{Music}

Emily: Hi. I'm Emily Ladau.

Kyle: And I'm Kyle Khachadurian.

Emily: And you're listening to another episode of The Accessible Stall.

Kyle: What are we going to talk about today, Emily?

E: Were gonna talking about parents of kids with disabilities except were not gonna talk about it by ourselves cause that’s no fun. And we don’t know anything about that.

K: Were not parents

E: We have someone who IS a parent and one of our FAVORITE bloggers. Can you introduce yourself? Special guest?

S: Oh, I like that title. I’m Ellen Siedmen, and I am mom to three kids, max whose 14, Sabrina who is 12 and Benjamin, who is almost 21 months.

E: I don’t think I realized that Max was 14.

S: Isn’t that crazy? He is.

E: Oh my gosh, Anyway I didn’t mean to cut you off. Please continue talking about wonderful you are.

S: Nah we don’t need to talk about me. We can talk about how wonderful my children are. I have no shame about that. I have been writing a blog Called love that Max, since he was 5 years old. It’s geared toward parents of children, now, teens, with disabilities. And I started it to just really inform the community and to just get support and to bounce things around. I had gone thru a bit of a tough time after Max was born and he turned out to be this amazing child and weren’t as near as awful or as dire as I thought at first. It was really hard at first when you hear that you are going to hear that you are going to have a child with disabilities when you’re a parent. And he did not turn out to be the worst; he turned out to be the best. SO I wanted to write about what I’d been through and what I continue to learn from Max, and share it with people, the parents with kids with disabilities and also the people that don’t have any sort of connection to the world of disability, to illuminate them, to educate them and have some fun along them.

K: Oh man

E: the two of us are obviously fangirling right now

K: You have touched on so many things

S: I just started talking, that just kind of poured out of me, so. You just need to stop me.

K: No its fine

E: No no we go for the organic the natural whatever comes out of your mouth at any given time.

S: Podcasts are great for me then

E: So we actually have been fans for a while but what really sparked us wanting to have you on was when you put up a post, I would say, just a couple weeks ago, the beginning of June actually. About Max informing you that he'd did not have special needs. ---

S: Oh yes

E: --- and I think it points to a much larger issue of how sometimes parents of PWD and PWD can sometimes end up being at odds with terminology and perspective on disability. But I think you and I'm guessing Kyle would agree, have found the balance of talking about your experiences as a parent and doing so also in a way that also recognizes the perspectives of PWD. And I think that's a hard balance.

K: It's also one that you don't see very often unfortunately

S: Well that is really awesome to hear because as max has gotten older I am really aware of how adults what disabilities perceive what I write about. You know how when you write you don't have any sensors in your head? But sometimes I'm like wait what would they think or how would that be taken? You know sometimes I get called on stuff like I wrote about Max having this tremendous meltdown at a parade on memorial day weekend and one of my long time readers was like would max be comfortable reading about that? So, you know, it did give me pause. I was writing it because I found it cathartic. I knew a lot of other parents would relate to what I was writing about. That's a tricky one for me to walk because Max, kind of, sort of understands that I'm writing about him but he doesn't totally get what a blog is. So there is that sensor too. And I'm respectful of his boundaries in other ways; I try to never write about things that I think could embarrass him when he gets older. I've always said that when he gets older and he turns around and says F*** you mom for writing a blog I will be SOO ecstatic because that would mean that he's reached that cognitive level. ----

K: That's pretty funny actually

S: ----Yeah but listen, there is a lot to be said about how parents of CWD view things and AWD view things. The truth is that when you are a parent and I don't know what your own parents went through but a lot of parents go through this period of struggle where you didn't expect to have a child with a disability and you don't yet understand when your children are little that there are many abilities in this world. All you know is that you didn't get the child that you "thought" you were gonna have. I think that sometimes AWD don't get that parents are going to go through that and sometimes there is always going to be this little part of you that's like wow that happened, but don't you guys agree that there is that divide sometimes?

K: I do, absolutely, hundred percent

E: Oh yeah, and you do shine an interest point to. About how a lot of parents just don't expect that their kids gonna have a disability and I imagine that that has to be a shock to the system. If you have a child and you have this vision on your head and the child may not match the vision you had but I don't think that means that you're an, ableist horrible person. I think it means that society has not prepared you for the possibility that your child might not be able bodied.

S: Correct like, its all how you're brought up and now I speak about that often on the blog. If only parents would educate their children, to treat CWD just like any other children, I say that all the time. So it took having Max for me to understand that. When you have a child with disabilities, you haven't had any experience in your life with PWD, I didn't, personally. And society has come a long way in some ways since I was little but there is still this sentiment that it's not a good thing. And as I know and you guys know it's just part of who max is. It's not all of him, its part of who he is as a person. And he is so much more than just a disability he is, ya know he's got character, he's funny, he's got great hair it's the whole package. I think that's one thing that I really learned along the way as parent, it's just one part. That's one thing as a parent that I try to get people to see that so many people cannot see. People look at PWD, I should speak about max, and people look at max sometimes and can only see that he can't speak like everybody else or that he has a drooling issue sometimes. Like that's what they see. And you feel like saying really….look beyond. Engage him, talk with him say hi.

K: yeah completely agree

E: I think it's also pretty reductive to say somethings good or bad too. So I think it was interesting how you were pointing out that it just is. It's just a fact of life. This is something that Kyle and I try to talk about a lot on this show, it's another form of reality, it's not that we are suffering and it's not that is horrible and it's not that it's the greatest thing in the whole world. Some days are good and some days are bad.

K: Some days are cool. It depends on the day for sure.

S: It's like any part of life. I have my own challenges in life; I don't choose to write about them every day because I would like to continue working. I sometimes lose my temper at my husband, whatever. We all have our challenges, not to compare that to disability but, it's part of humanity, everybody has their own share whether their visible or not visible. I was going to go back to something that you said that drives me up a wall now that I'm attuned to it which is when you are reading an article and they say a cerebral palsy sufferer.

K: Oh my God

E: UGuh

S: I hate that term. Or a victim of cerebral palsy… and you're like….no

K: Yeah Cerebral palsy came and got me in the night. Yeah that's exactly what happened I haven't been the same since.

S: Totally

K: Oh my goodness

S: That's victimizing, ya know? And it just perpetuates really bad stereotypes. Please don't use that language and it matters. The conversation matters

E: Do you find that people called you nitpicky ever? Because I know just from reading your blog that you do focus sometimes on a language choice that someone used or a portrayal of something and I know personally that I've been called nitpicky so many times so I wonder if you've had the same experience perhaps even from other parents or even from someone who doesn't have a disability who just doesn't recognize how much words have power.

S: I definitely have. I've spoken a fair amount over the years about the usage of the word retard and retarded and people have often said well don't you have any other battles to fight? And that's ridiculous, why would you focus on just a word that's not the problem. For the record, 1st of all I'm an editor for a living, so words really do matter to me. SO maybe I do care, maybe more than the average bear but this is something that parents care about. And max has an intellectual disability. And I don't want to perpetuate usage of a word that portrays people with ID in a really negative loser like pathetic light. He is so much than that. And I really hope that one day comes when Max becomes his own best advocate. And that's coming along but until then I'm going to stand there and I'm going to nitpick you about using that word if you want to call it that

K: I mean we're both professional nitpickers as well; we've been doing this show for awhile

S: Is that on your resume Kyle?

K: I'll put it there now

E: Oh yeah I'm definitely just gonna….

K: It's definitely on Emily's

S: Add that right to LinkedIn, there ya go

K: Professional nitpicker

E: It's hard to be called out for being a nitpicker

K: Yeah cause you're nitpicking about being called a nitpicker and it never ends

S: I've reached the point in life were I have such a thick skin at this point, the older you get the less you give a s***, so it's really helped me with whatever trolls come onto the blog---

K: brilliant

S: ----or haters or whoever. And you would think that if you're writing a blog that's basically for good you would get flack but oh my god---

K: People find flack for everything

S: --- it's so, that's the internet. Where did these people come from?

E: How do you handle getting flack? Or having a situation where somebody might say something might say something that is harmful or hurtful wether or not it is somebody that you know or it's somebody that is a troll on the internet, do you have a way to let it roll off your shoulders? Or do you channel it in a certain way? Because living so public I'm sure you keep plentily of things to yourself. But the stories that you do share on your blog, I imagine that it does open up some level of vulnerability so you have a coping mechanism?

S: I eventually put up a policy on my blog saying , I don't usually delete comments but I would delete comments if they were offensive it Max or to just to people in general so on occasion I'll hit delete. With trolls, depending on the level of insanity, sometimes I would just toy with them, like sometimes they would say something nasty and I would just say "does your mother know that you're writing this?" or "are your writing this from your mothers basement?" I would just start playing around with them---

K: that's pretty funny

S: but sometimes people lobby criticism at you and I do engage sometimes. I mean, there are parents out there that have kids with disabilities like Down syndrome and ID and have argued with me about the use of the word retard. Mental retardation is an actual diagnosis, I'll just come back to them with the facts and say, actually it's a defunct term, it used to be a medical diagnosis, if your doctor's office still has that on the paperwork it should be----

K: Find a different doctor

S: ----yeah seriously. Ill engage back. I mean a lot of times ill have lag. A lot of times ill just sit back and see if your readers will just step in and come to your defense and sometimes they do. A lot more discourse is happening on Facebook. I don't know what's happening with you guys and what you see out there but there is a lot of backing and forthing on Facebook.

K: Oh yeah

E: oh absolutely, I think that Facebook has become the new blog comment section.

K: But in like a much better way

S: It is, it's a really lively place. I love it's great for all sorts of reasons. It actually has more positive feedback than the blog for whatever reason. You can get quick information if you wanted. I've posted on Facebook from everything to "hey what kind of socks do you guys use for foot braces to what kind of bibs do you use if your child drools?" I mean it's just anything out there. I mean, it's just the hive mind. You can just ask anything and there will be somebody out there that will have dealt with what you're dealing with and can relate to what you're going through and help. I'm the person who asking sometimes and sometimes I'm the person who can answer.

E: disability crowdsourcing is a real thing.

S: Yeah?

K: Absolut for sure.

S: I don't think I'm betraying anything here if I say, ok actually, when, once, I needed a tool to see if I could get max to wipe himself in the bathroom and I got some really great ideas from an adults with CP advising parents of children with CP Facebook group. So there ya go. Max is going to need tools and assistance that I'm not going to necessary give him. But there are lots of adults out there that have all the wisdom. I'm going to be more reliant on them in upcoming years I think.

E: This actually raises an interesting question about how there seems to be the divide between disabled and parent communities. And you're pointing out that everyone can use everyone else as a resource, why can't we all just get along.

K: Well I don't think we should be, I don't think there is such a divide as a disservice to both communities as a whole. And the thing is, members of each community, blame the other and that doesn't get anyone anywhere.

S: As the years have gone on, I've been able to better understand and see both sides. I remember, maybe was it two years ago, there was a post on the mighty, that caused a lot of controversy, it was about a mom of a kid with Autism and I think she created some sort of board game, advance two spaces if your child calms down immediately, go back five if he has a tantrum in the middle of the store. It was meant to be funny but Adults with Autism were seriously angry and offended and they thought it portrayed Autism in this awful light. So I saw that but as a parent, sometimes a coping mechanism is humor when you're dealing with challenges. What's going on with your own stuff, what's going on with your child? So in a case like that I can see the adult community getting riled up over something like that and I can also see it from the parent perspective. I actually don't know what the answer to that is. You do try to write respectfully about your child but sometimes, you know if I look back at posts through the years I wrote about Maxs tendency to repeat the same thing again and again and I've written funny posts about or in my mind they were funny. I hope they won't be offensive to him when he grows up. But you know dealing with a child every five minutes says "I want to be a fireman when I grow up" can really grate on your nerves at some point.

K: Yeah I don't know, I'm pretty sure, I'm positive I've driven my parents crazy for some reason directly related to my CP at some point. Especially growing up

S: A child's job is to drive the parents crazy. Right?

K: Right

S: I mean that's part of the job description anyway. Yes max drives me crazy in some ways. Hey my tween twelve year old daughter drives me crazy in others. Although I don't choose to write about her sometimes. I don't really write about her, because mostly I write about parenting somebody with a disability so there you have it.

E: Yeah, I also remember that post from the Mighty.

K: wasn't that what started Cripping the Mighty or something close to it?

E: Yeah so I wrote a blog post sort of examining both sides of the situation and calling for people to figure out how to coexist peacefully.

S: Oh I have to look that up, I didn't even see that.

E: And I still don't think that we have figured out how to coexist peacefully. And I think the onus is on both sides and I hate that I have to say sides because there shouldn't be sides in this instance. But there definatly are some parents may cross a line occasionally but there are some disabled people that I think are very quick to go on the attack so I don't think that there is an answer either. I think it's just one of those things were everyone's just going to have to try to meet in the middle. And I don't know what that looks like but I do know that open lines of communication are necessary and shutting them down, even for parents is a problem. You can't just tell a parent not to talk about their experiences, what you can do is ask them to talk about it in a way that's respectful. So I think that you have found that balance. So I wonder have you spoken to other parents, to also find that balance.

S: Not really, if I'd started the blog when Max was younger, it would have been a very different blog because I was in a very hard place for the first couple of years after he was born. But by the time he was five years old I was like, this is my awesome son and this is who he is and you know he's going to develop on his own timeline, he's going to do things in his own way and that's totally cool. So no I haven't really discussed this with other parents. I've seen pretty dark blogs, and that's where those parents are at that time in their lives and it's all it's a clique but it is a journey and people jump onto the internet at different points I guess.  I've been accused of; people were saying that my blog was too positive. It's genuinely how I feel about Max and when something bothers me I write about it. But again I really am trying to respect him. But you know what? It really is a big circle of respect, because by respecting Max I'm respecting the bigger disability population hopefully as a whole. So there is that. I'm curious though, when you've read something by a parent that has offended you, what has typically offended you? What bothers you?

K: Oh God, we did a whole episode of this show sprung out of an article that someone that, I'm gonna say her name{redacted}, wrote in L magazine, ---

S: Ok

K: ---who basically was calling her child a piece of s***, like that's what she said in the article and she framed it in a way that was guilting the child into making her harm him. Which was the most offensive and then she compared it to the holocaust.

E: Oh and terrorism.

E&K: Talking over each other at 22.39

E: We'll send you the article.

S: WOW

K: It was atrocious, it was shameful

S: As a magazine editor I can tell you, I mean L usually does smart articles but obviously the editor was like woo woo, this is----

K: This is racy

S: ---- this is gonna stir up a lot of controversy lets publish it as an opinion piece, and obviously seriously offensive it sounds like. That's kind of over the top though.

E: When you are blaming your child, for being the reason that you want to inflict harm on them and you are publicly admitting that you want to inflict harm on your child, I would be very concerned.

S: yeah, that's kind of insane. ….Is there anything more garden variety?

K: I can't think of anything, maybe you can Emily, you read more about disability that I do, but when there is a parent and you can tell that they are clearly making an effort but they just missed the mark and you can just feel when you read it. I don't know, anything that supposed to garner sympathy for the person reading it. So anything that's supposed to gat sympathy for the parent rather than the child being spoken about. It's different, like you've said, you've used it on days when you've been frustrated with Max and used it at catharsis, that's not your MO so that's a very few and far between thing, I'm talking about blogs that do that constantly. That's what gets me.

S: Right it's not about you….it's really about everybody right? I mean yes as a parent you'll go through some stuff but in the end what are you doing to enable your child and help him or her along?

E: There is a huge difference to be between sympathy and empathy and I think that is where the line is for me. If you are looking for my sympathy them go play your violin somewhere else, if you are looking for empathy and you're making a real human connection and you're saying today was hard, today hurt, today I was hurting, today my child was hurting, this was difficult. ----

K: right yeah

E: ----Then to me I have empathy for you. Then to me I have been there because not every day when disability is involved is an easy day. And that's not to say that you shouldn't have sympathy for people once in a while when they are going through something particularly difficult----

S: That’s such a good point. I think the global problem to is that society still has pity for, I mean I can speak for only as Maxs mom but people still have a fair about of pity for Max and for teens and children like him. I’ve seen it CONSTANTLY, it’s sort of like “oh he’s so cute, too bad he’s disabled.” ---

K: I’m so sorry

S: --- And oh my god the sorry, I used to get a lot more of that when max was young. But even now, I wrote something, I don’t know, maybe half a year ago, where this woman in dunk N donuts handed Max free donuts and I wrote this post called You don’t have to give my child free Donuts. Dave and he had gone in to get some chocolate milk and a donut and the woman behind the counter was like “oh he doesn’t talk” and Dave said “he talks in his own way” and the woman just have him one of those looks and then just gave him free donuts. Now listen hey, great, free donuts but the point was they were coming from this place of pity and you know I actually did get some flack on that. Parent were like “what the hell just take some free donuts” But I don’t want people to feel that way about Max. Because it makes him this other human being instead of a human being just like any other. Ya know?

K: Yes

E: We’ve grappled with this before

K: All the time

E: I don’t know what to do in situations like that especially because my disability is more visible as a wheelchair user. I just never know, do I take the wheelchair perk or the disability perk and just go with it or do I just say no treat me like everyone else? But then also---

K: But—Oh I’m sorry go on Emily

E: I was just gonna say but also free donuts I remember that post vividly.

S: Vividly

K: I’m on the other end because I’m like where’s mine man, I have CP too. I know it’s because I pass. I realize that right. But it’s such a weird thing to be jealous of. Ya know?

S: And there is all sorts of intricacies to this like you know what, when we have gone to amusement parks like Disney world, or wherever and we’re about to use an alternate entry because we have a pass or whatever it is a “perk” that levels the playing field for Max and enables him to do a park and he can’t stand the lines for long periods of time. So I don’t have any issues with that. And heck yeah sure I’m glad to cut the lines in the amusement parks with Max but I in the end just do not want people to feel that he is in anyway a tragedy. And I do, you guys would know this better than me but when it comes to being the parent of a child with disabilities you so see that all the time and I just try to get people to see Max and not just the CP.

E: Yeah that’s the

K: That’s the struggle

E: the battle. I’m interested to hear your thoughts on this also, I’m sure you know that a lot of people consider disability to be an identity and something to be seen and recognized so how do you balance the idea that disability is part of who Max is and getting people to see that there is so much more to him. Do you think that there is a way to get people to see things in this all-encompassing manner rather than to completely separate the disability from him in order to see him as a whole person?

E: That is a great question. First of all, one thing that came to mind, in terms of my own evolution in terms of how I’ve seen things is that years ago I’d learned about people first language right? Like instead of saying Disabled adult you would say an adult with disabilities, the same with a child, a child with disabilities. And my first reaction was “hey that’s so great yeah yeah yeah” and you know who changed my mind, you know Shannon? From The Thinking Person’s Guide to Autism ---

E: Oh Yeah

S: --- who was like I have an Autistic child. He is hardcore. I met up with her, I think it was at a blogging conference and we talked about it. And she was like; I want Leo to embrace who he is. He has Autism, he is an Autistic child. He is not a child with Autism, necessary. Not that she had a problem with the words child with Autism but she was totally embracing the words Autistic child. So first of all that was really illuminating to me and I have in the past spoken out about people first but I dropped it, I was like, no, disabled child, disabled teen, disabled adult, fine, that’s part of who he is. In terms of just getting people, it’s just, it’s a sticky wicket for me and just something that’s evolving because max doesn’t yet, he doesn’t understand totally that he has CP, but what that means is still an evolution for him. Like he asked me not long ago if Ben, was gonna get CP, his baby brother, ----

K: Aww

S: -----so you can see that he’s still trying to understand what it means. But in terms of helping other people, I’m always happy to talk with people what I’ve learned about CP and what it means to have it. And hopefully if they understand the mechanism a little bit better they will understand why Max is the way he is and does the things he does and acts the way he acts sometimes. Because he also, he had a stroke at birth, which is how he got CP so got some brain damage in term of speech , it affects speech and learning and you know I’m not saying anything that you wouldn’t know by looking or talking with Max. Anyway, I think sometimes by talking about what CP is people don’t quite understand, that helps people better understand the whole of who he is, does that make sense?

E: Oh yeah that makes a lot of sense and I very much appreciate what you said about language choice however I know it’s hard because you really shouldn’t say cerebral palsy person. You just shouldn’t do it

K: Or you can but it just doesn’t work

E: Ok but some people seem to think well ok identity first well I’m just going to call the person by their diagnosis and that just doesn’t really work in some cases. It’s a challenge but I appreciate your insight regarding language and I think what it comes down to is respecting that everyone is going to use different language and as long as we can respect each other preferences at the end of the day and we're not calling someone something downright offensive.

S: Right, and we were talking before about words and nitpicking, listen, in the end this is one small thing in the end that we can change and relatively one small thing that we can try to influence but the bigger respect, not just respect but how people view people with all abilities, with disabilities, and that's untimely the bottom line. One thing I want to do is get other people to speak to their children while they are young which is when they are most impressionable about any children that they know with disabilities and make it clear that they should not be afraid of them and that they are children just like them but maybe with some visible differences. I think it starts when the kids are little.

K: we say that all the times. We don't understand, as people with disabilities, and I mean me and Emily, I don't mean to speak for every single one of us. We don't get it when she and I are rolling along and she's walking beside me and a parent will lift their kid out of the way as if Emily doesn't know what she's doing as if she doesn't know how to drive her wheelchair. And that's how you create fear. And their life is ruined now. Not permanently of course. They're not going to fix that because they thought they were doing the right thing.

S: As a parent I've experienced, similar things, and you don't forget this stuff because it pains you and your like "what the heck is wrong with you he's just a child?" Years ago Max was in Barnes and Noble and he went over and touched another little boy that was reading, because Max just doesn't have space boundaries sometimes, he's very friendly, and this mother whisked her child away. And I was just like "Shame on you and what exactly are you teaching your child?" So it could have been a great moment but it was just so awful. So as the years have gone on, I've gotten more vocal about helping people, or helping the parents I should say in situations, Sometimes people just get awkward, they don't know what to say, they worry. "Am I going to say the right thing?" I just talk directly to the child. If I see someone staring at max, I just go "hey do you want to say hi?" Or I'll just be like "Hey max go say hello" or "he's wearing a fireman hat because he wants to be a fireman when he grows up", whatever it is, I would like Max to speak up for himself and forge these connections on his own but we are not totally at that point so I am there to bridge that gap that may exist and try to get people to engage with him as a person.

E: And that's what it's all about. Engaging.

S: Right? I know

E: I just wish that parents would not be so quick to grab their child and yank them out of my way or if a child asks "why are you in a wheelchair?" the parent is so quick to say "You can't ask that.

K: Yeah

S: there is stigma about disability that is still out there, no matter ----

K: oh for sure but the kid doesn't know that. Yet. That's how they learn it

S: well right, and the parents grew up with the stigma so they have a sense of well, we don't talk about that. And children are naturally curious. And I have had children over the years say, even when he was like eight or something, "Is he a baby?" because, he will never, he doesn't talk like you or I do, so there is that, so I say no he just talks in a different way and the parents will be standing there looking mortified and I have to say, its ok they can ask questions. And Max wasn't often paying attention, NOW he is, so we bring max into the conversation so I'll be like, "Hey Max, you can talk right?" and he's like "YEAH" So you just try to get people talking and as a parent I definitely have to deal with that parent awkwardness or embarrassment, the kids are not, they're just kids, nosy, curious, if their parents, if their parents aren't going to help teach them then I will when I can.

E: Yeah it's all about doing what you can and I try really hard to even though Kyle and I must say this about every other episode about how I don't like to be a living breathing teachable moment.

K: But I do

E: I value the opportunity to show a child that I'm nothing to be afraid of just because I move around differently. And if a parent gives me that opportunity I find that so rewarding.

S: That's great that you have that attitude. I wonder if the majority of the public feels like you do, I wonder, we were talking about bridging gaps, how can adults with disabilities help with these situations better. Like, as a parent of a child with a disability I'm trying to do my thing, like what can we do in the grand scheme of things? Like, when I started the blog, Max was five and I started because I wanted to help other parents mostly, to reassure them. I started doing more advocacy as the years went on and I wanted people to know that he wasn't a tragedy that he was just my child who happened to have CP. So I guess writing can be one way, what else can be done, you know? I guess schools can help too, they are as much of an influence on children as parents, if not more so sometimes.

K: Sure

S: We can have more inclusion, I can go on about this and that's not the purpose of your podcast. There is not enough inclusion. And I say this again as a parent, but there's not enough, but there is so much better, in the fourteen years of his existence, I've seen more programing pop up and I'm really grateful. But when children have peers with disabilities in their nursey classes then they are just their peer. Then they are not any different. There needs to be more done in schools and with more programing in general, little bit extra-curricular stuff too. Now the amazing thing, living in the time of social media, for better or for worse is the social media shaming. I don't totally believe in it but it's made places turn around. Years ago, a local place near me refused to host a birthday party for a boy who had down syndrome----

E: What?!

S: ----- Right. So the mom wrote about it on Facebook and it exploded and they turned around. Do I wish things went that way? No at all. But that's one thing that's happening. I'm no saying go out and make a fuss but it really does have an effect when you're exposed as being disablist.

E: So I think we could do a whole other episode on the amazing things that you have been saying so by all means you can keep going for as long as you wanted too.

S: Sorry

K: oh no don't apologize

E: No apologies necessary. In fact you have said some of the most insightful things in regards to guests we've had on this show, not to say that any of our guest haven't said insightful things but I think we particularly appreciate your insights because we are trying to bridge gaps here and be connectors rather than dividers. So I really appreciate all that you had to say. And Kyle and I like to do this thing at the end of every episode call Final Takeaways which is pretty much what we say what we've gotten out of the conversation. So I think maybe we can go first and if you have a second to think what your final takeaway is, we would love to have you share it.

S: Ok cool, ok

E: So Kyle, final takeaway

K: Oh man, it's so hard to pick just one. You've been a fantastic, I guess I have a question more than anything and that is, what do you think, and I'm sorry if this is loaded, it isn't intended to be, what do you think the greater disability community at large or even Emily and I wouldn't understand as disabled people about being a parent that you wish disabled people did? What would that be?

S: I have to go back to something I touched on before. I do think that this is where the huge gap is. It's about the grief that you go through when you learn that you have a child with disabilities because neither of you have ever grappled with that. Maybe your parents did and I don't know what your parents went through. Do you have any idea?

K: Well actually that was going to be part of my question but I thought that was too personal so I didn't ask you. MY parents do not talk about it. They'll touch on it but when they talk about they clearly don't want to so I don't ever push it. So I've always wanted to know what that was, I mean I know how difficult that was so I've never really pressed anyone that I knew that could answer it but as someone with CP I sort of wish to know the sort of hellish earth that I've sort of created for my parents by virtue of my birth.

S: Now the hellish thing that you speak of is just something that I can speak for a lot of parents here. that you go through early on but then it dissipates. But then I go back to the stigma of disability that we were all raised on. I think it's changing to some extent, it's still there but I feel like were heading in a much better direction, even since max was little. And when you learn that you have a child with a disability, your first reaction is "OH MY GOD" especially nowadays there is such a focus on the perfect child and so you do go through this period of wow how did this happen to him, how did this happen to us, what will the future hold for him. There is so much anxiety and hand writhing. I can understand how adults with disabilities, I don't know if offense is too big of a word, they might take offense at that, you because there was a point where we were saying we did not want our kind to have a disability. But as somebody who is now the mom of now a teenager with a disability, I can say that I just see Max as a person.

K: that's fantastic, I'm sorry I didn't mean to interrupt you. That's so perfect

S: I think that's a journey that a lot of parents go through. I've met so many and spoken to so many though the blog and met some locally over the years, it's not to say that you don't face challenges and sometimes heartache and sometimes anxiety, but I think that is the biggest…..wait Kyle what was your question?

K: Oh no. It's just easier to ask you right now, because I can't look at you right now, than it is to ask them because they have all these years of experience and seeing me and knowing me and seeing how I turned out so if they tell me now they are almost embarrassed because of how I turned out. You know what I mean? How did we ever have that thought?

S: I've said that before, as max's parent, if you would have told me before, if you would have told me before, that I would have had a child that wouldn't have been able to speak like you and I, that walks a little differently and does things a little differently, I would have thought that sounded so awful. Now I don't because he's my child and he's just an awesome human being. It's been again and evolution for me, I think that is again, a journey that a lot of parents go through. I don't think, I shouldn't say that, I was going to say I don't think Max put me through hell, he did because I was anxious about him and about how he would turn out. That's also what you worry about because doctors also strike the fear of god into you.

K: Oh yeah

S: Oh my god, so this could be two hundred podcasts so I will stop talking.

E: No, I think what you said could be a finally takeaway in and of itself in that we have to realize that part of the reason that new parents freak out when they have a child with a disability is that society perpetuates the stigma and that stigma carries over when you have your own encounters with it. So I think the most important roles we can all play is to continue to combat that stigma and realize that if stigma comes into play initially, it doesn't make the parent a bad person per say, it just means they are grappling with the entire weight of societies discrimination against a person that shouldn't even be there in the first place but unfortunately still is.

S: And one other thing I should say is as I've met other parents, I've met adults with disabilities who have really given me hope. I know this is a really bad word and I've wrote about this word but I feel inspired not in the inspiration porn kind of way not like how awesome that you can go to a bookstore by yourself but I want Max to be independent someday and the adults that I've met do give me hope that someday Max could achieve that. So that's been illuminating to me and also sometimes, they will just slap me upside the head, do you know Andrew Pulman (Andrew Pulrang)? Do you guys know him?

K: He sounds familiar

S: Hess a writer and an advocate, he's commented on the blog over the years. He has CP also.

E: OH, this sounds familiar but I'm not placing him right now

S: Ok, trying to google him as I……I think it's really, when I had Max, I had not known any people with disability. Maybe if I had known you guys when Max was little maybe it would have been a way easier journey for me. I didn't. I don't know maybe that's another takeaway here, for parents that are listening to this. I don't know how can we forge greater connections? Are you guys in that Adult with CP advising Parents group?

K: I am, Emily doesn't have CP so she's not allowed. I'm definitely in that group.

S: But maybe there needs to be more groups like that?

K: I remember when I first found your blog, I think I was an intern in Washington, I think I emailed you my life story and my phone number, "if you need anything please let me know"

S: Can I ask you to babysit?

K: you know what? Sign me up. It was unlike anything I had read yet. Since there have been one or two that have been similar to yours with regards to disability and parenting but your blog was the first to attempt to bridge a gap and I think you've since done it.

S: Well that is really heartening to hear, it's a work in progress for all of us isn't it? We're all on the same page here. I think it would benefit everybody. I think we just need some more conversations like this so everybody can are whatever grievances they have. I never really had any grievances, I guess it can also just be a disability….im just like what the heck is the problem here? I guess I have seen it spark up over the years like with that one Mighty post, I don't really read other blogs, like I don't see what kind of crap parents are putting out there. If I saw a blog where someone was just slamming their kid all the time I would just be like get a grip, that's just not good for anybody.

E: But we all know you're too positive so you need to cool it with the positivity

K: Yeah be sad sometimes

E: But in all seriously this has been such a great conversation and we have had so much fun.

K: Oh yes

S: Well thank you!

K: Please come back

S: I will come back. This has been like an hour and it has just whizzed by.

K: Seriously

E: And also the fact that you gave us an hour when you have three children including a baby is amazing.

S: Are you kidding me?

K: yes thank you so much!

S: Talking to adults is such a dream

K: yeah I was gonna say.

S: I spent a whole day, the baby is obsessed with this five inch yellow bus so all he says all day long is BUS BUS BUS. I'm not kidding, he just wants me to find his bus all the time or he just wants to talk about his bus but all he can say is bus, Max likes to talk about his upcoming trip to Las Vegas which he has planned, he's going to Las Vegas for his birthday.

E: wow

K: Are you kidding?

S: Yup. We haven't like booked tickets or anything but he's likes planned this whole fantasy trip.

E: Oh ok

S: So he really likes to travel. So I'm really glad to have adult conversation.

E: Well we definitely will have more adult conversation when we convince you to go out to lunch with us where we continue to tell you how great you are.

K:Oh yes I would love that

S: And we don't even have to tape it we could just talk

E&K: YEAH

K: yeah definitely no taping that one

E: yeah we can have real life conversation without recording although hearing conversations like this uncensored and recorded is exactly what people need.

S: I hope this changes perspective in some way, what's that phrase? If you save one person's life, you save the world. And I've thought to myself, I want to change a lot of people's minds but if I could just change one person's mind and that one person could go out there and change who knows how many other people's minds. You always hope that the efforts that you make will pay off.

E: Oh yeah. And that's how we function with this podcast. We are honestly still confused about where our listeners are coming from because we just keep getting them and we are just like who are you and why do you care about disability but if we've gotten you to care about disability, that's great.

K: Yeah so we've done our job

E: So thank you thank you thank you and can you just quickly plug where people can find you even though you said it in the beginning?

S: Sure, My blog is LovethatMax.com and my other two children might need therapy someday because they don't have a blog. But that's what it is. It was originally called, TotheMax but when I went to get the domain it was taken by a company so LovethatMax and thank you for having me, this has been a real pleasure and I will talk with you both more.

E: Yes, absolutely we'll talk offline. But for now this has been another episode of the Accessible Stall.

K: G'Night everybody

E: Thanks for listening

K: Bye

E: Bye