**Parent Perspective: Madeline Cheney Part 1 Descriptive Transcript**

**[Visual Description]** A baby who is deafblind sits on a blanket and looks up toward the camera. He smiles happily.

**[On-Screen Text]**
Parent Perspective: Madeline Cheney
Kimball’s MomAccepting Early Intervention and Becoming Part of the Team

**Madeline Cheney:** As soon as we got home, I think it was like, the next week, we had early intervention, and there was like a developmental specialist. And then we also had the School for the Deaf. We had a PIP provider, so that for his hearing.

Um, and then a physical therapist, and so, and as well as all his medical appointments happening at the hospital, all the follow-ups we had. And I just remember thinking, like I’m just a secretary, now. Like I’m just making all these appointments and bringing him to the hospital, and having the strangers come into my home. And I was pretty resentful. I really didn't like them. I was like, I don't want you here.

I, like, why do I need all these professionals just to help my baby be a baby? Because, like I said, I have an older child, so I know what babyhood like, should be like, or what it normally would be like, you know, with her. And so, the idea that I like, wasn't good enough to just be his mom, but needed all these people to like, help me.

Um, was something, I wasn't like, I wasn't like this gracious, like, Oh, my gosh, I’m so grateful you're here! I was like, I hate that I need you. Like I hate that you’re supposed to be, you have to be here. I hate that you're telling me that I have to go do these different assignments. I don't want to do any of it. I can hurt. I'm like barely surviving, and so a lot of times I wouldn't do what they told me to. They'd be like, oh, you need to like, you know, the different assignments for the physical therapist, lift his legs or whatever it was, and put in his hearing aids every day, and you know the, pretty basic stuff.

But I was like, I am so beyond capacity, just trying to survive right now and then with my older daughter was really struggling, too. I was like, I mean. I can barely even have you in my home, let alone do all the things. And so, it also added a layer of guilt, because I’m a, very much a teacher's pet by nature, and I want to do all the assignments. I get all and get good grades. And I was like, I don't want them to come over, I'm gonna have to tell them I didn’t do any of it, you know. And so that was.

I ended up being really close with them, and they’re like my best friends after a while. I finally accepted them and got to a place, but at first, I hated them.

I think, just feeling seen, like truly seen. Um probably the biggest difference, because just even just contrasting the two where I was like, oh, yeah, they don't really care. And oh, yes, they do care.

Or like okay, like listening to me. So, like if I would be like, oh, you know, with that goal we made last time. I don't think it's a great goal. I didn't do it at all. Is there a way for us to like, shift it so that, like I don't really like this part of it. This feels kind of weird, And then, and then for them to be like, oh, okay, well, would this feel better or that feel better? And kind of working with me to create goals that really worked for me because I could tell they were listening, so the more I could tell they really cared about my feedback on it. I felt more like a partner in his care. It was less of like, you can't take care of your baby. They're behind. I need to come fix them.

It was more of like, where I have this knowledge, this, this clinical knowledge of all the studies I've done, and everything. You are the parent who actually has to instigate these things, and you actually know your child. And how can we work together to like, best help the child?

It all opened the door to become friends with them. And so, when I became friends with them, I actually looked forward to their visits, and I was like, oh, awesome so and so’s coming over. This is going to be so fun cause, like, we didn't chat the whole time we’d chat for like five minutes, so it wasn't like this big, long thing, but it just made it feel more human, and more of like, we have a relationship. Because we are humans. We're not just robots going through the motions to fix our kids. Like we're here to like, to both see how we can best support Kimball, and so, when that relationship's there, I felt more open. I was willing to work with them. I wanted, I wanted to do the goals because I was like, you know, she, we worked on this together, and I can tell her if it's not working, and you know we can modify it.

So, I just feel like um, that also really benefited not only me and my mental health, but also Kimball, because all of a sudden, I was doing things more. I was more interested, and I was like oh, she explained this so well, and I can do it for him.

All that being said about how distressing it often is for parents, um I think, treating our children like you would any other child, it's not like, obviously you're like taking into consideration they can't see or hear. But like, but interacting with them in a way that's joyful like any other child is interacted with or like. oh, my gosh! It's Kimball! I'm so excited to see him! And like, things like that. That is really profound for us, because a lot of people don't treat our kids like that.

A lot of them are like, Oh, my gosh! Look at this disabled child. I'm not sure how to interact. I'm just going to ignore them um, or make like, just these horrible comments to the parents. So, I think, like having some, like for me, like I knew that our providers that we loved, but they were going to treat Kimball like he deserved. Like they were going to be excited to see him, and not just see him as a tragedy, cause, although we're grieving, we don't want any, I mean you wouldn’t want anyone to see your child as a tragedy. You don't want to be seen as a tragedy, and so I think, um, help us.

I think it also helped me, like when they would treat Kimball like that. I was like, Oh, yeah, he is just a kid. He's not like he's an issue we're trying to fix. Because they become so, just there's so much intervention happening, like medically, and with therapies and stuff. So sometimes you can see them as like, oh, here, let's move Kimball here, and there, and let's do the different things. But just seeing him as a child and seeing the provider treat them that way, I think, can help remind us even to treat him that way. But it's also just, it's refreshing, because a lot of people don't treat our kids like that. But if you understand that, you know, like, see the humanity in our child, it can help us see the humanity, and it's just, it just means a lot.

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**[On-Screen Text]** To learn more about Madeline and Kimball Cheney and what it is like being a parent of a medically-complex child, listen and subscribe to “The Rare Life” podcast at therarelifepodcast.com.

**[On Screen text]**
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