in did not offer any kind of ASL support according to Matthew. They were told to try contacting the school for the Deaf. Matthew reports that as they were leaving their "first IFSP meeting with the [school] district, we were approached by the woman who was the coordinator for deaf education for [our] school district" and the coordinator asked them (Oliver's parents) for "any recommendations where she could take [an ASL] class."

Danielle recognized how fortunate they were to have an SLP who is fluent in ASL and aware of the needs of deaf children, because she knows that most are not. After a time, the SLP had to stop seeing the family because her job at the school demanded more of her time.

Matthew said that SLP "was always, I would say, dismissive of ASL and she was always kind of discouraging about it." She "kind of played up her experience in the Deaf community" events when she was younger and then would say "derogatory things about deaf adults like, 'Oh. You know, their English skills are never good' and 'Oh, you know, they're never going to get you." Matthew said his wife stopped going to see the SLP because what she was saying was "too insulting. It's just too awful." When they told the SLP they planned to attend the state school for the Deaf, the SLP told them that Oliver would not get a good education there.

Kordus, M. N. (n.d.). The impact of language deprivation on the overall development of deaf and hard of hearing children. Retrieved on September 30, 2022, from <u>https://www.healthymindsconsulting.com/language-</u> <u>deprivation/?utm_source=HMC+Newsletter+Feb+2019+-</u> +FINAL&utm_campaign=HMC+Newsletter+Feb+2019&utm_medium=email&fbclid=IwA R14QlbELsoDhQ7FkV6i1dBpKxezJOtTEZ1xyBGPhThcwlCf0ZA7so771dk

Petersen, B. T. (2022). *How Hearing Parents with Deaf or Hard of Hearing Children Construct Deafness Through Their Early Intervention Experience* (Doctoral dissertation, The University of New Mexico). <u>https://digitalrepository.unm.edu/educ_llss_etds/138/</u>