

## Interview #2

Name of Interviewee: Marcy Mamiya

Occupation: Works at Stanford, and is the mom of a student in the Special Education program at Mountain View High School

Date of Interview: 3/20/23

00:00:01:09 - 00:00:24:27

Could you please state your name and your relationship with Gabe?

Yes. My name is Marcy Mamiya, and I'm Gabe's mom.

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How old is Gabe? And what does he enjoy doing in his free time?

So Gabe is 18. He'll be 19 in June. And his biggest passion is taiko. But he loves music. Anything related to music and dance. And then also animals

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What are the best qualities of your child?

I have to say, for Gabe, it's that he doesn't hold a judgment. He just accepts people for who they are and he meets them where they are. I think he's been an incredible role model for all of us who have had the fortune of having him with us all the time.

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Marcy

And he has a very strong emotional intelligence in a way that even though his verbal and expressive communication might be challenged, he's still able to communicate really well and to, I think, offer people sort of solace in times when they might need that. That's cool.

What is one thing you wish people knew about your child that they don't?

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Marcy: I wish they didn't see Gabe for his diagnosis. I think because there are physical markers and characteristics for Down's syndrome, sometimes people see that and especially certain generations carry a bias for that because, you know, a lot of things have been changing even the past ten, 20 years and things have become a lot more open. But there are, I think, people who see him and then automatically assume that he is not able to do certain things, kind of building off of that.

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What is the biggest obstacle Gabe faces day to day?

I think like that while he's at Mountain View High School, a lot of the things that I think he'll encounter later on are not an issue because I think the student population has been just really warm and welcoming. The faculty are so supportive and the staff to just try to make everything possible and they really meet him where he is and they welcome his enthusiasm and just the person that he is.

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Marcy

I think we fear for when he leaves Mountain View High School. There will be challenges with, you know, making connections with people in the community and building friendships.

Kind of on that same note. Do you feel that it's more difficult for children with disabilities to make lasting friendships versus those without a disability?

Definitely, yes, because I think when children are young, just generally speaking, a lot of that falls on parents to arrange playdates and then as typically developing children get older, they arrange their own get togethers and meet ups with people.

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Marcy

And for a lot of people with developmental disability in particular, they are still reliant on an adult or caregiver to help facilitate a lot of that sort.

Do you feel that Gabe has ample opportunity to socialize with his peers and is there anything you wish was better in that department?

So I think part of that is why we're so active with the Silicon Valley Down's Syndrome network.

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Marcy

He has a lot of things that he loves to do, and he's so social. He loves to hang out with people. And so we try to create those opportunities for him, not only with his peers, with Down's syndrome, but also typically developing peers as well. And so I think that's why we started this food intake group. And that's been just really great because several of his classmates at Mountainview High have joined as well.

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Marcy

So for him, that's been really fun to get to share that with, you know, both fellow classmates and then also friends, too.

Can you talk a little more about that group and what kind of activities that speaks to?

Yes. So Taiko is the Japanese drumming with really big drums. And we were fortunate to connect with a young woman who's a pediatric occupational therapist who grew up in the Palo

Alto Buddhist temple playing taiko and has a passion for expanding taiko to other communities who might not otherwise get to experience it.

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Marcy

And I had gone to a workshop that she gave to talk about using Taiko as a therapeutic activity for people with Parkinson's, and then also with the pediatric population. And so then I approached her and she was willing to try to have a class for people with Down syndrome. And so from there we worked with San Jose Taiko for a couple of years and did one off workshops.

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Marcy

And then during the pandemic, we stood up a class for the Silicon Valley Down Syndrome network because it's sort of the perfect pandemic activity. You can be outside, you can be socially distanced. We had people wearing masks initially and we had like one family per drum. So it was the self advocate. But also if they wanted to have a sibling join in or a parent, play with them too.

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Marcy

So it was just a really fun way to still get together with other people and see them in person, but in a safe way. And since then, we have been able to thankfully, relax the pandemic restrictions that we had to do at first. But the group has been going strong and actually building, and then we've had different performance opportunities, which is a really nice way to, you know, get them out into the community and to interact with other people and then also to just reframe taiko.

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Marcy

Sometimes I think the way it's known contextually is for sort of this precision in musicality and speed and take it was actually really about giving self advocates an opportunity to express themselves creatively and their individuality and personality and just bring joy to people, both the people who are playing and also the people who are watching them. That's music.

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Do you find that it's important to have Gabe do activities where he can express himself?

Oh, yes, absolutely. I think especially for self advocates who have verbal and expressive challenges to try to find ways to give them a creative outlet in that way, because there are not a lot of opportunities for them. I think just because they have a harder time speaking doesn't mean they don't have things to say.

00:07:01:05 - 00:07:26:19

Marcy

So we're really trying to use taiko in that way that, you know, they have their moment in the spotlight and it's a very positive interaction that's what our Gage plans when he finishes high school.

And what are his biggest worries after he's out of school?

Well, it's a good question. So I think he will be going into the Mountain View post-secondary program.

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Marcy

And so I think I've heard it's moving to a place that's actually really close to the high school. So we're actually hoping to start up a taiko program there for the self advocates in that program. But then also have them continue coming back to Mountain View High to assist and teach for the Taiko class there. And then I think our biggest concern is just being able to facilitate friendships.

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Marcy

And then also I think vocational opportunities for him that will engage him. There are a lot of opportunities that involve things like maybe bagging groceries or stocking shelves. And I think if the individual's interested in that, that's fantastic. Gabe It's not really a sit inside under fluorescent lights kind of guy. So we're just trying to find ways to get him out in the community and also between music and animals, which I think are really what he would love to work with.

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Marcy

Yeah. Think some Oh, that's so interesting. I think I actually grew up doing it now. I'm pretty sure like one time someone came and taught a little bit about taiko. Oh, cool. Yeah. Got to take Bring Me back. I'm like, I think I remember that. Oh, that's so cool. It didn't sell well. Yeah. Yeah.

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All right. What is a misconception about your child or children with disabilities in general that you wish other parents or others in general understand?

I think when you have a child with an intellectual disability, um, there's a lot of maybe not fear necessary, but just sort of uncertainty of what that means and then how significant or how impactful is that?

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Marcy

And if it is a spectrum. And so I think there are sometimes we encounter people who really underestimate Gabe because they just assume because he has Down syndrome and is intellectually delayed, he's not able to have conversations or do certain things and he he

actually has taught us to, as we've gone through this journey with him, that he is his own best advocate.

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Marcy

I think when he was younger, we sort of went through this mentality of, you know, we try to model for him what we hope, You know, he goes out into the world with being able to advocate for himself. But we do it in the way that we know how, which is, you know, talking to people and making connections and connecting communities.

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Marcy

And then sometimes we watch him in different situations and realize, like, he does it even more effectively in a way that it's different from the way that we do it. And it's just like his own way of making connections with people and, you know, going over and taking somebody's hand and bringing him into an activity and things like that, which has been just really neat for us to experience and see.

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Marcy

Are there ways that your friends and peers can gain more of an understanding of raising a child with a disability? I think, you know, Gabe was the first person we ever met with Down Syndrome when we had him, and he was diagnosed the afternoon that he was born. So it was sort of a shock for us and at that time, the Internet didn't exist in the way it does today.

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Marcy

So it wasn't like I could hop into Google and put Down syndrome and learn more about it. We made a phone call and we had to wait for three days for a packet to come in the mail. And I think, you know, for us it was a really big learning curve. But I think what I really appreciated was people who had their first experience meeting somebody with Down's syndrome ask questions because, you know, we were learning at the time, too, but it was great to have people just come out and ask things to learn more on this journey with us.

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Marcy

I think we really appreciated that kind of response. Um, do you have times when you feel your own friends or peers are insensitive to the experience of raising a child with disabilities? And do you have any examples? Oh, yes. I think especially living in this area, there's a lot of pressure, right? There's a lot of pressure to succeed academically, but also in whatever endeavor you undertake.

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Marcy

Right. And not to just do something, but to do it at the highest level possible. And I think if we hadn't had Gabe, I think we probably would have been on that treadmill too. You know, because that's what this area is all about. So and, you know, for better or for worse, you know, I often think and I tell people the best thing that happened to his younger sister is that we had Gabe first because that really changed our mindset of what is important.

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Marcy

And, um, I think I just reframed everything. But, you know, I get together with my friends from high school. There's a group of us who are still close and they're lovely, wonderful, amazing people. But when we were first on this journey, sometimes it was really hard to hear them talk about certain things and, you know, oh, he's doing really badly in math.

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Marcy

And, you know, so we put him in this tutoring program. Now he's doing Russian school of Math and like all these kinds of things, it's like if we can give up to like, you know, handling money and like, making change for \$20, that would be amazing. So it's a different kind of way of looking at, you know, what where you're going to put your energy and focus.

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Marcy

And sometimes they would say things that just sort of internally, it sort of kind of makes me just feel like, oh, like he'll never have that and it's okay. But I wish that they saw things a little bit differently. Um, another mother said certain things bother her about the language people use regarding people with disabilities, for example.

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Marcy

She doesn't like when people say, What's your handicap when golfing? Is there a language or a general insensitivity that you hear that people may be unaware of? It's offensive. So we really try to emphasize people's first language. I know in the autism spectrum community, actually, they're actually a movement to sort of reclaim the language in a way.

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Marcy

So some of them want to be called autistic. And I think in the Down's syndrome community, I've noticed that the older generations of parents, maybe about 20 years older than us, so call people with Down's syndrome like Down. So, yeah, oh, yeah, he's Down's. And when you have a child with Down's syndrome, that's not the, you know, verbal context that we have now.

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Marcy

So it's sort of like, Ooh, that's interesting. But I think that doesn't bother me as much. I think it's more around, you know, the terminology actually on his individualized education plan until when he first started school. The classification for his needing extra services was called mental retardation and you know, colloquial colloquially. And even when I was growing up as a teenager, there was a lot of use of the word retarded.

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Marcy

I think that is currently the one that's the most hurtful, um, I know somebody actually who has a slightly older son who when his coworkers would use the word retarded, he would give them a very specific definition of that means that you have an IQ of this. And is that what you mean? And you know, there are different ways of addressing it.

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Marcy

But I think, you know, for us, it's just to explain that it carries a lot of weight and significance because we do have a son with Down's syndrome. So thank you for sharing that. How did you feel when you found out that your child had a disability? And how have those feelings evolved as he has gotten older?

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Marcy

That is an excellent question. So because we had a post-natal diagnosis, which is now almost never the case, but back in 2004, all of my, you know, they had it back then. It was a triple screen that they do when you're having a baby. And then because I was under age 35, you don't have an amniocentesis. So we had Gabe, and then I was actually the nurse who took him in to get his bath that noticed that he was a slightly different color of red when he cried from the other babies.

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Marcy

And that means that they're holding their oxygen differently. So when she saw that, then she started looking at the other soft markers, which are things like sometimes there's a crease across one palm, there's a slightly bigger gap in between. They're big too, and they're next to the placement of the ears on the head, all of those things. And then he had all of those.

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Marcy

So then she alerted the pediatrician on rounds that he was highly likely he had Down's syndrome, and they needed to get our permission to do a blood draw so they could send it to the labs to confirm and from the medical side, they knew he had Down's syndrome. And from the parents that were like, we have this perfect little baby and he's made us parents and it's amazing.

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Marcy

And then they come in and tell us the news and it's like the world drops out from under your feet. And I've heard another parent talk about it like it's like being on a roller coaster. And for most parents that we connect with, whether it's a prenatal or postnatal diagnosis, everybody remembers the moment they were given the diagnosis and what that feels like, but also what that person said and how they said it.

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Marcy

And what stuck with me from what this pediatrician we had never met before told us, you know, Oh, well, you know, half of them have heart defects that require surgery and a lot of them have passed her intestinal issues and you have to take them in right away. But we'll know in like one or two weeks if you need to have surgery for that.

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Marcy

It's going down this laundry list and holding Gabe just like, oh my gosh, what is this? And then he said, Oh, but you know, but those kids, you know, a lot of them go to school now. So it's not like before. And what struck me was, is like those kids are like, that's not those kids. That's my child.

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Marcy

But that sort of divisiveness of language and separation from when he's a few hours old. And I think, you know, at that time we didn't know anything about Down's syndrome. We were still learning and so for the first part of his life, I just think this was the best day of my life and the worst day of my life all rolled up into one.

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Marcy

And then when Gabe was six, he had pneumonia and we went to the doctor at the clinic that night, and then his oxygen saturation levels were really low. They kept changing. The O2 set the oximeter to like, This can't be right. Like, let's get another one. They put another one. I think it's like, okay, now let's try one.

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Marcy

And then and then they EMT led us over to El Camino Hospital and then they got his IVs and then they got him oxygen. Then the EMT was over to Lucile Packard Hospital and we almost lost him that night. And I thought actually, like the day he was going, that was just the best day of my life.

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Marcy

And this is the worst day of my life. And he I think he just brings so much joy that, of course, it's hard. Raising any child is hard. And there are challenges, but there is joy that I think people from the outside don't expect and don't see. And, you know, he's our ray of sunshine. And every day, let's say thank you so much for sharing.

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Marcy

Um oh how do you think that spirit has benefited Spartan bodies is amazing I think you know, and it's funny too, because with the timing of the pandemic, he was there for the first part of freshman year and then went back in person, I think, toward the end of junior year. And he thought it was super cool. He always looked forward to it.

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Marcy

He always remembered the day as Spartan, but this is happening. He's put on his Spartan buddies t-shirt and just looked forward to that. But then during the pandemic, you know, the fact that the Spartan body still met and did the zooms like that was the highlight of his week. It's just to get to see other people and get to chat and hang out and stuff was really cool for him.

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Marcy

And then, you know, to like around Homecoming when there's the parade and the Spartan Buddies marches in the parade and stuff like he loves all of that. So I think he just yeah, he really enjoys having those connections with the other students. Um, what are some of your hopes and dreams for Gabe? So I know Gabe's one of his hopes for himself.

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Marcy

He wants to live independently of us, and he wants to live with some of his friends. So we are hoping to make that happen. He let us know in sixth grade when they did the Walden West one week, you know, sleepaway camp. And he had so much fun. He didn't miss us at all. His teacher sent little videos of him and class and another friend having dance parties in the little cabin.

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Marcy

And then for us, that was eye opening because it made us realize that we didn't. He needs support and he still needs daily support, but it made us realize that doesn't have to be us. Providing that support and that there's this incredible community of people out there who, you know, are willing to help. So I think we are hoping that we can help him live the life that he wants to lead and, you know, sort of give him his wings.

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Marcy

I know that he wants to be out in the world and to work and, you know, contribute to society and all of that. So we're hoping to help him, you know, attain those goals, too. Do you find that when he goes to school that some of that daily support is from his classmates or. Oh, yes. Yeah, because I think I know, like when he went on to interact in some of the activities I think some of the police are, you know, assisting him with things.

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Marcy

So um, is there any program or activity that you wish that the school would provide that they currently don't? Oh, that's a good question. Like, I would actually love to see an inclusive take a group at school because it really lends itself to welcoming people of all abilities. And I know Gabe would love to just play with all of his friends, so we would love to see that happen.

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Marcy

And I think I feel like Mr. Key was so great about creating different opportunities for the students, and I think he's a great advocate. So a lot of the things that he has wanted to do, he's been able to do like in his own dance spectrum and just, you know, Miskito has been just incredible. So, you know, and then, you know, the music program as well.

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Marcy

He's been able to participate and, you know, he loves a pep band. And so there are a lot of things that, you know, he's really been able to take advantage of and to, you know, and the school just really embraces him. So we're incredibly grateful. Um, do you think it would be kind of building off of some of the things he said?

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Marcy

Would it be helpful to have some classes or clubs that integrate both the students with disabilities and peers? Oh, absolutely, yes. Yeah. Can you elaborate a little bit about what the class might look like? I think I would love to see some academic type classes as well because I think it brings benefit to the people who are not necessarily, you know, have, you know, learning challenges and just to help people see the world in a little bit of a different way and to sort of expand perspectives.

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Marcy

Um, you know, Gabe does a lot of things to connect with people that we don't necessarily think of, and it's just intuitive and in the way that he is. And I think, you know, the work that I'm trying to do. So I work at Stanford in an administrative role and we're trying to bring self advocates onto campus because it is this incredible bubble of opportunity for all of the students who go there.

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Marcy

And there's this whole section of the population that is not included. And so we felt like if we could bring these two groups together, then you have these people who have incredible intellectual resources, but also physical, you know, resources as well on campus and have them thinking about different challenges that impact the self advocates. And, you know, the self advocates will do whatever they can to advocate for themselves.

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Marcy

But sometimes you do need an ally and so if they can, you know, connect with people who maybe can help be that change, you know, that is what we're hoping for. So if we could, like, do that at all levels, that would be incredible. I think this is a really, really helpful example. Um, based on my research, there are programs that are employing students with disabilities like grocery stores and cafes like Ada's Cafe in Mountain View.

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Marcy

But what do you think about if companies like Google and Facebook made more of an effort to see the value in hiring adults with disabilities, I think that would be great. So there is an effort. There's a psychologist at Stanford, Lawrence then, and he is working on supported education and supported employment programs, actually working with Google. But it's primarily for self-advocates who are on the autism spectrum and they're looking at, you know, engineering kinds of coding types of jobs.

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Marcy

So I think there is even within the disability community, sort of a hierarchy and people with a developmental disability, intellectual disability are sort of at the bottom of that hierarchy. And so we're still trying to get over those hurdles as well. And so for people who have maybe physical disability or, you know, intellectual disability, that is not as impactful, then I think the work force sees them as like, it's not such a big challenge to incorporate them or if they see more value in them and we're trying to get them to see value in people who maybe, you know, aren't able to do certain things or maybe need some supports, but bring a lot of other

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Marcy

positive things to the workplace. Could you talk a little bit more about the hierarchy in the community? Yeah. So I think it's easier for typically developing people. Generally speaking, it's speaking in very broad speaking meeting terms. Of course, to incorporate or imagine incorporating people with, you know, certain physical disabilities. If you're in a wheelchair, it's like, oh, yes, you know, you put ramps here, you have to think about like, you know, you can make gardening very inclusive pretty easily through some physical adjustments.

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Marcy

It's like you create the raised beds, you know, the way you have, you know, the tools available to them. And I think when you get into other kinds of tasks where especially people with Down Syndrome have experienced previously because they were not always welcome in the education system, the way they are embraced more so today, they weren't given educational opportunities.

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Marcy

So then of course, they're not able to work in the same way once they finish their school system because they've been kept in a very sheltered kind of sequestered environment. And, you know, we know some self advocates who are going to finish with their high school diplomas and still face this huge wall because they have Down syndrome. And you can tell as soon as they sit down for an interview or walk into the room.

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Marcy

And so, you know, other people still carry this impression of the things that they cannot do. So I think there's still a lot of paternalism that's happening in society now. And, you know, I was also still guilty of it, too. Like having Gabe has really helped me sort of address it and work on it.

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Marcy

But when he was really little, we thought, okay, we need to put him in more occupational therapy and more physical therapy so then he can do these things and then it was actually working with this young woman, the occupational therapist who does the taiko with us of like, it's okay if he needs help buttoning his shirt or it's okay if he needs help lacing his shoes, like there are people who are just for our audience that may not know just some of the terms that you've been mentioning.

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Marcy

How could you define ableism? And also self-advocate affects South African is what we use for the person who has that condition. And even it's interesting too, because even within the Down syndrome community when we have new families that we've all come in and they have a baby like we still call them a self-advocate, and they think the parents are like, Who are you talking about?

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Marcy

We're like, Oh, your child. Because one day they will be right. They will be. They're their own advocates. And then ableism is this view that if you can't do something, then you're not as good

as somebody else. And it's yeah, it's something that is, I think, incredibly pervasive and something that isn't spoken of that much. I know there's a lot of, you know, things happening now around you, you know, diversity, equity kinds of movements.

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Marcy

And in some contexts I feel like the intellectual, the, you know, the delayed population is still being left out of this conversation. So that's but that's a whole other separate issue. It's actually, I think, would be really helpful if you talked about that a little bit. I think it's our documentary. Okay. So I think it's interesting because, you know, where I work, they are requiring every person who's a faculty staff member, and I, I don't have students, but faculty and staff are required to go through this training.

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Marcy

And it is that you have to read a whole lot of things. Some of it is self-paced. And then you go into a couple of Zoom, you know, meetings that have you know, it's thoughtfully done because they have actors that are participants in the Zoom meeting acting out different scenarios. And I think it's been, I think, helpful for people in terms of issues of race and also gender.

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Marcy

And throughout all of this, you know, some of the self reflection materials they do give articles about disability, but largely it is not part of the active conversation and dialog and among the Down syndrome community here, at least the parents, the other parents that we talked to were like, this is all about this. Because for years there is this mom who has a self advocate who is in his thirties, an incredible young man.

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Marcy

And one of his vocations is he's a deejay and he's a fantasy stick deejay. But I think what she said to me when Gabe was probably like three or four years old and she's like, you know, it's like we're living in the 1960s and we're doing this all over again with the civil rights movement. And it's the issue that a lot of families face in the school system when they're younger is that they are put in a separate classroom and they're given an IQ test.

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Marcy

Sometimes when they're three years old and it's like, how can you test and assign an IQ to somebody who's that age? And then it's the number that follows them and and I think it's a lot of families feel strongly about having your child categorized that early in life when you know, it's like, where's where's the growth mindset here?

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Marcy

It's like, good. So I think that I went totally off track, but I think that there's a sort of sense of like, you know, we just want them to be given a chance right? The opportunity to be in the room and to have a seat at the table. And, you know, I feel like his experience in high school has been really exceptional because, you know, in the areas that really matter to him, he has those opportunities.

00:34:01:06 - 00:34:23:23

Marcy

And we talked to a lot of families who have kids and a lot of the different school districts in the Bay Area. And that's not always the case. And it's just heartbreaking, right, to have somebody who looks like you could make such a difference for this person. And it doesn't take that much like money or time.

00:34:24:16 - 00:34:54:09

Marcy

And it could change the trajectory of their lives. So why wouldn't you want to do that? But I think that's unfortunately not always how things work. So we're still trying to figure out ways to address it. Um, would you be interested in actually being interested in your child working at a job with a salary and paid days off, but with understanding and flexibility of your child's disability?

00:34:54:09 - 00:35:30:09

Marcy

Oh, absolutely. Yes. That is the dream. Yeah. Um, what do you think? Like, like having some sort of, um, or like having flexibility built into a job, like even in, like, daily life. What would that look like? So I think the flexibility is really in terms of the support. Um, because what I've heard from families who have older self advocates who have left post-secondary or, you know, maybe went through some other kind of program after high school is they enter the workforce and often there is some kind of support in place.

00:35:30:27 - 00:35:58:26

Marcy

And while the support is in place, usually it's another person at varying degrees of support. And while that person is there, things are going great and everything is just fine. And then usually at a certain point then that support is drawn and then you have just the self advocate by themselves in that workplace. And for some it's totally fine and they've got the hang of it and it's all okay and some will always need some level of support.

00:36:00:09 - 00:36:22:09

Marcy

And so I think you know for Gabe I think right now like he will need some support because in it for him it will look like he will be focused on that task. But then if somebody more interesting

comes by and he wants to engage in some way, like then he will need to be recruited. So, things like that.

00:36:22:09 - 00:36:44:07

Marcy

So I think it's finding those levels of support that can be maintained for the self advocate to be successful, but also for, I think, the workplace to feel successful, because what we're seeing now is a lot of places where especially high tech sector like they want to hire in a more diverse fashion, but they sort of don't know what to do.

00:36:45:18 - 00:37:09:26

Marcy

So you need to have a very thoughtfully designed program to bring a self advocate into the workplace and have it be successful for everybody involved. I think it's the same thing as we've experienced in Cape School Journey, where, you know, the teacher might, you know, embrace Gabe even though they have no experience, you know, or training, working with somebody with, you know, different needs.

00:37:10:20 - 00:37:37:16

Marcy

And if they don't receive the support from, you know, the administration or have more resources, then it is not a successful equation for anybody involved. And it's really too bad when that happens. And it's really great when the administration does provide the support so that the teachers feel like they have the resources they need, they can support the student appropriately in the way that they would like to support the student, the way the student needs to be supported.

00:37:38:12 - 00:38:14:21

Marcy

And then just like the magic happens right? Yeah. Um, how do you help prepare your child for the future? Oh, it's one step at a time. So. So I think for Gabe, it is figuring out what he wants. And he's been, you know, we've been lucky to identify, like, the things that he loves. And also he let us know pretty early on that he wants to live not with us, and then figuring out, okay, what are all of the boxes that need to be checked along the way?

00:38:14:21 - 00:38:36:13

Marcy

So it's things like, you know, self-care. So it's like, okay, well, dude, if you live by yourself, like, we're not going to be reminding you to like, brushing your teeth every night. Like, you just have to do that on your own. So it's just like the small things like that. And then it's also the big things that are harder to address in terms of, you know, Gabe is so trusting.

00:38:37:07 - 00:39:03:23

Marcy

He is if somebody comes up to them and says, I'm going to I want to be your friend, he'd be like, okay, yeah. And you know, whether or not that person is ill intentioned, like he will just, you know, sort of go with it. And so as a parent, of course, that's the biggest one of the biggest worries is like, you know, will he you know, how can we keep him safe even though he's going to be on his own?

00:39:03:24 - 00:39:29:22

Marcy

And I think that's every parent's worry, right? Whether or not no matter what your child's needs are, you want them to go out into the world and be safe and be happy. Right. And so it's the same thing. But the scaffolding around that and maybe the ladder is the you know, the pathways a little bit longer and Cape might just need a few more supports along the way to get to that end goal.

00:39:29:22 - 00:39:52:13

Marcy

Um, what should Gage peers be taught about children with special needs? And what do you wish other kids your age understood about people with disabilities? MM That's a good question. I think. I think it's that right there, the common humanity of everybody, right. More alike than different is a common phrase that we use in the Down's syndrome community.

00:39:53:02 - 00:40:26:22

Marcy

Um, and even if, you know, I know some of his classmates, you know, use alternate like communication devices and talkers and stuff, but like when we're in San Diego and you give everybody a pair of budgie, the drumsticks, like everybody is the same way and everybody is finding joy in playing and making music and making music together and to try to find those equalizing kinds of opportunities that everybody can engage in and just create joy together.

00:40:27:05 - 00:41:00:20

Marcy

I think that that's ultimately what we would like for him. Um, do you have any stories about aid that you would like to share? And I don't mean, there's so many like moments that were particularly special or something funny. Okay. I actually have one that involves his sister. So his sister was seven, so I think junior high was about 12 years old and the three of us and my husband had a rare night.

00:41:00:20 - 00:41:28:13

Marcy

He was out and so the three of us were at the dining dinner table and it was October and October is Down Syndrome Awareness Month. And we've always been involved in the Silicon Valley Down Syndrome Network. And, you know, we have, you know, children's books that are like self advocates. And there's an ABC picture book with pictures of self advocates and the



different, you know, objects, four letters of the alphabet and storybooks and picture books and things.

00:41:28:13 - 00:41:54:14

Marcy

But we hadn't necessarily had a direct conversation, right, with Kiyomi, his sister, about Gabe having Down's syndrome. And so the three wishes sit at the table and she's like, Oh, like, so my child, it's this other little girl. She's like, Does she have Down syndrome? Mike Yeah, she does. I'm like, Why do you ask? She's like, Oh, because she looks like this little girl.

00:41:54:14 - 00:42:18:09

Marcy

In this video. Daddy showed me about Down's Syndrome awareness. And then every October we also have this big community wide buddy walk right down in like Cunningham Park and back in the day before the pandemic, like a thousand people would go. And it's families and self advocates and friends and sisters having a great day in the park. And so she knew this was coming up.

00:42:18:09 - 00:42:40:00

Marcy

And then she's like, it's like, so does Eric have Down's syndrome? And this young man that we knew who at that time was in his twenties and like, yeah, he does. She's like, his eyes kind of look like my tongue. Sighs. I'm like, okay. She's like, Do we know anybody else with Down syndrome? You're like, we actually do.

00:42:40:13 - 00:43:01:06

Marcy

She's like, really? And like, yeah, and like, like somebody in our family has Down syndrome. It's like what somebody in our family has Down syndrome. Like, yeah, it's like to be like most families in Silicon Valley Down Syndrome Network, they're they're, they have somebody with Down's syndrome in their family, like, really sick who, who in our family is Down syndrome.

00:43:01:15 - 00:43:23:05

Marcy

Like I think if you take a guess she's like, Gabe does Gabe have Down syndrome like he does. She's like, wow. She turns to Gabe and she's like, Gabe, Is it scary having Down's syndrome? It's like, nope. It's like, Oh, he's like, Want to watch a movie? She's like, Yeah, okay. And then it's like, the conversation is over.

00:43:23:15 - 00:43:48:18

Marcy

But it was just this moment of, like, of her, like coming into the awareness of, you know, this community that we've raised both of them in. And you know, how that hit her. And then for her, having a family member with Down's syndrome is not a big deal because she knows lots of

other families who have somebody with Down's syndrome in the family and she knows lots of other self advocates and she knows lots of other siblings.

00:43:49:02 - 00:44:17:22

Marcy

And it was something intentional on our part because we drew so, um, I think just strength and just joy from getting to know these other families and it's this incredibly generous community where you meet somebody and then you have the most like intimate conversations about like, you know, the day that you had your child and like all of these detail and all this kind of stuff, but it's this bond and this connection.

00:44:18:12 - 00:44:46:14

Marcy

And we wanted that for Gabe and we wanted that for Kiyomi, too. And Sweden is great in that they do a lot of inclusive activities. So it's not just things for the self advocate, which some organizations do focus on just the person with the special needs, but as feeds and have like yoga classes and dance classes and you know, we do take and it's you know, everybody is welcome to join in.

00:44:46:29 - 00:45:14:24

Marcy

And as a parent it's great because you don't want to tell your other children like, oh no, this is only for this child. You can't be a part of this. That's not the message we're trying to send because that's not inclusiveness either. So I think the other thing about Kiyomi is that she sometimes would go to this national conference and it's a great, you know, information gathering for us.

00:45:16:10 - 00:45:40:11

Marcy

And she said, are they looking for a cure for Down syndrome? Like, well, it's you know, it's a chromosomal issue, so it's not really a cure so much as different ways to sort of help address deficits or things that where they might need more help. And she's like, okay. She said, Well, that's fine. She said, But if there is a cure, it's like, we don't need it because Gabe's fine the way he is.

00:45:41:00 - 00:46:03:26

Marcy

And when she said that I feel like my job as a parent is to have like that. That's what I hoped for, right. Of, you know, she feels just so accepting of Gabe that he's fine just as he is. And, you know, if we could spread that like that, that's what we want. And I had a friend in high school who said, you know, like, oh, what would you change about Gabe if you could?

00:46:05:10 - 00:46:21:09

Marcy

And I thought about it and like, you know, actually, I wouldn't change Gabe. I would change the world because it's the world that needs to change how they see him and how they accept him.

So that's all the questions that we have to be asking.