

Radical Remedy - Courtney Shanley - Transcript

0:00:00 - Chloe

Hey guys, it's Dr Chloe and you're listening to the Radical Remedy podcast. Today's episode is with Courtney Shanley. Now, Courtney is actually Remy's caseworker here in the state of Colorado for Medicaid and she has so much information when it comes to the different supports for children with special needs. Not only that, but every time I see her, we end up nerding out for hours about the different ways that we can support our children and create more inclusive environments for everybody. She also is a mother to two children with special needs and just genuinely a very caring, kind and intelligent woman.

I think this episode brings so much to people, no matter whether you have a child with special needs or you don't. There's so many important topics in here where we look to find a kinder space for everybody to thrive. Please let me know what you think. If there's anything you want to add to the conversation, or if you think we crossed any sort of lines or made you uncomfortable with anything, I'd love to hear about it and I hope to have Courtney back in the future. I hope you guys are having a the future. I hope you guys are having a wonderful day. I hope you guys enjoy this conversation as much as I did, and I will talk to you soon.

All right, everybody, I'm so excited. This has been a long time coming. Courtney and I have scheduled and rescheduled this multiple times because we are both moms of children with some significant challenges and special needs. I don't know if challenges is the right word, though I can say for me personally, Remy has been fairly challenging this year. He's been going through a bout of hysterical screaming for about two hours a day on average, which is a really new thing for him and really apparently jarring for my nervous system somehow.

But anyway, I'm so excited to be here, Courtney. So anybody listening Courtney is actually Remy's caseworker and she is just brilliant. I love her perspective on how to support kids with special needs, her work as an advocate and her love for her children as a mom, and I think this is just going to be a really fun conversation. I'm really excited to see where it goes. So thank you so much for joining me, Courtney Of course, no, thank you for having me.

0:02:22 - Courtney

It's very. This space can be both so wonderful in finding people who have the same struggles as you and it can also be so isolating, because there are a lot of people who have similar struggles but don't view them in a similar way, and it's really hard to navigate finding your people in this space.

0:02:43 - Chloe

Absolutely. I think that that's why we connected so much, and there are only a handful of moms that I really do connect with in this space. I think you know I'm sure we've talked about it, but one of the things that's really challenging for me is with Remy's disorder. So Remy's got SCXBP1, which is a rare genetic disorder. So there are a lot of families who are very actively pushing to find a cure and looking into genetic research and doing all sorts of advocacy, and I'm in awe of their energy and their motivation and I don't know how they have all of that. I think they have a lot more support than I do, to be honest, but also like they're just really very focused on finding a cure for our kids.

And to me, I look at Remy and Remy is largely seizure-free right now knock on wood, I hate even saying that out loud and mainly very happy, despite the recent outbursts that have been challenging. And so I might be in a very different position in a couple of years if Remy's seizures increase, if he starts regressing, like a lot of the children do, all of those things. But to me I look at Remy and I think that Remy is exactly who he's supposed to be. I can't imagine Remy being any different, and I know it might be crazy or difficult for anybody listening who

has neurotypical children and do not have a child with special needs out there, but I truly would not trade Remy and all of our challenges for a child that was more neurotypical in any way, shape or form.

I just think that our journey is so unique and so much fun and I just really have got to a point of really honoring him for exactly who he is. And that was certainly a journey for me because I know for a long time I was really looking for answers and ways to support him. But I think that you have such a beautiful love for your children also in the same sort of vein, and I think that that's a new perspective on working with people with disabilities, is sort of the acceptance model. What has brought you to that sort of like, like just love and appreciation for your children and for all of the kiddos that you're working with, like it. That just rings so true in how you you talk about the kids no, I, that's huge.

0:04:56 - Courtney

I am for my littlest one. I have a toddler who is autistic and he is disabled. And then I have a teenager who is neurodivergent of many varieties and he is kind of learning how to navigate the world without feeling like he needs to mask or needs to blend in. And realistically, I mean, I, I put a post on Facebook because I just got tired of people thinking that like oh, jem doesn't talk yet, but like everything else is great and it's like no, I'm having a hard time, don't comment on this and tell me about your cousin who didn't talk till he was 12 and now he's a CEO. Because I don't need to have a picture of a bright future or what society considers a bright future to love him today, like where he is right now. That's where I'm meeting him. I love him that way and we have a lot of fun and love and laughs. And if things change and someday he's caught up to his peers and he's no longer considered disabled, that will be cool. But if we reach 17 and I'm putting a pull-up on him before he goes to his high school graduation, that's also going to be cool, like he's just my kid, no matter what, and I think I really have always had that kind of a heart.

I used to teach and so I've worked with kids with IEPs and different abilities for a very long time and I saw myself a lot in them and I also just it felt a lot like and I also just it felt a lot like parents and schools were aiming to get that child to like meet certain benchmarks that they thought were signs of success, which, with schooling, is never an actual sign of success teaching them the things that like could be helpful in their lives, like emotional regulation, or even just like can we do some hygiene work, like that is going to be something that this child benefits from learning, but like being able to sit quietly while you go through a PowerPoint is not actually a helpful skill, like they don't need that from you.

So, just seeing it from all sides from teaching and then to parenting and then to being a case manager I've kind of gotten a really bird's eye view of kids with disabilities and what services are available, which it's never enough to me. So sometimes I have to remind myself like situation here is better than the situation in a lot of other places. But yeah, it's just really it's a unique perspective and I think it's made it easier for me to navigate each space because I have an understanding of the people on the other sides of me in every space.

0:08:07 - Chloe

Yeah, it's. I think it's one of those things where it's interesting, because you don't you don't really realize what it's like to be a special needs parent until you are a special needs parent. You know, and like I know for me, I often feel really isolated because I don't feel like a lot of my friends have any sort of concept whatsoever what my, my life is actually like, and that includes people who are very close to me. But then I think about it and I'm like you know, I had no idea what this was like until I lived it, and I think there are a couple things that you touched on that are really important that I want to dive into one just in terms of for this conversation. I do want it to be also. I want it to help support our other mamas of kiddos with special needs, but also I would like for this conversation to help people who have more neurotypical kids but are looking

for ways to support their friends and their loved ones. You know, I want to find some ways to bridge that gap so they can understand a little bit more of our experience, because I think both of us are very open and honest about the beauties and also the trials and tribulations and that's something that I can be personally very guilty of is sort of putting a good face on when it comes to talking about Rennie.

Because, you know, one of the things that's really hard for me as a special needs mom is people hear about Rennie having this rare genetic disorder and he's nonverbal and he's non-ambulatory. Well, he's ambulatory now but like functionally ambulatory. You know like it's like you got to have a hand on him and an eye on him 24-7. He puts anything in his mouth. He is, you know, by. You know the neuropsych evals he is almost 10, but cognitively around two, for whatever that counts for, I don't think very much, but you know it's really challenging and it's really hard when people hear about that and their first response is the pity face. You know, and it's like I know that's coming from a place where they're just trying to show their love and their concern and their compassion, but it's really hard. And so, like my instinct is, like a mama bear, is to protect Remy and to be like, no, he's perfect, he's the best, he's the best fucking human that ever lived. And that's what I do all the time, to the point that, like you know I was telling you before.

I feel like I'm almost gaslighting myself, because then I get to the point where I'm like I am burnt out. What do I have to be burnt out about? I've got the best kid in the world and I'm like, right, Remy is a full care child, like he takes a one to one caregiver all day, every day, and that's that's emotionally and physically exhausting. So I think it's you know. So I'm just sort of curious, like what's what's been your experience with, like some of your friends and family members and like how have they been? Like, how have there been who has shown up well, and what are some things that make you feel supported as a mom?

0:11:07 - Courtney

So when Jem was born, we were in Georgia and it was during the height of COVID. The day that everything shut down was the day I was going into my third trimester and I was like absolutely terrified. I was like okay, okay, that's fine. There's like literally a plague and I'm about to have a baby. But, um, we one of the reasons that we moved here was because we didn't really have a support system. Both of our parents lived in the northeast and then I had some family in Georgia, but they have their own kids and their own worries and they also have typically developing children and that is different. It is a different experience. So in the beginning he was like a good sleeper and he was a good eater and he was like pretty independent and I was like, wow, like we got the best baby, we are so lucky. And then the bigger he got and the more he could do, I was like this baby is suicidal, I think.

He's trying to kill himself or he's trying to get me to die because I'm going to have a heart attack. And he's now. He's in a size 10 clothing. He's three and well, he'll be four in June. It's not okay. He is the biggest child and the other day he tried to run into the first grade classroom and the teacher was like oh buddy, are you coming to first grade today? And then another student walked in the first grade classroom and the teacher was like oh buddy, are you coming to first grade today? And then another student walked in the classroom and they were the same height and I was like why?

0:12:51 - Chloe

Why can't you do the same thing?

0:12:55 - Courtney

I don't want you to be in second grade looking down at me it's terrifying. But a lot of that, like the services available in Georgia, weren't great, um, to say the very least. And we are a uh, I'm queer and my son is trans, and we're a very loving and accepting family um, of literally

everybody at all times, unless you're a bigot and then you're not invited to the party, and so things weren't looking great on that end of things in Georgia, we were just kind of like hey, like we need to find a place where, right now, this is comfortable for our kids and us, but where can we build a life that is going to be a life that they continue, that they're not going to turn 18 and be like, okay, well, I have to get out of this state now? So we had some friends in Colorado that had been trying to get us to move here for a long time and I finally just reached out and I was like all right, so like how serious were you about that? And within five weeks we were like you hauling across the country, that's awesome, but yeah, so I didn't have the support really. And then we moved here. We do have friends here and they are amazing. They're really good in terms of like inviting us places, even though they know that that might be challenging and it also might be uncomfortable for people who's not Jem's family, because you know him in public is a lot sometimes, but we still get invited to every holiday. Like they know we don't have family here, so they invite us to Christmas and Thanksgiving and Easter and all of that and it's really beautiful. But they're just like I was.

It's like really hard to understand what it's like unless you're in it, and I knew what it was like to teach kids and I knew what it was like to babysit kids with needs and I just like so I felt so confident that I could tell you what it was like. And then I found myself here and I was like none of you get it, not a single one of you. You don't understand what's happening here. But I did the same thing. I was like sugarcoat at Sally and could not let anybody know that it was hard, because in my brain I'm like okay, let's say I vent to somebody on Facebook or in text messages and then someday my child sees that How's he going to feel that I was like so burnt out and so stressed and so exhausted, but at the same time, like I am. But at the same time, like I am and trying to support somebody who will exist in 10, 15, 20 years and lacking support for myself because of that choice, it's like it's still a full time job, just trying to tell myself that it's OK to say those things and to like, seek support for myself. But it's, it's really one of those things that like, unless somebody's in it, they really don't get it.

And one of our friends here she's amazing. My kids call her auntie and she works with people with disabilities, like in day program, and one of her co-workers is a mom of a disabled child and so they had become close and they had this whole big conversation about what it's really like and how you know what we show to people outside of our home is different than what we're experiencing 24 seven. And she came over that night. I was like how can I help you? Like, do you want me to clean while you do bedtime routine? Or do you want me to do bedtime routine while you clean? Do you need to take a shower? Like what are we doing? And I was like what is happening? She was like I had a really eye-opening conversation today and I just feel like you need more support than what we're giving you and I was like what I do. So that was like kind of my first big like oh, this is what it would be like if people got it.

0:17:18 - Chloe

Like yeah, well, I think I mean again it's it's so difficult to understand unless you live it. And then it's also for me, I think it's hard in terms of knowing where to draw the line in terms of what to share, also because you know, Remy has a genetic disorder. I do not expect for Remy's disorder to be magically cured and for him to understand or be able to read or whatever. Like I do think that Remy will continue to advance. We've got potentially stem cells up, coming up this summer, and there's a lot of things coming out that are really really cool.

My focus with Remy is always that I will give him every safe and reasonable opportunity to heal. That seems interesting to me and like a good opportunity for him. But I also, like you said before, I never I'm always gonna love him for exactly where he is. So I try and put no limitations on where he's gonna go, but also no expectations on where he might go. So it's just sort of like let me love him for exactly who he is and let me continue to give him options for healing.

And if him and his soul and his life path decide to align and move forward in whatever way, fucking awesome. And if not fucking awesome. I think more about a different modality and we had another experience at whatever, but like it's. You know, sometimes I'll talk to some of my friends and I'll mention something about Remy being in diapers and Remy's going on 10 and he'll likely be in diapers for the rest of his life and they'll be like, wait, he's in diapers and I'm like, yeah, yeah, he is very just like like I don't understand what you think is going on here, but like my kid is super disabled. Like it's not just like, uh, you know, like he's not, you know, like it. Like it's not like one disability, it's like multiple disabilities.

0:19:10 - Courtney

Right, there's layers. You know there's layers to this.

0:19:14 - Chloe

But it's also like, how much do I want to? Like there's still levels of like, dignity for him and also, like you know, like and also like safety. Like you know, part of me would love to share any more on social media because I'm sick of having him stared at and pointed at out in public and that's a little bit absurd to me at this point. But Remy is a very adorable and like, sort of like, he's just a very handsome, happy kid most of the time Again, most of the time these days not all of the time Make me crazy, but you know, like, he's the kid that like, people often fall in love with once they get to see him and meet him. So, like, in some ways I would love to share him more on social media.

But then there's also the mom of their protective aspect of me, where I'm like, do I want to put my very cute child on social media? But then there's also the mom of their protective aspect of me where I'm like, do I want to put my very cute child on social media? Do I want to put myself through that emotional stress of like what people are going to then say to me and the assumptions people are going to make and the criticisms, like I'm barely hanging on most of the time, like am I really capable of, like putting us out there in that way? So it's just so much more nuanced, I feel like, and it's different for every family, Like, obviously, anybody who's listening. We're not like generalizing for every special needs family. We're just talking about our experience and how we, we interact with our kids and are dealing with that.

0:20:42 - Courtney

Yeah, social media is really tough too because, like for a while, I was going through things that I was doing parenting wise with my teenager that I felt were really, really working. And one of those things was that he had a bank account and it was linked to mine so I could see his bank balance and I could see what charges were there, and then also I could transfer money into his account like super easily because they were connected and he had like a big trip coming up in the summer that he was really excited about. And he is a kid who, if you go into a store with him, he is going to get something like that is just, he's going to find something that really interests him, he loves, he collects all kinds of little knickknacks and trinkets. And so I was like, listen, dude, you're going on this big trip this summer. We're, we're all going to be at the beach. We were, we stayed in LBI in New Jersey, so it was like little beach town, tons of cute shops, and I was like I know that you're going to want to buy everything and that's great, dad, and I cannot do that for you. So we are paying to get us there, we are paying to stay there. We are paying to get us home, we will feed you, you're going to be fed and we'll probably buy a trinket or two, but we cannot do like the endless things that you're.

And thank God I did, because we went to an arcade and it was insanity. We paid for the tickets for the arcade but there were so many things. He was like I want this coffee mug and this thing and this thing. And I was like, but with that bank account, I had told him you know, we're going to put you on a spending freeze, because he is very impulsive and he was very much like seeing something on Amazon he wanted, and then he'd be like, okay, I'm going to buy that. And it would be something that he absolutely didn't need or something that he already had or

something that I just knew was like a momentary interest, yeah. And I was like you're going to run through all of your money before summer and then you're going to be super upset when you find things you really, really want and you can't get them. So he agreed.

He was like that's true, like I want to, I want to keep that money and I don't think I can do that on my own and so I'm telling the story on TikTok I think it was and he what he had eventually done is the idiot that he is spent all of his money on Roblox gift cards and then told us that the charges weren't from him. So we called the bank and we were like hey, like somebody hacked this account and the bank shut it down and everything. But Roblox said this account is using stolen gift cards, so this account's getting banned. And he had like 10 years in that Roblox account and probably thousands of dollars had gone into that Roblox account and he was thousands of dollars had gone into that Roblox account and he was absolutely devastated. But that wasn't like we didn't punish him further than that because that was big, like that was a big enough, harsh enough consequence that we were like okay, nothing that we would have done would have even come close to this. This is like aggressive, but we have no control over this, because we told the bank that somebody stole your debit card.

So like I don't know what to tell people and people were tearing me apart for having him on a spending freeze and I was like he's 13. Like I wish somebody had taught me how to not spend every penny that I got when I got it. I would be in a better place now as a parent and I also wouldn't have such a hard time with like budgeting and saving for things like I Like. I wish somebody would have taken the time to like teach me those skills and in my parents' honor, for their sake, they didn't have the skills either. So it wasn't that they just didn't teach me, they also did not know how to not spend every penny as it came in.

And I was like he asked, like he agreed on the spending freeze. That wasn't something that was imposed on him, it was something that we suggested. And he was like yeah, I think I need your support with this. And people were like well, it's his money. You can't just stop him from spending his money. I was like what? It's not like his dream car came into the driveway and somebody was like I'll give this to you for \$300. And he was like I'll give this to you for \$300. And he was like I have that. And I was like no, you don't, you're not getting that.

0:25:32 - Chloe

I don't think I was still a kid.

0:25:34 - Courtney

Right Social media is. So that's like. The hard part is, I love sharing my kids, and especially because I think I oh, why do I have such a hard time saying this? I know that I'm a very good parent and that I'm really conscious of my kids' emotions and like that behaviors are always a need and finding that need and addressing that instead of the behaviors I'm. I've gotten very good at that and I was sharing this so that other people could understand.

Like, oh, sometimes the consequence that the world gives your kid is so big you don't need to also ground them or take away their cell phone or whatever. Like, sometimes the natural consequence that occurs is enough for you to be like, I think that's enough for you to learn your lesson, and I'm not gonna further bury you in shame and guilt over a mistake you made that has already, you know, been really hurtful in consequence. And people were just so caught up on like, why is your bank account attached to his? And I was like, because 13 year olds can't have independent bank accounts? Like, I don't understand.

0:26:51 - Chloe

It's so like I feel like it's I get it's so. It's so daunting because you just get like so many opinions from people who have no idea what's going on and are getting a glimpse of the story and it's like it's. It's such a hard. I have such a hard time with it, cause it's like I really would like for

people to understand disability more. I would like for people to be less scared of my child. You know like we live in Boulder, Colorado. You know like I, it's it's like one of the yeah, and if you're here in Boulder, the fuck list it up, because I'm pissed and I trashed Boulder Valley School District all day. I like literally I bully them. I've taken to bullying Boulder Valley School District on my Instagram, like I tag them and shit all the time and I'm just like I don't care the time and I'm just like I don't care their social media managers just like huddled in a ball crying somewhere why?

who is this mom? But the? But Boulder Valley School District, just so, just so you guys know, like services, um, very and I guess this is just pulling me in a different direction now but services vary dramatically state to state. And so Remy was born in New York City. No well, Remy was born in Colorado. We moved back to New York and he was in preschool there where he was. So first anybody listening you start with early intervention, which is basically services where therapists will come to your house and work with your child. Remy in New York is getting 20 hours of early intervention a week. So that's a lot of work for him, a lot of work for me. So that was from when he was one until he was three. Then he went to preschool in New York. He was getting an hour of PT, an hour of OT and an hour of speech every day at school in New York. You know we had a lot of things unfold there that I'll probably get into on another podcast but seems unnecessary for this current point. But anyway, ultimately we moved back to Colorado and I'm super happy to be here.

There's a lot of reasons why it's a great state to live if you have a child with disabilities, which we'll get into also. But when it comes to the school district here, Boulder is like the wealthiest, wokest, like most inclusive town city that, like I've ever been to and like, let me tell you, the way that parents pull their children away from Remy when we're in the playground is just heartbreaking. Like it just demolishes it. Like I get that kids are going to be curious and so please, if you're listening, just understand that, like, at least for me again, I can only speak for myself and, like everybody else, I have good days and I have bad days, but 99% of the time I would rather an uncomfortable conversation that leads to inclusion than for you to avoid the situation and pull your child away from Remy.

I understand that kids are naturally going to have questions about why my child is in a wheelchair or an adaptive stroller or why Remy uses a speech device. That's totally natural and I'm absolutely happy to talk to you and your child about it. But, like, also recognize that, like I don't know your kid, I don't know what your that like, I don't know your kid, I don't know what your kid understands, I don't know what's going to be helpful in that conversation. So, like, if this is a situation that happens, which does happen often. I would much prefer if you also come over with your child to me and Remy so we can all have a conversation instead of instead of avoiding it, like it's just so frustrating to me.

0:30:28 - Courtney

It's super frustrating. I actually had a funny interaction after Jim got out of school the other day. He likes to run to the playground but of course he cannot be satisfied with the preschool playground. He needs to be big kids playground because he is a danger ranger. And so he's climbing up this giant slide and the bigger kids are like on the outside of the equipment just like dangling making me nervous no one else, no one else seems to care.

but I'm like you're not supposed to be in that spot, be in that spot. And so the one child she's had to be like 10, turns around and she's like, hey, does he talk? And I was like no, like he doesn't really talk. And she goes, guys, he doesn't talk. That's why he doesn't talk back to us. He's not being mean.

0:31:26 - Chloe

All of these older kids thought my two-year-old, was just like, or three-year-old was just too cool for them.

0:31:31 - Courtney

They could not be bothered like that is like, that is exactly what I'm looking for. Because if those kids were always, you know, like if the parents were like no, yeah, don't go over there, you're gonna ask questions that are uncomfortable, like I was so happy that kid looked at me and said does he talk?

0:31:54 - Chloe

totally well in in. I used to take Remy down to Ecuador to a neurologist down there for like a month at a time. We went like six times and down there people would just come up and be like what's wrong with your baby, you know, like, and like of course that's like very, you know, dysregulated nervous system to hear. But then I would be like, okay, they're coming from a place of like trying to understand, and then I would talk to them and it would lead to like a wonderful conversation and we would talk about their family members who might have some sort of cognitive or physical challenges or whatnot. And you know, like I'd rather. You know it's just such a stark difference here and I understand that people are doing it because they're trying to make it more comfortable for us, so that I'm not feeling uncomfortable or Remy's not feeling uncomfortable, but like, just as a side note, like we are both aware that Remy is disabled, like I know it, and I could not be more proud of him than I am, like I, you know. So again, it's one of those things where it's like I just think that more communication and more like the inclusivity, it just makes such a huge difference. And the kids. So Remy's integrated into a classroom in his school here in Boulder.

What I was getting at before, which I got sidetracked again for, was that here in Boulder Rennie gets half an hour of PT, OT and speech a week at school. But we do get services. I get paid as Rennie's caregiver here in Colorado, which is not something that most states have. So that is a tremendous, tremendous asset when it comes to Colorado. So I'm sort of skipping all over the place here because my brain is just excited about all the things, but I do think that it's interesting state by state.

So that's one thing I would love to talk about sort of just the basics of like services, so that people can understand you know what your friends are going through or what you should be looking for as a parent in terms of trying to support your child best, because some of these services are legitimately life changing for families. I mean, I get a full time salary as Remy's mom and if I did not have that I do not really know what I would have done this past year. So it's it's really quite astounding. But there's also dramatic differences state to state as well. So like even let's start from the basics in terms of like what is an IEP?

0:34:27 - Courtney

Right. So IEPs are individualized education plans and you're going to create an IEP with your school district if your child has a qualifying diagnosis school district if your child has a qualifying diagnosis. If you don't have a qualifying diagnosis but you can tell that your child still needs accommodations, you can make a 504 plan. Those don't require a diagnosis. They're more based on meeting your kid where they're at. But IEPs follow your kid from school to school and including to college. So if you get towards high school and you're still seeing that you need that support, if you keep your 504 plan, that won't go to college.

So I'd always recommend by high school, if we're still needing accommodations, let's make it official and get an IEP. But most of the time the IEP team is you, sometimes your child, if they're interested in being involved and if they're old enough. There's no like official age but you would know if your child can give good input or if things that they would hear during that

meeting might be hurtful, you might not want them to be there. And then the teacher and anybody in the district that works with your child.

0:35:39 - Chloe

If you're in OT or speech, those people are usually included and sometimes you even get like district level special ed people that attend, but it's usually you and the teacher, you and the people who work like really close with your kid who are doing the legwork and you're just looking. Just a side note of personal pride, I have like the head of the entire special education program of BBSD and like the lawyer for Boulder Valley on like half of my IEP meetings because they hate me so much, which is just like I'm very, very proud of as an advocate for my child. It just shows that Brooklyn is doing well and yes, it's necessary.

0:36:23 - Courtney

No, that's another thing. If you have a child with extensive needs, go live in New York for two years, toughen up, yeah, and then come back. Come back and advocate, but yeah, it's just a pretty intensive process. You're going to redo that IEP every year to adjust the accommodations and the school is going to be collecting data that entire school year to either support services that you're getting or to advocate for different services or to say this isn't really a needed accommodation anymore. Your child doesn't actually need access to that. So for Jem he's three his meetings look more like how can we accommodate the environment and the curriculum to be accessible, and I think a lot of it too is just. This is where me being his mom comes in. I absolutely do not let them do anything that is related to making him act or behave in a way that they think children his age should act or behave, or like there's no goals for making eye contact in his IEP, like all of that is scratched. We want him to engage and his teacher is amazing and she's not going to be his teacher next year and it's really upsetting, but she's amazing. And so when the class is tracing letters he's not like a big drawer colorer. He doesn't really care. So they give him a Hot Wheels and he uses that to trace his letters in his name and he says the letters and it's like that's what we're like. We don't need you to make him do the things that the typically developing kids can do. We need you to modify what you're asking in a way that makes it engaging for him, and so he knows his whole alphabet. Now he says it, he'll get like really attached to like a five letter sequence. So some days it's just like W-X-Y-Z, w-x-y-z. I'm like, yeah, man, those letters, they're really, those are good ones. And then like he can recognize the letters and we're like all right, cool. So what you're doing to make that engaging for him is working because he's learning the material. But if they had just sat with a crayon and tried really hard to get him to trace these letters, we might be looking at an ABC stop as his alphabet. So that's the goal of an IEP. The schools probably won't tell you that.

Piece of advice is to go on social media like TikTok and Instagram and find some accounts that are made by people raising children with whatever disability or diagnosis your child has, and look at the people who are like in real time, living that life, not the professionals who treat those children, not therapists who who treat those children, not therapists who work with those children, not schools that have a really good program for those children. You really want to look at the parents and like the things that make you feel good to see a parent doing with their child. That's what you want to lean into, because a lot of parents are going to be like, oh well, we're really trying to get potty trained, so I don't give my child water after 5:30 at night and I'm like that to me seems like a big problem, and big problem is like a wild understatement yeah, I'd rather have a bedwetter who's hydrated. I don't know Like I, that's me. So when I look at those accounts, I'm like, okay, if, if, what they're doing with their child, even if it's working, if that doesn't feel like something I would be proud to tell people I do with my child, that's not the account for me and that's okay.

Everybody parents differently, but you'll find your people and social media. It's just so much easier because, like, distance doesn't matter and location doesn't matter and like, my available time to scroll social media is like midnight to 2am, so I don't have to worry about if the person

that I'm trying to connect with is more of a nine to five. That's not going to work. I'm not going to find that connection, but you can if you're looking globally, and that's how I've learned a lot of the stuff that I know. I went, I have a degree in teaching, so I knew a lot about kids with extensive needs, but I didn't know a lot about living with them and teaching them how to be people. And I knew about, you know, like getting them to do a history essay and like how to modify that for a child's needs. But what I'm really proud of now is that I'm always looking at the why. There's never like a question that is just yes or no, because that's how it's supposed to be or that's how every other kid with autism.

This is in everybody's IEP. I don't care why. Why does he need to make eye contact? If you can tell me a good reason why he needs that skill, then we can discuss that. Why does he need to not have an emotional response when he doesn't get his way? He's allowed to have an emotional response.

Do I want you to let him beat up another kid? Absolutely not, do I think you can give him a squishmallow and let him throw it on the ground 40 times until he feels regulated again and can move on with his day. Yeah, I'm gonna tell you to let him hit the squishmallow, it's not gonna hurt anybody. So it's a lot of that. A lot of IEP work for me is looking at the why. If it's not contributing to a skill that I think he needs, um, and that's whether he's stays really delayed for the rest of his life or he catches up like eye contact is never going to be important. If it's important because it makes you more comfortable when he does it, then that's not important for my child. You need to learn how to be comfortable with someone who doesn't make eye contact. That's a you problem.

0:43:07 - Chloe

Yeah, absolutely it's. Yeah, it's funny the ways that so many like the education system largely is created to create good workers and so the explosion of neurodevelopmental disorders that are going on is creating quite a challenge for the school system. To try and put these kids in boxes, like they've literally tried to have Remy do math. Most adults, I know, can't do basic math. Like Remy does not need to do math. Like let the kid party. Like he's at school for socialization, because guess what Remy does not need to do math. Like let the kid party. Like he's at school for socialization. Because guess what Remy's not invited to birthday parties, never been invited to a birthday party, never been invited to a play date, there's no summer camp, there's no soccer, there's no sleepovers, there's no fucking nothing. So this is the only place that he gets hanging out with other kids.

Let's focus on that because largely, like the schools don't really understand supporting the neurology and the nervous system of our children. They're taught, you know, on a very old model of sort of. You know, have these kids fit into the appropriate box and literally one of the things from these OT Cal, if you listen to this, I love you. I'm sorry, but you know I meet the teach boxes she has for me, take these things and then put them in a hole it's called a teach box and she's like obsessed with them and she's so proud of how well he does with them and it makes my head want to explode. So one of the things you're talking about in terms of how you support your son is sort of really like the floor time model versus the ABA model. So I just wanted to break that down very briefly for anybody who's listening in terms of educational styles. So floor time was created I think his name is Richard Greenspan, I have all of his books but it's basically building upon circles of connection with a child and building upon their interests. So like exactly when you said, like they took the car and they have them trace it with that Brilliant, you know, with Remy he has always just loved bubbles and balls. So like getting Remy to throw a ball back and forth and continue to engage, or we'll sing like twinkle, twinkle little star and we'll leave off the star so that Remy can vocalize that and I'll go, oh, and it's absurdly adorable.

But so floor time is sort of following their natural interests in order to encourage that increased connection with the person that they're working with and increased understanding of whatever it is that they're that you're trying to work with the child is it's really like natural learning, like I think that's what we've always done largely, whereas ABA is something that you know I think I speak very harshly of as sort of you know, more of like a. You know, my understanding is largely a lot of ABA training is just trying to help the kids perform better in society to fit that mold and it's a lot of repetition and it's not very individualized. It's just more focused on getting the kid to smile, say hi, sort of rote memorization in order to mask more appropriately in society, and I understand that it's been like changing for some people. I've also read essays of people who have done ABA and said that it was like torture. It seems like torture to me. I don't think it would do well for me personally, so it's not something that I'm willing to sign Rennie up for. So I'm a very big fan of Flores. I'm not so much of ABA.

But those are also educational models that you can find in different schools and different therapists and, just on that note, like any therapist or doctor that you go to, if your child does not connect with them. If you do not connect with them, get a different one, like I used to be, like oh it's okay, and like I'd hate his pt or somebody like would be doing something I didn't like and I'd just be like really silent about it. But, like over the years of getting fucked over and fucked over by the system, eventually you just don't care anymore and then you're like the school district's number one enemy the school district's number one enemy.

0:47:19 - Courtney

It's such a goal, you know it is I want like a plaque I'm aspiring to. We should get you like a cape and like a little mask.

0:47:33 - Chloe

And the cape says like BVSD beware, it's so entertaining. I'm on the Special Ed Advisory Council and like the first day we had to go around and say like what's going well at BVSD? And so everybody goes around and they're like it's great and it gets me. And I'm like, well, my son's parents are phenomenal. I love them. They're like game changing. They take such good care of him Like I could not be more grateful of them changing they. They take such good care of him like I could not be more grateful of them. And then I was like, particularly since they're underpaid, under vacuumed, under trained, they are taken advantage of, they're not paid any days off, they're not paid for this, that or the other and they are not respected by the district whatsoever. And everybody there's just jaw just drops and I'm like let's tell it how it is. Like you know, like my son needs one-to-one care. My son needs his diaper changed, my son needs, you know, somebody who's really gonna be patient and loving with them.

And these people go above and beyond and they're getting paid. You know low 20s. You know like they have no education in this in boulder. They lean on the Paris for like all of the services. Like they argue that Remy doesn't need more PTOT and speech because the Paris are doing it, and I'm like, well, that's fascinating. Are the Paris trained in that? Like not that I don't think it's Paris can do it, but I'm like, are the Paris trained in that? Are the Paris paid for those additional services? Right, is that their job? So it's just, I'm always advocating for the powers because I'm like these are the lifeblood of some of these programs and they're just so unappreciated the um.

0:49:08 - Courtney

my son has paras in his classroom but he doesn't have a one-to-one. He probably needs a one-to-one. I'm hoping that next year he will have a one-to one. But the other day we were out for a walk and his para pulls up and she's like hey, jeff, how are you? And she's like in her car. He loves cars, so he's like so excited. She's like I love your sunglasses and I'm like. She stopped in the middle of a road, by the way. She's like not at a red light, not at a stop sign. She

just saw him and stopped and engaged with him and I was like I love you, I would like you to come over for Thanksgiving.

0:49:45 - Chloe

Like they become your family. The pairs are amazing. I will say I meant to say this before, since Remy is in an inclusive class, one thing that does also happen. As much as I talk shit about people like running away from us, we do often get stopped also by people who are in school with Remy and the kids will be like, is that ready? And they get so, so excited to get to see Remy and then to get to show his show their parents that this is Remy and I'm always like huh, she must go to school with Remy, but it's super, super, duper cute and like. I so appreciate that also. So, like the inclusivity is so important and, honestly, anybody who's listening.

If you have a hard time figuring out how to talk to your kids about disability and I'd love to hear what your sort of go to is, but, like for me, typically I just say you know Remy has a disability and his brain and body work differently than yours, so some of the things that are really easy for you or some of the things that you can do are pretty challenging for him. But in a lot of ways he's also very similar to you, like he loves to play with balls and to play with water and go swimming and blah, blah, blah. Um, but you know he also uses a speech device to talk, you know? So, even literally just saying, like, his brain and body work differently. But he, like this one kid, yeah, his brain and body work differently than yours because he's he, you know, his brain is a little bit different, but he likes to party too, and the kid was like cool and that was it. I love that.

0:51:18 - Courtney

I think it's so simple, sometimes so simple, and that's the thing too.

I think sometimes adults get in their head because, like the world is more complicated for us, we have a different view than the kids do, and I have this conversation with my clients' parents a lot, because so many kids are that kid where, like they're out grocery shopping and kids are coming up and saying hi and their kids just like, like not not engaging, and they're like I have to say hi back and it just seems like all of my clients that are, you know, kiddos with extensive needs are like the kid everybody recognizes and everybody knows and everybody knows and if that's happening when you're not around, the best thing that you can do is lean in because they're already doing the work of being inclusive.

It's when you pull back that that kid learns that pulling back is an option and the people they trust most in this world are doing that. So maybe they're supposed to also, and even like just knowing that it might feel to you uncomfortable to have that conversation and you might even think it feels uncomfortable to us to have that conversation, but think about how uncomfortable it would feel if you had an invisible 10 foot diameter barrier around you that no one wanted to enter, because we exist, we know what's happening. We see everybody taking that big bubble and not entering, so that's uncomfortable, honestly.

0:53:01 - Chloe

It's like my giant German Shepherd puppy when he crouches down and I'm like not everybody can see you, like you're not sneak attacking this dog. It's so ridiculous. Yeah, it's, you know. I think people mean well, but I think it's hard to understand and it's uncomfortable to face the challenges that we're doing. And so I think people sort of shy away and maybe that's something I know. For me, maybe that's something like I push people away because I'm scared or whatever.

I'm constantly working on my shit also. I'm certainly not a perfect human, but you know, when the pandemic hit for me it was just so eye-opening because all of my friends were calling and were freaking out and they were like this is just so awful. I've never been this isolated. I just

need to go out and see people and I've been a single mom to Rennie since he was one Right, so like full-time. He's never had a babysitter until a year ago and that's very sporadic. His dad does watch him sometimes and his dad and him are like absolutely love each other. But it's, it's really me. I'm fully financially and physically responsible for Remy. And so the pandemic hit and there's lockdown and everything. Everybody's freaking out and I'm like nothing about my life has changed.

0:54:22 - Courtney

Nothing. A lot of times we do self-isolate, but God, we only have so much energy and being in our house, where we have modified the environment to be as safe as possible so he doesn't have access to things that it would upset us if he broke. That is hard to stay in that environment all day long. So to take in somebody else's house where things are like in the last I want to say 14 days, I've cleaned poop off of the TV on four separate occasions. Nobody else is going to want that in their house. Okay, and guess what? It's not like I don't have an eye on him, it's just sometimes I also have to use the bathroom or I sneeze and I close my eyes for 10 seconds and when I open my eyes he's on the ceiling. I just not allowed, I can't take it. But so, like a lot of times we'll get invited to something I'll be so excited to go, and then the day of I'm like I am too exhausted to get him already, get him there and then have to be vigilant on it 100% of the time. And it's not like if I need to step out because I have to go to the bathroom or because I need to grab something from the car. I can't just like trust that another person, even if they're a parent, will be able to give him the level of attention that it takes to keep him safe, like that's. It's. It's unreasonable, it's, it's inhumane for me to have to keep this level of vigilance so much. And I'm grateful because I have a husband who is really on it and he's really with the kids and he actually because Jem's needs have escalated a lot in the last like two months. He stopped working so that he can be full time with Jem. Because I was like I totally understand that, like, you have a job and it's a job that you have, okay, but these kids depend on me and I can't leave my job because I have 37 kids in addition to Jem and Charlie who need me. Those kids are counting on me and the thing is the thing in this system, even the case managers, who care a lot they it is a job. They are clocking in and clocking out and a lot of times parents are not getting the support they really need and case managers can only do so much. If there's not providers, there's nothing I can do to connect you with a provider, but I might know of a weird thing you can buy on Amazon that will help alleviate that behavior for like 15 minutes at a time so that you can like go to the bathroom, make a cup of coffee, whatever it is that you're going to do. And so I have a lot of this like strange side knowledge that I can apply that helps people.

We had a case manager put in our group chat like a few months ago that the parents were traveling with their child for the first time with autism and they were asking, like is there anything that the airports do to support? And I was like you know most airports do, but it depends on where you're flying in and out of. But here are the things that I know that you can do in any airport and they have to honor it. So you know you can skip the security line. You can go through pre-check if you have a child with you who has autism, or if you have an adult with you who has autism, if you have autism, you can go through that TSA pre-check without TSA pre-check. You just tell them you have a disability and they're like OK, they don't ask for identification, they don't ask for identification, they don't ask for proof, they're not allowed to do those things, and then you don't have to spend two hours in a security line where your child's freaking out because they have to stand still or where your anxiety is getting so bad because the people around you are making that experience so uncomfortable and so painful. You don't have to do that. Skip the line.

Southwest doesn't assign seats. You have to pay a lot of money if you want to be one of the first people on the plane and if you're flying with a family, you might end up all having to sit in separate places on that plane if you didn't pay that extra money. Except if you have a child who has autism, you get to board first and it gets to be the person who has autism and one

additional person. So for both of my children, they both have neurodivergencies. So my husband boards with Charlie and I board with Jim and we get to do it ahead of everybody and we all get in the same row. Amazing, Wonderful. That's things a lot of parents don't know, though.

0:59:25 - Chloe

And the reason I know that is because of a weird obscure Facebook post that my sister-in-law sent me once. It's it's amazing the amount of information that we all gather over time and so much of it is like. For me it's like either the STXBV1 family pages where, like, people will give information, or like a local Facebook special needs parent group. Um, like you know, and and we'll go into the waivers now because I think it's so important because I, you know, in New York, I finally got Remy set up for a waiver in New York. Um, so basically, my understanding is there are different waivers based on the state and these waivers are basically through Medicaid and they provide people with disabilities or families of people with disabilities with certain services, and it all depends on the state.

And so in New York I had to file all this paperwork and then in a year later, as I'm about to move out because Remy was kicked out of school in New York, he gets approved, but the ones in New York you basically have to.

It covers a bunch of expenses, but then you have to file all of the paperwork to then be reimbursed for all of the expenses. So it covers up to like \$30,000 or \$40,000 a year in like transportations and additional doctors and like different things. But then you have to file all this paperwork which for me, I just can't do, like most of the time. If it's something like that, like just adding on to my mental load, which is already like beyond exhausted, to like fill out a paperwork to get like \$50 back from a taxi that I took to take him to therapy, like is not, I'll just eat that cost. I'd rather see another patient or do something like that than like spend an hour trying to figure out a form and submit it to wherever to be reimbursed at some point In Colorado. You know, as I said, I'm paid as Remy's in-home service provider.

1:01:13 - Courtney

Long-term home health.

1:01:14 - Chloe

Yeah, yeah, and there are different waivers here, so like unpaid hourly for a certain amount of hours that Remy needs additional support for. But can you break down sort of the waiver system and how they're different in different states, or just sort of you know an overview for anybody?

1:01:32 - Courtney

Everything varies state to state. The way it works in Colorado is what I'm most familiar with, and it's essentially getting on a waiver means that you qualify for Medicaid. So what it does is, if you don't qualify because of your income but your child has developmental delay or disability, they could qualify for Medicaid through the waiver. So then that covers all of those additional health costs and therapies and all of that extra stuff that comes with it, which is why a lot of people get on the waiver. So a lot of people are like I don't even care what the waiver does for me, I just really need that Medicaid.

1:02:10 - Chloe

Yeah, well, I mean, even just like everything for a child with special needs is upcharged like 2000%, like his Remy's adapted stroller is like \$4,000 if you get it, if you pay for that out of pocket, you know. So it's like there are a lot of like I've sent hundreds of thousands of dollars on Remy and his extra care and other supports and and then that is not an exaggeration I do not have that money.

1:02:37 - Courtney

I'm not like and then that is not an exaggeration, I do not have that money. I work with the HCBS waivers, which there's three of them. There's the CHCBS waiver and then there's the CES waiver and the CHRP waiver. Chrp waiver is residential, so there's a lot fewer kids on that waiver because most people are going to do everything they can to keep their child in their home and so the children living with their parents. The options are CHCBS or CES. The main difference is infuriating. Chcbs is essentially for children who need facility-level care at all times. So this is supposed to help their parents keep them from being put in a facility by supporting them financially and with Medicaid through taking care of their own child, which is awesome. But the CES waiver is full of therapies. So you can get movement therapy, you can get music therapy, massage therapy, water safety training, hippotherapy, and then on top of that you can get respite. You can get community connector, which is essentially just taking the child out into public and working on a goal. So for me, a lot of times the goal is just don't run away from us. The goal is stay next to us, hold our hand when we cross the street. The goal is if you are having a hard time emotionally don't beat the crap out of me. So every time we go into public we're doing this and you can either hire a provider to do that or parents can do up to 10 hours a week themselves of Community Connector and be paid. That's an amazing service, very, very helpful.

The problem is with the CES waiver. You have to have a physical intervention at least every three hours overnight for your child to be qualifying for the CES waiver, which I think is their way of mitigating what families need respite and homemaker services, which is somebody coming in to help you clean up. I think they're thinking okay, if parents are up all night long, respite is going to be necessary, homemaker is going to be necessary, but if parents are getting a good night's sleep, they might not need the break, which is an insane thought. But the fact of the matter is why do the kids on the CHCBS waiver that does not have nighttime intervention requirements not have access to the therapies of the other kids? Because getting a full night's sleep doesn't make a kid more successful in therapies or not. It doesn't make therapy less helpful. What you've done is the CHCBS kiddos. The only benefit essentially is Medicaid and if they're eligible for long-term home health, the parent can get paid for providing that.

But on the CES waiver the parent can be paid for providing homemaker and community connector to their child, which I'm sorry, but a lot of times going out in public with our kids is more work than it is worth. So if you want me to take my child with me to the grocery store, the best way to do that is to say, hey, that four hours you're about to spend at King Supers, you're going to get paid and I'm going to be like, okay, so that makes it a little bit worth it. Otherwise, the four hours I'm at King Soopers, when going by myself, would have taken one hour and way less energy. That's incentivizing me, which means kids with disabilities are being brought out in public more because these parents are incentivized and that means that all the kiddos who don't have disabilities are getting more experiences where in a regular setting in their life, during a regular activity, there is somebody with disabilities present and that leads to inclusion and so that's wonderful.

But why are we only offering that for kids who require nighttime interventions?

Why are we not offering the therapies for all kids?

And then let's say there's a higher tier for kids who do have nighttime interventions, and that one has added homemaker and added respite and additional supports for parents who maybe aren't getting sleep.

But the kids what they can get from a waiver, should not change based on whether or not they sleep through the night.

That is wild to me. It's one of the most upsetting, one of the most upsetting parts of working in the system and I've actually been like really not a lot of energy put towards it, but I've been working on drafting a letter to the state because I can see the big flaws in this system from a seat that not a lot of people working in the system have and like. Another thing that really frustrates me is that the kids have to be present for their annual. It's like a requirement when we do that annual assessment to make sure that they're still disabled enough to qualify for this waiver that the child needs to be present for. And they're like, oh well, it's fine because, like the child doesn't have to sit there the whole time, so you just have to see the child and then they can go like play in their room and I'm like, okay, and what about parents who live in a two bedroom apartment and now that child is in their room?

1:08:53 - Chloe

playing and hearing how difficult taking care of them is. Do we think that's healthy? Some of these kids are 16 years old, yeah Well. And on top of that, like, where would, where does Remy go? Like Remy's, not like Remy.

Again, there's no safe space for Remy, even in my very Remy proved house without eyes on him. Like yes, I feel like he's. You know, I have things blocked off, so like if he's in the living room I can go and peep, you know, like quickly, I feel pretty safe about that, but like there's some gray area there, you know, like he's a Tasmanian devil and he is a total risk to himself if he's not being watched. So like he would literally have to, you know, sit with you, which you know, that made I do. True, talk, real talk, that's always my goal with him. Like I talk about things and I'm just like, look, this is what it is, and like I try and just be, I try and speak to him Like, like he understands I don't know if he understands, he understands a lot more than he lets on. I'll tell you that much and you know, whatever, but yeah, it's a huge challenge to do those meetings while having the kid there. It's also sort of traumatic for the parents. This is something that I fight about a lot because we have to do all of those.

I don't know if you've gotten the joy of doing all of the assessments, but it's like every year I'd have to do at least like 20 pages of different, like multiple choice assessments and like a lot of them will start with like is your child able to make verbal decisions? And you're like no, he is nonverbal. And then I have to answer 250 questions that are based on that first one that are all no, um and like. Literally last year they had me fill out one that asked if Rennie could price shop for over-the-counter medications and make minor household repairs. I put it on Instagram to let Boulder Valley Schoolers like know what I thought of it.

I mean, it's just like are you like? Why are you like? And and now I just get really, really indignant about it and I'm like you are wasting my time and I am the mother of a child with a potentially life-limiting disorder. I do not have the time for you to waste, for me to go through these things, which are not only a waste of my time but they're traumatic, for us parents to have to answer no, all these times to these questions over and over again, like no these, you know, like that's a ramp, sorry.

1:11:09 - Courtney

I just didn't know it's necessary. I'm I have to do the assessments now from a parent point of view because gems on the waiver and from a case management point of view and the biggest flaw that I see, I understand with adults with disabilities. It makes sense for that person to need to be at that meeting, right, because a lot of times they are their own guardian. That's important. Even adults with guardians, it's still an adult and they should have a say in what supports they're getting and in what kind of things that they're not allowed access to. That is reasonable. But my three-year-old does not need to sit through me talking about all of the

hardest parts of being his mom and describing to you what ways I have to intervene that typical parents of typically developing children don't have to. That is traumatizing for me, traumatizing for him and I'm cognizant of it. So if that's a meeting I'm having and Jem is present, I will say I'm going to send you an email with that information when we're done with the meeting. Or I'll say you know, hold on one second. If we're going to touch on that, I'm going to have my husband take Jem outside on the tramp, like I'm not going to, I'm not going to put my child through that. Most parents don't have that understanding. They also don't have the bandwidth to try to fight with somebody in the system who might tell them no, your child has to be present, like it's just not. Every parent is clued into the fact that their child probably understands what's being said. And even if your child is like pretty close to typically developing, let's say they have a seizure disorder. Having to hear how traumatic it is for you when they have a seizure is traumatic for them. And guess what Anxiety about having seizures can trigger seizures. So are we now making this child's condition worse by requiring them to be present at this meeting, even if they don't have to sit there?

You're telling me, if my 16-year-old knew that I was having a meeting with people about him, he wouldn't be like at the top of the stairs listening like he's. He's a teenager, he wants to know what's going on and so that's infuriating that whole like system. And they understand too. It's like oh well, we are a checkpoint for if kids are being abused, and okay. But guess what, in the long and short of it, as a case manager I have to see that person physically, see them, that child, twice a year. Their teachers, their therapists, their doctors those are seeing the children every week, if not more often than that. So what kind of a checkpoint am I being if parents have to fake it for like four hours out of the year? They're going to be able to do that with me, but they might not be able to fly past an OT who sees them every week and comes into their home and is part of their support structure. So I don't think that child needs to be there for that appointment.

I think you're wrong. I think that meeting can be done without that child. Now, granted, you can have parents who say that things are a lot worse than they are, so that they can get the Medicaid and get the services. And if you don't see the kid, maybe you know you won't have been clued in. But I'm going to tell you right now.

And if this gets me in trouble at work, I'm sorry. But if a parent said to me my child is incontinent and we experience a lot of fecal smearing and that cleaning can take hours a day, and then their child walks by and I can tell that they are not wearing a pull-up, I am absolutely not challenging that parent on that statement I'm not going to be. Like really, because he looks like he can handle being using the toilet, like no, I'm not going to do that, no matter if I see a child and it aligns with what the parent's saying or not, because that's not my place. And also, Medicaid is one big system. So if what I'm putting in the system for the waiver does not match what their doctor, pediatrician is saying, then you're going to see that conflict. And if you don't have a system built to do that, that's not my problem, it's not a parent's problem, it's your problem.

1:15:40 - Chloe

Well, and to get onto that waiver it takes a lot of work. It took me about a year to get onto the New York one and to get onto the one in Colorado and it requires a tremendous amount of paperwork, a tremendous amount of information from doctors and from multiple doctors. We have neuropsych evals, all sorts of stuff I mean genetic, you know reports like it's not, like they're just like giving these out.

1:16:05 - Courtney

Taking your word for it, yeah.

1:16:06 - Chloe

Which is funny, I remember this is just a little anecdote I remember going to like Robbie's had an adapted stroller forever. He didn't walk until he was like six and he needs a stroller for longer things. And also like he just decides he doesn't want to walk or he has no legs. Randall Lane's just like me, I'm a jellyfish. And just like me, I'm a jellyfish. And you're like oh wonderful, let me carry you, uh. But so I had him in regular strollers all the time, because those fold up much easier, and so, as long as he fit in a regular stroller, I kept him in a regular stroller.

But I remember I would go to places like the aquarium or whatever, and they'd be like oh, you can't bring strollers in here. And I'd be like it's actually his wheelchair, he's disabled, um, he's got to be in the stroller, he can't walk. And they'd be like you can't. They'd be like, no, he's not. I'd be like yes, my, my child is disabled, this is his. I understand it's a stroller, but you can think of it as a wheelchair because he needs it in order to move and he's, you know, even at like four years old. They runny runny's a hearty kid. You know, I'm like I don't want to be carrying him around the entire exhibit, um, and that's not as much fun for him to like. You know he had more fun in the stroller, um. But I would always be like what maniac people are pretending that their kids are disabled to get? Keep their kids in a stroller, like, just assume that it's fine. And if somebody is that messed up in the head that they're making these things up, maybe let them go with the stroller anyway.

1:17:39 - Courtney

Like they clearly need some sort of help. Well, and my thing is like OK, first of all, I don't believe anybody is doing it. I just think people like, inherently like to be able to tell other people no and to like stand with that, and that is its own whole issue in having a child with disabilities. But even if there are people doing this, what harm is it causing?

Now, if you had every person who entered the aquarium in a stroller, would that be like a really difficult situation to navigate? Sure, but also, if somebody comes up behind us and says, well, you let that lady in with a stroller, you can say, oh, she has a child with a disability, do you have a child with a disability? And if that person's put on the spot, I guarantee you they're not going to go. Yep, they're like no, because a lot of people for you, having a child with a disability is like this really awful thing that they would never want to experience or wish on themselves. So, so they're not going to be like, yeah, this child's disabled. They're going to be like, oh, no, sorry, we'll get back in the other life.

1:18:54 - Chloe

I will tell you one of my favorite lines was my friend's girlfriend.

We went out to get dinner once I had just met her and she told me like multiple times luckily neither of them will listen to this but like she told me multiple times, your life is my worst nightmare. And I'm sitting there like okay, like I can understand why, if you don't have experiences with children with disabilities, or being a single mom or being a mom at all, like this is a very overwhelming thing for like anybody to really conceptualize. I get it, but like and I was like obviously now my favorite statement but like guess what? I'm pretty happy with my life. I'm very burnt out right now and it's challenging and I'm trying not to downplay that, but I am very happy with my life. And she just kept repeating it like multiple times throughout the dinner and I was just like girl, like I read the room, I wanted to fly the first time, but like you're continuing to push this, like do you want to meet my kid? Like he's amazing, and also I don't want him around you.

1:20:13 - Courtney

So there's that that I will never let you around him.

1:20:15 - Chloe

You're not my target audience for hanging out with my kid. Yeah, I was like I don't think we're gonna. I don't. You know, I wish everything well with you and my, my homie, but this is probably not your friendship I'm gonna pursue. Um, but it's just. It's amazing what people say. It's amazing what people think and like. It's just. It's amazing what people say. It's amazing what people think and like. It's like. You know.

Again, I understand that people's perspectives are different. We've all are coming from very different places with very unique challenges. Personally, inter-family issues, past traumas, you know. Like there's so many things about so many populations that I do not understand and I know that I do not support as well as I would like to, simply because I do not have the bandwidth to do more to try and fit into their shoes.

So I also try and give people the compassion of understanding that, like we're largely most of us are doing as much as we possibly can overall and there's just not much space for adding more. Like times are challenging right now. So like, as a special needs mom, I've also grown into having a lot more compassion around that. So like, if people don't understand, if people have questions, even if, to me, I'm like, come on, like I also am like much more compassionate and just like, okay, that's totally cool. Like there's so many people who are living experiences that I will never understand and that like I hope that they have compassion and patience for me, as I genuinely try and understand these things better with with love and an open heart, but maybe a dash of ignorance, you know. Yeah.

1:21:45 - Courtney

I think too a lot like what I've been working on with especially Charlie, because he's a teenager now and I feel like the world puts a lot of your value in, like how well you're doing in school and how hard of a worker you are and how determined you are, and it's like those things are great. But like if you come home with all A's and you're a complete douchebag to everybody and you don't take care of yourself and you don't think about other people and you lack compassion, I'm going to be really disappointed. And if you come home and you're like barely scraping by, you might graduate but you're not, you know, getting any scholarships. But you are kind and compassionate and you treat people with respect and you are like morally good and you think about the way that the things that you do could affect the people who love you and the people that you interact with and who you have in your circle. It affects the people who love you and the people that you interact with and who you have in your circle. That's pride.

So, like with Charlie, he's really artistic and he has, like he's, been doing photography in school and it's beautiful and he's winning awards and it's like the best, like seeks praise for the good grade or the award. I'm like you know that I'm super proud of you, but I'm proud of the art you're making and how much of you you're pouring into that. The award you won is like its own thing, Like that's very cool and I'm glad somebody else saw value in the art that you're making. But that's not the part I'm proud of you for. I'm proud of you for making the art. And the same thing with school.

I'll come home and be like guess what? I got 100 on my test today and I'm like that's great. Did you eat lunch? Because the things that I want you to feel are the most important things to do are taking care of your body and being a good person. So if you're getting 100 on the test but you skipped lunch so that you could study or whatever the case may be, that's upsetting. I want you to be. My pride is not tied to A's, b's, c's, d's. I don't have that. So with Jem it's been trying to have that same energy, because a lot of what he's accomplishing that we're proud of are things that are like milestones and benchmarks and goals and all of that. So lately I've just been trying really hard to like tell him he did a good job with things that aren't related. But since he is where he's at developmentally, he's just like still at developmentally, he's just like still making a lot of developmental movement. I it'll be like good toots bud you guys?

1:24:37 - Chloe

I don't know. It would be like he'd start picking his nose and be like great finger isolation that is amazing.

1:24:43 - Courtney

Your fine motor skills are killing it right now. Literally, that's what I'm doing all day. I'm like, oh, he sometimes has trouble with water on his face, so he's playing with his water bottle and then he spits the water up in the air and it rains down on him and he doesn't lose a shit. I'm like that's right, buddy, we can have water on our face and we won't die when that happens. Good job, we can have water on our face and we won't die when that happens.

1:25:11 - Chloe

Good job. Big learning today. It's great. I love that.

I think it's also I mean, I think that that's one of the important points for parents to remember also is that you know, I think we've all internalized I know I'm speaking for myself that my value comes from what I do and what I give and how I perform for other people, how I caretake.

I'm like very much a caretaker and I will self abandon in many ways, whether it's taking care of myself or whether it's, you know, just putting other people's needs first, and so that's been one of the hardest lessons that I've had to learn as Rari's mom was that the most important thing for him was for me to be happy and healthy.

And so I think, you know, for us parents, the more we can do our work to unpack some of these societal norms and expectations and the pressures we put on ourselves, we'll also be able to model that for our children and really also like live that with our children, because it really is so internalized. I think it's still hard not to be like, yeah, great, you got an, a, you know. And like it's always it is great, but like also, you know, like I know for me, I see, I I'm like crazy about my best friend's daughters. Like they're just like you're just fucking little things and it's like like Remy's, just like he's just like such big destructive energy, and they're just these little adorable little girls like dainty, yeah like they're like what, the pretty flowers, you know like they're just adorable.

You know like, uh, with kate's girls it's so hard for me not to be like you look so pretty because they're just so adorable and they're silly little dresses and um, and like you know, so I have to focus and be like you got back up so fast after you jump. You know like you're so brave, you're so strong. You know like and like just really trying to build that into my vocabulary with them, because, like, you're still sort of ingrained to be like how beautiful, and it's like this is not where the child's value is, like she can be beautiful, but also like that's not what we want to teach her is her only or most important value, like period, and it's the same with, like scholastic abilities or ambition, because, let me tell you, you can be super ambitious and miserable and that doesn't help anybody, yeah, and I was like the kid who got the best grades and never got in trouble, and I got a master's degree.

1:27:32 - Courtney

And now I'm freaking burnt out because I spent a lot of my life just pushing myself to the ends of my limits so that I could achieve things that people would be proud of, and that is not great, I gotta tell you.

1:27:47 - Chloe

No people largely don't care. Like I got my doctorate and my dad, like two years later, was like, why do you finish that program? And I was like the neurofeedback training program. And he's like, no, I was like the one year apprenticeship with the Japanese acupuncturist no, I was like

my doctorate. He's like yeah, no. And I was like I finished that one a couple of years ago, daddy, and I was like it was just like such a remarkable like you know, like I just always think of it as like you try and do these things for like whatever clout or steam or like, or for me it's like I always feel like I have imposter syndrome. So it's like, well, now I have the doctor and I'll feel more like a doctor, you know. And then you get it and you're like, oh, nobody fucking cares.

1:28:36 - Courtney

So it's like you might as well do what makes you happy, like that's what's most important. No, it's, that's exactly it. I learned so many things that were taught in American society and culture, especially with half my life being spent in Georgia, that we got to really unpack through their lens what those expectations and like stupid, like just norms, feel like. And especially knowing like okay, my kids both have diagnoses, like I know that they're not the typical kid. So like, yeah, my brain is naturally going to tell me that I can measure down for success, but that's not even what you're doing, because it's not linear. It's like what things do my kids succeed in? Now let me go to that thing my you know benchmark for whether or not they're getting putting in all their effort or they're doing what they should be doing or giving it their all.

For Charlie photography art, like his 100% effort. For that is like shooting for the moon, because it's exciting to him and he likes it and he enjoys it. But then, like with math, it's like, okay, your 100% effort is like getting all your work done, answering every question on the test. So like you don't, you might get a C or a D, but like you tried every question and some of them weren't right. Cool, like we can't even mark success on a linear way. Because, like god, that's almost gonna start me on a whole rant about schools and how taking arts out of schools is the reason why we're seeing so many children with extreme behavioral issues, and that's just its own podcast.

1:30:46 - Chloe

Yeah, no, I might have to just do this again because we've already been yapping for like an hour and almost 40 minutes. So I might even break this up into two and maybe we'll just do a yearly update, because I love talking to you about this and I think it's you open to learning in this journey and being wrong and seeing how things evolve, and I know that my experience with Remy now might be very different than my experience with Remy in a year, let alone two years, let alone five hours. You know, let these things switch real quick and we're always learning.

So I think, um, I think it's a conversation that we can just continue, because I think that there are just so many challenges, um, that we face as a special needs community, but also so many things that, so many ways that we can work together to find more inclusion. I think that everybody wins from that and I think it's a conversation that we really just don't have enough. So I love chatting with you about it. I think this has been really fun. Hopefully it's helpful to anybody listening.

1:31:56 - Courtney

And if it's not, I had an amazing time.

1:31:58 - Chloe

So that's great Same. It was entertaining for me.