

Powering Potential Podcast

Episode 6: Just a Kid

Ketty: She tells me that [there are] different [types] of hearing loss, then she says, "Do you have any questions?" And I said, "Yes. Is my daughter going to be deaf?" That was my first question. And she looked at me very startled because I could read on her face, "That's not the first question I want to answer here." And she said, "Well, we don't know the answer, but it is possible she could be completely deaf one day. But we don't know for sure. Because she passed the hearing screening, and this appears as a progressive hearing loss, so there is a chance."

And when she said that, the first thought in my head was about her future, and it was such an absurd question. I thought, "Who is going to invite Nura to prom?" [inaudible], I'm not a vain person, I really am not. I'm not into that kind of like thoughts, especially for a girl—

Dr. Teresa Caraway: But that was the first life event—

Ketty: First thought.

Dr. Caraway: ... that you could think of. Yes.

Ketty: That's the first thought I had. "Oh, who is going to invite Nura to prom? Is someone going to invite my daughter to prom?"

Dr. Caraway: Welcome to *Powering Potential*, a podcast from Hearing First where we explore the unique joys and challenges of raising children who have hearing loss. I'm Dr. Teresa

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Caraway, your host, a mother, and a speech-language pathologist specializing in Listening and Spoken Language. I'm here to share the incredible stories of families who are teaching their children who are deaf or hard of hearing to listen and speak.

When working with families, the first question that I often get from parents is a simple one, "What will life look like for my child?" As a professional, I know that there are developmental milestones and guidelines that help us understand what "normal" looks like, but I'm also a parent. And I know that from the other side, there is no such thing as "normal."

So in this final episode of season one of *Powering Potential*, we're going to explore what "normal" means for some families. What does it mean when our expectations are upended, and we find ourselves on a journey much different from the one we thought we'd be traveling? And what does it take to find beauty on the not-so-typical path— to find joy on the journey that you never thought you'd take?

When Ketty found out that her daughter Nura was deaf, she reacted in a way that's very common for parents who receive this news.

Ketty:

When she said that she could be completely deaf one day, the first thought I had was about her future, and it was such an absurd question. I thought, "Who is going to invite Nura to prom?" And I shook myself inside, I said, "What is this? Is that all you can think about? What's the next step?" And that was my next question, "So what do I do now?"

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- Dr. Caraway: I find it fascinating, Ketty, that your thought went to prom.
- Ketty: Yes.
- Dr. Caraway: Because being invited to prom, what does that mean to you? What would be involved in that, of being asked to go to prom? What's behind all that?
- Ketty: It represented very clearly just one word, one word that I don't like to use a lot because it's so subjective. It represented normalcy. It just represented normalcy. Will my daughter just be... just be a regular human being that can go through life without everything being an exception? So it was just that. Normalcy. Because as much as I want outstanding things for my daughter's future, I think that normalcy is such a balanced element of being in life. It should be part of that big equation. And it was just a reflection of that, I know, that, "Will she just have some normalcy?"
- Dr. Caraway: You wanted her to have all of those typical experiences of growing up...
- Ketty: Yeah.
- Dr. Caraway: ... That every child had opportunity to have.
- Ketty: Absolutely. Absolutely.
- Dr. Caraway: Yeah. And it symbolizes a lot of connections, the friendships, and being accepted and being part of a larger group of peers, of what they're doing at the time. Yeah. Yeah.
- Ketty: Exactly. That's truly it. And as you grow older in life, yes, you have a certain group of friends you might identify or associate yourself based

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on your likes and dislikes and say, "O.K., I belong to this group," and form that kind of identity. But to think that she would be forced, categorized, into only a certain group of friends, only a certain type of experience, that rattled me. It really did. And I feel even more guilty for that because again, here I am thinking, "But I'm the kind of person who is not into prejudice, into differentiating people. I work really hard every day making sure that there's a sense of equality for everyone. Why am I so terrified that that might not be the case for her?" It was a lot of emotions that way.

But of course I think through time I realized it was not about her being different but about her having the right to that normal sense of participating of life, no matter how different you are. And that was the guiding force I think into every decision I made from that day forward.

Dr. Caraway:

For Daily and Phin, whose son Roark has severe to profound hearing loss and needed cochlear implants, they worried that they wouldn't be able to give him a normal life. Their worries actually did move them towards a solution. Worrying gave them the motivation to define what "normal" meant for them and their family. It pushed them to do everything they could to help Roark become integrated into family life and their community at large.

Once they set their sights on the kind of "normal" they wanted to create for Roark, they didn't stop until it became his reality.

So you speak about "normal," you speak about "typical," and what were some of those hopes and dreams that you had for Roark? And then were you questioning anything about what hopes and dreams were for him at that point?

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Phin: For me it's not so much hopes and dreams as much as basic stuff like, "Will he have friends? Like, will we be able to communicate with him?" I'm very close with my parents, and I ... I guess the hope and dream there is that you have a similar relationship, especially I have one with my father, and I always dreamed about having that with my son.

So it wasn't like, "Oh now he can't be a professional athlete." I mean, he was never gonna be a professional athlete, given his family history, but it's more on a much more basic primary level.

Dr. Caraway: It's about the connecting level—

Phin: Yeah.

Dr. Caraway: ... and communication.

For Phin, he defined "normal" as having a close relationship with his son. Giving the word "normal" a specific definition and outcome helped him get there. It helped him let go of all the definitions of "normal" that other parents and society can push on us.

Another way that Phin and Daily decided to define "normal" for Roark was to allow for moments of healthy risk-taking. Trying new activities and pushing boundaries in a safe way are so important for a child's development. It helps them figure out who they are and where they fit into the world. Phin and Daily wanted to have those experiences, too.

Daily: We had heard a podcast from another source about a child who was blind, who grew up blind, but he would ride a bicycle, and he kind of was in a mainstream environment, and he

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used echolocation as his way of seeing. And the mother was talking [on] the podcast about people would say to her, "You're letting your son ride a bicycle? He's blind! He's gonna fall and hurt himself and break a leg," or whatever. And the mom would say, "Look, if he falls when he's riding a bicycle, that's terrible, that's a terrible accident. But if he never learns to ride a bicycle, that's a tragedy." And I think kind of keeping that perspective, like making sure that we immerse him in every experience like every other kid.

Dr. Caraway:

Phin and Daily have a strict "No processors, no play" rule, meaning Roark must wear his hearing technology during all waking hours, especially during playtime. This is not meant to be restrictive but rather to help him develop spoken language and integrate fully into the hearing world. They want him to be immersed in the sounds of life as much as possible since it's so important for developing listening and speaking skills.

Daily:

You know, even if he loses a processor or doesn't capture all of what's being said, the tragedy would be not letting him live a normal life and do all the activities he wants to do, like play ocean, or ride a bike, or travel, or whatever else. So I think that's the thing I keep in mind, which is losing, especially the losing a processor piece. Like that's annoying, but that's not a reason to limit his activity.

Phin:

And at least for me, I just don't think about it as much anymore now. He's just my son. He's not my deaf son, you know? The biggest issue with it now for me is, I read when we were first at the Center for Hearing Communication that for boys, but for boys with hearing loss, rough

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housing with their fathers can give them a sense of self.

Daily: Confidence.

Phin: And confidence. And so Roark and I have always wrestled. And he likes when I pick him up and throw him onto the bed, and the processors come off when that happens. And sometimes I think, "Ugh, why does that have to happen?" I was like, "Oh, if that's my biggest problem, then it's going pretty well."

Dr. Caraway: Yeah, and you said a key thing there. That for you, it seems like life is pretty normal.

Phin: It's what I envisioned it, in that fuzzy way when you can kind of see the outline of your life, but you can't see the specific things about it. It's what I envisioned. I mean, you have to assume there's gonna be a hiccup along the way, but as I think about one being nothing and whatever the worst thing you can imagine is... This is part of our lives still, obviously, and it's something we pay attention to, but it's just part of who he is now, and that's cool.

Dr. Caraway: At the end of the day, a child with hearing loss is just a child— a child who needs the same love and celebration that all children do, a child who grows up too quickly, right before parents' eyes. Cherishing those fleeting moments of tenderness and connection is advice that comes up again and again from parents on the journey.

If you could roll back the clock to give yourself advice, what you know now, what you didn't know then, what advice would you tell yourself?

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Phin: I'd say, just take a breath. It's gonna be O.K. I don't want to say that the doctors have this thing beat, but this is something where if you follow the playbook, your kid's gonna be O.K. So don't let it ruin the time you have with him, because they're only gonna be that age once. I don't want to say I got over it, because that's not a fair thing to say, but I didn't want it to ruin my opportunity to have a relationship with this child, and I never was really interested... And I think a lot of men might not admit this, but it's the truth, I was much more interested when my son was 3 and could throw a ball. And I think that the silver lining in this, if there's any, is that I got much closer to my son much faster, and that's been really awesome.

Dr. Caraway: So, I'm curious. You said that it's a blessing in disguise because you feel like it made you closer to Roark. In what ways? How did it change what you thought you had planned to do with your baby?

Phin: Well, you know, I didn't really have a plan, I would say. It's hard... You're falling into this abyss of parenthood forgetting the hearing loss. And the moms, I find, read all these books, and the dads just kind of sit there, you know, being useless. And someone gave me a book for dads, and you open the book, it said, "This is what you think your baby will look like," it's this clean baby in a diaper, and then the next page is what your baby actually looks like. It's like a shriveled head when it comes out.

I was like, O.K., I can't prepare for this. I'm just going to deal with it when it happens. But when we were told that 85 percent of speech and language is gained in the first three years of a child's life, I just realized how important it would be for both of us, and in a lot of ways for me in

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particular, to be even more involved. It forced me into... to jump into action in a very... and become a grownup at a very accelerated rate.

Dr. Caraway:

As you think of the future for Kevin and Keily, what do you see? What do you envision?

Mercedes:

There is always a fear as a mother, but because always as a mother... but I don't think it's because my kids are deaf or not. It's just as [a] mother, we always have concerns. But I always tell them about when having a dream when you want to approach or what you want to be when you're big... I know they could do anything. Anything they want. I really think that in my heart that whatever it is, the dream they have... But again, it takes time, practice, perseverance. It takes that for everybody.

Dr. Caraway:

Yeah, it does. So it really sounds like today where you are, as you think about Keily and Kevin's future, it is the typical mom things that moms worry about.

Mercedes:

Exactly.

Dr. Caraway:

All moms worry about.

Mercedes:

Exactly.

Dr. Caraway:

But it's wonderful that you're confident that whatever they want to do or decide to do, they can do it, because they have the Listening and Spoken Language skills to be able to navigate life.

Mercedes:

Exactly. Exactly.

Dr. Caraway:

So Matt, you're an educator, and so through your career prior to Fiona [entering] your life,

you had a student cross your path who had cochlear implants.

Matthew:

That's right. And the student was in middle school, so I saw kind of, not the end result, but I saw a student who had progressed through the system, and this student was thriving. She was getting As in every class, she was in a mainstream environment, she participated in all kinds of sports and clubs. And I developed a little relationship with the family once Fiona was diagnosed with hearing loss.

And I told the parents the same thing that I'll say here, which is that student really did provide the both of us with kind of a framework of what could be, and I think it really helped me know that we were on the right path, that here's this student with cochlear implants who is doing extremely well and is on track to be everything that she would want to be. So that was a really great inspiration for us.

Dr. Caraway:

That's terrific. So seeing another child who was further along on the journey gave you lots of hope.

Matthew:

Yes.

Dr. Caraway:

That's awesome.

As parents, we want to give our children as many opportunities as possible. We want to open every door for them, and a diagnosis of hearing loss can feel like there's a lot of doors closing. But that doesn't have to be the case. With the right hearing technology, intervention, and the support of a dedicated family, Listening and Spoken Language allows children with hearing loss to walk through life with the same

opportunities as a child with typical hearing. This is the new normal.

Whether you're a seasoned veteran or just beginning your journey, I want you to know that it's going to be O.K. So many families have felt the same emotions that you have, and walked this path before you. I hope that you found hope, joy, and inspiration in the voices you've heard on *Powering Potential*. I want to extend my deepest gratitude to Phin and Daily, Ketty, Matthew and Sarah, and Mercedes for sharing their experiences with such courage and love.

This podcast is a production of Hearing First, an educational endeavor of the Oberkotter Foundation. Be sure to subscribe now on Apple, Spotify, Google Podcasts, or wherever you listen to hear the latest episodes. You can also find the *Powering Potential* podcast on our website, hearingfirst.org, along with additional resources and information about Listening and Spoken Language. Thanks for listening.