Cheryl:

A diagnosis can sometimes be very discouraging. You don't know what the future holds for your child anymore. But don't put mental limits on it. There are many people like me who have good lives, have normal life. They get married. They have kids. They have families. They have jobs. Those things are not out of reach.

Courtney:

Welcome to Adjusting the Sails, a podcast for parents, caregivers and service providers for Children with Disabilities. I'm your host, Courtney Ring Staff, and this is my co-host, Melina Danko.

Melina:

Hi, everyone. We are so glad you've joined us.

Courtney:

I am a licensed social worker in Morgantown, West Virginia, and I've created this podcast to be a platform for parents, caregivers and service providers can come together, exchange information, educate one another, and find support and connection through the relatable topic discussions. We cannot change the direction of the wind or the strength of the storm, but together we can adjust the sails.

A quick disclaimer before the start of the episode. Today's discussion is our guest’s opinion only and is based on her own experiences.

Courtney:

First of all, thank you for being willing to come on and share your story and also debunk some of the myths that it seems society has about a person who uses a wheelchair. Because some of these things are specific to wheelchair use, but some of these things aren't. And some of these things are just about people with disabilities in general.

We're really glad that you decided to come on and share with us because we can learn a lot from you. Would you want to go ahead and introduce yourself?

00;00;27;22 - 00;00;52;13

Cheryl:

Sure. I'm Cheryl Childs. I work here at the CDC as a program assistant. I have a physical disability. It only affects my legs. I was born with it, and so it didn't show up until I was six years old. And then slowly, like over time, it gradually grew worse. I started using a walker about seven years ago in a wheelchair about five years ago.

00;00;52;13 - 00;01;11;13

Cheryl:

So most of my life until now, I was able to walk without too much assistance. I grew up in a household where my dad had a disability, my brother had a disability. It was the same type of disability. But our life didn't really differ that much from other peoples that I knew of as at least to me as a kid.

00;01;11;25 - 00;01;33;13

Cheryl:

We still went on family vacations. We went camping, amusement parks, traveling to see other family members. I felt that my family did pretty much what everyone else did. We just sometimes had to make different arrangements, like accessible hotel rooms and like renting a wheelchair to amusement parks for school. I attended a private Christian school with my sister who does not have a disability.

00;01;33;26 - 00;01;53;12

Cheryl:

As my disability progressed through my childhood years. My balance by while walking got worse, mainly through middle school and high school so I could walk. But it was visibly different. If I needed assistance, I would just ask my school friends if I could hold their arm while we walked together and they would gladly help me with, you know, no judgment there because they were my friends.

00;01;53;13 - 00;02;14;02

Cheryl:

After seventh grade, I couldn't run very well. So AP class, when we played games like kickball or softball, I would kick or hit the ball and another kid would run for me. I was still able to play on my high school's volleyball team, though I was valedictorian of my senior class. Then I attended college in North Carolina, which was 7 hours away from home.

00;02;14;19 - 00;02;36;28

Cheryl:

I had expected to walk the campus during my college years, but since my dorm room was across the street, my parents bought me a Segway to use just for my safety. And that helped a lot with navigating the campus and getting the classes on time and there as well if I needed assistance. My friends at college were always willing to lend me an arm or carry something for me.

00;02;37;14 - 00;02;59;00

Cheryl:

I worked through my sophomore year of college as an English professor's assistant and then graduated college with an associate's degree. After that, I returned to my parents home and worked a couple jobs as an appointment center for a year and then a temporary job with the records. Department of WVU until I got married a year after graduating college.

00;02;59;25 - 00;03;23;14

Cheryl:

After getting married, we moved a few times as my husband continued his education toward his career. I had three children in those first five years of marriage, and I was a stay at home mom. I managed the household basically all my own cooking, cleaning, changing diapers, feeding the kids, hanging laundry out on a clothesline, planting things in our garden and gathering eggs because we had chickens at the time.

00;03;24;16 - 00;03;43;15

Cheryl:

All this while my husband was away at school and work. Most of the day he would help out by carrying newborn babies up and down the stairs in our home in the morning, in the evening. And he would do the shopping and driving when we went anywhere. In 2015, we moved to Georgia as he started to attend the university there.

00;03;43;23 - 00;04;08;04

Cheryl:

I was still a stay at home mom. Then my husband, he had started physically abusing me in the children a year before we moved and his abuse increased. When we arrived in Georgia, it was scary. I felt I couldn't leave because I couldn't physically put my youngest baby in the car myself. But within a few months, I reached out to my church down there and received help in leaving my husband.

00;04;08;04 - 00;04;30;07

Cheryl:

My parents drove down and brought myself and my kids back to West Virginia. And through that, you know, God and my family, my church family supported me so I could get more stability in my life. I can't explain in words how overwhelming it was to all of a sudden be a handicapped single mom with three small children. Took a while for me to get a job, I felt, because I couldn't do a lot of the physical work.

00;04;31;05 - 00;04;57;24

Cheryl:

But thankfully I did have some experience with computers for my associate's degree and I had a short employment history. So long story short, I got divorced, got a job, got new vehicle and moved into a new home in 2019. And now I work full time. I shop, manage finances, manage my household. I do drive my kids to school and myself to work every day and take care of my children at home.

00;04;58;07 - 00;05;26;15

Cheryl:

When I do need help with babysitting or appointments, my kids have sports practices. My mom steps in because my parents live close by and she will help with those things when needed. A lot of things I thought I couldn't do, like even shopping, you know, things my husband did. And I just assumed I can't do that. I didn't even try, but I was the one I had when I got to a point where, Oh, I have to do these things.

00;05;26;25 - 00;05;47;07

Cheryl:

For me, it really came down to like having to do it, being the only breadwinner in my family. Of course, my parents and my other family members helped out so I wasn't alone, but I felt like I had to take over and do these things. And then when I realized I had to and I tried, I realized, Wow, I can do a lot of these things.

00;05;48;04 - 00;06;12;28

Courtney:

So you kind of had some like biases in your mind. We're going to talk about some myths or like biases that may be like the general public has. And so I think that might be like a good a good Segway to just kind of start that conversation. It helps give us a good picture of like why you're speaking about what you're speaking about and that you do have some like life real world experience to back the information that you're going to give us.

00;06;13;14 - 00;06;27;03

Melina:

Yeah, really a lifetime of experience, you know, starting with your family and then slowly progressing into your own personal experience with your life. It's a lot of experience that you have there.

00;06;27;28 - 00;06;40;10

Courtney:

So I know you mentioned that your dad and your brother has the same type of disability and now you have three children. So is there any reason for you to believe that maybe your children are will acquire this disability? Or do you know yet?

00;06;41;15 - 00;07;03;08

Cheryl:

I don't know yet. They could. There's always a possibility they have a 5050 chance. So far, they haven't really showed any signs of it. But I mean, I'm not worried about it because I have a lot of experience with it and a lot of experience from being the kid of like how I would want to have been directed or whatever.

00;07;03;08 - 00;07;23;23

Cheryl:

And so I'm mentally prepared if they do that. I haven't seen any signs yet. I don't know that I've really mentioned it to them. If it does come up in the future, I'll kind of explain, Hey, this is like what Mommy has and and then they can have that example in front of them. They're role models like that to you, and I'll be telling them, Hey, let's try this, let's try that.

00;07;23;23 - 00;07;42;04

Cheryl:

So I really haven't said, Oh, this could happen. I don't want to scare them with something that they don't know much about. I have had conversation with my parents, though, about like, what did you do if my kids have this, you know, what would be the best thing? And so I you talked to my parents about it. My oldest daughter is 11.

00;07;42;04 - 00;07;45;19

Cheryl:

And I have a son who's nine and his son who's seven.

00;07;46;23 - 00;07;52;09

Melina:

Do people with disabilities have unspoken expectations of people without disabilities?

00;07;53;15 - 00;08;08;17

Cheryl:

Just common courtesy? Usually when I go out places, people just automatically they hold the door for me or they let me go first. And I don't expect that. But it it is nice and it's just common courtesy.

00;08;08;23 - 00;08;23;06

Melina:

One of the myths that we have heard before is that people with disabilities can be disgruntled and thinking why me? Why did this happen? What are your thoughts on that myth?

00;08;25;05 - 00;08;52;15

Cheryl:

I think it's on an individual basis. Everyone in life experienced some hardships and in any kind of hardship, you can choose your own perspective on it. Some do think, why me? And they focus on the negatives and they're all complaining and disgruntled and others focus on the positives. In my life, I came to learn that my mindset about my disability is my choice and it usually can be greatly influenced by those around me.

00;08;52;25 - 00;09;27;00

Cheryl:

As a child, I was upset about being disabled and I was struggled with self-pity. Finally, I realized I was only making myself miserable. I was. Most people surrounding me were very positive. I didn't come into contact with anyone who was really prejudiced about it, which I consider a huge blessing. I think when I became an adult, I figured that complaining in my mind about how this or that would be easier without my disability or what just made me have a bad day because of my mindset and really wouldn't change my circumstances.

00;09;27;23 - 00;09;50;03

Cheryl:

So I realized that instead my mindset is within my control and I could choose to make the best of things instead of imagining the what ifs. Like, what if I could walk right? This would be so much easier. Instead of that, I could focus on just accomplishing the task and not think about how others may do them differently than I do with what they call mom guilt.

00;09;50;04 - 00;10;08;01

Cheryl:

I felt bad that I couldn't walk around with my babies in my arms, but in the end I realized that I'm able to provide what my kids truly need and those little extra things that I couldn't do, though they were, would have been special. They were not necessary for my kids well-being and happiness.

00;10;09;22 - 00;10;28;02

Courtney:

How can anyone who's a caregiver to a child who has a disability help to find a more positive self-talk for that child or help that child find more positive outlook? Like you kind of navigated it on your own. But what can a parent do if we're trying to, like, help encourage that.

00;10;29;26 - 00;10;51;20

Cheryl:

Focus on what they can do rather than what they can't? For the kids mindset, if they can't do sports, but they're good at other things like art or music, encourage them in pursuing what they're good at. I believe giving role models is important. Like I had my dad to look up to and learn from. He has seen disability and as a kid I watched him.

00;10;52;02 - 00;11;21;05

Cheryl:

He worked a full time job. He drove. He did household tasks. I learned a lot from him. If they don't have anyone that they know personally, there are there are famous people with disabilities. Let's conclude. Michelangelo, Van Gogh, Beethoven. Christopher Reeve. Stephen Hawking. Johnny Erikson. There are many very talented, famous people who have disabilities. And just remember, there's not one person in the world who can do everything.

00;11;21;22 - 00;11;39;06

Cheryl:

Everyone has something they're unable to do. And so focusing on what we can't do only brings that frustration and depression and maybe feelings of inferiority. But when we focus on what we can do, it opens up a whole array of options, and it empowers us to pursue those interests.

00;11;40;09 - 00;12;03;08

Courtney:

I'm glad you mention that, because while I may not be considered a person with a disability, there's lots of things I can't do I can't see without my glasses. You know, I have this assistive technology. And if everywhere I went, everyone was focusing on my need for glasses or the fact that I can't run very fast or whatever it is, that would really put a certain type of mindset about myself in my own mind.

00;12;03;23 - 00;12;23;02

Courtney:

So I think a part of this is changing the way that society thinks and perceives and communicates with a person who does have a disability, but part of it is also promoting that in a person themselves so that they feel proud of what they can do and they build the confidence like they have that foundation of confidence. To me, it's kind of like a two parter.

00;12;23;28 - 00;12;54;21

Cheryl:

And they need those role models. Those are very important because nowadays in TV and movies and everything they're watching, they're promoting, Oh, this is valuable in a person and this is valuable in a person. And really it's a lot of physical traits. They have this superpower or they're very athletic and some of the stuff that they're good at, they're not physical, is not really promoted a lot in social media as being valuable, but it is valuable.

00;12;55;28 - 00;13;20;12

Melina:

I think too, as parents and caregivers, we're always trying to protect our kids and we forget that sometimes we can protect them too much because we don't want them to get hurt. So I think what you're saying really resonates because I think it can pertain even more to parents who have a child with a disability because they're trying to protect their child.

00;13;20;19 - 00;13;51;17

Melina:

And so in doing that, they may think, oh, no, you can't do that. You could get hurt, or, oh, no, we we can't go there because this might happen where you're saying, no, have the positive side of look at what you can do and let them try and see how it goes and then find ways to do it along the way is a really powerful way to change the way that you're thinking and also the way that you're parenting.

00;13;51;26 - 00;13;54;21

Melina:

And so I think that that's a powerful message.

00;13;54;21 - 00;14;24;01

Cheryl:

Yeah, that's really important. And as a parent myself, I would want to be just prepared for any emergency. So I think with me, yeah, I would be scared about my kids trying something they might get hurt doing. But then a lot of times we learn from the hurts that we get or the pains that we get. And as long as it's not something fatal or like that would really hurt them, I just try to do my best to be prepared for as much as I can and letting them try new things.

00;14;24;25 - 00;14;41;22

Courtney:

And when we talked about this topic previously, Sheryl, you had mentioned that your mom was like that a lot for you and she didn't let your disability hold you back and she would take you and make you do things and say, nope, you're doing it anyway. Is that what you told me previously?

00;14;42;16 - 00;14;59;00

Cheryl:

Yeah. Yeah. I mean, she wouldn't, like, make me do anything I didn't want to do. But if I wanted to go out on the teen outing, teacher's outing with the other teens that don't have disabilities, she'd be like, fine, okay, I'll take you. And she would find ways to make it happen. Like, Do you need to take this?

00;14;59;00 - 00;15;18;06

Cheryl:

You know, you take that, make sure you basically have everything you need and we do that for our kids anyway. Naturally, make sure you have your coat, your shoes, but you could, you know, make sure you have your wheelchair and even talk to you like a trusted adult that's going with the group and say, hey, maybe keep an eye on them, but don't have to be an umbrella parent necessarily.

00;15;18;25 - 00;15;22;14

Cheryl:

But, you know, she would encourage instead of placing limitations on me.

00;15;23;09 - 00;15;41;13

Courtney:

So the next myth that we have found is about people with disabilities in romantic or intimate relationships. And the myth is basically that a person with a disability is not interested in that type of relationship. How would you feel about debunking that?

00;15;41;20 - 00;16;07;24

Cheryl:

It's not true. It's yeah, people with disabilities are just people. We feel the same things. We have the same feelings as everyone else does. Yes, we yearn for close relationships as people have asked. You know, can people with a disability have sexual relationships? Yes, they can. I was married and I have three biological children and I had no C-sections.

00;16;09;06 - 00;16;25;00

Cheryl:

So they are able to have those relationships. And I mean, they already have close relationships. They have family, they have friends. I don't see why a romantic relationship would be would not be doable for us.

00;16;26;24 - 00;16;51;11

Courtney:

Thank you. I know that sometimes there's a question on people's mind and we do have a plan for a future episode to discuss specifically sexual relationships and disabilities, because it's a taboo topic. It goes along with sex education and sexual health. Sometimes parents of any child don't know how to approach that topic, but especially a child with a disability.

00;16;51;11 - 00;17;12;22

Courtney:

They don't know how to approach that topic. So I appreciate you saying, yes, there's interest, and as long as that person is capable and willing and able to consent, then it's possible for them and they're probably they probably want those types of relationships because in the future we will have someone come on and be interviewed who is a, you know, quote unquote expert in that topic.

00;17;12;22 - 00;17;34;16

Courtney:

And so we can really kind of shed some light on that for the listeners and for the caregivers that are listening. So our next myth is you should be praised if you're dating a person with a disability like you're doing them a favor. This one always gets under my skin, but it is something that we found in our search for one of the frequent believed myths about disabilities.

00;17;34;16 - 00;17;39;02

Courtney:

And so I really wanted you to debunk this one because it just makes me feel icky.

00;17;39;05 - 00;18;01;16

Cheryl:

It does. It really it is basically saying that people with disabilities are inferior in some way and they're not. I mean, the whole point of dating is to get to know a person better. Now, if a person has a disability, you may have to change some of the activities you do on a date. But really the activities aren't the main focus of a date.

00;18;01;21 - 00;18;27;03

Cheryl:

A date is to get to know the person and you can get to know a person with disabilities as easily. They can get to know anyone else. We have our lives and routines just like everyone else. I don't see how it's too much different than dating someone without a disability. Adding in a disability, it only plays as much a part in their relationship as any other physical trait a person may have.

00;18;27;24 - 00;18;44;23

Cheryl:

I dislike it when men are considered helpless. I always hated that term. I am personally on dating apps and I feel like I have to explain when I have the picture of me and my wheelchair, I feel like I have to explain. I am independent. I run my own household. I work full time. I take care of my kids.

00;18;45;05 - 00;19;09;12

Cheryl:

So don't assume that if you're in a relationship with a person with a disability, that you will have to become their caretaker if you pursue the relationship further, because many of us don't need a caretaker. We have lived our lives up to this point without you being a caretaker. And I mean, what we look for in a relationship is companionship, love, respect, someone to share life with.

00;19;10;12 - 00;19;27;05

Cheryl:

I'm not in the market for a caretaker when I'm on a dating app. Yeah. Just to remember that they've already got their routines in their life under control and stepping into a relationship will not necessarily mean you're taking over that role of doing everything for them.

00;19;27;24 - 00;19;35;08

Melina:

I feel like you really answered that nicely and I feel like that all resonate because it's like, okay, I got this, you know.

00;19;35;11 - 00;19;36;23

Courtney:

Like.

00;19;36;23 - 00;19;43;09

Melina:

I want a partner and a companion, but everything else, I'm, I'm holding it down myself.

00;19;43;11 - 00;19;48;21

Courtney:

So, yeah, there are other apps out there to find caregivers. You don't have dating apps yet.

00;19;50;04 - 00;19;57;27

Melina:

I mean, we all want somebody that we can grow old with who will help take care of us and that we can help take care of and we can trust.

00;19;58;08 - 00;20;00;02

Courtney:

Trust to take care of us. But it's just.

00;20;00;02 - 00;20;20;13

Cheryl:

Part of what love is. It's not. I mean, the love that people show in taking care of a disabled partner is not any greater than the love someone would show taking care of their sick spouse. It's all that type of love. And it's amazing. But it's not a any different for people with disabilities.

00;20;20;13 - 00;20;39;15

Melina:

Very well said. Another myth that we hear about pertains to language. So this myth is the words that we use to talk about disabilities. Doesn't matter, like the way that we say things. People shouldn't take it personally, things like that. What are your thoughts?

00;20;40;18 - 00;21;05;10

Cheryl:

Words do matter a lot. And talking about a disability, it is a personal part of someone's life. They're going to take it personally. Yeah, it's very important. Words can heal or hurt my young stay at home mom. It would frustrate me that other people assumed that my mom helped me with the kids during the year. They're like, Oh, they just assumed that, oh, your mom comes and helps you.

00;21;05;10 - 00;21;29;04

Cheryl:

And she didn't. And it was just frustrating that when they wondered about things, they would either assume they thought I could do or they would even address other people. They would address my mother about it and not me. Even though I was married, I had my own home, I was my own kids and they had a question about me, even though I was obviously a mature adult.

00;21;29;05 - 00;22;02;29

Cheryl:

They would ask my mother and that was really frustrating. So like that's important. Like if your come into contact with someone with a disability, address them directly. They are a person and they can. They may have their own ways of communicating with you, but don't assume that you need to ask the person with them what they think. Now, people with different disabilities have different ideas of what words they like and dislike, but I have a few phrases that are just overall, we don't like them.

00;22;04;16 - 00;22;25;18

Cheryl:

When I was in college, when my friend would be helping me out, we had a program we were preparing for and I'd be standing there with my friend hanging on to my friend's arm, and someone would come up and tell my friend to put me over in the corner or something. It was like, Put me over there. I'm not an inanimate object, you know, I can walk.

00;22;26;03 - 00;22;51;22

Cheryl:

Okay. If you want me to go over there, ask me to go over there. Don't ask my friend to put me over there. Telling people that you're an inspiration is a no no. It's like if they've done something inspiring, yeah, you're an inspiration. But I think people with disabilities get this a lot just from living normal lives. People were surprised that I went to college.

00;22;52;03 - 00;23;14;25

Cheryl:

They assumed that my mom helped me out around the house. They would have been surprised to know that I did all that myself, which is kind of frustrating because it's just normal life. And yeah, we do it a little differently than other people do it, but it's not something worthy of inspiration. So it's telling them they're like, You're an inspiration.

00;23;14;26 - 00;23;42;06

Cheryl:

It made me think that people assume that I just sit around and do nothing all day, and that's what they expected me or they that's what they expect of people with disabilities with little expectation. Then they're assuming you can't do much. And it's kind of insulting. Another thing is when people wonder about having questions about disabilities and why they should approach you or talk to you, and it's fine.

00;23;42;06 - 00;24;01;27

Cheryl:

Some people with disabilities are more sensitive about it and they don't like answering questions. Other people like me, I would rather have someone come up to me and ask about How do you do this? Or How do you do that? Or You know, what is your disability? I'd rather have them ask than have them wonder and assume things.

00;24;01;27 - 00;24;27;09

Cheryl:

But there are ways to ask, you know, go up to someone and say, what happened to you or what's wrong with you? I have heard those before and it just a disability is not something wrong is not bad. It's not to be avoided or overlooked and what happen to you or what's wrong with you makes you feel like, well, something made you less of a person.

00;24;28;23 - 00;24;50;00

Cheryl:

Also, a lot of people say Don't talk extra loud or speak as if you're speaking to a child. You can speak like you normally talk. If they don't hear you correctly, then just repeat it like you would do for anyone else. That's another thing. It's just assuming more assumptions that they can't hear you, where they can't understand you.

00;24;50;00 - 00;24;50;28

Cheryl:

When you don't know that.

00;24;53;26 - 00;25;16;23

Courtney:

You had shared with me with that one specifically about restaurants and about being at a restaurant and a waitress looking over you to the person who's sitting with you and asking like, what will she have? Or asking? Like, You know what? You want to drink or to eat, even though you're sitting right there and you can look at them and make eye contact with them and you're fully receptive, but they will still speak over you like that.

00;25;16;29 - 00;25;17;14

Cheryl:

And that just.

00;25;18;10 - 00;25;19;01

Courtney:

Blows my mind.

00;25;19;25 - 00;25;32;26

Cheryl:

I've heard of other people, other people, disabilities as well, saying that that happened to them. And it's like you feel like saying, Hey, I'm a person, I can talk, ask me when I want.

00;25;32;26 - 00;25;37;15

Melina:

Like, there goes your tap, buddy. Guess who's paying the bill.

00;25;38;23 - 00;26;04;15

Courtney:

Yeah. Like, they're looking at your seven year old child and saying, like, what? Well, she have, you know, that that's a child. You're the adult there. I hope I hope this episode reaches them so they can learn as a note on this particular question, you had wanted to talk about correcting people or addressing issues in front of their child or in front of your child.

00;26;05;02 - 00;26;06;02

Courtney:

Do you want to speak on that?

00;26;07;01 - 00;26;30;25

Cheryl:

Sure. Really? It depends on the circumstances. It really depends on who's addressing your child. Like if an adult is saying things that are inappropriate, I would address them about it, say, hey, you know, can you speak this way to be kind and courteous? But as well, making them know that is not appropriate to say to my child or that is not appropriate way to treat my child.

00;26;30;25 - 00;26;50;02

Cheryl:

Whether you do it in front of your child or not depends on whether the child heard them and understood what they meant. Because if you if your child heard and understood what that person was implying and you went off to the side and your child didn't hear you correct it, then your child thinks, Oh, well, that's how they treat me.

00;26;50;02 - 00;27;13;18

Cheryl:

But if it happened in front of your child and you step up and say, Please don't speak that way to my child, then you're letting your kid know people shouldn't treat you this way, and that will help later on with self-advocacy. This will give them a foundation of how people are supposed to be treated and what is disrespectful and what is inappropriate.

00;27;14;06 - 00;27;25;12

Cheryl:

Similarly, setting an example for your child as well as teaching that person how to act appropriately around around your child.

00;27;25;12 - 00;27;43;23

Courtney:

Yeah, I'm really glad that you touched on that, because I think some parents would want to protect their child from it, like glaze over it like it wasn't heard or it's not noticed and maybe address it in private or maybe just let it slide. But I think the fact of your teaching your child how they should be treated is huge.

00;27;44;07 - 00;27;49;27

Courtney:

And you're teaching them what's okay and what's not okay. And if it's not okay, how it should be addressed.

00;27;50;23 - 00;28;10;20

Cheryl:

Yeah. And when to speak up and when not to really. Because some things are little, some things people don't do them intentionally. And if it's just a little thing and it's in passing, you may not need to stop that person and address it, but you can tell your child, Hey, there are some people out there who don't know any better how to treat other people.

00;28;11;00 - 00;28;15;11

Cheryl:

This is how they should have reacted it. But sometimes we just have to forgive and move on.

00;28;16;17 - 00;28;33;20

Melina:

Another myth is that a person who uses a wheelchair is confined to their wheelchair or wheelchair bound is another thing that I hear people say that just makes me cringe sometimes. What are your thoughts about that?

00;28;35;24 - 00;28;54;09

Cheryl:

Well, in my experience, like I used a walker before I use a wheelchair and using a walker to get around was difficult. It was sometimes painful. It took more energy and was stressful on my body. And then when I started using a wheelchair, of course, I was like, Oh, it's a stereotype. And people might look down on me.

00;28;54;20 - 00;29;20;19

Cheryl:

But then when I started using the wheelchair, it was like, Wow, I can get around places, I can get further without being worn out. I can get around places without pain, without the extra stress. I would say it's just the opposite of what a wheelchair bound. A wheelchair is a form of transportation. And wheelchairs make it a lot easier and enable it, which enables me to go to the store.

00;29;20;22 - 00;29;44;26

Cheryl:

Go in the store. You know, it enables me to get in and out of work. It enables me to go out places and go to activities and things and go on wheelchair accessible hiking trails, which I never could have done with my walker. Now I see a wheelchair as freedom. It gives us more independence to be out and about and makes things a lot easier for us.

00;29;46;17 - 00;30;03;14

Cheryl:

And not everybody in a wheelchair has to use one like I can walk a little bit. I don't. Because it would be painful to my legs if I did walk all the time. But I'm not my wheelchair all the time. Some people use a wheelchair due to like it's less painful or it just makes it easier for them.

00;30;03;15 - 00;30;07;02

Cheryl:

So not everyone in a wheelchair is in it every minute of the day.

00;30;08;17 - 00;30;27;21

Courtney:

I'm glad you mention that, because my bias was showing. One day I left. I walked out of the office and I saw you standing, getting into your vehicle. And I was had a double take and then just kept walking, like, don't don't make a big deal about it. I shouldn't have assumed anything, but I'm like, you're Cheryl is standing, putting her own chair on her own vehicle, getting in there to drive.

00;30;28;10 - 00;30;36;15

Courtney:

And here I made assumptions and the whole time that that would not be a possibility for you. And then here you are doing it. So, yeah, I had to check myself right there.

00;30;37;10 - 00;30;56;00

Cheryl:

I do. I do every day using my walker to get back there, getting in and out. Another thing people assumed, I guess it wasn't mentioned before, is that people in wheelchairs are weak and maybe their legs are weak. But I left that wheelchair in the car every day, at least twice a day, and it's like 25 to £50.

00;30;57;01 - 00;31;19;08

Cheryl:

It's not a lightweight wheelchair. So, I mean, people have just because they don't have strength in their legs doesn't mean they don't have strength in their other areas, even an inner strength, you know, to deal with that hardship and deal with it cheerfully. I mean, that inner strength is amazing that people show. So I don't think people see people in wheelchairs as weak or needing help all the time.

00;31;19;08 - 00;31;21;21

Cheryl:

It's just not a correct perspective on them.

00;31;22;19 - 00;31;41;07

Melina:

And I think Courtney mentioned to that that she saw you getting into your car to drive and you mentioned it earlier as well, that you drive yourself to work, you drive your kids to school. And a lot of people think that people who use a wheelchair aren't able to drive. What do you think about that myth?

00;31;42;19 - 00;31;59;16

Cheryl:

It's not true. Just like everything else, there are ways to do things, even if we don't do them the same way a lot of people do. Like I am able to drive, I'm still able to use my feet for the foot pedals. I do use my hand to move my foot from pedal to pedal and I've got a hand on the steering wheel.

00;31;59;16 - 00;32;19;04

Cheryl:

But like my dad, for instance, after he was able to drive like that for years and then later on it got more difficult to use his legs. And so they have their car changed, so there's a hand control for him. So it connects to the pedals on the floor and it's like a pull or a push for gas or the brake.

00;32;19;04 - 00;32;34;22

Cheryl:

And then they put a little like round thing on the steering wheel. So you could easily turn it as far as you need to with one hand. So there are things like that that make it a lot easier for people to be independent, to drive cars.

00;32;34;22 - 00;32;49;28

Courtney:

We probably have those technologies in our with its library in case anyone wants to try those out. We'll link with it in the show notes. So for you personally, Cheryl, how do you feel like your life is most impacted by your disability?

00;32;51;22 - 00;33;12;29

Cheryl:

My disability, of course, made my life difficult physically in some ways, and I struggle with self-pity. Sometimes I felt like no matter what I accomplished my disability made me inferior to others. I think this mindset came from influences of TV movies, maybe a couple prejudiced people to most of the people in my life did not judge me that way.

00;33;13;08 - 00;33;31;12

Cheryl:

However, on a positive note, my disability framed my personality in a lot of ways. Through it, I developed determination, creativity, adaptability, and a great empathy for others.

00;33;31;12 - 00;33;45;14

Courtney:

And so how do you feel that the lives of people with disabilities, the myth that the lives of people with disabilities is completely, totally different from the lives of their non-disabled peers? Do you see your life completely different?

00;33;46;04 - 00;34;07;13

Cheryl:

Not really. It's not really that different. I mean, physically, there are some things that I just cannot do. But for most of the things in ordinary life, I can do them. I just have to be creative and find different ways to do them. Maybe with a few more steps. Sometimes, I imagine. What would my life be like if I didn't have my disability?

00;34;07;13 - 00;34;37;24

Cheryl:

And other than it being me getting a little more exercise, getting in and out of work and maybe a few things being a little easier, like a walk or a hike really wouldn't be that different. I would still be driving my kids to school, driving to work, shopping, doing the all the household chores, managing finances. A lot of it would not be changed if I didn't have a disability.

00;34;37;24 - 00;34;48;24

Melina:

And what do you think about the myth that disability is taboo and should not be discussed or should only be discussed behind closed doors?

00;34;48;24 - 00;35;07;28

Cheryl:

I don't believe it's like taboo and shouldn't be discussed. It is a personal topic. So out in public, if you first time you meet a person, you shouldn't bring it up right away because that would imply then that that's the only thing you see about them instead of like getting to know them as a person first. I mean, you walk up to someone in public, say, hi, what's your name?

00;35;07;28 - 00;35;29;01

Cheryl:

You don't say, Oh, hi, what's your medical history? Yeah, it is a personal topic, so get to know the person first. You can talk about it. I think in public, especially with examples can examples to children. If you come across someone in public with a disability and your children are curious if you hush them away, be quiet, don't look at them, move away.

00;35;29;11 - 00;35;51;18

Cheryl:

Your child and a person with a disability sees the disability as being something bad. And it's not bad. It's not a bad thing, it's just a difference. I think it should not be considered taboo. As for discussion, depends on how personal it is. A person some people don't want to talk about it. You'd have to gauge whether they are open to questions about it.

00;35;52;15 - 00;36;13;07

Cheryl:

And just if you have questions, it just approach it like any personal thing you want to learn about someone you come in contact with. Be kind, be courteous, try not to assume anything. Be open to how do you do this or how do you do that? And open to accepting their answer instead of having an assumption in your mind, Well, they can't do it.

00;36;14;02 - 00;36;33;25

Cheryl:

So I'm going to I'll ask to be nice, but I think they can't do it but be open to accepting. Well, this is how I do it. Oh, okay. So there's nothing wrong with asking. Don't make it the only thing you focus on and ask them about and just be kind and in how you ask about it.

00;36;33;25 - 00;37;05;10

Melina:

Yeah. And, and don't ask somebody with a disability a question that you wouldn't ask somebody without a disability. And then when we were speaking the other day, you said that somebody asked you about having a C-section. And I thought, how strange no one's ever asked me if I had a C-section with my kids. So why would they just assume that you would and why would they even bring that up in a conversation unless you were specifically talking about like your childbirth story?

00;37;05;10 - 00;37;23;00

Melina:

So, you know, thinking about like, yeah, you can ask questions, but is it important? Is it necessary? Is it something that you would ask somebody else who didn't have a disability? You know, perhaps thinking about that too, because that just struck me as weird.

00;37;23;14 - 00;37;39;16

Cheryl:

Yeah. So I mean, even though if a disability may be visible to everyone, it's still a personal part of that person's identity or life. So yeah, you can't just talk about it with with them right away.

00;37;39;27 - 00;38;12;12

Courtney:

Yeah. And I also was thinking, you know, when we say like disability is taboo, the way that we combat that is by just making people with differences just more common in everyday life. And so if your child doesn't see a person with an obvious disability on a day to day basis, but you don't want that to be a taboo topic, then you need to make sure that they are watching TV shows with people with disabilities or that they have toys of, you know, people with disabilities or books or reading children's books.

00;38;12;12 - 00;38;43;03

Courtney:

That's the whose characters might have disability. So that's the way that we make this not taboo. It's not not talking about it at all. It's that exposure that you would want for any type of person, for your child, you know, any type of different type of person you would want that exposure so that when they do see that person in public or a person that maybe represents that, that they already kind of know, like, oh, my goodness, that's just like the book that I have or that's just like the doll that I have, you know, that maybe has like a walking cane or whatever it is.

00;38;43;13 - 00;38;59;26

Courtney:

And that's something that I've kind of had to learn. Having my own children is that there are TV shows that they watch that have characters, you know, who might be blind or who have autism. There's a show that my son likes and one of the characters has autism. And so there's just a there are options like that now.

00;39;00;09 - 00;39;20;01

Courtney:

And so if we can expose our children to that more, that is what diminishes that idea of a taboo subject. It's not that we have to teach our kid to like point at them and be like, Oh, look, look at them. Let's ask them this question that doesn't really get rid of that taboo idea. It's, you know, how we expose them.

00;39;21;03 - 00;39;46;08

Cheryl:

I agree. The same way we teach them how to handle any you know, it's a normal part of life. People with disabilities are in real life. And same way we teach our children how to react in certain circumstances, whether they will come in, can come in those circumstances or not. We teach them ahead of time. And that way, when they do come into contact with those circumstances or people with differences, they know how to react.

00;39;46;08 - 00;39;54;05

Cheryl:

So they don't think of it as unusual because they've been taught this is part of life.

00;39;54;05 - 00;40;23;23

Courtney:

Okay. One of the myths that we found consistently was that people should be put with people like themselves. So if a person has a disability, then they should be in school with other people with disabilities or in relationships with people with disabilities or even, you know, living arrangement wise. This is something we decided that you would discuss also, because apparently it's a very common myth that people have.

00;40;23;23 - 00;40;53;06

Cheryl:

Yes. And I believe that if everyone's needs should be assessed individually, like kids in a classroom, if this kid needs tutoring in a certain subject, they get tutoring, you know, if they need it, like if they need to be another classroom, that takes a different approach to the subject. They're learning that it's good to provide for those needs, but I believe it's not good to limit them to just those things.

00;40;54;02 - 00;41;22;16

Cheryl:

Community should be a variety of people that we learned from those that were around, and it's really nice. Even kids, adults, we all like to be around someone who is similar to us because that's comforting. We feel like that's my village, my people. But then we can also learn a lot from friends who are different than us. Growing up, none of my friends had a disability and you know, but we had other things in common, a lot of other things in common.

00;41;22;28 - 00;41;39;08

Cheryl:

So, I mean, I don't believe it's got to limit them to say you should only hang around with this type of people. It's almost like saying, oh, you know, we should put all the people with brown hair in this classroom and all the people with brown blond hair in this classroom. And I mean, see how silly that kind of sounds?

00;41;39;20 - 00;41;46;07

Cheryl:

I don't believe they should be limited in their group of friends or people that they interact with.

00;41;48;02 - 00;41;56;15

Melina:

And how can someone advocate or educate others about people with disabilities?

00;41;56;15 - 00;42;17;23

Cheryl:

Really, it will all come down to modeling the correct behaviors. Not a lot of people are going to go online and research how to act around someone with a disability because if they do come in contact with some of the disability, they aren't expecting it and so are they. It's something that comes up and they're like, Oh no, I don't know what to do.

00;42;17;23 - 00;42;49;16

Cheryl:

And I think that so there's not a lot of like you could have classes on it maybe for kids in school or college students or something just added in with a class on, you know, courtesy how we treat anyone. But really a lot of it comes down to modeling for like parents of kids with disabilities model in public how to treat your kid, talk to your kid, ask them what they want, show people what the correct way of being kind and courteous and how to treat them.

00;42;49;16 - 00;42;57;18

Cheryl:

Just show people by how you act.

00;42;57;18 - 00;43;06;00

Melina:

Are there other things, Cheryl, that you wanted to share that you feel like we didn't get a chance to touch on in any of these questions?

00;43;07;21 - 00;43;43;16

Cheryl:

Just I guess the overall thing for me is people with disabilities are just people. And I think that every individual person is unique and everyone is different in one way or another. People do things differently. People with disabilities are just regular people who do things the way that best suits them. And I think it would help if there was no stereotyping or prejudice or thinking of people as inferior or superior because of the way they do things.

00;43;43;16 - 00;43;49;00

Cheryl:

To just see differences as as normal, because differences are normal.

00;43;50;20 - 00;44;12;22

Courtney:

I'm trying to think of the best way to ask this, because I'm trying to think of what our listeners might be curious about in this moment, having, you know, you to just answer questions and to debunk our myths. And I'm trying to think of how to ask, but I'm thinking like, what would your advice be when looking for like a doctor or like in that medical, you know, in that medical setting?

00;44;12;22 - 00;44;31;11

Courtney:

Like what type of doctors do you steer from or what has been a good experience for you or a bad experience for you, for a parent who maybe, maybe their child just got a similar diagnosis or, you know, maybe we're just in an accident or we're just injured and are now looking at like the future or maybe, you know, or fostering or adopting a child who has disability.

00;44;31;21 - 00;44;38;26

Courtney:

Where do they start with finding like a good medical team that they can trust personally?

00;44;38;27 - 00;45;01;17

Cheryl:

Don't have a lot of experience with this. But if I were looking for a doctor, like for my child or for my situation, I would look for a doctor who's has a positive outlook. I have heard so many stories where doctors have told people, You'll never walk again. You'll never do this again. You'll never do that again. But those people, through their determination, hard work, are able to do those things later on.

00;45;02;06 - 00;45;22;24

Cheryl:

So I would want to choose a doctor who is sympathetic as well who says, okay, well, this is is the worst case scenario. You know, you could not be able to walk again or something, but there are always possibilities. I don't like doctors who sit there and make this diagnosis and just say, well, this is how it's going to be.

00;45;23;15 - 00;45;48;12

Cheryl:

They can give that as a possible outcome. But then I would like them to include some kind of positivity, have some like ideas of, you know, oh, well, we could make it easier this way or make it better that way. And just to listen to their doctor who will listen to the parent personally, my experience I went I went to a doctor a few years ago just to look into getting a replacement wheelchair.

00;45;48;21 - 00;46;09;01

Cheryl:

That was all I wanted. I had been to doctors growing up about and I learned, you know, there's no cure, my disability. There are things that make it easier when I cure it or whatever. So I was like, I have figured out my lifestyle and I've figured out ways to do things and I'm just going to the doctor to ask about When can I get a new wheelchair if the sun breaks down when I go in?

00;46;09;01 - 00;46;26;18

Cheryl:

And this is a specialist I had never seen before, and she's all about, wow, oh, no, let me in style. So she let me inspect your disability. So she had me walk for her. She inspected everything and her focus was only on how can we fix this? And she's mentioning we could do this surgery or that surgery or that.

00;46;26;18 - 00;46;43;05

Cheryl:

I'm like, I'm a single mom of three kids. I work full time. I have had these surgeries offered me in the past, and I said, no, I decided I didn't want them because I feel like it would, you know, limit me personally just for me. And I said, all I want to ask about is getting in your wheelchair.

00;46;43;12 - 00;47;03;26

Cheryl:

I don't want you to fix me. I don't need you to fix me. I have figured out my life. I have figured out how to do things and it works for me. And I have a good quality of life. My life may not be just like yours, but I have a good life. I think that's the thing they do is a quality of life and they have their own vision sometimes of what that is.

00;47;04;00 - 00;47;25;08

Cheryl:

And sometimes a good life doesn't line up with their idea of it, but it's still a good quality of life. And so, yeah, I got a little frustrated at that appointment just because their focus was not my focus. Like doctors should listen to a parent and be like, Well, what do you want for your child? And how can we help out in making this happen?

00;47;25;29 - 00;47;52;19

Courtney:

I feel like that's great advice because I feel like a parent might walk in and the doctor be talking about all these surgeries, for example, like you mentioned. And they might think, oh, I should be doing more or I should be doing something different, or I should have a different goal than what we do have. But you're bringing up a really good perspective is we shouldn't put our own bias or our own judgment on that person's situation and just be assuming that they want, you know, a surgery for that correction or whatever when they're just there for their goal.

00;47;52;19 - 00;48;09;06

Courtney:

Like their goal is not yours. It doesn't have to be because they're not looking at things through your perspective either. Like you would have to relearn a lot of things and you would have to be down for months recovering and you can't do that in your life and in your situation and your kids need you. And so that doctor wasn't taking any of that into consideration at all.

00;48;09;14 - 00;48;11;14

Courtney:

So I am really glad that you shared that.

00;48;11;25 - 00;48;31;18

Cheryl:

And that would be ideal to find a doctor or a medical team where you can talk about things. You can they can give you options. And then you decide that as a parent, like, what do I want for my kid? What kind of life salary able to do? And then if the parent and the doctor can have the same goal going forward.

00;48;31;23 - 00;48;45;27

Cheryl:

And yeah, that's how in the beginning and then figure out, well, maybe this surgery or that surgery or that therapy or whatever will help out. But just getting that goal set in the beginning and having to agree on that with the doctor would be amazing.

00;48;47;01 - 00;49;08;18

Melina:

Yeah, and I've heard that as well from a colleague who said that their son was supposed to wear splints at night on their legs and it was just torture for the child and the family because the child wasn't comfortable and didn't sleep. And so if the child didn't sleep at night, guess what? No one else in the family did either.

00;49;08;28 - 00;49;45;01

Melina:

And the long term goal for this child wasn't necessarily for them to walk. So why keep going through all of this with that goal when that goal is in alignment with the child's goal or the family's goal for their child? So I think that will really resonate with a lot of people to take a second and think, okay, well, that's a good way to look at it because they may, like Courtney has said, take a doctor's advice right away without thinking about the big picture and being person centered.

00;49;45;23 - 00;50;09;18

Cheryl:

I had experience with that too. Growing up I had like leg braces and they suggested me same thing. Wear them and I bet it hurt to wear them and night and I would take them off in my sleep. I didn't like wearing them. I could already walk to an extent and I didn't, you know, the leg braces made it more stable when I was walking, but I can only wearing for a few hours before they were hurting so much, and I didn't always have a place to take them off.

00;50;09;18 - 00;50;18;13

Cheryl:

So yeah, I had that kind of same experience there with I'm not going to use these because they hurt more than they're worth.

00;50;18;13 - 00;50;37;27

Melina:

Yeah. So I think again, similar to the restaurant is, you know, making sure that physicians know to talk to the person and not whoever may be accompany them and to not underestimate the patient's ability to have a very active role in care.

00;50;39;07 - 00;50;56;22

Cheryl:

Yes, because the patient knows better than anyone else, better than even their parent where it hurts, how much it hurts, what's more hard for them? What would make things easier? They would know better than anyone. And if they can communicate that, it's definitely important to listen to what they have to say.

00;50;56;22 - 00;51;16;29

Melina:

Thank you for sharing your story with others. I think it's important when you say for people to to look for a role models. I think that it's important for you to know that you are one as well, because people may not think that they can be a mom and live run their own household and things like that.

00;51;16;29 - 00;51;40;23

Courtney:

So and not rely on anybody else. Like she's like this single superwoman who's like, you know, any single mom is like a woman, but you have like the added task of doing all of these things with your chair. And, and so if I were a parent with a young child, especially a young girl who had a similar disability, I would look to you and be like, there is hope for my kid's future.

00;51;40;23 - 00;51;47;20

Courtney:

Like she can have a job, she can have a family, she can have kids. Like there is normalcy in her future and that would make me feel really good.

00;51;48;07 - 00;52;03;23

Cheryl:

And I'm glad there are those role models out there because you might look at somebody and they say, Oh, you can do it. And all those speeches out there. But then you look at them and say, Well, you're standing, you're walking. You don't have the troubles I have. But there are people who do have the troubles and they have done things.

00;52;03;23 - 00;53;00;05

Cheryl:

So just having those role models is saying, Oh, well, if they did it, I can do it.

Melina:

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