

Changing What's Possible - S. 1 Ep. 8 Transcript

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SPEAKERS

Dr. Marie McNeely, Keoke King, Dave Calver

D Dr. Marie McNeely 00:01

Hello and welcome to Changing What's Possible: The Disability Innovation Podcast brought to you by the Cerebral Palsy Alliance Research Foundation. I'm your host, Dr. Marie McNeely, and this season we are excited to bring you remarkable stories of life-changing technology. Today we have with us Keoke King, CEO and Co-founder of Participant Assistive Products and Keoke is going to tell us more about the high-quality wheelchairs and other assistive products they are developing and getting into the hands of underserved communities. In the second half of our episode, today, we are going to hear more from Dave Calver, Chief Clinical Officer and Co-founder of the company, who's going to share stories from some of the first users of their new Cub wheelchair in Mexico. So Keoke, thank you so much for joining us today. How are you?

K Keoke King 00:47

I'm doing fine, Marie, thanks so much for having me on your show.

D Dr. Marie McNeely 00:50

Well, thank you so much for joining us. We'd love to start if we can by having you tell us a little bit more about Participant Assistive Products and your role in the company.

K Keoke King 00:59

Well, thanks, Marie. Years ago, Dave and I were working together for an NGO and like many cool things, there's a road trip involved. And so we're driving and we're talking about all these kids that we know of in different places in Indonesia, and Nicaragua, Ukraine, and just being frustrated that the products that kids need, like really just didn't exist. And we're just kind of wondering, like, who's going to develop these products? Some kids need a tilt wheelchair like Cub. And there's lots of adults that have spinal cord injuries and other things. And it just seemed like the products that were available were not the quality that we really hoped for. So

that began kind of a journey of figuring out like, how can we make a not like a nonprofit, but a real commercial company that has the potential to scale to create these products, and then make them available, which is like a whole nother set of problems about distribution and provision and so on. But yeah, I mean, I think that was there driving along in Dave's truck. That's kind of how the conversation got started.

D Dr. Marie McNeely 01:54

That is phenomenal. So can you tell us a little bit more about your role in the company and what it is specifically that you do?

K Keoke King 02:00

Okay, well, we're three founders. So we have a Co-founder named Yoda. And he's like our Wozniak. He's our genius, mechanical engineer. And then Dave is got a career of work and less resource settings, and has provided wheelchairs to 1000s of people in the countries that I mentioned earlier, and many others. And I guess I'm more like the business and marketing guy. So we're really proud of the progress that we've made so far. And COVID, slowed us and everybody else down. But now we've actually gotten our products into production. And we're getting some nice response from big NGOs, and then also distributors in middle income countries. And that's a big part of our, I guess, business strategy.

D Dr. Marie McNeely 02:37

Absolutely. I think that's phenomenal. And I love that this company started with a road trip conversation. So can you tell us a little bit more about maybe the process? Like how did you go from that initial conversation to starting and having this company?

K Keoke King 02:51

Well, we kind of started with, like, there's a lot of things that we know, from years of working in all these different places, and from actually designing chairs, and from doing manufacturing, and things like that. But we have this kind of beginner's mind approach where we don't want to just assume that we understand. Or we could just go design a wheelchair by ourselves at the computer, but we didn't want to do that. So first, we actually got some animations together of some concepts and put them out on a Facebook group. And just asked people from all over the world, what do you see missing here in terms of features, how do you like the aesthetics and so on, and then created a first prototype. And Dave actually took that to Mexico, and got feedback from several users and therapists there, and then that created kind of a cycle, I guess, of going to the field somewhere, getting some feedback, and then coming back to the drawing board, making another prototype, I think the second trip was to Colombia. And then there was another trip to Colombia later on. Dave and I took the chair to Geneva and got feedback from a lot of NGOs there. And then I took the chair to Ukraine and the Middle East and Turkey, that was kind of like a long trip to get feedback from a lot of different people. But it's hard to do an inclusive

design or kind of like designing with, when we're far away from people all over the world. You can't design everywhere at the same time, so that travel in those product demonstrations and things in the other countries was a big part of how we developed the product.

D

Dr. Marie McNeely 04:12

Absolutely. And can you tell us what are some of the key problems that your company is solving or that your products specifically are solving?

K

Keoke King 04:19

So I think many families that have a person with cerebral palsy in the US or Canada, they're going to have a van, they have a converted van, and so you can get the wheelchair up into there. And it's kind of obvious, we think about India and took toots and smaller vehicles in many other countries. And so it just kind of immediately comes to mind. Oh, this thing it has to fold. We're not talking about a giant chair. So that was a key requirement. And then just more kind of obvious things - it needs to function well on rough terrain. There's a lot of broken pavement here in San Francisco, and certainly that's a global problem worse in many places, and it needs to be really adjustable. So there's a couple of reasons for that: many kids, there's no real solid number, but there's around 9 million kids who need a chair and don't have one. And so the things that we can often prevent with early intervention in more developed countries don't happen. So the presentations that kids have can be pretty complicated so the chair needs to be able to adjust a lot to accommodate all that. And then also to grow with the child, because the kid's gonna grow and the chair needs to grow. The government and whoever the other payers are involved are not excited about buying another chair every two or three years, it needs to be a chair that can grow. I think there's some kids that maybe could be fitted pretty early, three or four years old, and then the chair can grow with them up until maybe their teens even depending on where they are and how big they grow. So those are some of the things that we wanted to achieve with Cub and it seems like we've been able to do that. And then the pleasant surprise is that like in Japan, people have small cars. So then Cub got a market in Japan. And then in Australia, it seems like the culture is very outdoorsy - a word we would use here in California. So there's an interest about oh, Cub has these rough terrain features. And maybe it can serve kids there too. So we love that there's multiple use cases to see with Cub.

D

Dr. Marie McNeely 06:11

Absolutely. And Keoke, you mentioned a little bit about the process, I guess how you guys sort of brainstorm and work through this and just the user feedback aspects. But what does it look like when you were developing this first product? Or what is the process for deciding what products you want to develop next?

K

Keoke King 06:26

Yeah, so the World Health Organization actually helps us a lot here, they've produced a priority assistive products list. And I think there are seven wheelchair products on their transport chairs for elderly people or institutional use, and then several different active wheelchairs. So on one

hand, we want to follow that so that we've got all the products that these experts, you know, they're not just Ivory Tower people in Geneva, but these are experts that are really coming from all corners of the planet, collaborating on what's really needed. So we love that and we want to serve that list. But then we also see that there's other things that people really need, and they raise their voice, and we need to be responsive to the market also.

D

Dr. Marie McNeely 07:04

Definitely, and we touched on just some of these key features of your products that it's foldable, it's able to be used on rough terrain, very adjustable, able to grow with the user. Are there other things that really make your products such as the Cub wheelchair, different from other solutions available for disabled people, or maybe more accessible for people globally?

K

Keoke King 07:23

Yeah, so cost is huge, huge, huge. Just yesterday, I was in a diner with a fellow from Kenya, and we were reflecting on the market, and what are the high priorities in Kenya market, and it's like, well, price, and then price and probably price. And it really kind of goes to like the structure of the market. But it can't be overstated, like how much the price of the products that's offered to whoever the payer is - the government or the family or the insurance company or something like that, that price like creates huge disparities. And when I say the structure of the market, we understand that medical devices are expensive, and maybe unnecessarily expensive, because we have been able to make a chair that we think serves a lot of needs pretty well for a 10th of what the commercial market would price. That's something that we really want to work on. We're not anchoring our price on what Medicare will pay. We're trying to take a totally different approach and make a great quality of product available for a lot of people.

D

Dr. Marie McNeely 08:15

I think that's absolutely phenomenal. It's so important. Like you said, the cost of medical equipment that people need for their everyday lives can be astronomical. So what do you do? Or how do you make these products less expensive? Is there something in terms of the design or the development or the I guess, manufacturing that makes it possible?

K

Keoke King 08:33

For our Co-founder, Yoda, who is not on the call is like a verifiable genius. When I asked him some question about what if we had a wheel lock that was a little bit more this way than that way, he'll immediately go into this Rolodex of oh, well, Invacare developed the chair like this, and it worked this way. And then there was sunrise and on this thing, he's just got it in his head, 1000s and 1000s, of chairs, and parts and so on. So one of the big keys for making things affordable is to keep them really simple. The product is done when nothing else can be taken away, I forget who said that. But in any case, he's very good at simplifying designs and kind of pushing on Dave and I like, let's not make this unnecessarily complicated. Because there's more things to break, it's more cost, there's more things to train the providers on how to adjust

and so on. So I think keeping the design simple was really important. And then we did design for mass production in a big, big factory from the very beginning. We're not trying to go through the normal growth curve where a company would make more expensive products in pretty small batches and then gradually over time, get a lower cost, get economies of scale, we're getting those from the very beginning. And in part that's because we are able to sell to nonprofits and NGOs in large volumes. They already know the founders, they already know that we intend to offer great products. So they're willing to make those purchases right out the gate, which we're very grateful for that.

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Dr. Marie McNeely 09:55

Definitely so can you okay, I guess what are some of the biggest challenges that you've encountered while trying to make these low-cost products to ensure that they're a good fit for the diverse environments and the diverse cultures that they're going to benefit?

K

Keoke King 10:06

Funding has definitely been the biggest challenge. On one hand, you can say there's 9 million kids that need this chair and don't have it. Or you can say there's I heard somebody say 2 billion people with disabilities in the world, 90% are unserved. And so this is a giant market, and entrepreneurs should go after that. Okay, that sounds nice. But then when you actually talk to an investor and say, "Do you want to take a risk on this unproven market?" That can be a tough conversation. So it took us a really long time, and I'm raising money in Silicon Valley, there's like plenty of investors around here. So there was a huge number of pitches. And then eventually, we actually raised the money on WeFunder. So we went to kind of a, you know, like a crowdfund approach. And that worked for us. And I think the next raise that we'll do will be a lot easier. We'll go back to WeFunder again, but we have a lead investor for the next round that we'll do next year. And it seems like now that we have some traction, that that won't be as hard as it was before.

D

Dr. Marie McNeely 10:58

Certainly, and I understand you're already starting to have impacts for users in different countries there. But can you talk a little bit about the impacts that Participant Assistive Products is making or maybe has the potential to make for its users?

K

Keoke King 11:11

Thanks. So that actually goes to the name of the company, the impact that we want to make is increased participation. We're a B Corp, and so like a nonprofit, we'll have a mission statement, our mission statement is to increase the participation of people with disabilities by making high-quality, affordable products available. So when it comes time, the end of the quarter, and the board wants to evaluate the CEO's performance, then they're going to be asking questions like, "Okay, well, how did we do on growth and profit, and so on? And how did we do on increasing participation?" So for the users, this comes to just very simple things, you know, baseline, how much was this child getting out of the house before they received the chair, and

then afterwards? So that's going to be hopefully going to school, and definitely like going out to play with friends. But also, how easy is it for them to get to doctor's appointments, and for their caregiver, often their mother, we see that she's able to take the child with her to go shopping and go to her own doctor's appointment. So those are the kinds of real impacts that we want to see. And certainly there's clinical impacts, kids living longer, better posture, less pain, those are all impacts that we want to make.

D

Dr. Marie McNeely 12:18

Well, it sounds like there's a lot of potential for changing lives with these products there. And you mentioned that a lot of your work is focusing on children in particular, can you tell us why you decided to focus specifically on kids with the products that you're developing?

K

Keoke King 12:31

So there was a gap. I mentioned that list of products that WHO published and you could just look at the list and you say, okay, well, there are some products that fit most of these product descriptions. But there was one in terms of like a transportable chair for often children with cerebral palsy or that need postural support. And it's like, there's no product there. So that was just like, okay, this is probably the most difficult product on the list to make, because it's very complicated. But let's go ahead and do that first. So that's why we chose that.

D

Dr. Marie McNeely 13:00

Wonderful. For our listeners out there who might be interested, where are your products available? And do you have a timeline in mind for expansion to additional countries, perhaps including the United States?

K

Keoke King 13:10

Yeah. So we're submitting for FDA approval soon, that should be done. Maybe March or April next year. It looks like we'll have distributors in Australia soon. Definitely Japan, for all other countries, except the USA, regulatory approval is finished. So in theory, we could ship anywhere. But we are very interested to find distributors, like we're talking to distributors in Portugal and South Africa, Malaysia would be a great place for us to serve. But we don't have a distributor there. So that's one way that listeners can really contribute is point us to people that they know in, especially middle income countries, that could be a therapist, or it could be a distributor, but just kind of help us to get the right introductions, and then we can go through the process of getting the products available in those places.

D

Dr. Marie McNeely 13:53

Fantastic. So if our listeners want to learn more about Participant Assistive Products, or perhaps provide those connections, you mentioned, what is the best way for them to do so?

K

Keoke King 14:02

I would say go to the website. We are participant.life. And then there's the contact us form, easy to find. So yeah, just send us a message that way.

D

Dr. Marie McNeely 14:10

Perfect. Well, listeners, definitely check out the website for Participant Assistive Products, participant.life and get in touch if you have questions. And Keoke, thank you so much for joining us on the show and sharing your insights.

K

Keoke King 14:22

Thank you, Marie. I really enjoyed this.

D

Dr. Marie McNeely 14:24

It's been a pleasure to chat with you and listeners, stay with us. We'll be right back after this short message.

D

Dr. Marie McNeely 14:32

Listeners if you're enjoying what you've heard so far in this episode of Changing What's Possible, then there's another podcast we think you might like. Cerebral Conversations is created by Cerebral Palsy Alliance, an organization that works closely with CPARF. And this podcast is all about candid conversations exploring the biggest issues impacting people living with cerebral palsy and other disabilities. You can learn about early intervention, advocacy, research, inclusion and more from experts and people with lived experience. Listen and subscribe to Cerebral Conversations on your favorite podcast platform and visit cerebralpalsy.org.au to learn more about the Cerebral Palsy Alliance.

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Dr. Marie McNeely 15:12

Welcome back, listeners. I am excited to introduce you all to our second guest at Dave Calver. Listeners. Dave is an occupational therapist, and he's here to share stories from people who are using Participant Assistive Products. And Dave, we'd love to talk to you a little bit more about your side of the story. Thanks so much for joining us today.

D

Dave Calver 15:33

Good morning, Marie. Thanks so much for having us.

D

Dr. Marie McNeely 15:36

Well, David's a pleasure to have you here. We're looking forward to learning more from your perspective, can you start by telling us a little bit more about yourself and your role with Participant Assistive Products?

D

Dave Calver 15:45

I'm an occupational therapist from Canada. And as Keoke outlined to you earlier, he and I have worked overseas together and separately for many, many years. So when Participant was formed, we recognized that we needed to have a very strong clinical element in terms of how we develop these products to make sure that what we're putting out there is extremely appropriate for the widest band of users that we might interact with. So my role inside the company is that I try and maintain that clinical aspect and everything we do. So when we get down to is the chair getting...we're doing the design process for Cub, and it's complex, and we're eliminating pieces and it's my role to say, "well, this piece is actually essential, we can't get rid of this, it might cost a bit more, it might weigh a bit more, but we need this for X reasons." And then my other contribution is having worked in Canada and United States as well as overseas is that I have a pretty wide understanding of products that are currently available in the market and the clinical advantages and safe limitations of each of those, so that we can realistically compare our products to how they might stack up in the American market.

D

Dr. Marie McNeely 16:47

Absolutely. And for you, Dave, how are the products that you're creating, maybe impacting the clinical setting and clinicians and how they operate?

D

Dave Calver 16:54

Clinicians that we work with in the less-resourced context, we often see that they're often the sole charge clinician, so they're the only physiotherapist for example, maybe in the center, or even if they're amongst our team, they have huge caseloads, they'll see a client every 12 minutes. Where our therapists in Canada, you know, have much more time to assess, treat, follow up, recommendations, follow up, etc. We'll see dozens and dozens of people a day. So we try and design our products so that there as clinically relevant for the users that require them as possible. But we also designed them with the therapists that are provided in the mind trying to make an intuitive to provide easy to adjust, easy to readjust if something has changed during the assessment, and fast with a minimal of tools. This is another thing that at Participant we took on early in our design process, whereas we recognize that the average chair in United States might have 32 different sized bolts between metric and standard. Our design ethos has been simplicity in all the things we do so we reduce that down to one size bolt, one size, axle bolt and one tool that we can provide that they can adjust everything. Again, leading to speed of revision, ease of revision.

D

Dr. Marie McNeely 18:04

Absolutely. And Dave, you've had the opportunity to work directly with people in Mexico and

other countries as well to develop new products. And we'd love to share the stories with our listeners. So could you tell us a little bit more about one of the users that you've had a chance to work with.

D Dave Calver 18:17

He's one of my favorite people in the world. His name's Karim. He lives in Guaymas, Mexico. He's a young boy with cerebral palsy. And we met Karim early on in our prototyping, like he had our first prototypes, and used them much beyond the life expectancy that we thought they would have throughout COVID. And what we're getting back was feedback that the mother of Karim was extremely happy because she was able to get him to school and that the special education teacher at school was extremely happy with the chair. We were getting all this really positive feedback. But we'd also receive very important feedback in terms of wrist strap, for example, Mexico is quite hilly, if you lose control the chair, it's gone. So it's got to be strapped to you, so you can't lose it. That came from Karim's parents. So we formed this really great relationship with Karim where we made him a promise that if he used our first prototype and provided us feedback, we will provide him with our first production chair. So this last June Keoke, and I got to go down again in my truck, do a road trip down to Guyamas, Mexico, and we got to provide the chair to Karim and his family in their home. And then we also got the chance to go see him use it at school. And he goes to a school that is for special education needs students, but just watching the way that chair interacted in the school, as well as the way the teaching assistants interacted with Karim and with the equipment that they have, how quickly they understood how to put him in tilt - the ideal part for us was that Karim is a child with very intermediate to advanced postural problems, but Cub beautifully supports him in a posture that he can sit in all day and maintain healthy respiration and circulation while at the same time participating in school or church or wherever the family, they go for the day.

D Dr. Marie McNeely 19:51

That's wonderful. And I guess can you give us a picture of what Karim was life was like before he started using this prototype?

D Dave Calver 19:58

Yeah. When we met Karim, I think he was seven when we first met him and his mother had been carrying him for seven years. Oh, wow, they had a transport chair that was in very poor condition that was folded up in the corner of their house when we first met them. And Karim's mother had mentioned that Karim's father is not a small man, he's a big lad. So, Karim is kind of following in his dad's footsteps. And his mom was saying, it's difficult to carry him now. And it's also, he's getting old enough that it's not socially appropriate to carry him. That his peers in the neighborhood make fun of him and things. So they had this really poor transport chair, which was the only thing that the family could afford. The dad is a taxi driver, and the mom works in a local municipal government building. But living in a small city in Mexico, in northern Mexico, they're struggling to survive. So they couldn't afford an appropriate chair for him. So when we gave him the prototype, we literally wanted to try the prototype with them for a week and then take it home because we didn't trust to be safe to use for months, and they wouldn't let us. She's like, you're not taking this back. She said that the improvements in his posture are

so incredible. I can now cook dinner, I can now take them to a shop and shop without him in my arms. She said you can't take this from us now. So that's where we said, "Okay, well, we're going to monitor you closely, we're going to make sure that you know, be in touch, so if the prototype has problems, we can help resolve it, but then we'll promise you our first prototype." So we formed this really nice relationship with his family and as well as Karim and let them see the fruition of the design process. And this is what we did in June. And when we gave them the final chair, they're over the moon. It's way better than our prototype. It's smoother, it's tighter, it's a finished product now and they were just extremely excited to have it for the years to come.

D Dr. Marie McNeely 21:32

Absolutely. It sounds like this has been a really positive experience, both for Karim and for the family. But I guess what was the reaction, maybe the first time you rolled that prototype in there and had him try it?

D Dave Calver 21:42

Honestly, it tears me up, Marie. I've worked in services around the world and taught therapists around the world. And often we're providing chairs that I'm not proud of. Parents would come to us and say, "Oh, you're a gift, you're such a generous gift from God for us to provide this chair for my child. And I can't thank you enough." And I'm thinking no American or Canadian mother would accept this chair. It's a 25 year old design, it doesn't tilt. It doesn't provide them the postural support nor pressure relief that they require. But it's the only thing that this project has. So I did that three years. And the first time I provided our first prototype to Karim, we have dynamic tilt in it. So we can tilt him between negative 15 and 45 degrees. So we can get complete off weighting of his bum in a chair that we can also take the seat off, fold it up, fold the base flat and put it in Karim's father's Toyota Corolla taxi. So it brings me to tears because the application of this ability to have a child well-supported, and yet still fit into their family car into a local taxi to go to whatever service or function that they require is new. These big supportive chairs have always been very difficult to transport. So we're extremely proud of the fact that we can have a chair that is truly supportive and holds people in appropriate postural positions. But also it's highly transportable. And at the same time, we have a fifth wheel that we can put on the front of it and it becomes a true hike wheelchair, like can do off-road trails, can do broken pavement, can go to the beach. And the beauty part about Karim and his family is they're a beach family. We tested all of this with them. We walked from their house to the beach, and they pushed it through deep sand and said we've never been able to do this before. So in one case, in one child, we saw the expansion of what these possibilities were. And then from there, we took it to Colombia, and Bogota and MedellÃn. And we provided chairs to six kids, and I followed them for three months, and six kids with very different cases. We purposely chose different postural presentations. They were all accommodated, they all have the chair, they all wanted to keep the prototypes. So we wouldn't be where we at today with the families that we've worked with in Mexico, Colombia and Ukraine. They really brought our design to something that we think is ready for the market.

D Dr. Marie McNeely 23:49

Absolutely. And for Karim, specifically, did he enjoy the chair? Was this something that he was

willing and ready to adopt into his life?

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Dave Calver 23:56

Well, Kadeem is a-verbal, right, so a lot of Karim's, communication is through facial expressions, and we put him in the chair and he lit up, he grabbed a hold of it. He was rubbing his cable. They tried to take him out, and he grabbed a hold of the steep hand, he didn't want to get out. The prototype he was able to sit in for about two and a half hours before he would get sore. The new chair, he's in it for three, four hours at a time and mom's like we want to take him out. He doesn't want to get out.

D

Dr. Marie McNeely 24:21

Oh, wow.

D

Dave Calver 24:22

So we watched him in the school where Karim got put at a table and this other small child with autism came up and they were playing with shaving cream, and he put the shaving cream on Karim's desk. And then he kept touching his wheels and saying to the education assistant, "linda, linda, linda!" Which is "this is such a cute chair," touching it and Karim kept patting him on the head and say, yeah, it's my chair, it's such a cute chair. It was such a beautiful experience to watch immediately the effective and appropriate wheelchair in a child's life.

D

Dr. Marie McNeely 24:52

I love this story. And it sounds like it's had a tremendously positive impact on Karim's life. Was there anything else that you wanted to mention in terms of, perhaps things that he can do now that he wasn't able to do before?

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Dave Calver 25:04

Well, essentially, it would be a list. He's able to go to the beach, a lot of these countries through central South America, Mexico, families are very church religious based. So the number one feedback we hear you want to take your child to church, so that every morning, every Sunday, as a family, they go to church every Sunday, they go out for family lunch afterwards. When they do that Karim also has swallowing problems. He has swallowing issues, the fact that he's a-verbal, so before his mom would put him on his lap and have this very outside of what we might recommend clinically method of feeding him. But as soon as he got in the chair, she's like, he's not coughing after he's not sputtering. So we're not going to see secondary infections and pneumonia. Like we're not talking about just strictly that he's going to be able to go to the beach, but we're talking about long-term health outcomes related to proper posture, long term skin protection, right? All these things that the family really hadn't been taught before.

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Dr. Marie McNeely 25:56

That's absolutely remarkable. I appreciate you sharing the story of Karim and his family. Dave, is there another story or another user that you would like to highlight?

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Dave Calver 26:05

Yeah, we went to Medellín, which is a city in Colombia that was made famous for the Pablo Escobar scandals of cartels and violence. But it's very much a re-emerging city with outdoor restaurants and parks to walk in the community is really gathering together to support Medellín and bring it back to a vibrant city again, well, Medellín is different in the fact that the richest of the people live in the valley. And then as you go up the volcanoes, it's surrounded by three volcanoes, as you go up the hillsides of these volcanoes, you go into poor and poor and poor neighborhoods as you go higher. So we were connected with this mother, who were told had a child with cerebral palsy, quite complex extensor, spasticity, highly spastic cerebral palsy. And so we went to we ended up getting escorted in by gang members, because it's a closed community and in the poorer communities you're not allowed in unless you're no one. So we got escorted in on cars, we went into this massive complex, that was a huge Boulevard in the middle, and the rows of apartments, 2, 3, 4 apartments on either side, each family would have two and three of them in a row. So three, four generations would live in three houses. And then glued to that as another family. So you go down these staircases. And when you came into the community, we had to go down about 12 staircase. So we met this one mother. And as we're talking to her, we were made aware that there was another mother that also had a child with cerebral palsy. And then I heard that she had twins with cerebral palsy, and has no wheelchair for either.

D

Dr. Marie McNeely 27:31

Oh, wow.

D

Dave Calver 27:32

So we included her in the project for the trial and her house, where she lives, she doesn't actually have enough money to live in this community, you go down a walking path across a hand-built - a couple of planks across a little creek bed. And she lives behind the community in a little tin shack, tucked into the vegetation, and the hillside and going into her home, you know, Medellín is famous for moderate climate kind of spring like climate, but you're go in to enter her home. It's one open room with a very large kind of queen-sized plus bed. And on that bed are two children of the same age that both have very similar presentations of cerebral palsy. So I said to her like, honestly, when we talked to you and brought you into the program, we only were one, so we would provide the chair to her. And then she would adjust it to the other child when the other child had to go to medical appointments. The level of need was so big in this one family that you're like, hey, how does a one mother single mother in a poor country afford two wheelchairs. And we saw cases after cases like this, you know, unfortunately, these developmending contexts because there is not the same prenatal care, there is not the same postnatal care, we see higher incidences of disabilities like cerebral palsy or disabilities that are caused from not just events during birth. So we see higher per capita

rates. So we see these poor families. And it's very related to disability in a lot of these communities where you see a lot of these communities have children with cerebral palsy that are completely not supported. And unfortunately, they're far enough away, the local government health systems don't pick them up. So we're trying to figure out how we can then get representatives in the community that can go out and find these people and refer them back into a service that can then afford a proper chair, such as Cub. She was the same. We gave her a prototype, she used it, she used it for both kids at the end of the prototype, she refused to give it back. And at the end, I was like, I don't know why we would tell them we're taking this home because none of them wanted to give it back. We need to stop telling them that we're taking them on because we're not. But again, the feedback we get from these families is what's allowed us to get Cub to the point where we think it's ready for many, many users around the world.

D

Dr. Marie McNeely 29:39

Absolutely. And you've painted a picture of sort of what the family's life was like before they received this prototype. It sounds like it would have been very difficult for them to take their child anywhere. Take these two twins anywhere. And in these cases, how did the family react when you tried with those new wheelchairs with them?

D

Dave Calver 29:55

It's always the same. The mothers just cry and they thank God. I don't know how to explain this scenario, it's completely overwhelming, because they live in a scenario where they don't have any supports from the local governments. Most children with disabilities live in single parent homes far below the poverty line. And so they live in a state of poverty that, unfortunately, creates a lot of sense of hopelessness, they know the government's not going to give them a chair, their child is now growing. A lot of these mothers what we see traditionally and having to teach courses over the years, there's a compounding problem that these children that don't have mobility, because it's usually a mother, or a grandmother that cares for these children, they carry them. And generally, if a mother is right handed, they carry them on their left hip. Because they want to feed them with the right hand, it's just an automatic, right? Well, that posture against mom's body, what we see is the ribcages of these children conform to the shape of their mothers. If they're carried on the left, their left hip is chronically dislocated, because the moms jut out that left hip and carry them on at the top of their pelvis. So then when we also see as over the years, and they carry them until the kids toes rub on the ground, or until the child is physically too heavy for mom to pick up. So then what we see down the road years later is Mom has scoliosis mom has huge problems in her posture and in her pelvis - even chronic back pain - from carrying somebody too big, too heavy for a long time. And what we see in the child is the postures that are created through carrying make it very difficult to provide them a chair, they end up with fixed rotation and their pelvis, fixed rotation and their torso fixed rotation and their necks. Dislocations in their hips and limitations to an extension in their hip joints. So they become very advanced cases very quickly, because of the fact that they're carried in the same position all the time.

D

Dr. Marie McNeely 31:39

Definitely. And you touched on a few specific cases from Columbia, how did your product

impact them? Or can you talk about some of the changes that you saw from this pre-state to after they had this prototype?

D

Dave Calver 31:52

We see kids that are going to school that previously did not. A lot of these schools won't take kids if they don't have their own chair. So as soon as they get a chair, they're going to school, I can't think of any more profound change in their child's life than providing them with education.

D

Dr. Marie McNeely 32:05

Absolutely. I think this is amazing the work that you're doing and the impacts that you're having. Dave, did you have any other final thoughts or maybe any anecdotes that you'd like to share with our listeners?

D

Dave Calver 32:16

The only thing I would say is that we're extremely proud of what we're doing and the products that we're creating. And I think we're trying to show that the products that are currently available in the market are not worth what they're valued at. We know we can make high quality chairs for much, much, much less money and still sell them for a reasonable profit. There needs to become accountability in the medical industry for what these products cost and what the benefits are to the end user and get away from design to Medicaid codes and start back towards user centered design. So with Participant, this is very much what we're trying to do. We're trying to make high-quality, high-value, highly-durable, highly-flexible in terms of their environmental application and highly-transportable products that serve your users well in their home environments, and are affordable at their scale. It's not one company that can make a change in the entire culture. But I think if as an occupational therapist, I think it's a conversation we all need to be having with each other about how much are these products really worth?

D

Dr. Marie McNeely 33:19

Well, Dave, you brought up some great points. And I'm so glad you shared these stories with me and our listeners today. So Dave, can you tell our listeners where they can go to get a little bit more information and see some of these user experience stories firsthand?

D

Dave Calver 33:33

We're at our participant.life web page, as well as our social media sites. We now have videos up that shows our experience in Mexico with Karim so you'll be able to watch the video and meet [inaudible] hear her quotes directly on her experience with the chair. Meet Karim hear his experience, meet mom, and all that's on videos on our website. We're very much trying to share the experience with people so they can understand the power of what we're trying to do.

D

Dr. Marie McNeely 33:57

Phenomenal. You are having a tremendous impact out there. And we appreciate you joining us on the show.

D

Dave Calver 34:03

Thanks, Marie. It's been a real pleasure. Well, I appreciate you having Keoke and I both - it's a rare opportunity to talk about what we're trying to do and the only way you can do it is with people knowing what we're trying to do. So thank you.

D

Dr. Marie McNeely 34:13

Absolutely. We appreciate your time and listeners. It's been great to have you here with us as well. When you have a moment please subscribe and leave us a rating or review on your favorite podcast platform to let us know what you think of the show. And we look forward to connecting with you all again in our next episode of Changing What's Possible.