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The following is as published on “Love Doesn’t Pay The Bills” audio podcast

Produced and hosted by Lisa Tschudi and Two Squared Media Productions, llc.

Lisa Tschudi: Welcome to Love Doesn't Pay the Bills, where we make visible the often unseen experience of family caregiving.

Lisa Tschudi: I'm Lisa Chetty.

Lisa Tschudi: I'm a family caregiver.

Lisa Tschudi: Shasta Kearnsmore is a family caregiver, as well as a writer and host of Medicalmotherhood.com and an advocate for access to service in Oregon.

Lisa Tschudi: Welcome, Shasta.

Shasta Kearns Moore: Thanks for having me.

Lisa Tschudi: Would you give my listeners a brief version of a chronological outline of your caregiving experience?

Shasta Kearns Moore: Sure.

Shasta Kearns Moore: So I was a few years out of college and a reporting job and got pregnant with twins, and they had a couple of complications where I had to go on bed rest for like, five months.

Shasta Kearns Moore: So they were born three months early.

Shasta Kearns Moore: And about two weeks after they were born, brain scan revealed that my one son had a brain bleed.

Shasta Kearns Moore: And that was kind of when I fell into Disability World, and I was a stay at home mom for four years.

Shasta Kearns Moore: And then I tried to reenter the workforce and go back to my career as a reporter.

Shasta Kearns Moore: And that was challenging and rewarding, and I really loved it.

Shasta Kearns Moore: But school, once school started with the kids, we realized that until that point, what I thought was my non disabled twin also had some pretty significant issues and really had a hard time meshing with the school environment.

Shasta Kearns Moore: And so then I had to take a leave of work in order to move districts because we thought it was difficulty with the school district.

Shasta Kearns Moore: And so we tried another school and went back to work for a couple of years, and then it was like, you know what?

Shasta Kearns Moore: This isn't working at all.

Shasta Kearns Moore: Yeah.

Shasta Kearns Moore: So I've been at home since January 2019, and in between the crevices, I have been doing a lot of research and just learning that this phenomenon is not at all unusual, that women get out of the workforce for this exact reason all the time, for caregiving reasons.

Shasta Kearns Moore: And so then that kind of became at first became like the thrust of a book, but then COVID happened and publishing wasn't buying books.

Shasta Kearns Moore: So then I turned it into Medical Motherhood, which is a subsequent newsletter and podcast which we talk about all the different aspects of being what most people call a special needs mom.

Shasta Kearns Moore: But I've learned from the disabled community that they don't much like the term special needs.

Shasta Kearns Moore: So trying to come up with something else because this is definitely an identity.

Shasta Kearns Moore: Special needs motherhood is a thing, and so we need to be able to call it something and we need to be able to talk about it.

Shasta Kearns Moore: So I call it medical motherhood.

Lisa Tschudi: Yeah, which is a great term, I think.

Shasta Kearns Moore: To me, I still do use the term special needs world because to me, in my mind, that encompasses the whole mindset of, oh, you're different, you're disabled, your special needs, and so we have to give you these special things, and we have to make you jump through all these special hoops.

Shasta Kearns Moore: And that whole kind of philosophy to me is enmeshed in special needs world, which is kind of talking down to you and patronizing you and stuff like that.

Shasta Kearns Moore: So I do still use that term because of that reason.

Lisa Tschudi: Yeah.

Lisa Tschudi: Makes sense.

Lisa Tschudi: So one question that we often don't get asked as much as parents of a child who experiences disability is what makes your kids so awesome and what do you love about your kids?

Lisa Tschudi: So would you share that your two.

Shasta Kearns Moore: Yeah, both of them are amazing.

Shasta Kearns Moore: They're incredibly brilliant.

Shasta Kearns Moore: Just started reading from a very young age, doing math from a very young age.

Shasta Kearns Moore: Intellectually they're academically, they're very bright.

Shasta Kearns Moore: And so the difficulty really comes more from the motor piece and emotional selfregulation piece, but very funny and very empathetic.

Shasta Kearns Moore: And they love animals and I'm sorry, my cat hopefully is that soapy right now.

Lisa Tschudi: He comes in the picture.

Shasta Kearns Moore: She's a kitten going to get next week.

Shasta Kearns Moore: Yeah.

Shasta Kearns Moore: And I love travel too, which is great because both my husband and I are that was a really hard thing when they were diagnosed and just kind of feeling like, okay, we're never going to be able to go anywhere anymore.

Shasta Kearns Moore: And fortunately our particular needs are such that we still can travel with them.

Lisa Tschudi: Yeah, that's wonderful.

Shasta Kearns Moore: It definitely makes it more difficult and more expensive and more all the things, but it's not something where emotionally or psychologically, it's difficult for them.

Lisa Tschudi: That's awesome.

Lisa Tschudi: Yeah.

Lisa Tschudi: So what have been some of your biggest challenges to raising your kids to this point?

Shasta Kearns Moore: In the beginning it was the physical.

Shasta Kearns Moore: We thought it was all about malik, I won't be able to walk.

Shasta Kearns Moore: And so how do we get there?

Shasta Kearns Moore: Scouring the Internet, scouring books, trying to figure out what can be the thing that will fix it, and learning a lot about neurology and plasticity and all that.

Shasta Kearns Moore: We fell into a method called the not bunyal method based on filled in crisis.

Shasta Kearns Moore: You've heard of that?

Shasta Kearns Moore: It's kind of a narrow body movement.

Shasta Kearns Moore: We still do, it still great, but it's not like the all consuming thing that it was when they were little of going on trip to California, spending thousands of dollars trying to do this thing.

Shasta Kearns Moore: So that was really hard in the beginning and then once they reached school age, really the kind of more mental disabilities came into play and just kind of realizing how difficult it was for them to mesh with the outside world.

Shasta Kearns Moore: You know, it's interesting because I thought that we could just get him to walk, everything would be okay.

Shasta Kearns Moore: And now it's like, oh wow, actually that is not the most important thing.

Lisa Tschudi: It's easy to fix it on that one goal.

Lisa Tschudi: That one thing.

Lisa Tschudi: For me, for a long time it was learning for my daughter to learn to walk, but it also was stopping her seizures.

Lisa Tschudi: And we've gotten the seizures very well under control.

Lisa Tschudi: And that doesn't magically solve all of life by any means.

Lisa Tschudi: There's still lots of things going on over here.

Shasta Kearns Moore: Yeah, it's funny, I think a lot about shades of gray and kind of the differentiation, because that was something that we learned as part of malachi therapy, is that human beings are wired to think of things as either black or white, and then you kind of get these kind of more distinctions and shades of gray in there.

Shasta Kearns Moore: And that's definitely been the journey of going through and learning about disability and how varied it is.

Shasta Kearns Moore: Before I had kids with disabilities, I didn't think anything like I thought disability was one thing.

Shasta Kearns Moore: I just thought, oh, that's those people over there in that room.

Shasta Kearns Moore: Because my school was segregated and everything, I didn't ever think about how varied that experience was and how many different support needs there are and exceptionalities there are and diverse range of human beings.

Lisa Tschudi: Right.

Lisa Tschudi: Even two people with the very same diagnosis are still two very distinct individuals.

Shasta Kearns Moore: Yeah, absolutely.

Shasta Kearns Moore: Having identical twins, their needs are so different and yet they are identical in several ways genetically and then also just who they are.

Lisa Tschudi: Right.

Lisa Tschudi: What are some of the things that have been the greatest help in meeting some of these challenges that you might have found what's been helpful?

Shasta Kearns Moore: Other moms, for sure.

Shasta Kearns Moore: Other finding a community of people who get it once.

Shasta Kearns Moore: You know, I had a friend group of other moms who really got the medical piece, being able to just kind of think about things or say, hey, I'm having this problem.

Shasta Kearns Moore: Have you guys ever experienced that?

Shasta Kearns Moore: And getting a bunch of opinions or real actual experience, that was 100% the most helpful thing.

Shasta Kearns Moore: There's just nothing that people experience.

Lisa Tschudi: Absolutely.

Lisa Tschudi: So you've had good opportunity to be with others that have experience similar.

Shasta Kearns Moore: I mean, social media has been revolutionary, I think, for the population.

Shasta Kearns Moore: I mean, I cannot imagine what this life would be like without Facebook, without the ability to connect with other moms because we don't have time to go places like meet in person.

Shasta Kearns Moore: I mean, that's very rarely I was able to attend like a physical support group.

Shasta Kearns Moore: So it's very true, just having that.

Lisa Tschudi: That would be more of an informal versus a formal support.

Lisa Tschudi: And it is amazing how online has become such a support to so many people too.

Lisa Tschudi: My daughter is a bit older and Facebook kind of came into being and social media as we have it now, came into being during her lifetime.

Lisa Tschudi: And it did get a lot less lonely, for sure.

Lisa Tschudi: There were a lot more opportunity to yeah, okay.

Lisa Tschudi: It's not as nice in a lot of ways as meeting in person.

Lisa Tschudi: And it is a connection and you can build a real meaningful connection, especially you go into some of the groups and some of the designated areas where people are having some real conversation.

Shasta Kearns Moore: Yeah, definitely.

Shasta Kearns Moore: It had to be both like for my friend group, I started a brunch, and so we would come together once a month or two physically, but then the messenger group would kind of continue in between the times that we would physically meet.

Shasta Kearns Moore: But, yeah, I need people who got it.

Shasta Kearns Moore: I mean, especially because I had twins and cerebral palsy, it was really difficult to, you know, I would go to the cerebral palsy support group, and people be like, oh, it's so hard to have a kid with a disability.

Shasta Kearns Moore: And then I go to the twin support group and then go, oh, it's so hard to have twins.

Shasta Kearns Moore: And I was like, I have both until I found a couple other moms with cerebral palsy that I was like, okay.

Shasta Kearns Moore: It's not like comparing, like, how hard is my life versus yours?

Shasta Kearns Moore: It's just knowing that there is that overlap of hardness.

Shasta Kearns Moore: So, yeah, it's not possible for me to take them to all the therapy appointments.

Shasta Kearns Moore: I've got the other one.

Lisa Tschudi: Sure.

Lisa Tschudi: Yeah.

Lisa Tschudi: And as much as we are all individuals and our families are unique and our circumstances are unique, sometimes it's really, really helpful to find those couple of individuals who are very close to your own experience.

Lisa Tschudi: Yeah.

Lisa Tschudi: So when it comes to other people you're connected with informally, like extended family or your neighbors or your other friends, maybe before you had your kids, what kinds of responses are helpful and valuable for you?

Shasta Kearns Moore: I think they talk about and I don't know if this is scientific or anything, but I think they talk about different love languages and what my love language is doing.

Shasta Kearns Moore: You know, I have learned especially I've learned over the years with having care workers in my house.

Shasta Kearns Moore: Some people want to connect emotionally first and then do the thing.

Shasta Kearns Moore: I have to do the thing.

Shasta Kearns Moore: Once all those things are done, then I can connect emotionally.

Shasta Kearns Moore: And so, yeah, to me, it was years and years of not being able to connect emotionally because there's always so many things to do that makes sense.

Lisa Tschudi: That sounds familiar to me.

Shasta Kearns Moore: Yeah.

Shasta Kearns Moore: So to me, the most help is just doing something.

Shasta Kearns Moore: Just, you know, don't ask me don't, like, get me to unbear my heart to you.

Shasta Kearns Moore: I'm doing something.

Shasta Kearns Moore: And if you want to help and.

Lisa Tschudi: Do something, so, like, come over and bring the meal, fix up minor household repair that needs to be done, fold the laundry, whatever, things like that.

Shasta Kearns Moore: And that was what was so frustrating to me about special needs world and remains so frustrating to me is how much of these service systems are set up, and then they just come over and they talk to you, and it's like, I don't need somebody to come and talk to me.

Shasta Kearns Moore: I actually need you to physically put your hands on my kid and change a diaper or something.

Shasta Kearns Moore: Like, help me out here.

Lisa Tschudi: Absolutely.

Lisa Tschudi: I'm with you for sure.

Lisa Tschudi: I call it theoretical services, and a lot of times it just feels like we're spinning in these circles of like, meetings and paperwork and yeah, some help will be available when we set it all up.

Lisa Tschudi: And it's very much theoretical.

Lisa Tschudi: It's very much in this realm of, like, imaginary.

Lisa Tschudi: Sometimes it feels like the unicorn and said to be out there because some.

Shasta Kearns Moore: Hard work and no one else to actually do it.

Lisa Tschudi: And it's such a difference when you get something actually changed in your situation, whether it's piece of equipment you need or whether it is hours of a person there to change the diaper or whatever it is.

Lisa Tschudi: A lot of times it is very intensive, just number of hours right, of people willing to be there and yeah, change a diaper, prepare a meal, whatever is that needs to be done in that moment.

Lisa Tschudi: And every individual is different too.

Lisa Tschudi: The needs are always a little different.

Shasta Kearns Moore: Usually what I need is a break, which is why I'm able to be on this podcast.

Shasta Kearns Moore: I have a caregiver right now to do some of those things, but then there's also kind of the flip side of it.

Shasta Kearns Moore: Sometimes I want to be with my kids.

Shasta Kearns Moore: Sometimes I don't need to do the care tasks and stuff, but I also don't want it to be like, okay, you're over there, you know?

Shasta Kearns Moore: I mean, how is that even better than being in an institution if it's, like, so segregated that it's like, okay, well, now that you have a staff person, I'm not going to interact with you anymore.

Lisa Tschudi: I really hear that.

Lisa Tschudi: Yeah, I hear that.

Lisa Tschudi: And I felt that too, of longing to like, can I just be my kid's mom?

Shasta Kearns Moore: Right.

Lisa Tschudi: And just like, have something close to what those only those family experiences might have been without the disability.

Shasta Kearns Moore: Yeah, yeah.

Lisa Tschudi: And hear them talking about their day and have those conversations, maybe read a book or whatnot, without having to be responsible for so many things that feel heavy, that feel urgent, that feel like their life could be on the line from it.

Shasta Kearns Moore: That's kind of part of what I think about.

Shasta Kearns Moore: And I don't know if we want to get into this now, but with the paid parent caregiving thing, it's like this extra work isn't bad.

Shasta Kearns Moore: Yes, I get burned out if I'm the only one doing it all the time, but at the same time, I still do want to do some of that, but it does preclude a different job because it is actual labor and actual time and actual energy that is spent doing that.

Shasta Kearns Moore: And so, you know, I really feel like that's why families need that flexibility, so that there can be these opportunities to just sit and be with your kid and not have it be so overwhelming all the time.

Lisa Tschudi: It's time for a break.

Lisa Tschudi: Please stay right here and we will be right back.

Lisa Tschudi: Thank you for sticking around.

Lisa Tschudi: We continue our conversation.

Lisa Tschudi: I'm Lisa Chewy, and this is Love doesn't pay the bills.

Lisa Tschudi: So let's go into a little bit about what's happening in Oregon and this movement that you're at the front of one of the people in the front.

Shasta Kearns Moore: Like I said, I was researching a book title.

Shasta Kearns Moore: Special needs World.

Shasta Kearns Moore: And just finding out all of these kind of how disability impacts families economically and how what happened in my case is not at all unusual, that something like 75% of families, when they have a kid with a disability, have to go down to a single income.

Shasta Kearns Moore: You know, families tend to spend much more on those children for all kinds of reasons that aren't covered by insurance, like specialized clothes, specialized, specialized food.

Lisa Tschudi: I have started this podcast, and I am here because I'm really, really tired of every time I go on those Facebook groups about disability related areas.

Lisa Tschudi: The question is every single day, well, I just got a new diagnosis, and my kid in my case, that's where I'm hanging out.

Lisa Tschudi: But could be another elderly family member or something needs a level of care that is as I'll describe X, Y, and Z and ABNC, and these are the needs.

Lisa Tschudi: And I'm about to lose my job.

Lisa Tschudi: How do I provide for us?

Lisa Tschudi: What do I do?

Lisa Tschudi: And the answers that I've seen are.

Shasta Kearns Moore: Really.

Lisa Tschudi: I don't know.

Shasta Kearns Moore: I mean, at the point where we're in this capitalist society where the only value that you have is your work and the only way that you can provide what your family needs is through income, I just don't understand that.

Shasta Kearns Moore: We have these assessments where it says this child requires this many hours above and beyond what a neurotypical child their age would require.

Shasta Kearns Moore: Why aren't we paying the person doing that labor regardless of their genetic proximity to the child?

Shasta Kearns Moore: I just feel like it is the most equitable solution.

Shasta Kearns Moore: It cuts across race and economics and all of that kind of stuff to really provide what families need.

Shasta Kearns Moore: It's not a coincidence that people are falling into the river.

Shasta Kearns Moore: What was that quote?

Lisa Tschudi: There comes a point where we need to stop just pulling people out of the river.

Lisa Tschudi: We need to go upstream and find out why they're falling in Desmond Tutu.

Shasta Kearns Moore: We need to go upstream to find out why is it that people are stopping working.

Shasta Kearns Moore: It's one thing if that's your choice, if you decide, as many stay at home moms have done, that, this is what I want to do.

Shasta Kearns Moore: I want to raise my kids myself, blah, blah, blah.

Shasta Kearns Moore: It's a totally different thing when it's not a choice.

Shasta Kearns Moore: It's different emotionally, but it's also different economically when you don't have a choice.

Lisa Tschudi: Yeah, and I think that there's way too many mothers, especially when the child has a disability, that it really doesn't look like much of a choice to me.

Lisa Tschudi: Looking at other families, that didn't look like much of a choice to be in my situation for a long time.

Lisa Tschudi: And now we do have supports in place in the state of Oregon.

Lisa Tschudi: We do have theoretical anyway, that sometimes becomes real of an ability to hire in home caregivers where child is evaluated and assigned a certain number of hours per month that the family can hire an inhome caregiver.

Lisa Tschudi: And a lot of families are just not able to turn that theoretical offering into a real person on the ground for the number of hours that are needed.

Shasta Kearns Moore: And I'll go a step further that those hours require than more hours from the person trying to recruit, hire, train, all that kind of stuff.

Shasta Kearns Moore: I mean, right, it's kind of worked out now at my kids twelve and we have been through it a number of times that we're kind of able to get more stable that we're not using anywhere near our full allotment.

Shasta Kearns Moore: But that's the beginning of what's called the Cape Plan in Oregon in 2014.

Shasta Kearns Moore: I mean, I went through at 1.7 different hires of people who wouldn't show up, wouldn't show up to their interview, wouldn't show up to the first day, would work one day and then just quit without telling me.

Shasta Kearns Moore: Yeah.

Lisa Tschudi: And these kind of experiences are really common and the family is left as the default and the manager of these positions.

Shasta Kearns Moore: And it turns out HR is not easy.

Lisa Tschudi: Right.

Lisa Tschudi: That's an actual job.

Lisa Tschudi: Yeah, particularly for this kind of work.

Lisa Tschudi: It can be quite difficult to hire people and we're relatively lucky in Oregon, especially with the wages haven't been raised recently as far as what agencies get and therefore that they tend to pay two DSPs.

Lisa Tschudi: That makes the job a lot more attractive and that helps.

Lisa Tschudi: And at the same time, like these services are not something that most families or many families could rely on strongly enough to get to another job for both parents to go get to another job or the single parent to reliably show up at another job.

Shasta Kearns Moore: I don't know how it is in other states, but in Oregon we have an Oregon administrative rule that says that parents are not allowed to go to work or school while their BSc is working.

Shasta Kearns Moore: And that was sort of at least what I've heard in the rumor was that that was sort of put in place because the Republicans in the state at the time said we don't want to have to pay for a glorified babysitting service, quote unquote.

Shasta Kearns Moore: Now I will say that the state Republicans I've talked to in the last, in recent months have not said that at all.

Shasta Kearns Moore: They understand that this is, that caregiving is not parenting and in home service providing is not babysitting.

Lisa Tschudi: Right.

Lisa Tschudi: But it doesn't necessarily require both at the same time to be there and for the parent to have this additional layer of lining up the babysitter separate from the caregiver that relates to the disability needs.

Lisa Tschudi: You're like tearing a kid apart that's really silly.

Lisa Tschudi: This is one kid.

Shasta Kearns Moore: Totally silly.

Shasta Kearns Moore: I mean, for me to have gone to work at my job that paid like $20 an hour, I would have then had to pay somebody $20 an hour to watch both of my twins and then have a paid support worker from Medicaid there at the same time.

Shasta Kearns Moore: This is silly.

Shasta Kearns Moore: Oh, could I pay my kids to go to Daycare and then the support worker will go to daycare?

Shasta Kearns Moore: Oh, no, that's not allowed.

Shasta Kearns Moore: Right?

Shasta Kearns Moore: Okay, well, could I have the support worker pick my kid up from school so that I don't have to be home at 02:00 in the afternoon?

Shasta Kearns Moore: Oh, no, that's not allowed.

Shasta Kearns Moore: It was like any time that it was like, can we make this reasonable for families?

Shasta Kearns Moore: Can we make this something that we could actually use?

Shasta Kearns Moore: No.

Lisa Tschudi: Yeah, that's a lot of famous experience, and that definitely relates to mine.

Lisa Tschudi: So it's issues of finding people to hire at all and continuity of hiring people and whether they're going to show up when they're even scheduled to, and whether you can find people for the specific shifts you need, then these rules do come into play as well.

Lisa Tschudi: My daughter is older and I've forgotten about that piece of it, too.

Lisa Tschudi: Yeah.

Lisa Tschudi: There are these rules that separate out where the parents still need to be present.

Lisa Tschudi: Is there work being done to change that aspect of the rules where the parent has to be present or can't be at a paid job?

Lisa Tschudi: At least?

Shasta Kearns Moore: I know that in conversations with legislators, we've kind of brought it up.

Shasta Kearns Moore: The leadership group has, but I don't know of any specific efforts.

Shasta Kearns Moore: That is an administrative rule.

Shasta Kearns Moore: So that would be odds.

Shasta Kearns Moore: Office of Developmental Disability Services and the incoming new guru tutorial administration.

Shasta Kearns Moore: That would be their job to fix that.

Lisa Tschudi: It was my understanding.

Lisa Tschudi: I remember when my daughter was young anyway, because I used a CIAS before K plan came into place, and there were a few hours here and there that were enough to kind of give me a rest sometimes not where I could think about working on a job.

Lisa Tschudi: And I was told that if I did get a job, there was a switch to a different program I could go to where it would just be a different payment source for the caregivers.

Lisa Tschudi: Is that true?

Shasta Kearns Moore: An employment related daycare type in thing.

Shasta Kearns Moore: And I'm actually working on a story about this right now for a magazine about the childcare rules in Oregon.

Shasta Kearns Moore: But what I experienced and what I hear from so many people is how difficult it is.

Shasta Kearns Moore: Daycares won't even take your child if they have medical needs, and technically that's against the law, but I'm not really sure what the remedy is for that.

Shasta Kearns Moore: If you go to a day care and they say, no, you can't put your kid in here, and then you say, okay, I'm going to sue you.

Lisa Tschudi: It'S not something they want to force.

Shasta Kearns Moore: You to take my kids, right?

Shasta Kearns Moore: No, you don't want to put your kid in a place where adults don't want them to be there.

Shasta Kearns Moore: So I don't know how that ever gets fixed.

Shasta Kearns Moore: But yes, there's a different program that will pay and that's for anybody.

Shasta Kearns Moore: That's for anybody who's going to work employment related day care credits in Oregon and then on top of that, there's supposed to be a little bit of money for inclusive daycare for them to help hire staff member at the daycare.

Shasta Kearns Moore: But again, it's like paying five different people instead of just doing the logical thing, which is to allow the paper to be paid if that's what they want to do.

Lisa Tschudi: Right.

Lisa Tschudi: The one person who's already there qualified.

Shasta Kearns Moore: And trained and doing the work anyway.

Lisa Tschudi: Yeah, well, I mean, I think we do need to work on this, of doing the work anyway because I think that it is really wrong to assign to mom you are the default and you will be here regardless because A, in a lot of these situations, one person cannot do it all, just physically cannot be.

Lisa Tschudi: Mom is a human being too and mom deserves an opportunity to participate in the wider world and live a full life exactly the same as if her child didn't have a disability.

Lisa Tschudi: C, it's a lot better for the child when whoever is with them is really freely choosing to be there and content with being there and has their own needs met.

Shasta Kearns Moore: Yeah, I think if we had a functional K Twelve system, if we had a functional daycare system, if we had a functional social service system, if we had a functional healthcare system, all of these things would work in sponsor to make sure that children disabilities were not ostracized the way they have been and continued to be.

Shasta Kearns Moore: But I feel like one of the things that I've learned through Medical Motherhood and doing this newsletter every week is finding out how many of these systems that touch our families are deeply, desperately broken and have never really worked.

Shasta Kearns Moore: Well, we've under funded special education for decades.

Shasta Kearns Moore: We've implemented Ada, but as far as daycares go, not really.

Shasta Kearns Moore: And I don't really know how to fix that because I feel like it's all kind of rooted in this ablest mindset of well, let's find out how different you are than the norm and that's how much support it will give you based on how different you are.

Shasta Kearns Moore: And so if that's the question that you're starting with, I feel like you're always going to be kind of chasing after the ideal, which is that you're not different, that everybody has needs.

Shasta Kearns Moore: And so how about we just meet everybody's needs.

Shasta Kearns Moore: Because if you're qualifying for a program based on this interview, in which you're saying, this is how bad it is, this is how needful we are.

Shasta Kearns Moore: This is how much of a victim I am, and then you get into the program, and then you're like, okay, but now can I be like everybody.

Lisa Tschudi: Else now that my needs are met?

Lisa Tschudi: Right?

Lisa Tschudi: If my needs are met, maybe I can do X, Y and Z and maybe not.

Lisa Tschudi: Either way, I deserve warm, dry, safe and fed and social opportunities.

Lisa Tschudi: I think that's like a standard we really have to start with is like everybody being warm, dry, safe and fat regardless.

Lisa Tschudi: And I think that alleviates that mindset, alleviates a lot of these issues of putting people in these different boxes and these services in different places that are defined very specifically when it comes down to people seeking warm, dry, safe and fed.

Shasta Kearns Moore: Yeah.

Shasta Kearns Moore: I mean, the complexity is the problem in my mind that these systems have gotten so complicated and so complex that it's impossible to navigate them.

Shasta Kearns Moore: And it requires these experts in the state who may have their own agenda about what they want covered and what they don't want covered.

Shasta Kearns Moore: And so then they're able to hide what they're doing in all of these complexities and obfuscations.

Shasta Kearns Moore: And that's been a really interesting learning curve to figure out how much of this complexity is kind of a shield for those folks to do what they want to do.

Shasta Kearns Moore: Yeah, but as you say, it comes down to really simple needs and really simple like can we just be in our neighborhood school?

Shasta Kearns Moore: Can you just fill in the gaps of what's needed here and can we all just live in society together?

Shasta Kearns Moore: I really think it's been over complicated to the point that it's literally impossible to do to make it work in concert together when everybody has their own little turf about, oh, well, that's the school's responsibility to drive you to school and so we're going to make them do it.

Shasta Kearns Moore: But the school doesn't have the wheelchair van, they have this bus and this person isn't trained on it and so then they don't get to go to school.

Shasta Kearns Moore: All these different little turf wars come together and it's like, how about instead of focusing on whose jurisdiction it is, we just focus on the kid and the needs of the kid and then whatever government money bucket you guys have to take out or do what's right by the kid.

Shasta Kearns Moore: You guys figure that out.

Shasta Kearns Moore: But right now we're going to focus on the needs of the kid, right.

Lisa Tschudi: Which is what we do as parents and families for sure.

Lisa Tschudi: And we're often left holding so much of that picture ourselves and finding ways to fill in so many pieces that it really gets to be overwhelming and definitely preclude another sort of life for ourselves.

Shasta Kearns Moore: Not even just filling in the gap between services, but getting the services to do what they're actually supposed to do.

Shasta Kearns Moore: I mean, that was why I quit my job in 2019 was because it was like I was spending like 20 hours a week trying to get.

Shasta Kearns Moore: The school system to do right by my kids and what I do right by my kids.

Shasta Kearns Moore: I mean, like, they were strapping my son in from chest to toes all day long.

Shasta Kearns Moore: And he was neurotypically an eight year old boy who wanted to be moving around, and he had much more physical function than they were allowing him to have at school because of, quote, unquote, safety reasons.

Lisa Tschudi: Wow.

Shasta Kearns Moore: So he was freaking out.

Shasta Kearns Moore: He was, of course, throwing fists in the middle of class because, of course he was I was too, right?

Shasta Kearns Moore: I would do and now it's a behavior program.

Shasta Kearns Moore: And so now we have to do all this behavior things, and it's like, just get him out of his chair and put him in a rocking chair so he can, like, get some perpeceptive input and oh, no, that's too complicated.

Shasta Kearns Moore: Now we have to have 15 meetings about it.

Shasta Kearns Moore: Wow.

Lisa Tschudi: Like, the obvious thing is right there.

Lisa Tschudi: You as a parent are sitting there telling the professionals, this works at home, right?

Lisa Tschudi: This is what he needs.

Shasta Kearns Moore: They're just too concerned about liability or whatever it was.

Shasta Kearns Moore: And so it's really frustrating.

Shasta Kearns Moore: And it gets to a point where, I mean, it got to that point when COVID happened that Saturday that everything shut down was like a relief for me.

Shasta Kearns Moore: It was like, oh, my God, I don't have to do this anymore.

Shasta Kearns Moore: I don't have to interact with you people anymore.

Shasta Kearns Moore: And that's been the silver lining of COVID for us.

Shasta Kearns Moore: It's just realizing, oh, I don't have to engage with the system.

Shasta Kearns Moore: I can pick and choose the pieces that are actually valuable to me, and I can interact with the people.

Shasta Kearns Moore: I literally tell new people now.

Shasta Kearns Moore: Like, you have to prove to me that you are worth the time that I'm going to put into you, because if you're not, then bye.

Lisa Tschudi: Yeah, I think that's a learning curve for a lot of us with a new disability or our family member having a new disability for sure is I think there's this tendency to, like, do all the things and listen.

Lisa Tschudi: To all the experts, and they're going to make it all better.

Lisa Tschudi: And we just have to do these 20 different things every single day.

Lisa Tschudi: And eventually we start to realize, wait, this was helpful.

Lisa Tschudi: That's wasting my time.

Lisa Tschudi: This one would be helpful if I could get it.

Lisa Tschudi: Maybe I'm going to advocate a little more and really pick and choose where to put our time and energy.

Lisa Tschudi: I know I went through something like that, for sure.

Lisa Tschudi: I mentioned being really focused on seizures at a certain point, and then it just became more like we’re going to live life

Shasta Kearns Moore: Yeah, totally.

Lisa Tschudi: Yeah.

Shasta Kearns Moore: That's what I was thinking was when they were little about, wait a second, what am I doing all of this for?

Shasta Kearns Moore: Oh, I'm doing it to live a quote unquote normal life.

Shasta Kearns Moore: Well, is this a normal life?

Shasta Kearns Moore: No.

Shasta Kearns Moore: Why are we doing this?

Lisa Tschudi: Well, we've had a bit of a rambling conversation.

Lisa Tschudi: I've taken up more time of years than I intended, and it's been really wonderful.

Lisa Tschudi: But it seems that I should probably let you go.

Shasta Kearns Moore: No problem.

Lisa Tschudi: Whatever else you have for the evening.

Lisa Tschudi: Yeah, thank you.

Shasta Kearns Moore: I really appreciate it.

Lisa Tschudi: So can you tell my listeners where they can find you online once more?

Shasta Kearns Moore: Yeah.

Shasta Kearns Moore: So, Medicalmotherhood.com is my newsletter and podcast.

Shasta Kearns Moore: You can just subscribe there and it gets emailed to you every Sunday morning at seven.

Shasta Kearns Moore: And then on Facebook, it's like at Medicalmotherhood and then on Twitter, medmotherhood.

Shasta Kearns Moore: But probably my one is easier to find, which is Shasta Km on all the platforms.

Lisa Tschudi: Excellent.

Lisa Tschudi: Thank you.

Lisa Tschudi: And folks, if you're not already following Shasta, you definitely want to.

Lisa Tschudi: She's a brilliant writer and a beautiful presence to have in your social media world.

Lisa Tschudi: This is love doesn't pay the bills.

Lisa Tschudi: I'm Lisa Chudi.

Lisa Tschudi: You can find me on your favorite podcast app.

Lisa Tschudi: You.