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EHDI - PARIS

PARENTS' PERSPECTIVES ON ADOPTION OF CHILDREN WITH HEARING LOSS

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>> ELAINE SMOLEN: Good afternoon! Thank you for sticking with us.

My name is Elaine Smolen and this is my colleague, Maria Hartman. We are from Teachers College Columbia University in New York and along with our colleague, Elizabeth Rosenzweig, who is not here today, we have been doing research in the attitudes and experiences of parents who have adopted children with hearing loss. We're excited to share some of that research with you today.

So we kind of set out to do this, and the first thing when you do any kind of research project is just to kind of get some background into adoption in general and then we wanted to look at adoption of children with hearing loss.

So we know in 2016, which is kind of the last year that full data was available, about 5,000 children were adopted into the U.S. from international locations, from home countries that were not the U.S., and then a great deal more, about 53,000 were adopted domestically from the foster system.

So we know that right now a lot more kids are being adopted domestically and we know that most of the international adoptions from top‑sending countries like China are classified as special needs for ‑‑ due to some disability that the child has.

So that's really a trend that we're seeing. And we can see that over time there's been a boom and bust cycle in adoptions.

Private adoptions have risen and fallen. International has kind of rose, but now everything is kind of tapering off. There are many reasons for that. Sometimes there are better conditions in the home countries we're seeing or changes in laws in those home countries where many more children are being adopted within their home countries. We're also seeing some different kinds of children who are being adopted here, including those with hearing loss.

Sending countries also have kind of changed over time. So before the '80s, many children were adopted from South Korea, and then kind of changed to the USSR and then saw a lot of children from China. But overall most international adoptions are kind of tapering off now. There are many children who are being adopted internationally. So we were curious about the experiences of parents who have adopted children from other countries, as well as parents who have adopted children from the foster system here or kinship adoptions.

So we wanted to look at the literature. We wanted to see what had been written about previously concerning children with hearing loss who were adopted. So we looked at the literature and there has been some research about families who have adopted children with special needs in general.

So overall the research has shown that adoption has had a positive impact on the family. Families with children with special needs have been satisfied with the social work and other services that they were provided.

There were some behavioral issues noted and those were things that came up in our research as well. Which generally increased with the age at the time of adoption.

There also was some research that we saw about parents' attitude towards disability in general in trans‑racial adoptions or parents' experiences adopting children with specific conditions like HIV or oral‑facial clefts. But there were no previous studies we saw on experiences of parents who have adopted children with hearing loss specifically. So we did kind of an exhaustive search. We thought we would find something. We searched deaf, hearing loss, hard of hearing, all variations of the word adopt and found no results. There really has been no published research here. We know we're not revolutionary. We didn't just think of this idea. Professionally we worked with families who adopted children with hearing loss. We know there are vibrant online communities. There's deaf adoption late acquisition groups on Facebook and social media. We had personal interest as well from family members and our own personal interest in adoption so we knew that this ‑‑ that there was interest out there but there just had been no research. So we were excited to start exploring.

So we ‑‑ to start exploring we just kind of wanted to know what kind of common motivations, experiences and challenges and strengths were identified by parents who have adopted children with hearing loss, again, either internationally or domestically. So we were doing a qualitative research study to kind of find out what these experiences were so we could kind of shape our research further after that.

So we sent out an online kind of survey to start off. We posted in many of those social media groups as well as groups for children who are using auditory verbal therapy, for other professionals, signing professionals, signing families, we wanted to get everybody that we could.

Overall, 49 people responded to our survey and provided some quantitative data, which I'll share with you. And then we really were interested in qualitative data. We wanted to talk to people and find out what their experiences were. So we were able to connect with 22 different families. 11 completed video interviews which we did online through Zoom or Skype and 11 completed written interviews.

Everybody who responded was female. These were all mothers. They ranged in age from 25 to over 60 years and adopted children from just recently to 20, 25 years ago. So we had a nice range of experiences there.

Two of them had actually adopted more than one child with hearing loss. And three of the mothers who wrote to us or responded were deaf or hard of hearing themselves. The rest had typical hearing. They kind of had a diverse range of professions. We had stay at home parents, people who worked in business and professors. We were interested to see ‑‑ because we also had this anecdotal experience with friends, that several worked in the field of hearing loss. We had four interpreters, two audiologists and two teachers of the deaf who chose to then adopt children with hearing loss.

So they had some interesting perspectives to share with us.

And this is just a look at the people who responded to our quantitative survey. Most spoke English. Many people were using English and sign. We had kind of a range of education levels of the mothers who responded.

These are the children's age at adoption and the type of hearing loss that they had. So most of the kids were one to three years old when they were adopted. And when they came home. And the type of hearing loss was generally sensorineural. We had a large section that didn't know. That is something we want to probe further too.

Was it something that is unknown or it was not known ‑‑ something that the parents could recall immediately when they were doing the survey and why not.

And then most children had profound hearing loss although there was a range there too.

So those were some interesting kind of quantitative data but we really wanted to know more about their experiences. So Maria is going to talk about the qualitative data collection and what we found.

>> MARIA HARTMAN: Okay. A little bit about our methodology. We took the approach of a semi‑structured interview, which is where you try to elicit from the interviewee their own personal story about the experience. So we tried to create questions and our prompts to be really open ended so that it would invite as much of the person's own personal experience as possible.

That will be a little bit more clear on this next slide.

So these were the 14 topics that we were interested in finding information about. We wanted to elicit from people's experiences what motivated them to adopt and, you know, what was it like to go through the whole process? And what were the surprises and the challenges? And what were the successes and the feelings of joy that came from it?

So the way we tried to elicit this information, according to a qualitative approach was to try not so much to ask W-H questions but try to ask "how" questions or "can you tell me..." type of prompts.

So, for example, instead of saying "What communication decisions did you make for your child?," we said "How did you make communication decisions for your child?"

Which just opened up the avenue for the parent to give us their story.

Another example, instead of saying something like "Is your ethnicity different from your child's?," we said "How has your child's ethnicity influenced your family?"

Or, you know, "What is it like having different ethnicities within your family structure now? Can you share some of that?"

So we tried to really say as little as possible and then let the interviewee really have the stage.

It was hard to say as little as possible because everybody had a really interesting story, but we tried to be true to the methodology.

And then we used the thematic analysis approach. So we had our 11 audio taped interviews as well as our already written interviews with the audio taped interviews, we had them transcribed by a professional company, which I highly recommend if you're doing any kind of research like this, that takes the most time. And then we set about reading and re‑reading and re‑reading again, or what we call in elementary school now "close reading" of all of the transcripts.

And we not only read our own interviewees, because we had divided up the interviewees, we read each other’s, and we read them again and again and again.

And we organized them initially under those 14 topics that we were interested in looking at, but we also looked for sub‑themes within the topics.

So we looked for people's whose responses kind of went together and then we looked for ones within the topic that were very different from each other. So we're going to look at some of those now.

Because of time, we don't ‑‑ we can't go through every bullet on the slide, but we're happy to talk be you after if there's something you're interested in that we didn't cover.

Okay. So to give you an idea of the coding, under our large theme, which was motivation, we wanted to find out, what was the motivation people had to adopt a child with hearing loss?

We found actually three major sub‑groups. And then that fourth, the fourth bullet, one person said that. So the number‑one reason people were interested in adopting was faith‑based reasons. We found that interesting, because on the upper west side of New York City, you're more likely to hear that people adopt because they couldn't conceive within their own family, or for humanitarian purposes. So, oh, there are enough kids in the world. We have a great home, we give a child...

You don't hear a lot of the more faith‑based kinds of responses. So for somebody to say, we were called to adopt, was fascinating to us.

And, in fact, a number of people said that.

So that was something that was really at the top of that list of motivation.

Some other common themes under hearing loss identification and diagnosis, a number of families that we spoke with said that they intended to adopt a child with special needs but they didn't necessarily say what special need that child should have.

So once they identified that they were a match for a child with special needs, then the special need was revealed after they were matched with the child.

So lots of families had no idea why their child was deaf, whether they were prenatally deaf, whether they were postnatally deaf, whether or not there was an illness associated with the deafness. There just weren't those birth records available in some of the sending countries.

So there was lots of variation in terms of, you know, what was it like to find out your child was deaf.

Interestingly, that last bullet, it's labeled "grief" there. The parents said, "I was expecting my child to have a special need and found out then that it was hearing loss, but I didn't go through the grieving process that we typically associate with biological parents who have a child and have an anticipation of what the child is going to be like and find out the child has a special need.

She said, I didn't grieve as is often understood or, you know, we coach parents through that grieving process. She said, I knew what I was getting into. I was just upset that you know, my child came to me at three years old and it was so much time that we had lost in terms of supporting that child's language development.

In terms of technology and communication decisions, something that really struck us was this idea that a number of children came to their families after the early intervention age. So they came to their families at the time that they were going to enroll in school and maybe a preschool program.

So those families had missed the early intervention stage where we do a lot of parent coaching, and it's a lot of one‑on‑one within the home, and all of a sudden those kids came to their new home in the United States and then they were off to school already.

And the moms said they didn't feel as involved in the process as they might have had their child came to them earlier.

And then also the last bullet, Effects of Language exposure access.

So one parent shared that her child had come from a Spanish speaking country and the child was hard of hearing, so did have access to some language and actually used spoken language, but as the child was learning English, they maintained a Spanish accent. So in speech therapy, the SLP was labeling some of the child's misarticulations as speech errors when, in fact, they were due to the child's accent.

So that brought up this concept of English age, which we might not hear a lot in deaf education, but the idea that the child has language but the child has come to English. So for how long has the child been exposed to English.

So English age.

This was interesting too.

So as Elaine said, we had a number of moms who were in our field, right?

They were audiologists, TODs, they were SLPs, and strikingly, they said, well, you know, we knew this field. We knew what this was going to be like, but then once it was their child, they did some re‑thinking.

So in terms of technology and communication, they might have anticipated going down one road but maybe modified their thinking a little bit after they actually had the experience of parenting.

Also that there were lots of professionals in their lives who understood the adoption piece. They were in adoption support groups. They had a social worker usually connected to the agency. And then there were lots of people in their lives related to the hearing loss, but they didn't necessarily have the same knowledge base. So navigating those two areas.

Parents' reactions. This is parents' reactions to having the child with hearing loss as well as other people's reactions to the interviewee having a child with hearing loss.

So for all of these children, hearing loss was one of a number of issues that some of these ‑‑ that these kids had. So some of them came with multiple special needs. Sometimes the parents were expecting a child with, say, cerebral palsy and were prepared for that, and only later on found out that the child also had hearing loss.

So kids had multiple issues. Sometimes there were socio‑emotional issues. And then medical issues.

And there's always the issue ‑‑ I think there was another presentation about this today, that children who are adopted have symptoms of trauma because of the ‑‑ how adults are in and out of their lives at certain points, they're transitioned from one home environment to another. So there are those kinds of symptoms that remain.

So dealing with those.

As you can imagine, all kinds of insensitive reactions, even from people who didn't mean to be insensitive. We'll talk a little about that later.

And just, you know, the sides within our field became intensified when people were navigating those two areas with their child.

Okay. Mothers. I think that after having done this research project I will never again think of this concept of adoption as something that happens to children. Because the mothers were such an enormous part of this process. I think mothers of adopted children should be superheroes. They could be the president of the United States. Because what they manage on so many fronts and with so much strength was incredibly, incredibly impressive.

So we've got to hurry up. So I will close this part by saying that the sense of agency and conviction in all of the mothers that we interviewed was astounding and I participated in this research with some of the doctoral students at Teachers College but became more and more interested in the whole thing as I was going through it. These mothers were also incredibly, incredibly supportive of each other. Even if they lived across the country from each other, because these online support groups are really big.

Limitations. These interviewees came to us. So in that sense they were people who were willing to share their story.

Unfortunately, we didn't get fathers' perspectives. It's just the way it came out. And some of the parents, as Elaine said, had adopted their children numerous years ago, so sometimes we asked a question and they said... "I can't remember that at all. I have no idea."

So we're relying on the way they remember things.

Elaine is going to talk a little bit about implications for the field now.

>> ELAINE SMOLEN: So, as Maria mentioned, a lot of parents talked to us about not knowing that the child had a hearing loss until they came home or until kind of much later after they came home. So one of the implications we think is that a hearing screening and speech and language screening should be retune for all children adopted. If we have newborn hearing screening, if a child is coming home to the U.S. for the first time and they haven't been screened before, that's important to know. You know, what is going on to begin with.

We also heard this theme of lack of sensory input or lack of consistent response care giving. And we think about lack of sensory input part. For children with hearing loss we know they didn't have listening time in‑utero or however long before they got technology but for many of these kids who are adopted there's that kind of lack of consistency of care giving as well and something we as professionals need to learn more about. Maria mentioned the trauma informed care is really something I don't think most of us have a background in but something we really recommend for the field going forward, that we learn about, not just for children adopted but for many other kids as well.

Many of these kids have experienced food insecurity and toxic stress and things like that that we know impact language development just as much or maybe more so than the hearing loss for some of the kids.

We know that attachment leads to language. So for us in the field we're often really focused on that language piece, but if we are not working with family to make sure that the children are securely attached to their parents and the rest of their family members, that language is unlikely to come. So in auditory verbal therapy and in early intervention that uses sign as well, we're really focused on the parent coaching piece but we have to really make sure that we are doing that. We all think ‑‑ you know, we want to do that can, we think we're doing that, but we want to make sure everything in therapy is really to reorient that child toward their parent and to make sure that we're helping them actively explore their environment with the parents, that they're cooperating with parents, that they're building stronger relationships with that parent. You're important to coach, but as the professional, it doesn't matter if the child is actively oriented to you. That is not the most important thing certainly in children with hearing loss who have a background of trauma.

We also kind of explored this idea of hearing age which we think about routinely versus language age versus English age. That may be the same as language age or might be different. That's something again to consider. Versus the chronological age versus a family age. When did those people become a family? Maybe there are other siblings involved too. How is that family growing and changing? All of those things really you can imagine influence language and it's something that many of the parents said that professionals didn't seem to be cognizant of necessarily. Especially, I think, as Maria mentioned, you know, we seem to have our expertise. The parents kind of said in many cases they were trying to bridge that gap. So an SLP would say one thing about language development and say, hey, but remember about the trauma that might child experienced for the first two years. And an adoption social worker would talk about how attachment and say, right, but we're also trying to get that language. The child doesn't have the language to understand everything that I'm trying to do in the home for behavior, other sorts of attachment activities. So all of this was very complex, obviously, but the interesting thing it made us want to explore things further.

All of these things are things we can incorporate, orienting the child to the caregiver, modeling scripts for emotion and self‑regulation. So using language therapy to also think about how you are working with that child for their emotions, for their ‑‑ to integrate sensory smart therapy. All of these have great resources on line that we're happy to share as well. These are whole workshops in themselves. But it's very important for us to start that conversation, I think.

In using adoption positive language as well. We love this from Adopt Connect, taking away that negative language, which is mostly well‑intentioned, but many parents shared with us was frustrating and hard for them to hear the words like "real parent," "natural parent." Let's replace with birth parent. A child is "waiting," not "available." Those are important and not something we necessarily think about if we weren't oriented to this area of the field.

So finally we want to give a plug for Elizabeth. She is starting dissertation research. She is looking at something related to this, early childhood experiences and parenting and language outcomes for children with hearing loss. Both kids adopted and not adopted. This is open to anyone.

If you have a child between ages 3 and 5 or you work with parents, she would love if you send this out. She's trying to get a lot of kids for this study. There's a QR code if you want to scan it later or there's a website there and you can contact Elizabeth at that email address and would love to hear from you about that or our research as well. We have a short article out in the Hearing Journal about this research and we're continuing to do some more analysis of the pages and pages of transcripts that we have and think really more deeply about the implications for the field. We're hoping to have a bigger manuscript out soon.

I think we probably have time for one question. We have three minutes?

All right, so we have time for a couple questions, perhaps, if people have questions or comments.

>> AUDIENCE MEMBER: I have a couple. So, parents went into this looking to adopt a child with hearing loss or it was a mixture of ‑‑ sometimes they knew and sometimes they didn't?

>> ELAINE SMOLEN: Very much a mix. Sometimes that's what they were seeking. Sometimes they knew before the child came home or sometimes several months after they came home. Very different.

>> Or sometimes there was no anticipation that a child would have a special need. They were really surprised to find out their child had a hearing loss.

>> AUDIENCE MEMBER: I think I actually connected with you about the survey on one of the Facebook groups, because I am a mom of a kiddo with hearing loss and also an audiologist. I was just going to say two other things to keep in mind, on the attachment thing, not only redirecting kids back to their parents so they can attach, but checking in with parents, like how are you doing with the attachment? Sometimes people forget to check in with that.

And then also, you know, my son is my son. I happened to come by him through adoption, so being careful about that wording in reports and things. It bugs me when I read "his adoptive mom Betsy." I'm here today with my son who happens to be adopted from China. So some of that positive language.

>> MARIA HARTMAN: Thank you. We need you to keep telling us until we change. Another thing I wanted to add is that we have given this presentation before for a much longer time period. So a lot of the ideas you're talking about around attachment and ways that a professional could interact more fruitfully we have gone over. So we really want to emphasize how important that is.

>> I just wanted to make a comment. I think it's a great idea for hearing to be tested on all adoptees, because unless it's an open adoption, I have a lot of loss to follow‑up, when kids go into the foster care system or into ‑‑ or adopted and we can't contact them to tell them the child needs a referral or has referred.

>> That was amazing that parents often had no information about their child's medical history or about any kinds of physical challenges the child had before coming to their new home.

>> ELAINE SMOLEN: Let's make that happen. I love that.

I think we're out of time.

>> Thank you, everyone!

[Applause]